

September 2021 Newsletter

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

116 Lottie Lane Grovetown, GA 30813

Phone: 706-364-1662

Email: info@parkinsoncsra.org
Website: www.parkinsoncsra.org

Meeting Date & Time:

4th Tuesday each month, **September 28th at 6 PM**

Meeting Location:

Our September Meeting is Virtual Only, on Zoom and Facebook Live

September 28th at 6 pm: Drs. Seshadri and Kurek

For our 6 pm September 28th *virtual-only* meeting we are pleased to welcome **Dr. Sandhya Seshadri** of the University of Rochester, and **Dr. Julie Kurek**, of Augusta University, who will present "Palliative Care: From Beginning to End." Sandhya Seshadri, PhD, MS, MA, is an Assistant Professor at the University of Rochester and a co-investigator and the project manager for a project on implementing team-based palliative care for the Parkinson's Foundation centers of excellence. Her research focuses on the health and well-being of older adults and on patient-and family-centered approaches of care. Julie Kurek, MD, is a neurologist and movement disorders specialist and is Director of the Parkinson's





Foundation Center of Excellence at the Medical College of Georgia at Augusta University. She works to improve the quality of life for those living with Parkinson's disease using a holistic approach, addressing not only the motor but (perhaps more importantly) the non-motor symptoms these individuals face. *Please note, this meeting is only available virtually on Zoom and Facebook Live. There will not be an in-person meeting this month.*

Join the meeting on Zoom by clicking this link:

<u>us02web.zoom.us/j/85853349155?pwd=WVITTUltaE5EWEI1dmxOTTUxeGlvUT09</u> and Facebook Live at <u>facebook.com/parkinsoncsra</u>. We hope to see you there!



The People of Parkinson's Walk



POP Walk 2021 is Here!

Saturday, October 2nd, 2021, at First Baptist Church of Augusta, 3500 Walton Way Ext. Event starts at 9 AM, Walk at 10. Register and donate today at: **POPWalk.org** or mail in the form in this newsletter. There is no registration fee, but participants who donate \$25 or more will qualify for a **POP Walk 2021 T-shirt** at the event while supplies last. Join the fight today!

POP Walk U-Pick Raffle:

This year will mark the return of our popular raffle! For the *POP Walk U-Pick Raffle* this year, you can enter your raffle ticket(s) for the prize package you hope to win. Prizes this year include: A watch from Windsor Jewelers (men's or women's), a week stay in Hilton Head Island, a New Year's stay in Charleston, a pair of matching suitcases, a U-Step Laser Cue, a Scout Power Scooter, gift cards to local spas and restaurants, and more! You must be present to win.

POP Walk 2021 Continued...

Parkison's Artisans:

We are excited to include a gallery and silent auction of arts and crafts created by people with Parkinson's in our community again this year! Please contact Patti Kelley at 706-339-1799 if you are interested in contributing works to this year's Parkinson's Artisans showcase. If you would like to show your work but not donate it for auction, we will gladly include it and label it "not for sale." All proceeds benefit the CSRA Parkinson's Support Group's mission.

Registration and Donation FAQ:

Online registration and donation on <u>POPWalk.org</u> looks a bit different this year. To register, click "register" and sign up for a free ticket. Be sure to include your team name if you are starting or joining a team. Once you have completed registration, click the link in your email confirmation to make a donation, if you wish. You can also return to <u>POPWalk.org</u> and click "donate only." It is not possible to donate while you are registering this year. If you do not plan to attend the event, you can still donate by clicking the "donate only" button on <u>POPWalk.org</u>.

Teams:

To start or join a team for POP Walk 2021, simply add your team name when you register. Here is the list of teams that have registered so far at the time of this writing:

- AU DPT Class of 2023
- AU DPT Class of 2024
- Day One Fitness (Fighting to Win)
- KKR-Undefeated
- Papa Joe's Battle Buddies
- · Team Linda
- Team Navarro
- Wilde Bunch (Brandon Wilde)



Please note, teams and individuals no longer have their own fundraising pages this year, but we will be tallying team totals and presenting top team awards at the POP Walk celebration meeting!

