Pulmonary Fibrosis Foundation™ | 2025 Years

# 2025 Strategic Plan

# THE PFF IS ME.

## DEAR FRIENDS,

We are united by the impact pulmonary fibrosis has had on our lives and by our shared goal to find a cure. That spirit of collective purpose is reflected in the theme of our new strategic plan: **The PFF is ME.**

Developed by and for the PF community, the plan reflects the insights and priorities of over 350 members who came together to shape our path for the next five years. The 2025 PFF Strategic Plan identifies four key pillars that hundreds of constituents throughout our community identified as priorities – Accelerate Research, Expand Access to Expert Care, Improve the Lives of Patients Right Now, and Bring the Community Together. These are the themes we heard most clearly, and they define the direction of our work ahead.

Because of you, no one affected by pulmonary fibrosis has to face their journey alone. The PFF is here to provide trusted education and resources, connect patients to care and clinical trials, and build a supportive community that understands the challenges of living with this disease. Even as we drive research toward a cure, we understand that a PF diagnosis today can be frightening and isolating. Together, we can change that – and turn our hopes for a better future for people living with PF into reality.

For each of us at the PFF, this mission is deeply personal.

Scott: "I lost my mother to idiopathic pulmonary fibrosis in 2015. Before I joined the PFF, I wasn't familiar with the disease. But then I experienced firsthand the anguish and devastation that comes with having a loved one with PF. It only strengthened my resolve to help people living with this disease."

Wayne: "I worked at Genentech and used data from the PFF Registry for research on the effectiveness of the antifibrotic, pirfenidone. The Registry opened my eyes to the powerful role a patient advocacy organization can play in drug development. I saw how essential the PFF and the Registry are to driving progress – and I'm proud to be part of this effort."

Ours are just two stories among thousands nationwide. Each one reminds us why we do this work – and why we need your continued partnership. Together, we can implement this strategic plan, maximize our impact, and bring us closer to a cure.

Your generosity makes all the difference. Every gift you make strengthens our ability to accelerate research, expand patient support, and drive progress toward new treatments and, ultimately, a cure. With your help, we can ensure that everyone living with pulmonary fibrosis has hope, care, and a community behind them.

Warmly,

**Scott Staszak**
President and CEO

**Wayne Pan, MD, PhD, MBA**
Chair, PFF Board of Directors

Cover image: Isabel Sanchez (left), patient living with ILD, PFF volunteer Sybil Sutton (right), lung transplant recipient, PFF volunteer

THE PFF

## 25th Anniversary Highlights Shine Bright

**Much in pulmonary fibrosis (PF) and interstitial lung disease (ILD) care has changed since brothers Albert Rose and Michael Rosenzweig, PhD, founded the PFF 25 years ago. Their vision shaped the PFF to become what it is today – the leading patient advocacy organization for the PF/ILD community. Today's patients and their families have better care, more treatment options, and more opportunities to find community support than seemed possible in 2000.**

The PFF continues to grow as the foremost resource for our community. Much work remains ahead, but we are poised to lead. You'll read about two of PFF's great accomplishments, **The PFF Registry Program** and the **PFF Care Center Network**, in the following pages. Here are some other noteworthy highlights:

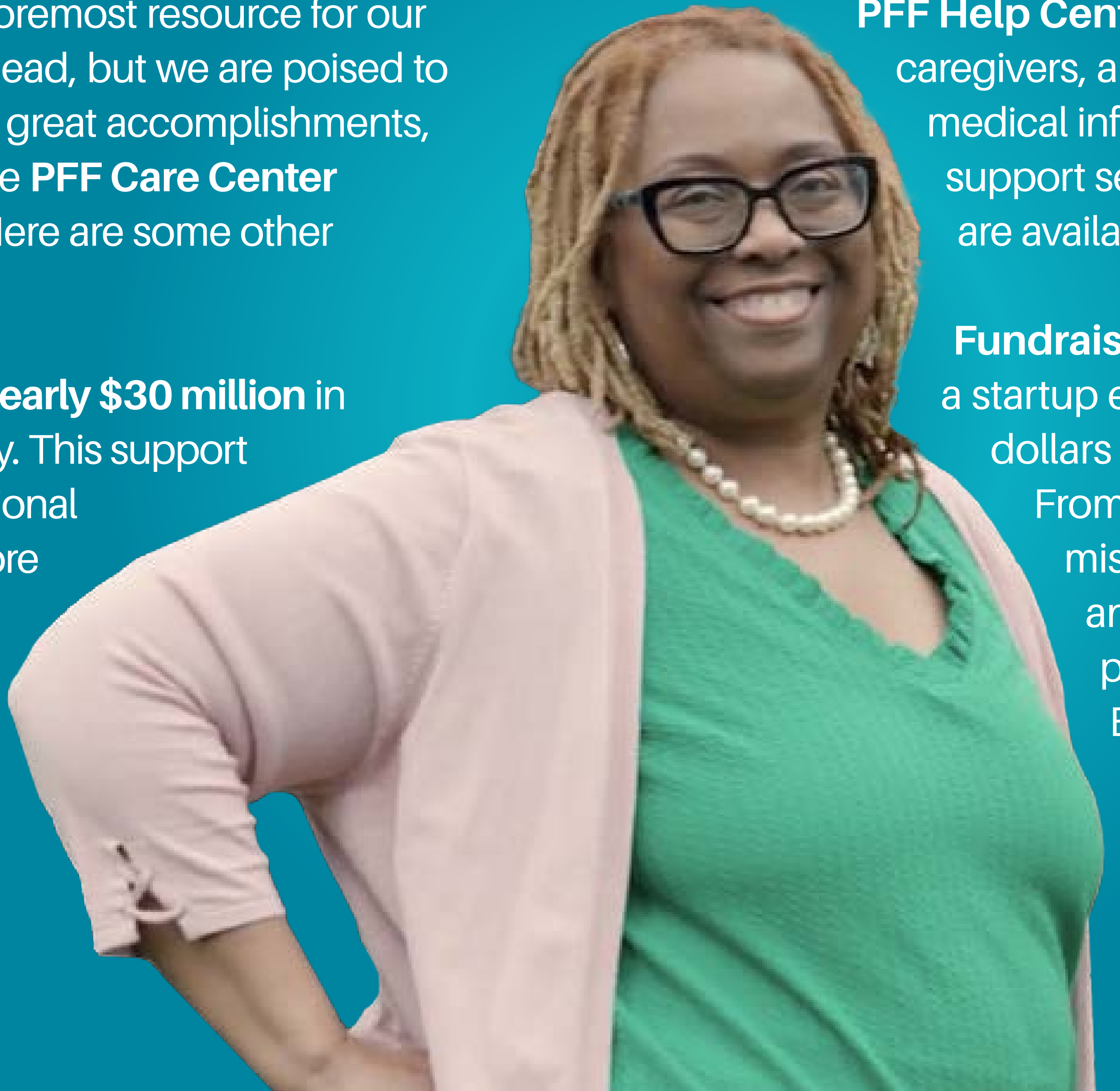
**Research**- The PFF has **invested nearly $30 million** in research grants and the PFF Registry. This support has unlocked **$300 million** in additional research funding and generated more than 80 studies through the PFF Registry. Powered by the Registry, two major collaborations, the PRECISIONS study and PROLIFIC Consortium, are advancing personalized approaches to diagnosis and treatment.

**PFF Summit** – Since 2011, The PFF has hosted the **world's largest conference focused on PF and ILD** research and education every other year. Nearly 1,000 patients, caregivers, lung transplant recipients, physicians, researchers, nurses, and others affected by PF/ILD gather to learn from global experts. Summit welcomes participants from every state in the U.S. and 20 countries.

**Support Groups** - In 2000, there were just a handful of support groups for people living with PF/ILD. Today, there are over 135 PF/ILD support groups across the U.S. and around the world.

**PFF Help Center** – Each year, we provide over 4,000 patients, caregivers, and healthcare providers with the most up-to-date medical information, and we communicate the availability of support services, and other essential resources. All resources are available free of charge.

**Fundraising** – Over 25 years, the PFF has grown from a startup effort with only a few hundred thousand dollars to an **$11 million annual organization.** From our humble beginnings, we have built a strong, mission-driven organization with national reach and impact. Fundraising has scaled dramatically, propelled by two signature programs, Broadway Belts for PFF! and the PFF Walk, that now anchor our annual calendar. In 2024, nearly 3,000 people participated in Walk events across the country, generating more than $1.2 million.



**JEANETTE AKUJUOBI**
Caregiver, PFF volunteer

## A Community-Driven Vision for the Future

**Today, the PFF is focused on the future and how we can best support the pulmonary fibrosis/interstitial lung disease (PF/ILD) community for the next five years and beyond. We will continue to offer our trusted programs while adding innovative new initiatives to support our community.**

At the PFF, everything we do focuses on improving the lives of people affected by pulmonary fibrosis.

