



Welcome to the January issue of HFEA Update.

In this issue, we provide a brief summary of the research conference which took place in November 2004 and present the forthcoming Annual Conference. We also take this opportunity to update centres about other ongoing or current projects.

Please distribute copies of the HFEA Update to other members of staff. The HFEA Update is also available online: [www.hfea.gov.uk/HFEAPublications](http://www.hfea.gov.uk/HFEAPublications)

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### HFEA Research Conference 2004

One of the HFEA's core functions is to regulate human embryo research. Our annual Research Conference is designed to provide an opportunity for staff from clinics, research centres, the HFEA and other professionals with an interest in human embryo research to hear more about current activities and discuss related issues. In November 2004, we held our second Research Conference in London, expanding the programme to cover not just scientific research but also areas, such as counselling, controlled clinical trials and the impact of the Freedom of Information Act.

HFEA Chair, Suzi Leather, opened the conference. In the first session, entitled "Is the 1990 Act a hindrance to embryo research in the 21<sup>st</sup> Century?", Professor Robin Lovell-Badge of the MRC National Institute for Medical Research spoke on current trends in research and new technologies. He questioned whether the Act was flexible enough to deal with the pace and changes in society and in science. Professor Emily Jackson reiterated the need for a clearer definition of an embryo, for example, and highlighted the gap in the HFEA's ability to license clinical trials. She also asked whether some of the restrictions in Section 2 of the 1990 Act would now be included if the Act was created from scratch.

Overall, Professor Jackson's view was that despite some shortcomings, the 1990 Act has been successful in enabling embryo research to go ahead in the UK within a regulatory framework which promoted public confidence.

The focus then moved to the importance of counselling. Ms Sue Truman of the British Infertility Counselling Association (BICA) explored the role of counselling in research, highlighting the need for people who were donating embryos to research to make an informed choice. Counsellors could help them to explore their motives and the many possible outcomes that might arise from their decision.

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Ms Judith Maunder an Associate at Morgan Cole outlined the implications of the new Freedom of Information Act on the HFEA and particularly the management of confidential information. There was lively discussion on the kind of information that people might request under the Act, and what – if any – exemptions might apply.

Dr Peter Brocklerhurst, Director of the National Perinatal Epidemiology Unit at the University of Oxford, looked at the importance of conducting randomised controlled trials. He highlighted the limitations of biased allocation of subjects in clinical trials, particularly in the field of assisted reproduction. The afternoon provided delegates with an opportunity to hear at first hand about some of the research projects currently licensed by the HFEA. These were:

The mechanisms of aneuploidy arising from human oocytes, by Professor Joy Delhany, Emeritus Professor of Human Genetics at UCL London and Scientific Director of the UCL centre for Pre-implantation Genetic Diagnosis).

Gene expression and regulation in the pre-implantation human embryo, presented by Dr Sue Kimber of the University of Manchester.

Derivation of human embryonic stem cells, presented by Dr Sue Pickering, from the Centre for Pre implantation diagnosis at Guys and St Thomas.

Growth of human embryonic stem cells in animal and feeder free conditions, by Dr Miodrag Stojkovic from the Centre for Stem Cell Biology and Developmental Genetics, University of Newcastle.

Henry Leese, Professor of Biology at the University of York concluded the conference with an overview of the future trends in human embryo research. This included understanding the molecular cell biology of the embryo, gene expression and developmental plasticity. He also addressed the importance of focusing on long term safety and efficacy to ensure the health of the offspring and that of second generations. This final discussion also raised the importance of developing a model to understand genome sequences as they are unravelled and to study the

development of human embryos in vivo as well as in vitro.

A full report from the Research Conference will be published on the HFEA website shortly.

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## **HFEA Annual Conference 2005**

We hope you will be able to attend the HFEA Annual Conference on Tuesday 15<sup>th</sup> March 2005. The all-day event, held at the Royal College of Surgeons in London, will be an opportunity for doctors, embryologists, nurses, counsellors, patient organisations and other interested parties to look ahead to the future of the ART sector.

The conference will be followed by a reception. Registration forms are available from the HFEA – please email [annualconference@hfea.gov.uk](mailto:annualconference@hfea.gov.uk)

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## **Welfare of the child consultation**

On January 13 2005, the HFEA launched a public consultation on our guidance to centres regarding welfare of the child assessments. Entitled *Tomorrow's Children*, the consultation lays out options for revising three areas of the welfare of the child guidance in the *Code of Practice*:

- Factors to be taken into account: should assessments focus solely upon medical risks to the child or should centres consider a broader range of psychological and social issues?
- Enquiries to be made: should centres continue to request further information from GPs, or should they rely either upon information from the patients themselves or from agencies such as social service department?
- Donor conception treatment: should assessment be more rigorous in donor conception treatment, or should efforts be focused more upon providing patients with better information and preparation?
- Unlicensed treatments performed in licensed centres: should the same level of assessment be used for treatments such as intrauterine insemination (IUI)?

We would like to hear the views of all the professional groups working in centres. To request a copy of the consultation document, or to respond to the consultation questionnaire, please visit the HFEA website at [www.hfea.gov.uk/AboutHFEA/Consultations](http://www.hfea.gov.uk/AboutHFEA/Consultations) or contact the HFEA on 020 7291 8200.

