



Laura Kelly

Nontuberculous Mycobacteria (NTM)

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“Fortunately, there finally are some promising therapies being developed. The problem for me and many like me, it is taking too long for them to be approved. I understand one of the FDA’s priorities is to make sure that approved drugs are safe, however, I can assure you that having this disease is not safe.”

In 2006 at the age of 46, through a random chest X-Ray, nodules were discovered on Laura’s lungs. She was asymptomatic, but after several CT Scans and then finally a bronchoscopy, Laura was diagnosed with Nontuberculous Mycobacteria, or NTM, a serious chronic lung illness caused by bacteria commonly found in dust, soil and water. Symptoms range from a severe cough and shortness of breath to scarring of the lungs that prevents the clearing of mucus.

For those living with NTM, days begin and end with pulmonary clearance to expel mucus from the lungs. This entails not only performing it but very carefully cleaning and sterilizing equipment so as not to re-infect. In addition to a lifetime of antibiotic roulette, NTM patients face endless cultures and scans to identify and appropriately treat bacteria and help manage lung function.

In June of 2007, Laura started on three antibiotics. After a few months, it appeared the drugs were positively impacting the bacteria, however Laura started experiencing peripheral neuropathy in her feet, which has never resolved. She also has significant ringing in my ears and hearing loss. For the next four years, Laura was on another three antibiotics. During this time bacteria-riddled lung cultures persisted, and her lung function was declining so another round of antibiotics was prescribed, but still with little impact.

In 2013, Laura participated in a drug trial for a new inhaled formulation of amikacin, which eventually gained accelerated approval in 2018. After being on as many as four antibiotics at a time from 2007 through 2013 with no results, in May of 2013, she finally cultured negative in less than six weeks. Although she was able to go off all antibiotics for a period after eight years, two new bacteria in 2016 and 2017 required another handful of drugs to attempt to harness infection. Fortunately, Laura has benefited from another round of inhaled amikacin, but her CT scans have worsened, and her pulmonary function is declining. Because current NTM treatment options involve months of toxic IV and oral antibiotics, often with serious side-effects and poor results, people living with NTM desperately need sustainable treatments that can better address the spectrum of symptoms their disease presents.

As a patient and the NTM support group leader for Georgia, Laura is keenly aware of the many ways that NTM can mentally, emotionally, and physically drain patients and their families. Simply leaving the house can often seem like it is not even worth the risk of contracting new bacteria. Laura is hopeful about promising therapies being developed, but the time is it taking and the progressive nature of NTM is an unfortunate combination.