



**PFF Registry**™

Patient powered.  
Data driven.  
Research results.

# 2021 Annual Report



Expanding Our Reach







## NEW PFF REGISTRY LOGO PUTS THE FOCUS ON PATIENTS

When the time came to design a new logo for the PFF Registry, one thing was clear: “We wanted to keep the focus on the patient and how we bring the PF community together,” says Junelle Speller, Vice President, PFF Registry. “Our focus on improving life for patients with pulmonary fibrosis drives everything we do.”

Remarkable in its simplicity, the new logo features an abstract drawing of a person. The upraised arms signify hope, while the PFF’s familiar blue and green colors represent the way the PFF Registry links patients and researchers. The figure’s

intersecting lines subtly remind the viewer of both the medical profession’s caduceus symbol and the helix of our own DNA.

The new logo complements — but never overwhelms — the bold type and stylized lungs of the PFF’s overall logo. Finally, the PFF Registry’s new tagline appears with the figure to round out the new logo in a fresh, memorable way.



**DEAR FRIENDS,**

As the newly appointed Chief Medical Officer of the Pulmonary Fibrosis Foundation, I am honored to help lead the tremendous effort to expand the PFF Registry.

With more than 250,000 Americans living with pulmonary fibrosis (PF) and interstitial lung disease (ILD), the quest for faster and more accurate diagnoses, better treatments, and a cure is more urgent than ever. What we do know is that more research is vital for improving the lives of patients and, ultimately, preventing these diseases.

We are proud to announce the launch of the PFF Community Registry. This new data set will share even more information — from patients living with PF and their caregivers and family members and lung transplant recipients who have had PF — with researchers for analysis.

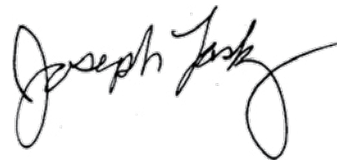
Researchers currently have access to almost five years of data from patients who joined the PFF Care Center Registry when it opened for enrollment in 2016. To date, almost 40 studies have been developed or are underway using this data at no cost to investigators.

These studies examine questions such as the use of antifibrotic medications, impact of cough on quality of life, and characteristics associated with patients using oxygen. This all translates to a value of over \$32 million that would be needed to conduct this research.

As we stand on the cusp of new solutions for patients with PF and their loved ones, we invite you to join us in the PFF Registry. Whether you enroll or make a gift to the Registry, your support of our efforts to accelerate progress and provide data to researchers is crucial.

The PFF Registry is the gateway to a world without pulmonary fibrosis. Join us today!

Sincerely,



**Joseph Lasky, MD**  
Chief Medical Officer



Visit the new PFF Registry website at  
[PFFRegistry.org](https://PFFRegistry.org)

# What is the PFF Care Center Registry?

## THE PFF CARE CENTER REGISTRY CELEBRATES FIVE YEARS

The PFF Care Center Registry is an observational database that follows the care of patients with interstitial lung diseases including idiopathic pulmonary fibrosis (IPF), hypersensitivity pneumonitis, and other diagnoses. It records, analyzes, and reports information about participants' health status and medical care over time. Since 2016, the PFF Care Center Registry has collected medical data from 2,000 patients with PF who receive care at one of the PFF Care Center Network hospitals throughout the U.S. Unlike a clinical trial where subjects follow a specific treatment protocol, the Care Center Registry captures data from patients' real-world healthcare experience. The PFF Care Center Registry is one of the first nationwide research studies and biorepositories that lets researchers

explore and find new ways to diagnose, treat, and potentially cure PF. By collecting and studying participants' data, blood samples, and high-resolution computed tomography (CT) scans, we are increasing our understanding of what a typical disease course might be in PF. Researchers also use the PFF Care Center Registry to study diagnostic and predictive biomarkers, proteins that indicate that a person has PF or may develop it. "During the past five years, the PFF Care Center Registry has made huge amounts of data available to researchers and a clearer picture of PF is now emerging," says Kevin Flaherty, MD, MS, PFF Registry Steering Committee Chair. "Looking forward, the Registry is poised to make even greater contributions to PF research."

