

Chicago Food Allergy Research Surveys

Ruchi S. Gupta, MD MPH

Assistant Professor of Pediatrics

Children's Memorial Hospital &

Northwestern Feinberg School of Medicine



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Background

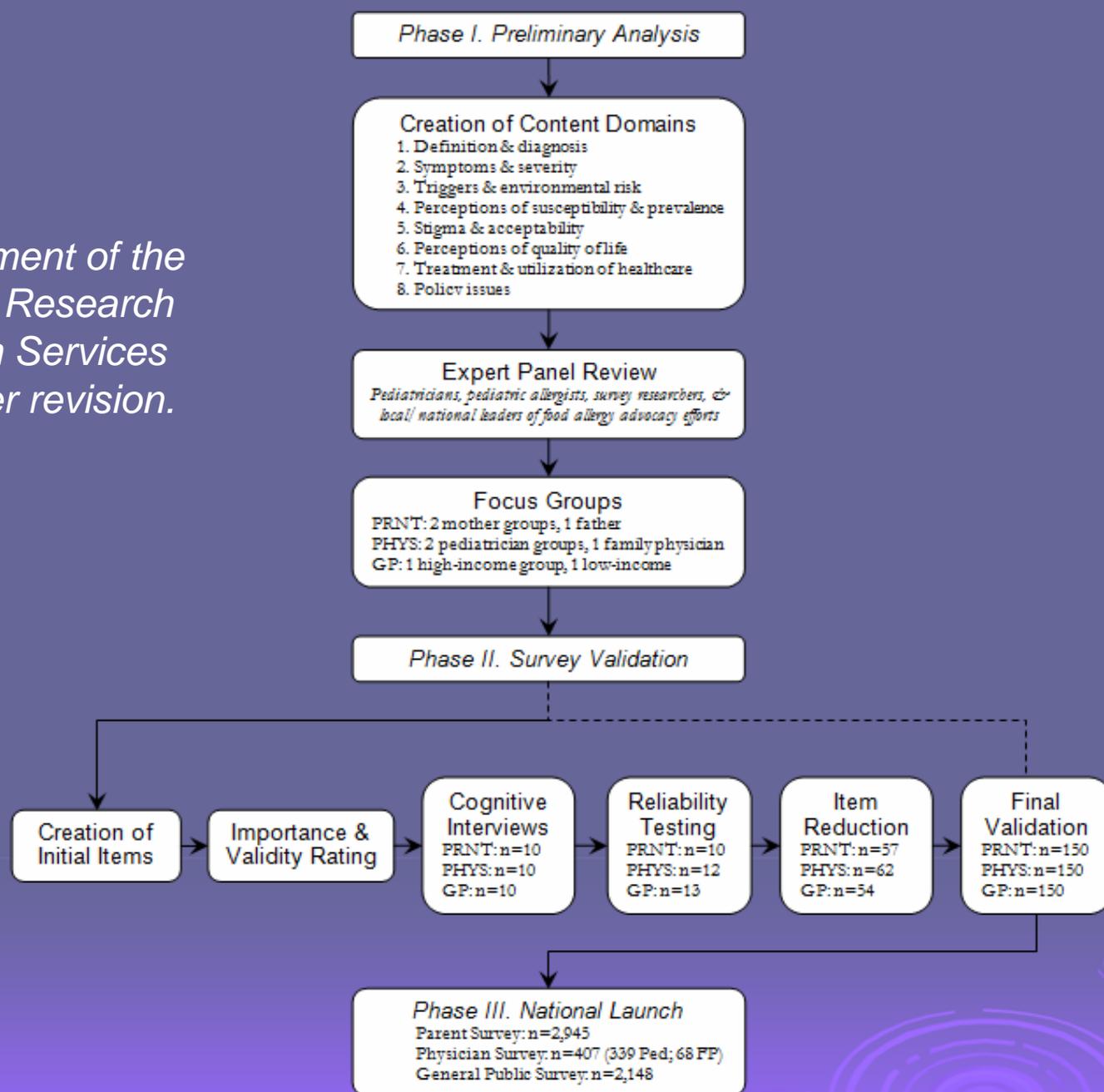
- Food allergy is increasingly common, affecting 4-6% of children in U.S.
- Standard of care is limited to avoidance and prompt response following ingestion
- Parents, primary care physicians and the general public play an important role in the safety of affected children:
 - The burden of risk assessment is placed on caregivers and has been shown to adversely affect quality of life
 - Pediatricians and family physicians are often the first/only clinicians to diagnose and manage food allergy
 - Members of the general public often interact with young children at restaurants, entertainment facilities, and schools

