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# FAQs for Out-of-State/International Oral Immunotherapy Patients

# What is Oral Immunotherapy (OIT)?

Oral immunotherapy is a desensitization treatment in which the immune system is retrained to tolerate food proteins to which it is currently sensitized. Food-allergic patients consume increasing quantities of the food protein through the gastrointestinal tract daily over the course of months to years. Once the maintenance dose has been achieved, and the body is desensitized to the allergen, the patient is able to consume the allergen without a reaction. In other words, the body is retrained to not react to allergenic foods. This is achieved by consuming increasing amounts of the food allergen by mouth every day.

# What is the goal of OIT and how much protection does OIT give?

The primary goal of OIT is to be able to offer the patient protection from anaphylaxis by allowing them to ingest a full serving of the allergen without any reaction. OIT would allow patients a better quality of life by allowing them to freely eat food without worry of accidental ingestion or cross contamination of their allergen. Some patients can incorporate the food allergen completely into their diet, if desired. Clinical studies have shown that the IgE trend down, with evidence of sustained unresponsiveness.

# Is my loved-one a good candidate for OIT?

Any patient with a food allergy and commitment to OIT is a good candidate. No patient is too allergic to undergo OIT – it just might take the severely allergic person longer to reach their maintenance dose.

Rather, patients with severe, life-threatening reactions to food allergens would benefit the most from OIT. Severe food allergies put patients at a high risk for anaphylaxis even without undergoing OIT. The risk of these severe reactions can be significantly decreased, if not completely prevented, with OIT. In addition, OIT is recommend for patients who experience anxiety from food avoidance, cross contamination, and epinephrine/adrenalin experiences. OIT offers increased safety and a better quality of life. OIT can begin for patients as early as 6 months of age.

A history of asthma, environmental allergies and eczema do not disqualify patients from starting OIT. It is important that these symptoms are well controlled before starting OIT because consumption of food allergies during OIT can lead to symptom flaring. Uncontrolled asthma is a contraindication of OIT because strong lung function is necessary due to increased risk of an allergic reaction during OIT.

In general, eosinophilic esophagitis is a contraindication to OIT because the inflammation in the esophagus can be worsened with exposure to ingested allergens. However, we have successfully treated a few patients with OIT that have eosinophilic esophagitis. If your loved one has EoE, we will discuss our methods for doing OIT in patients with EoE during our virtual consultation

# Will my child be "bite proof" or "free eating"?

Our clinic does not use these terms. As the treatment doses increase, child develops more tolerance to their food allergen. First and foremost, our goal is to make sure the patient is safe from cross contamination, "may-contain" and accidental exposures to their food allergen. Patients and parents may have additional OIT goals in mind, including incorporating their food allergen into their daily diet. We will discuss the other treatment goals in detail during our virtual consultation and during treatment in our clinic.

# Can we do OIT for multiple food allergens while I'm there?

Yes, we can treat multiple food allergens during one visit. Every patient is different, and treatments are customized according to the history of blood/skin test results, reaction history and response to initial treatments. The number of allergens introduced is also dependent on the amount of time that the patient can be present in our clinic. In general, the more food allergens the patient has and the more significant the history of reactions, the longer we would need the

patient to be here for treatment. Dr. Agrawal will give you a recommendation for how long you should be here based on your previous reactions, blood and skin prick test results. We have been successful in treating severely allergic patients with multiple food allergies during their time here without them having to return for a second course of OIT. You are provided with a detailed plan for continuing OIT at home prior to your departure and all questions will be answered so that you are comfortable with the treatment plan.

#### In general:

- -All tree nuts (NOT including peanut) are considered one allergen and are treated at the same time, starting with a mixture of all the nuts (ex. cashew, pistachio, walnut, pecan, hazelnut, almond, macadamia nut, etc.).
- -Peanut is started separately from tree nuts but can be treated during the same trip. We often start peanut a few days before or a few days after starting other allergens.
- -Egg, wheat, soy, and milk are started separately but can be done during the same visit as other food allergens.
- -We provide OIT for most food allergens, with a few exceptions. Both fish and shellfish can be treated with sublingual immunotherapy, also known as SLIT or allergy drops. In some cases, fish and shellfish can be treated with OIT.

