ALPHA-GAL SYNDROME PATIENT FACTSHEET









Alpha-gal syndrome (AGS) is a serious, potentially life-threatening allergy to alpha-gal (galactose-alpha-1,3-galactose), a sugar found in most mammals. Products made from mammals or containing ingredients made from mammals, including many foods and drugs, can also contain alpha-gal.

Tick bites cause AGS. In the U.S., most cases are caused by lone star ticks, which are common in the southern, midwestern, and mid-Atlantic United States.





Newly diagnosed? Start here

MAMMALS

Mammals are animals that feed their young milk. Most are furry. Examples include cows, pigs, sheep, goats, deer, squirrels, and rabbits.



SYMPTOMS OF AGS

Alpha-gal reactions usually occur 2-6 hours after people eat foods containing alpha-gal. Some non-food exposures - for example, some intravenous drugs - can cause immediate reactions. Note that people with AGS often do not react after every exposure.

Symptoms can range from a mild, itchy rash to life-threatening anaphylaxis. Some people with AGS only have GI symptoms, such as diarrhea or abdominal pain. Others only have joint pain.

Learn how to recognize and respond to the full range of allergic symptoms, especially anaphylaxis.



Symptoms of AGS



Recognizing and responding to anaphylaxis





FOODS TO AVOID

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

- 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 may also need to avoid:

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

Tips:

- Beware of poultry sausages made with mammal casings.
- When eating out, watch out for lard in fry oil and cross-contact with mammal meat.
- Read food labels!

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 Revivicor's genetically modified GalSafe pigs



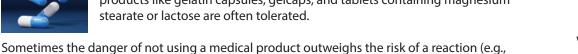


MEDICAL PRODUCTS

antivenom, rabies vaccine).



Many drugs, vaccines, and other medical products contain mammal-derived ingredients. Some medications, including the cancer drug cetuximab and gelatin-containing vaccines, should be avoided or used with caution. Other products like gelatin capsules, gelcaps, and tablets containing magnesium stearate or lactose are often tolerated.



Seek your healthcare provider's advice about the use of specific medical products, especially if you take thyroid medication, pancreatic enzymes, infliximab (Remicaid), ustekinumab (Stelara), or if you need a vaccine, antivenom, heparin, or medical procedure.





VeganMed can help you find medications that are free from animal-derived ingredients.

COFACTORS

Cofactors such as alcohol and exercise can make reactions more likely. For example, if you drink wine with dinner or jog after lunch, you are more likely to react to any alpha-gal you consumed. Other cofactors include NSAIDs (like Advil), illness, and stress.



OTHER EXPOSURES



Cosmetics, personal care products, and household products can also contain alpha-gal. If you react to them, try vegan products. Check for carrageenan, especially in toothpaste.

Dander, waste, saliva, blood, and amniotic fluid from pets, livestock, and game contain alpha-gal. Most people can keep their pets. Farmers may need to take special precautions, especially during calving. Hunters need to avoid direct exposure to blood.

Some people react to airborne alpha-gal, especially fumes from cooking meat.

MANAGING YOUR REACTIONS

Your provider will work with you to develop a plan for managing both severe reactions and milder symptoms, such as a few hives or mild GI symptoms. Your plan may include the use of antihistamines, epinephrine autoinjectors, and possibly steroids, oral cromolyn, or omalizumab (Xolair). Remember to keep your emergency medications with you when you go out!

Use FARE's Food Allergy and Anaphylaxis Care Plan to outline management recommendations in an easy-to-follow format. See below.

AVOID TICK BITES



New bites can make your AGS worse. If you avoid new tick bites, you may eventually be able to add mammalian foods back into your diet under the supervision of your allergist.

ADDITIONAL RESOURCES



Food Allergy and Anaphylaxis Emergency Care Plan



Alpha-gal Information



Two Alpha Gals mentorship program



GalSafe pork from Amaroo Hills