



# Hopes and Dreams

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

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## Our Momentum is Growing!

The Children's Fund for GSD Research is proud to announce that we have now received almost **\$1.4 million dollars** in donations from the generosity of friends like you.

Even more exciting is that the wheels are already in motion towards finding a cure. We have granted over **\$1.1 million** to study the world's most promising GSD1 research.

It is so incredibly amazing what year number three has meant for The Children's Fund and for the future of Glycogen Storage Disease. **Our momentum is growing.** New people are learning about GSD every day. The outpouring of support - both financial and emotional, has been overwhelming.

The more families and friends of children affected by GSD who get involved, the quicker we will reach our goal of a cure for this disease.

Thank you all for making a difference and for bringing us closer to realizing our 'Hopes and Dreams.' As promised before, we will not stop until there is a cure.



Shirley Goldenberg (GSD1a)



Jack Yuster (GSD1b)

Committed to  
funding research  
so that children  
born with GSD1  
will benefit from  
early detection,  
treatment and an  
eventual cure.

*If you have ever thought about hosting an event in support of someone you know whose life is affected by GSD1, now is the time. The more people who get involved, the quicker our Hopes and Dreams will become a reality.*

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

# The ABC's of GSD...

**What is GSD1?** GSD1 stands for Glycogen Storage Disease Type 1, also known as von Gierkes disease or glucose-6-phosphatase deficiency. In patients who have this disorder, a specific liver enzyme is either missing or dysfunctional, making it difficult to maintain normal blood sugar (glucose) levels between meals.

**How do you get GSD1?** GSD1 is a genetic disorder. Both parents have to be carriers of this disease in order to pass it onto their children. GSD1 has been found in almost every culture around the world. You can take a blood test to find out if you may be a carrier.

**When and how are children diagnosed?** Children with GSD1 are usually diagnosed anywhere between 4 – 10 months of age, with a DNA blood test or liver biopsy. Symptoms at the time of diagnosis may include: enlarged livers, failure to thrive, hypoglycemia, developmental delays, respiratory distress, acidotic shock, and seizures. There are many physicians even today, who are unfamiliar with the signs and symptoms which can point to GSD1.

**Will the child ever grow out of it?** No, a child born with GSD will have it for life, until a cure can be found.

**Why do people with GSD1 need to eat so often?** Children with GSD1 cannot release stored sugars when blood glucose levels start to fall and therefore must eat at regular intervals around the clock, (every 1-3 hours during the day and 3-4 hours at night) to avoid serious side effects.

**Is there any medication to take?** At this time, there is no medication for GSD1, only large doses of Argo cornstarch, which is a complex carbohydrate that can break down slower than other carbohydrates, thus allowing for more time in between feedings.

**Why do most children with GSD have a feeding tube?** The feeding tube assures that caregivers will be able to have a way to get food and cornstarch into the child. It also allows the child (though not the parents) to sleep during the nighttime feedings. It can also help to maintain blood glucose levels during times of illness.

**Why are there oral issues in patients with GSD?** As a result of the continuous feeding schedule, GSD children lack natural oral functionality and curiosity. Many must undergo intensive therapy to learn or relearn reflexes that we take for granted such as sucking, swallowing and even speech.



Rylee Graham (GSD1a)

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## GSDI Research Symposium

On May 21, 2005, it happened again. Healthcare professionals with an interest in GSD1 convened in Cheshire, CT for the 2<sup>nd</sup> Annual Alexion GSD1 Research Symposium. Many of those present have ongoing research or technology that is supported by *The Children's Fund for GSD Research* in hopes of making the lives of children and families touched by GSD1 better. For the entire day and good part of the evening, what we call the 'GSD Dream Team' presented, discussed and learned from one another's research and ideas.

