

Bert's IPF Journey

9:00AM, March 1, 2020: I am at One Kansas City Place wearing my oxygen backpack getting ready to climb 42 floors and 902 steps along with my daughter Bevin, grandson Cameron and our friend Brooke. Will I make it to the top? Am I crazy? How did I even get here?

It all began in 2016 when my wife Mary Jane and I retired and moved back to Kansas. I had great plans for getting back in shape, traveling and playing ice hockey again. After numerous walks around my neighborhood, in which I had to make several stops to catch my breath, I realized it was not going to be easy to get in shape.

A slow recovery from a bad cough/cold that Fall followed by a bout of bronchitis in early 2017 made me wonder if there might be another underlying health issue. Although altitude has never been my friend, a breathless trip to the Grand Canyon in September sealed the deal, and I went to see a pulmonologist in October.

The subsequent diagnosis of IPF rocked my world. After the initial shock subsided, I decided that I would live my life as fully as possible. Family and friends were enormously supportive when I told them about my IPF.

In 2018 my wife and I took wonderful vacations and enjoyed many visits and holidays with family and friends. After an amazing, but physically challenging cruise, I started using full-time oxygen and learned how to enjoy a pool while keeping my portable oxygen concentrator dry!

Early in 2019 I started seeing a new pulmonologist who stressed the importance of pulmonary rehab and discussed potential clinical trials for new IPF drugs.

In April 2019 I began pulmonary rehab at St Joseph Medical Center. As the months passed, I began to exercise longer and felt stronger and had greater endurance. In addition, I enjoyed the company and friendship of the excellent staff and fellow attendees.

In Oct 2019 I began participation in a Phase 3 clinical study of an investigational IPF drug. (I may be receiving the drug or a placebo).

A few weeks later, I saw an announcement on TV about the American Lung Association sponsored Fight for Air Climb to be held March 1, 2020. I got the wild idea that maybe I could do that. I registered for the climb and began to push myself more at rehab. March 1 was getting closer and I began to have doubts about my ability to complete the climb. But as a great fan of Tom Petty, I always tell myself "I Won't Back Down"...and I didn't. I made it to the top!

Thanks to the love and support of family, friends, excellent doctors & nurses and a great pulmonary rehab program, I was able to reach my goal (even though I finished in last place)!

Now I am looking for my next challenge...