

## Coping with Stress During the Current COVID-19 Crisis

by Charlinda Turner Brashear, LCSW, ACM-SW

**If** you're feeling freaked out or stressed by the current COVID-19 pandemic and social distancing, you're not alone. Stress is a normal human response to any event that disrupts the balance in our daily lives. Each person reacts differently to stressful situations, so there is no "right" or "wrong" way to be feeling.

Fear and anxiety can feel overwhelming, and taking steps to

manage your mental health is important. One of the first steps toward addressing stress is to acknowledge it, focus on what you can control, and then try your best to release what you cannot.

While social distancing is necessary right now for our health and safety, people are naturally social and want to connect with others—so this can be challenging. For those of us



## COVID-19 UPDATE

At the Northwestern Medicine Parkinson's Disease and Movement Disorders Center, nothing is more important to us than your health and safety. This issue of *On the Move* was largely created pre-COVID—but has been updated to be full of information to help you stay positive and connected during the challenging times ahead.

You'll find a comprehensive list of virtual resources, links to online exercise classes and support groups, as well as suggestions for coping strategies. From a clinic perspective, we are moving to televisits and are accommodating patients virtually.

We're always here to help and support our patients. We are all in this together!

## ***While we may need to practice social distancing for a while, you are NOT alone, and there are resources and people who can help.***

whose mobility is limited, or who are elderly, social isolation can be even more problematic. With that in mind, the following coping strategies and resources are available help you stay mentally healthy while you stay physically healthy.

Social distancing does mean zero physical social interaction, but we can get creative. All people need social interaction to help maintain mental health, and using technology at this time of crisis can help you to not feel alone. Tools such as FaceTime or video chats are a great way to stay emotionally connected with loved ones, even while staying physically apart.

Plan to schedule a daily check-in call or text time with loved ones to help fight feelings of social isolation. Also, try organizing a virtual “dinner” to share a meal, or a virtual “party” to play board games or watch movies.

Additionally, the act of “re-framing” how we view our time during social distancing can help us cope. For example, try to think about having more opportunities for self-care and quality time with your loved ones, instead of focusing on being “stuck inside.”

Using this time to practice some self-care can further alleviate stress and help us feel more in control. Self-care looks different to everyone—whether it’s playing

with a pet, calling or texting a loved one, watching a movie, or taking an online class. Finding an activity that brings you joy or a sense of accomplishment is important.

And remember not to neglect your need for physical activity. You can practice stretching or try an online exercise classes to help keep yourself in good physical condition while the gym is not an option. Also be mindful to get plenty of sleep, and try to avoid excessive caffeine or alcohol consumption.

Additionally, websites such as Calm.com, Headspace.com and Ten Percent Happier (tenpercent.com) feature daily live programming and resources, such as pre-recorded podcasts for guided meditation and stress management. These are great options to try, as mindfulness and meditation have been clinically shown to reduce anxiety and increase resilience. Most of these services are now being offered free of charge.

It should also be noted that, while we should all stay informed during a crisis, limiting media consumption also reduces stress and anxiety. Go ahead and watch the news; but if it’s negatively impacting your stress level, set a limit for yourself. That way, you stay informed, but you don’t spend the entire day in a stressful media spiral.

Being proactive with your schedule

can also be helpful. If you are working from home, make a set routine. Organize your desk—or kitchen table if you don’t have a desk—and keep your work confined to that area. Get up every day and get dressed. Set a time to take your lunch break, and schedule when to start and stop work.

If you are retired or not working during this time, similar advice still applies. Try to keep a routine by waking up at your normal time and getting dressed. Come up with a list of things you can do at home that you maybe haven’t had time to address. You can organize the house, tackle your reading list, or stream a television show you’ve been meaning to watch. Having a routine and a plan helps maintain a sense of normalcy during a crisis.

Also, take a moment each day to reflect and express gratitude. The practice of intentional gratitude is especially helpful during times of crisis. Consider starting a gratitude journal and making time for reflection in the morning to make a positive start to the day. Even something as simple as reflecting on the ability to have a peaceful cup of coffee in the morning can help boost your mood and bring calm.

Lastly, if you’re thinking about suicide, are worried about a friend or loved one, or if you would like emotional support, the Lifeline network is available 24/7 across the United States via phone at 1.800.273.8255.

Remember: while we may need to practice social distancing for a while, you are NOT alone, and there are resources and people who can help.

# TeleHD: Making Telemedicine an Option

by Danielle Larson, MD

Telemedicine is the use of video conferencing for meetings between patients and medical care professionals. This technology is being used more frequently for clinic visits, called “televisits,” as well as for research purposes. One main advantage of televisits is that they allow patients to see specialists that practice far away—decreasing the time and travel burden. Telemedicine is becoming a more routine part of the clinical care of Neurologic patients at hospitals across the country. In Neurology specifically, telemedicine was first used to conduct “tele-stroke” visits: stroke patients would get a quick evaluation from a stroke specialist over teleconference in order to expedite their stroke care and initiate immediate transfer to a stroke center if needed.

More recently, televisits are being used for Parkinson’s disease care. Several research studies on telemedicine in Parkinson’s disease showed that clinicians can perform Parkinson’s neurologic examinations during televisits with the same quality and accuracy as in-person clinic visits. These studies also showed that most patients were satisfied with the televisits, and even preferred some televisits over in-person clinic visits. Movement Disorder specialists at Northwestern’s Parkinson’s Disease and Movement Disorders Center have been conducting televisits for Parkinson’s patients since 2018. Patients who live far away, work during the day, travel frequently, or are snowbirds in the winter really appreciate the option of having a televisit with their Parkinson’s provider. Exemplifying the power of telemedicine,

the Parkinson’s Disease and Movement Disorders Center is leveraging its televisit capabilities to offer remote care to patients during the COVID-19 pandemic, to ensure the health and safety of our patients, especially the most vulnerable.

