

## MY STORY

- Diagnosed 9/16/2021
- Before diagnosis:
  - Symptoms at least 2 years prior
  - Fatigue
  - Tremor
  - Balance issues
  - Brain fog
- Was working as a school nurse, and having increased difficulty working at the level I had been
  - Left position in June 2021 due for safety reasons
- Brought concern with tremor w/ PCP in 2020 – was told it was probably due to meds
- In 2021, brought up with PCP during annual physical again
  - Did some basic neuro assessments
  - When asked to do a tight rope walk, failed miserably
  - PCP then made a referral to a neurologist
- Went to neuro on 9/16/21
  - Went alone, thinking it was no big deal
  - Maybe a script for PT and a recommendation for more exercise
  - Totally shocked when neuro mentioned PD
  - I was started on Carbidopa/Levodopa at that time
  - NEVER ENTERED MY MIND!!!!!!!

- Shared news with my husband, daughters and my siblings. Tough conversation to have.
- Did not know what to do or think; started reading everything I could, and watching many videos, which only served to increase my sadness and anxiety
- A friend told me about a support group in my town, and I reached out to the group leader.
  - 2 weeks post diagnosis, here I was at a support group meeting, not knowing anyone except my husband. Very powerful reaction being in a room where everyone, like me, had PD
- At that meeting, I met the sister of the group leader, who worked for a gym call Beat Parkinson's Today, a gym who served people who had PD. That woman was Vicki Kulas!
  - She shared with me that there was a study going on at Yale, looking at the benefits of exercise for PD and how it helped to slow down the progression of the disease.
  - She told me that she would speak to Michelle, and have someone reach out to me about participating in the study, especially since I was so newly diagnosed.
- Me, the consummate couch potato, doing exercise, doing exercise? I couldn't even picture myself exercising!!!!
- Nevertheless, I stuck it out, went through the evaluation and trial process, and knew I needed to do this for myself.
- I was a WRECK before classes. I felt that I couldn't keep up, was very out of shape, and really felt like packing it in on more than

one occasion. Despite being anxious beforehand, and sore and tired afterwards, the instructors were very kind and motivating, and I knew I needed to continue with the program that I had committed to, not only for the Yale study, but more importantly, for me.

- I wanted to start out in the Basic class, and I was told, oh no, no, no, you are definitely starting at the Bronze level. After I had been on that level for a good 6 weeks, I was 'encouraged' to move up to Silver. There went my anxiety level on the rise again!
- In June 2022 during my MDS visit, I was given the good news that my symptoms had actually improved, more than likely due to my participation in the exercise study. Great news!
- When the exercise study ended for me in July 2022, I was faced with the decision of what to do, now that I wasn't mandated to go exercise a minimum of 3 classes per week. The answer was actually a no-brainer for me; I had read so much about the importance of PD and exercise, so I knew I needed to continue with the program, and at the same frequency that I did during the study.
- I have continued on this track since the study ended last summer, even trying out some Gold level and strength classes. I try to be as diligent as possible to attend at least 3 classes a week, and I must admit I feel guilty when I don't meet my attendance goal for the week. I must admit that there are days when exercising is not something I want to do, but I know I have NO choice, if I want to stay healthy and hopefully continue to slow the progression.

- The icing on the cake for me is having been invited to become a Beat PD Ambassador. I was very honored to have been selected, and with all that Beat PD has given me, this is my way of giving back. The program is new and evolving, and I look forward to doing what I can to advocate for the importance of exercise, and how Beat PD has changed my life for the better.