

## PATIENT PROFILE

### Tarrie Barnes

#### *Putting an End to a History of Hepatitis C*



Tarrie Barnes

Tarrie Barnes was 12 or 13 years old when, on the way home from church, she and her siblings walked by the Baltimore hospital where her grandmother was staying. The image of her grandmother waving to her from the window holds a special place in Tarrie's memory. "It was a sunny day," she remembers. "And when I think of my grandmother, I think of happiness."

Although she was too young at the time to comprehend exactly why her grandmother was in the hospital, Tarrie would learn years later about the disease that eventually took her grandmother's life. "I just happened to be reading her death certificate, and it said 'cirrhosis of the liver,'" she recalls. "And I thought, well, my grandmother didn't drink, so why would it say 'cirrhosis'?" When Tarrie asked her grandmother's doctor about the death certificate, he told her that her grandmother's liver had succumbed to a disease called, at the time, "non-A, non-B hepatitis."

For Tarrie, the diagnosis was a premonition of her own future struggles with a silent yet debilitating and potentially fatal liver disease.

#### **"Something Doesn't Look Right in Your Blood"**

Tarrie, who is now 65, had been very close to her grandmother. As a child she would rather join her family at her grandparents' home on Saturdays instead of going to a park to play. At the house, festivities would begin: guitars, harmonicas, and food. Her grandmother was a first-rate cook—she would "dip her finger in something and make it taste good"—and would always greet Tarrie and her siblings by offering them something to eat. Her grandfather would proudly stand with his family and "put his fingers under his suspenders and bounce on his heels, and say, 'Look at what I started. I started all of this,'" Tarrie fondly reminisces. She treasures the memories of those Saturdays with her grandparents. "I just feel blessed that I was in the family I was in. And anytime we saw my grandmother smile, it made the day even nicer."

Tarrie's grandmother died in 1988. A year later, scientists published reports identifying a new virus, the hepatitis C virus, as the cause of non-A, non-B hepatitis.

Then, in 1990, after she had donated blood, Tarrie received a troubling letter from the American Red Cross. The letter, she remembers, essentially said: "Something doesn't look right in your blood." The hepatitis C virus—the same virus that had stricken Tarrie's grandmother—was suspected to spread through blood transfusions, so the Red Cross had begun to screen their supply for

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infected blood. Also unsettling for Tarrie was that 15 years earlier, well before the screening had started, she herself had received a blood transfusion during surgery, meaning that she may have been exposed to the hepatitis C virus.

While the Red Cross letter stated that Tarrie could have viral hepatitis, it also mentioned the chance of a “false positive,” which meant there was a possibility she wasn’t infected even though she tested positive. (At this time, the screening methods were not as accurate as they would be a few years later.) Nevertheless, the Red Cross recommended that she have her blood checked, so Tarrie went to her doctor to get tested. The results came back negative. “I never thought anything else about it,” remembers Tarrie. “I thought [the original Red Cross test] was a false positive.” So Tarrie went back to her career at a telecommunications company and life with her husband and two children. But, at her doctor’s recommendation, she stopped donating blood.

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Nine years would pass. In the meantime, Tarrie started taking classes to fulfill her dream of becoming a teacher. But she also slowly began to experience symptoms that she casually attributed to aging, like many people would. She had occasional dizzy spells, sometimes to a point where she needed to hold on to her chair to keep the room from spinning. And sometimes she felt a pain in her side when she lifted something heavy. Tarrie didn’t realize she had liver

disease; she remembers thinking that “it was maybe my blood pressure.” Most of all, she was slowly getting tired more easily—something that, understandably, many people could experience without raising alarm. “Some days I would feel more tired than others. Sometimes I couldn’t do all that I wanted to do. I would get tired without knowing I was tired, because you’re just used to it. You don’t realize that something is going on.”

It is common for people with hepatitis C not to realize that they have the disease. In fact, most people do not have any symptoms until the virus causes significant liver damage, which could ultimately result in the need for a liver transplant. Prior to the discovery of the virus and routine screening of the blood supply, many people acquired hepatitis C through a blood transfusion—the virus is most commonly transmitted by its introduction directly into the bloodstream. Once in the blood, the virus then infects cells in the liver, slowly killing them and causing scar tissue to form. Exposure to infected blood usually results in a chronic (long-lasting) infection because the body cannot get rid of the virus.

