

Surviving Cystinosis...one year later!

Dear Friends and Family,

September 2007 marked Kacy's first anniversary living with Cystinosis. It has been a year that has brought much change into our lives. It is a life run by the clock and controlled by medicine, but Kacy's personality and attitude have made it an easier transition than thought possible. In the last 12 months, thanks to the wonders of modern medicine and a very medically compliant little girl, Kacy's kidney function is good, her electrolyte levels are stable, she has grown 4.5 inches and gained 10 pounds. She feels better than ever.

In July Jen attended the Cystinosis Research Network Family Conference in San Antonio, Texas. It was an incredibly sobering and yet energizing experience. Jen learned, among many things, that having a child who lives with a rare disease has its medical advantages and disadvantages. That you can be both emotionally uplifted and emotionally drained at the same time. That there is a very small community of people who really understand what it means to raise a child with Cystinosis and that there is comfort in numbers, however small those numbers may be. It is not a disease that receives a lot of exposure and funding, so any amount raised makes a very large impact on a very small number of people. That the people affected with Cystinosis are incredibly strong and resilient. That the doctors and researchers are few in numbers but rich in heart and dedication.

As with any disease a cure is always the ultimate hope. We are not at that point yet, but the research possibilities are amazing. The Cystinosis Research Network is currently funding 8 studies. One of the most exciting involves the creation of an odorless, tasteless pro-drug form of cysteamine. This is the nasty medication that all Cystinosis patients take every 6 hours round the clock to keep Cystine levels in a normal range. The hope is that the medication will also eventually be altered to a state where patients will be able to take it every 12 hours instead of 6. That would be remarkable.

We have learned this year that one little person can change the way you live. We would do anything we could to take Cystinosis away from Kacy, but that isn't possible. All we can do is fight to make her quality of life the best it can be every single day. She has been a blessing in so many ways. We all have our own journeys. Some are easier than others. We believe Kacy has Cystinosis for a reason. Perhaps to make us all look a little differently at the way we live. Perhaps to remind us that living in the present is the only way to live...yesterday was a good day, today is moving along nicely, tomorrow is anyone's guess. Live in the moment...it's your only guarantee.

Research takes time and unfortunately a great deal of money. Since October, 2006, with your help and some amazing fundraisers, we have raised over \$70,000 for the Cystinosis Research Network. It is our hope that we can continue that trend. It is the only way we can be assured that continued progress will be made to finding a cure. On that note, if you find yourself searching for a charitable cause this giving season, we hope you will consider Kacy and the Cystinosis Research Network as an option. I promise, she's worth it. She was born to do great things.

As Always, Many Thanks and Much Love,

The Wyman Family