



2025 ACTIVITY REPORT



ATAXIE
ATAXIA
CANADA

50^e

THE MISSION OF ATAXIA CANADA IS TO IMPROVE THE WELL-BEING OF PEOPLE AFFECTED BY FAMILIAL ATAXIA, TO CONTRIBUTE TO THE SEARCH FOR PROMISING TREATMENTS AND TO BRING TOGETHER THE COMMUNITY OF INTERESTS IN CANADA.

A WORD FROM OUR PRESIDENT



Trinidad Ruiz
Président

BOARD OF DIRECTORS



It is with great enthusiasm that I address you for the first time as Chair of the Board of Directors. It is an honor for me to continue the work begun by Jean-Luk Pellerin, to whom I would like to express my gratitude for his commitment, vision, and numerous accomplishments during his presidency.

I would also like to highlight the exceptional work of François-Olivier Théberge, whose dedication and rigor have greatly contributed to the foundation’s influence and strength. I would also like to highlight the exceptional work of François-Olivier Théberge, whose dedication and rigor have greatly contributed to the foundation’s influence and strength. Thanks to their leadership and efforts, the foundation has grown and become a true voice for the families it represents across Canada.

Over the past year, the foundation has continued to make progress, both in terms of research and support for affected individuals and families. Our partnerships have grown stronger, our reach has expanded, and our community has never been more engaged.

As I begin my term, my priority will be to ensure the continuity of this momentum while preparing for the next steps in our development. Together, we will continue to build a strong, innovative, and deeply human organization.

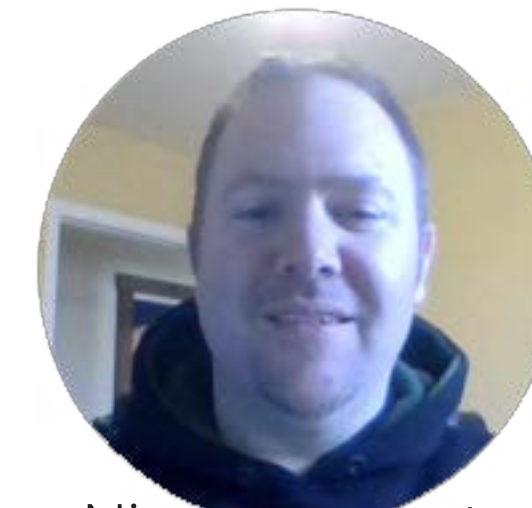
On behalf of the Board of Directors, I thank you for your trust and commitment to the foundation’s mission.



Nathalie Farley
Vice-president



André De Montigny
Secretary



Nicolas Parents
Treasurer



Maryse Tremblay
Administrator



Nicolas Théberge
Administrator



Jean-Luk Pellerin
Administrator

WORD FROM THE DIRECTOR



It is with deep gratitude and great pride that I present our report card. Ataxia Canada has become a mobilizing force, a catalyst for change for people with familial ataxia. Once again this year, our commitment has translated into concrete actions and strategic partnerships.

Over the past few years, Ataxia Canada has led a relentless campaign for access to the first treatment for Friedreich's Ataxia (FA), building bridges between industry, government, clinical communities, and patients. Through this collaborative approach, we made our voices heard: 135 responses to the patient survey, 600 letters sent to elected officials, 40 powerful testimonials, and more than 5.3 million people reached by our media campaigns.

When the initial recommendations excluded wheelchair users, we took decisive action to highlight the realities faced by people with FA. Today, the Canada Drug Agency's recommendations reflect a more inclusive approach. This progress is significant, but our work is far from over. We are continuing our efforts to overcome administrative barriers and obtain recognition of the therapeutic value of AF in Quebec.

At the same time, we are continuing to invest in research. We support more than a dozen researchers across the country, and we have adopted a complementary approach to investing in areas of research that are often overlooked but have the potential to have a direct impact on people with ataxia and their caregivers. These areas include adaptation, rehabilitation, and clinical research.

