

WINTER / SPRING 2020

MINNESOTA | Newsletter of the Minnesota  
American Parkinson Disease Association

# MESSENGER

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

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

## Oral Dysfunction in Parkinson's Disease



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

Two common and distressing problems that can develop in Parkinson's disease (PD) are swallowing dysfunction and drooling. I want to help you better understand these issues and learn what you can do to improve them – so read on!

Thank you to Christine Sapienza, PhD, CCC-SLP and Bari Hoffman Ruddy, PhD, CCC-SLP for contributing to this article.

### **Swallowing Difficulties in Parkinson's Disease**

The act of swallowing involves a complex series of activities that begin in the mouth, continue in the pharynx (or the throat) and end in the esophagus. These include chewing, using the tongue to move the bolus of food to the back of the throat and then coordinating the muscles that both propel the food into the esophagus and protect the airway or trachea from food penetration.

Swallowing dysfunction (also called dysphagia) can be considered both a motor and a non-motor symptom of PD. Loss of dopamine neurons in the substantia nigra area of the brain can cause the motor dysfunction that impairs swallowing. However, loss of neurons in other areas of the brain, such as the cortex and lower brain stem can also affect the overall control and coordination of swallowing, and can be thought of as a non-motor symptom of PD.

Swallowing issues are very important to diagnose. Impacts on your daily life and your health can range from difficulties with meals to more extreme (but less common) cases where it could lead to choking and aspiration which can be very serious or even fatal.

### **How do you know if you or your loved one has a problem with swallowing?**

Swallowing difficulties can start very subtly and initially not be obvious to

*(continued on page 2)*

## Oral Dysfunction (cont. from cover)

either the person with PD or their loved ones. There are signs to look out for before swallowing difficulty becomes overt (i.e. choking on food). Some of the signs you should pay attention to include:

- Slow rate of eating – people with difficulty swallowing may slow down their eating in order to avoid coughing or choking
- Fatigue during eating or decreased enjoyment of food
- A sensation that food is “sticking” in the throat
- Coughing or excessive throat clearing during eating
- Difficulty in swallowing pills
- Unexplained weight loss – people with difficulty swallowing may reduce their consumption in an attempt to eat without coughing or choking
- Change in dietary habits – people with difficult swallowing may alter their diet in order to avoid foods that cause difficulty. This may not be a choice made consciously
- Diagnosis of a pneumonia – this could be caused by aspiration, or entry of a foreign substance (i.e. food) into the airway

If you think there might be a swallowing issue, it is important to speak with your doctor about it. There are steps you can take to properly assess the situation (i.e., a swallowing evaluation) and improve your swallowing function. This can in turn reduce your risk of choking, make eating more enjoyable, and lessen the chances of unwanted weight loss and/or other discomforts.

### ***What is a swallowing evaluation?***

If because of the above signs there is concern that swallowing difficulties exist, your doctor may recommend a swallow evaluation, which can be performed by a speech and language pathologist.

There are two main ways to evaluate someone’s swallow:

- Modified barium swallow study – This is the most common test that is performed. The person is asked to ingest different consistencies of barium and moving x-rays are taken that follow the barium as it is swallowed. This x-ray video pinpoints the areas of the swallow that are problematic and helps to determine the correct exercises to address the problem.

- Fiberoptic endoscopic evaluation of swallowing (FEES) is another type of test that can be performed to evaluate swallow. During this procedure, a very thin flexible fiberoptic tube which is hooked up to a camera and light source, is passed through the nasal passage. The tube does not go down the throat, but allows swallowing to be observed. This procedure is painless and well-tolerated by most individuals.

### ***If you have swallowing difficulty, what can be done?***

In some cases, swallowing function varies in response to dopamine medication doses, much like other aspects of motor function. Therefore, if swallowing becomes problematic, an increase in dopaminergic medications can be tried. In addition, make sure you undergo a swallow evaluation when you are in the ON state.

