

MANAGEMENT OF CHILDREN WITH FOOD-INDUCED ANAPHYLAXIS

By

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DECLARATION

1. The candidate, Debbie Cohen, hereby declares that none of the work presented in this essay has been submitted to any other university or institution for a higher degree and that to the best of her knowledge contains no material written or published by another person, except where due reference is made in the text.
2. The study described in this essay was approved by the Ethics Review Committee (RPAH Zone) of the Central Sydney Area Health Service, and all subjects gave informed consent before participating.

Signature.....

Date.....

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- 2. Food-Induced Anaphylaxis Questionnaire**

ABSTRACT

Introduction: Food-induced anaphylaxis is the most severe form of food allergy. It consists of a complex of symptoms, which can be fatal if prompt emergency treatment is not given. Since there is no known cure, management involves strict avoidance of known food allergens and prompt emergency action when there has been inadvertent exposure to the offending food. Injectable adrenaline is the drug of choice for anaphylaxis, however its prescription can complicate the management of at-risk children and may contribute to parental anxiety. There is little information available regarding the circumstances surrounding episodes of food-induced anaphylaxis or the impact this condition has on the lives of patients and their families. **Aim:** To investigate a range of issues regarding the management of children at risk of food-induced anaphylaxis. **Methods:** The population surveyed in this study was children who had been identified as being at risk of food-induced anaphylaxis. Data was collected using a written questionnaire, which explored various aspects in the management of children with food-induced anaphylaxis and recorded the circumstances surrounding previous anaphylactic reactions, such as location, food triggers and emergency treatment. **Results:** Three hundred and three episodes of anaphylaxis occurred in 164 children. Almost half of those surveyed had experienced multiple reactions often to different foods. Peanut, egg and cow's milk were the most common food triggers and the majority of reactions occurred in the child's own home. Administration of adrenaline once a reaction had occurred was infrequent. While most schools had an emergency action plan for dealing with episodes of accidental exposure, several respondents had encountered problems with the school system, especially in relation to the administration of adrenaline. Nutritional concerns of parents and the social impact of food-induced anaphylaxis on patients and their families were also investigated. **Discussion:** Children with an identified food allergy should undergo skin prick tests for a range of other foods that could potentially cause anaphylaxis. In addition, all carers of at-risk children should be educated regarding the prevention and management of anaphylaxis, including the use of injectable adrenaline. A training package for schools would be useful to reduce anxiety amongst school personnel and to help ensure the safety of children at risk of anaphylaxis while at school.

INTRODUCTION

Food allergy, defined as an immunological hypersensitivity mediated by immunoglobulin E antibodies to certain proteins in food¹, can manifest clinically in a number of ways. The most acute and serious manifestation of food allergy is anaphylaxis, which can be fatal if prompt emergency treatment is not given. Foods most likely to trigger an anaphylactic reaction are cow's milk, eggs, nuts and fish.^{2,3}

In the past decade there has been an increase in the incidence of food allergy particularly peanut allergy.^{4,5} This is generally agreed to be due to changes in dietary habits. Published surveys and clinical experience indicate that most food-allergic children are accidentally exposed at least once a year despite their parents' best efforts at avoidance.^{5,6} Hidden ingredients, eating outside the home and food-swapping in pre-schools and kindergartens are the most common causes of fatal or near-fatal reactions.⁴

Information about mortality and morbidity associated with food-induced anaphylaxis is only available through published case reports from overseas and anecdotal evidence. Peanut allergy has been the cause of the highest number of reported fatalities.^{4,7-9} An analysis of the circumstances surrounding fatal and near-fatal allergy has identified: (a) a denial or lack of knowledge about food allergy, and (b) failure to provide emergency treatment in the form of injectable adrenaline because it was not available, as risk factors.^{3,10-12} Consequently, all those with significant food allergies are encouraged to carry adrenaline at all times, and to use it immediately in the event of a reaction.

While the use of adrenaline can be lifesaving in an emergency situation, its prescription complicates the management of at risk children and may contribute to parental anxiety. Not only must parents educate all carers about appropriate avoidance measures and management of accidental contact, they are also responsible for training others to administer the adrenaline. Anecdotal evidence suggests that parents are reluctant to use adrenaline when reactions have occurred. One aim of this study is to explore the reasons for this.

Other problems experienced by families with a food-allergic child are (a) a lack of knowledge and support from family members, school staff and health care professionals, and (b) difficulties associated with the necessary dietary restrictions and their impact on family functioning. Information gained from this project will help improve educational strategies and preventive measures for families with children at risk of food induced anaphylaxis.

FOOD ALLERGY

Food allergy is one manifestation of the ‘atopic’ predisposition – a genetic tendency to produce excessive IgE responses to common ‘allergens’. Sensitisation usually occurs early in life either when weaning foods are first introduced, or more often when protein fragments absorbed from the mother’s diet are transmitted to the infant via breast milk, resulting in the production of IgE antibodies.¹³ The allergy manifests clinically when the sensitised child is subsequently re-exposed to the relevant food or drink. Symptoms are caused by IgE mediated mast cell activation, with release of histamine and other inflammatory mediators. Most allergic reactions to foods are not severe and will disappear as the child gets older.¹⁴ Symptoms are immediate and reproducible and include swelling at the point of contact followed by hives, redness, swelling of the face and often vomiting. Infantile eczema is also highly associated with food allergy.^{1,15}

FOOD-INDUCED ANAPHYLAXIS

The most acute and serious manifestation of food allergy is anaphylaxis. Broadly defined, anaphylaxis is a complex of symptoms consisting of generalised urticaria, angioedema, wheezing, shortness of breath, laryngeal oedema, nausea, vomiting, diarrhoea, hypotension, shock or coma.¹⁶ Death can occur if emergency treatment is not given. While a variety of agents are known to precipitate anaphylaxis, foods are the most common cause in children.^{17,18} Foods most likely to cause an anaphylactic reaction are cow’s milk, eggs, nuts, fish.^{2,3} Anaphylactoid (non-IgE mediated) reactions to certain fruits and food chemicals can also occur but are rare.

PREVALENCE OF FOOD ALLERGY AND FOOD-INDUCED ANAPHYLAXIS

The prevalence of food allergy is estimated to be about four to six percent in infancy, one to two percent in early childhood and less than one percent in adults.¹³ All those with food allergy are potentially at risk of anaphylaxis, however only a small proportion will ever experience a life-threatening reaction. Late age of presentation and the type of food involved are fairly indicative of the risk of anaphylaxis.^{4,13,14} Other factors associated with an increased risk, identified by a previous study conducted at the RPAH Allergy Unit include: multiple food allergies; concurrent food intolerance (non-immunological adverse reactions to foods); asthma and house dust mite allergy¹⁹.

