Kaneland
allergy & asthma center

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Food Desensitization Frequently Asked Questions (updated 09/01/2017)

Background:

What is oral desensitization for foods (also known as oral immunotherapy, or OIT)?

Oral desensitization for foods is a method of re-training the immune system to tolerate food proteins to which it is currently sensitized. The process involves introducing incrementally increasing amounts of food protein through the gastrointestinal tract on a regular basis over an extended period of time. This gradually induces an increase in IgG4 blocking antibody and a decrease in IgE antibody, shifting the balance in the body from hypersensitivity to tolerance. Oral desensitization treats food allergies which are IgE-mediated, but has not yet been shown to be effective in the treatment of cell-mediated food allergy, celiac disease, or food intolerances.

What is sublingual desensitization (also known as sublingual desensitization, or SLIT)?

Sublingual immunotherapy works by a similar mechanism as oral immunotherapy. The difference is that the allergen is introduced to the mucosal tissue in the mouth under the tongue as opposed to being ingested. In addition, SLIT uses lower amounts of antigen and results in lower levels of tolerance. In our practice, SLIT is used for some patients as a lead-in to OIT, rather than as a stand-alone treatment. It works well as a means of priming the immune system in highly allergic patients.

What is the goal of treatment?

The primary goal of treatment is to be able to consume a full serving of the allergen without experiencing any adverse reaction. 1 glass of milk, 1 egg, a handful of nuts, a slice of bread, etc. Many patients are able to successfully incorporate the food allergen into their diets following completion of the program. Some patients who do not especially like the taste of the allergenic food choose not to deliberately consume it, but no longer worry about reading labels.

How do I know if food desensitization is the right choice for my child?

The decision to begin desensitization is based on a variety of factors. These include risk of reaction to accidental ingestion, difficulty in avoiding the allergen, and a number of quality of life issues (anxiety, ability to participate fully in school, sports and family/social activities, etc.). Another important consideration is the likelihood of spontaneous resolution of the allergy without treatment. For example, if it appears that the child is in the process of outgrowing a milk allergy, observation may be advised for 1-2 years instead of immediate treatment. There are also some patients who are generally advised to avoid attempting oral desensitization. These include patients with active

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inflammatory diseases of the gastrointestinal tract, such as eosinophilic esophagitis or inflammatory bowel disease. Food desensitization therapy should not be pursued in patients with uncontrolled asthma or severe generalized eczema, but can be considered once these conditions are brought under reasonable control.

Are there any age or other restrictions?

Sublingual immunotherapy can begin at 4 years of age. Oral immunotherapy can begin at 4.5-5 years of age, depending on a number of factors. These include: ability to follow directions, ability to maintain quiet activity for 2 hours once or twice daily, and the ability to articulate symptoms to a responsible adult. There is some evidence that food desensitization works more efficiently in young patients. Nevertheless, it is important to ensure that OIT is not initiated prematurely, because a significant percentage of food allergies are naturally outgrown in early childhood without any intervention.

What other options for food allergy treatment are available for my child?

Oral or sublingual desensitization is only one method of treating food allergies. However, it is one of the best studied and most accessible forms of treatment. Other methods include Chinese herbal therapy, percutaneous desensitization (via patch), and immunotherapy with attenuated food proteins or peptides (rather than the whole food). Some of these other therapies are not yet available outside of clinical studies.

My child tests positive on blood or skin testing, but has never experienced a reaction. Should we pursue oral challenge before attempting desensitization?

Depending on the clinical history and results of skin/laboratory testing, a supervised oral challenge may be recommended prior to pursuing OIT or SLIT. These challenges are designed to identify those patients who actually tolerate the foods to which they are sensitized. Example: We have on multiple occasions discovered that patients who were previously advised to avoid peanuts on the basis of a positive skin test are actually able to tolerate an entire serving of peanut butter (~20 peanuts) without experiencing an adverse reaction. These patients do not require desensitization. We do not generally perform food challenges in patients with a clear clinical history of food-associated reaction.

