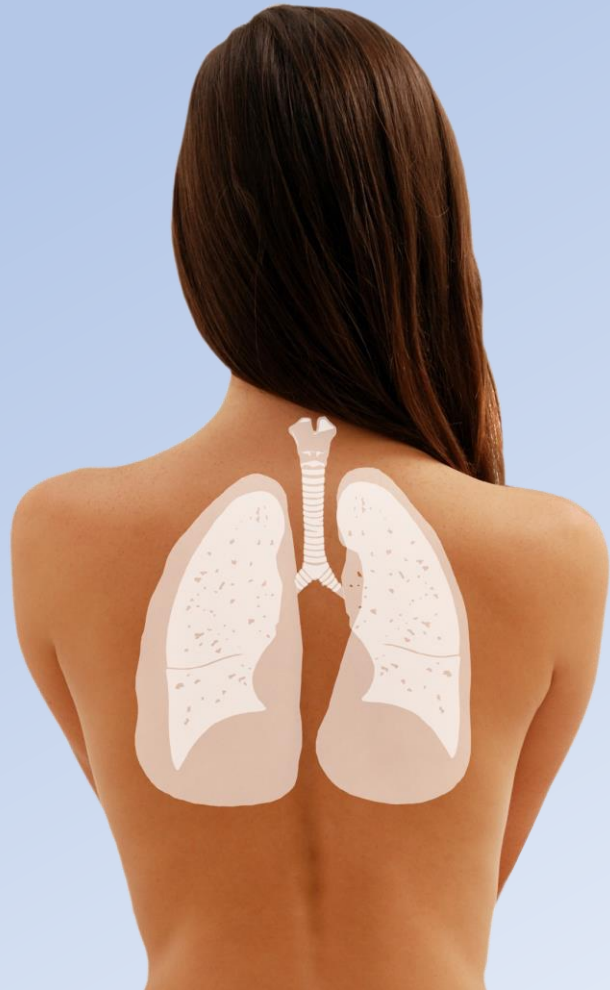


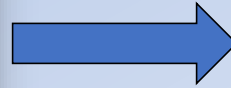
NTM Lung Disease & Bronchiectasis: *Resources for Patients*



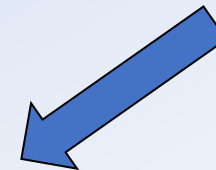
Amy Leitman, JD
Director of Policy & Research
NTM Info & Research



Co-founders:
Patient & caregiver



The website:
www.ntminfo.org



The pamphlet: A resource for patients

We Hear You and We Give Voice to Your Priorities and Concerns

Website:

- The patient's source of information on NTM lung disease
- Secure online chat forum

Patient Support:

- By phone and email
- Support groups
- Online support
- Social media: continually updated Facebook page, Twitter

A Catalyst for Research:

- Funded NTM section of Patient Registry
- Surveys on patient preferences and experiences – gives patients a voice
- NTM & Bronchiectasis Research Consortia
- Help recruit for clinical trials and studies
- Work with other organizations on patient-reported outcome screening tools

