

Alpha-gal Syndrome in New York

Background

Alpha-gal syndrome (AGS), is an IgE-mediated allergy to the sugar galactose- α -1,3- galactose (alpha-gal), which is found in all mammals except some primates.¹ Its onset is associated with tick bites.² In the U.S., lone star ticks are responsible for the majority of cases.³

People with AGS react to products made from mammals. This includes foods such as beef, pork, lamb, venison, dairy products, and gelatin.³⁻⁵ It also includes drugs and medical products, such as monoclonal antibodies, heparin, bioprosthetic heart valves, some vaccines, antivenom, medication in gelatin capsules, and many other medical products.³⁻⁵ Over 75% of people with AGS report reacting to a medication, and about 50% report that they have experienced anaphylactic reactions to a health product.⁶ Many people with AGS also react to personal care and household products with mammal-derived ingredients.³

Alpha-gal reactions are often severe and can be fatal.^{3,4,7} 60-75% of people with AGS experience anaphylactic reactions.^{8,9} In areas of high prevalence, reactions to alpha-gal can be the number one cause of anaphylaxis in adults and adolescents, accounting for a third of all cases, more than all other food allergies combined.¹⁰ Studies in Virginia suggest that AGS may be responsible for up to 25% of both IBS-like symptoms and rheumatological issues in high prevalence areas.^{11,12} Concerningly, preliminary research in both the U.S. and Australia found that people who are sensitized to alpha-gal, even if they do not develop allergic reactions, may be at increased risk of cardiovascular disease.^{13,14} The NIH is currently funding a follow-up study of this issue.²⁸

Due to growing lone star tick populations, the number of cases of AGS is increasing at an alarming rate.^{15,16} In a July 2023 report, the CDC recognized AGS as a growing clinical and public health concern.¹⁶ They reported that between 2010 and 2022, more than 110,000 suspected cases of AGS were identified and estimated that up to 450,000 Americans may be affected, making AGS the 10th most common food allergy.^{16,17} Yet alarmingly, 78% of physicians know little to nothing about AGS, and only 5% feel very confident in diagnosing and managing it.¹⁸

New York: an alpha-gal syndrome hotspot

Alpha-gal syndrome cases are not distributed evenly throughout the U.S. They are concentrated in areas where lone star ticks are found.¹⁶ The CDC found that 4% of all suspected AGS cases resided in Suffolk County, New York, making it *the most impacted county in the U.S.*¹⁶ We don't know how many New York state residents have AGS, which is why we need surveillance. However, we do know that lone star tick populations are exploding and rapidly expanding northwards, often outcompeting and replacing black-legged ticks as they do.^{15,16} Southern New

York is at the vanguard of this northern invasion, but lone star ticks are found in almost all New York counties.³⁶ Their numbers are expected to continue to explode, and as they do, so will AGS cases.^{15,16,36,37,38}

Alarmingly, in April of this year, the CDC published a report documenting a case of alpha-gal syndrome linked to a black-legged tick (*Ixodes scapularis*).⁴⁰ This confirms what many people in the AGS community already knew— that people in areas where black-legged ticks still predominate, including much of New York, are also at risk.

A call to action

In a July 2023 report, the CDC recognized AGS as a growing clinical and public health concern.¹⁶ Due to the current lack of surveillance, they state, the true prevalence of AGS is largely unknown.¹⁶ The CDC identified a “critical need” for state and local health authorities to initiate surveillance and encourages them to do so.^{16,32} The CDC recently laid the groundwork for states to make AGS reporting mandatory, publishing a National Notifiable Diseases Surveillance System case definition for alpha-gal syndrome (AGS)³³ and created an Alpha-gal Syndrome Case Report Form.³⁴ In September, 2023 Arkansas became the first state to make AGS a mandatory, reportable health condition,³⁵ and since then ten other states have followed suit: Delaware, Iowa, Kentucky, Nebraska, North Dakota, Oregon, South Carolina, Tennessee, Virginia, West Virginia.

In 2023, the NYC Health Code was changed to require laboratories to report alpha-gal syndrome to the NYC Health Department. However, a state-wide surveillance initiative is needed.⁴¹

Given the unknown and likely significant impact of AGS on both New York state residents with AGS, their families, and state healthcare systems, rapid implementation of improved AGS surveillance should be a top priority for the state.



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