



2021 Highlights
of the
Bronchiectasis and NTM Initiative

Announcing our Evolution from
an Initiative to
Bronchiectasis and NTM 360



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a global online platform by the COPD Foundation



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Medical Director,
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Dear Community Members,

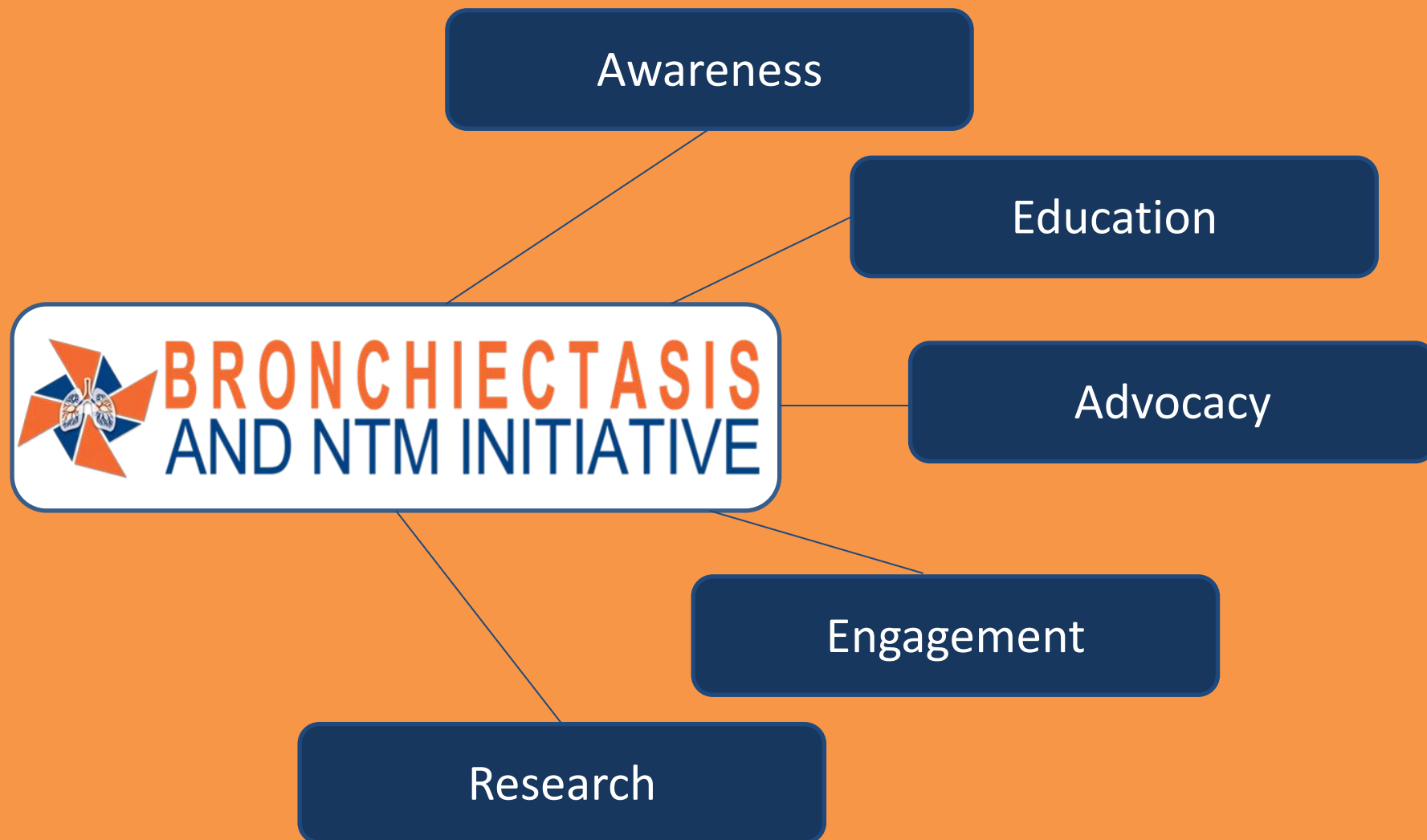
We are pleased to share this progress report which highlights the accomplishments of the Bronchiectasis and NTM Initiative. The Initiative was established by the COPD Foundation in an effort to meet the unique needs of the bronchiectasis and NTM communities. Programs within the Bronchiectasis and NTM Initiative include a global online platform for community members to connect and interact, educational resources for patients and caregivers, and research programs designed to assist in accelerating therapeutic solutions and cures for both, bronchiectasis and NTM.