Hoping to expand the use of telemedicine for neurologic patients, clinicians at Northwestern will be conducting a study on the use of telemedicine for individuals with Huntington’s disease (HD). This study will be led by Movement Disorder Fellow Danielle Larson, MD and the HD Huntington’s >





Disease Society of America Center of Excellence (HDSA COE) director Danny Bega, MD, MSCI. The name of the study is "TeleHD," and it is expected to start in Spring 2020.

The TeleHD study aims to confirm that televisits can be used to assess the motor and non-motor symptoms of HD as effectively as in-person clinic visits. It will also determine if individuals with HD and their families prefer remote visits with their neurologist, since a televisit can save time and decrease travel-related costs and stress. The TeleHD study will include 40 individuals with HD who receive care at Northwestern's HDSA COE and have access to a camera, a microphone and an internet-enabled device (such as a smart phone, tablet or laptop). Each individual will complete two regular, in-person clinic visits and two televisits during their time in the study, which will be less than a year. The motor and non-motor assessments done via televisit will be compared to the in-person visits to determine if HD symptoms are assessed similarly and accurately. Participants and their caregivers will complete a survey to determine their satisfaction with televisits, their preference for in-person versus televisits, and whether or not televisits decreased their time and cost burden.

If the TeleHD study shows that televisits can be effective for assessing HD symptoms, and that HD individuals and their families are satisfied with them, this will inform the Neurologic community that televisits can and should be done for HD patients. This would improve their access to specialized, expert care, and decrease the patient burden of receiving care. If televisits are incorporated into research practices, this could also increase the opportunity for HD patients to participate in clinical trials, as it would lessen the burdens of time and distance.

Telemedicine has great potential to improve access to quality care for Neurologic conditions, and improve the healthcare experience of patients and their caregivers. The PDMC at Northwestern is committed to being at the forefront of applying telemedicine and expanding its role in order to better our patients' care.

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**If you are interested in being part of the TeleHD Study, or have any questions regarding the study, please contact the research coordinator Bobby Modiest at 312.503.0787 or [robert.jr3@northwestern.edu](mailto:robert.jr3@northwestern.edu), or call the research hotline.**

# PARKINSON'S DISEASE RUN CLUB

**by Chris Dell**

*Written before COVID-19; we will resume scheduling when it is safe to do so.*

Looking for a time and place to stretch your legs, get some exercise and meet new friends? Join our PD Run Club! We will resume our running, jogging, or walking activities in April, once the winter breaks and spring warms up Chicago once again. We will gather twice a week at the Montrose Track on the Lakefront trail. On Thursdays, we run/walk intervals around the track, and on Saturdays, we go for a longer trail run along the lakefront path.

Run club isn't about who can run the fastest or the farthest. It's about staying physically and socially active and meeting friends who are on a similar journey. I encourage each of you to join us next time, and feel free to bring a friend or your spouse. Everyone is welcome.

The "B.E.A.T." in our mantra "B.E.A.T. Parkinsons" stands for Be Extremely Active Today. While there may not be



a cure for Parkinson's yet, it is well known that an active lifestyle can certainly help mitigate the severity of symptoms. So by being extremely active today, we give ourselves the best possible chance for tomorrow.

## Join us!

### Location:

All runs will start and end at:

**Montrose Lakefront Track  
Lakefront Trail & Wilson Dr.  
Chicago, IL 60640**

(It's called "Montrose Track" but it's actually closer to Wilson (4600N) and the Lakefront Trail. Ample parking is available at the lot across the street.)

### Thursday Night PD Run Club Schedule:

- Interval Training, 6-7 PM
- 6 - 6:15 PM: Stretching and warm-up (walking/jogging around the track)

- 6:15 - 6:45 PM: Track Workout
- High Intensity Option: 100 yd / 80 yd / 60 yd / 40 yd / 20 yd sprints with recovery breaks
- Low Intensity Option: Power-walking or light jogging
- 6:45 - 7 PM: Cool down

### Saturday Afternoon Fun Trail Run Schedule:

- Long Run, 9 AM (Runs typically last 1-3 hours)
- Ideal for those training for distance events like a half or full marathon. We will start with 4 miles and build up to 12+ miles, with multiple distance options depending on your level and training program. We run along the Lakefront Path, which is crushed gravel.
- 9 - 9:15: Stretching and warm-up walking around the track
- 9:15 - TBD: Long-distance run (run 3-4 minutes / walk 1 minute)





# An Idea Sparks a Movement

by Linda Egan with Susie Krueger

## Everyone has a spark inside.

Often, people with Parkinson's need a little help to turn the spark into a fire. The right idea coated with encouragement may just start the movement toward something enjoyable and beneficial. Imagine an opportunity that may be your perfect fit—the one that removes barriers, clears your runway and allows you to take off toward a rewarding destination. The risk you take to explore is worth the effort. But you won't know until you try. You never know how an idea can develop into something impactful when you believe in yourself and take the chance.

The downtown runners' club began with one person's love of running and the intent to "B.E.A.T." Parkinson's (Be Extremely Active Today). The goal of the group is to give hope and inspiration to those in the Parkinson's community. It combines physical activity with social interaction in a motivating and supportive setting.

The thought "we exercise our bodies, why not exercise our minds" inspired the Lake Forest book club. "I think sometimes we have forgotten about the book until the end, and just spent the time together sharing thoughts, ideas and other events that have occurred during the month," reveals the founder of the club. What a great idea, to meet where you can be warmed by the conversation and the fireplace!

IMPROV class developed from a desire to improve communication skills. This is an upbeat, laughter-filled class where there are no mistakes. It gives everyone a chance to express themselves and learn conversation strategies to enhance their interactions with others. A chance to learn something and have fun at the same time is a win-win.

The challenge of trying something new, or revisiting a youthful pursuit, was the inspiration for the horseback riding program. Whether you are a seasoned rider or a novice, the program teaches riding and horsemanship skills that empower riders and improve self-confidence, all while helping participants grow stronger.

