

Minutes of the ECHDO-Corience Meeting Barcelona, June 20, 2009

1. Reports on ECHDO and Corience, achievements and perspectives

After a cordial welcome of Maria* and short introduction Hermine* gives a brief overview of the formation and development of ECHDO and Corience. The final goal is advocating together.

She is delighted by the fact that 65 representatives from 22 countries are participating in the meeting. The still missing few countries are planned to be approached and invited to join ECHDO.

After that, Wiebke* summarises recent developments and the current state of affairs. As the two main goals she mentions the creation of an information website and networking within the CHD community.

In this context she points to the comment function and emphasises that the input of those concerned is needed for this tool.

Getting back to the suggestions gathered during the last workshop in Berlin (November 2008), she reports on the following new developments on the website:

- Meanwhile, about 16 heart defect descriptions with illustrations can be found on corience.org
- the glossary has been enlarged
- there are various new topics including check lists, interviews, personal stories etc.
- concerning the comment function, there have been only comments in English so far; however, everybody can feel free to use their mother tongue. Wiebke asks everybody to use this function actively.

Besides these new developments, Wiebke announces the following upcoming elements/topics:

- A treatment section
- Adolescent medicine
- A teenager section
- Transition
- Articles on drugs etc.

All these new elements will be part of a new website structure that will represent a target group oriented approach.

Further plans foresee more language versions. Accordingly, the Spanish version will be launched in August/September 2009. The German version will follow in October 2009, and in 2010, the Polish version can be expected. Wiebke points to the problem that at the moment no funding for further language versions is available. Therefore she asks everybody to tell the Corience team their ideas.

Subsequently, Wiebke gives an overview of the latest user statistics, acquired with an new analytic software. With 1,400 visits from 67 countries (including also those beyond Europe) in the past month, the numbers are at the moment still somewhat disappointing. It is noteworthy that the second most clicks come from the USA. The detailed statistics can be inspected at Wiebke upon request.

As the Corience budget does not include funds for advertising, Wiebke asks for the help and support of everybody. In this context she points to an information package including newsletters, flyers, banners etc. that is accessible via the internet. For the flyers, there is also the option to add supplements in local languages. The material can be found on www.corience.org/extranet.

Following a suggestion from the audience, Wiebke asks all organisations to send their own material to her so that it might be used for the website. By this, double work could possibly be avoided. However, the information on the website is reviewed doubly to assure its high quality.

Getting back to the omnipresent language and translation problem, Wiebke reports that translations of the homepage only are already in progress.

In addition to that the participants decide to provide translations of the newsletters. Everybody interested in translating is asked to approach Wiebke and give her their contact details.

Besides, this option will also be published on the website.

Wiebke states that everybody is free to look for funding options for professional translation of the website.

Finally, as a best practice example, the Norwegian magazine *Hjertebarner* is presented, which contains specially marked Corience pages including translated articles from the website.

2. New participants

Since the last ECHDO-Corience meeting, several new participants have joined. They are briefly introduced to the audience:

- **Italy:** the newly founded organisation *AICCA* is presented by Edward Callus and Milly Quadri from Milano who state that, although a GUCH organisation, they are open for all age groups.
- **Italy, South Tyrol:** with 3 years' existence, the organisation *Kinderherz* is relatively young and is presented by Maria Pawlus; it cooperates with Munich and Padua, which are the two available centres in this region.
- **Czech Republic:** the parent organisation *Srdickari* is represented by Michaela Bosakova; in their region, there is only one centre available
- **Denmark:** the umbrella organisation for children and parents has been in existence for 30 years now and is presented by Helle Meinhardt and Fleming Selmer Nielsen.
- **France:** Marie-Paule Masseron presents the French organisation *Association nationale des cardiaques congénitaux (ANCC)*, which is 46 years old and includes 415 families.
- **Switzerland:** Sandra Rosati presents the Swiss organisation *Elternvereinigung für das herzkrankte Kind (EVHK)*, which is by now 20 years old and includes approximately 700 members.
- **Catalonia:** the organisation *Associació d'Ajuda als Afectats de Cardiopaties Infantils de Catalunya (AACIC)*, which was originally founded by seven professional persons is presented by Ainara Garcia and has been in existence since 1944.
- **Lithuania:** the parents' association, which is represented by Daiva Jonauskine, was founded about six to seven months ago and by now includes 20 family members; the website can be found on www.mazojisirdede.lt. A first summer camp exchange is planned together with Norway; please contact kostas@mazojisirdede.lt if interested in such exchange programmes.

