ALPHA-GAL ALLIANCE AGA ACTION FUND

Alpha-gal syndrome in Illinois

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]

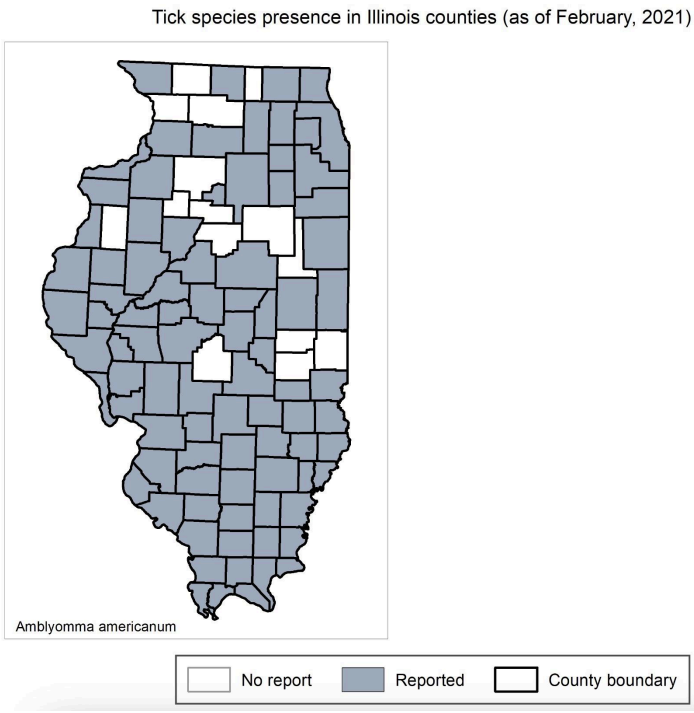
Due to growing lone star tick populations, the number of cases of AGS is increasing at an alarming rate.[15,16] In a July 2023 report, the CDC recognized AGS as a growing clinical and public health concern.[16] They reported that between 2010 and 2022, more than 110,000 suspected cases of AGS were identified 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]

Illinois: an alpha-gal syndrome hotspot

Alpha-gal syndrome cases are not distributed evenly throughout the U.S. They are concentrated in high prevalence areas.[16] The CDC has identified Illinois as a state with one of the highest AGS prevalence rates in the nation.[16] Currently, residents in southern Illinois are most impacted.[16] However, lone star ticks are already the most commonly encountered tick in Illinois and have been found in almost every county in Illinois (see map below).[30] Moreover, growing white-tailed deer populations and environmental changes are driving an explosion in lone star

tick populations and their expansion into north, including into northern IL.[29,31] As lone star tick populations grow, so will AGS cases.

There is a lack of AGS data from Illinois, but we do have data from other high prevalence states. In the most impacted areas, up to 47% of the population may be sensitized to alpha-gal.[19] Note that *not all* people who are sensitized to alpha-gal have full-blown allergy to alpha-gal syndrome, but 8-10% or more do.[9,25-27] A recent study found that more than 2% of an unselected cohort from central Virginia had AGS.[26] Other estimates suggest that up to 3% of people in the hardest hit areas may be affected.[3,25,27] We can safely assume that prevalence of AGS in areas of Illinois with similarly high numbers of lone star ticks is comparable.



Source: Information and Results. I-TICK. Accessed October 25, 2024. https://vetmed.illinois.edu/i-tick/info-and-results/

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.

Given the unknown and likely significant impact of AGS on both Illinois 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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