PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER

On The Move >>>

Northwestern University Feinberg School of Medicine

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Empowering the Spanish-Speaking Community

Through Education on Parkinson's Disease and Other Movement Disorders

By Dr. Paulina Gonzalez-Latapi, MD, MsC

Parkinson's disease (PD) and other movement disorders present a significant global health challenge, affecting millions of individuals across diverse cultures, including Hispanic populations. The disparity in health education and resources is particularly pronounced in these communities. Education about PD and other movement disorders can play a vital role in Spanish-speaking communities, advocating for more inclusive and accessible health information.

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The Challenge in Spanish-speaking Communities

Awareness and understanding of movement disorders like PD often lag in many Spanish-speaking communities. This disparity stems from language barriers, cultural misconceptions, limited access to specialized health care and a lack of tailored health education resources. Consequently, individuals suffering from these disorders often face delayed diagnoses, inadequate treatment and a lower quality of life.

Importance of Education

The need for early detection and management in movement disorders cannot be overstated.

Empoderando a la Comunidad de Habla Hispana

a Través de la Educación sobre la Enfermedad de Parkinson y Otros Trastornos del Movimiento

La enfermedad de Parkinson (EP) y otros trastornos del movimiento representan un significativo desafío de salud global que afecta a millones de individuos de diversas culturas, incluidas las poblaciones de habla hispana. La disparidad en la educación y los recursos de salud es particularmente pronunciada en estas comunidades. Este artículo subraya el papel vital de la educación sobre la EP y otros trastornos del movimiento en las comunidades de habla hispana, abogando por información de salud más inclusiva y accesible.

La versión en español continúa en la página 3 >>>

Educating the public about the early signs and symptoms is imperative for prompt diagnosis and treatment. These are progressive conditions where timing is crucial; the sooner they are identified and managed, the better the outcomes for patients. Through education, we can empower individuals to seek help early, managing symptoms to maintain a quality of life and ultimately improving their long-term health prospects.

Stigmas and cultural misconceptions about neurological disorders are barriers that can lead to significant social isolation and contribute to mental health struggles for those affected. Education is a transformative tool that can break down these barriers. By providing accurate information and raising awareness, we can challenge and change the misconceptions that lead to stigma. This not only helps in fostering acceptance but also aids in creating supportive communities where individuals with movement disorders feel understood and supported.

The role of education extends into empowering patients and their families. With a solid understanding of their conditions, patients and caregivers are better positioned to navigate the complexities of healthcare systems. They become adept at understanding the range of treatment options available and can make informed decisions that directly contribute to an enhanced quality of life. Knowledge, in this context, is more than power—it is a means to achieving a level of autonomy over one's health journey.

Finally, promoting advocacy and support through awareness is critical. Awareness acts as a catalyst for community advocacy, which can drive improvements in healthcare services and forge robust support networks. Moreover, this heightened visibility can influence policy changes, opening doors to better resources and more comprehensive care for those living with movement disorders. The collective voice of an informed community is a powerful agent for change, advocating for the rights and needs of those affected by these challenging conditions.

Strategies for Effective Education

In the pursuit of effective education about movement disorders within Spanish-speaking communities, it is critical to develop culturally relevant materials. Educational content must not only be translated into Spanish but also tailored to reflect the cultural nuances of these communities. This approach should encompass a variety of materials, such as brochures, videos and interactive online resources that resonate with and are accessible to the target audience. By ensuring the relevance of these materials, we uphold respect for cultural identities and enhance the educational impact.

Community engagement is a cornerstone of successful education initiatives. By organizing workshops, seminars and support groups facilitated by bilingual healthcare professionals, we can ensure that language barriers do not impede the exchange of vital information. These in-person events provide a platform for individuals to share experiences, gain knowledge and receive support in a setting that fosters trust and community solidarity.

The digital landscape also offers an expansive platform for spreading awareness and education. By leveraging social media, dedicated websites and online forums, it's possible to reach a broad audience with ease. Digital platforms can break down geographical barriers, allowing for the dissemination of information and support to those who may not have access to traditional in-person educational resources.

Lastly, the training of healthcare professionals plays a fundamental role in enhancing the quality of care provided to Spanish-speaking patients. By educating medical providers about the unique needs and potential communication barriers faced by these communities, we can promote more culturally competent and empathetic care. This not only improves patient-provider interactions but also ensures that healthcare services are more attuned to the cultural context of the patients they serve.

Northwestern Approach

At Northwestern, recognizing the importance of education and community involvement, we have inaugurated the PD Youth Ambassador Initiative to extend our outreach to Spanish-speaking populations. This pioneering program recruits young adults (ages 18-26) of Hispanic descent with a keen interest in learning about PD. These ambassadors collaborate closely with our faculty, including Dr. Larson and Dr. Gonzalez-Latapi, and a Movement Disorders fellow, Dr. Deliz, to create and conduct educational workshops within their communities. This initiative not only fosters awareness of PD among the younger generation but also ensures that Spanish-language educational materials become more accessible.

Furthermore, leveraging digital platforms, we have successfully conducted two online workshops, "PD 101" and "PD 201". "PD 101" provided an introduction to PD, covering the fundamentals of its pathophysiology and symptomatology. "PD 201" delved into the available treatments, encompassing medications and advanced therapeutic options. These workshops drew participants globally, from the US to Spanish-speaking countries including Mexico, Guatemala and Spain, demonstrating the extensive potential impact of such programs.

Conclusion

The imperative to provide tailored education on PD and other movement disorders in Spanish-speaking communities is undeniable. By closing the knowledge gap, we can not only empower affected individuals but also contribute to a more inclusive and supportive healthcare environment. This endeavor requires a concerted effort from healthcare professionals, community leaders, patients and their families.

Empoderando a la Comunidad de Habla Hispana a Través de la Educación sobre la Enfermedad de Parkinson y Otros Trastornos del Movimiento

El Desafío en las Comunidades de Habla Hispana

El conocimiento y comprensión de trastornos del movimiento como la EP a menudo se rezaga en muchas comunidades de habla hispana. Esta disparidad surge de barreras lingüísticas, malentendidos culturales, acceso limitado a atención médica especializada y falta de recursos educativos adaptados. En consecuencia, las personas que sufren de estos trastornos a menudo enfrentan diagnósticos retrasados, tratamiento inadecuado y una calidad de vida más baja.

Importancia de la Educación

La esencia de la detección temprana y el manejo de trastornos del movimiento no puede ser exagerada. Educar al público sobre los signos y síntomas tempranos es imperativo para un diagnóstico y tratamiento oportunos. Estas son condiciones progresivas donde el tiempo es crucial; cuanto antes se identifiquen y manejen, mejores serán los resultados para los pacientes. A través de la educación, podemos empoderar a las personas para buscar ayuda temprana, mejorando sus perspectivas de salud a largo plazo.

