



**The Kansas City Foundation for
PULMONARY FIBROSIS**

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Photo By Brian Delaney

Monthly Newsletter June 2021

[Announcements](#) pg. 2.

[National Pulmonary Fibrosis Foundation
Strategic Plan](#) pg. 3

[History of Pulmonary Fibrosis](#) pg. 4

[Idiopathic Pulmonary Fibrosis \(IPF\)](#) pg. 6

- Antibiotics Impact on Persons with IPF.

[Interstitial Lung Diseases](#) pg. 7

- Questions to ask the Pulmonologist.
- Pulmonary Fibrosis and Air Pollution.

[Health](#) pg. 8

- Tracking Your Pulse Oximetry Readings
- Digital Applications to Manage Pulmonary Fibrosis

[Medications](#) pg. 9

- Inhaled Pirfenidone

[Lung Transplant](#) pg. 10

- Tracking Your Sun and Immunosuppressants
- Minimally Invasive Lung Transplantation

[Clinical Trials and Studies](#) pg. 11

- Questions to ask the Pulmonologist.
- Pulmonary Fibrosis Foundation (PFF) Registry

[Preparedness](#) pg. 12

- Emergency Preparedness Plans.
- End of Life care with PF

[Volunteer and Email Distribution List](#) pg. 13

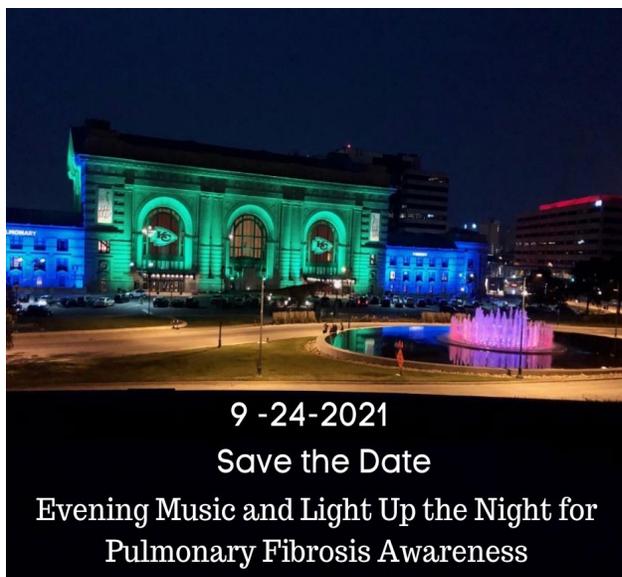
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Announcements



9 -24-2021

Save the Date

Evening Music and Light Up the Night for
Pulmonary Fibrosis Awareness

4th Annual Light up the Night for Pulmonary
Fibrosis Awareness (Union Station Grand
Plaza Room)

Tentative Program

- Starts 6:30 and Ends 10 pm.
- Presentations at 7 pm.
- Billy Ebeling & Late for Dinner Band 7:30 pm
- Union Station Lit Up 7:30 pm
- Silent Auction at 6:30 pm
- other activities to be announced.



Billy Ebeling & The Late For Dinner Band
For Billy's website [click](#) here and for bio for Billy click
[here](#).

Virtual 2021 PFF Summit

The 2021 PFF Summit dates are
November 8 - 13.

Click here for the [program](#).

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](#).

BioNews Services, LLC hires Kevin Olson.

He is a freelance writer/columnist on the Pulmonary Fibrosis News.

His column name is "Riding the Idiopathic Pulmonary Fibrosis Roller Coaster."

Kevin published two columns.

- Receiving My Diagnosis and Hopping on the IPF Roller Coaster
- Recovering: Day After Transplant, Hallucination, Defibrillator Paddles

To ride along on Kevin's roller coaster bookmark his Pulmonary Fibrosis News column site, click [here](#).

National Pulmonary Fibrosis Foundation Strategic Plan

By Dale Brommerich

As a PF patient, active member of The Greater Kansas City PF Support Group and past member of the Kansas City Pulmonary Fibrosis Foundation Board of Directors, I was invited to join one of four Groups to updating the current 3-5 Year Strategic Plan. I am one of ten people representing the Patients & Caregivers Group. The other three Groups are the Research Key Opinion Leaders, Healthcare Providers, and the Pharmaceutical Industry.

