



<b>Legal Name</b>	<b>Preferred Name</b>		
<b>Date of Birth</b>	<b>Sex</b>	<b>Gender</b>	<b>Pronouns</b>
<b>Primary Diagnosis</b> <ul style="list-style-type: none"> <li>G93.49 - Leukoencephalopathy with Brainstem and Spinal Cord Involvement (LBSL)</li> <li>E88.43 - Mitochondrial Aspartyl-tRNA Synthetase Deficiency</li> </ul> <b>Additional Diagnoses</b>			
<b>Medications/Supplements</b> <input type="checkbox"/> "Mito Cocktail" (list components and dose)			
<b>Allergies</b>			

Specialty	Provider	Phone Number
Primary Care		
Neurology		
Metabolic		
Genetics		
Pharmacy		
Rehabilitation		
OT		
PT		
Speech		
Dietary/Nutrition		
Palliative Care		
Psychology		
Social Work		



## About the condition

Leukoencephalopathy with Brainstem and Spinal Cord Involvement and Lactate Elevation (LBSL) is an ultra-rare, progressive neurological disorder that affects the brain and spinal cord. LBSL is caused by mutations in the DARS2 gene, which provides the body with instructions for making an enzyme called mitochondrial aspartyl-tRNA synthetase. As a result of mutations in DARS2, certain parts of nervous system do not have sufficient energy to function properly, affecting their function and the production of myelin.

## Key Considerations

- **HEAD INJURY** – Patients with LBSL are particularly vulnerable to severe consequences from **head injury**. Recommend thorough neurological assessment, extended observation, and low threshold for imaging.
- **AGGRAVATING CONDITIONS** – Prevent whenever feasible; otherwise treat quickly and aggressively.
  - Fever
  - Dehydration
  - Fasting
  - Overheating
  - Hypothermia
- **INFECTION** – Diligently look for source of fever or symptoms suggestive of infection; treat aggressively.
- **MEDICATION INTERACTIONS** - Patients may be taking custom prescription “*mito cocktails*” (high potency antioxidants and amino acids) to support metabolic needs. Consult with pharmacist and/or clinicians familiar with mitochondrial disorders and treatment. Additional labwork may be indicated.
- **ASSESSMENTS** - Patient vitals (especially body temperature), lab results, etc. may be **out of reference range**. Inquire about **baseline**, and trust patients/parents as experts on their own “normal” values.
- **PROTRACTED RECOVERY** – Patient recovery may be longer than expected. Plan for extended impact from surgery, anesthesia, illness, injury, aggravating conditions (see above), and/or change in medication.
- **REFERRALS AND FOLLOW UP:** Patients should be counseled to follow up with their primary care provider, neurologist, and/or metabolic specialist soon after discharge. Follow-up labwork may be indicated. Consult OT/PT as needed. Refer patient to new specialists as needed to complete care team.

## Frequently Reported Symptoms (may first arise or worsen following aggravating event)

<input type="checkbox"/> Fatigue / exhaustion	<input type="checkbox"/> Mobility challenges	<input type="checkbox"/> Headache
<input type="checkbox"/> Energy depletion	<input type="checkbox"/> Balance difficulty	<input type="checkbox"/> Nystagmus / opsoclonus
<input type="checkbox"/> Heat/cold intolerance	<input type="checkbox"/> Gait disturbance	<input type="checkbox"/> Seizures
<input type="checkbox"/> Constipation	<input type="checkbox"/> Ataxia	<input type="checkbox"/> Peripheral neuropathy
<input type="checkbox"/> Dysarthria	<input type="checkbox"/> Spasticity	<input type="checkbox"/> Neuropathic pain
<input type="checkbox"/> Sleep disturbance	<input type="checkbox"/> Dysphagia	<input type="checkbox"/> Cold extremities (esp. feet)

## Healthcare provider signature

Provider name:	Date:
Signature:	Contact number: