



KirbyGram

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

December 2004

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



Kirby's smile shines through

Kirby Update

September marked a fresh start for Kirby as she began her new school year at Lace Elementary School in Darien in a classroom filled with "special friends." Sue comments, "I think the transition was hardest on me that first day, leaving her with new staff in a different environment, even though the classroom teacher, Leslie Fisher, and an aide, Sharon, were able to spend time with her this summer." But it didn't take long for Mom to realize this change was just perfect for Kirby. "With each school day that went by I realized more and more how extraordinarily fortunate Kirby was to be surrounded by this group of dedicated and compassionate staff members," Sue continues. "Each is so ready, willing and able to challenge Kirby to be the best she can be and yet accepts her limitations with open arms."



Dear Friends,

As the Foundation enters its tenth year, Brad and I are able to reflect back on this journey with gratitude. It seems that over the years, just when we have thought our path seemed to narrow, we have been shown the way of courage and hope.

Kirby's challenges continue as the progression of the disease has become more and more apparent. But her fierce determination shines through as she embraces each obstacle with amazing fortitude and emerges with smiles and laughter. As she reaches to grasp our hands in hers to walk, guiding us down her path, Kirby teaches us the true definition of courage and constantly expands our vision of what is possible. She needs no words to express her wisdom. We are honored to be her parents and walk by her side.

Our hope comes from the advances in research and promising new methodologies of treatment for Sanfilippo. The Foundation has granted more than \$2.3 million to this research, and it is your enduring support and confidence in our mission that enables us to keep this hope shining brightly. Please continue to remember The Children's Medical Research Foundation, the dedicated scientists and the promise their work holds when giving this holiday season.

We wish you joy and peace.

Brad & Sue Wilson

Fundraising News



“Fore” Kirby

The Ninth Annual “Fore” Kirby Golf Fun Raiser was held June 4th with 21 participants. This devoted group “teed-up” to raise more than \$46,000 for research. Family friend, Nanci Makris, and The Flame of Countryside once again provided refreshments and dinner at the Wilsons' home as they have done for the past five years. Nanci is not only a long-time friend of the Wilsons but also a long-time supporter of the Foundation and is always ready and willing to do “fore” Kirby!

Interest in the event continues to grow as each year adds new participants who solicit per-hole pledges for their round of golf, on behalf of the Foundation. “We have always known how fortunate we are to have so many dear friends and family members willing to do whatever is asked of them to raise funds and awareness, but for the past few years, this group has included golfers who have never met Kirby or us,” says Sue. “They are friends of friends or people who have simply heard of the outing and have chosen to commit themselves to our mission.”

“The disease that afflicts Kirby is devastating, to say the least, but there has been much to be grateful for, as well,” Sue comments. “This event

really says it all ... we have friends and family who each year try to out-pledge each other, and then there are the “newcomers” who amaze us with their willingness to participate in such a big way,” she states.

The Foundation Gives Thanks ...

- To **Brian and Colleen McLachlan** for sharing the celebration of their wedding day with the Foundation. In lieu of table favors, a donation was made to the Foundation in their guests' honor. Bookmarks were given to each guest “to remember the joy we all had on this day and to keep Kirby in your thoughts.” Our best wishes and deepest gratitude to these very special newlyweds,
 - To **Jake Paloian of Hardin Paving** for turning his August gathering into a fundraiser as guests were asked to make a donation to the Foundation for each round of drinks served. Cheers to Jake for helping raise funds and awareness,
 - To the **LaGrange Highlands Woman's Club** for choosing the Foundation as its Charity of the Year. The Foundation will be the benefactor of its fundraising efforts this year, which include a craft show to be held at LaGrange Highlands Middle
- School on November 20th from 9:00 am to 2:00 pm. It's a great way to shop for Christmas and brighten the future for Kirby and others like her,
- To **Rob and Alison Credit** for their donation in celebration of the 40th birthday of their friend, Greg Hayes,
 - To **Josh and Sherrie Janovsky** for their donation in memory of Sherrie's dad, Bob Rounce, a dear friend and minister of the Wilsons,
 - To **Eleanor Rounce** for her donation in celebration of the 25th wedding anniversary of her son and daughter-in-law, Rob and Beth,
 - 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 filled them and helped to raise more than \$1,300 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.