As our mission clearly states –
**The Pulmonary Fibrosis Foundation is committed to advancing research, empowering our community, and transforming care so that everyone with pulmonary fibrosis can live a better life. Our ultimate goal is to find a cure for pulmonary fibrosis.**

**SAM KIRTON**
Lung transplant recipient
PFF volunteer

## Your Priorities Are the PFF's Priorities

**Community members always have a voice at the PFF. We created our 2025 Strategic Plan based on input from 350+ patients, caregivers, researchers, physicians, allied health professionals, and industry partners. We heard loud and clear that every PFF program must support one or more of these pillars:**

- **Accelerate Research**
- **Expand Access to Expert Care**
- **Improve the Lives of Patients Right Now**
- **Bring the Community Together**

The 2025 Strategic Plan reinforces PFF's successful programs and highlights bold new initiatives.

STRATEGIC PILLAR 1

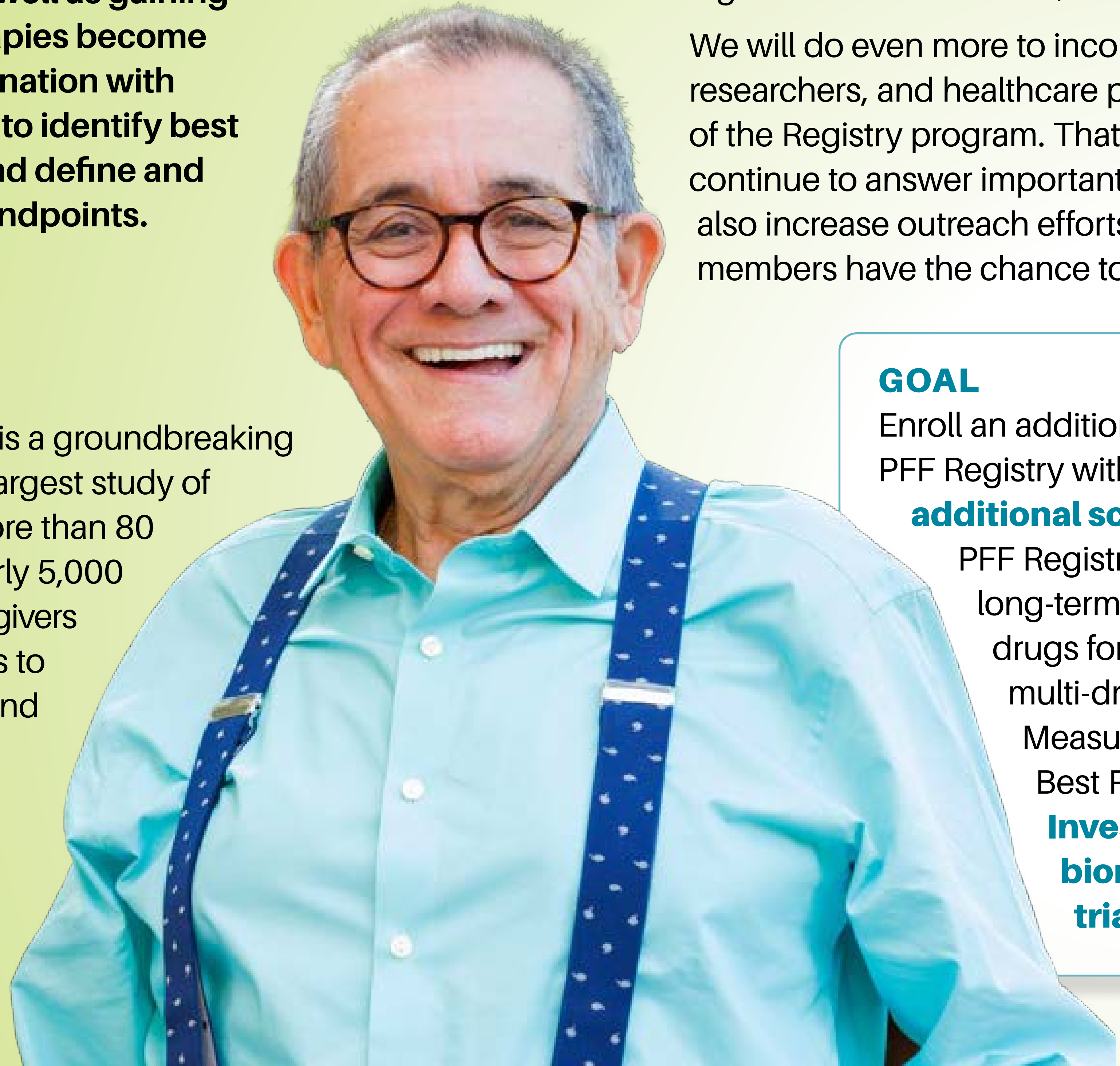
## Accelerate Research

**We need more effective treatments to prevent, stop and ultimately reverse lung fibrosis and inflammation. Scientific priorities include advancing our understanding of early and familial disease, as well as gaining real-world insights as new therapies become available and are used in combination with other treatments. We also need to identify best practices and quality metrics and define and refine meaningful clinical trial endpoints.**

### INITIATIVE

**Expand the PFF Registry**

**What:** The PFF Registry program is a groundbreaking research project and the world's largest study of PF/ILD, that has contributed to more than 80 research studies. Since 2016, nearly 5,000 patients, family members, and caregivers have shared data and experiences to contribute to drug development and a better understanding of the disease and how it affects them.



**MARIO LARREA**
Patient living with ILD
PFF volunteer

**Why:** The PFF Registry data can do even more to help scientists answer critical research questions. In the near future, we will once again add patients' clinical data (including blood samples and high-resolution CT scans) to the PFF Registry.

We will do even more to incorporate input from patients, researchers, and healthcare providers into the design and future of the Registry program. That will ensure that researchers can continue to answer important PF-related questions. We will also increase outreach efforts so that more PF/ILD community members have the chance to participate in this research.

### GOAL

Enroll an additional **6,000 participants** in the PFF Registry within five years. **Support 25 additional scientific publications** using PFF Registry data within five years. Measure long-term, real-world impact of approved drugs for IPF and PF, including how multi-drug therapies affect patients. Measure recommendations from Best Practices Interventions. **Investigate endpoints and biomarkers to make clinical trials more efficient.**

