The Children's
Medical Research
Foundation, Inc.

Kirby*Gram*

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

December 1999

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

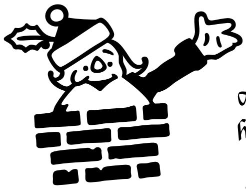
Dear Friends,

Although our challenges continue as the progression of the disease becomes more and more apparent, Kirby remains a very loving and powerful teacher. She refuses to succumb to changes she is experiencing by fighting back with amazing fortitude. Her strength is our determination. Her struggle, our mission. Her smile, our inspiration and her love, the light that guides us. We thank God for giving us our own shining star.

The new millennium brings great hope and optimism. Researchers have come a long way over the past five years, including the identification of the gene responsible for Sanfilippo, the ability to create a "good" gene in their laboratories, and their work with vectors and understanding the complexity of both the brain and the disease itself. Current research in the areas of gene therapy, enzyme therapy, cell replacement therapy and drug therapy is the proof of progress and provides afflicted children with real potential for treatment.

The Foundation has granted $892,000 and will go over the million dollar mark in the spring of 2000. This is a huge achievement for which we are eternally grateful to each and every one of you. Your continued support will help fulfill the needs of current research as well as the expansion of this work.

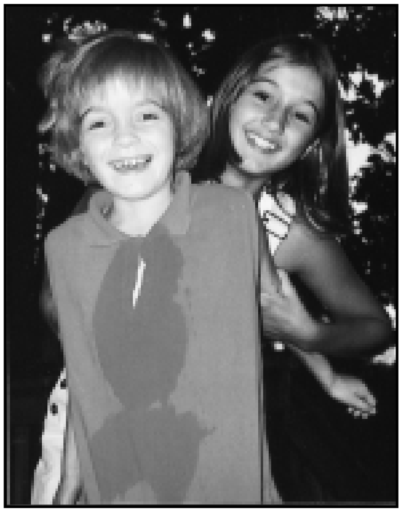
Please remember The Children's Medical Research Foundation
when giving this holiday season.



We thank you for your faith and commitment. And, as always, we wish you and your families great health and happiness this holiday season.

Brad and Sue Wilson

KIRBY UPDATE

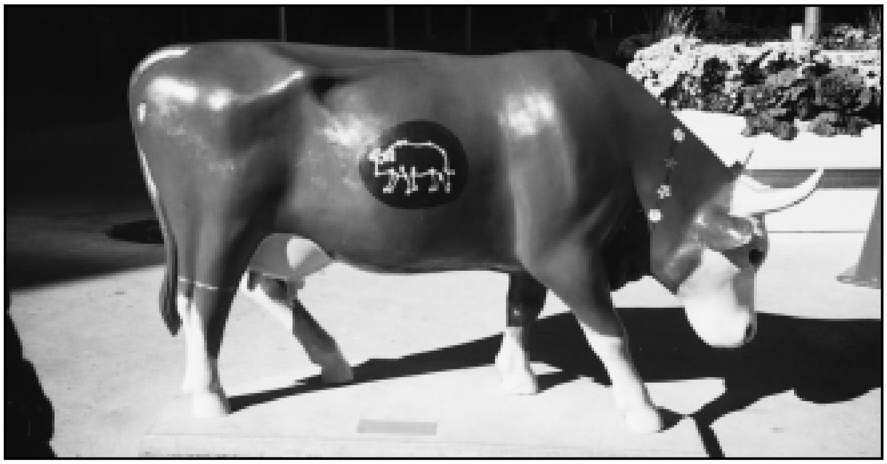


Kirby and big sister, Maggie, after their first day of school.

Once again, Kirby started her school year by showing her great ability to return to a routine which remains very important to her. Similar to last year, she starts her day in Alicia Felice's special education class at Forest Road School in LaGrange Park. Later, she's off in her own special school bus to LaGrange Highlands Elementary School, where she joins her second grade friends for the last hour of the day.

The Wilsons are extremely fortunate to have such a caring team of educators who constantly adjust to changes they see in Kirby. Sue Wilson explains, "Recently, Kirby has experienced some difficulties in handling her day and the tasks that are asked of her. But it is of great comfort to us to know that everyone involved is working together to adapt the program for the well-being of our child. We always knew Kirby was surrounded by a group of very talented educators, but it's only when "times get tough" that we realize the depth of their patience and concern for our dear daughter."

