Since 1978, DAPS has been impacting and improving the lives of those affected by Parkinson’s disease. We couldn’t do it without your support!

On Thursday, September 22, we need you to join people all over Texas who will be giving to the Nonprofit of their choice. Your gift to DAPS will help us continue to impact and improve the lives of those affected by Parkinson’s disease.

You can make a difference! Your gift will provide the funds needed for:

Please go online at bit.ly/NTGD-DAPS on Thursday, September 22, between 6:00 am and midnight to make a donation to DAPS. Donations of any amount are appreciated. Communities Foundation of Texas, sponsor of North Texas Giving Day, gives prize money to various nonprofits in part based upon the number of donors. To be counted toward the prize money, your gift needs to be at least $25. If you are uncomfortable giving online, you may call the DAPS office between 7:00 am and 7:00 pm and we will assist you in making your donation.

Thanks to generous donors willing to match your gift, here is how your money can go further:

⇒ From 6:00 am to 7:00 am, donations will be matched dollar for dollar up to $500 total.
⇒ From 11:00 am to 1:00 pm, donations will be matched dollar for dollar up to $2500 total.

If you would like to sponsor an hour of matching donations, please contact Mike Miles at 972-620-7600.

Thank you for your support and your impact on the lives of so many!
September Speaker Bio:

**Jeryn Laengrich, MS, CCC/SLP**

As one of the first employees hired at Cariloop, Jeryn has brought a tremendous amount of experience and enthusiasm to the table as the company’s Chief Service Officer. Jeryn was born and raised in the Dallas-Fort Worth area and graduated with a B.A. in Communication Disorders from Harding University and an M.S. in Speech Language Pathology from the University of North Texas. She has extensive clinical experience as a speech-language therapist in every healthcare setting, and she has held director positions over rehab services and business development for acute care hospitals and geriatric care facilities, as well as being very involved in fundraising. She also served as Director of the Parkinson’s and Movement Disorders Center at Texas Health Presbyterian Hospital Dallas, where she coordinated and implemented many programs to support the Parkinson’s community across North Texas.

Most recently, Jeryn held the position of Clinical Liaison for Presbyterian Communities and Services, where she was able to use her knowledge and expertise to guide families through the challenging maze of senior care. Jeryn has become an accomplished and sought-after public speaker, and her expertise ranges from clinical issues involving neuroscience and aging to end-of-life planning, insurance, and Medicare.

DAPS wishes to express great appreciation to Wildfire XM for sponsoring the printing of our September newsletter!
Health Topic: Nilotinib for Parkinson’s Disease

by Margaret B. Schroeder

In a recent webinar by the Michael J. Fox Foundation titled Update on Cancer Drug Nilotinib for Parkinson’s Disease (PD), benefits and risks were discussed. Nilotinib is used to treat chronic myelogenous leukemia, a cancer of the white blood cells. It is in a class of agents that block a tyrosine kinase chemical pathway called c-Abl. Scientists postulate that this drug can slow the progression of PD through the inhibition of c-Abl and increase the ability of cells to clear the abnormal protein called alpha-synuclein.

Tanya Simuni, MD, Director, Parkinson’s Disease and Movement Disorders Program at Northwestern University, explained that in people with PD, the cells accumulate alpha-synuclein. Scientists postulate that drugs such as Nilotinib help to clear the cells of alpha-synuclein through a mechanism called autophagy, possibly resulting in the slowing of the progression of the disease. However, it is very important to ensure that the drug is safe for people with Parkinson’s (PWP).

Todd Sherer, PhD, CEO, The Michael J. Fox Foundation, further explained that Nilotinib has potential cardiovascular side effects that could be life threatening. The FDA has issued a black box warning for Nilotinib, so patients taking it must be carefully monitored. This is a specific warning that is a level above those side effect warnings you hear in commercials for other drugs. People with PD comprise a different population than those with leukemia, which is one of the reasons Nilotinib needs further testing.