There is little information available on the mortality and morbidity associated with severe food allergy; however it appears to be a growing problem.^{4,5,10,17,18,20} Possible reasons for this are (a) the increasing use of protein additives in commercially prepared foods⁴ and (b) the common consumption of peanuts, in the form of peanut butter, especially as a weaning food in young infants.⁵ In particular, the incidence of peanut allergy appears to be on the rise.⁵ Peanut allergy tends to be a more serious allergy to acquire than allergies to other foods as it is the cause of more severe reactions and tends to be a life-long problem.^{4, 6-8,21,22}

MANAGEMENT OF FOOD ALLERGY AND FOOD-INDUCED ANAPHYLAXIS

Since there is no known “cure” for food allergy, management involves strict avoidance of the known trigger(s) and prompt emergency action when there has been inadvertent exposure to the offending food. The life-saving treatment for anaphylaxis is adrenaline, which works by reducing exudation of fluid and swelling of the airway, stimulating the heart and increasing blood pressure.² All those with significant food allergies are encouraged to carry adrenaline at all times, and to use it immediately in the event of inadvertent contact with the allergen. Even when apparently mild symptoms, such as generalised urticaria and angioedema, are present, adrenaline is still the drug of choice due to its ability to rapidly control symptoms and prevent the

progression of the reaction.²³ Adrenaline can be given by injection or inhalation and is also available in a pre-loaded self-injectable system, called the EpiPen[®], which is the preferred preparation for those most at risk, especially when those with little training may be called on to administer it.

Evidence suggests that parents are reluctant to use adrenaline when reactions have occurred. In a case series of six children with fatal food-induced anaphylaxis, self-injectable adrenaline had been prescribed for half the children, yet none had it available when they died.⁴ In another study only five out of nine children with a history of anaphylaxis had epinephrine self-administration devices available for use when they experienced a subsequent reaction and only three used them.²⁴ One possible reason for this reluctance to administer adrenaline is a lack of adequate training and advice regarding its use upon prescription^{25,26}, highlighting the need for improved education for all carers of at-risk children.

CIRCUMSTANCES SURROUNDING EPISODES OF FOOD-INDUCED ANAPHYLAXIS

There have been very few studies that have examined the circumstances surrounding episodes of food-induced anaphylaxis and none that have been conducted in the Australian setting. What information we do have comes from isolated case reports and a few studies from overseas. It appears that most patients have experienced definite reactions to the food on previous occasions, however, not all have experienced previous anaphylactic reactions, making identification of those at risk difficult.⁴ Further, the majority of instances occur when allergens are unknowingly consumed, often as an ingredient in a manufactured product, such as a biscuit, cake, or pastry.^{4,10}

As for the site of anaphylactic events, the figures vary considerably. In one study that described seven cases of fatal food-induced anaphylaxis, the reactions occurred when allergens were unknowingly ingested while eating away from the home.¹⁰ In another study, five of six fatal reactions occurred outside the home while all seven non-fatal reactions occurred in private homes.⁴ A more recent study reported that of 95 episodes of anaphylaxis (not only to food) occurring in 76 children, 57 percent of cases occurred in the home while the rest occurred either outdoors, in a restaurant, at the

doctor's office, in hospital, at a gym or at school.¹⁷ These studies highlight the importance of having an emergency "action" plan and medication available in all environments where at-risk children spend their time.

NUTRITIONAL IMPACT OF FOOD ALLERGY AND FOOD-INDUCED ANAPHYLAXIS

Dietary avoidance is the mainstay of preventive management of food allergy. This may involve the exclusion of only a single food or a range of foods depending on the extent of a person's allergies. Those with allergies to staple foods, such as milk or wheat, and those with allergies to multiple foods will need to follow a more restrictive diet than those with allergies to single peripheral foods, such as peanut or soy. Concerns have been raised that some "elimination" diets compromise variety and hence nutrient intake and may place certain individuals at risk of nutritional deficiencies.²⁷ Most of the studies that have assessed the impact of such diets on nutritional adequacy have focussed on cow's milk-free diets.²⁷⁻³⁰ As dairy products are the major source of dietary calcium, it is not surprising that children with cow's milk allergy who do not receive appropriate substitutes have calcium intakes below the estimated requirement. Providing patients and their parents with advice about obtaining appropriate substitutes for foods excluded from the diet, as a result of food allergy, is therefore an important part of the management of food allergic children.

SOCIAL IMPACT OF FOOD ALLERGY AND FOOD-INDUCED ANAPHYLAXIS

The prevention and management of accidental exposure to food allergens is often the cause of extreme anxiety for parents of food-allergic children and as a result, many adopt restrictive lifestyle changes in their attempts to avert potentially life-threatening situations. Because the risk extends to all environments where the child spends time, there is the need for education of all carers regarding avoidance measures and management of accidental contact. This includes training in the use of the Epipen[®], adding to the already heavy burden on parents.

Few studies have explored the social impact of severe food allergy on patients and their parents. One study found that allergic symptoms adversely affected the physical,

emotional and social health of adults with non life-threatening allergies.³¹ Another study reported that asthma and allergies interfered with the educational, social and work-related activities of American college students³², while a study by Richards found that allergic conditions contributed significantly to school absenteeism and may impair school performance and social adjustment.³³

AIM

The purpose of this project was to investigate a range of issues regarding the management of children at risk of food-induced anaphylaxis.

OBJECTIVES

1. To document the range of food allergies in a cohort of children with a history of food-induced anaphylaxis.
2. To document the frequency, circumstances and treatment of episodes of food-induced anaphylaxis.
3. To assess the benefits and problems associated with the use of the EpiPen[®].
4. To assess the social and nutritional impact of severe food allergy on children and their families.

METHODS

ETHICAL APPROVAL

Ethical approval was obtained from the Ethics Review Committee (RPAH Zone) of the Central Sydney Area Health Service.

RECRUITMENT

The population surveyed in this study included:

1. Members of the Food Anaphylaxis Children's Training and Support (F.A.C.T.S) Group from across Australia.

Names and addresses of F.A.C.T.S members were obtained directly from the NSW F.A.C.T.S Coordinator.

2. Children who attended the RPAH Allergy Unit whose parents had purchased an EpiPen[®].

Potential participants were identified from a list recording the sale of EpiPens at the Unit between 1990 and 1999. Addresses and phone numbers were then obtained from patient files.

DATA COLLECTION

Information was collected using a written questionnaire, consisting of mostly close-ended and some open-ended questions, which was developed after a review of the relevant literature and through consultation with immunologists and dietitians at the RPAH Allergy Unit. The questionnaire explored various aspects in the management of children with food-induced anaphylaxis and recorded the circumstances

surrounding previous anaphylactic reactions, such as location, food triggers and emergency treatment. Due to the young age of the study sample, parents were asked to complete the survey on behalf of their child.

Parents were sent a package inviting them to participate in the study containing:

1. A patient information sheet outlining the aims and procedures of the study (Appendix 1).
2. The food-induced anaphylaxis questionnaire (Appendix 2).
3. A reply paid envelope for return of the questionnaire if they decided to participate.

One week after the due date, a reminder phone call was made to parents who did not respond to the initial invitation for participation.

DATA ANALYSIS

The data from the returned surveys were analysed using the Statistical Package for Social Scientists (SPSS[®] for Windows, release 8.0, Chicago: SPSS Inc, 1998). The majority of analyses conducted were frequency distributions and descriptive statistics. Chi tests were performed to assess gender influences on incidence and frequency of anaphylactic reactions.

