



NTM Info & Research, Inc.

14411 S. Dixie Hwy Suite 205
Palmetto Bay, FL 33176
T + 305.901.4NTM (4686)
F + 305.662.8035

ntminfo.org / bronchiectasisinfo.org

2022 Annual Review

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 lung disease. 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.

Message from the President, Amy Leitman

In the past years, we've come to understand just how important connection is, perhaps now more than ever. Our strength has grown by staying connected to one another, to information, to hope.

I am proud and grateful to say that, together, we provided patients and their families with more connections in 2022 than ever before. Your support enabled NTMir to create and expand programs that empower patients with medical information, virtual support groups, coping strategies and hope through increased research. With our patient forum, there are thousands of active participants from over a dozen countries connecting every day.

Our founder, Fern Leitman, was an NTM and bronchiectasis patient. She started NTM Info & Research to give all NTM patients a voice, and it is her legacy that we continue today on behalf of NTM patients everywhere. Every day, I am reminded in so many ways of just how much our work touches the lives of people affected by NTM.

BOARD MEMBERS

Brandon Mitchell – Board Chair

James Zimny, Jr. - Treasurer

Candance Lerman – Director

Debbie Breslawsky – Director

Connie Kazanjian - Director

Elizabeth Glaeser – Director

Philip Leitman – Director and Co-Founder

TOTAL INCOME: \$ 471,183

END OF YEAR NET ASSETS: \$ 501,893

PROGRAM: \$ 334,793

KEY ACCOMPLISHMENTS

- NTM Connect has become the most used resource for patients. By the end of 2022, the forum had over 3,000 participants with representations from over 12 countries.
- NTMir support group network grew with 8 more leaders for the over 90 meetings held in 2022.
- Education reached a new level by hosting 17 webinars during 2022 with registration reaching over 3,500 patients.
- After years of isolation due to the pandemic, NTMir participated in ID Week, a society of infectious disease physicians to enhance NTMir's Physician Referral List.
- NTMir helped to advance research and clinical trials on NTM, MAC, bronchiectasis with over 50 clinical sites just in the USA. Currently, there are 6 clinical trials in the NTM space where researchers are looking for more options of treatment.
- NTMir is a key partner in helping to look for new treatments for lung diseases and partnered with advocacy organization for other NTM comorbidities like aPAP.

PATIENT AND PHYSICIAN OUTREACH

NTMir's biggest accomplishment was the capacity to reach the most patients by connecting them to one another. NTMir launched NTM Connect, a new patient forum with more than 3,000 participants and 700+ discussions and growing daily.

Patient support continues to be the focus of the organization, and we have held over 90

support group meetings; 34 active leaders, plus 8 new leaders, totaling 42 support group leaders. During 2022, we welcomed patients from United Kingdom to our patient network with a new support group.

Another assistance program for patients was the Educational Webinar Series with more than 15 presentations from top health care professionals and researchers. These presentations enhance our YouTube library with long lasting educational videos. These webinars, along with other videos on the NTMir YouTube channel generated more than 47,500 views in 2022.

Also, NTMir funded two ongoing research studies on hypertonic saline and biomarkers, key to finding new treatments for NTM lung disease.

Physician Referral List with more than 250 specialized physicians in Australia, Canada, New Zealand, Nicaragua and the United States.

- I. Professional Societies: Member of National Organization of Rare Diseases (NORD)
- II. Member of European Organization for Rare Diseases (EURORDIS)

RESEARCH

We are excited to announce that we have given a research grant of up to \$150,000 over two years to Oregon Health & Science University (OHSU). The grant funds a study to assess whether inhaled hypertonic saline helps improve symptoms and clearance of mycobacteria in patients with *M. avium* complex lung infections and attempt to determine how much treatment burden it places on patients. Although hypertonic saline has been used for other lung conditions and has been prescribed for treatment of pulmonary NTM, it has not been studied in the treatment of NTM/MAC. This study will examine the efficacy of hypertonic saline in culture conversion, improvement of clinical symptoms, and safety. Leading the study will be Kevin Winthrop, MD, MPH, a clinician, professor of medicine, and researcher at OHSU, and founder of the NTM Research Consortium. Dr. Winthrop and his team will also coordinate with a research group in the Netherlands conducting similar study, to share study protocols and harmonize some of

the data collection points.

Also, during 2022 NTMir awarded a grant to Rutgers University Rutgers Biomedical and Health Sciences on the study of Biomarkers. This research study will prospectively assess patient responses to treatment. Specific host biomarkers that relate to inflammation, lung damage and / or immune response will be measured to see how they relate to patient clinical

FUNDRAISING: \$ 59,071

During the last quarter, we transitioned to a new donor management platform, Neon One, to keep accurate constituent list, donations information. Also, this platform is more user-friendly for our donors, making a better experience as they give to NTMir.

We held the second edition of the virtual event called The NTM Balloon Challenge. The Balloon Challenge engaged families and created awareness of the challenges of NTM patients in a simple, easy-to-understand way.

NTMir continues to enhance its reach by participating in more events like Give Miami Day. During 2022, the campaign raised over \$1,250, more than tripled the amount from the previous year.

We also executed our traditional holiday mail solicitation, which continues to be our most important and efficient fundraiser with a 95% rate of return.

ADMINISTRATIVE AND MANAGEMENT: \$ 109,455

Maintained GDPR and US laws-compliant database.