the mature form has a molecular weight of $12 \mathrm{kDa} .{ }^{5,8,9}$ The 2 S albumin and a protein between 67 and 43 kDa have been identified as responsible for anaphylaxis after bread with roasted sunflower seeds ingestion. ${ }^{9}$ In our patient, although the clinical symptoms were similar, different molecular weight proteins were identified (mainly a $26-\mathrm{kDa}$ one), which were not previously described by Asero et al ${ }^{9}$ or by Kelly et al. ${ }^{8}$ Other studies ${ }^{10}$ suggested an LTP with a molecular weight 13 kDa as a potential sunflower seed allergen.

In conclusion, we present a case of anaphylaxis due to roasted sunflower seed ingestion with tolerance to raw sunflower seeds. Results from SBPCC and SDS-PAGE immunoblotting (IgE-binding bands of 26 kDa and 60,47 , and 40 kDa ) support these findings. It appears that it is the roasting process that induces the allergenic properties in some sunflower seeds proteins.

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# Parental and parent-perceived child interest in clinical trials for food allergen immunotherapy 

Food allergy (FA) affects an estimated $8 \%$ of children in the United States and is associated with negative psychosocial effects on children with FA and their caregivers, as well as substantial economic burden. ${ }^{1-3}$ No approved treatment for FA exists, but several experimental therapies are presently under investigation, including oral immunotherapy (OIT), sublingual immunotherapy (SLIT), and epicutaneous immunotherapy (EPIT). ${ }^{4}$ These therapies aim to desensitize patients through administration of gradually increasing doses of allergen, with goals ranging from protection against accidental ingestion to the development of sustained unresponsiveness with ad libitum allergen exposure. To facilitate the further development of these treatments, recruitment of participants for clinical trials is critical. Work in other fields has shown that the decision to enroll in clinical trials is influenced by many factors, including sociodemographics, cost, time, fear, and perceived benefits/risks of participation. ${ }^{5}$ However, little remains known about which factors influence the decisions of families with FA to participate in clinical trials for emerging FA immunotherapies.

FA patient advocacy and support organizations frequently support goals related to the advancement of disease treatment options, suggesting that this is a population from which clinical trial participants may frequently be recruited. Therefore, caregivers of children with FA were recruited from patient advocacy and support organizations (eg, Mothers of Children Having Allergies, Allergy and Asthma Network, Asthma and Allergy Foundation of America), and FA blogs (eg, Grateful Foodie) to characterize factors related to caregiver willingness to participate in clinical trials for FA immunotherapies. The survey tool was developed through a review of relevant literature and refined through cognitive interviews. The final survey captured information about FA type(s), reaction history and perceived severity, FA-related quality of life (FAQoL), and levels of caregiver

[^0]and caregiver-perceived child interest in enrolling in a hypothetical clinical trial for FA immunotherapy. The survey was distributed between February 1, 2016 and May 31, 2016. The study was deemed exempt by the Institutional Review Board of Northwestern University.

Frequency analysis was used to describe baseline sample demographics, the child's FA characteristics, caregiver attitudes and preferences, and caregiver and child interest regarding immunotherapy clinical trials. Unadjusted associations between caregiver, and caregiver-perceived child willingness to participate in a clinical trial were tested using $\chi^{2}$ tests, odds ratios, and $t$ tests. Adjusted associations were examined using multiple logistic regression models adjusting for participant clustering within families. Statistical analyses were conducted using Stata v14.0 (StataCorp, College Station, TX).

The final study sample consisted of 369 caregivers reporting on 420 children. The majority of children were white (92.6\%) and most respondents were female caregivers ( $96.2 \%$ ) (eTable 1). The majority ( $62.1 \%$ ) of children had at least 1 allergic reaction perceived as "severe or potentially life-threatening" in their lifetime, but only $22.1 \%$ had experienced 1 or more severe reactions in the past year. Peanut ( $74.3 \%$ ), tree nuts ( $64.5 \%$ ), and egg (39.0\%) were the most frequently reported food allergens.

