



# ACTIVITY REPORT 2022\*

## Mission

Improve the well-being of people with familial ataxia, contribute to research in promising treatments and bring together the community of interest in Canada.



ATAXIE  
ATAXIA  
CANADA

50<sup>e</sup>

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.

DATE :

29 | 11 | 2022

\* Fiscal year from October 2021 to September 2022

## A WORD FROM OUR PRESIDENT OF THE BOARD OF DIRECTORS



**Sébastien Huynh**

President

Our foundation turned 50 this year. Again, our community was able to come together and bring to life our vision of a world where those diagnosed with ataxia can aspire to a fulfilling life. We continue to increase our institutional, scientific and private partnerships. This allows Ataxia Canada to have more means to fund research, support our members and promote our foundation. Consulted by the MSSS as part of the Quebec action plan for rare diseases, we have also continued our efforts to serve all of Canada and strengthen our ties with international foundations serving the same cause (in particular, FARA and NAF).

I thank all those who contribute to our foundation and encourage us to remain determined to advance research as Claude St-Jean wished in 1972 when the foundation was created.



**Josée Goulet**

Vice-president



**André De Montigny**

Treasurer



**Sandy Sadler**

Secretary



**Maryse Tremblay**

Board member



**Sean Ramsden**

Board member



**Nicolas Théberge**

Board member



**Trinidad Ruiz**

Board member



**Diane Roch**

Board member

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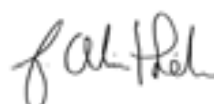
## A word from our general manager

It is with great pride that I present to you the results of our activities. This year marks the return to live events, but the most emblematic is the 50th anniversary of the foundation. Ataxia Canada is 50 years of substantial progress and small resolute steps towards the implementation of our programs improving the quality of life of ataxic patients. Ataxia Canada is 50 years of steady scientific advances towards a treatment. Research and clinical trials are conducted by seasoned researchers from here and abroad of international renown.

In addition to our loyal researchers and clinicians, our institutional and private partners, the efforts of our research committee have brought new early career researchers to take an interest in ataxias. The scientific evaluation committee has also been improved to respond to our growing portfolio to ensure that each dollar invested in research brings us a little closer to the finish line. After several delays in setting up a natural history study specific to the SCA; we finally joined the CRC-SCA in autumn 2022 in collaboration with the National Ataxia Foundation. The FACOMS study in Friedreich's ataxia, which is an international collaborative effort, has enabled us to position Canada as an important player and has attracted a clinical trial. We are still anticipating an increase in research investments for the next year through several partnerships. Our cash flow is excellent, our board of directors is well balanced and the new directors bring complementary skills. We are doing great things with the help of a small fraction of families and people with ataxia. So, daring to give itself the means to increase its resources and energies tenfold, Ataxia Canada is undertaking to expand its support network, its "circle of followers" committed to ataxias and ataxias. We hope that all families affected by ataxia join our cause. We have made significant progress this year and we are convinced that we can continue to pursue the initial fight of Claude St-Jean. Our foundation is still looking for ambassadors, volunteers, donors and organizers to be at work. Because science advances, technologies advance, and life is stronger than anything.

### Main objectives for the past year

- Develop new partners to increase our research efforts
- Continue to expand our network to reach more people and establish a pan-Canadian presence
- Increase our fundraising activities
- Lay the foundation of a clinical research center for SCA's.



**François-Olivier Théberge**  
General manager





The goal is to continue to attract and perform clinical trials in Canada

## 1 PARTNERSHIP

The Ataxia Canada Foundation supports research through partnerships with other foundations, organizations, companies or governments to create leverage with our research spending.



## 2 RESEARCH SITE

The Montreal Collaborative Clinical Research Network on the Friedreich's Ataxia Site (CCRN) and the CRC-SCA Natural History Study is led by Dr. Antoine Duquette, neurologist at CHUM and his research team. site houses two international natural history studies and established structure to host clinical trials.



## 3 RESEARCH GRANTS

Ataxia Canada funds relevant research where ataxia is the primary symptom and is genetic and progressive in nature. Research grants awarded are normally for one to two years and between \$15,000 and \$50,000 per year.

