

Jake's Story from Caring Bridge

November 1, 2015

Jake's life has been a story in and of itself. Some of it has been drama, some of it comedy, and some of it suspense. This particular story started in the Spring of 2015. Jake was playing travel lacrosse when he started complaining of his left foot hurting. As he was always playing sports and prone to hurting something, at first we didn't pay him any attention. But after listening to him complain about his foot hurting for a few weeks, Sheila took him to the doctor who thought he had a stress fracture.

Six months, 4 xrays, 2 MRIs, a bone scan, a PET scan, 6 consultants and 2 biopsies later, we found out that Jake had pseudomyogenic hemangioendothelioma of the bone. What started out as a simple pain in his foot turned out to be a very rare form of cancer. These tumors actually originate from the lining of blood vessels. It is so rare, the doctors at UNC had never heard of it before. The pathologists at Mayo Clinic had only heard of about 10 cases. With the help from friends, we were directed to a group of specialists in New York City at Memorial Sloan Kettering who were at least familiar with this disease. Unfortunately, to make this even more rare, and the treatment more complicated, these specialists had never seen this tumor occur in the bone.

So, since very little is known about this cancer, there is very little to guide the doctors on what to do to treat it. There are no medications. We hoped that radiation would be an option but the tumors are all over Jake's foot, ankle and even into the bones of his lower leg. The amount of radiation that would be necessary to treat this unknown tumor would likely condemn Jake to a life of pain and debility. And there is no chemo that is available for it, either. Hence, all of Jake's doctors have recommended surgery. After many days and weeks of prayers and tears, we have decided that surgery is the course of treatment that will give Jake the best chance for long term cure as well as a return to an active lifestyle.

Isn't it ironic that for our son to become active again, he has to lose his foot and leg?

So on November 23, 2015 Jake will undergo a below the knee amputation of his left leg at UNC Hospitals. He will likely be in the hospital for most of that week and then home for about 2 weeks. We will be working with his school so that he can transition back when he is able. He will need a lot of time to physically and emotionally heal.

None of us know what to expect in the coming months, but I assure you all that we will face it together.

Written by Jake's dad Craig Warner