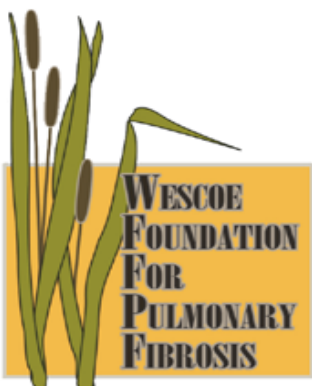


To Unite the Pulmonary Fibrosis Community



# **Wescoe Foundation for Pulmonary Fibrosis**

Annual Report  
**2023**



PA IPF  
SUPPORT  
NETWORK

The Wescoe Foundation for Pulmonary Fibrosis provides support, education, advocacy and resources for patients living with Idiopathic Pulmonary Fibrosis (IPF) as well as their care partners and families, in order to sustain the highest possible quality of life.

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## Message from our Executive Director

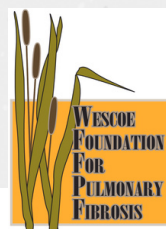
2023 was an exciting year for the Wescoe Foundation for Pulmonary Fibrosis! We continue to grow and expand our outreach adding support groups, enhancing education and expanding our awareness events. As I look back and reflect on the past year, I realize that the Wescoe Foundation family has many accomplishments to be proud of. New relationships were formed and outreach extended to include regional, national and international collaborations!

We are incredibly grateful for the patients, families, and healthcare providers we have met over the years. It is our honor to serve you everyday. The Wescoe Foundation's Board of Directors has worked tirelessly in effort to help the Foundation grow year after year, enabling us to fulfill our mission.

Looking to the future, Wescoe Foundation for Pulmonary Fibrosis will continue to build, working alongside our patients and families, board members, stellar staff and community partners to pursue our heartfelt mission.

**Jennifer Wescoe Singley, M.Ed., NCC**

Founder, Executive Director



PA IPF  
SUPPORT  
NETWORK

## Impact of Support Groups

A support group is a gathering of people facing common issues to share what's troubling them. Through the sharing of experiences, they're able to offer support, encouragement, and comfort to the other group members, and receive the same in return. Wescoe continues to focus on outreach and support, adding new support groups to serve our PF community. Always listening and responding to the needs of our members, a new Veteran's ILD support group and a Grief Group have both been added to the monthly schedule of meetings.

## Focusing on:

- **Support**
- Education
- Awareness

- Monthly meetings focus on patients sharing their concerns, asking questions and often feature a healthcare or other medical associated professional presenting on a relevant topic.
- Wescoe will continue to collaborate with PFF's Centers of Excellence, leading medical centers and community hospitals to facilitate the creation of new support groups nationwide.



# To Unite the Pulmonary Fibrosis Community

## Impact of Education

Reclaim control and peace of mind by empowering yourself with information to become your own advocate and have worthy conversations with your healthcare team.

**Discover New Resources:** We've done the research for you! We connect people to reputable and reliable resources as it is an empowering mechanism for patients and families.

## Focusing on:

- Support
- **Education**
- Awareness



## Monthly Podcast Series-

Our outreach has extended to 4,000+ downloads reaching 68 different countries! Monthly Podcasts encompass a wide range of valuable topics for patients and care partners living with pulmonary fibrosis. Tune in and learn from renowned specialists!

## Lung Transplant Educational Series-

Continuing to educate patients & care partners in their pre, peri, and post lung transplant journey

## Quarterly Seminar Series-

We proudly present these impactful virtual sessions quarterly for the patient / care partner community with our PA-IPF Support Network experts -- this year we had the pleasure of collaborating with Jefferson Health, patientMpower, Mount Nittany Medical Center, and Temple Lung Center!

# To Unite the Pulmonary Fibrosis Community

## Impact of Awareness

The Wescoe Foundation participates in and hosts various public events to raise awareness for Pulmonary Fibrosis. Being aware of a disease and its symptoms means people are more likely to take preventative action, and go for screenings, tests and check-ups.

