

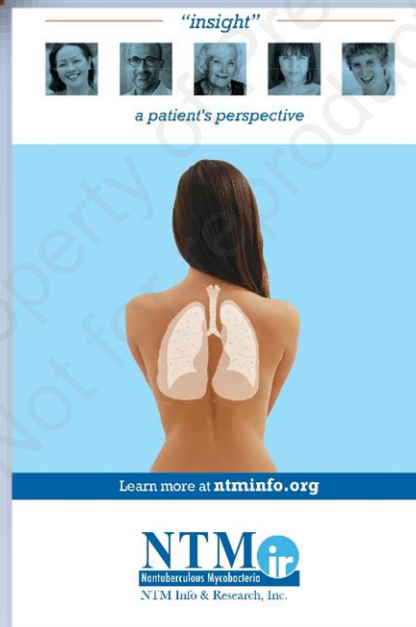
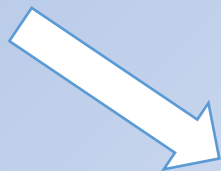


Resources for Patients

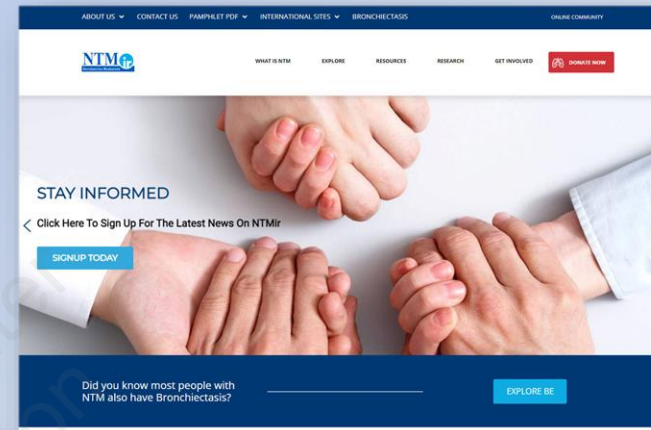
Amy Leitman, JD
President, NTM Info & Research



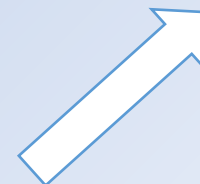
Co-founders:
Patient & caregiver



The pamphlet: A resource for patients



The website:
www.ntminfo.org



NTM Connect: Online Forum for Patients

NTM Connect: Online Forum for Patients

STAY INFORMED
Click Here To Sign Up For The Latest News On NTM
SIGNUP TODAY

Did you know most people with NTM also have Bronchiectasis?

NTM Connect
NTM Info & Research, Inc.

Home Communities Directory Events Browse Participate

Global Forum Settings

Communities / Community Home

Community Home Discussion 7.4K Library 77 Blogs 0 Events 0 Members 3K

Featured Post

BronchandNTM360social Coffee Break
By: [Laura Layton](#), one month ago

Hello, NTM Connect. We are excited to share info around these virtual events taking place on the second Wednesday of the month ...

Announcements Add

Last Day to Register!
By: [Helga Rosado](#), one month ago

Latest Discussions

RE: Not on any treatment right now

Sign In to Participate
Or register to become a member

360Social

Register | Login | Search

DONATE NOW

BRONCHIECTASIS | NTM LUNG DISEASE | REGISTRY | RESEARCH | ABOUT US

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.


Latest Discussions

RE: Not on any treatment right now

Sign In to Participate
Or register to become a member

Resources for Patients

Local Support Groups



NTMinfo.org
Nontuberculous Mycobacteria

WHAT IS NTM | LEARN MORE | **RESOURCES** | RESEARCH | GET INVOLVED | HCP | **DONATE NOW!**

LOCAL SUPPORT GROUPS

RESOURCES

- > News
- > Calendar
- > "Insight" Patient Pamphlet
- > Useful Links
- > Support Groups
 - > [Local Support Groups](#)
 - > NTMinfo.org Forum
 - > 360Social

The use of contact information (names, emails, phone numbers) of any NTM Support Group, on this page or anywhere else on our website, is strictly for persons interested in contacting support group leaders and volunteers for support and information ONLY. This contact information SHOULD NOT be taken from our website for solicitation or commercial use.

