LES TURNER ALS CENTER AT NORTHWESTERN MEDICINE

Northwestern University Feinberg School of Medicine is known the world over for leading groundbreaking ALS (amyotrophic lateral sclerosis) research, and for providing exceptional care and support to patients and families living with this devastating and complex disease. At Northwestern, we continue to make scientific inroads and to champion the way forward, even though the battle to overcome ALS is daunting.

ALS, also known as Lou Gehrig’s disease, is a progressive and fatal neurodegenerative disease that often strikes people in the prime of their lives. Anyone can be diagnosed with ALS: a mother, a son, a sister, or a grandfather. There are an estimated 140,000 new cases of ALS each year worldwide, with an average survival of three to five years. The degeneration of nerves leads to muscle weakness and impaired speaking, swallowing, and breathing, eventually causing paralysis and death. There is no cure. Every 90 minutes, someone in the United States is diagnosed with ALS, and every 90 minutes someone in the United States dies from ALS.

In 2014, we launched the Les Turner ALS Center at Northwestern Medicine with the transformational philanthropic support of the Les Turner ALS Foundation—a steadfast partner with Northwestern for more than 35 years. The Les Turner ALS Foundation has been Chicagoland’s leader in the fight against ALS since 1977 and is one of the nation’s preeminent organizations dedicated to treating and finding a cure for ALS.

Through the Les Turner ALS Center, we are offering hope and a pathway for the future of ALS care, research, training, and outreach. Currently, Northwestern and the Les Turner ALS Foundation are jointly leading a major effort to raise $10 million in funds to fully endow the Center in perpetuity.

The Les Turner ALS Center brings together all ALS research, including three world-renowned, dedicated ALS research laboratories, the Lois Insolia ALS Clinic, and other ALS research, clinical, and education activities at Northwestern, all under one comprehensive umbrella. The Center is a part of the Ken and Ruth Davee Department of Neurology and operates within the Institute for Translational Neuroscience at Northwestern Medicine.

Research to Find Answers and Provide Hope

Thanks to the Les Turner ALS Foundation’s tireless partnership and philanthropy over the years, Northwestern Medicine has been able to contribute significantly to scientific discoveries and medical treatment for ALS throughout Chicago and across the world. Our union with the Les Turner ALS Foundation has helped our scientists to establish themselves as forerunners in ALS research, both ensuring that the future for those fighting ALS is brighter and accelerating the progress toward ending the disease.

With a strong foundation in ALS studies, Northwestern continues to bring forth meaningful advances from the laboratories of Teepu Siddique, MD, the Les Turner ALS Foundation/Herbert C. Wenske Foundation Professor, P. Hande Ozdinler, PhD, associate professor of Neurology, and Evangelos Kiskinis, PhD, assistant professor of Neurology. They collaborate within multiple areas of Northwestern, including physiology, chemistry, molecular biology, bionanotechnology, and urology.

The Les Turner ALS Center has created a new ALS research grant program and awarded seven grants to collaborative ALS research projects in 2017. Funds were awarded to Northwestern scientists in the research areas of basic science, ALS drug development, and genetics. These seed grants allow our researchers to collaborate with scientists around the nation on new and novel ideas. The hope is that successful findings from these studies will enable Northwestern scientists to compete for large funding awards from the National Institutes of Health and other external funders. With these funds, they can then pursue larger-scale studies in ALS.

Dr. Siddique’s visionary leadership of the Division of Neuromuscular Disorders has helped to provide strong momentum for the research activities and programs of the Les Turner ALS Center. His laboratory has made several important discoveries in the field of ALS over the years, including the identification of significant genetic causes of ALS. More recently,

“The advantage of having all of the research and clinical activities joined as part of the Les Turner ALS Center is to enhance collaborations between our researchers and clinicians and, therefore, facilitate the development of new therapies for ALS.”

Robert Gordon Kalb, MD, Director of the Les Turner ALS Center and Chief of Division of Neuromuscular Medicine
a major breakthrough from Dr. Siddique and his laboratory was the discovery of a novel gene for typical Parkinson’s disease. This appears to be only the third gene definitively linked to confirmed cases of Parkinson’s disease.

Dr. Siddique and his colleagues also have developed genetic mouse models using the CRISPR/CAS9 technology for motor axonal disease (TRPV4) and ALS (UBQLN2). Experiments are underway to develop precision editing to correct genetic defects in their mouse models of ALS and in induced pluripotent stem cells (iPSCs) derived from patients with ALS.