Our financial support program, which was developed in direct consultation with our members, continues to grow and make a tangible difference in the quality of life of people with ataxia. Behind every project we support are stories of resilience, courage, and innovation.

Finally, I would like to emphasize that our community of donors and volunteers is the beating heart of the Foundation. To maintain our momentum, we need you: testimonials, engagement on social media, volunteering, connections with decision-makers—every gesture counts. Thank you for believing in our mission. Together, we are building a more just, inclusive, and hopeful future for all people affected by ataxia.

François-Olivier Théberge
Executive Director – Ataxia Canada





WHAT IS ATAXIA



Familial ataxias

Ataxia is a family of degenerative neuromuscular disease that affects thousands of young people and adults. There are several types and our foundation supports ataxias of a hereditary nature.

Some of the conditions are genetic without even a parent being symptomatic. A recessive disease is like a thunder strike in a blue sky.

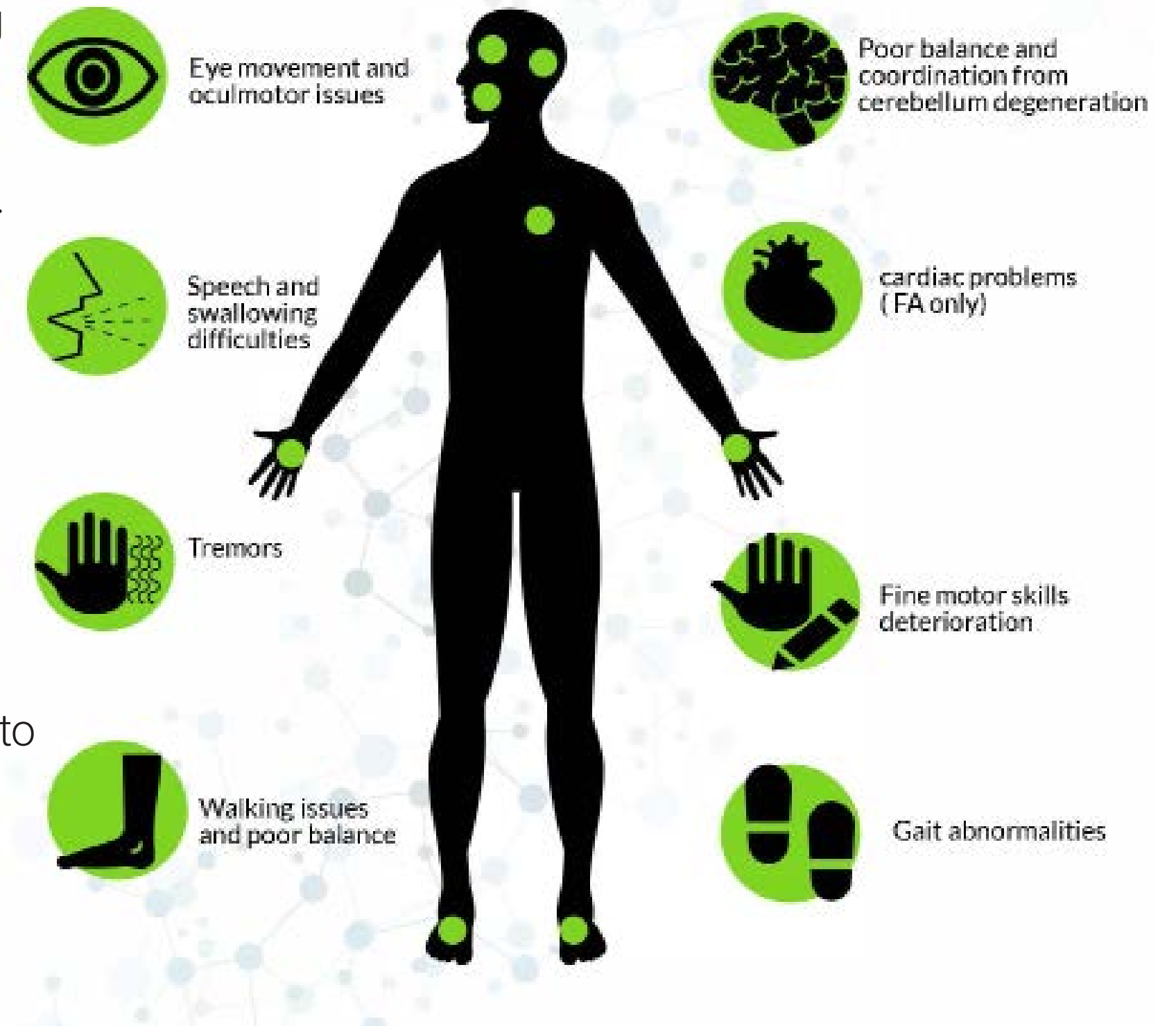
Others affect several generations within a family or community. These are called dominant conditions.

