

John Torrence

Bronchiectasis



I marked my 50th birthday by coughing. I didn't realize at that time that my whole world would be different than before. I tried all my own little things and after a while I realized, this is beyond me. I spent about a year seeing a general practitioner at a clinic who gave me a little bit of this, a little bit of that – none of which worked. At the end of the third year, I started getting emotional about it.

Usually, I'm a pretty calm, cool, and collected guy; nothing phases me. But at this point I was at my wit's end. I remember getting quite upset, really started having an emotional response, and one day I just went into the clinic without an appointment and told the doctor something is really going on. Eventually I was referred to a pulmonologist who said I had an incredibly rare bacterial infection of the lung that would require a long course of multiple antibiotics. My mother had had similar issues, so she

asked me to inquire about bronchiectasis, which I did. I get the impression the pulmonologist wasn't familiar with it at first...but eventually I was diagnosed with "acute exacerbations of bronchiectasis."

My life as a science experiment began – the bacterial infection required twice weekly blood tests, weekly bandage changes, daily vomiting, weakness, and not-so-fun airway clearance exercises to do. I was anxious about not knowing anything about this rare disease which was affecting my personal relationships. My then-wife wanted to know why I had to get a twelve-syllable disease of which no one had ever heard.

We were living in Maui, HI at the time. Our social structure was built around scuba diving. We went diving weekly, sometimes more. That's hard to do with an IV line attached to my arm. So, the group went on local and faraway trips without me. I felt isolated and alone. I could no longer do the things that I enjoyed most.

My wife grew impatient at the toll this disease was having on my life – and by extension, hers. After lung surgery in Denver, CO, I remember her irritation when I refused to heal as fast as the surgeon had assured her I would. The doctor wanted to keep me for a couple more days. That was too much for her, so she went home alone. I was alone in a hospital room, 4000 miles from home, with tubes coming out of everywhere.

When I made it home a few days later, my wife said all my “laziness” meant that we were now behind financially and that I needed to get to work immediately. I could see my world crashing down around me. I eventually cleared the bacterial infection... but the marriage did not survive.

I lost my wife, our house (that I had built with my own hands), my scuba diving friends, and my mental health. This disease affected so much more than just my lungs. I lost the life that I had so carefully built and was now in uncharted territory. I even moved to the desert of Las Vegas, NV, as doctors said I needed dry air. This was not a place I had ever envisioned myself living in, so far from the ocean I loved.



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Since moving, I have had more NTM infections. Each one is a two-year cycle of drugs, CT scans, blood tests, airway clearance exercises. The great irony is that my current infection is a species unique to the desert southwest, and particularly hard to treat. The toxicity of the medicine damaged my hearing to the point that I now have hearing aids.

But it hasn't been all bad living here. When I first arrived in Nevada, I just had an apartment that I only used to sleep in. Being new here, I went online and there were various websites where you could volunteer for different local activities. I came upon the Cystic Fibrosis Foundation. I figured, children with CF might have NTM and bronchiectasis, too, and be going through the same things physically and emotionally as I am. I've been volunteering with them for some time now.

I've also been working with the COPD Foundation, talking to new patients, moderating a monthly patient support meeting, helping hospitals, pharmacies and industry develop better answers for tomorrow's patients. I want to help others, because in doing so, I help myself.

Being able to help others has given a purpose to my suffering. In a weird way, as much as bronchiectasis has closed doors in my life, it has opened others.

It's been 14 years since that first cough. At least now I have balance in my life. New friends, new hobbies, new routines. I don't fear the disease anymore. I try to do something non-medical every day, so that I don't feel like I am just a science experiment.

I am grateful to my entire care team and many others who have helped me on this lonely journey. ●

Bronchiectasis

Bronchiectasis is a lung condition that causes cough, sputum production, and recurrent respiratory infections. The symptoms are caused by abnormal dilation (widening) of the airways of the lung (bronchi). In some cases, only one airway is affected. In other cases, many are affected. In very severe cases, dilation of the airways occurs throughout the lungs.

- Genetic diseases (such as cystic fibrosis and primary ciliary dyskinesia)
- Problems with the immune system (reduced ability to fight infections)
- Past lung infections
- Problems with swallowing causing aspiration of food or fluids into the lungs



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