Los estigmas y malentendidos culturales sobre los trastornos neurológicos son barreras que pueden llevar a un aislamiento social significativo y contribuir a las luchas de salud mental de los afectados. La educación es una herramienta transformadora que puede romper estas barreras. Al proporcionar información precisa y aumentar el conocimiento, podemos desafiar y cambiar los malentendidos que conducen al estigma. Esto no solo ayuda a fomentar la aceptación, sino que también ayuda a crear comunidades de apoyo donde los individuos con trastornos del movimiento se sienten comprendidos y apoyados.

El papel de la educación se extiende a empoderar a los pacientes y sus familias. Con un entendimiento sólido de sus condiciones, los pacientes y cuidadores están mejor posicionados para navegar por las complejidades de los sistemas de salud. Se vuelven expertos en comprender la gama de opciones de tratamiento disponibles y pueden tomar decisiones informadas que contribuyen directamente a una calidad de vida mejorada. El conocimiento, en este contexto, es más que poder; es un medio para alcanzar un nivel de autonomía en el viaje de salud de uno.

Finalmente, promover la defensa y el apoyo a través de el conocimiento es crítico. El conocimiento actúa como un catalizador para la defensa comunitaria, que puede impulsar mejoras en los servicios de salud y forjar redes de apoyo robustas. Además, esta visibilidad aumentada puede influir en los cambios de políticas, abriendo puertas a mejores recursos y atención más integral para aquellos que viven con trastornos del movimiento. La voz colectiva de una comunidad informada es un poderoso agente de cambio, abogando por los derechos y necesidades de aquellos afectados por estas condiciones desafiantes.

Estrategias para una Educación Efectiva

En la búsqueda de una educación efectiva sobre los trastornos del movimiento en las comunidades de habla hispana, es crítico desarrollar materiales culturalmente relevantes. El contenido educativo no solo debe ser traducido al español, sino también adaptado para reflejar las sutilezas culturales de estas comunidades. Este enfoque debe incluir una variedad de materiales, como folletos, videos y recursos interactivos en línea que resuenen y sean accesibles para la audiencia objetivo. Al asegurar la relevancia de estos materiales, mantenemos el respeto por las identidades culturales y potenciamos el impacto educativo.

El compromiso comunitario es un pilar fundamental de las iniciativas educativas exitosas. Al organizar talleres, seminarios y grupos de apoyo facilitados por profesionales de la salud bilingües, podemos asegurar que las barreras del idioma no obstaculicen el intercambio de información vital. Estos eventos presenciales proporcionan una plataforma para que los individuos compartan experiencias, adquieran conocimientos y reciban apoyo en un entorno que fomenta la confianza y la solidaridad comunitaria.

El paisaje digital también ofrece una amplia plataforma para difundir el conocimiento y la educación. Al aprovechar las redes sociales, sitios web dedicados y foros en línea, es posible alcanzar a una amplia audiencia con facilidad. Las plataformas digitales pueden romper las barreras geográficas, permitiendo la diseminación de información y apoyo a aquellos que pueden no tener acceso a recursos educativos presenciales tradicionales.

Por último, la formación de los profesionales de la salud juega un papel fundamental en la mejora de la calidad de la atención proporcionada a los pacientes de habla hispana. Al educar a los proveedores médicos sobre las necesidades únicas y las posibles barreras de comunicación que enfrentan estas comunidades, podemos promover una atención más culturalmente competente y empática. Esto no solo mejora las interacciones entre paciente y proveedor, sino que también asegura que los servicios de salud estén más sintonizados con el contexto cultural de los pacientes que atienden.

Los esfuerzos en Northwestern

En Northwestern, reconociendo la importancia de la educación y la participación comunitaria, hemos inaugurado la Iniciativa de Embajadores Juveniles de EP para extender nuestro alcance a las poblaciones de habla hispana. Este programa pionero recluta a jóvenes adultos (de 18 a 26 años) de ascendencia hispana con un interés marcado en aprender sobre la EP. Estos embajadores colaboran estrechamente con nuestro profesorado, incluyendo a la Dra. Larson y la Dra. González-Latapi, y un becario de Trastornos del Movimiento, el Dr. Deliz, para crear y llevar a cabo talleres educativos dentro de sus comunidades. Esta iniciativa no solo fomenta el conocimiento de la EP entre la generación más joven, sino que también asegura que los materiales educativos en español sean más accesibles.

Además, aprovechando las plataformas digitales, hemos llevado a cabo con éxito dos talleres en línea, “EP 101” y “EP 201”. “EP 101” proporcionó una introducción a la EP, cubriendo los fundamentos de su fisiopatología y sintomatología. “EP 201” profundizó en los tratamientos disponibles, abarcando medicamentos y opciones terapéuticas avanzadas. Estos talleres atrajeron a participantes de todo el mundo, desde los EE. UU. hasta países de habla hispana, incluyendo México, Guatemala, España, demostrando el extenso impacto potencial de dichos programas.

Conclusión

La imperiosa necesidad de proporcionar educación adaptada sobre la EP y otros trastornos del movimiento en las comunidades de habla hispana es innegable. Al cerrar la brecha de conocimiento, no solo podemos empoderar a los individuos afectados, sino también contribuir a un entorno de atención médica más inclusivo y de apoyo. Este esfuerzo requiere un esfuerzo concertado por parte de los profesionales de la salud, líderes comunitarios, pacientes y sus familias.

Are you living with Parkinson’s disease and interested in participating in research?

You may be eligible for the Voice-PD study that aims to objectively quantify the severity of vocal and speech related symptoms associated with Parkinson’s disease.

You qualify for the study if you are:

- Diagnosed with PD, or
- Prodromal PD, or
- Age-matched healthy control

What is involved if I participate?

- Study duration: 10 weeks
- 7 study visits of combined televisits and at-home assessments
- Speech tests, PD clinical assessment and short questionnaires

Participant Resources:

- Reimbursement will be provided for your time during on-site and telehealth visits.

If you are interested in participating or want to learn more, please contact:

Max Galarce
max.galarce@northwestern.edu
312.503.4270

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Donor Spotlight:
Meet Cathy Grider

Cathy has been a resident of the northern and western suburbs of Chicago since 1983. She is a devoted mother to a daughter and a son and is happily married to her husband, Scott. With a successful career as a sales executive in the print and marketing industry, Cathy now enjoys the freedom to pursue her passions for culinary arts and design as her children have grown and established their own families and careers. She takes great pleasure in witnessing the lives and careers of her two grandchildren, Jackson and Sydney, flourish.

Six years ago, Cathy received a life-altering diagnosis of Parkinson's disease, profoundly impacting her daily life. Despite the challenges, Cathy remains committed to staying active and engaged in Parkinson's therapy and activities. She dedicates three days a week to attending strength, balance and flexibility fitness classes at the Lake Forest Health and Fitness Center. Additionally, she finds solace and fulfillment in participating in the Equestrian Connection's horseback riding program specifically tailored for individuals with Parkinson's disease, an initiative closely aligned with the Lake Forest Health and Wellness Center.