It is the nervous system that is affected, the initial symptoms present in all ataxias are lack of balance and difficulty walking.

The disease progresses and deteriorates the ability to speak, swallow and write. For some it is also heart problems, scoliosis or diabetes.

It should be noted that cognitive functions are not affected.

Very few people know about this disease, which forces ataxics to constantly explain their condition.



The foundation

Ataxia Canada – Claude-St-Jean Foundation is, first and foremost, a community of women, men, adults, adolescents and children suffering from a hundred forms of ataxia, in every corner of the country.

50 years ago, the flame of hope was lit by founder Claude St-Jean, suffering from Friedreich’s ataxia.

We represents half a century of people who inspire us all because they embrace life despite the challenges of everyday life. These are volunteers who give time and money to ensure its continuity.

It is a series of stories lived by ataxics to defy time, the progression of the disease, to adapt to it, to live. And this, in every corner of the country, with the dedicated support and perseverance of their caregivers, doctors and researchers. Because science advances, technologies progress, and life is stronger than anything.



VISION FOR RESEARCH



1 Partnerships

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

Attribution



2 Clinical research site

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

Dr. Massimo Pandolfo, Associate Neurologist at McGill University and a world authority on ataxia, is leading the TRACK-FA study: a neuroimaging study to monitor changes in the brain and spinal cord in people with Friedreich's ataxia.



3 Research grants

Ataxia Canada funds relevant research where ataxia is the primary symptom of a genetic nature. Research grants are normally awarded for a period of two years and a maximum of \$50,000 per year.

As mentioned earlier, we are evaluating new projects for 2026. There is a positive and important element to note in these new applications: the majority come from new researchers, collaborators, and Canadian institutions.

RESEARCH IN ACTION

Ataxia Canada Impact: 2019 - 2025

Contribution to research in promising treatments



Research projects funded annually grew from 1 to 12



Stronger research capacity



Increase in realistic prospects for targeted treatments over the medium and long term

\$ 1.379 MILLION

Invested in research

Invested in 2025

\$ 415,000

Dre Lisa Julian
SFU

- Elucidating progressive disease phenotypes in cell models of SCA1 patients.

Dr Brais Tétreault McGill
Dre Martine Tétreault CHUM

- In search of genes for late onset ataxia.
- Transcriptomic and epigenomic modifiers associated with phenotypic variability in Friedreich's ataxia.

Dr Roberta La Piana McGill

- Elucidating progressive disease phenotypes in cell models of SCA1 patients.

Dr. Nancy Braverman McGill

- CNS-directed gene therapy to ameliorate ataxia and neurodegeneration in a PEX16 mouse model

Dr Éric Lécuyer IRCM

- Determination of the repertoires and therapeutic potential of RNA-binding proteins undergoing sequestration by toxic repetitive RNA in SCA.

Dr. Eric Samarut CHUM

- Elucidating progressive disease phenotypes in cell models of SCA1 patients.

