Celebrating 20 Years of Championing Lung Health



### 20 Years of Lung Health... and Counting

Welcome to the celebration of the COPD Foundation's 20th anniversary. We are grateful to our founders, to our current and former Board of Directors, to our collaborators and colleagues, and most of all, to the patients, caregivers and lung health champions who are the reason we are celebrating this milestone today.

We have made significant strides over the last 20 years. When the Foundation was started those many years ago, fueled by the passion of founder John W. Walsh and the support of Dr. Byron Thomashow, Dr. David Mannino, Dr. Gerard Turino and Dr. James Crapo, they faced a world where half of primary care physicians were unaware of COPD guidelines and most primary care physicians and pulmonologists believed COPD was self-inflicted.



"The COPD Foundation will lead the charge in improving lives, advancing care and ultimately finding a cure."

In 2004, National Institutes of Health funding for COPD research was \$66 million, and insurance complications restricted access to therapies. Our founders realized that not only was addressing COPD important, but it was also being neglected.

Born out of this vision, the Foundation's primary goal was an increased research agenda. But we didn't stop there. Soon, the Foundation emphasized the need for the patient voice to drive everything from increased awareness, advocacy and research to educational materials and resources.

We have come a long way in 20 years. We've amplified the voices of people with COPD, bronchiectasis and NTM lung disease, as well as their family, friends and caregivers. We've launched national awareness campaigns and contributed to an increased national research agenda. We've provided education and resources that improve the lives of patients. We've put patients' voices in front of legislators on Capitol Hill and created a robust, interactive online community.

But our work is far from over. The path ahead is clear — we will continue to raise awareness, drive groundbreaking research and advocate for the millions of people who are affected by COPD, bronchiectasis and NTM lung disease. With the dedication of our community, the COPD Foundation will lead the charge in improving lives, advancing care and ultimately finding a cure. The next chapter begins now, and we are ready to keep pushing forward—stronger, more determined and more united than ever before.

Jean Wright MD MRA

Jean Wright, M.D., MBA CEO, COPD Foundation



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People with COPD may also be at risk for other lung diseases

While COPD, bronchiectasis and NTM lung disease share symptoms like chronic cough, shortness of breath, and frequent lung infections, bronchiectasis and NTM lung disease have their own unique signs to watch for.

### Be on the lookout for:

- Mucus that can be thick, sticky and/or harder to clear than usual.
- Coughing up blood, even small amounts.
- Frequent and/or severe chest infections that seem worse than typical COPD flare-ups.
- Unexplained fatigue and weight loss.
- Fever or night sweats, which may signal an infection.

If you have COPD and notice any of these symptoms, talk to your health care provider to get an accurate diagnosis and the best treatment for your lungs.



If You Breathe, You Should Know About COPD

copdfoundation.org

### Foundation's Founders Turn Passion into Legacy

The COPD Foundation was founded in 2004 by the late John W. Walsh, a passionate patient advocate, with the support of several nationally renowned physicians including Byron Thomashow, M.D.; David Mannino, M.D.; Gerard Turino, M.D.; and James Crapo, M.D.

Walsh had a vision to create a patient-focused organization with a mission to move COPD forward through improving research and providing a way for patients to interact with researchers, health care professionals and decision makers.

"Our mission started with and remains focused on the patients," said Thomashow. "Everything we have done during the past 20 years has been with the patients at the forefront. By working together and 'keeping the faith' as John said many times, we will continue to move COPD forward to achieve our goal of finding a cure."

Walsh's leadership and vision led the Foundation to engage in research to better understand COPD, educate patients, caregivers and providers on improving care delivery and quality of life, and empower the entire COPD community.

Walsh, who was diagnosed with alpha-1 antitrypsin deficiency (a genetic form of COPD), commonly referred to himself as an "impatient patient." He used that passion and perseverance to encourage the Foundation to pursue a wide range of programs to further the Foundation's mission.

Walsh was instrumental in establishing the advocacy program and Congressional COPD Caucus, the Biomarkers Qualification Consortium, the COPDGene® study, the Patient-Powered Research Network, the Bronchiectasis and NTM Research Registry, and the *Journal of the COPD Foundation*. Walsh was also the vision behind COPD360, resulting in the creation of COPD360social, BronchandNTM360social and PRAXIS resources for health care professionals.

The Foundation continues to honor John W. Walsh's legacy and the vision of the co-founders as it works to improve the quality of life of those with chronic lung disease and, ultimately, find a cure for COPD, bronchiectasis and NTM lung disease.



"Everything we have done during the past 20 years has been with the patients at the forefront."

### **Celebrating the Power of Your Philanthropy**

Dear Friends,

As we reflect upon the last 20 years of the COPD Foundation, we could not imagine being where we are today without all of you by our side. You are our generous donors and our community volunteers, who are dedicated and committed to our mission to find a cure.

We thank you for sharing your time, your talent and your expertise with the COPD Foundation. Your involvement continues to enable us to make critical advances in our advocacy and policy efforts, to build our patient-centered programs, and to bring your voice to the table in vital research discussions.

You have a generous spirit. Your gifts are meaningful. You inspire community giving. You are caring. You are passionate. You are supportive. You see the big picture. You are a champion for those living with chronic lung disease. You are our devoted allies in finding a cure – and for that we are forever grateful. YOU are amazing!

We thank you, and we Celebrate the Power of Your Philanthropy.

COPD Foundation Board of Directors and COPD Foundation Team



### **Board of Directors Dedicated to a Healthier Tomorrow**

The COPD Foundation's Board of Directors is integral to our mission of ultimately finding a cure for COPD, bronchiectasis and NTM lung disease. These researchers, physicians, health care activists, business leaders and patient advocates help the Foundation advance our goal of improving the quality of life of those impacted by chronic lung diseases. We are grateful for their dedication and service.

F	PRESENT BOARD OF DIRECTORS	YEARS SERVED
J	ames D. Crapo, M.D., <i>Chair</i>	2007-Present
F	Richard Casaburi, M.D., Ph.D.	2015-Present
١	alerie Chang, J.D., <i>Vice-chair</i>	2021-Present
S	tew Cogan, Esq., Secretary	2010-Present
F	hyliss DiLorenzo, B.A.	2024-Present
Ν	Nark Dransfield, M.D.	2022-Present
L	eonard Fromer, M.D.	2016-Present
	Donald Gray	2006-Present
Ν	Лeilan K. Han, M.D., M.S.	2021-Present
J	im Harris	2023-Present
Ν	Nark Metersky, M.D., FCCP	2023-Present
٧	Villiam Pilkington, DPA, MPA, M.A.	2023-Present
	Cindy Praeger	2023-Present
N	Лike Rogers	2022-Present
J	ean Rommes, M.A., M.S., Ph.D.	2024-Present
F	lisa Stack, Ph.D.	2021-Present
E	Byron M. Thomashow, M.D., Co-founder	2004-Present
J	ohn Torrence	2024-Present
٧	Vayne E. "Chip" Withers, <i>Treasurer</i>	2004-Present
H	lerbert Yardley	2019-Present

### **EMERITUS BOARD MEMBERS**

Grace Anne Dorney Koppel, Esq., M.A., J.D., *Emeritus* Gerard Turino, M.D., *Emeritus, Co-founder* Robert Wise, M.D., *Emeritus* 

PAST BOARD MEMBERS	YEARS SERVED
Pamela Bird, Ph.D.	2010-2015
Peter Burgess	2013-2014
Gordon Cadwgan, Ph.D.	2008-2011
Bartolome R. Celli, M.D.	2004-2008
Corinne Costa Davis, MBA	2017-2018
Russell Gantt	2018-2021
Chip Gatchell	2004-2012
Sam Giordano, MBA, RRT	2008-2019
Suzanne S. Hurd, Ph.D.	2004-2008
Mel Kaufman	2019
David Mannino, M.D.,	2004-2015
Current COPDF Chief Medical Offi	cer
Michael Mayer	2011-2022

#### **YEARS SERVED**

2012-2019, Emeritus 2022-Present 2004-2022, Emeritus 2022-Present 2015-2022, Emeritus 2022-Present

PAST BOARD MEMBERS	YEARS SERVED
Bill Mayne	2016-2019
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Alvin Thomas, Jr., M.D., FACP, FCCP	2008-2015
Kathy Toner, Esq.	2015-2017
John W. Walsh, <i>Co-founder</i>	2004-2017
Jean Wright, M.D, MBA, Current COPDF	CEO 2016-2022

### **Driving Change: The Road to a Cure**

Exposure to diesel and car exhaust – and the resulting dust and fumes – is a significant risk factor for developing COPD. Race car and diesel rig drivers are using their platforms to raise awareness and to reach some of those most susceptible to developing respiratory disease.

From embellishing trucks and race cars with awareness logos to screening fans at NASCAR® and hot rod drag racing events, these dedicated advocates and initiatives are determined to find the missing millions through screening, education and public awareness.

### DRIVE4COPD -

DRIVE4COPD was the largest national public awareness campaign ever created to raise awareness of COPD. First launched in 2010, the initiative's goal was to raise awareness of COPD, use risk screening to help people get diagnosed earlier, help people access care and services, and help people with COPD lead full lives.

