ACTIVITY REPORT
2018-2019

Mission
Improve the well-being of people with familial ataxia and support research.

CONTACT:
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francois.theberge@lacaf.org

DATE:
16 | 11 | 2019
Hello,

It is with great pride that I present to you the report of our activities. Ataxia Canada - Claude St-Jean Foundation is an organization with a rich history, it begins with Claude St-Jean who chose not to remain inactive. He convinced Dr. André Barbeau to begin the research who is described to be the modern founding's on Freidreich's Ataxia research. Unfortunately, 47 years later, we do not yet have a treatment, but it is not a few dozen people who now contribute but several hundreds or thousands. We now work for all forms of ataxia and we collaborate with partners around the world to support all with familial ataxiafamiliales.

**OBJECTIVE OF THE LAST YEAR**

**IMPLEMENT THE NEW PROGRAM TO OFFER SERVICES TO PEOPLE OF HAVE FAMILIAL ATAXIA**

**CONTINUE OUR SUPPORT FOR RESEARCH**

**EXPAND OUR NETWORK TO COVER MORE PEOPLE AND ESTABLISH A PAN-CANADIAN PRESENCE**

**INCREASE OUR FINANCING ACTIVITIES**

**CREATION OF ADVISOR ADVISOR GROUP**

**INCREASE OUR COMMUNICATIONS TO MEMBERS AND OUR VISIBILITY**

Our revenues are stable with growth opportunities, our expenses are modest and managed by sound management practices, our tresory is excellent, our board is well balanced and new administrators bring complementary skills. We are still a small organization and need every volunteer and donor. We are still a small organization and need every volunteer and donor. It is essential that all families affected by ataxia join our cause. We have made significant progress this year and are confident that we can continue to grow.

“Alone we can go faster, together, we go further”

-African proverb

François-Olivier Théberge
General manager
1. **Insertion into Job Market**
   We hired a trainee to help create the Family Ataxia Support Program and help with other projects. She benefited from work experience and was able to land a job in her area of expertise.

2. **Financial Assistance for the Purchase of Equipment and Services**
   Establishment of the program
   
   Principles of crowdfunding
   
   Six specific applications, two projects received funding from other organizations
   
   4 completed projects (Quebec X2, Manitoba and British Columbia)

3. **Support Group by Teleconference**
   Several meetings were held in French and English. We give participants the chance to interact with each other in the comfort of their home with a smartphone, tablet or computer!

“**With the new services of the foundation, I feel closer to it and allows me to be more involved!**

Jessica Launeuville
The goal is to attract and perform clinical trials in Canada

1 **PARTNERSHIP**

We must support research through partnerships with other foundations, organizations, companies or governments to leverage our research spending.

2 **CREATING A RESEARCH SITE**

Dr. Antoine Duquette, a neurologist at the CHUM and the Center for Physical Rehabilitation Lucie-Bruneau of the CIUSSS of South-Central Montreal, and his research team, now participate in the collaborative clinical research network in Friedreich’s Ataxia in collaboration with the Friedreich’s Ataxia Research Alliance (FARA) and Ataxia Canada-Claude Saint-Jean Foundation. The project is co-funded equally by both organizations.

3 **GENE THERAPY**

We are currently supporting the research of Dr. Tremblay at Laval University. We are pursuing gene therapy projects at a total cost of $220,000 over the past two years.

4 **CLINICAL TRIALS**

The goal is to fund and attract clinical trials in Canada to benefit people with potential treatments that are under development.
This international network brings together 13 sites working together to advance treatment and clinical care.

The main objectives of the network:
- To identify and validate the clinical outcome measures and biomarkers required for clinical trials;
- Facilitate the implementation and delivery of clinical trials;
- Share data and resources to advance treatment;
- Define best clinical practices for AF and provide the highest level of clinical care to patients;
- In each clinical research center, encourage the establishment of a team of doctors, researchers, and professionals dedicated to the AF.

The research team is seeking the participation of individuals over 18 years of age with a Friedreich ataxia diagnosis to join the natural history study. This project aims to systematically document clinical symptoms and progression. This research project is approved by the CHUM’s Research Ethics Board. For more information, we invite you to contact Dr. Antoine Duquette: antoine.duquette@umontreal.ca.
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!

