



NTM Infection: What Matters to Patients

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Disclosures

Advisory Board member, MannKind Corporation

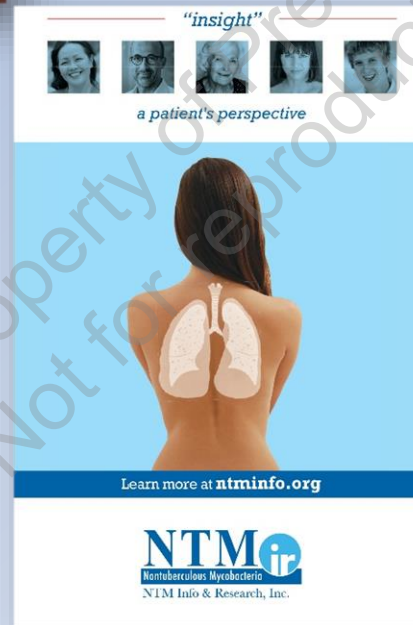
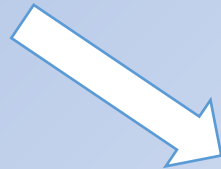
I will be discussing off-label uses of medications

Objectives

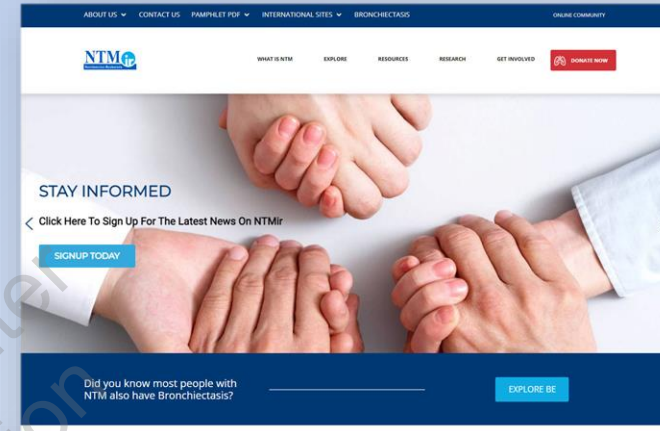
- Review tools and resources available to providers, patients, and caregivers to help patients with their care
- Discuss patient experiences related to illness, treatments, and outcomes
- Provide insight into how patient experience data has impacted clinical practice and the development of new therapeutics



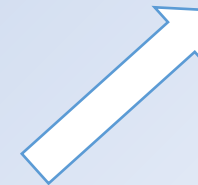
Co-founders:
Patient & caregiver



The pamphlet: A resource for patients



The website:
www.ntminfo.org



NTM Connect: Online Forum for Patients

ABOUT US CONTACT US PAMPHLET PDF INTERNATIONAL SITES BRONCHIECTASIS **ONLINE COMMUNITY**

NTM
Nontuberculous Mycobacteria
NTM Info & Research, Inc.

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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

BRONCHIECTASIS NTM LUNG DISEASE REGISTRY RESEARCH ABOUT US

DISCUSSIONS ACTIVITY FEED

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.

LOOK What I Found
everyday HEALTH

Sign In to Participate
Or register to become a member

Resources for Patients

Local Support Groups

NTM
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 listed on our website, is strictly for persons interested in contacting support group leaders and is for informational ONLY. This contact information SHOULD NOT be taken from our website for solicitation purposes.

For any other inquiries including clinical study or trial recruitment, please contact NTM Info at 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
Country: U.S.		
California	Los Angeles	Andrea Smith

Research Pipeline Page

NTM
Nontuberculous Mycobacteria

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

R&D PIPELINE

Click on any drug in the interactive pipeline below to learn more about NTM drugs in development or already in use by patients.

Refine Pipeline

Pre-clinical Enrolling Phase One Phase Two Phase Three Completed Available To Patients



