

Food Allergy Community Needs Assessment INDIANAPOLIS, IN

Conducted by:
Food Allergy Research & Education
(FARE)

Food Allergy Research& Education

FARE's mission is to improve the **LIFE** and **HEALTH** of all individuals with food allergies and to provide them **HOPE** through the promise of new treatments.

LIFE



HEALTH



HOPE



Community Engagement Initiative

- Piloting the initiative in 10 communities in 2017
- Building a sustainable, scalable model to enable consistent delivery of FARE's mission programs at the community level
 - Education and training of families and professionals
 - Advancing key state and local advocacy priorities
 - Growing awareness about the seriousness of food allergies and anaphylaxis
 - Collaboration with other stakeholders in the community
 - Raising critical funds to support local efforts

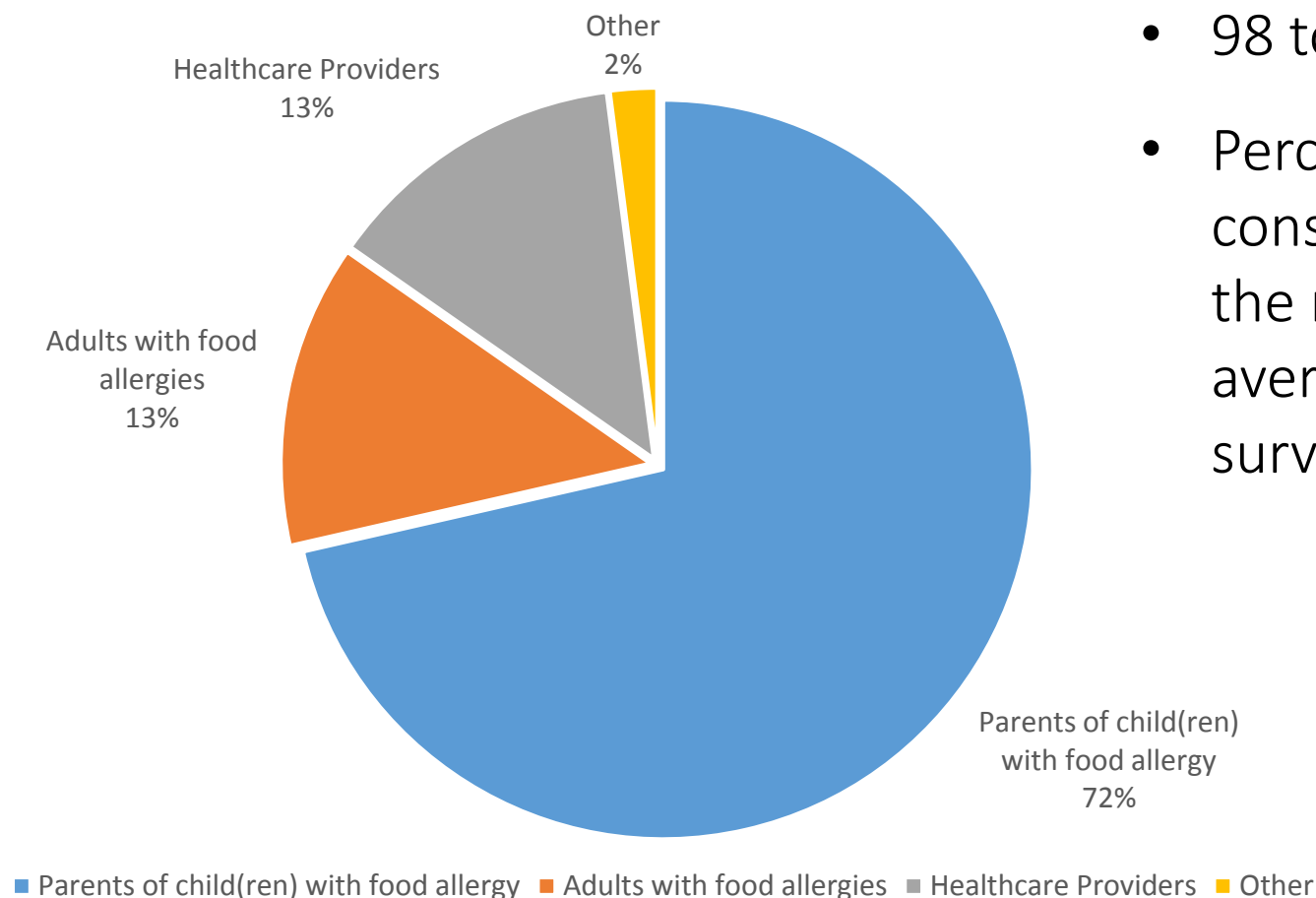
Community Needs Assessment

- Implemented a community needs assessment to collect data on specific areas of need within each of the pilot communities
- Surveys were deployed across the 10 pilot communities in late 2016 and early 2017
- Results will allow FARE to focus local efforts on unique or specific areas of need identified in each community while also directing national efforts to address those needs that were consistent across all markets

