

An Incredible and Very Challenging Journey

Meghan's Story



My name is Meghan Baskett, and I am 20 years old. I am from the Kansas City area. I am the daughter of Mary and Mel Baskett, the two most wonderful parents in the world. I also have a terrific older brother, Michael. I have two cats at home, named Britain and Lollipop. Within the last year, our family has been through a journey, one I never imagined and as I now write about my rare and life threatening disease.

“I have a rare genetic disease called Primary Hyperoxaluria Type 1 (PH1). It does not define me, but it is one more part of me.”

– Meghan Baskett

Here's a little bit about me: After graduating from high school, I began my collegiate career at the University of Wisconsin-Milwaukee, where I am now a junior. I am double majoring in Theater Studies and Organizational Administration, pursuing a career in arts management. One of my dreams is to open my own theatre company. When I'm not in class or working, I enjoy theatre, film, sports (especially college basketball-go Kansas Jayhawks!), traveling and cooking. I love watching movies (my favorite movie is

Love Actually). I also love to eat! My favorite foods are anything Mexican, fresh fruit and brownies and ice cream.

My family loves to travel. Some of my best memories are our family vacations, which include visiting 40 states and 12 countries. I can't wait to continue to explore the world! Someday I will set foot on every continent (well, maybe not Antarctica) and attend the Olympic Games or World Cup.

Oh yes, there is one more thing I want to tell you about myself. I have a rare genetic disease called Primary Hyperoxaluria Type 1 (PH1). It does not define me, but it is one more part of me. In August of 2008, at 19 years old, I experienced my first symptoms. I began suffering from severe lower back pain, became short of breath and was very weak. My primary care physician sent me in for an MRI of my back. Everyone was in complete shock when we discovered hundreds of stones in both of my kidneys—

OHF Patient Stories

some as large as an inch in diameter! Tests confirmed that my kidney function was starting to decline significantly. Fortunately my physician, Dr. Deborah Winburn, sent me to a great urologist, Dr. Scott Montgomery who referred me to one of the best surgeons in the world, Dr. James Lingeman at Methodist Hospital in Indianapolis, Indiana.

Dr. Lingeman performed three percutaneous nephrolithotomy procedures (12 hours of surgery total). Though I felt a great deal of pain while in the hospital, I recovered from surgery very quickly. Once all of the stones were removed, my doctors began investigating the cause of my stones. Initially they thought I had hyperparathyroidism or a urinary calcium disorder, and that was not the case. Thankfully Dr. Lingeman referred me to Dr. Dawn Milliner at the OHF funded, Mayo Clinic Hyperoxaluria Center. After two long months of testing, my blood and urine samples confirmed: I have PH1.

Every single doctor I worked with has been unbelievable. Dr. Lingeman and his team were amazing. With their incredible commitment to the well-being of their patients, I have no idea how they still manage to sleep! Dr. Milliner and her team of doctors at Mayo have been a huge help to my family and me, breaking down all of the science and serving as emotional support. Even before I received the news that my treatment was effective, my family, and friends were optimistic that I would live (all things considered) a healthy and normal life. Fortunately under the protocol from Mayo Clinic, I am responsive to treatment with Vitamin B6, Potassium Citrate and lots of water every day, and my kidney function is nearly normal.

I am so impressed with everyone I talk to through OHF. It has also been great to talk to others with PH (through the OHF website). The OHF provides me with a more extended support system and keeps me connected to oth-

ers with similar experiences. My family and friends have been amazing. My family struggled as they saw me hurting, but held my hand and showed me so much love and support. I learned that without a strong support system, one cannot get through an experience like mine. Someone was clearly watching over me, because I could not have asked for better people surrounding me.

Needless to say this past year has brought many ups and downs. It has been an incredible and very challenging journey. Some days I wake up and feel like it was all a bad dream. Despite how physically, mentally and emotionally painful and draining the past ten months have been I consider myself incredibly lucky. I was able to complete the semester at college which helps me stay on track for graduation. There were moments, days and even weeks when all I wanted to do was break down and cry. I could not understand why all of this was happening or why I was chosen

An Incredible and Very Challenging Journey

Meghan's Story

“... whether a family member or friend has been diagnosed with PH, that although our journeys and stories are different, we really can make a difference by coming TOGETHER.

If we share our experiences and educate everyone about PH and the OHF, we can get closer to finding a cure!”

– Meghan Baskett

to experience it. I soon realized that I was chosen because I am strong enough to get through it. Now almost a year later, my treatment is still working, and all things considered, I am still very healthy.

Being diagnosed with PH reinforced the concept that life is truly short. Rather than stressing over the small petty things, all of us should appreciate the fact that we are here, with such amazing opportunities in front of us. I consider myself a positive person, but my experience with PH has really taught me to value each day, take chances and live my life to the fullest. It sounds cliché, but PH opened my eyes even further to the world.

I get hope from reading others' stories on OHF Talk, knowing that some patients have been healthy for years. I decided that whatever is meant to be will happen, and there is no reason for me to let this disease stop me from doing anything.

I want all to know, whether a family member or friend has been diagnosed with PH, that although our journeys and stories are different, we really can make a difference by coming TOGETHER. If we share our experiences and educate everyone about PH and the OHF, we can get closer to finding a cure!

I want everyone to remember that as terrifying and awful as PH can be, there is always hope. My mother Mary and I are both members of the newly developed OHF Patient Advisory Board. Being members allows us to help make a difference in the lives of everyone with PH. If you would like to get in touch with me, I can be reached through OHF Talk, email (mbaskett@uwm.edu), or on Facebook.