On the Move

SUMMER 2025

Parkinson's and Movement Disorders Center

VCU Health™

Partnerships and growing with purpose to meet the needs of our patients and community

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

> **"As we look to the future, we plan to keep growing with purpose. That means expanding access to care, launching new studies, training more specialists, and staying focused on what matters most — meeting the needs of our patients and their families."**

ON THE COVER: Read the story and watch the video featuring cover photo patient Bill Hicks.

Article by Tim Shea, VCU Medical Philanthropy and Alumni Relations; Photos by Daniel Min, MCV Foundation; Video by Tyler Trumbo, MCV Foundation

Each day at the VCU Parkinson's and Movement Disorders Center (PMDC) I'm reminded of what makes our mission so meaningful, and our progress possible. We're caring for people with complex neurological conditions and working to better understand the diseases they live with. Through our commitment to these goals, we're collectively building a center that brings a community together with one focus: improving lives.

The work of the PMDC spans multiple areas — clinical care, research, education and outreach. And our team takes an integrated approach to tackling each, which is centered on the people we serve.

I am honored to share that our center continues to grow. We're seeing more patients, expanding our team and launching new programs. We now have more than 6,000 outpatient visits each year and provide multidisciplinary care that includes physical, occupational and speech therapy, as well as neuropsychology, nursing and social work. That's important because the conditions we treat often affect multiple aspects of a person's health, and coordinated care is essential to delivering effective treatment.

We have recently been named a **Lewy Body Dementia Association Research Center of Excellence,** a designation that reflects years of work by our team and a clear need in the community. This Center of Excellence recognition affirms the strength of our clinical and research programs and underscores the commitment our team has made to improving care for people living with Lewy body dementia. In support of the team's work, the PMDC is welcoming a cognitive neurologist to VCU, Trey Bateman, M.D., who will work closely with our Lewy body dementia program and support both patient care and research.

As we've grown in expertise, we've also focused on building access to new treatments. One of the most exciting recent developments has been our use of **subcutaneous dopamine pumps,** which can deliver dopamine medication for Parkinson's disease steadily under the skin throughout the day. For patients like Kellie Dalton, it's made a real difference. She shared that she's now able to do things she hadn't been able to in years.

Our team is also studying the connection between **sleep and brain health** through a long-running research project that looks at how disrupted sleep may contribute to cognitive decline in people with Parkinson's. That study has brought together experts from neurology, engineering, public health, nursing and beyond. Participants like Ken Konopky have told us how much they value contributing to something that may help others in the future.

We're also continuing to invest in research across VCU through our **PMDC Pilot Grants Program.** These grants help early-stage investigators pursue new questions in the movement disorders field and collect preliminary data that can lead to larger projects and funding opportunities. We also host an **Annual Research Symposium** where we share findings from these projects and other studies relevant to movement disorders being conducted around VCU and celebrate what's being accomplished.

Education and community outreach are another big part of what we do. In April, we partnered with **Power Over Parkinson's** to host **Parkinson's Education &**

Empowerment Day. More than 150 people attended the event, which focused on helping patients and caregivers take an active role in managing Parkinson's. Margaret Preston, president of Power Over Parkinson's, helped lead the day and continues to be a strong partner in our shared efforts to improve education and support.

We also continue to support caregivers. Our support group called **TOAD** (The Other Additional Dementia) gives caregivers of individuals with Lewy body dementia a space to learn from each other and speak with experts. People like Debbie Bryant, who cares for her husband, Bill, have shared how helpful the group has been. Caregiving can be isolating, and we want to ensure caregivers know they're not alone.

Another important part of our work is training. This summer, we're welcoming our third **movement disorders fellow,** and we continue to provide mentorship to students from across the educational spectrum. We even had two high school interns, Carson Spicer and Ella Kraft, spend the year with us learning about clinical care, outreach and research.

We've also seen strong outcomes from our **speech therapy program,** where we're helping patients regain their ability to speak clearly and be understood. Many people with Parkinson's experience voice problems that can affect confidence and connection with others. Our Parkinson's-focused speech programs offer targeted therapy that helps people feel heard again.

None of this happens without strong partnerships. That includes partnerships across VCU and VCU Health, with community organizations and with donors who support our research, education and patient programs. Their engagement allows us to take on new challenges and respond quickly when needs arise.

When I first arrived in Richmond five years ago, I quickly learned that this is a place where people want to be involved. That spirit is clear across our programs, and it's what makes this work so fulfilling. We're building something here with people who are invested in making life better for individuals and families living with movement disorders.

As we look to the future, we plan to keep growing with purpose. That means expanding access to care, launching new studies, training more specialists, and staying focused on what matters most — meeting the needs of our patients and their families.

Thank you for being part of this work. We're proud of what we've built together, and we're excited about what the future holds. ■

PMDC named a Lewy Body Dementia Association Research Center of Excellence

By Sean Gorman

The VCU Parkinson's and Movement Disorders Center (PMDC) is now officially recognized as a Lewy Body Dementia Association (LBDA) Research Center of Excellence, a designation that boosts the PMDC's efforts to unlock more answers on treating the neurodegenerative disease.