Simuni explained that alpha-synuclein exists in normal cells, but in PD it gets misfolded – it clumps and potentially clogs the cell. The primary postulated mechanism of action in Nilotinib, autophagy, could reduce the load of Parkinsonism pathology. Nilotinib might also improve the energy level of the cells through the mitochondria. It is a proven fact that there is mitochondrial dysfunction with PD. There is also some data pointing to the fact that inhibiting this pathway increases the level of dopamine, the major neurochemical transmitter that is associated with PD.

The results of the first clinical trial of Nilotinib for treatment of PD were released in June 2016 by Georgetown University. In this study, 12 participants were evaluated to determine the safety and tolerability of the drug. Samples of spinal fluid and blood were taken to determine the biological impact of the drug on the levels of alpha-synuclein. One participant withdrew from the study after having a heart attack and one withdrew voluntarily. The remaining 10 completed the 24-week study. Participants experienced pneumonia, urinary tract infections, and other side effects known to occur in the treatment of people with leukemia. Participants also noted improvements in motor skills and cognitive function. The dosages used in the study were lower than those used in the treatment of leukemia with the hypothesis being that there should be fewer side effects with a lower dose.

Because the study was so small, there can be no conclusions about the efficacy of the drug to treat PD. Tom Isaacs, President and Co-Founder, Cure Parkinson’s Trust, who was diagnosed with PD at age 27, said, “I don’t want to die simply because I’ve been taking a drug for Parkinson’s disease. The one thing that will cure Parkinson’s is teamwork. These are exciting times in Parkinson’s.”

Sherer explained that cancer drugs kill cells, so they’re typically designed not to enter the brain. However, if Nilotinib passes the blood-brain barrier, then it may be a happy accident. “This is intriguing, and we want to move on it quickly and collaboratively,” he said.

The original investigators at Georgetown University are planning a follow-up study to gather more data. Also, the Michael J. Fox Foundation, the Cure Parkinson’s Trust, and the Van Andel Research Institute are collaborating to better understand the safety of long-term use of Nilotinib, to determine whether the drug passes through the blood-brain barrier, and to determine the relationship between dosage and c-Abl activity. You can register with Fox Trial Finder to be notified when these trials begin recruiting, which should be within the next couple of months.

The Michael J. Fox Foundation Third Thursday Webinars

On the third Thursday of each month, MJFF conducts live webinars on topics concerning living with Parkinson's as well as the foundation’s work to speed medical breakthroughs. Anyone can register, submit questions to panelists and then log on to listen to expert discussion. The webinars are moderated by Dave Iverson, a veteran broadcast journalist and person with Parkinson's. Past webinars are archived and available to watch on YouTube.

To learn more, please visit bit.ly/MJFFwebinars.
The Kudos program was created to recognize people in the DAPS family, such as volunteers and group leaders, who are doing and outstanding job. The recipient of the award is recognized at our General Meeting and a donation is made by the DAPS Board of Directors and Office Staff in their honor.

Our most recent Kudos go to two women who have been an active part of the DAPS family for some time. The phrase “team player” is one that is sometimes overused and lightly tossed about. But in this case, it is extremely fitting of these two. Both are always willing to go the extra mile and they do so without any fanfare or recognition. They are supportive of DAPS in many ways and are both Good Will Ambassadors who frequently share positive information about the work of DAPS.

And so Kudos to:

Joyce Susman

Joyce recently rotated off the DAPS Board, where she served faithfully and very well. In addition to her past service on the DAPS Board of Directors, Joyce is always ready and quick to pitch in and help Jill or anyone else with things that are needed, especially at our General Meetings. She is one of those behind-the-scenes people good at seeing and responding to the need. Don’t you just love people like that? You don’t even have to ask, and they jump right in to help. That is Joyce.

Tammy Slauson

Tammy is one of our exercise leaders. She is leading and assisting with exercise in several DAPS locations. Beyond that, Tammy is always ready to step in as a sub when needed. She brings compassion, enthusiasm, and contagious energy to classes that she leads. In addition to exercise classes, Tammy helps with speech therapy classes. Tammy frequently talks about how much she loves working for DAPS. It is more than just sweet talk. Her love for DAPS and for leading groups is absolutely evident to all!

