

# **The Center for Parkinson's Disease**

Winter Newsletter

# **Administrator's Note**

April is right around the corner, and with it comes **PD Awareness Month**, a time to support Parkinson's research, as well as an opportunity to celebrate our amazing community here on the East End of Long Island. PD Awareness events are listed in the newsletter below, and I do hope you will join us!

The Center for Parkinson's Disease remains committed to providing wellness and support programs for the PD community. In addition, we currently have nine allied healthcare providers enrolled in the highly regarded Allied Healthcare Team Training through the Parkinson's Foundation. Our rehabilitation team is working to not only elevate PD knowledge and expertise, but to also streamline team communication to create a seamless transition from rehabilitation services to community programs. As we work to provide the best possible care, we welcome your feedback and suggestions. Please reach out anytime.

I look forward to seeing many of you at our PD Awareness Month events in April!

With gratitude, Sarah

## Sarah Cohen, Administrator

Center for Parkinson's Disease Stony Brook Southampton Hospital

# PD Awareness Month Events

## **PD Awareness Month Walking Challenge**

Back by popular demand, we will once again be hosting a virtual PD Awareness Month Walking Challenge! Last year, our team walked over **2000 miles** in the month of April. This year we need your help to not only beat our personal best, but also to out-walk the **Southampton High** 

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#### School track team.

**Here's how it works:** During the month of April, you may log your steps (seated counts too!), miles or time walked each day using this **link**. At the end of the month, we will host an awards ceremony to honor our Parkinson's and high school walkers. Stay tuned for event details!

# Parkinson's Disease Awareness Month Lecture and Panel Discussion

Thursday, April 27, 4:00 – 5:30pm via Zoom

Parkinson's Disease: Non-motor symptom management is a lecture and panel discussion organized and offered by the Long Island PD Coalition, an institutional collaboration between Stony Brook Southampton Hospital, Stony Brook Medicine, New York Institute of Technology College of Osteopathic Medicine and the Friedberg JCC in Oceanside. This free, virtual event will include the following speakers:

- Dr. Diane Saulle, CCC-SLP, BCS-S, NYIT Adele Smithers Parkinson's Treatment Center: *The Impact of Parkinson's Disease on Speech and Swallowing.*
- Dr. Guy Schwartz, MD, Director, SBM Parkinson's and Movement Disorder Center: *Parkinson's disease hallucinations and delusions: causes, treatment and prognosis.*
- Dr. Ian Storch, DO, Northwell Health: *Parkinson's and the GI tract: Everything you want to know and were embarrassed to ask.*

You may register **here**, or contact Sarah for more information: (631) 644-6667.

## Unity Walk

Saturday, April 22, 8:30am, Central Park

The 2023 Unity Walk will be held in Central Park on Saturday, April 22 starting at 8:30am. The Unity Walk brings together over 11,000 participants from all over the country with a shared goal - to find a cure for Parkinson's disease. All of the proceeds support Parkinson's research. You may join the Stony Brook team by registering **here**.

#### 5K Run/Walk for PD and MS

Sunday, April 2, 2023, 9am, Heckscher State Park, NY

Organized closer to home by Stony Brook University Doctor of Physical Theray students, this family friendly event will raise money for local PD programs. You may join our team by registering **here** and clicking on 'join team.'

# Program Updates

## A Matter of Balance for Parkinson's (AMOB-PD)

A Matter of Balance for Parkinson's is in full swing. The workshop is a PDspecific translation of the nationally acclaimed, evidence-based A Matter of Balance falls prevention program, which emphasizes practical strategies to reduce fear of falling and increase activity levels. Participants are learning how to increase strength and balance through exercise, setting realistic goals to increase activity and making adjustments to reduce fall risk factors. The 9-week, virtual program is designed specifically for people living with Parkinson's disease and their care partners.

Our pilot group continues to learn from one another, sharing attitudes and beliefs about falls and brainstorming falls prevention solutions. We are grateful for their reflections and innovative solutions:

As older adults the greatest risk we must face every day is danger of falling. Walking was something we did automatically, didn't have to think about when younger. We now must deal with different challenges in every new situation. Walking requires concentration. . . an awareness of our surroundings. Irregularities in pavement or carpeting become obstacles we never noticed before. Even thresholds in entryways can be a tripping hazard to watch out for. Those among us with balance problems are particularly vulnerable.

The AMOB-P program has been an enlightening way to share our experiences and learn how others are coping. The format is particularly suited for remote participation on Zoom.

- Gordon

If I cannot walk there, then I will ride!

- Courtney



If you are interested in joining a future workshop, please contact Ragan Ingram at: ragan.finalborgo@stonybrookmedicine.edu



## **Paint at the Parrish**

Paint at the Parrish is an arts program developed in collaboration with the Parrish



Art Museum. Each month, we enjoy art and discussion in one of the museum's galleries, followed by a hands-on multimedia arts project in the studio. Paint at the Parrish will be held on Thursday, March 16, and we would love to have you join us! You may register **here** or call: (631) 726-8800.

## **Care Partner Support Group**

Last month, Andrea P. Mottola of Mottola Law Office, LLC attended our monthly Care Partner Support Group to share her expertise in the area of Estate and Long-Term Care planning. Andrea provided a thorough overview of documents pertinent to long term care planning including: Power of Attorney, Living Will and the Medicaid application process. The group had time to ask questions and received detailed documents with additional information on each topic discussed.

A very big thank you to Andrea!

If anyone would like to receive the presentation handouts, please contact Ragan at: **ragan.finalborgo@stonybrookmedicine.edu**.

The SBM Parkinson's Care Partner Support group is held on the third Thursday of each month from 2:00 – 3:00pm. To register for the March session, click **here**.

# **Research Updates**

Students and faculty at the New York Institute of Technology's Physical Therapy program invite you to participate in an online survey. The purpose of this survey is to gain a better understanding of the interest in, and barriers to, the Parkinson's community with respect to participating in outdoor recreation activities such as hiking, mountain biking, fishing, skiing, canoeing, surfing, or bird-watching. You may access the survey questionnaire **here.** 

Questions? Please contact Rosemary Gallagher, PT, DPT, PhD, Principal Investigator at **rgalla01@nyit.edu** or the Institutional Review Board, NYIT at 516-686-7488.

# In the know...

Parkinson's Foundation Science News: AI predicts Parkinson's

Currently, there is no one test that can diagnose Parkinson's disease. However, according to the Parkinson's Foundation Science News blog, an article published in Nature Medicine, 2022 suggests scientists might be able to diagnose and track disease progression using artificial intelligence to monitor nighttime breathing patterns. You may learn more, and find links to the original article **here**.

**Dance for PD,** a program of the Mark Morris Dance Group, continues to offer virtual, live classes. Don't miss this **interview** with David Leventhal, Program Director to learn more about the program. You may access their schedule and program of events **here**.

All of our programs are offered at no charge, thanks to the generosity of our community. Please consider making a donation to the Center for Parkinson's Disease. **Donate here.** 



Stony Brook Southampton Hospital

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