The center is now the only one in Virginia that has that designation from the LBDA, a national nonprofit organization dedicated to improving the lives of those living with Lewy body dementia.

PMDC Director Brian Berman, M.D., notes that becoming a Lewy Body Dementia Association Research Center of Excellence is the latest distinction bestowed on the center. The PMDC has also been named a Center of Excellence for treating Parkinson's disease, Huntington's disease and Multiple System Atrophy and is also recognized as a Center of Care for people with Progressive Supranuclear Palsy.

"The research center of excellence distinction is a well-earned recognition of the expertise that the VCU PMDC offers in seeking groundbreaking, evidence-based treatments that better the lives of people living with Lewy body dementia," Berman says. "I'm proud of everyone on the team who secured this honor, which

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PMDC's designation as a Lewy Body Dementia Association Research Center of Excellence is the most recent distinction recognizing the center's extraordinary work in patient care and research to help individuals living with movement disorders.

Brooke Dexheimer, Ph.D.

Study examines how hand preference might influence impact of Parkinson's symptoms

By Sean Gorman

Whether you're left-handed or right-handed might do more than shape daily routines — it could help researchers better understand, screen for and treat Parkinson's disease.

That's the idea behind a study Brooke Dexheimer, Ph.D., is conducting on how hand preference might impact the daily life of a patient in the early stage of Parkinson's.

"We're interested in the really early stages of Parkinson's disease, when those motor symptoms are pretty subtle — tremor, rigid muscles, and so on — and lead to changes in movement that prompt people to seek out a neurologist," says Dexheimer, who is pursuing the research in partnership with the Parkinson's and Movement Disorders Center (PMDC). "We think the symptoms may look the same in each hand, but the ways they impact your day-to-day life are different."

That varying impact could stem from each hand's unique role when doing joint tasks — with the dominant hand accomplishing a task as the non-dominant hand stabilizes an object, Dexheimer says. For example, someone might use their non-dominant hand to hold a glass steady as their dominant hand pours water into it from a bottle.

Dexheimer, a VCU assistant professor of occupational therapy at the College of Health Professions, notes previous research by PMDC neurologist Matthew Barrett, M.D., indicates that people who have initial symptoms in their non-dominant hand generally are diagnosed more quickly than those whose first symptoms arise in their dominant hand.

"We'd all kind of intuitively think that if we had a tremor, if we had some issue with our dominant hand, we'd be quicker to notice and seek out our physician who would send us to a neurologist," Dexheimer says. "But actually, the research suggests otherwise: that people with non-dominant symptoms are the ones who are quicker to get diagnosed."

That might be because a common symptom of Parkinson's, like a tremor, might be more noticeable in a person's non-dominant hand as it's being used to stabilize an object, she says.

"Maybe there's something about the non-dominant hand or its specialization that's more disrupted," Dexheimer says. "That's our guess."

Dexheimer is pursuing the research through the C. Kenneth and Dianne Wright Center for Clinical and Translational Research that oversees the K12 Mentored Career Development Grant funding this research. These grants, funded by the National Institutes of Health, support early-career researchers like Dexheimer who are seeking answers that can help guide clinical treatment.

One part of the study is also examining whether current Parkinson's assessments are adequately picking up on the fine motor skills deficits in a patient's dominant and non-dominant hands.

Working with the PMDC, Dexheimer is enrolling patients in the early stages of Parkinson's. They will each work on two iPad tablets and a pair of Apple Pencils attached by a rubber band. Study participants will hold one stylus on one tablet screen and then use the other stylus to draw on the other tablet.

> **"We think the symptoms may look the same in each hand, but the ways they impact your day-to-day life are different."**

"This tablet task we programmed is meant to mimic the way our hands work together on functional tasks," she says.

This is a collaborative project pursued by Dexheimer and PMDC Director Brian Berman, M.D., who is serving as her primary mentor.

"He's overseeing the project and sharing his expertise," Dexheimer says. "He has that insight into this population and the subtlety of their fine motor symptoms. So he's been a guiding light for me in terms of pointing me in certain directions."

Peter Pidcoe, Ph.D., VCU's director of Engineering and Biomechanics Lab, and Dean Krusienski, Ph.D., director of VCU's Advanced Signal Processing in Engineering and Neuroscience Lab, are also mentors on the project. Barrett, the PMDC neurologist, is collaborating on the research as well.

"Our team consists of experts in occupational therapy, physical therapy, neurology and biomedical engineering. It's a project that spans across a lot of fields," Dexheimer says.

Dexheimer was drawn to Parkinson's research by a personal connection: her uncle lives with the disease, and her aunt passed away after being diagnosed with Parkinson's.