Even before a formal swallow study, you can take steps to increase the efficiency of your swallow. These include:

- Sit upright during all eating and drinking, even when taking pills
- Tilt the head slightly forward, not backward, as you swallow
- Take small bites of food, chew thoroughly, and do not add any more food until everything from the first bite has been swallowed
- Take small sips of liquid
- Concentrate while moving the food backward in the mouth with the tongue
- Double swallow” (swallow a second time) if the food did not go down completely with the first swallow
- Sometimes taking a sip of liquid between bites of food can help to wash the food down
- If eating is very tiring, try several smaller meals spaced out during the day instead of three large meals.

### ***Swallowing exercises can be very helpful to improve your swallowing***

After a formal swallow assessment, swallowing therapy sessions can be designed for you, involving exercises tailored to the specific parts of your mouth and throat that are causing the swallowing problem. Sessions may

involve practicing compensatory swallowing strategies with various types of foods in order to maximize safety and efficiency while swallowing.

During swallow therapy, recommendations may include:

- Best feeding techniques
- Exercises to strengthen oral and throat muscles
- Compensatory techniques to assist in safe swallowing
- Oral and mouth care techniques
- Appropriate food selection and ways to modify food texture
- Safe positioning strategies
- Patient/family education

### ***Choosing foods for successful eating***

Part of formal swallow therapy will be to make appropriate food suggestions that you can eat safely. Good food choices include:

- Foods that don't require vigorous chewing. Avoid dry and crumbly foods.
- Moderately textured wheat breads instead of very coarse, nutty breads or very soft, white breads.
- Oatmeal, cream of wheat or moistened dry cereals instead of coarse, dry cereals.
- Well-cooked, tender chicken/turkey, well-cooked fish without bones, chopped and ground meats, instead of stringy, tough meats that require a lot of chewing.
- Soft casseroles and poached or scrambled eggs
- Mashed potatoes or rice, moistened with gravy or margarine, instead of wild rice or French-fried potatoes.
- Soft, cooked pasta elbows, instead of long spaghetti.
- Soft, well-cooked vegetables, cut up or creamed, instead of raw vegetables or those with a hard texture.
- Pureed or mashed fruits, fruit juices and fruit sauces, instead of fruits with seeds or hard outer skins. Avoid nuts, seeds or coconut.
- Custard, yogurt, ice cream or other soft desserts

### ***Drooling & Parkinson's***

Poor control of saliva is known as sialorrhea. This problem may be mild and result in a simple issue such as a wet pillow in the morning. In some cases however, the problem can be severe, and causes excessive drooling. Drooling is not only an annoyance but can result in significant embarrassment and social isolation.

People with PD have problems controlling saliva because the muscles of the oral cavity, face, and neck may have less control than normal and there may be a delay in the person's ability to trigger a swallow. Sometimes there is excess saliva in the mouth because swallowing is less frequent, due to the general slowness of movement that accompanies PD.

### ***Solutions to drooling***

Anti-cholinergic medications such as glycopyrrolate and scopolamine can cause dry mouth and can be useful to control drooling. Unfortunately, because these medications enter the blood stream, they can also cause effects in other parts of the body such as urinary retention, constipation and blurry vision. Scopolamine can also cause cognitive side effects such as drowsiness and confusion. Therefore, these medications need to be used with caution.

Some physicians prescribe atropine ophthalmic drops (another anticholinergic medication) to be placed under the tongue to control drooling. This method is meant to deliver the anti-cholinergic effects more locally, thereby preventing the anti-cholinergic side effects in other parts of the body. However, this too must be used with caution as effects can still be widespread and much care has to be taken to deliver only 1-2 drops under the tongue at a time.

Botulinum toxin injections into the salivary glands can decrease production of saliva and thereby decrease drooling. They have become a common and effective method of controlling saliva with minimal side effects.

There are three sets of salivary glands: the parotid glands (in the cheek), the sublingual glands (under the

## Oral Dysfunction (cont. from page 3)

tongue) and the submandibular glands (under the jaw). Parotid injections are the most straightforward and can be performed by most movement disorder physicians during a routine office visit. If these injections are not sufficient to control the drooling however, the next step would be to try botulinum toxin injections of the sublingual and/or submandibular salivary glands. This is a more specialized procedure and may require a visit to an ENT physician.

It is important to note that botulinum toxin not only decreases saliva production but also weakens muscles, including the muscles of swallowing. Botulinum toxin injections are therefore not a treatment for swallow dysfunction and can in fact cause swallow dysfunction.