The 2<sup>nd</sup> Annual GSD1 Research Symposium featured an expanded program of experts from around the world in various fields including Glycogen Storage Disease, stem cell research, gene therapy, protein production and food science. **Dr. Stephen Squinto**, Executive VP

and Head of Research at Alexion Pharmaceuticals and **Dr. David Feldman**, co-founder of *The Children's Fund for GSD Research*, began planning the 2<sup>nd</sup> Research Symposium after the 1<sup>st</sup> Symposium generated a great deal of excitement, as well as a collaboration whose very early results were presented at this year's meeting. This unique symposium provides a continuing forum for researchers to discuss the practices, challenges and results of GSD-related research.

Thank you to all who presented: **Dr. David Weinstein** (Children's Hospital Boston), **Dr. Karen Kumor** (Alexion Pharmaceuticals), **Dr. Talmage Brown** (North Carolina State University), **Dr. Bryon Petersen** (University of Florida), **Nancy Parenteau** (CEO of Amaranth Bio), **Dr. Janice Chou** (NIH), **Dr. Dwight Koeberl** (Duke



Drs. Janice Chou and Cathryn Mah

University Medical Center), **Dr. Cathryn Mah** (University of Florida), **Dr. Reba Condiotti** (Hadassah Hospital in Jerusalem, Israel), **Todd Weiss** (Sonnenschein, Nath and Rosenthal Law), **Paul Pescatello** (CEO of CURE, Inc.) Thank you also to **Dr. Adrienne Block**, **Dr. Seng Cheng**, **Dr. Russell Rother**, and **Jayna Dolby**.

The day was truly a day where talented scientists came together

and candidly discussed new ideas and research possibilities in a unique forum - a 'think tank' for Glycogen Storage Disease Type 1. We can assure you that the day was a success and that *The Children's Fund* and everyone present are doing their best to pave the way towards finding a cure.

**For more details, please visit our website:**  
[www.cureGSD.org](http://www.cureGSD.org).



Drs. David Weinstein and Karen Kumor

## ABC's of GSD

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**What is one of the biggest concerns about GSD 1?** In a matter of minutes the disease can go from a well controlled situation to a complete disaster. This could happen by being late for a feeding or because the child may have a stomach virus. These situations and others can affect the blood glucose levels almost immediately, thus putting the GSD patient in serious danger. The health of a GSD1 patient is only as good as his/her last feeding.

**Are there dietary restrictions in GSD1?** People with GSD1 should avoid sugars such as sucrose (table sugar), fructose (sugar found in fruits), lactose and galactose (sugars found in milk). This is because the liver is unable to break down these sugars, which get stored and trapped in the liver as glycogen. Dangerous byproducts such as uric acid, cholesterol and lipids can build up. GSD1 kids should eat foods containing pure glucose or dextrose and foods high in complex carbohydrates such as potatoes and rice.

## How can you help your friends who have a child with GSD1?

You can help by understanding more about the disease and by learning how to help care for their child – perhaps learning how and when to feed a GSD child and what to do in an emergency.

**Will there be a cure for GSD1?** There are now a number of talented researchers around the world working hard and making amazing progress towards finding a cure for GSD1. We at *The Children's Fund* are confident that there will be a cure for GSD1 in the near future.

**What can you do to help?** You can join our organization's commitment to funding research so that children born with GSD1 will benefit from early detection, treatment and an eventual cure. Please consider organizing a fundraiser, volunteering on an existing project or simply make a donation. There is strength in numbers and we welcome your help and support.

*(For more detailed information about Glycogen Storage Disease Type 1, please visit our website)*

## Wristbands:

"Hopes and Dreams" bright blue wristbands are now available in both youth and adult sizes. Spread the CureGSD.org good news and proudly wear a blue band! We've distributed thousands of wristbands around the world so far. For wristband requests - please e-mail or call Fran Reed at [freed@lehman.com](mailto:freed@lehman.com) or work (212) 526-0805 or home (203) 972-9199. We are asking a modest donation of \$3.00 (\$2.50 each for 2 or more bands).