We are fortunate to be able to work collaboratively among all stakeholder groups including patients, caregivers, health care providers, pharmaceutical companies, and device manufacturers to offer programs critical to our common mission. Given the success of the Initiative, we established a dedicated Bronchiectasis and NTM team at the Foundation and we have made a decision to rebrand the Initiative as Bronchiectasis and NTM 360. In the coming months, we will be rebranding our website and materials accordingly.

We are grateful for your support and look forward to future collaborative efforts.

Sincerely,

Tim and Delia



MISSION

The Bronchiectasis and NTM Initiative aims to address the unmet needs of the Bronchiectasis and NTM communities by focusing on the following key areas:

- Awareness
- Education
- Advocacy
- Engagement
- Research



COLLABORATION



Collaboration among all stakeholders is critical to our mission.



Bronchiectasis and NTM 360 Team



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Bronchiectasis and NTM Research Registry Consortium Members

- **Doreen Addrizzo-Harris, MD**, New York University
- **Timothy R. Aksamit, MD**, Mayo Clinic Rochester
- **Juzar Ali, MD**, Louisiana State University
- **Alan Barker, MD**, Oregon Health and Science University
- **Ashwin Basavaraj, MD**, New York University
- **Keira Cohen, MD**, Johns Hopkins University
- **Charles Daley, MD**, National Jewish Health
- **Leigh Anne Daniels, MD**, University of North Carolina at Chapel Hill School of Medicine
- **Angela DiMango, MD**, Columbia University Medical Center/NY Presbyterian Hospital
- **Edward Eden, MD**, Mount Sinai St. Luke's and Mount Sinai Roosevelt
- **Margaret Johnson, MD**, Mayo Clinic Jacksonville
- **Michael Knowles, MD**, University of North Carolina at Chapel Hill
- **Nicole Lapinel, MD**, Louisiana State University
- **Christopher Lippincott, MD**, Johns Hopkins University
- **Diego Maselli, MD**, San Antonio Veterans Administration
- **Pamela J. McShane, MD**, University of Texas Health Science Center at Tyler
- **Mark Metersky, MD**, University of Connecticut
- **Edward Naureckas, MD**, University of Chicago
- **Anne O'Donnell, MD**, Georgetown University Hospital
- **Julie Philley, MD**, University of Texas Health Science Center at Tyler
- **Marcos Restrepo, MD**, San Antonio Veterans Administration
- **Matthias Salathe, MD**, University of Kansas
- **Andreas Schmid, MD**, University of Kansas
- **Byron Thomashow, MD**, Columbia University
- **Gregory Tino, MD**, University of Pennsylvania
- **Kevin Winthrop, MD**, Oregon Health and Science University

Industry Partners, Advocacy Organizations, Family Foundations, Private Donors

We are grateful for the support and collaboration from industry partners, advocacy organizations, family foundations, and private donors. Without their support we could not accomplish all that we have.

Collaborators and supporters have included:

- **Anna-Maria and Stephen Kellen Foundation**
- **Aradigm**
- **Bayer Healthcare**
- **Electromed**
- **Gilead Biosciences**
- **Grifols**
- **GlaxoSmithKline (GSK)**
- **Hillrom**
- **Insmed**
- **NTM Info and Research**
- **Private Donors**
- **Richard H. Scarborough Bronchiectasis Research Fund**
- **Talecris Therapeutics/Grifols**
- **Zambon**



ACCOMPLISHMENTS

The Bronchiectasis and NTM Initiative has accomplished a great deal in the last year. We are excited to share the accomplishments and progress in our programs.

