



The Phone Call That Changed Her Life

In an excerpt from her new memoir, *Still Positive*, Julie Lewis recounts when she discovered she was living with HIV.

June 8, 2023 By Julie Lewis with Jenny Koenig

It's the end of the world as we know it and I feel fine —R.E.M.

Wednesday, August 15, 1990, was a normal summer morning, not a sunny day, but definitely summer, warm and muggy. Exhausted from packing our house into moving boxes, I sat on the front steps trying to catch my breath and muster up the energy to finish the task at hand. I stared at the flowers in the yard I was about to leave behind, gazing at our neighbors' houses and taking in the cul-de-sac that had been my world for the past four years. I thought my life was about to change drastically because we were moving to a new city, miles away. This seemed like a milestone, a big deal. I had no idea that in a few moments the definition of a "big deal" was going to be lifted to a different level. The direction of my life was about to take a major detour.

The phone rang in the kitchen.

When the conversation started with "You'd better sit down," I knew with certainty that it wasn't going to be good news.

I can still hear the voice of my doctor from Bellingham on the other end of the line. "Do you remember the blood transfusion you had when Teresa was born?"

"Yes," I replied.

"Well, this is probably nothing to worry about, because it was six and a half years ago," he said, "but the blood bank just contacted me to inform us that one of the three people who donated blood for your blood transfusion now has AIDS."

I felt the blood draining out of my head as I stared at Scott from across our dining room table, making sure he could hear the whole conversation.

"They are suggesting that you get an HIV test."

Silence.

He went on, "Now, this donor could've been infected after your blood transfusion so don't get too

worried about it yet. There's a good chance you're just fine.

Awkwardly ending the phone conversation, I looked at my husband for some hint of assurance that everything was going to be okay, that this was not real. He looked concerned, but in true Scott Lewis fashion, he hid any inclination to panic. Nonetheless, inwardly, in that same moment, I knew in my gut, absolutely, positively, that I was infected with HIV.

For more than a year, normal effort had made me unusually tired, exhausted really. I'd visited several doctors and each time they would look at me with calm, "parent-like" eyes and say, "Oh, you're just so busy. You have so much going on; you have three little kids. You're exhausting yourself; you need to get some rest.

But, deep down, I knew what being exhausted felt like. I chronically did "too much," always burning the candle at both ends. This was different. I started thinking about diseases the medical community didn't give much credibility to, like chronic fatigue syndrome. I absolutely knew something was wrong with me, besides general tiredness.

His words went through my head again: "You should get an HIV test." This was the missing puzzle piece I had been searching for; this was what was wrong: I had HIV.

That call began the longest and hardest five days of my life. Hanging up the phone, my entire perspective changed in a moment. Things that had been important an hour before meant nothing to me. I no longer cared if my dishes were packed securely or if the boxes were being stacked in the truck properly. I could sense my body performing tasks, going through the motions, but my mind had disconnected.

Scott and I visited our doctor that day to strategize how to get tested without alerting our insurance. In 1990, a positive HIV test could elicit an insurance cancellation with no alternative replacements. He arranged a private test we could pay for in cash to be performed the next day. At the time, there was no definitive HIV test you could take and get the results back within hours. He explained it would take one or two days to receive the results.

Often, in extremely stressful situations in my life, there's some weird sideshow happening that makes me laugh. Well, the day I got my HIV test it was our nurse who provided that moment of comic relief. She started by getting out her notebook from a class she had taken about HIV testing and counseling. Opening it up she read the protocol, word for word. She appeared visibly nervous, continuing through the lengthy notebook in the most awkward way imaginable. Clearly, I was the first person she had ever tested.

I felt bad for her. She was literally shaking. In my heart I rooted for her, trying to make our answers as specific as possible and constantly giving her a reassuring look that she was doing great. Scott and I laughed about the whole scene on the way home. Of course, my insides were numb, heavily in denial ... the thing your body does when you hear bad news and start to think that maybe, just maybe, God will be extra nice to you and somehow, you'll wake up from this dream and go back to life as you knew it.

The next morning the nurse called to confirm. My test was positive. She said that I should return to the clinic for a more specific test, the Western Blot, to make sure the screening test was not a false positive. She explained that we needed to bring every member of our family in for HIV testing.

Again, my stomach sank to the floor.

