

# Hopes and Dreams

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

September 2004  
Volume 2/Issue 2

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This has been a wonderfully busy and exciting second year for our foundation. More and more people have answered our

### 'Call to Cure'

and have joined together to better the lives of those with  
Glycogen Storage Disease Type 1.

### The word is spreading!

Everyday we receive gifts of **Hopes and Dreams** from around the country and around the world. To date we have raised over \$725,000.

### We will not stop until there is a cure.

This past summer we granted \$591,710 to the world's most promising GSD1 research. Combined with the \$100,000 we granted last year, this unprecedented amount of research dollars allows for researchers to make advances in GSD1 that have not previously been seen.

### You are making a difference.

Again, from the bottom of our hearts, we thank you.



Adam, (GSD1a),  
California



Kevin, (GSD1a),  
Idaho

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

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

## About Glycogen Storage Disease Type 1

GSD Type 1 (glucose-6-phosphatase deficiency, von Gierke disease) is a serious genetic condition that is both life-threatening and life-altering for the entire family. Prior to the 1970's, the mortality rate for infants born with GSD was near 100%. It is estimated to affect one in 200,000 infants. It is not known how many infants actually die from this disease without ever having been properly diagnosed.

In children born with this metabolic disorder centered primarily in the liver, a specific enzyme that breaks down certain carbohydrates is either missing or dysfunctional, making it difficult to maintain normal blood sugar (glucose) levels. Children with GSD type 1 cannot properly release stored sugars when blood glucose levels start to go low. This in turn creates severe side effects including hypoglycemia (dangerously low blood glucose levels), a condition called acidosis or acidotic shock, respiratory distress and enlargement of the liver. Hypoglycemia can cause brain seizures, which can lead to a coma and death. Liver and kidney tumors occur in 50% of children who survive with GSD. For those afflicted with GSD, management is a lifelong ordeal. To maintain proper blood glucose levels, children (and adults) must be fed every one to four hours and dietary options are severely limited. GSD patients have to be constantly monitored for hypoglycemia through needle sticks with a glucometer. Prevention of hypoglycemia can be overcome by being hooked up to a feeding pump or by continually administering large doses of complex carbohydrates (uncooked cornstarch is a natural glucose polymer) through a stomach tube, commonly known as a "g-tube". The surgical placement of a g-tube is necessary for these frequent feeds, particularly throughout the night, and certainly during a seizure. As a result of the continuous feeding schedule GSD children lack natural oral functionality and curiosity and must undergo intensive therapy to learn or relearn reflexes we take for granted such as sucking, swallowing and even speech.

Long term prognosis is uncertain due to a lack of data and a virtually non-existing adult GSD population. But there are a number of talented scientists at research institutions around the world working hard and making progress toward a cure for this problem. The Children's Fund for GSD Research was created to fund these scientists so that our hopes and Dreams of a cure come true.

### Did you Know...

The Board of Directors of The Children's Fund has discussions via conference call almost every month.

### Did you Know...

A gift of stock is an excellent way to make a donation. Ask your accountant how beneficial it could be for you.

### Did you know...

The first time all seven board members met each other face to face was at the Alexion Pharmaceutical Research Conference in Cheshire, CT.

## GSDI Research Symposium

On April 24, 2004, Alexion Pharmaceuticals of Cheshire, CT hosted the First Annual Glycogen Storage Disease Type 1 Symposium. Co-sponsored by The Children's Fund for GSD Research, the symposium brought together experts from around the country in various fields including Glycogen Storage Disease, liver transplants, gene therapy, hepatocyte and stem cell transplantation. Never before had so many brilliant minds come together to focus on GSDI.

Alexion's Executive VP and Head of Research, **Dr. Stephen Squinto**, could not have been more pleased with how the day of presentations, discussions and discovery went. By bringing together scientists in various fields we are hoping for some interesting collaborations. This symposium brings so much promise and hope; not only for our children, but also for the endless other medical possibilities that could come out of knowledge shared on this day.



