



## 2021\* ACTIVITY REPORT

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.



**ATAXIE  
ATAXIA  
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.



## A WORD FROM OUR PRESIDENT AND BOARD OF DIRECTORS



**Sébastien Huynh**

Président

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.



**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

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## Director's word

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.

### 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 affected and establish a Canada-wide presence.
- Increase our financing activities
- Attract clinical trials to Canada


A handwritten signature in dark ink, appearing to read 'F. Théberge'.

**François-Olivier Théberge**  
General manager

“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.



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

### 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.

## THE SCIENTIFIC COMMITTEE IN ACTION

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.

### 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.

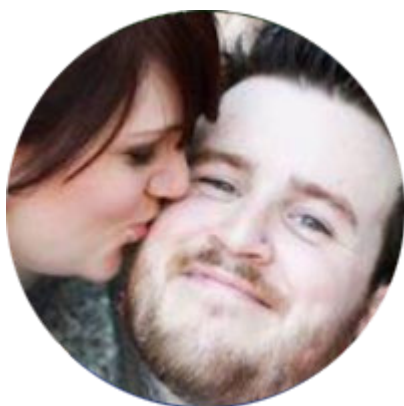
Two years ago: 2 projects; \$ 7,000; (Quebec, Manitoba)  
Last year: 6 projects; \$ 24,400; (Quebec, British Columbia)  
This year: 13 projects; \$ 62,000; (Quebec, Alberta, Manitoba, Ontario)



"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 IN ACTION



### 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

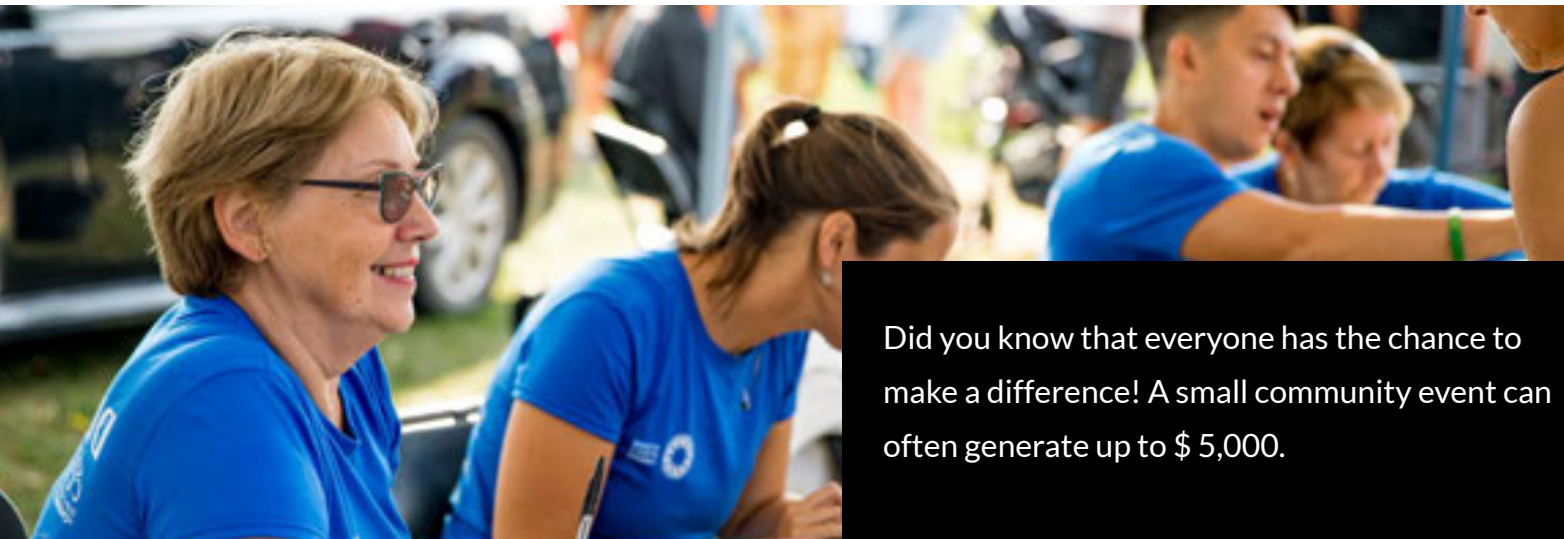
- Expand the pool of scientific contacts: researcher, physician and health professional in Canada
- Recruit volunteers to create fundraising opportunities within their network

