

# VOICES OF

## NTM LUNG DISEASE

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## VOICES OF NTM LUNG DISEASE

### **About *Voices of NTM Lung Disease***

The *Voices of NTM Lung Disease* eMagazine shares different perspectives from those familiar with this chronic condition to support readers throughout their own journeys. This first issue discusses the importance of early diagnosis, with tips on how to talk to your doctor. Upcoming issues will cover a range of other relevant topics for those impacted by NTM lung disease.



### **Searching for Answers and Finding Support: My Journey with NTM Lung Disease**

Debbie B. shares her 19-year NTM lung disease journey and how getting multiple opinions from doctors helped lead to her correct diagnosis.\*



### **Our Life with NTM Lung Disease: A Spouse's Perspective**

Debbie B.'s caregiver and husband, Marc B., discusses the lifestyle changes the couple has made since Debbie received her NTM lung disease diagnosis and how he has provided support along the way.



### **Why Catching Early Signs of NTM Lung Disease is Important**

Dr. Julie Philley, Pulmonologist and Associate Professor of Medicine at The University of Texas Health Science Center at Tyler, explores why it's important to catch the early signs of NTM lung disease and discusses tips on how to talk to your doctor if you're experiencing recurring symptoms.\*



### **Advocacy Spotlight: How the COPD Foundation is Increasing Awareness and Education of NTM Lung Disease**

Learn about how the COPD Foundation is raising awareness about NTM lung disease and access available educational resources.

\*Authors were compensated for their content and time.

# Searching for Answers and Finding Support: My Journey with NTM Lung Disease

By Debbie B., NTM Lung Disease Patient



Imagine having a simple cold that results in a lingering cough, usually for many months at a time. Or leading an active lifestyle and suddenly being sidelined for reasons that you just don't understand.

Coughing wasn't something new to me. As early as high school, I found myself coughing excessively on the school bus when bombarded by the cigarette smoke from my fellow classmates – yes, smoking was permitted on the school bus back then.

Over the years, I was prescribed an antibiotic and antihistamine for each new cough, and eventually, it disappeared. I consulted many physicians during this time. One incorrectly diagnosed me as being borderline asthmatic, and others could offer no explanation for my symptoms. Undergoing tests that all came back without a clear answer was frustrating, to say the least. When I was told nothing was found from my doctors, I thought that maybe there wasn't something serious causing my symptoms, and eventually my cough would disappear.

In 2000, my cough returned. But this time, it was different. I recall sitting at a family dinner and being unable to function. I experienced chills, fever and fatigue. I visited my local internal medicine doctor a few days later and was diagnosed with pneumonia. However, my x-rays told a different story – one that my internist couldn't decipher – so he referred me to a local pulmonologist. The pulmonologist couldn't explain my x-rays either. He ordered a CT scan and put me on a 10-day course of antibiotics.

My symptoms disappeared, but follow-up radiology reports appeared the same as before. This time my pulmonologist ordered a bronchoscopy and shipped the sample out for testing. I was diagnosed with a type of nontuberculous mycobacterial (NTM) lung disease known as *Mycobacterium avium-intracellulare* infection (MAI). At the time, I didn't realize that there are different types or species of NTM bacteria that can cause an infection, and mine was caused by a species called *Mycobacterium avium* complex (MAC). Different doctors have referred to my condition as "MAC" or "MAC lung disease" because it's the species most often identified in NTM lung disease patients.

It was a long road to diagnosis and took 15 years to finally receive a correct diagnosis. I grew frustrated of my persistent symptoms and hated coughing in public. I wanted to know what was wrong, so I could take action and manage the condition with the help from my doctor. Following my diagnosis, my pulmonologist educated himself on available treatment options and referred me to a patient website for more information. After years of seeing countless doctors, I was finally able to locate a team of medical professionals with the expertise to correctly diagnose and treat my condition.

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I have been living with NTM lung disease for almost 19 years now and am thankful I had the fortitude to continue searching for an answer. While an NTM lung disease diagnosis is not ideal, I'm relieved to finally know the cause of my symptoms.

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If you're experiencing symptoms, the first step is to recognize the problem and take action for early diagnosis by discussing with your doctor about testing for the condition, which can include a sputum culture and CT scan. Being your own advocate and starting these conversations with your doctor may help speed up the time to diagnosis.

I've found that it's helpful to connect with others living with the condition and learn about their experiences if you think you might have NTM lung disease. This led me to start the New York NTM lung disease support group, using my experience to offer support to those in the early stages of the NTM lung disease journey.



