

## PREPARATORY LESSONS.

### THE STEM CELL DEBATE

Nobody Lives Forever Teachers Resource

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# Introduction

Nobody Lives Forever explores the social, moral, scientific and political questions raised by stem cell research. The project has been developed in partnership with the Association of Medical Research Charities (AMRC), with seed-funding from the Medical Research Council (MRC) . It is the eighth in the Creating the Debate series of projects developed and produced by Y Touring.

## Aims

The overall objectives of the programme (play, debate and educational resources) are, through theatre and debate, to

- Encourage a more informed debate within schools about the potential of stem cell research and the issues it raises for individuals and society
- Clarify what the misunderstandings are surrounding stem cell research
- Provide a starting point for learning about new developments in medicine and biology

Included in these resources are

- A synopsis of the play by playwright Judith Johnson
- An outline of the characters and how they relate to the issues raised in the play
- Suggested preparatory lessons/exercises
- A glossary

## The Development of Nobody Lives Forever

Nobody Lives Forever was developed and delivered by Y Touring in partnership with the Association of Medical Research Charities (AMRC). The project developed out of the growing public concern about, and media attention to stem cell research, and aims to address some of the misunderstandings and debate surrounding this complex area of work.

The process of creating *Nobody Lives Forever* relied upon the in-put of various experts from an advisory group made up of the Association of Medical Research Charities, the Scottish Council on Human Bioethics, the National Institute for Medical Research, CORE (Comment on Reproductive Ethics) and the Society, Religion and Technology (SRT) Project, Church of Scotland. Representatives from these organisations were invited, along with young people from local schools, to participate in a workshop exploring perceptions around the issues the project proposed to explore.

## **The Advisory Group**

- **Dr Sophie Petit-Zeman, Head of External Relations, Association of Medical Research Charities**

Dr Sophie Petit-Zeman is Head of External Relations at the Association of Medical Research Charities, and a writer and journalist specialising in health, science and social care.

- **Dr Calum MacKellar, Director of Research, Scottish Council on Human Bioethics**

In 2003, Dr MacKellar became the Director of Research of the Scottish Council on Human Bioethics. He is also a member of an NHS Research Ethics Committee in Edinburgh.

- **Dr Robin Lovell-Badge, Head of Developmental Genetics, MRC National Institute for Medical Research**

Dr Robin Lovell-Badge, PhD, FRS, is Head of the Division of Developmental Genetics at the MRC National Institute for Medical Research, Mill Hill in London, UK.

- **Josephine Quintavalle, CORE - Comment on Reproductive Ethics**

Josephine Quintavalle co-founded Comment on Reproductive Ethics (CORE) in 1994, as a public interest group focusing on the ethical issues arising from the new reproductive technologies.

- **Dr Donald Bruce, Formerly Director of the Society, Religion and Technology Project, Church of Scotland**

Dr Donald Bruce was Director of the Society, Religion and Technology Project (SRT) of the Church of Scotland since 1992.

- **Dr Stephen Minger, Lecturer in Biomolecular Sciences at King's College London**

Dr Minger moved his stem cell research programme to Guy's Hospital in 1996 and was appointed a Lecturer in Biomolecular Sciences at King's College London in 1998. Dr Minger's research is funded by the Medical Research Council, Juvenile Diabetes Research Foundation International, and Diabetes UK, amongst others.

Some of the exercises found in the Preparatory Lessons included in these resources were used during the workshop to gain insight into peoples' perceptions and attitudes. Following the workshop, Judith Johnson undertook research, notably supported by Dr Steven Minger of King's College London, and Cath Stanley at the Huntington's Disease Association.

The Huntington's Disease Association exists to support people affected by the disease and to provide information and advice to professionals whose task it is to support Huntington's disease families. The HDA is financed through the generosity of trusts, foundations, the statutory and corporate sectors, branches of the HDA, members and friends. ([www.hda.org.uk](http://www.hda.org.uk))

Judith then submitted a synopsis, which the advisory group chose to commission as a full play.

The advisory group continued to contribute to the project by providing feedback on both the synopsis and the drafts of *Nobody Lives Forever*. The final stages of the project were a three-week rehearsal process at Y Touring's studio in King's Cross, London, followed by a 5-week pilot tour.

We hope that you have enjoyed *Nobody Lives Forever*, and will find these resources a useful complement to the production.