Objectives

- Develop survey instruments assessing food allergy knowledge, attitudes, and beliefs among:
 - parents of children with food allergy
 - pediatricians & family physicians
 - general public
- Characterize current knowledge & perceptions within each group by administering surveys nationally
- Develop tools to address identified misconceptions among pediatricians and family physicians
- Raise awareness of food allergy by sharing findings with the public and the academic community

Methods

Gupta, et al. Development of the Chicago Food Allergy Research Surveys. BMC Health Services Research, 2009; under revision.



Results: Focus Groups

Gupta et al. Food allergy knowledge, attitudes, and beliefs: Focus groups of parents, physicians, and the general public. BMC Pediatr, 2008; 8:36.

- Available at <http://www.biomedcentral.com/1471-2431/8/36>
- Parents
 - Good base-line knowledge
 - Emphasized effect on quality of life
 - Identified new issues regarding household disruption
- Physicians
 - Adequate base-line knowledge
 - Shared misconceptions
 - Little awareness of difficulties faced by parents
- General Public
 - Poor base-line knowledge
 - Multiple misconceptions, including general understanding & effect on quality of life

Parent Focus Groups

- *Emotional Response:* (M) “One of my sons has had two anaphylactic reactions, and it never leaves you. You cannot ever forget. It’s like a broken record.....just the feverishness, and this helplessness, horrible helplessness feeling you cannot describe. It is such a gut-wrenching squeezing of your body when you see your child going through that.”
- *Effect on Daily Social Life:* (M) “[Food allergy] affects every aspect [of your life] from where you take a vacation to whether and where you go out for dinner to play dates, which we certainly cannot do on the spur of the moment sort of basis as many [other] families can do. It affects literally every aspect of our social life.”

Parent Focus Groups

- Effect on Marriage: (F) “My wife is much more into 100% prevention all the time and I am much more into trying to maximize what my son can do. [I am] trying to figure out what that limit is so he can do the most he could possibly do where[as] she is much more in tune to ‘Let’s not take a chance at all’ and ‘I do not want put my son in danger.’”
- Diagnosis: (M) “It literally took six physicians before one said, ‘Let’s see if maybe this [eczema] is food-related with your daughter.’ And then when we went to our dermatologist, we were told that it was just a lucky coincidence that when the dairy was [removed from her diet], the eczema went away too. I do not think that the doctor was being ignorant. I think that perhaps the doctor just did not know that this was even a possibility because of her training.”

Physician Focus Groups

- Prognosis & Development of Tolerance

- (Ped): “I really do not know how many outgrow [food allergy]. I have no concept of what percent outgrow.”
- (FP): “One would think that [food allergies] are [more] prevalent the older you get because you [would] have more chance[s] to develop more allergies.”

- Diagnostic Criteria

- (Ped): “I do not ever treat eczema as food-related. It may be. It may not be. I never took it serious[ly] enough to react that way. Treat it [with] a little basic hydrocortisone or emollients. It gets better and move on.”
- (FP): “I actually kind of find out about a food allergy at the back end of an investigation for maybe persistent asthma or a persistent dermatological condition [rather] than discovering [food allergy] by testing. That has been my experience.”