#### For example:

A patient has allergies to egg, peanut, cashew and pistachio. We may begin treating peanut on day one. We may add cashew and pistachio a few days later, followed by egg if the patient is doing well with treatment.

# How long will I need to stay?

Typically, families stay from 3 - 6 weeks and come into the clinic 2 - 3 days a week for appointments. With appointment bookings far in advance, there is a possibility that Dr. Agrawal could be on family leave for a small portion of the patient's stay. He will not be away from the clinic for more than one week and will always have direct communication with his Nurse Practitioners so that the flow of patient care will not be interrupted.

#### What is the total cost for OIT?

The fee for the initial video consultation with Dr. Agrawal and his staff is \$250. The fee for the video consultation is deducted from the total clinic fees.

The total clinic fee for OIT is approximately \$5,500 USD for one child with one food allergen. The cost for a child with multiple food allergies is between \$6,000-7,000. Each additional person, such as a sibling, will cost between \$3,000-\$4,000 depending on the number of allergens.

This fee covers treatment in the clinic as well as 18 months of follow up by phone/email/video call. This provides time for the patient to reach their maintenance dose, as most people reach maintenance dosing in 9 - 12 months.

This fee **includes** skin prick testing for food and environmental allergies, any lung function testing needed and the clinic charges. The clinic fee **does not** include the price of any blood tests, treatment of environmental allergies or sublingual allergy drops.

# For example:

A patient has an allergy to peanut, walnut, pecan, cashew and pistachio. They will be considered to have <u>multiple</u> food allergies. Cashew, pistachio, walnut and pecan are considered one allergen; peanut is considered a separate allergen For example:

A patient has an allergy to walnut, pecan, cashew and pistachio. They are considered to have one food allergen.

# How much do I need to allow for lab costs?

This cost is not included in our clinic charges and is between \$350 - \$700 per person. These fees only include testing for food allergies related to OIT. It does not include testing for any other conditions, such as hives, hay fever/environmental allergies or frequent infections.

# How do I pay for the visits?

We request half payment upon arrival at your first visit, and the remaining balance on or before your last day. Payments can be made with all major credit cards, PayPal, or cash. We will also provide our bank details for overseas transfers

# How do we book our trip to start OIT?

Prior to booking your trip, you will have a video consultation with Dr. Agrawal and his staff. During this visit, Dr. Agrawal will review the provided blood tests, skin tests, clinic notes and reaction history. Combining this information with the patient's history of reactions, he will make a recommendation on how long you should stay and how the treatment plan will likely go.

# Which office can I make appointments at?

We are only able to accommodate our out-of-state and international patients at our main location in Peachtree City. We have clinic hours Tuesday through Friday from 8:30-5:00pm. Submitting an inquiry on our website under the International OIT tab is the easiest way to get in touch with us. One of our staff members will reach out to you via email to discuss setting up an appointment for a video consultation.

# What will happen at my first visit?

Upon arrival to our clinic for the first visit, we will review the plan discussed during the consultation to make sure there have not been any changes. We may do updated skin prick testing for food and/or environmental allergies. Please do not take any antihistamines or sleep aids for 3 days prior to your initial visit. Reach out to our office to clarify if you are unsure about any medications. Please continue to take all asthma medications as prescribed. If the patient has asthma, a spirometry test may be performed to test lung function and the stability of asthma prior to starting treatment. Any skin tests, spirometry or other office procedures will be included in your cost. Dr. Agrawal will determine what blood tests are needed and you will leave the clinic and go to the lab to have blood drawn. Treatment with OIT will begin promptly, either during your first or second visit. You may possibly return to the clinic after lab draws to start OIT.

# How long will my first OIT appointment be?

You will be in the office for 3-5 hours for your first OIT visit. We usually begin treatment immediately after we finish with skin prick testing and blood work on your first day. If your first visit is in the afternoon or you are very tired from jetlag, we may begin OIT the next morning. Be sure to eat a complete breakfast/lunch **before** arriving to the office. Over the course of 3-5 hours, doses of the allergen will be given every 15-30 minutes in increasing concentration. The patient will be monitored by Dr. Agrawal, the nurse practitioners, and other staff to ensure all doses are being tolerated. Dosing will stop at a predetermined maximum dosage, or at any sign/symptom of a reaction. There will be a one-hour wait period after the last dose is given to monitor the patient.

