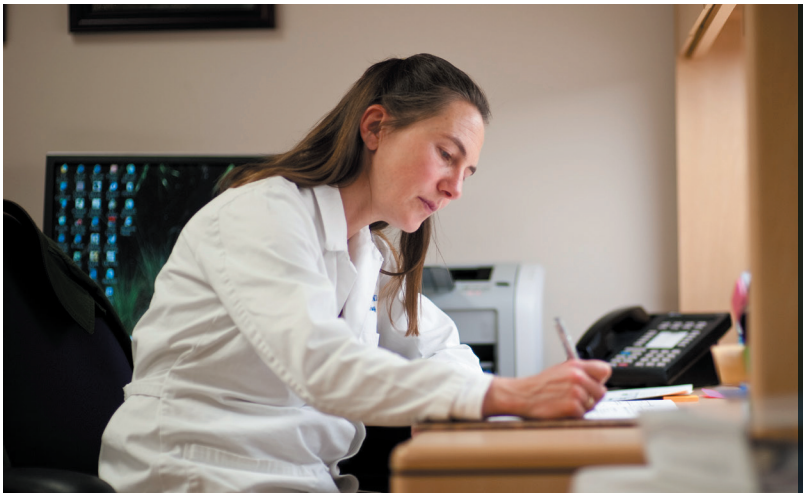
Movement Disorders Program

and the Murray Center for Research on Parkinson's Disease and Related Disorders

MUSC Health
Medical University of South Carolina

Movement Disorders Program | 208 B Rutledge Avenue, MSC 108 | Charleston, SC 29425 | MUSChealth.org/movementdisorders



> **Our focus is providing patients with the best care possible, from treatment options to the latest technology and research. We have an amazing team of experts that provides compassionate care to each individual that we see.**
>
> - Dr. Vanessa Hinson

Getting help from the MUSC Health Movement Disorders Program

Millions of Americans suffer from movement disorders. These are typically characterized by involuntary movements, shaking, slowness of movement, or uncontrollable muscle contractions. As a result, day to day activities like walking, dressing, dining, or writing can become challenging.

The MUSC Health Movement Disorders Program offers a comprehensive range of services, from diagnostic testing and innovative treatments to rehabilitation and follow-up support. Our team understands that Parkinson's disease and other movement disorders can significantly impact quality of life. Our goal is to provide you and your family continuity of care with empathy and compassion throughout the treatment experience.

Please use this guide to learn more about

- **Diseases Treated** – information about the disorders and symptoms you might feel
- **Specialty Procedures** – treatments that show significant improvement for many patients
- **Research** – opportunities to participate in clinical trials at the MUSC Health Movement Disorders Program
- **Profiles** – MUSC Health movement disorder specialists

We are dedicated to finding the cure for disabling movement disorders and to help bring about new treatments that can improve our patients' lives.

Sincerely,
Vanessa Hinson, M.D., Ph.D.
Professor of Neurology
Movement Disorders Program Director

Movement Disorders Clinic

a patient-centered approach

To achieve the best quality of life for people living with Parkinson's disease or other movement disorders, the MUSC Health Movement Disorders Program established a unique interdisciplinary clinic in which patients have the opportunity to receive a comprehensive evaluation from a team of professionals in a single, coordinated appointment – rather than having to schedule multiple appointments with several specialists.

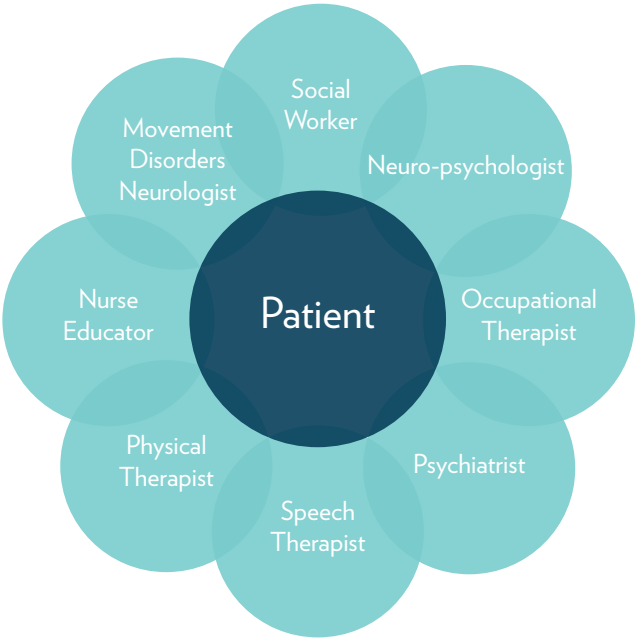
What to expect when you visit the interdisciplinary clinic