### WHAT IS PULMONARY FIBROSIS?

PF is not one disease but a family of diseases that cause scarring in the lungs. The PF family of lung diseases is part of an even larger group of diseases called interstitial lung diseases. ILDs have varied amounts of inflammation, scarring, or both, in the lungs. Even though more than 250,000 Americans currently live with PF and ILD, doctors know relatively little about these diseases, including how best to diagnose and treat them. In many cases, PF is incurable.

In PF, scar tissue and inflammation build up in the walls of the lungs' air sacs. When the damage becomes severe, it is difficult for oxygen to pass into the bloodstream. Breathing becomes a constant challenge. For far too many people with PF, premature death is the result.

PF symptoms — which include persistent cough, shortness of breath, and fatigue — are often mistaken for asthma, chronic obstructive pulmonary disease (COPD) or even the natural results of aging.

Because PF symptoms are not specific to the disease, making a prompt and accurate diagnosis is challenging. But it's important. Early treatment can delay and lessen symptoms, and some clinical trials have shown that current therapies can extend patients' lives.

The most common PF-related diagnosis is idiopathic pulmonary fibrosis, which means that no cause can be identified. In other cases, PF can be linked to airborne contaminants, autoimmune diseases, certain medications, genetics, or radiation therapy.





# Patient Powered

The PF patient journey is difficult and can feel isolating. Every person diagnosed with PF has a unique experience with the disease. Some patients remain in a stable condition for years, while others experience rapid deterioration. Most patients find themselves having both good days and bad days.



## **RICK RUDELL: REACHING THE FIVE-YEAR MARK**

Rick Rudell and his wife, Martha, observed twin milestones in 2021: five years since his IPF diagnosis and five years enrolled in the PFF Care Center Registry.

Earlier this year, the PFF Ambassador and support group leader from Virginia Beach, Virginia, made a big decision about his medical future.

“After years on the transplant list at Duke, I finally decided to opt out,” Rudell says. “I don’t think my body could handle transplant and would rather take what I’ve got, which seems to be a slow ride into the sunset.” In the meantime, life is good. “There’s nothing I can’t do that I want to do,” he added.



I’m now past the five-year mark they usually give you for mortality. I can only credit that to research and learning, so I think I have profited from the Registry.

### **RICK RUDELL**

PFF Ambassador and Care Center Registry Participant



## KEN VELLA: STABILITY IN A NEW HOME

For PFF Support Group Leader Ken Vella and his wife Eileen, the COVID-19 pandemic spurred the realization that it was time to live closer to their children and grandchildren. After initially retiring to the Carolinas, the couple moved to Traverse City, Michigan, in September 2020. "We're not afraid to make a change when it makes sense for us," says Ken, who was diagnosed with IPF in 2018.



The Michigan native and PFF Care Center Registry participant is also excited about joining the PFF Community Registry. "If the PFF Registry as a whole helps accelerate clinical trials and earlier diagnosis, then it's done something very valuable for all of us," he says. "I continue to want to help in any way I can."

Vella enjoys swimming laps at the local pool and walking the trail network near his new home. After daily morning exercise, his afternoons often include a nap. "Sometimes, I have to adjust that day's plans but my overall condition is stable, for which I'm grateful," he adds.

## PFF CARE CENTER REGISTRY BY THE NUMBERS

79

DISTINCT DISEASES  
ACROSS SIX  
CATEGORIES

300+

INDIVIDUAL DATA  
ELEMENTS  
COLLECTED PER  
PATIENT

## FIVE FACTS ABOUT THE PFF CARE CENTER REGISTRY



1. Launched in 2016, this safe and secure registry will enroll up to 2,000 eligible patients at PFF Care Centers starting in 2022.



2. The data includes patient demographics, diagnosis, medical history, medications, medical events, and lab and other measurements



3. Trained research coordinators enter patient data after office visits or hospitalizations.



4. Researchers have already used Registry data for nearly 40 studies that may translate into improvements in patient care.



5. The PFF Care Center Registry also contains a biorepository of participants' blood samples and high-resolution CT reports to help answer researchers' questions.



# The PFF Community Registry is Here!

If you've been reading updates about the PFF Care Center Registry during the past five years wishing you could participate, we have great news. The new PFF Community Registry has just come online, and you're welcome to join!

Everyone who is touched by PF can enroll, including patients living with PF from any part of the U.S., family members, caregivers, and lung transplant recipients who have had PF. Your experience matters!



