

## Welcome...

to the second edition of the HFEA Update for 2009. This issue includes an update on the last HFEA Authority meeting, progress on the Code of Practice and consent forms, a brief overview of what patients think about fertility services, and discussions at the latest Licensed Centres Panel meeting.

Summer 2009

## Outcomes from May's Authority meeting

May's Authority meeting was a landmark meeting for the HFEA in the run-up to the amended Human Fertilisation and Embryology Act coming into force in October 2009. It set out how we are growing in our role as a trusted information-provider to patients, centres and researchers.

The meeting came after a busy consultation period earlier this year, where we listened and responded to stakeholders' views on the Code of Practice, consent forms and the information we present about centres.

Authority members formally approved the draft Code of Practice for clinics and the revised consent forms. These will be used from October and will ensure that centres can clearly understand and meet the requirements brought in by the new legislation. The Code of Practice and consent forms have also been made more accessible and user-friendly.

The meeting explored the consultation feedback we received about how we present treatment data and information about clinics. As well as making clinic data more accessible to patients, May's meeting also focused on making our national dataset more accessible to researchers. The Authority agreed that we should develop an anonymised version of the national data we hold on treatment cycles, which anyone will be able to access and analyse.

From October 2009 the amended Act allows us to release identifying information about patients' treatment cycles to researchers, with patients' consent. How we will approach this in patients' best interest, whilst respecting patient confidentiality was also discussed.

Patients treated after October 2009 can withhold or withdraw consent and the HFEA is looking at a clear and straightforward way to enable patients, treated before 1 October 2009, to register their 'opt out'.

Visit [www.hfea.gov.uk](http://www.hfea.gov.uk) for more on the Authority meeting.

## Inside...

Outcomes from May's Authority Meeting	1
Incident reporting in the media	2
Improved HFEA website launched	2
Licensed Centres Panel – highlights from the last meeting	3
Results from patients' panel survey	4
HFEA carries out a fees review	5
Newly improved, easier to use 'For clinic staff' area	5
The HFEA reviewed	5
News in brief	6
Upcoming events	6

## Follow us on Twitter!

Follow us and keep up to date with news from the HFEA on the social networking site. Find us at <http://twitter.com/hfea>



## News

# Incident reporting in the media

In late April the HFEA issued a statement in response to reports about witnessing incidents at Guy's and St Thomas's Hospital Assisted Conception Unit.

In the statement we made it clear that all incidents that had been reported have been investigated or are

currently under investigation. We also highlighted our procedures for reporting incidents and the benefits and learnings that can be gained from this process.

# Improved HFEA website launched

The new HFEA website was launched on 15 April. The website has been redesigned to make it more accessible and to improve navigation and the search function. Its purpose is to provide independent and authoritative information about fertility treatment and clinics.

Since the launch there has been a 20 percent increase in visits to the website.

The major redesign of the website's content and visual style is the first of a series of improvements to come over the summer.

Feedback was gathered from a wide range of audiences via a survey, user-testing with patients and clinic staff, interviews with stakeholders and through workshops.

The feedback was invaluable in developing a website that meets the needs of the various audiences who have an interest in the fertility sector and the work of the HFEA.

## What's changed?

We have made a range of improvements to the site including providing more detailed treatment information for patients. These improvements will support patients in making informed choices and will give them a better understanding of their chances of success. We hope patients will now have a clear picture of what their treatment journey is likely to involve.



The website also features real life stories from people who have either had fertility treatment or are going through treatment.

The website's structure, navigation and search facility have been improved to make it easier to find information.

Further changes to the website will be introduced later in the year with the release of the new online HFEA Code of Practice and the new, improved 'Choose a Clinic', based on the outcomes of the recent HFEA information consultation.

For more information or to give us feedback, contact David Williams at david.williams@hfea.gov.uk

## News

# Licensed Centres Panel – highlights from the last meeting

The Licensed Centres Panel (LCP) engages with centres on core issues such as reviewing regulatory practice, identifying more efficient ways of regulating and implementing new initiatives. The panel is a forum that brings together counsellors, embryologists, fertility nurses, clinicians and PRs so that all professions have a say on issues that matter most to them.