Dr. Janice Chou

As a result of the First Annual GSD Research Symposium these scientists continue to look at GSD in different ways – all in an effort to make the lives of GSD patients and their families better. The Children's Fund for GSD Research is excited by the possibilities of what may come from this day.

Thank you to all who presented: **Dr. David Weinstein** (Children's Hospital Boston), **Dr. Dwight Koeberl** (Duke University Medical Center), **Dr. Carolyn Kahn** (Hepaticus, Inc.), **Dr. Simon Horslen** (University of Nebraska Medical Center), **Dr. Janice Chou** (National Institute of Health), **Dr. Pramod Mistry** (Yale University), **Dr. Stephen Squinto** (Alexion Pharmaceuticals) **Dr. Russell Rother** (Alexion Pharmaceuticals), and **Ms. Jean Campbell** (National Organization of Rare Disorders -NORD). We greatly appreciate the incredible efforts of **Dr. Karen Kumor** in collaboration



Dr. Stephen Squinto

with **Dr. David Weinstein** of Boston Children's Hospital and **Dr. Ralph Waniska** of Texas A&M. We are so grateful that **Dr. Kumor** has taken such a special interest in GSDI after learning more about this disease at the Symposium. Thank you to the many others who took the time out on a beautiful Saturday to learn more about GSDI and for participating and adding to the discussions. Special thanks to **Jayna Dolby** who coordinated the entire day.

## RESEARCH GRANTS AWARDED BY OUR FOUNDATION IN 2004

INSTITUTION	RESEARCHER	TOPIC	AMOUNT GRANTED
Goldyne Savad Institute of Gene Therapy, Hadassah University Hospital Jerusalem, Israel; NIH, Bethesda, Maryland, USA; Soroka Medical Centre, Beersheva, Israel	Drs. Reba Condiotti and Eithan Galun in collaboration with Drs. Janice Chou and Shimon Moses	Use of a non-primate lentiviral vector for stable and prolonged G6Pase expression for therapy of glycogen storage disease type 1a	\$145,000
Duke University Medical Center, Durham, North Carolina, USA	Drs. Dwight Koeberl and Haoyue Zhang, Ayn Schneider and Andrew Bird	Regulated G6Pase expression with AAV vectors to correct GSD1a	\$184,310
Beatrix Children's Hospital, University Hospital Groningen, The Netherlands	Dr. G.P.A. Smit and Danielle Martens	ISGSD1 project and patient database	\$32,400
Children's Hospital Boston, Harvard Medical School, Boston, MA, USA	Drs. David Weinstein, Emanuela Gussoni, Mark Flemming, and Morey Haymond	Quantification of Endogenous Glucose Production as a Marker of Glucose-6-Phosphatase Activity after Bone Marrow Transplantation	\$230,000

## The Children's Fund Goes to Washington

After reading a letter in the Camp Scatico Alumni newsletter about Jonah Feldman's battle with GSD1a, Scatico Alum **Todd Weiss** immediately volunteered to help. Todd is a Senior Managing Director at Sonnenschein, Nath and Rosenthal LLP, a lobbying firm in Washington, D.C. After several months of conference calls and e-mail exchanges, in mid-March, Todd hosted **Dr. David Feldman** and **Dr. David Weinstein**, in Washington, D.C. for a day of Congressional meetings.

### My trip to Washington: Dr. David Weinstein

The trip to Capitol Hill to advocate for GSD Research and The Children's Fund was a tremendous success. My main goal for the trip was to help members of Congress understand the problems (especially financial challenges) associated with doing research on glycogen storage disease type 1a. By talking to the congressional offices and sharing the video made by The Children's Fund, the challenges faced by children with GSD were clearly conveyed, and the need for research support was understood. I also feel that we were very successful at explaining how research into GSD can help people with other diseases including diabetes and other sugar disorders. Through the follow-

up efforts of Mr. Weiss, I am confident that GSD research will gain support from funding agencies in the future and that children around the world will be able to experience many wonderful things life has to offer, without the restrictions of this disease.