As the official health initiative of NASCAR®, the campaign hosted four "pit stops" where people could get screened for COPD. It encouraged people to determine their risk of developing COPD by educating them about the signs and symptoms of COPD.

Through the partnership with NASCAR, DRIVE4COPD reached more than 75 million fans through at-track events and races, as well as online. The effort screened more than 2.7 million people.

Celebrities who all had close family members impacted by COPD also joined the campaign, including race car driver Danica Patrick, Emmy-nominated actor Jim Belushi, Grammy Award-winning country singer Patty Loveless, Olympian Caitlyn Jenner (formerly known as Bruce), and former NFL star Michael Strahan.

NASCAR® is a registered trademark of the National Association for Stock Car Racing, Inc.



### Right2Breathe

Established from the momentum created by the DRIVE4COPD campaign, Right2Breathe is a grassroots effort, focusing on providing education, awareness, resources and free screenings for people currently diagnosed with or at risk of developing respiratory disease.

The organization was created by second-generation drag racers Joe Morrison and Tim Charlet in 2014. Both Morrison and Charlet have served as caregivers for family members with respiratory disease. Morrison, whose father had severe COPD, is also a COPD Foundation Captain for New Jersey.

Right2Breathe sets up near the pit area at professional race events, reaching fans when they come down to meet the drivers and see the cars. This allows them to provide information and screening to a diverse population, who is at high risk of developing COPD.



Right2Breathe CEO Joe Morrison dedicates his time to getting people screened for lung disease.

"Being a volunteer for DRIVE4COPD revealed how massive the mission to find the missing millions of undiagnosed people living with COPD is in this country. I felt inspired both by my dad's journey with COPD and COPD Foundation founder John W. Walsh to use my platform as a race car driver and COPD Captain to focus on early detection," said Morrison, CEO of Right2Breathe. "My dad's passion for racing helped him overcome the challenges of living with COPD, and I believe that others can use their passions in life to help them have the best possible health outcomes. I have made it my personal mission to make sure that everyone who is at risk can get screened and that people who are already diagnosed can be empowered to live their best lives."

The organization estimates it has screened more than 14,000 people at automotive and sporting events and other public venues across the United States.

### **Tom the Truck Driver**

Tom Manges, a semi-truck driver from Pennsylvania, is using his rig and time on the road to raise awareness of COPD.

His wife, Renee, was diagnosed with COPD 10 years ago and recently received a double lung transplant. Manges has seen how COPD has affected Renee as she progressed from only needing oxygen at night to needing it during the day and struggling to walk any distance.

Manges, who has driven a semi for 30 years, saw others use their rigs to raise awareness for causes like breast cancer and autism. When his current company allowed him to choose colors for his truck, he knew he wanted to use it for COPD awareness.

"I wanted to do it for COPD awareness for my wife," Manges said. "I don't want to see anyone going through what my wife has been going through."

Manges gets lots of attention as he drives across the county as people stop to take pictures of his truck. He uses those interactions to educate them about COPD.

"I let people take as many pictures as they want," he said. "I have a case of pamphlets with facts about COPD, and I give them one. I believe that through raising more awareness we could definitely save lives."





Tom Manges uses his semi-truck to raise awareness of COPD.

### **Maddox Rowley**

Teen race car driver Maddox Rowley uses his weekly races at Hawkeye Downs Speedway in Cedar Rapids, Iowa, to raise awareness of COPD.



Rowley had a close family friend who had COPD and later passed away. After seeing others' cars representing various organizations and nonprofits, he decided to use his racing platform to bring attention to COPD.

"I knew that if I was going to advocate for something, I wanted it to be connected to me," Rowley said. "I had a memorial for my friend on my car for a while, and then I decided I wanted to take it one step further this year and make it bigger by putting the COPD Foundation logo on my car to help spread awareness."

Rowley sees the opportunity he has to educate people about COPD and the importance of using his personal experience to connect to a larger cause.

"I hope to raise awareness and let people know that COPD is an issue that many are dealing with," he said. "If someone out there is struggling with COPD, we should be doing our best to support them and advance research. I'm looking forward to continuing to pursue racing and using my platform to spread the word."



### **Judge Charles Ramos**

Judge Charles Ramos, a retired Justice of the New York State Supreme Court, had an illustrious law career, serving for more than 30 years. And a bit of a unique hobby for a jurist – he's also a former race car driver.

Ramos raced a vintage 1995 Ford Mustang Cobra "R" in the Sports Car Club of America's (SCCA) amateur division from 2005 until 2023. Worried that his "day job" as a jurist would cause concern with other drivers, Ramos petitioned the SCCA to let him race using his mother's maiden name. That waiver was granted, and Ramos raced as Chuck Fernandez, just another "nobody special," he said.

A crash in 2023 ended the car's ability to race. That same year, Ramos started work on restoring it. Fifteen months in, working nights and weekends, it's still a work in progress.

"This car has an incredible racing history," Ramos said. "It was donated to its original owner by the Ford Motor Company on the condition it was converted to race in SCCA's World Challenge professional racing series, where it raced until it was no longer competitive as newer models were faster. When I raced it in amateur competition for more than 15 years, it finished in the top three in its class in more than 90% of its races."

The car also raced with the DRIVE4COPD decal. And it's Ramos' goal to duplicate that decal once the project is finished.

"Now that I've stopped racing, I want to do something positive with the car," Ramos said. "My plan is to restore it and auction it off for the benefit of the COPD Foundation."

I have made it my personal mission to make sure that everyone who is at risk can get screened and that people who are already diagnosed can be empowered to live their best lives.



### **COPD Shuttle: Journey to the Center of the Lung**

Launched in 2010 at the American Thoracic Society's annual conference, the COPD Shuttle was an interactive simulation used to educate people about COPD and its risk factors. The 20-seat mobile motion simulator took passengers on a ride to the center of the lungs, while providing facts about COPD and demonstrating the effect pollutants have on a person's airways.

The Shuttle also made public appearances across the United States, including stops in Raleigh, North Carolina, at the USA Science and Engineering Festival and on Capitol Hill in Washington, D.C., at Citi Field in New York, and at Johns Hopkins University in Baltimore, Maryland, among other locations.



# Congratulations to the COPD Foundation on the 20<sup>th</sup> Anniversary! Sanofi and Regeneron are proud to support the COPD Community.

Regeneron and Sanofi collaborate to help people with conditions that are often difficult to diagnose and treat, using innovative technology platforms. Regeneron is a leading biotechnology company that invents, develops and commercializes life-transforming medicines. Sanofi, an innovative global healthcare company, provides potentially life-changing treatment options and life-saving vaccine protection worldwide.

sanofi *regeneron*°

# Caring Through Education: Designing Resources to Help Patients Thrive

The COPD Foundation serves as a central resource for people with chronic respiratory diseases, their families and loved ones, and the health care professionals dedicated to their care.

With an abundance of resources created by knowledgeable staff, including respiratory therapists and nurses, the Foundation connects the chronic lung disease community with reliable information to help people live their best life.

### **COPD Pocket Consultant Guide**

To help improve disease management and provide a simplified approach to COPD care, the Foundation created the COPD Pocket Consultant Guide (PCG).

First developed in 2007 as a printed trifold card, the PCG provided health care professionals with an algorithm for COPD management based on seven severity domains, including spirometry, symptoms, exacerbations and more. The trifold card was distributed to more than 800,000 health care professionals.

To help prevent printed materials from becoming out of date and to increase the PCG's usability, the Foundation added a mobile app in 2017, which features tracks for both health care professionals and patients/caregivers.

The track for health care professionals includes a therapy flow chart, inhaler and nebulizer instruction videos, screeners, a pulmonary referral checklist, generic and brand name medication lists, and more. The patient/caregiver track features the My COPD Action Plan; inhaler, nebulizer and exercise videos; a wallet card for tracking medications and immunizations; COPD Digest blog posts; and more.

The app has more than 10,000 users in more than 175 countries and regions.



### Harmonicas for Health®

Harmonicas for Health (H4H), launched in 2016, is a program designed by respiratory therapists to mimic pursed lip breathing, which can help make breathing easier and lessen the stress of not being able to breathe well.



When people play the harmonica, they strengthen their breathing muscles, helping them pull air into and push air out of their lungs. When these muscles are strong, people can have a stronger cough and better control of their breathing. The program is also a good way for people to connect with others with COPD. The Foundation hosts a monthly virtual H4H play-along group, and no musical experience is necessary. Health care professionals, breathing support group leaders or others interested in starting an H4H program can participate in sessions online or in person. Materials are available in English and Spanish.

### **CIRCLES and MORE**

It is estimated that more than 2 million people with COPD live in rural and remote areas of the United States. COPD rates are significantly higher in rural areas compared to metropolitan areas.

In 2020, with the support of the National Heart, Lung, and Blood Institute's Learn More Breathe Better® campaign, the Foundation created the CIRCLES: Clinicians Improving the Rural COPD Landscape through Education in Self-care Goals project.

