4th May, 2008

Mr. Peter Hallahan
Committee Secretary
Senate Standing Committee on Legal and Constitutional Affairs:
Inquiry into the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008

Dear Mr. Hallahan

AMENDED DOCUMENT CONTAINING ADDITIONAL EVIDENCE

Response from Dr. David Gawler (representing Darwin Christian Ministers' Assoc.) to Senator Bob Brown's Questions on Notice.

Questions from proof transcript of Hansard transcript of evidence for the Senate Standing Committee on Legal and Constitutional Affairs:

Enquiry into the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008 hearing in Darwin on Monday, 14th April 2008.

"**Senator Bob Brown –** Dr Gawler, you might take these questions on notice. They will help the committee. You said that the Northern Territory Health Service had said that there was no great change in the approach to doctors or doctor treatments during the period during which the euthanasia legislation was potent here in the Territory. Did you mean no great change or no change at all? Could you provide the committee with any evidence that there was change and, if so, what it was? Secondly, there is anecdotal evidence that people left hospital. Can you provide the committee with any such anecdotal evidence which we might be able to put some substance to?"

REPLY FROM DR. DAVID GAWLER TO QUESTIONS ON NOTICE FROM SENATOR BOB BROWN:

(1) *Indigenous evidence regarding ROTI Act*:

Joy White (Public Officer of the Bagot (Indigenous) Community in Darwin) is 60 years of age, and as a highly respected Aboriginal lady has spoken of the impact of the ROTI Act on herself and her family at the time of its currency. Joy said that she and her extended family felt worried and fearful about what would happen to sick relatives going to the clinic and especially to the hospital. In fact she decided that she would not allow any of her relatives to go to the hospital, for fear that they would be killed. She said that she wanted to see her children and grandchildren grow up and she was worried that if she became ill and was admitted to hospital, she might be killed and therefore lose the opportunity to raise her family.

<u>(2)</u> ***Medical Practitioners' evidence regarding the ROTI Act:***

I have spoken to several doctors who were practicing in the Northern Territory at the time the ROTI act was potent. Each doctor was aware of concern and fear amongst Indigenous people in communities and towns regarding attendance at hospitals or clinics.

The most specific instance of fear engendered by the ROTI Act was in relation to an Indigenous baby with a life threatening cardiac condition. This baby was transferred from Royal Darwin Hospital to a southern paediatric hospital where the cardiac consultants diagnosed the baby's condition as inoperable, incurable and terminal. The baby was returned to Royal Darwin Hospital. The drug treatment regimen for the baby was futile, and the cessation of such treatment was discussed with the parents who became very disturbed, because they believed that their child was about to be euthanased under the ROTI Act. The paediatricians needed to spend considerable time explaining that the two issues were completely separate.

Certainly, in this instance as the senior paediatrician stated, ROTI "muddied the waters" and caused a lot more anxiety and fear and sorrow than would have been the case without ROTI.

> As a result of enquiring about the impact of the ROTI Act, another Senior Specialist Physician clearly recalls having numbers of conversations with Aboriginal patients who were frightened that they could be euthanized whilst in hospital. She said that considerable time was needed to reassure these patients.
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> Another Senior Physician, Dr. Bart Currie recalled an older Indigenous man who had a chronic illness, who was an inpatient at the time when the ROTI Act was current. This man, although a resident of Darwin, originated from a remote community, where his grandparents had given him 'first hand' accounts of massacres of Aboriginal people by white people. Dr. Currie noticed during a ward round that this man seemed extremely nervous and agitated. Dr. Currie then returned to speak to the him privately. Although this man was a strong Aboriginal Elder, he then dissolved into tears and cried. He was frightened, and was afraid that he would be killed under ROTI.

Understandably, the relatively recent tribal history of suffering and death at the hands of the white settlers had given rise to the fear of extermination by euthanasia, . Dr. Bart Currie needed to sit for a long time while he attempted to calm the man's fears. (NB. Dr, Bart Currie would welcome any inquiries from the Committee regarding this case, or his other experiences during the ROTI period.

Dr. Currie's email:

<u>(3)</u> ***I wish to refer to the Senate Legal and Constitutional Legislation Committee's report on the Euthanasia Laws Bill***
http://www.aph.gov.au/senate/committee/legcon_ctte/completed_inquiries/1996-1999/euthanasia/report/report.pdf which says:

5.19 Mr Mackinolty gave evidence that he was confident that most of the 800 Aborigines who attended the green Ant education sessions understood that euthanasia was voluntary.

However, even though he personally supported his own right to euthanasia as a non-Aboriginal, his experience in conducting the education campaign had brought him to favour the repeal of the ROTI Act because of its potential to deter Aboriginal people from seeking prompt medical attention.

Mackinolty was contracted by NT Health Services to run an education program on the ROTI Act in Aboriginal communities.

The following passage is also relevant:

5.28 The only positive evidence of misinformation which was provided to the Committee was that certain Aboriginal Communities have been told that euthanasia could only occur in Darwin so as to put them at ease in using local health clinics. Evidence was provided from Papunya Community via Alice Springs that these statements had been provided by local doctors:

The doctor here told us it was OK and that the clinic would never have the needle like that available. We were told Alice Springs would not have it either. Only in Darwin. But a lot of people are still a bit scared.(27)

5.29 It was also stated by Valda Shannon of the Julalikari Council who acted as the interpreter for Chips Mackinolty during the Green Ant Consultations in Tenant Creek: We had to tell people that at Tenant Creek hospital and at Alice Springs hospital nothing like this could ever happen. Because we did not want people to decide that they were not safe at these hospitals. We had to tell them that it was only available at Darwin.(28)

5.30 It is appreciated that this misinformation about the operation of the legislation was provided so as to encourage people to feel safe utilizing local health services. However, a question arises as to whether this may pose dangers for the future if there is a death in accordance with the ROTI Act at Alice Springs.

