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Dear Friends,

We are pleased to share the 2021 COPD Foundation Annual Report, highlighting our patient-centric approach to improving lung health, which is at the heart of all we do.

While we are eager to share our accomplishments, we would be remiss to ignore what is happening on the world stage.

Worldwide, we all live with the impact of COVID-19 – those taken too soon – and the lifelong respiratory challenges facing survivors.

Fires across the western United States, Australia, and other countries created smoke, ash, and unhealthy conditions in the air that we all breathe.

And, we know all too well from the lessons of 9-11 that breathing in the debris, dust, and matter from burning buildings is detrimental to first responders and all who live in affected areas, creating long-term health implications. Amplify those lessons by the millions when you add the effect of bombings and fires in war zones around the world.

Unfortunately, these problems will increase unless we and others in the global health community continue to advocate and influence for more funding, research, and policies that change our course and make breathing a priority.

This past year, the COPD Foundation focused on several patient-centric lung health priorities to support our community and address global lung health concerns, including:

• Studies to understand the patient-priority research agenda for the Foundation, reaffirming our commitment to developing cures and engaging patients at all stages of research.
• Expanding our board of directors, community engagement committee, and leadership team to improve diversity and inclusion in all that we do.
• Expanding our scientific, medical, and operational team to increase the impact we have on research and development of innovative treatments for chronic lung diseases.
• Elevating bronchiectasis and NTM lung disease from an initiative to a key focus.
• Advocating for safe, effective, and affordable oxygen therapy, improvements in the regulatory drug development process, and for clean air, tobacco and vaping control, and vaccines.

We also introduced a successful COPD awareness program, Lace-Up for Lungs, highlighting the need for better breathing and lung health, exercise and activity, and quality of life and caring for those impacted by COPD.

Thank you for supporting our mission this past year and recognizing the need for prioritizing global lung health. We look forward to working with you in 2022.

Respectfully,

Ruth and James
Patient priorities are at the heart of our research efforts at the Foundation. In 2021, the Foundation completed a two-year project, Bridging the Gap Between Patients/Caregivers and COPD Research (BRIDGE), funded by the Patient-Centered Outcomes Research Institute (PCORI), with the Foundation’s goal to increase the voice of the patient and caregiver in research and development in our COPD360Net® initiative.

The COPD Patient-Powered Research Network® (COPD PPRN) BRIDGE Project developed a research agenda focused on patient and caregiver priorities. PPRN study participants were asked, “What research in COPD matters to you?” The 3,000 responses included 500 free text comments the Foundation team, in partnership with a patient and caregiver advisory board, segmented into 25 categories. Members of the Foundation’s COPD360Social® community then voted for their top choices, resulting in new patient and caregiver research priorities for the Foundation.
A patient-driven research agenda evolved based on results. Top patient priorities include curing COPD, better therapeutics for shortness of breath and flare-ups, and improving symptoms.

“At the time, we didn’t have a cure as part of our mission,” said Cara Pasquale, Vice President of COPD360Net and program co-lead. “But our patients confirmed they want a cure. Today, our revised mission statement reflects their priorities,” Cara added.

What’s more, research at the Foundation will map back to the patient prioritization goals realized in the BRIDGE project, a unique approach that the Foundation believes will also benefit its partners and funders. To see the research agenda, visit the BRIDGE project online.

“When I joined a research team as a patient investigator for the first time, I quickly learned how much a patient’s point of view can positively impact a study. I am grateful for the opportunity to participate as part of a study team and encourage other patients to become investigators and improve the quality of research studies through their lived experiences.”

– Mary Ellen Houlihan, Patient Investigator and Governing Board Member, COPD PPRN

“I believe that as patients, we need to be, and must be, involved in research projects. I am a patient investigator to help ensure that our needs and concerns are addressed -- not just those of the medical community. Patients have ‘lived’ experiences that may be totally different from that of the researchers and are vitally important to be incorporated in any research.”

