
# On the Move

SUMMER 2024

## Parkinson's and Movement Disorders Center

VCU Health™

# Magnifying the crucial role of team science in advancing the movement disorder treatment landscape

**Brian D. Berman, M.D., M.S.**
PMDC Director and Movement Disorders Division Chief and Professor with the VCU Department of Neurology

**"By nurturing a culture of interdisciplinary collaboration and innovation, we are transcending traditional boundaries and driving transformative change in the field of movement disorders research."**

Team science is more than just a buzzword at the Parkinson's and Movement Disorders Center (PMDC) — it's the cornerstone of our approach that guides our strategic collaborations and pioneering research endeavors.

With patients at the forefront, we extend our vision beyond conventional boundaries, ushering in innovative pathways in both patient care and scientific exploration. This dedication propels us toward a deeper understanding of complex neurological conditions and transformative treatment modalities, shaping the future of movement disorders research and clinical care.

An example of our collaborative ethos is a partnership with the VCU School of Nursing, William & Mary and the PMDC's Leslie Cloud, M.D. This pioneering research focuses on vibration therapy for Parkinson's disease gait symptoms, aiming to identify optimal vibration doses to alleviate gait freezing in patients. By leveraging innovative approaches and interdisciplinary expertise, this work holds the promise of revolutionizing mobility interventions and enhancing the quality of life for countless individuals living with Parkinson's disease.

Simultaneously, the PMDC has embarked on a collaborative journey with the College of Health Professions (CHP) and VCU Health Physical Medicine and Rehabilitation (PM&R) to unravel the mysteries of motor deficits in Parkinson's disease patients. Through a grant-funded project in partnership with CHP's Brooke Dexheimer, Ph.D., we're delving into lateralized fine motor control impairment of these patients and seeking to develop novel assessment methods for early detection and personalized treatment strategies.

The PMDC's collaboration with the College of Engineering's Biomedical Engineering department has begun to yield insights into electroencephalogram (EEG) biomarkers in Lewy body dementia (LBD). Under the leadership of Matthew Barrett, M.D., this NIH-funded study aims to uncover novel EEG signatures associated with cognitive fluctuations in Lewy body dementia, offering new avenues for early diagnosis and informing targeted interventions. By harnessing the power of advanced neuroimaging techniques and computational modeling, this collaborative effort is paving the way for precision medicine approaches in neurodegenerative disorders.

These synergistic partnerships underscore the transformative potential of interdisciplinary research in driving scientific innovation and translating discoveries into tangible clinical outcomes.

Beyond the realm of research, the PMDC's partnership with the Parkinson's Foundation has facilitated transformative advancements in patient support and provider education. Through initiatives such as patient symposia and training events led by Dr. Cloud, we are collectively empowering health care

professionals with the latest insights and best practices in Parkinson's disease management and fostering a culture of continuous learning and excellence in care delivery.

All this work serves as tangible evidence that collaborative research is the linchpin of our success at the PMDC. By nurturing a culture of interdisciplinary collaboration and innovation, we are transcending traditional boundaries and driving transformative change in the field of movement disorders research. With each new discovery and breakthrough, we reaffirm our commitment to advancing the frontiers of science and improving the lives of individuals worldwide affected by movement disorders. ■

# PMDC pilot grant helps VCU researchers land DOD funding

*By Sean Gorman*

A pilot grant from the Parkinson's and Movement Disorders Center (PMDC) helped VCU researchers secure a federal grant to research links between pesticide exposure and cognitive decline.

Laxmikant Deshpande, Ph.D., an associate professor in the VCU Department of Neurology, and Joseph McClay, Ph.D., an associate professor in the Department of Pharmacotherapy and Outcomes Science, used a PMDC pilot grant they were awarded last year to study how organophosphates used in certain pesticides could impact neural connections that support memory functions.

That testing gathered preliminary data used to unlock a grant from the U.S. Department of Defense's Toxic Exposures Research Program for further research. The VCU research team learned in March they were being recommended for the DOD grant to undertake more testing into the cognitive impacts of chlorpyrifos, an organophosphate pesticide used on common crops like cotton, apples, and broccoli.

Deshpande says he and McClay have been examining how that kind of pesticide affects farmers who work fields treated with those chemicals and how organophosphates impacted soldiers, such as those who got exposed during their deployment in the First Gulf War.

"There is anecdotal evidence, and there is mounting epidemiological evidence for a link between pesticide exposure and neurodegenerative conditions," Deshpande says.