"For me, it's personal. But beyond that, it's one of the more common neurological disorders," she says. "Everyone I've talked to knows someone who's had it. So it feels like the work we're doing can have more of a direct impact, hopefully quicker." ■

Parkinson's Education & Empowerment Day offers insights for navigating treatment options

By Sean Gorman

About 150 patients, family members and caregivers gathered at this year's Parkinson's Education & Empowerment Day for insights on how they can take control of their journey with the disease.

Sponsored by the VCU Parkinson's and Movement Disorders Center (PMDC) and the Power Over Parkinson's nonprofit group, the April 12 event featured speakers from the PMDC and beyond offering expertise on the steps patients can take towards better health and how to track down reliable sources of information in the field of Parkinson's care.

"It was such a treat to be able to energize people around empowering themselves and being active, taking their diagnosis into their own hands and equipping them with information so they can hopefully live a fantastic life and live well with Parkinson's," says Margaret Preston, the president of Power Over Parkinson's.

Daniel Corcos, Ph.D., a professor of Physical Therapy and Human Movement Sciences at Northwestern Medicine's Feinberg School of Medicine, gave the keynote presentation at VCU's Larrick Student Center. Corcos guided attendees through the key benefits that exercise provides in boosting wellness for those living with the movement disorder. Additionally, Corcos offered a "prescription" of sorts for attendees to consider.

That insight included a regimen of weight training twice a week, endurance training three times a week, flexibility training several times a week and neuromotor and balance training once or twice weekly for people able to perform those activities. As a result of the event, Preston says Power Over Parkinson's has received additional inquiries from some attendees interested in taking part in the group's High Energy Amplified Training (HEAT) exercise program that was modeled on Corcos' research.

Leslie Cloud, M.D., director of the Parkinson's Disease Program at the VCU PMDC, offered tips on how attendees can find reliable information about the disorder.

"We live in the information age — with an ocean of information at our fingertips, but not everything you read on the internet is true," Cloud says. "I wanted to help patients critically evaluate the sources of the information they consume about Parkinson's so that they won't get dragged down the wrong rabbit holes."

Cloud's advice: be skeptical and don't believe everything you read about the disease.

"Always consider the source, their motivations/goals in producing the content, their credentials, the references, and so on," Cloud adds.

Antonio Abbate, M.D., Ph.D., a cardiologist and professor at UVA Health, worked to "demystify clinical trials" for people interested in taking part in that research, but who are also put off by the medical jargon used in those studies as well as common hurdles involved in taking part in them.

Ginger Norris, a PMDC genetic counselor and clinical research coordinator, says that in addition to the insights from all the speakers, the Education & Empowerment Day offered attendees the opportunity to make connections and build community with others facing some of the same issues in dealing with the disease.

"I think that one of the best supports for people is knowing others who are going through the journey and sharing tips amongst themselves," says Norris, who worked on the event's planning committee. "It makes you feel less isolated. It normalizes your condition a little bit. I think the sense of community really empowers people." ■

AWAKENING HOPE

The critical role sleep plays in brain health

How a VCU Parkinson's and Movement Disorders Center sleep study offers new insights and optimism for patients

By Tim Shea, VCU School of Medicine

When Ken Konopky was diagnosed with Parkinson's disease at age 54, his life shifted dramatically. What began as minor gait issues soon evolved into tremors, vivid and sometimes violent dreams and cognitive challenges. By age 61, the former supply chain analyst found himself grappling with both the symptoms of Parkinson's and the uncertainties of living with a progressive neurological disorder.

A self-described heavy sleeper who "hardly ever dreamed," Konopky's concern grew when his dreams blossomed into experiences that caused him to fall out of bed or think he was climbing out a window or down a ladder. With his expanding set of symptoms also came an equally expansive curiosity to understand his condition.

"I'm not going to sit at home and ask, 'Why me?'" Konopky says. "I'm going to live my life the best I can and find ways to adapt."

That drive brought him to the VCU Parkinson's and Movement Disorders Center (PMDC), where he found more than a team of physicians — he found a partner in his journey. One opportunity stood out: participation in a sleep study led by Brian Berman, M.D., director of the PMDC and an expert in the intersection of sleep and neurodegeneration. For Konopky, the study offered both insights into his condition and hope for others.

"I've always believed that knowledge is power," Konopky says. "When I see an opportunity to learn more about Parkinson's, I jump at it."

The sleep study: A window into neurodegeneration

The study, which Berman formally launched in 2019 with initial funding from the Parkinson's Foundation, investigates the critical role sleep plays in general brain health as well as its implications for neurodegenerative diseases like Parkinson's.

At its core, the research being led by Berman and his team aims to unravel a complex cycle experienced by many patients living with Parkinson's: disrupted sleep increases neuroinflammation, leads to memory and other cognitive impairments and hinders the brain's ability to clear toxins, potentially leading to accelerated neurodegeneration.

Central to the study is the glymphatic system, a network of vessels in the brain responsible for clearing waste that's often described as an "oil change" for the mind. Discovered in 2012, the glymphatic system operates most efficiently during deep, uninterrupted sleep.

