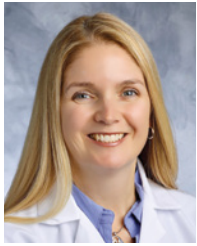


Parkinson's Disease Center of Excellence Newsletter



Team Member Spotlight



Ellen Walter, APRN-CNP

Ellen Walter is an acute care nurse practitioner in the Center for Neurological Restoration at Cleveland Clinic. She graduated summa

cum laude from Kent State University with a Bachelor of Science in nursing and received her Master of Science in nursing from Case Western Reserve University Frances Payne Bolton School of Nursing.

She has worked for the last 25 years in neurology and neurosurgery practices, which has involved caring for individuals who have had deep brain stimulation (DBS) surgery for the treatment of their movement disorder. She currently works with a team of specialists in the Center for Neurological Restoration's Section of Movement Disorders. Her position there, in addition to caring for those who have had DBS, involves a comprehensive approach to caring for individuals with Parkinson's disease, dystonia, essential tremor and other movement disorders. She has presented at both regional and national meetings on various topics and has created numerous programs to benefit those with movement disorders and their loved ones.

Q&A with Ellen Walter, APRN-CNP

I see a movement disorders specialist and take the medication I am prescribed. What else can I do to help my Parkinson's disease?

In our last newsletter, Erin Zinn, APRN-CNP, emphasized the importance of exercise when one has Parkinson's disease, so engaging in exercise by yourself or with others and doing an activity you enjoy is very important. Eating a healthy diet and getting good sleep are also necessary and reaching out to a healthcare provider if you are struggling with these can help.

Empowering yourself with accurate information is also crucial. Attending educational events is one way of getting good information and being around others who are also looking to learn more about Parkinson's disease. Every year, Cleveland Clinic presents a free, education-driven, one-day event called EMPOWER U that provides a positive, interactive approach to helping individuals with Parkinson's disease take control of their disease, maintain their identity and improve their quality of life.

There are also several reputable organizations that provide invaluable information about Parkinson's disease online, including the Parkinson's Foundation (parkinson.org), The Michael J. Fox Foundation (michaelfox.org) and The American Parkinson's Disease Association (apdaparkinson.org)

I heard EMPOWER U will be different this year. What does this mean?

This year we are holding the EMPOWER U EXPO, a unique and interactive health fair for people with Parkinson's disease and their friends and family. In the past, EMPOWER U has been a traditional symposium with a set schedule that all attendees followed. At the EMPOWER U EXPO, people "choose their own adventure" and attend the sessions of greatest interest to them. There will be two rooms with educational topics running all day discussed by local experts and one room with exercises led by local exercise leaders. We will have a Care Partner Corner with resources and information for care partners and several other exhibitors showcasing local and national resources, new medications and research, surgery options and other topics related to Parkinson's disease. Many of the exhibits will be interactive. There will also be an opportunity to meet with others who have Parkinson's disease and eat delicious food at different times throughout the day. You can come by yourself or bring family and friends who want to learn more about Parkinson's disease. You can register today by going to clevelandclinic.org/empoweru2023. For questions, call 216.444.0998 or email CNRCOE@ccf.org.

How can I find exercise programs and support groups near me?

The Ohio Parkinson's Foundation Northeast Region (OPFNE) is a great resource to help people find exercise and support groups. They also hold an annual symposium and, on their website, they list other local Parkinson's disease events as well. Also on their website, you can find general information about Parkinson's disease and all of the Parkinson Education Program (PEP) newsletters archived since 2017. The PEP News is a well-known newsletter in Northeast Ohio sharing the latest on Parkinson's disease research, various related topics, information on local events and more. For further information visit the OPFNE website at ohparkinson.com.

Fun Facts about Ellen Walter, APRN-CNP:

I grew up one of six kids in a blended family. There were three girls and three boys, so we were often referred to as The Brady Bunch. As a result of this big family, I now have 16 nieces and nephews who live throughout the country.

I used to love to scuba dive with my favorite being drift diving in Cozumel, Mexico, but I became a wimp after my daughter was born and have not done any diving since.