For example, studies have shown soldiers reporting mood and memory-related problems after returning from the First Gulf War (Gulf War Illness) and farmers having cognitive issues and — in some cases — an elevated risk for developing Alzheimer's disease after tending crops sprayed with organophosphate pesticides, he says.

It all began when researchers approached PMDC and secured a $50,000 award from the center. They used it to run tests on rodents exposed to chlorpyrifos to see if they experienced memory problems. Desphande says initial testing showed an effect on memory following occupational-like chlorpyrifos exposure. McClay generated additional data on epigenetic changes in the brains of rats that exhibited memory impairments.

"We used that pilot funding from PMDC to generate the preliminary data that was needed to successfully compete for this DOD application," Deshpande says.

Now the team will undertake a more in-depth examination of how pesticide exposure changes the brain, and researchers also plan to screen drugs to reverse those impacts.

**Laxmikant Deshpande, Ph.D.**

"The bigger question is: are these memory-related issues a harbinger of ultimately developing Alzheimer's?" Deshpande says. "That's the part that we don't know. But that is where we will go in the future years."

The exact funding amount from the DOD grant isn't known yet, but Desphande estimates it will cover additional research that will probably lead to $750,000 in total costs.

Desphande credits the PMDC grant for giving their study a crucial boost to overcome a key barrier to securing a larger pool of funding: covering the costs needed to run experiments generating high-quality preliminary findings that justify a DOD award.

"To generate preliminary data, we need to make an investment," Deshpande says.

"The fact that the DOD reviewers thought it was a very well-written and a very nicely put together application is a testament of the quality of data, which stems from the PMDC support," he says. ■

Matthew Barrett, M.D.

# PMDC conducting its first PSP clinical trial aiming to address patient symptoms

*By Sean Gorman*

Progressive supranuclear palsy (PSP) leads to rapid neurodegenerative decline in patients. With no treatment to slow or stop its fast progression currently available, patients and their care teams fight to manage various symptoms that often are not alleviated by current medications.

The Parkinson's and Movement Disorders Center (PMDC) seeks to change that. An important clinical trial is ramping up that hopes to bring symptom relief to this complex patient population.

PSP, a condition in which patients can experience balance problems, falls, and eye movement abnormalities, tends to progress more rapidly than Parkinson's disease, says Matthew Barrett, M.D., the principal investigator for the clinical trial at the PMDC. Yet doctors tend to have few medications available to treat PSP manifestations, he adds.

"We have some treatments for symptoms, but they're lacking and don't address most of the patient's symptoms," says Barrett, a VCU associate professor of neurology. "It's a group of patients who really need treatments that slow the disease."

Barrett says the PMDC was selected at the end of 2023 to be part of the clinical trial, which is the the first PSP study the center has undertaken. Called the ORION Trial, it seeks to study a treatment called AMX0035 that strives to protect brain cells. Researchers will work to determine its safety and efficacy in slowing down symptoms.

One of the assets the PMDC brings to the trial is that it already treats PSP patients who are seen as part of a monthly clinic in Short Pump. This provides an opportunity for prospective participants to learn more about the study for potential enrollment, Barrett notes. He also shares that PMDC has been named a Center of Care by the CurePSP non-profit group — a designation that recognizes the VCU-based center as a place where patients with the disorder can get the best possible treatment.

"Those kinds of things put you on the radar for doing clinical trials," Barrett says.

Roughly 5 in 100,000 people have PSP. It has no known cause, CurePSP says. Symptoms, which can include loss of balance, slurred speech, and difficulty swallowing, typically emerge when a patient is in their early 60s but can also show up in their 40s, the group says. There is no known cure.

In addition to the PMDC, a half-dozen centers around the U.S. are enrolling patients for the clinical trials and other sites in Europe and Japan might also take part in the future, according to Amylyx Pharmaceuticals, the company that developed the drug.

The PMDC is working to schedule screenings for patients to see if they will participate in the trial, and the center has already heard from about 15 people with PSP interested in being part of it, Barrett says.

That high level of interest is a sign better treatments are needed, Barrett says.

