

## Moving Forward to the Future 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 unequaled support and education resources for patients, caregivers, family members, and health care providers.

 $\bf 844.TalkPFF~(844.825.5733)~|~help@pulmonaryfibrosis.org\\pulmonaryfibrosis.org$ 











#### **DEAR FRIENDS,**

At the Pulmonary Fibrosis Foundation (PFF), we take very seriously our responsibility to fund and support research that may someday lead to better treatments and a cure for pulmonary fibrosis (PF). We have a robust and multifaceted research program and we're pleased to report progress from each PFF research program in 2021. These include:

**PFF Community Registry** - Throughout 2021, we finalized plans to enroll anyone touched by PF in our soon-to-launch registry that will feature self-reported data. This includes patients living with PF from any part of the U.S., family members, caregivers, and lung transplant recipients who have had PF.

**PRECISIONS** - This important trial, which received unprecedented public and foundation funding, is the first ever to apply precision medicine principles to diagnosing and treating idiopathic pulmonary fibrosis (IPF).

**PROLIFIC Consortium** - In its first full year, the Prognostic Lung Fibrosis Consortium of foundation and industry partners made progress. Consortium members agreed to study 12 potential biomarkers of IPF in four key categories of cellular damage.

**PFF Care Center Network** - This year, PFF CCN member sites conducted research that will help clarify the effect of the pandemic on the ongoing clinical care of patients with PF and identify gaps in care that can be addressed by the PFF.

PFF Scholars - Thanks to special funding received from both new and longtime donors, the Foundation was able to support six PFF Scholars in the 2020 funding cycle.

We once again worked tirelessly to maintain activities and to provide information and services to the community during the COVID-19 pandemic. This includes the new:

- · COVID-19 webinar series
- · PFF Insights medical team blog
- Position statements for patients
- · Pulmonary Rehabilitation (PR) toolkit

Despite the challenges of the pandemic, we were able to move our most beloved—and financially important—events to a virtual format. This includes our full roster of PFF Walks and the inimitable *Broadway Belts for PFF!* Both met their robust financial goals while still allowing the PF community to engage safely during a challenging year.

As we successfully complete a year that made many of us refine our priorities, we thank you for everything you do to increase PF awareness, education, advocacy, and research. Our close-knit community will continue to support you and your family every step of the way through your PF journey.

George Eliades Will T. Je lo

Sincerely,

George Eliades, PhD

Chair, Board of Directors

William T. Schmidt
President and CEO







## PFF CARE CENTER REGISTRY BEGINS PLANS TO RE-OPEN

The PFF Care Center Registry is an observational database that follows the care of patients with interstitial lung diseases including idiopathic pulmonary fibrosis, hypersensitivity pneumonitis, and other diagnoses over time. By collecting and studying participants' data, blood samples, and high-resolution computed tomography (HRCT) scans, we are increasing our understanding of what a typical disease course might be in PF.

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

Now, the PFF is proud to announce that the PFF Care Center Registry will reopen for patient enrollment until the Registry once again tops out at 2,000 participants. Data collection will continue from the original participants, as well as qualifying new enrollees who receive care at PFF Care Centers.

#### THE YEAR IN:

## Research





#### PFF COMMUNITY REGISTRY SET TO DEBUT

The PFF Registry team spent much of 2021 working toward a long-awaited goal: the unveiling of the PFF Community Registry. After many months of planning, the PFF Community Registry was nearly ready as we completed 2021.

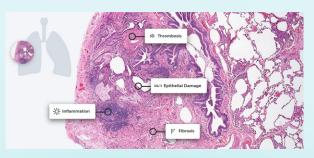
Everyone who is touched by PF will be able to enroll, including patients living with PF from any part of the U.S., family members, caregivers, and lung transplant recipients who have had PF. PFF Community Registry participants will report their own data from home via a series of regular questionnaires uploaded through a secure, easy-to-use online portal. Participants will receive regular updates, too, on how the information will help shape the future of PF research.

#### PRECISIONS TRIAL MAKING GOOD PROGRESS

The PRECISIONS trial, which received an unprecedented \$22 million in funding from the National Institutes of Health and Three Lakes Foundation, is the first ever to apply precision medicine principles to diagnosing and treating IPF. PRECISIONS studies whether the over-the-counter supplement N-acetylcysteine (NAC) can treat people with IPF who have a specific gene variant. The trial also seeks to identify genetic variants that influence an individual's risk of developing PF.

