

Giving the Gift of tape

Mikaela Aschoff collapsed at her first Homecoming dance, but doctors had no idea what was wrong with her. After a series of tests, she was diagnosed with a devastating disease. Now this Katy teen finds purpose and meaning giving gift boxes of love to other teens with chronic illnesses.

Here is her story...

Written by Mikaela Aschoff

October 23, 2010 was supposed to be the carefree day of my first homecoming. Prior to this date, I was a healthy teenager attending Seven Lakes High School who worked hard to make good grades. I was a driven teen with many passions and it was my plan to go to a prestigious culinary school after I graduated, and one day own my own cake and catering business. I had my goals set and my future planned – or so I thought.

At the dance, my friends and I hit the dance floor and we were having a blast. About an hour into the evening, however, I started feeling "off" and slightly dizzy. I have never had that feeling before, and I tried to push through it. Then I began having a sharp pain in my side. Before I knew it, I became instantly pale, my eyes rolled back, and I fainted right there in the center of the dance floor.

Misdiagnosed as Panic Attacks

The first hospital I visited had no idea what was wrong with me, so they said I had a panic attack. My mom disagreed, to put it nicely. She was my champion and was determined to find me help elsewhere.

My general practitioner was not sure what to do with me either, and because lab results were largely inconclusive, my ailments were mislabeled as anxiety. During this time, I had another really bad episode at home, so my mom took me to Memorial Hermann Katy Hospital. Instead of ignoring or mislabeling the issue, they decided to transfer me to the specialists at Children's Memorial Hermann Hospital in the medical center.

By this time, it seemed my body was in overdrive with symptoms. If I stood up for even a minute, I would faint. Sitting up became difficult. My legs were not working properly and I would require assistance just to walk a couple of steps. Being dizzy and nauseous became commonplace. My heart continued to race and my chest felt very tight. I had an intense pain on one side of my abdomen and I felt completely exhausted and unable to think clearly.

Experiments and Answers

The tests continued to come back normal, so the team decided to have me get up and walk to see if they could witness my reaction. As I got out of bed, I immediately became pale and my lower legs turned red. I became hot to the touch and only made it a couple of steps before collapsing. Doctors checked my vitals and noticed an extreme drop in my blood pressure and a racing heartbeat.

Because the inability to remain upright without symptoms is a hallmark symptom for a condition called Dysautonomia,

my doctor ordered a tilt table test from which I finally received my official diagnosis: Dysautonomia with subtype of Neurocardiogenic Syncope.

Dysautonomia refers to a group of complex conditions caused by a dysfunction of the autonomic nervous system. Basically, it means a person's autonomic nervous system is not functioning properly. The autonomic nervous system controls everything that your body does for you that you don't have to consciously think about (breathing, heartbeat, etc.). When your autonomic nervous system is not working properly, almost anything in your body can go wrong.

Unfortunately, there is no cure for my illness, although there is a chance I could outgrow it by my mid-twenties. There is also no exact treatment for the illness, so medications must continually be adjusted to keep up with my symptoms.

Giving the Gift of Hope

After being ill and homebound for over a year after diagnosis, and having to go through more rounds of extensive tests, I felt exhausted. I kept praying that God would bring something good out of my situation. It was then that I had the idea to bring Dysautonomia awareness to the forefront and help other teens with this disease and other

life-changing chronic illnesses; so my charity Mik's Hidden Hearts Alliance was born.

My idea was to send fellow teens gift boxes to let them know there are people who care. I also wanted to create a social outreach program to stay in contact so we could all support each other. Friends and family began donating gift cards and teen-focused gifts, and we delivered dozens of "Hope Kits" to the teens at Children's Memorial Hermann Hospital. Though my body was not well, helping others made my spirit come alive.

We have since sent hundreds of gift bags to Children's Memorial Hermann Hospital and have had Hope Kit requests from all over the country. We have met so many incredible patients along the way. Our local dysautonomia community even hosted its first annual Boo Bash event in Katy to raise awareness and funds for more hope kits.

Teens and their families who once thought they were alone with this underdiagnosed condition are grateful for Mik's Hidden Hearts Alliance. My new friends have inspired me just as much as they say I inspire them. My message to others is one of hope and serves as a reminder to focus on what YOU can do, not on what your body can't do. **KM**

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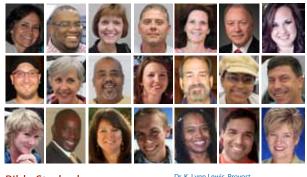






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