February 2024 Volume 9 Issue 2

# **Parkinson Press**

Parkinson Partners of NW PA, Inc. (814) 899-3030 www.parkinsonpartners.org

## "You are not alone."



Parkinson Partners' Mission Statement: To encourage, educate and support those with Parkinson's disease, their caregivers and loved ones as they cope with the challenges of disease. Exploring better resources, services and outcomes for people with PD.

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Please remember Parkinson Partners in your estate planning. Your gift can ensure that local services and support continue for the Erie PD community.

## **Local Resources Open to All**

Speech and Language Services: PennWest University-Edinboro is home to the Governor George Leader Speech & Hearing Center where we offer speech and language therapy services for both children and adults. As part of our clinic, we offer the Parkinson's Voice Project's SPEAK OUT! ® and LOUD Crowd® Programs. The mission of this program is to help individuals with Parkinson's and related movement disorders to regain and maintain their speaking abilities. As Parkinson's is a progressive, degenerative condition, those with Parkinson's Disease oftentimes find the muscles involved in both speaking and swallowing can become weak. During our speech sessions, we encourage our members to not only speak with intent but live with intent in their daily lives. The SPEAK OUT! ® program consists of individual therapy sessions followed by membership in the LOUD Crowd®- a group maintenance program. The key components that make up the LOUD Crowd® program are daily vocal exercise, the conscious use of INTENT, ongoing instruction from a speech language pathologist, and support and encouragement from care partners and peers. If you or someone you know would be interested in this therapy program at no cost - please contact the Governor George Leader Speech & Hearing Center at (814)-732-2433 or email at leaderenteredn@pennwest.edu. You can also contact Chris Shumaker, Clinical Instructor, at PennWest for additional information at <a href="mailto:cshumaker@pennwest.edu">cshumaker@pennwest.edu</a>.

Memory Café--1st & 3rd Thursday of each month – 1 to 3 p.m. Caring for a person with Alzheimer's disease or dementia of any kind, can take its toll physically, emotionally and financially. Opportunities for all involved to enjoy the company of others in a relaxed and friendly atmosphere are few. A Memory Café provides just such an opportunity, and Erie now has such a place. The Unitarian Universalist Congregation of Erie hosts a Memory Café on the first and third Thursday of each month from 1 to 3 p.m. The church is located at 7180 Perry Highway in Erie, just one mile north of the I-90 & State St. interchange. Attendance is free and open to the public. With dementia, caregivers and the afflicted have little opportunity to experience each other socially. At the Memory Café, participants can socialize, learn and share their experiences with others in similar circumstances in a stigma-free environment. More than 5 million Americans are living with dementia, and support is greatly needed in our community. The friendships and joy that resonate from these cafés bring light and life to both people with dementia and their caregivers. Reservations are preferred but not necessary and can be made by calling 814-864-9300.

Presbyterian Senior Care Network Adult Day Program is life-enhancing to your loved one with dementia—and to you! You might already know firsthand: Alzheimer's disease is life-changing for the person with the diagnosis—and for the people who love them. So, having a helping hand when you need it is key to reducing stress and feeling well-balanced. At *Woodside Place* at Manchester Commons in Erie, PA, adult day care support is ready to help. Call 814-838-9191 for more information. What is adult day care? It's a special program for people living with Alzheimer's or other dementias that gives them opportunities to socialize and participate in activities in a safe environment. The full- or half-day adult day program at Manchester Commons could be just the support you both need if: You are a full-time caregiver: Adult day care can give you a much-needed break: While your loved one is at Woodside Place, you'll have time to rest, run errands or finish other tasks. You work during the day: Adult day care at Woodside Place can help you balance a job with caregiving duties. You want a safe, caring environment for your loved one: Adult day care at Woodside Place is the chance for your loved one to share time with peers and engage in activities, such as music, exercise, and safe, supervised outings.

**Continued on Page 4** 

### **News and Notes**



Meeting Cancelations: Now that winter is upon us, there is always the possibility that we will need to cancel a meeting due to weather. If we need to cancel, an email will be sent out alerting the community to the change. If you are not signed up for our email alerts, sign up today:

https://www.parkinsonpartners.org/home-2/contact-us/ We will also post the information on our Facebook page. If in doubt, you are always welcome to call the office at 814-899-3030.