The goal of the CIRCLES project was to improve communication between rural patients and health care providers, in addition to promoting use of the PCG app, educational videos and the My COPD Action Plan to assist in self-managing their COPD.

The first phase of CIRCLES piloted those materials in two rural primary care clinics in partnership with the Rural Medical Education Collaborative. Phase two, supported by AstraZeneca and completed in 2022, focused on additional low-tech materials for those who may not have access to Wi-Fi or smartphone technology and included locations in 13 U.S. states.

The CIRCLES II program was redesigned again in 2023 based on feedback from patients and clinicians. Named "MORE" (Maximizing Outreach in Rural Environments), the program expanded its reach to 37 sites across 26 states. The MORE program served 2,000 patients in rural facilities such as pulmonary rehabs, physician offices, VA medical centers, critical access hospitals, an Indian (Creek Nation) Department of Public Health and a hospital-based palliative care program. The program offered free, high-quality educational materials to improve COPD self-management and to encourage and facilitate effective communication between patients and their health care team.

### **Educational Materials & Resources**

The Foundation's Education team provides an expansive library of educational materials and resources for patients, caregivers and health care providers.

Educational materials for patients include the Guides for Better Living series, The Basics of COPD, My COPD Action Plan, Impact of Smoking, immunization flyers and a medication and immunization wallet card. Many of these resources have been translated into multiple languages. In addition, the COPD Foundation website features information on breathing techniques, exacerbations, nutrition, exercise and more.

Bronchiectasis and NTM 360 offers a robust educational library of downloads, videos and a podcast to help people learn more about living with bronchiectasis and NTM lung disease. Downloadable materials include the All About Bronchiectasis Booklet, a Quick Guide to Airway Clearance and an NTM Lung Disease Management Tool, plus additional resources.

The Foundation's 101 Library is designed for health care professionals to deliver up-to-date, evidence-based information on various aspects of COPD.

Other resources for both patients and health care professionals include the COPD Educational Video Series, e-learning courses and the COPD Foundation and Bronchiectasis and NTM 360 podcasts.





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### What Impact Has the COPD Found ation Had Over the Past 20 Years?

As the COPD Foundation celebrates our 20th anniversary, we are grateful for the support of countless individuals and organizations that have impacted our work and the COPD, bronchiectasis and NTM lung disease communities.



**John Torrence**COPD Foundation Board Member and Patient Ambassador, Nevada

"The COPD Foundation is the RESOURCE that I needed to get my health condition under control. It gave me focus ... and answers. It let me know this is a condition that I can live with and also that I can be a resource to other people who are going through the same thing I went through."



**Molly Lynch** SVP & Chief Communications Officer, VillageMD

"When VillageMD was looking for a partner to strengthen our patient education efforts, we were encouraged by the shared passion the COPD Foundation team members had for those managing COPD. The Foundation reaches patients and caregivers where they are. The best place to address COPD is in primary care, and our partnership is a critical step to ensuring better outcomes for patients with COPD."



**Goldia "Gigi" Brown**Foundation Captain, Georgia

"The COPD Foundation means ADVOCACY, quality of life, transformation, opportunity and community ... it empowers you. As a woman of color growing up in the rural south, we had nothing like the Foundation when my mother was diagnosed, and I know it would have changed her life. The consistency and effort the Foundation continues to put forth is amazing; I'm amazed and blessed to be a part of it."



**Amy Leitman**President, NTM Info & Research

"The COPD Foundation has done more to advance progress in the field of chronic obstructive pulmonary disease than any other organization. Our collaboration has created an impactful alliance dedicated to improving the lives of patients with NTM lung disease, bronchiectasis and COPD. We have been able to accelerate research, increase awareness and provide enhanced support, ultimately driving progress towards better treatment options and improving patient outcomes."



**Karen Deitemeyer**Foundation Captain, Florida

"The COPD Foundation means HOPE, especially for future generations. From the beginning, the Foundation was the only group that was focused on research, advocacy and patient involvement. I learned that I was not alone, and I learned that my voice mattered. That is what the Foundation is all about: we care. That spelled hope. Hope for the future, hope for now."



Liz Bodin
Vice President, U.S. Respiratory
& Immunology, AstraZeneca

"The COPD Foundation has made significant contributions to the COPD and lung disease community. They have been instrumental in raising awareness of COPD, advocating for better care and treatment options, and providing support and resources for patients and caregivers. Together, we can transform respiratory care for millions of people and improved outcomes for vulnerable patient communities."



**John Linnell**Foundation Captain, Wisconsin

"The COPD Foundation means HOPE. It gives me purpose because I enjoy being involved in helping others and being a patient voice. Paraphrasing John W. Walsh, 'If it's without us, it's not about us.' The COPD Foundation allows me the opportunity to make sure that everyone knows the patient perspective and the patient voice."



**Mary Kitlowski** President & Founder, Running On Air

"One of the reasons Running On Air partners with the COPD Foundation is because we might not exist if it hadn't been for the encouragement of John W. Walsh. We are working together to bridge the gap among diseases where there is overlap in comorbidities and treatments, like bronchiectasis and supplemental oxygen. All patients benefit when we work together."



**Emily Seeberger** Foundation Captain, Idaho

"I am excited that there is a group specifically focused on this disease process. Through the Foundation, we have more resources and voices to reach the masses. I hope that by gaining this resource and allies I can better serve my community – not only with people who have COPD but with others for prevention."



**Raleigh Guice**President, Clean Air Dynamics

"The COPD Foundation is the anchoring point of information and support for those impacted by COPD and associated respiratory challenges. The COPD Foundation does an amazing job of providing resources and access to information to make living with COPD better. Clean Air Dynamics partners with the Foundation to help people learn about improved indoor air quality and create access for them to the best air disinfection technology available."



**Melissa Egts** Inventor, O2 Fresh nasal cannula prong cover

"The COPD Foundation enables and empowers the patient voice by providing best in class patient information and outreach. O2 Fresh supports the Foundation because donations of time and treasure are likely to have a large impact in the patient community. The Foundation's support for O2 Fresh, like their many partnerships, increases their value and effectiveness, successfully meeting COPD patients' needs in all areas."



**Demeshia Montgomery** Foundation Captain, Ohio

"The COPD Foundation has changed my outlook on having a chronic disease. They encouraged me to learn about COPD and advocate for myself and others. The COPD Foundation has a community that inspires me to fight, while supporting my efforts with love!"



**Scott Santarella**CEO, Alpha-1 Foundation

"The COPD Foundation's encouragement of lung-effected patients to test for alpha-1 antitrypsin deficiency has been essential in helping identify patients who are often misdiagnosed. In addition, the Alpha-1 Foundation and the COPD Foundation share a unique connection, having both been founded by John W. Walsh, who had alpha-1. We are proud to have supported the Foundation to ensure John's vision that all patients diagnosed with COPD are also tested for alpha-1, expediting diagnosis and treatment of this chronic genetic form of COPD. Our shared commitment to patient care and well-being makes it easy to collaborate on initiatives that benefit our respective communities."



**Alex Oshmyansky, M.D., Ph.D.** CEO & Founder, Cost Plus Drugs

"Cost Plus Drugs and the COPD Foundation both have a mission to improve access to affordable medication. The Foundation has collaborated with Cost Plus Drugs to ensure that essential COPD medications are available at Cost Plus Drugs. This relationship reflects the COPD Foundation's commitment to advocating for the inclusion of a comprehensive range of COPD treatments at affordable prices, ultimately supporting the Foundation's broader mission to enhance the quality of life for those affected by COPD."



Yamo Deniz, M.D., FAAAAI

Vice President & Head, Immunology & Inflammation Global Medical Franchise, Regeneron

"As a company dedicated to following the science of type 2 inflammation and serious diseases, we support activities that advance R&D, protect sustainable access and improve health. We are honored to support the COPD Foundation because of its long-standing, reputable promise to improving lung health for patients with COPD and other respiratory diseases as proven by the Foundation's robust disease awareness education and research efforts."



**Brian Foard** Executive Vice President, Specialty Care, Sanofi

"Sanofi shares a vision with the COPD Foundation to utilize science in transforming the future for individuals living with COPD. We have appreciated the Foundation's sustained and creative efforts over their 20-year history in delivering meaningful programs that educate and raise awareness about COPD and other lung diseases. As the battle to diagnose and treat lung diseases continues, we know the COPD Foundation will lead the charge to make change, and we are honored to support their efforts."



**Alana Clemens-Saliba**Executive Director, Patient Advocacy
& Professional Engagement, Insmed

"The COPD Foundation has and will continue to have a profound impact on the bronchiectasis and NTM community across all aspects of care delivery, starting with the foresight to create a clinical research registry that significantly advanced scientific knowledge within the community. The Foundation has demonstrated their commitment to addressing unmet needs and gaps in care facing their patient constituents for two decades. They are a trusted source of information and consistently strive to advance meaningful innovation for people living with bronchiectasis and NTM. We couldn't be prouder to support the Foundation as they celebrate this incredible milestone and look forward to all they have in store for the future."



