

# Moser Center for Leukodystrophies at Kennedy Krieger Institute

## Who We Are

For more than 30 years, Kennedy Krieger Institute has been internationally recognized as an authority on the study and care of patients with leukodystrophies, thanks in large part to the visionary thinking and enduring legacy of the late Dr. Hugo W. Moser. Considered one of the world's foremost leaders in the field, Dr. Moser believed that innovative research and collaboration were the keys to enhancing clinical care, advancing patient outcomes, and improving the lives of individuals with leukodystrophies worldwide.

Today, that commitment lives on through the Moser Center for Leukodystrophies, where leading-edge techniques in neuroimaging, genomics, biomedical engineering, and nanotechnology are helping our experts enhance understanding, diagnosis, and treatment of leukodystrophies.

The center's interdisciplinary approach brings together the fields of neurogenetics, genetic counseling, neurorehabilitation, endocrinology, and urology, along with physical, occupational, speech, and aquatic therapy to provide comprehensive care for patients. Alongside our clinicians, our investigators are exploring the most promising research, while collaborating with other leukodystrophy centers across the country and around the world.

## Who We Serve

Our interdisciplinary team of experts treats patients from infancy to adulthood who have been diagnosed with, or are suspected of having, a leukodystrophy.

Leukodystrophies are diseases in which a gene defect leads to abnormalities of either the axon, the myelin, or the cells that provide nutrients to the axon. Currently, over 40 different leukodystrophies have been described. They are progressive diseases, meaning that the disease gets worse throughout a lifetime. Some of these diseases start in early infancy and progress rapidly, while others only affect adults or progress slowly over decades. Other leukodystrophies can present either during childhood or adulthood.



Examples of leukodystrophies include:

- Adrenoleukodystrophy
- Alexander disease
- Canavan disease
- Cerebrotendinous xanthomatosis
- Krabbe disease (globoid cell leukodystrophy)
- Metachromatic leukodystrophy
- Pelizaeus-Merzbacher disease
- Vanishing white matter leukodystrophy
- Hypomyelinating disorders
- Undiagnosed leukodystrophies

We are all born with great potential.  
Shouldn't we all have the chance to achieve it?



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

## Our Team

Our core faculty members include specialists in the following disciplines:

- Neurology
- Rehabilitation
- Physical therapy
- Endocrinology
- Psychiatry
- Nutrition
- Urology
- Genetics
- Social work

In addition, we collaborate with other medical specialists as needed to provide optimal interdisciplinary care for our patients.

## Our Treatment Approach

At the Moser Center for Leukodystrophies, we believe that every patient should receive the best possible care while we work for a cure.

Although leukodystrophies are neurological diseases, they can affect multiple organ systems. To address all aspects of a patient's care, the center draws on Kennedy Krieger's broad range of expertise. Some of the services provided include management of muscle tone and pain (including Botox), gait and balance problems, incontinence, seizures, adrenal dysfunction, and osteoporosis.

Diagnostic evaluation is usually based on magnetic resonance imaging (MRI), clinical hallmarks, and different metabolic or genetic tests. For patients with unknown leukodystrophies, the center also offers an individualized medicine approach using advanced genomic techniques. Genetic counselors are available to counsel patients and their families about inheritance, prognosis, family planning, and other questions they may have about their disorder.

## Research Initiatives

Investigators at the Moser Center are exploring cell therapy, brain imaging, and clinical trials to find new therapies and drugs aimed at preventing and treating leukodystrophies, and are also working to implement newborn screening for X-linked adrenoleukodystrophy. Our research team includes clinicians, biochemists, molecular biologists, neuroscientists, biomedical engineers, and biophysicists.

Our center houses the world's largest clinical database and biorepository for adrenoleukodystrophy. We collaborate with numerous centers across the world and serve as a resource center for historical data and biospecimens for this disease.

The Moser Center also takes advantage of the Clinical Genetics Laboratories at Kennedy Krieger, a state-of-the-art facility and international referral center for cytogenetic and biochemical genetics testing. Due to the close proximity of the lab, the staff can provide timely results and expert interpretations. We use whole exome sequencing technology to search all genes for disease-causing mutations, and receive assistance from our in-house experts in bioinformatics to analyze the data.

## Collaborations & Partnerships

The center works collaboratively with other leukodystrophy centers across the country and around the world. Working together, leukodystrophy experts can share information that will help patients get the treatment they need, and seek funding for the most promising research. Kennedy Krieger researchers are founding members of ALD Connect, a non-profit organization that seeks to advance research and facilitate communication between researchers and those affected by ALD. The Moser Center is also a Global Leukodystrophy Initiative (GLIA) clinical center of excellence.

## Patient Support and Advocacy

- ALD Connect
- Global Leukodystrophy Initiative (GLIA)
- Hunter's Hope Foundation
- The Leukodystrophy Alliance
- The Myelin Project
- The Stop ALD Foundation
- United Leukodystrophy Foundation (ULF)

## Contact Information

### Moser Center for Leukodystrophies at Kennedy Krieger Institute

For more information or to schedule an appointment, please contact Kim Hollandsworth at **443-923-2772** or via email at **Hollandsworth@kennedykrieger.org**.

TTY: **443-923-2645** or Maryland Relay **711**  
**kennedykrieger.org/leukodystrophy**

### Physicians & Healthcare Professionals

To make a referral, call our Physician Referral Line at **443-923-9403**.

### Mailing Address:

707 North Broadway  
Baltimore, MD 21205

Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Care is provided in a manner that preserves cultural, psychosocial, spiritual and personal values, beliefs, and preferences. We encourage patients and families to become active partners in their care by asking questions, requesting resources, and advocating for the services and support they need.



Learn More. Get Involved. Stay Connected. Visit [kennedykrieger.org/connect](https://kennedykrieger.org/connect).