Monthly Newsletter

October, 2021

The Kansas City Foundation for Pulmonary Fibrosis

Inside this issue

The Foundation lit up Union Station for September Pulmonary Fibrosis Awareness Month!

The Foundation completed several events for PF Awareness Month.

- *8 KC PF Support group members shared their stories.*
- *Dr. Hamlin and his staff provided 7 educational presentations.*
- *Lit up Union Station.*

September 24, 2021 Photo by Matt Shanahan

September Pulmonary Fibrosis Awareness Month

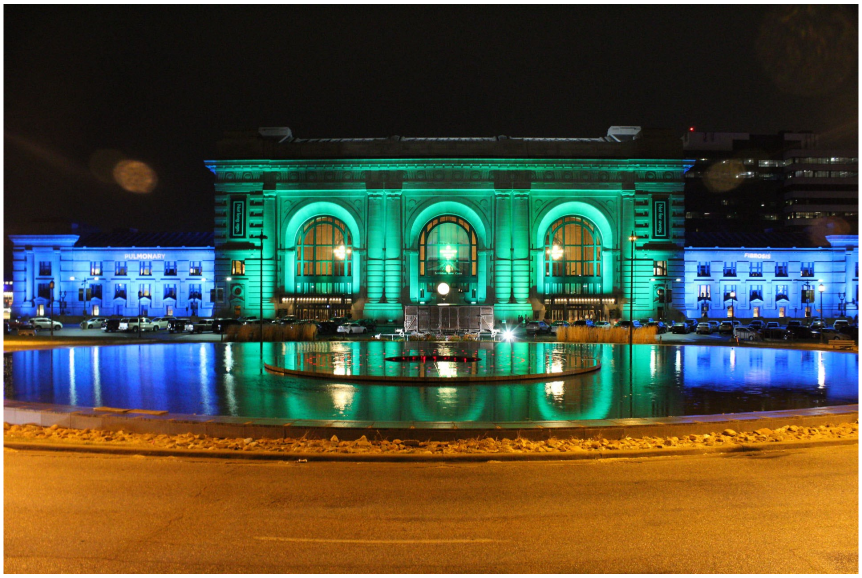
Dr. Mark Hamblin and his staff provided a virtual Patient Education Symposium.

Presentations

- IPF vs. PF – discussion of different types of pulmonary fibrosis—Dr. Hamblin
- Anti-fibrotic therapy and clinical trials—Dr. Hamblin
- IPF Co-morbidities (Cough, GERD, CAD, OSA) - Kristy Delaney, APRN
- Non-pharmacologic Therapy (without medications) (Oxygen, pulmonary rehabilitation, and other treatments) - Dr. Hamblin
- Lung Transplant—Dr. Hall
- PH-ILD – Pulmonary hypertension associated with Interstitial Lung Disease—Dr. Pandya
- Symptom Management and End of Life Care—Dr. Hamblin

For further patient education sign up for the Pulmonary Fibrosis Foundation 2021 Vitural Summit. It is held from November 8-13, 2021. KCFPF provide grants so it is no cost to the patient. Click here for more information.

4th Annual Light up the Night



September 24, 2021 Photo by Matt Shanahan

See more photos at KCFPF website. Click **Here**.

Support Group Members Stories

"My Attitude Is One of Gratitude" - Gail Hicks

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

"My Transplant Story" - Barbara Grubb

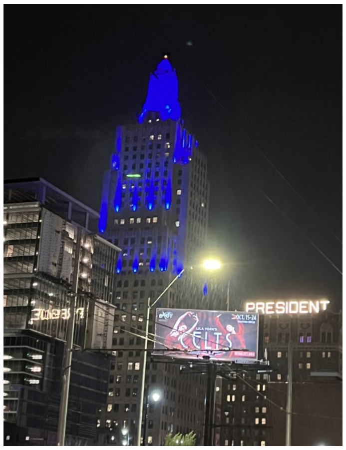
"Side By Side, A Journey Through the Unknown" By Rhonda Hitchcock

"Running a Marathon for my Dad" by Nicholas Sloop

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

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

"Honoring the Unforgettable Friends I've Lost" by Kevin Olson



Power and Light Building lit by Boehringer Ingelheim (Photo by Kevin Olson)

Autoimmune ILD

Autoimmune conditions are a subgroup of interstitial lung disease, according to the Pulmonary Fibrosis Foundation. These diseases include rheumatoid arthritis, lupus, systemic sclerosis, and more.

