Paul Brock

SUBMISSION TO THE SENATE STANDING COMMITTEE ON COMMUNITY AFFAIRS IN SUPPORT OF THE EXPOSURE DRAFT *SOMATIC CELL NUCLEAR TRANSFER AND RELATED RESEARCH AMENDMENT BILL 2006*

Dr Paul Brock AM FACE

I very much appreciate the invitation to make this submission to the Senate Standing Committee on Community Affairs concerning the exposure draft *Somatic Cell Nuclear Transfer and Related Research Amendment Bill 2006*. I also wish to thank publicly Senator Natasha Stott-Despoja for her intelligence, passion, and commitment which has produced this superbly impressive exposure draft Bill.

While my submission is an individual one made on my own behalf, I should point out that, despite being almost completely paralysed, I am still in full time employment as the Director of Learning and Development Research in the NSW Department of Education and Training. I am also an Adjunct Professor in the Faculty of Education and Social Work, University of Sydney; Vice President of the Motor Neurone Disease Association of NSW (which supports the legalisation of somatic cell nuclear transfer as recommended in the Lockhart Review Report); and a spokesperson for the Coalition for the Advancement of Medical Research in Australia (CAMRA). But, to reiterate, I make this submission in my own right.

At the outset I wish to make it clear that I am not a scientist (my PhD is in English). Having said that, I have been very well briefed on the scientific aspects of the Lockhart Review and this Bill under the Committee's examination by such eminent Australian scientists as Professor Bernie Tuch, Professor Rob Jansen, Professor Bob Williamson, as well as the following members of the Lockhart Review - Professor Loane Skene, Professor Peter Schofield, and Associate Professor Ian Kerridge.

My submission does not, therefore, focus on the scientific minutiae of the Bill. Rather, it sets out to support the fundamental substance and purpose of the Bill: which is to implement and express in Legislation the substance, argument, and recommendations of the Lockhart Review.

Background

I have been a strong advocate for the legalisation of embryonic stem cell research in Australia, under most strict scientific and ethical protocols, since 2001. My campaign of proactive advocacy has been conducted on a number of fronts: in political, bureaucratic, educational, community, financial and media contexts. As part of my endeavour, in the period leading up to the original Bill I wrote feature articles in *The Sydney Morning Herald* and *The Australian* and addressed a national press conference in Parliament House Canberra in 2002 in defence of embryonic stem cell research from an ethical perspective.

Since the publication of the Lockhart Review Report I have been as equally strong in my support of that Review's Recommendations – especially with respect to somatic cell nuclear transfer (SCNT) research, also known as 'therapeutic cloning'. For example, on 21 June I addressed an audience in Federal Parliament, Canberra, commemorating International Motor Neurone Disease (MND) Day. In that speech, attended by a dozen or so Members and Senators, I outlined my argument for supporting the Lockhart Review recommendations especially with respect to the need to legalise SCNT research in Australia.

It is clear that while acknowledging the power of scientific arguments and the reassurances about the imposition of rigorous research protocols, the really crucial factor in the lead up to the 2002 Bill proved to be the fact that by the time the 2002 Legislation was voted on by the Parliament, Australian community attitudes had swung its support behind the Bill. It is also now clear that, despite similar and in some cases sustained opposition by some in the community, the Australian community has now swung its support behind legalising therapeutic cloning.. The evidence for this is substantial: the Morgan Poll, showing around 80% support; *The Age* on-line poll, showing a similar figure; and the results of the poll commissioned by *The Sydney Morning Herald* (and presumably *The Age*) showing over 60% support.

Ethical Issues

In any multi-cultural, multi-faithed and non-faithed secular democratic society such as ours, the formulation of principles of ethical standards cannot be based exclusively upon any or only one religious creed, or denomination, or sub-denominations. And I speak as a Christian. Equally, any form of spineless ethical relativism must also be avoided. The United Nations Declaration on Human Rights is a classic example of an articulation of ethical standards that is not dependent on any one exclusive religious creed or its particular denominations, nor is hostage to some kind of amorphous ethical relativism.

The great ancient Greek philosopher Socrates provided us with a splendid formulation of the fundamental question of ethics as being: "What ought one to do?" Perhaps there are two fundamental questions to be addressed when considering profound ethical issues such as those associated with embryonic stem cell research. They are: what one <u>ought</u> to do; and what one must <u>not</u> do.

