

NTM Info & Research, Inc.

2020 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

Year of the Pandemic.

This year, amidst the tragedy of the pandemic and the loneliness of staying apart to stay alive and healthy, we have all learned new ways of reaching out to each other.

We are all adapting to new ways of connecting and supporting each other through what has been a challenging year, to say the least, especially for those with respiratory vulnerability. Thanks to technology, though we are far apart and staying home, we can still bring our NTM family together.

We quickly adapted our vital programs to meet the unique needs of 2020 through online webinars and virtual support groups. These virtual efforts have been met with widespread acclaim and appreciation from the people they serve.

Due to the high response rate and acclaim from participants, both patients and physicians, we plan to greatly expand this successful online programming for patients and families in 2021 with year-round webinars providing education and support with topics including research updates, equipment sterilization, financial planning, mindfulness, nutrition, and many more.

BOARD MEMBERS:

Connie Kazanjian - Board Chair
James Zimny, Jr. - Treasurer
Debbie Breslawsky – Director
Elizabeth Glaeser – Director
Philip Leitman – Director and President Emeritus

TOTAL INCOME: \$ 577,320

END OF YEAR NET ASSETS: \$ 390,900

PROGRAM: \$ 288,126

PATIENT AND PHYSICIAN OUTREACH

- I. NTM & Bronchiectasis Patient Virtual Conference

With our Patient Virtual Conference, we strive to overcome the challenge of these unique times and continue to be true to our mission to provide education and advocacy to NTM and bronchiectasis patients and their families. This virtual conference consisted of 5 presentations during October and November 2020

 - Airway Clearance - Pamela J. McShane, MD
 - Reducing Exposure and Reinfection - Rachel Thomson, PhD, MBBS
 - Medication Management - Julie Philley, MD
 - Fight Back with Food - Michelle MacDonald, MS, RD, CDE
 - Coping with Chronic illness - Kristen Holm, PhD, MPH
- II. Enhanced our YouTube library by adding each presentation of our 2020 Patient Virtual conference.
- III. Created a dedicated section of our website on COVID-19 to provide the best resources and information on the pandemic.
- IV. Held Support Group meeting online via Zoom.
- V. Implemented social media campaigns with links and resources on Covid.
- VI. Member of National Organization of Rare Diseases (NORD)
- VII. Member of European Organization for Rare Diseases (EURORDIS)
- VIII. Member of Global Genes Alliance
- IX. Physician Referral List with more than 130 specialized physicians in Canada, Nicaragua and the United States
- X. Website Translation to German and French
- XI. New website for the Australia NTM market

RESEARCH

NTM Info & Research Awards Grant to Oregon Health & Science University
Study Will Assess Efficacy of Hypertonic Saline in Treatment of Pulmonary NTM Disease

We are excited to announce that we have awarded a research grant of up to \$150,000 over

two years to Oregon Health & Science University (OHSU). The grant will fund 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 inhaled 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 a similar study, to share study protocols and harmonize some of the data collection points.

FUNDRAISING: \$ 22,831

The challenges faced in 2020 required us to reinvent and expand our fundraising efforts. By maximizing our existing resources, we found creative ways to reach more donors. For the first time, we held a 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.

For the first time, NTMir was approved to participate in Give Miami Day. Although the day only raised \$390, that was at no cost to NTMir and is a foundation on which we will continue to build.

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: \$ 82,971

Change of Command

It is with a mixture of gratitude and sadness that we announce the retirement of Philip Leitman as President of NTM Info & Research. Philip, who co-founded NTMir with his late wife, Fern, will continue as President Emeritus and a valued Board member.

For almost two decades, Fern fought a complex resistant *Mycobacterium abscessus* pulmonary infection, and 18 years ago she and Philip founded NTMir to channel their passion for helping patients. Philip looks forward to continuing his work in the Emeritus capacity.

The Board of Directors has unanimously selected Amy Leitman to fill the role of President. As Philip and Fern's daughter, she has gained a first-hand understanding of NTM lung disease and the impact it has on patients and families.

Since joining the team at NTMir a decade ago, Amy has championed the voices of the patients, healthcare providers, researchers, industry, and other interested stakeholders. As one of the most recognized public faces of this disease, she has presented patient-centered research, co-authored several papers on NTM lung disease, and collaborated on numerous research projects. As President of NTMir, she looks forward to continuing her work and increasing public awareness of this disease.

Amy is a member of the American College of Chest Physicians (CHEST), the American

Society for Microbiology, the American Thoracic Society, the Drug Information Association, the European Respiratory Society, and the Infectious Diseases Society of America.

Thanks to a dedicated Board of Directors and an impressive network of support group leaders to bring our patient constituency together, we have grown tremendously over the years as an organization. On behalf of the Board of Directors, I express my deepest admiration to Philip for his trailblazing efforts and gratitude for his commitment and ongoing service to our cause. We are delighted that he will continue his involvement with the organization, and we congratulate Amy as she steps up to lead NTMir along the path that lies ahead.

Hired new operations manager with over 20 years of non-profit public relations and event development experience. This staff addition supports NTMir's plan to continue to serve NTM patients worldwide.

Maintained GDPR and US laws-compliant database.