

The Kansas City Foundation for Pulmonary Fibrosis

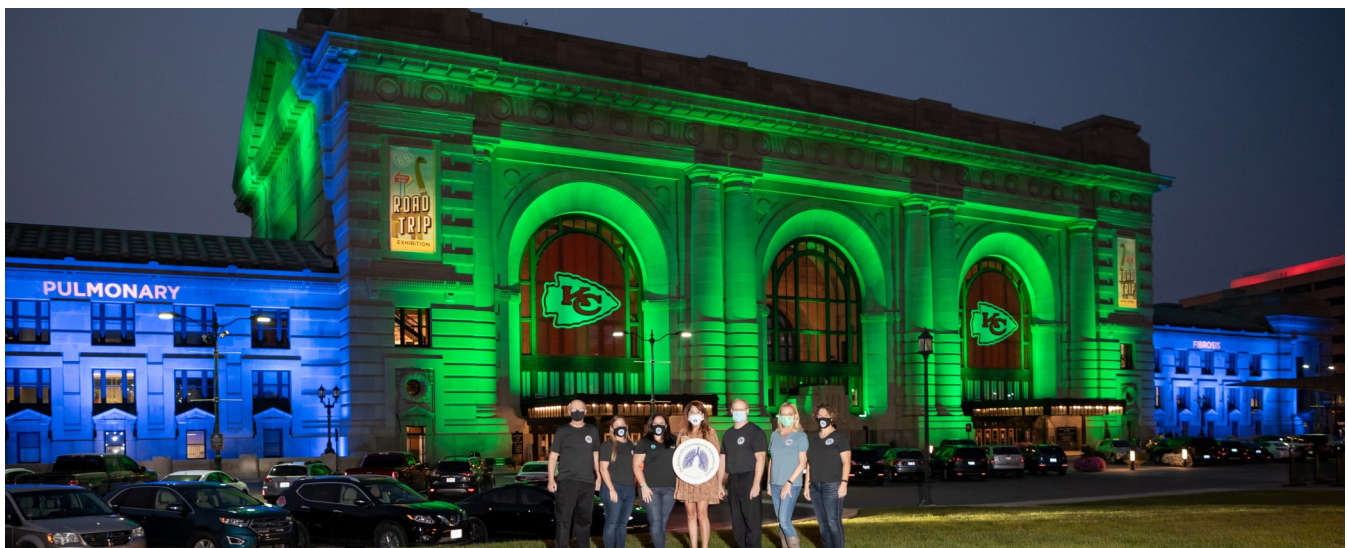
Bernie Williams Raises Awareness for IPF

Bernie Williams is best known for his time with the New York Yankees, acting as a center fielder and winning four World Series. In more recent years, however, he can be seen raising awareness for IPF after the diagnosis and loss of his father to IPF.

Read more [here](#) and [here](#).

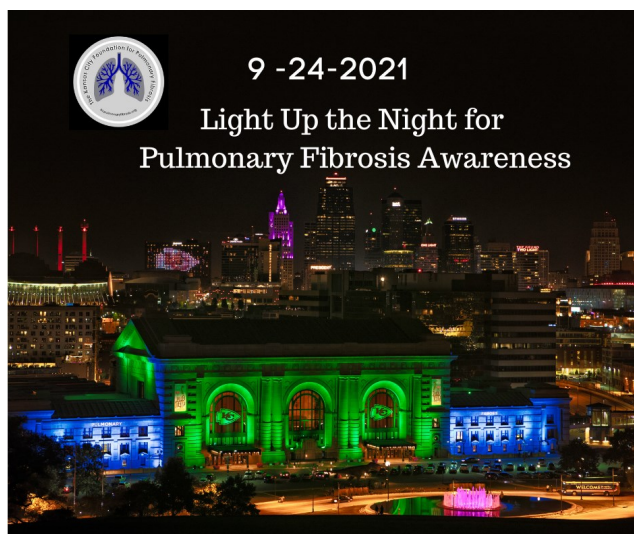
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Sep 19, 2020, KCFPF lit up Union Station for PF Awareness. Board Members (photo by Kay)

4th Annual Light up the Night for Pulmonary Fibrosis



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

The Light Up The Night for PF fundraising concert has been postponed because of the increase of Covid cases. The fundraiser is now scheduled for March 4, 2022.

However, the Foundation is still Lighting up Union Station that evening of the 24th. Along with the Foundation lighting Union Station, Boehringer Ingelheim is lighting the Power and Light Building.

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

September Pulmonary Fibrosis Awareness Month

In a few weeks, Pulmonary Fibrosis Awareness Month begins. Over the next 45 days, let's concentrate on getting more people involved with Pulmonary Fibrosis Awareness.