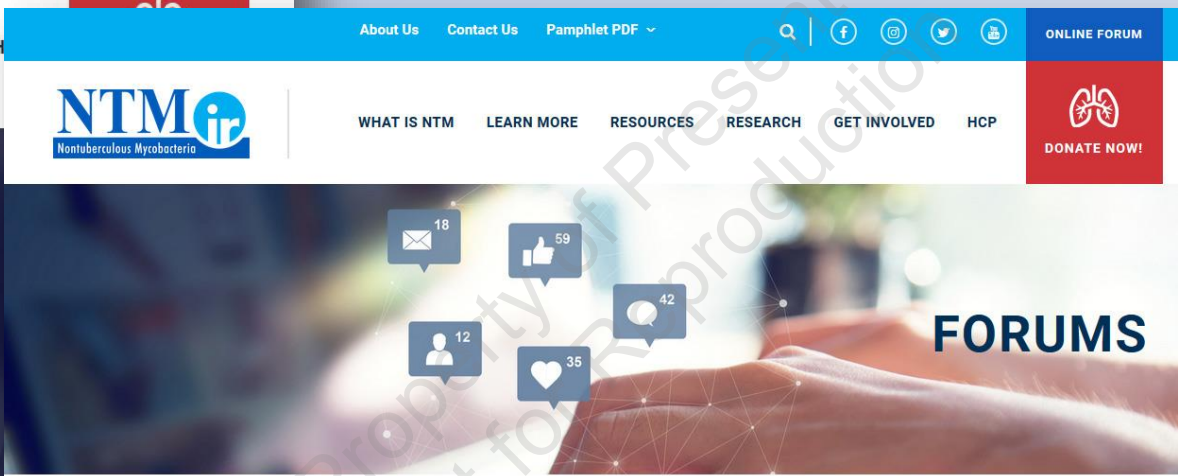
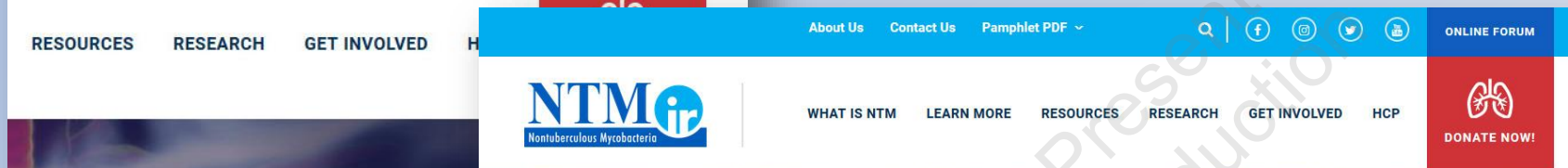
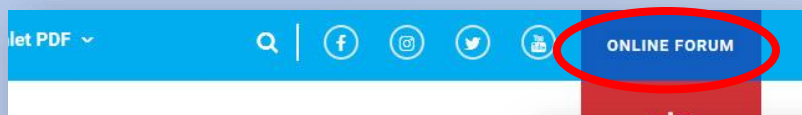
Advocacy:

- Government, health and regulatory agencies
- FDA's Patient-Focused Drug Development program
- Pharmaceutical companies
- Expert panelist for FDA workshops on the development of antibiotics and clinical trial design

Education:

- “Insight” patient pamphlet
- Patient/physician conference

Online Forum for Patients

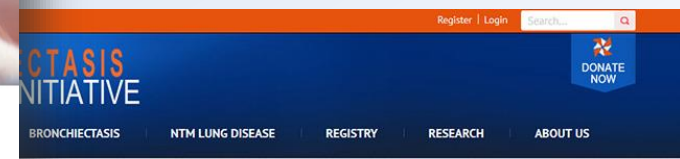


Home > Forums Log Out

Forum	Topics	Posts
NTM Support Forum	1,854	15,349
NTM Patient Support Group		
Find Others to Connect Locally	92	511
A place to list your location and contact information so that you may find others in your area with whom to meet.		
Group Leaders	8	25
Forum for Group Leaders		

[Sign In to Participate](#)
Or [register](#) to become a member

360Social



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.

Bre99 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
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.

4 hours ago

Resources for Patients

Local Support Groups

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 else on our website, is strictly for persons interested in contacting support group leaders and information 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 & Research 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

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

Additional Resources for Patients

“insight”
a patient's perspective

Learn more at ntminfo.org

NTM_{ir}
Nontuberculous Mycobacteria
NTM Info & Research, Inc.

Physician's View: Guide for Patients with NTM Infections

Edward D. Chan, M.D.
Health, Rocky Mountain Regional Veterans Affairs
University of Colorado Anschutz Medical Campus

Debbie Breslawsky
NTM Info & Research, Inc Board Member, National Jewish Health
Trustee, Support Group Leader & Founder, NY (co leader), Palm
Springs Area, California & Connecticut

Philip Leitman (President), Amy Leitman, J.D. (Director of Policy
and Advocacy), NTM Info and Research, Inc

Updated
June 3, 2019

BRONCHIECTASIS AND NTM INITIATIVE

The 1s, 2s, and 3s of Bronchiectasis



Or give us a call:

