

# The Kansas City Foundation for Pulmonary Fibrosis

***Kansas Governor Laura Kelly Proclaims  
September  
As Pulmonary Fibrosis Awareness Month!***

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# September Pulmonary Fibrosis Awareness Month

**The Pulmonary Fibrosis Foundation provides detailed information about PF.** Such as:

250, 000 Americans with PF

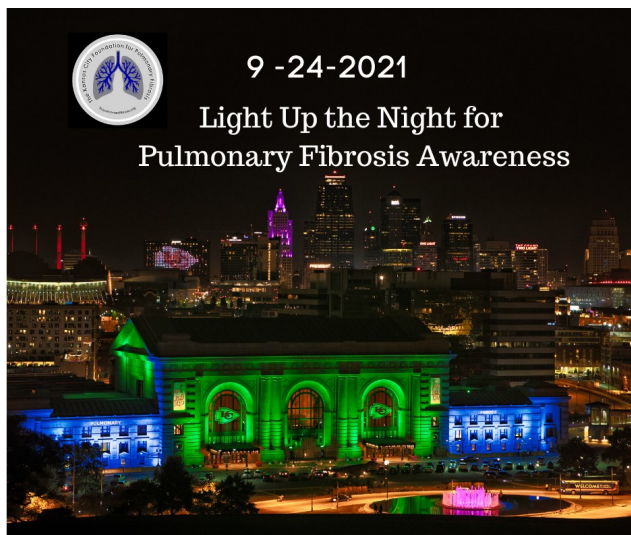
50,000 diagnosed with PF Annually

Symptoms

- Dry Cough
- Shortness of Breath
- Fatigue

It is always good to review this information from time to time. Go [here](#) to read more.

## 4th Annual Light up the Night for Pulmonary Fibrosis



*Sep 19, 2020, KCFPF lit up Union Station for PF Awareness (photo by Kay Trieb)*

Go to Union Station or to Liberty Memorial and see this incredible view on Friday, September 24.

The KCFPF Board Members will be there starting around 7:30 pm.

### Awareness Stories

Several people from the Greater Kansas City Area shared their stories for Pulmonary Fibrosis Awareness month.

Their stories will be published in the **30 Days of PF** initiative on Pulmonary Fibrosis News. Follow the stories throughout the month. The dates below are subject to change.

Sep 1: "My Journey as a Lung Transplant Care Partner" - Dana Olson

Sep 2: "My Transplant Story" - Barbara Grubb

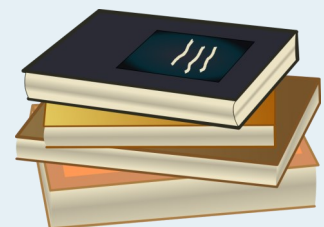
Sep 3: "My Attitude Is One of Gratitude" - Gail Hicks

Sep 7: "Embracing the Gift I've Been Given" by Mary Spilman

Sep 10: "Running a Marathon for my Dad" by Nicholas Sloop

Sep 12: "A Daughter's Ride on the IPR Roller Coaster" by Terri Dominick

Sep 28: "Side By Side, A Journey Through the Unknown" By Rhonda Hitchcock



# Story of The Greater Kansas City Pulmonary Fibrosis Support Group—Dale Brommerich

The very first Support Group meeting of patients diagnosed with Pulmonary Fibrosis in the Kansas City area met in March, 2013. The idea was the brain-child of Pam (Dawnie) Ellison, a Certified Respiratory Therapist, BS., who works in



the Pulmonary Rehabilitation Dept. at St. Joseph Medical Center in Kansas City Missouri. That first meeting was attended by 4 people along with Dawnie and

another co-worker, Eugenia Moley.

To encourage all P.F. patients in the area to participate, they called the informal group “The Greater Kansas City Pulmonary Fibrosis Support Group”. For the last 8 ½ years, the group has met every month, without fail, via various methods. Typically, the group meets the second Tuesday of every month from 4:30 to 6:00 PM at St Joseph Medical Center, 1000 Carondelet Drive, in Kansas City MO.