During my 15 years as a member of a Religious Order in the Catholic Church (the Marist Brothers), I spent 6 years of formal studies in philosophy, theology, and ethics. One of our lecturers in moral theology – trained in the Vatican – used to stress that the great Catholic philosopher and theologian, St Thomas Aquinas, would counsel his students faced with a new controversial intellectual or moral proposition to "rarely affirm, seldom deny, always distinguish". The failure to "distinguish" has been a depressing feature of much public discourse about embryonic stem cell research.

For example, opponents of embryonic stem cell research based on embryos surplus to requirement in IVF programs – which, under strict protocols, is now legal in Australia since 2002 - simplistically trotted out the assertion that the Bill should be rejected on the grounds that "the ends never justify the means": as if that assertion is a self-evident truth. A number of those opposing the legalization of therapeutic cloning continue to make the same assertion in 2006.

But, as I argued in one of the chapters in my autobiography *A Passion for Life* (ABC Books, 2004), absolutely central to the ethical and moral debate is the need to distinguish between some ends and some means.

> ….. there are some 'ends' that can *only* justify the 'means' ……The burning of living tissue by torturers is evil: the burning of living tissue in radium therapy to remove cancer, is good. (Digging out a kidney to inflict agony and probable death is manifestly evil – but for a surgeon to excise a kidney from a donor to help save the life of a person with terminal kidney disease, is manifestly good.)
>
> Ethical values find moral expression in living social contexts. It is wrong to kill. But for centuries the ends of collective self defence and striving to achieve a just, secure society have been used by Church and State to erect theological and philosophical 'just war' theories in order to justify the means of killing their fellow human beings in wholesale wars. Thus, the Allies argued that the end of quickly winning and ending World War II justified the means of annihilating hundreds of thousands of unarmed Japanese men, women and children in Hiroshima and Nagasaki.
> (page 195)

Because of the extremely stringent quality and accountability controls in the Federal legislation of 2002, and as also stringently articulated in the Bill proposed by Senator Stott-Despoja, the 'slippery slope' assertions of those claiming that embryonic stem cell research would lead to human reproductive cloning are as hollow as they are improperly alarmist. It's like saying that fertilizer production and nuclear medical research should be banned because terrorists can use these processes and products to make bombs. Or that aeronautical research should be banned because we know that evil people used civilian aircraft as terrorist weapons to murder thousands of people on September 11, 2001.

To put it in ethical terms, in 2002 the Federal Parliament decided that the ends of healing, of restoring life, of alleviating the incremental heartache and despair endured by family, relatives and friends of those of us savaged by incurable disease, compellingly did justify the means of using excess embryonic tissue superfluous to the IVF implantation and which otherwise would have to have been destroyed after either five or ten years under Australian legislation: provided that strict scientific and ethical protocols were put in place and monitored scrupulously. For the scientific and ethical reasons so cogently argued in the Lockhart Review, these very same ends do justify the legislative reform means articulated in the draft exposure Bill under review by the Committee.

Some Religious Opposition

It is a mistake to assume that all religions oppose SCNT. They do not. It would also be a mistake to assume that every branch or denomination of the whole Christian faith formally condemns therapeutic cloning.

The most outspoken opposition to the 2002 Bill's legalising stem cell research within strict protocols, and the Lockhart Review's endorsement of SCNT, has come from some very senior people within the Catholic Church. As a Christian, with a powerful Catholic heritage, I am proud of the great achievements of the Catholic Church throughout history. The Catholic Church has had a splendid commitment to social justice and the protection of the weak from the strong in contexts of employment and workers' rights. For example, the Papal Encyclical *Rerum Novarum* on Capital and Labour, written by Pope Leo XIII in 1891 at the height of the Industrial Revolution and its social and economic impact upon working people, remains one of the great statements about the rights of human beings within an industrialised society.

The magnificent care and compassion for the poor, the sick and the weak exercised by organisations like St Vincent de Paul and the many Catholic charitable organisations serving the needs of people in Third World countries help to transform our world. The Catholic Church's contribution to education – especially, but not exclusively, to the education of the poor and the lower 'classes' in 19th Century Europe and both 19th and early 20th Century Australia – has been highly significant in helping to shape a better world. I am proud to be able to say that I spent 15 years of my life as a Marist Brother in a prestigious Religious Order of the Catholic Church, and that I taught in Catholic schools for nearly 11 years.

