

April 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, *April 23rd*, at 6 PM

Meeting Location:

Sun Porch at Brandon Wilde 4275 Owens Rd. Evans, GA 30809

April 23rd: Jocelyn Pietro of MJFF

Please join us on **Tuesday, April 23rd at 6 pm**, in the **Sun Porch at Brandon Wilde** for special guest speaker Jocelyn Pietro, Advancement Officer for the Southeast Region for the Michael J. Fox Foundation. Jocelyn will be presenting about the current state of Parkinson's research and recent exciting breakthroughs, followed by a question-and-answer discussion. We will be meeting in person and Jocelyn will join us through Zoom projected on the screen. Please bring a covered potluck dish if you are able. We will provide chicken strips and beverages. *Please note: this meeting will be in the Sun Porch* because the Georgia Room is unavailable. Please enter the Commons through the main entrance and ask the receptionist to direct you to the Sun Porch. Hope to see you there!



Caregivers Lunch: May 2nd 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, May 2nd, 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 Caregivers Lunch in July.



Aiken Parkinson's Support Group

The Aiken Parkinson's Support Group meets on the **first Thursday of each month** (May 2nd), 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.



Save the Date: POP Walk 2024

Mark your calendars for our *25th annual* fundraising and awareness walk, POP Walk 2024, the People of Parkinson's Walk:

Saturday, October 5th, 2024
Event beginning at 9 AM, Walk at 10 AM

On the campus of First Baptist Church of Augusta

Stay tuned for more announcements and the link to register!

AU Brain Health Lunch and Learn: May 16th

Join the next Augusta University Brain Health Lunch and Learn on the 3rd Thursday, May 16th, for a presentation led by Dr. Nathan "Ben" Herz, entitled *Occupational Therapy – Everything you need to know but never asked!* There is no cost to attend. Registration is required. Seating is limited. Lunch will be provided. *Register here*: viacognitivehealth.org/education/brain-health/ or scan the QR code.



Thursday May 16th 12 to 1:30 PM

Via Cognitive Health 105 Lutheran Drive, in Augusta



Please note the new location, across from California Dreaming on Washington Road

Recap of the March 26th Meeting

32 attendees at our March 26th meeting enjoyed a lively (and active) presentation from Danielle Williams, Executive Director of Day One Fitness, about falling! Falling can be a big problem for people with Parkinson's. Learning not only to avoid falls, but also to fall as safely as possible when it can't be avoided, is essential.

We must avoid falls, but we must also be careful not to develop irrational fear of falling. Fear of falling can make a fall more likely by causing hesitation and decreasing activity in general. Tips to avoid falling include walking with intention, focusing on the task, and breaking a turn up into quarters. When completing tasks involving standing and turning, increase your stance width and keep the knees slightly bent. In the home, make sure you have adequate lighting including nightlights, remove rugs, make sure cords and cables are out of the way, and be aware of the location of pets.



The best way to learn to fall safely is to practice. Day One Fitness has large areas of soft mats and coaches to teach you to fall safely and get back up after a fall. If you are unable to join Day One Fitness, you should put a mattress on the floor at home and practice falling there. Avoid stiffening up and locking out your arms towards the fall. Instead, try to curl up and roll through a fall, landing on "the meat" such as buttocks, thighs, and the thickest parts of the arms and back. Use your arms to protect your head and tuck your chin into your chest.

Danielle also showed us some simple exercises to build strength and balance. We learned a lot from Danielle and from members in attendance who have fallen and/or practiced falling. Thank you so much Dani!

Lewy Body Dementia Support Group

The LBD meetings are held at 11 AM on 3rd Tuesdays (May 21st) 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



Day One Fitness

Day One Fitness (D1F) is an 8,000 square foot gym devoted solely to those 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.





Introducing the latest addition to the team at Day One Fitness – the vibrant and talented **Jessica Wilkerson!** Joining as the new Part-Time Program Director, Jessica, affectionately known as "Energizer," has been a cherished member of the coaching staff since September 2022. Renowned for her lively and dynamic workout sessions, Jessica's infectious energy has left a lasting impression on our community. Now, as she takes on the role of overseeing all programmatic needs, we are excited for the fresh perspective and enthusiasm she will bring to Day One Fitness.

The 2024 Birdies for Brain Health Charity Golf Tournament supporting Day One Fitness takes place May 13th at Woodside Plantation in Aiken, SC. Interested players/sponsors are encouraged to register at birdiesforbrainhealth.com. You'll find more details on the flyer on the next page.

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 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



Parkinson's Fit & Fun



Our FREE exercise group is growing and 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! Come check it out:

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

St. Mark United Methodist Church 2367 Washington Rd., at the intersection of Woodbine Rd.

Parking and the gym entrance are behind the church.



CHARITY GOLF FUNDRAISER

BIRDIES FOR BRAIN HEALTH CLASSIC



REGISTRATION:

\$145 PER INDIVIDUAL OR \$540 PER TEAM *Early Bird*

\$155 PER INDIVIDUAL OR \$580 PER TEAM *After 3/15/2024*

BirdiesForBrainHealth.com



EVENT START

MAY 13, 2024 12 PM START TIME



FOOD

BOX-LUNCH & HEAVY HORS D'OEUVRES AT THE AWARDS CEREMONY



WOODSIDE PLANTATION

1000 WOODSIDE PLANTATION DR AIKEN, SC

FUNDRAISER

Join us for the annual Birdies for Brain Health to partner with us in fighting back against chronic neurological disease and disability.