Hunter and Sydney Moff

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

Steven Moff, of Williamsport, Pennsylvania, father of Sydney and Hunter, who both are afflicted with Sanfilippo Syndrome, will be running in the Marine Corps Marathon. Steve chose to personalize his efforts in this marathon and “Race for the Cure” to promote awareness of Sanfilippo and encourage donations to the Foundation from family and friends. What a great way to cross the finish line!



Fundraising News



News From Connecticut

“Rhianna's Hope,” the committee formed by family and friends of Gene and Cynthia Logan, came through with shining colors with its seventh “Cut Against Time” fundraiser in honor of Rhianna. This Plainville, Connecticut, event started with **Generations of Design** and **Hair Spa** joining forces and donating haircuts and other spa services for the day, and now includes other salons and merchants within the town who hold raffles, bake sales and various kids' activities. Totals for this year were over \$9,000 in donations to the Foundation. Our deepest gratitude to the merchants of Plainville for giving us a “cut” we can live with!

September 25th marked the date for the Eighth Annual “Rockin' for Rhianna” benefit dance and silent auction. Once again, the Logans' friends, **Alan and Donna Theriault**, rallied their group of dedicated volunteers and worked tirelessly to plan the event and solicit donations. A big thank you goes to **Badger Printers** for donating all the printed material, as they have done for each and every year of the dance. Although the final numbers are not in yet, it is expected that total donations to the Foundation will reach \$16,000!



Rhianna cruisin' at the car show

We think the Theriaults and their group rock!

Each year these events remind the Logans of the compassion their

community has for their dear daughter, Rhianna, who continues with strong determination and smiles for all who are so fortunate to surround her.

And, the community's efforts continue ...

The **Bristol Auto Club** is still driving toward a cure with its “Cruisin' for Rhianna” car show, which raised \$4,500 in honor of Rhianna.

Mary Lou Cassille of **Cassille's Restaurant** and the eatery's customers show their commitment to Rhianna with their steady stream of donations to the restaurants “cash jar.”

Michael and Janice Maiorca honored Rhianna with a contribution to the Foundation in memory of their aunt, who they described as a “mother to a great many.”

Cory and Donna Gabel, Rhianna's aunt and uncle, 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.



Dennis Buckley

In Fond Memory

Dennis Buckley, a tireless supporter of the Foundation and dear friend of the Wilsons, passed away in August.

In lieu of flowers, his wife, Lauren, asked that memorials be sent to the Foundation. Incredibly, more than \$11,400 was given in his memory by his many friends and colleagues. He will be greatly missed by all who had the good fortune to meet this most kind and generous man.





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.

Our thanks to **the employees of UPS of California, University of Chicago Hospitals, SBC and WellPoint.**

Give Kirby Security

Tired of taxes? The Foundation now has a brokerage account available that allows you to donate appreciated securities. Why pay tax on the gains

A Match for Kirby

Does your company have a matching gift program? It could double your support of the Foundation.

when you can realize a charitable deduction of the full market value of your stocks ... and it's for Kirby, too! Contact Brad or Sue Wilson at (708) 784-0631 to learn more.

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 considering 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. There is no "fee," all you need to do is leave an amount up to them.





Save The Date

The 10th Annual Sweetheart Dinner Dance

Plans are now underway for the 10th Annual Sweetheart Dinner Dance to be held February 4, 2005, at The Drake Hotel in Chicago. Reservations are \$200 per person 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 10th 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 | | |

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 or call (708) 784-0631.

Please include your phone number: _____





Save The Date

10th Annual Sweetheart Dinner Dance

Friday • February 4, 2005

The Drake Hotel • Chicago



*Copyright 2004 The Children's Medical Research Foundation, Inc. All rights reserved.
Reproduction prohibited without the express written consent of The Children's Medical Research Foundation, Inc.*

KirbyGram

P.O. Box 70
Western Springs, IL 60558

**The Children's
Medical Research
Foundation, Inc.®**



FIRST-CLASS
U.S. POSTAGE
PAID
TINLEY PARK, IL
PERMIT NO. 222