New Educational Content

Several new educational webpages were developed, covering a variety of important topics, including exacerbations, coping with airway mucus, nutrition, and more! Additionally, many other webpages were updated with new information.

The screenshot displays the website's header with the logo 'BRONCHIECTASIS AND NTM INITIATIVE' and navigation links: 'BRONCHANDNTM360SOCIAL', 'BRONCHIECTASIS', 'NTM LUNG DISEASE', 'LEARN MORE', 'RESEARCH', and 'ABOUT US'. A 'DONATE NOW' button is also visible. The breadcrumb trail reads 'HOME > LEARN MORE > LEARN MORE > COPING WITH AIRWAY MUCUS'. The main content area is titled 'Coping with Airway Mucus' and includes a text block explaining that individuals with bronchiectasis and nontuberculous mycobacterial (NTM) lung disease struggle to keep their airways clear of mucus. It notes that bronchiectasis causes too much mucus, which collects in the lungs, and that cilia are often damaged, making it harder to clear mucus. A diagram below the text compares 'NORMAL BRONCHUS' and 'BRONCHIECTASIS'. The normal bronchus shows cilia and mucus being cleared, while the bronchiectasis diagram shows 'Loss of cilia', 'Increased mucus', and 'Damaged wall'. A sidebar on the left lists 'Learn More' topics: 'Breathing Techniques', 'Coping with Airway Mucus', 'Coping with Nausea', 'Diagnosis, Testing and Evaluation', 'Exacerbations', 'Exercise', 'Newly Diagnosed', 'Nutrition', 'Pneumococcal Aeruginosa Lung Infections', 'Pulmonary Rehabilitation', and 'Glossary'. At the bottom of the sidebar, there is a profile section with 'Edit my profile', a '975 points' badge, and 'My Questions (0)'.

Bringing the Community Together

- In response to the COVID-19 pandemic, we hosted a series of virtual, social “Coffee Breaks” to provide a venue for community members to connect in a virtual support group setting.
- We launched a “Share Your Story” series to increase engagement and encourage others to share experiences and advice on their journey with bronchiectasis and NTM.
- We strategically increased communications to our BronchandNTM360social community to ensure community members are up-to-date on the most recent opportunities and resources.



The Bronchiectasis and NTM Research Registry and Consortium Continues to Grow and Advance Research

- The Bronchiectasis and NTM Research Registry exceeded a major milestone of 4,000 participants enrolled.
- The Registry continues to grow and collect longitudinal data, with some participants having up to 13 years of data collected.
- The Registry now has 17 active sites across the U.S., with over 25 experts participating in the Consortium.
- The Registry continues to be utilized for studies, resulting in the development of conference abstracts and published manuscripts.



17
Registry
Sites

4,165
Participants

13
Years of Data

Blogs to Support the Community

Several new blog articles focusing on topics related to coping with bronchiectasis and NTM as well as COVID-19 were published on the BronchandNTM360social blog.



Patient Ambassadors Lend a Hand

We successfully recruited Ambassadors who are now supporting information and referral requests to the Bronchiectasis & NTM Information Line (833.411.LUNG).