Do you have a Facebook account, and do you like the KCFPF FB page? If you do, please invite your friends to follow the foundation's page. If you don't follow the page, please consider following.

On August 1, 2020, the KCFPF FB page had 143 followers. Now it has 259. Our goal is to increase the number of followers to 500. We request everyone's help.

Virtual 2021 PFF Summit

The 2021 PFF Summit dates are **November 8 - 13**.

Click here for the [program](#).

Recommend you attend this summit for the latest PF information. There are still plenty of grants available.

KCFPF will provide grants to persons with PF, family members, care partners, transplant recipients, or those who have lost a loved one to attend the virtual summit.

The grant will cover the registration fee. A family is limited to purchasing two packages. You will only need one package if multiple persons are attending the conference together (e.g., a Person with PF and their care partner watching at home). Persons with PF and transplant recipients must reside in Kansas or Missouri.

To request a grant, click [here](#).

2021 PFF Summit registration will be from June 14th through November 5th at 3 pm.

Mary Chapman's article on Pulmonary Fibrosis News provides a **summary of the summit**. Click [here](#) to read it.

IPF and the 5 Pillars of Pulmonary Wellness [VIDEO]

Noah Greenspan founded the Pulmonary Wellness and Rehabilitation Center. He has over 25 years of experience with cardio and pulmonary physical therapy.

In this video, Noah Greenspan discusses five essential parts of maintaining your health with living with IPF.

He discusses managing medications, exercise and oxygen usage, nutrition, managing stress and expectations, and finally, avoiding infection.

To watch the video in its entirety, [click here](#).

Dr. Noah Greenspan, Advocacy Groups: Avoiding COVID-10 Holds a Special Urgency for IPF Patients

Larry Luxner writes for Rare Disease Advisor

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Bill Vick, the PF Warriors support group founder, was diagnosed at the age of 72 with IPF. He is now 83 and living with a disease now more than eight years past the typical median life expectancy of 2-4 years of patients with the same diagnosis.

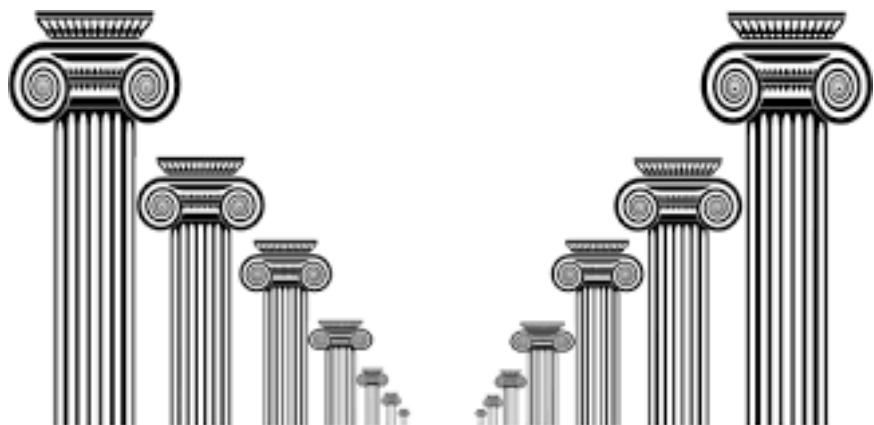
The article discusses the introduction of Noah Greenspan, DPT, CCS, EMT-B to the PF Warrior groups via a Zoom meeting who discussed the impact of Covid-19 on the PF community at large.

Of particular note in the article was the mention of the low number of IPF patients who contracted and/or passed from COVID-19 and the high rate of vaccinations among the PF community.

Luxner writes, "The pandemic has made it much harder for Dr. Greenspan's patients to focus on proper exercise, nutrition, and stress management. On the other hand, he said, coronavirus has spurred research into respiratory diseases, benefitting PF patients, as well as those with ILD in general. "

Even with more research, Greenspan, Vick, and most IPF patients interviewed agree that nothing will change in their day-to-day activities, even with vaccination. They will still social distance, and they will still mask up.

You can read the full article [here](#).



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Tips to Proactively Avoid and Manage Inflammation as an IPF Patient

In Pulmonary Fibrosis News, Charlene Marshall discusses the importance of managing inflammation as a patient living with IPF and other lung diseases. Pulmonary inflammation or pneumonitis causes a wide array of symptoms and is something that IPF and different ILD patients experience more often than those who are not immunocompromised.

Marshall lists various tips to help manage and avoid this inflammation, including limiting alcohol use, following a healthy diet, managing stress, and being aware of the environmental causes that can lead to exasperations.

Read the full article [here](#).

