

ADVOCACY-DISCRIMINATION

When Schools Discriminate

A Parent's Story

The Hard Road to Equal Treatment

By Maureen K.

When I first learned of my daughter's hepatitis B virus (HBV) infection, I was devastated. After our return from China, where she was born, we had a series of tests run on her. Days passed and I hadn't heard anything from her pediatrician's office. As time went on, I had a sinking feeling that something was wrong.

The doctor's office coordinator finally called with the bad news. Mary had "a touch of hepatitis B." This was followed by, "But you suspected that didn't you?"

I insisted on speaking to the doctor, who was at a loss for words. I was in an open court of a shopping area on my cell phone. Mary was next to me in the infant carrier. I called my husband at work and cried. We were both crushed.

Coming up to speed on the hepatitis B virus was not so easy at the time. Our home computer was old and slow, so the Internet was not an option. We knew of no other families in our situation. We discussed Mary's infection openly, never anticipating a problem. My husband and I felt very strongly that Mary's status was not something we wanted to keep secret. We did not want Mary growing up being ashamed that she was infected. We were naive.

In the beginning, there were few if any problems. All of our friends were very supportive. Those closest to us were vaccinated so they could help out in any at-risk situation. We felt very lucky to have such good friends.

Our families were also supportive, but it was sometimes obvious at large family gatherings that some people were a bit apprehensive about Mary. It was kind of like walking into a room with a bomb instead of a baby.

Mary also had other problems that required the services of the Infant and Toddler Program that was operated by our public school system. She was developmentally

delayed and required physical, occupational and play therapy. We disclosed Mary's hepatitis B status to the school. We felt it was the right thing to do. We thought that advance disclosure would give those who were not vaccinated the option to vaccinate.

It would also benefit Mary, as she would be starting interferon treatments in a few months. We felt it was important for the physical and occupational therapists to be aware of her treatment. All of the staff people we encountered were extremely supportive and professional. I never sensed they were fearful of interacting with her. Once again we were grateful for the support we received from those we encountered.

After another year (Mary was now 2) and with six months of unsuccessful interferon treatment under our belts, things began to change a bit. We had decided to enroll Mary in the same preschool as our oldest daughter. I was on the preschool board at the time, and spoke of disclosing Mary's status to the parents of her class. After all, it was a co-op school and parents were required to volunteer.

My husband and I felt it was only fair that they be made aware of Mary's status so we could offer standard precautions training to eliminate any risk. One of the parents was a doctor with a master's degree in public health. We were working together to make a presentation to the class. The night before we were to present he invited me to his home to try to convince me NOT to disclose Mary's HBV infection. He felt we were making a big mistake and that we should approach the situation differently.

He had spent much of his day talking to various state health officials who all confirmed his position that we should not disclose. Eventually he convinced me that we should at least wait, and not disclose at an open forum. Precautions were taken at school so no parent would be put at risk. Eventually, we decided we would take his recommendation and not disclose to anyone. Only later did we realize what a huge favor he had done for us.

At the same time, trouble was brewing with the Infant and Toddler Program at the public school. Mary was getting a new case coordinator. Friday afternoon before Mary's first meeting of the school year, she called to tell me that there was "a situation." Apparently some staff felt it would be "in the best interests of everyone" if Mary was moved to a new school. Because we had had such positive experiences with the school, it never occurred to me that it had anything to do with Mary's infection. I asked her why Mary was to be moved and she explained to me that only half of the school staff was vaccinated, while the staff people at the new school were all vaccinated.

It took a few minutes for all of this to register, but when it did, I was furious. I told her

that this was not an acceptable option. Mary had been in the program for an entire year. We had disclosed this very personal information to the school and there had been plenty of time for them to become vaccinated. I told her that I could not have Mary moved from school to school on the whim of some teacher who decided that she didn't want to teach the kid with viral hepatitis.

This needed to be nipped in the bud. I could tell she was very uncomfortable with this conversation and informed me that this was not her decision and that she had no problem working with Mary even though she was not yet vaccinated. She was accustomed to working with high-risk children and used standard precautions in her daily work. I told her she wasn't getting paid enough to be dishing out this kind of information and that the director of the program should get back to me.

