

1 ROYAL COMMISSION OF INQUIRY  
2 ON GENETIC MODIFICATION  
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8 Commission: Sir Thomas Eichelbaum (Chair)  
9 The Rt Rev Richard Randerson  
10 Dr Jean S Fleming  
11 Dr Jacqueline S Te M Allan  
12

13  
14 Mr Upton, Counsel  
15 Assisting the Commission  
16

17  
18 Ms Therese McLeod (Clerk)  
19  
20

21  
22 Stenographer: Ms Rawinia Hauraki  
23

24 Scopist: Mrs Sharlene Pilkinton  
25

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27  
28 Venue: 11th Floor  
29 Dalmuir House  
30 114 The Terrace  
31 Wellington  
32 NEW ZEALAND  
33

34 Date: 22 February 2001  
35

36 Commencing: 9.30am  
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1 PRESENTATION BY THE QUAKER SPIRITUAL ECOLOGY GROUP OF THE RELIGIOUS  
2 SOCIETY OF FRIENDS AOTEAROA NEW ZEALAND TE HAAHI TUUHAWIRI  
3  
4

5 CHAIR: Good morning. Would you be good enough to tell us your names  
6 so we can get a note of you?  
7

8 JOCELYN THORNTON: Jocelyn Thornton.  
9

10 BARBARA MOUNTIER: Barbara Mountier.  
11

12 HILDA DAW: Hilda Daw.  
13

14 ANNE MEULI: Anne Meuli.  
15

16 JOANNA PAUL: Joanna Paul.  
17

18 PETER HARRISON: Peter Harrison.  
19

20 CHAIR: Yes, thank thank you very much. Now, who is going to -  
21 you're a witness, Mr Harrison ?  
22

23 PETER HARRISON: I'm a witness.  
24

25 CHAIR: And who's going to speak or introduce the submission?  
26

27 JOCELYN THORNTON: I will be.  
28

29 CHAIR: Well, we're looking forward to hearing you.  
30

31 JOCELYN THORNTON: We are grateful for the opportunity to bring our  
32 concerns to you in person. We invite everyone present to join us in  
33 a short silence which is our Quaker way of acknowledging a power  
34 greater than ourselves.  
35

36 [Silence observed for half a minute]  
37  
38

39 HILDA DAW: Thank you. I would like to read from the Quaker book  
40 "Advice and Queries", section 42. "We do not own the world and its  
41 riches are not ours to dispose of at will. Show a loving  
42 consideration for all creatures and seek to maintain the beauty and  
43 variety of the world. Work to ensure that our increasing power over  
44 nature is used responsibly with reverence for life. Rejoice in the  
45 splendor of God's continuing creation".  
46

47 JOCELYN THORNTON: We have a great love and appreciation of nature and  
48 a passionate concern that she is not despoiled, that she must not be  
49 despoiled by genetic modification.  
50

1 The wonder of nature is captured beautifully in this little poem, it  
2 is called, "On a Seed".

3  
4 "For this was the goal of the leaf and root. For this did the  
5 blossom burn its hour. This little seed is the ultimate fruit.  
6 This is the awesome vessel of power. For this is the source of the  
7 root and bud. World unto world unto world remoulded. This is the  
8 seed compact of God wherein all mystery is enfolded".

9  
10 ANNE MEULI: Quaker thought on the unity of creation was expressed by  
11 John Woolman, an American Quaker, in 1772. He states, "The produce  
12 of the earth is a gift from our gracious creator to the inhabitants  
13 and to impoverish the earth now to support outward greatness appears  
14 to be an injury to the succeeding age".

15  
16 BARBARA MOUNTIER: We wish to present our statement about the  
17 sacredness of life. We, in the religious society of friends, known  
18 as Quakers, represent a spiritual tradition that finds special value  
19 in the individual experience of people, and special importance in an  
20 attitude of respect for life. This has led us into principled  
21 action to promote integrity, peace, equity and justice in the world.

22  
23 JOCELYN THORNTON: Within life we see an intrinsic sacred quality.  
24 Life demonstrates self-organising, self-repairing qualities;  
25 creativity, inherent wisdom and intelligence. Such a wonder calls  
26 for humility, respect and reverence.

27  
28 Nature is the provider and foundation of life. Therefore, we are  
29 accountable to nature in whatever we do. A deeper understanding of  
30 ecology and of ourselves increases our respect and reverence for  
31 nature and the earth.

