



Black People Like Me

# Addressing Barriers in Food Allergies and Empowering the Black Community

Presented by: Allergy & Asthma Network

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# Genentech

**Thank you Genentech for providing funding support to make this webinar possible.**

# Today's Speakers



Moderator  
Catherine Blackwell, RN  
Chief Health Equity Officer,  
Allergy & Asthma Network



Physician Speaker  
Nancy Joseph, DO



Patient Speaker  
Thomas Silvera

# Physician Speaker

Presented by: Nancy Joseph, DO

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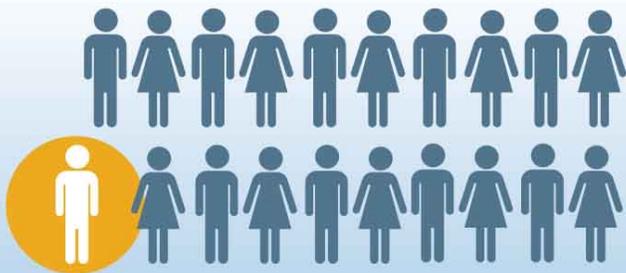
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# Road map – Where we're going

- General Stats and basics
- Disparities in the Black community
- Burdens of Food allergy (effects on quality of life, mental health, and economic)
- Food allergy vs other adverse food reactions
- Treatments
- Resources



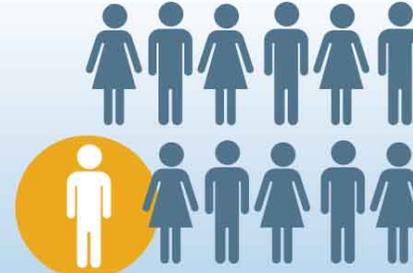
# Stats



**10%**  
**OF ADULTS**  
in the US have  
food allergies



**19%**  
**BELIEVE**  
that they have  
a food allergy



**1** in **12**  
**CHILDREN**  
in the US has  
a food allergy



# Food Allergy in the Black Community

- 4x more frequent in African Americans
- AA have higher rate of deaths from food allergies
- Higher levels of various allergy cells in AA individuals (**incl IgE**)
  - More on IgE later...



# Food Allergy in the Black Community

- AA children
  - Peanut allergy is present at an 8x higher rate in AA children
  - Higher rate of allergy to corn, shellfish and fish (*Mahdavinia et al 2017*)
  - 3x Higher chance of having shellfish allergy (*FORWARD Study, Carla Davis, MD 2021*)
  - More likely to have multiple food allergies
  - AA children with allergic disease or parental history of allergic disease (asthma, env allergies or food allergies) → higher incidence of shellfish allergy

# Food Allergy Research



- Genetics – still being studied
  - Some genetic variants occur more frequently in African Americans
- More studies on AA and food allergies needed
  - Lack of diversity in clinical trials
  - Europeans Americans are referenced in food allergy literature 5x more than African Americans
  - Access to care (or lack thereof) plays an important role
  - The FOWARD study (Carla M. Davis, MD) is helping to combat this

# The FORWARD Study

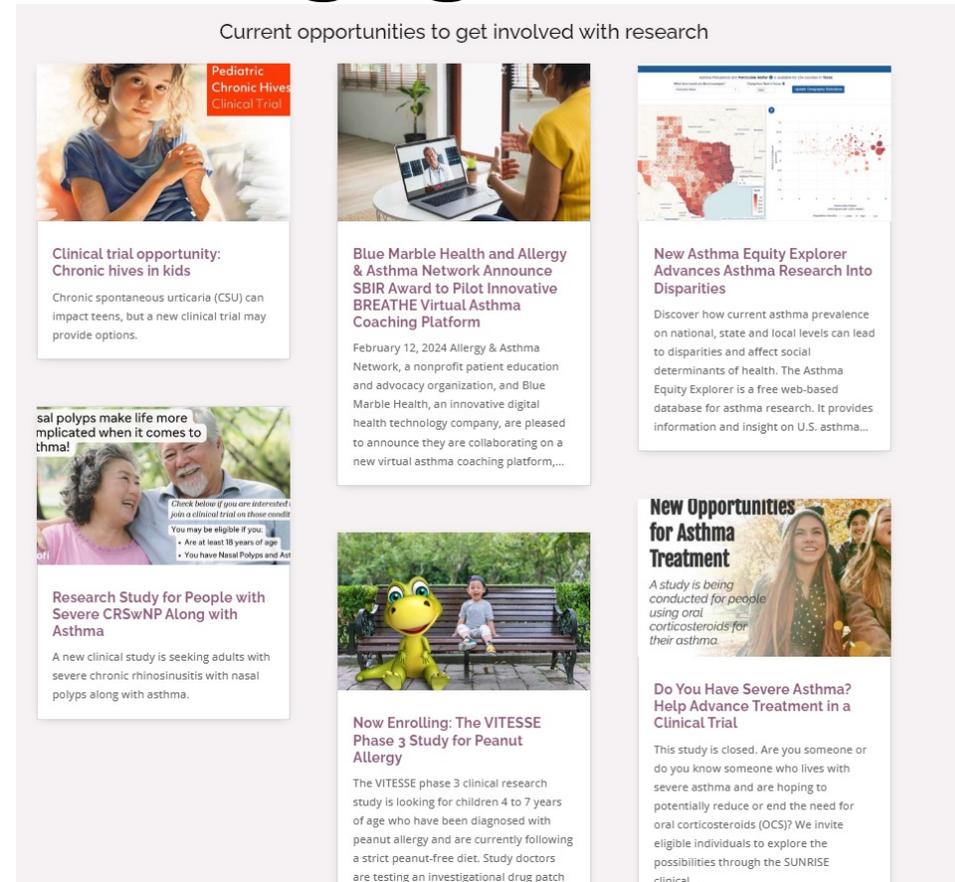
- Multi-centered
- Participants: white and African American children 0-12yrs old with food allergies (644 total)
- Results:
  - African American had 3x higher chance of having shellfish allergy
  - AA had 2.5x higher chance of having finned fish allergy
  - Less than 50% got confirmatory testing or were evaluated by an allergist
  - Higher rate of food-related anaphylaxis and ER visits