Over two thirds (67.4\%) of caregivers felt that their child's FA affected their own daily lives very much/extremely, but nearly half (49.5\%) thought their child's life was very much/extremely affected (eTable 1). About two thirds (66.0\%) were themselves very much/ extremely fearful of their child having an allergic reaction, but only $28.6 \%$ reported that their child was very much/extremely fearful.

Roughly half (53.3\%) of caregivers reported that they would be willing to enroll their child in a clinical trial, whereas $38.3 \%$ reported that they may be willing to enroll their child and $8.3 \%$ indicated that they would not enroll their child. The majority also felt that their child would want (25.7\%) or may want (44.1\%) to participate in a trial. Of caregivers who indicated their child might want to participate, more than three fourths ( $76.2 \%$ ) felt that fear would

Table 1
Clinical Trial Interest in Relation to Child $(\mathrm{N}=420)$ and Caregiver $(\mathrm{N}=369)$ Characteristics

| Characteristic | Interested in clinical trial, n (\%) |  |  |
| :---: | :---: | :---: | :---: |
|  | Yes | Maybe | No |
| Child's age (years) |  |  |  |
| 0-4 | 73 (61.3) | 41 (34.5) | 5 (4.2) |
| 5-8 | 71 (51.1) | 58 (41.7) | 10 (7.2) |
| 9-12 | 52 (52.5) | 40 (40.4) | 7 (7.1) |
| $13+$ | 28 (44.4) | 22 (34.9) | 13 (20.6) |
| Child's gender |  |  |  |
| Female | 75 (49.3) | 62 (40.8) | 15 (9.9) |
| Male | 148 (55.9) | 99 (37.4) | 18 (6.8) |
| Other/not specified | 1 (33.3) | 0 (0) | 2 (66.7) |
| Child's race/ethnicity |  |  |  |
| Caucasian/white | 210 (54.0) | 148 (38.1) | 31 (8.0) |
| Asian | 23 (62.2) | 11 (29.7) | 3 (8.1) |
| African American/black | 7 (58.3) | 3 (25.0) | 2 (16.7) |
| Hispanic/Latino | 9 (34.6) | 11 (42.3) | 6 (23.1) |
| Other | 9 (47.4) | 8 (42.1) | 2 (10.5) |
| Caregiver income |  |  |  |
| <\$50,000 | 4 (26.7) | 10 (66.7) | 1 (6.7) |
| \$50,000-\$74,000 | 22 (51.2) | 18 (41.9) | 3 (7.0) |
| \$75,000-\$99,000 | 27 (55.1) | 19 (38.8) | 3 (6.1) |
| >\$100,000 | 158 (56.0) | 101 (35.8) | 23 (8.2) |
| Caregiver education |  |  |  |
| High school/some college | 12 (36.4) | 19 (57.6) | 2 (6.0) |
| College degree | 95 (51.1) | 71 (38.2) | 20 (10.8) |
| Advanced degree | 114 (58.2) | 70 (35.7) | 12 (6.1) |
| Not specified | 3 (60.0) | 1 (20.0) | 1 (20.0) |
| Region |  |  |  |
