

# A Community of Care 2021 Annual Report



## OUR MISSION

The mission of the Pulmonary Fibrosis Foundation is to accelerate the development of new treatments and ultimately a cure for pulmonary fibrosis. Until this goal is achieved, the PFF is committed to advancing improved care of patients with PF and providing unequalled support and education resources for patients, caregivers, family members, and health care providers.

**844.TalkPFF (844.825.5733) | [help@pulmonaryfibrosis.org](mailto:help@pulmonaryfibrosis.org)  
[pulmonaryfibrosis.org](http://pulmonaryfibrosis.org)**



## DEAR FRIENDS,

After more than two years of learning how to co-exist with COVID-19, I continue to be humbled and grateful for the dedication and resourcefulness we've all seen from our healthcare providers throughout the pandemic. And I remain impressed by the continued energy and resilience of the pulmonary fibrosis (PF) community. Our collective willingness to embrace new approaches has meant that we at the Pulmonary Fibrosis Foundation (PFF) have continued to progress in our mission of accelerating the development of new treatments and improving care for people living with PF, all while providing unequalled support to those who care for them.

This year, the PFF launched one of its most important research initiatives to date: The PFF Community Registry. The PFF Community Registry is the first self-reported registry for all community members affected by pulmonary fibrosis or interstitial lung disease. Each case and experience is unique and much about PF and ILD remains unknown. Knowledge is the first step in understanding how to positively help all who are impacted by these diseases. You can learn more and enroll today at [PFFRegistry.org](https://www.pffregistry.org).

In another highly anticipated launch, I'm delighted to share that this year, the PFF Walk 2022 returned to the familiar series of live events we have all missed so much! The Walk was held in six cities, as well as the opportunity to participate in National Walk Day, a virtual component so that the community can participate from anywhere nationwide — or even globally.

In addition, the PFF participated in the first-ever Interstitial Lung Disease (ILD) Day on September 15 in conjunction with Pulmonary Fibrosis Awareness Month. Because PF can be seen in many types of ILD, we were proud to join other organizations including the Arthritis Foundation, Foundation for Sarcoidosis Research, The Myositis Association, PF Warriors, Scleroderma Foundation, Scleroderma Research Foundation, Sjögren's Foundation, and the Wescoe Foundation for Pulmonary Fibrosis in driving awareness of ILD, including participating in an informational webinar. Moving forward, this has become an annual occurrence for the PFF.

Clinical trial recruitment continues to be a challenge in all fields. In partnership with Carebox, an organization that connects patients and doctors with clinical trials, the PFF Clinical Trials Finder ([trials.pulmonaryfibrosis.org](https://trials.pulmonaryfibrosis.org)) is moving to a new level of search customization. The new and improved tool will help potential participants identify appropriate trials even more effectively.

The unwavering loyalty of the PF community has fueled all of this progress—and is key to our ongoing impact. In this report, I hope you take great delight in the accomplishments we've made together. It is only with your support that we can continue to push forward with more research and improved programming as we move closer to a cure.



**William T. Schmidt**  
President and CEO



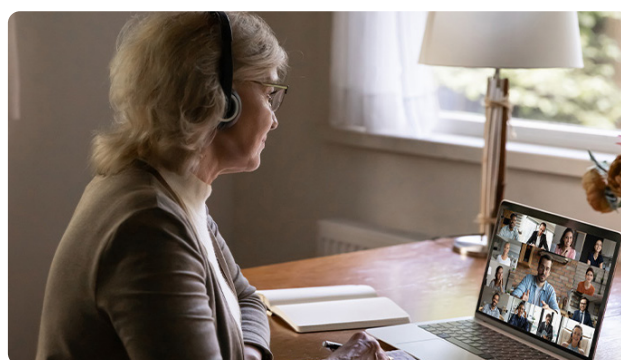
# Volunteers Raise Awareness and Receive Training from the PFF



PFF volunteers serve and advocate for the PF community through numerous roles. PFF volunteers receive training throughout the year to build upon their leadership and engagement skills as well as discuss best practices to approaching challenges the PF community is facing.

