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Department of the Senate
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Australia

Dear Mr Humphrey,

Somatic Cell Nuclear Transfer (SCNT) and Related Research Amendment Bill 2006

I wish to make a few introductory remarks, before commenting on the provisions of the *Somatic Cell Nuclear Transfer (SCNT) and Related Research Amendment Bill 2006*. (the Bill) First however a declaration: my position is that of someone who has been confined to a wheelchair by cerebral palsy for all of my 33 years. As such, I have a very personal, vested interest in seeing the scientific research and development proceed, and support the Bill wholeheartedly, while seeking some amendments of my own

To those who would oppose such a stance, I refer them to an image I have found compelling for a number of years. For reasons which are not important now, the movie *Star Trek IV* sees the late DeForest Kelly reprise his 23rd century alter-ego Dr. Leonard McCoy, who finds himself in a hospital from 1986. McCoy has this exchange with a patient:

“...McCOY: Why are you here?
PATIENT: Kidney dialysis.
McCOY: Dialysis! My God what is this – the Dark Ages?”^[1]

McCoy extracts a tablet from his medical bag, which he asks the patient to swallow, before adding: “If you have any problems, just call me.”^[2] At the heart of this exchange is the calling of those in medicine: to heal the sick. Some, like Health Minister Tony Abbott^[3] and Finance Minister Nick Minchin^[4] will claim that such an argument avoids certain questions of morality and, in relation to the stem cell debate, the position of the stem cell or embryo as human. But, as I will show later, this claim that an embryo is human is flawed, on the grounds of fact, law and science.

For now, I ask Ministers Abbott and Minchin why *their* morals should decide *my* access to the full gamut of therapeutic methods to ameliorate *my* condition. Has either man stopped to reflect that *their* declarations of prohibitions and moral absolutes are easy, when it is *others* who will suffer for *their* moral comfort? Equally, has either man thought of maintaining consistency in Government policy? After all, if you are free to choose what superannuation fund you sign up to, whether you join a union and, which schools you send your children to, why can't you exercise freedom of choice in relation to medical research?

^[1] For a general summary of *Star Trek IV* go to http://en.wikipedia.org/wiki/Star_Trek_IV:_The_Voyage_Home

^[2] See *ibid*

^[3] See for example, Tony Abbott, *What's changed about cloning in only four years?*, Opinion, Sydney Morning Herald, August 30th 2006, available at <http://www.smh.com.au/news/opinion/whats-changed-about-cloning-in-only-four-years/2006/08/29/1156816898384.html?page=fullpage#contentSwap1>

^[4] See for example Nick Minchin, *Facts don't match rhetoric in embryonic research debate*, December 2005, available at http://www.conservative.com.au/articles/nick_minchin_Dec_05.htm

For those who do not wish to use therapies or technologies derived from embryonic stem cell research, they can elect not to do so. This requires a disclosure and/or end product labelling regime that distinguishes between those therapies derived from embryonic stem cell research, adult stem cells or other cell therapies.

Recommendation 1: That the Bill be amended, so that any person recommending a therapy, medication or other intervention to a patient, be required to identify the derivation of the stem cells to be used in any such procedure or medication.

Another issue that needs to be discussed is the position of the Churches in this debate. In a previous submission to the Australian Law Reform Commission (ALRC) and Intellectual Property (IP) Australia, I acknowledged that not all churchmen were opposed to the development of stem cell technology.^[5] As I told the ALRC and IP Australia, Dr. Peter Carnley, former head of the Anglican Church, was quite able to find that conception occurred upon an embryo's securing to the uterus wall, a process which occurred 14 days after initial fertilisation of an egg.^[6]

Nonetheless, some church leaders and their followers hold to the notion that human life begins at the point of fertilisation, with a single cell. There are three ways to respond to this; firstly, one can say it is wrong and cite Dr Carnley's remarks. The second response is to say that if this *single cell* argument is true, why is it not equally as true for an adult stem cell as an embryonic stem cell? If the two types of cells are equally as potent and equally capable of "creating life," why are George Pell^[7] and others so confident that there is a distinguishable difference between them? After all, following the Church's own argument are not some adult stem cells equally as capable as embryonic cells of growing into any human tissue and thus, theoretically growing into a completely viable human being? As Peter Singer and Agata Sagan wrote in *The Bulletin* recently:

“...If an embryo is a possible child, then within that embryo a single cell is also a potential human being...”^[8]

By the same logic is not a stem cell obtained from an adult human being also capable of being *another potential human being*? If this is true, the rationale for the differential treatment of the two cells, purely on the basis of their origin, rather than their properties or potential, is flawed. Pell himself says that “it is not right to create human embryos to destroy them for research purposes.”^[9] Yet, he clearly *only* applies this standard to embryonic stems cells and not adult stem cells which he declares “offer the best chances of (research) success.”^[10] Here is a glaring double standard in the argument of those opposed to stem cell research.

Why would opponents fail to address this question, yet maintain such strident positions against stem cell research? I put it to this Committee that there is an answer, which many in

^[5] See my submission to Australian Council on Intellectual Property, *Inquiry into Patents and Experimental Use* available at <http://www.acip.gov.au/expusubs/Adam%20Johnston.pdf>, p.9

^[6] Carnley, Dr Peter, *In the Beginning*, *The Bulletin with Newsweek*, August 28 2002, available at <http://bulletin.ninemsn.com.au>

^[7] See generally, Cardinal George Pell, *No Cloning*, *Sunday Telegraph*, 10 September 2006, available at http://www.sydney.catholic.org.au/Archbishop/STC/2006/2006910_1525.shtml

^[8] Singer, Peter and Agata Sagan, *Stem cells*, *The Bulletin with Newsweek*, September 5th, 2006, available at <http://bulletin.ninemsn.com.au>

^[9] Pell, op. cit.

^[10] Ibid

the churches may well not want to talk about. It is the third potential answer to their opposition to stem cell research. Again, George Pell says that:

“...There is no one who would not welcome a cure for paraplegia or quadriplegia...”^[11]

But upon reflection, I have had cause to doubt the true sincerity of such remarks. The churches and their related charitable arms are generally held in high public esteem for their work with the sick, elderly, disabled and other marginalised groups in society. And there is no doubt that this esteem is merited. However, does stem cell technology represent a threat to that constituency, as people who were once ill and marginalised see the potential to be restored to mainstream life? The churches may well wonder whether many will continue to look to them for help, guidance and support, as stem cell science and other research progresses?

As it is, noted Australian social researcher Hugh Mackay describes Australians as "easygoing about religion".^[12] This extends to the Prime Minister John Howard himself, who said in a 1996 interview that while he was a church going Christian, he was discomforted by many forms of public evangelicalism, believing that religious values were predominantly a private matter.^[13] MacKay finds that such views are typical not only of many non-church-goers, but also those who attend on a semi-regular basis.^[14]

In this context, perhaps the churches have real cause to worry about their long-term future in the face of stem cell and related technologies. No doubt they wish to maintain influence with government, media and other opinion leaders, in Australia and similar Western nations. The response of a number of religious people (to a perceived societal departure from church values, if not scientific progress) has been to stand on overtly Christian platforms to enter secular parliaments.^[15] There are real dangers in this strategy, as explained by a leading theologian Tom Frame, who has recently counselled the churches that:

“...(their) capacity to act as a distinct and exemplary community, (is increasingly perceived as) a political ghetto ignored by parties unable to secure the so-called Christian vote.... This is evident already in the way left-wing political commentators infer all evangelical Christians are conservatives with a social and political outlook similar to the US religious Right...”^[16]

Thus, while I would generally consider myself conservative, in relation to the churches' response to scientific progress, I am opposed to their knee-jerk reaction, partly because I see it as partisan. Furthermore, the position of the churches and other fellow “moralists” tend to be somewhat hypocritical. While they will plead on the one hand for government and the community to spend more time and money supporting the sick, disabled and underprivileged, the same people will object about much of the scientific research and medical procedures which promise to liberate many from their infirmity. Furthermore, the same churches who call on government to spend more on social services pay little or no tax themselves, given their status as “not for profit” or charitable entities.^[17]

^[11] Ibid

^[12] MacKay, Hugh, *Turning Point: Australians Choosing Their Future*, Pan Macmillan Australia, 1999, p. 231

^[13] See *ibid*, pp. 231-232

^[14] See *ibid*, p. 231

^[15] For example, Reverends Gordon Moyes and Fred Nile represent the Christian Democratic Party in the NSW Legislative Council and Senator Steve Fielding leads Family First in the Australian Senate.

