

SUMMER 2019

MINNESOTA | Newsletter of the Minnesota  
American Parkinson Disease Association

# MESSENGER

## IN THIS ISSUE

Supporting Your Mind and the  
Activities In Your Day That Matter  
to You

Coordinator's Column / Update on  
APDA Minnesota Chapter Grant  
Program

2019 APDA Minnesota Optimism Walk  
Medical Director's Column

Pedaling for Parkinson's, an APDA/  
YMCA Collaborative Project

Botox Injections - Can They Help  
Your Symptoms of Parkinson's  
Disease?

Family Caregiver Resources  
Voices

DBS Educational Opportunities  
DBS Support Group  
APDA Grant Program

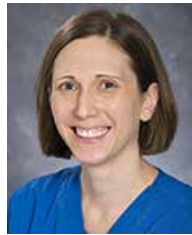
**Anushka Mohideen**  
American Parkinson's Disease  
Association Information &  
Referral Coordinator  
Newsletter Editor  
Abbott Northwestern Hospital  
800 E. 28th Street, MR 12209  
Minneapolis, MN 55407

**Jill Goolic**  
APDA Account Representative: MN  
718-981-3289

National APDA website:  
[www.apdaparkinson.org](http://www.apdaparkinson.org)

APDA Young Parkinson website:  
[www.youngparkinsons.org](http://www.youngparkinsons.org)

## SUPPORTING YOUR MIND AND THE ACTIVITIES IN YOUR DAY THAT MATTER TO YOU



*Mattie Anheluk, Occupational Therapist,  
Courage Kenny Rehabilitation Institute*

If you are experiencing cognitive or thinking concerns, you are not alone. Many people with Parkinson's Disease may notice subtle, moment-to-moment changes in their processing throughout the day. They may find it more challenging to focus, or feel like it takes more energy to remember something for a short time. They may notice small errors, or feel like it takes more time to complete tasks. It can take more energy to get started on a task. Others may notice more consistent concerns and experience difficulty engaging in more complex tasks in everyday life, including managing medications, cooking, or carrying out multi-step projects.

There are many things that can be done to support your mind. Talking with your support system and doctor can help you identify a plan and resources to address your concerns. Many people may benefit from talking with an occupational therapist or speech therapist who specialize in Parkinson's rehabilitation.

There are several lifestyle factors that can be supported to optimize thinking, including:

- Having a regular sleep schedule
- Eating well and staying hydrated
- Incorporating relaxation and strategies to cope with stress
- Exercising
- Engaging your mind in activities you enjoy
- Staying connected to people on a regular basis

*(continued on page 3)*

## Coordinator's Column



Anushka Mohideen, APDA  
Minnesota Information &  
Referral Coordinator

### Dear Readers,

I hope you are all doing well and enjoying the summer. As always, I encourage you to

call me with any questions that you have about Parkinson's disease, support groups, exercise classes, other resources in your community, and requests for informational literature about PD. You can reach me at 651-241-8297 or email me at [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com).

The APDA Minnesota Chapter hit an exciting milestone in July 2019, when we surpassed \$120,000 awarded in grants to the PD community across Minnesota.

Please call 651-241-8297 or email [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com) to receive your grant application.

Our chapter is passionate about giving back to the PD community. The money that we raise stays in Minnesota to support the local PD population. Here are some quotes from grant recipients in 2018-2019:

*"The generous funds you made available to me will help me take classes to improve my mobility. Thank you, APDA, from a grateful heart!"*

*"My husband has PD. Being a caregiver can take a toll on one's personal health. It is overwhelming and exhausting to keep up with the household duties, the yard, and doctor appointments while putting your loved one first. By receiving a grant, some of these anxieties have decreased. Thank you APDA Minnesota Chapter for the grant!"*

*"On behalf of my father and myself, we want to thank you so much for the grant my dad received, so he can participate in the BIG and LOUD for Life program. It is so deeply appreciated as Dad is a senior on a fixed income. We can't thank you enough! Thank you, to all of you, from the bottom of our hearts."*