Despite the pandemic, PRECISIONS' patient enrollment was on schedule in 2021. The trial is due to be completed in 2025.

#### PROLIFIC CONSORTIUM MAKES PROGRESS WITH POSSIBLE IPF BIOMARKERS



In 2020, the PFF partnered with Bristol Myers Squibb to create the Prognostic Lung Fibrosis Consortium (PROLIFIC for short). This collaboration includes 12 industry partners and two foundations. PROLIFIC's short-term goal is to cooperatively develop and validate tests that can detect biomarkers in patients with PF. Having a validated panel of biomarkers could enable early detection of therapies and comparison of drugs across clinical trials, which could hasten approval.

PROLIFIC made progress in 2021 toward its ambitious goal by selecting 12 potential biomarkers of IPF for further study in four key categories: epithelial damage, fibrosis, inflammation, and thrombosis. Additionally, the PFF created and launched a new website for the consortium.



## New Class of PFF Scholars Excels

The PFF Scholars program supports early-career investigators with two-year research grants that positions them to earn funding from the National Institutes of Health (NIH) and other prestigious funders in the future. Thanks to special funding received from both new and longtime donors, the Foundation was able to support six PFF Scholars for the 2020 funding cycle.



JOSEPH E. DRUSO, PHD University of Vermont Medical Center

TITLE: Collagen S-glutathionylation promotes pulmonary fibrosis through myofibroblast activation.

Funded by Boehringer IngelheimPharmaceuticals, Inc.

"Does the newly discovered protein S-glutathionylation activate cells to deposit more collagen in the lungs of IPF patients?" Dr. Druso asks. "If the protein affects how cells interact in the lung, targeting it might reformat how cells react to that environment and each other, thereby offering a new therapeutic target."



JASON GOKEY, PHD Vanderbilt University Medical Center

TITLE: YAP/Wnt interactions regulate epithelial cell proliferation and differentiation leading to abnormal repair and progression of IPF.

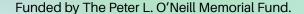
Funded by Boehringer Ingelheim Pharmaceuticals, Inc.

The YAP signaling pathway that activates genes within cells may be involved in forming and multiplying abnormal cell types in the lung. "We think the YAP pathway being upregulated makes disease progress rapidly," Dr. Gokey says. "If we can inhibit that process, we might be able to give patients more time and a better quality of life."



**GILLIAN GOOBIE, MD University of Pittsburgh** 

TITLE: Air Pollution: Clinical Outcomes and Epigenomic Effects in Interstitial Lung Diseases.



"There is likely a link between pollution and interstitial lung diseases but we still need to clarify how strong that link is and how patients can reduce their risk," Dr. Goobie says. "It's important to show whether an association exists so we can impact public policy to reduce air pollution exposure for everyone."



AVRAHAM UNTERMAN, MD, MBA Tel Aviv Sourasky Medical Center, Tel Aviv, Israel

TITLE: Single-cell Immunophenotyping of Chronic Fibrosing Interstitial Lung Diseases.

Funded by the Chuck and Monica McQuaid Family Foundation.

Unterman will use a new technology—single cell RNA sequencing—to study the gene expression profile of individual blood cells. The cells will come from people with either connective tissue ILD or IPF. "We will be able to identify specific immune system changes in the blood that reflect the specific cause of fibrosis in the lungs," Dr. Unterman explains. "These changes could later be used as biomarkers to better diagnose the cause of PF, without the need for a lung biopsy."



**BRIDGET GRANEY, MD**University of Colorado

TITLE: Improving Patient and Caregiver Outcomes in Pulmonary Fibrosis: A Novel, Dyadic Assessment of Caregiver Burden.

This award is partially funded by the Jenny H. Krauss and Otto F. Krauss Charitable Foundation Trust, in memory of Stephen N. Dirks.

"From the cancer literature, we know that patients who get palliative care live longer and their caregivers had better outcomes," Dr. Graney says. "Ultimately, my long-term goal is to lessen caregiver burden and improve outcomes, including quality of life, for both patients with PF and their caregivers. We in medicine should do more to support caregivers."



**ELEANOR B. VALENZI, MD**University of Pittsburgh

TITLE: Investigating the Master Regulators of Myofibroblasts in Systemic Sclerosis-Associated Interstitial Lung Disease.

Funded by The Peter L. O'Neill Memorial Fund.

