

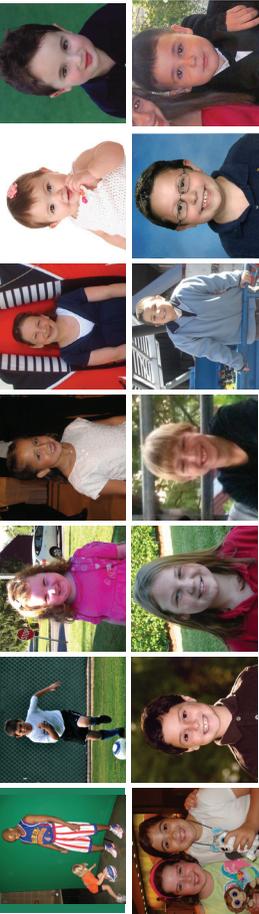
**The Children's Fund for Glycogen Storage Disease Research, Inc.**

917 Bethany Mountain Road  
Cheshire, Connecticut 06410

RETURN SERVICE REQUESTED

Be sure to visit our website  
[www.curegdsd.org](http://www.curegdsd.org)  
and add your email address  
to our mailing list.

To obtain a copy of our documentary  
DVD film *Life By the Clock* for  
fundraising and/or educational  
purposes, please contact us at [info@curegdsd.org](mailto:info@curegdsd.org)  
or call (203) 272-CURE



**Extraordinary Kids Living with GSD**

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# Hopes and Dreams

The Newsletter for Friends of  
The Children's Fund for Glycogen Storage Disease Research, Inc.



DECEMBER 2010 GSD NEWSLETTER VOLUME 8

### CONTACT US

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Cheshire, CT 06410  
(203) 272-CURE (2873)

### WEBSITE

[www.cureGSD.org](http://www.cureGSD.org)

### E-MAIL

[info@cureGSD.org](mailto:info@cureGSD.org)

### Mission Statement:

*We are committed to funding research so that children born with GSD I will benefit from early detection, treatment and an eventual cure.*

### Board of Directors

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David Feldman	Fran Reed
Wendy Feldman	Teri Reed
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As you all know, this is a challenging time for both businesses and non-profits alike. But GSD families are challenged every day – to stay healthy, to stay positive and to stay focused. The Children's Fund will continue to work hard to raise funds for the world's best GSD research. We are committed to curing this disease. "Every child deserves to be healthy" was written on one of the first checks we received some 9 years ago and today is still a rallying cry to get new families involved in fundraising and for 'old families' to continue their support. Thank you for your friendship, your support and your generosity - it means the world to us, and our children on our quest to cure GSD.

*We dream of no more...*

respiratory distress    seizures    feeding therapy    enlarged livers  
dietary restrictions    muscle fatigue    exhausted parents  
blood draws    low blood sugars    elevated lactic & uric acid levels  
hospital visits    middle-of-the-night feedings    finger pricks  
liver ultrasounds    setting alarms    feeding tubes  
developmental delays    liver and kidney tumors

*We can dream because of your generosity.*

## 2010 Scientific Update

This past year we approved and funded two grants: 1. Drs. Conlon, Weinstein and Byrne from The University of Florida. Their topic: Gene Therapy for GSD1a was awarded a total of \$570,553, over two years. 2. Dr. Dwight Koeberl from Duke University was awarded \$167,087 for Pre-clinical development of AAV vectors for gene therapy in GSD1a. Our Scientific Advisory Board is currently evaluating a grant submitted from Dr Janice Chou from the NIH. Dr Chou is looking at the long-term consequences of AAV-mediated gene therapy for GSD1a. She is seeking \$93,936 for a one and a half year study. All of the studies we have funded to date are completing the necessary pre-clinical work that we hope will one day soon lead to clinical trials for human GSD1a patients. While this is still several years away, we are supporting the world's best institutions and the world's best clinicians working towards the goal of a cure.