A second goal of the visit was to discuss how stem cell research can be helpful in glycogen storage disease and a multitude of diseases. Regeneration of the liver offers a possible way to cure GSD, and politicians need to understand how important stem cell research is. Hundreds of thousands of embryos are created for use in in-vitro fertilization, and yet the majority will be destroyed when some could be used for curing disease. Members of both parties clearly understood the potential benefit of stem cell work,

and almost universally there was support for helping the President understand why stem cell research should be allowed. While this was not the primary goal of our visit, I know that GSD research will benefit from educating members of Congress regarding the truth about stem cell work.

With the NIH budget being cut and more money going to special interests, the members of Congress clearly could understand why securing funds for GSD research is difficult. The support of some of the members that we met with will likely lead to increased awareness regarding GSD, and members of NIH granting committees are likely to view GSD applications more favorably in the future.

# I Get By With a Little Help from My Friends

(A recap of the "Movin' Out Under the Stars" GSD Benefit) by Jeanne Muchnick

If anyone asked me what the greatest gift that someone ever gave me was, I'd have to say the GSD benefit, held Saturday, June 13th. It was an emotional, heart-warming evenings I've ever been the recipient of.

And it all grew out of a causal conversation I had with my friends **Debbie Broder Walters** and **Susie Segal Teboul**. They are my best friends, Chelsie and Natalie. They have known Corey, now 11, since kindergarten. Corey has type 1a – but as far as they are concerned, he's "BFF." The fact that Corey has a serious medical condition rarely comes up in conversations – though everyone knows to give **David Feldman** about a year ago and casually mentioned something about their organization to Debbie and Susie. I told them that our new organization could raise more money so we can find a cure.

Before I knew it, my two friends were brainstorming (unbeknownst to me) on their commutes into NYC about how to help Corey. The venue was perfect: her parents have the perfect venue: an expansive lawn overlooking Long Island Sound. Add to that Susie's expertise in event planning, we invited **Wade Preston**, of the Broadway Show "Movin' Out", have Debbie's best friend and another awesome singer, **Kaydi J** for the auction, a tent, cocktails by the pool, and viola! "Movin' Out Under the Stars" was hatched: a night meant to showcase the "Cure" for the illness.

Though the event was built out of love for my daughter, **Corey Rosen**, it drew people from all over the tri-state area, including my friend **Lisa Hodes** and her two daughters, who came up from Florida, her in-laws, her parents, her brother, her sister-in-law **Ann Gordon**, parents of Jacob, and of course, Wendy and David, parents of Jonah and the founders of this organization. We all enjoyed the evening.

I know it was also a special night for my in-laws, as they got to meet other grandparents struggling with this illness. It's so special to have family and friends who understand. It was also special for me because people I never could have imagined would go so far out of their way to come – surprised that **Columbia Presbyterian** was there, as were **Colleen Iodice**, the nurse from Corey's school, and **Beth Foltman**, one of her teachers. The overwhelming support and love from the Larchmont community – people who are friends with Debbie and Susie – who maybe knew me but whose support and love gave from their hearts truly meant a lot.

I'm a gal who loves jewelry, clothing and fine things – what woman doesn't need another pair of shoes? — but for me, that was a special gift. And for all the other children with GSD.

## In The News...

Thank you **Marylen and Harvey Lazear** who celebrated their 40th wedding anniversary and Marylens 60th birthday on June 27th. They had a party to celebrate both wonderful events and in lieu of gifts asked their friends to make a donation to The Children's Fund in honor of their grandson **Adam Julius** (1a). They raised over \$500!

Thank you to **Mrs. Elaine Harris**, grandmother of **Emma Harris**, who has been selling GSD cards and donating all gifts to The Children's Fund.

