

Minutes of the Ataxia Canada- Claude St-Jean Foundation Annual General Meeting - held on November 29, 2020 via Zoom, from 1:10 p.m. to 3:00 p.m.

Presence:

Mr. Jean-Luk Pellerin, president
Mr. Sébastien Huynh, Vice-president
Mr. Marc Dansereau, treasurer
Mr. André De Montigny, secretary
Mr. François-Olivier Théberge, Managing Director
Mr. Bianca Guillemette, administrator
Ms. Diane Roch, administrator
Ms. Sandy Sadler, administrator
Mr. Nicolas Théberge, administrator

Members: 42 members attended the meeting, including Ms. Ella Pellerin and Ms. Josée Goulet, two candidates for a position on the Board of Directors.

1. Opening of the annual general meeting and words of welcome.

Mr. Jean-Luk Pellerin, President, opens the 48th Annual General Meeting at 1:10 pm and welcomes them. Simultaneous translation is available (in English)

2. Call for attendance and confirmation of quorum

Following the confirmation that 42 members are present, the opening of the assembly is 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 secretary of the assembly

It is proposed by Mr. Jean Phénix, seconded by Mr. André Allard, unanimously adopted to appoint Mr. Sébastien Huynh, chairman of the meeting.

It is proposed by Mrs. Solange Lavoie, seconded by Mrs. Ella Pellerin, adopted unanimously to appoint Mr. André De Montigny, secretary of the meeting.

4. Reading and adoption of the agenda

It is proposed by Mrs. Sonia Roy, seconded by Mrs. Sonia Florent, adopted unanimously that the agenda be accepted as presented. Note that videos of 3 researchers will be presented.

5. Reading and adoption of the minutes of the annual general meeting of November 2019 .

The secretary of the assembly summarized the highlights of the AGM held in November 2019: first year of the financial assistance service for people with Alzheimer's disease, partnership with FARA for the launch of a new clinical research site at CHUM, creation of a scientific evaluation committee for research projects as well as growth in the number of members outside Quebec.

It is proposed by Ms. Francine Lévesque, seconded by Mr. Jean Phénix, unanimously adopted to accept the minutes of the November 2019 general meeting, as presented.

6. President's word

The year 2020 has been difficult due to the pandemic, which primarily affected collective health and also economic sectors, in particular non-profit organizations. The Ataxia Canada Foundation has been able to do well in this difficult context due to the strong involvement of the members of its board and especially of its CEO, who has shown creativity and perseverance. Thus, the Physical Challenge has been replaced by a Virtual Challenge as well as by several local events from July to September. The strong involvement of our Executive Director, combined with the generosity of our donors during the Virtual Challenge, the direct mail and the travel lottery, ensured that the Foundation's regular income remained at the same level as the previous year. .

The President thanks the advisory committees for their advice throughout the year. He also underlines the contribution of the new scientific evaluation committee in order to enlighten us in the selection of the best research projects. Finally, he thanked all the members present at this assembly for their unwavering support to the Foundation.

7. Word from the general manager

The GM mentions that 73% of charities report a drop in their income in this pandemic year, with a drop of 30% on average for half of the organizations. Depending on our operating adjustments and the generosity of our donors, revenues increased by 5% in 2020 (excluding bequests). As mentioned by the president, the Chambly Challenge and the Toronto Challenge could not be held this year. They have been replaced by a Virtual Challenge and micro-events. The revenues collected as well as the reduction in expenses incurred have allowed us to maintain a healthy financial situation.

The collaborative clinical research network on Friedreich's ataxia (CCRN) at the CHUM was launched in partnership with FARA. This site is the starting structure for future clinical trials. A research project analysis policy, including objectives, priorities and criteria, was set up in 2020. In addition, a scientific evaluation committee (CES) was set up in 2020, which evaluated projects submitted by Canadian researchers for the award of the first research grants before the end of the year. Three reputable doctors with the most relevant experience are part of our CES. The number of members is constantly growing (+ 12% in 2020), reaching nearly 200. Statistics of increase in contacts and subscribers on Facebook are presented. The number of donors decreased by 25% in 2020; on the other hand, the average donation also increased by 25%, which explains the good performance in terms of income.

8. Presentation of the 2020-2021 budget

The general manager presents the 2020-2021 budget. Budgeted income is at the same level as in 2020, or \$ 375K despite the expected decrease in bequests. In terms of expenses, the budget planned to support research is \$ 235K. Remember that very little was achieved in 2020 due to covid (closed laboratories). Overall, we expect a small loss of \$ 47K in 2020-2021 due to support for research projects, which the Foundation can carry out since its net assets allow it. It is proposed by Ms. Karine Lévesque, seconded by Ms. Jessica Laneuville and unanimously adopted, that the 2020-2021 budget be accepted as presented.