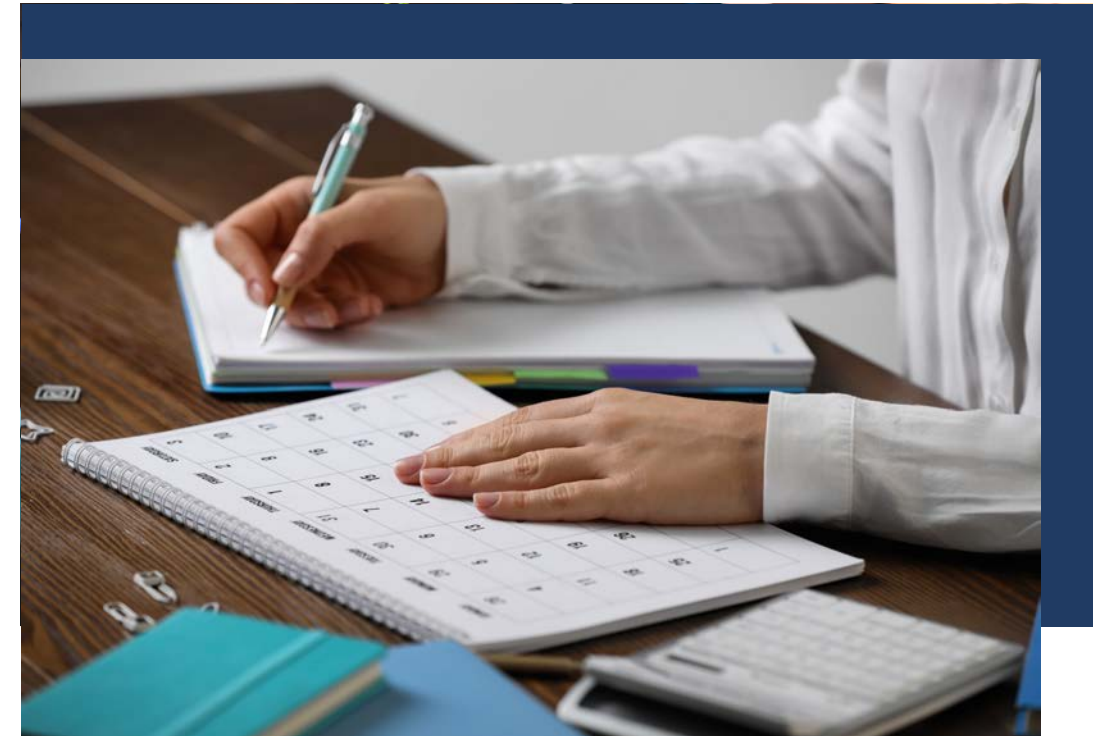
At-Home Sputum Collection Pilot for NTM Testing

In partnership with Insmmed, NTM Info and Research, and National Jewish Health, we have developed a pilot program aimed at assessing the utility of home sputum collection for both patients and physicians. By providing NTM patients access to accurate and comprehensive laboratory testing from the comfort and safety of their homes, we hope to minimize the gap between symptom onset and diagnosis, ultimately resulting in an optimized treatment plan.



Coming Soon...

LOOKING AHEAD



Committed to meeting the needs of the Bronchiectasis and NTM communities

We are very excited as we proceed in planning the Bronchiectasis and NTM 360 programs and activities for the next year and proceed with rebranding our website and materials.

Continued Development of Education Materials

We hope to continue developing new education materials (in both, electronic and print, formats) and making them freely available to anyone who wants to learn more about bronchiectasis and NTM.



Collaboration through Research

We will continue to collaborate with stakeholders in research in order to develop and implement a research strategy that will increase knowledge and understanding of bronchiectasis and NTM and push the needle closer to better treatments and therapies for individuals affected by these conditions.

Increase Awareness

We hope to continue spreading awareness of bronchiectasis and NTM to the COPD community, as well as to the general public. Increasing awareness will be important in helping to identify undiagnosed patients at an early stage so they can be properly diagnosed and placed on an appropriate treatment plan.



Continued Education and Engagement

Hosting more live, educational events will help in educating the community about how to properly manage their condition.

Additionally, we will continue recruitment of volunteer Ambassadors and refine ways to provide peer health coaching as well as advocacy opportunities.

Thank you to our donors, corporate partners, scientific and research partners and, of course, the patient community. Your support and partnership has enabled us to continue our efforts to support the bronchiectasis and NTM community. We have experienced incredible growth since our inception in 2016. We continue to work to positively impact the bronchiectasis and NTM community.

While the Bronchiectasis and NTM Initiative has achieved many goals, a great deal of work remains. We look forward working together to improve the lives of those with bronchiectasis and NTM.