HOLY COW! IT'S FOR KIRBY



Kirby's Cow

Mr. Jack Block of Block Electric Company has chosen The Children's Medical Research Foundation as the recipient of the proceeds from the auction of his company-sponsored cow, Taurus. This cow was part of a unique public art exhibition, Chicago's "Cows on Parade," which featured 320 life-size fiberglass cows that were displayed in public areas and buildings throughout the city of Chicago from June 15th to October 31st. The cows were sponsored by local businesses and transformed into art by hundreds of Chicago artists. At the live auction on November 9th, 65 of these bovine works of art were put up for bid by their sponsors. Taurus received a winning bid of $26,000.00!

The Wilsons are truly "moooved" and "udderly" amazed by Mr. Block's continued concern and support of the Foundation.

KIDS HELPING KIDS

June 6th was the date that three former classmates of Kirby — Amanda Goslawski, Meredith Dost and Monica Barc — embarked on their first philanthropic endeavor. This inspirational group of children formed a club, "Kids Helping Kids," with the idea of fund-raising to help others.

In an interview with a local paper, Amanda stated, "Just because I am small doesn't mean I can't do something." These 8-year-old girls, still remembering Kirby from their pre-school days together and understanding the importance of raising funds for research, proceeded to plan a "Walk for Kirby." This 1.5-mile walk encouraged other children and families to participate and solicit pledges from family and friends. The event also included a lollipop tree with prizes from local businesses, which the girls themselves collected.

There were 200 people that participated in the walk, and the event raised more than $5,000 for the Foundation. Sue Wilson states, "I'm amazed at the compassion that children have within toward other kids in need. Children really can make a difference in this world. I am thrilled Kirby has such caring friends."

Kirby and her friends pause for a photo at the start.

“FORE KIRBY,” WE THANK YOU

Ruffled Feathers Golf Club was the site of this year’s Fourth Annual “Fore Kirby” Golf Fun Raiser, with 27 golfers soliciting “per hole” pledges for the Foundation. The outing raised $62,000 for research, with all expenses of the event paid for by the Wilsons and the golfers themselves.

“These men put forth a huge effort on behalf of our daughter and the Foundation. We are grateful for their hard work and commitment,” Sue remarks.

SEASONS
GREETINGS

FRANK MAKES HIS MARK FOR KIRBY

Frank Signorelli wasn’t even an acquaintance of the Wilsons when he contacted them shortly after participating in last year’s 5K4 Kirby. That would soon change. Frank called to ask if it was possible for him to raise funds for the Foundation while attempting his first marathon — The Chicago Marathon — which was held October 24th. If he collected pledges, he explained, Kirby would provide an inspiration for him to train and achieve his goal of completing the marathon. Needless to say, the Wilsons were thrilled.

Frank started the race strong, but at the 17-mile mark his knee gave out. One would think that that would be the end. Not for Frank, as he explained to the Wilsons after the race. “I knew I wanted to finish the race for Kirby, telling myself what I was experiencing was nothing compared to what Kirby is dealing with. I would have crawled if I had to.”

Frank crossed the finish line, achieving his goal and touching the Wilsons’ hearts. Sue explains, “Brad and I have seen a lot over the past five years, but never have we witnessed such a personal sacrifice for our daughter. So far, pledges have reached $1,900 for Frank’s efforts on behalf of the Foundation, but in this case, the dollars raised will not be the indicator of Frank’s success. It is his incredible fortitude in finishing the race that will remain in our memory forever as a magnificent success story for Kirby.”

Frank at the finish.

THE COMMUNITY CARES AND CARES AND CARES . . .

Once again, this year proved to the Wilsons just how much their community cares. . . .

District 86 included The Children's Medical Research Foundation as one of the benefactors of its annual "24-Hour Relay Challenge." This team event requires high school student team members to solicit donations for the effort to "run, walk, cartwheel or somersault" one mile before passing the baton to the next team member over a 24-hour period. Kirby was a part of the opening ceremony and walked the track for the first leg of a very long day for these amazing students. As a result of their dedication, a $1,600 check was presented to the Foundation.

George's Hair Design in Western Springs was the host of a "Cut Against Time for a Cure for Kirby" on June 14th. Stylists and manicurists from both George's and Garden Market Barber Shop donated their time and talent to raise $1,400 for research. Kirby was present for a time, enjoying ice cream and thanking patrons for their support. Her mom and dad can't say enough about George's and the Barber Shop.

Sharon Gleich, a distributor of PartyLite Candles and a "school mate mom," will be donating the proceeds of three "Candles for Kirby" parties to the Foundation. The Wilsons thank Sharon for her generous concern and helping to "brighten their life."

CONNECTICUT UPDATE

The Logans' report....

In January, 1999, Rhianna Logan and her parents, Gene and Cynthia, moved into a new home. Everyone was pleasantly surprised by Rhianna's ability to quickly and happily adjust to her new space. In September, Rhianna began a full day program at school and returned to her horseback riding, showing great progress and pride.

