



Lymphangiomatosis & Gorham's Disease Alliance

*To give hope and find help*

April 9, 2017

Dear Community Member:

My name is Beth Mantey, I am The Event Coordinator for the 8<sup>th</sup> Annual LGDA Golf Outing. The LGDA stands for The Lymphangiomatosis and Gorham's Disease Alliance. In 2007 my oldest daughter, Claire, was diagnosed with Gorham's Disease. With this diagnosis came a lot of fear and confusion. The few articles that were available proclaimed the disease was usually progressive and almost always terminal. Because the disease is so rare very little information was available, no treatments, no cure, feeling isolated and very few doctors worldwide who would even agree to treat these patients due to the prognosis. After a lot of online research, I meet Jana Sheets, a adult patient who dedicated her short life to making sure this was not the case for families receiving this devastating diagnosis. We felt blessed to find Jana just as she was forming the nonprofit to improve like for those behind her, our family agreed to be featured on the Discovery Health show "Mystery Diagnosis" to bring awareness to the disease. Jana and her father were able to found the LGDA which helps connect families' across the world, connecting patients to doctors near them (usually regionally), educated doctors at national conventions, and fund research in the emerging field of study in Lymphatic research (which is also the newest hope to a cure to cancer). Jana lost her battle with the disease about 6 years ago but truly made a difference in her short life to help the warriors coming behind her. The LGDA has provided information, connection to other warriors, and connection referrals to the made specialist to successfully manage this disease and improve quality of life. We take our charge in continuing Jana's work very seriously and find a renewed sense of urgency every time we loss another warrior.

Would you please consider donating a gift basket, gift certificate, hole sponsorship or other donation to the LGDA Golf Outing. Please find attached a donation form so we can provide you a receipt for tax purposes. The event is taking place May 19, 2017 at Thornberry Creek. More information about the disease and organization can be found on the website [www.LGDAlliance.org](http://www.LGDAlliance.org). Please feel free to contact me with any questions and thank you for your consideration to help us "Reach for a Cure".

Sincerely,

Beth Mantey

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Golf Outing Event Coordinator

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