PFF Registry
Patient powered. Data driven. Research results.

Pulmonary Fibrosis Foundation

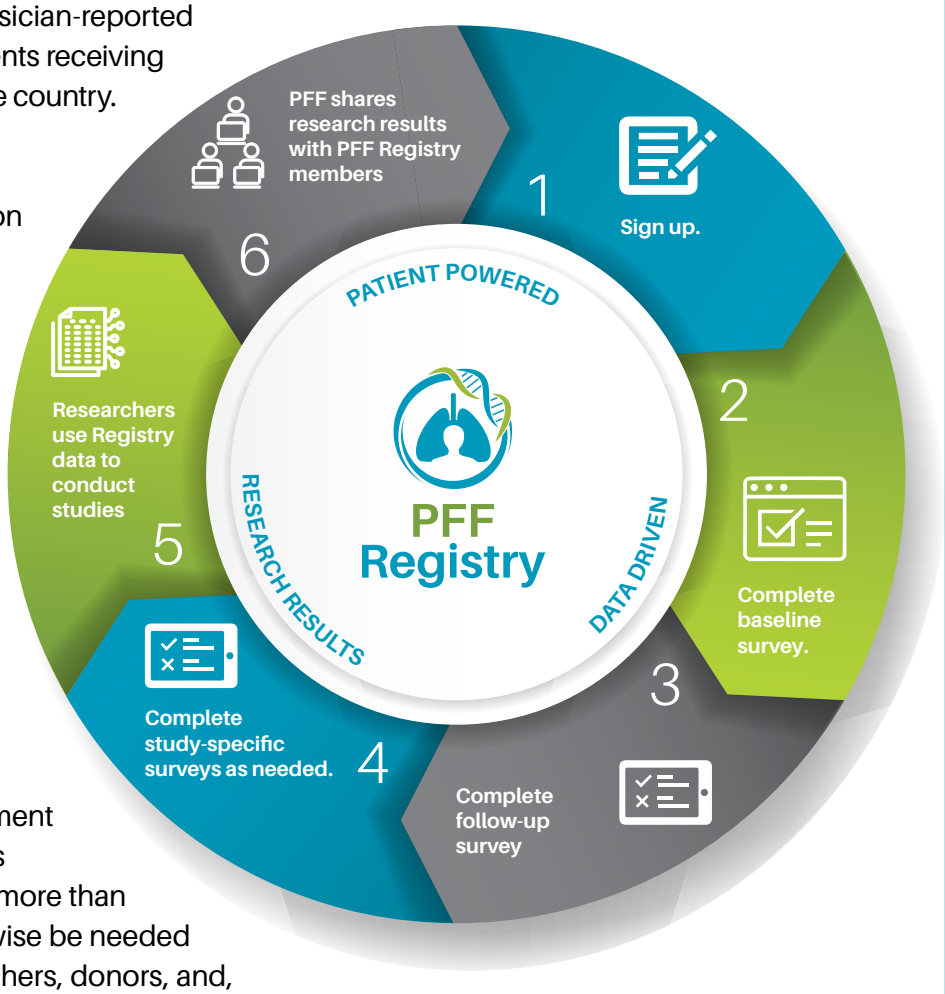
2025 Years

PFF Registry
2025 Annual Report

Turning Data Into Discovery

The PFF Registry reflects the Foundation's commitment to building a stronger future for everyone affected by pulmonary fibrosis (PF) and interstitial lung disease (ILD).

The Registry captures both clinical data and lived experience. From 2016 to 2022, the PFF Patient Registry collected physician-reported medical information from more than 2,000 patients receiving care at participating PFF Care Centers across the country. In 2022, the Foundation expanded this effort with the launch of the PFF Community Registry, which gathers self-reported information from patients, lung transplant recipients, caregivers, and biological family members.



Unlike a clinical trial, the PFF Registry does not require participants to follow a specific treatment plan or take additional medications. Instead, it captures real-world data based on the care patients are already receiving and the experiences they are having. That makes it an important resource for researchers studying care patterns, outcomes, and the factors that shape disease course and quality of life.

The Registry is the Foundation's largest investment and most powerful research tool. To date, it has supported more than 80 studies, representing more than $50 million in research value that would otherwise be needed to fund this work. We are grateful to the researchers, donors, and, most of all, the patients and families who share their data to help create a better future for everyone affected by PF and ILD.