"Sleep isn't just about rest," explains Berman, a professor in the Department of Neurology. "It's a time when the brain performs critical maintenance. Without good sleep, the risk of neurodegenerative diseases increases."

Combining advanced imaging techniques, blood biomarker analysis and cognitive testing, the study investigates how sleep fragmentation affects brain structure and function, toxin clearance from the brain and cognitive function in Parkinson's patients compared to healthy control subjects.

For people with Parkinson's, a good night's sleep can feel out of reach. Restless nights filled with vivid dreams, frequent wake-ups and daytime exhaustion are common, while symptoms like stiffness and dream-enacting further disrupt precious rest.

Early findings suggest that differences in biomarkers and toxin clearance are observable after just one night and that patients with more fragmented sleep show reduced cognitive performance and higher levels of neuroinflammation.

Berman's team has also uncovered significant differences in sleep efficiency and quality between Parkinson's patients and healthy controls. They've documented that non-REM sleep — which is essential for memory storage and retrieval — is disrupted in patients with mild cognitive impairment, a precursor to dementia, more than those patients with normal cognitive function.

Empowering patients through research

For Konopky, participation in the study has been transformative. The experience offered clarity about his condition and underscored the compassionate care he receives at VCU.

"Dr. Berman spends time answering my questions, often with students present," Konopky says. "It's not just about treating me. It's about educating the next generation of doctors, too."

"In my past life as a business analyst, I loved learning and problem-solving," Konopky says. "This study gave me a chance to understand my condition better and feel like I was part of something bigger. It's a positive experience, and it gives me hope."

Konopky has also found ways to bring his generosity of spirit beyond the study. He has spoken on frequent occasions to VCU pharmacy, nursing and physical therapy students, sharing his experiences to help future health care providers understand the human side of Parkinson's.

"It's about making connections," Konopky says, "and showing people that even with this illness, you can live a meaningful life."

A lasting and widening legacy

Berman holds the Bemiss Endowed Chair, a philanthropically-funded faculty position named in honor of the late Margaret and Fitzgerald "Gerry" Bemiss. The couple's advocacy and determination to find answers for patients and families were instrumental in both establishing the PMDC and recruiting Berman to VCU.

"Every breakthrough starts with a question," Berman says. "The Bemiss Chair provides me the financial support to both see patients in clinic and explore meaningful research questions with the goal of translating discoveries into better outcomes for patients."

The 2007 gift to establish the chair continues to fuel discovery and collaboration at the PMDC and across VCU. For the sleep study, a clinical research coordinator conducts the imaging and cognitive testing, and the sleep study is completed at the VCU Center for Sleep Medicine.

Experts in the College of Engineering and the School of Public Health work alongside Dr. Berman to provide complex data analysis essential to drawing meaningful and accurate conclusions. Faculty in the School of Nursing also play a crucial role by supporting the team's blood biomarker analysis.

Looking ahead, Berman is interested in developing a longitudinal study to explore how sleep patterns influence cognitive decline, and he sees potential for testing interventions such as neurostimulation during sleep to enhance toxin clearance and possibly slow neurodegeneration. Another promising avenue is the development of home-based sleep monitoring technologies, which could make the research more accessible to a wider range of participants.

While the study's immediate goal is to understand the link between sleep and neurodegeneration, its long-term potential excites Konopky.

"VCU has given me incredible care and the opportunity to learn," Konopky says. "I'm grateful to be part of something that's changing lives, and I'm optimistic about what's ahead." ■

To learn more about supporting the VCU Parkinson's and Movement Disorders Center, contact Bernadette O'Shea, senior director of development, at osheab@vcu.edu.

To learn more about the sleep study discussed in this story, contact Caileigh Dintino, clinical research coordinator, at pdcenter@vcuhealth.org.

PMDC Lewy Body Dementia support group offers resources and reassurance for caregivers

By Sean Gorman

Looking back, Debbie Bryant recognizes some of the early signs that indicated her husband Bill was struggling with Lewy body dementia (LBD).

"My husband would have trouble coming up with words," says Debbie, who lives with Bill in Glen Allen, Virginia. "So he would make up his own. There was definitely something wrong with him."

Bill also had "really bad nightmares," she says.

Since he's a Vietnam veteran, Bill's nightmares were initially thought to be the result of PTSD. But Lewy body dementia can also cause the kinds of sleep disruptions Bill was experiencing. Before seeking care at VCU Health, Bill underwent testing and went on a series of medications. Nonetheless, the root cause of his symptoms remained elusive.

"We went through two or three years in a haze really because he just wasn't himself," Debbie says.

Eventually, Bill was diagnosed with Lewy body dementia in 2019. After that, the couple's care journey led them to the VCU Parkinson's and Movement Disorders Center (PMDC).


