

# SUPER BOWL XLIV RAFFLE

## WINNING PRIZE PACKAGE INCLUDES:

- Two tickets to Super Bowl XLIV, Miami, Florida
- 5 days/4 nights accommodations at the Miami Airport Hotel
- Two playing spots in the 25th Annual Super Bowl XLIV NFL Charities Celebrity Golf Classic
- Two playing spots in Fifth Annual Super Bowl NFL Charities Celebrity Bowling Classic

### DRAWING TO BE HELD:

**Sunday, December 13, 2009 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**



As a way to raise money year-round Jeanne Muchnick's friend, Robin Daas and her company, *Causology* have created bracelets with information inside the packaging about GSD. They can be customized...and are a great thing to have kids go around and sell. The bracelets are often made by teenage girls who get community service hours for their efforts. It's a great and easy way to fundraise. For more information, contact robin@causeology.com.

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



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.



NOVEMBER 2009

GSD NEWSLETTER

VOLUME 7

### Contact Us

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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

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Mary Beth Schmidt, PhD

This has been a challenging year for non-profit organizations and The Children's Fund is no exception. Every single donation counts, as GSD research continues to progress in the right direction. We thank you for making contributions which allow our foundation to support the research projects that our scientific advisory board deems worthy. We are so grateful for the support we continue to receive from GSD families who lead the way in our fundraising efforts, and thankful for those families who have recently joined our cause. We

are proud to say that after almost 8 years, we are still run entirely by volunteers allowing for nearly 100 percent of every dollar raised, to go directly into GSD research. To date, we have raised over \$4 million dollars and almost all of this has gone into GSD1 related research. Please visit our website for a complete listing of research we have supported since the start of our foundation, 7 years ago. We remain committed to raise funds to fulfill our 'Hopes and Dreams' and our Mission Statement. As always, we will not stop until we find a cure.

### Research We Have Supported in 2009

Dr. David Weinstein, University of Florida Dr. Priya Kishnani, Duke University	A multicenter, double-blind crossover study of the dosing and efficiency of modified resistant cornstarch in patients with GSD1a	\$54,541
Dr. Dwight Koeberl / Dr. Carlos Pinto Duke University	Pre-clinical development of a highly efficacious AAV vector in GSD1a dogs	\$23,049
Dr. Thomas Conlon/ Dr. Catherine Mah University of Florida	Gene Therapy for GSD1a	\$100,000

### Research Projects Pending Approval by our Scientific Advisory Board:

Dr. Thomas Conlon, Dr. David Weinstein and Dr. Barry Byrne, University of Florida	Gene Therapy for GSD1a	\$570,553 over two years
Dwight Koeberl, Duke Univ.	Pre-Clinical Development of AAV Vectors for Gene Therapy in GSD1a	\$167,087

“...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

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“...because every child deserves to be healthy.”

# The Children's Fund

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. Dwight Koeberl,**  
Division of Medical  
Genetics/Department  
of Pediatrics, Duke  
University Medical  
Center, Durham, NC



In response to an invitation to provide information regarding our research funded by The Children's Fund for Glycogen Storage Disease, I wish to provide the update regarding our gene therapy research. The canine GSD Ia model has features similar to human GSD Ia that are highly relevant to the development of a new therapy, including profound hypoglycemia upon fasting and other biochemical parameters, glucose-6-phosphatase deficiency in the liver and kidney accompanied by glycogen accumulation in those tissues, and reduced survival. Treatment with an adeno-associated virus type 8 pseudotyped vector (rAAV8) has prolonged the survival of all three GSD Ia dogs to >12 months, in contrast to the abbreviated survival of untreated GSD Ia dogs. Vector-treated GSD Ia dogs thrived, no longer requiring carbohydrate supplementation following the newborn period and were fed only three times daily, every 8 to 10 hours, while untreated GSD Ia dogs previously required very frequent feedings of a high carbohydrate diet. Two of three GSD Ia dogs had normal glucose levels following 6 hours of fasting at 14 and 16 months of age, surpassing the degree and duration of efficacy previously reported following gene therapy in GSD Ia dogs. These latter two GSD Ia dogs, Risk and Lollipop, continue to thrive with normal care, completely asymptomatic at >two years of age. Lactic acidosis reflects poor metabolic control and a risk for renal complications in GSD Ia, and therefore the correction of lactic acidosis is an important endpoint for therapy in GSD Ia. Plasma lactate during fasting was reduced for vector-treated GSD Ia dogs at one month of age, equivalent to the level observed for carrier dogs. Plasma lactate levels have normalized at 14 and 16 months of age for Risk and Lollipop. We interpret this data as evidence for stable transgene expression and decreasing glucose requirements with age. Furthermore, recent experiments with an rAAV9 vector revealed correction of hypoglycemia. The first GSD Ia dog treated with this rAAV9 vector had normal blood glucose throughout >6 hours of