Learn More About the Registry
from Jessica Shore, PHD, RN
Chief Scientific Officer

CLICK TO PLAY

Patient Powered
Filling the Gaps, Creating Hope

"I'm grateful to be part of something that will help somebody else." That is why Gary Johnson joined the PFF Community Registry.

In 2014, he woke up with excruciating pain and was diagnosed with rheumatoid arthritis. Gary began treatment and, while the medication helped calm the inflammation in his joints, it caused another problem.

He became breathless, and in 2015, a pulmonologist confirmed that Gary had pulmonary fibrosis. Over the next several years, his lung function declined to about 50 percent. "I couldn't understand it," he said. "The 3-to-5-year life expectancy statistic was really stuck in my head."

As his disease progressed, Gary faced one of the most difficult periods of his life. He was eventually listed for a lung transplant in November 2020 and received the call for transplant just weeks later. Through it all, Gary found strength in a support group at Inova Fairfax Hospital. "That was the one thing that kept me whole," he said. Today, more than five years after transplant, Gary is back at work full time, active in the PF community, and committed to helping others as a PFF Ambassador and mentor.

That is what makes research so personal to him. "Research allows people to live longer and gives them a chance to thrive," Gary said. "This Registry is a time capsule. We all need to help fill in the gaps in research." By sharing his experience, Gary hopes others will feel the same thing that keeps him moving forward: hope.

> Research allows people to live longer and gives them a chance to thrive."

Gary Johnson
PFF Ambassador

CLICK TO MEET GARY AND LEARN MORE

By the Numbers:
What PFF Community Registry Participants Have Shared

At enrollment, **72% of patients reported shortness of breath**, more than half (59%) reported coughing, and nearly half (47%) reported fatigue.

47% of patients reported being prescribed supplemental oxygen at enrollment.

19% of participants are veterans.

5% of patients were lung transplant recipients at time of enrollment.

Registry participants report more than **35 types of ILD diagnoses.**

48% of patients are taking an antifibrotic medication.

Meet the PFF Registry Team

Left to right – Jamie Lederer, Jessica Shore, Ingrid Schwab , Aubrey Trecek

Led by Jessica Shore, PhD, RN, the PFF Registry and Care Center Network (CCN) team brings together expertise in research, clinical care, provider engagement, and participant support. Shore, now Chief Scientific Officer, has led the PFF Care Center Network and overseen the PFF Registry since joining the Foundation in 2020.

Dr. Shore is joined by:

Aubrey Trecek, Clinical Affairs Senior Coordinator
Supports Registry participants and CCN providers, manages rosters and surveys, and helps facilitate working groups.

Ingrid Schwab, Manager of Clinical Affairs
Serves as the primary communications contact for the CCN and supports its continued development.

Jamie Lederer, MSN, CNRP, Outreach Director, Clinical Affairs Supports the CCN and Registry with a focus on expanding education and collaboration through the Nurse and Allied Health Network.

Dr. Teja Kulkarni, Senior Medical Advisor, PFF Registry

Dr. Kulkarni brings deep expertise in ILD clinical care, biomarker research, and clinical trials. She joined the team in 2026 as Senior Medical Advisor of the PFF Registry.

Data Driven: PROLIFIC Risk Score Moves IPF Research Forward

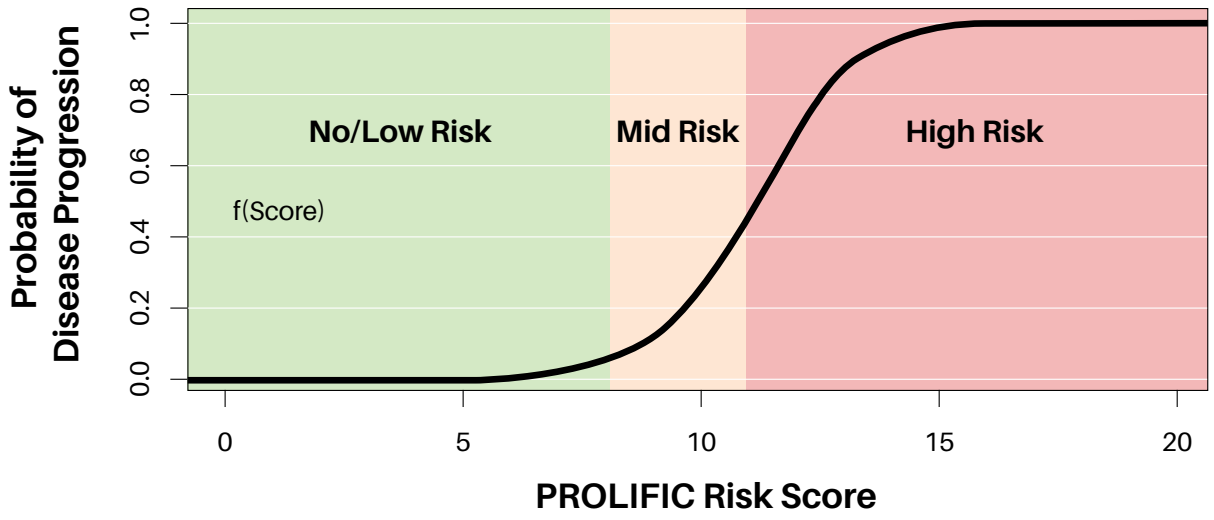
An important development in idiopathic pulmonary fibrosis (IPF) research is gaining national attention. The U.S. Food and Drug Administration recently accepted a letter of intent for a biomarker panel that includes the PROLIFIC Risk Score into its Biomarker Qualification Program.