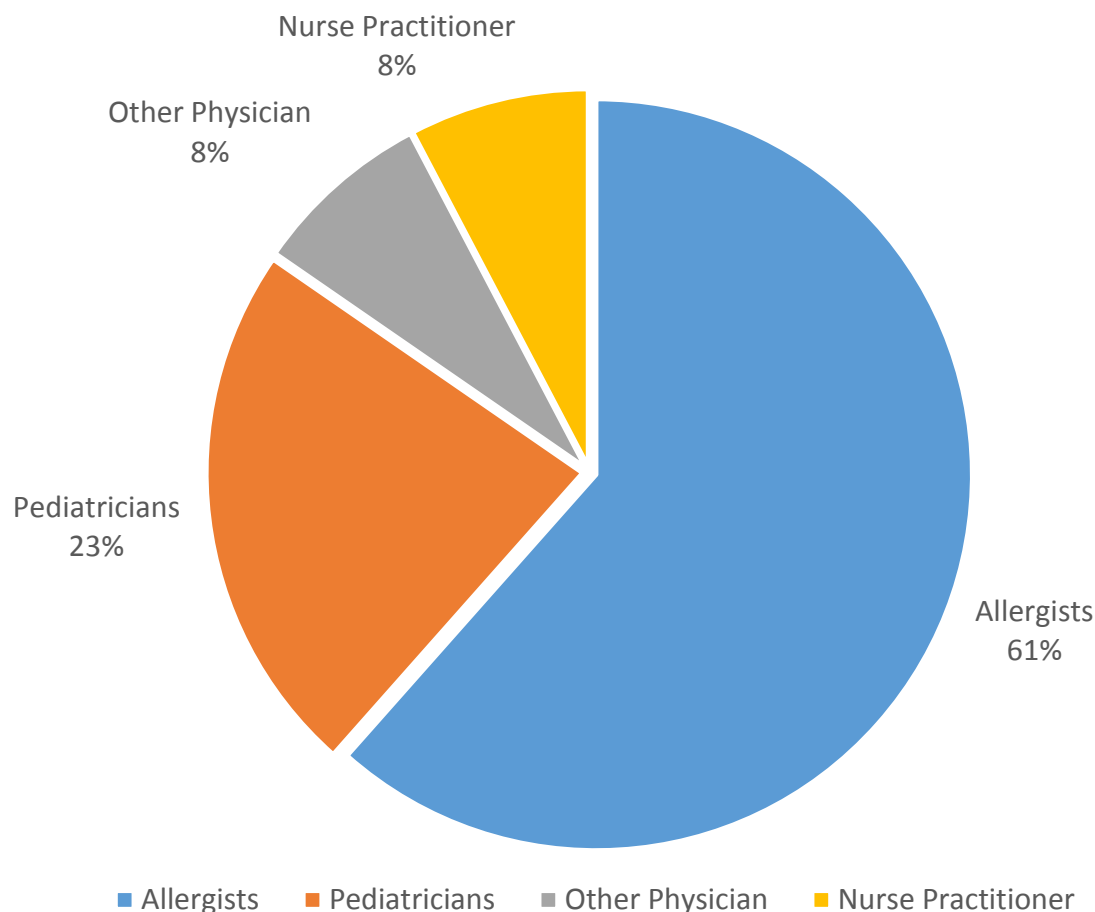
Summary of Findings: INDIANAPOLIS, IN

Respondent Breakdown

- 98 total responses
- Percentages were consistent with the national average for this survey



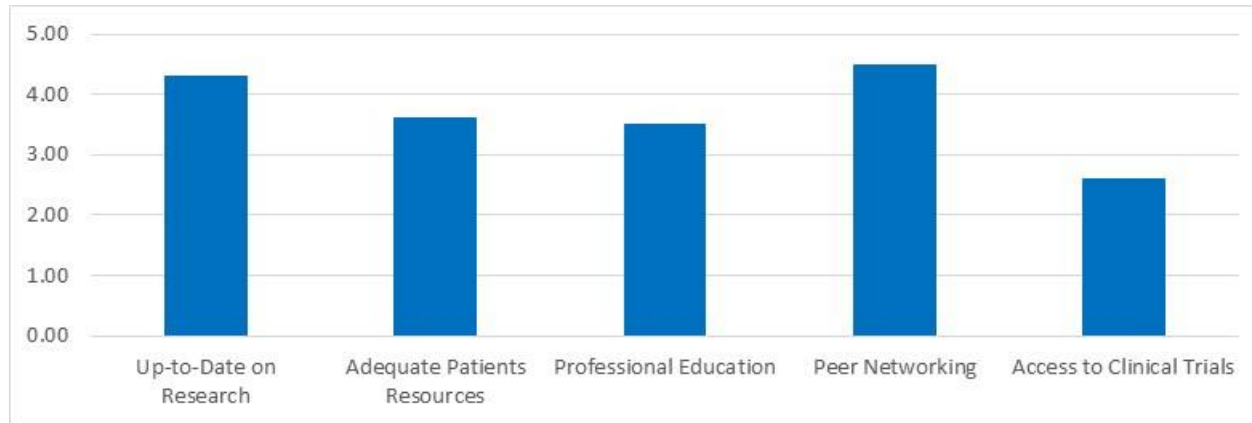
Healthcare Professional Respondents



- High level of engagement from allergists in Indianapolis
- Nationally, only 9% of healthcare professional respondents were allergists

Healthcare Professional Needs

Survey assessed healthcare professional needs related to **food allergy** information and resources. *Scale: 1 = strongly disagree, 5 = strongly agree*



- Results indicated a high level of agreement with statements about access to research updates and peer networking
- Lowest level of agreement regarding access to food allergy clinical trials
- Opportunity to improve access to patient resources and professional education

Healthcare Professional Needs

Patient resources that are needed include:

- Information about advocacy organizations
- 504 plans for schools
- Clinical trial information
- Mental health referrals
- Local support groups
- Books on food allergy

Most frequently provided resources to newly diagnosed:

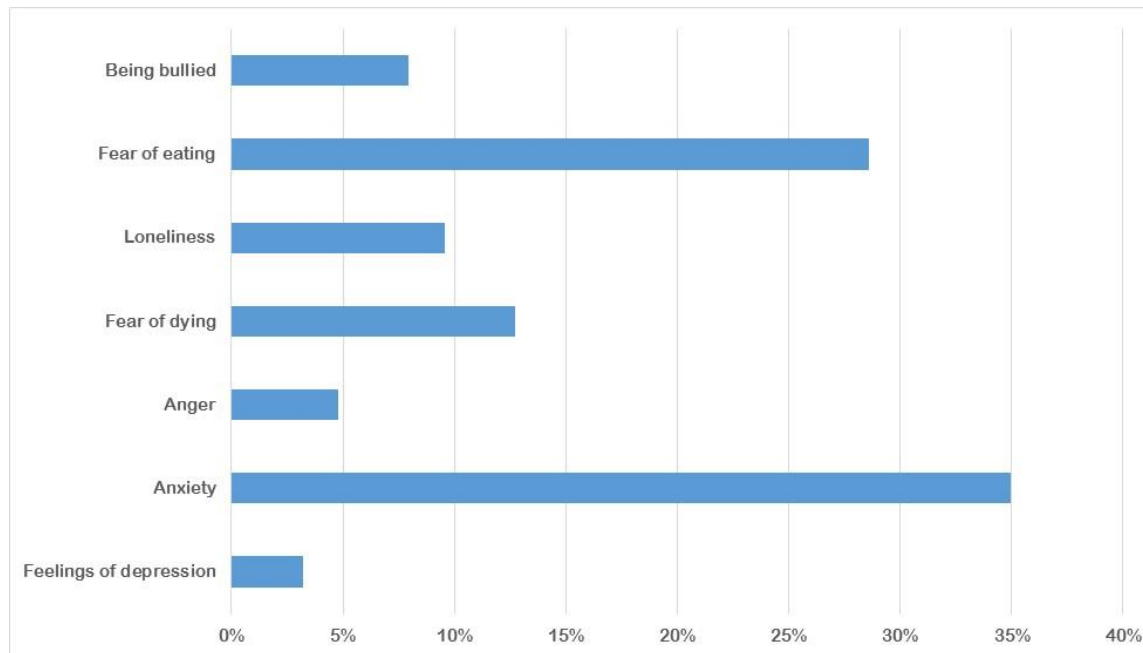
- Action plans
- Information on food allergy management
- Epinephrine use
- Education on anaphylaxis
- Information on food labeling
- Assistance with dining out
- Referrals to board-certified allergists

Healthcare Professionals: Additional Insights

- The majority of healthcare professionals in Indianapolis are interested in being made aware of local food allergy activities and initiatives, on par with the national average
- 80% of healthcare providers correctly indicated that Indiana has a law allowing public schools to stock undesignated epinephrine
- 40% of healthcare providers knew that Indiana does not have a law requiring schools to stock undesignated epinephrine. 50% were unsure.
- Only 20% of healthcare providers correctly indicated that Indiana has a law allowing public entities to stock undesignated epinephrine

