

Meeting Notes ERN Working Group Spina Bifida ITHACA | eUROGEN

ITHACA Board Meeting Satellite Meeting WG10 Spina Bifida
Online Meeting 11 December 2020 11.00 – 12.40h

Chair: Andrea Manunta, ITHACA (FR)

Core Working Group: Giovanni Mosiello, Co-Chair, eUROGEN (IT), Dr. Sylvia Roozen, IF Secretary General (NL), Ammi Andersson, ITHACA Patient Council, IF ePAG patient representative (SE), Alain Verloes, ITHACA Coordinator (FR), Anne Hugon, ITHACA Project Manager & Coordination Officer (FR)

Total participants = 27 persons - 14 persons register from the list of WG

Members: Ferdinand Dhombres, Timothee de Saint-Denis, Acuxart, Agnese Feresin, Anna Groma, Aurore Bouty, Benoit Fourcroy, Beth Padden, Claudia Rendeli, Ingrid Olsson, Jean-Marie Jouannic, Katab2, LM, Marek Turnovec, Michal Maternik, Michelle Battye, Alexander von Gontard, Nerea, Pablo Garcia Manau, Dan Wood, Gilvydas, Alice Faure, Ugne Mikalauskaite

AGENDA

Time Slot (Virtual Zoom Rooms)	W10 : Spina Bifida Chair : Andrea Manunta /Giovanni Mosiello	SPEAKER PM contact : Anne Hugon
11h00	Welcome to new members, Structure of the group : An Inter - ERN WG Patient perspective on the assessment framework	Sylvia Roozen, Andrea Manunta, Giovanni Mosiello, Ammi Sundqvist-Andersson
11h15	Update on dysraphisms classification and Orphacodes revision	Ferdinand Dhombres
11h35	Guidelines redaction on urological management of SB, methodology	Andrea Manunta, Benoit Peyronnet
11h40	Transition Guidelines	Dan Wood
11h55	Pediatric Guidelines	Giovanni Mosiello, K. Abrahamsson
12h10	Adult Guidelines	Andrea Manunta, Benoit Peyronnet
12h20	Discussion on guidelines	All attendees
12h30	SBWG research workshop within the EJP RD call - ERN RD Training and Support Program	Giovanni Mosiello
12h35	Participation to Cross ERN surgical-based working group, contact with BOND ERN	Andrea Manunta
12h40	Agenda 2021	All attendees

MEETING NOTES

1. Opening

Dr. Andrea Manunta opens the meeting. Also a word of welcome was shared by the new Secretary General of the International Federation for Spina Bifida and Hydrocephalus, Dr. Sylvia Roozen.

2. Patient Perspective on the Assessment Framework by Ammi Sundqvist-Andersson

The assessment framework was presented including measures for three goals to strengthen patient representatives and clinicians

3. Presentation by Dr. Ferdinand Dhombres and Dr. Timothee de Saint-Denis

Presented is a new way to describe dysraphism cases; you can use combination of findings (spinal cord, bone) and by combining them to make diagnosis. There is a need to have a more improved tool to describe cases. Current Orphanet codes require revision to also for an improved clinical use. Proposed is to cover all entities by a new model through a logical coding principle. This approach needs to be validated (100 dysraphism cases) and an Orphanet revision proposal will be made to cover all entities. Colleagues from different expertise in the field of human dysraphism are invited to join this expert group with the interest to further assist in this process.

Follow-up Action: A road map will be drafted to present to a wider panel of experts.

4. Presentation Dr. Andrea Manunta

Presented the need for guidelines on urological management of patients with Spina Bifida. Existing guidelines are not developed from a scientific point of view. Therefore there is a need to systematically develop evidence-based guidelines with a panel of experts.

- Roadmap and organizational structure are presented including steps and a timeline [see Annex].
- The working groups need to be established and steps forward need to be defined depending on the content/scope of the guideline (pediatrics, transition, adult). The due date of finalized text is June 2021.
- Publication peer reviewed journal. For each section and recommendations there is a max. of 5000 words

5. Presentation Dr. Dan Wood

Guidelines on urological transition. Without a clear transition plan there is severe risks for negative patient outcomes. Therefore is a need to establish guidelines on transition. We need to prepare cases well before going through transition. It is not a simple move from one professional to another, but a responsibility for healthcare center to ensure smooth transition care moving forward.

Some challenges and concerns: transition as a general guideline to overcome duplication with the pediatric and adult guideline; there is a lack of literature specifically on transition. Therefore based on the best possible evidence the guideline should be formalized; different healthcare environments exist and require tailored approached. Moreover, there is a need on a transition framework which works not only for urology but also other topics

6. Presentation Dr. Giovanni Mosiello

Existing guidelines (e.g., ICA, Italy, France, UK, Sweden) often do not focus specially on children. There is a need to develop new guidelines. Goal is to develop a new guideline for Europe including the participation of patients and their families.

The team consist of: Advisory board (members of the ERN-ITHACA Working Group) + ERKNET, ESPU, ICI, ICCS, ICS + patient representatives

7. Discussion on Guidelines

attendees are invited to join one of the 3 working groups

8. Presentation by Dr. Giovanni Mosiello

- A two-day workshop is given with the opportunity to train researcher and clinicians from different expertise on the topic of spina bifida management.
- The venue and date of this meeting is not yet defined. More details will be communicated with the members in the near future.

9. General comments

Dr. Ingrid Olsson shared it is good to learn from the scientific work on transition process in other related fields. Also, for the three groups it would be good to include multiple expertise and include someone who can also coordinate with the different groups to oversee the process and serve as a linking pin (e.g., neuropsychiatrician).

10. Closing remarks by Dr. Andrea Manunta

A follow-up email will be send to all members including the further details on the steps as well as the cross-ERN working group.

Organizational Structure WG10



Timeline 2021