“ We desperately need more research. I've been living with PF since 2009, and I just want my life back. ”

**VALERIA HATCHER**

Former PFF Ambassador

## MAKE YOUR VOICE HEARD

The PFF Registry now consists of two distinct data sets: the PFF Care Center Registry and the PFF Community Registry.

PFF Community Registry participants will report their own data from home via a series of regular questionnaires uploaded through an easy-to-use online portal. “Surveys will average about 45 minutes to complete, and we will tell you at the start how much time each will take,” says Junelle Speller, Vice President, PFF Registry. “You should be able to answer most questions in our surveys without consulting your medical provider or records, and you can stop participating at any time.”

The PFF Community Registry database is safe and highly secure. It uses the same technology trusted by doctor's offices, hospitals, and clinical trials worldwide. As a part of the PFF Community Registry, you will receive monthly emails and quarterly newsletters so you can see how your information is helping shape the future of PF research. To join the PFF Community Registry, enroll and complete the baseline questionnaire. You will receive follow-up surveys every six months and may receive additional questionnaires periodically.

Note: All Care Center Registry participants also should enroll in the Community Registry.





The PFF Community Registry will give us new perspectives on what's important to patients and their caregivers and family in diagnosing and treating pulmonary fibrosis. It will let us know where we can do better as providers in giving them what they need to live better with pulmonary fibrosis.



**TRACY LUCKHARDT, MD**

University of Alabama at Birmingham  
PFF Registry Steering Committee



### WHEN PF BECOMES A FAMILY AFFAIR

When Gary Cunningham received his pulmonary fibrosis diagnosis, it came as a shock but not a total surprise. His mother and grandfather had both died of the disease. "I was able to last for eight years post-diagnosis before I got a transplant, but it was extremely difficult," he says. During that time, he focused on preserving his health by exercising, doing pulmonary rehabilitation, and joining a PF support group.

As a transplant recipient, Cunningham is excited to join the new PFF Community Registry. "Lung transplant recipients know the challenges, pitfalls, and miracles that happen better than anybody," he says. "If you're looking for opinions on the process of getting care and coping with this disease, we're the ones to ask."

Gary's son, Greg, is also eager to share his thoughts in the PFF Community Registry as a family member and former caregiver. "PF comes on fast with a steep learning curve for caregivers, so there's a huge need for information from the community," he says.

Greg's hope is that data gathered in the PFF Registry will eventually translate to real clinical improvements. "Am I going to deal with PF myself 25 years from now?" he says. "We need more solutions than just transplants, and the way forward is to keep investing in projects like the PFF Registry to ultimately find a cure."



I'm really pleased that family members and caregivers can register for the PFF Community Registry because when I was awaiting my lung transplant, I was doing everything I could just to survive. I didn't have the strength or clarity of mind to answer questionnaires, but my family and caregivers could have shared information about that important time.

**LAURIE CHANDLER**

PFF Board of Directors  
Lung Transplant Recipient



**PFF REGISTRY PROBES HEALTH DISPARITIES**



Ayodeji Adegunsoye, MD, of the University of Chicago, believes that broadening the PFF Registry to two data sets will help researchers find answers more quickly. "My research has already shown that Blacks

develop PF 10 years earlier and die sooner, but we don't know why," he says. "The first step in eliminating health disparities is to understand them, and the PFF Registry can help."

**PFF COMMUNITY REGISTRY FAST FACTS**

This vital new research opportunity can help speed the progress toward a cure for PF.

