



Thriving in
School with
LBSL



Mobility &
balance
assistance



Prevent
energy
depletion



Head
injury
prevention



Avoid
overheating,
dehydration
and fasting.



Reduce
infection
risk

Leukoencephalopathy with Brain Stem and Spinal Cord Involvement and Lactate Elevation (LBSL)

LBSL is an ultra-rare, progressive, genetic condition that is both a mitochondrial disorder (affecting energy to the cells), and a form of leukodystrophy (a disorder affecting the white matter of the brain, the spinal cord, and/or peripheral nerves).

Fewer than 150 people have been identified with **LBSL** worldwide, so now you know someone super rare & unique!

A graphic of a spiral-bound notebook with a white page and a teal cover. The spiral binding is at the top. The page contains text about LBSL.

How You Can Help

Kids with **LBSL** can thrive at school, but we may need extra support from our amazing teachers, administrators, and classmates.

We know that you have lots of other kids who need your attention, so here's a quick presentation to help you learn what you can do to help a student with **LBSL**.

Special Considerations

Not all kids with **LBSL** have the same needs, but here are some of the more common concerns that come up at school.

- Mobility, coordination, & balance challenges
- Energy depletion
- Vulnerable to complications from dehydration, fasting, and overheating
- Serious harm from head injuries
- Higher risk of complications from infections

Mobility & Balance

In **LBSL**, the brain and spinal cord are affected to varying degrees, which can make walking and staying balanced a challenge. Fine motor and gross motor coordination may be difficult, and for some kids, there is a higher risk of falling.

Some kids with **LBSL** are able to walk on their own, although often slower and for shorter distances than their peers. Other kids use assistive devices such as orthotics, canes, walkers, or wheelchairs.

Mobility & Balance

You can help by:

- reducing tripping hazards
- seating student at easily accessible seat / desk / table
- making the classroom easy to navigate
- limiting the need to travel long distances in the building
- allowing extra time for transitions
- collaborating with OT & PT specialists

Energy Depletion

We all learned in biology class that mitochondria are the powerhouses of the cell. In **LBSL**, the mitochondria aren't able to produce full power, so kids are very prone to energy depletion.

You can help by reducing non-essential or excessive demands on their energy reserves. You can also help find a safe and private place to rest as needed during the day.

Please be flexible with workload and assignment deadlines.

Avoid Overheating, Dehydration & Fasting

Kids with **LBSL** are often particularly sensitive to the heat. They also are also very vulnerable to complications if they don't have enough water or high-energy food.

You can help a student with **LBSL** thrive at school by keeping them inside when it's too hot outside, allowing them to keep a full water bottle with them at all times, and by offering high-energy snacks (families will provide snacks and instructions).

Head Injury Prevention

One of the most important things you can do is help kids with **LBSL** prevent head injuries. Avoid activities that have a high risk of head injury like contact sports.

Some kids with **LBSL** wear a protective helmet during higher risk activities. During PE the student may also be given extra space for movement.

Remember - always report ANY head injury (even minor) to the family and/or health clinic staff right away! Check the health action plan for more details.

Reduce Infection Risk

Kids with **LBSL** are extra vulnerable to harm from fevers and infection. Not only is it dangerous and scary to be sick when you also have **LBSL**, but it can also mean lots of missed school.

You can help by reducing the infection risk at school with techniques like good handwashing, mask-wearing, and/or cohorting in small groups.

Please be alert for and report any signs of fever or illness. Tell families about any known or suspected exposures to people with contagious illnesses.

Planning for Success

One of the best ways to ensure that kids with **LBSL** have a successful school year is to plan in advance for how to prevent and respond to situations that may arise.

Teachers are expert planners, so we are excited to partner with you to help come up with some plans for this year.

Here are some sample plans and brainstorming tools get started to help your student with **LBSL**.

You can find more tools at www.curelbsl.org

Types of Plans*

- Health Action Plans
 - General Medical
 - Medication
 - Mental Health
 - Infection Prevention
 - Head Injury
 - Seizure
 - Asthma
 - Allergy
 - Emergency Plans
 - Building Access Plan
 - Transportation Plan
 - Special Education Plans
 - 504 Accommodations
 - IEP
 - Related Services
 - Assistive Technology
 - Transition
 - Self-Advocacy
 - General Academic Plans
 - Athletics / PE
 - Substitute Teacher
 - Attendance
 - Assignments
 - Field Trips
- *Not all kids will require all types of plans

Health Action Plans

- General health action plan
- Medication administration plan
(including 72-hr supply of medications for emergencies)
- Mental health plan
- Infection prevention plan
- Head Injury
- Seizure action plan
- Asthma action plan
- Allergy action plan

