

How Alpha-Gal effects people

I woke up one morning with a bite on the top of my left hand. I went to the doctor that day because I was concerned that it could be or cause an infection. The doctor looked at it and said “Oh, it’s a spider bite, but you’ll be fine because you are already on the medication used to treat it – Prednisone”. I didn’t have any idea how wrong he may be. Within a few days of this bite, I began experiencing all sorts of symptoms that I hadn’t had prior; the feeling of having to hold on to the wall so that I would not fall over, the worst stomach cramps I had ever experienced in my life (where I had to stop what I was doing to do the lamaze breathing through the pain), nose bleeds, intestinal bleeding, constant nausea and brainfog, extreme dizziness to the point my husband had to drive me back and forth to work.

I changed doctors but this one wanted to give me Vallium for the dizziness but didn’t want to test me for anything. I refused the medication. This was my first indication that they most likely did not believe me. 2 years after the “spider” bite, I developed hypothyroidism very fast. I had my normal annual blood tests for my physical in February and my results were normal, but by June my TSH was at 194.0, when it should have been between .5 and 5.0.

By this time, I had been feeling like I was getting sick every time I ate meat, but just couldn't believe that was a thing. I received a phone call from my sister one evening telling me to turn on channel 6 news quick, which I did. There was a woman in Maine that was talking about this thing called Alpha-Gal which she had recently been diagnosed with and explaining how she could not eat red meat or she would get anaphylaxis along with many other debilitating symptoms. At that point I began my research into Alpha-Gal and found a facebook support group which was helpful.

I went to my doctor and requested the Alpha-Gal test, but when she looked up Alpha-Gal she said "You can't have that, that's the Lonestar tick and it's in Texas". I pushed her to do the test anyway, which she did but the results came back negative at .10 because the standard for the test was .35, which was industry standard for allergy tests. I later found out through the Alpha-Gal group/community that allergy tests use the .35 standard but what was later discovered is that some people with Alpha-Gal could react below .35, so the standard was changed to .10.

I decided to see a Naturopath that specialized in tick-borne diseases, at which point I was diagnosed with Lyme, and Alpha-Gal with a test result of .10. I gave my doctor a copy of these test results, but my chart was never updated to include Lyme or Alpha-Gal. Since I had an official diagnosis, I could finally begin my journey to figure out how to get better after 11 years.

First, I stopped eating mammal which was 6 years ago now. Once I stopped eating mammal and cleaned it out of my environment, I began reacting to other things, like medications, preservatives, vegetables, spices, perfumes, lotions, etc. One after another each time I stopped using something-the next thing would make me reactive. It's like walking along on a daily basis and not knowing when you're going to walk into an invisible brick wall. It took all of my spare time to research medications, foods, household items, etc. to keep myself safe. When I need a prescription, my doctor sends it to the pharmacy, then I call the pharmacy to find out the NDC #, next I research the NDC and find out the manufacturer. I then call the manufacturer to find the ingredients in the medication. If the medication contained Alpha-Gal ingredients, I would start the process over by calling the doctor and asking them to send in a different prescription.

From my granddaughter in her own words:

Alpha-Gal doesn't only affect the people who have it, it can affect people's families and friends. Ask me, I should know, since my Grandma has Alpha-Gal. When she first got it, I couldn't even go see her because she was too sick. She couldn't go out to eat with friends or family. When I could come over, I had to be super cautious of what I wore or brought. Alpha-Gal can affect people's lives in so many different ways, from having to eat different foods to having to go to the emergency room.

Norah, age 11