### Ongoing project

Dr Nicolas Dupré and Francois Gros-Louis - CHUL - creation of an open science repository of induced pluripotent stem cells for ARCA1.

Dr Jacques P. Tremblay-CHUL-: development of a gene therapy for Friedreich's ataxia.

Dr Antoine Duquette -CHUM- development of virtual reality tools for the assessment of motor impairment in ataxic patients.

Dr. Hassan Marzban: University of Manitoba Assessing the relative contribution of different cerebellar nucleus neurons to the pathogenesis of Friedreich's ataxia.

### Grant 2022-2023

Dr. Julian - SFU Burnaby - Elucidating progressive disease phenotypes in SCA1 patient cell models.

Dr. Martine Tétreault - CHUM - Transcriptomic and epigenomic modifiers associated with FRDA phenotypic variability.

Dr. Brais -McGill- Looking for late ataxia genes.



## 4 RESEARCH GRANTS

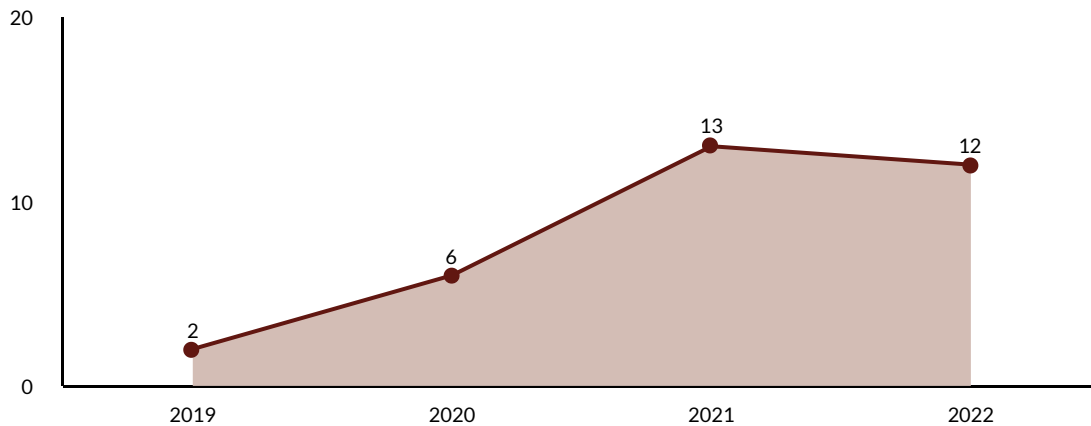
The goal is to continue to fund or attract clinical trials in Canada to benefit people with potential treatments that are in development. In 2021, we achieved these goals. A group at the CHUM and Sainte-Justine measures the effectiveness of a molecule in slowing the progression of the disease, the first clinical trial of this type in Canada for 15 years.



## B - SERVICE PROGRAM

This program, in line with our mission, aims to improve the general well-being of people with a form of ataxia by partially funding projects of various sizes for certain technical aids, adaptations, services or equipment.

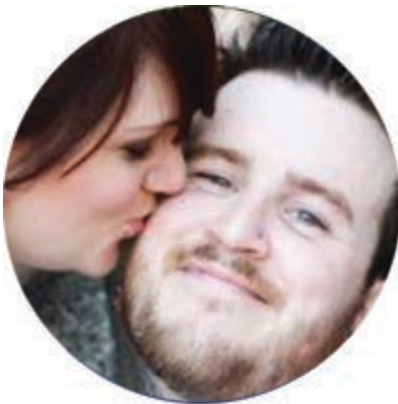
People helped by the financial support program



