

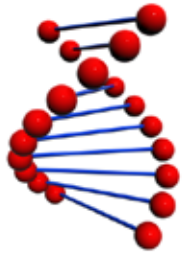
**MAY 2010**

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**GENETIC  
SCREENING**

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**CRAIG FAIRNINGTON**



**DEBATING MATTERS**  
**TOPIC**  
**GUIDES**

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**MOTION:**

**“GENETIC SCREEING  
OF EMBRYOS  
SHOULD BE  
CELEBRATED, NOT  
FEARED”**

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# INTRODUCTION

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# NOTES

**1** In 2009, a girl was born free of a gene that had caused breast cancer in three generations of her father’s family, reigniting an ongoing debate over the ethics of genetic screening of embryos [Ref: [BBC News](#)]. The number of genes and diseases that can be screened for is quickly increasing, as scientists discover new markers and tests – in 2006, the number of possible defects that could be detected was around 200 [Ref: [Independent](#)], but a recently developed technique (Karyomapping) now offers the possibility of screening for 15,000 different genetic disorders [Ref: [The Times](#)]. Supporters of genetic screening argue that the ability to use science to prevent a child being born with a debilitating illness is a great advance, which should be taken advantage of to prevent the suffering of a child born with a gene, chromosome or mitochondrial abnormality [Ref: [MedicineNet](#)].

Opponents argue that the screening opens up possibilities for the creation of ‘designer babies’ who are treated as consumer goods, purchased or discarded on the basis of their apparent quality; and that the focus on eradicating genetic anomalies devalues the lives of those who live with disabilities. The issues at stake include the ability to prevent unnecessary suffering from diseases with known causes, and concerns about the prospect of a society where even minor deviations from biological ‘normality’ are viewed as unacceptable.

## KEY TERMS

Eugenics

Preimplantation Genetic Diagnosis (PGD)



## Why genetic screening?

Every year, thousands of babies are born with diseases or conditions caused by specific genes in their body. These can result in a difficult life for the child and his or her parents, and many diseases can cause pain or early death. There now exist tests which can detect genetically inherited diseases, and these can be used to prevent the birth of a child suffering from one of these genetic disorders. If the mother is undergoing IVF, these tests can be carried out prior to implantation in a process known as preimplantation genetic diagnosis (PGD), with embryos affected by abnormalities not being selected for implantation [Ref: [Wikipedia](#)]. As well as avoiding babies being born with genetic disorders, these tests can improve the likelihood of the IVF treatment being successful [Ref: [The Times](#)]. PGD can also be used to screen for other genetic markers, such as a child's sex or hair colour. However, in the UK, use of the technology is tightly regulated by the Human Fertilisation and Embryology Authority (HFEA) [Ref: [HFEA](#)] and can only be used in relation to a prescribed list of inherited diseases and conditions [Ref: [HFEA](#)]. Sex selection is permitted in the UK, but only if this is for medical reasons, to prevent the birth of a baby with a sex-linked disorder [Ref: [HFEA](#)]. Sex selection for non-medical reasons is currently forbidden in the UK, but is permitted in the USA and elsewhere [Ref: [BioNews](#)].

## Preventing disease

Advances in both prenatal testing (such as non-invasive prenatal diagnosis) [Ref: [BioNews](#)] and the genetic screening of embryos, offer the prospect of a reduction in the incidence of a number of inherited diseases and disabilities [Ref: [Seattle Times](#)]. This,

some argue, can only be a good thing. Gene, chromosome or mitochondrial abnormalities can cause disease and early death in many generations of families, and many of these families welcome the ability to protect their child from suffering from the same illnesses that they or their relatives have suffered in the past [Ref: [Guardian](#)]. Couples can also choose to have genetic tests prior to attempting to have a child, which may mean they decide to undergo IVF, if they discover they are carriers of genetic mutations that could cause life-threatening disorders, in order to test and select an embryo to which they have not transmitted a disease or the risk of a disease [Ref: [The Times](#)]. However, such tests have sparked controversy as to whether they offer the hope of drastically reducing the incidence of inherited disease or play on people's fears, generating needless anxiety [Ref: [The Times](#)]. IVF is not a straightforward procedure, being expensive, unpleasant and often unsuccessful; and screening out inherited disease will not guarantee that a baby will be healthy in every other respect. There are fears that pushing people towards choosing scientific over natural conception can make the process increasingly stressful, based on an over-estimation of what science can achieve.

