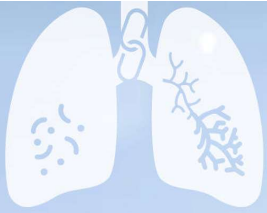


The Patient Perspective

Amy Leitman, JD
President, NTM Info & Research

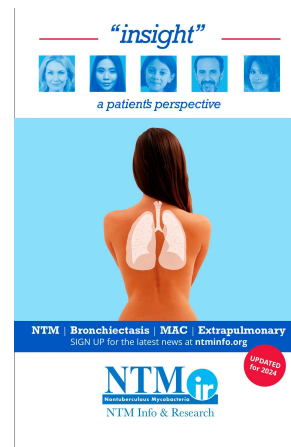




By Patients, For Patients

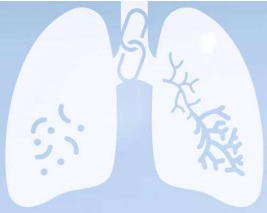


Co-founders:
Patient and
caregiver



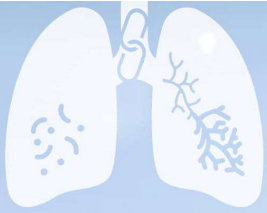
The website:
ntminfo.org

The pamphlet: A resource for patients



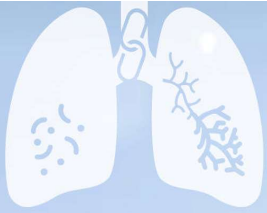
NTM and Bronchiectasis: The Patient Experience

- Long delays to proper diagnosis
- Long, burdensome treatment regimens
- Side effects, some permanent
- Hemoptysis
- Severe cough
- Extreme fatigue
- Shortness of breath
- Unpredictability in day-to-day health and functioning
- Social isolation and stigma



DIAGNOSED: What now?

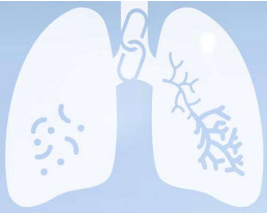
- What is it?
- Am I contagious?
- How will my life change?
- Will my family help me?
- Will my friends want to be around me?
- Am I getting the correct treatment?
- How long will I be on treatment?
- What are the side effects?
- Do other people have this?
- Where do I find more information?
- Am I going to die from this?



Patient-Focused Drug Development

Patients reported these three symptoms as having the most significant clinical impact on their daily lives:

- Fatigue
- Cough
- Shortness of breath



NTM Research Consortium

ANNALSATS SUPPLEMENT

Patient-Centered Research Priorities for Pulmonary Nontuberculous Mycobacteria (NTM) Infection An NTM Research Consortium Workshop Report

ANNALSATS SUPPLEMENT

Emily Henrick¹, Timothy Akazami², Alan Barker³, Charles L. Daley⁴, David Grittini⁵, Philip Leitman⁶, Amy Letim⁷, Elzbieta Malanga⁸, Theodore K. Mamas⁹, Kenneth N. Olivier¹⁰, D. Rebecca Prevots¹¹, Delia Prieto¹², Alexandra L. Quinlan¹³, William Skach¹⁴, John W. Walsh¹⁵, Kevin L. Werhberg¹⁶, and the NTMPC Patient Advisory

¹School of Public Health, Oregon Health & Science University-Portland State University, Portland, Oregon; ²Pulmonary Disease Critical Care Medicine, Mayo Clinic, Rochester, Minnesota; ³Pulmonary Critical Care Medicine, Oregon Health & Science Univ Portland, Oregon; ⁴Department of Medicine, National Jewish Health, Denver, Colorado; ⁵University of Texas Health Science C Tyler, Texas; ⁶NTM Info & Research, Miami, Florida; ⁷CDRF Foundation, Washington, DC; ⁸Department of Medicine, University of Toronto, Toronto, Ontario, Canada; ⁹Cardiovascular and Pulmonary Branch, National Heart, Lung, and Blood Institute, National Institutes of Health, Bethesda, Maryland; ¹⁰Subsidiary of Clinical Infectious Diseases, National Institute of Allergy and Infectious Diseases, Institutes of Health, Bethesda, Maryland; ¹¹Department of Psychology, University of Miami, Coral Gables, Florida; ¹²Cystic Fibrosis Foundation, Bethesda, Maryland; and ¹³Division of Infectious Diseases, Public Health and Preventive Medicine, Oregon Health & University, Portland, Oregon