Thanks to all who are proudly wearing our bands! Many thanks to those who purchased wristbands to sell or give away – The **Cotlars**, The **Harris Family**, The **Feldmans**, The **Gordons**, The **Jacksons**, The **Julius Family**, The **Reeds**, The **Goldenbergs** (a ton!), The **Grahams**, The **Centrellas**, The **Beckers**, **United Methodist Preschool**, **New Canaan Raquet Club**, **Debbie Simmons**, **William Gaine**, and **Paul Marcoullier** who set up a display selling wristbands at his toy store in Meriden, CT. Thank you to **Zachary Ploch** who sold wristbands door to door in Vernon, NJ, **Kelly McCabe** who sold wristbands in the New Canaan High School cafeteria, **The Castello Family** who sold wristbands at their daughter, **Jessie's** First Communion Party, **Joanne Ploch** who sold wristbands to Vernon High School students, **Gina Colella** who sold wristbands at her office, **JE Kelleher**, **Bridget Porto**, **Sue Hague**, **Deena Stern**, **Carol Glasz** and **Judi Brain** for selling wristbands to friends and family, and **Grandma Ruthie Nahoum** with "Uncle" **Abie Ades** for selling so many for **Shirley Goldenberg**.



## BBQ FOR GSD

*Kasen's Special Day*

By Dayna & Brian Andrushko - Manitoba, Canada

In the fall of 2003 our little boy Kasen, was diagnosed with GSD type 1a. It wasn't too long after his diagnosis that we decided we needed to raise money in some way for research to cure this disorder. So we decided to throw a big party! In August of 2004 we arranged the 1st Annual BBQ Fundraiser for GSD in honor of Kasen. Well, it turned out to be a great day - what better way to raise money for a great cause and have all of our family and friends in the same place having a great time!

This year the BBQ was held in July. It was another success with 150+ people in attendance. There were ponies and Bounceroos for the kids...and for everyone to enjoy...we even had a band! So many people had a great time that they are already excited for next year. The best part about it is that we raised money to find a cure for kids with GSD. And we hope that soon...really soon, a cure will be discovered. Dayna, Brian and Kasen's BBQ's for GSD have raised over \$12,700!

# The 1st Annual Children's Fund Golf Classic

By Lisa Hodes

It all started on April 30, 2004 at Samantha's 6<sup>th</sup> birthday party at our home. The mother of one of Samantha's school friends saw our feeding tubes and syringes laying out on the kitchen counter and asked about them. A closer friend of ours explained that Samantha and Kaitlyn both have GSD and tried to describe their treatment. Well, that is all Grace needed to hear. She immediately started brainstorming ideas on how to raise money to find a cure for my two little girls.

Being fairly new to South Florida (we had moved here only 2 years ago), I was a bit tentative about asking my new friends/acquaintances for help (asking for help has never come easy to me). But much to my overwhelming surprise and unending gratitude, many of these wonderful women were more than willing to jump in and help - and boy did we turn out an amazing event!

After a full year of planning, on May 16<sup>th</sup>, 2005, we hosted The First Annual Children's Fund Golf Classic at Weston Hills Country Club in Weston, Florida. It was a full day event, with a shotgun golf tournament starting at 1pm, followed by an Awards Dinner and Auction. There were 120 golfers and about 200 dinner attendees. And thanks to my fantastic volunteer committee of friends and the wonderful staff at WHCC, it all went off without a hitch!

The adrenaline was flowing from the minute we got to the course at 8:00am to set up. Luckily, the sun was shining, we managed to set everything up, and by 11:00am, people were actually showing up to play golf! It is an unbelievable feeling to put your heart and soul into something for so long and then see it come to life. While everyone was out on the course, we quickly got to work on setting up the awards dinner and auction. Not only was my committee working that day, but friends of friends that I didn't even know came out to lend a hand. It was very humbling. It took nearly 6 hours to set up the dining room to display more than 100 auction items. This left us only about 20 minutes to primp for the evening before the tournament ended and golfers began coming in.



