



# KirbyGram

December 2000

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



### A smile for Dad

Kirby is back to a full day school program at her home school, LaGrange Highlands Elementary, where friends and familiar faces surround her. She, in her classroom with other special friends, is fortunate to have a very patient, caring teacher and therapists that help her to maintain abilities as well as achieve new goals. Kirby's devoted, loving aide is there by her side to assist her as she joins many

school-age friends in gym, music, art, library, and recess.

The Wilsons are thrilled to have Kirby back at Highlands, a school that can provide many wonderful opportunities for their daughter. Sue Wilson comments, "It's an extraordinary feeling to

pick up Kirby each day and hear of an activity she achieved or the children that gathered around her at recess to play and be a part of her success and happiness. Brad and I are very proud parents and grateful for the tender thoughtfulness of the many adults and children involved in her day."



*Dear Friends,*

*As Kirby navigates her journey with unyielding tenacity, she continues to be our inspiration and teacher. Her smile remains, teaching us the depth and limitlessness of love. She shows us the extraordinary power of touch with her gentle, loving hug. We cherish her spoken word, and her playful songs allow our hearts to soar. She has strengthened our faith in a power much greater than our own.*

*We thank God for giving us such a precious gift and allowing us to join her on her most courageous journey. Brad and I are privileged to be her parents.*

*The Foundation has granted more than \$1.2 million toward research. Scientists are working hard to overcome the obstacles of the blood brain barrier and to spread the "good" gene throughout the brain. We are grateful for their diligence and your enduring support of the Foundation and its mission. Please continue to remember The Children's Medical Research Foundation when giving this holiday season. Together, we can make dreams come true.*

*Brad and I thank you for your compassion and confidence. We wish you the joy and peace of this holiday season, now and always.*

*Brad and Sue Wilson*



## FUND-RAISING NEWS

### Fore Kirby

The Fifth Annual “Fore Kirby” Golf Fun Raiser was held June 14th, with 19 golfers braving a very stormy, wet day. Three lightening delays did not deter these committed men from completing their round “Fore” Kirby. This year’s pledges totaled over \$50,000 in donations to the Foundation, with all expenses for the event paid for by the Wilsons and the golfers themselves.

“This is a group of men that has been with us for a long time and never ceases to amaze us with its devotion to our cause.” Sue says, “The weather was definitely not our friend that day, and yet all the men, wet and cold, slowly filed into our home with nothing but enthusiasm for the day and our child. We have one poor, loving soul who risks his reputation and ego just once a year by participating in the event, and he doesn’t even like golf! He can stand tall this year – he personally collected over \$7,600 in pledges.”

### High on the 95th

June was a very special month for Kirby, and The Signature Room at the 95th made sure of that! For the second year, The Children’s Medical Research Foundation was chosen as its June “Charity of the Month,” receiving 10% of the sales from the 95th’s Signature Selection menu. Not only did guests enjoy an elegant meal and an extraordinary view of Chicago, but also they contributed toward the 95th’s \$3,302 donation to the Foundation. That’s what we call a win win situa-

tion! Our heartfelt thanks to the management of 95th for its commitment to the Foundation.

### Frank’s on the Run Again!



#### Frank, Mary Kay, Family, friends and Brad, on the run for Kirby

Frank Signorelli, the Foundation friend who ran his first Chicago Marathon for Kirby last October has done it again. This year, Frank chose the Park Forest Scenic 10 mile & 5K Labor Day event to run and collect pledges for the Foundation. His wife, Mary Kay, friends and family joined him, as did Kirby’s dad! We won’t mention that Brad finished 13 out of 14 in his age group. We will dwell on the fact that he completed the run (his first) alive and proved to all that he will do anything for his dear daughter, Kirby!

The Signorelli group raised \$570 for the Foundation, with pledges still coming in for Brad. Frank’s already thinking of what he can do next year, as he puts it, “on a greater scale -- small acorns grow into great oak trees.” Sue Wilson remarks, “Frank and Mary Kay are very special people who have come into our lives and shown nothing but concern and generosity toward our family. After reading Frank’s words to

us, I will never look at another oak tree without thinking of the Signorellis and their steadfast kindness.”

