# CLSG AGM Minutes January 24, 2022

CLSG Board of Directors 47 Members of CLSG Catherine Eustace

## The following is a transcript of the meeting:

Andre Schuh welcomed everyone to the first annual general meeting of CLSG/GCEL, and gave a brief history of CLSG/GCEL.

## Why do we need CLSG/GCEL?

- Heterogeneity of acute leukemia treatment across the country.
- Need for a more collaborative culture and better networking for standard of care therapy, and research and clinical trial approaches to acute leukemia
- Need for a Canada-wide approach to Leukemia Care
- Need to be able to talk to federal and provincial regulators with one cross-Canada voice

CLSG/GCEL was formed as a nonprofit corporation to address these deficiencies. Purpose of CLSG: To improve the diagnosis and treatment of leukemia in Canada, by identifying diagnostic and management best practices, promoting Canada wide standards of care, fostering clinical, and basic leukemia research and improving new drug access.

#### Mission statement:

- 1. We wish to improve the diagnosis and management of leukemia in Canada, by collaboratively identifying and defining diagnostic and management best practices, promoting Canada-wide standards of care, fostering clinical, and basic leukemia research and improving new drug access.
- 2. We wish to improve leukemia care in Canada by advancing a world class standard of care for all Canadians and by facilitating the ability of leukemia treaters across the country to deliver such optimal quality care in an equitable manner.
- 3. We believe that all Canadians are entitled to the same standard of leukemia care, regardless of geography, age, or other circumstance, and this -- that this standard of care should match or exceed the best in the world.

Here's what we're going to do today. Here's our agenda. It's very straightforward. It's been sent to all of you. And we're just going to run through this from beginning to end.

## Brian Leber presented the Treasurer's report.

- CLSG/GCEL incorporated in October of 2019.
- In that first year we had generous contributions from pharma companies

- We had \$114,302 coming in as of last as of October, 2020 to carry forward.
- In 2021 we received support of \$200,000 as hands off educational grants from Astellas, AbbVie, Servier, Amgen and Pfizer.
- We also approached several other members also approached other pharma companies that expressed general interest but were not able to provide support to us this particular calendar year.
- Expenses include advertising, including maintenance of our website and hosting of meetings, medical writing, administration, and a license agreement with an online word and editing platform called Within3.
- We're in very good shape financially. We do have commitments as will be discussed to complete the projects that we proposed.

#### **Question from Karen Yee**

Is there ongoing commitment from the companies to do this on an annual basis?

# Reply Brian Leber/ Andre Schuh

Ongoing commitment depends on our output. We need to produce to maintain support from our Pharma sponsors.

#### **Question from Karen Yee**

Does any publication mention that there's unrestricted support from these pharmaceutical companies then?

# **Reply Brian Leber**

Our letter soliciting support says that no particular project will list any particular company. They're all listed as supporters of CLSG and any publication and or posting on our website will be through all of our sponsors. Some companies are more comfortable with full arm's length funding than others. All contributions have been made under that particular stipulation.

# Andre Schuh delivered the Report from the Board Overview of CLSG

- General structure of CLSG/GCEL there's a general membership which
  contributes to a number of specific subgroups, the board of directors, and an
  academic advisory group, which represents every leukemia treating university
  and in addition to a few more leukemia centers across Canada, and then what
  we've added more recently are, is a number of groups we call interest groups,
  discussed below
- Breakdown of general membership
  - 132 members, of which the biggest group is hematologists. The rest is comprised of Pharmacists, Nurses/Nurse practitioners, Hemato-pathologists, and others.

- Members from across the country representing every province, although Ontario and Quebec have disproportionate representation.
- Our goal is to represent all of Canada equally so we would like to attract more members from eastern and western Canada.
- Officers of the Board are Andre Schuh, Chair, Julie Bergeron, Vice Chair, Brian Leber, Treasurer, and Lynn Savoie, Secretary.
- All CLSG positions are unremunerated
- The academic advisory group represents every university affiliated leukemia treating center, as well as centers, not directly university affiliated. There's one vacancy in Kingston.
- The goal of the academic advisory group is to ensure regional representation. The role of the academic advisory group is to provide regional perspectives and to define or propose region specific priorities and initiatives, as well as to ensure region-specific participation in project working groups and interest groups.
- Stephanie Desilet from Sherbrook has volunteered to lead this group.
- The interest groups are subgroups of CLSG/GCEL members with unique discipline-specific perspectives or with particular interests in specific aspects of leukemia diagnosis, management, or research.
- Interest groups will identify discipline- or interest-specific priorities and propose interest group-specific initiatives.
- Interest groups will provide membership or participate in the working groups as appropriate.
- To date there are three interest groups including Nursing, Pharmacy and Hematopathology.
- The lead of the Nursing group is Cindy Murray, a nurse practitioner from Princess Margaret in Toronto. The nursing interest group has recruited 24 members. They've had several meetings, have developed terms of reference, and are working on project proposals.
- The lead of the Hematopathology group is Phil Berardi, a Hematopathologist from Ottawa. It's currently at the membership recruitment stage and terms of reference stage.
- The Pharmacy group is currently at the recruitment stage, with a first meeting scheduled in one weeks time.

## **Progress to Date**

# Guiding principles:

- 1. Working group outputs should advance a pan-Canadian consensus position that is inclusive with respect to geography, age, financial means or other demographics, et cetera.
- 2. We should strive for what is medically optimal, cutting edge, and forward looking, rather than focusing on what's currently funded or available, or what we can do.