RECRUITMENT OF SUBJECTS

1. F.A.C.T.S members from across Australia
2. Children seen at the RPAH Allergy Unit whose parents had purchased an EpiPen[®]



PACKAGES SENT

Containing:

Patient information sheet
Food-induced anaphylaxis questionnaire
Reply paid envelope

Reminder phone calls made one week after the due date



DATA COLLECTION

Questionnaires returned via mail by participants



DATA ANALYSIS

Figure 1: Diagram of Study Methodology

RESULTS

GENDER AND AGE OF SUBJECTS

Information was collected for 212 children representing 70.4% of the total survey sample. Of these, 58.5% were male and 41.5% female. The mean age was 5.5 years (SD 3.4), while the age range was 0.9 – 16.8 years.

GENDER AND AGE OF SUBJECTS COMPARED TO TOTAL SURVEY SAMPLE

There was no significant difference in the age and gender distribution of the survey subjects compared with the total survey sample. A summary of the results are presented in Table 1.

Table 1: *Gender and Age of Total Survey Sample and Subjects*

GENDER AND AGE	TOTAL SURVEY SAMPLE (N=301)	SURVEY SUBJECTS (N=212)
Gender		
Male (%)	59.5	58.5
Female (%)	40.5	41.5
Mean age (years)	5.5	5.5
Age range (years)	0.9-16.8	0.9-16.8

FOOD ALLERGIES

Past and present food allergies of the subjects, diagnosed by either skin prick test (SPT), radioallergosorbent test (RAST) and/or the child's medical history are shown in Table 2.

Table 2: *Past and Present Food Allergies of Subjects*

FOOD ALLERGY	% CURRENT (N=212)	% Past (outgrown) (N=212)
Peanut	84.0	4.7
Egg	61.3	11.3
Cow's milk/dairy	41.5	14.2
Tree nuts	35.4	2.4
Fish	13.7	4.2
Sesame	12.1	0.5
Soy	8.5	6.6
Wheat	7.5	11.8
Shellfish	6.6	0.5
Goat's milk	0.9	0

The majority (85.8%) of children were allergic to more than one food while almost half (47.6%) suffered from concurrent food intolerance (adverse reactions to food which did not show up in allergy tests or which were not tested for). Individuals reported "allergies" or intolerances to a range of other foods including: sausages, lamb, beef, chicken, pork, kiwi, melon, banana, citrus, grapes, passionfruit, strawberries, blueberries, apple, tomato, potato, sweet potato, avocado, garlic, corn, peas, beans, lentils, chick peas, rice, polenta, rye, sunflower seeds, baker's yeast, lecithin, food colourings.

OTHER ALLERGIC CONDITIONS

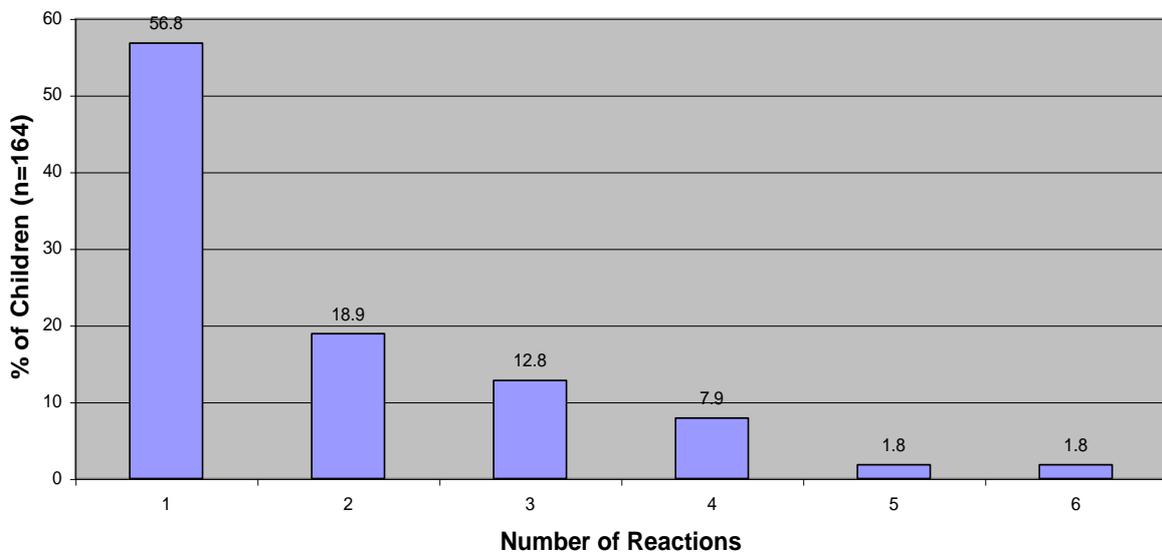
The majority of children were highly atopic with recurrent or previous symptoms of eczema (73.6%), asthma (56.1%) and allergic rhinitis/hayfever (42.0%).

ANAPHYLACTIC REACTIONS

For the purpose of analysis the reactions were separated into two groups: 1) the initial anaphylactic reaction, and 2) subsequent reactions.

Three hundred and three anaphylactic reactions occurring in 164 (77.4%) children were analysed. The number of reactions per child is shown in Figure 1. There was no influence of gender on the incidence ($p=0.869$, $df=1$) or frequency ($p=0.725$, $df=1$) of anaphylactic reactions in this group.

Figure 1: *Number of Anaphylactic Reactions Per Child*



The average age at the time of the first anaphylactic reaction was 1.8 years, while the average age for all anaphylactic reactions was 2.5 years. The majority of parents (78.5%) were not aware of their child’s allergy to the food at the time of the child’s first anaphylactic reaction.

Location of Reactions

The locations where the anaphylactic reactions occurred are shown in Table 3. Other locations included: shopping centre, park, car, beach, party, holiday, aeroplane, restaurant, doctor’s surgery, hospital and church.

Table 3: *Location of Reactions*

LOCATION	% INITIAL REACTION (N=164)	% SUBSEQUENT REACTIONS (N=139)
Child’s home	64.1	52.0
Home of friend or relative	17.1	14.6
Day-care/pre-school/school	6.2	13.9
Other	12.6	19.5

Principal Carer

The principal carer of the child at the time of the reactions are shown in Table 4. The child’s mother was the principal carer in the majority of initial (68.4%) and subsequent (57.6%) reactions.

Table 4: Principal Carer at the Time of the Reaction

PRINCIPAL CARER	% INITIAL REACTION (N=164)	% SUBSEQUENT REACTIONS (N=139)
Mother	68.4	57.6
Both parents	19.5	18.7
School staff	4.9	12.2
Grandparents	3.0	4.3
Father	1.8	5.8
Doctor	1.2	0.7
Friend	1.2	0.7

Food Triggers

The food allergens that caused the initial and subsequent anaphylactic reactions are shown in Table 5. Several individuals had anaphylactic reactions to more than one food and hence subsequent reactions were not always caused by the same food that precipitated the initial reaction. Peanut, milk and egg were implicated in 75.5% of all reactions.

Table 5: Foods Allergens Implicated

FOOD ALLERGEN	% INITIAL REACTION (N=164)	% SUBSEQUENT REACTIONS (N=139)
Peanut	34.8	33.3
Milk	23.8	18.7
Egg	19.5	20.9
Tree nut	12.2	7.7
Fish	3.0	4.3
Egg and milk	1.8	1.4
Sesame	0.6	2.2
Prawn	0.6	1.4
Soy	0.6	1.4
Goat's milk	0	1.4
Unknown	3.1	7.3

Of the food allergens implicated in the initial reaction 56.7% were consumed as an ingredient in a commercially prepared product (50.3% were packaged and 6.4% unpackaged), 31.7% were consumed as the whole food (e.g. milk, egg, nut) and 8.5% were consumed as an ingredient in a homemade product. Of the food allergens implicated in the subsequent reactions 51.4% were consumed as an ingredient in a commercially prepared product (31.5% were packaged and 19.9% unpackaged), 34.1% were consumed as the whole food and 7.2% were consumed as an ingredient in a homemade product. The types of foods implicated are shown in Table 6.

Table 6: *Type of Food Implicated*

TYPE OF FOOD	% INITIAL REACTION (N=164)	% SUBSEQUENT REACTIONS (N=139)
Whole (e.g. milk, egg, nut)	31.7	34.1
Peanut butter	30.4	11.9
Dairy (other than milk e.g. infant formula, cheese, yoghurt, custard, ice-cream)	18.9	7.2
Baked product (e.g. bread, cake, biscuit)	6.7	15.8
Confectionery	4.3	11.5
Meat/vegetable dish	3.7	11.5
Savoury snack	1.2	0.7
Unknown	3.1	7.3

In the majority (73.6%) of initial reactions the food was knowingly consumed, often for the first time, as parents were not yet aware of their child's food allergy. In those who had an identified food allergy, the food was either unknowingly or accidentally given to the child or the parents were unaware their child had eaten the food.

Accidental ingestion occurred due to incorrect labelling in two cases while 4 cases

were caused by contamination of a food that was thought to be safe, either during manufacturing or of utensils used to prepare the food.

Over fifty-six percent of subsequent reactions were caused by the same food that caused the initial reaction while 43.5% were caused by different foods. In the majority of subsequent reactions to the same food the food was either unknowingly or accidentally given to the child or the parents were not aware that their child had eaten the food. Twelve reactions occurred due to contamination and 6 due to incorrect labelling.

Severe reactions to a number of other foods (banana [n=3], kiwi fruit [n=3], avocado [n=1], potato [n=1], peas [n=1], citrus[n=1], melon[n=1]) were also reported by several individuals. Reactions to these foods are uncommon and rarely appear as isolated allergies and hence these reactions were not included in our overall analysis.

Route of Exposure

The routes of exposure to the food allergen in the initial and subsequent reactions are shown in Table 7.

Table 7: *Route of Exposure to Food Allergen*

ROUTE OF EXPOSURE	% Initial Reactions (N=164)	% Subsequent Reactions (N=139)
Swallowed	86.6	76.3
Skin contact	6.7	15.8
Skin and eye contact	2.4	0
Inhaled	1.3	2.9
Eye contact	0.6	1.4
Unknown	2.4	3.6

Emergency Treatment

Administration of adrenaline at the time of the reaction, before professional medical treatment was sought, occurred in only 10.2% of all reactions (4.3% of initial reactions and 17.3% of subsequent reactions). The most common reason cited (86.6%) for not using adrenaline was that it had not been prescribed at the time of the incident, usually because the food allergy had not yet been diagnosed. Other reasons for not using adrenaline included: symptoms had subsided (6.6%), wasn't sure if it was an anaphylactic reaction (2.5%), close to a hospital at the time (1.4%), had been prescribed but not yet purchased (1.1%), had been purchased but was not on hand at the time (1.1%) or used other medications (0.7%). In the reactions where adrenaline was used, a metered-dose inhaler was used in 13 cases, an EpiPen[®] was used in ten cases and an ampoule of adrenaline and syringe in nine cases.

Other medications used at the time of the reaction, before professional medical treatment was sought included oral antihistamines (51.3%), ventolin (14.7%) and corticosteroids (7.2%).

An ambulance was called in 15.3% of cases and in 55.7% of cases the child was taken either to a doctor or hospital or both. Of those children who were taken to either a doctor or hospital (or both), adrenaline was used as part of the emergency medical treatment in 35.8% (n=63) of cases.

ADRENALINE

The majority (86.8%) of respondents reported currently having one or more EpiPens[®] for treating their child in the event of an anaphylactic reaction. Reasons cited for not having an EpiPen[®] included: has alternative form of adrenaline (28.1%), has not been prescribed (25%), costs too much (18.8%), condition controlled by strict avoidance of food allergens (15.6%) or food allergy has been outgrown (3.1%). Of those who had an alternative form of adrenaline, four had an ampoule and syringe, three had a metered-dose inhaler and one child had a nebulizer and ampoule.

The average number of EpiPens[®] per child was two while 77.0% of parents said that at least one EpiPen[®] was kept with the child at all times. Reasons for not always keeping an EpiPen[®] available included: the required storage conditions of the device, not wanting to appear too over-protective and school staff unwilling or unable to administer adrenaline.

Respondents were asked who knew how to use the EpiPen[®] in the event of their child experiencing an anaphylactic reaction. The results are shown in Table 8.

Table 8: *People Who Know How to Use the EpiPen[®] in the Event of an Anaphylactic Reaction*

PERSON	% RESPONSE (N=184)
CHILD'S MOTHER	97.9
CHILD'S FATHER	92.5
DAY-CARE/PRE-SCHOOL/SCHOOL STAFF	71.4
OTHER RELATIVES	49.4
CHILD	18.7
FRIEND	17.4
BABYSITTER	5.1

Respondents were also asked about training and advice they had received regarding the use of the EpiPen[®]. Over eighty-two percent had been shown the EpiPen[®] by a doctor or other health professional, 72.7% had practised with the EpiPen[®] trainer, 62.6% had been given written material, 26.7% had been shown an instructional video while 2.2% said that no training or advice had been given. Of those that did receive training or advice, 63.4% said it was very useful, 32.7% said it was fairly useful and 3.9% said it was not at all useful. Only 23.2% said that they had received assistance in training others, such as school staff and relatives, to use the EpiPen[®].

Respondents were asked how anxious they felt about using the EpiPen[®] in the event of an emergency. Over twenty-four percent said that they felt very anxious, 29.6% moderately anxious, 30.1% somewhat anxious and 16.1% said that they didn't feel at all anxious about using the EpiPen[®]. When asked how confident they felt that the EpiPen[®] would help their child recover if they experienced an anaphylactic reaction, Almost half (45.9%) said they felt very confident, 40.5% moderately confident, 11.9% somewhat confident and 1.7% not at all confident.

DAY-CARE/PRE-SCHOOL/SCHOOL

Most (79.7%) of the children surveyed attended either day-care, pre-school or school. Staff were aware of the child's food allergy in the majority (98.2%) of cases and most (89.4%) facilities had an emergency action plan in place for managing instances of accidental exposure to food allergens.

Respondents were asked about measures in place at their child's pre-school/day-care/school for preventing accidental contact with the food allergen. The results are shown in Table 9. Supervision of the child at meal times, the education of staff and classmates and hand washing before and after eating was also mentioned.

Table 9: *Measures in Place for Preventing Accidental Contact at Day-care/Pre-school/School*

PREVENTIVE MEASURE	% RESPONSE (N=169)
Information about child displayed	75.3
Children taught not to share food	58.2
Information sent home to parents	30.6
Centre/school is allergen-free	16.5

Respondents were also asked about how supportive the day-care/pre-school/school staff were with regards to the child's food allergy. The majority (65.3%) said they felt

the staff was very supportive while 18.8% said they were moderately supportive, 13.5% said somewhat supportive and less than 3% said the staff were not at all supportive.

