Alpha-Gal Syndrome: From Diagnosis to (Ingredient) Detective

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ALPHA-GAL SYNDROME: FROM DIAGNOSIS TO (INGREDIENT) DETECTIVE
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Objectives

- Overview of Alpha-gal Syndrome
- Diagnosis, Treatment, & Support
- Be An Ingredient Detective
- Social and Emotional Support
- Q&A
Introduction

- 2004 ImClone asked Dr. Platts-Mills to develop a test for severe allergic reactions to Cetuximab (cancer drug).

- ImClone did not get FDA approval, and Martha Stewart got in trouble for insider trading.

- 2006, a patient died in Bentonville from the first dose of Cetuximab.

- Dr. Tina Merritt requested Dr. Platts-Mills develop a new test for this allergy.

- Galactose-alpha-1,3-galactose (Alpha-gal) is a carbohydrate expressed on non-primate mammal proteins.
Introduction

- Allergy to Alpha-gal is a food allergy to beef, pork, mammal products and some medications.

- Symptoms can be severe, and unlike other food allergy reactions, symptoms from mammal products can be delayed by up to 10 hours.

- These reactions were reported in Australia 30 years before the discovery in the US, and the number of people affected is growing.

- The reactions are associated with bites from the lone star tick, and recent findings found alpha-gal in the saliva of the black-legged tick in the US. AGS has also been implicated with other species of ticks in other countries.
Determining the link between alpha-gal-containing antigens in North American ticks and red meat allergy
Gary Crispell, Scott P. Commins, Stephanie A. Archer-Hartman, Shailesh Choudhary, Guha Dharmarajan, Parastoo Azadi, Shahid Karim

- Investigated the presence of Alpha-gal in four tick species.
- Using anti-Alpha-gal antibodies, Alpha-gal was identified in the salivary glands of both Amblyomma americanum (Lone-star tick) and Ixodes scapularis (black-legged tick).
- They fed these species human blood (lacks Alpha-gal) using an artificial membrane. Am. Americanum and Ix. Scapularis have Alpha-gal in their saliva and salivary glands.
Associated Ticks, United States

Additional ticks associated worldwide

Black-legged tick (*Ixodes scapularis*)
- Anaplasma phagocytophilum (anaplasmosis)
- Babesia microti (babesiosis)
- Borrelia burgdorferi and B. mayonii (Lyme disease)
- B. miyamotoi disease (a form of relapsing fever)
- Ehrlichia muris eauclairensis (ehrlichiosis)
- Powassan virus (Powassan virus disease)
- Tick paralysis

Lone star tick (*Amblyomma americanum*)
- Alpha-gal Syndrome, aka “Red Meat” allergy
- Bourbon virus (Bourbon virus disease)
- Ehrlichia chaffeensis and E. ewingii (ehrlichiosis)
- Francisella tularensis (tularemia)
- Heartland virus (Heartland virus disease)
- Southern tick-associated rash illness (STARI)
- Spotted Fever Rickettsiosis
- Tick paralysis
AGS Symptoms

- Reactions are usually delayed up 10 hours
- Hives/rash
- GI Distress: abdominal pain, vomiting, diarrhea
- Blood pressure drop
- Breathing problems
- Anaphylaxis

Photo Credit: FoodAllergy.com
foodallergy.org/life-with-food-allergies/epinephrine/epinephrine-options-and-training
For a suspected or active food allergy reaction:

For any of the following **SEVERE SYMPTOMS**

- **LUNG:** Short of breath, wheezing, repetitive cough
- **HEART:** Pale, blue, faint, weak pulse, dizzy
- **THROAT:** Tight, hoarse, trouble breathing/swallowing
- **MOUTH:** Significant swelling of the tongue and/or lips
- **SKIN:** Many hives over body, widespread redness
- **GUT:** Repetitive vomiting or severe diarrhea
- **OTHER:** Feeling something bad is about to happen, anxiety, confusion

Or more than one **MILD SYMPTOM**

- **NOSE:** Itchy/runny nose, sneezing
- **MOUTH:** Itchy mouth
- **SKIN:** A few hives, mild itch
- **GUT:** Mild nausea/discomfort

1. **INJECT EPINEPHRINE IMMEDIATELY.**
2. **Call 911.** Request ambulance with epinephrine.

