

The Transmitter

Parkinson's Disease and Movement Disorders Center (PDMD) Newsletter of Penn Medicine

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Celebrating 25 Years OF THE DAN AARON PARKINSON'S REHABILITATION CENTER (DAPRC)

In this issue of The Transmitter, we are excited about the 25th year of the DAPRC, which has grown and changed with the decades. Dan Aaron, as you will learn, was an innovative entrepreneur who turned his considerable talents first to cable television and then, after his diagnosis, to Parkinson's disease (PD). After a quarter of a century, the Center is something we can all be proud of.



APRIL IS PARKINSON'S
AWARENESS MONTH

REMEMBERING Dan Aaron

*Howard Hurtig, MD, Elliott Professor of Neurology, Emeritus,
Perelman School of Medicine, University of Pennsylvania*

Leader, visionary, philanthropist, humanitarian, champion for social justice, family man—just a few labels, although not the only ones, that describe Dan as I think back on our close, 20-year doctor-patient friendship. Dan's remarkable success in life could not have been predicted from the twin nightmares he experienced as a child: First, his escape from Nazi Germany to New York City in 1938, as a teenager with his parents and younger brother Frank; and second, the loss of both parents to suicide shortly thereafter because of their failure to adapt to life in America. Fortunately, Dan and Frank grew up in a series of foster homes under the guidance of caring surrogate parents.



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REMEMBERING *Dan Aaron*

A Force in Philadelphia

Dan graduated from Temple University and started a career in journalism, covering the business community for the now defunct *Philadelphia Bulletin*. One of the companies he covered was Jerrold Electronics, a manufacturer of equipment for the embryonic cable television industry whose owner Milton J. Shapp—later Governor of Pennsylvania—lured Dan away from the *Bulletin* to join Jerrold to oversee the development of cable in rural Tupelo, MS. In 1963, in a chance encounter with his friend Ralph Roberts, Dan convinced Ralph to partner with him to purchase the cable system in Tupelo. Rapid growth of the company evolved into the entity that in 1969 became Comcast, a name that combined “communications and broadcast.”

Living with Parkinson's

In 1980, at age 55, Dan developed a tremor and was told he had Parkinson's Disease (PD) by a Philadelphia neurologist. Four years later, when his doctor retired, Dan contacted me and asked if I would assume management of his illness at our Parkinson's Disease and Movement Disorders Center (PDMDC) at the old Graduate Hospital. At our first appointment, I knew right away that Dan would be co-manager of his illness. It was natural for Dan, the entrepreneur, to be in the front seat on decision-making, and it suited my own style of doctoring for me to be his equal partner.

Dan had a broader perspective than I had—beyond taking medication and periodic appointments—on how to live with PD. He knew instinctively that exercise was a key to living well, and he pushed hard on the idea that exercise programming should be a critical component of any Parkinson treatment plan. Correctly reckoning that symptomatic medication was not enough to combat what he called the “Reckless Hunter,” Dan knew that being in full control of one's own lifestyle was all-important.



Creating a Foundation

Dan retired from Comcast in 1991, still at the top of his game, and with funds raised at his gala retirement celebration, he established the Dan Aaron Foundation. Dan's passion for exercise fueled his determination to use the Foundation's money to create a facility that would make exercise and rehabilitation accessible and integral to the comprehensive management of PD for everyone with the illness.

Meanwhile, in 1997, the PDMDC had relocated to Pennsylvania Hospital. Dan eventually negotiated with Pennsylvania Hospital's administration to share the cost of creating the landmark Dan Aaron Parkinson's Rehabilitation Center (DAPRC), which opened in 2000. This, according to his daughter Erika Aaron, was his proudest accomplishment in a long list of major accomplishments. The DAPRC was and still is a personification of Dan's philosophy of taking charge of his own destiny, living by the mantra of “never giving up” that he imparted to his five children and creating an inspiring legacy to benefit all members of the greater Parkinson community by leaving behind a monument to his humane values.



DAPRC group boxing



David Auten and Joellyn Fox, DPT



DAPRC staff 2025

THE ROLE OF PT: *Stronger Now Than Ever Before*

The role of physical therapy (PT) in managing symptoms of Parkinson's disease (PD) has significantly evolved over the years. This important outcome was driven by the increasing understanding of the disease's complexity as well as the growing recognition of physical therapy's importance in enhancing quality of life.

