



NTM Info & Research, Inc.

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ntminfo.org

NTM Info & Research (NTMir) is a 501(c)(3) non-profit organization formed on behalf of patients with pulmonary nontuberculous mycobacterial (NTM) disease for patient support, medical education and research.

NTMir serves patients, healthcare providers, and researchers concerned with NTM. As a national organization, we can advance a broad agenda more successfully than individuals or institutions alone. Our voice is that of the patients, providers and researchers who comprise our collective constituency.

Our mission is to save and improve lives through research, education, early detection, and improved treatments for people with pulmonary nontuberculous mycobacterial (NTM) disease. By supporting innovative research, working with patients and support groups, engaging our constituencies to increase awareness of the disease, providing education opportunities for patients and healthcare providers, and demonstrating leadership at all levels to meet our goals, we strive to accelerate the development of new treatments that will help patients, and build a stronger network of doctors who are well-versed in treating this disease.

BOARD MEMBERS <https://www.ntminfo.org/board/>

TOTAL INCOME = \$338,277.00

END OF YEAR NET ASSETS = \$347,630.00

PROGRAM = \$247,677.94

Patient Outreach (total costs: \$80,213.¹⁴)

- May 2018, San Diego, CA – co-hosted with UC San Diego, a physician/patient conference on NTM lung disease and bronchiectasis; video of conference is available online
- Online support through multi-topic message board with improved features
- Held Support Group Leader training event
- Spoke at NJH's annual NTM Lecture Series for patients in Denver, CO
- Implemented social media campaigns
- Two shows on Doctor Radio (Sirius XM) on the topic of NTM lung disease in 2018
- Assisted ATS in planning NTM Lung Week
- Supported annual NTM Patient Workshop at NYU Langone Medical Center
- Co-hosted webinars on NTM and bronchiectasis
- Member of National Organization of Rare Diseases (NORD)
- Represented at 3rd World Bronchiectasis Conference
- Member of European Organization for Rare Diseases (EURORDIS)
- Member of Global Genes Alliance
- Physician Referral List with more than 130 expert physicians

Physician Outreach (total costs: \$92,883.³⁵)

- Co-hosted with UCSD, CME-accredited patient/physician meeting in May 2018 in San Diego, with nearly 300 in attendance
- Spoke at NJH's annual NTM Lecture Series for Providers in Denver, CO
- October 2018, San Antonio, TX – exhibited at CHEST 2018 (the American College of Chest Physicians annual conference)
- May 2018, San Diego, CA – exhibited at the American Thoracic Society International Conference
- Supported annual NTM Provider Workshop at NYU Langone Medical Center
- Represented at 3rd World Bronchiectasis Conference
- Participated in ATS Public Advisory Roundtable (PAR)
- President and co-founder participated in national media satellite tour from December 2018 to January 2019, in more than two dozen local media markets across the country, to educate physicians
- President and co-founder, Philip Leitman, has served on the joint committee to revise the Official ATS/IDSA Statement: Diagnosis, Treatment and Prevention of Nontuberculous Mycobacterial Diseases
- Physician Referral List with more than 130 expert physicians

Pamphlets (total costs: \$8,335.³⁸)

- Revised “Insight” pamphlet to print and to translate into 10 additional languages; as of 2018, more than 30,000 print copies of the pamphlet were distributed in English (6,000 distributed in 2018 alone)

Website (total costs: \$18,895.⁰¹)

- Launched revised and redesigned website with improved functionality
- Migrated secure online forum to new platform
- Physician Referral List with more than 130 expert physicians

ADVOCACY (total costs: \$9,675.⁵⁷)

- Delivered comments at the FDA Advisory Committee Open Public Hearing to advocate for approval of ArikayceTM, first FDA-approved treatment for pulmonary NTM disease; assisted in writing comments for other speakers at the meeting; final approval came on September 28, 2018
- Delivered comments at FDA workshop in inhaled antibiotic development for *P. aeruginosa* infections
- Delivered comments at FDA Advisory Committee meeting on inhaled liposomal ciprofloxacin
- Participated in FDA workshop on FDA draft guidance on Patient-Focused Drug Development (PFDD); submitted comments to the docket regarding final guidance
- Sponsored Rare Lung Disease Consortium (RLDC) Conference
- Member, American Thoracic Society (Philip Leitman; Amy Leitman)
- Member, Drug Information Association (Amy Leitman)
- Member, Infectious Disease Society of America (Amy Leitman)
- Served as presenter and panelist at DIA 2018 Conference (June 2018, Boston, MA) in workshop on the FDA's Patient-Focused Drug Development program
- Participated in Food & Drug Law Institute (FDLI) conference for patient advocates

RESEARCH (total costs: \$23,256.¹⁶)

- Added nearly 600 patients to the Bronchiectasis & NTM Research Registry
- Founding member of the NTM Research Consortium
- Serving as collaborator for Patient Centered Outcomes Research Initiative (PCORI) Engagement Awards for NTM Research Consortium and Bronchiectasis Research Consortium
- Identified multiple patients to participate in Patient Advisory Panels
- Serving on advisory committee for two clinical trials initiated by NTM Research Consortium
- Provided funding assistance for gut microbiome study at NYU Langone Medical Center
- Participated in FDA workshop on FDA draft guidance on Patient-Focused Drug Development (PFDD); submitted comments to the docket regarding final guidance
- Created Research Pipeline page on website to house information on clinical trials
- Created patient preference surveys to gather data on patient experiences and outcomes

FUNDRAISING (total costs: \$23,847.00)

- Received support from multiple corporate sponsors and foundation grants
- Compliant with all state fundraising registrations as needed
- Executed successful print and online annual campaign

ADMINISTRATIVE (total costs: \$2,974.⁴²)

- Hired office assistant
- Maintained GDPR and US law-compliant databases