



# KirbyGram

December 2007

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 Update

The big 16-year-old started her second year at Lyons Township High School this past fall and is privileged to have the same team surrounding her as last year. Classroom teacher Mike Detzner and staff have seen her struggle with Sanfilippo and continue with their efforts to help her with her challenges while nurturing her strengths, allowing her to be the best she can be.

Sue states, "Consistency in people and her environment has always been important to Kirby and is something she has not always been afforded in the school setting. Brad and I are fortunate to have the "C115" staff working with Kirby once again. They are a group of people who look at their students as having different abilities, not disabilities, realizing their viability and celebrating it. We see Kirby being treated with the compassion and dignity she so richly deserves, and we give thanks for this most precious gift."



The smile is back and speaks 1,000 words!

Dear Friends,

*Over the years, Brad and I have been honored to follow Kirby on her life's journey, watching and learning as she perseveres through her difficulties with quiet resolve, defining words such as fortitude and courage. And now, with the uncontrolled spasms and movements we are told Kirby will never be completely free from, it seems to only strengthen this resolve within her.*

*As she confronts these challenges daily, she shows us the meaning of tolerance, dignity and grace. With the smile we feared was gone forever, she teaches us to never give up on the possibilities or allow our lives to be burdened by seeming impossibilities. As our teacher continues down her path, our pride as her parents has no boundaries. She brings us joy and happiness each and every day and we are blessed.*

*This holiday season, Brad and I wish for your families and you the same joy and happiness. We ask that you remember Kirby's smile, and in her honor, continue to support The Children's Medical Research Foundation, its mission and the researchers who are working so diligently to find a cure.*

*May the blessings of this holiday season be yours, now and always.*

*Brad and Sue Wilson*

# Fundraising News



## “Fore” Kirby

The Twelfth Annual “Fore” Kirby Golf Fun Raiser was held June 1st at Ruffled Feathers Golf Club in Lemont. Bursts of thunder and rain throughout the day couldn’t dampen the spirits of the 18 participants who raised more than \$33,000 in honor of Kirby!

Sue comments, “This year’s group was one of the smallest yet, mainly close friends, but still raised more than last year! Brad and I are very fortunate to have such dear friends willing to do whatever is asked of them to help us raise funds and awareness. After the round of golf was complete, it was wonderful to have the opportunity to invite them to our home, where we enjoyed their friendship and were reminded of how privileged we are to call them our friends.”

The Foundation is actively seeking new participants for this unique golf outing. The event is held each year on one of the first two Fridays in June. Each participant is given pledge cards and is asked to secure pledges from friends and associates for each of the 18 holes of golf to be played.

Upon completion of the round, score cards are collected from each player, and the Foundation then contacts all of those who have pledged with the results of their player's

round and the total amount due. Participants also are asked to pay for their round of golf, which means that 100% of the donations go directly to the Foundation! Cocktails and dinner are served immediately following at the Wilsons’ home.

Interested in joining the fun? Please contact Sue at 708/784-0631 to learn more.

## “Oh What A Night!”

On Friday, October 5th, 92 of the Foundation’s friends were able to be the first in Chicago to see the 2006 Tony Award-winning best musical, *Jersey Boys*, thanks to support from Eileen LaCario of Broadway in Chicago. It was a wonderful opportunity for both the Foundation, which raised \$4,800, and the attendees, who were treated to the sound of Frankie Valli and the Four Seasons as they learned how these four men grew to be one of the most successful groups in pop music history. We all thank Eileen for this Broadway in Chicago experience!

## The Foundation Gives Thanks....

To the many contributors that used the donation envelopes as an opportunity to give to the Foundation. Donations from our June newsletter totaled \$3,800!

To **Luke and Alicia Massery** for their most generous donation to the Foundation in lieu of guests’ favors on their wedding day! For years, the Wilsons were blessed to have Alicia helping them with Kirby whenever possible between her time spent at school, work and volunteering. Sue explains, “One of our very special memories is when Kirby saw Alicia walk in our home after being away at college, she immediately squealed with excitement as she grabbed Alicia’s hand to run by her side. Kirby never seemed to forget Alicia, as we will never forget the time she shared with Kirby. Alicia is a very special, joyous person, and Brad and I are thrilled she has found someone like Luke to share her life with.”

