

## FIFTH MEETING OF THE HFEA

### MULTIPLE BIRTHS AND SINGLE EMBRYO TRANSFER ADVISORY GROUP

27 JUNE, 12.00PM

CONFERENCE ROOM, 21 BLOOMSBURY STREET, LONDON WC1

PRESENT

#### ADVISORY GROUP MEMBERS

Peter Braude (chair)	Jane Denton
Karl Nygren	Siladitya Bhattacharya
Helen Kendrew	Alun Elias-Jones
Brian Lieberman	Hossam Abdalla
Kate Brian	Clare Brown
Claire O'Donnell	

#### HFEA STAFF

Tim Whitaker  
Charlotte Augst  
Angela McNab  
Vishnee Sauntoo  
Stephanie Croker

#### 1 Apologies and welcome to the meeting

1.1 Apologies were received from David Barlow, Jan Gerris, Patricia Hamilton, Bill Ledger, David Morroll and Neelam Sood.

#### 2 Minutes and matters arising of the last meeting

2.1 The minutes of the February meeting were agreed.

#### Matters arising

2.2 Siladitya Bhattacharya has not, as yet got the data from the Australian follow up study on twins referred to at the previous meeting, however contact has been made with the Perinatal Data Unit in Sydney, Australia, which may be able to provide information about this.

2.3 Jane Denton established contact with Neena Modi from the South East Neonatal Network; at present they do not collect information about the way in which the child was conceived, however they do recognise the importance of this information, and would welcome some input from the group about the information that would need to be collected.

2.4 Clare Brown reported to the group that the National Infertility Awareness Campaign (NIAC) has now received funding and will be reviewing the implementation of the NICE guideline among PCTs. The survey will be sent out mid-July accompanied by a letter from Caroline Flint MP. The survey includes a question about whether frozen embryo transfer cycles are included in the funding of a cycle.

- 2.5 The Chair updated the group on the letter sent to Caroline Flint MP about the work of the group, however no acknowledgement has been received as yet.

**Action: TW to ensure the letter has been received**

- 2.6 National Infertility Day took place on the 10 June 2006 and both Clare Brown and Tim Whitaker briefed the group on the success of the event.
- 2.7 Tim Whitaker informed the group of a debate on the 3 July which follows up the last Science and Technology Committee report on the role of the HFEA. It was suggested that NIAC raise the issue of funding.

### **3 Update on Register data**

- 3.1 Charlotte Augst presented brief summary of the Register data.

**Action: CA to circulate graphs of the data**

### **4 Update on success rates work**

- 4.1 Charlotte Augst presented a summary of the presentation at the previous SCAG meeting. The work with NPEU is continuing and the Executive will take forward the work on outcome presentation during the next year.

### **5 Update on information gathered from commissioners**

- 5.1 Claire O'Donnell presented information gathered from commissioners about the funding of IVF in the different regions and PCTs.
- 5.2 Most commissioners have very robust prioritisation processes, and at present many do not class funding for IVF treatment as a priority.
- 5.3 There was uncertainty among the commissioners about the costs of a cycle and in particular the cost of a frozen embryo transfer cycle. It was suggested that giving commissioners explicit costs per patient (for example per 1000 woman 25 – 40 years) would remove misapprehensions.
- 5.4 Commissioners were in favour of single embryo transfer, but this doesn't mean that they could or would make additional funding for IVF available.
- 5.5 Her impression was that lobbying at a PCT level worked, as the Herceptin story showed.

### **6 Update on embryo morphology grading**

- 6.1 David Morroll provided information (presented by Charlotte Augst) on a pilot scheme being run by Leeds and Manchester hospitals on the grading of embryos by morphology. They have reached a consensus on the key factors: the number of cells, the fragmentation and the evenness of cell division.
- 6.2 ACE is in the process of developing a DVD that can be used to help embryologists grade embryos consistently. Hopefully, rolling out the pilot across the UK will lead to more consistent and informed embryo grading.
- 6.3 The group felt that patients needed reassurance in any policy option that the morphology of the embryos had been taken into account when making a decision about whether eSET was appropriate, but it was agreed that the group or the HFEA were not well placed to themselves develop and enforce embryo grading criteria.

## **7 Results of questionnaire sent out to members MBSET (27/06/06)01**

- 7.1 PB presented the outcome from the members' survey on preferred policy options.
- 7.2 The group agreed that extra funding would ease the introduction of eSET policies, but that the HFEA could not rely on extra funding for IVF being made available. The patchy nature of PCT funding for IVF might mean that patients will experience any policy change differently and might be more or less accepting of eSET depending on where they live.
- 7.3 A concern raised by the group was of the increased likelihood of patients travelling abroad for treatment if they cannot get the treatment they would like in the UK. The NHS would then still have to deal with the outcomes of multiple pregnancies, despite the HFEA having introduced policy change.
- 7.4 The group recognised the importance of a strong education programme for professionals from all disciplines.

## **8 Project timeline**

- 8.1 The draft report of the work that the advisory group has done will go to the Authority in October 2006 if a report is agreed before then.
- 8.2 If the Authority decides that it is inclined to change policy on embryo transfer, it would have to run a consultation. This means policy change would not happen before 2007.

## **9 Discussion of the draft report MBSET (27/06/06)02**

- 9.1 Presentation/language:
  - clear headings, tables and bullets where possible
  - executive summary at the beginning of the report

- needs to be stylistically consistent throughout the report
  - the term disability should be used carefully, to avoid any negative connotations
- 9.2 The report should include additional information about the experiences in other countries, which includes a description of the consequences of the policies for all involve.
- 9.3 The evidence in the report focuses on randomised controlled trials. It should also cover observational studies, and should also include information on the limitations of these studies.
- 9.4 The report should contain a critical section on the effects of data presentation and league tables on clinics reluctance to adopt SET.
- 9.5 There is no information about blastocyst transfer in the report and as it has high success rates and high twin rates it needs to be included.
- 9.6 The report gives very little information about fetal reduction.
- 9.7 The report should include additional information on twins (possibly in an appendix) in particular about the different risks of monochorionic and dichorionic twins.
- 9.8 The information about the risks of having premature babies should be expanded. This should include; a costing exercise (i.e. intensive care neonatal cots cost £1000 per day) and the effects of having a premature baby on the family (the risk of family break up after having a baby in neonatal care is increased, as does the risk of child abuse).

**Action: JD, AE-J and KN to review this section**

- 9.9 The importance of ensuring that patients are properly informed of all the risks needs to be highlighted in the report. The concerns about patients travelling abroad for treatment should be noted in the report.
- 9.10 The section of the report on the funding of treatment needs to give a more balanced picture.

**Action: CB and CO'D will review this section**

- 9.11 The possibilities of getting endorsement from the relevant professional bodies should be looked into. However the group were undecided on how this should be taken forward.

*Policy options*

- 9.12 The policy options should include a 'do nothing' option, in which policy remains unchanged and no increased effort to improve awareness is undertaken.
- 9.13 The policy options should also include an option which states that centres should aim for eSET in 51% of cases.
- 9.14 For policy options 2 and 3 evidence must be provided to justify any figures arrived at.

**Action: CA to rework the current draft version of the report and to send relevant sections and eventually the whole report out to the whole group**

**10 Decision on the need for further work or on possible adoption of the report, and on possible future meetings.**

- 10.1 The group decided that, if possible, further work should be done remotely via email, and if agreement cannot be reached, or a need for further detailed discussion is identified, the group will meet again.

**11 Next meeting**

- 11.1 The provisional date for the next meeting is the 19<sup>th</sup> September at 10.30am.