## The new eugenics?

There are critics who argue that the genetic testing of embryos amounts to eugenics [Ref: [Opposing Views](#)], with some arguing that embryos are increasingly being rejected for 'minor' disorders [Ref: [The Times](#)] and others raising concerns about the 'creep' from the testing of fatal diseases to those that do not kill the sufferer [Ref: [The Times](#)]. They say that the pursuit of genetically perfect babies can devalue the lives of disabled

people, who enjoy and make the most of their lives [Ref: [IVF.net](#)]. Others are already troubled by the way society accepts the abortion of foetuses affected by disorders [Ref: [The Times](#)], and are concerned about women feeling under pressure to have an abortion if anomalies are detected. Indeed, the lines which people draw in relation to disability can be different for different people – some deaf people have in the past demanded the right to be able to select for a child who is also deaf [Ref: [Telegraph](#)]. Critics point to the contribution to society that many disabled people have made, and suggest that the screening of embryos would have deprived us of many brilliant and important people [Ref: [Guardian](#)]. On the other hand, supporters of genetic testing point out that unlike eugenics movements in the past, nobody is forced to act upon the information they obtain from the tests [Ref: [BBC News](#)]. Many supporters of screening point to the importance of being able to make an informed decision about whether or not to have a baby with a particular disease or condition [Ref: [The Times](#)].

### Designer babies

Embryos can be also screened for traits for non-medical reasons and advances in PGD have led to renewed concerns about the prospect of ‘designer babies’. In February 2009, a Californian fertility clinic courted controversy when it offered parents the opportunity to select for eye, hair and skin colour [Ref: [Telegraph](#)]. Some have argued that the parents being able to choose these traits in their child turns having a baby into an extension of the ‘consumer society’, and that people may be led by social pressures and prejudices into making choices about the sex, appearance or abilities of their children based on

narrow ideas of advantage or perfection [Ref: [Washington Post](#)]. Arguing for the need to accept children ‘as they come’, some warn against the hubris of viewing ourselves as being able to master nature, failing to recognise the need to appreciate ‘life as a gift’ and the importance of forces outside of our control [Ref: [Christian Science Monitor](#)]. Others positively emphasise parental choice [Ref: [spiked](#)], arguing that sex selection merely allows parents to have the family they desire, just as developments in contraception allowed parents to control the number and spacing of their children [Ref: [Guardian](#)]. Some supporters of genetic screening argue that the name ‘designer baby’ insults parents [Ref: [Wired](#)], by implying that they do not have their child’s best interests at heart – when parents using PGD usually want to take advantage of whatever technologies give their child the best life possible [Ref: [hPlus Magazine](#)].

## ESSENTIAL READING

Commissioning and providing pre-implantation genetic diagnosis services

Megan Allyse *BioNews* 5 May 2009

Science - and ethics - of this screening are complex

Sarah Boseley *Guardian* 10 January 2009

The Big Question: Should we be worried by the latest step towards designer babies?

Jeremy Laurance *Independent* 20 June 2006

Head to head: Genetic Screening

Baroness Ruth Deech v Dr David King *BBC* 10 May 2006

## FOR

Choosing not to use genetic testing is an option. Ignorance isn't

Daniel McArthur & Daniel Vohaus *The Times* 23 March 2010

Eugenics or reprobogenetics? Call it what you will, but let's do it

Alexandre Erler *Practical Ethics News* 24 February 2010

Case Study: Forewarned is forearmed - I certainly would have taken the test

Hannah Devlin *The Times* 8 February 2010

Designer Babies: A right to choose?

