

Making Good Decisions In Biotechnology:

Stem Cell Research, Cloning and Genetic Information

THE INTERCHURCH BIOETHICS COUNCIL



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Introduction

All of us have to make moral decisions in life – whether to pay for using the firm’s photocopier for our private purposes; whether to declare all our income for tax purposes or whether cash jobs are OK ... and so on. We are also entwined in much larger issues such as the ones that have dominated recent headlines:

Is genetic modification of food OK?

Should cloning be allowed simply because we have the technology?

How do we balance infinite demand for services with a finite health budget?

Should doctors break patient confidentiality to protect an innocent party?

Bioethics (*bio as in living things, ethics as in how are we to live*) is concerned with moral (right/wrong, good/bad) values of human actions with and toward living things.

In this series of studies we are going to consider three bioethical issues: human reproductive cloning, embryonic stem cell research and the obtaining and use of genetic information.

Study 1: Stem cell research: “*Ethics and Embryos*”

Stem cell technology is a new but rapidly expanding field. Considerable public concern has followed recent reports that stem cells obtained from living embryos may be used for medical research. Stem cells are of interest because they are able to form any cell type in the body eg muscle, kidney, skin etc. Stem cells from embryos are able to do this better than adult-derived stem cells.

It is also suggested that ultimately tissues produced from stem cells may be used to repair damaged tissues and even to produce replacement organs, thereby assisting sufferers of burns, muscular degeneration, cancer, immunodeficiencies, inherited blood diseases, osteoarthritis, spinal cord injury, diabetes, heart failure, liver failure, kidney failure, Alzheimer’s disease, Parkinson’s disease, multiple sclerosis and other neurodegenerative diseases.

Most of us would know of someone who is suffering from one or more of these illnesses. So what’s the problem? Surely we want sufferers of these debilitating or disfiguring health problems to be helped? The problem arises because to obtain embryonic stem cells a viable embryo must be destroyed. This raises questions as to the value of the human embryo, and wider issues concerning the value of human life.

Study 2: Cloning: “*The Same or Different?*”

There has been a great deal of media publicity, particularly during the past year or so, about the possible cloning of a human being. Claims have been made, though not substantiated, that a baby has already been born by cloning, and in Italy the birth of several cloned babies during 2003 has been predicted. Human reproductive cloning is illegal in many countries, including Canada, Australia, the UK and France. In New Zealand, reproductive human cloning is not illegal, but a Bill on Human Assisted Reproductive Technology has been introduced into Parliament in 2003, which proposes a ban on reproductive human cloning.

Studies 3 and 4: Using Genetic Information: “*Genes and the Genie*”

These studies also raise ethical questions related to the obtaining and use of genetic information. The DNA, which makes up the genome of a cell, contains genetic information that determines the characteristics of that organism. Techniques have made it possible to determine the composition of the human genome, and to test for the presence of some defective genes. Questions arise regarding who owns the information about an individual’s DNA and what use should be made of this information. Should it be used to select offspring with particular characteristics, or to select against embryos that may be defective? Who should make these decisions?

In New Zealand, Privacy Laws regulate the right to confidentiality of personal information. However, there are obvious examples where there are conflicting interests, eg if a parent who carries defective genes considers his/her genetic information is confidential to them, lack of this knowledge may affect children who may have inherited the defective genes. There are other areas eg regarding employment and insurance where there could be an interest in obtaining genetic information about another person.

These studies

The studies in this book are designed to assist you to examine the ethical, spiritual and cultural issues raised by the above questions. These areas of research and their possible outcomes are currently being discussed by the community and by the government. A Bill on Human Assisted Reproductive Technology (HART) was introduced into Parliament in 2003 and is before a Select Committee. The Interchurch Bioethics Council (ICBC) made a submission on this Bill and made a presentation to the Select Committee. As an individual, you are also able to make a submission when Bills such as the HART Bill are before a Select Committee.

Study 1: Stem Cell Research

“Ethics and Embryos”

This conversation was overheard in a University coffee room near here.

Sophie (a philosophy student): I was just reading some great stuff on the use of stem cells from human embryos to repair damaged bodily tissues.

Brian (a cell biologist): That is really exciting stuff all right. It has tremendous promise for patients with strokes and spinal damage.

Anne (a neurologist): These stem cells create hope that we can not only repair but also regenerate damaged and impaired bodily tissues to restore the functions of the healthy body when crucial organs are compromised. The idea that we might repair organs rather than just saving what is left of damaged liver, muscle, heart and nervous tissue is very exciting for those of us who work with people suffering from serious diseases affecting these organs; especially where the tissues and their functions are irreplaceable and the disability is as major as a spinal cord injury.

Sophie: Why do they need the embryos for this work?

Brian: Embryos contain the cells that are going to give rise to all the different tissues of the human body and the embryo has not yet developed the markers or signatures that identify tissue as coming from a particular individual. Therefore embryonic tissue has the potential for growth into new tissue and does not provoke the same foreign tissue reactions as tissue from an adult individual (whether human or animal).

Anne: I agree that scientifically it is very exciting but I have some very profound ethical worries about it.

Sophie: Tell us about those worries.

Anne: Well, we are dealing with a potential human being here so that it is hard to draw the line between this stuff and abortion or even child murder; you are destroying a human life.

Brian: I can't go along with that. I mean this is not a human being, it is just a little bunch of cells. If I blow my nose a bunch of human cells comes out, we shed them all the time and I just throw that away in a tissue.

Sophie: Now this is a very interesting debate. Brian has a view that the embryo is just a clump of cells and Anne has a view of the embryo as a young human being.

Brian: I would say I have an objective view. All we have is a bunch of cells; they could, in certain scenarios, develop into a human organism but they are just a ball of cells. If I showed you a frog embryo or a human embryo you would not be able to tell the difference. This is nothing but a scrap of tissue.

Anne: No! No! No! This is already a human child in the making.

Sophie: Now back up a bit both of you. Let's just look at this argument. You both agree that we have a group of cells which does not look anything like a human being.

Anne: I agree but looks are only skin deep.

Brian: Precisely.

Sophie: So again you both seem to agree but that masks a deep disagreement.

Anne & Brian: How so? What do you mean?

Sophie: Anne sees something beyond the clump of cells in the embryo, she sees a potential human being.

Anne: That's right, what we have in an embryo is something that has the intrinsic nature of a human being waiting to be unfolded. It is a human organism at an early stage in a whole life journey that goes on into adulthood, and that is what we should take into account in our treatment of it.

Sophie: In philosophy this position is best associated with the name of Aristotle. He argued that every type of thing had its own specific form that made it the type of thing it is. For a living thing then it is not just the shape but its mode of living that counts. so that, for instance, it is part of the form of a frog to be a tadpole during part of its life. Aristotle regarded the human being as a rational, social being. Embryos, fetuses, and infants are all proper phases of the life of a human being.

Brian: That's all philosophy, I am a scientist and just interested in the objective facts.

Sophie: No, think about it. You yourself admit that a frog embryo is a different kind of thing from a human embryo.

Brian: Of course it is.

Anne: Well there you are. It *is* different, and a human embryo is morally important and has rights.

Sophie: Too fast! We haven't yet begun on the question as to when should we begin thinking of a human being as having those special moral properties.

Brian: And I tell you, objectively there is nothing about an embryo that makes it a moral being.