T-Shirts:

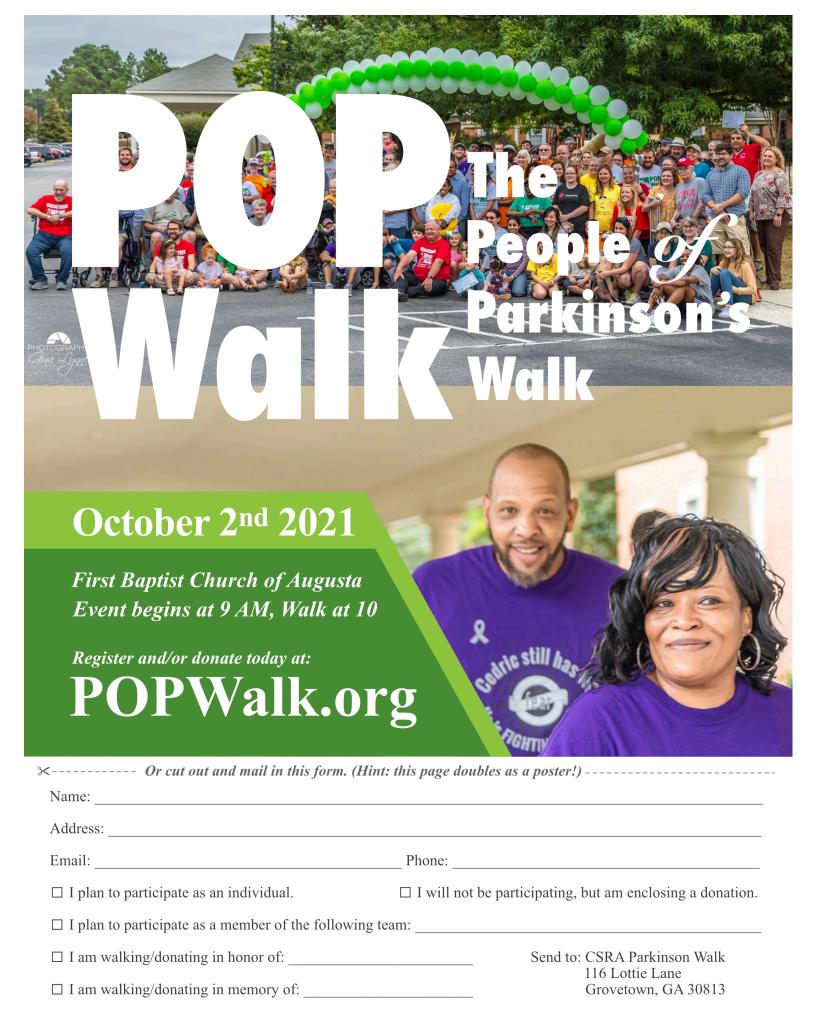
Remember, participants who donate \$25 or more will qualify for a POP Walk 2021 T-shirt, adult sizes small through XXL, one per qualifying participant at the event, while supplies last. Here is a mock-up of the new design!

POP Walk Details:

Registration begins at 9 AM. Everyone should start by visiting the registration tent to sign in and receive your t-shirt if you qualify. You can decorate a bib in honor or memory of your loved one, check out the sponsor tables, enjoy refreshments, buy raffle tickets, and watch or join the Tai Chi demonstration. Then we'll have the opening ceremonies and the Walk itself



kicks off at 10 AM at the balloon arch. We'll walk or roll along the approximately quarter-mile loop through the beautiful campus of First Baptist Church of Augusta, following the signs recognizing our sponsors, collecting paper bands with each lap. Once you've collected 8 bands, or as many as you're able, head to the walk prize table. Return to the center for Day One Fitness demonstrations, place your final raffle picks, gather for the balloon arch group photo, and then listen for your number to see if you've won the raffle!



Recap and Video of the August 24th Meeting:

For our August meeting we enjoyed an informative presentation from Neuropsychologist Dr. Jeremy Hertza,

Executive Director/CEO of Neurobehavioral Associates. Dr. Hertza presented about the personality, mood, and cognitive changes that occur as Parkinson's disease progresses. There were 20 attendees in person and othersjoining online via Zoom and Facebook live. Thank you so much to Dr. Hertza!

You can watch the full video on our YouTube page here: https://youtu.be/OzSJYO5zOK8 ... Please subscribe to our YouTube channel if you haven't already!