Parents of Children with Food Allergies

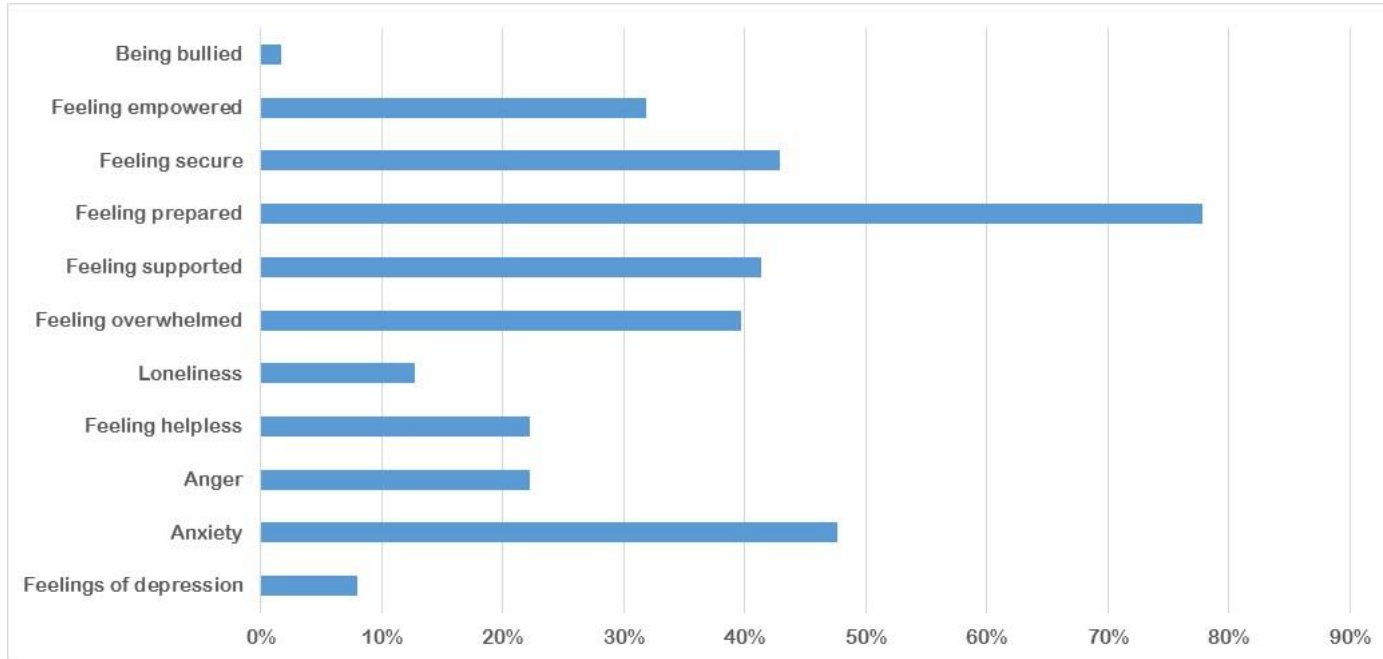
- General anxiety and fear of eating are biggest concerns of children with food allergies, as reported by their parents



- In line with numbers reported from other cities in the survey

Parents of Children with Food Allergies

- 80% of parents report feeling prepared
- But many also indicate high levels of anxiety and feeling overwhelmed



