

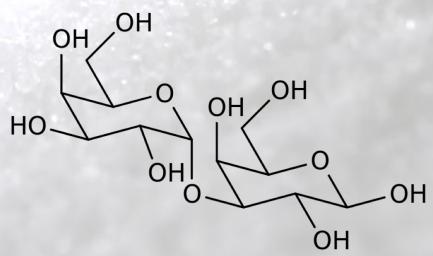
What is alpha-gal syndrome?

Or AGS

A severe, often life-threatening allergy
to a sugar



Galactose-alpha-1,3-galactose nickname: alpha-gal



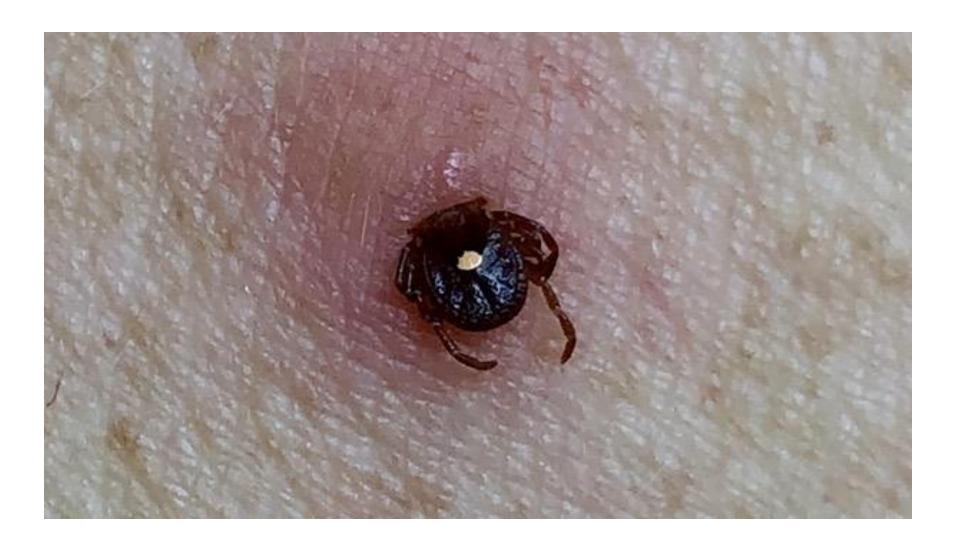
Also a nickname for alpha-gal syndrome



Why is it called a syndrome?

More than an allergy

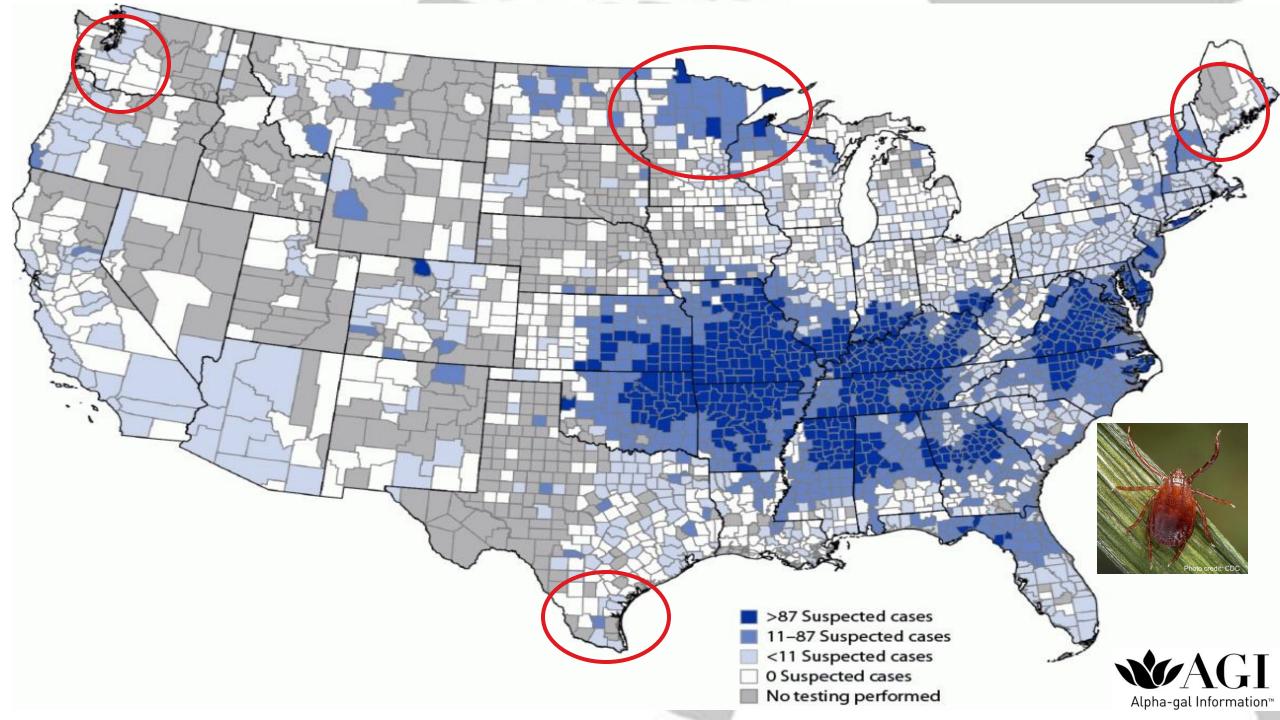






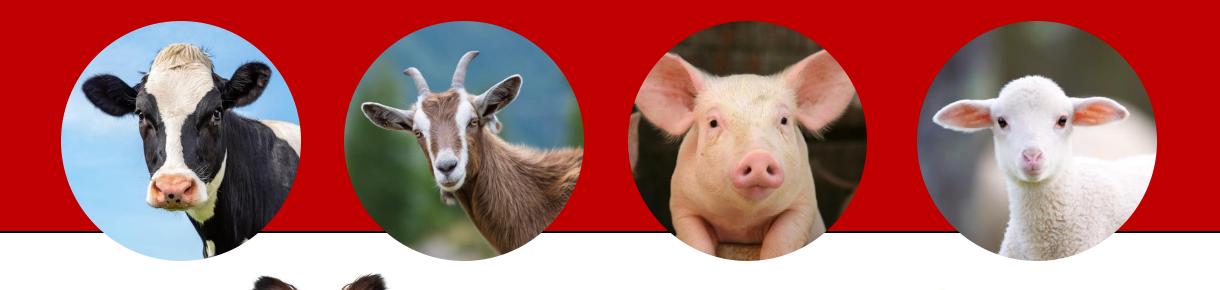






What is alpha-gal found in? Most mammals









What is else alpha-gal found in?

Alpha-gal Information™

ALPHAGALINFORMATION.ORG

- Some red algae
- Carrageenan





Alpha-gal is also found in:



- Products made from mammals
- Products made with ingredients from mammals or carrageenan

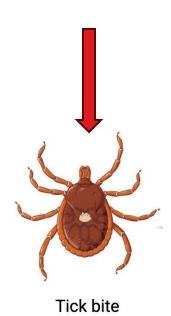


Foods & drinks

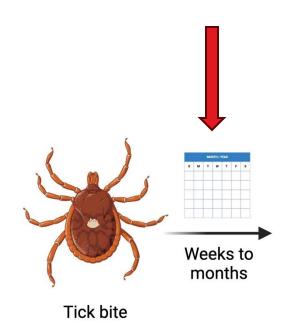
Drugs & other medical products

Personal care products

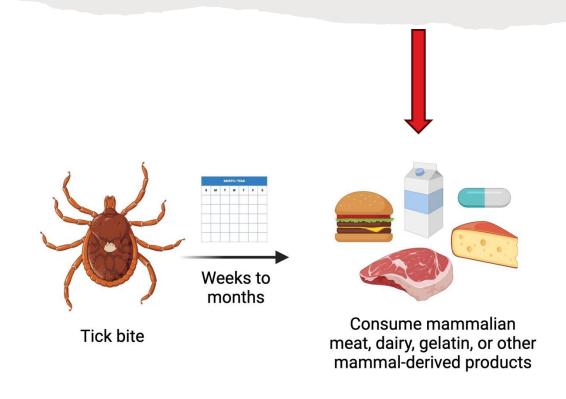
Household products



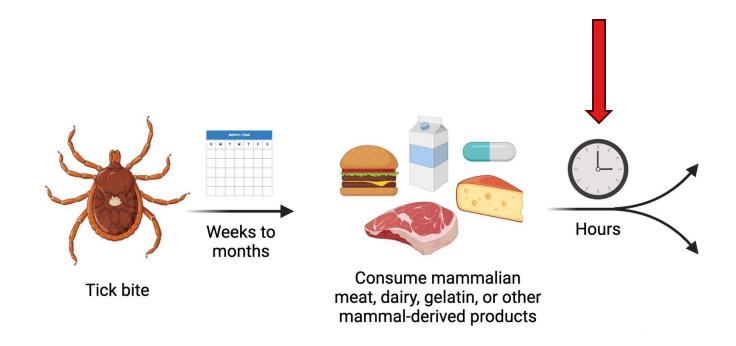
 $\begin{array}{c} \text{Alpha-gal Information}^{\text{\tiny{M}}} \end{array}$



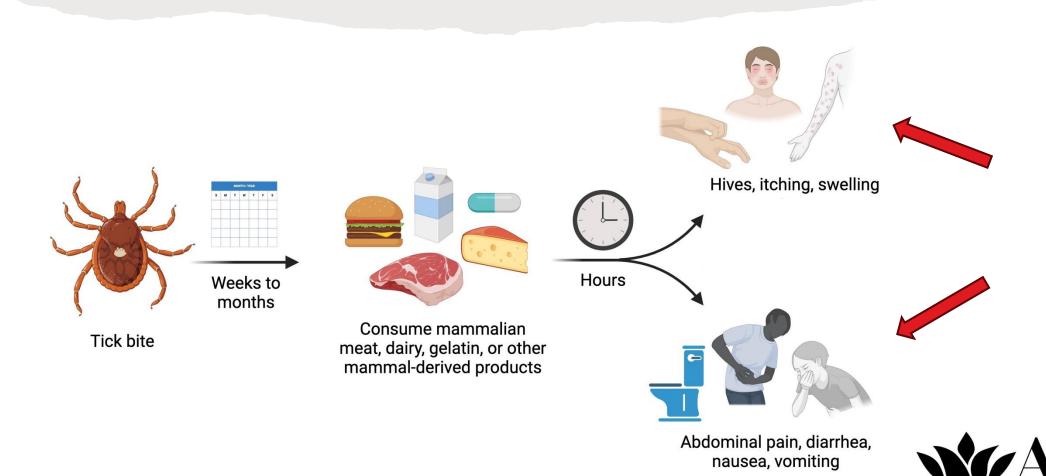












Alpha-gal Information™

Why is AGS a growing threat to public health?

- Lone star tick populations are exploding
- Lone star ticks are spreading



Huge increase in AGS cases









Lone star tick populations are exploding

Lone star ticks are spreading



Huge increase











2018 estimated cases











Why is A Sa arriving threat to bublic health?

