

## Brief minutes of the Corience workshop in Barcelona on June 19, 2009

### 1. Corience – what’s good, what’s missing?

Katharina\* presents the website and reports on the development of Corience. She states that, at the time being, the section *Living with a heart defect* is the largest one and that there are still more topics to come. In this context she describes the writing and review procedure which assures easy to understand articles (written by journalists) of a high quality (review by experts).

After that the plan of a new structure of the Corience website is introduced. By a target group oriented approach all different groups concerned, that is teenagers, adults and parents, are to be addressed appropriately in their respective voice and tonality. The new structure is planned to be available in late summer (2009), simultaneously with the launch of the new language versions in Spanish and German, which are currently being prepared. A Polish version is also planned. Concerning professionals, there will be no extra section, as the idea is that these will be able to decide which section they will refer to when caring for and counselling patients. Besides, the *Research* section containing a database with current clinical studies on CHD, which is linked to [clinicaltrials.gov](http://clinicaltrials.gov) (worldwide search), can be used as a tool by experts as well.

Katharina explains that the section *Diagnosis and Treatment* is still under construction, as it is being reviewed by relevant experts.

Katharina points to the comment function which was introduced on Corience some time ago to initiate discussion across Europe and to encourage an exchange of different ideas and views. She requests everybody to use it and asks for reasons for the scarce use up to now. Possible reasons given by the audience are a lack of time and the language barrier. Katharina points out that comments can be given in the respective mother tongue. Besides those present criticise the poor visibility of the comment function. Furthermore, they ask to point out that the comments are reviewed before publication.

Another issue of the Corience project is the language and copyright problem. Katharina explains that handling such a website includes a lot of project management, which costs a lot of time and money. Therefore translation alone would not be sufficient. On the other hand the need of more language versions, especially for Eastern Europe, is clearly visible and understandable. The Corience Core Group will discuss this issue and try to find suitable solutions soon.

Apart from that, everybody is welcome to put a link to Corience on their websites, if they want.

As another problem, the audience mentions the lacking visibility of local support organisations on the website. These should be found more easily.

In an interactive workshop those present are collecting ideas and their expectations with regard to Corience.

These are the results of the discussion:

#### Group 1:

idea	comments/discussion
a “patient zone” to find similar people	
leave bereavement to local organisations	

A Facebook page with links to groups etc.	this is currently being discussed within the Editorial Team, as they, too, consider this a good idea
Discussion forum	see below (Group 2)
Flyers/posters to countries with internet problems/poor internet access	this is already being done; flyers are presently distributed in different hospitals
Include all conditions (structural and physiological)	
change “local support groups” to “national support groups” for better understanding	

## Group 2:

Idea	Comment
Forum (discussion board)	
More intuitive website navigation/make things more visible	this request will hopefully be fulfilled by the new target group oriented approach
Russian language version	
Hospital statistics on the website	As a comparison is very difficult and has to be done by experts knowing how to deal with the statistics, this is not possible at the moment, particularly with respect to Corience’s task of remaining utterly neutral and evidence based. However, a link to the UK system (the only one existing to date) will be provided on Corience. The issue will be addressed in coming Core Group meetings.
availability of the information on the website to everyone, e. g. Poland	A Polish version is already planned.
More personal stories from GUCHs and adults	
Flyers/stickers for distribution in local languages	Currently, the Corience brochures are being distributed in clinics; they contain special supplements in the respective national language.

## 2. Campaigning

Thomas\* presents the idea of approaching the national Members of Parliament (MEP) to inform them about Corience’s concern. He explains that in the EU Research Programme there are no calls for projects on congenital heart disease because the community is not very strong. Therefore, no funding is available. As to the AEPC, this organisation has no predominant voice in the cardiologists’ section. To improve the current situation, lobbying by the patient organisations is needed.

Thomas presents a template letter prepared by the Corience team that can be translated and sent to the respective MEP that are working in the *Committee on the Environment, Public Health and Food Safety*.

These can be found for all European countries and in all languages via the website of the European Parliament:

<http://www.europarl.europa.eu/>

Paul\* suggests adding some real story to the letter to increase its effect and to invite the MEP to events related to Corience or the patient organisations' work.

### 3. Patient pass

Thomas presents the project of a patient pass that is currently being prepared by the German National Registry for Congenital Heart Defects. He emphasises that the prerequisite for such a patient pass is a central organisational structure with an established data privacy concept. An informed consent signed by the patients is required, in which they agree to the storage of their medical data and to releasing their attending physician from confidentiality.

To promote and improve the project, an exchange of ideas is planned between the countries that already have such a patient pass, ie Germany (see attached document) Italy and the UK.

### 4. Exchange programmes

Montse\* presents the current results from the summer camp workshop that took place within the scope of the ECHDO-Corience Meeting in November 2008. The programme will start in 2010 with teenagers, who are considered a good group to start with. The first experience will be the Nordic summer camp, where teenagers from Lithuania will participate. In turn, a Lithuanian summer camp including teenagers from abroad is planned. The next step will then be to gather information from all summer camps provided for teenagers with congenital heart disease across Europe. In this connection, further exchange opportunities shall be installed. Montse asks everybody to send brief information about summer camps in their respective country in English to [montsemireles@menudoscorazon.es](mailto:montsemireles@menudoscorazon.es) and to let her know if they are interested in the establishment of an exchange programme.

This is the feedback from those present regarding the planned summer camp exchange programmes:

- go with a nurse or a doctor
- connect funds
- look for funding opportunities
- develop template
- create programme-specific website

### 5. Problems – country specific?

In the following discussion those present find out that there are many common issues in the different countries, but only few country specific problems.

The common issues include:

- low visibility and awareness of congenital heart disease and everything it entails
- low visibility of legal rights and help patients are granted

Thomas will distribute a questionnaire per e-mail in order to be able to compile a qualified report on the current situation.

Coming back to the country specific issues, the following aspects are discussed:

- In **Romania** there is no specialised centre for the treatment of congenital heart defects; in general, the health system is not very good and the treating physicians are not

connected to the European network. This leads to relatively little trust in physicians and available facilities.

- In **Cyprus** children needing surgery for congenital heart disease are sent abroad for treatment, as there is no facility available in the country, which, with 700,000 inhabitants, is very small. The respective infrastructure is therefore not available.

Thomas states that the mentioned problems are mainly a problem of East and West. He proposes compiling statistics on how many children are transferred to which places for surgical treatment. Such an evidence based outcome could be presented to the funding bodies in Brussels.

- \* Montse Mireles: Menudos Corazones, Spain
- \* Thomas Pickardt: Competence network CHD, Germany
- \* Katharina Specht: Editor of the Corience website, Germany
- \* Paul Willgoss: GUCH, UK