“Since PF is a debilitating, life-threatening disease, a precise and early diagnosis is highly important.” - Samantha Simmons

Accurate and Timely Diagnosis Crucial for Those with Pulmonary Fibrosis

Samantha Simmons writes for Future of Personal Health

The article introduces the fact that symptoms experienced by people with PF are often the same as other lung diseases, which leads to the often late-stage diagnoses of pulmonary fibrosis.

The Pulmonary Fibrosis Foundation introduced a program titled “Pinpoint PF,” designed to “help patients pinpoint risk factors and symptoms early.”

The article links websites and a risk list for patients to take to future doctor’s appointments.

The essential need for having doctors be aware and listen for the lung crackling and tests such as the HRCT are also discussed.

See the full article [here](#).

ON THE ROAD AGAIN

Christina Hunt, a respiratory therapist, gives tips to plan road trips for patients with lung conditions:

- Health prior to traveling, yourself, your traveling companions, and your vehicle
- Have ample PPE and disinfectant, and tied to this, check hotel or motel policy on cleaning between visits
- What and how to pack
- What is the right amount of O2 to have?
- Medical information to have on hand
- Benefits of Roadside Assistance

See the full article [here](#).

IPF SIDE EFFECTS

Kristin Erikson Barton discusses how to manage some of the unwanted side-effects (nausea, diarrhea, sun sensitivity) of IPF medications in an article on Raremark.

Read the full article [here](#).

Patient-centered Outcomes Research in ILD

In an official American Thoracic Society research statement, the goal was “To summarize the current state of patient-centered outcomes research in ILD, identify gaps in knowledge and research, and highlight opportunities and methods for future patient-centered research agendas in ILD.”

Seven themes were identified around the patient-centered outcomes, and 28 research recommendations were put forth.

The conclusions were: “Patient-centered outcomes are key to ascertaining whether and how ILD and interventions used to treat it affect the way patients feel and function in their daily lives. Thus, ample opportunities exist to conduct additional work dedicated to elevating and incorporating patient-centered outcomes in ILD research.”

To read the full scholarly article, click [here](#).



Switching Between Antifibrotics May Help IPF Patients Live Longer

“Switching antifibrotic treatment is generally well-tolerated among people with idiopathic pulmonary [fibrosis] (IPF), and those who did generally lived several years longer than those who did not, a study from Japan reports.”

Marisa Wexler writes in Pulmonary Fibrosis News that it’s not uncommon to switch between medications in a clinical setting due to various reasons.

She goes on to summarize the study [here](#).

Automated Imaging accurately captures PF severity

Pulmonary Fibrosis News discusses the study where a “new automated computer image analysis technique was able to accurately assess and measure the severity of PF using lung tissue samples.”

[The full article and link to the study can be found here.](#)

Getting New Drug to Market

The PFF hosted a 45-minute webinar on the drug approval process. Highlights discussed include the requirements of approval, and the phases of clinical trials.

For a full summary and a link to the webinar, [click here](#).

For the Caregiver

The Pulmonary Fibrosis Foundation has more information on what care partners should know about assisting family, friends, or love-ones who live with pulmonary fibrosis.

The two primary responsibilities for a caregiver are:

- 1) Do what needs to be done each day to take care of your loved one.
- 2) Take care of yourself. The day-to-day life of a caregiver can be physically and emotionally draining.

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

Asking for emotional support when things get tough

One of the most important factors of being a caregiver is taking care of yourself. It's impossible to take care of others when you are struggling yourself.

Raremark has an article with some tips to getting support when things get difficult. [Click here to read it.](#)

Esopremazole for Acid Reflux May Ease IPF Inflammation, Scarring

Forest Ray, PHD, writes in Pulmonary Fibrosis News: "The acid reflux medication esopremazole, commonly used to ease symptoms of gastroesophageal reflux disease (GERD), may be able to reduce lung scarring and inflammation in idiopathic pulmonary fibrosis (IPF), a recent study suggests."

While antifibrotic medications slow progression, they can't stop or reverse the damage already caused. Some scientists believe that PPIs

(proton pump inhibitors) that reduce stomach acid may be an option.

Specifically, esopremazole reduces enzymes known to produce free-radicals that can be overactive in the lung cells of patients with IPF.

For the full article, [click here](#).



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Inhaled PRS-220 Aims to Treat Both IPF and 'Long Covid' PF

Marta Figueiredo writes in Pulmonary Fibrosis News that "Pieris Pharmaceuticals plans to start clinical development of PRS-220 in 2022 for idiopathic pulmonary fibrosis (IPF) — and also will advance the investigative, inhaled therapy for "long COVID" PF, or post-COVID-19 pulmonary fibrosis".

A received grant of nearly \$17 million will assist in accelerating and widening existing clinical investigations.

An essential function of this drug is that it can be delivered directly to the bloodstream, which allows it to effectively reduce lung function decline in IPF patients.

To read more, click [here](#).

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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