

Euro Heart Survey – Pregnancy in patients with structural heart disease

Patient enrolment starts 01 December 2007

This email is to draw your attention to this very important survey which is just about to begin. We hope you will be able to participate.

The survey is designed to assess the management and outcome of pregnancy in patients with structural heart disease (mainly congenital heart disease, valvular heart disease and cardiomyopathy). There is a lack of data in this area and a very large registry will provide information about current practice, the complications that occur and possibly the reasons why these complications occur. We hope it will produce information that will improve the survival of women with heart disease having babies and will help the survival of their babies.

The survey has been developed and the case record form designed by a collaboration of the Congenital Heart Disease and Valve Disease working Groups. This is an international survey and therefore anybody in the world who deals with this type of patient can enrol their centre as a participating centre. The centre does not have to be in Europe. The patients will be included prospectively but in addition to this any mothers giving birth after 01 December 2006 can have their data entered retrospectively. Data will be analysed overall and also by country and by world region

What we would like you to do:

- a) **If you deal with this type of patient please visit the website:**
www.euroheartsurvey.org and you can then log on to the site by using the following:

log in: pregnancy
password: pregnancy

This will give you access to the Euro Heart Survey website and allow you to visit the section relating to the Pregnancy Database. This will also allow you to register your centre to contribute data. All data entry will be web-based and will be anonymised so there is no possibility of the patients being identified from the database.

The main features to be found on the website are as follows:

- i) On the home page you will find the general regulations of the Euro Heart Survey which outline the governance of the survey.

- ii) There is also a form on the home page to allow centres to sign up to contribute data.
- iii) You can then enter the pregnancy part of the website by clicking at the top left hand corner where you will see a window saying “Survey”. Clicking on the down arrow on the right hand side of this window will reveal the “pregnancy” heading and you can then click on this to open the pregnancy database. On the pregnancy page you can access the protocol for the registry, and various other relevant slides.
- iv)
- v) The far right hand tab at the top of the page is labelled “Demo” and clicking this will allow you to enter a demonstration case record form so as to get an idea as to the type of information that needs to be entered.

Before you enrol patients you need to confirm whether or not you require ethical permission in your country for this kind of survey. Professor Roger Hall has checked with the central office of the Multicentre Research Ethics Committee in the UK and has discovered that in the UK permission is not required for this type of data collection which involves completely anonymised data with no specific interventions required for the protocol.

b) If you do not have this type of patient please contact anybody you know who does, either in your institution or elsewhere.

We are extremely keen to make contact with as many centres as possible who have this type of patient. As stressed above this is not solely a European survey and the centre can come from any part of the world.

Please do everything you can to help with this survey. We have a relatively limited period of time to collect the data and we need to get as many pregnancies as possible. This is the best way of getting information to help the management of these patients.

If you have any queries you can contact the Euroheart survey staff via the website

Yours sincerely

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