"My target is typically five patients for these interventional clinical trials," Barrett says. "We are seeing a lot of enthusiasm from the patient community, and certainly we could enroll more." ■

## PMDC Research Presented at 2024 AAN Annual Meeting

**The PMDC's Matthew Barrett, M.D., along with Post Doctoral Fellow Ahmed Negida, M.D., Ph.D., and VCU medical student Aashish Batheja presented a poster titled "Comparing the NIH Toolbox-Cognition Battery and Montreal Cognitive Assessment to Assess Cognitive Impairment in Patients with Parkinson's Disease" at the American Academy of Neurology's 2024 annual meeting held in Denver this past April.**

**The PMDC's clinical research coordinator Caileigh Dintino along with Brian Berman, M.D., M.S., presented their poster titled "Neurofilament Light Chain (NfL) Levels are Increased after Sleep in Parkinson Disease" at the 2024 AAN annual meeting as well.**

# Empowering Dystonia Patients

## New PMDC support group fosters community and research collaboration

*By Dan Carrigan*


**A new PMDC support group offers people with dystonia the opportunity to learn about groundbreaking research into the neurological disorder and to meet others who are also living with it.**

Patients grappling with dystonia, a neurological disorder characterized by involuntary muscle contractions, have begun gathering at the Short Pump Pavilion's 2nd-floor conference room as part of an enriching support group. Hosted by the Parkinson's and Movement Disorders Center (PMDC), the new support group welcomes members of the community grappling with various forms of idiopathic dystonia.

Led by Caileigh Dintino, clinical research coordinator with the PMDC, the sessions aim to provide a platform for sharing insights, discussing new research topics, and fostering connections among attendees. Dintino emphasized the importance of community building and collaborative brainstorming to shape the support group into a valuable resource for those affected.

"The goal is to bring people together to learn about dystonia and learn from one another to navigate the challenges that dystonia can create in day-to-day life," says Dintino. "We also understand the impact of community and encourage the development of lasting friendships and comradery. It's that heightened empathy and understanding of what each individual is going through that will continue to make these sessions special."

Registered with the Dystonia Medical Research Foundation, the support group sessions offer a blend of informative discussions and open conversations, allowing participants to learn from expert guest speakers and connect with peers facing similar challenges. The group's agenda includes 25 to 30 minutes dedicated to information or research topic discussions followed by 45 to 60 minutes of interactive dialogue and connection-building activities.

The first meeting was held in late May and drew 12 attendees who have a wide variety of dystonia subtypes.

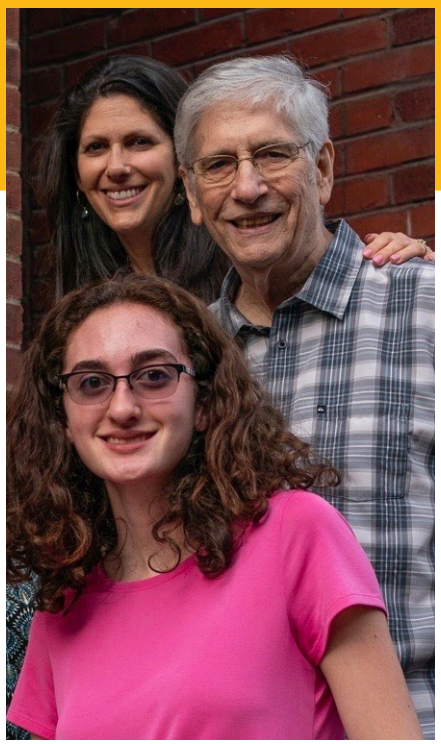
Recognized as a rare disorder, dystonia can lead to feelings of social stigmatization and a loss of independence. The support group sessions seek to address these challenges by offering a platform for education, mutual support and friendship.

Moving forward, the group plans to continue meeting on the last Thursday of every other month. There's a virtual option to accommodate those who live far away or who are too impaired to join in person. As the support group grows, Dintino hopes to incorporate additional events and activities to further enhance the sense of community and support among participants. ■

**"It's that heightened empathy and understanding of what each individual is going through that will continue to make these sessions special."**

# Rare disorder impacts, unites family

*By Sean Gorman*



**The Dolan family (from top): Jill; her father Steve, and Carly**

It didn't take long for Jill Dolan to notice her daughter, Carly, was experiencing delays in the early months and years after her birth in 2002.

Call it a blend of maternal instincts and training for the mom, who had a background in early childhood education. As an infant lying on her back, Carly wouldn't reach for toys dangling above her. What's more, when picked up, she wouldn't cling onto Jill or her husband, Bill. Carly had physical, cognitive and social delays and wasn't reaching speech, reading and other development milestones experienced by children her age.

Jill and her family wished for everything to be okay.

"My husband kept saying you just worry too much, and I'm like 'there's something going on,'" says Dolan, a 52-year-old Powhatan County resident. "The first couple of years were really rough, just not having direction," she recalls.

When she was about 9 months old, Carly started occupational therapy. She then began speech therapy as well at the family's home. Jill says continued care through the Children's Hospital Therapy Center in Midlothian made a world of difference for Carly's development.

"We were fortunate to start early intervention," she says.