305-667-6461

ext. 26 or ext. 32

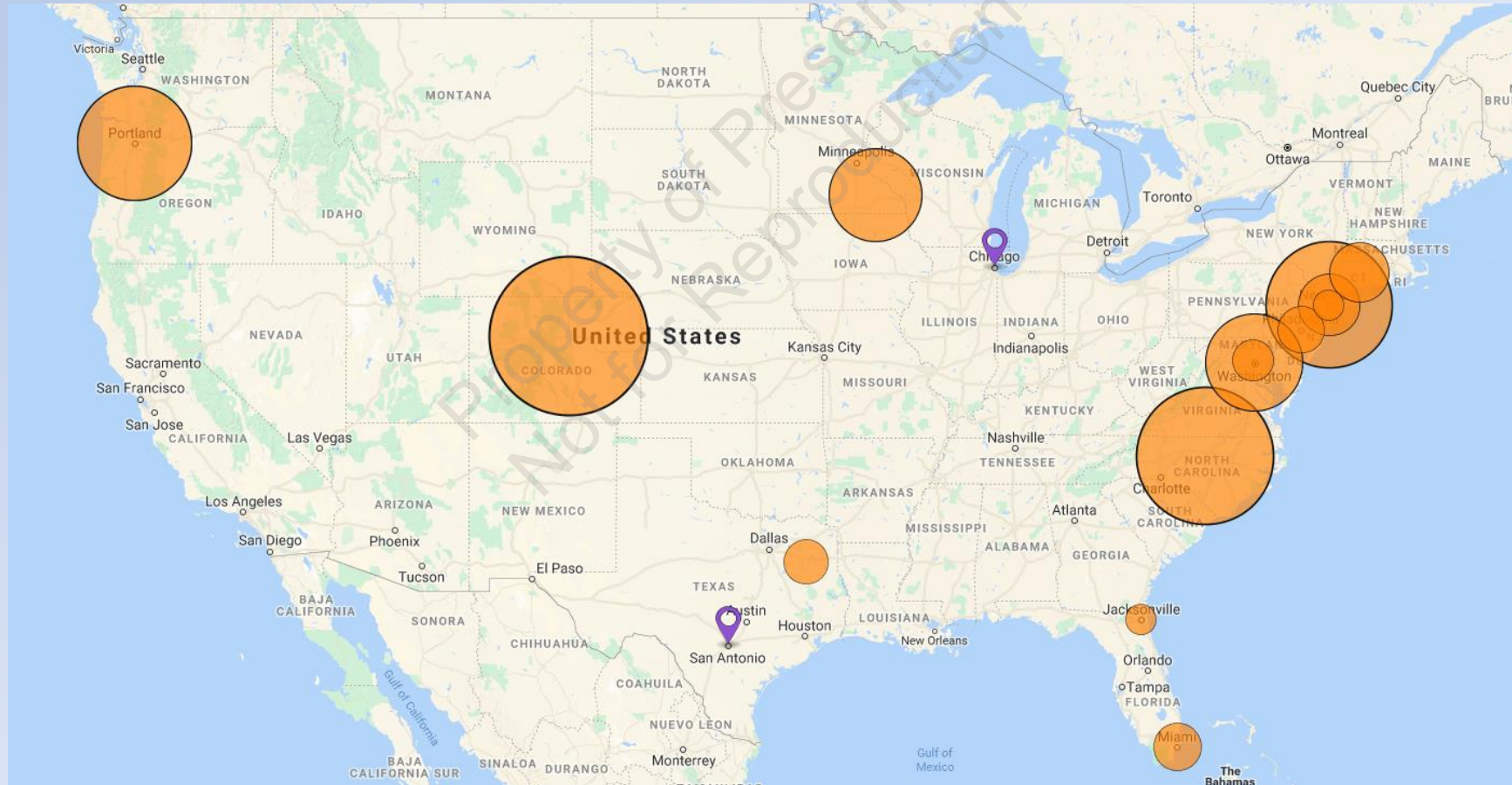
Live Events

NTM & Bronchiectasis Conference

- CME-accredited Physician/Patient Conference
- May 14-15, 2020, Philadelphia, PA
- May 14: Patient sessions; May 15: clinical & scientific sessions



Bronchiectasis & NTM Research Registry



NTM Research Consortium

ANNALSATS SUPPLEMENT

Patient-Centered Research Priorities for Pulmonary Nontuberculous Mycobacteria (NTM) Infection