Lone star tick populative
are exploding

Le star ticks are reading



Huge increase AGS cases







34,000

2018 ted cases



2023 estimated cases





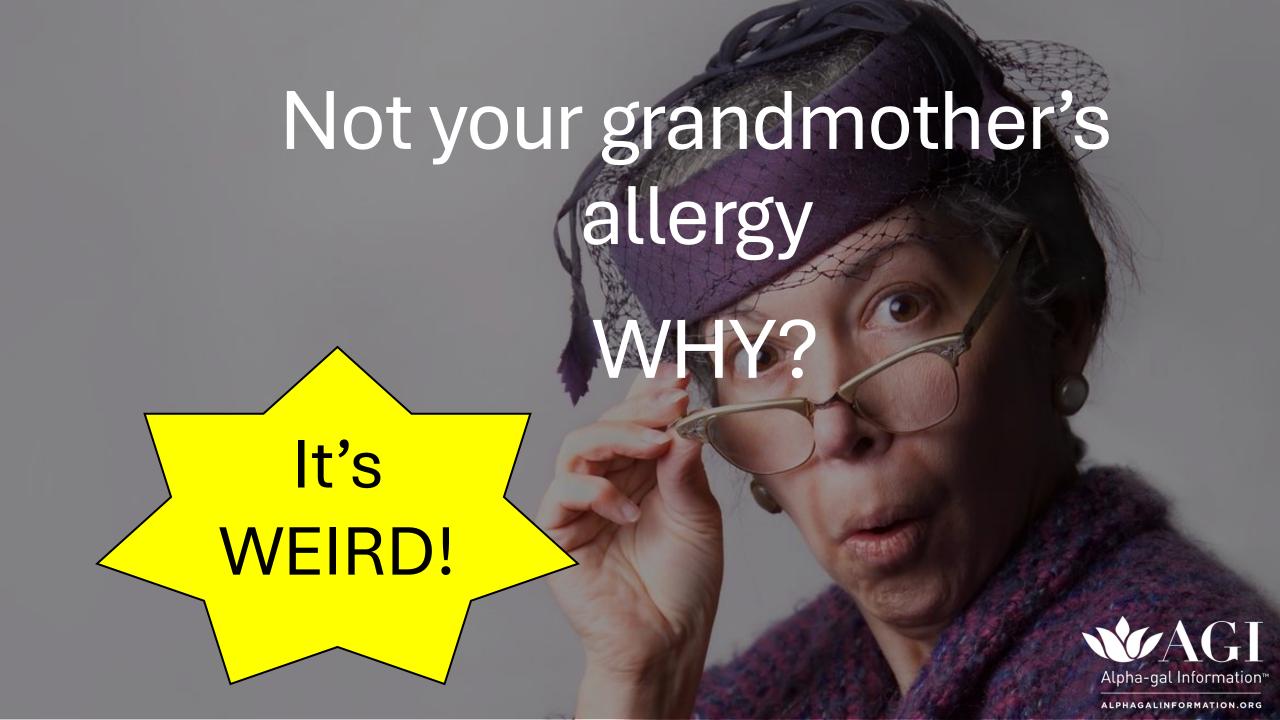
SAGI

Alpha-gal Information¹¹

ALDHAGALINEODMATION OF



Lack of provider awareness





Not your grandmother's allergy

Typical food allergies

Alpha-gal syndrome

VS









Don't know cause, not affected by tick bites

Alpha-gal syndrome

Caused by tick bites, new tick bites make it worse







Allergy to proteins, not fats or oils





Alpha-gal syndrome

Allergy to a sugar that is attached to BOTH proteins AND fats (lipids).







Alpha-gal syndrome

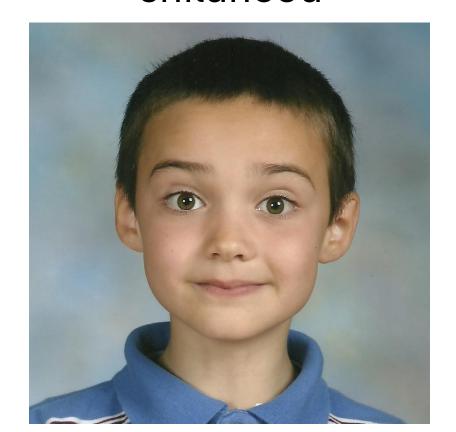
Allergy to proteins, not Allergy to a sugar that is fats of all states attached to both proteins AND Fat is the primary antigenic form of alpha-gal.







Usually start in childhood



Alpha-gal syndrome

Usually starts in adulthood





Alpha-gal syndrome

Reactions happen quickly (within minutes)

After eating

Due to the time it takes to digest and process fat

Reactions are <u>usually</u> delayed (~2-10 hrs)





Alpha-gal syndrome

Reactions happen quickly (within minutes)

Especially reactions to <u>medications</u> <u>administered by IV or</u> <u>injection</u> Some reactions are immediate



Alpha-gal Information

Alpha-gal syndrome

Reactions happen every time

Reactions only happen <u>sometimes</u>







Typical allergy symptoms, like hives and swelling

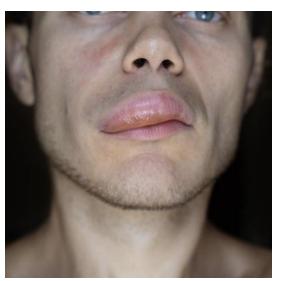
Alpha-gal syndrome

Often typical allergy symptoms like hives and swelling, but...





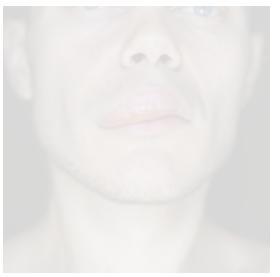






Typical allergy symptoms, like hives and swelling





Alpha-gal syndrome

Can mimic IBS or arthritis (no hives or other classic allergic symptoms)







Alpha-gal syndrome

Typical allergy symptoms, like hives and swelling

AND/OR

Can mimic IBS or arthritis (no hives or other classic allergic symptoms)







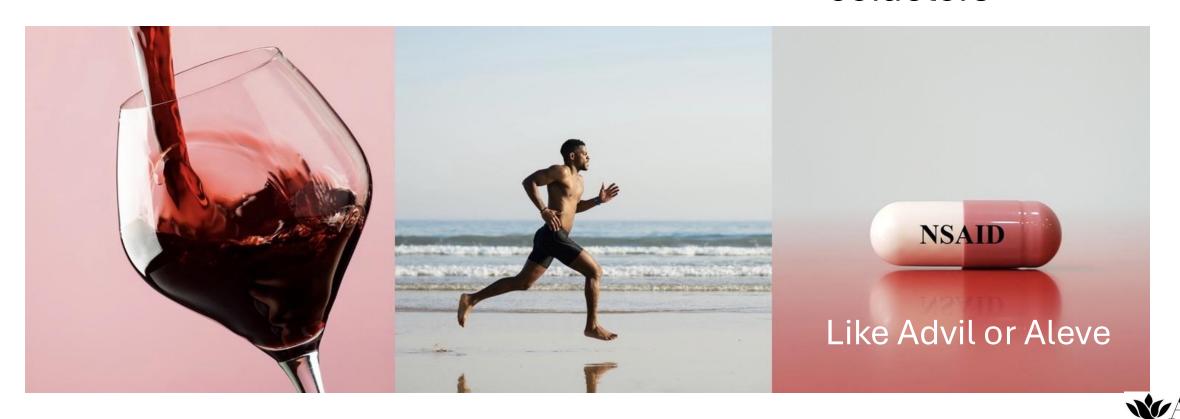




Alpha-gal syndrome

Sometimes influenced by cofactors

Often profoundly influenced by cofactors



Alpha-gal syndrome

Sometimes influenced by cofactors

Profoundly influenced by cofactors

Some people with alpha-gal syndrome <u>ONLY</u> react when a cofactor is involved

Cofactor-dependent alpha-gal syndrome

Like Advil or Aleve



Proteins:

- Big and heavy
- Rarely aerosolized (in the air)

Alpha-gal syndrome

Fats:

Easily aerosolized







Proteins:

- Big and heavy
- Rarely aerosolized (in the air)

Reactions to airborne allergens RARE

Alpha-gal syndrome

Fats:

Easily aerosolized



Reactions to airborne alphagal are COMMON



IgE is somewhat variable



Less variability between patients

Alpha-gal syndrome

IgE is extremely variable



More variability between patients



Everybody is different!

IgE variability is limited

IgE is extremely



Mostly straightforward food allergy

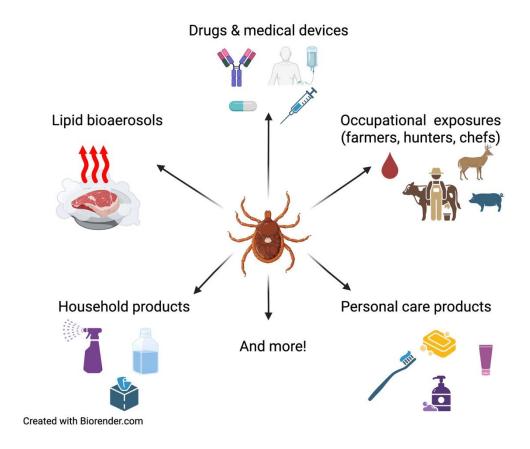
Alpha-gal syndrome

Much more than food allergy!

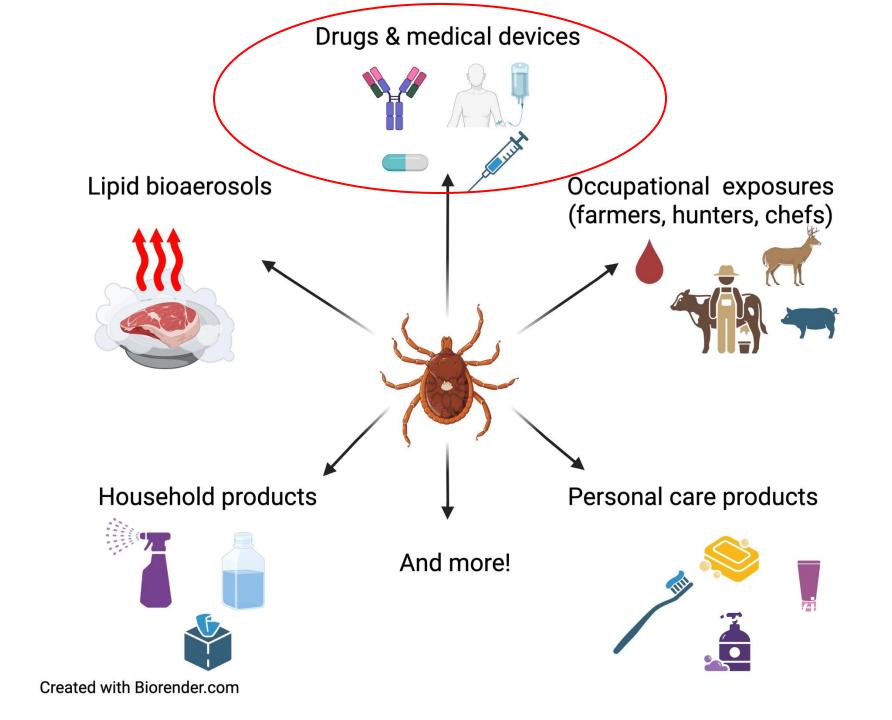
- An allergy to much more than food
- More than JUST allergy



An allergy to MUCH more than food!