One way to volunteer is to become an ambassador of the Foundation. The PFF Ambassador program empowers patients, caregivers, lung transplant recipients, family members, and those who have lost a loved one to serve as spokespeople for the PF community. Comprising a diverse and dynamic group of volunteers, PFF Ambassadors undergo formal training to prepare for speaking and advocating on behalf of the pulmonary fibrosis community. PFF Ambassadors represent the Foundation as they attend events like support group meetings, education panels, fundraisers, and other disease awareness programs around the country.

Another way to volunteer is by starting a support group. The PFF Support Group Leader Network provides a forum for PF Support Group Leaders to connect, exchange ideas, and share new approaches.



The PFF's Support Group Leader Network consists of over 150 support groups across the country.

On October 13, the PFF held the 2021 Annual Volunteer Meeting for PFF Advocates, PFF Ambassadors, Support Group Leaders, and other engaged volunteers. This year's meeting was a virtual event and the agenda included a PFF resource overview, a roundtable discussion on leading a successful support group facilitation, and an informative presentation on preparing for a successful event. The meeting included an opportunity to meet and connect with other volunteers from around the country over lunch. More than 60 volunteers registered to attend this event and learned to grow in their volunteer roles from attending.

The PFF launched a new opportunity for PFF Volunteers in January 2022. The PFF Volunteer Lunch 'N Learn is a networking and education opportunity exclusively for the Foundation's PFF Ambassadors and Support Group Leaders. The PFF Volunteer Lunch 'N Learn was created to offer volunteers the chance to meet with other volunteers, hear from PFF staff members, learn about other disease-specific nonprofit organizations, and more. PFF Volunteer Lunch 'N Learn sessions take place during the lunch hour (12:00 p.m. - 1:00 p.m. Central Time) and are hosted on Zoom. Topics covered this year began with an "Ask Me Anything" session with PFF Chief Operating Officer, Scott Staszak; a "Storytelling and Medical Outcomes" session focused on the power of storytelling to improve healthcare options; and

an overview from the Pulmonary Hypertension Association on their advocacy efforts, patient education programs, and support resources. The PFF looks forward to featuring more of our partners in future sessions.

In April 2022, the PFF introduced the Class of 2022 Ambassadors consisting of 19 new members to the program. This year's class of Ambassadors includes nine patients, five lung transplant recipients, one caregiver, and four individuals who have lost a loved one. Their stories span from across the United States showcasing their unique experiences and perspectives as members of the PF community. As PFF Ambassadors, they promote disease awareness and offer hope and inspiration to those affected by pulmonary fibrosis.

## PATIENT EDUCATION AND RESOURCES

The Pulmonary Fibrosis Foundation continued to provide accurate and comprehensive education materials for pulmonary fibrosis patients, caregivers, and lung transplant recipients in a variety of accessible formats. A number of videos were created and published on the Foundation's YouTube channel, including a video series on the types of pulmonary fibrosis and the Spanish translation of the "Myths and Misconceptions" series. The videos of the Spanish "Myths and Misconceptions" series have amassed over 9,000 views on YouTube and can be watched as a playlist for easy viewing.

Additionally, the Pulmonary Fibrosis Foundation created the Patient Stories and Disease Education DVD. This new resource features 23 of the Foundation's popular educational videos from YouTube. For those unable to access videos via the internet or inexperienced with the YouTube platform, the same information can now be viewed in a more traditional format. With this DVD, viewers can learn more about interstitial lung disease from pulmonologists, hear from patients living with pulmonary fibrosis, and discover ways to get involved in research or with a support group. The Patient Stories and Disease Education DVD was available at no cost via the PFF Help Center.

The Pulmonary Fibrosis Foundation Disease Education Webinar Series offered another source of education to the pulmonary fibrosis



community. The PFF Disease Education Webinar Series provides a free, convenient way for patients, caregivers, and families to learn from and connect with PF specialists on a variety of important topics. The PFF Disease Education Webinar Series hosted eight webinars during this timeframe along with two additional webinars in conjunction with the American Thoracic Society Public Advisory Roundtable. The PFF Disease Education Webinar Series topics included: research updates, genetic counseling, multidisciplinary care teams, financial assistance programs available to pulmonary fibrosis patients, palliative care, and more. The PFF Disease Education Webinar series hosted over 1,200 live attendees. Webinars are recorded and available for viewing on both the Pulmonary Fibrosis Foundation website and YouTube channel. Webinars from the PFF Disease Education Webinar Series from this timeframe have amassed over 7,000 views on YouTube alone.