– Karen Deitemeyer, Patient Investigator and Governing Board Member, COPD PPRN
COPD360Net: Mapping a Path Forward for Development of Chronic Lung Disease Treatments

To move the needle on finding new therapies and eventually a cure for COPD, bronchiectasis, and NTM lung disease, strategic partnerships with industry, academics, and the Foundation’s digital health and therapeutics network, COPD360Net, provide the opportunity to map a path forward. The COPD Foundation’s growing team of scientific and medical experts brings together many years of innovation, research, and drug development experience as evidenced by successful delivery of nine medicines to patients. This expertise is mobilized through COPD360Net® to accelerate innovation in the development and adoption of treatments that matter to patients.

Over the past year, COPD360Net expanded its accredited centers and practice-based research networks to 19, including international sites and several primary care networks. What’s more, COPD360Net increased its drug development and research partnerships in 2021 and welcomed a new partner in early 2022.
Medical and Scientific Team Grows

In 2021, the Foundation’s medical, scientific, and operational team expanded, bringing a new level of research and patient-centered development expertise to COPD360Net. The team is experienced in bringing multiple therapeutic products to patients and setting the Foundation apart as experts in supporting and facilitating clinical development and adoption of new treatments addressing the needs of our community. New team members include:

Timothy Aksamit, MD, Bronchiectasis and NTM 360 Medical Director. Tim is a consultant and Associate Professor in the Pulmonary Disease and Critical Care Medicine at Mayo Clinic and Mayo Mycobacterial and Bronchiectasis Clinic Director. His role is to support the Foundation’s bronchiectasis and NTM strategy.

Courtney Crim, MD, COPD360Net Medical Director. Courtney has worked in academic medicine at the University of North Carolina at Chapel Hill School of Medicine and spent more than 20 years with GlaxoSmithKline (GSK). His role at the Foundation is to support clinical development of COPD360Net pipeline and contribute to our education and outreach efforts.

Alan Hamilton, PhD, Senior Director of Research. Alan has over 20 years in senior scientific positions with Boehringer Ingelheim. Alan is a leading expert in assessing the impact of treatment on exercise capacity and leads the Foundation’s efforts in developing clinical outcomes that matter to patients.

Nicholas Locantore, PhD, Senior Statistical Director for the Foundation. Nick has more than 20 years of experience in clinical research, statistical consulting, and digital data integration. At the Foundation, Nick is primarily engaged with the COPD PPRN.

Bruce Miller, PhD, COPD360Net Senior Scientific Director. Bruce spent several years working in the pharmaceutical industry focused on early-stage clinical development and is an expert on lung microbiome and biomarkers in COPD. Bruce leads the COPD360Net pipeline evaluation committee and supports clinical development by partner companies.

Richard Mularski, MD, PPRN Medical Director. Richard leads health services research at the Kaiser Permanente Center for Health Research and is a professor at Oregon Health & Science (OHSU) and Kaiser Permanente Bernard J. Tyson School of Medicine. Richard is the co-patient investigator of the COPD PPRN and a member of COPD360Net.

Cara B. Pasquale, MPH, PMP, was promoted to Vice President of COPD360Net in 2021. Cara has been with the Foundation since 2014, building the COPD PPRN and increasing patient and caregiver engagement. Today, she leads the Foundation’s Digital Health and Therapeutics Accelerator Network.

Julie Yates, BS, Senior Clinical Investigation Director. Julie brings expertise in late-stage clinical development experience with respiratory medicines and worked with GlaxoSmithKline (GSK) for more than 30 years.

Learn more about our scientific, medical, and operational experts by visiting us online.
Bronchiectasis and NTM 360: A New Phase Takes Shape

This past year, the COPD Foundation reinforced the importance of bronchiectasis and NTM lung disease by adding them prominently to its mission. The Bronchiectasis and NTM Initiative also shed its single initiative moniker with a rebranding to Bronchiectasis and NTM 360 in late 2021.

What began as the Bronchiectasis Research Registry in 2007 evolved to include the Bronchiectasis and NTM 360 social community and ambassador program. The addition of an at-home sputum collection pilot program in 2021 further cemented the patient-driven focus and holistic approach of the recently christened Bronchiectasis and NTM 360.