^[16] Rowbotham, Jill, *Churches must not play God with Caesar*, *The Australian* – Features, September 02, 2006, available at <http://www.theaustralian.news.com.au/story/0,20867,20328705-28737,00.html>

^[17] See for example, ABC Television, *Australian Story: The Life of Brian – Transcript*, Monday, 1 August, 2005, available at <http://www.abc.net.au/austory/content/2005/s1428533.htm>. This is the story of Senior Pastor Brian

This overly favourable tax status should come to an end and, churches should be assessed for tax as standard business corporations. They should pay their fair share of tax, especially given their preparedness to critique governments' treatment of the poor.^[18] Full and proper contributions to the Exchequer should, in my view, also involve church income being assessed for liability to pay taxes and charges which while not relevant to business, do contribute to the common welfare and are levied on PAYG taxpayers, such as the Medicare Levy. The monies raised from the levying of corporate taxes on churches should go into a Scientific Research Future Fund (SRFF), to support all forms of medical research, including embryonic and adult stem cell research.

Recommendation 2: That the Bill be enacted alongside a companion *Income Tax Assessment (Church Fair Tax and Related Purposes) Amendment Bill 2006*. This would make churches liable for tax as corporations, but additionally require them to pay levies for the general welfare for which PAYG taxpayers are currently liable.

Recommendation 3: That monies recovered from the churches be placed into a Scientific Research Future Fund. (SRFF)

While having now achieved a funding stream for research, it still seems essential to try and ensure that funding and licences are not handed out on the basis (implied or otherwise) of a researcher being deemed as undertaking "religiously correct research". Therefore, we must ensure the National Health and Medical Research Council (NHMRC) and the related Licensing Committee are truly independent from the Federal Government. I have recently noted concerns expressed by Professor Ian Lowe, President of the Australian Conservation. Speaking at the National Press Club in Canberra, Professor Lowe alleged considerable Ministerial skewing of appointments to the NHMRC, saying:

"...The recent stacking of the NH&MRC ethics committee with people likely to favour Tony Abbott's view of the world aroused public concern. But this is only the most recent of a whole series of decisions. The independence of the Australian Research Council has been

Houston of the *Hillsong Church*. John Walker, Corporate Governance Analyst for IMF (Australia) said: "I have looked at Hillsong Church Ltd's annual report and its constitution. Hillsong is not unusual in the sense that, like all other churches, it is a not for profit organisation, which brings with it a privilege of not paying income tax. It differentiates itself however, from other churches in that it runs through a corporate model. This in a not for profit environment will ensure that Australian taxpayers keep a spotlight on Hillsong and its directors over the coming years." While I am not specifically concerned about Hillsong in particular, its example should make us reconsider whether churches, charities and religious orders should continue to have access to "not for profit" status and the taxation benefits this brings?

^[18] For example see Linda Morris, *Coalition sacrifices poor, says church leader*, Sydney Morning Herald, July 7 2006, available at <http://www.smh.com.au/text/articles/2006/07/06/1152175720997.html>. Nor do they limit themselves to the concerns of the poor. For example, George Pell has readily criticised the Howard Government Workplace Relations policies; see Misha Schubert and Jason Koutsoukis, *Pell warns on curtailing unions*, The Age, September 22, 2005, available at <http://www.theage.com.au/news/national/pell-warns-on-curtailling-unions/2005/09/21/1126982121917.html>. Despite this partisan anti-Government stance, a senior Government MP is happy to seek regular counsel from Cardinal Pell. When challenged over this fact by a journalist Tony Abbott responded: "The journalist was told that from time to time I did indeed have discussions with the Cardinal; they were always instructive and I wished they were more frequent. Two generations after it was thought sectarianism had finally vanished from public life, this is doubtless evidence that I am the Vatican mole in the Howard Government." – see Tony Abbott, *Silly sceptics thrive on bias*, The Australian, available at <http://www.theaustralian.news.com.au/story/0,20867,20229161-7583,00.html>

wound back and last year Brendan Nelson, as Minister, overturned ARC recommendations on advice from unqualified ideologues...”^[19]

The Bill makes various references to the NHMRC and its Guidelines. If these are to be important to the Bill’s operation, we must strive for the NHMRC to be reconstituted, so that the propriety, professionalism and credentials of its members are beyond reproach. Therefore, the members of NHMRC should be appointed, not on the recommendation of a single Minister, but with the agreement of all State and Territory Ministers on the Health Ministers Council, with the Federal Minister required to tender to the Governor-General advice signed by all his or her State and Territory counterparts.

Recommendation 4: Members of the NHMRC be appointed upon their nomination being agreed by all State and Territory Ministers, along with the Federal Minister, at the Health Ministers Council.

Recommendation 5: When considering nominations for appointment to the NHMRC, the Governor-General in Council shall satisfy himself that those so nominated are endorsed by all Health Ministers.

Clause 12 of the Bill prohibits the alteration of a human cell so that heritable changes are made. This is a mistake. A third paragraph should be added to the clause, which defines the nature of the alteration being to achieve or introduce genetic material into the cell, whose expression if implanted in a womb, would be deleterious to the resulting individual’s health or longevity.

Such an amendment is important, because some alterations to the genome may be highly advantageous. For example, as I told the Lockhart Review in my supplementary submission:^[20]

“...The genome of the chimpanzee has been recently decoded.^[21] This has resulted in a number of observations, many of which could ultimately have significant impacts on human health. For example, a Sydney Morning Herald report stated:

‘Already some of the bits of DNA that have been found to be duplicated in humans, but not in chimpanzees, have been linked to human diseases such as spinal muscular atrophy and Prader-Willi syndrome...On the other hand humans appear to have lost the function of a gene that may protect chimps and other animals from Alzheimer’s disease’^[22] ...”^[23]

Having watched my late maternal Grandmother suffer with failing memory from dementia, and understanding what this could mean for me, my immediate family and any descendants, I cannot stand by and watch the potential of chimeric or hybrid embryos being so constrained by legislation. Equally, having seen several school friends die a slow withering death

^[19] Lowe, Professor Ian (President, Australian Conservation Foundation), *Shaping a Sustainable Future*, National Press Club Address, 30 August, 2006, available at http://www.acfonline.org.au/articles/news.asp?news_id=921

^[20] See <http://www.pc.gov.au/study/healthworkforce/subs/sub098attachment1.pdf>

^[21] For example, see Deborah Smith (Science Editor), *Meet Clint, your closest relative*, Sydney Morning Herald, September 1, 2005, available at <http://smh.com.au/news/science/meet-clint-your-closestrelative/2005/08/31/1125302628279.html>

^[22] Smith, Deborah, *Humanity redefined*, Sydney Morning Herald, September 1, 2005, available at <http://smh.com.au/news/science/humanity-redefined/2005/08/31/1125302628430.html>

^[23] See <http://www.pc.gov.au/study/healthworkforce/subs/sub098attachment1.pdf>, p.1

courtesy of muscular dystrophy,^[24] such memories serve to heighten my annoyance at the ‘balance’ Lockhart Committee members and subsequently Senator Stott-Despoja felt they had to strike with the alleged ‘moral objectors’ to have recommendations and legislation considered. Again, my sense of urgency about the research (and my personal experience of disability) leads part of me to be suspicious that those who rise up in protest may not be motivated by as noble objectives as they attest.