- -Four man scramble, shotgun start
- -\$10,000 Cash Prize Hole in One Competition
- -Competitions (Longest Drive, Closest to the Pin)
- -Raffle

- -Silent Auction
- -\$580 cash prize and "Bragging Rights" to winning team



Eva's Purse Updates

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. To celebrate Valentine's Day, goodie bags were provided to 10 of our Parkinson folks residing in nursing home facilities, including Brandon Wilde, Georgia War Veterans, and Lake Crossing. The next event will be "Christmas in July." If you know a person with Parkinson's in a nursing home please contact Pam Elrod at 706-831-2777 or Mary Ann Navarro at 706-364-1662.



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:



Preventing Medicare Fraud

• April 24th - Do I Really Need These Tests?

Our Deepest Sympathy

- May 29th Virtual Healthcare Scams
- June 26th Calling All Volunteers: Get Involved with SMP

The link to the webinars will be posted on SMP's Facebook page: <u>facebook.com/georgiasmp</u>

To the family and friends of Danny Arnold Drake, in his recent passing To the family and friends of *Wyatt Theus*, in his recent passing



Honor & Memorial Gifts

In Memory of *Paul "Smitty" Smith*, from Sherri Rivers

In Memory of *Betty Jean Reeder Lariscy Ley*, from Rick and Pam Elrod

In Memory of *Wyatt Theus*, from Sadie Maguire
Janet Boshears
Dr. & Mrs. David Thomas III
Richard Magruder Jr.
Signard Hale & Janet Causey
Mr. & Mrs. William Barrett, Jr.

In Memory of Wyatt Theus, from
Murray & Sandra Freedman
Raymond & Caroline Brady
Dr. Jerry W. Howington
Shannon M. Schoenberger
Neal & Floride Dickert
Joel & Paulette Cohen
Joseph & Mary Hughes
Doreen Hastings
John Thorpe



The ASCEND Research Study is Enrolling Participants

If you or someone you know has been diagnosed with Parkinson's disease (PD), you or they may be eligible to participate in a clinical research study evaluating the safety and efficacy of a new investigational treatment. The study is evaluating an oral tablet for those with early, untreated Parkinson's. The tablet will be taken only once a day with the largest meal. Approximately 60 participants will be



recruited for this study and those enrolled will be asked to participate for up to 18 weeks, which includes the screening, treatment, and post-treatment follow-up periods. 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. Study participants receive study drug at no cost, and compensation for time and travel may be available. Learn more at ascendelinicaltrial.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



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

Bukwang SHINE Study for Dyskinesia

The SHINE study is researching moderate to severe dyskinesia in patients taking levodopa for Parkinson's disease (PD). Dyskinesia is uncontrollable muscle movement and is often found in people with PD. It can look like fidgeting, wriggling, restlessness, body swaying, or head bobbing. More severe cases can interfere with daily activities or may be painful. Study doctors want to learn if an



investigational drug may help control dyskinesia symptoms while taking levodopa. The researchers are enrolling participants now. If you have PD, take levodopa, and have dyskinesias, you may qualify to participate. Learn more here: tinyurl.com/yc2c7xn6. To enroll or if you have questions, contact Dedi McLane at 706-721-4912 or dmclane@augusta.edu



The CSRA Parkinson's Support Group has been providing support and education and fighting Parkinson's disease through local and national efforts **for 32 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: <u>parkinson.org</u> 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:** <u>michaelifox.org</u> Research activities/information, webinars, podcasts educational materials, community forums



• **Davis Phinney Foundation:** <u>davisphinneyfoundation.org</u> Fitness exercises, webinars, blogs, podcasts, free "Every Victory Counts" manual. Phone: 1-866-358-0285



• Parkinson Place: <u>parkinsonplace.org</u> Fitness exercises, music, dance, meditation, lectures, community. Phone: 1-941-893-4188



• American Parkinson's Disease Association: <u>apdaparkinson.org</u> 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:** <u>parkinsons.va.gov</u> This site provides Veterans with general information on PD and on what is changing in the VA, with monthly updates.



• The George Center Foundation: <u>thegeorgecenter.com</u> Music therapy, group singing (choir), voice practice. Phone: 1-281-342-6109



• Young Onset Parkinson's Mentoring: <u>vopdmentoring.org</u> Connecting people with YOPD with their peers for mentorship and support.



• **Me Over PD:** <u>meoverpd.org</u> 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:** <u>PDAvengers.com</u> 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: <u>immanuel-baptist.us/danas-room</u> 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.

April is Parkinson's Awareness Month!

For Parkinson's Awareness Month this year, the Parkinson's Foundation is highlighting the many symptoms of Parkinson's and ways to address them: the ABCs of PD. Check out their interactive alphabet page, which includes a print-out so you can fill in your own ABCs of PD: parkinson-awareness-month



Phone: (706) 364-1662

Email: info@parkinsoncsra.org

Website: www.parkinsoncsra.org

Facebook: facebook.com/parkinsoncsra

YouTube:

youtube.com/channel/UClqiDJnyoWfb9zjCrsmyquA

Twitter: @parkinsoncsra

PF Parkinson's Helpline in English/Español:

1-800-4PD-INFO (473-4636)

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

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 and Public Relations Chair.

616-566-2225

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

Amanda Waters, Board Member, 803-265-1699

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