In addition to the studies above, there are ongoing studies that our foundation is responsible for funding. Dr. Howard Sussman of Stamford University continues

to work on finding clues (molecular markers) as to why hepatic adenomas develop in about 50% of the GSD1a patients.

The alternative treatment trial at Duke and The University of Florida turned out to be disappointing as it was determined that the new starch supplied by Vita-flo was not of consistent quality which compromised the test results. We hope that once manufacturing is more reliable, Dr. Weinstein will resume testing the new starch.

The canine colonies at Duke University and The University of Florida continue to flourish. Duke currently has 6 GSD dogs ranging in age from 7 to 52 months old. They were treated at 3 days old with a single dose of gene therapy and show normal blood glucose levels after 6 hours of fasting. Florida currently has 3 GSD dogs that have also been cured of their hypoglycemia.

As we continue to work on giving our website a face-lift, we will look to have a section that we will post research progress, updates and hopefully some breakthroughs.

**"...because every child deserves to be healthy."**

"...because every child deserves to be healthy."



# The Lucky Winners of the 2009 Super Bowl XLIV Raffle!



Steve & Jill Stark

Our trip was fantastic! The game was one of the best Super Bowls I can remember seeing and the seats as you can see from our photo were fantastic. My wife, Jill, and I had a great time playing golf at Doral at which we were paired with Hall of Famer Dave Wilcox. We really enjoyed seeing so many Hall of Famers at the hotel. We are grateful for the opportunity provided to us by The Children's Fund. Thank you very much for all your hard work.

## Another Terrific Fundraiser! Manitoba, Canada

On July 17th, 2010 we held the 7th Annual BBQ Fundraiser for GSD Research in honour of our little boy Kasen. It is hard to believe it's the 7th one already! The weather wasn't looking great - it stormed all morning, and it wasn't looking much better in the early afternoon. Needless to say, we were a bit worried that it might not be a good turnout. But about 15 minutes before the party was to start the sun beamed through, the rain stopped, and our terrific family and friends began arriving.

Around 200 people attended our event - and we raised just under \$18,500! This is amazing - never did we think we could raise this much in just this one day, and we did it!

To date we have raised just under \$90,000 for GSD Research....and every year gets better and better. A heartfelt thank you goes out to all the people who donate to The Children's Fund for GSD Research... we have high hopes that a cure will be found for our kids and it is all because of your generosity.



See you next year!  
The Andrushkos

## SUPER BOWL XLV RAFFLE



### WINNING PRIZE PACKAGE INCLUDES:

Two tickets to Super Bowl XLV in Arlington, TX on 2/6/11

5 days/4 nights accommodations at the Sheraton Hotel at the Stonebriar in Frisco, TX

Two playing spots in the 26th Annual Super Bowl XLV NFL Charities Celebrity Golf Classic on 2/5/11

Two playing spots in Sixth Annual Super Bowl NFL Charities Celebrity Bowling Classic on 2/3/11

### DRAWING TO BE HELD:

Sunday, December 12, 2010 at 5 PM  
Ticket Price: \$100.

A Maximum of 1,000 tickets will be sold.

For more information, please contact  
Teri Reed at (203) 972-9199 or  
treed04@gmail.com

## Spin-a-Thons for GSD

Coral Springs, Florida

Our good friend Desiree Makovsky ran the NYC Marathon on November 6, 2011 in support of The Children's Fund. Rather than asking people to sponsor her race, Desiree hosted 2-hour spin-a-tons at her local gym, Intense Training, to help with her training efforts, spread GSD awareness and raise money for research. Thank you Desiree for giving up your Sunday mornings for us, and to everyone who actually came out to participate in those not-so-easy 2-hour spin classes! Your support and generosity is greatly appreciated. Congratulations Desiree on a great race!!



## Fundraising for Rylee

Exciting GSD Events in North Carolina!

A Zumba class was held at the Madison-Mayodan Recreation Center by instructor Britta Younts. Proceeds from the cost of the class as well as extra donations were contributed to our foundation and \$135 was raised! The Grahams are so appreciative of all of the locals in their area for supporting The Children's Fund in honor of Rylee!!

