



Our Story

Hope. Always Have Hope! Anthony's Inspirational Story

By Kim Anzell

My husband Roy and I have been married for 25 years and we have four beautiful children. Our oldest daughter Sarah is 23, Rachael is 21 and our twin boys, Anthony and Doug, turned 20 on the 4th of July. The first 18 years of our married life together was a whirlwind. All of our children were doing well in school and involved in sports, music, dance, scouts, etc. Our days were filled with running children from one event to the other. Life was good, life was exciting, and our lives were moving in the direction that we had hoped for. But, everything changed the day after Thanksgiving 2006.

We hosted Thanksgiving that year and had a wonderful gathering with 18 of our family members. We had much to be thankful for and we were now focusing on Christmas. The next morning, however, Anthony began complaining that he had a headache that he couldn't seem to get rid of. Over the course of the weekend the headache continued to worsen. The following Monday, we took him to the doctor. He was diagnosed with a migraine and we were very "politely" told that there really wasn't anything that could be done. Anthony just needed to wait it out. By the end of the week the headache worsened. Anthony was having trouble keeping food down and the pain was so intense he just wanted to lie in bed in a dark room. Concerned, we went to the emergency room. Again, we were told that he was suffering from migraines. The hospital administered IV pain killers which did not fully take away the pain, but we were told to go home and continue to "wait it out".

The following Monday we went back to the doctor's office. Same diagnosis, but this time pain killers were prescribed. They did not help. Anthony was now having difficulty walking, seeing, and was losing weight. By Wednesday we decided to go back to the emergency room. We sat there with our son, who was now emaciated, gray in color and in horrific pain, for 4 hours before they took him from the waiting room. We explained to the doctor that this had been going on for over a week and that the pain killers were not helping. AGAIN - The diagnosis was migraines. We were

dismissed and treated as though we were overly excitable parents who did not want to listen to the doctors. The following morning I could barely stifle my inner concern. My brain was screaming at me that there was something horribly wrong with my child.

We decided to go back to the doctor. Our doctor was out of the office so we had to see his partner. The minute my son walked into the waiting room the nurse saw him and could not believe how he had deteriorated since Monday. The doctor did some blood work and found that Anthony's white blood cell count was indicating an infection. I pleaded with him to call the emergency room to let them know we were on our way and that he needed to have a head CT. The doctor said that he would call the hospital but it was up to them to decide if he needed a CT. On the way to the hospital we decided that we would fabricate symptoms and convince the hospital

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that we thought Anthony had spinal meningitis. We knew that there was something wrong and we were willing to do whatever we needed to do to get the hospital to take action.

When we got to the hospital and proceeded to tell them the fabricated story they immediately took my son in for a head CT. Shortly after they brought Anthony back to the room where my husband and I were waiting, the doctor said, "I need to see mom and dad outside". Immediately our hearts sunk. The doctor informed us that Anthony had a mass taking up a quarter of his brain. They were not sure if it was an aneurism, a tumor or an abscess but he



needed to be transported to another hospital immediately.

Anthony had 120 ml of abscess in his brain! The doctors had to perform three different surgeries over the course of 10 days to remove the abscess. While in intensive care they also found an abscess in his liver. This required a tube to be inserted into his liver with a bag outside of his body to drain the abscess. Lastly they found two AVM's in Anthony's lung which caused the abscesses. He endured a 5 hour procedure to embolize the AVM's.

While in the hospital my son suffered a stroke due to the pressure and infection in his head. Anthony has lost the peripheral vision on the right side of both eyes due to the entry location to remove the brain abscess. My son was a healthy high school sophomore just weeks prior. Almost 6 feet tall he left the hospital weighing only 126 lbs. We are very, very fortunate to have him with us today. His neuro-surgeon told us that most adults would not have survived what Anthony endured. Just think, 120 ml of infection in your brain, that's 4 ounces, 1/2 a cup of infection. Horrifying!

During Anthony's hospital stay he was diagnosed with HHT. Anthony always had nose bleeds since he was very young and now finding the AVM's in his lung the doctors were sure that it was HHT. We are unaware of a history of HHT in either of our families and are in the process of undergoing genetic testing. My son Doug, Anthony's twin, and my husband Roy were screened in St. Louis in March of this year. Doug did not have any suggestion of HHT after the testing, but my husband Roy showed signs of shunting in his liver. We are hoping that the genetic testing will help us have a more definitive diagnosis.

The HHT diagnosis for Anthony has changed our lives. In some ways the change has been positive. Now, at least, we are aware of the condition. Early diagnosis for Anthony would have most likely avoided the brain and liver abscesses which threatened his life. Knowing that he has HHT, regular screenings should help us avoid these catastrophic issues in the future. Another positive event is that we have met the members of the Hope Crew in Michigan. It is a blessing to have an additional support system.

Our introduction to Jody Nissan's Hope Crew was pure coincidence, but it some ways I believe it was fate. The summer after Anthony's recovery I held a "Friends and Family Fiesta" to thank all of our family and friends for the tremendous support they gave us during Anthony's recovery. We enjoyed the party so much that it became an annual event. Last year I was driving to work a few days before our Fiesta and I heard on the radio that there was going to be the First Annual HHT walk-a-thon in Canton, Michigan. I could not believe my ears because no one I had spoken to had heard of HHT and I was suddenly hearing it on the radio! I missed the details but decided that we had to participate. We went on-line to the radio station website and found that the walk-a-thon was that weekend, the same day as the fiesta. We had 100 people coming over and could not

cancel it. I did, however, send Jody Nissan an email and she contacted me shortly after. Now, we are part of Jody's Hope Crew. We have had the pleasure of becoming friends with the Nissan and Purdy families who live with HHT as we do. The Hope Crew has given us valuable information, love, and support. Knowing that you are not alone in your fight is comforting as well as uplifting.

I am happy to say that today Anthony is doing wonderfully. In the fall he will be starting his junior year in college studying pre-med. He is on the university's crew team and is living life to the fullest. Although he has substantial vision loss, he is doing everything that the neuro-surgeon told him he probably would never be able to do.

My family believes that early diagnosis of HHT is extremely important and that education of the medical community is an urgent necessity. Awareness, detection, education.....God willing a cure will shortly follow.

HOPE. Always Have Hope! When I have bad days filled with worry, I take myself back to the summer after Anthony's event and diagnosis. My son, who left the hospital weak and facing 3 months of occupational therapy, put his faith in God and himself. He worked hard to regain his strength and to play baseball again - his true passion. That 4th of July, on his 15th birthday, my husband and I sat in the bleachers at a baseball stadium in Tennessee and watched Anthony pitch in the little league world series. Although the temperature outside was 100 degrees, I felt refreshed and on top of the world. My husband and I had tears of joy running down our cheeks and once again.... life was good, it was exciting, and our lives were moving in the direction we hoped for.

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