Sandy and Lisa Hodes



Golf Classic Volunteers

After getting dressed, I walked back towards the ballroom, and the first person I saw was **Dr. Weinstein** from Boston Children's Hospital. I cannot describe the feeling that came over me at that moment. This doctor's compassion for his patients, including **Samantha and Kaitlyn**, and his dedication to treating this disease created serious emotions of gratitude within me. Thank you, Dr. Weinstein.

The night was amazing! We had an incredible silent auction, followed by the GSD documentary film "Life by the Clock" (during which there was not a dry eye in the room), and a brief but impactful presentation by Dr. Weinstein. Then my two friends **Grace and Jodi** emceed the live auction, which included 2 tickets to the Super Bowl, a ride in the Goodyear Blimp, front row seats to a local Y100 Summer Concert and 6 tickets to sit in the batters box of a Florida Marlins Game. It was great fun!

All in all, an event like this is a ton of work (and we're not quite finished yet), but it is worth every second. We raised almost \$100,000.00, and more importantly, we generated awareness for GSD type 1. We have had an overwhelming response to the event and have already received commitments for next year's 2<sup>nd</sup> Annual Golf Classic.

Personally, the experience from beginning to end was extremely emotional. I have been involved with golf tournaments for years, both on the execution side, during my previous life in the corporate world, and as a participant. But at this tournament, everyone there, both on the production side and the participant side, was there for my two girls. Through this event, I discovered the true meaning of friendship. I also met lots of incredible

people and realized there is so much love and compassion in this world; you only need to tell your story and allow others to help.

A heartfelt thanks to **David and Wendy Feldman** for all your help from the foundation and to **Teri and Fran Reed** for all your advice and emotional support along the way. Thanks also to my amazing committee of friends, **Barbra Feller, Eva Ferrara, Renee Haubner, Jennifer Keller, Nancy Medvin, Karen Stein, Jody Sternfeld, Loren Walker and Debi Weisman**. I love all of you for loving my girls. A huge thanks to **Jim Keenan**, the king of golf tournaments, who volunteered to fly down from NY to help with the execution of our event. And, of course, a special thanks to my good friend **Grace Surdis**, because without you, this event never would have become a reality.

Finally, to my family: Thanks **Sandy**, for dealing with all of my disruptive phone calls to the office, my late nights on the computer and the constant "reminders" about soliciting sponsorships. Your contributions during the planning process and on event day insured all would run smoothly; Thanks **Samantha**, for putting up with all the "stuff" around the house, and **Kaitlyn**, for being so cooperative during all the phone calls and meetings I made you suffer through. You were all so wonderfully supportive. To show my gratitude, you all get two whole months of my full attention before we get started on next year!

If anyone is interested in learning more about our event, please feel free to call me at 954-263-1631 or email at [hodesl@yahoo.com](mailto:hodesl@yahoo.com). I will be happy to help you get started on your own Children's Fund Golf Classic.

## Outpouring of Support in Florida



**T**his past April, **MaryLen and Harvey Lazear** of The Villages, Florida hosted a Golf Cart Poker Run (which is like a scavenger hunt) in honor of their 5 year old grandson, **Adam Julius**, who lives in California and has GSD1a.

The event turned out to be a huge success – raising over \$2000 for The Children’s Fund and increasing public awareness of an often unknown disease. “Everyone’s help and kindness touched the whole family,” MaryLen said.

There were 110 participants in the Poker Run, not including all of the volunteers who helped throughout the evening. There were also many people who could not attend, but still sent checks to *The Children’s Fund* as a straight donation. Area merchants contributed by giving gift certificates and gifts to the winners. People were just outpouring with support. Friends, neighbors and new friends were absolutely wonderful.

The Lazears are looking forward to hosting this event next year.