- In line with numbers reported from other cities in the survey

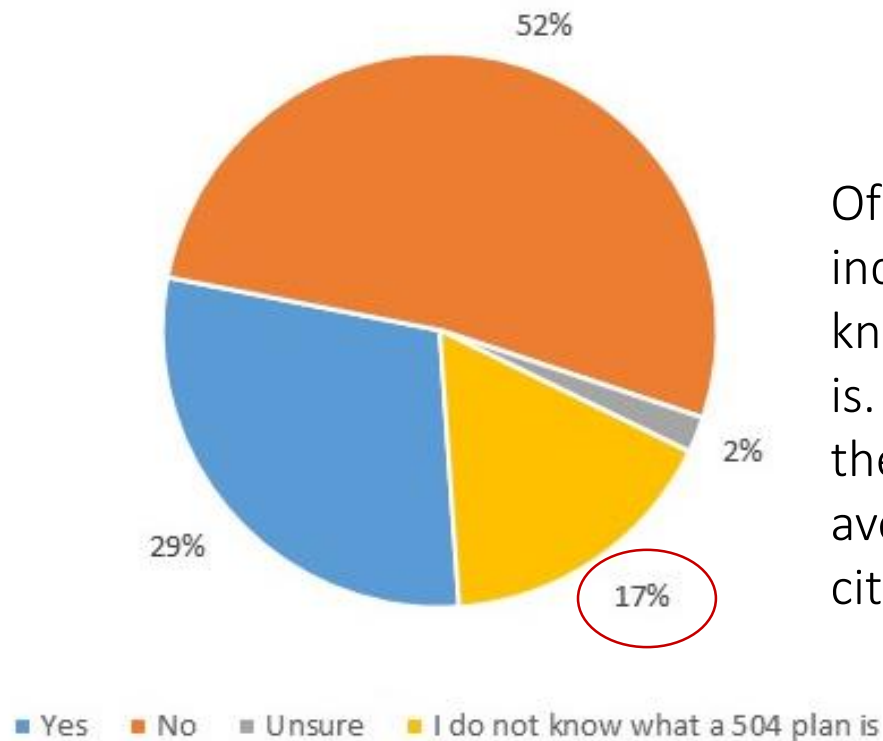
Food Allergies in Schools

	YES
The school trains staff on how to recognize and treat an allergic reaction (including how to use an epinephrine auto-injector)	71%
The school keeps food out of classroom celebrations and activities	16% ✓
The school provides basic food allergy awareness information to all staff	59%
The school recognizes that food allergy may be considered a disability under the Americans with Disabilities Act	37%
The school prohibits certain allergens from the cafeteria	16%
The school prohibits certain allergens from the whole school	8% ✓
The school provides allergy awareness information to students	16% ✓
The school has made accommodations to keep my child safe	86%

- Indianapolis was aligned with other cities included in the survey regarding a number of school issues
- Unique challenges to this community are noted by a red check mark.
