

CBANHC TASK FORCE

Report to the CNSF Board of Directors – December 8th, 2007

The CBANHC Task Force, created by the Board of Directors at its meeting on June 18, 2007, was assigned the following mandate: *To make recommendations to the Board of Directors of the Canadian Neurological Sciences Federation concerning the future role of CBANHC and, if appropriate, to identify candidates for the leadership of the organization.*

The members of the Task Force were: Charles Tator, Chair-CBANHC; Deanna Groetzing, VP-Multiple Sclerosis Society of Canada; Maureen Daniels, Canadian Alliance of Brain Tumour Organizations; Rob Brownstone, Canadian Association for Neuroscience; Inez Jabapurwala, President, Neuroscience Canada; Darlene Schindel, Canadian Association of Neuroscience Nurses; Drew Kirk, President-CNSF; Max Findlay, CNSF Board member; Dan Morin, CEO-CNSF; Garth M. Bray, VP-CNSF (Chair).

The Task Force held five biweekly teleconference meetings between September 6 and November 9, 2007. Based on the discussions at these meetings and among sub-groups of Task Force members, the Task Force reached a consensus on the following recommendations:

1. That CNSF continue to carry out its role in advocacy through CBANHC - the coalition of the CNSF and neuroscience voluntary health organizations (VHOs) created in 2002, and joined by NeuroScience Canada and the Canadian Association of Neuroscience in 2005.
2. That CNSF approve the revised mission and goals of CBANHC that are presented in Appendix A.
3. That CNSF encourage and support CBANHC to achieve these goals by undertaking appropriate strategies, including, among others:
 - a. Dissemination of the extensive data in the report on the *Burden of Neurological Diseases, Disorders and Injuries in Canada* (Canadian Institute for Health Information, June, 2007) to increase awareness among Canadians, including their policy makers, about the social and financial impact of these disorders [Appendix B – CBANHC TASKS];
 - b. Participation with NeuroScience Canada, the Canadian Association of Neuroscience, the VHOs, and other partners, including mental health organizations, in the development of strategic alliances to produce advocacy efforts with maximum impact to enhance awareness of, and to obtain increased support to alleviate the burden of, neurological disorders and injuries in Canada [Appendix C – STRATEGIC ALLIANCES].
 - c. The development of a strategic plan concerning the governance, leadership, and infrastructural support (including financial resources) for CBANHC (Appendix B).

CBANHC MISSION STATEMENT AND GOALS

The Canadian Brain and Nerve Health Coalition (CBANHC) is committed to improving the quality of life of Canadians with diseases and injuries of the nervous system (brain, spinal cord and nerves)*.

To achieve this mission, CBANHC will work with partner organizations and the Canadian Neurological Sciences Federation:

1. To promote greater awareness of the enormous impact of neurological diseases and injuries in Canada;
2. To work for timely access to cost-effective diagnostic services, comprehensive treatments, and rehabilitation for Canadians with nervous system disease or injury;
3. To build support for the unique needs of Canadians living with the long-term and often progressive physical and mental disabilities caused by nervous system disease or injury;
4. To advocate vigorously for increased resources and funding to expand basic, translational, clinical, and outcomes neuroscience research in Canada.

* Depending on the specific audience, the bracketed phrase could be included or omitted.

SPECIFIC TASKS FOR CBANHC

1. *Re-affirmation of Alliances with Voluntary Health Organizations (VHOs) and Other Partners by:*

- a. Confirming the VHOs and other partners who wish to continue as members of CBANHC and identifying new members as applicable;
- b. Offering different levels of participation (e.g. active, corresponding) to interested VHOs;

2. *Develop a Strategic Plan to ensure the Support and Infrastructure:*

To ensure that the mandate of CBANHC, which was delineated at the Planning Meeting on April 24, 2003 and has been reaffirmed and restated by the current Task Force, is carried out effectively and in a timely manner, CNSF and CBANHC need to have a strategic plan concerning the governance, leadership, and infrastructural support (including financial resources) for the organization.

3. *Follow-up to the Burden ... report by:*

- a. Encouraging and advocating for studies to correct the information gaps identified in the 2007 CIHI/CBANHC Report;
- b. Working with the Canadian Journal of Neurological Sciences on the presentation of regular new reports regarding the burden of neurological diseases, disorders and injuries; off-prints of which could be distributed to appropriate individuals.

4. *Methods to enhance awareness and to advocate:*

During its deliberations, the CBANHC Task Force considered various ways in which to enhance awareness and to promote the advocacy role of CBANHC. Suggestions included:

1. Writing letters to editors in relation to specific events in the news that are relevant to neurological disorders;
2. Preparing opinion articles to be submitted to newspapers for consideration as op-ed pieces;
3. Consultations with public relations professionals;
4. Working with individual VHOs to promote patient-related stories;
5. Recruiting a spokesperson who has a public "persona";
6. Developing working contacts with INMHA (CIHR);
7. Recruiting participants who have access to government decision makers.

STRATEGIC ALLIANCES

Recognizing that the achievement of the CBANHC goals of increasing awareness and advocacy for increased support to address the burden of neurological disorders and injuries will require engaging policy makers at many levels of Canadian society and government, the Task Force encourages CNSF and CBANHC to participate in strategic alliances and coalitions to address specific objectives as they arise. Participation in the up-coming discussions initiated by NeuroScience Canada is recommended as the first of such alliances.

To be most effective, such broader alliances would need to be targeted to specific projects with defined tasks assigned to each participant. Guidelines for such alliances and coalitions are summarized in the *Summary Report and Synopsis of the CBANHC Workshop* held on April 24, 2003 and in the *Final Outcomes Report* prepared by the Public Policy Forum on the basis of the NeuroScience Canada Roundtable Series (August, 2007). These documents emphasize the need to: i) articulate a clear value proposition for all partners; ii) clearly define the benefits and responsibilities of membership in the coalition; and iii) tell a compelling story that can be tailored to each target audience.

Leadership and governance: It is not envisioned that new administrative structures would be required for the proposed strategic alliances. "Leadership" would be defined collectively on a project-by-project basis. Support for these alliances will require applications for funding from governmental and non-governmental agencies.