

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: <u>www.parkinsoncsra.org</u> Meeting Date & Time:

4th Tuesday of the month, *March 26<sup>th</sup>*, *at 6 PM* 

### Meeting Location:

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

## March 26<sup>th</sup>: Danielle Williams

Please join us on **Tuesday, March 26<sup>th</sup> at 6 pm**, in the **Georgia Room at Brandon Wilde** for special guest speaker Danielle Williams, Executive Director of Day One Fitness. Dani will be presenting about fall prevention and demonstrating a few ways to build strength and balance, followed by a question-and-answer discussion. Please bring a covered potluck dish if you are able. We will provide chicken strips and beverages. *Please note*: we will not be streaming the meeting live on Zoom or Facebook, but we plan to record it and publish the video later on Facebook and YouTube, with a link in the next newsletter. Hope to see you there!



## Caregivers Lunch: April 4<sup>th</sup> 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, April 4<sup>th</sup>**, 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.



## Aiken Parkinson's Support Group

The Aiken Parkinson's Support Group meets on the **first Thursday of each month** (April 4<sup>th</sup>), 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.

## 2024 Brain Health Symposium: April 20<sup>th</sup>

Don't miss the annual Kapil D. Sethi Brain Health Symposium, coming up on Saturday, April 20<sup>th</sup>, 8:30 AM to 3:30 PM. Please see the flyer on the next page for details. There is no cost to attend. Registration is required. Seating is limited. Breakfast and lunch will be provided. *Register here*: <u>AugustaHealth.org/BrainHealth</u> or scan the QR code. REGISTER BY APRIL 7TH: AugustaHealth.org/BrainHealth FOR MORE INFORMATION: 706-721-2748

Please note: Because of the Symposium there will not be a Lunch & Learn in April. The next one is in May.

# Kapil D. Sethi 2024 BRAIN HEALTH SYMPOSIUM

## Everyone is invited! Don't miss this event!

Questions about Alzheimer's or Parkinson's disease?

Join us to hear the latest research and treatment options from the experts.

Special performance: "Yes and ... " by Dad's Garage Improv Comedy Group

FREE EVENT

## **BREAKFAST &** LUNCH INCLUDED



8:30 AM - 3:30 PM

#### **REGISTER BY APRIL 7TH:**



AugustaHealth.org/BrainHealth

FOR MORE INFORMATION:



🔊 706-721-2748



#### SPEAKERS

#### Memory



John C. Morgan, MD, Ph.D "They Said He Just Has Dementia, Not Full-Blown Alzheimer's'



James J. Lah, MD, Ph.D Advances in Alzheimer's Disease Research, Diagnostics, and Therapies



Elizabeth H. Prince-Coleman, PA-C Sleep, Aging, and Memory

#### Movement



Jessica M. McClard, MD Parkinson's Disease: Where We've Been and Where We're Going



Colin P. McLeod, MD Surgical Treatments for Parkinson's disease



Julie A. Kurek, MD Palliative Care in Parkinson's Disease

## Topics subject to change AFTERNOON SESSIONS

Intimacy and Relationships John C. Morgan, MD, Ph.D

Spirituality and Health

**Chaplain Frank** Penha

Legal Planning for Incapacity & Provision of Care Patrick Smith

Initiatives and Resources

Elizabeth Head + Francis Yelton

## Recap of the February Meeting

About 20 attendees at our February 27<sup>th</sup> meeting enjoyed a lively open discussion on a variety of topics. Part of the discussion focused on making the most of physician visits. One of the most effective ways to prepare is to keep a medical journal, tracking your motor and non-motor symptoms, blood pressure, medications, etc. We have a free medical journal binder available at our monthly meetings. Some suggestions for the next doctor's visit included requesting PT, OT, and speech therapy, avoiding



the temptation to mask symptoms during the visit, and requesting a note to take to the DMV to get a handicap tag. Anyone with Parkinson's should qualify for a tag, regardless of the severity of symptoms.

We also discussed the danger faced by people with Parkinson's when hospitalized. The Parkinson's Foundation has free hospital safety guides that you can request or print out here: <u>parkinson.org/resources-support/hospital-safety-guide</u>. People with Parkinson's may need to avoid certain medications often given at the hospital, such as antipsychotics, and the PF Hospital Guide includes a list of all those meds. Also, it was recommended to request case management as soon as possible in a hospital stay to get ahead of discharge planning.