- Evaluation with a team that includes a movement disorders neurologist, neuropsychologist, psychiatrist, social worker, and physical, occupational, and speech therapists, all with special interests and expertise in Parkinson's disease and other movement disorders
- Research opportunities review with a clinical nurse educator, who will provide information on disease-related concerns and available clinical trials and research projects
- Customized treatment plan that addresses all aspects of the condition and provides a complete picture of his/her unique needs and abilities

The choice is yours

You then have the choice to take your customized treatment plan back to your local neurologist, or to follow with a movement disorders specialist at MUSC Health. If you choose to follow up on a recommendation with a provider closer to home, our team will help you identify specially trained professionals close to your home.

For more information on the Movement Disorders Program and clinic appointments, please see the contacts on the back cover of this brochure.



Contact

If you would like to make an appointment, contact MUSC Health Connection at **843-792-1414** between 7 a.m. - 5 p.m. Monday through Friday.

If you would like to speak with someone about the Movement Disorders Program, including clinical trials, call **843-792-7262**.

If you would like to speak with someone about the Parkinson's Foundation Center of Excellence Programs, call **843-792-7859**.

To refer a patient to the Movement Disorders Program, please call MEDULINE at **843-792-2200** or **800-922-5250**. Additional resources for referring physicians can be found on our Physician Portal at **MUSChealth.org/physician-portal**

Please note there is an Expedited Referral Form for patients being referred for Deep Brain Stimulation treatment available at **MUSChealth.org/movementdisorders**

Opportunities for Giving

If you or a loved one have been touched by Parkinson's Disease or other movement disorders, you might have an interest in supporting the work we are doing at the MUSC Health Movement Disorders Program. Philanthropic gifts enable us to fund new research programs, patient education events, or an endowed chair position to attract more outstanding experts to MUSC.

To learn more about how you can make a gift in support of our mission, please contact Heather Parrish, Director of Development at 843-792-4342 or visit our web site at MUSChealth.org/movementdisorders

Parkinson's Disease

Parkinson's disease is a neurodegenerative disorder affecting at least one million people in the U.S. The disease is progressive and its hallmark features include slowness of movement, muscle stiffness, tremor, and imbalance. While historically categorized as a movement disorder, Parkinson's disease causes a variety of non-motor features such as difficulties with sleep or reasoning that can further impact quality of life. There is no definitive test for Parkinson's disease so the diagnosis depends on expert clinical assessment.

For these reasons, our program offers a multidisciplinary approach when assessing and treating patients with Parkinson's disease. This means we have neurologists and specialty staff such as physical therapists and psychiatrists with specific expertise in movement disorders who coordinate for each patient's needs. That is important because research shows that having a neurologist care for Parkinson's disease patients is associated with improved treatment and survival rates. We also offer neuropsychological assessments to test brain function; specialized rehabilitation therapies such as Lee Silverman Voice Therapy Program to improve speech volume; Lee Silverman Big therapy, a Parkinson's disease-specific exercise program; and a nationally recognized psychiatry program that can help patients understand and manage mental health issues related to their diagnosis.

We are actively involved in national, multicenter clinical trials and translational research to contribute to advancing both the understanding of the disease and the discovery of promising new therapies. As a National Institutes of Health-designated center for neuroprotective studies, our team is researching treatments that will slow or prevent nerve damage caused by Parkinson's disease. We are also conducting research on cognitive impairment, biomarkers, and freezing of gait (walking issues).

WHAT IS **NEURODEGENERATIVE DISEASE?**

Neurodegenerative disease describes a range of conditions which affect the nerve cells in the brain or spinal cord. When nerve cells are damaged and malfunction, or die prematurely, the nervous system does no longer function properly and problems with movement, thinking, and other function result.

Becoming a Parkinson's Foundation Center of Excellence

The designation as a Parkinson's Foundation Center of Excellence for the MUSC Health Movement Disorders Program is a validation of the work program members have done over the last 15 years, said director Vanessa Hinson, M.D., Ph.D.

The program has been named a Parkinson's Foundation Center of Excellence, joining 46 other medical centers worldwide, including 32 in the United States.

The designation is highly respected and sought after by Parkinson's researchers and clinicians, she said. Nor is it easy to get.

The foundation opens its application process only sporadically. Once the application process is open, centers must complete a lengthy written application and a two-day site visit — one day for foundation experts to speak with patients and see how the patients perceive the care they receive and one day to speak to the movement disorders team.

