Pulmonary™ Fibrosis Foundation

Meet the class of 2024 PFF Ambassadors

About the PFF Ambassador Program

The PFF Ambassador Program encourages and empowers patients, caregivers, lung transplant recipients, family members, and those who have lost a loved one to serve as spokespeople for the pulmonary fibrosis (PF) and interstitial lung disease (ILD) community on behalf of the Pulmonary Fibrosis Foundation (PFF).

PFF Ambassadors speak at Care Center Network sites, support group meetings, fundraisers, educational events, and many other settings.

PFF Ambassadors share a message of hope and inspiration to those affected by PF and ILD.

Interested in having a PFF Ambassador speak at your event? Complete the **PFF Ambassador Request Form.**

Bill Ashley

Diagnosed with pulmonary fibrosis and hypersensitivity pneumonitis in 2020

"I want my kids and family to know that I fought a good fight, and I did it with excellent partners like my medical experts and the people at the PFF. I feel like I'm fighting the battle of my life, but I have a great team behind me."

Bill was shocked when what he thought was an ordinary physical revealed that he had pulmonary fibrosis. He never dreamt that a little bit of wheezing could be so serious. After doctors told him to get his affairs in order, he got a second opinion and learned that with changes to his lifestyle, he could fight this disease to have more time. He retired early and started walking five miles a day. By eating healthy, practicing his exercises from **pulmonary rehabilitation**, and meditating, he remains stable. Today, he channels his energy into raising funds to support PF research to find better treatments and a cure. He's dedicated to learning all he can about the disease and helping other patients as a PFF Ambassador.

Brandi Ellis

Caregiver to her father, Richard, who was diagnosed with idiopathic pulmonary fibrosis (IPF) in March 2023 and received a single-lung transplant in November 2023

"Based on my family's experience, the best advice I can give you is to NEVER GIVE IN. Had we listened to the first doctor who told my father to get his affairs in order, he wouldn't be here today."

In early 2023, Brandi and her family were on top of the world with plans for the coming year, when her father was suddenly hospitalized. He went from playing golf and pickleball to being on 24-hour oxygen. Their world was turned upside down when he was diagnosed with IPF and given 6-12 months to live. A family of fighters, they banded together and found resources and support. Brandi helped her parents every step of the way as they navigated the process to receive a lung transplant. After receiving a single-lung transplant just 8 months after his diagnosis, her father is doing well. Grateful for the **guidance and support the PFF provided to her family**, Brandi jumped at the opportunity to spread awareness of the disease and give hope to patients and caregivers as a PFF Ambassador.

Carolyn Vega

Diagnosed with pulmonary fibrosis in 2001 caused by Sjögren's disease, received a single-lung transplant in 2013

"To those of you who are battling this disease, or any chronic illness, I want you to know that you are not alone. There is a community of support, a wealth of resources, and a world of possibilities still ahead of you."

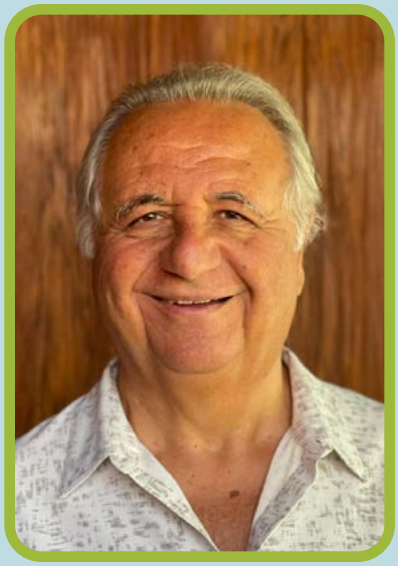
When Carolyn couldn't walk 10 feet without gasping for breath, she knew something was wrong. Simple tasks became monumental challenges, and she had to take a leave of absence from her cherished teaching career. After her dentist noticed her teeth were losing enamel and her mouth was unusually dry, Carolyn was diagnosed with Sjögren's, an incurable autoimmune disorder that attacks moisture-producing glands. The disease affected Carolyn's lungs, leading to pulmonary fibrosis. With treatment, medication, and **supplemental oxygen**, she was able to return to work for a while. However, the next decade became a roller coaster of emotions and uncertainty, culminating in a lung transplant. While the road to recovery wasn't easy, it was filled with hope as Carolyn discovered her new normal. Today, she is doing well and educates people about the disease as a PFF Ambassador.