Cynthia Gagnon Ph. D. Université de Sherbrooke
D.Toshifumi Yokota Ph. D., FCAHS Université de l'Alberta

- Selection of patient-reported outcomes to improve the assessment of dysphagia in myotonic dystrophy type 1 and Friedreich's ataxia.
- Development of an improved antisense therapy using lipid nanoparticles for Friedreich's ataxia et l'amyotrophie



CLINICAL TRIALS AND TREATMENTS

4 A real impact for clinical trials here

The goal is to continue funding or attracting clinical trials to Canada so that people with the disease can benefit from potential treatments currently in development. The Foundation wants to continue connecting pharmaceutical companies with our researchers and clinicians in Canada and serve as a conduit to encourage a healthy environment for private investment.

On a positive note, there are promising advances in clinical research:

Arrowhead Pharmaceuticals is advancing clinical trials for SCA2 at the Neuro and CRCHUM in Montreal.

Lexeo Therapeutics is advancing a gene therapy targeting the cardiovascular symptoms of Friedreich's ataxia. They are currently recruiting for a cardiac natural history study to better understand progression before launching a new phase of trials.

5 For access to treatments recently developed in the United States

Progress this year has been mixed. Skyclarys (omaveloxolone) suffered a setback in Quebec with a negative recommendation from INESSS for reimbursement, although a reassessment is underway. Other provinces have received positive recommendations from the Canadian Drug Agency (CDA), which is encouraging for patient access.

On a positive note, Ataxia Canada played a key role in the CDR process. The initial recommendation included restrictive criteria that excluded non-ambulatory patients. Thanks to our efforts to educate decision-makers about the patient journey and expectations, these criteria were modified, ensuring broader access for those who need it most. Biogen's BRAVE study will soon launch pediatric trials in Quebec City and Montreal for Skyclarys in patients under 16 years of age.

Internationally, the FDA has not approved Vatiquinone (Reata) for Friedreich's ataxia or Troriluzole (Biohaven) for ataxia, which is a significant disappointment for the community.



OUR SUPPORT TO PATIENTS



This program, in line with our mission, aims to improve the well-being of people affected by of a form of ataxia by partially financing projects of varying sizes for certain types of technical aids, adaptations, services or equipments. A health care professional must be on board!

Ataxie Canada has opted for “participatory” financing, meaning that for each request for accepted support, the foundation will match the money raised by donors up to a maximum of \$5,000.

This form of financing has many advantages:

- a favorable change in the quality of life of an affected person;
- collaboration and involvement of its own network and that of Ataxia Canada in the financing of its project;
- a community united around a common cause;
- a tax receipt for each donor.

The program has been implemented for several years and we are proud of it because:

- we helped around sixty people across Canada;
- our program is increasingly known to he ataxia community and health personnel and requests are increasing;
- due to inflation and the increase in purchasing costs for specialized equipment and services, we have decided to finance 100% of the cost of projects costing less than \$1000 (rather than \$500 until now). We will evaluate the impact of this measure this year.

