

S U M M E R 2 0 2 0

INSIDE THE CIRCLE...

Lancaster County Parkinson's CIRCLE OF CARE Alliance Issue #8

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

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Greetings from the Board...

With Summer 2020 just around the corner, we are faced with quite a few “unknowns”! Will our Beer Dinner; Red, White & Blue Wine Dinner; Arts Therapy Program; and our 2020 Circle of Care Symposium go on as planned?? Unknown, at this time! Unknown, but highly anticipated!!

While the Board remains enthusiastic about the events that are planned, our top priority is the good health and safety of our PD community! That being the case, we shall continue to monitor PA and Lancaster County’s “opening up” timeline and will proceed as advised. Stay tuned to the Circle of Care website for information as it develops.

In the meantime, we hope you find our latest issue of **INSIDE THE CIRCLE** enjoyable and informative. This edition marks two years of newsletters! We are happy and proud to serve you and your loved ones as you navigate your way through this journey of PD.

Best Wishes as always,
LCPCCA Board of Directors



A Student's Perspective: My Experience as a Rock Steady Boxing Student Intern

During my time as a Rock Steady Boxing Student Intern, I had the privilege of expanding my knowledge on Parkinson's Disease alongside of Sue Ludwig, owner and founder of Rock Steady Boxing Lancaster and NeuroSci Fit Instructor and Robert McKane, founder of Parkinson's Circle of Care Alliance. I actively engaged with clients in NeuroYoga and Rock Steady Boxing Level 1-2 and 3-4 classes. Within minutes, the clients, volunteers, Robert, and Sue greeted me with such a warm welcome that I automatically felt the sense of connection, friendship, and family that Rock Steady Boxing encompasses. Prior to my first day as an intern, I anticipated learning extensively about Parkinson's and how this disease affects ones' activities of daily living (ADLs) such as bathing, dressing, cooking, and instrumental activities of daily living (IADLs) such as driving, etc. Throughout the duration of my student intern experience, I witnessed a variety of boxing workout circuits that included exercises that specifically target the symptoms of Parkinson's. Sue and I were able to create a TikTok with both Level 1-2 and 3-4 RSB clients to the dance "Say So," which brought laughter and smiles to all involved. As pictured above, I was able to create and run my own fine motor skills station that included cognitive functional components as well. Clients were allotted eight minutes to utilize pinch grasps to manipulate candies, buttons, coins, and marbles and place them into their designated containers. Secondly, clients also used fine motor skills to share, in writing, the biggest challenge they are faced with relating to PD (as displayed on the poster above). In regard to my feelings after completing my student internship, I could not be filled with more gratitude and thanks to Sue and every client, volunteer, etc. who I had the privilege of being able to interact and foster a relationship with. I would highly recommend this student internship program to any perspective student as I will carry with me everything I learned into my future career as a healthcare provider.

"These are my friends; this is our fight"

Natalie Frantz
MSOT (Master's Student of Occupational Therapy)
Class of 2022
Alvernia University



Have You Ever Considered a Chair Lift??

As part of Parkinson's Circle of Care Alliance's mission, "...to help those with Parkinson's live well...", we are always on the lookout for ideas, places, and products that will enhance your life. Recently a client of Rock Steady Boxing Lancaster contacted us and asked if we had any resources to help them "downsize" and "relocate" to a single level house. The wife was no longer able to navigate the stairs in their bilevel home. After some conversation it was obvious that they really did not want to leave their home of 25+ years but saw no other possibility. I asked them if they had considered having a chair lift for the stairs. They had many years ago and said it was far too expensive and the company said it would be difficult to install with a bilevel.

Months earlier I happened upon a US company, with local offices, that helped those with limited mobility to maintain their independence and provide accessibility where they live, work and play. I mentioned this company to these folks and gave them a brochure.

Several weeks later I got a call that they had indeed talked with this company and were able to have one installed to meet their need and at a reasonable price. I was happy that the Alliance was able to make a difference in their lives.

(NOTE: We do not solicit or utilize any advertising for our newsletter, website, or social media. Any mention of any product or service is for information only and we do not endorse any of them. Information is provided for the reader to be able to research and decide to use or not use such products or services.)



Be well and Live well

Bob McKane
Founder
PCCA

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www.amramp.com



COVID-19: What People With Parkinson's Should Know

"[People living with Parkinson's disease](#) are at high risk if they contract COVID-19, whether they are above age 50 or if they have young-onset Parkinson's disease, which occurs in people younger than 50," said Dr. Frederick Southwick, an infectious disease expert at the University of Florida in Gainesville.

Southwick was part of a Parkinson's Foundation panel that held a live Facebook forum to answer questions about COVID-19's effect on people with Parkinson's.

Parkinson's is a neurodegenerative disorder that causes tremor, rigidity and problems with balance and gait.

"While people with Parkinson's disease don't have compromised immune systems by nature of the Parkinson's disease diagnosis, the respiratory tract is where the danger is," Southwick said in a foundation news release. "Issues with the respiratory system muscles can make it difficult for people with [Parkinson's disease](#) to take deep breaths and get enough oxygen into the lungs."

He urged family members of people with Parkinson's disease to stay home and avoid contact with others as much as possible to avoid COVID-19 exposure.

Loved ones living in group facilities should remain there, if possible, to take advantage of 24-hour resources, the foundation advised. Family members should try to ensure that facility employees are following safety guidelines, including hand-washing and social distancing. Use phone calls and video chats to stay in touch.

Some families may have the resources and support to bring a loved one with Parkinson's home, but the COVID-19 pandemic may last several months. Before making a decision, talk to your medical team and ensure you have the right gear, medication and support, the foundation advised.

