Feeling less alone: my journey with Samter's Triad (AERD)

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I grew up with mild hay fever, which began in my teenage years and was managed with a nasal spray during the summer. I had no other health issues until my early thirties, when I suddenly developed asthma symptoms and allergic reactions. After many doctor appointments and tests, I was diagnosed with allergies to dust and tree pollen. I was given inhalers and essentially told to carry on with my life.

One day while suffering from stomach-ache at work, I took an ibuprofen tablet. Until then, I had taken ibuprofen many times without any problems. On this occasion I suddenly felt hot and tingly, as though someone was sitting on my chest, and I struggled to breathe. Fortunately, I worked for a large organisation in London with an on-site doctor. They acted quickly, giving me a steroid injection and oxygen. An ambulance was called, I was treated, and then sent home.

Not long afterwards, I took aspirin for a headache without giving it a second thought. The same reaction followed. On Christmas Eve, after an ambulance visit and a very frightening few hours, I was back home recovering in bed.

Around the same time, I began experiencing sinus problems and completely lost my sense of smell and taste. I saw an ENT specialist and had my first nasal surgery to remove polyps and congestion. It was the first of many surgeries.

I also began experiencing severe stomach issues, with excruciating waves of pain that left me bedridden for months, alongside severe vomiting every few hours, day and night.

I saw NHS doctors, spent a fortune on private healthcare appointments as my work allowance ran out, and visited every specialist I could. Eventually, I was hospitalised and placed on a drip as my body was shutting down. With no obvious cause, my family and I were desperate for answers.

Finally, an incredible gastroenterologist persevered with my case and referred me to an immunologist at the Royal London. He diagnosed me with Samter's Triad, which is also known as Aspirin-Exacerbated Respiratory Disease (AERD), and internal urticaria.

My organs were reacting so severely to allergens that they were swelling inside and causing the pain and sickness. He prescribed an antihistamine, which to my great relief allowed me to eat and function again. However, despite three surgeries the polyps once again recurred, and constant chest and sinus infections were seriously affecting my life. By then, I had a young family and simply wanted to feel "normal". Steroid courses were a short-term solution, but I hated the side-effects.

A few years ago, I searched online to see if anyone else was living with Samter's like me. I found the SmellTaste website and community. I read their articles, signed up for their mailings, and shared my views through surveys. For the first time in a long while, I felt less alone. More recently, I read a piece in their newsletter about biologics finally becoming available in the UK and checked the eligibility criteria.

It gave me hope. I fought, faced brick walls and refusals, and I begged.

Finally, my ENT specialist confirmed that I am a strong candidate for Dupilumab and has approved my case. I hope to receive my first dose very soon.

SmellTaste makes such a difference to people's lives, and I am deeply grateful for their tireless research and for creating a community that gives people like me hope.

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