

**Lutheran Church of Australia  
COMMISSION ON SOCIAL & BIOETHICAL QUESTIONS**

3<sup>rd</sup> October 2000

Submission to the SA Parliament's Social Development Committee regarding

## **BIOTECHNOLOGY & HEALTH**

Thank you for the invitation to make a submission on this topic. I note that the Social Development Committee is to "investigate and make recommendations to the Parliament in relation to the rapidly expanding area of Biotechnology in the context of its likely social impacts on South Australians". You will appreciate that these are very broad terms of reference, and I will confine this paper to brief notes under 8 headings.

### **1) THE HUMAN GENOME PROJECT**

I recall that this project was launched in October 1990 with the aim of deciphering the 3.3 billion letter code that frames the DNA of our genetic makeup. The recording of the digital code of the bases adenosine (A), cytosine (C), guanosine (G) and thymine (T) was completed in September 2000. Mapping this chemical code may turn out to be the easy first step, as we have yet to determine exactly what the code means. While we may broadly recognise all our genes by 2003, defining the precise function of all our (roughly) 100,000 human genes seems likely to take decades, perhaps until 2050. Identifying and quantifying the contribution of our genetic makeup to human disease may take till 2100.

Francis Galton coined the term "eugenics" in 1883 to describe "the science of improvement of the human race germ plasm through better breeding". Galton, a cousin of Charles Darwin, listed three classes of people : desirables, passables, and undesirables. I am concerned that our 2000 mapping of the human gene sequence may be seen as a hypothetical norm that encourages premature interpretations of what are desirable and what are undesirable genes.

Biotechnology, particularly in the area of human genetics, is raising major social and moral questions about the appropriate use of the technology and how that use will affect human lives and will shape our community. Advances in science tend to race ahead like an Olympic sprinter, while law and ethics limp along behind. In the words of Prof C Ben Mitchell, "we are a culture dominated by technological giants and ethical pygmies."

One example is the Melbourne-based company DNA Solutions which on the Internet offers paternity tests to customers who send in hair samples for DNA testing. Issues such as consent, privacy, counselling and the proper legal chain of evidence appear to be irrelevant.

So-called genetic disorders usually have multiple factors involved in their causation. According to the National Health & Medical Research Council's Guidance on Genetic Testing (2000), the development of a multifactorial disease is attributable to a combination of items including genes, the environment, lifestyle, gene interaction, spontaneous genetic mutations during life, and chance. "Genetic information is often about possibilities rather than certainties because only a proportion of those with a particular disease-related mutation or other development will develop the disorder."

For example, we read of genes being identified that carry increased risk of breast cancer or colon cancer or Alzheimer's disease, and yet in each case these genotypes account for less than 3% of all cases of the disorder.

Life insurance companies, private health funds and some employers wish to use genetic testing to screen out persons considered to be at increased risk of illness. I believe that it would be unjust to discriminate against people who carry, through no fault of their own, a supposedly defective set of genes. Our understanding of gene function is too incomplete to begin to justify any such discrimination.

## **2) GENE THERAPY**

During the 1990s there was a great deal of optimism about gene therapy, and yet very little progress has been made. While the concept of correcting major single-gene disorders such as cystic fibrosis and haemophilia remains appealing, at present we do not know how to get genes into cells in a safe and effective way. Scientists have tried using viruses as carriers, but viruses have a great ability to change from carriers to pathogens. In the USA a teenager with a rare but mild metabolic disorder died of a massive viral infection in September 1999 after an attempt at gene therapy.

Over the next 10-20 years safer vehicles to deliver gene therapy are likely to be developed. I am comfortable with the idea of using genetic engineering to correct serious genetic disorders in a manner that respects the whole person, given fully informed consent. However, I am opposed to the notion of using gene technology to create "designer babies" intended to have enhanced physical or intellectual abilities.

Germline gene therapy, where one changes the genetic structure of a human egg or sperm, would create a new individual and a line of descendants with new genetic qualities. I believe that such germline therapy should remain illegal, as there are too many unknowns present. The long-term effects of changing reproductive cells in this way are too unpredictable.