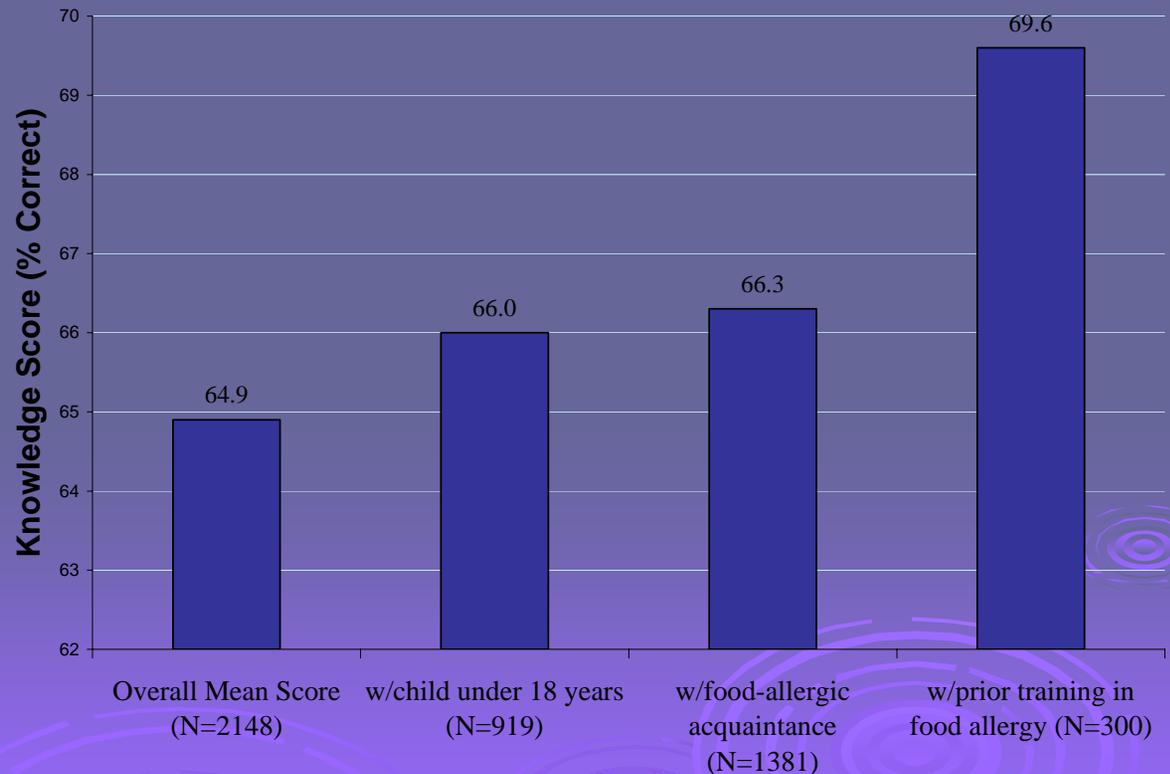
General Public Focus Groups

- *Definition of Food Allergy*
 - (H): “I think that [food allergy] may have something to do with the compromised immune system. [Food allergy] could also be due to environmental factors or conditions at birth or early illness or something that leaves the immune system in a weakened state or perhaps in a state where it is malfunctioning.”
 - (L): “[Food allergy is when] enzymes aggravate the nerves inside [and] stimulates pain to the brain.”

