

February 20, 2004

Dear Family, Friends, and Colleagues:

Many of you know why March 17th holds a special place for our family from the letter you received from us last year. Yes, it is St. Patrick's Day, but it is also the birth date of our son, Jack David Greeley. Jack, if you do not know, suffers from a rare metabolic, genetic disease called cystinosis (SIS-TIN-OH-SIS). Last year, in recognition of Jack's 3rd birthday, we reached out to family and friends to support our cause through the Cystinosis Research Network (CRN), an advocacy group in which we are involved. To our delight and amazing surprise, we were able to raise \$18,000 for CRN, which was used for cystinosis research and family support programs.

Now, with Jack's 4th birthday approaching on March 17, 2004, we have also made the decision for a multitude of reasons to have this be our grand-scale "public coming-out party" by significantly broadening the scope of the audience for this letter. The purpose of this correspondence is to not only make you aware of cystinosis and Jack's plight, but also to seek your support and assistance in any number of ways.

Cystinosis is an extremely rare disease that affects less than an estimated 1,000 people in the U.S. A person has a 1-in-4 chance of inheriting it from his or her parents when they both carry the gene for this disease - one has a better chance of winning the lottery than getting cystinosis. It has the potential to ravage every major organ system in the body - muscular, skeletal, neurological, gastrointestinal, and cardiovascular, among others. It is an intra-cellular disease in which an amino acid called cystine is not properly metabolized. Cystine crystals accumulate throughout the body, particularly in the kidneys, eyes, liver, muscles, pancreas, brain and white blood cells. Without specific treatment, children develop end stage renal failure at about nine years of age. Cystinosis patients routinely need to receive a kidney transplant; fortunately, their new kidney will not be affected by the disease. Cystine accumulation can also cause severe complications in other organs of the body. The complications include muscle wasting, difficulty swallowing, diabetes, blindness, and hypothyroidism. In essence, cystine accumulates in each and every cell of the body, creating a head-to-toe hazard.

The "lucky" victims are usually diagnosed during the first year of life. Early diagnosis is critical since there is no cure and it is not a problem that one outgrows. Thirty years ago, if a child were diagnosed with cystinosis, a feat by itself given its rarity, a doctor would essentially tell the kid's parents to take their son or daughter home and to love them for 7-8 years because that was the expected life span. Kidney failure, muscle wasting, digestive malfunction, malnourishment, and failure to thrive were but a few of the critical health repercussions that eventually led to death.

Now, however, despite the stark reality, that does not need to be the case. With some advanced treatments and emerging research, it is our belief that kids of Jack's era with cystinosis could be the first to not only live well into adulthood, but also have a meaningful and productive existence. To see this possibility through, we have begun our battle against cystinosis by serving on the Board of Directors of the Cystinosis Research Network, an all-volunteer group of parents whose kids have cystinosis. The CRN is a nationally recognized 501(c) (3) organization whose mission is to support and encourage research to find improved treatments and a cure for cystinosis, to increase public awareness of cystinosis, and to provide information and emotional support to children, adults, and families affected by cystinosis.

As a quick recap of our plight, Jack was first diagnosed in the early spring of 2001. After two hospital stays, countless trips to the doctors (i.e. - pediatrician and pediatric specialists in genetics, gastroenterology, nephrology, and ophthalmology), numerous tests (i.e. - biopsies, x-rays, cat scans, endoscopies, blood tests, upper GI's, and some surgical procedures) and a few cystinosis conferences, we were very fortunate to stabilize Jack's health within 18-24 months.

Now, almost three years later, we are lucky that Jack is perhaps one of the healthiest kids with cystinosis, but he still faces daily challenges. For example, Jack has a G-tube implanted in his stomach that sticks through his skin, essentially creating a faucet that we can attach a hose to that allows us to give him nourishment and medicine. Plus, he takes five medicines daily on a highly regimented every-six-hour routine...rain or shine, awake or asleep...which by comparison is much less than most. In the near term, he will also have to take special eye drops every hour that he is awake to battle cystine crystals that invade his corneas and threaten his eyesight. Jack faces a constant need to stay hydrated and goes to the bathroom frequently, all of which is a balance of liquids-in versus liquids-out. Although almost four, Jack must still wear diapers at night. Fortunately, he now only sees his doctors on a quarterly basis for his blood, urine and other body chemistry tests. Jack also takes regular speech and physical therapy that will hopefully catch him up to his age group both verbally and physically. Recently, he was fitted with a brace that he must wear at night while he sleeps to help straighten his right foot. Looking at his development, it is fair to say that he lost at least a year of his life given how sick he was in 2001.