# COPD FOUNDATION. Advocacy to Action: 20 Years of Championing Lung Health



established by John W.

surgery approved

1st LAMA for COPD

Launch of the C.O.P.D.

NTM Research Registry

COPDF/NHLBI cospor COPD case-finding workshop—leads to





435-the Foundation's 1st state captain effort

**CDC COPD Prevention plan** 

Roflumilast approved

(CBQC)created--led to SGRQ qualification

1st COPD Readmissions

Pulmonary Diseases: Journa





Launch of the Harmonicas for Health

Launch of IMPACT Lung Health advocacy

for NTM testing



**SOURCE study approved** 

programs expanded to



Bronchiectasis & NTM

11111111

**Care Center Network** 







Support communities are important to providing places where people can seek emotional support and encouragement from those who are going through the same or similar experiences.

A passion to share the voices of those directly affected by chronic respiratory diseases has allowed the Foundation to foster a strong, vibrant community of patients, caregivers, families and friends, united by a singular goal of ensuring everyone is able to live their best life.

The Foundation's dynamic community outreach encompasses 360 social online communities, website resources, informative e-newsletters and an active social media presence.

#### 360social

The Foundation's 360social online communities – COPD360social and BronchandNTM360social – serve as interactive, online networks for people with COPD, bronchiectasis and NTM lung disease, as well as their families, caregivers and health care professionals.

Both COPD360social and BronchandNTM360social encourage people to connect virtually and get support and answers they might not have had access to otherwise. The communities enable people to come together to access information, peer support, ask questions, and gain insight and helpful tips on their journey with these chronic lung diseases.

"Support communities are important to providing places where people can seek emotional support and encouragement from those who are going through the same or similar experiences. It's a safe space to ask questions, share frustrations and celebrate accomplishments," said Bill Clark, COPD360social Community Manager and Vice President of Patient Experience. "In person groups can be difficult to find or a challenge for people to travel to. The highly interactive communities we have fostered in our 360social communities allow our members to seek that same support in a virtual setting."

### **COPD360 Community Engagement Committee**

The Foundation realizes the importance of patient and caregiver involvement in all aspects of the organization's mission. With this in mind, the Foundation established the COPD360 Community Engagement Committee (CEnCo) in 2020.

CEnCo is comprised of individuals impacted by lung disease, family members, caregivers and health care professionals. The committee's role is to provide input from the patient and caregiver community, advise on priorities important to patients and their families, and help the Foundation ensure the unique experiences of patients and their families remain at the forefront of the Foundation's work to educate, empower and improve the quality of life for all those affected by chronic lung diseases.

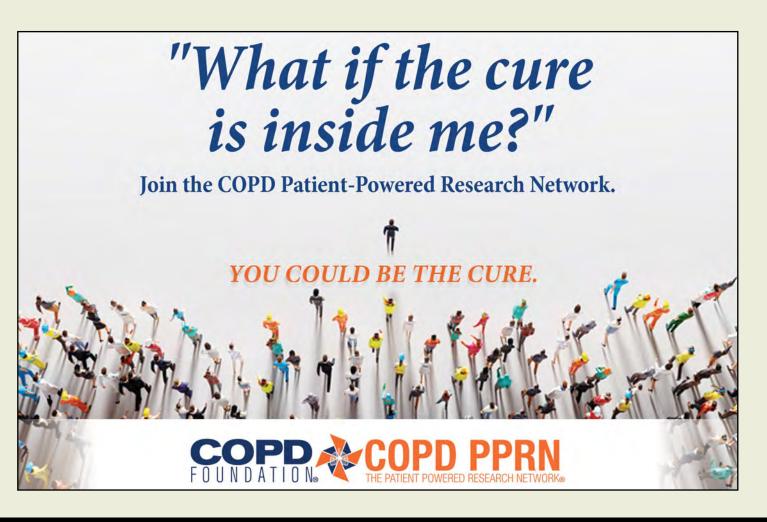
"Patient and care partner engagement is the key step to managing

COPD. The path for each patient differs, but education, awareness and
the necessary tools to navigate their journey are quite often the same,"
said Karen Erickson, Co-Chair of CEnCo. "The Community Engagement

Committee members are committed to diversity and aim to mirror that of
the COPD community itself. As part of the community, the committee is uniquely
equipped to take input from each stakeholder and to lean into patient priorities – the core of the COPD Foundation's
mission to help people live longer and healthier lives."

### By the Numbers

COPD360social – 60,000+ members
BronchandNTM360social – 4,000 members
Social Media – 125,000+ followers
Website Traffic – 4 million views per year
E-newsletters – 80,000+ subscribers
Media Outreach – 100 million+ reach monthly



# Advocacy in Action: Shaping Lung Health Care and Policy



Advocacy is at the core of the COPD Foundation's mission to help millions of people live longer and healthier lives by advancing research, advocacy, and awareness to stop COPD, bronchiectasis and NTM lung disease.

The Foundation doesn't simply advocate for better care—it pushes for public policy changes to enhance prevention, diagnosis, treatment and research for COPD, bronchiectasis and NTM lung disease. The Foundation is strongly committed to pushing for bold policy changes to improve access to care, health care delivery, quality of care, regulations of medication and medical devices, and public health.

The Foundation empowers those affected by these lung diseases to advocate for themselves and their loved ones. Whether it's sharing posts on social media, writing impactful letters to the editor, meeting with lawmakers or volunteering their time, community involvement in the Foundation's advocacy efforts is key to achieving the Foundation's mission.

### **Advocacy: Action Center** —

The Foundation consistently communicates with local, state and federal policy makers to protect access to treatments, improve care delivery, increase research funding and create policy to improve the lives of those with COPD, bronchiectasis and NTM lung disease.

The Advocacy: Action Center, launched in 2009, serves as a central place for people wanting to learn more about key public policy issues and to take action by emailing or calling elected officials.

The Action Center outlines the Foundation's current policy priorities and provides more detailed information on each priority. People interested in writing a letter or calling elected officials can use the sample letters provided in the Action Center.

I shared my personal lived experience of having a loved one with COPD to highlight the challenges faced by both individuals living with the disease and their families.

### **IMPACT Lung Health**

IMPACT Lung Health is an interactive, two-day workshop for patients, caregivers and health care professionals to train on advocacy and relationship building, culminating in networking opportunities and meetings with congressional offices.

IMPACT gives our community the opportunity to meet in person or virtually with their members of Congress. These meetings emphasize the importance of funding for COPD research, improved access to necessary treatments, public health education and other public policy priorities. Attendees spend time learning about the Foundation, clinical research, access to care challenges and how to effectively use storytelling in advocacy initiatives.

"I consider it a privilege to participate in IMPACT. Witnessing what advocacy looks like in action was a great learning experience. It stoked a fire in me," said Debbie Carter, a Foundation Captain from North Carolina. "I shared my personal lived experience of having a loved one with COPD to highlight the challenges faced by both individuals living with the disease and their families. This increased awareness can help legislators better understand the need for policy change and the importance of prioritizing COPD and other lung health diseases."

In 2019, the first group of more than 40 advocates visited Washington, D.C. for IMPACT, and it has grown from there. Since the first IMPACT event, more than 300 advocates for COPD, bronchiectasis and NTM lung disease have participated to help raise awareness, culminating in more than 500 meetings with members of Congress.



### **Captains Program**

Created in 2010, the Foundation's Captains Program is an international network of more than 100 patients, caregivers, loved ones and health care professionals. Captains work to spread awareness of COPD, bronchiectasis and NTM lung disease, participate in grassroots advocacy, community outreach and educational activities.

"I love being a Captain and the camaraderie not only with others with COPD, but also with Foundation staff and others," said Lisa Hall, a Foundation Captain from Minnesota. "I can help remotely, and I try to get others involved as well."

Foundation Captains can participate as much as they are able or want to and in varying ways that fit their time, skill set and interest.

"Our Captains are an integral part of our advocacy and outreach efforts," said Linda Walsh, Chief Mission Officer of the COPD Foundation. "We are grateful to them for sharing their stories of lived experience to raise awareness of COPD, inspire others and influence policymakers. We couldn't do what we do without their dedication and commitment."



### **COPDF Helps Pass Significant Legislation**

Here's a sampling of some of the Foundation's significant legislative accomplishments.

### 2024

- Priority language from IMPACT 2023 included in FY24 Appropriations package budget report.
- Priority language from IMPACT 2024 included in both House and Senate's preliminary FY25 budget report drafts.
- Priority supplemental oxygen access reform legislation introduced in both chambers with bipartisan support as S. 3821/H.R. 7829.
- \$500M increase in funding for lung health research since the onset of IMPACT Lung Health in 2019.
- Operation 435 successfully identifies a lung health advocate in all 435 Congressional districts in the United States.

### 2023

- Increased funding for lung health research.
- \$6M in funding for CDC Chronic Disease Education and Awareness program.

### 2020

 Continuation of suspension for supplemental oxygen from the CMS competitive bidding program.