Sophie: Yes, I think we are quite clear about your view here but perhaps we ought to think a little further. In general, the way we think of a thing takes a broad view of what type of thing it is. Think, for instance, of a ticket to a Datsuns' concert.

Brian: A What?

Anne: Oh you fuddy duddy scientists wouldn't know about what's going down at the moment.

Sophie: Moving right along. Say my mother uses it to start the fire and I lose my rag. If she says 'But what are you so upset about, it was only a little bit of paper?' Now,

she is right in one sense: my ticket is just a piece of paper, but this thing has a value "not dreamed of in her philosophy". And this is kind of the same.

Anne: You're right. The human embryo develops from almost nothing to being a living, loving, and loved child. It's a bit like a painting, the embryo takes shape gradually but it is still a thing of worth.

Sophie: This kind of thought is often used to support the gradualist position according to which a human organism increases in value as it develops. The embryo is therefore precious but not in quite the same way as a child or adult who is truly one of us. It is also compatible with the idea that a distinct human being comes into existence at conception.

Anne: And ...it is natural for such a being to become a human person. Thus our attitudes to embryos should be continuous with those we hold towards children.

Brian: Hold it, hold it, something got by me there. I just want the objective facts.

Anne: But Sophie has pointed out that the facts are somewhat deeper, according to both of us, than is revealed by just looking at things at the level where the embryo is indistinguishable from a frog embryo.

Brian: But mine are real facts – DNA and all that.

Anne: But your "real facts" as you call them are only significant because of what they tell us about the prospective life of the organism concerned. We have to take account of the place of this tiny creature, the beginnings of a human life, in the whole scheme of things.

Brian: That all sounds a bit religious.

Sophie: Not necessarily, our discussion has focused on a perfectly natural fact, to which Aristotle drew attention, that any living thing has an extended form which includes a life story of a certain kind. That is as much a fact about that living thing as anything about its composition.

Brian: Maybe.

Anne: Come on, lighten up, don't be such a sore loser.

Sophie: Not so fast.

Anne: I thought you were on my side.

Sophie: Perhaps but perhaps not, I'm mainly interested in nutting it all out. Now you both agree that a somewhat broader perspective on what the thing is in the whole order of things is the most appropriate one to decide these issues.

Anne: Yes, absolutely! I think Pope John Paul II expressed it beautifully when he suggested that what was at stake is whether we favour life and the affirmation of humanity or its rejection and destruction.

Brian: Oh come on, I can't abide this religious crowing!

Sophie: Calm down both of you. Take a step back. The whole story in the case of normal conception possibly includes the birth of a child and that, we both agree, should colour our attitudes here.

Brian: Colour, but not decide all the rights and wrongs.

Sophie: OK, we'll go with that for the moment.

Anne: Maybe.

Sophie: As far as I can see this has very different implications for embryos (or pre-embryos as some people call them) that have been created as part of the process of making stem cells from those which are created as part of the process of having children because the context and the story of which they are a part is totally different.

Brian: Aha, a Solomon come to judgment!

Anne: Run that by me again.

Sophie: Think about it; we have rejected the minimalist view whereby Brian wanted us to treat the human embryo as just a bunch of cells no different from any other.

Anne (cautiously) & **Brian** (with a hint of smugness): Yes.

Sophie: And the reason for doing that was that we wanted to take a bigger view of the total process that the thing in front of us - a piece of human tissue or a few human cells – was part of.

Anne: Ummm, Yes. **Brian:** Right again.

Sophie: So now, on the one hand we have a pre-embryo on the way to becoming a human being, and on the other we have a stage in the process of obtaining stem cells for therapeutic use – and these are different processes so the thing we are considering should be seen differently in each case.

Anne: At this stage I need lunch so I can think about this for a while.

Brian: Good idea.

Sophie: So, when shall we three meet again?

Brian: Soon!

Ethics and Embryos:

A Bible study on this dialogue is found on pages 28-29.

STUDY QUESTIONS:

1. Do you think of the embryo more like Brian or Anne, ie, is the embryo “just a ball of cells” or a ‘human being in the making’?
2. Who has the right to decide how embryos are used?
What are the rights of those who donate materials for stem cell research? For example, issues of amount and degree of information to be provided to potential donors, informed and genuine consent, privacy and confidentiality, whether donors are to share in the fruits of successful research either by (a) getting treatment; or (b) payments etc.
3. How do you feel about human embryos being created specifically for research? Does it depend at all on whether this is for commercial gain?
4. Is human life sacred? How do our beliefs about the sanctity of human life influence our understanding of these issues?

Further Discussion Options

5. Refer to the developmental history of the embryo in Appendix 3. Do you feel there a period post conception which is optimal or appropriate for obtaining stem cells?
6. At present some children are “born to order” to treat a sick sibling with a fatal disease. What do you think of this? Do you have a right to offer your potential child’s stem cells for someone else’s benefit?
7. What are the cost impacts? Is the expenditure on IVF justified? (No one ever died of infertility; perhaps the money is better spent elsewhere?)

Study 2: Reproductive Cloning

A further conversation in the University coffee shop.

The Same or Different?

Anne (a neurologist): Did you see the newspaper report about the human clone last week? I thought it was disgusting; it should never be allowed.

Brian (a cell biologist): I can't see what all the fuss is about myself.

Sophie (a philosophy student): How interesting!

Anne & Brian: What do you mean?

Sophie: Well, here is one of you morally outraged and the other one unmoved.

Anne: How can you be unmoved when people are planning to copy human beings like, ... like, cars coming off a factory line!

Brian: But it isn't quite like that, is it?

Sophie: Do you mean that's not what they are going to do or that the process is not like a factory process?

Brian: Well, both I guess. First, hardly any one is going to use it because it will be very expensive and what's the point when you can have a child in the normal way, and second, it's not like just stamping people out of the same mould.

Anne: But it's the principle of the thing.

Sophie: What principle is that?

Anne: The principles I am thinking about are such things as human uniqueness, dignity, and individual freedom, all of which seem to significantly threatened by cloning,

Brian: I'd like to hear the arguments – at the moment it sounds more like the sweeping claim that might be made by a politician or senior churchman.

Sophie: Yes, it would be worth spelling out the arguments.

Anne: OK, first off, uniqueness: you can't deny that there is a fundamental difference between the idea of a human being as an individual versus regarding a human life at its beginning as one of a possible set of copies.

Brian: But is this a human life at its beginning, particularly if it is part of a process to produce tissue for repair rather than producing a child?

Anne: Let's leave the whole therapeutic thing aside and concentrate on reproductive cloning. What we have is some form of producing a copy of a human being and that

is totally the wrong attitude. We are not commodities that can be produced as a series of copies of one another.

Brian: But is it really like that? I mean, it's just the same as having twins – two individuals with the same genetic makeup.

Anne: No, it isn't the same at all. You can take an adult cell or the tissue of a child killed in an accident and make another human being who is the same and that is objectionable.

Sophie: I agree that a clone is not the same as a twin because a twin does not occur as a result of an attempt at duplication. The twin is born at the same time as the sibling and pains are often taken to treat the twins as two independent individuals with their own personalities and identities. You can make a clone genetically the same as the person whose tissue is used but the clone will not have the same upbringing and formative experiences and so they could turn out to be very different from the original individual.

Brian: Do you mean that your genes don't determine the person you are?

