

A Word from the President

by : Claude St-Jean

Life is hard for ataxics, I can testify for it.

For a long time I have been reflecting on the future of medical research as regards all hereditary ataxias. At the moment, there exist in the world more than 60 forms of hereditary ataxias, like Friedreich's. Each form of hereditary ataxia has a gene, a protein, an age and different symptoms. To tell the truth, it is impossible to find a treatment for each form. For the time being, medical science had identified some 20 genes. No form of ataxia afflicts the brain, and the victims waste away little by little.

I regularly meet persons afflicted with all sorts of hereditary ataxias and I am very saddened to observe the evolution of their ataxia. All hereditary ataxias are cruel and fatal. They cause difficulties of coordination which only get worse.

I recently received a letter from Professor J.C. Turpin, a French neurologist. Here are the contents:

Dear Sir,

I have read the letter which you sent to Dr. PANDOLFO who is undisputedly he who has rendered the most service to the ill afflicted with Friedreich's ataxia during these last years. He is truly the father of the discovery and of the cloning of the gene.

As I exert myself to say regularly, when one is in the presence of a disease, it is important to know to what it is due, how it is controlled, but the discovery of a cause of ataxia does not necessarily bring about the treatment of this ataxia. Fundamental research is one thing, applied research is another. I had the opportunity at Beaune, during the meeting of A.F.A.B. (NB: French Association of Friedreich's Ataxia), to reply to this question on the metabolism of iron and the different data which were brought about on the pathology of the mitochondrion. I believe that we must still pay extreme attention here and not be fooled. It concerns a general manner, a way of therapeutic research and not of therapeutics which are expected to be generalized. When one undertakes research in any manner, one must know what will be the consequences, one must not despair, but one should know that in any manner, even the means which are given us to deploy, are evidently limited. As you say very precisely

in your letter, it is very certain that the present treatment is a uniquely symptomatic treatment which does not have the pretension to be able to stop the evolving process of the disease. This is why, all these efforts which you deploy with a lot of courage are not always crowned with success.

That which we have just lived since 10 years ago is so encouraging that we can hope that the day will come, when truly we will be able to respond to all your hopes. Ataxia is a syndrome and not a disease in itself; you know very well that there are multiple causes of ataxia, in order to be useful and efficient one must know of what one speaks, that is to try to modify the genetic control of ataxia when the gene was cloned. The efforts which were deployed on FRATAXINE are full of promise; the role of the mitochondrion is presently being tested.

One must know anyway that if the level of iron is increased in the mitochondrion, there is not in any fashion an increase in iron circulating in intra-tissular deposits of iron.

Please believe, dear Sir, that we are completely attentive to your requests, your remarks are great encouragements for us, there are however demands around which we must rally.

I think that one must always hope and never give up, one must go to the very end: one has no choice. I would very much like the researchers to be able to update treatments in order to slow down the evolution of the disease for Friedreich's ataxia and the other forms of hereditary ataxias. I urge you to keep up your courage faced with all the hardships of your disease and to remain as active as possible. Each one of you must try to apply a treatment adapted to your condition of daily life. To become angry will produce nothing.

It is certain that something must be done but it truly impossible to go any faster. I know that hundreds of specialists are doing research everywhere in the world.

I will not give up and I will go to the very end!

**CLAUDE ST-JEAN RENDERS HOMMAGE TO LIFE
WE SHOULD RENDER HOMMAGE TO CLAUDE ST-JEAN**

Today, that is the important word. Today I am going to express my aptitudes, my talents, my own qualities. Today, I am going to express my personal ideal which is to be the best possible in my daily relationships with my entourage, at home, at work, in the street, in my studies. In this way, I will even consciously change, and for the better, my part of the world.

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