*"As a grant recipient, I am most appreciative. I am a member of Rock Steady Boxing in Brainerd, MN, and I have applied the awards to the monthly dues. Not only are we fighting back against Parkinson's, we have become a very close "family" of victims and caregivers, all working together as a huge support team for each other. Thank you for the monetary assistance in this fight."*

*"The grant allowed me to participate in Rock Steady Boxing. Through this program I have improved my balance, gained strength in my core, and feel more confident. Using the grant has allowed me to encounter others living with Parkinson's and given me a support network I wouldn't otherwise have access to. Thank you!"*

*"Our Respite Care Grant we received last year was much appreciated! It was used for a weekly day away at a local day center. My husband had an outlet for social interaction outside our home meeting new people and having a great support staff at the ADC. I was able to plan for periods to follow up on my health care needs, time at fitness center and occasions to rejuvenate with a luncheon with my lady friends. Thank you!"*

Our grant program is entirely supported through donations and participation in the annual Optimism Walk, which is taking place on Saturday, September 14 at Roseville Central Park. Information on the Optimism Walk is included later in this newsletter issue. I encourage you to come out and attend our Optimism Walk, or visit us online at [apdaparkinson.org/MN](http://apdaparkinson.org/MN) to support the event even if you cannot attend in person. The more people who support the Optimism Walk, the more people we can help through our grant program.

The 2019 Optimism Walk will feature several fun events alongside the walk, including health and wellness stations, a silent auction, cake walk, health and wellness exhibits, exercise demonstrations, children's activities, and a complementary barbecue lunch for all participants.

The APDA Minnesota Chapter is also working to expand Parkinson's disease exercise programs across the state. We are partnering with the YMCA to expand the Pedaling for Parkinson's program into Prior Lake, New Hope, and Rochester, and partnering with the YMCA to launch Rock Steady Boxing in Edina.

Please "Like" APDA Minnesota Chapter on Facebook to stay in the loop about these exciting initiatives and more between issues of the newsletter!

I wish you all a happy summer.

Warmest regards,

*Anushka*

## Supporting your mind and the activities in your day that matter to you *(continued from page 1)*

Learning and utilizing supportive strategies can assist you throughout the course of the day. This is especially useful because cognitive symptoms can vary each day. You have used strategies your entire life to support your mind and your priorities within your day. It can help to think about the strategies you currently use and consider adding new strategies that make sense for you. The list of strategies that can help is endless. The following are strategies that can help a variety of concerns:

- Create a planning station in your home. A planning station is simply a space where you either sit down or walk past often, that cues thinking about your priorities for your time and energy today. Your planning station can include items such as a calendar, your reminder list, your smart phone or iPad, or whatever tools you use to support your daily plans and priorities.
  - Some people find a whiteboard useful as part of their planning station. It is a quick spot to write daily events and can be used for daily reminders, tasks to complete, or a general schedule for the day or week.
  - After creating a planning station, the next step is to develop a routine to use and check your calendar, task list, phone, whiteboard, etc.
  - Whichever system you develop, ask yourself if it is easy to use. If it seems to take too much energy to upkeep, consider a different system. Some people find smart phone calendars to be useful, others find it best to keep their paper calendars.
- Use reminder alarms within your smart phone. Voice activation alarms can turn your phone into a personal assistant. “Siri remind me to \_\_\_\_\_” can help in many ways.
- Choose to delegate. Create a list of activities that are important to you. Are there any activities you would

like to ask for support with in order to save your energy for activities that are most important to you?

- Prioritize purpose. What are the activities that really matter to you? Are they currently within your day or week? What can you do today that aligns with your sense of purpose?



- Prioritize your energy. Sometimes cognitive symptoms are a signal that a break is needed. Find out what breaks help. For example – going outside, taking a walk, or switching to a less demanding activity. Schedule breaks and downtime within your day.
- Build routines. Routines that are particularly helpful for cognitive symptoms include sleep/wake routines, medication routines, exercise routines, cognitive break routines, and routine times for participating in activities that bring you joy.
- Medication routines can be challenging. Talk to your doctor if you notice that you are taking your medications too early or too late or routinely forgetting dosages. Choose a strategy to support your routine such as setting alarms, using a pill box, and using travel pill case when leaving the house.
- Consider using the “pause strategy.” This strategy is simply taking a moment to “pause.” Naming it can help build this routine and work pausing into your day. Pausing can be used for a variety of reasons: to take a deep breath, take time for a break, checking in with your priorities for the day, or to make sure you have what you need. It can be especially helpful for supporting the mind to pause when transitioning between activities or when leaving your house.

