

Minutes of the Ataxia Canada Foundation Annual General Meeting

Held on December 4, 2022

Present:

Mr. Sebastien Huynh, Chairman of the Board

Mr. François-Olivier Théberge, Managing Director

Mrs. Sandy Sadler, Secretary

Mr. André De Montigny, Treasurer,

Mrs. Maryse Tremblay, Administrator

Mrs. Diane Roch, Administrator

Members : 40 members attend the meeting, whether in the room or by Zoom

Many researchers are also in attendance: Dr. Brais, Dr Duquette, Dr Pandolfo, and Dr Tétreault.

1. Opening of the Annual General Meeting and welcome

Mr. Sébastien Huynh, presides the meeting and opens the 50th General Members Assembly, at 13h10, and welcomes the attendance. Simultaneous translation is available (from French to English).

Mr. Huynh mentions the constant progression of the partnerships entered into by the Foundation, be it from the active participation of the Board members and volunteers, as well as with different research organizations involved in the research projects (CHUM, CHUL, FARA, NAF, CIHR) and of the corporations and individuals that support us.

2. Confirmation of quorum

Following the confirmation that 40 members are present, the opening of the assembly is therefore called by the President. The statutes and regulations of the Foundation stipulate that the quorum is reached with 20 members attending.

3. Appointment of a chairman and a meeting secretary

It is proposed by Mr. Jean Phenix, seconded by Mr. Marc Fredette, and adopted at unanimity that Mr. Huynh will chair the meeting and that Mr. De Montigny will act as secretary.

4. Reading and adoption of the agenda

It is proposed by Mrs. Roch, seconded by Mrs. Élise Arcan, and adopted at unanimity that the agenda be accepted as presented.

5. Reading and Adoption of the 2020-2021 General Assembly minutes

The Secretary summarizes the highlights of the GAM held in December 2021, when 42 members attended the meeting. In 2021, the Foundation supported financially more people for the purchase of equipments and services (13 in 2021 versus 6 in 2020). More research projects were approved and a new clinical trial was planned for in 2021 (and started in early 2022) at the CCRN-CHUM, a first in Canada over the last 15 years. We also mentioned the fact that BC Ataxia had joined Ataxia Canada. Finally, the Secretary mentions that the financial situation of the Foundation is sound, and allows the on-going continuation of the research projects and financial assistance to ataxia patients.

It is proposed by Mrs. Sonia Roy, seconded by Mrs Marie Steves, and adopted at unanimity to accept the minutes of the 2021 assembly, as presented.

6. Message from the Managing Director

The Managing Director mentions that this is the 50th anniversary of the foundation, started by Mr. Claude Saint-Jean, 50 years of progress and small steps, putting in place different programs to improve the quality of life of ataxic patients as well as supporting research.

In 2022, the Foundation has developed new partnerships with organizations such as CIHR, Génome Québec, and with FARA and NAF as well, both USA based. In particular, the FACOM study on Friedreich Ataxia is a collaborative international study, which has allowed us to position Canada as an important research place in North America, and has generated a new clinical trial. As well, we have implemented a site for the natural history of CRC-SCA in collaboration with the National Ataxia Foundation (NAF, in USA). Both these studies are happening at the CHUM (Montreal).

Three new research projects have been approved last fall, supported by the recommendations of our Scientific Evaluation Committee, which has been strengthened by the arrival of new Committee members in different parts of Canada. We are happy to see the arrival of new young researchers who show an interest towards ataxia, stemming from our annual research subsidy program..

Our network of volunteers is growing and has allowed us to organize fundraising events in Montreal, Gatineau, Toronto and Vancouver.

We have received the support of a greater number of individual and corporate donors.

Ataxia Canada wishes to continually grow its network. In particular, we wish that all families affected by ataxia join the Foundation and benefit from our programs. To that effect, we intend to push communications to reach the maximum population as possible.

7. Presentation and acceptance of the financial statements prepared by the firm Jacques Simard Bouffard Azzola Inc. for the year 2021-2022

Mr. De Montigny presents the results, in its capacity of Treasurer. The budgeted net result was for a loss of \$135K while actual results came in at a loss of \$3K only (in 2021, a loss of \$26K was encountered). Actual revenues in 2022 were \$300K, a 30% increase over 2021, although they were lower than the \$364K budget, mostly because of lower donations and testamentary legacies. To note that many corporate donations came in.

Expenses were at the same level than 2021, at \$300K. We had forecasted an important increase for 2022, at \$500K, however research projects related expenses were lower and the financial assistance requests were also lower. To be noted that 2022-2023 research projects expenses should be higher since three projects already approved in 2021 will be finalized and also because three new projects approved in late 2022 will be undertaken in 2022-2023.

Our cashflow situation is good and should allow us to continue our research programs and financial assistance programs.

It is proposed by Mr. Yan Frenette, seconded by Mrs. Kim Frenette and adopted at unanimity to accept the audited financial results for 2022-2023 as presented.

8. Presentation of the 2022-2023 budget

The year 2023 should be good. We are forecasting to double the expense level, at \$600K mostly because of the termination of 4 research projects that were approved in 2022 and 2022 (hence, final payment) and because of the start of three new projects approved in fall 2022. In addition, the natural history studies with FARA and NAF at the CHUM will continue in 2023.

We are budgeting revenues at \$500K in 2023, \$200K more than in 2022, mostly because of higher objectives for testamentary donations and corporate donations.

Global, we are therefore budgeting a net loss of \$100K. We have sufficient funds to cover such a projected loss.

