

WHAT IS LEIGH SYNDROME?

Leigh syndrome (sometimes called Leigh's disease) is a rare and severe neurometabolic disorder and a type of primary mitochondrial disease. It is a neurodegenerative disease that causes loss of abilities to walk, talk, swallow.



1 in 40,000

individuals are affected by Leigh Syndrome, although this number may be underestimated



2 mo - 3 yrs

age when symptoms typically start, although earlier or later onset is also possible



110+

genetic mutations in nuclear DNA and mitochondrial DNA can cause this syndrome, with more genes continuing to be discovered



Treatments for Leigh syndrome are focused on slowing disease progression.



Often, children have difficulties chewing and swallowing and it can be difficult to take in sufficient calories by mouth. A feeding tube - also known as Gastrostomy Tube (G-Tube) - can be really helpful in improving calorie intake and reducing the time needed for feeds.



A care team for a person with Leigh syndrome should include multiple specialists, such as geneticists, neurologists, cardiologists, gastroenterologists, ophthalmologists, palliative care, psychologists, speech, physical, occupational therapists, and others depending on the specific symptoms.

Caring for a child or loved one with a life-limiting condition like Leigh syndrome can be challenging. Lower stress and the risk of developing depression or anxiety by:

- Connecting with support groups familiar with Leigh syndrome
- Practicing self-care
- Asking for help
- Talking to a mental health professional if necessary

To learn more about Leigh syndrome, please visit curemito.org



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