

## Welcome...

to the winter edition of the HFEA Update for clinic staff. Read about the Code of Practice and consent forms consultation, the consultation on presenting clinic performance and outcome data and find out what happened at our Annual Conference.

Winter 2008

## Code of Practice and consent forms consultation

The Human Fertilisation and Embryology Bill recently passed through the House of Commons and the House of Lords. The HFEA have now started consultation on the draft Code of Practice and the revised consent forms. The consultation will run until 18 February 2009.

We value your feedback and would appreciate it if you could fill in the online questionnaire. Visit the HFEA website to view the draft Code of Practice and consent forms and give your feedback.

In developing the consultation version of the 8th Code we received valuable input from our Licensed Centres Panel and other groups. We also had the help of a reference group of clinics who estimated the economic impact of the 8th Code on their clinic. You will have the opportunity to respond to these cost estimates through the online questionnaire.

In addition to the online questionnaire, several public meetings are being held in London, Bristol and Manchester in January and February 2009. There will be further opportunities to comment on the Code at events such as the Fertility 2009 conference and our own open Authority meeting in Edinburgh in December this year.

Focus groups will be held with both nurses and patients to trial the consent forms. We aim to provide as many chances as possible for you to give much-valued feedback on the structure and content of the new Code and consent forms.

Once the consultation has closed, we will make final changes based on the results of the consultation. The aim is to publish the Code and consent forms in July 2009, contingent on Ministerial approval. This will give clinics time to implement changes before they come into force on 1 October 2009.

If you have any further questions about the Code of Practice consultation contact Danny Edwards at [danny.edwards@hfea.gov.uk](mailto:danny.edwards@hfea.gov.uk). For more information on the consent forms consultation contact Hannah Darby at [hannah.darby@hfea.gov.uk](mailto:hannah.darby@hfea.gov.uk).

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## News

# Consultation on presenting clinic performance and outcome data

The HFEA are currently holding a consultation on how we should present outcome data and clinic performance, in order to inform patient choice, promote good clinical practice and support HFEA policies.

At present we publish success rates for each clinic on our 'Find a Clinic' web pages. However we recognise there are limitations with this approach, and are looking to adopt a more holistic way of presenting the performance of clinics.

Some of the ways we could do this are outlined in our discussion document on clinic performance, which was sent to clinics in mid November 2008. It is also available to download on our website ([www.hfea.gov.uk/en/1742.html](http://www.hfea.gov.uk/en/1742.html)).

We would value comments from as many different clinics, and members of clinics, as possible. This will support

other engagement work we are carrying out with patients, the public, Primary Care Trusts (PCTs) and GPs.

Please pass on your comments using the online form on our website ([www.hfea.gov.uk/en/1742.html](http://www.hfea.gov.uk/en/1742.html)) by 15 December 2008. The feedback will be used to produce more detailed presentation models that you will be able to comment on during January – February 2009.

Feedback will be possible either online or by attending sessions we are holding as part of the meetings on the Code of Practice in London, Bristol and Manchester in January and February 2009. The Authority will then make a decision on how to present clinic performance in May 2009.

For more information on this consultation please contact Helen Richens at [helen.richens@hfea.gov.uk](mailto:helen.richens@hfea.gov.uk).

## Opening the HFEA Register for research

Upon commencement of the Human Fertilisation and Embryology Bill in October 2009 it will be possible for identifying and non-identifying information to be disclosed to researchers (subject to regulations) for medical and non-medical research necessary or expedient in the public interest or in the interests of improving patient care.

Section 33C of the Bill will broaden access to data on the HFEA Register. The Bill recognises that the data is an immensely useful research tool, whilst at the same time needs to be safeguarded.

The HFEA is in the process of developing a policy and procedures to deal with anticipated requests from researchers. Stakeholders will be consulted in the next few months.

For more information contact Hannah Darby at [hannah.darby@hfea.gov.uk](mailto:hannah.darby@hfea.gov.uk).

## Subscribe to the new HFEA e-newsletter!

Visit our website at [www.hfea.gov.uk/e-updates](http://www.hfea.gov.uk/e-updates) and subscribe to our new email newsletter service, HFEA e-update, which will be sent out every month.

Keep up to date with:

- the latest news from the HFEA;
- news from around the fertility sector, and
- upcoming events;
- changes to the HFEA website.



## News

# HFEA Annual Conference 2008

Delivering the Human Fertilisation and Embryology Bill in Practice



*Keynote speaker - Dawn Primarolo MP,  
Minister of State for Public Health*

Over 250 people, including clinicians, scientists, policy makers and journalists attended this year's annual conference in October. It was held at the Royal College of Surgeons of England.