Being one of only a few dozen Centers of Excellence within the U.S. has benefits for patients, Hinson said. The program will now have access to more money to expand community care programs and educational opportunities for patients. It will also be able to apply for funds for new and creative research ideas and have increased visibility, Hinson said.

"If we do good work but people don't know about it, that doesn't solve the problem. So we need to increase our visibility and let people with Parkinson's and their families know that such specialists exist and they're in their backyard, namely right here at MUSC," she said.

Parkinson's Foundation Centers of Excellence provide more than routine clinical care, although care is an important component of each center.

Each center is evaluated on:

- Its reputation within the Parkinson's community
- The research it conducts
- Its commitment to providing the best care to every person with Parkinson's
- Its commitment to serving the broader community
- How it integrates research and care
- Its demonstration of continuous and systemic improvement
- Whether it meets the foundation's patient and provider criteria

Parkinson's Foundation
CENTER OF EXCELLENCE

"The Center of Excellence designation recognizes the leaders in providing high-quality Parkinson's care," said John Lehr, president and chief executive officer of the Parkinson's Foundation. "The Parkinson's Foundation will continue to expand our reach across the country to ensure that every person diagnosed with Parkinson's disease has access to treatments that will improve their quality of life today."

Gathering all those components to create the movement disorders program as it is today took years of assembling the right people, training and finding the right space, Hinson said. The program is housed on Rutledge Avenue just off the main campus in a building that allows the team to easily share ideas and offers easy access for patients involved in research.

Today, the MUSC Health Movement Disorders Program includes neurologists with specialized training in Parkinson's disease and movement disorders, stereotactic neurosurgeons, neuropsychologists, speech therapists, physical therapists, occupational therapists, geriatric psychiatrists, palliative care specialists, a social worker, and a Parkinson's disease care coordinator/education nurse.

Hiring additional specialists in the last few years means that new patients have almost immediate access, Hinson said. The wait time for patient referrals has dropped from six months to just a week or two.

"The institution has put forward a major initiative in making us available to those who need us," she said. And although the full interdisciplinary team works only on the main campus, regular clinical visits with movement disorders specialists are available in West Ashley and Mount Pleasant.

The new funding that comes with this designation will further help patients, Hinson said. Each center receives $60,000 a year for five years to go toward something that is directly related to a benefit to the patient.

Examples of activities supporter by this grant are: An orientation day for people newly diagnosed with Parkinson's, informational and supportive sessions for caregivers, monthly educational Lunch and Learn seminars for patients, and the annual symposium "Living with Parkinson's," which reaches 450 families each year. The symposium includes lectures, question-and-answer sessions, roundtable discussions and an exhibit on the latest research.

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Atypical Parkinsonism

Other conditions may look like Parkinson's disease to some extent but have different features, such as a more rapid progression, lack of benefit from Parkinson's disease treatments, or more problems with memory, behavior, or balance. These conditions are often known as atypical parkinsonism and include conditions such as progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and multiple system atrophy (MSA), among others.

The recognition and treatment of these conditions are challenging, often requiring a multidisciplinary approach of people with experience in atypical parkinsonism. MUSC is one of 23 CURE-PSP Centers of Care across North America. These centers offer vast expertise in diagnosing and managing atypical parkinsonism and providing access to a network of resources for physicians, patients and their families.

CurePSP® | CENTER OF CARE

Dystonia

Dystonia is a neurological movement disorder characterized by sustained abnormal muscle contractions. The most common form is cervical dystonia, affecting the neck muscles. People with cervical dystonia often have abnormal pulling of their neck muscles to one side, and they experience neck pain or head tremor. Sometimes, dystonia affects the eyes (blepharospasm) and leads to involuntary eye blinking or even eye closure. In extreme cases, people with blepharospasm are unable to keep their eyes open for any extended period of time, and cannot read or drive. Dystonia can also be generalized, causing problems with muscle twisting in the arms, legs and torso. These generalized dystonias are often genetic in origin and usually start in early childhood.

A careful neurologic examination by a movement disorders specialist on our team can lead to an accurate diagnosis of dystonia. We also offer genetic testing and genetic counseling for those cases in which heredity is expected as the cause. Treatment options include oral medication, new therapies available in clinical trials, botulinum toxin injections or deep brain stimulation surgery (See more information on page 9) in selected cases.

Essential Tremor

Essential Tremor or ET is one of the most common movement disorders, occurring in up to 20 percent of those over 60 years of age, and it can range from bothersome to disabling. Tremors are commonly seen in the hands, when outstretched, or holding a specific posture, and can also be observed in the head, voice or legs. Medical therapy is available to treat ET and works well for most people. For others, conservative therapies, including special devices to help with eating and writing, can be considered. Sometimes patients have a tremor that has not responded to other treatments, called refractory. In some cases, surgery in the form of Deep Brain Stimulation is a highly effective therapy. (See more information on DBS on page 9.)

