



Community opinions regarding oral immunotherapy for food allergies

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ABSTRACT

Background: Food oral immunotherapy (OIT) is a promising but still investigational new therapy for food allergy.

Objective: We sought to investigate beliefs and opinions among OIT participants and nonparticipants to better understand community awareness of this therapy.

Methods: A 30-question on-line survey was administered to members, website visitors, and social media followers of the Kids with Food Allergy Foundation. Questions inquired about general knowledge and attitudes about OIT, its reported safety and efficacy, complications, insurance coverage, and its Food and Drug Administration (FDA) approval status.

Results: Among 1,274 survey respondents, 15.9% had discussed OIT as a treatment option with their allergy provider. Five percent ($n = 64$) of respondents reported that their child was currently participating in OIT, including 73.4% ($n = 47$) in a private practice setting. Participants reported varying degrees of being informed about OIT safety (85%), efficacy (46.4% told unrestricted ingestion), risks (relapse 53.4%, eosinophilic esophagitis 3.5%, oral allergy syndrome 10.7%, and failure 56.9%). Significantly fewer participants than nonparticipants agreed that OIT's present safety, efficacy, risks, and approval status would dissuade participation. Significantly fewer participants agreed that OIT should not be offered outside the research setting without definitive proof of both its safety and efficacy.

Conclusion: In this exploratory study, differences in beliefs and opinions existed between OIT participants and nonparticipants. Among participants, there were also significant differences in beliefs among academic versus nonacademic participants. Accurate and complete information about OIT safety, efficacy, risks, and approval status was not universally conveyed.

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Introduction

Food allergy is an important public health problem affecting between 4 and 8% of the pediatric population, with dramatic effects on quality of life.^{1–4} Current management strategies include only avoidance, because no treatment is available. Multiple treatment strategies are under investigation, including oral immunotherapy (OIT), however.⁵ Food OIT has been under investigation for the past few years in the United States and internationally, and though preliminary results are promising, many unknowns exist pertaining to the long-term safety, feasibility, cost efficiency, and overall efficacy of food OIT.^{6–19}

Though food OIT is an investigational therapy, preliminary trial results have received significant mainstream media attention. Some of the most prominent researchers in this area, however, have highlighted the unresolved issues regarding safety and efficacy and have made the case that food OIT is an investigational therapy not yet ready for widespread clinical use until it is better studied.^{5,6,20} Despite such concerns, practices in several regions of the United States currently offer and market OIT outside the research setting, as an available treatment for food allergy. Parental awareness of OIT, attitudes toward OIT, and potential motivating beliefs regarding participation in OIT have not been well studied among the general food allergic community.^{6,21,22} One previous study of early participants in a National Institutes of Health–sponsored academic center found that parents who had higher anxiety about negative outcomes from accidental ingestion were more likely to consent to experimental therapy for their child.²¹ We therefore designed this study to explore and compare attitudes and beliefs about OIT among reported participants and nonparticipants from a population selected from a large food allergy support and advocacy organization.

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Methods

A 30-question on-line survey was distributed using Survey Monkey (Portland, Oregon) to a convenience sample of members and visitors of Kids With Food Allergies Foundation (KFA), a national nonprofit food allergy education and support organization, via a direct link on the KFA website for both visitors and members, through email to KFA members, and distributed by KFA through their social media outlets (Facebook/Twitter). KFA is a national, tax-exempt nonprofit food allergy education and support organization with over 22,000 members across all 50 states. Their primary mission is to “improve the day-to-day lives of families raising children with food allergies and empower them to create a safe and healthy future for their children.” KFA’s programs help children with food allergies and their families cope with dietary restrictions, lifestyle adjustments, fear, and isolation through education, peer support, food/cooking assistance, and outreach programs. Access to the study did not require membership in KFA and was freely available on their website. Electronic informed consent was obtained, and the study was approved by the University of Michigan Medical School Institutional Review Board. Questions were formulated by the investigators from published data of OIT studies and editorial commentary about OIT. Ten members of the KFA Medical Advisory Team as well as a small pilot group of 15 KFA member volunteers assessed the survey instrument for face and content validity. Items specifically inquired about general knowledge and attitudes about OIT, its reported safety and efficacy, complications, insurance coverage, and its FDA approval status. Specific background demographic information was deliberately not obtained, given the study was exploratory in nature and at this stage was singularly focused on identifying a general level of perception of the therapy and the extent of participation outside of an academic center. We did not inquire or attempt to stratify the population based on participation in any particular food OIT, given a low overall number of known centers using OIT at present. This study was therefore only designed to investigate at the level of general participation in any protocol. Data were analyzed using Stata IC, version 12 (Stata Corp, College Park, Texas), comparing response proportions via chi-square or Fisher exact test where appropriate.