The written consultation will be complemented by three consultative meetings, designed to create an opportunity for professionals working in centres to discuss the ethical and practical aspects of welfare of the child assessments and to allow the HFEA to get a broader perspective on the issue. The discussions at each meeting will be used to inform our thinking about what changes should be made to the Code of Practice. The dates of the meetings are as follows:

Glasgow: 23 February, 2-5pm

London: 8 March, 2-5pm

Manchester: 22 March, 2-5pm

For more information or to register for one of the meetings, please contact Nicky Gibbs at [nicky.gibbs@hfea.gov.uk](mailto:nicky.gibbs@hfea.gov.uk).

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## Screening of Patients

Centres are reminded that Chair's Letter CH(01)09 (dated 6 June 2001) introduced a new policy on safe cryopreservation with an implementation deadline of 31 December 2004. This is also set out at paragraphs 9.2 to 9.4 of the HFEA Code of Practice. All patients placing gametes or embryos in storage should now be screened for HIV, hepatitis B and hepatitis C, with separate cryostorage of screened and unscreened samples. The purpose of this policy is to reduce the risk of cross contamination between samples.

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## Historic Audit Project

The recruitment for the Historic Audit Project is now complete for six teams and good progress is being made with the work.

The Operational Audit Team now has a full complement of auditors headed up by Hugh Pritchard.

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## House of Commons Select Committee Inquiry

HFEA appeared for the final time before the Select Committee's current inquiry into Human Reproductive Technologies and the Law. HFEA Chair, Suzi Leather, and Authority members Professor Neva Haites and Professor Emily Jackson gave evidence to the Committee together with Melanie Johnson MP, Minister for Public Health. The HFEA's evidence concentrated on the reforms required to

the 1990 HFE Act and improvements in regulation being made. A transcript of the session is available on the Committee's web site [www.parliament.uk/parliamentary\\_committees/science\\_and\\_technology\\_committee.cfm](http://www.parliament.uk/parliamentary_committees/science_and_technology_committee.cfm). The Committee have now concluded their evidence sessions and their report is expected by Easter.

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## Inspection Reports

Just a reminder to all Centres that we will soon be publishing all licence committee minutes and inspection reports on our main website. This is in line with both the HFEA Publication Scheme, but also to meet Freedom of Information Act requirements.

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## Donor information regulations: advising donors about updating contact details

The HFEA (Disclosure of Donor Information) Regulations 2004, which became law earlier this year, guarantee to donor-conceived people a right to receive identifying information (name, date of birth, address and appearance) about the donors whose samples were used in their conception *if those donors have registered with clinics on or after April 1, 2005*. Centres should be aware that a small number of past donors may possibly wish to re-register after 1<sup>st</sup> July 2005 so that they become identifiable.

Whilst the HFEA will make every effort to advise a donor when an application for identifying information about them has been made, and to inform them about services that may exist to mediate possible personal contact from donor offspring, its ability to do so will depend on the Authority having up-to-date contact details for the donor.

Centres are therefore reminded that they should strongly advise donors that it is in their own interest to keep the recruiting centre informed of their current address and contact details so that this may be reported to the HFEA and used to inform the donor should an application for identifying information be made.



**Bishop Richard Harries**

## Member Focus

### The Right Reverend Richard Harries, Bishop of Oxford

The Rt. Rev. Richard Harries, Bishop of Oxford joined the HFEA in November 2003. Bishop Richard has been the Bishop of Oxford since 1987 and took his seat in the House of Lords in 1993. Before that he was Dean of King's College, London, a lecturer in Christian ethics and a parish priest.

The Bishop brings to the Authority an expertise in medical ethics and chaired the House of Lords Select Committee on Stem Cell Research which enabled the recommendations of the Human Fertilisation and Embryology (Research Purposes) Regulations 2001 to go ahead. He also has specialist interests in the ethics of war and business.

Bishop Richard joined the HFEA because "important cutting edge decisions are made here and they need an ethical input", he adds "this is a very stimulating subject". He is a member of the HFEA Ethics and Law Committee and Licence Committees which requires him to travel to London at least two days a month.

He has been a member of the Nuffield Council on Bioethics for three years and is an experienced broadcaster and does a regular slot for BBC Radio 4's *Thought for the day*. Bishop Richard has also written a number of books and his latest book *The Passion in Art* reflects his interest in the Arts.

Bishop Richard is married to a doctor and has two children and 3 grandchildren. As well as enjoying the theatre and literature, Bishop Richard keeps fit by swimming and walking.

He is looking forward to the government's review of the Human Fertilisation and Embryology Act 1990 and says "it has existed for 14 years now and it gives the HFEA a chance to review its work".

The Bishop was involved in the HFEA working group on the review of the act which gave recommendations to the Department of Health on what areas of the act the HFEA would want to change to improve regulation and patient safety.

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## Staff news

Trish Davies has been appointed as Deputy Chief Executive  
 Mick Green joined on 2<sup>nd</sup> November as Quality Assurance Manager  
 Shelly Keir joined on 13<sup>th</sup> December as EDI Co-ordinator  
 Mark East, Mo Sarwar, Beverley Wright and Alison Basford will be joining on 17<sup>th</sup> January as EDI Trainers  
 Fidel Dola-Lami will be joining on 17<sup>th</sup> January as EDI Installation Engineer.

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## Diary Dates

**HFEA Open Authority Meetings during 2005**  
 Tuesday 8<sup>th</sup> February; Wednesday 18<sup>th</sup> May & Tuesday 11<sup>th</sup> October

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

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