AAN wants to make sure  
your voice is heard!

# Research – Ways to Get Engaged

- Patient advisory group
- Participate in a disease registry
- Focus groups
- Surveys
- Find and join study
  - More on Clinical trials later...

Current opportunities to get involved with research



**Pediatric Chronic Hives Clinical Trial**  
Clinical trial opportunity: Chronic hives in kids  
Chronic spontaneous urticaria (CSU) can impact teens, but a new clinical trial may provide options.

**Blue Marble Health and Allergy & Asthma Network Announce SBIR Award to Pilot Innovative BREATHE Virtual Asthma Coaching Platform**  
February 12, 2024 Allergy & Asthma Network, a nonprofit patient education and advocacy organization, and Blue Marble Health, an innovative digital health technology company, are pleased to announce they are collaborating on a new virtual asthma coaching platform,...

**New Asthma Equity Explorer Advances Asthma Research Into Disparities**  
Discover how current asthma prevalence on national, state and local levels can lead to disparities and affect social determinants of health. The Asthma Equity Explorer is a free web-based database for asthma research. It provides information and insight on U.S. asthma...

**Research Study for People with Severe CRSwNP Along with Asthma**  
A new clinical study is seeking adults with severe chronic rhinosinusitis with nasal polyps along with asthma.

**Now Enrolling: The VITESSE Phase 3 Study for Peanut Allergy**  
The VITESSE phase 3 clinical research study is looking for children 4 to 7 years of age who have been diagnosed with peanut allergy and are currently following a strict peanut-free diet. Study doctors are testing an investigational drug patch

**Do You Have Severe Asthma? Help Advance Treatment in a Clinical Trial**  
This study is closed. Are you someone or do you know someone who lives with severe asthma and are hoping to potentially reduce or end the need for oral corticosteroids (OCS)? We invite eligible individuals to explore the possibilities through the SUNRISE clinical...

**New Opportunities for Asthma Treatment**  
A study is being conducted for people using oral corticosteroids for their asthma.

# The Weight of it All

The Burdens of Food Allergy

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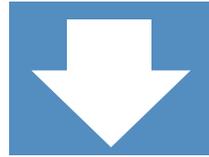
# The Burdens of Food Allergy

## Economic



more [allergyandasthmanetwork.org](http://allergyandasthmanetwork.org)

## Quality of Life



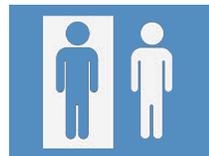
Decreases QOL to the point that some may qualify for disability



Avoidance of restaurants



Restricted social activity or travel



>50% of adults with food allergies have had a severe reaction



### Children w/food allergies

- **>40%** of children have had a severe reaction
- **2x** as likely to be bullied
- **1 in 3** bullied due to their food allergy
- Increased anxiety and panic attacks

### Mothers of food allergic preschoolers

- Higher blood pressures
- Increased stress

# The Burdens of Food Allergy

- Mental Health
  - FARE registry
    - Out of 1680 patients
    - 54% expressed feelings of anxiety
    - 32% expressed feels of panic
    - If more than 1 reaction per year → increased chance of having food-related mental health concern
  - Individuals with food allergy have an increased tendency to have food allergy-related anxiety
  - Caregivers of food allergic patients
    - Increase levels of anxiety and depression
    - One study showed: 45% of caregivers do not think their child is safe at school

# Major Key

There are a number of adverse food reaction that are not allergic in nature.

