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MARCH 2021

Doing Good

Message from Executive Director Mike Miles



Every day our lives are inundated with breaking news, local news, state news, national news, international news, and, of course, good news and bad news. Today I find myself thinking of the old phrase, “No news is good news.” Although I can understand the reasoning behind that, I have to admit I am a news junky. I like to hear the news, especially on the hot topics of interest on any given day. But even if you are one who generally avoids news, most everyone enjoys hearing good news.

So, I want to share some good news. Here’s the headline:

DAPS is Doing Good

Lest someone quickly points out my poor grammar, let me explain. First of all, DAPS is doing well despite the challenges of 2020. More importantly, we continue to fulfill our mission: *Dedicated to impacting and improving the lives of those affected by Parkinson’s disease.* As we have found new ways to accomplish that mission, we are doing good things!

Isn’t it refreshing to hear good news? In the DAPS office, we often hear stories about how DAPS makes a difference in people’s lives. Every once in awhile, we learn about people who have been touched by our programs in unexpected ways. Recently, we received a letter containing a testimony that we think everyone should hear. Please don’t miss Gretchyn’s story on [Page 3](#). We asked for and received permission to share it. It is especially encouraging at this time to receive news that DAPS is doing good—doing good work, doing good things, and doing good for the people we serve.

MARCH EDUCATIONAL SERIES



**Monday, March 8
2:00 p.m.**

TOPIC:
Taking ON Parkinson’s Disease

**Thursday, March 11
12:00 noon**

TOPIC:
Cookin’ with Chitnis

**Wednesday, March 17
1:00 p.m.**

TOPIC:
Prosperity: 3 Questions that Predict Your Quality of Life

**Thursday, March 25
11:00 a.m.**

TOPIC:
A Different Path to Treat OFF Time in Parkinson’s Disease

[Webinar links and speaker bios on Page 2](#)

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

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

MARCH EDUCATIONAL SERIES SPEAKERS:



March 8, 2021

Taking ON Parkinson's Disease

Nirav Pavasia, MD

Neurology Consultants of Dallas

When it comes to living with PD, knowledge really is power. Attending an event—either in person or online—is a great way to learn more about how you can take on Parkinson's (while making some friends along the way).

Please click the link below to join the webinar:

<https://w2ogroup.zoom.us/j/93510864697>



March 11, 2021

Cookin' with Chitnis

Shilpa Chitnis, MD, PhD

Professor of Neurology at UT Southwestern Medical Center

Join us for a live cooking demonstration with DAPS Medical Advisory Board member Dr. Shilpa Chitnis. Be a part of the feast and learn a new, easy, and PD-friendly meal. A list of the ingredients you'll need will be posted to the DAPS website and social media. Send your PD nutrition questions to daps@daps.org or ask Dr. Chitnis directly during the meeting.

Please click the link below to join the webinar:

<https://us02web.zoom.us/j/85626615550>



March 17, 2021

Prosperity: 3 Questions that Predict Your Quality of Life

Jeff Kort — Certified Financial Planner

This engaging seminar will help you plan for a financially secure retirement by considering these three questions: Who will...? How will...? When will...?

Please click the link below to join the webinar:

<https://us02web.zoom.us/j/87656695291>



March 25, 2021

A Different Path to Treat OFF Time in Parkinson's Disease

Raja Mahanna, MD

Associate Professor of Neurology UT Health Science Center, Houston

Dr. Mahanna has been in practice since 1995 and is dedicated to providing his patients expert diagnosis in all aspects of movement disorders and offering individualized treatment options.

Join us to learn about NOURIANZ™, a prescription medication used with levodopa and carbidopa to treat "off" periods in Parkinson's disease.

Please click the link below to register for the webinar:

<http://www.pharmethod.com/KYOWAKIRIN/register>

Gretchyn — A DAPS Testimonial



When we think of COVID-19, we may think of our feelings of loneliness, isolation, frustration, and wondering when this will end. We know that there is an end in sight, and that there is relief, but unsure of when.

This is what a diagnosis of Lewy Body Dementia feels like for my mom—an indefinite sentence, but without the promise of an earthly relief. My mother, Karen, was a professional figure skater before she committed to a 30-year career in special education and raising four children financially as a single parent. Her sense of humor and quick wit are appreciated by those who know her, and she still “zings” us unexpectedly with her clever quips. She was always light on her feet and known to dance with us in the kitchen. She now struggles to find her words. They are often in her head but she can’t pull them out. She cannot move her body or will her feet to move sometimes. Her memory fades fast, and she has felt alone with her symptoms.

