

June 2023

Volume 8 Issue 6

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.

Mead Transportation Grant and More

In 2020, we were pleased to announce a new grant in memory of past board member Sandra Mead, aimed at helping those with transportation needs.

Sandra's three children generously started a fund in her memory, providing \$50 gift certificates to Hansen's Errand Services to help those with PD receive transportation or errand services. The program is open to those with a diagnosis of Parkinson's disease or Parkinsonism and who live in Erie County.

We have been a little surprised that the program has not been utilized as much as we anticipated. When our community is surveyed, typically transportation is one of the top concerns. We know many may have benefited from increased pick-up and delivery services locally but we know there must still be a need.

Please keep this program in mind as you start to venture out with summer activities or if you need assistance getting groceries, medications etc. Our goal is to provide you with the opportunity to have access to transportation, to attend medical appointments, social gatherings, shopping or whatever you need without having to rely on family or friends for a ride. It can also be used to have the service run an errand for you.

If you are interested in this program, please call or email us to request a grant application. An application can also be downloaded from our website: <https://www.parkinsonpartners.org/home-2/programs/> Once approved, a \$50 gift certificate will be sent to the recipient that they can use any time by calling Hansen's to schedule the service.


If you already received a gift certificate, you are welcome to contact us and let us know you'd benefit from another. We'll be happy to help you out again.

We are also hoping to expand the program to provide small grants for equipment not covered by insurance (specialized eating utensils, writing utensils etc.). We understand these items can provide many with great independence and ease in performing every day tasks. Be on the lookout for more information when the program launches in the fall.


We once again extend our thanks to Chris, Karen and Eric Mead (and Eric's girlfriend Cathy) for this special gift in memory of their mom as a nod to her independent spirit. Their generosity will help so many in our community.





News and Notes

 **Mark Your Calendars:** Lake Erie Speedway will be hosting Great Lakes Cars and Coffee, a car show in tribute to Elmer "Porky" Chambers on Sunday, July 9th from 8:00 AM-noon. 50% of the gate proceeds will be split between Parkinson Partners and the Alzheimer's Association. For more information go to:

<https://www.lakeeriespeedway.com/great-lakes-cars-coffee>

 **Volunteers Needed:** Lake Erie Speedway has asked if we can supply some volunteers to help with parking at the Cars and Coffee event on July 9th. They will need people from 7-10:30 AM so any time you can give would be appreciated. Let Lynne know if you can help.

 **Social Clubs with Small Games of Chance:** Did you know that clubs that offer small games of chance in PA are required to donate some of the proceeds to charity? If you or someone you know is a member a social club, we would be very grateful if you would suggest Parkinson Partners as a possible recipient of the proceeds. As a small nonprofit, we rely on donations, fundraisers and grants in order to survive, and we continue to look for new ways to secure funds, all while the need for our services continues to grow, due to the increase in PD diagnoses. We'd appreciate your help and welcome ideas you may have for fundraising ideas.

 **Donation Options:** When you go to our website donation page, you will now find separate options to donate via PayPal or by credit/debit cards. We hope this option will make it easier for you to donate online. We also gratefully accept checks made payable to Parkinson Partners of NW PA, mailed to PO Box 10547, Erie, PA 16514. Thank you for your support!

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.

Local: 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:** <https://youtu.be/DKXrGoaizJ8>
- **NEW:** <https://youtu.be/C7Y8rLMUjzA>
- Winter 2021: <https://youtu.be/HqUZ7CyOcjA>
- Winter 2021: <https://youtu.be/shnsCH9rqC8>
- Fall 2020: <https://youtu.be/mowyEaf7qK0>
- Fall 2020: https://youtu.be/PZ62_U84Hq8
- Fall 2020: <https://youtu.be/fFkGBU-vJ90>
- Summer 2020 Part 1: <https://youtu.be/lcsBTPoX1dU>
- Summer 2020 Part 2: <https://youtu.be/l8pjybERaxA>
- Spring 2020 Part 1: <https://youtu.be/-ud1erTZcmA>
- Spring 2020 Part 2: <https://youtu.be/2XiSyoixBfM>

Seated:

- Power for PD: <https://www.youtube.com/channel/UC9QTeS9SMZKbSzDS-nvhr3g/videos>
- Sit and Be Fit: <https://www.youtube.com/user/SitandBeFitTVSHOW/videos>

Seated and Standing:

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

LIVE Classes from Parkinson Foundation of Western PA: 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://pfpwpa.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

June

15—Peggy Trichel
19—Patricia & Michael Hall Anniv.
26—Mike Hall
29—Deborah Hakel
30 – Paul Goodwin

July

1—Carl Asbury
8—Marge Montgomery
16—Carl & Sally Asbury Anniv.
18—Paul Hakel
20—Bob & Linda Sensor Anniv.
21 – Pat Gray



Make Plans to Have a Great Vacation: Traveling with Parkinson's Disease

By Melinda Douglas, nurse practitioner and freelance health writer

Whether you want to travel locally or internationally, following these simple suggestions can help you to travel safely, be as comfortable as possible, and have a great time with family and friends. Many families have found taking small local trips can build confidence for an individual living with Parkinson's Disease (PD) but it can also reassure caregivers that the trip will be enjoyable and not overwhelming. "Cassandra Brooklyn states, "Small trips may include lunch with friends, attending a concert in the park, or visiting a local zoo. You will be able to identify the level of comfort using a walker or wheelchair, using public bathrooms and navigating the uneven rock, grass and wood-chipped terrain in outdoor spaces." This can establish comfort levels before going on a longer trip. Plan some restful time and pace yourself. Consider purchasing travel insurance in case you need to cancel.