#### Note About the Newsletter:

Just a reminder that the newsletter is delivered several. different ways: via email, on Facebook, via the website and by US mail. US mail takes the longest when considering printing and mailing times. Sometimes deadline/dates will have passed by the time some people receive the newsletter. I try to provide dates in at least two newsletters so you can add events to your calendar. I encourage you to also sign up for our email alerts for updates, especially weather-related cancelations, and more timely updates.

Our sympathy to the families of **Patty Mattis** and **Ron Roscinski** who recently passed away. We send our prayers to their families.

MAY YOU FIND THE
SURPLINE
TO FACE TOMORROW
IN THE COND THAT
SURROUNDS YOU TO DAY

## **Home PD Exercise Options Including Local Options**

Here are some at-home exercise options. The links are LIVE so if you are reading this newsletter online, just right click on the link and you'll be taken directly to the website. Remember to consult your physician before starting any new exercise program.

<u>Local</u>: Our Purposeful Movement and Wellness team including Gannon University Professors Dr. David LeVan, OT and Dr. Courtney Roca, PT and retired Professor Tom Hudson, PT along with graduate OT students Taylor Mandley, Lily Bargabus, Ashley Tomasko and Brianna Murosky, Aurora Brown, Lauren Greenlee, Caitlin McKee, Carrie Pratt, Claire D'Amore, Alexandra Gyory, DPT student Brandi Tirado and Radiological Sciences student Riley Fanaro, have created some home exercise videos that you can access on YouTube:

- **NEW**: <a href="https://youtu.be/DKXrGoaizJ8">https://youtu.be/DKXrGoaizJ8</a>
- NEW: https://youtu.be/C7Y8rLMUjzA
- Winter 2021: <a href="https://youtu.be/HqUZ7CyOcjA">https://youtu.be/HqUZ7CyOcjA</a>
- Winter 2021: https://youtu.be/shnsCH9rqC8
- Fall 2020: <a href="https://youtu.be/mowyEAf7qK0">https://youtu.be/mowyEAf7qK0</a>
- Fall 2020: <a href="https://youtu.be/PZ62">https://youtu.be/PZ62</a> U84Hq8
- Fall 2020: https://youtu.be/fFkGBU-vJ90
- Summer 2020 Part 1: https://youtu.be/lcsBTPoX1dU
- Summer 2020 Part 2: https://youtu.be/I8pjybERaxA
- Spring 2020 Part 1: https://youtu.be/-ud1erTZcmA
- Spring 2020 Part 2: <a href="https://youtu.be/2XiSyoiXBfM">https://youtu.be/2XiSyoiXBfM</a>

#### Seated:

Power for PD:

https://www.voutube.com/channel/UC9QTes9SMZKbSzDS-nvhr3q/videos

 Sit and Be Fit: https://www.youtube.com/user/SitandBeFitTVSHOW/videos

#### Seated and Standing:

- Unique Physique Fitness
   Center: <a href="https://www.facebook.com/watch/UniquePhysiqueFitnessCenter">https://www.facebook.com/watch/UniquePhysiqueFitnessCenter</a>
- APDA: <a href="https://www.apdaparkinson.org/free-online-exercise-and-therapy/?eType=EmailBlastContent&eld=4c51adf3-809e-4c84-b67a-623c6512cf34">https://www.apdaparkinson.org/free-online-exercise-and-therapy/?eType=EmailBlastContent&eld=4c51adf3-809e-4c84-b67a-623c6512cf34</a>

<u>LIVE Classes from Parkinson Foundation of Western PA:</u> remember you must pre-register to attend these live classes. There is a large variety of options, so we encourage you to check them out. Thank you, PFWPA for including our group.

https://pfwpa.org/exercise/

## **Best Wishes for those with Special Celebrations**

Happy Birthday and Happy Anniversary to our members!

To have your birthday or anniversary added to our list call 814-899-3030 or email: info@ParkinsonPartners.org

<u>February</u>. 16—Corrine Dyakon

#### **March**

2—Dave Barron 4—Mike DiNunzio 20—Carolyn Bard 23 – Phil & Denise Wahler Anniv. 25—Chuck Leone 31 – Lynne Gotham







Parkinson's Progression Markers Initiative

The Parkinson's Progression
Markers Initiative (PPMI) is the
premier Parkinson's research study
from The Michael J. Fox Foundation.

PPMI aims to better understand how brain disease starts and changes.

Now it needs you.