Debbie and Bill Bryant

But Bill, 75, isn't the only one receiving support at the center. In addition to seeing a PMDC counselor to cope with caregiving challenges, Debbie is also part of a support group at the center for people like her who are themselves supporting a loved one with Lewy body dementia.

Caring for Caregivers

Following Bill's diagnosis, Debbie sought out Facebook groups for LBD. During an office visit with Matthew Barrett, M.D., Bill's PMDC neurologist, she learned about the center's caregiver support group, which is called The Other Additional Dementia (TOAD).

"He asked if I would be interested in attending, and I said 'definitely,'" she says.

Barrett says the support group offers caregivers coping strategies and the knowledge that others are facing the same challenges they are.

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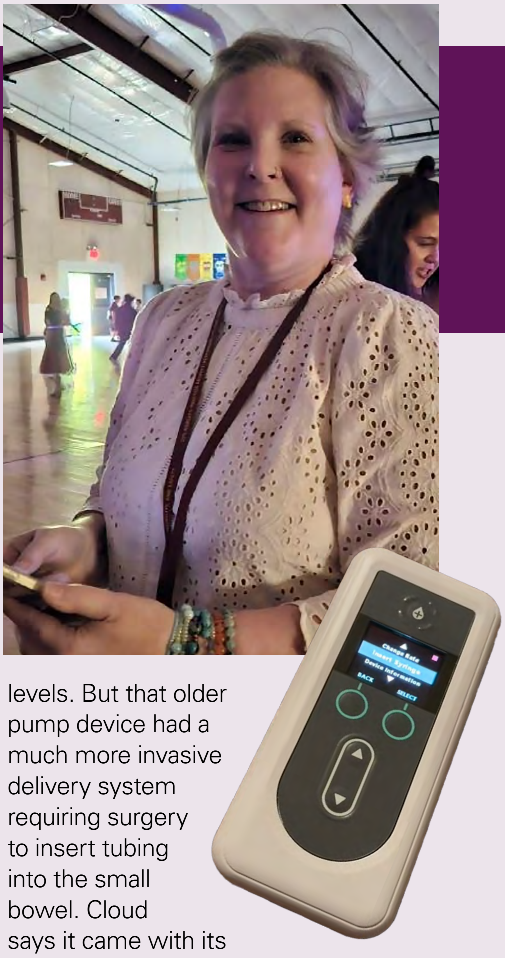
Dopamine pump treatment offers life-changing impact for patient

By Sean Gorman



Kellie Dalton hasn't been consistent over the years in taking the pills prescribed to control her Parkinson's symptoms.

Those pills boost her dopamine, a neurotransmitter produced in the brain that's crucial to motor control. People with Parkinson's have far lower levels of dopamine that contribute to the kinds of symptoms Dalton first started experiencing more than a decade ago.

For example, she couldn't use her right hand to wave. She also couldn't use her right foot to operate her riding lawn mower, and her right arm had curled in. But she found the pill regimen onerous, and the medicine made her feel sick.

"I would take my morning medication, but I wouldn't always take the afternoon or evening medication," says Dalton, 54, of Burkeville, Virginia. "They made me feel really nauseous, so I didn't want to take them. They made me feel worse than the Parkinson's did."

With her inconsistent record taking her pills, Dalton was a good candidate for a newly approved pump that can consistently regulate dopamine levels — and lessen symptoms. For Dalton, the device has had a life-changing impact.

A "game-changer"

Dalton is among the roughly half-dozen patients at the VCU Parkinson's and Movement Disorder Center who are using the VYALEV pump that the Food and Drug Administration approved in October 2024.

The VYALEV device administers Levodopa — a drug that converts into dopamine after it makes its way into a patient's brain — following a skin infusion. Leslie Cloud, M.D., director of the PMDC's Parkinson's Disease Program, says the pump offers doctors a valuable tool for alleviating a patient's symptoms.

"It's going to be a game-changer for a lot of people," Cloud says. "We already have some experience using it at the center, and that experience has been overwhelmingly positive."

For decades, doctors have used various means of delivering Levodopa into Parkinson's patients whose dopamine-producing brain cells have died off.

"If you think of your body as an automobile, dopamine is the gas pedal," Cloud explains. "It's what enables you to move successfully."

Parkinson's patients have long taken the drug orally or by inhaling it, but those approaches have resulted in fluctuating dopamine levels as the drug dissipates in the body, Cloud explains.

"Therefore, their symptoms are on a roller coaster around the clock too," she adds.

But the VYALEV pump offers 24 hours of stable dopamine levels as Levodopa is infused through the skin around the clock, she adds.

"It provides better, more consistent symptom control, and it does that without having to undergo any kind of surgery," Cloud says.

That skin infusion pump treatment has actually been widely available in Europe and other parts of the world for more than a decade, but only recently in the U.S., Cloud notes.

Prior to the newly approved skin infusion pump, a previous pump treatment had been used to boost a patient's dopamine levels. But that older pump device had a much more invasive delivery system requiring surgery to insert tubing into the small bowel. Cloud says it came with its share of complications and wasn't effective or popular.

