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## Rationale

- Food protein-induced enterocolitis syndrome (FPIES) is a non-IgE-mediated gastrointestinal food allergy.
- Little is known about demographics, food triggers and risk factors for FPIES.

## Methods

- We performed a retrospective analysis of surveys completed by members of the International FPIES Association (I-FPIES).
- The survey was administered to I-FPIES members both: (1) at the FPIES Education Conference for families of children with FPIES, held 8/4/2018 in Philadelphia, PA, and (2) available electronically on the I-FPIES website and on the organization's Facebook page to followers of I-FPIES 12/3/2018-1/7/2019.
- Families self-identified as having a child with FPIES.
- Not every question was answered by respondents so the total number of responses varies for each question.

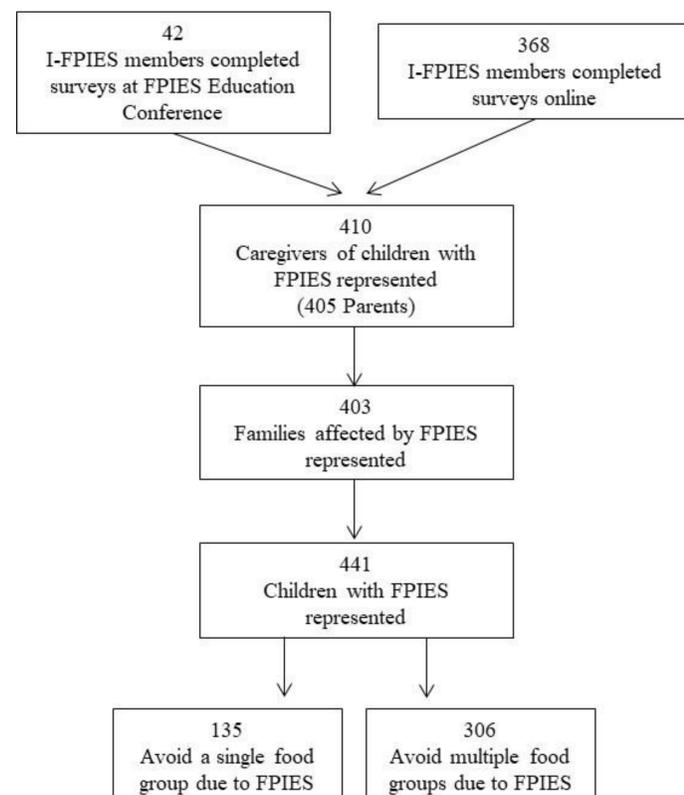


Figure 1. Overview of respondents and children represented.

## Results

Caregiver's age, median (range) (N=410)	35 yr, (20-62 yr)
Caregiver's relationship to child with FPIES (N=408)	% (N)
Mother	96.1% (392)
Father	3.2% (13)
Other	0.7% (3)
Caregiver's race (N=404)	
White	94.5% (382)
Hispanic	2.0% (8)
Asian	1.7% (7)
Native American	0.5% (2)
Native Hawaiian, Pacific Islander	0.5% (2)
Multi-race, non-Hispanic	0.5% (2)
African American	0.2% (1)
Child's age, median (IQR) (N=428)	2 yr, (1.25-4 yr)
Number of food groups avoided, median (range) (N=441)	3, (1-13)
Child's gender (N=274)	% (N)
Male	49.3% (135)
Female	50.7% (139)
Child's race (N=269)	
White	86.2% (232)
Other	5.2% (14)
Hispanic	3.7% (10)
Multi-race, non-Hispanic	2.6% (7)
Asian	0.7% (2)
Native American	0.7% (2)
African American	0.4% (1)
Native Hawaiian, Pacific Islander	0.4% (1)
Child's/children's school/daycare attendance (N=403)	
Attends	53.6% (216)
Does not attend*	46.4% (187)
Not attending due to concern for FPIES (N=184)	53.8% (99)

Table 1. Demographics of respondents. \*6 children  $\geq$  5 years old were not in school; 2/6 were not in school due to FPIES. IQR: Interquartile range.