# Food Allergy vs Intolerance

# What is Food Allergy

- Adverse food reaction
- Driven by a cell called IgE
  - Beware of tests that use IgG → this is not an allergy cell
- Occurs secondary to exposure or ingestion of a specific food
- Occurs within 4hrs of ingestion
- **Consistent/reproducible** reaction

# Top 9 Food Allergens

- Peanut
- Tree nuts
- Egg
- Milk
- Wheat
- Soy
- Fish
- Shellfish
- Sesame

**Peanut avoidance ≠ tree nut avoidance**  
**Coconut ≠ nut**



# Food Intolerance Defined

- Non-IgE mediated adverse food reaction
- Most adverse reactions to food fall in this category
- Examples include:
  - Lactose intolerance
  - Food protein induced enterocolitis (FPIES)
  - Gluten sensitivity

# Common Symptoms

## Food Allergy

- Mouth itching
- Hives
- Vomiting
- Throat tightness
- Lip or tongue swelling
- shortness of breath
- Anaphylaxis (when 2 or more of the above are present)

## Food Intolerance

- Bloating
- Abdominal pain
- Diarrhea

# Some Key Points

- Food allergy is driven by a cell called IgE while food intolerance/sensitivity is not
- Food sensitivity  $\neq$  food allergy
- No matter if intolerance or allergy, if the food causes discomfort, avoidance is recommended

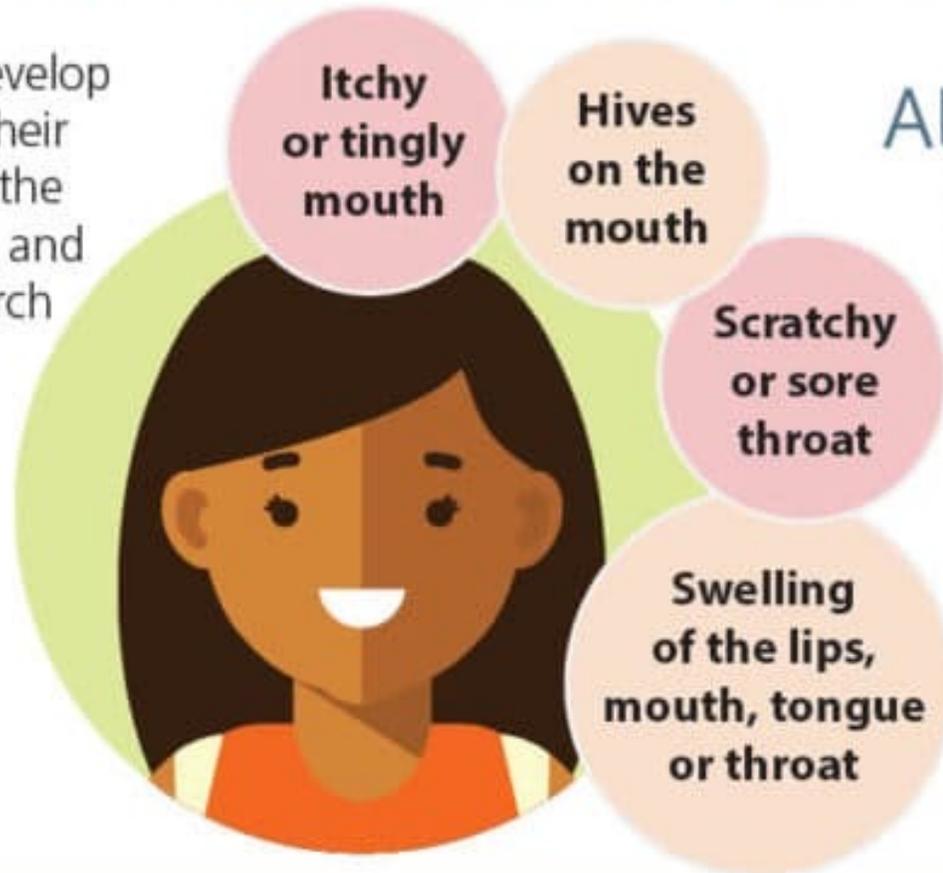
# A Word About Oral Allergy Syndrome (OAS)

# Oral Allergy Syndrome (OAS)

- A case of mistaken identity (aka mimicry)!
- Some food allergens have proteins that are similar to that of env allergens (i.e. birch pollen)
  - body thinks you are ingesting that env allergens → local itching
- Can also have lip swelling
- These proteins are very labile (which means they can be changed easily)
  - If food processed or heated → changes molecularly → no OAS symptoms
- Symptoms can be worse during the season of the specific pollen causing the mimicry

# ORAL ALLERGY SYNDROME (OAS)

People with OAS develop symptoms around their mouth from eating the following raw fruits and vegetables when birch trees, grasses and ragweed are pollinating:



The swelling of the throat is less common (occurring in less than 5% of people with OAS)

<https://www.uptodate.com/contents/oral-allergy-syndrome-beyond-the-basics>

# What foods cause oral allergy syndrome?

The following lists show foods that are botanically related to birch, grasses and ragweed:

## Birch pollen

- almond
- apple
- carrot
- celery
- cherry
- hazelnut
- kiwi
- peach
- pear
- plum
- potato
- pumpkin seed

## Grass pollen

- kiwi
- melon
- peach
- tomato

## Ragweed pollen

- banana
- chamomile
- cucumber
- echinacea
- melon (watermelon, cantaloupe, honeydew)
- sunflower seed
- zucchini

**NOTE:** one does not typically react to ALL the foods related to their env allergen

And now back to food  
allergy...