Many attendees endorsed various technologies that have helped improve their lives with Parkinson's, including medication tracking apps (such as Medisafe or Drugs.com), or the StrivePD app, which is specifically for Parkinson's symptom tracking, and setting up Medical ID on smart phones. Medical ID is activated in the Health App in iPhone and is a separate free app on Android devices. With it you can choose to have emergency information accessible from the lock screen without requiring a password for emergencies.

## Welcome Board President Jim Allen

We are pleased to announce the new President of our Executive Board, Jim Allen! Jim was diagnosed with Parkinson's in 2021 and has been an active member of the CSRA Parkinson Support Group since that year. He worked as a minister and attorney, including work in employment law and disability law, and serves as an Ambassador with the Davis Phinney Foundation. Jim takes a proactive and positive approach to Parkinson's, and he is passionate about not only living his best life with Parkinson's, but also empowering others in our community to make the best of their lives with PD in their own way.



## Our Thanks for Logan Banks' Leadership

It would be impossible for the board or members of the CSRA Parkinson Support Group to adequately express our gratitude for the leadership of outgoing Board President Logan Banks. Through prompting from long-time board members Dick and Kathleen Reynolds, Logan reached out to volunteer in July of 2020, amid the pandemic, and took on a huge role in the success of our virtual POP Walk that year. He became Board President in 2021, and his impact over the past 3 years has been immeasurable. Leading the group in returning to in-person meetings at Brandon Wilde while maintaining the virtual availability, overhauling our website, expanding our

outreach in the community, including continued POP Walk committee leadership, serving as MC for those events, and so much more. This picture is from an interview he did on WRDW Morning Mix to promote our 2023 Parkinson's Walk. Logan continues to serve on the board and walk committee. Thank you so much, Logan!



# 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 <u>dayonefitness.org</u> or call **803-265-1699** for details and pricing.





The 2024 **Birdies for Brain Health Charity Golf Tournament** supporting Day One Fitness takes place **May 13<sup>th</sup> at Woodside Plantation** in Aiken, SC. Interested players/sponsors are encouraged to register at <u>birdiesforbrainhealth.com</u>. We will be publishing more details in our April Newsletter.

For more information or to inquire about our online silent auction, please reach out to **Danielle Williams** at **803-265-1699**.

# Lewy Body Dementia Support Group

The LBD meetings are held at 11 AM on 3<sup>rd</sup> Tuesdays (April 16<sup>th</sup>) at:

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

Contact Nancy Martin at <u>nancy13lbd@gmail.com</u>, or Linda Lucas at <u>linda@daybreakcare.com</u>



# 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 <u>ccollins@thefamilyy.org</u>.

## 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.

Please note: There will not be classes Master's week.

# 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:

- March 27<sup>th</sup> *Protecting my Identity from Scammers*
- April 24th Do I Really Need These Tests?
- May 29th Virtual Healthcare Scams

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

## Marty Turcio's Therapeutic Golf

<u>Marty Turcios Therapeutic Golf</u> 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: <u>therapeuticgolfclinic.com</u> or call (706) 495-4538

# Veterans with Parkinson's

For veterans with Parkinson's disease, there is an opportunity to meet informally to discuss relevant issues and share concerns. Jim Daskal, a charter member of the new VFW in Evans, has offered their place for such a meeting. There's a private place to talk and share stories. Interested vets should leave a message for Jim Daskal at the VFW: 706-364-9604.

# Honor & Memorial Gifts

In Memory of *Dunbar Dyches*, from Christina Dunn

In Memory of *Betty Jean Reeder Lariscy Ley*, from Paul and Monica Baynham Kay Hays

# Our Deepest Sympathy

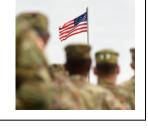
To the family and friends of Dunbar Dyches, Jr., in his recent passing



Senior Medicare Patrol











# **Research Spotlight**

## 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 <u>bfarrow@augusta.edu</u> 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 <u>bfarrow@augusta.edu</u>. 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

TOPAZ TRIAL OF PARKINSON'S AND ZOLEDRONIC ACID

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

Parkinson's Foundation

## 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: <u>tinyurl.com/yc2c7xn6</u>. 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>michaeljfox.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.

# Parkinson's Foundation Hospital Safety Guide

Having to stay in the hospital is challenging for anyone, but it can be even more dangerous for people with Parkinson's. Be prepared by having the Parkinson's Foundation's comprehensive Hospital Safety Guide on hand. It is available for free to order or download here: <u>parkinson.org/resources-support/hospital-safety-guide</u>























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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