But the Catholic Church has also been wrong. Galileo is but the most celebrated example of the Church not only being wrong in its decisions about science, but also in savagely persecuting those who hold views that dissent from dogmatic ecclesiastical pronouncements on matters of science. In our modern era the vast majority of the Australian population does not agree with, nor abide by, the Catholic Church's ban on contraceptive practices like the Pill. Indeed, I am confident that most Catholics in both belief and practice, dissent from the Church's ruling on contraception. The Church's banning of the use of condoms as part of a campaign to alleviate the scourge of AIDS is, I am sure, not supported by the vast majority of the Australian community.

I wonder how many Catholics support the Church's unequivocal opposition to IVF? Despite the fierce opposition of the Australian Catholic hierarchy to the proposal that excess embryos produced in IVF treatments should be allowed to be used for research purposes, with the explicit permission of the parents and under very strict scientific and ethical protocols, authoritative surveys of Australians supported the proposal which was, of course, endorsed by the Federal Parliament in a conscience vote in both Houses in 2002.

I would invite those who say that the Catholic Church never wavers in its teachings, to study Church history. Even in my own lifetime, I have witnessed significant shifts in positions previously assumed by us within the Church to have been immutable. For example, as youngsters we were taught by the Church that to deliberately eat meat on a Friday, with full knowledge of what we were doing and complete freedom of will, was a mortal sin: if we died before we had gone to Confession (the Sacrament of Penance) and expressed contrition for this 'wickedness' and had received absolution from the priest, we would go to Hell!

Similarly, the Church taught that there was a place called Limbo where God sent the souls of those who died without being baptised but who had led a good life. This is no longer part of Catholic teaching. I can remember that in the liturgy for Good Friday one of a series of prayers led by the officiating priest commenced as follows: "Let us pray for the perfidious Jews"! That disgraceful description is no longer found in the Catholic Church's Good Friday liturgy. Back in medieval times, it was a mortal sin to practise "usury" – which was lending or borrowing money at interest. This practice has long ceased to be considered a mortal sin!

I could give other examples of theological and / or moral positions once adopted and proclaimed as universal verities by the Catholic Church in earlier history, which are no longer taught or practised by the Catholic Church. Change is not only possible – the history of the Church demonstrates its capacity to change. It took the Catholic Church the best part of nearly 400 years to admit that it was wrong about Galileo – a devout Catholic. People like myself do not have the luxury of waiting for another 400 years for the Church to correct its current teaching on the science of stem cell research.

The Lockhart Review

The Bill before the Senate Standing Committee on Community Affairs sets out to express in Legislation the recommendations of the Lockhart Review. I would like to remind members of the Senate Committee that some, but certainly not all, opponents of what is proposed in this Bill have made some outrageous attacks on the membership of the Lockhart Review: whose members were chosen by the Australian Government itself. The Lockhart Committee has been accused of consisting of a bunch of scientists merely out to advance their own cause as scientists. An equally fallacious claim has been that there was nobody on the Review with expertise in ethics.

As the members of the Standing Committee would be well aware, the Review was headed by the late Justice John Lockhart AO – a most distinguished jurist and eminent Australian. I take this opportunity to remind the Senate Standing Committee that the other five members of the distinguished Lockhart Review were two outstanding Australian scientists, Australia's 2005 Nobel Prize winner for Medicine, Professor Barry Marshall and Professor Peter Schofield; a leading Australian neurologist, Associate Professor Pamela McCombe; and two of Australia's leading experts in the fields of ethics and law, Professor Loane Skene, a renowned lawyer, ethicist and academic who is Pro Vice-Chancellor and Professor of Law at the University of Melbourne, and Associate Professor Ian Kerridge, a highly regarded expert in the field of health ethics and who is Professor in Bioethics and Director of the Centre for Values, Ethics and Law in Medicine at the University of Sydney.

The Committee was, therefore, pre-eminently qualified to consider and to make judgments about the complex scientific, ethical and legislative issues under its consideration.