Teepu Siddique, MD

Hande Ozdinler, PhD

Dr. Ozdinler is one of the few scientists in the nation who studies corticospinal motor neurons in ALS. These are the cells responsible for collecting, integrating, and translating signals from the brain before transmitting the information to the spinal cord, which then initiates a voluntary physical action by the body. It had previously been thought that the spinal motor neurons died first and their demise led to the secondary death of the brain’s motor neurons. Dr. Ozdinler’s research has shown, however, that the motor neurons in the brain and spinal cord die simultaneously.

Among other studies, Dr. Ozdinler has initiated a new collaboration with Steve Vucic, PhD, professor of Medicine at the University of Sydney, on molecular characterization of upper motor neuron defects that occur early in ALS patients. Dr. Vucic is a world leader, discovering the early cortical hyperexcitability as one of the earliest events in ALS patients. Dr. Ozdinler has written a review paper with Dr. Vucic and his team on the topic.

Evangelos Kiskinis, PhD

Dr. Kiskinis is a highly regarded investigator who is addressing fundamental aspects of the neurobiology of motor neurons, as well as the degenerative processes that target the neuromuscular circuitry as a result of genetic disease and the natural aging processes. He is particularly interested in understanding the molecular mechanisms that underlie the degenerative process of motor neurons in ALS. His laboratory has ongoing collaborations with scientists at Harvard University and the University of Pittsburgh. In laboratory studies, Dr. Kiskinis and his team have used patient-specific, stem cell-based approaches to investigate the processes that give rise to the genetic types of ALS. He and his colleagues are working to understand the level and nature of heterogeneity in ALS, and to identify points of effective and targeted therapeutic intervention. He is conducting these research projects using a combination of in vitro, stem cell-based approaches, as well as global genomic assays and in vivo mouse models of the disease.

Patient Care and Support that Makes a Difference

The Les Turner ALS Center and the Les Turner ALS Foundation are proud to bring world-class care to people living with ALS in the Chicago area and beyond. Northwestern was recently ranked by U.S. News & World Report as one of the top nine hospitals nationwide for neurology and neurosurgery, making it the top-ranked Chicago area hospital in this specialty.

The Lois Insolia ALS Clinic at Northwestern was established in 1986 with funds from the James V. Insolia Family Foundation and the Les Turner ALS Foundation—one of the first such clinics in the country, and the first in Chicago. Through the multidisciplinary clinic directed by Senda Ajroud-Driss, MD, who is an associate professor of Neurology, Northwestern specialists are using a team approach to provide comprehensive treatment.

The clinic is dedicated to the total care and support of people with ALS, their families, and caregivers. During a visit, patients meet with several members of the multidisciplinary team, which includes five neurologists, two pulmonologists, and neuromuscular experts who provide genetic counseling, occupational therapy, speech therapy, respiratory therapy, dietetic counseling, and coordination of clinical trial studies. After 30 milestone years, the Lois Insolia ALS Clinic not only provides the pinnacle of care to those with ALS, but also remains the only fully multidisciplinary ALS clinic in the Chicagoland area.
Northwestern Memorial HealthCare and Northwestern University Feinberg School of Medicine are seeking to impact the health of humankind through Northwestern Medicine. We aspire to be the destination of choice for people seeking quality healthcare; for those who provide, support, and advance that care through leading-edge treatments and breakthrough discoveries; and for people who share our passion for educating future physicians and scientists.

Through the Les Turner ALS Foundation’s Home and Community Services Team, specialized support services are available to patients and their families in coordination with care provided at the Lois Insolia ALS Clinic. Services offered include home visits with a Patient and Family Advocate who provides valuable disease information and who can help with continuity of care; augmentative communication devices or durable medical equipment from its equipment bank; support groups throughout the Chicagoland area; and a patient resources guide and other personalized programs. For more information, please contact the Les Turner ALS Foundation at 847-679-3311 or visit lesturnerals.org

THROUGH NORTHWESTERN MEDICINE, WE ARE CREATING A NATIONAL EPICENTER FOR HEALTHCARE, EDUCATION, RESEARCH, COMMUNITY SERVICE, AND ADVOCACY.

NORTHWESTERN MEDICINE

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Through the Les Turner ALS Center at Northwestern Medicine, we are enhancing the care provided to people with ALS today and in the future and furthering scientists’ understanding of this very challenging disease.

Each day, we recognize that every positive contribution we have made to ALS discovery, care, training, and outreach has been made possible by donors who have continued to entrust us with their philanthropic support. We invite interested friends to join us in advancing our Center through gifts of outright support and endowment.