

## Introduction

As we come to understand the genetic basis of specific diseases we will learn how to address these diseases at the genetic level. There is no doubt that even now genetic research is generating promising new treatments for diseases. Research with stem cells, for example, could lead to growing organs for transplantation that would not be susceptible to rejection. For many people, the research being done on both human adult and embryonic stem cells raises ethical questions. Some make no moral distinction between the two types of cells. Others do not condone the use of embryonic stem cells, which requires the destruction of human embryos. Like abortion, this issue can be understood to centre on the question of who is a person. In Canada, a fetus is



not legally a person (and therefore the subject of rights) until it has been completely delivered from the birth canal of its mother. Society is divided on this legal position, with those opposing it arguing that a fetus should be considered to be a person from the time of conception. Both views have implications for the use of embryonic stem cells in research and experimentation. For those who oppose embryonic stem cell research, this experimentation is morally wrong since the embryo is a person who is killed as a result of such experimentation.

The use of adult stem cells does not involve this moral dilemma. These cells can be harvested from specific human organs and used to develop treatments for cells that have been destroyed by disease or that are genetically abnormal. Moreover, recent scientific advances in reprogramming adult

somatic or mature stem cells to a state similar to that of embryonic stem cells is changing the moral landscape, especially since this method also seems to solve the problems of rejection and tumour formation, both of which have impeded progress of the use of embryonic stem cells. In this session we will discuss how genetic technologies are being used – and are likely to be used in the future – in research on human and non-human subjects. The scenarios that follow are both fascinating and troubling. Each asks a difficult question raised by our developing technologies.

## Scenario 1

### Question to Think About

#### *Should we create transgenic beings?*

Our first scenario is based on a remarkable true event that occurred in 2001. The Oregon Primate Center announced the first successful germ-line engineering in a non-human primate. The Center had created a “transgenic” animal: a monkey with the inserted DNA of another species – a jellyfish – in every cell in his body. The experiment showed it is possible to genetically modify non-human primate embryos.

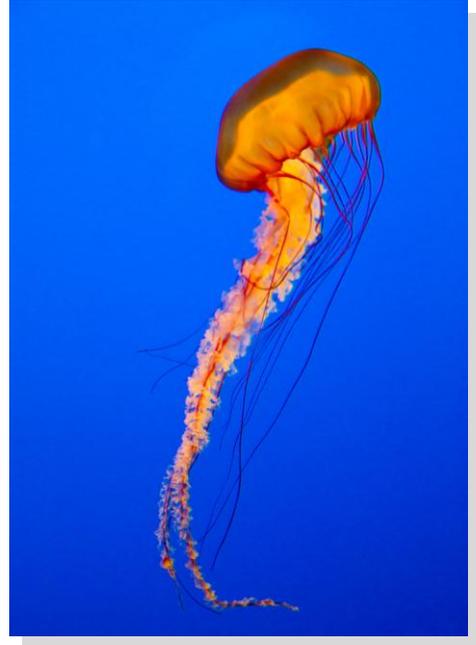
### Narrative: ANDi & the Jellyfish

Review Transgenics, noting especially the distinction between mixing genes from two or more organisms versus cloning the entire organism. The section on Human Engineering and Cloning in Embryonic Development and Genetic Engineering will also be helpful.

You are on an ethics panel at a prominent medical research centre. The research proposal being reviewed by the panel is from the lab of Dr. Chan, whose research team has made remarkable strides in genetic technology, including the successful birth of the first cloned nonhuman primate using the technique of in vitro blastomere separation. The experiment they want to perform involves the insertion of genetic material from a jellyfish (GFP) into the eggs of a Rhesus monkey. After the genetic material is inserted into the eggs, they will be fertilized and then implanted in the monkeys. If the experiment is successful the offspring will have the genetic sequence from the jellyfish in every cell of their body. GFP has been successfully inserted into mice without harmful side effects. The justification for the research is that if it is possible to insert DNA sequences into the germline of nonhuman primates, then it will eventually be possible to design nonhuman primates that are susceptible to human diseases. Such an animal will be very effective for research purposes and the research will also require far fewer animals.