It is proposed by Mr. Jean Phenix, seconded by Mrs. Diane Roch and adopted at unanimity that the budget for 2022-2023 be adopted as presented.

9. Appointment of a financial auditor for 2022-2023

It is proposed by Mrs. Sandy Sadler, seconded by Mrs. Lucie Lavoie and adopted at unanimity to appoint the firm Jacques Simard Bouffard Azzola Inc. chartered accountants, auditors of Ataxia Canada for the 2022-2023 financial year.

10. Reading of the advice of nomination on the Board

Mention is made that the notice of nomination was done in conformity with deadline required by the regulations of the Foundation. Some of the assets taken into consideration include bilingualism, experience in other associative organizations, in fundraising as well as previous experiences on a Board.

11. Nominating Committee Report and Recommendations

In accordance with the mandate to select new Board members, the Recruitment Committee (comprised of Mr. Huynh, Mrs. Roch and Mr. De Montigny) has discussed with many potential candidates throughout the year.

To note that the mandates of Mrs. Roch, Mrs. Sadler, Mr. De Montigny, Mrs. Trinidad Ruiz and Mr. Sean Ramsden are valid until the end of 2023.

2-year terms were ending for 4 administrators at the end of 2022, namely for Mrs. Josée Goulet, Mr. Nicolas Théberge, Mr. Huynh and Mrs. Tremblay. It is proposed that the four administrators renew their commitment for another 2-year mandate.

12. Election of Directors

The mandates of Mrs. Josée Goulet, Mr. Nick Theberge, Mr. Sébastien Huynh and Mrs. Maryse Tremblay are extended for a period of two years, to the end of 2024, in accordance with the proposal of Mrs. Sandy Sadler, seconded by Mrs. Elyse Arcan and adopted at unanimity.

Moreover, we have received the candidacy of Mr. Nicolas Parent, an accountant with over 20 years of experience and who is affected by ataxia. He is from the Quebec City region. He has demonstrated a high level of interest in joining the Foundation. We have decided to integrate Mr. Parent to the Board as a permanent invitee, for him to gradually know the organization

13. Election of the Executive Committee

The new Executive will be constituted by:

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

14. Presentations by researchers

Dr. Duquette (CHUM) gives an update of the projects currently in progress or which will be started in the near future. In particular, he mentions the followings:

- The natural history study (FACOMS) undertaken in the 13 CCRN sites, including at the CHUM which has one of the highest number of participants (41 to-date);
- The launch currently underway of a CCRN satellite site at the CHU Ste-Justine for children for children less than 14 years old and at McGill.
- The natural history study for CRC-SCA has been initiated at the CHUM, in partnership with NAF and Ataxia Canada
- A clinical trial with REATA on a new molecule is under review at the FDA (USA) and could eventually be started in Canada at the CHUM's CCRN
- MOVE-FA clinical trials on Vatiquinone to assess the efficiency and safety of the molecule for treatments. This is a global project (in 9 countries) in which CHUM and Ste-Justine (Montréal) are participating. First results could be available by the end of 2023.
- The project to develop virtual reality measurement tools continues in its feasibility analysis phase. The project could be completed by the end of 2023.
- Dr Duquette indicates that the FARA web site presents a summary table of projects in progress dealing with ataxia and their stage of development. Worth noting that many projects are now at phase 3 of their development.

Three new research projects have been approved in the fall of 2022. Here is a short summary of those projects.

Dr Brais, with his colleague Mr. David Pellerin, from the Montreal Neurological Institute, have recently identified new genetic causes that are responsible for Late-onset cerebellar ataxias (LOCA) (ataxia starting between 30 years old up to 50), through the discovery of the GAA expansion in the FGF-14 gene, that explains some 60% of the cases in Québec. Similar studies were performed in Germany, India and Australia. This is a major discovery that will permit faster diagnosis for LOCA. Ataxia Canada will fund the subsequent phase of this study, which is to uncover other genes responsible for undiagnosed LOCA cases.

Dr. Martine Tétreault, with her team at the neurological department of the CHUM, aims at analysing the transcriptome and methylation changes, combining these results with clinical information to see if transcriptome and/or methylation changes could explain symptoms variability among ataxia patients. These results could pave the way to a more personalized medicine by providing molecular signatures (biomarkers) that will improve patient groupings according to their probability to develop milder or more severe symptoms, which is essential to perform effective clinical trials.

Dr. Julian and her team at Simon Fraser University (BC), have a project to better understand the cellular processes that give rise to SCA (Spinocerebellar ataxia). Gaining a deeper understanding of the cellular mechanism of diseases is essential to develop new and effective treatments for SCA patients. The approach is to study the earliest stage of disease onset and to follow the progression of disease mechanisms by carefully examining our cerebellum and cerebral cortex at multiple stages of their development. SFU will use robotics to assess the ability of thousands of

chemical compounds, some clinically approved drugs, to reverse the abnormal cellular mechanisms that are uncovered.

15. Question period

Numerous questions and comments were made during the assembly. Namely:

- Questions related to the type of research projects: The Managing Director explains the six research projects currently underway that are funded by the Foundation. (Question from Elise Arcan)
- Mr. Jean Phénix encourages the Foundation to look for partnerships in Latin America.
- Dr. Pandolfo, returning to Quebec, mentions his interest in becoming active again in the community.

16. Closing of the Meeting

It is proposed by Mrs. Maryse Tremblay, seconded by Mrs. Sandy Sadler and adopted at unanimity that the 50th general assembly be adjourned.

André De Montigny

Secretary