

IASSIDD Down syndrome SIRC AGM (Zoom) 1/11/23

Present: Rhonda Faragher, Karen Watchman, Joann Douziech, Masauso Chirwa, Margie Douziech.

Apologies: Jill Porter, Roy Brown, Tonnie Coppus

Report from the Chair

Rhonda updated on work since the last AGM which was in Glasgow. This has led to committee roles being held for longer than would usually be the case. A reminder was given of the current SIRC committee.

SIRC activities:

- 2022 virtual conference Down syndrome around the world, 24 hour event
- 2023 webinar 18 October Down syndrome research across the lifespan.

Whilst not the same as meeting face to face there was still useful discussion. The preference was noted for future events to be in person.

Thoughts and good wishes were sent to Tonnie Coppus, Netherlands who has been a core member of the SIRC since inception and has made a crucial contribution.

Sue Buckley has retired from the SIRC since the last AGM. Roy Brown was recognised for reaching his 90th birthday in coming weeks, Roy has also played a major role in the SIRC since inception. All committee members were thanked for their contributions.

Financial report: no expenditure as all activities have been online. There was agreement that a travel scholarship should be made available for students, researchers with Down syndrome or researchers from low and middle income countries to attend the IASSIDD world congress in 2024. The successful applicant should have had an abstract accepted at the congress. Consideration was also given to fund a membership in the future.

Change to IASSIDD bye-laws

Rhonda advised all to consider nominations to the IASSIDD board – see recent emails. A number of roles are available and no experience of IASSIDD committee membership is required. Each SIRC is now represented collectively on the IASSIDD board by an elected director. Currently that position is held by Dr Mindy Scheithauer.

SIRGs are required to have 30 members to be viable. Part of the membership fee still comes to the members primary SIRC.

SIRC responsibilities are to plan and conduct activities such as conferences, events, roundtables, newsletters etc. The SIRC covers the expenses of their representation in an official capacity in IASSIDD activities and an annual report must be provided to the board.

Review of SIRC Statement of Purpose

There is no obvious statement of purpose on our website so the attendees reviewed the current SIRC mission statement.

This will be updated in 2024 and changed from a mission to a statement of purpose. Whilst not inaccurate it was felt that the current version could be amended to reflect the lifespan approach

seen in the membership and the global nature of our work. It is important that the new SIRC committee are involved in this.

New process of election of SIRC office bearers

This process no longer takes place at congress, instead there is an online process to nominate anyone for a role, or self-nominate. Some SIRGs may need interim exec members until Chicago.

Rhonda Faragher and Karen Watchman are stepping down from roles as chair and secretary. If no nominees for Chair are received, Rhonda Faragher will remain in the position until the Chicago congress.

Any other business

Members were encouraged to attend the World Down Syndrome Congress in Brisbane 2024.