

A
Research
Paper
from
No Less Human
Questions & Answers
on
HLA testing
(for saviour siblings)

Published by No Less Human

A GROUP WITHIN THE SOCIETY FOR THE PROTECTION OF UNBORN CHILDREN

FOR FURTHER INFORMATION PLEASE CONTACT:

Alison Davis

No Less Human

Society for the Protection of Unborn Children

5-6 St Matthew Street

London SW1P 2JT

Tel: 020 7222 5845

Contents

- 1) What is HLA testing? 3
- 2) When was HLA testing first performed? 3
- 3) Was the British Medical Association favourable to HLA testing at the time of Adam Nash's birth? 4
- 4) Was the HFEA also opposed to HLA testing? 4
- 5) When did the attitude of the HFEA change? 4
- 6) When did the HFEA allow HLA testing in all cases? 5
- 7) What is the current state of HLA testing in the UK? 5
- 8) Has there been any opposition to HLA testing in the UK? 6
- 9) What are the implications of HLA testing? 6
- 10) What would happen if the umbilical cord blood transplant did not work? 7
- 11) Is HLA testing a justified means of avoiding abortion? 7
- 12) Can HLA testing can ever be justified? 8
- 13) Is there an ethical alternative to HLA testing? 9

1) What is HLA testing?

HLA stands for Human (or “histocompatibility”) Leukocyte Antigen testing. It is an extension of Preimplantation Genetic Diagnosis (PGD), a method of testing embryos for disabling conditions before they are implanted in the womb (See No Less Human booklet “Questions and Answers on PGD.”).

- PGD involves embryos being tested to see if they have a disabling condition. Those who do have the condition are thrown away, while one or more of those without the condition are implanted in the woman’s womb.
- HLA tests the embryo for its tissue type, to see whether it matches that of a brother or sister who has a disabling or life-threatening condition.
- An embryo may be tested by PGD for disability and by HLA for tissue type compatibility at the same time. Thus in some cases the embryo must pass two tests – it must be free of disability and a perfect tissue match in order to be selected for life. Those who fail these tests or are surplus to requirements are thrown away.

2) When was HLA testing first performed?

It was reported in October 2000 that baby Adam Nash of Colorado, USA had been selected as an IVF embryo, using PGD and HLA testing.

Adam Nash’s selection, when he was an embryo, was on two grounds. He was selected by PGD because he did not have the genetic disability, Fanconi’s Anaemia, which his sister Molly had, and he was selected a second time by HLA because his tissue matched that of Molly.¹

Fanconi’s Anaemia is a bone marrow condition which causes learning difficulties kidney and gastrointestinal problems, and may also cause immune system problems and leukaemia as well as anaemia. Most children who have it live no more than seven years, and Molly was already six. Molly’s only chance of survival was thought to be a transplant of stem cells from a compatible donor, which would give her a 90% chance of a cure. Five “suitable” embryos (i.e. who were both free of the gene for Fanconi’s Anaemia, and were a suitable tissue match for Molly Nash) were implanted in Lisa Nash’s womb and of these only one, Adam, survived. When Adam was born blood from his umbilical cord was harvested and used in a successful stem cell transplant for Molly, who was then to all intents and purposes, “completely cured.”²

¹ “Couple select healthy embryo to provide stem cells for sister” by Deborah Josefson *BMJ* 14 October 2000

² “Ethics of using preimplantation genetic diagnosis to select a stem cell donor for an existing person” by Robert J. Boyle and Julian Savulescu. *BMJ* 24 November 2001

3) Was the British Medical Association favourable to HLA testing at the time of Adam Nash's birth?

The British Medical Association (BMA) said at the time of Adam Nash's birth that the use of PGD for any purpose other than eliminating embryos with disabilities "should remain strictly limited in this country." Vivienne Nathanson, Head of the BMA Ethics Committee said "Cases such as that of Adam Nash ought not to be allowed as a matter of course, but might occasionally be justified in exceptional circumstances." However, it has not taken very long for HLA testing to become accepted "as a matter of course" by the Human Fertilisation and Embryology Authority (HFEA) and by the BMA.³

4) Was the HFEA also opposed to HLA testing?