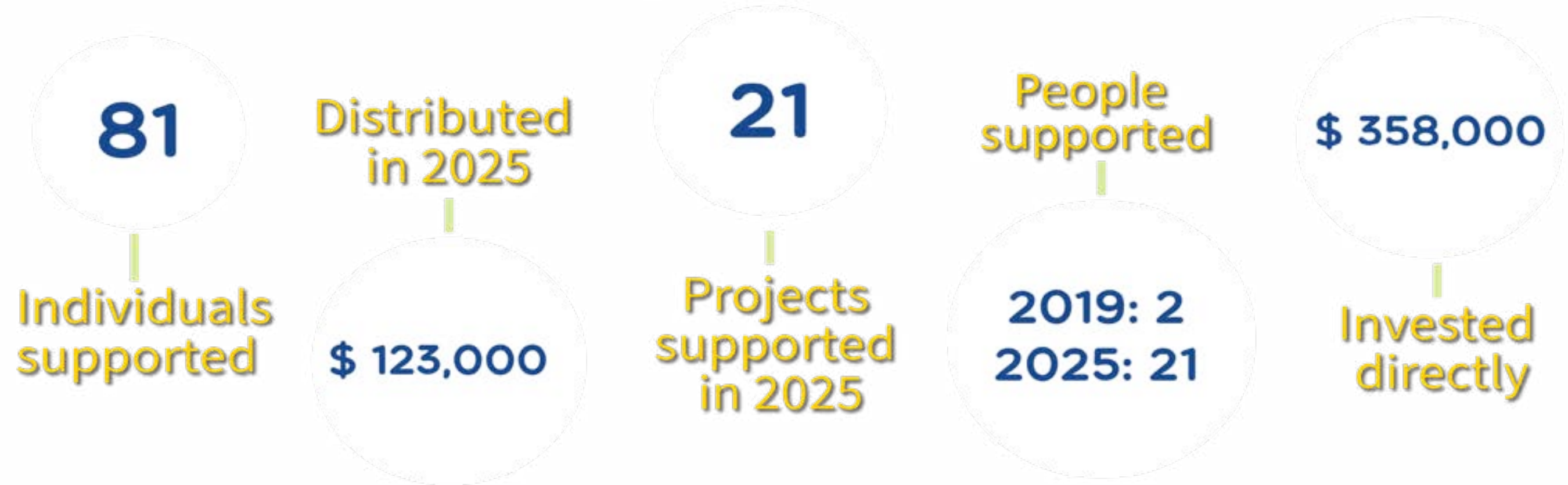


OUR SUPPORT TO PATIENTS: TESTIMONIALS



Ataxia Canada Impact: 2019 - 2025

Direct financial support program for people living with familial ataxia



Thanks to this program and fundraising support, the kitchen has been completely adapted to meet their needs. Modifications include countertops adjusted to their height, accessible cabinets, and open spaces allowing for easy wheelchair access. These adaptations have transformed their daily lives. They can now cook independently and safely, which brings them great satisfaction and a sense of independence. This change has also lightened the burden on the family, as they can now participate more easily in household chores. We were particularly impressed by the program’s flexibility and support throughout the process. We were able to rely on experts to assess specific needs and guide us in implementing the modifications, although some logistical challenges arose, including delays in obtaining the services of specialized workers.

We would definitely recommend this program to other families. The concrete adaptations it enables have a significant impact on the quality of life and independence of people with disabilities.

Thank you again for this valuable initiative, Nathalie, mother of Maude and Mélanie



OUR SUPPORT FOR PATIENTS



New project in development: All About Ataxia – Half-Day Patient Engagement Sessions!

In response to the needs expressed by our community, we have begun developing this new project: an initiative for people living with hereditary ataxia and their caregivers.

This project aims to create a space for discussion and learning where everyone can better understand the disease, break down isolation, and become actively involved in their health journey. We are grateful to Ataxia UK, the original developer of the project, who generously shared their knowledge and experience to help us develop our initiative. Through interactive meetings, educational videos, and participatory workshops, we hope to build a stronger, better-informed, and more supportive community.

We are very grateful to the Mirella and Lino Saputo Foundation, whose support is making this project possible. True to its mission, the Foundation supports organizations that work with people with disabilities and makes a tangible contribution to improving the quality of life of families affected by ataxia.



Thanks to this valuable support, we are one step closer to our vision: to strengthen our support and increase opportunities for engagement within our community.

Keep an eye out in 2026! Please pay attention to our newsletters in 2026 so you don't miss out on registering for the first bilingual (French and English) half-days of the All About Ataxia project.

2024-2025 FINANCIAL RESULTS



Income

- A good year for donations, fundraising activities, and corporate donations. We did not receive a significant bequest due to processing delays at Revenue Canada, but we are expecting this significant donation in the next fiscal year.

Medical research

- We continue to support research expenses through strategic partnerships, and the amounts have doubled! The mission of our founder, Claude St-Jean, continues.

Member Support

- A significant increase in services for members with ataxia to improve their quality of life.

Events and fundraising campaigns

- Expenses necessary to generate sources of revenue. Maintenance and optimization of existing fundraising campaigns and development of small events around volunteer action.

Administration fees

- Necessary for the operation of the foundation. Modest growth in administrative expenses.

