

**Minutes of the Ataxia Canada-Claude St-Jean Foundation Annual General Meeting – held on December 5, 2021 via Zoom, from 1:10 p.m. to 3:00 p.m.**

Presence :

Mr. Sébastien Huynh, Chairman of the Board  
Mrs. Josée Goulet, vice-president  
Mr. Marc Dansereau, Treasurer  
Mr. André De Montigny, secretary  
Mr. François-Olivier Théberge, Managing Director  
Ms. Diane Roch, administrator  
Ms. Sandy Sadler, Administrator  
Mr. Nicolas Théberge, director  
Mr. Sean Ramsden, Administrator  
Ms. Trinidad Ruiz, administrator

Members: 42 members attend the meeting via Zoom.

**1. Opening of the Annual General Meeting and welcome**

Mr. Sébastien Huynh, President, opens the 49th Annual General Meeting at 1:10 p.m. and welcomes. Simultaneous translation is available

**2. Roll call and confirmation of quorum**

Following the confirmation that 42 members are present, the opening of the assembly is therefore called by the president. The statutes and regulations of the Association stipulate that the quorum of the general assembly is reached with 20 members present.

**3. Appointment of a chairman and a meeting secretary**

It is proposed by Mrs. Josée Goulet, seconded by Mrs. Diane Roch, and adopted unanimously to appoint Mr. Sébastien Huynh, chairman of the assembly.

It is proposed by Mr. Jean Phénix, seconded by Mrs. Emmanuelle Poirier Saint-Georges, unanimously adopted to appoint Mr. André De Montigny, meeting secretary.

**4. Reading and adoption of the agenda**

It is moved by Ms. Trinidad Ruiz, seconded by Mr. Sean Ramsden, unanimously adopted that the agenda be accepted as presented.

**5. Reading and adoption of the minutes of the Annual General Meeting of November 2020.**

The secretary of the assembly summarizes the highlights of the AGM held in November 2020: The year 2020 was a year of strong pandemic. The foundation has done well financially with the Virtual Challenge, higher unit donations than before, and federal wage subsidies. The research grant policy was established and three research projects were validated by the Scientific Evaluation Committee and approved by the Board in November 2020. In addition, there was an increase in financial assistance for the purchase of equipment and services by people with Alzheimer's disease.

It is proposed by Ms. Manon Courcelles, seconded by Mr. Jean Phénix, and unanimously adopted to accept the minutes of the general meeting of November 2020, as presented.

**6. Message from the President**

Involved in the Foundation for several years, the President emphasizes two fundamental values of the Foundation, namely to be ambitious and to be inclusive. He thanked the members of the council as well as the general manager, the staff and all the volunteers for their constant and relevant contributions.

The ambition is reflected in the constant progress of the financial assistance program for people with dementia for their equipment and service needs.

An example of inclusiveness, he thanks the leaders and volunteers of British Columbia Ataxia who joined the ranks of Ataxia Canada in 2021.

As an example of projects combining ambition and inclusiveness, he mentions the constant increase in the number of quality partners, whether in terms of the active participation of board members and volunteers within the various committees, at the level of research with which we carry out projects (CHUM, CHUL, FARA, NAF, Canadian Institute for Health Research, etc.) and also at the level of the companies that support us financially (including the CDPQ, Fayolle and EXP).

He points out that 2022 will mark the 50th anniversary of the founding of Ataxia Canada – Fondation Claude Saint-Jean. Looking ahead to the next 50 years, the hope is that the Foundation will continue to support research and that a cure for ataxia will be possible. We would then have fully carried out our mandate.

## **7. Message from the Director-General**

The Executive Director recalls the major objectives for 2021, namely to pursue efforts to increase the number of people supported by the financial assistance program, to continue to expand our presence in all regions of Canada, to attract clinical trials in Canada and finally to increase our fundraising activities.

