

A Hero in Her Parents' Eyes

Leigh's Story



A retired Navy Commander, Greg Atchison and his wife Laine faced many battles in their lives, but nothing could prepare them for the battle they would face when their daughter Leigh was just a year old. Leigh had the usual symptoms of a stomach virus, but what struck them as unusual was the intensity of their little girl's cry for help. To this day, they believe that it was a virus, but what happened next was nothing short of a miracle to them.

That cry took them to the emergency room on Super Bowl Sunday, a week before her first birthday. Because of the extreme stomach pain Leigh was experiencing, x-rays were taken. However the doctor quickly reported that everything looked fine. That day, little Leigh was sent home where fortunately she did recover from the virus, but her future would soon begin to change.

Five days later with the virus already just a memory, the phone rang and a doctor from the hospital called to say, "Your daughter has many kidney stones, all you need to do is follow up in the future with your pediatrician." Greg & Laine's first thought was how was this overlooked a week ago in the emergency room? Looking back, it seemed they may have experienced two miracles: first, taking their daughter to the ER for a virus and

having the x-ray taken, and second that a radiologist re-read her films, finding the stones.

Quickly, Leigh's pediatrician, Dr. John Schneider, whom the Atchison's boast was phenomenal, referred them to a pediatric nephrologist at Children's Hospital of The Kings Daughters in Norfolk, VA. The nephrologist ordered an ultrasound that showed three large stones in each of her tiny kidneys. Greg and Laine still wondered how it was missed that night in the ER. The nephrologist suggested that Leigh stay for 3 days in the hospital so that they could conduct a 72-hour urine collection. Trying to schedule this test and other doctor's appointments began a process of cancelled appointments and delay of the procedure for the next three months. Frustrated with these delays, Greg & Laine fought for answers and finally were told a 12-hour urine collection at home would suffice.

The nephrologist reported after the collection that nothing was really found from the test and if Leigh should ever pass a stone again to contact her pediatrician. This did not seem right. Luckily for Leigh, her pediatrician had a year of specialty studies in kidney disease and questioned the nephrologist's report. He recognized that her oxalate count was

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— Greg and Laine Atchison

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through the roof. The situation was bad and prompted the nephrologist to do more investigating. With that, the devastating news came; their little girl had a rare disease, Primary Hyperoxaluria Type 1. He informed them that it was treatable, but not curable! This news brought two of the strongest people in the world to their knees.

As fate would have it for the Atchison's, they were referred to Dr. Jon Scheinman at Duke University who is a leading expert in PH. He told Greg & Laine that their daughter was very lucky, had this not been caught, Leigh would have been in kidney failure in less than a year. He gave them the HOPE that she would make it through this and be okay. Dr. Scheinman told them 2 things they will never forget: first, you need to be afraid so that as parents, you are successful in her treatment, and second, always remember that you need to be your child's expert regarding her medical care. Many times in the future this proved true. Too often, hospital staff knew nothing of the disease and continuously questioned them about the care they were giving Leigh.

By the time Leigh was 2 ½ years old, the devastating effects of PH really began. Greg said, "The next six years felt like a tornado in our lives. Leigh began to experience the cycle of ex-

cruciating pain, vomiting, IV fluids, passing out and hospitalization from passing stones. It seemed to hit her on a holiday of any kind, every 4 or 5 weeks." The tornado for Leigh fortunately came to an end when she was around 8 years old. She began to have remarkable success with Pyridoxine and of course, her never-ending intake of fluids. Leigh was left with 2 stones that eventually required at least seven painful procedures to remove. Greg and Laine remember how strong their daughter was through it all, at times seeming stronger than them - she was their hero!

Fast forward to the present and Leigh is attending her first year in college at North Carolina State University, where she continues to be a straight A student, pursuing her degree in Biomedical Engineering with hopes this will enable her to some day contribute to a cure for PH.

Leigh doesn't spend a lot of time worrying or talking about her disease. She is a typical young adult whose interests along with school include running cross country and coaching younger kids in the sport as well as a very active social life. Leigh has taken ownership of her disease, which is just a small part of who she is. She measures out her own medicines daily, always carries a water bottle, frequents

the OHF web site and writes about her disease along the way.

Her dad said, "We have never lost an appreciation for the magnitude of Leigh's disease." While he is aware she has had few symptoms the last seven years, at any moment things can dramatically change for the worse. The Atchison's are extremely grateful to Dr. Jon Scheinman for his medical support, the support of their families, in particular Greg's father, Richard Atchison, who is unfortunately no longer with them, Greg's military colleagues, Laine's co-workers at Mitsubishi Chemical and all their friends. Without their love and support it would have been even harder to get through these times. Greg would like all to know that he has HOPE that the OHF researchers will find a cure in time for his daughter.

Greg and Laine are members of the OHF Patient Advisory Board and would like to encourage all to support the Oxalosis & Hyperoxaluria Foundation, the only foundation in the world dedicated to funding research to find a cure for Primary Hyperoxaluria. They encourage all to join the OHF and learn more about this silent and life threatening disease. If you would like to reach out to the Atchison Family you may do so via OHF Talk at www.ohf.org.