## Super Bowl Raffle

Congratulations to **Hal Hermelee** of Thousand Oaks, CA, who was the winner of this years Super Bowl Raffle. Hal won two tickets to Super Bowl XXXIX in Jacksonville, Florida on February 6, 2005 along with two entries in the Super Bowl NFL Charities Celebrity Golf Classic at the Amelia Island Plantation. Hotel and airfare was also included. A HUGE thank you once again to **Nick and Mary Nicolosi**, grandparents of **Anna Reed**, who covered expenses for the raffle so that the entire dollar amount of the raffle ticket sales plus all matching gifts (\$200,000) could go to our foundation and be used for GSD1 research. In addition to **Mike and Pam Julius**, who sold most of the tickets (including the winning one – Mike and Hal are colleagues at Countrywide) thank you to all of those who sold tickets including **Jennifer and Gary Bagin** (parents of Justin), **Peter Catalano, Mike and Christy Centrella** (parents of Ellie), **Wendy and David Feldman** (parents of Jonah), **Howie and Lori Gilbert** (parents of Justin), **Carol Glasz, Bette and Douglas Goldenberg** (parents of Shirley), **Danny and Dana Harris** (parents of Emma), **Andrew Miller** (brother to Scott), **Regan and Barry Stein** (parents of Jason), **Jack Vax** (grandfather to John Henry) and **Teri and Fran Reed** (parents of Anna).



Justin Bagin (GSD1a)



Ellie Centrella (GSD1a)

## Team Cure GSD keeps on running!

By Fran Reed

Team CureGSD keeps on running! This year we had **Joanie Genirs, Carey Burwick, Valerie Rosen**, aunt of 4yr old Jonah and **Fran Reed**, father of 4yr old Anna, run the NYC Marathon in Nov 2004 – collectively we raised nearly \$90,000 through sponsorship from friends, family and colleagues.

Running the NYC Marathon has now become a great tradition in the fight to “CureGSD”. I feel so incredibly fortunate to have so many wonderful family members and friends who literally run with us and support us in so many ways. **Joanie Genirs**, one of my colleagues at Lehman Brothers ran for Anna and got her whole family and everyone in her apartment building involved.

**Carey Burwick**, a friend from New Canaan, and I literally ran every step of the 26.2 miles together - miraculously, we never became separated in a field of over 35,000 runners. **Michelle Meintzer**, also of New Canaan, selflessly rose each morning in the pitch dark and ran

every single 4:30am training run with me - despite not actually having qualified for the marathon herself! I am still deeply awed by her extreme generosity and true friendship. Michelle, Joanie, Carey, Valerie and of course my beautiful wife Teri are all incredibly strong and wonderful women who were the backbone of an amazing TEAM CureGSD marathon experience this past year.



I will be deferring my qualified entry into the 2005 NYC Marathon to focus on my family, **Teri, Jack and Anna**, and other foundation endeavors, but plan on being out there again in 2006! Anyone who will be in NYC on November 6<sup>th</sup> – please come out and cheer on **Stacey Becker, Erika Vogel and Steven**

**Julius** who will be running the NYC marathon as part of Team CureGSD. If you’d like to become a part of Team CureGSD please contact Fran Reed at [freed@lehman.com](mailto:freed@lehman.com), work (212)526-0805 or at home (203)972-9199.

# IN THE NEWS...

• Thank you to **Linda Martin** and **Stevens Memorial United Methodist Church** in South Salem, NY for donating over \$1000 from the Art Auction in October to *The Children's Fund* in support of **Anna Reed**.



The Reeds accept Art Auction check

• A very special thank you to **Chapdelaine Corporate Securities** for their extremely generous \$50,000 donation this past December in honor of **Adam Julius**. This is the largest corporate gift we have received to date!

• Happy Birthday to **Greysen Bauld, Jack and Anna Reed** and **Gillian and Patti Murray**, each of whom asked that friends make donations to our foundation instead of receiving birthday presents this year, all in honor of **Anna Reed**.



