



July 2024 Newsletter

Supporting people with Parkinson's disease, their families, and their care-partners in the CSRA

P.O. Box 31
Evans, GA 30809

Phone: 706-364-1662

Email: info@parkinsoncsra.org

Website: www.parkinsoncsra.org

Meeting Date & Time:

4th Tuesday of the month,
July 23rd, at 6 PM

Meeting Location:

Georgia Room at Brandon Wilde
4275 Owens Rd.
Evans, GA 30809

July 23rd Meeting: Open Discussion

Please join us on **Tuesday, July 23rd, at 6 pm**, in the **Georgia Room at Brandon Wilde** for an open discussion about how we are doing in our Parkinson's journey – our challenges, our victories, our concerns, our plans for days to come. We have heard a lot of speakers recently and can talk about what they have shared and any questions we have about those topics. We would also like to hear about any "life hacks" people are using to deal with the challenges of PD and of caregiving. Come and join us, bring your stories and questions, and be ready to tell us about the life you are living to the fullest. Please bring a covered potluck dish if you are able. We will provide chicken strips and beverages. Hope to see you there!



Caregivers Lunch: August 1st at Pizza Central

The monthly Caregivers Lunch is an informal gathering for Parkinson's caregivers to get together to share information and support each other. Please join the next Caregivers Lunch, which will be held at **12:30 pm on Thursday, August 1st**, at **Pizza Central, 526 N. Belair Rd. in Evans**. Please contact **Patti Kelley** if you will be attending by calling or texting **706-339-1799**. **Please note: There will not be a reminder email sent out for the August lunch. Please mark your calendars now!**

Join or Start a Team for POP Walk 2024 Today!

The **25th annual POP Walk** is less than 3 months away! The best way to support our organization is to start or join a team at POPWalk.org today. There are currently 4 teams registered:

- *The Undefeated* (Kathleen Reynolds' Top Team 2022) - givebutter.com/popwalk/the-undefeated
- *Team Pollock Searle* (Yours Truly) - givebutter.com/popwalk/team-pollock-searle
- *Fit & Fun* (Top Team 2023) - givebutter.com/popwalk/fit-fun
- *Day One Fitness* (Top Team 2020) - givebutter.com/popwalk/day-one-fitness

Register as an individual or create a team today by clicking the "fundraise" button. Or if you see your team listed, click "join a team." You can fundraise even if you can't attend or click "donate" to make a gift. This year we're upping the incentives for fundraising to include the POP Walk 2024 T-shirt and tickets to our amazing U-pick Raffle! \$25 = T-shirt, \$50 = T-shirt + 5 raffle tickets, \$100 = T-shirt plus 10 raffle tickets.



October 5th 2024

*First Baptist Church of Augusta
Event begins at 9 AM, Walk at 10*

POPWalk.org



Sponsors Needed

The CSRA Parkinson's Support Group cannot continue to fulfill our mission without the support of business sponsors. We have secured a few amazing business partners this year, but we need more to reach our goal and meet the needs of our community. If you have a business in mind that could be our partner in this effort, please let us know by email or phone, and we'll connect with them.

Seeking Parkinson's Artisans

We are excited to announce the return of the Parkinson's Artisans Silent Auction at POP Walk 2024. We are looking for donations of arts and crafts made by people with Parkinson's or works created in honor or memory of someone with Parkinson's. Works can be marked "not for sale" if you prefer. If you would like to display or donate, or want more information, please contact Patti Kelley by calling or texting 706-339-1799.



Aiken Parkinson's Support Group

The Aiken Parkinson's Support Group meets on the **first Thursday of each month (August 1st)**, at 1:00 p.m. in the Atrium of the James Rivers Education Building (E. Pine Log Rd. side of campus) of Millbrook Baptist Church, 223 S. Aiken Blvd. For more information, please contact **David Howard** at **803-502-4167**.