Click here to watch a video about the autoimmune diseases and ILD.

Occupational ILD

The Pulmonary Fibrosis Foundation states that environments with certain vapors, dusts, and airborne particles can lead to pneumoconiosis, a subgroup of ILD from occupational exposure.

Click here for a video to learn more.

Genetic Counseling: PF Genes and Families

Click here to watch a video regarding the role of genetic counseling in pulmonary fibrosis and families. The video is an hour long presentation from the Pulmonary Fibrosis Foundation. The presenters are Janet Talbert, a Genetic Counselor working out of Vanderbilt University Medical Center and Amy Hajari Case, the PFF Senior Medical Advisor for Education and Awareness from Piedmont Healthcare.

What is the Flu?

The Mayo Clinic discusses the basic differences between the common cold, viral gastroenteritis (stomach flu), and influenza.

Three illness that have some similar and some very different symptoms.

Click here to read the article and learn more so you are prepared for the coming months.

Mask Effectiveness

Dr. Donna Ginther and Dr. Carlos Zambrana of the University of Kansas discuss the effectiveness of masks in a 35 minute podcast.

The Morning Medical Update breaks down a study conducted in Kansas regarding how masking up impacted hospitalizations and even death rates due to Covid-19.

They discuss the study and answer community and reporters questions.

Despite cultural and political pushback, it was found that masks helped and were effective in the Covid-19 pandemic.

To listen to the full interview and hear questions, click here.

Do you have trouble remembering to take your medication?

Raremark.com gives some tips and suggestions for helping to remember to take your pills. Some of these are as follows: keeping a list of medications, turn it into a habit, using pill boxes, using a pre-packaged pill service, keep them in the open, utilize alarms and reminders on your smart phone, use visual clues of pills that have been taken, automate your refills, and more.

Click here to read the full article.

Oxygen can make breathing and exercise easier

The European Idiopathic Pulmonary Fibrosis and Related Disorders Federation posted a video from Ron Flewett, an IPF patient, about how oxygen can make breathing and exercising easier.

Not only does it make breathing and exercise easier, but it can prevent ot lessen complications of low blood oxygen levels, lower blood pressure, and improve sleep.

Watch the video here.

Antifibroids may extend lives for patients with IPF

"Mayo Clinic researchers recently learned that patients who are taking antifibrotic drugs for idiopathic pulmonary fibrosis (IPF) have a better chance of survival after a respiratory-related hospitalization compared to patients not receiving these medications. The study, which was supported by Three Lakes Foundation, was published recently in BMC Pulmonary Medicine. "

To read the full article, click here.

Idiopathic Pulmonary Fibrosis Epidemiology Forecast Report and Analysis 2030

The article published by DelvInsight outlines a deep understanding of IPF as well as the historical and forecasted IPF epidemiology in the US, Germany, Spain, Italy, France, UK, and Japan.

According to the study, the IPF population is expected to rise to upward of 280,000 by 2030.

To read more about the study, click here. Some sample pages from the report can be seen here.

New global network into pulmonary fibrosis research

Global Health Talks posted a 30 minute video on pulmonary fibrosis research for PG Awareness Month. Global Health Talks officially launched on October 1st.

To watch this video, click here.

Lung Allocation Score—Lung Education

In a video from Barnes-Jewish Hospital, Lung Allocation Score (LAS) is discussed.

LAS is the method set by UNOS to weigh the risks and benefits of a transplant. The scores range from 1 to 100 with 100 being the highest priority.

Also discussed are what to expect before, during, and after a lung transplant procedure .

For more, go here.

A Patient Pioneer: Minimally Invasive Lung Transplantation

Frank Coburn was possibly the first person in the united states to undergo a minimally invasive lung transplant.

The technique used involves an incision not much larger than a credit card. For a procedure that normally involves breaking the breastbone and a heart-lung machine, this new technique is a huge stem forward.

To read the full article, click here.

Weighing Risks and Rewards as a Lung Transplant Patient

Emma Schmitz discusses her mother's single lung transplant in the age of Covid-19. On the one hand, things are great, she's breathing easier, setting records, living better.

On the other hand, she is being told to stay away from unvaccinated individuals, which include her grand-children who are too young.

The risks-reward comes in when you have to determine which way you want to go, be with your family and loved ones, or run the risk of infection.

Read the full post 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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