With new leadership, including the promotion of Delia P. Oliver, to Vice President of Bronchiectasis and NTM 360, the inclusion of Timothy R. Aksamit, MD, as Bronchiectasis and NTM 360 medical director, and onboarding of Director of Bronchiectasis and NTM Research and Education, Christina Hunt, RRT, the Bronchiectasis and NTM 360 team got to work on its mission-driven approaches.

“We’re focused on increasing disease awareness, educational resources for impacted individuals and health care professionals, and community engagement, while also strengthening our commitment to research and the development of therapeutics for bronchiectasis and NTM,” Delia said.

Heading into 2022, Delia and the team, in partnership with more than 16 global patient advocacy organizations and professional societies, announced the declaration of World Bronchiectasis Day, to be observed annually on July 1 to raise awareness of the disease as a worldwide health issue.

To learn more, visit www.worldbronchiectasisday.org.

If your patient is suffering from symptoms or a confirmed case of NTM lung disease, visit our website for more information about our FREE home sputum pilot program.

Ensure your patients have access to full-service mycobacteriology laboratory testing from the safety and comfort of their own homes and help us reduce the gap between onset of symptoms and diagnosis.

Space for this pilot program is limited!

The home sputum pilot program launched in 2021.

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COPD Education: Empowering Learners On Their Lung Health Journey

The COPD Foundation’s education team is dedicated to improving awareness, understanding, and behavior change in people with COPD, bronchiectasis, and NTM lung disease and those who care for them. Our educational strategic direction is created with the input of our Community Engagement Committee (CEnCo), comprised of people with lung disease, family members, and health care professionals, and with input from the Foundation’s Medical and Scientific Leadership Team experts.

“A great organization with wonderful resources. . . If you have COPD, this is a great place to learn about your disease.”
- COPD community member

Lace-Up For Lungs Supporter
Our highly skilled multidisciplinary team of respiratory therapists, physicians, and nurse educators operate as a team to engage, educate, and empower learners wherever they are in their lung health journey. We strive to make content accessible to many audiences, translating complex medical information into simple text and graphics that more people can understand regardless of their education, culture or language.
Meet COPDF Educator
Stephanie Williams, BS, RRT

Sr. Director of Community Education Programs and registered respiratory therapist Stephanie Williams loves her work. Every day for the past seven years, Stephanie has had the honor of educating people with lung conditions as they move through their lung health journeys.

Stephanie manages the Foundation’s COPD Readmissions Institutes for health care professionals, designs innovative programs such as virtual Harmonicas for Health®, and ensures the community is supported through blog posts, social media events, educational webinars, quizzes, games, and more.

“Having dedicated my career to supporting and caring for people, it is a privilege to be part of such a hopeful, forward-thinking, and collaborative organization,” Stephanie said.

In 2021, the Foundation educators partnered with U.S. and global organizations to create and disseminate translated materials and to prioritize health equity across communities by expanding education and its delivery through various formats and media, including COPD podcasts and an interactive visual platform for those newly diagnosed with COPD. Also, the community was introduced to new, downloadable, and visually rich educational materials, including our Guides for Better Living, and an updated Pocket Consultant Guide (PCG) app, available to iOS and Android device users and a new virtual Harmonicas for Health® program.
COPDF & Hospitals Establish Respiratory Navigator and Peer Coach Program

In 2021, the COPD Foundation, in collaboration with Holy Cross Health, established the Respiratory Navigator and Peer Coach Program (RNPC), a hospital-based process improvement program designed to extend crucial personalized care to individuals with COPD and related lung conditions hospitalized for exacerbations or “flare-ups.”

The program, launched in July at the new Catherine Yardley Comprehensive Pulmonary Center, assists patients in the post-acute phase, including self-management at home. Patients work with an on-site Holy Cross Health navigator and have the added benefit of COPD360coach support through the Foundation’s online platform. The Foundation also supports patients with print and online COPD educational resources.
“We have been honored to provide our patients with enhanced pulmonary care through our partnership with the COPD Foundation,” said Helen Visco, RPT-NPS, CPFT, Clinical Manager of the COPD Clinic at the Catherine Yardley Comprehensive Pulmonary Center. “The level of communication has been beyond our expectations and has truly enhanced patient care experience. Not only does it give us peace of mind, but more importantly, our patients feel supported through their journey with lung disease.”