For several years, before the Covid pandemic, the group averaged about 25 people at every meeting. After Covid hit in March 2020, Dawnie communicated with patients and caregivers frequently via e-mail until meetings were converted to Zoom meetings in May of 2020. Even between Zoom meetings, Dawnie would send out encouraging e-mails, knowing that patients were in near total isolation. Currently, the group averages 12 – 15 participants per Zoom meeting.



Meeting formats are mixed to meet everyone’s needs. Sometimes there are open discussions to share knowledge and experiences as patients go through various stages of the disease. Participants determined that our mission should be to learn and share information and to encourage one another. At some meetings, we schedule guest speakers to share information. The subjects vary greatly and include topics like: Exercise for P.F. patients; Healthy eating; Oxygen usage; What are Pulmonary Function Tests; Travel issues for P.F.

patients; Preparing for emergencies; Transplant options; and Advance Directives and Trusts. Sometimes we get patients actively involved like: Making healthy smoothies; Chair Pilates; and How to Meditate.

Occasionally, we host a special event, typically in September, which is P.F. Awareness Month. Our first event was in Sept of 2017 when we co-hosted an Educational Event with Dr. Mark Hamblin and members of his team from The Kansas University Medical Center. Their Pulmonary Fibrosis program is recognized as a National Care Center Network, where people with PF can find experienced medical professionals who understand their rare disease and support services to improve the quality of their lives. This event was a great success and was repeated in 2018. Typically, over 50 patients and family members participate along with several healthcare workers from other area Medical Centers. As a result, Dr. Hamblin founded a local non-profit foundation called “The Kansas City Foundation for Pulmonary Fibrosis” in August of 2018. Dawnie and some of the P.F. Support Group patients serve on the Board of Directors. This relationship has developed into a close partnership with the two organizations.



The Greater Kansas City P.F. Support Group is one of the more active support groups in the country and as a consequence, serves as a source for others. The National Pulmonary Fibrosis Foundation in Chicago has both local medical professionals and patients serving on National Committees. Pharmaceutical Companies and Durable Medical Device Equipment Companies solicit local patients to participate in focus groups to hear the “Voice of the Patient” when developing new approaches to delivering drugs, advertising, and improving medical devices.

To learn more information about the KC PF Support Group, contact Dawnie Ellison at (816) 943-2040 and leave a message. You can try to email her at Pelli-son3@PrimeHealthcare.Com but some addresses are screened by the Medical Center for security reasons.



## Outcomes for hospitalized patients with idiopathic pulmonary fibrosis treated with antifibrotic medications

BMC Pulmonary Medicine published the study stating that “treatment with antifibrotic medications does not appear to directly improve 30-day mortality during or after respiratory-related hospitalizations. Post hospital discharge, however, ongoing antifibrotic treatment was associated with improved long-term survival.”

The full study and peer-reviews can be seen [here](#).

## Computerized Imaging Tool Helps ID New IPF Subtype

Discovered with the assistance of a computerized image analysis tool, the new subgroup of IPF is described as, “Idiopathic pulmonary fibrosis co-occurring with a second lung disorder.” The subset of patients have both IPF as well as what’s known as PPFE (pleuroparenchymal fibroelastosis). The main take away from finding this new subgroup was to be able to develop a more personalized approach to patient management due to the combination possible requiring a different treatment than patients without both diseases.

The importance of the study outlines that patients with both diseases were more apt to experience worse outcomes.

See the full article [here](#).

