



## Kayleigh's Story

Sandy Williamson, Parent

Being the parent of a daughter who has Down syndrome has been filled with many ups and downs. Like most parents, I wanted my daughter to have many of the same opportunities that other parents have for their daughters. Dance lessons, birthday parties, swim lessons, sleepovers, prom dates...you know, those fun things that would make her have happy memories. Those wishes never included struggles with her health. I was aware of her higher risk of developing sleep apnea and leukemia, but she always seemed so healthy along with those dance recitals or swim lessons that I never worried other than a passing thought occasionally.

By age 16, Kayleigh began to start putting on the same amount of weight that I was putting on. Then, she was diagnosed with sleep apnea. Trying to get her to use a c-pap machine would result in a battle each night when it was time to go to bed. Because of the apnea, she would fall asleep at the drop of a hat during the day. We could be driving for only 5 minutes and she would fall asleep or if she were just sitting at a desk at school, she would fall asleep.

Our biggest scare came in August 2008. Every two years, I always had a complete blood work analysis done on her. I wanted the doctors to check everything including her vitamin levels. That month, the doctor called me to tell me there were some abnormalities in her blood work. He said he did not think it was leukemia, but he could not rule it out and he wanted me to take Kayleigh for more testing.

For two days, the tears just did not seem to stop. I would watch my daughter sleeping and just could not seem to wrap my brain around the thought of a health issue. A few days later to my relief, I learned that Kayleigh did not have leukemia, but instead she had a blood platelet disorder called Idiopathic Thrombocytopenic Purpura (ITP).

This began our journey with autoimmune disorders. After two years of her platelets not going higher than 100, her hematologist at Texas Oncology tried steroids. That added a few more pounds but did not help her count.

By 2011, she was diagnosed with hypothyroidism. I was told this was common for individuals with Down syndrome and medication was started.

By 2012, Kayleigh and I both were over 200 pounds each and her sleep apnea was even worse. We joined Weight Watchers early that year. I saw the direction we both were headed with our health: my mother had had two major strokes.

## Texas Parent to Parent

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At this same time, the doctor told me Kayleigh was pre-diabetic and I had early signs of hyper-tension. After joining Weight Watchers, the pounds started disappearing from both of us and Kayleigh went from a diagnosis of hypothyroidism to hyperthyroidism. In 2014, she was diagnosed with Graves' Disease. The medication to treat the disease had one side effect – it caused the blood platelets to drop. That is when I pulled all artificial sweeteners from our diet.

I took the position that Kayleigh's diet changes would also be my diet changes. We started eating more lean meats like fish, chicken and turkey. We stopped eating and drinking any foods that contained high fructose corn syrup and I started cooking our meals at home as opposed to eating out all the time.

It was then that I started reading and listening to anything I could find on individuals with Down syndrome and their autoimmune disorders. I learned that the autoimmune gene is in the 21<sup>st</sup> chromosome. The 21<sup>st</sup> chromosome has the fewest genes at around 480, where other genes have 600 or more. However, the 21<sup>st</sup> chromosome is where the gene associated with Alzheimer's, autoimmune disorders, and leukemia is located. I began to realize just how important healthy eating, sleeping and exercise were to us in general, but it seemed magnified when it came to my daughter. I learned that she had a higher risk of developing celiac disease. She was tested and does not currently have celiac, but she does have a sensitivity to gluten--thus we are on a low gluten diet.

At the beginning of 2016, Kayleigh's platelets continued to fall to 30 and by April they had dropped to 15. The doctor decided that the only thing we could do was remove her spleen. It was at this same time that my mother was diagnosed with Alzheimer's – I then began my journey of researching the effects of this disease on individuals with Down syndrome. The risk is 90% due to the Amyloid Precursor Protein (APP) gene located in the 21<sup>st</sup> chromosome. This made my drive to keep Kayleigh on a healthy diet and exercise my number one priority.

Kayleigh wanted to participate in more races with me, so we started training for her first 8K in June just 4 weeks after her spleen had been removed. The success of her splenectomy left all of us, including her surgeon, amazed.

By August of 2016, her Graves' Disease was in full remission. She was taken off her medication and no longer had to get bloodwork every month. Her sleep apnea was no longer an issue as well.

By the first of October, she was able to swim a mile and on November the 4th, she completed her first 10-mile race (Run For The Water). After that race, I took Kayleigh to a doctor who specializes in running to help Kayleigh reach her goal – a half marathon. She continued to train for races thru Run- Lab and as of February 19th, she became the first individual with

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Down syndrome to complete the Austin Half Marathon. I continue to read medical information on the genes located in the 21st chromosome. I have learned that I have to keep myself informed not just of the effects of healthy living for Kayleigh but myself as well.

We follow more of a Mediterranean diet full of fresh fruits and vegetables along with lean meats. We have turned it into a fun time of learning new recipes and cooking together. We participate in races together and she has been named as a “true inspiration” by [www.People.com](http://www.People.com). Her finish of the Austin Half Marathon has been seen all over the world.

All the attention is nice, but what is amazing is the effect of our life style changes on our health today and what it means for our future. Through all the reading I have done about Alzheimer’s, I have learned that it is now considered type 3 diabetes. There are four major contributors: sleep, eating habits, aerobic exercising and socializing.

We still do Weight Watchers and we continue to train for more races. We are doing the Cap10K in April; Run for the Water in November and Austin Marathon has already offered her free entrance for her race next year. Run For The Water has asked if she will not only return to participate in the race this year but also be an ambassador. The idea that changes in our diet and exercise would have such a powerful impact is mind blowing.

Yes, the changes were difficult and there were many arguments over our healthy eating but it was worth it. I never want to lie in a hospital bed crying with my daughter for the pain she would have to suffer if I had not taken care of myself. I would not have been able to live with myself if my daughter was the one lying in a hospital bed because I did not to make these changes a necessity – a necessity that is now a way of life. No, we can’t prevent everything, but we can try to keep the things that are preventable from having such a devastating impact on our future.

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