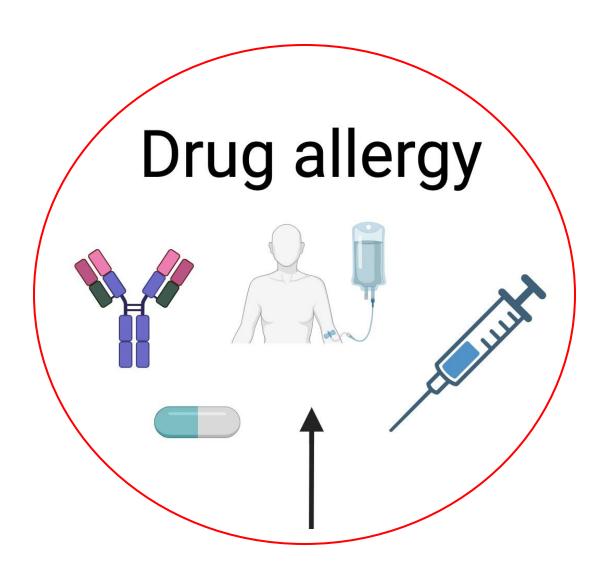






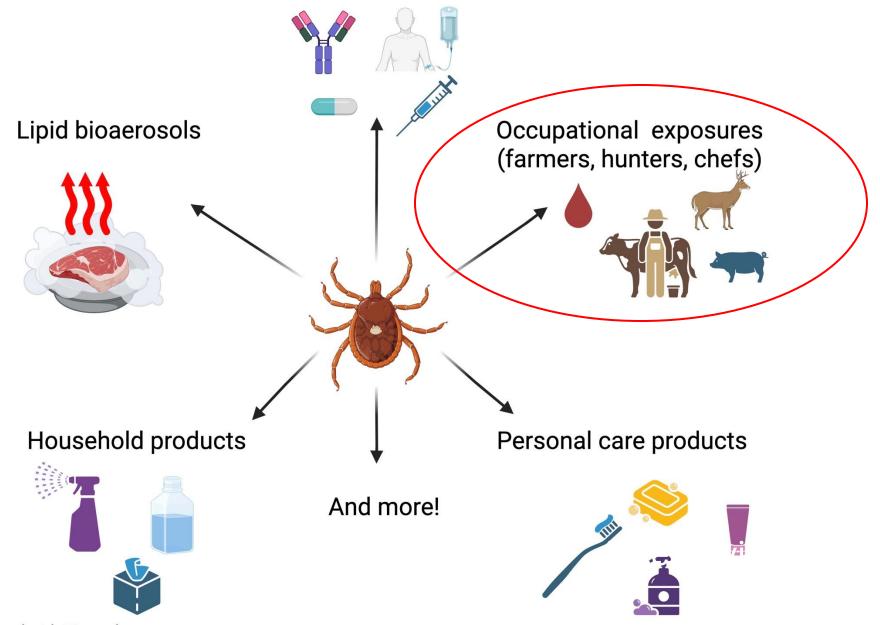


- Major drug allergy
- A top cause of perioperative anaphylaxis



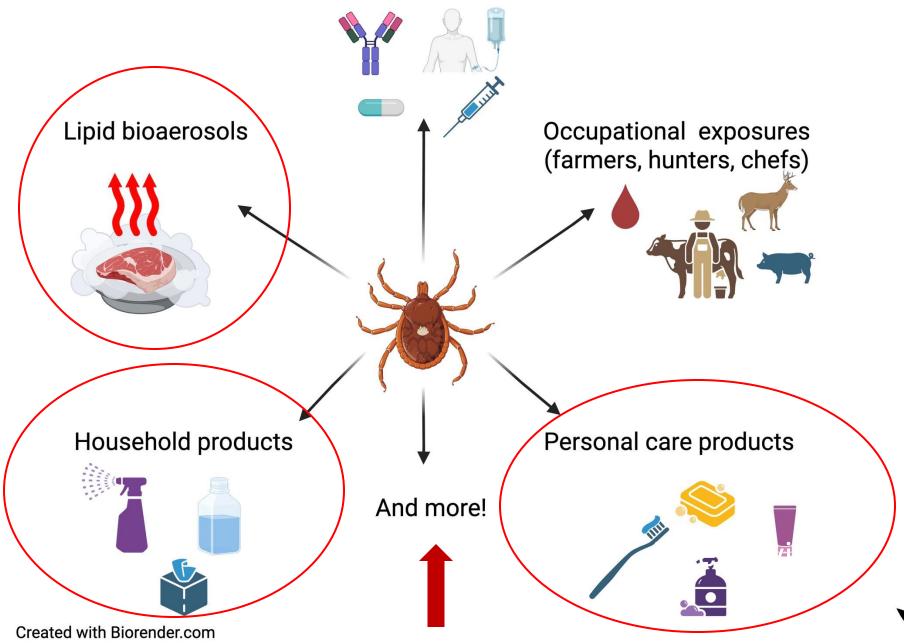


Drugs & medical devices



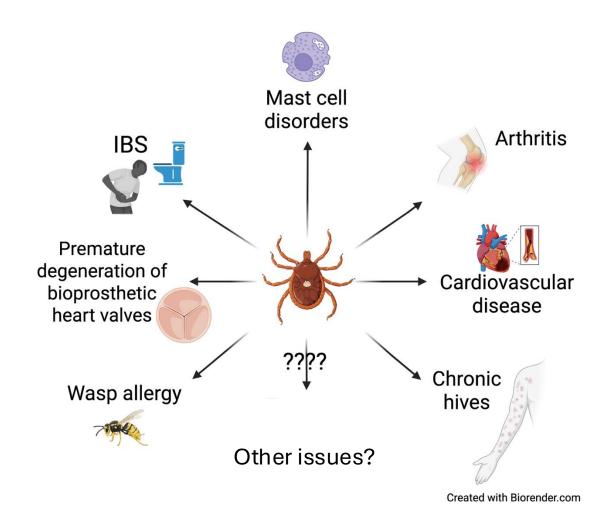


Drugs & medical devices

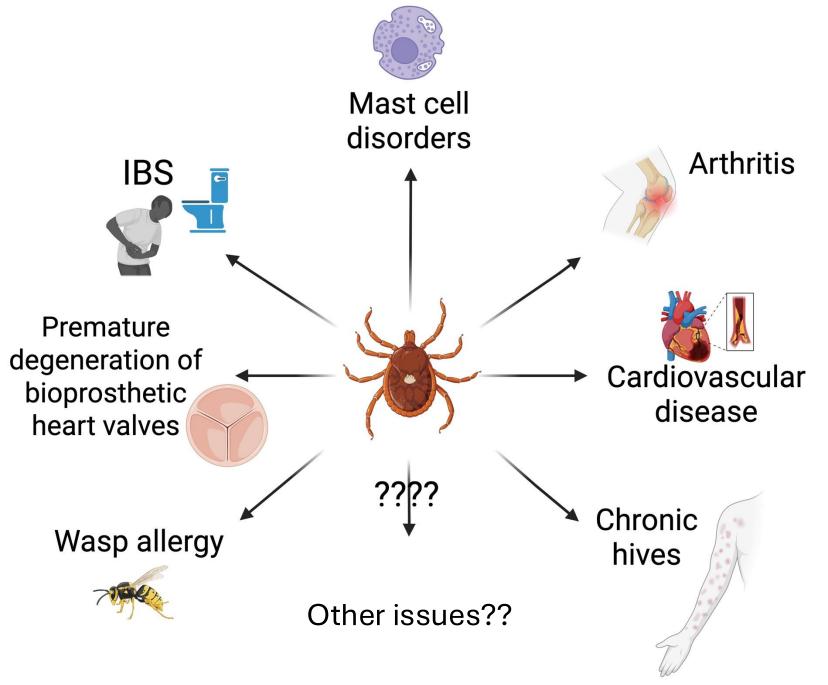




More than just an allergy

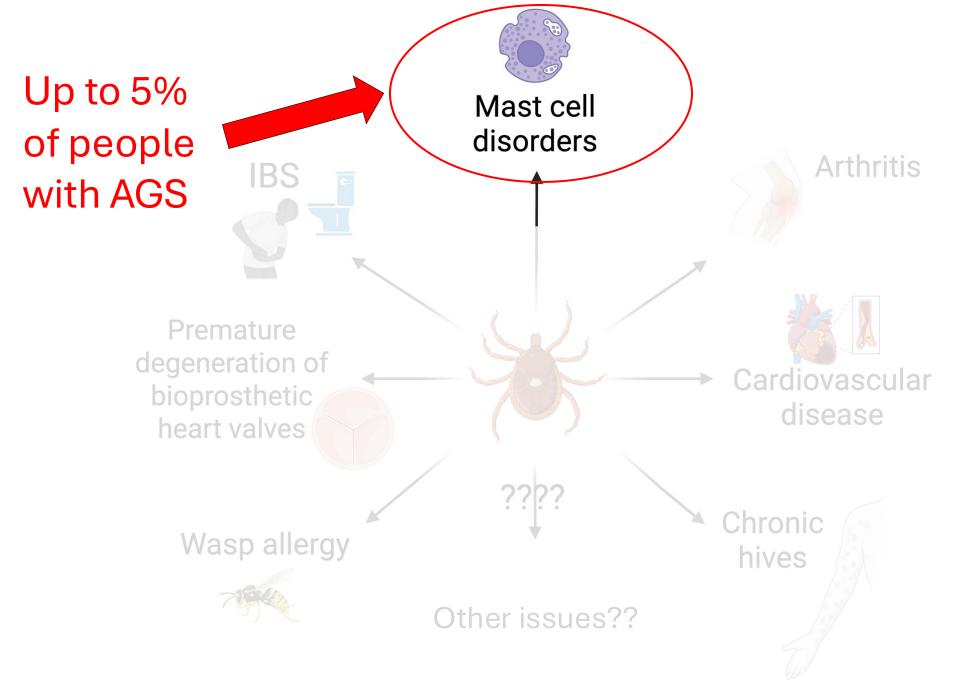




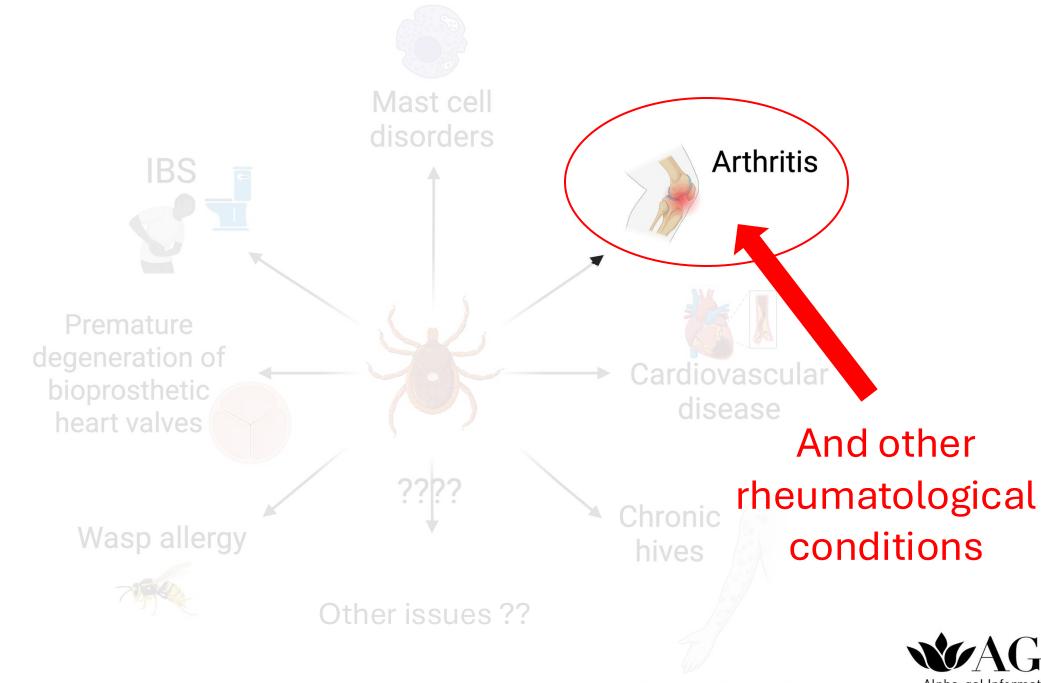


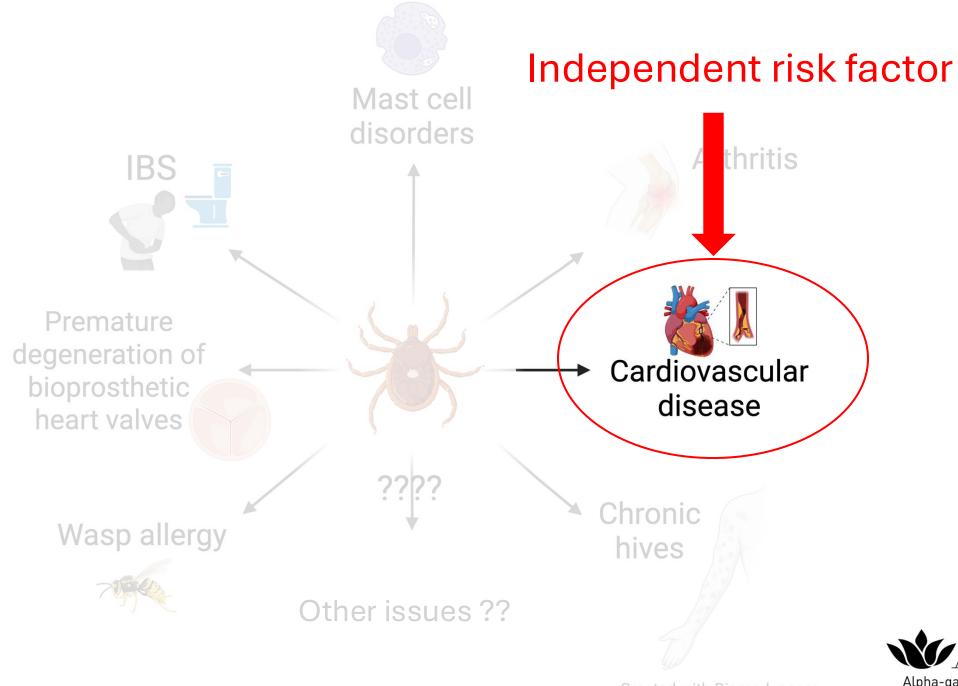


Created with Biorender.com