Beyond that early support, the family wanted answers on the root cause of Carly's developmental delays. They met with a number of specialists. That journey led them to the Children's Hospital of Richmond at VCU Genetics Department when Carly was 3 years old.

"We had a wonderful nurse practitioner at our pediatrician's office who spent a lot of time with us for Carly's 3-year wellness check. She sent us all over the place, to Neurology and all different departments," Dolan says. "But she also sent us to Genetics even though there was no family history. They tested for seven or eight things."

A blood test revealed Carly had Fragile X Syndrome. It's a rare genetic disorder that can lead to the kind of developmental delays she was experiencing.

The National Fragile X Foundation says while the exact number of the people who have the disorder isn't known, between 38,000 to 87,000 people in the U.S. could have Fragile X Syndrome. Research studies suggest that about 1 in 7,000 males have been diagnosed with the disorder as have 1 in 11,000 females, the foundation notes.

The condition involves a full mutation of a gene on the X chromosome, resulting in a wide range of different symptoms, the National Fragile X Foundation says.

It can cause mild to more severe intellectual disabilities and can include autism, anxiety, learning disabilities, ADHD, poor eye contact and other symptoms, according to the foundation. It adds that females tend to have milder intellectual and behavioral symptoms than males.

Family members who are carriers of partial mutation of the gene can be impacted by other disorders, such as Fragile X-Associated Tremor/Ataxia Syndrome (FXTAS), a neurodegenerative disorder that can lead to tremors, balance, and cognitive issues. Carriers can also be affected by Fragile X-Associated Primary Ovarian Insufficiency (FXPOI) that can affect fertility due to hormone issues.

The disorder is diagnosed more often in males, who have only one X chromosome, than in females, who have two X chromosomes, the foundation says.

## Carly and her family's journey with Fragile X

Despite learning of a new, life-altering condition affecting her young daughter, when VCU doctors told Jill and Bill of Carly's diagnosis, Jill says they had a surprising feeling: relief.

At last, they had not just a name, but an explanation for what was happening to little Carly. Even though there's no cure, having a name and a direction was reassuring, Jill says. Since Fragile X is a disorder that originates in a person's chromosomes — the threadlike strands at the heart of human cells made of DNA carrying our genetic code — it can be inherited. So Carly's family underwent testing following her diagnosis.

It involves a simple blood test that identifies a gene mutation that causes

**"It can be hard to find specialists who understand and treat ataxia," Bissonnette notes. "Because ataxias are rare, it takes a long time to have seen enough patients to get the exposure and the comfort with treating these patients."**

**At right, Carly and Jill Dolan**

Fragile X. It's more than 99 percent accurate, according to the National Fragile X Foundation.

In Jill's case, the testing revealed Carly wasn't the only one affected by Fragile X. The results showed Carly's condition originated with Jill's side of the family. Jill was a Fragile X carrier. That means she didn't have the full X chromosome mutation that Carly does, but instead a "pre-mutation" in her genetic makeup which put her at risk for developing a Fragile X-related disorder.

Jill was eventually diagnosed with FXPOI that causes symptoms similar to early menopause.

She was then diagnosed in her late 40s with another carrier disorder, FXTAS, that would eventually lead her to care at the Parkinson's and Movement Disorders Center.

It was the kind of discovery that often happens with family members after a child is diagnosed with Fragile X, says Stephanie Bissonnette, D.O., MPH, a VCU assistant professor of movement disorders who treats people with Fragile X and ataxia.

"We don't often think about associated diagnoses like Fragile X-Associated Tremor/Ataxia Syndrome until a child has been diagnosed (with Fragile X Syndrome)," Bissonnette says. "But it may have been in the family for generations before that."

That was the case with Jill's family. Testing also revealed her father — Steve — was a Fragile X carrier just like Jill. He was then diagnosed with FXTAS when he was around 65 years old.

"He showed no signs. But as you age, you are at higher risk for it," Jill says. "And within a couple of years after learning he was a carrier, he started showing signs."

The family got in touch with the National Fragile X Foundation, which led them to the MIND Institute at University of California Davis Health where top researchers have been working to unlock answers about Fragile X and associated disorders. The family started traveling to the West Coast to take part in research trials and studies and to receive treatment from Randi Hagerman, M.D., and her husband, Paul Hagerman, MD, Ph.D., the team who discovered the existence of FXTAS.

## One email leads to PMDC — and home

Jill's Fragile X-related ataxia affects her movement, memory, executive functioning and balance. She's had at least one serious fall.