| New England (CT, MA, ME, NH, NJ, RI, VT) | 15 (45.5) | 18 (54.6) | 0 (0) |
| New York, Pennsylvania, Delaware | 26 (59.1) | 18 (40.9) | 0 (0) |
| Mid-Atlantic (DC, MD, NC, SC, VA, WV) | 8 (36.4) | 12 (54.6) | 2 (9.1) |
| Southeast (AL, FL, GA, MS, TN) | 12 (54.6) | 6 (27.3) | 4 (18.2) |
| Indiana, Kentucky, Michigan, Ohio | 21 (58.3) | 13 (36.1) | 2 (5.6) |
| Great Plains (IA, MN, MT, ND, SD, WI) | 18 (51.4) | 14 (40.0) | 3 (8.6) |
| Illinois, Kansas, Missouri, Nebraska | 60 (55.6) | 38 (35.2) | 10 (9.3) |
| Arkansas, Louisiana, Oklahoma, Texas | 8 (42.1) | 11 (58.9) | 0 (0) |
| Mountain West (AZ, CO, ID, NM, NV, UT, WY) | 16 (45.7) | 13 (37.1) | 6 (17.1) |
| Pacific Coast (AK, CA, HI, OR, WA) | 28 (51.9) | 19 (35.2) | 7 (13.0) |
| Allergen |  |  |  |
| Peanut | 174 (55.8) | 119 (38.1) | 19 (6.1) |
| Tree nuts | 143 (52.8) | 107 (39.5) | 21 (7.8) |
| Egg | 85 (51.8) | 67 (40.9) | 12 (7.3) |
| Baked egg | 46 (52.3) | 35 (39.8) | 7 (8.0) |
| Milk | 66 (50.4) | 56 (42.8) | 9 (6.9) |
| Baked milk | 29 (39.7) | 38 (52.1) | 6 (8.2) |
| Shellfish | 25 (39.1) | 34 (53.1) | 5 (7.8) |
| Soy | 29 (52.7) | 21 (38.2) | 5 (9.1) |
| Wheat | 18 (36.7) | 26 (53.1) | 5 (10.2) |
| Fin fish | 17 (40.5) | 23 (54.8) | 2 (4.8) |
| Other | 84 (49.7) | 69 (40.8) | 16 (9.5) |
| Unknown | 5 (55.6) | 3 (33.3) | 1 (11.11) |
| Allergen causing severe reaction |  |  |  |
| Milk | 32 (45.1) | 32 (45.1) | 7 (9.9) |
| Peanut | 70 (58.3) | 45 (37.5) | 5 (4.2) |
| Wheat | 7 (33.3) | 12 (57.1) | 2 (9.5) |
| Egg | 29 (43.9) | 30 (45.5) | 7 (10.6) |
| Shellfish | 3 (37.5) | 5 (62.5) | 0 |
| Tree nut | 37 (46.3) | 29 (36.3) | 14 (17.5) |
| Fin fish | 3 (23.1) | 8 (61.5) | 2 (15.4) |
| Other | 28 (50.9) | 21 (38.2) | 6 (10.9) |
| Soy | 1 (20.0) | 3 (60.0) | 1 (20.0) |
| Unknown | 16 (55.2) | 13 (44.8) | 0 |
| Comorbidities |  |  |  |
| Asthma | 101 (50.3) | 86 (42.8) | 14 (7.0) |
| Eczema | 120 (51.7) | 96 (41.4) | 16 (6.9) |
| Seasonal allergy | 133 (53.0) | 98 (39.0) | 20 (8.0) |
| Indoor allergy | 63 (52.1) | 49 (40.5) | 9 (7.4) |
| Pet allergy | 106 (49.8) | 88 (41.3) | 19 (8.9) |
| Insect allergy | 8 (38.1) | 11 (52.4) | 2 (9.5) |
| Medication allergy | 24 (45.3) | 22 (41.5) | 7 (13.1) |
| None | 21 (60.0) | 12 (34.3) | 2 (5.7) |
| Other | 9 (45.0) | 9 (45.0) | 2 (10.0) |
|  |  | (continued on next column) |  |

Table 1 (continued)