May I say, as an author myself and somebody much of whose career has centred on the study and teaching of the English language and its literature, that the Lockhart Report is a masterpiece of thoroughness and fairness in exploring these highly complex scientific, social, moral, ethical and medical terrains. Not a single scientific, ethical or moral stone was left unturned. Unlike too many reports it did not seek refuge in ducking the big issues or throwing 'Hail Mary' passes to some other body, or hiding behind the gormless refuge of blathering on behind the veil of the passive voice – whereby nobody does anything but everything is to be done by some unnamed operator. It is also a masterpiece of clarity of expression. In summary, the Lockhart Review completely supported the current legislative position about embryonic stem cell research: that is to say, it maintained support for the use of surplus embryos produced within IVF programs. It quite correctly continued the ban on any attempt to clone a human being: an act which would be as scientifically idiotic as it would be ethically perverse.

The Lockhart Review put the focus on a current anomaly which the proposed Bill will redress. The 2002 Australian legislation allowed for the creation of human embryonic stem cell lines from <u>fertilised human eggs</u> that have become surplus to the needs of IVF implantation – which means that they would never be implanted into the woman's uterus. But the 2002 legislation currently does not allow creation of such human embryonic stem cell lines derived from an <u>unfertilised human egg</u> in the SCNT process, which would also never be implanted into the woman's uterus. This is a logically and ethically inconsistent situation. Maintaining the consistent logic of its ethical and scientific argument, the Lockhart Report recommends that legislation be drafted to allow the use of unfertilised eggs as well as the fertilised eggs for the creation of stem cell lines. This Bill would enable that to happen.

Motor Neurone Disease

I have Motor Neurone Disease - an incurable, inevitably fatal condition. Dr Dominic Rowe, distinguished Australian neurologist, clinician and chair of the Motor Neurone Disease Research Institute of Australia, declared in 2004 that: "If you were to design the worst possible disease that you could imagine, it would be Motor Neurone disease. It's a disease that slowly robs you of mobility and function but keeps your other senses, sensation and intellect intact".

MND progressively paralyses one's arms, legs, swallowing and speaking muscles and eventually, if you live that long, you end up with a mind and a consciousness inside a body capable only of eye-blinking - before the breathing muscles give way, and you die.

At any one time there are about 1,400 people afflicted with MND in Australia: every day one Australian dies of MND and one more is diagnosed with this wretched affliction. Published data in Australia has shown that MND now kills somewhere between 4 and 5 times the number of Australians who die each year from AIDS. Yet, there is a comparatively miniscule amount of research funds available for seeking a cure for MND when compared to other devastating diseases like AIDS. Thus there is a desperate need to raise the level of community and government awareness of MND.

For a disease first identified in the scientific literature by the great French neurologist Jean Charcot in 1869, it is a scientific / medical research disgrace that in 2006 nobody still understands the cause of, and nobody has yet discovered a cure for, MND.

The average period of survival of people with MND from diagnosis to death is around eighteen to twenty months. Most of us die within 3 to 4 years after diagnosis. At one extreme end of the survival spectrum are people like Pro Hart who lived for only three months after being afflicted. Others, most famously Professor Stephen Hawking, survive for much longer. Given at worst 3 years and at best 5 years to live in 1996, I am a very rare long term survivor.

Embryonic stem cell research has immense potential for understanding the cause or causes of, and of eventually finding a cure or cures for, MND.

In advocating the legalising of research that is the focus of this Bill, I have also strongly encouraged adult stem cell research – which has been carried on for quite a few decades now. Incidentally, embryonic stem cell research really commenced only around 1998 – less than a decade ago. In particular, I have expressed public support for one of adult stem cell research's quite recent development, ie olfactory ensheathing cells from the human nose. I have also strongly supported all of the other scientifically and ethically reputable avenues of research seeking to understand the causes of MND and its cure or cures - such as 'trophic factors' and, very recently, minocycline (although recent results reported in the research literature have been disappointing as far as minocycline is concerned). It must not be a question of either / or. We need to promote and support all forms of scientifically and ethically reputable research.

Countering some assertions, distortions and strawperson ‘arguments’

One of the more irritating features of the arguments mounted against the legalisation of research which is the substance of this Bill, is the assertion that people like myself are helpless dupes of ‘snake oil’ scientists promising overnight miracle cures. A similar anger is aroused when critics make the entirely false assertion that, since the passage of the 2002 Bill, there have been no advances whatever in embryonic stem cell research that would justify the passing of a Bill such as the one before the Standing Committee. As so many scientists supporting this Bill have pointed out, there have been very significant advances in research overseas. And the fact that SCNT has up until now been banned in Australia is the obvious explanation as to why SCNT advances have not occurred in this country!