I immediately got off of the phone and decided I should prepare myself for my conversation with the director. Over the next week, I worked my way through the Maryland State Health Department. The department was responsible for putting together the training materials on standard precautions that were used for training staff in public schools.

Their personnel also trained nurse coordinators at a number of schools who were then responsible for training school staff. The health department could see no reason why Mary should be moved to another school system. Any teacher wishing to be vaccinated could do so free of charge. Additionally, all public school staff were educated about standard precautions.

In the interim, I heard from the director of the Infant and Toddler Program. I informed her that disclosing Mary's viral hepatitis status had been our choice, not our obligation, and that most parents in our situation would not have done so. I assured her that if she thought Mary was the only child in the history of the program with an infectious disease that she was sadly mistaken. I told her we refused to move Mary to the other program. She said she needed to investigate the situation more thoroughly and would get back to me.

The next couple of weeks were spent on or waiting by the phone as I waited for return calls from the health department, Advocate for Children and Youth, School House Legal Services, the Americans with Disabilities Act regional advocacy organization and finally the American Disability Law Center. I also spent a tremendous amount of time on-line investigating the American Civil Liberties Union site.

The lack of information about civil rights and the hepatitis B virus was astounding. I

found myself educating many of the people I spoke to. Typically, I found I was contacting the wrong group or speaking to the wrong person. Everyone kept saying “well if she had HIV or AIDs this is what would happen...” Well she didn’t have HIV or AIDS and I was finding the information sparse and definitely unclear.

In the middle of my research, the director of the program got back to me and told me that she had conferred with the health department and the counsel for the public school system. Mary could be reinstated in the program if they received a letter from her pediatrician stating that “she was of negligible risk to staff and students.” She told me it was good that this had come to their attention. Perhaps policies would be changed due to this “situation.”

Once again I was furious. My only victory was that I had gotten to the health department before she had, and they had in fact called to tell me that she was wrong and would be calling. I informed the director that they had better not use Mary’s name during any of their discussions of the “situation.” This information was private.

Mary’s doctor agreed to the letter and quoted two sentences out of the Pediatric Red Book. We both later regretted sending the letter to the school. The school’s counsel later called and harassed the pediatrician informing him he was looking for a letter that stated unequivocally that there was no risk from Mary being in the school. The pediatrician told him he could not make that statement about ANY student in that school and any further correspondence should be in writing or through his lawyer.

Finally after weeks of research and phone calls, I received some assistance from the American Disability Law Center. I was assigned to an attorney who filled me in on what we needed to do to best protect Mary’s privacy. We were told to contact the school and request that Mary’s records be modified to remove any information pertaining to her hepatitis B. We also requested that her records be sealed. At that time they would not be available to anyone. We contacted the principal of the school by certified mail. She immediately called and set up a time for us to get together and talk and review the records.

The decision to remove the hepatitis B-specific information was left to the discretion of the school staff. Under the Family Education Rights and Privacy Act (FERPA), a parent may petition the school to have the information removed, but the school does not have to comply. As parents, we have the right to then request a hearing headed by an unbiased mediator or group, all of



whom are usually selected by the school. Our counsel informed us that this had been a problem in the past. What a surprise!

Fortunately the elementary school principal was very professional and apologetic. She was quite anxious to resolve the problem. Evidently she had been unaware of the “situation.” I expressed my concerns about safeguarding Mary’s privacy. I told her that if word about Mary’s viral hepatitis was to leak out, parents would be running home to their computers to look up hepatitis B, only to find that it is more prevalent in Asian and African cultures.

She was very aware of the impact of such a scenario and agreed wholeheartedly that it would be terrible for the minority students of our school to be singled out and discriminated against. She was very anxious to put the whole issue to rest.

My consultation with the ADA lawyer proved somewhat frustrating. She found no specific incidents or court decisions that addressed those with hepatitis B or C. All legal precedent concerned HIV/AIDS and she felt that viral hepatitis should be treated somewhat differently because the children with viral hepatitis are asymptomatic and are not taking medication at school.