32  
33 HILDA DAW: We are marched through nature and remain embedded in this  
34 living system. All life has gone before us - all life that has gone  
35 before us is a prerequisite for our existence. Humankind is not the  
36 specie to whom all others are subservient, but one among many. All  
37 parts are inextricably intertwined. We are connected to every  
38 tissue and fibre of the universe. Whatever we do to the world we do  
39 also to ourselves.

40  
41 [Jocelyn, Barbara and Peter present a timeline with markings on it]

42  
43 JOCELYN THORNTON: This is a timeline based on accepted scientific  
44 theory as described by Lynn Margulis and Dorion Sgan in their book  
45 "What Is Life?", published in 1995. We are presenting it to help  
46 show the enormous amount of time that's gone by, and the amazing  
47 development of life forms before the human species appeared on  
48 earth. This timeline is made to scale and is three and a half  
49 metres long. It represents 4.6 billion years.

50

1 Here at the beginning, 4.6 billion years ago, the earth was born and  
2 began cooling. 3.8 billion years ago life first appeared, and  
3 established as single celled bacteria called prokaryotes. Did you  
4 know that for 2 billion years the prokaryotes were the only form of  
5 life on earth? In that time they transformed the earth's surface  
6 and atmosphere and created virtually all of life's chemical systems  
7 in miniature.

8  
9 I'll mention two of these. One is photosynthesis. It's a very  
10 important innovation, it's a way of making food from the sun's  
11 energy, of which now provides a food base for most of the biosphere,  
12 including our own species.

13  
14 Also, when oxygen was building up to dangerous levels, prokaryotes  
15 invented a way of using it for energy and food metabolism. This  
16 saved the planet from being destroyed in a gigantic conflagration.

17  
18 Their clever creation is now, through the process of symbiosis in  
19 every cell of our bodies as mitochondria so that we too can make  
20 energy from oxygen. These are examples of how all life is  
21 interwoven.

22  
23 Human life was made possible only by the action of other organisms  
24 in the past.

25  
26 Eventually many life forms started evolving, and finally, in this  
27 last half centimetre, the human species appeared. The time since  
28 the introduction of the technique of genetic engineering would be  
29 represented by the thinnest of lines possible, just a flash.

30  
31 The human species has had absolutely nothing to do with the  
32 evolution of this marvellous world. Therefore, how could we  
33 possibly claim the right to release into it genetically modified  
34 organisms that are unpredictable, irreversible, and almost certainly  
35 damaging?

36  
37 We believe that humans do not have the right to put at risk the  
38 interweaving ecosystems of our amazing creative intelligent living  
39 planet.

40  
41 [Presenters take a position at the table]

42  
43 JOANNA PAUL: We base our concerns about genetic modification on the  
44 spiritual and ecological understanding that all life is sacred and  
45 that all life forms are interdependent and interconnected. The  
46 coherence of the biosphere is complex and precious. Maintaining  
47 biodiversity and integrity is vital to keep the whole imbalance.

48  
49 Increasingly, Quakers recognise that we rely physically and  
50 spiritually upon earth's biological systems. Life in all its forms

1 and the processes by which the whole complex web of life evolved,  
2 shows extraordinarily subtlety and intricacy of the - there is a  
3 complex coherence in the genome of each individual species that is  
4 far beyond our present understanding.

5

6 Because GM intervenes in these very processes and because genetic  
7 modification can have unpredictable results, the Precautionary  
8 Principle must rule.

9

10 BARBARA MOUNTIER: Our commitment to the sacredness of life gives rise  
11 to the following points on patenting. We believe the concept of  
12 patenting or ownership of life forms is intrinsically unethical.

13

14 On biodiversity: Genetic modification threatens biodiversity which  
15 is vital for the sustainability of life on earth.

16

17 On organic production and supply: Genetically modified crops  
18 threaten organic production in New Zealand with extinction.

19

20 On claims to solve world hunger through genetic modification: We  
21 reject the claims of GM producers to solve world hunger as unethical  
22 and misleading.

23

24 On democratic and human rights: The New Zealand Bill of Rights of  
25 1990 is compromised by the introduction of GM foods and products.  
26 It states that every person has the right not to be subjected to  
27 medical, or scientific experimentation without that person's  
28 consent.