The update effort is being led by Scott Wagers. Scott is the CEO of BioSci Consulting located in Belgium. Yes, this is a global strategic view of Pulmonary Fibrosis. Scott focuses on bringing together multiple stakeholders for major research and innovation projects in the life sciences. He has more than 11,000 hours of facilitation interactions and was also a pulmonary/critical care physician.

The first phase of the process is for each group to dialogue or brainstorm divergent thinking of multiple thoughts and ideas. This includes Foundation strengths, weaknesses, opportunities, and threats. We discussed problems, the causes, the effects, and the consequences.

The second phase is to move toward convergent thinking, where we discuss excellent ideas for the strategic direction of the PF Foundation.

The third phase, and I think the most difficult, is to consolidate the substantial feedback received from each of the four groups. Broad concepts that overlap between the different stakeholder groups begin to surface and a list of broad strategic goals that are both challenging and measurable develop.

Still to be completed is the first iteration and review process with the Foundation Steering Committee. They will discuss the amount of effort and the impact of each initiative and how much the Foundation can undertake that is an advantage for and supports the Foundations Mission.

This is an excellent best practice process, and I am honored to be part of it representing the patients and caregivers. I hope you will be excited to hear about the new Strategic Goals when they are introduced this fall.

History of Pulmonary Fibrosis

By Kevin Olson

A [tweet](#) from the Irish Lung Fibrosis Association (@ILFA_Ireland) mentioned scientific research on mummified remains at “The British Museum” in London. Also, it asked, “Is this the earliest known case of pulmonary fibrosis?”

Scientific research: evidence from mummified remains

Although written records from ancient Egypt are highly informative, there is much that they do not reveal about life expectancy, diet and nutrition, state of health and ancient disease, and the relationships between population groups. It is from the analysis of human remains that we can gain insight into these matters. Their study holds the potential to transform our understanding of ancient Egyptian society.

Mummies have fascinated visitors to Egypt since antiquity. The resin-blackened appearance of the bodies led to a confusion with bitumen or ‘mumia’ – a Persian word which is the origin of the modern term ‘mummy’. During the 17th and 18th centuries, many mummies entered the ‘Cabinets of Curiosities’ of European aristocrats, and heightened interest in ancient Egypt in the early 19th century led to the public unwrapping of mummies as a popular event. Although some of these investigations were motivated chiefly by morbid curiosity, the unwrappings (1820s–40s) carried out by the physicians Augustus Granville and Thomas Joseph Pettigrew were aimed at the recovery of scientific data. They were ahead of their time in applying scientific tests and adopting a multidisciplinary approach. It was not until the late 19th–early 20th centuries, and the work of Grafton Elliot Smith and Marc Armand Ruffer, that further significant advances were made in the study of mummification and ancient disease. Since the 1960s, the application of a wide range of scientific techniques has revolutionised the study of Egyptian human remains.



CT scanning

Unwrapping mummies is a damaging process, resulting in the loss of information, and is now rarely carried out. Conventional X-rays and, more recently, CT scanning allow researchers to look inside bodies without the need to unwrap them. CT (Computerised Tomography) scanners obtain a series of X-ray slices, which can be presented as conventional radiographs or formatted using volume graphic software to create accurate three-dimensional visualisations of the body. CT scans provide valuable data on human biological and pathological changes, as well as information about mummification techniques and objects, such as amulets, concealed within the wrappings. The CT scan data can also be fed into a 3D printer and high resolution replicas of the objects found within the wrappings – or even parts of the body – can be made without the need to remove or disturb them.



above: ‘Virtual unwrapping’ of the mummy of Tumat, an adult female. CT visualisations show the outer wrappings (top), the soft tissues and hair, and amulets placed on the body (centre) and the skeleton, amulets and artificial eyes (bottom).

left: Visualisation of calcified plaque deposits (arrow), called atherosclerosis, found in the femoral artery of the mummy of Tumat. This artery runs along the thigh bone (femur) and the presence of plaque in the segment above the knee indicates that she suffered from atherosclerosis and



left: Virtual section through the CT scan visualisation of an adult male mummy revealing the tool (green) found inside his head, together with part of the brain (blue). Made of wood, the tool appears to be a rare example of a probe lost by the embalmers during the process of removing the brain via the nasal cavity.

right: CT scan visualisation of the skull of the same mummy with several dental abscesses (arrows). Severe dental wear appears to have allowed bacteria to enter the pulp chamber – where the nerves and blood vessels are located – causing an infection and a pocket of pus at the end of the roots. He has also lost his upper right lateral incisor (to the left of the upper abscess), probably as the result of an earlier abscess.