Results: General Public Survey

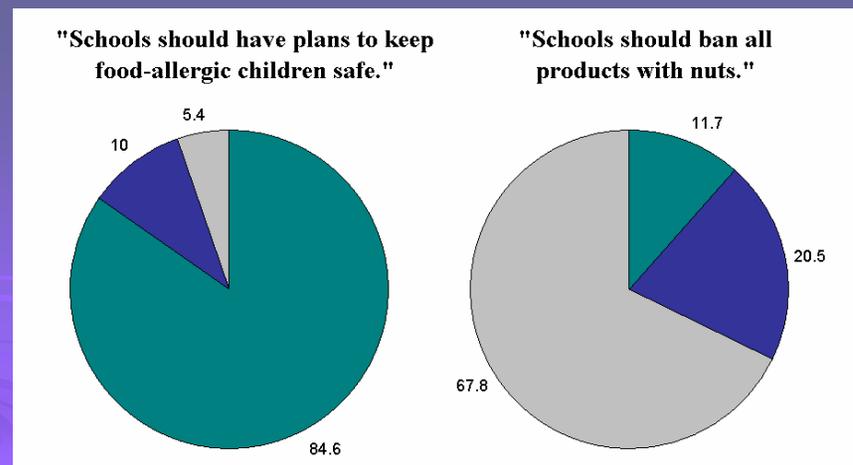
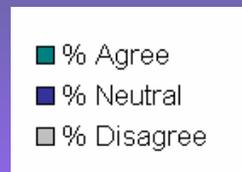
Gupta et al. Food allergy knowledge, attitudes, and beliefs in the United States. Ann Allergy Asthma Immunol, 2009; in press.

- Overall knowledge score was 64.9% (range, 12.5%-100%)
- Higher scores were significantly associated with self-report of prior knowledge/familiarity with food allergy



Results: General Public Survey

- Strengths: Knowledge of food allergy symptoms & severity; awareness of triggers & environmental risks
- Weaknesses: distinction between food allergy and food intolerance, the absence of a cure, & current treatment options
- Perceptions were well distributed, with a few exceptions
 - 65% believed food allergy a serious problem in the U.S.
 - Minimized stigma (e.g. 35% agreed people w/FA treated differently)
 - Parents w/non-food-allergic children likely to oppose specific policy actions in schools:



Knowledge Item	Knowledge Score (% Correct)*			
	Unadjusted	Stratified by child age	Stratified by prior training	Stratified by acquaintance
<i>Definition and diagnosis</i>				
Allergic reaction when body considers food harmful (T)	79	79	86	80
Lactose intolerance same as milk allergy (F)	50	51	57	52
<i>Symptoms and severity</i>				
Food allergy reaction can be fatal (T)	94	95	97	97
Hives common symptom of food allergy (T)	79	82	84	83
Sign of milk allergy reaction: hyperactivity (F)	87	86	87	86
Sign of milk allergy reaction: hives (T)	68	68	73	71
Sign of milk allergy reaction: tongue swells/trouble breathing (T)	74	77	78	76
Sign of milk allergy reaction: stuffy nose (F)	79	78	75	77
<i>Triggers and environmental risk</i>				
Allergic reaction from touching allergenic food (T)	69	72	79	72
Milk allergic child: safely drink low-fat milk (F)	66	66	74	68
Mother can pass food to child through breast milk (T)	86	89	88	88
Acidic food: common cause of food allergy (F)	40	40	42	41
3 most common childhood food allergies (egg)	41	46	43	40
3 most common childhood food allergies (milk)	71	68	70	69
3 most common childhood food allergies (peanut)	90	92	91	91
Most common adult food allergy (shellfish)	55	56	61	56
<i>Perceptions of susceptibility and prevalence</i>				
Allergic diseases run in families (T)	49	50	57	52
Food allergy can go away with age (T)	60	58	66	64
Food allergy more common in children (T)	48	49	57	50
Food allergy on rise in U.S. children (T)	71	72	83	75
<i>Treatment and utilization of healthcare</i>				
There is a cure for food allergy (F)	54	55	62	57
Avoidance is only way to prevent food allergy reaction (T)	57	60	57	55
Daily medicine can prevent food allergy reaction (F)	32	33	35	32
<i>Policy issues</i>				
Law in US requires foods to be labeled (T)	59	63	67	60

*Embodened values indicate score significantly *higher* than unadjusted with $p < 0.05$

Results: Physician Survey

Gupta et al. Food allergy knowledge, attitudes, and beliefs of primary care physicians. Pediatrics, 2009; under review.