29

30 On the priority of the public good: The wider public good must take  
31 priority over the interests of those who make money from GM  
32 technologies.

33

34 ANNE MEULI: For these reasons, therefore, our recommendations are as  
35 follows:

36

37 1. New Zealand should not proceed with growing GM crops.

38

39 2. New Zealand should refuse to allow or to acknowledge patenting  
40 of GM life forms.

41

42 3. New Zealand's best option is to engage in organic production.

43

44 4. Biomedical GM technology, if it must be pursued, should be  
45 rigorously monitored by an impartial body. This body should be  
46 independently funded and provide information for public debate. We  
47 believe legislation should be put in place to:

48

49 i. Keep New Zealand free from GM crops.

50

- 1 ii. Support a complete ban of GM food and food products.
- 2
- 3 iii. Address the Australia/New Zealand Food Authority's conflicting
- 4 objectives in the areas of health and trade.
- 5
- 6 iv. Confine GM biomedical research to independently rigorously
- 7 monitored and specified Government supervised laboratories.
- 8
- 9 v. Revoke any current legislation which allows patenting of GM
- 10 forms - life forms, sorry.
- 11

12 JOANNA PAUL: At this point we would like to offer a reflection on  
13 ethics. During the hearings of the Royal Commission so far  
14 Bishop Randerson has repeatedly asked, "What are the ethical  
15 questions here? Is there an ethical guide for the environment?"  
16 This can and has been answered by the words "do no harm". Taken  
17 seriously, the Hippocratic Oath could transform science.

18  
19 GM has already increased astronomically the numbers of experiments  
20 with animals. There have been official attempts to register numbers  
21 and to grade the sufferings of animals, this remains mere lab  
22 sociology unless we critique these practices.

23  
24 The radical alteration of the physiology of an animal should be seen  
25 as intolerable.

26  
27 An ethical question here is: Is knowledge acquired at too high a  
28 price? Sheep are knowingly being made defective and the immune  
29 system of mice have been supplanted by human ones, a human one in  
30 order for them to be infected with purely human diseases, and the  
31 knowledge gained is offered as the only rationale. We would not  
32 accept this excuse if small boys were to tear the wings from birds.

33  
34 When we interfere with the nature of an organism, whether microbe or  
35 mouse, we are teasing and muddling the complex links of a symbiotic  
36 universe. So, should we damage the earth and its creatures beyond  
37 their mechanisms of repair. Sound science and a religious reverence  
38 for creation are here at one.

39  
40 So, to summarise our ethical concerns, they are contempt for nature,  
41 cruelty, recklessness, and what the classical world called hubris,  
42 an overstepping the mark and what it means to be human.

43  
44 Our concerns echo Maori concerns of whakapapa, mauri, and the net of  
45 life. We fully sympathise with Ngati Wairere about the experiments  
46 on sheep and cows on their ancestral land.

47  
48 There is another issue here dear to Quakers who have a tradition of  
49 speaking truth to power: honesty. That golden rice is beneficial to  
50 the Third World is a surrogate truth, just as GM food is surrogate

1 food.

2

3 It is as if science now is in the business of converting fact to  
4 fiction and destroying the very subject of the scientist's scrutiny.

5

6 Even where intentions are good, harm can be done. Hubris is always  
7 followed by nemesis.

8

9 Ethics needs to enlarge its scope to look at ecological  
10 transgression, to affirm the goodness of the universe and enshrine  
11 compassion for all creatures.

12

13 BARBARA MOUNTIER: In closing, we are appalled at the prospect of  
14 endless numbers of living things being tampered with by enthusiastic  
15 biotech scientists and commercial companies.

16

17 We, in New Zealand, have destroyed and contaminated too much of our  
18 country in the past while pleading innocence of damage. This time  
19 we know that the consequences of releasing GMOs into our environment  
20 are beyond our control.

21

22 JOCELYN THORNTON: We are speaking to you on behalf of our  
23 grandchildren and your grandchildren, and of all future generations.  
24 New Zealand, as an island nation, has the opportunity to lead the  
25 world in becoming free of GM contamination.

26

27 Therefore, we ask you Commissioners, to recommend to the Government  
28 that New Zealand remain free of GM crops. And, as an alternative,  
29 promotes organic agriculture and horticulture in a unique trading  
30 opportunity which is sustainable and does not cost the earth.