### 2017

• The COPD National Action Plan is published by the National Heart, Lung, and Blood Institute as a result of years-long advocacy from the Foundation's Captains program and the Congressional COPD Caucus.

#### 2016

• The Air Carrier Access Act is amended to require airlines to allow passengers to bring approved oxygen concentrators on board.

### 2011

 A grassroots advocacy campaign resulted in the inclusion of a question about COPD in the Behavioral Risk Factor Surveillance System by the CDC, gathering critical data about the prevalence and impact of COPD in the United States.

- Successful advocacy for Medicare coverage of pulmonary rehabilitation as a Part B benefit.
- Successful advocacy for the establishment of the Patient-Centered Outcomes Research Institute.



# Shaping the Future: Addressing the Gaps in Bronchiectasis and NTM Lung Disease Care

Seeing a need to better serve the bronchiectasis and NTM lung disease communities, the COPD Foundation launched Bronchiectasis and NTM 360, an innovative initiative that has evolved significantly since its beginnings as the Bronchiectasis Research Consortium in 2007.

Originally created to fill gaps in collaborative research for non-cystic fibrosis bronchiectasis, the Consortium formed the Bronchiectasis Research Registry, which was later expanded to include NTM lung disease.

Through the establishment of additional programs and outreach efforts, including BronchandNTM360social, the Bronchiectasis and NTM Information Line, the Ambassador Program and the new Bronchiectasis and NTM Care Center Network, Bronchiectasis and NTM 360 is dedicated to increasing disease awareness, fostering community engagement, and advancing research, advocacy and education to propel forward the development of therapeutics for bronchiectasis and NTM.



#### **Care Center Network**

The Bronchiectasis and NTM Care Center Network (CCN) is the newest program from Bronchiectasis and NTM 360. The CCN's mission is to establish a network of centers across the country, with the goals of reducing the time to diagnosis and supporting high-quality care for those with bronchiectasis and NTM lung disease.

CCN members, which will include both large health care centers and smaller pulmonary and infectious disease clinics, have increased visibility, are nationally recognized as experts in the field, and have access to additional educational materials and patient resources.

"As the prevalence of bronchiectasis and NTM lung disease grows, it is even more important for us to create this Care Center Network to help care for individuals with these diseases and provide them with the specialty care and resources they deserve," said Doreen Addrizzo-Harris, M.D., Chair of the CCN Steering Committee. "The CCN's innovative, nationwide network will help us achieve our goals of improving care and quality of life for those with these conditions, as well as advancing toward a cure."

The CCN's goal is to have 150 designated care centers and clinical associate centers in the first three years of the program.

## Have you heard about the Bronchiectasis and NTM Care Center Network?

The CCN nation-wide network of centers will strive to:

- Reduce the time to diagnosis
- Provide high-quality bronchiectasis and NTM lung disease care
- Offer patient-centered resources, education and support
- Increase disease awareness
- Support research and clinical trials

Learn more: copdf.co/Bronch-NTM-CCN



### **Bronchiectasis and NTM Research Registry**

In 2007, a collaborative workshop among the COPD Foundation, the National Heart, Lung and Blood Institute, and key opinion leaders discussed the need to support collaborative research and clinical trials for the treatment of non-cystic fibrosis (non-CF) bronchiectasis.

The Bronchiectasis Research Consortium and Bronchiectasis Research Registry were established as a result of that workshop. The Registry is a platform for data collection that can be used in research to better understand non-CF bronchiectasis.

Since there is a link between bronchiectasis and NTM lung disease, the COPD Foundation partnered with NTM Info & Research in 2011 to expand the Registry to include NTM data and renamed it the Bronchiectasis and NTM Research Registry.

"The Bronchiectasis and NTM Research Registry is 'the' resource for bronchiectasis research in the United States. With more than 17 years of extensive data and nearly 7,000 subjects enrolled, it provides a comprehensive look at a large geographic area of bronchiectasis patients. In addition, the Registry provides a way for people with bronchiectasis and NTM lung diseases to participate in research studies and clinical



trials," said Pamela J. McShane, M.D., Chair of the Bronchiectasis and NTM Research Registry Consortium. "The Registry is an excellent resource for the development of therapeutics and additional treatments for bronchiectasis and NTM."

Now the Registry, led by the Consortium of physicians and researchers from 24 academic and medical centers from across the United States, has more than 6,800 individuals enrolled and up to 15 years of longitudinal follow-up on some participants.



### **Ambassador Program and Information line**

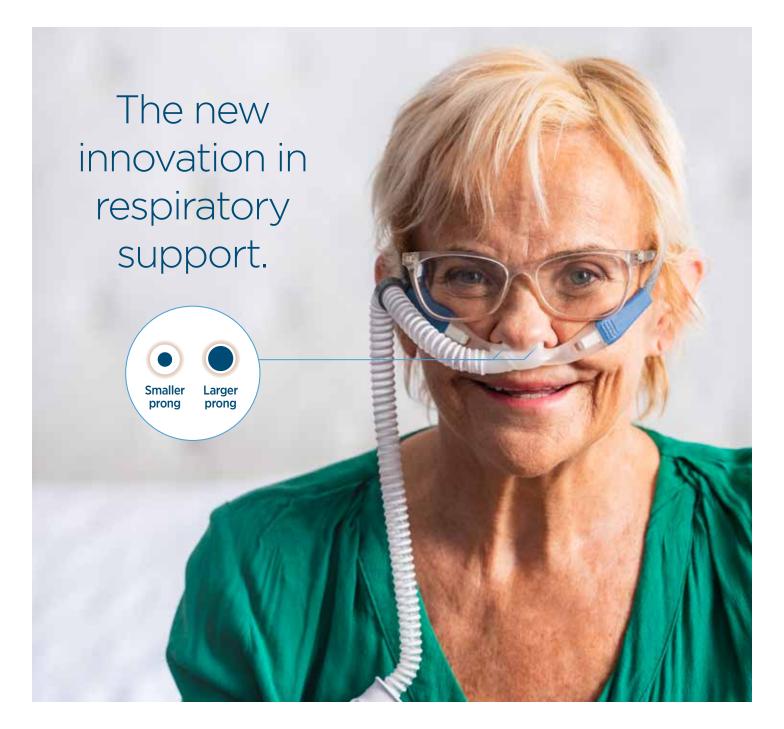
Community outreach, education and support is a large part of Bronchiectasis and NTM 360's mission. The Bronchiectasis and NTM Ambassador program and Information Line are just two of those outreach efforts.

Bronchiectasis and NTM Ambassadors help reach the community through engagement and by sharing educational materials and resources. Started in 2019, Ambassadors provide information and referrals for assistance (without giving medical advice), help people advocate for themselves and their family members, provide information on research studies and serve as support for patients and their families.

The Bronchiectasis and NTM Information Line, opened in 2017, is another way people with these conditions can reach out for more information, resources and support. The line is a toll-free number where people can seek peer-to-peer information and one-on-one support from trained staff in either English or Spanish.



Optiflow+ Duet Asymmetric Humidified High Flow Therapy



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### Introducing Ohtuvayre™: A new, FDA-approved maintenance treatment for COPD in adults

### Ohtuvayre is a first of its kind medication that offers:



### **Better breathing**

In clinical trials, patients using Ohtuvayre experienced significant improvements in lung function.\*



### Nebulized treatment

Taken in two 5- to 7-minute treatments a day, once in the morning and once at night.



#### A steroid-free approach

Ohtuvayre offers a unique, steroid-free approach to COPD maintenance treatment in adults.

\*In two, 6-month studies of over 1500 patients with COPD. COPD = chronic obstructive pulmonary disease.

Ohtuvayre works on its own or with other treatments.



Ask your healthcare provider about adding Ohtuvayre to your current treatment plan. See how it works at Ohtuvayre.com.

### Not an actual patient.

#### **Indication and Important Safety Information**

### INDICATION

Ohtuvayre is a prescription medicine used to treat chronic obstructive pulmonary disease (COPD) in adults. COPD is a chronic (long-term) lung disease that includes chronic bronchitis, emphysema, or both.

#### **IMPORTANT SAFETY INFORMATION**

#### What is the most important information I should know about Ohtuvayre?

Ohtuvayre can cause serious side effects, including:

- Sudden breathing problems immediately after inhaling your medicine. If you have sudden breathing
  problems immediately after inhaling your medicine, stop using Ohtuvayre and call your healthcare provider
  right away or go to the nearest hospital emergency room right away.
- Mental health problems including suicidal thoughts and behavior. You may experience mood or behavior
  changes when taking Ohtuvayre. Call your healthcare provider right away if you have any of these
  symptoms, especially if they are new, worse, or worry you: thoughts of suicide or dying, attempt to commit
  suicide, trouble sleeping (insomnia), new or worse anxiety, new or worse depression, acting on dangerous
  impulses, and/or other unusual changes in your behavior or mood.

Do not use Ohtuvayre to treat sudden breathing problems. Always have a rescue inhaler with you.

#### Who Should Not use Ohtuvayre?

Do not use Ohtuvayre if you have had an allergic reaction to ensifentrine or any of the ingredients in Ohtuvayre.