Abstract

Nontuberculous mycobacteria (NTM) cause an increasingly important chronic and debilitating lung disease in older adults. Diagnosis is often delayed, although awareness among clinicians and patients is increasing. When necessary, treatment often lasts 18–24 months and consists of three or four antibiotics that can have serious side effects. Relapses are common and consistently require resumption of prolonged therapy. Given the need for improved diagnostic techniques and clinical trials to identify new therapies or to improve existing therapies, a group of North American clinicians and researchers formed the NTM Research Consortium (NTMRC) in 2014. The NTMRC recognized the importance of including the patient voice in determining research priorities for NTM. In November 2015, patients, caregivers, patient advocates, clinical experts, and researchers gathered for a 1-day meeting in Portland, Oregon funded by the Patient-Centered Outcomes Research Institute. The meeting goal was

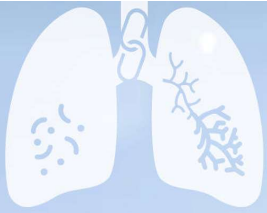
to define patient-centered research priorities for NTM lung in patients exposed to treatment with the number of people who underwent years of missed diagnosis or inadequate treatment or Participants identified a top research priority: the prevention infection, approval of more effective treatments with fewer side effects and easier administration, understanding the best chest physiotherapy methods, validating and using tools to measure quality of life, developing a disease-specific activity and severity assessment Workshop participants agreed that two complementary objectives are critical to ensure the best achievable outcomes for patient additional decision education to improve screening and diag NTM infections, and (2) development of a geographically diverse network of experts in NTM disease to offer consultation or a therapy after a diagnosis is made.

Keywords: nontuberculous mycobacteria, pulmonary disease, quality of life

Table 1. Nontuberculous mycobacterial lung disease: patient-centered research priorities by topic area

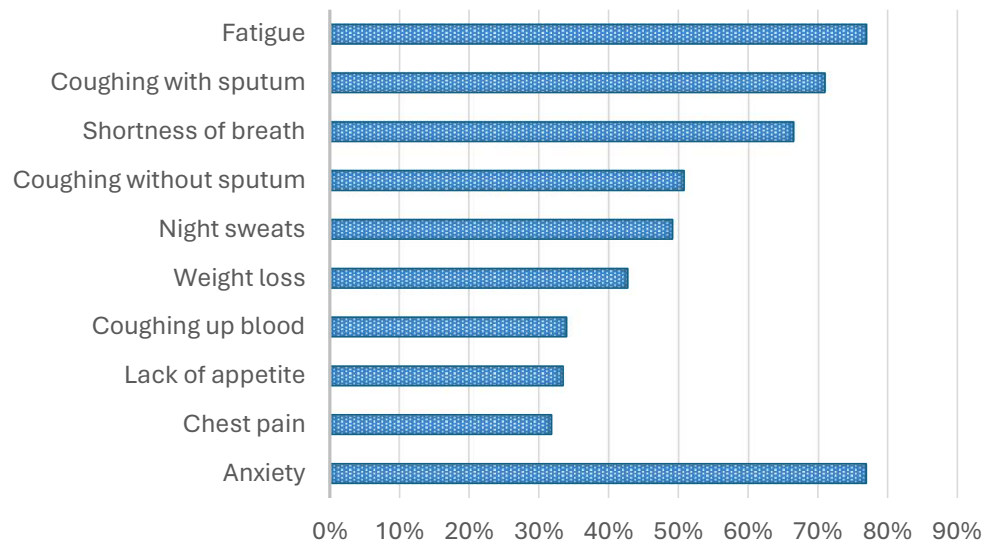
Topic	Priority	Potential Specific Questions and Next Steps
Prevention	1. Strengthen the role of patients in preventing NTM infection or reinfection	Evaluate whether aspiration increases the risk of NTM infection or reinfection
	2. Limit the risk of patient-to-patient transmission of NTM infection in cystic fibrosis clinics	Estimate the risk of person-to-person or indirect transmission in CF clinics Comparative effectiveness of standard and expanded infection control precautions Validate molecular diagnosis techniques being developed by National Jewish Healthcare
Diagnosis	3. Improve the timeliness of diagnosis and develop molecular techniques for rapid species identification and susceptibility	Predictors of positive culture Predictors of meeting ATS disease criteria at diagnosis Identify techniques that improve sputum collection Develop new collection devices
	4. Develop a screening algorithm for patients at risk for pulmonary NTM disease	Evaluate anxiety and depression after diagnosis or during treatment in patients with NTM disease Association between anxiety/depression and poorer treatment adherence Validate NTM Symptom Module [®] tool
Quality of life	5. Develop better methods for sputum collection and testing	Validate correlation between NTM Symptom Module and clinical outcomes
	6. Reduce the impact on patients of anxiety and depression	Develop and evaluate alternative delivery systems for intravenous antibiotics Repurpose existing therapies Develop new, more effective drugs with a shorter therapy duration Comparative effectiveness of exercise and lung clearance devices, taking into account ease of use and affordability Role of therapy in mild cases to prevent disease progression Predictors of treatment response
Treatment	7. Develop an NTM-specific Health-Related Quality of Life tool	Develop a composite index of disease activity or severity that includes microbiological, chest imaging, and quality of life measures Identify biomarkers associated with disease risk, prognosis, or treatment response
	8. Promote quality-of-life measures for assessing the effectiveness of treatment	
Clinical outcomes	9. Reduce the burden of antibiotic treatment for NTM disease	
	10. Develop and test the efficacy of nonpharmacological therapies and holistic medicine approaches	
Clinical outcomes	11. Improve understanding of who needs or benefits from antibiotic therapy	
	12. Develop a composite measure of disease activity or severity	
Clinical outcomes	13. Identify and validate biomarkers associated with disease risk, prognosis, and treatment response	
	14. Identify and validate biomarkers associated with disease risk, prognosis, and treatment response	