**The PFF Community Registry is:**

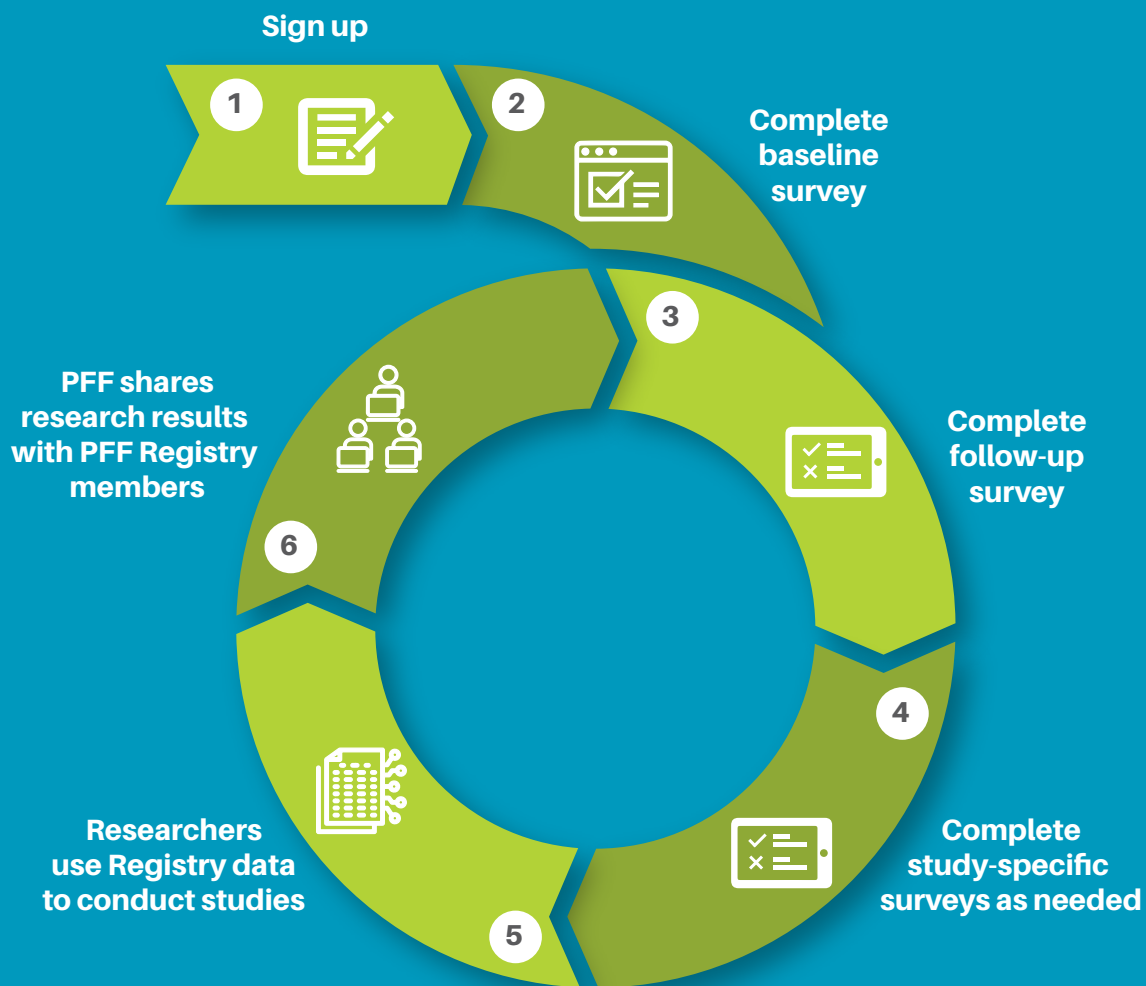
- Enrolling now**
- Safe and secure**
- Free and easy to use**
- Open to everyone touched by PF, anywhere in the U.S.\***

*\*Patients living with PF, caregivers, family members, and lung transplant recipients who have had PF can participate.*

# PFF Community Registry: Everyone Benefits

Participating in the new PFF Community Registry is easy! The more people participate, the more we all benefit. And those benefits will only increase over time. The more data the PFF Registry adds, the more questions researchers can answer.

**IF EVERYONE JOINS, THE POTENTIAL OF THE PFF REGISTRY IS UNLIMITED!**



## POSSIBLE LONG-TERM OUTCOMES

The PFF Community Registry hopes to contribute to tangible, positive change in each of the Registry's four target areas of improvement. Here's how that might play out:

**Research** » Published in peer-reviewed journals

**Education** » Resources for patients & families

**Advocacy** » Targeted legislative efforts

**Practice** » Improved care delivery methods

**ENROLL TODAY AT [PFFREGISTRY.ORG!](https://pffregistry.org)**



# Data Driven

Biomarkers — molecules that reveal whether a biologic process is happening inside the body — can potentially identify people who:

- Have a specific disease.
- Are at risk of developing that disease.
- Might have better or worse disease outcomes.
- Can receive a treatment safely.
- Might respond better to one treatment than another.

