ERN Support and Training programme- WP17- EJP RD

Report on "Trans-ERN Working Group for Spina Bifida (Spinal Dysraphism): Workshop for future research on innovative diagnostics and interdisciplinary treatment"

Date/Venue/Format

Dates: March 31 and April 1sr 2022

Venue: Centre de Référence Spina Bifida – Dysraphismes C-MAVEM

Centre Hospitalier Universitaire Pontchaillou

Rennes (FRANCE)

Format : Face to face meeting

Numbers (participants, speakers, ERNs represented, patient representatives)

22 speakers (two of whom connected on line):

Giovanni MOSIELLO

Leonardo CAFORIO

Giacomo ESPOSITO

Isabella FABIETTI

Sylvia ROOZEN

Wout FEITZ

Valeria CAPRA

Giovanni MONTINI

Michal MATERNIK

Jean Marie JOUANNIC

Alain VERLOES

Ferdinand DHOMBRES

Elena CARRERAS

Jacques KERDRAON

Emmanuelle SAMSON

Andréa MANUNTA

Sylvie ODENT

Marie FAOUCHER

Valérie DUPE

Benoit PEYRONNET

Charlene BROCHARD

Luc JOYEUX

33 participants mainly from ITHACA and eUROGEN but including also members of EpiCARE, ERNICA, ERN TransplantChild, ERN PaedCan and ERKNet

Analysis of the workshop satisfaction survey

After the workshop a satisfaction survey was mailed to all participants and was filed in by 26 of them. The overall response was very positive and is outlined in the pie charts.

23 out of 26 respondents (88.4%) rated the overall quality of the workshop as excellent or very good and 2 as good. The workshop was found to be "very useful for future research and professional activity" by 19 respondents, "useful" by 6 and "not at all useful" by one, the training contents were found appropriate in 24 out of 26 cases.

A few suggestions and free comments were added to the survey:

- The first day was a plenary sessions and some participants would have preferred the possibility of "breakaway sessions" for different disciplines
- 2 respondents found the program overloaded and would have preferred a more focused approach on two or three main topics

- One respondent found that important aspects of spinal dysraphism (notably orthopaedics) had been overlooked
- A few comments have been made about the absence of direct flight connections to the workshop venue

2-3 participants' testimonials

"Thank you very much to the organizing team for the interesting and propositive meeting we had. I think this kind of workshop is the correct way to interact with other disciplines and catch different points of view"

" Thanks for the invitation and two innovating days. Looking forward for valuable research in this field"

"It was a great experience. All was amazing and sharing ideas and projects is the key of the future. Looking forward for work together asap"

If applicable a main result of the workshop

The workshop has been the occasion to bring together experts from a very wide range of disciplines who, although all involved in the field of spinal dysraphism, have rarely the occasion to confront and compare their expertise. Geneticians involved in the study of polygenic inheritance mechanism of spinal dysraphism need a precise identification of the different patients phenotypes yet, up to now they rarely interacted with fetal medicine experts and neurosurgeons who are able to more precisely define these phenotypes.

The uncertainties concerning efficacy and safety of medical and surgical treatment of spinal dysraphism from preconceptional to adult life have been stressed.

A special focus has been put on the current advances and the need for future research in different fields such as fetal surgery, neurosurgery, medical and surgical management and non-invasive follow up using innovative techniques such as urinary biomarkers and radiomics

Conclusions, lessons learned, best practice to keep in mind.

The need to completely revise the classification of Spinal Dysraphism has been stressed particularly by our fetal medicine and fetal surgery experts. A Working Group has been constituted on the initiative of our colleagues from Trousseau Hospital In Paris and Vall d'Hebron Hospital in Barcelona who have already been working on this project. The next step will be a validation of a new classification by a panel of 10-15 experts of the field.