An NTM Research Consortium Workshop Report

Emily Henkle¹, Timothy Aksmit², 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 Pa

¹School of Public Health, Oregon Health & Science University-Portland State University, Portland, Oregon; ²Pulmonary Disease or 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 Institute 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	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
	4. Develop a screening algorithm for patients at risk for pulmonary NTM disease	Identify techniques that improve sputum collection Develop new collection devices
Quality of life	5. Develop better methods for sputum collection and testing	Evaluate anxiety and depression after diagnosis or during treatment in patients with NTM disease
	6. Reduce the impact on patients of anxiety and depression	Association between anxiety/depression and poorer treatment adherence Validate NTM Symptom Module* tool
Treatment	7. Develop an NTM-specific Health-Related Quality of Life tool	Validate correlation between NTM Symptom Module and clinical outcomes
	8. Promote quality-of-life measures for assessing the effectiveness of treatment	Develop and evaluate alternative delivery systems for intravenous antibiotics Repurpose existing therapies Develop new, more effective drugs with a shorter therapy duration
Clinical outcomes	9. Reduce the burden of antibiotic treatment for NTM disease	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
	10. Develop and test the efficacy of nonpharmacological therapies and holistic medicine approaches	Predictors of treatment response
	11. Improve understanding of who needs or benefits from antibiotic therapy	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
	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.

Patient Initiative: Taking Action

Leads to improved quality of life

NTM is not a passive disease

The more active you are in decision-making, the more you participate in your own care, the more you improve your chances of a better outcome.

In addition to taking medicine, you must commit to:

- Airway clearance
- Nutrition
- Exercise and fitness
- Proper rest
- Psychological support mechanisms

How Do You *Feel*?

Depressive symptoms are common in patients with COPD and those with severe COPD have a 2.5 times greater risk of developing depression.¹

Limitations on activity imposed by chronic medical illness may lead to gradual withdrawal from rewarding activities.²

- 1) Van Manen JG, et al. Risk of depression in patients with chronic obstructive pulmonary disease and its determinants. *Thorax* 2002;57:412-416.
- 2) Prince M, et al. A prospective population-based cohort study of the effects of disablement and social milieu on the onset and maintenance of late-life depression. The Gospel Oak Project VII. *Psychol Med* 1998;28:337-350.

What to Look For

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

What to Know, What to Do

- Depression can be exacerbated by fear, lack of knowledge, and the illness itself or its side effects
- **You and your family may benefit** from counseling and/or anti-depressant medications
- **PLEASE DO NOT** ignore this component – talk to your doctor about getting the mental health **support** you need for yourself and your family
- Continue to educate about your illness¹
- Make sure your physicians all work together; nearly 50% of patients with clinical depression are first diagnosed by a primary care physician^{2,3}

- 1) Zhang Q, et al. Disease knowledge level is a noteworthy risk factor of anxiety and depression in patients with chronic obstructive pulmonary disease: a cross-sectional study. *BMC Pulmonary Medicine* 2014, 14:92.
- 2) Mental Health Care Services by Family Physicians Position Paper. American Academy of Family Physicians web site. <http://www.aafp.org/about/policies/all/mental-services.html>. Accessed October 4, 2017.
- 3) Position Statement 13. Integration of Mental and General Health Care. Mental Health America web site. <http://www.mentalhealthamerica.net/positions/integrated-care>. Accessed October 4, 2017.

