

CANADIAN ASSOCIATION OF FAMILIAL ATAXIAS

- CLAUDE ST-JEAN FOUNDATION -

(Ataxia Canada)

RULES AND REGULATIONS

FEBRUARY 2024

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In order to facilitate the reading of this text, we have used the masculine as a neutral gender to designate both women and men.

EXTRACTS FROM CONSTITUTION STATUS

This Corporation was incorporated under Part III of the Companies Act (RSQ, chapter C-38, s.218), the letters patent were given and sealed in Quebec City on the 25th of October 1972 and registered on December 14, 1972, at libro C-227, folio 54. Once again, the letters patent were given and sealed in Quebec on December 19, 1973, and registered on December 20, 1973, in libro C-325, folio 22. Once again, the letters patent were given and sealed in Quebec City on October 15, 1990 and registered on October 15, 1990, in libro C-1334, folio 39. Again, the letters patent were given and sealed on the 17th of November 2002.

The name of the Corporation is: THE CANADIAN ASSOCIATION OF FAMILIAL ATAXIAS. It also operates under the name Claude St-Jean Foundation.

The head office of the Corporation is located in Montreal in the District of Montreal.

The value of real estate that the Corporation may own is limited to two million (\$2,000,000).

In the event of the dissolution of the Corporation, the net assets will be vested in a non-profit organization whose objects are similar to those of this Corporation.

GOALS OF THE ASSOCIATION

The Foundation's vision is: A world that will enable people diagnosed with ataxia to aspire to a fulfilling life through advances in research, support and inclusion throughout the Canadian community.

From this vision arise the following goals:

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

Raise awareness among health professionals, political decision-makers and the general population about the disease and its impacts on the physical and psychological health, employment and financial aspects of those affected;

Promote, protect and develop the economic, social, professional and leisure interests of people with ataxia;

Advance research on familial ataxias with a view to intervening on both the causes and the effects;

Inform members and partners of activities relating to familial ataxias (research, publications, activities, etc.);

Organize and hold conferences, meetings, exhibitions for information purposes;

Generate revenue through fundraising campaigns, activities, voluntary subscriptions, grant requests, sponsorships, and bequests, in order to achieve the mission of the Association.

GENERAL RULES OF THE CANADIAN ASSOCIATION OF FAMILIAL ATAXIAS

Chapter I : Definitions

1.1. In this By-law, the following expressions mean: :

- a) The Corporation: The Canadian Association of Familial Ataxias also known as the Claude St-Jean Foundation.
- b) The Act: Companies Act, Part III.
- c) The Board: The Board of Directors of the Corporation.
- d) The By-law: General By-laws or By-law No. 1.
- e) The assembly: The general assembly of the members.
- f) Familial ataxia: All forms of hereditary ataxia.
- g) Territory: The Corporation's territory is that of Canada having its head office in Montreal, Quebec.

Chapter II : The members

2.1. Members

There is only one category of membership :

The one category of membership, the regular member (however, members must declare their status at the time of donation or membership : affected person, family member, corporation, others).

The donor may refuse to become a member by unsubscribing through a link on the form.

Admitted into membership status are individuals making an annual donation of \$ 20.00 and over. People with hereditary familial ataxia are admitted free of charge but will have to complete the form Online or by mail to be considered a member. People with other ataxia will be redirected to appropriate associations or foundations.

2.2. Right to vote

Only members who have made an annual donation of \$ 20.00 or more and have confirmed their acceptance, as well as people with hereditary familial ataxia will have the right to vote. People wishing to exercise their right to vote may do so before the general assembly. People wishing to become a director must submit thirty (30) days prior to the general assembly their application and their donation to be eligible for the position of director.

2.3. Loss of membership

Membership is lost through resignation or exclusion.

2.4. Exclusion and suspension

The council may, by resolution, exclude or suspend a member if the latter:

- a) no longer meets the eligibility criteria
- b) harms or attempts to harm the Corporation by its actions or statements

The board must then send him a copy of the exclusion or suspension resolution.

2.5. Member's right

Members are entitled:

- a) to be summoned at general assemblies;
- b) to be informed by email, by mail at the request of a member or by social media;
- c) according to article 2.3: to vote, to propose, at a general assembly, any question concerning the Corporation and to be elected or elect to the positions to be filled in the council.

2.6. Territory

The corporation intends to recruit its members in Canada.

