

6310 LBJ Freeway Suite 213 Dallas, TX 75240 (972) 620-7600 www.daps.org

MAY 2022

Blooming...Where We're Planted

Message from Executive Director Leisha Phipps



A couple of months ago someone stopped by the DAPS office and gave Andrea and I a lovely orchid. It was beautiful – just like the ones you see at the nurseries and the grocery stores. If you aren't familiar with orchids, they have a reputation for being difficult to maintain and bloom (ESPECIALLY once they've been purchased and transferred to a new home). It wasn't long after receiving the orchid, the blooms began to drop. We weren't really surprised, acknowledging that when it came to orchids, neither of us ever had

any success at keeping them alive long enough to bloom again.

Nevertheless, we persisted and followed the instructions. We placed it in a location that got the right amount of sun, away from drafts and began to water it as directed. After some time, we both realized we had neglected to water it regularly. We started to water it again, thinking maybe we could just keep the plant alive. After all, having something green in an office space is a nice touch, right?

Last week I went to water the orchid and for the first time in my life, I saw 2 buds that were starting to bloom. I was shocked! It had been mildly neglected, probably needs to be repotted and has two inexperienced caretakers in charge of its survival. In the most unlikely of circumstances, our little orchid is showing signs of growth, resiliency and purpose. It has refused to get discouraged, it has sought out the light from the nearby window and it has managed to root itself in a flower pot that it outgrew a while ago.

As we all are growing at various paces and in different directions, I hope that you'll take the time to appreciate where you are blooming. It might not be where you expected or wanted to bloom, but that doesn't mean that it won't happen. If you can't see the buds or begin to doubt their ability to bloom, don't give up. You may be surprised where you'll blossom.

Kindest regards,

Leisha Johiggs

MAY EDUCATIONAL SERIES

Monday, May 9, 2022 11:00 a.m.

TOPIC

Nonmotor Symptoms of Parkinson's Disease

PRESENTED BY

Mazen Elkurd, DO

Tuesday, May 17, 2022 11:15 a.m.

TOPIC

I Break for Moments - Not Parkinson's

PRESENTED BY

Nirav Pavasia, MD

Monday, May 23, 2022 11:30 a.m.

TOPIC

Moving Forward: Learning more about PD & how it advances

PRESENTED BY

Nirav Pavasia, MD

Event information & speaker bios on Page 2.

INSIDE

educational series info 2

non-event final month 3

lifetime achievement award 4

volunteer spotlight 5

find act of 2021 6

memorials, honors, donations 7

class schedule 8

other classes & resources 9

thank you sponsors 10



Dedicated to impacting and improving the lives of those affected by Parkinson's disease

> **Executive Director** Leisha Phipps, MSW

Board of Directors

Martha Bonilla, President Robbie McCullough, Vice President Chuck Stewart, Secretary Marcie Salamone, Treasurer

Jo Klein Jim Armington Michael Braitsch Steven Markel Jared Caplan Michael McGiboney Stephen Holman **Greg Rector** Beth Jacobs **Chuck Stewart** Harold Kellogg

Advisory Council

Sarah Atwood Charlene Noe Ben Casey Sandi Pautler Carlie Dorshaw-Moe Joyce Susman Pat Goukler Barbara Taylor Shirley Hand

Medical Advisory Board

Michael Braitsch, PT, DPT Shilpa Chitnis, M.D., Ph.D. Richard B. Dewey, Jr., M.D. Mazen Elkurd, D.O. Rasheda El-Nazer, M.D. Thomas D. Franklin, Jr., Ph.D. Richard L. Fulbright, Ph.D. Dwight C. German, Ph.D. June Levitt, Ph.D., LDT, CCC-SLP Aashoo Mentreddi, M.D. Brad McDaniels, Ph.D., CRC Padraig O'Suilleabhain, M.D. Nirav Pavasia, M.D. Alexander Peralta, M.D. R. Malcolm Stewart, M.D. Aanchal Taneja, M.D.. Gary L. Tunell, M.D.

Community Engagement Consultants

Drs. Charles & Susan Sterling

DAPS Staff

Andrea Carter, Office Manager Belyne Bland - Xochihua, Community Liaison

Newsletter

Pam Michel, Production Editor

The DAPS newsletter is published monthly as an information guide only, and does not serve as legal or medical advice.