**STRATEGIC PILLAR 1**

# Accelerate Research

## INITIATIVE

### Increase Research Awards for Scientists

**What:** The PFF Scholars program awards two-year grants to early-career researchers. It has been extremely successful in funding high-quality, innovative research projects. The PFF has funded nearly 100 research awards, totaling approximately $7 million dollars. These awardees have gone on to receive over $300 million in additional research grants.

**Why:** Building the pipeline of future experts in PF is critical to our mission of developing new treatments and, ultimately, a cure. We plan to offer an additional year of funding support for each new PFF Scholar.

**GOAL**

Increase each PFF Scholar's research award from **$100,000** over two years to **$150,000** over three years.

**KSENIJA BERNAU, PHD**
2023 PFF Scholar

## INITIATIVE

### Urge the Federal Government to Invest in PF Research

**What:** Federal research funding is critical to ensuring a strong pipeline of researchers studying all aspects of ILD, including the causes and genetics of ILD, disease progression, and potential treatments. The National Institutes of Health (NIH) is the largest public funder of PF research, funding approximately $120 million in PF research projects annually. Between 2010 and 2019, the NIH funded research related to nearly every drug approved by the FDA—over 99% of them. We will continue to advocate for federal funding for PF research through advocacy alerts, PFF Hill Day, and sign-on letters.

**Why:** We are currently the only organization in the U.S. with a government relations program that advocates specifically for PF research funding. It is more important than ever that we speak up about the importance of PF research in this challenging funding climate.

**GOAL**

Ensure that Congress **highlights the importance of pulmonary fibrosis research** every year in its annual NIH funding report.

**STRATEGIC PILLAR 1**

# Accelerate Research

## INITIATIVE

### Educate Clinicians about PF Research Opportunities

**What:** Expand clinicians' knowledge and awareness of clinical trials so they refer more patients for research opportunities. To do this, we will develop provider-focused versions of existing PFF programs and materials that currently focus on educating patients about clinical trials. These could include webinars, the PFF Summit, the Clinical Trial Finder website and the Clinical Trials newsletter.

**Why:** Most patients who participate in clinical research do so because their trusted healthcare provider encourages it. It's important for providers who treat patients with PF/ILD to be aware of the many opportunities to participate in PF research.

