

Jennifer Chambers, a writer experiencing traumatic brain injury and a rare genetic disorder, shares stories of Oregon women who truly live up to the title of remarkable.

BY SUE ZALOKAR
STAFF WRITER



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JENNIFER CHAMBERS, AUTHOR OF "REMARKABLE OREGON WOMEN: REVOLUTIONARIES & VISIONARIES"

Sue Zalokar: Surely there are many remarkable Oregon women. What were your criteria for selecting women to feature in the book?

Jennifer Chambers: It was hard for me that there were many (women) who have been covered in other places. And some were so big that I couldn't cover them.

It was as much geography as impact, because each woman was important in her own way. I really wanted to show women that were important to each different part of the state.

I spoke recently at Powell's, and afterward I was asked if I had purposely chosen people of color. If I were going to do that, it would have been hard. There aren't as many (people of

color) written about in Oregon because Oregon was founded as such a racist state.

I did want to include women with as diverse backgrounds as possible. I wanted to dispute the fact that it was so racist. There were these amazing women who happen to be of color that were doing amazing things here.

S.Z.: Do you have a favorite of the women you featured in the book?

J.C.: Kind of (laughter). I don't have just one. Part of what was really fascinating to me and part of my impetus for writing the book were the pioneer journals of the women who crossed on the Oregon Trail.

The things they went through are really unfathomable – the kinds of deprivation and loneliness. Putting yourself in that spot is really interesting.

S.Z.: It struck me as I was reading her story in the book that it was interesting that you chose Marie Dorian because really, her contribution was specifically to her family. She didn't do something historic for the state of Oregon, but the importance of the work she did for her children, that was pretty remarkable. It speaks to the huge role, which is often not valued, that mothers play in society.

J.C.: Marie embodied this precisely, with very little recognition from her husbands. Except for the last one, I think they were all not real fantastic. She really did everything by herself. She kept her family together and she did what she had to do to make things happen for her family legacy to continue. Not just the future of her family, but the future of the state.

S.Z.: In reading your personal bio, you are a pretty remarkable Oregon woman yourself.

J.C.: I have a genetic disorder. It is so rare that the National Institute of Health might name it after me.

They have no idea what it is. It took about 20 years to find any kind of help for it. It's super rare. They think that six people in the world might have it besides me.

S.Z.: What? Wow. How does it present for you?

J.C.: It's similar to a fever disorder. Parts of my body will swell, like my calves or forearms or face, and then my joints hurt and my muscles hurt. It's a lot like rheumatoid arthritis, which is what they thought it was for a long time. It's really debilitating, and it makes it so that I can't walk (sometimes), which is crappy because I also don't drive because my brain injury happened when I was 15.

I'm very lucky, but I also use a lot of strategies that help me.

I've really learned how to schedule stuff. If everything's down to the minute detail, I can get it all done. Mostly.

S.Z.: There is a lot of talk about the brain

injuries that football players sustain and the condition of chronic traumatic encephalopathy, or CTE. It is something you have been living with for a long time. Can you talk about that?

J.C.: The experience of having this has given me a lot of gifts. It's been truly awful at other times. But I'm really very appreciative of everything that I have. I don't know any other experience. And I don't remember anything from before my accident. Everything from before 15 years old is completely a blank.

