ALPHA-GAL SYNDROME PATIENT INFORMATION SHEET



WHAT IS ALPHA-GAL SYNDROME?

Alpha-gal syndrome (AGS) is a serious, sometimes life-threatening allergy to alpha-gal (galactose-alpha-1,3-galactose). This is a sugar found in meat from mammals (such as beef, pork, and lamb). It is also in other products made from mammals (like cow's milk, gelatin, and some medications).



HOW IS ALPHA-GAL SYNDROME SPREAD?

Bites from certain tick species can cause an immune system response in some people that results in AGS. In the U.S., the lone star tick (Amblyomma americanum) is the main tick associated with AGS.



For help identifying ticks, visit www.vdh.virginia.gov/ticks/tick-identification/



WHAT IS A MAMMAL?

Mammals are animals that produce milk for their babies and have warm blood. Most have fur. Common examples include cows, pigs, sheep, goats, deer, and rabbits.



WHAT ARE THE SYMPTOMS OF AGS?

People having an AGS allergic reaction can have stomach pain, nausea, vomiting, diarrhea, heartburn, hives, and an itchy rash. In severe cases, people can experience a severe, life-threatening allergic reaction called anaphylaxis.

Symptoms of AGS may be mild or severe and can be different from person to person. Some AGS patients may be able to tolerate certain alpha-gal containing products. Other patients are more sensitive and cannot be in the same room where alpha-gal containing meats are being cooked. Symptoms of an AGS reaction usually start 2-6 hours after eating meat or dairy products. Symptoms can start sooner if you get an injection with medications containing alpha-gal.



HOW DO I MANAGE AGS?

Managing the symptoms of AGS includes:

- → Identifying and avoiding products with alpha-gal
- Reading food product labels carefully
- Developing a management plan with your healthcare provider
- → Preventing future tick bites

Your healthcare provider can help you make a plan to manage AGS. Working with a dietician might also be helpful.

New tick bites can make your AGS worse. If you **avoid new tick bites**, you may be able to add meat and dairy back into your diet.







WHICH PRODUCTS SHOULD I AVOID?

The Centers for Disease Control and Prevention have a list of products that might contain alpha gal:

<u>www.cdc.gov/alpha-gal-syndrome/data-research/products-containing-alpha-gal/index.html</u>



FOODS TO AVOID

All foods made from mammals or with mammal-derived ingredients might contain alpha-gal. However, you might not need to avoid all of these foods. Your healthcare provider can help you know what foods to avoid based on your sensitivity and preferences.

Foods you should avoid:

- Mammal meat, like beef, pork (including bacon), lamb, venison, bison, goat, and rabbit
- Mammal organs, like liver, kidneys, intestines (tripe), and Rocky Mountain oysters
- Mammal fat, like lard
- Foods made from the tissue or fluids of mammals
- → Mammal broth, bouillon, stock, and gravy
- Flounder roe (nitsuke)

You might also need to avoid:

- → Milk and dairy
- → Gelatin
- → Mammal byproducts
- → Carrageenan (made from red algae that produce alpha-gal)
- → Some natural flavorings





FOODS YOU CAN EAT

- Fruits, vegetables, and grains
- Eggs
- Fish and other seafood, except flounder roe
- → Poultry, like turkey, chicken, and duck
- Emu and ostrich (birds whose meat tastes like beef)
- → Pork from GalSafe pigs



MEDICAL AND PERSONAL CARE PRODUCTS

Many medications, vaccines, and other medical products contain ingredients from mammals.

Your healthcare provider can help you decide which medicines you need. Ask for help if you need a vaccine, antivenom, heparin, or are having a medical procedure.

You can learn more about what is in your medications at www.pillclarity.org.

Cosmetics, personal care products, and household products can also contain alphagal. If you react to them, you may need to use vegan products. Check for carrageenan, especially in toothpaste.



WHO IS AT HIGHER RISK FOR AGS?

Some people might be at higher risk of being bitten by ticks, and therefore are also at higher risk for developing AGS.

People who spend more time outdoors are at higher risk. Ticks live in grassy, brushy, or wooded areas. If you like hunting and camping, or if you **work outdoors** (e.g., utility workers, forestry professionals, people who work with livestock), you are at higher risk of tick bites. You can learn more about how to prevent tick bites at vdh.virginia.gov/ticks/prevention.



HOW CAN I LEARN MORE?

- → VDH tick webpage: vdh.virginia.gov/ticks
- → CDC webpage About Alpha-gal Syndrome: https://www.cdc.gov/alpha-gal-syndrome/about/index.html
- https://alphagalinformation.org/achecklist-for-the-newly-diagnosed/
- → Two Alpha Gals <u>www.twoalphagals.com</u>
- Alpha-gal Information alphagalinformation.org
- → Food Allergy Research and Education FoodAllergy.org
- → American Academy of Allergy, Asthma and Immunology <u>www.aaaai.org</u>
 - Alpha-gal and Red Meat Allergy <u>www.aaaai.org/tools-for-the-public/</u> <u>conditions-library/allergies/alpha-gal-</u> and-red-meat-allergy
 - Anaphylaxis Interactive Learning Guide <u>www.aaaai.org/tools-for-the-public/anaphylaxis</u>

