

*Chapter 5, Jamie Schanbaum, from "Overlooked Casualties: Stories of Families Affected by Vaccine-Preventable Diseases" by Tara Susan Haelle (MA dissertation, University of Texas at Austin, 2012) is reprinted here with the author's permission.*

Jamie Schanbaum has spunk. With long, curly black hair – a source of immense pride – and an incisive sense of humor that spares no one, including herself, Jamie is not the type to brag about her accomplishments, like recently winning the National Championships in Paralympic cycling, or to cry in her coffee when things get tough. In fact, she counts herself as pretty darn lucky: she's missing two hands and two lower legs, but she has her life and her brain intact.

And that's more than most bacterial meningitis survivors can say. That's not to say she didn't have to overcome the depression she experienced after she got sick. After more than seven months in the hospital and three more months before she could walk again, Jamie sometimes had to fight to remind herself who she was. But now, she takes every opportunity to ensure others know who she is too – if only to convey the importance of avoiding the experience she endured.

On November 13, 2008, Jamie was a 20-year-old University of Texas at Austin undergraduate who was doing about the most mundane ritual any other student might have been doing on a Wednesday night besides studying – finishing up her laundry at a friend's house. After she had been there a couple hours, she wasn't feeling well and took a nap about 8 p.m. That turned into an overnight stay with excessive vomiting accompanied by extreme weakness throughout her body – she couldn't even walk to the bathroom. In the morning, though she was hardly better, she gambled that she could probably go ahead and drive home, where the climb to her third-floor apartment left her so sick she couldn't keep anything down, not even water. She also noticed an odd sensation in her feet when she walked on the kitchen tile, a hypersensitivity that she hadn't experienced before. And she was so cold that even hibernating under a pile of blankets didn't offer her any warmth. Soon she had trouble walking, her steps becoming slower and more painful. When her sister called to check on her, Jamie told her to come over.

"So she came over and you could see in her face that she was really worried," Jamie says. When her sister touched Jamie's limbs, she recoiled and told her not to touch. "Then it clicked that it was very serious and we had to go to the hospital."

By the time they got down the steps, into her car, and two blocks away at Seton Medical Center, Jamie could no longer walk. Her entrance to the ER led to a flurry of activity, and a doctor asked her sister where their mother was. When she said their mother was out of town, the doctor didn't mince words: "She needs to be here right now."

"And Roni, my sister, looks at me directly across the room and we were both... we didn't say anything," Jamie says. "She knew that I heard and she just didn't know how to react. Then I was totally knocked out from there on out."

Though it took a couple of days for the test results to come back, the medical staff instantly recognized the symptoms of bacterial meningitis and began Jamie's treatment right away. But the severity of the illness still hadn't set in for Jamie. Her thoughts were, "Ok, cool, let's get this over with. Clean it up. Let's get out of here." She figured two weeks, tops. Instead, the next

seven months went by in a confusing, highly medicated jumble of disparate memories.

"I wasn't in a full coma, but I was very highly sedated," she says. "I had tubes in my mouth, I wasn't allowed to talk, my limbs were swollen, and I'm watching my limbs turn from red rash to purple to black, dead skin."

Though bacterial meningitis can live in a person for months without incident, one "spark" and it goes into overdrive. The body responds by entering "emergency shutdown mode," Jamie says, cutting off circulation to protect her inner organs.

"That's why my limbs ended up being what they call necrotic," she says. "They ended up dying. They looked like old raisins. Literally black socks up to my knees. Rotten. It was gross. The smell was terrible, and as soon as you lifted the blankets it was like I was half dead. I was in so much pain I couldn't even roll over."

The pain seemed unending. Jamie says she couldn't lift her arms over her head for three months, unable to hug anyone or lift anything. The doctors told her mother they would need to amputate her forearms and her legs above the knee, but her mother held off on the surgery, searching for better options. In early December, Jamie was transferred to St. Joseph's hospital in Houston, where she received hyperbaric chamber treatments daily for 50 days to provide more oxygen to her limbs.

"It was terrible," Jamie recalls. "If you went to my room, it was Antarctica, it was so cold, because I was really hot and my body was sweating all the time. There was nothing in there to help me make it a painless ordeal, but I had to do it every day."

By the time she did undergo surgical amputations in February, she had been having surgery at least once a week to manage her wounds. She thought she had already been through the worst pain she would experience, but the amputations were worse. They were able to avoid taking as much as she had been told, amputating both legs below the knee and parts of her hands, leaving the bottom halves of her fingers but skin grafting over them like a skin-glove to prevent infection.

"It's just an unbelievable, unbearable amount of pain," she says about the dressing and wound care after the surgery. Despite taking several doses of a painkiller stronger than morphine, she remembers screaming as the nurse ripped off long pieces of gauze.

More challenges lay ahead. She became depressed. She had lost her appetite from so much vomiting over the previous months and had trouble eating more than a single serving of applesauce for up to two days. She threw up every day, but because she couldn't move, someone had to hold her neck up and place a bucket in front of her face to catch the vomit. Her malnutrition became so severe that her hair fell out in clumps.

"I remember being wheeled out and I saw my reflection in the mirror and I was like, 'Whoa, whoa, whoa, whoa! Go back, go back!' And I'm like, oh my god. I was just in shock," she says. "I had lost my hair. I love my hair. I had bald spots here and here and there, and I lost about 80 percent of its length and 20 percent of its surface area."

Slowly, Jamie began to recover. When she was released to go home with her mother and sister, her family's tough love and regular physical therapy left her no choice but to work to get better. By August, after three months of trying, she was able to walk tentatively on her own. A year later, thanks to the encouragement of her prosthetist, she was learning how to ride a bike with her prosthetic limbs. Today, with her long hair grown back and her humor intact, Jamie doesn't hesitate to point out how lucky she is.

"When you get meningitis, you could be blind, deaf. You could have mental challenges after," she says. "You could have super organ failures and have to take 20 pills a day." Yet her amputations and scars are all she has, she says.

That hasn't left her complacent, though. She knows that she contracted meningitis because she wasn't vaccinated. Together with the parents of Nicholas Williams, she advocated for the passage of the law that requires Texas college students to get the meningitis vaccine even if they don't live in on-campus housing.

"I always think how I would react before, if this didn't happen to me, like, oh, what a drag! I have to go and get this vaccine," she says. "But now, on the other side, it's like I'm protecting people whether they know it or not, and they could have been a victim if they didn't get the vaccine. So I still do think of it as a really powerful and amazing thing."

She also thinks it's important that others understand what the disease is and what it can do to a person. Getting a shot is one thing, but without understanding that meningitis can take a person's limbs, mind, and life, the message doesn't always get through.

"It's unfortunate that tragedy has to hit in order for something to change," she says. "I wouldn't be advocating for this if I didn't get sick, right?"