

Hopes and Dreams

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



DECEMBER 2007

GSD NEWSLETTER

VOLUME 5

Host a GSD Event!

Please consider hosting an event in your area NOW in support of a friend, family member or neighbor whose life has been affected by GSD-1. We can help get you started!

2008 Super Bowl

XLII Raffle!

(generously donated by Nick and Mary Nicolosi, grandparents of Anna Reed)
Winning Prize Package Includes:

- *Two tickets to Super Bowl XLII in Glendale, AZ on 2/3/08 redeemable at the University of Phoenix Stadium.
- *One playing spot and one guest ticket for the Super Bowl XLII NFL Charities Celebrity Golf Classic on 2/2/08 redeemable at The Wigwam Golf Resort in Litchfield Park, AZ.
- *One bowling spot and one guest ticket for the Super Bowl XLII NFL Charities Celebrity Bowling Classic on 1/31/08 redeemable at the AMF Christown Bowling Lanes.
- *A room at the Hilton Pointe at Squaw Peak Hotel in Phoenix, AZ for four nights (1/31/08-2/3/08)

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

Gifting Options

The Children's Fund accepts gifts of stock.
For more information, E-mail info@curegsd.org.

We also accept matching gifts. If your company has a matching gift program, please include the proper forms with your donations.

'Life By the Clock'

This 18 minute documentary film produced by Harriet and Pierre Bonelli in 2003 explains what GSD1 is and shows several families living with it. To obtain a copy for fundraising and/or educational purposes, contact us at info@curegsd.org or call (203)272-CURE.

Contact Us

917 Bethany Mountain Road
Cheshire, CT 06410
(203) 272-CURE (2873)

WEBSITE
www.cureGSD.org

E-MAIL
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

Harriet Bonelli Michael Julius
David Feldman Fran Reed
Wendy Feldman Teri Reed
Lisa Hodes Valerie Rosen

FUNDRAISING COMMITTEE CHAIR

Fran Reed

SCIENTIFIC ADVISORY BOARD

Andrew Arnold, MD
UCONN Health Center

Hayden Bosworth, PhD
Veterans Affairs Medical Center

YT Chen, MD, PhD
Duke University Medical Center
Academia Sinica, Taiwan

David Feldman, DMD

Pramod K. Mistry, MD, PhD, FRCP
Yale Univ. School of Medicine

Mary Beth Schmidt, PhD

Now More than Ever

Over the past five years, we are proud to announce that over \$3 Million Dollars has been raised by *The Children's Fund for GSD Research*. We are honored and humbled by your generosity and your kind words of encouragement as we receive contributions each and everyday.

Now more than ever we ask for your continued support. As we raise more funds, medical research continues to progress and amazing success is happening in GSD1 laboratories throughout the world. With this success comes the need for more funding and larger research projects, which we hope will lead us to our ultimate goal of finding a cure for GSD1.

Please enjoy our newsletter and find out what you have helped us to accomplish over this past year. *The Children's Fund for GSD Research* is a huge group effort. As we've said before, there is strength in numbers. The more people who get involved, the faster our dreams will come true.

Thank you all for your support and for giving families affected by GSD1 the gift of hope.

Research Grants Awarded by The Children's Fund in the last 12 months:

Researcher	Topic	Amount Granted
Dr. Lawrence Chan Baylor College of Medicine	Curative Treatment for Glycogen Storage Disease Type 1a in a Dog Model	\$183,222 (over 2 years)
Dr. Janice Chou NIH	Renal Disease in Glycogen Storage Disease Type 1a	\$55,365
Dr. Cathryn Mah University of Florida	Gene Therapy for Glycogen Storage Disease Type 1a	\$499,538 (over 2 years)
Dr. Carlos Pinto NC State College of Veterinary Medicine	Pre-Clinical Development of a Highly Efficacious AAV Vector in GSD1a Dogs	\$251,211 (over 2 years)
Dr. Howard Sussman Stanford University	Identification of Pharmaceutical Targets for Hepatic Adenoma in GSD1a	\$95,091
Dr. David Weinstein University of Florida and Dr. Priya Kishnani - Duke University	A multicenter, double-blind crossover study of the dosing and efficiency of modified resistant cornstarch in patients with Glycogen Storage Disease type 1a.	\$249,382 (over 15 months)