Almost twenty percent of respondents said they felt that their child’s schooling had been comprised as a result of their food allergy while 13.1% of children had been denied access to a day-care, pre-school or school on account of their food allergy. A further 28 respondents said that while their child had not overtly been denied access to such a facility, they had encountered resistance on the behalf of the staff regarding the use of injected adrenaline. In one case the parents decided against public schooling altogether and had placed their child on the NSW Distance Education Programme on account of his food allergies. Eight others had delayed sending their child to school due to concerns about the adequacy of care available.

NUTRITIONAL IMPACT OF FOOD-INDUCED ANAPHYLAXIS

Respondents were asked about their perceptions of the nutritional adequacy of their child’s diet. The majority said they felt that their child’s diet was nutritionally adequate. The only nutrient of significant concern was calcium with 25.2% of respondents saying they felt their child’s diet was lacking in this mineral. We also asked about problems that they had experienced providing substitutes for the foods excluded from their child’s diet. The results are shown in Table 10.

Table 10: *Problems Experienced Providing Substitutes for Foods Excluded From Child’s Diet (as a result of food allergy)*

Problem	% RESPONSE (N=212)
Difficult to find in shops	35.3
Expensive to buy	33.8
Child refuses to eat the food	30.4
Difficult/time-consuming to prepare	22.1
No problems experienced	37.7

SOCIAL IMPACT OF FOOD-INDUCED ANAPHYLAXIS

A large proportion (61.2%) of respondents said they felt anxious about their child eating foods that had been prepared outside the home all of the time, 17.5% said most of the time, 20.4% said some of the time while 0.9% said never. Over sixty percent of respondents said that it was either somewhat (24.1%), moderately (19.8%) or very difficult (17.0%) to prepare meals that were both safe and acceptable for the whole family. Almost half (48.6%) said that they avoided social occasions on account of their child's food allergy, some of the time, 14.6% most of the time and 1.9% all of the time while 66.8% said that they avoided eating out.

DISCUSSION

RESPONSE TO THE QUESTIONNAIRE

The questionnaire was sent to the parents of 301 children with severe food allergy of which 212 replied. This high response rate (70.4%) was likely to be because parents of children with a potentially serious condition, such as food-induced anaphylaxis, are often highly motivated and therefore are more inclined to return the questionnaire.

The majority of those who did not respond had either moved (18.5%) or felt that their child did not fit the criteria for our study (42.3%). It is therefore unlikely that the non-responders would have affected the validity of the results.

LIMITATIONS OF THE STUDY

Incidents of food-induced anaphylaxis recorded by respondents were self-reported, therefore it is not possible to say for certain whether all incidents reported were “true” anaphylactic reactions. Determining exactly what constitutes an anaphylactic reaction can be a problem for researchers as even amongst the medical profession there is no universally accepted definition of anaphylaxis.¹⁸ The definition used in this study was any severe food-allergic reaction involving one or more of the following symptoms: 1) difficulty breathing or throat swelling, b) generalised urticaria (hives), and/or 3) collapse.

FOOD ALLERGIES

In concordance with the current literature, egg, peanut and milk were the most common food allergies reported in this study.^{4,34} There is no consensus as to why these foods are prone to cause allergies, but, there is speculation that the unique physiochemical properties of the proteins they contain may play a role^{15,35}. Over eighty-five percent of children in this study suffered from allergies to more than one food. Multiple food allergy is increasingly being recognised as a risk factor for food-induced anaphylaxis.^{4,19,26}

The preponderance of other allergic conditions in children with food-induced anaphylaxis is well documented in the literature.^{4,5,17,35} The majority of subjects in this study were highly atopic individuals with high rates of atopic dermatitis (73.6%), asthma (56.1%) and allergic rhinitis (42.0%).

ANAPHYLACTIC REACTIONS

One of the major aims of this study was to explore the circumstances surrounding anaphylactic reactions in children, in order to improve education strategies for those at risk. The majority of existing literature on this topic is in the form of isolated case reports. This is the first study of its kind to use such a large sample size and to focus solely on food-induced anaphylaxis (other studies have also looked at anaphylaxis due to latex, drugs, insect stings and exercise).

The population chosen for this study had been identified as being at risk of anaphylaxis, therefore, it was not surprising that the majority of subjects (77.4%) had experienced one or more reactions at the time of the survey. Reactions occurred early in life, often when the child was first exposed to the food. In the majority (78.5%) of initial reactions the parents were not aware that their child was allergic to the food that caused the reaction, making prevention difficult if not impossible.

Almost half of the children had severe reactions on more than one occasion and this was not always to the same food that caused the initial reaction. This was one of the most surprising findings of this study, which has not been reported elsewhere in the literature. Possible explanations for this include a) the high incidence (85.8%) of multiple food allergies amongst subjects, and b) the broader definition of anaphylaxis used in this study. There are several possibilities as to why many of the children experienced multiple reactions to the same food, despite parents having received advice regarding the avoidance of allergens. Firstly, exposure to allergens may occur due to hidden ingredients in foods, incorrect labeling, contamination during manufacturing, or of utensils used to prepare the food, or due to sharing of food between friends. Secondly, the child may not necessarily eat the food but instead may be exposed via skin or eye contact or inhalation if the food allergen is present in their

environment. Thirdly, secondary carers may be insufficiently aware of appropriate allergen avoidance measures and finally, medical professionals may not have properly diagnosed the potential severity of the allergy.

Location of Reactions

According to the literature, most non-fatal anaphylactic reactions occur in private homes while fatal reactions are more likely to occur away from home.^{4,17,24} In the present study, which only looked at non-fatal episodes of anaphylaxis, the majority of reactions occurred in the child's own home (58.1%) or the home of a friend or relative (15.9%). While many parents are very concerned about the safety of their child in other environments, such as school, they must be aware that most reactions do occur at home when they themselves are caring for their child. There are several possible reasons for this. Firstly, most reactions occurred relatively early in life (average age 2.5 years) when children are more likely to be at home than anywhere else. Secondly, children may be directly or indirectly exposed to the allergen if their home is not entirely allergen-free. Several of the reactions reported in this study occurred when parents were unaware the child had eaten the food or when a child inhaled or touched the allergen, or was touched by a person who had come into contact with the allergen while at home. The risk of having a reaction somewhere other than at home increased for subsequent reactions. This highlights the importance of having emergency medications available in all environments where the child spends time.

Principal Carer

No other studies have looked at the principal carer of the child at the time of the reaction. We did this not in order to lay blame on a particular group of individuals, but rather, to determine where education and training needs to be targeted. We found that the mother was the principal carer in the majority (63.0%) of reactions. This is almost certainly because most young children spend the majority of their time with their mother. The frequency of someone other than the mother caring for the child increased in subsequent reactions, and there were several instances where a secondary carer, such as a grandparent or teacher, failed to appreciate the potential severity of

the condition and accidentally gave the food to the child. Consequently, education of all carers regarding the avoidance of allergens and the management of accidental contact is essential. Parents also need to be aware that reactions are just as likely to occur when they are around, and they should therefore remain alert to the potential danger at all times.

