

My name is Sonia Gobeil and I am the co-founder of the Ataxia of Charlevoix-Saguenay Foundation.

I will reveal to you this morning my personal experience with scientific research. I am not a science person but life had its way and this is why I guess, I am standing here in front of you today.

In 2006, my husband and I received the tragic news that our 2 children, now aged 4 and 6, were affected by a genetic condition called ARSACS. What a shock this news was for us. At the time, we were also shocked to learn that there was no research being done to eventually stop or slow down the evolving condition of our 2 sons. How can there be possibly nothing out there in the medical world for people with ARSACS. For us it was imperative and urgent that research on ARSACS begins.

After we got over the shock of the diagnostic, we met with several doctors across the province of Quebec and, to make it short, we met with Dr Brais who accepted to conduct the research. A team of 4 doctors was also put in place to act as a scientific committee to review the research. The Ataxia of Charelvoix-Saguenay Foundation was thus created.

Dr Brais was specifically asked to conduct the research and, most importantly, to share any information, result or tool with any researcher where ever in the world. Our goal was, and is still is, to interest research on ARSACS so at the end, more people collaborate to the project.

In return, our commitment was total. We committed to provide the private funds for the research project. Without really realizing it, we had committed to becoming ARSACS advocates and fundraising experts. For both my husband and me, a new life was beginning.

Today, the Foundation is currently funding 4 researchers in Quebec and 1 in London, England with an approximate 500,000\$ budget per year. The Foundation has no employees and funds collected are totally dedicated to research. We hope the research team gets bigger.

I want to end my story by stressing that research is extremely important to us and to all the ARSACS families in Quebec. We know that we have to be patient, which sometimes I am not, but without research there is absolutely no hope for a treatment or a cure. Only research can heal and we are definitely counting on individuals like you.

THANK YOU FOR INVITING ME.