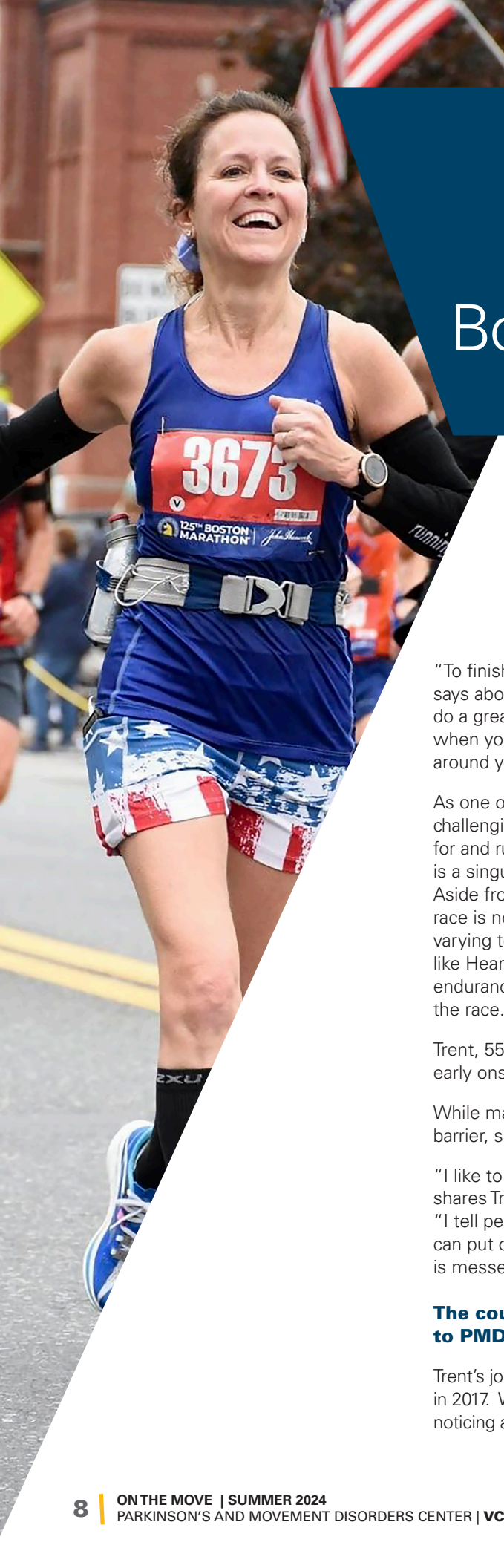
Ready to receive care close to home, she looked up the PMDC and sent an email directly to Director Brian Berman, M.D., M.S. She described her FXTAS diagnosis and how she had been out to the MIND clinic and had seen the Hagermans.

"(Berman) wrote back and said 'I went to medical school with the Hagermans' daughter,'" Jill says. "Dr. Paul Hagerman was also his professor."

Berman also said there was someone on the PMDC team — Bissonnette — who was familiar with FXTAS and could treat Jill, who was thrilled to finally find a provider in her area who knew about her — and her family's — condition.

Berman got Jill in contact with Bissonnette, who has a background in treating people with Fragile X and ataxia.

**—continued on page 12.**




# Grit, determination and personalized care make PMDC patient's 2nd Boston Marathon possible

*By Dan Carrigan*

WHILE DISNEY WORLD HOLDS ITS CHARM, RENEE TRENT SAYS THE MOST MAGICAL PLACE ON EARTH IS ABOUT 550 MILES NORTH.

"To finish the race is just magical," Trent says about the Boston Marathon. "They do a great job there in Boston, that when you finish it, there's always people around you."

As one of the most prestigious and challenging races in the world, qualifying for and running the Boston Marathon is a singular life achievement for many. Aside from the entry criteria, the race is notoriously difficult, featuring varying terrain and infamous sections like Heartbreak Hill that tests runners' endurance with a steep incline late in the race.

Trent, 55, has run Boston twice — with early onset Parkinson's disease.

While many may view the condition as a barrier, she doesn't see it that way.

"I like to make light of my Parkinson's." shares Trent, who is from Lynchburg, Va. "I tell people I can run a marathon, and I can put out all the pain because my brain is messed up!"

## The course from Lynchburg to PMDC

Trent's journey with Parkinson's began in 2017. What started as loved ones noticing a tremor in her right hand led to a diagnosis and an unexpected patient journey. Initially, she struggled to navigate the health care system and sought out the right doctor who could understand her unique needs as a young onset patient.

"When I was diagnosed, the doctor here in Lynchburg looked at me and said 'I have zero young onset patients,'" Trent recalls.

