



Human
Fertilisation &
Embryology
Authority

Annual conference 2018

Event booklet

Thursday 15 March 2018
#hfea2018

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Agenda

Registration	9.30-10am
Opening remarks Peter Thompson, HFEA Chief Executive	10-10.15am
Workshops	10.15-11.25am
Refreshments	11.25-11.40am
Chair's address Sally Cheshire CBE, HFEA Chair	11.40am-12.10pm
External speaker Jackie Doyle-Price MP, Parliamentary Under Secretary of State for Mental Health and Inequalities	12.10-12.30pm
External guests John Webster and Louise Brown	12.30-1pm
Lunch Visit our marketplace and surgery (see p10 for more details)	1-2pm
Workshops	2-3.10pm
PRISM: our new data submission system Nick Jones, HFEA Director of Compliance and Information	3.10-3.35pm
Intelligence-led regulation Peter Thompson, HFEA Chief Executive	3.35-4pm

Workshops

How research can benefit patients and professionals

Chair: Bobbie Farsides

Support: Anne Lampe

Panel members: Daniel Brison, Jenny Nichols, Charlotte Hall and Laura Riley

This workshop explores embryo and data research and the important contribution that clinics can make to it. It explores new methods to encourage better research and looks at some successful research collaborations and how to get patients involved.

Supporting patients

Chair: Kate Brian

Support: Lee Rayfield

Panel members: Kelly Da Silva, Avril Mackie, Ruth Wilde, Sue Avery and Esmée Hanna

This workshop discusses the importance of supporting patients throughout their treatment and how providing good support is the responsibility of everyone in the clinic. It looks at how effective leadership can help towards excellent patient-centred care.

Achieving better clinical standards of care – best practice in OHSS

Chair: Yacoub Khalaf (morning session) and Tony Rutherford (afternoon session)

Support: Nick Jones

Panel members: Raj Mathur, Paula Nolan and Jan Dutton

This workshop provides guidance on best practice methods of recording and reporting OHSS, including keeping in touch with patients throughout their treatment.

Using HFEA data effectively to benefit the sector and patients

Chair: Margaret Gilmore

Support: Anita Bharucha

Panel members: Lisa Whiting, Jessica Hepburn and Zeynep Gurtin

This workshop looks at how our data can be used effectively to benefit patients and the sector. We will discuss key findings from our annual statistical analysis and seek your input on how these can be further developed. We will also hear from patients and researchers on how they have used data.

Welcome from our Chair



I am delighted that you can join us for the 2018 conference in this milestone year for our sector.

This year the UK celebrates 40 years since the birth of the world's first IVF baby, Louise Brown. We are delighted to welcome Louise here today together with Dr John Webster, who was the registrar of Dr Patrick Steptoe. They will reflect on the pioneering journey she and her family took with Bob Edwards, Patrick Steptoe, Jean Purdy and the team to pave the way for millions more babies to be born across the globe.

We can be proud that the UK fertility sector remains at the forefront of scientific and clinical progress in the field. As we prepare ourselves for the first mother to have a baby following treatment for mitochondrial disease, continue work in gene editing research, and reach our 10% target for multiple births, I truly believe the UK is the best place for innovation to flourish whilst maintaining overwhelming public trust. The HFEA is cited as a pioneering force in ethical policy making and regulation, and we will continue to build on our excellent relationships with you across the sector so that we can offer all our patients the highest quality care and the best possible chance of having the families they long for.

We are well on the way to achieving our 2020 goals, and high-quality treatment and support remain at the heart of our ambition for patients, donors and donor-conceived people. We have worked with you to deliver safe, effective, evidence-based care, the best emotional support throughout treatment, and high-quality research which underpins continued scientific and clinical advances. Since 1991, the success rate for IVF has more than doubled and we have almost reached our 10% target for the multiple birth rate following fertility treatment, without impacting birth rates; a real public health success story.

