

4th Annual Children's Fund GSD Golf Classic (& Casino) by Lisa Hodes

On November 8th, 2008 the 4th Annual Children's Fund GSD Golf Classic took place at The Heron Bay Golf Club in Coral Springs, FL to support Glycogen Storage Disease. It was another beautiful day in South Florida and fun was had by all. A great day led into a fabulous evening, Las Vegas style. The dealers were dealing, the dice were rolling and the wheel was spinning, all for GSD. I wish to extend a special thanks to our title sponsor, **Ryder**, for believing in our cause. And to all of our sponsors, who, year after year, find a way to support our Foundation. Thanks to all of our friends and family who attended the event – we truly appreciate all of your support. To my friends who took time out of their schedules to help plan and execute – I thank you. **Jim**, I hope you know how much I value our friendship. **Grace**, my co-chair, who 4 years ago dreamed up this little event that has blossomed into one of our Foundation's biggest fundraisers, I love you. And to my family, **Sandy, Samantha & Katie** – we will find a cure... This year's golf classic raised **\$125,000** for GSD research! We hope to see you all next year!



Sam and Katie Hodes

2008 Super Bowl XLIII Raffle

to benefit
The Children's Fund for Glycogen Storage
Disease Research

Winning Prize Package Includes:

- 5 days/4 nights accommodations at the Innisbrook Golf Resort in Palm Harbor, FL
- Two tickets to Super Bowl XLIII in Tampa, FL on 2/1/09
- One playing spot and one guest ticket for the Super Bowl XLIII NFL Charities Celebrity Golf Classic on 1/31/09
- Two playing spots in the Super Bowl XLIII NFL Charities Celebrity Bowling Classic on 1/29/09

Drawing to be held:

Sunday, December 14, 2008 at 5 PM
Ticket Price \$100

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



For information on how to obtain
"green" GSD reusable shopping
bags, please contact Lisa Hodes at
hodesl@yahoo.com
or call 954-263-1631

Hopes and Dreams

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



DECEMBER 2008

GSD NEWSLETTER

VOLUME 6

Success Sparks Need for Increased Funds!

In the past 6 years since we began our quest for a cure, *The Children's Fund* has become the backbone of GSD1 research as we continue to fund the majority of research for this disease. You have helped us to raise almost **\$4 Million Dollars**. We are now at a crucial point – we have sparked so much research and progress which has resulted in more and larger grant requests. Our success has actually triggered the need for increased funds. This is EXACTLY what needed to happen to find a cure for GSD. This is exactly what we hoped would happen!

We ask that you host an event, a party, or a charity drive to help raise money for *The Children's Fund* as soon as possible. Ask friends, family and your communities for help. Our children deserve a cure. You will be surprised at how much people are willing to do for you and your children if you just ask. For fundraising ideas, please see the link on the home page of our website and contact us. We are all in this together. We must and will find a cure for GSD.

Please enjoy our newsletter and find out what you have helped us to accomplish over this past year!

A total of **\$803,919** has been dispersed by The Children's Fund in 2008 for the following grants:

Dr Janice Chou, NIH	Long-term consequences of AAV-mediated gene therapy for GSD-1a.	\$74,030
Dr Howard Sussman, Stanford Univ.	Identification of Pharmaceutical Targets for Hepatic Adenoma in GSD1a	\$97,748
Dr Dwight Koeberl, Duke Univ.	Development of AAV Vectors for GSD1a	\$67,159
Dr. Lawrence Chan, Baylor College of Medicine	Curative Treatment for GSD1a in a Dog Model	\$89,668 (year 2 of 2007 grant)
Dr. Cathryn Mah, Univ. of Florida	Gene Therapy for GSD1a	\$256,054 (year 2 of 2007 grant)
Dr. Carlos Pinto, NC State College of Veterinary Medicine	Pre-clinical Development of a highly efficacious AAV Vector in GSD1a Dogs	\$98,049 (year 2 of 2007 grant)
Dr. David Weinstein Univ. of Florida Dr. Priya Kishnani, Duke Univ.	A multicenter, double-blind crossover study of the dosing and efficiency of modified resistant cornstarch in patients with GSD1a	\$121,211 (year 2 of 2007 grant)



Anthony Quant



Vincent Padilla



Kasen Andrushko



Anna Reed

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

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



RETURN SERVICE REQUESTED

The Children's Fund
for
Glycogen Storage Disease Research
917 Bethany Mountain Road Cheshire, CT 06410
www.cureGSD.org

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

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

The Children's Fund Scientific

The research funded by The Children's Fund for GSD Research is improving the quality of life of GSD-1 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-1.