Undeterred, she sought out specialists who could provide the level of care she needed. Through perseverance and determination, she finally found a supportive neurologist in PMDC Director Brian Berman, M.D., M.S. He not only treated her condition, but also shared her passion for running.

"We've worked for a while to keep her treated as well as possible, so that she can continue to stay active, which we know can help slow the disease down," Berman says.

"He understood the physical parts of running a marathon and the pull on your reserves and your energy and everything," Trent explains. "He really was able to say, 'Well, how about if we tried this?'"

"The medication only works for four hours. So, as you well know, I'm not finishing a marathon in under four hours," Trent adds.

### Trent's First Boston Marathon in 2021

To manage her condition, running became more than just a hobby for Trent — it became a form of therapy and a way to reclaim control over her life. Encouraged by friends and other patients online, she set her sights on qualifying for the Boston Marathon.

"I had started running, a lot," Trent explains.

Around that time, her training plan consisted of a combination of long runs, speed workouts, and strength training sessions. Berman, meanwhile, was there to offer health care and medication to manage her condition.

In 2021, she qualified as an adaptive athlete for her first Boston Marathon.

With miles of running in the hills and mountains of Virginia behind her, she took on the grueling course. The result? A 3:52, sub-4-hour marathon that in any other race would have secured her spot without an adaptive athlete designation.

"She just keeps going and finding new, bigger challenges," Berman says. "I'm just very, very impressed by her."

### 'Boston Marathon does not reach out to people'

Despite rarely communicating directly with would-be runners, organizers of the Boston Marathon emailed Trent to see if she'd be interested in running again in 2024 as a para-athlete. Parkinson's patients could run under the new classification.

"I was like, 'Oh my God, you actually received a proactive email from the Boston Marathon,'" Trent recalls.

Turns out, the Boston Marathon didn't have enough para-athletes participating and invited Trent to run in the division.

"When I saw that, I was just like, I mean, this is groundbreaking," Trent says.

However, to take on Boston a second time, she'd need to find the strength to train quickly and overcome flaring symptoms.

"I really didn't train as well because, obviously, I didn't have enough time. But I also have been having a lot more symptoms," Trent explained.

Despite these challenges, she had a goal in mind.

"But you know, the answer was: I was going to go, and I was going to finish," she says. "That was always going to happen, it was going to happen regardless."

But race day conditions proved challenging, including a warm Boston day. Trent also faced challenges during the race related to her Parkinson's symptoms.

"I did have some of my symptoms come. And I was kind of hunched over when I was running at first, but the medical team pulled me aside and said, 'Hey, we want you to kind of sit down and get your wits about you.' So, I sat down for 10 minutes. And the medical team let me go, and I finished with a 5:01 across the finish line."

### Extending an Invitation and Inspiring Others

Trent extended a heartfelt invitation to Berman to join her in her next Boston Marathon, should she decide to tackle the race again.

"As an adaptive athlete, I can run with a guide runner. And I told Dr. Berman, I said, 'You're going to go to Boston either as a runner or as my guide runner because you got to run Boston.'"

**"[Dr. Berman] understood the physical parts of running a marathon and the pull on your reserves and your energy and everything. He really was able to say, 'Well, how about if we tried this?"**

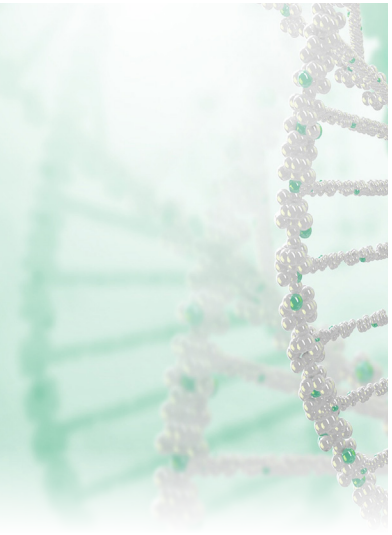
"I'd welcome the opportunity to lace up my running shoes to support Renee on another step of her inspiring journey," Berman says.

Trent — who also participates in races to raise funds and awareness for Parkinson's research — says she hopes to help those who supported her journey and to inspire others.

