April X, 2025

The Honorable Shelley Moore Capito
Chair
Subcommittee on Labor, HHS, Education,
and Related Agencies
Senate Committee on Appropriations
Washington, D.C. 20510

The Honorable Tammy Baldwin
Ranking Member
Subcommittee on Labor, HHS, Education,
and Related Agencies
Senate Committee on Appropriations
Washington, D.C. 20510

The Honorable Robert Aderholt
Chair
Subcommittee on Labor, HHS, Education,
and Related Agencies
House Committee on Appropriations
Washington, D.C. 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, HHS, Education,
and Related Agencies
House Committee on Appropriations
Washington, D.C. 201515

Dear Chairwoman Capito, Ranking Member Baldwin, Chairman Aderholt, and Ranking Member DeLauro,

As the Committee begins work on the Fiscal Year 2026 appropriations process we, the undersigned organizations, write in support of two requests in the Labor, Health and Human Services, Education and Related Agencies Appropriations bill focused on alpha-gal Syndrome.

Alpha-gal Syndrome (AGS) is an emerging tick-bite associated allergy to alpha-gal, a sugar found in most mammals and products made from mammals – including meat (e.g., beef, pork, and lamb), milk and dairy products, gelatin and many other items. According to a CDC study, 75% of people with AGS experience life-threatening anaphylactic reactions. In areas of high prevalence, reactions to the alpha-gal sugar 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.

AGS develops after tick bites. In the U.S., most cases are associated with lone star tick bites – these ticks are most common in the South, Midwest, and Mid-Atlantic. In some areas, 3% or more of the population is affected. The CDC reports that AGS is a growing public health threat and estimates that 450,000 people in the U.S. have it, making it the 10th most common food allergy. Due to growing lone star tick populations, AGS cases are growing at an alarming rate with new suspected cases increasing by more than 15,000 per year.

Provide CDC Funding for Alpha-gal Syndrome Health Care Provider Education - $4.5 Million in funding and report language requested under CDC Emerging and Zoonotic Disease Account

Health care provider education of AGS is limited. CDC survey data reports that 78% of providers report having little to no knowledge of AGS. Moreover, 1 in 5 providers were somewhat or very confident they could diagnose or manage patients with AGS. Not surprisingly, AGS is significantly underdiagnosed and misdiagnosed. On average, it takes over 7 years for a patient with AGS to be diagnosed. During this long time, people with AGS often experience debilitating symptoms – over half require emergency department treatment, 7% require multiple hospitalizations, and many are subject to unnecessary, invasive procedures and surgeries – at a high cost to our healthcare system and to the affected individuals. Funding to increase awareness of AGS among healthcare providers and education in the diagnosis and management of AGS is a critical first step towards improved, faster diagnosis, better patient care and reduced economic burden on both patients and the healthcare system.

We would encourage CDC to focus on high or growing prevalence states and to increase its collaboration and partnership with local governments and the health, education, community, non-profit, and faith-based sectors in those high-incidence communities.

Accelerate NIH Alpha-gal Syndrome Research – report language requested under NIH NIAID Account

There is an urgent need to deepen our understanding of how tick-borne disease mechanisms drive chronic illness. This includes not just mechanisms related to tick-borne disease caused by pathogens, but also mechanisms related to immunological responses to tick bites themselves. AGS is a paradigm-shifting tick-borne disease caused by immune response to tick bites. Unfortunately, classic allergic symptoms like hives and anaphylaxis are the tip of the iceberg. AGS is also a major driver of chronic disease. In high-prevalence areas, AGS may be responsible for up to 25% of IBS. Just having the allergic antibody to alpha-gal, which is true for 50% of the population in some areas of the U.S., is an

independent risk factor for atherosclerosis and cardiovascular disease. The alpha-gal immune response has also been implicated in arthritis, mast cell disorders, chronic urticaria, and autoimmune disease. AGS researchers are also exploring its possible connection to Alzheimer's disease and post-infectious syndromes. Understanding alpha-gal syndrome's cellular and molecular mechanisms and natural history by accelerating NIH research in this area is a prerequisite to understanding how ticks drive allergy and other chronic disease so that effective therapies can be developed.

On behalf of stakeholder organizations working to improve the lives of those with AGS – in the allergy, vector- and tick-borne disease space and the healthcare professionals who support and care for these patient populations - we appreciate your attention to this critical issue.

Sincerely,

Sharon Forsyth, Executive Director
Alpha-gal Alliance Action Fund

Debbie Nichols and Candice Matthis, Co-founders
Alpha-gal Foundation

Sung Poblete, Chief Executive Officer
FARE

Kenneth Mendez, Chief Executive Officer and President
Asthma and Allergy Foundation of America

Eleanor Garrow-Holding, President & CEO
Food Allergy & Anaphylaxis Connection Team (FAACT)

Fallon Schultz, MSW, LCSW, CAM Founder & CEO
International FPIES Association

Chris Martinez, President and CEO
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Jennifer Burton, Founder
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Erin Malawer, Executive Director
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Wendy Gordon Pake
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Erin Martinez, CEO
Food Equality Initiative