### Food, Fun and Fashion

On September 30th, the LaGrange Highlands Presbyterian Church Women’s Association hosted a salad luncheon and fashion show by Mary Anne’s Shoppe in LaGrange Park, benefiting the Foundation. The sold-out event, coordinated by Jean Spencer, included a delicious salad buffet, every dish created by the women themselves, and a wonderful selection of new fall fashions modeled by members. All the hard work and effort by these women paid off for the Foundation -- \$2,010 was raised!

“This church and its members have welcomed us with open arms and have been instrumental in renewing our faith,” Sue Wilson explains. “They were one of the first to gather by our sides and remain a constant in our lives. Our indebtedness and gratitude to this very special group go beyond what our simple words can express.”

### A Night to Remember....

On the evening of June 2nd the Wilsons had the privilege of listening to the **Lyons Township High School Treble and Concert Choirs** perform for Kirby and the Foundation. It was an evening filled with “specials” for the Wilsons. Kirby was there for the performance and sat the entire time entranced with the songs and clapping when appropriate. Sitting for any length of time in a public setting can be very difficult for Kirby, yet some-



how, somehow, she sensed the comfort and compassion in the filled sanctuary of the **First Congregational Church of Western Springs** and was at peace. Emotions ran high. As these young adults sang and looked out to see Kirby, tears filled their eyes. Needless to say, the Wilsons could have used a few tissues, maybe even a box!

Not only did these students make time in their busy schedules to attend special rehearsals for the event, but they also publicized and sold tickets to the performance, pursued donations and even baked treats for after. Sue Wilson comments, "The magic of the evening was something we never expected. First, there was Kirby, then the students, with their talent and most sincere emotions. We thank Mr. Wolniakowski, the choirs' director, and the members for giving us a memory that will last forever in our hearts."

## The Foundation Gives Thanks....

To **LaGrange Highlands Middle School**, coordinator Miss Jean O'Brien, teachers and students for their amazing \$1,000 donation from the proceeds of the school's home room "Silver Wars" Change Challenge competition/fund-raiser,

To friends of Don Karpiak at **CSC Consulting, Inc.** in Oak Brook for collecting \$400 for the Foundation,

To **Lyons Township High School** and the student members of the **Peaceable Schools Initiative** for choosing the Foundation as one of the benefactors of the group's first year's efforts and donating \$300,

To the **Indian Head Park Woman's Club** for its most generous donation of \$200,

To Jennifer Stucker and fellow employees of **American Express** for their most generous donation of time and talent for the "mountainous" task of preparation and mailing of the Sweetheart Dinner Dance invitations, and

To Ms. Marsha Sprayberry and the **Krackeroos' Smiles Foundation, Inc.** for their \$500 donation in honor of Andrew Bowman.



Andrew (right) and brother, Simon Bowman, enjoying the moment

## NEWS FROM CONNECTICUT



Rhianna, taking a break

**Rhianna's Hope** (the committee formed by the Logan family to raise research funds) continued its mission this year with the **Fourth Annual "Cut-Against-Time,"** which was held on June 4th. Over \$13,000 was raised this year for the Foundation.

Committee members Linda Casorio, Debra Dawson, Tabitha Wazorko, and Donna Theriault, realizing how precious the time spent with Rhianna is for the Logans, did this one on their own!!

**Renbrook School**, where committee member Tabitha Wazorko teaches, chose to have a **"Dress Down Day"** for students as a way of contributing funds toward the "cut-a-thon." The \$690 raised was a great kick-off to this annual event.

"Cut-Against-Time" is a true example of the impact community people and businesses have when forces are joined for a common cause. The Foundation is thrilled this group has chosen Rhianna and children like her as the benefactors of its hard work!

**Suffield Academy** high school senior and Logan family friend **Andrea Rich**, initiator of **"Charity Challenge,"** certainly made her own impact in our hearts with this one! The first "Charity Challenge," a fund-raising competition between Suffield Academy and Ethal Walker schools, raised \$1,788 for the Foundation in honor of Rhianna. The **Ethal Walker School** just edged out Suffield to win the rights to the plaque. Andrea's hope is that her idea will continue for many years.