fasting at 5 months of age. In summary, long-term efficacy of AAV vector-mediated gene therapy was demonstrated by the correction of hypoglycemia and lactic acidemia during prolonged fasting in canine GSD Ia.



**Janice Chou, Ph.D.**  
National Institute of Health

We have identified the gene for the G6Pase enzyme and generated a mouse model of GSD-Ia 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 that uses a modified adeno-associated viruses (AAV) vector where G6Pase is controlled by the commonly used regulator from chicken-actin promoter and a powerful CMV enhancer to deliver the G6Pase gene into a GSD-Ia mouse. We have shown that using this modified vector, we can deliver a good copy of the G6Pase gene into the liver of a GSD-Ia mouse, where it expresses the G6Pase protein and corrects the GSD-Ia defects. This suggests that gene therapy could be a way to treat the disease in GSD-Ia patients, but more research needs to be done before we can try this approach with patients. Prior to any experimentation with human gene therapy, we have to improve the safety of the virus used in gene therapy and make sure the G6Pase gene is expressed correctly. Funded by The Children's Fund for GSD Research, we have generated a safer, more effective version of the AAV virus. In most gene therapy studies, to get the best level of expression of the gene being used, researchers use very powerful gene promoters and enhancers, like the chicken beta-actin promoter and CMV viral enhancer used in our study. However, despite the fact that the AAV-based vectors, like the one we use, have the best safety profiles among the viruses widely used in gene therapy, a recent study showed that neonatal mice treated with an AAV vector expressing a human gene directed by the regulator, chicken -actin promoter/CMV enhancer, have an increased incidence of hepatocellular carcinoma. To address the possibility that the non-human gene controls are part of the cause of hepatocellular carcinoma, we identified the native human G6Pase gene regulator and enhancer and used them to replace the non-human parts of the

original virus (the chicken beta-actin promoter and CMV enhancer). More importantly, we have shown that this new virus can still effectively correct the GSD-Ia defects in the mouse model. Indeed when we compared the efficacy of liver G6Pase delivery of our new virus, to the previous version of the virus, we showed that the new virus not only directs more efficient expression but also more persistent G6Pase expression in the liver than the previous virus.

Our work has established two key milestones in GSD-Ia research. Firstly, unlike the old virus, the new virus expresses G6Pase activity in the liver of GSD-Ia mice as effectively as the natural G6Pase gene in wild-type mice at age 6 months. Secondly, these levels of expression are therapeutic, with the new virus-treated GSD-Ia mice no longer suffering from fasting hypoglycemia. Indeed, the blood glucose levels in the treated GSD-Ia mice were unchanged after 6 hours of fasting, indistinguishable from that in the wild-type mice.

What remains to be determined is if the changes in our new virus will also reduce the incidence of gene therapy-induced hepatocellular carcinoma or not, and how long the introduced gene will continue to function efficiently. These issues must be further investigated before AAV-mediated gene therapy in human GSD-Ia could be contemplated. We are now examining the long-term consequences of our new virus-mediated gene therapy using the GSD-Ia mice. The goal of our study is to generate an AAV virus that possesses the best safety profile as a candidate for future clinical gene therapy trials for human GSD-Ia patients.