## PFF Advocates Promote Policies that Support PF Research

PFF Advocates communicated with their lawmakers to promote funding for pulmonary fibrosis research. The United States federal government is a key source of funding for basic, translational, and clinical research into PF. By advocating with their members of Congress, PFF volunteers ensured that PF would continue to receive robust research funding.



PFF Hill Day was held in March 2022 when more than 40 patients living with PF, lung transplant recipients, caregivers, and healthcare providers met with their congressional offices to ask for support for PF research. Volunteers made two requests of their congressional offices:

- Include language in the congressional funding report for Fiscal Year 2023 for the National, Heart, Lung, and Blood Institute (NHLBI) on the importance of pulmonary fibrosis research

- Maintain pulmonary fibrosis as a topic area in the Peer Reviewed Medical Research Program (PRMRP) at the U.S. Department of Defense

Both of these requests were successfully implemented by Congress. Throughout the year, PFF Advocates also communicate with their members of Congress via email to continue to raise awareness of PF and to ensure that PF research is funded.

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## Get Matched With Clinical Trials!

This year, the Pulmonary Fibrosis Foundation launched the Clinical Trial Finder on the PFF website, hosted by Carebox. The PFF Clinical Trial Finder is a comprehensive list of studies for pulmonary fibrosis related conditions. Upgraded tools and functionality have been added to increase the ease of use for patients, caregivers, and families. Simply fill out a short questionnaire, and the Finder will automatically identify trials in North America with eligibility criteria that are a preliminary match!



Participation in clinical trials is important for patients, as research allows care providers to expand their knowledge on pulmonary fibrosis. This leads to improvements in medications and treatments of the disease. Additionally, clinical trials can show which medical approaches work best for specific types of illnesses or groups of people. Studies follow strict scientific standards which protect patients and help produce reliable study results.

Visit [trials.pulmonaryfibrosis.org](https://trials.pulmonaryfibrosis.org) to begin searching today!

## New Class of PFF Scholars Excels Research

The PFF Scholars program focuses on engaging early-career investigators in their emerging research in the field of pulmonary fibrosis. With the goal of advancing research that could translate into successful therapies for PF, the PFF Scholars program is designed to support and enable promising researchers to obtain independent funding and continue their cutting-edge research. Scholars will receive up to \$75,000 over a two-year period.



**MARGARET  
FREEBERG, PHD**  
Virginia Commonwealth  
University

*Proposal Title: Targeting  
multiple disease pathways*

This proposal is funded by Boehringer Ingelheim Pharmaceuticals, Inc.

Idiopathic pulmonary fibrosis is driven by multiple overlapping disease-causing processes. Most current research focuses on treating single pathways, resulting in challenges and failure when translated from the lab to clinical trials. Freeberg will investigate a recently identified overlap of two previously presumed independent processes that promote fibrosis: tissue stiffness and energy metabolism by lung cells. "I've identified a probable cell receptor involved with these processes that has potential to be developed into a therapy that targets these multiple disease pathways at the same time," she says. "The long-term goal is to identify a co-targeting treatment option that will more effectively block the progression of fibrosis compared to current single therapies."



**PETER JACKSON, MD**  
Virginia  
Commonwealth  
University

*Proposal Title: Targeting  
multiple disease  
pathways; Investigating  
postTB lung impairment*

This proposal is funded by Boehringer Ingelheim Pharmaceuticals, Inc.

Up to half of acute tuberculosis (TB) survivors will develop post-TB lung impairment (PTLI). With over 90 percent of TB cases occurring in low- to middle-income countries, PTLI often results in food insecurity, worse socioeconomic status, and increased mortality from secondary causes. Building on a postulated link between the bacteria that cause TB and the patient's immune system, Jackson's study will be the first not only to determine clinical risk factors for PTLI development, but also to evaluate over time the immunologic pathways that cause this disorder. He will analyze inflammatory cytokines (molecules secreted from immune cells that promote inflammation) and regulatory lipids (compounds that regulate certain biological processes) in the blood and lung "to identify the cause of PTLI and discover targets for therapies that can prevent this devastating disease," Jackson says.



