



NTM Info & Research:  
*Resources for  
Providers and Their  
Patients*

Amy Leitman, JD  
President  
NTM Info & Research



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Disclosures

No relevant financial disclosures to report

Off-label uses of medications may be discussed

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Objectives

- Review tools and resources available to providers, patients, and caregivers to help educate patients about their illness and treatments
- Discuss patient experiences related to illness, treatments, and outcomes
- Discuss the role of new regulatory initiatives in future research, clinical practice, and therapeutic development

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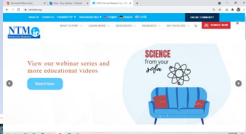
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NTMir  
National Translational Medicine Institute  
A Catalyst for Research



Co-founders:  
Patient & caregiver



The website:  
[www.ntminfo.org](http://www.ntminfo.org)



The pamphlet: A resource for patients

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NTMir  
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A Catalyst for Research

**Patient Support:**

- Online and print information
- Local support groups
- Online support group meetings
- Patient forum
- By phone and email

**Education:**

- In print and online
- Video library
- Regular webinars
- (Eventually, again) In-person meetings

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NTMir  
National Translational Medicine Institute  
A Catalyst for Research

**A Catalyst for Research:**

- Funded NTM section of Patient Registry
- Surveys on patient preferences and experiences – gives patients a voice
- NTM Research Consortium
- Help recruit for clinical trials and studies
- Input on the development of 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

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NTMRC

PFDD

FDA

Studied patient priorities

Published paper

FDA-led meeting (2015)

Voice of the Patient

Meeting on new therapies

Draft guidance for industry

Nontuberculous Mycobacterial Pulmonary Disease Caused by *Mycobacterium avium* Complex: Developing Drugs for Treatment

Guidance for Industry

DRAFT GUIDANCE

This guidance document is being distributed for comment purposes only.

Comments and suggestions regarding this draft document should be submitted within 60 days of publication in the Federal Register of the notice announcing the availability of the draft guidance. Submit electronic comments to <https://www.regulations.gov>. Submit written comments to the Division of Regulatory Policy, DOP, 1015, Food and Drug Administration, 1015 Fishers Lane, Room 3041, Rockville, MD 20852. All comments should be identified with the draft number listed in the notice of availability that publishes in the Federal Register.

For questions regarding this draft document, contact Mark Natanjani at 240-402-4026.

NTM and Patients Society

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NTM

NTMIR



Bronchiectasis & NTM Research Registry

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NTM

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What Patients Need More than just surviving

NTM is not a passive disease

*The more active patients are in decision-making, the more they participate in their care.*

*In addition to the appropriate regimen of medications, patients need:*

- Airway clearance
- Nutritional support
- Psychosocial support
- Regular follow-up and monitoring
- Compassion and kindness

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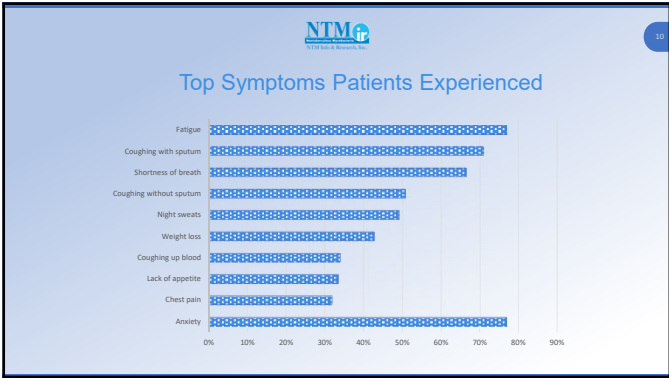
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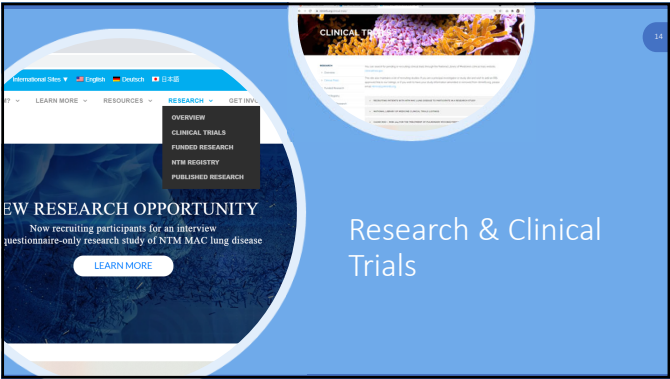
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Additional Resources  
for Providers

305-901-4NTM (4686)

ntmmail@ntminfo.org

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Emotional Wellbeing  
Program for Patients

- Pamphlet
- Handouts
- Webinars

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Nutrition Program  
for Patients

- Pamphlet
- Handouts
- Webinars

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NTM Info & Research, Inc.

Scientific Webinars

- Phage Therapy
- Lung Microbiome
- Hollow Fiber Research
- Patient-Reported Outcomes
- Medical Management of GERD
- Novel Biomarkers for NTM Treatment

SCIENCE  
from your  
sofa

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NTMir

NTM Info & Research, Inc.

Live Events: Eventually!  
NTM & Bronchiectasis Conference

Patient sessions; Clinical & scientific sessions

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