Janice Chou, Ph.D. NIH, Renal Disease in GSD1a

While current dietary therapies can control blood glucose levels, they can not prevent the longer term complications of the liver and kidney. We have identified the gene for the G6Pase enzyme and generated a mouse model of GSD-1a to increase our understanding of the pathogenesis of this disorder 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).

Prior to any experimentation with human gene therapy, we have to improve the safety of the virus used. Funded by the Children's Fund for GSD Research, we have now generated a new G6Pase gene therapy virus, AAV-G6Pase-HP, and shown that this new virus can correct the GSD-1a defects in the mouse model. We have also initiated studies to evaluate the efficacy of liver G6Pase delivery of our new virus, compared to the previous version we used. Our new virus has several new advantages. First, it is more efficient in directing G6Pase expression in the liver. Secondly, it directs a more sustained G6Pase expression in the liver. Finally, it is tissue-specific and delivers the G6Pase only to the liver and kidney, unlike our previous virus.

We now propose examining the long-term consequences of our new virus-mediated gene therapy using the GSD-1a mice. The goal of our study is to generate an AAV virus that possesses the best safety profile for future clinical trials for human GSD-1a patients.

Chronic renal disease is one of the most challenging complications of GSD-1a. The recent advances in animal trials of gene therapies have failed to prevent the progression of renal disease. We need to understand the early steps, and how they progress. This will enable us to develop assays to detect the start of renal complication before it has progressed to the stage of clinical significance. Using the mouse model we have shown that activation of the angiotensin system that promotes renal fibrosis plays an important role in the development of renal disease in GSD-1a. More recently, supported by the Children's Fund for GSD Research, we showed that renal glycogen storage and fibrosis may activate the toll-like receptor 2 (TLR2) in the kidney that initiated inflammatory responses and cell death in the kidneys. These studies represent only the early steps toward understanding renal disease in GSD-1a. However, the identification of genes involved in the progression of renal disease in GSD-1a will help develop an effective treatment for renal disease in GSD-1a.

Dr Cathryn Mah, Univ of FL, Gene Therapy for GSD1a

In a short period of time, we have made large strides in the progress of our gene therapy studies on GSD1a dogs and have been able to expand our original colony of 2 males and 1 female carrier to include 8 carrier male and 4 carrier female dogs that are all now of breeding age. To-date, a total of 4 GSD1a puppies have been born in our colony. We have been able to determine the optimal glucose requirement and dosing regimen for these dogs to maintain normal glucose levels and avoid high lactate and lipid levels. One of the GSD1a dogs born into the colony received a high dose of a recombinant adeno-associated virus pseudotype 8 (rAAV8) gene therapy vector as a newborn. Soon after treatment, this dog could sustain normal blood glucose levels after 2 ½ hours of fasting. The GSD1a dog that did not receive gene therapy could not sustain normal blood glucose levels for even an hour. Unfortunately, by 2 months post-treatment, this gene therapy-treated dog could no longer maintain normal blood glucose levels after 1 hour of fasting and glucose supplementation had to be resumed to maintain normal blood glucose levels. We gave the dog a second dose of gene therapy vector, but this time a rAAV pseudotype 1 (instead of 8), vector was used. The sole difference between the different pseudotype vectors is in the structure of the outside of the virus. The differences in structure results in differences in how the virus infects a cell and what cell types they can infect. Just over a month after the second dose of gene therapy vector, the dog could maintain near-normal blood glucose levels after a full 9 hours of fasting. These results were a dramatic improvement. At that point, all glucose supplementation was stopped and the dog has not had any glucose supplementation in her diet since it was originally discontinued 8 months ago. The dog is bright and playful and we have even taught her to do some tricks. She continues to thrive on normal dog food and is now 14 months old. We very recently had another 2 GSD1a dogs born into our colony. Both dogs received AAV gene therapy vectors and those studies are currently ongoing.