Samantha and Kaitlyn Hodes (GSD1a's)

• The **MOMS Club** chapter of Parkland, Florida chose *The Children's Fund* as its benefactor for all fundraising efforts this past year. Through various events, including the sale of greeting cards, a holiday party raffle, a Chinese Auction and a giant tag sale, the Club raised almost \$4,000 for GSD Research in support of **Lisa Hodes**, mother extraordinaire!

• **Justin Gilbert's** mom, **Lori** hosted a 'Southern Living Party' in Long Island, NY and donated proceeds to *The Children's Fund*.

• **Cindy Stevens** organized a collection from the faculty of Cheshire High School, Cheshire, CT for our foundation. Thank you!

• **Kids in Motion**, a gym and dance studio in New Canaan, CT held a 'Cartwheelathon' in June, raising \$2,700 to benefit GSD research. Family and friends pledged money for every cartwheel completed within a 5-minute span. **Jack Reed**, brother of **Anna**, completed 141 cartwheels and got his family members to donate \$934!!



Jack and Anna Reed

• Photographer **Susan Morrow** generously donated to *The Children's Fund* using proceeds from her photo exhibit at *Starbucks* in New Canaan, CT.

• Thank you to **Belia Pena**, who held a tag sale at her home and raised \$200 for *The Fund* in South Norwalk, CT. Her daughter, **Gisselle**, friend of **Anna Reed**, helped by selling wristbands to family and customers.



Tag Sale for Anna (GSD1a)

• *The Children's Fund* was awarded a \$10,000 grant from **Lehman Brothers**, through the Lehman Brothers Philanthropic Foundation, due to a request from **Fran Reed**, father of 4 year old **Anna**, and an employee of the firm.



Jonah Feldman (GSD1a)

• Thank you to **Rosemary Castiline** of Hamden, CT who collected over \$600 for our foundation in hopes of finding a cure for her friend, **Jonah**.

• Thank you to the **Cheshire Grange** for spreading the word about GSD at your annual Grange Fair, and for donating \$700 from this wonderful event to *The Children's Fund*.

• **Sandy Visentin** of Cheshire, CT published an anecdotal book, "*Lawyers Unplugged*", which depicts her humorous experiences as a court reporter. Sandy has donated over \$2000 from sales of her book. Thanks to **Sandy** and her kids, **Katie** and **Steven**, for giving their mom this great idea in support of their

orthodontist's son, **Jonah**. To obtain a copy, contact us at [www.info@cureGSD.org](mailto:www.info@cureGSD.org)

• Several **Mazel Tovs** are in order: **Natalie Teboul**, in honor of her friend, **Corey Rosen**, **Zachary Barness**, in honor of his cousin, **Jack Yuster**, **Kayla Helitzer** in honor of her cousin **Adam Julius** and **Leah Demakovsky** in honor of **Jonah Feldman** – all had their Bar or Bat Mitzvahs this past year and had gifts sent to our foundation. Thank you so much and congratulations!



Natalie Teboul and Corey Rosen (GSD1a)

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## In the News

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- **Elizabeth Carney**, friend of **Teri Reed**, is donating part of the proceeds from sales of her custom photographic handbags to our foundation. For more info, go to [www.lizchiu.com](http://www.lizchiu.com)
- Thank you to **Kim, Kenny and Lauren Cassarella** for once again hosting their Super Bowl Pool in Southington, CT and raising \$1,300 for our foundation.
- There were several families who lost loved ones this past year and were kind enough to ask that donations be made to our foundation in celebration of their lives. *The Children's Fund* would like to extend its deepest sympathy to those families and thank them for such a wonderful request which will help so many children and families.
- Special thanks to **Sue Wolff** of Vancouver, Canada for speaking with groups of colleagues about our foundation and showing the documentary film, 'Life By the Clock' to help raise awareness of GSD1.
- Thank you to **Lisa Hodes** who donates all proceeds from her 'Photo Fashions' to *The Children's Fund*. You can visit her website, [www.photofashions.com](http://www.photofashions.com) for more info.



