

CARE TEAM

Leigh Syndrome is a multisystem disease that might affect several organs and body functions. Therefore, it needs a multidisciplinary and holistic approach. After getting a Leigh Syndrome diagnosis for your child, a team of doctors is needed to monitor the disease. There's a list of specialists that you might need in your team:

General practitioner – The role of the GP is to treat general conditions and to refer patients to hospitals and other medical services, help you find the closest metabolic ward, with doctors specialized in mitochondrial diseases.

Metabolic doctors/mito specialists – Metabolic doctors and mito specialists are specialized in disorders caused by inborn errors of metabolism and are familiar with mitochondrial diseases.

Neurologist – Leigh Syndrome is a neurometabolic disorder that affects the central nervous system. All children diagnosed with LS present neurological symptoms at some point. Movement disorders, epilepsy is common in LS and children need monitoring by a neurologist.

Gastroenterologist – Leigh Syndrome patients often have gastrointestinal disorders, feeding difficulties and weight problems, many children are tube fed, therefore, finding a gastroenterologist is very important.

Dietitian and Nutritionist – Many children with Leigh Syndrome are tube fed and are on special diets, so you might need to have a dietitian or nutritionist in your child's care team.

Cardiologist – Leigh Syndrome is often associated with cardiomyopathy or other cardiac disorders, cardiac assessments and monitoring are important.

Nephrologist – LS can affect kidney functions and can cause complications in addition to other symptom manifestations.

Ophthalmologist – Optic atrophy, ophthalmoplegia and other eye problems, progressive vision loss are common in LS and regular ophthalmology check-ups are recommended.

ENT specialist – Hearing impairment and progressive hearing loss is also common in LS. ENT specialists also treat swallowing and speech, breathing and sleep issues, allergies and sinuses that can often occur in children with mitochondrial diseases.

Pulmonologist – Infections, pneumonia and other respiratory symptoms might occur more often in children with progressive neurometabolic disorders. Some LS patients are tracheostomy carriers.

Physiotherapists and occupational therapists are needed for children with developmental delays caused by neurodegenerative diseases.

Orthopedic doctors can help monitor the musculoskeletal system, prevent and treat scoliosis, kyphosis or other malformations caused by movement disorders, physical disabilities.

Psychologists and support groups are really helpful for families who receive a devastating diagnosis such as Leigh Syndrome.

Endocrinologist - Some patients with mitochondrial disease have endocrine manifestations. Endocrinologists are qualified to diagnose and treat conditions associated with LS like diabetes, thyroid disorders, growth issues.