



ACTIVITY REPORT 2018-2019

Mission

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



**ATAXIE
ATAXIA
CANADA**

CONTACT:

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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 treasury 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

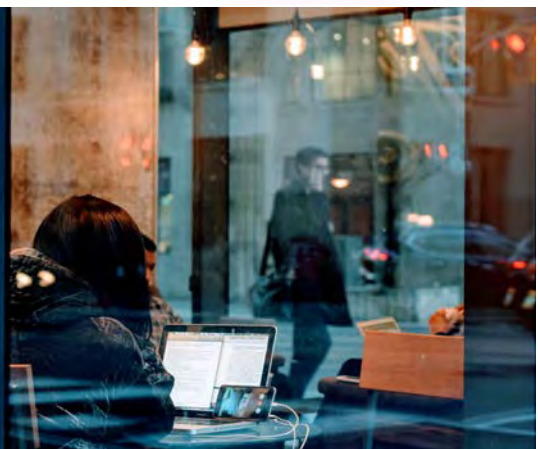
Six specific applications, two projects received funding from other organizations

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

CREATION OF A RESEARCH SITE



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CANADA



2019 - New Montreal site - Collaborative Collaborative Research Network on Friedreich's Ataxia (CCRN in FA)

*** NEW CCRN 2019 SITE: CHUM University Hospital of Montreal**

University of California at Los Angeles - Philadelphia Children's Hospital - University of Colorado - University of South Florida - Emory University - Atlanta - University of Iowa, Ohio State University - Murdoch Children's Research Institute - Australia - Sick Kids - Toronto (no clinical trials) Data Coordination: University of Rochester - Rochester, NY - Clinical Data Science GmbH - Switzerland

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.

FINANCING ACTIVITIES



Fundraising activity

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!



1 ATAXIA CHALLENGE

Walking and Cycling event in Chambly

2019: 75 000\$ 400 participants



2 GREATER TORONTO AREA WALK

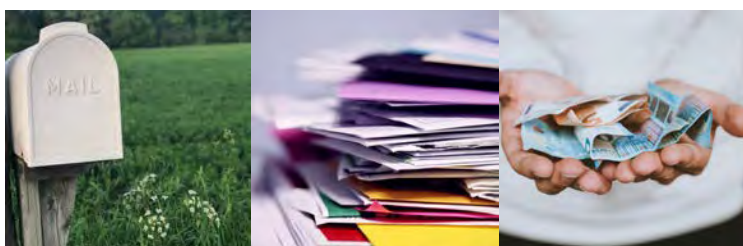
Walking in the Greater Toronto Area

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

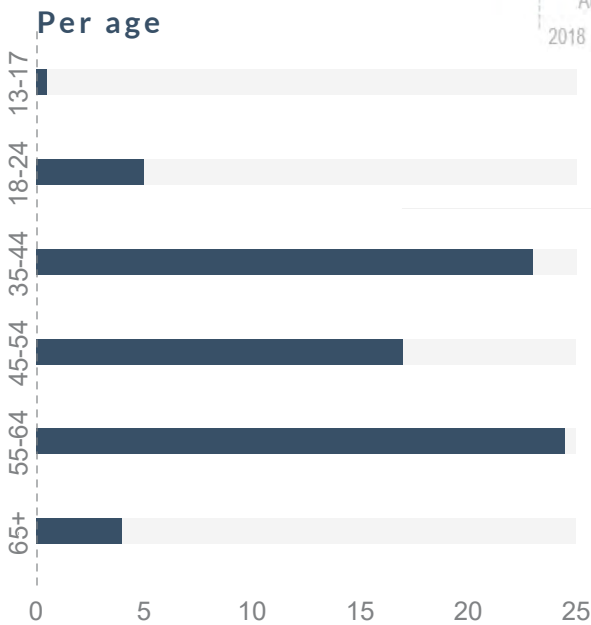
Production and distribution in hospitals and relevant organizations of a new information leaflet on the Foundation

Partnership Developments

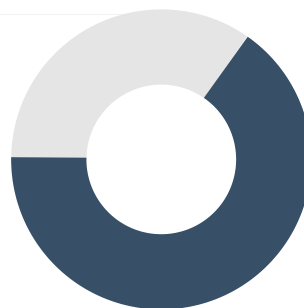
New members with ataxia registered



f Facebook



Per gender



24%
Men

76%
Women

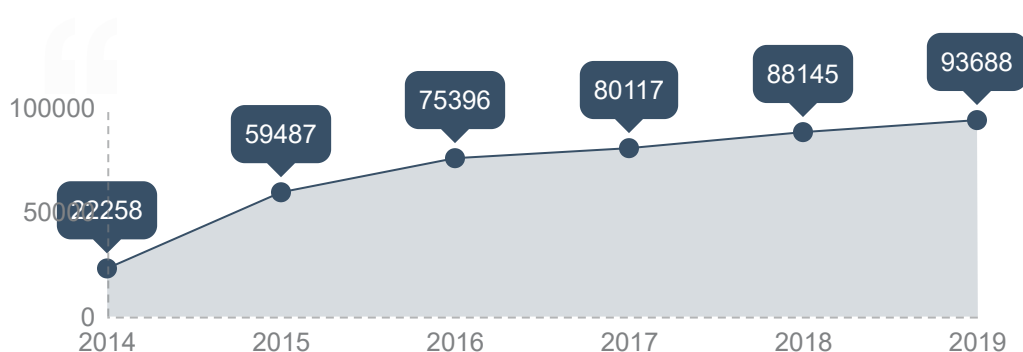
Web site

UPDATE INFORMATION

KEYWORD ENHANCEMENT FOR WEB SEARCH
ENGINE OPTIMIZATION (SEO)