- **Poland:** the newly founded GUCH organisation has been in existence since 2007 and is represented by Aleksandra Lignar.

3. Reports on previous day's workshops

Thomas* reports on the Corience workshop the day before. He presents and comments on the ideas that were collected by the participants:

Idea	Comment
patient forum on www.corience.org	Patient forums are more suitable for websites from local organisations
language problem	The Corience team is aware of that and is currently trying to find appropriate solutions
hospital statistics on www.corience.org	A corresponding system is currently being discussed in Germany; there is the difficulty of interpreting such statistics appropriately. A link to the UK system, which is the only quality assessment system currently existing, will be provided on the Corience website.
Lack of visibility	Information material, as well as banners for websites can be downloaded from www.corience.org/extranet .
Lacking visibility of organisations	The Corience team is already working on this problem.

Subsequently he gives an overview of the other issues discussed on the previous day. For campaigning, the idea of approaching Members of Parliament who work in the *Committee on the Environment, Public Health and Food Safety* was discussed. Apart from that, the German patient pass project was introduced. Comparable approaches currently exist in Italy, Poland and the UK. Members of these organisations are to form a contact group to exchange experiences. Furthermore, the summer camp exchange programmes were discussed and ideas were collected. Feedback from different countries is to be sent to Montse. A checklist for the establishment of a summer camp is available.

Thomas then briefly describes the discussion on country specific problems and states that there are hardly any country specific issues, but many common problems, such as a poor visibility of congenital heart disease. He also mentions the plan to document journeys of patients to receive surgical treatment in other countries to present the results in Brussels. Like campaigning, this might help to initiate the implementation of funding programmes for congenital heart disease in Europe, which are so strongly needed.

After that Hermine briefly reports on the results of previous day's ECHDO workshop. She states that working groups were established to raise extra money and to work out bylaws. Besides, the statutes could be finalised.

4. Lecture by John Hess

The ensuing lecture presented by John Hess deals with heart valve implantation and the Melody valve in particular (see attached presentation).

5. Lecture by Ines Hartwig-Zaidan

Ines Hartwig-Zaidan introduces the concept of selfmanagement for anticoagulation (see attached presentation). The discussion following the presentation reveals that the respective device is covered by insurances only in Germany, Luxembourg and Denmark. Besides, there is the problem of lacking medication dosages for children. Thomas points out that this is also a matter of particular interest for ECHDO.

Asked about the difference between Warfarin and Heparin, Ines Hartwig-Zaidan explains that Heparin has to be given subcutaneously and that it takes immediate effect. Besides, it is considered to cause osteoporosis (see attached presentation).

6. Concluding remarks

Thomas thanks everybody present for the two successful days and the active participation and commitment.

He is sorry to point out that within the scope of the current FP7 Research-Programme, an elongation of Corience beyond the initially granted two years will be difficult to obtain; accordingly the project is funded until February 2010. Currently, the Corience team is looking for other funding options. The team will certainly approach the EU - Executive Agency for Health and Consumers, where proposals can be submitted in May 2010.

Thomas reminds that without funding meetings like the one just held will not be possible, unless the participating organisations accept the costs from their own budget.

However, he hopes that the community will stay together and keep on pursuing their common tasks. He strongly wishes for the good cooperation to continue irrespective of there being any funding.

- * Maria Escudero: Menudos Corazones, Spain
- * Hermine Nock: Bundesverband Herzranke Kinder, Germany
- * Thomas Pickardt: Competence network CHD, Germany
- * Wiebke Lesch: Editor-in-chief of the Corience website, Germany