Addressing Barriers in Food Allergies and Empowering the Black Community

Presented by: Allergy & Asthma Network
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
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 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…

Johansson and Mersha, 2021
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…

[Image showing current opportunities to get involved with research]

[Links to AAN's website for finding a study and more information on clinical trials](https://allergyasthmanetwork.org/research/find-a-study/)
The Weight of it All

The Burdens of Food Allergy
The Burdens of Food Allergy

According to foodallergy.org FARE Food Allergy Stats and Facts

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

Economic
Food allergy costs US families
$25 BILLION a year

Allergy-friendly foods cost
30% MORE THAN other foods

Quality of Life

more allergyandasthmanetwork.org
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

<table>
<thead>
<tr>
<th>Food Allergy</th>
<th>Food Intolerance</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Mouth itching</td>
<td>• Bloating</td>
</tr>
<tr>
<td>• Hives</td>
<td>• Abdominal pain</td>
</tr>
<tr>
<td>• Vomiting</td>
<td>• Diarrhea</td>
</tr>
<tr>
<td>• Throat tightness</td>
<td></td>
</tr>
<tr>
<td>• Lip or tongue swelling</td>
<td></td>
</tr>
<tr>
<td>• shortness of breath</td>
<td></td>
</tr>
<tr>
<td>• Anaphylaxis (when 2 or more of the above are present)</td>
<td></td>
</tr>
</tbody>
</table>
Some Key Points

• Food allergy is driven by a cell called IgE while food intolerance/sensitivity is not
• Food sensitivity ≠ 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:

- Itchy or tingly mouth
- Hives on the mouth
- Scratchy or sore throat
- Swelling of the lips, mouth, tongue or throat

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

What foods cause oral allergy syndrome?
The following lists show foods that are botanically related to birch, grasses and ragweed:

<table>
<thead>
<tr>
<th>Birch pollen</th>
<th>Grass pollen</th>
<th>Ragweed pollen</th>
</tr>
</thead>
<tbody>
<tr>
<td>almond</td>
<td>kiwi</td>
<td>banana</td>
</tr>
<tr>
<td>apple</td>
<td>melon</td>
<td>chamomile</td>
</tr>
<tr>
<td>carrot</td>
<td>peach</td>
<td>cucumber</td>
</tr>
<tr>
<td>celery</td>
<td>tomato</td>
<td>echinacea</td>
</tr>
<tr>
<td>cherry</td>
<td></td>
<td>melon (watermelon, cantaloupe, honeydew)</td>
</tr>
<tr>
<td>hazelnut</td>
<td></td>
<td>sunflower seed</td>
</tr>
<tr>
<td>kiwi</td>
<td></td>
<td>zucchini</td>
</tr>
<tr>
<td>peach</td>
<td></td>
<td></td>
</tr>
<tr>
<td>pear</td>
<td></td>
<td></td>
</tr>
<tr>
<td>plum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>potato</td>
<td></td>
<td></td>
</tr>
<tr>
<td>pumpkin seed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

https://allergyasthmanetwork.org/food-allergies/
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 ≥ 6 weeks after suspected reaction
  - Avoids false negative
Treatment of Allergic Reactions

- Avoidance, Avoidance, Avoidance
  - Guidance on safe dietary practices
    - AAAAI.org
    - AllergyAsthmaNetwork.org
    - 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)
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 ≥ 600mg of peanut and increased amount of their other food allergens (cashew, egg, and milk)
    • Injection every 2-4 weeks for 16-20 weeks
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

https://dbv-technologies.com/our-science/viaskin-platform/
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.

<table>
<thead>
<tr>
<th>DAIRY</th>
<th>EGG</th>
<th>PEANUT</th>
<th>SESAME</th>
<th>SOY</th>
<th>WHEAT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Casein</td>
<td>Albumin</td>
<td>Cold-pressed peanut oil</td>
<td>Benne</td>
<td>Miso</td>
<td>Farro</td>
</tr>
<tr>
<td>Curds</td>
<td>Lysozyme</td>
<td>Goobers</td>
<td>Gingilly</td>
<td>Natto</td>
<td>Food starches</td>
</tr>
<tr>
<td>Ghee</td>
<td>Meringue</td>
<td>Legumes</td>
<td>Sesamol</td>
<td>Shoyu</td>
<td>Graham flour</td>
</tr>
<tr>
<td>Lactalbumin</td>
<td>Ovalbumin</td>
<td>Marzipan</td>
<td>Sim Sim</td>
<td>Soya</td>
<td>Malt</td>
</tr>
<tr>
<td>Sodium caseinate</td>
<td>Surimi</td>
<td>Nut meat</td>
<td>Tahini</td>
<td>Tamari</td>
<td>Semolina</td>
</tr>
<tr>
<td>Tagatose</td>
<td>Whey</td>
<td>Nougat</td>
<td></td>
<td>Tempeh</td>
<td>Spelt</td>
</tr>
</tbody>
</table>

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

- 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
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

https://foodiversity.org/news/
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
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
Elijah-Alavi Foundation
www.elijahalavifoundation.org

Elevating Food Allergy and Asthma Awareness through Comprehensive Training, Educational Research, Community Outreach, Advocacy, and Promoting Equity for All
Registered Charity # 864001838

Black People Like Me
2024
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.

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

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.
Importance of Diversity in Clinical Trials
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.
What questions do you have for Dr. Joseph, Thomas, or Catherine?