

Welcome to the first issue of the relaunch of the HFEA Update.

The new HFEA Update will be published quarterly to communicate key messages about progress and developments at the HFEA. We hope that centres, professional organisations, patient groups and anyone else with an interest in the work of the HFEA will find the Update both interesting and informative.

HFEA Update is also available online: www.hfea.gov.uk/HFEAPublications

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Sex Selection report and sixth Code of Practice to be published before the end of 2003.

Sex Selection

Throughout 2002/2003 the HFEA has conducted a review of sex selection. The HFEA consultation entitled *Sex Selection: Choice And Responsibility In Human Reproduction* ran from October 2002 to January 2003 and was open to all UK residents. An opinion poll was also commissioned by MORI to canvass the views of a representative sample of 2,000 members of the public.

Over 700 responses to the consultation were received by the HFEA. **The report, including advice to UK health ministers on options for legislation, will be launched at the House of Commons during November.**

HFEA Code of Practice

The consultation on the sixth edition of the *Code of Practice* closed in August. The aim of the consultation was to provide licensed centres with the opportunity to comment on new sections of the *Code* and to submit suggestions as to how the *Code* could be made a more practical and comprehensive document. The HFEA also consulted a wide range of organisations with an interest in assisted reproduction and related practice.

In all 61 responses to the consultation were received, of which 24 were from HFEA licensed centres, 23 from relevant professional organisations, 11 from inspectors and three from members of the public. **Based on evaluation and analysis of the responses, the HFEA will publish the sixth edition of the Code of Practice by the end of 2003.**

The HFEA will be undertaking a detailed revision of the *Code of Practice* before publication of the seventh edition.

Incident Alert System

Over the last three months, the HFEA has piloted a new alert system where anonymised details of incidents are disseminated to HFEA licensed centres supported by best practice recommendations. The incident alert system was set up as a warning to clinics about any incident which could have an adverse effect on patient care and staff safety, thereby helping to minimise the possibility of the incident occurring at another centre.

Incident alerts are e-mailed to staff at centres and an archive of alerts is available on the new HFEA centres website <http://centres.hfea.gov.uk> Six alerts have been released to date.

Each alert has asked for feedback on the clarity of the description of the incident and the recommended actions. Feedback on the pilot has been very positive with helpful comments on developing the system. The Authority will be reviewing the first three months of the pilot during October, including how well the original aims of the system have been met and how the system could be improved.

New HFEA website

The new HFEA website was launched in August. The site has been designed to reflect the current work of the HFEA and allow improved communications with patient, clinics and the media. The HFEA has also launched its password-protected centres only website. We are currently in the process of developing this site to contain centre personalised information.

Centres can obtain passwords for the centres only website by contacting Daisy Thomas, Information Officer: daisy.thomas@hfea.gov.uk

Egg giving consultation

In July the HFEA contacted all licensed centres asking them to provide information on whether they are practising egg giving and if so what protocols they have in place. Key stakeholders were also asked for their opinion of egg giving as a suitable practice.

The HFEA is currently analysing the responses and will produce guidelines on egg giving by the end of 2003.

Historic Audit Project

As part of its data register replacement project, the HFEA is undertaking an audit (the Historic Audit Project) of key data in the HFEA Register relating to children born from treatment before April 2002. At the request of the Department of Health this will be completed for all centres, including those no longer in operation.

The HFEA is currently undertaking pilot audits at several centres, exploring different methodologies. This will assist us to complete the audit as efficiently as possible and to minimise the disruption to clinics. The HFEA expects to reimburse direct costs incurred by centres associated with the project (such as retrieving files from archive storage).

In order to avoid the need for a similar retrospective audit in future, the HFEA is aiming to integrate checking of forms against source data into the inspection programme.

Patient information leaflets

The HFEA has recently redesigned its patient information leaflets. Free copies of the leaflets can be obtained by contacting the HFEA or can be downloaded from the HFEA website.

