

SURVIVING CYSTINOSIS...FOUR YEARS LATER

October, 2010

Learning to ride a bike is much like living your life: It's all about balance and support. This is also a fitting metaphor for Kacy's battle with Cystinosis. First there are fears about even trying to move forward, about lifting your feet off the ground on an unknown journey, hoping you don't end up falling over. Well...as we all know, you do fall over, sometimes over and over again. But at some point you do figure out how to balance your body with the bike and off you go, never looking back. It takes drive and determination, patience and perseverance, hard work and encouragement, all of which Kacy has both in her efforts at learning to ride a two-wheeler and in life. We have spent the last four years balancing doctor visits and an around-the-clock medication schedule, with school and soccer and swimming and play dates. I must say with much support and encouragement we have found our balance...for now.

This spring Kacy moved from all liquid medications to 37 pills taken orally each day. She still drinks upwards of 5-7 liters of water a day, receives a growth hormone shot nightly, follows a rigid every-6-hour dosing schedule, and wakes at 2 AM to take her cystagon. We still travel to Grand Rapids for her Pediatric Nephrologist, to Ann Arbor for her Geneticist and to Bethesda, Maryland for her Ophthalmologist. Her kidney function is stable, at present, but we anticipate a kidney transplant within the next couple years. She just hit 4 feet tall and for the first time since she was a year old, Kacy is back on the growth charts. All in all, despite everything Kacy does to maintain her "wellness", she is an energetic happy, thriving girl with a zest for life.

Kacy has had a great year. She swam her first year competitively on the Woodside Swim Team this summer and will continue swimming for BBA this fall and winter. She plays soccer for her school, begs for play dates with friends every day, and rides her two-wheeler every chance she gets. Life is an adventure for her. She is thrilled by everything it has to offer and still wakes up each morning asking, "What do we have today?"

Likewise, the future looks strong for basic research into cystinosis. Cellular models hold promise for revealing the precise cause of the tissue destruction in cystinosis. Animal models are revealing the potential benefits of stem cell transplantation. In the clinical arena, better delivery systems for oral cysteamine are being developed. Cysteamine eye drops are moving toward FDA approval. Spurred by an effective therapy, physicians across the globe are diagnosing cystinosis earlier and applying treatments more diligently. There may be potential for newborn screening for cystinosis, and for stem cell therapy. Finally, patient advocacy groups such as the Cystinosis Research Network are inspiring clinical and basic research into cystinosis and promoting improved care for affected individuals. Simply put...there is "good stuff" happening in the world of Cystinosis research.

Initially we thought our annual fundraising letter was about finding for a cure. After hearing from so many, we now realize that our annual missives are about sharing hope and courage and optimism. Kacy can and will continue to dust herself off when she falls. She will continue to find balance again and again, both literally and figuratively. In many ways, Kacy is an inspiration and will continue to be for those that know her. She has blessed us beyond compare and has given us a chance to share these wonderful gifts. We will never be able to fully convey our gratitude to all for your care and concern.

The Cystinosis Research Network has been not only a support system for our family, but also a source of knowledge, guidance and, most of all, HOPE for a better tomorrow. We will continue our fundraising efforts to give back to CRN and all it has done and continues to do for Kacy and others living with this rare and relentless disease. Thanks for considering a contribution as you are able and helping with the ride.....

With Continued Love and Gratitude,

The Wyman Family



Life is like riding a
bicycle-in order to
keep your balance;
you must keep
moving

~Albert Einstein

Yes, I would like to donate to the Cystinosis Research Network
in honor of Kacy Wyman and her HOPE for a better future.

Please accept our tax deductible donation of \$_____.

Checks made payable to:

Cystinosis Research Network
c/o The Wyman Family
6375 West Surrey Road
Bloomfield Hills, MI 48301

For more information or to make an online donation please visit
www.cystinosis.org or www.kacywyman.com

Life is an OPPORTUNITY...Benefit from it.

Life is BEAUTY...Admire it. Life is a DREAM...Realize it.

Life is a CHALLENGE...Meet it. Life is a DUTY...Complete it.

Life is a GAME...Play it. Life is a PROMISE...Fulfill it.

Life is SORROW...Overcome it. Life is a SONG...Sing it.

Life is a STRUGGLE...Accept it. Life is a TRAGEDY...Confront it.

Life is an ADVENTURE...Dare it. Life is Luck...Make it.

Life is LIFE...LIVE IT.

~Mother Teresa