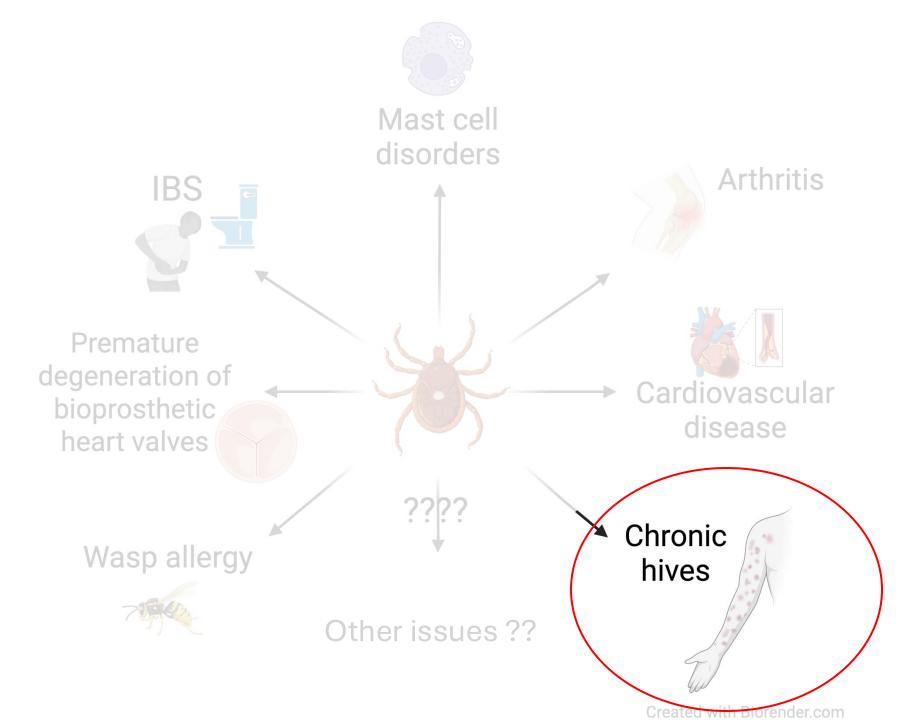




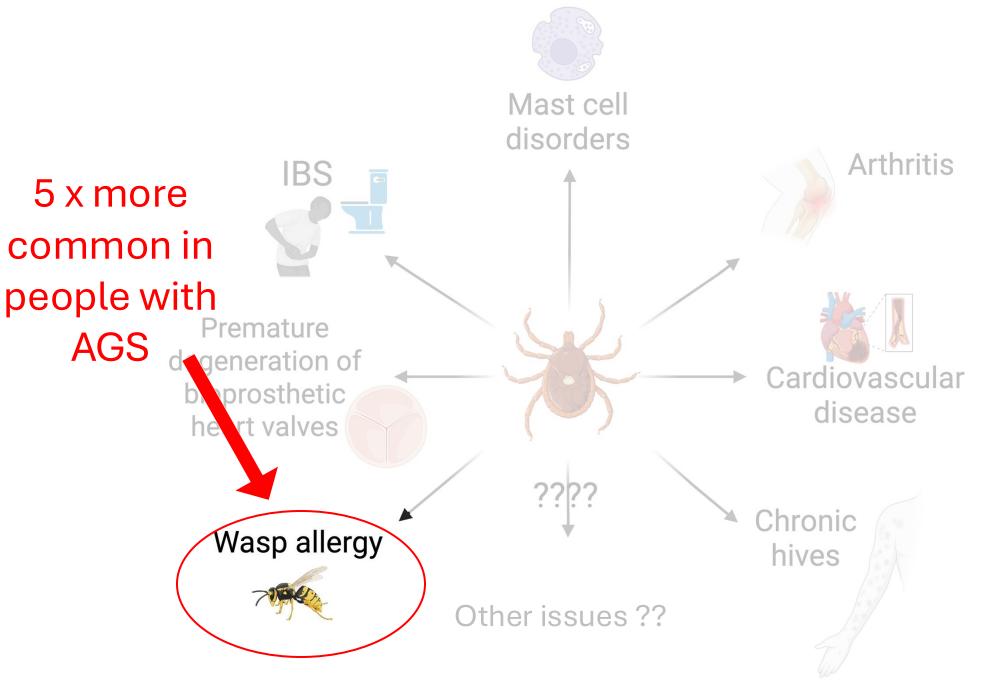




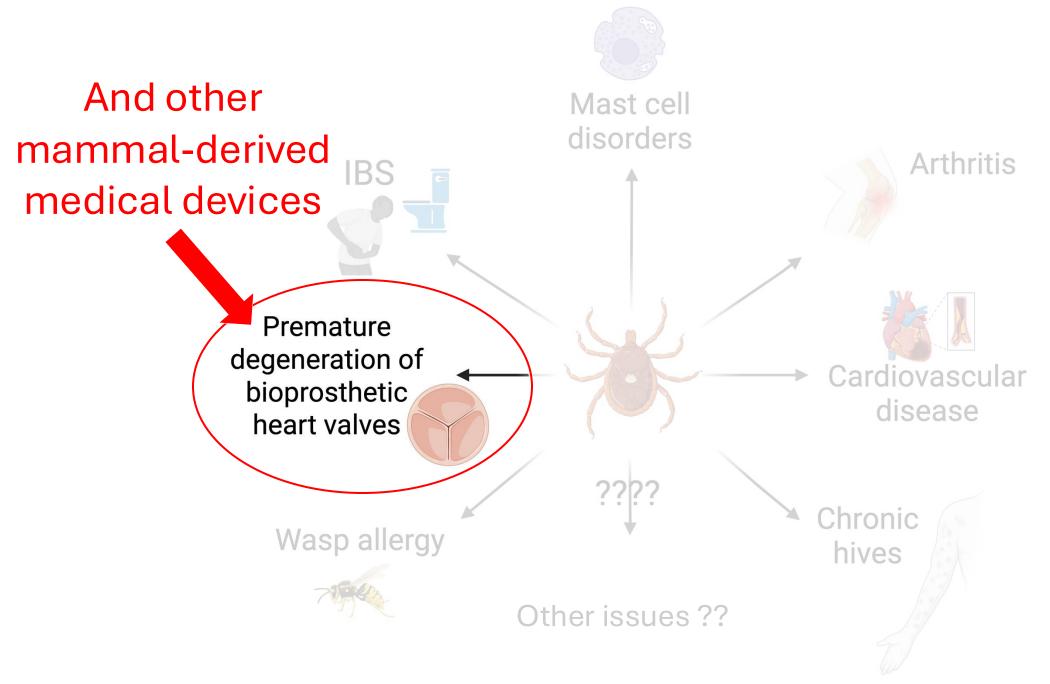




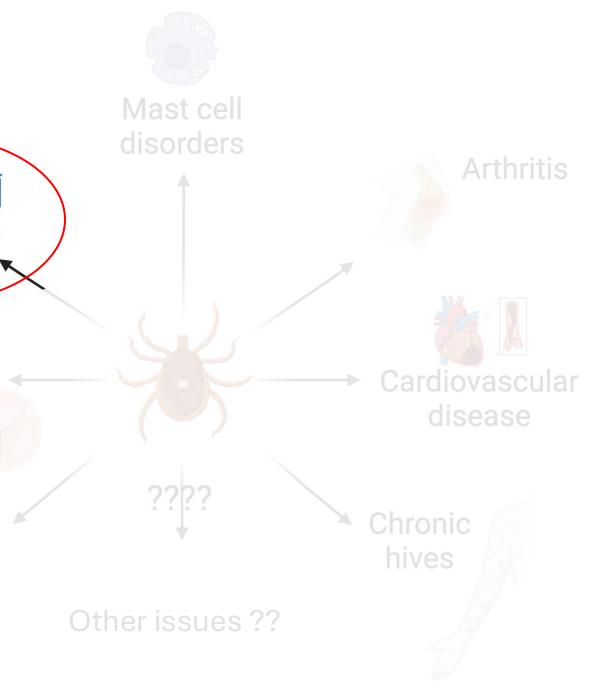












IBS

Premature

Wasp allergy

Up to 25% of IBS thetic

cases in hight valves

prevalence areas



Other issues that have been tentatively linke alpha-gal immune response in gene

- Certain kinds of transfus
- Kidney issues
- Autoimmune disease

This has
NOTHING to do
with dairy or any
other food
"damaging your
organs"

This does NOT mean that AGS is an autoimmune disease!