Special Education Plans

- 504 Accommodations
- Individualized Education Plan (IEP)
- Related Services
 - Occupational Therapy
 - Physical Therapy
 - Speech Therapy
- Assistive Technology (AsTech)
- Transition Planning
- Self-Advocacy Tools

Emergency Plans

- Building evacuation
 - Fire alarms (unplanned)
 - Fire drills
 - Wheelchair evacuation
- Bus evacuation / safety drills
- Aide or buddy system
- Lockdown /Shelter-in-place
 - 72-hrs of medication/supplies

Transportation Plans

Make sure to consider needs for:

- Daily transportation
- Field trip transportation
- Accessible parking spots and entrances at school
- School Bus / Van
 - Aide and/or buddy
 - Wheelchair accessibility
 - Infection prevention
 - Bus safety drills and evacuation

Field Trip Plans

- How will student navigate the site? Is it fully accessible?
- Will they need an aide or a buddy?
- Who will monitor energy needs? Is there a place to rest?
- What is the plan to avoid overheating, dehydration, and/or fasting?
- Are there any special transportation needs?
- What supplies or medications are needed?
- What emergency medical care is available on/near field trip site?

Substitute Teacher Plans

- Where is a written plan for substitute teachers located? Do the administrators have a copy?
- Is the substitute aware of accommodations?
- Who is another staff member who is familiar with child's needs? _____
- Is there a plan to notify the families of scheduled or long-term teacher absences?

Athletics & PE Plans

- How can the curriculum be modified to avoid contact sports, running, etc.?
- Are there meaningful alternative activities?
- What plans are in place to avoid head injuries?
(i.e. may use helmet)
- How can student access water and high energy snacks?
- What are the infection prevention practices?
(i.e. no shared water bottles, disinfected equipment, etc.)

Attendance Plan

- What is the plan if the student has an extended absence due to illness or quarantine after exposure?
- Are there any in-school services available that can reduce the need for the student to be pulled out for private appointments?
- Would a reduced schedule be appropriate? $\frac{3}{4}$ day?
 $\frac{1}{2}$ day?
- Can we limit high-demand classes in the later part of the day?
- Are there hybrid learning options?
- What are the home schooling options?

Assignment Plan

- Who will make sure student knows what was missed if they leave class early / arrive late / need to rest?
- How can student catch up on missed assignments during absences?
- Who can help if it gets overwhelming?
- Can assignments be reduced without affecting learning?
- Can student dictate or type instead of handwriting?
- What assistive technology might be helpful?

A graphic of a spiral-bound notebook with a white page and a teal background. The spiral binding is at the top. The text is centered on the page.

Thank you!

We look forward to working with you this year to help _____ thrive! Please contact us any time.

Family:

Phone:

Email:

References & Resources

- **LBSL**
 - www.curelbsl.org
 - <https://rarediseases.org/rare-diseases/leukoencephalopathy-brain-stem-spinal-cord-involvement-lactate-elevation/>
- **Mitochondrial Disorders – School Advocacy**
 - <https://www.mitoaction.org/school-education/>
- **Leukodystrophy / Neurology Family Companion**
 - <https://www.huntershope.org/wp-content/uploads/2020/10/FamilyCompanionNeuroFINALDRAFT6.29.pdf>

References & Resources

- **Advocating for Your Child With a Rare Disease At School**
 - https://globalgenes.org/wp-content/uploads/2019/01/GG_toolkit_educational-advocacy_web-hyperlinked.pdf
- **Self Advocacy for Children and Teens with Disabilities**
 - <https://www.imdetermined.org/>
- **Special Education Advocacy**
 - <https://www.wrightslaw.com/advoc.htm>
- **How to Prepare for an IEP Eligibility Meeting**
 - <https://www.understood.org/en/articles/what-to-expect-at-an-iep-eligibility-meeting>
- **Assistive Technology**
 - <https://www.wrightslaw.com/info/atech.index.htm>

References & Resources

- **Emergency Planning for Students with Disabilities**
 - https://www.ssdmo.org/cool_tools/inclusive/Resources/emergency_plan.pdf
- **Seizure Action Plans**
 - <https://www.epilepsy.com/preparedness-safety/action-plans>
- **Asthma Action Plan**
 - <https://www.aafa.org/asthma-treatment-action-plan/>
- **Allergy Action Plans**
 - <https://www.foodallergy.org/living-food-allergies/food-allergy-essentials/food-allergy-anaphylaxis-emergency-care-plan>
- **Head Injury Action Plans**
 - <https://www.cdc.gov/headsup/schools/index.html>

Thriving At School With LBSL

was created by the Cure LBSL patient advocacy organization.
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For more information or additional resources, please visit
www.curelbsl.org

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