

## On the brink of starting Kindergarten...

### Clare Paulson's Story



*“We have learned so much about this disease by working directly with Dr. Milliner and everyone at the Mayo Hyperoxaluria Center.”*

— Sara Paulson

In July 2006 when Clare Paulson was ten months old she wasn't feeling well and was running a high temperature. What appeared to be a normal childhood illness of strep throat, turned into a trip to the ER, after her temperature reached 106 degrees and vomiting. At the ER they ran a few initial tests, such as a urine sample to determine the cause of the high fever and admitted her for further evaluation.

The following morning at the hospital she had an ultrasound which uncovered a severe kidney infection and a kidney stone the size of 1 cm in her right kidney. She was transferred from their local hospital to Children's Hospital in Minneapolis that afternoon, to work with a pediatric urologist. The next day, Clare had surgery for a stint tube to be placed between the kidney and bladder, to keep the ureter open and allow the infection to clear up. After three days at the hospital Clare was able to return home, but unclear and uncertain

about what she was facing and why she had a very large kidney stone.

Over the next seven months Clare had multiple surgeries and other tests to work towards a diagnosis. It was after the first stone removal surgery and analysis of it, that the doctors started to make connections with possible diseases that could have caused this stone. Unfortunately during those months, additional stones were formed requiring more tests such as kidney scans, timed urine collections and blood work. These results in combination with the stone analysis started to make it very clear that Clare almost certainly had a form of Primary Hyperoxaluria. Her doctors started her on a course of a number of medications based on this information, including an increase in her fluid intake.

To assist in officially diagnosing Clare, she was enrolled in a study at Mayo Clinic Hyperoxaluria Center, where genetic test-

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ing was completed. In February 2007, it was confirmed that Clare had PH Type II. Eric and Sara, Clare's parents, continued to work with a number of doctors on monitoring her stone development, including ultrasounds and urine collections every three months. Stone development continued, but luckily not at a very fast pace. She had two stones that were monitored for a number of months and her last stone removal surgery was in November of 2008.

Her parents discovered early on in Clare's journey, that her doctors were consulting with world renowned Dr. Dawn Milliner, at Mayo's Hyperoxaluria Center. They decided to focus Clare's care and treatment of PH II, with one doctor and began to go to Dr. Milliner directly in 2009. Sara

said "we have learned so much about this disease by working directly with Dr. Milliner and everyone at the Mayo Hyperoxaluria Center. Dr. Milliner also helped us get our son Colton tested for this disease, though a 24 hour urine collection. His results did not show indications of PH II."

In 2010, Eric and Sara, wanting to find a better way to treat the disease, enrolled Clare in a drug study for a medication that may have benefits to patients with PH. The six month trial included a medication to be given twice a day, in addition to the three medications she was already taking. The study included specific urine and stool collection times, to determine if the medication was having an impact on her oxalate levels. They have not yet

received Clare's individual study results, but are anxiously waiting on them to arrive.

Clare is currently five years old and on the brink of starting Kindergarten this fall. She has been stone free since November 2008, when she had her last stone removal surgery and currently has normal kidney function. She has never let anything she has had to endure, whether a test, a surgery, or a medication get in her way of living life to the fullest. Clare is her family's inspiration.