> *Motivated by her compassionate nature and firsthand understanding of the challenges posed by Parkinson's disease, Cathy is deeply committed to giving back and supporting those in need.*

Cathy expresses immense gratitude for the invaluable resources provided by the Lake Forest Health and Fitness Program and Lake Forest Hospital's Parkinson's Disease and Movement Disorders Center, which have become indispensable assets for her and fellow members of the Parkinson's community. She commends the staff for their generosity, expertise and compassion.

In addition to maintaining an active lifestyle, Cathy remains actively engaged in staying informed about the latest Parkinson's disease research. She firmly believes that ongoing research holds the key to finding a cure, driving her to seek opportunities to expand her knowledge about breakthroughs and treatment options. Cathy maintains regular communication with her physicians and care team to ensure she remains well-informed about her care plan and abreast of recent research and developments.

Surrounded by a supportive and caring family, Cathy cherishes the friendships and connections cultivated through her involvement in Parkinson's disease programs and activities. This firsthand experience has heightened her awareness of the profound impact of Parkinson's disease on individuals and their loved ones. Motivated by her compassionate nature and firsthand understanding of the challenges posed by Parkinson's disease, Cathy is deeply committed to giving back and supporting those in need. She actively contributes as a donor to Northwestern Medicine, driven by her desire to make a meaningful difference.

To discover more about philanthropic opportunities in support of the Northwestern Medicine Parkinson's Disease & Movement Disorders Center, please reach out to Leslie Post-Weissinger at lpostwei@nm.org or 312.926.0450.

Shirley Ryan AbilityLab Now Offering Boot Camp for People with Parkinson's in Burr Ridge

By Kaley Brouwer, Senior Occupational Therapist and PDMD Program Manager at the Shirley Ryan Ability Lab

The Shirley Ryan AbilityLab Parkinson's and Movement Disorders (PDMD) Program is excited to launch a new boot camp programming model for people with Parkinson's at Burr Ridge Day Rehab. The boot camp will bring individuals with Parkinson's together to work with an interdisciplinary team to address all mobility, self-care, voice and swallowing goals to improve function and quality of life.

This program, developed by Caitlyn Seuschek, PT, DPT, NCS and Kathleen Sweeney, SLP, provides diagnosis-specific care to individuals with Parkinson's to enhance patient outcomes, meet patient goals and maximize abilities.

The interdisciplinary team, composed of physical therapy, occupational therapy and speech therapy professionals, will collaborate directly with each participant to enhance daily performance. This interdisciplinary approach has been shown to improve patient outcomes and satisfaction with care, creating the optimal environment for recovery.

During individual and group sessions, patients will collaborate with their therapists to optimize independence, mobility and communication. In addition to the therapy team, psychology and social work services will be available to provide additional support for participants as needed.

Within the Day Rehab model, the boot camp will run three hours per day, three days per week, with a program length of approximately 6-8 weeks. The team will also conduct research on this new care model to assess feasibility, satisfaction and program effectiveness from both patient and clinician perspectives. Patient functional outcomes and satisfaction surveys will be used for research purposes.

With research supporting the benefits of interdisciplinary care, we eagerly anticipate the results of this pilot program. In the future, we hope to offer this programming at other Day Rehab sites and group patients by Parkinson's disease stages. We look forward to witnessing the excellent progress and outcomes individuals with Parkinson's will achieve within the Parkinson's boot camp at Shirley Ryan AbilityLab in Burr Ridge.

If you or a family member are interested in participating in this program, physician orders for PT, OT and SLP at Day Rehab can be faxed to 630.388.6777. Once orders are received, the Burr Ridge team will reach out to assist with scheduling and the research team will contact you regarding interest in participating in the study. For more information or questions, please contact Caitlyn Seuschek at 312.238.7382 or via email at cseuschek@sralab.org.

Parkinson's Disease Interdisciplinary Boot Camp

Our new Parkinson's disease "Boot Camp" program at Burr Ridge DayRehab Center is comprised of physical, occupational and speech therapy — customized to address your individual needs and maximize your abilities.

This comprehensive and intensive program will provide resources and help you develop strategies and routines that will set you up for success today and into the future.

Optimize movement and enhance quality of life

- Have you noticed a change in your mobility that is impacting your daily life?
- Is your family finding it harder to hear you due to a quiet voice?
- Are you finding it more challenging to multi-task?
- Are you looking for a more comprehensive approach to your Parkinson's disease care?
- Do you want to find safe exercises that challenge you?
- Do you need advice on how to access resources near your home?

What sets us apart

Our experts team with you to enhance your abilities and well-being through integrated and innovative care. We will work together to create a customized program to address your needs that will include:

- Individualized evaluations
- An assessment of walking, balance, posture, voice, cognition, swallowing and activities of daily living
- Custom exercise plans that promote independence and work to slow the disease progression
- An environment and community for you to engage and interact with other patients with Parkinson's disease
- A focus on interdisciplinary care to treat the whole person

This program is available at Shirley Ryan AbilityLab Burr Ridge DayRehab Center located at 7600 County Line Road in Burr Ridge, Illinois.

For more information or any questions, please call 630.388.6700.

The Definition of a Disease

By M.C. Rydel

Parkinson's is a gated community
Outside of Phoenix, in the desert,
Where I wake up in the morning darkness
At a time when the house starts to grab me
With its pedicured artifacts big as feet.