**Howard H. Sussman, M.D.**  
Stamford University

After 10-20 years about 50% of GSD1a patients develop hepatic adenomas from which many succumb to hemorrhages because the hepatic adenomas affect the clotting mechanisms. The basis for the development of the hepatic adenomas is not known. The objectives of the present investigation are to identify genes that are expressed in the liver of patients with GSD1a which will provide us with molecular markers for understanding the basis for the risk of developing hepatic adenomas and for use in identifying the transformation to the adenoma state. The goal is

## A Huge Canadian Success by The Andrushko's



Kasen Andrushko

In July of this year we held the "6th Annual BBQ Fundraiser for GSD Research" in honor of our little boy **Kasen**. This day went way beyond our expectations! We were able to raise over \$18,400 - the most to date totalling over \$70,000 raised over the past six years at our event. The families and friends of all the GSD families involved in Manitoba are one of a kind. We truly appreciate the kindness you have all shown us for our fight to finding a cure for these precious kids.

We could not have asked for a better day - the sun was shining, it was hot outside, and there was so much to do! From great food & music, to bouncers & ponies - everyone was entertained - over 200 of you!

A special thank you to the **Ultimate Canadian Motorsports Association** who have joined our fight for a cure! In honor of **Kasen Andrushko**, the organization has shown their support and we have raised over \$1000 and counting by them allowing us to raffle off items at their motorsports events. Please check out the website at [ucma.ca](http://ucma.ca) for more events to come! Thank you **Jake & Lisa Funk!**

## Shooting for a Cure by Stacey Becker

My fiancé, Jonathan Wanicur and I joined an organization called **Zogsports** in New York City, which runs adult sports leagues in every sport imaginable. Zogsports, whose motto is "Play for Your Cause," has each team choose its favorite charity. At the end of each season, the winning team's charity receives a check. The latest and greatest league to come out this past winter: adult, co-ed floor hockey, and we decided to give it a try.

We named our team "Two for Slashing." **Jonathan Wanicur** and **Dion DeVries** were co-captains of our team, and chose *The Children's Fund for GSD Research* to be its charity, after I informed the team about my nephew, **Jonah Feldman**, and all the wonderful work being done by the foundation.

Thank you to our fellow members of "Two for Slashing": **Dion DeVries, John Saroff, Michael Palan, Piper Loving, Sean Stevens, Alex Gagnon, Alex Pugatch, Zach Abramowitz, Alana Benjamin, Paul Benjamin, Geetha GoPalan, Laura Guy, Simon Chan and Chris Larkin** for choosing *The Children's Fund* and spreading awareness of GSD on behalf of **Jonah Feldman**, and all children and their families everywhere affected by GSD. Let's get ready for next season!



## A Taste of Delray! by Jennifer Mills

On December 4, 2008, the parents of **Zoey Robinson**, (GSD type 1a) hosted "**A Taste of Delray**" in Delray Beach, Florida. It was a cocktail reception featuring amazing culinary delights from some of the area's best restaurants. There was a silent auction, a Wheel of Hope, where you got to spin and win some great prizes, and a live painting that was raffled off at the end of the night.

Thank you to **Delux Nightclub** for doing an amazing job sponsoring the event! Sandy and Lisa Hodes were there to help as well as some other fabulous volunteers. It turned out to be a great success! They raised \$6,650 for *The Children's Fund for Glycogen Storage Disease*. They look forward to next year's event and raising even more money to find a cure for GSD!



Zoey Robinson

## EMS Bike Ride for GSD The Belot Family

**Brent Belot**, father of **Jessie** who has GSD 1a works for the **Winnipeg Fire and Paramedic Service**. He helped to organize this year's 'Emergency Medical Services Bike Ride.' The event raised \$1,340.00 for *The Children's Fund*. During the Bike Ride, **Northpride Sportswear** raised \$70.00 from the sale of t-shirts and shorts. We all had a great time and very much enjoyed the day!



Jessie Belot and supporting friends from the Winnipeg Fire and Paramedic Service



## The Race to Cure GSD Intense Training's 5k Challenge for a Cure by Lisa Hodes



Jeta Piekarski, Denise Harrison, Lisa Hodes, Kim Harris

Our first ever **Race to Cure GSD** took place on June 14<sup>th</sup> at Quiet Waters Park in Deerfield Beach, FL. About 200 people from the ages of 7 to 79 came out to participate in the 5K run/walk in support of Glycogen Storage Disease. Medals and trophies were awarded to all of our top finishers, but we congratulate everyone who completed the 3.1 mile course. Thanks to all of our sponsors, in-kind donors, friends and the

Northwest Broward Roadrunners Club who helped to make sure this inaugural event was a success. With your support, we raised about \$6,000 for GSD Research. A special shout out to Brian and Desiree Makovsky of Intense Training for being our title sponsor and for their unending and ever-present support. We truly appreciate all you do for our family and all others who are affected by Glycogen Storage Disease.