PROLIFIC

Prognostic Lung Fibrosis Consortium

"For people living with IPF, the disease can behave very differently from one person to the next," said Dr. Amy Hajari Case, Chief Medical Officer of the Pulmonary Fibrosis Foundation. "Tools like the PROLIFIC Risk Score, which uses data from the PFF Registry and other sources, could help researchers make better risk assessments and design more efficient clinical trials."

Over time, advances like this could help accelerate research, strengthen trial development, and support more personalized approaches to treatment for people living with the disease.



Data Driven: PRECISIONS Expands the Promise of Precision Medicine

The PRECISIONS study is helping move pulmonary fibrosis research toward a more personalized future, and the PFF Registry has been central to that work.

PFF Registry samples provide the study's baseline phenotypic data, including disease symptoms, demographics, social characteristics, and longitudinal information that shows how disease changes over time. That depth of data gives researchers a stronger foundation for understanding the differences among patients and how those differences may shape outcomes.

While the clinical trial of N-Acetyl-cysteine (NAC) as a potential treatment for a subset of patients is one important part of PRECISIONS, the project extends well beyond treatment testing. Through additional research aims, investigators are using molecular phenotyping to better distinguish idiopathic pulmonary fibrosis from non-IPF interstitial lung disease, identify high-risk and low-risk patients, improve diagnosis, and better predict treatment response.

Researchers are characterizing gene expression and protein biomarkers within the PFF Registry cohort to define the genetic and molecular signatures that may help guide more precise care in the future.

The impact of this work has already been substantial. PRECISIONS has led to 43 ancillary studies, with additional findings still to come. The project has generated important advances in genetics, risk scores, proteomic classifiers, and other areas, many of them built using the PFF Registry data.

By the Numbers: What We've Learned from the Research

People who live farther from specialized ILD care centers, or in under-resourced communities, tend to use health care services less often; however, this does not always lead to measurably worse clinical outcomes. *(Baldomero & Kim, 2025)*

Among people living with connective tissue disease-related ILD, disease severity, gender, symptom burden and disease treatments were associated with poorer health-related quality of life. *(O'Hare et al., 2025)*

Caregivers of people living with ILD reported **spending an average of 39 hours per week across six different caregiving activities.** *(O'Hare et al., 2025)*

Through the PROLIFIC Consortium, **five serum proteins were identified for study** based on their prognostic associations with death, lung transplant, and decline in forced vital capacity, reflecting key biological processes in IPF, including lung cell injury, inflammation, and fibrosis. *(Clinical Leader, 2026)*

The PROLIFIC Risk Score may help predict disease progression and improve clinical trial design, and was accepted by the Center for Drug Evaluation and Research as the first IPF biomarker in its Biomarker Qualification Program. *(Clinical Leader, 2026)*

Research Results

Insights from ATS 2025

Important advances in pulmonary fibrosis and interstitial lung disease were highlighted at the 2025 American Thoracic Society conference in San Francisco, where researchers shared major clinical trial findings and updated guidance on early detection and diagnosis. These developments reflect the growing momentum in PF and ILD research and the progress being made toward better care, better tools, and better outcomes for patients and families.