### What should I tell my healthcare provider before using Ohtuvayre?

Before you use Ohtuvayre, tell your healthcare professional if you have or have had a history of mental health problems including depression and suicidal behavior; have liver problems; are pregnant or plan to become

pregnant; are breastfeeding. It is not known if Ohtuvayre may harm your unborn baby. It is not known if the medicine in Ohtuvayre passes into your breast milk and if it can harm your baby.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

#### What are the most common side effects of Ohtuvayre?

The most common side effects of Ohtuvayre include back pain, high blood pressure, bladder infection and diarrhea.

These are not all the possible side effects of Ohtuvayre. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

This summary does not include all the information about Ohtuvayre and is not meant to take the place of a discussion with your healthcare provider about your treatment.

Please see additional Important Facts about Ohtuvayre on the following page. Full Prescribing Information is available at Ohtuvayre.com.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.



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### Important Facts about OHTUVAYRE (ensifentrine) What is OHTUVAYRE?

- OHTUVAYRE is a prescription medicine used to treat chronic obstructive pulmonary disease (COPD) in adults. COPD is a chronic (long-term) lung disease that includes chronic bronchitis, emphysema, or both.
- OHTUVAYRE is an inhibitor of phosphodiesterases 3 and 4 (PDE3 and PDE4).
- Decreasing PDE3 activity helps the muscles around the airways in your lungs stay relaxed to prevent symptoms such as wheezing, coughing, chest tightness, and shortness of breath, which can happen when muscles around the airway tighten, making it hard to breathe. Decreasing PDE4 activity helps to decrease inflammation in the lungs. Inflammation in the lungs can lead to breathing problems.
- OHTUVAYRE is used to improve symptoms of COPD for better breathing and to reduce the number of flare-ups (the worsening of your COPD symptoms for several days).
- OHTUVAYRE is used long-term as 1 ampule of OHTUVAYRE, 2 times each day (1 in the morning and 1 in the evening) inhaled through your nebulizer that is fitted with a mouthpiece.
- OHTUVAYRE is not used to relieve sudden breathing problems and will not replace an inhaled rescue medicine.
- OHTUVAYRE should not be used in children. It is not known if OHTUVAYRE is safe and effective in children.

#### When should I not take OHTUVAYRE?

Do not use OHTUVAYRE if you have had an allergic reaction to ensifentrine or any of the ingredients in OHTUVAYRE. **Active ingredient:** ensifentrine **Inactive ingredients:** dibasic sodium phosphate, monobasic sodium phosphate, polysorbate 20, sodium chloride, sorbitan monolaurate and water for injection.

### What should I tell my healthcare provider?

Before taking OHTUVAYRE, tell your healthcare provider about all your medical conditions, including if you:

- have or have had a history of mental health problems including depression and suicidal behavior.
- have liver problems.
- are pregnant or plan to become pregnant. It is not known if OHTUVAYRE may harm your unborn baby.
- are breastfeeding. It is not known if the medicine in OHTUVAYRE passes into your breast milk and if it can harm your baby.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

### What warnings should I know about OHTUVAYRE? OHTUVAYRE can cause serious side effects, including:

- Sudden breathing problems immediately after inhaling your medicine. If you have sudden breathing problems immediately after inhaling your medicine, stop using OHTUVAYRE and call your healthcare provider right away or go to the nearest hospital emergency room right away.
- Mental health problems including suicidal thoughts and behavior. You may experience mood or behavior changes when taking OHTUVAYRE. Call your healthcare provider right away if you have any of these symptoms, especially if they are new, worse, or worry you:
  - thoughts of suicide or dying
  - attempt to commit suicide
- trouble sleeping (insomnia)
- new or worse anxiety
- new or worse depression
- acting on dangerous impulses
- other unusual changes in your behavior or mood

### What are the side effects of OHTUVAYRE? Most common side effects of OHTUVAYRE include:

- back pain
- high blood pressure
- bladder infection
- diarrhea

These are not all the possible side effects of OHTUVAYRE. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

The risk information provided here is not comprehensive. To learn more, talk about OHTUVAYRE with your healthcare provider or pharmacist. The FDA-approved labeling can be found at www.Ohtuvayre.com or 1-888-672-0371.

Manufactured for: Verona Pharma, Inc. Raleigh, NC, 27615

### Verona Pharma®

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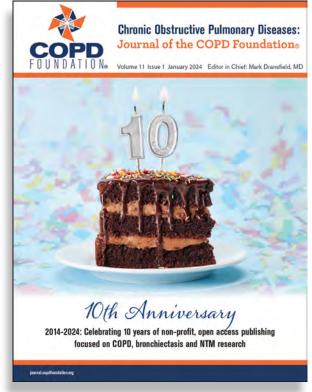
# Journal of the COPD Foundation Celebrates 10 Years of Open-access Publishing

This year marks a decade of publishing impactful COPD, bronchiectasis and NTM lung disease research in *Chronic Obstructive Pulmonary Diseases: Journal of the COPD Foundation (JCOPDF)*, the COPD Foundation's official peerreviewed, open-access journal.

Established from the vision of the late John W. Walsh, COPD Foundation co-founder, and James D. Crapo, M.D., *JCOPDF* is dedicated to publishing original research, reviews and other perspectives to further the understanding of chronic lung disease. Their determination to create an open-access journal ensured that innovative research is available to everyone, with the mission of turning discoveries into practical applications to improve care for chronic lung disease.

"An important goal of the *JCOPDF* is to give a strong voice to the clinical community attempting to manage this disease and to optimally foster interactions between this community and those doing the basic science to better define its pathogenesis and those who are focused on the development of new therapies," Dr. Crapo said in the first issue of *JCOPDF*.

Since its inaugural issue in 2014, the Journal has interacted with more than 3,000 researchers, accepted manuscripts from more than 30 countries, and had online articles accessed more than 23,000 times a month. The Journal is indexed by PubMed, PubMed Central, Web of Science's Science Citation Index Expanded and Scopus.



In 2024, the Journal marked its anniversary by expanding from publishing four issues a year to six. The Journal also has an active Editorial Board comprised of more than 50 global COPD, bronchiectasis and NTM lung disease experts, who serve as reviewers and advisors. In addition, a team of 9 dedicated associate editors volunteer considerable time to assist Editor-in-Chief Mark T. Dransfield, M.D., with the journal's rigorous peer review process.

"We are thankful for John's and James' vision in founding the Journal and for the continued support and expertise from numerous distinguished professionals over the past decade," said Dransfield. "We are excited to maintain our commitment to publishing top-tier research and providing valuable insights into chronic lung disease for many years to come."

### Some of the Key Research Published in Journal of the COPD Foundation

National and State Estimates of COPD Morbidity and Mortality — United States, 2014-2015

This report provided a summary of COPD-related morbidity and mortality in the United States, finding that the levels were severe with significant variability by state. (2018. Volume 5, Issue 4)

COPDGene® 2019: Redefining the Diagnosis of Chronic Obstructive Pulmonary Disease

This study published data from the COPD Genetic Epidemiology study (COPDGene) and proposed new criteria for diagnosing COPD. It proposed expanding diagnostic criteria from a single measure of lung function to include environmental exposure, symptoms and abnormal CT scans. Using the new criteria allows individuals to be diagnosed in an earlier stage of the disease, improving their quality of life, extending their life and providing researchers with more information about the earlier stages of the disease. (2019. Volume 6, Issue 5)

A Risk Prediction Model for Mortality Among Smokers in the COPDGene® Study

This study used data from COPDGene to examine the mortality risk of current and former smokers over a 10-year period. The authors developed a risk score model that can be used to identify individuals at higher risk who can be targeted for interventions/therapies to reduce their mortality risk. (2020. Volume 7, Issue 4)

Chronic Obstructive Pulmonary Diseases:

Journal of the COPD Foundations

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Editor in Chieft Mark Drandfield, MO

"A Plant-Centered Diet is Inversely Associated with Radiographic Emphysema: Findings from the CARDIA Lung Study" and "Association Between Dietary Fiber Intake and Prevalence of Chronic Obstructive Pulmonary Disease in a Middle-Aged and Elderty Population: A Study Based on the National Health and Nutrition Examination Survey Database"—in this issue.

Decrease in Exacerbations During the Coronavirus Disease 2019 Pandemic in a Cohort of Veterans with COPD

This study – one of many *JCOPDF* articles published about COVID and COPD – followed a group of veterans from 2017 to 2020 to track how often they experienced exacerbations prior to and during the COVID-19 pandemic. The study found there was a significant decrease in exacerbations during the pandemic. (2021. Volume 8, Issue 4)

Chronic Obstructive Pulmonary Disease and Lung Cancer: A Review for Clinicians

This review informs clinicians about the link between lung cancer and COPD, the epidemiology of the two diseases, when people with lung cancer should be screened for COPD and risk factors to consider. (2022. Volume 9, Issue 3)

A Plant-Centered Diet is Inversely Associated With Radiographic Emphysema: Findings from the CARDIA Lung Study

This study examined the connection between emphysema risk and diet in young smokers, concluding that those who consumed a nutritionally rich, plant-centered diet had a reduced risk of developing emphysema. (2024. Volume 11, Issue 2)



For nearly 90 years, Chiesi has been committed to being a force for good by helping to improve quality of life for patients, their families, their communities and society. Our commitment goes beyond delivering innovative medicines; we also support providers, patients and caregivers across the care continuum to help them achieve the best possible results. And we are determined to share our resources to support local communities and help them thrive.