Teresa was born before my blood transfusion, but because I had breastfed her, she had a small chance of being infected. Our other two kids, Laura and Ryan, were born to an HIV-positive mother and each had about a 25 percent chance of having contracted the disease from me. Lastly, there was Scott. I'd been pregnant two of the years of my infection, and then Scott had a vasectomy. We hadn't protected ourselves the prior six years from what we didn't know was there. We never once used a condom. Statistically, we were told, Scott had a high chance of being HIV positive.

Piling into our old Volkswagen Vanagon, we set out to the doctor's office to get our blood drawn. It was Thursday, August 16th. On that drive, looking in the backseat at our kids, my emotions started to kick in. There they were ... my babies ... the three people in the world I would give my life for, my two-year-old, four-year-old, and six-year-old on their way to get tested for a disease that would not only most likely kill them but also that had so much stigma, so much discrimination and baggage connected to it, that I knew it would shatter their innocence. Fighting tears, I looked out the side window, trying my best to keep them from thinking anything was wrong.



I started performing mental gymnastics to remember which one of my kids had been sick the most, which one of them had been the smallest, which one of them had had the most sinus infections, and which one had displayed any kind of sickly look. I kept coming back to Laura. Laura had struggled to gain weight all her four years. She threw up almost everything she ate until she

was nine months old, which was attributed to food allergies. Even then, she was only in the fifth percentile in weight. In my mind I just reconciled that Laura was probably infected, and Scott. And, of course, me.

Because we received the results of my first test in one day, I expected the same for my family. Instead, the nurse told us that the lab was closed on Fridays so they would call us on Monday. In four days.

We headed home to our almost-empty house with the moving truck sitting out front. Opening the garage, I confronted a mountain of baby goods spilling across the floor. I had thrown it haphazardly into a heap to pass on to the couple who had bought our house. They were expecting their first child. There it all was, lying there, staring at me. Six years of baby paraphernalia taking up almost half of the floor. If these parents knew that we had gone for HIV tests, would they just burn this stuff?

We decided we were going to tell almost nobody about any of this HIV drama. There were so few people we could trust at that point. This was the era of Ryan White, who had died in April of 1990. Only a teenager, he had been in the national headlines for several years, not being allowed to go to school for fear he would spread AIDS.

Also in the news was the Ray family, in Florida. They had three young boys who all had been infected with HIV through blood products for hemophilia. A week after a judge had ordered their school district to allow the boys to attend public school, their house was burned to the ground, and they had to move. These were the stories we followed in the media; there was hardly an article or story about AIDS that wasn't cloaked in fear.

That weekend, waiting for the results, we barely slept. I lost several pounds. Nothing looked appetizing, and nothing tasted right.

I kept thinking, "When I die and Scott dies, who is going to raise our kids?" We had good friends and awesome family members, but I couldn't think of one of them, not one, whom I wanted to raise my kids. I couldn't talk because when I did, I usually ended up crying and I didn't want to let on to the kids that something was seriously wrong. My brain was numb; my heart was broken. Life as we knew it was over. Our world was a mess, that much I knew. I was just waiting until Monday to see how big of a mess it was going to be.

Monday morning finally came. It was supposed to be Scott's first day of work in a new town, three hundred miles away. He called in sick. I'm not sure what he said to get out of work that day, but I am sure it wasn't, "Sorry I can't make it in. We're just sitting here waiting for our HIV tests to come back to see if we have AIDS."

The phone rang. I picked up the receiver and could barely believe the nurse's words: "Everyone in your family is fine, no HIV." I had braced myself for the worst possible news; every muscle in my body was tense and prepared. Tears ran down my face and my body breathed a huge sigh of relief.

But then she added the clincher, “Unfortunately, your second test result came back positive. You are definitely HIV positive.

Since getting those test results, I’ve met so many people who are HIV positive who say that getting their diagnosis was the worst day of their life. But that Monday, I also found out my family, my whole entire family, for some inexplicable reason, was spared this disease. That was such good news it made my own HIV diagnosis not feel so bad in the moment.

I’d survived the worst week of my life, and all I could think was, “I’ll figure this out. I can handle this.

We got in our moving van that afternoon and drove across the state to our new home, three hundred miles away.

[Click here](#) to purchase a copy of Still Positive.

Julie Lewis, a 38-year AIDS survivor, and mother to Grammy Award winning musician, Ryan Lewis, was infected with HIV in 1984 but not diagnosed until the early 1990s when she was given three to five years to live. After years of silence about her disease, she found an unlikely community of friends to fight alongside and began using her story to make a difference. Her experiences as a woman living with AIDS offers insights about grief and loss, caregiving, spirituality, and the importance of community in the midst of tragedy.

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