Day One Fitness News:

Day One Fitness is an 8,000 square foot gym devoted solely to those living with movement and memory disorders. Through classes using non-contact boxing and other uniquelytailored exercise programs, we seek to improve our participants' quality of life. Call **803-265-1699** for details and pricing. Here's some of the latest news at Day One:



YOGA, DANCE, and **MANUAL DEXTERITY with Speech & Voice** is happening on Tuesdays at 9:00, 10:00 and 11:00 AM.

Nordic Pole Walking with a physical therapist in Hitchcock Woods on the 2nd and 4th Tuesday of each month at 4:30 PM. Come walk like you've never walked before with the benefits of Nordic Poles. Charlotte Chatto, PT, leads you through beautiful Hitchcock Woods in Aiken. Free to gym members. Additional cost to non-members.

According to the **Brian Grant Foundation** (briangrant.org/how-hiking-helps-parkinsons/):

"Nordic walking amplifies the movement of ordinary walking in order to produce gains in speed. This high-intensity exercise has even more cardio or aerobic activity than hiking, but it can still be carried out on a variety of surfaces and terrains by anyone who can walk regardless of age or fitness level. Multiple studies conducted around the world have shown that people with Parkinson's who participated in Nordic walking programs saw improvements in their gait, balance, posture, flexibility and mood."

Mobile PT: PT SOLUTIONS now offers mobile PT services for our fighters at our gym. Instead of having to go elsewhere for your PT, you can have it at the gym. This is NOT included in your gym membership but is paid through insurance OR private pay.

PT Intensives: What better time than FALL to sign up for a 4-week Saturday PT intensive on Fall Prevention: **October 9th**, 16th, 23rd, and 30th at 10:00 AM. Come join Maddie Quail, PT, as we learn better how to prevent falls as well as how to fall better. Free to gym members. Additional cost to non-members.

Parkinson's Fit & Fun:

Our free exercise class at St. Mark UMC has a new name: *Parkinson's Fit & Fun*! The camaraderie of the group, which includes people with Parkinson's and their care-partners, and the Parkinson-specific chair-based exercise routine remains the same but with a fun new moniker. We hope that more of our readers will join the class, every Monday and Wednesday at 10:30 AM at the gym at St. Mark UMC at the corner of Washington Rd and Woodbine Rd. The parking and gym entrance are behind the church. The gym and class are limited mobility accessible. Check out this flyer, spread the word, and join us for Parkinson's Fit & Fun!



PARKINSON'S EXERCISE CLASS

FUNDED BY



MONDAYS & WEDNESDAYS 10:30 to 11:30am

NO COST TO PARTICIPANTS

Visit
WWW.PARKINSONCSRA.ORG
for more information









Parkinson's Fit and Fun

This program is based on Parkinson's specific exercises; focusing on assisting with movement, vocalization, balance, memory, and everyday challenges such as standing from a chair.

The exercises are done primarily in chairs, focusing on both the upper and lower body, with the use of light weights and some walking.

This promotes socialization among people with Parkinson's. Family and Care-partners are welcome and encouraged to participate.

LOCATION

ST. MARK UNITED METHODIST CHURCH 2367 WASHINGTON RD. AUGUSTA, GA 30904

At the intersection of Woodbine Rd. The gym entrance is behind the church.

Our Motto is...
"I have Parkinson's but
Parkinson's doesn't have me!"





Caregiver Corner:

Caregivers Support Group Luncheon: October 7th:

The next Caregiver's Luncheon will be held at 1 PM on Thursday, October 7th, at the Pizza Joint in Evans, 4301 Washington Rd. They have a covered outdoor area so that we can meet safely. Please contact **Patti Kelley** to RSVP if you will be attending by calling or texting 706-339-1799. We hope to see you there!

Parkinson's Care-Partner Awards Deadline is October 1st:

To promote awareness of the importance of Parkinson Care-Partners, the AU Movement Disorders Center are hosting the Outstanding PD Care-Partner Awards for care-partners of PD patients served in their program. Simply email your nominee's name and what makes him/her an outstanding care-partner to Martha Anne Tudor, center coordinator, at <u>mtudor@augusta.edu</u>. Photos encouraged! Nominations are due by October 1st.

Three AWARDS will be announced in November as part of National Care-Partner Appreciation Month. Prizes include:

- \$500 gift card from Amazon
- Personalized trophy
- Personalized photo and story

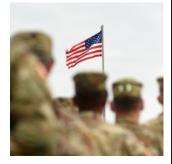


Caregivers: Need a Break?