We know ET is hereditary; however, no gene has been identified. We do not fully understand how ET occurs, but there is scientific evidence that the cerebellum, an area of the brain controlling balance and coordination, is involved. The MUSC Health Movement Disorders program is engaged in pharmaceutical studies and collaborations with the brain stimulation lab to improve the understanding of ET and develop new therapies.

Huntington's Disease

Huntington's disease is an inherited disease associated with progressive degeneration of the brain that manifests with disabling movement, cognitive, and psychiatric symptoms. Some of the more common symptoms associated with Huntington's disease are involuntary movements known as chorea, balance impairment, slowness in thinking, difficulty organizing thoughts, depression, and anxiety. The condition runs in families and the symptoms may manifest as early as in childhood and as late as the ninth decade. Given the wide array of symptoms and their severity, a comprehensive approach to the care of those with Huntington and their families is needed.

In recognition of their quality of care, the Medical University of South Carolina Movement Disorders Program received designation as a Huntington's Disease Society of America (HDSA) Center of Excellence in 2021 from the HDSA Center Programs and Education Advisory Committee.

What does MUSC have to offer?

Our approach to the care of those with Huntington's disease is founded on four goals: caring for the patient as a whole, supporting their families, educating the community about Huntington's disease, and developing better opportunities for treatment for future generations through research.

As an HDSA Center of Excellence MUSC offers a comprehensive list of resources for the diagnosis and management of Huntington's disease. Multiple specialties collaborate in the care of Huntington's disease:

- Neurologists who specialize in movement and cognitive disorders
- Psychiatrists
- Genetic counselors
- Neuropsychologists
- Therapists
- Physical therapy
- Occupational therapy
- Speech therapy
- Social workers
- Palliative care specialists

Huntington's Disease Society of America Center of Excellence Medical University of South Carolina

The care is coordinated by the neurologist who will help arrange access to the different specialties. This can be done in separate visits or at our interdisciplinary clinic. At the interdisciplinary clinic, patients are evaluated by all the specialties listed above who will then get together and discuss the case to propose a management plan. The goal of the plan is not only to help the patient with Huntington's disease but also the caregivers.

MUSC collaborates with members of the Huntington's disease community by holding a support group every month. The goal of the support group is to discuss issues or concerns related to the impact of Huntington's disease in someone's life. Periodically, the different specialties will present to the support group on topics that range from medical care to social services. In addition, MUSC holds educational events for the Huntington disease community.

As an academic institution, research is a big part of MUSC. Therefore, our patients have access to research opportunities that aim to advance our understanding and management of Huntington's disease. MUSC is also part of the Huntington's disease study group (HSG), a non-profit organization focused on the research of Huntington's disease.

SPECIALTY PROCEDURES

Botulinum Toxin Therapy

Botulinum toxin injections are the most effective treatment for dystonias that affect the neck and eyes. We also use these injections to treat people with limb dystonia, spasticity or muscles that are constantly tight or stiff, spasms on one side of the face and drooling. Botulinum toxin injections are a precise and long lasting way of relaxing the affected muscles without drowsiness and the other common side effects of oral muscle relaxers.

Botulinum toxin decreases the overactive contraction of the muscles and reduces abnormal postures and pain. In addition, it can also dry up secretions in conditions associated with excessive drooling. Our physicians have extensive experience administering botulinum toxin therapy and use electromyography guidance for enhanced precision.

Deep Brain Stimulation

Deep brain Stimulation or DBS is a highly effective therapy for movement disorder patients in advanced stages of their disease process. Patients with movement disorders have dysfunctions in the circuits in the brain that control movement. By placing a small stimulating electrode in these circuits, we can normalize the electrical activity and restore function.

Candidates undergo a thorough movement disorder evaluation, followed by neurosurgical and neuropsychological evaluations. Each patient's case is reviewed by our full interdisciplinary team to ensure the patient is a good candidate.

Our neurologists use highly sophisticated imaging to identify relevant circuit structures for the DBS surgery. This ensures proper placement of the DBS stimulating electrode through live mapping of the relevant structures. It also allows for testing and examination prior to permanent placement. Following the surgery, patients are monitored closely by our team to program the device, tailor the stimulation and monitor medications to account for the changes in stimulation. The MUSC Health DBS program has more than 15 years of experience in caring for DBS patients, including many of the most complex cases in the Southeast.