- Nationally and in Indianapolis, there is a low level of awareness about food allergy as a disability
- Also room for improvement in providing food allergy awareness to students

Food Allergies in Schools

- 29% of parent respondents indicated they have **504 plan** in place at school for their child. This is in line with the aggregate national average from other cities



Of note, 17% indicated they did not know what a 504 plan is. This is well above the aggregate national average from other cities (8%).

Food Allergies in Schools





Overall, how well do you think the school is managing your child's allergies?

1 Star = Very Poorly (The school has actively created barriers to accommodating my child.)

2 Stars = Adequately (The school provides the minimum accommodations required for my child.)

3 Stars = Well (The school has been proactive in accommodating my child.)

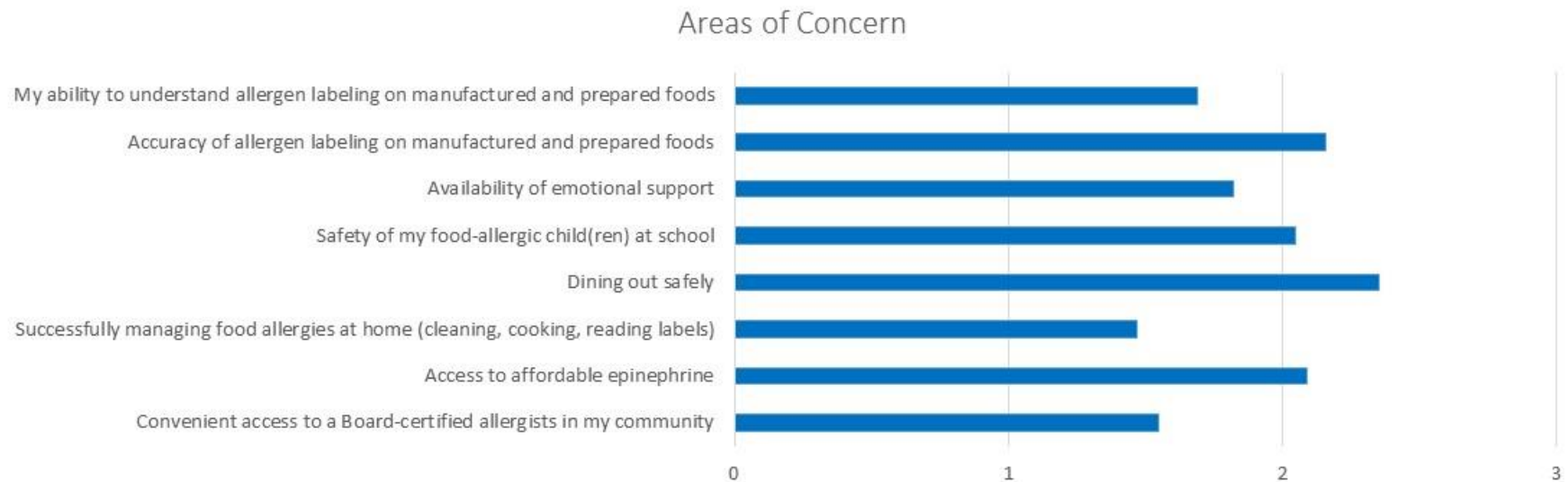
4 Stars = Very Well (The school consistently goes above and beyond to accommodate my child.)