Implementing the new HFE Act, revised consent forms and improving presentation of clinic data were the focus of February's LCP meeting.

Key topics and dates on the Act the panel discussed included:

- **6 April 2009 – introduction of legal parenthood** with the discussion clarifying only a single treatment form is needed and not separate forms.
- **1 July 2009 – publication of the 8th Code of Practice and revised consent forms.** Members suggested having more specific forms and removing sections such as IUI/GIFT and storage from the main treatment form. They also said guidance on research, counselling and withdrawal of consent would be helpful, such as making clear a letter from a patient is sufficient to withdraw consent.
- **July 2009.** In advance of the Act and its new provisions, new licences will be offered to centres.
- **1 October 2009.** Start of the **8th Code of Practice and HFE Act 2008.**
- **February 2010.** Start of the **licence fees review consultation.**

Members welcomed a review of the current fee structure and also the new approaches to inspection and licensing planned to support the introduction of the new Act and 8th Code.

To help patients easily understand clinic performance, members suggested information be shown on a single website page. They felt patients should not be overwhelmed with data but would find statistics comparing clinics against a national average helpful.

Members also supported the monthly HFEA mailing to PRs being sent by email, instead of hard copy, which would give them greater flexibility on how to share and store this information.

The next LCP is scheduled for June. For more information contact Alan Tipping on 020 7291 8233 or email [alan.tipping@hfea.gov.uk](mailto:alan.tipping@hfea.gov.uk)



## Are you ready? Legal parenthood provisions

New laws relating to legal parenthood were introduced on 6 April 2009. These will primarily affect couples receiving treatment with donor sperm or embryos created with donor sperm.

Visit the HFEA website to find out what this means for you. View guidance for clinics at <http://www.hfea.gov.uk/areyouready>  
There is also an FAQs area for patients.



# Results from patients' panel survey

Improving the information we provide is one of the main strands of our work in the run-up to the introduction of the HFE Act 2008. We particularly wanted to improve the information we provide for patients.

*"I would like a further breakdown of the success rates for different diagnoses."*

Last October, we asked our patients' panel, Fertility Views, to tell us where they would expect to find information about infertility and whether the information we provide is helpful.

The panel told us that the information on our website and in our Guide to Infertility was helpful. The survey results showed that respondents found these areas beneficial:

- information about HFEA licensed clinics – **60%**
- general information about infertility problems – **56%**
- information about treatments – **54%**

However, there were a number of topics that patients would like more information about. These were:

- patient experience feedback – **86%**
- information about cost – **86%**
- quality of service – **86%**
- clinical safety – **80%**

These and many other suggestions have been incorporated into the content of our new website, with more detail on various treatments and techniques. Other suggestions have helped us develop a new version of the 'Choose a clinic' search tool that will be launched later this year.

Over 400 people responded to the survey, with **49%** of respondents having stopped treatment because it was successful; **27%** were having treatment and **16%** had stopped, having had unsuccessful treatment. A further **8%** were considering treatment.

*"Information and support if a cycle has to be stopped mid-cycle. This nearly happened to us twice and we were devastated."*

## Subscribe to the HFEA e-newsletter!

Visit our website at [www.hfea.gov.uk/e-updates](http://www.hfea.gov.uk/e-updates) and subscribe to our monthly email newsletter service, HFEA e-update, and keep up to date with:

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





## News

# HFEA carries out a fees review

HFEA is carrying out a review of its fees structure with the aim of consulting on new proposals early in 2010. Fees are charged to centres to cover the HFEA's costs of regulation under the Human Fertilisation and Embryology Act 1990.

HM Treasury and the Department of Health have asked for the review to ensure that HFEA's charges are sufficient to cover these costs and meet Treasury guidelines. It has also been a number of years since the HFEA carried out a review of its fees.