Therefore, I recommend that Clause 23 be so amended in order that chimeric and hybrid embryos can be created to further the study of disease and, to import those hybrid and chimeric genes into the human genome that could prevent human infirmity.

Additionally, the use of the word “human” in the Bill is arguably an emotional flashpoint in the debate. A neutral and more scientifically accurate phrase would be “homosapien”.

Recommendation 6: That Clause 23 of the Bill is amended to permit chimeric and hybrid embryonic genetic material may be used for therapeutic purposes.

Recommendation 7: That the word “human” be replaced with “homosapien,” wherever the former occurs in the Bill.

Another issue that needs attention is the high level of State^[25] micro-management of researchers in this area of science. We have the NHMRC issuing Guidelines, a Licensing Committee, the Customs Minister gazetting import and export regulations, a possible further legislative review, not to mention internal protocols which each research institution would subject researchers to.

How anyone can continue to rationally oppose stem cell research when understanding the ‘labyrinth of red tape’ under which it is being asked to operate, is quite amazing. Indeed from my perspective, there is far too much regulation of the science. This is in contrast with the US situation where despite the recent refusal of President George W. Bush to make federal funding available for any new stem cell lines,^[26] California Governor Arnold ‘The Governator’ Schwarzenegger lent the California Institute of Regenerative Medicine (CIRM) \$150 million. While Californians had approved referendum Proposition 71 to publicly support embryonic stem cell research, it is currently the subject of a court case^[27]

Due to these constraints advances can only be made on adult stem cells, meaning CRIM researchers are “seeing more investment outside this country (referring to the US).”^[28] Australia should take note of this, while also being aware that Singapore (a nation with whom we have recently entered a Free Trade Agreement^[29]) has adopted an aggressive government policy of supporting biotechnology.^[30] If Australia wishes to remain competitive with not

^[24] See *ibid*, pp.4-5

^[25] The phrase is used in relation to all levels of Government and their regulatory agencies.

^[26] See generally, Office of the Press Secretary, *President Discusses Stem Cell Research Policy* (The East Room), July 19, 2006, The White House, available at <http://www.whitehouse.gov/news/releases/2006/07/20060719-3.html>

^[27] See Red Herring, Inc (Contact the Writer: Editorial@RedHerring.com), *Stem Cell Speed Bumps: Despite Bush veto, work steams ahead*, Red Herring: The Business of Technology, August 7, 2006 Print Issue, also available at <http://www.redherring.com/article.aspx?a=17975>

^[28] *Ibid*

^[29] See Singapore-Australia Free Trade Agreement (SAFTA), available at http://www.dfat.gov.au/trade/negotiations/australia_singapore_agreement.html

^[30] Arnold, Wayne, *Singapore Acts as Haven for Stem Cell Research*, New York Times (World Business), August 17, 2006, available at

only Singapore, but the emerging economies of India and China, then we should take advantage of our position as a developed nation with a ready and willing community of scientists, some of which I had the privilege of meeting as I've attended various seminars and conferences.

They are ready, but government and its preparedness to regulate are always getting in the way. This contrasts with the US where private philanthropy plays a very significant role in funding libraries, galleries and the like. This is partly because American public 'culture' places emphasis on small, limited government, regardless of what the reality may be. This means that:

"...American school textbooks recounted tales of the practical genius of men like Henry Ford and Thomas Edison...The first instinct of policy makers has generally been to stand back and give businesspeople the room that they need to exercise their creative genius. America has been much more inclined to let public work be covered by private philanthropy than Europe has. The country's landscape is littered with monuments to business philanthropy; great universities like Stanford and Chicago; great galleries like the Getty and the Frick..."^[31]

This private philanthropy extends to science, with the co-founder of the internet payment system Paypal recently stating publicly that he would make available \$3.5 million US:

"...to support scientific research into the alleviation and eventual reversal of the debilities caused by aging..."^[32]

While Australia clearly cannot operate on the same scale as the world's largest economy, we could take lessons from *both* Singapore and the United States. From Singapore we could learn much about strategic public investment, while from the US we must learn the benefits of limited regulation. For example, while the Singapore Government makes a lot of funds available, it expects a return on its investment (like any wise investor) and "recently severed a link with prestigious Johns Hopkins because the US university had failed to achieve its agreed staff recruitment goals."^[33]

Similarly, while there has been much said about the stance of President Bush, his announcement only relates to *federal* funding of research. As shown by the earlier example of Governor Schwarzenegger, the US States have a greater freedom and willingness to pursue their own policies. The one clear disadvantage of the Bush decision was that institutions would now have to differentiate and segregate facilities which conducted federally funded and approved work, as opposed to other research.^[34]

While acknowledging this adds administrative complexity for institutions and researchers, it at least provides some space for research of which one level of government approves, but another does not. As such, I call on the Committee to amend the Bill, as well as provisions of

<http://www.nytimes.com/2006/08/17/business/worldbusiness/17stem.html?ex=1159243200&en=3cc23acbd2a57dd9&ei=5070>

^[31] Micklethwaith, John and Adrian Wooldridge, *The Right Nation: Conservative Power in America*, The Penguin Press, 2004, p.328

^[32] Davidson, Keay (Chronicle Science Writer), *BAY AREA: Entrepreneur backs research on anti-aging: Scientist says humans could live indefinitely*, San Francisco Chronicle, Monday, September 18, 2006, available at <http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2006/09/18/BAGF5L7LQS1.DTL>

^[33] Cook, Michael (ed.), *Singapore races for stem cell supremacy: A nation with liberal ethics and generous funding*, BioEdge 215 -- Tuesday, 22 August 2006, Australasian Bioethics Information, available from www.australasianbioethics.org

^[34] See Red Herring Inc, op. cit

the *Research Involving Embryos Act 2002* and the *Prohibition of Human Cloning Act 2002*, so that the prohibitions of the legislative package only apply to those institutions and researchers seeking *federal* funding. This will allow State Governments and private investors to pursue research policies which can be quickly adapted to keep pace with the ever moving frontiers of science. In making this recommendation, I note the Senate Committee which inquired into the 2002 legislation made clear the original Council of Australian Governments (COAG) agreement was based on the exercise, by all jurisdictions, of concurrent powers. It stated in particular, that:

"...the (Research Involving Embryos and Prohibition of Human Cloning) Act is not intended to exclude the operation of State and Territory laws except where the State and Territory laws are inconsistent with the Act and cannot operate concurrently. The explanatory memorandum notes that one of the intended effects...is that if a State has existing legislation that, for example, bans the use of excess ART (Assisted Reproductive Technology) embryos, such a law would not be capable of operating concurrently with the Act and as such it is intended that the Act override the State law to the extent that it is inconsistent..."^[35]

