

Summary – CCSVI Working Group Meeting, September 20, 2010

The CCSVI Working Group held its first meeting on September 20 after being established by the MS Society of Canada National Board of Directors in July. Participants included:

Linda Lumsden, Chair
Shelley Black
Anthony Feinstein
Marilyn Lenzen
Samuel Ludwin
Lindsay Machan

Linda Molyneux
T.J. (Jock) Murray
James Orr
Julian Spears
Brock Winterton
Yves Savoie (ex officio)

Regrets: Diana Gordon

Staff resource: Deanna Groetzinger
Facilitator: Suzanne Lawson

The group devoted time initially to determine how they would work together. It was noted the group is an advisory group to the National Board of Directors. It was agreed the group will plan to meet by teleconference at least twice before the meeting of the board in mid November 2010.

Emphasis was placed on group members being direct and truthful as well as being respectful to each other. It was agreed to honour the privacy of group members and agreed reports to the public about working group meetings will reflect the group's discussion and the varying points of view, but that individual members will not be named.

The group worked together to create a timeline of information to establish shared knowledge related to CCSVI and MS. This process allowed the group to pinpoint crucial events.

Following this exercise, the working group identified key issues for its upcoming work. Issues to be addressed will include topics such as:

1. What is needed to move forward with pan-Canadian therapeutic clinical trials of chronic cerebrospinal venous insufficiency (CCSVI) and MS? If published studies of CCSVI in relation to MS become available in the near future, how can they help speed the development of pan-Canadian therapeutic clinical trials?
2. Should a patient registry be established in Canada to follow those who have angioplasty for CCSVI elsewhere?
3. Why can't people with MS have compassionate access to angioplasty for CCSVI when other conditions are treated and paid for by the healthcare system?

4. What is role of MSSC in providing information about CCSVI, e.g., where to go for treatment, how to navigate the system, information about medical tax deductions?
5. What is true level of risk associated with CCSVI treatment?

The group also reviewed the terms of reference and agreed the national board would be asked to approve several amendments:

- **Norms, point 4** – Communicating to the national board: add that the chair will explicitly tell the national board what the other views are if there is absence of consensus on an issue;
- **Norms, point 5** – Communicating to MS Society or the public: adapt to state that members of the working group can speak as private individuals about participating in the working group or the work of the group but cannot speak on behalf of the working group.
- **Objectives, point 1** – Adapt to add that the group, as well as monitoring evolving peer-reviewed, scientific evidence, will also monitor other levels of evidence and information.