

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

Presented by

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

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Education
Research
Advocacy



TBCUnited.org



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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 euclairensis (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



Photo Credit: FoodAllergy.com

foodallergy.org/life-with-food-allergies/epinephrine/epinephrine-options-and-training

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



FARE

Food Allergy Research & Education

www.foodallergy.org

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

UNDERSTAND LIMITATIONS OF THE LABEL WHEN CONCERNED WITH FOOD ALLERGIES



FALCPA regulations apply only to foods regulated by the FDA, which do *not* include meat, poultry and eggs.



**THE LABEL CAN WARN YOU THAT THE
PRODUCT IS NOT SAFE FOR YOU**

Manufacturers must clearly indicate when any of the following eight allergens are *ingredients* of the product: peanuts, tree nuts, eggs, milk wheat, soybeans, fish, shellfish.



**THE LABEL CAN'T TELL YOU FOR SURE
THAT THE PRODUCT IS SAFE FOR YOU**

Manufacturers are *not* required to tell you when there is a possibility of *cross-contamination with these allergens!*

Additional warnings like "*May contain...*" and "*Manufactured on equipment with...*" are entirely voluntary. There are no standards for when they are used, how they are worded, and where they are placed.

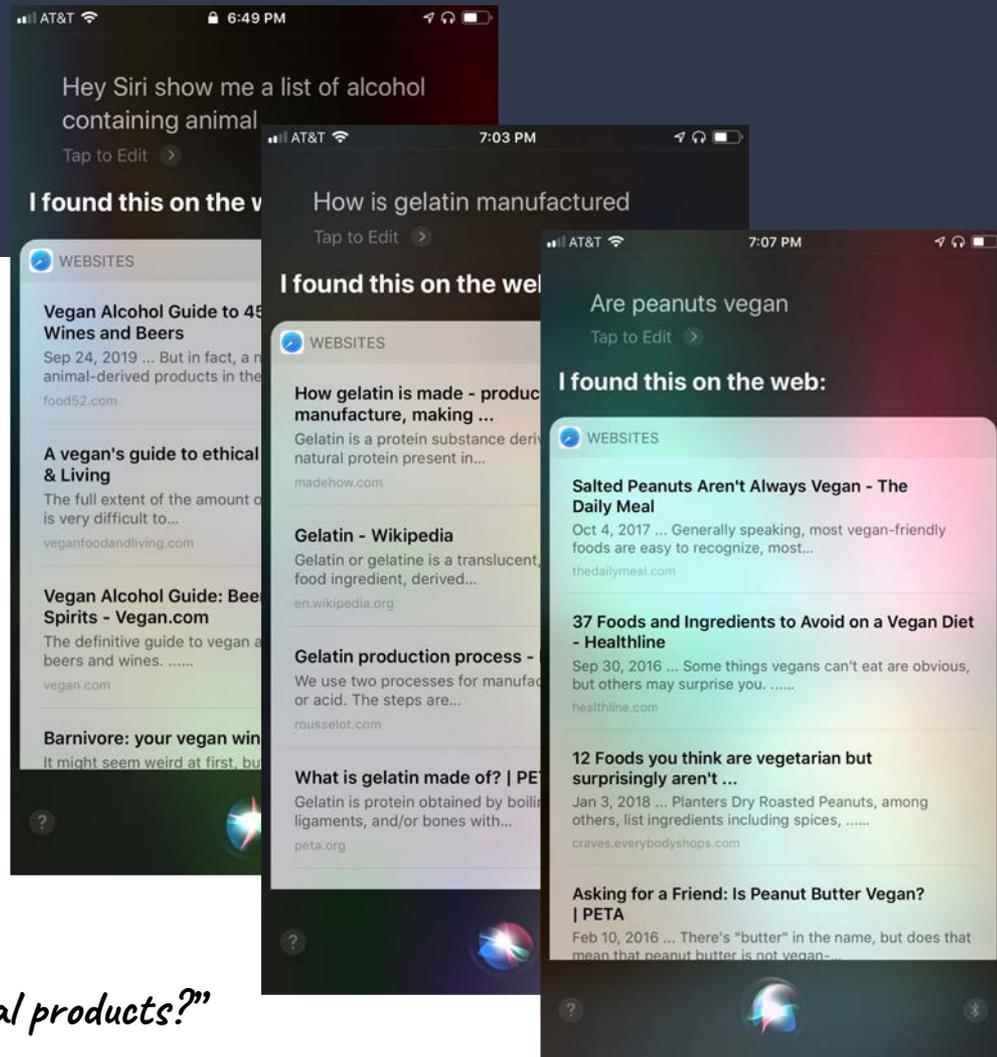
Their absence does not mean the product is safe!

Hey Google/Siri!

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



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



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
- Dairy & “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”)

<https://www.cdc.gov/vaccines/pubs/pinkbook/downloads/appendices/appdx-full-b.pdf>

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:

<http://www.fda.gov/safety/report-problem/how-report-non-emergency>

- 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](https://www.facebook.com/groups/AlphagalSyndrome)
- Dr. Scott Commins, UVA: AllergytoMeat.wordpress.com
- AGS Resource Blog (*patient driven*): AlphagalInformation.org

Resources



- F.A.R.E. - <https://www.FoodAllergy.org>
- Food Allergen Labeling and Consumer Protection Act (FALCPA)
<https://www.foodallergy.org/life-with-food-allergies/newly-diagnosed/laws-and-regulations/food-allergen-labeling-and-consumer>
- FASTER Act - <https://www.foodallergy.org/about/media-press-room/introduction-of-food-allergy-safety-treatment-education-and-research-faster>

- Tick-Borne Disease Working Group (TBDWG)
<https://www.hhs.gov/ash/advisory-committees/tickbornedisease/meetings/index.html>
- CDC Vaccine Ingredient List
<https://www.cdc.gov/vaccines/pubs/pinkbook/downloads/appendices/appdx-full-b.pdf>
- 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



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Thank you!