The Graham family raised \$1,500 this year from their raffle. Tracey Hennis of Madison, NC won two tickets to the Bristol race in August 2010. Debbie and Patrick Simmons, aunt/uncle to Rylee bought and donated the tickets for the raffle. Thank you for your continued generosity! The Grahams are very thankful to everyone who bought a ticket!



The Staff of Huntsville Elementary School, where Rylee Graham goes to school and where her mom works, participated in a dress down Friday for The Children's Fund and raised \$250! Great Job!

## Kuring Kenslee

by Jason Cash

Just over five months ago my wife Carlee and I were told our 9 month old daughter Kenslee was diagnosed with Glycogen Storage Disease Type 1a. Like most people we'd never heard of GSD until our child was diagnosed and it directly affected our family. In the past several months we've been especially blessed for Kenslee's treatment and our education regarding GSD by the folks at Cincinnati Children's Hospital. The nurses and the doctors there have been a true blessing to our family.

For years I've worked in a financial capacity for different Clinical Research Organizations who conduct clinical trials for pharmaceutical and biotech companies. I've seen firsthand how much clinical research and clinical trials cost. As my wife and I began to research GSD and as we read stories of fundraisers on [cureGSD.org](http://cureGSD.org), our family wanted to do our part in fundraising for new research.

This October, our family held a 'Spirit Night' at a local Chick-fil-a restaurant. As we've been going there once a week for their family night since my oldest daughter was eating table food, the people who work there have known Kenslee by name since she was born.



On the night of our fundraiser Chick-fil-a was generous enough to donate 20% of sales to the Children's Fund for Glycogen Storage Disease Research for all those attending Spirit Night between 5-7 pm. Additionally, Chick-fil-a donated two gifts of one-year supply of Chick-fil-a coupons (one adult, one child) which we'll be able to auction off in the coming month.

This was the first of many Kenslee Cash fundraisers to come. I'd like to say a special thank you to Chick-fil-a for their generosity in supporting our fundraiser. Also, I'd like to thank The Children's Fund for Glycogen Storage Disease Research for your website, newsletter and assistance in preparing for our fundraiser. If anyone would like to contact our family my wife has a facebook page titled Kuring Kenslee. We'd love to hear from you and hear your stories as we're all a family when it comes to finding a cure for this disease.

## Kids Kreation Fundraiser

Cheshire, CT

Just in time for Mothers' Day 2010, Deb Fowler of Cheshire, CT decided to run a fundraiser for The Children's Fund. Being a close friend of the Feldman family, she knows a lot about what it's like to raise a child with Glycogen Storage Disease. Deb got her three boys, Wade, Troy and Bradley involved with spreading awareness of GSD. They went around to friends and neighbors and asked them to create their own 'Kids Kreation.' Many kids made gifts like mugs, note cards and jewelry with their own artwork on them. It was such a fun and easy way to raise money and awareness for Glycogen Storage Disease while giving their moms a



personalized keepsake at the same time! Thank you to everyone who got involved with this fundraiser and especially the Fowlers for all of your friendship and support!

## 5th Annual Children's Fund GSD Golf Classic & Casino

by Lisa Hodes



We held our 5<sup>th</sup> Annual Children's Fund GSD Golf Classic & Casino on April 9, 2010 in Coral Springs, FL. It was a bright sunny day and thanks to our great friend Jim Keenan, our MLB themed tournament went off without a hitch. Prior to tee off, golfers took a few practice swings on the driving range, tried to sink one in the putting contest, and enjoyed lunch which was kindly donated by Pollo Tropical. Then each foursome hopped into their team-identified golf cart and headed out to the course, hoping to bring home the Championship. Congratulations to the winning teams.

Following the golf tournament was Casino Night, where guests tried their luck at blackjack, roulette, craps, and other Vegas style games. It was a fantastic evening shared with many long time supporters, as well as lots of new friends whom we welcome into the GSD community. With all of your help, we were able to raise \$125,000, bringing us to over \$600,000 since we started this event in 2005. Thank you to our title sponsor, Ryder Charitable Foundation, and all of our supporting sponsors, family and friends, for joining our fight and for giving us hope. We still have a long way to go, but with your continued friendship and support, we will find a cure.