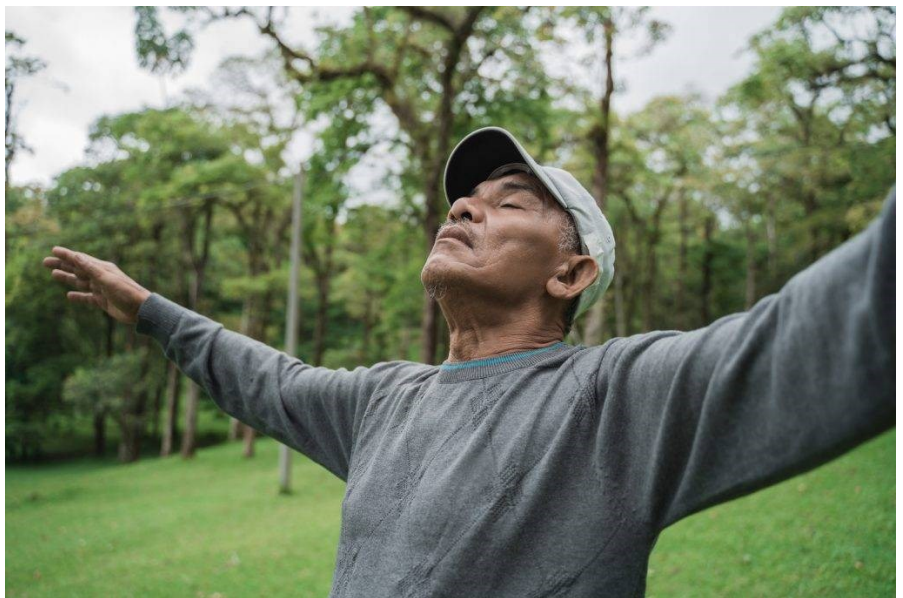
## Daily Breathing Exercises Seen to Slow Progression in IPF Patients

Lung rehabilitation and exercise can not only improve heart health and quality of life, it is shown to be a key therapeutic approach for patients with IPF. Simple breathing exercises have been showing to slow the decline of lung function.

The small study published in the *Annals of Palliative Medicine* show that at 6 months and 12 months, there was great improvement in exercise capacity and “lower rates of lung function decline and mortality”.

The exercises, done consecutively, include slow and gentle arm movement while practicing focused and deep breathing.

Read the full article [here](#), and the original study [here](#).



## Lungs of People With IPF, Like Disorders 'Primed' for Severe COVID-19

In an article published on the Pulmonary Fibrosis News website, Nicholas Banovich, a main researcher of the discussed study, states that patients with IPF and other chronic lung diseases are more prone to infections by Covid-19. In fact, they are more vulnerable to severe cases which could lead to long-term hospitalizations and/or ventilation.

The researchers set out to determine what changes on a molecular level may lead to these poorer outcomes due to SARS-CoV-2.

The full article can be seen [here](#), the study can be read [here](#).

## Ron Flewett Interview: Impact of COVID-19 & Benefits of Virtual Healthcare for IPF Patients — patientMpower

In 2014, Ron was diagnosed with IPF. He has since then become a strong advocate for people with IPF and works with organizations in the UK, Ireland, and the USA.

patientMpower conducted an interview with Ron to discuss Ron's experience during the Covid-19 pandemic.

Read the short article and watch the interview [here](#).



## Epidemiology of Idiopathic Pulmonary Fibrosis Among U.S. Veterans, 2010 – 2019

In a study published by the Annals of the American Thoracic Society, researchers look to learn more about the epidemiology of IPF patients among United States Veterans. It looked at trends over time and risk factors associated with IPF. While this is a new look at the disease in this population group, the study suggests further studies should be conducted.

To download a full copy of the study, [go here](#).

## Pulmonary fibrosis is a progressive, debilitating lung disease.

Aboutpf.org lists some basic statistics about pulmonary fibrosis. Along with the 50,000 or more new cases of IPF and ILD diagnosed every year, there are upwards of a quarter of a million Americans living with the disease.

The website linked below has various videos and resources regarding the scarring of lung tissue, the risk factors that are associated with a PF diagnosis, and how Covid-19 plays into the disease.

Pinpoint PF (Pulmonary Fibrosis Foundation)