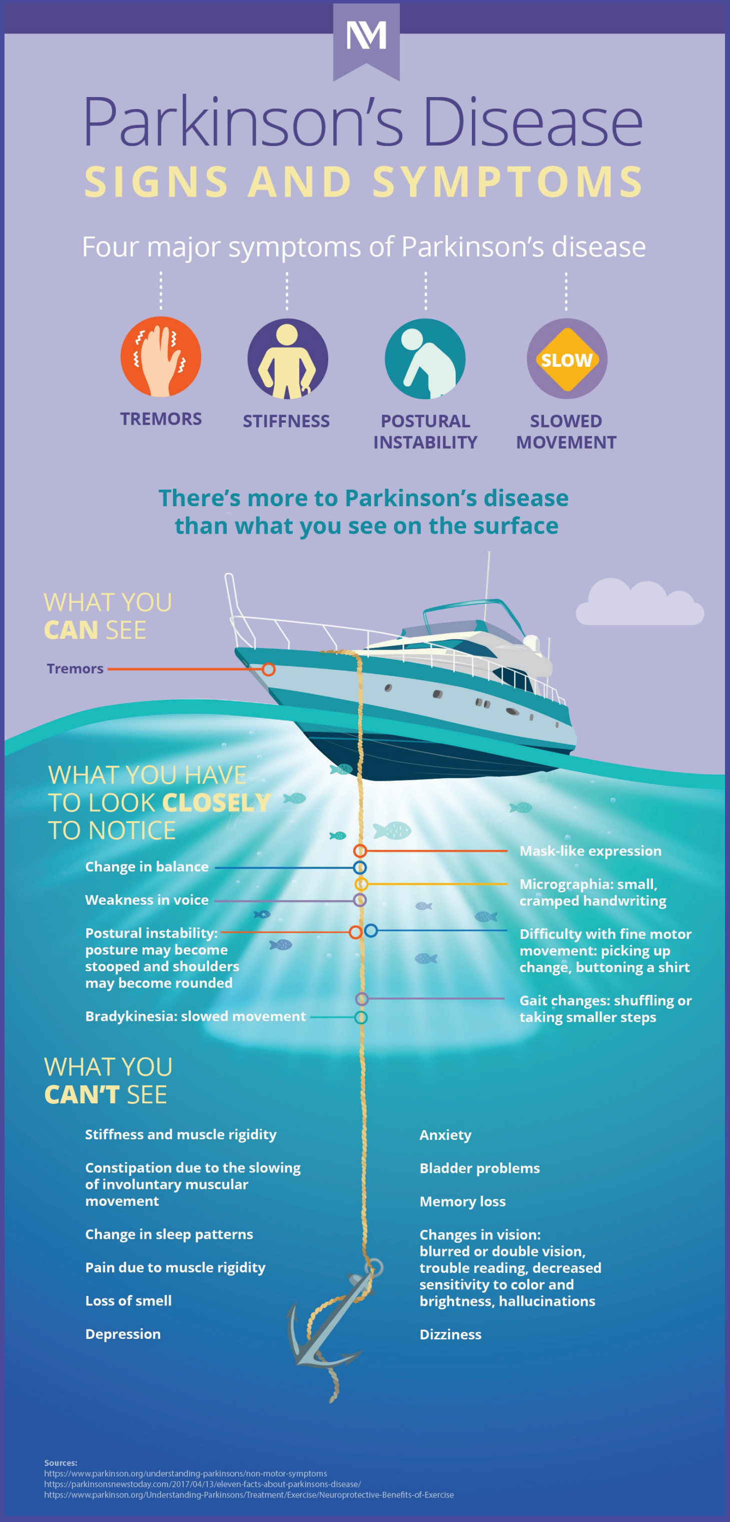
Wrapped in sheets like compression socks,
I pry open the eyelid stuck in a closed position,
The floor cluttered with my grandchild's toys,
Hanging wreaths snag my woolen sweater,
And rugs prepare to trip the next foot that comes near.

Trapped in my mansion, no car keys,
No passport, no guitar, no voice, no
Damned voice, no clarity, and nothing
But thoughts trapped in my mouth
Like a plosive puff of cigarette smoke

Or the sibilance of Satan in Milton,
And I am lost, lost in my own house,
Trying to remember why I went to the bedroom,
Hoping that a shaman can exorcise
My stutter with the touch of his magical hands.

I speak so much better when I am singing
In the church choir like the Methodist girlfriend
Who broke up with me just before her parents arrived.
I raise my tremorous hands to Heaven,
Jerk my head, clench my fists, revel

In the raw randomness of facial tics,
Neuralgia neuralgia, neuralgia
Say it three times like a Muslim
Declaring divorce before he pays a harlot
With bit coin for bottles of pure dopamine.



Parkinson's Disease
SIGNS AND SYMPTOMS

Four major symptoms of Parkinson's disease

- TREMORS
- STIFFNESS
- POSTURAL INSTABILITY
- SLOWED MOVEMENT

There's more to Parkinson's disease than what you see on the surface

WHAT YOU **CAN** SEE

Tremors

WHAT YOU HAVE TO LOOK **CLOSELY** TO NOTICE

Change in balance

Weakness in voice

Postural instability: posture may become stooped and shoulders may become rounded

Bradykinesia: slowed movement

Mask-like expression

Micrographia: small, cramped handwriting

Difficulty with fine motor movement: picking up change, buttoning a shirt

Gait changes: shuffling or taking smaller steps

WHAT YOU **CAN'T** SEE

Stiffness and muscle rigidity

Constipation due to the slowing of involuntary muscular movement

Change in sleep patterns

Pain due to muscle rigidity

Loss of smell

Depression

Anxiety

Bladder problems

Memory loss

Changes in vision: blurred or double vision, trouble reading, decreased sensitivity to color and brightness, hallucinations

Dizziness

Sources:
https://www.parkinson.org/understanding-parkinsons/non-motor-symptoms
https://parkinsonsnewstoday.com/2017/04/13/eleven-facts-about-parkinsons-disease/
https://www.parkinson.org/Understanding-Parkinsons/Treatment/Exercise/Neuroprotective-Benefits-of-Exercise

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M.C. Rydel resides in Chicago, his native city. He has a background as a Dean at the Hadley School for the Blind. Currently, he teaches composition, literature and creative writing at the College of Lake County and Loyola University Chicago. Rydel's poetry performances have graced iconic venues such as the Heartland Café and Flatts & Sharpe Music Company in Chicago, the Sedona Poetry Slam in Arizona, the Parkside Lounge in New York City and La Cave Café in Paris. Readers can find his debut poetry collection, "Almost a Memoir," on his website www.mcrydel.com, as well as on Amazon and Barnes & Noble.

Meet the Team

Jessica A. Karl, PhD, PA-C

Jessica A. Karl, PhD, PA-C, is a physician assistant and clinical researcher who recently joined the team at Northwestern Medicine/Northwestern University. Her clinical and research focus is on deep brain stimulation and interventional therapies for Parkinson's disease and other movement disorders.

Dr. Karl received a master's in PA studies in 2013 from Rush University and began her clinical work in movement disorders at that time. She earned her doctorate degree in 2020 from Rush University, which focused on deep brain stimulation and its effect on gait, balance and speech impairment in Parkinson's disease. She is very excited to join the team at Northwestern!

Kaley Brouwer, OTR/L, CLT

The Shirley Ryan AbilityLab Parkinson's Disease and Movement Disorders Program is pleased to welcome Kaley Brouwer, OTR/L, CLT as the new program manager. She will be working alongside Dr. Benjamin Friedman, MD, Medical Director of the Parkinson's Disease and Movement Disorders Program, and Assistant Professor at the Northwestern University Feinberg School of Medicine, and Miriam Rafferty, DPT, PhD, Director of Implementation Science and lead Parkinson's Researcher, as well as the rest of the PDMD team at Shirley Ryan AbilityLab.

Kaley earned her Bachelor of Arts in Psychology and Master's in Occupational Therapy from St. Ambrose University and has worked across multiple practice settings, including acute care, long-term acute care, home health, and outpatient in Dallas and Chicago.

She started at Shirley Ryan AbilityLab in 2019 as an outpatient therapist, working with the neurologic, oncology and lymphedema patient populations. With a passion for working with people with Parkinson's and other movement disorders, she was trained to complete early intervention OT evaluations and has completed Team Training with the Parkinson's Foundation. Kaley is excited to serve our patients, build a greater community for people with Parkinson's and advance research in her new role. She can be reached at Shirley Ryan AbilityLab at 312.238.5429 or kbrouwer02@sralab.org.