Myofibroblasts are cells involved in pulmonary fibrosis due to their overproduction of the collagen that leads to fibrotic tissue in the lungs. "My goal is to be able to determine the parts of the DNA the myofibroblasts are interacting with to ultimately design new therapies targeted at these specific cells," Dr. Valenzi says.



At the Pulmonary Fibrosis Foundation, improving life for patients with pulmonary fibrosis and their families is our top priority. A major part of our mission is to provide the most accurate, comprehensive educational resources available anywhere. In 2021, we created several new patient resources to share with our community.

#### **PFF RESPONSE TO COVID-19**

As the COVID-19 pandemic continued, the PFF expanded its efforts to help the PF community understand and cope with the crisis. PFF support groups continued to meet online throughout the year. Additionally, the new PFF Insights blog provided the latest information about both pulmonary fibrosis and the newest coronavirus developments.

#### **NEW WRITTEN MATERIALS AND WEBINARS**

The PFF created a slew of new written materials in 2021 to help the community. These include a Telemedicine Basics booklet and Telemedicine Checklist to help the PF community navigate the world of virtual healthcare with ease.

As part of its growing resource library for healthcare providers, the Foundation produces position statements that provide clinicians with insights based on currently available evidence. In 2021, we developed position statements with both providers and patients in mind. The first dedicated patient-friendly versions focused on Genetic Testing in PF and Stem Cell /Cell-Based Therapies statements.

The Foundation also included a series of COVID-19-related webinars in the Disease Education Webinar Series. As always, our educational materials provide reliable information about pulmonary fibrosis to support and empower patients, their families, and friends while living with PF. We are proud to offer all resources to the community free of charge.

#### THE YEAR IN:

## Patient Resources





#### **NEW VIRTUAL PULMONARY REHAB TOOLKIT**

The PFF and the American Association of Cardiovascular and Respiratory Care (AACVPR) partnered to launch a digital Pulmonary Rehabilitation (PR) Toolkit for PF patients. The toolkit features videos and written pieces explaining what pulmonary rehab is, as well as mindfulness resources. It also includes exercise videos and tools enabling users to track exercise and vital signs. While it provides resources that you would receive through a PR program, it is not meant to be a substitute for an in-person PR visit. The new toolkit came at an especially important time, since the pandemic limited many patients' access to PR for a year or more.

#### **COVID-19 SAFETY KITS A BIG HIT**

The PFF offered free COVID-19 safety kits to help protect patients and their caregivers during the pandemic. The kits included two reusable face coverings, hand sanitizer, sanitary wipes, and tips on preparing for a doctor visit. Demand was so high that the first kits were quickly snapped up, leading the Foundation to offer another batch of kits later in the year.



Part of serving and supporting patients with PF and their families is to spread the word far and wide about this devastating group of diseases and how we work to support our community. The PFF enacts change both at the national level, by educating and lobbying government officials, and at the grassroots level, by building our community via our popular PFF Walks and Pulmonary Fibrosis Awareness Month.

#### PFF WALKS GO VIRTUAL DURING THE PANDEMIC

As the 2020 PFF Walk season approached, the continuing COVID-19 pandemic meant that the PFF needed to make a quick pivot from live Walk events to a fully virtual experience. The virtual PFF Walk Kickoff kept the community connected and built excitement while encouraging Walk registration.

PFF Board member and *Broadway Belts for PFF!* host Julie Halston and PFF Vice President of Development, Amy Wardzala, co-hosted the livestream event on YouTube and Facebook. The program featured special appearances by PFF Walk stars and celebrities including Bernadette Peters,

Robert Creighton, Mitchell Tenpenny, and Bernie Williams. The virtual program also helped participants learn how to stay safe and healthy while fundraising for the PFF during the COVID-19 pandemic.

Following September virtual walks in Chicago and San Francisco, the series continued with the PFF Walk - At Home Edition in late September during Community Walk weekend. With virtual walks in Washington, D.C., and Dallas in October, Walk season wrapped up with a final virtual celebration party in November. In total, the PFF Walk raised more than \$570,000 this year.

#### THE YEAR IN:

# Awareness and Advocacy





#### PULMONARY FIBROSIS AWARENESS MONTH

Pulmonary Fibrosis Awareness Month (PFAM) in September is always a highlight of the year at the Foundation. The 2021 PFAM theme, "Celebrating PF Heroes" gave our community many opportunities to mobilize family members and supporters to spread the word about PF.

