

Unprotected People #68

Hepatitis B

One Family's Story: Living with Hepatitis B

Immigrants and refugees from areas where HBV infection is high, such as Asia, make up one of the highest risk groups in the United States for developing HBV infection. The Asian Liver Center (ALC) at Stanford University reports that the Asian American/Pacific Islander (API) population in the United States experiences HBV infection at a rate 100 times greater than that of the U.S. white population: About 10% of the API community is chronically infected with HBV, compared with 0.1% of the white population.

According to ALC statistics, chronic HBV infection causes 80% of liver cancer in the United States, leaving the API community particularly vulnerable to a type of cancer with a high mortality rate. National Cancer Institute statistics indicate that the five-year survival rates for primary cancers of the liver and intrahepatic bile ducts are exceedingly low in the United States, usually less than 10%.

The following account, of three young adults in the Wise family, exemplifies the toll undetected HBV infection takes among API immigrants and the serious consequences misinterpreted HBV test results can have. Written by Helen Wise, mother of the HBV-infected young adults, the article was first published in "Hi Families" magazine in January/February 2004. It is reprinted here with the kind permission of Helen Wise and "Hi Families," which holds the copyright. ["Hi Families" is published by Holt International Children's Services, a U.S. organization involved in domestic and international adoptions since the 1950s.]

One Family's Story: Living with Hepatitis B

By Helen Wise

How could it possibly happen? Every precaution and care was taken. Matt, our only child with hepatitis B, had been monitored since he was two-and-a-half-months old. Three generations in our family had been tested and vaccinated for the virus. Then,

suddenly and without warning, our middle son, Andrew, was diagnosed with hepatitis B-related liver cancer. How? How? How?

We had felt so lucky. Matt, born in Korea, joined our family in 1984. Soon after he came home, he was diagnosed as a hepatitis B carrier. At that time hepatitis B was a fairly new phenomenon on the American pediatric scene, and there were still many unknowns about the virus. A specialist explained the consequences of hepatitis B, including the risk of liver cancer, the risk of infection for anyone handling the child's body fluids, and the importance of vaccinations for the whole family.

The doctor was realistic about the panic hepatitis B carriers could cause (in 1984), so we decided to say nothing about Matt's condition for the moment. We began training our little corner of the world in how anyone should handle someone else's blood, and I dealt with all diapers, spit, etc. We all got our vaccinations, hoped Matt would show the possible spontaneous remission by school age, and were grateful the virus seemed to have no effect on his body. Then we went about our lives.

In 1985 our family grew again. Andrew, 7, and his sister Jenny, 6, arrived from Korea in December, and the same pediatrician tested [them] for hepatitis B. We were happy to hear the tests were both negative, and both Andrew and Jenny were vaccinated. We thought nothing more of it.

By the time Matt started school, we found the Hepatitis B Foundation and the Liver Cancer Prevention Center at Fox Chase Cancer Center [in Philadelphia], and Matt was part of a funded study of hepatitis B carriers. Year after year, our questions were patiently answered, and the answers changed as research revealed more about hepatitis B.

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Somewhere between diapers and dating, we learned that urine and saliva, like most body fluids, do not contain a high enough virus count to have [caused] any documented cases of infection from routine contact. Bites were a danger, but kisses were not.

We explained to Matt's teachers that he had inherited a blood disorder and they needed to wear gloves if they had to handle any body fluids. I had a private conversation with the school nurse. No one ever asked questions. I . . . knew of parents who could not find daycare or friends for their child with hepatitis B. So, we felt lucky.

As a very little boy, Matt learned that he in particular must not share a toothbrush or razor, and must be careful about any blood contact. He learned earlier than most about his liver and that he must always protect it. We talked about the importance of a healthy diet, exercise, and avoiding alcohol. We did not use the words "hepatitis B" until he was old enough to read and ask questions. We waited for him to ask about liver cancer prevention, but once he had questions, his doctor and we answered honestly. By middle school, we talked about everyone's responsibility to avoid sexually transmitted infections and his obligation to protect a future partner from hepatitis B infection.

At 18, Matt's visits to the Liver Cancer Prevention Center increased to twice a year, since the risks increase with age. He had a baseline ultrasound of his adult liver, against which to measure any future changes.

A son-in-law and two grandchildren joined our family and were all vaccinated. Matthew turned 20, still showing no hepatitis B side effects. All was well. We were so lucky.

Then on Sept. 2, 2002, our other adopted son, Andrew, woke complaining of abdominal pain. By then I had six children and had been a mother for over 30 years. Stomachaches were routine. I suggested he get dressed and go to work; maybe he would feel better. But by the time breakfast was over, Andrew was in such pain that his sister took

him to the emergency room. By that afternoon he was admitted to the hospital. I was stunned when two doctors came to tell us Andrew tested positive for hepatitis B. Then I saw "Oncology" on their nametags. I said to them, "You believe you'll be seeing us later, don't you?" They nodded yes. I knew.

A biopsy confirmed a diagnosis of stage IV hepatocellular carcinoma metastasized to the lungs. An earlier diagnosis could have meant surgery or a transplant, but now chemotherapy was our only option, and even then it only shrank the tumor in a small percentage of patients. Our best chance was a clinical trial and a miracle.

Neither was to be. By the time Andrew qualified for a trial, his liver function was so low he was rejected. Andrew Lee Wise died at home on Dec. 11, 2002. He was only 24 years old.

But that is not the end of our story. After Andrew's cancer diagnosis, I called our former pediatric group to see the results of all the original hepatitis B tests. Their office said the lab's records before 1992 were no longer available. One doctor gave me a handwritten copy of their file reports, and said, "See! Their tests were negative. Matthew's was positive." I read it for myself: Andrew's test read HB surface antibody negative. Just surface antibody negative means nothing! I felt and still feel like screaming. How could a leading pediatric group in a university town get it right in 1984 and so wrong in 1985 and 2002? How? How? How?

Everyone in the family was re-tested for the virus. All results were negative. Jenny, Andrew's biological sister, got the good news from a local clinic . . . but her world was shattered when the [state health department] called to say her results had been misinterpreted there also. She is a carrier. We can't be sure without testing their biological mother, but it appears both Andrew and Jenny, like Matt, were infected at birth. Jenny is being monitored by the Liver Cancer Prevention Center and is doing fine.

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Our family has been devastated by Andrew's death. We are weary and wary, and painfully aware his life could have been prolonged and might have been saved had his pediatricians recognized he was a hepatitis B carrier. Jenny's second misdiagnosis brought us near the brink of hysteria. It is one thing to know in the abstract of a threat to a family member. It is quite another to live with a double threat after experiencing its reality.

The lessons we learned were painful and need to be passed on, but the experience is rare. The head of the Liver Cancer Prevention Center said he has never seen cancer like Andrew's in one so young.

What advice do we have? Older adoptees and their families should [be] re-test[ed] for the virus. Be sure you see and understand the tests and

results. Vaccinate the entire family. If you have been vaccinated, ask your doctor for quantitative as well as qualitative test results to be sure you are still adequately protected. A booster or revaccination may be needed. Persons younger than 18 years old with hepatitis B should see a doctor annually to monitor the liver, and if older than 18, have a baseline ultrasound and see a doctor semiannually. Inform any past and present partner. Stay informed about the latest research on hepatitis B. And enjoy life.

When our youngest daughter Mary was in high school, our youth minister asked, "What was the best gift you ever got?" Mary replied, "Andrew, Jenny, and Matthew." We are still very lucky parents.