2.7. Creation of sections by the Association

One section is a group of members of the CANADIAN ASSOCIATION OF FAMILIAL ATAXIAS - FONDATION CLAUDE ST-JEAN serving a select portion of the territory. To create a section, a group of members in good standing with the Association on a given territory makes a written request to the Board of Directors of the Association. The section is committed to collaborating in advancing the objectives of the Association. The creation of a section is accepted by a majority vote of the members of the board of directors at a meeting duly convened for this purpose.

STATUS OF SECTIONS

Each section will submit its articles of association or any other document describing the section's proposed activities as well as its internal management rules when submitting a written request for its establishment to the Board of Directors of the Association. Each section is responsible for providing written reports to the Association's Board of Directors for approval, at least once a year. These reports will include the status of the activities as well as the net revenues generated.

DISSOLUTION OF SECTIONS

Each section may dissolve itself by providing written notice of its wish to dissolve through its members. The section will be formally dissolved after acceptance of the written notice by the majority of the Board of Directors at a meeting duly convened for that purpose.

ANNUAL REVIEW

The Board of Directors of the Association will review the written reports of the Section at the first Council meeting after submitting such a report. The Board of Directors of the Association may submit a report to the Section in response to any questions contained in the report, and may advise the Section on any other matter relating to the activities of the Section. In addition, the Board will review the activities of the section and determine whether it is justified to dissolve the section due to inactivity. Such a decision will be made by consensus of the Board of Directors and the members of the section.

Chapter III: The General Assembly

3.1. Composition

The general assembly is legally composed of all the members of the Corporation.

3.2. Convocation

The general assembly is summoned by the board of directors. The notice of meeting must reach the members by email, by mail at the member's request, ten working days before the assembly. The notice of meeting must indicate the place, date and time and the agenda of the meeting. The notice of meeting must mention the By-law or By-laws that may be adopted or amended and the wording of the amendments.

3.3. Reunion

The general assembly of members shall be held at least once (1) a year on or before November 30 of the current year at the place and on the date and at the time determined by the council.

3.4. Quorum

The quorum of the general assembly is made up of at least 20 members of the Corporation.

3.5. Proxy

A member has the right to be represented for his right to vote or to speak by proxy. A person can not hold more than one (1) power of attorney.

3.6. Vote

Voting is by show of hands unless one-third (1/3) or more of the members present demand a secret ballot. The questions submitted are decided by a simple majority of votes.

3.7. Conduct of the assembly

- 1) The Annual General Assembly must include at least the following activities;
- 2) Registration.
- 3) Opening by the president.
- 4) Reading and adoption of the agenda.
- 5) Adoption of the minutes of the last assembly.
- 6) Presentation of the activity report.
- 7) Presentation of the financial report.
- 8) Presentation of budget forecasts.
- 9) Election of directors.
- 10) Appointment of an external auditor.
- 11) Deliberation on all other matters concerning the Corporation
- 12) Closing or adjournment.

3.8. Powers and attributions of the general assembly

The general assembly is sovereign in the affairs of the Corporation. It has the power to:

- a) Adopt, amend and repeal the By-laws and regulations of the Corporation.
- b) Have financial reports.
- c) Receive income and expense forecasts.
- d) Receive the annual report of the council, evaluate it and rule on the proposals presented by the council or the members.
- e) Adopt the business plan forwarded by the board.
- f) Define the overall policy of the Corporation, that is, decide on the goals, objectives and directions to be given to the Corporation.
- g) Elect the directors who will form the board of the Corporation.
- h) Appoint the External Auditor.

- i) Create committees and subcommittees to study a particular issue relating to its goals and objectives.

3.9. Extraordinary general assembly

The board of directors may convene an extraordinary general assembly. The notice of meeting must indicate the subject (s) on the agenda and only these topics will be discussed.

Upon written request addressed to the Chair of the Board and signed by 20 or more members, the Board shall convene, within a maximum of one week, an Extraordinary General Assembly to be held no later than fifteen (15) days after reception of the request for notice of assembly.

3.10. Assembly procedures

Assembly procedures are those usually followed in deliberative assemblies. In ordinary times, the decision belongs to the Presidency. In the case of difficulties, refer to the Morin code.

Chapter IV : The Board of Directors

4.1. Composition

The board of directors is made up of seven (7) directors or nine (9) directors, at the discretion of the Board of Directors. Directors are elected by the members at the Annual General Assembly. The person occupying the position of director participates on the board of directors as a resource person, but without the right to vote.

4.2. Mandate's duration

Directors are elected for a two (2) year term with the possibility of renewal. It is agreed that 5 directors will be elected for a term of two years in even years and that 4 directors will be elected in odd years respectively for a term of 2 years for the purpose of continuity of the Corporation.