Is there such a thing as biomarkers for PF? If so, what are they and what information can they provide? The PFF and the PFF Registry are supporting two major efforts — the PROLIFIC Consortium and the PRECISIONS clinical trial — to answer these crucial research questions.



“

A registry is the central way we can understand rare diseases like pulmonary fibrosis. We learn about the disease’s basic biology and over time can elevate quality of care for all patients. The PFF Care Center Registry has made a major contribution to our field in a remarkably short time.

”

**PAUL WOLTERS, MD**

University of California San Francisco  
PFF Registry Steering Committee

## PROLIFIC: BIOMARKERS MAY HOLD THE KEY TO PF

The PFF partnered with Bristol Myers Squibb to create the Prognostic Lung Fibrosis Consortium (PROLIFIC for short), which has an ambitious goal:

To simplify drug development by promoting cooperation among competing drug manufacturers. This collaboration includes 12 industry partners and two foundations.

- **Epithelial damage** (CYFRA21-1, SP-D, CA-19-9, CA-125, KL-6)
- **Fibrosis** (MMP-7, TN-C, POSTN)

- **Inflammation** (CCL 18, CXCL13, ICAM-1)
- **Thrombosis** (PAI-1)

The PFF Care Center Registry will play a key role in PROLIFIC’s efforts. Once a multi-assay panel has been developed, consortium members will test patient samples from the PFF Registry’s biorepository to validate their results.

Learn more at the new PROLIFIC website:  
[www.pulmonaryfibrosis.org/prolific](http://www.pulmonaryfibrosis.org/prolific)



# PRECISIONS Study

Both biomarkers and the PFF Care Center Registry play a critical role in PRECISIONS, a multicenter clinical trial that relies on PFF Care Center Registry data and biosamples. In one of the largest governmental grants for PF-related research, PRECISIONS has received \$22 million in funding from the National Heart, Lung, and Blood Institute (NHLBI) and the Three Lakes Foundation across six years.



## PRECISIONS: NAC UPDATE

PRECISIONS studies whether the over-the-counter supplement N-acetylcysteine (NAC) can treat people with IPF who have a specific gene variant. Co-principal investigator Fernando Martinez, MD, MS of Weill Cornell Medicine and New York-Presbyterian Weill Cornell Medical Center, reports that PRECISIONS is on track. "Enrollment is exactly on schedule and the percentage of patients with the gene variant are exactly as predicted," he says. "NHLBI is pleased with our progress and ability to recruit patients even during the pandemic."