Be on the lookout for information regarding the 6<sup>th</sup> Annual GSD Golf Classic & Casino scheduled for Fall 2011. We look forward to seeing you all there!



## Walk-a-Thon for GSD



For their mitzvah project in March, Alex and Danielle Weisman decided to organize a walk-a-thon for GSD in honor of their friends Samantha and Katie Hodes. They promoted the event at Mitzvah Day at their synagogue and gathered later that afternoon for a 1-mile walk around the neighborhood. They collected donations and then matched the total they received with their own money. Thank you to the Weisman family for organizing the event, to all who participated, and especially to Alex and Danielle for being such good friends.



# In The News

Thank you to Mr. James A. Ward, III and Mr. William J. Ward of The Martin Foundation for their \$7,500 donation to our foundation in honor of The Willingham Family of Atlanta, GA. Your continued support is greatly appreciated.



Thank you to everyone who participated in the 2010 Superbowl Boxes for GSD Fundraiser, run each year by the Casarella family and David Feldman. Congratulations to our winners: Dane Drobny, Phil Falivene, Ben Alliger, Dave Halperin, George Heseltine, Jim Mooney, Marc Jacobson and Josh Kampf! This year we reached over \$4,000... thanks to many of the winners donating back their winnings!



Thank you to the Meusel Family who purchased a NASCAR flag signed

by all the drivers, which was donated by Patrick Simmons, Rylee Graham's uncle. The Meusel family also donated \$500 to The Children's Fund in memory of Joseph and Anna Rolfes. Your generosity is greatly appreciated!



Thanks to Tricia Blechman and her mom Letty for having a yard sale and raising \$1,000 for our foundation in honor of Max Blechman.



Thank you very much to all of the children and families of Temple Beth David who give so generously every week to the tzedakah fund. This past year, The Children's Fund received these donations and we are so appreciative! All of those coins really add up! Thank you to Jane Kessler, TBD principal and Ally and Sarah Feldman for nominating and seconding the nomination!!

Thank you so much to Stacey and Jonathan Wanieur, (aunt and uncle of Jonah Feldman,) who made a very generous donation to our foundation in place of giving favors out at their wedding in March 2010. They spread GSD awareness on their special day by having photo tags at each place setting with our website and a description of our foundation. We really appreciate your thoughtfulness!



Elan Harris of Chicago, IL, celebrates his "Upshernish," The Jewish tradition of cutting a boy's hair for the first time at the age of three. In lieu of gifts, Elan requested donations be made to The Children's Fund in honor of his cousin Adam Julius of California. Elan received almost \$1400 for those goldie locks.

Thank you to the Ryder Charitable Foundation for its donation of \$10,000 in support of our GSD Awareness Run in Disney on 1/9/10. Your generosity kept us motivated throughout 13.1 miles in 30 degree weather!



Great job Jake Gordon for having a lemonade stand at which he raised \$158.00! The S.H.A.R.E. Jr./Leadership Club at his school will donate the money raised to our foundation. Thanks to everyone who bought a cup.

Thank you to Donna McNeil for having another \$1,000 cash raffle in honor of her granddaughter, Kamryn Jackson. This year's raffle raised \$11,400!



Eliza Rosen of Bedford, NY, cousin of Jonah Feldman graciously asked that guests to her Bat Mitzvah make donations or do something good for several charities, including The Children's Fund. The Feldmans have been deeply touched by the continued generosity of Eliza and her family in their quest to find a cure for GSD!



Many thanks to the Middle School Student Government of North Broward Preparatory School in Coconut Creek, FL. Throughout the year, and through various means, they raised money for The Children's Fund. Thank you to all of the students who took part in this and thank you to Mr. Reiner, the group's advisor, for raising money in honor of Samantha and Katie Hodes.

