## Sandi's Story

### Who are you? A Primary Sclerosing Cholangitis (PSC) Story-GRDR participant

Who are you? Really, think about it before you answer. Who are you? Did you answer with what you do? Librarian, teacher, dentist, you name it? The specifics don't matter, just the identity exercise. Who are you? So often that's answered as if the question was asked, "What do you do?" For those of us with chronic illness, invisible and visible, who are we? What do we do? What are we in a world that defines itself by what our bodies are able to do or not able to do every single day?

I'm a million different things. I bet you are, too. But I have an illness, one that most people have never heard about; one that most doctors have never heard about. It's incurable, has no viable treatments, can strike anyone at any time; and, often, it's one that is invisible to the naked eye. I have Primary Sclerosing Cholangitis, PSC. It's a rare, incurable disease of the liver and bile ducts that changes the way I have to live my life every single day. I itch as though somebody poured itching powder in my bloodstream and then shoved me into an endless pile of fire ants. I'm nauseous. I have pain every single day and my brain and body can no longer function the way they used to. My exhaustion is so pervasive that it’s mental, physical and emotional. Even my skin color is different. I live inside a body that I can’t even recognize most days and, yet, to the casual observer, I may look healthy. I get dirty looks when I use my handicapped pass in parking lots even though often by the time I’ve gotten from the car to the front of the store I’m too tired to accomplish my task.

I’m no longer who I used to be. I’m no longer a librarian or a driver or somebody who can run a mile. But I’m a warrior. I’m a fighter and an educator. I’m unafraid to say I have PSC or to take the time to explain to a physician or a bystander what it is. I shout my differences in the name of education and awareness. I teach others not to judge by sight alone. I teach them to listen and help them to find compassion and to want to cure me, to cure those like me. I show those with my disease that they are not alone and that we’re in this together. I’m not a victim. I’m a survivor. And if my disease takes me tomorrow, it will be on my terms and because I’ve taught what I’ve needed to teach and I’ve said what needed to be said. It will be because my body can no longer take being “other,” finding itself inflicted with a disease that very few know and that its resources cannot fight off. It will be because my soul has more work to do than my tired physique can support. And yet, should that happen, I won’t cease to exist. Who I was, what I did, those questions may still be asked. The answers? My answers? More researchers and doctors and civilians will know the name PSC and will realize there is a war to win than before I came. Who am I? I’m me of course, bum liver, devastating disease and all. Who are you?