



James Libby
Senator, District 22

THE MAINE SENATE
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3 State House Station
Augusta, Maine 04333

Testimony of Senator James D. Libby

Sponsor of LD 2100, An Act to Require the Reporting of Alpha-gal Syndrome to the Maine Center for Disease Control and Prevention

Public Hearing, Wednesday, January 24, 2024, 10:00 a.m.

Cross Building, Room 209

Senator Baldacci, Representative Meyer, and esteemed members of the Joint Standing Committee on Health and Human Services,

My name is Jim Libby, and I am a State Senator representing Senate District # 22, comprised of the towns of Naples, Sebago, Baldwin, and Standish in Cumberland County; Hiram and Porter in Oxford County; and, Limington, Limerick, Cornish, Parsonsfield, Newfield, Acton, and Shapleigh, in the County of York.

It is my honor to bring to your attention the contents of L.D. 2100, "An Act to Require the Reporting of Alpha-gal Syndrome to the Maine Center for Disease Control and Prevention"

Committee members, Alpha-gal syndrome (AGS) is a type of food allergy that makes people allergic to red meat and other products made from mammals. It usually occurs after a bite from the Lone Star tick, which transfers a sugar molecule called alpha-gal into the body. There are other ticks, such as the Black Legged tick that have not been ruled out as carriers. In some people, this triggers a reaction from the body's immune system. AGS causes mild to severe allergic reactions to red meat, such as beef, pork or lamb. It also can cause reactions to other foods that come

from mammals, such as dairy products or gelatins. The symptoms of an alpha-gal allergic reaction usually take longer to start compared with those of other food allergies. Most reactions to common food allergens — peanuts or shellfish, for example — happen within minutes after you are exposed to them. In alpha-gal syndrome, reactions usually appear about 3 to 6 hours after you are exposed. Symptoms of alpha-gal syndrome may include: Hives, itching, or itchy, scaly skin. Swelling of the lips, face, tongue and throat, or other body parts. Wheezing or shortness of breath. Stomach pain, diarrhea, upset stomach or vomiting. There's no treatment, other than avoiding red meat and other products made from mammals. If you have a serious allergic reaction, you may need medicine called epinephrine and treatment at the emergency room. To prevent alpha-gal syndrome, we need to avoid tick bites. Wear long pants and long-sleeved shirts when we're in wooded, grassy areas. Use bug spray, and check your whole body for ticks after you spend time outside.

You may ask, why do we need to elevate our knowledge and the reporting of AGS? First, tick-borne illnesses are serious business. You will hear from Mainers affected by this disease. Second, we just don't know enough about it. According to a July, 2023 report (Carpenter, et al) in the US CDC's Morbidity and Mortality Weekly, responses to a survey revealed that 42% of the 1500 health care providers that questioned had no knowledge of AGS, and another 35% were not confident in their ability to diagnose or manage AGS patients. While the Maine CDC has worked to inform the public, my personal interest in the ability educate constituencies and accurately diagnose health problems and allergies comes from my own long, personal experience with Celiac Disease. My daughter Grace was diagnosed with Celiac disease (and she has agreed to share this information on behalf of the public good), but the months that my wife and I spent searching for expert physicians to figure out a diagnosis while my daughter went downhill really scared us. Like AGS today, Celiac was in a place 15 - 20 years ago where health care providers had less

knowledge, and experienced some difficulty ruling out other health issues in order to find their way to a correct diagnosis. We've lived with the allergy, the tiny bits of cross-contamination, and so many other related issues. I know first-hand, the toll on the family of experiencing medical unknowns over weeks and months, and then dealing with a disease thereafter.

If this Committee can do anything to help with AGS, I implore you to do so. The USCDC now says that AGS may be affecting nearly a half-million people in the United States, and the mobility of humans and animals that carry Lone Star ticks and others from states with higher tick counts make this issue of high importance to us here in Maine as well as every other state. Recently the Today Show reported that Suffolk County, New York now has a high count of Lone Star ticks relative to other areas of the country. Why? We don't know, but we do know that ticks travel.

Now is the time to act.

I am happy to take questions from the Committee, although with my doctorate, I am not even qualified to take your temperature.