

# Center for Genetic Muscle Disorders at Kennedy Krieger Institute

## Who We Are

The Center for Genetic Muscle Disorders at Kennedy Krieger Institute is an interdisciplinary clinic dedicated to the diagnosis and treatment of a variety of muscle disorders including muscular dystrophies (hereditary, progressive muscle diseases) and congenital myopathies (muscle disorders present at birth). Kennedy Krieger's 70-plus years of helping patients with physical and cognitive disabilities, combined with our newly expanded, world-class facilities provides patients at the Center much-needed access to innovative rehabilitative and assistive technology services under one roof.

## Who We Serve

We provide expert care for children and adults who have, or are at risk of developing, a muscle disorder from genetic causes, no matter the severity. We see patients with a range of disorders and diagnoses.

- **Muscular dystrophies:** Duchenne, Becker, Facioscapulohumeral, Myotonic, Congenital, Distal, Emery-Dreifuss, Oculopharyngeal, Limb Girdle
- **Congenital myopathies:** Central Core, Myotubular, Nemaline, Ullrich/Bethlem
- **Metabolic muscle diseases:** Mitochondrial Myopathy, Pompe Disease, McArdles Disease, Carnitine Palmitoyl Transferase Deficiency

## Our Team

Our Center features a unique collaboration between experts in genetic muscle disorders, research scientists, and rehabilitation professionals. Key disciplines include:

- Neurology
- Pulmonology
- Cardiology
- Orthopedics
- Endocrinology
- Physical therapy
- Occupational therapy
- Genetic counseling
- Nutrition
- Social work



*"I know that this is a place where my son will get the care he needs as he grows up. Kennedy Krieger is going to open so many doors for Collin."*

—Lilleen Walters, mother of patient

Every child is born with great potential.  
Shouldn't every child have the chance to achieve it?



Kennedy Krieger Institute

For more information, visit [www.kennedykrieger.org](http://www.kennedykrieger.org) or call 888-554-2080

## Our Treatment Approach

As a first step, we discuss the onset and progression of symptoms, examine muscles and other organ systems, and review any previous testing. Our team may recommend a blood test or muscle biopsy. A genetic counselor guides patients through the diagnostic process. Once a diagnosis has been confirmed, we tailor a treatment plan to the needs of each patient. The team may provide medical management through the use of corticosteroids or other drugs, which need to be carefully monitored. In addition, patients receive an assessment and individualized rehabilitation treatment plan. The team also manages contractures (shortening of the muscle or tendon), scoliosis, and heart and lung function. Finally, to help ensure each patient's success in community life, our social worker assists patients and families in securing any needed social, financial, and educational support.

## Our Research Program

At the Center for Genetic Muscle Disorders, our laboratory and clinical research programs play an important role in patient care. We are devoted to finding and developing new therapies for these disorders and have already had considerable success in the area of muscle regeneration. We have strong collaborations with other academic centers, parent and patient advocacy groups, and industry partners throughout the U.S. and the United Kingdom. To learn more about our clinical studies and trials, please visit [www.kennedykrieger.org/research](http://www.kennedykrieger.org/research).

## Contact Information

For more information or to schedule an appointment, please call 443-923-9525, or toll-free at 888-554-2080.

TTY: 443-923-2645

## Physicians & Healthcare Professionals

Healthcare professionals wishing to make a referral can also contact us at 443-923-9525.

## Center for Genetic Muscle Disorders

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Baltimore, Maryland 21205

[www.kennedykrieger.org/muscledisorders](http://www.kennedykrieger.org/muscledisorders)