She felt this strengthened the argument that there was no need for this information to be disclosed any further. Unfortunately, she said there was really little or nothing we could do. We could never protect Mary against gossip. She recommended contacting the lawyer and asking him to return the letter. She also recommended asking the principal to identify the number of staff and their names in a letter, stating that they had all been informed about the importance of keeping this information private. Sadly, at this time she also informed us that her caseload was too heavy and that she would no longer be able to assist us. After so many dead-end leads, we were losing the only truly helpful person we had encountered.

Surprisingly the school counsel refused to return the letter, although he did send me a letter stating he was aware of the privacy issues surrounding the letter. He and I had a very nasty exchange over the telephone. The principal did eventually send me a letter stating that five people had been informed of Mary’s hepatitis B status and that they had been told to treat the information with confidentiality. No names were mentioned. I can say with conviction I believe this number to be very low. I found that every time I called the school I was immediately connected to the correct personnel—without asking. It made me wonder.

At one point, I was even connected with the woman who had requested that Mary be

moved to the other school. She told me she was unable to be vaccinated due to medication she was taking. She was the speech therapist. I guess she thought I would be sympathetic. I was not. Mary was moderately hearing impaired for quite some time yet never received services from the speech therapist. That was OK because I would never want her interacting with my child.

Mary will be turning 4 this fall. She is no longer in the Infant and Toddler Program, and did not require preschool program services. Her records were sealed at the age of 3. She does however attend the preschool as a peer. Last year, her case coordinator taught preschool and requested Mary in her class. I suspect it was a win-win for both sides. (We all loved Mary's teacher. Mary was obviously one of her favorites.)

The incident is now two years behind us. I guess you could say we won, but it was a watered-down victory. I am still angry and bitter over what occurred at that time. I am also angry at myself for being so naive to think that people would be open-minded once they understood and were not afraid.

We were stupid to let the "cat out of the bag" and then try to "stuff it back in." I also feel as though I will never truly know how many people were or are aware of Mary's hepatitis B status. As a result, I am ever-vigilant, and wonder when one of these "ghosts" will pop out to haunt us. I am also constantly on the lookout for subtle forms of discrimination—such as staff who appear leery of touching her, hugging her or helping her.

This year, Mary will have a new teacher at preschool, and I am nervous. But we are here to stay. Fortunately, Mary has a winning personality. It is almost impossible to resist her charms.

While there appear to be policies and procedures set in place to protect children with viral hepatitis, there are also huge loopholes. Finding consistent information about how children should be safeguarded is nearly impossible. Just as in the treatment of hepatitis B, there are no black and white answers, just lots of gray. I suppose if someone was willing to sacrifice their child for the good of the cause, we might be able to make a court challenge to clarify all of this, but who wants to do that? There are no specific legal cases addressing children and students with hepatitis B or C infections—only HIV and AIDs.

Also, those of us with children infected with hepatitis B are caught between a rock and a hard place. I am extremely grateful for the hepatitis B vaccine. It helps me sleep at night knowing that I don't have to fear every interaction. On the other hand, the fact that she

is not vaccinated is what makes her stick out like a sore thumb. How can I claim that she didn't get the hepatitis B vaccine for religious reasons when she's had every other vaccine? I have considered having her vaccinated, but have been told not to by her treating specialist. So I lie on the forms about all questions regarding infectious diseases and hope they confuse the hepatitis A vaccine for the hepatitis B vaccine. So far this has worked for us, but how long can our luck hold out?

There are no easy answers when choosing whether or not to disclose. It never occurred to me that we would ever encounter issues like these when you consider that we live less than 30 miles from two major cities on the East Coast. The area is very ethnically diverse and well educated. This school system has got to be kidding itself if they think Mary is the "only one."

So I take pride in my mantra when someone across from me is sitting so smug in his chair. I mention how infectious diseases are spread through injecting drug use (many are still smug). Then I mention sexual partners and how rare it is to find two partners who have never been with anyone else (very few are smug, but college was a long way off and they feel safe from their past sexual activities).

Then I start working my way down to tattoos and body piercing—even earrings. (By now he or she is sagging). Then I mention the 40 percent of people with HBV infection who have no idea how they contracted the virus. Sometimes people just need to have things put into perspective. Viral hepatitis is completely non-discriminating. It cares nothing about race, religion, gender or socio-economic background. We are all vulnerable.

