

**EFFECTS OF A PARENT EDUCATION PROGRAM ON  
MATERNAL SELF-EFFICACY AND PERCEPTIONS OF THEIR  
CHILD'S SELF-MANAGEMENT OF A LIFE-THREATENING  
FOOD ALLERGY**

**By**

**JANICE SUSAN FOGG**

**A Thesis Submitted to the Faculty of Graduate Studies  
in Partial Fulfillment of the Requirements for the Degree of**

**MASTER OF NURSING**

**Faculty of Nursing**

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## Abstract

Care of young children diagnosed with life-threatening food allergy involves strict avoidance of the allergen, early recognition of symptoms and prompt administration of adrenaline to reverse a severe reaction. Parents report that exercising extreme dietary vigilance and living with constant uncertainty causes disruption in their child's daily activities and impairment in family and social interactions. Guided by Bandura's self-efficacy theory, a randomized controlled trial using a pre-test post-test design was conducted to examine whether participation in an education program would increase maternal self-efficacy and perception of child self-management. One hundred sixteen mothers of 4 to 12 year old children diagnosed with life-threatening food allergies were randomly assigned to the intervention or the control group. The intervention group attended a 4-hour group education session. Using repeated measures ANOVA, the experimental group had significantly higher levels of maternal self-efficacy and perception of child self-management 3 months after exposure to the intervention compared to the control group. Self-efficacy was significantly positively related to self-management ( $p=.27$  to  $.45$ ). These results suggest that an education program may improve a mother's confidence in her ability to manage her child's life-threatening food allergy and result in improved perception of her child's self-management skills.

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Maternal Self-Efficacy for Diabetes Management Scale, from “Self-management development in children and adolescents with diabetes: The role of maternal self-efficacy and conflict” by Leonard et al., 1998, *Journal of Pediatric Nursing*, 13(4), p. 232. Permission to reprint obtained March 28, 2006 from Michael J. Lacovara for Elsevier, ref: FoggThesisML3-06 found in Appendix A; page 129.

Diabetes Family Responsibility Questionnaire (DFRQ), from “Self-management development in children and adolescents with diabetes: The role of maternal self-efficacy and conflict” by Leonard et al., 1998, *Journal of Pediatric Nursing*, 13(4), p. 232, by Barbara J. Anderson et al. (1990). Permission to reprint obtained April 3, 2006 from Barbara J. Anderson; found in Appendix A; page 129.

## CHAPTER I

### Statement of the Problem

The immune system is the body's defence against harmful foreign materials and abnormal cells. It is a complex system responsible for resisting and eliminating disease-producing microorganisms, removal of worn-out cells and tissue debris so that tissues can heal or be repaired, identification and destruction of abnormal cells that have originated in the body, and at times for inappropriate responses when the body produces antibodies against itself leading to destruction of a particular type of the body's own cells, or when the body turns against a normally harmless entity in the environment (Sherwood, 2001, p. 390). The focus of this thesis concerns a particular aspect of the latter function; family response to the diagnosis of severe food allergies in children between the ages of 4 and 12 years of age.

This chapter will describe the problem of severe food allergy in children, including prevalence, common allergens, natural history of food allergy, medical assessment and recommended management, public perception, and the psychological impact of diagnosis of severe food allergy. Bandura's theory of self-efficacy will be introduced, and the purpose and significance of the study stated.

### *Background and Significance of the Problem*

Food allergy or hypersensitivity refers to a group of disorders characterized by abnormal or exaggerated immunologic responses to specific food proteins. Responses range from classic Immunoglobulin E (IgE) mediated reactions; which are often rapid in onset, to IgE related reactions, and non-IgE mediated reactions; taking hours or even days to become apparent. Gastrointestinal, oropharyngeal, cutaneous and respiratory

symptoms can occur, and severity can vary from a localized reaction to anaphylaxis, a severe systemic and potentially fatal reaction (Sampson, 1997, 2000).

Although potentially any food may cause an allergic reaction, eggs, milk, peanut, soy, fish and wheat account for up to 90% of foods causing allergic reactions in children; and peanuts, nuts, fish and shellfish account for up to 85% of foods causing allergic reactions in adolescents and adults. Generally, the allergens are glycoproteins. Foods often contain between 10 and 30 glycoproteins but usually only a few glycoproteins are implicated in allergic reactions (Sampson, 2000).

Many myths exist concerning allergies. Sloan and Powers (1986) conducted household interviews of 200 women in 20 metropolitan U.S. areas and found that as many as 30% reported that they or some member of their family had a food allergy. More than half had never consulted a physician and based their belief on self-diagnosis. They avoided the food and waited for the allergic symptoms to disappear. "Allergy" was defined as any adverse reaction the consumer connected with the ingestion of certain foods or food ingredients.

Allergists, however, believe that true prevalence of food allergy is far less. They report that the prevalence of food allergy is greatest in the first years of life, affecting six to eight percent of children (Sampson, 2000, p. 2), when the gut barrier is immature and the immune system is still refining its ability to tolerate foods. About 2% of young children react to cow's milk and a similar number react to egg (Sampson, 2000). Some allergies will resolve by four to six years of age, especially allergies to milk and egg. By the end of the first decade, prevalence of severe food allergy is about 2%; similar to levels found in the adult population (Sampson, 2000). Young children appear more likely to become tolerant, or outgrow their food allergies than older children and adults.

Older children and adults may also lose sensitivity if the responsible food allergen can be identified and completely eliminated from the diet (Sampson, 1997), although the stronger the family history of allergy or severe the initial reaction, the less likely this would seem to occur.

Allergy to peanuts and tree nuts is the leading cause of fatal and near-fatal food allergic reactions, and peanut allergy appears to be increasing in prevalence (Sicherer et al., 2003). In 1997 Sicherer et al. reported the prevalence of peanut and tree nut allergy in the general population of the United States based on a nation-wide, cross-sectional, random telephone survey, using a standardized questionnaire. Sixty-seven percent of households contacted participated, resulting in 4374 households and 12,032 individuals. Peanut or tree nut allergy was self-diagnosed in 1.4% of individuals surveyed. When criteria of Ig-E mediated reactions were applied, 10% were eliminated. Only 53% of those remaining had ever seen a physician about the allergy and only 7% had self-injectable adrenaline available. Correcting for various factors, the author concluded that peanut and tree nut allergy affects approximately 1.1% of the population or about 3 million Americans. Sicherer et al. repeated the study in 2002, with a 53% participation rate. Of 4855 households representing 13,493 individuals, prevalence was virtually unchanged at 1.2%. Despite severity and reaction frequency, only 74% of children and 44% of adults had been assessed by a physician, and less than half of those assessed by a physician were prescribed self-injectable adrenaline. Although self-reported prevalence of peanut and/or tree nut allergy reported in the population as a whole did not change between 1997 and 2002, self-reported prevalence in children had doubled from 0.6% to 1.2% (Sicherer et al., 2003).

For most children, severe peanut allergy is diagnosed at a very young age. Peanut and tree nut allergies are known to develop early in life and affect about one percent of preschool children (Pham & Rudner, 2000). Moneret-Vautrin, Rance, Kanny, Olsewski, Gueant and Guerin (1998) found that 46% of children with life-threatening peanut allergy were diagnosed before their first birthday. Sicherer, Burks and Sampson (1998) conducted a similar study and found that 72% of children with peanut allergy exhibited signs of a severe allergic reaction between the ages of six months and nine years; the mean age of diagnosis being 24 months. IgE mediated allergy to peanuts is relatively common in childhood and is a problem that has become increasingly prevalent in the past decade (Zeiger, 2000). Peanuts and tree nuts often cause the most severe reactions and are known to have multiple allergenic properties (Clarke, Kilburn, Hourihane, Dean, Warner, & Dean, 1998).

Approximately 100 deaths are attributed to food allergy in the United States annually (Sampson et al., 1992). Canadian statistics are difficult to find. The Canadian School Boards Association (1996) cites the Canada Health Monitor (March/June, 1995) for estimating deaths due to anaphylaxis (including causes other than food) each year in Canada as ranging from 12 to 50. These figures are difficult to confirm because anaphylaxis is not a reportable cause of death in Canada. It is thought that deaths due to anaphylaxis are frequently registered as "cardiac arrest" or "asthma" on official records. Despite the absence of precise data, Dr. Milton Gold at the Hospital for Sick Children in Toronto reports that allergists are seeing increasing numbers of children with peanut allergy in their practices (Canadian School Boards Association, p. 8). Causal theories range from increased use of protein additives in prepared foods, early childhood exposure to allergens, and the absence of parasites in the environment.

### *Assessment and Management of a Life-threatening Food Allergy*

Because of the complexity of food allergy, assessment and diagnosis is best done by a certified clinical immunology and allergy specialist who will take a careful history, including presence of other atopic disease and family history of atopy, perform a physical examination, and investigate and interpret selective skin tests and possibly radioallergosorbent tests (RASTs). Food challenge may be conducted under controlled circumstances. Risk of anaphylaxis will be determined and avoidance of specific allergens and availability of self-injectable epinephrine (adrenaline) may be prescribed (Canadian Paediatric Society, Allergy Section, 1994).

Eliminating foods from one's environment can be a difficult task, even for those persons who fully understand the seriousness of the condition. Parents of preschool children with life-threatening allergies frequently insulate their child in a world of immediate family caregivers, fearing risk of exposure to the potentially fatal allergens outside their home. Parents who must rely upon out of home child care and/or whose children are approaching school age, are left hoping that legislation which prohibits the serving of peanut products in child day care facilities, policies in schools and recreational programs, and the good will of other families to cooperatively avoid sending products containing peanuts, nuts, or other allergens, will keep their child safe. But products containing peanuts and nuts are ubiquitous, often hidden in a myriad of processed and packaged foods. Invitations to children's parties, play dates, eating out, travelling, grocery shopping, participating in community events and even a visit to the local play structure require extra vigilance and planning, and contribute to the ever present angst experienced by the parents of these children.

Public schools and child daycare facilities report an increasing number of children with life-threatening allergies registered in their programs. In 2003, four of the six school divisions in the city of Winnipeg (Winnipeg School Division, St. James School Division, River East Transcona School Division & Louis Riel School Division) reported 1,048 children out of a total of 77,620 students carry an EpiPen® for severe allergies (WRHA Regional URIS Pilot Project, Winnipeg School Division [WSD] Central Registry of Children with Special Health Care Needs 2003). Their parents expect that they will be kept safe at school and that staff will recognize symptoms of an allergic reaction, and act accordingly by administering adrenaline if required. Administrators of schools, child daycare and other community programs have turned to the medical community for assistance. Nurses employed in community settings have been asked to assist with the development of policies and practices in order to keep these children safe. As well, nurses working in patient education, clinician or case-management roles are responsible to assist families in managing their child's chronic health condition in ways that support normal childhood development.

All caregivers, including immediate family, must learn to appreciate the risks associated with an inadvertent exposure, how to read labels and recognize terminology that may indicate the presence of an allergen, how to assess risk on poorly labelled products, how to recognize an allergic reaction, to have adrenaline readily accessible, and how to correctly administer it and activate the emergency response system. Identifying potential allergens is a difficult task, even for those with the most at stake. It requires vigilance each and every time a product is purchased. Equally important is the ability of children and their caregivers to promptly recognize allergic symptoms and quickly administer adrenaline to reverse a severe reaction.

Established in 1991, the Food Allergy and Anaphylaxis Network (FAAN) is a highly respected American resource for individuals with serious allergies, and includes families, dietitians, nurses, physicians, school staff, representatives from American government agencies, and the food and pharmaceutical industries. Their mission is to raise public awareness, to provide advocacy and education, and to advance research on behalf of all those affected by food allergies and anaphylaxis. Resources available to families and others include newsletters, books, booklets, videos and other products designed to educate about food allergy.

In 1995, the Canadian Society of Allergy and Clinical Immunology, Ontario Allergy Society, and Allergy Asthma Information Association published recommendations for schools and other child care settings concerning how children with life-threatening allergies should be managed. Gold, Sussman, Loubser and Binkley were the principle authors. This document has been widely referenced and used in the development of similar documents by medical professionals and information and support groups in North America, Europe and Australia (Allergy/Asthma Information Association, Canadian Allergy, Asthma and Immunology Foundation, Calgary Allergy Network, Moneret-Vautrin & Kanny (1999), Canadian Pediatric Society, American Academy of Allergy Asthma and Immunology, Australasian Society of Clinical Immunology and Allergy).

In 1997 Vickers, Maynard and Ewan reported the development of a training package for schools regarding 56 children with potentially dangerous food allergies (55 children were allergic to nuts, 1 child was allergic to milk), attending 45 different schools. They emphasized the importance of expert assessment of the allergy and a written treatment plan. They identified that parents as well as schools require training



and support, and that administration of adrenaline was only one aspect of good practice; that education, prevention and recognition of an allergic reaction were also essential. They reported that 41 parental questionnaires and 33 school questionnaires completed after exposure to the training session showed participants found the training beneficial, and that parents and school staff felt less anxious. They concluded that adequate support to these children is complex and time-consuming and requires close liaison between clinicians, schools, families and those responsible for policy making.

In my experience as a Nurse Educator working with children with special health care needs in the public school system, it is my perception that the seriousness of the problem is not fully appreciated by the community at large and sometimes not by parents of food-allergic children themselves. Some children who are identified by their parents as requiring an EpiPen® to treat a serious allergic reaction do not carry an EpiPen® or even have one provided by their parents. Their parents cite cost as a factor, or fear of it being used inappropriately by school staff or other students as a reason why it is not provided. Others fail to purchase a new EpiPen® when the old one expires and others want it kept at home instructing the school to phone and they will bring it to the school if required.

Upon meeting with parents of children with diagnosed life-threatening allergies to develop a plan to keep their child safe at school, many parents are unfamiliar with how to properly use the EpiPen®, especially if they were not present when the diagnosis of life-threatening food allergy was made. They usually welcome further instruction. Some parents will indicate that an EpiPen® has been prescribed, but that the allergy is not very serious. Dozens of children are listed as having a peanut or nut allergy and parents will say that no EpiPen® is required. Occasionally a parent will indicate that

they have avoided contact with peanuts after an episode of facial swelling and difficulty breathing, but have never thought to mention it to the child's physician or did not attend the appointment with an allergist. Many parents relate that they did not know to go to the hospital when the allergic reaction occurred and have in fact been reluctant to give the EpiPen®, opting to wait and watch when allergic symptoms appeared. Yet they all usually request strict dietary avoidance. Many children have never participated in avoidance strategies, leaving that responsibility to the adults in their world. Other parents will indicate that their four year old knows to not eat anything containing the allergen and that no other avoidance strategies need be implemented. At times it is hard to know what to make of this information. In the absence of an appropriate assessment, diagnosis and follow-up, a good understanding by both parents of the seriousness of the allergy, and knowledge about when and how they should respond should allergic symptoms appear, it is difficult for school personnel to know what to do. There would appear to be many inconsistencies in the knowledge of some parents of children with food allergies about the seriousness of the allergy, about how to reduce risk of exposure, and how to recognize and respond to allergic symptoms.

Most parents of food-allergic children do seek appropriate diagnosis, work very hard to avoid inadvertent exposure to the allergen, and plan for the EpiPen® to be accessible should allergic symptoms appear. These parents are particularly wanting of more information about why the allergy exists, prospects for treatment, and any help that can be offered to reduce risk and have care givers prepared to recognize and respond appropriately in case of an allergic reaction.

It is not surprising that parents are not homogeneous in their response to the diagnosis of life-threatening food allergy. What is clear is that some parents appear to

require more information and training, and some admittedly want more information and training.

The literature supports the need for appropriate assessment and diagnosis, appropriate determination of the need for available adrenaline, appropriate understanding by parents and other caregivers about the seriousness of the allergy including avoidance strategies and recognizing and responding to an allergic reaction, and ongoing follow-up and support. Yet there is very little reported in the literature about how parents acquire this understanding, let alone about what educational strategies are most effective to give parents the skills and knowledge necessary to keep their child safe.

### *Psychological Impact*

Having a life-threatening allergy alters the lives of children and their families. In studying the psychological burden of peanut allergy as perceived by adults with peanut allergy and the parents of peanut-allergic children, Primeau and colleagues (2000) found that parents perceived more disruption in their peanut-allergic child's daily activities and impairment in family and social interactions than in a control group of children with rheumatologic conditions, due to fear of death. Parents felt a loss of control when someone else was caring for their child, something that caused substantial parental burden.

Parents must learn to manage their child's care in relation to ever changing conditions such as age, growth, and cognitive and psychosocial development. Management of an infant varies greatly from that of a school-aged child or adolescent. In fostering self-management behaviours, parents must balance a child's willingness to learn, ability to reason, solve problems and make decisions, with their own willingness

to let go of the locus of control, and their perception of the abilities of others in their child's world to support and keep their child safe.

Perceived self-efficacy is an important concept that can impact on self-management for both the parent and child. Self-efficacy, in the context of parenting, is the degree to which a parent feels confident and competent to manage their child's care (Johnston & Mash, 1989). Bandura (1977) contends that knowledge of a person's efficacy views is an important factor in predicting coping responses. Mullins, Chaney, Hartman, Olson, Youll, Reyes and Blackett (1995) suggest that a mother's level of emotional distress is related to her child's ability to cope with a chronic illness. Accordingly, lack of parental self-efficacy can delay or be detrimental to a child's self-management of his/her chronic health condition. Hence, parents need to feel confident and competent in managing their child's life-threatening allergy, understand goals of self-management, and have the skills to be able to transfer knowledge and skills to their child. Bandura contends that self-efficacy can be enhanced through educational interventions, and that there is a relationship between self-efficacy and self-management of a chronic health condition. In the context of children with chronic illness, self-management often involves the gradual transfer of responsibility for self-monitoring and decision-making, collaboration with family and others, and ultimately the ability to make day to day judgements on one's own as is developmentally appropriate.

However, little is known about the effects of educational interventions in enhancing parental self-efficacy concerning children with life-threatening food allergies, and self-management skills of children with life-threatening allergies. Reports on educational interventions have been self-reports and impressions, and have lacked criteria by which causality can be inferred, including randomization, control and a valid

instrument by which to measure significance. In studies that have examined self-efficacy in relation to chronic illness in children, none have examined children with life-threatening allergies and their families.

### *Purpose of the Study*

The purpose of this study is to determine whether participation in an educational program will increase maternal self-efficacy and perception of child self-management among mothers of 4 to 12 year old children with life-threatening food allergies.

### *Significance of the Study*

Young children with life-threatening food allergies are becoming increasingly prevalent in the developed world. It is clear that there is a need to teach the families of these children how to care for them, and how to train children to manage their own allergy in developmentally appropriate ways. Through understanding the relationship between parental self-efficacy and parent perception of their child's self-management, patient and family education can be tailored to most effectively meet this need. If it can be demonstrated that a structured parent education program can enhance parental self-efficacy and perception of child self-management, this may become a treatment standard for all children diagnosed with life-threatening food allergy.

## CHAPTER II

### Review of the Literature

Much of what has been published about life-threatening food allergies has focused on prevalence, pathophysiology, clinical manifestations, diagnosis, description and associations of those who develop life-threatening allergies, natural history of food hypersensitivity, medical management, prospects for immunotherapy, and case reports of fatal and near-fatal reactions. A few authors have reported on the success of patient/family education programs and on skills and knowledge that health providers hoped families would have acquired. Gaps in knowledge exist concerning how families gain the skills and knowledge required to safely manage their child's life-threatening allergy, and how they transfer skills and knowledge to their child to equip him or her to safely lead as normal a life as possible. This chapter reviews what is reported in the literature about gaps in skills and knowledge about life-threatening food allergies, patient education as it applies to children and self-management in chronic illness as it applies to children.

#### *Gaps in Skills and Knowledge*

Gaps in patient/family skills and knowledge were reported by Sicherer, Forman and Noone (2000), who studied the use of self-administered epinephrine among 101 families of food-allergic children (mean age 6.4 years) and paediatricians at Mount Sinai Hospital in New York. Six children were over 12 years of age and considered to be most likely to self-administer epinephrine. They completed the survey and demonstrated use of the adrenaline injection device instead of their parent. Sicherer et al. found that only 32% of parents of severely food-allergic children and teenagers could correctly

demonstrate how to use their self-injectable epinephrine and only 55% of families carried self-injectable epinephrine that was not expired. Of 47 pediatricians/residents enrolled in this study, only 18% were familiar with and correctly able to demonstrate use of an epinephrine self-injector and only 24% of the pediatricians gave written instructions to their patients when prescribing epinephrine self-injectors. They concluded that improved patient and physician education is needed to ensure proper use of this life-saving medication. Mullins (2003) reported that compliance with carrying epinephrine and administering was poor in 432 patients referred to a community-based specialist practice in Australia. Of those prescribed epinephrine,  $\frac{3}{4}$  carried it,  $\frac{2}{3}$  were in date, and only  $\frac{1}{2}$  of patients who experienced anaphylaxis actually administered it.

Many families recognize that they need more education and guidance about their child's life-threatening allergy. In spite of increasing public and medical interest in the management of children with life-threatening peanut allergies, little has been published about the effects that a diagnosis of life-threatening peanut allergy has on children and their families. In 2002, Gillespie reported on her qualitative research in Winnipeg, Manitoba about the mothers' perspective of parenting a 6 to 12 year old child with a life-threatening food allergy (N=6). Gillespie reported that several mothers felt that they were left on their own to find out about the severity of the allergy, about what they should avoid, how to obtain more information, how to use the EpiPen®, and the availability of supports. One mother was quoted as saying "I should have been taught originally and I didn't know to ask. ... It was all new to me" (p.108). Gillespie found that living with risk, living with fear, worry about well-being, looking for control and relying on resources were the main themes identified by six mothers of 6-12 year old children with life-threatening food allergies about their experience.

Primeau and colleagues (2000) studied the psychological burden of peanut allergy as perceived by adults with peanut allergy and the parents of peanut-allergic children, comparing 153 peanut-allergic children with 69 children with rheumatologic disease, as well as 37 peanut-allergic adults with 42 adults with rheumatologic disease. Parents served as proxies for children less than 18 years of age, completing self-report questionnaires about the impact of the condition on quality of life and family relations. Although the authors hypothesized that patients with other chronic conditions such as inflammatory bowel disease or diabetes experienced impairment in quality of life and family relations of similar magnitude, they had access to patients with rheumatologic conditions and that motivated their choice of this group as controls. They found that in peanut-allergic children, parents perceived more disruption in their child's daily activities and impairment in family/social interactions than the control group, due to fear of death. Dietary restrictions, although stress producing in that they greatly limited daily activities, represented a means for parents to achieve mastery over the condition. Parents felt a loss of control when someone else was caring for their child, and this created substantial parental burden. The authors observed that until recently, peanut allergy has not been perceived by the public, including the media, schools and physicians other than allergists as a condition presenting major problems for patients and their families. They recommended the need for educational and emotional support for children with life-threatening allergies and their families, improved manufacturing and labelling practices, and accurate diagnosis, involving a detailed history taken by an allergist, combined with skin testing and potentially food challenge.



### *Patient Education*

There is no paucity of literature about patient education. Much of the literature, however, focuses on adults. Literature focusing on patient education for children with life-threatening food allergies and other chronic health conditions was reviewed, including those where parents were used as proxies.

In France, Rance and Bidat (2000) reported the effects of a patient/parent education program for children with life-threatening peanut allergies who were seven years of age and older. Using a convenience sample from their practice, children and their parents attended a forty-five minute education session with the aim of improving basic knowledge about allergies, reading labels and recognizing allergens hidden in foods, recognizing early signs of allergic reaction and use of epinephrine as a rescue treatment. They followed a structured program that included role play and situational problem solving games. Three months after the program they conducted an evaluation and reported that families found the educational program to be beneficial, that they experienced fewer allergic reactions after attending the program, and were able to respond with the appropriate behaviour when symptoms appeared. Sample size and design were not reported.

In 2004, Kapoor et al. published the results of a study conducted in England on the impact of multidisciplinary parent consultation on parental knowledge of food allergy and subsequent rate of allergic reactions. Sixty-two subjects enrolled in their study, with 52 enrolled at the completion of the study. Parental knowledge was assessed by questionnaire and EpiPen® trainer. Families saw a paediatric allergist, clinical nurse specialist and dietician. Knowledge was assessed at 3 and 12 months. They found significant improvement in knowledge of allergen avoidance, managing allergic

reactions and EpiPen® usage. They also found a significant reduction in allergic reactions, children with egg, milk or multiple allergies being more likely to have subsequent reactions. They concluded that a single visit to a multidisciplinary clinic considerably improved families' ability to manage allergic reactions to foods and decreased subsequent reactions. Focus was placed on children with coexisting asthma due to evidence that suggests an association with severe allergic reactions.

Bansal et al. (2005) surveyed 44 child care centres to evaluate the ability of child care centres to recognize, evaluate and treat anaphylactic episodes in 1 – 6 year old children. Child care directors completed the surveys. Centre directors and teachers were then offered an allergy seminar addressing anaphylaxis avoidance, recognition, evaluation and treatment. Centre directors completed a questionnaire after the seminar. Knowledge and willingness to administer epinephrine increased significantly.

Little else is reported in the literature concerning educational programs for children with life-threatening allergies and their families. Studies about self-care and children with type 1 diabetes reveal many parallels with children with life-threatening allergies. Both conditions require careful planning and monitoring of oral intake, prompt recognition and response to potentially life-threatening symptoms should anaphylaxis or hypoglycaemia occur, and accessibility of treatment. In both conditions, the individual may not be able to either recognize their own worsening symptoms or be able to reverse a reaction by self-administering their treatment. As well, there are demands for life-style modifications, threats to personal control and body image, and complex treatment requirements. Parents are responsible for the care of young children until the child begins to assume responsibility for self-care, the transfer of responsibility usually achieved in incremental steps. Review of the literature about how children with diabetes

and other chronic health conditions learn to manage their care may reveal information that is transferable to children with life-threatening food allergies.

Based upon the belief that the transfer of self-care responsibility from parent to child is best accomplished gradually and in a structured fashion, McNabb, Quinn, Murphy, Thorp and Cook (1994) developed a behaviour-oriented self-management education program intended to teach children to become more responsible for the day-to-day management of their diabetes. They hypothesized that 8 to 12 year old children with type 1 diabetes can learn to become more independent in their own diabetes self-management without compromising their metabolic control. Of 76 eligible subjects, 24 children and their families volunteered to participate in the study. The researchers controlled for developmental and sociocultural influences by pairing the children by age and race and randomly assigning them to the experimental group or control group. The experimental group attended six one hour weekly sessions where children learned and practiced relevant self-care behaviours, and parents were separately taught specific parenting skills to enhance their ability to promote developmentally appropriate self-care in their children. Parents and children met at the end of each session to set a self-care behavioural goal and practice the behaviour related to their goal with their parents. The control group continued to receive usual care, for example, saw their physician for routine scheduled care including team care provided by the clinic nurse and others. The Children's Diabetes Inventory, a questionnaire developed by the authors for the study, was administered to parents at baseline and 12 weeks after baseline (6 weeks after the experimental group completed the educational program) to determine the frequency with which 35 diabetes management behaviours were performed and the degree to which children assumed responsibility for these behaviours. Glycohemoglobin levels were also

monitored at baseline, posttreatment, and 12 weeks post treatment. At posttreatment, children in the experimental group were found to be assuming significantly more responsibility for their diabetes self-care than were children in the control group. No decrease in frequency with which self-care behaviours were performed was observed, and metabolic control was maintained. Results suggest that a diabetes self-management education program for 8 to 12 year old children with type 1 diabetes can be effective in facilitating children becoming more responsible for their own diabetes management.

Carvalho and Saylor (2000) evaluated the effectiveness of a nurse case-managed program for 56 parents with children ranging in age from 14 months to 17 years of age (mean age of 9.8 years) with type 1 diabetes using measures of self-management, quality of life and self-efficacy. They used a quasi-experimental design because they were unable to recruit a control group. Instead they compared the previous 12 months of care. They cited literature reporting that education alone is not sufficient to effect the necessary lifestyle changes that result in effective self-management, but that information must be presented in a way that considers the educational and psychosocial needs of the child and family, the family system and its dynamics, the developmental stage of the child, and the cognitive maturity of the child. They also stressed the importance of counselling to teach coping and adaptation skills. Self-efficacy was an integral part of the empowerment education program, where diabetes was seen as a biopsychosocial illness rather than a physical illness, with behaviour change being internally motivated. They reported improvement of all self-management measures, statistical significance being reached for parents' self-efficacy scores, and the other measures being reported as clinically significant.

Grey, Kanner and Lacey (1999) reviewed empirical studies reporting results of educational interventions for children and adolescents with type 1 diabetes and/or their families, published between 1980 and 1998, to determine effectiveness and outcomes. The majority of studies focused on adolescents, and suggested that traditional educational interventions are successful in increasing knowledge, but less successful in increasing quality of life or improving metabolic control. Psychological and family coping training were found to more successfully improve both quality of life and metabolic outcomes. More studies of younger children and families using well-controlled experimental designs with adequate samples were recommended.

Leonard, Skay and Rheinberger (1998) investigated maternal self-efficacy and its relationship to maternal perception of the child's self-management of diabetes using the Maternal Self-Efficacy for Diabetes Management Scale, developed by the investigators, and the Diabetes Family Responsibility Questionnaire (DFRQ) (Appendix A) developed by Anderson et al. (1990). One hundred and four mothers of children 8 to 17 years of age were asked to rate their own and their child's ability to manage the child's diabetes. Overall, mothers expressed a high degree of self-efficacy in managing their child's diabetes, and perceived their children as average or above average in managing their own diabetes as compared with age mates with diabetes. The mother's level of self-efficacy was significantly positively related to their perceptions of their child's self-management.

These studies suggest that there is a relationship between a parent's confidence in managing his/her child's health condition, and the child's ability to take responsibility for care requisites related to his/her chronic health condition.

### *Self-Management*

The term self-management is a compound word; the first element 'self' beginning innumerable compounds referring to one's individual person or interest, or the object of one's own reflective consciousness (Webster, 1971). 'Management' is a transitive verb, meaning to handle or direct; to have under control or direction; to conduct, carry on, guide or administer; to get under control; to wield, to treat with caution or judgement (Webster, 1971).

The National Institute of Health (NIH, 2000) describes self-management and chronic illness as a changing concept. Noting that self-management of chronic disease has been an expectation for much of the past century; they describe the role of health care providers as no longer giving instructions to patients and hoping that they will adhere to them, but that those persons with a chronic illness are expected to take an active role in their care. "Effective self-management now includes the person undertaking a broad range of health, lifestyle, self-assessment and treatment behaviours with support and assistance of others. The promotion and maintenance of a healthful and satisfying life, in the presence of chronic disease, requires individuals to assume both leadership and partnership roles with health care providers" (NIH, 2000, Research Objectives, ¶ 1). In 1997, the American Diabetes Association defined self-management training, traditionally called 'patient education', as the process whereby individuals learn to manage their diabetes. They revised national standards for diabetes self-management education programs to better reflect research findings and health care trends concerning self-management goals as determined by individuals with diabetes. Although they did not call it self-management, Jenkins and Emmett (1997) captured the essence of this evolution of terminology in describing the ethical dilemma of health education. They

stated that health education should enable patients to make informed choices, not coerce them into merely following instructions. In doing so, health education must involve choice, autonomy and freedom.

Utilizing Bandura's (1986) self-efficacy construct, Bartholomew, Parcel, Swank and Czyzewski (1993) measured self-efficacy expectations in 199 children with cystic fibrosis under 18 years of age (mean age 8.7 years), defining self-management as "behaviours that patients and family members perform to lessen the impact of a chronic illness" (p. 1524). They differentiated self-management from compliance to medical regimens in that it includes complex cognitive-behavioural skills of self-monitoring, decision-making and communicating about symptoms and treatment regimens. They identified five aspects of self-management: medical judgement and communication, coping, family communication, compliance and acceptance. It is interesting to note that authors such as Dickenson (1999) and Anderson et al. (1991) have argued that compliance and acceptance are value laden terms that are inconsistent with concepts of choice, autonomy and freedom.

Magyary and Brandt (1996) defined 'self-management' for youth with chronic health conditions as the use of self regulatory skills for enhancing stress-management and building parallel construction of self-efficacy. Multiple measures were used to operationalize these attributes. Delamater, Bubb, Davis, Smith, Schmidt, White and Santiago (1990), defined self-management of 3 to 16 year old children with type 1 diabetes as self-monitoring of blood glucose for initiating behavioural changes regarding eating, exercise, and insulin use, in collaboration with the health care team, identifying technical skill and adherence as measures of self-management. Christian, D'Auria and Fox (1999) refer to 'self-care management' in their qualitative study into the meaning of

the chronic illness experience for adolescents with type 1 diabetes. They describe the concept as gaining self-responsibility and independence. Citing developmental theory and cognitive abilities, Wilkinson (1998) described the positive impact of collaboration on patient outcomes for effective self-management by children with asthma. He stated that 'collaboration is a cooperative venture based on shared power and authority, refuting the notion ... that children are subjected to the will of others' (p.30).

