

Meeting of Ataxia Canada-Claude St-Jean Foundation – held on December 3, 2023

Présence :

M. Sébastien Huynh, Président du conseil
M. François-Olivier Théberge, directeur-général
M. André De Montigny, trésorier
Mme Josée Goulet, administratrice
Mme Sandy Sadler, secrétaire
M. Nick Théberge, administrateur

Plusieurs chercheurs assistent également à la rencontre : Les docteurs Brais, Duquette et Tremblay.

Au total, 40 membres assistent à la rencontre, via Zoom.

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

Mr. Sébastien Huynh, President, opens the Annual General Meeting at 1:00 p.m. and welcomes everyone. Simultaneous translation is available, both by voice and by subtitles. (to English).

The President reports that the Foundation is doing well, particularly in terms of research, while a major project with Génome Québec and the DMC Foundation will be announced shortly. He notes that there is some movement at the board level as well as the addition of new resources within the organization. These elements will be discussed later in the meeting.

The 2023 achievements are numerous and we are confident in the constant progress of the Foundation for the coming years.

2. Call for attendance and confirmation of quorum

Following confirmation that 40 members are present, the opening of the meeting is therefore called by the president. The statutes and regulations of the Association stipulate that the quorum of the general meeting is reached with 20 members present.

3. Appointment of a chairman and a secretary of the assembly

It is proposed by Mr. Benoît Angers St-Marie, seconded by Ms. Tina Karisini, and adopted unanimously to appoint Mr. Sébastien Huynh, president of the assembly and André De Montigny as secretary of the assembly.

4. Reading and adoption of the agenda

It is proposed by Mr. Jean Phénix, seconded by Ms. Jessica Laneuville, adopted unanimously that the agenda be accepted as presented.

5. Reading and adoption of the minutes of the annual general meeting of December 2022.

The secretary of the meeting summarizes the highlights of the AGM held in December 2022: 40 members attended the meeting in 2022. Last year's meeting marked the 50th anniversary of the Claude St-Jean-Ataxia Canada Foundation. The original mission of helping people with the disease and supporting research remains strong in our minds and we are continuing it. Three new projects were approved in the fall of 2022, namely those of

Dr. Brais and David Pellerin (McGill Neurological Institute), Dr. Tétreault of the CHUM and Dr. Julian of Simon Fraser University in British Columbia. Also noteworthy is the return to Canada of Dr. Pandolfo who has indicated his desire to resume his activities at McGill. Financially, income and expenses were balanced, at the \$300K level. The Foundation has net assets of just over \$1M and is therefore well positioned to support people affected as well as the most promising research projects. Finally, we proceeded to elect the members of the Board of Directors and announced the composition of the executive.

It is proposed by Mr. Benoît Angers St-Marie, seconded by Ms. Manon Courcelle, and unanimously adopted to accept the minutes of the December 2022 general meeting, as presented.

6. Word from the Director General

The Director General mentioned the Foundation's progress over the past 5 years, particularly in terms of the number of researchers involved in recent projects across Canada and in several new institutions, all supported by our Foundation and our partners. In fact, eight research projects are currently underway and we are evaluating 14 potential projects. The financial assistance program for people with ataxia is also expanding, as it becomes better known across Canada. The Foundation benefits from the valuable support of its many members – people with ataxia and their families, researchers, volunteers, donors and members of the Board of Directors.

In research, the Foundation has partnered with several partners: FARA, NAF, Génome Québec, the Canadian Institute of Health Research, the Muscular Dystrophy Foundation of Canada and several others. In addition to research projects, the Foundation is proud of the clinical research site set up at the CHUM, through partnerships with FARA and NAF. Clinical trials are currently underway at the CHUM (2021: molecule allowing the possible slowing of the progression of the disease and 2023: start of recruitment for a gene therapy trial). The Director General also briefly presents the projects in progress.

The Director General discusses the new drug developed by Reata (acquired by Biogen) and approved by the FDA, SKYCLARYS, which is not currently available in Canada. He mentions that we are making the necessary representations to the company and Health Canada to promote the availability of the drug in Canada.

Ataxia Canada is undertaking to expand its support network. We hope that all families affected by ataxia will join our cause and benefit from our programs. We therefore intend to undertake a communications program in order to reach as many of these people as possible.

Our two new employees, Ms. Olga Karmanova (philanthropy coordinator) and Benoît Augers Ste-Marie (social media and development coordinator) introduce themselves.