Sophie: That's exactly what I mean, the view that they do is called genetic reductionism and it neglects all the other things that have an effect on the way the brain and body develop during life.

Brian: But we can see how the genes shape the human being whereas all these other things – mother-love, conversations, education, culture and so on are all a bit ephemeral.

Sophie: Not at all! The brain, which, for the purposes of argument we could say was the seat of personality, is designed to be changed by the environment and the experience of the person; otherwise we could never learn or remember anything.

Anne: But what about the values that spring from within? Where do they end up in this picture of a piece of biological tissue jointly moulded by genes and the environment?

Brian: They are obviously just comfortable fictions.

Sophie: No, that does not follow at all. The process of learning and forming memories, even though it is a physical process, reflects the choices and values of the individual in an increasingly important way as any human being develops.

Anne: That's fascinating.

Sophie: Not only that but it is firmly grounded in things we know to be true about the human body and brain.

Brian: Mmmm, I'll have to think about this. But we still do not have any reason to think that there is anything wrong with cloning.

Anne: Of course we do. How can we make a stand on the moral importance of human dignity when we treat a human being as a piece of tissue which can be manipulated and copied at will according our purposes. A human being should not

just be a produce or commodity “made to order” on a preformed pattern and that is just what a clone is.

Sophie: That’s all right if you believe in all that but let’s face it – a human being can start off in a number of ways these days, even in a test tube. The person that results is still treated as an individual in his or her own right with moral consideration and personal dignity and all that. Can you really believe that we would treat a cloned child in any way differently from the way we currently treat children who started life as “test tube babies”?

Anne: Perhaps not, but what would it feel like to be born knowing that you were . . .

Brian: A chip off the old block?

Anne: More than that, something made for somebody else’s purposes without the dignity or mystery of coming into being through a loving act.

Brian: Oh don’t give me all that “love child” stuff, conception is a biological process as is cloning so let’s stick to the facts. There is no mystery these days, we know all about fertilisation, embryogenesis, and the development of tissues and organs and that is how we all came into being.

Anne: What about the human soul and the god-given spirit in each one of us?

Brian: Old fashioned mumbo jumbo!

Sophie: No, let’s just pursue the traditional Christian line for a moment and say that the soul of this kind is not the same as what we might call flesh and is a unique gift of God to each person.

Anne: Right on!

Sophie: But now there is no problem with cloning because however the flesh gets itself into shape – for instance through cloning – the soul remains a distinct contribution unique to each person.

Anne: Oh . . . but . . . I don’t know what to say about that.

Brian: Shot down in flames. Just what such an archaic idea deserves.

Sophie: I’m not so sure here. We clearly do feel a sense of wonder and mystery about the coming to be of a new human being. Cloning does touch on that area of our thinking but it’s hard to say just why the use of cloning techniques has that effect. There is a certain “made from predetermined ingredients” quality to what is involved – symbolically at least.

Anne: I agree and every one of us should have the freedom to carve out our own destiny rather than living out an already known pattern of life.

Brian: But we have already agreed that life takes shape importantly influenced by environment and experience. Even as a clone you are not a re-run of the person you have been cloned from.

Anne: Agreed, but a clone is sort of produced to order as it were – and surely that detracts from a person's human dignity.

Sophie: But is it more than the case with cloning than with any other kind of assisted reproductive technique like IVF or Donor Insemination through which a couple gets a baby that they cannot have “naturally” as it were.

Anne: But why would you ever do it?

Brian: There are cases which would make cloning one of the only options. For instance, if a lesbian couple wanted to have a genetic child then one way in which they could do it would be for the nucleus of a cell from one of them was introduced into the cytoplasm of a cell from the other. Surely we should not take the fact that they are same-sex partners to exclude them from what is a widespread human desire – to have their own genetic child?

Anne: I can think of objections based on other issues like same-sex marriage and so on but I suppose that is not the present focus. And anyway, even with lesbian parents there would only be DNA from one person, the person whose cell nucleus was used.

Brian: No, strictly speaking this is not correct. The cytoplasm also contains mitochondrial DNA, which works with the nuclear DNA. Some of both persons' DNA is included in that way.

Sophie: Right! But we need to think a little more about such possibilities because these are uncharted waters and we do not quite know what the dangers and risks for the resulting children might be. There are reports of cloned animals having genetic damage of various kinds and perhaps being subject to premature aging.

Brian: But these arguments from uncertainty are not very strong because we will never know enough to be sure that any new technique is complete without risk.

Sophie: But this is a special case in that we are creating a human life of certain kind and that person will have to live with whatever outcome.

Brian: But children are often born with some kind of defect or genetic anomaly and, if we exclude the most obvious of them we could say that this is just par for the course.

Sophie: However the case is a little different in that creating a clone is not just accepting the risks that nature throws up but doing something which creates possible human suffering or a child who will have to live with a harm that would not otherwise have eventuated.

Brian: Yes I can see that we incur special responsibilities when the person that results is produced by our actions.

Anne: But here we are right back into it again. This person is a product and not a being who is special in the way that human children should be.

Brian: This is that wishy washy mystery and wonder stuff all over again.

Sophie: I have to say it is a little difficult to see the point but we could try to unpack it a little. You, Anne, claim that a clone is a product that is manufactured to specifications that pre-exist him or her?

Anne: Exactly.

Sophie: But that assumes that a person is totally determined by their genetic constitution in a way that we have already decided is implausible.

Anne: I see that. There is a problem here though, that I am trying to put my finger on.

Sophie: Well, let's see: a person normally comes into being without any clear prescription for how that person's life will unfold.

Brian: Not true – some parents have very distinct expectations of what their children will do.

Anne: That's true, in some cases children do have a path of life virtually decided for them as soon as they are born or even before and this would be worse when the parents had some particular reason for cloning the child concerned.

Brian: Give me an example.

Anne: Well, for instance, what if a baby was killed in a car accident and the parents wanted to have that baby back again and so cloned another one from the tissue of the dying child? How would the second child feel knowing that he or she was just a replacement for a dead sibling?

Sophie: Replacement children, if we want to call them that, are not uncommon in a number of just such settings and nobody questions a couple's right to have such children by normal means, so why should this be different?

Anne: I think it's the copy thing. In the normal case there is a certain openness about the future. Everybody knows that this is a new start and a new individual with her own life and path to follow. I think that for a clone that would not be the way people close to them thought about what was going on.

Sophie: But, if we are right about the effect of environment and relationships then the child would very soon just be loved in their own right and the concerns about origins would fade away.

Brian: I'm not so sure about all this non-genetic stuff but I agree with that point.

Anne: I still think that a conception of our origins is an essential part of our idea of a human being and to introduce cloning is to change those conceptions in a way that is potentially very harmful to our understanding of human life and its value.

Reproductive Cloning

A Bible study on this dialogue can be found on pages 29-30.

STUDY QUESTIONS

1. What makes a person unique? How would you feel if you discovered at 16 that you were a clone? Is there a difference between cloning humans and cloning other animals?
2. What are some of the reasons/motivations people may want an identical copy of another human being, and how do you feel about these reasons? How would the reason/motivation for cloning affect your thinking about whether cloning a human being is acceptable?

Further discussion options:

1. Need the positions taken be Christian or non-Christian positions? What common intellectual ground is there on which Christians and those without a Christian belief can meet to discuss issues of this type?
2. How does the 'right to have children' compare with rights to other benefits such as food, water, shelter, health care? What are the boundaries, if any, to our use of science to help people to become parents?