Self-management is closely connected with empowerment; a process by which people gain mastery over their affairs (Rappaport, 1987). Wallerstein and Bernstein (1988) describe empowerment as power to act with others to effect change. Frustrated by their inability to motivate patients to comply, Funnell et al. (1991) adopted an empowerment model in diabetes education. They reviewed the literature to identify the elements of successful patient education programs. They cited the traditional approach to patient education as the 'medical disease-as-pathology model' in which the professional is viewed as having the power, and the patient as passive recipient. Dissatisfaction in this model led to consumerism, where patients felt the full burden of responsibility for their health care. They were often seen as demanding and manipulative, and the relationship between patients and health care professionals was often thought to be antagonistic. Closely tied with nursing, social work and psychology theories, the empowerment model views the patient as an expert on his/her own life, and the professional as an expert in the disease. The professional acts as a resource for the patient, helping the patient acquire skills; overcome barriers through education, and by providing support. Based on these assumptions, Anderson, Funnell, Barr, Dedrick and Davis (1991) recommended that evaluation of empowerment patient education be based on the achievement of self-selected diabetes care goals.



Although Savinetti-Rose (1994) and Bannister (1996) use the terms 'self-management' and 'self-care' interchangeably, they shed some light on the attributes of self-management/self-care of children with chronic illness from 4 to 12 years from a developmental perspective. They cite factors to be considered when determining readiness for self-management that include cognitive, emotional and physical development, the child's capabilities in each of these realms, and the family environment. The diagnosis of a chronic illness in a child has been observed to cause a crisis within the family, and coping and adaptation are closely associated with psychological adjustment within the family and parental willingness to relinquish control.

Dorothea Orem is perhaps the best known author on the topic of self-care. She defines self-care as "the practice of activities that maturing and mature persons initiate and perform, within time frames, on their own behalf in the interests of maintaining life, healthful functioning, continuing personal development, and well-being" (1995, p.461). Through the evolution and development of this theory, roles have emerged in related concepts of self-care agency; that is, one's ability to care for one's self, and dependent-care agency; that is, the ability to care for others. Self-care requisites can be: universal, common to all human beings throughout life; developmental, contributing to age/ stage appropriate development; or health deviation, seeking and following medical care. In the context of young children, the supportive and collaborative role of family can be explained through dependent-care agency. Orem's theory of self-care has not been used, however, to explain self-care behaviour of young children. Orem's definition of self-care includes a broad constellation of behaviours, contributing to overall health maintenance. In the context of health, the term self-management has been used in reference to disease,

consistent with a medical model of care. Self-care is a broader term, referring to a wide array of health maintenance and promotion behaviours. Self-management is narrower in scope, referring to behaviours that promote health and homeostasis within the context of a chronic health condition. Self-care, by definition, includes self-management behaviours as described by health deviation requisites. Self-management does not include all self-care behaviours, however. In spite of this apparent difference, the terms continue to be used interchangeably in the scientific and social science literature.

Self-management for children with chronic illness is not an absolute. It represents a process or continuum of skills and knowledge. Because of the complexity of human behaviour and the individual nature of human responses to illness, children and their families will define self-management in a way that fits for them and they will accomplish these tasks at their own speed. Progress can be measured, however, by repeated measures of the defining attributes of self-management, those being developmentally appropriate self-monitoring and decision-making, self-efficacy, and collaboration/communication with family, caregivers and health care professionals.

There does not appear to be a consistent approach to measure self-management. Some researchers have focused only on measures of self-efficacy, such as Bartholomew, Parcel, Swank and Czyzewski (1993), who developed psychometric characteristics of a measure of self-efficacy expectations for the self-management of cystic fibrosis (CF) using performance objectives of medical care, coping and communication. The instrument was administered to 199 parents of children with CF and adolescents with CF.

Most researchers have utilized multi-dimensional measures, while others have focused on outcomes of self-management and not its presence per se. For example,

Grossman, Brink and Hauser (1987) developed a self-efficacy scale for adolescents with type 1 diabetes to predict metabolic control using the children's locus of control scale (Nowicki & Strickland, 1973), an instrument reported to be used in numerous investigations with diverse populations of children (p.326), the Coopersmith self-esteem questionnaire (Coopersmith, 1959), and physiologic measures of average blood glucose levels, urine glucose levels, urine acetone measures and 24 hour glycosuria to establish construct validity. Massouh, Steele, Alseth and Diekmann (1989) used glycosylated hemoglobin as an outcome measure for diabetes self-regulation of 12 – 15 year old children. Grey, Cameron and Thurber (1991) also used glycosylated hemoglobin, together with The Self-Care Questionnaire (Saucier, 1984), a 15 item self-report inventory of insulin administration and blood glucose testing to measure the influence of self-care on psychological, social and physiologic adaptation on 103 children with type 1 diabetes, aged 8 – 18 years and their parents. Dickinson (1999) argues that using physiologic outcomes as measures of self-management perpetuates oppression of persons with diabetes, and that this is ultimately counter-productive in the promotion of self-management behaviours.

Yet adherence and compliance remain deeply rooted in outcome measures of self-management. Magyary and Brandt (1996) used a pre- and post-test control group design to measure the effects of a school-based self-management program on therapeutic adherence, child self-responsibility and self-efficacy for 65 children with long-term health conditions, aged 7-13 years and their parents. The self-management intervention consisted of a two hour family session held at the home prior to twelve 75 minute peer group sessions, held twice a week for six weeks, and three 90 minute parent sessions held every other week for six weeks. Children in the intervention group showed

significantly higher therapeutic adherence and more self-responsibility in managing their health condition than controls. Carvalho and Saylor (2000) measured glycosylated hemoglobin, and administered a Quality of Life Parent Questionnaire and a Self-Efficacy for Diabetes Parent Questionnaire to determine changes in self-management after a comprehensive diabetes care model was instituted. Others have managed to steer clear of physiologic outcomes. McNabb, Quinn, Murphy, Thorp and Cook (1994) measured the effects of a self-management education program on 24 eight to twelve year old children with type 1 diabetes using the Children's Diabetes Inventory, a questionnaire which examines 35 diabetes self-care behaviours. Ryan-Wenger and Walsh (1994) used the Schoolagers' Coping Strategies Inventory to measure coping strategies of 78 children with asthma from a child's perspective. Faulkner (1996) used semi-structured interviews to determine influences on self-care for children with diabetes, and Leonard, Skay and Rheinberger (1998) studied self-management development in 8 to 17 year old children with diabetes, using the Diabetes Family Responsibility Questionnaire and the Maternal Self-Efficacy for Diabetes Scale (Appendix A). It would appear that the lack of a key instrument to measure self-management, combined with the inconsistencies in operationizing the concept hinders comparison of results across studies.

In 2000, Kieskhefer and Trahms promoted a developmental model for children with chronic health conditions that moved from compliance to self-management. They contended that regardless of the chronic condition, children and parents needed to develop a systematic approach to improving self-management skills and responsibilities that allowed them to participate fully in family and community life. They promoted a forward approach where parents monitored their child's progress and emotional state,

supported their child's efforts and negotiated changes in responsibility. They contended that "working with" their child and not "doing for", parents will come to trust that their child has mastered skills at their current level and are ready to move forward. They cited that one of the most frequently encountered patterns of parental management that does not support transfer of management from parent to child is the parent who "does it all" even past the childhood years. At adolescence, responsibility is transferred without adequate preparation for either parent or child. This becomes a source of conflict and control resulting in negative outcomes over time. Kieskhefer and Trahms (2000) promote a model of systematic leadership transition, where the parent guides the movement and where both the parent and child have active roles.

Based on the literature review, attributes which best define self-management for children with chronic illness include: (1) developmentally appropriate self-monitoring and decision-making, (2) self-efficacy, and (3) collaboration and communication with family, caregivers and health care professionals. These three attributes appear to be more closely aligned with the associated concepts of choice, empowerment and autonomy, than with strict compliance or adherence, concepts not currently considered to be favourably associated with self-management. One can argue the semantic differences between 'self-management' and 'self-care', in the context of chronic illness. There would, however, appear to be little difference in usage of the terms in the scientific and social science literature. Increasing interest and access to children as subjects of research has resulted in knowledge on this topic that may be transferable between disease entities.

### *Summary*

The diagnosis of a life-threatening allergy is perceived by families to cause significant burden to the child and to the family as a whole. Parents have recommended that there be more education and guidance available to help them manage their child's condition. Gaps in parental skills and knowledge as well as skills and knowledge of some health care professionals have been demonstrated. Although there has been little reported in the literature about the success of education programs for families with children with life-threatening allergies, knowledge gleaned from research about children with other chronic health conditions may be transferable in these cases. It would appear that children are capable of participating in their own care in developmentally appropriate ways and that families will transfer the skills and knowledge required when they are confident that their child is ready to assume responsibility. Self-management has been closely aligned to the concept of self-efficacy in the literature. Theories such as Bandura's social learning theory (1989) may provide a useful framework for studying self-management of chronic illness in children.

## CHAPTER III

### Theoretical Framework

This study will be guided by Bandura's self-efficacy theory. In this chapter, the theory and its concepts will be explained and illustrated, as they pertain to the study purpose. Hypotheses will be stated and dependent and independent variables identified.

#### *Development of the Framework*

The concept of self-efficacy was developed primarily in the discipline of social psychology to explain motivation and learning theory and has been widely adapted by psychology and nursing to predict health behaviours. In her concept analysis of self-efficacy, Kear (2000) credits Robert White (1959) for first introducing the term "effectance" to describe the motivational aspect of competence (p.1). White proposed that persons may be motivated to act if perceived to be competent in effecting a desired change in their environment, and that, with repetition, will master a new skill and gain confidence in their ability to be successful. The concept of efficacy was not explored further in the literature until 1977 when Bandura developed the construct of self-efficacy.

According to Bandura's early social learning theory of behaviour change, people strive to exercise control over events that affect their lives. The ability to affect outcomes makes events predictable. Conversely, the inability to exert influence over events in one's life contributes to apprehension, apathy or despair. Being able to produce valued outcomes and prevent unwanted outcomes is a powerful incentive in the exercise of personal control. However, according to Bandura (1995), individual motivation, affective state and actions are often based more on what an individual believes than on

what may objectively be the case. Cognitive processes mediate behaviour change and cognitive events are induced or altered by experiences of mastery, human agency and control.

Perceived self-efficacy refers to beliefs in one's ability to organize and execute a course of action. Efficacy beliefs influence how people think, feel, are motivated and how they behave. Although not considered to be causal, self-efficacy beliefs consistently contribute significantly to human motivation and attainments (Bandura, 1992).

Bandura (1995) contends that self-efficacy beliefs can be developed through mastery experiences, vicarious experiences, social persuasion, and physiological and emotional states. Mastery experiences build robust beliefs in one's personal efficacy. Success breeds success, and failure undermines it, especially if failure occurs before one's sense of efficacy is firmly established. Developing a sense of mastery does not come easily. It involves developing cognitive, behavioural and self-regulatory tools for developing and executing a plan of action to manage changing circumstances. For example, if one experiences success relatively easily, one will come to expect that further success will come equally easily. If that does not happen, the individual will likely become discouraged and not persevere. Resilience occurs when one learns to overcome obstacles through sustained effort. Adversity serves a useful purpose in this process.

Vicarious experiences involve identifying with the experiences of others, whether those experiences are successful in nature or not. The greater the assumed similarity with the model, the more persuasive the experience. The more dissimilar the individual views their life to that of the model, the less influence there will be on personal efficacy. Competent models can influence others through behaviour and



expressed ways of thinking, and effectively teach skills and strategies to manage environmental demands.

Social persuasion can strengthen one's belief in his or her ability to master a skill and mobilize and sustain effort. An individual can be persuaded that he or she has what it takes to be successful. Although persuasion may boost self-efficacy beliefs, self-affirming beliefs promote skill development and a sense of personal efficacy. Unrealistic boosts in efficacy related to social persuasion, are quickly disconfirmed by lack of success. Social persuasion itself is not sufficient to build sustained self-efficacy, but can play a role in supporting the development of self-efficacy beliefs. Social persuasion can be used to structure experiences where an individual will experience success and be encouraged to measure success in terms of self-improvement.

Physiologic and emotional states play a role in an individual's judgements about his or her abilities as well. Positive mood enhances perceived self-efficacy, despondent mood diminishes it. Efficacy beliefs can be enhanced by improving physical states, reducing stress and negative emotions, and correcting misinterpretation of body states. Perception and interpretation are very important factors when considering how physiologic and emotional states influence a personal sense of efficacy.

Information acquired through mastery, vicarious experiences, social persuasion, and affective states is not inherently instructive. Information becomes significant only through cognitive processing. Information will be selected, weighed, and integrated into self-appraisal of efficacy depending on personal, social and situational factors.

Efficacy beliefs regulate human functioning through cognitive, motivational, affective, and selection processes. Most courses of action are initially organized in thought. Those with high self-efficacy visualize success; those who doubt their efficacy

visualize failure and dwell on what will go wrong. Efficacy beliefs contribute to motivation by determining the goals people set for themselves, how much effort they expend, how long they persevere in the face of difficulties, and their resilience to failures. An individual's beliefs about his or her ability to cope with threats or adversity, affect feelings of stress or depression as well as motivation. What this means is that individuals live a psychic environment that is largely of their own making. A person can exercise control over recurring thoughts, regulating feelings or anxiety and depression. Bandura (1988) demonstrated that through guided mastery, he could improve coping efficacy for individuals with phobias, enabling them to manage threats which formerly would have produced anxiety and autonomic arousal without experiencing distress, autonomic arousal or stress-related hormones. By supporting effective modes of behaviour, threatening environments can be changed into safe ones. The stronger the sense of efficacy, the bolder an individual will become when taking on a problematic situation, especially when accomplished collectively with others.

According to this theory, an individual's level of confidence to perform a behaviour significantly influences specific behavioural choices, persistence of specific behaviours, and goal-directed effort expenditure. Positive views of self-worth and control over life events are associated with fewer symptoms of distress. Efficacy expectation, in this case 'maternal self-efficacy', mediates between the person (the mother) and the behaviour (teaching self-management skills to her child), and is the expectation of capacity to perform a given behaviour. Outcome expectation mediates between the behaviour (teaching self-management skills) and the outcome (maternal perception of her child's self-management skills). The stronger the self-efficacy beliefs, the stronger the relationship between the behaviour (teaching self-management skills)

and the desirable outcome (maternal perception of her child's self-management skills) is expected to be. Bandura's general self-efficacy model (1989) is shown below (Figure 3.1).

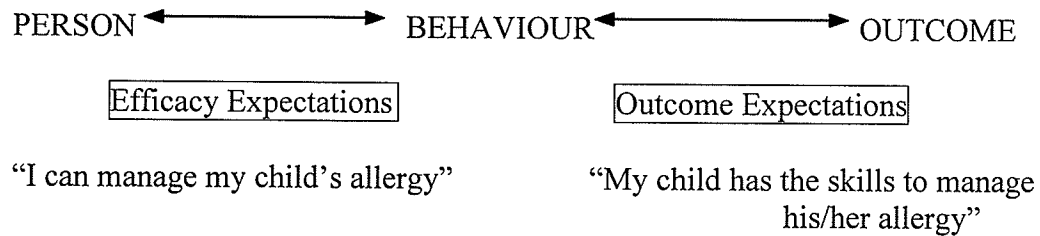


Figure 3.1 General Self-Efficacy Model  
Adapted from: Leonard, Skay & Rheinberger (1998)

The individual's behaviour, self-efficacy beliefs and specific outcomes are dynamic and multideterminant, i.e. direct and indirect parent management behaviours and expectancies influence and are influenced by particular outcomes. Perceived self-efficacy can affect health behaviour by self-judgements of choice (which behaviours are attempted or avoided), amount of effort devoted to a task, and persistence when difficulties are encountered. Research has shown that self-efficacy, as it relates to health, can be enhanced and that enhancement is related to subsequent health behaviour change (Leonard et al., 1998). In the context of children with life-threatening allergies, mothers who believe that they can confidently manage their child's allergy and teach their child to take more responsibility for self-management should be able to do so.

In summary, although there are a growing number of young children with life-threatening food allergies, very little is known about how they learn to self-manage their condition. Knowledge about how children with type 1 diabetes learn self-management may be transferable to the population of children with life-threatening food allergies.

Bandura's self-efficacy model will guide the investigation into the relationship between maternal self-efficacy and mothers' perceptions of self-management of their 4 to 12 year old children with life-threatening food allergies and the effects of a parent education intervention on maternal self-efficacy and maternal perception of child self-management. Variables of age and gender of the child, age at diagnosis, allergen, maternal age, maternal education and income, and sources of education/support concerning the food allergy will also be considered.

### *Hypotheses*

1. Mothers of children with life-threatening food allergies who attend a parent education program will feel more confident in their ability to safely manage their child's allergy three months after attending the education program, than mothers who do not attend the parent education program.
2. Mothers of children with life-threatening food allergies who attend a parent education program will perceive that their child has better self-management skills three months after attending the education program than mothers who do not attend the education program.
3. Mothers' confidence in their ability to manage their child's life-threatening allergy will be positively related to their perception of their child's skills in managing their life-threatening allergy.

*Definitions of Relevant Terms*

EpiPen®: Epinephrine (adrenaline) auto-injector

Maternal Self-Efficacy: A mother's confidence or belief in her ability to keep her child with a life-threatening food allergy safe and to teach her child to manage his/her allergy in developmentally appropriate ways, operationalized as a composite score on the adapted Maternal Self-Efficacy Management Scale (Appendix B).

Self-Management: In the context of children with chronic health conditions, the theoretical definition of self-management includes developmentally appropriate self-monitoring and decision-making, self-efficacy, and collaboration and communication with family, caregivers and health care professionals, operationalized as a composite score on the adapted Family Responsibility Questionnaire (Appendix B).

## CHAPTER IV

### Design and Methods

This chapter describes the research design; identifies the sample population including criteria for participation, sample size as determined by power analysis, recruitment and sampling methods, expected response rate and compensation for attrition. Power level, alpha level and effect size are discussed. The setting is described, and the instruments for measurement presented; including their development, scoring methods, level of measurement, and methods used to determine reliability and validity. Description of procedure includes how randomization occurred, how subjects were contacted, how the questionnaires were administered to both the control and intervention group, and how the parent education program was conducted. The education plan that describes outcomes, content, allocation of time, instructional methods, and the characteristics and credentials of the presenters is described. The ethical review process is outlined, including approval from the thesis committee, and the University of Manitoba Education/Nursing Research Ethics Board. Potential risks and benefits to participants are discussed and information and consent forms presented. The plan for data analysis is described, including parametric and non-parametric methods. Methodological limitations are discussed, as well as how results will be communicated to participants and the academic and clinical communities.

#### *Design*

A randomized clinical trial (RCT) was conducted, using a classic pre-test-post-test design. The RCT involved manipulation of a treatment or intervention, in this case an educational program for mothers of children with life-threatening food allergies.

Other features of the RCT included the use of a control group that is not exposed to the intervention, control over threats to internal validity and the conditions of the intervention, and random assignment of participants to the intervention and control groups (Polit & Hungler, 1999). The RCT allowed statistical comparison of how the two groups changed over the time span of the experiment. The strength of the experiment is in the confidence with which causal relationships can be inferred.

Subjects were randomly assigned to one of two groups to promote unbiased distribution of sample characteristics in both the experimental and control groups at the outset (Brink & Wood, 1998). The advantage of having a control group was that threats to internal validity such as the effects of historical events that are out of the control of the researcher, maturational changes in the participants, loss of study participants during the course of the study and the effects of simply being exposed to the means of measurement were equivalent or were known since each group was theoretically exposed to the same conditions. Pre-testing allowed the researcher to identify differences between the groups such as demographic differences not equalized through random assignment. Attrition rates were closely observed for differences between the intervention group and control group that may indicate threats to either or both internal validity and external validity. These differences were considered when determining the strength of any effects of the intervention. Changes in the control group over time are explained by events other than the intervention, and brought into question whether those events also affected the intervention group (Polit & Hungler, 1999).

Figure 4.1 illustrates the design; one group was experimental, one group was control. In this study all participants were measured (the pre-test) prior to randomization and prior to the experimental group being exposed to the intervention. In this way, both

groups were treated equally, completed the questionnaire package under the same conditions (Polit & Beck, 2004, p. 174), and pre-test data collected in a double blinded manner, with neither the researcher nor the participant knowing what group they would be allocated to. Both groups were measured again (the post-test) 12 weeks (3 months) after the experimental group had been exposed to the intervention.

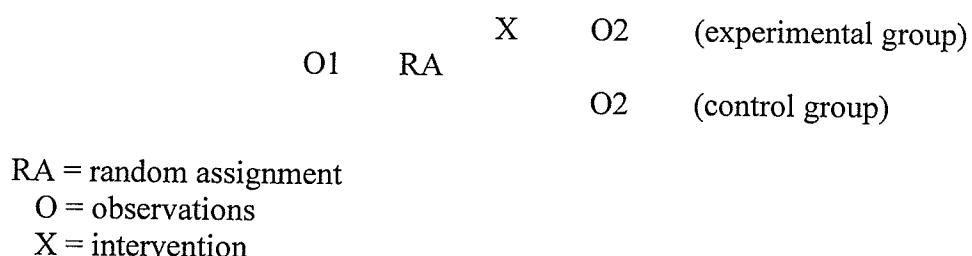


Figure 4.1. Pre-test Post-test Control Group Design

The independent variable (intervention) was the parent education program. The primary dependent variable (outcome measure) was the mother's perception of her children's self-management of the life-threatening allergy, operationalized as a composite score on the adapted Maternal Self-Efficacy Management Scale (questions 5 to 21 in the questionnaire package, Appendix B), as completed by the mother. Another dependent variable (outcome measure) was maternal self-efficacy operationalized as a composite score on the adapted Family Responsibility Questionnaire (questions 22 to 38 in the questionnaire package, Appendix B) as completed by the mother. According to Bandura's self-efficacy model, an increase in maternal self-efficacy would result in an increase in maternal perception of child self-management. Therefore, according to Bandura, maternal self-efficacy became both a dependent variable, in that it was subject



to change as an effect of the intervention, and an independent variable, in that it had a potential effect on child self-management.

### *Sample*

Mothers with a child with a life-threatening food allergy, between the ages of 4 and 12 years at the time of enrolment were eligible to participate. Children between the ages of 4 and 12 years were chosen because most children with life-threatening allergies are known to have their allergy by this age, because they represent the age range of children in elementary school, and because school attendance is identified by most parents as a significant source of stress because of the loss of parental surveillance and control over their child's environment. It is also a time where some children have been observed to participate in their own care and others have been observed to not participate in their own care, their parents expecting others to take complete responsibility for their child's safety concerning exposure to allergens. Because literature suggested that mothers continue to assume greater responsibility for health care management than fathers (Leonard, Brust & Spaienze, 1992), only mothers were eligible to enrol in the study.

Other criteria for participation were that the child must have had an assessment with an allergist within the previous two years to confirm their allergy, the mothers must speak and read English, and the child must have no diagnosed developmental disability that resulted in a level 2 or 3 Special Education designation in the public school system. The latter criterion was related to the longer time needed by children with learning disabilities to master concepts and skills.

A desired sample size of 126 was estimated to be required to compare mean differences between two groups to achieve a power equal to .80, with an alpha level of

.05 and moderate effect of .50 (Polit & Hungler, 1999, p. 492). It was anticipated that there would be some attrition considering that attrition at educational interventions it is commonly reported in the literature. Enrolment of up to 200 subjects would have been possible if eligible mothers had wanted to participate.

### *Setting*

The study was conducted in Winnipeg, Manitoba, a south-central Canadian city of approximately 700,000 people. Individuals from surrounding rural communities were welcome to participate, as long as they met the participation criteria and were willing to attend the Parent Education Program if assigned to the intervention group. Since approximately three quarters of the provincial population live in or around Winnipeg, and there were about 200,000 children registered in school between the ages of 4 and 21 years in the province of Manitoba, it was roughly estimated that of the 150,000 children in school in or around Winnipeg, that a conservative estimate of 1% (approximately 1500 children) had been diagnosed as having a peanut and/or tree nut allergy, and 1-2% (approximately 3000 children) had been diagnosed as having other severe food allergies. There was likely to be overlap in the potential participants due to the fact that many of these children have multiple allergies, including peanut, tree nut and other food allergy. At least half of these children ( $3000 \div 2 = 1500$ ) were likely to meet the age criteria and therefore would have mothers who would be eligible to participate in this study if they chose to participate.

The Parent Education Program was offered as a half day workshop at a central location in Winnipeg, easily accessible by public transportation. Parking was available at no charge. Adult family members were allowed to attend, if this facilitated maternal participation. Any children in attendance were under the supervision of an adult.

### *Procedure*

A submission was made to Manitoba Health and approval granted by the Health Information Privacy Committee (HIPC) (Appendix C) to access personal health information for health research purposes. An invitation to participate in the study (Appendix D) and a cover letter from Manitoba Health (Appendix E) was mailed by Mail Management, an independent third party used by HIPC, on April 25, 2005 to 1005 parents with addresses in the Winnipeg area with a child born after January 1, 1992 and before July 1, 2000, who had seen an allergist (code 017) in the province of Manitoba who had submitted a claim to Manitoba Health after July 1, 2001 using the ICD-9 code 693; "dermatitis due to substances taken internally." Those interested in participating in the study were asked to respond on or before May 6, 2005. ICD-9 code 693 was known to not capture a clean cohort of children diagnosed with a life-threatening food allergy. Therefore, the invitation to participate (Appendix D) and the telephone interview of potential participants (Appendix F) were used to clearly define and confirm that subjects met the criteria to participate.

As well as the Manitoba Health mail out, the Manitoba Anaphylaxis Information Network labelled and mailed invitations to participate to its 205 member families on April 25, 2005. Those interested in participating in the study were asked to respond on or before May 6, 2005. It was likely that many of these families would receive invitations to participate from both sources. At no time did the researcher have access to the names or addresses of MAIN members.

Phone responses were received from 138 parents who either wanted more information about the study and/or indicated their willingness to participate. Anyone calling for information on behalf of someone else was given information but the written

information and consent forms were only sent to mothers who had spoken with the researcher or office assistant. An answering machine recorded messages from interested parties in the absence of the researcher. One mother declined participation after learning more about the study, and two mothers who left phone messages could not be reached after multiple call backs. All callers were screened using the script (Appendix F) to determine whether or not they met all the conditions of the study, and would be available to attend the parent education program on June 11, 2005. Several callers indicated that they had received two invitations to participate through the mail, one through the Manitoba Health mail out and one from MAIN. One father called and asked to participate in the study.

One hundred thirty-five (135) mothers who met the criteria and wished to proceed were mailed instructions for completing the consent forms and questionnaire (Appendix G), two copies of the Consent Form (Appendix H); a copy for the participant, and a copy for the researcher, and the pre-test questionnaire package (Appendix B) together with a stamped, self-addressed envelope. Participants were instructed to read the consent form, complete both consent forms, keep the form marked "Participant's Copy" and send the copy of the consent form marked "Researcher's Copy" and the completed pre-test questionnaire package back to the researcher in the enclosed self-addressed stamped envelope. One reminder phone call was made between May 16 and 23, 2005 using the approved script (Appendix N) to mothers who had not returned Questionnaire #1.

Completed consent forms and questionnaires were received from 128 participants. Four mothers had addresses outside of Winnipeg. Responses were entered

into the SPSS 13.0 database and participants randomized using the SPSS software into Intervention (n=64) and Control (n=64) groups.

Letters (Appendix M) were mailed on May 30, 2005 to all participants informing them of their group allocation. The Intervention group was instructed to come to the Life and Learning Centre at Deer Lodge Centre on June 11, 2005 between 8:00 and 8:30 AM. They also received a map and information about how to find Deer Lodge Centre, where they should go once they entered the Centre, what they could expect at the education program, and when they would receive the second questionnaire in the mail. The Control group was sent a letter (Appendix M) explaining their group allocation, when they would receive the second questionnaire and how and when they would receive the educational materials and EpiPen® trainer after the second questionnaire was completed and returned.

Upon arrival at the Parent Education Program, participants were checked in and directed to one of six stations and asked to demonstrate use of the EpiPen® with the same verbal instructions (Appendix K). A registered nurse scored each participant using the 5-point scoring rubric (Appendix K). Any errors were corrected after the demonstration. Participants were then given the instructional manual containing educational materials, EpiPen® trainer and the session evaluation form. At the break, participants were again asked to demonstrate use of the EpiPen® and similarly scored and corrected if they did not perform all five steps correctly.

The Parent Education Program began at 9:00, and continued until 12:00. The researcher was introduced by the moderator who thanked the participants for their attendance and briefly reviewed their role as intervention group participants, including that they were asked not to share the instructional manual with anyone they may know

who was assigned to the control group. There was a 20 minute coffee break scheduled mid-morning. Coffee, tea, water and juice, as well as muffins and fruit were provided. Attendance at the parent education program took approximately 4 hours plus travel time.

In the three days prior to the parent education program, 18 mothers from the Intervention group had called to indicate that they would be unable to attend the parent education program. Reasons given for being unable to attend included difficulty in finding child care, car trouble, religious reasons, a child's dance competition, a birthday party, family going to the lake, going out of town, and being unable to attend. Being unable to attend (no specified reason) was the most common explanation given. Most mothers requested to receive the educational materials and EpiPen® trainer even though they would be unable to attend the educational program. Six participants did not show up at the educational program, leaving  $64-18-6=40$  mothers in the Intervention (showed) group, and 24 mothers in the Intervention (no show) group.

Post-test data was collected by mailing questionnaire #2 three months after the intervention (September 10, 2005) to all participants. The three month interval was chosen to allow mothers to implement interventions with their child and experience some successes. Consistent with Bandura's theory, mothers needed to experience mastery in order to boost their confidence levels. The educational program and instructional materials encouraged them to try, and reinforced information taught, but sustained improvement was theorized to only occur after mastering certain skills by both mother and child. This was believed to require time and sustained effort.

One phone call reminder was made using the approved script (Appendix N) during the week of September 26, 2005 to all participants who had not yet returned a completed questionnaire #2. One hundred sixteen completed questionnaires were

received; 35 from the Intervention (showed) group, 19 from the Intervention (no show) group, and 62 from the Control group. The educational materials and EpiPen® trainers were mailed to participants from the Control group and Intervention (no show) group after the completed questionnaire #2 was returned.

The names, addresses and phone numbers of participants were entered on the researcher's computer in a data base and used to print labels for mailing and generating reminder phone call lists, to separate the intervention and control groups, and to track questionnaires sent and received. A hard copy of the list will be printed and stored separately from the raw data as required after the study is completed. The database will otherwise be deleted after the study. The questionnaires were coded O1 - 1 to 135 (observation 1) and O2 - 1 to 135 (observation 2) with the same 1 - 135 number the participant had initially. For example, a participant who completed questionnaire#1 with code O1- 15 received questionnaire #2 with code O2 -15.

The following table summarizes those who received invitations to participate, those who enquired about the study, those who completed the consent form and questionnaire #1, the randomization process, those who showed and did not show for the parent education program, and those who completed questionnaire #2.

Table 4.1 Summary of Participation

Letters of Invitation	Manitoba Health database via MDA 1005	MAIN 205		Total 1210
Enquiries				138
Quest. #1 sent				135
Quest. #1 received				128
Randomization	Experimental Group n=64		Control n=64	
Intervention	Exp. Group Showed n=40	Exp. Group No Show n=24		
Quest. #2 sent	40	24	64	128
Quest. #2 received	35	19	62	116

### *Instruments*

Without instruments designed for use with families of children with life-threatening allergies, adaptations to existing instruments were necessary. The questionnaire package (Appendix B), was developed based on The Maternal Self-Efficacy for Diabetes Management Scale by Leonard Skay and Rheinberger (1998) (Appendix A) and The Diabetes Family Responsibility Questionnaire by Anderson, Auslander, Jung, Miller and Santiago (1990) (Appendix A). Leonard et al. used both instruments to study self-management development in children and adolescents with diabetes. Their overall purpose was to investigate maternal self-efficacy and its relationship to maternal perception of the child's self-management of diabetes. The



Maternal Self-Efficacy for Diabetes Management Scale is a 17 item, 5 point Likert-type scale of statements about maternal confidence in independently managing day-to-day tasks in caring for her child with type 1 diabetes. Responses include: 1= Not confident at all, 2 = Somewhat confident with help, 3 = Very confident with help, 4 = Somewhat confident without help, and 5 = Very confident without help. Leonard et al. (1998, p.227-228) reported that content validity was established by two parents of children with diabetes and three nurse practitioners. The authors also reported that maternal ratings of self-efficacy were related to a number of aspects of child self-management as well as age and overall self-care ( $r=.35$ ,  $p=.01$ ). They reported that mothers whose self-efficacy ratings were higher tended to rate their children higher in the same skill areas. A similar trend in the relationship with self-efficacy was found with scores of low independence and high independence as identified on the Diabetes Family Responsibility Questionnaire (Anderson et al., 1990).

