

Setting a Safer Table: *Managing Alpha-gal Syndrome*

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Allergen Odyssey

- Raised two sons with severe food allergies (soy, wheat, dairy, egg)
- Multiple food allergies, including recent diagnosis of AGS
- Advocacy led to CFP involvement



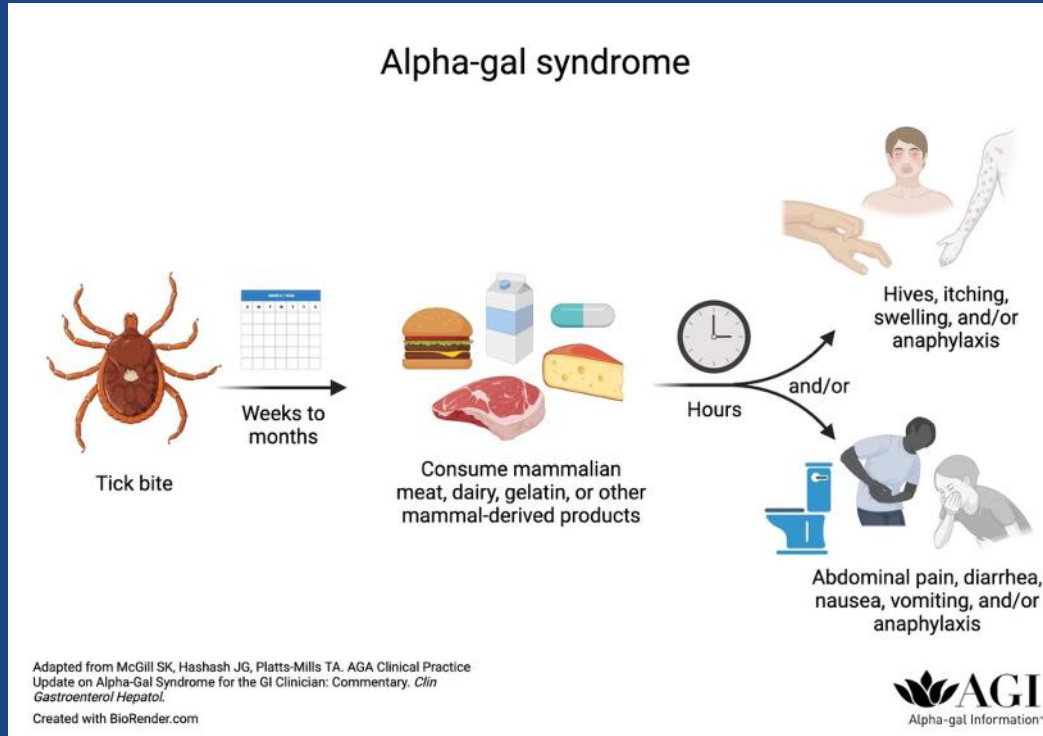
Michelle HW Hill



Candice Matthis

- Diagnosed with multiple food allergies in 2007 and Alpha-gal Syndrome in 2019
- Co-founded Two Alpha Gals and The Alpha-gal Foundation
- Patient Advocate & Policy

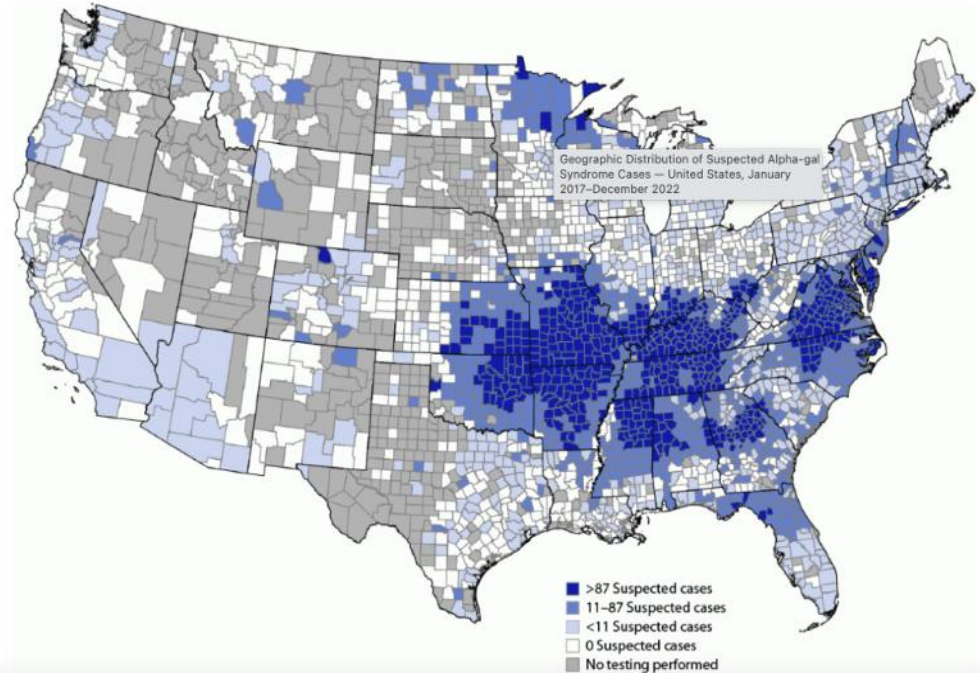
Alpha-gal Syndrome - an allergy and a tick-borne condition



The Science and Scope

- Up to 450,000 could be living with AGS in the US
- Seems to be a gross underestimate of actual cases (based on provisional data from KY and VA)
- Public Health Concern for US (via CDC)
- Could AGS be the #10th major food allergen?
- 77% of HCP have little to no knowledge of AGS