This last year has been pivotal for us in the way we communicate with you and your patients. We rolled out Clinic Portal and are completing the final stages of our data submission system, making it easier for you to input and access your data. Our new website contains more extensive and easily accessible information for patients, helping them make informed choices about their treatment.

Our sector has come a long way since Louise Brown was born. Our collective task now must be to deliver greater consistency in patient outcomes and a real culture of responsible innovation. By this, I mean involving patients on a much wider scale in your clinics to advise on care and support and ensure innovative treatments can be tested and introduced with a consensus that they work effectively. I encourage you to reflect, when you go back to your clinic, on what you can change to improve patient care and outcomes.

I would like to thank all of you, and the HFEA staff and members, for your continued hard work and collaboration. I am delighted that our workshops today are once again being chaired by Authority members and I hope that you will find the day both enjoyable and worthwhile. We look forward to working with you again this year in the best interest of our patients.

A handwritten signature in black ink that reads "S Cheshire".

Sally Cheshire CBE

Chair

Intelligence-led regulation



The relationship between you and us, the clinic and the regulator, has, I believe, never been better. That's not to say that it's always easy, and I don't expect that you look forward to a visit from the HFEA. But I do believe that most of you think that the inspection process adds value and highlights ways that you can provide even better services to your patients.

But it works both ways. We learn a lot from you. I know from the conversations that I've had with clinic staff over the past 12 months, that you know we are listening. We really do want to hear what you say, because we know that to regulate well, we must understand how our policies work in the clinic and in the laboratory.

This year we will issue the 9th edition of our Code of Practice. As you know, the code is the key guide to providing high quality services within the framework of the law. At workshops across the country you're telling us that the code is clear and helpful. That's great, but we're also hearing that it could be better. I'm clear that the new code must meet your needs – if it doesn't, please tell us.

For some years now, we have been developing a new range of information services for patients and clinics. Our new website represents a step change in patient-centred information. Clinic Portal should be your central point of contact with us for applications, guidance and much more. I'm delighted that at this conference we'll be able to demonstrate our new data submission system, which will come on line in the autumn. I know it's been a long time in development and I want to thank you for your support and patience, but a fast and easy electronic data submission system is now within reach.

But it's not just a question of making it easier to submit accurate data; we also want to use our new information systems to strike a new bargain between us. Your side of the information bargain is to submit accurate treatment data on time. Our side is to turn clinic data into sector-wide intelligence and to make more of that information available to you and the public. That's why I'm delighted that the latest 'Fertility trends report' contains more up-to-date statistics than before. Looking ahead, it will become an annual publication, alongside our 'State of the sector report', which we published for the first time late last year.

This is just the start of 'intelligence-led regulation' to help improve the performance of your clinic and provide better information to the public.

A handwritten signature in black ink that reads "Peter Thompson". The signature is fluid and cursive.

Peter Thompson

Chief Executive

Our Senior Management Team



Peter Thompson
Chief Executive

Peter leads the Senior Management Team and is responsible for our overall performance and strategic direction. He also has responsibility for the organisation's HR and legal functions.



Clare Ettinghausen
Director of Strategy and Corporate Affairs

Clare joined us in 2018. She leads the teams working in policy, communications and engagement, intelligence and research, and governance. She was previously Deputy Chief Executive of the Electoral Commission, working on the regulation of political parties and best practice in elections management.



Nick Jones
Director of Compliance and Information

Nick is responsible for our inspection, incidents and Register teams. He is leading the Information for Quality programme to transform the way in which clinics submit data to us and the uses to which it is put.



Richard Sydee
Director of Finance and Resources

Richard joined us in November 2016 and is also Director of Finance and Resources for the Human Tissue Authority. He leads the finance and facilities functions, ensuring they support us to deliver our objectives.



Our Authority members



Sally Cheshire CBE

An Authority member since 2006, Sally has personal experience of unsuccessful IVF. She has been our Chair since January 2014, when she took on the role on an interim basis, before becoming permanent in April 2014. Her background is in finance & business.