Income	2022	2023	2024	2025 Results vs budget	2026 Budget
Donations and fundraising activities	176 069	208 083	271 055	319 848 260 000	300 000
Testamentary legacy and exceptional donation	114 00	140 000	458 500	60 000 500 000	560 000
Investment income	9 172	34 954	43 175	34 393 30 000	30 000
Total income	299 241	383 037	772 230	414 241 790 000	890 000
Expenditures					
Medical research	110 867	254 787	410 988	436 477 434 000	221 000
Member Service and Communication	80 584	109 541	179 111	216 194 278 000	280 000
Events and fundraising campaigns	86 584	82 614	90 111	118 215 96 000	119 000
Administration costs	23 739	24 312	26 716	26 475 32 000	35 000
Total expenditures	311 179	471 254	706 926	797 361 840 000	655 000
Excess of products over charges	- 2 887	-88 217	65 304	-383 120	235 000

YOUR INVOLVEMENT, OUR FUTURE



1 Simple donation

[A Simple donation](#); easy and safe; you will receive your tax receipt in just a few minutes.

2 Monthly donation - The road to the cure

Join our monthly giving community. It's a cost-effective and simple way to invest in our mission. We are grateful to the families who continue to engage in ataxia research through the "road to the Cure."

You are joining a loyal community invested in creating a path to treatments for ataxia through research. With your consent, your name and/or that of the person honored will appear on a page dedicated to this new initiative.

3 Testamentary gift

A [planned gift](#) is easy to set up and usually generates a tax advantage for the estate. It is the best way to support the Foundation without having too much impact on the heirs of the estate.

4 Double donation- New initiative

Many companies offer [matching gift programs](#) to encourage philanthropy. Your donation to the Foundation could be matched dollar for dollar by your employer, doubling your impact! Explore our interactive online form!

5 Become an ambassador or volunteer

As an ambassador, you are a key resource and source of information for our community, the public, and potential donors. We want you to help us generate interest, start conversations, and increase the number of people who, like you, want to and can play a vital role in promoting our mission.

There are so many ways to [get involved](#): organizing events, serving on committees or the board of directors, spreading the word about Ataxia Canada, networking with the business and professional community, and monitoring the digital landscape for new information about ataxias.

6 Participate in annual events - Ataxia Challenge

This walk aims to support and encourage people with ataxia, but also to raise funds through participants. More link: [About us](#)

It has been just over a year since we began requesting permission to include donors' names, and we are very grateful to those who have allowed us to do so:

Linda Boulet	Haida Paraskevopoulos	Matthew Levang	Carl and Beverley Lucas	Louise Hélène Brunelle
Marie Lord	Howard Tanzer	Christiane Savoie	Manon Côté	Marielle Lemay
Suzanne Martin	Jocelyne Vien	Barry Palynchuk	Gilles Larocque	Bill Folliott
John and Mai Spina	Marilou Beaulieu	Myriam Guenette	Clément Boyer	Julie Brodeur
Ida Seca-Miani	Esther charron	Cheryl Davenport	Vivianne Moreau	Shannon Moules
Paul Morrison	Philippe Raymond	Hélène Dionne	Hélène Ravenda	Claude Desmarais
Giuseppina Trasatti	Chantal Gaudreau	Dominique Payette	Andre Perron	Janice Duffy
Domenic & Gina Rocca	Josianne Ledoux	Gail Cryer	Rémi Asselin	Danielle Beausoleil
Pierre Duquette	John Swatski	Judith Mendelsohn	Cécile Hébert	Bruno Barny
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Lucie Brunelle	Hélène Pellerin	Jacinthe Lachance	Claudette Collin	Pierrette Lavoie
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Lynn Cleary	Andre De montigny	Louis P. Gagnon	Hélène Pagé	
			Louise Chenard	

We would also like to thank our donors who have chosen to remain anonymous. Your support is just as essential to our work. If you would like your name to appear on this page in next year's report, please indicate this when making your donation using our donation forms.



We would like to thank everyone who has contributed, directly or indirectly, to the mission of Ataxia Canada.

Ataxia Canada – Claude St-Jean Fondation

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Consult our [financial statements](#)

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