

Jenna &
Patrick's

STORY OF

H O P E



DEAR FAMILY AND FRIENDS Four years ago we found out that our twins, Patrick and Jenna, have a terminal illness called Cystinosis. This is their story. We crave normalcy for our family, so this intimate look at their life is difficult to share; yet we realize the only way to achieve normalcy is to create awareness about cystinosis and do our part to find a cure. Thank you for knowing their story, and for being a big, beautiful part of it!

Teresa & Kevin

Love, Teresa and Kevin Partington
August 24, 2009






At 1:30 am, Jenna and Patrick
are jostled from their sleep

medicine


to take a drug called
Cystagon, which must
be taken every 6 hours,
every day, 365 days a
year. This is the first of
19 doses of medications
taken over the course
of each day. Children
with Cystinosis have
severe metabolic
complications, thus this
routine, in the dead of
night, includes a diaper
change, a bedding
change and a clean,
dry pair of pajamas.



Fast paced and happy, this part
of the day feels “normal,”

morning

even as doses 2-8 of
required medications are
administered and the
washer is filled with the
night's bedding and the
garbage with the night's
diapers. The metabolic
complications also mean
that Jenna and Patrick
eat an unusually large
breakfast for four year-
olds: 2 eggs, 3 pieces
of sausage, a couple of
pancakes, o.j. and yogurt.
We have become superb
short order cooks!



In addition to routine pediatric visits, children with Cystinosis

testing

are under the constant care of a pediatric nephrologist (kidney specialist). Blood draws are routinely required to assure that proper medications are given to treat their kidney disease and ensure that high cystine levels are not attacking other organs in their body. Jenna and Patrick adore their doctors, though they know it means they'll be faced with an all-too-familiar and frightening needle.




Playtime is the
cornerstone of childhood,

playing

and like any parent,
we savor every giddy,
carefree moment;
yet it is often bittersweet,
as we consider what
the future holds for
our children.

HOPE is the only thing
that enables us to
focus fully on the
happy moments right
in front of us.
Kevin says: "it's a
marathon, not a
sprint," yet the
clock is ticking.

A young child is sleeping peacefully in a bed, covered with a white blanket. The child is holding a water bottle in their right hand. Several other water bottles are scattered around the child on the bed. The entire image has a blue tint.

Children with cystinosis crave
water, salt and essential nutrients

napping

that are lost as a result
of kidney disease.
Jenna and Patrick
drink two gallons of
water (each) per
day, resulting in a
multitude of trips to
the bathroom. The kids
go to sleep with 48 oz.
of water and a diaper
on, and they always
wake up soaked.
Sleep is not a simple
luxury for those living
with Cystinosis.

A photograph of two young children in a bathtub, completely covered in white soap bubbles. The image has a strong blue color cast. The child on the left is looking towards the camera with a neutral expression. The child on the right is looking upwards and to the right with a wide, joyful smile, showing their teeth. The bubbles are dense and create a soft, textured background.

They look normal, yet Cystinosis is attempting
to ravage every cell in their bodies.

bath & bed

Our kids have never experienced a full night's sleep, their thirst is insatiable and their medications make them throw up frequently. In a matter of time, Jenna and Patrick will understand Cystinosis and how it makes them different from their peers; and we pray they handle the knowledge with strength and grace.



LEMONADE 10¢

Kevin and I have been fortunate to meet researchers studying Cystinosis,

cure

and they are **SPEAKING OF A CURE!** Current studies on mouse models show that Cystinosis and the organ damage it causes may be reversed. Your generous contributions to Jenna & Patrick's Foundation of Hope will be matched up to \$250,000 this year by an anonymous donor, and will continue to fund Cystinosis research. We thank you for your support. "It takes a village," and we are happy to have you in ours!

As of September 2, 2009, Jenna and Patrick's Foundation of Hope is grateful for the support from the following individuals and companies:
 Please visit www.jennaandpatrick.org to preview one-of-a-kind exquisite donations for our Live Auction on October 16.

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