

Channels



News & Events from the Lymphangiomatosis & Gorham's Disease Alliance

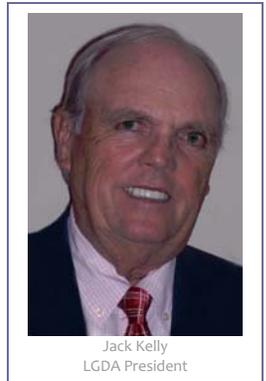
Fall 2010



Channels is dedicated to all those who live with lymphangiomatosis & Gorham's disease and the Angels who watch over them.

President's Column

We have recently passed our three-year anniversary of the founding of the LGDA. In pursuit of our mission, we are earnestly focused on the goals set out at the beginning: to provide support, improve care, and promote research. We have been able to bring into action research and medical professionals, volunteers, institutions and laboratories all around the world, and we have formed partnerships and relationships with a number of relevant rare disease advocacy foundations. Our patient community continues to grow with inquiries averaging more than one new case each week.



Jack Kelly
LGDA President

For our patient community, we are pleased to report that we now have relationships with five medical centers with specialty teams that assist in the evaluation, diagnosis, and treatment of Gorham's disease or lymphangiomatosis. We will be featuring each of these in upcoming issues of *Channels*. We expect to add more of these centers to our resource list in the coming year.

In furtherance of our goal to establish a research platform, we recently organized and hosted the first-ever assembly of international specialists in research and medicine to discuss the state of understanding of lymphangiomatosis and Gorham disease. As a follow-up to that meeting we are exploring how we may develop and implement a more fluid collaborative process among the vascular anomalies centers so we can begin the long-awaited research to find the cause and develop treatments for these complex disorders. This issue of *Channels* features a research article with more details about this historic meeting. We will continue to report on this very, very important work.

As always, we are enormously grateful to so many---some of whom wish to remain anonymous. In the next issue of *Channels*, we will honor those who have made it financially possible for us to do this important work.

We send our best wishes to all for good health.

With Best Regards,

Jack Kelly
President, LGD Alliance

"Reaching for a Cure"



Where to find more information about us:

www.lgdalliance.org

Follow us on

Facebook

Go to www.facebook.com and type Lymphangiomatosis & Gorham's Disease in the search box.

First International Conference Held on lymphangiomatosis & Gorham's disease



For many years patients diagnosed with lymphangiomatosis and Gorham's disease and their families have been strangers in a strange land. Oftentimes diagnosis is elusive. Misdiagnoses are common. Too often patients and families are left to search alone for someone---anyone---who might have answers to their basic questions: What is wrong with me; can anyone help my child; is there a cure? Everywhere they turn the answer seems to be, "We don't know," setting them adrift with no captain, trying to navigate dark waters while praying for calm seas.

This summer the LGDA brought together for the first time physicians and researchers from around the world on a mission to change that.

Bethesda, MD, was the site of the 1st International Conference on Research and Medicine for the Study of Lymphangiomatosis & Gorham Disease. The meeting was held June 4-5, 2010, with the primary purposes being to discuss the current state of diagnosis and treatment of lymphangiomatosis and Gorham's disease and the implications for the future of research, diagnosis, and treatment.

The conference featured presentations by physicians and researchers from the United States, Europe, and Great Britain on a wide range of topics. From basic biology to clinical experiences and case presentations, the group covered many important aspects of pathology, diagnosis and treatment, theories of possible origins of lymphangiomatosis and Gorham's disease, and the need to define the common characteristics of these conditions in order to delineate standard treatments. The subject frequently returned to the importance of a uniform international system through which to collect and store patient data and conduct research.

The LGDA is very excited about this critical step in the process of building a research platform, developing uniform classification and characterization of these conditions, and identifying viable treatments for lymphangiomatosis and Gorham's disease. Preliminary plans are already underway for the 2nd International Conference.

Founder's Award

First Founder's Award Presented to Children's Hospital Boston

The LGDA is pleased to announce the presentation of its first Founder's Award to the Interdisciplinary Medical Team, Vascular Anomalies Center, Children's Hospital Boston. With nearly 30 medical professionals working in aspects of vascular anomalies evaluation, diagnosis, treatment, and patient care the CHB VAC is reportedly the largest in the world. Co-Directors of the team are John Mulliken, MD, Steven Fishman, MD, and Ahmad Alomari, MD, top experts in the field. Each member of the team has advanced training and expertise in one or more of 18 specialties.

