

## Speech delivered by Sally Cheshire CBE Chair, Human Fertilisation and Embryology Authority Science Museum, London, 5 July

Thank you, Roger, for that introduction.

As the chair of the HFEA, the UK's regulator of fertility treatment and human embryo research, I feel immensely proud and privileged to be here today to celebrate the 40th anniversary of the world's first IVF baby, Louise Brown, with such a distinguished audience.

I am delighted to be welcome Aileen Feeney from Fertility Network UK, who celebrate their 15<sup>th</sup> birthday today, and Jane Denton, President of the British Fertility Society, representing together the medical world which allowed the pioneering science of IVF to reach patients across the UK and around the world after Louise's birth in Oldham in 1978.

Similarly, I welcome many of the current and some former HFEA Board members including clinicians, a patient representative and my deputy chair, Margaret Gilmore, who as a cub reporter 40 years ago, had the pleasure of documenting Louise's birth.

But it is to Professor Sir Robert Edwards, Dr Patrick Steptoe and Jean Purdy that we owe the most, for inventing in vitro fertilisation or IVF, persisting until it succeeded and allowing millions of patients after Lesley and John Brown, Louise's parents, to create their much longed-for families.

I would like to acknowledge Bob and Patrick's family members here today, to say a very public thank you to them for what was achieved and to remind everyone here today that IVF is just one example of the huge potential the UK has for scientific and clinical innovation, respected the world over and celebrated in the Science Museum's wonderful exhibitions - today, of course, focused on IVF.

It is significant today that we celebrate this medical innovation that has changed so may people's lives, on the same day as the 70th anniversary of the NHS celebrations that take place later at Westminster Abbey and York Minster.

Although the first IVF treatments took place privately, Louise and all the other IVF babies would not have been born without the NHS and those extraordinary people working together more than 40 years ago. So we do indeed have double cause for a celebration today.

Louise's birth was a defining moment in medicine and one that, as Roger said, went on to have a huge impact on both the lives of individuals and society as a whole. The UK has reached the milestones of 1 million IVF treatment cycles and 300,000 babies born. Estimates of the number of children born through IVF across the world vary from 5million, 6million to even 10 million. We will probably never know the exact number.

And a recent article in Reproductive BioMedicine Online estimated that by 2100, 400 million babies or 3% of the global population could exist by virtue of IVF, if you include all original IVF babies and their descendants.

That's quite a statistic to come out of Oldham and Bourn Hall clinic, where the first lab work and clinical treatments were carried out.

But if we rewind 40 years, it wasn't all plain sailing. The public's initial reaction to the development of IVF was divided.

Some were proud that the UK spearheaded this new technique, while others were uneasy about the apparently uncontrolled advance of science, bringing with it new possibilities for manipulating the early stages of human development.

IVF was controversial enough that the Medical Research Council refused to fund it and Dr Kay Elder, who worked in the early days at Bourn Hall has revealed that much of that money came from an American millionairess, Lillian Lincoln Howell, who herself suffered from fertility problems and remained anonymous as a benefactor until her death in 2014.

It was society's unease that led the then Government to commission an inquiry, chaired by Mary Warnock, to consider the social, ethical and legal implications of IVF and what safeguards should be put in place.

The Warnock report, published in 1984, identified the need for principles and limits to govern fertility treatment and human embryo research.

MPs from all parties came together to support the Human Fertilisation and Embryology Act because they supported the idea of the regulation of fertility treatment and embryo research, and ultimately, our organisation, the Human Fertilisation and Embryology Authority (or HFEA for short) started work in 1991.

If you listen to MPs who supported the Parliamentary bill at the time, it wasn't a given that the legislation would succeed, and I pay tribute to those across the political spectrum who had the courage and foresight to support pioneering legislation as Edwards, Steptoe and Purdy had pioneered IVF as a medical treatment.

Our remit at the HFEA remains the same today as it was in 1991 – to ensure treatment is safe and ethical. We want to ensure that everyone who steps into a fertility clinic, and everyone born as a result of treatment, receives the best quality care.

We do this by licensing, monitoring and inspecting UK fertility clinics, as Mary Warnock's Committee envisaged and as was set out in the HFE Act.

We set standards by which clinics operate and we use the data we collect by law to improve the quality and consistency of clinic performance and the service patients receive.