## **3) TRANSGENIC ANIMALS**

Transgenic animals are those who have had genes from another species inserted into their genome. In the 1970s scientists began to genetically engineer bacteria by the introduction of human DNA (recombinant DNA technology) to produce human insulin, human growth hormone, vaccines such as Hepatitis B vax, and interferon (a protein capable of defeating viral infections).

In the 1980s the scientists moved on to genetically engineering mammals (usually sheep) by the insertion of human genes so that the sheep milk yields proteins of medical benefit, such as human blood clotting factors. This allowed the safe production of the factor 8 needed by haemophiliacs, who had previously been at risk of HIV-AIDS infection when given factor 8 extracted from pooled human blood.

This insertion of one or two human genes into an animal does not appear a significant violation of species integrity. There are no observable changes to the animal, and there are major therapeutic benefits to the people receiving the factors. I believe that this minimal level of trans-species genetic engineering is morally acceptable. However, I am opposed to human and animal cells being combined in any way potentially leading to a semi-human hybrid species. This includes the harvesting of stem cells from cow-human or pig-human embryos (see section 8).

## **4) ORGAN TRANSPLANTS FROM OTHER SPECIES**

To overcome the shortage of human organs for transplants scientists are developing special clean pigs. Pig organs are about the right size for humans, and human genes can be spliced into the pigs to make their organs more acceptable to the human immune system. When I question the ethics of creating part-human pigs, I am told that if I eat ham or bacon I should not quibble about using pigs in other ways.

Using pig organs for transplants does risk transmitting viral infections that are new to humans. HIV-AIDS moved from monkeys to humans, and the Hendra virus killed 16 horses and trainer Vic Rail in Queensland in 1994. A nastier virus than Hendra is one called Nipah, which killed thousand of pigs and 80 people in Malaysia in 1999. The human variant of "mad cow disease", variant Creutzfeld-Jacob disease or vCJD, also comes from animals.

Our present knowledge of pig viruses is not enough to be sure that pig organs are safe for transplants. We do know that pigs have viruses incorporated into their DNA which are able to infect human cells. Dr Ian Wilmut and his Roslin group, the team who cloned the sheep Dolly, have withdrawn from pig organ transplant work because of their inability to exclude unknown viruses. I am concerned that Australian scientists are continuing their research on pig organ transplants into humans.

## 5) ASSISTED REPRODUCTIVE TECHNOLOGY

As many as one in five couples of child-bearing age in Australia are involuntarily childless. Over the last 20 years doctors and scientists specialising in assisted reproductive technology (ART) including in-vitro fertilisation (IVF) have been able to help many but not all of these couples, with the average live-birth rate per cycle of treatment being only 12%.

At its best, ART can increase the chance of a couple having a child. At its worst, it can treat human eggs and sperm and embryos as items for sale, as shopping at a genetic supermarket. It is possible to shop on the Internet and place a bid for "eggs from beautiful, healthy and intelligent women." It is also possible to contact an egg and sperm auctioneer who asks for US\$50,000 for "superior" eggs and US\$15,000 for "superior" sperm.

Our Australian NHMRC guidelines on ART open with "respect for, and protection of, human embryos from their beginning" - and yet embryos less than 14 days of age "surplus to the needs of the couple" may be used for research ending in their destruction. The guidelines forbid "developing embryos when it is unlikely that they will be used for treatment" - and yet over 20,000 human embryos are in frozen storage in Australia today.

**A key concern in ART is the lack of genuine respect for the human embryo.** About 22 hours after the human sperm enters the egg cell there is a defining moment when the 23 chromosomes of each unite to create the 46 chromosomes that carry the unique genetic code of that human life. All the genetic qualities of that human are decided at that moment of syngamy. Each one of us spent the first half an hour of life as a single cell. Each one of us is here because we were allowed to develop beyond our embryonic potential. Each one of us is the same individual human life that we were as an embryo.

Genuine respect for the human embryo requires that all embryos should be treated with the utmost care. I believe that a couple using ART should decide in advance how many embryos they require and direct the ART team to create only that number of embryos. Every human embryo that is created deserves a chance in the mother's uterus.