Other issues ??



In summary...

- Tick bites cause/make worse
- Usually starts in adulthood
- Reactions delayed (2-10 hrs)
- Reactions: sometimes
- Can mimic IBS or arthritis
- Profoundly influenced by cofactors,
- Airborne reactions COMMON
- More inter-individual variability
- Much more than food allergy





- Tick bites cause/make worse
- Usually starts in adulthood
- Reactions delayed (2-10 hrs)
- Reactions: sometimes
- Can mimic IBS or arthritis
- Profoundly influenced by cofactors
- Airborne reactions COMMON
- More inter-individual variability
- Much more than food allergy





- Tick bites cause/make worse
- Usually starts in adulthood
- Reactions delayed (2-10 hrs)
- Reactions: sometimes
- Can mimic IBS or arthritis
- Profoundly influenced by cofactors
- Airborne reactions COMMON
- More inter-individual variability
- Much more than food allergy





- Tick bites cause/make worse
- Usually starts in adulthood
- Reactions delayed (2-10 hrs)
- Reactions: sometimes
- Can mimic IBS or arthritis
- Profoundly influenced by cofactors
- Airborne reactions COMMON
- More inter-individual variability
- Much more than food allergy





- Tick bites cause/make worse
- Usually starts in adulthood
- Reactions delayed (2-10 hrs)
- Reactions: sometimes
- Can mimic IBS or arthritis
- Profoundly influenced by cofactors
- Airborne reactions COMMON
- Much more than food allergy

AGS is a:

- Drug hypersensitivity
- Independent risk factor for perioperative complications
- Tick-borne/immunoparasitologic disease
- Significant driver of chronic disease, including:
 - o IBS
 - Mast cell syndromes
 - Cardiovascular disease
 - Rheumatological disease











LUNG

THROAT

MOUTH

Classic allergic symptoms of the repetitive cough la phangal syndrome tongue or lips









Classic allergic symptoms

Skin

Hives, other rashes, itching

Swelling

• Swelling of the palms, soles of feet, lips, throat, tongue, or eye lids

Gl

- Abdominal pain
- Diarrhea, nausea, vomiting
- Heartburn, indigestion

Breathing

- Cough
- Shortness of breath, difficulty breathing

Cardiac

- Drop in blood pressure
- Dizziness or faintness



Classic allergic symptoms

Skin

Hives, other rashes, itching

Swelling

 Swelling of the palms, soles of feet, lips, throat, tongue, or eye lids

GI

- Abdominal pain
- Diarrhea, nausea, vomiting
- Heartburn, indigestion

Breathing

- Cough
- Shortness of breath, difficulty breathing

Cardiac

- Drop in blood pressure
- Dizziness or faintness

- Delayed (usually)
- Don't happen every time
- Influenced by cofactors



20% --GI symptoms ONLY.













Itching or swelling of the palms & soles of feet: often first symptom of an AGS reaction

Alpha-gal Information™

Bioaerosols from cooking meat

Personal care products



Cardiac symptoms

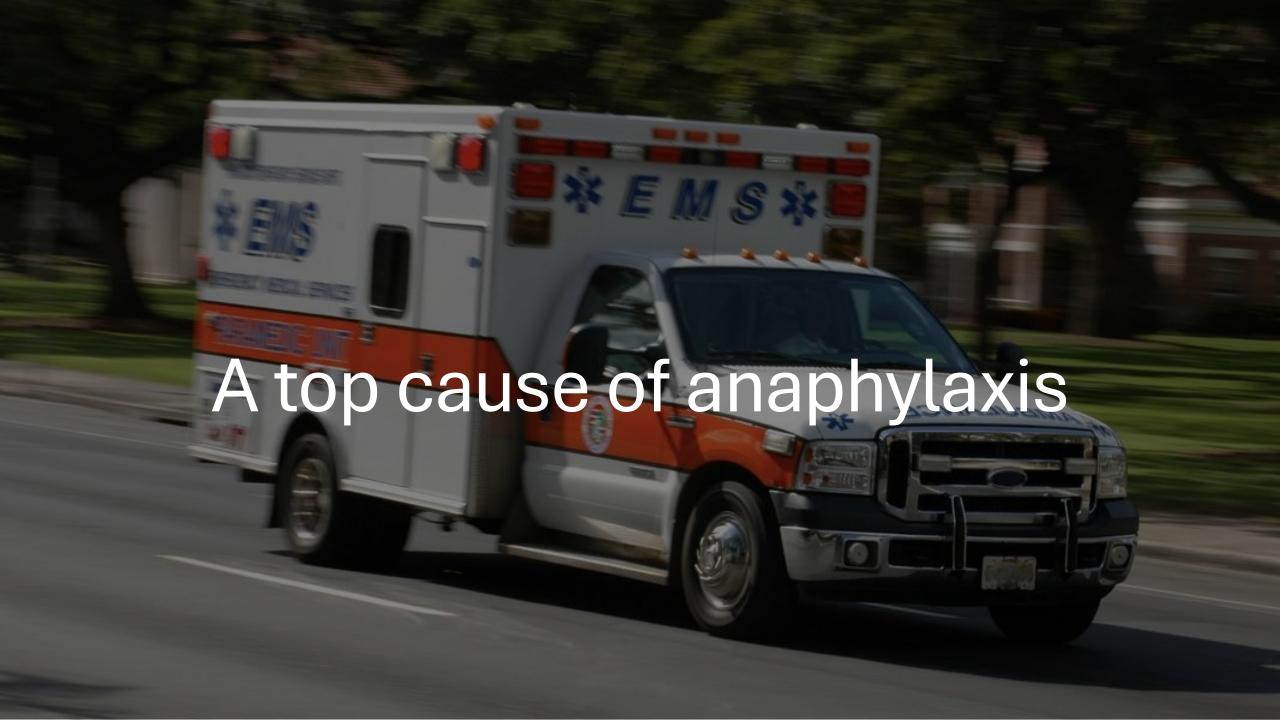
- 30-40% of people with AGS have cardiac symptoms
- ❖ Adults → less cardiac resilience
- Can lead to:
 - Loss of consciousness
 - Heart attacks



Anaphylaxis

- Severe, life-threatening reaction
- 75% of people with AGS
- Higher percentage than for any other food allergy—even peanut allergy!



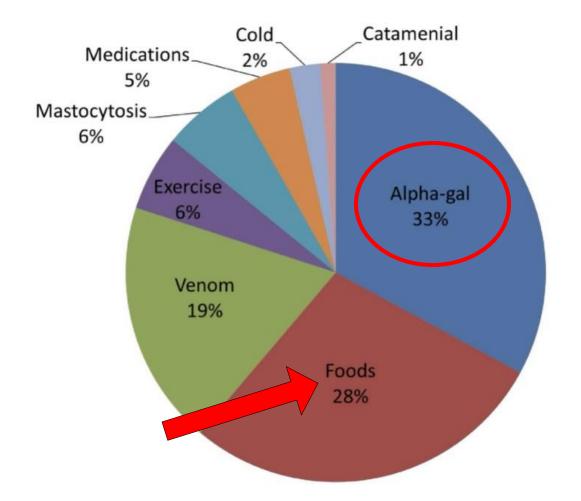


A top cause of anaphylaxis

High prevalence areas:

#1 cause of anaphylaxis in adults and adolescents





A top cause of anaphylaxis

High prevalence areas:

- #1 cause of anaphylaxis in adults and adolescents
- A third of all cases of anaphylaxis
- More than <u>all other food allergies</u> combined

Figure 1. Etiologies of anaphylaxis based on proposed "definitive cause." Alpha-gal, galactose-a-1,3-galactose.











Alpha-gal syndrome presenting as

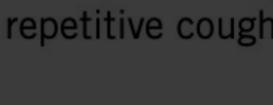
repetitive cough

HEART

THROAT

MOUTH

tongue or lips



chronic disease









GI variant of AGS

- GI symptoms ONLY
- No hives or other classic allergic symptoms

Typical symptoms:

- Abdominal pain
- Diarrhea
- Other IBS-like symptoms

Common misdiagnoses:

- ❖ IBS
- ❖ IBD
- Gallbladder disease





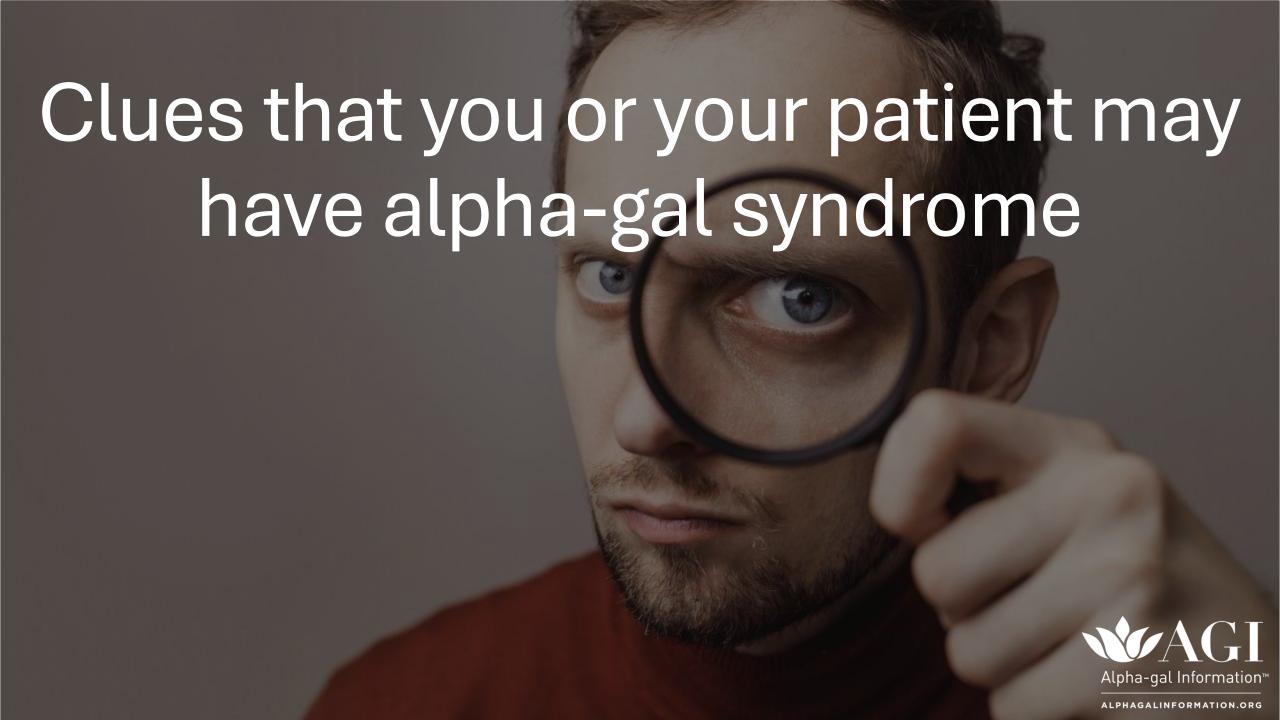
Rheumatological symptoms, like joint pain



How do I know if I have AGS?