To **Loni Green** for her donation in thanks to **Dr. Peter S. L. Rosi**,

For the very generous posthumous contribution from **Dr. Bertha M. Levy**,

To Kirby’s grandma, **Joanne Wilson**, for her donation in memory of **Phyllis Sievers**,

To **Mr. & Mrs. Alfred Angeli**, for their donations to the Foundation in memory of **Martha Ventura, Lois Aikala, and Gene Cristan**,

To **Barbara Cummings Bolduc** for her donation in memory of **Billie Willison**,



## Fundraising News

To **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 \$675 to date this year, your "hometown girl" thanks you from the bottom of her little heart,

To **Margaret Dawe, Colleen McClaran, Nicholas Megofna**, and the anonymous donors who designated the Foundation as their charity of choice in their various employers' United Way campaigns. We appreciate them uniting for Kirby!

And, to **The Marmon Group LLC** in Chicago, for its matching gift donation. A perfect match for Kirby!

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



Brooke

To **Arthur and Roberta Kidwell**, proud grandparents,

**Aunt Judy, Uncle Kent**, and cousins **Mitch and Kyle Bible** for their donations in celebration of both **Brooke** and **Ashleigh Kidwell's** birthdays!



Ashleigh

And, to **Rob and Wendy Slattery** for their donation to the Foundation in loving memory of their dear son, **Andrew Thomas Slattery**, who passed away in June of 2005, just short of his 11th birthday.

### News From Connecticut

**Alan and Donna Theriault** are rockin' again! That is for Rhianna, of course! The tenth annual **"Rockin' for Rhianna"** was held on November 3rd. This year's event was attended by approximately 175 guests who were entertained by The Rockin' Heartbeats, who have donated their talent to the event for the past nine years. Tom Buonocore of Badge Printers of America donated all printing, as he has done each year. A piece of art created by Rhianna herself was the top money-

maker for the auction. A newcomer to the event paid \$750 and immediately donated it to Rhianna's grandmother, realizing how priceless it would be to her! Although the final figure is not in yet, it is estimated that this year's dance will raise \$17,000!



Alan Theriault and Gene Logan

**The Manafort Family Foundation** donated \$5,000 in honor of Rhianna from the proceeds of its third annual charity golf tournament, which is held in memory of **James Manafort, Sr.** Our thanks to all the members of the Manafort family for once again teeing up their support for "Rhianna's Hope."

Donations were received by the Foundation in memory of **Harvey Wilson**, a longtime member of **The Bristol Auto Club** and steadfast supporter of the Foundation through "Rhianna's Hope." Over the years, the club's annual "Cruisin' for Rhianna" car show has raised thousands of dollars toward research.



# Fundraising News



(Continued from Page 3)

**The Bristol Auto Club's members** donated \$300 in proceeds from this year's show in his memory. The Foundation and the Logans, Rhianna's parents, appreciate club members continuing Mr. Wilson's commitment to "drive" to find a cure for Sanfilippo.

Once again, car enthusiasts **Mr. & Mrs. Leonard Roberts**

of the **Clinton S. Roberts Foundation**, who attend the show each year, donated \$2,000 to the Foundation in honor of Rhianna.

Our thanks to **Katherine McLeod** for her donation to the Foundation in honor of Rhianna.

And, as always, our thanks to **Cory and Donna Gabel**,

Rhianna's aunt and uncle, for their ongoing donations of a portion of the proceeds from Cory's solo piano instrumental CD, "One Road," and his latest release, "Alabaster Sky," 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](http://cdonavan.com).



Happy times at school for Kirby.