"If I can help one person understand what they have to do to live well, it's all worthwhile," Trent says. ■

# Revitalized genetics clinic expands testing, serves as statewide resource for patients and providers

*By Dan Carrigan*

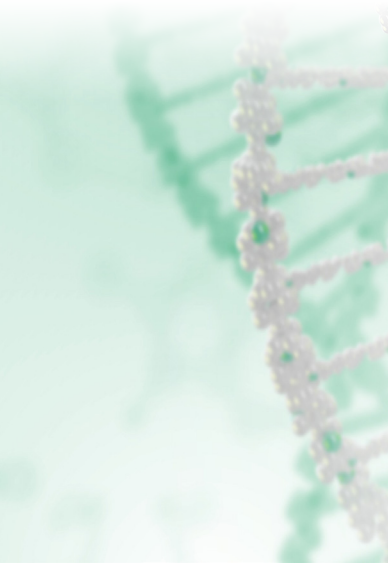


Earlier this year, the PMDC rolled out a new, reinvigorated genetics clinic — providing patients, families and health care providers enhanced support and knowledge surrounding Parkinson's disease and other disorders.

Ginger Norris, a licensed genetic counselor and research coordinator who has been a member of the PMDC since 2012, helped oversee and launch the renewed clinic. Norris holds a master's degree in Genetic Counseling (MGC) and is a genetic counselor certified by the American Board of Genetic Counseling.

"I do what I do because I love genetics. And I think it is such an integral part of everybody's health story," Norris says.

**"Everybody who wants genetic testing should meet with a genetic counselor to understand the implications and what genetics can tell them — and not tell them — before they get testing, so that they are the most informed users."**



The clinic, initially focused on Huntington's disease, expanded its offerings earlier this year under the leadership of Stephanie Bissonnette, D.O., MPH. As part of the renewed focus, the genetics clinic offers testing for Huntington's disease, Parkinson's disease and ataxia. Patients access the clinic through referrals from health care providers or by seeking information online and contacting the clinic directly.

"Doctors across the state refer to us, but patients also look us up and find us. It's patients who are largely presymptomatic but they know it runs in their family that contact us. Others are people who say, 'I think I might have X condition, and I should come in and get tested,'" Norris says.

Housed out of the PMDC's Short Pump location, the clinic serves patients on an outpatient basis with the potential to expand as demand grows. Norris says the field of genetics can be complex, which is why the clinic is structured to allow extra time so that patients can receive a crash course on the field and what it means for them.

"Everybody who wants genetic testing should meet with a genetic counselor to understand the implications and what genetics can tell them — and not tell them — before they get testing, so that they are the most informed users," Norris says.

Genetic testing for Parkinson's disease and other movement disorders involves analyzing an individual's DNA to identify specific genetic mutations or variations that may contribute to the development of these conditions. Through a simple blood or saliva sample, genetic testing can provide valuable insights into a person's genetic predisposition to these disorders. While not all cases of Parkinson's disease or movement disorders have a genetic basis, identifying genetic factors can help in understanding disease risk, prognosis, and potential treatment options.

Research also plays a significant role in the clinic's activities. "We're involved in a Parkinson's study sponsored by the Parkinson's Foundation," Norris shares. "We're trying to really understand the genetics behind Parkinson's disease. What are all the different genetic players? How do these genes interact? What's causing them to cause Parkinson's disease?" Norris says.

For Norris, the clinic is a symbol of a deep commitment to patients, embracing and charting the course for the future of the genetics field.

"At this point, we're building the pathway to very individualized care based on your genetic change," Norris says. ■

Madison Clemons

# A passion for research and a candid email brings new clinical research coordinator to PMDC

*By Dan Carrigan*

Madison Clemons' journey to the Parkinson's and Movement Disorders Center (PMDC) began with a single bold step: a cold email to Leslie Cloud, M.D., Director of the Parkinson's Disease Program at PMDC.

In the note, Clemons — who'd never met Cloud — expressed her fervent interest in clinical research. Her proactive approach yielded fruitful results when Cloud responded with enthusiasm, ultimately paving the way for Clemons' successful application to the position of Clinical Research Coordinator.

"I remember holding my breath for a second before hitting 'send' on that email to Dr. Cloud," Clemons recalls. "It felt like a leap of faith, but her positive response was incredibly validating. It's a reminder that sometimes taking that initial step can lead to extraordinary opportunities."

In February, the PMDC welcomed Clemons as the newest addition to the clinical research team. Clemons, a graduate of Virginia Tech with a bachelor of science degree in biological sciences, brings a wealth of knowledge and enthusiasm to her role. Prior to joining VCU Health, she earned her certification as a clinical medical assistant and gained valuable experience working with neurological patients at TPMG Neurology at Williamsburg.

In her PMDC role, Clemons works closely with Matthew Barrett, M.D., serving as one of the team's six clinical research coordinators at the leading research center. She oversees various clinical research activities, including conducting study visits, obtaining Institutional Review Board (IRB) approvals, liaising with trial sponsors and patient recruitment. Clemons also plays a crucial role in managing multiple trials.