Each week the VAC Team at Children's Hospital Boston reviews cases submitted by physicians and patients from across the United States and around the world. These case reviews and consult reports are provided at no cost to the patient. Where necessary, or requested by patients and/or their physicians, members of the team see patients in their specialty clinics at CHB, often continuing consultant relationships with the patient's local physicians. For many years, the VAC team at CHB has been a tremendously



Jack Kelly (center) presenting the LGDA Founder's Award to the Co-Directors & members of the Interdisciplinary Medical Team, Vascular Anomalies Center, Children's Hospital Boston

important resource for patients with lymphangiomatosis and Gorham's disease.

The late founder of the LGDA, Jana Sheets, described the work of the VAC staff at CHB: "They took cases where there was no one else to turn to; they extended care, treatment and consultation when we were orphaned; they brought us hope where there was despair. Above all, they have been so generous with their time and human kindness."

These are but a few reasons the LGDA is proud to present its first Founder's Award to this outstanding team of professionals.



Spotlight on the Rare Bone Disease Patient Network

The Rare Bone Disease Patient Network (RBDN) is a coalition of rare bone disease organizations, established under the U. S. Bone and Joint Decade (USBJD), that shares information, expertise, and resources in a collaborative effort to increase awareness and understanding of and promote research into rare bone disorders. The LGDA is an active member of the RBDN consortium. Most recently, Jack Kelly, LGDA president, completed a term as co-chair of the Network.

The RBDN and the USBJD together organized the 1st Advances in Rare Bone Diseases Scientific Conference held at the National Institutes of Health in October 2008. This conference featured leading international authorities discussing the most recent advances in the diagnosis and treatment of eight rare musculoskeletal diseases. At this conference John D. Reith, MD, Professor, Departments of Pathology, Immunology, and Laboratory Medicine & Orthopedics and Rehabilitation, University of Florida College of Medicine presented "Gorham's Disease and Related Lesions of Bone and Soft Tissue." During his lecture, Dr. Reith discussed the characteristics and rarity of Gorham's disease.

Many patients with lymphangiomatosis and Gorham's disease suffer with pain and mobility issues related to the bone destruction that often accompanies these diseases. Membership in the RBDN supports our goal to improve the lives of patients by providing them a voice with which to bring awareness of their needs to large groups of professionals in the musculoskeletal and orthopedic fields, other associations with similar interests and goals, and government health agencies. This year, through the efforts of several RBDN member-organizations, along with the Bone Coalition, language has been included in legislative initiatives proposing funding for research for rare bone diseases, including lymphangiomatosis and Gorham's disease.

The LGDA will continue to be an active partner with the other members of the Rare Bone Disease Patient Network and we thank our fellow member-organizations for their collaboration and sharing. We also thank the United States Bone and Joint Decade for its sponsorship of the Network.

Caregivers Month

November is National Family Caregivers Month

Please make time to celebrate the efforts of the family caregivers in your life.

Calling All Artists



Second Annual EveryLife Art Contest

The Kakkis EveryLife Foundation recently issued an invitation for artists affected by rare diseases to participate in the Second Annual EveryLife Art Contest. The contest is open to anyone affected by a rare disease age 5 and older, including family members, close friends, or caretakers. The purpose of the event is to give artists affected by Rare Diseases an outlet through which they can express their talent and unique stories.

For more information on how to enter go to <http://www.rareartist.org> and click on *About the EveryLife Art Contest*.

You know you're an LGD parent if...

You compare ERs and doctors instead of grocery stores and malls.

You wake up several times a night to "Just check on her."

You've fired at least 3 doctors and can teach your child's pediatrician a thing or two.

The ER doctor asks you to "look at" your child's x-ray to see if it's "normal for him" or not, because she's "never seen anything like this before."

The doctors, nurses, x-ray technicians, etc all know your name---without looking at the chart.

You are on a first name basis with receptionists, admission clerks, the pharmacist, and the customer service reps at your insurance company's call center.

You can dial the phone numbers of a dozen different doctors and hospitals--without consulting a phone book.

You know that spilled grape juice on your new carpet is nowhere near the worst thing that could happen.

You keep your appointment with the specialist 200 miles away even though a tropical storm is raging because THIS ONE might have a treatment AND you waited 8 months to get it. Besides, no one else will be there!

You can recall the dates and results of every test your child has undergone in the past year, but forgot your mother's birthday.

You never take a new day for granted.



Original author unknown. Adapted for use in *Channels*.

Have "ifs" you would like to add? Send them to Channels@LGDAlliance.org and we will publish a new list in a later issue of *Channels*.

Coming Soon...

In the next issue of *Channels*

- Rare Disease Day
- Fundraising
- Outreach
- CaringBridge Partnership



Questions or comments about our newsletter? Have a story you want to include in an upcoming issue of *Channels*?

Send an email to Channels@lgdalliance.org

Thank You,

Lisa K. Klepper, Editor

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