### 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!

## FINANCING 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

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







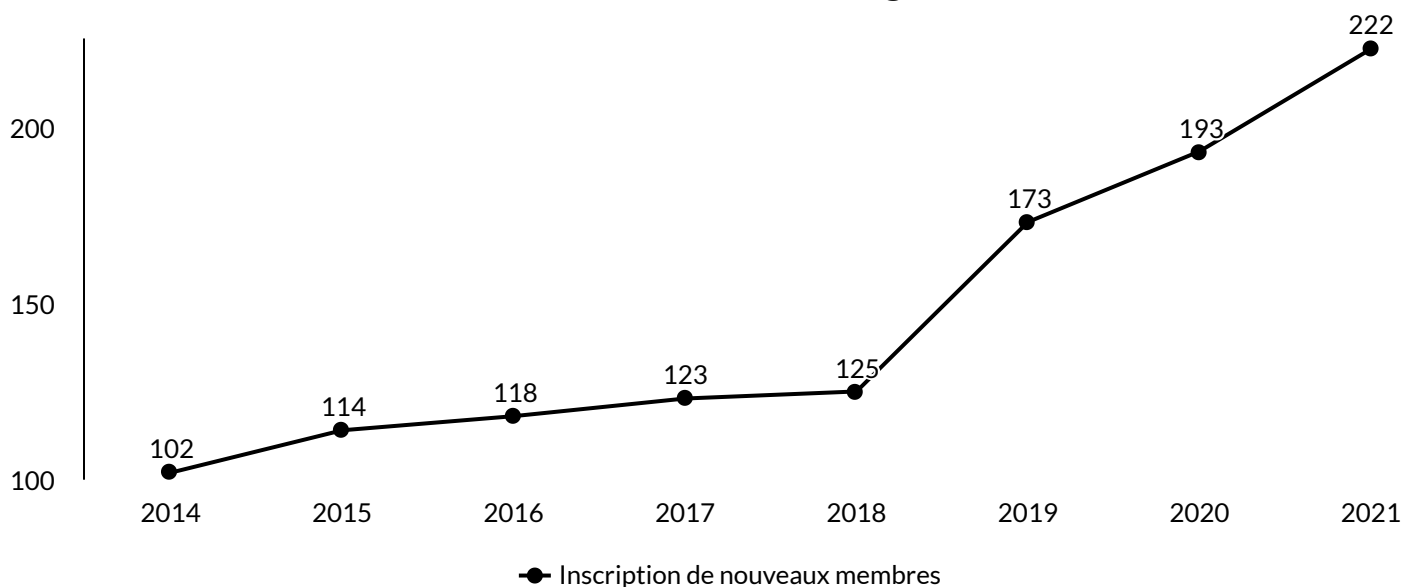
### Communication strategy

#### WHY THE CHAMELEON ?

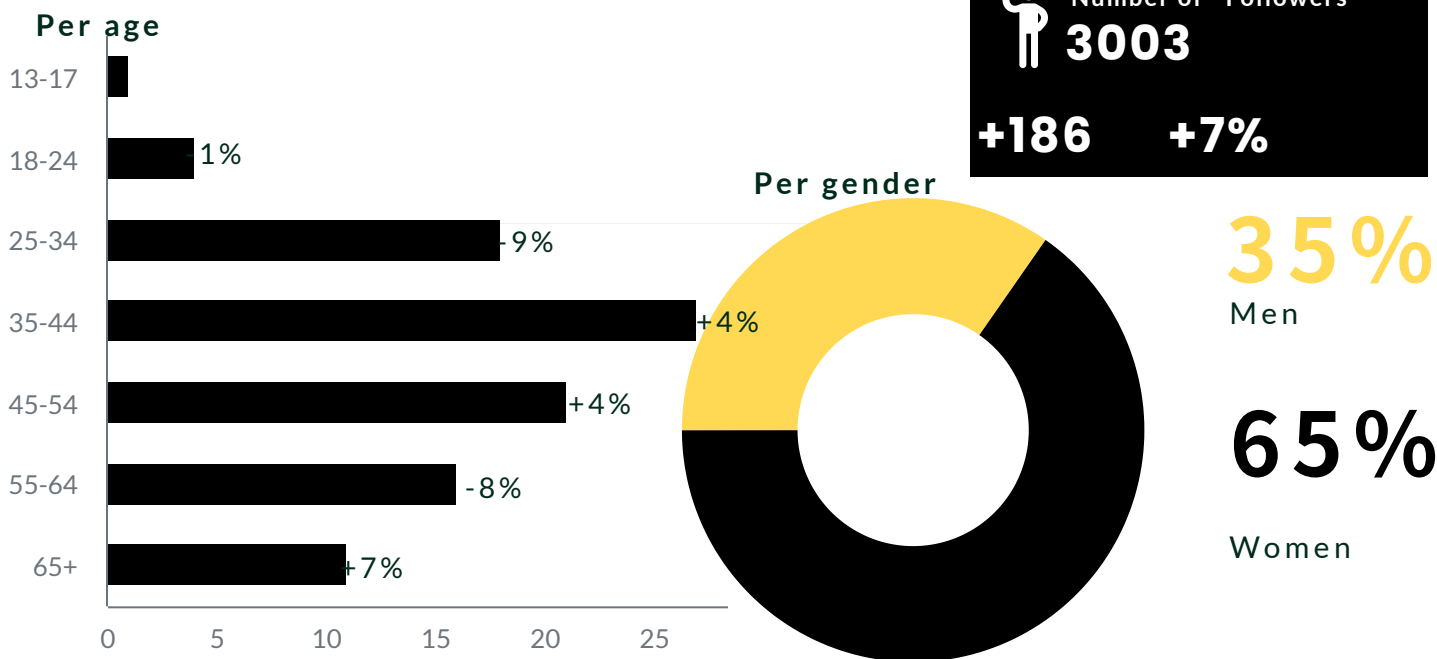
Without having high physical capacity, the chameleon is very sensitive to its surroundings;  
it can adapt to any environment.

