



# ACTIVITY REPORT 2020

## Mission

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



**ATAXIE  
ATAXIA  
CANADA**

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.

## CONTACT:

**Francois-Olivier Théberge**  
francois.theberge@lacaf.org

## DATE:

16 | 11 | 2020

## Director's word

It is with great pride that I present to you the report of our activities. This year was difficult for us all. Like many industries, the financial crisis caused by COVID-19 has hit the philanthropic sector hard across the country. Several organizations are reporting significant drops in their revenues and some do not think they will survive the year 2020. Our revenues were obviously affected but less so than anticipated because of some dedicated volunteers, socially distanced micro events, new fundraising initiatives and strong donor retention. We controlled our expenses through added value management practices and lowered administrative expenses. We wish we could have reached our budget for scientific spending. Our contractual disbursement for research activities are based on progress and most laboratories and clinical sites activities were halted for a good portion of the year. Our treasury is excellent, our management board

is well balanced and new administrators bring complementary skills. We are able to do much with a small fraction of families and people with ataxia involved. Imagine if we had the full support of all. 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. We are still a small organization and need every volunteer and donor.



### OBJECTIVE OF THE LAST YEAR

**CONTINUE ONGOING PROGRAM TO  
OFFER SERVICES TO PEOPLE OF HAVE  
FAMILIAL ATAXIA**

**CREATE A SCIENTIFIC COMITEE**

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

**INCREASE OUR FINANCING  
ACTIVITIES**

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

“

73% of charities report a drop in donations since the start of the pandemic. and revenues fell on average by 30.6% for more than half of charities in the country.

”

A handwritten signature in black ink, appearing to read 'f. olivier theberge'.

**François-Olivier Théberge**  
General manager





The goal is to attract and perform clinical trials in Canada



### 1 PARTNERSHIP

We will continue to support research and create partnerships with other foundations, organizations, companies or 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 home of a international Natural history study and the starting structure for clinical trials. The impact of COVID on this site was important this year and slowed down the recruitment of patients and in patient visit.

### 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.

## CREATION OF A SCIENTIFIC COMITEE

Since its inception, the Ataxia Canada Foundation has had the mission of supporting research to contribute to the development of therapies targeting both the causes and the effects of the various forms of ataxia. The pursuit of this goal is still very much alive and topical within the administration and members of the Foundation.

In a context where it is essential for us to invest judiciously and to finance research according to a rigorous and fair process, the establishment of a Scientific Evaluation Committee (SEC) makes perfect sense. The SEC is made up of 3 external members with an interest and expertise in the field of ataxia as well as peer review of research grant applications.

### The Scientific Evaluation Committee (SEC)

Ataxia Canada relies on the expertise of its CES to ensure that research grants are evaluated with rigor, fairness and according to the priorities of the Foundation.



**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 genetic basis of neurogenetic disorders with founder effects in Quebec, with an increasing focus on disorders with ataxic manifestations such as Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay (ARSACS)



**Dr. Gerald Pfeffer**  
University of Calgary

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

**Dr. Anne Fournier**  
University of Montreal

Cardiometabolic and vascular health: from genetics to environmental approaches



More specifically, the CES has the following mandates:

- Evaluate grant applications objectively
- Provide assessments and recommendations to the Foundation's Board of Directors about the quality and scientific merit of the applications
- Suggest external expert resources who can feed the CES 'reflections when evaluating research grant applications.
- Play an advisory role with the Board of Directors (CA) on the selection of research priorities and on the improvement of the grant application evaluation process

## SERVICE PROGRAM



### INSERTION INTO JOB MARKET

We hired a trainee to help around with various projects.  
He benefited from work experience in accounting.



### FINANCIAL ASSISTANCE

This program, in connection with our mission, aims to improve the general well-being of people with ataxia by partially funding projects of various sizes for certain assistive devices, adaptations or equipment. Ataxia Canada has opted for crowd funding, which means that for every accepted application, the foundation will match up to 50% of the money raised by donors and give up to \$ 5,000 0 so 10 000\$ total per project.

Last year :4 completed projects, 7 000\$ (Quebec , Manitoba)

This year :6 completed projects, 24 400\$ (Quebec ,BC)

## COMITEE CREATION



### ADVISORY COMITEE

### SCIENTIFIC

### FINANCE

### SERVICE TO MEMBERS

### COMMUNICATION

### DEVELOPMENT OF ENGLISH CANADA

### FUNDRAISING



*The creation of committees allows us to integrate and regroup our volunteers, our collaborators and the administrators of the foundation in committees where each can bring his experience to advance the priorities of the foundation. If you would like to join with us, please do not hesitate to contact us.*



## 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!  
Visit our new fundraising platform



### 1 ATAXIA CHALLENGE

Are Flagship Walking and Cycling events were s cancelled this year in Chambly, QC and Ajax, Ontario. We were able to salvage these events trough a series of small local family gatherings

2019: 85 000\$  
2020: 67 000\$

Revenues are down but the cost of operating these events was drastically reduced.

