LGMD Advocacy Organizations

The Speak Foundation (TSF) was established in 2008 to address the unmet needs for individuals living with LGMD and other neuromuscular diseases. TSF is a patient-led and patient-focused organization dedicated to those who often do not have a voice in regulatory, legislative, and pressing issues regarding the lack of systemic care for those living with catastrophic forms of muscular dystrophy. Since 2008, we have provided leadership along with our partner organizations to the LGMD patient community through landmark initiatives such as the International LGMD Conference, *LGMD News* Magazine, LGMD Scientific Workshop, Patient Listening Session, and the Patient Focused Drug Development Meeting with the FDA. Improving the quality of life for those living with LGMD is an important mission to all of us. Our organization was founded on the principle: "Speak up for those who have no voice." (Proverbs 31:8). **TheSpeakFoundation.com**.

CureLGMD2i Foundation is a 501(c)3 non-profit organization, founded in 2011 by the Brazzo family when their daughter was diagnosed with LGMDI 2I/R9. Their mission is providing advocacy, spreading awareness, and supporting scientific research and drug development with the goal of finding a cure for LGMD 2I/R9. Their vision is to pioneer a future where every individual affected by LGMD 2I/R9 can be treated early and live a life unencumbered by its challenges. By relentlessly pursuing innovative research, collaborative partnerships, and advancing drug development, they envision accessible and effective treatments that slow or prevent the progression of the disease. **CureLGMD2i.org**.

Formed in September 2013, the **LGMD2D Foundation** is a registered 501(c)3 non-profit foundation built for families living with LGMD2D—both patients and caregivers—by families with the same diagnosis. Our mission is to expedite the development of treatments or a cure for LGMD, type 2D/R3 (LGMD2D). In addition to educating patients, researchers and physicians, the foundation: Maintains the only international patient registry for LGMD2D; Funds research and monitors progress of clinical trial development; Provides financial support to accelerate clinical trials; Encourages scientific collaboration and partnerships; Participates in LGMD community events including, most recently, the Externally Led Patient-Focused Drug Development meeting (LGMD Coalition Member / September 2022), International LGMD conference (2023 Advocacy Sponsor) and FDA Scientific workshop (Patient Advocacy / February 2024). **LGMD2d.org**.

Coalition to Cure Calpain 3 (C3) has a pinpoint focus: to drive research towards a cure for LGMD2A/R1, (Calpainopathy). For the last decade, C3 has been the U.S.-based non-profit leader of funding for LGMD2A/R1 research and is led by Dr. Jennifer Levy, C3 Scientific Director, who directs the grant program, with a portfolio focused on gene and cell therapy, novel approaches, tool creation, and clinical trial readiness. **CureCalpain3.org**.

LGMD Awareness Foundation, Inc. is a 501(c)(3) non-profit advocacy organization dedicated to globally raising awareness of the rare neuromuscular diseases known as LGMD. In collaboration with other LGMD foundations, our focus is to provide curated educational information and resources for the LGMD community. By increasing awareness of and advocating for individuals living with limb-girdle muscular dystrophy, individuals living with this progressive debilitating disease will have an easier time accessing diagnosis, care and treatment. We also coordinate a worldwide Limb-Girdle Muscular Dystrophy (LGMD) Awareness Day annually on September 30th. **LGMD-Info.org**.

The **Dion Foundation** (DF) is a non-profit organization established in 2023 with the mission to raise awareness of rare and ultra-rare genetic diseases affecting children, primarily LGMD2C. We advocate for supportive legislation at both local and federal levels, and we are dedicated to allocating funds for research and the development of potential treatments and cures for these devastating conditions. Since its founding, the DF's current initiatives include advocacy efforts: working with legislative and policy stakeholders to support legislation to improve the lives of patients in the rare disease community. The DF supports pre-clinical research projects and has committed to funding the first-ever clinical trial for LGMD2C. At the Dion Foundation, we believe that no child should be left behind. Every child matters, and so do the countless others affected by rare genetic neuromuscular diseases. **TheDionFund.org**.

The family of Kurt and Peter Frewing founded the **Kurt+Peter Foundation** to apply available scientific techniques to treat or potentially cure limb girdle muscular dystrophy, type 2C. The Kurt+Peter Foundation funds "translational research" to take science from the lab to produce drugs that will treat the disease. The Kurt+Peter Foundation works with top tier research institutions and biotechnology companies. When necessary, the Kurt+Peter Foundation will act as a non-profit drug company, directly licensing the technology, applying for regulatory approval, and funding clinical trials. **KurtPeterFoundation.org**.