

What happened to Julia?

In late July 2005, Julia was having some flu-like symptoms. Fatigue, sore throat, fever off and on. She rallied as needed to work at the Sierra Club, do her weekly babysitting job and work on Saturdays at bridal shop downtown. On Sunday, July 31, she had a nosebleed that was hard to stop. We took her to Urgent Care that night and after a quite thorough exam, they concluded that she had a kidney infection (which was probably unrelated to the nosebleed). They sent her home with a prescription for antibiotics.

We were planning to leave on a driving trip to Yellowstone National Park on Friday August 5th. Her condition didn't improve much by Tuesday, so we visited her regular pediatric office. They prescribed a stronger antibiotic and asked us to check back before we left town. On Thursday we returned to the clinic. Things were looking up, but when the doctor touched Julia's lower back, there was still considerable sensitivity. The doctor sent her directly to Children's Hospital for a CT scan. Once those test results were finally in, they reported that her kidneys were fine, but her gallbladder was inflamed. They admitted her at Children's and put her on an IV antibiotic drip to get the presumed infection under control and prepare for routine surgery to remove the gallbladder. (This is one of those expendable organs; functional but not necessary.) Her condition was stable, but if it got worse—and her platelet count was sufficient high—they would have to operate on short notice. For this reason, she was on a liquid diet or “nothing by mouth.” She was understandably cranky, but mostly just tired.

They ran her through a number of other tests, with the results invariably “weird.” That's the word that was often used. The docs weren't sure what was wrong, other than that the gallbladder was inflamed. They assumed that it would need to be removed.

On Tuesday there was a test (called an ERCP) that had to be done at Abbott Northwestern Hospital next door, because they weren't equipped for it at Children's. The results were again “weird,” and the GI doctor who administered the test wasn't sure that they should proceed with gallbladder surgery, which was scheduled for Wednesday, the next morning. He consulted with the surgeon in the morning, however, and they decided to go ahead, and get a liver biopsy at the same time. Perhaps that would shed light on the mysterious lab and test results.

Julia was prepared for surgery and eager to be done with it. It would be done laparoscopically (with three very small incisions), reducing her recovery

time. She wanted to be ready for swim team practice as soon as possible.

After about 90 minutes, the surgeon reported that the gallbladder removal had been completed successfully. There had been minimal loss of blood, but Julia's hemoglobin was unusually low. They provided a unit of blood, and another unit and fresh frozen plasma had been ordered and was on hand. The surgeon's colleagues were finishing up and Julia would be returned to her room after spending an hour or so in recovery. This hour stretched to 90 minutes and we were finally admitted to see her. She was conscious and conversational, though in some pain. She had passed a bloody stool in recovery, but she was telling the nurse about the movie that she had watched in her room that morning before surgery.

She was released from post-op and we helped return her to her sixth floor room. Once things seemed stable, Dan left to buy some presents—gift cards at her favorite restaurants—and pick up Julia's sister, Hannah. Welcome stayed with Julia.

Things began to go wrong almost immediately, as her vital signs began deteriorating. She had another bloody stool; her blood pressure was dropping and heartbeat racing. After about an hour, Julia lost consciousness. Welcome was at her side and Dan was racing back to the hospital. An emergency response team took over and they worked for 90 minutes trying unsuccessfully to save her. Julia was pronounced dead 5 hrs and 25 minutes after she entered surgery.

After the fact, the pathologists discovered that Julia was subject to a massive Epstein-Barr viral infection. Mono. This compromised her liver to such a degree that it couldn't maintain or restore her blood's clotting capacity. She died of internal bleeding—a condition known as Disseminated Intravascular Coagulation, or DIC, which has been described to us as a train wreck of the circulatory system.

Children's Hospital immediately began an exhaustive internal review, and instituted many procedural changes as a result of Julia's death. We appreciate the openness and candor of the Hospital and Julia's medical team in the aftermath of this tragedy.

Elsewhere in this website, we have provided additional information about the changes that have been instituted at Children's, and about our efforts to address medical error in pediatric resident education.

-- Dan Berg and Welcome Jerde