- Regular value-added 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



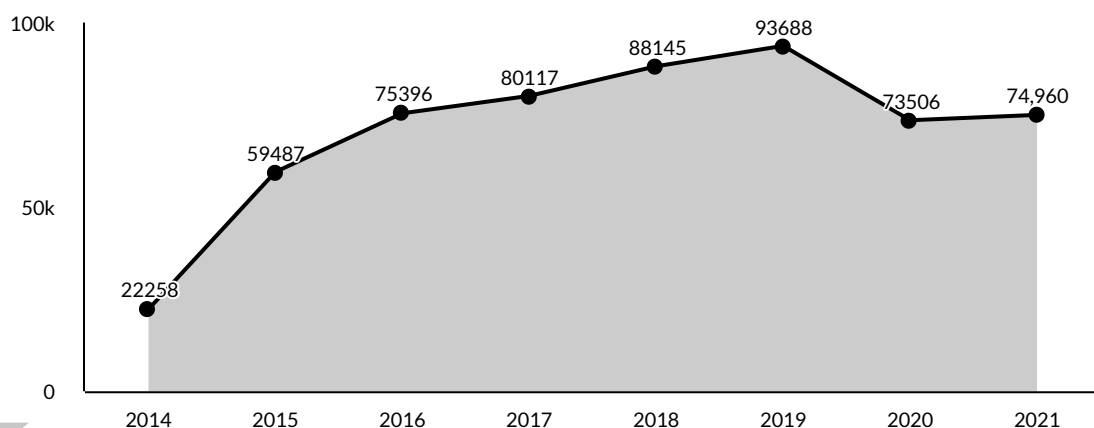
## Facebook



## Web site

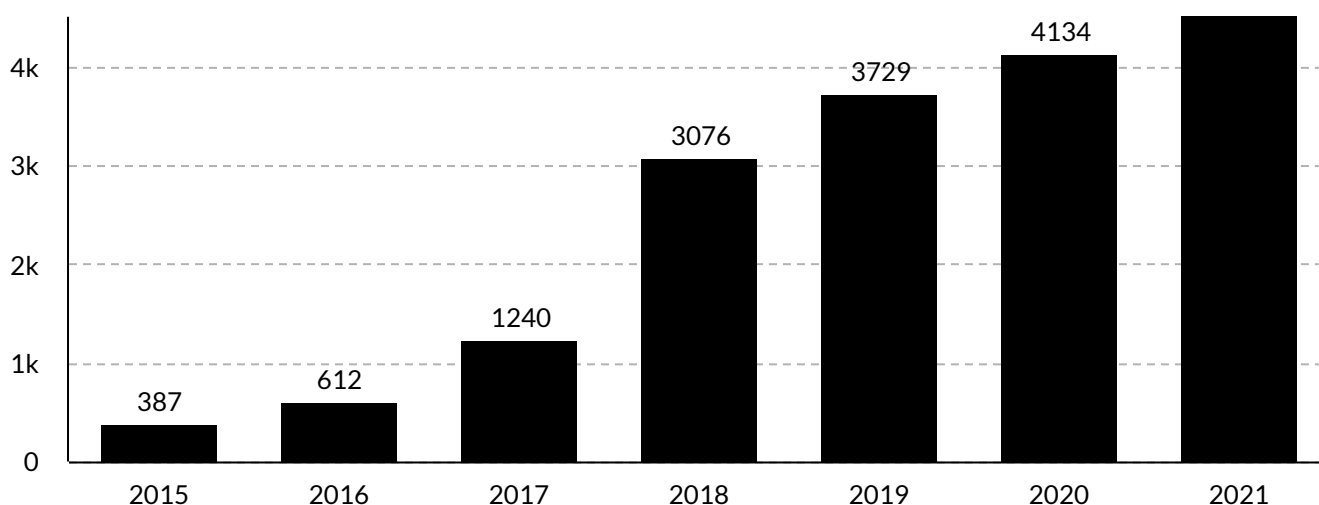
- Update information
- Keyword enhancement for web search engine optimization ( SEO)
- Diversification of content (articles, blog )

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.

■ number of donors

|                     | 2018         | 2019         | 2020         | 2021         |
|---------------------|--------------|--------------|--------------|--------------|
| Quebec              | 1678<br>89%  | 1594<br>77%  | 1177<br>77%  | 1024<br>75%  |
| Ont, SK<br>Manitoba | 98<br>5%     | 266<br>13%   | 276<br>18%   | 105<br>8%    |
| Western<br>Canada   | 69<br>3,5%   | 97<br>4%     | 56<br>5%     | 224<br>16%   |
| Eastern<br>Canada   | 9<br>0,5%    | 17<br>1%     | 14<br>1%     | 15<br>1%     |
| USA                 | 38<br>2%     | 107<br>5%    | 0<br>0%      | 0<br>0%      |
| Total               | 1893<br>100% | 2082<br>100% | 1501<br>100% | 1368<br>100% |

“

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

| INCOME   | 2018           | 2019            | 2020            | 2021            |
|--|----------------|-----------------|-----------------|-----------------|
| Donations and fundraising                      | 175 173        | 191 462         | 205 780         | 219 163\$       |
| Testamentary donation and exceptional revenues | 28 000         | 315 000         | 150 000         | 51 003          |