### 2 Travel Lottery

We had our first travel lottery this year were we raised 17 000\$.

### 3 MAIL CAMPAIGN

Annual Direct Mail Fundraising Campaign

2019: 32 000\$  
2020: 36 000\$



### Communication strategy

#### WHY THE CHAMELEON ?

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

Regular value-added communications

Using all modes of communication

Increase our reach via social media;

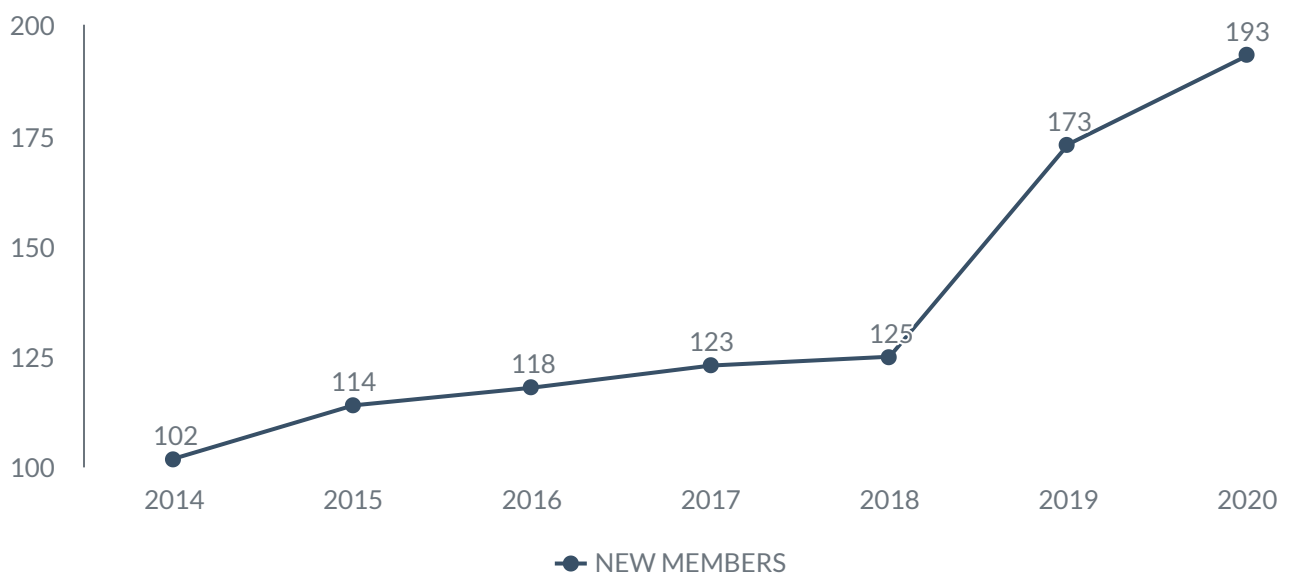
Segmentation of the communication according to the categories of donors

