

March 12, 2009

Dear Family, Friends, and Colleagues:

One of the beauties of sports is that they act as metaphors for life. For our son Jack, his first experience with fast pitch baseball last summer was no exception. As a third grader facing a menacing, flame throwing fourth grader, Jack did not get out of the way of a pitch and got plunked in the chest, leaving a healthy welt. Jack was displeased to say the least, plus his remaining season was effectively over, since he tried to hit each pitch standing about three feet away from home plate.

Jack had an important lesson reinforced that day, literally; when life knocks you down, you need to get back up, dust yourself off, and take another swing. How will he respond this season? It is tough to say, but “getting back up” is something that Jack has done quite a bit of over the past eight years when, just after his first birthday, March 17, 2001, he was diagnosed with Cystinosis (www.cystinosis.org), a chronic, life threatening metabolic genetic disease. So, while a pro ball career is not in Jack’s future, the good news is that Jack does have a promising future, which was not always necessarily the case.

Over the past six years around St. Patrick’s Day, in celebration of good cheer and Jack’s birthday, we have contacted our “network” through an old fashioned letter writing effort...no FaceBook, no LinkedIn. The letter writing started as a simple task; to raise funds for the Cystinosis Research Network (CRN), an all-volunteer, 501(c)3 charitable organization committed to improving the lives of those with Cystinosis. As time passed, it became clear that sharing our story was about much more than raising funds. We knew to help Jack, we simply had to tell our story; the more people who knew, the more likely Jack and others with Cystinosis would be helped.

Now, as Jack’s 9th birthday approaches this St. Patrick’s Day, March 17, 2009, we know that Cystinosis has been our calling card to share our experiences, our growth, our wisdom, and our perspective with those whose paths we have crossed. This has provided a collective set of rewards and good fortune that is hard to describe. Retracing, briefly, our odyssey might help:

- There is no cure for Cystinosis. It is an inherited disease that he will not outgrow. Improved treatments, and ultimately a cure, are paramount.
- Approximately 500 people in the U.S. have it. There might be another 1,000 worldwide.
- Jack’s early diagnosis and responsiveness to treatments have helped him largely avoid the significant health challenges that Cystinosis poses, like muscle wasting, diabetes, blindness, reduced pulmonary capacity, hypothyroidism, and neurological damage. There is a cascading effect that potentially harms every bodily system.
- Cystagon is Jack’s miracle drug. Jack’s specific problem is that his body cannot deplete an amino acid called cystine from his cells. Cystagon allows this to happen, preventing cystine crystal formation in every cell of his body.
- Jack has a 24/7/365 medical routine. Every six hours he takes 6-12 pills. In his short nine years, he has taken roughly 70,000 pills or injections into his g-tube, which was implanted through his stomach wall when he was 2 years old.
- When Jack was 12 – 30 months old, he was hospitalized twice, did not eat solid food, and vomited 10-15 times per day. His feeding tube absolutely saved his life. As his health improved, the tube was removed when he was 6 years old.
- Jack is mainstreamed in all his activities. An incredible slew of professionals have continued to make it possible - pediatrician, gastroenterologist, geneticist, nephrologist, ophthalmologist, social worker, speech therapist, physical therapist, and occupational therapist.
- Dave and Christy have served on the CRN Board, with Christy taking the leading role for the group presently as its Executive Director and President. CRN headquarters continues to be run out of our home.

In 2008, Jack participated in the third phase of a neurological study at UC-San Diego. We can confirm it via MRI; Jack does indeed have a brain, but one could think otherwise if you tried to get him away from his DS or Play Station video games. ☺ This past year, Jack also started to take eye drops, an oral variation of Cystagon every two hours. This clears his corneas of crystals that have been formed from cystine build-up. Yes, all of this means more maintenance and more health care, but that has become the easy part because it has become routine for us and Jack...our own version of normal.

Now in third grade, Jack has finally realized that his normal is different than others. The newest, most magnified challenge is social development for Jack. For example, Jack has always been physically slow, but he has not really been aware of the difference from others, nor has he cared. Now, being slow is not the social hindrance; rather, it is the label of being slow. With unsupervised playground time, teasing and being called “slow” and worse is inevitable, even kids intentionally running away from him because he is not as fast as the rest. Jack has had to endure worse. His main medicine, for instance, sometimes leaves a slight body odor. So, imagine being on the bus and being called “stinky” and other derivatives thereof. As a result, more than once or twice this school year, Jack has cried himself to sleep. Let’s face it; feeling alone or picked on will happen again in his life; probably a lot more in Jack’s case. Just like the kid who was drilled

by the fastball, Jack will also need to learn to overcome this. It is not fair nor fun, but it his reality, his plight. For Jack and our family, this fighting is not new; instead of doing so at Rush or Children's Hospital or the doctor's office, it is now just everyday life.

Looking ahead in 2009, Jack has been granted a wish from Make-A-Wish, so our family will be heading to Orlando for spring break so that Jack can be a behind-the-scenes helper at Sea World for a day. We also have a CRN Family and Medical Conference set for Atlanta this summer. This biennial event promises to be the best to date with families and doctors from across the country and world coming together for one common cause – to battle Cystinosis. Also this year, planning is underway for a 2010 international nephrology conference that will be held in New York City. This is the leading event for hundreds of nephrologists around the globe; fortuitously for CRN, a featured disease at their medical summit will be Cystinosis. Such reach and relevance has potential breakthrough for our relatively small community. Plus, this year will be interesting when baseball season opens up. How will Jack do in dusting himself off both mentally and emotionally? For some reason, one athletic feat that Jack was pretty decent at was hitting a baseball. The bat on ball contact came relatively easy for him, but who knows what fast pitch and the threat of another hit by pitch will offer? It will present Jack with both a challenge and opportunity. Clearly, it will be his chance to wipe the dust off from last season and give it another try.

Practically, our letters have been about fundraising (approximately \$125,000 total in our fist six installments). Realistically, our letters have grown and evolved to share hope and optimism. That has become our message. Jack can and will continue to wipe himself off when he gets knocked down, literally or figuratively. In many ways, Jack is an inspiration and he will continue to be for those that know him. He has blessed us beyond compare and has given us a chance to share these wonderful gifts. Our gratitude to all for their support and listening can never be properly conveyed.

So, by the grace of God, another year has passed and it is time to put 2008 far out of view. Looking beyond the economic doom and gloom, the future is bright and with St. Patrick's Day upon us once again, we humbly ask for your blessings of Jack on his 9th birthday and those others who might benefit from good tidings. Hopefully your current financial situation will allow you to consider support of the Cystinosis Research Network. We thank you and wish you and your family nothing but the best. Cheers!

Sincerely,

Dave "Jack's Dad" Greeley

Christy "Jack's Mom" Greeley

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 9th Birthday Celebration, please send your check to:

Jack's 9th Birthday Celebration - Cystinosis Research Network - 302 Whytegate Court - Lake Forest, IL - 60045 -
(866) 276-3669 – www.cystinosis.org



**Jack participates in a research study
at UCSD in May 2008**



The Greeleys, Christmas Eve 2008