Do not depend on antihistamines. When in doubt, give epinephrine and call 911.
Testing for IgE to Alpha-gal

- The main commercial laboratory in the United States is Viracor-Eurofins, but the test is ordered through a referring laboratory (Ex. Quest Diagnostics test code 95241).
- The code for IgE to Galactose-alpha-1,3 galactose is 30039 at Viracor-Eurofins, there is a panel as well. Some laboratories will do the IgE to beef, and pork at a different lab.
- It is generally a good idea to check IgE to milk if an allergy to Alpha-gal is suspected.
- Some insurance companies cover with specific diagnosis codes (Ex. Allergic urticaria).
- A positive result is >0.10, and Alpha-gal IgE does not fit the traditional scale for IgE mediated allergy.
Patient Drive/Self Report

Alpha-gal Syndrome Map

Search online: “Where in the world is Alpha-gal?”
Medications

- Certain vaccines (influenza, measles/mumps/rubella, varicella, rabies, shingles (zoster), typhoid oral
- Gelatin capsules
- Medications/supplements from pregelatinized starch
- Some pancreatic enzymes (Panges-CN 10 is ok)

- Medications containing stearic acid or magnesium stearate (often animal derived)
- Some commonly used medications including heparin, simvastatin, omeprazole, synthroid, etc. contain animal products including animal by-products, lactose, gelatin, or stearic acid etc.
- Check with your Pharmacist, may need compounded medicine.
Top Patient Concerns:

- 89% Lack of healthcare provider knowledge
- 79% Ingredient labeling on food and pharmaceuticals
- 36% Funding for additional research of Alpha-gal
Labeling: AG-Free

Food Allergen Labeling and Consumer Protection Act (FALCPA)

FASTER Act

Photo credit: SnackSafely.com
Hey Siri! Does Jiffy Mix contain animal products?

“Hey Siri! Does Jiffy Mix contain animal products?”

- How is _____ made?
- Is _____ vegan?
- Does _____ contain animal?
Mammalian Ingredients

- Beef
- Bison/Buffalo
- Goat
- Lamb
- Rabbit
- Pork
- Venison (deer)

- Broth/Stock
  
  (e.g. mammal - bones, fat, skin, meat)

- Sauces, gravies, marinades - 
  
  (e.g. beef or pork ingredient names)

- Fat/Lard (e.g. refried beans, fillers, baked potatoes, baked goods)

- “Natural” flavorings

- Diary & “Non-dairy” products.
  
  (e.g. lactose, casein and whey proteins)

- Alcohol (e.g. filtering, gelatin)
Hidden Mammalian Ingredients: Gelatin

- Nuts—may use gelatin to make salt stick
- Gummy candies
- Gummy multivitamins
- Gelatin desserts
- Marshmallows
- Altoids brand mints

- Kellogg’s Frosted Shredded Mini Wheats
- Kellogg’s Frosted Pop Tarts
- Candy corn
- Starburst
- Lanolin: lipstick, nursing ointments, lotions
- Clothing: wool, cashmere, alpaca, leather, suede
- Animals: pets and livestock
  - Animal feed and manure
- Stearic Acid/Magnesium Stearate
- Body/Personal care items: lotions, soaps, detergents, deodorants, cosmetics and cosmetic brushes

*Vegan ingredients exception: Carrageenan sensitivity (red algae)

Other products may contain Alpha-gal
• Bovine
• Pig
• Canine
• Calf
• Cocker Spaniel
  *(Madin Darby Canine Kidney)*
• African Green Monkey
• Lactose

• Magnesium stearate
• Glycerin
• Hydrolyzed porcine gelatin
• Fetal bovine serum
• Fenton medium (contains bovine extract)
• Casamino acids (eg. in “Mueller’s growth medium”)

How to Report a Non-Emergency Reaction

If you are a consumer, health professional, or member of the food industry who wants to voluntarily report a complaint or adverse event (illness or **serious allergic reaction**) related to any **food or product shown below**, the FDA provides contact info. on their website: 

- Food
- Dietary Supplements
- Medicines, Medical Devices, Blood Products, Biologics, Special Nutritionals
- Vaccines
- Blood Transfusions and Donations
- Animal Feed
- Veterinary Products
- Cosmetics
- Tobacco
- Radiological Health Products
Support: Local and Online

- Healthcare provider - grow together
- TBCUnited
- Food Allergy Resource and Education (FARE)
- Food Allergy support groups
- Tick-borne Disease support groups
Resources

- TBC United: TBCUnited.org and Facebook.com/groups/AlphagalSyndrome
- Dr. Scott Commins, UVA: AllergytoMeat.wordpress.com
- AGS Resource Blog (patient driven): AlphagalInformation.org
Resources


• Tick-Borne Disease Working Group (TBDWG)
  https://www.hhs.gov/ash/advisory-committees/tickbornedisease/meetings/index.html

• CDC Vaccine Ingredient List

• CDC | Tick-borne Diseases of the United States
  https://www.cdc.gov/ticks/index.html
TBC United Webinars & Surveys

Surveys: www.TBCUnited.org/surveys

2020 Wednesday Webinars Series:
- Planning for Protection and Prevention - Jan. 29
- AGS Restaurant Training - Feb. 5
- AGS Wellness Series: Nutrition - Feb. 12
- AGS Wellness Series: Emotional Support - Feb. 19
- AGS: School & Employment - Feb. 26

Connect & Register at TBCUnited.org
Thank you!