Minutes
Fetal Therapy Special Interest Group
Lisbon, Portugal
5 June 2013, 8:30 am

1. Proposals and discussion on theme for preconference course 2014, Brisbane

The members agree that focusing on a particular fetal disease and its prenatal treatment options is preferred, with invited experts to give interactive lectures. When possible the preconference course should take advantage of expertise present in the region or country where the meeting is held.

After considering several options, the group decided that for the 2014 meeting, the preconference course will be focusing on Congenital Diaphragmatic Hernia (CDH).

We expect that in July 2014, preliminary results will be available of the two TOTAL trials. Local expertise is available including the neonatal pulmonary pathology research group from Melbourne. Animal models and simulators can be used to offer a workshop on fetal tracheal balloon insertion and removal. Genetics of CDH is a rapidly advancing field that will be included. In addition, the long term follow-up of surviving children will be addressed.

2. Following discussion after the presentation this year of the largest RCT in the field of fetal therapy, the Solomon trial, several members stressed the need for more discussion on the management of monochorionic twins with twin anemia polycythemia sequence (TAPS). The group will propose including TAPS as a topic for lectures and or debate in the plenary sessions of next year’s meeting, the chairmen will pass this on to Dr Jon Hyatt and the ISPD board.

TAPS was further discussed, and a proposal by Dr Enrico Loriore from Leiden, The Netherlands was unanimously supported to look into the option of setting up an international web-based TAPS registry, similar to the successful fetal cardiac intervention registry (www.ifcir.org) originating from the Fetal Therapy SIG meeting at the ISPD 2010. Enrico Lopriore, Piotr Wegrzyn and Venu Jain volunteered to take first steps.

Apart from a database to enter cases, management and outcomes, the website should enable online communication, e.g. a discussion forum where colleagues can be consulted about complex cases. ISPD president Jan van Lith suggested expanding this idea of international collaboration through web-based databases, asking us to advise the ISPD board on solutions for use of such online tools across countries. There is an urgent need to develop and improve the essential basic elements of these new web-based tool in our field, such as unity of language and definitions of variables to be entered in databases.

The fetal therapy SIG feels that it should take responsibility for promoting and maintaining the safety of invasive procedures in obstetrics in general, also given the recent disappearance of the invasive procedures SIG. The rapid rise of non-invasive DNA testing in pregnancy
already leads to significant reductions in numbers of procedures performed. This will soon affect the safety of the procedures, and calls for action stressing the importance of centralisation as the only means to ensure sufficient numbers of procedures per operator. These developments will also affect training and teaching opportunities, and on quality control options, and in time it may also result in a generation of fetal therapy specialists who have far less experience with amniocentesis and CVS than the current group of experts, who all feel that this background has aided in enabling them to perform more complex interventions.

Devlieger and Oepkes propose to write a draft Position Statement on this topic, to be circulated among the members present at this SIG meeting, and submitting the final version to Alessandro Ghidini, the ISPD board member and Prenatal Diagnosis co-editor responsible for ISPD Position Statements.

To other controversial and unresolved clinical problems in monochorionic twin pregnancies are discussed: TRAP sequence and selective IUGR. The option to include these complications and their management in the TAPS registry was thought to make such an enterprise too complex. In the event of a highly successful TAPS registry, perhaps in the future we could add TRAP to this database if the users so desire. Selective IUGR is actually a quite common disease, occurring at least as often as TTTS. Other forms of research are needed here, to start with international consensus on the definitions and how to exactly measure the relevant signs associated with severity and outcome. An initiative taken last year at the fetal therapy SIG preconference course on MC twins in Miami to write a Opinion piece on this topic with a group of internationally recognised experts was recently reinforced again at the IFMSS meeting in Jerusalem, and this paper will soon be submitted to Prenatal Diagnosis.

The group feels that this should be another topic to be addressed preferably in a plenary session in next year’s meeting, and will suggest this to the organisers.

Roland Devlieger
Dick Oepkes

ISPD Fetal Therapy SIG chairs