Total approved this grant cycle: \$1,333,809



Kamryn Jackson



Jonah Feldman



Zoey Robinson



Max Blechman

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

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



RETURN SERVICE REQUESTED

917 Bethany Mountain Road Cheshire, CT 06410
www.curegsd.org
Glycogen Storage Disease Research

for

The Children's Fund

Non Profit Org.
U.S. Postage
PAID
Cheshire, CT
Permit No. 29

The Children's Fund Scientific Update...

The research funded by The Children's Fund for GSD Research is improving the quality of life of GSD-I patients, and playing a vital role in funding research that not only helps us to understand the disease better, but also develop new strategies that promise to prevent long-term complications, and eventually find a cure for GSD-I.



Dr. Carlos Pinto with a GSD pup

Dr. Janice Y. Chou, NIH

While current dietary therapies can control blood glucose levels in GSD-Ia patients, they still suffer longer term complications of the liver and kidney. We have identified the gene for the G6Pase protein and used it to create a mouse model of GSD-Ia. We are now using this mouse model to increase our understanding of the pathogenesis of GSD-Ia and to develop new therapies.

Using the mouse model, we have developed a promising gene therapy, based on the use of adeno-associated viruses (AAV) that have the best safety profiles and no known association with any human disease. This AAV-G6Pase-mediated gene therapy has corrected the symptoms of GSD-Ia in the model mice. While promising, the initial results were not optimal because AAV-G6Pase used does not contain the native regulator to ensure that G6Pase will be expressed only in the liver and kidney where the naturally occurring G6Pase is found. We have now generated this new version of the G6Pase-containing AAV virus, controlled by the native regulators of the G6Pase gene, and shown that this new AAV can correct the GSD-Ia symptoms in the mouse model. Presently, we are refining this new gene therapy. The goal of our study is to generate an AAV virus that possesses the best safety profile for future clinical trials for human GSD-Ia patients.

The work described above offers the promise of correcting disease progression in GSD-Ia, but has failed to prevent the progression of chronic renal disease. Using the mouse model we recently showed that a biochemical pathway called the angiotensin system that promotes renal fibrosis leading to the impairment of renal function is inappropriately activated in GSD-Ia kidney. This represents only

the first step toward understanding renal disease in GSD-Ia. However, the identification of genes involved in the progression of renal disease in GSD-Ia will help monitor disease progression and develop an effective treatment for renal disease in GSD-Ia.

Dr. Carlos Pinto,
North Carolina State University

GSD-Ia in dogs closely resembles the one affecting humans and understanding the canine disease may lead to the development of novel therapies to be applied in humans affected with GSD-Ia. At the North Carolina State University, College of Veterinary Medicine (NCSU-CVM) a study to evaluate the efficacy of viral vectors engineered to deliver the missing gene to GSD-affected pups was carried out. From July to December 2006, five GSD affected pups were born from three different female dogs at the NCSU-CVM and treated with gene therapy at 3 days of age...

Three of the GSD-Ia pups were treated with AAV vectors and two with HDAd vectors. Although these two different viral vectors differ from each other, both have in common the fact they have the potential to induce minimal immune response, thus ensuring safety. Four pups have been treated only once at 3 days of age and all five are alive and doing well. Importantly, no side effects were observed following the administration of the viral vectors. Four of the five pups are offered a balanced diet and eat unassisted. No cornstarch or routine glucose treatment is administered to them.