Recently the Sex Discrimination Amendment Bill has been tabled in Federal Parliament. I support the aim of that bill to restrict access to ART to women who are either married and living with their husband on a genuine domestic basis, or living with a man in a genuine de facto relationship. I agree that this issue primarily involves the right of a child within our society to have the reasonable expectation, other things being equal, of the care and affection of both a mother and a father.

The SA Act 1988 concerning ART insists that **the paramount concern in ART is the welfare of any child to be born as a result of that technology.** I believe that this key principle that the rights and interests of the child are paramount should not be bent to meet the desires of single persons and same-sex couples. In my opinion people who make lifestyle choices that preclude the normal procreation of children have no right to demand to have children by other people and by other means.

It can be seen as degrading to a child to be regarded as a commodity that can be manufactured and distributed to any adult who expresses a desire to own a child. We share a common link of humanity with each one of these infants, and I would argue that it is wrong to treat a child as a consumer good to be bought and sold in this fashion.

## 6) SURROGACY

My understanding is that the Australian Capital Territory is currently the only jurisdiction in Australia to allow surrogate motherhood, provided that no money is involved. In 2001-02 it is likely that there will be moves to have surrogacy accepted in SA.

In the past 10 years about 30 Australian couples have gone to commercial surrogacy agencies in the USA and paid around \$A80,000 each to bring home a baby. The Mother Goose agency in California advertises that after a court declaration the baby can obtain both US and Australian passports within 7 days. US laws against discrimination allow that gay and lesbian couples and individuals can purchase a baby to rear as their own. Those who favour commercial surrogacy see it as a business transaction between consenting adults on an equal basis. I can see two problems with this view. Firstly, it treats a baby as an item to be bought and sold - provided, as many surrogacy contracts stipulate, the baby is born without disease or defect. Secondly, women who rent their wombs often do so out of poverty. A woman is not exercising true freedom of choice when she prefers being exploited to being poor.

Some people compare surrogacy with adoption, but I believe there is a key difference. Adoption is a child-centred practice in which a couple take into their home and their hearts a baby already conceived or born. In contrast, surrogacy is an adult-centred practice in which a baby is deliberately conceived and born to be given away.

Women may agree to serve as altruistic surrogate mothers because they wish to be seen as good, generous, loving people. However, within families there can be an element of emotional blackmail. In some ethnic groups the more a woman sacrifices herself the more she will be praised, regardless of how much she hurts herself in the process. The emotional bond between mother and baby makes it unnatural to bear a child in order to give him/her away, as if baby were a hand-knitted pullover.

The Warnock Report to the British government in 1984 stated - "There is an implied attack on the value of parental relationships by the introduction of a third party into the process of procreation, there is a distortion of the relationship between the mother and the child in surrogacy, there is a difference between the single act of semen donation and the more intimate and personal role of gestation, and there is the degradation to the child who is 'bought'." Australian ethicist Nicholas Tonti-Filippini writes similarly - "Surrogacy sets up a matrix in which no-one has that particular relationship to the child of being genetically, gestationally and as a consequence socially related to the child. Parenthood is too hard a battle to entrust to any weaker form of bonding."

## **7) HUMAN CLONING**

Cloning can be defined as "the practice of forming an embryo or an entity capable of embryogenesis which is genetically identical to, or substantially identical to, another human being, living or deceased."

Cloning of humans seemed comfortably remote, something in the realm of science fiction, until the news of the first cloning of an adult mammal (a six-year-old ewe) to produce the sheep Dolly was announced in February 1997. A team headed by Dr Ian Wilmut of the Roslin Institute in Scotland was able to persuade an adult mammalian cell to rekindle all the genetic instructions that shut down as the cell divides and specialises and ages, and to begin a whole new life.

There is much potential for good in the study of tissue cloning. If we can learn why adult cells in brain tissue and spinal cords and heart muscle cease to regenerate after injury, and learn how to turn on cell regeneration and repair damaged tissues when needed, the benefits will be immense. If we can discover how cancer cells revert to an embryonic stage and multiply uncontrollably, and how to turn that growth control back to normal, then a true cure for cancer will be possible.