- Overall knowledge score was 61% (range, 23%-87%)
 - Pediatricians: 62%; Family Physicians: 54%
- Strengths: Items assessing knowledge of food allergy triggers & environmental risks, susceptibility & prevalence, and treatment & utilization of healthcare
- Weaknesses: Items assessing knowledge of treatment & utilization of healthcare, definition & diagnosis of food allergy, and symptoms & severity

Item	Knowledge Score (% Correct)*		
	U	P	FP
Overall Mean Score	61	62	54
Definition and diagnosis			
Tests to diagnose FA (Food specific IgE levels)	64	68	43
Tests to diagnose FA (Oral food challenges)	24	25	22
Tests to diagnose FA (Skin-prick test)	57	59	49
Positive skin prick test or RAST is sufficient FA diagnosis (F)	68	71	53
Symptoms and severity			
Chronic nasal problems are symptom of FA (F)	12	13	6
Child can die from milk allergy reaction (T)	72	77	50
Mechanism of 'milk protein allergy' symptom: blood in stool (T-cell mediated)	21	21	22
Mechanism of 'milk protein allergy' symptom: colic (Non-immune mediated)	57	60	38
Isolated symptom of FA in infant (Hives)	79	82	63
Isolated symptom of FA in infant (Eczema)	75	78	63
Sign of IgE-mediated milk allergy (Flushing)	43	46	28
Triggers and environmental risk			
Asthma is important risk factor for severe anaphylaxis (T)	68	65	79
Percent moderate-severe atopic dermatitis associated w/food allergy (25-50%)	36	37	32
Children w/IgE-mediated milk allergies tolerate some yogurts/cheese w/milk (F)	23	26	10
Food allergens are passed from maternal diet into breast milk (T)	83	88	59
Okay for children with egg allergies to eat egg yolks (F)	65	65	63
Food additives are common food allergens (F)	39	40	34
3 most common childhood food allergies (Egg)	66	66	63
3 most common childhood food allergies (Milk)	73	73	72
3 most common childhood food allergies (Peanut)	77	76	84
Contains food ingredients that could cause allergic reaction (Play-doh)	57	56	63
Contains food ingredients that could cause allergic reaction (Medicines)	82	81	82
Contains food ingredients that could cause allergic reaction (Toothpaste)	48	47	53
Contains food ingredients that could cause allergic reaction (Lotions/creams)	70	71	61
Food component that causes allergic reaction (Protein)	90	91	90
Vaccines unsafe for children with egg allergy (Influenza)	80	82	80
Perceptions of susceptibility and prevalence			
Number of children in US w/FA is increasing (T)	90	90	91
Teenagers are at higher risk for fatal FA vs. younger children (T)	34	37	22
Age group most likely to have food allergies (0-5 years)	79	83	60
Percent children with <u>milk</u> allergy develop tolerance (> 75%)	35	57	22
Percent children with <u>peanut</u> allergy develop tolerance (1-25%)	44	44	43
Treatment and utilization of healthcare			
Daily antihistamine prevents FA reaction (F)	86	87	85
There is a cure for FA (F)	80	80	81
No contraindication to prescribing self-injectable epinephrine (T)	63	65	49
Timely administration of epinephrine prevent fatal anaphylaxis (Most of the time)	75	75	75
Dose of epinephrine, 60 lb child (EpiPen/Twinject, 0.3mg epinephrine)	51	56	25
Epinephrine injection location (Lateral thigh)	91	92	82
Treatment for child after peanut ingestion (Epinephrine 1:1,000 IM)	50	52	41
Policy issues			
Mandates of FALPCA (Plain language ID of common allergens on ingredient list)	71	72	65

*Emboldened values indicate score significantly different than unadjusted score, p<0.05

Results: Physician Survey

- 99% of participants reported caring for children with food allergy
- Participants consistently expressed concern regarding their ability to care for children with food allergy
 - 28% felt comfortable interpreting lab tests to diagnose food allergy
 - 22% felt adequately prepared by their medical training to care for food allergic children
- 74% referred patients with food allergy to an allergist at least “some of the time”
- 67% felt parents of children with food allergy are hyper-vigilant

Results: Parent Survey

Currently drafting manuscript.