FIGURE. Geographic distribution of suspected alpha-gal syndrome cases* per 1 million population per year — United States, 2017–2022

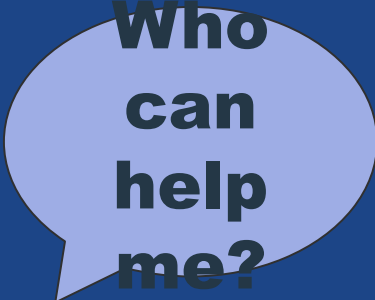


The Knowledge Gap - Patient perspective

- No lifestyle guidance
 - “Don’t eat beef.”
- Gap between healthcare and human care
- Little information available



**What
do
I do
now?**



**Who
can
help
me?**

The Knowledge Gap - Regulatory perspective

- FDA Food Code for Retail Food establishments requires CFPM to name the major food allergens and describe the symptoms of reaction
- Major Food Allergen Framework - does not call out Alpha-gal specifically
- Document applies to the FDA Major Food Allergens and addresses minor allergens.
- Labeling applies only to protein - need to include sugar and lipids.

Culinary Concerns

Alpha-gal is not "just no red meat"

- Mammalian organs, muscle meat, byproducts of, including:
- Fats and cooking oils
- Sausage casings
- Gelatin
- Natural flavors
- Carrageenan
- Vegan labeling can be problematic
- Cross-contact



INGREDIENTS: (ALL VEGAN)

Tapioca Syrup, Cane Sugar,
Filtered Water, Tapioca Starch,
Carrageenan, Soy Protein,
Natural Vanilla Flavor.

Contains: Soy.
Gluten Free. Dairy Free.

Manufactured in a Peanut & Tree
Nut Free Facility.

The Age of Invincibility: 17 - 24

- Loss of parental control over diet and health
- Want to be independent
- Feel invincible
- Want to be seen as carefree
- May not carry Epi
- May eat food without understanding what it is

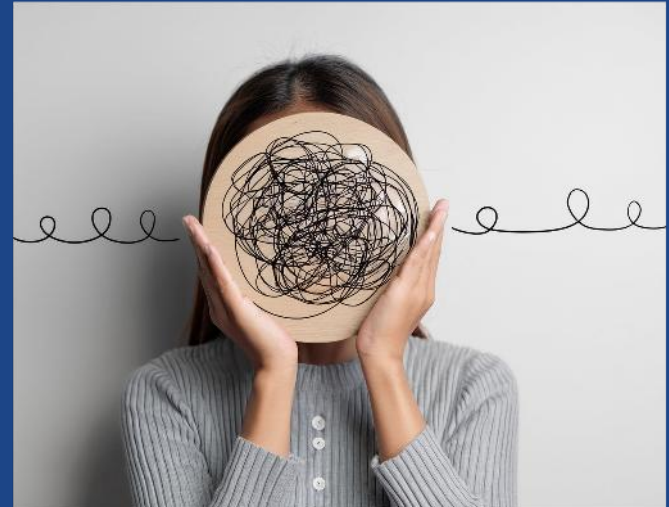
Goal: Form Partnerships, we're on the same team!



Everyday Concerns

- Burden of finding relevant research and understanding it
- PCP lack of knowledge leads to missed or incorrect diagnosis
- Foodservice workers lack of knowledge
- Constantly surveilling for exposure
- Atypical allergic response

Goal: Remove the problem, not the person!



Minding the Training Gap

FDA Food Code

- Codified allergen awareness training
- Requirements for food handlers and managers (PIC/CFPM)
 - must be able to describe the major food allergens
 - must describe symptoms of allergic response

Framework

- Specifies food allergy training specifications
- Provides food handling policies and practices
- Describes aspects of consumer notification tools
- Provides emergency response guidance

Approved at the CFP 2023 Biennial Meeting



Major Food Allergen Framework

Conference for Food Protection - 2023 Biennium
Council II: Allergen Committee

Minding the Human Gap

- Food safety begins with human behavior
 - Kindness, empathy, compassion
 - Self-assessment
- Human error and lowering risk factors
 - Anaphylaxis can happen at compliant restaurants
 - What part of the flow are you in?
- The system is working... but not for you
 - Changing the situation to include the person
- *You don't have to wait for policy change to do the right thing!*

Systems-Change: Foodservice Perspective

- Food safety culture
- Staff training
- Menu infrastructure
 - Menu variation
 - No “go to” dishes
 - Seek new recipes



Systems-Change: Customer Perspective

- Creating a positive culture
- Staff education builds trust
- Reinforces reassurance
- Variation impacts wellbeing
 - Food isn't just fuel
 - Community
- Advocacy = policy change



Action Steps

Before setting your menu:

- Understand dietary restrictions of your student population
- Supplier selection process rooted in dietary considerations
- Train your people: procurement → production → service

Assess results - are you setting a safe table?

- Student feedback
- Worker feedback
- Supplier feedback

Q&A and Resources

CFP Major Food Allergen Framework

foodprotect.org/guides-documents (current version; updated version in development)

CDC: cdc.gov/alpha-gal-syndrome

TwoAlphaGals.com

kitchen guide, hidden ingredients, patient navigation, mentorship

AlphaGalinformation.org

mammalian byproducts spreadsheet, the most comprehensive community-built resource

FARE Pilot Guidelines for Managing Food Allergies in Higher Education

Alpha-gal Allergen Inclusion Act

For those who want to carry this beyond their kitchen

AllergenFreeCooking.com

200+ allergen free recipes



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