I was once searched by the Secret Service when I got out of an elevator to go to a hotel exercise room because unbeknownst to me, I was going to be exercising in the same room as the President of the United States. There ended up being only a handful of us in a very small gym, so it was an interesting experience.

Research Highlight

DiSCERN: Advanced PD Therapy Candidacy and Evaluation System

PI: Benjamin Walter, MD

Contact: Julia Kosco – 216.444.6626 or koscoj@ccf.org

The purpose of this study is to design, develop and clinically assess DiSCERN (a software application system) for identifying patients with Parkinson's disease who would benefit from advanced therapies and determining when advanced therapy recipients need therapy adjustments. The DiSCERN system is a continuous recording system that includes a smartphone app and wrist-worn smartwatch to measure and monitor physical motion and context-aware activity. Study activities include questionnaires/surveys, assessments and home monitoring. Compensation provided.

Parkinson's Disease Center of Excellence Resource Center

Do you know that the Parkinson's Foundation has a helpline staffed by nurses, social workers and health educators to support you and answer your questions? You can call 1.800.4PD.INFO (1.800.473.4636) Monday through Friday from 9 a.m. to 7 p.m. or email Helpline@parkinson.org anytime. They can provide information and answer questions in English or Spanish about living with Parkinson's disease, clinical trials, fitness and rehab therapies, care partner concerns, and many other topics. They can also make referrals to local resources (exercise programs, support groups and Parkinson's disease specialists) and to organizations that may provide financial assistance when it is needed to get the prescribed care.



Parkinson's Disease Inpatient Program



Shannon Shaffer,
APRN-CNP

The Parkinson's Disease Inpatient Program, directed by Benjamin Walter, MD, aims to identify individuals with Parkinson's disease as they are admitted to the hospital for any reason to help prevent medication errors and exacerbation of Parkinson's disease symptoms while the patient is hospitalized. The program is offered at Cleveland Clinic main campus and is staffed by two movement disorders nurse practitioners: Shannon Shaffer, APRN-CNP, and Patricia Clark, APRN-CNP. They review the patient's home medication regimen to ensure the hospital regimen reflects what they have been taking and identify any other factors that may put the patient at risk for decline. They also reach out proactively to the admitting team regarding contraindications and disease specific issues that may occur during the hospital stay.



Patricia Clark,
APRN-CNP

The program recently received a generous grant from the Parkinson's Foundation to allow our team to study the benefits of the program and find more ways that healthcare providers can make hospitalization a better experience. If you know of any planned hospitalizations, please notify the healthcare provider who treats your Parkinson's disease as it will allow the Parkinson's Disease Inpatient Program team to better serve you. While the goal is to offer these services at other locations in the future, the program currently is only available at main campus.

As a reminder, the Parkinson's Foundation offers an Aware in Care kit at no cost to help prepare you for hospitalizations. This can be ordered by calling 1.800.4PD.INFO (473.4636) or visiting parkinson.org/resources-support/hospital-safety-kits.



UPCOMING EVENTS

August 19 – Cleveland Clinic's 5th Annual EMPOWER U: Taking Control of Parkinson's Disease

Register: clevelandclinic.org/empoweru2023

September 10 – InMotion's Pals In Motion 7th Annual Walk

More information: beinmotion.org/pals

October 7 – Cleveland Clinic's 4th Annual Care Partner U

More information coming soon.

First Tuesday of every month – Young Onset Parkinson's Support Group (currently at 59 years and younger)

Register: clevelandclinic.org/yopdsupportgroup

Living Well with Parkinson's Disease Tip

From Afiah Hasnie, PsyD



Stay Connected: Social isolation can be one of several significant challenges for people diagnosed with Parkinson's disease, and it is a risk factor for worsening depression or anxiety. Reach out and connect regularly with family, friends and your community to create a diverse and strong social support network. Set a routine for phone calls, text messages, cards, visits or outings, and keep the plans flexible in case symptoms fluctuate. Maintain activities

that align with your personal life values and consider connecting with others through volunteer programs, fitness classes, book clubs, prayer groups and Parkinson's disease-specific support groups. Remember, you do not have to go at it alone!

If you would like to view our previous newsletters, visit clevelandclinic.org/empoweru.