# When to See an Allergist

- Noted food trigger – **reproducible**
- Discuss with your doctor if a referral is appropriate (dermatologist vs allergist)
  - let your PCP know your exact concerns
  - Work with your doctor to determine the most appropriate specialist to address your concerns

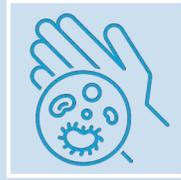


# Preparing for Your Visit to the Allergist

- Note any **reproducible** reaction to foods
- Timeline
  - When did you first notice a reaction? (have a good approximate time)
  - How long after eating the food does the reaction occur?
  - When was your last reaction to the suspected food
- Have you been avoiding the suspected food(s)
- Pertinent family history
  - Any family history of allergic diseases?
  - *Note: you do not inherit the specific food allergy but only the propensity for an allergic disease*



# Food Allergy Testing



Skin Prick Tests



Blood Tests



Oral Food Challenges

# Testing

- Oral food challenge is the gold standard
  - Done medically supervised in the office
- Panel testing for food allergy – highly DISCOURAGED
- Test based on clinical history
  - Diet history and **consistent/reproducible** reaction history guides testing (including exposure via breastfeeding)
- Blindly eliminating food in diet – not recommended
  - Malnutrition
  - Development of food allergy due to lack of exposure
  - Early exposure to foods encouraged – improved tolerance
- Skin test typically done  $\geq 6$  weeks after suspected reaction
  - Avoids false negative

# Treatment of Allergic Reactions

- Avoidance, Avoidance, **Avoidance**
  - Guidance on safe dietary practices
    - AAAAI.org
    - AllergyAsthmaNetwork.org
      - <https://allergyasthmanetwork.org/food-allergies/living-with-food-allergies/>
    - Guidance based on the child's age
- EpiPen
  - Food allergic = carry an EpiPen

# Treatment

- Food allergy action plan
  - Completed by your doctor
  - Guide to what you should do during a reaction
  - Research shows more white children are given a food allergy action plan than African American children (FORWARD study)

FARE
FOOD ALLERGY & ANAPHYLAXIS EMERGENCY CARE PLAN

Name: \_\_\_\_\_ D.O.B.: \_\_\_\_\_

Allergy to: \_\_\_\_\_

Weight: \_\_\_\_\_ lbs. Asthma:  Yes (higher risk for a severe reaction)  No

NOTE: Do not depend on antihistamines or inhalers (bronchodilators) to treat a severe reaction. USE EPINEPHRINE.

Extremely reactive to the following allergens: \_\_\_\_\_

THEREFORE:

If checked, give epinephrine immediately if the allergen was LIKELY eaten, for ANY symptoms.

If checked, give epinephrine immediately if the allergen was DEFINITELY eaten, even if no symptoms are apparent.