31

32 As we observe a short closing silence, we invite you to reflect on  
33 the effects of our choices on the future of our nation, our  
34 grandchildren and their children.

35

36 [Silence observed for 50 seconds]

37

38 JOCELYN THORNTON: Thank you

39

40 PETER HARRISON: Members of the Commission. This oral submission is  
41 not so much an expansion of my written submission as a collection of  
42 observations prompted by information gathered during the course of  
43 this hearing.

44

45 The essence of my submission is that ethical considerations must  
46 take precedence over all other aspects. No temporary national  
47 advantage should be tolerated if it involves having part in a scheme  
48 of things that seriously threatens the complex web of life on the  
49 planet. The fast pace of science and technology has out-stripped  
50 ethics in a way that is endangering all of life. This is the

1 context in which the matters before the Commission must be  
2 considered.

3  
4 I will not attempt to bring scientific or other expert evidence.  
5 The Commission will have heard sufficient of this. I regard what  
6 mankind is doing in endangering the entire fabric of life on this  
7 planet, as perhaps the most serious challenge which humans as a  
8 species face. If we fail to collectively address our priorities,  
9 then it is likely we humans will rapidly join that vast array of  
10 species whose extinction we have already caused. This, I believe,  
11 is a view held by a significant number of leading scientists and  
12 philosophers of the modern era.

13  
14 This hearing was set up to make recommendations to the Government of  
15 this country, but it has potential to affect, in some degree, all  
16 future generations worldwide. We might not have wished for this  
17 responsibility, but I believe it exists, and it requires wisdom to  
18 face it.

19  
20 I wish to focus on the commercial greed that is driving the GM gold  
21 rush, and on the associated disregard of basic ethics.

22  
23 What is at stake is not just commercial advantage or hunger or  
24 health, but the future of our planet, and a future for our  
25 children's children. I say this not only because of the unknown  
26 risks and adverse outcomes from GM but also from the enormous surge  
27 of corporate power which GM adds to a world already torn and wracked  
28 by obsessive competition for control.

29  
30 The power I speak of is not that of Governments but of corporations  
31 vying for control of the world's resources, in food, in fuel, in  
32 minerals, fresh water, armament and human resources, and now in  
33 genetic diversity. These systems are driven ultimately not by the  
34 objective of improved welfare, but by the relentless pressure of  
35 competition.

36  
37 In the past century we have witnessed what in cosmic terms is a  
38 sudden and possibly catastrophic imbalance. We are experiencing an  
39 explosion of human population, massive extinction, destruction of  
40 forests, poisoning of the environment, and global warming. These  
41 demonstrate the recklessness of human ingenuity. Into this sea we  
42 add GM. This global process is totally relevant to the enquiry.  
43 What is the point in competing in a race that is likely to end in  
44 widespread disaster? Ethical questions relating to this situation  
45 must override all short-term economic or political considerations.

46  
47 We should learn from the pattern of mistakes of our own country.  
48 New Zealand became a brave leader in "Think Big" projects, in  
49 privatisation and world free trade politics. The promises were  
50 efficiency, reduced costs and trickled-down benefits. The result is

1 increased national debt, foreign control, increased wealth for the  
2 top 10%, and financial struggles for the rest of us. Our  
3 universities, our media, our Government, are all more or less in the  
4 hands of global power brokers.

5  
6 In the global scene it is well-known that there is enough food for  
7 all, but the trans-national corporations, which I will refer to as  
8 TNCs, are instrumental in destroying local cultures, exploiting food  
9 production and mineral resources, and leaving countries with less  
10 food, unmanageable debt and subservient to foreign masters. The  
11 Commission has heard evidence that GM gives more power to the  
12 powerful and exacerbates the helplessness of the underprivileged.

13  
14 My concern is not directed against scientific research or against  
15 technology, it is against the headlong rush to apply biotechnology  
16 for commercial gain. Claims of benefits for humanity have often  
17 shown up to be brazen window-dressing.

18  
19 The driving power in all this is not attributable to any single  
20 person or any group, but rather to systems collectively created by  
21 the western world. TNCs are more powerful than any Government or  
22 any individual. They are driven by the least admirable of human  
23 traits: power, control and domination. It is relevant to this  
24 Inquiry that these are the systems competing in the GM gold rush.  
25 The most powerful nation on earth today is not able to stop for fear  
26 of losing its supremacy. Global power has higher priority than the  
27 fate of the planet.