Around the Network

In this segment, we present updates from NM sites outside of downtown.

Central DuPage Hospital:

Central DuPage is preparing for its annual Spring Symposium, "Living Well with Parkinson's." The event will be held in person at Central DuPage Hospital on May 7 from 1-4 PM. We aim to incorporate a wellness fair where individuals with Parkinson's disease can share their strategies for maintaining well-being. Our support groups continue to thrive—and in the coming months, we plan to reintroduce Resilient Rhythms, our music therapy program, and the Loud Crowd. Stay tuned for finalized dates!

Lake Forest Hospital:

The Parkinson's Program at Northwestern Medicine Lake Forest Hospital offers a patient-centered approach to managing Parkinson's disease, providing rehabilitation, wellness and supportive services. Our comprehensive team includes movement disorder specialists, general neurologists, cognitive/behavioral specialists and an experienced rehab team comprising PT, OT and SLP. Our community program features exercise specialists, Parkinson's-specific exercise classes and monthly in-person support groups. We offer nine different Parkinson's exercise classes focusing on aerobic exercises, strength training, balance/agility/multitasking and stretching. Additional programming includes Dancing with PD in collaboration with The Joffrey Ballet, and instructional cardio tennis and ping pong clinics.

For information on the Parkinson's programs offered, please contact Linda Egan at Linda.Egan@nm.org.

Palos Hospital:

Dr. Sachin Kapur, the Movement Disorders Specialist at Palos Hospital, serves as an extension of the downtown Northwestern Neurology Movement Disorders department. He provides patients with opportunities to participate in studies and clinical trials offered by the department. However, please note that clinical trials and genetic testing are conducted at the downtown clinic. Parkinson's-specific exercise classes are available at Orland Park Fitness. Additionally, virtual support groups, including General Parkinson's, Women & PD, Care Partner and Young Onset, are available. Virtual art therapy sessions are also offered.

For more information on these programs, email movementdisorders@nm.org or visit this link.

Glenview Outpatient Center:

Dr. Neil Shetty is available at the Glenview office on Mondays, offering a wide range of services, including advanced therapeutics. Appointments at this location are currently limited.

Northwestern University Ataxia Clinic Designated as a Center of Excellence

By Dr. Puneet Opal, MD, PhD

The Northwestern Ataxia Clinic has been honored with the prestigious designation of *Center of Excellence* by the National Ataxia Foundation. This esteemed recognition places Northwestern among the inaugural cohort of 15 sites chosen for this distinction.

Ataxia, characterized by incoordination, stems from deficits in the cerebellum, a crucial brain region involved in motor control. Founded in 2003 by Dr. Puneet Opal, MD, PhD, the Ataxia Clinic at Northwestern Medicine stands as a beacon of care for patients with cerebellar disorders.

Situated within Northwestern Memorial Hospital, a cornerstone of the Northwestern Medicine health system spanning 11 hospitals and over 200 locations across Chicago and its environs, the Northwestern Ataxia Clinic offers leading-edge facilities for diagnosing and treating patients with cerebellar disorders.

In line with its multidisciplinary approach, the clinic boasts a team of physicians and nurses adept in ataxia management. Patients also benefit from access to specialists in neuro-ophthalmology, urology and psychiatry, as well as speech and physical therapists tailored to their individual needs. Given that many ataxic syndromes arise from genetic mutations, the clinic features a licensed genetic counselor, Lisa Kinsley.

Beyond its clinical endeavors, the Ataxia Clinical Center serves as a hub for both basic and clinical research. As a proud member of the Clinical Research Consortium for the Study of Cerebellar Ataxias (CRC-SCA), a research initiative funded by the National Ataxia Foundation, the clinic contributes to advancing understanding and treatment of cerebellar ataxias. Spearheading clinical research operations is a dedicated team led by clinical coordinator Justin Wong, under the guidance of senior research coordinator Karen Williams.

Moreover, the clinic is committed to nurturing the next generation of movement disorder specialists, with fellows gaining invaluable experience in treating patients with cerebellar ataxia.

Dr. Opal's pioneering work in the field has garnered support from the National Ataxia Foundation and the National Institutes of Health (NIH). His research focuses on unraveling the fundamental biology of spinocerebellar ataxias, with a view toward identifying pathways for potential treatments.

In tandem with its clinical and research endeavors, the clinic maintains a robust educational outreach program. Managed by movement disorder social worker Katie Fagan, MSW, LCSW, community outreach initiatives aim to foster awareness and support, providing a lifeline for patients and their families.

For inquiries or patient referrals, please contact the clinic's outreach coordinator, Katie Fagan, at movementdisorders@nm.org

NAF
National Ataxia Foundation

ATAXIA
Center of
EXCELLENCE

April is **Parkinson's Awareness** Month

Parkinson's disease (PD) is a gradually progressing disorder of the nervous system, marked by slowness of movement, tremor at rest, muscle stiffness and problems with gait.

- 60,000 people are diagnosed with PD each year.
- 1 in 100 people over age 60 have PD.
- Men are 1½ times more likely than women to have PD.
- Exercise is vital in managing PD.
- The causes of PD are unknown.

Join us in our efforts by:

- Getting the latest information about Parkinson's from our center at www.nm.org/parkinsons or from our partner, the Parkinson's Foundation, at www.parkinson.org
- Sharing what you've learned with your family, friends and community
- Making an impact. Donations are gratefully accepted online at www.nm.org/foundation or by contacting Leslie Post-Weissinger at either 312.926.0450 or lpostwei@nm.org. She will ensure your gift is designated for the Parkinson's Disease and Movement Disorders Center.

Partnering with Parkinson's Foundation

The Northwestern Medicine Parkinson's Disease and Movement Disorders Center, recognized by the Parkinson's Foundation (PF) as a Center of Excellence, collaborates with the foundation on such events as conferences, professional training and the annual Moving Day Chicago fundraiser.

Founded in 1957 and located in Miami, PF is a premier international organization that funds research and provides support services, educational outreach and advocacy for people with PD and their loved ones. Its Centers of Excellence must provide the highest quality in patient care, implement best practices, provide leadership in developing targeted research to extend knowledge of PD and create innovative models of education, services and outreach. Northwestern and PF work together to deliver high-quality patient care, form a united front against Parkinson's and make a difference.

Parkinson's Foundation
CENTER OF EXCELLENCE

To receive education and support and find events in your area, visit Parkinson's Foundation Greater Illinois Chapter Website at: www.parkinson.org/GreaterIllinois

Parkinson's Foundation Expert Briefings Webinars

Whether you are an individual touched by Parkinson's disease (PD) or a healthcare professional, the Parkinson's Foundation's online Expert Briefings offer a course for you. These webinars provide first-hand access to the latest PD research and updates from experts in the field. Designed with the Parkinson's community in mind, each hour-long webinar offers an opportunity to learn more about managing PD symptoms, progression, treatments and more.

