Parkinson Association of Alabama, Inc. 00

Your State Resource on Parkinson's Disease



Proclamation

By the Governor of Alabama

WHEREAS, Parkinson's Disease (PD) is a chronic, degenerative neurological disease that affects one in 100 people over the age of 60; and

WHEREAS, currently, there is no treatment to slow, stop or reverse the progression of the disease, nor is there a cure; and

WHEREAS, existing Parkinson's treatments are limited in their ability to address patients' symptoms and remain effective over time; and

WHEREAS, there is no Parkinson's test or biomarker, so the rate of under-diagnosis can be relatively high; and

WHEREAS, at least one million people in the United States and more than five million worldwide are living with PD; and

WHEREAS, motor and non-motor symptoms can include resting tremor, stiffness, and slowness of movement, as well as depression, sleep disorders and cognitive impairment;

NOW, THEREFORE, I, Kay Ivey, Governor of Alabama, do hereby proclaim April 2021, as

Parkinson's Awareness Month

in the state of Alabama.



Given Under My Hand and the Great Seal of the Office of the Governor at the State Capitol in the City of Montgomery on the 1st day of March 2021.

Kay Vey

NEWSLETTER - April 2021

CARE

Learn to care for yourself or your loved one using our resources.

COMMUNITY

Connect with others in the Parkinson's community and find your support network.

CURE

See how PAA is partnering with UAB through grants and research for a cure.

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- April Webinars-National & Local

PARKINSON'S AROUND ALABAMA

- April is Parkinson's Awareness
 Month-Alabama State Proclamation
- UAB Udall Study-Still Recruiting
- Movement to Music (M2M) Still Recruiting
- Birdies for Charity
- Glencoe Senior Health Fair
- U of AL-Huntsville "Get Up"
- "You are Loved" T-Shirts for Sale
- Living Well in AL (M4A)
- Panda Project Shelby County

NATIONAL FOCUS ON PD

- World Parkinson Coalition (WPC)
- Ending PD Red Letter Campaign
- Research Summaries from APDA

HELPFUL RESOURCES

- PD Helpmates Support Group (V)
- Central AL Support Group (Virtual)
- M4A Caregiver Support Group (V)
- UAB Post-Covid Help

PAA NEWS

- Parkinson's Disease (PD) Outreach
- How to support PAA

"You are Loved"

T-Shirts for Sale



Artist and PD Supporter, **Elizabeth Hubbard** (<u>Elizabeth K Hubbard Art</u>) has graciously offered to donate a portion of the proceeds from the sale of these precious long and short-sleeve T-shirts to PAA!









You can call Elizabeth's cell (205) 919-2385 or email her at: ekhubbard@bellsouth.net

Thanks Juarez Boxing for the fun photo shoot location!



UAB - UDALL PD STUDY (Still Recruiting)

The University of Alabama at Birmingham Department of Neurology/Movement Disorders

Healthy controls needed for research study looking at Parkinson's Disease - neuroinflammation.

Who are we looking for?

- PD individuals 50 years and older (preferably males over 65 without PD, particularly spouses, partners or other family members)
- Individuals with no history of autoimmune conditions or neurological disorders

What do I have to do?

- Complete a series of questionnaires and receive a neurological exam, memory testing, & blood draw
- If eligible and willing, participate in spinal fluid collection and PET/MRI scanning
- You will receive up to \$175 for completion of all study activities

If interested, please call 205-934-5954.

Greenwood Gravel Grind Saturday, April 17, 2021

Off-road cycling benefiting Davis Phinney Foundation. This beautiful ride has 50K and 100K route options and features a mega party at Tallahachie Flats afterward. Greenwood, MS. TO REGISTER ONLINE:

https://greenwoodgravelgrind.raceroster.com/



WORLD PARKINSON COALITION

World Parkinson Coalition (WPC) Virtual Congress: Advancing Science, Care, and Living with Parkinson's

Monday - Friday, May 17 - 21, 2021.

Topics presented during this five-day virtual program will include updates on:

Basic Science, Clinical Science, Treatment Options, Comprehensive Care, and Living with Parkinson's. The program will also include two 4-part wellness series as part of the week, looking at PT wellness and Speech/Voice wellness.

Registration opens April 1, 2021 and the fee to attend the five-day virtual event is **\$25**.

Additional information may be located at https://www.worldpdcoalition.org/page/WPCVirtual

UAB'S POST-COVID HELP

Patients who are still experiencing COVID-19 symptoms and want to learn more about **UAB's Post COVID Treatment Program** can call 205-975-1881.

