What happened to Julia?

In late July 2005, Julia had some flu-like symptoms. Fatigue, sore throat, fever off and on. She rallied as needed for her internship at the Sierra Club, to 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 they sent her home with an antibiotic for a suspected kidney infection.

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 afternoon 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 ordered a CT scan and sent us to the Children's Hospital radiology department. 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 her platelet count was low and needed to be higher for surgery. Surgery was on hold from day to day because of the platelets, and for this reason, she was on a liquid diet or "NPO" (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 used by more than one doctor looking at her chart. They weren't sure what was wrong, other than that the gallbladder was inflamed.

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 gastroenterologist who administered the procedure wasn't sure that she should have surgery, which had been finally scheduled for the next morning. He said he would consult with the surgeon in the morning. We found out later that the adult GI doctor, who had performed the ERCP, spoke with the pediatric gastroenterologist, who in turn spoke with the surgeon. We wonder what might have been lost in this second-hand exchange. They decided to go ahead to remove the gallbladder 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 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 hours and 25 minutes after she entered surgery.

An autopsy was performed, and the pathologist discovered that Julia had a massive Epstein-Barr viral infection. Mononucleosis. 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—especially diagnostic error—nationally.

-- Dan Berg and Welcome Jerde