In this special video recap, three members of the PFF medical team share their perspectives on the research shaping the future of the field. Dr. Kevin Flaherty discusses promising clinical trial data on nerandomilast for idiopathic pulmonary fibrosis and progressive pulmonary fibrosis. Dr. Joyce Lee reviews the latest ATS Clinical Statement on Interstitial Lung Abnormalities and what it means for earlier identification of disease. Dr. Amy Hajari Case highlights innovative projects led by PFF Scholars and Care Center teams, underscoring the Foundation's role in helping fuel new ideas and scientific discovery.

American Thoracic Society Conference Highlights

WATCH THE COMPLETE VIDEO

Understanding the Caregiver Experience

At the 2025 European Respiratory Society Congress, **Dr. Lanier O'Hare** presented first-of-its-kind research showing the toll pulmonary fibrosis can take not only on patients, but also on the people who care for them. Using data from the PFF Community Registry, the study captured a fuller picture of life with PF by including caregivers and the many ways they support loved ones every day.

The findings showed that caregivers provide an average of six different types of care and spend about 39 hours each week helping someone living with pulmonary fibrosis. The median caregiver age was 63, and many were still working while balancing these responsibilities. Yet only 22% reported participating in a support group. The study also found that caregiver strain increased as the number of caregiving tasks and hours grew. This research is helping shine a light on the caregiver experience and identify where support and resources could make the greatest difference.

Research is revealing a gap between how patients and physicians experience breathlessness.

A 2025 study using PFF Registry data found that while both groups rate mild dyspnea similarly, patients consistently categorize severe breathlessness more severely than their physicians do. Read the study.

Turning Patient Data Into Discovery

A Q&A With Dr. Kerri Aronson,

Pulmonologist, Former PFF Scholar and Assistant Professor of Medicine at Weill Cornell Medicine, Division of Pulmonary and Critical Care Medicine

What are patient-reported outcomes, and why are they such an important part of PF and ILD research?

Patient-reported outcomes are surveys filled out by patients themselves, in their own words, about how they are feeling and how their condition affects their daily life. These surveys cover a wide range of topics, such as quality of life, symptoms, mental health, and how satisfied patients are with their care and treatments. They play a crucial role in PF and ILD research because they capture what it is actually like to live with these conditions. This is something that clinic performed tests like pulmonary function tests or CT scans simply cannot tell us. They help us understand whether treatments are making patients feel better, easing their symptoms, and whether they are manageable to take and allow us to understand patient priority topics for future research.

> The PFF Registry has been an incredibly useful resource for helping us understand what matters most to patients."

How do you approach measuring quality of life in your research, and what insights can that provide?

A big part of my research is focused on measuring and improving quality of life in PF, so I spend a lot of time thinking about the best way to do that for each study. Choosing the right survey is important. The survey needs to fit the specific question we are trying to answer in the research study. It also needs to work well for the particular group of patients we are studying, whether that is people with PF in general or a more specific group, such as those with IPF or PF related to connective tissue disease. Before using any survey, we carefully check that it has been shown to be a reliable and accurate tool to describe the experiences of the patients included in our study.

In my current trial, I also worked with a patient advisory committee who provided their input and feedback to make sure the surveys we chose felt meaningful and relevant to what matters most to them in the context of the study.

In what ways has data from the PFF Registry informed your research?

I have used both the PFF Patient Registry and PFF Community Registry in my research. The PFF Registry has been an incredibly useful resource for helping us understand what matters most to patients. One example is fatigue, a symptom that is very distressing for many people with PF but has not been well studied or treated. The PFF Registry is one of the few large collections of patient data that includes a survey measure of fatigue, and this has allowed us to better understand how to measure it accurately in people with PF and explore some of its possible causes. I have used the Community Registry to look at how things like social isolation and loneliness affect people living with PF, and how these experiences might impact their symptoms and day-to-day lives. We have also used the Registry to invite patients to take part in focus groups, where we can hear directly from people about their experiences and perspectives on topics ranging from joining clinical trials to how they feel about their treatments.

Turning Patient Data Into Discovery

What would you want other researchers to know about the value of the PFF Registry?
The PFF Registry is a remarkable resource that I would encourage any researcher in this space to explore. It brings together a large and well-characterized group of people living with PF, which can be incredibly difficult to do on your own. What makes it especially powerful is the breadth of data it contains. This spans from biosamples and CT scans through to patient-reported outcomes that capture the real lived experience of PF, including symptoms and quality of life. This means it can support a wide range of research questions, from more basic and translational science all the way through to clinically focused work, making it a valuable tool for researchers across many different disciplines.

