1.0 Purpose

Cystic Fibrosis Canada values the diverse perspectives of the cystic fibrosis (CF) research community in the execution of its strategic directions. Cystic Fibrosis Canada is committed to providing a mechanism where it will benefit from the scientific knowledge and expertise of the CF research community. Informed decision making and evidence based policy making are integral to the achievement of Cystic Fibrosis Canada’s mission, goals and objectives.

The Research Advisory Council is an advisory body that provides a forum for dialogue between Cystic Fibrosis Canada and the CF research community. The purpose of the Research Advisory Council is to provide scientific advice and make recommendations to Cystic Fibrosis Canada on the implementation of research programs and initiatives.

2.0 Scope of Activities

In carrying out its mandate, the Research Advisory Council:

- Provides input on the development of new research programs and initiatives in an advisory capacity to management;
- Advises management on the programs and funding mechanisms required to successfully implement the organization’s strategic directions and business plan specific to research;
- Considers and advises on issues where scientific input is required on an ad hoc basis;
- Convenes temporary task forces or working groups to evaluate and make recommendations on health research initiatives as requested by management;
- Provides stewardship of the peer-review framework for research funding, including evaluating the peer review processes used to assess applications for research funding and making recommendations for improvements as required;
- Recommends candidates to serve as chairs and members of standing and ad hoc Scientific Review Panels where needed;
- Supports the ongoing evaluation of the organization’s research programs to ensure they contribute to achieving Cystic Fibrosis Canada’s mission and strategic directions;
- Provides information on emerging trends, developments and opportunities in CF research; and
- Based upon advice from Scientific Review Panels, makes recommendations to the President/CEO on the approval of Cystic Fibrosis Canada grants, awards and other research funding initiatives.
3.0 Reporting Structure/Governance

The Research Advisory Council is an advisory body to the President/CEO and the Office of Research.

The President/CEO and members of the Office of Research attend all meetings of the Research Advisory Council on an ex-officio, non-voting basis.

4.0 Membership

4.1 Size and composition

The Research Advisory Council shall have a minimum of seven and a maximum of ten scientific members. In addition, there shall be three lay members, including a person with cystic fibrosis.

Members act collectively as an advisor to Cystic Fibrosis Canada with respect to the mandate of the Research Advisory Council.

The President/CEO appoints the scientific and lay members of the Research Advisory Council following an open selection process.

Scientific members are selected to provide broad representation of the health research community and must have credibility in the CF arena.

Members are normally appointed for a single three-year term, with the option of an additional one, two or three year extension, up to a maximum of six consecutive years of service. Former members may be reappointed after a break in service of at least three calendar years.

In extraordinary circumstances, a member’s appointment may be terminated by the President/CEO.

4.2 Chair and Vice Chair

The President/CEO appoints the Chair and Vice Chair from among the scientific members.

The Chair and Vice Chair shall serve for a term of two years or until the next Chair is appointed.

The Vice Chair acts on behalf of the Chair in his/her absence. In prolonged absences of the Chair, the Vice Chair assumes all accountabilities of the Chair.
5.0 Operational Protocol

5.1 Responsibilities

Members shall offer their independent and objective advice to Cystic Fibrosis Canada, be available and prepared to participate in meetings, and avoid situations of real or perceived conflict of interest.

5.2 Meetings

The Research Advisory Council meets a minimum of three times per year, with additional meetings as required at the call of the Chair or upon the request of the President/CEO. There shall be at least one in-person meeting per year.

The Chair in consultation with the Office of Research will determine the time and duration of meetings.

A simple majority of the Research Advisory Council shall constitute quorum.

Determination of the actual meeting agendas will be done jointly by the Chair and the President/CEO or designate. A list of future agenda items will be maintained on an ongoing basis.

Agenda packages will be circulated electronically to members no later than five working days in advance of meetings.

Input and advice from the Research Advisory Council need not be consensus, as all opinions and perspectives are important, however whenever possible consensus based advice will be sought. When voting is appropriate, a simple majority (50% of voting members plus one) shall constitute a majority for the purpose of votes. All members have one vote, except for the Chair, who will vote only in the event of a tie.

5.3 Relationship with the Scientific Advisory Committee of the Board of Directors

Members of the Scientific Advisory Committee may attend meetings of the Research Advisory Council as observers.

5.4 Operational Support

Administrative support for the Research Advisory Council is provided by the Office of Research.

Any individual or organization shall contact the Research Advisory Council regarding any of its activities through the Office of Research.

All media requests related to the Research Advisory Council’s activities will be directed to Cystic Fibrosis Canada’s Communications Director who will coordinate responses.
5.5. Review

The President/CEO shall cause a review of the Terms of Reference of the Research Advisory Council every two years.

Approved by the Board of Directors on September 21, 2013