<p style="text-align: center; font-weight: bold; font-size: 0.9em;">FOR ANY OF THE FOLLOWING: SEVERE SYMPTOMS</p> <div style="display: flex; flex-wrap: wrap; justify-content: space-around;"> <div style="text-align: center; width: 45%;">   <b>LUNG</b>  <small>Shortness of breath, wheezing, repetitive cough</small> </div> <div style="text-align: center; width: 45%;">   <b>HEART</b>  <small>Pale or bluish skin, faintness, weak pulse, dizziness</small> </div> <div style="text-align: center; width: 45%;">   <b>THROAT</b>  <small>Tight or hoarse throat, trouble breathing or swallowing</small> </div> <div style="text-align: center; width: 45%;">   <b>MOUTH</b>  <small>Significant swelling of the tongue or lips</small> </div> </div> <div style="display: flex; flex-wrap: wrap; justify-content: space-around; margin-top: 10px;"> <div style="text-align: center; width: 45%;">   <b>SKIN</b>  <small>Many hives over body, widespread redness</small> </div> <div style="text-align: center; width: 45%;">   <b>GUT</b>  <small>Repetitive vomiting, severe diarrhea</small> </div> <div style="text-align: center; width: 45%;">   <b>OTHER</b>  <small>Feeling something bad is about to happen, anxiety, confusion</small> </div> </div> <p style="text-align: center; font-size: 0.7em; margin-top: 5px;">OR A COMBINATION of symptoms from different body areas.</p> <ol style="list-style-type: none"> <li>1. <b>INJECT EPINEPHRINE IMMEDIATELY.</b></li> <li>2. <b>Call 911.</b> Tell emergency dispatcher the person is having anaphylaxis and may need epinephrine when emergency responders arrive.                     <ul style="list-style-type: none"> <li>• Consider giving additional medications following epinephrine:                             <ul style="list-style-type: none"> <li>» Antihistamine</li> <li>» Inhaler (bronchodilator) if wheezing</li> </ul> </li> <li>• Lay the person flat, raise legs and keep warm. If breathing is difficult or they are vomiting, let them sit up or lie on their side.</li> <li>• If symptoms do not improve, or symptoms return, more doses of epinephrine can be given about 5 minutes or more after the last dose.</li> <li>• Alert emergency contacts.</li> <li>• Transport patient to ER, even if symptoms resolve. Patient should remain in ER for at least 4 hours because symptoms may return.</li> </ul> </li> </ol>	<p style="text-align: center; font-weight: bold; font-size: 0.9em;">MILD SYMPTOMS</p> <div style="display: flex; flex-wrap: wrap; justify-content: space-around;"> <div style="text-align: center; width: 45%;">   <b>NOSE</b>  <small>Itchy or runny nose, sneezing</small> </div> <div style="text-align: center; width: 45%;">   <b>MOUTH</b>  <small>Itchy mouth</small> </div> <div style="text-align: center; width: 45%;">   <b>SKIN</b>  <small>A few hives, mild itch</small> </div> <div style="text-align: center; width: 45%;">   <b>GUT</b>  <small>Mild nausea or discomfort</small> </div> </div> <p style="text-align: center; font-size: 0.7em; margin-top: 10px;">FOR MILD SYMPTOMS FROM MORE THAN ONE SYSTEM AREA, GIVE EPINEPHRINE.</p> <p style="text-align: center; font-size: 0.7em; margin-top: 10px;">FOR MILD SYMPTOMS FROM A SINGLE SYSTEM AREA, FOLLOW THE DIRECTIONS BELOW:</p> <ol style="list-style-type: none"> <li>1. Antihistamines may be given, if ordered by a healthcare provider.</li> <li>2. Stay with the person; alert emergency contacts.</li> <li>3. Watch closely for changes. If symptoms worsen, give epinephrine.</li> </ol>
<p style="text-align: center; font-weight: bold; font-size: 0.9em;">MEDICATIONS/DOSES</p> <p style="font-size: 0.7em; margin-top: 5px;">Epinephrine Brand or Generic: _____</p> <p style="font-size: 0.7em; margin-top: 5px;">Epinephrine Dose: <input type="checkbox"/> 0.1 mg IM <input type="checkbox"/> 0.15 mg IM <input type="checkbox"/> 0.3 mg IM</p> <p style="font-size: 0.7em; margin-top: 5px;">Antihistamine Brand or Generic: _____</p> <p style="font-size: 0.7em; margin-top: 5px;">Antihistamine Dose: _____</p> <p style="font-size: 0.7em; margin-top: 5px;">Other (e.g., inhaler-bronchodilator if wheezing): _____</p>	

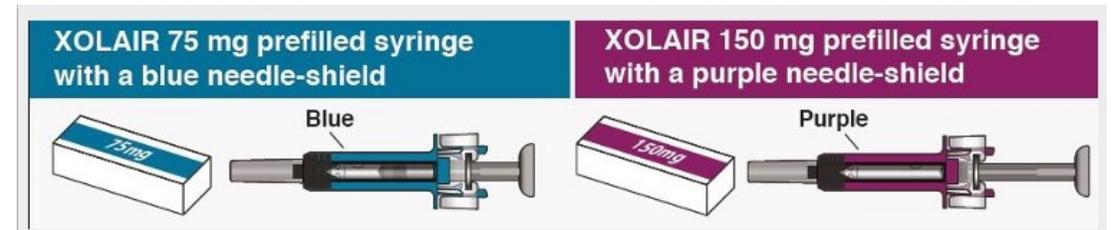
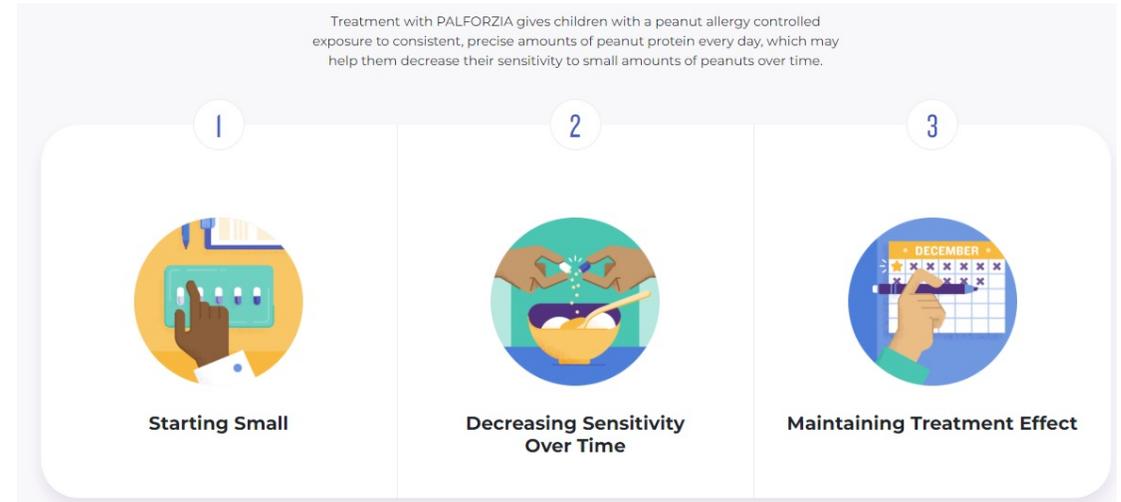
PATIENT OR PARENT/GUARDIAN AUTHORIZATION SIGNATURE \_\_\_\_\_
DATE \_\_\_\_\_
PHYSICIAN/HCP AUTHORIZATION SIGNATURE \_\_\_\_\_
DATE \_\_\_\_\_

