

The Transmitter

Parkinson's Disease and Movement Disorders Center (PD&MDC) Newsletter of Penn Medicine

Volume 14, Number 1 | Spring 2019

Get **CONNECTED**

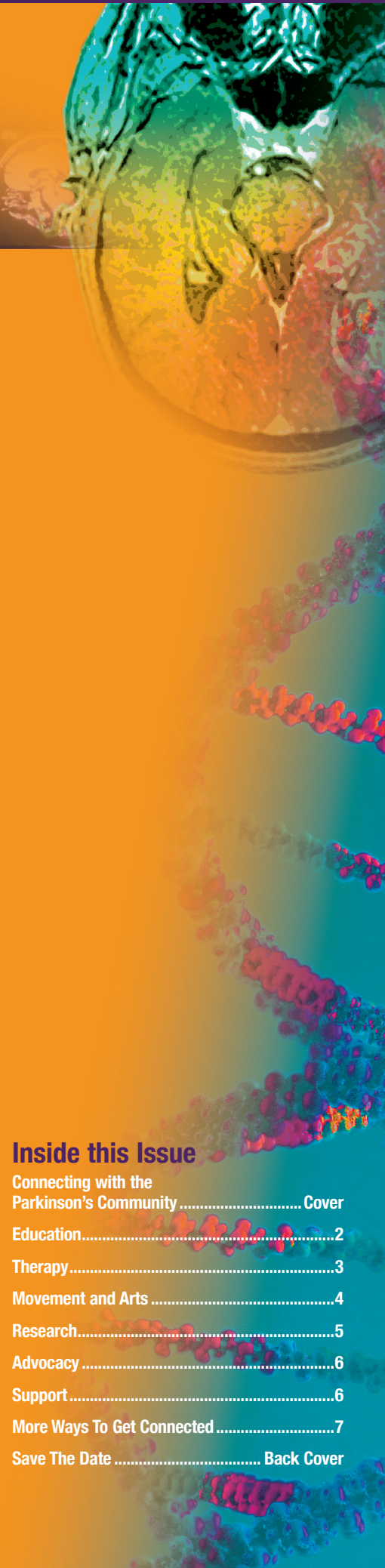
In this edition of The Transmitter, we open the door wide to the variety of resources available for people with Parkinson's disease (PD) and their loved ones. From movement to therapy to research to education and advocacy, the Parkinson's Disease and Movement Disorders Center (PD&MDC) and the community has a rich palette of offerings you may wish to explore.

CONNECTING *with the* **PARKINSON'S COMMUNITY** *By Suzanne Reichwein, MSW*

When we think back to the happiest moments in our lives, we usually place ourselves within a circle of people we love, who understand us and share many of our feelings and experiences. Remember your wedding, a family reunion, or an important event in your past.

The same is not generally true of living with a chronic neurological disorder such as Parkinson's, which can lead to feelings of isolation. You think that no one has ever felt the way you do. It's common to feel sad and anxious. And who actually knows what it is to experience the intense emotions you go through when you have tremor or rigidity, or you lose your balance frequently? Feeling alone often accompanies anxiety and depression.

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CONNECTING *with the* PARKINSON'S COMMUNITY

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The literature tells us that up to 50 percent of people with PD will suffer from depression at some point in their illness. This depression often takes the form of a lack of enjoyment in things and activities that brought us pleasure in the past. Much of this can be attributed to the changes one is feeling in the body, which can create adjustments in lifestyle. However, there is evidence that biochemical changes in the brain may also be a factor. In fact, researchers have found that depression may be an *early* sign of PD.

Anxiety is also a major mood problem; up to 40 percent of people with PD have some sort of anxiety. For many who were looking forward to their retirement, a diagnosis of PD is more than upsetting—it completely changes expectations for the future. Depression or anxiety may cause us to pull away from family, friends and social settings.

It is for this reason that we need to work closely with our healthcare providers and bond with those who are traveling through this transition with us. Other patients and care partners are going through similar changes to ours!

Andrew Siderowf, MD, the Hurtig and Stern Chair of Movement Disorders, states, "It's a lot easier to fight back against Parkinson's when you have a team behind you. Networking with other people with PD can give you tips for living well, insights on what to expect from medications and an inside track on new treatments and research." Being around others who have PD can be empowering. Many of the thoughts and feelings expressed in support groups are common, and it can be comforting to know that you share these with others.

The PD&MDC is launching a new campaign in April, Parkinson's Awareness month. Our initiative is called "Get Connected," and there are so many ways of doing this! The goal of this project is to provide all people with PD and their care partners with resources in the community to combat isolation and foster self-awareness.

