The mission is to improve the well-being of people affected by familial ataxia, contribute to research in promising treatments and bring together the community of interest in Canada.

Ataxia Canada - Claude St-Jean Foundation is an organization with a rich history. It begins with the involvement of Claude St-Jean who chose not to remain inactive in the face of his diagnosis. He convinced a medical community to begin the research which is described as the modern foundation of Friedreich's ataxia research.

* Fiscal year from October 2020 to September 2021
In the context of COVID, we continued our efforts to increase the foundation's reach, bring our community closer together and serve affected members. I want to thank Francois-Olivier and his team, our board members, our volunteers and our institutional, scientific and private partners for their contributions to a year rich in achievement. As we celebrate the foundation's 50th anniversary this year, we remain confident and committed to achieving our vision of a world where those diagnosed with ataxia can aspire to a fulfilling life thanks to advances in research and the support of an entire community.

Sébastien Huynh
Président

Marc Dansereau
Treasurer

André De Montigny
Secretary

Sean Ramsden
Board member

Sandy Sadler
Board member

Josée Goulet
Board member

Nicolas Théberge
Board member

Trinidad Ruiz
Board member

Diane Roch
Board member

CONTACT
Ataxia Canada – Claude St-Jean Fondation
4388 Saint-Denis street, suite 200, Montreal, QC, H2J 2L1
Telephone : 514-321-8684
Toll free : 1-855-321-8684
ataxia@lacaf.org
It is with great pride that I present the results of our efforts. This year has once again been marked by the pandemic. We were hopeful with the coming of the immunization that our daily lives and fundraising activities would return to normal. We have had to adapt as an organization. Like many institutions, COVID hit the philanthropic sector hard across the country. Many have been successful, and we are one of them. Dedicated volunteers had success in creating fundraising events including our first major event in the Vancouver area following the integration of the Ataxia BC society into our ranks. We have controlled our expenses through sound management practices and reduced administrative costs. Our research activities are on the rise, and our partnership opportunities are also growing. There are unfortunately some things that were delayed due to the pandemic. For example, a natural history study site and research center specific to the SCA. We anticipate an increase in investments for research for the next year through several partnerships. Our cash flow is excellent, our board of directors is well balanced, and the new administrators bring many complementary skills. We are doing great things with the help of a small fraction of families and people with ataxia. We want all families affected by ataxia to join our cause. If we had everyone's full support, imagine what we could accomplish. We have made significant progress this year and will continue the initial vision of Claude St-Jean. We are still a small organization and need every volunteer and donor.

Medical research ranks second among the causes favored by donors, behind aid to the poor.

A sector survey reveals that health organizations have experienced more declines in income than those in other sectors.

For those who have reported a drop of income, they have lost on average 48% of their revenues.

**Objectives of the last year**

- Continue our efforts to offer more services to people who have ataxia, and increase the number of people supported.

- Continue to expand our network to help more people who are effected and establish a Canada-wide presence.

- Increase our financing activities

- Attract clinical trials to Canada

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translated from: Les affaires, November 2021
1 **PARTNERSHIP**

We will continue to support research and create partnerships with other foundations, organizations, companies, and governments to leverage our research spending.

2 **RESEARCH SITE**

The Montreal Collaborative Clinical Research Network in Friedreich’s Ataxia (CCRN) site is lead by Dr. Antoine Duquette, a neurologist at the CHUM, and his research team. This site is the home of an international natural history study and the foundation for clinical trials. The impact of COVID on this site was significant this year and slowed down the recruitment of patients and inpatient visits.

3 **RESEARCH GRANTS**

Ataxia Canada funds relevant research where ataxia is the primary symptom and is genetic and progressive in nature. The research grants awarded are normally for a period of one to two years and between $15,000 and $50,000 CDN as total annual budget allocated, although in exceptional circumstances it may be higher.

4 **CLINICAL TRIALS**

The goal is to fund and attract clinical trials in Canada to benefit people with potential treatments that are under development. There are ongoing discussions with pharmaceutical groups for clinical trials.
Since its creation, the Ataxia Canada Foundation’s mission has been to support research to contribute to the development of therapies targeting both the causes and the effects of different forms of ataxia. The pursuit of this objective is still very much alive and relevant within the administration and the members of the foundation. The Scientific Evaluation Committee (CES) is essential to invest wisely and to fund research according to a rigorous and fair process. The Ataxia Canada CES is made up of 3 external members with an interest and expertise in the field of ataxia, as well as peer reviews of research grant applications.

