



# Channels

News, Events & Features from the  
Lymphangiomas & Gorham's  
Disease Alliance

"Reaching for a Cure"  
Summer 2009

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## PRESIDENT'S COLUMN

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Welcome!

As we enter our third year, the LGD Alliance continues to focus on support for patients and families affected by lymphangiomas and Gorham's Disease, and, this year, we have devoted considerable efforts to raise the awareness of the Alliance and the need to raise money to fund research to study these two orphan diseases. Awareness is so essential to the mission.

We are so pleased to share with you some very exciting news! Discovery Health Channel's award-winning program "Mystery Diagnosis" will feature a young girl with lymphangiomas from the LGD Alliance community. The episode circles around the diagnostic process of a young girl from Green Bay, Wisconsin - Claire Mantey, 11. This very moving story chronicles the considerable life and health impact of having such a rare, understudied and unknown disease.

We sincerely thank Claire and her family for letting the world in to witness lymphangiomas for the first time.

Please join us on Monday, August 24th at 10:00 p.m. (EST), to watch the episode. **CHECK YOUR LOCAL TV LISTINGS.** We hope you will consider supporting the LGD Alliance in its mission of providing support to patients, finding medical expertise to treat children like Claire, and in helping us to raise money to fund research so desperately needed to study the long-neglected orphan diseases of lymphangiomas and Gorham's disease.

The journey has begun. We are moving the Alliance in the right direction. Please join us on the journey.

Thank you all, so very much, for your interest and support for the LGD Alliance

Warmest regards,

*Jack Kelly*

***LGD Alliance community member to be featured on Monday, August 24th episode of Mystery Diagnosis on the Discovery Health Channel!***

On August 24th, 2009 at 10:00 p.m. (EST), Discovery Health Channel's award-winning program "*Mystery Diagnosis*" will feature the story of Green Bay, Wisconsin child; Claire Mantey and her family while they struggle to find a diagnosis for her rare health condition - lymphangiomatosis. "The Lymphangiomatosis & Gorham's Disease Alliance (LGD Alliance) is grateful to Claire, her family, and the doctors, nurses, and support staff at Children's Hospital of Wisconsin in Milwaukee who came together to re-create Claire's story. The episode of "*Mystery Diagnosis*" will bring lymphangiomatosis into the media spotlight for the first time ever and hopefully educate viewers about this rare condition. Families reach out to us out of desperation for fear of the unknown and due to their inability to find knowledgeable doctors and overall support. This is a huge step for all affected by this orphan disease" said Jack Kelly, President of the LGD Alliance.

Lymphangiomatosis is a multi-system disorder characterized by a proliferation of complex, irregular channels in the lymphatic system infiltrating soft tissue, vital organs and bone. It is so rare that the number of people affected is unknown. There are no evidence-based guidelines for any treatments, and to date, there have been no clinical studies on it of any kind.

Discovery Health's "*Mystery Diagnosis*" chronicles the experience of patients who suffer from conditions outside the medical mainstream. Each episode features patients who are initially misdiagnosed or undiagnosed altogether due to the uncommon nature of their symptoms and general lack of awareness regarding their conditions. This popular series - in its seventh season on Discovery Health - profiles the strength and courage of heroic patients and determined medical practitioners as they struggle to make sense of their baffling conditions.