Risks and Benefits:

What are the benefits of treatment?

The benefits of treatment include the ability to ingest the allergen without experiencing an adverse reaction. This results in improved safety and quality of life.

What risks are associated with treatment?

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Mild reactions during food desensitization are not uncommon, and tend to be self-limited. Transient itching of the mouth and throat occur, and generally resolve within a few minutes without medication. In these cases, we recommend rinsing the mouth, drinking water, and eating safe foods which are moisture-rich (such as applesauce).

Abdominal pain, gas, reflux, nausea, and vomiting have also occurred, and are among the most common side effects of treatment. These symptoms are typically managed with the following: dietary modification, antacid medication, and immunotherapy dosing adjustments. The vast majority of patients are able to resolve these symptoms with the above measures, and complete the immunotherapy protocols.

Any time that a food allergen is deliberately administered to an allergic individual, the potential for a body-wide allergic reaction (anaphylaxis) exists. Although it is not typical, anaphylaxis has occurred in the context of oral immunotherapy dosing. When systemic reactions are noted, they are immediately treated with epinephrine and additional adjunctive medications as appropriate. Systemic reactions do not preclude the patient from moving forward with the protocol. In fact, most patients who have ever required epinephrine in the course of treatment go on to graduate from their respective desensitization programs.

I keep reading about eosinophilic esophagitis (EoE), and it sounds scary. What is EoE? Does food desensitization cause this disease, or can it be a trigger in patients who already have the condition?

Eosinophilic esophagitis is an inflammatory condition of the lining of the esophagus (food pipe) which can be worsened by exposure to environmental or ingested allergens. Symptoms include trouble swallowing, a sensation of food getting stuck in the throat, and severe reflux symptoms that do not respond to standard antacid medication. EoE is diagnosed by endoscopy (a procedure involving inserting a small camera into the digestive tract through the mouth) and biopsy which demonstrates an accumulation of eosinophils (allergic white blood cells) in the lining of the esophagus. New research suggests that there is a genetic basis for eosinophilic esophagitis. Therefore, we believe that symptoms of EoE that develop in patients undergoing OIT represent an “unmasking” of the disease process in genetically susceptible individuals who were otherwise asymptomatic due to allergen avoidance. When therapy is discontinued and strict elimination of the allergen re-instituted, EoE symptoms generally resolve within a few months. In most cases, active EoE is a reason to discontinue OIT.

Some centers have identified a syndrome of delayed vomiting and GI symtpoms (2-6 hours after dose), which is associated with an increase in the blood eosinophil count. This syndrome has been termed ELORS (Eosinophilic Esophagitis Like Oral Immunotherapy

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Related Syndrome). It is possible to continue to treat patients with ELORS with OIT, by reducing the dose to a very low level and maintaining the low dose for months at a time before attempting increases.

If my child needs to discontinue treatment before the protocol is completed, will he/she end up being "more allergic" that he/she was prior to beginning treatment?

The allergen-specific IgE initially rises upon exposure to the allergen, so it is possible that a patient who discontinues therapy would have a higher food-specific IgE at the time of discontinuation that they started with at baseline. However, this number will likely fall back to baseline levels with the resumption of allergen avoidance. Additionally, it is important to recognize that although the food-specific IgE does rise at first, the protective food-specific IgG4 (blocking antibody) tends to rise at a faster rate. Therefore, it is unlikely that a patient who needs to stop treatment will be worse off from an allergy standpoint.

Experience:

How long has the doctor been performing desensitization for foods?