				
Indianapolis	10%	38%	40%	13%
National Average	8%	40%	35%	16%

Life with Food Allergies: Additional Insights

Please share how challenging each of the following issues is personally for you/your family

Scale of 1 to 3, where 1 = not at all challenging and 3 = very challenging



- Individuals and families with food allergies in Indianapolis face the same challenges as those in other cities
- Dining out safely is the chief concern locally and nationally

Life with Food Allergies: Additional Insights

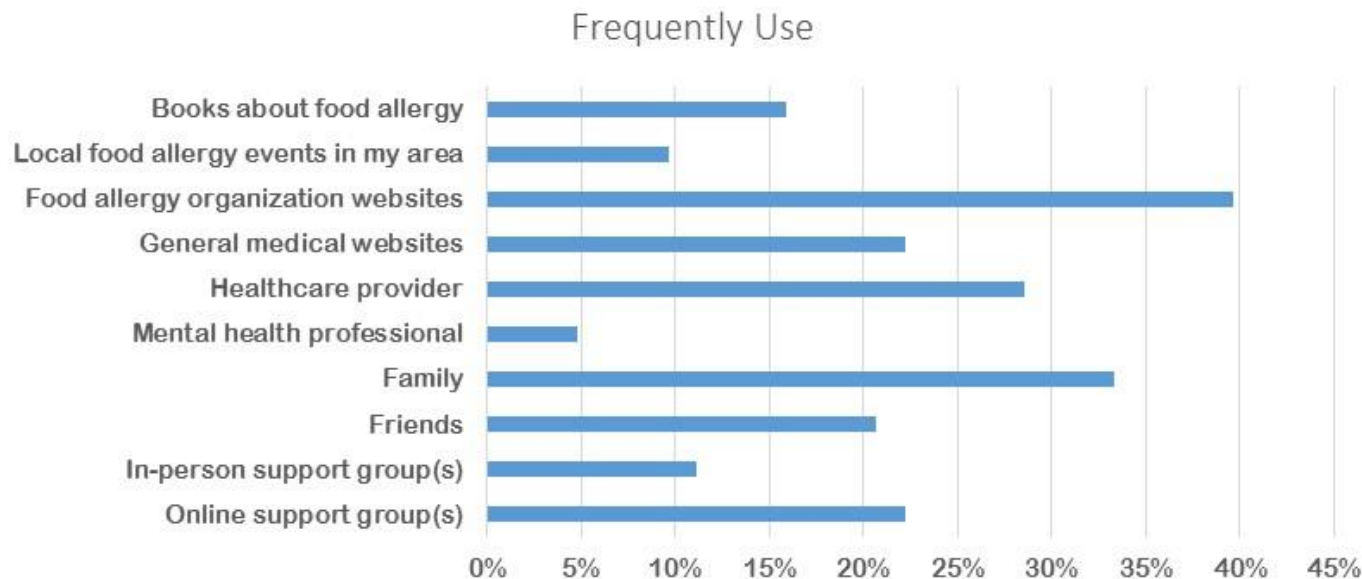
- Nationally and locally 1/3 of respondents reported that they were not provided adequate information at the time of the food allergy diagnosis.
- In Indianapolis, less than 40% of parents/individuals correctly indicated that Indiana has a law allowing public schools to stock undesignated epinephrine
- Only 11% were able to correctly note that the Indiana law requires schools to stock undesignated epinephrine
- And only 10% correctly indicated that Indiana has a law allowing public entities to stock undesignated epinephrine
- Indianapolis had the lowest awareness rate nationally for local clinical trials at 37%. But it is worth noting that 2016 marked the start of the first clinical trial in the area, which would explain this number.