Our local **Respite Care Grant Program** is available to you to receive reimbursement for times you may need to hire someone to stay with your person with Parkinson's (PWP) when you cannot be there. For example this could help you keep appointments, shop, visit, or stay home and take a break. Guidelines and applications for Respite Care Grants are available on our website: parkinsoncsra.org/assistance. Call Mary Ann Navarro at 706-799-2995 for more information.

Veterans Fighting Parkinson's Disease:

The Veterans Administration has 51 Consortium Centers, clinics that offer specialized Parkinson's disease and movement disorder care to Veterans. The VA has partnered with the Parkinson's Foundation for their expertise in research, fundraising, and educational and supportive resources. The VA clinicians who work at the Consortiums were specifically chosen for their skills and knowledge of Parkinson's and similar diseases. Some of available resources include research, education, and supportive resources for patients, families, and providers. In addition, books, pamphlets, and reference cards for



every stage of PD are available at Movement Disorder Clinics. The director of the Augusta Consortium Center is Dr. John Morgan: 706-733-0188 x12415. Learn more: parkinsons.va.gov

The 9/11 Attacks and Parkinson's:

Here we are, 20 years later and the after-effects of the September 11th terrorist attacks continue to evolve. First responders and survivors of the attacks who were exposed to smoke and toxic dust have developed numerous health conditions, including neurodegenerative disorders such as Alzheimer's disease and Parkinson's disease (PD). PD has been previously linked to exposure to toxins, one prominent example being the Agent Orange defoliant used widely in the Vietnam War.



In 2019, the Administrator of the World Trade Center (WTC) Health Program denied a petition to add Parkinson's disease to the List of WTC-Related Health Conditions, citing insufficient evidence. However, researchers continue to study the contents of the WTC dust and its connection to neurodegenerative disorders.



Research Spotlight:

Sheffield Memorial Research Grant Recipient: Cannabidiol Study

The CSRA Parkinson Support Group is pleased to announce the awarding of the Sheffield Memorial Research Grants for 2021. One of the \$10,000 grants goes to Dr. Babak Baban, professor in the Dental College of Georgia at Augusta University (pictured here on the left along with Dr. John Morgan and Dr. Hesam Khodadadi). Recently named the associate dean for research for the Dental College, he will be studying the "Potential Role of Cannabidiol (CBD) in the Treatment of Parkinson's Disease (PD)". This study aims to determine the precise role of the immune system and inflammatory responses in the disease



progression of PD. The results will most likely be applicable to other neurodegenerative diseases, making this a potentially powerful tool and novel therapeutic for treating brain diseases like PD. CBD is the non-psychoactive part of the cannabis plant (marijuana). Cannabidiol is most commonly used for **seizure disorder (epilepsy)**. It is also used for anxiety, pain, a muscle disorder called dystonia, Parkinson's disease, Crohn's disease, and many other conditions, but so far there is little to no scientific evidence to support these uses. One of the primary purposes of Dr. Baban's study is to lay down actual scientific evidence to support the treatment of PD with CBD.

There is some scientific evidence that PD is an auto-immune disease and is also accompanied by chronic inflammation. Mounting evidence suggests that dysregulation of the immune system and accompanying inflammatory responses are responsible for the progression of PD. Imagine if these could be slowed or stopped in their tracks! In this year-long study, Dr. Baban will be testing the hypothesis that CBD will improve the adversarial symptoms of PD by modulating the inflammation and re-establishing the immune balance using mice in his lab. Should this approach net positive results, Dr. Baban would plan to move ahead with a funding request from the National Institutes of Health (NIH) to support a pilot Phase I clinical trial. We wish Dr. Baban the best with this research pursuit and that he will push the science of PD treatment ahead with new treatment modalities!

Parkinson's TAKEDA Study Seeking Participants:

The TAKEDA Parkinson's Research Study is evaluating an investigational drug, TAK-071, to determine if it is safe and effective in the treatment Parkinson's disease patients with cognitive impairment and an elevated risk of falls. Please contact Dedi McLane at 706-721-4912 or dmcLane@augusta.edu for more information and to be considered for participation in the study. Additional information may also be found on the clinicaltrials.gov site at https://bit.ly/38WXYKZ.

Genetic Counseling Quick Survey Study:

If you have a diagnosis of Parkinson's disease, you are invited to participate in a research study. Sydney Richards, a Master's student in the Genetic Counseling Training Program at the University of Maryland School of Medicine is conducting a new research study to better understand the experience of individuals with Parkinson's disease with genetic testing.