Lewy Body Dementia Support Group

The LBD meetings are held at **11 AM** on **3rd Tuesdays (August 20th)** at:

Lessie B. Price Aiken Senior & Youth Center
841 Edgefield Ave. NW, Aiken, SC

Contact Nancy Martin at nancy13lbd@gmail.com,
or Linda Lucas at linda@daybreakcare.com



Summary of the June 25th Meeting

At our June 25th meeting, Physician Assistant Elizabeth Prince-Coleman from the AU Movement Disorders Clinic spoke to us about how to understand the medications we take, how they are researched, and how to read and understand the material we are given about them. She spoke about how to realistically look at the "side effects" language on medications (which are broadly obtained) and to speak to our doctors about which side effects are more common in the real world. It was an excellent meeting and we enjoyed meeting Elizabeth and her husband who joined us.

Preview of the August 27th Meeting

At our August 27th Meeting, we will have presentations to help People with Parkinson's (PWP) and caregivers better understand what each is dealing with. We will begin the meeting with the potluck supper together, then split up into a PWP group and a caregivers group. We will have experienced caregivers speak with the People with Parkinson's about caregiving, the challenges caregivers face, and how to help make the caregiver's life easier and more rewarding. We will have People with Parkinson's speak with the caregivers to discuss what the experience of PD is like for the patient and the challenges their loved ones face every day.

Plan to End Parkinson's Act Signed by the President



According to the Michael J. Fox Foundation, “As of July 2nd, 2024, President Biden has signed the **National Plan to End Parkinson's Act** into law! The U.S. Department of Health and Human Services (HHS) will now establish an advisory council and the *National Parkinson's Project*, a first-ever federal initiative to prevent and cure Parkinson's disease, treat its symptoms and slow or stop its progression.” Learn more and find future updates about the National Parkinson's Project here:

michaeljfox.org/national-parkinsons-project

Scientists Identify Important Neuro Regulator

Scientists have discovered a new regulator, called Nuclear Hormone Regulator 49 (NHR-49), that may inform further study and open potential new therapeutic treatments to prevent the formation of toxic protein clumps, a hallmark of Parkinson's disease.

According to Parkinson's News Today, “Using embryos of the roundworm *Caenorhabditis elegans*, they found that NHR-49 is activated in response to stress and elicits pathways to promote cellular repair and proteostasis, the process by which cells maintain a healthy balance of correctly folded functional proteins and eliminate misfolded or damaged ones. The findings may hold promise for the development of new strategies to halt the progression of diseases like Parkinson's, which is marked by the loss of proteostasis. This loss is believed to contribute to the accumulation of toxic clumps of alpha-synuclein protein, a disease hallmark.”

Free U-Step Neuro Walker Available

A member of the CSRA Parkinson Support Group has a U-Step Neuro rolling walker that they can no longer use. The U-Step Neuro is an assistive device specifically designed for people with neurological disorders such as Parkinson's disease (this picture is for example and not the actual device being offered). If you or someone you know could benefit from this walker, please contact our office at 706-364-1662 or info@parkinsoncsra.org, and we will connect you with the donating member.



Brain Health Lunch & Learns Return in September

The Augusta University and Via Cognitive Health Brain Health Lunch and Learn program is set to resume on the third Thursday, September 19th, at the new location, Via Cognitive Health, 105 Lutheran Drive, on Washington Rd across from California Dreaming. Look out for more details in next month's newsletter.

Day One Fitness News

Day One Fitness (D1F) is an 8,000 square foot gym devoted solely to people living with and recovering from neurological disorders. Through classes using non-contact boxing and other uniquely tailored exercise programs, they seek to improve participants' quality of life. Learn more at dayonefitness.org or call **803-265-1699** for details and pricing.



Join the Day One Fitness POP Walk Team

Day One Fitness has created their team for POP Walk 2024 coming up on October 5th! Check out their page here: givebutter.com/popwalk/day-one-fitness. Join the fun by clicking “Join a Team” there or at POPWalk.org. Once registered, use the fundraising tools on the site to raise money for the CSRA Parkinson Support Group and help make Day One Fitness the top team this year!



