

# Alpha-gal Patient Perspectives: David (Patient) Meets Goliath (Health Provider).

Jennifer L. Platt, DrPH  
Beth Carrison, INHC

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*“I’ve been the patient being wheeled into surgery at a major university hospital being told ‘You’re our first patient with Alpha-Gal, do YOU know if this anesthesia is safe for you?’ I had previously spent hours personally researching that very question but that should never be my responsibility.”*

*“I was in the hospital 2 weeks ago with ana[phylaxis] and not one person there, not one, had any idea what I was trying to tell them. I have a \$31k bill for all the heart tests they ran. Nothing wrong with my heart.”*

To gain a rapid assessment of the top concerns of patients with Alpha-gal Syndrome (AGS), Tick-borne Conditions United (TBCU) conducted a survey in early August 2019. This survey was sent via e-mail to newsletter subscribers and posted on social media accounts. Due to the need for a quick turnaround, the survey was posted for 48 hours. One hundred thirty-one (131) people responded.

As shown in Table 1, the top three concerns AGS patients center on lack of knowledge of healthcare providers, ingredient labeling, and the need for research funding.

<b>89%</b> Lack of healthcare provider knowledge
<b>79%</b> Ingredient labeling on food and pharmaceuticals
<b>36%</b> Funding for additional research on Alpha-gal
<b>35%</b> Other
<b>21%</b> Lack of non-mammal ingredient vaccinations
<b>21%</b> Broader tick testing to capture additional conditions
<b>15%</b> Need for treatment, prevention, and signage in public places
<b>8%</b> Coping in the workplace and school environment
<b>5%</b> Mammal-free tick repellents and yard treatments
<b>5%</b> Lack of understanding and support from family and

Table 1. Top Concerns of AGS Patients

To diagnose and treat Alpha-gal Syndrome, healthcare providers must ignore much of their immunology training, including how allergies occur, how they are triggered, and who gets affected. Patients often learn about AGS from “Dr. Google”, friends, social media, or news articles. Further, because so little is understood about Alpha-gal Syndrome, patients are often told it is “in their head” and that their symptoms are not relevant to their condition.

In addition to patient concerns about the lack of healthcare provider knowledge, a lack of knowledge about AGS exists across numerous players in the healthcare system including pharmacists, dentists, medical and dental device manufacturers, and emergency medical technicians. Survey participants noted lack of awareness across myriad facets of life: schools, employers, policymakers, legal counsel, public health practitioners, product manufacturers (household products, cosmetics), and the general public. Because of this severe gap in awareness, numerous concerns were listed, as summarized below.

### **AGS Patient Fears, Frustrations, and Concerns**

- Patients are misled with incorrect diagnosis.
- Senior population
- Rehab or assisted living cafeteria support
- Cleaning, laundry, soaps, shampoos
- Medical support, medications, surgical
- Meal safety and dining adjustments.
- Incarcerated - Rights upheld and proper training (see above and below comments.)
- Insurance and disability costs and access to documented, credible information
- Children of all ages; infant, pre-k, school age, teen, college age
- Prevention and support at school, camps, activities (e.g. Prevention, tick checks, removal, reporting, and execution of healthcare needs related to AGS. Groups such as scouts, athletics, outdoor activities (hunting, fishing, playing).)
- Nurses trained and authorized to remove, (report, and submit biting ticks immediately for lab testing - nationwide!
- Diagnosis & treatment plan communication (age, impaired social or verbal skills and trouble communicating.)
- Food Services education (e.g. meal, prep and dining safety)
- Split family challenges. Safety and legal support.
- Patients avoiding routine and needed medical care. (Costs, and the challenges explaining AGS. (e.g. social emotional toll.)

- Regularly scheduled review of critical and core information with a clear path to request updates and accountability in response time and completeness.
- The Lone Star tick is an aggressive hunter.
- LS “doesn’t exist in our area”
- Lack of awareness about LS behaviors (e.g. leaves the preferred “tall grass areas”)
- Video of ticks in a “swarming” behavior (nymphs and adults)
- \*Lone Star tick does not adhere to typical tick behavior and can detect CO2 up to 100’ away without regard to the terrain

### **Social and Emotional Impacts**

- Unintended hurtful remarks such as, “I’d die if I couldn’t eat red meat!” (Some almost *have* died from anaphylaxis.)
- Are you sure it’s not all in your head? Family, physician, friends.
- Exclusion from social events
- school or work, and/or family holiday party anymore.
- Children bullied in school and on the bus and not supported.
- Employees not supported, affect job performance.
- Healthcare provider implying drug and alcohol usage, and discredits due to lack of knowledge.
- Limited travel (e.g., food, detergents, airborne, medical support out of area. Can impact job performance.).
- Grieving stages (Denial, Anger, Bargaining, Depression, Acceptance).

TBCU is committed to work with AGS patients and healthcare providers and to educate about timely, science-based research, guidance, education, and training for individuals, teams, and organizations.