## Focusing on:

- Support
- **Education**
- **Awareness**



## Wescoe Walk For Pulmonary Fibrosis

**18 years** raising awareness and educating the public about Idiopathic Pulmonary Fibrosis (IPF) with this annual event celebrating patients, care partners and those in the healthcare field. Held rain or shine, everyone and anyone is welcome to join us.

## Pulmonary Fibrosis Awareness Golf Outing

Inspired by one of our patient participants, this event continues to grow year after year. Great venue, great prizes, great food, and a great day spent outdoors with friends raising awareness for IPF.

## Coopersburg 5K For Pulmonary Fibrosis

Over the past **17 years**, thousands of runners have hit the streets of scenic downtown Coopersburg, PA running for those who struggle to breath. There is something for everyone, including a Kid's Fun Run and a Health & Wellness Expo.

While IPF is five times more common than Cystic Fibrosis and Lou Gehrig's Disease (or ALS), the disease is often misdiagnosed or under-diagnosed. IPF remains virtually unknown and receives a fraction of the research funding. Raising awareness of IPF is crucial to our mission as it impacts those we care about most: IPF patients and their care partners.

# To Unite the Pulmonary Fibrosis Community

# Collaborative Efforts & Partnerships:

- PF Warriors- co-hosted Lung Transplant Panel Discussion
- Quarterly Seminar Series- Jefferson University Health, Mnt. Nittany Med. Center, Temple Lung Center
- patientMpower- co-hosted Improving Patient Access to Care Through Technology Webinar
- Pennsylvania Rare Disease Advisory Council (PARDAC)- Jennifer Wescoe named Co-Chair
- Participated in Boehringer Ingelheim Patient Advocacy Organization Summit 2023, Frankfurt, Germany
- Pulmonary Fibrosis Foundation (PFF) Nov. Summit- WFPF Abstract presentation of our Support Group Assessment Survey

American Thoracic Society (ATS) International Conference- Jen Wescoe showcased the Wescoe Foundation/ PA-IPF Support Network as both an exhibitor and an expert speaker, presenting "Meet the Experts: Integrating ILD Support Groups in Community Medical Centers."

We have the privilege to work with Temple University College of Public Health throughout the past 2 1/2 years on a patient-engaged research project funded by the Patient-Centered Outcomes Research Institute (PCORI).

A project team led by Dr. Ilene Hollin, Sophia Kreider (Project Coordinator), and Wescoe Foundation is getting the word out about patient-engaged research, which is an approach to research that includes patients and care partners as members of research teams.