This edition of *The Transmitter* is a start. Whether it is a support group, clinical trial, an exercise or movement class, or creating a team for the annual Walk, you will find others to commune with. You are not alone on this journey.



EDUCATION

By Josue Etienne, BSN, RN

Getting accurate information is critical, especially as it pertains to a chronic condition such as Parkinson's disease. Individuals and their care partners have an opportunity to attend a multitude of programs we offer at the PD&MDC, such as PD 101 (an introduction to PD), and a 12-week educational course on PD known as PD Self. For those considering surgical options to aid in the management of PD, there is a course for you in our deep brain stimulation (DBS) clinic, which is offered on a monthly basis. Our greatest educational program is the Jane Wright Patient and Caregiver Symposium, which occurs annually during the spring, where trending topics are discussed.

We also emphasize the importance of healthcare provider education, to better inform these individuals so that they can utilize their knowledge within the communities they serve. The PD&MDC is a pioneer in training fellows (post-graduate physicians) who have gone on to illustrious neurology centers across the country. Our staff members also conduct community outreach to educate healthcare providers about the nuances of PD.

In addition, our center is affiliated with the Visiting Nurse Faculty (VNF) program. This program educates nursing faculty about PD, so that they may in turn educate nursing students. Having this core education will subsequently improve patient outcomes and experiences. These educational offerings help us to provide high quality and family-centered continuity of care for our patients and the community.

For more information, please contact Josue Etienne at Josue.Etienne@uphs.upenn.edu.

“Getting a diagnosis of Parkinson's is never in anyone's life plan, and it truly feels like you have to start life anew. Penn's multi-varied programs support me in reordering my new normal and help me prepare to move forward in the most positive way. Penn educational programs are now part of my team. And there is strength in numbers.” - Susan L.



THERAPY

Physical Therapy

By Kelly Gasper, PT, DPT

Physical therapy (PT) for PD includes interventions that focus on walking, balance/coordination, flexibility, and endurance in order to improve safety and efficiency with movement during all stages of the disease. It is also critical to not only exercise the body, but also the brain. That's why at the Dan Aaron Parkinson's Rehab Center (DAPRC) at Penn Therapy & Fitness, cognitive challenges are always incorporated into treatment in order to optimally fight back against PD!

For more information please call the DAPRC at 215.829.7275.

Occupational Therapy

By Julia Wood, MOT, OTR/L

Occupational therapy (OT) can help people at any stage of Parkinson's—right after diagnosis up to and including later years of disease—with any task that is difficult to perform or may become impacted by PD. Occupational therapists (OTs) analyze how a person performs a task that has become bothersome to figure out how and why it's challenging, and collaborate with the individual to provide solutions to make the task easier and safer to perform. OTs take a holistic approach, addressing a person's movement, cognition, fatigue and visual issues. This type of therapy may enable people with Parkinson's (PWP's) to resume or enhance their daily activities.

OT also deals with cognitive therapy. I facilitate our "Fit Brains" cognitive fitness class, which incorporates exercise, education, and activities to challenge the various domains of cognitive function impacted by PD. I host a quarterly "Book Nook" club for PWP's and care partners with readings selected by participants to foster social engagement and community.

For more information, contact Julia Wood at Julia.Wood@uphs.upenn.edu

Speech Therapy

By Meredith Pauly, MA CCC-SLP; LSVT LOUD® provider

As a speech language pathologist (SLP), I work with people who have difficulty communicating or swallowing (dysphagia). Communication is a two-way street, so it is important for the person with PD and their caregivers to understand the typical speech, voice or language changes that people with PD experience. The SLP evaluates for strategies to promote effective communication, which may include LSVT LOUD® (Lee Silverman Voice Treatment), which trains people with PD to use their voice at a more normal loudness level. I encourage patients to get connected by reaching out to their existing circle of friends and family to schedule dedicated time for phone conversations or in-person meetings to practice communication skills and strategies. Preliminary studies on singing in a choir have shown potential to improve voice quality of life and may have positive effects on swallowing function, though they are not a substitute for individual therapy.

For more information, call Meredith Pauly at Penn Therapy and Fitness, 215.829.7275.

"It's for your own self-esteem. When you do the exercises, you retain your ability to hold your own in conversation. As for me, conversation is a very important part of my life." - Ed M.



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MOVEMENT AND ARTS

Dance for PD

About 20 years ago, the Brooklyn Parkinson's Group, under the leadership of Ollie Westheimer, reached out to the Mark Morris Dance Group with a unique proposition: Might they be interested in creating a dance class for people living with Parkinson's disease? This initial conversation led to what is now an international program bringing the joy of movement to people all over the globe. Dance for PD has been available in the Philadelphia area for the past eight years, with weekly sessions now being offered in the city and in the greater tri-state area.