FORM PROVIDED COURTESY OF FOOD ALLERGY RESEARCH & EDUCATION (FARE) (FOODALLERGY.ORG) 5/2018

# Treatment: Immunotherapy

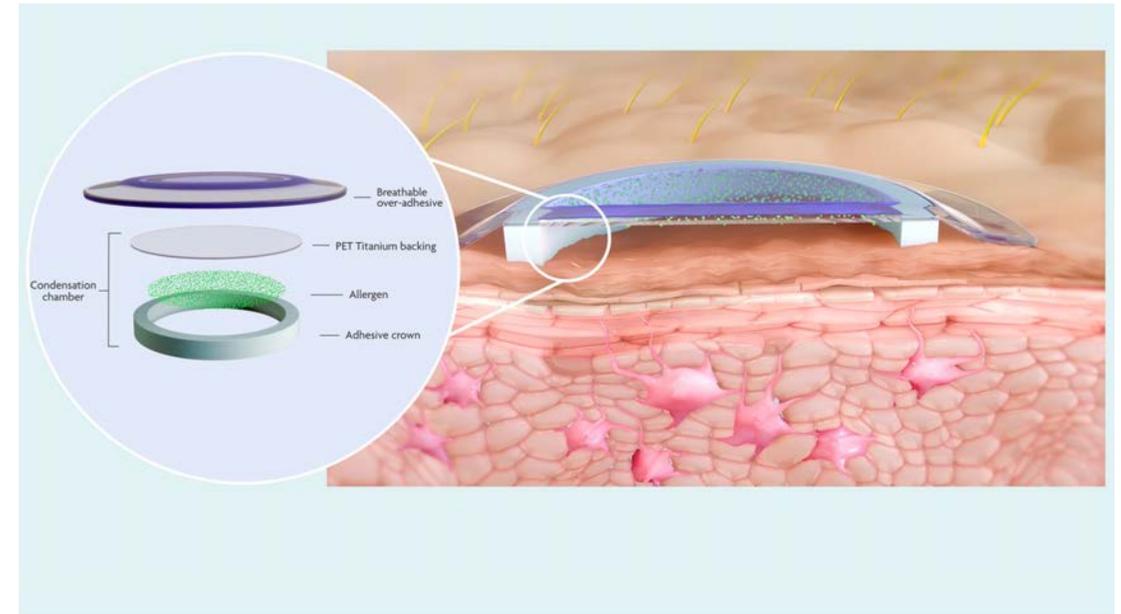
- Immunotherapy – **not** a cure
- Palforzia: FDA approved
  - A capsule (peanut powder)
  - For ages 4-17 years
  - Must be taken every day
- Xolair – recently approved
  - Approved for 1yr and older with multiple food allergies
  - Injection that decreases likelihood of a reaction
    - In the study participants could consume  $\geq$  600mg of peanut and increased amount of their other food allergens (cashew, egg, and milk)
    - Injection every 2-4 weeks for 16-20 weeks

<https://www.palforzia.com/>



# Food Allergy Treatment: The Patch

- Epicutaneous immunotherapy (EPIT)
  - Researchers are evaluating Viaskin™ patch technology
  - The patch contains a tiny amount (mcg) of the allergen
    - Currently one for peanut and one for milk
    - In clinical trials
      - Peanut trials include kids as young as 1 year old
  - Patch not FDA approved yet



# Reading Labels

- Be aware of other alias for common food allergens
  - Aka ovalbumin – eggs
- Highly refined oils
  - Separates the protein (the allergic part) from the oil
    - i.e. highly refined peanut or tree nut oils
  - Companies not required to list
  - Likely fine to ingest, but if worried/nervous avoid

# Hide & Seek Food Allergens

Ingredients derived from common food allergens can be listed under many different names on the food label.