Food Triggers

It is widely reported in the literature that the foods most likely to trigger an anaphylactic reaction are cow's milk, eggs, nuts and fish.^{2,3,17} These foods accounted for over eighty-five percent of all reactions reported in this study. As outlined above, a large proportion of subjects had subsequent reactions, which were not always to the same food that caused the initial reaction. This highlights the need for children with an identified food allergy to undergo skin prick tests for a range of foods in order to identify any other allergies they may have.

Most previous studies have only documented the food allergen that caused the reaction without specifying the form in which the food was consumed e.g. whole food, home-made food or commercially prepared food. We felt this information would be beneficial for educating those at risk. In the majority of both initial (56.7%) and subsequent (51.4%) reactions the food allergen was consumed as part of a commercially prepared product. In the initial reactions this is almost certainly due to the high number (49.3%) caused by ingestion of peanut butter and dairy products (other than milk which we considered as a whole food), such as infant formula, yoghurt and cheese. These foods commonly form part of the diet of young children in this country and were often given for the first time before the food allergy had been diagnosed. In the subsequent reactions, baked products, confectionery and meat/vegetable dishes caused a higher proportion of reactions. Accidental exposure to a previously identified food allergen was more common with these foods.

Commercially processed foods may be more likely to cause accidental exposure to the food allergen because it is not always obvious what ingredients they contain. Foods that do not come packaged or labeled require detailed detective work on the part of

the allergic person or their carer to ensure they are safe to eat. Even foods that list the ingredients on the product packaging can be unsafe. Eight of the reactions recorded in this study occurred due to incorrect labeling. Several other reactions occurred when a food thought to be safe was contaminated during manufacturing. In two instances children reacted to soy ice cream, and in one case to soy cheese which were labeled dairy-free but contained traces of milk protein from the equipment used. A study by Gern et al reported three instances where milk-allergic individuals reacted to milk-contaminated “nondairy” products and argued for more stringent regulations to ensure the safety of those with food allergies.³⁶

Route of Exposure

In the majority (81.5%) of reactions the food was swallowed, however, it was interesting to note that a sizeable number of reactions occurred when the food was touched or inhaled. This demonstrates the exquisite sensitivity of some individuals and all carers should be made aware that any form of contact with the allergen can provoke a severe reaction. It is therefore advisable that all environments where the child spends time are kept allergen-free, although achieving this may not always be possible. This again highlights the importance of ensuring that emergency medications for treating instances of accidental exposure are available at all times.

Emergency Treatment

Similar to the findings of other studies, the administration of injectable adrenaline once a reaction had occurred was infrequent.^{4,5,17,24,26} There are several possible reasons for this. Some suggest that few patients and their parents are given adrenaline for self-administration by their doctors and that those who are prescribed adrenaline receive inadequate training and advice regarding its use.^{17,26,37} Another possible explanation is that many parents are unclear about when they should use the adrenaline and tend to adopt a “wait and see” approach.¹¹ This can be dangerous since some reactions progress rapidly and milder symptoms do not always precede a severe, potentially fatal attack.

In this study, the majority (86.6%) did not use adrenaline because it had not been prescribed, often because it was the first reaction and the allergy and its potential severity had not yet been diagnosed. However, in those who had had previous reactions and who had been prescribed adrenaline, its use was still uncommon. Instead of using adrenaline immediately, carers sought professional medical help, used other medications, or did nothing at all. Adrenaline is the drug of choice for treatment of anaphylaxis and is most effective if given immediately upon the onset of symptoms. From the results of this and other studies it appears that this message has not yet been convincingly delivered to patients and their parents and further education is necessary.

ADRENALINE

Those at risk of anaphylaxis are advised to have injectable adrenaline available at all times. One of the aims of the present study was to find out whether this advice was being carried out in practise. The majority (86.8%) of respondents reported currently having one or more EpiPen[®] syringes for treating their child in the event of an anaphylactic reaction, and most (77.0%) said that at least one EpiPen[®] was kept with their child at all times. Of those who did not have an EpiPen[®], some had an alternative form of adrenaline while for others adrenaline had not been prescribed. Cost was an issue for a small proportion (3.3%) of respondents. At present, the EpiPen[®] device is not subsidised by the government and costs \$110.23.

Most (97.8%) parents had received advice and training regarding the use of the EpiPen[®]. Despite this, the vast majority of parents still said they felt anxious about using the EpiPen[®] in the event of their child experiencing an anaphylactic reaction. This may be one reason for the infrequent administration of adrenaline reported above.

DAY-CARE/PRE-SCHOOL/SCHOOL

Children spend a significant percentage of their waking hours in the school setting and therefore parents of at-risk children, in conjunction with their doctors, must ensure that school personnel are instructed in the prevention, identification and treatment of anaphylactic reactions. One very positive finding of this study was that the majority (98.2%) of schools were aware of the child's food allergy and most (89.4%) had an emergency action plan in place for dealing with instances of accidental exposure. However, while the majority of parents felt their child was receiving adequate care and support at school, a significant minority (19.5%) said that their child's schooling had been compromised, and some had been denied access to such facilities on account of their severe food allergies. Several respondents also said that school personnel were reluctant to take responsibility for administering adrenaline in the event of accidental exposure. An education programme in the United Kingdom has been established to train school staff in the prevention and management of anaphylaxis with very positive results.³⁸ A similar programme would be beneficial in the Australian setting to reduce anxiety amongst parents and school personnel and to help ensure the safety of children at risk of anaphylaxis while at school.

NUTRITIONAL IMPACT OF FOOD-INDUCED ANAPHYLAXIS

The impact of food allergy on the nutritional adequacy of childrens' diets has been reported elsewhere.²⁷⁻³⁰ The focus of this study was to concentrate more on parents' perceptions of the nutritional adequacy of their child's diet and the problems they experienced feeding their child as a result of their severe food allergy. This information is important from a counseling point of view as it can help to address client needs and concerns more effectively.

Interestingly, the majority of respondents perceived their child's diet to be nutritionally adequate. The only nutrient of significant concern was calcium. Dairy foods are the major source of calcium in the Australian diet and children with a milk allergy may be at risk of calcium deficiency.²⁷⁻³⁰ There is, however, a range of milk substitutes on the market, some of which provide similar amounts of calcium to dairy

products. Although these substitutes may be unpalatable to the child, and are more expensive than regular milk, those with milk allergy should be able to obtain a nutritionally adequate diet with the proper dietetic advice.

Problems experienced by parents, with regard to providing a nutritionally adequate diet for their severely food-allergic child, will vary (depending on the particular food or combination of foods involved). As outlined above, those with allergies to staple foods, such as milk or wheat, and those with allergies to multiple foods will need to follow a more restrictive diet than those with allergies to single peripheral foods, such as peanut or soy. Even so, avoiding these peripheral foods is becoming increasingly difficult due to their widespread presence in commercially prepared foods.⁴ The majority of respondents in the present study experienced some problems providing substitutes for foods excluded from their child's diet. Some said they had difficulty finding suitable substitutes in shops, while others were concerned about the cost and extra preparation time involved. Many of these problems could be overcome with improved client education, highlighting the important role that dietitians have to play in the management of children with food allergies.