The GSD dogs, now aged 12 to 16 months, have documented partial correction of glycemia (lasting 2 to 4 hours after fasting) and other liver biochemical abnormalities related to GSD-Ia. This correction, despite partial, is a remarkable improvement over that of GSD dogs not treated with gene therapy (glucose in non-treated GSD dogs is low as early as 30 minutes after fasting). Future studies should lead to the improvement of biochemical correction following gene therapy. These dogs are extremely valuable not only to assess the efficacy of gene therapy but also to document how long its beneficial effect will last.

This will help to determine if and when additional vector doses are administered.

Dr. Howard H. Sussman,
Stanford University

The goal of our investigations is to identify genes that are potential targets for pharmaceutical agents that will block the transition to hepato-cellular adenomas (cancer) or to treat the adenomas in patients with GSD 1. To achieve this goal we are conducting investigations at a molecular level to reveal the genetic basis for the transition to liver tumors in patients with GSD 1 following long term management. The transition to hepatic adenoma affects nearly half of the patients with GSD 1, suggesting that there also may be genetic basis for the development of the adenomas.

Currently, we are examining specimens of tissue from GSD 1 patients obtained from Dr. David Weinstein (Univ of FL). Clinical records and pathology reports are available and non-hepato-cellular liver and hepato-cellular liver portions taken from the surgical specimen were obtained from all patients. The observation that only 50% of the patients develop hepato-cellular adenomas is consistent with there being a genetic basis involved in the protection or loss of protection from neoplastic transformation.

The molecular data that will result from our investigation will identify genes or sets of genes that define the progression from non-adenoma to hepato-cellular adenoma in the



Dr. David Weinstein with a GSD pup

The Children's Fund GSD Golf Classic

by Lisa Hodes

Monday, November 5, 2007 was a picture perfect day in South Florida. The sun was shining and the birds were singing as friends and colleagues took to the course for the *Third Annual Children's Fund GSD Golf Classic* at *Weston Hills Country Club* in Weston, Florida.

In the spirit of Fall Football Season, it was the AFC vs. the NFC, with the New York Jets and the Carolina Panthers reigning as Conference Champs! Congratulations guys and gals! And a high-five goes out to all of our Division, Wild Card, Goal-in-One and Contest winners - Nicely done!

The perfect day led into a wonderful evening filled with laughter and tears as we learned a little more about living with GSD and the progress being made towards finding a cure.

Our event raised over \$125,000 for *The Children's Fund for GSD Research*. This revenue will directly impact the lives of GSD patients and their families. We appreciate the kindness and compassion of all of our sponsors, tournament partners, players and friends.

A special thanks to **Grace Surdis**, my good friend and co-chair who

spends countless hours spreading awareness and soliciting donations for GSD, just because she cares - you are truly an angel; **Cheryl Hersch** for your unwavering support and friendship (and for taking care of me throughout the entire planning process); **Dr. David Weinstein** for taking time out of your incredibly busy schedule to share the most recent GSD news with us; my good buddy **Jim Keenan** for helping to put the whole fantastic day together; **Gordon Latz**, our wonderful auctioneer; the high school kids who helped out: **Holly Beilin, Matthew Maizes, Eric Stone, Siddarth Sharma, Andrew Sokolow**; all my friends who volunteered their time to make sure the day went off without a hitch; and, of course, my wonderful family, who put up with my late nights, long phone calls and piles of paperwork and supplies all over the house during the last few months.

Thank you all for helping to make this event such a huge success. On behalf of all families affected by GSD, we feel truly blessed to have your support.

We look forward to seeing you all again next Fall.

Another Great Success!!!!



East Selkirk Fire Department with honorary members

On July 28th of this year we held the 4th Annual 'BBQ Fundraiser for GSD Research' in honor of our little boy, **Kasen**. It was a great turnout with over 250 people in attendance. The event was an all day affair with tons of fun for both kids and adults. We had 3 giant bouncers, a petting zoo, horseshoe tournaments, terrific food, great fireworks and even a DJ!

Kasen and two other children with GSD 1a were surprised by our local fire department. They were made Honorary Fire Chiefs for the day and were taken for a ride in the fire trucks! This is a memory that will never be forgotten.