**GOAL**

Increase use of the PFF Clinical Trial Finder by **15% over five years.**

## INITIATIVE

### Develop Improved Clinical Trial Endpoints to Make Trials More Efficient

**What:** Develop improved clinical trial endpoints to facilitate clinical trial development and get faster, more meaningful results. (Endpoints are the planned outcomes of a clinical trial that researchers analyze to help determine whether the intervention being studied is safe and effective.) We will do this by launching a new scientific consortium to study possible PF/ILD endpoints. This initiative complements PROLIFIC (the Prognostic Lung Fibrosis Consortium), where PFF and its pharmaceutical partners have advanced protein blood biomarker research and helped drive progress in the IPF drug development pipeline.

**Why:** Having one or more alternative measures besides the currently accepted clinical trial endpoint of forced vital capacity (FVC) will lead to more innovative, groundbreaking research. This, in turn, should lead to better patient outcomes.

**GOAL**

Prepare to publish possible new endpoints in scientific journals **within five years.**

**DIONN TUNIS**
Patient living with ILD
PFF volunteer

**STRATEGIC PILLAR 2**

## Expand Access to Expert Care

**PF and related diseases are complex. Research has shown that people with PF/ILD do best when they receive care from healthcare providers who have specialized knowledge of PF/ILD. These experienced providers actively support clinical research in PF and are up to date with all current guidelines and other clinical developments. One of the PFF's top priorities is making this high-quality, expert care accessible to more people than ever before.**

### INITIATIVE

### Add More Centers to the PFF Care Center Network

**What:** The PFF Care Center Network (CCN) is a network of medical centers across the country dedicated to providing state-of-the-art care to people with PF/ILD. Each CCN site offers pulmonologists, radiologists, respiratory therapists, nurses, and other experts who pool their knowledge using a team-based approach to help patients. Each site must apply to join the CCN and continue to meet rigorous standards to remain a member. When the CCN launched in 2013, it had just nine centers. As of October 2025, the CCN has grown to include 86 sites across 38 states. The CCN has recently begun expanding beyond large academic medical centers to community-based sites as well.

**GOAL**

Establish a CCN presence **in five new-to-us states,** underserved rural areas, and/or safety-net hospitals **within five years.**

**Why:** The more the CCN expands, the more patients and families affected by PF can get the expert care they need and deserve.

### INITIATIVE

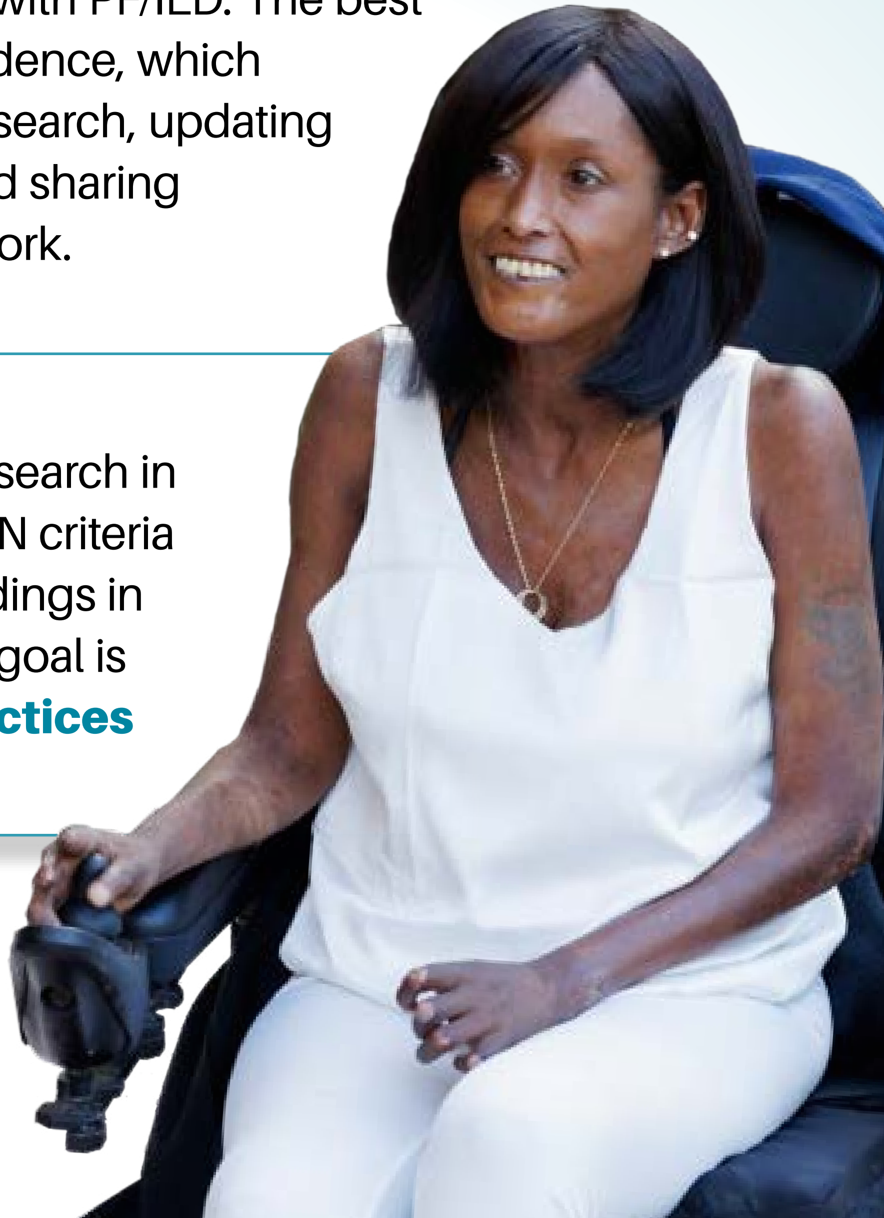
### Identify Best Practices in Patient Care