Shortly after the event, the Foundation learned that Andrea wasn't done yet! Each year, her school presents the Hirschmann Humanitarian Award to a senior who has made an exceptional





contribution to community life. It was no surprise to the Foundation that Suffield had chosen Andrea for this award. What was a surprise was that as part of this award, the recipient designates a charity of his or her choice to receive a donation from the school. Andrea chose to help Rhianna again, and the Foundation was the recipient of a \$400 check from Suffield Academy. We thank Andrea for her concern and compassion and wish her all the best in her future endeavors.

Bob Ibitz, chairman of the annual **Bowtie Classic All Chevy Show**, designated the Foundation, on behalf of Rhianna, as the beneficiary of the proceeds of the show for the fourth year. The Foundation received a \$3,000 check! Our heartfelt thanks to Bob for keeping the “peddle to the metal” for Rhianna and her friends!

Kathy Sloane of **West Main Pizza** knows how to throw a party! For Rhianna, of course. The Foundation received a \$400 check as a result of the party. Cheers to West Main Pizza!

**Alan and Donna Theriault** are busy with the last minute plans for their annual **“Rockin’ For Rhianna”** fundraiser which will be held November 21st. This year’s entertainment will be provided by The Heartbeats. A silent auction also is planned. Rock on, Theriaults!

## The Logans reflect....

Thank you seems inadequate for all the hard work that has kept “Rhianna’s Hope” rolling. As our energy is drained by other priorities such as medical needs, educational issues, pursuit of alternative therapies and an intense need to be with Rhianna, we are truly grateful to those who contin-

ue to fund-raise and support our hope for a cure! The impact on medical research over the past five years has been tremendous. Our heartfelt thanks to all of our family, friends and the Wilsons.

## BEN’S DREAM

As Stuart Siedman’s Xerox Corporation Service Leave draws to an end, he’s busy finishing a fund-raising events portfolio, as well as pursuing corporate support for the Foundation.



### Ben, flying high

“**Ben’s Dream**,” the committee formed by Stuart and Jennifer Siedman to raise funds for the Foundation in honor of their son Benjamin, hosted the second annual **“Birdies for Ben”** golf fund-raiser on August 21st. Stuart and 23 golfers completed their rounds

of golf at the Sandy Burr Golf Club in Wayland, MA, and joined the Siedmans at their home for a picnic, fun and games with their families. This year’s event, modeled after “Fore Kirby,” has raised over \$86,500 and, with pledges still coming in, is expected to reach the \$90,000 mark! **This is the single, most successful event held in the five-year history of the Foundation.** The Foundation gives its heartfelt thanks for this incredible achievement.

## The Siedmans give thanks...

Our second “Birdies for Ben” was a huge success thanks to the hard work of our family, friends and business associates. This year the event had special meaning as Ben has taken up “mini-a” golf. On a recent outing (Dad’s only tune-up before the event), Ben carded three holes-in-one! True to his nature, only the first thrilled him; the other two were but an annoyance that detracted from his ability to take the most shots. He promptly removed the last two from the cup, called “do over,” and ran back to the tee in his quest to squeeze the most out of life.

On the course and off, everyone took after Ben’s example and pitched in to help us raise this astounding total for research on behalf of Ben. We continue to be overwhelmed by the generosity and support of our friends and community. It is not possible to convey the full extent of our gratitude – we thank everyone involved from the bottom of our hearts.

**Poorman-Douglas Company** of Portland, OR, learned about Benjamin and the CMRF from Ben’s uncle, Howard Carpenter III, a P-D employee. What they learned led them to turn



their annual fall employee outing, **The Haunted House and Harvest Festival**, into a fund-raising event with the proceeds going to CMRF. P-D enlisted the support of the local Xerox office to put together a three-day Halloween extravaganza on October 27th, 28th and 29th. It featured a Haunted House with professional quality props on loan from the Portland Zoo and an outdoor tent area with carnival games, food and entertainment for all.

LaDonna Burgess of P-D felt “the ability to merge our employee outing with support of a good cause was a perfect fit.” The event was open to all P-D and Xerox employees and their families and friends. Totals for the festival are not in yet, but with a combined workforce in excess of 600 persons, LaDonna is expecting the event to be a huge success.

