

## Welcome...

to the summer edition of the HFEA Update. This edition includes information on how to prepare for an inspection, the HFEA anonymised Register, our donation review and the launch of a brand new patient publication. Read on to find out more...

## Brand new patient publication

**We have recently launched a new patient publication, *Getting started: Your guide to fertility treatment***

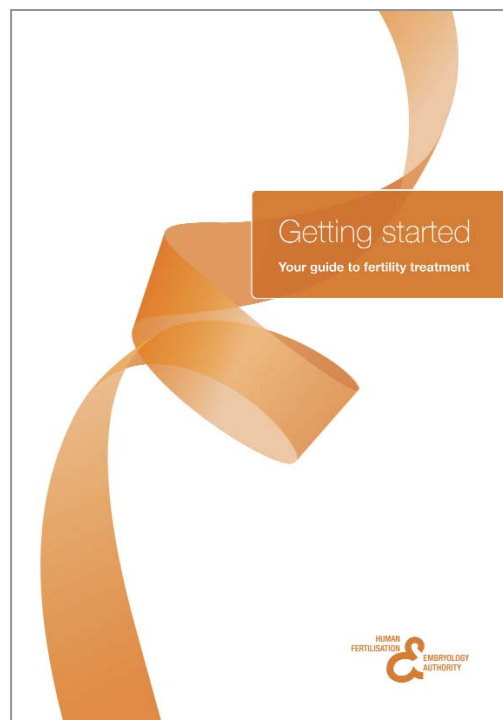
*Getting started* replaces the old *Guide to Infertility*, and is available for patients to order through clinics or directly from us via our website. It is aimed at people who are at the beginning of their fertility treatment journey.

The publication is free and contains simple, straightforward information on a patient's journey from start to finish. The new guide explains the different fertility treatments available, how to research a clinic and what to expect. Information on freezing and storage, as well as where to get support is also included. Each section of the guide directs people to the HFEA website for more detailed information.

To make sure we got our new guide right, we tested *Getting started* with patients, counsellors and fertility nurses, using their feedback to create an accessible, easy to read and informative publication.

To promote the new guide, the HFEA has produced a leaflet which will be distributed to GP surgeries nationwide. Prospective patients can easily pick it up and order the guide directly from the HFEA.

For any further information, please contact: [sharon.neaves@hfea.gov.uk](mailto:sharon.neaves@hfea.gov.uk)



Summer 2010



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## News

### Donation review

Over the summer and autumn of 2010 the HFEA will be reviewing a number of its policies relating to sperm, egg and embryo donation. The review aims to ensure that no unnecessary barriers are posed to donation, while protecting the interests of all involved.

The policies to be reviewed include:

- expenses and compensation for donors
- donation between family members
- the restrictions which donors can place on the use of their gametes or embryos

A fundamental part of the review is listening to the views of experts – the people who are involved in donation including clinics, donors, recipients and donor conceived people.

The Authority will gather evidence to ensure that the public consultation, which will begin in autumn, includes workable options which avoids unnecessary regulation.

Research during the first phase will incorporate a review of relevant literature, public opinion polling, focus groups and interviews with people affected by donation, and a clinic survey.

#### Clinic survey

Thanks to those who responded to our recent survey. The purpose of the survey was to help the Authority map out the real issues faced by clinics in providing donor treatment, however difficult and complex they can sometimes be.

The results of the survey will be analysed and presented to the public Authority meeting in July 2010.

If you have any questions regarding the donation review generally, or the clinic survey, please contact us: [donationreview@hfea.gov.uk](mailto:donationreview@hfea.gov.uk)



## News

### Choose a Fertility Clinic

The latest clinic figures for April have been published on our *Choose a Fertility Clinic* service.

The figures we published are for live births from July 2007 - June 2008 and pregnancies for July 2008 - June 2009. We will be refreshing this data at the end of August and at the end of October.

Visits to the site are up by 40% from this time last year, and we appreciate all the effort clinic staff put into providing the data for this valuable patient tool.

