At the Tick-Borne Disease Working Group’s virtual meeting on February 12, 2018, four of the eight people giving public verbal comments talked about the alpha-gal allergy, also known as alpha-gal syndrome (AGS).

AGS develops after a person has been bitten by a lone star tick (*Amblyomma americanum*) and becomes seriously allergic to meat and products that contain mammalian ingredients, such as glue, gelatin capsules, and natural flavorings. AGS is not thought to be a tick-borne infection per se, but rather an immune response to a substance carried in the tick’s gut.

The four people giving public comment at that meeting were Beth Carrison-van der Heide, Jennifer Burton, Tim Opiela, and Jennifer Platt. They spoke about their own experiences with AGS and of the need for recognition of the problem on a wide variety of levels.

Jennifer Burton said, “I was diagnosed with alpha-gal syndrome after months of battling the common escalating symptoms of AGS—extreme fatigue, joint pain, rashes, vomiting, diarrhea, GI distress and bloating, angioedema, urticaria, and four anaphylactic episodes (two nearly fatal).”

“Prior to this, the Lyme community was left in the dark without being considered,” said Jill Auerbach of Dutchess County, New York, one of 11 patients selected by the Department of Health and Human Services (HHS) for the six subcommittees of the Working Group. Now that the first phase of the group’s task is nearing completion, I wanted to find out how these patients felt about their experience.

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She noted that the majority of doctors send AGS patients away with the following instructions: “Just don’t eat beef or pork and it will go away in two to five years.”

Speaker Timothy Opiela, the father of a daughter with AGS, pointed out that the condition is not limited to ingestion of meats and/or byproducts. He focused on the impact of vaccines on children with AGS: “AG children are not able to be safely vaccinated for many of the recommended and required vaccines, because they are grown in mammalian product or byproduct, such as gelatin.” He said that of 61 vaccines deemed important by the CDC, 38 contain mammalian-derived ingredients.

In response to those comments, the Working Group added alpha-gal allergy as a topic to be considered by the Subcommittee on Other Tick-Borne Diseases and Co-infections.

In its report to the Working Group, the subcommittee stated:

This alpha-gal meat allergy was only recently reported (in the early 2000s), first in the southeastern United States where *Amblyomma americanum* is common. There is no evidence for other tick species causing the allergy in North America. Since then however, the alpha-gal allergy meat has been reported in other areas of the world where it is due to other tick species including *Ixodes ricinus, Ixodes holocyclus, Amblyomma cajennense, Amblyomma sculptum, and Haemaphysalis longicornis*. *H. longicornis* has recently been identified as an imported tick species in New Jersey raising the possibility of alpha-gal sensitization by this invasive tick species.

The magnitude of the problem and the true number of cases is unknown, as there is very little awareness of alpha-gal allergy. Alpha-gal allergy it is not a reportable disease. Endemic regions in the United States correspond to the distribution of lone star ticks and range from Long Island to the Southeastern states.

The subcommittee recommended increased research, education, awareness and surveillance related to AGS.

The Working Group evidently took the subcommittee's suggestions to heart and included the following recommendation in its draft report to Congress:

Improve the education and research on the pathogenesis of alpha-gal allergy, also known as the tick-caused "meat allergy."

It further stated:

Increased awareness and public health education programs targeting both the general public and clinicians in endemic areas are…needed. In addition, raising pre-diagnosis awareness and providing counseling and education after diagnosis on how to prevent exposure to the allergen will help to improve the care of those suffering with this potentially life-threatening illness.

Editor’s note: Any medical information included is based on a personal experience. For questions or concerns regarding health, please consult a doctor or medical professional.