



CALIFORNIA HEPATITIS C TASK FORCE

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October 20th, 2003



Aubrey's Story

A real life story that will bring love and compassion to those suffering from Hepatitis C

Mom's Perspective

Aubrey was born on May 11, 1990, two months ahead of schedule because her twin brother was showing signs of fetal distress. At a day old, on a ventilator and with enough tubes and wires attached to her to make her look like the engine compartment of a Toyota, she was Life Flighted around 100 miles away to Hershey Medical Center because she was born with Transposition of the Great Vessels, a somewhat rare cardiac defect.

At a week old she had the first of two open-heart surgeries and it was at this time she was infected with hepatitis C during a blood transfusion. We were not told that she was a recipient of infected blood until she was almost 10 years old. Anyhow, . . . the way we were informed was a letter from the blood bank telling us she needed to be tested for HCV.

Until this time, I had never heard of hepatitis C. I had hepatitis A and B vaccinations when I was in nursing school, but this was a new one to me so I started doing research and asking a lot of questions.

When I read the letter I was driving to work and I didn't stop crying for quite a while afterwards. By the time the shock wore off, we had found info on the net, in medical texts, and bugged a heck of a lot of doctors. We also went through a lot of doctors. Some of the doctors didn't think it was necessary to get a genotype, or a quantitative PCR. We got rid of those doctors. . . .

When all was said and done Aub ended up having doctors at Johns Hopkins in Baltimore treat her. She went through 5 1/2 months of Intron A treatment, but although she initially responded, after TX stopped, the virus came back. She had severe side effects to the interferon including neurological tics, so she isn't a candidate to try it again.

Aub was in stage 2, grade 2 at her last biopsy. I was told to use gloves when she had a cut or there was a chance of contact with any of her body fluids, I will not do that. We went for all those years not knowing she was infected and we never took any precautions, and

we didn't get infected, I won't start now and make her feel any different than she already feels. I have raised her to believe she is not disabled because of her heart disease and asthma, and this helped her deal with this virus.

She is now in 8th grade and doing fairly well. She is a peer mediator and has done a public service ad for the Max and Lorraine Foundation, an asthma foundation that puts on a camp for asthmatic children in July in the Pocono Mountains. She has accomplished a lot so far in her life.

Aub is the kind of person who will stand up for what she feels is unfair. That is the major reason she has decided to go ahead and do this. She's incredibly mature for her age, and doesn't want pity from anyone, she just wants people to understand that people with HCV are not lepers.

When we first discovered that Aubrey had hepatitis C, we informed her elementary school assistant principal (He was the more accessible of the administrators.) It was decided that the only people who were to know what Aub had were the school nurse, the principal, assistant principal and the school superintendent.

I was told that there was too much of a chance of it leaking to the community if the knowledge wasn't contained. They were afraid of parents refusing to have their children in the same school as my daughter, so this was done for her protection. Although I didn't agree with this, we went along with it because I didn't want Aub to have anymore trauma on top of what she was already going through. I felt that her teacher should be informed in the event that Aub might get hurt on the playground.

The Asst. Principal, Mr. Thomas Kubasek, took Aubrey under his wing and made sure she was protected. I later found out he was an AIDS counselor, and had some idea of what hepatitis C was. This was at the Greater Nanticoke area school district in Northeast Pennsylvania.

Right before school ended that year we moved back to Pottstown, in southeast PA, the area in where I was raised. The following year Aub started school in the Boyertown Area School District. The way she was treated was completely different. In this district her teachers were also notified of her illness, where in northeast PA I had to fight to have her get a Chapter 15, in Boyertown, they accommodated her absences because of her chronic illnesses without a fight.

She began treatment in the summer of 6th grade. She had almost every single side effect that a person could get from interferon. I forget just how many days she did miss because of this but it was well over a third of the school year. Somehow she managed to keep her grades up and pass the year. When she started Jr. High, she wasn't able to fight off any of the illnesses that she caught in the first quarter of school. She again missed a lot of days, If my memory serves me, she missed two out of every three days. The district gave her a tutor who came out to our house several times a week for the rest of the year and again, she kept her grades up and passed the year.