Dr. Bajowala first started researching the possibility of offering oral desensitization to her patients in 2009. Kaneland Allergy and Asthma Center was opened in 2011 with the goal of offering innovative and cutting-edge evaluation and management of food allergy. We first started offering food desensitization in late 2011, and the first food OIT patient graduated in 2012. Since then, we have continued to expand the offerings by adding additional foods and treatment modalities, such as sublingual immunotherapy. We have over 100 graduates, and continue to add new patients to the program regularly. Dr. Bajowala has more experience with food desensitization in the private practice setting than any other board-certified allergist in the area, and has offered guidance and advice to other board-certified allergists seeking to add this treatment option to their practices.

What is the success rate of food desensitization in this practice?

The success rate of food desensitization in Dr. Bajowala's hands is ~95%. We are committed to helping our patients succeed, and have the ability and experience to personalize treatment protocols to each individual, offering them the best opportunity for success. We are committed to precision medicine, a medical model that proposes the customization of healthcare, with medical decisions, practices, or products being tailored to the individual patient. None of our patients have EVER followed the same protocol, because food desensitization is not a cookie-cutter therapy. It must be precision-tailored to each patient to optimize success.

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Preparation and Planning:

We live out of town. Is an initial consult really necessary or can we begin directly with desensitization?

A one-on-one consultation is critical to receiving the highly personalized care that your child deserves. In order to offer your child the most appropriate treatment, Dr. Bajowala must be able to fully understand the clinical history and assess current levels of allergic inflammation in the gut, skin, lungs and sinuses. This is not possible without an in-person evaluation and physical exam.

Initial phone consultations are offered for patients who must travel out of state to visit our office, to offer families the opportunity to learn more about the protocol without travelling. However, this does not preclude the need for an in-person evaluation prior to initiation of therapy. It is likely that multiple in-office visits will be necessary prior to desensitization.

My child has already had testing performed to confirm the allergy. Will repeat testing be required?

Almost certainly. It is important to have accurate baseline laboratory values within a few months of beginning desensitization. In addition, our office utilizes component testing for a variety of food allergens. This type of testing breaks the food allergy down into the individual protein within the foods that a patient might be sensitized to. These tests are only now becoming more common, and many patients have never had them performed. Our office also tracks food-specific IgG4 for certain foods, in addition to baseline peripheral eosinophil counts and Vitamin D3 levels. We recommend that you do not have blood drawn immediately prior to your consultation, as it is likely that additional evaluation will be needed. We wish to minimize the number of blood draws our patients require.

Additionally, our office recommends environmental allergy skin testing for all patients with rhinitis wishing to pursue food desensitization, who have not already been treated with aeroallergen desensitization.

How do I prepare for the initial consultation?

1. *Schedule an appointment by visiting our website at: http://www.kanelandallergy.com/new-patients/appointment-request.*

   We understand that you may be very eager to begin therapy. Please do not worry if we are not able to offer you an appointment time right away. Because food desensitization is not widely available, there is a very high demand for our expertise. Initial consultations

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with Dr. Bajowala are typically booked 3-6 months out. We deliberately do not "squeeze in" appointments, as this reduces the quality of care we are able to provide. Rest assured that your family will receive our full attention and focus at the time of your appointment, and we will work together to create a comprehensive food allergy risk management plan. We appreciate your patience.

2. *Gather your records.*

   The most important information to have is a reaction history and copies of any skin testing or blood work (both food and environmental). It may take a few weeks to obtain this information, so please plan accordingly. We recommend recording the laboratory data using a spreadsheet, with dates on the columns, and allergens on the rows.

   It is very helpful to have reaction history completed in the following format:

   - Age at time of reaction
   - Food trigger
   - Amount ingested
   - Reaction
   - Treatment
   - Time to resolution of symptoms

My child is allergic to multiple foods. Do you perform desensitization for multiple food allergies at once?

We typically perform food allergen desensitization one food group at a time. We generally elect to start with the food that is most impactful to safety and/or quality of life. Once a patient has been on their maintenance dose of one food allergen for at least a 6 month period, desensitization for a second food may begin, pending schedule availablility.

My child is very nervous about the prospect of ingesting his/her food allergen. How can we ease the anxiety associated with the desensitization process?