Dance for PD is fun: a wide, lively range of music (show tunes, oldies, folk, world music and more) and movements suitable for seated and standing dancers. Dancers are both challenged and free to enjoy the class however their bodies feel on that particular day. The dance class is designed just for their needs, reminding us that dance is enriching for all bodies at all stages of our lives.

For more information, please contact Keila Cordova at <https://954dmc.weebly.com/dance-for-pd.html> (for Philadelphia class) and The Parkinson Council (www.theparkinsoncouncil.org) for all other classes in and outside the city.

Yoga

Theresa Conroy Yoga Therapy, located in Lafayette Hill, just outside Philadelphia, specializes in group and private yoga classes for PWP. These are not ordinary yoga sessions. Theresa Conroy, a certified yoga therapist, creates therapeutic yoga classes that address specific, personal needs through the use of yoga postures and practices. The classes focus on making strong connections: between our own minds and bodies, among participants, and between the yoga practice and everyday life.

For more information, contact Theresa Conroy, theresa@theresaconroy.com or 215.888.9123.

Parkinsingers

The Parkinsingers are more than a choir. We welcome PWP's, their care partners and friends to sing, but also to support one another in many different ways. According to an article in The New York Times: "Research shows that music helps foster deeper social connections." Many of our participants have said that the warm, caring individuals they meet when they sing together have become as close as family.

No prior musical experience is necessary. Our music director, Holly Phares, believes the Zimbabwe proverb: "If you can walk you can dance, and if you can talk you can sing."

We meet Mondays from 2 to 4 p.m. at Congregation Rodeph Shalom (Broad and Green Streets, Philadelphia). We sing songs that motivate and inspire us to get up and move, from pop and show tunes to chants and spiritual songs.

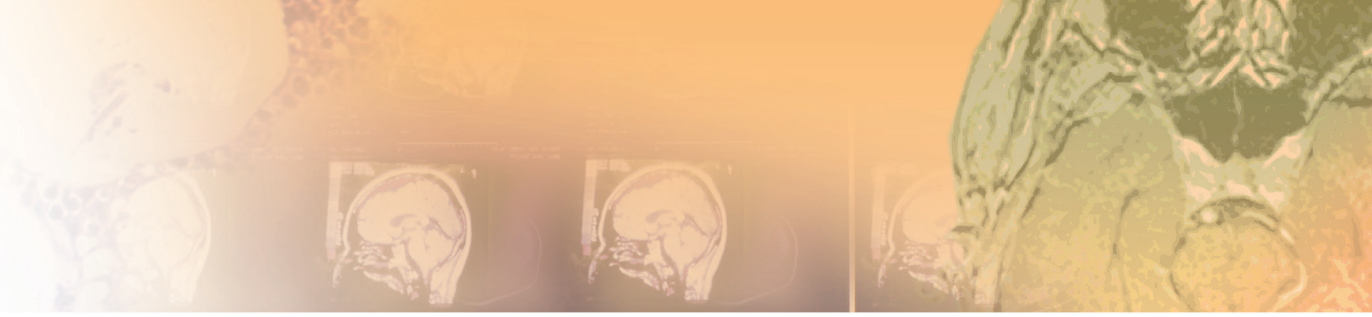
For more information, contact Marjorie Samoff at masamoff@aol.com or 215.668.0116.

Close Contact for Couples

A new program, offered this spring at Ralston House, is "Close Contact for Couples." Judith Sachs, a Dance for PD certified teacher, discovered that many couples (spouses, adult children, and parents or other family members) react to the changes in movement that occur over the course of time with frustration and accommodation. Instead of moving together when they perform activities of daily living such as walking, showering, putting on a coat, or getting out of bed or into a car, they try to force the activity or do it the way they used to decades ago.

In this training program, couples are taught to move like dancers, learning to shift weight, to verbalize the movement they are about to do, and to make eye contact. Breaking the mold with movement is often eye-opening and may increase body awareness and safety, which in turn helps with PT, OT, and all other types of therapy.

For more information, contact Judith Sachs at www.anyonecandance.org or 609.577.1928.



Accessible Art at the Philadelphia Museum of Art (PMA)

For over fifty years, the PMA has provided meaningful arts engagement opportunities to those with disabilities through the Accessible Programs office. Since 2013, the PMA has offered a range of workshops for individuals with PD, together with their care partners. These workshops were designed to provide a relaxing, supportive environment, in which individuals could fulfill their creative desires, all while playing an active role in the life of Philadelphia's largest visual arts organization. Activities include in-gallery tours led by trained museum educators or guides, and hands-on studio activities so that participants can actively create and express themselves.