James Hughes *Wired.com* 9 March 2009

Debating 'designer babies'

Ellie Lee *spiked* 17 April 2003

## AGAINST

Wiping out human variation

Dan Kennedy *Guardian* 2 February 2010

Pushing eugenics as smart science

Wesley Smith *Opposing Views* 8 March 2009

Autism Test would deprive the world of geniuses

James Randerson *Guardian* 7 January 2009

Michael Sandel makes 'The Case Against Perfection'

Gregory M. Lamb *Christian Science Monitor* 5 June 2007

There's more to life than being Joe Normal

Bryan Appleyard *Independent* 6 June 1996

## IN DEPTH

'When Is a Life Form Worthy of Life?'

Charles Hawley *Spiegel Online* 7 July 2010

A rush towards embryo screening

Mark Henderson *The Times* 4 March 2010

Gene Testing Spurs Decline of Some Dire Diseases

*Centre for Genetics and Society* 19 February 2010

Embro Genetic Screening Controversial - and Successful

Dan Vergano *USA Today* 10 January 2010

Color I.D.

William Saletan *Slate* 17 February 2009

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# BACKGROUNDERS

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BioNews

How a Community Stamped out Tay-Sachs Disease with Genetic Screening

*The Times* 8 February 2010

Will Down Syndrome Disappear?

Lachlan de Crespigny *Practical Ethics News* 25 October 2009

Disease free babies? New embryo screening

Woman's Hour *BBC Radio 4* 7 July 2009

The Lives of Babies with Down Syndrome are not Worthless

John Hogan *Guardian* 29 May 2009

Newborn genetic screening - The New Eugenics?

*Citizens' Council on Health Care* April 2009

Breast cancer gene-free baby born

*BBC News* 9 January 2009

The Toughest Test

Gautum Naik *Wall Street Journal* 25 October 2008

Fresh Hopes and Concerns as Fetal DNA Tests Advance

*Washington Post* 26 October 2006

Our Gentle Decent Towards Eugenics

William Saletan *Slate* 19 May 2006

## ORGANISATIONS

British Fertility Society

Comment on Reproductive Ethics (CORE)

Genetic Interest Group

Human Fertilisation and Embryology Authority (HFEA)

Human Genetics Alert

Progress Educational Trust

## IN THE NEWS

Blood test for Down's syndrome

*Daily Telegraph* 30 June 2010

Making babies naturally may be a dying art

*The Sunday Times* 16 May 2010

New technique could make in-vitro more reliable

*CBS2 Chicago* 16 April 2010

Call for choice on genetic testing to allow babies born without risk of diseases

*Daily Mail* 14 April 2010

Clinics destroying embryos with minor genetic conditions

*Daily Telegraph* 24 January 2010

First baby born from screened egg

*Daily Telegraph* 2 December 2009

Screening test 'doubles the chance of pregnancy for woman on IVF'

*The Times* 19 October 2009

Hereditary diseases could be eradicated before birth by

'genetically modifying' eggs

*Daily Telegraph* 26 August 2009

The IVF embryo test that can detect 15,000 genetic diseases

*Daily Mail* 1 July 2009

Parents to be offered test to detect inherited diseases in embryos

*The Times* 1 July 2009

Demand for 'designer babies' to grow dramatically

*The Times* 9 January 2009

Trials for embryo quality test give infertile couples new hope

*The Times* 29 June 2008

Deaf demand right to designer deaf children

*The Times* 23 December 2007

Outcry as clinic offers 'designer baby' embryo screening for 200 diseases

*Evening Standard* 13 November 2006

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NOTES



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**“TEENAGE CITIZENS  
THINKING DEEPLY  
ABOUT...SOCIAL  
ISSUES”**

**IAN GRANT, CEO, BRITANNICA**