Results

Among 1,274 survey respondents, 89.9% were aware of OIT as a potential therapy, and 15.9% had discussed OIT as a treatment option with their allergy provider. Respondents reported gaining awareness of OIT from a variety of sources, including print and online news sources or radio (42.3% cumulatively), online food allergy support groups (17.1%), physicians (13.4%), other families affected by food allergy (13%), television (10.4%), and social media (3.7%). Of those that heard about OIT from a physician, 70% were informed by an allergist in private practice, 23% from an allergist practicing in an academic setting, and the remainder from a nonallergist physician. Tables 1 and 2 further detail additional frequency analysis of this population, stratified by participation in OIT.

A total of 5% ($n = 64$) of respondents reported that their child was currently participating in OIT, and among these individuals, 84.7% reported that OIT was an available service offered at their

Table 2

Beliefs regarding food oral immunotherapy among therapy participants and nonparticipants

Agreement with statement/belief	Participants ($n = 1,440$)*	Nonparticipants ($n = 57$)*	P
OIT must be proven effective before it is offered as a therapy	17.8%	56.4%	<.001
OIT must be proven safe before it is offered as a therapy	31.6%	70.8%	<.001
Any type of allergy provider should be able to offer OIT as a therapy	57.9%	32.6%	<.001
I trust my allergist would not prematurely offer OIT as a therapy	60.7%	80.4%	.001
Only food allergy “specialists” should be able to offer OIT	51.8%	56.1%	NS
Only academic practices should be able to offer OIT as a therapy	12.5%	14.1%	NS
Insurances should not reimburse for OIT before it has been proven safe	28.5%	25.4%	NS
Insurances should not reimburse for OIT before it has been proven effective	17.2%	17.5%	NS

*69 nonparticipants and 8 participants did not respond to this section of the survey.

allergist’s office. Of these 64 individuals, 73.4% ($n = 47$) reported receiving OIT in a nonacademic setting. Among all participants in OIT, 31.9% reported that they were informed OIT was not an FDA-approved treatment and was still investigational, and 39% reported that they were advised to potentially expect to develop allergic reactions of varying severity. Participants reported they were counseled on specific risks of OIT reported in the literature, including reactions with home dosing (85%), relapse of their allergy (53.4%), failure (56.9%), development of eosinophilic esophagitis (3.5%), and oral allergy syndrome (10.7%). Significantly fewer participants in nonacademic settings, compared with academic settings, reported having received counseling on the potential for allergy relapse ($P = .006$), treatment failure ($P = .001$), or the safety of the treatment ($P = .037$). Figure 1 details the specific outcomes of OIT discussed with participants, stratified by practice setting.

Significant differences in beliefs and attitudes about OIT were found among reported OIT participants vs reported nonparticipants. No significant differences were seen in the proportion of participants compared with nonparticipants who reported agreement that OIT should only be offered by someone with specific expertise in food allergy; should only be offered at an academic center; or that insurance should not provide reimbursement for OIT until the therapy is proven safe or effective (respectively).

