

## Memorandum

**Date:** February 27<sup>th</sup>, 2009  
**From:** Dan Morin, CNSF CEO  
**To:** CBANHC Steering Committee Members  
**Topic:** **CBANHC Update - Responding to the Changing Landscape in Advocacy**

The CCNS (now the CNSF) created CBANHC in 2003 as a program for advocacy. CBANHC was originally a coalition of the CNSF, Canadian Association of Neuroscience Nurses and VHOs dedicated to different neurological disorders. Under Charles Tator's leadership the most significant accomplishment of CBANHC between 2003 and 2007 was the development, funding and publication, in June, 2007, of the CIHI-CBANHC study, *The Burden of Neurological Diseases, Disorders and Injuries in Canada*. Using data collected by the Canadian Institute for Health Information (CIHI) from health-care institutions across Canada and from the Public Health Agency of Canada (PHAC), this study documented the economic burden (direct and indirect costs) of eleven of the most common neurological conditions and presented estimates of the disability burden inflicted by six of these conditions.

Following the completion of the *Burden Study*, Charles Tator asked to be replaced as Chair of CBANHC and the CNSF Board of Directors created a Task Force to review the status of CBANHC. In December, 2007, the Task Force submitted its report to the Board. The Task Force re-drafted the CBANHC mission statement and goals, and recommended that the CNSF's advocacy objectives be promoted, in part, by entering into alliances with other groups. The Task Force also recommended the development of a strategic plan for the governance, leadership and infrastructure support of CBANHC.

Early in 2008, many of the VHOs (especially CBANHC Steering Committee members) that had been members of CBANHC joined with other VHOs representing specific neurological disease/disorder groups across Canada to form *Neurological Health Charities Canada* (NHCC). The purpose of NHCC is to advocate for neurological diseases, disorders and injuries by serving as one voice to provide a stronger sense of community and influence for positive change. The ultimate goal, similar to that of CBANHC, is to improve the quality of life of those afflicted with a neurological disorder through education, advocacy, research and improved methods of diagnosis, treatment, rehabilitation, and management of disability.

The NHCC has evolved into an effective organization that has obtained financial support from both the Federal and Ontario governments for two important projects concerning the incidence and management of the disabilities caused by chronic neurological conditions.

When Dr. Richard Riopelle succeeded Dr. Tator as Chair of CBANHC in July 2008, efforts were started to carry out the recommendations of the 2007 CBANHC Task Force report. To address the recommendation concerning the building of alliances, the CNSF was accepted as a member of the NHCC. With guidance from the CNSF Executive Committee, Dr. Riopelle, Dr. Garth Bray, a CNSF Vice-President and I drafted the following governance structure and terms of reference that are designed to adapt and make CBANHC more current and relevant.

### **Structure:**

- i) Membership in CBANHC will include:
  - one representative and one alternate from each of the four constituent Societies of the CNSF;

- one representative from each of the Associate Societies of the CNSF – the Canadian Association of Neuroscience Nurses (CANN), the Canadian Associate for Neuroscience (CAN), and the Physical Medicine and Rehabilitation Society (PM&RS);
  - representatives from the Affiliate Societies, as required for specific projects;
  - other organizations or individuals may be recruited to CBANHC on an *ad hoc* basis as required for specific projects
- ii) **Advocacy:** The current advocacy efforts of CBANHC will be channeled through the NHCC where appropriate or through the CNSF, as necessary.
- iii) **Governance:** As the CNSF Advocacy Committee, CBANHC will be directly responsible to the CNSF Board of Directors and will be chaired by a member of one of the four Societies (similar to the CNSF's Professional Development and Scientific Program Committees).

**Terms of Reference:** Although detailed terms of reference still need to be developed, CBANHC will function as follows:

- i) The CBANHC Executive Committee (i.e. the CBANHC Chair, the CNSF CEO, and a CNSF V-P) will be responsible for the day-to-day activities of CBANHC. This Executive will report regularly to the CNSF Executive Committee, the Board of Directors, and the members of CBANHC.
- ii) The CBANHC members will meet at the annual CNSF Congress, as required, and hold at least one teleconference yearly. At these meetings, the CBANHC Executive and members will set directions for advocacy and plan projects designed to achieve the goals of the CNSF advocacy program.
- iii) The CBANHC Executive Committee will represent CBANHC at the NHCC and other external organizations.

The CNSF strongly supports the alliance of the NHCC and the CNSF, which brings together the VHOs and the professional organizations concerned with neurological diseases and disorders. Such an alliance will be in a position to advocate more effectively by presenting one strong message with one voice. The CNSF encourages former CBANHC VHO's, both general and Steering Committee members, to investigate the possibility of joining the NHCC.

The CNSF is proud of the accomplishments of CBANHC over the last 5+ years and greatly appreciates the efforts of our partners in the original coalition; partners whose collective efforts ensured the successful publication of the CBANHC report. The report served as the catalyst for many of the activities currently underway by other organizations, particularly the NHCC.

Please feel free to contact me if you have any questions or comments.

Yours truly,

Dan Morin, CEO  
Canadian Neurological Sciences Federation

Cc: Richard Riopelle, Chair, CBANHC, Garth Bray, CNSF VP  
Executive Committee, CNSF