**Fundraising activity**

1. **Ataxia Challenge**
   - Walking and Cycling event in Chambly
   - 2019: $75,000 400 participants

2. **Greater Toronto Area Walk**
   - Walking in the Greater Toronto Area
   - 2019: 100 participants: $15,000

3. **LUSM**
   - Online fundraising in partnership or the goal is to move our community, bring visibility and raise funds

4. **Mail Campaign**
   - Annual Direct Mail Fundraising Campaign
   - 2019: $32,000
WHY THE CHAMELEON?
Without having high physical capacity, the chameleon is very sensitive to its surroundings; it can adapt to any environment.

**Communication strategy**

Regular value-added communications
Using all modes of communication
Increase our reach via social media;
Segmentation of the communication according to the categories of donors

Database Analysis
Production and distribution in hospitals and relevant organizations of a new information leaflet on the Foundation
Partnership Developments

New members with ataxia registered

![Graph showing new members with ataxia registered over years](image)
Facebook

Number of "Followers"
2,220
+345  +18.4%

Per age
0 5 10 15 20 25
65+ 55-64 45-54 35-44 18-24 13-17

Per gender

24% Men
76% Women

Web site

UPDATE INFORMATION

KEYWORD ENHANCEMENT FOR WEB SEARCH ENGINE OPTIMIZATION (SEO)

DIVERSIFICATION OF CONTENT (ARTICLE, BLOG)

Web site traffic
The challenge is to increase our list of subscribers and donors. We must maintain the interest of our subscribers and offer varied, interesting and engaging content.
OUR DONORS

- **Total Donors**
  - Growing!

- **Donors in Ontario**
  - Growing due to the return of the walk!

- **Donors in Quebec**
  - Need to involve new families and reconnect with our donors and historical supporters.

<table>
<thead>
<tr>
<th>Number of Donors</th>
<th>2017-2018</th>
<th>2018-2019</th>
<th>difference</th>
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<tbody>
<tr>
<td>Québec</td>
<td>1678</td>
<td>1594</td>
<td>-84</td>
</tr>
<tr>
<td>Ontario</td>
<td>98</td>
<td>266</td>
<td>+168</td>
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<tr>
<td>Western Canada</td>
<td>69</td>
<td>97</td>
<td>+28</td>
</tr>
<tr>
<td>Eastern Canada</td>
<td>9</td>
<td>17</td>
<td>+6</td>
</tr>
<tr>
<td>United States</td>
<td>38</td>
<td>107</td>
<td>+69</td>
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<tr>
<td>Total</td>
<td>1893</td>
<td>2082</td>
<td>+189</td>
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If you want happiness for a year, inherit a fortune. If you want happiness for a lifetime, help someone else.

–Confucius
### FINANCIAL RESULTS

#### REVENUES

Strong growth due to Testamentary Successions received in 2018-2019. Our donor base is stable with growth opportunities.

#### EXPENSES

Modest and managed by sound management practices. The increase in administration costs are linked to the full-time General manager.

#### 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

Projects for service program and trainee salary.

#### DECREASING COSTS TO ORGANIZE AND PLAN EVENTS

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<tbody>
<tr>
<td></td>
<td>Donations and fundraising</td>
<td>203 173$</td>
<td>497 527$</td>
<td>+294 354$</td>
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<tr>
<td></td>
<td>Investment income</td>
<td>8310$</td>
<td>8935$</td>
<td>+625$</td>
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<td></td>
<td>Total Income</td>
<td>211 483$</td>
<td>506 462$</td>
<td>+294 979$</td>
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<table>
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<tr>
<th>EXPENSES</th>
<th>2017-2018</th>
<th>2018-2019</th>
<th>Difference</th>
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<tbody>
<tr>
<td>Medical research</td>
<td>62 232$</td>
<td>66 783$</td>
<td>+451$</td>
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<tr>
<td>Service and communication to members</td>
<td>44 020$</td>
<td>76 380$</td>
<td>+32 360$</td>
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<tr>
<td>Events</td>
<td>69 277$</td>
<td>58 301$</td>
<td>-10 976$</td>
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<tr>
<td>Administration costs</td>
<td>17 496$</td>
<td>36 505$</td>
<td>+19 009$</td>
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<tr>
<td>Total expenses</td>
<td>193 025$</td>
<td>237 969$</td>
<td>+44 944$</td>
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<td>EXCESS OF INCOME ON EXPENSES</td>
<td>+18 453$</td>
<td>+268 493$</td>
<td>+250 040$</td>
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