**The Cut Against Time – Wellesley Style** was modeled after the cut-a-thon started on behalf of Rhianna Logan in Plainville, CT. This “Cut Against Time” event was seen as a way for **Lisa James Salon** of Wellesley, MA, to help speed the way to a cure on behalf of one of its best customers, Benjamin Siedman.

Nancy Pizzotti was the driving force behind getting the support of salon owner James Mortenson and the staff. On Sunday, November 5th, James donated the use of his salon and the staff donated their time and energy to make their version of the cut-a-thon a success. Through advertising, flyers and word of mouth, they turned salon traffic, haircuts and raffle ticket sales

into funds for research. Their concern has warmed our hearts.

## MAY WE INTRODUCE TO YOU “LITTLE JACQ’S CORNER”

Greg and Toni Graham of Salinas, CA, have formed a foundation, “**Little Jacq’s Corner**,” in honor of their five-year-old daughter, Jacqueline, for the purpose of raising funds for research and The Children’s Medical Research Foundation. Beautiful Jacqueline was diagnosed with Sanfilippo in October, 1999.



**Jacqueline riding high on dad, with mom and sister Kelli by her side**

“Little Jacq’s Corner’s” first fund-raising event, “**Pig Out**,” was held September 9th and attracted more than

850 caring people. The outdoor barbecue received publicity from five radio stations, as well as a local television station. This event had something for everyone! For adults, there was a silent auction, raffle, a door prize of a trip to Cabo San Lucas, t-shirts and a band named Crossfire which sang the blues as entertainment. The children had their own raffle, with a bike being the grand prize, bounce houses and carnival games, from which they collected tickets for prizes. Growers Ice provided a truly unique activity for these California kids.... snow, complete with saucers for sledding! The Grahams wish to thank all the people that helped to make this fund-raiser possible.

All the effort and time that went into this event, with its many fun activities, paid off. Little Jacq’s Corner issued a \$19,000 check to the Foundation for Sanfilippo research. Thanks to Greg and Toni, their friends and family, Scott and Terri Wemmer and Rodney and Carolina Cortez, who did all the hard work. Sue Wilson comments, “The Grahams are an incredible family. Their decision to form a foundation in order to expedite California fund-raising was a huge surprise for me. Toni made me aware of their foundation and its fund-raiser only after it was all said and done. She knew how much I wanted to ‘carve out’ time in my life to just ‘be a mom to my kids.’ Their understanding of my situation and willingness to relinquish a part of their valuable time are extraordinary gifts to me for which I am deeply grateful.”



## GEMS FOR JULIA



### Julia Gray, a happy school girl

Dorsey and Bernadette Gray of Atlanta, GA, are the parents of four-year-old Julia, diagnosed with Sanfilippo just this past June. The Gray family is already encountering the overwhelming compassion of friends that so many other families with afflicted children have been so fortunate to experience.

Bernadette's employer, **Coca-Cola Retail and Trademark Operations**, based in Atlanta, recently chose the Foundation as the recipient of proceeds of its annual "Sample Sale," which offers licensed merchandise to employees. The Foundation received a check for \$3,000 as a result of the employees' shopping spree! Family friends, **Karen Gipson** and **Allison Phelts**, are hard at work planning a golf fund-raiser, "**Fore Julia**," scheduled for April 27, 2001. On behalf of Julia and other children like her, the Foundation thanks Coca-Cola, Karen and Allison for joining in our effort.

## FUNDING IDEAS

### "One Road"

C. Donovan (Cory), Rhianna Logan's uncle, has created this solo piano instrumental CD, with Aunt Donna's artwork on the cover, just for her. 100% of the proceeds of this very special sale goes to the Foundation. Hurry and place your order today. The cost is just \$15 and a limited quantity is available. Please contact Sue Wilson at 708/784-0631 to place your order.

### Give Kirby Security

Tired of taxes? The Foundation now has a brokerage account available, which 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

Soon the time will come when your company will wonder what it should give clients for Christmas. How about 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.

### Time to Holiday Shop? Do It OnLine

If you plan to surf the Web this holiday season (or anytime) for online purchases and gifts, make your starting point our GreaterGood.com shopping portal. As a registered partner with GreaterGood.com, The Children's Medical Research Foundation will receive a cash donation of up to 15% of every purchase.