What I am proposing would allow the States and Territories the freedom to pursue their own initiatives without offending Commonwealth law, because Federal legislation would only apply to those seeking Federal funding. Premiers Beattie and Bracks have previously stated their Governments' preparedness to "go it alone" if necessary^[36] and, this stance is to be welcomed. This stance also pays due regard to the proper place of federalism in our democracy. Regrettably, neither Labor nor Liberal Commonwealth Governments have practiced federalism, beyond its political value in providing "someone else to blame" when electors complain about service delivery failures. As Nethercote has observed:

"... (F)or both practical and ideological reasons, arguing for the virtues of federalism has been a position which, for much of the past century, has not been popular in Australia even though, as an institutional structure, the federal system has proved extremely resilient. As a consequence, federalism in Australia has created a paradox. The structure of government is clearly federal; there is a strong national government with involvement in many areas of policy-making, but most government services are delivered by powerful State governments reflecting the views of six widely dispersed State political communities, now joined by two territorial governments with similar characteristics. Yet the legitimation of the system through the acceptance of the desirability of federalism as a way of dispersing power between different spheres of government is largely absent from public debate. Federation has been a great success, but federalism remains an idea with limited public acceptance..."^[37]

Therefore, the stem cell debate provides a great opportunity to reinvigorate our federal structure, the Commonwealth being bound by section 118 of the *Constitution* to give 'full faith and credit' to State laws.^[38] As a consequence of this, I believe the Customs Minister should be required to consult with State and Territory Ministers over regulations which may be made regarding the export or import of stem cells. This consultation would ensure that any regulation made under clause 18A (3) of the Bill.

^[35] Humphrey, Elton (Committee Secretary), *The Senate Community Affairs Legislation Committee: Provisions of the Research Involving Embryos And Prohibition of Human Cloning Bill 2002*, Parliament of the Commonwealth of Australia, October 2002, p.95

^[36] See Metherell, Mark and Steve Burrell, *Iemma stirs researchers' ire with realignment on cloning*, Sydney Morning Herald, July 15, 2006, available at <http://www.smh.com.au/news/national/iemma-stirs-researchers-ire-with-realignment-on-cloning/2006/07/14/1152637872185.html>

^[37] Nethercote, JR (ed) *Liberalism and the Australian Federation*, The Federation Press, 2001, pp. 287-288

^[38] See Sawyer, Geoffrey, *The Australian Constitution*, Australian Government Publishing Service, Canberra 1988, Reprinted 1990, Commonwealth of Australia, p.63

Recommendation 8: That the Bill's scope be limited, so that its terms only apply to those institutions and researchers who seek federal funding for their work.

Recommendation 9: That the scope of the *Research Involving Human Embryos Act 2002* and that of the *Prohibition of Human Cloning Act 2002* also be limited, so that its terms only apply to those institutions and researchers who seek federal funding for their work.

Recommendation 10: That the States and Territories are permitted the freedom to pursue research and development polices, with regard to stem cells, as they see fit.

Recommendation 11: That the Customs Minister should be required to consult with responsible State and Territory Ministers, to ensure than any import or export regulations made pertaining to stem cells, do not conflict with State or Territory laws or policy objectives.

I ask you to take particular note of Recommendation 11, given my prior discussion of the stem cell research being carried on in Singapore. Consulting the text of the Free Trade Agreement, you find that Article 14 specifically allows the parties to make exceptions to the Agreement in relation to an eclectic collection of things ranging from public morals, intellectual property and “the goods and services of handicapped persons”.^[39]

At one level I object that for possibly the most paternalistic of reasons, my Government has decided (on the basis of nothing more than my handicap) that I should *not* be a full participant in or beneficiary of globalisation and international trade. However, this is an argument for another time and another place.

Insofar as it is relevant to the current Bill, I can foresee a Commonwealth Government banning Australian researchers from importing or exporting stem cell materials from Singapore (or a country with similarly liberal research policies) on the basis of such a Treaty exemption. Therefore, the Bill should be amendment so that the Commonwealth is prohibited for exercising its treaty making, external affairs or other heads of exclusive authority to inhibit the operation of State-based stem cell legislation.

The Committee should also seek advice from the Government as to whether any international instruments, be they proposed or in force, will have any adverse impact on stem cell research in Australia. Equally, the Government should be asked to specifically address potential interpretations of Article 14 of the Singapore-Australia Free Trade Agreement (SAFTA).

Recommendation 12: That the Bill specifically restrains the Commonwealth from exercising any of its exclusive powers to inhibit the operation of State-based stem cell legislation.

Recommendation 13: That the Committee seek clarification from the Government as to whether any international instruments will adversely impact upon the operation or interpretation of the Bill. Furthermore, the Government should specifically be asked to advise the Committee as to the appropriate

^[39] SINGAPORE-AUSTRALIA FREE TRADE AGREEMENT (SAFTA), p.41, available at <http://www.austlii.edu.au/au/other/dfat/treaties/2003/16.html>

interpretation of Article 14 of SAFTA and, whether this has the potential to inhibit collaborative ventures between Australian and Singaporean stem cell scientists.

And while we are discussing the operation of free trade agreements, I am not convinced of the need to ban trade in egg cells. Indeed, such a stance looks contradictory when considering that human DNA has been patented. While there might be a perception that permitting ownership of eggs cells may “commodify” the human body, the ALRC has stated in relation of DNA that:

“...Commodification arguments have been criticised on the basis that treating parts of humans (such as natural genetic materials) as objects does not necessarily equate with treating whole persons as objects or commodifying individuals. Critics further suggest that it is not apparent that the widespread grant of patents on isolated human genetic materials has led to a change in how human beings are perceived and treated...”^[40]

Given such an authoritative statement from a body such as the ALRC, I do not believe we should be overly concerned about commodification, individual ownership or trade, given an appropriate legal framework. While acknowledging that the ALRC continues to have some reservations about the ideas I and others have proposed,^[41] I nonetheless believe there are adequate safeguards to be found in renovating old English feudal law. Consider this description of feudal tenure:

"...Under a hypothetically perfect and complete feudal economy, the type of tenure would have denoted not merely the services due from a tenant but also his status and way of life.

The king at the top had the greatest bargaining power, the peasant at the bottom none.

Everyone had his place in the hierarchy: tenure, rank and economic position were interdependent...Life was not, however, as neat as this in reality...A man might hold different lands for different kinds of service, or the same land for a mixture of services. It was quite possible for a tenant to hold part of his lands by knight-service and another part by socage. Moreover, tenure by knight-service did not make the tenant a knight, any more than tenure in villeinage made him a villein...”^[42]

Now I will modernise the description and replace the concept of land holdings with a concept of personal holdings in egg cells and other bodily products, like DNA. Placing the individual research participant at the top of the hierarchy, who could on reasonable terms, invite a variety of interested scientific parties to study his or her DNA and the like, should go some way to addressing the concerns that people will be pressured into providing egg cells or other samples.