This year we raised over \$12,000 Canadian Dollars in our hopes to finding a cure!

So this means that over the past 4 years over \$40,000 has been raised from our one day event. This is amazing, and we thank each and everyone of you who attended and donated for our fundraiser. We truly have great family and friends! See you next year!

The Andrushko's



A NIGHT OF FUN, SOUTHINGTON, CT

Kim and Kenny Casarella of Southington, CT continue to find ways to raise awareness of Glycogen Storage Disease, Type 1, while instilling awe inspiring values into their 13 year old daughter, **Lauren**. This past year when Lauren turned 13, her birthday party was dedicated to raising funds for *The Children's Fund* in honor of her friend, **Jonah Feldman**. She asked that her friends make a donation in lieu of gifts for her birthday, but that's not all. Her mom, Kim went around to many local businesses and restaurants and asked that they contribute items or gift certificates that would be used during a raffle drawing at the party. Kids bought raffle tickets and won lots of prizes. Jonah helped call out the winning raffle numbers on a microphone! There was music and dancing and lots of food too. The night was a great success. The Feldmans are humbled by the outpouring of support the Casarellas showed on this special evening, and always.



Lauren Casarella and friends

CureGSD Candles

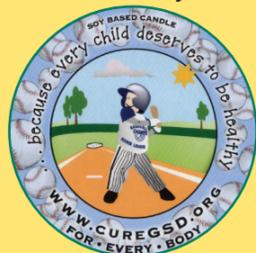
Burning to find a cure for Glycogen Storage Disease Type 1

In the Spring of 2007, Wendy, David, Jonah and Ryan Feldman of Cheshire, CT decided to do a small fundraiser by selling scented candles to friends, family and neighbors and having the proceeds benefit *The Children's Fund for GSD Research*. The response we got was incredible. So many of our friends offered to sell candles to their friends and families that the idea sky-rocketed and a total of 732 candles were sold!!

One afternoon, we received a delivery of a huge crate containing all of the candles. It filled our entire garage. For the next week, our garage was like a makeshift warehouse as we organized all of the candles to get them to the different homes of people who had volunteered to sell for us. A huge thank you goes out to Will



Jonah Feldman



Thomann who came over to help us put custom-made stickers on the covers of all of the candles.

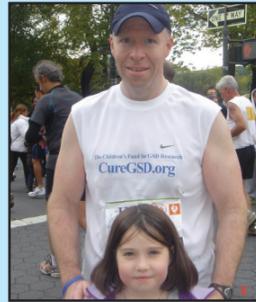
Thanks so much to everyone who became candle salespeople: **Michelle Wolff, Nora Marcoullier, Stephanie O'Connor, Gina Colella, Monika Corcoran, The Ruocco's, Irene Cullagh, The Canatta's, The Drescher Boys, The Gaudios, Dawn Stark, Keays Calcagni, Barb Davis, The Casarella's, The Thomanns, Lauren Hague, Patty and Denny Buller, Kathy Ferguson, Jamie Gryk, Margaret Colella, The Hergets, Lisa Sallak, Diane Julius, Jillian Molinari, Deb Fowler, The Bagins, Monica Oris, The Gordons, The Barils, and Lisa Speakman**. We really appreciate your time and efforts and your willingness to help!!

Also, many thanks to **Janet Jacaruso**, the owner of **Scooter School** in Cheshire, CT (where both of our boys went and go to preschool.) Janet got the word out to all of the families at the school about the candles and she also made a very generous donation to *The Children's Fund*.

We would love to make this an

Running for Anna

By: Fran Reed



Fran and Anna Reed

I ran the 2007 ING New York City Marathon on November 4th for my daughter **Anna**.

