

Lib at Large: Huntington's sufferer puts a human face on a cruel disease

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CHRIS FURBEE is in a race against a disease that killed his mother, his aunt and his grandfather. Like them, the 46-year-old caregiver and part-time musician has Huntington's disease, a genetic brain disorder so cruel it's been likened to suffering from cancer, muscular dystrophy and Alzheimer's at the same time. There is no cure for it, and it's always fatal.

His goal is to shine some light on a little known disease. Older people may be aware that Huntington's took the life of the legendary folksinger Woody Guthrie, but that's about all they know. Younger generations may not even know that.

To raise the money he needs to finish post production, Furbee and his friends are organizing "Furb on the Green," a concert on Sunday at McNears Beach in San Rafael, where he used to work as a park aide. It's the seventh straight year he's put on a benefit show for the project. This one, he's certain, will be the last.

"It's going to happen this year," he says one afternoon at a coffee shop in San Rafael, banging his fist on the table where he's sitting. "I'm not sure what the date is as of yet, but I'm going to finish it this year."

Furbee grew up in West Virginia, living with his divorced mother, who was showing the early symptoms of Huntington's disease but wouldn't admit it to him or anyone else. Right after graduating from high school in 1984, he left home and headed west, settling in Marin County.

"I didn't want to be an unemployed coal miner, and I needed to get away from Huntington's disease — 3,000 miles away," he remembers.

He hadn't seen his mother in five years when he got a call from his aunt that she was gravely ill and needed help.

Furbee is now a personal care provider for mentally ill adults at Buckelew Programs in San Rafael, where he lives several days a week. But back then he was working in a photography store and had become interested in filmmaking. So when he returned to West Virginia to look in on his mom, he took a movie camera with him.

He was gripped with anxiety as he drove the rural roads to his mother's modest house. Stepping onto her front porch, he had no idea what would await him when he opened the door.

"I knew it was going to be bad," he says, his voice quavering with emotion. "But I had no idea how bad."

Once inside, he didn't recognize the emaciated woman asleep on the couch. He thought at first she was his aunt, and went into the kitchen expecting to find his mother there, but the kitchen was empty. There was no one else in the house.

"I realized that woman on the couch was my mom," he recalls. "It was one of the hardest moments in my life. Tears just started rushing out of me. I went outside and let go, let out all the emotion and pain I had."

Furbee spent two months with his mother, filming his interactions with her. That footage — of her writhing on the floor, unable to control her body or her mind, her words twisting tortuously in her mouth — are in the sample reel he shows when he gives talks on Huntington's disease.

"People are speechless after seeing it," he says.

His mother ended up in a nursing home, where she died a few years later. Her story pushed him to keep plugging away at his documentary. And he realized he could no longer be in denial about the disease, to go blithely along not knowing if he had the Huntington's gene or not.

With one parent afflicted, he understood that he had a 50-50 chance, one way or the other. And he knew that if he

tested positive, he would get the disease. It was just a matter of time. There was no getting around that terrifying fact.

A year after visiting his dying mother, he decided to have the DNA test that would reveal his fate. It came back positive. He was 30 years old. An only child, he has never married or had children for fear of passing the deadly gene to the next generation.

"I was devastated," he recalls. "It was heartbreaking. I can remember being numb for two weeks. I couldn't sleep. I just stared at the ceiling."

Depression and suicide are common among Huntington's sufferers, but Furbee slowly pulled himself out of the gloom, finding some relief in humor.

"I decided to take my life back," he says, smiling. "I wrote a letter to life, complaining about his job performance. I told life that if things didn't change for the better, I was going to go over his head. It was a way for me to deal with all this stuff. Eventually I came out of my funk."

But he didn't do it alone. He's done a lot of talking with Andrea Zanko, a genetic counselor at the University of California at San Francisco. She'd given him his dreaded test result and helped him deal with it. He also attends a monthly Huntington's group she facilitates at Westminster Presbyterian Church in Tiburon.

"He's really taken this on like a warrior," she says. "He has decided with great integrity to put a human face to this disease, so that people understand it and want to help in any way they can."

Now close friends, she and Furbee teach classes together for medical students at UCSF and at Stanford.

"Those people will never forget him," she says. "Whether they become scientists or physicians, they will have his story in their minds, and they will never forget it. He's done an amazing service for this condition. He's my inspiration."

Now that he's in middle age, Furbee notices some of the symptoms of Huntington's. When he inadvertently saw a video of himself recently, he was taken aback by the jerky movements his hands were making.

"My symptoms are getting worse," he admits. "And, to be honest with you, I've been having a hard time, knowing that's happening. But when I was talking to a friend of mine recently and he said I looked good, I realized that I'm finally at peace with all the stuff I've been going through. I go to meetings once a month and see my friends get worse and worse. Some of them are my age and are in nursing homes. Some are dead. So I'm fortunate to be where I am with this disease."

Furbee is more than well enough to play bass in Ik Nak Fu, a band that is on the bill at his upcoming concert. And he's up for the task of finishing "Huntington's Dance," to show it to more people, especially those in the medical field.

"Instead of being a paragraph in a medical journal, which they may or may not remember, these future doctors and researchers are going to remember me and my mom," he says. "That is the important thing for me."

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What: Furb on the Green VII

Where: McNears Beach Park, 201 Cantera Way, San Rafael

When: Noon to 7 p.m. Sunday

Admission: Free, but 100 percent of food and drink sales go to "Huntington's Dance"

Information: www.huntingtonsdance.org.