

Bloorview Research Institute Family Engagement Committee (RFEC) Terms of Reference – June 2016

Role

The Bloorview Research Institute Family Engagement Committee (RFEC), works in partnership with the Bloorview Research Institute to engage families in all aspects of research conducted by the BRI.

Purpose

The Bloorview Research Institute Family Engagement Committee (RFEC) advises and makes recommendations to the Bloorview Research Institute and its staff in order to promote family engagement in research not merely as research participants, but as partners in all aspects of the research process from idea conception to dissemination of results.

Responsibilities and Opportunities

- To assist in identifying the research needs and priorities of clients and families through teamwork with staff
- To promote opportunities for communication of research initiatives and results, and design and arrange opportunities for collaboration among clients, families, and staff at Holland Bloorview Kids Rehabilitation Hospital and community partners
- To facilitate the development and enhancement of access to information, support, and educational resources which help clients and their families become more familiar and engaged in the research
- To advise and share information on research initiatives as they relate to Holland Bloorview
- To bring the family voice through active membership on the RFEC and various subcommittees
- To promote Bloorview Research Institute initiatives with families and community partners

Accountability/Reporting Relationships:

- The RFEC has a direct communication relationship with the Vice President of the Bloorview Research Institute
- The RFEC staff liaison, as the resource support for the Committee, works with the committee, the senior management and the Bloorview Research Institute staff to identify and coordinate topics of interest and focus.

Membership:

The RFEC is comprised of family members and staff of the Bloorview Research Institute

Qualifications

- Family member of a Holland Bloorview client or client of Holland Bloorview (current or past) or Family member of a participant or participant in a BRI research study (current or past)
- Respects diversity and differing opinions
- Works collaboratively with staff and other families/clients
- Remains open-minded and maintains a non-judgmental attitude
- Active listener
- Maintains a sense of humour, a sense of vision, and a positive attitude
- Has the ability to maintain respect for privacy and confidentiality
- Is available to represent families as a well informed participant whenever issues concerning families of children with disabilities are being discussed

Key Requirements

- Attend a screening interview
- Undergo a police reference check (including a vulnerable sector check)
- Sign a confidentiality agreement and volunteer contract
- Complete Family Leadership Program training
- Wear a volunteer identification badge visibly
- Sign in and out at the volunteer sign in station
- Report in and out with the staff designate when volunteering

○ **Voting Members of the Bloorview Research Institute Family Engagement Committee:**

1. shall consist of a core group of **Voting Members** with the minimum of

- 6 parent/family or client representatives whose children are receiving or have received services at Holland Bloorview or are have participated in research
- 1 member representing youth/ adults with disabilities who is a current or former client of Holland Bloorview, recruited by the RFEC staff liaison, in collaboration with staff and members of the RFEC
- Senior Management Representative
- The RFEC staff liaison
- 1 Representative from Communications and Public Affairs
- 1 Representative from Evidence to Care

2. shall attend all meetings as best as can be expected

- a Voting Member is expected to attend a minimum of **8** meetings through the course of the meeting year, June to May
- any voting member absent from **4** meetings without notice will no longer qualify as a voting member **however** they will be contacted for discussion before final removal from the RFEC

3. shall be one member of a family, except where that family member is member at large
4. shall vote on matters concerning RFEC Terms of Reference and other business requiring a vote
5. shall elect one co-chair at the May meeting
6. shall elect one vice-chair at the May meeting
7. shall elect one secretary at the May meeting

○ **Staff Members participating on the RFEC include:**

1. A Senior Management Representative Consisting of either the Vice President, Bloorview Research Institute and/or delegate
2. The Bloorview Research Institute Family Engagement Committee staff liaison providing resource support
3. A representative from Communications and Public Affairs
4. Other staff may be invited to meetings by this committee, from time to time, who would be considered essential in assisting the RFEC to achieve it's goals and accomplish current projects

○ **Guests**

1. Are welcome to attend meetings, and provide input.
2. Shall notify the RFEC staff liaison, in consultation with/at the discretion of the RFEC co-chairs, of their wish to attend a particular meeting a week in advance
3. Scientist are welcome to attend meetings, and provide input

Term of Office:

Members are appointed for, but not limited to, one year

Meetings

The RFEC will meet monthly, at least 10 times a year.

Meetings can also be called at the discretion of the co-chairs

All meetings will be publicized internally, on the website and sent to RFEC members

Officers:**Co-chairs**

The Bloorview Research Institute Family Engagement Committee will elect one (1) family leader co-chair for a one-year term every year at the May meeting.

The Bloorview Research Institute shall appoint one (1) BRI staff co-chair for a one-year term every year at the May meeting.

Qualifications for the family leader co-chair:

- Must serve a minimum of one year on the Bloorview Research Institute Family Engagement Committee
- Shall be actively involved and participated in subcommittees
- Should demonstrate an understanding of the roles and responsibilities of the RFEC
- Must possess the ability to work constructively with senior management, staff and members of the RFEC
- Was not co-chair for both of the preceding years.

The co-chairs shall:

- Call and chair meetings
- Develop the meeting agenda with vice-chair and RFEC staff liaison
- Review and revise meeting minutes
- Communicate with RFEC members
- Confer with senior management on matters related to RFEC work
- Write an annual report summarizing the RFEC's activities and achievements during the year
- Represent and speak on behalf of the RFEC at special events and functions related to the Bloorview Research Institute's work

Vice Chairs

The Bloorview Research Institute Family Engagement Committee will elect one (1) family leader vice-chair for a one-year term every year at the May meeting.

The vice chair shall:

- Assist the co-chairs in their duties
- Execute the duties of the co-chair where needed
- Assist in planning discussions with the co-chairs and the RFEC liaison

Past Chair

- Provides continuity and support to the new Chair and committee during transition of committee leadership
- Briefs new Chair on position responsibilities and key information
- Provides advice, support and information throughout the year as needed to the new Chair and committee

Qualifications: Served as committee Family Leader Co-Chair immediately preceding a new Chair

Secretary

- A volunteer position for a period of one year
- Shall be responsible for taking and distributing the minutes of the meetings

Quorum

Decisions made by the Bloorview Research Institute Family Engagement Committee will be derived by consensus of the group. Where there is no consensus, a simple majority will be accepted.

A minimum of fifty percent of the voting members must be present for a vote to be taken.

Voting

A quorum is required for a vote to take place.

Voting can be taken by a show of hands.

The voting group can request a secret ballot.

Minutes

Minutes shall be circulated 1 week prior to each meeting via e-mail.

Copies of minutes shall be distributed to:

All members of the Bloorview Research Institute Family Engagement Committee

Vice President of the BRI

Staff liaison of the Holland Bloorview Kids Rehabilitation Hospital

Other interested individuals based on request

Records Retention

The Bloorview Research Institute Family Engagement Committee's records are subject to the *Freedom of Information and Protection of Privacy Act* (FIPPA) and are governed by Holland Bloorview Kids Rehabilitation Hospital's Records Retention Policy.

Review

The Terms of Reference will be reviewed annually by May 31.