

## A Spirited Child's Strength Encourages his Family

### Reuben's Story



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

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– Debbie Doustan

Reuben Doustan is described by his family as a happy, active 6 ½ year old boy. Reuben loves to play sports, ride his bike, jump off the diving board at camp and being a big brother. When Reuben was 11 months old, he became very sick and his family brought him to the 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. Rick 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, who was very familiar with the disease. Reu-

ben spent the next 10 days in the hospital and by the time he was discharged, he had already passed 9 stones.

At the age of 2, it became harder for Reuben to drink the amount of fluids necessary to keep his kidneys flushed and he struggled to take his medication. It was at that time, his parents decided that the best option for Reuben was to get a feeding tube. The G-Tube allowed Reuben to get most of his fluids through the night while he slept. Reuben even nicknamed, his G-Tube, “his special button”. During Reuben's gastrostomy surgery the doctors also found that he had a floating appendix and his intestines were malrotated. If left undetected Reuben's blood supply would have become comprised and it could have proven to be fatal. The g-tube surgery saved his life in many ways.

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Debbie said, “The G-Tube can sometimes be an inconvenience, but the tradeoff is his life”. The great news is that currently at 6 ½ years old, Reuben is stone FREE.

Reuben is looking forward to his family vacation this summer and entering the second grade 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 of fluid, they know that his kidneys may

shut down.

Reuben has a great team of doctors, nurses and staff at TheChildren’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 member of the OHF Board, working everyday to find a cure for his grandson.

The Doustans would like to thank their family, friends, Dr. Rick Kaskel and all at The Children’s Hospital at Montefiore Medical Center. Their outstanding love and care is what gives them strength and carries through the “what-ifs” of PH. Debbie said, “Words cannot describe how grateful we 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 real-

ize if everyone helps The OHF just a little, the results will be a lot for their child or family member”.

Debbie is a member of The OHF patient Advisory Board. She has been instrumental in the development of a PH children’s coloring book that helps 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](mailto:ddoustan@yahoo.com) or through [www.ohf.org](http://www.ohf.org) – via OHF Talk.