Asserting a form of limited, diffuse, neo-feudal individual proprietary interest over one's body would in my view, help avoid litigation over the appropriateness of scientists patenting genes (or other materials) obtained from research participants.^[43] The limitation on an

^[40] Australian Law Reform Commission, *Genes and Ingenuity: Report*, Report 99, Commonwealth of Australia, June 2004, p.71

^[41] See Australian Law Reform Commission and National Health and Medical Research Council, *Protection of Human Genetic Information: Discussion Paper*, Discussion Paper 66, Commonwealth of Australia, August 2002, pp. 451-460

^[42] Baker, J. H., *An Introduction to English Legal History*, 3rd ed., Butterworths, 1990, p.260

^[43] See Australian Law Reform Commission, *Gene Patenting and Human Health*, Discussion Paper 68, Commonwealth of Australia, February 2004, p.74; note, in particular, Paragraph 3.66 and the unfortunate story of the Greenberg family.

individual's dominion would come in the form of the contracts which a person entered with various scientific interests being placed on a public register overseen by an independent authority. This was a suggestion I made during the joint ALRC and NHMRC inquiry into the protection of human genetic information,^[44] I restate it now for the purposes of this inquiry, as a means of securing each individual's proper position in the debate over proprietary interests in egg cells, should they so choose to enter trading relationships.

The “independent authority” referred to earlier should be the Inter-State Commission referred to in section 101 of the *Constitution*. While Sawyer notes that this body has largely fallen into disuse,^[45] it could oversee trade in stem cells within the Commonwealth, as well as adjudicate any disputes between parties. An additional advantage of this arrangement is that I have achieved organisational separation between the NHMRC Licensing Committee and the dispute resolution and adjudication body in the Inter-State Commission.

Should some commentators continue to have difficulty with the concepts of “trade” and “the human body”, I draw your attention to an article by N. Stephan Kinsella concerning “Lockean Homesteading” and its possible application in these circumstances.^[46] Furthermore, you should be aware that “(a centre) to develop and market stem cells has been launched in Scotland.”^[47] As such, the “trade genie is out of the bottle”, so to speak.

Recommendation 14: That clause 15 of the Bill is deleted.

Recommendation 15: That an individual should be permitted to hold limited proprietary rights in their own body, by means of feudal-style tenure arrangement.

Recommendation 16: That the Inter-State Commission be revived and be charged with overseeing the trade in egg cells, stem cells and related materials within the Commonwealth of Australia.

It would be preferable to see in the objects of the Bill that the Parliament aims, by the enactment of this Bill, to advance science in the spirit of the Enlightenment, secular, liberal democratic traditions of the Commonwealth of Australia. There is compelling evidence for understanding Australia's civic spaces as predominantly and appropriately secular.

For example, Professor Helen Irving of Sydney University cites section 116 of the Constitution, in its prohibition of the Commonwealth establishing or requiring its officers to submit to any religious observance or examination.^[48] She argues that section 116 was the product of concern by Australia's founders that official recognition of any religion could lead to intolerance by providing a legal excuse for persecution of those practising a faith other than that publicly sanctioned. It is significant to reflect that Edmund Barton, our first Prime Minister, stated that Australia's "whole mode of government, the whole province of the State,

^[44] See Australian Law Reform Commission and National Health and Medical Research Council, op. cit., pp. 457-458. Also, see generally my submission to the *Australian Council on Intellectual Property – Inquiry into Patents and Experimental Use*, available at <http://www.acip.gov.au/expusesubs/Adam%20Johnston.pdf>

^[45] See Sawyer, op. cit., pp. 31-32

^[46] See Kinsella, N. Stephan, *How We Come to Own Ourselves*, Ludwig von Mises Institute: Mises Daily Article [article@mises.org], available at <http://www.mises.org/story/2291>

^[47] Nji Che (All Headline News African Correspondent), *Edinburgh Center To Trade Stem Cells*, September 27, 2006 9:26 a.m. EST, available at <http://www.allheadlinenews.com/articles/7004994027>

^[48] Irving, Helen, *Australia's foundations were definitely and deliberately not Christian*, Sydney Morning Herald, 3 June 2004, available at <http://www.onlineopinion.com.au/view.asp?article=2272>

is secular".^[49] This view is contested by Elizabeth Kotlawski, who notes that the first Australian Parliament was opened with a prayer and that State Governors have historically proclaimed a number of holy days.^[50] Kotlawski also relies on judicial acknowledgement of Christianity, highlighting colonial jurisprudence as well as a 1992 judgment in the Victorian Supreme Court describing this nation as "predominantly a Christian country".^[51]

On balance, it would seem our founders did indeed mean the State to be secular, because it was only after "a flood of petitions from church organisations (that) they added eight words to its hitherto-secular Preamble: Humbly relying on the blessing of Almighty God."^[52] It would also appear that Australia's founders were made of sterner stuff than our contemporary leaders. After all, if the recent controversy over the Exclusive Brethren is any guide, the moment a religious orders' credentials or conduct are challenged today, no less than the Federal Treasurer *and* the Prime Minister will publicly defend tax breaks for the churches.^[53]

This is all the more surprising because of three important factors. Firstly, the earlier citation of Hugh Mackay's research showed that Australians thought of religion as a private matter and were "easygoing" about it.^[54] Secondly, even more recent research shows church influence to be dwindling, with many teenagers uncertain of or ready to change their religious beliefs any number of times.^[55] Thirdly, the church is implicitly conceding at least some of these concerns when it commissions research specifically on Generation Y. For the Catholic Church this research, undertaken by Monash University, the Australian Catholic University and the Christian Research Association, found that:

"...By the time young Catholics reach 29 about a quarter had left the church, and there was little prospect of their return..."^[56]

In this context, it seems strange that politicians like the Prime Minister and Treasurer would react so readily to church sensitivities, and defend taxation exemptions for religious groups. This preparedness to make such concessions be they financial or otherwise can have disastrous consequences, particularly for science. A good example of this is the current controversy over the concepts of intelligent design (ID) and evolutionary theory. Religious theology should play at most a marginal role in the public policy debate about medicine, science and research. Yet, lobbyists in Australia and the US would have ID taught in schools, as if it were a legitimate part of science. But as Richard Dawkins and Jerry Coyne^[57] point out, advocates of ID tend to make assertions inspired by theology, but when their lack of evidence is pointed out, they cite shortcomings in the evolutionary record or 'the inherent complexity of life'. As Dawkins and Coyne go on to say, this line of argument leads to a:

^[49] Ibid

^[50] See Kotlawski, Elizabeth Rogers, *Southland of the Holy Spirit: A Christian history of Australia*, Christian History Research Institute (Dr Graham McLennan, Publisher), 1994, pp. 14-15

^[51] Ibid, p.287

^[52] Irving, op. cit

^[53] See Coorey, Phillip (Chief Political Correspondent), *Costello defends sect's tax breaks*, Sydney Morning Herald, September 28, 2006, available at <http://www.smh.com.au/news/national/costello-defends-sects-tax-breaks/2006/09/27/1159337221265.html#>"

^[54] See Mackay, op. cit., pp. 231-232

^[55] See Zwartz, Barney, *Try before you die: teens test religions*, Sydney Morning Herald, April 3 2006, available at <http://www.smh.com.au/text/articles/2006/04/02/1143916409578.html>

^[56] Morris, Linda (Religious Affairs Reporter), *Motherhood message for Gen Y Catholics*, Sydney Morning Herald, September 28, 2006, available at <http://www.smh.com.au/news/national/motherhood-message-for-gen-y-catholics/2006/09/27/1159337221268.html#>

^[57] Richard Dawkins is a Professor at Oxford University; Jerry Coyne is a Professor at the University of Chicago.