Running marathons has not only become a productive way of fundraising and building awareness about GSD, but also a way to keep me healthy for Anna and the rest of my family. It's very ironic actually. When Anna was initially diagnosed with GSD as an infant, one of her doctors at Yale compared Anna's extreme fatigue due to a severe lack of glucose to that of what a marathoner experiences. He explained to us for the first time how a complete lack of glucose will cause lactic acid levels to sky rocket creating a sense of utter fatigue.

Thanks to the kind generosity of wonderful people like you we've raised over \$350,000 cumulatively over my 4 marathon runs. **Team CureGSD** runs marathons, half-marathons, and 5-K run/walks all around the country.

Please contact **Fran Reed** for more information about becoming a member of Team CureGSD. freed@lehman.com (212) 526-0805.

annual fundraiser since it was such a fun and easy way for people get involved and to raise funds for GSD1 research. If you are interested in selling candles and getting your friends and family to help in 2008, please contact us at info@curegsd.org or (203) 272-CURE.

livers of patients with GSD 1. The capability to define the properties of each of these stages in the transition to hepato-cellular adenoma on the basis of the gene expression profile will provide necessary information for understanding the disease and for identifying the pharmaceutical targets for which therapy can be developed.

Dr. Priya Kishnani, Duke University
Dr. David Weinstein, University of Florida

As many of you know, having a child with GSD means round the clock feeds. Last year *The Children's Fund* funded research at the University of Florida to study a new starch that may allow GSD patients and their families to sleep through the night. The initial study was completed in February 2007. The goal of this first study was efficacy - does this SUPER STARCH work better than our beloved Argo? Initial results show improvements in several different areas. In particular, the Super Starch was found to have a slower rate of blood sugar decrease when compared with Argo. However, much of the benefit was found after the blood glucose level fell below 70mg/dL. So a second study was designed by both Drs. David Weinstein (FL) and Priya Kishnani (Duke) to determine if metabolic control can be improved. If modifying the dosing levels can improve this control, GSD patients and their families may be able to sleep through the night. *The Children's Fund* is very excited to provide the funds to these institutions and to a study that may change the lives of so many people.

The Difficult Part...

Research in the field of Glycogen Storage Disease continues to progress at an exponential rate. *The Children's Fund* is a family-run, all volunteer, non-profit foundation, which supports most of the world's GSD1 research. When we received grant requests for over \$1.7 Million this year we knew we were faced with some very tough choices. **Dr. Reba Condiotti** and her team at Hadassah Hebrew University Hospital have previously received funding from us and their work is progressing nicely. Our Scientific Advisory Board helped us make some difficult decisions, and despite their commendable work, we were not capable of funding Dr. Condiotti's research grant. We will continue to work hard to raise funds, but ironically, progress is expensive. We urge you to get involved and help our cause - to CURE GSD.

Lehman Brothers Liquid Markets Philanthropy Event

Lehman Brothers Inc, the Wall St. investment bank, hosted its first Lehman Liquid Markets Philanthropy Event in New York City at **Spotlight Live** on Wed, Oct 3rd. The exciting event was called "Lehman Idol" as employees of the Liquid Market Division of Lehman Brothers showcased their singing talent towards raising money for *The Children's Fund for GSD Research*.

Fran Reed, Senior Vice President in Interest Rate Derivatives at Lehman Brothers and Board Member of *The Children's Fund for GSD Research* addressed the 300+ Lehman attendees about his daughter **Anna** and our foundation. Employees pledged to attend the event (combined with Corporate Matching Gifts) and also participated in a Silent and Live Auction at the event. "It was really a spectacular evening! I was amazed at the talent of many of my colleagues. Working in a stressful fast-paced fixed income trading floor environment, I usually only see the



Anna Reed

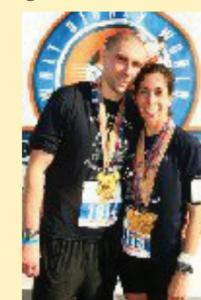
professional aspects of my colleagues. However, it was terrific to see everyone singing and having a blast and it was all for us! It was just a remarkable experience - one that was also a bit humbling to be the recipient of such extreme and genuine kindness from so many of my colleagues who are also my good friends." said Reed.

