CAN-BIND Patient and Family Advisory Committee (PFAC)

Description of Study and Committee Terms of Reference

Background of Study:

The Ontario Brain Institute recently announced funding of a groundbreaking new study to help identify biological tests to help doctors choose the best treatment for individuals with clinical depression, Canada's leading cause of disability. The research, headquartered at the University Health Network in Toronto, involves multiple provincial, federal, and private funders who will contribute to the Canadian Biomarker Integration Network in Depression (CAN-BIND). This research will integrate a variety of clinical measures, blood tests, and brain imaging tests to identify when a treatment is working, in order to be able to match the right treatment to each person. Currently, no tests exist that help doctors choose one of the many possible treatments for depression, and most treatments are only effective in a subset of patients, meaning that an individual may have to try several different ones before finding a treatment that works for them.

The CAN-BIND initiative will use state-of-the art tools to examine biomarkers before and during standard antidepressant treatment. Because the current diagnosis of 'clinical depression' is entirely based on symptoms, it is unlikely that a single biological marker will be useful to predict the best treatment for an individual depressed patient. However, using a combination of several state-of-the-art laboratory-based blood analyses, neuroimaging, and clinical characteristics, the CAN-BIND team will be able to identify key features that predict treatment outcome.

Major depression (also called clinical depression), affects close to 2,000,000 Canadians annually and is the leading cause of time lost from work, more than cancer or heart disease. The identification of biomarkers to guide treatment will reduce the lag time between diagnosis and successful treatment of depression. CAN-BIND is a coordinated effort of Canadian researchers at the University of Toronto (University Health Network and Centre for Addiction and Mental Health), McMaster University (Hamilton), Queen's University (Kingston), University of Guelph, University of Ottawa, McGill University (Montreal), the University of Calgary, and the University of British Columbia (Vancouver).

Purpose of the Committee

The PFAC will provide the research team with advice and suggestions on how to improve the research, how to make the research more immediately relevant to people and families dealing with depression, and provide guidance on public education and advocacy on topics involving clinical depression.

Practical Considerations

The PFAC will require individuals who are willing to spend some time reviewing documents or products of the study such as newsletters, and participate actively in several meetings each year when the study will be discussed. In order to serve a provincial mandate, some members must be drawn from outside of the greater Toronto area, and should reflect the diversity of the general population. Expenses for travel and refreshments at meetings, as well as an honorarium of meeting attendance, will be provided. In view of the collaboration of CAN-BIND with the Mood Disorders Association of Ontario (MDAO), most PFAC members will be drawn from the MDAO membership.

Specific Terms of Reference – Patient and Family Advisory Committee

Purpose:

To improve depression research, outreach, and ultimately clinical care

Membership:

- Open to individuals with lived experience with mood disorders and members of families who have experience with depression.
- The committee will include 4-8 members, of whom at least 2 represent families, and at least 2 represent areas outside the GTA.

Actions:

- 1. Become familiar with the overall depression study.
- 2. Provide feedback on the current study and on plans for future research
- 3. Review materials produced by the study, including patient information material, talks, videos, etc
- 4. Provide advice on the use of public information channels like websites, Facebook and Twitter
- 5. Suggests ways to improve advocacy for Depression

Administration:

The Knowledge Translation Coordinator of CAN-BIND will communicate with committee members, organize meetings, take minutes, and provide all necessary documents and manage all financial details.

Reporting:

Directly to Dr. Sagar Parikh, study co-investigator and lead for Knowledge Translation, and indirectly to Dr. Sid Kennedy, principal investigator for CAN-BIND.

Scheduling:

Meetings will be held 4 times per year in Toronto, with attendance by teleconference available. Meetings will be scheduled for 2 hours.