Delegates heard keynote speeches from HFEA Chair, Professor Lisa Jardine, Minister of State for Public Health, Dawn Primarolo MP and Lord Justice of Appeal, Sir Alan Moses.

The Minister of State for Public Health spoke of her confidence in the legislative framework that is being put into place and her support for the wider implementation of the NICE guidelines.

Sir Alan Moses focused on society being best served by an independent regulator, rather than parliamentarians or judges, weighing up the finely balanced ethical issues in embryology and research.

HFEA Chair, Professor Lisa Jardine spoke about the HFEA's role, how we take decisions and who we serve, describing the HFEA as 'decent people trying to do a decent job'. She highlighted the importance of making use of the information we collect and emphasised that engaging with patients and the sector is central to how the HFEA moves forward.

### **Making better regulation happen**

Session 1 began with Professor Julia Black from the School of Law, London School of Economics. Her presentation on principles based regulation highlighted that mutual trust is essential for effective regulation. Dr Simon Fishel, Managing Director, CARE Fertility looked at what clinics want from regulation and what improvements the HFEA can make.

Kate Brian a former IVF patient, writer and journalist, interpreted patient survey findings to give her views on the motivations and priorities patients have about their treatment.

### **Preparing for the future of ART: HFEA's Horizon Scanning work**

Dr Robin Lovell-Badge, Head of Stem Cell Biology and Developmental Genetics Division at the National Institute for Medical Research overviewed and assessed the main themes identified through HFEA's Horizon Scanning process following an introduction by Dr Maybeth Jamieson, Consultant Embryologist, Glasgow Royal Infirmary.



*Keynote speaker - Sir Alan Moses,  
Lord Justice of Appeal*

### **Information for improvement**

Sir Muir Gray, Chief Knowledge Officer at the National Health Service gave a memorable presentation on how we should all recognise and support growing demands for making decisions about treatment in partnership with medical professionals.

In the following Q&A many delegates supported the idea of the HFEA and clinics publishing online information about the full patient experience to help place the outcome data into a wider context.

## News

### HFEA Annual Conference 2008 (continued)...

Enda McVeigh, Senior Fellow, Reproductive Medicine, University of Oxford shared his experience in implementing a management system that focuses on quality and patients.

The final speaker, Tim Kelsey, Dr Foster Chief Executive called for greater availability and accessibility of information to help patients make informed choices about their treatment.

#### Knowing and telling: Opening the HFEA Register to families and donors

In the last session, the first speaker, Jennie Hunt, Senior Infertility Counsellor at IVF Hammersmith set the scene by highlighting the human and emotional dimension of the HFEA's work.

Marilyn Crawshaw, Senior Lecturer in Social Work, University of York talked about her experiences from running the UK DonorLink Register Service. One of the key messages from Olivia Montuschi's

presentation from the Donor Conception Network, was donor conception obligates everyone, including clinicians to think more carefully about the wider consequences of treatment rather than just focusing on the immediate priority of achieving a pregnancy.

Sharon Pettle, a Consultant Clinical Psychologist at Great Ormond Street Hospital and Hon Senior Lecturer at the Institute of Child Health was the final speaker. She talked about her work with many donor-conceived children that showed by being open early on about the circumstances of their conception left them feeling with a positive identity about themselves and their families.

The conference proved to be a success and positive feedback has been received from a number of delegates.

## Opening the HFEA Register to people affected by donor conception

In September 2008 an Opening the Register HFEA Policy Group was established to advise the HFEA on the long term policy for Opening the Register to donor-conceived people seeking information about their genetic origins, parents of donor-conceived people and donors.

The HFEA has developed its thinking and policy around Opening the Register over the past five years. The Human Fertilisation and Embryology Bill, which has recently completed its passage through parliament, expands information access rights considerably and the Policy Group's work encompasses these changes in legislation, which are expected to come into force in October 2009.

The Group is applying a principled approach to the development of the policy and is considering, amongst other things, the duty of care the HFEA and clinics owe applicants who have been affected by donation.

As is currently the case, it is likely that clinics will play a key role in providing information to donors and parents, but the HFEA will have responsibility for providing information to donor-conceived people. The HFEA is engaging with key stakeholders from the donor-conception and donation sectors as well as clinics. We are also looking closely at models from adoption.