## Using the *Nobody Lives Forever* Education Resources

Not all material will be appropriate to your group's needs or attainment levels. Be prepared to select and adapt the material according to your own judgment, that of your staff team and your joint perceptions of:

- your group's abilities and skills
- your group's personal experiences of genetic or hereditary conditions

- your group's cultural and religious backgrounds
- group dynamics

## **Discussion**

In discussions, the views of all students should be heard wherever possible. It may be necessary to speak for groups of individuals who are too vulnerable or not represented in the classroom.

Try to avoid using students as representatives of their religious or cultural groups. If a student makes a prejudiced remark, try to respond by asking for their reasons and by giving factual information in a neutral way.

Remember, values are learnt informally, by example. Be aware of your own values, attitudes and assumptions, so that you can avoid promoting them unconsciously or inappropriately.

## **Sensitive issues**

Please remember and respect the personal histories and experiences of individuals within your student group. There may be students who have direct or indirect experience of devastating genetic disorders, or the play may raise other issues which you could not predict but which are nevertheless difficult for them.

It will assist you if you can find out some of the background of your group before starting work on the programme. If there are personal histories of hereditary disease, loss of close family members, "IVF" conception or adoption, the group will need to be prepared to provide support and a trusting atmosphere for discussion.

## **Preparatory Lessons**

If short on time, we suggest that you prioritise the 'What does it mean' and the 'What do we think' activities, as they offer the most direct way for students and teachers to prepare for both the play and the debate.

## Synopsis

Ageing DJ TRACEY has two children: RIVER (RIV) and PHOENIX (PHEE). RIV is in his early twenties. Conceived during an Ecstasy-fuelled night in the late 1980s, RIV has grown up never knowing the ‘beautiful stranger’ his mother chose that night. In 1994, TRACEY, in her early thirties, gets broody again. This time her selection process involves a sperm bank rather than an actual person; this time she wants brains. A donor is chosen from a private sperm bank, a very talented violinist who mountain-climbs in his spare time. Nine months later, Phoenix (PHEE) is born.

PHEE grows up somewhat precocious. Guilty for the rather neglectful way she brought up RIV (dragging him round raves in a moses basket, living in squats, forgetting to take him to school) TRACEY has slightly overdone it with her daughter. PHEE has been hot-housed since the womb and can already speak fluent French, dazzles everyone with her maths skills, and read the latest Harry Potter book in one day. Sadly, she hasn’t inherited her donor father’s attributes. Her violin playing is lamentable, and she can barely make it to the kitchen, let alone climb any mountains. TRACEY is still a ‘free spirit’ though, so RIVER does the cooking, cleaning and generally holds the household together.

In 2006, TRACEY has a short-lived fling with a Christian guy. The relationship (and TRACEY’s interest in church) soon grinds to a halt. But in the meantime, RIVER has met CASSIE, another churchgoer. Despite CASSIE’s deep faith and RIVER’s unwillingness to convert to Christianity, the two fall madly in love.

Soon after, PHEE meets Dr. Khaled, a scientist specialising in stem cell research, at a lecture for Gifted and Talented children. She develops a crush on Dr. Khaled, and becomes absolutely fascinated by his research. She cruises the internet, addictively searching for more information about stem cells.

Despite their unconventionality, our family has rubbed along happily enough, until now. Now TRACEY’s hands seem to have developed a life of their own. Uncontrollable muscular movements are making it difficult for her to spin the vinyl at all and she is having unsettling mood swings (even more than usual). Could it be that all those drugs she used to take are finally taking their toll? PHEE does some internet research and begins to wonder if her Mum has some form of neurodegenerative disease.

TRACEY is adamant that this is not so. But then she starts getting more and more clumsy and keeps stumbling for no good reason. Eventually, she is diagnosed with Huntington's Disease.

TRACEY was adopted, so she never knew, but with her diagnosis the whole family is presented with a ticking time bomb. Both RIVER and PHEE could have it too. Huntington's is a life-shattering, so far incurable disease. The brain, body and emotional life of sufferers deteriorate slowly until they are no longer able to control movement or mood or speech. Everyone is shell-shocked. The burning question is, do PHEE and RIVER want to take the test and find out if they will have it too? If the answer is yes, they will live the rest of their lives knowing what is waiting for them. They are witnessing TRACEY's deteriorating condition on a day to day basis. They know what's in store. If they do have Huntington's, they could also pass it on to their children.

PHEE scours the internet for information, inundates Dr. Khaled with emails, looks up prominent Huntington's experts, reads anything she can get her hands on. She soon discovers that stem cell research provides future hope to sufferers of many diseases and conditions, not just Huntington's. She is amazed by the different possibilities being thrown up.