"30 Facts in 30 Days" was a successful way to share information and amplify awareness. Each day in September, the PFF shared medically-accurate PF facts on Facebook, Instagram, and Twitter. Additionally, the Foundation promoted the "Portraits of PF" Facebook series throughout the month to highlight stories from patients, caregivers, and healthcare professionals affected by PF. Supporters then boosted the reach of these messages by liking, sharing, commenting, and re-tweeting facts to their own groups of friends and followers. Everyone in the PF community was invited to share their story and be featured as a spotlight on the PFF's social media accounts.

Supporters also wore PFF blue and Breathe Bracelets, took selfies, and used the hashtag #BlueUp4PF to convey strength and encouragement. Prominent skyscrapers and monuments across the U.S. were lit up blue for the cause.

#### **BROADWAY BELTS FOR PFF!, ONLINE EDITION**

When times get tough, the tough adapt. COVID-19 meant that we couldn't gather in person in New York City to enjoy the 11th edition of our beloved *Broadway Belts for PFF!*, but that didn't stop us. Instead, the Foundation brought the glitz and glamour of Broadway directly to living rooms across the country to help draw attention to PF with a special virtual edition that raised \$346,000 for the PFF.

Broadway's brightest stars, including Robert Creighton, Christine Ebersole, Darlene Love, and more than 30 others delivered heartfelt performances that captivated a nationwide audience. In addition to the outstanding musical entertainment, the third annual Ralph Howard Legacy Award was presented to Laurie Chandler. Chandler, who is a PF patient and lung transplant recipient herself, is a devoted advocate and PFF Board member.

#### THE YEAR IN:

# Awareness and Advocacy

#### **NEW INITIATIVE HELPS "PINPOINT PF"**

In 2021, the PFF unveiled its new "Pinpoint PF" education and awareness campaign aimed at symptomatic individuals and those at a higher risk for pulmonary fibrosis.

The campaign's mission is to empower patients to "Pinpoint PF" symptoms and to take action early by starting conversations with their doctors. According to a 2020 national survey by the PFF, more than 8 in 10 Americans do not know PF symptoms, which include shortness of breath, fatigue, and a dry, persistent cough. These symptoms are common and are often attributed to other causes, which can lead to late-stage PF diagnoses.

The campaign features targeted digital and traditional advertising supplemented by public relations efforts to further raise awareness of signs and symptoms of PF. "Pinpoint PF" enables at-risk patients, caregivers, and healthcare providers to ensure more accurate and timely diagnoses, improve patient outcomes, and maximize treatment options.

#### CHRONIC COUGH OR PULMONARY FIBROSIS?

**PF affects more than 200,000 Americans**, yet it can take up to two years to diagnose. Pinpoint early warning signs today.

#### Pinpoint PF

#### PULMONARY FIBROSIS SYMPTOMS INCLUDE:

- · Shortness of breath
- · Chronic cough
- · Feeling run-down

#### WHO IS MOST AT RISK?

- Current or past smokers
- Age 60 or older
- Family history of interstitial lung disease

### TALK TO YOUR DOCTOR TODAY





Pulmonary fibrosis, an interstitial lung disease, is progressive, debilitating and hard to diagnose

Visit **AboutPF.org** or call **844.TalkPFF** (844.825.5733) to take action.

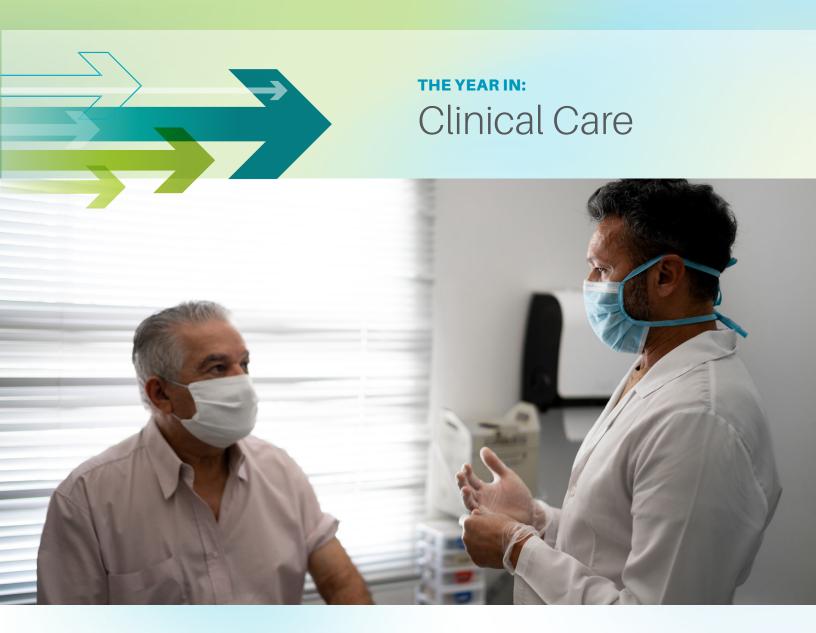
#### **LEGISLATIVE ADVOCACY PROGRESS CONTINUES**