Adaptations were made to The Maternal Self-Efficacy for Diabetes Management Scale (Leonard et al., 1998) relevant to children with life-threatening allergies and appear as questions 5 through 20 in the questionnaire package (Appendix B). Scores would range from 17 to 85, higher scores indicating higher maternal self-efficacy or confidence in a mother's ability to independently manage her child's severe allergy.

The Diabetes Family Responsibility Questionnaire (DFRQ) was developed by Anderson, Auslander, Jung, Miller and Santiago (1990) (Appendix A) to determine parent initiated, shared responsibility, and child initiated tasks in caring for a child with type 1 diabetes. The 17 questions break down into three subscales: general health domain, regimen domain, and social presentation domain. In adapting the questionnaire for this study, the responses for each item were increased from three to five, in order to

provide greater information about the transition of independence. Tasks that parent(s) take or initiate responsibility for all the time were given a score of “1”, tasks where the child is beginning to take or initiate some responsibility were given a score of “2”, tasks that parent(s) and child share responsibility about equally were given a score of “3”, tasks where the child takes or initiates responsibility most of the time were given a score of “4”, and tasks that the child initiates responsibility for all the time were given a score of “5”. Anderson et al. (1990) reported internal consistency with alpha coefficient ranging from .69 (subscale, social presentation) to .85 (total DFRQ scale) on the original questionnaire with mothers of diabetic children. Concurrent validity was found with the regimen task subscale and the total DFRQ. The authors of the DQFR utilized factor analysis methodology and Leonard et al. (1998) reported that the instrument could have been analysed as a continuous variable, but they considered only high-low tertile scores. In this study, the DFRQ was adapted for children with life-threatening food allergies and appeared as questions 20 through 36 in Appendix B. Measures of validity were no longer relevant since the questionnaire had been adapted.

Demographic questions (1 through 4 and 37 through 40) were included in the questionnaire package (Appendix B), concerning age and gender of the allergic child, age at time of diagnosis, allergens, maternal age, education and family income, and source and satisfaction with education and information about managing a child with a life-threatening allergy that was received prior to enrolling in the study.

Questions were worded and the questionnaire formatted according to recommendations by Dillman (2000) for ease of completion and improved response rates. Principles of simplicity, regularity and symmetry were applied to make the task of completing the questionnaire easier. The questions were bolded, but not the responses

and the response area was given ample blank space as recommended by Dillman. White paper was chosen for contrast, avoiding bright colours and pastels. Questions were grouped as a unit, each unit introduced briefly. The questionnaire was printed and assembled in booklet form, and bound with two staples. The title indicated the importance of the study. The responses were centred to provide a clear navigational path. Subjects were thanked for their participation in the study but not in a way that is distracting while the final questions were completed. Demographic questions about the child with the allergy were placed at the beginning of the questionnaire to show connectedness between the subject and the purpose of the study, while questions about the mother that may be perceived as personal or intrusive were placed at the end of the questionnaire, when the subject would be more likely to understand why they were being asked (Dillman, 2000, p. 94). A statement explaining their purpose preceded these questions. The booklet was formatted to enhance the visual aspects of design (Dillman, 2000).

The follow-up questionnaire (observation 2 for both the intervention and control groups) did not repeat the demographic questions. Both groups were asked a question about what self-learning they had engaged in since the first observation (Appendix I).

#### *Content Validity Index (CVI)*

Prior to use, content validity was established for the two adapted instruments using a content validity index (CVI) (Polit & Hungler, 1999, p.419). Five content experts were selected and asked to rate each of the items in the questionnaire and the questionnaire as a whole on a 4 point scale; “a. not relevant”, “b. somewhat relevant”, “c. quite relevant” or “d. very relevant” (Appendix J). A paediatric allergist, 2 nurse

educators who had extensive experience working with children with severe allergies and their families, and 2 knowledgeable parents of children with severe allergies were recruited to complete the CVI. With a goal of achieving at least 80% agreement between at least 3 but preferably 5 content experts that the total number of items are rated as 3 (c) or 4 (d) out of 4, the following results were achieved: 95 % of items were rated “c) quite relevant” or “d) very relevant”, 90 % of items were rated “d) very relevant”, and all 5 content experts rated the instrument as a whole as “d) very relevant”.

Although the desired agreement on content validity was achieved, three items were noted to have caused the respondents some concern. These were: “15. I can advocate for better health care for my child if I am concerned about unfairness or unreasonableness”, “20. I can organize our family meals so that my child can eat the same meals as the rest of the family”, and “22. Remember the day of the clinic appointment”.

Two respondents were unable to answer item 15, unsure of what was being asked. Another respondent rated item 15 as “c”. This item was part of the original instrument and had not been modified. I agreed that the question was unclear and decided to drop it from the questionnaire. Item 20 was rated “c” twice and “b” once with a suggestion that adding “or almost the same meal” might be more appropriate where major food groups were implicated. The item was modified accordingly. Item 22 was rated “c” once, “b” twice, and “a” once. Again this was an unmodified item from the original instrument and it was dropped as well.

Other suggestions and comments were reviewed and used to strengthen other parts of the study such as instructing parents with more than one child with a life-threatening food allergy (or allergies) in the study age range to consider the oldest child

when responding. This was added to the script when parents phoned to express interest in participating. Other suggestions were included in content areas in the intervention and instructional materials. The results are summarized in the following table:

Table 4.2 Results of the Content Validity Index (CVI)

Participant	1	2	3	4	5
# of items rated "c" or "d"( of 34)	34	31	32	33	31
Instrument as a whole	d	d	d	d	d
Items rated "c"	14,15,20,22	16	6,10,14	20	
Items rated "b"		22	20		16,22
Items rated "a"			22		
Items unanswered		15,31			15

### *EpiPen® Scoring Rubric*

The skills of mothers in the Intervention group to administer an EpiPen® were assessed at the parent education program prior to beginning and again after group instruction of EpiPen® use using a 5 point scoring rubric (Appendix K). Volunteer registered nurse evaluators were trained to administer the scoring rubric. Mothers were informed about any errors they made at the time of testing, and given brief instruction on how they should correctly perform the skill. Further instruction was given to the group in the Parent Education Program. Participant codes appeared on the pre-test and post-test

scoring rubrics. The scoring rubric consisted of five required skills necessary to successfully administer an EpiPen®; those being 1. Holding the EpiPen® firmly by the barrel (no thumb covering the distal end), 2. Placing the black tip against the vastus lateralis at a 90 degree angle, 3. Removing the grey cap (may occur prior to step 2), 4. Pressing until a click is heard, and 5. Holding for at least 5 seconds.

Study participants attending the parent education program were asked to complete an anonymous program evaluation form (Appendix L), with open ended statements about what they liked about the session, what they felt was not useful, what they would have liked to receive more information or instruction about, instructor evaluation and any other comments they wished to make. Content analysis was used to analyse the results of the education session, looking for themes, although individual comments were considered for their merit.

#### *Parent Education Program*

The Parent Education Program consisted of three hours of instruction. Key stakeholders refined the content and delivered the parent education program. Consistent with Bandura's self-efficacy theory, learning outcomes, course content and teaching methods incorporated mastery experiences, vicarious experiences, social persuasion and parental emotions (Bandura, 1995).

Because success is believed to build the most robust beliefs in one's personal efficacy (Bandura, 1995, p. 3), course content focused on practical strategies that parents could implement in every day family life concerning informing others about the allergy, recognizing and avoiding exposure to allergens, and recognizing and responding to allergic symptoms. Mastery is known to be a cognitive process, closely linked to motivation, effort, perseverance and resilience. Therefore, for parents to feel confident in

their own skills and knowledge, they must first understand why the problem exists, what happens in an allergic reaction (local and systemic), how the rescue drug works, and what is being done to treat or cure the condition. For this reason, the parent education program covered basic knowledge of allergy and prospects for treatment, followed by recognition of early signs of anaphylaxis, how to assess the severity of an allergic reaction, emergency response and use of the adrenaline (epinephrine) auto-injector, (EpiPen®). Each family received an auto-injector trainer free of charge for participating, and written instructions on its use, as well as instructions on how to train their child, family and caregivers in its use. Written materials were provided to support content presented verbally (Appendix O).

The next portion of the parent education program involved practical avoidance strategies; who decides what your child eats, recognition in food labelling, resources to assist in ingredient identification, suspect foods and undeclared ingredients, and eating out. A calm, knowledgeable parent of a child with severe food allergies presented some of these strategies, providing a competent model for participants (vicarious experience). Interacting with other parents whose experiences may be assessed by the participants as similar to their own, or not similar to their own, listening to the questions asked by other parents, talking with other parents before the program and during the break also made vicarious experiences available to the participants.

It was hoped that the parent education program would strengthen the participants' beliefs in their ability to inform others about the seriousness of the allergy, to reduce risk to their child, to competently teach their child, family members and other care givers to recognize an allergic reaction in a timely manner, to be able to administer the EpiPen® properly and activate the emergency response system when required. It is

recognized that boosts in efficacy related to social persuasion are temporary. This is why approaches focused on mastery experiences; i.e. practical strategies parents could implement in their every day lives. Parents hopefully felt persuaded to identify and attempt strategies that were appropriate to their situation, strategies they thought might be successful. The emotional stress felt by parents of children with life-threatening allergies was also acknowledged and validated.

The final portion of the program was devoted to training parents how to promote responsibility in their food-allergic child in developmentally appropriate ways. They were helped to identify their child's abilities, behaviours to expect and support in their child, themselves and in others, how to build a team, the importance of communication, consequences and consistency, recognizing that their child is different, being determined to live as normal a life as possible, appropriate expectations and the importance of continuous evaluation. Strategies about how best to work with school systems were also presented.

A summary of information presented and other resources available to parents was provided to all participants in the form of a booklet titled *A Guide for Parents of Children with Life-threatening Food Allergies* (Appendix O), written by the researcher with assistance from the presenters. Their contributions were acknowledged on page 2.

### *Ethical Implications*

This thesis proposal was reviewed and approved by the thesis committee members and subsequently approved by the Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba on October 25, 2004 (Appendix P). Application was made to the Health Information Privacy (HIPC) Committee of Manitoba Health in October 2004 to access the Manitoba Health database. The HIPC granted conditional



approval in December 2004 subject to changes to the invitation to participate and the consent form. A request to amend the protocol was approved by the ENREB (Appendix Q) on March 15, 2005 consistent with the HIPC requests and prior to any recruitment of subjects. The HIPC approved the request for data on March 22, 2005 (Appendix C).

Informed consent (Appendix H) was obtained from all subjects voluntarily participating in the study. Volunteers, speakers and the office assistant participating in the Parent Education Program and making telephone contact were advised of their responsibility to keep the identities of participants confidential. Questionnaires were coded and at no time did participants' names appear on the response records, assuring confidentiality and anonymity. Only the investigator, office assistant and advisor had access to the list of participants and questionnaire codes. Participants were informed that they had the right to withdraw from the study at any time without prejudice.

Content delivered in the educational session was reviewed for accuracy and appropriateness by a pediatric allergist, and a nurse educator. There were no perceived harmful effects from the educational intervention anticipated. There was potential benefit to the participants in the experimental groups inherent in the study. For their participation, participants in the Control Group received the instructional materials, including the EpiPen® trainer at the completion of the study.

### *Data Analysis*

A statistician from the Department of Community Health Sciences, Faculty of Medicine, University of Manitoba was consulted throughout the project. Descriptive techniques including frequencies and measures of central tendency were used to analyse the demographic data. Chi square and t tests were used to examine differences in

characteristics between groups. Internal consistency of the instrument was tested using Cronbach's alpha. The three hypotheses were analysed as follows:

*Hypothesis 1. Mothers of children with life-threatening food allergies who attend a parent education program will feel more confident in their ability to safely manage their child's allergy three months after attending the education program, than mothers who do not attend the parent education program.*

Distribution of data was analysed using measures of central tendency and the One Sample Kolmogorov-Smirnov test procedure. Repeated measures analysis of variance (ANOVA) was used to control for some of the variation due to individual differences (Munro, 2005). It is a design that involves taking repeated measures of the same variable(s) over time on groups of subjects. The two different groups (the experimental and the control group) constituted the between-group measure. Comparing these groups answered the question of whether the intervention had an effect on the outcome. The within-group component is due to the fact that each group was measured two times on the same variable(s), and the question answered here was whether there were pairwise differences between these measures. Repeated measures ANOVA also examined the interaction between study group and time (Munro, 2005, p. 216). F tests are reported to show significance. Estimated marginal means give an estimate of predicted mean values and allow for visual display of the relationships (SPSS 13.0).

*Hypothesis 2. Mothers of children with life-threatening food allergies who attend a parent education program will perceive that their child has better self-management skills three months after attending the education program than mothers who do not attend the education program.*

Distribution of data was analysed using measures of central tendency and the One Sample Kolmogorov-Smirnov test procedure. Repeated measures analysis of variance (ANOVA) was similarly used to control for some of the variation due to individual differences (Munro, 2005). The design involved taking repeated measures of the same variable(s) over time on groups of subjects. The experimental and the control groups constituted the between-group measure and comparing these groups answered the question of whether the intervention had an effect on the outcome. The within-group component was due to the fact that each group was measured two times on the same variable(s), and the question answered here was whether there were pairwise differences between these measures. Repeated measures ANOVA also examined the interaction between study group and time (Munro, 2005, p. 216). F tests are reported to show significance. Estimated marginal means give an estimate of predicted mean values and allow for visual display of the relationships (SPSS 13.0).

*Hypothesis 3. Mothers' confidence in their ability to manage their child's life-threatening allergy will be positively related to their perception of their child's skills in managing their life-threatening allergy.*

1. Mean scores on the maternal self-efficacy instrument and the maternal perception of child self-management instrument (minus SM9) were calculated.
2. Because the data was not normally distributed, Spearman's Rho correlation coefficient was used to describe the relationships between the child's level of self-management and maternal perception of self-efficacy. Decision-making criteria of significance included a two-tailed probability (p) level of  $< .05$ .
3. Multivariate analysis utilizing backward stepwise multiple regression was utilized to determine the strength of the relationships between independent variables (demographic

characteristics and other factors) and the dependent variables of maternal perception of self-efficacy and maternal perception of child self-management at time 2. Univariate analyses were first conducted to determine which factors were significantly associated with the dependent variables and these factors were then entered into the respective multivariate regression models.

Pre- and post-test scores of performance with the EpiPen® trainer were measured before and at the break at the Parent Education Program on participants in the intervention group, calculated and compared using the Wilcoxon signed-rank test. Common areas of difficulty in administering the EpiPen® were analysed. Content analysis was used to analyse the comments on the Parent Education Program Evaluation Form looking for themes, regularities and patterns. As well, individual comments were considered for their merit.

## CHAPTER V

### Results

This chapter will describe the results of the study, including a description about what is known about those who participated, the effects of randomization, data handling, internal consistency of the instrument and the effects of the parent education program. Chi square and t-tests were used to test for any significant differences in demographic characteristics between the groups. Differences within groups and between groups were tested using repeated measures analysis of variance (ANOVA). The Spearman correlation coefficient was used to describe the relationship between mothers' perceptions of child self-management and maternal self-efficacy. Backwards stepwise multiple regression was used to examine the strength of the relationships between independent variables of age of the child, length of time since diagnosis, age of the mother, maternal education, family income and the dependent variables of maternal self-efficacy and maternal perception of child self-management. The parent education program was evaluated using content analysis. EpiPen® trainer use demonstrated at the parent education program was analyzed using the Wilcoxon Signed Ranks Test.

#### *Characteristics of Participants*

One hundred twenty-eight mothers enrolled in the study and completed the first questionnaire. One hundred sixteen of these mothers (91%) completed the second questionnaire. The mean age of the mothers who participated was 37.90 years; range 22 – 50 years. The mean age of their children was 6.88 years; range 4 – 12 years as per the criteria for participation. The mean age of the child's diagnosis with a severe food allergy was 2.5 years, and the mean time since diagnosis was 4.38 years. Fifty-five

percent of the mothers reported having a boy with severe food allergy, and 45 % reported having a girl with severe food allergy. Many children had multiple allergies; 84% of mothers reported a child with allergy to peanut, 45% reported allergy to tree nuts, 20% reported allergy to egg, 12% reported allergy to fish and/or shellfish, 10% reported allergy to milk, and 3% reported allergy to soy. The modal family income was between \$40,000 and \$75,000 per annum, although 10.9% of the mothers did not answer this question. The majority of mothers had completed high school, with 87.5% of mothers reporting having some college or university, and 68% having completed a college or university degree.

### *Instrument Scores*

#### *Missing Data*

Overall, of the 244 questionnaires received (128 at Time 1 and 116 at Time 2), there were 44 items on the self-efficacy and self-management instrument that had no responses (NR); representing a  $44 \div [(32 \text{ items} \times 128 \text{ Q1}) + (32 \text{ items} \times 116 \text{ Q2})] = 0.56\%$  item no response rate. Of the 44 NR's, 22 were associated with item SM9, from 18 respondents (4 respondents did not respond to this item on both questionnaires); representing 14.06% of all respondents having difficulty interpreting this item. Of the remaining 22 NR's, 8 came from one respondent (3 NR from questionnaire #1, 5 NR from questionnaire #2, with the same 3 items not answered both times), 3 NR's from another respondent, and 2 respondents each not answering 2 items. Overall, 21 respondents (16.4%) chose to not respond to 1 or more items. Excluding item SM9, 14 respondents (10.94%) did not respond to 1 or more items. Of these, 3 mothers who did not respond to an item on questionnaire #1 did not return questionnaire #2. Items with more than 1 NR included:

SE14 (1 NR Q1, 1 NR Q2) = 2 NR

SM2 (2 NR Q1, 1 NR Q2) = 3 NR (2 respondents)

SM8 (2 NR Q1, 2 NR Q2) = 4 NR

SM9 (13 NR Q1, 9 NR Q2) = 22 NR (18 respondents)

SM 12 (1 NR Q1, 1 NR Q2) = 2 NR (1 respondent)

SM 13 (1 NR Q1, 1 NR Q2) = 2 NR

SM 14 (1 NR Q1, 1 NR Q2) = 2 NR (1 respondent)

As a result of the apparent difficulty in interpretation of item SM9, it was deleted from the calculation of the instrument score. As well, item mode (maximum likelihood) responses were calculated for all other items where there was no response, using SPSS 13.0 software and individually imputed to the remaining NR's to complete the instrument scores (Duffy, 2000, p. 93). Regarding the items requesting demographic information, only the item about annual income yielded non-responses; 14 (10.93 %) respondents chose not to answer this item.

### *Randomization*

The purpose of random assignment is to assign subjects such that each subject has an equal chance of being assigned to any group. This process avoids systematic bias with respect to attributes that may affect the dependent variable under investigation (Polit & Hungler, 1999, p. 177). In order to determine if the randomization process successfully distributed attributes and whether there were any significant differences in characteristics in the intervention and control groups, chi-square was used to test for differences between nominal and ordinal level variables (Table 5.1), and t-tests to compare interval level variables (Table 5.2).

Table 5.1 Comparison of Characteristics between the Intervention and Control Groups, using Chi Square Analysis

Variable		Intervention n=64 n (%)	Control n=64 n (%)	$\chi^2$	$p$
Gender of child	Boy	36 (56.3)	35 (54.7)		
	Girl	28 (43.8)	29 (43.3)	.032	.859
Allergy	Milk	6 (9.4)	8 (12.5)	.321	.571
	Egg	12 (18.8)	14 (21.9)	.193	.660
	Peanut	55 (85.9)	51 (79.7)	.878	.349
	Tree nuts	35 (54.7)	22 (34.4)	5.345	.021
	Fish	8 (12.5)	8 (12.5)	.000	1.00
	Shellfish	8 (12.5)	7 (10.9)	.076	.783
	Soy	2 (3.1)	2 (3.1)	--	--
	Wheat	0 (.0)	1 (1.6)	--	--
Mother's Education	≤ high school	9 (14.4)	7 (10.9)		
	Some college or university	12 (18.8)	13 (20.3)		
	College diploma	15 (23.4)	23 (35.9)		
	University degree	28 (43.8)	21 (32.8)	2.974	.396
Family Income	≤ \$40,000	15 (25.4)	9 (16.4)		
	\$40,001 to \$75,000	18 (30.5)	23 (41.8)		
	> \$75,000	26 (44.1)	23 (41.8)	2.156	.340



There were no significant differences between the intervention and control groups in gender of the child, mother's educational level or income, or type of child's food allergy, with the exception of a significantly greater number of children with tree nut allergies in the Intervention group.

Table 5.2 Comparison of Characteristics between the Intervention and Control Group, using Independent T-tests

Variable (yrs)	Intervention n=64 M (SD)	Control n=64 M (SD)	t statistic	p
Current age of child	6.91 (2.26)	6.85 (2.38)	.726	.396
Age at time of diagnosis	2.56 (1.97)	2.43 (1.95)	.020	.887
Time since Diagnosis	4.34 (2.55)	4.42 (2.38)	1.867	.174
Mother's Current age	37.63 (4.77)	38.20 (5.98)	1.44	.232

There were no significant differences between the Intervention and Control groups for age of the child, age at diagnosis of the food allergy, time since diagnosis of the food allergy, or age of the mother. (Table 5.2).

Although 64 mothers were randomly assigned to the intervention group, only 40 of those mothers actually participated in the intervention ("Intervention Showed" group) while 24 did not attend ("Interview No Show" group). In order to determine if there were any significant differences among the characteristics of those who participated in the intervention and those who did not, Chi square and t-test analyses were conducted (Table 5.3 and Table 5.4)

Table 5.3 Comparison of Differences in Characteristics between the Intervention Showed and Intervention No Show Groups, using Chi square test

Variable		Intervention. Showed n = 40 n (%)	Intervention No Show n= 24 n (%)	$\chi^2$	P
Gender	Boy	25 (62.5)	11 (45.8)	1.69	.193
	Girl	15 (37.5)	13 (54.2)		
Allergy	Milk	5 (12.5)	1 (4.2)	--	--
	Egg	7 (17.5)	5 (20.8)	.109	.741
	Peanut	35 (87.5)	20 (83.3)	.215	.642
	Tree nuts	24 (60.0)	11 (45.8)	1.22	.200
	Fish	7 (17.5)	1 (4.2)	--	--
	Shellfish	5 (12.5)	3 (12.5)	--	--
	Soy	2 (5.0)	0 (0)	--	--
	Wheat	0 (.0)	0 (0)	--	-
Parent education	≤ high school	3 (7.5)	6 (25.0)	4.348	.226
	Some college or university	8 (20.0)	4 (16.7)		
	College diploma	9 (22.5)	6 (25.0)		
	University Degree	20 (50.0)	8 (33.3)		
Income	≤ \$40,000	5 (13.5)	10 (45.5)	7.90	.02
	\$40,001 to \$75,000	12 (32.4)	6 (27.3)		
	> \$75,000	20 (54.1)	6 (27.3)		

Proportionally more mothers of boys (62.5 %) showed up at the parent education program than mothers of girls (37.5%) although this difference was not statistically significant. The specific food allergies reported were relatively equally distributed between the intervention showed (per protocol) group and the intervention no show group. Although the more highly educated parents were better represented in the intervention showed group, with over 90% having had some college or university education or better, as compared to only 75% in the no show group, this difference was not significant. However, there was a statistically significant difference in income level between the two groups, with 86.5 % of families in the intervention showed group reporting an annual income of > \$40,000, versus only 54.6% of families in the no show group.

Table 5.4 Comparison of Intervention Showed and Intervention No Show groups, Using independent T-tests

Variable (yrs)	Intervention Showed M (SD)	Intervention No show M (SD)	<i>t</i>	<i>p</i>
Current age of child	7.01 (2.44)	6.73 (1.93)	3.23	.077
Age at time of diagnosis	2.24 (1.62)	3.08 (2.39)	2.01	.162
Time since diagnosis	4.76 (2.61)	3.64 (2.35)	1.87	.175
Mother's current age	38.05 (5.03)	36.91 (4.30)	2.27	.137

There were no statistically significant differences between the groups for current age of age, age at time of diagnosis, time since diagnosis and maternal age.

*Internal Consistency of Instruments to Measure Self-Efficacy and Self Management*

Since the instruments used in this study to measure self-efficacy and self-management in mothers of children with a severe food allergy were adapted from instruments used for studies of diabetes (Anderson et al., 1990, & Leonard et al., 1998), the internal consistency reliability of the adapted instruments was determined using Cronbach's alpha. Both instruments used in this study demonstrated a high degree of internal consistency reliability (Table 5.5), with coefficient alpha greater than the .80 desired (Polit & Hungler, 1999, p. 417). This is similar to the results of Anderson et al. (1990), who reported internal consistency of .85 for the total Diabetes Family Responsibility Questionnaire, the 17 item self-management instrument that the self-management portion of the questionnaire was based upon.

Table 5.5 Internal Consistency Reliability of Self-Efficacy and Self-Management Instruments, using Cronbach's Alpha

Variable	Time	Correlation coefficient $\alpha$
Self-Efficacy	1	.874
	2	.860
Self-Management	1	.913
	2	.910

*Distribution of Data on the Self-Efficacy and Self-Management Instruments*

Tests for normality indicated that the data were not normally distributed. The One-Sample Kolmogorov-Smirnov Test procedure was run to compare the observed cumulative distribution function for each of the primary outcome variables with normal

distribution. Table 5.6 shows the degree of skewness, the One-Sample Kolmogorov-Smirnov Test statistic and p-values on the total scores for the primary outcome variables. The distribution of self-efficacy total scores at time 1 and time 2 showed a long left tail. The distribution of total scores for self-management (minus item SM9) at time 1 and time 2 showed a long right tail. Therefore the majority of the analyses were conducted using non-parametric tests. There were, however, sufficient number of subjects ( $n > 30$ ) to have confidence in the robustness of repeated measures ANOVA for parametric analysis.

Table 5.6 Tests for Symmetry

Variable (total score)	Skewness	SE	K.S.Statistic	p-value
Self-efficacy (time 1)	-.714	.225	.189	<.001
Self-efficacy (time 2)	-1.155	.225	.120	<.001
Self-management (time 1)	.825	.225	.091	.020
Self-management (time 2)	1.552	.225	.115	.001

Figures 5.1 to 5.4 graphically display the distribution of total scores.

Figure 5.1      Distribution of total scores for Self Efficacy at Time 1

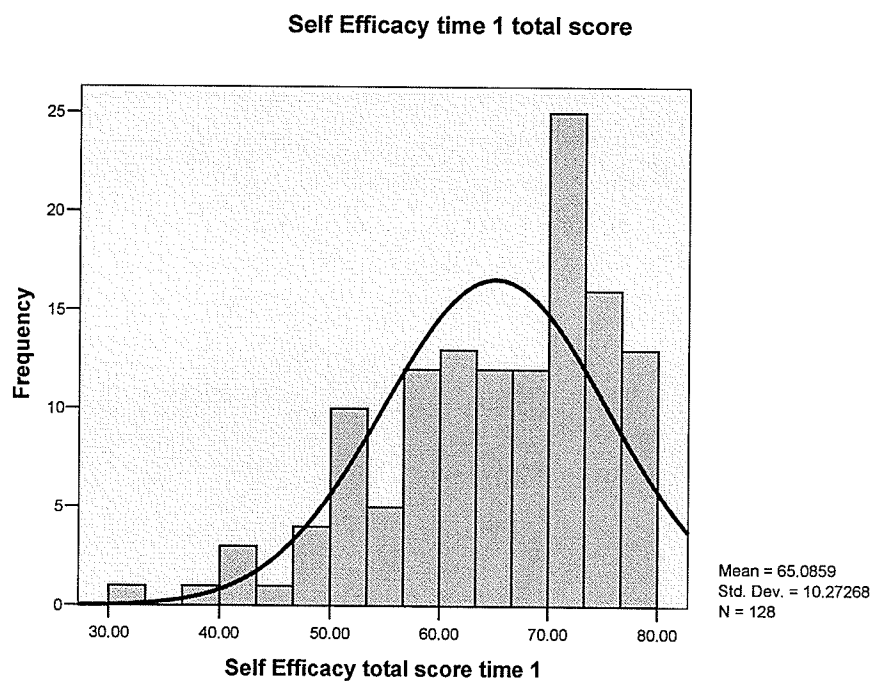


Figure 5.2      Distribution of total scores for Self Efficacy at Time 2

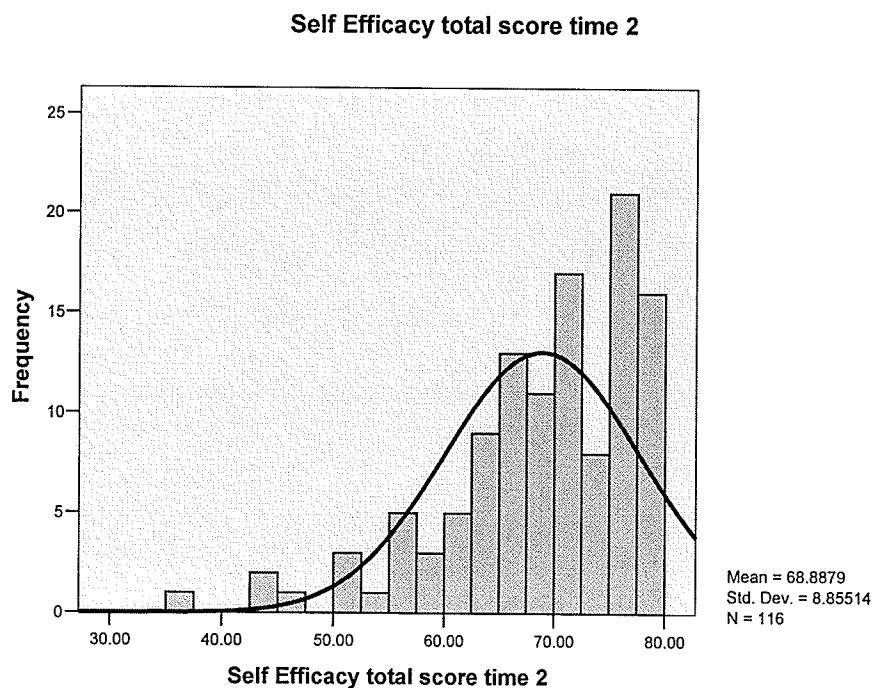


Figure 5.3 Distribution of total scores for Self Management at Time 1

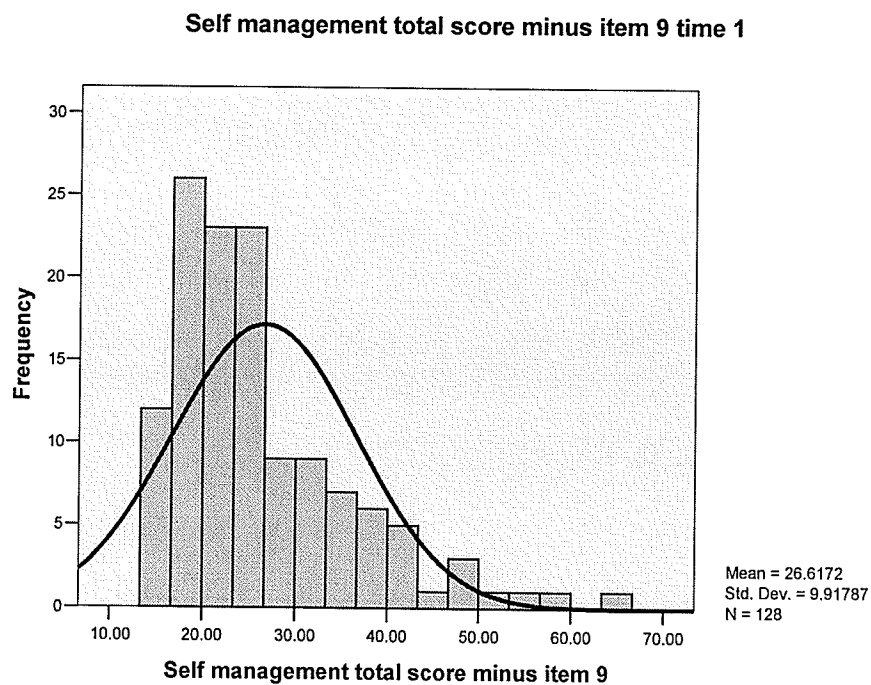
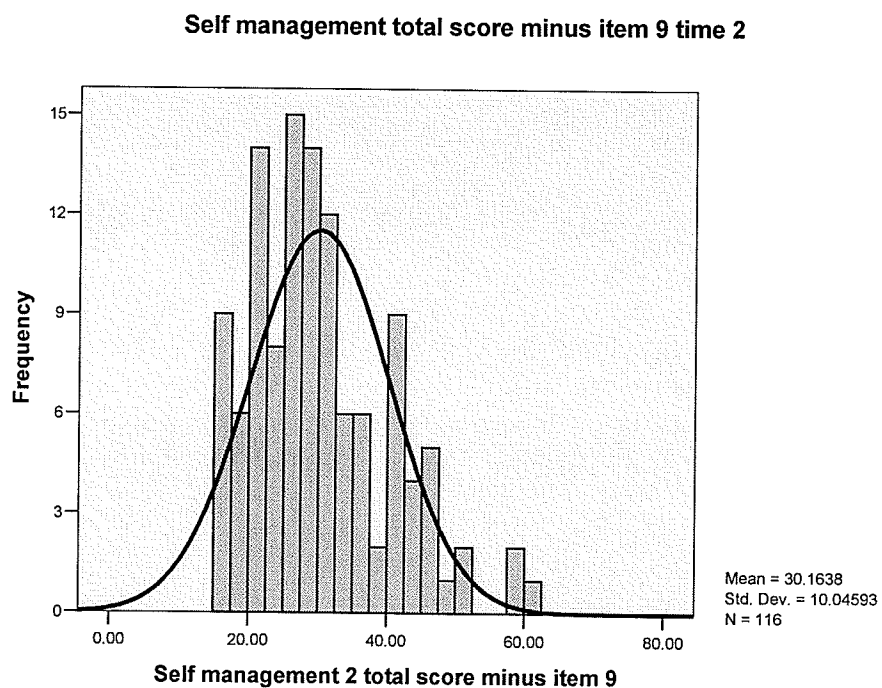


Figure 5.4 Distribution of total scores for Self Management at Time 2



### *Repeated Measures Analysis of Variance (ANOVA)*

The primary outcome variables will be reported in two ways. First, all those who were randomly assigned to the Intervention will be considered the “Intent to Treat” group because they represent an unbiased estimate or real world comparison where some subjects may opt to not continue with the intervention for some reason (DiCenso, Guyatt & Ciliska, 2005, p. 246-250). The “intent to treat” group will be compared to the control group as per the study design. Secondly, the outcome variables will be analyzed comparing the “per protocol” group, i.e. comparing those in the intervention group who did attend the educational program to those in the control group. The results from the “intervention no show” group will also be reported, although with  $n=19$ , the significance of the findings related to this group will be considered with some caution.