Table 3 further explores the beliefs and attitudes among participants, stratified by the type of practice setting. No significant difference was found in the proportion of academic or nonacademic participants who agreed that they trusted that their allergy provider would not prematurely offer OIT as a therapy before it was proven safe, effective, and approved by the FDA. Unanimous agreement was seen among both academic and nonacademic participants that the provider prescribing OIT was obligated to discuss the risks and benefits of OIT, as well as was obligated to disclose the FDA approval status of OIT. Table 4 compares reported information sources regarding OIT, as stratified by type of practice setting.

Discussion

OIT is still in the early stages of investigation. Limited published data are available pertaining to the short-term (1 year) safety and efficacy of OIT from a handful of studies, but the long-term outcomes are still under evaluation.^{7,9,12,14,19} Whether food OIT will be able to only provide desensitization, as has been shown for many participants in several of the trials, or can produce a more lasting or permanent tolerance, which has yet to be demonstrated, remains

Table 1
Trends regarding information sources about OIT among survey respondents

Trend	N (1,274)	Percent
Aware of OIT as a therapy	1146	89.9
Another family discussed OIT with me	523	41.1
I know another family enrolled in OIT	186	14.6
My allergist discussed OIT with me	457	35.9
Heard about OIT from a food allergy support group	577	45.3
Heard about OIT from the internet	705	55.3

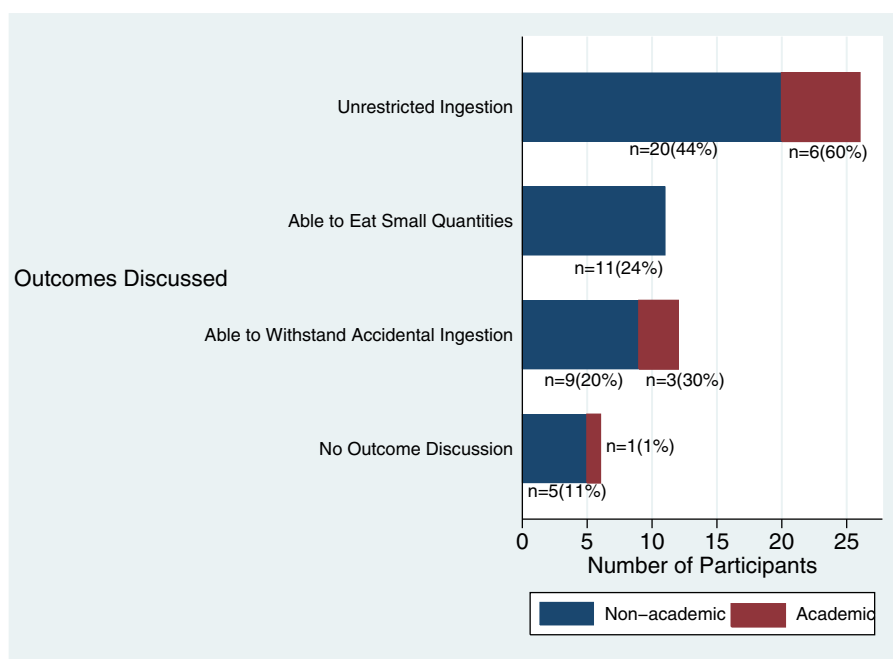


Figure 1. OIT outcomes discussed with participating patients, stratified by type of practice setting offering OIT. Stacked graphical representation of key outcomes of OIT discussed with participants before initiating therapy, stratified by practice setting (nonacademic in blue, academic in red).

unknown. Little information is known about the attributes, core beliefs, opinions, and understanding of the immunotherapy process, risks, and expected outcomes among OIT participants and nonparticipants regarding the therapy, and this study sought to address some of these issues.^{7,9,12,14,21}