Anything is possible! The world is full of wonderful, exciting activities that you can explore and adopt as your own. Be brave enough to try something new, and be kind to yourself no matter the result. Focus on what you can



do rather than what you cannot do. Staying engaged in activities and connecting with others helps to give one a sense of purpose and belonging—whether it is at play or at work, having lunch with your grandchildren, or playing golf with your buddies.

Do not give up on things you enjoy doing, and remind yourself that you can manage every situation that is ahead of you. For instance, an evening out can still be fun, but may require a bit of advance planning. It may require playing close attention to meds, taking a nap or allowing plenty of time to get ready. Take the stress out of travel with a bit of pre-arranging for help. Was entertaining your forte? Recruit help for cleaning and set-up, and remember that not everything has to be a gourmet presentation. The important part is enjoying the company of friends. >



Happy times are not in the past. Modify to meet your needs and remember this quote from Susie: "Relax your standards!"

Be energized by the possibilities: cooking, gardening, photography, art, music. Any activity you try is an opportunity to build your confidence and develop pride in your accomplishments. Believe in yourself. Use positivity to reverse any negative feelings Parkinson's wants you to feel—remember our support group motto: "I can and I will!" If you are having difficulty getting started, allow family and friends to support you. Doing an activity with others can turn it from daunting to fun. What about setting up a reward system? Create a celebration that you can look forward to, and then keep it in focus. Perhaps compliment yourself. Write down what you would say to someone else who accomplished what you have. Or place a \$1 in a jar every time you meet a goal and when it gets to \$50, treat yourself to something just for you. Remember, you don't have to be good at something for it to be good for you. Embrace and share any opportunity. Remember, your idea can spark a movement. What are you waiting for?





# COVID-19 Update: Virtual Services Available

Dear Movement Revolution  
and Rock Steady Boxing Family,

We have been closely monitoring the status of the COVID-19 Coronavirus and wanted to provide you with an update. As of Wednesday, March 18, 2020, all facilities will be closed, including all Chicagoland Rock Steady Boxing locations.

Exercise is an incredibly important and effective way to keep you and your immune system strong. We encourage you to keep moving at home and would like to provide you with an alternative virtual service.

We are a family and must stick together in times like these. As your specialists, our duty extends beyond the one-hour class or session you're with us. We want to provide you with all the tools necessary to stay strong, especially in times of adversity. We have initiated several alternative programming options outlined below, including our new Revolution @Home program.

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## PROGRAM STATUS UPDATES

One-On-One Services:

- Virtual Training: Virtual training via Zoom online webcast meeting. There is no registration required, and your specialist will simply email you a link to the session for your scheduled time.
- You will need to use a device with a camera (smart phone, tablet, laptop computer, or computer with a webcam).
- You may need a friend/family member present if balance is a concern; this can be determined between you and your specialist.
- If you are interested in virtual training, please email [daisy@movement-revolution.com](mailto:daisy@movement-revolution.com) for more information.

## ADDITIONAL ONLINE EXERCISE CLASSES: (Click on the links for info / videos.)

**Parkinson's Exercise Essentials:**

<https://www.davisphinneyfoundation.org/resources/parkinsons-exercise-essentials/digital-download/>

**Power for Parkinson's Strength & Balance:**

<https://www.youtube.com/watch?v=wM8rXq2DkxE>

**Parkinson's Home Exercise Class, Brain Teasers and More:**

<https://www.youtube.com/watch?v=ewFluJlK-Lc>

**Power for Parkinson's Move & Shout:**

<https://www.youtube.com/watch?v=jexuL2CQjSU>

**Power for Parkinson's Brain & Body Challenge:**

<https://www.youtube.com/watch?v=EGL-4AyJAUe>

**Sitting, Standing and Laying Down Sample Exercises:**

<https://www.youtube.com/watch?v=QsWdW0tbw8s>

**Parkinson's Home Speech Therapy Workout:**

<https://www.youtube.com/watch?v=Dy217qLXhyA>

**The Parkinson's Fitness Project (Paid Membership):**

<https://theparkinsonsfitnessproject.com>

**Classes for Aging Adults (Paid Membership):**

<https://www.silversneakers.com/learn/ondemand/>

**Seated Exercise:**

<https://www.youtube.com/watch?v=KNWqyKluZgg>

**Balance Skills and Drills:**

<https://www.youtube.com/watch?v=09eH35bR6tQ>

**Brian Grant Boot Camp Warm-up:**

<https://www.youtube.com/watch?v=NfkXjyJ5IVM>

**Brian Grant Boot Camp Boxing:**

<https://www.youtube.com/watch?v=nnjQSEFaqdE>

**Brian Grant Boot Camp Tai Chi:**

[https://www.youtube.com/watch?v=L\\_mcYRuhJvE](https://www.youtube.com/watch?v=L_mcYRuhJvE)

**Brian Grant Boot Camp Activity and Agility Course:**

<https://www.youtube.com/watch?v=Vsol-bfOoaQ>

**Brian Grant Boot Camp Pilates and Yoga:**

<https://www.youtube.com/watch?v=DXQr9SGyO>

**Brian Grant Boot Camp Lunges:**

<https://www.youtube.com/watch?v=DqPxXtrXQZo>

**Meditation:**

<https://www.tenpercent.com/coronavirussanityguide>



# Stronger Every Day: Movement Revolution

by Eric Johnson

**W**ith a mission to “Empower people with neurological conditions to live stronger every day,” Movement Revolution was established in 2013 to use movement and evidence-based exercise to revolutionize the health of those living with neurological conditions in Chicago, Deerfield and the Western suburbs. We specialize in providing tailored exercise programs to those living with a neurological condition, such as Parkinson’s disease, PSP, MSA, LBD, Huntington’s disease, stroke, MS, brain injury or other complex medical condition.

Our team of Neuro Exercise Specialists are passionate experts in the field of adaptive exercise and hold specialized certifications to work with neurological conditions. This gives them all the tools necessary to challenge clients at all ability levels.