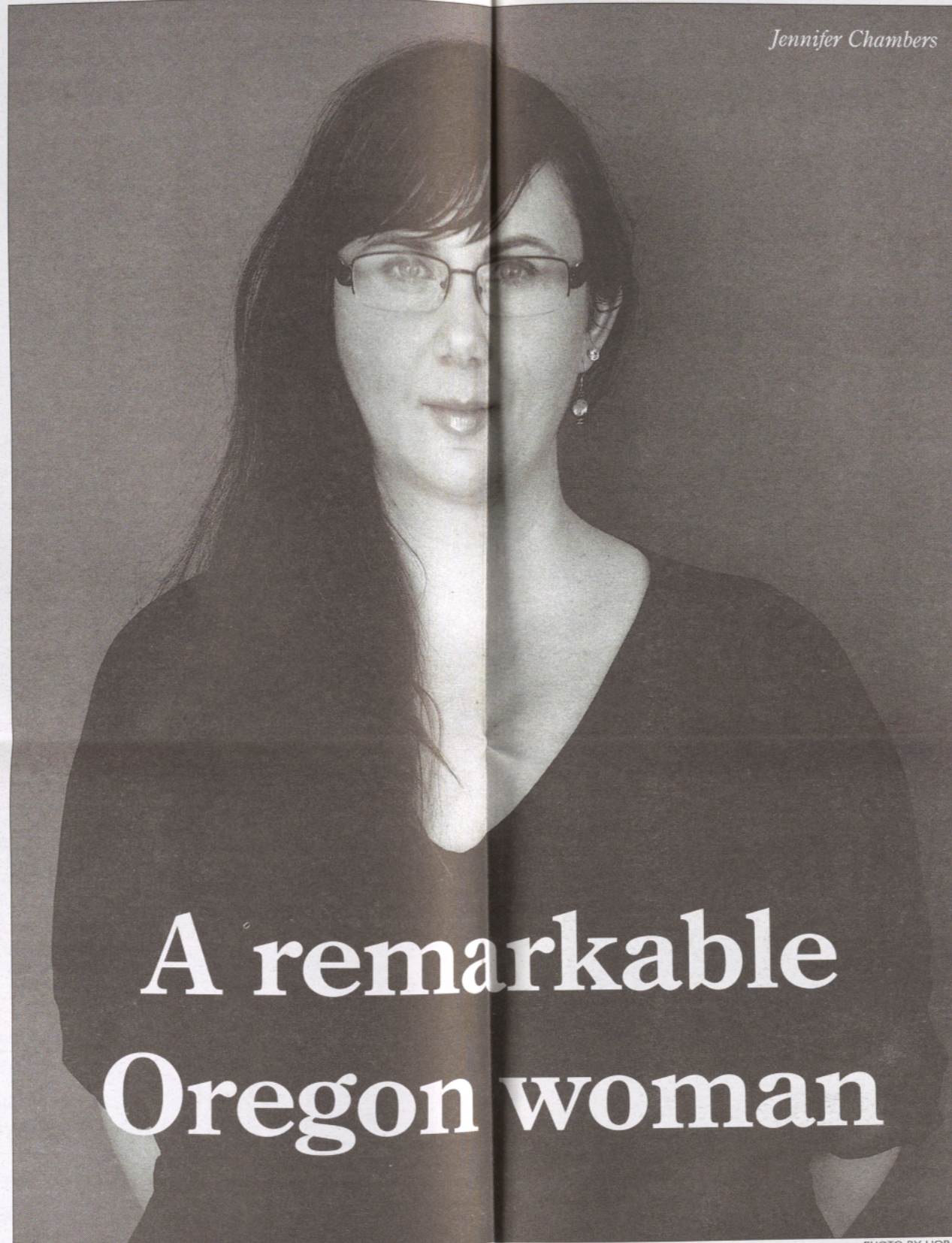
I had to re-learn everything. I didn't know who my parents were. For the longest time, I called my dad by the name of my dog.

I had incredible doctors.

I was very lucky in that because of my weird genetic disease that they didn't know about, I had an incident where the inside of my eye hemorrhaged and I went to an ophthalmologist and they injected steroids into my eye to stop it. By doing that, I found out that I was allergic to steroids. This information came in handy a few years later when I experienced my brain injury. At that time – it was '92 – they treated brain injuries with a giant dose of steroids, which would have made me blind.

I don't know that I believe in things happening for a reason, but I was in a coma

Jennifer Chambers



A remarkable Oregon woman

PHOTO BY LIORA K.

J.C.: Exactly. It's funny because I have been down that road since then. It took me a while to go down it, more it was just the thought of it. I don't remember it, so it doesn't bother me.

