

Canadian CAPS Network

Terms of Reference

June 2010

Mission

The mission of the Canadian CAPS Network (CCN) is to improve the lives of all those affected by Cryopyrin-Associated Periodic Syndromes (CAPS) and related disorders.

Objectives

- To improve awareness of CAPS and related disorders among the public, patients and family, clinicians, researchers, and policy makers;
- To provide information and support to patients and families affected by CAPS and related disorders;
- To encourage and support collaborative research into the causes and treatment of CAPS and related disorders toward improved diagnosis, treatment, and care;
- To promote and support improved prevention, diagnosis, treatment and care for patients and families affected by CAPS and related disorders
- To provide a common voice for patients, families and supporters of CAPS and related disorders
- To serve as a forum for bringing together patients and families, healthcare professionals, researchers, industry, funders, and policy makers to raise funds and promote health policies that improve the lives of those affected by CAPS and related disorders

Membership

Membership in the Canadian CAPS Network is open to any individual or corporation who ascribes to the mission and objectives of the network.

Board of Directors

The Board of Directors shall be responsible for the governance, direction, and implementation of the programs of the CCN. The officers of the Board shall consist of the following positions, elected on an annual basis. The Board of Directors will serve without financial compensation (other than expenses) and will make public any conflicts of interest.

- President
- Vice-President
- Secretary
- Treasurer
- Board Members (2 – 4)

Committees

The Committees of the Board will be responsible for the effective operations of CCN. The following committees shall consist of Board and general members. The Board may choose to establish additional committees by simple resolution and majority vote. Working Groups, Ad Hoc Committees, and Task Forces may be established by the Board to help carry out its objectives.

- Finance Committee
- Membership Committee
- Programs Committee

Board Operation

- The Board will operate primarily through email and teleconference. The Board will follow Robert's Rules of Order. Decisions will be made by consensus whenever possible. Where consensus cannot be achieved, a simple majority vote will prevail, with opportunity for record of dissenting vote. Each board member has one vote, including the president; however the President may, in cases of tie and from time to time, be called upon to cast a deciding vote.
- The Board shall meet from time to time but no less as necessary than once in a quarter year
- The Board and CCN will be supported by a volunteer Secretariat provided through the Canadian Organization for Rare Disorders, which will provide day-to-day administrative and communications support, as needed.