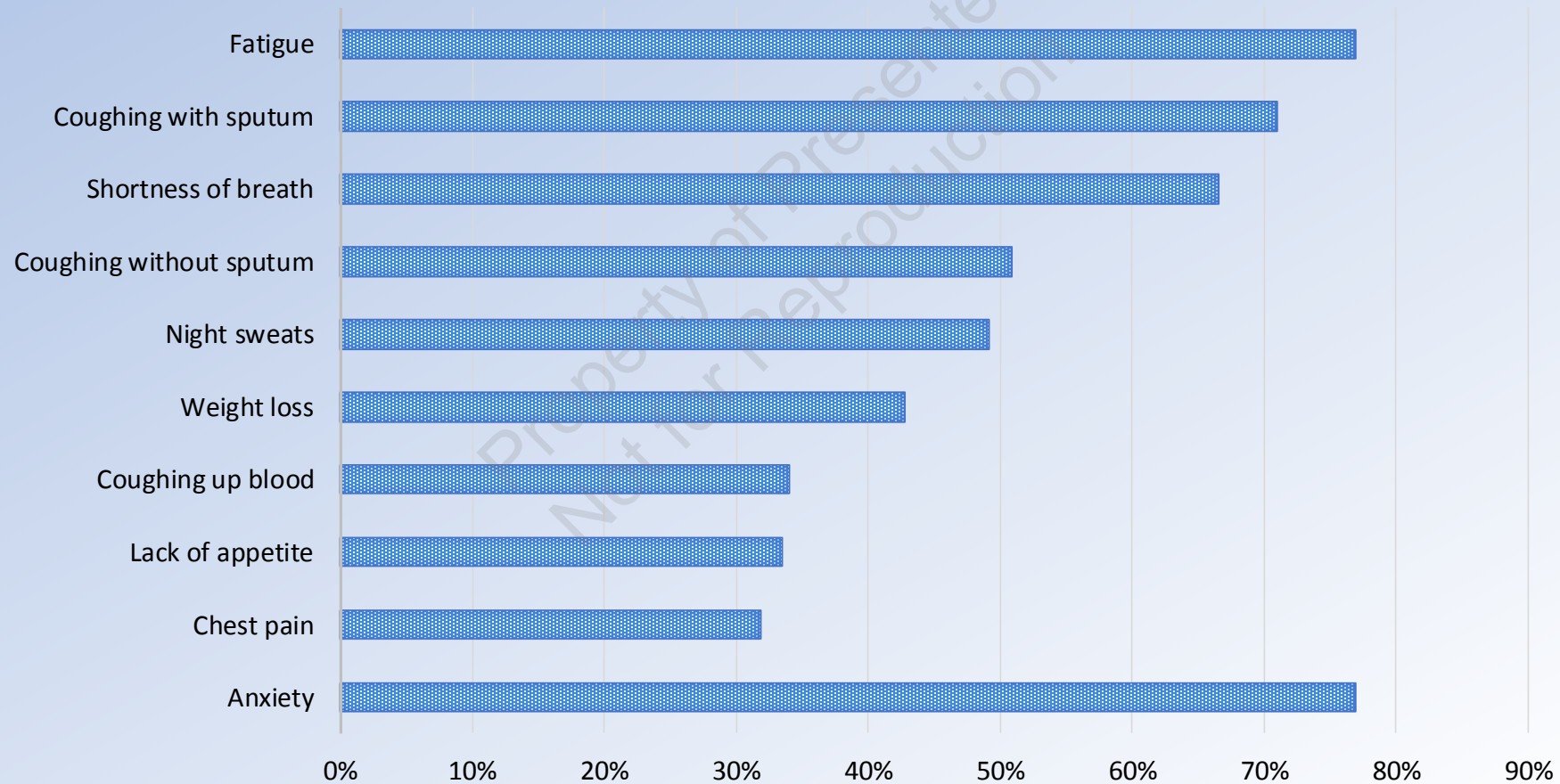
Patient-Focused Drug Development

- *Patients reported these three symptoms as having the most significant clinical impact on their daily lives:*
 - Cough
 - Fatigue
 - Shortness of breath