The parotid gland in the cheek is far enough away from the swallowing muscles that impairment of swallow is typically not a side effect, although it can be in rare cases. Sublingual and submandibular salivary glands are in close proximity to the swallowing muscles and injections of these salivary glands therefore have a higher risk of causing swallow dysfunction. Therefore, only someone trained specifically in these injections should perform them.

### *Tips and Takeaways*

- Swallow impairment and drooling are two common symptoms of oral dysfunction in Parkinson's disease.
- Subtle signs of swallow dysfunction can include slow eating, coughing with eating and weight loss.
- If swallow dysfunction is suspected, a swallow evaluation can pinpoint what the problem is and swallow therapy can help improve it.
- Drooling can be helped by oral medications or injections of Botulinum toxin but need to be used carefully so as not to cause swallowing difficulties.
- Do not suffer silently or wait until the problem is very advanced before seeking help. Talk to your doctor as soon as you notice any issues or potential difficulties so proactive steps can be taken to lessen the impact of swallowing issues or drooling and also to keep you safe and comfortable.

## Parkinson's Choir

Do you want to have fun, meet others, and make music, while exercising your voice, respiratory muscle strength, and mind? The Parkinson's Choir is a great community resource!

**Everyone is welcome, with or without singing experience, as well as their care-partners.**

There is **no cost** to participate, due to grant support by APDA Minnesota Chapter.

Rehearsals take place every other week from 2:30 – 3:30 PM on Thursdays, at St. Stephen's Lutheran Church (1575 Charlton Street, West St. Paul MN 55118).

Upcoming rehearsals are March 12 & 26, April 9 & 23, and May 7 & 21.

For more information or to join the PD Choir, please contact Sara M. Oberg, B.M., M.A, CCC-SLP, at **651-254-8118** or [Sara.M.Oberg@Healthpartners.com](mailto:Sara.M.Oberg@Healthpartners.com).

## Coordinator's Column

### Dear Readers,



*Anushka Mohideen,  
APDA Minnesota  
Information  
& Referral  
Coordinator*

I hope you all are doing well and enjoying the season. 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 books and 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).

I am looking forward to an eventful year with APDA Minnesota, filled with programs and services for the PD community across the state. In this issue, you will see an event invitation for the 2020 Spring Parkinson's Symposium, offered in collaboration with the Udall Center of Excellence in Parkinson's Disease Research at the University of Minnesota and the Parkinson Foundation Minnesota-North Dakota Chapter.

You will also see information about the APDA Parkinson's Roadmap for Education and Support Services, also known as PRESS. PRESS is a special 8-week program for people who have been diagnosed with Parkinson's disease within the last 5 years. This unique program melds education about different aspects of living well with PD with psychosocial support and sharing.

Care-partners and adult family members of the person with PD are encouraged to attend PRESS sessions as well. There is no cost to attend the PRESS program, but pre-registration is required.

We are excited to offer the PRESS program with partners in Coon Rapids, St. Cloud, and Baxter, MN in 2020. More details are on the program fliers on the following pages.

We will be offering educational events in Mankato and Alexandria in April, and hope to offer an educational program in the Marshall area later this summer. Fall will bring our annual Optimism Walk in Roseville, as well as the Fall Parkinson's Conference, location TBD.

I am looking forward to seeing you at APDA events this year!

Warmest regards,

*Anushka*

## APDA Minnesota Chapter Tango in the Night Event – Saturday, March 7

Join APDA Minnesota Chapter for an evening filled with inspiration, hope, and dancing! This event will include a program about APDA Minnesota's impact on the community and a professional tango performance followed by tango dance lessons. Enjoy the evening with cocktails, hors d'oeuvres, and a silent auction.

Professional dancers and instructors from Dancers Studio will entertain you and teach you how to tango and strut your moves on the dance floor. Dancers Studio has been located in the Twin Cities for over 30 years and has been voted the Best Ballroom Dance School in the Twin Cities by Mpls/St. Paul Magazine.