The VYALEV skin pump, on the other hand, is typically worn in a fanny pack with the skin infusions typically done on the abdomen. The makers of VYALEV say the device weighs less than a pound and is about the size of two cell phones stacked on top of each other.

A key benefit of the skin infusion pump is it can control a patient's overnight symptoms, allowing them to sleep, Cloud notes. Just having a restful night without waking up can have a direct positive impact on their symptoms, she adds.

"It's been a miracle"

During a doctor's visit with Dr. Cloud around the start of this year, Dalton asked if there was a pump option to consistently deliver her medicine.

"She was like, 'This was just approved,'" Dalton says. "Dr. Cloud got the ball rolling."

Dalton explains her device is kind of like a diabetic's insulin pump that administers medicine through injections on the skin of her stomach. And it didn't take long to see an impact.

Dalton chokes back tears recalling what her son, who was 15 when she was diagnosed 10 years ago, said about her just a month into using the pump.

"We were standing in the kitchen — and this always kind of makes me cry telling this story," Dalton says. "He says, 'she's the mom I used to have before Parkinson's. She looks like she used to when I was a teenager.'"

Dalton's face, once expressionless from Parkinson's, is softer and has begun to move again. She talks using her hands nowadays — like she did before her symptoms started. She no longer scrawls her signature.

"When I used to try to sign my name, I couldn't do it," she says. "I can write my name now. It looks pretty again. It's been a miracle."

Dalton's mom, a nurse who moved to Virginia to help take care of her, passed away in February shortly before she started using the pump.

"She would be so excited to see how well I'm doing," Dalton adds.

Dalton says life with the pump comes with some challenges. It's not particularly heavy, but she says it is bulky, likening its size to an old Walkman cassette player that she wears under her clothing throughout the day. And she's had skin infections at injection sites on her abdomen.

But even with those tradeoffs, she doesn't want to go without using it.

"My life is 100 times better," she says. "I know I still have Parkinson's. There are some things I just can't physically do. But there are so many more things I can do now that, three months ago, I couldn't do."

Last October, before she started using the pump, she went to a Taylor Swift concert in Miami with her daughter-in-law but couldn't sing.

Things are different now.

"I was playing Taylor Swift the other day cleaning the house," she says. "I was singing at the top of my lungs." ■

LBD Support Group, continued from page 7

LBD can be particularly demanding on caregivers given the range and complexity of symptoms, Barrett notes. It can cause motor control issues, hallucinations, sleep disruptions and autonomic symptoms like a sudden drop in blood pressure, he adds.

"The people taking care of the individuals who have these diseases have become isolated because of the needs of the patients," Barrett explains. "We don't have ways to slow this disease down or make it go away, unfortunately. But there are better ways to cope and manage with it. Providing an outlet where caregivers, who are often family members, can learn from each other, support each other and also learn from experts in the field outside of a clinic visit is a very valuable resource."

Laura Wadsworth, a community member and a nurse by training, volunteers as the co-facilitator of TOAD along with Bonnie Mahl, the PMDC's senior community engagement and outreach coordinator. Wadsworth and Mahl help lead discussions and organize the speakers who meet with the group. TOAD meets monthly, except for July and December, at the VCU Short Pump Pavilion, and caregivers can also attend virtually.

A Source of Support

Debbie, who started attending the support group more than a year ago, says it offers coping strategies as well as answers about medications and other aspects of LBD care. And it provides camaraderie for those who attend.

"It's good to know that there are other people who understand what you're going through," Debbie says. "It's important just to know that there's support if you need it, that there's somebody there."

Through the caregivers group, Debbie met Sarah K. Lageman, Ph.D., a PMDC neuropsychologist whom Debbie turns to for counseling while caring for Bill.

"She makes great recommendations," Debbie says. "With Lewy body dementia, you have these ups and downs. You just never know, and that's the worst part of it. You're always on edge."

In addition to the care she and Bill get at the PMDC, Debbie continues to turn to the caregiver support group for insights on how to deal with the disease's impact on the couple's lives.

"I think the main thing to know is that you're not alone," Debbie says of meeting with other caregivers. "It's very beneficial." ■

For more information about the PMDC's Lewy body dementia caregiver support group (TOAD), and other PMDC support groups, please contact Bonnie Mahl at Bonnie.Mahl@vcuhealth.org or scan the QR code here.

PMDC speech therapy program boosts communication, connection for people with Parkinson's and other disorders

By Sean Gorman

Along with causing tremors, muscle stiffness and other symptoms, a movement disorder can seriously hinder a person's ability to speak.

People living with Parkinson's and other diseases — like Progressive Supranuclear Palsy and Multiple System Atrophy — might talk with a raspy voice, stutter or speak so quietly that others can't tell what they're saying, notes Woodford Beach, Ph.D., a speech pathologist at the Parkinson's and Movement Disorders Center (PMDC).

