

Welcome...

to the Autumn edition of the HFEA Update. This quarter's edition features an interview with our new Chair, Professor Lisa Jardine, news of the Bill being delayed, the publication of the Focus on Improvement report as well as other HFEA news.

Autumn 2008

Delay of the HFE Bill

The Human Fertilisation and Embryology Bill, which has been progressing through the House of Commons over the spring and summer, has been delayed.

The Bill was scheduled to have both the report stage debate and third reading on 14 July 2008. However, new business introduced to the House at a late stage has resulted in parliamentary timetable changes, including the postponement of these latter stages.

The final debates are now expected to occur some time in the autumn, though no firm dates have been scheduled as yet.

The HFEA continues to base its Bill implementation planning on a timetable that assumes Royal Assent in the autumn and aims for release of the 8th edition of the Code of Practice in October 2009.

Updates to the Bill's timetable and further amendments to be debated at these stages will continue to be posted at <http://services.parliament.uk/bills/2007-08/humanfertilisationandembryology.html>

Inside...

Delay of the HFE Bill	1
HFEA at BFS Summer College 2008	1
Oneatime Update	2
Professor Lisa Jardine, HFEA Chair	3,4
Root and branch review	4
Focus on improvement report published	5
Update on the HFEA Change Programme	5
News in brief	6
Upcoming events	6



HFEA at BFS Summer College 2008

The HFEA will be exhibiting at the BFS Summer College 2008 event in Liverpool from 2 - 5 September. Alan Doran, HFEA Chief Executive will be speaking at the event, where there will be talks by international experts on various fertility issues.

The meeting is aimed at Persons Responsible and senior staff at fertility clinics and is open to all those involved in reproductive medicine and reproductive sciences.



News

Oneatotime Update

Oneatotime.org.uk was recently launched and has received 16 000 page views over the last month. The website has received positive feedback from both the sector and patients.

Currently one of the most popular areas is the patient stories, where patients share their personal experiences with multiple pregnancies and births.

Oneatotime is a professionally-led website aimed at reducing the risks of multiple pregnancies from fertility treatment. Focused on the importance of accelerating the reduction in multiple births, a series of workshops were held across the UK aimed at all staff in fertility centres and all those who commission fertility services.

The workshops proved to be a valuable opportunity to share the changes and developments of this initiative. Jane Denton from the Multiple Births Foundation, said: "the workshops have proven to be an excellent opportunity to share experience and help clinics to develop their own strategies and discuss concerns about reducing the twin birth rate from IVF."

Rachel Cutting from the Association of Clinical Embryologists also commented that the workshops were a success and the feedback was excellent from those attending.

She thought that the discussions at the end of the meetings were lively with views expressed such as more funding is required for elective single embryo transfer to be successful.

Some of the topics covered in the workshops included:

- Whether there is a need for change in clinical and laboratory practice;
- Outcomes for children after IVF;
- Practical issues in the clinic that need to be taken into account;
- Looking at what information patients need;
- Quality issues in commissioning care; and
- What the local issues are in your area.

Visit oneatotime.org.uk for more information or to view the presentations from the workshops.

Subscribe to the new HFEA e-newsletter!



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

News

Professor Lisa Jardine, HFEA Chair

Professor Jardine tells us about her experience as Chair of the HFEA...

What made you want to be the Chair of the HFEA?

The moment I was asked if I would be interested I knew that I badly wanted the job. Infertility is one of the biggest challenges to face us in the modern world, and I knew it would be a privilege to steer the organisation that ensures infertility treatment is delivered safely in the UK.

Scientific research on human embryos is at a critical point in its rapid development, and it also seemed to me a real challenge to be closely involved in monitoring that research on behalf of a concerned general public.

What did you do before you were Chair of the HFEA?

I have been an academic all my life, working on European Renaissance History, particularly History of Ideas and History of Science. I work in archives and libraries, studying manuscripts and rare books.

Nothing could really be farther from HFEA matters! But I believe the skills of close attention to detail, patience and a passionate concern for the truth will stand me in very good stead at the HFEA.

As a senior academic and public figure, I have also chaired and led a number of organisations, and learned how to do so with confidence.

How do you see your role at the HFEA? What are the most important aspects of the job for you?

The most important part of my role as a lay Chair of the HFEA is leadership. I want to earn the trust of all the constituencies I serve - patients, clinicians, scientists, donors, donor-conceived people and the concerned public at large. I am already enjoying mastering all the disparate areas of knowledge needed to enable me to provide that leadership.



What parts of your work at the HFEA do you enjoy most?

I love it all! I enjoy meeting people - particularly patients. I enjoy grappling with the difficult science, and the increasingly complex medical issues raised by treatment.

The team of staff and experts I work with are, without exception, talented and exceptionally hard-working, and I am proud to spend time with them. And I suppose in the end, what I love is being at the peak of my career but still learning new things every day because of the issues the HFEA raises.

Which parts of the job do you find the most challenging?

Quite often there are conflicts between what different groups regulated by the HFEA want and need. It is really hard to have to tell a patient that the law does not let us make what seems to them an obvious exception to what is allowed. And I do have a constant sense that treatment and scientific research are moving so fast that it is a real challenge to keep up.

How do you see the role of the Chair compared to the Chief Executive and other full-time members of staff?

I rely absolutely and entirely on my Chief Executive and full-time staff. After all, I am a lay Chair. I represent the HFEA all over the world, and I rely on the accuracy, sensitivity and general intelligence of the information and advice I get from my executive team. They guarantee that what I do has force and credibility.

News

Professor Lisa Jardine, HFEA Chair (continued)...