## Medical Director's Column



*Eleanor Orehek, MD, Noran  
Neurological Clinic*

### Dear Readers,

Since this is the summer issue, I'm hoping that it's warm and beautiful outside and that you're able to get out and take advantage of it. Hopefully

everyone stuck to or expanded on an exercise program over the winter, but if not, the nicer weather is a perfect time to explore new exercise opportunities. In this newsletter, there's a plethora of information on available exercise classes around the state, so be sure to look for classes to try out. The APDA MN chapter is also working to expand availability of exercise programs such as boxing and cycling classes, particularly for greater MN.

As many of you living with PD or caring for a loved one with PD know, it is a complex disease. There tends to be a focus on the more visible motor symptoms of PD, such as tremor or other motor changes like shuffling and slowness of movement, but there are a large range of non-motor symptoms that are important to consider. One of these areas is temperature regulation. People with PD have a harder time in extreme cold or heat, which is one of the reasons the winter months in Minnesota can be particularly challenging. The heat and humidity of summer can also be tough. If you're outside this summer doing yard work or other activities, be sure to drink regular amounts of water or hydrating liquid and take regular breaks. If it's time for your medication, take a short break from what you are doing to stay on schedule.

One area of PD that is frequently misunderstood is related to the abnormal jerky movements that people can experience. This is called "dyskinesia." The name is technical sounding, making it confusing and hard to remember, and there's not a good substitute word that's easier to understand or remember.

Dyskinesia, like many medical terms, has roots in Latin. "Kinesia" means movement and the prefix "dys" means abnormal. The abnormal movements are involuntary. In PD, they are caused by the medication levodopa and are specifically called "levodopa-induced dyskinesia." Dyskinesias can result in a variety of abnormal movements that can cause head bobbing movements, abnormal jaw movements that can cause slurred speech, swaying when standing, or wiggly, writhing type of movements of the arms and legs. When they are minor, people with PD are often unaware of them and it usually means the levodopa has taken effect in an ON period, so generally people feel good during these times.

Dyskinesias can become bothersome and it is important to recognize these movements as dyskinesia because medication reduction or other treatments can help significantly. At the point that we have a hard time controlling dyskinesias with medication adjustments alone, this is often when we would start talking about other therapies such as deep brain stimulation (DBS). It's important to note that tremor is a different abnormal involuntary movement that occurs in PD, but is considered part of the underlying disease. Tremor causes a different, more rhythmic type of movement most commonly seen in the hands, but tremor can also affect the legs or jaw. It is important to distinguish between tremor and dyskinesia symptoms because the treatments for them are different. Understanding the difference between tremor and dyskinesia also furthers your understanding of PD.

PD is a tough and complex disease. It is important to surround yourself with a good support system and network to help you navigate the journey. There is a lot of research under way into potential disease treatments that are promising, and that is a reason to have hope and optimism.

Enjoy the summer!

*Eleanor K. Orehek, MD*



# AMERICAN PARKINSON DISEASE ASSOCIATION

Strength in optimism. Hope in progress.



**JOIN US!**

## Minnesota Optimism Walk

Saturday, September 14, 2019

Roseville Central Park

Jaycees Shelter • Roseville, MN 55113

Arrive: 9:00 am • Walk: 10:00 am

Register online today!

[apdaparkinson.org/minnesota](http://apdaparkinson.org/minnesota)



ph 651.241.8297

### What is an Optimism Walk?

- A fun-filled fundraising event!
- A short non-competitive walk with family-friendly activities!

### Why Walk?

- Every 9 minutes someone is diagnosed with Parkinson's disease.
- Funds raised provide local support, education and research.
- **The more funds we raise, the more people we can help.**

## Walk with us and help put an end to Parkinson's disease!

NATIONAL SPONSORS



Raise \$100+ and get an Optimism Walk t-shirt!  
 Raise \$500+ and get an Optimism Walk hat!