HFEA Directory of Clinics

The HFEA Patients' Guides for 2003 are to be renamed the HFEA Directory of Clinics. This Directory will consist of more detailed information about clinics and services. The content of the Directory of Clinics has been determined following feedback from patient groups.

The nature of the Guides has been changed for this one year due to the ongoing HFEA data register replacement project. The project means that the HFEA is currently unable to produce validated data extractions for clinic outcomes. For this reason, clinic outcome data will not be included in this year's publication.

The HFEA is consulting with a range of stakeholders as to how the clinic outcome data can be presented in the future to ensure that it is accessible for patients. This will inform the 2004 Patients' Guide.

The HFEA has recently contacted all treatment and storage centres asking them to complete a questionnaire in order to provide information for the Directory of Clinics. **The deadline for returning questionnaires to the HFEA is 20 October. For further information please contact Trevor Clarke, Business Process Manager on: 020 7375 3017.**

Policy review on dewars

As a result of a number of incidents involving dewars, the HFEA will be undertaking a regulatory impact assessment at the end of October. The HFEA will then consult centres to formulate a revised policy on dewars by early 2004.

Electronic Data Interchange

The HFEA is currently using paper based forms to obtain information from licensed centres on patient and partner registration, donor information, donor gamete treatment, IVF treatment, embryo creation and use, and pregnancy outcomes. However, HFEA staff are engaged in a large, complex programme of work that will in future allow this information to be collected electronically.

Electronic Data Interchange (EDI) will begin in 2004 reducing the workload for centres associated with the completion of paper forms.

Freedom of Information Act

As a public authority, the HFEA has a duty under the Freedom of Information Act 2000 to make a range of information available to the public. Much of this information has not been previously accessible and the HFEA wants to ensure that it is made available in a manner which allows for informed discussion, but not misrepresentation of centres' activities.

The following items of information are of most relevance to centres: Inspection Reports, Licence Committees outcomes, titles and lay summaries of research licences granted by the HFEA. The HFEA is currently consulting on the format of these documents which will become available later this month.

Any centre with questions about this issue should contact Paul Gemmill, Director of Regulation on: 020 7375 3017.

**Clare Brown**

Member Focus

Clare Brown joined the HFEA in December 2002 with a specific focus: the expectations and needs of patients. As Executive Director of CHILD – the National Infertility Support Network, she is a leading advocate on issues that affect patients across the UK.

Clare feels strongly that patients receiving treatment for infertility should get appropriate representation on issues that affect their treatment and is also aware that infertility does not always receive the publicity it deserves. Clare's main role as Executive Director is to oversee the operation of the charity which focuses on the provision of appropriate services for couples and women undergoing fertility treatment. The charity is sensitive to the real needs of women and couples receiving treatment. "Once you've faced infertility, as I have, you never forget what it was like."

Clare has been involved with CHILD since 1980. Today, she is not only a Member of the HFEA but also President of the National Infertility Awareness Campaign, a Member of the Fertility Guideline Development Group, and also President of the International Federation Of Infertility Patient Associations.

HFEA Members determine HFEA policies and review treatment and research licence applications. Authority Members bring to the HFEA a broad range of expertise including medical, scientific, social, legal, managerial, religious and philosophical.

Staff news

The appointment of Angela McNab as Chief Executive in July completed the HFEA's new Senior Management Team. The team will continue to implement the HFEA's demanding agenda of modernisation and improvement.

HFEA Senior Management Team

Angela McNab Chief Executive

Paul Gemmill Director of Regulation

Barry MacDonald Director of Resources and Corporate Development

David Tellis Director of Information Management

Tim Whitaker Director of Policy and Communications

DIARY DATES

Tuesday 18 November 2003 **HFEA Research Conference**

Wednesday 21 January 2004 **HFEA Annual Conference**

Wednesday 18 February 2004 **Open Authority Meeting**

For further information about these events please contact Wai-Yee Choy, Communications Assistant: wai-ye.choy@hfea.gov.uk or 020 7539 3329.

The HFEA appreciates any comments on the content of the HFEA Update.

Please contact
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