The potential for harm is also great. As one example, cloning carries the risk of damaging sensitive genetic material. The Roslin team created 277 sheep embryos and achieved 29 sheep pregnancies to get one live-born Dolly. It seems likely that many of the embryos failed to implant or were miscarried because of genetic defects. It is still not clear whether Dolly will

prove as healthy as a regular sheep (her genetic material appears to be ageing swiftly), and subtle damage would be more likely in humans than in sheep.

I strongly believe that the current ban in SA on human cloning to produce a baby should continue. A few bereaved parents have argued that cloning should be allowed to replace a tragically killed child. But one person can never replace another, and genetic identity is not the same as personal identity. The new child might not have the opportunity to develop in his/her own distinctive way, and might not be loved for his/her own sake. To quote from Dr Bernadette Tobin, "a certain readiness to accept a child unconditionally is an integral part of the respect which parents owe their children ... we give our children names, not numbers ... when we love a partner or a child, we love that person in all his or her particularity." There are many other ethical objections to cloning human infants that are beyond the scope of this brief paper.

Some scientists have proposed legislation allowing "therapeutic" or "non-reproductive" cloning, meaning the creation of human embryos for research, while banning "reproductive" cloning, meaning the extension of assisted reproductive technology to implanting cloned human embryos in the uterus to produce a baby. I would argue that this alleged distinction is inaccurate and misleading. **The production by cloning of a human embryo is reproductive cloning, and the major ethical issues raised by the cloning of human embryos for research should not be obscured by terming such cloning "therapeutic" or "non-reproductive".**

Cloning of cells not involved in human embryo formation appears morally preferable. For example, cloning sheets of skin cells for burns victims or bone marrow cells for persons with leukaemia could eliminate the problem of rejection of donated tissue. Safety concerns regarding more rapid ageing, unpredictable mutations and cancerous changes in cloned tissues will need to be addressed.

## **8) HUMAN STEM CELLS**

Stem cells are our biological building blocks. They are the ancestral cells from which all 210 different kinds of tissues in the human body are formed. Stem cells evolve into the brain, heart, lung, blood, skin and all the other organs of the body. In November 1998 scientists reported that they had isolated and cultured human embryonic stem cells. These cells were obtained by the destruction of "surplus" human embryos donated by reproductive technology clinics in the USA.

Studies in mice suggest that stem cells may repair the damage of Parkinson's disease and Alzheimer's disease, strengthen failing hearts, and perhaps restore insulin production in diabetes. The researchers believe that if they can learn how to direct the maturation of stem cells they will eventually be able to grow new tissues and new organs and to renew ailing body parts with injections of stem cells.

The prestigious medical journal, *The Lancet*, on 26 August 2000 had a lead editorial entitled "Overexcitement on embryo stem cells." This concluded with the following words - "In just a few days a moral issue that ought to trouble even those with no religious beliefs has been taken over by scientists, by politicians, and by money. The irony is that by the time the matter is resolved it may no longer be relevant. If stem cells do turn out to be a significant source of therapeutic agents they could come not from human embryos but from alternatives such as reprogrammed adult cells."

Adult stem cells are found in a wide variety of tissues, including blood, and appear to be as versatile as embryonic stem cells. In the *Science* journal of 25 February 2000, Verfaillie writes from the USA that adult stem cells are "better behaved" in that they are more stable than embryonic stem cells and less likely to spontaneously differentiate into a variety of cell types in an uncontrolled fashion.

Adult stem cells extracted from blood can be directed to make neurones (nerve cells) to repair brain or spinal cord damage. Using an adult's own stem cells carries the advantage that they will not be rejected by the immune system of the patient.

Accordingly, I believe it likely that over the next few years embryonic stem cell research will be overtaken by more effective and morally acceptable research using adult stem cells.

In closing, I recommend the six ethical rules for biotechnology set down by Dr John Habgood, the Archbishop of York:

- 1 - Human beings are more than their genes. Genes are only a set of instructions.  
We are more than a set of instructions.
- 2 - Remember the valuable diversity of human nature.
- 3 - Look for justice in the dealings of human beings with one another and for fairness in the use of resources.
- 4 - Respect privacy and autonomy.
- 5 - Accept the presumption that diseases should be cured when it is possible to do so.
- 6 - Be very suspicious about improving human nature; and be even more suspicious of those who think they know what improvements ought to be made.

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