In terms of research, Ms. Sandy Sadler, head of the Research Committee, mentions the implementation of the grant policy and the awarding of the first research grants for 3 projects in the fall of 2020, projects which all started in 2021. Also, new projects were submitted in the fall of 2021 and are currently being reviewed by the scientific evaluation committee. The Executive Director mentions that clinical trials on ataxia have recently started at the CHUM, a first in more than fifteen years.

Ms. Trinidad Ruiz, head of the Member Services Committee, presents the strong increase in financial assistance provided to people with cancer, a growth of more than 100% in 2021 compared to 2020.

The Director-General reports on the activities of the specialized committees set up in 2020-21, in which all the members of the Board actively participate as well as many volunteers. In terms of fundraising activities, the Virtual Challenge, made up of several local events just like in 2020, was a great success, allowing us to reach a record level. He would also like to thank everyone involved and the donors. The Foundation has also benefited from contributions from a few companies.

Finally, he thanks all the volunteers who constitute an important part of all the energy devoted to the Foundation. Their participation and contribution are essential to the progress of the efforts of the Foundation.

## **8. Presentation and acceptance of the financial statements prepared by the firm Jacques Simard Bouffard Azzola Inc. for the year 2020-2021**

Mr. Marc Dansereau, treasurer, presents the audited financial statements. He clarified that the drop in income in 2021 is solely caused by a drop in income from bequests (income of an extraordinary nature). The Foundation was able to benefit from the federal government wage subsidy program set up due to covid, as well as a business loan (no interest charges on the loan). The significant increase in research expenditures is the direct result of the establishment of the research grant program and therefore the approval of three projects in 2020-21. The net

result was a minimal loss of \$26,000. The net assets of the Foundation are \$1.2 million, which allows research projects to be carried out.

It is moved by Ms. Jessica Laneuville, seconded by Mr. Nick Théberge, adopted unanimously, to accept the 2020-2021 financial statements, as presented.

#### **9. Presentation of the 2020-2021 budget**

The Director-General presents the 2021-2022 budget. Revenue growth is budgeted for 2022 due to higher corporate donation targets and the expected inflow of bequests. The increase in expenses is mainly generated by the growth in research expenses following the continuation of the research grant program and new partnerships that we have just finalized recently (National Ataxia Foundation and the Canadian Institute of Health Research) . The budgeted net result is a loss in the order of \$100,000, which we believe is reasonable based on the net assets of the Foundation, the objective being to minimize the actual loss by making every effort to increase income.

It was moved by Mr. Sean Ramsden, seconded by Mr. Vassilios Pylarinos and adopted unanimously, that the 2021-2022 budget be accepted as presented.

#### **10. Appointment of a financial auditor for the year 2021-2022.**

It is proposed by Mrs. Jessica Laneuville, seconded by Mr. Jean Phénix, and adopted unanimously to appoint the firm Jacques Simard Bouffard Azzola Inc., chartered accountants, auditors of Ataxia Canada-Fondation Claude St-Jean for the year financial 2021-2022.

#### **11. Reading of the notice of nomination**

Reading of the notice of nominations is done and in accordance with the deadline required by the regulations of the association. In addition, the selection committee called on other sources of information, such as the Charity Village website, Concertation Montréal, social media and Board members.

The AGM must approve 5 candidates for director positions. Of this number, there are three term renewals since the initial two-year terms have expired. They are Ms. Sandy Sadler, Ms. Diane Roch and Mr. André De Montigny. In addition, during 2021, two directors left the Board and had to be replaced, namely Mr. André Valiquette and Ms. Ella Pellerin, due to increased professional obligations which no longer allowed them to get involved. Mr. Sébastien Huynh thanks them for their involvement in the Foundation.

It should be noted that Mr. Marc Dansereau, who is currently Treasurer, announced to us that he was to leave the Board as of December 2021. Mr. Sébastien Huynh thanks him for his contribution, on behalf of all the directors. Due to his recent decision, we do not have a candidate today for this position, which will be filled during 2022.