#### *Hypothesis 1*

The within and between groups effects of self-efficacy using repeated measures ANOVA is presented in Table 5.7, comparing the intervention (intent to treat) and the control group at time 1 and time 2. Table 5.8 presents the estimated marginal means for self-efficacy for the intent to treat and control groups at time 1 and time 2. Figure 5.5 plots the estimated marginal means of self-efficacy for the intervention “intent to treat” and the control groups at time 1 and time 2.



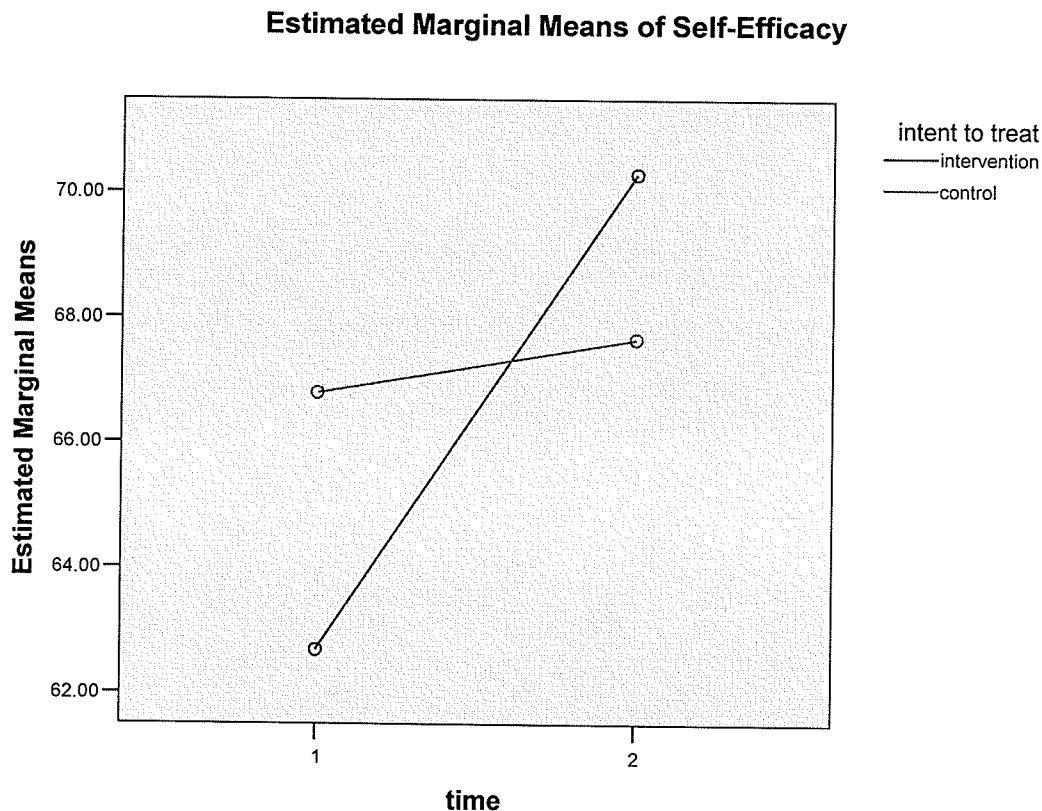
Table 5.7 Sources of Variation for Self-Efficacy (Intervention versus Control)

	Sources of Variation	MS	Df	F	p-value
Between subjects	Group	31.19	1	-0.22	.641
	Error (group)	142.27	114		
Within subjects	Time	1038.25	1	28.29	<.001
	Group X Time	655.59	1	17.86	<.001
	Error (group X time)	36.701	114		

Table 5.8 Estimated Marginal Means for Self-Efficacy (Intervention versus Control). Range of possible scores for Self-Efficacy was 16 – 80.

group	Time	Mean	SE	95% CI (lower)	95% CI (upper)
Intervention	1	62.69	1.37	59.97	65.40
	2	70.30	1.20	67.92	72.67
Control	1	66.79	1.28	64.25	69.32
	2	67.66	1.12	65.45	69.87

Figure 5.5 Estimated Marginal Means for Self-Efficacy (Intervention versus Control)



The upper and lower confidence intervals for the intent to treat group do not overlap for time 1 and time 2, indicating a significant improvement in self-efficacy from time 1 to time 2. The upper and lower confidence intervals for self-efficacy for the control group do overlap, indicating that the overall change in self-efficacy from time 1 to time 2 was not significant in this group.

Table 5.9 presents sources of variation for self-efficacy for the per protocol group, the intervention no show and control groups, while Table 5.10 presents the estimated marginal means for self-efficacy for the same three groups. Figure 5.7 plots the marginal means of self-efficacy for the intervention per protocol group, the intervention no show group and the control group.

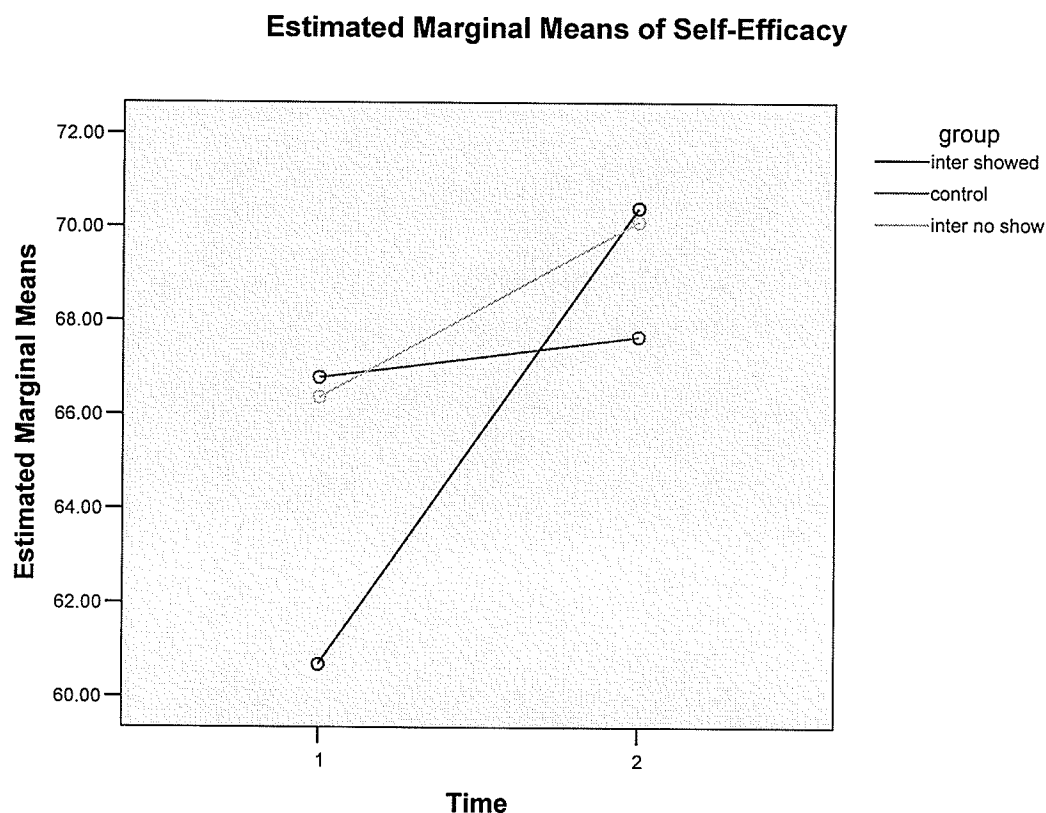
Table 5.9 Sources of Variation for Self-Efficacy (Intervention Showed, Intervention No Show, Control)

Sources of Variation		MS	Df	F	p-value
Between subjects	Group	104.97	1	.739	.480
	Error (group)	141.95	113		
Within subjects	Time	1053.6	1	30.04	<.001
	Group X Time	437.8	2	12.48	<.001
	Error (group X time)	35.079	113		

Table 5.10 Estimated Marginal Means for Self-Efficacy (Intervention Showed, Intervention No Show, Control)

group	time	mean	SE	95% CI (lower)	95% CI (upper)
Intervention Showed	1	60.67	1.68	57.35	64.02
	2	70.40	1.49	67.44	73.36
Control	1	66.79	1.26	64.287	69.29
	2	67.66	1.12	65.44	69.88
Intervention No Show	1	66.37	2.28	61.85	70.89
	2	70.11	2.03	66.09	74.12

Figure 5.6 Estimated Marginal Means of Self-Efficacy (Intervention Showed, Intervention No Show, Control)



Comparing change in self-efficacy from time 1 to time 2 in the intervention showed group, the intervention no show group and the control group, the no show group and the control group reported greater confidence in their ability to keep their child safe at the outset. Although the control group showed little change in self-efficacy between time 1 and time 2, the intervention no show group did improve in their confidence level. This should be considered cautiously however, since the number of subjects in the intervention no show group completing the second questionnaire was only  $n=19$ . The upper and lower confidence intervals for the intervention showed group do not overlap indicating a significant improvement in self-efficacy between time 1 and time 2, whereas

the upper and lower confidence intervals for the intervention no showed and control groups do overlap indicating that the change in scores from time 1 to time 2 was not significant. Although it would appear that the mean score at time 2 for the intervention showed group and intervention no show groups are similar, the small number of subjects ( $n=19$ ) in the intervention no show group is insufficient to reliably interpret intervention no show data with any confidence. Hypothesis 1 is therefore supported by the findings in that mothers of children with life-threatening food allergies felt more confident in their ability to safely manage their child's allergy three months after attending the education program, than mothers who did not attend the parent education program.

### *Hypotheses 2*

The following tables present the results of the repeated measures ANOVA for self-management scores for the Intervention (Intent to Treat) Group and the Control group. Table 5.11 shows the sources of variation for self-management for the intent to treat and control groups. Table 5.12 and Figure 5.6 show the estimated marginal means for the intervention "intent to treat" and control groups for self-management at time 1 and time 2.

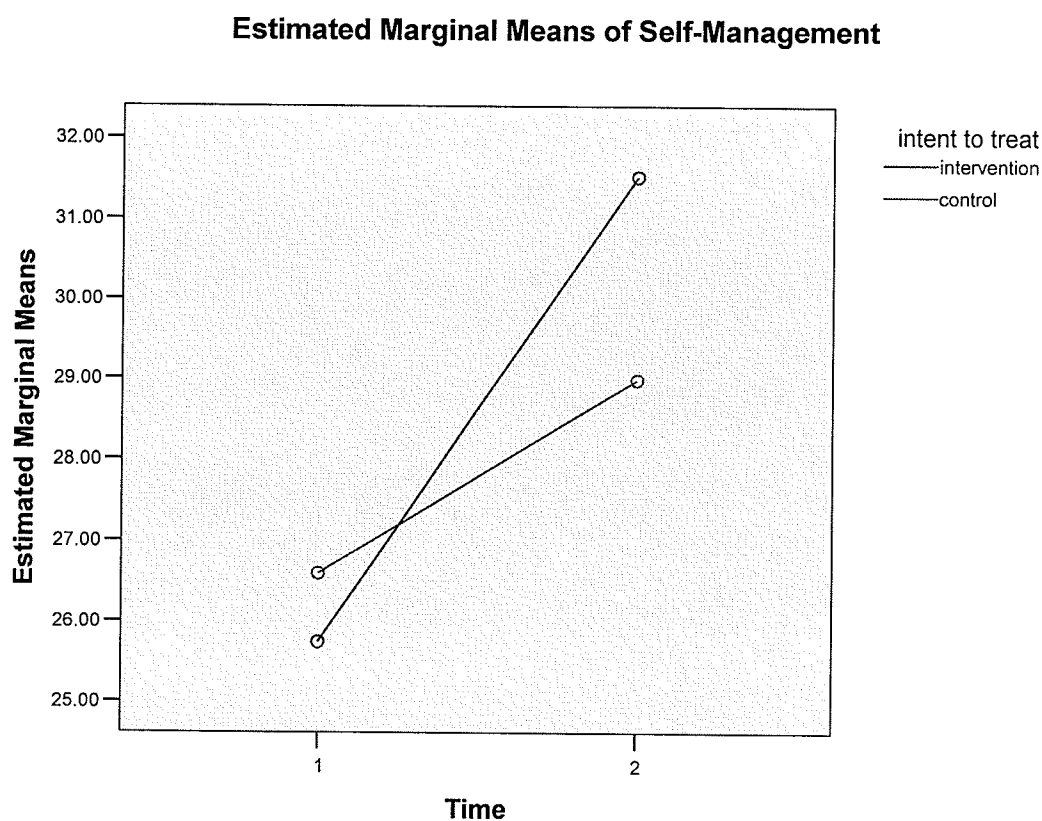
Table 5.11 Sources of Variation for Self-Management (Intervention versus Control)

	Sources of Variation	MS	Df	F	p-value
Between subjects	Group	40.66	1	0.24	.626
	Error (group)	170.26	114		
Within subjects	Time	962.05	1	42.98	<.001
	Group X Time	165.91	1	7.411	.008
	Error (group X time)	22.386	114		

Table 5.12 Estimated Marginal Means for Self-Management (Intervention versus Control) Range of Possible Scores for Self-Management was 15 to 75.

group	time	mean	SE	95% CI (lower)	95% CI (upper)
Intervention	1	25.74	1.31	23.15	28.33
	2	31.52	1.36	28.82	34.22
Control	1	26.60	1.22	24.18	29.02
	2	28.98	1.27	26.47	31.50

Figure 5.7 Estimated Marginal Means for Self-Management (Intervention versus Control)



The intervention and control groups had a similar mean score for self-management at the outset. The control group improved in perceived self-management

between time 1 and time 2, but not nearly as much as the intervention group. The upper and lower confidence intervals for the control group overlap between time 1 and time 2, indicating that the change over time was not significant. The upper and lower confidence intervals for the intent to treat group did not overlap, indicating the improvement in self-management for this group from time 1 to time 2 was significant.

Table 5.13 shows the source of variation between subjects and within subjects. Table 5.14 and Figure 5.8 show the marginal means for the intervention showed ("per protocol") group, the intervention "no show" group and the control group for self-management at time 1 and time 2.

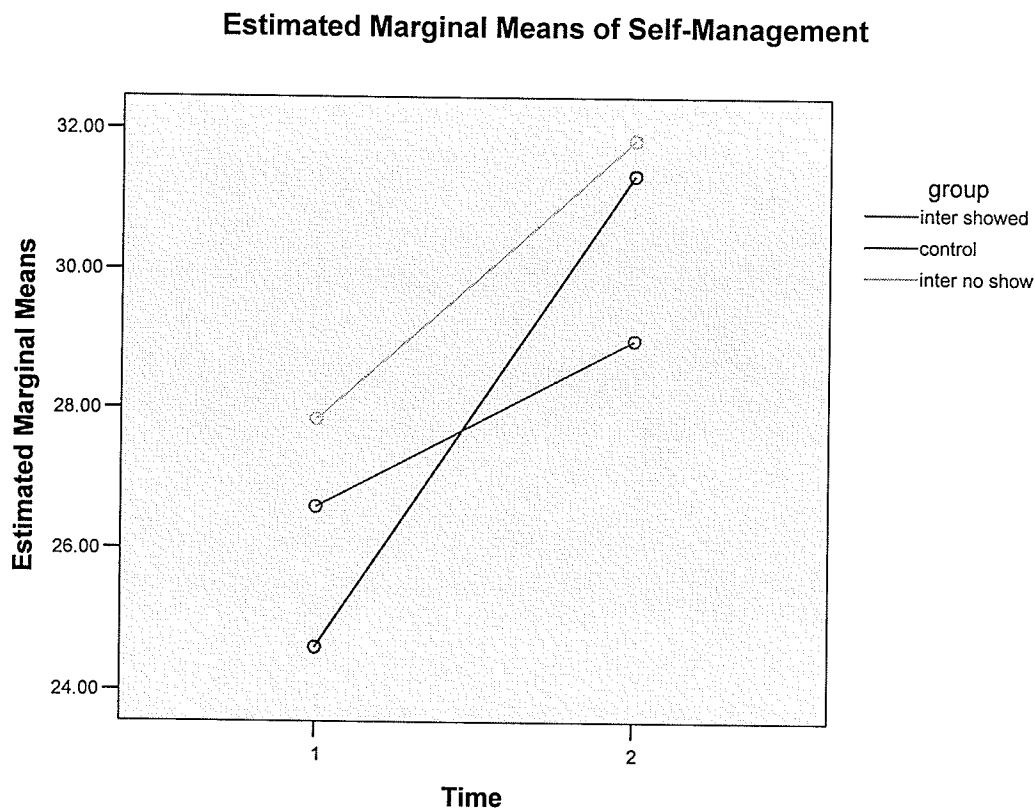
Table 5.13 Sources of Variation for Self-Management (Intervention Showed, Intervention No Show, Control)

Sources of Variation		MS	Df	F	p-value
Between subjects	Group	63.43	2	.371	.691
	Error (group)	171.0	113		
Within subjects	Time	885.61	1	39.94	<.001
	Group X Time	106.12	2	4.78	.01
	Error (group X time)	22.174	113		

Table 5.14 Estimated Marginal Means for Self-Management (Intervention Showed, Intervention No Show, Control)

group	time	mean	SE	95% CI (lower)	95% CI (upper)
Intervention Showed	1	24.60	1.62	21.39	27.82
	2	31.34	1.70	27.98	34.71
Control	1	26.60	1.22	24.18	29.01
	2	28.98	1.28	26.45	31.51
Intervention No Show	1	27.84	2.20	23.48	32.21
	2	31.84	2.31	27.27	36.41

Figure 5.8 Estimated marginal means of self-management (Intervention Showed, Intervention No Show, Control)





The no show group and the control group demonstrated a similar slope between time 1 and time 2, and a similar degree of improvement. The upper and lower confidence intervals for the intervention no show group and the control group overlap however, indicating that the change between time 1 and time 2 was not significant. The degree of slope is greater and upper and lower confidence intervals in the intervention showed group do not overlap, indicating a significant level of improvement in this group from time 1 to time 2. Hypothesis 2 is thus supported by the findings in that mothers of children with life-threatening food allergies who attend the parent education program perceived that their child had better self-management skills three months after attending the education program than mothers who did not attend the education program.

### *Hypothesis 3*

Spearman's rho correlation was used to test for an association between maternal self-efficacy and perceptions of child self-management (Table 5.15).

Table 5.15 Correlation Coefficients for Self-Efficacy (SE) and Self-Management (SM), using Spearman rho

Test	SE1	SE2	SM1	SM2
Spearman's rho				
SE1	1.00	.520*	.112	.170
SE2		1.00	.271*	.445*
SM1			1.00	.758*
SM2				1.00

\* Significance  $p < .01$

There was no significant relationship between self-efficacy at time 1 and self-management at either time 1 or time 2. Self-efficacy at time 2 was significantly correlated to both self-management at time 1 and time 2, although the strength of the relationship would appear to be moderate in this sample of mothers of children with life-threatening food allergies. As expected, self-efficacy at time 1 was significantly correlated to self-efficacy at time 2, and self-management at time 1 was correlated to self-management at time 2. Hypothesis 3 was partially supported by the findings, in that mothers' confidence in their ability to manage their child's life-threatening allergy at time 2 was positively related to their perception of their child's skills in managing his/her life-threatening allergy.

### *Multiple Regression Analyses*

Backwards stepwise multiple regression analyses were performed to further explore the effects of demographic and other factors on the dependent variables of maternal self-efficacy and perception of child self-management. These analyses estimate the coefficients of the linear equation, involving one or more factors that best predict the dependent variable(s), adjusting for other covariates, and measuring the unique impact of each variable after controlling for the influence of all the other explanatory variables in the model (SPSS 13.0). In the model to predict self-efficacy at time 2, the variables entered on step one included maternal education (high school or less versus some college or more), current age of the child, self-efficacy at time 1 total score, and intervention showed versus other group status. The variables remaining in the final model for self-efficacy are presented in Table 5.16. After controlling for other variables, self-efficacy at time 1, the intervention and current age of the child were significant

predictors of self-efficacy at time 2, and accounted for 39% of the variance ( $r^2 = .393$ ).

Table 5.16 Multiple Regression Analysis for Predictors of Self-Efficacy at Time 2, Final Model

Factor	B	SE	t	p-value
Self-Efficacy Time 1	.509	4.586	6.63	<.0001
Intervention	5.193	1.473	3.526	.001
Current Age of Child	.573	.293	1.937	.055

In the model to predict self-management at time 2, the variables entered on step one included current age of the child, time since diagnosis, mother's age, self-efficacy at time 1 total score, and intervention (intervention showed versus other group) status. The variables remaining in the final model for self-management at time 2 are represented in Table 5.17. After controlling for other variables, self-management at time 1, the intervention, current age of the child, and mother's age were significant predictors of self-management at time 2, and accounted for 64% of the variance ( $r^2 = .636$ ).

Table 5.17 Multiple Regression Analysis for Predictors of Self-Management at Time 2, Final Model

Factor	B	SE	t	p-value
Intervention	3.236	1.261	2.567	.012
Current Age of Child	1.187	.349	3.403	.001
Self-Management Time 1	.673	.073	9.159	<.001
Mother's age	-.260	.127	-2.046	.043

#### *Parent Education Program Evaluation*

Parents who attended the intervention (Intervention Showed group) were given an evaluation form (Appendix L) in their package. Thirty-eight of the forty mothers submitted a completed form; representing 95% of participants at the intervention. The form was anonymous and contained five open ended sentences about the session and speakers. There was a place for additional comments and a 5 point Likert-type scale to rate the educational session from low (1) to high (5). Twenty-five of the forty mothers (62.5 %) rated the session (5) or high. One mother (2.5 %), rated the session 4.5 out of 5, and 11 mothers (27.5 %) rated the session as 4. One participant (2.5 %) rated the session as 3.5. Overall, 37 (97.4 %) of the 38 mothers who completed the evaluation form rated the session 4 or above out of 5, or 37 (92.5%) of the 40 mothers who attended the parent education session indicated that they rated the session 4 or above out of 5.

When asked what they liked about the parent education program, 35 participants out of 38 responded. There were common themes in the sentence completion. Examples

were: “I liked ... ‘everything’, ‘the chance to ask questions’, ‘hearing about other mothers’ experiences’, ‘all the information’, ‘all the speakers’, ‘resources and displays’, ‘that the presenters made themselves available at the break’, ‘meeting so many mothers that wear the same shoes that I wear’, ‘learning how to use the EpiPen®’, ‘the opportunity to come here’, ‘discussing the child’s feelings’, ‘knowing when to give the EpiPen®’, ‘that this topic is being discussed and knowing that research is being done’ ”.

One mother stated: “I have never received so much information”. Another wrote:

“seeing the number of participants was reassuring to me because sometimes living with a child like mine makes me feel isolated”. Another mother wrote: “I like the whole thing. Tons of valuable information that I should have learned a long time ago”.

Only three mothers completed the “Not useful ...” sentence. Their comments were: “the medical information was over my head”, “I personally did not feel that I needed information on avoidance strategies”, and two comments refuted detailed information from two speakers.

“I would still like ...” yielded many responses including a desire for a parent support group, websites for more information, annual clinics for schools, day cares, and health nurses, more information about the possibility of a child out-growing an allergy, similar sessions for fathers, babysitters and grandparents, more information like this and videotapes and booklets to be available when the diagnosis is made, an opportunity to ask more questions, more information on handling allergies as a child gets older, simple food recipes, and more information on handling issues at school. One mother wrote: “I now feel comfortable and in control”.

“I feel the presenters were ...” was completed by comments such as: “excellent”, “well prepared”, “appropriate”, “knowledgeable”, “helpful”, “relevant”, “practical”,

“able to put things in perspective”, “thorough”, “positive”, “able to provide lots of information parents were looking for”. There was one negative comment: “I feel the presenters were not taking parents’ experiences seriously, such as egg is ubiquitous, wind pants are slippery, emergency care in hospitals is not always adequate.”

“For next time ...” was completed with comments such as “we should have been asked to come for 8:30, it was too long to wait”, “please invite me again”, “more time for questions”, “do everything the same and maybe include children 10 and over”, “invite fathers and caregivers”, “more free time to interact with other parents”, “more time on eating out at restaurants”, “could be a whole day”, and “better parking”.

Many respondents completed the “Comments ...” sentence, including: “thanks for keeping to the schedule and ending on time”, “excellent way to spend a Saturday morning”, “I really liked Alison’s lay out”, “listening to speakers raises some emotions of anxiety from dealing with past food experiences with my child however I feel that the opportunity to learn and reinforce what I know has been valuable for me here today”, “excellent”, “thank you”, “the resource manual will be helpful”, “thank you so much for bringing us together!”, “We are not alone”, “sharing personal experiences is a useful method of training”, “worthwhile experience for participants”, “really really great”, “very much appreciated”, “well run”, “on time”, “time well spent”, “Very good”, “Helpful”, “was glad to be able to participate”, “Will share information with family and friends”, “This should be a must for all parents”, “I have never attended an allergy awareness group and not learned something new”, “Everybody needs to know that you cannot do harm if you inject and didn’t need to – most people in the room didn’t know this”, “great education program”, “very glad that I was involved in this study”, “I wish there were lists of peanut-free foods/brand/products”, “thank you soooo much!”, “the

large number of questions shows that people do not feel sufficiently informed”, “I am so thankful to be invited today. I don’t believe I have received satisfactory help from my doctors. This was fabulous.”

Overall themes identified were: (1) gratitude for the opportunity to learn more about how to manage their child’s allergy, (2) liking the interactive nature of the educational session; that there was an opportunity to ask questions of the speakers and learn from other parents’ experiences, (3) that they received practical advice about how and when to use the EpiPen®; that there was individual instruction, and written information provided, (4) that many parents felt there was a lack of knowledge about resources parents could access, including the existence of a parent information and support group, and where they could access recipes and ingredient lists, and (5) that mothers wanted instruction for fathers and other care givers including school and day care staff.

#### *EpiPen® Use Demonstration*

Upon arrival at the parent education session and at the mid-morning break, all 40 mothers who attended the parent education session were asked to demonstrate how they would use an EpiPen® using the EpiPen® trainer. Seven registered nurses were instructed by the researcher on the morning of the parent education session to use the EpiPen® trainer using the 5 point scoring rubric (Appendix K). The researcher demonstrated each point to the registered nurses, observed a return demonstration of correct EpiPen® use and led a discussion about what would constitute proper demonstration of each point and typical errors the researcher had observed in 10 years of teaching this skill to teachers, teacher assistants and parents as a nurse educator. Using the EpiPen® Scoring Rubric form (Appendix K) the registered nurse said to each mother

“Please show me exactly how you would give the EpiPen® using this EpiPen® trainer. Please demonstrate on yourself.” The mother was scored by the registered nurse on the form for correct demonstration of the EpiPen® trainer. Any skill that was not correctly demonstrated was then taught to the mother until she could properly demonstrate the 5 point sequence. During the first half of the morning session, a pediatric allergist taught correct use of the EpiPen® to all 40 mothers in the group, using the same cue words as the scoring rubric. The mothers were asked to go back to the check-in tables during the break and demonstrate correct use of the EpiPen® to the same registered nurse. All 40 mothers participated as asked. Scores were calculated out of 5 for each of the two times each participant demonstrated EpiPen® use. The participant’s scores appeared on the same form as time 1 and time 2. The mean score at time 1 was 4.35, while the mean score at time 2 was 4.85. The non-parametric Wilcoxon matched-pairs signed ranks test was used to test for differences in the two paired groups because the measurement of the dependent variable was ordinal. The Wilcoxon test indicated that the improvement in scores from time 1 to time 2 was significant (Mean rank 8.77 vs. 10.75;  $Z = -2.75$ ,  $p = .006$ ). The following table shows the number of mothers who were able to correctly demonstrate each step in the sequence of administering the EpiPen® trainer.



Table 5.18 Proportion of Mothers Attending the Educational Session (n=40) Who Correctly Demonstrated Use of the EpiPen®

Skill	Time 1 n (%)	Time 2 n (%)
1. Holds EpiPen® firmly by the barrel	29 (72.5%)	37 (92.5%)
2. Presses black tip against vastus lateralis	35 (87.5%)	37 (97.5%)
3. Removes grey cap	36 (90%)	40 (100%)
4. Presses until a click is heard	38 (95%)	39 (97.5%)
5. Holds for at least 5 seconds	36 (90%)	39 (97.5%)

Individual instruction did not result in all mothers being able to correctly demonstrate all steps in the sequence of EpiPen® trainer use even after individual instruction followed by remedial instruction and group instruction. Of the individual skills, holding the EpiPen® firmly by the barrel, such that sufficient pressure can be exerted in order to activate the auto-injector device (step 1), and land marking the correct area for injection (step 2) appeared to be to the two areas where the greatest difficulty was observed.

### *Summary*

This chapter described the findings of the study. Randomization equally distributed characteristics of the participants between the intervention and control groups. One item was excluded from the test scores because of higher than expected no responses. Mode scores were imputed to complete the test scores for other missing data. The internal consistency of the instruments was shown to be high. Differences within groups and between groups using repeated measures analysis of variance (ANOVA) showed that the intervention significantly improved scores for both self-efficacy and self-management from time 1 to time 2. There was no significant improvement in the control or intervention no show groups for either self-efficacy or self-management from time 1 to time 2. The relationship between mothers' perceptions of child self-management and maternal self-efficacy was statistically significant. Backwards stepwise multiple regression identified final models for both self-efficacy and self-management and explained a percentage of the variance. One-on-one and group training resulted in a significant improvement in EpiPen® trainer use from pre-test at the beginning of the parent education program until post-test mid-morning at the parent education program. Content analysis of the parent education program revealed five themes and other phenomena of clinical interest. The following chapter will discuss the implications of these findings.

