

Channels



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

Summer 2010



This issue of *Channels* is dedicated to Jana K. Sheets, founder of the Lymphangiomatosis & Gorham's Disease Alliance, whose tireless efforts lit a candle in the dark that continues to provide help & hope to people the world over by drawing them to its ever-growing flame of support.

"Reaching for a Cure"



Where to find more information about us:

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President's Column

Much has happened since our last issue of *Channels* and there are many exciting things to report. In recent months the LGD Alliance has

- expanded internationally with the formation of our affiliate group, LGDA-Europe,
- established its Scientific & Medical Advisory Board,
- appointed LGDA's new Research Committee Chair,
- held the first-ever Conference of Scientists & Clinical Researchers to discuss the state of understanding of lymphangiomatosis & Gorham disease,
- entered into a partnership agreement with the National Disease Research Interchange (NRDI) to store biospecimens donated by members of our patient community for research,
- appointed LGDA's new Registry Coordinator to lay the groundwork for an active Patient Registry,
- joined the American Thoracic Society's Council of Public Representatives,
- attended National Institutes of Health/National Heart, Lung, and Blood Institute annual Public Interest Organization meeting in Bethesda, and
- completed term as co-chair of the Rare Bone Disease Network.

Our organization is growing. Our patient community is growing. Unfortunately, in the midst of this growth have been sad reminders of the reasons the LGDA exists and why the work we do is so urgent. The one with which most of our readers are familiar is the passing in January of our founder, Jana Sheets.

In addition to founding the LGD Alliance, Jana was also our Director of Patient Support. Because patient and family support is such an important part of our mission, finding the right person to fill this position has taken some time, but we are confident that Jana would approve wholeheartedly of the person who is now filling this important role.

This issue contains more information about our new Director of Patient Support, our European expansion, and our activities as a member of the NIH/NHLBI Public Interest Organization, among other things. Also remember you can always visit at www.lgdalliance.org for even more information.

We are enormously grateful to so many: our patient community, along with their families and friends, for their continuing support of the LGDA; our volunteers and donors who make it possible for us to do this important work; the scientists and medical professionals who are searching for better treatments and caring for those affected by lymphangiomatosis or Gorham disease. Your efforts are bringing desperately needed hope and help to people all over the world.

With best regards,

Jack Kelly
President, LGD Alliance

Meet our New Director of Patient Support: Beth Mantey

The LGD Alliance is pleased to introduce our new Director of Patient Support, Elizabeth (Beth) Mantey. Beth lives in Green Bay, Wisconsin, with Ryan, her husband of 20 years, and their children: Claire, 13, Grace, 7, and Jack, 11 months. She also has a stepson, Victor, 24, and she and Ryan are excited about becoming grandparents this September.

Like many of the volunteers who keep the LGDA working, Beth has an affected child: her eldest daughter, Claire. “After an eight-year struggle to find out what was wrong with Claire,” says Beth, “we finally found the LGD Alliance. For the first time, I felt hopeful, more educated, and understood. I hope to be able to help other families find this same hope.”



A graduate of the University of Wisconsin – Green Bay, Beth holds degrees in Human Development and Psychology. Of her professional work, she says, “My most rewarding and challenging position was as a Crisis Counselor at Family Services of Green Bay.” About five years ago Beth became a stay-at-home mom so she could focus on Claire’s healthcare. She is active in her church, is a Troop Leader for the Girl Scouts, and for 11 years has acted as an advocate for a cognitively disabled woman through the “Citizen Advocacy” program at ASPIRO, a Green Bay non-profit. She enjoys gardening, scrapbooking, traveling, and camping with the family.

Of her work with LGDA, Beth tells us, “I am very excited about being able to help other families in their journey after being diagnosed with lymphangiomatosis or Gorham’s disease.” Indeed, the LGDA is very fortunate to have such an enthusiastic director for our Patient Support program.

To learn more about Beth and Claire’s experiences with lymphangiomatosis, read their “Stories from the Heart” under the Patient Information link on our website, www.lgdalliance.org.

About Titta Anttila & LGDA-Europe



The LGD Alliance is pleased to announce the establishment of the Lymphangiomatosis & Gorham’s Disease Alliance - Europe (LGDA-Europe).

LGDA president Jack Kelly observed, “This is a significant step in advancing the worldwide mission of the LGD Alliance: to improve the care of patients with lymphangiomatosis & Gorham’s disease and to promote research that will lead to effective treatments and a cure.”

The driving force behind LGDA-Europe is Titta Anttila, of Oulu in Northern Finland, where she lives with her husband, a telecommunications engineer, and their three children; two sons, aged nine and four, and a daughter, six. She holds a Masters degree in Environmental Engineering and is currently at work on her doctoral thesis. She works for Pöyry Finland in its Water and Environment sector as a Design Manager. Titta stays busy “with my daily work, taking care of three kids and their hobbies, and taking care of the house.” Titta has been also involved in the development of a co-operation project in Nicaragua through Oulu-Matagalpa friendship association, in addition to her work with LGDA and LGDA-Europe.