If you have been diagnosed with Parkinson's disease, you may be eligible to participate in a program to learn how to exercise from home.

Guidelines for Exercise Training in Underactive Parkinson's Disease or GET UP.

GET UP is an exercise program designed to assist you through a home-based aerobic and muscle strengthening exercise program. The program also includes one-on-one conversations with a person who will step you through the program.

This guided exercise experience will last 16 weeks (4months).

Participants will receive

- One-on-one Zoom or telephone calls to guide you through the program
- Motivational and instructional newsletters
- Instructional videos of exercises on DVD
- Use of a Garmin VivioSmart activity monitor
- Elastic bands for muscle strengthening exercises
- \$50 compensation following completion of preprogram assessment
- \$50 compensation following completion of postprogram assessments

Duration

- Assessments performed at three time-points, from home, by Zoom or phone call
- 16-week at home exercise program
- No in-person contact
- No travel to a clinic or gym

Are you eligible?

- Age 40-80 years
- Diagnosed with PD and able to exercise
- Not currently engaged in an exercise program.
- No known cardiovascular disease

Aerobic and Strength Exercise



If you're unsure if you meet the requirements, call or email a member of the study team:

Shannon Mathis, PhD
Assistant Professor of Kinesiology at The
University of Alabama in Huntsville
Shannon.Mathis@uah.edu
Office: 256-824-2187

*Cell: 615-400-8740





BIRDIES FOR CHARITY PROGRAM TO START APRIL 1st CHIP IN FOR THE PAA!

Charity begins on the golf course at the Regions Tradition and Birdies for Charity is your opportunity to support Parkinson Association of Alabama. When you chip in to help PAA through the Birdies for Charity program, you can help make us a big winner! That's because as a participating charity, we will receive every single penny of the donations collected in this program, plus a bonus match of a minimum 5% on every dollar raised (in 2020 the match was 11%). Simply make a flat donation of \$20 or more, or a pledge of \$0.05 or more per birdie. A pledge per birdie is based off the total number of birdies made by PGA TOUR Champions players during the competitive rounds of the 2021 Regions Tradition. Please help us reach our goal by making a donation to PAA through the Birdies for Charity program! To make a donation, go online and donate here. The last day to submit your donation is Friday, June 25. Thank you in advance for your support!

Bibby Bailey, Executive Director, Parkinson Association of Alabama, Inc.



DRIVE-THROUGH SENIOR HEALTHFAIR



For more information contact:

Melanie Yancey-Council on Aging
of Etowah County
256-543-3616

HelpMates (Zoom)

A virtual support group for wives and companions of a PD loved one meets via Zoom the **second Tuesday of each month at 6 p.m.** This is an open group to talk about things happening and to provide information, ideas, and support to each other.

To Join Zoom Meeting:

https://us02web.zoom.us/j/2058354074?pwd= TG9hTzM3aDJGbDBHd3FXNIMzMWI0Zz09 Meeting ID: 205 835 4074 Passcode: 2058354074

Passcode: 2058354074

For more information email: **Vevelyn Peterson Wilson** at vevelyn.wilson@yahoo.com

M4A Caregiver Support (4/8/21)



CENTRAL ALABAMA PD <u>VIRTUAL</u> SUPPORT GROUP

This Support Group meets **virtually** on the 2nd & 4th Monday of each month at 10:00 A.M.

For more information and to join them, please contact:

Carolyn Goza (256) 245-6739 carolyntgoza@gmail.com

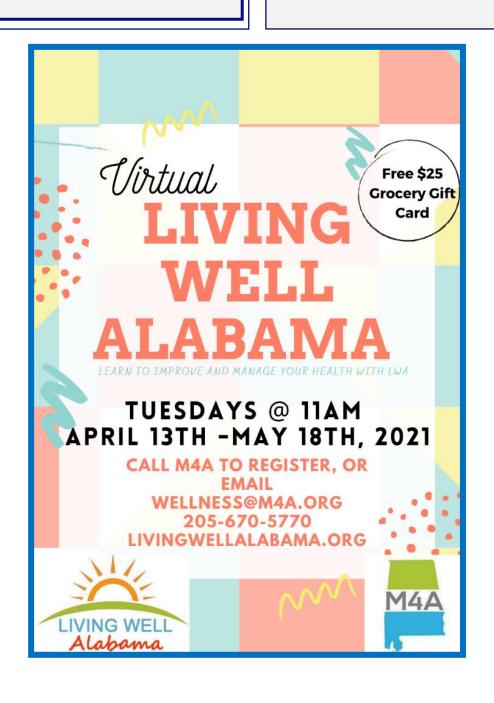
WE GIVE A DIME ABOUT PARKINSON'S

WE GIVE A DIME ABOUT PARKINSON'S RED LETTER CAMPAIGN

(It is not too late to mail the White House)