All of that hardship aside, Jack is like most other four year olds where games, stories, videos, wrestling, and fighting with his sister play key parts in his life. Jack is truly "all boy" and his determination is profound, which should serve him well with life-long challenges in front of him, whether it is school and social development, bathroom training issues, unrelenting medical routines, or kidney transplantation. For more details on our saga, including a copy of our letter from last year, and to learn more about cystinosis, please visit www.cystinosis.org, the website of the CRN.

Speaking of last year, through the amazing giving of family and friends in response to the aforementioned letter writing campaign, we generated over \$18,000 for CRN. People were wonderfully generous whether they made personal donations, spread our cause to people within their own network, or conducted small fundraisers of their own. That kindness was heart-warming and reminded us that, despite the negative world we live in, goodness does prevail.

Here's where this letter gets tough to write. What does it mean to open up your life to many and let them know your most intimate and personal information? We have asked ourselves that as we pondered other questions. Why should we bother people with our problems when so many others have issues of their own? Do we risk coming across as selfish, presumptuous, or self-promoting? Are there any personal versus professional conflicts of interest? What is the rest of God's plan for us? We are not sure of those answers nor have we come to philosophical grips with all of that, but here is what we do know: Jack is our son, we love him, we have a moral obligation to help him, and we would almost do anything to do so. We hope no parent could disagree. Plus, if we do not speak up, how will anyone know? Pride is one thing, but in the end it does not matter; only Jack's well-being does. Last year we cracked the door open and this year we need to push it wide open and set our sights on the future and knocking down doors (or walls or anything else that stands in our way of helping Jack).

There are no magic formulas, but here is where you could help. When considering the charities and organizations that you support, please consider the Cystinosis Research Network. More specifically, we would respectfully ask you to please consider making a donation to the Cystinosis Research Network in the honor of Jack and his 4th birthday. Any amount that would work for you would be most appreciated. Like last year, we would urge you to send your donation directly to us to make a group donation in honor of Jack to the CRN. Certainly you could alternatively send a donation directly to the CRN. It would be our goal to exceed last year's highly respectable mark of \$18,000.

We understand with so many causes, sources, and considerations coming at you each and every day that a donation to the CRN might not make sense, so please do not feel that you "have to" support it. By simply reading this, we think we have made progress and thank you for taking the time to become more aware of cystinosis, CRN, and our son, Jack. With other committed

families across America , there are much larger goals for CRN on the horizon. Assistance from many people and organizations will be needed to help realize that vision, so please also consider how you might help this cause in the future, on top of anything you may be able to do now.

To date, we have considered hosting a charity wine auction and/or golf tournament. We have also formed relationships with prospective strategic partners in the March of Dimes and Goldman Philanthropic Partnerships. With our network of family, friends and business colleagues, we know we could be successful. Please think about how you or your organization might be willing to help the CRN. The possibilities include donations, but go beyond that. For example, could you: Volunteer for a fundraiser? Host a fundraiser? Deliver support via your corporate foundation? Make in-kind donations for a fundraiser? Generate publicity for cystinosis? Volunteer to work on a CRN committee? Form a strategic alliance between CRN and another charitable group? Create governmental awareness of cystinosis and other rare diseases? This is just a partial list of possible ways you could help.

As we battle cystinosis, each day, we try to maintain perspective in our lives. The days of “Why us and why Jack?” are behind us, as we now focus on more positive matters. How fortunate are we that Jack’s diagnosis came early? How fortunate are we that Jack has more than a fighting chance? How fortunate are we to be in Chicago with some of the world’s best healthcare? How fortunate are we that Alex, Jack’s 7-year-old sister, does not have cystinosis? How fortunate are we that dedicated doctors and scientists are researching cystinosis and other similar rare diseases at renowned institutions such as the NIH, Tulane, and UCSD when so many resources are committed to high-profile and profitable diseases, even though the number of rare diseases combined would total to create the most prevalent illness in America? How fortunate are we that we had a network of family and friends that could personally donate \$18,000 last year? How fortunate are we to have a network of family, friends, and business associates that are generally very blessed and privileged and in a position to consider supporting us and the CRN?

So, in the spirit of St. Patrick’s Day and in celebration of Jack’s 4th birthday, we ask you to raise your glass – whether it is full or, in a worst case, half-full – and toast your blessings and reach out to those who are less fortunate. From the bottom of our hearts, both now and in the future, we would appreciate your support of Jack and others who suffer from cystinosis.

Sincerely,

Dave “Jack’s Dad” Greeley & Christy “Jack’s Mom” Greeley
