ALS Clinic

MUSC’s Amyotrophic Lateral Sclerosis (ALS) Multidisciplinary Clinic was founded nearly 10 years ago. The clinic’s establishment is largely attributed to General Thomas Mikolajcik, who dedicated the remainder of his life to ALS patients nationwide. As a result of his commitment, patients in South Carolina are seen in Charleston at MUSC for treatment and management of ALS.

General Mikolajcik (August 17, 1947– April 17, 2010), Commander of the 437th Airlift Wing at the Charleston Air Force Base, was diagnosed with ALS after serving 27 years in the military. After his diagnosis, he became an advocate for ALS victims, especially veterans who show a greater risk of developing the disease. General Mikolajcik testified before the Congressional House Committee on Veterans’ Affairs in 2007, and his testimony led to the US Department of Veterans’ Affairs decision to list ALS as a service-associated disease. Now, Veterans with ALS can be treated at the Ralph H Johnson VAMC ALS clinic.

As General Mikolajcik advocated for veterans nationally in the mid-2000s, he also expressed that there wasn’t a place for ALS patients in the Charleston area to receive care. Dr. Jerome Kurent then reached out with a proposal to establish an ALS Clinic at MUSC. General Mikolajcik and his friend, Paul Hollen, enlisted the involvement of the ALS Association (ALSA) as a key partner in establishing the ALS Multidisciplinary Clinic at MUSC. General Mikolajcik and his daughter Christina founded the South Carolina-ALSA Chapter. In 2006, the MUSC ALS Multidisciplinary Clinic was established and codirected by Dr. David Stickler and Dr. Kurent.

Since the original establishment of the ALS Clinic, the Muscular Dystrophy Association (MDA) continues to be an important partner and supporter of this clinic. MUSC is grateful for the MDA’s continued support in both the neuromuscular clinic and the ALS clinic.

Now under Dr. Amy Chen’s leadership, the MUSC ALS clinic is in a phase of growth and continued improvements. The multi-disciplinary ALS clinic is made up of a team of highly dedicated professionals, including physical therapists, occupational therapists, respiratory therapists, dietitians, speech and swallowing professionals, social worker, nurse practitioners, and neurologists...

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About the Neuromuscular Division

Providers in the Division of Neuromuscular Diseases at MUSC evaluate and treat patients with problems in the nerves and muscles. These problems may affect a patient’s ability to move, feel, or communicate, and often cause disability. The Neuromuscular Division has three neurologists, a physiatrist, and a nurse practitioner who have significant experience in the diagnosis and treatment of neuromuscular diseases.

Dr. Amy Chen is the acting Director of the Neuromuscular Division, and Director of the MDA/ALS clinic. She joined MUSC’s Department of Neurology in 2015 as Associate Professor. Dr. Chen has extensive experience in the diagnosis and treatment of neuromuscular diseases, including muscular dystrophies, myopathies, nerve and muscle junction diseases, and neuropathies. Her main clinical and research focus is on Amyotrophic Lateral Sclerosis (ALS).

Dr. Jerome E. Kurent, who joined MUSC in 1984, is Professor of Neurology, Medicine and Psychiatry. Dr. Kurent believes his patients are “a continual source of inspiration in the face of adversity.” Dr. Kurent’s clinical activities are primarily based at the Ralph H. Johnson Veterans Affairs Medical Center (VAMC) and his special interests include ALS, electrodiagnostic evaluation, clinical ethics, and palliative and end-of-life care. Dr. Kurent believes the neuromuscular division, under the new leadership of Dr. Chen, is poised for the next level of excellence in patient-centered care, education and research.

Dr. Katherine Ruzhansky joined us in 2014 as Assistant Professor of Neurology and Director of MUSC’s EMG lab. Her clinical interests include electrodiagnostic testing, diagnosis and treatment of neuromuscular disorders, myasthenia gravis, and neuromuscular manifestations of systemic amyloidosis.