Study 3: Using Genetic Information

“Genes and the Genie”

Another conversation in the University coffee room.

Brian (a cell biologist): I was watching a programme on genetics last night and I would have to say, that this is a blue ribbon year for genetics and the things we are discovering about the human genome.

Anne (a neurologist): Yes, I must say it gives me the creeps a bit though.

Sophie (a philosophy student): Why is that?

Anne: It always seems to me that when we interfere with something as basic as our genetic makeup we are playing God with human lives.

Brian: I agree that we are able to have profound effects on human health and disease but isn't that what medicine does anyway?

Anne: Oh, I think there are a huge number of ethical issues raised by the human genome project. I worry about choosing only what we call 'good quality' human beings, about the predicaments we get into when we learn about unborn children and what might happen to them, the whole idea of altering human destiny makes me feel that I am shifting deck chairs on the Titanic. What about possible ecological disasters, global poverty, the break up of the family, wars and political violence, and the growing number of young people committing suicide.

Sophie: We definitely ought to explore that set of problems, but not all together, we ought in fact to unpack them and take them one at a time.

Brian: It's all just making a mountain out of a molehill as far as I can see; we decide how to detect or alter the genes causing certain problems and we intervene as we do in any disease process, end of story.

Sophie: Perhaps you are right but we should look a little closer for a tad. Let's look first at the possibility of screening children for genetic defects and selectively aborting those with truly awful diseases. We could call that "the problem of the chosen" and it is created when we start to be able to mark genetic deficiencies in the womb. Some of these deficiencies are clearly evils and to correct them can only benefit everybody concerned.

Anne: Give us an example.

Brian: That's easy. A disease like Huntingdon's disease could be eradicated by genetic surgery for any embryo or conceptus that tests positive for the Huntingdon's trait. We could do that by splitting some cells off the embryo and testing for the Huntingdon's gene as it occurs in that family. At present we do not do genetic surgery for this but we can do genetic testing and offer termination in the event of a positive test.

Anne: A search and destroy policy which poses the question of who should live and who should die is what you are talking about.

Sophie: I think you are right Anne, the individual aborted and the individual subsequently born are not the same human being, and therefore we are literally choosing one human being over another. I mean if you think of me as being the joining of a particular sperm and egg then it would be another sperm and egg if I was found to have an abnormal genome and aborted.

Anne: Quite apart from abortion, do you really think we have the right to do that?

Brian: When you think about it, it isn't such a big thing and therefore not so bad as all that, I mean this would be a very early stage of pregnancy.

Sophie: We have had this discussion in relation to stem cells, haven't we? I don't know what you would call a bigger thing than deciding who will be born. What values should guide such a decision?

Brian: Getting more healthy people is my value.

Anne: But what is healthy? - blonde haired, blue eyed, well proportioned beautiful people or something more diverse which allows for those types of people who are less striking on first acquaintance but may be crucial in human history such as Wilberforce, Dostoyevsky, van Gogh, or Lord Byron?

Sophie: That is true. It is sometimes hard to predict who will make a great contribution to humankind or even whether, in fact, sometimes those who have a disadvantage are spurred to greater achievements.

Anne: I just object to the whole idea of rating people for quality or accomplishments, and choosing some over others.

Sophie: I'm sure there is something to that, because all people are valuable.

Brian: But, of course, we don't have to abort people. We will eventually be able to fix defective genes by genetic surgery in the embryo.

Sophie: That also seems problematic to me. I think we do get into a number of problems when we become able to predict the genetic futures of children in the womb. There is, for instance what we could call "the unwitting sacrifice problem".

Brian: What is that?

Sophie: It can be raised in a general way about decisions in relation to the future of our children but we can best understand it as it applies to the case of manic depressive psychosis or bipolar disorder. We know that the genetic trait associated with bipolar disorder is possibly also associated with giftedness and rare talent. Thus, if we identify the genetic marker then we will have to ask whether we are right to ask the embryos carrying that genetic marker to run the risk of a severe psychiatric disorder just so we do not eliminate some gifted individuals who may be of value to humankind in general.

Brian: I am interested in this, what did you say, "unwitting sacrifice problem".

Sophie: Yes, think of it – a child is going to be born with a future which is quite likely to involve a serious illness with a risk of depression, severely disrupted relationships, and even suicide. By allowing the pregnancy to go on when we have a positive test, we condemn that child to this future without being able to consult them about it.

Anne: But who would ever choose not to be born?

Brian: That's a common saying isn't it – "I wish I'd never been born".

Sophie: It is, but it is a self contradiction when you think about it. We cannot go back into the past and alter events and the person saying it would not be there to say it if it had been true. But this issue does raise the problem of the responsibility of genetic counsellors and those doing work in the area of prenatal diagnosis. They are the ones who actually have to get involved in genetic counselling and trying to help people make good decisions.

Brian: It seems obvious to me – if there is a genetic disease then you should eliminate it and that is totally different from trying to create your children so that they have particular attributes. The second seems to be where you have real problems.

Sophie: But that is exactly what the bipolar example is driving at. Bipolar disorder is a well-recognised disease but should we try to eliminate it?

Brian: Yes. Surely a person is better if they are not born with a congenital disease.

Sophie: But again we might take note of those people who claim that if they were born without some condition or other such as bipolar disorder or autism they would in fact not have been born at all. Perhaps somebody else would have had the privilege of life.

Anne: Exactly, and if you had the choice of being born with Huntingdon's disease or not being born at all then why should you not choose life – at least you have 40+ years of unaffected life.

Brian: But hang it all, we can eliminate these genetic diseases so easily.

Anne: Only by accepting the problematic role of deciding who will be born.

Sophie: That's why some would argue that non-directive counselling is the only ethical policy.

Brian: I can see that there is a grey area here.

Anne: It makes one wonder about the whole idea of changing our destiny by genetic engineering which is the spectre raised by germ line gene therapy.

Sophie: What exactly do you mean by that?

The group may decide to break the study here, and to discuss questions 1 and 2.

Continuation of Study 3

Brian: Germ line gene therapy is where you change the reproductive cells so that not only the individual but also all children they conceive have a different genetic constitution.

Anne: And who are you to say what genes ought to be eliminated from the human gene pool.

Brian: Well, all the bad ones for a start.

Sophie: But what if, as in the case of bipolar disorder, it seems that the bad ones come closely linked to other characteristics towards which we have a more ambivalent attitude – such as giftedness in various ways.

Brian: But we can't just creep around the place afraid to do anything just in case something bad happens.

Sophie: That does seem a defeatist philosophy.

Anne: I just feel that we shouldn't do this kind of thing.

Brian: That's because you're superstitious by nature

Sophie: I think we should recognise this hesitation for what it is. We sometimes get a bad feeling when we hear of some of the new genetic initiatives but do not quite understand why we have misgivings.

Brian: Isn't that just superstitious?

Anne: I would say that it is more cautious than superstitious.

Sophie: I agree with Anne here. Sometimes we get an intuitive feeling that despite its appeal a suggestion or tendency in society is heading in a very bad direction, perhaps here the sort of bad direction that is hinted at in stories like the film "GATTACA".

Brian: I never saw it.

Sophie: You should have because it concerns a possible future in which everybody is locked into a life pattern by virtue of their genetic endowment.

Anne: That sounds really bad.