**What:** The PFF is currently conducting research into best practices in clinical care for people with PF and ILD. When that research is complete, we will share the results with CCN member institutions and receive their feedback. We will then update CCN membership requirements and clinical care criteria throughout the network.

**Why:** Patients and healthcare providers all want the best possible care for people with PF/ILD. The best care is based on the latest evidence, which means an ongoing cycle of research, updating best practices documents, and sharing the updates through the network.

**GOAL**

Complete best practices research in **Years 1 and 2**. Update CCN criteria to reflect best practices findings in Years 3 – 5. Long term, the goal is to **spread these best practices beyond the CCN.**



**DEMESHIA MONTGOMERY**

Patient with ILD

PFF volunteer

(1981-2025)

**STRATEGIC PILLAR 2**

# Expand Access to Expert Care

## INITIATIVE

### Reach More Clinicians with Education and Expert Knowledge

**What:** The PFF offers many educational opportunities and resources to healthcare providers. In addition to offerings for physicians, we also have materials for nurses, pharmacists, and respiratory therapists.

We know that many people who have PF live too far away from a large academic medical center to receive regular care there. That's why it's important to reach and educate community-based providers who live and practice in rural areas.

**Why:** Too many healthcare professionals are unaware of the PFF's educational resources for patients, families, and their own professional development. Increased provider education should contribute to better understanding of PF diagnosis and treatment.

Supporting pharmacists should enhance and increase patient access to specialty medications. Long term, more provider education should contribute to improvements in key metrics that matter to patients. These include earlier and more accurate diagnosis, more widespread use of specialty medications, increased clinical trial participation, and more access to lung transplants.

**GOAL**
Increase the number of healthcare providers contacting the PFF Help Center by **20% over five years.**

**JOYCE LEE, MD**
PFF Senior Medical Advisor
Director of ILD Program,
University of Colorado School of Medicine

STRATEGIC PILLAR 3

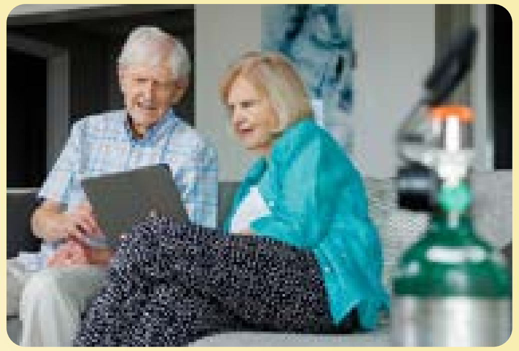
# Improve the Lives of Patients Right Now

**We are keenly focused on improving the lives of people with PF/ILD right now. Helping patients and families build better lives now is a priority that just can't wait.**

**MARK McCORMICK**
Patient with ILD, PFF volunteer
(1951-2024)

## INITIATIVE

**Increase Patient Access to Oxygen**



**What:** Many people with PF/ILD have difficulty accessing their prescribed supplemental oxygen through Medicare due to the federal government's competitive bidding program. We are an active member of an oxygen coalition made up of patient advocacy, industry, and professional groups urging Congress to enact the Supplemental Oxygen Access Reform (SOAR) Act. The SOAR Act will transform patients' ability to get the oxygen that they need. Before—and even after—the SOAR Act passes, we will continue educating patients, caregivers, and healthcare providers about overcoming access challenges.