In December 2001 the HFEA announced that the creation of "designer babies" or "saviour siblings" would be allowed. Ruth Deech, Chair of the HFEA said "Where PGD is already being undertaken we can see how the use of tissue typing to save the life of a sibling could be justified. We would see this happening only in very rare circumstances and under strict controls."⁴ As will be seen the supposed "strict controls," which would in any case have allowed the screening of embryos for disability and for tissue type, and the destruction of these young human beings if they did not prove "desirable", were to be removed after only three years.

5) When did the attitude of the HFEA change?

The HFEA decided initially that it would allow HLA testing only in cases where parents were already using PGD to select non-disabled embryos. This meant that two sets of parents both seeking HLA testing to create "saviour siblings" were treated differently.⁵ Shahana and Raj Hashmi were given permission to attempt to use HLA testing to create a "saviour sibling" for their 2 year old son, Zain, who has Beta Thalassaemia Major, because they would be testing the embryos both to ensure that they did not have the condition, and also to check whether or not their tissue type matched Zain's. Beta Thalassaemia Major is a life threatening, genetically inherited, progressive deficiency of red blood corpuscles. However, Michelle and Jayson Whittaker's 3 year old son Charlie has Diamond Blackfan Anaemia (DBA) a condition caused by a failure of the bone marrow to

³ "'Embryo selection on the basis of tissue typing" BMA Ethics Brief. Issue 65.ARM 2003

⁴ "HFEA to allow tissue typing in conjunction with preimplantation genetic diagnosis" HFEA Press Release 13 December 2001.

⁵ "HLA Tissue typing may only take place when PGD is required to avoid a serious genetic disease" HFEA Press Release 1 August 2004

produce red blood cells. They were refused permission for HLA testing on the grounds that no PGD test for his condition was available.⁶ This would mean that the embryos were being tested solely for compatible tissue type, and not to see whether or not they were affected by DBA. This “strict rule” decided by the HFEA was to last only two years.

Mr & Mrs Hashmi’s six attempts at producing a “saviour sibling” failed as either the embryos were not of the right tissue match or were, but later miscarried.⁷

Mr & Mrs Whittaker went to the USA for HLA testing, and baby Jamie was born in June 2003, “the most suitable” of nine embryos.⁸ The rest were thrown away. Stem cells were immediately collected from the umbilical cord and tests carried out to see whether Jamie also had Diamond Blackfan Anaemia. Later, tests confirmed that he was a perfect genetic match for Charlie. When Jamie was 6 months old, Charlie was given a transplant of stem cells from his umbilical cord, and his consultant said he was “effectively cured” of DBA.⁹

6) When did the HFEA allow HLA testing in all cases?

In July 2004 the HFEA lifted its ban on selecting embryos purely to donate tissue to sick siblings (i.e. even if there was no PGD test for the condition the sick sibling has.) With a revealing choice of words, this was reported in the press as “overturning the longstanding principle that embryo screening is acceptable only to weed out inherited disease.”¹⁰ What was really meant, of course, was that embryos found to have a disabling condition would be “weeded out.”

7) What is the current state of HLA testing in the UK?

The HFEA’s lifting of the ban opened the way for Julie and Joe Fletcher of Moira, Northern Ireland, to have embryos HLA tested to provide a “saviour sibling” for their son Joshua, then 2 years old, who had Diamond Blackfan Anaemia, the same condition as Charlie Whittaker.¹¹

Nine embryos were fertilised, but only one was a girl. Julie Fletcher had “always wanted a girl” so the female embryo was implanted, and in July 2005, Julie Fletcher gave birth to Jodie, dubbed “the UK’s first saviour sibling.”¹² Stem cells were collected from her umbilical cord immediately, and are now in storage. Just a few weeks after the birth it was found the Jodie was a perfect tissue match for