It is understandable that a child (and his/her parents) would have a certain level of anxiety when faced with the prospect of deliberately ingesting a food allergen. One of the best ways to ease the anxiety associated with this process is to speak with other families who have already completed desensitization. We have many wonderful families who have offered their time to speak with prospective patients about food desensitization. It will not be difficult to find a peer that your child can talk to as well. There are also a number of excellent facebook support groups focused on OIT- specifically "OIT 101" and "Private Practice OIT".

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Procedure:

What can we do to increase the chances of successful desensitization?

The most important thing to do when preparing the body for desensitization is to focus on obtaining excellent control of gut inflammation, eczema, allergic rhinitis, and asthma. This may require a combination of dietary modification, environmental control, medication, probiotics, skin care, and/or aeroallergen immunotherapy. You will be given a plan to "calm the system" at the end of the first consultation visit. The amount of work necessary to get other allergic conditions under control will have impact on the timeline for beginning food desensitization.

During the desensitization process, consistency and routine are key. Attempt to administer all doses within the prescribed time periods, as irregular dosing is associated with a higher risk of reaction. Be sure to offer a healthy diet with plenty of complex carbohydrates to aid in the buffering and steady absorption of the allergen dose. Never dose on an empty stomach. Offer plenty of healthy snacks throughout the day. Drink plenty of water, and avoid dehydration. Strictly observe any recommended exercise restrictions (1 hour for SLIT, 2 hours for OIT) after dosing. Avoid dosing during asthma flares, GI illnesses or fevers.

What is the timeline for food desensitization?

- SLIT lead-in takes ~6 months of once daily dosing with weekly up doses.
- Rapid desensitization occurs on a single day, and takes ~7 hours from start to finish.
- OIT takes ~5-6 months of twice daily dosing with weekly up doses. Some patients may be advised or elect to pursue a slower schedule of once daily dosing with upsides every 2 weeks. This will result in a 10-12 month treatment period for OIT.

What do we bring to the rapid desensitization appointment?

On the rapid desensitization day, incrementally increasing doses of allergen will be administered every 15-20 minutes over 6-7 hours. Because you will not be able to leave the office during this time, it is important to come prepared. Items you may wish to bring include:

- Safe snacks and lunch (we have a fridge where you can keep some food if needed)
- Water bottle (patient will be ask to drink LOTS of water today!)
- Books, homework, computer (we have Wi-Fi access)
- Electronic games, tablet, DVDs (we have a TV and DVD player for your use)
- Cards, board games
- Pillow, blanket, lovey
- An insulated lunch bag or cooler to take your dose solution home

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How long should we expect to be in the office during "up dose" visits?

- SLIT up dose visits take ~15-20 minutes for intake, with a 30 minute observation period.
- OIT up dose visits take ~15-20 minutes for intake, with a 60 minute observation period.

After up dosing in the office, what is the procedure at home?

SLIT is administered once daily at the dose tolerated during the prior up dose visit. OIT is administered twice daily (every 9-15 hours) at the dose tolerated during the prior up dose visit.

What is the procedure for reactions that occur in the office setting?

Mild reactions such as oral itching or just a few hives around the mouth are treated with drinking liquids, washing the area with water, and observation. If symptoms do not resolve spontaneously within 20 minutes, Benadryl may be administered.

Moderate reactions (abdominal pain, nausea, vomiting) are treated with liquids, food (complex carbohydrates and applesauce), and medication (antihistamines, antacids) if needed.

Systemic reactions (multiple organ systems) are treated with intramuscular epinephrine, Benadryl and steroids at the discretion of the physician. Systemic reactions that occur in the office setting are monitored in-house until the patient has been symptom-free for at least 1 hour. If needed, transport to an emergency facility will be arranged. We are within close driving distance to 2 local hospitals.

Following any reaction, dosing adjustments will be made at the physician's discretion.