The Lung Microbiome



Fight back with
food



Emotional Wellbeing Webinar Series



Understanding and
Managing Fatigue

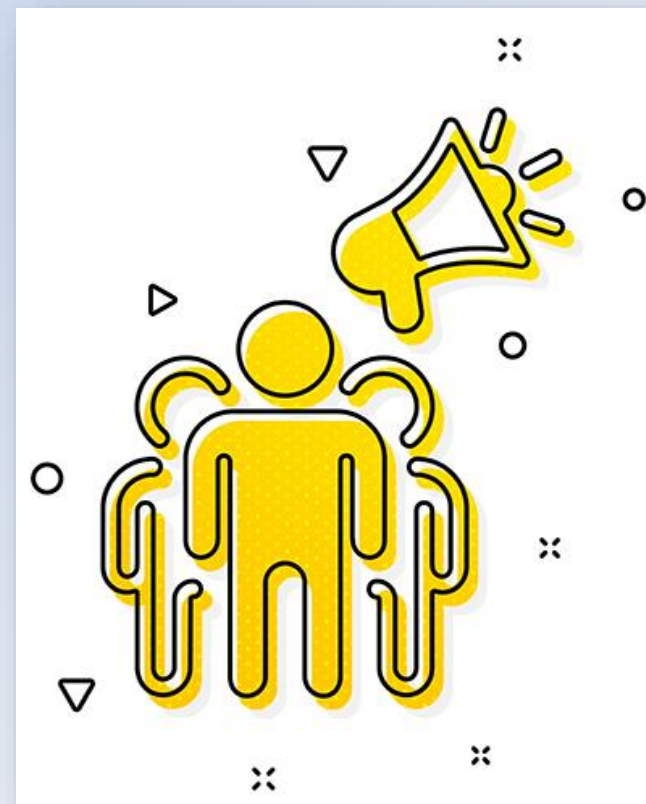
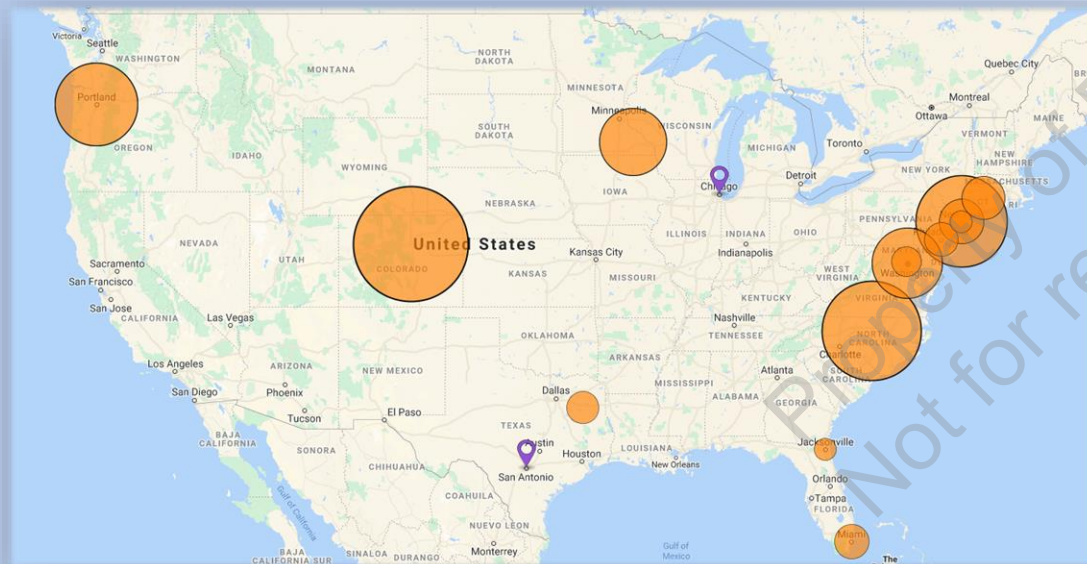


Additional Resources for Patients & Providers



305-901-4NTM

Joint Projects with the COPD Foundation



What matters to patients?

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

Diagnosis: A Life Altering Moment

- 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?
- Am I going to die from this?

Helping Your Patients:

What Can You Do?

In addition to taking medicine, help your patient get access to and get the most out of :

- 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!

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

Depression Screening

- Is your patient feeling OK?

DEPRESSION

- plays a big role in chronic illness.
- How does your patient **LOOK**?
- Ask your patient how they're **FEELING**.
- **LISTEN** to their answers for signs of depression.

What To Look For

- Sadness
- Anxiety/ Fear
- Social isolation
- Anger
- Sleep disruption (too much or too little)
- Feeling of “not wanting to get up or go on”
- Suicidal thoughts or ideations

PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)				
Over the <u>last 2 weeks</u> , how often have you been bothered by any of the following problems? (Use "✓" to indicate your answer)	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING: 0 + _____ + _____ + _____
=Total Score: _____

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.

