



## TENACIOUS PHIL

Written by Karen Edwards

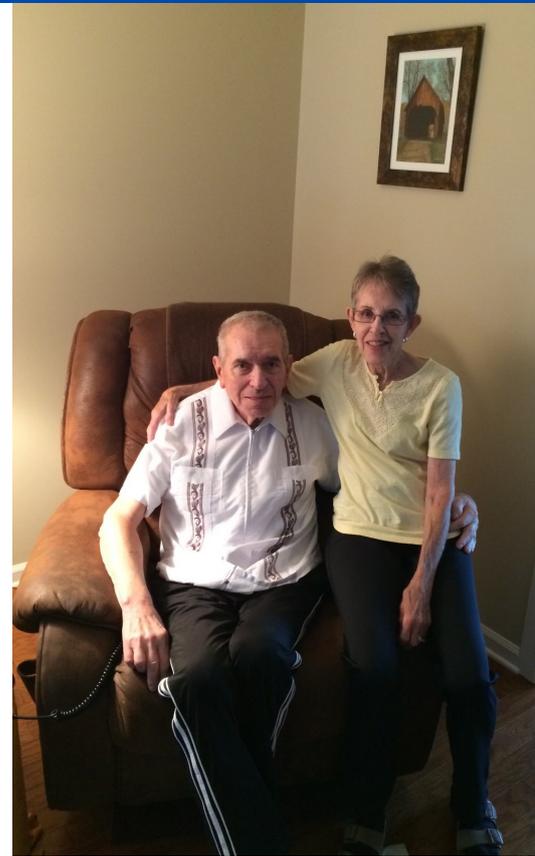
My name is Karen Edwards and I am the captain of Team Tenacious Phil. We participate in P4P to raise funds first in honor of, and now in memory of my dad, Phil Kulinski, who lived with Parkinson's since being diagnosed in 2004 at the age of 66 until his death in January 2021, ironically not from Parkinson's but from COVID-19. This will be our team's eighth year participating. In 2017, I sat down with my parents to learn about their journey with Parkinson's Disease in order to share their experiences with other P4P participants and family members. Here is their story, updated to reflect what's happened over the last four years since our initial discussion.

In 2004 Phil noticed his right arm was twitching and he was unable to control it. The tremor was getting progressively worse and his eyesight seemed to be deteriorating. When he could no longer read the newspaper due to his tremors, he made an appointment with a neurologist in Harford County, MD. He was diagnosed with Parkinson's Disease.

He was very depressed to learn of his diagnosis because he had spent his entire life being extremely active in sports. He was an all-state athlete in both soccer and basketball at Baltimore Polytechnic Institute and continued with sports throughout his adult life, playing on softball teams through church and work. He was in several bowling leagues and served as president of his league up until just a few years ago. In talking to him about how he felt upon hearing the diagnosis he said, "It was a tough pill to swallow."

His wife, and my mother, Ginny, said that she thought it would mean dealing with tremors and other annoying symptoms and at least it was not fatal. She said the first six years or so seemed to just be dealing with the tremor and they thought it wouldn't be so bad. "He was still able to do what he and I always did - bowl, take trips, do yard work, etc.," she explained.

Shortly after his diagnosis he was introduced to Dr. Joseph Savitt, a



*Above: Phil and Ginny Kulinski  
(mom and dad)*

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*Above: Team Tenacious Phil,  
2019 and 2015*

neurologist at Johns Hopkins and they developed a strong relationship. Phil participated in a video that Dr. Savitt made about Parkinson's patients and even appeared in front of students at the school who would evaluate his symptoms and try to make a correct diagnosis.

After the first six years, Ginny said that it seemed like each year or so, there would be a new symptom that would develop. "We would have to figure out how to deal with it and combat it," said Ginny. "You have to find a way to function and to make adjustments so that you can keep doing the things that you want to be able to do."

