



The Oxalosis &  
Hyperoxaluria  
FOUNDATION

## The Tough Journey Gunnar's and Alex's Story



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*“We take what comes at us and deal with it the best we can. Our fingers are crossed that a cure or better treatment of some type, will be found for this disease.”*

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— Jamie Schmitt

In February 2009, then 17 month-old Gunnar Schmitt was admitted to the hospital for dehydration following a short illness. Doctors thought an X-ray of his stomach was needed to make sure it wasn't distorted from his prior week of vomiting. X-ray's showed several kidney stones in both kidneys and also hydronephrosis in his right kidney due to a blockage. In addition to adding medications to control crystal formation in his urine, Gunnar has had over 13 surgical procedures, including shock wave lithotripsy (ESWL) to remove his stones. In May 2009 his doctors moved toward a diagnosis of Hyperoxaluria Type II. After testing his blood and sending it to Mayo Clinic, his DNA test came back showing two mutations that have never been seen before or identified. Finally a liver biopsy was performed and sent to London, England for testing which confirmed what the doctors had feared, Gunnar had Primary Hyperox-

aluria Type II. Unfortunately, symptoms presented themselves for Gunnar's brother Alex and he too has now been diagnosed with PH Type II. Their two older brothers do not have the disease, but are carriers.

Gunnar finished out 2009 with a double nephrostomy due to stone blockages in both ureter tubes and a nephrostomy tube inserted through his back directly into his kidney, which allows urine to drain into bags. He spent seven months with the nephrostomy, making it hard for the one year old. In December 2009, Gunnar had reconstructive surgery to repair his ureter tube on his left side. A stone that had become lodged in his ureter tubes had grown into the tissue and was unable to be removed. They felt hopeful that the new year would bring Gunnar some relief and that his medications would begin to work, but the next year wasn't much different from 2009. Gunnar had 6 surgeries in 2010 alone for stones

and also had a PEG tube placed in which he receives nighttime fluids. They are hopeful that the placement of the PEG will allow him the intake of the amount of fluid he needs on a daily basis.

Despite Gunnar's tough journey, he is a happy and very active toddler. He enjoys running and keeping up with his older brothers. Even with tubes and bags he does not slow down. He is a tough little boy that wins the heart of everyone he meets. Jamie said, "We are a family with two PH type II children and a road that is a rapidly changing crazy one, continuing to toss and turn us every which way. We take what comes at us and deal with it the best we can. Our fingers are crossed that a cure or better treatment of some type, will be found for this disease.

Not only to help our children but to help others' as well."

The Schmitt family would like to thank Gunnar's medical team at King George Pediatrics, Children's National Medical Center in Washington D.C, and Dr. Dawn Milliner at the world renowned Mayo Clinic Hyperoxaluria Center, for taking time to listen to all of their care and concerns. Because of the fantastic care he has received from them, they are hopeful that his treatment plan will help him improve in the future.