The PFF Community Registry has expanded this even further by reaching a broader group of patients with PF, as well as their caregivers. This has opened up an entirely new set of questions that we can ask about what it is actually like to live with PF day to day. This includes how people navigate their care, what gaps exist in the support and treatment they receive, and how the disease affects not just patients but the people closest to them.

Why does participation from patients, caregivers, family members, and lung transplant recipients matter so much in advancing PF and ILD research?
Research is most meaningful when it reflects the experiences of the people it is meant to help. Patients can tell us what symptoms disrupt their lives the most, caregivers can shed light on the broader impact of these diseases on families, and lung transplant recipients can help us understand life beyond diagnosis in a way that is deeply important and still not well understood. The more diverse and inclusive our research participation is, the better equipped we are to develop treatments and support systems that truly make a difference for the entire PF and ILD community. We are deeply grateful to everyone who participates in this research. We understand that it takes time and energy, and that contribution is the foundation of any meaningful progress in this field.

Where the Registry Is Headed — and Why Now Matters

In November 2025, the PFF launched The PFF Is Me, a bold five-year strategic plan to accelerate progress for everyone affected by pulmonary fibrosis and interstitial lung disease.

At the center of that plan is a commitment to grow the PFF Registry by **6,000 participants** and support **25 new peer-reviewed publications by 2030.**

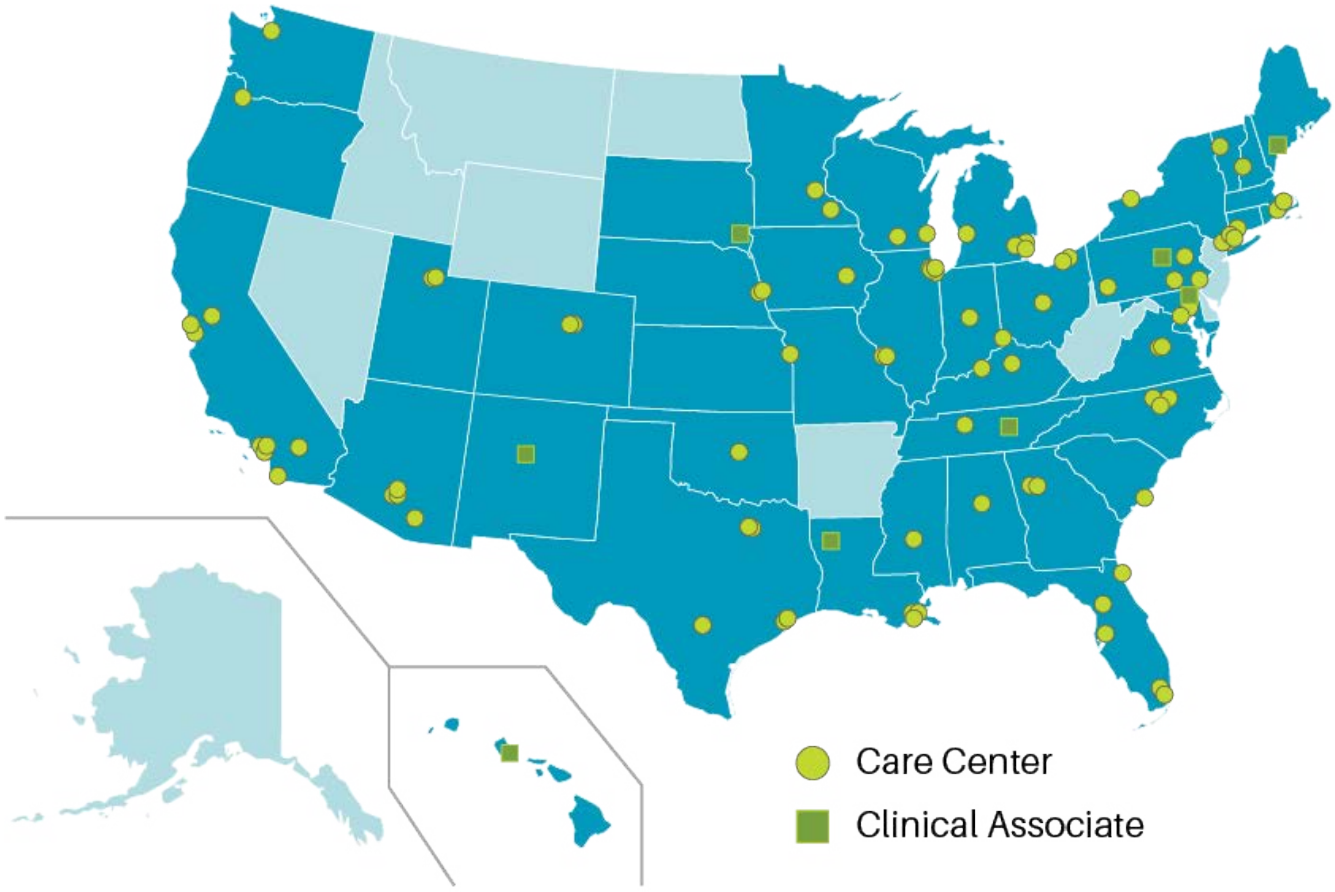
These goals matter because they help answer the questions patients, families, clinicians, researchers and industry partners ask every day: *Who is most at risk? Why does the disease progress differently from person to person? How can we identify it earlier? And how can we increase the speed of promising treatments?*