We noted several differences in beliefs and attitudes between OIT participants and nonparticipants. In particular, compared with nonparticipants, OIT participants reported less concern about the therapy having proven safety or proven efficacy, or about the therapy being approved for use by the FDA, especially among those participating in nonacademic settings. Compared with academic participants, nonacademic participants' practices were significantly less likely to have reported having discussed specific risks of the therapy, such as allergy relapse, treatment failure, and overall procedure safety, which is concerning. Although determining the extent to which recall bias may have played a role in explaining these differences, or how actively these parents sought to obtain such information, is difficult, no differences were seen in the por-

portion of participants reporting discussion of other key factors pertaining to OIT, such as development of eosinophilic esophagitis, potential of home reactions, FDA approval status, insurance reimbursement, or development of oral allergy syndrome. Thus, these differences may truly be from lack of discussion. All participants, regardless of venue in which they were receiving OIT, unanimously agreed that the prescribing physician is obligated to disclose the therapy's risk and FDA approval status, and there was no significant difference in the proportion of academic vs nonacademic participants who reported that they trusted that their physician would not prematurely offer this therapy before it had been proven safe and effective.

Examining sources about how participating families learned about OIT revealed some informative trends. Academic participants were significantly more likely to have reported hearing about OIT from the internet and from another participating family (respectively) than nonacademic participants. The specific website(s) used to obtain this information were not further probed, but presumably may include www.clinicaltrials.gov, where the trials are registered, and possibly the websites of the advocacy groups, who have advertised the trials, and their sponsorship of some of these trials. Neither group was more likely to have reported actually knowing another family that was participating in OIT (as opposed to having just discussed the general experience with another family). The specific role of information bias was not explored in this

Table 3
Differences in agreement with beliefs between OIT participants in academic settings vs nonacademic settings

Agreement with statement/belief	Academic (n = 11)*	Nonacademic (n = 46)*	P
OIT must be proven effective before it is offered as a therapy	54.5%	10.8%	.004
OIT must be proven safe before it is offered as a therapy	81.8%	21.3%	<.001
I trust my allergist would not prematurely offer OIT as a therapy	72.7%	56.5%	NS
Any type of allergy provider should be able to offer OIT	27.3%	63.8%	.042
My provider is obligated to discuss the risks of OIT	100%	100%	NS
My provider is obligated to discuss the FDA approval status of OIT	100%	100%	NS
Only academic practices should be able to offer OIT as a therapy	54.5%	2.17%	<.001

*8 participants did not provide responses for this section.

Table 4
Comparison of participants' information sources regarding OIT

Source of information	Academic (n = 16)	Nonacademic (n = 42)	P
Heard about OIT from my allergist	81.8	93.2	NS
Heard about OIT from the internet	90.9	54.5	.036
Heard about OIT from another family	63.6	66.7	NS
Heard about OIT from my primary care physician	13.8	10	NS
Know another family participating in OIT	81.8	80.8	NS
Another family discussed their experience with OIT	100	65.9	.025

study, but this may be a future area in need of investigation, to determine how the influence of the information source and specific framing of the information regarding OIT may influence the propensity for someone to elect to participate in the therapy.

Importantly, this study did not attempt to characterize the physicians or practices that offer this therapy, nor did it explore to what extent patients or families enrolling in the therapy actually sought to determine approval status, safety, and efficacy. Both of these omitted variables may be mediating or moderating factors that may influence the propensity to participate, and they merit further detailed study but were not explored because the team did not have *a priori* assumptions regarding their potential roles. Specific future investigation should include exploration of motivating factors that influence patient participation or dropout or refusal to enter a trial, the role of informed consent, attitudes toward off-label use of therapy, the role of self-referral for the therapy vs directed referral by a health care provider, and the role of baseline quality of life as a motivating factor in seeking this type of therapy.

