

## **A person to discover**

By Richard Walker

We have among us, since last March 15<sup>th</sup>, a very famous person who is in temporary accommodation here at St-Charles for 4 to 5 weeks. Everyone has already seen him on television; he is Claude St-Jean, president of the Canadian Association of Friedreich's Ataxia. I asked him a few questions in order that we could know him better.

Richard: Good day, Claude, I would like to know if you have ever walked and how your disease evolved.

Claude: Up until the age of 15 years, I walked very well. Then I started having difficulties, I was falling everywhere. I had a wheelchair at the age of 22 years. When you take to a wheelchair, you never get out of it! Since ataxia is a progressive disease which is always evolving, later I started being a diabetic. Like everyone, I used to cheat; I used to nibble on sweet things. Since I travelled a lot, I often ate in restaurants and the occasions to eat sweet things were numerous, and this led me to secondary troubles such as pains in the feet and in the toes, and given that my disease was continuing to progress, 5 years ago I started having insomnia. I had to be hospitalized. Neurologists had me undergo all sorts of tests to finally discover that I had respiratory problems.

Richard: Have you always lived with your parents?

Claude: Yes, I have good parents, I am lucky. My father is 73 years old and my mother is 71. They always told me: "Claude, we want to keep you". My mother had 5 children and 4 of us are afflicted with Friedreich's ataxia. Two of the children are deceased following cardiac problems.

Richard: How did it happen that you became so popular and that we see you on television?

Claude: I had seen 27 neurologists who had all told me the same thing: "Claude, we can do nothing for your case." I said to them: "Bunch of fools! You say anything at all! I am going to found a movement for research on ataxia." I met Dr. Barbeau from the Clinical Research Institute of Montreal who was known worldwide and who said to me: "Claude I am going to help you." We organized scientific committees everywhere in the world; there were meetings here in Quebec and elsewhere which I attended. I often had to meet different Ministers of Health; I also had to collect money for plane tickets in order to be able to get to the places where the meetings among researchers from across the world were taking place, in Europe and in South America. It is thanks to these associations of Friedreich's ataxia that I have made myself known.

Richard: Who told you about St-Charles-Borromée?

Claude: 25 years ago, I knew well Claude Brunet, the founder of the provincial committee for the ill, who lived here and who is now deceased. Through the media a few years ago I had often heard about the problems which St-Charles was undergoing. But I also knew Mr. Leon Lafleur who previously worked at Lucie-Bruneau. I remember that unlike other directors who had very large offices, he had taken a small space in order to be closer to the clients. He is a man who makes me think of Jean Vanier. I believe that he can do a lot for St-Charles. One

day he said to me: “If ever you are in a bad way, Claude, you can always be put up at our place,” speaking of here.

Richard: Are you satisfied with the care and services which you have received here during your stay?

Claude: I am very satisfied. Here, they accept everyone, all forms of handicaps. There are even people who have psychiatric troubles. I have spoken a lot with the members of the personnel. I felt that they wanted to help and that they were doing their utmost. It is an exceptional centre. In the media, one hears only of problems of troubles at St-Charles-Borromée. Myself, I have discovered here another side, it is beautiful here and we receive good care, the government must stop making cuts to a centre like this one, it must save it. I have a friend who lives in Gaspé where there is no service for her. I am going to advise her to come and live here.

Richard: As president of the Claude St-Jean Foundation, can you tell us where the research on ataxia stands?

Claude: It is advancing a lot at the moment, which is encouraging; it is that the doctors have discovered a medication which is at the experimental stage and which would slow down the effects of the disease. Dr. Massimo Pandolfo, here in Montreal, is a neurologist who works full-time on ataxia. What complicates things is that there are not two persons afflicted with ataxia who have the same difficulties. There are great differences from one person to another. Like for example, since a year ago I have hearing difficulties, which makes communication difficult. In spite of everything, I will not give up my fight as long as no one has found a solution to ataxia.

Richard: Thank you Claude. You will always be welcome at the St-Charles-Borromée residence and I hope that you will keep a good memory of us. You are an extraordinary person! Congratulations on your endurance, your courage and your good work!

Ataxic persons should consult a social worker of their CLSC, as well as the social intervener of the Saint-Charles-Borromée Residence in order to make a decision.

Taken from the newspaper “Pour tout vous dire” of the Saint-Charles-Borromée Residence.  
May 99 interview with Claude St-Jean

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