Discoveries about Neuroplasticity

In the early 1990s and 2000s, more research into neuroplasticity and motor learning emerged, leading to a stronger emphasis on PT for those living with PD. Neuroplasticity is the brain's ability to reorganize and form new neural connections when exercises and activities are targeted and structured. This is possible despite the inevitable neurodegeneration that occurs with PD. Our appreciation of the benefits of neuroplasticity has guided physical therapists in their emphasis of functional movement, balance, coordination and exercise prescription.

“Exercise is Medicine”

The concept of “exercise is medicine” gained prominence in the 2000's as research gave us clear evidence that physical activity can positively impact motor symptoms of PD. The Parkinson's Foundation summarized the robust amount of research on the impact of exercise on PD symptomology and acknowledged that moderate-to-high-intensity exercise (aerobic exercise) is part of the puzzle, but it is not the only piece. The Foundation wrote that the most impactful exercise regimen that one can adhere to includes aerobic exercise, strengthening, balance/coordination/agility and stretching. It is the PT's role to adapt this structure to each individual in order to enhance compliance, progression and positive impact while reducing likelihood of injury, lack of adherence and boredom.

Joellyn Fox, DPT

Working with Your PT

Additionally, the role of the PT has expanded to include education and empowerment, helping individuals with PD and their families navigate the complexities of the disease. Many therapists are also involved in training caregivers to assist with mobility and daily activities, since they play a crucial role in maintaining the person with Parkinson's (PwP) independence. In addition, assistive devices can enable the PwP to stay safe and do more physically. These devices—a rollator, a walker, a cane, trekking poles, or a combination of devices—may be recommended as needed by the PT. In PT sessions, multiple devices may be trialed to determine the best device depending on the time of day as well as the situation. Your PT can also educate and support you with information on the most economical devices and ways in which to purchase.

In summary, physical therapy has evolved from a basic, symptom-focused intervention to a dynamic, individualized, and holistic treatment approach that improves both physical and emotional well-being of those living with PD and their care partners. Although the evidence continues to grow to show the strength of these interventions, it proves that all PwPs can live strong and fight back against this disease!



DAPRC boxing class cardio

The Role of Rehab in Parkinson's Disease Care: **PARTNERS THROUGHOUT THE JOURNEY**

Casey Hasenbein, PT, DPT

PD is a complex disorder that affects every facet of a person's life. Given the diversity of symptoms, it's understandable that a person with Parkinson's (PwP) needs a diverse team. The more we learn about PD, the more we understand how crucial rehabilitation professionals are in treatment of this disease. Rehabilitation or "rehab" professionals include physical therapists (PTs), occupational therapists (OTs), and speech-language pathologists (SLPs). Here at the Dan Aaron Parkinson's Rehab Center, we are lucky to have all three professions as part of our multi-disciplinary team.

What is Rehabilitation?

Rehabilitation is defined as "the act of restoring someone to health or normal function." Most people have experience with at least one form of rehab (usually physical therapy), most often for back pain or a knee replacement. But they often don't understand ways in which therapies can "rehabilitate" a progressive disease. Unlike traditional PT, OT and SLP, our work is less about strengthening a weak muscle after an injury, or improving range of motion after a surgery, and more about teaching new ways to think about movement so you can manage the symptoms of Parkinson's – like slowness, stiffness, soft voice – that are limiting your function and quality of life. With this approach, rehabilitation professionals can have a huge impact on the course of this disease.

What is Pre-Habilitation?

We can get even better results by starting early, with pre-habilitation. Pre-habilitation is "the process of improving the functional capacity of a patient prior to a surgical procedure so that patients can reduce their risk of complications, shorten their recovery time, and enhance their overall quality of life."

While PwPs are not prepping for a surgery, they are preparing for a lifelong fight against PD. Rehab providers can offer their services early as "pre-hab" before symptoms start limiting function. This helps prepare you for your journey and teaches you all the ways to modify movement, lifestyle, behavior and habits to keep you as independent as possible for as long as possible. We offer education about pre-hab, and general rehab, in our PD101 seminar – a quarterly presentation for newly diagnosed patients run by the PDMDC. We emphasize the importance of starting PT, OT and SLP even before you have symptoms that limit your function.

But what happens when people do have symptoms? Can we really "rehab" them? There is an abundance of research that shows the answer is yes, there are many improvements to function with PT, OT and SLP, even as the disease progresses. Your rehab team can help manage symptoms in all stages of your disease with home modifications, recommendations for assistive devices, practicing new ways to move around the house, updating home exercise programs, cues for moving and talking more efficiently, and educating caregivers. We want you and your loved ones to learn these tips and tricks as soon as you can so that you will have as many different tools as possible to fight back against PD.

