Turning hope into progress

2025 ANNUAL REPORT

Advocacy, Awareness, & Advancing Science for LGMD2I/R9

Prepared by

Kelly Brazzo, Co-Founder, President/CEO

Turning hope into progress

Celebrating 15 years of CureLGMD2i

15 years of driving research, raising awareness, and standing with families affected by LGMD2I/R9.

Mission of CureLGMD2i

Providing Advocacy, Spreading Awareness, Supporting Scientific Research and Drug Development with the Goal of Finding a Cure for Limb Girdle Muscular Dystrophy 2I/R9.

Vision of CureLGMD2i

Our vision is to pioneer a future where every individual affected by Limb Girdle Muscular Dystrophy Type 2I/R9 can be treated early and live a life unencumbered by its challenges. By relentlessly pursuing innovative research, collaborative partnerships, and drug development, we envision accessible and effective treatments that slow or prevent the progression of the disease.

Kelly Brazzo,
President/CEO
CureLGMD2i

2025 was a year of momentum, collaboration, and new breakthroughs. Our community's strength continues to drive progress toward treatments and a future free from the limitations of LGMD2I/R9. We expanded advocacy efforts, strengthened research partnerships, and elevated awareness across scientific and patient communities. Thank you for being part of this journey and inspiring the path toward approved therapies for all of our patients impacted by LGMD2I/R9. Join us as we continue to celebrate 15 years of CureLGMD2i!

Kelly Brazzo

Turning hope into progress

CureLGMD2i is Growing!

Shown Left to Right:

Kristen Olsen – Secretary/Treasurer
Dan Pope – Vice President/Advocacy Director
Kelly Brazzo – President/CEO/Executive Director
John Spencer – Officer/Creative Director
Kaitlyn Neroladakis – Officer/Communications Director

CureLGMD2i is expanding into Canada, thanks to the leadership of Jen Zuchetto, mom of Jaxson & Chloe, living with LGMD2I/R9!

Visit: curelgmd2icanada.org

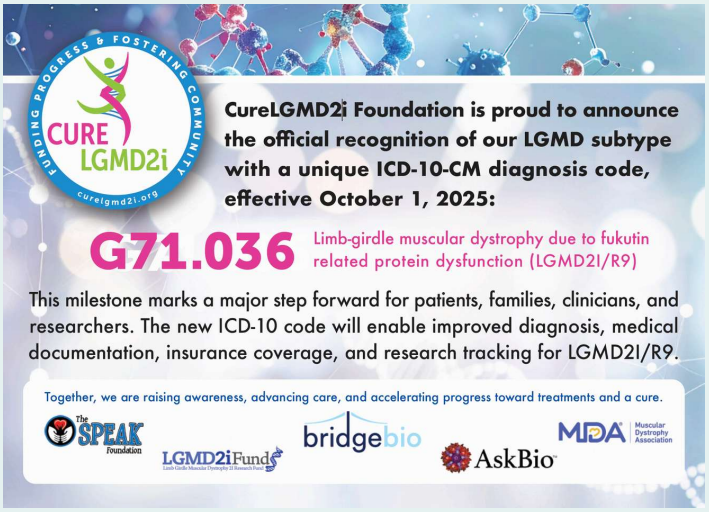
We are excited to share that Lacey Woods has joined us as our Community Engagement Coordinator!

"I'm thrilled for the opportunity to work with CureLGMD2i, an organization I deeply believe in, and to be actively involved in the journey toward a cure."
Lacey Woods

Turning hope into progress

Advocacy Efforts

- Obtained our ICD-10 Code for LGMD2I/R9 (G71.036)
- Rare Disease Day on the Hill
- MDA Neuromuscular Advocacy Collaborative
- Rare Across America
- LGMD Day on the Hill
- Hosted an Advocacy Power Hour Webinar
- Presented to FDA CBER on facilitating the Development and Review of Cell and Gene Therapies
- Presented at ASGCT Empowering Patients 2025: A Cell and Gene Therapies Summit
- Led patient focus groups for our industry partners
- Presented at the Rare Disease Congressional Caucus Briefing
- Member of the following advocacy coalitions:
  - Save Rare Treatments Task Force
  - Genomic Answers for Children's Health Alliance
  - Pediatric Inclusion Alliance
  - EveryLife Foundation Community Congress
  - Critical Path Institute LGMD Task Force



Turning hope into progress

Awareness Programs

- Launched the Rare Disease Day Ambassador Campaign
- Served on LGMD Awareness Day Planning Committee
- Participated and hosted awareness tables at MDA, Iowa Wellstone and International LGMD Conferences
- Rare Disease Day Documentary, “Growing up with LGMD”
- Sponsored the podcast, “Unbalanced” featuring Cerys Davage, living with LGMD2I/R9
- Produced the Connecting for a Cure Documentary for the 15th Anniversary of CureLGMD2i
- Served on the Global FKRP Registry Steering Committee
- Contributed to the LGMD News Magazine
- Committed to hosting the 2nd European LGMD2I/R9 Conference

Turning hope into progress

Advancing Science

Conference Sponsorships

- International LGMD Conference
- Iowa Wellstone Dystroglycanopathy Conference
- European LGMD2I/R9 Conference

Research Grants

- Dr. Emma Rybalka, Victoria University - Preclinical screening of adenylosuccinic acid (ASA-001) in a mouse model of LGMDR9
- MDA - Developing a Core Muscular Dystrophy Clinical Trial Research Network
- Dr. Peter Currie , Monash University - Examining the clinical significance of FKRP's regulation of Fibronectin Sialyation
- Drs. Emerson & Wolf, UMass - FKRP gene correction via prime editing (CRISPR)

Industry Investments

- Invested in Cure Rare Disease for the development of Myo-AAV for LGMD2I/R9, which is headed toward a clinical trial!

Patient Registry

- Newcastle University - Ongoing Global FKRP Registry

*Many of these programs co-funded with our partners:

Turning hope into progress

2025 was our most successful year to date!. Through donations, grants and sponsorships, we raised a total of **$543,356.45!**

We provided **$133,914** in scientific program grants, **$9,545.22** in conference expenses, and **$32,479.07** in awareness projects for LGMD2I/R9.

Your Support is Making an Impact!

To make a tax deductible donation, visit: curelgmd2i.org

$500
Covers one Travel Stipend for LGMD2i Conference

$1,000
Office and overhead expenses for one month

$5,000
Creation of an LGMD2I/R9 Awareness Campaign

$10,000
One year International FKRP Registry Grant

$25,000
Provides a new LGMD2I/R9 Scientific Research Grant

$100,000
Investment in a new biotech startup

$200,000
Covers the cost of dosing one patient with gene therapy + 5 year follow up

To date, CureLGMD2i has provided over $1.5 million in funding programs for LGMD2I/R9

Programs Funded by CureLGMD2i