

Case # 95809836-8292-429a-8bf1-3b16763bccb6

Submitted by Patient

Aug 03 2026

Disease	Alpha-gal syndrome
Drug(s)	Benadryl Epinephrine 0.004 Mg/ML Injectable Solution Magnesium L-Threonate (Magtein) Vitamin B12 L-Methylfolate Levocetirizine (Xyzal)



*This drug is approved by the FDA for this disease/indication.

^ Collapse All

Case Characteristics	^
Age Group:	21 - 30 years
Sex assigned at birth:	Male
Country Treated:	United States
Race(s):	White
Ethnicity:	Not Hispanic/Latino
Other Conditions	^

Underlying Conditions prior to infection: Cutaneous Mastocytosis

Clinical Presentation

Start of first acute infection symptoms: 2022

How diagnosis was made: PCR or other nucleic acid test (e.g., NAAT) or rapid antigen test

Level of care for acute infection: The patient was admitted to the hospital

Medications for acute infection: Ondansetron (Zofran, Zuplenz), Epinephrine 0.004 Mg/ML Injectable Solution

Symptom duration: >48 months

Symptom: Allergic Reactions

Impact on quality of life: Very severe

Symptom: Anaphylaxis

Impact on quality of life: Very severe

Symptom: Alternating bowel habits (e.g., constipation and diarrhea)

Impact on quality of life: Severe

Symptom: Changes to your mood or increased emotional volatility (Mood disturbance/affective disorder)

Impact on quality of life: Severe

Symptom: Digestive issues

Impact on quality of life: Severe

Symptom: Food intolerances (e.g., lactose, gluten, etc.)

Impact on quality of life: Very severe

Symptom: Anxiety

Impact on quality of life: Moderate

Symptom: Irritability or emotional lability

Impact on quality of life: Severe

Symptom: Obsessive/compulsive disorder (OCD) or symptoms

Impact on quality of life: Moderate

Symptom: Personality or behavior changes

Impact on quality of life: Severe

Symptom: Symptom flare with stress (Stress intolerance)

Impact on quality of life: Moderate

Symptom: Urinary urgency

Impact on quality of life: Severe

Treatment Details

Benadryl:

Epinephrine 0.004 Mg/ML Injectable Solution:

Magnesium L-Threonate (Magtein):

Vitamin B12:

L-Methylfolate:

Levocetirizine (Xyzal):

Additional medication details: I tried auricular acupuncture to resolve the Alpha-gal. She would not be argued with. No improvement. I believed that having the acupuncture procedure/treatment performed again would be sufficient based on anecdotal evidence, but having needles in my ear for weeks made it hard to shower. I turned to vitamins and other supplements. My main symptoms were psychological unless I accidentally consumed a mammalian product. Building willpower to find a way to live in a new world where my society suddenly felt hostile (don't try to sell me a hamburger) towards me was strange – and arguably still is the most difficult part of having AGS. I find myself yelling at Carl's Jr. ads and being angry at and jealous of those who don't have AGS. Finding ways to relieve stress and cope with not being dietarily normal pushed me away from certain events and communities. It's isolating and ironic to be the AGS-bearing son of a small-time cattle rancher who loves to flaunt his

beef. CBT helped me process the emotions I was developing the first couple years after diagnosis, but the hardest part is feeling alone.

Helpful alternative therapies: Cognitive behavioral therapy (including talk therapy), Special diets

Outcome

Symptom: Anaphylaxis

Treatment: Benadryl, Epinephrine 0.004 Mg/ML Injectable Solution

Outcome: Significant symptom improvement

Time to outcome: 1 Day(s)

Symptom: Allergic Reactions

Treatment: Benadryl

Outcome: Moderate symptom improvement

Time to outcome: 1 Day(s)

Symptom: Changes to your mood or increased emotional volatility (Mood disturbance/affective disorder)

Treatment: L-Methylfolate, Magnesium L-Threonate (Magtein), Vitamin B12

Outcome: Moderate symptom improvement

Time to outcome: 1 Day(s)

Symptom: Obsessive/compulsive disorder (OCD) or symptoms

Treatment: L-Methylfolate, Magnesium L-Threonate (Magtein), Vitamin B12

Outcome: Moderate symptom improvement

Time to outcome: 1 Day(s)

Symptom: Symptom flare with stress (Stress intolerance)