MAY EDUCATIONAL SERIES INFORMATION AND SPEAKERS

May 9, 2022

Non-motor Symptoms of Parkinson's Disease **Preston Hollow United Methodist Church** 6315 Walnut Hill Lane **Dallas. TX 75230**

Meeting sponsored by



Mazen Elkurd, DO

Baylor University Medical Center, Dallas



Dr. Mazen Elkurd is a board-certified neurologist with additional fellowship training in movement disorders. He has strong interests in Parkinson disease, tremors, dystonia, and other movement disorders. Dr. Elkurd has published numerous peer-reviewed papers in the area of movement

disorders. He is involved in education of medical students and residents as well as numerous professional organizations locally, nationally and internationally.

May 13, 2022

I Break for Moments - Not Parkinson's

St. Gabriel the Archangel Church 110 St. Gabriel Way McKinney, TX 75071





Nirav Pavasia, MD Neurology Consultants of Dallas

Dr. Nirav Pavasia is a Certified Movement Disorders Specialist and a Board Certified General Neurologist. Dr. Pavasia found his passion in movement disorders through the challenges of treating Parkinson's disease and other movement disorders. He believes in a multidisciplinary

approach to patient care and loves to connect with his patients. He manages patients with Deep Brain Stimulation (DBS) for initial programming and subsequent follow up care.

May 23, 2022

Moving Forward: Learning more about PD and how it advances

First United Methodist Church 403 S Main Street **Duncanville, TX 75116**

Meeting sponsored by abbvie

SPEAKER: Nirav Pavasia. MD

Neurology Consultants of Dallas



MAY IS THE FINAL MONTH FOR OUR NON-EVENT.

WE HOPE YOU WILL JOIN US!

DONORS WILL BE RECOGNIZED IN THE
JULY NEWSLETTER.

SUPER ELLES



GIVING LEVELS

THE HULK..... \$ 15,000 +

BATMAN..... \$ 10,000 +

SPIDER-MAN...... \$ 5,000 +

SUPERMAN..... \$ 2.500 +

WONDER WOMAN.... \$ 1,000 +

| RON MAN..... \$ 500 +

BLACK PANTHER.... \$ 250 +

CAPTAIN AMERICA... \$ 100 +

BLACK WIDOW up to \$99

HAT IS A NON-EVENT?

The Non-Event is an excursion into our imaginary theme. We ask you to join in the fun of a playful journey; no need to schedule flights, buy tickets, pack a suitcase or clear your calendar. Just jump into your Superhero mindset and enjoy. Non-Event is also the largest single fundraiser that DAPS conducts every year and is critical to meeting our annual needs. This way, DAPS can continue to provide FREE essential services to people impacted by Parkinson's disease.

MOW TO GIVE:

- Go online to daps.org and use the Non-Event Donation button.
- Call the DAPS office with your credit card info.

Help DAPS reach the \$30,000 goal!

Highlights from the 2022 Kenneth H. Cooper, MD, MPH Lifetime Achievement Award

This year's Lifetime Achievement Award included virtual elements from when our awardee, Davis Phinney, was presented with the award.

Davis Phinney is an Olympic Bronze medalist and Tour de France stage winner who has celebrated the most victories of any cyclist in American history. From the late 1970s until his retirement from professional

cycling in 1993, Davis achieved more wins—328 victories in all—than any other US cyclist.

Davis was diagnosed with Young Onset Parkinson's Disease (YOPD) in 2000. He started the Davis Phinney Foundation for Parkinson's to promote and fund innovative research that seeks to improve the



quality of life of those living with Parkinson's

The Foundation has expanded far beyond research to become a leading source for education and resources to help people with Parkinson's take action to live well today.

Also recognized, was DAPS volunteer, Nikhil Sampath, for his help in implementing the Community Tulip Project.

Oragami tulips were made and displayed in wreaths at the Lifetime Achievement Award luncheon. The red tulip wreath was made from 164 oragami tulips representing the number of people diagnosed daily with PD in the United States. Read more from Nikhil on Page 5.









Volunteer Spotlight



Nikhil Sampath



My passion for Parkinson's disease (PD) is a tribute to my grandfather. He was diagnosed with Parkinson's well before I was born, and as a result, I never formed the connection every grandchild desires. Everything I know about him, I learned from family members. Sadly, as I grew up, he deteriorated. From a very young age, I was cognizant of the enormous effect PD has, and it always confused me. My childlike innocence clouded the futility of the disease and I was hurt by the emotional stress it placed on my entire family. When I was 11, my grandfather passed away, leaving a kernel of grief in my heart that remains to this day. After his passing, I vowed to use my grief and my intimate understanding of the struggle PD patients and their families go through to make a positive difference in the world, a motivation that directly led to my work with DAPS.