Although, a consultation was initially planned for this year, the Authority has decided, in light of the complexity of the issue, to take more time to gather

evidence and assess the likely impact of proposed changes on the sector.

We are currently exploring a range of options, including alternatives to the current fee per cycle charge. A three month consultation on the options is planned for early 2010, with a view to introducing any changes from April 2011.

The final decision on the fee structure will require sign-off by the Department of Health and HM Treasury and will be communicated to centres by the end of 2010, giving at least 3 months' notice of any change. We will keep professional bodies up to speed on developments in the run up to the consultation.

# Newly improved, easier to use 'For clinic staff' area

As part of the many changes to the new HFEA website, launched on 15 April, the 'For clinic staff' area has been thoroughly improved.

We have now made it much easier to find current HFEA guidance, as all out-of-date guidance has been archived. We hope this will now provide absolute clarity about what is current advice and what has been revoked.

Equally important are the improvements to the structure of the area. These have made it much more straightforward to find information such as forms, which are now all in one place.

Visit the 'For clinic staff' area of the new website now at <http://www.hfea.gov.uk/26.html>



# The HFEA reviewed

The HFEA is one of 31 national regulators being reviewed this year as part of the Government's implementation of the Hampton principles of better regulation. The purpose of the reviews is to promote more effective and efficient regulatory activity.

Over three days of intensive interviewing in April, the Hampton review team spoke to staff, Authority members and key stakeholders about the HFEA.

The report by the review team will be published later this year by the Better Regulation Executive.

Thanking the review team, Alan Doran said:

"The Hampton team has taken an objective look at how we operate. It has been a valuable experience for the HFEA and we look forward to receiving the draft report in the next few weeks.

"Just as we inspect centres, now it has been our turn to face the inspectors. And, just as we would expect centres to respond positively to our inspections, this is an opportunity for us to listen, learn and improve.

"I would like to thank the Hampton team and the centre and patient representatives and members of staff who helped them conduct this review."



## News in brief

### New 'Choose a fertility clinic' service

Currently the 'Find a clinic' search tool has been renamed 'Choose a fertility clinic' in anticipation of the launch of the new service in October 2009. The online tool is designed to help patients make informed choices about where to go for treatment.

As a result of extensive consultation about what information should be included, 'Choose a Fertility Clinic', as of October, will be presenting much more information about the services clinics offer. It will also present the most recent data on treatment cycles per clinic in a more understandable way, for example, by providing a snapshot of how a clinic is performing against the national average.

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

### Reminder about Alert 16

The HFEA would like to remind clinics about Alert 16 regarding patient confidentiality breaches. Clinics need to pay particular attention to ensuring that their administrative systems prevent correspondence regarding patients' treatment from being incorrectly addressed.

To view this alert visit the 'For clinic staff' area of the HFEA website and log in. If you are not sure what your login is, contact us at [admin@hfea.gov.uk](mailto:admin@hfea.gov.uk) for assistance.

## Upcoming events

### Open Authority Meeting, Oxford – 8 July

The meeting will be held at the Conference Centre, Oxford. For more information email [openmeeting@hfea.gov.uk](mailto:openmeeting@hfea.gov.uk)

### Annual Conference, Central London – 1 October

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

### Events for donors, donor - conceived people and their relatives

As a result of the new Human Fertilisation and Embryology Act 2008, we will be holding two events in July 2009. This will be to update the fertility sector on changes surrounding information access rights for donor-conceived people.

When the Act comes into force on 1 October 2009, donor-conceived people, their parents and donors will have greater access to information held by the HFEA.

These events will inform the sector of the legislative and policy changes and will seek views on what type of information the HFEA should provide to support applicants through the process of accessing data from the Register.

Both events will be held in London:

**For donors** – 22 July

**For donor – conceived people and their relatives** - 29 July

To register for these events, email [donorconception@hfea.gov.uk](mailto:donorconception@hfea.gov.uk)

Spaces are limited. Priority will be given to donor-conceived people, their parents and donors. Please specify which group you fall into, which event you would like to attend, and whether you have any special mobility or dietary needs.