AMERICAN PARKINSON DISEASE ASSOCIATION - MINNESOTA CHAPTER

## Advancing Parkinson's Disease



You're invited to attend a special educational event to learn more about advancing Parkinson's disease. The first part of this seminar will focus on the management of motor and non-motor symptoms in advancing and advanced Parkinson's disease. The second part of the seminar will discuss topics relating to advanced Parkinson's disease, including planning for the future, support for caregivers, community resources that can provide assistance, advanced health care directives, home modifications, if/when to transition to care out of home, and end of life issues.

**Presenter:** Anushka Mohideen, APDA Minnesota Coordinator

**Register by phone:** 651-241-8297

**Register by email:** [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com)

There is no charge for this program, but registration is required.

Lunch will be provided.

Thursday, September 26

10 AM - 12:30 PM

Wood Lake Meeting Center

210 Woodlake Dr,  
Rochester, MN 55904



[APDAParkinson.org/Minnesota](http://APDAParkinson.org/Minnesota)  
[Facebook.com/APDAMNChapter](https://Facebook.com/APDAMNChapter)

Allina Health 

AMERICAN PARKINSON DISEASE ASSOCIATION  
MINNESOTA CHAPTER

# Fall Parkinson Conference Owatonna, MN



## Presentations

Deep Brain Stimulation & Parkinson's Disease - Kyle Nelson, M.D.,  
Metropolitan Neurosurgery

Rehabilitation & Exercise Options for Parkinson's Disease - Jennifer  
Tuccitto, M.P.T., G.C.S., Courage Kenny Rehabilitation Institute

Autonomic Dysfunction & Parkinson's Disease: More Often Than Not -  
Jeremy Cutsforth-Gregory, M.D., Mayo Clinic

Every Day is a Gift - Dave Gehrke

There is no cost to attend this event, but pre-registration is required.

Register by phone: Call Anushka at 651-241-8297

Register by email: [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com)

Lunch will be served.

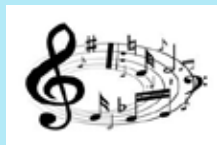
Saturday, October 5

9 AM - 1 PM

Elks Lodge, 126 E Vine St,  
Owatonna, MN 55060

[APDAParkinson.org/Minnesota](http://APDAParkinson.org/Minnesota)  
[Facebook.com/APDAMinnesotaChapter](https://www.facebook.com/APDAMinnesotaChapter)





## **A Choir for Individuals with Parkinson's Disease:**

**Do you want to have fun, meet others, make music, while exercising your voice, respiratory muscle strength, and mind? I would love to have you join the choir!**

**EVERYONE IS WELCOME WITH OR WITHOUT EXPERIENCE AS WELL AS THEIR SPOUSES/PARTNERS/CARE PARTNERS!**

**We want to thank the American Parkinson Disease Association very much for making this FREE for everyone!!**

### **SCHEDULE:**

**I am hoping and planning to have a performance/fun sing out around our last rehearsal in December as well as one in the spring! TBD!**

We will rehearse every other week from 2:30-3:30 PM on Thursdays:

September 12 & 26  
October 10 & 24  
November 7 & 21  
December 5

January 16 & 30  
February 13 & 27  
March 12 & 26  
April 9 & April 23  
May 7 & 21

### **LOCATION OF REHEARSALS:**

St. Stephen's Lutheran Church 1575 Charlton Street, West St. Paul, MN 55118.

**(Accessible parking is available)**

**If you would like to join, please contact:**

**Sara M. Oberg, B.M., M.A., CCC-SLP**

Speech-Language Pathologist, Clinical Voice & Aural Rehabilitation Specialist, Certified in Vocology, LSVT, SPEAK OUT!, and Vocal Pedagogy, singer, & Bachelor's Degree in vocal performance & vocal music education.

Health Partners Specialty Center - Division of Regions Hospital

**651-254-8118 (direct)**

**[Sara.M.Oberg@Healthpartners.com](mailto:Sara.M.Oberg@Healthpartners.com)**







## Introducing Two Parkinson's Specific Music Therapy Groups

*Looking for a fun, therapeutic way to decrease the impact of Parkinson's symptoms?*

Living Spirit Therapy Services will be offering two weekly music therapy groups specifically for individuals with Parkinson's Disease this fall.