Rhianna's Connecticut friends continue to find ways to bring joy to the 7-year-old. Because of the efforts of a 12-year-old friend, Ashleigh Woodfield, Rhianna was presented with a five-day program of "dolphin assisted therapy" in Key Largo, Florida. Realizing Rhianna's love of the water and large animals, Ashleigh had written to the dolphin program, telling them of her friend and the disease she is fighting. Gene and Cynthia were amazed by their daughter's focused awareness and performance while with these loving creatures.

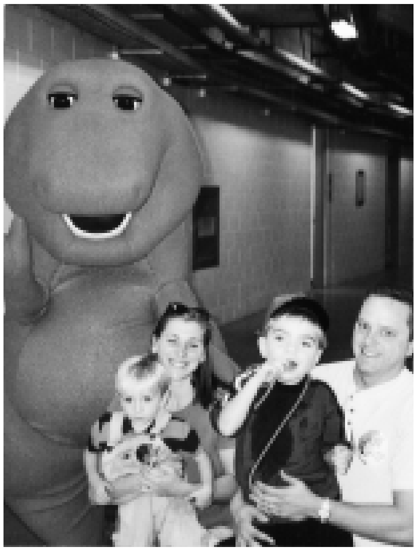
Connecticut fund-raising efforts included the Third Annual "Cut Against Time," which raised more than $10,000. Vintage car owners in the Bristol Auto Club, lead by Harvey Wilson, raised $5,000 for the Foundation with their fund-raiser, "Cruisin' For Rhianna." This event was followed by the third year of support from Bob Ibitz's CT Chevelle Connection and a $3,000 donation.

On November 20th, "Rockin' For Rhianna" rolled again thanks to the huge heart of family friend, Alan Theriault. The Wanderers returned, again donating their musical talent for the evening. The silent auction was a huge success, thanks to the generosity of sports figures and collectors.

Cynthia summarizes, "Time has moved so quickly this year, it is frightening. We are truly grateful to all our supporters, researchers and most of all, the Wilsons, for their continued fight against time."

Swimming with dolphins — a dream come true for Rhianna.

THE SLATTERY FAMILY JOINS THE EFFORT



Andrew Slattery (front, right) and family enjoy a very special day with his favorite dinosaur, "Barney," courtesy of the Make-a-Wish Foundation.

When Rob and Wendy Slattery of Ventura, California, learned of their 4-year-old son Andrew's diagnosis of Sanfilippo this past April, they were devastated. But Rob and Wendy chose to fight and give all children afflicted with this disease a chance. They soon joined the Wilsons in their fund-raising efforts.

Through publicity in a local paper, word spread of their plight. School and community members took action. Alex and Alison Mizraji opened up their home for a dessert benefit, spreading awareness of the Slattery's story and raising $1900. Portola Elementary School, the school where Wendy works as a teacher, planned a spaghetti dinner that drew so much support that the dinner was moved to a different school which had more space. It raised $16,000 for the Foundation.

With each gesture, Rob and Wendy become more overwhelmed by the number of people who care about their little son. As Wendy said in trying to describe the appreciation they felt for the outpouring of support, "Who would have thought that one little boy with a 10-word vocabulary would cause such a commotion?"

DREAMS ARE ALIVE WITH "BIRDIES FOR BEN"

Benjamin Siedman dreams of being a farmer, and his parents, Stuart & Jennifer Siedman of Wellesley, MA, are determined to make his dreams come true. Ben, a robust 3-year-old diagnosed with Sanfilippo B, has parents who refuse to give up.

"Ben's Dream," the committee formed by the Siedman family to raise money for Sanfilippo research and the Foundation, hosted its first annual "Birdies for Ben" golf fund-raiser on August 10th at the Sandy Burr Golf Club in Wayland, MA. Stuart and 23 friends "teed off" for a wonderful day of golf, followed by a picnic at the Siedmans' to thank the participants and their families.

The golf event, modeled after "Fore Kirby," was an overwhelming success, raising an astounding $74,000. With pledges still coming in, Jennifer reflects, "No words can adequately express the depth of gratitude we feel for the support, hard work and concern of the golfers and our community. Our sincere appreciation to the dozens of businesses and hundreds of contributors for all the effort and caring that went into your participation in "Birdies for Ben."

Not stopping there, Stuart, a product manager at Xerox Corporation, applied for and was granted a 12-month company-sponsored service leave. The leave will allow Stuart to work full time for the Foundation. He plans to develop a portfolio of fund-raising events and recruit families across the country to host them. He also hopes to expand corporate awareness of CMRF and the plight of Sanfilippo children. Anyone interested in helping should contact Stuart at 617/556-3423 or bens.dream@att.net.

