

Interview with Edith Savard

Interview done by Sonia Gobeil, January 2018



Can you describe the type of person you are?

I'm 35, I'm suffering from Ataxia Charlevoix-Saguenay and I'm an artist-painter. I was born in 1982 in Hauterive, Côte Nord, Quebec. I was a dreamy little girl but rejected by kids of my age because of my difference. When I was a teenager, my mother enrolled me at Alma's art studio to take portrait classes.

I studied at Jonquière CEGEP in special education. I also started a DEP in secretarial but I did not finish it due to a hospitalization.

I am a positive person, friendly, smiling, honest, respectful, generous, persevering, and social. I like to laugh and make people laugh. I must admit that I have not always been so positive.

I will not hide that I have a tendency to procrastinate but I believe that it is human nature. I have to make an effort to follow the recommendations of the physiotherapists to do my strengthening and balance exercises. Even to go to the workshop to paint I need a kick in the butt (laugh).

I am still able to walk with technical help but I often move in a wheelchair.

I am in a relationship with a wonderful man who has no difference. We do not have children by personal choice. I have a little dog and I am happy; it is my little kid!

At what age did you get diagnosed with Charlevoix-Saguenay Ataxia?

I received my diagnosis very early. I was 18 months old.

How did you and your family react to this diagnosis?

Since I was very young I did not really understand. I realized that I was different when, at the age of 6-7, I met one of my grandmother's sisters who had ARSACS. She was confined to a wheelchair, her words were very slow, hard to understand and her movements were very spastic. It was at that time that I realized and became aware of the seriousness of the situation.

My mother felt helpless and could not believe this diagnosis. My father, on the other side, was not surprised since he already had 2 of his maternal aunts with the disease. Furthermore, my little "no-coordination" prepared him for the final diagnosis.





What are you doing now?

I am an artist- painter: I was introduced to decorative painting on wood in 2007, as a result of a long convalescence that forced me to end my studies. I then took some painting lessons on canvas and I continued later self-taught to paint. I fell in love with art!

The medium used is acrylic with which various mediums, reliefs and textures are amalgamated. In the approach with my brushes, I wish to create unity and depth through my creations. I create pictorial works combining the abstract and the figurative but sometimes completely abstract, according to my instinct and the inspiration of the moment. I would rather opt for freedom and beauty, two elements that make me dream! Thus, I make the graphic representation of emancipated women, well in their body and with their sexuality.

Also, I love to paint animals. I am fascinated by their fragility, their strength, their agility and the sense of freedom they make me feel.

What are your current projects and plans for the future?

Since 2013, I have participated in several painting symposiums in various municipalities of Lac-St-Jean, my region of which I am particularly proud. I dream of participating in other events of this kind throughout Quebec.



We say that individuals with ARSACS have little manual dexterity, is that correct?

It is true that one of the characteristics of the disease is the lack of coordination, which makes it difficult to execute specific movements, for example, to write or to participate in certain activities of daily life. As the ARSACS does not affect individuals at the same level, I have to believe that I am lucky to have excellent motor skills. It may be a gift from heaven that allowed me to paint with great precision. Art for me is a therapy. Painting brings me so much that I almost forget my difference when I have a brush in my hands!

How can you paint successfully when you have ARSACS ?

It's like asking the human being how does he breathe? I do it that's all! (laugh). Actually, I started to draw and paint a long time ago. So I was able to work my muscles. This allowed me to keep my mobility, so precious, mobility that is lost when the muscles are not or almost not used.

My regular practice of drawing and painting allows me to maintain good fine motor skills. If I did not have painting in my life I would feel a huge void. I prefer to focus on the present moment.

Do you have leisure activities (sports, cultural activities, etc.)?

The only sport that I used to practice, and unfortunately I do not practice any more was swimming: before I used to go twice a week in my old city. Having moved to a village with less services and away from the city, I had to reluctantly give up swimming, which is the only complete activity that helps to control the disease.

My hobbies are drawing and painting, I love reading, cooking. I spend a lot of time on the internet or listening to various TV series and movies. For more than a month, I have been going to the day center in Alma, one day a week. It is a beautiful service that allows me to break the isolation. In addition, it allows me to participate in various physiotherapy activities and classes given by a teacher. It's really interesting. I made good friends there. People who participate have different types of physical limitations.

If you had some advice for someone who has ARSACS or a parent whose child has the disease, what would it be?


The life of a person with ARSACS is not all pink like my hair (hihihi I currently have pink fuchsia hair) because there are difficult periods. We cannot think that everything is beautiful and everything goes like clockwork. On the other hand, one must be realistic and not pessimistic about the situation.

At the present time, I am less mobile than before but I have never been feeling so good in my body. I am really Zen with my difference.

So my advice is to find a goal or a passion that allows you to flourish and shine! You have to surround yourself and get help. Attending meetings with support groups allows us to discuss our reality.

For parents of children with the disease, the only advice I can give is to love your child as is despite his difference. Encourage him in his personal development to allow him to flourish. Do not overprotect your child and do not do everything in his place even if you think you're doing him a favor, it's exactly the opposite! Leave him his autonomy. Furthermore, I must insist that your child does physical activity or at least the exercises suggested by the physiotherapist to maintain his mobility.

I invite you follow me on facebook with my new artistic creations and the various events in which I will participate!

 www.facebook.com/Edith.Savard.artiste.peintre

