

The Kansas City Foundation for Pulmonary Fibrosis

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September 24, 2021 Photo by Matt Shanahan

Bernie William's Breathless Ballad Challenge

Boehringer Ingelheim Pharmaceuticals sponsors Bernie Williams' Breathless campaign.

The four-time World Series champion, New York Yankees legend, Bernie Williams' life was changed after losing his father to idiopathic pulmonary fibrosis (IPF). Bernie is fighting to change the lives of those living with IPF by raising awareness. click [here](#) for information on his initiatives.

Bernie's Breathless Ballad Challenge provides the song "Breath of Life (Para Don Berna)" by Bernie, Jordin Sparks. The lyrics were written by David DePinho who was the winner of the challenge. The lyrics are set to "Para Don Berna," an instrumental ballad written by Williams in honor of his father, who passed away from idiopathic pulmonary fibrosis. The song Breath of Life is beautiful, powerful and very emotional song especially for lung transplant recipients.

Click [here](#) to listen to the song.

IPF Roller Coaster

Read how Kevin Olson's Roller Coaster ride continues. Kevin Olson was a columnist for [Pulmonary Fibrosis News](#).



His six column is "**My Crazy Experience Waiting and Preparing for Lung Transplant**".

His fifth column is "**My Lung Transplant Evaluation Was a Roller Coaster Ride of Emotions.**"

This article provides Kevin's breakdown of his transplant surgery and discusses the below areas.

He discusses his lung transplant evaluations and talks about the following areas.

- ⇒ Determining the need for evaluation
- ⇒ Initial assessment
- ⇒ Final evaluation

- ◆ Waiting for the call
- ◆ Preparing for surgery
- ◆ Going into preop
- ◆ A successful surgery

Click [Here](#) to read his story.

Click [Here](#) to read his column.

Pulmonary Fibrosis

Raremark: What is genetic testing?

This article writes about interviews with specialists on genetic testing.

The article discusses:

- ⇒ Describes genetic testing
- ⇒ What happens when someone has a genetic test?
- ⇒ What are the benefits of genetic testing?
- ⇒ What are the challenges of genetic testing?
- ⇒ What should families ask their doctors about genetic testing?
- ⇒ What does the future hold for genetic testing?

Click [here](#) for the full article.

Raremark: How can I be more in control of my IPF?

Living with IPF has its challenges and this column provides some ways to be in control.

The discuss points are:

- Learn more about IPF
- Track your symptoms and know your triggers
- Plan ahead
- Get support
- Focus on what matters most to you

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

British Lung Foundation

Encouraging greater participation in pulmonary rehabilitation

This page has a video with stories from people who discuss their experiences with pulmonary rehabilitation.

Also, it has short narratives on:

- * What is pulmonary rehabilitation?
- * Who is pulmonary rehabilitation for?
- * What are the benefits of pulmonary rehabilitation?

Click [here](#) for the full article.

IPF Progression

An Introduction to Pulmonary Fibrosis Progression

In a brief video by the Pulmonary Fibrosis Foundation, David Lederer, MD, MS defines the PF progression. He talks about the following areas of progression.

- * Understanding PF progression
- * Monitoring PF progression
- * PF progression is different for everyone

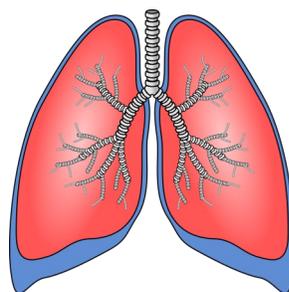
Click [here](#) for the full article.

Patients, Ofev, Esbriet Found to Significantly Reduce Risk of Death In IPF

Marisa Wexler MS, a Pulmonary Fibrosis News writer, summarizes the study, “Efficacy of antifibrotic drugs, nintedanib and pirfenidone, in treatment of progressive pulmonary fibrosis in both idiopathic pulmonary fibrosis (IPF) and non-IPF: a systematic review and meta-analysis,” that was published in the journal BMC Pulmonary Medicine.

For the Marisa Wexler article click [here](#) .

For the BMC article click [here](#) .



