

Unprotected People #2

Hepatitis B

Parent of child with HBV testifies about importance of hepatitis B vaccination

A parent whose son is chronically infected with the hepatitis B virus delivered the following testimony in 1997 at a public hearing on the implementation of a hepatitis B school entry law.

The parent spoke on a personal level of the pain her entire family has suffered because of one family member's chronic illness. She concluded by urging parents to learn as much as they can about hepatitis B so that they can make truly informed decisions regarding school immunization and how to best protect their children. The testimony is as follows:

I'm here to talk about my family. I'm not here to add to the list of statistics related to immunization issues. I'm here to personalize them, to bring them to a level that you can relate to from the heart rather than from a business, political, or clinical standpoint. My husband and I have three young children. One is a hepatitis B carrier. Although he is asymptomatic, biopsies at ages 3 and 4 confirmed that he already has cirrhosis. He did not respond to a 7-month course of interferon, a form of chemotherapy, and no other treatment has been available for him.

There is a four-letter "F" word which we try to shield our children from. It's something they shouldn't know anything about at such a young age. The word is Fear. Fear of social repercussions, fear of financial ruin, fear of sickness, death and loss.

You may have noticed that I have not provided our family name. I can't. The first thing hepatitis B families learn, usually after rejection by friends or family, is to go to extreme lengths to protect their child's privacy. We desperately want to reach out for comfort when we learn our child has an incurable illness, but we can't. Local hospitals offer support groups for parents of children with cancer, but no help is available for

parents of children who have life-threatening infectious diseases.

We feel an overwhelming need to warn daycare workers, teachers, Sunday school caretakers, babysitters, playmates and their parents that extra care needs to be exercised if our child scrapes his knee, bites or is bitten, has a bloody nose, and so on. We want to tell everyone to get the shots. Yet we agonize over the negative consequences of "telling" . . . Will our child be treated fairly? Will he be ostracized on the playground? Will we ever find a babysitter? Will they have any friends or will our children be singled out as the kids to avoid? Will information given to the school nurse in confidence wind up as the topic of conversation at a PTA meeting? There are discrimination and disability laws that guarantee our child a public education, but there are no laws to protect my child's heart . . .

My husband and I attended a school meeting regarding one of our other children. During casual conversation, a mom mentioned that she'd heard that there was a child with hepatitis B in our school district. She went on to tell the other concerned parents that she had visited the school superintendent in an effort to identify the child so that she could better protect her son. We sat paralyzed in silence, waiting for glances to turn in our direction (they didn't!), and all I could think was, get your kid the shots if you want to protect him. We supervise our child's play, we coach his soccer games, we are there as much as possible in order to protect other people's children. But it's obviously impossible to continue this vigilance as the children grow older. A neighbor tried to bandage our child's bleeding cut and I body slammed her away. She thinks I'm over-protective. She has no idea I was protecting her.

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No one else should have to live with this virus. It's preventable.

We worry about our ability to provide the best care for our child. His interferon treatment cost well over \$20,000 and only a portion was covered by insurance. We are self-employed and we watched our health insurance premiums triple. We can't change carriers because we fear he could become sick or need a transplant during the "pre-existing condition exemption period" with a new policy. If no cure or control is found in the very near future, the likelihood that he will need a transplant is high. We have been warned that transplant and post-transplant care will most likely ruin us financially, and it is only a temporary solution. The virus would eventually attack the new liver as well. We wonder whether we will be able to afford to put our children through college, how we will manage to retire.

I call this virus "IT." Capital I, capital T. Stephen King fans will understand why. IT invades our lives, our thoughts, our spiritual beliefs, no matter what defenses we erect. I watch my happy children playing and IT reminds me that we will soon have to tell my son that he has a serious illness. Whenever he doesn't feel well, I wonder, "Is this IT"? How long will IT allow him to play the sports he loves? How will IT affect his school performance? The quality and length of my son's life are frightening unknowns, but statistics related to the progression and charac-

teristics of this disease make it difficult to be optimistic. You can all look at your young children and fantasize about their senior proms and weddings. I cannot.

My son is a leader. He is clever, creative, charming. He is very protective of our other children and they look up to him. I fear the effect IT will have on his siblings, worry about how they will deal with their brother's illness, or worse. I fear that I will watch my child die, the worst possible thing that can happen to a parent. Doctors and parents have no control over the course this illness chooses within our children's bodies. However, the availability of the hep B vaccine allows us to control the spread of the disease to others. No other family should ever have to experience this pain. Three shots can prevent IT.

Hepatitis B is transmitted primarily through blood and sexual contact with infected persons. There are young, asymptomatic carriers who have not yet been diagnosed. Infected children will be socializing with and dating your children. It is clear to me that those of you who oppose immunizing our state's children are well informed about vaccine composition and side effects. I beg you to learn as much about the hepatitis B virus and disease progression as well. Only then will you be able to make a truly informed decision regarding school immunizations and how to best protect your children.

*Signed,
A Parent*