Margaret Gilmore

Margaret is our Deputy Chair. A former BBC journalist, she continues to write, lecture and commentate on national security and communications issues. She is also an Assistant Boundary Commissioner for England.



Anita Bharucha

Anita is an independent management consultant who has personal experience of unsuccessful IVF. She brings 18 years' experience as a civil servant, working in the Home Office, Cabinet Office, Northern Ireland Office and as a Director in the Ministry of Justice.



Mr Yacoub Khalaf

Yacoub is the Medical Director of the Assisted Conception Unit (ACU) at Guy's and St Thomas' Hospital, Director of their pre-implantation genetic diagnosis (PGD) programme, and an Honorary Senior Lecturer at King's College London.



Professor Bobbie Farsides

Bobbie is Professor of Clinical and Biomedical Ethics at Brighton and Sussex Medical School. She has more than a decade of experience in researching ethical issues relating to healthcare, especially fertility treatment and antenatal screening.



Dr Andy Greenfield

A geneticist, Andy is Programme Leader at the Medical Research Council's (MRC) research unit and Chair of their Ethical Review Committee. His research is mostly focussed on studying how the structure and function of mammals' genes develop at a molecular level.

**Kate Brian**

Kate has personal experience of fertility problems and her two children were born following IVF. A former television journalist, she continues to write and is Women's Voices Lead at the Royal College of Obstetricians and Gynaecologists.

**Dr Anne Lampe**

Anne is a consultant in Clinical Genetics at the South East of Scotland Clinical Genetic Service in Edinburgh. She has a special interest in rare syndrome diagnosis and eye genetics and is a Fellow of the Royal College of Physicians (Edinburgh).

**Mr Tony Rutherford**

Tony is a consultant in Reproductive Medicine and Gynaecological Surgery at the Leeds Centre for Reproductive Medicine. He was one of the first to introduce vaginal ultrasounds and gonadotropin-releasing hormone agonist drugs into routine practice.

**Ruth Wilde**

Ruth is a counsellor with over 18 years' experience, specialising in infertility since 2002. Currently a Senior Fertility Counsellor at the Complete Fertility Centre in Southampton, she has previously worked in Birmingham and London.

**The Rt Reverend Dr Lee Rayfield**

Lee is the Bishop of Swindon and a member of the Society of Ordained Scientists (Holy Order). In the past, he was a member of the UK Gene Therapy Advisory Committee.



Marketplace and surgery details

Marketplace

Donor Conception Network

www.dcnetwork.org

Fertility Network UK

www.fertilitynetworkuk.org

Progress Educational Trust

www.progress.org.uk

British Infertility Counselling Association

www.bica.net

National Gamete Donation Trust

www.ngdt.co.uk

Louise Brown

www.louisejoybrown.com

Fertility Fest

www.fertilityfest.com

Surgery

Our staff will be on hand to answer your questions about our new data submission system, PRISM (Patient Register Information System).



Resources

Clinic Portal

Our dedicated website for clinic staff. Use it to:

- view your performance data
- see our latest news
- find regulatory guidance and requirements
- make licensing and authorisation applications
- download forms, and
- update the details about your clinic that appear on the Choose a Fertility Clinic (CaFC) area of our website.

Clinic focus

Our monthly e-newsletter for clinic staff, available on Clinic Portal.

Our leaflets and guides

We've produced a series of useful leaflets which you can download and print for your patients and donors. These include:

- **Getting started** – a complete overview of the fertility treatment process from start to finish.
- **Guides to consent** – with versions designed for patients and their partners and donors, these guides explain more about the process of giving consent and the support that clinics should offer.
- **Becoming the legal parents of your child** – explains how those who are having treatment with donated sperm or embryos, and who are not married or in a civil partnership, can make sure they are recognised as the legal parents of any child born from treatment.
- **I have remaining embryos, what are my options?** - explains what can be done with stored embryos if a patient no longer needs them for their own treatment.

Find them all in the 'about us' section of our website, www.hfea.gov.uk, under publications.

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