OIT is perceived to have great appeal to those significantly affected by food allergies, including both patients and providers.¹⁵ The lay media, patients, and food allergy advocacy groups have helped publicize the results of the early studies. Two major US advocacy groups have directly sponsored some of the research and have advertised links to the clinical trials for potentially interested participants.^{23–28} The National Institute of Allergy and Infectious Diseases (NIAID) is the main sponsor of the ongoing trials.²⁹ The NIAID-sponsored consortium has been public about their cautious optimism of the early trial results, as detailed in an editorial explaining several gaps in knowledge based on the ongoing clinical trials, highlighting limitations in patient selection, few numbers of randomized controlled trials, and still unknown outcomes as reasons in particular for why OIT is not ready for application in the community.⁶

Alternatively, OIT is offered by a growing number of private practices both within and outside of a clinical research setting.^{30–35} Several practice groups have been vocal advocates for the therapy in the practice setting and have presented research at the past few American Academy of Allergy, Asthma & Immunology and American College of Allergy, Asthma and Immunology meetings detailing their experiences, including evidence that quality of life among participants has been improved (similar evidence is emerging from the academic sites as well).^{33–35} Furthermore, clearly physicians are no longer the sole source of information regarding medical therapies, and this influence requires further study. The effect of the type of information source could have significant impact in influencing a family's desire to participate in more higher-risk/higher-reward therapies such as OIT. It is hard to estimate exactly how many practices across the country currently offer this service. Moreover, an equally unknown number of otolaryngology practices have been offering sublingual food therapy as yet another alternative means to seek food-specific therapy. In this study we did not capture any participants that specifically identified their provider as an otolaryngologist.

Given the different settings and conditions under which OIT is available, our rationale for this study was to investigate knowledge and attitudes about OIT within a population of a large national food allergy support organization, which we *a priori* assumed would be familiar with OIT. We believe that members of an advocacy group or viewers of their content represent a realistic population of individuals who are highly likely to represent potential OIT participants. However, our subject pool for this study likely is not representative of the typical food-allergic individual across the United States, nor was it intended to serve as such. This population was chosen as a convenience sample for initial large-scale exploration into potentially important attitudes and beliefs about the therapy.

This study was exploratory, hypothesis generating, and designed to determine only a general level of understanding about the therapy as a basis for a more comprehensive future study. Several methodologic limitations are present. This study was deliberately not designed to imply causal inference into specific motivation factors associated with participation, understand how sociodemographic or allergen-specific factors (including food item, child age, duration of diagnosis, and underlying severity of reaction) influence participation, explore the differences in propensity to participate in the therapy, or explore the propensity to participate in a research at an academic center as compared with participating in a nonacademic setting. The influence of membership or viewership of an advocacy group website also was not explored, nor was the baseline quality of life of these individuals. These key factors should be a part of any future study of patient attributes that influence OIT participation, as predictor variables. Motivations and characteristics of the physician offering therapy were not explored in this study, nor was the motivation of the parent to either enroll their child or the extent to which a parent sought information regarding their therapeutic options or specifics of the therapy. Other important limitations include the use of self-reported data (specifically self-identification of food allergy status), recall bias, the use of a convenience sample from an advocacy group, and the small sample size of participants. We do believe it is generally accurate to assume that only a small number of the overall population of food-allergic individuals participate in OIT, but again, this study was not intended to define such a population or its attributes.

We acknowledge these factors as potential confounders requiring further exploration, specifically to determine whether the model of influence that we present is more representative of factors most attributable to the family or the provider. In the pilot stage, we determined that investigating these (and other) factors without some evidence that trends of interest may exist was less appropriate, and that it was financially infeasible to design a large-scale representative survey of food-allergic individuals without some preliminary proof of concept. We acknowledge that these are all crucial future areas of influence to explore, but we believe that our information is of present value, given a paucity of information about participants in OIT, so that others with an interest in better understanding OIT participation can build off of any emerging hypotheses.