DAIRY	EGG	PEANUT	SESAME	SOY	WHEAT
<ul style="list-style-type: none"> <li>▪ Casein</li> <li>▪ Curds</li> <li>▪ Ghee</li> <li>▪ Lactalbumin</li> <li>▪ Sodium caseinate</li> <li>▪ Tagatose</li> <li>▪ Whey</li> </ul>	<ul style="list-style-type: none"> <li>▪ Albumin</li> <li>▪ Lysozyme</li> <li>▪ Meringue</li> <li>▪ Ovalbumin</li> <li>▪ Surimi</li> </ul>	<ul style="list-style-type: none"> <li>▪ Cold-pressed peanut oil</li> <li>▪ Goobers</li> <li>▪ Legumes</li> <li>▪ Marzipan</li> <li>▪ Nut meat</li> <li>▪ Nougat</li> </ul>	<ul style="list-style-type: none"> <li>▪ Benne</li> <li>▪ Gingilly</li> <li>▪ Sesamol</li> <li>▪ Sim Sim</li> <li>▪ Tahini</li> </ul>	<ul style="list-style-type: none"> <li>▪ Miso</li> <li>▪ Natto</li> <li>▪ Shoyu</li> <li>▪ Soya</li> <li>▪ Tamari</li> <li>▪ Tempeh</li> <li>▪ Textured vegetable protein</li> </ul>	<ul style="list-style-type: none"> <li>▪ Farro</li> <li>▪ Food starches</li> <li>▪ Graham flour</li> <li>▪ Malt</li> <li>▪ Semolina</li> <li>▪ Spelt</li> </ul>

# Resources: Allergy & Asthma Network

AllergyandAsthmaNetwork.org  
(<https://allergyasthmanetwork.org/food-allergies/living-with-food-allergies/>)

- Living with food allergies
- Back to school check lists
- Food allergy and food insecurities
- Resources to help with food costs
  - Both state and nationwide
- And more!!

Back to School Checklist for Families  
**Life-Threatening Allergies**



## Before School Begins:

---

- Make an appointment to see your child's healthcare provider.
  - Be sure your child's emergency medication dose is appropriate for their weight.
  - Update medication orders if needed.
  - Update or complete an Anaphylaxis Emergency Plan for use at home and at school.
  - Have school forms completed – get a statement from the doctor about any foods to which your child is allergic so that it can be filed at school.
- Make an appointment to visit the school to discuss your child's life-threatening allergy if needed.
  - If your child is starting a new school, it's a great idea to have a conversation with school staff.
- Be sure your child/teen has full access to their emergency medication.
  - Review emergency symptoms with your child so they are sure when they should have their emergency medication.
  - Review how to use an epinephrine auto-injector if age appropriate.
  - Review your child's Anaphylaxis Emergency Plan with your child and school staff.
  - Be sure your child knows when to get help and who to go to in an emergency.

## When School Starts:

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- Talk to your school nurse or school administrator to be sure that they are aware of your student's life-threatening allergy.
- Take medication, forms and supplies to school.

# Resources: FARE



- FoodAllergy.org
  - How to avoid cross-contamination
    - Especially while dining out
  - How to read labels
  - Preparing others to care for children with food allergies
  - Support groups
  - And more!

# Food Insecurity and Resources

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# Food Insecurity: Definition and Resources

- Limited access to good quality and/or quantity of food
- Allergy & Asthma network
  - Ideas of how to help with food cost
- FOODiversity.org
  - They have a network that includes food pantries, school nurses, and physicians
  - Connects individuals and families with:
    - Consistent and reliable sources of safe foods
    - Education materials and support
    - May even provide gift cards



# Resources – Access

Food Equality Initiative (FEI)  
(<https://www.foodequalityinitiative.org>)

- Founded by Emily Brown in 2014
  - Mission: “to provide people diagnosed with food allergy and celiac disease equal access to the foods they need to be healthy, regardless of race, geographic location, or economic status”
- Fights for nutrition security and health equity



Emily Brown  
Founder of FEI  
Co-Founder and CEO of  
Free From Market

# Resources - Access

## Food Equality Initiative

- **Access** - Improves access to nourishing food
  - **Food Is Medicine Access Home (FIMH) program** - subsidizes a direct-to-door grocery delivery service for qualified clients
  - Must reside in Jackson (MO), Johnson (KS), or Wyandotte (KS) counties and/or referred by an FEI partner
- **Education** – provides educational resources
- **Advocacy** – advocates for underrepresented populations

# Resources - Access

Free From Market (<https://attane-health.com/>)