Eight years after his diagnosis, Dr. Savitt began talking to Phil and Ginny about the potential benefits of deep brain stimulation (DBS) surgery. He believed Phil would be an ideal candidate. "It wasn't an easy decision to make," said Ginny, "because no one can tell you what the end result will be so your decision is based on sound medical advice and a great deal of hope." Phil agreed and said, "I hoped that it would stop the tremor and help with my speech."

Phil underwent the DBS procedure in 2014 and it was successful in controlling the tremors and helped his speech, though it didn't help with his ability to walk, which they knew was probably going to be the case. Dr. Savitt was pleased with the outcome as well. "Dr. Savitt, in our eyes, is a very special, dedicated, thorough individual," remarked Ginny. "We have a special bond with him. We stay in close touch through email in between visits."

Ginny said that one thing they learned is that every Parkinson's patient's story is unique, that the disease affects each person differently, making a cure difficult to achieve. "One person can walk, and another one can't," she explained. "Or you meet someone that has tremors and another one who doesn't."

Each step along the journey brought new challenges. "You eventually reach the point where you finally realize that this is life-altering," said Ginny. "You have to find ways to figure out how to keep your lifestyle going with the help of aids such as walkers, specialty beds, canes, scooters, special utensils, and more."

One step that was a major hurdle and very difficult to accept was giving up driving. It was not safe for Phil to continue driving when he was no longer able to pick his foot up to put it on the brake. The last big decision that they had to make was how long to stay in their home of 40 years. It was a large home on nearly three acres of land in southern York County, PA and proved to be too much for Ginny to manage the



property while being Phil's full-time caregiver.

So, in the fall of 2015 they moved to a cottage in a continuing care retirement community. Ginny said that the continuing care option was important to them because they knew that they might need it. As Phil's Parkinson's progressed, they relied upon in-home caregivers that came six days a week to assist Ginny with caring for Phil.

During our initial conversation in 2017, when I asked, "How are you doing today?" Ginny answered, "There are tears that we shed together, there is fleeting resentment at times for healthy individuals." Phil offered, "After a visit to the neurologist, I don't feel so bad because I see that there are a lot of people who have it worse than me."

"You have to make the best of what life gives you and it doesn't always give you what you think it will," said Ginny. "I always hear the saying that humans plan and God laughs, but we have to have a plan, how can you live without a plan? Our goal is to stay here as long as we possibly can with help."

Dad managed to stay in the cottage until complications led to the need for more care, so he first moved into the memory Care unit in June 2018 where he enjoyed a private, comfortable room while Ginny visited every day. Unfortunately, Phil was experiencing more frequent falls and in December 2018 the care team recommended he move into the skilled care facility for his safety.

Ginny continued to visit every day, and I was able to stop in frequently as the facility was located within walking distance. The last time my brother and I visited was March 11, 2020. After that the world shut down and the doors were closed to visitors. In April, the staff advised us they believed Phil was nearing the end and they allowed Ginny to visit him in his room, while the immediate family gathered outside of his window, but his tenacity won again and he improved. FaceTime and occasional window visits were allowed throughout 2020.

The facility had taken great efforts to protect residents from COVID-19 and managed to have a handle on it until January 2021 saw an outbreak with more than 50 of the 80 residents testing positive. Phil tested positive on Monday, January 4, yet had no symptoms. By Tuesday, there were symptoms and it proved to be too much for him and he passed on January 8. We are grateful and thankful that Ginny was able to visit him in personal protective equipment, touch him, hold his hand, and comfort him. In a FaceTime session just hours before he passed, she was able to tell him how much we loved him, that he had provided well for us and it was ok for him to go.

That is Phil's Parkinson's story but it's NOT really his story. His story was a full life of many achievements, a caring person who supported others, and in my eyes a man who could do anything. I encourage all of you to learn more about him here: <https://www.mykeeper.com/profile/PhilipKulinski/>

There are ten million people worldwide living with Parkinson's and nearly one million in the U.S. according to the Parkinson's Foundation. Each one of those individuals has a unique story. The more we tell these stories, the more researchers can learn about this disease and one day develop a cure.



*Above: Griffin, Phil, and Ava*