Thanks to **Pamela Pantel, Colby Smith** and everyone at TopForm Data of Rio Rancho, NM for their continued support and generosity in printing our stationary.

**Michelle Witrock** generously donated \$500 of her Bat Mitzvah gifts in honor of **Jonah Feldman** to The Children's Fund and made a beautiful speech about GSD on her special day. Congratulations and thank you!

Thank you to **Irva Solomons** and the Employees of Preferred Services Group in White Plains, NY who made contributions to our foundation in lieu of having a grab bag or secret Santa for the holiday season.

**Jack Reed**, big brother to 3yr-old Anna (1a), requested in lieu of birthday gifts for



Jack & Anna Reed

his 5th birthday on January 24<sup>th</sup> that donations be made to our foundation to "help find a cure for Anna." He raised \$225 for his little sister!

Friends and relatives of 3 year old **Mendel**

**Collar** (1a) of Texas, made donations to The Children's Fund in honor of the first haircutting ceremony (Upsherinish). Mazel Tov and thank you.

**Kim, Kenny and Lauren Casarella**, of Southington, CT, certainly made watching

the Patriots and Panthers play Super Bowl 38 even more exciting. Many of their friends, family and co-workers filled in boxes with their names, and as the game was played **Jay Cushing, Spider Platt, Billy and Peggy Casarella** and **Linda and Al Roy** were all winners. The big winner was GSD – **Kim, Kenny and Lauren** raised \$1300 for our foundation!

Thanks to **Karen Marino** and The Cheshire, CT Grange for choosing our foundation as their charity throughout this upcoming year.

When **Danielle Gersh** had her Sweet 16 birthday party, she wanted to do something special for her cousin, **Jack Yuster** (GSD1b). In lieu of gifts for herself, she asked her friends and family to make donations to our foundation. What a *sweet* thing to do!

### Did you Know...

Our biggest donation so far is \$28,258.30. Our smallest is \$3.

June 26<sup>th</sup> in Great Neck, Long Island. It was honestly one of the most

are not only my friends – but are the moms of my daughter, Corey's  
are concerned, she is a "normal", fun-loving, playmate, friend and  
e Corey her drink exactly on time "or else." I had met **Wendy and**  
m how impressed I was with them and how I wish so badly that this

o Corey – and raise money for the Fund. Debbie's wheels started  
in promotions, and soon they had come up with an awesome plan:  
**Johnson** sing beforehand, have a "picnic" under the stars, a silent  
GSD stars" – the kids and their parents who struggle daily with this

ding other GSD families I had heard of but never met. I was thrilled to  
nd assorted friends. I also got to meet **Fran and Teri Reed**, parents of Anna and board members of this fund; **Karen and Michael**  
ked that it was the most GSD parents together anywhere.

ometimes hard to remember it's not just us parents who are feeling challenged!

l me – all in honor of Corey and the illness she so valiantly fights every day. Corey's gastroenterologist, **Dr. Amy DeFelice** from  
chers. Their presence really brought tears to my eyes because it made me realize how special my daughter is. I also felt over-  
e from afar, but never truly understood what my husband and I deal with on a daily basis. The fact that they schlepped so far – and

evening was the best present anyone could have given me: the gift of love, support and hope for a better future for my daughter,



Susie Segal Teboul, Jeanne Muchnick Rosen and Debbie Broder Walters joined together to raise over \$50,000 for The Children's Fund.

Thank you to The Student Government Association of Marjory Stoneman Douglas High School for raising \$400 to help further GSD research.

**Alyssa Miller** of Cheshire, CT took it upon herself to walk door-to-door in her neighborhood to raise money for GSD to help her little buddy, Jonah – great job!

**Rita Turner** and family of Brighton, MI ran a fundraiser at their 7-Eleven store this past Easter and raised \$500 in memory of **Ruth Vax**, grandmother of 3 year old **John Henry Vax** (1a) of Prague, Czech Republic.



John Henry Vax

Thank you to **Betsy and Anthony Depaulo** who had a tag sale and donated all their proceeds to The Children's Fund.