For any other inquiries including clinical study or trial recruitment, please contact NTM Info & Research at 305-667-6461 ext. 26 or ext. 32, or email ntmmail@ntminfo.org.

If you are interested in starting a support group in your area or becoming a group leader, please email Susan at susanw@ntminfo.org

State	City	Group Leader	Email Address
Country: U.S.			
California	Los Angeles	Andrea Smith	absmith@dock.net

Clinical Trials

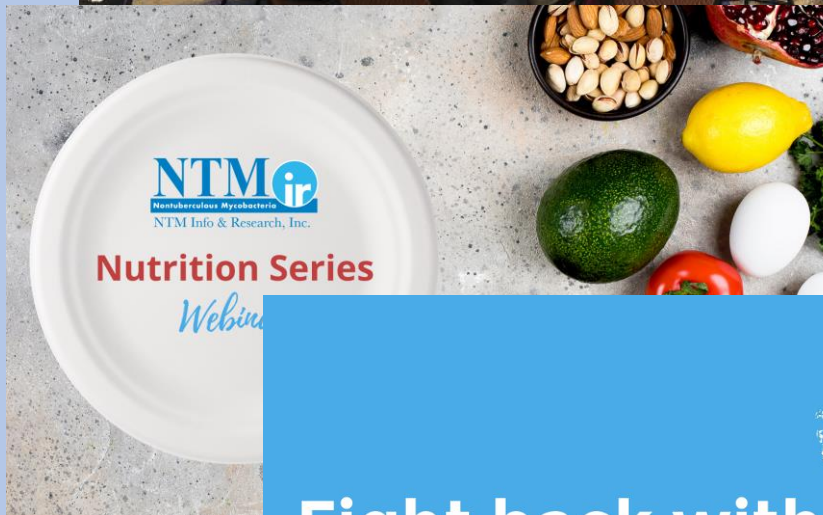
CLINICAL TRIALS

Do you have Nontuberculous
Mycobacterial (NTM) Pulmonary
Disease?

[EXPLORE](#)

You can search for pending or recruiting clinical trials through the National Library of Medicine's clinical trials website, clinicaltrials.gov.

This site also maintains a list of recruiting studies. If you are a principal investigator or study site and wish to add an IRB-approved trial to our listings, or if you wish to have your study information amended or removed from ntminfo.org, please email ntmmail@ntminfo.org.