#### **12. Nominating Committee Report and Recommendations**

In accordance with the mandate to select new Board members, the recruitment committee (made up of Sébastien Huynh, Diane Roch and André De Montigny) discussed with several potential candidates during the year. Two people were chosen by the 2021 running council and are recommended:

- Ms. Trinidad Ruiz, already a volunteer with the Foundation, who has direct knowledge of ataxia (ataxia affects a member of her family) and who is an expert in new media marketing.
- Mr. Sean Ramsden, who also has a direct knowledge of ataxia, works in a company in the field of medical productions, and therefore has knowledge of pharmaceutical companies. Mr. Ramsden is located

in Toronto.

- The committee proposes that one position remain vacant, the one previously occupied by Mr. Marc Dansereau, who will be leaving in the coming weeks.

### **13. Election of director**

The mandates of Sébastien Huynh, Josée Goulet and Nicolas Théberge are in effect until the end of 2022.

The mandates of Diane Roch, Sandy Sadler and André De Montigny are renewed for a new period of two years following the proposal submitted by Mr. André Allard seconded by Ms. Jessica Laneuville and adopted unanimously.

Trinidad Ruiz and Sean Ramsden were elected to the Board following a proposal by Mr. André Allard, seconded by Mrs. Jessica Laneuville and adopted unanimously.

### **14. Address by researchers**

Doctor Antoine Duquette gives an update of the projects currently in progress or which will be in the near future. In particular, he mentions the following projects:

- The natural history study (FACOMS) undertaken at the 13 CCRN sites, including at the CHUM which has one of the highest numbers of participants (35 to date)
- An upcoming launch of a CCRN satellite site at the CHU Ste-Justine for children under 14 and a possible future site at the MUHC
- A clinical trial of REATA on a new molecule was approved in the United States by the FDA in November 2021 (accelerated path), which could eventually be used in Canada for clinical trials.
- MOVE-FA clinical trials on Vatiquinone to assess the efficacy and safety of the molecule for the treatment of ataxic patients. This is a global project (9 countries) in which the CHUM and the CHU Ste-Justine participate. The first studies should be completed in mid-2023.
- The project to develop virtual reality measurement tools continues with the feasibility phase which will take place in the first half of 2022 followed by the research phase which will end at the end of 2022 or the beginning of 2023.
- A new project will begin shortly with NAF, which will extend the role of the CCRN at the CHUM to all ataxias (the current CCRN focuses on Friedreich's ataxia).
- Mr. Duquette indicates that the FARA site presents a table which summarizes all the projects in progress and their stage of development.

Doctor Jacques Tremblay presents the development project for Friedreich's ataxia based on the deletion of the GAA repeat in intron 1 of the frataxin gene.

### **15. Question period**

Many questions were asked and comments made during the meeting.

- Discussion on the existence of specialized resources (physios, ergos, osteos) that focus on rare diseases: in Canada, the Lucie Bruneau center is a good example, but only covers young people up to 18 years old. There are few such centers because the number of patients is low. Check if there are other specialized centers.
- Existence of discussion groups organized in Toronto by Hope for Ataxia (Mark Desa), which constitute a support for the participants who share their problems, their solutions, their

contacts. Another example: The Adapted Sports Foundation of Quebec can provide references on places that allow adapted practice of downhill, cross-country and water skiing.

#### **16. Election of the Executive Committee**

The new executive will be made up as follows:

- Mr. Sébastien Huynh as Chairman of the Board
- Ms. Josée Goulet as Vice-President
- Mr. André De Montigny as Treasurer
- Ms. Sandy Sadler as Secretary

#### **17. Closing of the meeting..**

It is moved by Mrs. Sandy Sadler, seconded by Mrs. Josée Goulet, adopted unanimously that the 49th general meeting be adjourned.