

About the Alliance

Founded by a patient in 2007, the LGDA is a 501(c)(3) nonprofit incorporated in the United States and serving a worldwide community of patients, many of whom are young children, and their families.

The mission of the LGDA is to improve the quality of life of patients with complex lymphatic anomalies (CLAs): generalized lymphatic anomaly (GLA), also known as lymphangiomatosis, kaposiform lymphangiomatosis (KLA), central conducting lymphatic anomaly (CCLA), and Gorham-Stout disease (GSD).

To accomplish its mission, the LGDA:

- provides information and a support network for patients and their families;
- distributes information to patients and families, clinicians, researchers and others;
- promotes and supports basic science and patient-centered clinical research that will improve understanding of CLAs and establish best practices for their diagnosis and management; and
- advocates for public policies that benefit those living with these rare lymphatic diseases.

The Board of Directors has established that the LGDA be focused on patient support, education and outreach; supporting scientific and clinical research; and building partnerships that advance the mission.



You're not alone. We're here to help.

To learn more visit us online:



www.lgdalliance.org



www.facebook.com/LGDAlliance



www.twitter.com/LGDAlliance

To get help from our patient support network contact our Director of Patient Programs:

Email: support@lgdalliance.org

Phone: 318-734-8240

For information about research and to quickly be informed about new research studies and clinical trials in which you or your child may be eligible to participate, join the *International LGDA Patient Registry for Complex Lymphatic Anomalies*:

www.lgdaregistry.org



Lymphangiomatosis & Gorham's Disease Alliance
19919 Villa Lante Place
Boca Raton, FL 33434
561-441-9766

*Patient Driven Solutions for
Complex Lymphatic Anomalies*

Patient & Family Support Guide

For more information, visit our website:

www.LGDAlliance.org

Patient & Family Support

Online Support Group

The LGDA has created a support group through Facebook for adult patients and the parents of young children from all over the world to share experiences and support one another. In order to preserve members' privacy, the group is closed and membership is by invitation only. For more information or to request an invitation to join the group, email us at support@lgdalliance.org.

Patient and Family Matching

For those who do not use social media, the LGDA patient support team is available to help locate and introduce patients and families through other channels, such as email. If you are interested in being matched or acting as a match for others, email us at support@lgdalliance.org.

Patient/Family Conferences, Education & Advocacy

The LGDA conducted its well-attended patient and family conferences in 2014 and 2018, one of the LGDA's major efforts to provide education and advocacy. The LGDA also provides information through its website, newsletter, social media and other channels; plans and supports clinical and research conferences focused on GLA, KLA, GSD, and CCLA; and partners with other organizations to raise awareness and leverage resources. For more information or to become an advocate, visit our website: www.lgdalliance.org.

Research Support

LGDA Patient Registry

The *International LGDA Patient Registry for Complex Lymphatic Anomalies (LGDA Registry)* is an information network for patients and families and serves as a recruiting source for researchers.

The LGDA Registry collects and analyzes information provided by patients with GLA, KLA, GSD, and CCLA in order to expand the basic knowledge about these diseases, better understand the patient experience, and to identify avenues of research of importance to patients.

For more information and to enroll a patient, visit the LGDA Registry website: www.lgdaregistry.org.

Tissue Needed for Research

The LGDA strongly encourages patients to donate blood, plasma, and tissue for research when the opportunity arises, such as when a patient has surgery for any reason.

Scientists study patient-donated tissue to understand how CLAs start and progress, and in the hope of finding better ways to diagnose and treat these diseases. It is critical that opportunities for scientists to get the tissue needed for their research not be missed.

Anytime a patient is hospitalized for any reason or scheduled for surgery, please contact the LGDA right away at support@lgdalliance.org or call 561-441-9766 so that we can help you to arrange for tissue donation.

More Research Support Information

The LGDA is dedicated to supporting research that will improve understanding of GLA, KLA, GSD, CCLA, and other rare lymphatic diseases and identify effective therapies. For more information about research efforts, visit the LGDA website at www.lgdalliance.org and that of its research partner, the Lymphatic Malformation Institute (LMI), at www.lmiresearch.org.

Partners & Affiliates



Proud member of the Rare As One Network

