

## Marin 10: Chris Furbee, and the 'Dance' of his life

by David Templeton | Posted: Thursday, August 29, 2013 9:00 am

When musician-filmmaker Chris Furbee set out 18 years ago to make a documentary about his mother's battle with a rare and incurable brain disease, he had no idea that before it was finished he would become a subject of the film as well.

Furbee, who lives part-time in San Rafael, is now showing symptoms of Huntington's disease, the little-known, genetically transferred illness that disabled his mother and eventually led to her death.

"When I went back to West Virginia, 18 years ago, to take care of my mom," Furbee says, "and I started shooting all this footage, I was doing it as therapy, in a way. It helped me face what was going on with my mom, And then I started working toward turning it into a film about Huntington's—but, no, I had no idea that it would turn out the way it is today."

As a born filmmaker and storyteller, however, the 47-year-old admits that from a certain ironic point of view his situation does have certain artistic benefits.

"Here's the thing," he laughs, "and this is the truth. Right before I found out that I had the disease, waiting for the test results, what went through my head was, 'I hope I don't have it—but if I do...it's going to make an even better story for the film!' That's really what went through my mind! It's kind of weird, I guess, but I've always been honest about this, always wanted to tell the truth about Huntington's. So for me, there has never been a question about leaving anything out. When I was diagnosed, I knew that I was going to make that a part of the movie."

The film, called Huntington's Dance ([www.huntingtonsdance.com](http://www.huntingtonsdance.com)) is nearly finished. It's edited, sans sound mix and color finishing, and it's already been entered in some film festivals. Furbee has been hard at work raising the money to complete the project and then fund the expensive process of entering film festivals and traveling to promote the film. The year ahead will, hopefully, see the completion of an effort that is close to his heart in more ways than one.

Named for the strange, jerky dance-like movements of those with late-stage Huntington's disease, Huntington's Dance, includes some deeply moving footage of Furbee's mother, "dancing" through her house, writhing on the floor.

"I started it as a kind of diary, a way for me to escape from what was going on with my mom, to use the camera as my confidante," he explains. "I didn't have anyone there to talk to as I was going through this, so shooting my mom through the camera was great for me.

That footage, in ad-dition to grounding the film in the stark realities of what Huntington's disease—fatal in all cases—really is, has become a powerful tool as Furbee has turned himself into one of the most passionate spokespersons for sufferers of Huntington's. He regularly addresses students at medical

schools, and talks about the disease, and how little is still known about it, to any group that will have him.

"I want to educate people so they don't go, 'Huntington's disease? What's that?' or 'Did you mean to say Hodgkins?' All of which happens a lot," Furbee says. "I've actually met doctors who don't know what Huntington's disease is."

Some know that Huntington's is the disease that ended Woody Guthrie's life, but the disease's most high-profile victim is Dr. Remy "Thirteen" Hadley, on the acclaimed television show *House*.

"People don't know much about it, so I've basically been trying to educate as many people as I can," Furbee says. "And the best way to do that is through showing the footage of my mom, which is very powerful. When people see that, they get it."

Furbee admits that his film might have been completed sooner had he not started out trying to edit it himself.

"I finally realized, I just can't," he admits. "I'm too close to it. My first instinct is to leave everything in. I have an editor now, but it took a long time to get the money together to do that."

In addition to educating people, Furbee hopes the film might draw more attention to efforts to find a cure for Huntington's. There is promising work being done at Stanford and UCSF, and UC Davis has recently started work on a possible stem-cell therapy for Huntington's. Though such treatments are probably still years away, Furbee is hopeful that he might eventually benefit from such research.

"I have to have hope," He laughs. I mean, I'm a realist. I know how symptomatic I am, I've seen friends die of this disease, and I have no delusions about how serious this is. But at the same time, I realize I have to have hope. It will depress me otherwise. I have to face this the best I can. So yes, I do hold out hope that someone is going to come up with a cure.

"That helps me get through some of the hard days," he says.

The other major reason for working so hard on his film for so many years, concedes Furbee, is that the finished project, even in rough form, has already proven to be extremely inspirational, something he also takes very seriously.

"This is a story about Huntington's disease, it's a story about me and my mom," he says, "but the reality is, it can relate to almost anyone going through a difficult time. The story reaches way beyond the realm of any one disease. It helps me to know I am helping other people, inspiring other people."

Since the children of Huntington's sufferers have a one-out-of-two chance of inheriting the gene, Furbee long ago decided not to have children of his own. Asked if, in a way, Huntington's Dance has taken the place of the child he never had, he takes a moment to answer.

"I've never thought of it that way, but there may be something to that," he says. "I have dated women over the years who had kids, so I have had some kid experience, but I guess, maybe, this film is my kid."

"Eighteen years ago," says Furbee, "I gave birth to it. And now, 18 years later, I'm getting ready to put it out into the community, to let it go—and, hopefully, it will do well out there and do some good things in the world."