The Lung Microbiome



Fight back with *food*



Understanding and Managing Fatigue

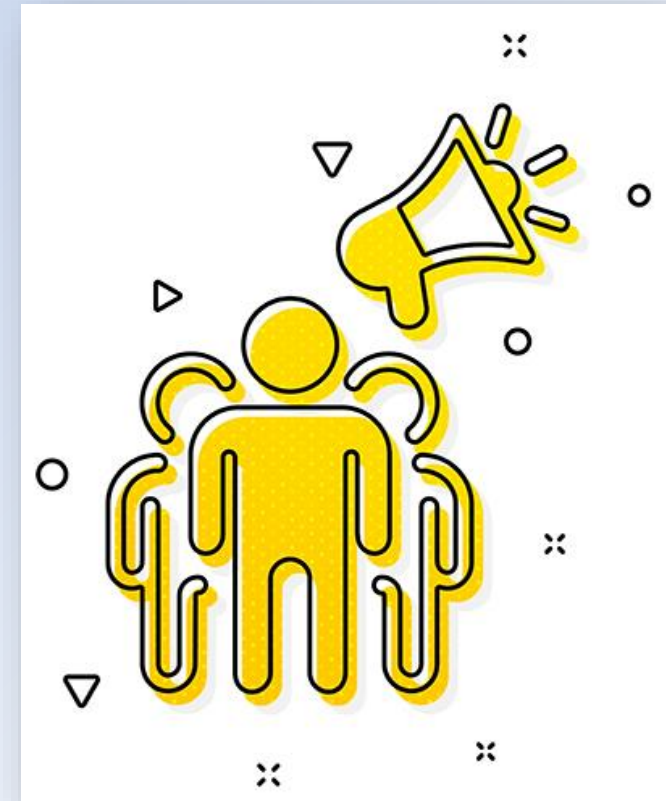
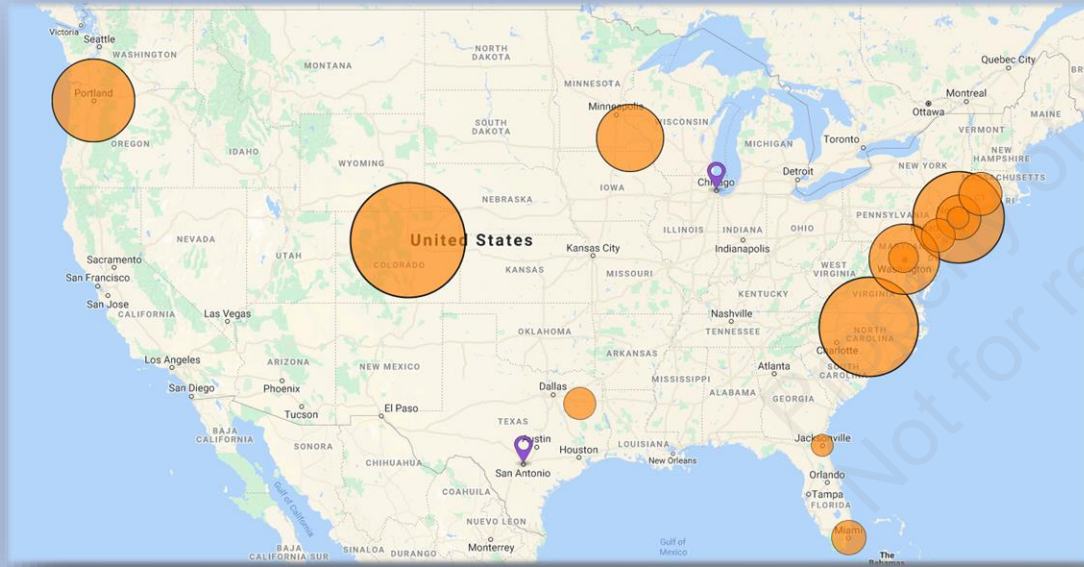


Additional Resources for Patients & Providers



305-901-4NTM

Joint Projects with the COPD Foundation



What matters to patients?

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

Complete Care Looks Like:

In addition to taking medicine, these can help you:

- 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
- Check out clinical trials!

Join NTM Connect for online support and join an online support group that holds regular meetings!

NTM Patient Experiences

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

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

Emily Henkle¹, Timothy Aksamit², Alan Barker³, Charles L. Daley⁴, David Griffith⁵, Philip Leitman⁶, Amy Leitman⁶, Elisha Malanga⁷, Theodore K. Marras⁸, Kenneth N. Olivier⁹, D. Rebecca Prevots¹⁰, Delia Prieto⁷, Alexandra L. Quittner¹¹, William Skach¹², John W. Walsh⁷, Kevin L. Winthrop¹³, and the NTMRC Patient Advisory Panel

¹School of Public Health, Oregon Health & Science University-Portland State University, Portland, Oregon; ²Pulmonary Disease at Critical Care Medicine, Mayo Clinic, Rochester, Minnesota; ³Pulmonary Critical Care Medicine, Oregon Health & Science University, Portland, Oregon; ⁴Department of Medicine, National Jewish Health, Denver, Colorado; ⁵University of Texas Health Science Center at Tyler, Texas; ⁶NTM Info & Research, Miami, Florida; ⁷COPD 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 (NIH), Bethesda, Maryland; ¹⁰Laboratory of Clinical Infectious Diseases, National Institute of Allergy and Infectious Diseases, National 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 & Science 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 commonly 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 infection. Patients expressed frustration with the number of people who have endured years of missed diagnoses or inadequate treatment of NTM. Participants identified as top research priorities the prevention of NTM 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; and developing a disease-specific activity and severity assessment tool. Workshop participants agreed that two complementary objectives are critical to ensure the best achievable outcomes for patients: (1) additional clinician education to improve screening and diagnosis of NTM infections; and (2) development of a geographically distributed network of experts in NTM disease to offer consultation or direct therapy after a diagnosis is made.