Sophie: It is meant to because it relies on a very organised form of social control and a very thoroughgoing belief in genetic determinism.

Brian: Well I'm not so sure about the second because the science seems to be telling us that the context of development can significantly affect gene expression so that the idea that everything about you is determined by your genes would seem to be a mistake.

Anne: In fact the disabled persons' literature makes exactly that point – that genetic abnormalities are only defects in relation to a context where people that have them cannot have normal lives.

Brian: But hold it, you can't tell me that being born with haemophilia a severe brain abnormality is just a variant of normal – these things definitely are abnormal because they wreak havoc with the life of the child and those who have to care for them.

Anne: But that very much depends on the community that cares for the affected family and the love and care that they are shown.

Brian: I agree that all that sound very nice but come on, let's face the facts.

Sophie: If we accept the idea that the family and community setting are important in determining how a person with a certain genetic disadvantage copes, then it seems that we could accept that narrowing our gaze to focus only on the genetic abnormalities themselves might be unnecessarily restricting for that person.

Anne: Exactly, and this is where my "shifting deck chairs on the Titanic problem" arises. We are so busy trying to work out and fiddle about with the human genome but there are much more serious problems to tackle such as those I mentioned – youth suicide, global poverty, war and violence, and our neglect of the ecology of the planet that we live on. We can only tackle these other broader and perhaps more significant problems by taking them seriously and funding efforts to overcome them rather than pouring money into genome research.

Sophie: But the two are not necessarily mutually exclusive.

Brian: And perhaps we might find out about the genes for greed, violence, irresponsibility and so on and learn how to make better people.

Anne: If we only knew what 'better' really is.

Sophie: Yes, we have already raised some problems for that idea and so far we have not even touched upon issues surrounding who has the right to genetic information, privacy laws and their role in regulating the use of genetic information, insurance worries, consent to genetic testing and the whole troublesome idea of the genetic enhancement of human beings.

Brian: Well, I'm going to have to call it quits and get off to a lecture on genetic studies in populations of human beings.

Sophie: Very pertinent because the very idea of population studies and the ownership of research are themselves thorny ethical issues.

Anne: About which we ought to talk sometime.

Brian & Sophie: Agreed.

“Genes and the Genie”

A Bible study on this dialogue can be found on page 30.

Study Questions:

1. What is the definition of a happy, healthy human being now? What will it be in the future? By whose standards will we determine what characteristics are desirable?
2. In the film “GATTACA”, mentioned in the text, a class system - the ‘naturals’ and the elite ‘gen-rich’ is very precisely determined. How could this situation lead to discrimination? Is there anything new in this situation?
3. What do you think genetic screening means for people with disabilities?
4. Studies show that patients with a disease are prepared to take a much higher risk than their doctors (and society as a whole) are prepared to allow them to take. How does this relate to gene therapy?
5. What impact do you think genetic engineering may have on your faith?

Options for further discussion.

6. Is it possible engineer a ‘perfect person’, and what might such a person be like?
7. In what ways is the biological view of human nature inadequate?
8. “Is genetic research an example of responsible stewardship or an abuse of power?” – Professor Sheila McLean, Glasgow University.

Study 4: A Second Conversation on Genetics

A further conversation on genetics.

Sophie (a philosophy student): Last time we didn't really talk about who has the right to genetic information or about privacy laws and their role in regulating the use of that information. These issues lead to worries about insurance, consent to genetic testing, and the whole troublesome idea of the genetic enhancement of human beings.

Brian (a cell biologist): And don't forget that I mentioned genetic studies in populations of human beings.

Anne (a neurologist): So we have quite a few ethical issues to address.

Sophie: The right to genetic information is one topic that is of great concern and interest to a number of people.

Brian: I don't know where all these rights spring from if they are not legal rights. I understand that people have a right to see their own medical information when they want to, so what else is covered by this kind of right? In any event, I would have thought that the rights questions go with the ownership question so we just decide who owns the information and then it all goes like a row of dominoes.

Sophie: But it isn't clear to me that ownership is the right concept here. For instance, the information about your genetic make up is also information about other members of your family.

Anne: But isn't it like medical information, where the doctor gets it from talking to you? It is up to you whether you share it or not. You should be able to keep control over it.

Sophie: In one respect, it seems that if the doctor gets it from you, through a blood test or something, then surely you alone should decide what he or she does with it.

Brian: Before we get too carried away here I think that much of the time it isn't like that. The problem is that every genetic variation is just that – a variation – and sometimes the only way to know if it is associated with a nasty genetic disease is to see whether that problem has shown up in other members of the family with the same variation in their genetic material. Therefore there is a sense in which the knowledge about genetic tendencies is a product of participation by a number of members of the family and does not just arise from one person.

Sophie: That is extremely interesting because it seems to be the sort of thing that would underpin a kind of collective view of whose information it is. Such a view would be highly relevant if, for instance, one member did not want other people to know about some genetic condition and refused to allow the doctor or genetic counselling service concerned to carry out the test for it.

Anne: Why ever would she do that?

Brian: I heard of a case where the woman so hated her sister she rejoiced in the fact that her sister might have a child with a serious genetic disease.

Anne: That's awful, it doesn't even bear thinking about.

Sophie: I'm sure there can be more understandable cases where the fear of stigmatisation and so on are the motives.

Brian: But still, I think you have to regard the information as family information belonging to those who share your lineage, and not private information.

Anne: I think the ethical problems arise when people other than the individual concerned or their family want to know things about your genetic makeup.

Sophie: Yes, there are some settings in which insurance companies, for instance...

Brian: Or prospective employers...

Sophie: Exactly, could request a genetic screening profile to help them decide about employment or acceptance of a client for an insurance package.

Brian: Which seems exactly like any other medical information in some respect, but not in others.

Anne: I think it seems totally different.

Sophie: But we have to say they're different. What are the possibilities here? It does relate to future possible disease.

Brian: Which is exactly the same as smoking or dangerous occupations, both of which are likely to cause future health effects even though the person may be healthy at the time.

Anne: No it's not that; it's something about determining a person's future.

Brian: So God could never be in the insurance business?

Sophie: Cut that teasing out, Brian!

Anne: What do you mean?

Brian: Well, isn't it obvious? He (or she) knows the end from the beginning and therefore would always just be "doing the math", as they say, rather than entering into a risk sharing contract with the client. God could just calculate how long you were going to live, what kinds of returns could be achieved on your money, and adjust the policy accordingly.

Sophie: Let's not go down that whole predestination and foreknowledge track. The point is that it smacks of what we discussed last time – the whole genetic predestination thing and makes a mockery of what we are increasingly believing to be true which is that most genetic effects, except for one or two clear cut diseases, are produced by an interaction between genes and the environment.

Anne: And I've been reading about holistic types of medicine and natural healing in which a lot of things have an effect on your tendency to develop various diseases.

Brian: Most of that is just garbage.

Sophie: Too hasty Brian! I think we can say that the human system is very complex and all kinds of things may have effects that currently do not appear in the standard scientific stories. But I take it that we think that discrimination for jobs and financial arrangements such as insurance on the basis of genetic characteristics is not right.

Anne: It definitely seems worse than what we currently do and perhaps that is not only because of this hard edged genetic determinism...

Sophie: You mean that people are totally shaped by their genes...