Definition of abbreviations: ATS = American Thoracic Society; CF = cystic fibrosis; NTM = nontuberculous mycobacteria.
*From Reference 22.

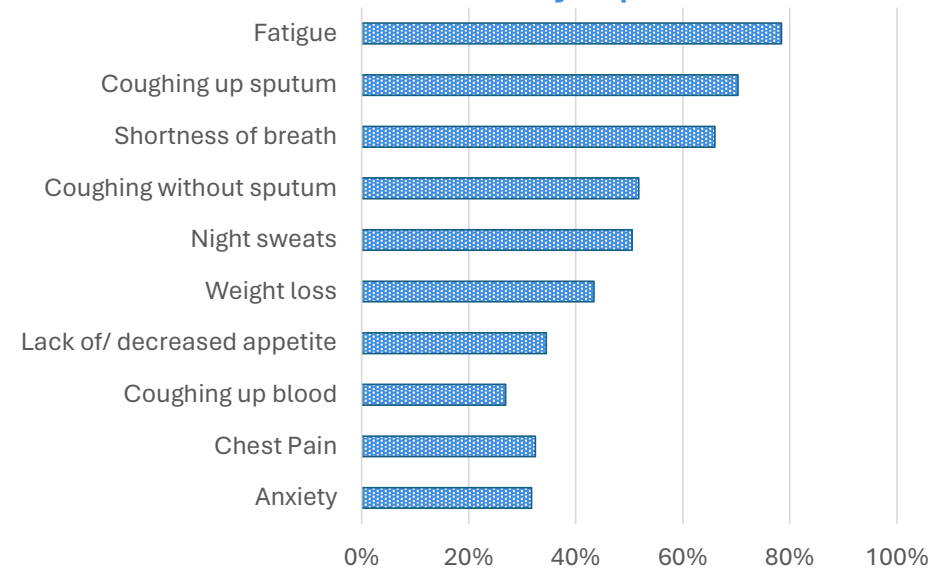


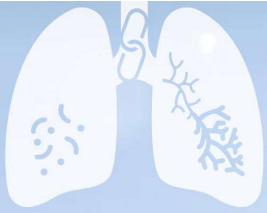
Patients: Telling Us How They Really Feel

Top Symptoms Patients Experienced



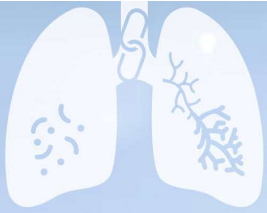
Most Bothersome Symptoms





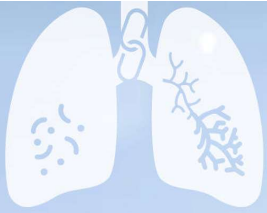
What Matters to Patients?

- Quality care
- Effective treatments
- Sound information
- Solid support



True Story...