"Special Thanks to **John Gallo**, Global Head of Rates, FX and Commodity Sales, **Kaushik Amin**, Global Head of Liquid Markets Trading, **Jeff Michael**, Head of Rates Trading, **Jerry Rizzieri**, Head of Treasury, Agency and MBS Trading, **Jim Iorio**, Head of FX Sales, **Dan Malone**, Head of Rates Sales, **Sarah Strang**, Head of Rates Sales, **Greg Cignarella**, Head of Third Party Sales and each and every one of my Liquid Markets colleagues at Lehman Brothers. I am incredibly indebted to each of you for your kindness and generosity." **The Lehman Liquid Markets Philanthropy event raised \$100,000 for The Children's Fund for GSD Research.**

RUNNING TO CURE GSD - by Lisa Hodes

Well, it was a little warmer than we had anticipated, but none the less we were all gathered in the parking lot of Epcot at 4am doing our pre-race stretching and tuning up our Ipods. It was our first official race as **TEAM INTENSITY**.

TEAM INTENSITY was created by **Brian and Desiree Makovsky**, owners of **Intense Training**, in Coral Springs, FL. Both avid marathon runners, Brian and Desiree created a training program to help both the experienced and not so experienced reach their goals. After learning about my daughters, **Samantha and Katie** (and GSD), Brian and Desiree decided that **TEAM INTENSITY** had a higher goal... to find a cure for GSD.



Brian & Desiree Makovsky

We banked lots of mileage training for **The Disney Marathon & Half Marathon** which took place in January of 2007 in Orlando, Florida. As most of us were first time runners, nothing

could have been more exciting than Disney. And knowing that we were running to reach a specific, and most worthy goal, we kept each other motivated and smiling throughout it all.

Thanks so much to Brian and Desiree for orchestrating the entire event and for your tireless hours of training; **Bob Fatovic** for securing Ryder as our title sponsor; **Ryder Systems Inc.** for the donation match and confidence in our team; and to all of our sponsors, runners and friends who were so generous to support this cause. We are so appreciative of all of you.

TEAM INTENSITY is committed to our cause. We will not stop running until we find a cure for GSD. Our next race is scheduled for February 17, 2008 in Fort Lauderdale, FL. So lace up your running shoes and join us for the Fort Lauderdale A1A Marathon & Half Marathon. We welcome any and all sponsors and participants. For information, visit our website at www.cureGSD.org.

Or, create a "Cure GSD" team in your hometown. For assistance in getting started, please contact Lisa Hodes at HodesL@yahoo.com.

IN THE NEWS...

Congratulations to **Carol and Tom Lenahan** of Wallingford, CT on their marriage! They raised almost \$1,500 for *The Children's Fund* by asking guests to make a donation in hopes of helping their little friend, **Jonah Feldman**.

Since our last newsletter, we have been fortunate enough to be recipients of some extremely generous donations. We thank **Armen Avanesians**, NYC in memory of **Morrie Stein**, **Grassroots.org** and **Andrew Miller** of Boston, **Peter and Barbara Kenner** of NYC in honor of **Jonah Feldman**, **Laurence and Carla Stein** of New Rochelle, NY in honor of their nephew, **Jason Stein**, **Gayle and Steve Temkin** of Torrington, CT and **Joan Temkin** of Bloomfield, CT in honor of **Alyssa Temkin**, **Hill Farber & Co.** in honor of **Adam Julius**, the **Beloin and Gagne Families** of Rochester, NH in honor of **Jonah Feldman**. The **Craig B. Tate Foundation** in honor of **Anna Reed**, **Tricia and Scott Blechman** of Manhattan Beach, CA in honor of **Max Blechman**. Your incredible generosity astounds us.