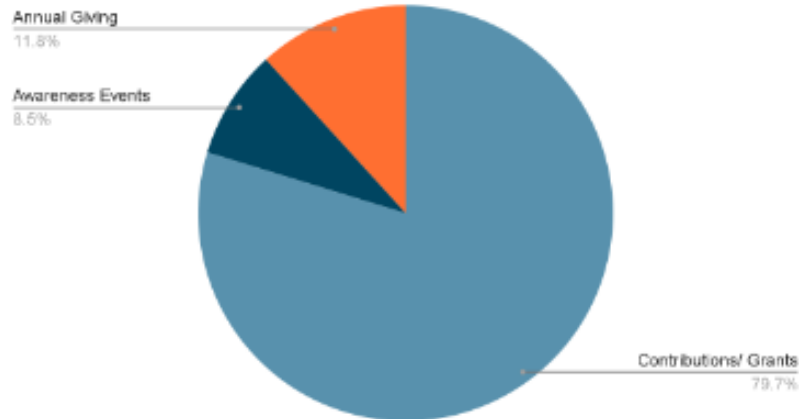




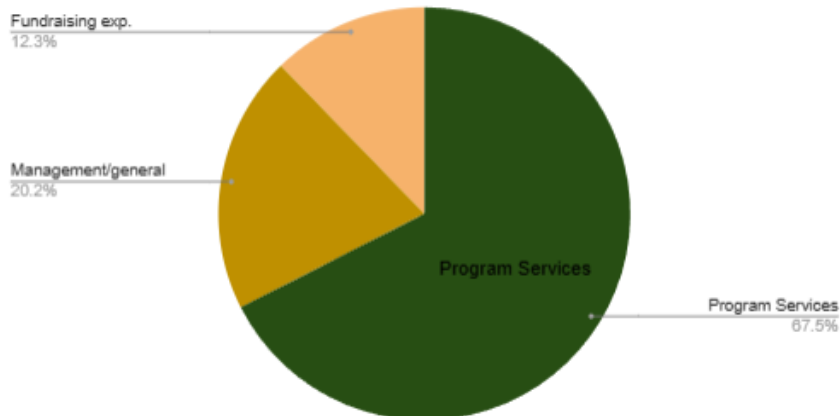
# Financials

Thank you for your confidence in the Wescoe Foundation for Pulmonary Fibrosis and joining us to make a positive impact in the pulmonary fibrosis community! Your kindness supports our pulmonary fibrosis support groups, care partner support, education programs, lung transplant mentorship program, as well as valuable resources and advocacy for the pulmonary fibrosis community! We are deeply humbled and privileged to be a part of dedicated individuals living with pulmonary fibrosis and their loving families, healthcare professionals, and industry.

2022 Revenue



2022 Expenses



- Most successful **Annual Giving Campaign** ever!  
Not only met our goal, but blew it away- raising +\$18,000

To Unite the Pulmonary Fibrosis Community

# 2023 A YEAR IN REVIEW

## **January**

- Co-host Lung Transplant Panel Discussion with PF Warriors and Temple Lung Center

## **February**

- Celebrated the two year anniversary of the launch of the PA-IPF Support Network
- Jennifer Wescoe named Chairperson of Pennsylvania Rare Disease Advisory Council (PARDAC)

## **March**

- Earned Standards for Excellence® Basics recognition administered by the Pennsylvania Association of Nonprofit Organizations' (PANO)
- Launched Veterans ILD Support group

## **April**

- PA-IPF Support Network Podcasts exceed 4,000 downloads in 64 different countries

## **May**

- Co-host webinar with patientMpower and Mount Nittany Medical Center, "Improving Access to Care through Technology"
- ATS exhibitor and presenter "Meet the Experts: Integrating ILD Support Groups in Community Medical Centers"
- Hosted the 17th Annual Coopersburg 5k with 300+ runners and a community Health & Wellness Expo

## **June**

- Patient-Centered Outcomes Research Institute (PCORI) Temple University's College of Public Health patient engaged research project approved to move to next phase



# 2023 A YEAR IN REVIEW

## July

- Wescoe Foundation recognized and presented at PANO's annual Board of Directors retreat

## August

- Wescoe Foundation completes groundbreaking Support Group Assessment Survey

## September-*Global Pulmonary Fibrosis Awareness Month*

- Poster Campaign, sent 250 awareness posters to PA Pulmonary Rehabs
- 27 PA landmarks illuminated blue
- 3rd Annual PF Awareness Golf Outing
- PA passes Resolution No. 203 delegating the week of 9/17-23 IPF Research and Awareness Week
- Coopersburg Borough and Town of Bloomsburg pass proclamations delegating Sept. as PF Awareness Month
- Jen Wescoe recognized by PA House member Ryan Mackenzie for her tireless service to the PF Community

## October

- 18th Annual Wescoe Walk to raise awareness
- PCORI- Conference Presenter

## November

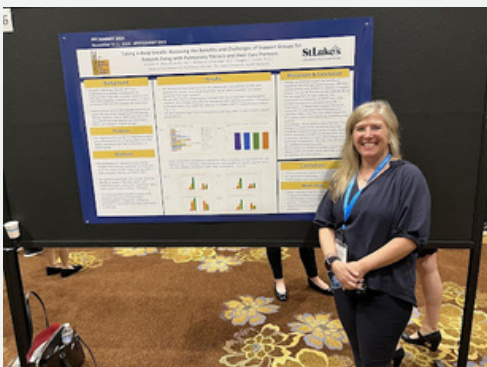
- PFF Summit Abstract Poster Presenter- WFPF Support Group Assessment Survey and speaker at Veterans ILD Meeting
- Participated in Patient Advocacy Organization Global Symposium, roundtable discussion, Frankfurt, Germany

