

Canadian Bleeding Disorders Registries Committee

Terms of Reference

The Canadian Bleeding Disorders Registries Committee (CBDR-C) of the AHCDC is constituted to ensure that all the registries maintained by the AHCDC are:

- fulfilling the need and scope of the organization
- generating quality epidemiologic data
- supported by the AHCDC membership as required
- harmonized to ensure efficacy and avoid redundancies
- equally supported by the AHCDC, taking into account the resources available

The CBDR-C will deliberate on the above matters and provide advice to the AHCDC Executive, which will be solely responsible for decisions with financial implication for the AHCDC.

The CBDR-C meets at least quarterly, including an in-person meeting during the annual AHCDC general meeting, or more often via teleconference as needed.

Full or associate members of the AHCDC are eligible to serve on the committee, and can express their interest to the Chair. The AHCDC Treasurer will be a standing member of the committee, to act as a liaison with the Board and to facilitate discussions of financial support of registry activities. All other members will serve for a three-year term, renewable pursuant to their ongoing interest and participation to the committee. The committee will consist of at least five and no more than nine members. Four of those members will fulfill the following functions:

- a representative of the CHR technical group
- a representative of CBDR technical group
- a representative of the Rare Inherited Bleeding Disorder Registry (RIBDR)
- a representative of the Privacy Committee

The committee members will nominate the candidate committee Chair to the AHCDC Executive for appointment for a three-year term, renewable once.

It is recommended, but not mandated, that the representative for CBDR will be the McMaster project lead for CBDR and the representative for the RIBDR will be a member of the AHCDC Rare Inherited Bleeding Disorders committee.

The committee chair can extend invitations to any or all meeting to non-committee members, for part or all of the meetings, as required to fulfill the mandate of the committee. This would include representative of patients, nurses, physiotherapists, social workers, CBS and HQ, and to technical members of the McMaster CBDR working group.

Agendas and minutes for the meetings will be copied to the AHCDC secretariat. An annual report will be provided to the AHCDC membership at the Annual General Meeting.

(cont'd overleaf)

Interim disposition

The CBDR-C committee replaces the CHARMS committee, which will be dissolved with the appointment of the CBDR-C.

The initial composition of the CBDR-C will be the current members of the CHARMS committee:

- Dr. Alfonso Iorio, chair (CBDR representative)
- Dr. Irwin Walker (CHR representative)
- Dr. John Wu (RIBDR representative)
- Dr. Laurence Jardine (Privacy Committee representative)
- Dr. Jayson Stoffman
- Dr. Jerry Teitel
- Dr. Alan Tinmouth
- Dr. Margaret Warner
- Dr. Anthony Chan