Adam Julius

Many thanks to **Rona Coffee** www.ronacoffees.com for donating a portion of 'Hopes and Dreams Coffee' sales to *The Children's Fund* in honor of **Danielle**. We would especially like to thank **Kathy and Ron Turi** of Richboro, PA for getting so involved with this fundraiser in honor of their daughter, **Julianna**. They raised over \$2,200!!

Thank you to the entire **Feldman Orthodontic Staff** of **Cheshire and Wallingford, CT** for their generous gifts to our foundation during the Holiday Season.



Our table at the AGSD Conference

Special thanks to the **AGSD** for allowing us to sponsor their 2007 conference which was held in North Carolina. We really appreciate all of the efforts of **Mary Chapman** for helping the AGSD and *The Children's Fund* work together.

Our sincere appreciation goes out to **The Elk City Masonic Lodge** of Elk City, OK for hosting a Masonic Pancake Breakfast two years in a row, raising a total of \$5,000!!! Special thanks to **Danny McClure** and **Ryan Horn** for all of their hard work. The Breakfasts were done in honor of **Donna McNeil's** granddaughter, **Kamryn Jackson** of Amarillo, TX.

Many thanks goes to **The Visentin Publishing Group** and **Sandy Visentin** for donating \$500 from the sale of her book, *Lawyers Unplugged*. To date she has raised over \$3,600 for *The Children's Fund*!

Thank you to **Margie Ostrove**, longtime friend of **David Feldman**, who recommended that **Old Oaks Country Club's** Charity Day (of Westchester, NY) benefit *The Children's Fund*. The Club has donated \$1,500 to our foundation from funds raised during the past two Charity Days.

Many thanks to **Alex Ashkinos**, **Matthew Hassenfeld**, **Ari Moskowitz**, **Jacob Schulman**, **Ben Sorkin**, **Jaegger Steck** and **Alec Tuckey**, who got together and had a bake sale at **Temple Beth Torah** in Melville, NY to benefit *The Children's Fund*. **Jacob Schulman** helped choose this fundraiser because his cousins, **Samantha and Katie Hodes** have GSD1a.



Samantha and Katie Hodes

Thank you to the **Old Well Christian Church** of Spencer, VA for having a love offering in honor of **Rylee Graham** of Stokesdale, NC. The congregation donated money which was matched by **Donald and Ilene Newman** of Spencer, VA (church members and Rylee's grandparents). A total of \$2,000 was donated to *The Children's Fund*.

Thank you to **The Stevens Memorial United Methodist Women** of South Salem, NY, who once again chose to support our organization as part of their Mission Outreach Program in honor of **Anna Reed**.



Jessie Belot with his aunt & uncle

Congratulations to **Helene and Ben Szuuts** of Manitoba, Canada who took the opportunity to donate to *The Children's Fund* instead of handing out wedding favors at their wedding, to help raise funds to find a cure for their nephew, **Jessie Belot**.

Thank you again to **Bette and Douglas Goldenberg** of Oakhurst, NJ who raised over \$1,000 for our foundation at their Super Bowl party in honor of their daughter, **Shirley!**



Shirley Rose Goldenberg

Many thanks to the **Casarella Family** of Southington, CT for organizing their annual Super Bowl Boxes Raffle and raised \$1,250 for GSD research!!

Thank you so much to the **Student Council of Ebenezer Avenue Elementary School** in Rock Hill, SC for sponsoring a fundraiser in honor of their classmate, **Austin**. Children who brought in money for *The Children's Fund* were able to bring in their favorite stuffed animal on "Bring a Bear to School Day." The collection raised \$626.32 for GSD1 research!



Alyssa Temkin and her Grandmother Bonnie Weiner

This past summer **The Temkin Family** celebrated two special birthdays: **Alyssa's** and her grandmother, **Bonnie Weiner's**, of Elmsford, NY. Their party raised over \$26,000 for *The Children's Fund*. Thank you so much for having GSD1 research benefit from your party!

Thank you to **Eliza Rosen** of Katonah, NY for donating part of her tzedaka money to help her cousin, **Jonah Feldman**.