Improving your quality of life as a client begins with our understanding of what a “fulfilled life” looks like to you. Whether your goal is to play golf again, run a marathon, play with your grandchildren or simply feel more confident in your daily life, you must know where to start. We first get to know you by guiding you through our comprehensive Neuro Intensive Evaluation. This is an opportunity for us to help you establish goals, discuss your current ability level and assess physical outcome measures. This evaluation is the foundation from which we build your personalized wellness plan to help you think, move and feel stronger in your everyday life.

Once we’ve established a starting point and an initial goal, we build your customized roadmap, which consists of a variety of programming

built to engage, stimulate and empower you. Our programs include symptom- or performance-specific 1:1 training, small group classes that focus on posture, cardiovascular exercise, strength and balance, and large group programs such as Rock Steady Boxing.

One of our core values at Movement Revolution is community. Every facility, program and class starts to form a unique, natural, supportive environment that helps our clients relate and empower each other. Our community is rooted in a no-judgment philosophy that fosters hard work, education and collaboration between the clients, their family, our coaches and the healthcare community. A strong community thrives with the right resources, which is why we are committed to collaborating with our clients, the local clinical and research teams and national advocacy organizations in an effort to unite and engage the movement disorder community. Although everyone fights their own fight, no one is alone. We’re all stronger together.

We have two very exciting community collaborations coming in 2020, including a grant from the Parkinson’s Foundation, and an opportunity to host a unique research project with Northwestern University and the Shirley Ryan Ability Lab called the Neurobility Pilot. Our Rock Steady Boxing Windy City program was a proud recipient of a Parkinson’s Foundation Community Grant in 2019, which has been a catalyst for our community by providing opportunities for social engagement, education and financial support. We invite you to join us for our events this spring, which include an Improv for Parkinson’s event in Deerfield, as well as a hands-on Diet & Nutrition workshop in Chicago. >



Our client experience is the motor that keeps this revolution rolling. The following is a testimonial from one of our clients, who is in his 50's, and was diagnosed with Parkinson's roughly 3 years ago:

## ***"Surrender is not an option. Fleeing is not an option. I choose to fight."***

*I was unsure of my diagnosis, my prognosis, and what it meant for me personally and professionally. But before the medical diagnostic process was even completed, I was introduced to Movement Revolution. And even before I began drug therapy, I began intense exercise therapy. Working with Movement Revolution has improved*

*my own physical condition. This not only alleviates my own anxiety, but also that of my family and friends. They see my abilities increasing notwithstanding the disease, and they – like I – realize that this diagnosis need not be a sentence to rapid decline.*

*It is common in our society for people confronting a difficult diagnosis to be told to "fight" their disease, and for those who succumb to be lauded for having fought hard. Often, fighting unfortunately means merely enduring difficult symptoms and treatments, while remaining in good spirits. But this is different. Thanks to Movement Revolution, I really am fighting this disease. And with enough*

*commitment, it's a fight that I know I can win, or at least fight to a draw for years to come. So surrender is not an option. Fleeing is not an option. I choose to fight.*

We're fortunate to have so many wonderful resources in Chicago that help our clients be more active with their conditions. It's time to act and move! I invite you to stop by one of our locations, observe a class, take a tour and let us show you how we can help you personally live stronger every day.

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**For more information on our programs please contact us at: (312) 465-3921 or [info@movement-revolution.com](mailto:info@movement-revolution.com).**





# Rock Steady Boxing, Rock-steady Improvement

by **Danielle Larson, MD**

**R**ock Steady Boxing (RSB), is a non-contact boxing, group fitness program intentionally designed to help those diagnosed and living with all levels of Parkinson's disease (PD). RSB was founded in 2006 by an individual with PD to apply the fundamentals of boxing training to PD-specific exercises. RSB classes include aerobic exercise, strength training and core training, as well as balance and flexibility exercises. It puts a focus on the motor aspects of PD, and loud vocalizations are encouraged to improve participants' speech. The RSB program is growing rapidly and broadly. Currently, there are an estimated 43,500 participants at approximately 900 worldwide RSB sites, including 12 in the greater Chicago area.

Anecdotally, individuals with PD say that they enjoy RSB classes, and are motivated to attend classes and make friends through the program. Some PD patients who do RSB also report that the exercise class improves various symptoms of PD. Providers at Northwestern wanted to learn more about what makes people start RSB, what makes them stick with it and what benefits they get from the program.

With that intention, Danielle Larson, MD and Danny Bega,

MD, MSCI, with physical therapist and researcher Miriam Rafferty, PT, DPT, PhD, conducted an online survey study about RSB. With the help of advertising through the Parkinson's Foundation and RSB Headquarters, 1,700 people completed the survey. This made it the largest survey on RSB ever conducted.

People who completed the survey were individuals with PD who had at least heard of RSB. All participants either participated in RSB, had previously participated but had stopped, or had never participated. The survey answers were compared between these three groups to understand what motivates people to start and continue RSB, and what people get out of participating.

Survey responses revealed that most individuals started RSB because it is a Parkinson's-specific exercise (83%), and because of the group-structure of the classes (52%). Individuals who never tried RSB said that the classes were difficult to access (37%) or too expensive (25%). Very few individuals chose not to participate because it is a boxing exercise, because it is a group class, or because it is Parkinson's-specific exercise.

The survey results showed that the majority of individuals





who had previously done RSB or are currently participating reported improvement in several important non-motor symptoms of Parkinson's through participation in RSB. This included 70% reporting improvement in their social life, 63% reporting improvement in fatigue, 60% reporting improvement in depression and 58% reporting improvement in anxiety. Notably, these are symptoms that are difficult to treat in PD.



When compared to individuals who have never participated, those who have participated or are currently participating in RSB had better scores on scales of Parkinson's-related quality of life and exercise self-efficacy. Though it is unclear if RSB causes these higher scores, the results of this survey suggest that RSB could improve the quality of life and the empowerment that individuals with PD feel toward exercising. Importantly, 99% of individuals who currently participate in RSB, and 94% of previous participants, said they would recommend it.