Getting Your Team Together

It is crucial to find a rehab team that has experience treating Parkinson's disease. There are a lot of certifications that exist, such as LSVT BIG/LOUD, Speak Out, PWR!, etc. While these are all great tools that rehab professionals can use to arm our toolboxes, certifications alone don't guarantee that a provider is an expert in treating PD.

That is why we encourage all PD patients seen at the PDMDC to meet with our rehab team at least once, even if they live too far away to undergo regular therapy with us. We frequently help PwPs find quality providers closer to home should continued services be needed, and often collaborate with local providers who may be less experienced working with PD patients. We also encourage PwPs to check in with the rehab team when they are in town for their neurology appointments at the PDMDC. We recommend an evaluation with our rehab team every 6 to 12 months or sooner if major changes occur.

Please Come for a Visit!

The Rehab Center is found on the first floor of the Penn Neurological Institute at 330 S. 9th Street. The Parkinson's Disease and Movement Disorders Clinic (PDMDC) is conveniently situated on the floors above. Stop by after your next neurology visit and schedule an appointment or call 215.829.7275! We look forward to joining your team.



How Can a **SPEECH THERAPIST** Help You?

Victoria Gonzalez, MS, CCC-SLP

Beyond assisting with communication and thinking, a speech therapist can carefully evaluate and treat swallowing problems, such as coughing or choking while eating or drinking, or feeling that food is getting stuck in your throat. These techniques are critical to maximize airway safety and enhance the pleasure of eating. Patients at the DAPRC undergo comprehensive swallow evaluations and, if needed, more objective imaging at a local hospital. Thereafter, we use this information to teach you specific compensatory strategies such as eating slowly or using postural changes that redirect the passage of food away from your airway, or even exercises to improve your swallowing.

A Note on Hospital Safety

If you or your loved one with PD are ever admitted to the hospital, it may be important to communicate to healthcare staff about any communication challenges. Sometimes, the “slurred” or unclear speech of some folks with Parkinson’s may be mistaken by healthcare staff as either alcohol abuse or a sign of other, more medically urgent conditions (such as stroke or brain injury). Providing this information as well as potential speech strategies may help optimize communication between you and your care team, so that you can receive the care you need.



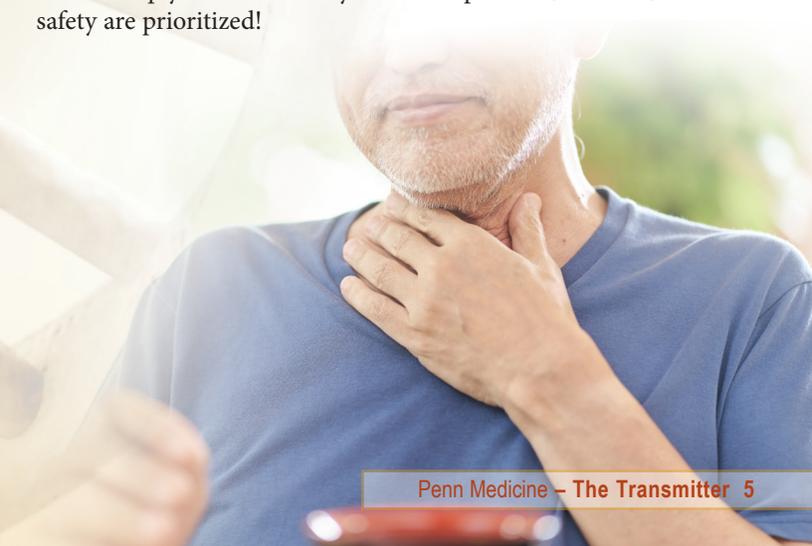
Have you often been asked by friends, family, or even strangers to repeat yourself? Have you found yourself losing your train of thought or searching for the right words? If this pattern sounds familiar, you may get to a point where you might even avoid speaking. Or another problem: Have you been coughing while eating and/or drinking?

What Is a Speech Language Pathologist? (SLP)

At the DAPRC individuals with Parkinson’s can work with a speech therapist. Another term for a speech therapist is a “Speech Language Pathologist,” or “SLP.” This specialty covers several different problems. An SLP is a communication expert who helps people with speech, language, and swallowing challenges.

Your therapy may involve energetic, high-intensity vocal exercises to improve the volume, clarity, and intelligibility of your speech. It can also help you to identify personalized word-finding strategies to continue your flow of thought even when you can’t find the right word. For example, suppose you were at a loss to come up with the word “magician.” You might say, “one of those entertainers who pulls a rabbit out of a hat.” We might also work closely with care partners to identify individualized communication strategies for both the speaker AND listener to keep you both participating in daily conversations. We might narrow down brain health activities that you can enjoy, which will stimulate your attention and memory (e.g., puzzles, reading, baking cookies).

