

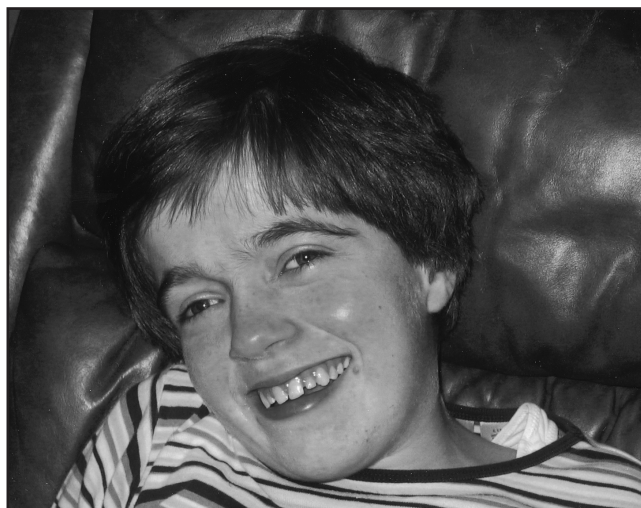


KirbyGram

The latest news on Kirby Wilson and friends and the search for a cure for Sanfilippo Syndrome

December 2005

Our goal is to create awareness of Sanfilippo Syndrome and other neuro-genetic disorders, fund medical research and find a cure.



Kirby Update

Kirby began her 8th grade year at Gower Middle School in Burr Ridge in a classroom filled with special friends. Her teacher, Kitty, and three of the therapists servicing children in the room were already familiar with Kirby, as they all had the opportunity to work with her last year.

Angie, a classroom aide in Kirby's room this year, first met Kirby five years ago as a high school senior who was interested in special education and volunteered her time in Kirby's classroom. She has helped the Wilsons care for Kirby at home ever since, while studying to become a special education teacher.

Sue comments, "The past couple years, Kirby has had to change schools. Brad and I have been concerned about the transition for Kirby with new staff and a different environment. But as luck would have it, last year turned out to be the best year Kirby has had in a long time, and this year is looking just as good. We are extraordinarily fortunate that Kirby, once again, is surrounded by a group of dedicated and compassionate staff members who are so willing and able to challenge Kirby to be the best she can be and yet accept her limitations with open, caring arms."



Dear Friends,

Kirby continues to confront her unrelenting challenges with resilience and fortitude. Her silent perseverance speaks volumes to us as she teaches us courage. Her laughter and smile are constant reminders to us to step back from our hurried lives and enjoy the moment with her, because the moment soon turns to a cherished memory. Kirby remains a powerful teacher, as we remain her very privileged parents who are blessed to be able to accompany her on her journey.

The Foundation has granted more that \$2.5 million toward research and promising new methodologies of treatment for Sanfilippo. It has been your enduring support of our mission that has empowered the Foundation and our lives to make a difference for all children struggling with this devastating disease. We give thanks for your dedication to our cause and hope that you remember The Children's Medical Research Foundation when giving this holiday season.

We wish you joy and peace, now and always.

Brad and Sue Wilson

Fundraising News



“Fore” Kirby

The Tenth Annual “Fore” Kirby Golf Fun Raiser was held June 3rd with 19 participants. The group “teed-up” to raise more than \$36,000 for research. Long-time supporter and family friend Nanci Makris and The Flame of Countryside helped the Wilsons by once again providing refreshments and dinner at their home after the event. The delicious buffet prepared by The Flame is just one of the many things Nanci does “fore” Kirby throughout the year.

Interest in the golf event continues to grow with the addition of new participants willing to solicit per-hole pledges for their round of golf on behalf of the Foundation. “Brad and I are very fortunate to have such dear friends and family members willing to do whatever is asked of them to raise funds and awareness,” says Sue. “But this event, in recent years, has also made us aware of the concern and generosity of others who are friends of friends or have simply heard of the outing and have chosen to commit themselves to our mission.”

Sue continues, “As I have said before, the disease that afflicts Kirby is devastating, to say the least, but there is much to be grateful for, as well. We are constantly being reminded of this by newcomers’ compassion for Kirby and their willingness to be a part of our mission of a cure for Sanfilippo.”

THE FOUNDATION GIVES THANKS....

