

Sarah Jones

Vasculitis



Before I begin to tell parts of my story, I have to say that my heart is full of gratitude for the health care team that I currently have. Their hard work and dedication are appreciated far beyond the gifts, notes, and flowers that I can bestow upon them. My heart is full.

And.

It has taken two years to assemble them.

With two Master's Degrees, one in Public Administration with a health care focus, and one in Strategic Design, I have always lived my life steering toward positive outcomes. No one would ever call me a shrinking violet, but the process of diagnosis and post-diagnosis care has tested that.

For 12 months I struggled to get an answer to my sudden severe asthma, expansive new allergies and recurring bronchitis, pneumonia, and hives. The process was demoralizing, exhausting and painful.

On three separate appointments, a pulmonologist diagnosed me with GERD and prescribed erythromycin. His only recommendation was surgery for a hiatal hernia that didn't exist. (And I don't have GERD.)

Following that I began to see an asthma/allergy doctor. He said my recurring pneumonia was due to allergies. Four visits to him resulted in only antibiotics, and steroids. I questioned the hives, telling him that according to my own research, they looked like vascular hives. This was never addressed.

During my eighth case of bronchitis, I went to the allergy/asthma office – again. The NP I saw was the first one to take my blood pressure, and she promptly sent me to the Emergency Room. My BP was 210/117, I had a cough and shortness of breath. The doctor did a COVID-19 test, x-ray and sent me home. When I inquired about my BP – he said, “It is just nerves, go home and just take it again in the morning.” I did. It was 224/128; my BP would continue to be unmanaged for the next eight months. This was the exact same emergency room that my brother went to with a BP of 230/120 and was promptly admitted and tested for days. In my opinion, sexism in health care is alive and well.

Several weeks later, I had bronchitis for the ninth time. This time we drove to a new ER, but again, the COVID-19 test defined my care. The doctor was furious. He said, “We just can’t help people who need testing and evaluation during a pandemic.” He was quick to prescribe another round of antibiotics and steroids, and I was out the door.



Upset, I began studying my lab and EKG history. If the doctors were not going to look at it, I was. I noted my abnormal EKGs, elevated D-Dimer, chronic shortness of breath, cough, bronchitis, vascular hives, and my eosinophils at three times the normal range. Several weeks later my bronchitis returned and was clearly pneumonia – again.

Desperate, and armed with my history, my wife drove me two hours to the medical center in a nearby city. We were not doing this dance with doctors that would not listen and did not care.

James Komara, D.O, the ER physician at the Mayo Clinic, was the first person to really listen. I can still hear his voice, “You are a very sick woman. We will figure this out.” It was the first time I had felt seen and taken seriously. He diagnosed pneumonia, noted the extensive inflammation in the lungs, flagged the eosinophils, injected steroids for hives, admitted me and ordered a skin biopsy. Mayo’s curious culture tested every system and ordered a skin biopsy, which led to the diagnosis of EGPA.

Finally.

Diagnosis is not the end of the story for a person with a rare disease, but it is an essential step in the journey of dealing with a life-threatening disease.

In March 2021 I woke up with a 103 fever and pulse/ox in the 80s. That week in the hospital was the first hospitalization since receiving the EGPA diagnosis. We showed up and immediately asked for a rheumatology consult due to my condition and gave everyone information on EGPA. The hospitalist refused the rheumatologist request and had the pulmonologist stop in. He proclaimed that I was fine.

On day four, it took my refusal to take any more medications and a complaint to the hospital against the hospitalist to get a rheumatological consult. The rheumatologist knew to order ABGs, which then resulted in a diagnosis. This five-day hospital stay could have been one to two days if they had listened to us.

In the last several months I saw my new pulmonologist. My lungs looked good, but I was still short of breath. He took that opportunity to tell me at least six times I was overweight. I was humiliated. I had been on steroids for 16 months, of course I had gained weight. My wife, exasperated, asked him if my breathing issues could be tied to the fact I could not breathe through my nose. That comment led to a three-and-a-half-hour sinus surgery and a clear nasal passage, for the first time in years. The EGPA was directly responsible for the sinus issues.

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To the doctors reading this, thank you. Thank you for caring and showing up every day! And please, look at more than labs and scans. Please listen closely and respectfully with a curious mind.

Eighteen months into this disease, I am thrilled to have doctors who partner with me, listen, and seek to understand. It helps the daunting future seem less formidable.

Vasculitis

Vasculitis is a general term that refers to inflammation of the blood vessels. It is used to describe a family of nearly 20 rare diseases, characterized by narrowing, weakening, or scarring of the blood vessels, which can restrict blood flow and damage vital organs and tissues. Vasculitis can affect any of the blood vessels of the body, including arteries, veins, and capillaries. Symptoms depend on the organs and tissues affected and can vary from person to person. Early diagnosis and treatment are extremely important to avoid potentially life-threatening complications.

- Vasculitis is classified as an autoimmune disorder, which occurs when the body's natural defense system mistakenly attacks healthy tissues. Triggers may include infection, medication, genetic or environmental factors, allergic reactions, or another disease. However, the exact cause is often unknown.
- Most forms of vasculitis are chronic, with periods of relapse and remission. In addition, medications used to treat vasculitis carry the risk of side effects, so follow-up medical care is essential.



Learn more

Vasculitis Foundation