## December

- Completed 12 months of educational Podcasts collaborating with experts in the field of ILD care

# 2023

## A YEAR IN REVIEW





## The PF Community... *in their own words*

Temple Lung Center has worked together with the Wescoe Foundation for Pulmonary Fibrosis for many years and is happy to see the expansion of the PA IPF Support Network. Through our involvement with the support network's PF podcast, educational seminars, lung transplant series, and IPF Carebook, we are finding that this is an exceptional resource for Pennsylvanians living with pulmonary fibrosis. I encourage you to connect with the PA IPF Support Network and all that it has to offer.

**Dr. Gerard J. Criner, MD, FACP, FACC, Director, Temple Lung Center**

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The Wescoe Foundation and, specifically, Jen Wescoe have been a wonderful source for education, emotional support, and life changing adjustments since being diagnosed with IPF in April 2017. Through Jen's untiring efforts, leadership and empathy, Nancy and I have met many other IPF patients who shared their stories and because of Jen, this journey has been made a little easier. We can never thank Jen and the Wescoe Foundation enough for all the selfless work they do for us. Thank you.

**Dennis and Nancy H., IPF Patient & Care Partner**

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I cannot stress how beneficial and important the Wescoe Foundation for Pulmonary Fibrosis and the PA IPF Support Network is to my patients. When a patient is diagnosed with pulmonary fibrosis, it can often be scary, isolating, and difficult to find accurate information. The Wescoe Foundation /PA IPF Support Network provides a community of caring people who can help others going through a similar situation, providing invaluable support and guidance. Additionally, the clear and accurate education available provides an opportunity for the patient to learn the most accurate and timely information about pulmonary fibrosis from a trusted source.

**Dr. Douglas S. Corwin, MD, Associate Program Director, St. Luke's Pulmonary and Critical Care Associates**

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The Wescoe Foundation for Pulmonary Fibrosis is a beacon of hope in an often turbulent and dark storm. The Wescoe Foundation for Pulmonary Fibrosis not only supports pulmonary fibrosis patients, their caregivers, and families...they educate the medical community and public about this terminal illness. The Wescoe Foundation for Pulmonary Fibrosis not only provides support groups for patients that have PF...they recognize and provide support groups for caregivers of patients that have pulmonary fibrosis. The Wescoe Foundation for Pulmonary Fibrosis not only advocates for and supports research about pulmonary fibrosis...they provide opportunities for patients and caregivers to have access to the most recent trends in medical treatment for pulmonary fibrosis patients. The Wescoe Foundation for Pulmonary Fibrosis is our constant supportive connection to traversing the ups and downs of pulmonary fibrosis.

**Kym Z. B., IPF Care Partner**

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Thank you, Jen, on behalf of the faculty and staff of the Simmons Center, for your leadership and tireless advocacy for patients who suffer from pulmonary fibrosis. We greatly appreciate that you have built the PA IPF Support Network and have engaged pulmonary fibrosis patients, their caregivers, and allied health providers from across the Commonwealth to advance the mission of supporting patients through this devastating illness. You have congregated the leaders from the major academic institutions and have brought education to patients living in the cities, towns, and rural districts in Pennsylvania. You have developed robust fundraising efforts to support the PA IPF Support Quarterly Seminar Series. We stand in awe of your strength and determination. You have turned your family's tragedy with pulmonary fibrosis into a living monument to the many patients who have succumbed to this terrible disease. Your determination will help us all see a day when pulmonary fibrosis is curable. I consider myself very lucky to work with you.

**Dr. Daniel J. Kass, MD, Director, Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease at UPMC**

## ATS Podcast Highlight

The American Thoracic Society's Breathe Easy Podcast, "Pulmonary-Palliative Care: We Be-LUNG Together" hosted by and Dr. Patricia Fogelman, DNP, ACHPN, globally highlights Jen Wescoe and the Wescoe Foundation for Pulmonary Fibrosis's critical engagement in the PF community.