## Discussion Questions

- 1) What questions would you ask if you were a member of an ethics board faced with this proposal?
- 2) Are there ethical concerns that you might have because the experiment was being performed on a Rhesus monkey rather than, say, a mouse or a nematode? What are the principles you would use to distinguish between species if you were developing research regulations for different classes of animals?
- 3) Should society allow transgenic experiments? We have already inserted human genes in some species (cows for instance) to produce proteins used to treat human diseases. The UK allows enucleated cow eggs to be combined with human material for experimental purposes. What are the possible risks of inserting human DNA sequences into a Rhesus monkey? Is it possible that we might create a half human-half monkey hybrid? What are the ethical implications of such a possibility?
- 4) Genetic manipulation of germline cells is perhaps the ultimate trajectory of genetic research. What does this kind of potential for control over our own evolution and the evolution of other species mean?



## Scenario 2

### Question to Think About

*Who is a person? What is the status of a human embryo?*

Some of the recommendations of the 1994 Royal Commission on Reproductive Technologies were incorporated in the Assisted Reproduction Act, 2004. This Act allowed experimentation on “spare” embryos in Canada, for therapeutic but not reproductive purposes. Earlier, in 1978, Pierre Soupart had submitted a proposal to do research on human embryos. His proposal was instrumental in the development of the first policy statement on embryonic research in the United States. In 1983, in defense of research on human embryos, he wrote, “Because of its human origin the embryo undoubtedly deserves to be paid a high degree of respect when treated as a research object. What higher form of respect could be paid to human embryos than to ask them to provide vital information leading to the alleviation of some types of human infertility, the prevention of birth defects, contraceptive and cancer research, and the actual causes of natural embryonic losses in man?”

Embryonic stem cell research remains a controversial ethical topic and we continue to ask questions about what we now know about the human embryo. Is there anything distinctive about its status or its use in research?

What do we mean by human “personhood”? The question of when a fetus becomes a person is complicated and troubling, and is answered in different ways by different groups. In Canada a fetus is not legally a person until birth, and therefore embryonic stem cell research is allowed, since the embryo has no legal rights, including a right to life. Here are two scenarios that raise the question of what it means to be a person.



## Narrative: Use of Embryonic Stem Cells and Fetal Tissue in Medical Treatment

- 1) You are a genetic counselor and Tom and Jackie have come to you with a dilemma. Their six-year-old daughter, Molly, has Fanconi anemia, a rare genetic disorder that prevents the production of bone marrow and can kill at a very young age. A bone marrow transplant from a matching sibling has an eighty-five per cent chance of curing Molly. Tom and Jackie have conceived a child with the intention of using stem cells from the umbilical cord and placenta after the birth to try and save Molly. They had not wanted a second child but had no doubt that this was the only and best option for Molly. They want to use pre-natal testing to find out if the fetus, a) has the same disorder as Molly and b) is a good match for transfusion.
- 2) Mark and Anna have come to you with the intention of testing a fetus they have conceived with the intention of aborting if it is a good match for Anna's father who is dying of Parkinson's disease. They want to use the fetal tissue in what they have been told is a very effective treatment for Parkinson's.

## Discussion Questions

1. German philosopher Immanuel Kant talks about the ethical principle of never using a human being as a means to an end, however great the end might be. Can this principle be applied in these two scenarios? Is there a moral difference between Scenario I and Scenario II?
2. Abortion is permitted under the Criminal Code in Canada. The motives of women asking for abortion services are regarded as their business. Is there anything different about the two cases under discussion here?
3. Should processes like these be regulated? If so, what kind of regulations should be developed?