What is the procedure for reactions that occur at home?

Observe a similar procedure as in-office reactions. Dr. Bajowala and Ankita Shah, PA-C should be notified by text message at the onset of any symptoms. They will then advise as to the most appropriate treatment course. For severe reactions, administer epinephrine, and then contact Dr. Bajowala/Ankita +/- 911 as appropriate.

Is there flexibility in the dosing schedule if conflicts arise (exams, sports, vacation, etc)?

Of course! Pursuing food desensitization doesn't mean that the rest of your life gets put on hold. Skipping an up dose here or there, or staying on one dose longer that 1-2 weeks is never a problem. As long as regular dosing continues uninterrupted, there will be minimal impact.

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How do we handle illnesses?

Dosing should be avoided during fevers >100F, during gastrointestinal illness, and during the first 24 hours of taking a systemic antibiotic. If only 1-2 doses are missed, home dosing can be resumed with Dr. Bajowala or Ankita's guidance. If 3 or more doses are missed, the next dose will need to be given in the office under supervision.

Is twice daily dosing a requirement? Is there an option for once daily dosing?

We offer our patients the option of pursuing either twice daily dosing with once weekly updoses or once daily dosing with updoses every 2 weeks. In selected cases, Dr. Bajowala may recommend a different protocol or updose schedule.

Financial:

Does the office bill insurance?

We participate with a number of commercial insurance PPO plans. We bill for our time and counseling, and the vast majority of visits will be billed as straightforward specialist office visits. If you have a deductible, co-insurance, or co-pay, these will apply. Sublingual immunotherapy supplies are not reimbursable by insurance, and will be an out of pocket expense (~$60/month). During OIT, most protocols require a one-time supply fee of $200, which is also not reimbursable by insurance.

Do I need to call my insurer to verify coverage? What should I ask?

The most important thing to verify is that we are a participating provider in your plan. The best way to do this is by calling your insurer or checking their website. It is the patient's responsibility to verify in-network status. Most people on the end of the phone line at your insurance company will not have the slightest idea what OIT or SLIT are, so it will not be especially helpful to ask. Instead, you can confirm coverage for specialist allergy/immunology care (in general), determine if you have a specialist co-pay or co-insurance, and find out how large your deductible is.

What is the cost of treatment for self-pay patients?

- Phone consult: $150
- New Patient Consultation: $180-$215, depending on complexity
- SLIT supplies: ~$60/month,
- SLIT up dose visits: $70/visit
- Rapid desensitization: $1000 + $200 supply fee
- OIT up dose visits: $90/visit
- Ingestion challenge (graduation): $150

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Scheduling:

Do you have a waiting list?

We do have a waiting list, which currently is ~1-2 years long. We add patients to their list after their 4th birthday, depending on physician discretion. This timeline is not set in stone, and may decrease or increase depending on how quickly our current patients progress through treatment. We are working diligently to expand our ability to safely care for more desensitization patients at any given time, which will help us shorten the waiting period considerably. ☺

We don't want our child to miss any school. Can we schedule in the evenings or weekends?

In order to care for all the patients requiring treatment, we cannot promise late afternoon or weekend updose appointments. New patient visits, rapid desensitizations, and ingestion challenges are only performed on weekdays during regular business hours. We are open most Saturdays for SLIT/OIT updose visits. However, these appointments are available on a first-come, first-served basis, and are not guaranteed. You should anticipate that your child may need to miss class periodically for medical treatment, and our office will support your request for excused absences with medical documentation and a doctor's letter.

We are not ready to begin yet, but would like to establish care so that desensitization can begin as soon as possible once the time is right. Is this permitted?

Certainly. Our practice is not limited to desensitization alone. We are happy to care for your family in any capacity necessary.

We appreciate your interest in Kaneland Allergy and Asthma Center's Food Desensitization Program.

Thank you for taking the time to read this FAQ. We will be happy to answer any additional questions at the time of your initial consultation.