To the employees of **Sealed Air Corporation**, in Hodgkins, IL, for choosing the Foundation as the benefactor of its dress-down day, “Making a Difference One Friday at a Time.” A check was presented to Sue, Maggie and Kirby for \$171. What a difference a day can make!

To the employees of **UPS** in Los Angeles, CA, and **SBC and University of Chicago** in Chicago, IL, for designating the Foundation as the recipient of their United Way pledges. The Foundation has received more than \$3,600 to date as a result of their generosity. Uniting for Kirby works!

To **Grainger** in Lake Forest, IL, and **Bank of America** in Charlotte, NC,

for their matching gift donations. A perfect match for Kirby!

To **Adam Wilner** for his donation in honor of **Grace Bellontine**, the beautiful four-year-old daughter of John and Joan Bellontine of South Huntington, NY, diagnosed this year with Sanfilippo,

To **Tom and Karen Begg** for their donations in memory of **Callista P. Wicklander** and Tom’s two uncles, **Bill and Bob Conrad**,

To **Donna Hagerty-Payne** for her donation in memory of Foundation board member Kathi Brummet’s father, **Edward Flannery**,

And To The Families Working Together For The Cure ...



The pretty school girl,
Allison Kirch

Larry and Susan Kirch of LaCrosse, WI, parents of Allison who is afflicted with Sanfilippo, recently purchased 25 “One Road” CDs from the Foundation to be handed out at the MPS Society’s upcoming Family Conference in Scottsdale, AZ. “One Road” is the solo piano CD by Rhianna Logan’s uncle, Cory Gabel. Now that’s families working together!



Fundraising News

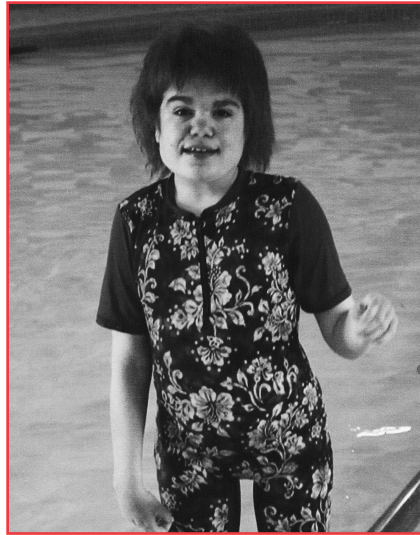


To **White Hen Pantry, Kirschbaum's Bakery and Casey's Market**, all from Kirby's hometown of Western Springs, for their continuous fundraising efforts using cash jars. And to the people of the community who fill them and have helped to raise more than \$700 to date this year, your "hometown girl" thanks you from the bottom of her little heart, and

To the **LaGrange Highlands Presbyterian Church** and its members for their continued support of the Foundation, as well as the Wilsons.

NEWS FROM CONNECTICUT

As the Logans' days remain centered around ensuring appropriate care and therapeutics for Rhianna, their community continues with its own support of "Rhianna's Hope."



Rhianna Logan of Plainville, CT, stepping out from a swim.

The Bristol Auto Club once again held a "Cruisin' for Rhianna" car show benefit as the Club's way of supporting the Foundation and the "race for the cure."

Courtney Pendleton, a caregiver and friend of Rhianna, sold rubber bracelets in honor of Rhianna.

The Artisan's Marketplace is planning its annual "Santa for Hope" raffle and is busy getting supplies ready for Rhianna's friends to assemble the "Star for Hope" craft kits. Customers purchase a kit, allowing their children to create the star and keep it, reminding them of Rhianna. Or they can return the star to the Artisan's Marketplace, where others can purchase it, doubling the donation to the Foundation. "Stars for Hope" continues to grow in popularity as customers are already inquiring about availability.

Cory and Donna Gabel, Rhianna's uncle and aunt, continue their fundraising efforts with a portion of the proceeds from Cory's solo piano instrumental CD, "One Road," going to the Foundation. Interested in this new "spin" to help? Just contact the Foundation to obtain a copy, or log on to Cory's website at cdonavan.com.

In Fond Memory

Jillian Noel Fitzpatrick, granddaughter of George and Willa Fitzpatrick of Venice, FL, was diagnosed with Sanfilippo at the age of four and as her loving grandmother phrased it, "earned her angel wings" at the age of seven. Donations were sent to the Foundation in fond memory by friends of the family. Our appreciation to them and the Fitzpatricks for thinking of the Foundation at this most difficult time.