Anne: Yes, and that seems quite threatening to human society (as in that film, "GATTACA", which I have now seen by the way) but also because it means that we are discriminating against people on the basis of what is in effect a genetic lottery. That just seems unfair.

Brian: Although we have also realised that looked at in one way it is a means of risk adjustment so that individuals bear a weighted cost for insurance based on factors, which would otherwise mean that they were being subsidised by others.

Anne: You mean that the fact that I am a high-risk person should not push up everybody's premiums and should be reflected in a weighting on my own, like smoking.

Sophie: But our reason for distinguishing that was that smoking is, to a significant extent, under a person's control whereas genetic risks were like the rain which falls on the just and unjust alike and should be shared.

Brian: Of course, that whole sharing and caring thing is fine for a community but not so appealing to hardheaded business minds.

Sophie: Well, perhaps it should be, perhaps we need to make sure that all the institutions in our society have a more caring spirit than one of narrow-minded financial efficiency and so called economic rationalism. Some people would argue that that kind of thing destroys a society and undermines its shared moral life.

Anne: I agree.

Brian: I can see the point you are making which, for an arch-rationalist and scientifically minded person like myself, is a major concession.

Sophie: Bravo!

Anne: Don't encourage him too much.

Sophie: OK, OK, in fact all this talk about consequences for a person's life makes genetic testing a pretty major decision for a person to make. That raises the issue of consent and the need for adequate information so that the person being tested makes an informed decision.

Brian: Yes, I guess it is not just like any other test that is done to sort out what is going on in a patient.

Anne: Particularly not if people such as insurance companies and employers believe in genetic determinism.

Sophie: Even if they don't it seems to me there is potentially life changing knowledge to be gained, and it is like toothpaste, once it's out you can't put it back in.

Anne: Or, even more, like one of those puzzle pictures which, once you have seen it, you can never go back to your naïve state again and approach it afresh.

Sophie: What a good analogy!

Anne: I mean it could change your whole way of looking at yourself, and, even if you don't tell other people, it could your way of relating to them.

Brian: I suppose that could be quite important for a person.

Sophie: Nevertheless, it seems to me that the principle of consent in general is OK here too. A person needs to know the things that tell them how the choice they are making is likely to affect their lives, as far as that can be clearly known ahead of time.

Brian: So you would have to have some general information about the problem of genetic testing and an indication of the sorts of things that might be found out.

Anne: But any person's concerns might be quite specific to that person themselves, so there would have to be a chance to talk to somebody who could help you understand it all and get it in perspective.

Brian: That seems reasonable.

Sophie: Of course, the implication is that we need clinical geneticists and genetic counsellors and all that costs money. Every dollar you spend here cannot be spent on heart operations, child health problems and looking after babies with congenital diseases.

Anne & Brian: True.

Anne: That takes some thinking about.

Sophie: And people all over the world are thinking about the correct balance to strike in allocating health dollars but it is a topic that takes us far beyond this conversation.

Brian: I am really interested in the genetic enhancement of human beings.

Sophie: We will very soon find that that gets us straight back into the problems we discussed last time about who to choose, what counts as better in relation to human lives, and so on.

Anne: It just seems arrogant and wrong to me that we, living at the beginning of the twenty first century, should decide what human beings will be like as a whole created species . . .

Brian: Or inhabitant of the earth...

Sophie: . . .when we have so many conflicting ideas of what is a good human life in the first place. I mean, should we be more competitive? Should we enhance those traits we currently recognise as intelligence? Should we make ourselves “more beautiful” by current fashions, *et cetera, et cetera, et cetera*?

Brian: As the King said to Anna.

Sophie: I tend to agree, nature has got us to where we are and has its own built in checks and balances and perhaps we should not play around with it too much.

Brian: Come on, we do that all the time! I agree, we may need some caution, but let's not just hunker down into our shells and settle for some kind of anti-progress nostalgia and anti-technology prejudice.

Sophie: I think that some guidance as to this big issue comes out of the current debate about genetic studies in populations of human beings.

Brian: Surely that is a good thing?

Sophie: Some indigenous groups, such as Maori or North American Indians, would be very suspicious of it. They claim that their genetic makeup is a treasure that their ancestors have given to them to take good care of, and that its secrets should be held in reverent guardianship by those whose spirit is in continuity with those ancestors. This treasure should not be open to exploitation or interference by others who do not share in that spiritual heritage and bond.

Anne: That's an amazing thought.

Brian: I can respect the thought but all the same, it has a whiff of *hocus pocus* about it to an ordinary old flat-footed scientist like myself.

Sophie: Perhaps there are more things in heaven and earth than are dreamed of in your philosophy, Brian?

Brian: Perhaps there are.

Anne: But surely we don't have to just stall on this, we can have some kind of guardianship arrangement which looks at research and knowledge arising from it and has a certain amount of control over it and adequately represents the spiritual legacy of the group concerned by having a membership which is aware of those things. That way we keep things out of the hands of those who might use the knowledge in insensitive and exploitative ways, or at least we make those hands commit themselves to acting in a way constrained by proper spiritual guardians of the heritage we recognise and respect.

Sophie: Well said!

Brian: I suppose a scientist could go along with that but you might have a job convincing the insurance industry that these spiritual things are important.

Anne: As I see it they should not have a choice, they should have to shape up or ship out.

Sophie: Of course, that has resource implications, which opens up the whole topic of ethics and the economics of health care and health research – a thorny set of issues.

Brian: I need a break. My brain is tired.

Sophie: Quite an admission from a scientific rationalist like yourself.

Anne: For once, I agree with Brian's brain.

Study Questions:

A Bible study for this dialogue can be found on page 30.

1. To whom does information about your genetic makeup and predispositions 'belong' to? What rights, if any, does your immediate family, for whom it may have ramifications, have to any of your genetic information?
2. How can we take into account the Maori viewpoint that information may belong to whanau or Iwi rather than an individual?
3. It has been suggested that we are creating a world in which people are uninsurable, or in which employment opportunities are denied on the basis of genetics. To what extent and why should employers and insurance companies have access to genetic information about an individual?

Bible Studies

Read over the study material relevant to each particular topic, and divide into groups to discuss.

The following biblical principles will provide additional input and questions into your discussion.

Study 1: Stem Cell Research

In the year 2000, a 12 year old child, Georgia, suffered a tragic fall while paragliding. Her spinal cord was severed. The public differs on their opinions about stem-cell research for nerve cell generation to repair damage such as Georgia's. One person commented that stem-cell research holds the promise for many common diseases as well as other conditions. She hopes that paralysis, diabetes, Parkinson's disease and other conditions may be overcome. Another person is concerned that using stem cells for research is using a human life to benefit others. This seems to contradict notions of "do no harm" and of not using defenceless persons for others – a type of slavery and genocide.

What does your group believe?

General Biblical Principles:

No biblical passage directly addresses the ethical choices involved in stem cell research. There are general principles that may guide all choices, however. Isaiah 44:24-28 sets up a paradigm that can shape a discussion.

Isaiah 44:24-28. From this passage certain themes arise.

- A. God is the sole creator of the universe.
- B. God created all the beings who inhabit the universe.
- C. God values all life and is involved in all aspects of existence: nations, individuals, families, social institutions and so forth.
- D. God is the giver of knowledge. Some knowledge promotes divine characteristics such as justice, mercy, healing, love. Other knowledge is harmful.
- E. All individual lives have purpose.