For more information, contact Marissa Clark at maclark@philamuseum.org or 215.684.7602.

Rock Steady Boxing

The DAPRC at Penn Therapy & Fitness was the first in Philadelphia to introduce Rock Steady Boxing (RSB) to the Parkinson's community six years ago. RSB is a non-contact boxing-based fitness curriculum tailored to those with PD. There is a strong sense of motivation and dedication displayed by all our boxers. Led by a physical therapist, our RSB class incorporates elements to challenge balance, coordination and cognitive processing in an effort to fight back against PD in an effective and fun way!

For more information, contact Joellyn Fox at Joellyn.Fox@uphs.upenn.edu or 215.829.7275.



RESEARCH

By Whitney Richardson, MS, Research Coordinator

Being involved in our research community here at the PD&MDC can keep you connected in many ways. First, being involved in research usually means more face time with the staff and physicians. When you spend more time with us, you can ask us more questions and learn about other opportunities.

In addition, the research staff are very knowledgeable about all types of resources. We can pass on information about support group and educational opportunities, as well as other research opportunities and new clinical trials. When we see our participants frequently, we have more opportunities to let them know about the exciting things that are coming up here at the PD&MDC.

Finally, taking part in a research study is a great way to feel like you are directly involved in improving understanding of and therapies for PD. Without research, our science and treatment options would not evolve and improve. Research would never progress if it weren't for our wonderful and generous participants!

For more information contact Suzanne Reichwein at sreichwein@pahosp.com or 215.829.7273.



PARTNER WITH US BY MAKING A DONATION TODAY!

The Philanthropy helps provide essential resources to advance the PD&MDC's mission to improve the lives of individuals with movement disorders and accelerate discovery of new therapies.

- > To make a gift online, visit us at:
www.pennmedicine.org/supportpdmdc.
- > To make a gift by check, mail to us at:
Penn Medicine Development
Attn: Mary Tong, PD&MDC
3535 Market Street, Suite 750, Philadelphia, PA 19104
Please make checks payable to "Trustees of the University of Pennsylvania".

Contact Mary Tong at 215.746.2204 or tongm@upenn.edu to learn more.



ADVOCACY

The Parkinson Council

By Wendy Lewis, MNPL, Executive Director

The Parkinson Council (TPC), established in 1987, is the premier local organization dedicated to improving the quality of life for people with Parkinson's, their carepartners and families. The Council invests in research, education, and programs provided by world-renowned institutions and innovative service organizations in the greater Philadelphia area. The Council strengthens its role in the Parkinson's community by increasing the number of lives touched every year.

After nine years in the role of executive director, I continue to be amazed and humbled by our grantees and partners who work tirelessly to make every day memorable and meaningful for people with PD. One of the best things about being part of TPC is the variety and diversity of services and programs we fund that support local people with PD and their families, including the Philadelphia Museum of Art Accessible Workshops for people with Parkinson's and their carepartners. TPC is incredibly grateful for the generous support of the Susan O. Jaffe Quality of Life Initiative that helps make this program possible.

For more information, contact The Parkinson Council at www.theparkinsoncouncil.org or call 610.668.4292.

Parkinson's Foundation

By Kristy Pomes, Senior Manager, Communications and Marketing

The Parkinson's Foundation is the nation's leading community for people living with PD, those who love them and those who are working to end the disease. We believe in expert PD care, which is why we designate 45 medical centers around the world as "Centers of Excellence"—including the PD&MDC. These Centers of Excellence provide care to more than 145,000 people with PD worldwide. The Foundation believes in empowering our PD community through free resources, from our podcast and webinar series to our life-saving hospitalization kits that protect and prepare you for a planned or unplanned hospital stay.

For more information, please call our bilingual helpline for the latest information on medications, treatments and tips at 1.800.4PD.INFO (1.800.473.4636). Visit www.parkinson.org.



SUPPORT

Counseling

By Isabel P. Johnson, MA

The diagnosis and journey of Parkinson's can be both challenging and stressful. For some, the emotional consequences and adjustment to this disease are alleviated by counseling. The counseling program at the PD&MDC offers supportive mental health services for both the patient and the care partner. The Parkinson Council underwrites this service, which is staffed by experienced clinical social workers. The goal for the recipients is a healthy adjustment to living with PD.

For more information, contact the counseling line at 215.829.6688.