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# Global Awareness Campaigns Promote Advocacy, Educate About Chronic Lung Diseases

The COPD Foundation is driven to expand and elevate awareness of COPD, bronchiectasis and NTM lung disease. That passion to shine a brighter light on chronic respiratory diseases has led the Foundation to spearhead several impactful, global awareness campaigns. These campaigns continue to grow with the support of dedicated partners, patients, their families and industry stakeholders.

#### **COPD Awareness Month**

In November, the COPD Foundation plans a month of activities to increase awareness of COPD. The COPD Foundation shares resources and education so people can learn about COPD, how to reduce their risk, and how to improve quality of life if already diagnosed. The campaign also emphasizes the importance of early diagnoses.

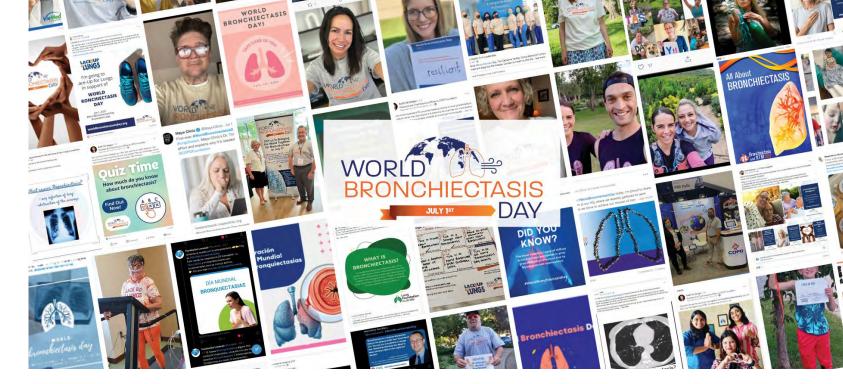
### Lace Up for Lungs -

The Lace Up for Lungs campaign was created in 2021 to highlight the importance of exercise and activity to help with better breathing and quality of life. People can join the Lace Up for Lungs Challenge (pledging to participate in 30 minutes of activity a day) and a dedicated Facebook group, create a DIY fundraiser, share the Foundation-provided toolkit with their connections and take part in advocacy efforts.









### **World Bronchiectasis Day**

Bronchiectasis and NTM 360, a division of the COPD Foundation, created World Bronchiectasis Day in 2022 by bringing together a coalition of international organizations dedicated to increasing awareness of bronchiectasis. Held annually each July 1, World Bronchiectasis Day is a collaboration of more than 20 global partners from patient advocacy organizations, professional societies and leading experts, all focused on raising awareness of bronchiectasis through sharing knowledge and discussing ways to reduce the burden of bronchiectasis for patients and their families.

Outreach efforts include an expansive, coordinated social media campaign and educational resources such as videos, webinars, toolkits and information sheets (available in multiple languages).

The global event has expanded its reach each year, reaching nearly 800,000 people in its inaugural year to more than 10 million people in 2024.

### World Oxygen Day –

The World Oxygen Day campaign celebrates everyone who benefits from oxygen therapy. Even though supplemental oxygen is important for millions of people with respiratory problems, many struggle to get the oxygen equipment they need.

World Oxygen Day, observed annually on October 2 ("O-2"), brings attention to challenges facing the oxygen therapy community, helps reduce the stigma of oxygen therapy use, and advocates for better access to appropriate oxygen equipment. By drawing attention to the importance of oxygen therapy, the campaign hopes to make oxygen therapy more acceptable, accessible and affordable.



In its inaugural year, World Oxygen Day outreach spanned more than 20 countries with a social media campaign, a "Let's Talk About Oxygen!" summit, an Oxygen Stories video series and bi-weekly email newsletters. The 2024 campaign focuses on strengthening international partnerships, including promoting webinars occurring around the world, a broader social media campaign and other global outreach efforts.

### The Movement

Marking the COPD Foundation's 20th anniversary, the Movement is a global campaign designed to create widespread awareness about what COPD is, who it affects, why they might be at risk and where they can find resources.

The campaign highlights COPD as an urgent public health crisis and emphasizes the need for early diagnosis and treatment and for increased collaboration within the health care system, starting with primary care.

A robust advertising campaign, including a billboard in Times Square, focuses on "If you breathe, you should know about COPD" and is supported by various facts about COPD. Facts highlight the millions of people that don't yet know they have COPD, that you can get COPD even if you never smoked and the risk of developing other diseases, including bronchiectasis and NTM lung disease.

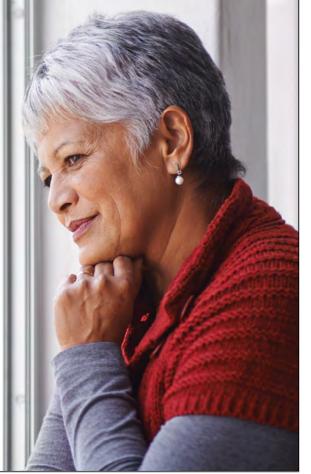


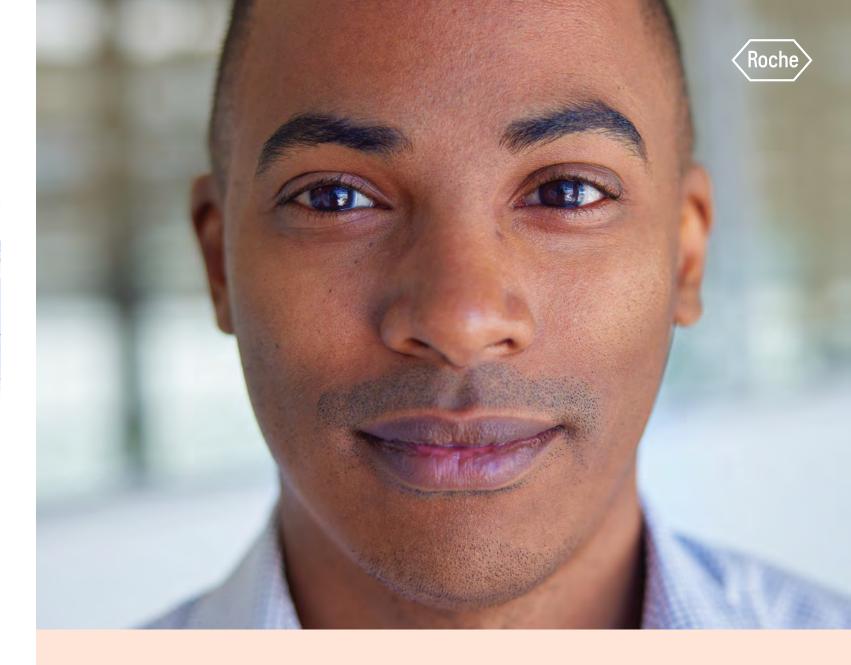


A patient-centric framework to determine meaningful outcomes and valid measures of treatment benefit for people with chronic lung disease.

Learn more: copdf.co/PIVOT







A healthier future. It's what drives us to innovate.

Continuously advancing science to ensure everyone has access to the healthcare they need today and for generations to come.

Creating a world where we all have more time with the people we love. That's what makes us Roche.

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From its inception, the Foundation has pursued ways to increase research efforts. Since 2004, the Foundation has partnered with leading health care professionals, researchers and patients to help shape the national research landscape for COPD, bronchiectasis and NTM lung disease, championing studies that put patients at the center of scientific discovery.

### COPD360

COPD360 is the Foundation's research framework and is used to align the goals of government, advocacy groups and industry partners. This framework puts patients and caregivers at the center of all stages of research

"The goal of the Foundation's research priorities is to ultimately find a cure for COPD," said Bruce Miller, Ph.D., Chief Scientific Officer of the COPD Foundation. "We will continue to involve a diverse group of stakeholders to support the implementation of digital health tools, medical devices and therapeutics that focus on early diagnosis, treatment and prevention of COPD, bronchiectasis and NTM lung disease."

COPD360 is designed to manage longitudinal research studies and clinical trials, surveys and focus groups and has a flexible, HIPAA-compliant infrastructure for all stages of research – from exploring the research question and study design to data analysis and results dissemination.

The framework also includes COPD360coach, a care management solution that uses peer-to-peer health coaches to communicate with participants.

> The goal of the Foundation's research priorities is to ultimately find a cure for COPD.

### Patient-Powered Research Network

Another way the Foundation is putting patients first in research is through the Patient-Powered Research Network (PPRN). Established in 2014, the PPRN is a patient registry of people with COPD or people who may be at risk of developing COPD and is overseen by a patient-led governing board.