Keeping You Involved Through SLP



At the DAPRC, we want to keep our patients actively involved with speech and language. Some of the most important moments of our lives are spent socializing and enjoying meals – we can help you ensure that your self-expression, comfort, and safety are prioritized!

OCCUPATIONAL THERAPY, COGNITION, and the Care Partner Role

Megan Barbuto, MOT, OTR/L

The term “occupation” refers to activities that are meaningful to each person. Occupational therapists (OTs) identify strategies and tools to allow individuals to continue to engage in these important activities. People with Parkinson's (PwPs) may struggle with self-care tasks, meal preparation, rest and sleep, leisure, work, and health management. Care partners may find themselves frustrated with knowing how best to help.

OTs can help determine appropriate adaptations to increase the independence, safety, and self-confidence of PwPs and their care partners. We work on fine motor skills (handwriting, buttoning, typing), fatigue management, sleep hygiene, activities of daily living, anxiety/stress management, organization of day-to-day activities (structure), as well as all the facets of cognition.

Cognition is a term that encompasses memory, language, thinking and processing. PwPs may experience challenges with attention, slow processing speed, trouble planning and completing tasks, memory, word finding and visuospatial skills. Not all PwPs will experience mild cognitive impairment or dementia, however those who do often rely heavily on their loved ones to assist in management of daily tasks. This may result in care partner burnout and what is known as “compassion fatigue.” If you as a partner have struggled to give care over years without any assistance, you may have lost the ability to feel empathy and compassion, and this can lead to major emotional distress. Compassion fatigue may show itself as increased irritability, decreased energy, isolation, and feelings of self-doubt.

Skills2Care Program for Care Partners

If the PwP is also dealing with dementia, an OT can assist by administering an evidence-based program known as Skills2Care. This program is implemented as part of an occupational therapy plan of care. During the program, the care partner works directly with an OT who performs an evaluation to determine individualized needs and develops an action plan while providing education on managing challenging behaviors. Skills2Care offers ways to promote better function, communicate effectively with your loved one, and learn ways to take care of yourself. As an OT certified in the Skills2Care protocol, I am eager to share my knowledge to improve the well-being and quality of life for PwPs and their care partners.

Working with Your OT

If you think you may benefit from these OT services, here's what you can do to get started:

- Reach out to your care provider and request a script to see an occupational therapist.
- Schedule an initial evaluation.
 - We are happy to coordinate schedules with a neurology visit for those who are traveling far distances. After this initial evaluation, we can locate a specialized therapist who is closer to you for ongoing services if warranted.
- If you need a dementia-care specialist, you can search for OT's certified in Skills2Care near you by visiting their website at www.dementiacollaborative.com/pages/find-a-certified-skills2care-occupational-therapist.
- For additional information or help navigating OT care you can reach out directly to Megan via email at megan.barbuto@penntmedicine.upenn.edu.



My 25 Years at the DAPRC

Heather Cianci, PT, MS, GCS

When the DAPRC was founded in the fall of 2000, I had no idea what an integral part of the Parkinson's community it would become, and how it would shape my life and career. The Rehab was named after Dan Aaron, a co-founder of Comcast Cable, who was diagnosed with Parkinson's in his early 50s. With the assistance of Drs. Howard Hurtig and Matthew Stern, nurse practitioner Gwyn Vernon, and social worker Jane Wright (formerly of Graduate Hospital), Mr. Aaron's foundation raised funds and created the rehab at Pennsylvania Hospital.



The First Rehab Team

Although at first I was the only physical therapist (PT), we now have grown to three PTs, an occupational therapist and a speech language pathologist – all of whom specialize in the treatment of movement disorders. The DAPRC was the first of its kind in the northeast and helps to set the standard of what interprofessional care should be for people living with PD. In the early days I educated myself by attending support groups, reading the limited research in therapy that was available, shadowing our amazing movement disorders team, and getting to know my patients and their families. They were some of my best teachers and I thank those early folks for trusting me with their care. We learned so much from each other.

Dan Aaron Center Becomes a "Center of Excellence" in Rehab

Soon the team at the DAPRC were the ones taking part in research, teaching at conferences and universities, and being the go-to team that other rehab professionals in the country wanted to learn from. We grew from having one group exercise class of 5 people to having multiple classes with over 20 people! We helped raise funds and participated in the Unity Walk in New York City before Philadelphia had *The Parkinson Council's Walk to Stamp out Parkinson's*. We have been proud volunteers every year since 2001.