Pioneering work is being done to create embryos from animal eggs, extract stem cells from amniotic fluid, and take stem cells from the hip bones of people with heart disease and inject them into their hearts to mend the damage. Perhaps one day it will even be possible to grow new organs and prolong human life far beyond present life expectancies!

CASSIE and RIVER have been trying for a baby. Should they go ahead with their plans to start a family? They could just take their chances (in CASSIE's terms, accept God's will). Or they could go for Preimplantation Genetic Diagnosis (PGD), which will allow them to screen out embryos with Huntington's, if RIV has the disease. CASSIE finds this very difficult; her faith teaches her that all life is a gift from God. A baby with potential for Huntington's is just as important as a baby without. Major pressure is put on the young relationship, and is complicated further by PHEE waxing lyrical about the use of stem cells.

All these tensions lead to arguments. CASSIE feels that scientists working with embryonic stem cells are playing God. PHEE calls her stupid, doesn't she understand that these are just tiny little blobs with no feelings? RIVER tries to make a compromise. Maybe God, if there is a God, created scientists to do just this kind of work? TRACEY is

with CASSIE; despite not being religious, she does believe in the sanctity of life, and does not think embryonic stem cells should be used.

Sick of all the pressure, RIVER explodes. He is sick to death of it all. He jumps on his motorbike and rides off .

## Issues raised in the play

Nobody Lives Forever explores the complex issues that surround a family, their experience of Huntington's disease and the ethical questions the disease forces them to face. The play provides a starting point for exploring sensitive issues, providing an opportunity for audiences to explore their own feelings and attitudes. It aims to get the audience to question any preconceptions they may have about science and scientists, the ethical issues surrounding the use of embryonic stem cells for medical research and therapeutic cloning, and to encourage serious debate on these issues.

- Is research using cloned embryos acceptable?
- What is the moral status of the human embryo?
- Is it acceptable to create and use embryos of any sort, including hybrid embryos (the shell of an animal egg injected with human DNA) as a resource for stem cells?
- Should the public trust the government on new developments in science and technology?
- Should the public trust scientists to make ethical decisions?
- How do families cope with the discovery of a genetic condition, and what choices do they face?

## The Characters

### **RIVER**

Kind, hardworking, lovely young man. Overdeveloped sense of duty due to being brought up by a not always reliable mother.

## **TRACEY**

Ageing raver and 'free spirit'. Mother of River (Riv) and Phoenix (Phee). Has lots of energy and love of life but not great on practicalities.

## **PHOENIX**

Gifted pre-teen. Very clever, but socially? Not great.

## **CASSIE**

River's missus. Warm hearted, with an earthy sense of humour.

# Preparatory Lessons: Activities

## 1. What does it mean?

### **Objective**

A brainstorming exercise to ensure that your students are familiar with the key words and phrases referred to in the play

### **Materials**

Flipchart and Whiteboard

### **Process**

1. Explain that you are going to say a word or phrase and that when you call out their name, you want each of your students to say the first word that comes into their head.
2. Explain that if they can't think of a word or if their mind goes blank, they can say pass.
3. After each round, clarify the actual meaning of the word or phrase if appropriate, and discuss as a class some of the associations that have been shared.

### **Words & Phrases**

Embryo

Stem Cell

Neurodegenerative disease

Research

Preimplantation genetic diagnosis

Hereditary

Blastocyst

Nervous system

Cure

Donor

Symptoms

## 2. What do we feel?

### **Objective**

To explore the emotions associated with some of the key phrases associated with stem cell research.

### **Materials**

Flipchart

Whiteboard

### **Process**

Repeat the above activity asking your students to think of an emotion rather than an adjective that they associate with each of the words or phrases below.

After you have completed the activity, ask your students if they want to comment on the groups' responses.

### **Words & Phrases**

Progress

Medical breakthrough

Pro-life

Status of the embryo

Hybrid

Playing God

Cord blood

Therapeutic cloning

Tissue

## 3.Sculpture

### **Objective**

To enable a non-verbal student exploration of pre-conceptions about people who support and oppose stem cell research.

### **Materials**

Ideally a large space, i.e. drama studio or cleared classroom.

### **Process**

1. Split the class into groups of three, asking them to decide who is A, B and C (a group of four is also fine).
2. A is the sculptor, and the rest of the group (B, C and D if required) are the sculptor's clay. The sculptor must guide the clay into an image representing the titles below.
3. After the first sculpture is complete, invite the group to look at each-others' sculptures and comment on what they see. Then swap so that another person becomes the sculptor.