- Overall knowledge score was 75%
 - Parents with multiple children with food allergy scored significantly higher (79%)
- Although open to all parents of children with food allergy, participant distribution was skewed:
 - 89% White; 73% with Bachelor's degree or higher; 42% with household income >\$100,000 (84% >50K); 91% married
- Strengths: Performance was strong on multiple items across domains, especially regarding symptoms and severity of food allergy
- Weaknesses: Unaware that food additives are not common allergens; difficulty with items assessing susceptibility and prevalence

Item	Knowledge score, % correct		
	Unadjusted	1 child w/FA ^a	≥2 children w/FA ^b
Overall mean score	75.3	74.6	79.2 ^c
Definition and diagnosis			
FA involves immune system (T)	85.2	84.4	89.7 ^c
Medical test only way to know child has FA (F)	65.4	64.3	71.7 ^c
Symptoms and severity			
Eczema may be first sign of FA (T)	84.3	83.4	89.1 ^c
Sign of milk allergy reaction (hives on face/chest)	94.9	94.8	95.10
Sign of milk allergy reaction (tongue swells/trouble breathing)	94.7	94.3	96.8 ^c
Triggers and environmental risk			
Asthma risk factor for anaphylaxis (T)	77.7	76.6	83.9 ^c
Foods can pass from mother to child by breast milk (T)	92.0	91.6	94.2
Food additives are common food allergens (F)	36.4	35.3	42.2 ^c
Food ingredients could cause allergic reaction (Play-doh)	80.0	78.9	94.7 ^c
Food ingredients could cause allergic reaction (medicines)	91.9	91.6	93.4
Food ingredients could cause allergic reaction (toothpaste)	74.4	73.2	80.9 ^c
Food ingredients could cause allergic reaction (lotions/creams)	93.5	92.9	96.1
3 most common childhood food allergens (egg)	70.9	70.4	73.2
3 most common childhood food allergens (milk)	87.6	86.8	91.9 ^c
3 most common childhood food allergens (peanut)	87.5	87.5	87.8
Perceptions of susceptibility and prevalence			
Teenagers at > risk for fatal FA than children (T)	48.1	46.8	54.6 ^c
Age group most likely to have FA (0-5 years)	79.2	78.4	83.5 ^c
% of children w/milk allergy who develop tolerance (>75%)	25.7	25.4	27.2
% of children w/peanut allergy who develop tolerance (1-25%)	58.6	58.5	58.9
Treatment and use of healthcare			
Daily antihistamine can prevent FA reaction (F)	68.4	67.0	75.8 ^c
Best place to use EpiPen/Twinject (outer thigh)	85.8	84.8	92.1 ^c

Abbreviations: F, false; T, true

^aThese participants had 1 child with physician-diagnosed FA (n=).

^bThese participants had ≥2 children with physician-diagnosed FA (n=).

^cThis score was significantly higher than the unadjusted score ($P<0.05$).

Results: Parent Survey

- 19% of parents felt that people take food allergy seriously
 - Compared to 58% of physicians and 65% of the general public
- 9% of parents agreed that most people know symptoms of food allergy
 - Participants in general public survey answered 80% of questions addressing symptoms/severity of food allergy correctly
- 49% of parents agreed that schools should ban all peanuts with nuts
 - Compared to 52% of physicians and 12% of the general public
- 81% of parents agreed that how they deal with child's food allergy affects how child deals with his/her food allergy
- 25% of parents reported their career suffered due to child's food allergy
- 29% of parents reported child's food allergy caused a strain on marriage/relationship
- 56% of parents felt they worried more about child's food allergy than spouse/partner