Also, in 2021, in collaboration with Johns Hopkins University and Allegheny Health Network, the COPD Foundation developed a six-month peer-supported virtual pulmonary rehabilitation (VPR) process improvement pilot program. COPD360 peer health coaches remotely support and assist in patient adherence to physical activity aiming to improve health outcomes. Goal setting and disease management education are also included in the program.

“Ask us how you can participate in our Respiratory Navigator & Peer Coach Program today!”

| **Tips to manage your COPD** |
| **Get 1-to-1 support** |
| **Personalized guidance from another patient** |

All in the comfort of your own home at no cost to you!

Questions?
Toll-free: 866.680.RNPC (7672)

Holy Cross Health

COPD Foundation®

COPD360 peer health coaches remotely support and assist in patient adherence to physical activity aiming to improve health outcomes. Goal setting and disease management education are also included in the program.
Meet Claudya Greig: Patient Serving Patients

COPD360coach Claudya Greig said she’s honored to help people with COPD in her role as a COPD360coach. Claudya started with the C.O.P.D. Information Line about eight years ago while researching COPD and the resources at the Foundation.

A Foundation leader asked Claudya at the time if she’d like to learn more and help other people with COPD, it was an offer she was eager to accept. “I was thrilled to do it,” said Claudya, who has severe COPD and uses continuous supplemental oxygen, was experienced as a caregiver for her mother and husband who both had COPD.

“When you’re talking to someone else recently diagnosed, it’s always good for them to have someone in the same shoes to talk to. It’s comforting to know that you’re not alone,” Claudya said. Today, she’s a peer health coach and loves what she does.

Before coming to the Foundation, Claudya lived in Chile for 28 years and is fluent in Spanish. In her role as a coach at the Foundation, she connects with English- and Spanish speakers who may need assistance, which she finds especially rewarding. In fact, Claudya recently recorded a Spanish-language video educating our global partners on the success of the 360coach program.

“You know, you go to college and get a degree in this or that,” she said. “But I have a degree in COPD – I found that experience has helped a lot of people.”

Learn more here about the COPD Foundation COPD360coach program.

Linda Walsh, Chief Community Engagement Officer, COPDF Lace-Up for Lungs Supporter
Advocacy 2021: An Engaged Community Makes an Impact

Advocacy is critical to meeting the mission and objectives of the COPD Foundation. By working with local, state, and federal policymakers to increase research funding, improve care delivery, and enhance the lives of those with COPD, bronchiectasis, and NTM lung disease, we help people in our community find their voices as champions for change.

Each year, the Foundation establishes advocacy priorities, which for 2021 included:

- Access to safe, effective, and affordable oxygen therapy.
- Access to effective and affordable pulmonary rehabilitation (and advocating for much-needed treatments important to patients).
- Improvements in the regulatory process of qualifying drug development tools to support the development of new treatments for chronic lung conditions.
We also collaborated on advocacy efforts with other leading organizations on important issues such as clean air, tobacco and vaping control, health disparities, and vaccine recommendations and access. Many of those initiatives, including tobacco and vaping control, will continue into 2022.

In October, the Foundation hosted IMPACT 2021, an advocacy event that brings together patients, caregivers, and others in the community – all volunteers – to meet with Congressional representatives and their staff in Washington, D.C., to inspire action for COPD in government.

“We are all advocates. Whether we meet intentionally or accidentally. Everyone has a story that resonates and touches different lives. We need to encourage others to tell their stories. Connect COPD to the people you love and care about.”

- Valerie Chang, COPD Patient, Foundation Board Member, and Advocate

Although typically held face-to-face in the offices on Capitol Hill, COVID-19 prompted the Foundation to transform IMPACT 2021 into a virtual event. More than 35 COPD Foundation advocates from 25 states shared experiences about the critical needs in our COPD community. Learn more about IMPACT 2022.