“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



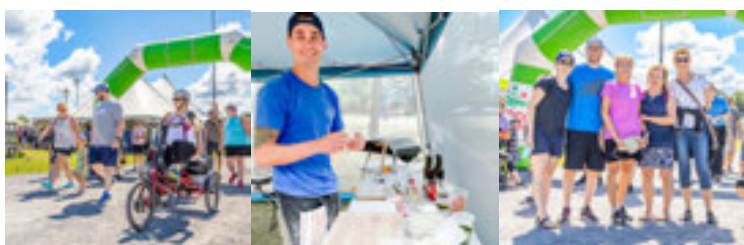
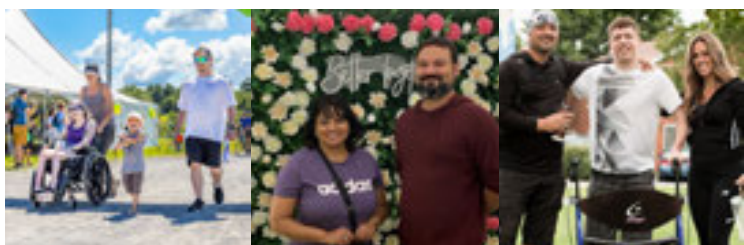
“This program allows us to flourish. Thanks to donors and the Foundation, I was able to get an electric tri cycle so I can finally ride a bike with my daughter !! What a joy to know that I can still have fun with my daughter despite my illness!  
Jessica ,Bécancour, Québec

## C-FUNDRAISING ACTIVITIES



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

It's finally the return of the Ataxia challenge. Thank you to the volunteers and participants for a great day in Chambly. Not to mention the events in Toronto, Gatineau and Vancouver.

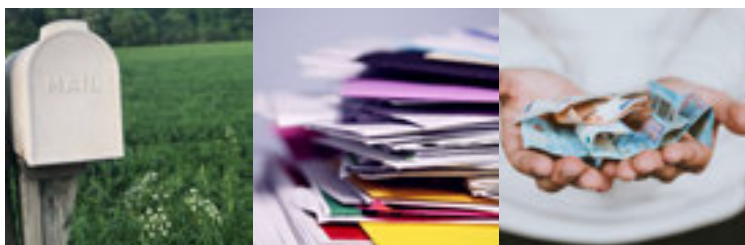
2019: 85 000 \$

2020: 67 000 \$

2021: 93 000 \$

2022: 96 000 \$

## 2 MAIL CAMPAIGN



Annual Direct Mail Fundraising Campaign

2019: 32 000 \$

2020: 36 000 \$

2021: 35 000 \$

2022: 36 000 \$

## 4 Corporate donation

Thank you to our corporate partners who support scientific research



LA  
PROMESSE  
PRÊTS À AGIR

**ThermoFisher**  
SCIENTIFIC



## D-OUR DONORS



### ■ nombre de donateurs

|                    | 2019                | 2020                | 2021                | 2022                |
|--------------------|---------------------|---------------------|---------------------|---------------------|
| Québec             | <b>1594</b><br>77%  | <b>1177</b><br>77%  | <b>1024</b><br>75%  | <b>1118</b><br>83%  |
| On, SK<br>Manitoba | <b>266</b><br>13%   | <b>276</b><br>18%   | <b>105</b><br>8%    | <b>112</b><br>8%    |
| Ouest du<br>Canada | <b>97</b><br>4%     | <b>56</b><br>5%     | <b>224</b><br>16%   | <b>105</b><br>8%    |
| Est du<br>Canada   | <b>17</b><br>1%     | <b>14</b><br>1%     | <b>15</b><br>1%     | <b>17</b><br>1%     |
| États-<br>Unis     | <b>107</b><br>5%    | <b>0</b><br>0%      | <b>0</b><br>0%      | <b>0</b><br>0%      |
| Total              | <b>2082</b><br>100% | <b>1501</b><br>100% | <b>1368</b><br>100% | <b>1353</b><br>100% |



We are doing great things with the help of multiples families. Imagine if we had the support of every canadian family with a history of ataxia!