SOCIAL IMPACT OF FOOD-INDUCED ANAPHYLAXIS

One of the aims of this study was to explore the social impact of severe food allergy on children and their families. The prevention and management of accidental exposure to food allergens causes considerable anxiety in many parents, and food allergen avoidance requires constant vigilance. Labels on commercially prepared products must be scrutinised meticulously each time the food is purchased. Children and their parents must also obtain detailed information about the ingredients of all food prepared outside the home. In addition, there is the need for the education of all carers regarding avoidance measures and the management of accidental contact, including the training of others to administer adrenaline. Most parents in this study experienced considerable anxiety about their child eating foods that had been prepared outside the home. Preparing meals that were both safe and acceptable for the whole family was perceived as a problem for many. Almost half of the respondents reported avoiding social occasions and over two thirds avoided eating out, on account of their

child's food allergy. These issues warrant further investigation and would probably be more effectively elucidated by qualitative research methods, such as focus groups. Many respondents said they would be willing to participate in group discussions which will form the basis of a subsequent research project.

CONCLUSION

RECOMMENDATIONS

The aim of this project was to investigate a range of issues regarding the management of children at risk of food-induced anaphylaxis. On the basis of our findings we have formulated the following recommendations:

1. Children with an identified food allergy should undergo skin prick tests for a range of other foods which could potentially cause anaphylaxis.
2. Injectable adrenaline should be available at all times for children at risk of food-induced anaphylaxis.
3. All carers should be educated regarding the prevention and treatment of food-induced anaphylaxis, including the use of injectable adrenaline. A training package for schools would be beneficial for reducing anxiety amongst staff and improving the safety of children at risk of food-induced anaphylaxis in the school setting.
4. Parents of children with an identified food allergy should be referred to a dietitian with expertise in this area for education regarding allergen avoidance and the use of substitutes for foods and nutrients excluded from the child's diet.

FUTURE STUDIES

While the present study has touched on many issues regarding the management of children at risk of food-induced anaphylaxis, more detailed investigation is warranted in order to gain a better understanding of the specific problems patients and their families face. The results of this questionnaire will lay the groundwork for focus-group discussions to be conducted with respondents who have agreed to participate in further studies. Issues to be addressed include:

1. The education and training needs of those involved in the care of children at risk of food-induced anaphylaxis.
2. The social impact of food-induced anaphylaxis on patients and their families.
3. Anxiety associated with the use of adrenaline for the treatment of instances of accidental exposure to food allergens.

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March 1999

Dear Parent,

You and your child/children are invited to participate in a research study investigating how families cope with children who have severe food allergies, particularly those with food-induced anaphylaxis. The purpose is to improve the quality of information made available to families, schools and health-care professionals, and to help make preventive strategies more effective. The research is being conducted by Drs Velencia Soutter, Robert Loblay and Anne Swain, and Ms Debbie Cohen (student dietitian) at the RPAH Allergy Unit, together with Dr John Ruhno (paediatrician) and Ms Meg Johnson (President of FACTS — the Food Anaphylactic Children Training Support Group).

We are approaching you either because you have attended the RPAH Allergy Clinic or because you are a member of FACTS. If you would like to participate, please fill out the enclosed questionnaire and return it in the attached self-addressed, postage-paid envelope. If we have not heard from you in the next two or three weeks we will contact you by phone or send you a postal reminder.

All information obtained during this study will be treated confidentially. If your child has been seen at RPAH, your questionnaire will be incorporated into his/her Allergy Unit dietetic file. Otherwise it will be held securely in the Allergy Unit, and only the researchers named above will have access to it. The overall results of the study will be summarized in the FACTS newsletter, and will be reported to professional groups, but individual names or other identifying information will not be revealed.

You are in no way obliged to participate in this study. If you do not wish to answer the questions, simply throw away the questionnaire and let us know when we call you. Rest assured that your decision will not influence your relationship with your medical or dietetic advisers, or with FACTS.

When the questionnaire responses have been collated, we plan to call for volunteers to participate in small group discussions ('focus groups') so that we can find out more about the issues which are of particular concern to parents. If you are interested in participating in a focus group, please let us know by ticking the box at the end of the questionnaire.

We do hope you can find the time to help. If you wish to discuss the study or require any further information, please contact Debbie Cohen on 9515 5026 or Dr Velencia Soutter on 9515 6307.

Yours sincerely,

Velencia Soutter

Robert H Loblay

Anne Swain

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Central Sydney Area Health Service. Any person with concerns or complaints about the conduct of the study can contact the Secretary of the Ethics Review Committee on (02) 9515 6766.

*Allergy Unit
Royal Prince Alfred Hospital*

***FOOD-INDUCED ANAPHYLAXIS
QUESTIONNAIRE***

CHILD'S NAME:

*If you have any questions, contact Anne Swain, Valencia Soutter or Robert Loblay
Allergy Unit, Suite 210, RPAH Medical Centre, 100 Carillon Ave. Newtown 2042
Phone: 9515 8244 Fax: 9550 1029 E-mail: anne@immu.rpa.cs.nsw.gov.au*

If Yes, list foods/reactions:

..... (cont'd over)

3. (cont'd)

.....
.....

4. How often does your child experience minor allergic reactions (e.g. swelling of the face, hives etc.) to foods?

- about once a week
- about once a month
- every few months
- about once a year
- rarely
- never

5. What other allergic conditions does your child have?

(You may tick more than one box)

- Asthma
- Eczema
- Hayfever
- None

6. If your child has asthma, which of the following medications do they take on a regular basis?

(You may tick more than one box)

- | | | |
|---------------------------------|----------------------------------|----------------------------------|
| <input type="radio"/> Relievers | <input type="radio"/> Preventers | <input type="radio"/> Prednisone |
| e.g. Ventolin | e.g. Becotide | (for acute attacks) |
| Bricanyl | Pulmicort | |
| Serevent | Flixotide | |
| | Intal | |
| | Tilade | |

7. Do you receive a Child Disability Allowance?

- Yes No

8. Do you have a Health Care Card?

- Yes No

SECTION B: ANAPHYLAXIS

An ANAPHYLACTIC REACTION is a severe allergic reaction involving one or more of the following symptoms:

- *difficulty breathing or throat swelling*
- *hives all over*
- *collapse (allergic shock)*

9. Has your child ever experienced an anaphylactic reaction to food?

- Yes No

If No, skip to Question 31

If Yes:

10. How many anaphylactic reactions to food has your child experienced?

..... *(number of separate incidents)*

11. Age at first anaphylactic reaction to food:

12. Age at most recent anaphylactic reaction to food:

(May be the same as above if child has only experienced one anaphylactic reaction to food)

The following questions should be answered for the MOST SEVERE food-induced anaphylactic reaction your child has experienced

- Other nuts
- Wheat
- Don't know
-
-
-
-

17. What form was the food in?

(For example, if the food that caused the reaction was peanut, was it eaten as whole peanuts, peanut butter, cake, biscuit etc.)

(specify)

18. Was the food containing the allergen:

- Homemade?
- Commercially prepared (packaged)?
- Commercially prepared (unpackaged)?