Database Analysis

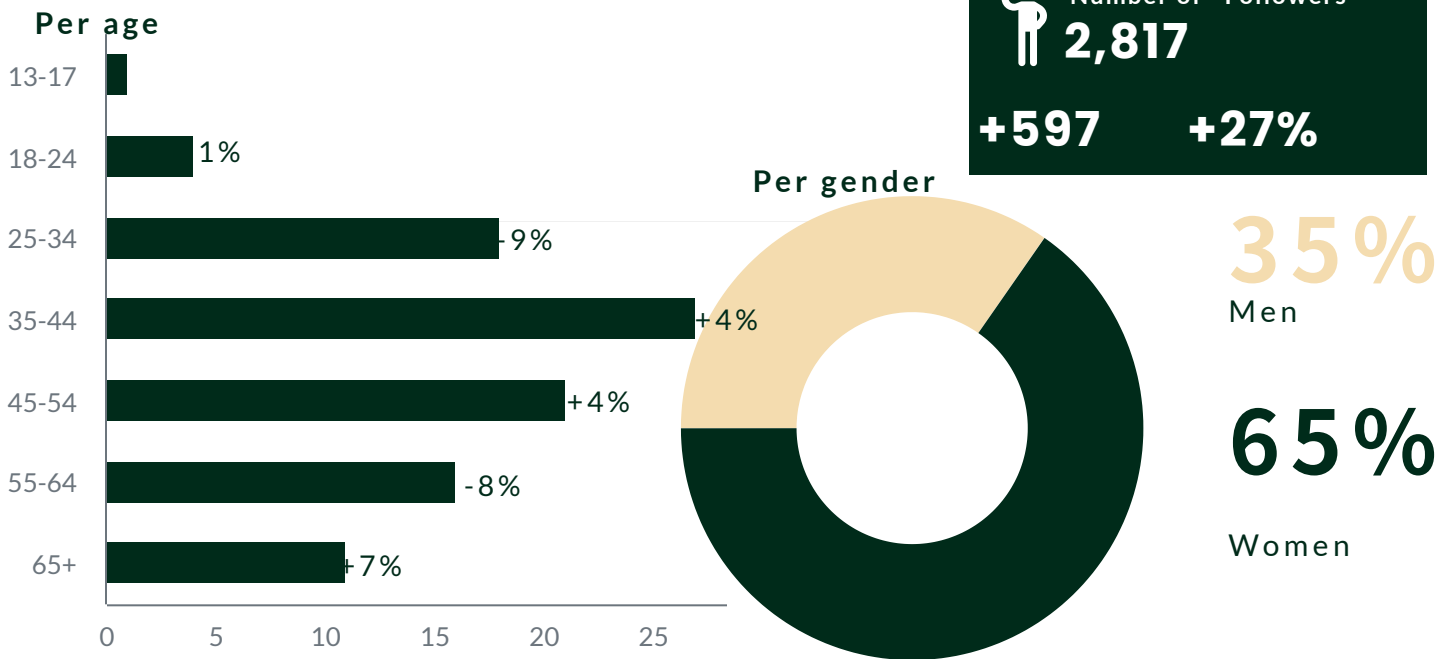
Production and distribution in hospitals and relevant organizations of a new information leaflets