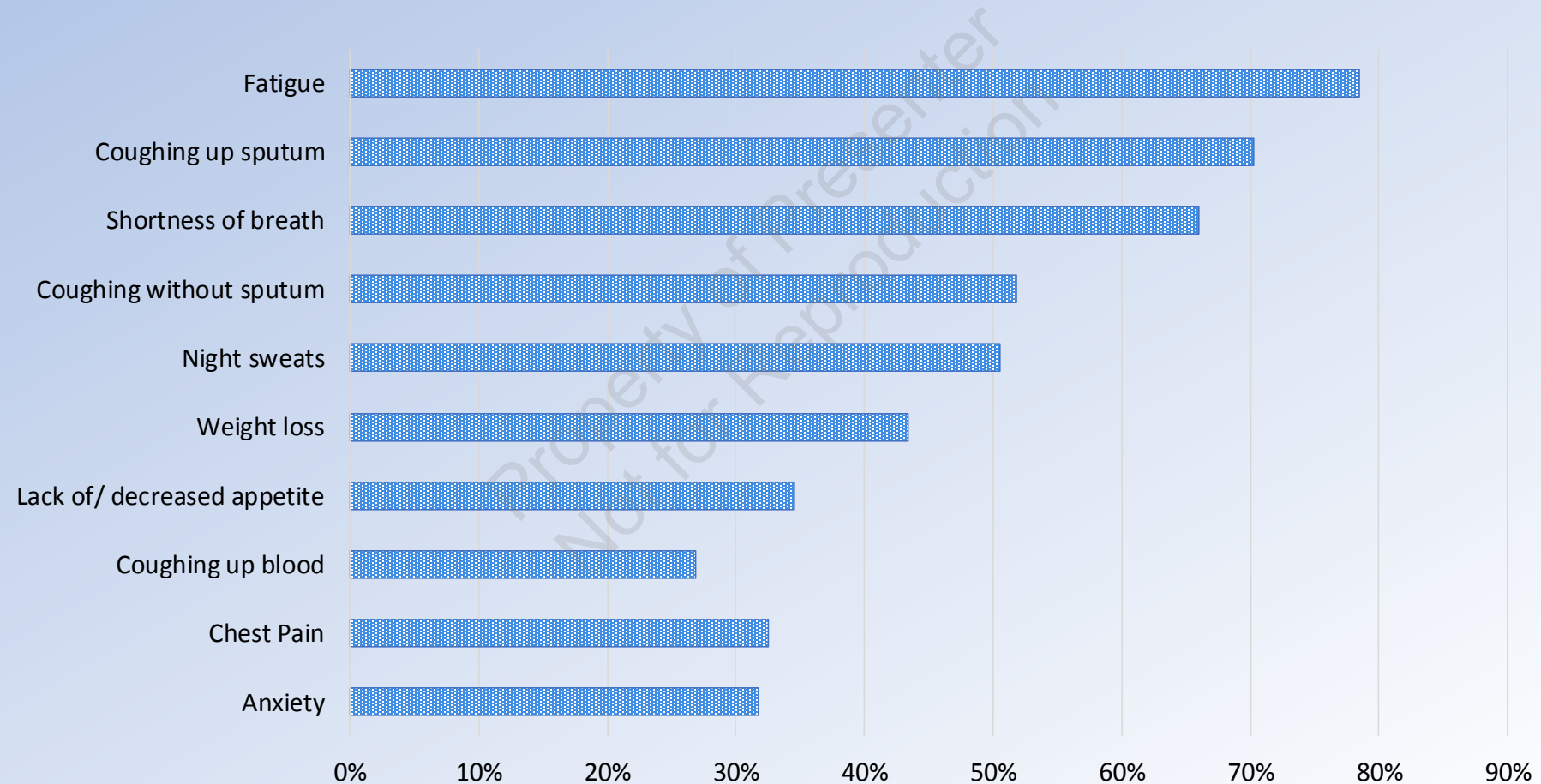
Survey: Patient Preferences in Clinical Trials & Treatment Outcomes

- 57 questions
- Joint project with Spero Therapeutics
- Reviewed by internal and external staff and researchers, NTM patients
- Circulated through NTMinfo.org, social media channels, blast emails, Social360 forum
- 465 respondents
- Results presented at April 8th FDA workshop on *Development of Antibacterial Drugs for the Treatment of Nontuberculous Mycobacterial Disease*