For more information: email INFO@ENDINGPD.ORG

To Register: Give A Dime Registration — Ending Parkinson's Disease: THE BOOK (endingpd.org)





Helping People with Dementia and Intellectual Developmental Disabilities Live in their Communities

The PANDA Project provides supportive services for People with Dementia (PWD), Aging Adults with Intellectual and Developmental Disabilities (IDD) and Caregivers in Shelby County, Alabama. We also help the caregiver through personalized training, intervention, homemaker and respite services, supplemental supplies, education, and legal assistance.

"I am 83 years old and live alone and my Doctor just diagnosed me with Alzheimer's Disease. I am still independent but need some extra support. I am so glad for the PANDA Project."

GETTING THE EXTRA HELP AND SUPPORT YOU NEED FOR YOUR LOVED ONE AT HOME.

"I am a caregiver for my 60 year old brother with IDD and need a lot of support for him to continue to live in my home.

PANDA has been such a great help!

CONTACT PANDA TODAY

Middle Alabama Area Agency on Aging (M4A)

(205) 670-5770 panda@m4a.org
www.m4a.org/panda





The PANDA Project is made possible through a grant by the Administration for Community Living (ACL).

Research Summaries

From the American Parkinson Disease Association (APDA)

"A Closer Look" (blog)

Emily Rocha, PhD was a grant recipient in 2015 from the APDA. Here is a brief summary of the results of that project and its potential implications for the PD community:

This project yielded very promising preliminary data. We concluded that overexpression of GBA (the gene that encodes GCase) can help to move more TFEB into the nucleus where it does its job. We also found that overexpression of TFEB can prevent accumulation of α -synuclein in a rat dopaminergic cell line.

Based on the preliminary data collected from this postdoctoral award we were able to move forward. We are now working with a start-up company based in Pittsburgh named Generian Pharmaceuticals. This company has developed a small molecule that uniquely allows TFEB to remain active longer. Based on recent preliminary data we have collected, we hypothesize that allowing TFEB to remain active longer is neuroprotective and prevents dopaminergic degeneration.

Serene Paul, PhD was a grant recipient in 2015 from APDA. Here is a brief summary of the results of that project and its potential implications for the PD community:

The potential implications of our findings are that (1) people with mild to moderate PD are capable of learning new tasks with practice, underscoring the importance of rehabilitation to improve and maintain function, and (2) as there is no evidence that levodopa hinders motor learning, the motoric benefits of levodopa may augment learning.

Rahul Srinivasan, PhD was a grant recipient in 2017 from APDA. Here is a brief summary of the results of that project and its potential implications for the PD community:

I discovered that the neuroprotective effect of a smoking cessation drug, cytisine occurs only in female mice and that estrogen and cytisine act in combination to exert neuroprotection. Thus, the APDA funding has enabled me to launch an entirely new research program in my lab focused on sex differences in PD, which I will be pursuing for the foreseeable future. My hope is to utilize knowledge gained from this research to develop a new class of neuroprotective drugs for PD, based on our understanding of sex differences in neuroprotection due to the drug cytisine.

For details, go to: www.apdaparkinson.org/blog

ADPA DISCLAIMER: Any medical information disseminated via this blog is solely for the purpose of providing information to the audience and is not intended as medical advice. Our healthcare professionals cannot recommend treatment or make diagnoses but can respond to general questions. We encourage you to direct any specific questions to your personal healthcare providers.