Lawrence Chan, MD (Baylor College of Medicine and NC State College of Veterinary Medicine) Curative Treatment for GSD1

We intravenously injected a vector carrying the enzyme G6Pase to 3 GSD1a pups 3 days after birth. The vector, first developed in our laboratory, is one of the most efficient vehicles for delivering genes to the liver. The treatment completely corrected the hypoglycemia in all 3 pups. One pup died of an accident at one month of age. The other two dogs had normal blood sugar until 6 months later when they started to develop fasting hypoglycemia, indicating that the treatment effect was waning. We re-treated these two dogs with another injection of a modified vector. The second treatment immediately restored normal blood sugar in both GSD-1a dogs. The first dog has remained free of hypoglycemia and has continued to thrive for well over a year since retreatment (it is about 23 months old now). The other dog is younger (about 10 months old), and has also maintained a normal fasting blood glucose, after a 12 hour fast, since retreatment about 4 months ago.

These results are exciting, but much remains to be done. We need to determine if the excellent therapeutic response is reproducible in a large number of GSD-1a dogs. We will determine if there are possible signs of toxicity (so far not evident in the 3 treated dogs), and what is the average duration of the therapeutic benefit. Will it be necessary to repeat treatment later on and when? Can we prevent the long-term complications of GSD-1a, like liver cancer and high blood cholesterol? We will seek answers to these important questions as we go forward in pursuit of our dream of developing a curative treatment for Glycogen Storage Disease.

Dr. Priya Kishnani, Duke University, Dr. David Weinstein, University of Florida Study of the Dosing and Efficiency of Modified Resistant Cornstarch in GSD patients

Although cornstarch therapy has dramatically improved the quality of life for patients with GSDI, it is far from an ideal treatment. Even the highest quality cornstarch only prevents hypoglycemia for a limited time in children, and all children (or the parents) must awaken in the middle of the night to administer this life sustaining therapy. In 2003, the need for improved therapies was emphasized by the parent representatives at

Quant Family Hosts Vacation Raffle!!!

The Quant Family of upstate NY hosted a raffle drawing in honor of **Anthony Quant** who suffers from GSD1. The drawing included a one week vacation in Ft. Lauderdale, Florida for up to 8 people. Many thanks to **Jim and Jo-Ann Quant**, the proud grandparents of Anthony, who donated the grand prize. The Quants raised a total of almost \$5,000 for GSD research! Thanks so much to everyone who got involved and helped sell tickets...

Gayle Kopin, Tricia King Blechman, Lynn Nezin, Doug Goldenberg, June Lazzaro, Rob Pryor, Lisa Hodes, Elizabeth Perez, Eva Padilla, John Willingham, Margaret Guilderland, and Shane Quant. Congratulations to winner **John Willingham** of Atlanta, GA. Enjoy your vacation!



Anthony Quant

The Children's Fund Featured on Helmet

By Kathy Graham

NASCAR's own **Chandra and Jimmie Johnson** launched the *Jimmie Johnson Foundation* in February 2006. Johnson, the two-time reigning Sprint Cup champion, drives the No. 48 Lowe's Impala SS. The mission of the foundation is to assist children, families, and communities in need throughout the United States. The foundation has committed more than \$1.7 million to various charities. The "Helmet of Hope" initiative was introduced in July 2008 and offered six race fans and six media members the opportunity to have their charity of choice featured on Johnson's race helmet.

Due to the large number of requests to help so many worthy charities throughout the year and the inability to help... the helmet was a way of getting some recognition for charities that are special to people who follow and work in the racing community.

I completed the nomination information to raise awareness of GSD in honor of my 6 year old daughter, **Rylee**. Each nomination became part of a drawing. Jimmie Johnson then drew one fan charity and one media charity a week for six weeks collecting a total of 12 winning organizations. To my excitement, *The Children's Fund* was the fifth charity chosen.

I nominated *The Children's Fund* for



Jimmie Johnson

Glycogen Storage Disease, as an organization "committed to funding research so that children born with GSD will benefit from early detection, treatment and an eventual cure." I explained that GSD is a rare genetic metabolic disorder centered in the liver. I hope that with increased awareness and research a cure is in the near future. I explained that researchers are making great advances however so few people even know GSD exists.

Johnson wore the helmet straight to victory lane in the August Sprint Cup race at Auto Club Speedway in California with *The Children's Fund* emblem proudly adorning the back.

For more information about the Jimmie Johnson Foundation, please visit www.jimmiejohnsonfoundation.org.