## CHAPTER VI

### Discussion

A randomized controlled trial was conducted to examine the effects of a parent education program on mothers of children between the ages of 4 and 12 years who had been diagnosed with a life-threatening food allergy. The primary outcome variables examined were maternal self-efficacy and maternal perception of child self-management as measured using instruments adapted from the literature for children with type 1 diabetes. The instruments were tested by five experts using a content validity index and further adaptations made prior to being used in the study.

The theoretical framework for the study was Bandura's theory of self-efficacy (1995). Bandura contended that an individual's level of confidence to perform a behaviour significantly influences behavioural choices, persistence of specific behaviours and goal-directed effort expenditure. According to his theory, perceived self-efficacy can affect health behaviour by self-judgements about which behaviours are attempted or avoided, the amount of effort that is devoted to the task, and persistence when difficulties are encountered.

This chapter will include discussion about whether the hypotheses were supported or rejected by the findings, and the relationship of the findings to the theoretical framework and to demographic variables of interest. The results of the study will be discussed in relation to previous literature. Implications for practice, research and policy will be identified. Strengths and limitations of this study and plans for dissemination of results will be discussed, and the findings summarized.

## *Hypothesis Testing*

### *Hypothesis 1*

At the outset, mothers generally saw themselves as having a high degree of self-efficacy in managing their child's life-threatening food allergy; as the mean self-efficacy score was 68.89 out of a possible score of 80. When comparing the intent to treat and control group self-efficacy mean scores at time 1, the control group would appear to have been more confident than the intervention group from the outset. The degree of slope and upper and lower confidence intervals however revealed that change was not significant in the control group, whereas both the intent to treat group and the per protocol group showed a significant improvement in self-efficacy from time 1 to time 2. A significant change in self-efficacy total scores for both the intent to treat and per protocol groups of mothers supported the hypothesis that efficacy beliefs could be increased three months after attending a parent education program.

Leonard et al. (1998) reported high self-efficacy among 104 mothers of 8 – 17 year old children with type 1 diabetes. These authors did not compute total score, but instead reported the proportion of scores on the 17 point Maternal Self-Efficacy for Diabetes Management Scale at or above 4 ("somewhat confident without help"). Other differences among subjects, including age range of children and diagnosis, do not permit further comparison of findings.

### *Hypothesis 2*

Self-management scores at time 1 indicated that mothers perceived that the responsibility for most tasks associated with managing their child's allergy remained with the parents or at best with the child beginning to take some responsibility in self-

management tasks; mean self-management score being 26.62 (range 15-66). It was observed that all mothers, including those in the intent to treat, per protocol, intervention no show and control groups rated their child's self-management skills higher at time 2 than time 1. Becoming sensitized to the behaviours of interest to the researcher through exposure to the instrument is the most likely explanation for the improvement in scores in the intervention no show and control group mothers from time 1 to time 2. This is known as testing effects (Polit & Hungler, 1999, p. 229). However, only the intent to treat and per protocol group had a change in mean score for self-management from time 1 to time 2 that was statistically significant however.

The intent to treat group and the control group had similar time 1 scores for self-management. Looking at the per protocol and no show groups however, there would appear to be a difference in mean scores at time 1 for self-management. The small number of subjects in the intervention no show group ( $n=19$ ) is not sufficient to infer significance of these findings, but it is of interest that those who showed perceived their self-management skills to be lower than those who did not show. One explanation might be that the mothers who perceived their child's ability to self-manage the allergy to be relatively high may have been less motivated to make the effort to attend the parent education program on a Saturday morning in June. This finding may be useful when structuring future parent education programs. Other teaching methods may be more appropriate for parents who perceive their child/family's current management of the allergy to be satisfactory.

A statistically significant change in total scores on the study instrument for the intent to treat and per protocol groups supported the hypothesis that maternal perception

of child self-management of a life-threatening food allergy could be increased three months after attending a parent education program.

Comparing similar studies found in the literature, Leonard et al. (1998) measured maternal perception of child self-management in 104 mothers of 8-17 year of children diagnosed with type 1 diabetes using the Diabetes Family Responsibility Scale (Anderson, 1990). Total scores were computed based upon categories of parent responsibility, child responsibility and shared responsibility. Children were categorized into three age groups; 8-10 years, 11-12 years, and 13 years and over. Overall, the mothers perceived their children as average or above average in managing their own diabetes when compared with age mates with diabetes. Differences in analysis, as well as the children's age and diagnosis, do not permit comparison of self-management scores with this study. Findings regarding correlation between self-efficacy and self-management will be compared in the next section.

### *Hypothesis 3*

Self-efficacy at time 2 was significantly correlated to self-management at both time 1 ( $\rho = .271, p = .01$ ) and at time 2 ( $\rho = .445, p = .01$ ). The correlation between self-efficacy and self-management was relatively low at time 1, but increased to the moderate range at time 2, as self-efficacy increased. This may suggest that there exists a threshold for self-efficacy where a relationship with self-management begins to develop. This would be an area where further study might reveal the dynamics of this relationship. The relationship between maternal self-efficacy and perception of child self-management ( $r = .35, p = .01$ ) reported by Leonard et al. (1998) in 8-17 year old children with type 1 diabetes is similar to the findings of this study.

The relationship between self-efficacy and self-management is not known to be causal. There does remain however, an association that is likely complex. Dishman et al. (2005) found that self-management strategies mediated the association of self-efficacy with physical activity in samples of 6<sup>th</sup> and 8<sup>th</sup> grade girls (n= 309 and n= 296, respectively). They used factor analysis to test the validity of a measure of self-management strategies regarding self-efficacy and physical activity. Consistent with Bandura's theory, self-efficacy had direct effects on social cognitive variables such as perceived barriers, outcome expectancy and enjoyment.

This study supports the theory that there is a relationship between self-efficacy and self-management, and that the relationship can be strengthened, increasing the likelihood that children with life-threatening food allergies can be trained to avoid exposure to their allergens, to have their rescue drug accessible and communicate to their caregivers about their health condition and about symptoms, should they appear. Hypothesis 3 was supported by the findings, in that mothers' confidence in their ability to manage their child's life-threatening allergy was positively related to their perception of their child's skills in managing his/her life-threatening allergy.

#### *Predictors of Self-Efficacy and Self-Management*

Multiple regression analysis revealed more information about the relationships of independent variables to the primary outcome variables of self-efficacy and self-management. Univariate analysis of variables associated with self-efficacy at time 2 found correlations with self-efficacy at time 1, as expected, as well as with current age of the child. The model identified through backward step-wise multiple regression, found that 39% of the self-efficacy total score at time 2 could be predicted by the self-efficacy total score at time 1, the current age of the child, and exposure to the

intervention. Factors such as maternal education, family income, mother's age, time since diagnosis, and gender of the child did not prove to be predictors of maternal self-efficacy, after controlling for the influence of other factors.

Univariate analysis of variables associated with self-management at time 2 showed a relationship between the current age of the child, time since diagnosis, self-efficacy (time 1 and time 2), and self-management at time 1. These findings again are not at all surprising. The model identified through backward step-wise multiple regression found that 64% of the self-management score could be predicted by the self-management score at time 1, the current age of the child, exposure to the intervention, and maternal age. Maternal age was negatively correlated ( $t = -2.04$ ) to self-management, with younger mothers perceiving their child's self-management skills to be greater than older mothers. Self-efficacy was not a predictor of self-management in the model.

The findings suggest that greater confidence at the outset was a good predictor of later confidence and that the older the child, the more likely the mother will have greater confidence in her ability to manage her child's severe food allergy. Similarly, the greater the maternal perception of child self-management at the outset, the greater the mother perceived her child's abilities to self-manage later on, and the older the child the better the perception of self-management skills by the mother. Attendance at the parent education program significantly improved both maternal confidence and perception of child self-management in this sample. Older mothers reported lower child self-management scores than younger mothers did. Possible explanations for this finding might be that older mothers may be more protective than younger mothers, that greater life experience might make older mothers more cautious than younger mothers, and/or



that younger mothers have higher expectations of independence for their children.

Another consideration is that the construct of perception of self-management may in fact not have been the best indicator of ability.

Comparing findings in the literature, Leonard et al. (1998) reported a relationship between maternal education, family history of diabetes and higher levels of child self-management of type 1 diabetes. The variable of family history of allergy was not identified in this study. In spite of this, Leonard's findings are in contrast with the findings of this study where no relationship was found between child self-management and maternal education. Anderson et al. (1990) found that age, sex and disease duration were significant predictors of child responsibilities (self-management) regarding type 1 diabetes care; age and sex predicting 56% of the variance in child scores. Because of the relationship between age of the child and time since diagnosis in the population of children with life-threatening food allergy, (mean age of diagnosis being 2.5 years in this study), disease duration is a related variable. In contrast with Anderson's findings, gender was not found to be a predictor of self-management in this sample of children with life-threatening food allergies.

### *Theoretical Framework*

Bandura (1995) theorized that people will strive to exercise control over events that affect their lives in order that events will become predictable, and that inability to exert influence over events in their lives contributes to apprehension, apathy or despair. He contended that being able to produce valued outcomes and prevent unwanted outcomes is a powerful incentive in the exercise of personal control. Perceived self-efficacy, or efficacy beliefs influence how people think, feel, are motivated and how they behave. Bandura believed that self-efficacy could be developed through mastery

experiences, vicarious experiences, and social persuasion and was influenced by physiologic and emotional states. It was therefore important to structure an intervention that incorporated these beliefs.

This study measured self-efficacy beliefs of 116 mothers of young children with serious food allergies, randomly allocated them to either the intervention group or the control group, and then exposed the intervention group to a structured educational program that focused on mastery of everyday activities experienced by a family with a young child with a severe food allergy. Interaction with other parents who lived the same experience was provided. The mothers who attended the session reported that they learned from the expert speakers and from each other's questions, sometimes admitting that they had not even thought of some of the issues presented or that they had not allowed themselves to think ahead due to fear or anxiety about loss of control over their child's world. They reported that they felt supported and not alone through the interaction with other parents like themselves, and by being given practical strategies they could try now and as their child got older.

The overall themes identified by the mothers who attended the parent education program supported Bandura's theory of self-efficacy development. Qualitative analysis of the parent education program evaluation revealed the following themes: gratitude for the opportunity to learn more about how to manage their child's allergy, liking the interactive nature of the educational session; the opportunity to ask questions of the speakers and learn from other parents' experiences, the practical advice about how and when to use the EpiPen®; and the individual instruction, and written information provided. Many parents felt there was a general lack of knowledge about resources parents could access, including the existence of a parent information and support group,

and where they could access recipes and ingredient lists, and that mothers wanted instruction for fathers and other care givers including school and day care staff.

These themes are consistent with the findings of Krishbaum, Aarestad and Buethe (2003), who reviewed the empirical evidence from 1985 to 2001 to determine factors that contribute to effective diabetes self-management in adults with a specific focus on self-efficacy. They found that factors that improve outcomes included involving people with diabetes in their own care, guiding them in actively learning about the disease, exploring feelings about having the disease and teaching necessary skills to adjust their behaviour to control outcomes. They concluded that the goal for educating people with diabetes is to improve their individual self-efficacy and accordingly their self-management skills. They recommended fewer lectures and more practical interactive exercises focused on skill development.

However, not all research findings support Bandura's theory and the relationship between self-efficacy and self-management. Zebracki and Drotar (2004) investigated outcome expectancy and perceived self-efficacy in adolescent self-management of asthma. They found that in 77 adolescents with asthma, aged 11 to 17 years, self-efficacy was associated with adherence to treatment but was not related to self-management and asthma morbidity. They concluded that psychological factors may influence behaviour and that social cognitive theory may not be generalizable to adolescents. Considering the strong association between asthma and severe allergies, further study concerning the relationship between self-efficacy and self-management and the association with developmental factors may have implications on the assumption of this study that improved child self-management skills will reduce risk for children with life-threatening food allergies.

## *Implications*

### *Implications for Practice*

The purpose of this study was to determine whether participation in an educational program would increase maternal self-efficacy and perception of child self-management among mothers of 4 to 12 year old children with life-threatening food allergies. Significant increases in self-efficacy and self-management were demonstrated in the intent to treat and per protocol groups three months after attending the parent education program. This study demonstrated the efficacy of a parent education program for mothers of children with life-threatening food allergies. That is, it answered the "Can it work?" question. Effectiveness, the "Will it work?" question can only be answered by implementing a parent education program broadening the admission criteria to include all parents of children diagnosed with a life-threatening food allergy and properly evaluating its success. Participation rates and economic factors would need to be considered when determining what instructional methods should be offered. In evaluating the longer term effects of a parent education program it would also be helpful to see if a sustained improvement in both self-efficacy and self-management could be demonstrated 6 months and 12 months after the intervention.

There was some improvement in self-management scores from time 1 to time 2 in all groups, although the findings were of statistical significance only in the intent to treat and per protocol groups. The implication of being able to increase maternal efforts to teach self-management skills to young children with serious food allergies simply by exposing the mothers to the instrument, that is being sensitized to the desired behaviours, is an interesting concept. I would caution that increased perception of child self-management as an outcome should not be viewed in isolation, without considering

that the mothers' confidence level was not enhanced by exposure to the instrument.

These mothers remained as anxious as they had been at the outset. One would hope that more confident and consequently less anxious mothers should be a desired outcome as well.

Supporting parents of children with serious food allergies is a complex process that involves more than informing one parent of a diagnosis, providing a prescription for an EpiPen® and recommending avoidance of certain foods. Families desire practical information about how to recognize a serious allergic reaction, know when and how to administer an EpiPen®, how to activate the emergency response system, how to avoid exposure to their child's allergen, and how to maintain some sense of normalcy in their lives. They want to be able to attend social gatherings and go to restaurants, and they want to know how best to work with school systems, recreation programs, and other caregivers including their spouse, relatives and friends. Parents and children need to set developmentally appropriate goals and recognize that as children get older they need to be able to identify their allergen, assess risk and take the necessary steps to keep themselves safe. The content analysis of the parent education program evaluation form revealed that parents want more instruction at the time of diagnosis for themselves and for the other caregivers in their child's life.

Training of parents and other caregivers to recognize signs of anaphylaxis and to administer an EpiPen® should not be considered sufficient or complete after annual individual or group training. It was clear that the mothers in this study were not able to consistently demonstrate EpiPen® use after one-on-one instruction, followed by group instruction reinforcing the steps. Whether this was due to performance anxiety or some other factor, it is a significant finding that must be considered when training parents and

other caregivers how to recognize a serious allergic reaction and how to respond in this stressful situation.

The content analysis of the parent education program revealed that the format was well received and considered to be helpful by those who did attend. However, not all families will want to attend a group parent education session, as was shown in the 37% no show rate for the intervention group. Reasons for non-attendance need to be considered when structuring parent education programs. Many parents in the intervention no show group telephoned to offer an explanation for their inability to attend the parent education program, citing access to transportation and/or child care and busy family life activities as reasons for non-attendance. In this particular sample, it was the mothers with a higher annual family income and those reporting higher education from the intervention group who attended the parent education program. These parents either valued the instruction or had fewer barriers to attending the parent education program in the format offered. Other factors such as lack of confidence and/or comfort in attending a group session, and personal preference should also be considered when structuring parent education programs. Some families may benefit from or prefer to receive electronic instruction, written material or individual instruction, or another form of instruction.

The content analysis of the parent education program supported the premise that there exists a high degree of anxiety surrounding this diagnosis, and that parents want education and practical support about how to manage their everyday lives. Parents also revealed other issues that frustrate them, including the inconsistent approaches to treating anaphylaxis they encounter when they present to an emergency department with their child, and the apparent different advice mothers receive from allergists when their

child is diagnosed. The findings regarding mothers' emergency room experiences are supported in the literature. Munoz-Furlong (2004) reported that many patients seen in the emergency room for anaphylactic reactions are not given instructions to see a specialist to determine the cause of the reaction nor are they prescribed epinephrine upon leaving the emergency room. Clark et al. (2004) and Clark and Camargo (2005) reported that among patients with severe allergic reactions visiting the emergency room, only 24% received epinephrine, over 97% were discharged home, only 16% were prescribed self-injectable epinephrine at discharge, and only 12 % were referred to an allergist. Concordance with guidelines specific to management of acute allergic reactions was found to be low. These findings supported the need for collaborative efforts between allergists and emergency physicians in the development of educational programs and materials for emergency department patients and staff. However, there appears to be some controversy regarding the appropriate amount of time to stay under observation in hospital after anaphylaxis. Fogg and Pawlowski (2003) acknowledge the clinical controversy and recommend four hours for "mild anaphylaxis", and up to 24 hours for more severe cases. Many of the mothers in this study reported having been discharged from the emergency room in far shorter periods of time. Many of these parents are well read regarding current recommendations and it is hard for them to feel confident in the advice they receive from an emergency medical physician when such variability exists.

### *Implications for Research*

Recommendations for research include replication of this study to see if the findings can be repeated in a larger and possibly more heterogeneous sample of mothers and fathers of children with life-threatening food allergies. Considering the contrasts found with studies by Leonard (1998) and Anderson (1990) on children with type 1

diabetes, the disease specific independent variables as predictors of maternal self-efficacy and perception of child self-management would need further study before generalizing the findings to children with other chronic health conditions. Further research would also shed more light on the apparent phenomenon regarding maternal age and perception of child self-management.

The possible effect of the pre-test on the intervention no show and control groups suggests that replicating this study using a Solomon Four Group Design would be useful in order to determine whether changes in the dependent variable might be due to the pre-test or the treatment. The Solomon Four Group Design is a tight experimental design, controlling both internal and external sources of error (Polit & Hungler, 1999, p.181; LoBiondo-Wood & Haber, 1994, p.218) such as the effects of the pre-test on the post-test. As well, further psychometric testing of the instruments to establish reliability and validity would improve their utility for further research with this population.

The large cancellation/no show rate (37.5%) in the intervention group does not reveal the full extent of the problem of non-participation. The overall participation rate may be as low as 13% in this study, when considering that over 1000 invitations to participate were mailed to parents of 4-12 year old children who had been assessed by an allergist in the province of Manitoba for ICD-9 code 693 in a specific 2 ½ year period. Acknowledging that the ICD-9 code did not capture a clean cohort, there were many mothers who were likely eligible to participate who chose not to. This represents a substantive number of mothers who did not participate and the reasons can only be speculated as to why they did not want to do so. Likely reasons might include that they did not feel a need to participate, that they felt intimidated by the process, that they did not fully understand the implications of participating in the research study, that it was



not convenient to participate or that there were other barriers that prevented them from participating. The findings suggest that socioeconomic factors did play a part in participation in the parent education program, since lower income families randomized to the intervention group were more likely to either cancel or not show up. There was also a trend observed in the findings that mothers who reported lower education did not show up at the parent education program, although this was not a statistically significant finding. If education of parents with children diagnosed with severe food allergies is to be considered usual treatment, this will have tremendous implications on both participation and success of educational interventions. Further research that examines participation rates, effectiveness of various educational strategies and economic feasibility of group education sessions is indicated.

It would be important to understand why so many parents had difficulty in answering item SM9 on the family responsibility questionnaire, regarding who takes responsibility to administer the EpiPen®. One expert did not complete this item when completing the CVI, citing that parents may not know how to answer if they had never had to administer the EpiPen®. The other 4 experts rated it highly relevant. Fourteen percent of mothers in this study left this item blank. Several parents wrote a comment next to this item confirming the theory of the nurse educator who participated in the CVI; that because they had never had to administer the EpiPen®, they were unsure how to answer the question. One would expect within families that someone is designated as responsible for administering the EpiPen® should it be needed, but this assumption may not be correct. Further exploration of this phenomenon would be clinically useful.

A significant relationship between self-efficacy and self-management was demonstrated in this study that supported Bandura's theory. The relationship between

self-efficacy and self-management appeared to strengthen however, as the level of self-efficacy increased. Whether there exists a threshold for self-efficacy in this population of mothers of young children with severe food allergies, and whether the relationship between self-efficacy and self-management is a dynamic one, would be worthy of further investigation.

### *Implications for Policy*

Knowing that self-efficacy and perception of child self-management can be enhanced through an education program has important implications for clinical practice. As well, the relationship between self-efficacy and self-management is important to remember when structuring education for parents and other caregivers of these children. Understanding how self-efficacy beliefs are developed and sustained through mastery experiences, vicarious experiences, social persuasion and physiologic and emotional states should guide clinicians and health educators in the development of educational interventions that will be effective. The impact this knowledge has on policy development is limited to acknowledgement that education of those entrusted with the care of these children is not only recommended, but required in order to reduce risk and keep them safe. Other elements of this study shed light on the issues faced by these children and their families. The content analysis of the parent education program and the results of the EpiPen® skill evaluation revealed themes that do have implications for policy development.

Mothers were grateful to have the opportunity to learn more about their child's condition. They felt there was a lack of knowledge about resources that parents could access, even when there were resources available. They wanted training for other family members and caregivers. The mothers in this study identified that there is a lack of

recognition and understanding of the potential seriousness of food allergy, in the general public, and even within the medical community. As a consequence mothers said that they feel isolated by this diagnosis and are faced with justifying their requests for support within their own families, with their neighbours, with school and day care staff, and even to some physicians. They get concerned when they encounter inconsistent approaches to medical management. The latter finding is supported in the literature by Clark, et al. (2004), and Clark and Camargo (2005), citing that only 24% of patients who presented to the emergency department with severe reactions received appropriate treatment with epinephrine, and that 97% were discharged home instead of being observed for 24 hours in hospital.

Debates in the medical and lay literature regarding what constitutes appropriate prescribing of epinephrine have not helped to convince the public that this is a situation to be taken seriously. The use of terms such as "EpiPen® epidemic" (Gold, 2003; Kemp, 2003; Smith, 2004) have undertones of scepticism and contribute to a belief that requests to act upon this diagnosis are somehow contrived or irrational. This kind of debate makes it difficult for government and educational policy-makers who usually have no medical background, to weigh the evidence and develop appropriate policies and practices regarding reducing risk of exposure to allergens, and planning for caregivers to take responsibility to recognize and respond to allergic symptoms. Some published recommendations have not been inclusive of all perspectives and have lacked feasibility in many jurisdictions. Collaborative documents like the guidelines published and widely distributed by the Canadian School Boards Association (1996 & 2000) seem to be the best approach because they reflect the perspectives of all stakeholders, including physicians, school administrators and parents.

The mothers in this study used the parent education evaluation form to tell their stories, to explain their frustrations and to ask for more support. Hu, Kerridge and Kemp (2005) described how uncertainty and perception of unpredictable danger felt by parents of young children with food allergy is in contrast to the apparent medical rational approach to these patients. The authors concluded that there needs to be an acknowledgement of the interrelationship between the rational and the emotional, and that this approach would lead to more appropriate clinical decision making under conditions of uncertainty. Bandura would likely agree, recognizing that self-efficacy beliefs are strengthened when emotional states are in check.

Simplistic approaches like banning nuts in public institutions do not adequately address the layers of issues faced by these children and their families. Schools and child day care facilities are complex social structures and what children eat and who provides their food are values held very closely by all parents, including those whose children do not have food allergy. Teachers continue to use food and candy in the social context and as incentives for behaviour and performance. There needs to be more awareness and education about this issue and public policy needs to support education and training for all those involved in the care of children with life-threatening food allergies.

Bansal et al. (2005) surveyed the ability of child care workers in 44 child care centres to recognize, evaluate and treat anaphylaxis in children aged 1 to 6 years, then offered a seminar to the staff. They found that only 24% of child care centres surveyed were willing to administer epinephrine for a severe allergic reaction. After the seminar, 77% of centres reported a willingness to administer epinephrine if required. The authors reported a need for greater anaphylaxis education among child care workers and that skills could be increased through education about anaphylaxis. Efforts need to continue

to improve public awareness of this serious health condition, and policies need to be in place that ensures formal training of all those responsible for the care of these children. Some parents requested this kind of support on the parent education evaluation form.

Mothers in this study also expressed frustration regarding inadequate description and disclosure of ingredients and standardization on food labels and restaurant menus. Simon et al. (2005) reported the results from a survey of 489 food allergic individuals or parents of food allergic children who depend upon the accuracy of food labelling to avoid allergens. One hundred forty-eight individuals reported reactions to foods in a restaurant, some on more than one occasion, in spite of carefully reading labels. Inadvertent allergic reactions were attributed to misreading label terms (16%) and to non-specific terms (22%). They recommended that improved product allergen labelling would reduce inadvertent allergic reactions and simplify allergy management. Munoz-Furlong (2004) reported on the patient's perspective and public policy regarding anaphylaxis, citing that reactions occurred from incorrect ingredient information in food service or restaurant settings, incorrect product labels or mistakes in label reading. She concluded that much work remains to be done in education and public policy regarding anaphylaxis.

### *Strengths and Limitations*

Several factors contributed to the strength of this study, including its design and the fact that this is one of very few studies investigating the effects of parent education for this population reported in the literature. The study was guided by a theoretical framework that enabled the exploration of the relationships between maternal self-efficacy and maternal perception of child self-management of a life-threatening food allergy. Theories that make specific predictions are considered to be important when

evaluating effective nursing interventions. Accordingly, the absence of a conceptual framework is associated with weak intervention effects and makes the determination of causality between intervention and outcomes difficult to interpret (Conn et al., 2001).

The study design was a randomized controlled trial, considered to be ideal for studying cause and effect relationships (Polit & Hungler, 1999, p. 184). Strengths inherent to the randomized controlled trial included random allocation to the intervention and control groups, manipulation of the independent variable and control of extraneous variables. The randomized controlled trial helped to provide insight into the impact of the parent education intervention and the factors that contributed to variance. The protocol was followed as planned and there were few unexpected problems encountered. Qualitative analysis of the parent education program provided supportive evidence to the statistical findings of the study, and revealed other factors of clinical importance.

Careful consideration was given to the methodology, design, instrument development, recruitment methods, incentives, burden to the participants, and clarity of communication with participants. As well, attention was paid to the control group and the intervention group, and key stakeholders were included on the intervention team in order to optimize outcomes and avoid pitfalls (Pruitt & Privette, 2001).

Sufficient numbers of subjects were recruited to have confidence in the statistical analysis of the results. Adding strength to the design was the randomization of the subjects to the intervention and control groups after the baseline measure was taken, thus blinding the subjects and the researcher at the outset to the final group allocation. Randomization appeared to have successfully distributed differences between the groups and allowed greater confidence in the interpretation and generalizability of the results

regarding the effects of the intervention. The intervention was administered at one time, adding confidence that all intervention showed subjects received the same treatment.

The incentive appeared to be successful in that attrition was minimal (overall participation rate of 91%). The intervention no show rate was larger than expected and this finding suggests further study into the determinants of participation and success of parent education programs is needed.

Content validity of the instruments was established by CVI with five experts; a paediatric allergist, 2 nurse educators with extensive experience working with children with life-threatening allergies and their families, and 2 experienced parents with a child diagnosed with life-threatening food allergies. The internal consistency of the instruments was high, for both self-efficacy and self-management. Considering that the instruments did not have established reliability and validity for mothers of children with life-threatening food allergies, this finding was reassuring and suggests that the instruments may be useful for others conducting research in this area.

There were several threats to both internal and external validity inherent in the design of this study. Potential interactions between internal and external threats are acknowledged. As expected, these potential threats impact on generalizability of the findings as well as on confidence placed in the interpretation of differences between the intervention group and control group findings.

It was possible that participants who were exposed to the pre-test became sensitized or biased to the issues of interest to the investigator, and may have reacted differently to the experimental variable/intervention or to the effects of time than they would have had they not been exposed to the pre-test. Therefore, simply being exposed to the experience of taking the pre-test likely became an intervention or independent

variable in and of itself, introducing an element of bias and limiting the ability to infer causality from the parent education program and therefore affecting the generalizability of the results of the research (Brink & Wood, 1998; Polit & Hungler, 1999).

It was expected that many parents would want to participate in the study. The parents who participated in this study may have represented more motivated and possibly better educated and/or wealthier families. This may have constituted a selection bias, the sample not estimating a population parameter, impacting on generalizability of the findings. These differences were supported in analysis of the demographic data, especially evident in the per protocol and intervention no show groups.

An obvious risk of this study design was loss of participants over the duration of the study. Subjects who enrolled in the study and were assigned to the experimental group needed to be available on the day of the intervention, and needed a means of transportation and child care. This may have limited participation by families of lower socioeconomic status and constituted another form of selection bias, another factor limiting generalizability. Loss of motivation over the duration of the study, disappointment in not being selected to the intervention group and potential compensatory rivalry by control group members and/or drop-out did not appear to be a significant problem. Unequal attrition between groups was considered in determining why subjects left the study (Brink & Wood, 1998, p.33-36). It appeared that the instructional materials and EpiPen® trainer acted as an incentive for all participants, including the intervention no show group, to complete the second questionnaire.

The instruments in the questionnaire package lacked established reliability and validity with mothers of children with life-threatening food allergies and may have not been transferable from use with children with type 1 diabetes. Measures of internal



consistency were high however and contributed to confidence in the reliability of the instruments. As previously described, efforts were made to ensure content validity and to anticipate problems with clarity and understanding of the questions. Further testing for construct validity would be beneficial.

Timing of the post-test was arbitrarily set at three months post intervention for practical reasons. Because self-efficacy is a cognitive process, three months was allotted for the mothers in the intervention group to reflect upon and consider attempting strategies suggested in the intervention. In fact, 3 months may not have been sufficient time to measure effects of the intervention, or conversely, effects may have occurred earlier and already begun to recede or fail to be sustained without ongoing encouragement and support. In spite of these and other possible limitations, randomization, control and manipulation of the independent variable were three essential elements of controlling for the effects of extraneous variables and contributed to the rigor of the design.

#### *Dissemination of Results*

Results of the study will be shared with the Child Health Program of the Winnipeg Regional Health Authority, the Department of Pediatrics and Child Health University of Manitoba by Grand Rounds presentation, and through a mailed summary to interested mothers who participated in the study through a mailed summary. Abstracts will be submitted for presentation at local and national child health conferences such as Canadian Association of Pediatric Health Centres (CAPHC), allergy and immunology and nursing conferences, including The Pediatric Nursing Research Symposium. The results will also be submitted for publication in a peer-reviewed journal(s).

### *Summary*

Food allergy is a potentially life-threatening problem affecting 6-8% of infants and toddlers, declining in prevalence in the first decade of life to about 2%. Care of food allergic children requires strict avoidance of the allergen, early recognition of allergic symptoms, and prompt administration of adrenaline to reverse a severe reaction. Parents report that exercising extreme dietary vigilance and living with constant uncertainty causes considerable disruption in their child's daily activities, as well as impairment in family and social interactions.

As children mature, they become increasingly capable of participating in their own care, depending upon factors such as complexity of self-care, and cognitive and social development. The transfer of self-care responsibility from parent to child is best accomplished gradually, in a structured and guided fashion. Yet, little is known about the development of self-care behaviours in children between the ages of 4 and 12 years. Bandura proposed in his self-efficacy model that an individual's level of confidence to perform a behaviour significantly influences behavioural choices, persistence of behaviours, and goal-directed effort. Using Bandura's model as a theoretical framework, this study examined whether participation in an educational program would increase maternal self-efficacy and perception of child self-management among mothers of 4 to 12 year old children with life-threatening food allergies.

Using an experimental pre-test-post-test design, the effects of a parent education intervention on maternal self-efficacy and perception of child self-management were evaluated. One hundred twenty-eight mothers with a child between the ages of 4 and 12 years with a life-threatening food allergy participated. They completed a questionnaire consisting of 34 Likert-type items measuring maternal self-efficacy and family

responsibility for children with life-threatening food allergies plus questions about age and gender of the child, age at diagnosis, food allergen, maternal age, and socioeconomic variables. The self-efficacy and self-management instruments were subjected to content validity analysis and modified accordingly. Both instruments demonstrated a high degree of internal consistency (.86-.91) in the study.

Mothers were randomly assigned to the intervention group or control group after time 1. The intervention group attend three hours of instruction about food allergy, recognizing and responding to an allergic reaction, avoiding exposure and building responsibility in a food allergic child. One hundred sixteen mothers (91%) completed the second questionnaire 3 months after the educational intervention. The groups were compared using Chi-square and t-tests and the effects of the parent education program evaluated using repeated measures ANOVA. Relationships were evaluated using Spearman's rho correlation coefficient and backward stepwise multiple regression. There was a large cancellation/no show rate in the intervention group 24/64 (37.5%), yet 19/24 mothers (70%) in the no show group responded to the second questionnaire.

