

March 1, 2008

Dear Family, Friends, and Colleagues:

In early December, millions of people in Chicagoland watched, listened, and read about the top news story over a few days – the nation’s first simultaneous organ transplant surgery for twins, which took place in Chicago. The story, while scientifically fascinating and heartwarming at the Holidays, was tempered by the reality that a little girl had to die for her two kidneys to be harvested and transplanted into two 10-year-old twin sisters. This medical first resonated loudly and emotionally for the Greeley family because the little told part of the story was the underlying reason why the twins desperately needed kidney transplants; they both have Cystinosis (SIS-TIN-OH-SIS), “a rare disease the blocks the body’s normal production of amino acids that leads to a host of chronic health problems, including kidney failure,” as simply put by the *Chicago Sun-Times*.

As many of you know from previous correspondence, our son, Jack (8-years-old on March 17, 2008) has Cystinosis. Due to early diagnosis in Spring 2001, fortunately Jack is doing remarkably well today after a very tough stretch in 2001 and 2002. Over the last half dozen years, we have become heavily involved with the leading research and advocacy group supporting our medical community, the Cystinosis Research Network (CRN, [www.cystinosis.org](http://www.cystinosis.org)). Some highlights and recap:

- There is no cure for Cystinosis, only treatments that must occur soon after the appearance of symptoms or the consequences are severe (i.e. – the twins).
- Cystinosis is very rare; roughly 1,000 people in the U.S. have it. This low prevalence and easily-mistaken symptoms make it hard to diagnose.
- Every day Jack takes 30 pills divided between doses at 8 am, 2 pm, 8 pm, and 2 am. This every six hour routine will continue forever and dosages will increase as Jack grows until better formulations are available.
- Jack sees a bevy of doctors each quarter – pediatrician, gastroenterologist, geneticist, nephrologist, and ophthalmologist. This is in addition to regular visits with other professionals that help Jack with his development – social worker, speech therapist, physical therapist, and occupational therapist.
- Jack got rid of a g-tube over a year ago that had implanted into his stomach for almost five years, because for 18 months after diagnosis Jack stopped eating.
- Jack has largely avoided other significant health challenges that Cystinosis poses, like muscle wasting, diabetes, blindness, reduced pulmonary capacity, hypothyroidism, and neurological damage. With continued good health care Jack will hopefully avoid or minimize the harsh ripple effects of a severe metabolic, genetic disease.
- CRN manages a full slate of initiatives, including a biennial family and medical conference (next stop Atlanta, GA, July 2009), daily e-support group, website, newsletter, Scientific Advisory Board, fundraising, and research grants.
- Recently, a milestone event took place when CRN funded a fellowship at the National Institutes of Health in Washington, DC. This doctor will train under the leading Cystinosis clinician and researcher in the world, Dr. Bill Gahl, who will be retiring in the next decade. Getting younger medical talent to focus on Cystinosis will continue to be a focus of CRN, which is critically important as Cystinosis patients continue to live much longer, healthier lives.
- CRN “World Headquarters” has moved to our house, which took place last summer after Christy was elected President of CRN in addition to her role as Executive Director. She is humble about her role, but Dave is not – true rock star performance!

Overall, Jack leads a very normal life, if not a maintenance-free one. He is doing well in school, has many friends, and continues to develop, grow, learn, and socialize like his peers. CRN continues to grow...more research, more outreach, and more family support. Our family has been blessed by being able to share our story and as a result, many people have kindly and generously supported CRN. Like many of the 25 million Americans who also battle a rare disease, the often harsh reality of dealing with Cystinosis has bestowed our family with a gift that is quite special and unique in today’s world. Through it all – and anyone of adult age knows it – anything can happen in life and you just never know what might be on the horizon.

While we started writing this letter a few years ago to simply gain financial support for the fledgling CRN to help our son and others, we have learned that we have received a truly special opportunity from Jack's plight. It is said that to whom much is given, much is expected. For us, Cystinosis has also become an instrument to touch the lives of others; to truly give others pause to reflect and appreciate what they have and what they can do in life. It has become a gift of perspective and appreciation for us to share and for others to embrace. This was abundantly clear at two times this past year. Two young adults were touched by Jack's story and these are their words in letters sent to us:

8-27-07

*Dear Greeley Family,*

*I am a junior at Stevenson High School. I recently had a garage sale with my family and collected a small amount of money. My family and I stumbled upon your article in the (local) newspaper. It was heartbreaking to hear about a child that has to live with the disease of Cystinosis. I envy him for having enough courage as to fight this and live his life as any other child would. I also am amazed at how many doses of medicine Jack has to take a day, but thankful that there is such a medicine. We decided as a family to donate our earnings to your family (CRN). It is clear that it will be much more useful in your hands. We hope what little we could donate will help in researching a cure for this disease.*

1-21-08

*To Whom It May Concern,*

*In honor of my Bat Mitzvah I have asked to do a Mitzvah project. A Mitzvah project is when a young Jewish adult chooses to do something that will contribute to the community and help those in need. I have chosen to make a donation of \$200 to the Cystinosis Research Network in honor of Jack Greeley. I know Jack through my family's relationship with the Greeleys.*

Listen to how these people have been touched! This is from a 16 and 13 year old, respectively. Feel their words...the maturity...the compassion...the sincerity. What is the chance we would have made such a gesture ourselves 20 or 30 years ago? Who would have ever thought we could have had such an influence on others? This is part of the reason we continue to write each year. Our journey with Cystinosis has shown us how much good still exists in today's complex world. We have chosen to embrace it and we invite you to embrace life too, no matter what it has to offer.

So, with St. Patrick's Day rolling around once again and in celebration of Jack's 8<sup>th</sup> Birthday, we humbly ask for your support of the Cystinosis Research Network. We thank you and wish you and your family nothing but the best in 2008 and beyond. "Life is good indeed" and we appreciate being able to celebrate it with you.

Sincerely,

Dave "Jack's Dad" Greeley

Christy "Jack's Mom" Greeley

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As a 501(c) 3 advocacy group, your donation made payable to the Cystinosis Research Network is fully tax deductible. To be part of Jack's 8<sup>th</sup> Birthday Celebration, please send your check to:

Jack's 8<sup>th</sup> Birthday Celebration - Cystinosis Research Network - 302 Whytegate Court - Lake Forest, IL - 60045 - (866) 276-3669 - [crn@cystinosis.org](mailto:crn@cystinosis.org)



*The Greeley clan in Hawaii, November 2007. From left to right: A family picture at Kapalua overlooking the Pacific. Surf's up with Jack and Alex playing at the beach. Jack hangs on and "hangs loose" atop windy Haleakala on Maui.*