Team Intensity's next race to support GSD Awareness will be the Walt Disney World Half-Marathon (13.1 miles) on January 9, 2010 in Orlando, FL. Please support our efforts by visiting [www.cureGSD.org](http://www.cureGSD.org), clicking on **Team Intensity** and making a donation. We will not stop running until we find a cure!

If you would like to join Team Intensity and

organize an event or participate individually in your area, please contact Lisa Hodes at [HodesL@yahoo.com](mailto:HodesL@yahoo.com) or 954-263-1631. A pair of sneakers and some motivation is all you need to help find a cure for our children. Run on...



Team NBPS

## Awesome GSD Fundraising Events in Honor of Rylee Graham!!



Rylee with her Great Aunt Lisa, brother Reese and cousins, Lyndsey and Mason

This past summer, a golf tournament was held in Martinsville, Virginia in honor of **Rylee**, GSD 1a. We would like to take this opportunity to commend the **Lynwood Ladies Golf Association at Lynwood**

**Country Club** as well as all of the fine women who participated in the golf tournament. The tournament raised \$1500 for *The Children's Fund for Glycogen Storage Disease Research*. Rylee's great-aunt, **Lisa West**, is a member of the Lynwood Ladies Golf Association and brought *The Children's Fund* to the association's attention. This was our first experience with this type of fundraiser. We cannot tell you how incredibly grateful we are to everyone who helped and for all of the gracious donations. We are confident that GSD can be cured in the near future .... We're grateful to the Lynwood Ladies for helping us in our endeavors.

Thank you to the **Western Rockingham Junior Service League**, a community service organization which helps to raise money for charitable organizations. This year they chose to give our foundation \$250 in honor of **Rylee Graham**.



**Zeb Williams** and **Lexi Blackard** of North Carolina had a combined 12th birthday party to raise money for *The Children's Fund* in honor of their friend, **Rylee**. The party raised \$1,100. WOW!!

**Rylee's** brother **Reese** had a birthday and asked for donations to be sent to our foundation. He raised \$110 in March 2009. Thank you and Happy Birthday!



In January 2009, the children of **Ilene and Donald Newman** of Spencer, VA – **Kathy Graham, Debbie Simmons and Eddie Newman** threw their parents a surprise 50<sup>th</sup> anniversary party. They requested that gifts be made to *The Children's Fund* in their honor, to help one of their grandchildren, **Rylee Graham** who has GSD1a. Their celebration raised \$1,600.

Thank you to the staff at **Huntsville Elementary School** in Madison, NC. They participate in *'Huntsville Gives Back'* each month when they donate money to wear jeans the first Friday of each month and the money is sent to a deserving charity. *The Children's Fund* was chosen for the month of April and they raised \$265.00!! This is the most money they have raised in a single month – It was in honor of **Rylee Graham** who attends the school and her mom, **Kathy** who works there!

Thank you to **Racing 2 Save Lives** – *The Children's Fund* was awarded \$4,000 as a result of the 2008 fundraising efforts in honor of **Rylee**.

# Scientific Update...



**Dr. Thomas Conlon, University of Florida**

Glycogen storage disease type Ia is caused by a deficiency in glucose-6-phosphatase. GSD1a patients are unable to maintain glucose homeostasis and

suffer from severe low blood sugar and an enlarged liver. The canine model of GSD1a is naturally occurring, and recapitulates almost all aspects of the human form of disease. We investigated the potential of recombinant adeno-associated virus vector-based therapy to treat the canine model of GSD1a. After delivery of a therapeutic gene therapy vector to a one-day-old GSD1a dog named "Dulce", improvement was noted as early as 2 weeks post-treatment. Correction was transient, however, and the treated dog could no longer sustain normal blood glucose levels after one hour of fasting by two months after treatment. The same animal was then dosed again, but delivered directly into the liver's circulation. Two months after the second dose of gene therapy, both blood glucose and lactate levels were normal at 4 hrs after food was withdrawn. With more prolonged fasting, the dog still maintained normal glucose concentrations, but lactate levels were elevated by 9 hours, indicating that partial correction was achieved. All dietary glucose supplementation was discontinued starting at one month after the second dose delivery, and the dog continues to thrive with minimal lab abnormalities at 25 months of age. These results demonstrate that delivery of our gene therapy vectors results in significant correction of the GSD1a symptoms, and that this strategy may be a promising alternative therapy for this disease or other forms of glycogen storage disease.

