who's afraid of DESIGNER BABIES?

PENNIE STOYLES **STUDY GUIDE**

NFSA

Synopsis

Australia is at the forefront of new genetic technology that may let us choose our descendants. Pre-implantation genetic diagnosis, or PGD, allows scientists to screen embryos conceived through IVF and to choose which ones will or will not be implanted.

But what is the potential of this technology and who should decide how to use it?

For families suffering incurable or debilitating genetic diseases, PGD seems to be the longed-for miracle. But where do you draw the line? Some believe the next step is selecting genes that code for intelligence, athletic ability or hair colour, for example.

This compelling documentary follows a couple trying to have a child with the right genetic make-up to save the life of their son, who is dying from an hereditary illness called Hyper IgM.

For them, it's not a question of creating a 'designer baby', but of using science to help them have a much-wanted second child, whose bone marrow will provide the cure for their first son and who will also be free of the same fatal condition.

The film also talks to parents who have used PGD for gender selection and to leading scientists and ethicists from around the world who provide cases both for and against PGD.

Going beyond sensationalist media headlines, this fascinating

and thought-provoking program presents a wide range of perspectives on a complex and emotionally charged issue, in a brave new world where science fiction is now science fact.

Curriculum links

Who's Afraid of Designer Babies? is suitable for middle to senior secondary students in English, Science (biological sciences) and Health and Physical Education (health of individuals and populations).

The program serves as a springboard to discussion on genetics, inheritance, and human reproduction including in vitro fertilisation. It could also be used to encourage students to examine their own views on issues relating to bioethics, eugenics, and the nature/nurture debate, as well as rights and responsibilities.

Before watching

1. Ask friends and family about 'designer babies'.

- What do they understand is meant by the term 'designer babies'?
- What is their opinion about whether people should be able to choose a baby's characteristics?

2. Look at the key words below and discuss their meanings.

- biopsy
- chromosome
- DNA
- embryo
- ethicist
- eugenics
- gene
- genetic engineering
- implantation
- immune system
- in vitro fertilisation
- pipette
- sibling
- hereditary

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3. Acronyms

An acronym is a 'word' formed from the initial letters of other words. Acronyms are used as a sort of shorthand and can be useful for shortening the names of complex chemicals or medical procedures.

Find out the full names of the following acronyms used in the documentary and explain what they are:

- DNA
- IVF
- PGD
- IgM

4. The following ideas are raised in the film.

Discuss what you think the film is going to show you.

- Spare-parts baby
- Selective breeding of humans
- Hospital ethics committees

After watching

Fertilisation and differentiation

When a human sperm cell and a human egg cell join together, a single fertilised cell called a zygote is formed. The zygote contains all the information needed to create a new person. The zygote begins to divide into two identical cells, then four identical cells, and then eight identical cells. Cell division continues, but soon the cells begin to differentiate. This means that, although they contain all the information needed to form a human, most of the information is switched off and the cell concentrates on a particular function.

- Research the first steps in cell differentiation and find out about blastocysts.
- How are identical twins formed?
- At what stage can one of the cells be removed to be tested without harming the development of the embryo?
- What is meant by the term 'embryonic stem cells'?

In vitro fertilisation

In vitro fertilisation technology was developed in the 1970s and 1980s to assist couples who have difficulty conceiving children in the normal way. In vitro is Latin for 'in glass'. It means that the fertilisation of the egg happens in a test tube (glass) instead of in the mother. Babies conceived in this way are sometimes referred to as 'test tube babies'. Before this can happen the eggs have to be harvested from the mother. The eggs can only be harvested when they are 'ripe' and the mother is ovulating. She is given fertility drugs to cause many eggs to ripen at once. The eggs are removed using an ultrasound machine and a very fine needle. They are mixed with the sperm and allowed to develop for about three days before being implanted into the mother's uterus.

- Research the most common causes of both male and female infertility.
- Find out about Professor Carl Wood, who was an IVF pioneer at Monash University in Melbourne.
- Find out what (if any) regulations or laws there are about who can use IVF in your state (area).
- Choose an issue about IVF and discuss this in class. (eg. IVF using donor sperm or eggs, IVF for same sex couples, surrogacy.)

For more information on causes of infertility go to http://monashivf.com/preparing-for-pregnancy/infertility-explained/

For more information about IVF go to http://monashivf.com/category/research-and-education-foundation/research-interests/

For more information about Professor Carl Wood go to http://monashivf.com/the-history-of-ivf-a-chronology/

Sex selection

The sex of a baby is determined by the chromosomes it inherits from its parents. Research the inheritance of gender by answering the following questions:

- How many pairs of chromosomes do humans have?
- How many of these determine the sex of a baby?
- Comment on the statement: 'Men are responsible for determining the sex of their babies'.

Many people believe that there are other factors (such as diet) that can influence the sex of a baby. Some of these may be 'old wives tales' but there have been many books written on the subject.