People with Parkinson's should get seasonal flu and pneumonia shots, if they haven't already received them. The [vaccines](#) aren't effective against COVID-19, but can prevent or lessen infections from those diseases -- and preventing pneumonia in people with Parkinson's is crucial.

Dr. Michael Okun is the foundation's national medical director. He said that decisions about medical appointments for Parkinson's patients to manage their disease "should be a discussion between you and your medical team. Regular checkups and even appointments for urgent concerns may be able to be conducted virtually, so check with your doctor to see if that is an option."

Okun suggested that "people with Parkinson's disease -- and their care partners -- should postpone elective or preventative doctors' appointments."

The foundation noted that the combination of low mood, depression and anxiety has the greatest impact on the health of people with Parkinson's, even more than the movement problems associated with the disease.

Therefore, it's critical for people with Parkinson's to combat loneliness and anxiety caused by self-isolation. Use social media to connect with others multiple times a day, or call people on the phone for a chat, the foundation suggested.

(Reprinted from WebMD News from HealthDay)





A PROGRAM OF THE MARK MORRIS  DANCE GROUP

DANCE for PD Offers At-Home Options

Dance for PD®, founded in 2001, offers specialized dance classes to people with Parkinson's, their families, friends and care partners in eight locations around New York City and through our network of affiliates in more than 300 communities in 25 countries around the world. Dance for PD classes invites people with Parkinson's to experience the joys and benefits of dance while creatively addressing symptom-specific concerns related to balance, cognition, motor skill, depression and physical confidence.

The program's fundamental working principle is that professionally-trained dancers are movement experts whose knowledge about balance, sequencing, rhythm and aesthetic awareness is useful to persons with PD. In class, teaching artists integrate movement from modern, ballet, tap, folk and social dancing, and choreographic repertory to engage participants' minds and bodies and create an enjoyable, social environment for artistic exploration.

The eight points below explain why dance is particularly beneficial for people with Parkinson's disease. They are demonstrated in the "Why Dance for Parkinson's Disease?" DVD.

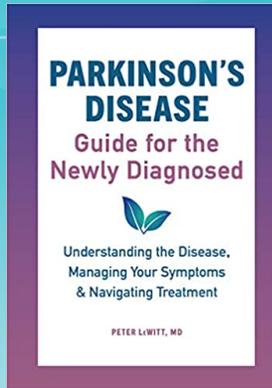
1. Dance develops strength, fluidity, flexibility, stamina, and balance.
2. Dance helps us master skills through progressive training.
3. Dance is a stimulating cognitive activity that connects mind to body.
4. Dance helps us to forge social connection and a sense of belonging.
5. Dance harnesses imagery, rhythm, and music in the service of intentional movement.
6. Dance helps us express stories and emotions through our bodies.
7. Dance sparks creativity and develops problem-solving skills.
8. The essence of dance is joy.

Now, DANCE for PD is offering at-home options. DVD's are available, as they have been for several years. But, with the Covid-19 phenomenon, they are now providing on-line streaming and/or Zoom classes. Classes include: Dance, Guided Meditation, Pilates and Sing for PD. Check out all these opportunities at <https://danceforparkinsons.org./resources/dance-at-home>.



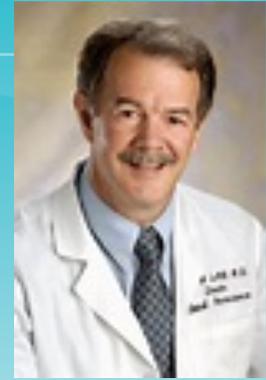
Also available online is Vocal and Facial Work with Coach Brett of 110 Fitness:
<https://m.youtube.com/watch?v=fDihj8Gjjn8>.

BOOK CORNER:



**Parkinson's Disease:
Guide for the Newly
Diagnosed**

by
Peter LeWitt, MD
(To be released June 6, 2020)



Lancaster County Parkinson's Circle of Care Alliance strives to provide resources and information for clientele at all stages of the PD journey. This month, we found a book slated to be released on June 6th, specifically geared for people who have been recently diagnosed with PD. The information can be so overwhelming! This book is intended to deliver the basics—understanding PD, managing symptoms and navigating treatment. We hope you find it beneficial!

Dr. LeWitt was appointed Professor of Neurology at Wayne State University School of Medicine in 1990. A graduate of Brown University School of Medicine (and also awarded a M.Med.Sc. in Biochemical Pharmacology), his neurology residency training was at Stanford University School of Medicine. His completed fellowship training in experimental therapeutics at the National Institute of Neurological and Communicative Disorders.

Whether it's you or a family member, receiving a diagnosis of Parkinson's disease can generate emotions of anger, frustration, sadness, and confusion—but you're not in this fight alone. *Parkinson's Disease for the Newly Diagnosed* is one of the most helpful Parkinson's disease books, giving you the tools to conquer those feelings of being overwhelmed and helping you to be better prepared for life post-diagnosis.

In one of the most extensive, up-to-date Parkinson's disease books, you'll find resources for maintaining realistic optimism while living with Parkinson's disease. With helpful information and advice from how to build a community and patient-caregiver relationships, to assembling your primary care team and more, there's practical advice for addressing what life will be like moving forward.

This standout among Parkinson's disease books includes:

- **Set expectations**—Go beyond other Parkinson's disease books with an in-depth overview of all the stages from early to advanced.
- **Tailored for you**—Use strategies for managing your symptoms that are straightforward and specifically designed for the newly diagnosed.
- **Positive, practical advice**—Find out about support groups, how best to adapt your home, preserve your independence, and more in one of the most comprehensive Parkinson's disease books available.

(Reprinted from the Amazon website.)



QUOTE OF THE SEASON:



Katrina Mayer



Author
of
The Mustard
Seed Way