Parkinson's Fit & Fun

Our FREE exercise group includes people with Parkinson's at various stages and their care-partners. These Parkinson-specific exercises are scientifically proven to slow the progression of symptoms, and we have fun while we're at it!

Mondays and Wednesdays, 10:30 AM to 11:30 AM

St. Mark Methodist Church

2367 Washington Rd., at the intersection of Woodbine Rd.

Parking and the gym entrance are behind the church



Join the Fit & Fun POP Walk Team

Fit & Fun has once again created a team for POP Walk 2024 on October 5th. Check out the team page here: givebutter.com/popwalk/fit-fun. Please consider joining the team and raising money for our support group, even if you are unable to attend. Go to the team page, or to POPWalk.org and click "join a team" to join the Fit & Fun team, use the provided tools to fundraise, and click "donate" to make a gift. You can help make Fit & Fun the Top Team again this year!

Aquatic Exercise for Parkinson's

Aquatic exercise can slow the progress of Parkinson's disease, and it's fun too! The Wilson Family Y on Wheeler Rd in Augusta has a world class adapted aquatics program. The programs are fee-based and open to both Family Y members and non-members. An initial evaluation is required. To schedule an evaluation or for additional information, please contact Claudia Collins at 706-922-9664 or at ccollins@thefamilyy.org.

Marty Turcio's Therapeutic Golf

[Marty Turcios Therapeutic Golf](https://therapeuticgolfclinic.com) provides free therapeutic recreation to anyone with a disability, using the latest high-tech equipment, at **Wedges & Woods Driving Range**, 3731 Wrightsboro Road in Augusta. Clinics are held every **Wednesday and Thursday from 10 AM to 12 PM**. Learn more at: therapeuticgolfclinic.com or call (706) 495-4538



Eva's Purse

In 2023, we implemented a new program called Eva's Purse to distribute "goodie bags" to people with Parkinson's living in nursing homes. This project was established in memory of Eva Erwin (pictured right), a founding and faithful member who spearheaded this activity in the past. The next Eva's Purse event will be "Christmas in July." If you know anyone who has Parkinson's and resides in a nursing facility (not assisted living), please contact Pam Elrod at 706-831-2777 or the Support Group phone at 706-364-1662 to have them added to the list. If you have little items to donate such as puzzle books, tissues, socks, etc., that will fit in a small gift bag, please bring them to a support group meeting, Fit and Fun class, or a Caregivers Lunch. Monetary donations are also welcome and can be given at the above events, by clicking "donate" at parkinsoncsra.org, or mailed to P.O. Box 31, Evans, GA 30809.



Senior Medicare Patrol Webinars

Learn how you can help prevent fraud and avoid becoming a victim of increasingly sophisticated scams by tuning in to the Senior Medicare Patrol Wednesday Webinars. Upcoming dates and topics:

- July 31st - *Did my doctor order this? DME Fraud & Scams*
- August 28th - *Rx Fraud*
- September 25th - *Home Health & Hospice Red Flags*

The link to the webinars will be posted on SMP's Facebook page: [facebook.com/georgiasmp](https://www.facebook.com/georgiasmp)



Our Deepest Sympathy

To the family and friends of
Captain Leigh Herbert Cheney,
in his recent passing

To the family and friends of
Paul "Sammy" W. Samolchuk
in his recent passing



Honor & Memorial Gifts

In Memory of *Dr. David R. Thomas III*, from
Martha Baxter
Mr. & Mrs. Hal D. Beman III
Madeline & Dudley Bowen
Dr. & Mrs. James J. Carswell III
Charlotte Drew
Sarah Ellerbee
Dr. & Mrs. H. Victor Moore
Debra Mundy
Joanne Roebuck
Robert & Anna Sisk

In Memory of *Robert Olson*, from
Sherri Rivers
John & Peggy Thompson
Dori & Donald Thorstad
Dr. & Mrs. T. Barrett Trotter
Mr. & Mrs. Steve Wilkerson

In Memory of *Wyatt Theus*, from
John & Tellene Sylvester

Special Thanks for a Generous Estate Gift

We wish to thank *Jeffrey N. Travis* for his generous gift to the CSRA Parkinson Support Group in his will. Mr. Travis' legacy gift will impact the future of our organization and will directly support people with Parkinson's and their families in the CSRA.