The purpose of this event is to raise community awareness of Parkinson's disease, raise funds to benefit PD research, increase programs and support services for those living with PD in Minnesota, and bring a social event to the PD community. APDA Minnesota is proud to have seventy-five percent of funds raised at this event go back to the local PD community through educational events and individual patient aid scholarships to allow people with PD to live life to the fullest. To date, we have provided over \$150,000 in patient aid scholarships over the past four years.

Tickets are available at [APDAParkinson.org/Minnesota](https://www.APDAParkinson.org/Minnesota). If you are not able to attend, donations are welcome.



*present.*

# SPRING PARKINSON'S SYMPOSIUM

SATURDAY APRIL 18, 2020

8:00AM-1:00PM

## LOCATION

Inwood Oaks  
484 Inwood Ave North  
Oakdale, MN 55128

## REGISTRATION

The event is free to attend however registration is required. Lunch will be served.

**TO REGISTER:**  
[tinyurl.com/SSMN2020](http://tinyurl.com/SSMN2020)

## CONTACT

Questions? Call  
Anushka at  
651-241-8297

## CONFERENCE HIGHLIGHTS

### NON-MOTOR SYMPTOMS IN PARKINSON'S DISEASE

Dr. Roger Albin  
University of Michigan  
Udall Center

### STAGING PARKINSON'S DISEASE

Dr. Eleanor Orehek  
Noran Neurological Clinic  
APDA Minnesota Medical Director

### PARKINSON'S - THE HARD QUESTIONS

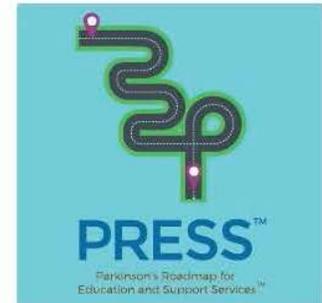
Susan Vold, BSN, RN  
University of Minnesota  
Department of Neurology

### RESEARCH & ADVOCACY

Karlin Schroeder  
Senior Director of Community Engagement  
Parkinson's Foundation

### QUESTION & ANSWER PANEL





## APDA Parkinson's Roadmap for Education and Support Services (PRESS)™

American Parkinson's Disease Association (APDA) Minnesota is proud to partner with Independent Lifestyles, Inc. to offer a special 8-week program for people who have been diagnosed with Parkinson's disease within the last 5 years.

This unique program, titled PRESS, melds education about different aspects of living well with PD with psychosocial support and sharing.

Care-partners and adult family members of the person with PD are encouraged to attend the PRESS sessions as well.

There is no cost to attend the PRESS program, but **pre-registration is required**.

Complimentary refreshments will be served.

**Date:** 2<sup>nd</sup> Week of March – 4<sup>th</sup> Week of April

**Location:** Independent Lifestyles, Inc., 215 N Benton Dr, Sauk Rapids, MN 56379

**Time:** 3:00 – 4:30 PM

**Session 1: What's Next After Diagnosis (March 10)**

**Session 2: Medication Management of Parkinson's Disease (March 17)**

**Session 3: Importance of Exercise in PD (March 24)**

**Session 4: Dealing with Physical Symptoms of PD (March 31)**

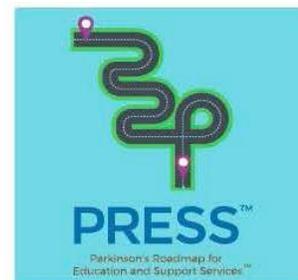
**Session 5: Impact of Parkinson's on Daily Coping and Relationships (April 7)**

**Session 6: Tips for Daily Living (April 14)**

**Session 7: Caring for Others, Caring for Yourself (April 21)**

**Session 8: Building Your Healthcare Team (April 28)**

The group is open to any adult who has been diagnosed with Parkinson's disease within the last 5 years, their care partner, and adult family members. The group will be facilitated by Pam Tritz-Okia. To register or for additional information please contact Pam Tritz-Okia at 320-281-2031 or Anushka Mohideen at 651-241-8297.



## APDA Parkinson's Roadmap for Education and Support Services (PRESS)™

American Parkinson's Disease Association (APDA) Minnesota is proud to partner with the Baxter/Brainerd Lakes Area Parkinson's Support Group to offer a special 8-week program for people who have been diagnosed with Parkinson's disease within the last 5 years.