Partnership Developments

Members with ataxia registered

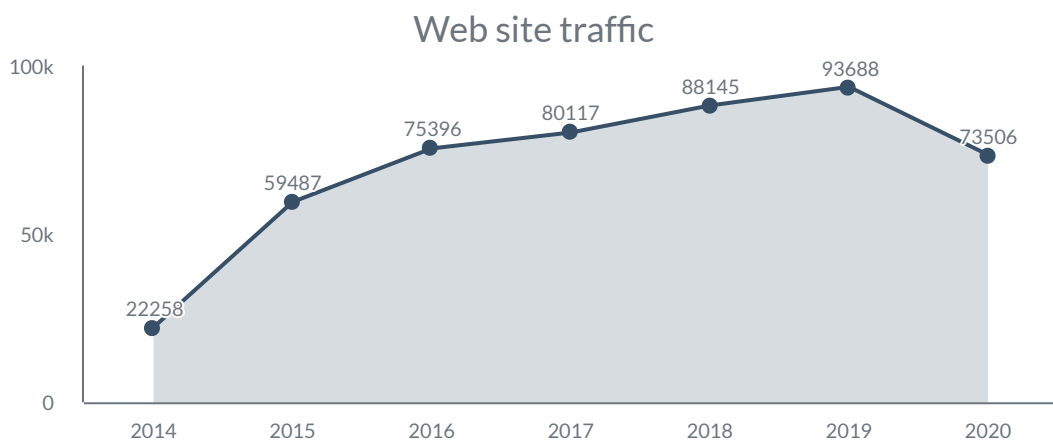


## Facebook

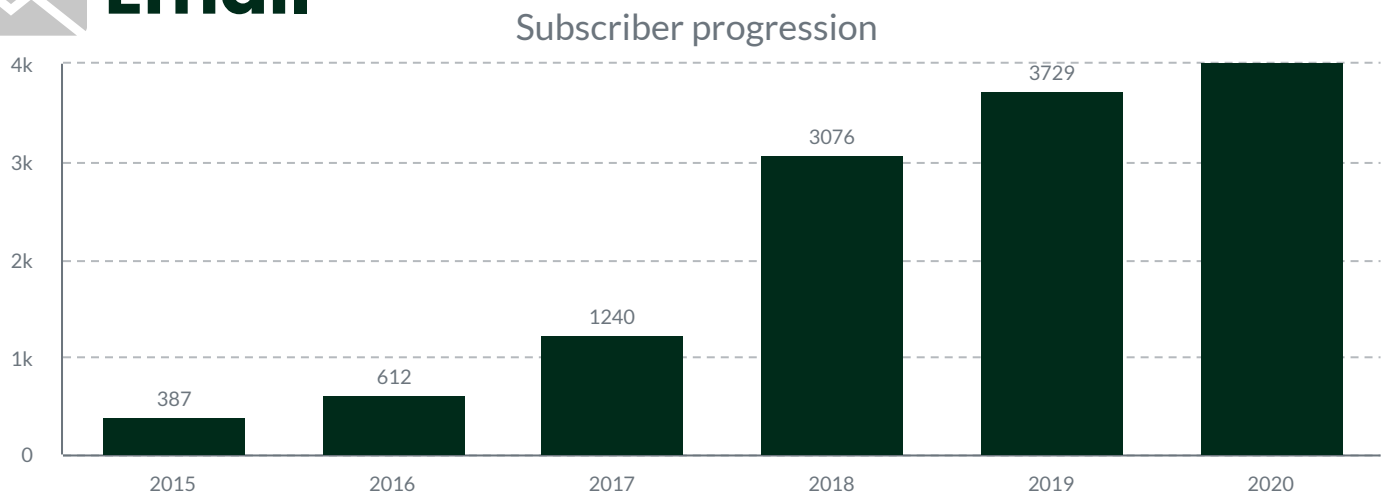


## Web site

- UPDATE INFORMATION
- KEYWORD ENHANCEMENT FOR WEB SEARCH ENGINE OPTIMIZATION (SEO)
- DIVERSIFICATION OF CONTENT (ARTICLE, BLOG)



## Email





OUR DONORS



■ Total Donors

Decrease donors due to COVID

■ Donors in Ontario

Slowly Growing

■ Donors in the n USA

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

■ Number of Donors

	2018	2019	2020
Quebec	1678 89%	1594 77%	1177 77%
Ontario	98 5%	266 13%	276 18%
Western Canada	69 3,5%	97 4%	56 5%
Eastern Canada	9 0,5%	17 1%	14 1%
United States	38 2%	107 5%	0 0%
Total	1893 100%	2082 100%	1501 100%

“

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”

## FINANCIAL RESULTS



### REVENUS

Extraordinary results during the difficult times. We also received a testamentary successions this year but much less than the previous year

### EXPENSES

Modest and managed by sound management practices.

### MEDICAL RESEARCH

Less than anticipated due to the halt in research and delays caused by

### COVID

### 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

INCOME	2018	2019	2020
Donations and fundraising	175 173\$	191 462\$	205 780\$
Testamentary and exceptional donation	28 000\$	315 000\$	150 000\$
Investment income	8 310\$	8 935\$	17 404\$
Total Income	211 483\$	506 462\$	373 184\$
EXPENSES	2018	2019	2020
Medical research	62 232\$	66 783\$	15 773\$
Service and communication to members	44 020\$	76 380\$	82 979\$
Events	69 277\$	58 301\$	52 845\$
Administration costs	17 496\$	36 505\$	32 912\$
Total expenses	193 025\$	237 969\$	184 509\$
EXCESS OF INCOME ON EXPENSES	+18 453\$	+268 493\$	+230 315\$

## A WORD FROM OUR PRESIDENT AND BOARD OF DIRECTORS



**Jean Luk Pellerin**  
President

Dear Friends,

It is with pride that we present our 2020 results to you. In the context of COVID 19, your board of directors and your general manager have been able to demonstrate creativity and resilience and thus deliver a performance that lives up to their expectations. I would also like to underline the always relevant contribution of the advisory committee in our reflections to grow the foundation. I am particularly proud of our new scientific evaluation committee: Doctor Brais, Fournier and Pfeffer have graciously agreed to join our team to help us in our research investment choices. Finally, I thank you for your unwavering support in a context where, to my knowledge, several foundations have experienced a difficult year



**Sébastien Huynh**  
Vice president



**Marc Dansereau**  
Treasurer



**André De Montigny**  
Secretary



**Sandy Sadler**  
Board member



**Josée Goulet**  
Board member



**Nicolas Théberge**  
Board member



**Bianca Guillemette**  
Board member



**Diane Roch**  
Board member

## CONTACT

Ataxia Canada – Claude St-Jean Fondation  
1751 Richardson (1050), Montreal, Qc, H3K 1G6  
Telephone : 514-321-8684  
Toll free : 1-855-321-8684  
[ataxia@lacf.org](mailto:ataxia@lacf.org)