

**Sickle Cell Foundation of Alberta (SCFA)
Annual General Meeting (AGM) and Educational Seminar
“New Innovations in the Treatment of Sickle Cell Anemia”**

Minutes of annual general meeting

Time: 10:00 AM
Date: August 15, 2020
Place: Virtual (Zoom)/Edmonton/Calgary/various other locations based on Attendee
Chair: Bernice Asiedu-Ampem/Abisola Ojikutu
Minute taker: Racquel Ramsumair

Agenda item 1: Welcome, attendees and apologies

1.1 Chair

Bernice Asiedu-Ampem was confirmed as chair for the meeting.

1.2 Attendees

Name	Position	Participation method
Jean Walrond	President	by videoconference
Bernice Asiedu-Ampem	Vice President	by videoconference
Abisola Ojikutu	Board Member	by videoconference
Michelle Patterson-Nipp	Past President	by videoconference
Carlyle Ross	Auditor	by videoconference

Please see attached Attendees Report for all in attendance. All attended by videoconference.

1.3 Meeting open

The chair declared the meeting open at 10:01AM and that a quorum (3 Directors) were present. There were nine (9) Directors/ Board members present in total.

Stephanie Burlie (vocalist) – “O Canada”

Agenda item 2: Review of AGM agenda

2.1 Confirmation of agenda

Proposed resolution: That the agenda of the general meeting held on 15/08/2020 be accepted.

Moved by: The Chair-Bernice Asiedu-Ampem **Approved by:** Abisola Ojikutu

Seconded by: Michelle Patterson-Nipp

Decision: Resolution carried

Agenda item 3: Activity report

3.1 *President's report*

Document/s tabled: Oh a Very Busy Year, Oh How Time Flies

Moved/presented by: Jean Walrond/Bernice Asiedu-Ampem/Abisola Ojikutu

Seconded by: Hannah Eche- Ameh

Key points:

- purchasing a computer and furniture to make a more permanent place
- completion of branding
- continue outreach into community, attended many cultural events such as Cariwest, Black girls Leadership Celebration, Black History Month Events
- joined the SCDAC and participated in the National Conference
- research about blood donation of non-white Edmontonians
- apply for funds and hiring students and book keeper
- Calgary to resolve distribution of communications
- Covid-19 presented challenges with communicating to the membership
- The Sickle Cell Consortium assisted in providing information about Covid-19, and travel to Calgary for transplant
- Received funding from Canadian Gov't for World Sickle Cell Day, and for support during Covid
- Application is on the website
- Social Media has all been and is being updated regularly
- Launching 'Pint-Size' App
- Future brings, more support for families and youth

Action required and/or resolutions arising from the report:

- **Action required** to continue working on goals for the rest of 2020 into 2021
- The CEO report for the year ended December 31, 2019 was taken as received

Decision: carried

3.2 Treasurer's 2019 financial statement report

Document/s tabled: Financial Report-not audited yet

Moved/presented by: Carlyle Ross

Seconded by: Jean Walrond

Key points: Everything looked extremely good in terms of finance at the end of June 2019
-Please see attached report with analysis and figures
-Charles Gillander did a great job and should be recognized for the work he put into this report

Action required and/or resolutions arising from the report:

- **Action required: Say Thanks to Charles Gillander**
- The directors report for the year ended 30 June 2020, was taken as received

Decision: carried

Agenda item 4: Election of directors

Expiring/vacant directorships

The terms of appointment for the following people expired:

- Kale Vizor- Vice President
- Michel Ngatcha-Treasurer

Nominations

The chair called for nominations for the vacant positions and the following people were nominated:

- Treasurer-no nomination
- Secretary-no nomination

Result-N/A as there were no nominations

Agenda item 5: Future path

Bernice Asiedu-Ampem

-Education/Awareness/Support

-going forward our focus will be on Awareness and Support

-we need to know who the SC community is

-we will be setting up a registry to get to know the community

-encourage sickle cell patients to contact SCFA

-we need the support of the community for volunteerism/building partnership/word of mouth/participation

-peer to peer referral system

-building our social media presence

-website will have timely information about events and information

-support through donations

-Thank you to all members and support personnel

Agenda item 6: “CRISPR-Cas 9 and Sickle Cell Anemia” by Dr. Turner

Introduction by Abisola Ojikutu

Questions arising during the Q&A. Responses to be posted on SCFA website.