Keywords: nontuberculous mycobacteria; pulmonary disease; quality of life

ANNALSATS SUPPLEMENT

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 2. Limit the risk of patient-to-patient transmission of NTM infection in cystic fibrosis clinics	Evaluate whether aspiration increases the risk of NTM infection or reinfection 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 4. Develop a screening algorithm for patients at risk for pulmonary NTM disease	Predictors of positive culture Predictors of meeting ATS disease criteria at diagnosis Identify techniques that improve sputum collection Develop new collection devices 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 6. Reduce the impact on patients of anxiety and depression 7. Develop an NTM-specific Health-Related Quality of Life tool 8. Promote quality-of-life measures for assessing the effectiveness of treatment	Validate correlation between NTM Symptom Module and clinical outcomes 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 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
Treatment	9. Reduce the burden of antibiotic treatment for NTM disease 10. Develop and test the efficacy of nonpharmacological therapies and holistic medicine approaches 11. Improve understanding of who needs or benefits from antibiotic therapy	
Clinical outcomes	12. Develop a composite measure of disease activity or severity 13. Identify and validate biomarkers associated with disease risk, prognosis, and treatment response	

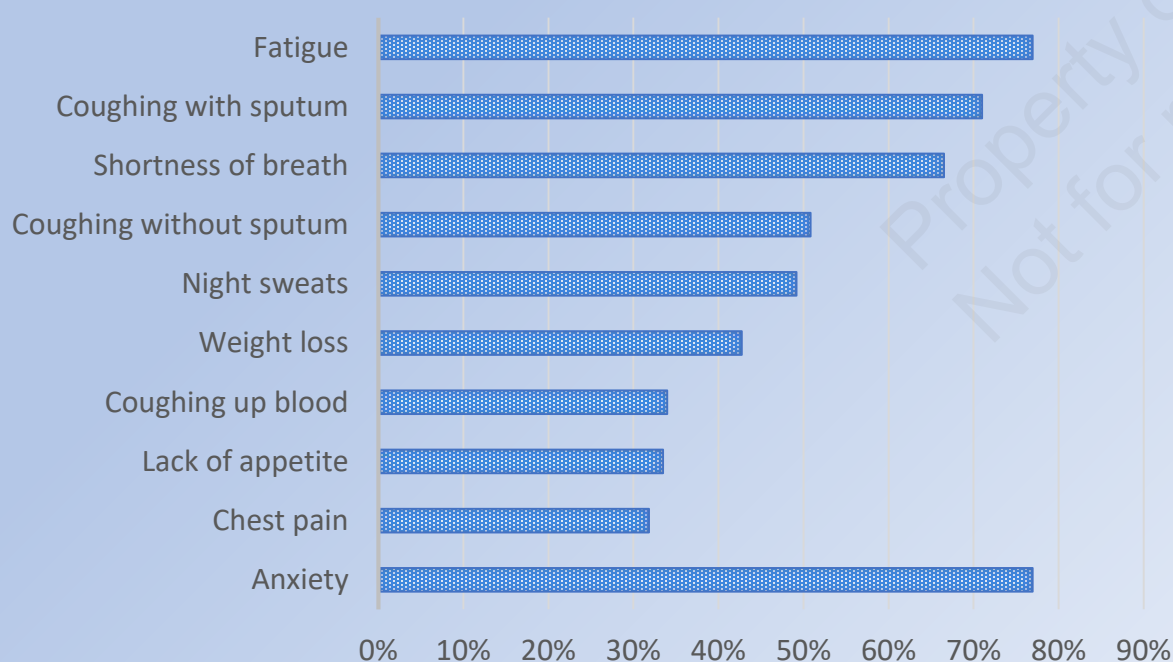
Definition of abbreviations: ATS = American Thoracic Society; CF = cystic fibrosis; NTM = nontuberculous mycobacteria.

*From Reference 22.