Donna Dinkin

Diagnosed in 2015 with interstitial lung disease and pulmonary fibrosis caused by scleroderma

"Sharing my story with others not only helps me process my thoughts and emotions, but it also connects me with a community of individuals who understand my journey. Conversations with fellow patients can be a source of strength, comfort, and information."

When Donna struggled to exercise or walk up the stairs without gasping for breath, her negative inner voice told her it was because she was lazy or gaining weight or getting older. She never suspected a serious health condition was at the root of her troubles until she was diagnosed with ILD and PF caused by scleroderma, an autoimmune disease. Terrified, she listened as her inner voice narrated horrible scenarios for the future and worried about how her teenage sons would get through life without her. Thankfully, she found a behavioral health therapist who was able to help her deal with the emotional side of living with ILD and scleroderma. The experience showed Donna the healing power of talking. Today, she educates people about the disease as a PFF Ambassador and encourages other patients to find someone to talk to – whether it's a therapist, friend, or **support group.**



Fred Shirzadi

Diagnosed with idiopathic pulmonary fibrosis in 2023

"Those two days at the PFF Summit and subsequent interactions with the Foundation staff gave me back my hope. It gave me a will to live. I felt like I could be happy again and enjoy every day."

When Fred's doctor told him he had pulmonary fibrosis, it came as a complete surprise. Although he didn't have any symptoms, an X-ray to monitor a blood clot found scarring in his lungs. A quick internet search of the disease shattered his world. Although Fred was surrounded by a supportive group of loving family and friends, he felt scared, lonely, and hopeless. The turning point came when his son took him to the **PFF Summit,** where he shared experiences with other patients and spoke to healthcare providers who answered his questions. It was a turning point that helped him regain his zest for living. Today, he maximizes every moment and lives life to the fullest. He educates people about the disease and gives back to the community that helped him as a PFF Ambassador.

Gary Johnson

Diagnosed with pulmonary fibrosis in 2015, received a bilateral lung transplant in 2020

"My new focus in life is to help others who may have lost all hope. I want to be a living example of encouragement."

Gary woke up one morning and felt like all the joints in his body were on fire. It was the most pain he had ever experienced. Diagnosed with rheumatoid arthritis, Gary was prescribed medications to help, but he didn't realize those medications were affecting his lungs. Climbing stairs or walking his dog became nearly impossible. After he was diagnosed with pulmonary fibrosis, he lived with about 50 percent lung capacity for years until a high-altitude trip to Colorado triggered an exacerbation. From then, Gary worked hard to get listed for a lung transplant and eventually received a bilateral lung transplant. Today, he is doing well and encourages others who are considering or receiving a **lung transplant.** He also educates people about pulmonary fibrosis and supports patients as a PFF Ambassador.

Linda Dominy

Diagnosed with interstitial lung disease in 2012 and idiopathic pulmonary fibrosis in 2021

"I developed very close friendships with many of my patients. I thought I was helping them, but it turns out that they were teaching me. I now find myself living with pulmonary fibrosis and putting into action all the advice I gave to my patients for so long."

As a respiratory therapist, Linda was very familiar with the symptoms of pulmonary diseases. When she noticed that climbing the stairs at work or walking during a tour left her breathless, she knew something was wrong. Having worked with many pulmonologists, she advocated for herself by requesting a high-resolution computerized tomography (HRCT) scan, which showed she had ILD. After being diagnosed, Linda immediately went to the PFF website to find the **top medical providers near her.** She became her own best patient, practicing all she learned about pulmonary rehabilitation on herself. Today, she is doing well with the help of her supportive family. She takes her medication, exercises daily, and continues to travel the world. Linda shares her knowledge and experience to help educate people about the disease as a PFF Ambassador.