### WHY THE CHAMELEON ?

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

## Communication strategy

Regular value-added communication

Using all modes of communication

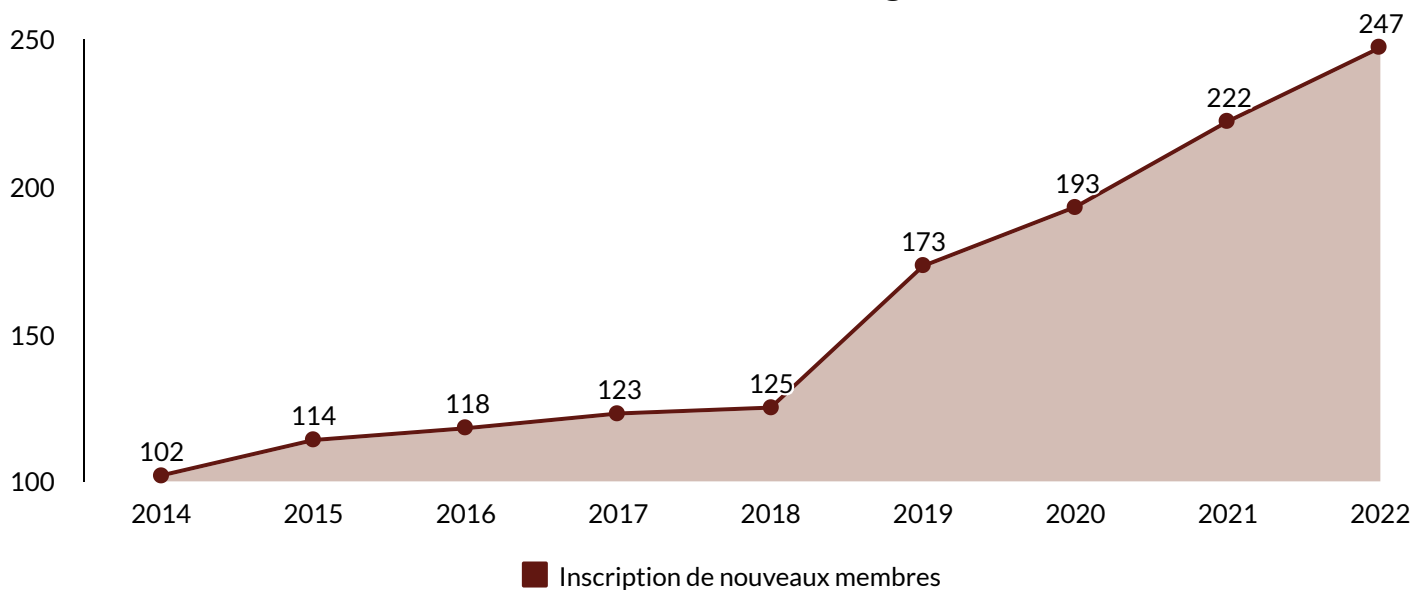
Increase our reach via social media

Database Analysis

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

Partnership Developments

### Members with ataxia registered



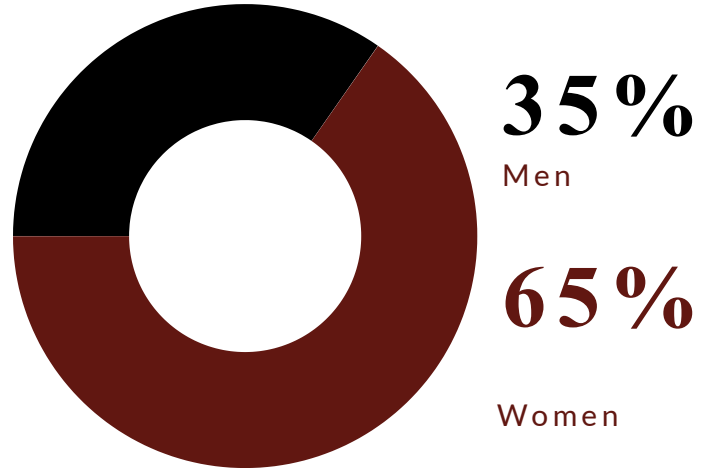
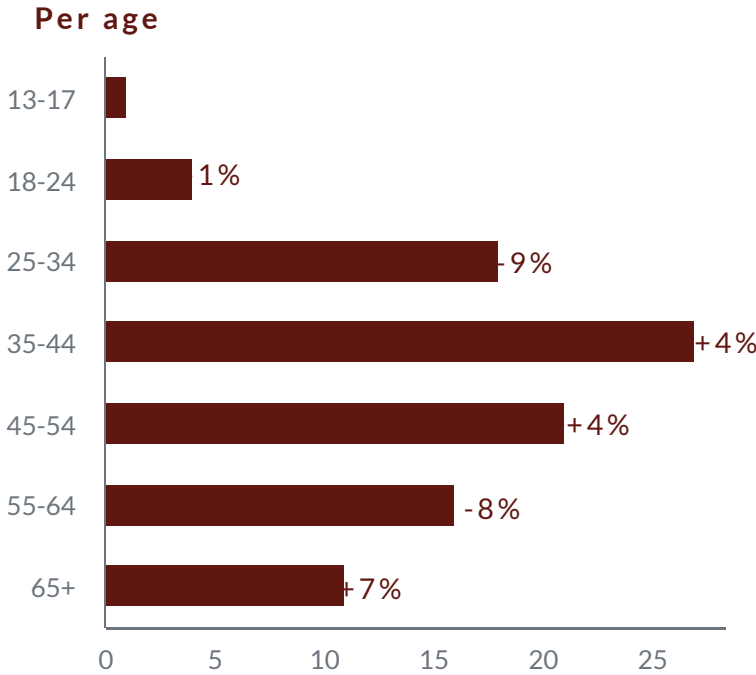
# Facebook