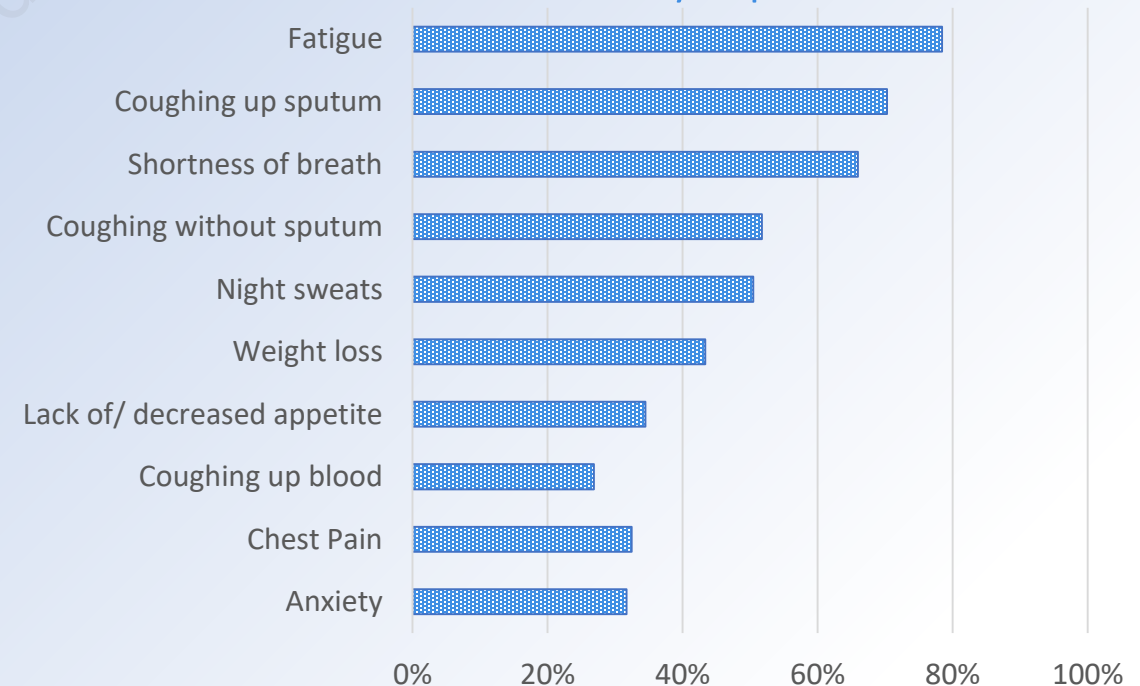
Survey: Patient Preferences in Clinical Trials & Treatment Outcomes

Development of Drugs for Nontuberculous Mycobacterial Disease: Clinicians' Interpretation of a US FDA Workshop (CHEST August 2020)

Top Symptoms Patients Experienced

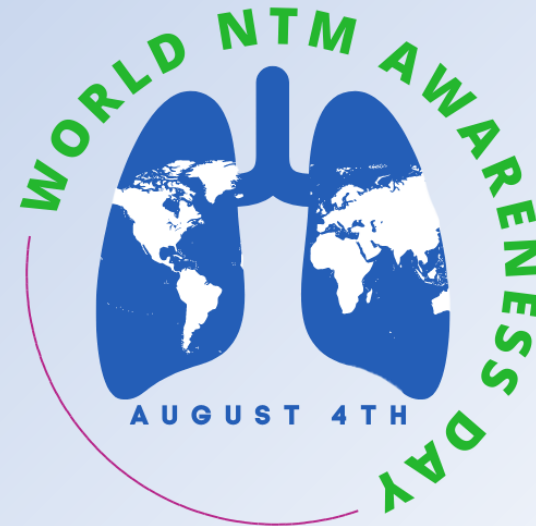


Most Bothersome Symptoms



Upcoming Projects

- Customized exercise program for NTM/BE
 - Licensed physiotherapists
 - Online program
 - Machine learning: predict and prevent
- World NTM Awareness Day
 - August 4th (right after...)
- World Bronchiectasis Day
 - July 1st





14411 S. Dixie Hwy, Suite 205
Palmetto Bay, FL 33176

305-901-4NTM (4686)

ntmail@ntminfo.org

www.ntminfo.org



@NTMinfo



Facebook.com/NTMinfo



Youtube.com/ntmir



NTMir



@ntminfo

Learn more and sign up for the latest news: ntminfo.org