- For individuals outside of the Kansas Area
- online marketplace to provide access to healthy foods
  - **“1,500 Nutrient dense foods that can be sorted and searched by ingredient, health condition, price, brand, certification, and more.”**
- Order personalized diet-specific food that gets delivered straight to your door
- Provides telehealth coaching and nutrition education

A few examples of focused populations we currently work with



Maternal Health



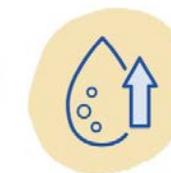
Diabetes



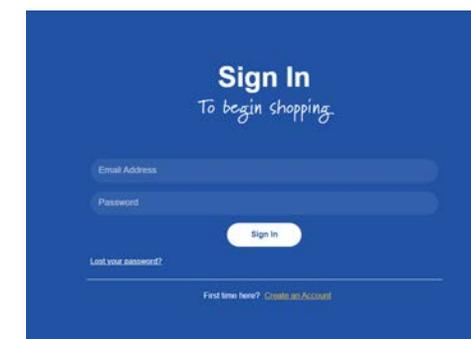
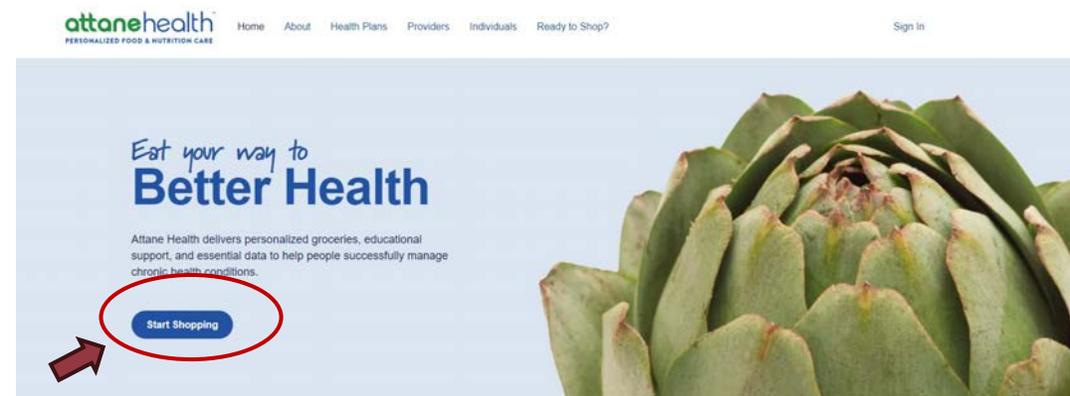
Hypertension



Food Allergies/  
Gastrointestinal



Hyperlipidemia



# Where We've Been

- Understand the prevalence of food allergy and food allergy disparities in the black community
- Understand the definition of food allergy
- Understand food allergy vs other adverse food reactions
- Describe burdens of food allergy
- Understand when to see an allergist
- Understand food allergy testing and when it is needed
- Understand current treatments for food allergy
- Describe preparation for a visit with an allergist
- Understand the concept of food insecurity and the resources available to combat it



# Patient Story

Presented by: Thomas Silvera



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## Elijah-Alavi Foundation

[www.elijahalavifoundation.org](http://www.elijahalavifoundation.org)

Elevating Food Allergy and Asthma Awareness  
through Comprehensive Training, Educational Research,  
Community Outreach, Advocacy, and Promoting Equity for All

Registered Charity: 501 (c) (3)



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# Research Studies

Catherine Blackwell RN, MBA  
Chief Health Equity Officer  
Allergy & Asthma Network

# What is a Clinical Trial?

Clinical trials are research studies in which people volunteer to help find answers to specific health questions. Clinical trials provide an opportunity to explore alternative treatments beyond the standard options and can also be considered a treatment option. They aim to improve existing treatments or discover new treatments.

Remember that participating in a clinical trial also involves risk, such as potential side effects or uncertainty about if the treatment will work. It is essential to discuss these factors with your healthcare provider and carefully weigh the pros and cons before deciding to participate.

## Potential Benefits to Participating in a Clinical Trial

1. Access to new treatments
2. Contribution to medical knowledge
3. Close monitoring and care
4. Potential cost savings
5. Empowerment and advocacy

# Importance of Diversity in Clinical Trials

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# Why is Diversity Important in Clinical Trials?

- People may experience the same disease differently.
- Including a variety of lived experience, living conditions, and characteristics (such as race, ethnicity, age, sex, and sexual orientation) ensures that all communities can benefit from scientific advancements.
- Diverse clinical trial participants help researchers understand safety and how the drug works for different populations.
- It also helps researchers better understand patterns of difference in health and illness based on different backgrounds.

The Black/African American community makes up 13% of the US population. But only 7% of the of the participants in clinical trials for treatments approved from 2015-2019.

# Q+A

What questions do you have for Dr. Joseph, Thomas, or Catherine?