

Rhonda & Wayne Nelson

AERD



Wayne: Rhonda's symptoms began early in 2001, just before she turned 34. They included two-to-three-hour sneezing attacks at about 3:30 a.m., sinus headaches, and difficulty breathing due to nasal polyps. For a couple years the condition was treated as allergies, but the tests were never conclusive regarding what she was allergic to. One test came back saying she was allergic to everything.

In 2003, we moved from Tennessee to North Carolina and all her symptoms got worse, despite a nasal surgery that had removed all the polyps the year before. Her new ENT had just returned from a one-month seminar with Max Samter, MD, the doctor who discovered Samter's Triad. The three prongs of the disease are nasal polyps, asthma, and allergic reactions to most pain medicines, progressing to anaphylactic shock.



He diagnosed Rhonda's condition as Samter's Triad, now known as Aspirin Exacerbated Respiratory Disease (AERD), within a few minutes.

The disease was very underdiagnosed. For years, we would have to explain in detail to emergency rooms all that was going on when Rhonda had a bad reaction to either mold or chemical smells like bleach or cigarette smoke. After moving to Florida in 2011, she had another nasal surgery that removed the entire lining of her nasal passages. That allowed her body to rebuild that lining, but the result was that she lost all the function of the cilia, so her nose couldn't clear itself of any foreign matter. She rinses her nose twice a day with a saline solution dissolved in distilled water. She also lost her sense of taste and smell almost 20 years ago. That has become a common indicator of the disease now.

And oddly enough, when she contracted Covid-19, she got her smell and taste back for a few days. It was overwhelming to her and made her nauseous.

About five years ago, the Allergy Asthma Network (AAN) realized how prevalent this disease was and lobbied for it to be added to the list of chronic asthmatic diseases. AAN has done wonders exposing the dangers of asthma in children and adults, and AERD has been brought under its umbrella as a major cause of suffering for patients that have been misdiagnosed like Rhonda was. The AAN provides important statistics about all asthmatic conditions, including eczema, AERD, and childhood asthma, which is the leading cause of school absences in the U.S.

Rhonda has become a spokesperson for AAN and acts as a patient activist with drug companies that are realizing more and more just how widespread these diseases are. They lobby the U.S. Congress for lower and fairer drug prices for people who can't afford the medicine, and/or don't have insurance. One of Rhonda's meds would cost almost \$50,000 per year were it not for her insurance and the work of AAN.

As bad as Rhonda's case was, her medicine has finally made life more bearable. Her flare-ups are fewer, and don't last as long as they used to. But she's on a couple of forums where people describe life-altering symptoms. Without treatment, the disease is miserable for patients and families to live with. One of the most difficult issues to deal with is that the violent and constant sneezing hurts the whole upper body, and the pressure from the sinus headaches is intense, but AERD patients can't take most pain relievers. And at this moment, there is still no definitive cause that can be detected. There are lots of theories yet to be tested, but no solid evidence yet. That makes it even more exasperating. ●

Aspirin Exacerbated Respiratory Disease (AERD)

Aspirin (acetylsalicylic acid, or ASA) is a non-steroid anti-inflammation drug. It is used to reduce pain, decrease inflammation and block platelet activity. Aspirin can have serious side effects, such as stomach ulcers and kidney injury.

In some patients with asthma, aspirin can cause an asthma flare. The typical symptoms (Aspirin Exacerbated Respiratory Disease, AERD) include:

- Asthma
- Nasal polyps
- Aspirin-sensitivity