This unique program, titled PRESS, melds education about different aspects of living well with PD with psychosocial support and sharing.

Care-partners and adult family members of the person with PD are encouraged to attend the PRESS sessions as well.

There is no cost to attend the PRESS program, but **pre-registration is required.**

Complimentary refreshments will be served.

**Date:** Thursday, April 9 to Thursday, June 11

**Location:** Lord of Life Church in Baxter, MN – 6190 Fairview Rd, Baxter MN 56425

**Time:** 12:00 – 2:00 PM

**Session 1: What's Next After Diagnosis (Thursday, April 9)**

**Session 2: Medication Management of Parkinson's Disease (Thursday, April 16)**

**Session 3: Importance of Exercise in PD (Thursday, April 23)**

**Session 4: Dealing with Physical Symptoms of PD (Thursday, April 30)**

**Session 5: Impact of Parkinson's on Daily Coping and Relationships (Thursday, May 7)**

**Session 6: Tips for Daily Living (Thursday, May 28)**

**Session 7: Caring for Others, Caring for Yourself (Thursday, June 4)**

**Session 8: Building Your Healthcare Team (Thursday, June 11)**

The group is open to any adult who has been diagnosed with Parkinson's disease within the last 5 years, their care partner, and adult family members. The group will be facilitated by Lynda Erickson, BSW.

To register or for additional information please contact Anushka Mohideen at 651-241-8297.

## Spotlight on Deep Brain Stimulation (DBS) & Parkinson's Disease – Mankato

**First Congregational United Church of Christ**  
**150 Stadium Court, Mankato, MN 56001**  
**Free parking available at the venue**

**Monday, April 13 | 10:30 AM**

*Complimentary refreshments will be served*

You are invited to join APDA Minnesota for an educational session focusing on Deep Brain Stimulation (DBS) as a treatment option for people living with Parkinson's disease. This event will address the following questions:

- What is DBS?
- What symptoms can DBS help with?
- What are the goals and expectations of DBS?
- Who is a candidate for DBS?
- A person with Parkinson's who has had DBS will also share his experience.

**SPEAKER:**

**Dr. Kai Miller, M.D., Ph.D.**

*Mayo Clinic*

This is a free program, but registration is required.

To register, please call Anushka at 651-241-8297.

Email: [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com)

*This venue is fully accessible for people with disabilities.*

## APDA Good Start Program – Alexandria

### **First Lutheran Church**

**1655 – 18th Ave E, Alexandria, MN 56308**

**Free parking available at the venue**

**Thursday, April 30 | 9 – 11:30 AM**

*Complimentary refreshments will be served*

Have you or a loved one been diagnosed with Parkinson's disease within the past three years? The Good Start Program, offered by American Parkinson Disease Association (APDA) Minnesota, is an educational session that will help you learn more about:

- What Parkinson's disease (PD) is
- Treatment options for PD
- The healthcare team for PD management
- The role of rehabilitation and exercise in PD management
- Medication management for optimum functioning
- Positive coping strategies in living with PD
- Supportive community resources

### **SPEAKER**

**Anushka Mohideen**

*APDA Minnesota Information & Referral Coordinator*

This is a free program, but registration is required.

To register, please call Anushka at 651-241-8297.

Email: [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com)

*This venue is fully accessible for people with disabilities.*

## APDA Advancing Parkinson's Disease – Alexandria

**First Lutheran Church**  
**1655 – 18th Ave E, Alexandria, MN 56308**  
**Free parking available at the venue**

**Thursday, April 30 | 1 – 4 PM**

*Complimentary refreshments will be served*

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
- End of life issues

**SPEAKER:**

**Anushka Mohideen**  
*APDA Minnesota Information & Referral Coordinator*

This is a free program, but registration is required.  
To register, please call Anushka at 651-241-8297.  
Email: [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com).

*This venue is fully accessible for people with disabilities.*

## Medical Director's Column



*Eleanor Orehek, M.D., Noran Neurological Clinic*

Dear Readers,

I am writing this column in the middle of a snowstorm. We are in the midst of winter with all of its glorious snow, cold and ice. There can be some great things about winter, especially if you enjoy outdoor activities like ice fishing, skiing, or snow shoeing and then coming to the warm indoors for a mug of hot chocolate.