## Update from the Laboratory of Dr. Elizabeth F. Neufeld, Department of Biological Chemistry at UCLA, October 2007

We have been studying a mouse model of Sanfilippo Syndrome type III B in order to better understand the development of the disease, particularly in the brain. The mouse model was generated eight years ago (with the help of funding from the CMRF) by disrupting the gene encoding  $\alpha$ -N-acetylglucosaminidase, one of the enzymes required to break down heparan sulfate in lysosomes. As a result, heparan sulfate accumulates in lysosomes of many organs. Last year we reported that some neurons which accumulated heparan sulfate in the brain also accumulated other substances, which were not biochemically related to heparan sulfate or to each other and did not require  $\alpha$ -N-acetylglucosaminidase for degradation. These other substances included lipids (GM3 ganglioside and cholesterol) and proteins (ubiquitin and SCMAS). What role this secondary storage of apparently unrelated substances plays in the disease process is not known; furthermore, it is not unique to MPS III B but also occurs in other lysosomal storage diseases. We believe that the primary storage material (heparan sulfate in MPS III B) causes lysosomes to become large and numerous and to generate signals to

which the neurons respond by storage of the other substances named above. This constellation of stored material occurs only in a limited number of neurons, which we dubbed "vulnerable." In order to learn what kind of signals are sent out by the vulnerable neurons, we are examining the expression of genes in these neurons from an MPS III B mouse brain compared to expression in similar neurons from normal mouse brain. We are also comparing them with neurons in an adjacent area that does not have such storage. Using the technique of "laser capture microdissection," we have teased out about 500 individual vulnerable neurons from the brain of the MPS III B mice and a similar number of neurons from the corresponding area in the brain of normal mice. That was

sufficient to obtain gene transcripts (i.e., messenger RNAs) and determine the genes to which they correspond, using another state-of-the-art technology named "gene microarray." This work is only starting, and to date, we have performed one study to determine feasibility of the approach. There was interesting information even in this preliminary experiment, but we prefer to wait till we have confirmed it before describing it in this forum. We hope that this approach will lead to the discovery of unsuspected pathways, which contribute to the disease process and which may eventually be used as targets for pharmacological intervention.





## 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! Simply give your local United Way agency the Foundation name, address and our Federal ID #36-4033667.

### Give Kirby Security

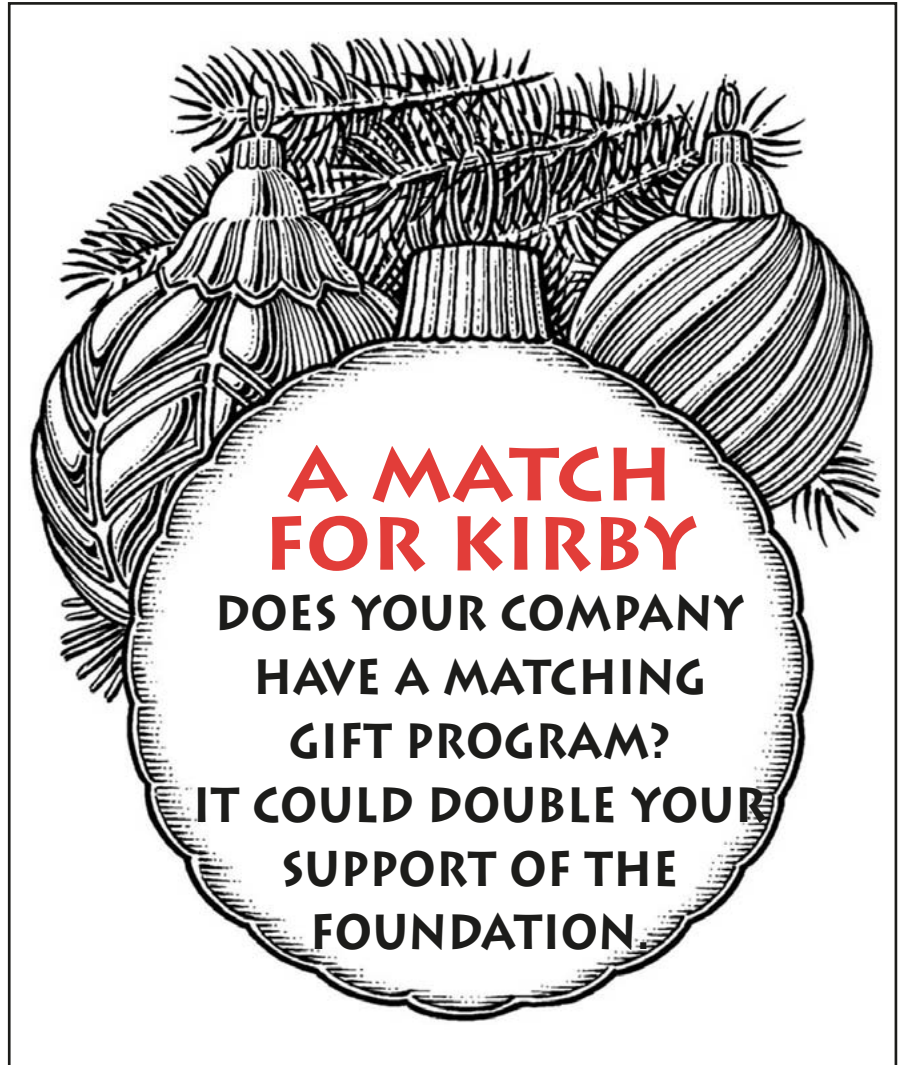
Tired of taxes? The Foundation now has a brokerage account available that allows you to donate appreciated securities. Why pay tax on the gains when you can realize a charitable deduction of the full market value of your stocks . . . and it's for Kirby, too! Contact Sue Wilson at (708) 784-0631 to learn 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.