DAPS office staff and Board of Directors have made a donation in honor of each of these valued DAPS members and gives Kudos for all they do for DAPS.

REMINDER...

If you wish to participate in the Kroger Community Rewards Program, it is time to re-enroll. Please call the DAPS office if you need assistance: 972-620-7600.

You may also bring your card to the general meeting on September 12, and Jill will have her computer there to assist with enrollment.

So far in 2016, DAPS has received $457 from the Tom Thumb Good Neighbor Program, $265 from Kroger Community Rewards and $27 from iGive.com. These donations help fund the 30+ hours of classes and programming provided by DAPS each week.

It is our hope that you will continue to participate in these donation programs, and that you will encourage your friends and family to do so as well. It costs you nothing, but means everything to DAPS and the people we serve!
MEMORIALS · HONORS · DONATIONS

JULY 2016

In memory of Harvey Schein
From: Laurie & Zola Blicke
Thursday Mah Jongg Ladies

In memory of Dottie Winchester
From: Betty Franzl

In memory of the father of a friend
From: Charles Hirschberg

In memory of Mildred Hatcher
From: Brenda & Billy Merriman

In memory of Pat Sterling
From: Charles & Susan Sterling

In honor of Caroline Pajda
From: Catherine Lisch

Donation to DAPS
From: Anonymous Individuals at
July Jubilee luncheon
Tom Thumb Good Neighbor Program
DAPS at Custer Road (Plano)
DAPS at Preston Hollow (Dallas)
DAPS at Trinity (Duncanville)

About Memorials, Honors, and Donations

Flowers fade within days. Memorial tributes to DAPS have a lasting effect, funding our more than 25 Parkinson’s exercise, speech, and support groups and education programs.

Your generous donations will be listed in our DAPS newsletter. Both you and your honoree will receive letters of acknowledgement and thanks, but the dollar amount will be included in your letter only for tax purposes.

Send these special tributes to the DAPS office, with instructions regarding who the donation is in honor of or in memory of and who should be recognized as the donor.

You may also make memorial donations at www.daps.us. Just click the Honors & Memorials button on the right side.

“I’m glad to tell you why I give to and support DAPS. This organization has been a blessing to me and my husband, who is my primary care giver. It has become a family to us and supports us in so many ways. DAPS is also a great way to honor or give in memory of someone.”

~ LaTrelle Power

GEMs are donors who Give Every Month.

Our GEMs are very valuable!

Sign up on the DAPS website.

<table>
<thead>
<tr>
<th>Your monthly donation of this amount...</th>
<th>...will provide for this each year:</th>
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<tbody>
<tr>
<td>$5.00</td>
<td>1 exercise class session</td>
</tr>
<tr>
<td>$15.00</td>
<td>2 speech therapy class sessions</td>
</tr>
<tr>
<td>$25.00</td>
<td>12 Dance for Movement Disorders Classes</td>
</tr>
<tr>
<td>$50.00</td>
<td>12 care partner support group sessions</td>
</tr>
<tr>
<td>$100.00</td>
<td>12 General Membership Meeting room rental fees</td>
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Have you heard?
Moving Day is coming to Texas for the first time!

Moving Day®, A Walk for Parkinson’s, is a fun event that unites families, friends and communities in the fight against Parkinson’s disease. This celebration of movement will feature a family friendly walking course, a kids area, a caregivers relaxation tent and a special Movement Pavilion featuring yoga, dance, Tai Chi, boxing and more, all shown to help manage the symptoms of PD.

Moving Day DFW appreciates the tremendous support from DAPS in helping organize this event.

The walk begins at 10:45 a.m.
Teams are forming NOW!

