



The Kansas City Foundation for **PULMONARY FIBROSIS**

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Monthly Newsletter January 2021

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1. KC Foundation for Pulmonary Fibrosis Website: The [website](#) has been updated and several new pages have been added. If you have not been out to the website recently, recommend you go visit it for the new information. Below is some of the new pages. We will continue to update and add new pages over the next month.

- a. [Patient Financial Initiatives and Grants](#) (New Page)
- b. [Care Partners](#) (new page)
- c. [Pulmonary Rehabilitation](#) (new page)
- d. [Supplemental Oxygen](#) (new page)
- e. [Lung Transplant](#) (new page)
- f. [Patient Education Resources](#) (updated)

2. Tribute:

Patricia Ann Gahr: October 5, 1949 – November 10, 2020



Excerpt from Obituary

“Patricia Ann (O'Connor) Gahr joined her parents, two brothers, and her beloved daughter in Heaven on Tuesday, November 10, 2020, after a 6-year battle against pulmonary fibrosis. Pat received a much-needed lung transplant from a hero donor, but complications resulting in an infection throughout her body made it necessary for us to say goodbye to this wonderful wife, mother, sister, cousin, "Mamie," friend, and more.” For the complete Obituary go to

<https://www.legacy.com/us/obituaries/kansascity/name/patricia-gahr-obituary?pid=197118789>.

3. Nicholas Sloop Marathon: Thank You again Nicholas Sloop for raising over \$2,000 for the KC Foundation for Pulmonary Fibrosis. Barbara Sloop Facebook comment about "Nicholas Sloop running his solo marathon to raise money for the Kansas City Foundation for Pulmonary Fibrosis; but I want to share his video of his run. Not only did Nicholas run 26.2 miles but he also carried a Go Pro video camera and recorded his run and commentated while he was running. Wow, that's exerting a lot of energy. If you would like to see his 26.2-mile route through Lawson, watch his video that he put together. He impressed his Mom and Dad ❤️, plus he did it for a good cause. Good job Nicholas." You can relive his marathon by watching his video on YouTube.

https://www.youtube.com/watch?v=eQ6IxNwxQgk&feature=share&fbclid=IwAR1Thqfb9G63UF6GV3qZ7yvHBTXtzD-z_YUkeW59RxdTNjNEpdSNO4TRTnQ



4. Educational Links:

a. Links to Pulmonary Fibrosis Foundation (PFF) articles.

- (1) PFF is having a Webinar on the Covid-19 vaccine. It should provide some good information about the vaccine and PF. From PFF “PFF Response to COVID-19 Vaccines: Hope is on the Horizon” on Wednesday, January 27th at 12 pm Central Time. We are excited to have Dr. Jesse Couk as our guest speaker and Dr. Amy Hajari Case as our moderator, both from Piedmont Healthcare. Dr. Couk is an infectious disease specialist at Piedmont Healthcare at the Shepherd Center. You can register using the link below.”

<https://register.gotowebinar.com/register/4586727516297504524?fbclid=IwAR2cFaAKLaZ-0hvyN2kV52ASN4I72FyDTJ4a3ah5-DifLvU-dJ3mSXT9x5w>

- (2) From PFF Breathe Winter Issue page 10: “PRECISIONS Trial Will Lay Foundation for Personalized Medicine in PF Biomarkers—biological molecules found in blood that convey information about disease status—play a critical role in PRECISIONS. This ambitious clinical trial is the first ever to apply the principles of precision medicine to the diagnosis and treatment of IPF. And it will use data and blood samples from the PFF Registry.” Consider joining the PFF registry (see para: 4 a(3))

https://www.pulmonaryfibrosis.org/our-role/news-media/breathe-bulletin?fbclid=IwAR1YIVA3-rnt1qudI_Ar7Xo2MVxddL04Txxnr4POR-ftBo74UgFSP3-7

- (3) From PFF Breathe Winter Issue page 10: "PFF’s PROLIFIC Consortium Aims to Break Down Barriers in IPF Research What if proteins in your blood known as biomarkers could give your doctor information about what your future with PF might be? And what if the presence or absence of a biomarker could predict whether a specific medication would help you? That’s the promise of precision medicine."

https://www.pulmonaryfibrosis.org/our-role/news-media/breathe-bulletin?fbclid=IwAR1YIVA3-rnt1qudI_Ar7Xo2MVxddL04Txxnr4POr-_fTBo74UgFSP3-7

- (4) 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_7tvNBstShOQtJd1k9lkJ4rtITqA7Rg5U0.

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>

- (5) Ofev, Esbriet Use Seen to Lengthen Life for IPF Patients With ‘Mild’ Disease

<https://pulmonaryfibrosisnews.com/2020/11/04/ofev-esbriet-benefit-ipf-patients-with-preserved-lung-function-real-world-study/?cn-reloaded=1>

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>