# THE SWEETHEART DINNER DANCE

## FEBRUARY 8, 2008 • THE RITZ-CARLTON CHICAGO

*An elegant new setting at one of the world's finest hotels*

The 13th annual Sweetheart Dinner Dance will be held Friday, February 8, 2008, in the Ballroom of The Ritz-Carlton Chicago.

We're "Puttin' on the Ritz" at our new venue with a new menu and an exciting live auction hosted by Radio Disney's Greg "G Man" Dellinger. Executive Chef Mark Payne will serve a signature four-course dinner from his award-winning kitchen, following a cocktail reception in the adjoining Loge.



Guests will be treated to the magical sounds of the Michael Lerich Orchestra, which has entertained us for the past twelve years! And live auction packages promise to tempt sports, travel, dining, spa and shopping enthusiasts.

Reservations are \$225 per person or \$2,250 for a table of ten and must be made in advance. Invitations will be mailed in December. Please plan to join us by marking your calendars now.

### *We need your help to make it a success*

This dinner dance is the primary fundraising event of the year, and we're asking you to help ensure its success. We have designated five sponsorship levels for the Sweetheart Dinner Dance, as listed below. In appreciation of your sponsorship, you will receive prominent event 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 Thirteenth Annual Sweetheart Dinner Dance*

#### ~ SPONSORSHIP REPLY FORM ~

|                     |  |   |
|---------------------|--|---|
| <b>Sponsorship:</b> | <input type="checkbox"/> Diamond \$ 10,000 | Please charge my ( <i>check one</i> )     |
|                     | <input type="checkbox"/> Platinum \$ 5,000 |   |
|                     | <input type="checkbox"/> Gold \$ 3,000     | <input type="checkbox"/> Visa/MC          |
|                     | <input type="checkbox"/> Silver \$ 1,000   |   |
|                     | <input type="checkbox"/> Sweetheart \$ 500 | <input type="checkbox"/> American Express |

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

☐ Check Enclosed

Cardholder Name (print) \_\_\_\_\_

Account Number \_\_\_\_\_

Expiration Date \_\_\_\_\_ Signature \_\_\_\_\_

#### *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

**Friday, February 8, 2008**

## **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 8th in taffeta and tux, sipping champagne, dining in  
the Ballroom of The Ritz-Carlton, and dancing to the music of the  
Michael Lerich Orchestra. Cheers!**

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**KirbyGram**

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