## Masquerade!

By Mary and Emory Chapman

Gastonia, North Carolina-October 2004

It was our pleasure to host a dinner masquerade party at Cramer Mountain Country Club to help raise funds for The Children's Fund for Glycogen Storage Disease Research. Our son **Christopher** who is five years old and will be entering kindergarten in September, was diagnosed with GSD1a in October of 2000 at 8 months old. We are so fortunate to have good friends who have supported Christopher by attending our masquerade fundraiser and helping raise awareness and money for research to find a cure.

Our event was made possible because many of our friends helped organize the evening. Our friends donated their time and musical talent of their band, **Sonic Tonsils**. **Martin Ray Vineyards of California** donated all the wine for the evening. All the beautiful table decorations were also created by friends. Everyone wore very creative and beautiful masks and prizes were given for the most original mask for both male and female. Our event was a big success; we raised over \$20,000.

Thanks to *The Children's Fund* for their vision to form an organization focusing on GSD 1a research.

*We believe a cure is possible!*

## Some Great Faces of GSD



Vincent Padilla (GSD1a)



Julianna Turi (GSD1a)



Kamryn Jackson (GSD1a)



Emma Harris (GSD1a)

## Wine Tasting

Approximately sixty friends and colleagues attended The Second Annual Mortgage Backed Securities Wine Tasting hosted by **Pam and Michael Julius** on May 19th 2005 at **The Italian Wine Merchant** in



Michael and Adam Julius (GSD1a)

New York City. Guests enjoyed eight different wines from the region while dining on a fabulous meal in the **Studio Del Gusto**. Over \$37,000 was raised this year to support the most promising GSD research. A special thanks to **Bob Eick** for organizing this year's event and to **Greenwich Capital** for sponsoring the event. We hope to see everyone again next year.

## Research Grants Awarded by Our Foundation in 2005 (\$561,517.86):

Topic	Researcher	Institution	Amt Granted
Gene Therapy for Glycogen Storage Disease Type 1a	Drs. Cathryn Mah and Barry J Byrne	University of Florida College of Medicine	\$155,285.86
Gene/Stem Cell Therapy for the Correction of GSD1 Patients	Bryon Petersen, Ph.D.	University of Florida College of Medicine	\$125,175.00
Long-term Correction of Canine GSD1a using AAV2/8 Vectors	Dr. Talmage Brown	North Carolina State Univ College of Veterinary Medicine	\$111,809.00
Clinical and Molecular Evaluations in Glycogen Storage Disease Type 1a	Drs. Priya Kishnani and Deeksha Bali	Duke Children's Hospital and Health Center	\$169,248.00 (over 2 years)

### Get Ready for Our 2006 Raffle Drawing!

#### 2006 PRO BOWL NFL ALL STAR GAME PACKAGE

February 6th – February 13th

**Honolulu, Hawaii**

*The winning ticket includes:*

- One week stay at Hilton Hawaiian Village Hotel on Waikiki Beach
- Two tickets for the Pro Bowl NFL All Star Game at Aloha Stadium
- One playing Slot - 2006 Pro Bowl NFL Charities Celebrity/Amateur Golf Classic at Waialae Country Club
- Round trip airfare

*For more information on purchasing tickets, please contact Teri Reed at (203)972-9199 or terifranr@snet.net*

### Our Documentary Film, "Life by the Clock"



This is an 18 minute film produced by **Harriet and Pierre Bonelli** in 2003. It is a powerful, educational film depicting the personal side of GSD1 and what these families deal with everyday. If you are interested in obtaining a copy of this documentary for fundraising and/or educational purposes, please contact The Children's Fund either by email or by phone.