Raffle in honor of Rylee Graham, Stokesdale, NC

Another year yielded another successful raffle. Thanks to a wonderful family friend, **Franky Nester**, we were able to organize this fun event. With tickets to the NASCAR race in Bristol, Tennessee including pit tours, and VIP seating, we were able to raise \$6,700 for The Children's Fund for Glycogen Storage Disease Research.

Originally from Martinsville, VA we still live nearby, and racing is a part of our everyday lives. Locals are interested in racing and have giving hearts when it comes to children. Our friends and family sold, bought and advertised the raffle tickets for such a wonderful cause. In a time of "financial turmoil", we feel fortunate to have so many people participate.

We want to congratulate, **Devonne Duncan** of Sandy Ridge, NC for winning this prize. He had a fun filled day in Bristol.

Since Rylee's diagnosis in February 2003 at a mere 5 months of age, we have devoted ourselves to her health and vow to help in the quest for a cure. The Children's Fund has proven to be one of, if not the primary source of funding for research. We are so proud to be affiliated with this organization.

SO thank you to The Children's Fund, Franky Nester, and our dear friends and families for supporting our endeavors. A very special thank you to **Rylee** for making our lives so much richer!!!



Rylee Graham

Michael Gordon Fights for his son, Jacob

Since the establishment of the Children's Fund for Glycogen Storage Disease Research in 2002, I watched in amazement at the initiative, drive and dedication of the GSD families raising money and awareness for their children and the disease. While my wife, **Karen** and I had done some fundraising, I was looking for a way to raise more money and awareness for GSD. My desire to do something bigger was often overwhelmed by what I called the "fundraising excuse checklist".

- I don't like asking people for help;
- How much of an impact will my event really have?
- How will I find the time to balance all of my other responsibilities?

This past winter things came to a head when I was reading about a Wall Street boxing match that took place at the *Hamerstein Ballroom* in New York City in the Fall of 2007. After reading the story, I started thinking about whether I could enter into the next event as a way to raise money for GSD. So, in early February I sent an email to the sponsor of the event to find out if there was going to be another event and inquired about the process for determining who gets to fight. The next day, I received an email back that I could go and audition for the event the following week. I proceeded to tell Karen about the event and the audition and she asked me if I lost my mind and begged me to do something else. We "discussed" it further and we agreed that I could go for the audition and then see what happens from there.

I went for the audition and a couple of days later I got an email informing me that I was selected as a boxer to fight in the next event, to be held on June 26th. I was told that I should begin training immediately. Several thoughts came to my mind not least of which was how I was going to break the news to my wife. My thoughts consisted of what was going to be more painful, the trek to lower Manhattan from my home in Northern Westchester or getting repeatedly punched in the face? For those outside the tri-state area you probably would take the commute over the "getting punched in the face option."

Karen and I had further discussions about my foray into boxing and ultimately I was able to convince her that I would be okay. With that, I adjusted my morning schedule to be as follows:

- 4:55am – wake up
- 5am – check Jacob's sugar and give him his cornstarch
- 5:46am – take train to Manhattan's Grand Central Station
- 6:40 am – take subway to Wall Street and walk to Trinity Gym
- 7am-8am – workout
- 8:45am – begin workday

The first few weeks of training were generally in line with my expectations. After about a month of training, I arrived at the gym and the head trainer told me to hurry up and get ready as he wanted me to spar. I quickly changed, took my mouth piece out of my gym bag and headed to the ring. This was it, my first sparring session. How would I react to getting punched? I was about to find out. The guy I was sparring with wasn't fighting in the event, he was just a member of the gym who happened to be built like a tank. He knew it was my first time sparring and he understood the objective was to work with me and exchange punches so I could get the feel of it. The bell rang and we started exchanging punches. A few of his punches connected with my face but I was able to keep on fighting. Overall, I did fine for my first sparring session and importantly I now knew that I would be able to fight in the event.

Sparring became a regular part of the training regime. In fact, on Friday nights, the trainers wanted us to come to the gym after work to get more time in the ring. At the first Friday night session I attended, I proceeded to the ring and there was a guy in the ring waiting to spar with me. I was told by the trainer that he is a professional fighter but that I shouldn't worry - he will work with me. He proceeded to tell me that his nickname is **The Butcher**. Moments later I found myself exchanging punches with The Butcher but thankfully The Butcher was truly just trying to work with me so I was able to leave the ring unscathed. As the weeks went by, the



Zachary, Michael & Jacob Gordon

intensity of the sparring sessions necessarily increased. It was okay to work on your technique in the ring but you also need to know how to handle a full barrage of punches. Recognizing this, I started sparring on the weekends up by my house to gain more experience in the ring. Slowly, I started to improve and took a beating along the way. During one sparring session I got punched so hard in the nose I could have hosted a successful blood drive.