The data identify several areas of potential interest for how information about an experimental therapy, including its safety, efficacy, and approval status, are presented as well as how they are interpreted by individuals who may be quite willing to forgo risks given a disease with little hope for resolution. The potentially moderating effects of the type of practice/physician offering OIT and the effect of the influence of advocacy group membership on emerging therapeutics are of particular interest for future exploration. Importantly, this study did not intend to assess appropriateness of the practice of OIT in either the academic or nonacademic setting, but rather to assess overall what issues may be of more or less importance to participants in an emerging therapy, and to stratify the responses by the type of practice setting to compare and contrast the experiences. No significant differences were noted in the proportion of overall participants compared with nonparticipants who agreed that only food allergy specialists or academic centers should offer OIT. Understanding what the patients desire for the type of provider and setting in which the therapy is administered (or lack of preference) should be an important focus, given that currently no barriers prevent any willing allergist from initiating an oral immunotherapy program, and that, if the therapy is offered, patients will seek out such practices.

We present exploratory data, identifying some key early patient trends that might be used to initiate more detailed study into patient perspectives of oral immunotherapy. Future study should

continue to specifically explore the roles of how information about OIT is disseminated, how physicians frame discussions about this therapy, and to explore, through qualitative study, specific motivations for patient participation in OIT as well as attributes of providers (and their motivations) for offering OIT at present.

Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.anai.2012.08.012>.

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1. Introduction

We are interested in surveying your opinions on a series of statements about oral food immunotherapy, otherwise known as food allergen desensitization. We kindly ask that you select the choice that you think best answers the question asked, or reflects your agreement or disagreement with each statement. We thank you in advance for your participation. This survey should take approximately 15 minutes to complete.

The information obtained from this survey will be anonymous and stored in a secure location. Your identity will not be linked to your responses. Your participation in this survey is completely voluntary. We do not anticipate that your participation in this survey would result in any risk to you. This study is survey based and does not involve any physical contact with you.

The next section will give you the opportunity to elect to participate in this survey. We thank you in advance if you do indeed choose to participate.

1. The following are a series of questions and statements pertaining to oral food immunotherapy. These statements ask you to either choose the best answer possible, or rate your agreement or disagreement with the statement on a 3 point scale. We do not ask for any personal information that would in any way identify you, or any family member. Participation in this study is completely voluntary. Data collected will be analyzed to determine general allergy perceptions of this therapy, to help us better serve everyone's needs in the allergy community. This information will be kept in a secure location, under electronic encryption. We intend to publish the results in the medical literature. This survey is being conducted as a research partnership between Kids With Food Allergies, The University of Michigan Medical School, Division of Allergy and Clinical Immunology; and Children's Hospital of Pittsburgh of University of Pittsburgh Medical Center, Division of Pulmonary Medicine, Allergy & Immunology.

Please read the following statement carefully, and answer the question below.

I hereby consent to participate in this study titled Community Perceptions and Beliefs about Food Oral Immunotherapy. I understand that information obtained in this survey will potentially contribute to a future publication in the medical literature. The study authors will keep any data collected under electronic encryption and password protection, and are not collecting any information that can be used to identify any individual participant.

- ☐ Yes, I consent to participate in this study
- ☐ No, I do not consent to participate in this study

2.

The following are a series of statements. Please rate your level of agreement with each statement, or in some instances, select the choice which most accurately answers the question.

1. Have you heard of oral immunotherapy (food desensitization)?

☐ Yes

☐ No

1. From whom or from what source did you hear about food oral immunotherapy (food allergy desensitization)?

	Yes	No
Allergist or physician who manages my food allergy (or my family member's food allergy)	☐	☐
Primary care physician	☐	☐
Other families affected by food allergy	☐	☐
Newspaper	☐	☐
On-line news source (e.g. Yahoo, CNN, etc.)	☐	☐
Television story	☐	☐
Magazine	☐	☐
On-line support group/advocacy group	☐	☐
Twitter/Facebook/MySpace	☐	☐
Radio	☐	☐

2. Have other food allergic parents or families discussed oral immunotherapy (food desensitization) with you?

- ☐ Yes
- ☐ No

3. Do you know any families with a child or other family member who is currently participating in a oral immunotherapy (food desensitization) program?

- ☐ Yes
- ☐ No
- ☐ I do not know

4. Has your allergist (or your physician who manages your or your child's food allergy) ever discussed oral immunotherapy (food desensitization) with you?