#### What do I need to bring to our appointments?

You will remain in the office during the entire visit, so bring snacks and drinks, and items to occupy your time.

We suggest bringing a drink, such as juice, and some snacks, including applesauce, crackers, chips, pretzels, and goldfish. We have a microwave and refrigerator available for you to use if you would like to bring lunch with you.

We also recommend bringing something to occupy your time because there is a lot of time spent under observation. Some items you may want to bring include a tablet/iPad, video games, laptop, books, coloring books, Legos/building blocks, puzzles, or card games. We also suggest that you bring a notebook to jot down any instructions for dosing between visits and information provided during the visit. You should also bring an insulated lunch bag/cooler to take your dose solution home.

Also, per your regular allergy action protocol, continue to carry your epinephrine/adrenaline and inhaler (for asthma patients).

# How frequently will my appointments be?

While you are here in Peachtree City, the patient will generally dose 1-3 times daily and will come to the clinic 2-3 times per week. This treatment plan is highly individualized and is based upon how the patient tolerates the treatment.

# Do I need to have blood tests done before coming?

No, you do not need to have lab tests done prior to your visit. During the first day in the clinic, Dr. Agrawal will determine which labs are necessary and write and order for those tests. You will leave the clinic and go to the lab that first day. It generally takes a few days for the results to be done, but treatment will not be delayed waiting for the results.

# What is your starting dose?

This will be decided during your first clinic visit. The starting dose is extremely low and based on previous reactions and test results. We have not had any patient require epinephrine/adrenalin or a hospital visit with this starting dose.

# Can I share dosing and schedule with other members?

All dosing and treatment plans are exclusively for you. This is also considered intellectual property, and it is prohibited to share any dose specific information.

### What does ongoing treatment and communication look like?

Before you leave, Dr Agrawal will provide a dosing regimen that is individualized to your allergen and patient needs. You will also be given information regarding what to do if the patient misses a dose due to illness and how to safely restart. You will also be given a detailed treatment plan on what to do in the case of an allergic reaction. Continue dosing at home, as you have been while here, according to the plan and reporting any adverse reactions via e-mail. Urgent questions can be texted to Dr. Agrawal's cell phone.

Please FOLLOW YOUR ALLERGY ACTION PROTOCOL, and do not rely on Dr Agrawal or staff to instruct you to give epinephrine/ adrenaline or Benadryl (antihistamine). Due to the possible delay in communication, this is not safe or in the best interest of the patient to delay treatment.

Repeat lab tests should be done every 12 months, or as indicated by Dr Agrawal to check progress, until maintenance dose is achieved. Thereafter, you should expect to have blood work annually.

#### **Escalation and At-home Dosing Questions**

This is very personalized to the patient's specific needs and will be discussed in detail during your appointments.

# Does your office help in finding accommodation?

We recommend staying near our Peachtree City office. Other nearby locations include Fayetteville, Tyrone, and Sharpsburg. We do not have any specific recommendations; however, please feel free to ask previous out-of-state patients for specific recommendations.

#### Where is your nearest emergency room?

Piedmont Fayette Hospital is about 4-6 minutes by ambulance. Peachtree City has a quick ambulance response.

# Has anyone needed to be sent to the hospital?

So far, none of the OIT patients have required epinephrine/adrenalin in office **or** to be sent to the hospital for an acute allergic reaction/anaphylaxis from the office. Our office has successfully started nearly 800 patients on OIT and have done more than 5000 updoses in office.

# How often do I have to comeback for follow ups?

If you can stay here for the recommended time frame for your number of allergens, generally between 3 to 6 weeks, you will likely not have to return for follow-ups. The clinic fee includes 18 months of follow up via email/telephone/video call. We are always happy to see our Freedom Allergy families again, so you are welcome to come back whenever you would like.

# Do you recommend probiotics?

Please continue with any probiotics you are taking. Further probiotics recommendations will be discussed during your video consultation.

#### Do you need vitamin D level?

Yes, it is strongly recommended to have vitamin D level and start supplementation if it is low prior to your visit. This blood test can also be done during your stay if you are not able to start before you arrive.

### Resources before coming to OIT appointments:

Facebook pages: Private Practice OIT, OIT 101

Web resources: OIT101.org

Food Allergy Fix by Dr. Sakina S. Bajowala and Crushing the Peanut by Katy Patrick (mother of one of our OIT patients)