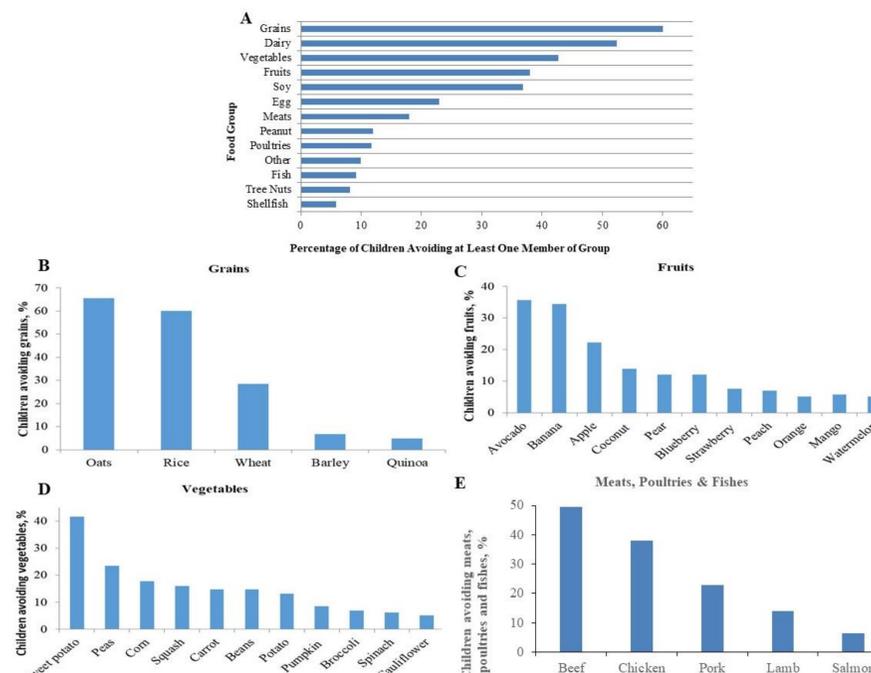


Figure 2. Food groups avoided due to FPIES. A. Percentage of children (N=441) avoiding individual food groups. B-E. Individual foods avoided within a group. Only foods avoided by  $>5\%$  within the food group are represented.

## Results, cont'd

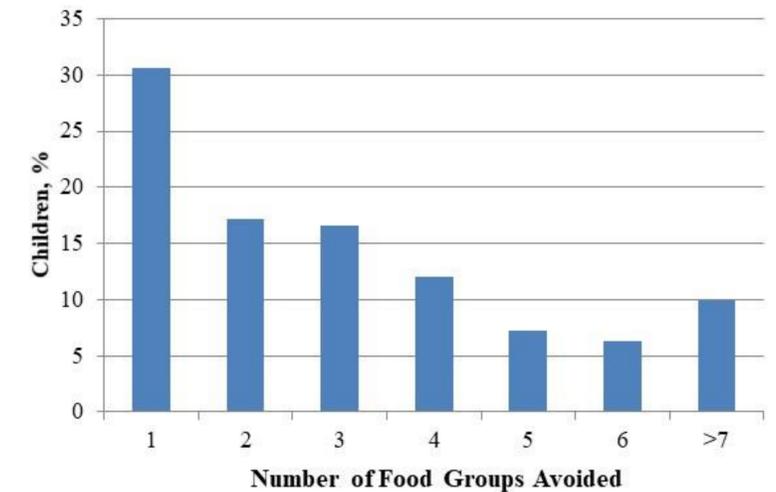


Figure 3. Number of food groups with at least one member avoided. Percentage of respondents (N=441 respondents) avoiding number of food groups. Food groups were defined as: cow's milk, soy, egg, peanut, tree nuts, fishes, shellfishes, poultries, meats, grains, vegetables, fruits and other.

	Child			Parent		
	Single food group avoided % (N)	Multiple food groups avoided % (N)	P-value	Single food group avoided % (N)	Multiple food groups avoided % (N)	P-value
Male child	46.7% (35/75)	48.7% (77/158)	0.768	--	--	--
White race	83.8% (67/80)	87.2% (156/179)	0.465	--	--	--
Any atopy	50.4% (62/123)	56.9% (152/267)	0.229	41.8% (56/134)	51.7% (156/302)	0.057
Allergic rhinoconjunctivitis	15.4% (19/123)	18.7% (50/267)	0.430	26.9% (36/134)	33.8% (102/302)	0.152
Asthma	12.2% (15/123)	15.0% (40/267)	0.463	20.9% (28/134)	24.2% (73/302)	0.454
Atopic dermatitis	27.6% (34/123)	37.0% (99/267)	0.068	10.4% (14/134)	17.5% (53/302)	0.058
IgE-mediated food allergy	22.8% (28/123)	26.6% (71/267)	0.420	7.5% (10/134)	11.3% (34/302)	0.225
Celiac disease	1.6% (2/123)	1.1% (3/267)	0.682	2.2% (3/134)	4.6% (14/302)	0.233
First-degree relative with FPIES	14.2% (19/134)	23.0% (69/300)	0.035	--	--	--

Table 2. Factors associated with avoiding multiple foods due to FPIES. Any atopy was defined as the presence of allergic rhinoconjunctivitis, asthma, atopic dermatitis or IgE-mediated food allergy.

## Conclusions

- Avoiding multiple food groups is common.
- Having a first-degree relative with FPIES is associated with the affected child avoiding multiple food groups.
- These insights may impact recommendations for food introduction.

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