The Foundation's annual Hill Day moved online so that the PF community could still meet with elected officials despite the pandemic. As a result of Hill Day efforts by 60 PF patients and family members, the U.S. House of Representatives Appropriations Committee included the PFF's requested language regarding pulmonary fibrosis in their fiscal year 2021 appropriations report. Including this language helps raise the profile of pulmonary fibrosis research and encourages the National Heart, Lung & Blood Institute (NHLBI) to focus on PF research.

The Committee recognizes that PF is a family of more than 200 different lung diseases that all look very much alike despite having a variety of causes. This heterogeneity presents significant challenges for diagnosis and treatment. The Committee commends NHLBI for its recent efforts to apply the principles of precision medicine to PF research, especially by funding a major new study that will evaluate a promising treatment for a subset of patients with a particular gene variant. This study, known as PRECISIONS, also aims to identify genetic variants that play a role in certain forms of PF. The Committee urges NHLBI to prioritize basic research on PF, particularly to better understand the causes and process of scarring and the varying impacts on patients.

Additionally, PFF volunteers lobbied to maintain pulmonary fibrosis as a topic area in the Peer Reviewed Medical Research Program at the U.S. Department of Defense, one of the largest funders of PF research.

With the start of the pandemic, the PFF and other patient advocacy and healthcare professional organizations asked the Centers for Medicare & Medicaid Services (CMS) to clarify that respiratory therapy can be reimbursed as a telehealth service. In July 2020, CMS made this change.



The PFF's Care Center Network consists of 68 medical centers nationwide that offer expertise in accurately diagnosing and treating people living with pulmonary fibrosis. Patients visiting CCN sites benefit from a comprehensive evaluation and diagnosis, assistance with social services, and opportunities to participate in research. Medical centers in the CCN have met criteria developed with both pulmonary fibrosis medical experts and patient input. All sites offer multi-disciplinary teams with expertise in pulmonary medicine, rheumatology, radiology, pathology, and dedicated clinical staff.

Centers collaborate with the PFF to actively engage their local PF communities with resources including support groups, educational activities, and materials for patients, caregivers, and their loved ones.

#### THE YEAR IN:

## Clinical Care

## VIRTUAL TOOLKIT FOR CARE CENTERS HELP DURING COVID-19

The PFF developed a new toolkit to support the Care Center Network sites nationwide in hosting virtual patient education webinars and events during COVID-19. Through a webinar platform provided by the PFF, medical centers were able to make use of numerous resources to virtually educate and connect with patients, caregivers, and family members who are affected by pulmonary fibrosis.

#### **CCN TO DEVELOP PLAN TO EXPAND**

The PFF began development of a new strategy to expand the Care Center Network and Nurse and Allied Health Network. The goal is to include centers and providers not yet engaged with the network and have further outreach to impact the delivery of care to patients living with PF.

#### **BEST PRACTICES IN PULMONARY TRAINING**

The Foundation's Clinical Education Working Group surveyed pulmonary and critical care medicine fellowship directors at medical schools nationwide to gather input on best practices in training. This survey created the basis for a peer-reviewed article, "Fellowship Education in Interstitial Lung Disease: A National Survey of Program Directors and Trainees," which was published October 2020 in ATS Scholar.





#### BEHIND THE SCENES

## At the PFF

At the Foundation, we know that having a strong, healthy infrastructure in place will help us do the most good for people with PF and their families. That's why we take seriously our obligation to hire the right people to help us reach our goals. We also prioritize developing resources that help us communicate our mission clearly to the rest of the world.