- Speak to parents, friends and teachers and list some of these ideas.
- List the ideas that are mentioned in the documentary.
- List reasons why you think parents would want to choose the sex of their baby.

Discuss these reasons with your classmates and clarify your own opinions about the sex of your future children.

Genetically inherited characteristics

There are a number of genetically inherited characteristics that cause faults in the way our bodies work.

Some inherited characteristics are regulated by a single gene, some by several genes, and others by whole chromosomes. The inherited 'faults' can range from almost harmless (such as colour blindness) to life threatening (such as Hyper IgM).

In the case of Leanne and Steven, Leanne is a carrier for the genetically inherited disease Hyper IgM. This results in low production of an immunoglobulin in the blood.

- Explain, in terms of dominant/

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recessive inheritance, what a 'carrier' means.
- Explain what a 'sex-linked recessive gene' is and how mothers who do not show a sex-linked recessive characteristic can carry it and pass it on to their sons.
- Find out why immunoglobulins are important for our survival.
- Research other more common genetically inherited diseases such as sickle cell anaemia, cystic fibrosis or Huntington's disease.
- Recent studies have shown that some people may have a genetic make-up that makes them more likely to get certain forms of cancer. Find out more about genetic links to cancer, in particular colon and ovarian cancers.

Pre-implantation genetic diagnosis (PGD)

Today it is possible to diagnose embryos for virtually every gene that is known to cause disease.

Narrator

Linda Wilson is featured in the documentary. Although she could conceive in the normal way, she had a daughter using IVF technology. Steven and Leanne had a baby with a rare genetically inherited disorder and they wanted another child to donate blood tissue to their son.

Both used pre-implantation genetic diagnosis (PGD) to have a baby that they wanted.

- Explain how the diagnosis takes place and hence its name PGD.

Linda's embryos were being diagnosed to check their sex. Steven and Leanne's embryos were being diagnosed to check that they were clear of the disease Hyper IgM *and* that they were compatible with their sick son.

- Do you believe that PGD should have been used for both these cases?
- Do you feel differently about the motivations of the two sets of parents?
- What is meant by the term 'non-therapeutic PGD'?
- Is saving a sick child different from just choosing the sex of your baby?
- Should PGD be regulated?

Frozen embryos

One of the results of IVF technology is that a couple may produce many more embryos than they need for implantation. IVF is a risky business and the success rate is not high. Usually, more eggs are harvested than are needed. This is because there is failure at every step. Some eggs may not be fertilised successfully. Some of the fertilised eggs may not develop successfully and can't be implanted into the uterus. Some of the embryos will not implant properly, and then there is a chance that a miscarriage may occur. But if everything goes well, a mother may end up with many more healthy embryos that she needs. The question is – what to do with them?

In many cases the embryos are frozen in liquid nitrogen. This puts them into 'suspended animation' so that they can be stored indefinitely and be thawed for use at a later date. It is estimated that in the USA alone, there are over 200,000 frozen embryos left over from the IVF process. At present they are left in storage to be used by the couple at a later date, donated to other couples, used for research or disposed of. Researchers can use the embryos to make stem cell cultures. These stem cells could then be used to treat diseases like Alzheimer's.

However there are ethical and moral issues around the use and disposal of frozen embryos.

Discuss the following points:

- Are frozen embryos living beings?
- Who owns frozen embryos?
- Who should be able to decide what is done with a frozen embryo?

Stem cells

Find out more about stem cells at http://science.howstuffworks.com/life/cellular-microscopic/stem-cell.htm

- Apart from embryos, where else can stem cells be obtained?
- What is meant by the term 'pluripotent'?
- What illnesses could be treated using stem cells?
- Why are high profile people including Michael J. Fox, Nancy Reagan and the late Christopher Reeve crusaders for stem cell research?
- Explain why there is controversy surrounding the use of stem cells.

Read the article 'Women Adopt Frozen Embryos, Save Them from Science' at http://www.nzherald.co.nz/technology/news/article.cfm?c_id=5&objectid=10113122 or

http://www.theage.com.au/news/World/Women-adopt-frozen-embryos/2005/03/01/1109546828185.html

Discuss the article with your friends, family and classmates.

- What is your opinion of adopting frozen embryos?
- What do you think is the main motivation of the 'adoptive parents'?

Headline grabbers

One of the things that I have really struggled with is, I just think that they missed the point. Things like the 'Designer baby first', and there were also things along the lines of 'Sydney doctors created baby', you know, they didn't. They, this baby, these embryos are made up of my eggs, Steven's sperm, our

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DNA, they're our embryos and this is our baby. Doctors did not create this baby…

Leanne talking about the press

In the documentary, you see television news articles and newspaper headlines using the terms 'spare-parts baby' and 'designer baby'.