Medications will continue to work in hot or cold weather but remember to stay hydrated.

If you are traveling to different time zones set alarms as reminders to take medications as your regular times. Keep all medications in bottles and have extra doses on hand if the trip is extended or delays occur. Have a note from the doctor listing all your medications, along with the dose and timing of medications. This will be especially useful if traveling overseas and going through customs. If flying, keep medications in your personal bag. Have a backup kit in your checked baggage.

Notify the airline in advance you will need assistance. You can inquire about early boarding, seating arrangements near exits and order your wheelchair. "Carry-on luggage limits do not apply to medical supplies, equipment and mobility aides." If you have a Deep Brain Stimulator (DBS) some additional planning can offer peace of mind during your travels. Make sure to pack your charger and programmer. Ask your doctor for a phone number for a DBS specialist at the travel destination in case you need help. Have insurance information up to date in case you need medical care on your trip. Be ready to show your DBS patient ID card if requested by security. It is suggested to apply for TSA prescreening ahead of your flight. Security equipment may turn off the DBS so it is not advised to go through a metal detector but instead ask for a public screening or pat down. After leaving the security area, check to make sure the stimulator is turned on.

Fatigue or sleeping issues may worsen during your travels especially in changing time zones. Try not to plan activities the day you arrive at your destination. "Unfortunately, there's no way to predict how Parkinson's will react to travel." Because weather extremes can impact PD, stiffness and pain may increase and it could be difficult to regulate body temperature. Make opportunities to stay active indoors during weather extremes. Each individual is unique so try to plan travel during times of the year when symptoms are less severe. When you reach your destination, search out local PD support groups so you can have the opportunity to make lasting connections. "Don't let the unpredictability of Parkinson's stop you from attending important events, visiting family members and having fun." Most important of all, enjoy yourself and don't worry. Planning ahead can give everyone peace of mind so you have an enjoyable vacation.

Editor's Note: Melinda Douglas, the article author, reached out to Parkinson Partners and volunteered to write some articles for our newsletter. We are so grateful to her for sharing her time and talents with us. If you have story ideas for Melinda, please let us know.

References:

Cassandra Brooklyn, USA TODAY. *From local adventures to a family road trip: Here's how we tested my mom's travel needs.* April 7, 2022.

Kate Kelsall, MSW, Brain Health Community. *Traveling Tips for Long Road Trips with PD – Shake, Rattle and Roll.* June 9, 2017.

Michael J. Fox Foundation. *Tips on Traveling with Parkinson's Disease.* June 30, 2014.

Jamie Askari. Parkinson's News Today, A Bionews Brand. *Traveling with Parkinson's disease is predictably unpredictable.* May 9, 2023.

**Parkinson Partners of
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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.

PARKINSON PARTNERS AND SPRINGHILL PRESENT

STILL
THE APPLE TV+ MICHAEL J. FOX DOCUMENTARY

**WHAT HAPPENS WHEN AN INCURABLE OPTIMIST
CONFRONTS AN INCURABLE DISEASE**

Wednesday, June 28th at 6:30 PM

Springhill Senior Living
2323 Edinboro Road

Light refreshments will be provided.



RSVP 814-899-3030 OR
INFO@PARKINSONPARTNERS.ORG

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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

Remember: all events are also listed on our Events Calendar on our website including live links to Zoom meetings.

ZOOM MEETINGS:

- **Parkinson Partners Support Group Meeting** via Zoom on **Wednesdays, June 14th and 28th at 1:00 PM.** Join Zoom Meeting:
<https://zoom.us/j/93010770942?pwd=bzhTYTgxVEIXV0pONnYwbEt5TnZzZz09>
- **Parkinson Caregiver Only Support Group Meeting** via Zoom on **June 22nd at 1:30 PM.** Join Zoom Meeting:
<https://zoom.us/j/96391675305?pwd=ZHqxbXhnRS9GTGpKdlpTeURHSiJJdz09>

IN-PERSON MEETINGS:

- **Wegman's PD Support Group will be off for the summer.** Meetings will resume in September. We will be moving the meetings to Springhill Senior Living or Panera. If you have a preference, let us know.
- **Care Partner Only Lunch:** Join other Care Partners for conversation at **Sara's at Presque Isle (moved for the summer) on Monday, June 26th at 11:30 AM.**