This year, in 8th grade, Aub is doing much better with illnesses, although the beginning was pretty rocky, but she is trying her best to fit in and keep her grades up. She went thorough peer mediation training at school and is now a peer mediator.

Aub has always wanted to make a difference. She does, on a daily basis. She's my hero. Aub is a "miracle kid" for the Children's Miracle Network. During a radio-thon a few years ago, Aub tried to bring attention to hepatitis C. While there another miracle kid who had hepatitis C was there also. His father kept up on research, but his mother was in major denial. This boy was operated on about the same time Aub had her second surgery and he knew Aub from other events. He opened up to her, and he said he didn't know too much about what was wrong with him: it had not been made clear to him. Both kids are the same age.

I was shocked. The boy's mother kept talking about was a lawsuit; she didn't even bother to help educate her child about this virus. It scares me that the problem is so big and the denial is so great. A lot of what we see around us in society with children and adults is the same ignorance and lack of basic human decency as a response to the suffering of this dreadful illness.

Kathy, Aubrey's Mother

My Version

I found out I was diagnosed with Hepatitis C when I was about 9 years old. At that time I thought of myself as a normal kid. It came as a shock to me when I found out.

The first person I called as always was my big brother. He knew

it hurt, and he tried his best to help.

As time passed I found help and guidance from at that time Big Sam's Hepc Chat. The people helped me out so much and helped me face the virus head on. Soon these people became my friends.

As time progressed, I soon was an expert on what hepatitis C is and treatments to help. My mother as always helped me with everything.

I was always sick a lot before and after I found out. I always thought it was cause of my heart problems. I didn't let a little scar bring me down then so I carried on a normal role in life. I was just a kid who supposedly wasn't scared of anything. I soon helped other new people and became very wise on the subject and helping people.

I got sick and I had a choice for treatment or not. The doctors at John's Hopkins were very helpful and really showed me which way to go. I tried out interferon, which is a chemical used to fight off viruses. I checked up on what it is and learned everyone's body makes their own interferon.

I went on treatment and as hard as it was my family was there 100 percent. I missed tons of school and basically did most work at home. It was all the normal shots until the company changed the look on the box.

The pharmacist accidentally mixed up the dosages. When it came time for the shot my mom and I were clueless about the mistake. When the needle hit my skin, it stung -- and I cried as the medicine went into my body. My mom knew it never hurt me so she checked the box and noticed the mistake.

I had temporary nerve damage and hardly could walk. As you could guess, I was out for at least two weeks. We had to go back to John Hopkins to get checked out. I was doing better and we all hoped the nerve damage wasn't permanent.

After that, I chose to quit the interferon, and it remained undetectable. My whole family was so happy. So was my second family, in hepcnet.

Soon the happiness turned to tragedy the virus came back. My dream was shattered temporarily. My big brother got another call, one he didn't like. He tried his best to help me but it hurt too badly. I was depressed for a long period of time.

I soon hardly went on helpcnet -- not wanting to talk to anyone just needing my space. Only about five months ago I started checking in.

Although I was depressed, it hurt worse when my grandmother died. I was so "rebelled out" I didn't cry until after she was buried. My grandmother was the kindest most generous person ever. She took me everywhere; didn't care about my disease just loved me for me as the rest of my family did.

The pain that hurt the most was feeling trapped not being able to tell anyone but people who could understand. Even at school they brought up hepatitis C, and they got it all wrong. I wanted to jump up take the microphone and correct them all. I couldn't because doing that would make me look like a freak to them. They had no idea what any of it was. What it did to people. They just said what the causes are and how they could get it, and it was all wrong!

The shock of people not understanding made me paranoid, afraid that someone would find out. That I'd be caught in the act of being different, afraid of laughing and pointing and never living a normal life ever again.

I have been stuck with this too long and I feel no one should go through all I did. I bet the kid who got expelled would feel the same. Even though he might not understand all about it. If I had one wish, I wish people would understand what hepatitis C is and how it affects people's lives. How people can get it.