Results: Epidemiology

- Ongoing
 - Will better characterize food allergy among children of participants in parent survey; will assess:
 - Type of allergy(s), both physician-diagnosed and parent reported
 - Odds of experiencing anaphylaxis
 - Odds of co-morbid conditions (asthma, eczema, and seasonal allergies)
 - Thoughts or suggestions?
- 

Results: Tolerance

- Ongoing
- Will describe characteristics of children who do and do not develop tolerance using data from parent survey; will assess:
 - Type of allergy(s) children are likely to outgrow
 - Demographic trends among children who do and do not develop tolerance (e.g. race/ethnicity, geographic location)
 - Genetic trends among children who do and do not develop tolerance (e.g. birth order, sibling history of allergy)
 - Odds of co-morbid conditions (asthma, eczema, and seasonal allergies) and history of anaphylaxis among children who do and do not develop tolerance
- Thoughts or suggestions?

Results: Quality of Life

- Ongoing
 - Based on responses of 2500 parents to a quality of life survey and comments received from participants
 - Identified 5 major themes:
 - Emotional burden
 - Stigma/normalcy
 - Social interactions/limitations
 - Daily burden
 - Health/nutrition
- 

Results: Quality of Life

- Emotional Burden

- “These worries are constant. They don't ever go away and can sometimes become so overwhelming that I feel paralyzed with fear. It is a daily struggle to provide a "normal" life for my son while keeping him safe from the food allergens that are so dangerous for him.”
- “Why focus on all these negatives? Food allergies only rule your life if you allow them to. My son leads a perfectly normal life because we don't treat him like he needs to be in a bubble.”

- Stigma/Normalcy

- “My children are singled out, they are different. I feel badly for them, I do not wish this hurdle on anyone.”
- We have been living with food allergies for almost 20 years now. We live as normal a life style as possible, taking care to ensure foods are safe to eat.

- Social Interactions/Limitations

- “I work out of the home and home school our children because of food allergies. I do not feel schools are adequately trained to handle children with life threatening allergies.”
- “My child has a peanut allergy. Her school, friends and extended family are all aware of it. She has an EpiPen in her backpack and in the office at school. I am comforted by a high level of awareness around her.”

Results: Quality of Life

- Social Interactions/Limitation (Cont'd)

- “He has been at 2 birthday parties in the past week. At one his right eye got red & swollen, he took Benadryl and was fine. The mom called me, I let him stay b/c I don't want to make him feel even more 'different' but I was at home nervous - car keys in my hand. It made me so sad.”
- “My child is sad and feels different than his peers. He gets anxious around others because he does not know what they have eaten and if he will have a reaction. He doesn't get invited to many birthday parties, we suspect it is because the parents do not want the burden of a child with food allergies at their party!”

- Daily Burden

- “Still, after 7 years, I find myself still struggling daily with meal preparation.”
- “It is tiring to have to always be on the alert for any food situations involving my child.”
- “[Due to insurance limitations]...I cannot afford visits to the allergist ... I really feel the need to visit a nutritionist or a dietitian ... but resources ... are limited in this community and we can't afford a trip to the big city and the medical bills.”

- Health and Nutrition

- “My son experiences anxiety when eating foods out of the house and has limited his food choices as a result. ... I believe that his food allergies have affected ... his nutritional intake.”
- “The one positive aspect of our daughter's allergies ... is she in general eats very healthy foods.”
- “My son was hospitalized (age 2) with respiratory distress, etc. and even the hospital could not meet his special needs ... We had to bring stuff from home.”

Next Steps: Prevalence

- National survey of at least 50,000 households with children
 - Questions will provide a better estimate of childhood food allergy rates; will assess:
 - Current allergies
 - Methods of diagnosis
 - Types of reactions
 - Age at first reaction
 - Past allergies/tolerance
 - Age tolerance was observed
 - Thoughts or suggestions?
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Thank You!

- Questions

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