Dr. Noreen Herring is board certified in Physical Medicine and Rehabilitation (PM&R) and Electrodiagnostic Medicine. She is an Assistant Professor who has practiced at MUSC since 1996. She focuses on the development of a comprehensive program for patients with physical disabilities due to disease or injury to maintain or regain physical functions.

Ms. Susan Nease is an adult Nurse Practitioner and she joined MUSC in 2014. She evaluates and manages follow-up care for patients with nerve and muscle diseases, and coordinates the complex care for patients with ALS. She also assists in the management of patients with spasticity due to spinal cord injuries and performs skin biopsies for the diagnosis of patients with small fiber neuropathy.

MUSC’s neuromuscular physicians see the majority of patients at the Rutledge Tower clinic located in downtown Charleston, and serve patients at a Community Outreach Clinic located at East Cooper Medical Center in Mount Pleasant. A comprehensive clinical evaluation is completed by a physician at the initial visit to determine if the patient has a peripheral nervous system disease.

The Neuromuscular Division strives to improve the quality of care by combining expertise and innovation. Dr. Chen is collaborating with colleagues in Neurosurgery, Pathology, and other institutions to offer less invasive diagnostic tests to patients: including needle-muscle biopsy in the clinic and ultrasound testing in the EMG lab. These tests are associated with less pain and fewer complications compared to alternatives, and provide complementary information for diagnosis.

Our team provides education and counseling to the patient and family, and coordinates with the patient’s primary care physician and members in other disciplines to provide the utmost comprehensive care for the patient. We strive to conform to practice guidelines as affirmed by the American Academy of Neurology.
The team takes a comprehensive approach and discusses specific issues related to each patient at meetings, both before and after the clinics, to discuss a patient-oriented treatment plan. When you arrive at the clinic, you are greeted by Ms. Carolyn Kay, our Licensed Practical Nurse, who is recognized for going above and beyond for our ALS patients. We have extended the ALS clinic visit for established patients to 90 minutes. Before you leave, you will notice the compassionate care provided by Ms. Susan Nease, NP. She has initiated an informational packet, designed to empower you with the knowledge to partner with us to manage your illness. Ms. Nease coordinates the complex medical needs for patients so that care with us continues beyond the clinic visits.

Besides providing advanced evaluation and treatment for patients with ALS, MUSC is a site member of the Northeast ALS (NEALS) Consortium. This means that patients have the opportunity to participate in clinical studies and trials to help the ALS medical and scientific communities better understand causes of this disease, and identify new treatments and a cure.

It was less than a decade ago that the critical involvement of General Thomas Mikolajcik, SC chapter of ALSA, and a Multidisciplinary team helped establish MUSC’s ALS clinic. We continue to build upon the original mission of the ALS clinic by providing the most comprehensive and individualized care for our patients. In the future, we plan to enhance access for patients and expand the scope of services. One day, we hope that these efforts will lead to the development of treatments and eventually a cure for ALS.

Healthy Tip
Be social. Studies show how social isolation can cause major psychological and neurological impairment or even death. Social separation disrupts myelin production, which is essential for nerve signaling and transmission. Make it a priority to get involved in the community or make plans with friends and family.

Did You Know?
Did you know that some fats are considered “good” fats? Poly and monounsaturated fats found nuts, vegetable oils, and greens, and omega-3 fatty acids found in fish are desirable for a better brain. Avoid trans fats and minimize saturated fats (red meats, butters, etc.). Dr Trayford, Michael. My Top 10 Brain Health Tips. Carolina Functional Neurology.

Patient Story: Larry McCravy

It started with foot pain that became a back ache. A ‘slipped disc, perhaps’, is what Mr. Larry McCravy thought when he decided to see a doctor. After a visit to his primary care physician, a physical therapist, and eventually to a neurologist at MUSC, Mr. McCravy was diagnosed with Amyotrophic Lateral Sclerosis or ALS on January 17, 2008.