DAPS Advisory Council member,
Dusty Berry
is the DFW Moving Day chair.
Contact him for more information at:
angela6545@att.net

Thank You Sherita!
DAPS would like to thank Sherita Glanville for writing the Caregiver’s Corner column and for leading Partners-in-Care groups during 2016. Sherita has accepted a new job opportunity and will no longer be able to continue working with DAPS. We wish her all the best in her new endeavors!

A WALK FOR PARKINSON’S
DFW
Saturday, November 5, 2016
Globe Life Park
Arlington, TX

Register Today At
www.MovingDayDFW.org

Miles on Miles
There is a saying, “Don’t judge a man until you have walked a mile in his shoes.” There have been endless variations of this proverb that I believe remind us to have empathy. One humorous one that I heard, finished with, “and you will be a mile away from him in his shoes.”

Hanging in my office is another quote. This one is from Pablo Picasso. “The meaning of life is to find your gift. The purpose of life is to give it away.” It adorns my wall because it reminds me of the many times that I have heard from different DAPS members about the “gift” or the “blessing” that Parkinson’s disease has been in their lives. I’ve not taken a single step in those shoes, much less walked a mile. As I have asked them to explain how that could be, I have heard that Parkinson’s, even with its challenges, has changed their lives in some good ways. I think we would all like to find the silver lining without having to deal with the storm. Unfortunately that is not how it works, and we don’t get to choose our storms.

Picasso’s words encourage us to find our gift and then give it away. I find in that a perfect description of many of our DAPS members, who somehow in the midst of their storms generously give back to others in so many ways.

On Thursday, September 22, North Texas Giving Day, you can join DAPS members and many others around Texas in giving back to your community. I hope you will be one of the many making an online donation to DAPS on that day at bit.ly/NTGD-DAPS. Your gift will help DAPS provide services that make a real difference in the lives of people and families facing the daily challenges of living with Parkinson’s disease!

Kindest regards,

A message from Mike Miles
Executive Director

DAPS would like to thank Sherita Glanville for writing the Caregiver’s Corner column and for leading Partners-in-Care groups during 2016. Sherita has accepted a new job opportunity and will no longer be able to continue working with DAPS. We wish her all the best in her new endeavors!

Thank You Sherita!
THPHD GROUPS & CLASSES

The Movement Disorders Education and Resource Center at Texas Health Presbyterian Hospital Dallas (THPHD) at 8200 Walnut Hill Lane, Dallas, TX 75231 offers the following for free:

- PD Patient Support Group
  3rd Thursday each month at 6 pm

- Essential Tremor Support Group
  2nd Wednesday of odd months at 1 pm

- Care Partner Support Group
  4th Monday each month at 1 pm

- Atypical Parkinson’s Support Group
  (PSP/MSA/CBD)
  3rd Saturday each month at 10 am

For more information or to RSVP, please contact Kathryn MacDonell at 214-345-4224 or DallasMovementDisorders@TexasHealth.org.

DAPS’ NO-CHARGE
exercise · speech therapy · support groups

CARROLLTON:
Grace Lutheran Church
1200 E. Hebron Pkwy. (972-492-4474)
Group Exercise:  
Wednesday...10:00 to 11:00 am  
Speech Therapy:  
Wednesday...11:15 am to 12:00 pm

DALLAS:
Finley Ewing Cardiovascular & Fitness Center, Studio 3
5721 Phoenix Drive (214-345-7074)
Dance for Movement Disorders:  
Tuesday...2:00 to 3:15 pm  
Thursday...2:00 to 3:15 pm  
1st Saturday...11:00 am to 12:15 pm
Lakeside Baptist Church
9150 Garland Rd. (214-324-1425)
Dance for PD®:  
Wednesday...9:30 to 10:30 am  
Speech Therapy:  
Wednesday...10:30 to 11:15 am  
Partners-in-Care Group:  
Wednesday...10:15 to 11:15 am
Preston Hollow United Methodist Church
6315 Walnut Hill Lane (214-363-4393)
Speech Therapy:  
Tuesday...11:30 am to 12:30 pm  
Group Exercise:  
Tuesday...10:30 to 11:30 am  
Thursday...10:30 to 11:30 am

