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WHAT IS LEUKODYSTROPHY?

Leukodystrophy describes a group of more than 50 inherited neurological disorders that affect myelin, the protective covering on nerve cells in the brain and spine. Leukodystrophies cause a progressive loss of neurological function in infants, children and sometimes adults.

Are there different types of leukodystrophy?

Researchers have identified more than 50 types of leukodystrophy. They're still discovering new forms. Each form of leukodystrophy is the result of a different gene mutation (change) and causes different symptoms.
Leukodystrophies affect about 1 in 7,000 live births.

What are the symptoms of leukodystrophy?

The symptoms of leukodystrophy vary widely across the different disease types. But most forms of the disease result in gradual loss of neurological function. This means the body and brain have trouble talking to each other which can cause problems with:

- **Balance, movement and coordination**
- **Breathing**
- **Cognition (learning, thinking, remembering).**
- **Eating and swallowing**
- **Hearing**
- **Speech**
- **Vision**

How is leukodystrophy diagnosed & treated?

Diagnosis comes from evaluating symptoms, physical and neurological exams, reviewing personal and family health history, blood and saliva tests that check for mutated genes in the DNA and imaging exams, such as an MRI or CT scan, to check the white matter in your brain and spinal cord.
Even with testing, leukodystrophy is difficult to diagnose due to the wide-ranging symptoms. Many leukodystrophies go undiagnosed.

ABOUT THE FOUNDATION

The United Leukodystrophy Foundation (ULF), incorporated in 1982, is a nonprofit, voluntary health organization dedicated to providing:

- **Programs to aid & support families**
- **Financial support for research Support to newly diagnosed**
- **Annual Scientific & Family Conference**
- **Patient Advocacy Groups (PAG's) a platform to partner with**

YOUR DONATIONS FUND

- **Grant Awards to researchers from all over the world who are advancing treatments and means of a cure for leukodystrophies**
- **Our annual conference, where networking between families and the most respected doctors and medical researchers in the field is encouraged.**
- **Hultman Family Assistance Program**
- **Development of State Ambassador Program**

Our Mission

is to provide support to the leukodystrophy community and enable platforms to accelerate improving patient quality of life and finding cures.

Our Vision

is to meet the needs of patients and families, whether newly diagnosed or living with a leukodystrophy. Through unified collaboration with advocacy groups, medical and research professionals, and pharma/biotech companies, we provide support, networking, and education to help navigate the journey of the disease.