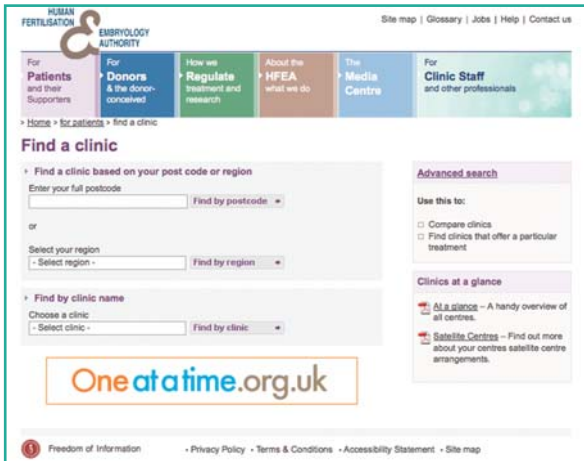
For more information contact Danielle Hamm at [danielle.hamm@hfea.gov.uk](mailto:danielle.hamm@hfea.gov.uk)





## News

# Release of 2006 Find a clinic data



The 2006 clinic figures were published on the HFEA website in the 'Find a clinic' guide ([www.hfea.gov.uk/guide](http://www.hfea.gov.uk/guide)) this October.

The number of women having successful in vitro fertilisation (IVF) treatment topped 10,000 for the first time in 2006, according to the new figures. There were 10,242 births resulting in 12,596 babies in 2006, an increase of 13.1% on the number of births in 2005.

Live birth rates also rose - 23.1% of treatments resulted in a live birth in 2006, up 1.5% on the previous year. In 1992, the first year the HFEA started collecting data, the live birth rate was 13%.

The number of patients and the number of treatments also increased. These latest figures show that 34,855 women were treated at UK clinics in 2006 - an increase of 6.8% on the previous year - and underwent 44,275 cycles of treatment.

Overall success rates increased in every age group. For women under 35 using their own fresh eggs, the live birth rate was 31% compared to 29.6% in 2005.

For women over 44 using their own fresh eggs, the rate increased from 0.8% in 2005 to 4% in 2006.

There were more than 1.2 million views of the HFEA 'Find a clinic' search ([www.hfea.gov.uk/guide](http://www.hfea.gov.uk/guide)) with each visitor looking at 14 pages on average, showing that patients are doing thorough searches across a number of clinics.

Professor Lisa Jardine, Chair of the HFEA said:

"In the year that we celebrated the thirtieth anniversary of the birth of the world's first IVF baby, these latest figures show just how far we've come. IVF is now commonplace, with the number of treatment cycles and births rising yet again.

"A key function of the HFEA is to be an information resource, helping to guide people through their treatment journeys and giving them the information they need to feel properly informed about the choices they are making.

"We are currently at the start of a consultation process that will look closely at how we might further improve the information that we publish to best capture the performance of clinics. A more sophisticated analysis of national data would be valuable to patients, clinics and the NHS.

"However, the number of donor insemination cycles and births continues to fall. While more couples are able to take advantage of techniques such as ICSI, for those patients whose treatment requires donor sperm, this is of great concern.

"The HFEA is supportive of clinics that are actively recruiting donors and we welcome the BFS Working Party proposals to introduce a national system for donor recruitment."



## News in brief

### HFEA at BFS Conference

The HFEA exhibited a stand at the British Fertility Society Conference from 2-5 September. HFEA Interim Chief Executive, Alan Doran was a guest speaker at the event where he outlined some of the changes that the HFEA are making to improve the way we regulate and provide information. This prompted a lively debate amongst delegates at the conference who were keen to share their views with us.

### Donor centre report

In order to help clinics accurately track the 10 family rule for donor gametes the HFEA are setting up two new systems. For imported gametes, the 'donor centre report' is now available on EDI (Electronic Data Interchange) to allow clinics to search using the donor code in order to check which other clinics in the UK have registered the same donor.

For UK donors, in order to check that a donor hasn't already donated at another clinic without informing the clinic, clinics are asked to contact their QA representative before registering any new donors. Your QA representative will be able to search the Register using the donor's name for you.

### Donor codes reminder

The HFEA would like to remind clinics of the importance of ensuring donor codes are entered accurately, not only on the donor information form but also on the treatment form.

### Pen portraits

A number of queries have recently been received about whether pen portraits can be shown to patients. The pen portrait and goodwill message are completed by the donor for any children born as a result of their donation. This can be given to parents to show to their children, but not to patients.

If there is any information on either the pen portrait or goodwill message that could potentially lead to identifying the donor then it must not be shown to the parents.

If you are in any doubt as to whether the information could be passed on or not please contact your QA representative.

## Upcoming events

### Open Authority Meeting, Edinburgh – 17 December

The meeting will be held at the Royal College of Surgeons in Edinburgh.

Some of the items to be discussed include the information and guidance we provide to patients who are considering travelling abroad for treatment and an update on communications around our forthcoming consultations.

Further details on the agenda and arrangements to be announced.

For more information email [openmeeting@hfea.gov.uk](mailto:openmeeting@hfea.gov.uk)