“...’default’ assumption that if Theory A has some difficulty in explaining Phenomenon X, we must automatically prefer Theory B without even asking whether Theory B (creationism in this case) is any better at explaining it. Note how unbalanced this is, and how it gives the lie to the apparent reasonableness of ‘let’s teach both sides’. One side is required to produce evidence every step of the way. The other side is never required to produce one iota of evidence but is deemed to have won automatically the moment the first side encounters a difficulty — the sort of difficulty that all sciences encounter every day, and go to work to solve, with relish...”^[58]

I think many of the same dangers exist when debating issues around stem cells, be they adult or embryonic. We need to be absolutely sure of our science and are accused of offering “false hopes,” while our opponents trot out a range of emotional cliques and declare a moral panic, without anything like the same level of scrutiny. We should not be tempted to canonise the human cells or tissues; they are not valuable for their own sake, but for what they do – particularly when therapeutic application may save a life.

Some would say that such a stance is overly utilitarian and fails to show the necessary mystique or reverence for life. Thirty-three years of disability is enough to convince me that any mystique or reverence is something which can be indulged in, principally by those who are able-bodied and have rarely, if ever, been admitted to hospital for major surgery. When you know that multiple hospitals contain multiple files on your multiplicity of admissions for a smorgasbord of orthopaedic procedures, people telling you about the supposed “sanctity of life” prompt in one an urge to hysterical laughter. I have an image of in my mind of a car in a mechanic’s garage, covered from bumper to bumper with defect notices from the Roads and Traffic Authority (RTA); the car is my body, the mechanic my surgeon and the garage a hospital, while the RTA is the recurring cost and inconvenience of my disability.

Furthermore, the additional “rub” for not only me as the patient, but my family and friends is the cost and inconvenience of my hospitalisation, the length and difficulty of recuperation and, the knowledge that not all procedures will have lasting long-term benefits. Indeed, extended recuperation has at times accentuated a loss of muscular strength and tone, while some muscular tension released by surgery will re-tighten over succeeding years. After all, orthopaedic surgery can only deal with the outward manifestations of spasticity, such as tight muscles. It cannot deal with the cellular, neural and nerve damage which lies at the heart of the condition. Cellular regeneration and replacement can strike at the heart of my condition and that of many others.

Herein lies the promise of stem cells; and let me add, with every passing day it is becoming less of a promise and more of a reality! An example of how these technologies can be employed was provided when US researchers at the Tissue Engineering and Organ Fabrication Laboratory at Massachusetts General Hospital in Boston. Dr. Joseph Vacanti and his team were able to build a system of scaffolding, cultivate some cells and grow a human ear on the back of a mouse.^[59] The PBS report stated that:

“...(ultimately), custom-made hearts, livers, breasts, corneas, kidneys, bone marrow and bladders could offer elegant solutions to most life-threatening illnesses...”^[60]

^[58] Dawkins, Richard and Jerry Coyne, *God and science don't mix*, The Age, September 11, 2005, available at <http://www.theage.com.au/news/general/god-and-science-dont-mix/2005/09/10/1125772732711.html>

^[59] See Alan Alda in Scientific American Frontiers, *The Bionic Body – Web Feature: The Body Shop*, available at <http://www.pbs.org/saf/1107/features/body.htm>

^[60] Ibid

This stands in stark contract to the “mend the manifestation” capacity of say, most orthopaedic surgery I have undergone. Stem cell therapies will be part of the medical armoury that “addresses the cause”. Indeed, a recent report says some Australian scientists are developing small plastic tubes to reconnect severed nerves, and encourage them to grow.^[61] The exciting medical era we are potentially entering can be summed up nicely, by another line for Dr McCoy, who in Star Trek IV says to a 20th century surgeon:

“...My God man! Drilling holes in his head’s not the answer. The artery must be repaired. Now put away your butchers’ knives and let me save this patient before it’s too late!...”^[62]

Is it too late? That is, will this Committee, this Senate and this Parliament let the new technology be applied in Australia? Put another way, why should this Parliament deny me and thousands of others access to technology which will become available in Singapore and California. The Government of Singapore and Governor Schwarzenegger clearly see the economic, social and political benefits of encouraging stem cell research. Clearly, they will not be intimidated by religious institutions and neither will I. This is because it is my belief that medicine should be based on one overriding concern. As the Chair of Medicines Australia John Young put it to the National Press Club recently:

“...I believe very passionately that one person needs to be the focus for all of us involved in the healthcare sector, whether we are doctors, nurses, pharmacists, allied healthcare professionals, politicians, healthcare policy makers, journalists, or those of us who work in the pharmaceutical industry. I refer to patients...”^[63]

Again, as someone with a disability, who has been in hospital more times than he cares to remember and, has plenty to do with any number of health care professionals, this is the kind of clear-headed, pithy statement I want to hear. In many respects, the finer points of ethics, guidelines and protocols are a sideshow populated by theorists, academics and theologians. It may come as a surprise to them, but all I care about in the end is the therapeutic outcome for me, or one of my kin whom I love.

Therefore, whether politicians, religious leaders or other supposed “keepers of the communal view” approve of my willingness to support or receive stem cell therapies is not critical; my ability to find an appropriately qualified clinician to undertake the procedure is the only question of real concern. After all, to paraphrase the Prime Minister John Howard and his famous ‘*We will determine*’^[64] address:

“...I am the patient and I will determine the treatment to which I consent and the terms under which that consent will be given...”

No doubt, some religious types and their ilk will accuse me of elevating egocentricity to an art form (amongst other things). But to invoke the great Aussie vernacular, “bugger them!” The science is just too important to be continually making concessions to religion;

^[61] See ABC News Online, *Researchers work on way to regrow nerves in damaged limbs*, Last Update: Wednesday, September 20, 2006. 4:04pm (AEST), available at <http://www.abc.net.au/news/newsitems/200609/s1745526.htm>

^[62] Star Trek IV, op. cit.

^[63] Young, John (Chair, Medicines Australia), *A patient centred prescription for the PBS*, Address to The National Press Club, 6th September 2006, p.1, available at

[http://www.medicinesaustralia.com.au/pages/images/JY%20NPC%20Speech_final_060906%20\(2\).pdf](http://www.medicinesaustralia.com.au/pages/images/JY%20NPC%20Speech_final_060906%20(2).pdf)

^[64] See Solomon, David (ed), *Howard’s Race: Winning the Unwinnable Election*, HarperCollins Publishers, © 2002, p.106

Australian scientists and physicians will fall behind their counterparts in Singapore and other places, while others have already left for overseas.^[65]

And I have always found it interesting how people, like George Pell and other religious leaders (including Tony Abbott), can make declarations of principle about things that may never impact on them directly, but when *their* principle is applied, *others* will face devastating consequences. In the face of a denial by the Church of embryonic stem cell research and all its potential, it is worth reflecting on just how George Pell manages to reconcile his public statements with his supposed witness for a Saviour who came to heal the sick, preach deliverance to the captives and cast many demons (illnesses) out of people during the course of His Ministry.

Of course, Pell could respond that I am using Biblical texts and principles selectively; but that accusation can cut both ways. The real question should be how either one of us can credibly invoke a manuscript over 2 millennia old, and expect to reliably extrapolate lessons from messages addressed to an agrarian society which no longer exists. More importantly, we need to ask deeper questions of those who argue ethics or morals (be they Christian or otherwise) mean we should prohibit embryonic stem cell research. This does not mean I lack faith, or that the Bill should require anyone to abandon their faith. Rather, might you consider three things in concert; firstly, faith in God need not bind you to an equal faith in the Church that invokes His name. After all, churches are manned by fallible, mortal human beings and not by the Almighty. Secondly, just because a churchman says something and claims a Biblical authority does not mean he is right. As stated earlier, I have read newspaper columns or other public utterances of George Pell and others, only to conclude they are politically partisan, just plain wrong, or both. Thirdly, in a world confronted by a War on Terror, based in large part on a perversion of religion, I take Edmond Barton's words to heart and call on all MPs (regardless of their personal faith) to jealously guard the secular institutions of our Government.