Location and session time to be determined.

**The Therapeutic Singing Group** will use singing, chanting, functional speech, breath exercises, and movement to:

- Improve posture and breath control to increase voice volume
- Improve clarity, articulation, and intelligibility of voice
  - Increase range and resonance of voice
  - Improve rate of speech

**The General Parkinson's Specific Music Therapy Group** will use singing, movement, instruments, songwriting, and music assisted relaxation to:

- |   |                                 |
|---|---------------------------------|
| • Improve gait, range of motion, and symmetry of movement | • Provide psychosocial support  |
| • Improve clarity and volume of voice                     | • Decrease tension and rigidity |
| • Improve balance and posture                             | • Enhance relaxation            |
|   | • Improve attention             |

\$160 per person for 8 group sessions.

1:1 music therapy sessions are also available!

**To register for sessions please contact:**

Melissa Spiess, M.M., MT-BC, Neurologic Music Therapy Fellow

[melissa@livingspirittherapy.com](mailto:melissa@livingspirittherapy.com)

651-363-3936

<https://www.livingspirittherapy.com/>

## Pedaling for Parkinson's – New Collaboration Between APDA Minnesota Chapter & YMCA



In 2018, the APDA Minnesota Chapter began a collaboration with the Twin Cities YMCA to implement an exciting new Parkinson's disease exercise program. Pedaling for Parkinson's is a cycling program that aims to improve the lives of people living with PD and their care-partners.

The APDA Minnesota Chapter partnered with the YMCA of the Greater Twin Cities to offer this program because regular exercise is one of the key components in managing the many symptoms of PD, and both organizations are passionate about making exercise more accessible to the PD community.

Research has shown that pedaling a bicycle can have a beneficial impact on people with PD. Research conducted at the Cleveland Clinic showed a 35% reduction in symptoms by the simple act of pedaling a bicycle at a rapid pace, optimally 80-90 revolutions per minute. Fast pedaling is not a cure for PD, but there is compelling evidence to show that it does make a real difference to many who try it.

The Pedaling for Parkinson's program launched in January 2019 at four YMCA locations across the Twin Cities, in Eagan, Burnsville, Edina, and Coon Rapids. Twenty-one people with PD attended classes over the four locations. Participants in the program found it very impactful. Several class members shared their thoughts about the program.

*"My mental health has improved with this program. I was feeling quite depressed because of the limitations caused by my symptoms. I have noticed that I am more optimistic and feel happier."*

– PFP Participant

*"I really like the class. I sleep better on nights after the class, and I wake up feeling better the next day."* – PFP Participant

*"I am already noticing my husband walks better and has more confidence after just a few weeks of attending class."*

– Spouse/care-partner of PFP Participant

*"I have attended the Pedaling for Parkinson's class at the Southdale YMCA four times in the last six weeks. I am looking for ways to attend the class on a regular basis. As of mid-April, the Southdale Y stationary bicycles are brand new. Almost all of the dozen or so participants I've met, arrive at class early enough to adjust their bike and begin warming up before the "official" start time. Because the class is blocked for one hour, we have time to warm up and have a good 45 minute session. We always have two instructors in class, a leader on the bike and the second in the room to help with equipment, answer questions, or my favorite: fill my water bottle!*

*Some folks have expressed concern about the rigors of cycling. PFP is tailored for those of us who aren't as fit as we once were. The level of exertion is quite low with emphasis on pedal speed NOT resistance! How hard you work will be up to you. You won't walk away exhausted and sore, but you'll know you got a workout AND you should feel energized and notice a reduction of PD symptoms. For me, the rest of the day is noticeably better."*

– PFP Participant

Pedaling For Parkinson's classes are available at the Eagan YMCA, Burnsville YMCA, Southdale YMCA in Edina, and Emma B. Howe YMCA in Coon Rapids, River Valley YMCA in Prior Lake, and the New Hope YMCA. Email Jennifer Menk at [Jennifer.Menk@ymcamn.org](mailto:Jennifer.Menk@ymcamn.org) to get more details or enroll in the program.