Additionally, we have recently shown that our gene therapy provided enough correction of the disorder in "Dulce" to allow her reproductive organ systems to fully develop to the extent that she could have puppies. This finding is extremely exciting to us as it has not been shown that animals with this disease are able to carry a litter. Finally, we have developed a new method of watching the progression of the disease, results of gene therapy and possible formation of Adenomas through Magnetic Resonance Imaging and Spectroscopy (MRI/MRS) in a live dog or patient without having to take a liver sample.

Since, we have increased the size of our group of GSD1a dogs to include additional GSD diseased animals and a group of animals that are carriers for the disease as well as normal dogs. Data is being collected in upwards of 20 animals in order to track the progression of the disorder as a model of the human form in comparison to people without the GSD. The significant amount of data will help support an Investigational New Drug submission for the FDA to review in an effort towards moving this therapy to the clinic.

to identify a genetically recognizable subset of patients who develop hepatic adenomas. The hope is that in this patient subset it will be possible to predict the transition to hepatic adenoma.

Our studies have been directed to this goal to identify molecular markers that may be indicative of the transition to hepatic adenoma. Experiments using micro-array methods that identify approximately 44,000 genes that are either up- or down regulated in GSD1a in association with transition to hepatic adenoma have been completed. These data are being analyzed at the present time



**Dr David Weinstein, University of Florida and Dr. Priya S. Kishnani, Duke University Medical Center**

Although cornstarch therapy has dramatically improved the quality of life for patients with glycogen storage disease type I, it is far from an ideal treatment. Even the highest quality cornstarch only prevents hypoglycemia for a median time of 4.25 hours in children, and all children (or the parents) must awaken in the middle of the night to administer the life sustaining therapy. Even in adulthood, few people can make it through the night, and most people with glycogen storage disease never obtain a full night of sleep. Yet, people with GSD are dependent upon receiving the cornstarch on time. Delayed administration of the cornstarch is associated with development of hypoglycemia which can result in seizures, brain injury, and even death. The constant anxiety associated with living by the clock and the need to interrupt sleep 1-3 times per night is deeply detrimental for the children and their families. The effort is exhausting, and eventually delayed administration of cornstarch occurs due to the unavoidable fatigue. In 2003, the need for improved therapies was emphasized by the parent representatives at 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

to determine pathways that may be involved in this transition. We will be conducting micro-array tests on microRNAs from the same specimens that were used for the genomic RNA analyses, as described above. MicroRNAs are a species of RNA that regulate gene expression.

Also to be noted is that we have increased the number of GSD1a liver specimens for analysis, as well as obtaining an increase in non GSD1a liver specimens. The addition of more specimens increases the statistical value of the data.

2006 – 2007 using grant funding provided by the Children's Fund for GSD Research. In a pilot study of 12 children, 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 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, a second study was needed to learn how the new product should be optimally dosed. The 2 major GSD institutions in the United States are collaborating on this work, and investigations began in 2008 on 60 children and adults with type Ia GSD. To date, approximately 35 subjects have been studied as part of the second dosing study, and investigations should be completed by 2010. Because the study is blinded (to both the investigator and subject), it is not known at this point how the 2 starches compare or which dose will be best. We remain hopeful that the new starch will allow patients to maintain normal blood glucose levels for longer periods of time.

The Children's Fund for GSD Research continues to be the only source of funding for this work. As a result of the investigations completed to date, approval for the use of the modified cornstarch has been obtained in England, Australia, and throughout most of Europe. Approval in the United States and Canada is dependent upon improved dosing information.