Tissue analysis

The study of mummified tissues using a wide range of microscopic and analytical techniques provides evidence of pathological changes and prevalence of disease. An important method is histology – the staining and microscopic examination of thin sections of tissues.



left: Histology of lung tissue showing evidence of pulmonary fibrosis.

right: Lung tissue from a Canopic jar. Photo: James H. McKerrow

Ancient DNA

In 1985 the Swedish scientist Svante Pääbo recovered DNA extracted from the tissue of an Egyptian mummy. DNA does not always survive in ancient human remains but its extraction offers the potential to understand relationships between individuals in the past, and links between larger population groups both in antiquity and across time. As methods improve, ancient DNA sequences should add to our understanding of the past inhabitants of the Nile valley and allow research to investigate ancient migration patterns. DNA studies can also throw light on the history of diseases, since the DNA of a virus which was active at the time of the host's death may be

Photo provided by the Irish Lung Fibrosis Association (@ILFA_Ireland)

The British Museum gallery "[Egyptian death and afterlife: mummies](#)" is a collection from about 2686 BC-AD 395. So, the mummy with Pulmonary Fibrosis would have been from this time.

The 1987 "[Idiopathic pulmonary fibrosis: a historical review](#)" article by Jiri Homolka, MD, Ph.D. indicates Idiopathic Pulmonary Fibrosis linked persons to PF in 1872.

The article "[Back to the Future Historical Perspective on the Pathogenesis of Idiopathic Pulmonary Fibrosis](#)" by Paul W. Noble and Robert J. Homer mentions Dr. Louis Hamman and Dr. Arnold Rich's studies. Noble and Homer wrote, "The discussion of pathogenesis of IPF must begin with the extraordinary clinical-radiographic-pathologic description of four patients who succumbed to respiratory insufficiency between 1931 and 1943 at the Johns Hopkins Hospital.

Regardless of what date we chose as the start of PF, PF has been around a long time.

Idiopathic Pulmonary Fibrosis

ANTIBIOTICS IMPACT ON PERSONS WITH IPF

Julie Grisham wrote, "Antibiotics don't improve outcomes for rare lung disease." The Cornell Chronicle published it on May 19, 2021.

She reported on the results of the clinical trial CleanUP-IPF. Several research institutes and clinical centers participated in the trial. KU Medical center was one of the centers. Some of you might have been in this trial. The trial patients were on Bactrim, doxycycline, or a placebo. The study found that the antibiotics did not affect the outcomes of IPF patients.

[Click here for complete article.](#)

Interstitial Lung Diseases (ILD)

Questions to ask the Pulmonologist.

The CHEST Foundation developed the document "Progressive Fibrosing Interstitial Lung Disease." The document is eight pages long, with several discussions on ILDs by many different physicians.

One of interest is the one on "What questions do patients with IPF have?" on page 4. These questions are suitable for newly diagnosed individuals and long-time persons with PF.

Click [here](#) for the document.

Pulmonary Fibrosis and Air Pollution.

Air Pollution is a cause of Pulmonary Fibrosis. Dr. Amy Hajari Case, Pulmonary Fibrosis Foundation, provides an in-depth discussion on PF and air pollution.

Click [here](#) to read her column

Health

TRACKING YOUR PULSE OXIMETRY READINGS

Apr 17, 2021, PFF Blog |
Jessica Shore, PhD, RN

"A recent report suggests that pulse oximetry may provide less accurate readings in Black patients than in White patients. The US Food and Drug Administration (FDA) has issued guidance that skin pigmentation (how dark a patient's skin is), skin thickness, and other factors and affect the accuracy of pulse oximetry readings. The FDA provides guidance on what that may mean to you and those using pulse oximetry to monitor oxygen saturation."

See full [article here](#).