APRIL WEBINARS

DATE	PROVIDER	TOPIC	SPEAKER(S)	Website-Registration
4/1/21	PMD Alliance	Therapy Break-Voice Aerobics	Mary Spremulli, CCC- SLP, a speech- language pathologist	https://events.blackthorn.io/ en/2EmH006/g/ N9b0S61cMa/ therapy-breaktm-voice- aerobics-5a222E2utml/ overview
4/6/21	Davis Phinney	Health Disparities and Parkinson's: Understanding the Role of Trust	Altaf-Saadi, MD, MSC, and Consuelo H. Wilkins, MD, MSCI	https://secure2.convio.net/ dpf/site/SSurvey?SURVEY _ID=2165&ACTION _REQUIRED=URL ACTION USER _REQUESTS&autologin =true
4/6/21	Lewy Body Dementia Association	Ask the Expert: Managing Behaviors in Lewy Body Dementia	FL Medical Professionals	Ask the Expert: Managing Behaviors in Lewy Body Dementia - Lewy Body Dementia Association (lbda.org)
4/7/21	Boston Scientific	What Are My Options When PD Medications Aren't Enough?	Dr. Seth Kareus, Movement Disorder Neurologist	www.DBSandMe.com/ Webinar
4/9/21 to 4/10/21	Parkinson Study Group-Virtual Conference	Planning for Prevention of Parkinson's: A trial design symposium and workshop	Several Speakers	Checkout Page (accelevents.com)
4/14/21	APDA	Dr. Gilbert Hosts: Hacks, Tricks & Medication Tweaks to Improve Your Movement and Your Day with Dr. Joseph Friedman	Dr. Rebecca Gilbert & Dr. Joseph Friedman	Dr. Gilbert Hosts: Hacks, Tricks, & Medication Tweaks to Improve Your Movement and Your Day with Dr. Joseph Friedman APDA (apdaparkinson.org)
4/20/21	PMD Alliance	How to Help Your Loved One with Movement	Teepa Snow, MS, OTR/L	Overview: Spotlight® Online- How to Help Your Loved One with Movement: Blackthorn: Events
4/21/21	PMD Alliance	Managing the Return of Parkinson's Symptoms with a Unique Inhaled Treatment	Michael Soileau, MD	Overview: Managing the Return of Parkinson's Symptoms with a Unique Inhaled Treatment: Blackthorn : Events
4/27/21	Boston Scientific	Deep Brain Stimulation: How Well Does It Work and How Safe Is It?	Dr. Casey Halpern, Neurosurgeon and Traci Hornbeck, PA-C	www.DBSandMe.com/ Webinar
4/28/21	APDA	Sing Loud for PD	Dr. Rebecca Gilbert	Meeting Registration - Zoom
4/29/21	PAA/Sunovion	Understanding OFF Times When PD Symptoms Return	Dr. Daniel D. Dees, MD Neurology Specialist in Mobile, AL	https://zoom.us/j/99394699527 (312) 626-6799 (CT) Meeting ID: 993 9469 9527 Passcode: 5409191

The PAA is proud to invite you to a FREE upcoming webcast:



Understanding OFF Times When PD Symptoms Return

Thursday, April 29, 2021 2:00 p.m. CT

Details:

- Hear from a Parkinson's disease specialist.
- Learn about OFF times (when PD symptoms return)
- Pick up tips on how to manage living with Parkinson's disease.

Speaker:

Dr. Daniel D. Dees, MD Neurology Specialist in Mobile, AL

Program registration link: https://zoom.us/j/99394699527

Passcode: KYNMOBI

+1 646 558 8656 US (New York) Audio +1 312 626 6799 US (Chicago)

Number: +1 301 715 8592 US (Washington DC)

+1 253 215 8782 US (Tacoma) +1 346 248 7799 US (Houston) +1 669 900 9128 US (San Jose)

Meeting ID: 993 9469 9527

Passcode: 5409191

UAB / Lakeshore Research Collaborative

(Still Recruiting)







RESEARCH COLLABORATIVE

promoting the health and wellness of people with disabilities

Movement-to-Music (M2M) Exercise Program



The M2M Program is a rhythmic-based exercise program delivered through a web-based platform in which you can actively engage from the comfort of your home.

You may be able to participate if you meet the following criteria:

- Diagnosed with one of the following: traumatic brain injury, spinal cord injury, spina bifida, cerebral palsy, stroke, Parkinson disease, or multiple sclerosis.
- Between 18 and 70 years of age.
- Have stable cardiovascular conditions.
- Have not participated in a similar research study in the past 6 months.

Please contact Lori Theriot, Recruitment Coordinator, for more information

> (205) 313 - 7455 M2MStudy@uab.edu

PAA's New Program Offering

Parkinson's Disease (PD) Outreach

The PAA's Parkinson's Disease Outreach program is designed to provide telephone support and companionship to individuals with PD. Our trained volunteers develop relationships with people with PD via phone calls to those who are lonely, isolated, and in need of friendly and supportive conversation.

Clients may enter the program by contacting the PAA Care Navigator at 833.473.5465 or through email at pdnavigator@pdlink.org and requesting this service.



Join our Mailing List! <u>Email us</u> your mailing address and you will receive any information that we send out.

AND...PLEASE GIVE to the PAA!

To give Memorials, Honorariums, or a general donation, please go to this link:

Give - Parkinson Association of Alabama (parkinsonalabama.com)

We appreciate you!



Bibby S. Bailey
Executive Director
Parkinson Association of Alabama
www.parkinsonalabama.org
833.473.5465

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