About three weeks before the fight, I finished up my workout and the head trainer handed me a medical form that I needed to complete to get my amateur boxing credentials which are required for the fight. I had already passed my physical so this form should have simply been a formality. However, as I reviewed the form, I noticed that the third line on the form asked the doctor to attest that the patient/boxer does not have a history of Lasik eye surgery. I was shocked to see this as I had Lasik surgery around five years earlier and up until now no one had mentioned this as an issue. I spoke to the event sponsor and he went to the boxing association to try to get an exception on my behalf, which was ultimately denied.

So, after nearly three months of training, I was disqualified from the fight. While not being able to box at the event was a huge disappointment, I have absolutely no regrets for the time I put into training. I got into great shape, dropped 15 pounds, lowered my cholesterol dramatically and most importantly, I raised awareness and funds for GSD.

Over 80 people donated to *The Children's Fund* in honor of Michael and Karen's son **Jacob Gordon**, and over \$41,000 was raised!!

Update...

the first Children's Fund for GSD Research symposium. A task force was created, and multiple products were tested over the past 5 years. Through the help of Dr. Philip Lee in England, an outstanding new sustained release cornstarch preparation was identified, and the product underwent initial testing in 2006 – 2007 using grant funding provided by The Children's Fund for GSD Research. In a pilot study of 12 children and adults performed at the University of Florida, the new product was found to last several hours longer than the conventional therapy, and it had an improved safety profile since the rate of glucose fall was much slower even after hypoglycemia develops. The results from this study were recently published in the *American Journal of Clinical Nutrition*.

While the new product offers hope that people with GSD will be able to sleep through the night in the future, more work is needed to learn how to optimally use the product. Earlier this year, a study aimed at assessing dosing of the new product began as a collaborative effort between the Duke University and the University of Florida GSD teams. This study involves testing the product in 60 children and adults with type 1a GSD, and it is the largest clinical study ever attempted for this disease. The Children's Fund for GSD Research continues to be the only source of funding for this work.

Dr Howard Sussman, Stanford University, Identification of Pharmaceutical Targets for Hepatic Adenoma in GSD1a

We have accomplished the goals set forth in the initial phase of our studies, to compare gene expression patterns of normal liver, GSD1a liver and GSD1a hepatic adenoma liver. Microarray analysis was performed on tissues from five GSD1a patients who had developed hepatic adenoma.

Our study demonstrated that there is a substantial cascade of molecular events in the GSD1a liver. Approximately 10% of the active genes are greater than two-fold up regulated in GSD1a liver as compared to normal liver. There are many more genes down regulated in GSD1a liver as compared to normal liver. Included in the large set of genes are many genes that have significant roles in the malignant transformation of normal tissue. Oncogenes are present in the up regulated set of genes in the GSD1a liver, suggesting that these may be candidates for involvement in the processes that define the transition to adenoma. Similarly, we have shown that there is a difference in the gene expression pattern between GSD 1a liver and GSD1a adenoma tissue. Thus, there is a continuum in the gene expression pattern from normal liver, which is the base reference, to GSD1a normal liver, which is at risk for adenoma transformation, to GSD1adenoma, which is the post transformed state.

Another Great Andrushko Success!

Wow! We had another wonderful turnout by our family and friends for the *5th Annual BBQ Fundraiser for GSD Research*. On July 26th, 2008 we held the fundraiser again in our yard and over 200 people joined us! We raised over \$12,200 that day and that takes us to over \$52,000 raised by our family and friends over the last 5 years. We truly appreciate all of your support and just want to say thank you for helping us continue our fight for a cure for our little boy, **Kasen**. We live for hope. See you next summer!



Andrushko Family

Radman Rides for Reed

On May 18th, 2008 **Stephanie Radman** participated in a 62 mile bike tour in Westport, CT in an effort to raise money for **Anna Reed** and all children with GSD. She was completely amazed by the generosity of friends and family members. Everyone in the community who knows Anna and her family would tell Stephanie how happy they were to help the Reed family. The miles were hard at times and it was Anna's sweet, smiling face that helped her through the rough spots! Stephanie would like to thank The Reed Family for being "such wonderful people and an inspiration to us all." Stephanie raised almost \$8,000 for GSD research!