For Tarrie, the diagnosis did not come until she went to her doctor for a routine checkup in 1999. Her doctor told her that her liver test results were abnormal, and it was recommended that she see a liver specialist—the same specialist, coincidentally, who had treated her grandmother. Still not realizing she was sick, Tarrie’s big shock came when the specialist walked into the examination room: “We’re not going to talk about a liver transplant” were the first words out of his mouth. Taken aback, Tarrie began to realize that she could be dealing with something serious.

By 1999, there was a more accurate test for hepatitis C, and Tarrie tested positive. After a liver exam, she was diagnosed with advanced hepatitis, which means her

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liver was damaged so badly by the virus that it was beginning to scar and lose functionality. If unchecked, the disease would ultimately cause her liver to fail.

## Managing Life with Hepatitis C

Armed with advice from her liver specialist, and knowing how the disease affected her grandmother, Tarrie began her fight against hepatitis C. Her liver specialist encouraged her to join a hepatitis C support group that he supervised, and she began to learn as much as she could. “My mother believed in education and reading,” says Tarrie. “She always made sure we read. I inherited that bug.” The support group was a diverse assembly of people with hepatitis C who shared their experiences and learned from each other’s struggles and successes. They discussed the symptoms they were having and how to deal with them. They talked about the changes in lifestyle they should adopt when dealing with a damaged liver, such as eating healthy and avoiding alcohol. When you have advanced hepatitis, you need to be careful, says Tarrie. “Anything you put in your body goes to your liver.”

Tarrie eagerly soaked up knowledge about hepatitis C while giving encouragement to other members of the group. “By that time I was 51, and I had become more of a talker,” she says. “I liked sharing. I liked learning about what was going on. And we did help each other....It was a good thing.”

Tarrie’s liver specialist also convinced her to undergo a 6-month clinical trial at the hospital in Baltimore. She went on medical leave from her job, because “I wasn’t sure about what I would be facing,” she recalls. Her support group had prepared her for potential side effects that would come along with anti-hepatitis medications. “I was told what I might

experience would be similar to chemotherapy. You might lose your hair, or get chills or a fever. It affects each person in a different way.”

The treatment ultimately wasn’t successful for Tarrie, and her hepatitis remained at an advanced stage. But this was still only the beginning of her long, complicated battle with hepatitis C.

## The First Trials at the NIDDK

Shortly after Tarrie’s diagnosis, her daughter, then a biology major at Bowie State University, was selected for a research internship at the NIH. “She is so smart. She gets it from my mother, not me,” Tarrie says glowingly of her daughter. “She loves biology.”

Inspired in part by her mother’s predicament, Tarrie’s daughter began working in the laboratory with Dr. Theo Heller, a clinical investigator in the NIDDK Intramural Research Program, under the direction of Dr. T. Jake Liang, Chief of the NIDDK Liver Diseases Branch. She was a part of one of the first teams to successfully produce the hepatitis C virus in cultured cells, a major milestone that allowed scientists to study the life cycle of the virus more closely. She also told Dr. Heller about her mother, and he suggested that Tarrie participate in a clinical trial at the NIDDK. Dr. Heller “asked my daughter three questions about me,” Tarrie remembers. “Did I join a study? Did I complete the study? Did I still have hepatitis C? The answer was ‘Yes’ to all three. From that, I qualified to go there.”

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*“I enjoy going there,” says Tarrie of her visits to the Clinical Center. “Everyone there at NIH has been so nice....It’s like a big happy family.”*

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In 2001, Tarrie enrolled in her first NIDDK clinical trial at the NIH Clinical Center in Bethesda, Maryland. For 6 months, she took a combination of two antiviral drugs: interferon, which helps the body to defend itself against viruses, and ribavirin, which slows the replication of viruses. The treatment brought her virus levels down, and her liver began to show some signs of recovery. There were side effects, but for the most part they were manageable. “At the beginning I was in bed with chills and fever,” recalls Tarrie. “Then I was just tired, but I didn’t realize that the tiredness was probably more from the hepatitis.”