Tax-deductible planned giving through a will or trust is an incredible way to support our cause and make a lasting impact on local families affected by Parkinson's. If you are considering ensuring your legacy through planned giving, please consider including the CSRA Parkinson Support Group in your will or trust.



Research Spotlight

ATLANTIS Study Seeks Participants with PD

The ATLANTIS Study is evaluating a once-daily investigational oral medication in 35 to 80-year-old people living with Parkinson's disease who were diagnosed 5 or more years ago and have fluctuating motor (movement) symptoms. For more information, visit atlantis-study.com. To see if you may be eligible to participate in this trial, please contact Paula Jackson at 706-721-4152 or paujackson@augusta.edu.



ORION Study Seeks Participants with PSP

The ORION Study is researching a new medication to see whether it influences the progression of Progressive Supranuclear Palsy (PSP), a rare neurological condition with similar symptoms to Parkinson's disease. You may be able to take part if you are 40-80 years of age, have been diagnosed with PSP, and have been experiencing PSP symptoms for less than 5 years and can walk at least 5 steps independently or with minimal assistance. Please visit AmylyxPSPTrial.com to learn more about the study. If you are interested in participating or have any questions, contact Dedi McLane at 706-721-4912 or dmclane@augusta.edu.



The ASCEND Research Study is Enrolling Participants

To participate in this study, participants must be age 30 or older, have a clinical diagnosis of Parkinson's disease, must not be currently receiving any medication for PD, must not have previously received any medication for PD for more than 28 total days at a time, and must be freely ambulatory (with or without assistive device). *Other eligibility criteria apply.* Learn more at ascendclinicaltrial.com. Contact Buff Farrow at 706-721-0619 or bfarrow@augusta.edu to see if you qualify and/or enroll in the study.



Lenrispodun as Adjunctive Therapy for Motor Fluctuations

Researchers at Augusta University are looking at whether an investigational study drug for people with Parkinson's disease can help improve movement-related PD symptoms that can occur between doses of levodopa. Buff Farrow 706-721-0619 or bfarrow@augusta.edu. Learn more: clinicaltrials.gov/study/NCT05766813

Join the TOPAZ Study Without Leaving Home

People with Parkinson's disease and parkinsonism have a higher risk of fractures (breaking bones). The TOPAZ study will test if an investigational medicine called zoledronic acid can prevent fractures in people 60 years old or older with Parkinson's disease or parkinsonism. This study is done from your home and you can earn \$100 upon enrollment & \$50 per year during the study. *Learn more:* topazstudy.org



PD GENERation:
Mapping the Future
of Parkinson's Disease



Join the PD GENERation Study

PD GENERation: Mapping the Future of Parkinson's Disease is a national initiative that offers genetic testing for clinically relevant Parkinson's-related genes and genetic counseling at no cost for people with Parkinson's disease (PD). Participation can be either in-person at a Movement Disorders Center of Excellence or from home through a telemedicine appointment and at-home cheek swab collection kit. *Learn more:* pdgeneration.org



Resource Round Up

The CSRA Parkinson’s Support Group has been providing support and education and fighting Parkinson’s disease through local and national efforts **for 33 years!** The resources available and how we access them has evolved tremendously since 1991, not to mention all the changes over the past few years. In *Resource Round Up*, we’ll “wrangle” national resources by maintaining and updating a list of those available to people with Parkinson’s and their care-partners. If

you know of a resource that is not listed here, please let us know so we can include it in future lists!

