

Normal
is what you make of it



Angie and Nicole Hall

August 16, 2007... that was the date we received news that our daughter Nicole suffers from a disease called cystinosis. We had never heard of this disease, so we did not know what to expect.

In a way, it was a relief to finally get a diagnosis after over a year of doctor's appointments trying to determine why she was struggling to grow. However, with this answer, a new round of questions were being asked since the weight of this diagnosis seemed astronomical at the time – how would this change our lives and would our little girl ever get to lead a “normal” life?

It is hard to believe that we received that news just over five years ago. Nicole turned seven in October and is now in first grade. She is beginning to understand that she is different from her friends, and has started to realize that she doesn't need to be embarrassed by it.

This year she gave a presentation to her entire school about cystinosis and why she gets her nourishment through her “button” – the feeding tube that was inserted into her stomach when she was nine months old. The school has done a great job catering to her special needs by administering her midday medication, giving her eye drops, and feeding her during the day. She now wheels her pole down to the cafeteria and “eats” with all of the other students at lunchtime, which makes her enjoy school that much more. Her class recognizes that she is different from them, but they deeply care for her and surround her with love. We feel so blessed that she is in such a great environment.

Nicole receives over 17 doses of medicine each day to keep her system regulated. This requires attention to detail when planning on leaving the house for the day – we need to be sure that we bring medicine and eye drops with us in the event we are away from home when her medicine is needed (the 11:00s and 5:00s have forever been changed in our family). Nicole has encountered some “speed bumps” when her medication needs to be adjusted, however, she takes them in stride, which shows her amazing strength of character. She teaches us each day to live life for both the big AND small things, and that every issue thrown at you can be overcome.

Nicole's sister, Angie, is now 5½ and is in kindergarten at the same school. Although Angie is 17 months younger than Nicole, she has her responsibilities in helping care for her older sister. She enjoys being a part of Nicole's daily routine – whether it is helping prepare Nicole's medicine or filling up bottles for Nicole to drink during the night, she happily participates. Angie has accepted that Nicole isn't physically capable of doing everything she can do, but makes an extra effort to find activities that they can do together.

We will hold our 5th annual *Race for Nicole* event in early December. This year we hope to have four or five teams compete in the Dallas Marathon Relay. Every year, we are overwhelmed by the support we receive from family and friends. We are deeply grateful for everyone who donates their time, effort and financial support to find a cure for cystinosis. We are confident that the funds provided by supporters of *Race for Nicole* and other organizations supporting cystinosis research will lead to advancements in containing this disease, and one day a cure. It is this support that gives us hope for Nicole and the other children suffering from cystinosis.

Over the last five years, our definition of a “normal” life has been altered from what we used to think it means. But as we have adjusted to a family member with cystinosis, we have learned that we are, in fact, living a “normal” life – we may have a different routine than other families that requires additional attention, but at the end of the day, “normal” is what you make of it.

*All our love and bottomless thanks,
Aaron, Stephanie, Nicole and Angie*



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