



CONQUERING CYSTINOSIS By Christie Greeley

Jack Greeley is my hero. And my husband Dave's. And my daughter Alex's. Really, it's hard to get to know Jack and not understand why.

As many in Lincolnshire know, my son Jack was diagnosed with Cystinosis in the spring of 2001, only a few months after our family moved to this wonderful community. My daughter Alex was 4 then (now a sophomore at the Savannah College of Art and Design) and Jack (now 16 and a Junior at Stevenson) was 14 months old. Our lives would never be the same, of course in so many frightening, gut wrenching ways, but surprisingly in so many more extraordinarily positive and life affirming ones.

Cystinosis is a rare metabolic, genetic disease (500 cases in the U.S., 2,000 worldwide) in which the amino acid cystine fails to leave the cells of the body, instead forming crystals which build up in every cell and have the potential to impact all organ systems. This buildup can lead to kidney failure, muscle wasting, diabetes, blindness, pulmonary deficiency, hypothyroidism, orthopedic issues, and neurological damage. It is an incredibly tangled and complicat-

ed disease with largely symptomatic treatments, no cure, and lots of health by-products.

Since Jack was diagnosed at 14 months of age his everyday existence has included hundreds of appointments across every pediatric subspecialty, profuse vomiting, heavy urination, muscle weakness, dehydration, imbalanced body chemistry, mobility issues, failure to grow, hundreds and hundreds of visits to hospitals across America, a slew of procedures including CAT scan, X-ray, NG tube, G tube, leg braces, blood draws, slit lamp tests, DEXA scan, echocardiogram, swallow tests, and pulmonary function tests, four surgeries with a fifth upcoming next summer and a regimen of 13 current medications which has totaled nearly 200,000 pills swallowed plus over 1,000 shots over the years.

I have served on the board of the patient advocacy organization for Jack's disease, The Cystinosis Research Network (CRN), since soon after his diagnosis, serving as Executive Director, President, VP of Research, and chairing every family conference since 2003. Our

calling as a family was to move treatment and support for this disease forward to not only help our son, but the entire community. To that end, we have sent a fundraising letter to friends and family each year to celebrate Jack's St. Patrick's Day birthday to raise funds for CRN to support these efforts. The 14

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letters to date have raised approximately \$250,000 and led to a variety of other community fundraisers such as Family Fun Days at Tamarak Day Camp and Prairie House and The Village Club of Lincolnshire's adoption of CRN as their charities. What an incredible amount of support we have felt from this community, how blessed were we to move here just months before his diagnosis.

Following are some of my favorite excerpts from these letters, which may give you some idea of why Dave, Alex and I are in awe of Jack every day.

2016–Jack’s 16th birthday

Jack continues to amaze all that know him with his can-do spirit, positive mental attitude, and heart-warming smile. His days are busy and his effort starts from his heart, which has proved to be impenetrable from Cystinosis. At school, it takes more from Jack to simply walk to class, carry his backpack, or hold a pencil and write for an hour. Yet, he is unrelenting in all that he does. He has achieved High Honor Roll at one of America’s top high schools. With his extra-curricular activities from IM golf to table tennis team to archery club to student manager for both the sophomore and Varsity basketball teams, he keeps very active. Like academics, it requires more effort from Jack – traversing hills, bunkers, and greens on the links, carrying gear from the locker room, walking to the top of the bleachers to film a game, pulling back the bow and holding it steady, or moving side to side with paddle at the ready. No matter the challenge or obstacles at hand, being “one of the boys” is Jack’s reward with all his activities.

We have learned that people generally put energy into a room or they take it out of it...take your pick, but it is usually one or the other. With Jack, he puts life into the room, not with a dynamic, big personality or an imposing, charming physical presence. Jack simply has an unmatched attitude and a wonderful way he lives life. He finds joy, love, and happiness in everything he does. That is Jack’s secret – he gets more out of life, because he has to put more into life. In the crazed world of today, Jack leaves us all with a gift. He keeps life balanced and in perspective allowing



those who know him to find their own middle ground. He gives more and gets more and personifies what good is. He sets an example and an approach from which we can all learn. From that, we all benefit by getting to know Jack more.

2011–Jack’s 11th birthday– Go Cubs Go!

One of the beauties of sport is that it acts as a powerful metaphor for life... you win, you lose, you have ups and you have downs. Jim McKay, one of sports all-time great broadcasters popularized a phrase that will live forever from its humble beginnings as the opening to ABC’s Wide World of Sports: “The thrill of victory and the agony of defeat.” While McKay was referencing world-class athletes, Olympians and the like, those words might apply to any level of sport...or life...including (and perhaps especially) a 9-10 year old little league baseball team.

Last baseball season, Jack played on the Cubs in the local rec league. There was plenty of “thrill” and a fair dose of “agony” along the way. En route to finishing the regular season with a not-so-stellar 3-7 record, the Cubs were stuck in a dog fight with another sub-par team. Heading into the top of the final inning, the home Cubs held a 3-1 lead when they quickly allowed their opponent to score two runs to tie the game. As Dave headed out to coach 3rd base, he knew Jack was second to bat in the bottom of the sixth. He said a prayer: “Lord, PLEASE be there for the kid...help him to build some confidence...give him a moment.” Jack’s teammate batting first hit a routine ground ball, which in this league could easily result in a runner on base. A fielder scooped it up nicely, but overthrew first base...lead-off batter went to second and up came Jack. The pitcher threw a wild one, moving the runner to 3rd base. No outs, winning run on third, and Jack is at the plate!

The drama built as the manager huddled up the entire infield telling them that they had to throw to the catcher to get the runner out if Jack hit the ball into play. There was actually tension. A few more pitches were thrown and a foul ball, leading to a full count. Jack, who is actually a pretty decent contact hitter, connected with the next pitch, hitting it solidly toward right field. Mind you, it was not Ruthian or a scene out of “The Natural,” but it was a solid shot... now would it stay fair or would the outfielder catch it? Dave knew his duty... the runner needed to tag up...no matter what!!! Guess what? The ball was hit well and went past the right fielder’s out stretched arm. While the kid on 3rd advanced home, Jack got to first base, turned around, and with the biggest smile any 10 year old had ever showed, yelled, “YES!,” raising his arms in Rocky Balboa triumph. Cubs win! The 3rd base dugout cleared and the team ran to Jack in celebration. A game winner for Jack!

It was pretty simple. That was a moment of pure karma; not only for Jack, but also for the Cubs. The team rode that karma wave into the playoffs and totally dominated. The Cubs scored 51 runs in three games and took the championship game 23-3. Jack contributed in every game as did all the boys in carrying out the coaches’ simple game plan – have fun and swing the bats! In some small way, that whole baseball season showed the “thrill of victory and the agony of defeat.” Certainly, the boys learned some lessons last spring; hopefully the parents did too.

We hope that a common thread from year to year with our letters is that Jack is one of many special beacons of light in the world that remind us all that life is never worse than half-full...in victory or defeat.