Dr. Bernard Brais  
McGill University  
Neurologist, co-director of the Rare Neurological Diseases group of the Montreal Neurological Institute and Hospital  
His research largely focuses on the origin of neurogenetic disorders with founding effects in Quebec, with an increasing focus on disorders with ataxic manifestations such as Autosomal Recessive Spastic Ataxia.

Dr. Anne Fournier  
University of Montreal  
Cardiometabolic and vascular health: from genetics to environmental Approaches. Dr. Fournier has also developed expertise in cardiac-related dysfunction associated with neuro-muscular diseases and pediatric pulmonary hypertension.

Dr. Gerald Pfeffer  
University of Calgary  
Research into genetic causes of hereditary neuromuscular disorders, principally adult-onset conditions including myopathy, neuropathy, and ALS.

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**Review of 2020-2021: Award of 3 grants**

Dr Nicolas Dupré and Francois Gros-Louis: Creation of an open science repository of induced pluripotent stem cells for ARCA1

Dr Jacques P. Tremblay: Development of gene therapy for Friedreich's ataxia

Dr Antoine Duquette: Development of virtual reality tools for the assessment of motor impairment in ataxic patients
FINANCIAL SUPPORT PROGRAM

This program exists to improve the well-being of people who have been diagnosed with ataxia by helping to fund the purchase of technical aids, adaptations, equipment, and other services that will be beneficial to their condition.

A multitude of requests will be analyzed and processed each year across Canada. We hope to reach as many as possible and provide them with support they need.

Two years ago: 2 projects; $7,000; (Quebec, Manitoba)
Last year: 6 projects; $24,400; (Quebec, British Columbia)
This year: 13 projects; $62,000; (Quebec, Alberta, Manitoba, Ontario)

“The financial support program allowed me to acquire a bicycle adapted to my condition. I feel privileged to be able to benefit from such support and to cycle with my family at various events.”
Raphaël, Granby, Québec

“Having a degenerative disease means that we have to constantly adapt and that becomes expensive. I would like to thank the foundation because without its help I would not have been able to buy my scooter.”
Kim, Mandeville, Québec

“The power tie down is in and it was the last thing I needed in my adapted van for my complete autonomy and liberty. Ataxia Canada is a huge piece of financial support that would not have happened without their generosity and moral support. I am forever grateful and blessed by Ataxia Canada and I am so thankful for what they have done for myself and my family.”
Matthew, Calgary, Alberta

“Thanks to the programs, I was able to expand the physical activities that I can practice such as therapeutic riding and hockey. Thank you”
Karine, Laval Québec

“This program allows us to flourish. Thanks to donors and the Foundation, I was able to get an electric tri cycle so I can finally ride a bike with my daughter!! What a joy to know that I can still have fun with my daughter despite my illness!”
Jessica, Bécancour, Québec
The committees structure allows us to integrate and regroup our volunteers, our collaborators and the administrators of the foundation. Everyone can share his experience to advance the priorities of the foundation. If you would like to join the team, do not hesitate to contact us!
Did you know that everyone has the chance to make a difference! A small community event can often generate up to $5,000.

We can help you create your own fundraiser! Visit our new fundraising plateform

1 **ATAXIA CHALLENGE**

Once again this year, the flagship walking and cycling events have been canceled. Thanks to a series of smaller gatherings and new volunteer involvement in western canada, we have increased our annual income!

- 2019: 85 000$
- 2020: 67 000$
- 2021: 93 000$

2 **Travel lottery**

In the context of the pandemic, we have decided to temporarily suspend this fundraising activity. We are hoping for a favorable travel environment next year!

3 **MAIL CAMPAIGN**

Annual Direct Mail Fundraising Campaign

- 2019: 32 000$
- 2020: 36 000$
- 2021: 35 000$

4 **Corporate donation**

Thank you to our corporate partners who support scientific research
**Communication strategy**

- Regular value-added communication
- Using all modes of communication
- Increase our reach via social media
- Database Analysis
- Production and distribution in hospitals and relevant organizations of a new information leaflets
- Partnership Developments

**WHY THE CHAMELEON?**

Without having high physical capacity, the chameleon is very sensitive to its surroundings; it can adapt to any environment.

**Members with ataxia registered**

![Graph showing the number of members with ataxia registered from 2014 to 2021. The x-axis represents the years (2014 to 2021), and the y-axis represents the number of members ranging from 100 to 222. The line graph starts at 102 in 2014 and shows a steady increase, reaching 222 in 2021.](image-url)
Facebook

Number of "Followers"

- 3003
- +186 (+7%)

Per age

- 13-17: 1%
- 18-24: 9%
- 25-34: 4%
- 35-44: 4%
- 45-54: -8%
- 55-64: -7%
- 65+: 0%

Per gender

- Men: 35%
- Women: 65%

Web site

- Update information
- Keyword enhancement for web search engine optimization (SEO)
- Diversification of content (articles, blog)

Website internet traffic

Email

Subscriber progression
Our Donors

Total donors
Decrease in donors following COVID but average donation is up

Donors in western canada
Growing!