**BHAVIKA KAUL, MD**

**University of California  
San Francisco;  
Veterans Affairs Center  
for Innovation in Quality,  
Effectiveness and Safety  
(IQuEst)**

*Proposal Title: Targeting  
multiple disease pathways;  
Understanding gaps in  
access to care*

This proposal is funded by The Chuck and Monica McQuaid Family Foundation

Kaul's project focuses on improving outcomes for patients with idiopathic pulmonary fibrosis (IPF). In her prior work, she has identified a national cohort of 139,000 U.S. veterans diagnosed with IPF between 2010-19 and found that less than 5 percent were prescribed antifibrotics. "Utilization was disproportionately low among female, Black, and rural patients with variability in practice patterns across Veterans Health Administration facilities," she says. During her tenure as a PFF Scholar, Kaul will explore the reasons for these disparities, identify access barriers, and suggest ways to address them. "My long-term goal is to develop new care delivery strategies to bridge access gaps and improve outcomes for patients with IPF," she says.



**ANDREA OH, MD**

**University of California,  
Los Angeles**

*Proposal Title: Targeting  
multiple disease  
pathways: Speeding the  
diagnosis of PFILD*

This proposal is funded by Shomala Tambyraja in memory of Dr. Samuel Tambyraja

New antifibrotic drugs slow disease progression in progressive fibrosing interstitial lung disease (PF-ILD). However, PF-ILD currently requires documentation of disease progression by imaging or pulmonary function tests, which may delay treatment. "There is an urgent, unmet need to identify patients with PF-ILD as early as possible to improve long term outcomes," Oh says. Advanced computer techniques using artificial intelligence (AI) show promise as a better method than radiologist readings to assess fibrosis on computed tomography (CT). One AI technique, called data-driven textural analysis, can automatically detect and calculate the amount of fibrosis on CT. Oh will develop "a statistical model using patient-related factors including demographics, pulmonary function tests, blood work results, and CT scan results (with both an expert radiologist's interpretation and AI-generated fibrosis scores) to try and identify those patients with PF-ILD as early as possible," she says.

# Patient Input Crucial to Finding a Cure

The Pulmonary Fibrosis Foundation (PFF) Patient Registry continues to spur important research about the causes, diagnosis, and management of pulmonary fibrosis and interstitial lung disease.



Since its founding in 2016, patients enrolled in the PFF Patient Registry have contributed a variety of test results, CT scans, biological samples, genetic information, and outcomes to a growing repository of pulmonary fibrosis data. These data have been used in more than 40 studies representing research valued at more \$32 million. Among the highlights of the research results reported this past year are:

- **Anne Dimmock, MS**, at the Penn State College of Medicine, and her colleagues identified differences between rural and urban patients. Rural patients suffer higher rates than their urban counterparts of fibrotic HP and exposure related ILD, which are associated with the use of wood and coal for fuel.
- **Joyce S. Lee, MD**, at the University of Colorado School of Medicine, and her colleagues identified variations in outcomes for patients at multiple PFF Care Center Network sites. Their findings suggest that further investigation could identify practice patterns and resources associated with improved patient outcomes.

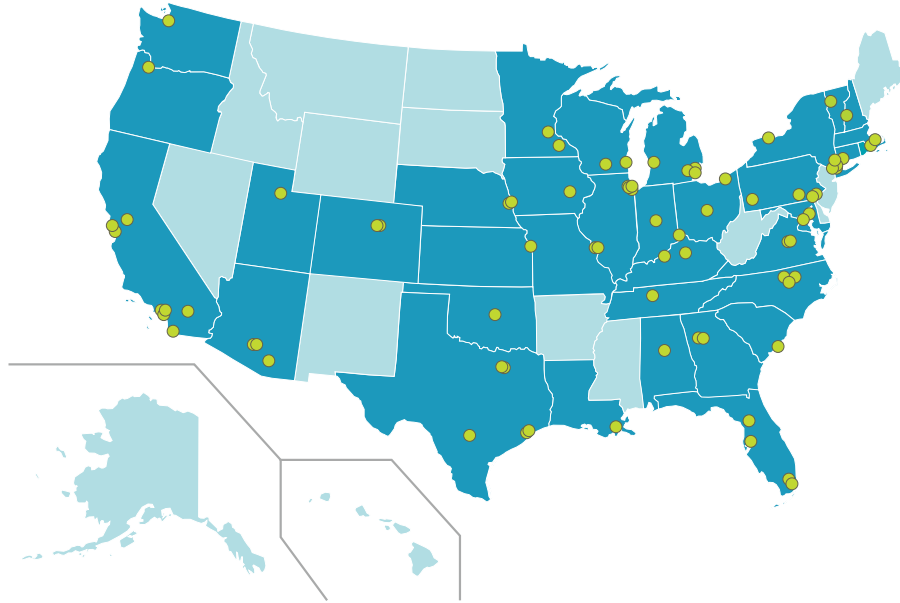
- **Janet Lee, MD**, at the University of Utah School of Medicine, and her colleagues reported in the journal CHEST – The American College of Chest Physicians that if a patient’s cough is serious enough to significantly reduce quality of life, it also raises the risk of hospitalization, death, or transplant.