**“Oh no, I don’t have NTM.
I have MAC.”**

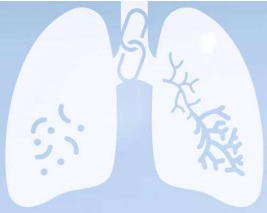


How You Can Help Your Patients

In addition to taking medicine, seek out the following:

- Regular follow-up testing
- Airway clearance and **referral to RT**
- Nutrition and referral to dietitian
- Exercise and fitness, referral to physiotherapy if needed
- Proper rest
- Psychological support mechanisms, referral to therapy
- Clinical trials

Contact us at NTM Info & Research for online support, support groups, and information on clinical trials



Manage Expectations: What to Expect When You're Expecting Side Effects

Peer support can be crucial in helping you learn from each other about side effects and how to reduce them. Support and knowledge can help reduce your anxiety and increase your likelihood of continuing treatment.

n = 98

Hoarseness/Loss of Voice

Gargling with salt water: 12

Reduce frequency of dosing: 22

Discontinue temporarily: 8

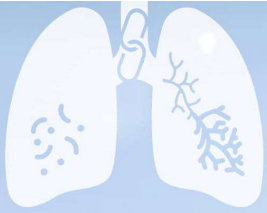
Lozenges: 3

Coughing

Nebulize with bronchodilators: 10

GI side effects

Probiotics: 6



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NTM Info & Research

Resources for Patients

ABOUT US CONTACT US PAMPHLET PDF INTERNATIONAL SITES BRONCHIECTASIS DONATE

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WHAT IS NTM EXPLORE RESOURCES RESEARCH GET INVOLVED **DONATE NOW**

REGISTER TODAY

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FAIRMONT GRAND DEL MAR
SAN DIEGO, CA

REGISTER

Did you know most people with NTM also have Bronchiectasis?

NTMINFO SUPPORT GROUPS REFERRAL LIST

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BRONCHIECTASIS
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HOME ABOUT US BRONCHIECTASIS SUPPORT **DONATE**

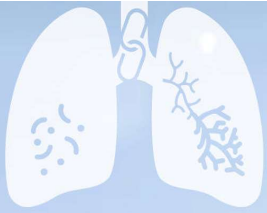
AIRWAY CLEARANCE:
AN ESSENTIAL PART OF YOUR TREATMENT

LEARN MORE

QUICK FACT

ntminfo.org

bronchiectasisinfo.org



SUPPORT GROUPS FOR NTM AND BRONCHIECTASIS PATIENTS

Did you know most people with NTM also have Bronchiectasis?

[EXPLORE BE](#)

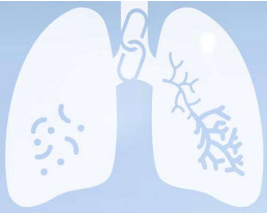


42 GROUPS

37 US

5 Ex-US





A safe space for patients to support one another.

Home

Global Forum

Settings

...s to collaborate, support, and share

[Communities](#) / Community Home

Community Home

Discussion 12.5K

Library 118

Blogs 0

Featured Post

RF: Ask Me Anything Event with Michelle McDonald



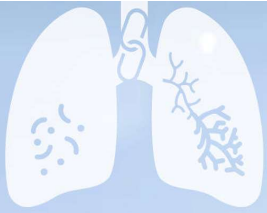
Connect

Others with whom you may seek



Engage

Participate in discussions with your peers



Update
NTM Lung Disease and Airway Clearance
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let's talk
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Meal Planning Matters
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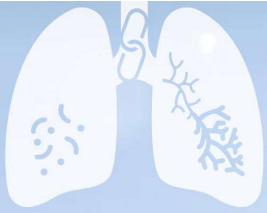


Building Confidence
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“insight”