Members of our team lecture nationally and internationally for organizations such as the Parkinson's Foundation, CurePSP, LSVT Global, and The World Parkinson Coalition. We even have one team member who will be running her second marathon in support of those with PD. I often tell people that the Center is a kind of utopia – a place where everyone is working together for the good of others. A truly special aspect of the DAPRC is that we have worked with some people living with Parkinson's for nearly 25 years. Being able to provide hope and help along their journey has been a true gift.

The Parkinson Council News

SAVE THE DATE!

Acing Parkinson

Monday, June 23, 2025

9:30 am – 1:00 pm

Germantown Cricket Club



Tennis lovers, join fellow "acers" at the historic Germantown Cricket Club for a day of play on grass to benefit The Parkinson Council. For information about how to join, email info@theparkinsoncouncil.org or call **610.668.4292**.

SAVE THE DATE!

"A Shore Event!" Flip Flop Walk

Saturday, July 12, 2025

8:30 am – 10:30 am

Avalon Community Hall



Founded by a family with a connection to Parkinson's, the Flip Flop Walk returns to celebrate a milestone 16th year! This family-friendly, hope-driven, and community-focused event, FFW2025, is the only "shore" event designed with families living with Parkinson's in mind. Funds raised at this event support 2026 programs and services in the Delaware Valley region, and help The Parkinson Council invest local dollars into the local community for research, comprehensive care, movement programs, and quality-of-life initiatives. Email info@theparkinsoncouncil.org for more information.

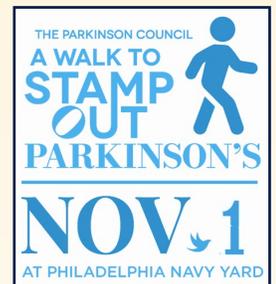
SAVE THE DATE!

24th Annual Walk to Stamp Out Parkinson's

Saturday, November 1, 2025

11:00 am - 2:00 pm

Philadelphia Navy Yard – Central Green



Join The Parkinson Council's oldest and largest community awareness and fundraising gathering in the Philadelphia region to celebrate 24 years of *A Walk to Stamp Out Parkinson's* at the iconic Philadelphia Navy Yard. A Walk to Stamp Out Parkinson's remains one of the biggest grassroots community fundraising events to support people with Parkinson's and their families in the Philadelphia region. Family, friends, colleagues, and healthcare providers are part of our movement against Parkinson's disease. What's even better is that the funds raised at the Walk stay in our region. For information, please email walk@theparkinsoncouncil.org. #raisedlocal #stayslocal



Penn Medicine

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The Transmitter is published biannually to inform the public about Parkinson's disease and other movement disorders. The information contained herein is solely to raise awareness of developments in the field of movement disorders. Nothing written in this newsletter should be used as a guideline for treatment.

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The Parkinson's Disease and Movement Disorders Center is a Parkinson Center of Excellence.

Events and Programs

18th Annual Jane Wright Patient and Care Partner Symposium **"New Approaches to Diagnosis and Treatment of Parkinson's Disease"**

Thursday, May 15, 2025 at 10 am
Hilton Philadelphia City Avenue
Email sreichwein@pennmedicine.upenn.edu or call **215.829.7273** to register. Fee is \$25 per person or \$40 per couple. Scholarships available based on need.

Moving Day Southeast PA **Parkinson Foundation Annual Walk to Raise Funds**

Saturday, May 17, 2025 at 9:30 am
Bucks County Community College
For more information, please visit www.parkinson.org/events/2025/MD-Southeastern-PA.

Living Well at Home

Living Well at Home is the online series to keep PwPs and care partners connected. This program consists of a support group every Monday as well as movement groups throughout the week. For more information email Sue Reichwein at sreichwein@pennmedicine.upenn.edu or call **215.829.7273**



Dance for PD

Dance for PD at Hall Mercer

Music, lights, action! We are either dancing or working on balance and gait in person across from Pennsylvania Hospital at Hall Mercer, 245 South 8th Street, Philadelphia, every Thursday at 2 pm. Join us for an hour of seated and standing movement every week. For more information visit www.anyonecanmove.com/contact-us.

PingPongParkinson®

In addition to motor skills, table tennis challenges our visuospatial processing, strategy formation, and executive functioning. PingPongParkinson in Philadelphia runs every Friday from 2-3:30 pm at Pingpod, 325 Chestnut Street. Contact santanavelezcarlos@gmail.com for more information.