This large survey of RSB participants shows that not only do participants enjoy this unique exercise class, but also that participants feel the exercise regimen is improving their PD symptoms. Exercise is very important in PD, especially since there is growing evidence that regular exercise could delay the progression of the disease. RSB in particular is a great option for individuals with PD to get involved in a program that can improve their quality of life, social life, and PD symptoms.

## FUNCTIONAL MOVEMENT DISORDERS A Path Forward for Patients with Disabling Symptoms

by Kathrin LaFaver, MD

If you have never heard of Functional Movement Disorders (FMDs), you are not alone. Despite being one of the most common reasons for patients to see a movement disorder specialist, FMDs have largely stayed out of the spotlight. Triggered by emotional or physical stress factors, FMDs can cause tremors, limb jerking, speech problems, abnormal balance and trouble walking. Affected patients also often complain of fatigue, mood symptoms and difficulties with concentration and thinking. The disorder can start at any age and affect each gender, but it is most common in women during early adulthood and midlife. Symptoms are often sudden in onset and interfere with daily activities, school, work and family life.

The diagnosis of FMD is made based on typical clinical findings by a movement disorder specialist after a detailed history and neurologic exam. There are currently no blood tests or imaging studies available to confirm the diagnosis, but diagnostic studies may be helpful to rule out other causes of neurologic disease. Research has shown that brain circuits in FMD function differently compared to healthy controls, and they may overstimulate the motor system and cause abnormal movements.

The most important step to treating an FMD is to receive a timely diagnosis and to make an individualized treatment plan. Depending on the severity of affected movements and associated health problems, patients can benefit from specialized physical, occupational and speech therapies to retrain the motor system. They can also seek appropriate medical therapy if depression or anxiety are present—or cognitive behavioral therapy, a form of psychotherapy.

Northwestern Medicine Parkinson's Disease and Movement Disorders clinic offers appointments for evaluations to establish the diagnosis of FMD, or for second opinions by movement disorders neurologists. To schedule an appointment, contact 312-695-7950.

For FMD patients who have already received a diagnosis, the Shirley Ryan AbilityLab Parkinson's Disease and Movement Disorders rehabilitation program offers a multidisciplinary team approach for functional assessments and rehabilitation treatment planning. Patients may be seen by a team that includes neurologist Kathrin LaFaver, MD, psychologist Erica Sieg, PsyD, as well as psychiatrists, nurses and an allied health team of physical therapists, occupational therapists and speech-language pathologists. **To learn more about this program, contact 312-238-PDMD (7363).**

*Additional information about FMD can be found at [www.fndhope.org](http://www.fndhope.org), a patient-led organization for which Dr. LaFaver serves as Medical Advisor.*



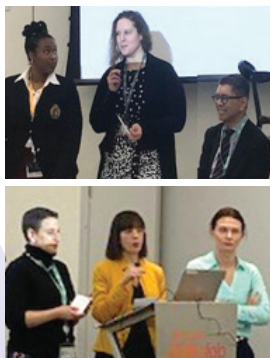
# Parkinson's Disease and Movement Disorders Program at the **Shirley Ryan AbilityLab**

**Article contributors: Jennifer G. Goldman, MD, MS; Anne Armstrong, OTR/L, Senior Occupational Therapist; Anne Montana, M.A., CCC-SLP, Senior Speech Language Pathologist; Lori Bravi, MS, OTR/L, BCPR, CLT-LANA, Master Occupational Therapist**

**T**he Parkinson's Disease and Movement Disorders (PDMD) program at Shirley Ryan AbilityLab provides comprehensive and personalized care in neurorehabilitation for people with Parkinson's disease and other movement disorders. The PDMD program offers interdisciplinary clinical visits customized, early-stage PD evaluations; individualized, outpatient rehabilitation therapy services; fitness center classes; educational sessions; and a broad range of research opportunities.

## Parkinson's Education and Outreach at Shirley Ryan AbilityLab

On November 2, we launched a 10-month education and support series entitled "Parkinson's Disease: All you ever wanted to know about neuropsychiatric and non-motor issues but were afraid to ask." This series is led by Jennifer G. Goldman, MD, MS, Section Chief of PDMD at Shirley Ryan AbilityLab and Professor of PM&R and Neurology at Northwestern. It is generously supported by a Parkinson's Foundation community grant, and focuses on topics that are very important in PD, but not always discussed—including interdisciplinary team care, depression, anxiety, cognition, fatigue, sleep, nutrition, vision and many others. Sessions are free of charge to people with PD and their care partners, and they are held on the first Saturday of



the month at Shirley Ryan AbilityLab, as well as by webinar for viewing online. For more information, please contact us at 312-238-PDMD (7363).

## April showers bring May flowers - and also blossoming opportunities for PD rehabilitation therapies!

**Did you know that April is National Occupational Therapy Month, and May is National Better Speech and Hearing Month?** Here at Shirley Ryan AbilityLab, occupational therapists (OT's) and speech-language pathologists (SLPs) are part of your interdisciplinary care team. Have you ever seen an OT or SLP? We provide the best personalized care for you by offering OT and SLP in the outpatient PDMD interdisciplinary clinic, in our Early Intervention PD program, through outpatient therapy, Day Rehabilitation and inpatient services.

## Top 10 Ways the OTs and SLPs of the Shirley Ryan Ability can help people with PD:

1. Hand tremors, weakness and incoordination can occur in PD. An OT can help with equipment recommendations and home exercise programs for improved control and function during daily activities.
2. An OT can help with strategies for handwriting, if micrographia (small writing) is an issue.
3. Vision changes can be a symptom of PD. A muscle-strengthening exercise

program formulated with an OT can promote better environmental safety and awareness due to certain vision changes.

