Patient Engagement
Cure LBSL

Patient Engagement
Melody Kisor, MS  
Director of Patient Engagement  
A Cure For Ellie / Cure LBSL

• Education
  • BA in Public Health
  • MS in Biomedical Ethics (maternal/child & genetic ethics)

• Related Experience
  • Birth defects surveillance, registry, & research
  • IRB and research ethics
  • Perinatal health educator

• Personal
  • Leukodystrophy sister
  • Mother of two (one is longtime KKI patient)
  • US Navy wife
  • Long-time supporter of A Cure for Ellie
Goals

- Connect patients & families
- Promote CureLBSL
- Collect and create resources
- Expand access to research
- Get FDA ready for treatments and cures
Connect Patients & Families
Connect Patients & Families

A new RareConnect community:

LBSL

CONNECTING RARE DISEASE PATIENTS GLOBALLY

WWW.RARECONNECT.ORG
We can now connect with international families with automatic translation to their choice of 13 languages:

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<tr>
<th>Language</th>
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<tr>
<td>Čeština</td>
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<td>فارسی</td>
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<td>日本語</td>
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<td>Українська (в стадії розробки)</td>
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Здравствуйте и спасибо. Не только во Франции я ищу во всех странах мира семью с очень маленьким ребенком, затронутым этой болезнью.

Здравствуйте, у нас есть дочь с ЛБСЛ. Она старше, ей 15 лет. Мы живем в Чехии...

Cure LBSL
11 дней назад - Edited
Оригинал написан на Английский язык
Promote CureLBSL with Partners
Partner Organizations

Already connected
• NORD
• MitoAction
• GLIA

Pending connections
• MedLine Plus
• NIH – GARD
• United Mitochondrial Disease Foundation
• Leukodystrophy Family Forum
• Eva Foundation
• Hunter’s Hope

New connections
• EURORDIS
• RareConnect
• Disease InfoSearch
• United Leukodystrophy Foundation
• Alex TLC - The Leukodystrophy Charity
• Global Genes / Genetic Alliance
• Gene Reviews

Future connections
• OrphaNet
• Human Disease Genes
• ELA
• Who are we missing? Please connect if you know of other international partners.
Researchers & Clinicians
Create Resources for Patients and Clinicians
Sick & Emergency Protocols

- Vomiting Protocol
- Fever & Infection Protocol
- IV Fluid & Surgery Protocol
School Advocacy, Healthcare and IEP/504 Plans

Does your child or student have mitochondrial disease or complex medical needs? Do you know how to help?

“Energy for Education”
IEPs, Health Care Plans and school survival tips for kids with complex medical conditions

Cristy Balcells RN MSN
Executive Director

Kirsten Casale
Chair, Education & Advocacy
www.MitoAction.org

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Newly Diagnosed Action Plans
Comprehensive Patient Care Guides

The Care of Congenital Myopathy
A Guide for Families
Expand Access to Research
International Contact Registry
International Patient Registry & Biorepository
LBSL Patient App
Get “FDA Ready” for Treatments & Cures
On-demand telephone interpreting in over 150 language, 24/7/365

• Video call interpreters

• Translation of documents, emails, website content, etc.

• Voice-overs and subtitles for videos
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