

6/22/2010

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Dear Family and Friends,

Our Sarah is five years old today. This is truly a miracle. Sarah has Cystinosis so every birthday is a miracle. In celebration of this day Jeff and I want to share Sarah's story and express our heartfelt gratitude to the Cystinosis Research Network. The CRN continues to provide support and education we need to care for Sarah. They are leading the way to a cure.

Sarah was diagnosed with Cystinosis and the accompanying Fanconi Syndrome at 15 months of age. We have been battling this devastating disease every second since. Cystinosis is a very rare genetic metabolic disease affecting only 300 children in the US and about 2000 in the world. In Cystinosis the amino acid cystine cannot pass through the cells of Sarah's body, thus accumulating and forming crystals that slowly destroy the organs in her body. Her kidneys and corneas are already affected. The disease will slowly progress to her brain, heart, and muscles. Sarah will soon need a kidney transplant. Even after the transplant, she will continue to fight this disease until a cure is found. Sarah's life expectancy is unknown. With the help of the cystine depleting drug Cystagon we have hope. However, most children with Cystinosis succumb to the disease or its complications by age 40.

In some ways, Sarah is a normal five year old girl. She loves princesses and dressing up, stickers and painting. She likes to follow her sisters and irritate her brother. She loves hair bows and flip flops and having her toes painted. She loves water and going to the beach. Sarah's smile is breathtaking. To know Sarah is to know love in its simplest, purest form. She is beautiful in every way.

On the other hand, Sarah weighs 29 pounds. She has a feeding tube and takes a medicine cocktail of six drugs every six hours around the clock. She gets drops in her eyes 12-14 times a day to reduce the corneal crystals. She wears sunglasses outside because bright lights hurt. She can not play outside when the weather is hot because she does not sweat. She vomits frequently and does not eat enough to sustain her body so she gets formula feedings through the tube directly into her stomach. She gets an injection of growth hormone every evening. She has never slept through the night. She needs medicine at 2am and must use the bathroom about five times a night.

Dedicated to a Cure.
Committed to our Community



Cystinosis
Research Network 

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Most children visit a pediatrician occasionally. Sarah visits a pediatrician, a nephrologist, an endocrinologist, and an ophthalmologist regularly. She has x-rays, ultrasounds, and monthly blood work. We travel to the National Institute of Health yearly to try to control the corneal crystals and prevent eye lesions and blindness. We are blessed to have a dream team of medical professionals keeping our daughter alive.

None of this will change for Sarah until a cure is found. The Cystinosis Research Network is very busy raising private funds for research. Federal funding is as rare as Cystinosis itself. Our gratitude to this organization can not be put into words. The sharing of information and experience has been invaluable in our battle for our daughter. We are united with the CRN in our hope for a cure.

Jeff and I are asking for your help. Sarah and children like her are desperately depending on research to ultimately cure this horrific disease. Please help us give back to an organization that has provided a beacon of hope to our family for three and a half years. Together we can keep the hope alive.

To celebrate the miracle of Sarah's fifth birthday Jeff and I ask that you please consider making a tax deductible donation to the Cystinosis Research Network. Please help fund the research needed to cure Sarah.

Please keep Sarah and all Cystinosis sufferers in your prayers. With your help we can be a little closer to our greatest wish.... a cure.

With much love and gratitude,

Jeff and Katie Larimore



Please accept my tax deductible donation in honor of Sarah Larimore's fifth birthday.

Cystinosis Research Network
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