

THE STORY OF LONI

Hi. My name is Loni and I am telling my story to my mother who is typing it for me. But these are all my own words. I am 22 years old. I have FAS. I was diagnosed when I was 7 years old at B.C. Children's Hospital. When I was little, I lived with my birth mother. She was an alcoholic who could not stop drinking. She did not do this on purpose. Alcoholism is a disease.

I was in some foster homes that I do not remember but mostly with my birth mom. When I was five she decided she could not take care of me and gave me up for adoption. I was adopted by my mom and dad when I was seven. I live in a big family with lots of people with FAS.

HOW FAS HAS AFFECTED ME

I am mentally handicapped. My IQ is 47. Doctors said I would never learn much, but they were wrong. I weighed four pounds and three ounces when I was born. I am not sure what I weigh now, but I think it is a little bit more. I was in the hospital for a long time.

I was born with four things wrong with my heart. It is called TETRALOGY OF FALLOT (*Tetralogy of Fallot*). I had five heart surgeries to fix it.

I have a very small head because my brain is small. I have small sinuses in my head and face which means I get a lot of sinus infections. I am waiting to have a CAT scan because they don't go away and I get headaches and have to take medicine for infections.

I need to wear glasses because I have something different in my eyes that is hard to say. (*astigmatism*). I had a different face which is not as noticeable now. People grow out of the FAS face. I needed braces on my teeth for over five years because my teeth were very messed up because my face is so flat. I have different fingers and toes and the bones in my arms are different too. I was very small and skinny until I was about twelve and then I grew and got a lot taller.

I used to be very hyper!!!!!! And could not pay attention to things. I am much better now. I stutter a lot if I do not speak very slowly.

THINGS THAT ARE HARD FOR ME TO DO

Lots of things are very hard for me to do, but I always try. Physical things that are hard for me are riding a bike, handwriting and drawing, roller skating and anything that needs balance. My balance is very poor.

Learning things that are hard are telling time, counting money, math, left and right directions, understanding what I read, things like that. The doctors said I would never learn to read, but I did, and I can even read upside down things.

I bet the doctors didn't think I could do this either, but I can, and I am!

I have trouble remembering things. I forget where I put things and then I get mad and blame someone else. Then I find it and I feel bad because I got mad at someone for no reason. I had trouble making friends in school until I was in a special program for kids with disabilities in high school. School was very hard for me. I did way better in high school because it was a life skills class and it was fun!

THINGS I AM GOOD AT

I am good at swimming (can't dive – never will learn how!!). I was the leader in my class in high school. I learned sign language to help a deaf girl in my class. I use it at my program too with a deaf man.

I am perfectly capable of taking care of myself at home. I cannot move out because I need help, but with help, I can do lots of things. I change and make my bed, I make my own breakfast and lunch. I wash my own hair. I choose my own clothes to wear. I help with household chores.

I am very good with animals. They like me and I like them. I babysit the dogs for my sister Sera whenever she goes out.

I help teach medical students about FAS with my sister and Dr. Loock. I have to do this 8 times in March and April every year. I am a good person to do this because I know a lot about having FAS.

Now I go to work every day at a program. I make ribbons for prizes, which means I do the tracing and cutting. I also do freezer bags and transit pins and brochures for holidays. I do this for money – this is my job and I get paid every two weeks. I love my job. I also exercise and play basketball and do community outings. We have social time where we do karaoke, paint our nails, watch movies, go for walks and things like that.

WHAT I WANT YOU TO KNOW

Just because I can't do things doesn't mean I am dumb. I have a disability, I am **NOT** stupid!! I want the government to find programs and jobs for all people with FAS. I don't think it is fair. Why do people who are "normal" get to have a job and the people who have FAS don't?? We can work, but we need help to work. I am lucky, I get help because I am mentally

handicapped. My sister has FAS but she is not mentally handicapped. She really wants a job, but she needs lots of help so she cannot get a job. That is not fair.

Moms who have a problem with drinking alcohol need help. Alcoholism is a disease. I wish I did not have FAS, but it is not anyone's fault.

I have a disability but that's life!

I really wanted to do this. Thanks for reading!