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 generalized lymphatic anomaly (GLA), also known as lymphangiomatosis, kaposiform lymphangiomatosis (KLA), and Gorham-Stout disease (GSD). The LGDA:

- provides information and a support network for patients and their families;
- distributes information to patients, the public, the medical community, and the media;
- promotes and supports basic science and patient-centered clinical research that will improve understanding of these diseases 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: 844-588-5771 (Toll Free)
Direct: 561-880-8923

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 Registry for Lymphatic Malformations:

www.lgdaregistry.org

Lymphangiomatosis & Gorham’s Disease Alliance
19919 Villa Lante Place
Boca Raton, FL 33434
561-588-5771 (Toll Free)

Patient & Family Support Guide

To give hope and find help

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 inaugural patient/family conference in 2014, 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, and GSD; 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 Registry for Lymphatic Malformations (LGDA Registry), established and funded by the LGDA, 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 other rare lymphatic disorders in order to expand the basic knowledge about these diseases, the impact they have on patients and their families, and to inform interested patients about research in which they may be eligible to participate.

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 tissue for research when the opportunity arises, such as when a patient has surgery for any reason. Anytime a patient is hospitalized for any reason or scheduled for surgery, please contact the LGDA right away at support@lgdalliance.org or call 844-588-5771 so that we can help you to arrange for tissue donation.

Scientists study patient-donated tissue to understand how GLA (lymphangiomatosis), KLA, and GSD 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.

More Research Support Information
The LGDA is dedicated to supporting research that will improve understanding of GLA, KLA, GSD, 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.