Number of "Followers"  
**3,256**

**+256**

**+10%**

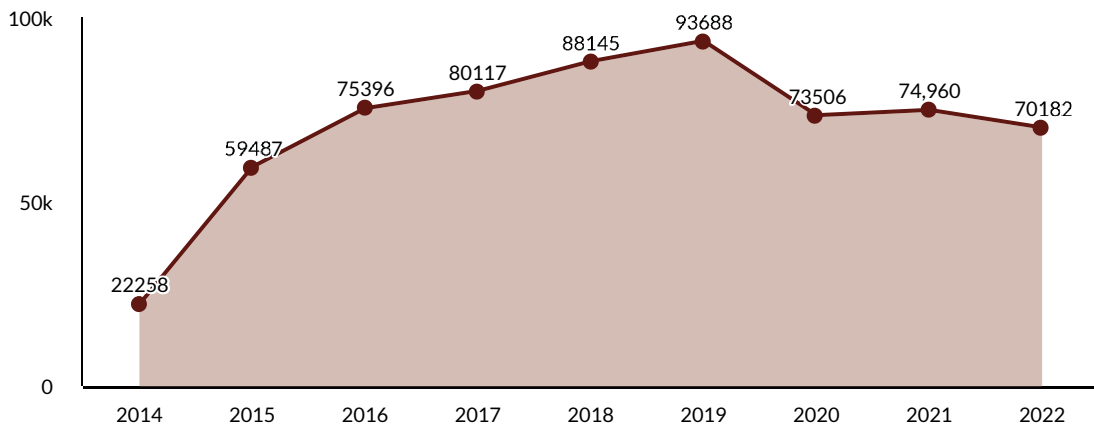
Per gender



## Web site

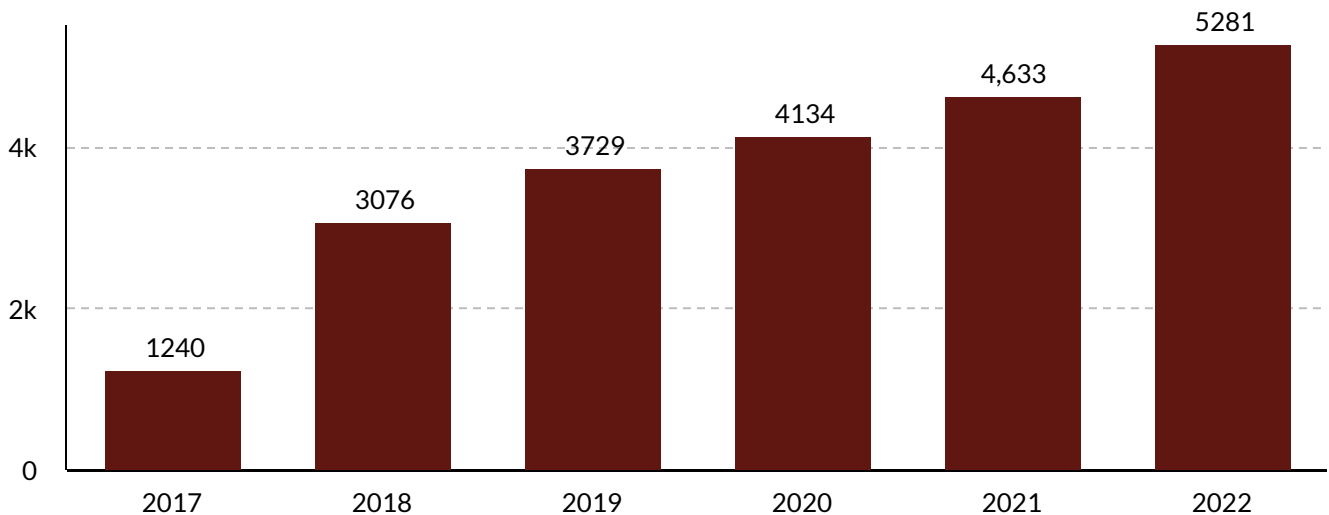
- Update information
- Key word enhancement for web search engine optimization ( S E O )
- Diversification of content ( articles ,blog )