The assisted living community where she was living prior to COVID-19 offered fantastic movement and dance classes that she loved and she was committed to doing these three days a week for an hour and a half each time. It kept her going. The people she was able to socialize with gave her a tribe that she was missing for years after retiring from her school in New York. She had spent her years navigating raising her children without thought to a social circle that would sustain her after we flew the nest.

Fast Forward:

Last year Mom’s facility was locked down, isolating the residents, and the effects were evident in her both cognitively and physically. My husband and I decided to move her in with us

to our small farm. With our two daughters, horses and dogs, we thought the interaction would be good for her. Later last year, Mom found out that her beloved older brother, Jeff, was diagnosed with Parkinson’s disease, and she felt some common ground in that he was able to share some of her symptoms, experiences, and struggles. Jeff, being the magnanimous, kind brother he is, introduced Mom to the idea of her joining your program at DAPS and shared the details with us.

As her primary caregiver, I can’t express how grateful I am for all of the thought that goes into the outreach of your program, the ease of use and accessibility. Your simple calendar with speech and exercise under one umbrella is just what we needed but are missing here in Oregon. I am juggling a full-time job, two grade school children learning from home, and the chores that are required of residing on 7 acres with animals. It is time consuming to try to find resources, navigating separate schedules from different practitioners, and then work her through the barrier of anxiety that often comes with trying something new. Quite honestly, the responsibilities and tasks sometimes feel endless.

By DAPS offering a virtual space, you have reconnected siblings that are 75 and 80-years old, living thousands of miles apart during one of the most difficult trials in their lives—navigating this horrible disease. Your programs have opened the doors giving my Mom a sense of belonging and community with people who share her struggle, and a renewed confidence and strength. She would much rather be on your call than at a speech therapy appointment.



DAPS has also provided the opportunity for my children to witness their Grandmother persevering and the example to not give up when things get hard. Please know the work you do and how you are doing it positively impacts so many. I am just one testimony. Thank you so much for giving my Mom renewed hope. Thank you for bridging the many miles between siblings who really need each other right now. I hope you do continue to maintain this schedule online when our country and the world opens back up.

I LOVE THE 60s!

The 1960s produced some of our all-time favorite music. The British Invasion roared throughout America with the Beatles and The Rolling Stones. Elvis Presley and Aretha Franklin gained titles as the King of Rock and Roll and the Queen of Soul respectively. These are just a few of the iconic musicians that shaped this decade of music.

For this year's DAPS Non-Event Fundraiser, we invite you to join us as we fondly remember some of our favorite songs and artists from the '60s. Let's have a rocking good time as we recall our music favorites and perhaps call to mind fond memories of our youthful days in the '60s.

Whether Parkinson's has touched you and your family personally or you are a supporter of the work that DAPS does, let's all "Come Together" as the Beatles sang in the '60s and support the important work that DAPS provides to those impacted by PD.

WHY IS IT CALLED A NON-EVENT?

We select a theme and then build an imaginary excursion or event around that theme. We ask you to join in the fun of this imaginary journey. There's no need to schedule flights, buy tickets, pack a suitcase, or clear your calendar. Together, we will enjoy this imaginary experience while making very real donations to support DAPS. Every gift of any size is important and helps us reach our goal.

HOW DO I GIVE?

Go online to <https://daps.us> and use the Non-Event Donation button; or call the DAPS office at 972-620-7600.

AN ANONYMOUS DONOR WILL MATCH UP TO \$25,000 OF CONTRIBUTIONS MADE TO THE NON-EVENT!



GIVING LEVELS

	\$ 10,000 +	<i>Twist and Shout</i> by The Beatles
	\$ 5,000 +	<i>Sweet Caroline</i> by Neil Diamond
	\$ 2,500 +	<i>Jailhouse Rock</i> by Elvis Presley
	\$ 1,000 +	<i>Respect</i> by Aretha Franklin
	\$ 500 +	<i>Good Vibrations</i> by The Beach Boys
	\$ 250 +	<i>Ain't No Mountain High Enough</i> by Marvin Gaye and Tammi Terrell
	\$ 100 +	<i>I Can't Get No Satisfaction</i> by The Rolling Stones
	up to \$ 99	<i>Fly Me to the Moon</i> by Frank Sinatra

WHAT IS A NON-EVENT?

The Non-Event is the largest single fundraising event that DAPS conducts every year and is critical to meeting the annual budget. Money raised during the Non-Event helps DAPS continue to be on the forefront of serving the Parkinson's community in the Dallas area and beyond. With your support to the 2021 Non-Event, DAPS is able to provide **FREE** essential services that help people impacted by Parkinson's disease live active and fulfilling lives.