In 2022, the PFF prepared to launch the Community Registry, which will bring valuable insights from a broader cross section of patients, family members, caregivers, and lung-transplant recipients. Community Registry participants will share important information about their disease and their experiences by completing online surveys twice a year and possibly additional, more targeted surveys, if they choose.

“Since 2016, the PFF Patient Registry has made huge amounts of data available to researchers and a clearer picture of PF is now emerging,” said Kevin Flaherty, MD, MS, Chair of the PFF Registry Steering Committee. “With the launch of the new PFF Community Registry, we are poised to make even greater research contributions as we learn about the experience of individuals living with PF or ILD, and the impacts on them and their families and caregivers.”



# Care Center Network Expands



**The PFF Care Center Network (CCN) is a group of medical centers dedicated to improving the lives of those living with pulmonary fibrosis (PF). Care Centers have expertise in treating adult patients with fibrotic lung diseases and utilize a multidisciplinary approach to deliver comprehensive patient care, engage in patient-oriented PF research, and work with the PFF to provide educational materials and engage the local community through PFF programs.**

As part of the PFF Strategic Plan 2021, the CCN Steering Committee and PFF Leadership updated and approved Care Center criteria to expand the Network. Updates included an emphasis on engagement between Care Centers and the PFF to ensure that Care Centers are participating in patient-centered activities in coordination with the PFF and are actively involved in the implementation of the PFF CCN strategic goals:

- **Improve Diagnosis Process**
- **Enhance Quality of Care**
- **Accelerate Research**
- **Effectively advocate for the PF Community**

The CCN Selection Committee, comprised of healthcare providers from the Network, patients, and PFF Leadership, reviewed applications and recommended six new centers to the Network in Summer 2022, as follows:

- Center for Advanced Lung Disease at Keck Medicine of University of Southern California (Los Angeles, CA)

- Froedtert & the Medical College of Wisconsin  
Froedtert Hospital (Milwaukee, WI)
- Rush University Medical Center (Chicago, IL)
- OU Health (Oklahoma City, OK)
- University of South Florida-Tampa General Hospital (Tampa, FL)
- VCU Health (Richmond, VA)

## **CCN PUBLICATIONS (2022 ATS)**

At the 2022 American Thoracic Society (ATS) International Conference in San Francisco, the PFF presented research results from four studies examining access to care and outcomes for patients living with pulmonary fibrosis (PF) and interstitial lung disease (ILD). One highlight of the conference was a poster discussion entitled "Differences in Patient Outcomes Across the PFF Care Center Network," by authors Dr. Joyce Lee, Dr. Ryan Boente, Ms. Emily White, Dr. Caitlin Baxter, Dr. Jessica Shore, and Dr. Hal Collard. Using PFF Patient Registry data, this study suggests that site-level variation exists with respect to key clinical outcomes for patients with ILD managed at Care Centers. This research supports further investigation to identify practice patterns and resources that are associated with improved patient outcomes. Building upon this, the Care Center Network is continuing to prioritize the development of a research project to further investigate.

# PFF Summit 2021 Goes Fully Virtual

In consideration of the ongoing health risks to our community during the COVID-19 pandemic, the sixth biennial PFF Summit was presented on a virtual platform from November 8 - 13, 2021. Registered attendees tuned in to the live program each day, with re-broadcasts available during the week and for three months following.



After the conference's conclusion, the program was loaded onto the PFF YouTube channel for the general public. Total registration reached nearly 1,200, with over 600 patients and caregivers attending. Participants came from 47 states and 21 countries, a good increase over the 2019 in-person event that brought people from 44 states and 10 countries.