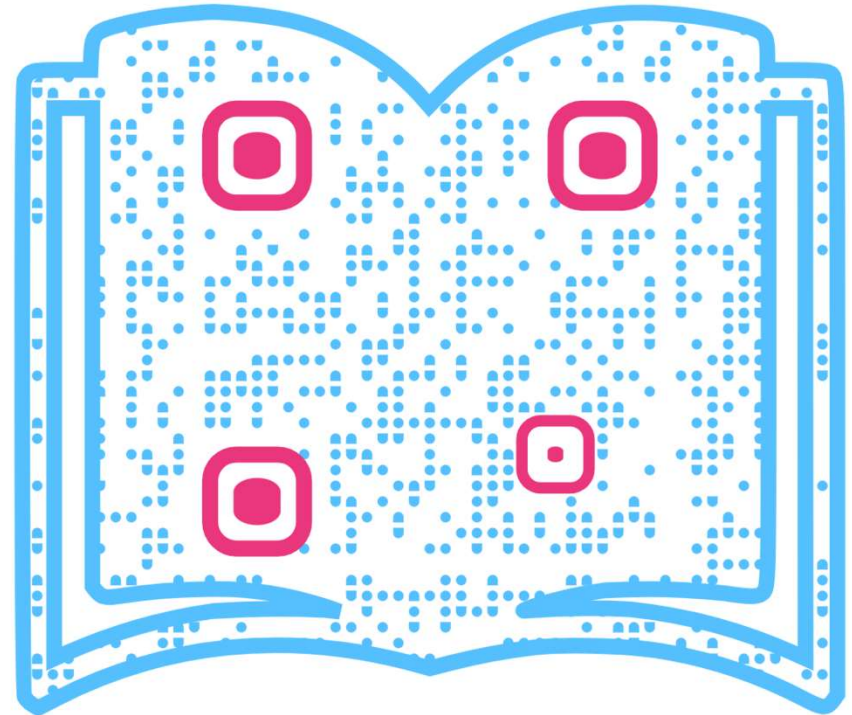
a patient's perspective

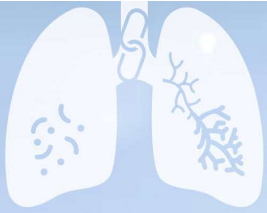


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Community Discussions

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How to Participate

Sign In to Participate

Or register to become a member

Welcome to BronchandNTM360social

BronchandNTM360social is an online community for individuals affected by Bronchiectasis and/or NTM, including patients, family members, caregivers, physicians and other healthcare providers. It serves as an online home for these communities and provides a comfortable venue to share thoughts and ideas, ask questions, start discussions, read and comment on blogs, and communicate with peers, thought leaders and community managers.

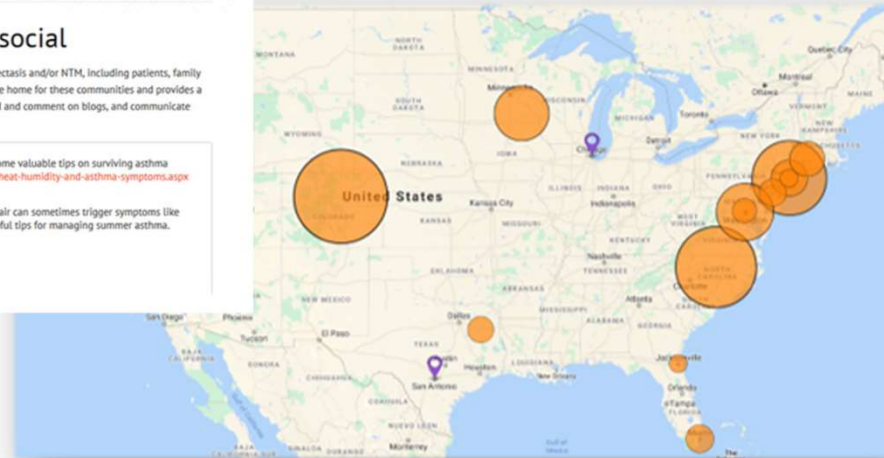
Bret99 Extreme heat can also trigger asthma symptoms. Here are some valuable tips on surviving asthma during heat emergencies. <https://www.everydayhealth.com/asthma/heat-humidity-and-asthma-symptoms.aspx>

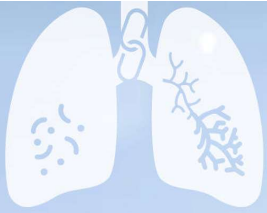
LOOK What I Found everyday HEALTH

Heat, Humidity, and Asthma Symptoms

People with asthma know that hot, humid air can sometimes trigger symptoms like coughing and difficulty breathing. Get helpful tips for managing summer asthma.

Registry

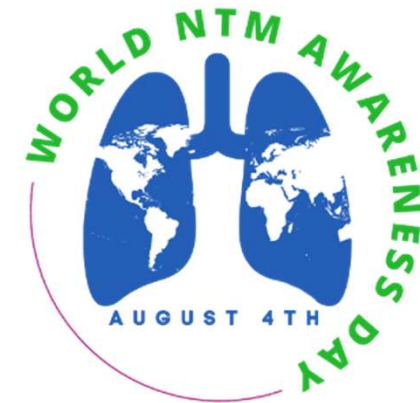




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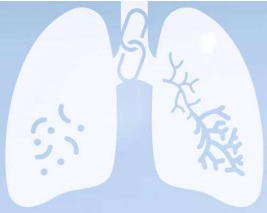


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worldntmday.org

5/16-17: NTM/BE Patient Conference
7/1: World Bronchiectasis Day
8/4: World NTM Day



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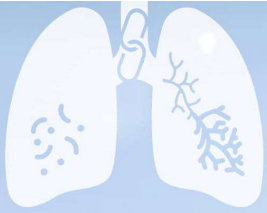
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Operations Director



Trisha Kemp,
Community
Engagement Director



Vanessa Hevia,
Office Administrator



Laura Layton,
Community Manager