January 24, 2024

Senator James Libby
38 Quail Ridge Road
Standish, ME 04084

Re: Bill LD 2100 "An Act to Require the Reporting of Alpha-gal Syndrome to the Maine Center for Disease Control and Prevention"

Dear Senator Libby;

As advocates for alpha-gal syndrome, tick-borne disease, and allergy communities, we write to commend you for the introduction of HB LD 2100 and would like to register our strong support for the bill, which would direct the Maine Board of Health to add alpha-gal syndrome to the list of diseases required to be reported to the CDC. Passage of HB LD 2100 would meet an urgent need for surveillance of alpha-gal syndrome (AGS), an emerging, tick-borne condition characterized by potentially life-threatening allergic reactions to a carbohydrate found in mammals and products derived from mammals. The CDC (2023) reports that AGS is a growing clinical and public health concern, and state-level surveillance is a "critical need" to determine its true prevalence and trends in its expansion. This information is vital for public health decision-making. Importantly, passage of HB LD 2100 would also serve as a mechanism to educate the scores of healthcare providers who remain unaware of AGS.

Although Maine is not considered an endemic area for AGS yet,our neighboring states have reported "endemic areas". (see attached map for information about AGS in ME).

A recent Maine Public Health Alert (12/7/23) reported 5 cases of (IgE) AGS, and noted as "travel related". We are aware of several diagnosed with AGS who currently live in the state, with three coincidentally within the same dental practice located in York County and recently on the island.

Over 60% of people with AGS experience anaphylactic reactions. 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. Other studies suggest that AGS may be a frequent cause of both irritable bowel syndrome (IBS)-like symptoms and rheumatological issues. Concerningly, research conducted at UVA and elsewhere 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.

The CDC encourages states to report cases of AGS and has laid the groundwork for states to make AGS reporting mandatory. In September 2023, Arkansas became the first state to make AGS a mandatory, reportable health condition. Other states in high prevalence regions are expected to follow suit, while states like Maine will take this as a progressive approach to further contribute to groundbreaking research related to "ticks of concern" in Maine.

The University of Maine received $6.2M in federal funds to help identify ways to control tick populations, identify and study emerging tick species and expand public health efforts. The "Ticks of Concern" noted in the Tickborne Diseases - Maine 2023" report, Asian Longhorned and the Lone Star, as well as the Blacklegged and American dog tick all overlap with areas of interest such as the (reportable); Spotted Fever Rickettsiosis(SFR)/Rocky Mountain Spotted Fever)RMSF), Powassan virus/deer tick virus, and Tularemia, as well as (non-mandated reportable) STARI and Alpha-gal Syndrome.

As noted in the CTST Standardized Case Definition for Alpha-Gal Syndrome, "AGS has been reported worldwide; in the United States, it is most closely associated with lone star tick (Amblyomma americanum) bites. Research has suggested that other tick species, including Ixodes spp., may also be associated with AGS development. Reports of AGS in the scientific literature have been increasing over the last decade, but the true burden of cases is unknown. Additionally, much of the country may be at risk given the expanding geographic range of lone star and other ticks. Responding to the increased diagnosis of cases and public interest, multiple states have expressed a desire to quantify the burden of AGS."

We believe that by passing HB LD 2100, you can help make a lasting impact on the health and well-being of thousands of Mainers. This legislation presents a pathway to document the true prevalence of AGS and monitor its expansion, which is needed to facilitate and fund public health measures addressing this issue.

We stand ready to provide any additional information or assistance you may require as you work to advance this important legislation. We are eager to work with you and your colleagues in the Maine Assembly to ensure that HB LD 2100 becomes law and benefits both residents of Maine with alpha-gal syndrome and those at risk of developing it.

Sincerely,

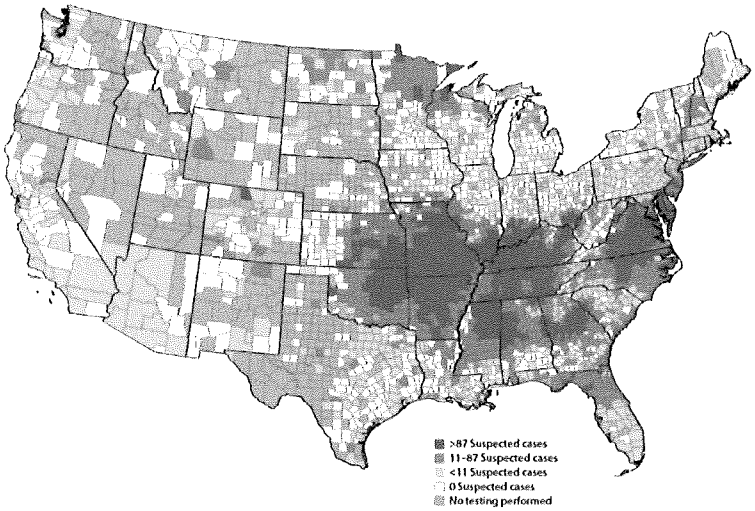
Beth Carrison, Co-founder, Tick-Borne Conditions United
https://www.tbcunited.org/