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# Our Life with NTM Lung Disease: A Spouse's Perspective

By Marc B., NTM Lung Disease Patient Caregiver



For 15 years, my wife – Debbie – experienced respiratory symptoms while we were left in the dark about what was causing them. We sought opinions from countless doctors and sometimes traveled to health institutions across the country based on their expertise. During this time, I stayed by my wife's side and remained positive that we would find the answers we were looking for.

It wasn't until we met with a specialist in 2000 that we learned she was suffering from a progressive and chronic condition that we had never heard of, known as nontuberculous mycobacterial (NTM) lung disease. Before receiving this diagnosis, the local doctors we visited knew little or nothing about her condition. I was happy and relieved to finally have a correct diagnosis after years of not knowing the cause of her symptoms. However, I didn't know then how much our lives would be impacted after she was diagnosed.

Life with NTM lung disease has meant learning how to make adjustments. I have helped more around the house and with running errands, and supported making lifestyle changes to help Debbie.

We started eating dinner earlier so that Debbie does not go to bed on a full stomach and sleep in an inclined position in bed to help with her breathing. Although she is not as active as she used to be, we still try to enjoy outdoor activities like hiking. She becomes short of breath when hiking uphill, so we stick to flat trails now.

“Our travels have also become more restricted. We avoid humid climates – which rules out vacations to places like Hawaii – and the climate control systems used on cruise ships mean the air may not be healthy for my wife to breathe. We also don't ski anymore, since the high altitude makes it difficult for her to breathe. Wherever we go, NTM lung disease is a factor in our plans, but I'm grateful for the things we can do together.”

My wife and I had been planning to retire in Florida, where most of our friends and family live, but her doctor advised against it, informing us that the humid climate would not be a good match for her NTM lung disease. Instead, we decided to move closer to the desert in California. We were disappointed at first, but we've made a number of close friends over the years who now feel like a surrogate family to us. While it's less convenient to visit our children and grandchildren back on the East Coast, my wife is more comfortable, so it is a relatively small sacrifice.



Although my wife has coped very well, we have lost friends who have had very bad cases of NTM lung disease. While each loss has taken a toll on us, my wife continues taking great care of herself. She is diligent in her daily airway clearance and hasn't needed the doses of antibiotics that she did years ago. As she continues to do well, I am optimistic about our future.



# Why Catching Early Signs of NTM Lung Disease is Important

By Dr. Julie Philley, Pulmonologist and Associate Professor of Medicine at The University of Texas Health Science Center at Tyler



**P**ersistent cough, fatigue, weight loss, night sweats. You may experience these symptoms and assume they are being caused by an already diagnosed lung condition, like bronchiectasis or chronic obstructive pulmonary disease (COPD), not realizing they could be signs of something else. However, you could be living with undiagnosed nontuberculous mycobacterial (NTM) lung disease.

The unfortunate reality for many patients is that it can take several years of seeing various doctors – including multidisciplinary teams of different specialists, in some instances – to learn they have NTM lung disease. While every patient’s journey is different, three critical elements can contribute to a correct diagnosis: 1) communicating with your doctor about your symptoms and medical history 2) if symptoms persist, requesting a referral to a pulmonologist or infectious disease (ID) specialist who sees NTM lung disease patients and 3) getting proper testing, which can include a sputum test, CT scan, lung function testing and blood work.

When left untreated, the symptoms can worsen over time and cause severe or even permanent damage to the lungs. The earlier patients receive a proper diagnosis for their NTM lung disease, the more treatment options may be available to help them manage their symptoms. A timely diagnosis may also help prevent patients from adhering to incorrect antibiotic regimens.

As a pulmonologist, I encourage patients who are concerned about symptoms to initiate a discussion with their doctor – especially if they think they might have NTM lung disease. Here are some tips to help you talk through what you’re experiencing and get answers to any questions you may have.

- 1 Speak about the symptoms you’ve been experiencing, how long they’ve been persisting and the impact on your day-to-day life
- 2 Discuss your medical history with your physician, including other lung conditions you may have like COPD or bronchiectasis, and any medications you are taking or have taken in the past for your respiratory symptoms
- 3 Ask your doctor about how to test for NTM lung disease and if you should get tested
- 4 Check with your doctor if you should be referred to a specialist, such as a pulmonologist or ID specialist

Proactive communication should continue beyond diagnosis as well, throughout your NTM lung disease journey. Make sure your doctor is aware of any persisting or worsening symptoms and ask questions about treatment options or healthy lifestyle changes (such as exercise and a well-balanced diet) that may be able to help you manage them. The following questions may be helpful to discuss with your doctor.

