

First CureDuchenne Clinic Opens in Greater Dallas Area to Provide Specialized Care for Underserved Duchenne Muscular Dystrophy Patients

Neuromuscular Clinic Will Provide Dedicated Services, Eliminating Barriers Facing Hundreds of Patients Living with Rare, Fatal Genetic Disease

DENTON, TEXAS – March 3, 2023 – <u>CureDuchenne</u>, a global nonprofit committed to finding and funding a cure for Duchenne muscular dystrophy, today announced the opening of <u>The CureDuchenne Clinic</u>, providing dedicated care and services to underserved and uninsured individuals with Duchenne and Becker muscular dystrophy. Located at the Neurology & Neuromuscular Care Center in Denton, Texas, the clinic will remove significant barriers of access for patients requiring highly specialized care, filling a gap in existing care for patients with the fatal neuromuscular disease.

The goal of the CureDuchenne Clinic is to provide high quality care for patients living with Duchenne or Becker muscular dystrophy from childhood through adulthood and to never deny care due to lack of insurance. Duchenne muscular dystrophy is a progressive, muscle-wasting disease in children, affecting 15,000 individuals in the United States. Usually, patients are diagnosed before age 5 and require lifelong care.

While there is not yet a cure for Duchenne, comprehensive care from an experienced, multidisciplinary healthcare team is essential to manage the unique needs of an individual living with the disease. Because of the complexity of the disease, patients and caregivers traditionally must navigate significant hurdles to obtain quality care. Insurance coverage, or lack thereof, is one of the most significant limiting factors for patients to access care. Texas has the <u>highest percentage</u> of uninsured residents in the nation, with Dallas being the second least-insured large city in the country. Large racial disparities also exist in insurance rates with Hispanic individuals being uninsured at a rate of nearly <u>38 percent</u>, nearly double the state average.

"Imagine getting a devastating diagnosis like Duchenne muscular dystrophy, and then wondering how you will access the highly specialized, and often very costly, care that is required for your child," said CureDuchenne Founder and CEO Debra Miller. "We must eliminate these barriers to care and improve the lives of everyone affected by Duchenne, while also offering hope for families as we strive for a cure. We're honored to partner with Dr. Castro and the team at the Neurology & Neuromuscular Care Center to ensure that high quality care is available to those who need it most."

The CureDuchenne Clinic at the Neurology & Neuromuscular Care Center, led by Dr. Diana Castro, will provide neurology, cardiology, pulmonology, nutrition, physical therapy, durable medical equipment, diagnostics, and chest radiography for both pediatric and adult Duchenne and Becker muscular dystrophy patients. The clinic will provide care and resources in both Spanish and English, for insured and uninsured patients. Dr. Castro sees great need for such services in the Dallas area, estimating that 30 percent of the families she sees are uninsured and 45 percent are on Medicaid, which is not accepted at all care centers but will be accepted at the CureDuchenne Clinic. CureDuchenne has granted \$900,000 over three years to support the clinic's Duchenne and Becker operations.

"Our ultimate goal is to help patients to the best of our ability, and we do that by offering specialized and inclusive care for all patients, especially the most vulnerable and underserved populations," Dr. Diana Castro said. "The CureDuchenne Clinic will bring compassionate care to everyone with Duchenne and Becker and would not be possible without CureDuchenne, who is not only focused on accelerating a cure, but also improving the health and wellbeing of patients living with Duchenne."

Neurology and Neuromuscular Care Center (NNCC) is a nonprofit private practice clinic started by Dr. Diana Castro to provide care to all patients, including the underserved population, with neuromuscular conditions. Dr. Castro, a board-certified neurologist and neuromuscular physician, is a pioneer in research and management of patients with spinal muscular atrophy (SMA), Duchenne muscular dystrophy (DMD), myasthenia gravis, and acquired neuropathies. Since completing training in pediatric neuromuscular medicine, Dr. Castro has conducted multiple clinical research trials in SMA, DMD, and Charcot-Marie-Tooth (CMT) disease, among other conditions. After more than ten years, Dr. Castro left academia with the objective of creating a nonprofit private practice and research institute for neuromuscular conditions.

CureDuchenne was founded by Debra and Paul Miller in 2003 after their son was diagnosed with Duchenne muscular dystrophy. The organization combines fundraising and venture philanthropy, leveraging donor dollars to maximize support for promising research into transformative treatments for those living with Duchenne. CureDuchenne also provides resources and guidance for families affected by the fatal genetic neuromuscular disorder, which affects more than 300,000 individuals worldwide, and delivers the education and programs needed to support Duchenne patients and their families, caregivers, and healthcare providers. To date, the organization has funded 17 research projects that have advanced to human clinical trials and invested \$25 million in research projects.

About CureDuchenne

Twenty years ago, CureDuchenne was created with one goal: to find and fund a cure for Duchenne muscular dystrophy, the leading genetic killer of young boys. Today, CureDuchenne is recognized as a global leader in research, patient care, and innovation for improving and extending the lives of those with Duchenne. CureDuchenne's innovative venture philanthropy model has advanced transformative treatments for Duchenne muscular dystrophy, including 17 projects that advanced to human clinical trials and multiple projects to overcome the limitations of exon-skipping and gene therapy. In addition, CureDuchenne contributed early funding to the first FDA-approved Duchenne drug, pioneered the first and only Duchenne physical and occupational therapist certification program and created an innovative biobank and data registry, accelerating research toward a cure. For more information on how to help raise awareness and funds needed for research, please visit <u>cureduchenne.org</u>.

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