

## Letter from Jean François Collard

March 2018

*“My name is Jean François Collard and I am 43 years old. I am from Chicoutimi Saguenay Lac Saint-Jean. I have lived in Quebec City for 20 years, I came to study at Laval University in 1998 to for a Bachelor's degree in Psychology and Public Communication.*

*During my first 11 years, I was walking like a drunk person. I was constantly questioned about why I was walking like this. I was naively answering that I was out of balance. That did not stop me from being like all kids of my age: running, playing baseball at the park, playing hockey on the street, cycling and swimming in the family pool. However, the more time progressed, the more I fell frequently. Through a contact, I managed to meet a neurologist at the Chicoutimi hospital to find out why I was walking like this. He immediately diagnosed me with the autosomal recessive spastic ataxia of Charlevoix Saguenay (ARSACS).*

*From that moment, my emotions were mixed in my head. I was surprised at the same time relieved and frustrated to know that my lack of balance was not the fruit of my imagination. My adolescence was not easy because like many teenagers I was looking for my identity and to add to the difficulty I was trying to cope with my new diagnosis that frustrated me even more. I wanted to find whose fault was it: my father or my mother in order to take away my guilt. At that time, I was very popular in my entourage whether it was with boys or girls. I had a lot of friends. Secretly with some girlfriends I had hope that with time the friendship would turn into love, but unfortunately it did not happen which made my frustration to my disability resurfaced. My parents, to help me get through my girl disappointments, minimized my anger by reminding me that at that age, girls gave more importance to the physical than to the person herself.*

*My parents felt very guilty and were questioning themselves. They were doing all the daily things for me in order to relieve their discomfort, but I have to admit that it was very convenient for me at that age.*

*I have been working for four years at the Quebec shared services center as a human resources management consultant, but I have been working in the public service for 14 years. I am pleased with the position I currently hold. I am a Regional Respondent for the Employability Program for Persons with Disabilities. This is important to me because I was a participant in this program in 2004. Thanks to my perseverance and to La Croisée (which helps people with disabilities who want to find a job), this organization has allowed me to demonstrate my knowledge and skills within the government.*

*One of my important projects is to keep walking on Canadian crutches for as long as possible to keep my flexibility. I have a manual wheelchair that I use frequently at work to maximize my endurance and in my daily life to facilitate and secure my movements. I also do physiotherapy twice a week since I was 12 years old. Another of my important projects is to live with my girlfriend in a few years from now. I would also like to continue traveling, driving my car and keeping my condominium. My goal is to work until age 60 if my condition allows it.*

*Despite the evolution of my disability, I maintains a lot of physical abilities through my determination, physiotherapy and indoor training. Not to mention that I had surgery in 2015. This type of intervention consists of reducing my spasms and maintaining an acceptable balance. All of these factors have helped me to keep more manual dexterity. My job often requires being in front of the computer. In order to work faster I tried to use the voice recognition application. Unfortunately, this software did not work for me because between what I said and what was actually written did not often correspond to reality. So, I resigned myself to typing more slowly. Fortunately my bosses are understanding. I feel privileged to walk at my age, I am very happy and I use everything in place that will help me walk for many years.*

*I am a sociable person, dynamic and positive. Thanks to these qualities, I managed to surround myself with good people. I have good friends, this allows me to go beyond my limits. I have been doing adapted downhill skiing for many years. This summer my project is to do therapeutic riding.*

*My advise to people with ARSACS is: Do not to get discouraged, believe in yourself, go ahead even if it takes longer, anything is possible. It is often the mind the first barrier. In addition, I would tell parents to develop their children's autonomy as much as possible with their limitations. It will help them later.*

*Hoping that this letter gives you another vision of disability and gives you hope."*

*Jean-François Collard*