I have always been fascinated by the ability art has to span cultural, linguistic, and regional boundaries. It connects the entirety of humanity, and is one of the few universals to which all members of society can relate. One of my favorite forms of art is origami. I love how it creates abstractions of the natural world using paper, and from the time I was 6 years old, I have been constantly folding something or another. Every time we went to India to visit my grandparents, I would make sure to bring some paper with me. It offered me solace on the endless 18-hour flights, and the lazy afternoons on the porch of my grandparents' home lent themselves well to origami.

I remember one instance when I folded a small cat out of a square of purple tissue. It was a flimsy piece of paper, but I was still able to finish the model. When it was done, I placed it atop a wall phone for everybody in the house to see. My cousin, who was very young at the time, was excited by the new decor. She scooped it up in her little hands, and toddled over to my grandfather, who was sitting quietly. As she handed the cat to him, their hands met, and for

a brief moment, I could have sworn he smiled. That afternoon, I realized something incredibly important. Through origami, I could nurture a much needed connection with my grandfather. I began to fold more models, some simple, some complex, all of them infused with my desire to see that smile once more. My grandfather watched intently, sometimes mumbling questions, sometimes sitting in tranquil silence. I explained everything to him, discussing the intricacies of each fold, and the subtleties of each model. Those days were a defining period in my life. By some miracle, I was handed a key that allowed me to finally connect with my grandfather, who I feared was too far away for me to ever reach. This is what inspired the tulip project.

In last few months, I've taught many people, some old and some young, how to fold a tulip. Some had Parkinson's, some knew people with Parkinson's, and some just wanted to make paper flowers. Above all else, everyone who folded a flower appeared happy with the whole process. One class was at a local nursing home. It was a small group with only 10 people, but all of them, once the class was done, began to laugh and compare their tulips, commenting on how fun they were to make. They all looked so happy with their tulips, I decided not to take them. I let them keep the flowers. Some of them attached the tulips to their walkers, others hung them up, and a few kept them in their purses. The tulip project wasn't about making a tangible product for display as much as it was about fostering a sense of community that connected people under the umbrella of PD awareness, like how I found a connection with my grandfather.

Parkinson's is a common disease, but it doesn't necessarily have awareness that correlates with this. One way to improve the lives of people diagnosed with PD is to help them cope with their struggles, while helping others who have no experience with the disease understand its impacts. The Community Tulip Project successfully connected nearly 1000 people from all walks of life, all ages, nationally and internationally. I could not have done it without the support of my parents, DAPS, and countless others. It was a far-fetched idea—using origami is a rather unconventional approach to raising awareness. Nevertheless, I succeeded, and anyone reading this has the potential to do the same. My involvement with the PD community doesn't end here, and yours shouldn't either. I implore each and every one of you to try and form your own connections, support groups, and make waves in your own communities.

The Facilitating Innovative Nuclear Diagnostics (FIND) Act of 2021

Along with 71 other organizations around the country, DAPS signed a letter that went to Washington, DC to advocate for early diagnosis of diseases like PD using advanced nuclear diagnostic sources. The legislation being considered is *The Facilitating Innovative Nuclear Diagnostics (FIND) Act of 2021 (H.R. 4479)*.

Improving health outcomes often starts with early and accurate diagnosis. Recent innovations in nuclear medicine now allow physicians a safe, non-invasive way to gather specific medical information that would otherwise be unavailable or only available through surgery.

With each passing year, newer, more precise diagnostic radiopharmaceuticals are used in nuclear medicine procedures, which aid clinicians ability to diagnose and plan the most effective treatment pathway for diseases, such as Alzheimer's, Parkinson's, advanced cardiovascular, and cancers of the prostate, neuroendocrine system and breast. All diagnostic radiopharmaceuticals are statutorily considered drugs but are treated as supplies by the

Centers of Medicare & Medicaid Services (CMS).

20 million Americans benefit from nuclear medicine procedures annually, but more can be done to increase access to advanced nuclear diagnostic tests, which can provide for more accurate diagnosis and treatment plans, saving both the patient and Medicare from unnecessary or inappropriate testing. Oftentimes, the only thing standing in between the patient and the nuclear medicine therapeutic is access to the appropriate PET scan. H.R. 4479 is a bipartisan, bicameral, budget neutral legislation that would direct CMS to pay separately for all diagnostic radiopharmaceuticals with a per day cost that exceeds \$500 and were FDA-approved on or after January 1, 2008. This policy will safeguard Medicare beneficiary access to the most appropriate diagnostic radiopharmaceuticals and help spur continued innovations in nuclear imaging studies.

To see the letter in full, please visit: https://bit.ly/FIND_ACT_hearing_letter.