- We want to set a very high Canada wide standard. We want to end up where we would like to be rather than we are currently able to be.
- 3. The outputs of our priorities should be framed to inform regulators and institutions where we should be, rather than where we currently are, or what we can currently do. And these should be Canada wide guidelines so that we can speak to the regulators and our institutions with a common voice. And we specifically also added that our guidelines or working group statements should incorporate currently unavailable or unfunded drugs or diagnostics as appropriate rather than being restricted to what is currently available.

## 2021 Priorities:

- 1. In 2021, we identified seven priorities, of which the following four have been initiated:
  - a. Treatment of AML in the elderly-be an update of previous Canadian guidelines from 2017 which in turn were an update of a 2014 guideline.
    - i. Lead Joseph Brandwein, Edmonton
    - ii. Manuscript submission Q2 2022
  - b. Treatment of APL- an update of the pre previous Canadian guidelines from 2014, that actually predate the approval of arsenic trioxide in Canada.
    - i. Lead Matt Seftel, Vancouver
    - ii. Manuscript submission Q2 2022
  - c. A guideline regarding the use of pegylated asparaginase in ALL. These are new recommendations to address the many questions arising from the switch to pegylated asparaginase.
    - i. Lead- Andre Schuh, Toronto
    - ii. Manuscript submission Q3 2022
  - d. To clarify the utility of quantitative assessment of FLT3 ITD allelic ratio at diagnosis new recommendations, hoping to address the disparity across the country in the interpretation of FLT3 ratios.
    - i. Lead Phil Berardi, Ottawa
    - ii. Manuscript submission Q3 2022

The final three priorities were treatment of relapsed/refractory ALL; management of Philadelphia positive ALL; and th

The Canadian leukemia registry was added as an important priority during 2021. The goal is to expand the existing Canadian APL Registry run by Kristjen Paulson in Winnipeg...

Kristjan Paulson discussed the Canadian leukemia registry.

 Developed a proposal and a plan for a Canadian national, acute leukemia registry, both AML and ALL.

- The project has been operational now at the Winnipeg site for the past six weeks or so.
- Six or seven patients have been enrolled.
- The aim over the next few months is to roll that out nationally. This is a fully funded project, with ~\$350,000 in support. There is a startup fee of around \$3,000 per center and then a \$500 per patient fee to help facilitate data collection.
- There is a data capture form that was reviewed and discussed with the members of the academic advisory group, their feedback was incorporated.
- The goal is to accrue several hundred patients over the first year at all of the centers.

#### **CADTH and PCODR**

One of the things that CLSG wants to do is to provide Canada wide consensus opinions to CADTH and PCODR regarding new drugs. CLSG has drafted recommendations, comments, replies, and opinions to CADTH and PCODR.

The top five are that we've worked on in the last year and a half are opinions on:

- blinatumomab for MRD positive B-ALL.
- venetoclax and azacitidine for AML.
- venetoclax plus low dose cytarabine for AML
- glasdegib plus low dose cytarabine for AML.
- CPX-351 for AML with myelodysplasia related changes.

We will continue to need help with these as they come up, as they are a lot of work...

# Pharma Supporters

- Pharma is our funding source so we want to keep them engaged. We want to recruit additional supporters as well as encourage repeat funding. In order to do this, we need to have some outputs.
- We had a separate launch webinar for pharma in October, 2021, which was extremely well attended by virtually every oncology-related pharma company in Canada.
- We also sent a progress letter to all our Pharma supporters in June 2022
- Our next activity is a webinar on Feb 25<sup>th</sup>, 2022

#### 2022 Priorities

We did not complete all of our 2021 priorities. We picked only the top four. We propose revisit the remaining the remaining three proposed priorities in 2022, and to add a fourth:

- Relapsed/refractory ALL (new guidelines)
- 2. Management of Philadelphia positive ALL (new guidelines)
- 3. MRD in Philadelphia negative ALL (new guidelines)
- 4. MRD in AML (new guidelines)

We are open to expanding this list and expect to receive some ideas from the AAG as well as from the interest groups. We would also like to hear from the General membership regarding ideas.

#### **CLSG Board**

- Board member tenures and the tenures of the executive of the board or the officers of the board are all defined in our incorporation documents.
- Because of COVID, and because it's still early days for CLSG, after some discussion our proposal would be that the current board membership and the officers remain in place for 2022.
- It is our intention to start adding new board members this year. We would like this to come from a variety routes.
  - The AAG requires representation on the board.
  - There is the question of the interest groups having representation on the board. We have not yet addressed this.

# Affiliation with Current Oncology

- We have an agreement with the journal Current Oncology giving our members a discount with Current Oncology.
- Most of our manuscripts will be sent to CO first

#### **Question from Jill Fulcher**

"Will members have the opportunity to review the guidelines pre-publication or pre-posting?"

## Reply – Andre Schuh/Brian Leber

We will not be circulating manuscripts widely to members for review prior to publication. However we will do the following to ensure that manuscripts are as inclusive and representative as possible.

- 1. Include recognized experts from across Canada on the faculty
- 2. Seek opinions outside of the faculty if necessary
- 3. Manuscripts will undergo review by an international expert, where possible
- 4. Manuscripts will undergo external, peer review prior to publication

Thank you for coming to our AGM in this difficult time. Half of our staff is at home quarantined and the other half is shoveling snow. So thank you all for coming. We will keep you posted with future developments. Thank you. Thank you. And thank you, Brian, Catherine, and Kristjan, for your help. Thanks everybody for attending.