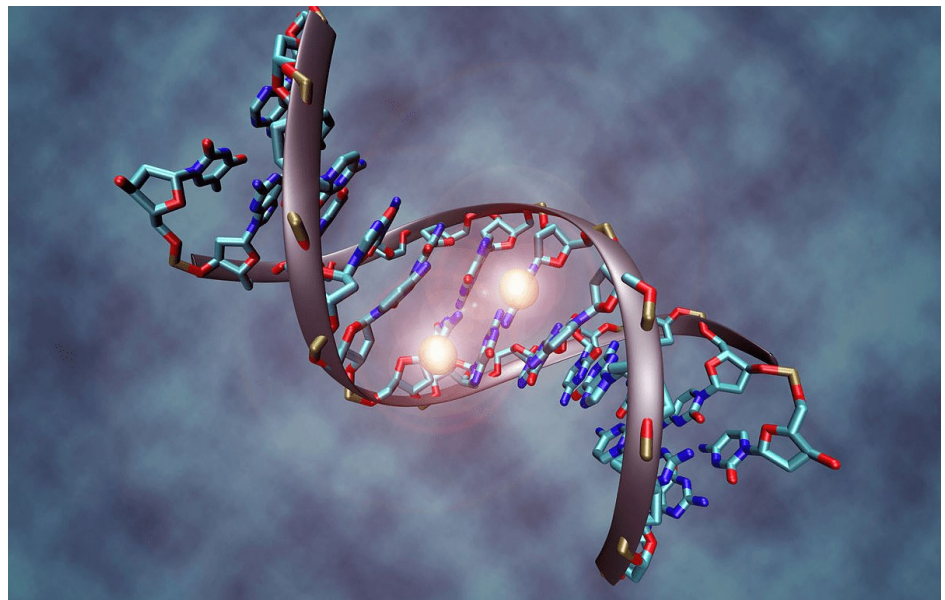
Suggestions are provided on how to effectively care for the loved one and yourself [here](#).

## Genetic Testing in Pulmonary Fibrosis

The Pulmonary Fibrosis Foundation discusses the role of genetic testing in Pulmonary Fibrosis. Familial PF is estimated to account for up to 20% of patients with PF. The article discusses genes, and variants and what part of those can go into the PF diagnosis of families.

Discussions of how to get genetic testing and if a patient should consider it are also discussed.

To see the full statement, click [here](#).



## More Than 40% of Patients Wait Year or Longer for PF Diagnosis

According to a European Study published in the journal Frontiers in Medicine, a diagnosis takes upward of a year for 40% of patients with IPF.

Due to the degenerative nature of the disease, a prompt diagnosis is extremely important to prevent bad outcomes.

According to the article, “this highlights the need to raise awareness of pulmonary fibrosis amongst the general public, so that individuals seek medical assistance earlier.”

The full article can be found [here](#), the original study is [here](#).

## Lung Transplant Rejection

Prana2Live Advanced Fab Technology is concerned with improving the quality of life and longevity through awareness of practical knowledge of Pulmonary Fibrosis.

One of the resources they have made available is a set of slides by Patrick Fernandez discussing why and how lung transplants are rejected, as well as some of the symptoms that can be associated with rejection. Also discussed are preventative measures.

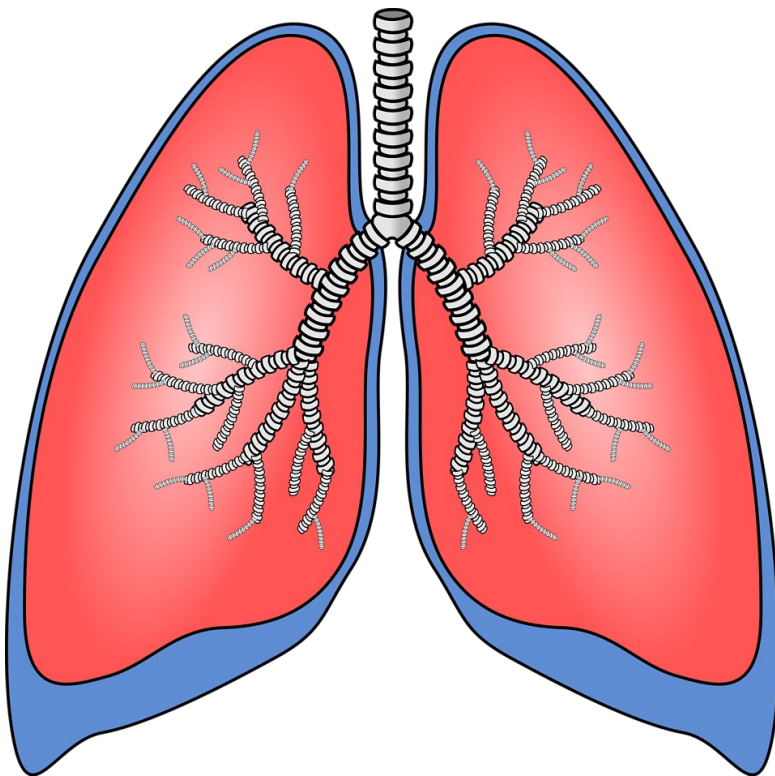
To see the full set of slides, go [here](#).