## PRECISIONS: GENETIC VARIANTS UPDATE

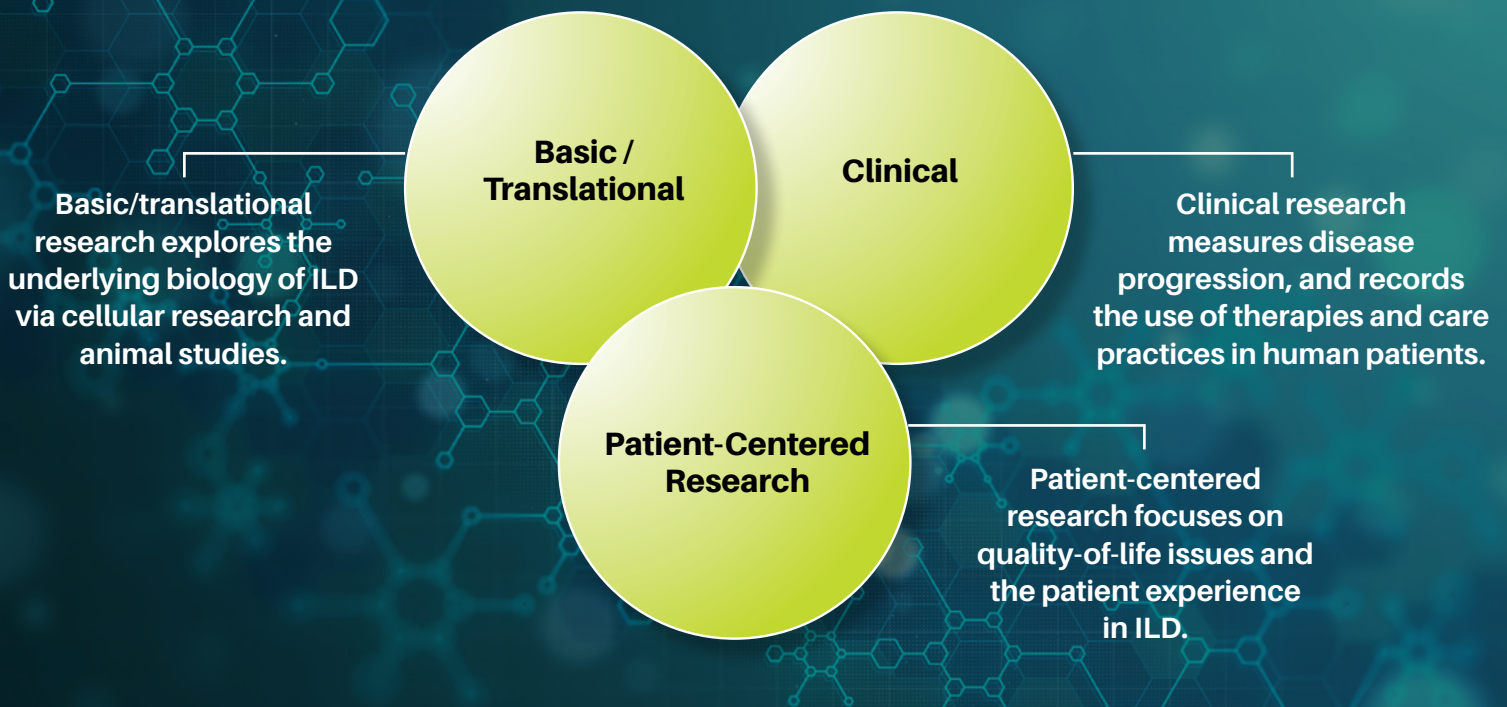


PRECISIONS also has another goal: To identify genetic variants that influence an individual's risk of developing PF. This portion of the research consists of determining the genetic makeup of certain samples within the PFF Care Registry. "We've been able to accelerate some of this analysis, so that we're ahead of schedule," Martinez says. PRECISIONS is due to be completed in 2025.

# Research Results

With the answers to many key questions about PF closer than ever before, it's important for the PFF to use our resources and influence strategically to further the most promising research. We do this in several different ways.

To submit a proposal to use PFF Registry data in your research, visit:  
[bit.ly/pffregistryresearch](http://bit.ly/pffregistryresearch)



## RESEARCH: THE PFF CARE CENTER REGISTRY

Currently, almost 40 research projects are underway or have been completed using data and/or biosamples from the PFF Care Center Registry. Most of these studies are clinical in nature, but basic/translational projects and patient-centered research are also well represented. The PFF Care Center Registry makes this research possible, because it collects:

- Test results, including pulmonary function tests
- Medication use, including antifibrotics
- High-resolution CT (HRCT) scans, uploaded for researcher access
- Medical outcomes such as hospitalization



Hyun Kim, MD, of the University of Minnesota, is using PFF Registry data to determine whether rural vs. nonrural locations affect ILD diagnosis and access to care. "My hypothesis is that rural patients face

disparities based on their geographic location," she says. The PFF Registry will provide summary CT reports, pulmonary function test results, and medication use data, which Kim can then cross reference by ZIP code.



The PFF Registry allows us to answer a lot of questions about natural history, access to care, treatment, and quality of life. This registry is unique in that it will give us the opportunity to figure those things out, even as it encourages collaboration among investigators from multiple institutions.

**HYUN KIM, MD**  
University of Minnesota



**PFF CARE CENTER REGISTRY BY THE NUMBERS**



**PFF SCHOLARS**

The PFF Scholars program provides financial support and mentorship to promising early-career PF researchers via competitive two-year research grants. The goal is to prepare them to earn future support from key funders like the National Institutes of Health. “Later governmental funding is critical to enable PFF Scholars to advance their research careers and stay committed to the study of interstitial lung disease,” notes Zoe Bubany, Vice President, Board & External Relations for the PFF. “We want to give these young researchers the best start down that path.” PFF Scholars can use PFF Registry data for their approved research projects.



