

Jack's Story

My son, Jack, was born on a beautiful October afternoon in 1999. He was my third child and first son. At his two-week checkup, our pediatrician heard a slight murmur in Jack's heart, but eased our fears by saying babies sometimes are born with slight murmurs and outgrow them. At Jack's two-month well baby visit, that slight heart murmur had turned into a "racing" murmur. An appointment with a pediatric cardiologist was made within the hour. There we learned through an echocardiogram that Jack had a hole in the upper chamber of his heart (an atrial septal defect, or ASD). The hole was too large to close on its own; Jack would need open heart surgery.

The Respiratory Syncytial Virus (RSV) hit the Kansas City area hard that winter, so Jack's surgery was postponed until the spring. In May of 2000 Jack had his ASD repair done at Children's Mercy Hospital. Jack's surgery took longer than the three hours estimated for his type of surgery. Even though we were updated often by one of the surgical team nurses, we were somewhat anxious about the length of the surgery. We waited at the Ronald McDonald House Family Room when Jack's surgeon, Dr. Lofland, came to tell us about the events and difficulties of Jack's surgery.

One thing my husband and I noticed and appreciated from the beginning of our involvement with Children's Mercy was the honesty and forthrightness of the medical professionals. We were always treated with respect, and the facts were presented to us thoroughly and in layman's terms, yet not insulting to our intelligence. Constant, honest communication with parents is a hallmark of Children's Mercy.

After Jack's surgery we could finally see him in the PICU. No preparation or description could prepare us for what Jack looked like. We understood he would be connected to monitors and tubes, and he would be unconscious. It turned out Jack's chest could not be closed due to swelling, so his chest was just bandaged up. Chest tubes, breathing tube, IV tube, so many monitors, blood seeping onto his bed. The only spot on his little body we could access was his big toe on his right foot. That big toe got more kisses that day!

My husband and I marveled at Jack's nurse; she explained to us exactly what was happening, how to read the monitors, what to look for and what to do, all the while taking excellent care of Jack and charting. I'm sure we drove the doctors and nurses crazy with our questions, but each question was answered patiently and completely. After nine days in PICU it was determined that Jack would need a pacemaker. After his pacemaker was implanted we spent two more days in the hospital, and then were finally discharged. Because of the medical professionals and staff of Children's Mercy Hospital, Jack is now a healthy 8-year-old who loves to see his cardiologist for his annual heart and pacemaker checkup.

Cathy Laylin - Peculiar, Missouri



Diagnosed at 8 weeks with ASD



Jack at 5 months



Playing t-ball



2007 school picture

Anna's Story

As our car inched through the snow-covered streets of Kansas City to the pediatrician's office during a late afternoon blizzard in February 2005, my husband and I discussed turning back and postponing the appointment. The bumps that seemingly appeared overnight on my 8-month-old daughter's temple and forehead and slight discoloration around her right eye were too worrisome for us not to have an answer, so on we trudged. The pediatrician's office examined Anna and drew a lab. The lab results showed Anna's platelets were dangerously low. The doctor alerted Children's Mercy Hospital and said the ER was standing by for our arrival.

Another trek through the blizzard with our hearts in our throats trying to guess what the diagnosis could be: Leukemia? Brain tumor? More labs and more tests were run late into that evening, with a preliminary diagnosis of neuroblastoma. "Neuroblastoma, what's that?" we asked. "Cancer." When your world stops and all you can do is clutch your child to your heart and try to stifle the panic, the people at Children's Mercy take you by the hand, patiently explain the next steps and intuitively sense how much information parents can handle.

The first step that night was to get Anna settled into her room on 4 Henson, where she was given her first of many blood transfusions and we were given resource material.

My husband, Jeff, left to break the news to the rest of the children waiting at home. As the February blizzard changed to gently falling, fluffy snow, Anna slept on my chest and I fought to keep my thoughts from jumping to conclusions. The next few days were tumultuous with many tests for Anna, my husband holding down the home front and me making phone calls to family, friends and co-workers.

Anna had the main tumor removed from one of her adrenal glands a few days later, but the cancer had spread to other organs and to her bones. The cancer on Anna's bones caused the bumps on Anna's temple and the discoloration around her eyes. Anna was in the hospital for 11 days, and had her first chemo treatment there.

Every step along the way someone from Children's Mercy, be it a nurse, doctor, social worker or volunteer, was there to explain every step, every procedure and every medication, very patiently and in detail so they were sure we understood what was being done to our child. For the next 15 months Children's Mercy Hospital became our second home, with several admits, treatments at the clinic, and periodic tests and scans. Anna has grown up at Children's Mercy Hospital. Anna is now 4 and loves going to the hospital for her periodic scans and clinic visits. I remember one particularly stressful moment in the midst of this journey, I vented to Anna's nurse that I just wanted our lives to be normal! She gently took my hand and said, "This is normal, it's just a new normal." Our family has handled our new normal just fine.

Cathy Laylin - Peculiar, Missouri



Anna at 1 month



Mom and Anna @ Children's Mercy Hospital



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