- ☐ Yes
- ☐ No
- ☐ I do not know

5. Has your allergist (or your physician who manages your or your child's food allergy) discussed oral immunotherapy (food desensitization) as a treatment option for your child or family member with food allergy?

☐ Yes

☐ No

4.

1. To the best of your ability, please describe the type of practice that best reflects the allergist (or your physician who manages your or your child's food allergy) who discussed this therapy with you.

- ☐ University setting, academic allergy faculty of a medical school
- ☐ Private allergy practice
- ☐ The person who discussed this with me is not an allergist, but is an ENT (otolaryngology) physician
- ☐ The person who discussed this with me is not an allergist, but is a family medicine or other type of primary care provider

2. Are you, or a family member, currently participating in an oral immunotherapy program for a food allergy?

- ☐ Yes
- ☐ No

1. If you or a family member is currently participating in an oral food immunotherapy program, please select the most accurate description of the setting in which this occurs.

- ☐ Private Practice Office (without this being a research study)
- ☐ Private Practice Office (as part of a research study)
- ☐ Academic center (without this being part of a research study)
- ☐ Academic center (as part of a research study)
- ☐ Other

2. In discussing oral immunotherapy (food desensitization) as a treatment option for your child or family member with food allergy, is your allergist (or your physician who manages your or your child's food allergy) currently offering this practice in his or her office?

- ☐ Yes, they are offering it in their office
- ☐ No, they are offering to refer my child or family member to another site for this procedure
- ☐ No, they are not currently offering this, but it was discussed as a potential future therapy

3. In discussing oral immunotherapy (food desensitization) as a treatment option for your child or family member with food allergy, was the FDA approval status of this therapy discussed?

- ☐ Yes, and my allergist (or your physician who manages your or your child's food allergy) told me this is NOT currently approved for use by the FDA
- ☐ Yes, and my allergist (or your physician who manages your or your child's food allergy) told me that this IS currently FDA approved
- ☐ Yes, and my allergist (or your physician who manages your or your child's food allergy) told me that while this is not currently FDA approved, it has been shown to be an effective therapy for use in the office setting (e.g., by effective it means this treatment works)
- ☐ No, my allergist (or your physician who manages your or your child's food allergy) did not discuss the FDA approval status of this therapy

4. In discussing oral immunotherapy (food desensitization) as a treatment option for your child or family member with food allergy, did your allergist (or your physician who manages your or your child's food allergy) discuss the safety of this procedure?

- ☐ Yes--he/she told me this is a safe procedure
- ☐ Yes----he/she told me this is NOT a safe procedure
- ☐ Yes--he/she told me that this procedure is safe, but that many of the participants will have mild reactions during the process
- ☐ Yes--he/she told me that this procedure is safe, but that many of the participants will have reactions of varying severity, including anaphylaxis, during the process
- ☐ The safety of this procedure was not discussed

5. In discussing food oral immunotherapy (food desensitization), did your allergist (or person who manages your or your child's food allergy) mention if this procedure would be covered by your insurance?

- ☐ Yes--he/she said that I would have to pay for this out of pocket, as my insurance would not pay for it
- ☐ Yes--he/she said my insurance would pay for it
- ☐ No--he/she never mentioned anything about how this service would be covered

6. In discussing food oral immunotherapy (food desensitization), with your allergist (or person who manages your or your child's food allergy), was it discussed with you how reactions occurring through the home dosing period would be managed (e.g., what to do if your child or family member reacted)?

- ☐ Yes
- ☐ No
- ☐ I do not know

7. In discussing food oral immunotherapy (food desensitization), with your allergist (or person who manages your or your child's food allergy), what did this physician state was the expected duration of therapy?