Treatment: Levocetirizine (Xyzal), Magnesium L-Threonate (Magtein)

Outcome: Significant symptom improvement

Time to outcome: 1 Day(s)

Miscellaneous



Research priorities: The intense psychological impact of sudden forced dietary contraction due to fear of another life-threatening reaction while being isolated from family/friends who don't need to adapt their diet is an interesting response to AGS I haven't seen much focus given to. Here's my AGS story. I knew I had been bitten. Six Lone Star ticks showing like a constellation on my left leg - all sunk in and drinking deep. They'd been there for hours and I hadn't noticed since I'd been working in jeans all day. To be honest, I'm not sure how they got there with all the peppermint oil and bug spray I'd applied for this very reason. Oh well, I thought as I removed the arachnids. Oh well was the wrong reaction. Oh well kept me from diving into the potential effects of the bites I'd received. I knew about Lyme's, knew ticks were bad, but had no idea about the haunting reality I'd been submitted to. For a few months, nothing seemed amiss. I ate what I wanted, lived life carefree. All that changed one night after eating a 7PM steak dinner with a friend. At first I was fine. Showered, went to bed with my wife around 10PM like normal. Started dreaming about reverse sear methodology when... hold on.... I woke up feeling... not right... There was no more Oh well. There was only rushing to the restroom to feel my body giving out on me in every sense as an unknown force took hold of my faculties to end my short 22-year life. I started to cry out - barely a whimper in my weakened state - hoping my wife would hear me and call for an ambulance. Vision closing in as I sat there shaking. Next thing I know my wife is shaking my EpiPen in my face and asking permission to inject it. I'd forgotten about the Epi since my mastocytosis hadn't flared up enough warrant its use in the 2 years since I'd been diagnosed. She stabbed my thigh. My vision stopped dimming. 911 was on the way and I needed to make it to the hospital. We were sitting out in the truck - me vomiting, my wife calling my mother - when the ambulance pulled up and rushed me down the highway to the hospital. The staff was fantastic. Me shivering and convulsing while strapped to a gurney was the opposite. IV fluids and Zofran helped me stabilize as the epinephrine started to wear off. By 4AM I was released and in need of a meal. Whataburger is open 24 hours. Don't expect a good burger at 4AM. I ate it anyway not knowing that beef had gotten me here in the first place. Thankfully, my body had some kind of tolerance built up with the recent exposure and

last bits of Epi in its bloodstream. No additional reaction at this time. But we still didn't know what had caused the reaction. My religious background said demon! but the Facebook groups my wife had rabbit-holed into made it clear what this delayed anaphylactic reaction to beef actually was. Alpha-Gal Syndrome. We made sure - got a lab test (Alpha-Gal Syndrome Allergy Panel from Quest Diagnostics) and confirmed my IgE levels for beef were over 400x higher than baseline. I wasn't optimistic about ever eating beef again and that was crushing. The allergist wanted to tolerance test me - I feared death and didn't come back. My parents stayed optimistic as they could, but they couldn't seem to relate to my situation no matter how hard they tried. My wife had to stop me from sneaking beef jerky once. It all felt like a fever dream - almost like a joke. I've had AGS a little over 4 years now and it's still not a joke. There have been several moments where cross-contamination or a secret ingredient gets the best of me and I'll have to take 3+ Benadryl to feel good enough to sleep. Thankfully, my levels have decreased, but the false hope and tentative nature of AGS resolution is a sink I had to cut out to stay sane. I'm not expecting to heal spontaneously. I'm expecting to always be aware, to always ask about food prep in restaurants, to mostly cook at home with whole food ingredients, to always communicate my nature to friends and family in hope that they remember (they don't) the severe consequences of accidentally serving me chicken tenders fried in tallow (It's NOT SAFE just because it's CHICKEN). Those are baseline expectations. With enough time and reminder I have seen certain groups improve their behavior in the kitchen and with ordering food. I expect regressions because good behaviors aren't reinforced more broadly (these are white Southerners raised on BBQ). I have hope in the professionals pursuing the true nature of the disease to be able to develop a therapeutic that works for patients broadly. I think that could solve some of the problem. I think awareness solves the major part, though, and sites like <https://www.regulations.gov/docket/FDA-2024-P-4512/>, which I was so excited to see come online, now sit apparently ignored. Alpha-Gal shouldn't keep any person from living a healthy, socially-balanced life.