The results were analysed in 2 ways; intervention (intent to treat) vs. control (2 group), and intervention showed (per protocol), intervention no show, and control (3 group). Chi-square and t-tests demonstrated equal distribution of characteristics between the groups except for a significantly lower income ( $p=.02$ ) in the intervention no show group. The intervention no show group appeared to be more confident at time 1, although the number of subjects in the intervention no show group ( $n=19$ ) was not large enough to interpret results associated with this group with any confidence.

There was a statistically significant improvement for both self-efficacy and perception of child self-management in both the intent to treat and per protocol groups 3

months after exposure to the intervention. Although there was an increase in self-management scores from time 1 to time 2 for both the intervention no show group and control groups, the improvement was not statistically significant. The increase in scores was likely due to mothers being sensitized to the behaviours of interest through exposure to the instrument at time 1. Self-efficacy did not change significantly in the control and intervention no show groups from time 1 to time 2.

Spearman's rho showed that self-efficacy at time 2 was significantly correlated to self-management ( $p=.27-.45$ ). Using backwards step-wise multiple regression analysis, significant predictors of self-efficacy at time 2 included how confident the mother was at the outset, exposure to the intervention, and the current age of the child ( $r^2=.39$ ). Significant predictors of maternal perception of child self-management at time 2 included self-management score at time 1, exposure to the intervention, current age of the child, and age of the mother ( $r^2=.64$ ); older mothers having a lower perception of child self-management than younger mothers.

Since improving self-management or the ability of young children to participate in their own care was the primary purpose of this study, the latter findings suggest that the self-management skills of young children can be improved through a parent education program and that older mothers may require more support for this to happen. The relationship between confident mothers and child self-management also suggests that efforts to improve self-efficacy will not only reduce parental anxiety, but will contribute to better self-management for children.

The Wilcoxon Signed Ranks Test was used to compare EpiPen® trainer skill pre- and post- one on one instruction followed by group instruction in the per protocol group at the parent education program. A statistically significant improvement was

demonstrated on a 5 point scoring rubric. It is clear that even for these mothers, who have good reason to perform this skill correctly and consistently, some mothers continued to have difficulty in performing this skill correctly. This has tremendous implications for education of other caregivers; if the expectation by the prescribing physician is that the parent who learns to administer the EpiPen® initially will go home and train others.

The qualitative analysis of the parent education program supported the premise that there exists a high degree of anxiety surrounding this diagnosis, and that parents want education and practical support about how to manage their everyday lives. Parents also revealed other issues that frustrate them, including the inconsistent approaches to treating anaphylaxis they encounter when they present to an emergency department with their child, and the apparent different advice mothers receive from allergists when their child is diagnosed.

It would appear that young children with life-threatening food allergies are becoming increasingly prevalent in the developed world. It is clear that there is a need to teach the families of these children how to care for them and how to train children to manage their own allergy in developmentally appropriate ways. Through understanding the relationship between parental self-efficacy and parent perception of their child's self-management, patient and family education can be tailored to most effectively meet this need. It was demonstrated that a structured parent education program could enhance maternal self-efficacy and perception of child self-management. It was evident that a structured parent education program will not attract all parents. Further research is required to examine whether these results are applicable to fathers and what factors contribute to and interfere with successful parent education. Research into the

determinants of successful parent education programs should not impede action however, because what is clear is that parent education should be considered an important component when treating children diagnosed a with life-threatening food allergy. In conclusion, this study supported the hypotheses that maternal self-efficacy and maternal perception of child self-management can be increased after attending a parent education program.

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## Appendix A

### Original Instruments



APPENDIX A. Maternal Self-Efficacy for Diabetes Management Scale  
How confident do you feel in independently managing the following tasks?

Directions: Circle a number 1-5. Use the following as a guide:

- 1 = Not confident at all  
2 = Somewhat confident with help  
3 = Very confident with help  
4 = Somewhat confident without help  
5 = Very confident without help

1. I am confident in my ability to help my child manage diabetes.	1	2	3	4	5
2. I can help my child fit his/her diabetes management plan into a normal lifestyle.	1	2	3	4	5
3. I can adjust my child's management plan if s/he gets a cold or the flu.	1	2	3	4	5
4. I can determine what to do if my child's blood sugar is higher than it should be.	1	2	3	4	5
5. I can adjust my child's management plan when s/he is more active than usual.	1	2	3	4	5
6. I can adjust my child's insulin dose based on the results of blood or urine tests.	1	2	3	4	5
7. I can adjust my child's management plan to avoid low blood sugar (insulin reactions).	1	2	3	4	5
8. I can advocate for my child's best care in community settings (school, church or synagogue, recreation programs, etc.).	1	2	3	4	5
9. I can teach my child how to take more responsibility for diabetes management.	1	2	3	4	5
10. I can talk to my child about the realities of long-term complications without undue upset.	1	2	3	4	5
11. I can advocate for better health care for my child if I am concerned about unfairness or unreasonableness.	1	2	3	4	5
12. I can change my child's doctor if I don't like him/her.	1	2	3	4	5
13. I can adjust my child's management plan to allow for an overnight stay away from home without parents.	1	2	3	4	5
14. I can adjust my child's management plan with changes in schedule (for example, from school to summer schedule).	1	2	3	4	5
15. I can be successful in getting my child to follow his/her management plan, even when s/he may be reluctant or resistant at first.	1	2	3	4	5
16. I can organize our family mealtimes and schedule so that my child can eat most meals at the same time each day.	1	2	3	4	5
17. I can organize our family mealtimes and schedule so that my child can eat most meals with other family members each day.	1	2	3	4	5

APPENDIX B. Diabetes Family Responsibility Questionnaire (DFRQ)

Below are different tasks or situations that relate to diabetes management in your family. Choose the letter P, S, or C from the three statements that describes the way each task or situation is handled in your family.

P = Parent(s) take or initiate responsibility for this almost all of the time.

S = Parent(s) and child share responsibility for this about equally.

C = Child takes or initiates responsibility for this almost all of the time.

Situations or tasks:

- \_\_\_ 1. Remembering day of clinic appointment. (GH)\*
- \_\_\_ 2. Telling teachers about diabetes. (S)
- \_\_\_ 3. Remembering to take morning or evening injection. (R)
- \_\_\_ 4. Making appointments with dentists and other doctors. (GH)
- \_\_\_ 5. Telling relatives about diabetes. (S)
- \_\_\_ 6. Taking more or less insulin according to results of blood sugar tests or urine tests. (GH)
- \_\_\_ 7. Noticing differences in health, such as weight changes or signs of an infection. (GH)
- \_\_\_ 8. Telling friends about diabetes. (S)
- \_\_\_ 9. Noticing early signs of an insulin reaction. (R)
- \_\_\_ 10. Giving insulin injections. (R)
- \_\_\_ 11. Deciding what should be eaten when family has meals out (restaurants, friend's home). (GH)
- \_\_\_ 12. Examining feet and making sure shoes fit properly. (GH)
- \_\_\_ 13. Carrying some form of sugar in case of an insulin reaction. (R)
- \_\_\_ 14. Explaining absences from school to teachers or other school personnel. (S)
- \_\_\_ 15. Rotating injection sites. (R)
- \_\_\_ 16. Checking expiration dates on medical supplies. (GH)
- \_\_\_ 17. Remembering times when blood sugar or urine should be tested. (R)

\*GH = General Health domain; R = Regimen domain; S = Social Presentation domain.

Developed by Barbara J. Anderson, Wendy F. Auslander, Kenneth C. Jung, J. Phillip Miller, and Julio V. Santiago, 1990.

Note. From "Self-management development in children and adolescents with diabetes: The role of maternal self-efficacy and conflict" by Leonard et al., 1998, *Journal of Pediatric Nursing*, 13(4), p. 232. Permission to reprint obtain March 28, 2006 from Michael J. Lacovara for Elsevier, ref: FoggThesisML3-06

## Appendix B

### Questionnaire

Including:

1. Demographic questions
2. Maternal Self-Efficacy Questionnaire (questions 5 -21)
3. Family Responsibility Questionnaire (questions 22-38)

EFFECTS OF A PARENT EDUCATION PROGRAM ON MOTHERS OF  
CHILDREN WITH SEVERE FOOD ALLERGIES:

A Research Study

Questionnaire # \_\_\_\_\_

**START HERE:**

1. What is the current age of your child with the life-threatening food allergy?

\_\_\_\_\_ years

2. How old was she/he when the life-threatening allergy was diagnosed? You may indicate age in months if that is more appropriate.

\_\_\_\_\_ years      **OR**      \_\_\_\_\_ months

3. What is the gender of your child with the life-threatening allergy? Place an X in the appropriate box.

- ☐ boy  
☐ girl

4. To what foods is your child highly allergic? Place an X in all boxes that apply.

- ☐ milk  
☐ egg  
☐ peanut  
☐ tree nut(s)  
☐ fish  
☐ shellfish  
☐ soy  
☐ wheat  
☐ other (please state) \_\_\_\_\_

For Questions 5 to 21 place an X in the box that best describes how confident you feel in independently managing the following tasks:

5. I am confident in my ability to help my child manage his/her severe allergy.

- ☐ Not confident at all  
☐ Somewhat confident with help  
☐ Very confident with help  
☐ Somewhat confident without help  
☐ Very confident without help

**6. I can help my child manage his/her severe allergy to lead a normal life.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**7. I am confident that I could recognize a severe allergic reaction.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**8. I am confident that I could correctly administer the EpiPen® if needed.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**9. I am confident that the EpiPen® will be within reach if my child has a severe allergic reaction.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**10. I am confident that I can identify my child's allergen on packaging information.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**11. I can adjust what my child eats to avoid an allergic reaction.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**12. I can advocate for my child's best care in community settings such as school and recreational programs.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**13. I can teach my child to take more responsibility in managing his/her severe allergy.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**14. I can talk to my child about the realities of a severe allergic reaction without feeling overwhelmed.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**15. I can change my child's doctor or seek a second opinion if I choose.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**16. I can make arrangements to safely plan to allow for an overnight stay away from home without my being there.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**17. I can adjust my child's safe eating plan with changes in routine such as eating at a restaurant.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**18. I can be successful in getting my child to follow a safe eating plan, even when s/he may be reluctant or resistant.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**19. I can organize our family meals so that my child can eat the same or almost the same meals as the rest of the family.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**20. I am confident that meals/snacks that I prepare for my child do not contain my child's allergen.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**Questions 21 to 36 describe different tasks or situations that relate to severe allergy management in your family. Place an X in the box that best describes the way each task or situation is handled in your family.**

**21. Explain to teachers and other school personnel about the severe allergy.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**22. Remember to take the EpiPen® with him/her.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**23. Read labels to look for a potential allergen.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**24. Tell relatives about the allergy.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time



**25. Ask about the ingredients in foods at a restaurant or friend's home.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**26. Decline foods that may contain the allergen, if offered at a social function.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**27. Tell friends about the severe allergy.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**28. Notice early signs of an allergic reaction.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**29. Administer (give) the EpiPen®.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**30. Decide what should be eaten when family has meals out at a restaurant or friend's home.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**31. Notice the presence of an obvious allergen and distance oneself from it.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**32. Carry the EpiPen® in case of an allergic reaction.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**33. Demonstrate correct use of the EpiPen® to relatives and babysitters.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**34. Check the expiry date on the EpiPen®.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**35. Describe to relatives and babysitters what an allergic reaction might look like.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**36. Explain when an EpiPen® should be given.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**The following information will help to determine how education programs for parents of children with life-threatening allergies can best be planned.**

**37. What is your age?** \_\_\_\_\_ years

**38. What sources of information have been most helpful in learning about your child's severe allergy? You may indicate more than one source if you wish.**

- ☐ Physician
- ☐ Nurse
- ☐ Parent Support group
- ☐ Internet
- ☐ Other parents with children with severe allergies
- ☐ Other (please state) \_\_\_\_\_

**39. What is the highest level of education you have attained?**

- ☐ Some high school
- ☐ High school diploma
- ☐ Some college or university
- ☐ College diploma or certificate
- ☐ University degree

**40. Which of the following categories best describes the annual income of your household before taxes for 2003?**

- ☐ \$20,000 or less
- ☐ \$20,001 to \$40,000
- ☐ \$40,001 to \$75,000
- ☐ \$75,001 or more

Thank you for completing this questionnaire
---

## Appendix C

### Health Information Privacy Committee Approval to Access Data

# Manitoba



Health

300 Carlton Street  
Winnipeg, MB R3B 3M9

## HEALTH INFORMATION PRIVACY COMMITTEE

March 22, 2005

File No.: 2004/2005-20

Ms. J. Fogg

Dear Ms. Fogg:

Re: Efforts of a parent education program on maternal self-efficacy and perceptions of their child's self management of a life threatening illness

Thank you for supplying us with the requested information, your request for data is now *approved*. Leonie Stranc should be contacting you shortly regarding the particulars of your mail out.

Please note that any significant changes to the proposed study design should be reported to the Chair for consideration.

If you have any questions or concerns, please do not hesitate to contact Leonie Stranc, Committee Coordinator at 786-7204.

Yours truly,

Dr. R. Walker  
Chair

Please quote the file number on all correspondence

cc. L. Barre

## Appendix D

### Invitations to Participate



UNIVERSITY  
OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7452  
Fax (204) 474-7682

### INVITATION TO PARTICIPATE

#### **EFFECTS OF A PARENT EDUCATION PROGRAM ON MOTHERS OF CHILDREN WITH SEVERE FOOD ALLERGIES: A Research Study**

You are invited to participate in a study of mothers with a child who is between 4 and 12 years of age with a severe food allergy. The purpose of the study is to investigate the effects of a parent education program on how confident mothers feel in their ability to manage their child's severe food allergy and how mothers perceive their child's ability to participate in their own care.

The study is being conducted by Susan Fogg, a graduate student in the Faculty of Nursing at the University of Manitoba. Her advisor is Dr. Maureen Heaman, Associate Professor at the Faculty of Nursing at the University of Manitoba. The study has been approved by the Education/Nursing Research Ethics Board, University of Manitoba.

In order to participate in the study, your child must have had an assessment by a doctor who specializes in allergies within the past two years to confirm a severe food allergy. The child must be between 4 and 12 years of age and have no diagnosed learning disability that would result in level 2 or 3 Special Education designation at school. If you have received this letter, you may or may not meet the conditions of the study.

Participation in the study is voluntary. You are under no obligation to participate. By contacting the researcher you will identify yourself and indicate your interest in participating in the study. You may change your mind and withdraw from the study at any time. If you chose to participate, you will be asked to complete two questionnaires about 3 months apart. Each questionnaire will take about 15 minutes to complete. The questionnaire will arrive by mail and will include a stamped self-addressed envelope. You may receive a telephone reminder if you have not returned the completed questionnaire within 10 days of receiving it. You can elect to not answer any question. Participants will be randomly assigned to one of two groups. One group will be asked to attend a ½ day parent education program on a Saturday morning while the other group will not. All study participants will receive an instructional package that includes an EpiPen® trainer. One group of participants will receive the instructional package at the parent education program while the other group will receive it after completing the second questionnaire. Both groups play a very important part in this study. You cannot ask to be assigned to one particular group.

Your decision to participate will not affect the care you currently receive from your physician/allergist. You may benefit by participating in the study by learning more about your child's food allergy. You will also contribute to the body of knowledge on parenting a child with severe food allergy. There are no known risks to participating in this study. Your participation in the study and responses will be kept confidential. Your name will not appear on the questionnaire. No information that could identify you will appear in the findings of the study.

**If you would like to participate in this study or would like further information about the study, please call Susan at before May 6, 2005.** If you have enrolled in the study and change your mind about participating, you can withdraw by phoning Susan at 489-9410 and saying you no longer wish to participate. Thank you for considering this request.





UNIVERSITY  
OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7452  
Fax (204) 474-7682

### INVITATION TO PARTICIPATE

#### **EFFECTS OF A PARENT EDUCATION PROGRAM ON MOTHERS OF CHILDREN WITH SEVERE FOOD ALLERGIES: A Research Study**

You are invited to participate in a study of mothers with a child who is between 4 and 12 years of age with a severe food allergy. The purpose of the study is to investigate the effects of a parent education program on how confident mothers feel in their ability to manage their child's severe food allergy and how mothers perceive their child's ability to participate in their own care.

The study is being conducted by Susan Fogg, a graduate student in the Faculty of Nursing at the University of Manitoba. Her advisor is Dr. Maureen Heaman, Associate Professor at the Faculty of Nursing at the University of Manitoba. The study has been approved by the Education/Nursing Research Ethics Board, University of Manitoba.

In order to participate in the study, your child must have had an assessment by a doctor who specializes in allergies within the past two years to confirm a severe food allergy. The child must be between 4 and 12 years of age and have no diagnosed learning disability that would result in level 2 or 3 Special Education designation at school. The Manitoba Anaphylaxis Information Network (MAIN) has agreed to send this letter to all member families. The envelopes were labelled and mailed by MAIN. The researcher does not have access to the names or addresses of MAIN members.

Participation in the study is voluntary. You are under no obligation to participate. By contacting the researcher you will identify yourself and indicate your interest in participating in the study. You may change your mind and withdraw from the study at any time. If you chose to participate, you will be asked to complete two questionnaires about 3 months apart. Each questionnaire will take about 15 minutes to complete. The questionnaire will arrive by mail and will include a stamped self-addressed envelope. You may receive a telephone reminder if you have not returned the completed questionnaire within 10 days of receiving it. You can elect to not answer any question. Participants will be randomly assigned to one of two groups. One group will be asked to attend a ½ day parent education program on a Saturday morning while the other group will not. All study participants will receive an instructional package that includes an EpiPen® trainer. One group of participants will receive the instructional package at the parent education program while the other group will receive it after completing the second questionnaire. Both groups play a very important part in this study. You cannot ask to be assigned to one particular group.

Your decision to participate will not affect the care you currently receive from your physician/allergist. You may benefit by participating in the study by learning more about your child's food allergy. You will also contribute to the body of knowledge on parenting a child with severe food allergy. There are no known risks to participating in this study. Your participation in the study and responses will be kept confidential. Your name will not appear on the questionnaire. No information that could identify you will appear in the findings of the study.

**If you would like to participate in this study or would like further information about the study, please call Susan at ..... before May 6, 2005.** If you have enrolled in the study and change your mind about participating, you can withdraw by phoning Susan at 489-9410 and saying you no longer wish to participate. Thank you for considering this request.

## Appendix E

### Manitoba Health Cover Letter

# Manitoba



HEALTH  
Finance  
Health Information Management

300 Carlton Street  
Winnipeg MB  
R3B 3M9

April 17, 2005

Dear Recipient:

**Re: Effects of a parent education program on mothers of children  
with severe food allergies**

This letter is being sent to you to tell you about a study, entitled, "Effects of a parent education program on mothers of children with severe food allergies". The study is being undertaken by researchers from the Faculty of Nursing at the University of Manitoba. A more detailed description of the study and an invitation to participate in the study is attached.

You are receiving this letter because, according to our records, sometime in the last four years your child saw an allergist about a skin condition that may have been related to something that he or she ate. ***This is not necessarily the case, and if it is not, please accept our apologies for troubling you.***

This study has been approved by the Health Research Ethics Board at the University of Manitoba and by the Health Information Privacy Committee to comply with the Personal Health Information Act.

Manitoba Health has agreed to send out this letter to potential study participants to ensure your privacy is protected. ***The researchers have no knowledge of who has received this letter.*** No information about you, not even your name, has been shared with the researchers. They will not know who you are unless you choose to participate in the study.

It is your choice whether to participate in this study. Your medical care will not be affected in any way by your decision. If you are interested in participating in this study, or would like more information, please call Susan at .

Sincerely,

Louis Barre  
Director, Health Information Management

## Appendix F

### Script When Potential Participants Phone for Information

Script when potential participants phone for information:

“Thank you for calling about the study. Do you have any questions for me?”

“I’d like to start by asking you some questions to make sure you meet the criteria for participating in the study.”

“Are you the mother of a child with a severe food allergy?” If not, “I will want to speak with the mother.” “How old is the child right now?” “To what food is your child highly allergic?” “When did you last see your allergist about the allergy?” “Was an EpiPen® prescribed?” (If there is more than one child in the family who meets the criteria, instruct the mother to respond concerning the oldest.)

“Do you have any difficulty in reading or speaking English?” “Has your child been diagnosed with a learning disability?” If yes, “Does your child have level 2 or 3 Special Education designation at school?”

“If you chose to participate, do you understand that you may or may not be selected to attend the parent education program? If selected to attend the education program, would you be able to attend on Saturday, (month/day) in the morning for about 3 hours? If so, please mark that date on your calendar.”

If any of the responses are not consistent with the criteria of the study, “I’m afraid that I can only enrol mothers of children who \_\_\_\_\_, but thank you very much for your interest.”

“Please know that the role of the mothers who do not attend the education program is very important to the study. Mothers who do not attend the parent education program will receive an informational package after completing the second questionnaire. Do you wish to participate?”

If so, "I will need your name, address and phone number. I will mail you an envelope that will contain 2 copies of the consent form and a questionnaire. Please follow the directions and return one signed copy of the consent form and the completed questionnaire to me in the stamped return envelope provided. You will receive a reminder call if I do not receive the package within 14 days. What is your name, address and phone number?" "You may call me at \_\_\_\_\_ if you have any questions. Thank you for calling."

## Appendix G

### Instructions for Completing the Consent Form and Questionnaire

### **Instructions for Completing the Consent Form and Questionnaire**

Two copies of the Consent Form and the Questionnaire are attached. Please read the Consent Form carefully. If you wish to participate in the study, sign and date one copy of the consent form where it says "Participant's Signature". Return the signed copy of the Consent Form to Susan in the return envelope along with the completed Questionnaire. The other copy of the consent form is for you to keep for your records.

The Questionnaire booklet should take you about 15 or 20 minutes to complete. There are instructions as you read through the Questionnaire that will guide you along. When you have completed the Questionnaire, place it in the return envelope with the signed consent form, seal the envelope and drop it in the mail.

When there are a sufficient number of participants enrolled in the study, you will be randomly assigned to either the group that will attend the parent education program, or to the group that will not attend the parent education program. Regardless of whether or not you attend the parent education program, you will receive the educational package and the EpiPen® trainer. You will receive a letter in the mail telling you what group you have been assigned to, and what you can expect to happen next.

If you have any questions, please call Susan at .



## Appendix H

### Consent Form



UNIVERSITY  
OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7452  
Fax (204) 474-7682

Return this copy  
to the researcher

### CONSENT FORM

Research Project Title: Effects of a Parent Education Program on  
Mothers of Children with Severe Food Allergies  
Researcher: Susan Fogg, B.N., Graduate Student, Faculty of  
Nursing, University of Manitoba

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask the researcher. Please take the time to read this carefully and to understand any accompanying information.

Participation in the study is voluntary. You are under no obligation to participate. By contacting the researcher you will identify yourself and indicate your interest in participating in the study. You may change your mind and withdraw from the study at any time. If you chose to participate, you will be asked to complete a questionnaire with 42 questions. It will take you about 15 minutes to complete. You will be asked to complete a similar questionnaire, a bit shorter in length 3 months after completing the first. The questionnaire will arrive by mail and will include a stamped self-addressed envelope. You may receive a telephone reminder if you have not returned the completed questionnaire within 10 days of receiving it. You can elect to not answer any question. Participants will be randomly assigned to one of two groups. One group will be asked to attend a ½ day parent education program on a Saturday morning, from 8:30 until 12:00. There will be approximately 100 mothers of children with life-threatening food allergies attending the parent education program. The other group will not attend the parent education program. All study participants will receive an instructional package that includes an EpiPen® trainer. Some participants will receive the instructional package at the parent education program while others will receive it after completing the second questionnaire. Both groups play a very important part in this study. You cannot ask to be assigned to one particular group. Your participation in the study and responses will be kept confidential. Your name will not appear on the questionnaire. No information that could identify you will appear in the findings of the study. The findings of the study will be presented to physicians and nurses and submitted for publication in a nursing journal. Participants who wish to know about the findings of the study will be mailed a summary of the results.

I agree to participate in the study "Effects of a Parent Education Program on Mothers of Children with Severe Food Allergies". I have read, understand and have a copy of the "INVITATION TO PARTICIPATE". I understand that I may or may not be asked to attend the ½ day parent education program, but that I will receive the instructional package in any case.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, or refrain from answering any question you prefer to omit, without prejudice or consequence. You may withdraw from the study by phoning Susan at 489-9410 and saying you no longer wish to participate. You can also indicate if you wish to withdraw from the study if you receive a reminder phone call. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Researcher: Susan Fogg ph.  
ph. 474-6222

Supervisor: Dr. Maureen Heaman

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above named persons or the Human Ethics Secretariat at 474-7122, or e-mail \_\_\_\_\_. A copy of this consent form has been given to you to keep for your records and reference.

Thank you for agreeing to participate in this study.

Participant's Signature \_\_\_\_\_ Date \_\_\_\_\_

Researcher and/or Delegate's Signature \_\_\_\_\_ Date \_\_\_\_\_

## Appendix I

### Additional Item for Questionnaire #2

Observation 2 Question:

**33. What have you done in the past 3 months to enhance your learning about your child's life-threatening food allergy?**

- ☐ Spoken with a doctor
- ☐ Spoken with a nurse
- ☐ Contacted a Parent Support group
- ☐ Looked up information on the internet
- ☐ Spoken with another parent of a child with severe allergies
- ☐ Read newspaper or magazine articles, pamphlets or books
- ☐ Other (please state) \_\_\_\_\_

## Appendix J

### Content Validity Index

## QUESTIONNAIRE PACKAGE

For the Research Study

THE EFFECTS OF A PARENT EDUCATION PROGRAM ON MOTHERS OF  
CHILDREN WITH LIFE-THREATENING FOOD ALLERGIES

**PLEASE NOTE:**

It is important that you return this Questionnaire Package together with the Content Validity Index Record to Susan Fogg after completing the content validity index. Thank you for your assistance and expertise.

## CONTENT VALIDITY INDEX RESPONSE RECORD

For the Questionnaire Package for the Research Study

THE EFFECTS OF A PARENT EDUCATION PROGRAM ON MOTHERS OF  
CHILDREN WITH SEVERE FOOD ALLERGIES

### Instructions:

1. Open the Questionnaire package to page 2 and the Content Validity Index Response Record to page 2. Pages in the Questionnaire will correspond with the pages in the Response Record. For example, questions 1 to 5 in the Questionnaire package are on page 2. Responses for questions 1 to 5 for the Content Validity Index will appear on page 2 of the Content Validity Index Response Record.
2. Follow the directions for each group of questions.
3. When you have answered all questions in the Response Record, please return **both** the Questionnaire package and the Content Validity Index Response Record to Susan in the envelope provided.



START HERE:

Questions 1 to 4:

Please comment on the clarity of questions 1 to 4 and offer any suggestions you may have for improvement.

Questions 5 through 21 were adapted from a maternal self-efficacy scale that measured how confident mothers of children with a chronic illness feel about managing their child's health needs.

Read each question and **circle** the letter of the response in the Response Record that best describes how relevant you feel the question is concerning mothers of children with life-threatening food allergies.

Question 5. I am confident in my ability to help my child manage his/her severe allergy.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 6. I can help my child manage his/her severe allergy to lead a normal life.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 7. I am confident that I could recognize a severe allergic reaction.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 8. I am confident that I could correctly administer the EpiPen® if needed.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 9. I am confident that the EpiPen® will be within reach ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 10. I am confident that I can identify my child's allergen on packaging ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 11. I can adjust what my child eats to avoid an allergic reaction.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 12. I can advocate for my child's best care in community settings ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 13. I can teach my child to take more responsibility ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 14. I can talk to my child about the realities of a severe allergic reaction ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 15. I can advocate for better health care for my child if I am concerned ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 16. I can change my child's doctor or seek a second opinion ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 17. I can make arrangements to safely plan to allow for an overnight stay ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 18. I can adjust my child's safe eating plan with changes to routine ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 19. I can be successful in getting my child to follow a safe eating plan ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 20. I can organize our family meals so that my child can eat the same meals ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 21. I am confident that meals/snacks that I prepare for my child ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Questions 22 to 38 were adapted from a questionnaire that determined how different tasks or situations are handled in a family with a child with a chronic illness.

Question 22. Remember day of clinic appointment.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 23. Explain to teachers and other school personnel ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 24. Remember to take the EpiPen® ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 25. Read labels to look for a potential allergen.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 26. Tell relatives about the allergy.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 27. Ask about the ingredients in foods at a restaurant ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 28. Decline foods that may contain the allergen ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 29. Tell friends about the severe allergy.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 30. Notice early signs of an allergic reaction.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 31. Administer (give) the EpiPen®.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 32. Decide what should be eaten when family has meals out ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 33. Notice the presence of an obvious allergen ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 34. Carry the EpiPen® in case of an allergic reaction.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 35. Demonstrate correct use of the EpiPen® to relatives ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 36. Check the expiry date on the EpiPen®.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 37. Describe to relatives and babysitters what an allergic reaction ...

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Question 38. Explain when an EpiPen® should be given.

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant



Questions 39 to 42:

Do you have any comments or suggestions about questions 39 to 42?

How would you judge the questionnaire **as a whole** for relevance to mothers of children with life-threatening allergies? (Circle your response)

- a. not relevant
- b. somewhat relevant
- c. quite relevant
- d. very relevant

Are there any issues that I have neglected to ask about? Please comment:

Thank you for completing this Content Validity Index.

## QUESTIONNAIRE PACKAGE

For the Research Study

THE EFFECTS OF A PARENT EDUCATION PROGRAM ON MOTHERS OF  
CHILDREN WITH SEVERE FOOD ALLERGIES:

**PLEASE NOTE:**

It is important that you return this Questionnaire Package together with the Content Validity Index Response Record to the researcher after completing the content validity index. Thank you for your assistance and expertise.

Questionnaire # \_\_\_\_\_

**START HERE:**

1. What is the current age of your child with the life-threatening food allergy?

\_\_\_\_\_ years

2. How old was she/he when the life-threatening allergy was diagnosed? You may indicate age in months if that is more appropriate.

