Nemours/Alfred I duPont Hospital for Children, Designated a Certified Duchenne Care Center

Parent Project Muscular Dystrophy Designates Nemours/Alfred I duPont Hospital for Children, a Certified Duchenne Care Center

Nemours/Alfred I duPont Hospital for Children (Nemours) in Wilmington, Delaware, became the 17th clinic named a Certified Duchenne Care Center by Parent Project Muscular Dystrophy (PPMD), a nonprofit organization leading the fight to end Duchenne muscular dystrophy (Duchenne), the most common fatal genetic disorder diagnosed in childhood, affecting approximately one in 5,000 boys.

PPMD's Certified Duchenne Care Center Program, which supports standardized, comprehensive care and services for all people living with Duchenne, began certifying qualifying centers in 2014. Certification means centers maintain the highest standards in clinical and sub-specialty services, rapidly apply new evidence-based knowledge, minimize heterogeneity in clinical research outcomes, and comply with standards in clinical care that were established by the CDC Care Considerations. As part of its ongoing mission to end Duchenne, PPMD continues to insist that all people with Duchenne receive comprehensive care.

The Nemours Neuroscience Center at duPont Hospital for Children provides a specialized Neuromuscular Program under the direction of pediatric neurologist Dr. Mena Scavina. The program offers coordinated care by a skilled team of experts in neurology, orthopedic surgery, pulmonology, advanced practice nursing, cardiology, and genetic counseling. A complement of team members from respiratory, physical and occupational therapy, social work, nutrition, rehabilitation medicine and engineering, biomedical research, behavioral health, and orthotics and prosthetics, are all available to provide care for boys with Duchenne at each clinic visit.

Dr. Scavina was delighted to receive the designation as a PPMD certified center. She said: "On behalf of our Nemours Neuromuscular Program co-directors, Dr. William Mackenzie and Dr. Robert Heinle, our Advanced Practice Nurse, Alisa Clark, and the entire team, we are honored to receive certification from Parent Project Muscular Dystrophy. We look forward to working together with PPMD and are dedicated to continuously improving the care we provide to individuals with Duchenne muscular dystrophy and their families."

Kathi Kinnett, MSN, CNP, PPMD's Senior Vice President of Clinical Care and co-director of Transforming Duchenne Care Initiative (TDCI), is pleased that Nemours is joining the list of certified centers. Kinnett says, "We are very proud to include the Nemours/Alfred I. duPont team in our growing network of CDCC's. Dr. Scavina has a compassionate team of very knowledgeable providers who have worked to meet our robust standards for certification. Families living in this area should feel confident in the care and services provided at Nemours."

Kinnett says that PPMD receives numerous requests from centers wanting to be considered for certification. "When PPMD launched our certification program in 2014, we had no idea that the Duchenne community would respond so positively. Families have come to rely on our certification as an indication that these centers are the best of the best. We will continue to certify more centers across the country throughout 2017, recognizing teams of physicians for their leadership in Duchenne care, which in turn will enable families to make the best choice for the care of their child."

To learn more about PPMD's Certified Duchenne Care Center Program, visit PPMD's website. Click here to learn more about the history of PPMD's Certified Duchenne Care Center Program and to access PPMD's first published article on the program.

Duchenne is a fatal genetic disorder that slowly robs people of their muscle strength. Parent Project Muscular Dystrophy (PPMD) is the largest most comprehensive nonprofit organization in the United States focused on finding a cure for Duchenne muscular dystrophy—our mission is to end Duchenne.

We invest deeply in treatments for this generation of people affected by Duchenne and in research that will benefit future generations. We advocate in Washington, DC, and have secured hundreds of millions of dollars in funding. We demand optimal care, and we strengthen, unite and educate the global Duchenne community.

Everything we do—and everything we have done since our founding in 1994—helps people with Duchenne live longer, stronger lives. We will not rest until every person has a treatment to end Duchenne. Go to www.ParentProjectMD.org for more information or to learn how you can support our efforts and help families affected by Duchenne. Follow PPMD

on Facebook, Twitter and YouTube.

Nemours is an internationally recognized children's health system that owns and operates the Nemours/Alfred I. duPont Hospital for Children in Wilmington, Del., and Nemours Children's Hospital in Orlando, Fla., along with outpatient facilities in six states, delivering pediatric primary, specialty and urgent care. Nemours also powers the world's most-visited website for information on the health of children and teens, KidsHealth.org and offers on-demand, online video patient visits through Nemours CareConnect.

Established as The Nemours Foundation through the legacy and philanthropy of Alfred I. duPont, Nemours provides pediatric clinical care, research, education, advocacy, and prevention programs to families in the communities it serves.

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