4. An OT can help you apply strategies to everyday activities affected by cognitive, mood or motivation changes in PD.
5. A soft voice is a common symptom in PD. Addressing speech and voice changes with an SLP early in the disease can help you to maintain your loud voice.
6. Swallowing changes can occur even in the early stages of PD. An SLP can evaluate your swallow function and recommend strategies and/or exercises to improve or maintain safety during eating and drinking.
7. An SLP can provide strategies to help compensate for memory and thinking changes that can occur in PD. SLPs often work together with OTs and other team members for cognitive strategies.
8. Exercise isn't just for the gym! An SLP can help identify a personalized, home-based exercise program for speech, swallowing and cognitive stimulation to help maintain function and abilities.
9. Expiratory muscle strength training can strengthen the muscles used for swallowing, breathing and coughing.
10. Therapy with an OT or SLP is not a one-time occurrence! There should be an ongoing relationship over the course of PD to keep addressing different goals and strategies that may change with different stages of PD.

# Fire Up PD

by Emily Zivin, LCSW

## The Michael J. Fox Foundation

and Massachusetts General Hospital are funding a new initiative to enhance diversity in Parkinson's disease research. The FIRE UP PD (Fostering Inclusivity in Research Engagement for Underrepresented Populations in Parkinson's disease) study is a partnership to advance representation in, and awareness of, clinical research opportunities for underrepresented individuals and communities in the Parkinson's disease field. Five intervention sites and five control sites were selected from submitted proposals, and Northwestern University was chosen as an intervention site.

As their intervention, a team at Northwestern University has created the Chicago Movement Coalition (CMC) for Parkinson's disease, and clinical trial education in under-represented communities. The CMC is a multi-stakeholder partnership including patients, caregivers, community leaders and physicians. The CMC is initially partnering with the University of Illinois at Chicago (UIC) in addition to Northwestern, with a UIC Movement Disorder specialist on the leadership team. For its initial work, the CMC is focusing its activities in two communities: North Chicago (Edgewater/Roger's Park) and South West Chicago (Brighton Park/Little Village). These neighborhoods are ethnically and racially diverse: each is over 50% non-white, with rich populations of non-white Hispanic, African American and Asian minorities.

To date, the CMC has had two successful leadership meetings. These meetings helped members identify barriers, successfully recruit for focus groups and select literature for our educational tool kit. The CMC has also conducted focus groups in the two targeted Chicago communities which enabled the team to have conversations with diverse members of the neighborhoods, understand barriers to care, gather research and offer additional education about Parkinson's Disease.

The CMC is now building an educational toolkit and providing a series of educational workshops in the targeted neighborhoods. In December, the CMC completed an educational workshop at El Valor, a community social service agency in the Little Village area. Three additional workshops are scheduled for early 2020. After the educational

workshops, the CMC will have two more community focus groups to understand the impact that the workshops have had, as well as to get feedback from the community.

In the future, the CMC is hoping to grow to include more academic partnerships and host educational workshops in more Chicagoland neighborhoods.

**For more information and a schedule of educational workshops, visit**

**<https://www.chicagomovementcoalition.com/>.**





# Monthly Support Groups

Call 312.926.8048 for More Information • Chicago – Northwestern Medicine (251 E. Huron, Chicago)

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**ATTENTION:** The health and well-being of our Parkinson's Disease and Movement Disorders Center community is our top priority. At this time, all in-person exercise classes and groups are on hold due to COVID-19 coronavirus concerns. However, we are working hard to offer alternative virtual options. See below for additional information on how to sign up and participate. We will resume the normal, in-person, monthly schedule as soon as it is safe to do so.

**NOTE:** Online exercise classes and virtual fitness offerings can be found on page 8 of this newsletter!

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## Monthly Parkinson's Disease Support Group

### ON HOLD

**Date:** First Tuesday of the Month

**Time:** 10:30 AM to 2 PM

**Location:** Northwestern Memorial Hospital, Feinberg Pavilion, 251 E. Huron Street, Third Floor, Conference Room A, Chicago

**Schedule of Activities:** Rotating exercise, demonstration, boxed lunch (provided), guest speaker

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## Parkinson's Disease Care Partner Support Group

### • NEW VIRTUAL OPTION •

**Date:** Second Tuesday of the Month

**Time:** 3:30 PM to 4:30 PM

**Location:** This is an online community. Once registered, you will be given the community URL and login information.

**Contact:** Emily Zivin, LCSW for more information or registration at [emily.zivin@northwestern.edu](mailto:emily.zivin@northwestern.edu)

**Requirements:** Consent form required

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## Parkinson's Disease 101

### ON HOLD for APRIL

**Date:** First Wednesday of the Month

**Time:** 3 PM to 4:30 PM

**Location:** Northwestern Medicine Prentice Women's Hospital, 250 E. Superior Street, Conference Room P, Chicago

**Contact:** Carolyn Taylor, APN, at 312.695.1822

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## Art and Yoga

### ON HOLD

**Date:** Second, Third, Fourth (& Fifth) Tuesday of the Month

**Time:** 1 PM Art Therapy and 2 PM Yoga

**Location:** Northwestern Prentice Women's Hospital, 250 E. Superior Street, Third Floor, Conference Room Q, Chicago

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## Young Onset Parkinson's Group

### • NEW VIRTUAL OPTION •

**Date:** Fourth Wednesday of the Month

**Time:** 6 PM to 7:30 PM

**Location:** This is an online community. Once registered, you will be given the community URL and login information.

**Contact:** Emily Zivin, LCSW for more information or registration at [emily.zivin@northwestern.edu](mailto:emily.zivin@northwestern.edu)

**Requirements:** Consent form required

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## Parkinson's Disease & Women Online Support Group

### • VIRTUAL OPTION •

**Date:** Second Tuesday of the Month

**Time:** 11:30 AM to 12:30 PM

**Location:** This is an online community. Once registered, you will be given the community URL and login information.

**Contact:** Emily Zivin, LCSW for more information or registration, by calling 773.516.5864

**Requirements:** Must be a patient of a PDMDC Neurologist and sign a consent form

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## Northwestern and Huntington's Disease Society of America (HDSA) Support Group