## Scenario 3

### Question to Think About

*Should human embryos be cloned for medical research?*

Ian Wilmut made international headlines in 1996 when he announced that he and his team had successfully cloned a sheep using somatic cell nuclear transfer technologies. The Roslin Institute was granted a license, the second in the UK, to clone human embryos for research purposes. Wilmut's work raises fundamental questions, not just about the disposability of human embryos in research, but also about the application of cloning technologies to human beings.

There are two broad categories that frame the debate on human embryo cloning:

- a) cloning for the purpose of research, in which case the embryo is ultimately destroyed, and
- b) cloning for the purpose of reproduction. To date, cloning for reproduction is illegal in most countries.

The focus of this session is on using embryos for research. Should we allow scientists to clone human embryos if such research might lead to breakthroughs in treatment for human diseases (for example, motor neuron disease)?

Another important distinction is that between cloning using blastomere separation and cloning using nuclear transfer. Blastomere separation occurs in nature and leads to identical twins, or even quadruplets. In 1993 human embryos were cloned using



technology based on blastomere separation. Nuclear transfer involves the direct transfer of genetic material into an enucleated egg, which is then coaxed into a totipotent state' that is, it becomes an embryo. The purpose of this type of cloning is for experimentation, and the same moral questions arise here as in the use of "spare" embryos.

## Narrative: Cloning Human Embryos & Motor Neuron Disease

You are a member of the federal board established to regulate the use of genetic technologies. Two researchers have come to the board to request permission to clone human embryos for research on motor neuron disease.

They want to clone embryos using tissue from sufferers of motor neuron disease so they can learn something about the developmental mechanisms of this terrible disease. They have located women willing to donate eggs for this project and are ready to proceed if the licensing board will agree. The board has already granted one laboratory a licence to clone human embryos, but you are having doubts about the morality of this kind of research. You have just finished reading some research on human reproduction and have had great difficulty working out in your own mind how to think about human embryos. One of the researchers makes the following argument: the best way to learn about this disease is to clone human embryos. If we can understand this disease we can cure it. Thousands of people and their families will benefit.

You are aware that recent stem cell research may make the need for cloning redundant. Further, use of these stem cells does not incur the same moral problems as the use of embryos.

## Discussion Questions

- 1) Bioethicist Andrea Bonnicksen writes about human embryos that, “we cannot talk about germline therapy without considering the policies on embryo research. And much of the concern relates to the sanctity or the non-sanctity of the embryo. What the embryo is will determine what people believe about what should be done with it.” Discuss.
- 2) Mary Mahowald suggests in the *American Journal of Bioethics* that it might make a moral difference if researchers allowed embryos to die before extracting stem cells, since this action would preserve the letting die/killing distinction. She also suggested that some form of ritual at the disposal of embryos used in this way might allay the moral concerns of some groups. Here is the quote: “Allowing embryos to die before retrieving their stem cells thus provides a means by which some individuals can preserve their moral integrity. Extra embryos may also be dealt with respectfully or disrespectfully. Presumably, the notion of ‘respect’ or ‘disrespect’ for early embryos makes no sense for those who regard them as having no moral value or status. For those who do, however, respectful disposal is surely possible.” Discuss.
- 3) Here are two suggestions on how to derive stem cells from embryos without destroying them. Would either suggestion solve the moral problem of embryonic stem cell research?
  - a. Remove one cell from the embryo and derive stem cells from that instead of destroying the whole embryo.
  - b. Create human embryos that cannot be brought to term, even if we wanted to.
- 4) In some ways, the debate about human embryos is similar to the older debate about abortion. Do you see ways in which the discussion about human embryos can move forward in ways that the abortion discussion cannot?
- 5) The debate about embryo-derived stem cells is part of a larger conversation about embryos generally. When we do research on embryos, they die. When we use embryos obtained through IVF, many are destroyed or stored and later destroyed. When we derive stem cells from embryos, the embryo dies. How should we develop policies that affect human embryos?
- 6) What would you say to the researchers?