Tick bite?

Itchy reaction?

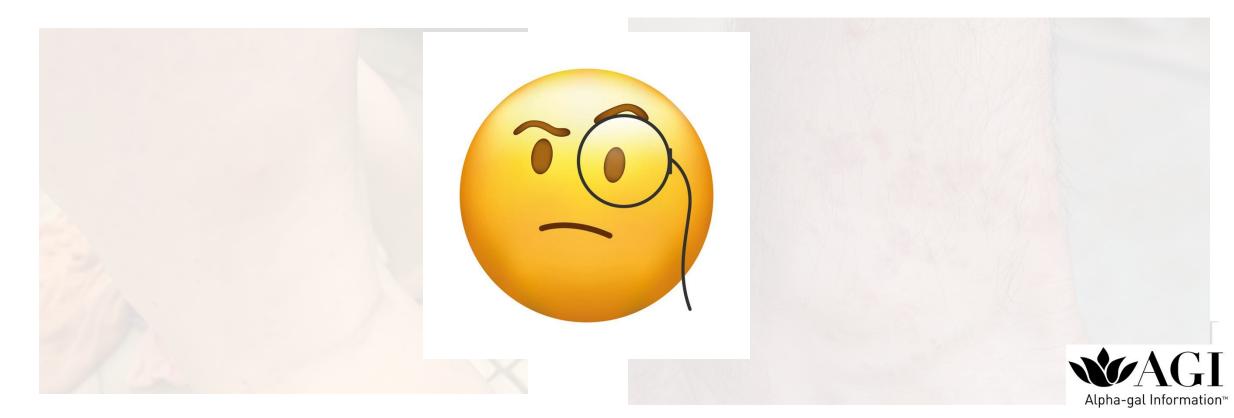
Bites like this?





Tick bite

Half the time, tchy reaction? people don't notice tick bites!





Clue #2 React <u>hours</u> after eating mammalian (red) meat?



2-10 hours later...



- May not react every time
- May only react when exercise or drink alcohol











"Any time you see a patient who is coming in saying they are waking up in the middle of the night with an allergic reaction, you better prove that it is not this [alpha-gal syndrome]."

Erin McGintee, MD

Late-night reactions?





Adult-onset allergy?







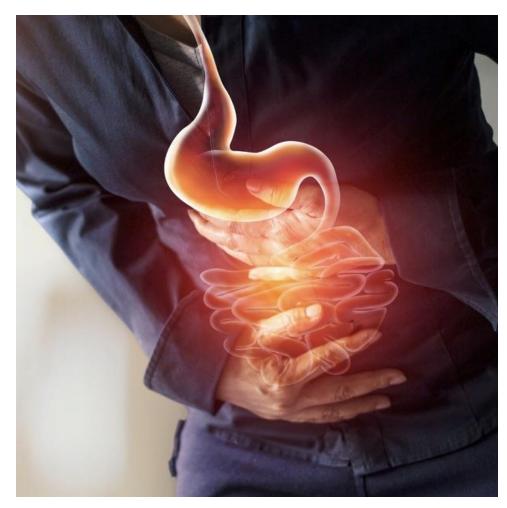
Idiopathic anaphylaxis or chronic hives?







New GI or joint symptoms weeks or months after tick bite?





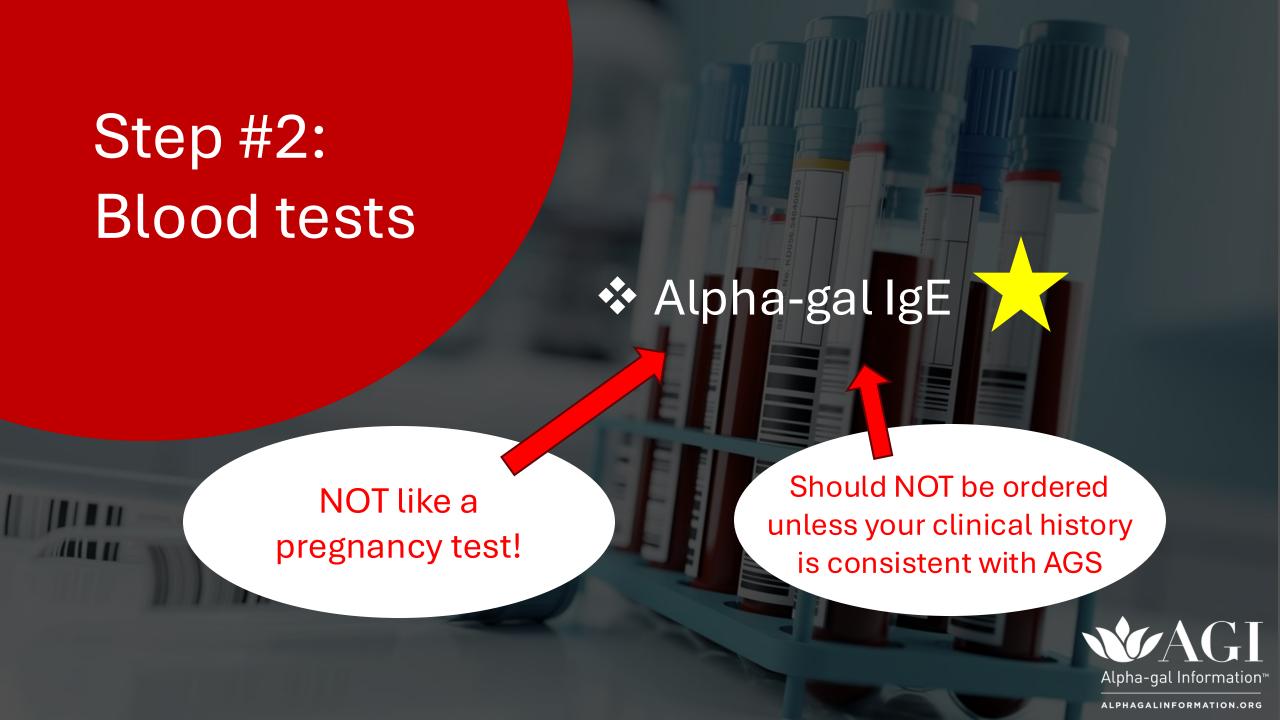
Diagnosis of alpha-gal syndrome

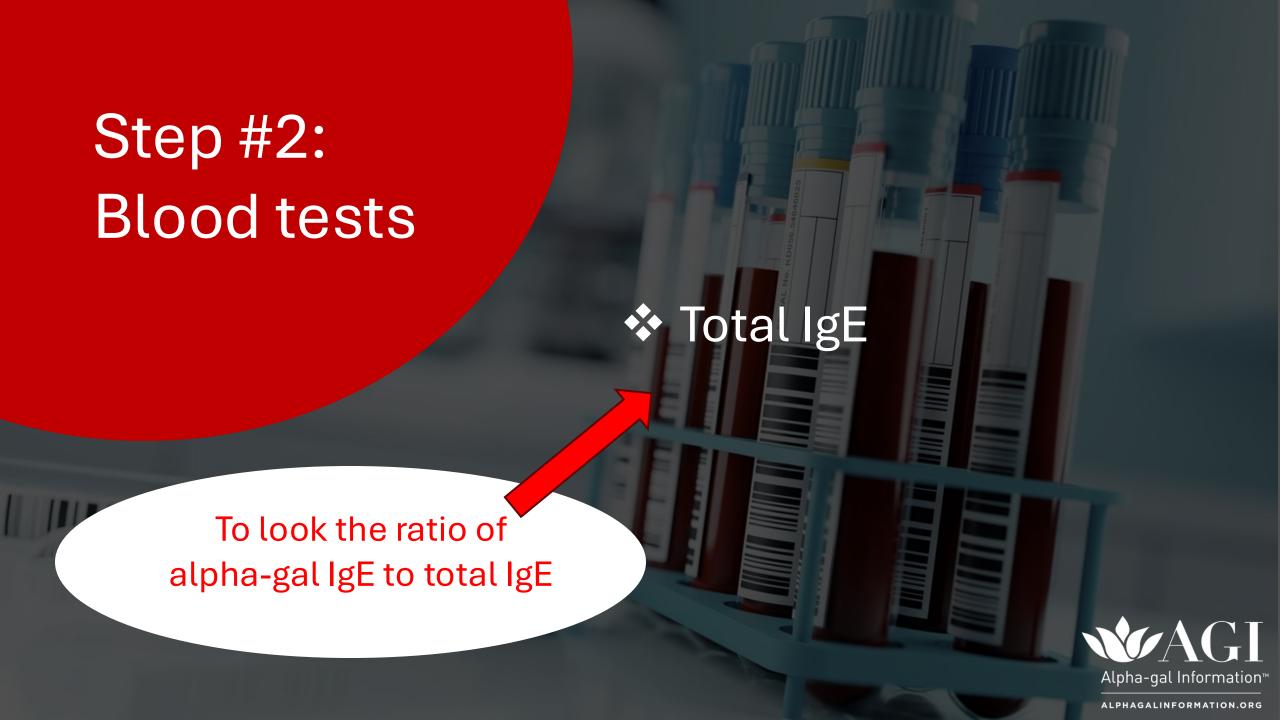




Step #1: Clinical history







If another meat allergy is suspected...

Providers may also order:

- Beef, pork or lamb IgE
- Casein or whey IgE
- Cat IgE

Or component tests like:

- ➢ Bos d 6 (bovine serum albumin)
- Sus s 1 (pork serum albumin)
- > Fel d 2 (cat serum albumin)
- ▶ Gelatin

To rule out other meat allergies



This is NOT usually necessary, because other meat allergies do NOT cause delayed reactions.



In special cases...