**Why:** The current situation for patients trying to access supplemental oxygen is completely unacceptable. Many patients end up virtually homebound due to limits on the number of tanks that they can receive and lack of access to liquid oxygen, a vital form of portable supplemental oxygen. We are dedicated to improving access through the SOAR Act. Even after the SOAR Act becomes law someday, we expect that additional advocacy work will be needed to ensure that patients' access to supplemental oxygen improves as stated in the legislation.

**GOAL**
Continue to advocate for Congress to pass the SOAR Act. Following passage, we will work to see it put into practice correctly.

**STRATEGIC PILLAR 3**

# Improve the Lives of Patients Right Now

## INITIATIVE

### Provide High-Quality Educational Materials to Patients and Caregivers

**What:** We will continue to develop accurate, clear educational materials and support resources. Possible topics include resources for younger people living with ILD, materials to explain PF to children, and grief support materials. We will also encourage our existing community members to share our educational materials widely with anyone who needs them.

**Why:** The PFF is a trusted resource in the community and needs to continue to produce education materials that clarify PF/ILD causes and symptoms, treatment options, and other aspects of this disease for different demographics in order for all to benefit. While we have an extensive library of educational materials, we need to continue to develop new materials to reflect changes in care and the evolving needs of the community.

**GOAL**

Develop at least **two new patient education materials** each year.

**JENNIFER SIMOKAITIS**
Manager of the PFF Help Center

**STRATEGIC PILLAR 4**

## Bring the Community Together

**At the PFF, our community includes everyone affected by PF and all types of ILD. Strength in numbers—and strength in focus—is the best way to make progress in the fight against PF and ILD.**

### INITIATIVE
### Add More PFF Walks

**What:** Each year, the PFF hosts PFF Walks in six cities, plus a virtual National Walk Day. The PFF Walk unites everyone affected by PF and ILD and provides a special opportunity to raise funds, build awareness, and make a meaningful impact on those affected by the disease. The Walk helps to expand our reach to extended families and social networks. It also gives many people their first opportunity to connect and engage with us. We want to bring the Walk to additional cities.

**Why:** Every Walk brings more people and families to us who need our support to live the best lives they can with PF/ILD. With more Walks, we can reach all of our goals more quickly because our community will be that much bigger and that much stronger.

**GOAL**

We will add a new Walk location **every two years.**

**GINA HARVEY**
**MICHELE ENDORF**
**LAUREN GIGNAC**
PFF Walk Participants

### INITIATIVE
### Ensure that People with ILD Feel Welcome

**What:** Pulmonary fibrosis isn't just one disease. It is a family of more than 200 different lung diseases that all look very much alike. The PF family of lung diseases is part of an even larger group of diseases called interstitial lung diseases, which includes all of the diseases that have inflammation and/or lung scarring. The PFF is emphatically an organization for people with all types of PF and ILD.

**Why:** While some people in the community identify as having pulmonary fibrosis, others primarily identify as having a form of ILD. People who primarily identify as having an ILD have expressed that they did not realize that the PFF is a resource and community for them. We want people with all forms of ILD to know they are welcome. We have resources for IPF, but also for autoimmune-related ILDs, hypersensitivity pneumonitis, familial PF, and many other forms of ILD.

**GOAL**

**In Year 1,** we will assess the language we currently use about ILDs throughout our materials, including our website. We will also develop a plan to update our language for disease inclusiveness.

**In Years 2 - 5,** we will roll out additional language so that everyone with an ILD feels welcome.

THE PFF IS ME.

## Get Involved!

**With your help, we can ensure that everyone living with pulmonary fibrosis and interstitial lung disease has hope, care, and a community behind them.**

We encourage you to explore our comprehensive programs. Click on the headers below to visit our website.