Unfortunately when you are living with Parkinson's disease, the cold and ice can make it harder to function and manage your symptoms. If winter has you feeling down emotionally, or feeling like your symptoms are worse, I would encourage you to reach out to your support network of friends, family, physician, therapists and/or anyone else that can help support you and find things to do that can help improve things for you. This is true for care-partners as well. It is important to find outlets that help cope with stress or low mood during the colder months.

Many of my patients that I see want to know what the future holds. I tell them that for the most part, that is a crystal ball question. So much of the future is difficult to predict. Parkinson's disease is a progressive disease, so generally symptoms progress and worsen over time. However, there are major variables that make it very difficult to predict how people will do moving forward.

I understand that planning for the future is important, and uncertainty about the course of PD makes it challenging to make those plans. I would recommend having a plan for the future that includes an idea of what you would want or need if you do reach a point when you need more help managing your care. What would that look like? That can look like many different things for different people, such as in-home care from a home health aide part time or full time, in-home respite to support the care-partner, or transitioning to a different living situation such as assisted living.

After making that plan for the future, try to put that plan aside for now. Live each day in the moment, and take advantage of the things and opportunities that you can do today.

A major variable that impacts how people with PD do moving forward is exercise. The impact of regular exercise cannot be overstated. Some of you may be sick of hearing me talk about exercise, but it's important enough that I'm willing to take that risk and continue to talk about it. Find exercises that you enjoy and do them as often as you can.

Another major variable that impacts how people do in the future is response to varying treatments. The right medication regimen can make a huge difference. There are a lot of medications available that can have significant beneficial impacts on disease symptoms. Make sure you are working with your providers to find the best medication plan.

Additionally, there are promising advances that are being made in our understanding of PD. These research advances are leading to development of treatments that could impact the progression of PD. These treatments take years to develop from when they are first developed or tested clinically, but there are several that are in mid-phase testing at this time. It will be exciting to monitor the progress of these treatments. There is reason to maintain hope in the face of this tough disease.

Strength in optimism. Hope in progress.

## APDA Optimism Walk 2020



**AMERICAN  
PARKINSON DISEASE  
ASSOCIATION**

### **SAVE THE DATE!**

**Saturday, September 12, 2020**

Roseville Central Park, Jaycees Shelter - Roseville, MN

Funds raised at the Optimism Walk will support the APDA Minnesota Chapter's mission of providing support, education, and research for people with Parkinson's disease across the state.

## APDA & YMCA Pedaling for Parkinson's – New Exercise Program in Rochester



Pedaling for Parkinson's is a cycling program that aims to improve the lives of those living with Parkinson's disease and their caregivers.

The YMCA of the Greater Twin Cities offers this program because regular exercise is one of the key components in treating the many symptoms of Parkinson's disease, and it has been proven that pedaling a bicycle may change the life of someone with Parkinson's disease.

Research conducted at the Cleveland Clinic showed a 35 percent 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 Parkinson's disease, but there is compelling evidence to show that it does make a real difference in many who try it.

Pedaling for Parkinson's is offered at the Rochester Family YMCA, 709 1st Ave. SW, Rochester, MN 55902. This class is **free** for members and non-members of the Y due to a grant from APDA Minnesota. Please call (507) 287-2260 for more information or to sign up.

## Deep Brain Stimulation (DBS) Support Group



*Jim Russell*

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.

Our DBS support group meets quarterly. 2020 meeting dates are **January 14, April 14, September 8, and November 10**. The group meets from 12 PM – 2 PM at Wentworth Library, 199 East Wentworth St, West St. Paul, MN 55118.

Please reach out to Jim at 651-457-5331 or [jimkayruss@earthlink.net](mailto:jimkayruss@earthlink.net) to be added to the email list for DBS support group meetings.

## Community Resource Spotlight

**Minnesota Network of Hospice and Palliative Care** provides information and referral services for hospice in Minnesota. Its website provides a search tool that allows user to locate hospice programs in their communities.