- ☐ 1-6 months
- ☐ 6-12 months
- ☐ 1-2 years
- ☐ 2-3 years
- ☐ 3-5 years
- ☐ Indefinite period of time
- ☐ My allergist (or physician managing my child or family member's food allergy) did not specify the duration of this therapy

8. In discussing food oral immunotherapy (food desensitization), with your allergist (or person who manages your or your child's food allergy), what outcome was anticipated after your child or family member successfully completed the oral immunotherapy program?

- ☐ Able to eat as much of the food in question as desired without any restrictions
- ☐ Able to eat only small amounts of the food only, and continue to carry emergency medication
- ☐ Not able to eat any quantity of the food willingly, but able to tolerate an accidental exposure without worrying
- ☐ There was no discussion of the anticipated outcome

9. In discussing food oral immunotherapy (food desensitization), with your allergist (or person who manages your or your child's food allergy), which of the following long term risks were discussed (please answer yes or no for each choice)

	Yes	No	I don't know or can't remember
Failure of the procedure	☐	☐	☐
Relapse of allergy	☐	☐	☐
Development of Eosinophilic Esophagitis	☐	☐	☐
Development of Oral Allergy Syndrome	☐	☐	☐

1. How many doses of self-injectable epinephrine (e.g., EpiPen, Twinject, Adrenaclick) do you maintain at home?

- ☐ None--I was told my child's food allergy is not severe enough to need self-injectable epinephrine
- ☐ None--this has been prescribed, but there is no current unit(s) available at home
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4 or more
- ☐ I do not know

2. Were you ever provided training in how to use self-injectable epinephrine?

- ☐ Yes
- ☐ No, but it was prescribed
- ☐ No, because a device was never prescribed

3. Experimental therapies, such as oral immunotherapy (food desensitization), should only be performed in large, University-based clinics under research protocols until definitive results show the therapy to be effective.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

4. Experimental therapies, such as oral immunotherapy (food desensitization), should only be performed in large, University-based clinics under research protocols until definitive results show the therapy to be safe.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

5. Experimental therapies, such as oral immunotherapy (food desensitization), should not be covered by insurance or other 3rd party payers until they are proven to be effective.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

6. Experimental therapies, such as oral immunotherapy (food desensitization), should not be covered by insurance or other 3rd party payers until they are proven to be safe.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

7. Any allergy provider should be able to offer experimental therapies, such as oral immunotherapy (food desensitization), regardless if they are conclusively shown to be safe or effective, so long as the patient or family consents to undergo the procedure.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

8. I trust that my allergy provider would not prematurely offer my child or family member an experimental therapy that has not been conclusively proven safe, effective, and approved by the FDA.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

9. I would not permit or consent my child or family member to undergo an experimental therapy that has not been conclusively proven safe, effective, and approved by the FDA, even if I thought it could potentially be of benefit.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

10. My allergist (or physician managing my child or family member's food allergy), if he/she is offering food oral immunotherapy (food desensitization), is obligated to disclose all potential risks and side effects of the therapy.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

11. My allergist (or physician managing my child or family member's food allergy), if he/she is offering food oral immunotherapy (food desensitization), is obligated to disclose if the therapy has been proven both safe and effective.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

12. Only certain allergists, who focus exclusively or nearly exclusively on food allergy in their practice, should be offering food oral immunotherapy (food desensitization) as therapy to their patients.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

13. Only academic or University-based allergists, and not allergists in private practice, should be offering food oral immunotherapy (food desensitization) as therapy to their patients.

	Agree	Disagree	Neutral
Your opinion	☐	☐	☐

7. End of Survey

Thank you very much for participating in our study. This survey was initiated and designed by Kids With Food Allergies, The University of Michigan Medical School, Division of Allergy and Clinical Immunology; and Children's Hospital of Pittsburgh of University of Pittsburgh Medical Center, Division of Pulmonary Medicine, Allergy & Immunology. Your participation will hopefully improve the care of food allergic patients across the country.

If you have any further questions or concerns pertaining to this study, the Principal Investigator, Dr. Matthew Greenhawt, can be contacted at the University of Michigan Division of Allergy and Clinical Immunology via email.

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