⁶ “Is conceiving a child to benefit another against the interests of the new child?” Dr. Merle Spriggs. *J. Med Ethics* 2005; 31:341-342

⁷ “Law Lords give the go-ahead for creation of ‘saviour siblings’” by Clare Dyer *BMJ* 7 May 2005

⁸ “Boy, 5, receives transplant from brother” by Catriona Davies. *Daily Telegraph* 28 July 2004

⁹ “Brother’s tissue ‘cures’ sick boy.” *BBC News* 20 October 2004

¹⁰ “Parents can design donor babies” by Mark Henderson. *The Times* 22 July 2004

¹¹ “Couple allowed to select an embryo to save sibling” by Clare Dyer. *BMJ*. 11 September 2004

¹² “Born to save her big brother’s life” by Nigel Gould. *Belfast Telegraph* 18 July 2005

Joshua. It is expected that a transplant of the umbilical cord stem cells from Jodie to Joshua will be performed sometime in 2006.¹³

8) Has there been any opposition to HLA testing in the UK?

Pro-life groups including No Less Human have been very vociferous in opposing PGD, the technology on which HLA depends, and in opposing HLA itself. Additionally, the group Comment on Reproductive Ethics (CORE) took the HFEA to the courts in a case which started in July 2002, arguing that authorising HLA testing for Raj and Shahana Hashmi to use HLA testing to create a “saviour sibling” for their son Zain was beyond the remit of the HFEA.¹⁴ However, the five Law Lords ruled unanimously that HLA testing could be authorised by the HFEA.

9) What are the implications of HLA testing?

There are many dangers associated with HLA testing some of which are recognised even by Lord Robert Winston, who himself developed PGD technology in 1989, has recognised some of the dangerous implications of HLA testing. He said during a public lecture entitled “Creating Humans” in Auckland, New Zealand in September 2004, that “It does raise important questions about whether society might be at risk of allowing babies to be used as commodities. You are subjecting an embryo to removal of cells for DNA analysis that is of no benefit to that embryo. That is having a medical procedure without any informed consent.”¹⁵

While this is true, it is worth pointing out that PGD, on which HLA testing depends, also has “no benefit to the embryo” - destruction and death is certainly not a benefit to embryos with disabling conditions, and even some of the non-disabled embryos may well be discarded as “surplus to requirements.” PGD is thus equally a medical procedure “without any informed consent.”

¹³ “Designer baby is a perfect match” by Nigel Gould. *Belfast Telegraph* 4 August 2005

¹⁴ “I want to wake up this nation’s conscience” by Gaby Hinsliff. *The Observer*. 27 February 2005

¹⁵ “Baby at risk of being ‘commodities’” by Simon Collins. *New Zealand Herald* 2 September 2004

10) What would happen if the umbilical cord blood transplant did not work?

Lord Winston also raised this question, wondering whether the “designer baby” then be expected to serve as a bone marrow donor, or a kidney donor for the sick sibling.

This is by no means a rhetorical question. It was reported in March 2005 that documents obtained under freedom of information legislation had revealed that the HFEA had cleared doctors to perform invasive bone marrow harvests on “saviour siblings,” lifting a previous ban. The ban was actually lifted in 2004, but was not publicised at that time.

As the court case brought by CORE failed, its Director, Josephine Quintavalle, said “The HFEA resisted with self-righteous indignation any accusations that saviour siblings were being set up as future bone marrow donors. Now the HFEA has completely changed its mind by suggesting that bone marrow donation is OK after all.”¹⁶ She pointed out that bone marrow extraction requires invasive, painful and potentially hazardous surgery, and there would be no benefit from the procedure at all for the sibling.