#### **Benefits of Participation**

- You play a role in better health and care for all
- You get access to world-class Parkinson's experts
- You contribute to the most robust data set in Parkinson's research
- Once enrolled, PPMI covers the cost of study-related travel
- You may be compensated for completing study visits

PPMI is open to anyone over age 18 in the U.S., but certain groups are especially needed:

V<sub>?</sub> Recently Diagnosed with Parkinson's Disease

Medical centers are enrolling people with Parkinson's disease (PD) who have been diagnosed within the last two years, and who are not yet taking standard PD medications.

- Age 60+ without Parkinson's Disease
  Age is a risk factor for PD, and so is smell loss.
  PPMI asks everyone not diagnosed with PD,
  age 60+, in the U.S. and Canada to take a
  scratch-and-sniff test.
- Act Out Your Dreams

REM sleep behavior disorder (RBD) is a condition that causes some people to punch, kick or yell while they sleep. It may be a risk factor for brain disease.

18+ Anyone Age 18+ in the U.S.

Anyone age 18 and older in the U.S. — with and without Parkinson's — can join PPMI. Share valuable data on health and wellness in our online platform.

Find your PPMI starting point at michaelifox.org/ppmi

## Parkinson Partners of NW PA, Inc.

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PHONE: 814-899-3030

E-MAIL:

info@ParkinsonPartners.org

DONATIONS:
Checks should be made
payable to "Parkinson
Partners" and mailed to the
address above. Donations can
also be made via PayPal on
our website.

## **Local Resources Continued from Page 1**

Encompass Health Walking Assessment: If you are interested in participating in an independently led community walking group, Encompass will perform a screening at the hospital to match participants into groups of similar function. This will help you find a walking partner with similar goals and abilities so you can be matched up more easily. If interested, please call Ryan Chambers at Encompass Health at (814) 878-1201, leave your name and phone number and you will be contacted once dates and times of the screening are determined. If there is enough interest, we will hold a Walking Meet and Greet Kickoff to help with introductions and to celebrate everyone's commitment to exercise. HINT: exercise is the one thing we know that can help slow PD's progression. Let us help you kick off a new commitment to moving and also connect you to others in the PD community. Thank you, Encompass Health, for your continued commitment and support of the PD community! We are so grateful!

A Matter of Balance: Learn to manage concerns around falling and overcoming the fear of falling. During this 8-week course, you will work as a group to overcome the mental and physical fears of falling. The class incorporates exercises for strength and flexibility to improve your balance. As well as an at personal survey for fall hazards in your home and other surroundings. For more information about upcoming sessions visit <a href="https://www.ymcaerie.org">www.ymcaerie.org</a> or call 814-899-9622.

Parkinson Partners of NW PA, Inc. PO Box 10547 Erie, PA 16514

Like us on Facebook!



We're on the Web!

See us at:

www.ParkinsonPartners.org

DISCLAIMER: The material presented in this issue is solely for the information of the reader. It is not intended for treatment purposes, but rather as a basis for discussion with the patient's physician.

## **Support Group Meeting Schedules**

See our upcoming meeting schedule. Remember: all events are also listed on our Events Calendar on our website including live links to Zoom meetings. **Make sure to sign up for our emails so you are alerted to any last-minute weather cancelations.** 

#### **ZOOM MEETINGS:**

- Parkinson Partners Support Group Meeting via Zoom on Wednesday, February 21st and March 6th and 20th at 1:00 PM. Join Zoom Meeting: https://zoom.us/i/93010770942?pwd=bzhTYTgxVEIXV0pONnYwbEt5TnZzZz09
- Caregiver Only Zoom Meeting on Thursday, February 22nd and March 28<sup>th</sup> at 1:30 PM. Join Zoom Meeting: <a href="https://us06web.zoom.us/j/96391675305">https://us06web.zoom.us/j/96391675305</a>

#### **IN-PERSON MEETINGS:**

- Evening PD Support Group will be held on Tuesday, March 12<sup>th</sup> at 6:00 PM at Springhill Retirement Community, 2323 Edinboro Road (Community Room). We will have a pot luck supper so please RSVP so we can plan. All are welcome.
- Care Partner Only Lunch: Join other Care Partners for conversation at Wegman's Café, 6143 Peach St. on Monday, Feb. 26<sup>th</sup> and March 25<sup>th</sup> at 11:30 AM.