7. Presentation and acceptance of the financial statements prepared by the firm Jacques Simard Bouffard Azzola Inc. for the year 2022-2023

Mr. André De Montigny, Treasurer, presents the audited financial statements.

The net result was a loss of \$88K, better than the budget which was \$-112K. Gross revenues were \$383K in 2023, an increase of 30% compared to 2022. The growth in testamentary legacies explains this increase.

In terms of expenses, they reached \$471K in 2023, an increase of 56% compared to 2022. This increase is entirely explained by the foreseeable growth in research expenses, based on the number of projects approved and underway over the last two years. Research expenses increased from \$110K in 2022 to \$250K in 2023.

At the end of the financial year, we had net assets greater than \$1M. Our liquidity is sufficient to allow us to foresee the financing of other research projects and our current operations in the coming years.

On the balance sheet, note that the COVID loan of \$40K must be repaid by mid-January 2024, and will therefore no longer be on the balance sheet at the end of 2024.

It is proposed by Mr. Paul St-Laurent, seconded by Ms. Manon Courcelle, adopted unanimously, to accept the 2022-2023 financial statements, as presented.

8. Presentation of the 2023-2024 budget

Sébastien Huynh presents the 2023-2024 budget.

An ambitious budget is presented for the year 2024, while expenses will increase by \$200K to reach \$684K. This increase will be mainly felt in research expenses. If research expenses were \$110K in 2022 and \$250K in 2023, we expect them to reach \$400K in 2024, in particular because of the projects in collaboration with Génome Québec in which we will invest approximately \$200K. In addition, the addition of our two coordinators will increase salary expenses by approximately \$50K.

An increase in revenues is also expected, from \$383K in 2023 to \$605K in 2024, or +\$220K. Additional revenues will come mainly from new testamentary legacies as well as major and corporate donations that will result from the ongoing analysis for a major fundraising campaign in 2024-2025.

Overall, the budget projects a loss of \$79K, therefore a low use of our available cash.

It is proposed by Ms. Jessica Laneuville, seconded by Ms. Francine Lévesque and adopted unanimously, that the 2023-2024 budget be accepted as presented.

9. Appointment of a financial auditor for the year 2022-2023.

It is proposed by Ms. Manon Courcelle, seconded by Ms. Francine Poirier, and unanimously adopted to appoint the firm Jacques Simard Bouffard Azzola Inc., chartered accountants, as auditors of Ataxia Canada-Claude St-Jean Foundation for the 2023-2024 fiscal year.

A market review will be conducted in 2024 to ensure market prices for auditing services, with a view to optimizing them.

10. Proposed change to the number of directors on the Board of Directors

Mr. Huynh explains that the context has changed to the effect that in the past, the directors were very involved in day-to-day operations, supporting the DG but that with the addition of the two coordinators, in addition to Francine Lévesque for financial operations, the role of the directors

will be more at the level of strategy and governance.

As such, we believe that 7 directors would be sufficient. Moreover, for the first 40-45 years of the Foundation, the number of directors was 7.

The proposal is therefore stated by André De Montigny to amend the statutes of the Foundation and that section 4.1 of the statutes reads as follows: The Board of Directors is made up of 7 to 9 directors, at the discretion of the Board of Directors. The proposal is made by Mr. J-P Tremblay, seconded by André Allard and adopted unanimously

It should be noted that the Board of Directors proposed for the next year is still made up of 9 people. The increased flexibility sought will be used over time, according to needs and situations.

11. Reading of the notice of nominations for the CA

André De Montigny mentioned that the notice of nominations was made and complied with the deadline required by the association's regulations (communicated on October 18). Bilingual candidates with relevant experience in the associative environment, fundraising and experience on a board of directors are sought-after assets.

12. . Report and recommendations of the nominating committee

First, Sébastien Huynh thanks Ms. Diane Roch and Ms. Josée Goulet who will be leaving the Board. Ms. Goulet, Vice-President, was a key person in planning the messages and activities for the Foundation's 50th anniversary (in the midst of COVID) and also in the ongoing study on the potential of a major fundraising campaign. As for Ms. Roch, she was very active on the marketing and fundraising committees. On behalf of the entire organization, Mr. Huynh warmly thanks them and wishes them good luck in their future activities.

Excluding these two departures, the mandates of Sébastien Huynh, Maryse Tremblay and Nick Théberge are in effect until the end of 2024.

Also, four director mandates are up for renewal: André De Montigny, Sandy Sadler, Trinidad Ruiz and Sean Ramsden. All four directors have indicated their desire to continue for another term.

