

SPRING 2020

INSIDE THE CIRCLE...

Lancaster County Parkinson's CIRCLE OF CARE Alliance

Issue #7



Greetings from the Board....

Dear PD Warriors:

Happy Spring from the Lancaster County Parkinson's CIRCLE OF CARE Alliance!

INSIDE THE CIRCLE this month, you'll find several upcoming events...meet a new Board member...read an inspiring story about woman with a "warrior" attitude in combatting PD...and be introduced to an Art Therapy Program that we have "in the works".

Our mission, as always, is to provide ways for our PD community to take control and responsibility for improving their lives on a day-to-day basis.

We invite you to keep "in the loop" through our quarterly newsletter, our facebook page and our website. Email us with any questions you may have regarding resources or how to get connected with the PD community!!

Have a wonderful spring and we hope to see you at the PARKINSON'S AWARENESS WALK on April 25th!

Best Wishes,
LCPCCA Board of Directors

OUR MISSION:

"To give those with Parkinson's Disorder and their caretakers hope in awareness, education, encouragement, and action to take control of and responsibility for their future."

OUR VISION:

"To improve the lives of those with Parkinson's Disorder and their caretakers."

PARKINSON'S CIRCLE OF CARE ALLIANCE

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BOARD OF DIRECTORS

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Connie McKane—Sec/Treasurer

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Patricia Kline

Nancy Mulhearn

Drew Nesbitt



Up-Coming Events:

Parkinson's Awareness Walk: April 25

**2020 Circle of Care Symposium:
September 12**

**Beer Dinner & Red, White and Blue Wine Dinner:
to be determined**

Welcome to our Newest Board Member...

NANCY MULHEARN

In 2006 Nancy was diagnosed with Young Onset Parkinson's Disease at the age of 44. Her first symptom was a pinky finger that felt like it had a mind of its own while trying to wave to a neighbor while jogging.

Thankfully, in time, she discovered The Michael J Fox Foundation and Team Fox. Motivation set in, and Nancy went on to organize five "Leave Parkinson's Behind" galas, raising more than \$100,000 for The Michael J Fox Foundation for Parkinson's Research.

She has hosted additional PD fundraisers as well, and enjoys mentoring and attending Parkinson's-related events, finding great strength from friends also battling PD.

Nancy has participated in research studies, the Parkinson's Unity Walk, and been interviewed by the NY Times and Neurology Now about disclosing a PD diagnosis and overcoming the stigma of a neurological illness.

Her biggest regret is keeping her diagnosis a secret for a few years before getting involved to help find a cure. Inaction breeds fear.

Nancy and her husband, Joe, recently relocated to Lititz from Hunterdon County, NJ. The best find is Rock Steady Boxing! The support, workout, music, laughter, and friendship are a powerful combination!



My Parkinson's Attitude: Meet the Friedmans

I was diagnosed with Parkinson's disease at age 69. My life prior had been very full, challenging, and worthwhile. I grew up in a small town in New Jersey. After graduating high school, I had an opportunity to join the US Cadet Nurse Corps during WWII. I graduated from the Jersey City Medical Center School of Nursing as a registered nurse in 1948; married in 1950 and after a few years I stopped working and began raising a family. . .one boy and three girls. I was busy. My husband had graduated from Seton Hall University and as an accountant with a lot of drive moved often up the corporate ladder. This meant quite a few moves from one state to another, renting houses, building houses, selling houses - whatever was required to keep the family running smoothly. We finally settled in Shelton, CT and lived there for forty years. We became active in the Huntington Historical Society, making friends and helping to raise funds for moving and restoring a historic house. At the same time, we became active at the Catholic Church and schools where our children attended. Life was good. But there was an undercurrent.

Once our youngest child went off to college and I finally had time on my hands, rather than return to nursing after so many years, I took a job in retail and worked in retail until my Parkinson's symptoms began. The symptoms began with a slight tremor on my left side. My husband had become a deacon in the church and visited nursing homes frequently. One day he commented that I appeared to walk like the Parkinson's patients he had seen and suggested I check with our family doctor. The doctor diagnosed it quickly. He said, "It is a degenerative disease, no cure and the medicines don't work very well!" He sent me to a neurologist for a second opinion which was the same as his.

How could this be happening to me? I was the healthy strong one who took care of everyone else? Now, folks watched me for fear I would fall. How could this happen to me? I always lived right. I never smoked or drank. I watched my diet and exercised. I tried to do everything right? Again, how could this happen to me? There are no answers.

Eventually, I retired from my job and found an excellent neurologist at Yale who began treating me with Mirapex about five years after my diagnosis. I had resisted medication until one day when my feet seemed to stick to the floor! Fortunately the medication helped and life went on quite normally. Some years later, one of our daughters moved her family to North Carolina and encouraged us to follow. She said she would take care of us as we grew old, so we did. The decision turned out to be an excellent one. We bought a new ranch house which is easier to care for and created a garden at the back of the property with a delightful bird sanctuary. We call it "our Camelot."