Stephanie Radman & Anna Reed

Band Together for a Cure

A fundraiser to help find a cure for GSD

It was BYOB (bring your own bottle) and BYOC (bring your own checkbook) at the March 8th *Band Together for a Cure* event organized by **Susie Sigel Teboul** and **Jeanne Muchnick** of Larchmont, NY. The event, which the two billed as "not your average fundraiser" featured two suburban dad-bands, **Where's Dave** and **Boneless Chicken**, along with a chock-full-of-goodies silent auction, and a brief celebrity sighting in the form of local **DJ Jimmy Fink** of The Peak radio station, who announced the bands. The event raised more than \$7,000 in hopes of finding a cure for a youngster in their community and others with Glycogen Storage Disease.



Susie Sigel Teboul and Jeanne Muchnick

IN THE NEWS...

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

The Student Council from Ebenezer Avenue Elementary School held a special fundraiser in each classroom to honor one of their students, **Austin**, who has GSD. A special thank you to **Robin Ellison, Amy Koterba** and the entire Student Council for organizing such an amazing event, which raised \$812!!



Austin Grubb

Thank you to the Elk City High School Student Council for donating \$419.50 to GSD Research. They sold Valentines to students and placed them on lockers on Valentines Day. This brought in over \$200 and then their principal, **Rick McNeil** donated an additional \$200.

6 Nights of Camping Fun for Anna Reed!

Anna Reed (7, GSD 1A) went to sleepaway camp this past summer! She was lucky enough to attend *The Hole in the Wall Gang Camp*, a camp founded by **Paul Newman** 20 years ago for children with serious medical disorders. Anna rode horses, swam in the pool, fished in the lake, sang on stage, slept in a bunkbed, did all kinds of crafts, and had the time of her life. The camp



Teri, Fran & Anna Reed

nurses and doctors took excellent care of her, even waking up and riding to her cabin in golf carts to administer her cornstarch in the middle of the night. Anna's parents Teri and Fran enjoyed 6 nights of uninterrupted sleep and a few nights away together at an inn. Thank you Paul Newman!

There are now *Hole in the Wall Gang Camps* all over the US and the world. There is no charge to campers or their families to attend the camp; all money to run the camps is raised through donations. For more information about *The Hole in the Wall Gang Camps*, visit holeinthewallgang.org.

Seniors at McMichael High School in Madison, NC raised \$100 in only 2 hours! The seniors there have to complete a project in order to graduate. **Brittany Wright**, friend of **Rylee Graham** chose GSD awareness. Thanks to Brittany, lots of young people now know about GSD.

Much appreciation goes out to **Kathy Turi**, mom of **Julianna** for enthusiastically becoming our liaison to Igive.com. It's a website where The Children's Fund benefits each time you make a purchase. Check it out!



Julianna Turi

Once again, we would like to thank the **Casarella** family of Southington, CT for hosting the Superbowl Boxes Raffle for GSD. This past year raised a total of \$3,825! Congratulations to the winners: **Diane Julius, Ron Pizzano, Bill Casarella, Danny Oshatz, Chris Wolff, Neil Casarella, Jay Cushing and Charlie Hague**.

Happy Birthday to **Jackson Kirkpatrick** of Madison, NC! He was in kindergarten with **Rylee Graham** and saw firsthand how her diet is limited and how her wellness is always more vulnerable than her peers. Jackson accepted donations for The Children's Fund at his birthday party in Rylee's honor. A total of \$200 was collected.



Rylee Graham & Jackson Kirkpatrick



Adam Julius

Congratulations to **Randy Petsoff** of Glen Ridge, NJ who won the Super Bowl raffle last year and enjoyed a fabulous trip to Super Bowl XLII in Phoenix, AZ. **Mike Julius** sold him the winning ticket.



Scott Lazear



Lazear Family

Way to go - **Scott Lazear**, who ran the Disney World half-marathon in Orlando, Florida on January 12th for his nephew, **Adam Julius** of Westlake Village, CA. Scott raised over \$2,400 for GSD Research. Many thanks to Scott's parents, **Harvey and Marylen Lazear**, and his daughter, **Parker**, for coming out to support and cheer on Scott during his race!