"The best way to gain a deeper understanding of COPD is by talking to people living with it every day and caregivers who see the impact of COPD first-hand," said Richard Mularski, M.D., Senior Medical Director of the PPRN. "The PPRN serves as a valuable resource to connect researchers with people interested in participating in research to help make an impact on symptom management, disease treatment and, hopefully, a cure."

Participants agree to share their health information in a secure database for use in research, and PPRN enrollees are contacted for future, voluntary involvement in studies that are of interest to them.

The PPRN's goal is to become the largest network of patients impacted by COPD, and it currently has more than 8,000 consenting participants.



#### BRIDGE

The COPD PPRN BRIDGE (Bridging the Gap Between Patients/Caregivers and COPD Research) Project was designed to increase patient and caregiver voices in COPD research. Funded by the Patient-Centered Outcomes Research Institute, the BRIDGE project enlisted an advisory board of patients and caregivers, as well as representatives from advocacy organizations and federal agencies.

BRIDGE, which was active from 2019 to 2021, used input from the advisory board and the Foundation's COPD360social online community to establish priorities in current and future research. More than 3,000 responses helped guide new research priorities for the Foundation, including reverse/cure COPD; develop better drugs for managing symptoms; improve medical equipment access and reimbursement; improve mobility; and reduce anxiety, fear and depression.

In addition to shaping the Foundation's research priorities, the BRIDGE project also developed Patient to Investigator Training. This self-paced, online training educates people with COPD and caregivers on the research and drug development process so they can join research teams as patient investigators, providing their perspectives and voices to research opportunities.



### **COPD Biomarkers Qualification Consortium**

The Foundation-led COPD Biomarker Qualification Consortium (CBQC) was established to help gain regulatory acceptance of new COPD Drug Development Tools to develop better treatments for COPD. By supporting qualification of these novel endpoints, the goal was to use them in registration studies of COPD therapies.

The CBQC was formed in 2010 and included academic disease experts and health outcomes, imaging and industry experts. It resulted in qualifying plasma fibrinogen as the first biomarker for COPD, approval from the U.S. Food and Drug Administration (FDA) to cite St George's Respiratory Questionnaire in drug labels, and the establishment of a Drug Master File for the COPD Assessment Test questionnaire.

### PIVOT -

After a successful 2021 patient listening session with the FDA focused on chronic lung disease, the Foundation took on a more prominent role in incorporating patient voices to determine what outcomes mattered most to patients in the evaluation of treatment benefit. From that session, the Foundation established the PIVOT initiative (Patient-Inspired Validation of Outcome Tools).

PIVOT's patient-centric framework focuses on coordinating activities to develop and validate biomarkers, clinical outcome assessments and digital health technologies used to evaluate treatment benefit for people with COPD and bronchiectasis.

A critical foundational component of PIVOT is the development of a unified set of patient-inspired health concepts – one for COPD and one for bronchiectasis – informed by high-quality, qualitative research that offers a deep understanding of the patient's experience (symptoms and functioning) of living with a disease.

"Aligned with the FDA's vision for Patient-Focused Drug Development, the Foundation identified a pressing need to be an active, driving force in ensuring the meaningful integration of the patient voice into the development and testing of medical products for the treatment of COPD," said Alan Hamilton, Ph.D., Senior Director of Research at the COPD Foundation. "The creation of PIVOT allows us to identify patient-inspired health concepts in COPD and in bronchiectasis that can serve as a north star that inspires innovative and expedited therapeutic solutions, allowing the full potential of the Patient-Focused Drug Development vision to be realized."



### **COPDGene®**

The Foundation also supports and participates in collaborative, observational research studies to increase our understanding of disease.

COPDGene (COPD Genetic Epidemiology) is an observational study involving 10,000 study participants and more than 20 clinical centers in the United States. Funded by the Foundation with the support of industry partners and the National Heart, Lung, and Blood Institute (NHLBI), the study enrolled current and former smokers to help identify risk factors that contribute to the development and progression of COPD.

COPDGene is currently in its 15th year of longitudinal follow-up and imaging studies. The study aims to identify risk factors that predispose some people to not only develop COPD but to progress to more severe disease, and, in turn, use that information to develop new treatment and management approaches.

### **SPIROMICS**

The goal of SPIROMICS (SubPopulations and InteRmediate Outcome Measures in COPD Study) is to understand COPD to a level we collectively never have before. Increased understanding of genetic, physiologic and other clinical changes over time will help identify better treatments and outcome measures that can impact the course of COPD. Similar to COPDGene, SPIROMICS is funded by the Foundation with the support of industry partners and the NHLBI.

## Celebrating the 10th Anniversary of

Chronic Obstructive Pulmonary Diseases:

Journal of the COPD Foundation



Marking a decade of publishing peer-reviewed, open-access research focused on COPD, bronchiectasis and NTM lung disease.

Want to learn more about the history of the Foundation? Scan the QR code to read "The COPD Foundation on Its Twentieth Anniversary" article in the Journal.







### **Joining Together for Better Lung Health**

Partnerships are essential to advancing health care and improving outcomes for people living with chronic health conditions. As the COPD Foundation strives to help millions of people living with COPD, bronchiectasis and NTM lung disease, creating strategic collaborations with nonprofits, industry, federal agencies and others is crucial.

Through these partnerships, the Foundation can share resources and expertise to ultimately advance COPD, bronchiectasis and NTM lung disease care and help millions of people live longer, healthier lives.

### COPD Foundation Corporate Support and Corporate Social Responsibility Programs

The COPD Foundation's Corporate Support Program is intended for pharmaceutical, durable medical equipment and medical device companies interested in providing mission-focused support to the COPD Foundation.

The Foundation's Corporate Social Responsibility (CSR) program is designed to create collaborations with additional companies and organizations whose missions align with the Foundation. CSR partners include foundations, digital health companies, primary care networks and companies who manufacture products that may benefit our community.

The Foundation is grateful for the support, collaboration and dedication of our corporate and CSR program members.

# DON'T SETTLE FOR AN INCOMPLETE SOLUTION



### Give patients complete bronchiectasis treatment

Bronchiectasis-COPD Overlap Syndrome may be present in 54% of patients with COPD.<sup>1</sup> Treating infection but ignoring airway clearance leaves a gaping hole in your treatment strategy. Excess mucus persists, fueling the cycle and putting patients at risk of exacerbations and lung damage.

The SmartVest® Airway Clearance System helps break through the vicious vortex, removing the fuel for future infections and inflammation.

### >>> Triple down on Bronchiectasis-COPD Overlap



CLEAR the airways with SmartVest



TREAT the infection



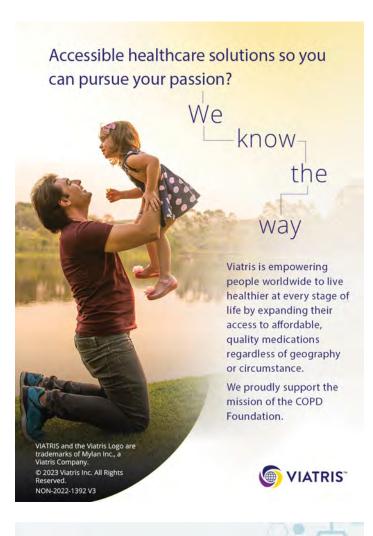
**REDUCE** the inflammation



Learn more at smartvest.com



Chalmers J. and Sethi S. Raising awareness of bronchiectasis in primary care: overview of diagnosis and management strategies in adults. NPJ Prim Care Respir Med. 2017;27:18 martVest" is a registered trademark of Electromed, Inc.





### Learn More Breathe Better® and the Breathe Better Network

Learn More Breathe Better is a national health education program from the National Institutes of Health's National Heart, Lung, and Blood Institute (NHLBI). Launched in 2007, the program offers a wide range of educational resources focused on lung diseases and conditions, including COPD.

The COPD Foundation was one of the first organizations to partner with the Learn More Breathe Better Campaign, creating programs to offer lung screening and followon support via phone to those the NHLBI's awareness program reached.

The COPD Foundation has received several subcontracts from Learn More Breathe Better over the last 12 years, enabling employer education, community outreach and rural health professional training.

### **Speak Up for COPD**

Speak Up for COPD is a coalition of partners across the nonprofit sector and industry, including the COPD Foundation, working together to raise awareness and understanding of COPD among policymakers and health care decision makers.

The group's critical goal is to establish COPD as a public health priority. To do that, Speak Up for COPD uses the voices of people with COPD, the COPD community and the public to emphasize the need for action to address the burden of COPD.

The coalition recently released The State of COPD global report and 10 accompanying country profiles.

Speak Up for COPD partners are the COPD Foundation, the Global Allergy & Airways Patient Platform, the International Federation of Ageing, the International Coalition of Respiratory Nurses and the International Pharmaceutical Federation, with funding from AstraZeneca, Roche, Sanofi and Regeneron.

### **20th Anniversary Corporate Supporters**

The COPD Foundation is grateful for the commitment and collaboration of our partners. We are proud to celebrate our 20th anniversary with their support.