We would also like to remind you that the earlier your reports are cleared or confirmed, the more time you will have to check the data and query any anomalies.

If you have any queries please contact your Register Information Officer.



### Donor Sibling Link

Donor-conceived people are now able to get in touch with their genetic siblings through the Donor Sibling Link (DSL) if they were born after 1 August 1991 and are over 18 years old.

By signing up to the DSL, donor-conceived people can share and/or receive contact details of their genetic siblings who have also consented to join the service.

Find out more about Donor Sibling Link at: [www.hfea.gov.uk/donor-sibling-link.html](http://www.hfea.gov.uk/donor-sibling-link.html)



## News

# HFEA anonymised Register

In order to allow professionals in the fertility sector and the wider research community to make good use of the data we collect, we have launched an anonymised version of our Register.

The anonymised Register allows researchers to access a large and rich data set, but one that does not identify any patients, or children born as a result of treatment.

### What information is in the Register?

The anonymised Register contains information, shown on a treatment cycle basis, such as:

- reasons for infertility
- the age of patients at treatment
- number of embryos transferred

This is the first edition of the anonymised Register and it will be updated with the latest figures on a quarterly basis. We also hope to add further data fields over time.



### Who is the anonymised Register for?

The anonymised Register is designed for those working in the IVF sector and professional researchers, or research organisations, with an interest in the epidemiology of fertility treatment.

## Improving the information we send you

Thanks to all of you that responded to our survey about the information we send you. We were pleased to hear that many of you regularly read this *Update* as well as the monthly email we send you and that you find them both useful and relevant.

We have redesigned the monthly email we send you (now known as *Clinic Focus*) to make it more simple and clear. You told us that Quality and Nurse managers should be receiving this email - your inspectors will be in touch with you to collect their contact details.



You also told us that you would like to see best practice case studies - we will be developing these for future issues.

### Tell us what you want

If you didn't have a chance to complete our survey, or have any comments about *Update*, *Clinic Focus* or any other material we send to clinics, please email Alan Tipping: [alan.tipping@hfea.gov.uk](mailto:alan.tipping@hfea.gov.uk)

## News

# Workshops on multiple births and consent to disclosure for research

Over the spring, we held a series of workshops for centre staff around the UK. The aim of the workshops was to update centres about the revised multiple births policy and the new regulations on disclosing patient information for research. Getting staff together from different clinics also gave them the opportunity to share successes and failures and to discuss best practice. Workshops held in Birmingham, Glasgow, Leeds and London, brought together over 150 clinic staff from 60 NHS and private centres.

### Multiple births: evaluation of year 1

At the workshops, we gave an update on the first year of the multiple births policy. The good news is that the proportion of elective single embryo transfers (eSET) is rising, with the greatest increase in those women aged under 35. Our data also shows an increase in blastocyst transfers.

This increase in eSET cycles appears to have resulted in a lower multiple pregnancy rate in 2009 compared to 2008, especially for women under 35. Importantly, the current impact on overall pregnancy rates appears minimal. Approximately two-thirds of centres are predicted to meet the year 1 maximum multiple birth rate of 24%.

During the discussion about how clinics are implementing the policy, a number of lessons emerged:

- embryo quality appears more important than age as even older women with good embryos or blastocysts are at risk of a multiple birth
- it is not good practice to transfer two good quality blastocysts as the multiple pregnancy rate is extremely high
- patients eligible for eSET must feel that this is their best clinical option, with a subsequent frozen embryo transfer if needed
- clinics should give information early and throughout treatment provide consistent, positive advice from all their staff

### Consent to disclosure for research

New regulations which came into force in April mean that the HFEA can release patient-identifying information from the Register to researchers, provided that they meet certain strict criteria. We can also release information entered onto the Register since October 2009, but only with patient consent.

The workshop helped to bring clinics up to speed on the new regulations and to enable clinic staff to share ideas about how to discuss this issue with their patients.

At present, only 30% of patients are consenting to the use of their data. However, clinics reported that they are finding this easier as time goes on and that the consent rate is increasing. One key message from clinics was that they would find it helpful for the HFEA to produce information which they could distribute to patients. This will be published in the summer.