The Wescoe Foundation always provides an incredible amount of support, education, advocacy, and resources for my patients and their families living with IPF. The immense strain covid and its resultant fibrotic disease process has inflicted on our healthcare systems in the past year has affected many providers' ability to appropriately treat patients with this disease. The Wescoe Foundation has been able to remedy the shortcomings in our hospital systems and let the pandemic ignite their drive to further advocate for disease awareness, management, and emotional support for so many people. When I refer a patient to the Wescoe Foundation, I know, at the very least, that my patient will be heard.

**Emily Pettit, RRT, AE-C, Registered Respiratory Therapist,**  
WellSpan Health and Encompass Health

If you are a patient or caregiver looking for up-to-date information about Pulmonary Fibrosis, the Wescoe Foundation and PA IPF Support Network are the sites you want to visit. Not only will you find up-to-date information about this disease, but you will be able to hear firsthand experiences from people who have gone through exactly what you are going through.

**Jim C., IPF Patient**

Jen Wescoe has shown the passion and perseverance to continue to bring relevant education and support directly to the people who are most affected by IPF. She and the Wescoe Foundation have been committed to help patients and caregivers understand a very complex disease so they can be better equipped to partner in their care to make choices that are right for them. All of you at the Wescoe Foundation- Thank you for all that you do!

**Dr. Namrata B. Patel, MD, Clinical Director, Penn Interstitial Lung Disease Program**

A. A. Milne once wrote: "There is nothing that you and I could not accomplish together, if we gave our minds to it." And that's Jen Wescoe, the force behind the Wescoe Foundation - nothing is impossible if we do it together. When Jen invited me to become part of this collaboration over a decade ago, I would never have imagined the many ways it would take off. What began as a joint collaboration for a patient support group through my Pulmonary Medicine Division at Geisinger Medical Center in Danville, PA has now grown into a pulmonary fibrosis podcast, a state wide recognition and awareness for pulmonary fibrosis accommodations every year, lighting landmarks blue throughout Pennsylvania, the submission of multiple proposals to national medical organizations and societies about the need for improving the access and availability of patient and caregiver support groups in the management of pulmonary fibrosis as well as the newest accomplishment, a national podcast with the American Thoracic Society, "Pulmonary-Palliative Care: We Be-LUNG Together."

**Dr. Patricia Maani Fogelman, DNP, ACHPN, Clinical Director of Palliative Medicine Department, Mount Nittany Health**

I love working with the PA IPF Support Network because pulmonary fibrosis is the sort of tough disease that is best fought with a sustained, community-based effort. The first time I met Jen, she introduced me to the Wescoe Foundation's IPF patient Carebook. This simple, practical, yet powerful patient-centered tool can be used by all patients, regardless of their location, community, or personal situation.

**Dr. Rebecca Bascom, MD, MPH, Professor, Department of Medicine - Division of Pulmonary, Allergy, and Critical Care Medicine and Department of Public Health Sciences for Penn State Health Milton S. Hershey Medical Center**



# Meet the Board

## Wescoe Foundation for Pulmonary Fibrosis

### **Dr. Gerard Petersen**

*President*

Chief Pulmonologist at Lehigh Valley Health Network

### **Trish Colasurdo, D.C.**

*Vice-President*

Co-Owner Coopersburg Family Chiropractic

### **Kyle Elsenbaumer, CPA**

*Treasurer*

Campbell, Rappold, Yurasits, LLP

### **Mike Pfeiffer**

Regional Account Manager  
Alexion Pharmaceuticals

### **Dr. Doug Corwin**

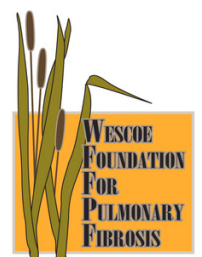
Clinical Assistant Professor and Associate Program  
Director for Pulmonary Critical Care Fellowship,  
St. Luke's University Health Network

### **Dr. Dennis McGorry**

Primary Care Physician  
Pulmonary Fibrosis Community

### **Jennifer Wescoe Singley, M.Ed., NCC**

Founder, Executive Director  
Wescoe Foundation for Pulmonary Fibrosis



# To Unite the Pulmonary Fibrosis Community