"I just feel very grateful for this opportunity to hopefully advance science in medicine because I'm passionate about that but then also to be able to work with these patients that you just develop this relationship with," Clemons says.

As Clemons settles into her role, she looks forward to contributing to the center's mission of advancing knowledge and improving patient outcomes. She encourages others to recognize the caliber of research happening at VCU, emphasizing the institution's commitment to excellence and patient-centered care.

"I believe that patient care goes beyond the confines of medical treatment — it's about building meaningful connections and providing support every step of the way," Clemons says.

"I'm honored to be part of a team that prioritizes patient well-being and strives to make a difference in their lives. Each interaction with patients reinforces the importance of empathy, compassion and dedication in health care." ■

# PMDC monitors, celebrates progress of National Plan to End Parkinson's Act

*By Dan Carrigan*

The PMDC this year has been closely tracking the progress of the Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act — a landmark piece of legislation aimed at prioritizing research funding, streamlining treatment approvals and enhancing care standards to combat Parkinson's disease.

Introduced in the U.S. House of Representatives in 2022, it marked Congress's inaugural focus on legislation dedicated to curing and preventing Parkinson's disease as well as ensuring quality care, according to the American Parkinson Disease Association (APDA).

Virginia has played a pivotal role in recent legislative victories. Representing Virginia's 10th District, Wexton collaborated with Parkinson's advocates statewide and the APDA's Virginia Chapter.

"It's heartening to witness the congressional focus and support dedicated to addressing the challenges posed by Parkinson's disease," "says PMDC Director Brian Berman, M.D., M.S.

"As we vigilantly monitored the progress of this legislation in 2024, we're reminded of the collective determination to improve the lives of those affected by Parkinson's and drive advancements in research and care."

The comprehensive legislation calls for establishing an advisory council to unite the Parkinson's community — patients, caregivers, providers, advocates and more — with federal officials to develop strategies for eradicating Parkinson's.

Key elements also include seeking increased funding for research, streamlining treatment approval processes, raising public awareness and nationwide enhancements to early diagnosis. ■

**Editor's Note: At the time of publication, the legislation had cleared the House and Senate and awaited President Joe Biden's signature.*

## Dolan Family, continued from page 7

"It can be hard to find specialists who understand and treat ataxia," Bissonnette notes. "Because ataxias are rare, it takes a long time to have seen enough patients to get the exposure and the comfort with treating these patients."

The PMDC has about 50 patients with ataxias, a number that has been on the rise, Bissonnette says. She adds that the center hopes to eventually start a multidisciplinary clinic for those patients where they can get different treatments and therapies they need for their condition.

### Patients turned advocates to help families across Virginia and beyond

In addition to taking part in numerous studies that help researchers better understand their conditions, Jill, her father and Carly have all been to Capitol Hill on behalf of the National Fragile X Foundation to urge lawmakers to provide funding for research and to pass legislation that supports people like them who have rarely diagnosed disorders.

Carly's first Capitol Hill event was actually a unique virtual experience in the COVID-19 era, when she spoke as a self-advocate for people with Fragile X.

"She's always been very, very shy, which can be a part of Fragile X Syndrome and females," Jill Dolan says. "And she just rocked it."

Since then, Carly has participated at additional in-person advocacy events at the Virginia State Capitol in Richmond and on Capitol Hill in Washington, D.C.

### Forging a new path spreading awareness of early detection and support

Jill advocates for more people to get a simple blood test that can uncover a Fragile X diagnosis, the kind of information that can be used to treat it earlier in families who may have no noticeable symptoms and no idea the disorder is in their genetic makeup.

Carly, meanwhile, is a member of the Young Adult Rare Representatives that supports youths who have rare disorders. And Carly has also shared her Fragile X experience with "Remember the Girls," a group for females with X-linked disorders.

"Your disability should not define who you are as a person," Carly wrote in a 2023 post for the group. "I wouldn't be where I am today if I didn't push myself outside of my comfort zone to try new things."

Jill now has peace of mind that she's able to be treated closer to home by Bissonnette, a provider with a background in treating ataxia and Fragile X-related health challenges.

"It just feels very uplifting and encouraging," Dolan says. "It's great to have someone to check in with who is knowledgeable about the most recent research and meds and therapies." ■

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Philanthropy plays an important role in bolstering our multidisciplinary clinical team, funding innovative research and supporting our training and outreach efforts. For information about how you can support the VCU PMDC, please contact the Neuroscience Development Team at 804-628-8287 or vcuhealthdevelopment@vcuhealth.org.

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