Sleep Disorders in Parkinson's Disease

by Shilpa Chitnis, M.D., Ph.D., FAAN, FANA

Professor of Neurology at UT Southwestern Medical Center

Parkinson's disease (PD) is the second most common neurodegenerative disorder and affects 1-2% of adults over the age of 65 years. Its cardinal motor features are bradykinesia, rigidity, and tremor at rest. However, non-motor features have also been recognized as important constituents of PD and have marked effects on quality of life. Sleep disorders were found to be the second most prevalent non-motor feature in the PRIAMO study and up to 90% of PD patients experience some form of sleep dysfunction.

Sleep is divided physiologically into REM (rapid eye movement) and NREM (non-rapid eye movement) stages. These stages run cyclically throughout the night. Sleep disorders in PD include insomnia (difficulty with initiation and/or maintenance of sleep), excessive daytime sleepiness (EDS), restless legs syndrome (RLS), periodic limb movement of sleep (PLMS), REM sleep behavioral disorder (RBD), and obstructive sleep apnea (OSA). The pathophysiology of sleep disorders in PD is likely multifactorial due to underlying damage to key regions involved in sleep regulation and/or side effects of medications. There is a loss of hypocretin neurons in PD patients; hypocretin is known to promote wakefulness. Alterations in hormonal rhythms such as those of cortisol and melatonin are also seen in PD patients.

Excessive daytime sleepiness can impair alertness and the ability to stay awake, and can cause patient safety issues. Altered sleep architecture and disrupted sleep patterns may lead to EDS, but medications, especially dopamine agonists, have also been shown to contribute. Restless legs syndrome can affect around 30% of patients and is characterized by a marked urge to move the legs during periods of rest, especially while trying to sleep, and is relieved by moving the legs. Dopamine dysfunction and iron deficiency have been implicated, along with renal disease, type 2 diabetes, and pregnancy. Periodic limb movement of sleep (PLMS) is present in up to 80% of individuals with RLS. Breathing disorders such as obstructive sleep apnea are also a recognized feature of PD and can contribute to EDS, headache, and fatigue in the

morning. RBD occurs when patients lose the usual muscle atonia associated with REM sleep, leading to dream enactment behaviors and/or vocalizations. The dreams can be vivid, unpleasant, and frightening and can occasionally cause the patient to fall out of bed. Over 80% of individuals with RBD go on to develop an overt α -synucleinopathy—disorders of the protein alpha-synuclein, which include PD, multiple system atrophy (MSA), and dementia with Lewy bodies (DLB).

Management of sleep disorders in PD patients begins with simple measures which aim to ensure good sleep hygiene and optimal management of motor symptoms with avoidance of wearing off in between doses, especially at night. Patients are advised to regularize bed times, avoid alerting substances such as nicotine and caffeine in late evening, minimize prolonged time in bed watching TV or reading, limit excess fluid intake in late evening hours, and avoid exercising later in the day. Management of EDS includes avoiding frequent naps during the day to ensure restful sleep at night, limiting use of sedating medications such as dopamine agonists (which can also cause sleep attacks without warning), managing OSA at night, and occasional use of alerting substances such as caffeine, modafinil, armodafinil, etc., during the day. Patients with RLS require lab work for iron deficiency, renal disease, and diabetes, with appropriate management including iron replacement therapy where applicable. It is prudent to avoid medications known to exacerbate RLS such as antidepressants, antihistamines and antidopaminergic agents. For more severe RLS requiring medication management, drugs such as dopamine agonists, levodopa-carbidopa, gabapentin, pregabalin, and (in rare cases) opiates can be tried. Management of OSA requires polysomnography (sleep study) along with use of CPAP/BIPAP machines which aren't necessarily tolerated by all patients due to discomfort with machinery. RBD can potentially result in injury to patient or bed partner, hence altering the sleep environment to make it safer (sleeping with a mattress on the floor, moving

[SLEEP continues on Page 6](#)

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furniture and placing cushions next to the bed) is recommended. Medication management of RBD includes use of over-the-counter melatonin with upward dose titration to optimal benefit (higher doses up to 50 mg may be required at times to see benefit) and the prescription medication clonazepam, both taken 1-2 hours prior to bed.

Sleep disturbances are quite common in patients with PD and comprise the entire spectrum of sleep disorders. These can not only contribute to reduced quality of life but can also raise safety concerns, hence appropriate diagnosis and management of these disorders is crucial.

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A Fond Farewell to Jill Dominguez



Jill Dominguez has been associated with Dallas Area Parkinsonism Society in one way or another since 1996 when she first answered an ad in the Dallas Morning News about a local nonprofit organization looking for a newsletter editor. Since then she has served as a DAPS volunteer, board member, office manager,

and for the last couple of years an independent contractor. She has enjoyed her contractor role, working with DAPS on the website, newsletter editing and social media postings. But now, Jill has decided that it is time to move on to new things. She will be greatly missed!