The APDA Minnesota Chapter is excited to continue our relationship with the YMCA to offer the Pedaling for Parkinson's program at other locations in the Twin Cities and throughout the state. Pedaling for Parkinson's is launching at the Rochester, Prior Lake, and New Hope YMCA locations in Fall 2019.

The YMCA is also launching Rock Steady Boxing at the Edina YMCA in Fall 2019.

Please email Jennifer Menk at [Jennifer.Menk@ymcamn.org](mailto:Jennifer.Menk@ymcamn.org) for more information or to enroll in these programs.

## VOICES



*This new column will spotlight the stories and perspectives of people with Parkinson's disease and their care-partners. Please share your stories of what steps you have taken that have helped you in your Parkinson's journey, from taking a new exercise class, to practicing meditation and mindfulness, making connections at a support group, and anything else that has made a positive impact on you. To submit your story, please contact Anushka via email at [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com), or via phone at 651-241-8297. You can submit anonymously or include your names.*

This story was submitted by Linda J.

"My husband Brad was diagnosed with Parkinson's disease just months after retiring in 2009. Of course, looking back, his symptoms began many years earlier. Carbidopa/levodopa was the medication prescribed by his neurologist. It was prescribed in low doses at first, but with the increase of medication came an increase in side effects like nausea and dizziness. Before long he was incapacitated by these side effects, and not able to participate in most of life's activities including those of self-care.

The next logical option appeared to be deep brain stimulation. After two years of evaluation, it was determined Brad was not a good candidate for DBS due to cognitive loss.

We were excited and hopeful at an introduction to a medical device called "Duopa." This is a pump that would deliver carbidopa/levodopa suspended in a gel through a stomach tube directly to the small intestine. The upsides of Duopa are lesser and more effective doses of the medication, a continuous dose (no peaks and valleys), no strict schedule for eating, and far less dizziness and nausea. The challenges have been having a stomach tube, the necessity of keeping the medication refrigerated while traveling, and being tethered to a pump that must be worn on the chest or at the waist.

Although Duopa has not been the miracle treatment we were dreaming of, it has improved the quality of our life together and has given us a hope for better and less invasive treatments down the road."

*"My husband Brad was diagnosed with Parkinson's disease just months after retiring in 2009. Of course, looking back, his symptoms began many years earlier. Carbidopa/levodopa was the medication prescribed by his neurologist. It was prescribed in low doses at first, but with the increase of medication came an increase in side effects like nausea and dizziness." — Linda J.*



## USES OF BOTULINUM TOXIN IN PARKINSON'S DISEASE

*Dr. Rebecca Gilbert, Chief Scientific Officer, American Parkinson's Disease Association*

You most likely know that Botulinum toxin (more commonly referred to as

Botox®, among other brand names) is used for cosmetic purposes to decrease wrinkles. Prior to being used in this way, Botulinum toxin was used for medical purposes to control abnormal movements. In the right hands, it can be a very effective measure to control a variety of problems related to PD.

### **What is botulinum toxin?**

Botulinum toxin is a substance produced by the bacteria *Clostridium botulinum*. Botulism is caused by the harmful effects of this toxin. If the toxin enters the bloodstream, it can spread throughout the body, causing widespread muscle weakness. In its full-blown form, botulism can cause difficulty with swallowing and breathing by causing weakness of the muscles that control these functions.

The good news is that decades ago, scientists learned how to isolate the toxin and harness its power for medical use, and it can be safely injected into particular muscles in order to decrease unwanted movements of those muscles.

### **How does Botox work?**

Usually, a message gets transmitted from the nerve to the muscle by release of the chemical acetylcholine from the nerve endings. When Botulinum toxin is injected into a muscle, it gets taken up by the nerve endings that interface with the muscle, and interferes with the release of acetylcholine, thereby stopping communication between the nerve and the muscle. When this communication is decreased, the muscle is weakened and certain Parkinson's symptoms are lessened.

