



# KirbyGram

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

**December 2012**

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

Dear Friends,



**F**or the past 18 years Brad and I have spoken of Kirby's qualities of strength and character. Her vibrant energy never has allowed us to dwell on what might have been but instead has given us a reason to be thankful for what we have – joyful moments throughout the day.

Each morning Kirby has awakened, smiling with renewed enthusiasm for small delights, relishing joy. Certainly, there are days when as adults we lose sight of this simple gift, letting the pressures of our lives overshadow what we all have within us – the choice to find joy and smile, at least for a moment in each day. Brad and I know Kirby's joy is still within her. We find comfort in this and delight when a twinkle in her eyes appears just before that now-rare but ever-joyful smile.

We thank you for your years of devotion to The Children's Medical Research Foundation. Your donations have and will enable us to continue to participate in the funding of research, bringing it to a successful conclusion – a cure for Sanfilippo and giving families such as ours a lifetime of joyful moments with their children.

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

– Sue and Brad Wilson



# *Kirby's Going Green!*

We will no longer be issuing the June edition of the *KirbyGram*. But you can receive late-breaking news and event updates via email while helping The Foundation to go green and save much-needed funds at the same time. Please e-mail your name

and phone number to [curekirby@sbcglobal.net](mailto:curekirby@sbcglobal.net) to help us start a new, greener database of our supporters. We will continue to mail the print version of the December *KirbyGram*.

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## *Fundraising News*

### **"Fore" Kirby**

The Seventeenth Annual "Fore" Kirby Golf Fun Raiser was held June 1st at Ruffled Feathers Golf Club in Lemont. This year's 14 participants raised more than \$28,000 "fore" Kirby!

Sue comments, "This is always a fun event for Brad and me as it enables us to relax with friends while raising money each year. We are very fortunate to have these people in our lives, always willing to help us as a family or do whatever it takes for The Foundation to succeed."

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

Upon completion of the round, scorecards are collected from each player. 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 or [curekirby@sbcglobal.net](mailto:curekirby@sbcglobal.net) to learn more.

### **The Foundation Gives Thanks . . .**

To **Margaret Dawe, Nicholas Megofna, Mark Leavitt, Ralph Siegel, Raymond Brazell, and Gregory Miller**, who designated The Foundation as their charity of choice in their employers' United Way campaigns. Thanks for uniting for Kirby!

To Kirby's friend, **Dorothy Flannery**, who celebrated her 85th birthday by requesting that donations be made to support The Foundation's mission. Our thanks to her many family members and friends who contributed.

To **Kirschbaum's Bakery** and **Casey's Market**, both 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 \$600 to date this year, your "hometown girl" thanks you from the bottom of her little heart.

A special thanks goes out to the person who took the time to create the very special origami from bills and placed them in Casey's Market's cash jar. The Wilsons have chosen to fund the donation and start a collection!



# Fundraising News

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

**Ashleigh, Brooke, Anna and Dave Kidwell** would like to thank the **IPA Foundation** (Independent Pilots Association Foundation) in Louisville, Kentucky, for its generous donation to The Children's Medical Research Foundation.



**Anna and Dave Kidwell with Brooke and Ashleigh**

Dave is an Airbus FO for UPS and an IPA member. The contribution is in honor of daughters **Brooke and Ashleigh**. The Foundation's mission is "dedicated to providing for the well-being of children and their basic needs with a focus on making life-changing differences for children with exceptional medical requirements." The Children's Medical Research Foundation is grateful for IPA's commitment and support in helping us to achieve our goal of

a cure for Sanfilippo and making a life-changing difference for a small group of exceptional children.

To **Judy Bible** for her donation to The Foundation honoring **Brooke and Ashleigh Kidwell's** birthdays.

To **Vassallo Engineering & Surveying** for its donation honoring **Hunter and Sydney Moff** and to **Drs. Glenn Bloiso and Margaret Crabtree** for their donation in celebration of Hunter and Sydney's mom, **Theresa Moff**.

To **Les and Teri Sheaffer** for donating in honor of their daughter, **Brittany**.

And last but certainly not least, a very special shout-out to **Chelsey Montgomery** of Cedar Rapids, Iowa, for her thoughts on being a sister to **Lucas**. "My reality is brighter than your dreams." Now that girl has an attitude!



**Lucas, surrounded by sisters Chelsey and Hailee**

## News From Connecticut . .

### A Note From Rhianna's Mom

Thank you seems like such a little thing to say when our life has been blessed in such a big way. After 17 years, to see these wonderful donations sent on behalf of Rhianna is truly a blessing. Our gratitude for those who continue to donate is infinite, as is our gratefulness for the steadfast commitment of the Wilsons and the remarkable work of the researchers.

At the age of 20, each day my beautiful child awakes to numerous physical challenges and yet Rhianna always starts the day with a smile. She continues to amaze us with her determination and her desire to participate and connect with those around her. Rhianna puts tremendous effort into using her switch-activated voice output device. Many days I can feel her pull the energy to raise that pointer finger all the way from the other side of her body. She is always so pleased to get a response back. She works just as hard to play the guitar with her music therapist. As the day goes on and her challenges wear her down, she always manages to save one last smile for her Dad when he arrives home from work. Our hope remains strong as the research moves forward with such great promise. Thank you for giving us hope.