GEMs are donors who Give Every Month.

Our GEMs are very valuable! Sign up on the DAPS website.

Anonymous Hattie E Anderson James Armington Sarah Atwood Laura Boyle Shirley Brouillette Dean Brown John & Wanda Call Jared Caplan Larry Christensen Mitzi Clark **CNC Homecare** Bruce & Janiece Crozier **David Crozier** Kim Dague John Davis Christine Dobson Richard & Rita Doelling Raul & Jill Dominguez **Betty Dorsey** Carlie Dorshaw-Moe Dr. Lee & Kay Egbert

Bentley & Iris Foster James Foy Karen George Bruce Gibbs Barbara Glass Barry & Pat Goukler Steven Holman Geri & Harold Kellogg Jo & Bert Klein Leon & Marilyn Levin Scott MacPherson John Marty Robbie McCullough Chip & Ginny Melara Pam & Matt Michel Donna Miles Mike Miles Bobbi & John Myers Rod Myers Susan Norvell Tom & Cecilia Paida Sandi Pautler

Leisha Phipps Fred Ransdell John Rapier Greg Rector Marguerite Riccardi Yolanda Russell Salvatore & Marcie Salamone Adana & Samuel Sanford Nancy Scaramella Charles Schlinke **Charles Stewart** Joyce Susman Dr. Chad Swank Linda & Mike Swanson Randy Visser John & Ruth Walker Carole Ann Watson Michele White Diana Winkelmann Sharon & Greg Wood

3000



Memorials • Honors • Donations

March 2022

In memory of John William Morton

From: Rehrig Pacific Company

In memory of Donald Curtis Ramp

From: Holly, Mark, Whitney, CJ and the girls

Liz & Jim Currie Pam & John Hughes

Marla Lacy Helene Morris Kathy Nardelli Andy O'Connell

Paul & Lynn Slaney Silguero

Bonnie Sueflohn

Mac and Bob Spitzer Fund at the Community Foundation of Sarasota County

In memory of Floyd P Wilson

From: Betty & Raymond Jones

Facebook Fundraiser

From: Shannon Brown
Diana Fazakerly
Sharon Hockensmith
Catheryne Jarmakowicz
Leisha Scott Phipps

Brent Scott

Donations to DAPS

From: J'Anna Barrington Gina Borgognoni Bryan Brown

Rosemary Edwards
Cecilio Garcia
Mary Hempkins
Velma Marsh
Helene Morris
Sharon Saller
Annette Schlaf
Rich Self

Pamela Welsh Donna Kay Wright DAPS @ Hunters Glen DAPS @ McKinney









Thank you for sponsoring the Community Tulip Project



Dallas Area Parkinson Society

exercise • speech • support groups

6310 LBJ Fwy Ste 213 Dallas, TX 75240-6400 972-620-7600 daps@daps.org

For the best of both worlds, check out our HYBRID classes where you can attend in person or virtually.

MONDAY		1:00	Exercise with Tammy via Zoom	
9:30	Exercise with Tammy		(For the link, see www.daps.org)	
	South Garland Baptist Church			
9:45	Exercise with Angie via Zoom	<u>THUF</u>	<u>THURSDAY</u>	
	(For the link, see www.daps.org)	9:30	Exercise & Voice Support with Barb	
10:30	Exercise & Voice Support with Tammy		South Garland Baptist Church	
	South Garland Baptist Church	9:40	Exercise with Erika	
2:00	Exercise with Jonathan		Hunters Glen Baptist Church, Plano	
	First United Methodist Church of Duncanville	10:15	Exercise with Tammy HYBRID	
3:00	Speech with Danielle		Preston Hollow United Methodist Church, Dallas	
	First United Methodist Church of Duncanville	10:30	Exercise with Barb	
*3:00	Care Partner Support Group with Belyne		South Garland Baptist Church	
	First United Methodist Church of Duncanville	10:30	Care Partner Support Group with Zee	
	* 1st & 3rd Monday of the month		South Garland Baptist Church	
		10:45	Speech with Pat HYBRID	
TUESDAY			Hunters Glen Baptist Church, Plano	
9:15	Exercise with Barb via Zoom	12:30	Exercise with Barb	
	(For the link, see www.daps.org)		Semones YMCA, Dallas	
10:15	Exercise with Amanda	2:00	Exercise with Jonathan	
	St. Gabriel the Archangel Church, McKinney		First United Methodist Church of Duncanville	
*10:30	People with PD Support Group with Belyne via Zoom	2:00	Dance for PD with Misty via Zoom	
	* 1st & 3rd Tuesday of the month		(For the link, see www.daps.org)	
	(For the link, see www.daps.org)			
11:30	Speech with Lynn HYBRID	FRID/		
	Preston Hollow United Methodist Church, Dallas			
12:30	Exercise with Barb	10:00	Exercise with Tammy	
	Semones YMCA, Dallas	44.45	St. Gabriel the Archangel Church, McKinney	
1:00	Speech with Pat via Zoom	11:15	Speech	
	(For the link, see www.daps.org)	*44.45	St. Gabriel the Archangel Church, McKinney	
2:00	Dance for PD with Misty via Zoom	*11:15	Care Partner Support Group	
	(For the link, email Misty - danceforpd.dallas@gmail.com)		St. Gabriel the Archangel Church, McKinney * 1st & 3rd Friday of the month	
WEDNESDAY		*2:00	NEW! Speech/Swallowing FAQs with June via Zoom	
9:30	Exercise with Tammy		* 2nd Friday of the month between 2-4PM	
2.00	Lakepointe Church at White Rock, Dallas			
10.00	Exercise with Diana via Zoom	SATU	IRDAY	