9. Presentation and acceptance of the financial statements prepared by the firm Jacques Simard Bouffard Azzola Inc. for the year 2019-2020

Mr. Marc Dansereau, Treasurer, presented the audited financial statements. He specifies that the drop in income in 2020 is only caused by a drop in income from bequests (income of an extraordinary nature). The Foundation was able to benefit from the federal government's wage subsidy program set up as a result of the covid,

as well as a business loan (no interest charges on the loan). The Foundation's net assets are \$ 1.2 million, which enables research projects to be carried out. It is proposed by Ms. Paule Vaillancourt, seconded by Ms. Solange Lavoie-Guillemette, unanimously adopted, to accept the 2019-2020 financial statements, as presented.

10. Appointment of a financial auditor for the year 2020-2021.

It is proposed by Mr. Jean Phénix, seconded by Mrs. Lise Martin, unanimously adopted to appoint the firm Jacques Simard Bouffard Azzola Inc., chartered accountants, auditors of Ataxia Canada-Fondation Claude St-Jean for the financial year 2020 -2021.

11. Reading of the notice of nomination

Reading of the notice of nominations is made and in accordance with the deadline required by the association's bylaws. Three (3) positions are vacant.

In addition, the selection committee called on other sources of information, such as the Charity Village site, Concertation Montréal, social media and members of the Board of Directors.

The three vacant positions result from the departure of Mr. Jean-Luk Pellerin, Ms. Bianca Guillemette and Mr. André Valiquette.

Mr. Sébastien Huynh warmly thanks Mr. Valiquette for his contribution in establishing the Foundation in Ontario; he thanked Ms. Guillemette for her important involvement in the Board of Directors, particularly in the organization of the Défi Chambly; and he thanked Mr. Pellerin who was on the Board of Directors for nearly 5 years, including the last two years as Chairman of the Board. His contribution was particularly essential at the level of the constitution of the current team of the CA and the scientific evaluation committee.

12. Report and recommendations of the Nominating Committee

In accordance with the mandate to select new board members, the recruitment committee (made up of Sébastien Huynh, Diane Roch and André De Montigny) met around ten candidates. Two people are recommended:

- Ms. Josée Goulet, was President of Bell Quebec and President of the Foundation for Research on Juvenile Diabetes. Madame Goulet was introduced to us by Diane Roch.
- Ms. Elsa Pellerin, doctor in psychology, coach with business leaders and individuals; she is regularly involved with the Foundation and is very familiar with ataxia.
- The committee is proposing that one position remains vacant for the time being as we are looking for someone based in Ontario. The research continues.

13. Election of directors

The mandates of Sandy Sadler, Diane Roch and André De Montigny are in effect until the end of 2021.

The mandates of Sébastien Huynh, Marc Dansereau and Nicolas Théberge are renewed for a new period of two years following the proposal submitted by Sonia Florent, seconded by Yves Tapp and unanimously adopted

Josée Goulet was elected to the Board following a proposal from Solange Lavoie-Guillemette, seconded by Paule Vaillancourt and adopted unanimously.

Ella Pellerin was elected to the Board following a proposal from Lise Martin, seconded by Francine Lévesque and adopted unanimously.

14. Speech by researchers - doctors (items 14 and 15 in the agenda)

Doctor Antoine Duquette provides an update on the state of clinical research. Of course, research activity in 2020 was severely slowed down by covid: research centers closed, patients hesitant to travel, etc. Despite this fact, several clinical researches are underway. He then presented the project that was accepted by the Foundation, namely the development of virtual reality tools for the assessment of motor impairment in ataxic patients.

Doctor Nicolas Dupré then thanked the Foundation following the acceptance of his project on the creation of a stem cell bank for patients suffering from ataxia known as Beauce.

Doctor Jacques Tremblay presents all of his research projects with an emphasis on the project of developing exosomes as a modality for the transport of therapeutic molecules .

15. Covered in point 14 (researcher presentations)

16. Question period

- Question on the functioning of the Chaudière-Appalache committee: this committee was created last year but was not active.
- Question on the perspectives of research programs : unfortunately unknown horizon to find a remedy that would cure ataxia. More research is needed

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17. Election of the executive committee

The new executive will be constituted as follows:

- Mr. Sébastien Huynh as Chairman of the Board
- Mr. Marc Dansereau as Treasurer
- Mr. André De Montigny as Secretary
- The position of vice-president remains open for the moment, the time to integrate the new members to the board and to see the functioning of various committees with the involvement of all the members of the board. Our goal is to fill the position of Vice President by mid-2021.

- Mr. Sébastien Huynh once again thanks the outgoing president and declares himself honored to become the president of the board. With his entire team, he intends to continue the development of the Foundation, both in its support activities for people with the disease and in research activities.

18. Closure of the meeting .

It is proposed by Mr. Jean-Luk Pellerin, seconded by Mrs. Bianca Guillemette, unanimously adopted that the 48th general assembly is closed at 3:00 pm.

André De Montigny

Secretary