### **Conditions treated using botulinum toxin in Parkinson's disease**

1. **Dystonia** – Dystonia refers to an involuntary twisting of a body part, which can be painful and

can interfere with a person's desired movement. In PD, dystonia can be a motor symptom due to the disease, appearing first thing in the morning before taking medication or as a dose of medication is wearing off. Alternatively, dystonia can be a side effect of Levodopa. A common dystonia in young onset PD involves toe curling or foot inversion (turning in). This dystonia often occurs only in particular circumstances such as while walking or running. Other dystonias involve frequent and persistent eye closure, known as blepharospasm, or neck turning, known as cervical dystonia. These can be associated with PD, but may also accompany other forms of parkinsonism such as Multiple System Atrophy or Progressive Supranuclear Palsy. Botulinum toxin injections, targeting the particular muscles that are moving excessively, can be effective in all these scenarios.

2. **Tremor** – Although Botulinum toxin is not commonly used for this purpose, there are case reports in the literature showing its effective use for the control of tremor.
3. **Drooling** – Likely due to the decreased swallowing rate of patients with PD, sialorrhea, or drooling, can be a feature of the disease. Drooling is not only an annoyance, but can result in significant embarrassment and social isolation, Botulinum toxin injections into the salivary glands can decrease production of saliva and thereby decrease drooling.
4. **Urinary incontinence** – This can be caused by a small, contracted bladder. Botulinum toxin injections into the bladder can relax the bladder thereby allowing for more normal urination. A known side effect of this treatment however, is urinary tract infection, so make sure you are aware of all the risks and benefits before starting the treatment. In addition, there are causes of urinary problems in PD that are not amenable to Botulinum toxin treatment, so you will need to discuss your particular situation with a urologist.

Botulinum toxin is used in various other medical settings such as dystonia that is not related to

Parkinson's disease, migraine, and limb spasticity or stiffness after stroke.

### *Different types of Botulinum toxin*

There are eight different botulinum toxin species that occur in nature. There are only two however, that are produced commercially – Botulinum toxin A and B.

The commercially available products are:

1. Botox® – Botulinum toxin A
2. Dysport® – Botulinum toxin A
3. Xeomin® – Botulinum toxin A which is produced free of complexing proteins
4. Myobloc® – Botulinum toxin B

Each of the above agents are FDA approved for a slightly different list of clinical indications.

### *What does Botulinum toxin treatment for Parkinson's look like?*

The effects of Botulinum toxin take hold about 3-10 days after the injections and last approximately three to four months, so the treatments typically need to be repeated on a regular basis. Although this means routine injections, it also means that Botulinum toxin injections do not have any permanent side effects. Some side effects may still occur with Botulinum toxin injections and the doctor who performs the procedure will review these with you. An advantage of using Botulinum toxin for the treatment of the conditions noted above, is that the toxin typically only impacts the areas into which it is injected, as opposed to oral medications which have a more widespread effect, and therefore more potential for side effects.

### *Side effects of using Botox*

In general, side effects of Botulinum toxin can be due to over-weakening of the injected muscle, which, if done on leg and foot muscles, for example, could interfere with walking.

Uncommonly, Botulinum toxin can diffuse to neighboring muscles and cause more widespread side effects. For example, injections of neck muscles could result in toxin diffusing locally to muscles used for swallowing and cause difficulty swallowing. Even less common, are side effects due to travel of the toxin to more distant parts of the body via the bloodstream. For example, injections of any body part could theoretically result in difficulty swallowing or breathing if the toxin travels to these muscles. This is very rare however and Botulinum toxin injections are typically very safe. The full risk profile for your particular situation however, needs to be discussed with the physician performing the injections.

There are typically no limitations after the injections and you can return immediately to your normal activities.

Although dermatologists often use Botulinum toxin for cosmetic purposes, only a neurologist is qualified to determine whether the injections can help with certain PD symptoms. If you are interested to investigate whether Botulinum toxin injections may help you, discuss this with your neurologist. If he/she feels that they may be helpful, but does not perform them, he/she can refer you to a neurologist who does.

### *Tips and takeaways*

- Botulinum toxin injections can help in the management of certain features of Parkinson's disease.
- If you think you have a symptom that can be treated with Botulinum toxin (dystonia, drooling, urinary incontinence), discuss it with your neurologist.
- There may be a role for Botulinum toxin injections in control of tremor, but this is less commonly done.