She needs your help and wants to hear about your experience and opinions! People who have and have not had genetic testing are encouraged to take part by completing a short, online survey that should only take about 15 minutes. All answers are anonymous. This study is voluntary, and your decision to participate will not affect your medical care. Your participation is much appreciated!

If you are interested in learning more about this study, please use this link to complete the survey by November 16th, 2021: https://umaryland.az1.qualtrics.com/jfe/form/SV_bpEhuQEvdjAcoyG



The CSRA Parkinson's Support Group has been providing support and education and fighting Parkinson's disease through local and national efforts for 30 years! The resources available and how we access them has evolved tremendously since 1991, not to mention all the changes over the past 12 months. 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. Please let us know what works for you so we can pass it on to others!

- 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: michaelifox.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.















Resource Highlight: PD Expert Briefings

There is an ongoing series of Expert Briefings put on by the Parkinson's Foundation that includes the following upcoming topics. Registration is simple and you receive reminder emails as the webinar approaches: www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-ExpertBriefings-Webinars

Sept. 1^{st} , 2021 - The Parkinson's Journey - Understanding Progression Oct. 6^{th} , 2021 - PD & Medications: What's New?

Dec. 1st, 2021 - The Skinny on Skin and Bone Health in Parkinson's Feb. 2nd, 2022 - Sights, Sounds and Parkinson's Mar. 2nd, 2022 - Conversations about Complimentary Therapies and PD

Apr. 6th, 2022 - Can we put the Brakes on PD Progression?



Beyond the Diagnosis: Managing Mid-stage PD:



Beyond the Diagnosis: Managing Mid-stage PD

Saturday, Oct. 30, 2021 10 a.m. - 12:00 p.m. ET

Online Program (Zoom)

Registration Required:
Parkinson.org/MaconEdu or
770-450-0792

After several years of good management, Parkinson's symptoms may become more challenging. Learn how symptoms may change over time and options for treating them. This program will also provide information on care partner resources and tools for building support systems to cope with new challenges.

Featured Speakers:

John Morgan, MD, PhD Colin McLeod, MD Martha Anne Tudor, MEd, NCC, LAPC

Our Deepest Sympathy:

To the family of Kathleen Walden, in her recent passing

To the family of Carter Roper, in his recent passing

To the family of Pastor R. Larry Brown, in his recent passing



Honor/Memorial Gifts:

In Memory of Rob Garrison:

** From Verna Garrison

In Memory of Dickey Boardman: ★ Lang and Sherri Rivers



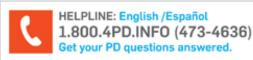
To the folks who have birthdays in September, we wish you a very Happy Birthday!

Switch to Paperless:

Email <u>info@parkinsoncsra.org</u> with "e-newsletter" in the subject.







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616-566-2225

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Outreach Chair: Pam Elrod: 706-831-2777

Board Member: Connie Nesteruk: 215-205-2440

Board Member: Kathleen Reynolds: 706-863-5123

Join us for Exercise!

Parkinson's Fit & Fun:

Join us for fun PD-specific exercise Mondays and Wednesdays from 10:30 to 11:30 AM, at St. Mark United Methodist Church, at the intersection of Washington Rd and Woodbine Rd in Augusta. Please note: no class on Columbus Day, Oct. 11th.

Aquatic Exercise Classes:

Aquatics classes are currently on hold until further notice. Contact: Claudia Collins: (706) 922-9664 or ccollins@familyy.org

Day One Fitness:

<u>Day One Fitness</u> is non-contact boxing training, and much more, designed specifically for people with movement and memory disorders.

Visit <u>DayOneFitness.org</u> to learn more and call or email the gym to schedule an initial assessment: (803) 265-1699, <u>Info@DayOneFitness.org</u>

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. Visit: therapeuticgolfclinic.com or call (706) 495-4538

Sending Donations or Memorials:

CSRA Parkinson Support Group ATTN: Penny Triplett 886 Lake Royal Dr. Grovetown, GA 30813

Lewy Body Dementia Support:

The LBD meetings are held at 11 AM on 3rd Tuesdays (October 19th) 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 (803) 226-0288

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



Paper Newsletter Opt Out:

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(706) 364-1662 or info@parkinsoncsra.org