### • NEW VIRTUAL OPTION •

**Date:** Saturdays (call for schedule)

**Time:** 10 AM to 11:30 AM

**Location:** This is an online community. Once registered, you will be given the community URL and login information.

**Contact:** Emily Zivin, LCSW for more information or registration at 773.516.5864

**Requirements:** Consent form required

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## Parkinson's Wellness Initiative

### ON HOLD

**Location:** Hyde Park JCC, 5200 S. Hyde Park Avenue

**Contact:** Emily Zivin, LCSW for more information or registration at [emily.zivin@northwestern.edu](mailto:emily.zivin@northwestern.edu)

**Cost:** \$40 monthly

**Exercise Classes:** PD Strength and Balance on Tuesdays, 11 AM to 12 PM & Silver Sneakers classes on Mon., Wed., & Fri. from 9 to 10 AM

**Support Group for PD:** 2nd Wednesday of every month, 10:30 to 11:30 AM

## Lake Forest (Lake Forest Health & Fitness Center)

### ON HOLD

**Location:** 1200 N. Westmoreland Rd., Lake Forest, IL 60045

**Contact:** Call 847.535.7000 for more information about class times or visit [lakeforesthfc.com/parkinsons-programming](http://lakeforesthfc.com/parkinsons-programming)

### Exercise Classes:

- TRX for Parkinson's Levels 1 & 2
- Pedal for Parkinson's
- Strength & Balance
- Pilates for Parkinson's
- Yoga for Parkinson's
- Functional Fitness
- Aqua for Parkinson's
- Rock Steady Boxing
- Stride and Strength

**Support Group:** 2nd Wednesday of the month from 10 AM to 12 PM

## Symposiums & Educational Events

### May 17th:

Spring Symposium at  
Lake Forest NM Campus  
RSVP to 224.271.6402

### Oct 10th:

Parkinson Symposium,  
9 AM to 12 PM,  
Chicago campus

## New Team Members

### Charlinda Turner Brashear, MSW, LCSW, ACM-SW

As a Licensed Clinical Social Worker (LCSW), Charlinda Brashear has spent her professional life working with adult and geriatric populations, predominantly in a medical setting. Charlinda earned a Master of Social Work (MSW) degree from the University of Kentucky, with a concentration in mental



health. Charlinda worked at UK Chandler Hospital in Lexington, KY for nearly seven years prior to relocating to Chicago and starting at Northwestern Medicine. She worked as a hospital social worker on an inpatient unit at Northwestern Memorial for over four years before joining the Parkinson's and Movement Disorders team.

Charlinda has a passion for working with individuals who have experienced a life-altering medical diagnosis. She also has a background in vocational rehabilitation, and she is a nationally accredited case manager (ACM-SW). Charlinda seeks to empower all patients to live their lives to the fullest extent possible.



### Emily Zivin, LCSW, MPA

earned her Master of Social Work degree from Columbia University and a Master of Public Administration degree from New York University Wagner School of Public Service. She has worked within the health care field in many different capacities, and she is currently the social worker for

both the HD clinic at Northwestern and the HDSA Illinois Chapter. She is also working on a Parkinson's disease community grant here at Northwestern.



# Research Participation Opportunities at Northwestern Medicine

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**ATTENTION:** The health and well-being of our Parkinson's Disease and Movement Disorders Center community is our top priority. At this time, all in-person clinical research study visits are on hold due to COVID-19 coronavirus concerns. However, if you are interested in participating in any of our clinical trials, please send an email to: [pdclinicaltrials@northwestern.edu](mailto:pdclinicaltrials@northwestern.edu)

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For more information call (312) 503-0755 or email: [pdclinicaltrials@northwestern.edu](mailto:pdclinicaltrials@northwestern.edu)

For more information about Parkinson's disease research at Northwestern, visit our website at: [http://www.parkinsons.northwestern.edu/clinical\\_trials.htm](http://www.parkinsons.northwestern.edu/clinical_trials.htm)

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*A special  
thank you!*

As you know, April is Parkinson's Awareness Month—and the Northwestern Parkinson's Disease and Movement Disorders Center Team would like to send a huge THANK YOU to our research study participants and their families.

We are so grateful for your time and efforts in helping us find a cure for Parkinson's disease through your participation in our clinical research programs.

We couldn't do it without YOU!

THANK YOU ALL!

**Research Study Title:** Parkinson's Foundation: PD GENERation: Mapping the Future of Parkinson's Disease

**Funded by:** Parkinson's Foundation

**Clinical Trial Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** To assess the feasibility, impact and participant satisfaction of offering certified genetic testing as part of clinical care for people with Parkinson's disease.

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**Research Study Title:** Northwestern Movement Disorders Center Biorepository

**Clinical Trial Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** The Movement Disorders Center (MDC) Biorepository is a registry aimed to collect biologic and clinical information, such as blood and tissue samples, and family and medical histories from patients diagnosed with a movement disorder. The purpose of studying materials from the registry is to identify factors that either cause these neurologic conditions or increase one's risk for developing them. Samples collected for this biorepository include a blood sample (or a saliva sample) and a skin biopsy. Participants may choose to donate one or both samples.

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**Research Study Title:** A Multi-center, Prospective, Longitudinal, Digital Assessment Study of Disease Progression in Subjects with Early, Untreated Parkinson disease (WATCH-PD)

**ClinicalTrials.gov Identifier:** NCT03681015

**Funded by:** University of Rochester/Biogen

**Clinical Trial Investigator Name:** Tanya Simuni, MD

**Clinical Trial Description:** The purpose of this study is to obtain and compare information on early PD progression from traditional examinations and questionnaires with health-related information from wearable sensors and study-supplied mobile devices over 12 months.

**Research Study Title: A Phase 2, Randomized, Double-Blind, Placebo-Controlled Study of K0706 in Subjects With Early Parkinson's disease (SPARC)**

**ClinicalTrials.gov Identifier:** NCT03655236

**Funded by:** Sun Pharma Advanced Research Company Limited

**Clinical Trial Investigator Name:** Tanya Simuni, MD

**Clinical Trial Description:** The purpose of this study is to determine the effects of K0706 on individuals with early Parkinson's disease. K0706 is a type of drug that works by blocking a substance in the body called Abl. It is possible that K0706 may slow the course of PD.