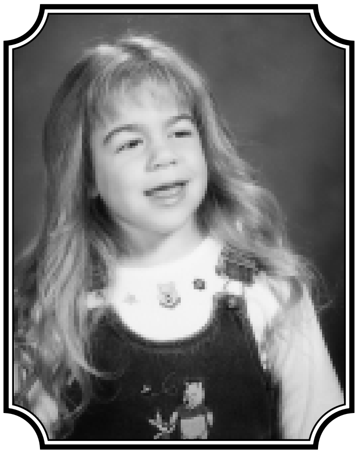
Ben Siedman - a smile that melts your heart.

LETTERS, LETTERS AND MORE LETTERS

Les and Teri Sheaffer of Kempton, Pennsylvania, are parents of Brittany, a pretty 6-year-old girl afflicted with Sanfilippo. Les is working with the National MPS Society to help make our government aware of the urgent need for funding research of the MPS disorders and to help members of the Society stay abreast of ever-changing laws affecting genetic research, as well as insurance and health plan reform.

A letter from you to your Senator and House Representative would be greatly appreciated and go a long way in helping to increase funding for genetic research and unhindered access to care for children afflicted with these disorders. For more information or a sample letter, please contact Les at 610/285-2304.

It is a time-consuming job for Les that is very much appreciated by members of the Society and the Foundation.



Brittany Sheaffer posing pretty.

A SPECIAL GIFT FROM A SPECIAL MAN

Mr. Richard Driehaus of Chicago recently surprised the Wilsons with a very special donation to the Foundation. A Trans II golf cart was delivered to their home this past July, with the proceeds from its future sale to be donated to the Foundation. This unique gift, pictured below, can be yours. It is equipped with headlights and turn signals and reminds the Wilsons of a VW bug. It must be seen to be appreciated!!! For further information contact Brad or Sue at 708/784-0631.

The Wilsons thank Mr. Driehaus for this most generous gift and for giving Kirby some very happy time cruisin' with her dad.

Kirby enjoys the ride.

FUNDING IDEAS

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 "Agency Number" is 3025558.

Our thanks to the employees of Adventist Health Care Systems, University of Chicago Hospitals, Sears and CSC for designating their United Way pledges for the Foundation.

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 Internet this holiday season (or anytime) for online gift ideas, make your starting point GreaterGood.com or curekirby.org. As a registered partner with GreaterGood.com, the Children's Medical Research Foundation will receive a cash donation of at least 5% of every purchase.

GreaterGood.com brings together the explosive economic growth of the Internet with the increasing desire to "give back" to the charitable institutions like ours that make the world a better place. Now, you can support the CMRF by shopping online. GreaterGood.com builds, markets and manages "online shopping villages" for not-for-profit partners' sites like ours, where every purchase benefits the not-for-profit's cause. Each online shopping village includes a broad assortment of brand-name merchandise offered by leading Internet retailers, such as Amazon.com, eToys, OfficeMax, J.Crew and Orvis. When you shop at our online shopping village, you automatically support our mission - at no additional cost to you or the organization.

It's simple to help. Just designate CMRF as your shopping beneficiary with GreaterGood.com, or start at our website and click on Shop Online to automatically benefit CMRF. You can enjoy your purchase knowing that you've made a very valuable contribution to our cause.

SAVE THE DATES:

Charity of the Month at The 95th

The Signature Room at the 95th, located in Chicago's John Hancock Center, has once again chosen The Children's Medical Research Foundation as its charity of the month for June, 2000. Previously, this event raised $2,600 for the Foundation! As the charity of the month, the Foundation will receive 10% of the sales from the 95th's Signature Selection menu offered during dinner throughout the month of June. When thinking about dining out, consider The Signature Room at The 95th. You can help the Foundation while enjoying an elegant dinner and an extraordinary view of Chicago.

Take a "Chance" with the Jr. Woman's Club of Deerfield

The Jr. Woman's Club of Deerfield has selected The Children's Medical Research Foundation as the benefactor of its April 8th benefit, "Chances for Children," a casino night which will be held at the Harrison Center in Lake Bluff, Illinois, at 7:30 pm. The event will include a dinner buffet with cash bar. This is a great opportunity to get a group together and give Kirby and her friends a "chance." For tickets, further information, sponsorship or volunteer opportunities, please contact Joan Butzow, Ways & Means chairman, at 847/940-8045.

5th Annual Sweetheart Dinner Dance

Plans are now underway for the **5th Annual Sweetheart Dinner Dance to be held February 4, 2000 at The Drake Hotel in Chicago.**

We Need Your Help!

The Foundation is seeking dinner dance sponsorships and silent auction donations. Please see the Reply Form on the back page.