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

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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	<ol style="list-style-type: none"> 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 	<p>Evaluate whether aspiration increases the risk of NTM infection or reinfection</p> <p>Estimate the risk of person-to-person or indirect transmission in CF clinics</p> <p>Comparative effectiveness of standard and expanded infection control precautions</p> <p>Validate molecular diagnosis techniques being developed by National Jewish Healthcare</p>
Diagnosis	<ol style="list-style-type: none"> 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 	<p>Predictors of positive culture</p> <p>Predictors of meeting ATS disease criteria at diagnosis</p> <p>Identify techniques that improve sputum collection</p> <p>Develop new collection devices</p> <p>Evaluate anxiety and depression after diagnosis or during treatment in patients with NTM disease</p> <p>Association between anxiety/depression and poorer treatment adherence</p> <p>Validate NTM Symptom Module* tool</p>
Quality of life	<ol style="list-style-type: none"> 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 	<p>Develop and evaluate alternative delivery systems for intravenous antibiotics</p> <p>Repurpose existing therapies</p> <p>Develop new, more effective drugs with a shorter therapy duration</p> <p>Comparative effectiveness of exercise and lung clearance devices, taking into account ease of use and affordability</p> <p>Role of therapy in mild cases to prevent disease progression</p> <p>Predictors of treatment response</p> <p>Develop a composite index of disease activity or severity that includes microbiological, chest imaging, and quality of life measures</p> <p>Identify biomarkers associated with disease risk, prognosis, or treatment response</p>
Treatment	<ol style="list-style-type: none"> 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	<ol style="list-style-type: none"> 12. Develop a composite measure of disease activity or severity 13. Identify and validate biomarkers associated with disease risk, prognosis, and treatment response 	

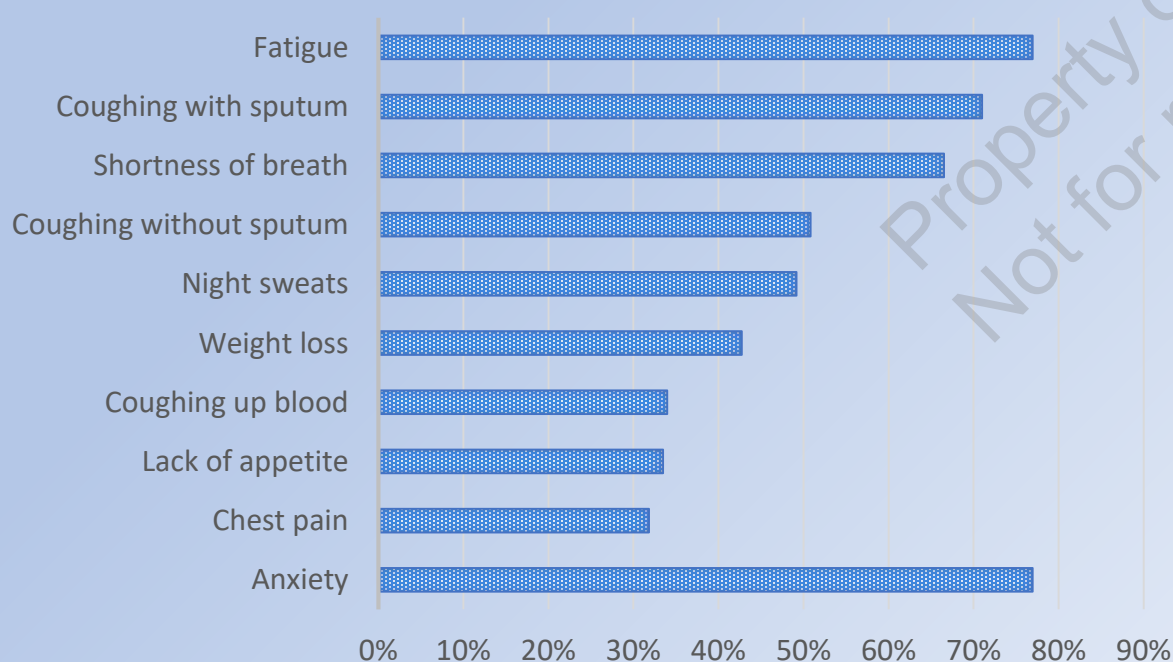
Definition of abbreviations: ATS = American Thoracic Society; CF = cystic fibrosis; NTM = nontuberculous mycobacteria.

