



Jordan Sutherland & Family

We would like to introduce our oldest daughter, Jordan. She is 5 1/2 and she has a younger sister Reece, who is 2. To the eye, Jordan looks like every other Kindergarten child. She loves to play outside, ride her bike and laugh with her sister. She is shy at times but very observant and resilient.

Both of our girls have grown up here as Leah and I have lived in Londonderry for the last 10 years, since 2007. We are both in the education field. Leah is a high school counselor and I am an Assistant Principal at Londonderry Middle School. We consider ourselves very lucky to be part of this caring and giving community and couldn't think of raising our children anywhere else.

Jordan has a rare genetic disorder called Glycogen Storage Disease or better referred to as GSD 1A. It affects one out of every 100,000 people worldwide. More information on GSD may be found at: www.globalcenterforgsd.com (You can then click the News link on that site for an informative article from UConn Today.) In general, to keep her alive, she ingests a cornstarch drink every 3 hours (24 hrs. a day) along with a carbohydrate snack. She has a very specific diet (high carbs & NO sugar) to maintain her blood glucose level. Some sicknesses can be life threatening and require hospitalization.

Dr. Weinstein is the world leader in developing a cure for GSD. Due to the rarity there is very little government funding for research on the disease. Nearly all of the funding is done through private donations. Jordan's future and care are unknown right now. We hope that Dr. Weinstein's move to Connecticut's UConn School of Medicine and Connecticut Children's Medical Center will help insure advancements in his initial phase of gene therapy trials so that he and his team may deliver on what he has dedicated over 20 years of his life to address, "Our goal is to very soon finally find a cure for GSD and its complications."

We hope that this carnival will raise awareness of this rare disease as well as contribute to Jordan's long-term care and research for a cure. A gene therapy cure would mean no worrying 24 hours a day about blood sugar levels, no IV's and hospital visits with a simple stomach bug, no 10PM and 2AM g-tube feedings every night. It would mean that we could travel without having to worry about where the nearest hospital is and if they will know to listen to us to treat Jordan properly if she were admitted. These are things that every GSD parent grapples with every minute of every day.

Londonderry is where we live, work, & play and are thankful to everyone who is already part of our life in helping keep Jordan safe and healthy.