

# BIOPSY

## When Your Child has a Liver Biopsy

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### *A Parent's Perspective* **Our Daughter's Liver Biopsy**

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*When a child with chronic hepatitis B or C has elevated liver enzymes, which can indicate that liver cells are being injured, your doctor may perform a liver biopsy before recommending treatment.*

*A liver biopsy is the only way to determine the true health of a liver. While liver Enzyme levels, revealed through blood tests, provide indications of liver health and while an ultrasound may find swelling or tumors, a sample of the liver tissue is the only way to determine the extent of inflammation, fibrosis or scarring.*

*Most liver biopsies take place at an out-patient setting in a hospital. But fasting before the test, the strangeness of a hospital setting and having to lie still for hours after the procedure can be challenging for young children and their parents.*

*Here is a description of a child's liver biopsy from a mother's perspective. The child, who has hepatitis B, underwent a liver biopsy when she was age 13 months old and then again when she was 32 months old.*

### **Our Daughter's Liver Biopsy**

When our daughter underwent her first liver biopsy, our plan was to have her admitted to Johns Hopkins Children's Hospital in Baltimore to have the biopsy and then spend that night in the hospital, after receiving her first injection of interferon alpha. Our situation was unusual. If she was only having a liver biopsy, she would not have had to spend the night. Because she was also receiving her first injection of interferon after the liver biopsy, she was to spend the night for observation.

The day before the procedure, our daughter had her blood work done to check standard

blood chemistry including Complete Blood Count (evaluating red and white blood cells) with differential, platelets and prothrombin times the day before. The tests indicate any abnormalities and whether a person is at increased risk of clotting problems or internal bleeding. The tests are performed again shortly after the biopsy and then again the day after the biopsy to check for internal bleeding.

Before the biopsy, she had to fast the night before the procedure until it was over. This proved to be tough in our situation. Her biopsy was scheduled and then cancelled time and time again because there were no available beds in the pediatric ward and because her procedure was considered a lower priority than others.



*artwork by Paige*

The first time we went to the hospital, we waited until 1:30 in the afternoon hoping a bed would become available so she would be able to start her interferon treatment and spend the required time at the hospital following her biopsy. She was miserable.

It was torturous for all involved. We had to get her up early in the morning to go down to Hopkins to have her blood work done. Unfortunately, we did nothing but sit around, stroll around, wait, and try to soothe an unhappy 13-month-old baby who was being deprived of all nourishment and water.

My husband and I felt terrible and helpless and the pediatric nurse felt badly for us too. We went the next couple of weeks with the pediatric nurse calling us early in the morning to let us know whether or not we could get a bed for the day. Finally, they decided to schedule the biopsy through the outpatient center and gamble that a bed in the hospital would be available after 5 p.m. Because of all of the delays, we had to have the blood tests run again.

Once again, we arrived at Hopkins in the early morning. As usual, our daughter had fasted since the night before. She screamed and writhed through the ultrasound examination, angry to have the doctor invade her personal space even though there was no pain from the procedure. The doctor marked a black "X" at the site on her abdomen where her liver biopsy would be taken from.

With the doctor's report in hand, we took her back up to the outpatient surgical center. We had been told she would be placed under conscious sedation, but because of her

irate response to the radiologist, they decided it would be better that she be completely anaesthetized. It is critical that the patient not move at all during the biopsy procedure. We were a little concerned about this change, but knew the risks of her moving while under conscious sedation during her biopsy were probably worse than having her put under.

The day of her biopsy was a scheduled pediatric day at Hopkins, so all the patients there were children. The kids had toys and videos while they waited. Both the anesthesiologist and my daughter's pediatric gastroenterologist (GI) came out to speak with us before the procedure. Our daughter was going to be given a liver-friendly anesthetic. I carried her into the operating room. She was frightened and screamed despite my efforts to comfort her. For me, the most difficult moment was holding her down while they placed the mask over her face, and listening as her screams wailed on and then faded away as she was put under.

My husband and I waited while the procedure was carried out. Her pediatric GI came out to tell us that she had given her a thorough exam while she was under and that the liver sample looked okay (just an eye-ball look!). Of course we would not have anything definitive until the biopsy report was read early that evening.

Our daughter was waiting for us in the recovery area. We could hear her screaming as we walked in. It was difficult settling her down and the nurses finally worked her IV etc. around so she could be comforted in my arms in the rocking chair provided. Because she was a baby at the time, there was no reasoning with her and even favorite objects from home were of little or no use. What made things worse, the IV was taped to her hand with a splint. It was bulky, cumbersome and foreign to her.

Our daughter was adopted from China. At this time, she had only been home with us for three months. She was not completely settled and was quite angered by the whole biopsy experience. Finally she settled down in my arms and went to sleep. They continued checking her vital signs every half hour or so, which would typically awaken her and set her off wailing again. Lab tests were repeated after four hours to assess if bleeding had occurred as a result of the biopsy.