To sign up and to find more information:
www.parkinson.org/resources-support/online-education/expert-briefings-webinars

New Staging System for PD and DLB Research

By Sarah Brooker, MD, PhD, Neurology Movement Disorders Fellow

A major recent development in Parkinson's disease (PD) research is the proposal of a new staging system to define the stages of PD and related disorders. This system is called the "neuronal alpha-synuclein disease integrated staging system," or NSD-ISS for short. The details of the staging system were published in the journal Lancet Neurology earlier this year. The purpose of this new staging system is to incorporate information about the biology of PD to improve clinical research trial design.

Currently, the most commonly used scale to define stages of PD is the Hoehn & Yahr scale, which rates the severity of clinical features such as mobility. While clinical features are of course very important, there are some limitations to how we currently define PD and related disorders. Firstly, there is a large amount of variability in symptoms between different individuals. In addition, we now know that changes in the body can potentially be detected even years before an individual develops symptoms of PD. A staging system that includes individuals who are at risk for PD but who have not yet developed movement symptoms could be a very useful tool for designing clinical trials. Evaluating these individuals could help in testing treatments to delay or prevent the development of symptoms. One way to identify these individuals is with the use of biomarkers. A biomarker is an objective test, oftentimes a laboratory test, that can be used to indicate the presence or severity of a disease.

There has been major progress in the development of biomarkers for PD and related disorders in recent years, and the NSD-ISS staging system would incorporate this biological information. While the biology of PD is very complicated, there is a large amount of research that has shown that a protein called alpha-synuclein plays a major role in PD and also in the related disorder Dementia with Lewy Bodies (DLB). Alpha-synuclein is present inside neurons of all individuals. However, in people with PD or DLB, alpha-synuclein forms an abnormal shape and over time aggregates, or clumps up, inside neurons. These clumps of aggregated alpha-synuclein have harmful effects on neurons, particularly the dopamine-producing neurons in the brain. The loss of dopamine neurons in the brain ultimately causes the movement disorders that we see in individuals with PD and DLB. Based on the importance of alpha-synuclein, there have been major efforts to develop biomarkers that can measure alpha-synuclein. Importantly, recent research has shown that alpha-synuclein can be measured in the spinal fluid of individuals with PD. There is also evidence that alpha-synuclein can sometimes be detected in the spinal fluid of people who have risk factors for PD, such as reduced sense of smell, but who have not yet developed the classic symptoms of PD.

The NSD-ISS staging system would incorporate multiple pieces of information to place individuals into different stages. The different pieces of information that would be used include the following:

1. **Synuclein:** the presence or absence of alpha-synuclein aggregation in neurons, which could be measured with alpha-synuclein biomarker tests
2. **Dopamine neuron function:** Whether an individual has evidence of dysfunction of the dopamine-producing neurons in the brain
3. **Clinical signs and symptoms**
4. **Functional limitations:** the degree to which a patient's symptoms impact their ability to perform activities of daily living
5. **Genetic information**

By incorporating all of these important pieces of information, this scale can help to group individuals at all stages. Importantly, this would include individuals at very early stages of the disease and even people with risk factors who have not yet developed clinical symptoms.

A primary goal of the new staging system is to help with the design and implementation of research trials for PD and DLB in order to accelerate the development of new therapies. Currently, the staging system is not intended to be used for individual patients in clinic. The staging system is expected to be refined over time as more and more is learned about the biology of PD and DLB.

Movement Disorders Support Groups and Programs

Central Region: Northwestern Memorial Hospital

General Parkinson's Disease Support Group

Date: First Wednesday of the Month

Time: 2 pm - 3 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Parkinson's Disease Care Partner Support Group

Date: Second Wednesday of the Month

Time: 2 pm - 3 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Young Onset Parkinson's Disease Group

Date: Fourth Wednesday of the Month

Time: 6 pm - 7 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Women and Parkinson's Disease Support Group

Date: Second Wednesday of the Month

Time: 11 am - 12 pm (CT) >>>>>

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Chair Yoga

Date: Second, third, fourth and fifth Wednesday of the Month

Time: 10 am - 11 am (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Therapy Tuesday Exercise Class

Date: First Tuesday of the Month

Time: 11 am - 12 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Parkinson's Disease 101

About: This informational class provides an overview of Parkinson's disease, including history, causes, symptoms, and treatments.

Date: April 10 and September 18

Time: 4 pm - 5:30 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Movement Disorders Support Groups and Programs Continue on Page 15

Parkinson's Disease 201

About: This informational class provides a deeper understanding of medications, treatments, and advanced therapies available for managing Parkinson's disease.

Date: November 13

Time: 4 pm - 5:30 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Art Therapy

Date: Third Monday of the month

Time: 10 am – 11 am (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Dancing with Parkinson's

Date: Thursdays March 7-May 23

Time: 11:30 am - 12:30 pm (CT)

Location: The Joffrey South Loop Studios
1920 S. Wabash, Chicago, IL 60616

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Parkinson's Players (Ping Pong)

Date: Saturdays until Summer

Time: 11:15 am - 1:00 pm (CT)

Location: Edgewater Fitness Center
1106 W. Bryn Mawr, Chicago, IL 60660

Cost: Free

Contact: For more information and to register, email movementdisorders@nm.org

Improv for PD

Date: Thursdays
Spring Session: April 18 - June 6
Fall Session: October 3 - November 21

Time: 2 pm - 3:30 pm (CT)

Location: The Second City
230 W. North Ave., Chicago, IL 60614

Cost: $100 for 8-week series

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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Music Therapy for Parkinson's Disease

Date: TBD

Location: This is a virtual/online group. Once registered, you will be given information to join the group

Cost: TBD

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

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General Huntington's Disease Support Group:

Date: Second Wednesday of the month
January, March, May, July, September, November

Time: 7 pm (CT)

Location: Virtual via zoom

Contact: Email emily.zivin@northwestern.edu for zoom link

Huntington's Disease Caregiver Support Group:

Date: February, April, June, August, October, December

Location: Winnetka Library, 768 Oak Street, Winnetka, lower level community room

Note: Meeting dates are set 2 months in advance due to library scheduling. To be added to the caregiver email list, please email emily.zivin@northwestern.edu

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Atypical Parkinson's Support Group

Date: Second Thursday of the month

Time: 4 pm (CT)

Location: This is a virtual/online group. Once registered, you will be given information to join the group.

Cost: Free

Contact: For more information, please email Emily Zivin, LCSW at emily.zivin@northwestern.edu

Wilson's Disease Support Group

Date: Last Thursday of the Month for the month of January, April, July, and October

Time: 7 pm - 8:30 pm (CT)

Location: This is a virtual/online group. Once registered, you will be given information to join the group.

Cost: Free

Contact: For more information, please email Emily Zivin, LCSW at emily.zivin@northwestern.edu

Central Region: Shirley Ryan Ability Lab

Virtual Peer Support Group for People with Parkinson's Disease who are Working

Date: The Group meets two Fridays per month.

Time: 4:40 pm - 5:40 pm (CT)

Location: This is a virtual/online group. Once registered, you will be given information to join the group.