9:30	Exercise with Tammy	
	Lakepointe Church at White Rock, Dallas	
10:00	Exercise with Diana via Zoom	
11:00	Speech with Lynn HYBRID	
	Grace Lutheran Church, Carrollton	

CLASS LOCATIONS

Preston Hollow UMC

6315 Walnut Hill Ln, Dallas (214-363-4393)

First United Methodist Church of Duncanville

403 S Main St, Duncanville (972-298-6121)

Enter on Ave. C, Aldersgate Building

Semones Family YMCA (Town North)

4332 Northaven Rd, Dallas, Rm MP2 (214-357-8431)

Lakepointe Church at White Rock

9150 Garland Rd, Dallas (214-324-1425)

Grace Lutheran Church

1200 E Hebron Pkwy, Carrollton (972-492-4474)

Exercise with Diana via Zoom (For the link, see www.daps.org)

South Garland Baptist Church

1330 E Centerville Rd, Garland (972-271-5428)

St. Gabriel the Archangel Church

110 St. Gabriel Way, McKinney (214-548-4357)

Hunters Glen Baptist Church

4001 Custer Rd, Plano (972-867-1610)

Other Classes Resources

New Class!



THE PRESTON

OF THE PARK CITIES

Join us for a new Move. Laugh. Connect. class on Tuesdays at 2:30 p.m.



Do you have questions about how speech and swallowing are impacted by PD? DAPS Medical Advisory Board member and speech pathologist, June Levitt, is available via Zoom on the 2nd Friday

of each month, from 2-4 PM. Join at any time to ask questions and learn more about when or if a speech assessment might be helpful for you or vour loved one:

> Friday, May 13, 2:00-4:00 Meeting ID: 556 087 4938 PW: LOUD

Tribe Wellness Group Classes

TRIBE Boxing, tai chi, and yoga groups are available of the second and in-person with discounted pricing for DAPS members.

In-person classes Wednesdays at 1:30 pm at Preston Hollow United Methodist Church.

Class size is limited to 15; please reserve your spot.

See the full class calendar at www.tribewellness.org/calendar.

For more information, please contact tribewellnessllc@gmail.com.

Updated Protocol for

"In-Person" Groups

The health and safety of DAPS members, instructors and staff and service providers has always been at the forefront of our mission. Procedures and policies have been revised according to guidelines for the Center for Disease Control (CDC).

DAPS new guidelines highly recommend individuals to wear masks due to the higher risk population that we serve, but masks are not required.



ACADIA

Thanks to a generous grant from our friends at Acadia, DAPS is now able to provide additional classes at our Preston Hollow and McKinney locations, through the Parkinson's **Comprehensive Care Initiative!** In addition, the Initiative helps support noncontact boxing through Tribe Wellness at Preston Hollow. Learn more at

www.moretoparkinsons.com.

yowa Kirin

THANK YOU

for sponsoring the **Dallas and Plano Exercise and Speech** classes.



Dallas Area Parkinson Society



THANK YOU TO OUR SPONSORS FOR THE LIFETIME ACHIEVEMENT AWARD LUNCHEON!

We couldn't have done it without your generosity.



abbvie











Connect with DAPS!







facebook.com/daps.us



instagram.com/daps.us



Sign up for DAPS monthly e-news!

Disclaimer: The contents or opinions expressed in this newsletter are those of the individual writers or presenters and do not constitute an endorsement or approval by DAPS staff. Please consult your personal physician regarding your individual medical problems.