Eventually, we were able to give her some juice and easily-digestible baby snacks. By 4:30 p.m. they had located a bed for her in the hospital, and we transported her from the outpatient center to the children's floor. We were lucky to have a private room, but she was not happy with a crib that resembled a cage. Her vitals continued to be monitored regularly while we waited for the results from the biopsy and her first injection of interferon alpha.

At 13 months of age, her biopsy report read as follows: “Mild panlobular hepatitis without extensive necrosis. Slight portal expansion and fibrosis, but no septate fibrosis and no evidence of cirrhosis.” We were later told that she was about 20 percent of the way to cirrhosis. (Keep in mind that liver disease progression is not linear, so this is in no way a timeline for her future with the disease.)

### **Second Biopsy at Age 32 Months**

Her next biopsy occurred when she was 32 months old. She had just experienced a pretty significant flare in her liver enzymes (ALTs/ASTs) and her pediatric GI recommended that we try another course of treatment. At this point, our daughter had been through six months of interferon injections and had been off all medication for one year. She was considered a non-responder.

She would begin one year of lamivudine following another liver biopsy. We were told she would also conclude her lamivudine treatment with yet another biopsy. Although this process is very difficult for parents, the information derived from biopsies is necessary to find treatments that successfully work on children infected with hepatitis B.

Fortunately, our daughter was much more settled into our family by this time and accustomed to the frequent visits to the doctor and the blood draws. We went into this biopsy with less apprehension than we had the first time. There would be no overnight in the hospital this time. The procedure would be performed once again at the Johns Hopkins Outpatient Center.

Again, she had her blood work done the day before the procedure. I cooked her favorite foods and she ate a large meal, then fasted until the time of the procedure. We brought some of her favorite stuffed animals and her blanket. I also packed some bland snacks, juice and a sippy cup. We also brought along some favorite videos.

A few months prior to this biopsy, she had undergone another procedure for her ears and had had extensive testing for growth hormones. She was becoming an old pro at this at the tender age of 32 months.

This time she sailed through the initial ultrasound without any complaints. Her black "X" was placed where the biopsy was to be performed. We brought her back up to the surgical center and got her dressed for the procedure. Once again, we spoke with the anesthesiologist and her pediatric GI.

She happily played with her surgical hat and showed off her outfit to all who would

indulge her. I carried her into the operating room, but there were no tears this time. She still fought the mask, but went to sleep more peacefully than the first time. My husband and I took our place in the waiting room and awaited the doctor.

Fortunately, her second biopsy went fine. Her doctor said she had never performed a biopsy from the angle she had used on my daughter this time (this entry point was recommended by the radiologist after he examined the ultrasound report). We went into the recovery room to find our daughter sound asleep on her stomach. She slept that way for an hour or so and woke up a bit disoriented and in need of comfort.

As before, her vitals were taken every 30 minutes or so and she had blood drawn after four hours to test for internal bleeding. She remained in the recovery area for the required six-hour minimum. (We returned the next morning to have the final set of blood tests done to ensure there was no evidence of internal bleeding from the biopsy procedure.)

She was much happier this time. She ate a popsicle, had some juice and some snacks. Her bed was elevated so she could watch her beloved Barney's Birthday video and snack on graham crackers. She was the perfect patient and the nurses were entertained by the antics of this toddler, who was so visibly at home with the staff.

Her biopsy results came back much as before and read: "Chronic portal inflammation and mild panlobular hepatitis without extensive necrosis. Mild portal fibrosis but no septate fibrosis or evidence of cirrhosis. Note: The changes are similar to those in the December 1998 biopsy specimen, and there is no evidence of progression towards cirrhosis." We were obviously relieved there had not been significant progression toward cirrhosis!

In summary, there was a huge difference between having a biopsy performed on a newly-adopted 13 month-old baby and a hospital-seasoned toddler who was nearly three years old. As a toddler, it was much easier to talk to her, comfort her and distract her.

For a baby undergoing this procedure, I would recommend taking a stroller for walking around or waiting, which you may be faced with in the hospital. It's very comforting for the child to be "strolled" around.

Although we brought a much-loved stuffed animal and her musical mobile, her greatest comfort was the perpetual singing of her mother (much to everyone else's dismay!). As a toddler, videos, stuffed animals, Mommy and Daddy's arms, and the hospital staff more readily entertained her. She was a much more willing patient. The stroller was still

a necessity, but the video, her blanket, and favorite snacks were equally important. In hindsight, I think deprivation of food and drink was a major concern for our daughter during both biopsies. I recommend to parents that if you feel the need to eat and drink, do so where your child cannot see you.