Once again, we would like to thank **Tom Kaplan** of Cheshire, CT who continues to donate his time, energy and expertise to hosting our foundation's website ([www.cureGSD.org](http://www.cureGSD.org)) and thanks to **Wendy Feldman** for constantly updating the site with new information

Special thanks to **Theresa Davidson** who organized the clients of Gleneden Dressage in Bedford, NY to raise funds for GSD Research. The friends of **Fern Feldman** (grandmother to Jonah Feldman (1a)) honored their fellow horse enthusiast with donations totaling \$12,866.00 in hopes of moving research along and finding a cure.

Special Thanks to **Steve Littman** and The Mailing Company of West Haven, CT for their generosity and help with mailing this newsletter.

**Pam Julius** of Oak Park, CA recently hosted a Pen Pals Stationary party at

which all of the proceeds, \$1,500, were donated to The Children's Fund in honor of her son Adam (type 1a). A big thank you to **Ellen Sussman** for her huge effort and generosity in making the day such a success.



**Sydney Rosen** (right) collected and donated tzedeka money at her Hebrew school to raise funds and help find a cure for her sister **Corey** (left)

#### Did you Know...

You can order t-shirts and hats that say, "The Children's Fund for GSD Research" and "Team CureGSD."

cont'd on page 6

## IN THE NEWS...

cont'd from page 5

Thanks to **Igo and Sylvia Alstreits** for their overwhelming kindness. They have regularly sent donations, along with heartwarming, notes after reading an article in the Cheshire Herald about our foundation. They have never even met anyone with GSD! Your thoughtfulness means so much!

Thank you to **Ellen Webber** and the employees of Aronson & Company of Rockville Maryland who generously contributed \$715 to our Fund.



Norm Becker, Jonah & Wendy Feldman, Stacey Becker

Congratulations to **Wendy Becker Feldman**, her sister **Stacey Becker** and Uncle **Norm Becker** for running in the 2003 NYC Marathon as part of Team CureGSD in honor of **Jonah Feldman** (1a). Together they raised more than \$37,000 for GSD Research! Thank you to so many who gave so generously!

Special thanks to marathoners **Greg Huges, Richard Koch, Sinead Logue, Steve Metro** and **Simon Moore** who all joined Team Cure GSD.

There were several families who lost loved ones this year and were kind enough to ask that donations be made to The Children's Fund 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 that will help so many children and families.

### Did you Know...

Over 2,600 people have made donations to our foundation since we began.

## Bagin Family Fun Run Raises \$14,000

**Gary and Jennifer Bagin**, parents of Justin (age 5, 1a), and their family recently raised more than \$14,000 for The Children's Fund by organizing and participating in an Atlantic City, N.J. fun run on June 19.

About six months before the event, the Bagins asked their immediate family to compile a mailing list of all their friends and other contacts. The Bagins then mailed a personalized letter – with Justin's picture – to each contact, explaining GSD's severity, and the need for research funding. They asked for donations to support their participation in a New Jersey shore 10k/5k/2-mile run and walk.

"The overwhelming response was heartwarming," Jennifer said. "We couldn't believe how generous people were – and some have never met Justin or even heard of GSD."

"Justin is an inspiration to our entire family," Gary added. "We can't thank them enough for their love and support."



The participants who devoted their time and effort to this great cause were: **Justin** and his 3-year-old brother, **Connor** (unaffected), **Don and Carole Bagin, Frank and Elaine Messina**, and children **Rachel and Frankie; Alex and Denise Munn**, and children **Alex and Parker; Mike and Gina Pecorilli**, and children **Drew and Brooke; Scott and Stephanie Samuelson**, and children **Ben and Sophie; John and Cathy Trimble**.

A special thanks to the Feldman and Reed families for paving the way to a cure.