Andrew Slattery, son of Robert and Wendy Slattery of Ventura, CA, passed away this past June, just weeks before his 11th birthday. Rob and Wendy not only supported the Foundation within their community by hosting a fundraiser but also permitted the Ventura County Star newspaper to document Andrew's struggle with Sanfilippo since 1999, shortly after the family received the diagnosis. This publicity even led television's drama "ER" to do an episode featuring Sanfilippo. Rob and Wendy stated, "Andrew didn't come here to learn...He came here to teach us." We give our sympathy to the Slattery family and our deepest gratitude for their courage in documenting Andrew's life and allowing him to teach so many others.





Fundraising Opportunities

United Way Can Be for Kirby, Too

Does your company have United Way pledges at your workplace? Although we are not a United Way member, you can designate The Children's Medical Research Foundation as your recipient, and the funds will be forwarded to us through the United Way Campaign! Our United Way Chicago "Agency Number" is 3025558. For those of you out of state wishing to participate, please supply your local United Way agency with the Foundation name, address and our Federal ID #36-4033667.

Celebrate, And Make It for Kirby

Is there a special birthday coming up for a family member or friend? Are you looking for an alternative to the typical "over the hill" gift? Be different. In lieu of gifts, donate to The Children's Medical Research Foundation. Kirby always loves a party!

A Gift Like No Other

This holiday season give clients a donation to The Children's Medical Research Foundation in their name. It's a gift that won't gather dust and goes far beyond any other.



Go Kasual for Kirby

Tired of wearing those heels, hose or ties five days a week? Why not suggest a "Go Kasual for Kirby Day" to your employer? It's a great way to give a "relaxing feel" to a workday and raise funds for the Foundation. Simply send a memo to co-workers explaining the day and set the "fee" to participate.

Still in school but want to help? How about a "Hat Day" done the same way! It's fun for the kids and a great way for them to participate in a good cause. No "fee," just leave an amount up to them.





The 11th Annual Sweetheart Dinner Dance

February 3, 2006

Plans are now underway for the 11th Annual Sweetheart Dinner Dance to be held February 3, 2006, at The Drake Hotel in Chicago. Reservations are \$200 per person or \$1,400 for a table of eight and must be made in advance. Invitations will be mailed in December.

We Need Your Help

This dinner dance is the primary fundraising event of the year, and we'd like you to consider helping ensure its success. There are many ways you can show your support.

A silent auction will be included in the evening's activities, for which the Foundation is seeking donations.

We also have designated five sponsorship levels for the Sweetheart Dinner Dance, as listed below. In appreciation of your sponsorship, you will be mentioned in our promotional efforts and will receive event and program book recognition. We ask that you indicate your wishes on the following Reply Form and return it to the Foundation. Please contact Sue Wilson at 708/784-0631 with any questions.

The Eleventh Annual Sweetheart Dinner Dance

~ SPONSORSHIP REPLY FORM ~

Sponsorship:	<input type="checkbox"/> Diamond	\$ 10,000	<input type="checkbox"/> Silver	\$ 1,000
	<input type="checkbox"/> Platinum	\$ 5,000	<input type="checkbox"/> Sweetheart	\$ 500
	<input type="checkbox"/> Gold	\$ 3,000	<input type="checkbox"/> Other	\$ _____

Name as you want it to appear (Please print): _____

☐ Check Enclosed

Please charge my (*check one*) ☐ Visa/MC ☐ American Express

Cardholder Name (print) _____

Account Number _____

Expiration Date _____ Signature _____

Silent Auction Donation: Item Description _____

Value \$ _____

Expiration Date: _____

Please return this form to:

***The Children's Medical Research Foundation, Inc., P. O. Box 70, Western Springs, IL 60558,
fax to (708) 784-1978 or call (708) 784-0631.***

Please include your phone number: _____





Save The Date

February 3, 2006



The Sweetheart Dinner Dance Makes a Romantic Holiday Gift

This holiday season, give your sweetheart a gift of good cheer – a romantic evening at the Sweetheart Dinner Dance.

**You'll avoid last minute shopping in crowded stores when you call
708-784-0631 now for reservations.**



**Then enjoy February 3rd in taffeta and tux, sipping champagne, dining in
The Drake Hotel's magnificent Gold Coast Room, and dancing to the music of the
Michael Lerich Orchestra. Cheers!**

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