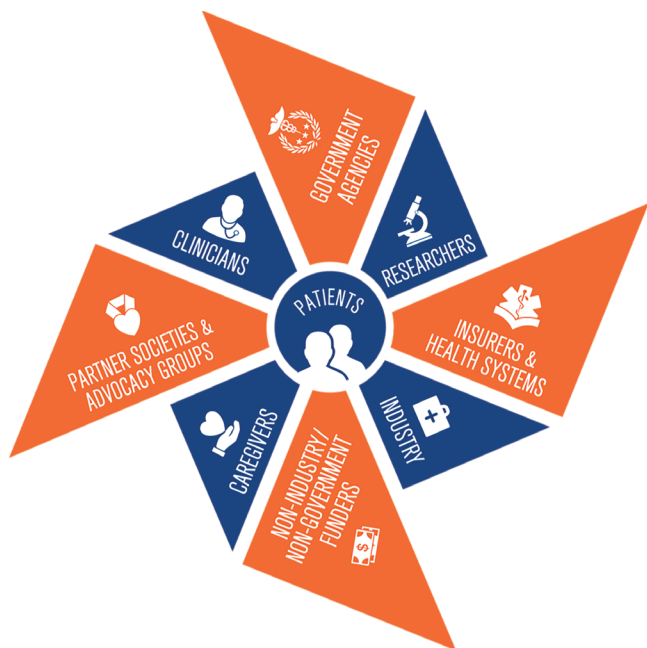
- 1 What are my treatment options based on my medical history?
- 2 Does the species of NTM I have affect which treatment you recommend? For example, *Mycobacterium avium* complex or MAC is one type of species.
- 3 Other than treatment, are there other things I can do to help manage my symptoms? For example, certain exercises or types of food that can help improve lung health.
- 4 Are there any techniques you recommend to help clear my airways and better manage my breathing?
- 5 How will I track my progress and know if I am getting better?
- 6 How often will I need to schedule follow-up visits with you?
- 7 Is there anything I can do to reduce my exposure to NTM bacteria in the environment?

In my work treating NTM lung disease, I’ve learned that while everyone’s experience with this disease is unique, communication is vital. I often support patients on their journeys by pointing them to resources where they can learn more, and by encouraging them to join support groups with other patients and share information about the different challenges they are facing. If you think you have NTM lung disease, don’t be afraid to speak up. Visit the discussion guides and educational resources available at [AboutNTM.com](http://AboutNTM.com) and head into the next appointment with your doctor prepared to have a productive conversation about what management options might be right for you.

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# Advocacy Spotlight: How the COPD Foundation is Increasing Awareness and Education of NTM Lung Disease



As a community-based organization, the COPD Foundation is dedicated to improving the lives of people living with lung disease and aims to keep patients at the center of everything they do – from research to education to advocacy. Through their work, the organization has learned how to help support patients and caregivers through every step of the journey, beginning with diagnosis.

## Empowering Patients Through Education

While members of the COPD Foundation’s community may have chronic obstructive pulmonary disease (COPD) and bronchiectasis, many don’t realize that these diagnoses can put them at increased risk for developing NTM lung disease, a serious condition that can worsen and cause permanent damage to the lungs. This organization strives to provide education about the risk factors and symptoms of NTM lung disease by sharing resources to help empower patients to have conversations with their doctors if they think they might be at risk.

The COPD Foundation has a variety of educational content available on their website to help patients understand more about NTM lung disease and have productive conversations with their doctors if they think they may be at risk, including:

A Live Discussion about NTM Lung Disease on Facebook Live

Information about NTM Lung Disease

NTM Lung Disease Support Groups

The COPD Foundation also offers an online community where bronchiectasis and NTM lung disease patients can talk about their experiences, ask questions and connect with others who can empathize with what they may be going through.

The Bronchiectasis and NTM Information Line is another resource available for individuals in need of direct assistance, empathy and support. By calling the toll-free number, 1-833-411-LUNG (5864), members can speak directly to a staff member about their questions and concerns.

## Taking on Challenges Together

While an NTM lung disease diagnosis is an important first step, it can be overwhelming for patients and cause mixed emotions. As an advocacy organization, the COPD Foundation is dedicated to helping patients navigate roadblocks that may occur on their journey and find solutions along the way.

*Insmed Incorporated provides financial support to the COPD Foundation through corporate sponsorships and charitable contributions.*



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