A robust program of 37 sessions included two plenaries, three Clinical Trial Innovation Series presentations, as well as daily sessions designed specifically for patients and caregivers, and five days of sessions for healthcare professionals. Continuing Medical Education (CME) credit was available to healthcare professionals. The program also included two half-day sessions for community pulmonologists and two half-day sessions for the PFF Nurse and Allied Health Network.

The virtual conference featured an interactive exhibit hall with over 20 sponsors and exhibitors, including booths for the PFF Community Registry and the PFF Care Center Network.

## More than a conference: The PFF Summit offers a chance to socialize

Going fully virtual didn't stop the PFF from offering attendees a chance to socialize. Other popular sessions were the Monday night poster program where attendees could chat virtually with poster abstract authors. Tuesday night offered a fireside chat with the PFF Medical Team where the Medical Team introduced themselves and invited questions from the audience.

A virtual Summit Social night was held on Thursday evening with eight separate topics ranging from a soothing musical performance, cooking and cocktail demonstrations, a pet party, and a very popular talk on the connection between modern medicine and space exploration.

### Diamond Sponsor



### Gold Sponsors



### Silver Sponsors

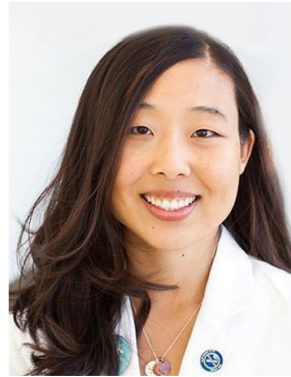


## Nine Organizations Celebrate the First ILD Day

The PFF joined eight patient advocacy organizations to present the first annual ILD Day on September 15, 2021 to drive public and healthcare industry awareness of interstitial lung disease.

The day was recognized with a special webinar titled “Connective Tissue Disease, Sarcoidosis, and Interstitial Lung Disease,” presented by PFF Senior Medical Advisor Dr. Joyce Lee (University of Colorado Anschutz Medical Campus) and Dr. Erin Wilfong (Vanderbilt University). In addition to the PFF, this collaboration featured the Arthritis Foundation, Foundation for Sarcoidosis Research, The Myositis Association, PF Warriors, Scleroderma Foundation, Scleroderma Research Foundation, Sjögren’s Foundation, and Wescoe Foundation for Pulmonary Fibrosis.

ILD Day was widely promoted by the PFF and the participant organizations. We created a special landing page and implemented a comprehensive marketing campaign to inform and engage constituents of partner organizations and the at-risk public.



**DR. JOYCE LEE**



**DR. ERIN WILFONG**

## Here For Each Other: Pulmonary Fibrosis Awareness Month

This September, we are  
**Here For Each Other**

[pulmonaryfibrosis.org/pfam](https://pulmonaryfibrosis.org/pfam)

Pulmonary Fibrosis Awareness Month (September) is when the PF community unites as a collective voice to enhance disease awareness and provide outreach to those in need.

During Pulmonary Fibrosis Awareness Month, the PF community joined the PFF with the 2022 theme, “Here For Each Other,” and participated in the #BlueUp4PF campaign, attended virtual educational and Team PFF events, participated in webinars, and spread PF awareness through social media. More than 100 buildings across the United States shined blue, and the PFF reached more than 533,000 users across all social media platforms.

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## Clinical Trials Take Over the PFF's Social Media

The PFF hosted its second annual Clinical Trials Week on social media.

In conjunction with Clinical Trials Day on May 20, the PFF hosted a 7-day social media campaign to share all its valuable resources about clinical trials. The campaign encouraged followers to learn about clinical trials and consider using the Foundation's Clinical Trial Finder Tool. The campaign resulted in a 65% increase to [trials.pulmonaryfibrosis.org](https://trials.pulmonaryfibrosis.org) compared to previous months and earned more than 43,500 impressions across social media.



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## The PFF's Nationwide Campaign Ties in with Pulmonary Fibrosis Awareness Month

### Pinpoint PF

The PFF's Pinpoint PF awareness campaign generated more than 1.57 billion impressions in the media throughout the year.

