

The case for informed debate

Jane's* story

'My lovely daughter Emma was born 8 years ago, and was diagnosed with Turner Syndrome at birth. This condition affects 1 in 2,000 female babies every year and a key characteristic is infertility. IVF with egg donation is the only way for those affected to have a child themselves.*

The Progress Educational Trust (PET) has played a key role in keeping Emma's options open if she wants to have a family in the future.

Let me explain: after Emma was diagnosed, I decided to freeze my eggs, so if she wanted a family using IVF, she not only had access to eggs, but those eggs would also have a genetic connection to her.

In 2009, there was a move to reduce the amount of time eggs could be stored for and to annul the current regulations, which would mean my frozen eggs would be destroyed before Emma would want to use them. PET worked with me and the Turner Syndrome Support Society (TSSS) to write up my personal case and a statement to circulate to members of the House of Lords, ensuring our views on the proposed annulments were brought to their attention.

I stayed up and watched the debate on TV, and thankfully, the proposed annulments were rejected. Through PET's influence, the TSSS raised their profile amongst policymakers, and Emma still has choices if she decides to become a mother herself.'

*names have been changed

Arlene Smyth, Executive Officer of the TSSS adds:

'The society is very grateful to the Director of PET for her help and support...as [to comment on the proposed regulations] was a first for the society.'

1 in 3 will be infertile in 10 years time

Daily Mirror, June 2005

Now parents can design donor babies

The Times, July 2004

Human babies grown in lab

London Evening Standard, May 2005

The brave new world of GM man

Daily Mail, February 2001

I'm not God, says life-in-a-lab doc

The Sun, July 2010



Progress Educational Trust

informing debate on assisted conception and genetics

Our role in the debate

Fertility treatment, genetics and embryo/stem cell research are complex and fast evolving areas of science – which are often misrepresented and misunderstood.

Yet these are subjects which affect everyone – not just families and individuals threatened by infertility and genetic disease – but anyone who questions how far science and society should go in these areas.

The Progress Educational Trust (PET) is an independent charity whose purpose is to raise public awareness of embryo/stem cell research, genetics and assisted conception, and to engage with policymakers and medical professionals to inform debate. We believe this is important because it creates an environment in which ethically sound research and practices thrive – for everyone's benefit.

How we inform the debate

- First and foremost, we are a publisher: every week we produce BioNews, a FREE online publication providing balanced comment and news on genetics, assisted conception, embryo/stem cell research and related areas. We encourage our 10,000 readers (who include patients and medical professionals) to post comments online and to debate topics with each other. We also produce a range of booklets and guides.
- Throughout the year, we organise free public debates. We have a reputation for identifying future hot topics, and because of this, these events are very well attended and raise new questions and provide new answers for policy, practice and regulation.
- Our annual conference gives us and our audience the opportunity to explore the scientific and ethical implications of one topic more deeply.
- We inform policymakers and legislators by representing and coordinating the views of professional bodies, patient groups and other interested stakeholders, some of whom are smaller organisations and minority groups who otherwise would struggle to be heard.

Become a Friend of PET

We need your help to keep the debate going because, as a registered charity, we rely on public donations. By becoming a Friend of PET and committing to a regular donation, no matter how much, you'll be helping:

- people affected by genetic disease or infertility who want to have their views heard
- researchers and academics who need to keep up to date on the ethical and social implications of their own and related fields
- regulators who must keep abreast of shifting public opinion
- medical professionals who want to exchange experiences and ideas with the public

Just two additional Friends would enable us to arrange another speaker at one of our public debates. And five more Corporate Friends would cover the cost of publishing one edition of BioNews. Whatever you're able to give, your support means a lot to the people we help.

Act now to keep the debate going

'As the regulator of the assisted reproduction sector in the UK, we know that every day brings new techniques, new possibilities and new dilemmas. BioNews is, in our view, unique... in the way it informs and explains and indispensable in that it combines technical understanding with a fearlessly independent stance.'

Lisa Jardine and Alan Doran (*Chair and Chief Executive of the Human Fertilisation and Embryology Authority, the UK's regulator of fertility treatment and embryo research*)

'PET provides an invaluable, independent forum for the discussion of topics central to the application of genetics in medicine... In addressing such subjects, PET is a significant contributor to healthy and informed discourse within UK society.'

Professor Alan Bittles (*Director of the Centre for Human Genetics, a renowned Australian research centre based at Edith Cowan University*)

'PET does an excellent job of enabling and promoting measured and balanced public debate of the complex and sensitive issues facing expectant parents in the 21st century.'

Jane Fisher (*Director of Antenatal Results and Choices, the UK's charity supporting couples affected by a diagnosis of fetal abnormality in pregnancy*)

Becoming a Friend of PET is easy – just visit our website where you can read more about the benefits of becoming a Friend, and join online. You'll also see how you can help in other ways, including by subscribing to BioNews for FREE.

However you support us, thank you for joining the debate.

www.progress.org.uk/friends

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