Other passages that further our understanding of these themes are Psalm 139, Genesis 1:26-31, Genesis 11:1-10, Job 38-39.

Questions:

1. Christians vary considerably on their beliefs about beginning of human life. Some believe that God is involved from before conception. Others see the sacredness of life occurring with the first breath. How does your answer to "when does human life begin?" impact your view of stem-cell research?
2. What is your interpretation of being made in the "image of God"? How does your understanding affect your beliefs about an embryo? What might it mean to a scientist conducting research?
3. How can we discern which knowledge brings forth life and health and which results in pain and suffering?

4. What other themes can we find from Isaiah 44 and the other passages mentioned?
5. Which of the biblical themes are most helpful in their evaluation of stem-cell research?
6. What is the best approach to take when Scripture does not give specific answers to 21st century issues?

Study 2: Cloning for reproductive purposes

The film “GATTACA” (1997) portrays a world in which genetic engineering makes people more beautiful, intelligent and desirable. GATTACA’s website raises the following question: Your two-month-old baby is about to be taken off life support. You and your partner can no longer bear children. Would you clone the child if it were an option? Discuss how you would answer this question and why.

Biblical Themes Involved:

Definition of human life and relationship between parents and children:

Family Relationship – Ephesians 5, Commandment to honour mother and father, etc

Definition of Human Life – Genesis 1:24-2:4

It is not clear, however, precisely what it means that humans are in God’s image. Obviously, human beings are physically limited, while God is not. But there must be some inner likeness. Over the centuries, Jewish and Christian interpreters have suggested close to a dozen possible ways in which humans are in “the image of God”.

If time allows, you may ask your group members what they think are some of these ways. You may want to write these on a chalkboard or easel:

1. conscience
2. reason
3. personality
4. creativity
5. free will – freedom to choose/make decisions
6. one’s biography, one’s nature
7. capacity for love
8. immortal soul

Ask these questions:

1. Is there anything we might add to this list?
2. Which of these qualities do you think is most important to being made in God’s image? Why?

For each participant, hand out a piece of paper with a list of the following actions that biotechnology has made possible or may do so within the foreseeable future:

1. Clone a human being
2. Clone an animal
3. Genetically modify plants to resist insects or carry vitamins
4. Do pre-natal tests to determine whether embryos and fetuses are genetically predisposed to develop serious illness
5. Select genetic characteristics of potential children, such as intelligence and size

6. Alter the genes of an adult whose illness has some hereditary component, such as heart disease, so that none of his or her offspring will have the gene anomaly.

After reading these over, have individuals cross out the ones they believe should not be allowed. Then discuss as a group:

Which of these did you approve or disapprove and why?

Studies 3 & 4: Ownership of Genetic Information

The Burlington Northern and Santa Fe Railroad in the United States recently tested many of its employees, without their knowledge, for a rare genetic condition that might cause carpal tunnel syndrome. The company wanted to avoid responsibility for its employees' workplace injuries by blaming the problem on their worker's genes.

Question:

Discuss what ethical principles and issues are involved in this scenario.

Biblical Passages:

Those involved with ownership of others, eg slavery. While in existence during biblical times, it is condemned in numerous passages. Does ownership of genetic information or genetic material differ in principle from owning another human being?

The Golden Rule (Mk 12:28 - 31) based on Lev. 19:17-18 indicates that one should treat others in ways that one wants to be treated. How does ownership of genetic information or material comply with this command? If ownership is allowed, how should it be used?

Discussion Questions:

1. How does the concept that God is creator of all things affect your attitude to the use of human intelligence to develop new life forms and to control them through ownership?
2. Matthew 9:35-36 –How do you view the use of genetic information to assist in healing of disease, as an appropriate Christian response?
3. How do you interpret genetic engineering in the light of I Corinthians 10:23-24:
“All things are lawful, but not all things are helpful. All things are lawful, but not all things build up. Let no one seek his own good, but the good of his neighbour”.

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Appendix 1

The Interchurch Bioethics Council (ICBC)

The Council was set up in 2000 by three churches: Anglican, Methodist and Presbyterian as the Interchurch Commission on Genetic Engineering, with the purpose of making submissions on behalf of the churches to the Royal Commission on Genetic Modification (RCGM). Since then, issues of public concern which were outside the brief of the Royal Commission have been raised, including human reproductive cloning and the use of embryonic stem cell for research purposes. In 2002, the Interchurch Commission on GE was re-named the Interchurch Bioethics Council and its brief enlarged to address such issues.

Topics and issues are brought to the attention of the ICBC by the media, by members of the churches, by government agencies and by information on websites and in e-mails from interested individuals. We welcome comments from all of these sources.

Terms of Reference of ICBC

1. To provide opportunities for consultation and dialogue with church members and the community generally on the ethical, theological, spiritual and cultural issues in the use of biotechnology.
2. To take an educational role for the Anglican, Methodist and Presbyterian churches on the above issues.
3. To make submissions and comments to Government, to the New Zealand Bioethics Council and other relevant bodies on the above issues.
4. To report at least annually to the three churches.

Activities of ICBC

Members of the ICBC have spoken at church gatherings throughout New Zealand, addressing the ethical, spiritual and cultural issues raised by biotechnology. In October 2000 a 40 page written submission was made to the RCGM, followed by an oral submission and a closing submission. Many of the recommendations made by the ICBC were included in the RCGM recommendations and have been evident in the government report.

The ICBC has met with Ministry for Environment officials, and presented submissions on the public discussion papers on Improving the Operation of the HSNO Act for New Organisms, and on the New Zealand Biotechnology Strategy. ICBC will make a presentation to the HSNO Act Amendment when it comes before a Select Committee later in 2003.

The ICBC has also met with the Secretariat of Toi te Taiao the Bioethics Council and will take opportunities as they present to have an input into the activities of the Council.

Contacting ICBC

Members of the ICBC contribute expertise in ethics, theology, philosophy, science, medicine and cultural issues. They are available for discussions or presentations in church groups and in the general community. It is expected that this group of studies will be followed by other series on other biotechnological topics. For further information please contact the chairperson or a member of ICBC in your area. The Council is chaired by Dr Audrey Jarvis, Palmerston North, Phone (06) 357 3089, E-mail: jarvis.ab@xtra.co.nz. The other members are Dr Chris Downs, Prof. Grant Gillett, Dr Graham O'Brien, Dr Briar Peat, Dr Barbara Peddie, Ms Maree Pene, Mrs Deborah Stevens and Dr Susan Werstein.

Appendix Two

Current Legislation

Country/ Group	Reproductive Cloning	Therapeutic Cloning	Embryonic Research	Stem-cell Research
Austria, Brazil, Costa Rica, Ecuador, Hungary, Ireland, Switzerland, Tunisia	Banned	Banned	Banned	No guidelines to date
France, Germany, Norway, Peru, Poland	Banned	Banned	Banned	Allowed
Australia, Spain, Sweden, USA	Banned	Banned	Allowed	Allowed
Japan	Banned	Allowed	Allowed	Allowed
Israel	Banned	No guidelines to date	Allowed	Allowed
United Kingdom	Allowed (but very hard to obtain license)	Allowed	Allowed	Allowed
Canada, Finland	No guidelines to date	No guidelines to date	Allowed	Allowed
Belgium	No guidelines to date	No guidelines to date	No guidelines to date	Allowed
Netherlands, South Korea	No guidelines to date	No guidelines to date	No guidelines to date	No guidelines to date

Appendix 3

The birth of Louise Brown on July 25 1978, proved that a human egg fertilised *in vitro* – that is, in a glass petri dish – and transferred to a woman’s womb could implant and develop into a normal baby. Hailed as a medical miracle, the birth of this first *test-tube* baby (a term coined from Huxley’s “Brave New World”) brought hope to millions of infertile couples worldwide.