Digital Applications to Manage Pulmonary Fibrosis

It is a daunting task for a person to manage their Pulmonary Fibrosis. A person monitors treatment, symptoms, medications, lab results, and other information. Several digital applications can help an individual to organize and maintain most of the information. The information can be helpful for the pulmonologist.

Charlene Marshall, a Pulmonary Fibrosis News columnist, writes about seven practical applications.

Click [here](#) for her column.

Medications

Inhaled Pirfenidone

Avalyn Pharma is doing a clinical trial for an inhaled formulation of Pirfenidone. Two articles discuss the decrease in lung function loss caused by PF and the decrease in the side effects of Esbriet of the initial trial results.

One is by Nick Paul Taylor "Avalyn advances inhaled twist on Roche fibrosis drug." Click [here](#) to see the article.

The other article is by Forest Ray Ph.D., "Inhaled Pirfenidone Prevented Lung Function Decline in IPF. Click [here](#) for the article.

Lung Transplant

Sun and Immunosuppressants

A lung transplant recipient is more susceptible to skin cancer. It because of the immunosuppressants they are taking. Christie, a Pulmonary Fibrosis News columnist, writes about tips to stay safe in the sun.

Go to column [click](#) here.

Transplant and Covid-19 Vaccine

There are multiple studies on Transplant Recipients and Covid-19 Vaccine. In the New York Times, an article by Candia Moss discusses these studies and their effects on herself. The article is "I'm a Vaccinated Transplant Recipient. I Don't Have Antibodies. Now What?"

Click [here](#) for the article.

Minimally Invasive Lung Transplantation

Pedro Catarino, MD, a writer for the Cedars Sinai Blog, writes, "A miracle that resulted from Coburn becoming the first Southern Californian—and possibly first in the U.S. to receive a minimally invasive double lung transplant. The procedure was performed at the Smidt Heart Institute."

Click [here](#) for article.

Clinical Trials and Studies

Finding a cure for Pulmonary Fibrosis is a goal. A person could take two actions to help find a cure.

- Discuss with their pulmonologist about doing a clinical trial. Did you know the first-ever clinical trial started on May 20, 1747? The test was for a cure for scurvy.
- Discuss with their pulmonologist about providing your medical information to a registry. The registry allows researchers to conduct various studies using an extensive database of medical information.

[What to expect from a clinical trial](#)

Megan Truman, Raremark
Community Manager

"Taking part in a clinical trial, sometimes called a clinical study, may seem daunting. We've put together a rough guide on the clinical trial process, so that you know what to expect."

See full Raremark Article [here](#).

The National Pulmonary Fibrosis Foundation is a good resource for information on Clinical Trials.

For Clinical Trials Education Center Click [here](#) resources.

Click [here](#) for "Empowering Patients to Participate in Active Pulmonary Fibrosis Trials" Sr. Medical Advisor of Research/Health Care Quality at the Pulmonary Fibrosis Foundation.

Pulmonary Fibrosis Foundation (PFF) Registry

PFF started the current Registry in 2016 and has information on 2,003 PF patients. It has people's diagnoses, symptoms, test results, medications and monitors each person's condition.

Supports the PF patient:

- 1. By assisting research.*
- 2. Empower sooner diagnosis.*
- 3. Pinpoint person who progresses and needs early treatment.*

This registry is currently closed. See more information click [here](#).

In the fall, the Registry will open and expands to include data reported directly from PF patients, lung transplant recipients, care partners, and family members.

For updates, contact registry@pulmonaryfibrosis.org.

Preparedness

Emergency Preparedness Plans

Are you prepared for an emergency? Recommend persons with PF plan for an emergency. It helps the person and their care partners and reduces stress.

Charlene Marshall, a Pulmonary Fibrosis News columnist, talks about items in an emergency plan.

Click [here](#) for her column.

Fiona Akhtar, Raremark, writes "Planning ahead with a chronic condition".

Click [here](#) for article.

The Breathe Support Network provides an article on a tough subject. It is called "End of Life care with PF".

Click [here](#) to read the article.

The book "The Art of Dying Well" by Katy Butler is recommended for another view on the topic.

VOLUNTEER:

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 an annual 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 main role of the Media Subcommittee will be to spread awareness, distribute educational and grant information, advertise events which are developed by the other subcommittees. The primary focus will be on website and Facebook updates, but other media will be used dependent upon the target audience.

Sign Up using link below.

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