Unless the board of directors agrees; a member of the board of directors can not sit for more than four years (two two-year terms). The members of the board of directors are responsible for filling all the vacant positions, at the general assembly or subsequently if necessary, by looking for the quality of any new candidate meeting the criteria defined by the board of directors.

4.3. Election procedure

- 4.3.1. A nomination precedes the election of the directors. Election is by simple majority of the members present.

Five (5) positions are open years ending in an even number and four (4) positions are open years ending in an odd number.

4.3.2 Nominating Committee

The chair of the board of directors must appoint a nominating committee for the directors. This committee is composed of three (3) members, namely the President, another member of the executive and a director, to choose from. The committee ensures that it is maintained for the duration of its mandate as a standing committee looking for potential candidates. The Executive Director will assist the Committee without the right to vote.

NOMINATION

Any member wishing to stand as a member of the Board of Directors must send a written notice of his nomination signed by himself, no later than 30 days before the date fixed for the holding of the annual general assembly.

At the meeting of the board of directors preceding the summer period, the board of directors determines by resolution the qualities of the candidates sought and the number of positions to be filled in order to help the nomination committee base its recommendations.

A call for applications specifying the positions and related criteria is then sent to all members of the association as soon as possible.

At the request of the Board of Directors, the Nominating Committee will nominate and make recommendations at the Annual General Assembly for election purposes.

4.4. Eligibility

Only members meeting the requirements are eligible to vote and / or be elected as directors of the Corporation.

4.5. Loss of administrator status

The quality of director of the board is lost by resignation or exclusion. A director who wishes to resign must give a written notice to the board.

4.6. Suspension and exclusion of administrator

The board may suspend or exclude an administrator:

- a) who violates some provisions of the rules and regulations,
- b) who, by his conduct, harms or attempts to harm the Corporation,
- c) who is absent from three (3) consecutive meetings for no reason deemed valid by the Council.

4.7. Powers of the board of directors

The board administers the affairs of the Corporation between general assemblies; it is responsible in the general assembly for any decision it has taken and it must fulfill the mandates entrusted to him by the assembly in accordance with the laws.

The board of directors may, in particular:

- a) exclude or suspend members
- b) fill vacancies on the board of directors
- c) establish the procedure for hiring employees
- d) fix the working conditions of the employees
- e) select, hire and fire permanent staff
- f) establish committees and subcommittees to study a particular issue related to its goals and objectives
- g) designate the signatories of checks and other bank instruments
- h) make any provision concerning administrative acts not provided for in this Regulation

4.8. Duties of the board of directors

In carrying out its mandate, the board must, in particular :

- a) administer the affairs of the Corporation;
- b) supervise the execution of the decisions of the general assembly;
- c) forward the program of activities for recommendation to the annual general assembly;
- d) make an annual report of activities to the general assembly;
- e) report on his administration to the General Assembly, by producing a financial statement and a balance sheet of activities;
- f) appoint from among its members the officers of the Corporation;
- g) determine the working conditions of the permanent staff;
- h) form, mandate and coordinate the activities of the Standing Operating Committees;
- i) form, mandate and abolish ad hoc committees; coordinate their activities according to the needs expressed by the general assembly;

- j) divide among its members the responsibilities of the standing committees and the ad hoc committees, to endorse, modify or reject the action plans put in place by the various committees;
- k) manage budgets;
- l) see the administration of the budget and the administration of self-financing;
- m) designate the financial institution or institutions in which the funds of the Corporation shall be deposited in an account opened for that purpose;
- n) ensure the dissemination of the activities and the promotion of the Corporation;
- o) perform any other function not provided for in this By-law, in accordance with the purposes of the Corporation.

4.9. Reunions

The council meets as often as necessary, but at least 5 times during the year. The notice of meeting shall be given by letter or in any other form determined by the Board.

4.10. Quorum

The quorum for meetings of the Board is five (5) directors.

4.11. Vote

All questions put to the vote are decided by a simple majority of votes. In the event of a tie, the person occupying the position of Chairman of the Board may exercise a casting vote.

4.12. Special reunion

The board may hold special assemblies at the request of a director. In this case, the notice of meeting is at least forty-eight (48) working hours.

4.13. Vacancy

Any vacancy on the board is filled by decision of the board. The person so appointed is only to complete the mandate of the person whose vacancy it fills.

4.14. Declaration of interest and legal limit

An interested director, either personally or as a representative of a member, in a contract with the Corporation must declare his interest. An interested director abstains from voting on a contract in which he is interested; if he does, his vote is invalid. An interested director who voluntarily fails to declare his interest is liable to lose his status as a member of the Board. A salaried position holder within the Corporation may not be a member of the Board of Directors.