As such lobbying from the churches and other "fellow travelers" must be viewed with caution. There were no doubt those who complained about everything from the release of the contraceptive Pill, Elvis Presley's music and the first organ transplant, to name but a few touchstones. Now, the Pill is commonplace, Elvis is probably regarded by many as good middle-of-the-road listening (as well as being a man of deep and abiding faith), and organ transplants have saved many lives. Similarly, I believe stem cell therapy will become commonplace and uncontroversial. Some people currently fear it, so they present the technology within an ethical framework that says it is unethical. What they are *really* saying is that *they fear it*. History suggests that the fear-threat reaction will pass.

When this reaction does pass, we will also be able to think more clearly about the true nature of the stem cell and the embryo. As I told the Lockhart Review,^[66] in common law and statute sharp distinctions between an embryo and a baby have been drawn; often for the purposes of establishing liability. For example, in the case of *Watt v Rama*,^[67] the Victorian Supreme Court was confronted by a negligent driver, whose conduct had injured a pregnant woman on her way to hospital. The question therefore became one of whether a child en

^[65] Dayton, Leigh (Science writer), Stem cell scientist joins the exodus, *The Australian* — Science & nature, August 12, 2006, available at <http://www.theaustralian news.com.au/story/0,20867,20098892-30417,00.html>

^[66] See <http://www.lockhartreview.com.au/public/content/ViewCategory.aspx?id=19>, pp. 4-5, and repeated here because of its immediate relevance to this inquiry

^[67] [1972] VR 353 Supreme Court of Victoria (Full Court), extracts cited in Harold Luntz and David Hambly, *Torts: Cases and Commentary*, 4th edition, Butterworths, 1995, pp. 403-405

ventre so mere could sue for damages? Judicial opinion was positive on this point, with Gillard J saying:

"...By the very nature of things, (the defendant) should reasonably anticipate that if he drives carelessly and collides with another motor car, he may injure not only those already in esse [in being], but those to be born, so that when they are born, they may suffer damage by the physical disabilities caused by his careless act..."^[68]

US case law is also compelling in determining the legal distinction between embryo and baby. It is in this context that I draw your attention to the case of *Allaire v St Luke's Hospital* and the noted dissent of Justice Boggs. In that case, a pregnant woman had been seriously injured in an elevator accident at St Luke's Hospital prior to giving birth. Her son was handicapped as a result of the hospital accident, but the Court rejected her claim for damages on her son's behalf. The majority of the Court decided that prior to birth the child was "in fact, a part of the mother".^[69]

However, acknowledging that mother and unborn child could have separate legal identities, Justice Boggs said:

"...In the case at bar the infant, when the injury was inflicted, had, as the declaration alleged, reached that advanced stage of foetal life which would have, according to the experience of mankind, and according to the medical learning of the age, endowed it with such vitality and vigour, and with members and facilities so far complete and mature, that it could have maintained independent life, and the death of the mother would not have deprived it of life. It is but natural justice that such an infant, if born alive, should be allowed to maintain an action in the courts if for injuries so wrongly committed upon its person while so in the womb of the mother..."^[70]

Justice Boggs demonstrated his consideration of the unborn child's potential to be self-sustaining as a marker of humanity. As such, with guidance like this we should be able to frame legislation which can reasonably allow somatic cell nuclear transfer.

On the basis of the above, I specifically asked the Lockhart Review to declare that a blastocyst was not human, and I repeat the call here.

Recommendation 17: That the Bill include amongst its Objects, "the advancement of science in the spirit of the Enlightenment, secular, liberal democratic traditions of the Commonwealth of Australia".

Recommendation 18: That the Bill declare in law, that a blastocyst is not human.

Finally, I would like to draw to the Committee's attention some additional research I have been doing into the question of how mechanical devices could be used to overcome disability. Combine this with stem cell technology and you have a multifaceted platform of treatment options, by which you can eliminate disability from contemporary human experience.

^[68] Ibid, p.405

^[69] Hershiser, M. M, *Preconception Tort Liability -- The Duty to Third Generations: Enright v Eli Lilly & Co (1991) 24 Creighton Law Review 1479*, extracts cited in Penelope Watson (ed), *Law 522 Advanced Torts: Cases and Materials 2001*, Vol. 3, Part B, Macquarie University Division of Law, 2001, p. 280

^[70] Ibid (quoting Justice Boggs at case citation 184 Ill, 372, 56 N.E. at 641-42)

This after all, is the ultimate goal. And yes, I have a distinct personal interest; ever since the late Christopher Reeve visited Sydney as a guest of the then NSW Premier Bob Carr, I have been convinced that his spinal lesion and my cerebral palsy can ultimately be ameliorated by stem cell technology.

Let me put this in context for you. On 1995 figures, 324,670 men and 139,760 women received the disability support pension, while 22,300 people received the mobility allowance and 87,120 children received the child disability allowance.^[71] Can you imagine a world where disability is a concept and an experience consigned to history? I can! Such a change would stand alongside the harnessing of fire, Magellan's circumnavigation of the globe, the development and wide use of the printing press, the dawning of the Enlightenment and Neil Armstrong's step onto the lunar surface. And not only will such a development immeasurably improve the quality of life for many millions across the globe, but it will save billions in welfare payments from Treasuries around the developed world.

Therefore, I will consider stem cells, chimeric cell therapy, exoskeletons, Biomedical Engineering and Mechatronics. Equally, I would happily undergo a combination of all these therapies. A multi-disciplinary, multifaceted approach is most likely to bring results. In this spirit, I appeal to the Committee *not* to use the Bill to ban any potential therapy of therapeutic value. In all good faith, I seek to demonstrate to you my preparedness to consider all treatment options.

For example, I have investigated the idea of bringing some Japanese research into exoskeletons to Australia, which was widely publicised last year in the media.^[72] Dr Keijirou Yamamoto of the Kanagawa Institute of Technology was kind enough to refer me to Professor Sankai, from the University of Tsukuba after I made inquiries about his Wearable Power Assist Suit. Dr Yamamoto advised that the device was developed to assist the lifting of a patient, rather than walking.

I emailed Dr Yamamoto and also contacted the then Science Minister, Dr Nelson.^[73] These inquiries met with limited success, however when I read a newspaper article about developments in robotics^[74] I contacted Dr Gordon Wyeth from the University of Queensland.^[75]

I advised Dr Wyeth of correspondence I had received from the Science Minister, but while supportive of my idea, he believed the science linkages program was inappropriate. Previously, I had approach my own university's Technology Arm. However, the HAL project did not align with the research objectives of Macquarie IT. So, Ben Smith of Macquarie referred me to Dr. Timothy Scott of Royal North Shore Hospital.^[76]

^[71] See Blackall, Simon (Project Director), *The Book of Australia: the Essential Information Book on Everything Australian for Office, ice, School Home -- Almanac 1997-98*, The Watermark Press 1997, p. 189

^[72] See, "Robot Suit HAL early emails", pp. 8-19 (Document located in "Attachment to Submission")

^[73] See "Dr Jade Sharples 18 January 2006". Also see "Email 31 July 2006" – this is the last time I tried to contact the Japanese developer of HAL. (Document located in "Attachment to Submission")

^[74] See "How the Six Million Dollar Man fantasy is nearing reality". (Document located in "Attachment to Submission")