Cost: Free

Contact: For more information, please contact Paulo Aco at paco@sralab.org or 312.238.7275

Adaptive Fitness Center Programs

Location: Shirley Ryan AbilityLab Adaptive Sports and Fitness Center, 541 N. Fairbanks Ct., Mezzanine Level, Chicago, IL 60611

Contact: To obtain additional information or to register, please contact Aleks Gebska at 312.238.5003 or agebska@sralab.org

PWR! Circuit Virtual Class

Date: Tuesdays and Thursdays

Time: 10 am (CT)

Location: This is a virtual/online group. Visit www.sralab.org/services/adaptive-sports-and-fitness-program for access.

Cost: $220 (22 classes or $15 drop-in fee)

PWR Circuit In-Person Class

Date: Mondays, Wednesdays, and Fridays

Time: 9:45 am (CT) >>>>>

Location: Shirley Ryan AbilityLab Adaptive Sports and Fitness Center, 541 N. Fairbanks Ct. (accessible entrance at 303 E. Ohio), Mezzanine Level, Chicago, IL 60611

Cost: $330 (33 classes or $15 drop-in fee)

Nordic Poles Agility

Season: April-October

Date: Thursdays

Time: 9 am (CT)

Location: 808 N. Lake Shore Park Drive

Cost: $110 (11 classes or $15 drop-in fee)

Yoga

Date & Time: Gentle Chair is Fridays at 9 am.
Mat Yoga is Mondays and Wednesdays at 8:45 am.

Location: SRALab Adaptive Sports and Fitness Center, 541 N. Fairbanks Ct., Mezzanine Level.

Cost: Free

Contact: Shirley Ryan AbilityLab Fitness Center 312.238.5003

The Goldman Functional Fitness Program

Date: Mondays-Fridays

Time: 6:15 am - 4 pm

Location: In-person and virtual telefitness coaching sessions available

Cost: $60 45-minute session or $550 10-pack

Contact: Shirley Ryan AbilityLab Fitness Center 312.238.5003

ProACTIVE PD Exercise Class

Date: Tuesdays and Thursdays

Time: 8:15 am - 9 am

Location: SRALab Adaptive Sports and Fitness Center, 541 N. Fairbanks Ct., Mezzanine Level

Cost: $220 (22 classes or $15 drop-in fee)

Adaptive Pilates

Date: Tuesdays

Time: 2 pm

Location: SRALab Adaptive Sports and Fitness Center

Cost: $110 (11 classes or $15 drop-in fee)

Chair Based Dance

Date: Fridays

Time: Wednesday 3 pm or Friday 10:45 am

Location: SRALab Adaptive Sports and Fitness Center

Cost: $110 (11 classes or $15 drop-in fee)

Progressive Resistance Training Group - Strength and Bone Resilience Class

Date: Monday and Wednesday 11:45 am

Location: SRALab Adaptive Sports and Fitness Center

Cost: $220 (22 classes or $15 drop-in fee)

Balance and Stability

Date: Wednesday 2 pm (Participants with assistive devices)
Friday 11:45 am (Participants without assistive devices)

Location: SRALab Adaptive Sports and Fitness Center

Cost: $110 (11 classes or $15 drop-in fee)

North Region: NM Lake Forest Hospital

Dancing with Parkinson's

Date: Mondays

Time: 11:30 am- 12:30 pm (CT)

Parkinson's Players Ping Pong

Date: Tuesdays and Thursdays

West Region: Central DuPage Hospital

Parkinson's Support Group

Date: Second Thursday of the month

Time: 10:30 am - 11:30 am (CT)

Location: This is a hybrid group. Some group members are come to the meeting online and some come in person. Once registered you will be given information to join the group.

Contact: For more information and to register, please call 630.933.4234

Memory Caregiver Support Group

Date: First Thursday of the month (virtual)
and third Thursday of the month (in person)

Time: 10 am - 11:30 am (CT)

Location: Once registered you will be given information to join the group.

Contact: For more information and to register, please call 630.933.4234

PD 101

Date: February 8, July 11, and November 14

Time: 4 pm – 5:30 pm (CT)

Location: This program is hybrid

Contact: For more information and to register please call 630.933.4234

Resilient Rhythms

Date: Fourth Thursday of the month

Time: 4 pm- 5 pm (CT)

Contact: For more information and to register please call 630.933.4234

South Region: Shirley Ryan Ability Lab

Making Conversation: Parkinson's Conversation Group

Date: Jan 8, Feb 12, March 11, April 8, May 13, and June 10

Time: 3:15 pm – 4 pm (CT)

Location: Homewood Day Rehab Center, 19260 S. Halsted Street Homewood, IL 60430

Contact: For more information and to RSVP, please call 312.238.2160

Research Participation Opportunities at Northwestern Medicine

For more information call 312.503.0755
or email: pdclinicaltrials@northwestern.edu

For more information about Movement Disorders research at Northwestern, visit our website at: https://www.neurology.northwestern.edu/divisions/movement-disorders/clinical-trials.html

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Research Study Title: Northwestern Movement Disorders Center Biorepository

Clinical Trial Description: The Movement Disorders Center Biorepository (MDC-Biorepository) is a registry aimed to collect biologic and clinical information from patients diagnosed with a movement disorder. The purpose is to identify factors that either cause these neurologic conditions or increase one's risk for developing them.

Clinical Trial Eligibility Criteria:
- Disease subjects and family members
- Diagnosis of a movement disorder

Research Study Visits: 1 visit (can be conducted during a regular clinic visit, includes blood or saliva sample)

Coordinator Contact: Rachel Lewandowski, 312.695.0508, rachel.lewandowski@northwestern.edu

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Research Study Title: The Parkinson's Progression Markers Initiative - Establishing a Deeply Phenotyped PD Cohort (PPMI 2.0)

Clinical Trial Description: The overall goal of PPMI 2.0 is to identify markers of disease progression for use in clinical trials of therapies to reduce progression of PD disability.

Clinical Trial Eligibility Criteria:
- Diagnosis of PD 2 years or less -OR-
- PD with genetic mutation < 2 years duration -OR-
- Prodromal and Healthy Control

Research Study Visits: Annual visits with DatScan, MRI, Lumbar Puncture and blood sample

Coordinator Contact: Sophia Melton, 312.503.8229, sophia.melton@northwestern.edu

Research Study Title: Parkinson's Foundation PD-GENEration: Mapping the Future of Parkinson's Disease (PD-GENE)

Clinical Trial Description: The purpose of this study is to evaluate how offering certified genetic testing for PD genes to patients with Parkinson's impacts clinical care and potential enrollment in clinical trials.