"Very often in a social situation when you can't hear someone talk, you're probably not going to interact with them as much because you don't know how to politely say, 'I can't hear you,'" Beach says. "So people just won't talk with them."

But speech therapy at PMDC can help those living with Parkinson's and other movement disorders regain their voice — and maintain their connection with those around them.

Beach notes there's a significant need for speech therapy interventions. For example, while 80 to 90% of Parkinson's patients will eventually develop speech problems, only 5% get treatment for them, he says.

That wide disparity is due to many factors, including a person not realizing they have a problem, lack of motivation to undergo treatment, or not knowing what can be done about it, Beach says.

At the PMDC, speech therapists like Beach use different therapy approaches — known as LSVT LOUD® and SPEAK OUT!® — to elevate a patient's voice. LSVT stands for "Lee Silverman Voice Treatment" and is named after a woman who has Parkinson's, according to LSVT Global, the Arizona-based organization that runs LOUD.

Say it LOUD

Many of the patients who undergo PMDC speech therapy are Parkinson's patients whose disease has eroded their speaking volume.

There are a couple of schools of thought about why Parkinson's disrupts a patient's speech, Beach notes. One is that Parkinson's patients have lower levels of dopamine, a hormone and neurotransmitter produced in the brain.

> **... speech therapy at PMDC can help those living with Parkinson's and other movement disorders regain their voice — and maintain their connection with those around them.**

"So when they're not really thinking about it, they have insufficient dopamine to give the 'oomph' necessary to produce a loud voice," Beach says.

Another hypothesis is that a person living with Parkinson's has a "miscalibrated loudness meter" and incorrectly thinks their faded voice is still spoken at a normal volume, Beach adds.

To fix that, PMDC therapists offer LSVT LOUD® — an intensive therapy approach that requires patients to take part in four hour-long sessions for four weeks. The program is a total of 16 sessions.

"It demands a lot of endurance," Beach says.

Patients do vocalizations and change the pitch of their voice. As Beach tracks their volume using acoustic measuring software, patients also read from something that interests them, like the Bible or a novel. One man who went through Beach's therapy read from financial reports of the stocks he followed, Beach says.

"We start out the first week by having them just read words. Then we move to sentences. Then we move to paragraphs," Beach says. "And then the final week is a conversation that's sort of open-ended."

Patients build up their voice over time, even consciously working to speak louder at home with their family, he says.

"Many of my patients will say after they've successfully completed the program that their waiter is not leaning in to try to hear what they have to say," Beach says. "They don't feel isolation that otherwise happens if it's hard for people to hear them."

Beach says data from the organization that runs the LOUD program suggests that 80% of those who complete the program maintain proper volume for two years. There are also studies suggesting LOUD can help improve other symptoms like slurred speech, swallowing issues, respiratory control and facial masking, he adds.

Another Option

Given the intensity of the therapy, Beach knows LOUD is not for everyone.

Both he and others at the PMDC use SPEAK OUT!®, a speech therapy approach developed by the Parkinson's Voice Project that entails fewer visits where a patient works on talking with more intent and more deliberation, which often results in a louder voice.

Generally, patients undergo two sessions each week for four weeks, he says.

Both SPEAK OUT!® and LSVT LOUD® suggest keeping tabs on a patient's speech patterns over the long term and returning for follow-up therapy sessions as needed, Beach says. Regardless of which therapy approach is used, Beach notes it's important to address speech problems as early as possible.

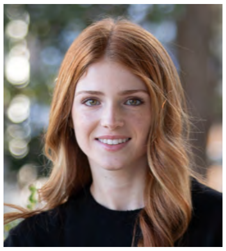
"It's very difficult to treat people late in the course of their disease when they are talking in a whisper," Beach says. "At that point, we're probably looking towards electronic communication devices."

And through therapy, someone who was once barely audible in a quiet room can become easily heard while conversing in most settings, Beach says.

"When we conclude therapy, unless there is some incredibly loud noise, they're going to be heard as well as I," Beach says. "They feel much better because they find that people are not asking them to repeat, that people aren't just nodding without understanding them but are actually getting what they're saying." ■

PMDC interns get firsthand experience in movement disorders field

By Sean Gorman


Carson Spicer


Ella Kraft

High school seniors Carson Spicer and Ella Kraft are on different career tracks in health care that led them both to internships at the VCU Parkinson's and Movement Disorders Center (PMDC).

Kraft, a biology major, is planning on becoming a physician assistant while Spicer envisions going into public relations in the health care space. From August 2024 to May 2025, the two Maggie Walker Governor's School students got a firsthand look at the PMDC's work helping patients living with movement disorders and advancing research in the field.

Through the mentorship program, Kraft shadowed Brian Berman, M.D., the PMDC's director, as he met with patients who have Parkinson's disease and dystonia.

And she worked on a study with PMDC Clinical Research Coordinator Caileigh Dintino that examines overnight heart rate changes in Parkinson's patients and what those heart rate variations might mean for a patient's underlying health.