I have now tolerated Parkinson's disease for fifteen years and am treated at Duke University. I have reached a resignation about my symptoms, which keep changing as time moves on. I am still uncomfortable with the attention these symptoms cause, but control my feelings remembering that I cannot change other people...only myself. I try not to dwell on what others may be thinking. I find this is an illness one can live with for a long time. The trick is keeping a positive attitude along with keeping one's mind busy with hobbies, etc. During the past four years, I have picked up an old hobby...oil painting. I have completed about fifty paintings during that time. I give them as gifts to family and friends and the activity helps me to forget my symptoms. I also love caring for my house, reading, gardening and 1000 piece jig saw puzzles.

Mirapex and Carbidopa-levo are the two drugs that work for me. All others have been disappointing due to side effects, especially the Neupro patch which caused heavy suicidal thoughts. Parcopa quickly caused my hair to fall out. I promptly stopped taking it and my hair is finally growing back. I don't know what will happen if I build up a tolerance to my current meds. At this stage, I have a lot of dyskinesias and rigidity in my back, but I keep moving and doing as much as I can. I have some trouble swallowing and loss of appetite which has led to weight loss. I have learned some swallowing techniques from a speech therapist, softened my diet and increased my calorie intake. So far, so good.

Otherwise, life is good with a loving husband and family giving me generous support. I feel as if my body is gradually going downhill, but the aging process is taking its toll too, I'm sure. I live in the moment...one day at a time. "The longer I live, the more I realize the impact of attitude on life. Attitude to me is more important than facts. It is more important than the past, than education, than money, than circumstances, than failures, than successes, than what other people think or say or do. It is more important than appearance, giftedness, or skill. It will make or break a company...a church...a home. The remarkable thing is we have a choice every day regarding the attitude we will embrace for that day. We cannot change our past...we cannot change the fact that people will act in a certain way. We cannot change the inevitable. The only thing we can do is play on the one string we have, and that is our attitude. I am convinced that life is 10% what happens to me and 90% how I react to it. And so it is with you...we are in charge of our attitude!"

Linda Maitan & Ron Friedman (Printed from the Parkinson's Foundation: Living with Parkinson's)



INSIDE THE CIRCLE RESEARCH & RESOURCES

In the Works... Art Therapy Program



In the works...we have an Art Therapy Program that the Board is developing for our Lancaster PD Community. Watch future issues of our newsletter, as well as our website and facebook page for developments in the following areas: Art, Percussion, Pottery, Voice and Dance. CIRCLE OF CARE Alliance is planning to offer class sessions for our clients who experience PD, as well as their caregivers, hopefully during the 2020 calendar year, possibly unveiling it for this summer!

*** Preview of 2020 CIRCLE of CARE Symposium ***

Date: September 12, 2020

Times: To be announced

Location:

PA College of Health Services
850 Greenfield Road Lancaster PA 17601

Keynote Speaker:

Dr. Laurie K Mischley, ND, MPH, PhD
Author of NATURAL THERAPIES FOR PARKINSON'S DISEASE
Graduate of Bastyr University and University of Washington
Staff member at Seattle Integrative Medicine
Recognized expert in the field of nutritional effects on PD

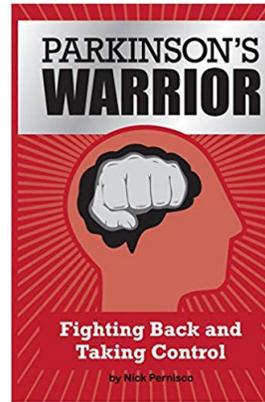


April is...
**PARKINSON'S
AWARENESS
Month!!**



**April 25: Parkinson's
Awareness Walk**

Mark your calendars now for our second PD Awareness Walk to celebrate Parkinson's Awareness Month! Details will be posted soon on the website!! Stay tuned!!



Book Review Corner:

PARKINSON'S WARRIOR

by
Nick Pernisco

Nick Pernisco was busy with a promising academic career when a Young Onset Parkinson's diagnosis at age 33 upended his carefully laid plans and almost derailed his life. This is the story of how he learned to cope and thrive - through education, self care, and the power of adopting a Warrior Mentality. PARKINSON'S WARRIOR provides information and inspiration for all People with Parkinson's to live a better, happier, and healthier life. Through the lens of his experiences and learnings, Nick shows you how to move past grief to fight back and take control, so you too can become a Parkinson's Warrior.





QUOTE OF THE SEASON

You are the hero of your life and those you care about. Therefore, you have to develop a warrior mindset and learn to grow from pain, setbacks, failures, obstacles, challenges, losses, and all the hard times in in your life. Unknown