Care Partners' Workshop

By Patty Davis, LCSW

Caring for a loved one with Parkinson's can be stressful, physically demanding and isolating. The Supportive Older Women's Network (SOWN) telephone workshop connects PD care partners through teleconferencing in the comfort of their own home. Here they form connections with others, share common experiences and knowledge of PD resources.

For more information, please contact Patty Davis, LCSW, senior social worker, at Pattydavis@sown.org or 215.487.300, ext. 25.

Patient Support Groups

By Yuliis Y. Bell, MSW

Social Worker/Outreach Coordinator, PD&MDC

The PD&MDC at Penn promotes 48 support groups in Pennsylvania, New Jersey and Delaware. There are groups specifically for women and groups that support those who have opted for DBS (deep brain stimulation) surgery. We're very proud of our culturally specific groups that serve our Asian-American PD population and the EMPower'D Support Group, which stands for Engaging Minorities with Parkinson's disease. There's something for everybody!

For more information, please contact Yuliis Bell at 215.829.6500.



EVENTS—MORE WAYS TO GET CONNECTED

DANCE *for* PD®

Dance for PD Demonstration Class For persons with Parkinson's and their families, friends and care partners

Thursday, April 4, 2019 | Gwendolyn Bye Dance Center
3611 Lancaster Ave., Philadelphia, PA 19104

Free, but registration is required. Space is limited. Contact The Parkinson Council at 610.668.4292 or info@theparkinsoncouncil.org for more info.

Stand Up for Parkinson's Comedy Night at Punchline Philly

Tuesday, April 9, 2019 | Punchline Philly
33 East Laurel Street, Philadelphia, PA 19123

Featuring Aunt Mary Pat, Ken Kolaski, KD Cole, Carrie White, and Josh Kosh. Tickets on sale via LiveNation.com.



Trivia Night

April 27, 2019, 6:30-9:30 pm
Mishkan Shalom Synagogue
4101 Freeland Avenue, Philadelphia, PA 19128

Call 610.668.4292 to purchase tickets or for more information.



The 19th Annual Jane C. Wright Patient and Caregiver Symposium

May 3, 2019, 9:30 am | The Hilton on City Line Avenue
4200 City Avenue, Philadelphia, PA 19131

Call 215.829.7273 for more information or to reserve a seat.

The Parkinson's Research Fair

May 22, 2019, 11:00 am - 1:00 pm
Fox Rehabilitation

7 Carnegie Plaza, Cherry Hill, NJ 08003

Call Myra Hirschhorn for more information at 609.304.5761.



Moving Day Southeastern PA

Sponsored by The Parkinson's Foundation

June 9, 2019 9:00 am -12:30 pm

Core Creek State Park
901 Bridgetown Pike
Langhorne, PA 19047

Call 732.639.1475 for more information.



The Parkinson Council's Golf Classic

Celebrating 20 Years

– Let's Sink Parkinson's Together

Monday, June 24, 2019
Huntingdon Valley Country Club
2295 Country Club Drive
Huntingdon Valley, PA 19006

Join colleagues and friends for a day of good, spirited competition while raising funds to support quality of life programs, research and comprehensive care. Email for info at golf@theparkinsoncouncil.org or call The Parkinson Council at 610.668.4292.



12th Annual Flip Flop Walk in Avalon

Saturday, July 13, 2019
Avalon Community Hall
3001 Avalon Ave., Avalon, NJ 08202

The Parkinson Council, in partnership with the Storbeck Family, is proud to celebrate the Flip Flop Walk in Avalon for the 12th year! Join us on the boardwalk for a family-fun day. All proceeds benefit The Parkinson Council. For information, email info@theparkinsoncouncil.org.



Victory Summit

Brought to you by the Davis Phinney Foundation

Saturday, August 24, 2019 | Philadelphia Marriott Downtown
1201 Market Street, Philadelphia, PA 19107

Call 215.829.5078 for more information.



Penn Medicine

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The Transmitter is published biannually to inform the public about Parkinson's disease and other movement disorders. The information contained herein is solely to raise awareness of developments in the field of movement disorders. Nothing written in this newsletter should be used as a guideline for treatment.

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The Parkinson's Disease and Movement Disorders Center is a Parkinson Foundation Center of Excellence.



Save **THE**
Date

OCTOBER 12
2019

7:45 AM – 10 AM

A WALK TO
STAMP
OUT
PARKINSON'S
THE PARKINSON COUNCIL



ALL-DAY access to The Philadelphia Zoo

Join the oldest and largest community gathering devoted to raising funds in support of local families impacted by Parkinson's. If you would like to participate or have questions, please email walk@theparkinsoncouncil.org.