## Running the NYC Marathon and a 20-yd Dash with Anna

By Fran Reed

Running the 2002 and the 2003 NYC Marathons for my daughter Anna has truly been a life-altering experience for me. However, the most memorable and meaningful race for me was a 20-yard dash I ran with Anna. On April 18<sup>th</sup>, I brought my family to Central Park for the "Run for the Parks" race and family fun day. There were various races for kids of all ages with distances from 20-yds to a half mile – and all finishers received medals. My 5yr-old son Jack completed his 100-yard dash and he was just so incredibly happy and proud when he crossed the finish line and received his medal.

I will never forget that sunny Saturday morning standing at the starting line holding Anna's hand. She was wearing a race-tag pinned to her shirt, her face was beaming with happiness and I was on top of the world. The race began and we were holding hands. Briefly my thoughts flashed back to a very different time for us - when Anna was just a few months old, lying near death in a hospital bed. We were all living minute-to-minute not knowing if she would survive. No parent, and more importantly, no child should ever have to experience what she did in her darkest hours.

My thoughts returned to the present and I will always remember the overwhelming wave of emotion that welled up from deep inside my heart as I carried Anna across the finish line and knelt down beside her to place the ribbon & medal around her neck. At that very moment in time she was the happiest little girl in the world, there was no more pain & suffering or needles, tests and doctors visits rather, for that special instant she was perfectly healthy.



Jack, Teri, Fran and Anna Reed.

## Superbowl XXXVIII Raffle

**Jim Anchin** was the grand winner of our second annual Super Bowl Raffle. This very special event raised over \$110,000 and almost every penny of it is going directly to the most promising research which will find a cure for GSD1a.

Thanks to **Nick & Mary Nicolosi**, Grandparents of 3yr-old Anna Reed (GSD1a), who donated 2 tickets to the Super Bowl game, 4 nights hotel accommodations and 2 entries into the NFL Charities Celebrity Golf Classic on the day before the big game. Nick, President of All Sports Marketing, also runs the NFL Charities Super Bowl & Pro Bowl Celebrity Golf Classic. Nick personally escorted Jim and his son around the NFL Charities Golf Classic dinner and pairings-party the evening before the tournament.

Special thanks to all who sold tickets, especially **Pam and**

**Mike Julius**, parents of 4yr-old Adam (GSD1a) from Los Angeles, who sold over 750 tickets of the 1,000 total. Thank you also to the **Yuster family, Reagan and Barry Stein, the Gilbert family and Andrew and Scott Miller** for selling most of the remaining tickets.

**Teri Reed**, Nick's daughter and mother of Anna, organizes and runs this extremely popular and successful event.

The Super Bowl XXXVIII Raffle promises to be our biggest yet! Jacksonville, FL will host next year's Super Bowl on Sun, February 6, 2005 and we will begin selling tickets in November – so please let us know if you want a shot at going to the biggest football event of the year!!!

To purchase tickets or to get more information, please call **Teri or Fran Reed** at (203)972-9199 or e-mail [terifran@snet.net](mailto:terifran@snet.net). Thank you!!!



Jimmy Taylor, Paul Hornung, Jim and his son Lee, Ron Kramer and Marv Fleming

## Team CureGSD

Join our Team! Run a marathon, participate in a Fun Run/Walk, triathlon, bike race, or golf tournament. Anyone can be a part of a Team Cure GSD, which was established to promote public awareness and to raise funds that will find a cure for Glycogen Storage Disease Type I.

To learn more about Team CureGSD call or email **Fran Reed** at work 212.526.0805 [freed@lehman.com](mailto:freed@lehman.com) or at home 203.972.9199, [terifran@snet.net](mailto:terifran@snet.net).

### Did you Know...

This is a disease that CAN and WILL be CURED with your research dollars. We will not stop until there is a cure.