\_\_\_\_\_ years      **OR**      \_\_\_\_\_ months

3. What is the gender of your child with the life-threatening allergy? Place an X in the appropriate box.

- ☐ boy  
☐ girl

4. To what foods is your child highly allergic? Place an X in all boxes that apply.

- ☐ milk  
☐ egg  
☐ peanut  
☐ tree nut(s)  
☐ fish  
☐ shellfish  
☐ soy  
☐ wheat  
☐ other (please state) \_\_\_\_\_

For Questions 5 to 21 place an X in the box that best describes how confident you feel in independently managing the following tasks:

5. I am confident in my ability to help my child manage his/her severe allergy.

- ☐ Not confident at all  
☐ Somewhat confident with help  
☐ Very confident with help  
☐ Somewhat confident without help  
☐ Very confident without help

**6. I can help my child manage his/her severe allergy to lead a normal life.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**7. I am confident that I could recognize a severe allergic reaction.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**8. I am confident that I could correctly administer the EpiPen® if needed.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**9. I am confident that the EpiPen® will be within reach if my child has a severe allergic reaction.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**10. I am confident that I can identify my child's allergen on packaging information.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**11. I can adjust what my child eats to avoid an allergic reaction.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**12. I can advocate for my child's best care in community settings such as school and recreational programs.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**13. I can teach my child to take more responsibility in managing his/her severe allergy.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**14. I can talk to my child about the realities of a severe allergic reaction without feeling upset.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**15. I can advocate for better health care for my child if I am concerned about unfairness or unreasonableness.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**16. I can change my child's doctor or seek a second opinion if I choose.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**17. I can make arrangements to safely plan to allow for an overnight stay away from home without my being there.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**18. I can adjust my child's safe eating plan with changes in routine such as eating at a restaurant.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**19. I can be successful in getting my child to follow a safe eating plan, even when s/he may be reluctant or resistant.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**20. I can organize our family meals so that my child can eat the same meals as the rest of the family.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**21. I am confident that meals/snacks that I prepare for my child do not contain my child's allergen.**

- ☐ Not confident at all
- ☐ Somewhat confident with help
- ☐ Very confident with help
- ☐ Somewhat confident without help
- ☐ Very confident without help

**Questions 22 to 38 describe different tasks or situations that relate to severe allergy management in your family. Place an X in the box that best describes the way each task or situation is handled in your family.**

**22. Remember day of clinic appointment.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**23. Explain to teachers and other school personnel about the severe allergy.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**24. Remember to take the EpiPen® with him/her.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**25. Read labels to look for a potential allergen.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**26. Tell relatives about the allergy.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**27. Ask about the ingredients in foods at a restaurant or friend's home.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**28. Decline foods that may contain the allergen, if offered at a social function.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time



**29. Tell friends about the severe allergy.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**30. Notice early signs of an allergic reaction.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**31. Administer (give) the EpiPen®.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**32. Decide what should be eaten when family has meals out at a restaurant or friend's home.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**33. Notice the presence of an obvious allergen and distance oneself from it.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**34. Carry the EpiPen® in case of an allergic reaction.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**35. Demonstrate correct use of the EpiPen® to relatives and babysitters.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**36. Check the expiry date on the EpiPen®.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**37. Describe to relatives and babysitters what an allergic reaction might look like.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**38. Explain when an EpiPen® should be given.**

- ☐ Parents take or initiate responsibility for this all of the time
- ☐ Child is beginning to take or initiate some responsibility
- ☐ Parents and child share responsibility for this about equally
- ☐ Child takes or initiates responsibility most of the time
- ☐ Child takes or initiates responsibility for this all of the time

**The following information will help to determine how education programs for parents of children with life-threatening allergies can best be planned.**

**39. What is your age?** \_\_\_\_\_ years

**40. What sources of information have been most helpful in learning about your child's severe allergy? You may indicate more than one source if you wish.**

- ☐ Physician
- ☐ Nurse
- ☐ Parent Support group
- ☐ Internet
- ☐ Other parents with children with severe allergies
- ☐ Other (please state) \_\_\_\_\_

**41. What is the highest level of education you have attained?**

- ☐ Some high school
- ☐ High school diploma
- ☐ Some college or university
- ☐ College diploma or certificate
- ☐ University degree

**42. Which of the following categories best describes the annual income of your household before taxes for 2003?**

- ☐ \$20,000 or less
- ☐ \$20,001 to \$40,000
- ☐ \$40,001 to \$75,000
- ☐ \$75,001 or more

Thank you for completing this questionnaire
---

## Appendix K

### EpiPen® Scoring Rubric

## EpiPen® Scoring Rubric

Code # \_\_\_\_\_

### **Instructions:**

**Hand the study participant the EpiPen® trainer and say “Please show me exactly how you would give the EpiPen® using this EpiPen® trainer. Please demonstrate on yourself.”**

**Place a check mark next to each skill demonstrated correctly by the mother.**

	Observation 1	Observation 2
1. Holds the EpiPen® firmly by the barrel. (Does not place thumb over either end).	_____	_____
2. Places the black tip against the vastus lateralus at a 90 degree angle.	_____	_____
3. Removes the grey cap. (May occur before step 2.)	_____	_____
4. Presses until a click is heard.	_____	_____
5. Holds for at least 5 seconds	_____	_____

**“Did you come with someone today?”**

Yes / No

**“If yes, what is your relationship to the person with you?”**

\_\_\_\_\_

## Appendix L

### Parent Education Program Evaluation Form

# Parent Education Program Evaluation Form

Date:

Presenters:

*Please complete the following statements.*

1. I liked ... \_\_\_\_\_  
\_\_\_\_\_
2. Not useful ... \_\_\_\_\_  
\_\_\_\_\_
3. I still would like ... \_\_\_\_\_  
\_\_\_\_\_
4. I feel the presenters were ... \_\_\_\_\_  
\_\_\_\_\_
5. For next time ... \_\_\_\_\_  
\_\_\_\_\_
6. Comments: \_\_\_\_\_  
\_\_\_\_\_
7. Overall I rate this educational program (circle one) ...

Low      1                  2                  3                  4                  5                  High



## Appendix M

### Letter Informing Participants about Group Participation

Letter Informing Participants about Group Allocation:

Dear \_\_\_\_\_ (name),

Thank you for enrolling in the research study "Effects of a Parent Education Program on Mothers of Children with Severe Food Allergies". Thank you also for returning the completed consent form and questionnaire package to me. All participants are now enrolled in the study and have been randomly assigned to one of two groups. Both groups are very important to the outcomes of the study.

For the Intervention Group:

You have been assigned to the group that will attend the parent education program. The program will be held on Saturday, June 11, 2005 from 8:30 AM until 12:00 noon at Deer Lodge Centre, 2109 Portage Avenue. A map of the area is attached showing parking areas, bus stops and the entrance to the building.

The topics that will be covered include basic knowledge about allergies, how to assess the severity of an allergic reaction, emergency response and use of the EpiPen®, how to train your child and others to use the EpiPen®, avoidance strategies (food labelling, resources to assist in identifying ingredients, suspect foods, undeclared ingredients), how to promote responsibility in your food allergic child, and how to work with school systems.

Please call me @ \_\_\_\_\_ to confirm that you are able to attend. You will receive a phone reminder a few days before the parent education program. It would be helpful if you would plan to arrive between 8:00 and 8:15 AM to check in and receive your educational materials.

At the program, you will be asked to demonstrate the use of the EpiPen®, and to complete a general evaluation of the program. Twelve weeks after the program, you will receive a questionnaire package in the mail, similar to the first one, and asked to return it to me.

If you have any questions, please feel free to call me @ \_\_\_\_\_ .. Thank you for participating in this study.

For the Control Group:

You have been assigned to the group that will not attend the parent education program. You will receive a questionnaire package in the mail in about twelve weeks, similar to the first package. Please complete the questionnaire and return it to me. Once I have received the completed questionnaire, you will receive the educational package and EpiPen® trainer, delivered to your home address.

The binder will include information on basic knowledge about allergies, how to assess the severity of an allergic reaction, emergency response and use of the EpiPen®, how to train your child and others to use the EpiPen®, avoidance strategies (including food labelling, resources to assist in identifying ingredients, suspect foods, undeclared ingredients), how to promote responsibility in your food allergic child, and how to work with school systems.

If you have any questions, please feel free to call me @ 489-9410. Thank you for your participation in this study.

Sincerely,  
Susan Fogg

## Appendix N

### Script for Reminder Phone Call

Script for reminder phone call:

- “Could I speak with \_\_\_\_\_?”
- “I’m calling about the allergy study.”

“Did you receive the questionnaire package in the mail?” If no, check address. “Can I mail you another package?” If yes, “Did you have an opportunity to complete the consent forms and questionnaire / questionnaire (in the case of the post-test mailing) and mail it back?” If no, “Will you be able to complete and mail the package today or tomorrow?” If no, “Do you still wish to participate in the study?” If yes, “Thanks so much. I’ll look forward to receiving it in the mail.”

## Appendix O

### A Guide for Parents of Children with Life-Threatening Food Allergies

## **A Guide for Parents of Children with Life-threatening Food Allergies**

June 2005

A Guide for Parents of Children with Serious Food Allergies was developed and distributed by Susan Fogg, RN, BN, as part of the thesis requirements of the Master of Nursing degree at the University of Manitoba. It is to be used as a guide to help families and other care givers understand the many issues to be considered when caring for a child diagnosed with serious food allergies. The information included in this resource should be used only as a guide. It is not a substitute for the advice and guidance of your physician and other members of the health care team.

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## Section 1

### Basic Understanding of Food Allergy

#### Introduction

The immune system is the body's defence against harmful foreign materials in the food we eat, the air we breathe, and the things we touch. At times the immune system is responsible for inappropriate responses when the body produces antibodies against a normally harmless substance such as food.

#### What is an allergy, an allergen, an allergic reaction, and anaphylaxis?

An *allergy* is an abnormal sensitivity to a substance which is normally tolerated and generally considered to be harmless. An *allergen* is a substance that causes an allergic immune response. An *allergic reaction* is an abnormal immune response to an allergen in the environment. *Anaphylaxis* is the most severe kind of allergic reaction, involving a variety of body systems. In severe cases, anaphylaxis can be fatal.

Food allergy or hypersensitivity refers to an abnormal or exaggerated response of the immune system to specific food proteins. Gastrointestinal, oral, skin and respiratory symptoms can occur, and severity can vary from a localized reaction to anaphylaxis, a severe systemic and potentially fatal reaction.

#### How common is food allergy?

The prevalence of food allergy is greatest in the first years of life, affecting six to eight percent of children when the gut barrier is immature and the immune system is still refining its ability to tolerate foods. Although potentially any food may cause an allergic reaction, eggs, milk, peanut, soy, fish and wheat most frequently cause allergic reactions in children, and peanuts, nuts, fish and shellfish cause most allergic reactions in adolescents and adults. Allergy to peanuts and tree nuts is the leading cause of fatal and near-fatal food allergic reactions, and peanut allergy appears to be becoming more common.

Family history is an important factor. It is estimated that 48% of children will develop allergies of some kind if one parent has allergies. If both parents have allergies, the risk rises to 70%. It is not fully understood why some substances trigger allergies and others do not. Children with eczema are more likely to have food allergies. Children with food allergies are more likely to develop environmental allergies and asthma.

### **Do allergies to foods go away?**

Some allergies will resolve by four to six years of age, especially allergies to milk and egg. Young children appear more likely to outgrow their food allergies than older children and adults. Some older children and adults may also lose their sensitivity especially if the responsible food allergen is completely eliminated from the diet.

### **What happens in an allergic reaction?**

An allergic person has antibodies (IgE) attached to certain cells (mast cells) that contain histamine and other substances. When exposed to an allergen these chemicals are released into the tissues and blood stream. Anaphylaxis is the most severe kind of allergic reaction. It is a generalized response, involving a variety of body systems. In an anaphylactic reaction these substances can result in hives, swelling, a sudden drop in blood pressure, increase in heart rate, leakage of fluid from the blood vessels into the tissues, and difficulty breathing. Without intervention, death can occur within minutes.

### **How is a food allergy diagnosed?**

An allergy specialist will take a careful history, including presence of other allergic disease and family history of allergy, perform a physical examination, and decide which tests if any may be helpful. These may include selective skin tests and possibly blood allergy tests. A food challenge may be conducted under controlled circumstances.

When you leave the allergist's office, you should know:

- **what you should avoid,**
- **how to recognize and respond to an allergic reaction, and**
- **when to return for follow-up.**

## **How is a food allergy managed?**

### **The 3 A's of Anaphylaxis are:**

- **Awareness**
- **Avoidance, and**
- **Action**

#### **Awareness:**

Families of children with serious allergies should take an active role in the treatment of their children. This includes communicating with your doctor and health care team, with friends and relatives, and with all caregivers, including school staff, child day care workers, recreation program staff and babysitters. Open communication is an important part of managing allergies successfully.

#### **Avoidance:**

Eliminating foods from one's environment can be a difficult task, even for those persons who fully understand the seriousness of the condition. Parents of preschool children with life-threatening allergies frequently insulate their child in a world of immediate family caregivers, fearing risk of exposure to the potentially fatal allergens outside their home. Parents who must rely upon out of home child care and/or whose children are approaching school age, are left hoping that policies in day cares, schools and recreational programs, and the good will of other families to cooperate by not sending products containing peanuts, nuts, or other allergens, will keep their child safe. But products containing peanuts and nuts are found everywhere, often hidden in processed and packaged foods. Invitations to children's parties, play dates, eating out, travelling, grocery shopping, attending community events and even visiting the local play structure requires extra attention and planning, and contribute to the ever present worry experienced by the parents of these children.

#### **Action:**

All caregivers, including immediate family, must learn to appreciate the risks associated with an unexpected exposure to an allergen, how to read labels and recognize words that may indicate the presence of an allergen, how to assess risk on poorly labelled products, how to recognize an allergic reaction, to have adrenaline readily available, and how to correctly administer it and activate the emergency response system. Identifying potential allergens is a difficult task, even for those with the most at stake. It requires reading labels each and every time a product is purchased. Equally important is the ability of children and their caregivers to promptly recognize allergic symptoms and quickly administer adrenaline to reverse a severe reaction.

## **Prospects for therapy**

There are many scientists studying various aspects of food allergy. Some are investigating treatments with the hope of turning off or blocking unwanted allergic reactions. Other studies have investigated what causes food allergy to develop, ways to diagnose food allergy and treatment of anaphylactic reactions. Some researchers study the effects that a diagnosis of food allergy has on parents and children themselves, and ways to help families cope and lead as safe and normal a life as possible.

## Section 2

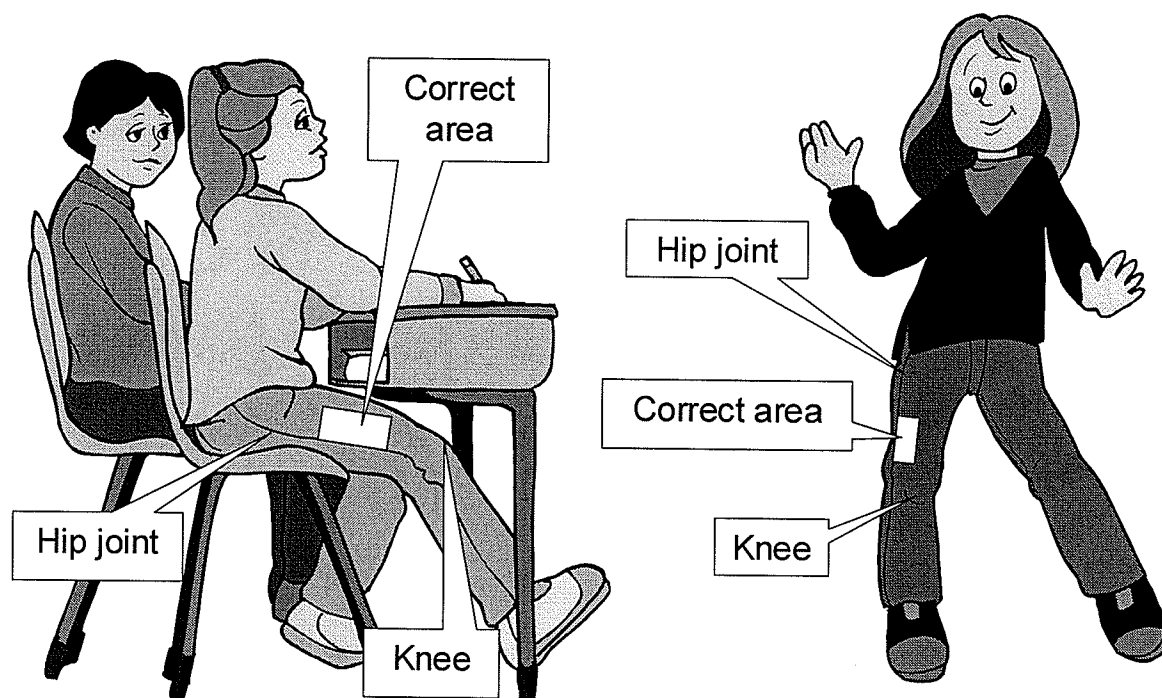
### Recognizing & Responding to an Allergic Reaction

#### How do I know when to give the EpiPen®?

1. You are never wrong to use the EpiPen®!
2. If the reaction is **mild** and **outside** (confined to the skin e.g. a few hives) the EpiPen® may not be needed. Do not leave your child alone. **Watch carefully for other signs and symptoms. Ask yourself:**
  - **Is the reaction outside but severe or all over?** (e.g. hives all over or face swelling). **Give EpiPen®.**
  - **Is there anything wrong on the inside? Give EpiPen.**
  - **Is there anything wrong with your child as a whole?** (anxious, agitated, dizzy, fearful, too quiet, lethargic, limp, wanting to fall asleep, not responding, pale, grey or bluish colour) **Give EpiPen®.**
  - **Is there anything wrong in the mouth or throat?** (choking, gagging, trouble talking or swallowing, noisy breathing, sticking fingers in the mouth, grabbing throat, complaining of itching or swelling of tongue or throat) **Give EpiPen®.**
  - **Is there anything wrong with breathing?** (difficulty breathing, coughing, wheezing, complaining of sore chest) **Give EpiPen®.**
  - **Is there anything wrong with the stomach?** (vomiting, pain, complaining of nausea, sudden cramps, diarrhea) **Give EpiPen®.**

**Call 911 or your local Emergency Response System.  
If you are unsure, use the EpiPen®.**

## Where to give the EpiPen®



## Where to give the EpiPen® ...

- Half way between hip joint and the top of the knee
- OR
- Anywhere in the area bordered by the centre crease of the pant leg, the side seam of the pant leg, and the middle third of the leg between the knee and the hip
- The EpiPen® can be given through clothing
- Check for hard objects in pockets and avoid thick seams

## **How to use the EpiPen®:**

- 1. Hold the EpiPen® firmly** by the barrel. (Do not place thumb over either end)
- 2. Place the black tip against the upper outer area of the thigh** (see the diagrams), at a 90 degree angle to the leg.
- 3. Remove the grey cap.**
- 4. Press firmly.** (You will hear a click when using the EpiPen® trainer, but will not hear a click when administering the real EpiPen®. You will however feel a jolt when the real EpiPen® activates)
- 5. Hold for a count of ten.** When you remove the real EpiPen® the needle should be exposed. If not, it did not activate and you should try again.



## **Transport & observation at the hospital**

1. **Call 911**, EMS or leave immediately for the Emergency Department of the closest hospital.
2. The EpiPen® works for about 10-15 minutes. Try to **get to the hospital** within that time period.
3. A **second EpiPen®** should be given if the reaction does not improve, or if signs and symptoms come back while you are on your way to the hospital.
4. Ideally there should be at least 2 adults, one to drive and one to reassure and observe the child.
5. You should plan to **stay at the hospital** for at least 4 hours in case the reaction flares up again.
6. If you live, camp or travel more than 15 minutes from a hospital, you should **carry extra EpiPens®** (one for each 15 minute period).
7. If you are unsure, **use the EpiPen® and go to the Emergency Department**. Remember it's never wrong to use the EpiPen®.

## How to train family and other caregivers to avoid allergens and how to recognize & respond to an allergic reaction

All care givers, including family members, grandparents, aunts and uncles, school staff, babysitters, child day care workers, and parents of your child's friends who agree to have your child in their care, should be familiar with what to avoid giving your child that could be harmful, how to recognize and respond to an allergic reaction including administering the EpiPen® and, how to activate 911/EMS.

- Review the instructions about when and how to administer the EpiPen® with routine caregivers on a regular basis (for example, every 3 months).
- Leave **written instructions** when you leave your child in someone else's care. Demonstrate the use of the EpiPen®, using the EpiPen trainer® and **ask for a return demonstration** so that you are confident they can administer it correctly. (Put the EpiPen trainer® away so that the caregiver does not confuse the trainer with the real EpiPen® if it must be administered)
- Ensure that the location of the EpiPen® is known to the caregiver and that it is **accessible**.
- Leave emergency contact numbers close by the phone, and include your house number and street name so that someone calling 911 can give that information in an emergency. When calling 911, the caller will be asked if they want "Police, Fire or Ambulance". They should know to indicate "Ambulance" and when asked the nature of the emergency, should state that they have administered an EpiPen® to a child having an allergic reaction. They should know the age of the child and any other relevant health information.

## **Can I get help to purchase an EpiPen® for my child?**

An EpiPen® or EpiPen Jr.® can cost close to \$100.00, and will expire in less than 2 years. Many families will want to have at least 2 EpiPens® available at school, for excursions and/or for travel.

### **Income Based Pharmacare**

Residents of Manitoba are eligible to apply for Income Based Pharmacare, a program that uses a formula to determine an annual deductible based on total family income and the number of dependents within the family. An application can be made at any time during the year. The Income Based Pharmacare is most helpful to those families with a low annual income.

For more information about Pharmacare:

- Visit the Manitoba Health website at:  
<http://www.gov.mb.ca/health/pharmacare>
- Call: 204.786.7141 or toll free at 1.800.297.8099
- Visit the Manitoba Health office at 300 Carlton Street in Winnipeg

### **Third Party Insurance**

Most private health insurance companies offer individual and group benefit plans with differing maximum claim amounts. You will want to find out if the cost of your child's EpiPen(s)® can be claimed through a parent's work plan or through the purchase of an individual or family health insurance plan. If you do not have a private insurance plan, you will need to carefully consider the costs and benefits of purchasing private insurance.

Most families receiving social assistance benefits can obtain prescription drugs through their assistance program. In some cases, a letter from your doctor may be required in order to have more than one EpiPen® dispensed for a particular child or adult.

For low income families not covered by an insurance plan and who are having difficulty paying for medications such as an EpiPen®, community clinics like Mount Carmel Clinic, Youville Clinics, Klinik and Women's Health Clinic may be of help.

## **Section 3**

### **Avoidance Strategies**

**Who decides what your child eats? You decide what your child eats.**

1. Either provide food for your child, or carefully check all food before allowing him/her to eat it.
2. Teach your child not to accept food from others. He/she should eat only food that you supply or approve.

**What can I do to avoid an allergic reaction from foods I provide for my child?**

Avoidance of allergens is the cornerstone of management in preventing a serious reaction. There are a number of things you can do to prevent accidental ingestion of a dangerous allergen.

**1. Read labels each time you use a product.**

Although this may add extra time to the already difficult task of grocery shopping it is crucial because food companies often make changes to products without notice to the consumer. Having your allergic child assist with checking labels will save time and establish the practice of checking food products for safety prior to purchasing them.

**2. Familiarize yourself with the ingredient labelling requirements for Canadian food companies.**

These fall under the Canadian Food and Drug Regulations. (The next section provides a summary of food labelling requirements in Canada)

### **3. Be sure to know the alternate names for allergens.**

Currently, in North America manufacturers are not required to use common names on food labels. In some cases there are numerous terms that may indicate the presence of an allergen on an ingredient list. For example, *whey* or *casein* may indicate milk protein; and *ovalbumin* may indicate egg in a product.

**If you haven't already received one, ask your allergist for a list of terms that may indicate the presence of your child's allergen(s).** As well, lists of alternate names, and a wealth of other information about allergens are available from Anaphylaxis Canada [www.anaphylaxis.org](http://www.anaphylaxis.org) and The Food Allergy & Anaphylaxis Network (USA) [www.foodallergy.org](http://www.foodallergy.org) and go to [www.foodallergy.org/allergens](http://www.foodallergy.org/allergens) Lists can also be found in the book *The Complete Kid's Allergy and Asthma Guide: the Parent's Handbook for Children of All Ages*. Hospital for Sick Children, Dr. Milton Gold, editor, (\$24.95).

### **4. Contact food companies to check products.**

There is a possibility that allergens not listed on the label of a product will be present as a result of cross contamination during either the processing or packaging stages of production. Also there are currently a number of exemptions to labelling such as the components of some ingredients, mixtures or preparations. By contacting companies you can often get detailed information regarding whether or not a particular allergen could be present in a product. At the same time you can get information about the company's labelling practices. Knowing whether or not precautionary labelling is used on their products can be helpful in deciding which products are safe for your allergic child.

### **5. Sign up to receive food recalls and allergy alerts.**

Information regarding products that have been removed from the market place will be forwarded to you via email by setting this up through the Canadian Food Inspection Agency. Go to [www.inspection.gc.ca](http://www.inspection.gc.ca) or call 1-800-442-2342.

**6. Be aware that there are differences in labelling practices in other countries.**

Each country has its own regulations for labelling and these may differ from Canada. Also, a product made by the same company and available in Canada, the United States or other countries may have different ingredients in each country. When calling companies to check on ingredients be clear about where you are planning to purchase the product.

**Is there legislation that requires Canadian companies to include allergens on ingredient labels?**

There is often misunderstanding with respect to the requirements of Canadian food companies regarding what has to be included in food ingredient labelling. The following will summarize the major aspects of food labelling in Canada from the "2003 Guide to Food Labelling and Advertising."

**THERE ARE COMMON ALLERGENS THAT ARE REQUIRED TO BE ON THE LABEL WHEN AN "INGREDIENT" OF A PRODUCT.**

Legislated under the Food and Drug Regulations, the following are the common allergens that companies are required to include on the label when they are an "ingredient" of a product:

- Peanuts
- Tree nuts (almonds, Brazil nuts, cashews, hazelnuts(filberts), macadamia nuts, pecans, pine nuts, pistachios, walnuts)
- Sesame seeds
- Milk
- Eggs
- Fish
- Crustaceans (e.g. crab, crayfish, lobster, shrimp)
- Shellfish (e.g. clams, mussels, oysters, scallops)
- Soy
- Wheat
- Sulphites

## HOWEVER, THERE ARE EXEMPTIONS WHEN ALLERGENS ARE "COMPONENTS" OF "INGREDIENTS"

In some circumstances, when the common allergens listed previously are "components" (that is, "ingredients of an ingredient"), they are exempt from being included on the label.

The following are examples of some foods that when used as ingredients in other foods do not have to be declared as "components" (ingredients of ingredients):

- Butter
- Margarine
- Shortening
- Lard
- Flour
- Soy flour
- Graham flour
- Whole wheat flour
- Baking powder
- Cocoa
- Hydrolysed plant protein
- Whey, whey powder, concentrated whey, whey butter and whey butter oil

However, peanut oils and lysozyme from egg white must always be declared.

## THERE ARE FOOD PREPARATIONS AND MIXTURES THAT ARE EXEMPT FROM DECLARING "COMPONENTS"

The following are examples of food preparations and mixtures that when used as ingredients in other foods do not have to be declared as components.

- Food colour preparations
- Flavouring preparations
- Artificial flavouring preparations
- Spice mixtures
- Seasoning or herb mixtures
- Vitamin preparations
- Mineral preparations
- Food additive preparations
- Rennet preparations
- Food flavour-enhancer preparations
- Compressed, dry, active or instant yeast preparations

However, salt, MSG, hydrolysed plant protein, aspartame, potassium chloride, peanut oils and lysozyme from egg white must always be declared.

#### THERE ARE A NUMBER OF FOODS THAT ARE NOT REQUIRED TO HAVE AN INGREDIENT LIST

Some of these include:

- One-bite confections, such as candy or a stick of chewing gum, sold individually
- Fresh fruit and vegetables and components of wax coatings used on them
- Pre-packaged products packed from bulk at the retail outlet
- Pre-packaged individual portions of food served with meals or snacks by restaurants, airlines etc (coffee creamers, ketchup, etc.)
- Pre-packaged individual servings of food prepared by commissaries and sold in mobile canteens or vending machines ( this would included foods sold in the deli at a grocery store)
- Pre-packaged meat, poultry and poultry meat by-products that have been barbecued, roasted or broiled on the retail premises
- Pre-packaged baking made at a store

#### **Are companies required to use precautionary labelling such as "may contain peanuts" when there is a chance that allergens are present in a product due to cross contamination?**

#### USE OF PRECAUTIONARY LABELLING BY COMPANIES IS VOLUNTARY

The Canadian Food Inspection Agency (CFIA) works to inform the food industry about the requirements for food labelling and encourages companies to adopt manufacturing practices that provide the consumer with detailed information about ingredients or components in products. The CFIA suggests production practices that reduce the potential for cross contamination of products with common allergenic substances. Despite these precautions there remains a possibility of the presence of allergens not declared on the label. The CFIA developed a policy that allows companies to use "precautionary labelling" on products that may inadvertently contain substances



that have the potential to cause a severe allergic reaction (e.g. "may contain peanuts"). This does not fall within any legislation and is a practice that is totally voluntary on the part of the company. Some companies choose to use precautionary labelling for some of the allergens and others do not use it at all. This means that there are products that may contain allergens of concern through cross contamination with no indication of this possibility on the product label. Also, there is no standard of practice with regard to how precautionary labelling is used from one company to another.

Calling companies to check for the possibility of allergens of concern in their products and enquiring about the use of precautionary labelling will provide you with the greatest knowledge to make decisions regarding which foods to consume.

For more information on food labelling in Canada visit the CFIA website at [www.inspection.gc.ca](http://www.inspection.gc.ca) Under Table of Contents choose "Labelling/Retail Food" then scroll down to "Inspection Manuals/References", choose "2003 Guide to Food Labelling and Advertising", choose "Chapter 2, Basic Labelling Requirements".

### **What foods might be unsafe for people with food allergies?**

Potentially unsafe foods for people with life-threatening food allergies include:

- Bulk foods since there is a high risk of cross contamination.
- Desserts and baked goods
- Imported foods. These are often recalled due to inaccurate labelling
- Foods that have "may contain...." on the label
- Ice cream products

### **How can I prepare for eating out at social events or restaurants?**

Although eating out creates some level of risk for people who have life threatening allergies there are a number of ways you can reduce the risks when eating at a restaurant or at social events whether a small family gathering or large celebration.

This first step in preparing to eat away from home is to decide if you trust that the person or people preparing the food will provide food that free of the allergens of concern. Some people do not feel comfortable with having others prepare food for their allergic child so choose to bring food for their child.

## **Social Gatherings**

If you are planning to have your child eat the food prepared for a social gathering you want to start by making sure the person preparing the food clearly understands the seriousness of life-threatening allergies. Without having the experience of living each day with life-threatening allergies you can't expect others to understand or be aware of the procedures you follow to avoid allergens. There are a number of ways you can prepare to provide a safe meal for your child:

- Go over the menu in detail with the person preparing the meal.
- Read ingredient labels for all items used in food preparation.
- Ask if any other guests will be bringing food and if so check to see if they are aware of your child's allergies and the need to take precautions.
- Discuss concerns regarding potential for cross contamination in the kitchen.
- Discuss the importance of cooking utensils, pots and pans, and preparation surfaces to be free of allergens
- Bring treats for your child in case someone else brings a surprise treat that your child cannot have.
- If there are allergens of concern in some of the foods, serve your child before other guests, to avoid contamination with utensils while the food is being served.
- Depending on the age of your child and the allergen, you may want to ask the host to not have the allergen present while your child is present, for example; a bowl of peanuts when the child has peanut allergy.

## **Eating at Restaurants**

Most of us look forward to eating out at restaurants once in awhile. For individuals and families dealing with life-threatening allergies this can be extremely challenging. The way people handle this, like the way they handle many issues regarding food allergies, varies from family to family. Everyone must make their own decisions about whether or not to eat out, where to eat and what precautions to take. It is possible to feel confident about your restaurant choices and avoiding contact with allergens.

The following suggestions will help to prepare for eating at restaurants:

**Plan ahead.** Contact or visit the restaurant well in advance of when you plan to go to allow time to choose another restaurant if you are not happy with the information you receive. Do this during off-peak times. Be prepared to accept that answers to questions you ask may not be what you would like to hear and you may have to make alternate plans to feel comfortable about eating out.

**Speak with the cook, chef or manager to assist in planning.** Make sure that the people you are speaking with clearly understand what life-threatening allergies are and what you are asking. Ask questions to gain the information you need to make your own decision as to whether or not the situation is safe rather than asking others to make a judgement about the safety.

**Ask specific questions.** You may want to prepare a written list of questions ahead of time. Ask about past experience the restaurant has had in providing for customers with life-threatening allergies. Ask about safeguards or policies that are in place to deal with life-threatening allergies. Ask about any training that the staff has received to help them understand and deal with life-threatening allergies.

**Review the menu.** Check for foods that contain the allergen of concern. If there are allergens of concern in the restaurant, ask about the possibility of cross contamination from other products that are prepared in the same area such as a cooking grill, preparation counter or deep fryer, etc.

**Check into ingredients of foods and possible cross-contamination with allergens.** Ask to read food labels. Be sure to know all the possible alternate names for the allergens. Ask for a master list of ingredients in the foods on the menu. Ask to see packages for ready-made foods so you can read the ingredients. Ask which foods are prepared at the restaurant from scratch and which are brought in partially prepared or ready-made from other suppliers. Ask about the possibility of cross-contamination of foods from suppliers. Do suppliers guarantee products are free of specific allergens? You may want to obtain names and phone numbers of suppliers to check directly with them about ingredients and cross-contamination.

If you are dealing with a restaurant chain you can contact both the head office and the specific restaurant you plan to eat at. Ask if there are standard products, ingredients and procedures for all outlets or if each restaurant prepares their own products.

**Order simple meals.** Avoid sauces, foods with coatings, desserts or baking and buffets due to a high chance of cross-contamination.

**Avoid sharing.** Do not share food, utensils, straws or drinking glasses.

**Dine at off-peak times.** You are more likely to receive better service and the staff will have more time to attend to your special needs. Request that the area where you will be seated be well cleaned prior to sitting down.

**Ask questions each time you go to a particular restaurant.** Check for changes that could make the situation unsafe. Get to know managers or owners of the restaurant and let them get to know you. This may help them to remember your special needs and inform you if any changes have been made that might affect you.

**ALWAYS CARRY AN EPIPEN®**

## **How do I prevent my child from coming into contact with allergens from other sources?**

There are a variety of ways parents can reduce the risk of accidental ingestion of an allergen that is dangerous to their child. There are also resources available that provide detailed guidelines for dealing with life threatening allergies at school. See the resource section for information on how to obtain these.

### **1. Teach your child to avoid allergens**

It is important for children with life-threatening allergies to share in the responsibility for their safety. Teaching your children at a young age to take appropriate precautions will help to develop good habits for avoidance.