-Would you say that gene edited using CRISPR is a lower risk than stem cell transplants?

-How effective is CRISPR in patients who have their vital organs already affected?

-I'm getting confused with the different protocols. Does CRISPR use HIV as the lentivector?

-How soon do you think this treatment will be available to patients in Canada?

-which pharmaceutical company is running this trial and are there any plans to do this in Alberta?

-If anyone wants more info they can email Dr. Turner at Robert.turner@ualberta.ca

-what are the requirements to participate in the Canadian the trials?

-what are the steps for taking a therapy from trial to use by the general public?

Stephanie Burlie (vocalist) – “What a Wonderful World”

Agenda item 7: “21st Century Nursing and the Sickle Cell Patient” by Trudy Sale

Introduction by Abisola Ojikutu

Questions arising during the Q&A. Responses to be posted on SCFA website.

- From your experience what would you say are the biggest barriers and myths about using Hydrea?
- Does your team ever collaborate with the U of A counterpart?
- How does Hydroxy Urea affect already damaged kidneys?
- What do you recommend for patients during Covid?
- I know the Calgary clinic now offers wallet size emergency cards for SCD patients to carry and present to emergency rooms when they present with a crisis. Is this something practiced across the country? If not, are there plans for widespread adoptions?
- Any tips for sending children back to school or do you recommend home-schooling?
- Is an individualized patient pain treatment protocol available at all ERs across Alberta?
- Can your service only be accessed by referrals from family physicians? I am thinking about educational support.
- Is there any correlation between the consumption of foods like milk and development of pain crisis? Since noticing episodes of muscle pain, cramping, muscle fatigue, and fever resulted in hospital visit following the child's ingestion of large amounts of milk. It has now been almost half a year without any episodes of pain or fever.
- With a pain crisis is there ever analysis specific to change in lactic acid level comparative to lactic acid level during a non-episode blood test?

Agenda item 8: 1“Highlights from National: New Drugs and New Outreach Programs” by Biba Tinga

Introduction by Abisola Ojikutu

Questions arising during the Q&A. Responses to be posted on SCFA website.

- This is wondering- 6000 people with this disorder, however how many of these [people] are SCD organizations able to reach and communicate with? Privacy policy [is] quoted when discussing this communication barrier and this needs to change.
- What is the next thing we can do to help move things forward?
- Can these new drugs not be introduced into Canada through the Special Access program with Health Canada?
- How can we help to break down stigmas in our community?

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-I understand that these drugs are registered with the FDA as orphan drugs. This reduces the review timeline; can this approach be used as well here in Canada in collaboration with the manufacturers?

-If a patient in their opinion, feels current therapy is not helpful (no decreases in number of episodes) and is interested in trying out one of the new drugs, how would they approach this?

Agenda item 9: “Blood, You Have It to Give: Meech's PintSize App”

Introduction by Abisola Ojikutu

Questions arising during the Q&A.

-No questions

Agenda item 10: Closing message

The meeting was declared closed at 1:04 PM.

Confirmation of the minutes

These minutes are a true and accurate record of the meeting.

Original paper copy filed with SCFA documents.

Signed by:

BAsiedu-Ampem

Bernice Asiedu-Ampem

May 17, 2021

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(signature)

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(name)

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(date)

JWalrond

Dr. Jean Walrond Ph. D.

May 17, 2021

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(signature)

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(name)

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(date)