^[75] See "Gordon Wyeth 6 June 2006". (Document located in "Attachment to Submission")

^[76] See "Email 15 June 2006 Dr Timothy RD Scott". (Document located in "Attachment to Submission")

In pursuing this project, I have also contacted the Minister for Health^[77] and NSW Senator Marise Payne, regarding Australian Government funding of research and technology.^[78] Her staffer, Matt Gijselman referred me to the Industry Department and the COMET program.^[79] However, Dr. Andrew Ruys from Sydney University has advised me that the COMET program is inappropriate as I need a company and a University to work in partnership.^[80]

I was referred to Dr. Ruys by Professor Rebecca Mason,^[81] whom I heard discussing Cyborg-type technology on ABC Radio's The World Today.^[82] The interview made me consider whether element of a HAL-type technology could be implanted into a patient, rather than being a bulky exoskeleton? Undertaking some internet research, there does appear to be some potential for the human body to be a deliberate conduit for electronic signals,^[83] with one author suggesting skin can be patented as a technology component.^[84]

This concept draws upon a number of ideas either already in production, or under development. While refining of the concept may take some work, I noted Professor Mason's comments that:

“...What you describe is on the interface between Biomedical Engineering and Mechatronics. You have come to the right place as our large School of about 1000 people (staff and students combined) has disciplines in Biomedical Engineering, Mechatronics, Mechanical Engineering (also Aeronautical and Space). We are something of a one-stop-shop in advanced engineering...”^[85]

I have also contacted technology company 88 Eyes, and while they did not believe my ideas were ready for commercialization, and they were not in a position to assist me,^[86] I nonetheless retain hope that those with more business acumen than me will be able to commercialise such concepts in Australia.

The exoskeleton concept and its potential merger with stem cell technology excite me. Indeed, all the technology I have described throughout this submission enthalls me. To reprise my analogy of the motor car, for the first time in human history, we can take that jalopy in the mechanic's garage and put on the road of life a Formula One racing car. Stem cells and related technologies are the new 21st century tools on the mechanic/surgeon's workbench. I urge you to put nothing in the Bill that would inhibit collaboration and convergence of a variety of biological and mechanical technologies.

Recommendation 19: That the Bill not be used to ban any potentially therapeutic procedures.

^[77] See “Email 19 June 2006” and see also “Judith Davis-Lee July 2006”. (Document located in “Attachment to Submission”)

^[78] See “Email 24 July 2006 Marise Payne” and “Sydney Companies Benefit from Innovation Funding”.

^[79] See “Email 7 August 2006 Matt Gijselman”. (Document located in “Attachment to Submission”)

^[80] See “Email 8 August 2006 Dr Andrew Ruys”. (Document located in “Attachment to Submission”)

^[81] See “Email 19 July 2006”, pp.2-4 (Document located in “Attachment to Submission”)

^[82] See transcript “The World Today 4 July 2006”. (Document located in “Attachment to Submission”)

^[83] See “NTT Prototypes use Human Body As Digital Transmission Path”. (Document located in “Attachment to Submission”)

^[84] See “Patenting Skin as a Technology Component”. (Document located in “Attachment to Submission”)

^[85] See “Email 19 July 2006”, pp.2-4 (Document located in “Attachment to Submission”)

^[86] See “Memo to 88Eyes” and “88Eyes Response 5 September 2006”. (Documents located in “Attachment to Submission”)

Recommendation 20: That the Committee be aware of advances in mechanics and engineering, and the possibilities for convergence of technologies. Furthermore, in making any amendments to the Bill, you should avoid inserting any clauses which might inhibit collaboration or convergence of technologies.

In closing, I should point out that I alone have written this document and, I alone accept responsibility for its contents. Others have been cited, or their comment relied on, but as any author says who is prepared to stand behind his work, *any errors or omissions are mine alone.*

I am passionate about stem cell technology and what it offers. In preparing this submission, I have readily pushed the bounds of my own knowledge, be it scientific, legal or general. I have also pushed the Bill in a variety of directions and admit to attempting to push this Committee into areas of deliberations it had probably not planned.

Ten years ago, I would have said my disability was a given; something that would remain with me always. Not any more!

In this respect, this submission (and your inquiry) represents something very personal to me; the fight of my life, to gain a fighting chance at life without disability!

SUMMARY OF RECOMMENDATIONS

- 1: That the Bill be amended, so that any person recommending a therapy, medication or other intervention to a patient, be required to identify the derivation of the stem cells to be used in any such procedure or medication.**
- 2. That the Bill be enacted alongside a companion *Income Tax Assessment (Church Fair Tax and Related Purposes) Amendment Bill 2006*. This would make churches liable for tax as corporations, but additionally require them to pay levies for the general welfare for which PAYG taxpayers are currently liable.**
- 3: That monies recovered from the churches be placed into a Scientific Research Future Fund. (SRFF)**
- 4: Members of the NHMRC be appointed upon their nomination being agreed by all State and Territory Ministers, along with the Federal Minister, at the Health Ministers Council.**
- 5: When considering nominations for appointment to the NHMRC, the Governor-General in Council shall satisfy himself that those so nominated are endorsed by all Health Ministers.**
- 6: That Clause 23 of the Bill is amended to permit chimeric and hybrid embryonic genetic material may be used for therapeutic purposes.**
- 7: That the word “human” be replaced with “homosapien,” wherever the former occurs in the Bill.**
- 8: That the Bill’s scope be limited, so that its terms only apply to those institutions and researchers who seek federal funding for their work.**

9: That the scope of the *Research Involving Human Embryos Act 2002* and that of the *Prohibition of Human Cloning Act 2002* also be limited, so that its terms only apply to those institutions and researchers who seek federal funding for their work.

10: That the States and Territories are permitted the freedom to pursue research and development polices, with regard to stem cells, as they see fit.

11: That the Customs Minister should be required to consult with responsible State and Territory Ministers, to ensure than any import or export regulations made pertaining to stem cells, do not conflict with State or Territory laws or policy objectives.

12: That the Bill specifically restrains the Commonwealth from exercising any of its exclusive powers to inhibit the operation of State-based stem cell legislation.

13: That the Committee seek clarification from the Government as to whether any international instruments will adversely impact upon the operation or interpretation of the Bill. Furthermore, the Government should specifically be asked to advise the Committee as to the appropriate interpretation of Article 14 of SAFTA and, whether this has the potential to inhibit collaborative ventures between Australian and Singaporean stem cell scientists.

14: That clause 15 of the Bill is deleted.

15: That an individual should be permitted to hold limited proprietary rights in their own body, by means of feudal-style tenure arrangement.

16: That the Inter-State Commission be revived and be charged with overseeing the trade in egg cells, stem cells and related materials within the Commonwealth of Australia.

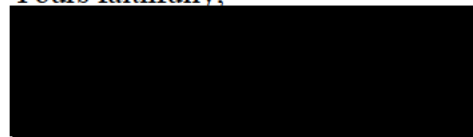
17: That the Bill include amongst its Objects, “the advancement of science in the spirit of the Enlightenment, secular, liberal democratic traditions of the Commonwealth of Australia”.

18: That the Bill declare in law, that a blastocyst is not human.

19: That the Bill not be used to ban any potentially therapeutic procedures.

20: That the Committee be aware of advances in mechanics and engineering, and the possibilities for convergence of technologies. Furthermore, in making any amendments to the Bill, you should avoid inserting any clauses which might inhibit collaboration or convergence of technologies.

Yours faithfully,

A solid black rectangular box redacting the signature of Adam Johnston.

Adam Johnston