

# HUMAN FERTILISATION & EMBRYOLOGY AUTHORITY

## MINUTES OF THE AUTHORITY COMMITTEE MEETING

held at Royal College of Obstetricians & Gynaecologists on 18 September 2003

The meeting was preceded by morning presentations on embryo transfer given by Professor Alison MacFarlane and on corporate governance issues led by Barry MacDonald, HFEA Director of Resources and Corporate Governance. Authority Members met in closed session immediately before the Authority meeting.

The Authority meeting was quorate with 14 members in attendance, of whom 7 are professional members and 7 are lay members.

### PRESENT

Suzi Leather [Chair]  
Tom Baldwin [Deputy Chair]  
David Barlow  
Chris Barratt  
Peter Braude  
Ivor Brecker  
Clare Brown

Iain Cameron  
Jane Denton  
Neva Haites  
Emily Jackson  
Maybeth Jamieson  
Simon Jenkins [*until 5:30 p.m.*]  
Walker Merricks

### IN ATTENDANCE

Angela McNab [Chief Executive]  
Barry MacDonald  
Paul Gemmill  
David Tellis  
Tim Whitaker  
Dan Wentzel [Committee Secretary]

Frances Clift  
Alison Cook  
Anita Krajewski  
Charles Lister  
Peter Mills  
Chris O'Toole

### OBSERVERS

Hilary Harris  
[Human Genetics Commission]

Liz Woodeson [Department of Health]

The Chair asked all members to declare whether they had a conflict of interest for any of the items on the agenda.

**Authority Meetings:** Authority Members with Executive and Official Observers.  
**Open:** No member of public observing but Minutes published.  
**Closed:** Authority Members, Executive and Official Observers – no Minutes published.

## **ACTION**

### **Item 1 Apologies**

1. Apologies for absence were received from Andrew Grubb, Michael Nazir-Ali, Sharmila Nebhrajani and Ted Webb. Also, an apology was received from Sara Nathan who was not able to attend this portion of the Authority Meeting.

### **Item 2 Minutes of the July Meeting**

[Paper (18/09/03) 92]

2. The minutes of the meeting held on 10 July 2003 were approved as a true and accurate record.
3. It was noted that the minutes of this and future open meetings be prepared with the awareness that they will be made fully public. Therefore, care needs to be taken with use of jargon.

### **Item 3 Internet Summary of the July Meeting**

[Paper (18/09/03) 93]

4. The Internet Summary of the 10 July 2003 meeting was approved for release on the website, subject to the following amendments:
5. The date of the previous Authority meeting was incorrectly stated as June, not July. **DW**
6. As the full minutes of the open meetings will be available on the website, the Internet Summary will no longer be provided as of this meeting.

### **Item 4 Matters Arising**

[Paper (18/09/03) 94]

## ACTION

7. The summary of the progress to date on all actions from previous meetings noted, with special attention given to the following items:
8. CHILD Regional Organisers had been unable to find any patients who had participated in an egg giving scheme and were therefore unable to gather feedback on their experiences. **CB**
9. The MRC Pilot for obtaining embryos to be used for stem cell research will last for 10 weeks, covering as many different centres as possible, including one large centre.
10. The HFEA's previous comments relating to the consent form were discussed in the light of MRC's concerns. Questions were considered over how the form will apply if patients' consent changed. There was also concern that patients were not being given the option of consenting to their embryos being used for stem cell use for research alone, but not treatment.
11. MRC is keen to use one consent form covering research and treatment, and not enable patients to opt out of one for the purpose of the pilot.

*[Barlow, Jamieson, Cameron, Braude, Barratt left the room for the remainder of the discussion on this item]*

12. A discussion followed on the need to cover treatment and research. It was noted that the pilot will find out if there are participants who do not want to consent because both treatment and research are covered.
13. It was agreed to support the MRC proposed process and forms with the view that this is a pilot and will provide evidence on how individuals respond.

*(Barlow, Jamieson, Cameron, Braude and Barratt returned to the room)*

## **Item 5 Chair's Report**

**ACTION**

- 15 The Chair welcomed the appointment of Angela McNab as Chief Executive. Frances Clift was welcomed to the Authority as the newly appointed legal adviser.
- 16 Beginning in November, there are changes in chairing for two standing committees:
- Ethics and Law will be taken over by Tom Baldwin from Bishop Michael, who is retiring.
- Scientific Clinical Advances Group(SCAG) – Neva Haites will take over from Chris Barratt who is taking responsibility for laboratory standards.
- Emily Jackson, the newest member of the Authority will join the Audit Committee and the Ethics and Law Committee.
- 17 After polling the Members, it was found that Wednesday is the best day to hold Authority meetings for the next calendar year. These will be scheduled. **DW**

**Item 6 Chief Executive’s Report**

- 18 Pending the completion of work on new ways on presenting outcome data, we are not including data on outcomes in the new Directory of Clinics. However, the Directory will provide detailed information on individual clinics’ activities. This directory is being produced with the support of “Dr. Foster”, a company with experience of producing patient focused information. The data gaining survey will be distributed by HFEA and the Directory would be clearly branded as an HFEA Directory.