Teach your child to:

- recognize the allergen(s) of concern. This would include being aware that allergens may be present in non food products such as body products (lip chap/gloss, shampoo, lotions, etc), vitamins, craft materials, pet foods, toys such as bean bags (nut shells may be used in these), bird and animal feed.
- recognize unsafe situations or environments and remove him/herself or speak to an adult in charge.
- never share food, utensils, straws, drinking cups
- eat only food provided or approved by his/her parent
- carry treats or snacks for situations when other children they are with have snacks
- wash hands prior to and after eating
- not eat if he/she has forgotten his/her EpiPen®

## **2. Educate the people who will be caring for your child**

It is crucial that the people who are caring for your child understand the seriousness of your child's medical condition and are aware of the potential for accidental ingestion or exposure. This would include people such as day care workers, grandparents, babysitters, teachers, coaches and club leaders. You should make them aware of the rules you have set regarding avoidance. Providing this in writing will help to make sure that your expectations are clearly understood and it is more likely they will be adhered to. Minimally they should be provided with the same information you have given to your child.

## **3. Educate the people who will be in contact with your child**

Providing information that helps people understand your child's special concerns is the key to gaining their support. Although much of your child's time away from home will be spent at school, children are also often involved with many other groups through family and friends, sports teams, clubs, church groups, or a variety of extra curricular activities. In order to reduce risks as much as possible it is important to seek support from others who are involved with your child.

## **4. Ask for support in avoiding allergens**

There are a variety of ways, in the various situations your child will be, that you can gain the support of others. Almost anywhere your child goes, you can ask others to help, including school, sports and recreational events, clubs, family gatherings, vacations and travel.

- At school programs, sports teams or clubs, summer camp programs, etc., send letters asking that participants not bring specific allergens in lunches or snacks.
- Ask that those who are participating in activities with your child wash hands prior to attending, particularly if peanut butter has been consumed.
- Post signs with information about life-threatening allergies and how people can help.

- Provide reminders about requests for avoidance. It is somewhat unrealistic to expect people who are not dealing with life threatening allergies on a daily basis to consistently remember your requests. This is especially important at times when the risk is greatest and people are likely to bring treats and candies. This includes parties or events celebrating birthdays, Halloween, Christmas, Valentine's Day, Easter, or other religious occasions, when your child's group is travelling or going on a field trip, or end of season parties.
- Send notes of thanks for support or ask for a "thank you" to be printed in the school newsletter. People generally appreciate being acknowledged for their contributions. This will also serve as an additional reminder.
- At social events you can request that your child's allergen(s) not be served and/or within reach particularly when you have a young child who does not understand the seriousness of his/her allergy or is not developmentally able to avoid allergens.
- When travelling on airplanes, trains or buses, you can ask the attendants to make an announcement requesting that other travellers not eat peanuts or nuts while your child is present. This can be done in advance in the waiting area or when travellers have boarded. You can also request in advance that peanuts or nuts not be served on the flight.

## **5. Make appropriate physical arrangements to avoid contact**

- If you are at a social event where the allergen(s) of concern is present, serve your child first before there is a chance of cross contamination from serving utensils.
- At school have an area designated as allergen free and have desks washed after eating
- When traveling on airplanes, trains or buses etc ask to board early and clean the area where your child will be sitting. For young children you can bring a blanket for them to sit on. Teach your child to never stick their hands in areas that are likely not cleaned such as between seat cushions.
- When staying in hotel rooms or rented cottages request in advance that they are given a thorough cleaning and explain the importance of your special request. Upon arrival ask to preview the accommodations prior to moving in. If you are staying in a place that has a kitchen, plan to spend some time cleaning prior to settling in.

## **6. Be aware of vulnerability posed by bullying with an allergen**

Make sure those who are caring for your child are aware of the potential for bullying and understand the serious nature of a child being bullied with a dangerous allergen. Teach your child to be able to respond appropriately to a situation if he/she is being bullied, by informing an adult in charge and by removing him/herself from danger. Soliciting the help of others in advance will help support and protect your child should this happen.

## **7. Evaluate each situation your child will be in for potential risks**

The greatest risk of accidental ingestion or exposure to allergens is in new situations or when daily routines are interrupted, such as school outings and field trips, birthday parties or travel with teams. As a parent you need to decide if you want to trust the people in charge of your child to be responsible for avoidance or if you should go with your child.

## **Avoid a Fatal Reaction**

Despite taking a variety of precautions, accidents happen and an anaphylactic reaction may occur. Always be prepared to react promptly. Time is of the essence.

- Always carry an EpiPen®. Once old enough your child should carry the EpiPen® in a pack on his person. Always have it close at hand so it can be used as soon as a reaction begins. More than one EpiPen® should be available if you are more than 20 minutes from a medical facility.
- Ensure your child is always wearing a medical ID bracelet.
- Teach your child and anyone who is caring for your child to recognize a reaction.
- Make sure you know how to properly administer the EpiPen®. Teach your child (when age appropriate) and anyone who is caring for your child how to administer the EpiPen®. EpiPen® trainers are available so you can practice how to use a real EpiPen® in an emergency.



- Have an emergency plan in place wherever your child goes. Be prepared to get medical treatment for your child immediately after using the EpiPen®. Plan in advance how you would get to an emergency centre. If you are travelling in a rural area know where the nearest emergency centre is. You do not want to waste time trying to determine where you are going to go and how you will get there in the midst of an emergency. When in rural areas you can contact the emergency centre to enquire about the hours of operation and what services are available. You can also speak with the ambulance service for the region to decide whether you would use their service or drive to the nearest emergency centre. Some ambulance services in rural areas are staffed by volunteers who may take considerable time to get to where you are.

## Section 4

### How to promote responsibility in your food-allergic child

**How do you promote responsibility in your food-allergic child? It will take teamwork – and the steps are A-B-C-D-E.**

Responsibility is a learned skill. Responsible food-allergic children are responsible children. They are the children whose teachers, coaches and peer group will comment on their being responsible – responsible about their allergy, their homework, their chores. Teaching this skill to a child requires teamwork. The team consists of you, your child, your extended family, babysitters, teachers, schools and your community. It is a skill that can be applied at all ages and stages. It is a skill required by all members of your child's team.

The steps to learning this skill are like following the alphabet:

A= Ability

B= Behaviour and Building a team

C= Communication, Consequences and Consistency

D= Different and Determined to Do

E= Expectations:

- Expect responsibility from your child
- Expect responsibility from others
- Expect to respectively advocate for your child
- Expect that your child's abilities and needs will change over time
- E also means that you will need to Evaluate, Evaluate, Evaluate

Becoming responsible doesn't just happen. It is an incremental skill beginning with small steps and building upon skills and experience over time. As a parent, you will decide when and how much responsibility your child can handle. Obviously, developmental factors are a determinant of ability and there is variation among children of the same age. Don't let this become an excuse for not having a plan to teach responsible behaviours and taking advantage of those teachable moments. Some strategies will be offered to you. Consider them carefully and formulate a plan to move forward and teach your child to take as much responsibility as is developmentally appropriate to practice safe behaviours. Have a goal – break it down into do-able steps, and practice these skills over and over.

Remember that your child will change over time. The needs of a 4 or 5 year old will be very different than the needs of a 10, 12 or 15 year old. An adolescent will not suddenly become responsible about managing his/her life-threatening allergy – remember to carry an EpiPen®, tell friends and others about his/her serious allergy, carefully consider the risks of ordering food at a restaurant, etc. if he/she hasn't practiced those skills in a supportive way throughout childhood. These early years are the training ground for adolescence and adulthood. Making decisions to keep your child safe without involving him/her in the process may keep him/her safe in those early years, but your child may be ill-prepared for independent activity come adolescence. This can be a scary proposition considering that your adolescent may be going on overnight trips with teams and groups of friends, camping trips, eating in unfamiliar places – just in the normal course of growing up. Now is the time to instil knowledge and skills that will reduce risks and ensure that an EpiPen® or two is always accessible and that those around your child understand the seriousness of this condition and know how to recognize and respond should an inadvertent exposure occur.

### **A is for Ability:**

Abilities change over time. Often you will hear this referred to as growth and development. At certain ages and stages we expect children to behave in certain ways.

Ability should take into account:

- Dependency needs: “What assistance is required?”
- Age of first or last serious allergic reaction. Can your child remember how he/she felt, what caused it and what happened? If your child cannot remember the allergic reaction, he/she will have no unpleasant memories or associations with the food, he/she will be less likely to be determined to avoid that food. Memories affect ability which in turn affects behaviour.

- Expressive language skills and ability to read and comprehend labels
- Style of learning: Does your child learn best by seeing, doing, reading, listening or a combination of these ways? Remember that receiving the same message in a variety of ways will serve to reinforce what you are trying to teach. Use books, videos, conversation, role play and any other resources you can find.
- Ability to understand abstract concepts. Children typically begin to develop the ability to do this between 6 and 10 years of age. Your 4-year-old really can't understand cause and effect very well – even though you may hear him/her say that “eating nuts will make me sick”. Your school-aged child understands that death is irreversible and may even have exaggerated concerns about dying. In the same way, your adolescent is intellectually capable of understanding the finality of death, but adolescents have a sense of invincibility that conflicts with understanding the risks of a severe anaphylactic reaction. This explains why teenagers take risks.

It is important to understand your child's developmental progression. This will help you set reasonable goals and consequences. For example, you would not leave your 5-year-old alone but in most cases it would be reasonable to leave your 14-year-old alone for a few hours. In the same way, it is not reasonable to expect a 2-year-old to responsibly carry their EpiPen®, but it may be reasonable to expect your 6-year-old to do so. You would not expect a 3-year-old to explain the symptoms of an allergic reaction, but you would expect a 12-year-old to be able to do this.

Knowing what behaviours and abilities are developmentally appropriate can help you determine what expectations are reasonable. What you decide will have to feel right for you and your child. You may however, be faced with teachers and others who may have different expectations than you feel are right for your child.

## **B is for Behaviour.**

Behaviour is what you do.

Behaviour is what others do.

Behaviour is what your child does.

Your child may be mentally and physically **able** to clean his/her room, and yet it doesn't happen. Your child may be mentally and physically **able** to carry his/her EpiPen® and yet takes it out and plays with it, and shows it to other children in the school yard. What has happened here? **Ability** and **behaviour** don't match.

You can and should expect ability and behaviour to match. You will need to determine what behaviour you expect to see and from whom – and then **when, where and why** might this not happen. This begins the task of problem-solving – involving you, your child, extended family, daycare, school, etc. in order to achieve solutions.

Remember that you and the adults around your child are role models. Children learn from what they see and hear. If you want behaviour from your child, then expect the behaviour from yourself. For example, work through the process of selecting food from a restaurant menu with your child. Help your child select something that is simple and less likely to contain multiple or unknown ingredients. Ask to speak with the manager or chef together with your child, so he/she can learn how to ask about ingredients and how to evaluate the information you are given by restaurant staff. If you select something from the menu without involving your child, you lose an opportunity to teach your child this very important skill.

### **You need to think about:**

**When** might I not see the behaviour I expect?

**Where** might I not see the behaviour I expect?

**Why** might I not see the behaviour I expect?

Celebrations & parties are times you may not see the behaviour you expect. Risk of an inadvertent exposure increases when routine is changed, when food is served by others who may not fully understand the implications and seriousness of the food allergy, or who didn't recognize terminology that indicated the presence of the allergen – or perhaps never checked, or who didn't understand the risks of cross-contamination of ingredients. Add to this that your 4-year-old expects that all adults know how to keep him safe so he accepted what any adult gave him ... Or perhaps your 12 year old who has been taught to only eat food from home or that has been checked by you decides to challenge your adult authority or try something offered by a popular classmate. It is natural that children of this age will begin to make independent decisions, sometimes to the surprise of their parents. Let's explore the 12 year old some more. A deeper why may be that she doesn't want to be "different" from her friends. She wants to eat the same things as they do, she's afraid of being teased. Why's are never simple.

They require us to be alert, tuned into our child, always listening and communicating. You want to be considering the **when**, the **where** and the **whys** ahead of time.

Once you have defined the behaviour you want, and the when, where and why you might not see it, think of solutions. You need to explore with your child and you need to role play. For instance, before the birthday party you discuss “the birthday cake”. Don’t assume she will be uncomfortable eating a cake that looks different from the birthday cake – let her tell you. If it really is a problem, look for solutions, discuss feelings, and then role play. What will you say when ... What will you do when .... By role playing, you and your child will have confidence when the party day arrives.

What about your child wearing the EpiPen®? That’s the behaviour you eventually want to see. But how do you get there? It’s a process you can start as early as possible. When going out with your young child, verbally and physically have them know that you are checking that you have the EpiPen® on you. For example, every time you go out with your toddler, say out loud, “Do I have the EpiPen®? Yes, here it is in my purse. I will keep my purse with the EpiPen® with me and you while we are out.” Do you expect your child to understand all of this? No. You are role modelling. Children learn from what they see and hear. Your child is watching you and learning.

Now your child is four. You talk about how your child is growing up and he/she will one day be old enough to wear the EpiPen®. Make this a celebration, a rite of passage – not a burden. Once again explore the when, the where and the whys. When, where and why might he/she take the EpiPen® off or be pressured to take it off. Maybe in gym class and it gets left behind? As you take each step in your child responsibly wearing the EpiPen®, ask yourself these questions, then problem solve and role play. Review the rules about being a responsible EpiPen® carrier. A responsible EpiPen® carrier does not take it off, does not take it out and play with it, etc. Once your child can confidently state the rules – load the EpiPen® tote or fanny pack with something like a toothbrush, plastic container or similar object that will feel like the EpiPen® will feel. Tell you child that when he/she is responsibly wearing and looking after the tote or fanny pack with the object, he/she has earned the privilege of being responsible for the EpiPen®. This truly will be the rite of passage and involve your child in the process. Involve your child in planning a celebration of this milestone.

## **B is also for Building a Team**

You are the coach and captain or your child’s team. Successful coaches are encouraging. They praise successes. They break down skill acquisition into small steps. They work with the team. Successful coaches are firm but fair. This requires non-judgemental listening.

## **C is for Communication, Consequences and Consistency**

In order to build a committed team, you will need to clearly communicate the behaviour you expect to see. It is important that the adults entrusted with your child's care understand the behaviour you expect from your child and the importance of consistency and consequences should behaviours not be demonstrated. To build responsibility in your child you need to make sure that ability and behaviour match, and then you need to provide consistent, reasonable consequences for when it doesn't. Make sure that your child knows ahead of time what will create consequences and what the consequences will be. Remember that developmentally your child does not understand the finality of a severe anaphylactic reaction, even though he/she may say that if they eat the allergen they could die. Keep the consequences understandable and clear. For example, you may find yourself saying to your child, "I need to know that if you have a reaction that your EpiPen® is available to help you. Because you keep playing with your EpiPen® and losing it I will have to go with you on your play date. When you show me that you are responsible by ... you will once again be able to go to your friend's house without me."

Be clear and consistent yourself. If your child is allergic to milk and you want him/her to avoid products containing milk, don't say "Here's your milk" when handing a glass of soy to your 2 year old. If you want your child to consistently read labels before eating, your child needs to consistently see you reading labels before giving him/her something to eat. Give consistent consequences when your child eats something without reading the label carefully or checking it with you.

It takes courage to be consistent, to expect responsible behaviour, and to follow through with consequences when expectations and behaviour don't match. Being consistent and enforcing consequences are no different when it comes to life-threatening allergies than for other aspects of parenting. If you are not consistent about having the EpiPen® available, your child will not be. Remember the toddler always watching and listening to the parent checking for the EpiPen® before going on an outing? Our children never stop watching and listening to us. They are watching and listening for consistency and their consequences may depend upon how consistent you are.

## **D is for Different and Determined to Do safely**

Yes, your child has a life-threatening allergy. That does make him/her different. Your child is different because he/she must avoid certain foods and situations, and must wear an EpiPen®. That's a fact. Another fact is that we all have differences. A child with diabetes must balance how much carbohydrate he eats, how much energy he expends and has to prick his finger to test his blood sugar and have insulin injections throughout each day. Other children have health conditions that affect their every-day lives too. We all have differences. Different is a reality for your child.

Determined to do safely means acknowledging and accepting the difference and having the will and energy to create environments where your child can do. Your choice is to be a parent who is determined to have your child do safely. You want your child to lead as normal a life as possible. You can be determined for your child to do everything that other children do. Your child can attend daycare, school, birthday parties, play with other children, play sports, go on school trips safely and enjoy them without being fearful. To be a determined doer, you and your child must look at ability and behaviour, not just his/hers, but the ability and behaviour of others. Then you need to assess the risks, decide the responsible behaviours, examine the when, where and why ability might not match behaviour of all concerned, and go about finding solutions.

## **E is for Expectations**

Expect responsibility from your child. Expect your child to wear a medical information bracelet or necklace. Expect that your child will safely and responsibly carry the EpiPen® on his/her person. Many children have demonstrated that they are capable of doing this by 5 years of age. Expect your child to follow avoidance strategies.

Expect responsibility from yourself. You need to accept responsibility for teaching your child to be responsible. Yes, there are others to help support you in doing this; your spouse, family, teachers, coaches, health professionals and others. The primary people to do this are the parents.

Expect responsibility from others. When your child enters daycare or school, you should expect certain minimal standards of safety. Having said that, you will need to make sure that those standards are in place. Several months prior to your child's entry into any program, you will need to assess the knowledge and standards of that program.



To do this you need to:

- Ask for a meeting with the principal or director of the program. If at all possible, ask that the teacher be there as well. Don't expect that they will know or understand anything about your child's allergy. In fact, they may have pre-conceived ideas about serious allergies that may not be correct.
- Start by telling them about your child's allergy, clearly and calmly.
- Then tell them what expectations you have for your child and for yourself. They will respond more positively to your requests when they know that you and your child are willing to take responsibility too.
- Respectfully ask what experience the organization and specific individuals that will be in charge of your child have had with serious allergies in the past. What was done in these situations? Remember, you are getting them on board and building your support team.
- Ask the when, where and why questions? Consider what will happen when a substitute teacher (home room, gym, music, computer, etc.) is in charge of your child. Problem solve together.
- Plan to help all school staff, students and their families be informed and aware of the seriousness of your child's condition and what they can do to help make the school environment safer. Stay calm. Avoid arguments about who's right it is to do what. These situations usually escalate emotion and are difficult to diffuse.
- Refer to the provincial URIS (Unified Referral and Intake System) guidelines regarding children with life-threatening allergies. If the principal is unaware of the guidelines, refer him/her to the school division's Director/Coordinator of Student Support Services.

If problems arise, ask for a meeting with the Director/Coordinator yourself. You can go higher to the superintendent if necessary, but remember that you may lose support if you go over the head of your principal and others without allowing them the opportunity to work with you. You want the principal fully on board.

Remember that staff, other students and families and circumstances change from year to year, and sometimes within the year. You will need to meet to revise and/or reassess the plan at least at the beginning of every school year and perhaps more frequently if there are personnel changes.

If the organization is going to assist you in teaching your child to be responsible, you need to be ever vigilant. Look for change, assess the gaps in safety. When action is required, ask for the team to be brought together (you, your child, the administrator, teacher(s), etc.) so that the action can be developed.

### **Developing a Health Care Plan at School:**

The principal can arrange for a registered nurse to assist you and the school to develop and implement a health care plan specific to the health needs of your child. A complete health care plan will include developing strategies to make other families and classmates aware of the condition and how to avoid exposure to the allergen at school. The nurse can also train school staff in how to recognize and respond to a severe allergic reaction. The Student Services Director/Coordinator of your school division has a URIS Manual that explains how the school can access provincial funding to pay for the nurse through URIS, which is one of the Children's Programs in the Department of Family Services and Housing, Manitoba Government.

### **Consider the following strategies for inclusion in your child's health care plan:**

#### Information & Awareness for the school community

- Is there a staff in-service (at least annually) on anaphylaxis; including when and how to use of the EpiPen®?
- Is there a poster in the staff room with your child's name and picture, allergen(s), and instructions about how to respond in case of an allergic reaction?
- Is there an allergy alert on the classroom door to remind other students, their families and others not to bring the allergen into the classroom? (A stop sign symbol with a text box saying "NO KIWI"; for example, works well)
- Is there a bold Allergy Alert in the substitute teacher file?
- Are there general allergy reminders in the school newsletter in September and periodically?

**Avoidance strategies/Risk reduction**

- Teach your child to take as much responsibility to avoid the allergen(s) as is developmentally appropriate
- Request that a letter be sent home to families in the class/lunchroom/entire school if appropriate asking cooperation to not send products containing the allergen to school
- Request that a reminder be sent to families in the class before excursions and special occasions about sending snacks/lunch containing the allergen(s), especially regarding peanut butter and nuts.
- Request to be notified well in advance before excursions so you can plan with the teacher/administrator such things as supervision (you might decide to go along as a parent volunteer to keep a close eye on your child), number of EpiPens® to accompany your child and who will carry them, if there will be a telephone available and extra transportation and/or whether you want your child to go on the excursion
- Discuss lunchroom planning (table allocation, table washing, garbage placement, hand washing practices, etc.) to reduce risk
- Ask about policies regarding teasing or bullying
- Be clear that your child will only be eating food from home and/or checked by you
- Consider providing a supply of non-perishable safe treats for your child for unexpected special occasions
- Ask if the teacher uses food for activities such as math manipulatives, finger painting, art, or has pet food in the classroom. Ask about hand washing practices
- What about locker assignment (individual or shared)
- Foods lab (may be located at a different school and the allergen may be part of the teacher's menu or present in the lab, or the classroom may be used for cooking classes in the evening)

### Emergency response/Action

- All staff in charge of your child should be able to recognize your child, know how to recognize and respond to an allergic reaction, know where the EpiPen® is located and attend an annual inservice about life-threatening allergies.
- Location of the EpiPen(s)® (preferably on your child); is there a back-up?
- Does your child wear a medical information/identification bracelet or necklace?
- Ambulance to be called for any severe reaction
- Parents to regularly review with their child how he/she might feel in the event of a severe allergic reaction (signs & symptoms) and role play who he/she would tell and what he/she would say if able to notify an adult

### **E is also for Evaluate**

You must constantly evaluate. Evaluate your child's ability and the ability of others. Evaluate behaviour and the match between ability and behaviour. Evaluate that communication about expected behaviour is clear, that consequences are consistent. Evaluate that all members of the team are involved and committed. Evaluate that your child is doing safely. Evaluate that expectations are being met.

Don't become complacent, believing that your child understands what to do and needs no reinforcement. Your child's abilities, desires and the social pressures will change over time. You as parents may feel that your child and family fully understand what to do to keep your child safe right now. That may be true. But remember that things will change as your child gets older.

Building responsibility in your child requires that the adult team surrounding your child works together in a responsible manner. You the parent must assume the role of team coach and captain. Communicate clearly to your child and the team the behaviours you expect to see. Communication also means that you listen to your child and to the concerns of the team. Communication goes both ways. Expect consistency and have the courage to give your child safe consequences. Accept that your child is different and make your child determined to do safely. Constantly evaluate ability, behaviour and consequences. Ask the when, where and why questions. Problem solve as a team and remember that your child is a very important member of the team. These strategies will help create a safer environment for your child, empower him/her with the skills and knowledge to feel confident, and ensure that those around him/her will have the skills, knowledge and tools required should an allergic reaction occur.

## Section 5

### Resources & References

#### Resources: organizations

**Allergy Asthma Information Association (AAIA);** [www.aaia.ca](http://www.aaia.ca) (1-800-611-7011), a Canadian organization established in 1964 providing information, education, & advocacy in partnership with health care professionals, business, industry and government.

**Anaphylaxis Canada;** [www.anaphylaxis.org](http://www.anaphylaxis.org) , a non-profit organization created by and for people with anaphylaxis, providing information and support, working to improve safety standards for people with anaphylaxis, working with the food industry to improve food labels, with school boards, restaurants, the airline industry, government and others, raising public awareness about anaphylaxis, and conducting research and raise funds for research into anaphylaxis treatment and prevention.

**Canadian Food Inspection Agency** [www.inspection.gc.ca](http://www.inspection.gc.ca) for food recalls & allergy alerts.

**Manitoba Anaphylaxis Information Network (MAIN),** a sub-group of AAIA is a support network for individuals living with life-threatening allergies, providing information & resources, newsletters, raising community awareness about anaphylaxis, and advocating for individuals and families regarding issues that arise from this medical condition. Contact Nancy @ 654-2676 or [mainmanitoba@shaw.ca](mailto:mainmanitoba@shaw.ca) for more information.

**The American Academy of Allergy, Asthma & Immunology:** [www.aaaai.org](http://www.aaaai.org) , is the largest professional medical specialty organization in the United States, representing allergists, asthma specialists, clinical immunologists, allied health professionals, and others with a special interest in the research and treatment of allergic disease. The mission of the American Academy of Allergy, Asthma & Immunology is the advancement of the knowledge and practice of allergy, asthma and immunology for optimal patient care.

**The Food Allergy & Anaphylaxis Network (USA)** [www.foodallergy.org](http://www.foodallergy.org) (1-800-929-4040) for a broad range of information and services including awareness, education, publications, products, advocacy and research. The Food Allergy & Anaphylaxis Network (FAAN) was established in 1991, with membership of more than 27,000 worldwide, including families, dietitians, nurses, physicians, school staff, representatives from

US government agencies, and the food and pharmaceutical industries. This is an excellent resources, offering suggestions regarding shopping, cooking, cookbooks, schools and camp, dining out and travel, resources for parents, children, teens, posters, booklets, books, videos, EpiPen® carriers and more.

**MedicAlert® Foundation** is a national registered charity with an annual fee providing immediate access to medical information by health professionals in an emergency. A bracelet or necklace is purchased and worn and engraved with specific medical information. Additional information can be retrieved 24 hours a day from anywhere in the world by calling a hotline and using the ID number engraved on the necklace or bracelet. (1-800-668-1507) or [www.medicalert.ca](http://www.medicalert.ca)

**Canadian School Boards Association** [www.cdnsba.org](http://www.cdnsba.org)

**Calgary Allergy Support Network** [www.calgaryallergy.ca](http://www.calgaryallergy.ca)

## **Resources: books**

Gold, M. (ed). *The Complete Kid's Allergy and Asthma Guide: the Parent's Handbook for Children of All Ages*. Hospital for Sick Children, Toronto

### **Children's books:**

- Habkirk, L (1995) *A preschooler's Guide to Peanut Allergy*
- Munoz-Furlong, Anne (1999) *Alexander Goes To a Birthday Party*
- Munoz-Furlong, Anne (1999) *Alexander Goes Trick-Or-Treating*
- Munoz-Furlong, Anne (1999) *Alexander & His Pals Visit the Main Street School*
- Munoz-Furlong, Anne (1999) *A Special Day at School*
- Nassau, Elizabeth Sussman (2001) *Peanut Butter Jam*

- Weiner, Ellen (1999) *Taking Food Allergies to School*
- Zevy, Aaron (1995) *No Nuts for Me!*

**Available at the Children's Hospital Family Information Library:**

CK204 – 840 Sherbrook Street  
 Winnipeg  
 (204) 787-1012  
 email: Lprice@hsc.mb.ca

- Alexander the Elephant Who Couldn't Eat Peanuts (videotape). The Food Allergy Network, 1999 (10 minutes)
- Commonly Asked Questions About Food Allergies. The Food Allergy Network, 1999.
- Brostoff, J. & Gamlin, L. (1989). *The Complete Guide to Food Allergy and Intolerance: Prevention, Identification and Treatment of Common Illnesses and Allergies Caused by Food*, Crown Trade Paperbacks.
- The Food Allergy News Cookbook, (1999), The Food Allergy Network.
- Getting Started with Food Allergies: A Guide for Parents, (1999) The Food Allergy Network.
- It Only Takes One Bite: Food Allergy and Anaphylaxis (videotape), (1993) The Food Allergy Network (18 minutes).
- Harris, M. and Nashsin, W. (1996) *My Kid's Allergic to Everything Dessert Cookbook: Sweets and Treats the Whole Family Will Enjoy*, Chicago Review Press.
- Nutrition Guide to Food Allergies, (1992) The Food Allergy Network.
- Off To School with Food Allergies: A Guide for Parents and Teachers – Parent's Guide, (1999). The Food Allergy Network.
- Off To School with Food Allergies: A Guide for Patents and Teachers – Teacher's Guide, (1999), The Food Allergy Network.
- Travel Guide: Tips for Travelling with Food Allergies, (1999) The Food Allergy Network.

- Travelling with Food Allergy: Foreign Sources of Information, (1999) The Food Allergy Network.
- Understanding Food Labels, (1999), The Food Allergy Network.

**Available at the Winnipeg Public Library:**

- It Only Takes One Bite: Food Allergies and Anaphylaxis (1993), Food Allergy Network (videotape: 18 minutes)
- Ansorge, R and Metcalf, E. (2001) *Allergy Free Naturally*.
- Barber, M., Bartoszek Scott, M. & Greenberg, E. (2000) *The Parents' Guide to Food Allergies: clear and complete advice from the experts on raising your food allergic child*.
- Brostoff, J. & Gamlin, L. (2000). *Food Allergies and Food Intolerance: the complete guide to their identification and treatment*.
- Cipriano, L. (2000) *Caring For Your Child with Severe Food Allergies: emotional support and practical advice from a parent who's been there*.
- Engel, J. (1997) *The Complete Allergy Book*.
- Gamlin, L. (2001). *The Allergy Bible*, Reader's Digest.
- Koerner, C.B. and Munoz-Furlong, A. (1998) *Food Allergies*, written for The American Diabetes Dietetic Association.
- Lipkowitz, M.A. and Navarra, T. (1997) *Allergies A to Z*.
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- Muth, A.S. (Ed) (2002) *Allergies Sourcebook: basic consumer health information about allergic disorders, triggers, reactions and related symptoms, including anaphylaxis*.
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## **Resources: EpiPen® Carrying Cases and Trainers**

### **Available in Winnipeg:**

CD Pharmacy  
Unit D-123 Scurfield Blvd., Winnipeg  
488-1819

Matcel Pharmacy  
Southwood Medical Centre  
100-2385 Pembina Highway, Winnipeg  
269-2391

Shoppers Drug Mart, Manitoba Clinic  
790 Sherbrook Street, Winnipeg  
779-1996

Stevens Home Medical Supplies Store  
Health Sciences Centre  
700 William Avenue, Winnipeg  
787-3532

Diamond Athletic Supplies  
1387 Grant Avenue, Winnipeg  
488-7820 or 1-800-781-9127

Pam Kok  
Nuttin' With Nuts  
84 boule de la Seigneurie, Winnipeg  
254-5104  
[www.nuttinwithnuts.com](http://www.nuttinwithnuts.com)  
email: [nuttin-with-nuts@shaw.ca](mailto:nuttin-with-nuts@shaw.ca)

**Available outside Winnipeg:**

Pen & Puffer Bag

AAIA

514-694-0679

[www.aaia.ca](http://www.aaia.ca) (under resources for you)

E-Beltby Zoni

[www.zoniinc.com](http://www.zoniinc.com)

Epi-Mate by Lindon Products (USA)

[www.epimate.com](http://www.epimate.com)

Protectube

[www.protectube.com](http://www.protectube.com)

Food Allergy & Anaphylaxis Network (USA)

1-800-929-4040

[www.foodallergy.org](http://www.foodallergy.org)

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CFIA, [www.inspection.gc.ca](http://www.inspection.gc.ca)

## Appendix P

University of Manitoba Education Nursing Research Ethics Board Approval



UNIVERSITY  
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RESEARCH SERVICES &  
PROGRAMS

Office of the Vice-President (Research)

244 Engineering Bldg.  
Winnipeg, MB R3T 5V6  
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Fax: (204) 261-0325  
www.umanitoba.ca/research

APPROVAL CERTIFICATE

25 October 2004

**TO:** J. Susan Fogg (Advisor M. Heaman)  
Principal Investigator

**FROM:** Stan Straw, Chair  
Education/Nursing Research Ethics Board (ENREB)

**Re:** Protocol #E2004:085  
"Effects of a Parent Education Program on Maternal Self-efficacy and  
Perceptions of their Child's Self-management of a Life-threatening  
Allergy"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note that, if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

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## Appendix Q

University of Manitoba Education Nursing Research Ethics Board Amendment



UNIVERSITY  
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### AMENDMENT APPROVAL

15 March 2005

**TO: J. Susan Fogg**  
Principal Investigator

**FROM: Stan Straw, Chair**  
Education/Nursing Research Ethics Board (ENREB)

**Re: Protocol #E2004:085**  
**"Effects of a Parent Education Program on Maternal Self-efficacy and Perceptions of their Child's Self-management of a Life-threatening Allergy"**

This will acknowledge your e-memo dated March 9, 2005 requesting amendment to the above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.

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