A larger, more diverse Registry will help:

- **Strengthen the data.** More participants give researchers a clearer understanding of how PF and ILD affect different people, families, and communities.
- **Improve representation.** The Registry can help researchers examine certain overlooked groups, such as families affected by familial PF, patients in rural and underserved areas, and people living with ILD subtypes beyond idiopathic pulmonary fibrosis.
- **Support earlier detection.** By including biological family members, the Registry opens the door to studying early lung changes and genetic risk factors in people who may not yet have symptoms.
- **Move research forward.** More peer-reviewed publications mean more opportunities to build knowledge, sharpen understanding, and bring better care and treatments to patients.
- **Strengthen the path to clinical trials.** A larger Registry can help identify more potential trial participants, giving researchers and industry partners greater confidence to pursue PF and ILD studies that may otherwise be difficult to recruit for.

This is why continued investment matters now. A larger, more diverse Registry strengthens the research infrastructure needed to support new studies, accelerate discovery, and move promising treatments closer to every PF family.

Collaborations



PFF Care Center Network™
Care. Education. Innovation.

The PFF Care Center Network, which includes 96 medical centers across 40 states, is essential to the growth and impact of the PFF Registry. The Centers help connect patients to the Registry, educate them on the value of participation, and serve as clinical sites where data is collected. Their involvement helps ensure the Registry reflects the real-world patient needs and remains a strong resource for advancing research, improving care, and accelerating progress for people living with PF and ILD.

Researchers

The PFF Registry offers researchers and health care professionals a unique opportunity to learn directly from the experiences of people living with pulmonary fibrosis and interstitial lung disease. Researchers and HCPs can examine Registry data to better understand patient experiences, explore new questions, and help inform future research, education, and care. Learn more about submitting a proposal here.

PFF Registry Donors and Partners*

**Genentech,
a member of the Roche Group**

**Boehringer Ingelheim
Pharmaceuticals, Inc.**

Chiesi Farmaceutici S.p.A.

United Therapeutics Corporation

InterMune, Inc.

**Mr. and Mrs. Chuck
and Monica McQuaid**

The Cowlin Family Fund

Peter L. O'Neill Memorial Fund

Three Lakes Foundation

Rattner Family Foundation, Inc.

**Gift in memory of
Dr. Nalinkant A. Patel**

Biogen, Inc.

The Buckeye Foundation

The Hales Family Foundation, Inc.

Mrs. Sally Willis

The Goldhirsh-Yellin Foundation

Ms. Nelda Hagaman

**Mr. and Mrs. Fred and Virginia
Krauss**

Steffy Family Foundation Fund

2015 Hike Around Mont Blanc

Rouine Run

**Michael P. Savoca
Memorial Foundation**

**2013 Pete DeVito
Memorial Foundation Golf Outing**

**Mr. and Mrs. Paul
and Susan Bergna**

Ms. Ellen Kirchner

Mr. John Murray

Mr. Mike Henderson

G. Johanneson Family Foundation

Stoelting Co.

Mr. Bill Amick

**Minnesota Pulmonary Fibrosis
Support Group**

** Donor List of $5,000+ as of May 15, 2026*

Donate to the PFF

Behind every finding in this report is a patient who chose to participate, a family who hoped it would matter, and a community that showed up.

Your gift is what makes their contribution count.

Give today and help us reach the patients who need us next.

Pulmonary Fibrosis Foundation | 2025 Years