## Sligo lung transplant recipient Vera Dwyer passes away 33 years after life-saving operation

Ms. Vera Dwyer, the world's longest surviving single lung transplant recipient, died last month.

The article discusses how Ms. Dwyer was diagnosed and the process of receiving her lung transplant after she was bedridden by the fast progressing disease.

The full obituary can be read [here](#).



## Clinical impact! Surgical lung biopsy & pathological diagnosis in patients

“Diagnosis of interstitial lung disease is based on the analysis of clinical, biological, radiological and pathological findings during a multidisciplinary discussion (MDD). When a definitive diagnosis is not possible, guidelines recommend obtaining lung samples through surgical lung biopsy (SLB). We sought to determine morbidity, mortality, diagnostic yield, and therapeutic impact of SLB in the management of patients with interstitial lung disease. “

The researchers analyzed various statistics regarding SLB between 2015 and 2019.

The summary and full study can be found [here](#).



## What it Takes to Prepare for Transplant as a Care Giver by Dana Olson

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The moment we learned Kevin was going on the transplant list, we started preparing. We made a list of what we would need to take and get done prior to getting "the call." I had to pack a bit more to take initially than he did because he would be in the hospital for at least ten days (it ended up being 31 days). I got duplicate toiletries to keep a suitcase packed for both of us and in the trunk of the car to be ready to go no matter where we might be when the call came in. We also made a call list of the people we needed to notify immediately when we got the call, as well as family and friends we would want to share info with once we got to St Louis for the transplant. We also had more supplies and clothes that we would be needing but not immediately. Our daughter

came by our house after we left and picked up the rest for us on her way to the transplant center.

The hard part is not thinking about things that you have in your home kitchen - spices, utensils, pans, etc. The apartment we stayed in had a sparse amount of cooking utensils. You might want to buy some inexpensive things like a couple of dish towels, a couple of large bath towels, a tablecloth and placemats, and a small crockpot.

When considering where to stay if you don't live within a 50-mile radius of the transplant center, please consider these things: 1) Staying close to the transplant center so while your care partner is in the hospital, you don't have to travel far. 2) The closeness makes getting to 5-day a week rehab plus lab draws, chest rays, and every 2-week clinic appts easy. 3) Consider a place with a

parking garage - no getting out in the rain, snow, etc., and is much safer for you and your vehicle.

We made sure that we had all electronic Bill Pay set up as well as receiving bills electronically/paperless. Or consider having a neighbor check your mailbox periodically at home to collect it and mail it to you occasionally.

Use the Transplant Guidebook you should have received on your first visit. It has information on things you may need and how to prepare. Google was my best friend as far as looking for places to eat and buy groceries!





*The Kansas City Foundation for Pulmonary Fibrosis (KCFPF) is a nonprofit organization dedicated to improving the lives of patients with pulmonary fibrosis and other rare lung diseases through education, technology, and research.*

## Volunteers Wanted!

The Foundation would like volunteers for these committees.

**Fundraiser Committee:** Subcommittee will be to make recommendations to the Board on the annual fundraiser. The subcommittee will also explore additional fundraising opportunities outside of a yearly event.

**Patient Initiative Committee:** The purpose of the Foundation Patient Initiative Committee is to be good listeners and observers of the Pulmonary Fibrosis Community and identify, research, and propose opportunities the Foundation can financially support to make life easier.

**Media Committee (Website, FB, News, Newsletter):** The primary role of the Media Subcommittee will be to spread awareness, distribute educational and grant information, and advertise events developed by the other subcommittees. The primary focus will be on website and Facebook updates, but the use of different media will depend on the target audience.

Visit Here to sign up: <https://www.kcpulmonaryfibrosis.org/want-to-help>

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