- Do you think Leanne and Steven's baby was 'designed' or a 'spare-parts baby'?
- Do you think that the general public would understand or care about Leanne's annoyance?
- Do you think reporters understand the complex scientific procedures?
- Do they have a greater responsibility to sell newspapers or to report science factually?
- Do you believe the general public are scientifically literate?

Spare parts donor

This is the issue of a child being born basically for the sole purpose of being a donor, a parts donor to an older sibling. And I think we have to do research on how our children are going to be affected by this.

Dr Jeffery Nisker talking about Leanne and Steven's situation

- Do you agree with Dr Nisker, that spare parts are the only reason that Leanne and Steven are having their second baby?
- If you were in Leanne and Steven's situation, would you want to have another child to save your first child?
- What would you tell the second child when they grew up?
- How do you think you would feel if you were the second child?

Eugenics

PGD offers a whole new type of eugenics. It won't be on a large scale; it will be on a smaller scale. But by selecting specific traits, that is eugenics.

Dr Jeffery Nisker

The shadow of the German Nazis and their infamous obsession for creating a master race hangs over any discussion of science tampering with human genetics.

Narrator

- Find out the meaning of the word 'eugenics'.

Discuss the following:

- What are the advantages and disadvantages of creating a healthier race of people?
- What are the advantages and disadvantages of finding possible cures for genetically transmitted diseases?
- Do you think PGD should be able to be used so that Todd and Sue (the deaf couple) could have a deaf baby? Is this an example of eugenics?

Rules and Regulations

Discuss these two opposing viewpoints:

The best people for making choices about these technologies are either the individual for making choices about themselves, or parents making choices about their children, because by and large they make mistakes and they may not be absolutely wise about things, but they are going to have to suffer the consequences of their errors. And historically, the greatest evils have been perpetrated upon us by governmental or groups that are trying to do what's right for society as a whole and are willing to step upon the individual in order to accomplish those greater social goods.

Dr Greg Stock

The decisions that parents make with regard to what they can and can't do with their children is not simply a private decision and so, in my view, what you need is for the legislatures of different countries to establish broad guidelines and this is happening in fact in many countries around the world. I mean, they are in the process of setting up precisely this kind of new regulatory institution to deal with the ethical challenges that the technology creates.

Dr Francis Fukuyama

- Do you believe that there should be laws regarding the use of reproductive technology?
- Give examples that would support Dr Stock's claim that 'the greatest evils have been perpetrated upon us by governmental or groups that are trying to do what's right for society as a whole and are willing to step upon the individual in order to accomplish those greater social goods'.
- Find out what laws exist in your state or country.
- What is the role of a hospital ethics committee?
- Do you think scientists need to be regulated?

Find out more about Australian laws regarding the use of embryos at www.nhmrc.gov.au/embryo/

When does life begin?

Is a two-cell embryo a conscious living being? When does life begin? Is it when the sperm enters the egg? Is it when the zygote implants in the uterus? Is it when the primitive streak appears around day 14, OR, is it when the heartbeat becomes detectable at 6 weeks?[1]

From the Monash IVF website

A large part of the controversy surrounding all reproductive technologies is the debate about when life begins. Governments and organisations have different definitions about the beginning of life.

- Survey your friends and family about their opinions. Share you data with the class.
- Use the internet to research the opinions of governments and other organisations.
- Do different cultures have different views on the beginning of life?
- What is your opinion?

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Enhancement

….. And so there may come a day where we can actually make a lot of eggs and a lot of embryos and therefore increase the chances of finding a particular trait that a couple may want, that a couple may desire. Obviously, this is going to create new ethical dilemmas and hurdles that we will need to overcome.

Dr David Cram

If Dr Cram is right, PGD will soon be radically different. The next generation of couples will be able to select from hundreds of (their own) embryos. Choosing from combinations of their genes, like drinks at a cocktail bar, to get the child of their choice. In the genetics trade it's called 'enhancement'.

Narrator

- What do you think are your desirable characteristics?
- If you could, which of these would you pass on to your children?
- What do you think motivates parents to want to choose what their children are like?
- Discuss what other people perceive as being desirable. Make a list and ask friends and family to rank them. Share your results with your classmates. (You may include characteristics such as: height, weight, intelligence, beauty, hair and eye colour, athletic ability, resistance to disease, nose shape, longevity, etc.)

Fact or fiction

- View the bioethical science fiction film *Gattaca* and relate it to the issues raised by *Who's Afraid of Designer Babies?* The parents in the documentary discuss how they would choose a 'perfect baby' to meet their own needs. These include a child without Hyper IgM, a girl and a deaf child. Discuss how it is possible to judge genetic makeup as more or less 'perfect'.

Endnotes

1 http://www.monashivf.edu.au/basics/con-index.html Accessed 23 March 2005

References & Further Resources

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Executive Producer: Mark Hamlyn
Narrator: Rachel Ward
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