28  
29 Research as to the dangers of GM are underfunded. The privately  
30 funded proponents of GM do not want this research, and it is far  
31 beyond the resources of Government or private research.

32  
33 I wish to speak about benefits and risks.

34  
35 I submit that GM has a level of risk and unpredictability which is  
36 far greater than is acknowledged by those in favour of this  
37 technology, and that there exists a campaign to influence  
38 authorities and public opinion in favour of accepting GM by  
39 down-playing and by trivialising and by discrediting the risks.  
40 People like Dr Pusztai, who are qualified and motivated and free to  
41 express accredited concern, are an endangered species.

42  
43 I don't have a problem with intelligent life striving to understand  
44 the building blocks of their own existence, it is just that this has  
45 come about at a time when humanity is swamped in a dominant culture  
46 of commerce and greed. The combination is proving to be toxic, if  
47 not lethal to life. If you want facts, then this is basic fact  
48 which we ignore to our peril. This fact is substantial, if rather  
49 difficult to quantify. It is undeniable that within this mindset  
50 humanity has, along with the acclaimed benefits, destroyed 50% of

1 the earth's topsoil, fuelled global warming, caused an appalling  
2 level of extinction, and created perilous biosphere imbalance.

3  
4 Scientists of high repute have challenged that opposition to GM is  
5 not based on fact. I wish to spend a little time on this question  
6 of fact and proof.

7  
8 It is characteristic of new developments, such as GM, that benefits  
9 are readily identified. We have all heard of the increased yields,  
10 reduced pesticide demand, increased vitamins, longer shelf-life,  
11 medicinal prospects and deliverance from hereditary scourges. All  
12 of which, taken on their own, seem to make the restriction of GM a  
13 crime against humanity.

14  
15 The case for precaution is by its very nature much more difficult to  
16 prove because it rests to a large extent on what is as yet unknown,  
17 on hunches, on intuition, on parallels, on forecasts, on what is yet  
18 to show up, but also on significant instances of worrying scientific  
19 reports.

20  
21 While it is possible to imagine a wide range of benefits from  
22 biotech, it is also possible to imagine adverse outcomes that far  
23 outweigh any conceivable benefit. What protection is there against  
24 such outcomes? The greatest danger of GM lies in the determination  
25 of its proponents to aggressively dismiss evidence which calls for  
26 caution, or which threatens their objective. Therefore, the  
27 Commission would be failing in its duty if it restricted its  
28 interest to what can be proven.

29  
30 GM is being touted as solving many of the problems extant in  
31 civilisation, but can we trust the system which created the problem  
32 to find the solution? To do so is to further strengthen the system;  
33 this is just what it thrives on. I put the case, that we do not  
34 have a warrant to look for deliverance toward the system which has  
35 enslaved us. Science as a profession has lost the independence and  
36 objectivity which in the past could be more or less relied on for  
37 the welfare and protection of humanity.

38  
39 One most significant fact to emerge from this Inquiry is the  
40 unreliability of so-called scientific fact.

41  
42 I submit to this Commission that risk assessment in the area of GM  
43 is so undeveloped, so untested, as to be valueless. There is no way  
44 in which risks which will exist in perpetuity, however minimal, can  
45 be reliably balanced against perceived immediate gains.

46  
47 While on the topic of risks, I wish to mention that I have attended  
48 public meetings where respected scientists have campaigned that GM  
49 is substantially equivalent to traditional breeding, with the  
50 advantage of being more precise. The audience seemed to be

1 persuaded. Scientific evidence received later indicates that this  
2 claim is a misleading simplification.

3  
4 One lesson from this is that partially informed public opinion is  
5 not something which can be relied on in the matter of GM. I wish at  
6 this point to make a recommendation; that reliable sampling of  
7 public opinion could only be trusted in a situation where a  
8 representative sample of the public were selected to hear all the  
9 available facts before being asked for a judgment. Something  
10 equivalent to a jury system.

11  
12 I invite the Commission to consider this and to make a  
13 recommendation to the Government along these lines in the event that  
14 the Government wish to appeal to public opinion.

15  
16 I wish now to speak about GM and human health and well-being.

17  
18 Human health is not something that exists in isolation. It is  
19 intimately connected to our environment, "Good health comes from the  
20 soil".