Life with Food Allergies: Emergency Medicine

- In Indianapolis, about half the patient respondents indicated an experience with treatment in an emergency department
- About 2 in 10 did not believe the ED staff was knowledgeable about food allergies
- Three quarters of respondents agreed that the ED staff was knowledgeable about food allergies and knew that epinephrine was the first line of defense for anaphylaxis
- Only 2 in 10 respondents had an experience with care in an ambulance
- Of those, about a quarter agreed that the first responders were knowledgeable about food allergy and anaphylaxis treatments

Life with Food Allergies: Resources

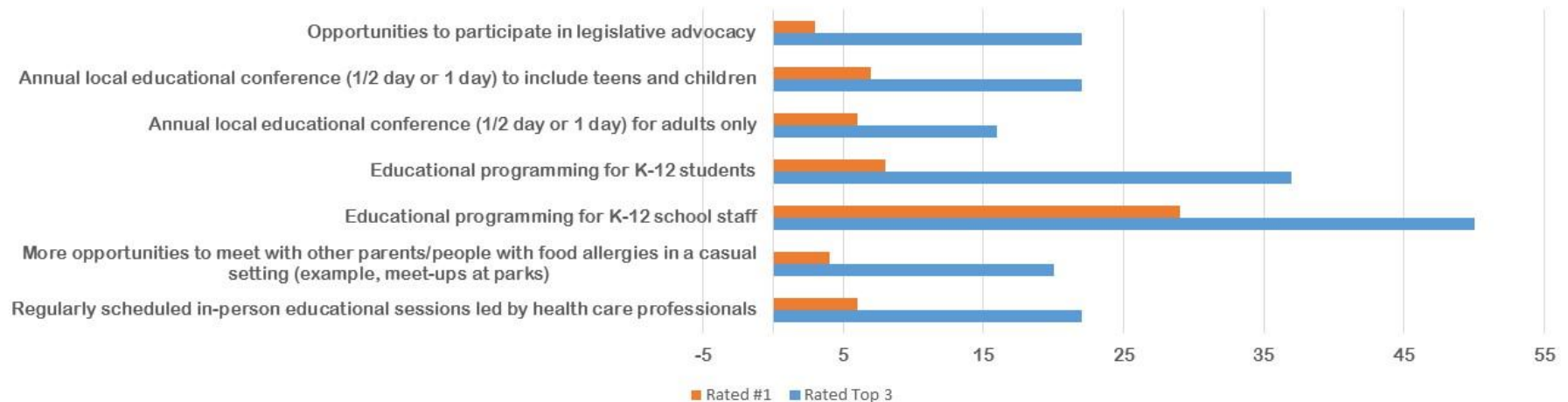
- When asked to identify the most frequently used resources for managing food allergies, food allergy organization web sites and family were most often cited



- Indianapolis over indexed for frequent use of in-person resources compared to the national aggregate of other responding cities: in-person support groups (11% vs. 3%), local food allergy events in the community (10% vs. 4%).

Life with Food Allergies: Solutions

Respondents were asked to rank 7 different food allergy resources based on the perceived value



- Educational programming for K-12 staff received 29 #1 rankings, representing nearly 50% of responses
- When looking at resources that received top 3 rankings, K-12 education remains the highest ranked, followed by education programming for K-12 students

Conclusions

- The FARE 'Community Needs Assessments' asked important questions to provide a look into the day to day life of food allergy.
- The results provide a starting point to establish programs to address identified needs and make life easier for those who have and for those who care for people with food allergy.
- While survey questions were asked about adults living with food allergies and their experiences in college and the workplace, there were not enough respondents to report out results.
- Additional work will need to be done to gain a better picture of their needs.