GreaterGood.com brings together the explosive economic growth of the Internet with an increasing desire by users to "give back" to charitable institutions like ours that make the world a better place. Now you can support the Foundation by shopping online. GreaterGood builds and manages "online shopping villages" for not-for-profit partner sites like ours, where every purchase benefits our cause. Our village includes a broad assortment of brand-name merchandise offered by leading retailers such as:

1-800-Flowers, Amazon.com, the BabyCenter, the DisneyStore, FogDog Sports, the Gap, igoGolf.com, J.Jill, j.crew, K-Bkids, Nordstrom, Pets.com, REI, Starbucks and others.

When you shop through our online village, you support our mission - at no additional cost to you!

It's simple to help. Just click on The Children's Medical Research Foundation's "Shopping" button on our website - [www.curekirby.org](http://www.curekirby.org) to automatically benefit the Foundation. You can enjoy your purchase knowing that you've made a valuable contribution to our 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

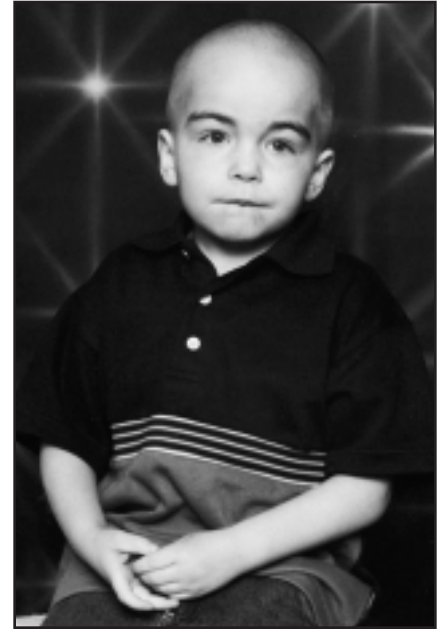
Does your company have United Way pledges at your workplace? Although we are not a United Way member, you can designate The Children's Medical Research Foundation as your recipient, and the funds will be forwarded to us through the United Way Campaign! Our United Way Chicago "Agency Number" is 3025558. 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 University of Chicago Hospitals, Sears, CSC Consulting, Wellpoint Health Network, UPS and the Kidwell family for designating their United Way pledges for the Foundation.

## IN FOND MEMORY OF

We wish to extend our deepest sympathy to the Smith family on the loss of their dear child, Cody.

The Foundation thanks the faculty and staff of **Clark Elementary School** for their most generous donation in memory of Cody.



**Cody Smith, the Smiths' little angel**

## SAVE THE DATES:

### Winter Ball

The University of Illinois at Chicago College of Medicine's Class of 2003 has selected The Children's Medical Research Foundation as the benefactor of its Winter Ball. The date is set for January 20th at the Harold Washington Library Winter Garden. The gala will include hors d'oeuvres, desserts, open bar, dancing and a silent auction. Please contact Sue Wilson at 708-784-0621 for details and reservations.

### 6th Annual Sweetheart Dinner Dance

Plans are now underway for the 6th Annual Sweetheart Dinner Dance to be held February 2, 2001, at The Drake Hotel in Chicago. Reservations are \$200 per person and must be made in advance.

### We Need Your Help

A silent auction again will be included in the evening's activities of the Sweetheart Dinner Dance, and the Foundation is seeking donations. Sponsorship also will be available for the champagne cocktail reception, dinner wine, flowers and entertainment. Please contact Brad or Sue Wilson at (708) 784-0631 for further details, or simply complete the Reply Form on the back page.





**The Sixth Annual Sweetheart Dinner Dance**  
**SPONSORSHIP REPLY FORM**

**Sponsorship:**

*(Circle One)*

Entertainment.....\$ 3,500  
Dinner Wine.....\$ 2,500  
Flowers.....\$ 2,100  
Champagne .....\$ 950

**Benefactor:** \$ 500 & Above Donation

Toward Expenses \_\_\_\_\_

**Silent Auction Donation:**

Item Description \_\_\_\_\_

Value \$ \_\_\_\_\_

Check Enclosed \_\_\_\_\_

Please charge my *(check one)*

Visa/MC

American Express

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  
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P.O. Box 70  
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