21  
22 Our dominating and disrespectful attitude toward nature, towards the  
23 earth, is the cause of a whole catalogue of illnesses peculiar to  
24 our day. Yes, we have conquered some major scourges through  
25 technology, but the swing to dependence on technology is creating  
26 new scourges, the worst of which are predicted to emerge. But  
27 commercially driven health providers find much higher profits in  
28 providing cures for ill health than in addressing its causes. In  
29 this lies a rather insidious pattern where technology generates  
30 dependence on its systems, at the same time alienating us from our 4  
31 billion years of heritage. This is unethical, unsafe, unnecessary.

32  
33 Every technological solution prizes us away from our earth  
34 ground-base. In doing so it creates new problems, for instance  
35 antibiotic resistant pathogens, for which technology is only too  
36 willing to provide ever more sophisticated remedies, and so on. It  
37 usually takes a generation or more to see the full range of effects.

38  
39 Pessimism? No, realism. A discerning look at the facts shows that  
40 optimism based on scientific hopes have not been fulfilled due to a  
41 failure to acknowledge the affront to nature on the one hand and the  
42 significance of perversity on the other.

43  
44 Power systems are hijacking society away from a true future in which  
45 we discover what it means to be human, to be earthlings; the  
46 enormous potential from which we have been deceptively diverted.  
47 Instead we are racing down uncharted territory of increasing  
48 technology along with alienation from abuse of that which has  
49 nurtured us until now. A pattern of "power over", rather than  
50 "power with".

1

2 The dismissive attitude on the part of pro-GM agencies towards  
3 concerns expressed as to risks should be a red light to the  
4 Commission. If the experimental results as to Dr Pusztai's research  
5 are as yet inconclusive, for reasons made clear to this Commission,  
6 the "steam hammer" reaction from the heavies sends an unambiguous  
7 message.

8

9 I wish to speak specific as to ethics.

10

11 Ethics is firmly based on the understanding that one's own happiness  
12 can never be at the expense of someone else's. Such happiness is  
13 not genuine, nor can it be long lived. It is the transgression of  
14 this basic concept which is destroying the world, empowering the  
15 greedy, and driving the GM gold rush.

16

17 Way back in 1947 C S Lewis in his book "The Abolition of Man",  
18 wrote, "Man's power over nature turns out to be power exercised by  
19 some men over other men, with nature as its instrument - each new  
20 power won by man is power over man as well". I suggest that this is  
21 exemplified today in GM technology.

22

23 Some aspects we must face are: GM objectifies all life forms. It is  
24 the beginning of a new level of control over nature. Can we imagine  
25 where this will lead?

26

27 All life is susceptible to manipulation. Who will define the  
28 limits?

29

30 Does GM have any potential for biochemical warfare? If so, then can  
31 we be assure it will not eventually be used in that way?

32

33 GM is not an issue of freedom of choice, since all of humanity are  
34 affected by the outcomes of the choices of a very small group.

35

36 The whole scientific focus, and in particular the gene scene, would  
37 be very different today if there were not enormous power and profits  
38 at stake.

39

40 We are talking about systems where ruthlessness is a treasured  
41 quality.

42

43 No-one in their right mind would advocate on the basis of benefit to  
44 humanity; a herbicide resistant canola, knowing that it could become  
45 a serious weed and pass on its herbicide resistance to related  
46 species. However, it seems somehow acceptable for this to be done  
47 on the basis of commercial rights. To my mind, this is a crime.

48

49 One wonders whether there has been a deliberate strategy to  
50 infiltrate field experiments with GM crops in all parts of the globe

1 so that no country can claim to be GM free.

2

3 Science must be freed from the imperatives of corporate profit.  
4 Until that happens, we must act drastically for our collective  
5 safety. You might note that I changed that word from - what I  
6 originally had was "salvation", a good old fashioned word I changed  
7 under peer pressure. But, I rather like the idea of giving a new  
8 meaning to that word "salvation".

9

10 The concept of "agreed relinquishment" might govern the world until  
11 ethics recovers its leading role. That concept of agreed  
12 relinquishment is one that's been suggested by a leading scientist,  
13 and I think is a valuable one.

14

15 I wish to make a plea for sanity. The pace of development in GM is  
16 frenetic and headlong. There is something reckless and frightening  
17 about the intensity, the behaviour the persuasiveness which calls  
18 for a red alert for drastic action. Some country needs to nail its  
19 colours to the mast on this issue. Commercial and political issues  
20 must take second place in a situation where nations combine on a  
21 reckless course which has a powerful potential for unimaginable  
22 global disaster.