My role is different though because I am appointed by a public process. I am not an employee so I try very hard to relate all that I do to the needs of the public.

What are the main immediate differences people will see with the HFEA now that you are Chair?

I think I am perhaps out there more, talking about what the implications for all of us are of fertility treatment and scientific research involving human embryos. I am utterly committed to informing the general public about everything the HFEA does. Communication is more than a job for me - it is a passion.

I think it is already clear that I want to be in the public eye on behalf of the HFEA, talking and explaining what we do and what the outcomes of our regulation are. If I were asked what the one thing is that I want people to feel when they listen to me it is that the HFEA can be trusted.

What are the biggest differences you would like to make to the HFEA in the longer term?

I want it to be clear that the HFEA goes hand in hand with those we regulate - that it is a two-way process of confidence and trust. I also want us to make more use of the mountain of data we have collected since the HFEA was set up. That data can be used for far greater understanding, particularly of success and failure rates in fertility treatment. Research in the field could take far greater advantage of our resources.

What would you say are the biggest challenges for the sector? In treatment? In research?

In treatment I think the biggest challenges are embryo selection and adjuvant treatments, including reproductive immunology.

In research, the challenges lie in the area of stem cell research, where there will be increasing pressure to attempt manipulation of embryonic material which many people find morally troubling.

Root and branch review



The HFEA collects a large range of information and we are looking into how it can be best used. This includes how the HFEA might collect and publish performance data in the future on the 'Find a clinic' section of our website. The HFEA will be discussing information needs with centres and we

are very keen to involve as many of you as possible in developing our strategy on information.

The HFEA will be visiting individual centres to hear your views about the information we collect and how we can improve the presentation of information.

There will also be events held in September with patients and the public and also with researchers to hear their views on the subject. Both events should provide important pieces of evidence for our review of information.

If you would like to be involved contact Rachel Hopkins at rachel.hopkins@hfea.gov.uk



News

Focus on improvement report published

A new report published in August this year gives the latest overview of standards of performance across the UK fertility sector.



Focus on Improvement, a follow up to 2006's *Driving Improvement*, analysed findings from inspections, patient comments and complaints, and incidents reported between April 2006 and March 2007. The report's purpose is to help clinics improve their practice and the service they provide to patients.

Overall, clinics met the standards required by the HFEA and provided a good service to their patients. Patients also reported a high level of satisfaction with the services provided.

However, the report also identified areas where clinics could improve their performance.

The top five areas include:

- laboratory processes and practice;
- equipment safety, servicing and maintenance;
- information for patients and donors;
- clinical practice, and
- consent.

Around 173 incidents were reported during the reporting period and three alerts were issued, two of which related to issues with witnessing practices.

The number of incidents was very low when set against the 48,000 treatment cycles undertaken during the year. As a result of these alerts, HFEA developed new directions and provided an audit tool for Persons Responsible to use when checking laboratory protocols.

Further information and copies of the report are available on the HFEA website.

Update on the HFEA Change Programme



With the new legal and regulatory requirements, such as the Hampton Review, the Legislative and Regulatory Reform Act, the Regulators Compliance Code and

the Regulatory Enforcement and Sanctions Act, we are looking at how we can become a better regulator.

Most importantly, we await the outcome of the Human Fertilisation and Embryology Bill which, once passed into law, will have a fundamental effect on the way the HFEA regulate and provide information.

As part of the change process, we will need to change our role as an information provider and improve our inspection process.

The Code of Practice will be revised and this has implications for:

- What is inspected and how it is inspected
- Patient and donor information
- The responsibilities of centres and the HFEA

We have also taken into account your feedback on the 7th Code and are acting on this. The Licensed Centres Panel met recently to discuss proposals after which we wrote to all Persons Responsible and Quality Managers to explain the work so far.

A formal consultation on the Code will take place in November. In the meantime we are keen to hear the views of as many of you as possible.

For more information contact Rachel Hopkins at rachel.hopkins@hfea.gov.uk



News in brief

Reminder: 2006 live birth rates

We would like to remind centres that the deadline for all corrections and submissions for the 2006 live birth rates is 25 September.

The deadline for Persons Responsible to sign off the final data produced by the HFEA in order to have it published as 'confirmed' on the 'Find a clinic' section of the HFEA website is 26 September. The success rates will be published on the website on 1 October.

Please ensure you confirm your verification reports allowing sufficient time, so any queries can be dealt with before the deadline.

If you have any questions regarding the verification reports or your statistics please contact your QA Officer.

Reminder: Applications for PGD and aneuploidy

Applications for pre-implantation genetic diagnosis (PGD) and aneuploidy screening should be submitted electronically to PGD@hfea.gov.uk

Upcoming events

HFEA Annual Conference 'Delivering the future: Bringing the Bill to Life'

Central London - 13 October

This year's conference will be focusing on a range of topics including:

- Putting better regulation into practice
- New scientific developments: HFEA Horizon Scanning
- Improving information to aid decision-making by patients and clinics
- Implementing Opening the Register

The key note speakers will be:

- Rt Hon Dawn Primarolo MP, Minister of State for Public Health
- Lord Justice Moses
- Professor Lisa Jardine, new HFEA Chair

The conference brings together experts from across the assisted reproduction and embryo research sectors. There will be an opportunity to ask questions, contribute to debates and participate in a panel discussion. The conference which includes a drinks reception, is free to attend and places are limited. Invitations will be allocated on a first come first served basis.

To register email annualconference@hfea.gov.uk no later than **1 October 2008**.

Open Authority Meeting

Edinburgh – 17 December

Details on venue, agenda and arrangements to be announced.

For more information email openmeeting@hfea.gov.uk