

## **ESHRE PGD Consortium**

**Newsletter,  
November 2008**

Welcome to the 8th Consortium newsletter with an update of our activities.

### **Statutes**

The Steering Committee is in the process of reviewing and updating the Consortium Statutes. The Consortium has expanded greatly over the last few years and the intention is to introduce more detailed rules regarding the management of the Consortium, which will include details of a formal balloting process for electing members to the Steering Committee and defining the term of office. The changes proposed will be circulated for a vote by the membership in March 2009. If the Consortium approves the changes then the revised statutes will be submitted to the Executive Committee for approval.

### **Data collection**

The consortium now has data on almost 22,000 PGD cycles.

### **Data IX and X**

Data IX is almost complete. We received a record breaking number of cycles (almost 6000 cycles from 57 centres). The paper will be submitted soon and a copy will be sent to all participating centres.

Data X – submission of cycles is now open and the deadline is 31<sup>st</sup> December 2008. If you have completed your cycle database you can send this in now and send in your pregnancies and babies when you have completed them (but by 31<sup>st</sup> December 2008). Please send cycles to Veerle.

### **Success rates per centre**

Celine has agreed to prepare the pregnancy rate by centre graph again for all centres and all indications for data IX. When this is completed all participating centres will be sent a copy and they can see how they rank compared to the other centres.

### **Regression analysis of the data**

The committee agree that it is now time to analyze the data more thoroughly by looking at which factors predict success in PGD. This will be done by performing a regression analysis of all PGD data.

### **Frozen cycle data**

Since there has been an increase in the number of biopsied and subsequently frozen embryos, we felt it was important that this data is collected. Celine and Katerina are preparing the information that we need to know and it will be in

the form of an independent filmmaker Pro file. This will hopefully be sent to all centres soon so that we can collect data to report with data X (see database working group).

## **Working Groups Update**

### **1. Accreditation – Chair: Katerina Vesela**

The workshop on Quality Management and Accreditation process in PGD clinics and laboratories was a great success. Over 70 delegates attended. On the first day talks included the need for accreditation and quality management, EQA for FISH, analysis of spare embryos following PGD/PGS, transport PGD and emerging technologies in PGD. On day 2, two parallel workshops ran; one on FISH and one on PCR. Both included talks on personnel, training and staff development, quality assurance, EQA and validation of tests.

This course was such a success that Joyce will be running this again in London in 2010.

We are preparing a guide to PGD laboratory accreditation which we hope will be submitted to Human Reproduction early next year.

### **2. PGS – Chair: Sjoerd Repping**

Since ESHRE have set up a PGS task force (see below), the work of the PGS working group is complete and this group will now finish.

### **3. Misdiagnosis – Chair: Joanne Traeger-Synodinos**

The paper titled: **The causes of misdiagnosis and adverse outcomes in PGD**, Wilton, L, Thornhill, A, Traeger-Synodinos, J, Sermon, KD, Harper, JC has been accepted for publication in HR and will be sent to everyone when we have the proofs.

Following the completion of two questionnaires (one that attempted to evaluate experience of PGD centres with respect to misdiagnosis and the other with follow-up studies of untransferred embryos- see Minutes from the Consortium meeting in Barcelona July 5<sup>th</sup> 2008), it was decided to initiate a co-ordinated study with centres who perform confirmation analysis of untransferred embryos. Jan Traeger-Synodinos will co-ordinate this for PGD cycles analysed by PCR and Gary Harton for PGD cycles analysed by FISH. PGD centres who wish to participate in either of these collaborative studies should contact Jan ([jtraeger@med.uoa.gr](mailto:jtraeger@med.uoa.gr)) or Gary ([gharton@givf.com](mailto:gharton@givf.com)) as appropriate.

### **4. Database – Celine Moutou**

The database group is working on the results of pregnancies and babies. We plan to simplify the tables in data X and further papers. This will not change the way data are collected.

A new database is in preparation for the outcome of transfer of thawed embryos. This will only consider embryos which were frozen after biopsy and

PGD. The database should be ready soon so that we can include the first results in data X paper.

### **5.PGD Guidelines – Gary Harton**

The committee have agreed that the Consortium will form a new working group on Guideline development and update. Currently we envisage four documents: General PGD including laboratory set-up, counseling and inclusion/exclusion criteria, FISH-based PGD, PCR-based PGD, and a joint document with the Embryology SIG on embryo biopsy and embryology as it pertains to PGD. Transport PGD will be added as a sub-topic on each document as needed due to the important nature of this fairly new development in PGD testing. Each document will have a working group of specialists involved in determining key questions and developing the text for the guidelines. ESHRE has recently developed a set of Guidelines on writing Guidelines which will, of course, be followed to make these documents the best they can be.

