

Preface

It is rare in the course of a lifetime to have the privilege of living a fascinating adventure. It is even rarer to share it with a remarkable being like Claude Saint-Jean. Yet this is exactly what has happened since the birth of the Canadian Association of Friedreich's Ataxia. Very involuntarily involved in the first beginnings of the new Foundation, I knew Claude Saint-Jean well, of whom I became the doctor, the confidant, the friend and especially the collaborator. But what is really unique is the pleasure to be able to read the description of this journey in a book at once brilliant and human, precise and profound.

By reading the volume which Arlette Cousture is proposing to us, we can guess the complexity of a personality which continually shows exemplary courage and perseverance to later allow the weaknesses of being shy to appear in a face of pride. The epic of Claude Saint-Jean is that of Terry Fox and of several unknown handicapped people who did not accept the lot which seemed to be reserved for them and who resolved, in the measure of their means, to fight the inevitable. Thanks to these formerly obscure patients now rendered more daring by modern publicity and the <<snowball>> effect, science and medicine have made giant steps since a few years ago. Our knowledge of the physiopathological mechanisms of ataxia have progressed in seven years at a more rapid rate than in the course of the previous hundred years. Claude Saint-Jean is mainly responsible for it and the book does him just homage.

But Claude Saint-Jean is not a god, and if on some days he seems like a hero, most of the time nothing distinguishes him from the majority of us. He cries, laughs, works, gets discouraged and gets angry like everyone else. In a word, Claude is an ordinary man, but he was able to conquer his weaknesses and to act. This dichotomy, this fascinating paradox, Arlette Cousture has captured it right to its smallest details and recounts it in a lively and true style.

I hope that reading this book will be interesting, moving, convincing, and that it will motivate the reader in order to finally incite him to act as well. This would be a well-merited reward by the author... and by Claude.

André Barbeau, M.D.

Taken from <<Aussi vrai qu'il y a du soleil derrière les nuages>> by Arlette Cousture
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