Visit the COPD Action Center to follow pressing policy issues. We welcome your voice!
SOS for Breath: COPD Foundation Prioritizes the Patient Voice at FDA Listening Session

In October, the COPD Foundation sponsored a patient listening session with the Food and Drug Administration (FDA), called SOS for Breath, highlighting the common elements of disease burden, such as breathlessness and activity limitation, across chronic lung conditions.

People with COPD, cystic fibrosis, bronchiectasis, and other chronic lung conditions shared powerful stories describing the daily impact of their unmet medical needs as they experience dread when unable to breathe. Their voices united on a common theme – breathlessness and the inability to carry out activities of daily living need to be addressed.

The session also provided the opportunity for the Foundation to propose a concept of interest framework for progressing qualification of clinical outcome assessments (COAs) and to discuss opportunities to advance essential drug development tools (DDTs) collaboratively. More than 250 interested parties joined the virtual session attended by representatives from several FDA divisions and functions.

Individuals with chronic lung conditions shared personal stories about living with their condition during an FDA Listening Session sponsored by the COPD Foundation in early October 2021. These are excerpts from their statements:

“Those of us suffering from COPD need drugs that will address this breathlessness so we might have a better quality of life. I cannot stress it enough. I realize that COPD is not a one size fits all disease. Many of us suffer from different conditions caused by COPD, but breathlessness is a main component of the disease.”

− Jan Cotton, COPD Patient, Advocate, and Volunteer

“You see a flight of stairs; I see a mountain. I am always fearful that another attack of breathlessness will force me to stop walking, stop talking, stop putting on my shoes, stop breathing. My chest tightens, I gasp, sometimes gulp for air. I feel as if I am suffocating, and worst of all, I am not sure when or if my next breath is coming...... It is raw fear. It is worse than pain because to stop breathing is to stop living.”

− Grace Anne Dorney Koppel, COPD Patient and Advocate
Did You Know?

COPD360social, the Foundation’s online community reached a New milestone!

53,000 Members on COPD360social

Chronic Obstructive Pulmonary Diseases: Journal of the COPD Foundation Received First Impact Factor (IF 3.226) in June 2021!

COPDF Captain Tina Moyer and co-worker support COPD Awareness.

Ndd Medical Technologies and Wellinks support Lace-Up for Lungs and COPD Awareness.
As a non-profit 501(c)(3) organization, the Foundation is only able to make an impact and accomplish its mission through the generosity of our donors and corporate partners (see page 42), and the funding of industry, foundations, and governmental grants.

**FINANCIALS**

<table>
<thead>
<tr>
<th>Financial Item</th>
<th>Amount</th>
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<tr>
<td>Total Revenue</td>
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<td>Contributions</td>
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<tr>
<td>Total Expenses</td>
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<tr>
<td>Programmatic Expenses</td>
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</tbody>
</table>

**Assets**

- Cash and cash equivalents: $2,876,265
- Marketable securities: $5,188,565
- Accounts receivable: $1,672,165
- Prepaid expenses: $596,356
- Property and equipment, net: $20,324
- Marketable securities, long term: $437,452

Total assets: $10,791,127

*For complete information, please refer to the independently audited financial states of the COPD Foundation at www.copdfoundation.org.*
Thank You, COPD Foundation Supporters

Your support in 2021 was instrumental in helping us achieve our mission-critical activities.

The COPD Foundation appreciates the support of donors and corporate sponsors who seek to improve the lives of those affected by COPD, bronchiectasis, and NTM lung disease. We welcome engagement with the Foundation at various levels to enhance shared goals across research, advocacy, care delivery, and community development.

To join our corporate partners’ program, potential sponsors demonstrate a commitment to the patient/caregiver community and the Foundation’s mission, principles, public positions, policies, and standards.

As we continue to evolve and expand our partnerships in 2022, we remain committed to patient-centricity in all aspects of our industry partnerships.

If you are interested in learning more about the COPD Foundation Corporate Partner Program, please visit us online.

Or visit us online to learn more about giving/support opportunities with the Foundation.
Friendraising and Fundraising with Our Circle of Friends

The COPD Foundation’s Circle of Friends is an extraordinary family of generous supporters who propel the Foundation’s lung health mission forward. Each contribution made to the Foundation makes a difference in the lives of patients and caregivers and helps to power our research, education, community support, and advocacy initiatives. The Foundation is grateful for the trust and confidence that donors place in us to effect meaningful change for millions of people globally. We do this work with donors by our side.