Jill has been married to Raul for 28 years and they have two children in college. Though they have not experienced Parkinson's disease first-hand in their family, all four have volunteered for DAPS at some time in their lives and have been deeply touched by the dedication of the organization and the spirit of the people DAPS serves.

Memorials • Honors • Donations

JANUARY 2021

In memory of Virginia Bankston

From: Kenneth Krushinski

In memory of Cynthia Bem

From: Aldeen Bem

In memory of Robert J Dunn

From: Barbara Dunn

In memory of Eugene Hervey, Jr

From: Sheleika Hervey

In memory of Marianne Lichtenstein

From: Wendy & George Palmer

In memory of Jesse Morales

From: Guy & Kay Senter

In memory of Charles Robert Richardson

From: Nancy Pottinger

In memory of Robert Rubio

From: M R Gonzales
B & M Ligus

In memory of Doyle Wayne Traylor

From: Anne Collier
Donna Rush

In appreciation of Amanda, Dianna, Barb & Tammie for their dedication to leading exercise classes

From: Beth Jacobs

Facebook Fundraiser Donations

From: Brian Beck
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Margaret Clench
Ruth Ann Crowson
Stan Fernald
Gary Furney
Leslie Hensch
Caroline Mitchell
Judy Morris
Karen Rich
Natalie Tully Ugarte
Frances Turner

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Susan Callender
Jill Dominguez
Bradley McDaniels
Donald Purinton
Sally & Robert Woodward
The Kroger Company
Pepsico Employee Giving Program
Vizient

Virtual Classes & Resources



DAPS Zoom Classes

We can help you stay active and connected with our live exercise, speech, and support groups. Let us know if you need help getting set up and ready to Zoom by contacting us at daps@daps.org. Please note that the best response times to receive login information are during office hours: Monday–Thursday, 9:00 am to 2:00 pm.

Below is a general schedule of live classes DAPS offers each week via Zoom. For the most up-to-date list, descriptions, and links to our virtual classes, please visit our website and view the calendar at <https://daps.us/events>.

Join us for recorded EXERCISE class any time at <https://bit.ly/DAPSYoutubeChannel>.

All times are Central Standard Time, then Central Daylight Time starting March 14, 2021

MONDAYS

9:45 am EXERCISE
10:45 am SUPPORT GROUP
1:00 pm SPEECH
4:00 pm GENTLE YOGA

TUESDAYS

9:00 am SPEECH
10:00 am EXERCISE
11:30 am SPEECH
2:00 pm DANCE

WEDNESDAYS

9:45 am EXERCISE
11:00 am SPEECH
12:30 pm EXERCISE

THURSDAYS

10:00 am EXERCISE
2:00 pm SPEECH
2:00 pm DANCE

FRIDAYS

9:45 am EXERCISE
12:30 pm EXERCISE

SATURDAYS

1:00 pm EXERCISE

SUNDAYS

1:00 pm EXERCISE
2:30 pm EXERCISE



Tribal Wellness Group Classes

Boxing, tai chi, and yoga groups are available every day online with **discounted pricing for DAPS members**.

See the full class calendar at www.tribewellness.org/calendar.
For more information, please contact tribewellnessllc@gmail.com.

Young Onset Parkinson's Disease (YOPD) Support Group

The YOPD Support Group meets virtually every Tuesday at 6:30 pm.

For details, contact yopd.dfw@gmail.com.



UPCOMING MEETINGS



ALL PROGRAMS ARE CURRENTLY ONLINE ONLY

Please check the DAPS website at <https://daps.us> for schedule changes. For assistance, contact the DAPS office Monday–Thursday, 9am–2pm at 972-620-7600 or daps@daps.org

MARCH VIRTUAL EDUCATIONAL SERIES

MONDAY, MARCH 8, 2021, 2:00 P.M.

<https://us02web.zoom.us/j/84411227764>

Speaker: Dr. Nirav Pvasia

Topic: Taking ON Parkinson's Disease
Meeting sponsored by



THURSDAY, MARCH 11, 2021, 12:00 P.M.

<https://us02web.zoom.us/j/85626615550>

Speaker: Dr. Shilpa Chitnis

Topic: Cookin' with Chitnis

WEDNESDAY, MARCH 17, 2021, 1:00 P.M.

<https://us02web.zoom.us/j/87656695291>

Speaker: Jeff Kort, CFP

Topic: Prosperity: 3 Questions that Predict Your Quality of Life

THURSDAY, MARCH 25, 2021, 11:00 A.M.

Register for this webinar at:

<http://www.pharmethod.com/KYOWAKIRIN/register>

Speaker: Dr. Raja Mahanna

Topic: A Different Path to Treat OFF Times in Parkinson's Disease

Meeting sponsored by



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