

SPECIAL INTEREST GROUP SPINA BIFIDA AND HYDROCEPHALUS PANEL



The “World Federation of Neuro-rehabilitation” (WFNR), has approved on the 8th of October 2010, the formation, of the Special Interest Group: Spina Bifida and Hydrocephalus Panel (SIG - SBHP).

The SIG was proposed, earlier this year, by Dr. Mario Patricolo, Chair of the Spina Bifida and Hydrocephalus Panel – Gulf Area (SBHPGA). The SBHPGA, apart from its highly beneficial role in the Arabic Gulf, has also served the role of basis and example, for setting up of the SIG – SBHP.

After revision by the *SIG Task Force* and by the WFNR Management Committee, the SIG-SBHP has been added to the previously existing ones, and listed on the Federation Website (www.wfnr.co.uk).

Special Interest Groups, (SIGs), are formal groups, approved by the WFNR Board, whose Members have unique interest in a particular diagnostic group or a focused area of practice. SIGs are self directed and have an agenda of work or involvement that sustains the group, throughout the year.

All SIG Members must be in accordance with the WFNR and SIG Membership Criteria.

BACKGROUND:

Spina bifida (SB) and hydrocephalus (HCP) are complex conditions with devastating consequences for patients, relatives and society. Healthcare facilities and family and social costs require a high level of organizational and financial commitment from the healthcare systems. The incidence of spina bifida varies in different countries and is, on average, 1:1500 live births. Urinary and faecal incontinence, constipation and soiling, life-long neurosurgical management, complex orthopaedic abnormalities, rehabilitation issues and neuro-developmental delay, are associated with SB and HCP. Moreover, sexuality, mobility and psychological issues, influence the quality of life (QoL), for older patients. In the last 40 years, as a consequence of the improvement in ante-natal diagnosis and of the increased number of spontaneous interruption of pregnancy, (S.I.P), the number of cases with Spina Bifida, referred to the specialized teams, has reduced dramatically. Nevertheless, many Centres, worldwide have developed multidisciplinary Incontinence - Spina Bifida Clinics. Unfortunately, these clinics are isolated efforts supported, in most cases by few Physicians, Surgeons and Clinician, with a particular passion and dedication to the improvement of the outcome of such patients. Furthermore, lack of consensus on structured and standardized guidelines for the management these patients make the delivery of adequate and equitable service almost impossible. There is a clear need for agreement amongst all concerned on guidelines, policies and terminology, incorporating all aspects of SB and HCP management. Once agreed, these guidelines, etc. should be implemented globally, both in the hospitals and in the community settings.

MISSION STATEMENT:

The Special Interest Group - Spina Bifida and Hydrocephalus Panel aims at improving the quality of life of all patients affected by spina bifida, other neural tube defects (NTDs), hydrocephalus or its complication. This effort will result in the publication of guidelines, policies, integrated care pathways (ICPs), identification of resources, facilities and specialized centres worldwide. Given the global nature of the SIG, a particular effort will be made to work carefully in a culturally adjusted fashion, to reduce the risk of unequal support, in different geographical areas.

GOALS OF THE SBHP:

- 1) Create guidelines and policies
- 2) Create and implement a framework.
- 3) Publish articles on the WFNR Newsletter.
- 4) Achieve excellence of care for SB and HCP worldwide.
- 5) Engage in relevant research on SB and HCP.
- 6) Organize an annual meeting of the SIG, and other *ad hoc* meetings.
- 7) Standardize terminology
- 8) Produce documentation for families and patients.
- 9) Organize Educational Courses under the patronage of WFNR.
- 10) Develop standardized special clinics, services, divisions.
- 11) Actively participate to national/international scientific events on the subject.
- 12) Obtain best QoL for all patients.
- 13) Guarantee availability of modern and up-to-date continence aids, products and other necessary medical devices.
- 14) Follow WFNR policies and procedures.
- 15) Meet at each WFNR World Congress.
- 16) Organize ad interim additional meetings for SIG's Members.

GOVERNANCE STRUCTURE:

Chair (Executive Director): Dr. M. Patricolo (Paediatric Surgeon & Urologist UAE)

Chair Elect: Mr. M.R. Cervellione (Paediatric Urologist - UK)

Executive Secretary: Dr. S.A. Wasti (Neurorehabilitation and Physical Medicine)

Nursing Coordinator: J. Fishwick (Sr. Specialized Nurse)

Past Chair: N/A

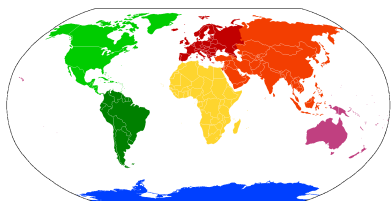
In collaboration with the Management Committee, separate dues may be assessed to SIG Members to defray the cost of activities undertaken. The International WFNR office will provide a combined dues collection process, ensuring that funds earmarked for the SIG, are accounted appropriately. WFNR will support the work of the SIG by assisting with Member mailings and other administrative functions.

RESPONSIBILITIES, ROLE & DUTIES OF THE SBHP CHAIR:

- Evaluate, discuss and authorize/reject all the activities of the International Teams and of the Governance Structure Members.
- Develop “Mission” and “Goals.”
- Devise an action plan.
- Make assignments.
- Prepare and agenda for the SIG meetings and mail copies to the Executive Director.
- Plan SIG projects and timelines.
- Conduct SIG meetings at the WFNR World Congress (with minutes).
- Document Members attendance to the meeting; send minutes, project timelines and assignments to SIG Members and National Office.
- Submit SIG action plan to the Executive Director.
- Discuss with the President any project requests that may require funding or staff support.
- Schedule and conduct additional SIG meetings, as approved.
- Communicate with SIG Members at least twice a year, via email.
- Communicate with SIG Members who have accepted assignments by email or conference calls.
- Copy the President and the Executive Director on correspondence.
- Submit a year-end report to the Management Committee with an executive summary for distribution when there is a World Congress and subsequent publication in the WFNR Newsletter.

In all the above mentioned responsibility the Chair will receive active support and advice from the Chair Elected, the the Past Chair and the Team Leader of each Continent.

TEAM LEADERS:



MIDDLE EAST AND ASIA: Dr. Sabahat Asim Wasti
Consultant Neurorehabilitation & Physical Medicine
SKMC, Abu Dhabi, UAE.

AFRICA: Prof. S. Shehata (Head of Paediatric Surgery, Alexandria, Egypt).

AMERICAS': TBD

ANTARTICA: TBD

EUROPE: Mr. A.P. Dickson - Clinical Director Consultant Paediatric Urologist
RMCH, Manchester, UK.

OCEANIA: TBD

The Chair of the SIG – SBHP will forward quarterly report, regarding the progress of the SIG works, to the WFNR President, to the WFNR Executive Director and to all the Team Leaders and Members of the Panel. First report due in March 2011.

The next WFNR World Congress will be held in Melbourne, Australia, from the 16th to the 19th of May, 2012 - <http://www.dconferences.com.au/wcnr2012/pdf/flyer.pdf> .
In that occasion we will organize the 1st Reunion of the SIG – SBHP.

November 9, 2010

Mario Patricolo MD
Paediatric Surgeon and Paediatric Urologist