

## **Cystic Fibrosis Canada Community Stakeholder Membership**

### **TERMS OF REFERENCE**

#### **Objective**

In keeping with the tradition of upholding best practices in the charitable granting sector, Cystic Fibrosis Canada wishes to include two (2) community stakeholder members on its scientific review panel. In so doing, the organization seeks to secure, in a timely way, a stakeholder perspective on research policy decisions and recommendations; to provide an important, additional mechanism for evaluating the relevance of research applications to cystic fibrosis; and, to enhance accountability of Cystic Fibrosis Canada's highly regarded process of peer review.

The mission of Cystic Fibrosis Canada is to end cystic fibrosis. The organization helps all people with CF by:

- funding targeted world-class research;
- supporting and advocating for high-quality individualized CF care; and
- raising and allocating funds for these purposes.

Definition of a community stakeholder:

- Community stakeholders are members of Cystic Fibrosis Canada, and are strong supporters of the mission of the organization.

#### **Requirements**

The community stakeholder member must:

- have broad knowledge of and a proven interest in cystic fibrosis;
- have an appreciation of the multidisciplinary approach to cystic fibrosis treatment and care;
- value scientific inquiry;
- have current or prior experience in serving on a Cystic Fibrosis Canada committee, Cystic Fibrosis Canada Chapter/Association Executive committee, or a Chapter committee;

- participate in the annual January panel meetings (three to four days, in Toronto) which are conducted only in English;
- review all materials, and report on materials, in advance of the meeting (time commitment of 40 to 60 hours of work, as described above);
- adhere to Cystic Fibrosis Canada policies pertaining to confidentiality and infection control;
- have at least moderate abilities in spoken/written English.

### **Description of role**

The role of community stakeholders is distinct from that of other members who are scientists and health professionals. The community stakeholder role is valued equally with the roles of all other panel members. The community stakeholder is responsible for forging a working relationship with other panel members, based on mutual respect, communication and trust. Each panel member who is a CF clinician or CF investigator brings expertise in one or more sub-disciplines, helping to assure the highest process of scientific review. In contrast to these panel members, community stakeholders are invited for reasons other than their professional expertise in science and/or medicine. Community stakeholders are invited as people with unique life experiences that allow them to take a step back from the details of the science and medicine and provide a broader view. Often community stakeholders will have a personal experience with CF, as an individual living with CF or a parent or other caregiver.

The most important role of community stakeholders is to provide an outlook based on their own life experiences, which is something other members are not asked nor expected to do. The role does not imply any obligation or expectation on the part of community stakeholders to comment on or assess the science, nor does the role imply that community stakeholders must comment on, and analyze each proposal. Indeed, the scientific and medical experts on the panel do not necessarily provide comments or analyses respecting every proposal. However, it is the role of the community stakeholder to contribute, wherever appropriate, a personal perspective about CF.

### **Term of service**

Membership is at the discretion of the Selection Committee.

Participation will include attendance at the annual meeting held in January. *Please note that Cystic Fibrosis Canada's Infection Control policy is, as always, in effect for these meetings.*

### **Detailed Role**

The role of the community stakeholder member is to:

- serve as a sounding board, and as a source of advice, with respect to the identification of relevant research proposals;
- participate in recommended training, pertaining to Cystic Fibrosis Canada's granting programs, which support CF research;
- attend the panel meetings which are conducted only in English;
- maintain complete confidentiality of all panel discussions and documents;
- report back to Cystic Fibrosis Canada on the experience of serving as a community stakeholder member, by completing a questionnaire.

### **Specific Responsibilities**

The responsibilities of the community stakeholder member, as a voting member (except where noted), are to:

- review (and report on – please see below) the lay summary of all research applications, focusing on relevance, and assess relevance to the broader CF community and the mission of Cystic Fibrosis Canada (note that this may involve over 40 hours of reading);
- complete a *Report Form for Community Stakeholder Members* to record comments on the relevance of the applications, and submit completed forms to Cystic Fibrosis Canada one (1) week prior to the January meetings; forms will be circulated to the members of the scientific review panel, and comments may be incorporated into the feedback sent to applicants;
- provide input, as appropriate during the January meetings, into the discussion and scoring of relevance of the research applications.

### **Selection Process**

The selection of the community stakeholder member will be assessed by a Selection Committee consisting of Cystic Fibrosis Canada's scientific review panel Chair; the organization's CEO, staff within the Office of Research, and additional



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volunteers of Cystic Fibrosis Canada (to be named). The Selection Committee will rank all applicants based on the requirements (listed on page 1), and the highest-ranked community stakeholder member(s) will be chosen.

Please note, the Selection Committee wishes to ensure that many members of the CF community have an opportunity to serve in the role of Community Stakeholder. For this reason, the Selection Committee may not give precedence to prior experience when selecting a candidate for this role.