For more information about the study, please contact Anne Boney at Duke University (919-681-1932) or Laurie Fiske at the University of Florida (352-273-6655).



Ally and Jonah Feldman

This past holiday season, **Ally Feldman** of Cheshire, CT – asked that her Secret Santa make a donation to GSD instead of receiving a gift. She wants to make the world a better place by helping to find a cure for her cousin, **Jonah**. She also gave up her last night of Hanukah presents and made a donation to *The Children's Fund*. She truly knows the meaning of the holiday season! Thank you Ally!!

In March 2009, **Letty King** of Tucson, AZ decided to do some spring cleaning and had a huge garage sale. She donated all of the proceeds to *The Children's Fund* in honor of her grandson, **Max Blechman**! Thank you so much.



Max Blechman & Letty King

Thank you to everyone who participated in the 2009 Super Bowl Pool for GSD run by the **Casarella** family of Southington, CT once again! Congratulations to winners: **Marc Jacobson, Holly Blanchette, Dennis Rodin, Ken Casarella, Larry Fiedler, Bill Gould, Charlie Hague and Natale DiNatale**. This year's pool raised \$3,500!!



Great job **Jack and Anna Reed** and their cousins **Timothy, Zachary and Chris Ploch** of New Canaan, CT! Their lemonade stand raised \$55.35 for GSD Research!

Thank you to **Girl Scout Troup #64088 of Chase Collegiate School**. They donated \$150 to our foundation from money raised by selling Girl Scout Cookies. The members of the troop are all friends with **Ally Feldman** and they know how committed she is to a cure that would help **Jonah** and others with this disease.

A special thank you goes to **Mr. Richard Iagrosse** of Northford, CT whose generosity is truly appreciated!



Tom O'Day and Family

Thank you to **Tom O'Day**, friend of the **Reed family** for making a splash at the New Canaan Sidewalk Sale. He sat in a dunking booth for an hour and raised \$278 for us!



Chase Madorsky, Dani Josephson and Danny Rosen

This past year, 3 friends did 3 very special things. **Danny Rosen** of Katonah, NY celebrated his Bar Mitzvah and asked his guests to contribute to The Children's Fund for GSD Research instead of receiving his own gifts. He was able to raise almost \$6,000 for the foundation. **Chase Madorsky** of Livingston, NJ chose GSD as his Mitzvah project for his Bar Mitzvah and had a garage sale in the pouring rain that raised \$800. And, most recently, **Dani Josephson** of Jericho, NY generously and unexpectedly contributed to our charity on her Bat Mitzvah day. All of these kids did this because they want to make a difference for **Jonah Feldman** and kids like him. Danny, Chase and Dani have grown up together, and now go to the same summer camp where their fathers met Jonah's dad when they were kids at **Camp Scatico** in Elizaville, NY. The values that each of these families has instilled in their children are truly amazing. The Feldmans are so touched by their generosity and for their willingness to spread the word about our cause to their friends and families. We love you guys!!



Ryan Salinas and his parents.

In February of 2009, **Elizabeth Perez** organized a fundraiser in Texas for her son, **Ryan Salinas**. The party went well – the clown and moonwalk were lots of fun! Over \$400 was raised for GSD Research. Thank you so much to everyone who was there!



Justin Bagin

In 2009 we lost someone very near and dear to one of our GSD families, Mr. **Donald Bagin**, grandfather of **Justin Bagin**. Our foundation received so many contributions made in his memory. Mr. Bagin even requested that *The Children's Fund* be gifted \$15,000 from his estate. In total, almost \$28,000 was received to help his grandson and others born with GSD1a. We send our condolences to the Bagin family and our thanks for all of the support during this difficult time.

Happy 2<sup>nd</sup> Birthday to **Henry Solomon** of Atlanta, GA – his friends and family donated to our foundation at his party in honor of **Jonah Feldman**! How sweet!!

A special thank you to **Kathy Turi**, mom of **Julianna**, who has been working hard to spread the word about **igive.com**, a website that donates \$ back to our cause when you make purchases!

Thank you to **Sue Wolff** who continues to speak on our behalf to **The Optimist Club of Winston-Salem** about our cause. We appreciate your efforts!