Jeff & Lew Stone

This past year **Jeff Stone**, a friend of the **Hodes Family** ran a 5K race and asked for donations to go to The Children's Fund as a school project. Jeff raised \$1,572.20 for GSD Research!



Jonah Feldman

Thank you to **Stevie and Shannon Paymer** of Trumbull, CT who hosted a party at their home and raised \$621 for The Children's Fund for GSD Research in honor of **Jonah Feldman**.

Wendy and David Feldman of Cheshire, CT organized selling For.Every.Body candles to raise \$ and awareness of GSD for the second year in a row. Thanks so much to everyone who bought and sold candles - **Stacey Becker, Ginger Clarke, Shelly Fisher-Parsley, Shirley Frager, Lori Gilbert, Gina Kelly, Shane Quant, and Denise Schoeneberg**. Together, we raised almost \$4,700!

Thank you to **Andrew Burwick, Jack and Anna Reed, Randy Starvis, Anthony Quant, Suzanne Amato** and everyone else who asked for donations instead of gifts for their birthdays. Happy Birthday!

Thank you to **Eva Padilla** of Round Rock, Texas who hosted a Southern Living at HOME party and earned \$140 towards GSD research!

This past winter, **Donna McNeil**, grandmother of **Kamryn Jackson**, organized a TV raffle drawing and raised \$12,200 for our foundation! Awesome!



Kamryn Jackson

Thanks to **Maya Rabban** of Livingston, NJ who donated her tzedaka money in honor of her friend, **Alyssa Temkin**. Thank you to **Sydney Rosen** of Larchmont, NY for also donating her tzedaka money to The Children's Fund in honor of her sister, **Corey**.

Many thanks to **Margie Ostrove** who contributed to The Children's Fund during Charity Day at the Old Oaks Country Club, in Purchase, NY. In addition, she nominated our foundation to receive contributions from the club and we received an additional \$500!!!

Great job **Scott & Tricia Blechman**. They had a garage sale and raised \$500 in honor of their son **Max**.



Max Blechman



Team Intensity ran 2 runs for GSD1 this past year; Disney and Ft. Lauderdale. We thank our sponsors and our participants for supporting our cause. And a special thanks to **Brian and Desiree Makovsky** for organizing our team and keeping everyone motivated. Our next GSD race will be a 5K in June where we hope to get the whole community involved. Stay tuned for details. We will not stop running until we find a cure.

Online Giving Contest Helps Family Raise Funds for GSD Research

by Suzanne Amato



Max Blechman and Family

Early in 2008, *Parade* magazine ran an advertisement about a contest called, "America's Giving Challenge." It was an online giving contest co-sponsored by *Parade, Network for Good, and The Case Foundation*. The contest challenged the public to champion a cause of their choice. The sponsors promised to award a \$50,000 prize to the

eight charities that collected the highest number of donors before January 31st. When we read the *Parade* ad, we thought of our nephew, **Max Blechman**, of Manhattan Beach, California, who has GSD. Why couldn't we win one of the \$50,000 prizes for *The Children's Fund for GSD Research*?

We followed the instructions on the *Parade* website to create a "donor button" for *The Children's Fund*. We then put together a lengthy email explaining Max's story, introducing *The Children's Fund*, and asking for donations. The contest was unique in that the winners would be chosen based on the number of donations, not the size. So the email merely asked for a \$10 donation to help win the contest. We enlisted all of Max's family (grandparents, aunts and uncles, cousins) to "sign" the email plea and together they blasted it out to everyone they knew, including **Wendy Feldman** on *The Children's Fund* Board, who, in turn, sent it to hundreds of other GSD families/supporters.

The outpouring of support was amazing! Over two hundred people signed onto the donor button to give generously to the cause. Our total donations totaled \$9,400 as the contest deadline approached. In the end, we did not make the top eight charities for one of the large prizes. But a month after the contest concluded, an email from *Parade* arrived letting us know that we were a "Participation Winner," one of the Top 100 charities who generated the most donations during the Challenge. Each "Participation Winner" was awarded an additional \$1,000, putting our contest total over the \$10,000 mark! It was a thrilling result for a cause so dear to our hearts.

Thank you to all the GSD families who logged on to support the effort!



GSD friends **Aliya, Grace, Allison, Caroline, Abby and Baylor** (not picture) raised \$92.00 at their lemonade stand in honor of their friends **Samantha & Katie Hodes, GSD1a**.