In 2021, the Circle of Friends embraced the Foundation’s highly successful COPD awareness campaign, Lace-Up for Lungs, highlighting the need for better breathing and lung health; exercise and activity; and quality of life and caring for those impacted by COPD. Lace-Up for Lungs also tied together two fundamental goals in the friendraising/fundraising program at the Foundation.

The first was to engage people to learn about our mission and purpose. The second goal was to invite our lung health community of people with COPD, family members, health care providers, donors, partners, and the community at large to participate and Lace-Up for Lungs.

The Foundation reached more than 400,000 people between World Lung Day in late September and COPD Awareness Month in November with messages of education, advocacy, and hope.
Lace-Up for Lungs also activated many to give back to the community as generous donors launched the 2021 Lace-Up for Lung Challenge Match, an annual end-of-year giving event, which inspired the community to join in the spirit of collective giving on behalf of the Foundation’s work.

We were honored to host the virtual Lace-Up for Lungs and Circle of Friends celebration of our shared commitment to pursuing innovation, raising awareness, and amplifying patient voices around respiratory wellness. We look forward to embracing Lace-Up for Lung awareness and invite you to join us on behalf of World Bronchiectasis Day on July 1, 2022.

“I chose to be a major part of Lace-Up for Lungs because I am honored to be the COPD Foundation’s California captain. As a strong, caring advocate for our illness, I get to represent every person living in California and hopefully help anyone in any state live life with COPD.”

- Jimmy Slover, COPD Advocate and Patient

“As a caregiver for my husband with COPD, I believe advocating for COPD is a powerful avenue toward research and development of new treatments, technology, and equipment.”

- Debi Kealing, COPD Advocate and Caregiver

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- Jimmy Slover, COPD Advocate and Patient

“As a caregiver for my husband with COPD, I believe advocating for COPD is a powerful avenue toward research and development of new treatments, technology, and equipment.”

- Debi Kealing, COPD Advocate and Caregiver

“My father, Bob Harris, was a visionary and champion for good health and a tireless advocate for COPD—chronic obstructive pulmonary disease—and the millions of patients and caregivers it impacts every day. Through our family foundation, he contributed generously in hopes of expanding awareness of COPD as the fourth leading cause of death in this country—ahead of Alzheimer’s, stroke, or diabetes—even though it’s 176th when it comes to federal funding.

My father passed away last July. But, integral to his legacy, our family continued my father’s commitment to the COPD Foundation and provided a gift in his memory to the 2021 COPD Foundation Lace-Up for Lungs Challenge Match, a collective giving effort by a group of dedicated donors to invite others to raise awareness and to join in the COPD Foundation’s efforts around research, education, and advocacy—all of which meant a great deal to my father. Please join our family as we honor my father in making a difference.”

- Susan Harris, COPD Foundation Development Committee Member and Advocate
Thank You

2021 Corporate Partners

Tier 4
AstraZeneca Pharmaceuticals
Boehringer Ingelheim
GlaxoSmithKline
Grifols
Pfizer Pharmaceuticals
Philips

Tier 3
Insmed Incorporated
Midmark Corporation
Takeda Pharmaceutical Company
Theravance Biopharmaceuticals
Viatris Pharmaceuticals

Tier 2
Regeneron Pharmaceuticals
Sanofi Genzyme
Verona Pharmaceuticals

Tier 1
Belluscura
Electromed
4D Medical
Hillrom
Ndd Medical Technologies
Olympus Corporation
Omr
Polarean
Pulmonx
Respira Labs
Vitalograph

In addition, the COPD Foundation is grateful for the generous participation by supporters in furthering our philanthropic efforts through a variety of ways, including awareness campaigns, membership drives, workplace giving, and peer-to-peer team events.

Medical and Scientific Advisory Committee Members

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Gerard Turino, MD
George Washko, MD
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CO-CHAIR, CA

Linda Walsh, BS, TTS  
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