The HFEA had agreed to approve bone marrow transplants after the UK Children’s Cancer Study Group presented evidence that these transplants were generally likely to be more successful than cord blood treatments, especially for children with thalassemia, the blood condition that Zain Hashmi has. It ruled that it was now a “relatively routine treatment strategy” provided that the donor was over one year old. The HFEA claimed that the best interests of the “saviour sibling” could be served by donating bone marrow to a sibling who would otherwise die. There was no recognition of the right of a child not to be expected to undergo invasive, possibly painful treatment for the benefit of someone else. The HFEA did not mention how long the “saviour sibling” would be expected to provide tissue for his or her sick brother or sister, thus raising the possibility of an expectation of life long donations.

11) Is HLA testing a justified means of avoiding abortion?

Lisa Nash, mother of Adam and Molly said she “would have had to” abort any baby who also had Molly’s condition. She said “I could not bring another baby into the world to go through what Molly is going through” but claimed she did not want to abort.¹⁷

¹⁶ “ ‘Designer babies’ rule changed” by Mark Henderson. *The Times* 7 March 2005

¹⁷ “Joy of the family in front line of science” by Damian Whitworth. *The Times* 5 October 2000

Shahana Hashmi was said to have “had to” abort a baby who was found to have beta thalassaemia major, the same condition as her son Zain.^{18 19}

It is interesting to notice the choice of words, as if it were in some way compulsory to abort a baby found to have the disability for which the sibling needed treatment. Both parents clearly felt that selecting an embryo was a preferable alternative to abortion, even though most of the embryos produced would be discarded as either affected by disability or unsuitable as a tissue donor. And both, while claiming to love their sick child, clearly demonstrated that they would not be prepared to welcome and love another child with the same condition.

12) Can HLA testing can ever be justified?

It is, of course, no more acceptable to kill a disabled human embryo than to kill a disabled fetus, newborn baby, toddler, adult or elderly person for that reason. It is wrong to kill a human being of any age because s/he has a disability, and it does not become any more acceptable because the individual concerned is very young. Killing or discarding an embryo is no more ethical or acceptable than killing an adult. Size does not determine a human being's value or worth.

Although the media presented these children as being “saviour siblings”, it entirely ignored the human embryos who had been thrown away in the process; human beings who deserve the same rights and protection from harm as any other human being.

Human beings should be welcomed as they are, and for who they are as individuals, not because of what they can provide for another person.

In other words, human beings are ends in themselves, not means to ends. They should be valued for who they are, not for what they can do, for themselves or for anyone else. HLA testing treats human beings as means to ends and as commodities to be used for the benefit of someone else. It should never be authorised.

¹⁸ “A gain for autonomy and reproductive choice – the issue of saviour siblings resolved” by Dr. Jennifer Gunning. *Cardiff Centre for Ethics, Law and Society*. May 2005

¹⁹ “Don't let the law kill our little boy” by Zoe Catchpole. *Daily Telegraph* 3 April 2003

13) Is there an ethical alternative to HLA testing?

Dr. Peter Hollands, Scientific Director of Cells for Life, a private umbilical cord blood bank in Markham, Ontario, Canada, has said that HLA is not necessary to find tissue matches for people in need of transplants. He said “I do not agree with the process [of HLA testing]. If we focused more on collecting umbilical cord blood from most births and storing the samples in a public bank, there would then be a suitable match for almost everyone. The ‘designer babies’ would then not be needed as the cord blood banks could easily support the demand for cells for transplantation.”²⁰

Lord Winston concurs with this view, saying it would be better to invest more into alternatives, such as finding compatible tissue donors.²¹

This is an entirely ethical and simple way of treating people in need of cell transplants and it should be strongly encouraged. HLA testing is thus both entirely unethical and entirely unnecessary to provide appropriate treatments for sick people.

Alison Davis September 2005

²⁰ “Umbilical Cord Blood Stem Cell Expert Says Designer Babies Not Necessary for Treatments” *LifeSite News* 10 May 2004

²¹ “Fertility authority gives go-ahead for ‘designer babies’ By Roger Highfield. *Daily Telegraph* 13 December 2001