I, like many others supporting this Bill, am well aware of the time lag that generally exists between research breakthroughs and eventual therapies. For example, it took nearly 20 years for Professor Ian Frazer, current Australian of the Year and strong advocate for legalising SCNT research, to move from his initial research towards the production of a vaccine to protect women from the Human Papilloma Virus that causes cervical cancer. Only quite recently a commercial product was approved for use in the USA by the American Government. And even more recently Professor Frazer has commenced immunisation of young women in Australia. It is also worth noting that it took many years for the research of Australia’s winner of the 2005 Nobel Prize for Medicine, Professor Barry Marshall (a member of the Lockhart Review) to reach fruition and win acceptance.

From the perspective of MND, and probably other currently incurable diseases, there are three potential opportunities to be opened up by the legalising of SCNT. First, it can help us understand the cause or causes of this wretched disease. Second, it has the potential to extend the current life expectancy and quality of life of those currently living with MND. Third, it has the potential eventually – and who knows how many years away this might be – to find a cure for MND. Although I have never given up hope of an eventual cure being identified within my lifetime, nor ever will, I am well aware that this disease will probably have killed me before such a cure is found. Echoing recent comments by Professor Frazer in another context, it is more likely that the fruits of such research will be enjoyed by those not yet afflicted with MND.

But none of these therapeutic possibilities in the future that arise from therapeutic cloning research - both in its own capacity as well as in conjunction with other avenues of stem cell research along with other modes of scientifically and ethically supportable research - can take place in Australia unless the substance and purpose of this Bill are ratified by the Australian Parliament. In doing so, the Parliament must endorse the strict scientific, ethical and legal protocols enshrined in the Bill. If South Korea, for example, had had such strict protocols in place supported by the kind of intensive monitoring processes articulated by this Bill, then the disgraceful research fraud perpetrated by Professor Hwang would not have occurred.

A decision by the Australian Parliament to support the Bill before the Standing Committee would hardly be radical, when an international perspective is applied to the issue. I take the opportunity to remind the Committee that SCNT is already legal in a number of countries, including: England, Scotland, Wales and Northern Ireland; Sweden; in some States of the USA; China; Singapore; and Israel. Already in the UK, where SCNT is legal, a major SCNT research project involving a man with MND is already underway at the University of Edinburgh.

In Conclusion

I thank the members of the Senate Standing Committee for taking the trouble to read my nine page submission. Rather than summarising my submission thus far, I would end on a different note. Throughout this submission I have focussed on rational argument. I do not seek your support for this Bill merely because of my own quite devastating physical crippling nor even on behalf of others struggling to live with this mongrel of a disease. Nor even just because of what passing this Bill could mean to those of the next generation yet to be afflicted with MND. I believe that my advocacy for this Bill rests on powerful rational argument: it is not founded on pity.

But let me conclude on a more emotional level. Never – and I repeat, never – has anybody in the scientific research world ever come up with an answer to the question “what is the cause of Motor Neurone Disease?” (except for the 10% of sufferers who have acquired it because of a direct genetic line). Embryonic stem cell research, including therapeutic cloning, offers a quite dramatic opportunity to help crack the code of what neurologists have referred to as “the black hole” of neurology.

So, for a minute or two could I ask you to imagine looking fairly and squarely into the eyes of my 90 year old mother. My 43 year old wife. Our two daughters, Sophie (15) and Millie (11). And, if you would not mind, imagine looking into the eyes of the author of this submission who ten years ago had nothing wrong with him except a slightly weak forearm but who now is completely paralysed – except for two fingers, some neck muscles, and those muscles enabling him still to speak and swallow. Can you really imagine telling us that for you to support a Bill such as this would be wrong?

I have sufficient knowledge of the political process – some of that knowledge having been acquired very practically during 1990 to 1996 when I was on the personal staff of the then Commonwealth Minister for Employment, Education and Training John Dawkins and later as the Special Advisor to the National Board for Employment, Education and Training – to know that Bills such as this one are inevitably be exposed to the cut and thrust, the give and take, the ‘tweakings’ and editings that are central to our Parliamentary democracy. What I ask of you is that in so doing you do not lose sight of the essential substance and purpose of this Bill. And, even more, I ask you with all the power of persuasion that I can muster, that you please support the substance and purpose of this Bill. Why? Because it is the right thing to do.