23

24 Our responsibility, our challenge, is to do this within a populous  
25 already numbed by a feeling of helplessness, in a world only a hair  
26 trigger away from nuclear holocaust, biological genocide or  
27 ecological collapse. A response by this Commission and this  
28 Government to act responsibly on the side of potential has potential  
29 to instill a new hope and vitality into this nation and into a  
30 debilitated world.

31

32 We are being ushered into a world which, if it were given the  
33 opportunity, we never would have chosen. This Commission has a rare  
34 opportunity under the heading of ethics to make a well informed  
35 statement on an issue of paramount importance to humanity.

36

37 For more than a century we have been warned about pollution and  
38 climate changes, more than half a century, we have been warned about  
39 pollution and climate change. The probability of catastrophe has  
40 been acknowledged for decades, yet there is no overall reduction in  
41 causal pollution. This exemplifies the hopelessly inadequate  
42 controls globally over potentially devastating technologies.

43

44 Environmental degradation and species extinction both advance  
45 unabated along with our pervading trust in science and increasing  
46 dependence on technology.

47

48 Science and technologies don't have to be dangerous but the reality  
49 is that money spent daily on armament, that is destructive power,  
50 would solve the world's food shortages for a year.

1

2 Mankind's premature demise may be inevitable unless we heed the  
3 wisdom bequeathed to us.

4

5 What is needed is that a stand be taken, a visible turning point,  
6 the embrace of new but old values which will enable humanity to  
7 safely achieve its potential. To add GM to the existing system, or  
8 to sanction what is already underway, is to fuel what is already  
9 well on the way to destroying civilisation and countless eons of  
10 evolution.

11

12 I wish to speak about alternatives and futures.

13

14 It would be presumptuous of me to claim to have the answer for  
15 humanity's future, but I appeal to this Commission that this  
16 question should not be ignored. All I can say at this point is that  
17 intelligence is one thing, wisdom is another. It is wisdom that is  
18 needed. The wisdom needed exists and is available.

19

20 We can only learn an alternative future by stepping out in another  
21 direction.

22

23 I am concerned that decisions made now, which are in the context of  
24 the existing unsustainable order, will make it so much harder to  
25 reach toward where we ought to be in the coming age. Our spiritual  
26 potential is emerging, but it depends in part on a living  
27 environment which is being whittled away by persistence of the  
28 passing order.

29

30 It amounts to a call for a new moral, spiritual, ecological,  
31 consciousness, one with profound implication, not just for biotech  
32 but for our economic and political systems as well. In order to  
33 handle technology as powerful as genetic modification, we humans  
34 need to be far more compassionate and wise than we currently give  
35 evidence of being. Ultimately, if we as a society wish to employ  
36 some forms of genetic technology for truly beneficial purposes, we  
37 must begin not with the technology itself but with an ethical  
38 reappraisal and reform of our collective institutions and  
39 priorities.

40

41 New Zealand has a very special role to play in this world's drama.  
42 A unique environment, physical isolation, moderate population, and  
43 relatively free from external pressures. New Zealand, though small,  
44 is ideally placed to insist on a precautionary stand while nurturing  
45 sustainable alternatives. For New Zealand to become an experimental  
46 plot for GM would be a tragic loss.

47

48 In closing. Our own country bears the name of being linked with  
49 USA, Canada and Australia in opposing The Hague last year the plans  
50 for curtailing global greenhouse emissions. Also in Tehran, August

1 last year, the same group of four countries were key figures in  
2 threatening the future of the global bank of genetic resources of  
3 food plants. These facts are reported in the New Scientist,  
4 16 December 2000 in an Article headlined, "Sold To the Highest  
5 Bidder". The article illustrates the driving forces and outcomes  
6 and the light in which this country is seen.

7  
8 The focus is now on New Zealand as to the outcome of this  
9 Commission. We appeal to you to give prime consideration to the  
10 contextual aspects, the difficult but challenging questions, the  
11 broad issues, and to consider those aspects which are of positive  
12 value to ensure a safe and worthy future.

