

A Spirited Child's Strength Encourages his Family

Reuben's Story



“PH has changed our lives in many ways, most of all, it has taught us not to take anything for granted.”

– Debbie Doustan

Reuben Doustan is described by his family as the happiest most active little 5 year old boy in the world. He loves all sports and there isn't enough time in the day for him to play with all of his favorite rescue vehicles, ambulances, fire trucks and police cars.

When Reuben was 11 months old, a stomach virus so violent, brought the family to Children's Hospital at Montefiore Medical Center in the Bronx. Reuben was dehydrated, but his ultrasound showed something more shocking. The doctors informed Reuben's parents, Debbie and Mike that their little boy was suffering from 18 kidney stones.

Within no time, Reuben was miraculously diagnosed by Dr. Fredrick Kaskel of Montefiore with Primary Hyperoxaluria Type 1. Luckily for the Doustan family, Dr. Kaskel had consulted previously with PH

specialist, Dr. Dawn Milliner of the OHF funded, Mayo Clinic Hyperoxaluria Center and was very familiar with the disease.

Reuben spent the next 10 days in the hospital and by the time he was discharged, he had already passed 9 stones. His parents will tell you that his quick diagnosis is what saved his life. They were fortunate enough to be at a hospital where a physician was aware of such a rare disease.

At the age of 2, Reuben decided he was no longer going to take his medicine or drink the amount of fluids needed to keep his kidneys flushed. It was at that time, his parents decided to have a feeding tube surgically implanted. The feeding tube allowed Reuben to receive most of his fluids through the night while he slept. Reuben even nicknamed, his g-tube, "the special button."

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During Reuben's gastrostomy surgery the doctors also found that he had a floating appendix and mal-rotated intestines. If left undetected Reuben's blood supply would have become compromised and it could have proven to be fatal. The g-tube surgery saved his life in many ways. Debbie said, "the g-tube may sometimes be an inconvenience, but the trade-off is his life". The great news is that currently at 5 years old, Reuben is stone FREE.

Reuben is looking forward to his family vacations and when he will be a big kindergartner at Baker School. His parents try not to think about the uncertainty of the future; they take it day by day, considering each day a success!

Debbie said, "PH has changed our lives in many ways, most of all, it has taught us not to take anything for granted". The Doustan's worries are

more daily now. In addition to the g-tube fluids Reuben receives at night, they worry if he is getting enough fluids at school and when he spends time with his friends. If only a few days go by without the proper amount, they know that his kidneys may shut down.

Reuben has a great team of doctors, nurses and staff at The Children's Hospital at Montefiore Medical Center where his grandfather, Don Ashkenase works. His parents also find comfort knowing that his grandfather lends his expertise as an active OHF Board of Director, working everyday to find a cure for his grandson.

The Doustans would like to thank their family, friends, Dr. Rick Kaskell, and all at The Children's Hospital at Montefiore Medical Center. Their outstanding love and care is what gives them strength and carries them through the

"what ifs" of PH. Debbie said, "Words cannot describe how grateful we also are to the OHF for bringing awareness of PH to the medical community, and not giving up trying to find a cure. Reuben's story and others' make us realize if everyone helps the OHF just a little, the results may be a lot for their child or family member."

Debbie is a member the OHF Patient Advisory Board. She has been instrumental in the development of a PH children's coloring book that will help kids better understand their bodies, this disease and ease their worries. If you would like to reach out to Debbie you may email her at ddoustan@yahoo.com or through www.ohf.org - via OHF Talk.