



KirbyGram

December 2003

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

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



Kirby's sparkling personality shines through.

Kirby Update

Kirby's return to the familiar faces and routine of school was, once again, a success thanks to the staff at LaGrange Highlands. This year, Kirby made a smooth and happy transition from the elementary school to the middle school because of the planning and effort that was put forth by both elementary and middle school staff. Her year started in the same elementary classroom, with the same teacher, aide and therapists. Slowly, with her caring aide of three years by her side, she was introduced to the new building, room and teachers. As luck would have it, one of Kirby's new middle school teachers had worked with her in the past so had a little "jump start" on her sparkling personality! Although Kirby's challenges with the disease continue, she is extraordinarily fortunate to be surrounded by a group of dedicated and compassionate staff whose goals of maintaining abilities, while striving to improve, remain the same.

As a big 6th-grader, Kirby is also with the same children who have grown up by her side at Highlands, volunteering to help their "special" friend, as opportunities arise. "This is a huge gift for our daughter," Sue comments. "These kids have been with Kirby through good times and some that were a bit difficult, and they are still there for her with not only an incredible understanding of her challenges but also with enthusiasm and compassion. She is a very lucky little girl."



Dear Friends,

Kirby fuels our determination as she continues to navigate her challenges with fortitude and tenacity, and her voiceless, yet resounding message of innocence continues to inspire us. Her soul radiates purity. Kirby's spirit is uncomplicated. The world's trappings of competition, jealousy, anger, prejudices and wealth do not encumber her. Kirby is an angel in our midst who teaches love, without condition, and reminds us of the wealth that simplicity can bring to our lives, seemingly the purpose for which she was born.

As parents, we realize our purpose is our children and our children are our blessing.

The Foundation has granted more than \$2.1 million to research. Your continued generosity has allowed researchers to include new, promising methodologies of treatment in their studies. We are grateful for your enduring support of the Foundation and its mission and for empowering our lives with your commitment. Please remember The Children's Medical Research Foundation when giving this holiday season. It is your gifts that enable work to continue toward a cure for Sanfilippo.

We wish you and your families the joy and peace of this holiday season, now and always.

Brad & Sue Wilson



Fundraising News

“Fore” Kirby

The Eighth Annual “Fore Kirby” Golf Fun Raiser was held June 6th, with 19 golfers participating in the event. Threats of rain, with just a little lightening thrown in to keep them on their toes, did not dampen the spirit of this devoted group, which “teed-up” to raise more than \$55,000 for research. Family friend, Nanci Makris, and The Flame of Countryside once again provided refreshments and dinner at the Wilsons’ home. 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 couple of 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 reflects. “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 quite simply just blow us away with their willingness to participate in such a big way,” she states.

The Foundation Gives Thanks.....

To **Rich and Kathi Brummet** and **Mark and Maureen Blaber** for their “End of Summer” bash, complete with music by local favorite, Tunage, which benefited the Foundation. The oh-so-fun party was attended by over 60 friends and family members, and more than \$1,100 was donated to the Foundation,

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 \$1,600 to date this year, your “hometown girl” thanks you from the bottom of her little heart,

To **Alison Credit** for celebrating her 30th birthday in such a special way....donations to the Foundation. Happy Birthday to Alison!

To **Haley Johnson**, long-time classmate and friend to Kirby, who did trick or treating for the Foundation and raised \$60. A real sweet treat!

To Foundation board member **Charlie Notarus’** family and friends, for their donations in memory of Charlie’s dad, Sol Notarus,

To **Josh and Sherrie Janovsky** for their donation in memory of Sherrie’s dad, Bob Rounce, a dear friend and minister of the Wilsons, and

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



Just a few “Fore Kirby” participants pausing to pose for the camera





Fundraising News



A group of special kids always brings a smile to Alan's face. Alan and Donna's own Marissa and Michael, with Rhianna front and center.

News From Connecticut

The Logans' family friend, **Linda Casorio**, came through with shining colors with her planning of the annual "Cut Against Time" fundraiser that was held June 8th and raised more than \$7,200 for the Foundation. Many of the town's hairdressers who participated in the first cut-a-thon returned this year to show their support for Plainville's sweetheart, Rhianna, and ensure the success of this event, which is in its sixth year.

October 12th was the date for this year's "Rockin' for Rhianna" benefit dance and silent auction. Once again, **Alan and Donna Theriault**, friends of the Logans, took charge and put together another successful event,

raising more than \$23,000 for the Foundation, in honor of Rhianna Logan. This was the seventh year in a row that the Theriaults have gathered their group of dedicated volunteers, who work tirelessly each year to plan the event and solicit donations. It always proves to be an incredible evening for Gene and Cynthia Logan, as it reminds them of the compassion their community has for their dear daughter, Rhianna.

And, their community doesn't stop there....

Our hats go off to **Linden Street Elementary School** and **Toffolon Elementary School** for each holding a "Hat Day" for Rhianna and raising more than \$680 for the Foundation.

The Bristol Auto Club is still "Cruisin' for Rhianna" and raised a cool \$2,300 in honor of Rhianna!

Donations also were received in memory of **Scott Dawson**. Scott's stepmother, Debra, has been an enthusiastic participant in fundraising for Rhianna.

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.



Douglas Nicoll

In Fond Memory

We wish to extend our deepest sympathy to Doug and Tracie Nicoll of Colorado Springs, CO, on the loss of their dear son, Douglas, this past summer.





The National MPS Society Update

Les Sheaffer, Society Board Member and Chairman of the Committee on Federal Legislation, will be retiring from both positions at the end of this year. His persistence and commitment to making our legislators aware of all MPS disorders throughout his time with the Society have led to millions of dollars of federal funding for MPS-specific research and, most recently, funding specific to the blood brain barrier.

Les and his committee were instrumental in ensuring inclusion of language addressing children with degenerative disorders in the Senate IDEA reauthorization report, which

has already been included in the bill passed by the U.S. House of Representatives.

Les also played a major role in the NIH-sponsored symposium focusing on the central nervous system (CNS), which brought experts in the field from around the world together to discuss and exchange ideas on the CNS as it specifically relates to MPS disorders. We are grateful for his work and the hope it has generated for all families of children afflicted with these devastating disorders, and we wish him well as he moves on

to spend more time with his family and daughter, Brittany, who has been his inspiration.



Les takes time for Brittany

Fundraising Opportunities



A Match for Kirby

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

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 Fidelity, SBC, Wellpoint Health Networks, Inc. and David Mendenhall of San Diego, CA.**

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 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 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.





Save The Date

Ninth Annual Sweetheart Dinner Dance

Plans are now underway for the 9th Annual Sweetheart Dinner Dance to be held February 6, 2004, 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 Ninth 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 \$ _____

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

9th Annual Sweetheart Dinner Dance

Friday ♥ February 6, 2004

The Drake Hotel ♥ Chicago



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