Website internet traffic



## Email

Subscriber progression





## F- FINANCIAL RESULTS



### ■ INCOME

A gradual return to a pre-Covid level of income.

### ■ EXPENSES

Modest and managed through sound management practices.

### ■ MEDICAL RESEARCH

Fewer new projects awarded in 2022 but 3 new researchers approved for 2023!

### ■ TESTAMENTARY SUCCESSION

It is clear that the impact of bequests is significant and donors should continue to be informed of this mechanism.

### ■ SERVICE TO MEMBERS

Lots of small member service projects.

### ■ EVENTS AND FUNDRAISING COST

Increased cost to organize and plan events. Special budget for the 50th anniversary.

| INCOME   | 2019            | 2020            | 2021            | 2022           |
|--|-----------------|-----------------|-----------------|----------------|
| Donations and fundraising                      | 191 462         | 205 780         | 168 160         | 176 069        |
| Testamentary donation and exceptional revenues | 315 000         | 150 000         | 51 003          | 114 000        |
| Investment income                              | 8 935           | 17 404          | 14 029          | 9 172          |
| <b>Total Income</b>                            | <b>506 462</b>  | <b>373 184</b>  | <b>233 192</b>  | <b>299 241</b> |
|  | 2019            | 2020            | 2021            | 2022           |
| Medical research                               | 66 783          | 15 773          | 163 357         | 110 867        |
| Service and communication to members           | 76 380          | 82 979          | 91 064          | 80 584         |
| Events and fundraising                         | 58 301          | 52 845          | 34 490          | 86 698         |
| Administration costs                           | 36 505          | 32 912          | 22 268          | 23 779         |
| <b>Total expenses</b>                          | <b>237 969</b>  | <b>184 509</b>  | <b>311 179</b>  | <b>301 928</b> |
| <b>EXCESS OF INCOME ON EXPENSES</b>            | <b>+268 493</b> | <b>+230 315</b> | <b>(26 984)</b> | <b>(2 887)</b> |

## C-LES COMITÉS EN ACTIONS



### ADVISORY COMMITTEE

- Made up of volunteers
- Fuel the efforts of the board of directors
- Comment on the strategic plan, the annual priorities, and the content of the services offered to patients and their caregivers.

### SCIENTIFIC

- Attract clinical trials to Canada to benefit our anadian patients
- Further promote the Ataxia Canada research fund to attract new researchers

### FINANCE

- Perform quarterly audits
- Present results on a quarterly basis for approval by the board of directors
- Prepare the annual audit documents

### MEMBER SERVICES

- Promote the financial support program for equipments and services

### COMMUNICATION

- Create contact with a greater number of people with familial ataxia
- Content creation for social media

### ENGLISH CANADA DEVELOPMENT

- Expand our scientific contacts: researcher, physician and health professional in Canada
- Recruit volunteers to create fundraising opportunities within their network

### FUNDRAISING

- Increase revenue generated by fundraising activities
- Corporate giving strategy



*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!*



## 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 Lamy  
Sonia Prasad  
Ron Singh  
Sonia Roy  
Gino Martel  
Emmanuelle Poirier St-Georges  
Bianca Guillemette

Kim, Marc et Huguette Frenette  
Jessica Laneuville  
Dominique Ruiz-Courcelle  
Manon Courcelle  
Trinidad Ruiz  
André Allard  
Susan Harding  
Brittany Sommerfield  
Nicolas Théberge  
Sakina Rehmanji  
Juzer Rehmanji  
Solange Lavoie Guillemette  
Alain Brulotte