### **Paediatric follow up – Alison Lashwood**

The UK ethics approval has been approved and data collection can now begin in the centres that have met the ethical requirements of the study proposal. The questionnaires will be administered locally at each participating centre and then forwarded to the Chief Investigator (Alison Lashwood). The data entry on the new paediatric database will be done centrally.

### **FISH EQA**

Twenty five centres took part in the pilot which was organised by Ros Hastings, UKNEQAS/CEQA (UK National External Quality Assessment Scheme/Cytogenetics European Quality Assessment), Joyce Harper, Alan Thornhill and Sjoerd Repping. The pilot was in two parts. Part one involved assessing two sets of images (PGD and PGS) via the web and participating centres had to score the images. Part two involves submitting a report for one previously reported PGD or PGS case – the deadline is Friday 14th November. The assessors will meet in January to discuss the results of the pilot and prepare the reports for the participating centres. Centres will have the opportunity to comment on the pilot. We will also organise Phase 2. At the moment it is envisaged that participating centres do the EQA annually. In all correspondence to Ros, can all centres quote their EQA number.

### **Members of the EQA for FISH PGD working group:**

Ros Hastings, Joyce Harper, Alan Thornhill, Sjoerd Repping, Edith Coonen

### **PCR EQA**

#### **In collaboration with UK NEQAS (UK National External Quality Assessment Scheme)**

The working group for the pilot molecular PGD EQA met in Brno, in the Czech Republic on October 23<sup>rd</sup> 2008. The planned scheme will rely on sending 'parental' DNA samples and single cells from commercially available cell lines to participating labs to carry out tests for the diagnosis of cystic fibrosis. After much negotiation with the commercial company, the cell lines are now available and the DNA has been validated by the working group. Single cells have been isolated and transported to PGD labs within the working group in Europe and the USA to test the feasibility of a 'wet lab' approach for single cell analysis. The first round of results was generally good and a variety of methodologies were tested including different lysis methods, direct mutation detection and linkage analysis both with and without prior whole

genome amplification. A second round of single cells will be sent to PGD labs in the working group in November to determine the extent of variability that can be expected from the single cell analysis. The working group plans to meet again in December to discuss all the validation results and marking criteria for the scheme. The proposed schedule for the pilot scheme is as follows:

January	DNA from 'parental' and 'affected relative' cell lines sent to participating labs
February	Participating labs return PGD feasibility report for the 'family'
February	Single lymphocytes from 'offspring' cell lines sent to participating labs who have a protocol that can be applied to the 'family'.
March	Participating labs return PGD report
March	Assessors mark feasibility and/or PGD reports and send feedback to participating labs

**Members of the EQA for molecular PGD working group:**

Sandi Deans (UK), Martine De Rycke (Belgium), Francesco Fiorentino (Italy), Gary Harton (USA), Céline Moutou (France), Pamela Renwick (UK), David Robinson (UK), Sioban SenGupta (UK), Jan Traeger-Synodinos (Greece)

**ESHRE PGS task force**

The ESHRE PGS task force is hoping to set up a multi-centre RCT using polar bodies and arrays, but preliminary work to assess the efficiency of the array platforms will be needed before the trial begins. The next meeting of the Task Force will be on December 1 and further news will be included in the January Focus on Reproduction and in the next Consortium newsletter.

**Web site**

The consortium web site will be updated to fit in with the new ESHRE site.

**Update of centres details on web site**

We will contact each centre to ask them to update their details for the web and we will also include whether they perform transport PGD.

**TRAINING AND EDUCATION – DATES FOR YOUR DIARY**

**Basic Genetics for ART practitioners**

The SIG Reproductive Genetics plan to run the course in the following locations:

Strasbourg April 2009, Portugal (either Lisbon or Porto) 2010, Roma 2011.

**Use of arrays in PGD workshop**

There will be an array post congress course in Amsterdam on Thursday 2<sup>nd</sup> July, 2009. The programme is being prepared. If you are currently working on arrays for PGD and would like to be involved, please contact [joyce.harper@ucl.ac.uk](mailto:joyce.harper@ucl.ac.uk).

**Biopsy trouble shooting workshop**

We aim to run another biopsy trouble shooting post congress course in Roma 2010.

**Quality management in PGD**

A two day workshop will be held in London in 2010 (March or April).

**Steering Committee**

The members of the steering committee are:

Chair, Joyce Harper, Past Chair, Karen Sermon, Deputy Chair, Alan Thornhill. Veerle Goossens (Belgium), 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)

**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](mailto: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](mailto:Veerle.Goossens@eshre.com)