Untreated IPF Linked to 50% Mortality Rate at 3 Years

Yedida Y Bogachkov PhD, a Pulmonary Fibrosis News writer, analyzes the study, “Mortality and Respiratory-Related Hospitalizations in Idiopathic Pulmonary Fibrosis Not Treated With Antifibrotics,” that was published in the journal Frontiers in Medicine.

For the Yedida Bogachkov’s article click [here](#) .

For the Frontiers in Medicine’s article click [here](#) .

Mental health

British Lung Foundation

Your mental health when living with a lung condition

"Experiencing mental health problems when living with a long-term lung condition is common. This article, will explain why this is and the different mental health issues you might face."

It discusses:

- * What's the link between lung conditions and mental health problems?
- * What mental health problems might I face?
- * Loneliness and social isolation

Click [Here](#) for the story.

Guided Meditations to Help with Pain

Pulmonary Fibrosis Now! interviewed a specialist to learn about natural ways to help with pelvic pain, bowel or bladder dysfunction, and incontinence. They shared two different guided meditations.

Meditation #1: Noticing Weather Patterns

Meditation #2: Using Your Senses

Click [here](#) for the full article.



Wellness

Sleep—The Other Essential Nutrient

This article from Responsum for PF discusses the important of sleep. It covers these main topics.

- ◆ Sleep, physical function, and well-being
- ◆ How we fall asleep
- ◆ Optimal amount and deficiency
- ◆ Example strategies for better sleep
- ◆ Talking to your doctor

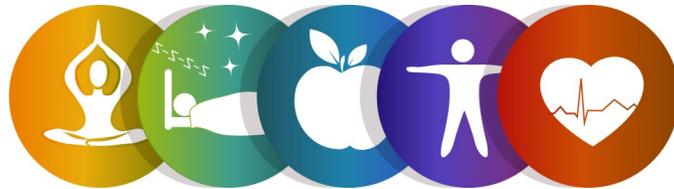
Click [here](#) to read the full article.

IPF and the 5 Pillars of Pulmonary Wellness

"On Raremark Health, Noah Greenspan, DPT goes over five aspects of your health that are important to consider while living with IPF."

- 1) Medical Management doctors, diagnosis and drugs
- 2) Exercise and O2 use
- 3) Maintaining proper nutrition
- 4) Managing stress by managing expectations
- 5) Avoiding Infection

Click [here](#) to listen to the video.



3 Ways to Increase Levels of Oxygen in Your Home

Pulmonary Fibrosis Now! discusses some natural methods to help increase levels of oxygen in the air. They are:

- ⇒ Ventilation
- ⇒ Trees
- ⇒ Houseplants

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

Reflections from the Trek by Stephen Berger

Stephen Berger discusses how PF patients should adapt and overcome to live full lives and have an impact.

Enjoying Jazz

In this article Stephen Berger discusses PF in these terms:

- ◆ Leading a double life
- ◆ Life keeps changing
- ◆ Managing your time, treasure, and talent
- ◆ Leaving a lasting legacy
- ◆ What is your 'forced vital capacity?'
- ◆ Finding the right song

To read the full article, click [here](#).

This Is Your Life

In this article Stephen Berger discusses the PF Life in these terms:

- ⇒ A new life emerges
- ⇒ How are your relationships?
- ⇒ Focusing on the big picture

To read the full article, click [here](#).



Keeping an Eye on the Stress Gauge

Stephen Berger offers self-proven ways of feeling more relaxed in these areas.

- * Stress Scale
- * New Life
- * Living with Purpose
- * Three ways to reduce stress

To read the full article, click [here](#).

Resources

PFF Offers Educational Tools for PF for International Quality of Life Month

Patricia Inacio PhD, a Pulmonary Fibrosis News writer, discusses the various Pulmonary Fibrosis Foundation educational resources.

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

Know Your Oxygen Rights with PFF's Medicare Patient Brochure

This article from Responsum for PF discusses the Pulmonary Fibrosis Foundation's document that explains patients' rights for those whose supplemental oxygen is covered by an original Medicare plan.

It focuses on the eleven (11) oxygen therapy legal rights Medicare patients should know.

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



PFF Video Resources

This site has various videos on several PF topics you might be interested to watch. Explore and listen to the videos of interest.

Click [here](#) to view videos.

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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