*From Reference 22.

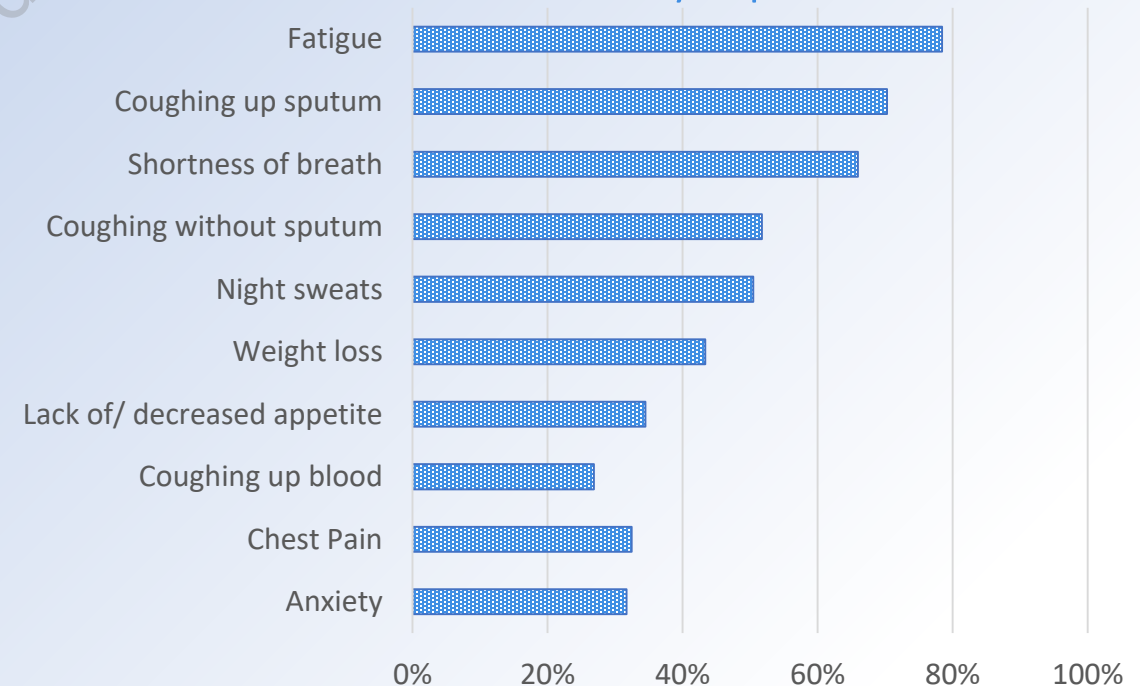
Survey: Patient Preferences in Clinical Trials & Treatment Outcomes

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

Top Symptoms Patients Experienced

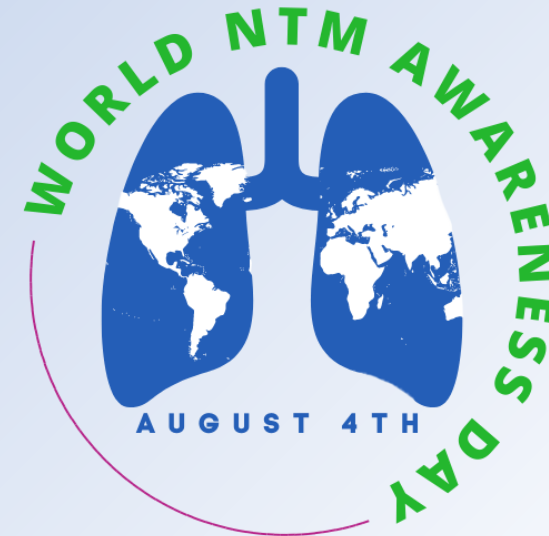


Most Bothersome Symptoms



Upcoming Projects

- Customized exercise program for NTM/BE
 - Licensed physiotherapists
 - Online program
 - Machine learning: predict and prevent
- World NTM Awareness Day
 - August 4th
- HCP website with searchable information
 - Treatment options and drug substitutions



NTM Case Conference Series



Show us your NTM cases!

- Bi-monthly Zoom presentations on NTM cases
- Discussion and Q&A
- Pulmonary and extra-pulmonary
- Open to providers only

Elisa Ignatius, Ruvandhi Nathavitharana, Colin Swenson
Co-Chairs

If you have a case you would like to present, email
NTMCases@ntminfo.org



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