It is proposed that the two departures be filled as follows:

- o Mr. Nicolas Parent, a candidate last year but who due to lack of openings, had been appointed as a full-time observer for 2023. Mr. Parent is an accountant by training, has more than 20 years of experience, and currently works at Price Waterhouse Cooper.
- o Mr. Jean-Luk Pellerin, who was Chair of the Board of Directors of the Ataxia Canada Foundation from 2018 to 2020, is returning to the Board. He is therefore very familiar with ataxia, the Foundation, and the partners. He has been a member of senior management in various companies in Canada and internationally, as VP Human Resources and an officer on boards of directors. He has also taught in the MBA program at HEC in addition to having his own consulting business.

13. Élection des administrateurs

Les mandats de André De Montigny, Sandy Sadler, Trinidad Ruiz et Sean Ramsden sont

renouvelés pour une nouvelle période de deux années. De plus, l'arrivée au CA de Nicolas Parent et de Jean-Luk Pellerin est également approuvée, le tout suite à la proposition soumise par M. Jean Phénix secondée par le Dr. Tremblay et adoptée à l'unanimité.

14. Election of directors

The new executive will be constituted as follows:

- Mr. Jean-Luk Pellerin as Chairman of the Board
- Mr. Sébastien Huynh as Vice-Chairman
- Mr. André De Montigny as Treasurer
- Mr. Nicolas Parent as Secretary

15. Presentation of Genome Quebec

Ms. Hélène Fournier, Strategy Director at Génome Québec, presents the Innovative Therapies for Hereditary Ataxias project, set up by Génome Québec, Ataxia Canada and Muscular Dystrophy Canada. 2 to 4 projects will be approved in early 2024 and announced around March 1 via a webinar. A total envelope of \$1M is planned for these projects. As for Ms. Marie-Hélène Bolduc of the Muscular Dystrophy Foundation of Canada, she mentions the power of collaboration and innovation in order to identify possible avenues for future therapies.

16. Address by researchers

Dr. Tremblay updated his project to deliver CRISPER components through extracellular vesicles. The importance of removing the GAA repeat is crucial in the development of gene therapies. New mice with a higher GAA (800 rather than 200) could allow advances in the coming years, improving the level of frataxin in the brain.

Dr. Brais presented a summary of his work on the search for genes and treatments for late-onset ataxias (SCA27B). More than 450 cases have been observed worldwide, including more than 100 in Quebec, in addition to cases in Ontario. Therapeutic studies will be undertaken shortly, including at the CHUM with Dr. Duquette, for new potential treatments.

Dr. Duquette then updated his projects. First, he mentions that the CHUM has been recognized as a center of excellence by the NAF, a first in Canada, a status valid until April 2028. Recognition of the quality of activities in clinical therapies, training (physio, neurologists), and research, the CHUM will therefore be part of the NAF registry to host future clinical studies. Second, the project on the use of virtual reality, funded by Ataxia Canada, has demonstrated that patients can benefit from virtual reality headsets for certain examinations, therefore not having to travel. This project will continue with other funding, to continue testing with other equipment and on a larger number of patients. Thirdly, the natural history sites (with FARA for Friedreich's ataxia - which will now be known as UNIFY, with the equivalent European sites - and the site with the NAF for SCA 1,2,3,6, 8 and 10, and soon SCA27B and Canvass) continue their activities and are asked to participate in clinical trials.

17. Question period

Several questions were asked and comments made throughout the meeting. Here is a summary:

- From Mr. Frédéric de Médina: discussions around the new drug SKYCLARYS and its current unavailability in Canada (the same situation as in the UK and Australia). Representations are

and will be made to Biogen and Health Canada to encourage their approval and marketing of the drug in Canada.

- From Mr. Yannick Gallant: on the financial assistance program for the purchase of equipment / services for people with: to provide more information on the content of the program, to make a specific communication plan for its promotion.

- From Ms. Jessica Laneuville: who wants to participate in various government assistance programs and who would need support: Mr. Théberge will contact her then with Mr. Augers Ste-Marie (our social media coordinator), they will help her in her efforts together.

- From Ms. Manon Courcelle who mentions that biotech companies are those which attract financial risk capital and therefore can be sources of discoveries, just as much as government programs which often have less significant financial means.

18. Closure of the meeting.

. It is proposed by Ms. Jessica Laneuville, seconded by Mr. Jacques P. Tremblay, adopted unanimously that the 51st general meeting be adjourned.

André De Montigny,
Secretary