Clinical Trial Eligibility Criteria:
- Willingness to undergo genetic tests
- No hematologic malignancies such as lymphoma or leukemia
- Have not received a blood transfusion within the past 3 months of study visit or had a bone marrow transplant within the past 5 years

Research Study Visits: Initial visit, genetic counseling session and online surveys

Coordinator Contact: Max Galarce, 312.503.4270, max.galarce@northwestern.edu

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Research Study Title: The Fox Bionet ECV 004 Study

Clinical Trial Description: The overall goal of this study is to identify reliable markers of LRRK2 activity in human CSF. This study is looking for non-manifesting LRRK2 mutation carriers, LRRK2+ Parkinson Disease (PD) participants, idiopathic PD (iPD) participants and healthy control (HC) participants.

Research Study Visits: 1 visit

Coordinator Contact: Sophia Melton, 312.503.8229, sophia.melton@northwestern.edu

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Research Study Title: Study in Parkinson Disease of Exercise Phase 3 Clinical Trial (SPARX3)

Clinical Trial Description: The primary objective of this study is to determine whether the progression of the signs of PD is attenuated at 12 months in non-medicated people with PD when they perform moderate vs. high-intensity endurance treadmill exercise.

Clinical Trial Eligibility Criteria:
- Diagnosis of PD 3 years or less and 40-80 years of age at screening
- Not expected to start PD meds least 6 months from baseline
- Currently exercising less than 2 hours of moderate intensity exercise per week within last 6 months

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Research Study Visits: 2-year study with 10 clinic visits and regular exercise training visits (Datscan required)

Coordinator Contact: Max Galarce, 312.503.4270, max.galarce@northwestern.edu

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The Research Study Title: A Novel Measurement Concept To Objectively Quantify Severity of Vocal and Speech-Related Symptoms Associated With Parkinson's Disease (Voice-Pd)

Clinical Trial Description: The overall goal of this study is to objectively quantify severity of vocal and speech-related symptoms associated with Parkinson's disease. You will be provided with an iPhone to complete assessments at home.

Clinical Trial Eligibility Criteria:

- Diagnosed with PD on standard of care -OR-
- Prodromal participants - as identified via clinician-determined predictive criteria -OR
- Healthy age and sex matched controls

Research Study Visits: 10 weeks with 1 in-person visit and 3 remote visits

Coordinator Contact: Max Galarce, 312.503.4270, max.galarce@northwestern.edu

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Research Study Title: A Phase 2b, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Determine the Efficacy and Safety of BIIB122 in Participants with Parkinson's Disease (LUMA)

Clinical Trial Description: The primary objective of this study is to evaluate the efficacy of BIIB122 225 mg compared with placebo by time to confirmed worsening in MDS-UPDRS Parts II and III combined score over the treatment period.

Clinical Trial Eligibility Criteria:

- Diagnosis of PD 2 years or less and 30-80 years of age at screening
- MDS-UPDRS Parts 2+3 OFF score ≤40 at screening
- 80% untreated or treated with PD meds for at most 30 days with last dose at least 60 days prior to screening OR
- 20% Treated with stable dose (MAO-B or LD) for minimum 90 days and on PD treatment for less than 1 year AND
- Not expected to start or change PD meds for at least 48 weeks from time of enrollment
- Positive DAT within 2 years

Research Study Visits: minimum 50 weeks and maximum 146 weeks

Coordinator Contact: Roxana Jabbarinejad, 312.503.0009, roxana.kermani@northwestern.edu

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

Clinical Trial Description: The primary objective of this study is to evaluate the safety and tolerability of multiple doses of BIIB094 administered via intrathecal (IT) injection to participants with Parkinson's disease (PD).

Clinical Trial Eligibility Criteria:

- Between 35 to 80 years of age who have a clinical diagnosis of PD with and without LRRK2 mutations
- Diagnosis of PD within 7 years without motor fluctuations or dyskinesias
- Treatment naive or on stable medication for at least 8 weeks prior to screening

Research Study Visits: 47 weeks total with up to 11 weeks screening, 4 monthly doses of study drug and 24-week follow-up

Coordinator Contact: Monika Szela, 312.503.2693, monika.szela@northwestern.edu

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Research Study Title: A Phase 2, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Efficacy, Safety, Tolerability, Pharmacodynamics, and Pharmacokinetics of BIA 28-6156 in Subjects With Parkinson's Disease With a Pathogenic Variant in the Glucocerebrosidase (GBA1) Gene

Clinical Trial Description: To assess the efficacy of BIA 28-6156 in delaying meaningful clinical motor progression in subjects with Parkinson's disease (PD) who have a pathogenic variant in the GBA1 gene (GBA-PD).

Clinical Trial Eligibility Criteria:

- Between 35 and 80 years of age who have a clinical diagnosis of PD (H&Y ≤ 2.5)
- On stable medication for at least 30 days prior to screening
- Known GBA-Pd risk-associated variant

Research Study Visits: 78-week treatment period with 35 days screening

Coordinator Contact: Noa Justine Houseman, 312.503.2128, noa.justine@northwestern.edu

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Research Study Title: Web-based Automated Imaging Differentiation of Parkinsonism

Clinical Trial Description: The purpose of this study is to test the performance of the wAID-P algorithm in differentiating different types of diseases including Parkinson's disease (PD), multiple system atrophy parkinsonian variant (MSAp) and progressive supranuclear palsy (PSP). Each site will perform

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imaging, clinical scales and diagnosis. The clinical diagnosis will be blinded to the diagnostic algorithm and the imaging diagnosis will be compared to the movement disorders trained neurologist diagnosis.

Clinical Trial Eligibility Criteria:
- All subjects will be in the age range of 40-80 years at baseline evaluation
- For PD- symptom duration of 5-9 years and either H+Y 2 or 3 on medication at baseline
- For MSAp and PSP, subjects can be included in the study initially with a possible or probable diagnosis

Research Study Visits: 2 visits

Coordinator Contact: Max Galarce, 312.503.4270, max.galarce@northwestern.edu

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Research Study Title: A 17-week, Phase 2, Randomized, Double-blind, Placebo-controlled, Flexible-dosing, Parallel-group, Multicenter Study of the Efficacy and Safety of Suvecaltamide in the Treatment of Moderate to Severe Residual Tremor in Participants with Parkinson's Disease (Jazz-PD)

Clinical Trial Description: This is a randomized, placebo-controlled double-blind study to evaluate the effects of Suvecaltamide in PD tremor.

Clinical Trial Eligibility Criteria:
- Between 40 and 80 years of age
- Diagnosed with PD within 5 years
- Moderate to severe residual tremor despite treatment with medication
- Stable con meds for at least 6 weeks

Research Study Visits: Up to 23 weeks

Coordinator Contact: Nicholas Bobbitt, 312.503.1999, nicholas.bobbitt@northwestern.edu

Join the Mailing List / Questions?

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 bi-annual newsletter FAQ section—please email 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.

Partnerships

Northwestern University is proud to be affiliated with a number of patient advocacy organizations.

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WDA WILSON DISEASE ASSOCIATION

PSG PARKINSON STUDY GROUP

Parkinson's Foundation
CENTER OF EXCELLENCE

Huntington's Disease Society of America
Centers of Excellence

NAF National Ataxia Foundation

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