IVF is now an accepted practice – indeed, it is seen as a routine procedure.

Science does not stand still - scientific developments that have built on the process of IVF have lead, among other things, to Stem Cell Research, Cloning and Pre-Implantation Genetic Diagnosis.

Stem Cells are cells that have the ability to divide continuously and to develop into various kinds of specialised tissue.

As mentioned in the introduction to this resource, many scientists believe that with research, stem cells will be able to be used to treat a wide variety of serious injuries or diseases from spinal cord injury to cancer. However, ethical issues arise when we consider the various sources of stem cells that may be used for research or treatment purposes.

Stem cells can be obtained from early embryos, foetuses from pregnancy terminations, umbilical cord blood and adult tissues. The particular ethical issues needing discussion in NZ arise from the use, and therefore destruction, of embryos as a source of stem cells. Thus, within the development of stem cell research there are fundamental ethical questions including: *Is an embryo just “tissue” or is it a life? *If it is life, is this stage of life as morally significant as that of a newborn infant, a child or an adult? *Does embryonic life deserve the same rights as adult life?

In order to answer these questions we must also consider the questions of *what it is to be human?* and *when does human life begin?* Is there a precise moment when human life can be said to have begun?

Human development begins when a sperm fertilizes an egg and creates a single cell with a full complement of chromosomes that has the potential to form an entire organism. However, fertilisation may be viewed as a process rather than a single instantaneous event. It takes a number of hours for the nuclear membranes of the egg and sperm to break down, for the chromosomes to pair up and for a new nuclear membrane to form around the nucleus of the fertilised cell. This cell may then divide into two identical cells. Each of these cells then divides into two so that there are four cells, then eight and so on.



Fig 1

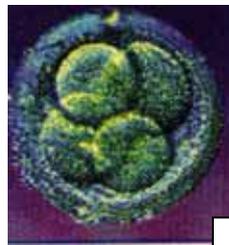


Fig 2

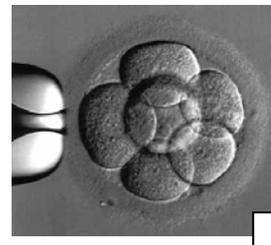


Fig 3

The eight cells stage is known as the **blastomere**. At this early stage each of the cells is **totipotent** – that is, each cell has total potential. Given the right circumstances each cell, if placed into a woman’s uterus, has the potential to develop into a foetus. Some of these cells at this blastomere stage will become placenta, some amniotic fluid and some the tissue of the new individual. It is impossible at this stage to tell which cell will become what.

Approximately four days after fertilization and after several cycles of cell division, these totipotent cells begin to specialize, forming a hollow sphere of cells, called a **blastocyst**. The blastocyst looks a little like an inverted diamond ring, with a layer of outer cells and inside the hollow sphere, a cluster of cells called the inner cell mass.

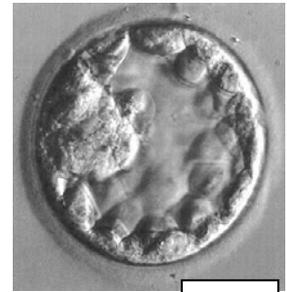


Fig 5

The outer layer of cells will go on to form the placenta, amniotic fluid and other supporting tissues needed for foetal development in the uterus.

It is cells from the ‘inner cell mass’ that can become any of the over 200 tissues that make up the human body. These cells are **pluripotent** - that is, they have plural potential. It is these cells that are important in the stem cell debate. To use these cells destroys the embryo.

As normal development continues, the pluripotent stem cells undergo further specialization. At around 14 days, what is called the primitive streak appears. This stage is also known as *individuation* as it is at this stage that the cells of the inner cell mass specialise and become committed to give rise to cells that have a particular ‘bodily’ function. It is only after individuation that there is no longer a chance that the embryo will divide into monozygotic twins.

This was the basis of the Warnock Report adopted by the British House of Commons in 1973, allowing experimentation on embryos up to 14 days.

Very frequently the early embryo is referred to as “just a ball of cells”. One reason for this is that until the primitive streak appears the zygote has the potential to divide in such a way that twins are formed. Suppose the result of fertilisation is eventually the formation of twins; can it be said that each was an individual before the critical division occurred? (Warnock Report, 1973)

(Once we move away from conception or 14 days, there is a wide range of opinions as to when “personhood” should be conferred including sentience, viability, birth and beyond.)

At present, human pluripotent cell lines have been developed from two sources – stem cells derived from very early embryos at the blastocyst stage or from foetal tissue obtained from terminated pregnancies. The early embryos are usually embryos that are surplus to a couple’s requirements following IVF treatment. The embryos were made for purposes of reproduction, not research. (There is, of course, the additional problem of whether it is ethical to create embryos specifically for the purpose of research.)

Stem Cell Type	Description	Examples
Totipotent	Each cell could potentially develop into a new person	All of the cell in a human embryo in the first few days
Pluripotent	Cells that can develop into any of the over 200 different cell types found in the human body	Some of the cells in the blastocyst stage of the early embryo between (approximately) 5 and 14 days
Multipotent	These are cells that are already differentiated, but which can give rise to a limited number of other cell or tissue types	Foetal tissue, cord blood and adult bone marrow cells

So far in this discussion we have only considered embryos that have been formed by the fusion of egg and sperm. However, this is not the only way to produce an embryo – it can also be done via *Somatic Cell Nuclear Transfer* (SCNT).

In animal studies using SCNT, researchers have taken a normal animal egg cell and removed the nucleus that contains the chromosomes, leaving behind the cytoplasm that contains nutrients and other energy-producing materials that are essential for embryo development. Next, a somatic cell – that is, any body cell other than an egg or a sperm cell - is placed next to the egg from which the nucleus had been removed, and the two are fused. The cell is stimulated electrically and may begin to divide into totipotent cells that will soon form a blastocyst. Cells from the inner cell mass of this blastocyst can then be used to develop pluripotent stem cell lines.

However, somatic cell nuclear transfer (SCNT) is *Cloning*.

Essential to any discussion regarding human cloning is the distinction between therapeutic and reproductive cloning.

Human reproductive cloning wants to create complete individuals that will live and grow into adulthood much like any naturally conceived child. In contrast, therapeutic cloning seeks to produce single tissues or organs. Organ transplants are now commonplace in medicine, occurring for a wide range of problems such as kidney or heart failure. However, we are also familiar with the frequency with which organ transplants fail. Immune rejection is the most common cause of transplant failure. In addition, there is a serious shortage of donor organs. (An average of 40 organs are available for transplant in NZ each year.) It is possible that the use of therapeutic cloning via somatic cell nuclear transfer may overcome both of these problems.

Fig 1: www.acrm.com/ART/IVFImages.htm

Fig 2: web.ukonline.co.uk/webwise/spinneret/genes/clones.htm

Fig 3: www.rmanj.com/Newsite/index.asp?

Fig 4: www.advancedfertility.com/ivfchanges.htm