The UK has the largest database of fertility treatment in the world (all one million cycles) and we seek to analyse that data for the sector and for patients so that they can make the best informed decisions on their treatment.

There have been huge advancements in scientific research and medicine over the past 40 years and the UK remains at the forefront of scientific and clinical development in IVF.

We are leading the way with a regulatory model, which has managed to support innovation while maintaining the trust of the public and patients that we will be ethically robust in our decision-making. It's what is sometimes called the bargain between science and society.

The HFE Act has now been in place for 27 years and society is very different in 2018 to 1978.

In partnership with the fertility sector and Parliament, we face continued controversy, public debate and legislative change head-on and we have managed to successfully navigate changes to legal parenthood and donation amongst other topics.

Doubtless there will be calls for further legislative change in areas Mary Warnock's committee were simply not forced to consider, like storage of frozen eggs and sperm beyond the current 10-year limit, but that is a matter for Parliament.

What I can say in 2018 is that the ethical lines laid down by Baroness Warnock, such as the 14-day rule for keeping embryos for research, still stand and there has been no "slippery slope".

The UK still bans sex selection and human cloning and I believe we have successfully upheld the morality the HFEA was set up to preserve.

On a positive front, we have seen embryo testing developed to allow people to avoid passing on serious inherited diseases to any children they might have.

The UK was the first country in the world to license ground-breaking mitochondrial donation techniques which allow women who carry the risk of serious mitochondrial disease to avoid passing it onto their children.

We also continue to lead the way in gene editing research.

So, as we celebrate Louise's birthday, what of the future? IVF now happens globally; but the way it is regulated varies from country to country.

I believe firmly that the world looks to the UK model as the blueprint, with the right mix of allowing innovation but maintaining public trust. The bargain between science and society that I mentioned earlier.

We, as the regulator, will continue to encourage world class research and clinical trials.

We will continue to help patients make informed choices by being the go-to source for clear, unbiased and reliable information on fertility treatments and clinics.

There's a plethora of information out there about fertility treatments, success rates and what clinics can offer. We know patients care about the cost of treatment, which varies widely. As shown in the exhibition, a standard treatment cycle should cost between £3,000-5,000 and yet we know that in some private clinics it can cost many times more. This can be driven by so called add on treatments to standard IVF which we know from extensive media coverage in recent months lack medical evidence on whether they work or not. EHSRE – the International Conference on Assisted Reproduction - this week have published papers showing there is no effective evidence for some of the common add on s and come can even be potentially harmful.

That same media coverage this week has also revealed some positive developments in medical research such as the possibility of an artificial ovary.

As we encourage the fertility sector and researchers to develop that evidence base and further increase success rates, the HFEA will continue to act as a bridge between scientists, clinicians and patients.

Since 1991, when the HFEA was set up, birth rates from IVF treatment in the UK have nearly doubled – around one in three treatment cycles for patients under 35 results in a baby, more than 20,000 of whom were born in 2016.

40 years after Louise Brown was born, we do live in a different world, but it's important to remember the heartache her parents went through is still very real for millions of people.

I often say that IVF has become more common, but never commonplace.

For a fortunate minority, IVF has been the 'miracle' science that's brought them the baby they've longed for but the reality is that around two in three people who have fertility treatment are unsuccessful. Which is why 40 years on from Louise's birth, clear information from clinic staff about a patient's real chance of success without these unproven add ons, and emotional support before, during and after treatment is so important. I know she's here at the Science Museum lates event in July and I'm sure she will be just as well received.

Louise Brown came to our HFEA annual conference earlier this year and thanked the hundreds of clinic staff who attended for the work they do day in, day out, to help people like Lesley and John Brown who "just wanted a baby" and she received a standing ovation.

In the country that gave the world IVF, we need to both support those who don't ultimately achieve their dreams of a much longed-for family whilst celebrating the UK's achievements and looking to a bright scientific future.

On behalf of everyone at the HFEA and across the fertility sector, I would like to close by saying a big thank you to Roger, Connie and everyone at the Science Museum who helped to bring this exhibition to life.

The Science Museum is the world leader in exhibiting complex scientific developments for a public audience and I am proud IVF is now part of that story.

Happy birthday to Louise Brown and the many millions who followed her.

Thank you.