

Word from the Founder-President...

Delivered at the General Assembly of November 17, 2002
by Claude St-Jean

Good day, I thank you for having accepted our invitation to participate in this 30th general assembly of ACAF. It is always with great pleasure that all the team of the administrative committee welcomes you.

We are meeting in order to learn the recent developments on the state of medical research concerning ataxia and, among other things, to decide on the approval of the modifications to the statutes and rules of ACAF. Changes have been judged necessary in order to increase the efficiency and the smooth running of the activities of the organization.

The association has its reason for being. It should be efficient, dynamic and energetic.

Medical research has made good and very interesting breakthroughs in the understanding of ataxias since 30 years ago. One has only to think of the description of the list of the symptoms specific to ataxia which assure the right diagnosis, of the discovery of several forms of ataxia and for some, of their respective genes, of the development of a screening test for Friedreich's ataxia, of therapeutic trials, of the discovery of the important role of antioxidants such as Vitamin E and of idebenone. We must especially not forget the effort and the worldwide contribution of the researchers.

What remains very clear is that to arrive at solving ataxia, research must be pursued. The teams of researchers are multiplying their efforts to know the numerous mechanisms which come into play and to understand their interactions. The more the number of pieces of the "ataxia" puzzle will be revealed, understood and assembled, the greater the possibility of undertaking experimental treatments with new molecules will be conceivable.

Since our existence, 30 years ago already, research has been refined and techniques have been modernized. 30 years ago, no one knew my problem. I founded the Association and I recruited doctors, researchers, and other persons presenting the same symptoms as mine. Nothing was done with ease and we still see that the organization is more necessary than ever. The research can seem stagnant to us, but this is just a false perception. The reality is that on the level of understanding, the noose is tightening. For the researchers, the work will only be more targeted, more precise. The fact of having discovered and having worked with several forms of ataxias will bring about the discovery of supplementary information which will come to supply the existing data bank for a better understanding of ataxia.

Let us keep up hope. Let us have confidence in our researchers. Let us allow them to work and let us encourage them to persevere.

For its part, the association will put more energy into the recruitment of new ataxic persons and new scientific researchers; it will increase the information to afflicted persons, to the population in general and to health professionals in order to obtain better care without forgetting to solicit financial aid.

According to all of us, the ataxic persons, let us concentrate on our quality of life. In order to make the most of our present and future life, there are technical and professional help as well as various supports to which we can be referred. The goal is simple and logical: to remain autonomous for as long as possible. This is surely the most beautiful present which can be given to us.

It is equally important to surround ourselves with good friends. Let us look for persons who are sensitive to that which we live. I thank all the volunteers, the immediate and the distant families who contribute an inestimable physical, moral and financial help. I would like to personally thank all the members of the administration council who perform admirable work. Without them, the Association would not exist.

By our life, we the ataxics know to what point life can be difficult. We live the same anguish, the same fears; we feel the same sentiments, the same emotions. With all these things in common, we are in a position to understand one another, which gives us another good reason to gather together.

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