“I got involved with LGDA because of our daughter, Siiri,” Titta says. Last year after months of consultations with doctors all over the world, Siiri was diagnosed with lymphangiomatosis. Determined to help Siiri and others like her, Titta chose to become involved with the LGDA because, “I believe strongly in co-operation and the power of many. It seemed like the most active and best option for the benefit of these patients.”

“I see it as a little sister of LGDA,” Titta says of the LGDA-Europe, “that will be better positioned to address the specific needs of European patients and advance research in Europe.” She points out that official registration in a European country opens doors for full participation on EU efforts on rare diseases. It expands European fundraising opportunities, as well.

The LGDA is fortunate to have Titta, whose vision and determination have helped birth an international organization.

Illinois Girls Raise over \$3,000 for LGDA

On behalf of the entire community of patients around the world, the LGDA would like to express a *GINORMOUS THANK YOU* to two young ladies in Illinois who organized a neighborhood fundraising event in support of the LGDA.

Madeline's 9-year old brother Zachary was diagnosed with lymphangiomatosis when he was three. Madeline has always been so proud of her brother's strength and determination in dealing with his condition. Wanting to do something to try to help her younger brother, she talked with her close pal, Elle. Together they came up with an idea to raise money that they would donate to the LGDA, which Madeline calls "Zac's Charity." The girls decided to host a fashion show to raise awareness about Zachary's disease and money to help LGDA in its mission to provide patient support and promote research programs to develop effective therapies to improve the well being of patients like Zachary.

Madeline and Elle started planning the show in late December 2009 and spent many months making necklaces, bracelets, tie-dyed scarves, belts, and other trinkets to sell at the fashion show fundraiser. Madeline's parents recently hosted the event at their home in Barrington, IL. It was a great success with more than 50 people attending.



Madeline and her friend Elle, who acted as co-chair of the event, eagerly counted the money and called the president of the LGDA to announce they had raised \$3,385!

These young ladies truly are an inspiration! The LGD Alliance extends to them its heartfelt thanks and congratulations on a job well done. We also extend our sincerest thanks to those who attended this fundraiser for their generous contributions, which go to support the mission of the LGDA.



Spotlight on the American Thoracic Society

In order to give voice to and promote the interests of patients with lymphangiomatosis and Gorham's disease, the LGDA actively seeks and fosters relationships with other non-profit organizations and professional associations. Among other things, these relationships help all involved to gain access to larger funding resources and research entities, such as the National Institutes of Health, and advance their shared goals: education, research, patient care, and advocacy.

One organization in which the LGDA is active is the American Thoracic Society (ATS). The ATS is the leading medical association dedicated to the advancement of clinical and scientific understanding of pulmonary diseases around the world. A core component of the ATS is its Public Advisory Roundtable (PAR), whose purpose is to bring the patient's perspective to the ATS. The PAR Council of Public Representatives (PAR Council) is made up of individuals who represent the interests of those affected by respiratory disease and sleep disorders. We are fortunate to have the interests of our patient community represented on the PAR Council by LGDA president Jack Kelly.

The development of standard diagnostics and approaches to treatment for the pulmonary complications with which members of our patient community often struggle is essential to improving their lives. Membership in the PAR Council of Public Representatives affords the LGDA the opportunity to bring awareness of rare pulmonary disease to large numbers of thoracic investigators, pathologists, pediatric pulmonologists, thoracic surgeons, and other professionals. We look forward to a long and productive relationship with the ATS and PAR Council.

LGDA at the NIH/NHLBI Public Interest Organization Meeting

This spring the LGDA received an invitation to the Annual Public Interest Organization (PIO) meeting hosted in May by the National Heart, Lung, and Blood Institute (NHLBI), an entity of the National Institutes of Health (NIH) in Bethesda, MD. Representing the LGDA were Jack Kelly, president of the LGDA, and Denise Adams, MD, a member of the LGDA's Scientific-Medical Advisory Board.



During the two-day meeting Mr. Kelly and Dr. Adams had several discussions with NHLBI staff about working with their researchers and scientists, and increasing visibility for the study of lymphatic malformations, in particular, those affecting the thoracic region. Additionally, Mr. Kelly met with the executives of other pulmonary-related rare disease foundations to discuss common issues such as tissue donation, patient registries, NIH research programs, and fundraising. While Dr. Adams met with NHLBI officials to discuss clinical research, Mr. Kelly attended several breakout sessions addressing how to be more effective when working with the NIH.

LGDA in the News



Among the several scientific and medical societies and patient advocacy groups with which LGDA is affiliated is the American Thoracic Society through its Public Advisory Roundtable - Council of Public Representatives. LGDA president Jack Kelly and the LGDA were the subject of a feature article, "Who's Who at ATS PAR," on page 4 of the Mar/Apr 2010 edition of ATS-PAR News. This article is an excellent example of the work Jack does to bring attention to the LGDA. The article can be found on the Internet at <http://patients.thoracic.org/par/newsletters/resources/march-april-2010.pdf>.

Coming Soon...

In the next issue of *Channels*

- learn about the 1st meeting of our Scientific-Medical Advisory Board,
- find out who received our very first Founder's Award,
- check out our Affiliations column where the Spotlight will focus on the Rare Bone Disease Network.



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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