Mrs. Malanowski and Samantha Hodes

In April the Student Council at **North Broward Preparatory School** in Coral Springs, FL elected *The Children's Fund*, along with 2 other charities, to be a beneficiary of a dress down day. Students who brought a minimum donation of \$2 were given permission to wear attire other than their usual school uniform. A total of \$300 was raised for GSD Research. Thanks to **Kathleen Malanowski, Licia Campbell, the Student Council officers**, and all who participated for their support.

'Shopping for the Holidays' in Florida raised almost \$800 for GSD Research with a holiday boutique – Each vendor donated a portion of their proceeds to GSD and we all walked away with new jewels, purses and gifts for the holidays. Thanks to **Grace Surdis** for organizing the event and hosting at her house and to all the vendors who so generously donated to our cause. We look forward to another girls night in a few months!!



The Hodes Family

Thank you to all who participated in *Spa Day for GSD* at **Simply Me Day Spa** in Coral Springs, FL on behalf of Sam and Katie Hodes. \$200 was raised!

### 2<sup>nd</sup> Annual Band for the Cure by Jeanne Muchnick

The music was jamming, the conversation enjoyable and the silent auction quite busy at the 'Second Annual Band for the Cure', organized by GSD mom **Jeanne Muchnick** (daughter is **Corey Rosen**). The event was held at *The Globe Restaurant* in Larchmont which generously donated their space. Singers **Elza** ([www.elzamus.com](http://www.elzamus.com)) and **Michael Nappi** ([www.michaelnappi.com](http://www.michaelnappi.com)), musicians with cd's and a long list of accolades, also donated their time and energy to create a coffee shop atmosphere, complete with wine, food and amazing silent auction items donated mostly by Westchester-area stores and businesses. The event raised \$5,885.00, all in an effort to "band together" and find a cure for GSD. "I'm constantly amazed by the warmth and support of the community," says Jeanne, "Especially when you open up and tell them about what life is really like with a GSD kid. To be honest, I was afraid to do this event in this economy... I didn't think I'd be able to raise much money... but I exceeded my goal. To me, every little bit counts and I'm happy for whatever we raise."



Singers Elza, Michael Nappi and Jeanne Muchnick

## GSD raffle for Christmas Cash!!

by Donna McNeil

Thank you so much to **Donna McNeil** for organizing a wonderful raffle held on Dec. 6, 2008 in honor of her granddaughter, **Kamryn Jackson**. The raffle was for \$1,000 cash and it raised \$18,450 for GSD research! A special thanks goes to **Kamryn, Rylee and Taner**, who went around the neighborhood selling tickets, raising \$210.



Kamryn and family with winner Jack Farrell

The way it worked: It was a very easy way to raise money with very little work. I simply wrote a letter to all the friends and family who have helped us in the past, with Kamryn's picture and an update on her condition and told them about the raffle. The response was great! The raffle was held just before Christmas – who couldn't use \$1,000 for their holiday shopping? Tickets were sold for \$10 each. We were going to take the \$1,000 out of the proceeds, but God Bless **Jack Farrell**, the man who won. He bought \$1,000 worth of tickets then gave his winnings back to us. When we took the picture for the newspaper and presented him with his money, Jack turned to Kamryn and said "Now that that is done, you take this and use it for finding a cure for you and all those other precious kids." So everything we made was profit for the raffle. I am sure not everyone would have done this. I always feel God has a hand in matters such as this. I am so glad our family can be a part of finding a cure for GSD. We are passionate about raising money to help with this cause. Thank you for everything you do to make this possible.

## Kure for Kamryn Bike-a-thon!!



**Kamryn Jackson's** preschool, *The Christian Learning Center* at the First Baptist Church in Canyon, TX had a Bike-a-thon to help raise money for "Kure for Kamryn" and The Children's Fund for GSD Research. **Mrs. Susan Young** is the school director, and she is very interested in helping us raise money and awareness for GSD. The children brought their bikes and helmets to school. **Mrs. Young** and the staff blocked off the parking lot, placed cones to form a race track, and the children rode their bikes for about an hour. Everyone had a great time, especially **Kamryn**.

The 5th Annual GSD Golf Classic will be held in Florida on May 7th 2010. Please visit [www.curegsd.org](http://www.curegsd.org) for details!