| Investment income                              | 8 310          | 8 935           | 17 404          | 14 029          |
| <b>Total Income</b>                            | <b>211 483</b> | <b>506 462</b>  | <b>373 184</b>  | <b>284 195</b>  |
| EXPENSES                                       | 2018           | 2019            | 2020            | 2021            |
| Medical research                               | 62 232         | 66 783          | 15 773          | 163 357         |
| Service and communication to members           | 44 020         | 76 380          | 82 979          | 91 064          |
| Events   | 69 277         | 58 301          | 52 845          | 34 490          |
| Administration costs                           | 17 496         | 36 505          | 32 912          | 22 268          |
| <b>Total expenses</b>                          | <b>193 025</b> | <b>237 969</b>  | <b>184 509</b>  | <b>311 179</b>  |
| <b>EXCESS OF INCOME ON EXPENSES</b>            | <b>+18 453</b> | <b>+268 493</b> | <b>+230 315</b> | <b>(26 984)</b> |

## 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 Prasas  
Ron Singh  
Sonia Roy  
Gino Martel  
Emmanuelle Poirier St-Georges  
Bianca Guillemette  
Solange Lavoie Guillemette  
Alain Brulotte  
Kim, Marc et Huguette Frenette  
Jessica Laneuville  
Dominique Ruiz-Courcelle  
Manon Courcelle  
André Allard  
Sakina Rehmanji  
Susan Harding  
Brittany Sommerfield