DIVERSIFICATION OF CONTENT (ARTICLE, BLOG)

Web site traffic





MailChimp®

1092

average open
messages per
campaign
(29,3%)

18% industry
average



43 %



57 %

3729

subscribers

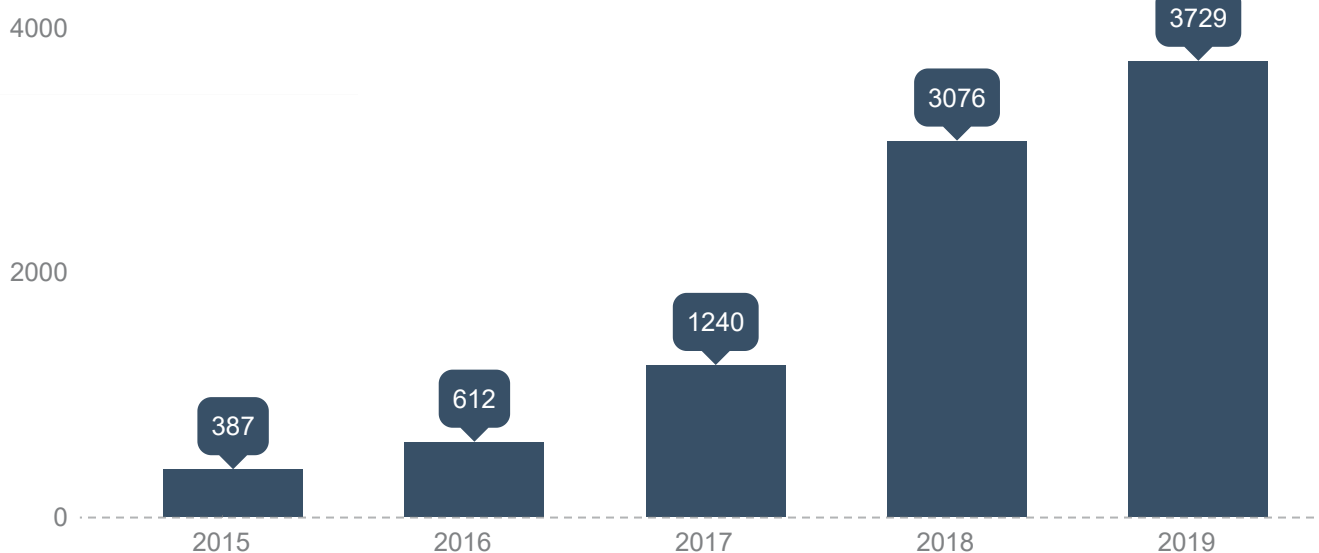
98.8%
delivery
successfully

2.6%

Average click

2.1% industry
average

Subscriber progression



“

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.

■ Number of Donors

	2017-2018	2018-2019	difference
Québec	1678 89%	1594 77%	-84 ▼ -12%
Ontario	98 5%	266 13%	+168 ▲ +8%
Western Canada	69 3,5%	97 4%	+28 ▲ +0,5%
Eastern Canada	9 0,5%	17 1%	+6 ▲ +0,5%
United States	38 2%	107 5%	+69 ▲ 3%
Total	1893 100%	2082 100%	+189 ▲ +10%

“

If you want happiness for a year, inherit a fortune. If you want happiness for a lifetime, help someone else.

–Confucius

”

FINANCIAL RESULTS



REVENUS

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

Résultats

INCOME	2017-2018	2018-2019	Difference
Donations and fundraising	203 173\$	497 527\$	+294 354\$
Investment income	8310\$	8935\$	+625\$
Total Income	211 483\$	506 462\$	+294 979\$
EXPENSES	2017-2018	2018-2019	Difference
Medical research	62 232\$	66 783\$	+4551\$
Service and communication to members	44 020\$	76 380\$	+32 360\$
Events	69 277\$	58 301\$	-10 976\$
Administration costs	17 496\$	36 505\$	+19 009\$
Total expenses	193 025\$	237 969\$	+44 944\$
EXCESS OF INCOME ON EXPENSES	+18 453\$	+268 493\$	+250 040\$

BOARD OF DIRECTORS



Jean Luk Pellerin
President



André De Montigny
Vice president



Sébastien Huynh
treasurer



Solange Lavoie Guillemette
Secretary



Nicolas Théberge
Board member



Marc Dansereau
Board member



André Valiquette
Board member



Bianca Guillemette
Board member



Diane Roch
Board member

CONTACT

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