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**Research Study Title: A randomized controlled study to compare the safety and efficacy of IPX203 with Immediate-Release Carbidopa-Levodopa in Parkinson's disease Patients with Motor Fluctuations (RISE-PD)**

**ClinicalTrials.gov Identifier:** NCT03670953

**Funded by:** Impax Laboratories, LLC

**Clinical Trial Investigator Name:** Tanya Simuni, MD

**Clinical Trial Description:** The purpose of this study is to see how safely and effectively a drug called IPX203 works in treating Parkinson's disease compared to a marketed form of the drug (immediate-release carbidopa-levodopa).

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**Research Study Title: A Phase 1 Single- and Multiple-Ascending-Dose Study to Assess the Safety, Tolerability, and Pharmacokinetics of BIIB094 Administered Intrathecally to Adults with Parkinson's disease (REASON)**

**ClinicalTrials.gov Identifier:** NCT03976349

**Funded by:** Biogen

**Clinical Trial Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** The purpose of this study is to evaluate the safety and effectiveness of the study

drug (given as an injection into the back) in PD patients with or without mutations in the LRRK2 gene.

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**Research Study Title: A Randomized, Placebo Surgery Controlled, Double-blinded, Multi-center, Phase 2 Clinical Trial, Evaluating the Efficacy and Safety of VY-AADC02 in Advanced Parkinson's disease with Motor Fluctuations (RESTORE-1)**

**ClinicalTrials.gov Identifier:** NCT03562494

**Funded by:** Voyager Therapeutics

**Clinical Trial Investigator:** Avram Faint, MD

**Clinical Trial Description:** The purpose of this study is to assess the efficacy and safety of VY-AADC02 and the delivery and resulting enzyme activity of VY-AADC02 administered into the brain using enhanced surgical gene delivery.

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**Research Study Title: Resistant Maltodextrin for Gut Microbiome in Parkinson's disease: Safety and Tolerability Study**

**ClinicalTrials.gov Identifier:** NCT03667404

**Funded by:** Northwestern University

**Clinical Trial Investigator Name:** Roneil G Malkani, MD

**Clinical Trial Description:** This study will evaluate the safety and tolerability of a dietary fiber, resistant maltodextrin, in people with Parkinson's disease. It will also evaluate the fiber's effect on the gut microbiome and potential effects on motor function and non-motor functions. Half of the participants will receive resistant maltodextrin and the other half will receive a control substance, maltodextrin.

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**Research Study Title: Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA) to Study Natural History and Genetic Modifiers in Spinocerebellar Ataxia (SCA)**

**ClinicalTrials.gov Identifier:** NCT01060371 >



**Funded by:** National Ataxia Foundation

**Clinical Trial Investigator:** Puneet Opal, MD, PhD

**Clinical Trial Description:** The purpose of this observational research study is to bring together a group of experts in the field of spinocerebellar ataxia (SCA) for the purpose of learning more about the disease, finding out how the disease develops over time (its natural history) and what may be the best way to measure its development.

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**Research Study Title:** A Phase III, Long-Term, Randomized, Double-blind, Placebo-controlled Trial of BHV-4157 in Adult Subjects with Spinocerebellar Ataxia

**ClinicalTrials.gov Identifier:** NCT03701399

**Funded by:** Biohaven Pharmaceuticals, Inc

**Clinical Trial Investigator:** Puneet Opal, MD, PhD

**Clinical Trial Description:** The purpose of this study is to compare the efficacy of BHV-4157 versus placebo after 48 weeks of treatment in subjects with spinocerebellar ataxia (SCA).

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**Research Study Title:** Impaired sensorimotor integration for prosodic speech production in Ataxic Dysarthria

**ClinicalTrials.gov Identifier:** N/A

**Funded by:** Northwestern University

**Clinical Trial Investigator Name:** Charles Larson, PhD

**Clinical Trial Description:** The goal of this study is to understand how people use auditory feedback to control and produce speech. Participants will complete hearing tests, cognitive tests and voice recordings while they perform different speaking tasks.

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**Research Study Title:** A Phase 3, Randomized, Double-Blind, Placebo-Controlled Study to Assess the Efficacy, Safety, and Tolerability of Valbenazine

**for the Treatment of Chorea Associated with Huntington's disease (KINECT-HD)**

**ClinicalTrials.gov Identifier:** NCT04102579

**Funded by:** Neurocrine Biosciences

**Clinical Trial Investigator Name:** Danny Bega, MD

**Clinical Trial Description:** The purpose of this research study is to evaluate the effectiveness, safety and tolerability of Valbenazine to reduce chorea associated with Huntington's disease (HD).

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**Research Study Title:** A Phase 3, Randomized, Rater-Blinded, Multi-Center Study to Evaluate the Efficacy and Safety of ALXN1840 Administered for 48 Weeks Versus Standard of Care in Patients with Wilson's disease Aged 12 Years and Older with an Extension Period of up to 60 Months

**ClinicalTrials.gov Identifier:** NCT03403205

**Funded by:** Alexion Pharmaceuticals

**Clinical Trial Investigator Name:** Danny Bega, MD

**Clinical Trial Description:** The purpose of this study is to test ALXN1840 (formerly known as WTX101), an investigational drug being developed for the treatment of Wilson's disease, compared to Standard of Care (SoC) medications currently used for the treatment of Wilson's disease.

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**If you would like to be added to the On the Move mailing or email list—or if you have public questions you would like to pose to our collaborative care team (including physicians, social workers, physical and speech therapists or our research team) for our Fall newsletter FAQ section—please email [jessenia.erickson@nm.org](mailto:jessenia.erickson@nm.org).**

**Please make sure all questions are general and not related to your personal care; for medication and appointment-related questions, please contact your care team.**