19. If the food was commercially prepared and packaged, did the product label include a list of ingredients?

- Yes
- No
- Don't know

20. If yes, was the food that caused the reaction listed on the label?

- Yes
- No
- Don't know

21. Was the food eaten or was the reaction caused by the food coming into contact with the skin or the eye?

- Food was eaten
- Food came into contact with the skin
- Food came into contact with the eye
- Don't know

SECTION C: EMERGENCY ACTION

*Note: If your child has experienced **MORE THAN ONE** anaphylactic reaction to food, then please answer questions 22 to 30 in the separate answer booklet provided.*

22. Was adrenaline used at the time of the incident?

- Yes No

23. If adrenaline was not used, why not?

- Had not been prescribed.
- Had been prescribed but not yet purchased.
- Had been purchased but was not on hand at the time.
- Was on hand but no-one present knew how to use it.
- Was on hand but those present were too afraid to use it.
- Other
(specify)

24. If adrenaline was used, was it an EpiPen[®] (adrenaline in a preloaded automatic release form) that was used?

- Yes No

If No:

25. What form of adrenaline was used?

- Ampoule of adrenaline and syringe Metered-dose inhaler

Nebulizer and ampoule

Other

(specify)

26. Who gave the adrenaline to the child?

Self-administered by child

Child's mother

Child's father

Day-care/ pre-school/school staff

Doctor

Other

(specify)

27. What other emergency medications (apart from adrenaline) were used at the time of the incident (before going to hospital)?

(You may tick more than one box)

Oral antihistamines

Nebulized

Ventolin

Others

None

(specify)

.....
.....

28. Was an ambulance called?

Yes

No

29. Was the child taken to a hospital?

Yes

No

If Yes:

30. What emergency medications were used at the hospital?

(You may tick more than one box)

- Intravenous adrenaline
- Antihistamine injection
(for example Phenergan)
- Intramuscular adrenaline
- Oral antihistamines
- Inhaled adrenaline
- Other
(specify)
- Hydrocortisone injection
- No medications used
- Prednisone tablets
- Don't know

SECTION D: ADRENALINE

31. Do you currently have an EpiPen[®] for treating your child in the event of an anaphylactic reaction?

- Yes
- No

32. If No, why not?

- Has not been prescribed
- Costs too much
- Condition controlled by strict avoidance of food allergens
- Child has grown out of their food allergy
- Other
(specify)

33. Which other forms of adrenaline do you have?

(You may tick more than one box)

- Ampoule of adrenaline and syringe
- Metered-dose inhaler
- Nebulizer and ampoule
- Other
(specify)

- None

*Note: The following questions apply to those who have an **EpiPen**[®] only. If you do not have an **EpiPen**[®], skip to Question 44.*

34. How many EpiPens[®] do you keep? (specify)

35. Where are the EpiPens[®] kept?

(specify)

36. Is an EpiPen[®] kept with the child at all times?

- Yes
- No

37. If No, why not?

.....

38. Who knows how to use the EpiPen[®] in the event of your child experiencing an anaphylactic reaction?

(You may tick more than one box)

- The child
- Child's mother
- Child's father

- Day-care/pre-school/school staff
- Others

(specify)

39. What training and advice have you received regarding the use of the EpiPen[®] in the case of an emergency?

(You may tick more than one box)

- Shown EpiPen[®] by doctor/nurse
- Practised giving injection with EpiPen[®] Trainer
- Given written material

- Shown a video

- Other
(specify)

- No training or advice given

40. If you did receive training and advice how useful was it?

- Very useful
- Fairly useful
- Not at all useful

41. Did you receive assistance in the training of others (for example, school staff, relatives etc.) to use the EpiPen® in the event of your child experiencing an anaphylactic reaction?

- Yes
- No

42. How anxious do you feel about using the EpiPen®?

- Very anxious
- Moderately anxious
- Somewhat anxious
- Not at all anxious

43. How confident are you that the EpiPen® will help your child recover if they experience an anaphylactic reaction?

- Very confident
- Moderately confident
- Somewhat confident
- Not at all confident

SECTION E: DAY-CARE/PRE-SCHOOL/SCHOOL

Note: If your child does not attend day-care/pre-school/school, skip to Question 51.

44. Are the staff at the day-care/pre-school/school aware of your child's food allergy?

- Yes
- No

45. Does the day-care/pre-school/school have an emergency action plan for treating your child in the event of accidental contact with the food(s) he/she is allergic to?

- Yes
- No

46. Which of the following measures are in place at the day-care/pre-school/school to prevent your child from being accidentally exposed to the food(s) he/she is allergic to?

(You may tick more than one box)

- Information about your child, including photo and details of allergy, are displayed
- Information has been sent home to other parents
- No children are allowed to bring the food to school
- Children are taught not to share foods
- Other
(specify)
- No such measures have been put in place

47. How supportive have the day-care/pre-school/school staff been?

- Very supportive
- Moderately supportive
- Somewhat supportive
- Not at all supportive

48. Do you feel that your child's schooling has been compromised because of his/her food allergy?

- Yes
- No

If Yes:

49. How has your child's schooling been compromised because of his/her food allergy?

.....
.....

50. Has your child ever been denied access to a day-care, pre-school or school because of his/her food allergy?

- Yes
- No

SECTION F: PREVENTIVE MEASURES

51. The following questions relate to measures you take to prevent your child from being accidentally exposed to foods they are allergic to:
(Tick the most appropriate box)

a. We read food labels to check for the presence of the food allergen(s):

- All of the time
- Most of the time
- Some of the time
- Never

b. Our home is kept free of the food(s) my child is allergic to:

- All of the time
- Most of the time
- Some of the time
- Never

c. All members of our family avoid eating the food(s) my child is allergic to:

- All of the time
- Most of the time
- Some of the time
- Never

d. My child takes his/her own food to birthday parties:

- All of the time Most of the time Some of the time Never

e. My child takes his/her own food to the homes of friends and relatives:

- All of the time Most of the time Some of the time Never

f. I feel anxious about my child eating foods that have been prepared outside the home:

- All of the time Most of the time Some of the time Never

SECTION G: NUTRITION

52. Which of the following information, regarding the nutritional management of your child's food allergy, have you received?

- a. Substitutes for foods excluded Yes No
- b. What to look for on labels Yes No
- c. Preventing cross contamination Yes No
- d. Other
(specify)

53. Where did you receive the information from?

(You may tick more than one box)

- GP Specialist Hospital

No problems experienced

57. Do you feel that your child's diet is lacking in:

Adequate nutrition Yes No

Energy (Cal/kJ) Yes No

Protein Yes No

Carbohydrates Yes No

Fat Yes No

Calcium Yes No

Iron Yes No

Other minerals Yes No
(specify)

.....

Vitamin C Yes No

B vitamins Yes No

Vitamin A Yes No

Other vitamins Yes No
(specify)

.....

SECTION H: FAMILY

58. How difficult is it to prepare meals that are both safe and acceptable for the whole family?

Very difficult Moderately difficult Somewhat difficult No at all difficult

59. To what extent does your family avoid social occasions because of your child's food allergy?

All of the time Most of the time Some of the time Never

60. Does your family avoid eating out at restaurants, cafes etc. because of your child's food allergy?

Yes No

61. How supportive are members of your immediate family?

Very supportive Moderately supportive Somewhat supportive Not at all supportive

62. How supportive are other relatives and friends?

Very supportive Moderately supportive Somewhat supportive Not at all supportive

Thank you for taking the time to answer this questionnaire

If you live in Sydney, would you be interested in participating in a focus group to discuss the issues touched on in this questionnaire further?

Yes No