

The Kansas City Foundation for **PULMONARY FIBROSIS**

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Monthly Newsletter December 2020

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1. Patent Initiatives:

One of the primary missions of the KCFPF is to help make the daily lives easier for those individuals diagnosed with Pulmonary Fibrosis.

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.

Donation of Pulse Oximeters

Our focus needed to take a dramatic shift to support P. F. patients during this new environment of self-isolation and fear of contracting the virus.

The Board of Directors decided to use Foundation funds to purchase 100 Nonin finger pulse Oximeters and donate them to Pulmonologists in the Greater Kansas City area with the intent to ask the Physicians to give them to patients with Pulmonary Fibrosis related disease and may not be able to purchase one.

This activity also increased our Foundation exposure to area Pulmonology practices.



Donation of Spirometers

In August, 2020, our Foundation applied for and in Oct. was approved to purchase and distribute an additional 100 Nonin finger pulse Oximeters and 75 Vitalograph Bluetooth Spirometers to Pulmonologists using Kansas CARES Act funds. This effort supports tele-medicine virtual doctor appointments with P.F. patients fearful of visiting medical facilities.

Our original manufacturing partnership and logistic design will allow the ordering and delivery of all the medical devices within the short government defined timeline. These efforts will help 175 P. F. patients



2. Tributes:

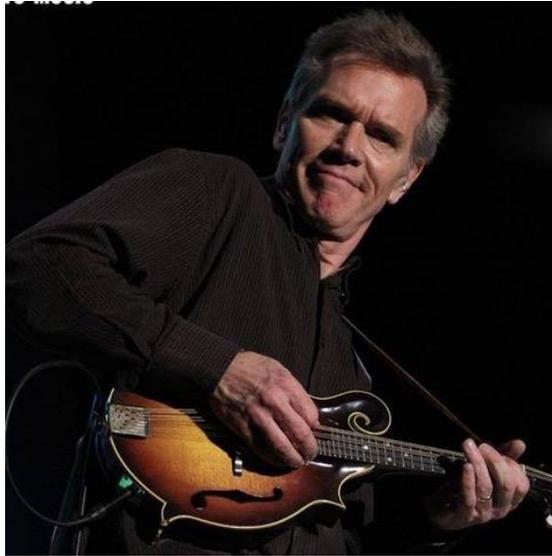
James Lynn Tipton: August 24, 1940 – March 31, 2020



James Lynn Tipton August 24th, 1940- March 31st, 2020 James (Jim) Tipton was promoted to heaven on March 31st, 2020, after a long battle with pulmonary fibrosis. He was 79 years old and a devoted husband, brother, father, grandfather, and a great friend to many. He was a strong Christian who attended church and Bible studies regularly and was eager to proclaim Jesus Christ as his Lord and

savior. Jim Tipton family held a memorial for him on Oct 24, 2020 due to COVID-19.

Stephen P Phillips: January 4 - September 29, 2020



Stephen P Phillips passed away on September 29, 2020 at home surrounded by loving family. A dedicated family man, Steve is well known for his roles in popular Kansas City bands including Steve, Bob & Rich, The Rainmakers, and The Elders. He was generally a healthy guy who began feeling the affects of his obscure pulmonary fibroses in late 2019. His symptoms progressed rapidly, and he died less than a year later. Stephen’s mother died of pulmonary fibrosis in 2016. The family hopes KCFPF will be able to raise public awareness, explore the genetic connection, and support professionals in working together toward the prevention and cure of pulmonary fibrosis.

There is a Collaborative Video Tribute to Stephen Phillips of The Elders called “Right With the World”. You can download this tribute at <https://www.eldersmusic.com>

For additional information on James Tipton and Stephen Phillips go to <https://www.kcpulmonaryfibrosis.org/tributes>.

3. Nicholas Sloop Marathon: Nicholas Sloop decided to run a marathon for his dad (Nick Sloop) and raise donations for the Kansas City Foundation for Pulmonary Fibrosis.



Nicholas Sloop posted on Facebook.

"I am going to be doing a solo marathon run the weekend after thanksgiving. Since the one I was signed up for was called off I wanted to still do a run and it be for a purpose. I am going to fundraise for the Kansas City Foundation for Pulmonary Fibrosis. (My dad has idiopathic pulmonary fibrosis, reason for choosing this foundation). Please consider making a donation. Hoping to try and raise \$260 (10x\$26 donations because a marathon is 26.2 miles). Thanks for your support!!"

