



The Kansas City Foundation for **PULMONARY FIBROSIS**

13725 METCALF AVE, BOX 286
OVERLAND PARK, KS 66223
KCFPF@KCPULMONARYFIBROSIS.ORG

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1. KC Foundation for Pulmonary Fibrosis Website: The [website](#) continues to be 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. All text that is in bold blue and underlined, you can click on it and go directly to that page. Below is some of the updated and new pages.

- a. [About Pulmonary Fibrosis](#) (Was Patient and Care Partner page) (updated). The Interstitial Lung Disease (ILD) Classifications now have links to sites describing them.
- b. [Stages of Idiopathic Pulmonary Fibrosis](#) (new page): There is no formal stages of IPF. The National Jewish Health and the American Lung Association describes possible stages of IPF.
- c. [Familial Pulmonary Fibrosis](#) (new page): Some families have multiple persons with PF. This page provides to some links on Familial Pulmonary Fibrosis.
- d. [About Health](#) (Health Management) (new page): This page has information on Pulse Oximetry, Pulmonary Function Test, telemedicine, Spirometry testing at home and Exercise.
- e. [Support for PF](#) (new page): One section discusses a new program to help people find mentors and get volunteers to be mentors. This is in response to a request from the Greater KC Pulmonary Fibrosis Support group. If you would like a mentor or would like to volunteer to be a mentor, please go the [Mentorship](#) page.

2. Tribute:

Dan Bodenhamer December 5, 1938 - January 9, 2021



Dan Bodenhamer had Pulmonary Fibrosis and was a long-time member of The Greater Kansas City Pulmonary Fibrosis Support Group.

Excerpt from Obituary

"John Daniel "Dan" Bodenhamer was born on December 5th, 1938 to Fred and Thelma Bodenhamer in Okmulgee, Oklahoma. On January 9th, 2021, our Heavenly Father called him home. He died peacefully surrounded by his family, after a short battle with recurrent pancreatic cancer.

Dan truly never met a stranger, a one man welcome wagon. As a man of abundant faith, his witness was inspirational. His thoughtfulness was unmatched and his contagious laughter will forever echo in the hearts of many. He was a true treasure, someone that will be deeply missed by those lucky enough to call him family, friend, and neighbor. He fought the good fight, he finished the race, he kept the faith."

For the complete Obituary go to

<https://www.dignitymemorial.com/obituaries/kansas-city-mo/dan-bodenhamer-9994107>

3. Educational Links:

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

(1) In 2020, several Pulmonary Fibrosis patients had lung transplants during the Covid-19 pandemic. Everyone has a difference experience. Here are a

couple of articles talking about transplant during the pandemic and how to prepare for a lung transplant.

"Transplant in the Time of Coronavirus"

<https://pulmonaryfibrosisnews.com/2021/01/13/transplant-time-coronavirus>

"How to Prepare for a Loved One's Care as They Await Transplant"

<https://pulmonaryfibrosisnews.com/2021/01/29/preparing-care-transplant-patient-caregiving>

(2) "Toward a Better Understanding of the IPF Cough"

<https://pulmonaryfibrosisnews.com/2021/01/21/ipf-cough-causes-symptoms/>

(3) Everyone has questions about getting the Covid-19 vaccine. The Barnes Jewish Hospital Advance Lung Center allows their transplant recipients to get the vaccine. There have been 40 plus patients who has received the vaccine with no issues. Below is an article from the CDC on patients with rare disease on getting the vaccine.

"COVID-19 Vaccines Pose Little Risk to Rare Disease Patients, FDA, CDC Say"

<https://pulmonaryfibrosisnews.com/2021/01/28/covid-19-vaccines-pose-little-risk-to-rare-disease-patients-fda-cdc-officials-say/>

(4) An update on OFEV. "Ofev May Be Less Tolerable Over Long Term in IPF Patients in Poorer Health"

<https://pulmonaryfibrosisnews.com/2021/02/02/ofev-may-be-less-tolerable-over-long-term-in-ipf-patients-in-poorer-health/>

b. National Organization for Rare Disorders (NORD) has a program aimed at providing caregivers with Relief. It is called "Rare Caregiver Respite Program" It was started on May 20, 2019.

<https://rarediseases.org/nord-launches-new-program-aimed-providing-caregivers-relief/>

4. 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>