

Jon Bernhard

NONTUBERCULOUS
MYCOBACTERIAL DISEASE



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I have lived over 30 years of battles and incredible achievements. I was first diagnosed with nontuberculous mycobacterial disease (NTM/MAC) in 1987 when I was 22 years old. My life as a top-end athlete in road bicycle racing came to a complete halt. I was devastated with facing the end of my life, right when I felt my life was only beginning. Through the support of my doctors and heaps of medications, I have clawed my way back to a semblance of my former self.

My journey is marked by countless medication regimens and numerous horrific side effects. Today I am working my way through cryptogenic organizing pneumonia as a result of the scarring and damage due to bronchiectasis, and other effects of the disease.

Childhood memories of backpacking, canoeing, and exploring helped me remember 'life's true meaning,' and kept me from giving up. My brother introduced me to rock climbing and brought me back to pursuits of the outdoors. It was like the disease fueled a new fire to live, and I wanted to approach every moment with genuine intention. I rode my bicycle across the U.S., stood atop the tallest peaks of Alaska, and climbed the faces of El Capitán in Yosemite. Instead of seeing limits with my physical ability, I worked with a new range of focus. I still viewed the world and my place in it as a great adventure.

In the three decades of living with NTM/MAC, I have been fortunate to participate actively in my treatment plans and rehab routines. I even co-authored a peer-reviewed paper on the prevalence rates of the disease in the U.S., and I created a foundation for pediatric patients.

The medical, physical, and emotional struggles of NTM/MAC are daunting. Patients and their families obsess over the day-to-day questions of:

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Nontuberculous Mycobacteria (NTM) is a naturally occurring environmental pathogen which impacts tens of thousands of people every year in the United States alone. The bacteria are widely found in the environment, including soil and tap water.

An estimated 50,000 to 90,000 people in the United States have pulmonary NTM disease at any given time, and between 12,000 and 18,000 people become infected each year.

Underlying pulmonary problems and prior pneumonia are but a few risk factors, and a number of genetic diseases including Cystic Fibrosis, COPD, and Alpha-1 Antitrypsin Deficiency have a statistically demonstrable link with NTM. Slender Caucasian women are particularly vulnerable to infection.

Learn more from ATS Public Advisory Roundtable member Nontuberculous Mycobacteria Info and Research (NTMir) at ntminfo.org.

“How am I breathing today?”

“Am I well or am I sick?”

“Will this small cold turn into a full-blown infection?”

“Will being active today lead to overall health conflicts?”

“Will I be able to keep up with the demands of work and my relationships?”

Often our questions and doubts win the day. But by surmounting these fears, we go to a place of ownership and civil disobedience against the disease.

I believe each patient should be treated in a way that activates and unlocks their hidden potential. I climb, adventure, bicycle, and much, much more to prove that we need to adjust our vision, and I aim to show to my physician team that as an NTM/MAC patient we can reach for success well outside the mean.