Lisa Reed

Diagnosed with interstitial lung disease and pulmonary fibrosis in 2022

"Whether it's getting the right diagnosis, learning what treatments are available, or finding resources for caregivers, there are answers and support out there. The PFF is a great place to start and to get help along the way."

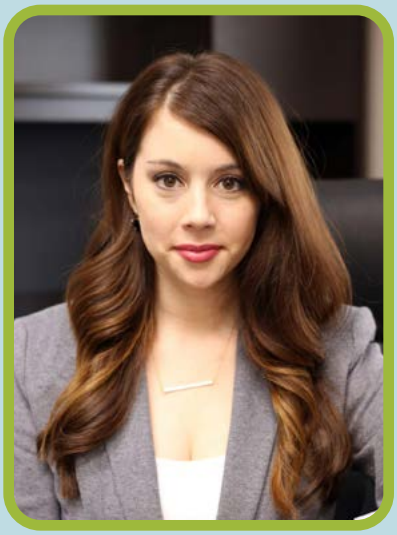
Lisa was planning to celebrate a milestone birthday with a trip to Italy when a lingering cough sent her to the emergency room. After a chest X-ray, she and her husband were shocked to read the words pulmonary fibrosis in the test report. Unsure how to fight a disease she had never heard of, Lisa found a great medical team who provided excellent care. That same year, her two brothers were also diagnosed with pulmonary fibrosis and went to the same hospital for treatment. Stunned that so **many members of her family had PF,** Lisa made it her mission to make everyone aware of the symptoms and help all those touched by the disease. Today, she raises funds for research and educates people about pulmonary fibrosis as a PFF Ambassador.

Michael Gordon

Diagnosed with idiopathic pulmonary fibrosis in 2019 and received a double-lung transplant in July 2022

"If you are in a similar situation, know that there is hope. The PFF has resources to help you navigate living with the disease."

When Mike developed a persistent dry cough and felt breathless, he knew that the cause could be IPF. He had lost three relatives to complications from the disease, including his brother. The diagnosis was heartbreaking for Mike and his family. Determined to show his two children that IPF is not a death sentence, he focused on staying healthy and being open to **testing and research opportunities**. With the advice of his pulmonologist, he decided to explore a lung transplant. Throughout the transplant evaluation and listing process, he tried to remain calm and keep a positive outlook. After many challenges along the way, Mike received a double-lung transplant and began the long road to recovery. Now post-transplant, Mike is feeling better than ever and considers himself to be one of the luckiest people alive. He is pleased to share his experience and educate people about the disease as a PFF Ambassador.



Rebecca Hall

Diagnosed with autoimmune-related interstitial lung disease (ILD) in 2020

"The PFF changed my outlook on life and helped me understand my disease. This is a very scary and overwhelming disease to navigate on your own; finding your people makes a huge difference."

Rebecca was busy running a business, raising a daughter, and planning to grow her family, when she suddenly struggled to breathe while walking to the beach during a family vacation. After several misdiagnoses, she found out she had autoimmune-related ILD. The diagnosis was terrifying. Just as her life was getting started, it seemed like it was over. Feeling scared and alone, she searched for others like her who were coping with the disease while working and raising children. When she struggled to find those connections, **she started a support group** for young women with ILD with the help of the PFF. After finally finding her people, Rebecca realized it is possible to thrive with this disease and help others along the way. Today, she raises awareness and educates people about the disease as a PFF Ambassador.

Thank you to all of our PFF Ambassadors!

Want to book an Ambassador to speak at your support group, educational event, fundraiser or conference?

Book a PFF Ambassador

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