### Further information

For more about multiple births please contact Helen Richens: [helen.richens@hfea.gov.uk](mailto:helen.richens@hfea.gov.uk) or talk to your Inspector.



## Compliance matters

### Preparing for your inspection

As part of the Compliance cycle an onsite inspection aims to give centres an opportunity to demonstrate their compliance with the law and HFEA Code of Practice (8th Edition).

**Before your inspection** - the lead inspector will advise you what areas of practice will be reviewed and will provide you with a proposed agenda. It is important that all clinic staff review the proposed agenda prior to an inspection and make sure that the most appropriate staff have been selected to meet with the inspection team on the day.

It is essential for these members of staff to review the mandatory requirements in the Code of Practice (CoP) guidance notes before the inspection. They can then plan in advance what to provide to the inspection team. Staff can also prepare evidence in the form of documents or information, or arrange for inspectors to observe activities that provide first hand evidence.

**During inspections** - focus in 2010/11 will be on a number of key themes. One of the themes is witnessing and assuring patient and donor identification (Guidance Note 18). You should identify a member of the team to lead this part of the inspection.

The person taking responsibility for this part of the inspection could:

- ask the inspector to observe egg collection and/or sperm preparation processes
- provide copies of the standard operating procedure (SOP) and highlight how the SOP complies with the Code of Practice guidelines
- provide evidence of how witnessing activities have been audited against regulatory requirements and quality indicators and if any corrective actions have been implemented
- have relevant training records and/or evidence in the form of competence assessments available.



Inspections give clinics the opportunity to demonstrate compliance. If an area of practice is shown as being non-compliant, clinics will be given an opportunity to provide additional information or to put matters right – sometimes this is achieved before the report is considered by a Licence Committee or Panel.

**Inspection feedback** - We have been introducing this approach to inspections since October 2009 and the feedback received so far has been encouraging. From nine inspections, seven clinics said that the inspection resulted in service improvements and eight clinics commented that the inspection had been better than before.

**Feedback** – If you have feedback on your experience of the inspection process or suggestions for improvement please contact Debra Bloor, Head of Inspection: [debra.bloor@hfea.gov.uk](mailto:debra.bloor@hfea.gov.uk)

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The inspection process was more relaxed as we have more understanding of the process. The inspector's task for guidance and support of the unit's improvement was very encouraging.

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## News in brief

### How we consider interim inspection reports

The method used by HFEA Licence Committees and the Executive Licensing Panel to consider interim clinic inspection reports has been published on our website.

The decision tree shows clearly the points the committees discuss when looking at the reports and guides them in their decision making process.

The decision tree can be found on our website at: [www.hfea.gov.uk/1128.html](http://www.hfea.gov.uk/1128.html) under 'relevant links'.

### Changes to HFEA telephone system



The HFEA is replacing its old phones with a new Microsoft phone system.

We have rolled out the system for internal calls and expect to start using it for external calls in May 2010. We apologise in advance for any disruption as we transfer to the new system.

We are always contactable via email at: [admin@hfea.gov.uk](mailto:admin@hfea.gov.uk)

## Upcoming events

### Open Authority meeting

7 July 2010 – London

If you would like to register to attend or for further information about the event, please email: [openmeeting@hfea.gov.uk](mailto:openmeeting@hfea.gov.uk)



### Planning a patient information event?

If you, or a colleague, are thinking about holding a patient information event for prospective patients we can provide your centre with the following:

- **Getting started: Your guide to fertility treatment**

Introductory information for patients who are at the beginning of their fertility treatment journey.

- **Fertility – Have your say**

We have re-launched our online patients' panel *Fertility- Have your say* to gather the views of people who have had, are undergoing or are preparing for fertility treatment. We want to hear what patients have to say to help us and the sector improve fertility treatment services and shape the broader policies affecting the fertility sector as a whole.

To order these publications, please email Sharon Neaves: [sharon.neaves@hfea.gov.uk](mailto:sharon.neaves@hfea.gov.uk)