<u>Additional Information and comments from Dr. David Gawler</u>

In regard to the Green Ant Education Sessions I would say two things:-

(1) (a) A sample of 800 is quite small and not necessarily representative, especially if drawn from one localized area.

(b) Even if Mr. Mackinolty and his team thought that they had allayed fear (even by misinforming people that euthanasia would never occur in AliceSprings), one must question the quality and certainty of communication.

I have observed many instances where doctors, myself included, believed that we had adequately communicated with indigenous people via an interpreter, when it later became apparent, that such was not the case.

(c) Mr. Mackinolty's experience persuaded him to support the repeal of the ROTI Act even though he would have personally preferred to have euthanasia available to himself. Clearly, he recognized that Indigenous people were at risk and thus were disadvantaged by the ROTI Act.

(2)The Northern Territory Health Department statistics reportedly did not show a decline in numbers of clinic consultations or hospital admissions. However, one must consider the following facts:

(a) The Royal Darwin Hospital is virtually always 100% occupied and in addition there are usually people waiting for elective and acute beds Therefore if a number of indigenous people deferred or refused admission to hospital beds, then the occupancy statistics would not alter.

(b) It is commonly believed that the statistics of some remote clinic attendances were less than accurate and reliable at that time, especially prior to computerization. One Senior Physician who was present during the ROTI era, said that the Health Department could not have had reliable figures at that time and would have estimated the numbers.

(c) Remote Indigenous people only attend clinics when they are very ill indeed. Consequently, they may have reasoned that if they didn't attend, they would probably die and that it was worth risking the hazards of the ROTI Act, by seeking medical help. People may also have been given misinformation to allay their fears. Hence clinic and hospital attendances may not have been noticeably affected.

N.B. It is however, impossible to quantify the numbers of people who decided NOT to attend a clinic or hospital because of the ROTI Act while it was potent.

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***(4)** I would also like to direct the Committee to the comments of the Director of Palliative Care at the Royal Darwin Hospital, Dr. Mark Boughey to the Committee on Monday, April, 14, 2008.*

Dr. Boughey- …………..I guess today I am really talking about a personal reflection of working in the Territory over the last three and a half years, coming from Victoria and having been a palliative care physician for about 18 years, and really coming to terms with the legacy that the six-month period of the activation of the original euthanasia bill is still having, I believe, in the Territory. I think it is a timely reminder as to the sort of double effect……….that repealing the Commonwealth law is going to have in reactivating the Territory's laws.

…………It is important to understand that a lot of fear is expressed by patients coming to palliative care that somehow we are going to be involved in euthanasing them. It is not a view that is commonly known, but is certainly a view such that, time and time again, we have to speak to patients, reassure them and give promises that palliative care is not part of the euthanasia process, that there is not some sort of subversive, covert operation. This has particularly been highlighted in the last two and a half years since we opened the Darwin hospice………..It is quite a common theme that we have to talk to people about before they come to the hospice so that they will even accept palliative care services in the community or accept admission to the hospice. It is also important that this often can delay engagement of palliative care services and optimum management of symptoms, which are pain and so forth.

…………Interestingly, in that project (*Indigenous model of palliative care*) we did, time and time again people who could remember back to the days of 1995 or 1996 would reflect on that process. Even with regard to palliative care services getting engaged with Indigenous patients, we spend a lot of time educating health workers and community people to dissipate some of the fears around death and dying, but still the current theme is that any intervention that is perceived as acting towards assisting the dying has negative consequences in terms of the bereavement period and so forth.

…………….From talking to staff that were present at the time (*1996),* I know of the amount of scrutiny and stress- being emotional stress- that staff who were working in palliative care came under during that period and after………But when I was talking to people at this time, I noted – …….there was a real sense that there was a burden of scrutiny due to – and there was chaos in which they were working due to – fearful Territorians, who thought that somehow they were going to be covertly euthanased; euthanasia tourists who moved up here from interstate and placed further demands; the accountability that was imposed on them through the Territory Government; and certainly overt media scrutiny as well. There was quite a lot of covert media scrutiny, with a lot of people posing as family, staff and so forth to try to get information about patients. These are stories that I heard from the original staff in the last few days.

Senator Bartlett – Dr. Boughey, I just want to clarify something. From what you have said, my impression is that this concern people have about entering palliative care and fear about ending up in a euthanasia situation is more emphasized in Darwin since you have come here. Is that right?

Dr. Boughey – I think it is certainly more emphasized.   I was head of palliative care at the Royal Melbourne Hospital in Victoria for about 13 years.   …….Rarely would people associate palliative care with euthanasia…………
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I wish to thank the Committee for this opportunity to respond to Senator Brown's Questions On Notice.

Yours faithfully,

Dr. David M. Gawler MB BS, FRACS, FRCS (Eng.), FRCS (Glasg.) FICS.