## DEEP BRAIN STIMULATION (DBS) EDUCATIONAL OPPORTUNITIES



Interested in learning more about Deep Brain Stimulation as a treatment option for Parkinson's disease? There are several free educational opportunities across the Twin Cities and beyond about DBS.

**Noran Neurological Clinic** has an upcoming DBS educational seminar on Monday, September 23, 2019. The seminar will take place at the Metropolitan Ballroom, 5418 Wayzata Blvd, Golden Valley, MN 55416. A light meal will be served from 5:30 to 6 p.m. Dr. Eleanor Orehek and Dr. Kyle Nelson will share information about DBS from 6 to 7 p.m. Call Kelly O'Neill at 612-879-1675 for more information and to register. Pre-registration is required. There is no cost to attend this program.

**Struthers Parkinson's Center / HealthPartners Neuroscience** has two free upcoming DBS classes on Saturday, August 24, and Saturday, November 16. Classes take place from 9 a.m. to 11:30 a.m. Call 952-993-5495 for more information and to register; registration is required. Patients referred by their clinicians and those who self-refer are welcome.

**The University of Minnesota** offers free DBS classes for patients who are seeing providers at the U of M, and for those who are considering DBS at the university's program. Classes take place on the U of M campus on the third Wednesday of the month from 10 a.m. to noon. Call Karen Ellis at 612-626-6688 for more information and to register; registration is required.

## DBS SUPPORT GROUP



Those of us who decided to have Deep Brain Stimulation (DBS) did so based on our own evaluation of our life with Parkinson's disease. I have

made the decision and now live with DBS. There is hardly a day that goes by that I do not wonder, "Am I using it properly? Am I getting the most of it that I can? What are others' experiences with DBS? How can I explain DBS to my best friend, or life partner, or my other family members?"

It is this type of thinking that has led my wife Kay and I to seek out others who have questions about DBS, its usage, and the amount of clinical support that exists. We are interested in hearing the experience of other people with Parkinson's disease who have had DBS. I believe we can learn from each other's experiences with DBS. All are welcome – people with PD who have had DBS, their family members or care-partners, and people without DBS who are interested in learning more about it.

The group meets at the Ramsey County Library in Shoreview at 10 a.m. My phone number is 651-470-3349, and my email address is jimkayruss@earthlink.net. Please feel free to call me or email me with questions about the DBS support group.

## APDA MINNESOTA GRANT PROGRAM

The mission of the APDA is, “Every day, we provide the support, education, and research that will help everyone impacted by Parkinson’s disease live life to the fullest.” The APDA Minnesota Chapter has implemented a set of Patient Grant Programs to support the PD community. People with PD and their families can apply for and receive monetary grants that help subsidize various expenses. Grants will be given in an amount of \$500 per year, but may be less based on need and the availability of funds.

The grant program is available to anyone in need of financial assistance and is based on the honor system. Funds can be used for exercise classes, medication, respite care, transportation, driving assessment tests, etc.

To qualify for a Support Grant, the applicant must:

- Be on the APDA Minnesota Chapter mailing list.
- Reside within Minnesota.
- Have a diagnosis of Parkinson’s disease or be caring for a family member at home with a diagnosis of Parkinson’s disease.
- Complete and submit the entire Patient Grant Program Application.
- Not currently have a grant with another Parkinson’s organization.

To receive a Patient Grant Program application, please contact Anushka Mohideen, APDA Minnesota Information & Referral Coordinator, at 651-241-8297 or [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com).

### *Parkinson’s Disease Exercise Classes*

For a complete listing of Parkinson’s disease exercise classes in Minnesota, please visit <https://www.apdaparkinson.org/community/minnesota/local-resources-support/>

### *Parkinson’s Disease Support Groups*

For a complete listing of Parkinson’s disease support groups in Minnesota, please visit <https://www.apdaparkinson.org/community/minnesota/local-resources-support/>



Allina Health   
**ABBOTT  
NORTHWESTERN  
HOSPITAL**

**American Parkinson Disease Association  
Information and Referral Center of Minnesota**  
Abbott Northwestern Hospital  
800 E. 28<sup>th</sup> St., MR 12209  
Minneapolis, MN 55407