## ACTION

19 Regarding the accommodation for the HFEA, the Lyons Committee, which has reviewed public bodies' need to remain in London, recently considered HFEA. The early indications are that the HFEA is seen to need to stay in London. This gives the HFEA the opportunity to find suitable accommodation in Central London. There are discussions about either taking all of Paxton House or looking for other accommodation elsewhere. One option is a government building in the Holburn area near Tottenham Court Road. It was agreed to give OFC decision making powers in this issue.

**Item 7 Code of Practice**  
*[moved to Confidential Meeting]*

**Item 8 PGD/PGS Form**  
[Paper (18/09/03) 96]

20 The Authority approved the suggested change in the use of the existing treatment form to record and report PGD/PGS screening activities.

**Item 9 IVF Culture Media**  
[Paper (18/09/03) 97]

21 The Chair outlined options for the role of the Authority in this area ranging from circulating information received from clinics to carrying out a risk assessment or more detailed surveillance.

22 It was agreed that culture media should certainly be in the Alerts System. We need to focus both on risks and quality concerns.

23 In the past, clinics did not keep detailed records of the culture media. There have been variations in the culture media used.

24 It was agreed that the HFEA will work on a risk assessment on Culture Media. This would involve experts in various fields to calculate theoretical risk assessments. A programme of work will be outlined and costed and discussions over resourcing will take place with DH.

**Charles  
Lister**

**ACTION**

*[Simon Jenkins left the meeting at 5:30 pm.]*

**Item 10 Draft Response to DTI Green Paper on Civil Partnership Registration**  
[Paper (18/09/03) 98]

25 The Members approved the proposed HFEA response to the DTI consultation.

**Item 11 Nice Fertility Guidelines**  
[Paper (18/09/03) 99]

26 The consultation period was launched in February and ends 23 September.

*[Barlow and Brown left the room]*

*[Barlow and Brown returned to the room]*

**Item 12 Corporate Plan**  
[Paper (18/09/03) 100]

27 The Corporate Plan has already been approved. The Authority noted the timescales that were put into the plan to meet the Minister's request.

**Item 13 Draft Annual Report**  
[Paper (18/09/03) 101]

28 The production schedule for the annual report is very tight because it needs to be laid before Parliament by 31 October. The draft was approved subject to minor amendments. The Chair offered thanks to Denise Darrell-Lambert who has edited the report. Members should e-mail any suggested changes to Denise.

**Members**

**Item 14 Proposed name revision for the License & Regulation standing committee to be known henceforth as the "Regulation Committee"**

**ACTION**

29 The Members approved this change in order to reduce confusion for the public between the formerly-named License & Regulation Committee which is one of the Members six standing committees and License Committees which are statutory.

**Item 15. Donor Information Form**  
[Paper (18/09/03) 102]

30 It was pointed out that we cannot do anything official until decisions are made by DH on Donor Anonymity.

31 However, the Chair suggested that a “writing group” be formed to develop a guidance leaflet for donors on completing the donor information form.

**TW**

32 Some Members noted that children reading of serious conditions listed on the donor form as hereditary in nature may be unnecessarily distressed.

33 A DH representative noted that Insurance Companies ask for “serious illnesses” with definitions of what those are, and that perhaps a language change may need to be made to the form.

34 Another Member said that suggested guidelines should be developed for clinic staff members who are guiding others to complete the form. Walter Merricks volunteered to be on the “writing group” who would work on these guidelines.

**Walter  
Merricks**

35 The Chair suggested that expertise from BICA, Progar and BAAF may be invaluable to this “writing group” and recommend they write to them and invite the to join it.

**Suzi  
Leather**

36 David Tellis, Director of Information Management, said that a filtering mechanism, to separate out information that should be given out with that which must remain confidential, will be brought to a future Authority meeting.

**David  
Tellis**

The meeting closed at 6:05 p.m.

I confirm this to be a true and accurate record of the meeting.

Signed .....

Chair

Dated .....