- **Join the PFF Registry**
- **Become a PFF Advocate**
- **Participate in Clinical Trials**
- **Find a PFF Care Center Network Site Near You**
- **Support the Supplemental Oxygen Access Reform (SOAR) Act**
- **Join a Support Group**
- **Attend a PFF Walk**
- **Donate to the PFF**

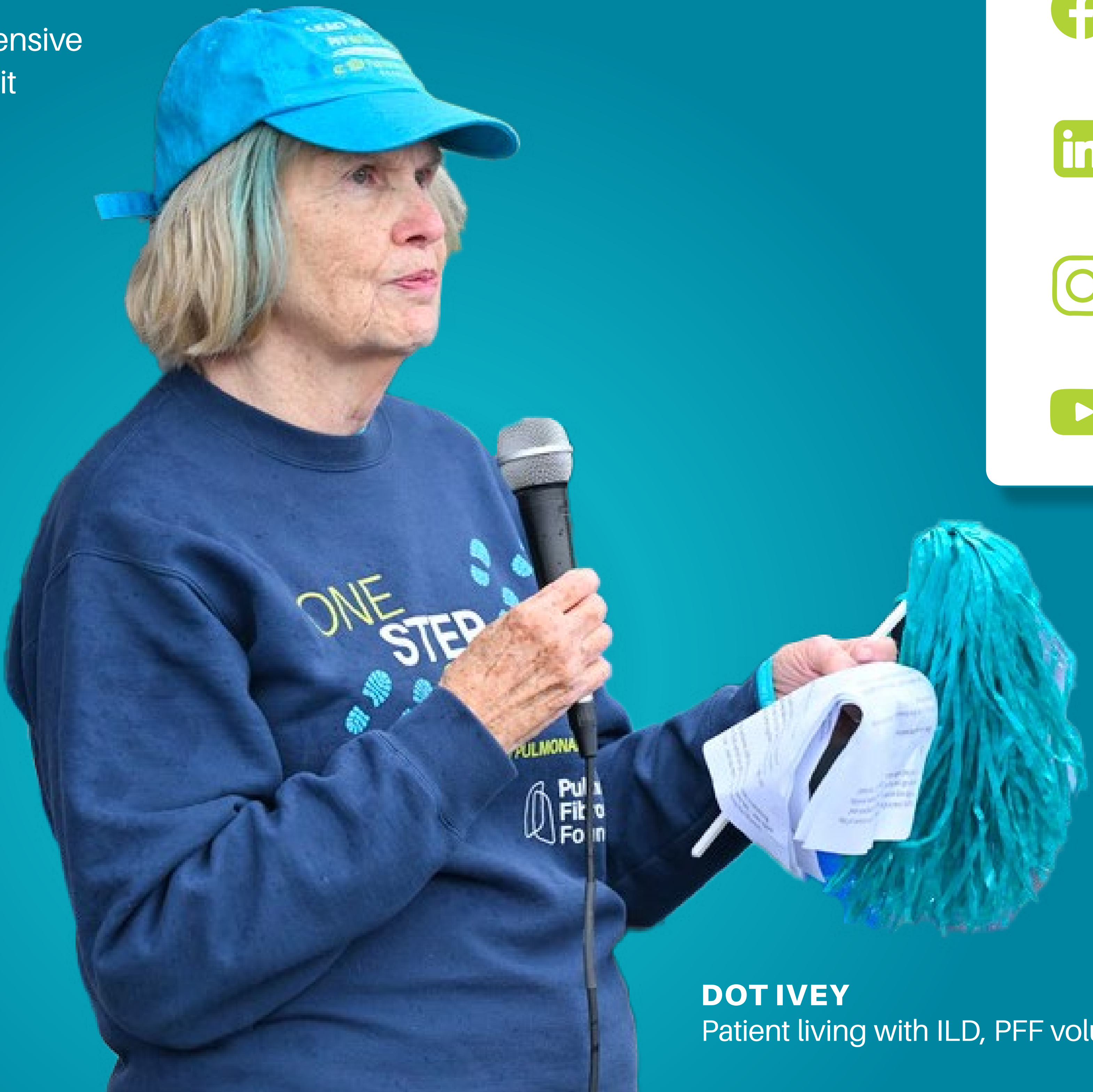
### Engage with the PFF's Social Media

**Facebook**

**LinkedIn**

**Instagram**

**YouTube**



**DOT IVEY**
Patient living with ILD, PFF volunteer

## PFF 2025 STRATEGIC PLAN ACKNOWLEDGEMENTS

The PFF would like to express our gratitude to the many community members who offered their time and expertise to aid the Foundation in developing this strategic plan.

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* Indicates Co-Chair for each group

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## OUR MISSION

The Pulmonary Fibrosis Foundation is committed to accelerating research, empowering our community, and transforming care so that everyone with pulmonary fibrosis can live a better life. Our ultimate goal is to find a cure for pulmonary fibrosis.

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