

# DELIBERATE DECEITS

Protecting Children in Daycare and School

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## *A Parent's Perspective*

### **Coping with the Necessary Deliberate Deceits**

By Claudia

When our son first came home seven years ago at age 18 months, we told neighbors and friends indiscriminately about his hepatitis B viral infection. We didn't think the implications of disclosure through at all; we just blurted the information out in our confusion and panic.

We didn't know a thing about hepatitis B, and we were desperately seeking information from anyone. We were very lucky in that our neighbors and friends have (with one minor exception) fully and completely accepted our son.

He regularly plays with other children on the block, sleeps over, and is handed a bandage whenever he gets a cut. The one minor exception was when one neighbor lobbied us pretty intensively to use her daughter as a babysitter. I knew her daughter had not been vaccinated against the hepatitis B virus because, at that time, only children of about seven years or younger had been affected by the state law requiring vaccination.

We did not know this neighbor particularly well, but given the general climate of acceptance we had encountered among our other neighbors, we decided to tell her, hoping she would agree to have her daughter vaccinated. She declined, and gave as her reason the fact that she had been vaccinated because of a previous possible exposure, and had found the shots to be extremely painful.

Because I myself was receiving shots at the time, I knew they were not at all painful. This neighbor, nonetheless, has been very friendly and pleasant to my son. On the other hand, another neighbor chose to have her daughter vaccinated so that her daughter would be able to babysit our son.

## **Daycare**

When it became time for my son to attend daycare, we were very fortunate. A local nonprofit agency provided a service in which they contacted potential daycare centers for us and discussed my son's hepatitis anonymously. We were able, therefore, to "shop" for childcare at licensed facilities without having to disclose my son's status.

Some centers in our city receive government funds in the form of voucher payments for subsidized daycare slots. This meant they should be aware of rules and regulations that prohibited discrimination based on a person's disease status and would be well-trained in universal precautions. And, indeed, this was true.

We switched daycare centers after about a year without the aid of the local nonprofit. The new center had a much higher quality program, was more reasonably priced, was right down the block from us and had a very flexible schedule. The children of one of our neighbors attended this center, too. In other words, it was perfect.

I held off from revealing my son's hepatitis status until right before he was due to start. I was terrified because I wanted him to go there so very badly. In some ways, the director's response to my disclosure is the most painful experience that I've had to go through when dealing with my son's hepatitis.

When I told her, she received the news with complete calm and acceptance. She told me that her twin sister also had a hepatitis B viral infection, which she had probably acquired during her kidney transplant operation. (The daycare director was the donor.) She was well aware of all the concerns and fears that her staff might have about dealing with my son. She told me not to worry. Because of her familiarity with the disease, she knew she had nothing to fear from my son.

She made sure her staff was educated about the hepatitis B virus and how it could not jeopardize their own health. I felt lucky because I knew her own experience with the disease made her a wonderful advocate for my son. It is sad to me that I feel lucky because of another person's ill health.

In response to concerns the staff had, she called in a public health nurse to educate the staff about the virus. She also arranged for one child, who had put off the required hepatitis B vaccine because of an allergy to eggs, to start the program one month late in order to have received the first two shots before joining the classroom that he and my son would share.

I know the director did not disclose my son's name to this person, because of a conversation I had with her a few years later about the postponement. In the three years that my son attended that daycare center, he was never in any way treated any differently from any child. His tears were dried and his scrapes were bandaged. He was hugged and kissed as much as anyone else. And next week, he will be returning to be a "teacher's helper" with the toddlers.

### **Accidents**

When we adopted our son seven years ago, there wasn't the support network available to children with hepatitis B that exists now. It felt like we stumbled through all our decisions with almost no guidance.

For quite some time, I refused to let my son be supervised by anyone who was unaware of his medical status. Given the culture of his daycare center, over time this began to be somewhat peculiar. I think I got the reputation as being a somewhat over-protective mom. So, at my husband's urging, I agreed to let a mother we were friendly with take my son to the playground with her daughter.

About 30 minutes after they left, the mother returned with my son in her arms—he was crying and bleeding badly out of a gash in his lower lip. We were forced to tell her that she had been exposed to the hepatitis B virus. This, of course, caused an uproar in her life because she immediately had to get tested and possibly vaccinated.

That day was probably the worst of my entire life, because I feared that my decision might have caused another person to contract an extremely serious and potentially life-threatening disease. She is a single mother, and I could not stop myself from imagining that my actions would lead to her daughter becoming an orphan.

It took a bit of work, but I was able to repair the relationship. A key part of this, I think, was the fact that the mother found out that she was immune to the hepatitis B virus. She had no idea that she had had the disease, and successfully fought it off, at some time in the past.

### **Rejection**

One of the reasons I had agreed to this play date was because we had experienced the fear and pain of having our son rejected because of his hepatitis B infection. Since I was at home almost full-time with my son, I was eager to connect with other nearby stay-at-home moms of similar-aged children. I had posted a notice in my neighborhood

supermarket and had found a mother and boy who seemed congenial.

After two or three months of fairly regular play dates, I told the other mother of my son's status. She, at first, was very sympathetic. However, after consulting her pediatrician, she decided that our children could no longer play together. I was devastated, and my husband, while supportive, could not help but remind me that he had advised against disclosure.

We put the incident behind us, and as my son moved into public school we were delighted to find out that he had lost the e antigen. At this point, we felt that we could safely allow him to go on play dates unsupervised by us. However, much to my surprise, the boy whose mother chose to break off contact with us wound up not only in the same school as my son but also in the same kindergarten classroom.

I had not expected this because in our city parents may choose to send their children to any school in the city. We got through the kindergarten year somewhat awkwardly, and the mother, as far as I can tell, kept her knowledge in strict confidence.

When this boy and my son wound up being assigned to the same first grade classroom, however, we felt we had to request a reassignment. The awkwardness was too much to let continue for a second year. This meant we had to tell the principal and hope she would be sympathetic.

Although our city requires hepatitis B vaccination in order to attend school, I did not have to tell the principal of my son's school about his hepatitis. Disclosure to the school system had been made by the nurse practitioner in my pediatrician's office, and a nurse in the central office of the school system.

To our great relief, she was sympathetic and my son was reassigned. Given the small size of the school, which serves 300 children in grades kindergarten through eight, the fact that my son was moved into the classroom of the most-desired first grade teacher required us to come up with a plausible explanation to other parents. It wasn't fun lying to people whom we consider friends, but we felt we had no choice.

I continue to feel constrained and guilty and dishonest in my dealings with parents of my son's playmates, people whom I genuinely like a lot, and with whom I desire some level of friendship. I feel there is a very large, very important part of my experience of being a parent that I cannot share with people I otherwise feel close to.

We are exceptionally lucky in that we live in a very cosmopolitan, very progressive city.

By and large, people who work in the public sector are aware of the true health risks posed by children with hepatitis B and other bloodborne infectious diseases. They are also very aware of the legal protections for our children provided by the Americans with Disabilities Act.

Nonetheless, every time my son, who is very physically active, joins a new activity such as camp or Little League, I become very anxious and fearful. I don't know how I would explain it if he were banned from an activity. As yet, we have not disclosed his hepatitis status to him. Given his age and reading level, I feel certain his next visit to his hepatologist will require that we give him some basic information. I don't know what he will do with that. He is still young enough to let it slip out, but that is the chance we will have to take.