RESEARCH & CLINICAL TRIALS

Research

The Murray Center for Research on Parkinson's Disease and Related Disorders is the part of our program that offers patients the opportunity to participate in clinical trials as part of their treatment.

What is a clinical trial?

A clinical trial is a scientific way to find out whether a new medication or other intervention (e.g. devices, procedures and exercise programs) is safe and effective in treating a medical condition. In the field of movement disorders, this means that we are partnering with the National Institute of Health, disease-specific foundations, industry and private sponsors, to bring about new treatments for Parkinson's disease, Essential Tremor, Huntington's disease, Dystonia and other conditions. Every clinical study is led by a principal investigator who is a medical doctor and movement disorders specialist. Clinical studies also have a research team that may include nurses, research coordinators, neuropsychologists and other health care professionals.

What to expect from a clinical trial visits?

Clinical trial visits are very similar to outpatient office visits with a neurologist. Patients will receive a detailed history and physical examination, in addition to safety assessments such as blood work, electrocardiogram, and vital sign monitoring. Our physicians will perform an in-depth evaluation of the severity of the movement disorder and discuss quality of life and other assessments of the patient's well-being. The patient will usually take their study medication home and take it along with their regular daily medications between study visits. The physician in charge of the study along with the institutional oversight board called an IRB will monitor safety issues. Participation is completely voluntary and patients can withdraw from a study at any time if they wish to do so.

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What are the benefits of enrolling in a clinical trial?

There are a number of important benefits of participating in clinical research. The patient will gain access to new treatments that are usually not accessible outside of the clinical trial, receive close monitoring and detailed assessments of their movement disorder, and help advance the knowledge and speeding up the race for the movement disorders cure.

How to sign up for a clinical trial?

Patients can talk to a MUSC Health Movement Disorders specialist, or ask their primary physician to make a referral to our Movement Disorders program. However, patients do not have to be a patient at MUSC Health to be part of our research program. To learn more or sign-up for a clinical trial, email Sandra Wilson at **wilsosan@musc.edu**.

TELEHEALTH

MUSC Health and the Movement Disorders Program offer Virtual Telehealth Consultations (VTC) and Doxy.me Video Conferences for your convenience and easy access to our specialists.

Access to specialty care is limited in many parts of South Carolina, often requiring patients to travel over 100 miles to receive care. Additionally, many patients have limited transportation resources, or cannot drive.

MUSC telehealth started in 2011 with support from the Duke Endowment and continues to expand and transform specialty health care services in South Carolina. In October 2017, MUSC was named a Telehealth Center of Excellence and given a federal grant to become a model for telehealth and telemedicine programs across the country. At the start of the Covid-19 pandemic, MUSC Health additionally brought on the HIPPA secure Doxy.me Video conference platform allowing patients the opportunity to have a face to face video visit with their provider from their home without the risk of exposure. For convenience for the patients, MUSC Health continues to offer this platform for those unable to come to the facility or with no access to a telehealth center.

What are the benefits of Virtual Telehealth?

Alleviates strains on patients by bringing that specialty care closer to home. Telemedicine is cost-efficient and has been shown to increase patient satisfaction. By keeping patients within their local health care facilities, travel burden is reduced and patients remain closer to their support systems.

How does Telemedicine work?

The patient will present to their local hospital and MUSC Health Movement Disorders Program specialist will remote in via telemedicine equipment, a service currently offered for return patients. Technology includes telemedicine-enabled stethoscopes and handheld exam cameras. We prefer to evaluate new patients thoroughly in person, but in case the patient cannot access our facility, then a Doxy.me video conference from the patient's home can be substituted.

COMMUNITY ENGAGEMENT

Living with Parkinson's Disease Symposium

Shine A Little Love Fest

Center on Aging Senior Expo

Putting for Parkinson's

Parkinson's Foundation Moving Day

Huntington's Disease Society of America Team Hope Walk

Latin American Festival

MUSC Health Movement Disorders Team

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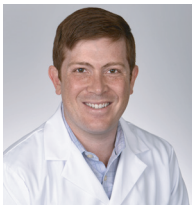

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Stereotactic Neurosurgeon

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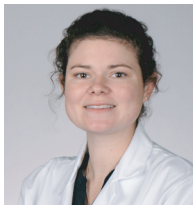

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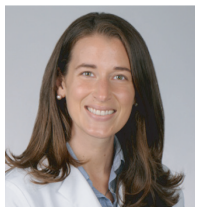

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For more information visit MUSChealth.org/movementdisorders or call 843 792 1414.

MOVEMENT DISORDERS PROGRAM

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Medical University of South Carolina

Changing What s Possible

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