

**ESHRE
PGD Consortium**

**Newsletter,
April 2008**

Welcome to the 6th Consortium newsletter with an update of our activities.

**BARCELONA - Dates for your diary
Consortium members meeting, Barcelona**

This will be held on Saturday 5th July 2008 from 16.00 to 19.00. The agenda and the minutes of the last meeting will be circulated a few weeks before, but will include an update of the data, the working groups, quality assessment for FISH and PCR, paediatric follow-up and a discussion about transport PGD. If you will be able to attend this meeting, can you please let Veerle know, quoting your centre number. We hope that you can all make it as this is usually a very lively meeting.

**Special Interest Group in Reproductive Genetics, Pre-congress course,
Barcelona, Sunday 6th July**

Sex chromosomes in human reproduction: towards understanding their basic function. Course co-ordinator(s): Peter H. Vogt, Stephane Viville and Karen Sermon. See the ESHRE web site for further details

**Special Interest Group in Reproductive Genetics, Business meeting,
Barcelona. Tuesday 8th July from 13.00 – 14.00.**

Everyone welcome.

**ESHRE PGD Consortium session during the main meeting
Tuesday 8th July, 14.00 – 15.00.**

Joyce Harper will be presenting a detailed analysis of data I-IX during this session and an update of the consortium activities. There will be plenty of time for discussion during this session so we hope everyone will attend. The data will be covered in more detail than during the Consortium members meeting.

PGD session during ESHRE

Tuesday 8th July. Session 44, 15.15-16.30: Genetics - PGD/PGS

Update on membership

Total number of members: 91

Full members: 57

Associate members: 34

At our recent steering committee meeting it was agreed that centres can stay as associate members for more than one year.

Data collection

The steering committee are starting to look at the data per indication in more detail. Sjoerd Repping has already completed a regression analysis of the PGS data (see PGS working group). We will do this for the other indications in due course.

The steering committee identified a number of questions that we need to ask centres who send in data, including if they are doing transport PGD, if they are doing polar body biopsy do they take just the first or both, do centres conform to the PGD guidelines, etc. A short questionnaire is being prepared and will be sent to all centres.

Data VIII and IX

We have had a slight delay in submitting data VIII (2005) for publication but it will hopefully be submitted next week and so all centres who contributed data will receive a copy of the submitted paper. The end point for all the indications is delivery rate, rather than clinical pregnancy rate. This is the first time we have managed to achieve this.

For data IX (2006), 57 centres sent in their data. It has almost all been checked and the updates are being done. We will have the full data analysis ready for Barcelona and will submit the paper just after Barcelona.

Success rates per centre

Celine Moutou has prepared several tables of pregnancy rates per OR in relation to each centre for the main indications. These graphs show the wide variation in pregnancy rates. This information will be sent to all centres who sent in data for collection VIII and a summary table will be included in data VIII. This graph shows centres how they fair compared to other centres. A more detailed analysis of this information will be conducted (taking into account patient age, etc). We will discuss this data at the consortium meeting in Barcelona.

Why continue with data collection?

The steering committee have discussed if there is a need to continue with data collection and it was agreed that the data is important as it is a valuable source of monitoring PGD, it shows trends of the indications, it shows how the techniques are improving, which new technologies are being used and we can feedback success rates to individual centres (see above).

Centres providing data on pregnancies and deliveries

We would like to encourage all centres to follow up PGD pregnancies and deliveries, especially as we now are reporting the consortium data as deliveries per OR and ET. There are a few centres who rarely follow up the outcome of their pregnant PGD patients, which is not good practice. The end point of PGD is the delivery of a healthy baby, not just the presence of a fetal

heart. We are aware that following up pregnancies is difficult for some centres, especially those performing transport PGD, but it is important to do so.

Working Groups Update

1. Accreditation – Chair: Katerina Vesela

Karen Sermon has stepped down from chairing this group and Katerina has taken over. There are two aims for this group for 2008;

1. Accreditation workshop in October. More details to follow.
2. A paper on 'A beginners guide to accrediting a PGD laboratory' is being prepared.

2. PGS – Chair: Sjoerd Repping

Sjoerd has performed a regression analysis of all the consortium PGS data and this is being prepared for publication.

ESHRE have set up a task force to look into setting up a multi centre randomised trial for PGS.

3. Misdiagnosis – Chair: Joanne Traeger-Synodinos

Alan Thornhill has stepped down as chair of this group and Jan has taken over. There are two aims for this group for 2008;

1. A paper on the possible causes of misdiagnosis which we hope to have finished before Barcelona. You have all been sent a questionnaire about misdiagnosis so if you have ever had one can you please fill this in and return it to Veerle.
2. We are also going to conduct a survey on analysis of untransferred embryos. An email will be sent to all centres very soon.

4. Database – Celine Moutou

A new database is being developed to study the results of the paediatric follow-up. If it works well it will be developed for all the data collection.

Paediatric follow up – Alison Lashwood

Sixteen centres are taking part in this study but there has been a slight delay as UK ethics approval is still being sought. Ten of the centres have been given the go ahead to start collecting data.

The questionnaire has been translated and back translated in 5 languages and reviewed by different health professionals. This has taken time but from the comments has been a worthwhile procedure.

Alison will report on the initial findings at ESHRE.

External Quality Assessment for PGD FISH testing – Alan Thornhill and Sjoerd Repping in collaboration with Ros Hastings

The way this is going to be set up has altered. The new system will involve a letter to all centres to invite them to register (April). The site will be developed by mid June and all registered centres will send in one of their cases for retrospective review by a panel of experts. A prospective analysis will be open for all registered participants by August. In November the reviewing panel will assess all the findings and create a report and the results will be published early in 2009.

External Quality Assessment for PGD PCR testing – Sioban SenGupta in collaboration with Zandra Deans

This is a new venture and initial talks are underway. A meeting has been arranged in June.

PGD Guidelines

The Consortium guidelines were published 3 years ago and the steering committee felt that it was time to update these. When the guidelines are drafted they will be on the ESHRE website for three months to allow consultation. This item will be on the agenda for the members meeting in Barcelona.

Web site

The whole ESHRE web site is currently being updated. We are hoping to make access to the consortium web site easier. We also intend to make it easier to search for which centres are offering PGD for a particular disease. We are going to put sample consent forms and patient information leaflets on the site.

Steering Committee

The members of the steering committee are:

Chair, Joyce Harper, Past Chair, Karen Sermon, Deputy Chair, Alan Thornhill, Stephane Viville (France), Christine deDie (Netherlands), Paul Scriven (UK), Gary Harton (USA), Celine Moutou (France), Alison Lashwood (UK), Sioban SenGupta (UK), Sjoerd Repping (Netherlands), Joanne Traeger-Synodinos (Greece), Katerina Vesela (Czech Republic), Tugce Pehlivan (Spain) and Francesco Fiorentino (Italy), Maartje Van Rij (Netherlands).

Email list

If there is anyone at your clinic who would like to receive this newsletter, please send their email address to Veerle.Goossens@eshre.com quoting your centre number.

Further information

If you would like to make any comments, suggestions or need any further information about the consortium please email Veerle.Goossens@eshre.com