DUNCANVILLE:
Trinity United Methodist Church
1302 S. Clark Rd. (972-296-2155)
Speech Therapy:  
Thursday...1:00 to 1:45 pm  
Group Exercise:  
Monday...12:00 to 1:00 pm  
*New Time No class last Monday of the month
Support Meeting:  
Last Monday...6:00 to 8:00 pm
Partners-in-Care Group:  
3rd Thursday...1:00 to 2:00 pm  
Dance for PD®,  
Monday...10:30 to 11:30 am  
*New Time No class last Monday of the month

GARLAND:
South Garland Baptist Church
1330 E. Centerville Rd. (972-271-5426)
Group Exercise:  
1st & 3rd Monday...9:30 to 10:15 am  
Thursday...9:30 to 10:15 am
Dance for PD®:  
Monday...9:30 to 10:00 am  
Partners-in-Care Group:  
Monday...9:45 to 10:45 am  
Thursday...10:30 to 11:30 am  
Discussion Group:  
Monday...9:30 to 10:30 am
IRVING:
MacArthur Hills Sr. Living
1295 Kinwest Pkwy. (469-251-4349)
Group Exercise:  
Tuesday...10:00 to 11:00 am  
Friday...10:00 to 11:00 am

MESQUITE:
Mesquite Rehabilitation Institute
1023 North Belt Line Rd. (972-216-2400)
Speech Therapy:  
Tuesday...9:30 to 10:00 am  
Group Exercise:  
Tuesday...10:00 to 11:00 am

PLANO:
Custer Road United Methodist Church
6601 Custer Road (972-618-3450)
Speech Therapy:  
Thursday...11:00 to 11:45 am  
Group Exercise:  
Monday...9:45 to 10:45 am  
Thursday...9:45 to 10:45 am  
Partners-in-Care Group:  
Monday...9:45 to 10:45 am

RICHARDSON:
Arapaho United Methodist Church
1400 W. Arapaho Rd. (972-231-1005)
Group Exercise:  
Tuesday...10:00 to 11:00 am  
Friday...10:00 to 11:00 am

NON-CONTACT BOXING FOR PARKINSON’S DISEASE

Title Boxing Club of Allen
300 N. Greenville Ave.  
214-644-2640  
 allen-greenville.titleboxingclub.com
Tuesday/Thursday...10:30 to 11:30 am  
Wednesday...8:15 to 9:15 pm  
Saturday...10:15 to 11:15 am
DAPS has partnered with Title Boxing of Allen to obtain reduced rates. Learn more about the program at FreeMotionPD.com.
Contact the class trainer, Heidi Weimer, with any questions regarding schedules or rates.
MARK YOUR CALENDAR

**september annual kickoff meeting**
Monday, September 12 - 1:00 p.m.
Speaker: Jeryn Laengrich, MS, CCC/SLP
Topic: How Skilled Nursing and Rehab Can Keep You Moving

**open board meeting**
Monday, September 19 - 1:00 p.m.

**september in mckinney**
Tuesday, September 20 - 10:00 a.m.
Speaker: Tim Powell, Cerna Homecare
Topic: Beyond Homecare: Advocacy and Entertainment for Patients and Caregivers

**october general meeting**
Monday, October 17 - 1:00 p.m.
Topic: Move.Laugh.Connect…extending the functional years

**october in mckinney**
Tuesday, October 18 - 10:00 a.m.
Speaker: Dr. Aanchal Taneja, Texas Parkinson and Movement Disorders
Topic: PD and Swallowing

All General Membership and Board Meetings are held at University Park United Methodist Church, 4024 Caruth Blvd., Dallas, TX 75225. For more information, call 972-620-7600.

DAPS McKinney meets on the 3rd Tuesday of every month at St. Gabriel the Archangel Church, 110 St. Gabriel Way, McKinney, TX 75070. Email mckinney@daps.us for more information.

**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.

For change of address or corrections, please indicate the changes on this page and mail it to DAPS, or email: daps@daps.us