This awareness campaign targeted patients, caregivers and family members, and healthcare providers. Our first major push came in September for Pulmonary Fibrosis Awareness Month (PFAM). Dr. Amy Hajari Case, PFF Senior Medical Advisor for Education and Awareness, led a radio media tour in which she completed 16 interviews throughout the country. Dr. Case reached listeners to raise awareness of events taking place during PFAM and

to encourage individuals to note PF symptoms early and start conversations with their doctors. Additional coverage during PFAM featured PFF Ambassador and retired NYPD detective and 9/11 First Responder Tom Frey, who helped the Foundation shine a light on PF through national media in conjunction with the 20th anniversary of 9/11. A final PFAM highlight was a satellite media tour showcasing PF advocate, comedienne and Board Member, Julie Halston, who received the 2020 Isabelle Stevenson Tony Award in recognition of her charitable work for the PFF.

The PFF's awareness campaign successfully grew visits to the [AboutPF.org](https://AboutPF.org) website and to the PFF's website, [pulmonaryfibrosis.org](https://pulmonaryfibrosis.org). The campaign also drove increased inquiries to the PFF Help Center.

# Together toward a cure.

## LEAD THE WAY

NATIONAL SPONSOR  
**Genentech**  
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The sixth annual PFF Walk returned in the summer of 2022 in cities across the country! After two years of virtual walks due to the coronavirus pandemic, the Walk took place both in person and virtually from July through October.

“We were thrilled to invite the community to come out and join the PFF Walk that summer,” said Amy Wardzala, Vice President of Development. “The Walk is a major celebration for our community, and we encourage everyone to gather their friends and family, build a team, and raise funds so we can drive research and support those living with PF.”

Since its inception in 2017, the PFF Walk program has raised over \$2.5 million. The Walk has expanded over the years with new cities added to the lineup each year. The San Francisco Walk, originally scheduled to launch in 2020, was delayed and took place for the first time in 2022.

“The indomitable spirit of our community continues to enable us thrive, and we are so grateful,” Wardzala said.



## PFF WALK

Making a path towards a cure.

# Broadway Belts For PFF! Raises Record \$475,000!



Tony Award winner and PFF Board member Julie Halston and a star-studded cast presented the 12th annual Broadway Belts for PFF! on April 29 at the Edison Ballroom in New York City. The gala was a hybrid celebration with guests joining in person and virtually from home. A record \$475,000 was raised to support PF research and programs for individuals living with PF.

Tom Viola, Executive Director of Broadway Cares/Equity Fights AIDS (BC/EFA), was honored with the 2022 Ralph Howard Legacy Award. Viola, who has supported Broadway Belts for PFF! since it began, has contributed significantly to health and family service organizations nationwide.

## And the award goes to ... Julie Halston!



The national spotlight shone on the Pulmonary Fibrosis Foundation on September 26 when actress and comedienne, Julie Halston, received the 2020 Isabelle Stevenson Tony Award in recognition of her charitable work

and fundraising efforts on behalf of the PFF. Halston, a dynamic advocate for people living with pulmonary fibrosis, has raised more than \$2 million and brought international awareness to the cause through the annual *Broadway Belts For PFF!* gala.

The 2020 Isabelle Stevenson Tony Award is presented annually to a member of the theater community who has made a substantial contribution of volunteered time and effort on behalf of one or more humanitarian, social service, or charitable organizations. Halston received this award from the Tony Awards Administration Committee for the 2019-2020 season.

BROADWAY  
BELTS  
FOR  
PFF!

# PFF Seeks Better Outcomes with Commitment to Diversity, Equity and Inclusion



In late 2021, the PFF Strategic Plan designated the implementation of a Diversity, Equity and Inclusion (DEI) plan as a top priority. Through research programs and education, the PFF is committed to ensuring that everyone impacted by pulmonary fibrosis receives the care and treatment they need.

Diversity refers to more than just race and ethnicity. It also represents socioeconomic and geographic diversity, which can require different approaches for optimal care and support. In addition, DEI issues concern not only patients but also researchers, advocates, and policy leaders.