Thanks to **Bobby, Reagan and Ryann Mushkin** of New Canaan, CT for giving part of their allowance money to help their friend **Anna Reed**.

Great job and Thank you to **Jaxson Domino**, who presented **Anna Reed** with a check from the lemonade stand he staffed at **East School** in New Canaan on Field Day in June to raise money for *The Children's Fund*!



Jaxson Domino and Anna



Ben Shoham and Jason Stein...then!

Thank you to **Ben Shoham** from West Hartford, CT. He is a lifelong friend of **Jason Stein**. Ben raised funds by asking people for their change. He raised over \$750.00!! He titled this mitzvah project at his school mitzvah fair "change for a change". He even had cornstarch goop at his activity booth. Ben recently celebrated his Bar Mitzvah and asked that donations be made to *The Children's Fund* in honor of this special event and he raised almost \$2,200!



Ben Shoham and Jason Stein...now!

Congratulations to **Rylee Graham's** dad, **Brian** who raced to raise funds for our foundation in the *Racing2SaveLives* Charity Event which took place at the Virginia International Speedway in August. The event raised \$5,000 for our organization.



Rylee Graham and her dad, Brian.

Congratulations and many thanks to **Tricia Blechman's** friends, **Karen and Scott Steinhardt**. They made a very generous donation to our foundation in lieu of favors at their wedding in honor of Tricia's son, **Max** from Manhattan Beach, CA.



The Siegel girls

Many thanks to **Allison and Abby Siegel** of Miami, Florida for organizing a lemonade stand to help their friends, **Samantha and Katie Hodes**.



Jacob and Zachary Gordon

Zachary and Jacob Gordon's cousin, **Andrew Weiss** from Merrick, NY, was assigned to do a Bar Mitzvah project for his Hebrew school. He immediately chose to fundraise for GSD in order to help Jacob, and other children with Glycogen Storage Disease. Andrew's mother, **Sharon**, had her friend **Jeff Sardis** design the t-shirts which say

'Hopes and Dreams, cureGSD.org. Andrew enlisted the help of his friends and family including his brother **Evan** and cousins **Jacob and Zachary**. With Andrew Weiss' leadership, almost \$2,000 has been raised so far and donated to *The Children's Fund for GSD Research*. Andrew's goal is to create awareness and to raise money to help find a cure.

This past year, **Donna McNeil**, grandmother of **Kamryn Jackson** sold "Kure for Kameron" cookbooks and raised \$11,200. We thank you for your commitment to help to find a cure for GSD.



Donna McNeil with her three granddaughters

Way to ride **Dr. Carla Iudica-Souza**, of Ramsey, NJ! She did the 5-boro NYC bike ride to raise money for our foundation in honor of **Anna Reed**.

Thanks to the **Padilla Family** from Austin, TX for always spreading the word about our foundation to family and friends!

Thank you to the **Daron and Ron Barness Family Foundation** for a very generous \$5,000 grant to *The Children's Fund*.



Jack, Fran and Anna Reed

Thanks to **Jack Reed** for raising \$41.50 by setting up a lemonade stand on one of the hottest days in August and sitting out there for six hours to help his little sister, **Anna** of New Canaan, CT.

Thank you to everyone who has sold and continues to sell Super Bowl raffle tickets.



Ellie Centrella

Happy Birthday to **Andrew Dodson** of Sandy Ridge, NC, **Tyler Carney** of New Canaan, CT, **Ally Feldman** of Cheshire, CT, **Jack Kelly** of Santa Barbara, CA, **Cameron Murray** of West Haven, CT, **The Wolf Kids - Nathaniel, Rebecca and Sarah** of Maplewood, NJ, **Jonah Feldman** of Cheshire, CT, **Jack and Anna Reed** of New Canaan, CT, **Rylee Graham** of Stokesdale, NC. They all celebrated their birthdays and asked that contributions be sent to *The Children's Fund* instead of receiving presents for themselves!!!