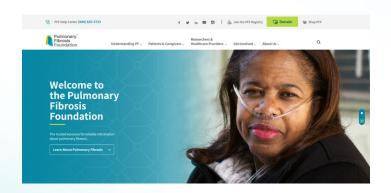
#### PFF WELCOMES NEW MEDICAL TEAM MEMBERS

Joseph Lasky, MD, assumed the role of the PFF's Chief Medical Officer in August 2021. Dr. Lasky is a professor and Pulmonary/Critical Care Section Chief at Tulane University Medical School. He serves as the Site Principal Investigator for numerous ongoing clinical trials in pulmonary fibrosis. Dr. Lasky has authored more than 100 peer-reviewed publications spanning basic molecular science to clinical trials in PF. He is a Fellow of the American College of Chest Physicians and a member of the American Thoracic Society. In his new role, Dr. Lasky will be instrumental in setting the Foundation's scientific priorities.

The PFF also added three new senior medical advisors to the medical team. Amy Hajari Case, MD, practices at Piedmont Healthcare in Atlanta. Sonye Danoff, MD, PhD, practices at the Johns Hopkins University School of Medicine in Baltimore. Joyce Lee, MD, MS, practices at the University of Colorado Anschutz Medical Campus in Aurora. Together, they bring a combined 40-plus years of expertise in treating individuals with interstitial lung disease.

#### **NEW PFF WEBSITE KEEPS THE FOCUS ON PATIENTS**

In 2021, the PFF launched a comprehensive new website, pulmonaryfibrosis.org, thanks to a grant from Three Lakes Foundation. The site highlights educational resources and tools to help patients learn more about their diagnosis and to locate care, clinical trials, and support. In addition, healthcare professionals can find continuing medical information materials and research opportunities on the site.



#### **BEHIND THE SCENES**

## At the PFF

#### **PFF BOARD OF DIRECTORS**

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#### **NEW LOGOS ENCAPSULATE PFF MISSION**

The PFF has developed a new logo, which features powerful lettering with an abstract pair of lungs in the organization's signature teal and green colors. Attention-grabbing, easy to understand and memorable, the new logo ties directly back to the mission and work of the PFF. The logo promotes modernity, positivity, and forward-thinking. The overlap of the lungs represents the close-knit community fostered by the PFF. The organization's name is promoted in a clear sans-serif type called Aileron, which is easy to read at any size and features a thickness that denotes the seriousness and action-orientation of the PFF's support and research capabilities.

Similarly, the Foundation also created a new logo for the PFF Registry. 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.

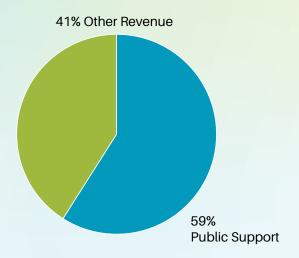




## **Financials**

Total Revenue	\$	10,275,440	100%
Other Revenue		4,199,070	41%
Public Support	\$	6,076,370	59%
SOURCES OF REVENUE			
Change in Net Assets	\$	1,264,557	
Total Expenses		9,010,883	
		10,275,440	
Total Revenue Without Donor Restrictions With Donor Restrictions	\$	10,833,524 (558,084)	
Audited Numbers			
YEAR ENDED JUNE 30, 2021			
STATEMENT OF ACTIVITIES			
Total Net Assets	\$	9,312,283	
Total Liabilities		5,433,309	
Total Assets	\$	14,745,592	
Audited Numbers			
AS OF JUNE 30, 2021			
STATEMENT OF FINANCIAL POSITION			

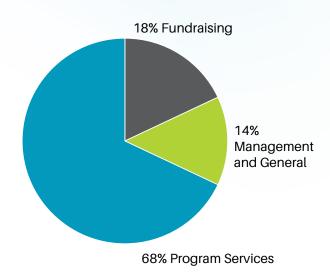
#### **SOURCES OF REVENUE**



#### **ALLOCATION OF EXPENSES**

#### **Audited Numbers Program Services by Category** Education 1,211,362 Legislative Advocacy 293,493 Outreach and Awareness 808,376 PFF Care Center Network 417,294 PFF Registry 2,095,135 PFF Summit 194,570 **Program Support** 621,082 Research Grants 400,063 **Support Groups** 131,480 **Program Services Total** 68% 6,172,855 Management and General 1,243,132 14% Fundraising 1,594,896 18% **Total Expenses** \$ 9,010,883 100%

#### **ALLOCATION OF EXPENSES**



## 2021 Donors

#### **\$500,000 AND GREATER**







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