For example, Gillian Goobie, MD, is using PFF Registry data to help understand how exposure to airborne pollutants over time affects clinical outcomes in patients with fibrotic ILD. “I can cross reference

de-identified PFF Registry patient data with atmospheric pollutant data to further explore early associations between higher pollutant exposure and increased mortality in ILD patients,” she explains.



# The Power of Collaboration

As one of the largest nonprofit funders of PF research, the PFF forges meaningful collaborations with the nation's top research institutions, industry partners, and government agencies with the shared goal of finding a cure for these devastating diseases. These collaborations take many forms, but all have the goal of working toward a cure for PF.



## UNITED THERAPEUTICS COMES ON BOARD

Earlier this year, the PFF Registry added its newest sponsor, United Therapeutics, as Visionary Partner. Meredith Broderick, PharmD, JD, Director, Medical Affairs at United Therapeutics, calls the partnership mutually beneficial.

Broderick notes that FDA approval for drugs is based on short- to medium-term data from clinical trials. This can leave manufacturers with knowledge gaps about how their therapies perform in the real world. "We wanted to get long-term data on our therapies in clinical practice and then learned that the PFF Registry already collects this type of data," she says. "The PFF Registry does fantastic, meaningful research, and we're honored to support this important resource."

## THANK YOU TO OUR REGISTRY LEAD SPONSORS

The PFF Registry is an invaluable resource, but it wasn't created in a vacuum. Rather, a vast network of clinical and research expertise, including from many industry partners, has helped make it possible.

The PFF would like to recognize some of the most important partners including:

**Genentech**  
Founding Partner

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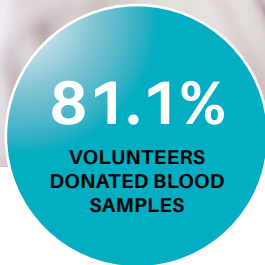


SABER’s primary aim is to help researchers get maximum use out of this precious resource — the data and samples provided by patients — so that many scientific questions may be answered and added to the body of knowledge. This will ultimately improve the lives of patients with PF now and in the future.

**ELIZABETH FREIHEIT, PHD**  
Data Coordinating Center Director,  
SABER at the University of Michigan



**PFF CARE CENTER REGISTRY BY THE NUMBERS**



**SABER SUPPORTS THE PFF REGISTRY**

The Statistical Analysis of Biomedical and Educational Research (SABER) Data Coordinating Center (DCC) at the University of Michigan is another important part of the PFF Registry infrastructure. SABER provides computing support and houses the PFF Registry’s clinical databases and biosamples.

SABER also coordinates researchers’ access to PFF Registry data and sends out biosamples and HRCT scans to approved researchers as needed.

Additionally, SABER biostatisticians work with researchers to hone their ideas and verify that PFF Registry data can support the proposed study. Support from SABER data scientists continues throughout the research process, up to and including preparing manuscripts for publication.