— *Cynthia Logan*



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# *Fundraising News*

The **Bristol Auto Club** revved up its support of The Foundation by donating the proceeds of its annual “**Cruisin’ for Rhianna**” **Auto Show**. We appreciate the group’s never-ending drive to find a cure.

Our thanks to the Logans’ friends **Tabitha and Justin Manafort** for again giving the proceeds of the **Manafort Family Foundation’s** annual golf outing to The Foundation. The Logans are thankful for all the people like Tabitha and Justin who continue to think of Rhianna.

**The Roberts family** showed its loyalty and faith in our mission of a cure with yet another donation in honor of Rhianna through the **Clinton S. Roberts Foundation**.

Family friends **Donna and Alan Theriault** and Rhianna’s grandparents **Martha and Jim Couture** celebrated her birthday with donations to The Foundation.

**Dennis and Laurel Colgan** of **Picture Fame** again donated for “Rhianna and the kids.”

A donation honoring Rhianna also was received from **John St. Pierre** of **Saints Restaurant**.



Rhianna communicating with Cynthia using her adaptive tech device.



Allison with sister Helen

## *In Memory Of*

The Foundation would like to express its deepest sympathy to Susan and Larry Kirch of LaCrosse, Wisconsin, on the loss of their daughter Allison at the age of 17.



# Fundraising Opportunities

## Have Fun With This Office “Fun” Raiser – Kirby Dares You!

Here’s a fundraising idea that can be challenging and fun for everyone in your office. Are you willing to take a dare for Kirby? Here’s how it works. Your company pledges a total amount it would be willing to donate to The Foundation. Then each employee willing to take on a dare chooses the dare and the amount to be donated if he or she follows through. There can be a list of suggested dares with donation amounts, or you can leave it up to the employees to get creative and have some fun. Do a dance or perform a song on the street, or for the office, wear heels for a day (that would be a guy thing), get a Mohawk, do cartwheels down a hall, eat or drink a mystery concoction....all for fun and a great cause.

## 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! 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

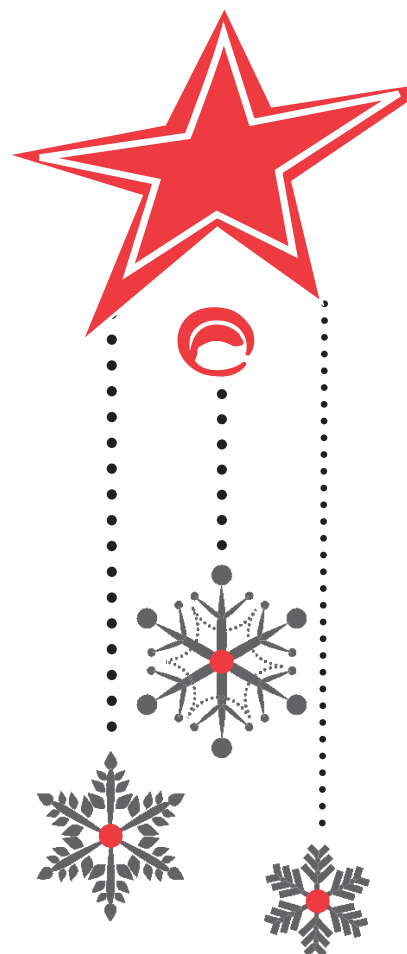
This holiday season give clients a donation to The Children’s Medical Research Foundation in their names. It’s a gift that won’t gather dust and goes far beyond any other.

## 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.



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# *The Sweetheart Dinner Dance*

**February 8, 2013 • The Ritz-Carlton Chicago**

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

The 18th annual Sweetheart Dinner Dance will be held Friday, February 8, 2013, in the Ballroom of The Ritz-Carlton Chicago.

This elegant venue is the setting for The Foundation's celebration of its 18th year, which is filled with hope that a breakthrough to a cure is now within reach.

Executive Chef Mark Payne will serve a signature four-course dinner from his award-winning kitchen, following a champagne cocktail reception in the adjoining Loge.

We will be treated to the magical sounds of the Michael Lerich Orchestra, which has entertained us for the past 17 years! And silent auction packages promise to tempt sports, travel, dining, spa and shopping enthusiasts.

Reservations are \$250 per person or \$2,500 for a table of ten and must be made in advance. Invitations will be mailed in December, or you can reserve your place now online at [www.curekirby.org](http://www.curekirby.org). 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 or visit us online at [www.curekirby.org](http://www.curekirby.org). Please contact Sue Wilson at (708) 784-0631 or [curekirby@sbcglobal.net](mailto:curekirby@sbcglobal.net) with any questions.

## **The 18th 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 (*Please print*): \_\_\_\_\_

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

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

Please include your phone number \_\_\_\_\_

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.**





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**KirbyGram**



# Save The Date

**February 8, 2013**

**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 at  
The Ritz-Carlton Chicago and dancing to the music of the Michael Lerich Orchestra. Cheers!



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