### Did you Know...

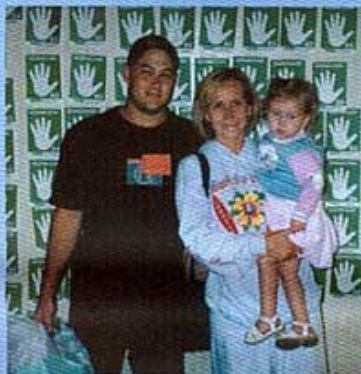
You can order t-shirts and hats that say, "The Children's Fund for GSD Research" and "Team CureGSD."

## A Night in NYC – wine, food and friends

On Thursday evening, April 22, 2004 **Pam and Michael Julius** hosted the first annual Mortgage Backed Securities Wine Tasting event at "The Italian Wine Merchants" in New York City. The evening raised nearly \$33,000 for The Children's Fund. Approximately 50 friends and colleagues gathered in a private tasting room to sample red and white wines from various regions of Italy. A gourmet meal was served to compliment the wine and everyone enjoyed a wonderful evening. A special thank you to close friend **Bob Eick** who planned and helped coordinate the tasting and menu for the event. Also, big thanks to Greenwich Capital, who sponsored a large portion of the evening. We are already looking forward to next year's event!!

## Helping Hands July is for Emma

by Danny Harris



Danny, Dana and Emma Harris

Throughout the month of July the local SuperFresh grocery store in Frederick, Maryland ran a fundraiser for GSD that raised more than \$2000.00. The entire month they collected donations from customers. Each person who donated \$1 got his or her name placed on a "Helping Hand" and the hand was placed on the wall of the store.

On Saturday, July 10<sup>th</sup> SuperFresh had a party at the store to raise additional money. Vendors donated soda, hot dogs and ice cream to sell at the party with all the proceeds going toward the fundraiser. We held a raffle with donations from some local businesses in the community. SuperFresh had employees on hand to help with the party as well as donating additional time, money and materials to make this party a hit! Our family attended the party so that people could meet Emma and we could answer questions about GSD and explain more about the disease and why we need help for research.

We contacted the local media about the event who ran pieces in both the paper and T.V. It was really great to see the community open up and give us a "Helping Hand." Every time we went shopping during the month of July, we were truly amazed at the amount of hands that were on the walls of the store. "Helping Hands" was a great fundraiser that was an easy way of raising money for research as well as informing the community of this rare disease. We are extremely thankful to SuperFresh, the vendors, businesses in the community and most of all to everyone who showed they care by making a donation. It is generosity like this that will make our Hopes and Dreams come true.

**The Children's Fund  
for  
Glycogen Storage Disease Research**

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

### **A Call to Cure From our foundation's Board of Directors**

Doctors and researchers involved with Glycogen Storage Disease are excited by our foundation's initial successes. As parents and family of children with GSD, we are excited as well. But the road to a cure will be a long one and the more people who get involved, the quicker our hopes and dreams will be realized. We have been overwhelmed with the generosity and the willingness of others to participate. Please consider organizing a fundraiser, volunteering on an existing project or simply make a donation; we welcome your help and support.

Join our organization's commitment to funding research so that children born with GSD1 will benefit from early detection, treatment and an eventual cure. There is strength in numbers.

### **GSD Documentary Film**

**Life By the Clock**, the first-ever documentary about GSD1, is an amazing look at the lives of four different GSD families. The 18 minute film, produced in 2003 by **Harriet & Pierre Bonelli**, does a wonderful job at raising awareness about Glycogen Storage Disease Type 1. It has been viewed by groups large and small - medical researchers, hospital staff, teachers and their classrooms, friends, family, strangers...all with the same effect - a better understanding of GSD and those families who live Life By the Clock.

Please contact us if you would like to obtain a copy of this video documentary for fundraising and/or educational purposes. There is a one-minute trailer that can be viewed on our website, [www.cureGSD.org](http://www.cureGSD.org).

#### **Did you know...**

You can double and sometimes even triple your charitable donation if your company participates in a Matching Gift Program. Many do, just ask.

**Did you know...** Our very first fundraiser was in October 2002.