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Bilateral Wilms Tumor: New Protocols and Procedures

by Dawn Wolf

Masses...tumors...oncologist...straight to the ER.... Those were the words the doctor was using as he talked about our nine-month-old daughter. As I sat with my Dad in the doctor's office and heard those words about my beautiful baby, I began to miss parts of the conversation. But I knew, as we left the doctor's office and drove to the hospital, that my role as Kelly's mom was changing.

Diagnosis

Kelly was born full term after a healthy pregnancy. She was simply a very happy baby and I enjoyed every second of her life. Kelly was our third child, and I knew that the moments went by so fast, so I took time to soak them all in. Kelly was meeting her milestones, but was not gaining weight. Since she was exclusively breastfed and her brother was never on the growth charts, I dismissed the concern.

When Kelly was about eight months old, I felt a lump in her tummy while I was nursing her. Occasionally I would try to find the lump again with my fingers and over time it became more and more noticeable. I pointed the lump out to the pediatrician myself and will always wonder what path our lives would have taken if I had not been so proactive. We then saw two different doctors, had a CT scan at a local hospital, and began our journey to the local children's hospital.

While sitting in the ER that day, my Dad and I were at the mercy of the doctors and the filtered information they wanted to share with us. My husband left work and drove 300 miles to be with us at the hospital. We had a second abdominal CT scan and saw an oncologist and a surgeon. That was when we first heard what kind of cancer they thought Kelly had. The suspicion was Bilateral Wilms Tumor, cancer on both kidneys. They called it Stage 5. As a lay person I knew Stage 4 was bad and could only imagine what Stage 5 would mean for my baby.

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A New Protocol

Kelly was admitted that evening and my husband and I stayed with her all night preparing for a biopsy in the morning. The next morning, as I had Kelly down the hall for lab work, we learned that plans had changed. Our oncologist made a phone call to Dr. Jeffrey Dome at the National Institute of Health, a leading doctor in Wilms Tumor Research. He informed our oncologist that there was a brand new protocol for Bilateral Wilms Tumor and the research had not even been published yet. This very simple phone call changed Kelly's future.

The decision was made to start chemotherapy before biopsy. This was hard to understand as we just wanted the cancer out of our daughter! The day after her diagnosis, they sent Kelly down to insert a port, a type of implantable central line.

While she was coming out of anesthesia, they finally handed me a pamphlet to read on Wilms Tumor. We had already learned that most children who are diagnosed with Wilms are between three and five years old. We had a three-year-old and a five-year-old at home. The first page of the pamphlet listed seven symptoms: weight loss, diarrhea, abdominal swelling, anemia, shortness of breath, urinary tract infections (UTIs), and fever. Our three-year-old son also had the first five symptoms, and if anyone seemed symptomatic, it was him, not Kelly.

I instantly put the pamphlet down and spent the next 48 hours thinking I had two children with cancer. In hindsight, Kelly's symptoms included failure to gain weight, her nine month check up showed slight anemia, she had an unexplained cough and she did have a UTI upon diagnosis, but feeling the tumor was the only obvious sign that Kelly had cancer. Kelly started chemotherapy late that evening and the very next morning our son had an abdominal ultrasound. The wonderful tech happily pointed out my son's two very healthy kidneys!

At that point I knew I could do this. I had a child with cancer--but only one child with cancer--and I could do this.

Treatment

Kelly had one large tumor, over eight centimeters, in her left kidney in the renal pelvis, the area where the ureter, renal artery and renal vein flow into the kidney. This was the tumor I could feel as I rubbed her tummy. On the right were two smaller tumors, one in the upper lobe and one in the lower lobe. 12 weeks of chemotherapy shrank the tumors by over fifty percent. This great response to the chemo led the doctors to believe Kelly did in fact have a specific type of kidney cancer called Favorable Histology Bilateral Wilms Tumor.

After the 12 weeks of chemo it was time to remove what was left of the tumors. Surgeons at two different children's hospitals were ready to perform her surgery, as both had a performed a few Wilms Tumor surgeries in the past. Both surgeons agreed that they would remove the entire left kidney and leave us with maybe a third to half of the right kidney. The experts all tell us that you can live on one kidney, but can you live on less than half? Most likely the answer was no and that as Kelly grew she would need dialysis, and eventually a possible kidney transplant.

At this point we had moved to a new hospital and oncologist closer to home, but our first oncologist kept in touch. The same oncologist who talked to us in the ER, diagnosed Kelly, and had made a simple phone call, made yet another phone call. She asked permission and mailed Kelly's scans to St. Jude Children's Research Hospital in Memphis, TN.

Bilateral Nephron-Sparing Surgery

Dr. Andrew Davidoff was the man who agreed to accept Kelly as a patient and do her surgery at St. Jude. Being Kelly's advocate and a voice for my baby--too young to talk--I called the surgeon myself. He returned my call and answered all of my questions. He said he did this surgery a few times a month, as opposed to the local surgeons who had performed a couple in their careers. Dr. Davidoff agreed to perform Kelly's tumor removal and believed he would be able to preserve functioning kidney tissue on each

side. Four days after her first birthday we were on a plane heading to St. Jude for Kelly's surgery.

I later learned that Kelly was part of a study being done at St. Jude, bilateral nephron-sparing surgery. During this surgery Dr. Davidoff had to determine how much tumor could be removed without damaging the renal pelvis. In a six hour surgery, he was able to preserve two thirds of each kidney. After a few days, I reconfirmed with him: "Two thirds on each side?" I asked. He confirmed that I had indeed heard correctly. This was simply amazing to us, since previous surgeons had prepared us for total removal of the left kidney, and half of the right kidney.

This new procedure is finding the line between kidney preservation and cancer remission. In Kelly's case, the pathology came back confirming our diagnosis of Stage 5, Favorable Histology Bilateral Wilms Tumor. They staged the left kidney as Stage 3 and the right as Stage 2. Stage 3 meant that the margins on the removed tumor went all the way to the edge, and therefore some cancer cells were still remaining on the renal pelvis. Kelly had six short days of radiation therapy to the left kidney. Although she had some post surgical complications and an infection, her kidneys continued to function. Kelly then had four more months of chemotherapy before she was considered in remission.

Remission!

The success rate for Kelly's cancer is 90%, and now we struggle to find the balance between preserving kidney function and quarterly scans to watch for tumor re-growth. Now a spunky two and a half-year-old, Kelly is in complete remission. She has been diagnosed with secondary chronic kidney disease, but at this time her kidney function is still within normal range.

Whatever the future holds, we will always be grateful for the brand new research, protocols and procedures that were made available to Kelly.

For more information on Nephron-sparing surgery at St. Jude, please see this article: http://www.stjude.org/stjude/v/index.jsp?vgnextoid=8373c66a92a19110VgnVCM1000001e0215acRCRD&vgnextchannel=0bf695e614977110VgnVCM1000001e0215acRCRD&SearchUrl=search_results.jsp&QueryText=bilateral%20nephron%20sparing%20surgery