Jennifer Platt, Co-founder, Tick-Borne Conditions United
https://www.tbcunited.org/

Yan Zelner, PhD, Director of Science & Research
https://lymetv.org/

Adina Bercowicz, Founder & Executive Director
https://lymetv.org/

FIGURE. Geographic distribution of suspected alpha-gal syndrome cases* per 1 million population per year — United States, 2017-2022

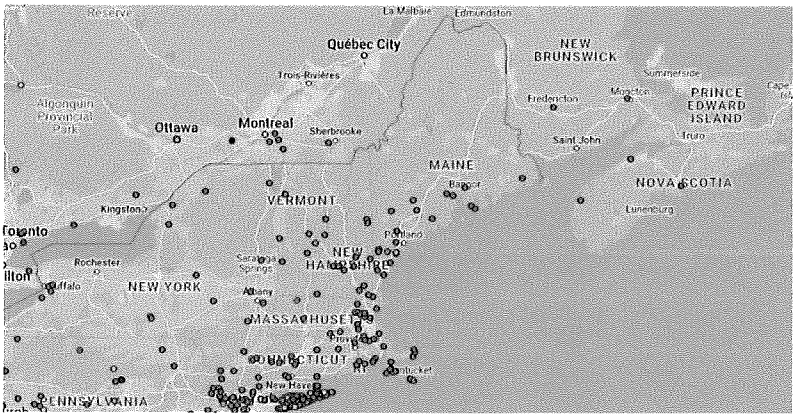


Abbreviations: IgE = immunoglobulin E; IU = international unit; kU = kilounit.

* A suspected case of alpha-gal syndrome was defined as being in a person who had confirmatory laboratory evidence (serum or plasma alpha-gal–specific IgE ≥0.1 IU/mL or ≥0.1 kU/L) with no clinical information available.

Thompson JM, Carpenter A, Kersh GJ, Wachs T, Commins SP, Salzer JS. Geographic Distribution of Suspected Alpha-gal Syndrome Cases — United States, January 2017–December 2022. MMWR Morb Mortal Wkly Rep 2023;72:815–820. DOI: http://dx.doi.org/10.15585/mmwr.mm7230a2

AGS Patient Tracking Map *(pt reported)* - (Maine shown, as of 1.22.24)



Publications and Resources Cited -

CDC | Alpha-gal Syndrome - https://www.cdc.gov/ticks/alpha-gal/index.html

CTST Case Definition and Surveillance - https://www.cdc.gov/ticks/alpha-gal/for-public-health-officials.html

CDC: Publications, Free CME) Training, and Resources - https://www.medscape.org/viewarticle/988550

Assessing Current Practice in the Diagnosis and Management of Alpha-Gal Syndrome - https://www.medscape.org/viewarticle/988550_sidebar1

Geographic Distribution of Suspected Alpha-gal Syndrome Cases — United States, January 2017–December 2022: https://www.cdc.gov/mmwr/volumes/72/wr/mm7230a2.htm

Health Care Provider Knowledge Regarding Alpha-gal Syndrome — United States, March–May 2022" - https://www.cdc.gov/mmwr/volumes/72/wr/mm7230a1.htm

Investigation into the alpha-Gal Syndrome: Characteristics of 261 Children and Adults Reporting Red Meat Allergy. https://pubmed.ncbi.nlm.nih.gov/30940532/

Alpha-gal "Zee Map" (patient-led tracking map used in various literature.) https://www.zeemaps.com/mobile?group=555038

Tick-Borne Diseases - Maine 2023 - https://www.maine.gov/DACF/mfs/projects/forestry_fridays/documents/Vectorborne_Tickborne_%20Public%202023.pdf

Maine CDC Reports Record Number of Lyme Disease Cases - December 7, 2023 - https://www.maine.gov/dhhs/mecdc/newhan.shtml

van Nunen S. Tick-induced allergies: mammalian meat allergy, tick anaphylaxis and their significance. Asia Pac Allergy 2015;5(1):3–16.

Commins SP, James HR, Kelly LA, et al. The relevance of tick bites to the production of IgE antibodies to the mammalian oligosaccharide galactose-α-1,3-galactose. J Allergy Clin Immunol 2011;127(5):12861293.e6.

Young I, Prematunge C, Pussegoda K, Corrin T, Waddell L. Tick exposures and alpha-gal syndrome: A systematic review of the evidence. Ticks and Tick-borne Diseases 2021;12(3):101674.

Crispell G, Commins SP, Archer-Hartman SA, et al. Discovery of Alpha-Gal-Containing Antigens in North American Tick Species Believed to Induce Red Meat Allergy. Front Immunol 2019;10:1056.

Eisen RJ, Eisen L, Beard CB. County-Scale Distribution of Ixodes scapularis and Ixodes pacificus (Acari: Ixodidae) in the Continental United States. J Med Entomol 2016;53(2):349–86.