In 1978, Mr. McCravy and his wife Debbie moved to Charleston from Birmingham, AL. Never did they imagine that their move would mean Mr. McCravy would be a patient at MUSC’s ALS clinic. Indeed, the McCravys are thankful there is an ALS clinic here in Charleston. Patients travel to Charleston from around the state to receive treatment, so living nearby on James Island is a blessing. Mr. McCravy describes MUSC’s ALS clinic as a “one-stop shop.” MUSC’s multidisciplinary approach allows patients to complete specialized visits in one appointment. This is particularly helpful for patients with mobility issues.

Mr. and Mrs. McCravy are especially grateful for the physical therapist at MUSC who fit Mr. McCravy for his power chair. Mr. McCravy will also never forget MUSC’s occupational therapy team, which gave him padded tubes to place at the end of his silverware so he can grip it. These details have transformed his life. Being cared for by Dr. Kurent, who has treated Mr. McCravy since 2008, has been the best part of his experience at MUSC. Mr. McCravy and his wife describe Dr. Kurent as a highly compassionate, kind, and caring person.

Mr. and Mrs. McCravy, who met on a blind date in high school, just celebrated their 40th anniversary in December with an "all-expenses-paid" cruise. They are grateful to Team Gleason for their trip, which is an organization founded by Steve Gleason, the NFL Saints player who was diagnosed with ALS. A Team Gleason representative approached Mr. McCravy on Facebook asking him what he enjoyed doing. Mr. McCravy said “traveling.” The next thing he knew, the foundation arranged for a cruise to travel around the Caribbean! Mr. McCravy explains that, like the ALS Clinic, a cruise is wonderful for someone with mobility problems.

Upon returning home, Mr. McCravy “paid it forward”...and recommended a PALS friend to Team Gleason. PALS or People with ALS is a wonderful way to meet others with ALS.

As awful as an ALS diagnosis can be, the McCravys admit that they have had some amazing experiences because of their involvement in the community. Besides the cruise, the Ashley River Baptist Sunday School class came to the McCravy’s house every Saturday for 10 months and renovated their bathroom to be handicap accessible, in honor of his 60th birthday. In addition, the local chapter of the ALS Association provided him with the co-pay monies for his power chair.

A key to remaining positive is surrounding yourself with cheerful people. Mr. McCravy emphasizes, “Debbie is amazing. She said ‘in sickness and in health’ she is keeping her promise.” Mr. McCravy is fortunate to have her as his soulmate, caregiver and wife. He believes that the disease is harder on the caregiver than on the patient. Debbie’s compassion won her the Caregiver of the Year Award from Brigance Brigade, which recognizes phenomenal care of someone who is living with ALS.

Mrs. McCravy, who works in MUSC’s development office, is grateful to have MUSC’s support. When Mr. McCravy had a fall, her boss, Leigh Manzi heard about it and met her in the Emergency Room. She believes it’s important to let people help you when you are a caretaker.

Mr. McCravy is appreciative for the many resources available to ALS patients. Facebook has been able to connect him to PALS, Team Gleason, the ALS Association and the OJ Brigance Foundation. Mr. McCravy favors OJ Brigance’s Strength of a Champion novel, which explains how Brigance himself found faith and strength through life’s challenges. Like Brigance, Mr. McCravy believes keeping faith and having hope are crucial to success. Mr. and Mrs. McCravy definitely both serve as inspiration for the Charleston ALS community.

Giving Back

If you or a loved one has ever been touched by ALS or other Neuromuscular disorders, you might have an interest in supporting the work we are doing here in the Department of Neurology at MUSC Health. Philanthropic gifts enable us to fund a variety of initiatives, including new pilot research programs and clinical trials, research and patient education events.

To learn more about how you can make a gift in support of our mission, please contact Meredith Gale, Director of Development at 843-792-4342, gale@musc.edu or visit our website at musc.edu/neurology.