Providers may also order:

- Basophil activation testing
- Intradermal skin tests
- Skin testing with gelatin or cetuximab
- Prick-to-prick skin testing using cooked meats

If diagnosis still not clear

The alpha-gal IgE test is NOT available

Seronegative cases









Skin prick tests w/ meat extracts

The Alpha-gal panel

Alpha-galactosidase

Has *nothing* to to with AGS







Summary

Step #1: Clinical history

Tick bites

Symptoms

Step #2: Blood test (alpha-gal IgE)

Step #3 Change diet (2 months)

→→symptoms improve



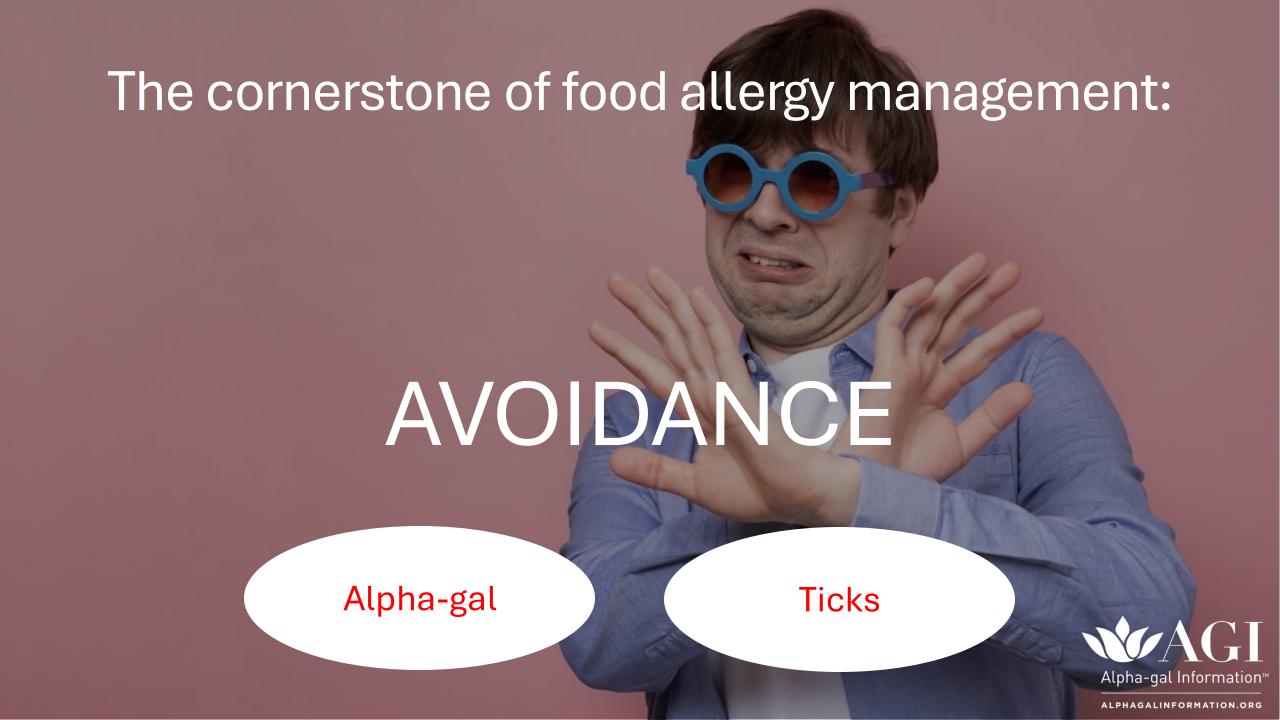


Managing alpha-gal syndrome









Next level tick bite avoidance tips: lone star tick edition





An Alpha-gal Information webinar



Let's take these one by one!





Foods & drinks

Drugs & medical devices

Personal care products

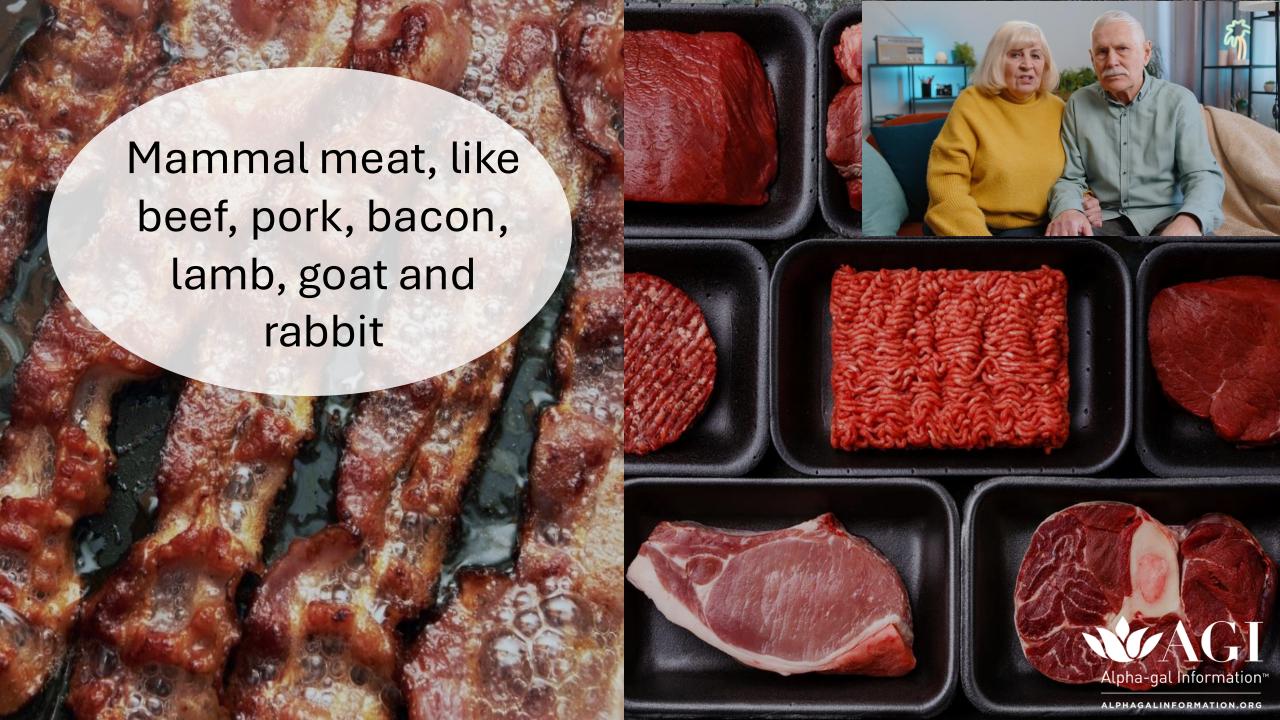
Household products



Foods and drinks

Household products

















Mammal organs, like beef and pork liver, kidneys, lungs, intestines, & Rocky Mountain oysters



Remember: fat is the primary antigenic form of alpha-gal!



Mammal fat, like lard beef tallow, fatback, & suet



Refried beans







Tortillas

Vegetables



Hidden mammal fat



Chips



Baked goods

Pies & pastries



Baked Beans



Gravy & sauces



Mashed potatoes



Hidden mammal fat



















Mammal broth, stock & bouillon

Can be hidden in soups & sauces



Poultry sausages in mammal-derived casing, like pig/lamb intestine or collagen









Some flounder eggs







Foods some people with AGS need to avoid



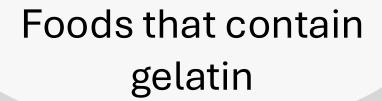


















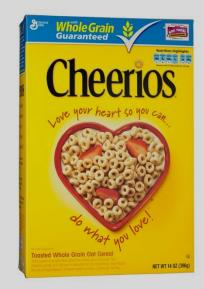






PLANTERS

Dry Roasted







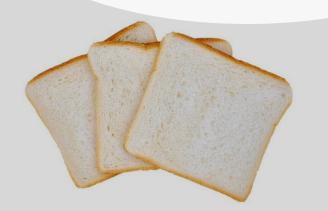








Foods made with *many* other mammal-derived ingredients



Alpha-gal Information™

ALPHAGALINFORMATION.ORG

Foods made with carrageenan



These algae also make alpha-gal.





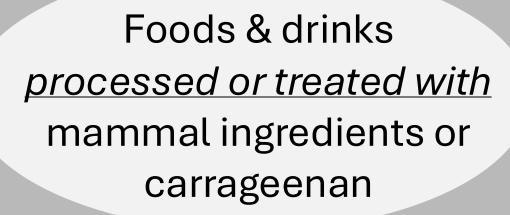






























Mammal ingredients hidden in natural flavors, spices, & coloring









Foods & drinks

Drugs & other medical products

Personal care products

Household products







Foods & drinks

Drugs & other medical products

Household products

Alpha-gal Information

Remember, unlike typical food allergies...

- Alpha-gal syndrome is a
 - Major drug allergy
- A top cause of perioperative anaphylaxis



Allergic reaction to a medication





Anaphylactic reaction to a health product





Deaths





Hundreds of thousands of drugs, biologics and medical devices are mammal-derived or may contain mammal-derived ingredients





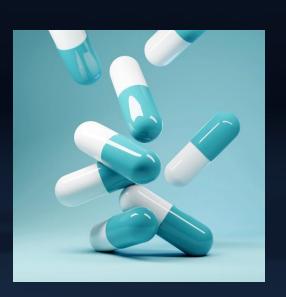




Drugs

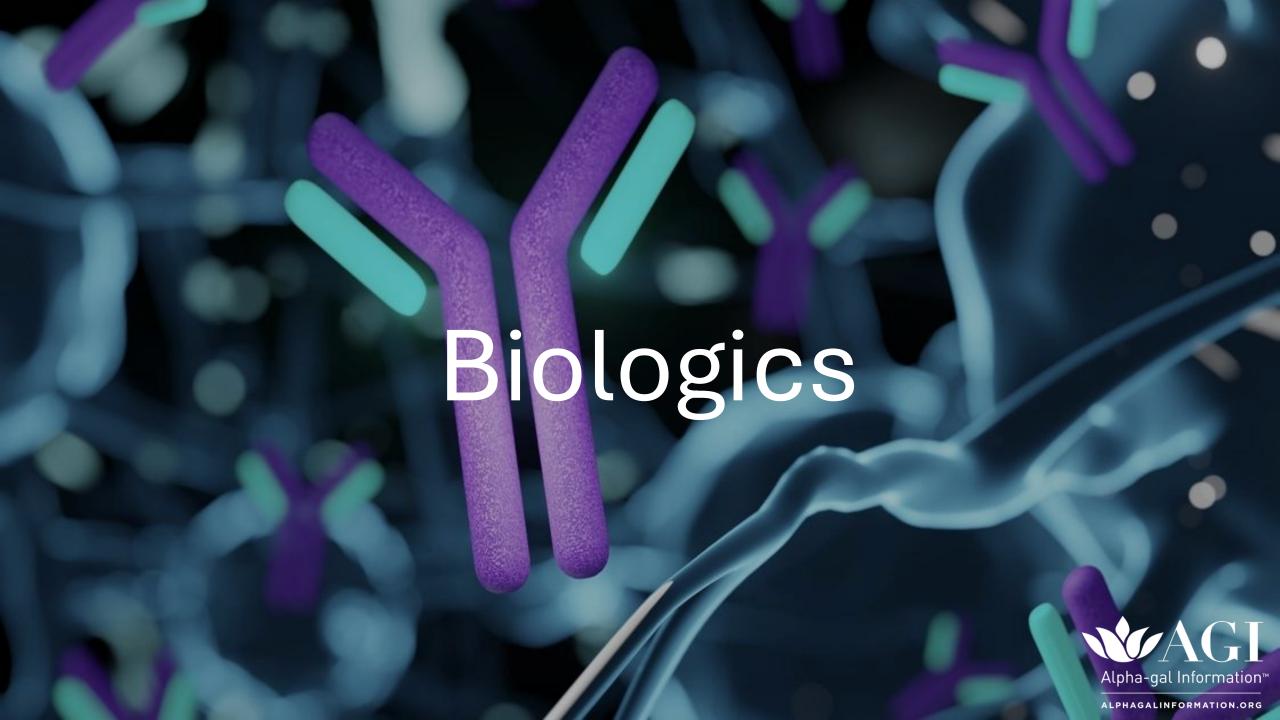
Such as:

- Pancreatic enzymes
- Armour thyroid
- Heparin
- Gelatin capsules
- Gelcaps
- Suppositories
- Vaginal capsules
- Topical medications
- Many other drugs









Biologics

Such as:

- Cetuximab
- Infliximab (Remicade)
- Abatacept
- Ustekinumab
- Antivenom
- Some vaccines
- * Thrombin







Medical devices

Such as:

- Heparin flushes
- Bioprosthetic heart valves
- Extracellular matrix (ECM)
- Heart patches
- Hernia mesh
- Hemostatic agents

- Lubricants
- Viscosurgical devices
- Sutures





Pill Clarity

Check meds at PillClarity.org



Email info@pillclarity.org









Foods & drinks

Drugs & medical devices

Personal care products

Household products





Foods & drinks

Personal care products

Drugs & medical devices

Household products





















Occupations with risk of alpha-gal exposure











Fluids—most dangerous

Amniotic fluid

Blood

Saliva









Other livestock exposures

- Waste
- Contact with animals
- Fumes

Products used in livestock care—e.g. lanolin









Everything But the Oink

By-Products from Pigs

From Blood...

