

A Word from the President...

By Claude St-Jean

Being a little positive does some good!

I was able to observe many times that the victims of Friedreich's ataxia or of another form of hereditary ataxia show bitterness and sadness in their everyday life.

As our newspaper says so well, <<being a little positive does some good>>. First of all, one must know how to accept his limitations in order to better understand life and to make himself accepted by others. It is useless to think that a miracle is going to happen to solve the situation.

The medical research of Dr. Massimo Pandolfo and his team have all my confidence. I believe that one day they will find a treatment capable of improving the situation of victims of Friedreich's ataxia and perhaps even of other forms of hereditary ataxias.

Like many, I find that they are taking a lot of time before doing experiments on the chelation of iron treatment for Friedreich's ataxia, but we must understand that the researchers are held to demonstrate extreme prudence.

As for me, I am interested in participating in the chelation of iron treatment. Dr. Pandolfo told me that it might be at the beginning of summer. Even if my hopes are high, I do not think that I will become completely cured; I believe however that, in a general manner, my health will be found improved.

Optimism and positivism are necessary: one must never give up. The struggle is long, one must fight every day, you know it as well as I.

Afflicted by Friedreich's ataxia since 1967, I know something about it. My privileged encounters with ataxics from all parts of the world made me aware that they are continuing to see the positive side of things.

I hope that some day very soon there will be experiments on treatments and that they will have positive results for ataxics.

I would like to say a word about my friend Louis Boudreau, who left us last May. Louis was afflicted with Charlevoix-Saguenay ataxia. He knew my neighbour Denise in 1982 who acted as a volunteer during a boat trip. Like in a beautiful love novel, Denise became his wife. Louis was a great builder and an ex-director of administration of Friedreich's ataxia, I will miss him very much.

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