- **Parkinson's Foundation:** parkinson.org Webinars, fitness exercise/meditation classes, podcasts, community discussion forums, and online and kindle/tablet educational materials and booklets, free hospital kits, and more. PF Helpline: 1-800-4PD-INFO (1-800-473-4636)
- **Michael J. Fox Foundation:** michaeljfox.org Research activities/information, webinars, podcasts educational materials, community forums
- **Davis Phinney Foundation:** davisphinneyfoundation.org Fitness exercises, webinars, blogs, podcasts, free “Every Victory Counts” manual. Phone: 1-866-358-0285
- **Parkinson Place:** parkinsonplace.org Fitness exercises, music, dance, meditation, lectures, community. Phone: 1-941-893-4188
- **American Parkinson’s Disease Association:** apdaparkinson.org Support group network, resources for specialized populations, online discussion forum, rehabilitation resource center, educational video library, webinars, and more. Phone: 1-800-223-2732
- **Veterans Administration:** parkinsons.va.gov This site provides Veterans with general information on PD and on what is changing in the VA, with monthly updates.
- **The George Center Foundation:** thegeorgecenter.com Music therapy, group singing (choir), voice practice. Phone: 1-281-342-6109
- **Young Onset Parkinson’s Mentoring:** yopdmentoring.org Connecting people with YOPD with their peers for mentorship and support.
- **Me Over PD:** meoverpd.org informational resource for people with PD, including a blog, forums, a podcast, newsletter, attack plans for PD, links to a wealth of resources, and a unique “Symptom Map”
- **PD Avengers:** PDAvengers.com a global alliance of people with Parkinson’s along with partners and friends, standing together demanding change in how the disease is seen and treated.
- **Dana’s Recovery Room:** immanuel-baptist.us/danas-room providing durable medical equipment at no cost for those in need at Immanuel Baptist, 615 Old Edgefield Rd, in N. Augusta, Wednesdays from 12 to 4, or contact Sandra Nuss at 803-634-9638.



Resource Highlight: PD Avengers

The PD Avengers’ mission is to add urgency to research, wellness, and advocacy by uniting people and organizations to the cause of ending Parkinson’s. The PD Avengers subscribe to the tenet “think global, act local.” In their pursuit of global advocacy, they believe the activation of local PD Avengers and partner organizations can fulfill the needs of local communities. PDAvengers.com



CSRA Parkinson Support Group

P.O. Box 31
Evans, GA 30809



Phone: (706) 364-1662

Email: info@parkinsoncsra.org

Website: www.parkinsoncsra.org

Facebook: facebook.com/parkinsoncsra

YouTube:

youtube.com/channel/UClqiDJnyoWfb9zjCrsmYquA

Twitter: [@parkinsoncsra](https://twitter.com/parkinsoncsra)

PF Parkinson's Helpline in English/Español:
1-800-4PD-INFO (473-4636)

Officers and Board Members:

Jim Allen, *President*, 706-836-1066

Angie Rainier, *Vice President*, 706-951-7035

Dick Reynolds, *Secretary & Research Chair*,
706-951-9657

Tambra Wilkerson, *Treasurer*, 706-799-9506

Logan Banks, *Past President*, 616-566-2225

Amanda Waters, *Public Relations Chair*, 803-265-1699

Mary Ann Navarro, *Respite Program Chair*,
706-799-2995

Nathan Searle, *Newsletter & Web Chair*, 615-504-4739

Pam Elrod, *Outreach Chair*, 706-831-2777

Kathleen Reynolds, *Board Member*, 706-863-5123

Kay Hays, *Board Member*, 803-292-1908



Paper Newsletter Opt Out:

If you no longer wish to receive our mailed newsletter, or would prefer to get it by email, please let us know at: (706) 364-1662 or info@parkinsoncsra.org



Calling Post Update:

We are updating our Calling Post Contact List. Would you prefer to receive a phone call reminder about our meetings? Or are you on our Calling Post list and wish to be removed? Please let us know at: (706) 364-1662 or info@parkinsoncsra.org