Donors from USA
Following fraud attempts, we have suspended the possibility of accepting donors outside of Canada.

<table>
<thead>
<tr>
<th></th>
<th>Number of Donors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2018</td>
</tr>
<tr>
<td>Quebec</td>
<td>1678</td>
</tr>
<tr>
<td></td>
<td>89%</td>
</tr>
<tr>
<td>Ont, SK</td>
<td>98</td>
</tr>
<tr>
<td>Manitoba</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5%</td>
</tr>
<tr>
<td>Western</td>
<td>69</td>
</tr>
<tr>
<td>Canada</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3,5%</td>
</tr>
<tr>
<td>Eastern</td>
<td>9</td>
</tr>
<tr>
<td>Canada</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0,5%</td>
</tr>
<tr>
<td>USA</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>2%</td>
</tr>
<tr>
<td>Total</td>
<td>1893</td>
</tr>
<tr>
<td></td>
<td>100%</td>
</tr>
</tbody>
</table>

We are doing great things with the help of a small fraction of families and people with ataxia. Imagine if we had everyone's full support.
**FINANCIAL RESULTS**

**INCOME**
Extraordinary results during the se difficult times.

**EXPENSES**
Modest and managed by sound management practices.

**MEDICAL RESEARCH**
Increase in number of currently funded research

**TESTAMENTARY SUCCESSION**
It is clear that Testamentary Successions impact is important and donors should continue to be informed of this mechanism.

**INCREASE IN SERVICES TO MEMBERS**
More projects for the service program

**DECREASING COSTS TO ORGANIZE AND PLAN EVENTS**

<table>
<thead>
<tr>
<th>INCOME</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations and fundraising</td>
<td>175 173</td>
<td>191 462</td>
<td>205 780</td>
<td>219 163$</td>
</tr>
<tr>
<td>Testamentary donation and exceptional revenues</td>
<td>28 000</td>
<td>315 000</td>
<td>150 000</td>
<td>51 003</td>
</tr>
<tr>
<td>Investment income</td>
<td>8 310</td>
<td>8 935</td>
<td>17 404</td>
<td>14 029</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td><strong>211 483</strong></td>
<td><strong>506 462</strong></td>
<td><strong>373 184</strong></td>
<td><strong>284 195</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical research</td>
<td>62 232</td>
<td>66 783</td>
<td>15 773</td>
<td>163 357</td>
</tr>
<tr>
<td>Service and communication to members</td>
<td>44 020</td>
<td>76 380</td>
<td>82 979</td>
<td>91 064</td>
</tr>
<tr>
<td>Events</td>
<td>69 277</td>
<td>58 301</td>
<td>52 845</td>
<td>34 490</td>
</tr>
<tr>
<td>Administration costs</td>
<td>17 496</td>
<td>36 505</td>
<td>32 912</td>
<td>22 268</td>
</tr>
<tr>
<td><strong>Total expenses</strong></td>
<td><strong>193 025</strong></td>
<td><strong>237 969</strong></td>
<td><strong>184 509</strong></td>
<td><strong>311 179</strong></td>
</tr>
</tbody>
</table>

**EXCESS OF INCOME ON EXPENSES**
+18 453 +268 493 +230 315 (26 984)
THANK YOU TO OUR VOLUNTEERS

We want to thank our volunteers who are essential to the achievement of our mission. Some are loyal collaborators and others are new to the activities of the foundation. They volunteer on committees, organize fundraising events and volunteer their precious time to our cause.

Thanks everyone. We hope to you will continue with us next year!

Viveka Parameswaran
Antoine Gervais
Brenda Dixon
Maria Rideout
Joel Houghton
Hugo Cresp-Lacroix
Julie Brisson
Morbi Lamya
Sonia Prasas
Ron Singh
Sonia Roy
Gino Martel
Emmanuelle Poirier St-Georges
Bianca Guilemette
Solang Lavoie Guillemette
Alain Brulotte
Kim, Marc et Huguette Frenette
Jessica Laneuville
Dominique Ruiz-Courcelle
Manon Courcelle
André Allard
Sakina Rehmanji
Susan Harding
Brittany Sommerfield