By the time Tarrie completed the trial, the drugs had reduced the amount of virus in her blood, but they did not eliminate it. The virus continued to multiply over the next few years, and the condition of Tarrie’s liver regressed. It didn’t stop her from achieving her goal of becoming a teacher, however. In 2006, she graduated from Morgan State University and started teaching the first grade. But her health continued to decline, and she reluctantly decided to retire after a few years. “I didn’t really have a choice,” she remembers. “I could tell that confusion was starting to set in, and it was starting to interfere with my ability to teach. It was emotional ... because I didn’t want to leave.”

Still, Tarrie was not discouraged, and she enrolled in another trial at the NIDDK, using a drug regimen similar to her last trial. However, this time one of the drugs was coated in lactose—and Tarrie didn’t know she was lactose intolerant. “That trial was my worst,” she recalls. “That really did me in. I was living in the bathroom.” Determined nonetheless, she completed the grueling 6-month trial. But the treatment did not clear her of the virus—it soon rebounded again, and Tarrie was back at square one. Yet, she still held out hope.

Tarrie gives accolades to her faith and her family for helping her through the rough times. “Life has been an adventure,” she says. “Faith has gotten me through a lot. And just having a loving family has made all the difference. It all started with my grandparents—letting us know to put God first, then family, and friends. As long as you have that love that connects you, you can get through anything.”

### **One More Clinical Trial at the NIDDK: Saying Farewell to Hepatitis C**

After three unsuccessful treatments for her hepatitis, Tarrie once again signed up for a clinical trial at the NIDDK. She was encouraged by breakthroughs in the understanding of the disease, and she had developed a close relationship with Dr. Heller. “He’s fantastic. He told me they were always working on new and better medications. The more they learned about the virus, the better the medications they could get to help clear it.”

The trial was, in fact, testing two new drugs called daclatasvir and asunaprevir that directly target specific components of the hepatitis C virus. Also, due to advances in the understanding of the virus, the staff at the NIH Clinical Center were able to identify the subtype that had infected Tarrie: it was called “genotype 1b.” Because different genotypes of the hepatitis C virus can respond uniquely to different medications, knowing the genotype allows doctors to predict how successful a treatment will be. In Tarrie’s case, the “b” was crucial. “I was excited when they told me that I was type b, because that meant I didn’t have to take interferon [for this trial],” she explains.

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Tarrie began the 6-month trial near the end of 2013. Three months after she completed the study, the virus could no longer be detected in her blood—the new drugs had worked. Tarrie was ecstatic. Moreover, the two pills she took had absolutely no negative side effects. “It was like heaven compared to the last study,” laughs Tarrie. In fact, Tarrie was so thrilled by the results that she presented Dr. Heller with a challenge: if she remains clear of the virus, he will have to dance a jig for her. When Dr. Heller said he didn’t know how to do the jig, Tarrie responded playfully, “Google it!”

## **A New Chapter: Living Hepatitis-free**

The hepatitis C virus has now been undetectable in Tarrie’s blood for over 8 months, which means the odds of the virus recurring are very low. Her dizzy spells have become less frequent. In September 2014, she

flew to Hawaii to visit her son, who is a naval officer, and to celebrate her 40<sup>th</sup> wedding anniversary with her husband. She still makes visits to the NIH to have her progress monitored. “I enjoy going there,” says Tarrie. “Everyone at NIH has been so nice. The first or second time I went there, they already knew my name. I would even see doctors who I didn’t know, but knew of my case, and they would say ‘Hi, I heard you were doing well.’ So, it’s great. It’s like a big happy family.”

Not only has Tarrie’s health improved, but her participation in the trials at the NIDDK also allowed her to contribute to the ongoing research on treatments for hepatitis C. “Those two pills, I think they can help a lot of folks,” she says, referring to the two medications she took during her last NIDDK trial.

Tarrie holds a deep admiration for her grandmother, the woman who always made her happy. She would love the opportunity to continue to share the same happiness with her own grandchildren—in fact, she once told her church pastor that all she wanted to do was to live as long as her grandmother did.

Thanks to Tarrie’s perseverance, along with a good dose of progress in medical research, she is well on her way.