Nicholas raised more than \$1600 which is six times over his goal of \$260. Thank You Nicholas!!

Nick Sloop (father) is still walking in 5Ks. See Nick's IPF story at <https://www.kcpulmonaryfibrosis.org/kc-support-groups>.

4. Educational Links:

- a. Over the last couple of months Dr. Mark Hamblin has given an interview on empowering patients and a presentation on Telemedicine. These two articles support each other.

- (1) Oct 2, Nonin published the blog article "Even During a Pandemic, Kansas City Pulmonary Fibrosis Foundation is Finding a Way to Empower Patients". Interviews with Dr. Mark Hamblin and Dale Brommerich, Patient Advocate.

<https://www.nonin.com/even-during-a-pandemic-kansas-city-pulmonary-fibrosis-foundation-is-finding-a-way-to-empower-patients/>

- (2) On Nov 18th, Dr. Mark Hamblin and Jamie Ludwig, RN, provided a presentation on “Telemedicine 101: Making the Most of Your Virtual Visits” on the Pulmonary Fibrosis Foundation Webinars.

<https://www.pulmonaryfibrosis.org/life-with-pf/pff-educational-resources/webinars/telemedicine-101-making-the-most-of-your-virtual-visits>

b. Links to Pulmonary Fibrosis Foundation articles.

- (1) With Covid-19 and it being winter, a PF patient is more vulnerable to Exacerbations. Here is a PFF Webinar on "Exacerbations and Emergencies: How to Prepare".

https://www.youtube.com/watch?v=aoe6II9MSKk&fbclid=IwAR2CxwhYW3TPbQWntHW2orrYMn3tRrc7p7KK28HiauwoQWEBCG9_jE6tpOw

- (2) In 2021, PFF is doing another PFF registry. It will have information on PF patients as well as caregivers, transplant recipients, and family members. The registry information will provide researchers information for their studies. You can sign up for emails which will tell you when the registry is open at

https://www.pulmonaryfibrosis.org/pff-registry-microsite/subscribe?fbclid=IwAR37Gn0y2So6Ik5vltiyiNX9P_7tvNBstShOOQtJd1k9lkJ4rtITqA7Rg5U0.

Currently, PFF has a PFF Registry database which is being replaced with the new one. This registry has information on 2003 PF patients. Researchers use this registry for their studies. Hundreds of studies have been done using this information. Here is information on the current registry.

<https://www.pulmonaryfibrosis.org/medical-community/pff-patient-registry>

- (3) PFF Awareness Campaign, ‘Pinpoint PF,’ Opening in December
<https://pulmonaryfibrosisnews.com/2020/11/17/pff-awareness-campaign-pinpoint-pf-opening-december/>

- (4) How to Talk to Kids About Chronic Illness.

<https://pulmonaryfibrosisnews.com/2020/11/05/talking-kids-about-chronic-illness/>

c. On A&E TV: “Beyond Breathless Special Premieres” Dec 5 12P EST

"About Award-winning actress, musician and TV producer, Queen Latifah and New York Yankees legend and Latin Grammy-nominated musician, Bernie Williams share a unique connection: both lost a parent to interstitial lung disease (ILD), a group of serious lung diseases that may cause irreversible scarring of the lungs and make it difficult to breathe." Source: A&E TV.

<https://www.aetv.com/specials/beyond-breathless>

Bernie Williams father passed away with Pulmonary Fibrosis being the cause. He has been an advocate for PF Awareness for several years. In 2020, Bernie Williams conducted a Breathless® Ballad Challenge: in honoring his dad and other heroes by becoming the lyricist to his instrumental song.

<https://apnews.com/press-release/pr-newswire/6e24167548b41a17c427a69a4a3e25c3>

In 2018, Bernie hosted Breathless Blowout game days at select Minor League Baseball™ games. <https://www.breathlessipf.com/bernie-williams-ipf>

5. Volunteer: The foundation is looking for a volunteer to be a newsletter assistant. If interested go to the website and complete the volunteer form.

<https://www.kcpulmonaryfibrosis.org/want-to-help>