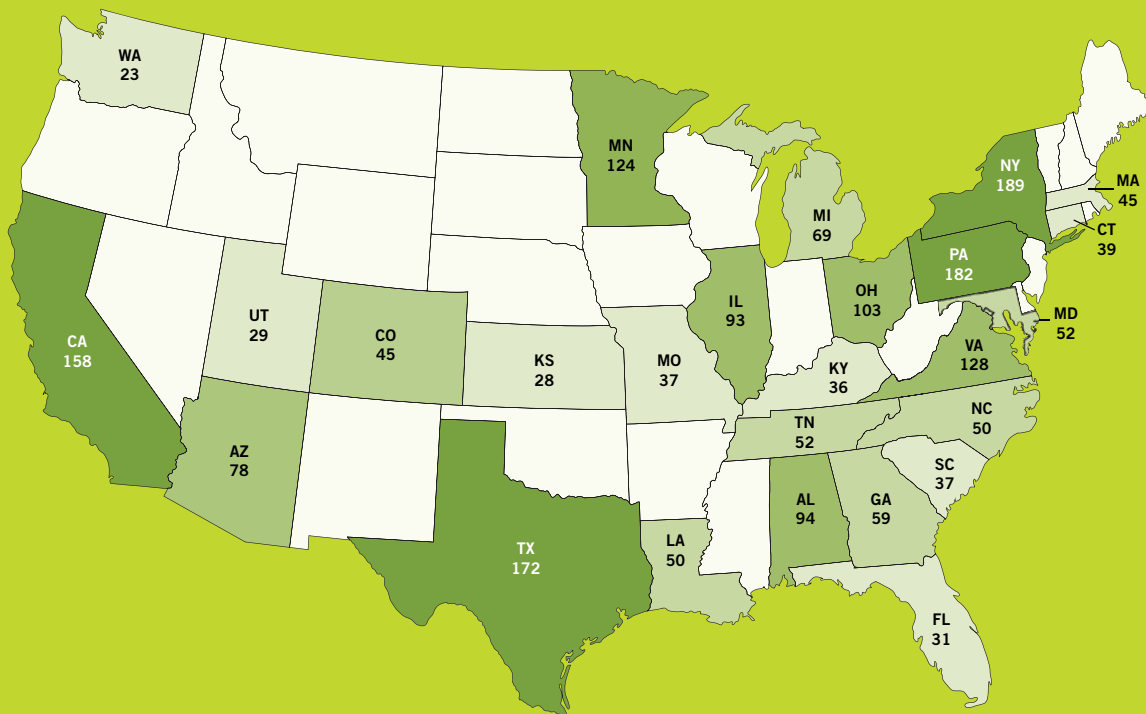
“We never forget that there is a real person behind every statistic in the PFF Registry,” says Cathie Spino, ScD, Director of SABER. “That knowledge drives us forward every day.”

# Care Center Network: Accelerating PF Care and Research

The PFF Care Center Network, consisting of 68 centers in 33 states with high-quality interstitial lung disease (ILD) programs, forms the basis of the PFF Care Center Registry. Patients who participate in the Care Center Registry must receive their care at a PFF Care Center.

When the PFF Care Center Registry launched in 2016, the Care Center Network had 42 member institutions. Registry enrollment, capped at 2,000, was limited to patients at those centers.

## NUMBER OF PATIENTS IN THE PFF CARE CENTER REGISTRY BY STATE



If you receive your PF care at one of the PFF Care Centers, you may be eligible to join the PFF Care Center Registry in 2022. Ask your care team if you qualify!

### PFF CARE CENTER REGISTRY TO REOPEN

Now, in conjunction with the PFF Community Registry launch, the PFF Care Center Registry will once again open to enrollment in 2022. Patients at any of the current Care Centers will be eligible to join until full enrollment of 2,000 has been achieved.

“Including patients from the expanded Care Center Network will give a better understanding of how care is delivered across the country,” says Jessica Shore, PhD, RN, Vice President, Research and Programs for the PFF. “It will highlight best practices across the network so we can replicate these care practices nationwide, benefitting all patients.”

# Sponsorship and Funding

Contact Jennifer Mefford, Vice President, Corporate Partnerships for the PFF, at [jmefford@pulmonaryfibrosis.org](mailto:jmefford@pulmonaryfibrosis.org) to discuss corporate sponsorship of the PFF Registry.

In order for the PFF Care Center Registry to reach its full potential, this multimillion dollar effort must reopen to patient enrollment to repopulate as patients leave the Registry due to death or transplant. Planning and fundraising are underway for the next phase of the PFF Registry. Your gift to the PFF Registry will

enable us to expand patient enrollment and provide even greater access to investigators as they progress toward finding for a cure for PF.

**The PFF gratefully acknowledges Genentech, a member of the Roche Group, as Founding Partner of the PFF Registry.**

**\$3.5  
MILLION**

NEEDED ANNUALLY  
TO OPERATE THE  
REGISTRY

**\$1,250**

COST PER PATIENT  
PER YEAR

**\$600**

COST PER BLOOD  
COLLECTION SAMPLE  
FOR ITS USABLE  
LIFE

**\$150**

COST TO ADD EACH  
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The science of interstitial lung disease is advancing because of collaborative efforts of the patient community, industry, academia, advocacy groups, and the government all working together to help patients. Genentech was very proud to be the Founding Partner for the PFF Registry.



**JACK STAUFFER, MD**

Senior Medical Director, Genentech, Inc.

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\*\*As of October 2021. Donors listed have given \$5,000 or more to the PFF Registry

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