### **Sculpture One**

Sculpt an image of a stem cell scientist

### **Sculpture Two**

Sculpt an image of a pro-life activist opposed to embryo research

### **Extension:**

Sculpt an image of an animal-human hybrid cell (ie. A rabbit/cow egg 'shell' with human DNA implanted).

## 4. What do we think?

### Objective

To prepare your students for the debate that will follow the play. The debate will explore issues surrounding the benefits and drawbacks of stem-cell research.

### Materials

Ideally a large space i.e. drama studio, or a cleared classroom

### Process

1. Ask your students to stand in the centre of the space.
2. Explain that there is an imaginary line running down the centre of the space. One end of the line represents Agree and the opposite end of the line represents Disagree. The middle of the line is Don't Know.
3. Explain that you are going to read out a series of statements. If they agree with the statement students should go and stand at the end of the line that is Agree. If they disagree they should go and stand at the end of the line that is Disagree. If they are not sure or don't know what they think they should stay in the middle. They can take up any position on the line that represents their opinion.
4. After they have taken up their positions, ask your students to explain why they have chosen their position. After hearing from several students give your group the opportunity to change their position.
5. Repeat the process for each statement.

### Statements

1. I don't think you should create any kind of life– even if it “lives” for an hour in a test tube - simply so that you can destroy it and take cells from it

2. Life begins at the moment of birth and not before
3. Embryonic stem cell research (using cells from embryos up to 14 days to look for cures for diseases) is legal, and this is right.
4. It is OK to create 'hybrid' embryos using the egg of a cow injected with the DNA of a human
5. Scientists are the people who understand new technologies, and should be the ones to make moral decisions about using them
6. Stem cell therapy has the potential to make a real difference to people's lives, and this overrides the ethical cost
7. There are other ways of curing diseases, we do not need to clone embryos
8. It is dangerous for human beings to 'play God' by creating human life in this way
9. There are not enough human egg cells available to create enough treatment the number of potential patients who might benefit, so the therapy could only treat a few rich people which is not acceptable
10. The stem cell debate has been blown out of all proportion by the media
11. We owe it to sufferers of chronic diseases to try and find cures. It is therefore more unacceptable NOT to do embryonic stem cell research than to do it
12. Rather than looking for cures by cloning embryos, we should learn to accept pain and suffering

# Glossary

## A) Blastocyst

The cell stage reached by mammals when the embryo begins to develop while being encased in an outer layer known as the blastoderm

## B) Cord blood:

Blood from the umbilical cord, that is rich in adult stem cells

## C) Cure:

To get rid of an ailment or problem; to heal

## D) Donor

Person who makes a donation – of money, or their blood or their eggs etc

## E) Embryo

The stage of prenatal development after fertilization

## F) Hereditary

Factors that can be transmitted genetically from one generation to another

## G) Hybrid

An animal or plant resulting from a cross between genetically unlike individuals. In the case of stem cell research, human DNA is inserted into the shell of an animal egg,

although these hybrids do not develop into any kind of organism.

## H) Nervous system:

The sensory and control apparatus of animals, consisting of a network of neurones

## I) Neurodegenerative disease:

A condition in which cells of the brain and spinal cord are diseased or lost

## J) Preimplantation genetic diagnosis

PGD (or also known as embryo screening) refers to diagnostic procedures that are performed on embryos following IVF and before implantation into the uterus, to avoid the transmission of potentially harmful hereditary conditions

## K) Progress:

Advance towards completion or perfection

## L) Pro-life:

Supporting the life of the unborn; against abortion, experiments on embryos etc.

## M) Research:

Systematic investigation to establish facts or collect information on a subject

**N) Status of the embryo:**

The relative position or legal standing of the embryo in relation to born human beings

**O) Stem cell:**

An undifferentiated cell that gives rise to specialized cells. A focus for much recent research and debate

**P) Symptoms:**

Any sensation or change in bodily function experienced by a patient, that is associated with a particular disease

**Q) Therapeutic cloning:**

A laboratory technique used in regenerative medicine, whereby an embryo is created with a donor nucleus from an adult cell. Stem cells are extracted from the embryo and used to replace damaged cells in the patient.

**R) Tissue:**

A part of an organism consisting of a large number of cells having a similar structure and function, for example all the cells of a certain organ create tissue