| Characteristic | Interested in clinical trial, n (\%) |  |  |
| :---: | :---: | :---: | :---: |
|  | Yes | Maybe | No |
| Number of reactions in lifetime |  |  |  |
| 0 | 0 | 0 | 0 |
| 1-5 | 124 (54.2) | 86 (37.6) | 19 (8.3) |
| 6-10 | 44 (55.0) | 27 (33.8) | 9 (11.3) |
| 11-15 | 15 (53.6) | 12 (42.9) | 1 (3.6) |
| 16 + | 28 (47.5) | 26 (44.1) | 5 (8.5) |
| Cannot recall | 13 (54.2) | 10 (42.7) | 1 (4.2) |
| Number of reactions perceived as severe/life-threatening in lifetime |  |  |  |
| 0 | 66 (60.6) | 35 (32.1) | 8 (7.3) |
| 1-5 | 136 (52.1) | 103 (39.5) | 22 (8.4) |
| 6-10 | 21 (48.8) | 17 (39.5) | 5 (11.6) |
| $11+$ | 1 (14.3) | 6 (85.7) | 0 (0) |
| Number of reactions in the past year |  |  |  |
| 0 | 1 (100.0) | 0 (0) | 0 (0) |
| 1-5 | 200 (53.2) | 144 (38.3) | 32 (8.5) |
| 6-10 | 9 (60.0) | 4 (26.7) | 2 (13.3) |
| 11-15 | 5 (50.0) | 5 (50.0) | 0 (0) |
| 16 + | 8 (66.7) | 4 (33.3) | 0 (0) |
| Cannot recall | 1 (16.7) | 4 (66.7) | 1 (16.7) |
| Number of reactions perceived as severe/life-threatening in past year |  |  |  |
| 0 | 172 (52.6) | 128 (39.1) | 27 (8.3) |
| 1-5 | 50 (56.2) | 31 (34.8) | 8 (9.0) |
| 6-10 | 2 (100.0) | 0 (0) | 0 (0) |
| $11+$ | 0 (0) | 2 (100.0) | 0 (0) |
| Food allergy-related quality of life |  |  |  |
| How much does your child's food allergy affect YOUR daily life? |  |  |  |
| Not at all-moderately | 76 (55.5) | 43 (31.4) | 18 (13.1) |
| Very much-extremely | 148 (52.3) | 118 (41.7) | 17 (6.0) |
| How much does your child's food allergy affect HIS or HER daily life? |  |  |  |
| Not at all-moderately | 116 (54.7) | 71 (33.5) | 25 (11.8) |
| Very much-extremely | 108 (51.9) | 90 (43.3) | 110 (4.8) |
| How fearful are YOU of your child having an allergic reaction? |  |  |  |
| Not at all-moderately | 75 (52.5) | 51 (35.7) | 17 (11.9) |
| Very much-extremely | 149 (53.8) | 110 (39.7) | 18 (6.5) |
| How fearful is your CHILD of having an allergic reaction? |  |  |  |
| Not at all-moderately | 156 (54.4) | 110 (38.3) | 21 (7.3) |
| Very much-extremely | 56 (48.7) | 46 (40.0) | 13 (11.3) |

be a reason for their child's hesitation, whereas $30.3 \%$ felt that time constraints were a factor.

Although a high rate of willingness ("Yes" or "Maybe") was observed across all age groups, caregivers of children 0 to 4 years of age ( $61.3 \%$ of whom responded "Yes") were the most willing, and caregivers of children at least 13 years of age ( $20.6 \%$ of whom responded "Yes") were least willing (Table 1). Caregivers of children allergic to peanut ( $55.8 \%$ of whom responded "Yes"), tree nuts (52.8\%), soy (52.7\%), baked egg (52.3\%), egg (51.8\%), and milk (50.4\%) more often than not indicated that they would be willing to participate in a trial. Among children with reported asthma, nearly all caregivers responded they would or would maybe participate in a trial. The number of food allergens reported, the number of reactions experienced and the perceived severity of those reactions were not associated with willingness to participate in a trial. Quality of life also did not appear to influence caregiver willingness to enroll their child in a trial.

For all allergens, the majority of caregivers ( $55.6 \%$ to $86.4 \%$ ) reported their therapy goal would be for their child to be able to eat their allergen freely (eTable 2). However, a substantial proportion of caregivers of children allergic to peanut (27.8\%), tree nuts ( $22.6 \%$ ), and shellfish (29.1\%) indicated that their desired outcome would be protection against accidental ingestion. Half (50.3\%) of caregivers

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