As a part of its strategic plan, the PFF seeks to:

- Enhance outreach to diverse communities with our support, education, and research programs
- Lead a study of access to PF care in Black and Hispanic communities
- Broaden staff diversity
- Increase Board and Board committee diversity

**PFF**

# Board of Directors

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# Financials

## STATEMENT OF FINANCIAL POSITION AS OF JUNE 30, 2022

Audited Numbers

Total Assets	\$	17,064,469
Total Liabilities		7,089,463
<b>Total Net Assets</b>	<b>\$</b>	<b>9,975,006</b>

## STATEMENT OF ACTIVITIES YEAR ENDED JUNE 30, 2022

Audited Numbers

Total Revenue		
Unrestricted	\$	10,104,838
Temporarily Restricted		909,068
		11,013,906
Total Expenses		10,351,183
<b>Change in Net Assets</b>	<b>\$</b>	<b>662,723</b>

## SOURCES OF REVENUE

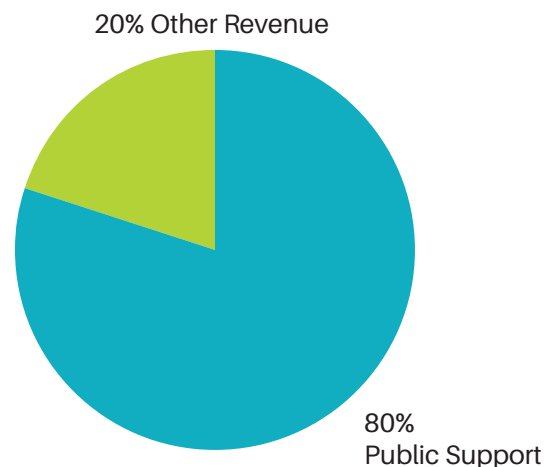
Public Support	\$	8,819,449	80%
Other Revenue		2,194,457	20%
<b>Total Revenue</b>	<b>\$</b>	<b>11,013,906</b>	<b>100%</b>

## ALLOCATION OF EXPENSES

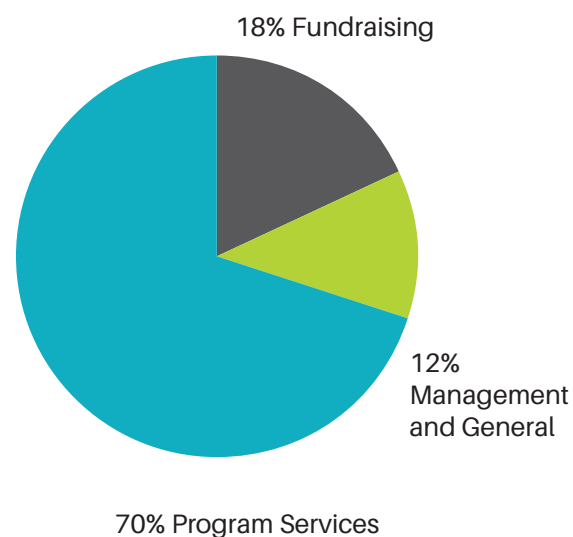
Audited Numbers

Program Services by Category			
Education	\$	707,487	
Legislative Advocacy		378,316	
Outreach and awareness		894,699	
PFF Care Center Network		622,259	
PFF Patient Registry		2,911,005	
PFF Summit		471,055	
Program Support		672,876	
Research Grants		403,965	
Support Groups		179,112	
Program Services Total		7,240,774	70%
Management and General		1,291,032	12%
Fundraising		1,819,377	18%
<b>Total Expenses</b>	<b>\$</b>	<b>10,351,183</b>	<b>100%</b>

## SOURCES OF REVENUE



## ALLOCATION OF EXPENSES



## 2022 Donors

**\$500,000 AND GREATER**

**Gift in memory of  
Dr. Nalinkant A. Patel  
The Estate of  
Richard Schiffman**

**\$100,000-\$499,999**

**The Buckeye Foundation  
Genentech  
Nelda Hagaman  
The Hastings Foundation  
Horizon Therapeutics  
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**\$50,000-\$99,999**

**Chiesi Farmaceutici S.p.A.  
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Foundation  
FibroGen, Inc.  
Galecto Biotech  
The Hales Family  
Foundation, Inc.  
Inbavazhu Irrevocable Trust  
The Estate of Samuel McGill  
The National Board for  
Respiratory Care  
Pliant Therapeutics  
Steffy Family Foundation Fund  
Three Lakes Partners  
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**\$10,000-\$49,999**

**Accredo  
AllianceRx Walgreens Pharmacy  
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