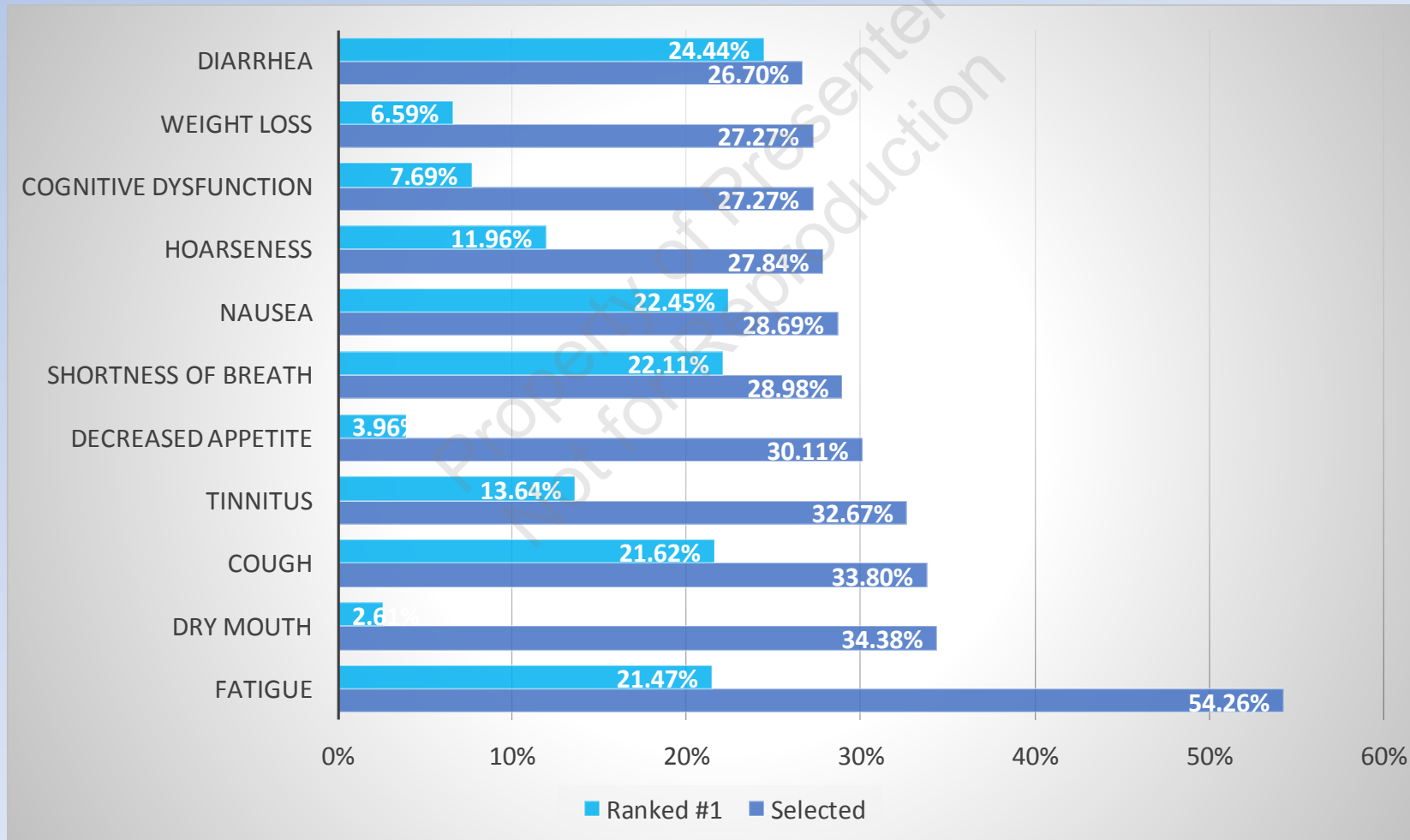
Top Symptoms Patients Experienced



Most Bothersome Symptoms



Side Effects of Antibiotic Treatment



Survey: Airway Clearance

- 5-8 minutes long
- Take the survey today at ntminfo.org



Property of Presenper
Not for Reproduction

FDA Workshop Nov. 18-19, 2019: *Exploring the Clinical Trial Enterprise for Antibacterial Drug Development in the United States*

- Co-sponsored by FDA, IDSA, and Pew Charitable Trusts
- Strategies to better support clinical trials for antibiotic development



THANK
YOU

Property of Presenter
Not for Reproduction



NTM Info & Research, Inc.

1550 Madruga Avenue, Suite 230
Coral Gables, Florida
33146

305.667.6461 ext. 26
ntmmail@ntminfo.org
www.ntminfo.org



@NTMinfo



facebook.com/NTMinfo



youtube.com/ntmir

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