

# HI, MY NAME IS COOPER

I am 9 years old and have been diagnosed with a rare condition.



Cooper's journey began on June 16th, 2010. A doctor let us know that he believed Cooper had a rare chromosomal syndrome called Beckwith-Wiedemann. When you hear a word like syndrome in reference to your baby, it makes your heart stop and your stomach clench, but I only loved him even more fiercely. I knew that it didn't make a difference to me.

Chromosomal tests confirmed BWS, and we learned the challenges that our Cooper would face. BWS is an "overgrowth" syndrome that is widely varied in its impact on children. All BWS kids have an increased risk for childhood cancer. We took in all the information and as our beautiful baby grew, we noticed he had trouble closing his mouth as his tongue inhibited him. Upon the advice of our medical team, we made the wrenching decision to have surgery done on Cooper's tongue to reduce its size. Cooper endured the pain, the stitches, and the difficulty feeding with an amazingly good nature. As his tongue healed, I breathed a sigh of relief, but the challenges were just starting for us. During a regular ultrasound after his 1st birthday, a spot was revealed on Cooper's liver. Our fears were realized when an MRI revealed a tumor. After a 90-minute surgery, a grape-sized tumor was removed. Our incredible son took it in stride, and after a 7-day hospital stay, we were home and he was crawling again! Then the rug was pulled out from under our feet yet again. Testing on Cooper's tumors revealed it to be a malignant hepatoblastoma. We were devastated, but hopeful that we were able to act so quickly and detect the cancer. It took our breath away when the doctors recommended a full 4 cycles of chemotherapy to keep the cancer from returning. There were no good studies for Cooper's situation, so the doctor's were erring on the side of caution.

Every day I am grateful the cancer has not returned, even now, when we realized the chemotherapy caused irreversible hearing damage, I am just thankful my beautiful son is here with us today. The challenges placed before him have not diminished however, his autism diagnosis has led us down a path of hours of therapy and hard work to help him speak and make his way in school. Through it all, his soul shines through in his infectious joy and beaming smile. He is a quick wit and a master of words and numbers. He loves to be around people. I love the boy so much, it fills my soul and gives me the courage to carry on with clear purpose and hope.

Cooper's Motto:

**“Be Kind, Work Hard, Smile Often”**