Call (800) 214-9597 or visit <http://www.mnhpc.org/>.

**Minnesota Association of Area Agencies on Aging (AAAs)** offer aging services, including:

- Information and assistance
- Care management
- Nutrition services (i.e., Meals on Wheels)
- Legal assistance
- Services for family caregivers through the Family Caregiver Support Program (FCSP)

Contact them by phone via the Senior Linkage Line at (800) 333-2433 or visit their website at <http://www.mn4a.org/>.

## 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 Claire Grubich in September 2019.*

*Some days are good, and some days are better, is the reflection we might have in living with Parkinson's Disease. It goes without saying that our mood influences our physical tolerance, and physical discomfort bears on our mood.*

*The clues I had overlooked before my PD journey began were a loss of balance and a subsequent fall. The following year, my primary care physician suggested Parkinson's disease and my diagnosis was confirmed by a neurologist.*

*Not being a quitter, I decided that despite being denied full activity in retirement due to the new diagnosis, I would focus on the strengths that I had. Retirement arrived in the next year, and I gracefully accepted physical therapy and LSVT BIG and LOUD classes into the routine of my life.*

*I practice my LSVT exercises often and have impressed my providers with my determination. It has now been three years since my diagnosis was confirmed. I made a decision to recapture the lost two years I initially planned for after my retirement.*

*I successfully moved to an apartment complex where I could own a dog and enjoy the amenities of community living, including a gym and pool on site, a clubhouse to entertain guests, and celebrations for the holidays. The transition was immensely gratifying. I learned precautions to guard against falls – moving slower when physically uncertain, walking on level surfaces, looking ahead to potential hazards, and above all, not rushing! In addition, I had two handrails installed near my shower and chose a first floor apartment. I am not restricted to an otherwise limited existence. I keep track of what I can accomplish.*

*I believe in the need for future planning and backup planning in all phases of life and decision-making with PD. I have a home care agency in mind for future needs. I am fortunate to have long term care insurance, and I have a circle of friends who can help out if needed.*

*The future is unknown. Living in the present and not trying to guess my destiny are my objectives. My plan for the present is to enjoy what I have!*

## APDA Minnesota Resources

APDA's mission is that 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 offers a patient aid scholarship program designed to provide financial support to people with Parkinson Disease (PD) and their families. Approved applicants will be eligible to be granted up to a \$500.00 one-time payment per 12-month period. Funds are limited and will be awarded on a first come basis. This Patient Aid Scholarship Program is intended for individuals with PD in need of financial assistance for programs, services and/or activities, such as—

**Exercise/Wellness:** Supports costs associated with exercise/wellness programs and activities that focus on evidence-based treatment to improve and maintain the health for persons with PD. This is for exercise-related activities and classes such as, but not limited to: boxing, dancing, yoga, tai-chi, physical therapy, occupational therapy, etc.

**Medication:** Defray expenses not covered by other programs or health insurance.

**Respite/Adult Day Program:** Subsidizes the cost of respite care for the person with Parkinson's disease. Respite Care enables care providers to take time away from their responsibilities to rejuvenate.

**Assistance at Home:** Covers expenses for home services, such as housework, light yardwork, snow shoveling, and other tasks that a person with PD or a care provider are not able to complete.

**Transportation:** Covers costs associated with travel to and from doctor's appointments, support groups, and other events for those who are no longer driving or for whom driving is significantly limited due to the effects of Parkinson's disease.

**Childcare Assistance:** Subsidizes the cost of childcare for people with Parkinson's.

**Adaptive Equipment:** Offsets costs associated with the purchase and/or installation of equipment or modifications needed in the home to Aid in activities of daily living, such as, but not limited to: grab bars, hand rails, widening doorways, bathroom accessibility, etc.

Call Anushka at **651-241-8297** or email [anushka.mohideen@allina.com](mailto:anushka.mohideen@allina.com) to receive a patient aid scholarship application.

**Visit our website at [APDAParkinson.org/MN](http://APDAParkinson.org/MN) to access a list of PD support groups and exercise classes available statewide.**

AllinaHealth 

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HOSPITAL

**American Parkinson Disease Association  
Information and Referral Center of Minnesota**

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