Chapter V: Office Holders of the Corporation

5.1. Denomination

The incumbents of the Corporation are (also named officers): the president, the vice-president, the secretary and the treasurer. There is also the founding president. The Founding President is a title reserved for Mr. Claude St-Jean as founder of the Corporation. It is understood that no other person will be able to assume this position.

5.2. Nominations

The Corporation's office holders are appointed by the directors at the end of the annual general assembly or at the first meeting of the board.

5.3. Mandate's duration

The incumbents of the Corporation are appointed for a period of one year, with the possibility of renewing their mandate.

5.4. Duties of Honorary President

In agreement with the members of the board of directors or mandated persons, he participates in events, solicits partnerships in accordance with the objectives of the Corporation. This person does not have a voting right.

5.5. Duties of the President

The person appointed to the presidency is elected by the other members of the board of directors. Among his functions he:

- a) presides automatically at the meetings of the general assembly and of the board of directors;
- b) formally represents the Corporation in any other jurisdiction;
- c) signs the transactions, drafts and other bank instruments as well as any important document that binds the Corporation as well as the minutes of the assemblies;
- d) has a casting vote in the case of litigation;
- e) performs any other function entrusted to it by the general meeting or the board of directors.

5.6. Duties of the Vice President

The person appointed to the vice-presidency:

- a) assists the person appointed to the presidency in his office and replaces him whenever he is absent or unable to act;
- b) performs any other function assigned to him by the general assembly or the board of directors from time to time.

5.7. Secretarial functions

The person appointed to the secretariat:

- a) ensures the custody of the Corporation's charter, records and other important documents;
- b) ensures that notices for meetings are made in consultation with the President;
- c) ensures that the minutes and extracts are prepared in accordance with the rules of the art;
- d) performs any other related duties assigned to him by the board.

5.8. Treasury functions

The person appointed to the treasury:

- a) manages and controls the accounting and all property of the Corporation;
- b) ensures the preparation of the estimates and the financial statements;
- c) performs any other related duties assigned to it by the President.

Chapter VI: The Executive Committee

6.1. Composition

The board of directors may elect an executive committee composed of four (4) directors: the president, the vice-president, the treasurer and the secretary.

6.2. Meeting and quorum

The executive committee meets as needed. The quorum consists of three (3) members.

6.3. Powers and duties

Between the meetings of the board of directors, the executive committee deals with the day-to-day business of the Corporation, takes urgent decisions and carries out all other functions entrusted to it by the board of directors. The executive committee reports its decisions to the board of directors. Decisions taken by the executive committee must be approved by the board of directors.

Chapter VII: The permanent team

7.1. Management of the Corporation of current affairs

The day-to-day business of the Corporation is managed by a team of permanent staff whose titles, duties and responsibilities are determined by the Board of Directors.

Chapter VIII: Financial Administration

8.1. Financial exercise

The fiscal year runs from October 1 to September 30 of the following year.

8.2. Bookkeeping

The books are audited by an auditor appointed by the general assembly at its annual meeting.

8.3. Bank account

The funds of the Corporation are deposited in one or more accounts opened for this purpose in one or more financial institutions designated by the board of directors.

8.4. Signatures

All checks, bills of exchange and contracts must bear two (2) signatures of persons authorized by the board.

8.5. Expenditure authorization

Regular and budgeted expenses for day-to-day administration are authorized by the Director. Extraordinary and non-budgeted expenses must first be approved by the Executive Committee based on an amount determined by the Board of Directors.

BY-LAW NUMBER 2. GENERAL BANK REGULATIONS OF THE CANADIAN ASSOCIATION OF FAMILIAL ATAXIAS

Directors may, when they deem it appropriate, by simple resolution:

- a) borrow money on the credit of the Corporation;
- b) issue bonds or other securities of the Corporation and give them as security or sell them for the prices and sums deemed appropriate;
- c) delegate the foregoing powers to one or more directors or officers of the Corporation.

Le présent règlement a été adopté à une assemblée générale régulièrement convoquée et tenue le 17 novembre 2002. Il a été modifié à une assemblée générale régulièrement convoquée et tenue le 13 novembre 2005, le 12 novembre 2006, le 4 novembre 2007, le 9 novembre 2008, le 14 novembre 2010 puis lors d'une assemblée générale extraordinaire dûment convoquée et tenue le 2 mai 2016, lors de l'assemblée générale du 18 novembre 2018 et lors de l'assemblée générale du 3 décembre 2023.

Jean-Luk Pellerin

André De Montigny

President

Secretary