- Medicines
- Sticking agent
- · Leather treating agent
- · Plywood Adhesive

Ham

- Protein source in feeds
- Fabric printing and dveing

From Hair...

- · Artist's brushes
- Insulation
- Upholstery

From Internal Organs...

.... Knee

Pastern

Isulin

From Brain...

· Other medicines

Cholesterol

Loin or Top

Underline Elbow

Cannon Bone

Dewclaw

Rib Shape:

· A variety of medicines

Shoulder\

- Surgical sutures
- Heart valves

From Skin...

- Gelatin
- Footballs
- Porcine Burn Dressings
- · Luggage, purses
- · Gloves and shoes
- · Pigskin garmets
- Drumheads

- Bone Meal
- · Minerals for feed
- Fertilizer
- Porcelain enamel
- Glass
- Water filters

Foot (toes) From Fatty Acids and Glycerine...

- Insecticides
- · Weed killers
- Lubricants
- · Oil polishes Rubber
- Cosemtics
- Antifreeze
- Nitroglycerine · Plastics
- · Plasticizers
- Printing rollers
- Cellophane
- · Floor waxes Cement
- Waterproofing agents
- Fiber softeners
- Cravons
- Chalk
- Phonograph records
- Matches
- Putty
- Inulation

From Meat Scraps... Linoleum

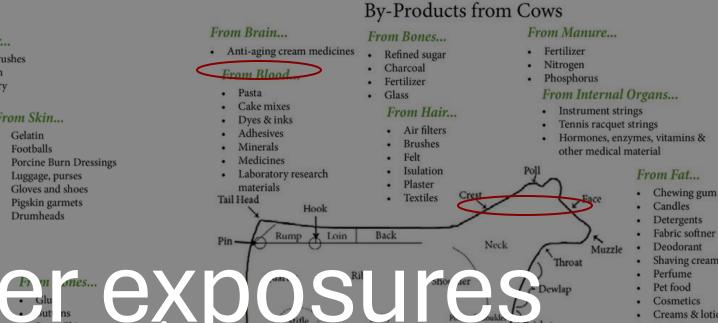
- · Commercial feeds
- Pet food

AND OF COURSE: bacon, ham, sausage, pork chops, ribs, BBQ and more!

so many products come from pigs that we really do use everthing but the



Everything But the Moooo



-Forearm

From Skin ...

Flavorings

· Sheet rock

Wallpaper

Adhesives

Medicines

· Candies & confectionary

Emery boards

Gelatin

←Knee

From Hooves and Horns...

Rear

Flank Sheath (steers)

Navel (heifers)

From Milk ...

Adhesives

Cosmetics

Plastics

· Medicines



Cannon

Bone

Plastics

Pastern -

- Pet food
- Plant food Photo film
- Shampoo & conditioner
- Emery boards
- Lamination
- Wallpaper
- Plywood

so many products come from cows that we really do use everthing but the mooo!

- Detergents
- Fabric softner
- Deodorant
- Shaving cream
- Perfume
- Pet food
- Cosmetics
- Creams & lotions
- Crayons
- Paint
- Oil & lubricants
- Biodiesel
- Plastics
- Waterproofing agents
- Cement
- Ceramics
- Chalk
- Explosives
- Fireworks
- Matches
- Fertilizer
- Antifreeze
- Insulation
- Linoleum
- Rubber

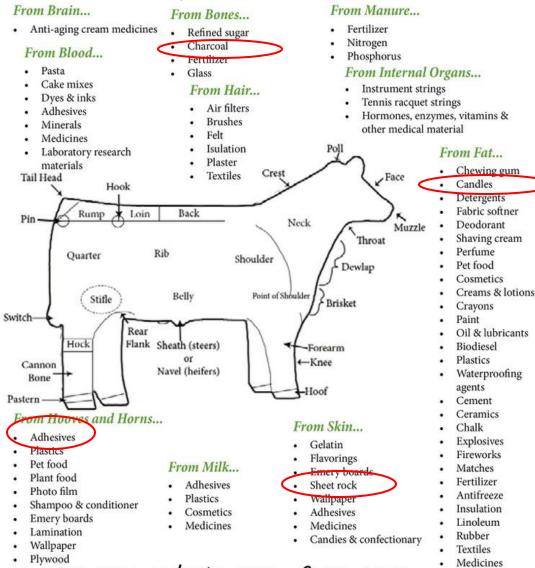
Alpha-gal Information

ALPHAGALINFORMATION.ORG

Thousands of other products made from mammals

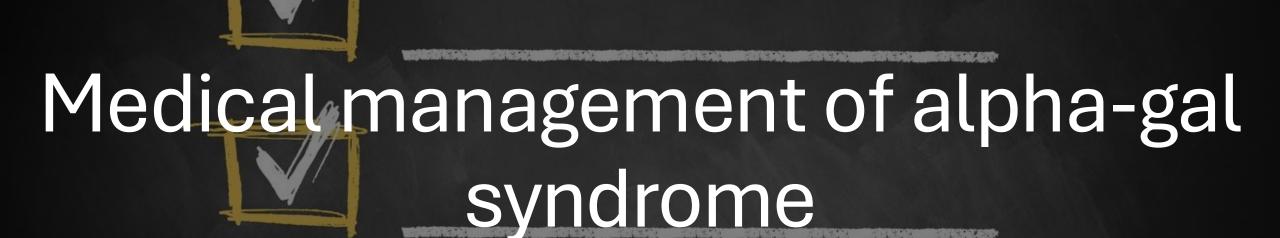
Everything But the Moooo

By-Products from Cows



so many products come from cows
that we really do use everthing but
the mooo!









Epinephrine

The vast majority of people with AGS need:

2 or more doses of epinephrine

Because of the severity and unpredictability of our reactions





- H1 antihistamines like cetirizine, levocetirizine or fexofenadine (Zyrtec, Xyzal, Allegra)
- + H2 antihistamines, like famotidine (Pepcid)
- Corticosteroids



For people with continuing reactivity

Mast cell issues, reacting to unavoidable exposures

- Xolair
- Ketotifen
- Oral cromolyn
- Inhaled beta-agonists (like Albuterol)
- Masks



For people with continuing reactivity

GI Symptoms

- Xolair
- Ketotifen
- Oral cromolyn
- Inhaled beta-agonists (like Albuterol)
- Masks



For people with continuing reactivity

Reactions to airborne alpha-gal

- Xolair
- Ketotifen
- Oral cromolyn
- Inhaled beta-agonists (like Albuterol)
- Masks

































Alpha-gal Information*

















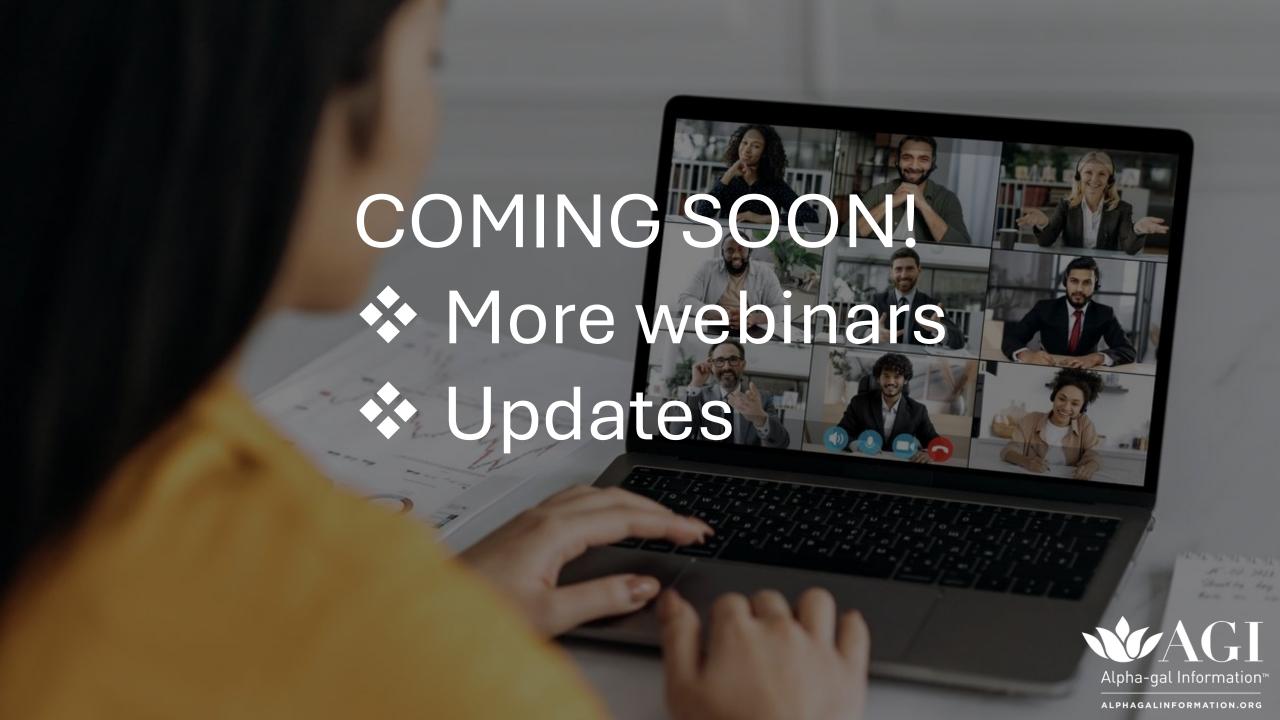
















Home management of anaphylaxis

For people with alpha-gal syndrome

An Alpha-gal Information update



Alpha-gal information Resources

- Alpha-gal Information webinar page
 - Webinar recording
 - Slides
 - Additional resources







Questions, comments, feedback, welcome!

More information: https://alphagalinformation.org