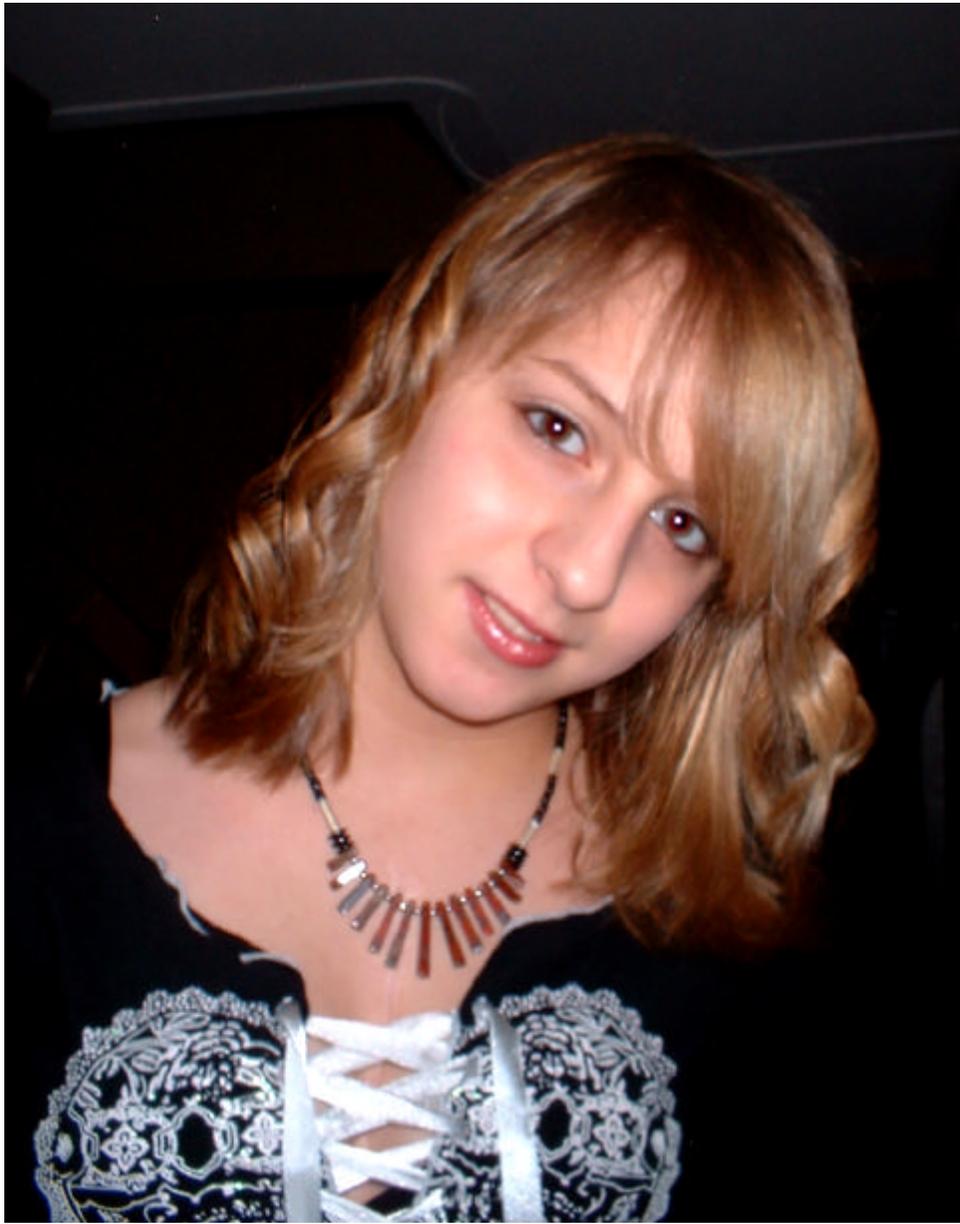
Most of all I wish there could be a cure, a vaccine to stop people who are suffering from this virus and stop future sufferers.

I swear I didn't jump up and say; "I want hepatitis C, Please! Come on!"

I got hepatitis C from a blood transfusion. Not by drugs or any other way. I was an innocent child who needed to live. I want to help. I want to show people their mistakes. I love helping people. I joined peer mediation to help people. I wish the best for all.

Aubrey

See recent photo of Aubrey on next page



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