S.Z.: Are there genetic markers? Are you able to tell if your children have a genetic disposition to this disease?

J.C.: Actually I just went to see NIH. I was looking on the Internet, and I found that I fit their study. They did all of my genetic testing, and they have my DNA all mapped out.

They are still trying to pinpoint which specific gene has the abnormality. They know that something does, but they don't know for sure because they haven't matched anyone else who has it. The hope is they can figure out exactly what (gene is effected). They're keeping (my genome) in their database and if somebody matches me, hopefully within the next 10 to 15 years ...

I just asked someone on my team about my kids. And until they show any symptoms, (they might have lucked out). They do know that the two abnormal genes have to mate to make the bad cocktail of me.

So far, my husband has strong genes.

S.Z.: But your children may be carrying the recessive gene for this rare disorder, so their children could be affected.

J.C.: Yeah. Absolutely.

S.Z.: You have written a lot of horror. It seems like an interesting mesh – historical fiction and horror?

J.C.: It was an easy place for me to break in and start writing something that was non-threatening. Genre fiction is fun because people want it. They kept buying it, so I kept selling it to them.

I can identify with things that are horrific. There is nothing really more frightening than things that I have experienced. After my accident, my brain was impaired. My body was better before my brain was, and so I got to experience some really horrible human beings.

S.Z.: I'm so sorry.

J.C.: It happens.

S.Z.: Tell me about Groundwaters. Why is it important?

J.C.: I had just had my second child, and I was really starting to feel serious and competent as a writer, having done a few of those horror stories. I answered an open call for submissions here in the Willamette Valley, and it ended up being the magazine was based here in Veneta. I thought that was a cool coincidence. I went to the meeting and started writing for them.

The owner of the magazine started it as a gift to the community, and her whole thought was to make it possible for people who lived in rural areas to be heard.

Because of my brain injury, part of my whole operating idea was I wanted people to understand where I was coming from. I felt so foreign and other and different. It was awesome to find (an organization) that wanted to hear what I had to say.

I kept writing for them and I became an editor, and eventually the owner decided to

S.Z.: That idea of "it takes a village."

sell it so three other people and I bought it, and we kept it going until just this last year. We decided to stop producing the magazine because it was becoming too expensive even with grants. Now we do a yearly anthology, and we publish other people's work.

S.Z.: I have a few favorite women you feature in your book, "Remarkable Oregon Women: Revolutionaries & Visionaries," but one that leaps to mind is Sarah Winnemucca. She was a Nevada-born Paiute woman. Many members of her family were killed by U.S. Cavalry in the Paiute War. She became a Native American activist and wrote the first known autobiography by a Native American woman. What do you think she would have to say about the what took place at the Malheur National Wildlife Refuge?

J.C.: That's an interesting question. My husband's family is Paiute. My husband's grandmother was half Paiute, so they are of that area. For me, I think she would be so appalled. She wouldn't want those resources that had been preserved to be taken away. The building of roads that might damage the artifacts there, that's the part that is such a shame – public land vs. private land aside. It is just reprehensible.

I personally get the struggle for land, but I think that is the wrong place to do it. I understand the struggle for small ranchers; that's very real. Small ranchers need a place to run their cattle; I get that. They are trying to make a big point, but they are hurting a lot more than they are going to gain.

S.Z.: Full circle, where are you on the spectrum of healing?

J.C.: Sometimes things are easier than others – just like everybody. I think that I am very determined and super stubborn, and I think that has served me well.

I'm interested in everything. That has served me well, too. I like to learn, and I've learned how to learn. It's humiliating to have to ask for help, but I have to ask for help. Learning to ask for help has been incredibly useful. I think that being willing to ask has been my saving grace.

S.Z.: And then being able to receive it.

J.C.: Yeah. There's the trick. It's really hard to admit that you can't do it or that you don't know how. There is an image in our society that you should know that already. So often, I don't already know. I have to figure it out.



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Sarah Winnemucca, a Native American activist, and wrote the first known autobiography by a Native American woman.