Kraft interned at the PMDC while taking a college-level course on how physiology and anatomy impact human behavior.

"It's been incredible," Kraft says about working at PMDC. "I'm in a physiological psychology class at VCU right now, and a lot of the material that I'm learning aligns with what I'm learning in my PMDC mentorship. It's really cool being able to use that information in real life."

Spicer also got experience on the clinical side during her internship in addition to working with PMDC Senior Community Outreach and Engagement Coordinator Bonnie Mahl on outreach and marketing initiatives.

Among the projects Spicer worked on was designing surveys that seek insights on how the PMDC can spread the word about the support groups and other resources it offers to caregivers with loved ones living with Parkinson's disease.

"My grandfather has Lewy body dementia," Spicer says of the neurodegenerative illness. "I've watched my dad and my grandmother as caregivers and seen how hard it is to find resources, so I thought 'this is something that needs to be done.'"

Spicer has also been working on the PMDC's website design and social media channels as well as writing an article about the center's community outreach during Parkinson's Awareness Month. The internship provided key firsthand experience in a future role in health care marketing that she plans to pursue.

"I took the same VCU class Ella's taking, so that really made me interested in neurology. With my grandfather's diagnosis, too, I've always thought I would go into a field related to health care," Spicer says.

She got connected to the internship after reaching out to Leslie Cloud, M.D., director of the Parkinson's Disease Program at the PMDC. Cloud got Spicer in touch with Mahl.

Kraft found out about the internship through her grandmother, who is one of Berman's patients with Parkinson's disease, and asked him about internship opportunities for high school students. During her time at PMDC, Kraft has witnessed the empathy and patience Berman displays while treating people living with movement disorders.

"It's been really cool to see that, and it's something that will definitely help me down the road," Kraft says. ■

Check out Carson's story in 'Grid'

Read PMDC intern Carson Spicer's recent story "Parkinson's Awareness Month in Richmond: A Story of Empowerment, not just Awareness," which was published this spring in the greater Richmond Publication "Grid."

PMDC named LBDA Research Center for Excellence,

continued from page 3

further establishes our center as a destination for patients wanting to be part of cutting-edge studies that help improve Lewy body dementia care."

The honor raises the PMDC's visibility for patients seeking care and positions the center as a top candidate to participate in clinical trials on ways to treat the neurodegenerative disease, adds Matthew Barrett, M.D., a movement disorders neurologist and the Lewy Body Dementia Association Research Center of Excellence director at the PMDC.

"It means patients are coming to a place where their disease is really understood, where they can get the best treatment and where they can also participate in research studies," Barrett says. "We're actually finishing two clinical trials right now, but there will certainly be more on the way."

Those two existing studies are examining whether certain drug treatments might slow the progression of Lewy body dementia — the second most common form of dementia after Alzheimer's disease.

Lewy body dementia is characterized by a progressive neurological decline after symptoms first arise, which is typically in a patient's older years. It causes movement disturbances as well as problems with sleep, cognition, hallucinations and other symptoms, according to the Lewy Body Dementia Association.

"It's a difficult condition. The symptoms are often quite severe, impairing and debilitating," says Trey Bateman, M.D., a behavioral neurologist at Wake Forest University who will soon be joining the faculty at VCU. "But being treated by people who really understand that particular condition increases the likelihood that you're going to get a good outcome for managing symptoms."

PMDC's depth of research into the disease was a key factor in being named an LBDA Research Center of Excellence. In addition to the two current clinical trials, the PMDC has been working to develop a "biomarker" to detect and diagnose Lewy body dementia earlier. Also helping the center's application is the PMDC team's wealth of expertise in treating the disorder and its support group for caregivers of Lewy body dementia patients.

The PMDC applied for the distinction last summer and learned in late November they had received it. The honor includes a $12,500 annual award that will help cover the cost of having a coordinator focused on Lewy body dementia research, and it comes just as Bateman is preparing to join the PMDC in August.

"He's trained as a behavioral neurologist, and that's important because patients with Lewy body dementia might first be referred to a movement disorder specialist or a cognitive neurologist," Barrett says. "It's important to have both types of providers for patients."

Bateman says being a research center of excellence offered an additional incentive to join VCU Health, noting he's already been collaborating with Barrett on research studies and will continue to do so at the PMDC.

"I was already pretty set on coming to VCU, but the LBDA Research Center of Excellence designation is definitely something that was another thing that drew me in because I, like Matt, see patients with Lewy body dementias," Bateman says. "I think it's really a fantastic expansion of what the PMDC has already been doing in the space." ■

Support the PMDC

Find all the ways you can support our work to transform current treatment models for movement disorders.

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 Bernadette O'Shea, senior director of development for the Neurosciences, at osheab@vcu.edu.

www.parkinsons.vcu.edu/support-our-work/

To opt out of receiving fundraising communications from VCU Health, contact 1-844-445-9126 or FundraisingOptOut@VCUHealth.org.

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