13  
14 We ask you to urgently counsel the Government to address those  
15 fundamental issues which make GM unsafe, an absolute prerequisite  
16 for any GM development. That the cost of not doing so is far  
17 greater than any short-term pain. New Zealand caused ripples around  
18 the world with its nuclear-free stance. We stand to demonstrate our  
19 integrity also in the GM issue.

20  
21 To summarise. It is irresponsible to condone the use of GM  
22 technology at this point in history insofar as GM is possibly the  
23 most powerful instrument ever to be in the hands of humanity.

24  
25 Risk assessment is insufficient to protect against adverse outcomes.

26  
27 No adequate controls exist, neither are there safe grounds for any  
28 to be established.

29  
30 GM is wanted for commercial advantage, but not needed for basic  
31 benefits.

32  
33 GM emerges as the play thing of systems which cannot be relied on to  
34 act for the good of humanity and the environment.

35  
36 The Precautionary Principle must be based on the premise that  
37 unexpected outcomes fatal to life are a reality.

38  
39 There are viable alternatives which are threatened by GM.  
40 Compromised outcomes would give no assurance. It seems that only a  
41 clear-cut outcome will be effective in guiding us safely into a  
42 progressive and sustainable future.

43  
44 In closing, I leave the Commission with a sobering challenge. It is  
45 not so much a question of whether New Zealand can survive without  
46 GM, but whether the earth will survive with it. Thank you.

47  
48 CHAIR: Just for the record, can you help us with a couple of your  
49 quotations? What does "JTLB" stand for please? Excuse my ignorance  
50 .

1

2 PETER HARRISON: I put those in really for my own benefit, but the  
3 book from which those are quoted is "Jung to Live by".

4

5 CHAIR: Thank you, and what is "CTB"?

6

7 PETER HARRISON: CDB was another interesting book called "Cloning the  
8 Buddha".

9

10 CHAIR: Now, Mr Forman, you want to ask some questions?

11

12 MR FORMAN: Yes, thank you.

13

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16

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[10.25am]

18

18 MR FORMAN: My name is John Forman, I represent two organisations. The  
19 first is Lysosomal Diseases New Zealand, which is an organisation to  
20 represent those families who are affected by lysosomal storage  
21 diseases, which is a group of very rare diseases. And secondly, the  
22 New Zealand Organisation for Rare Disorders, which is an umbrella  
23 group which is set up to represent the interests of the many many  
24 rare disease support groups that there are in New Zealand.

25

26

26 My first questions are about what was presented in writing, and I'll  
27 just state the question and invite anyone in the group to respond.  
28 In section B(J)(iv) number 1, headed "Reverence for Life", there's a  
29 sentence there which reads, "From cells to ecosystems we see a  
30 self-organising, self-repairing whole". I presume that because you  
31 are a group that has ecology very much in your title, that you're  
32 referring to the ecology of the planet rather than the health of  
33 individuals, because.

34

35

[Joanna Paul nods]

36

37

37 MR FORMAN: And you will agree that there are many things that we as  
38 humans have that does not require repairing, and requires some sort  
39 of intervention to correct them?

40

41

41 JOANNA PAUL: Yes, we're talking about the planet as a self-repairing  
42 whole by and large, though there's a point at which it may not be  
43 any longer able to repair itself. I think the only way, from the  
44 longest perspective, to look at rare diseases; to see them as part  
45 of the machinery of life, that I believe the computers that are  
46 recording the DNA in the genome are making mistakes at about the  
47 same rate as nature does. The little mistakes, which are huge if  
48 one happens to bear them in an intimate sense, are the condition of  
49 most of the time nature getting it right. This is an unsentimental  
50 view, but I think it is a realistic view. I think there are certain

1 conditions which it's probably impossible to correct.

2

3 MR FORMAN: Thank you. Well, if we then - this leads us then to how  
4 medicine is applied to improve human health and how GM technology  
5 may assist medicine. And, in your section A(1)(iv) you say that,  
6 "Claims about prospective medical benefits of GM technology need to  
7 be viewed with great caution". Now, is that saying that there must  
8 be caution about the application of this technology, or are you  
9 suggesting it is a basis for rejecting the technology?

10

11 JOANNA PAUL: I'll take this, and I hope that somebody else will also  
12 speak to this. I would think that, yes, caution but better still,  
13 agreed relinquishment. That is my instinctive feeling as a Quaker,  
14 though I have been associated with other churches in the past. One  
15 has to go by the inner light, and I feel such passionate distrust of  
16 genetic modification as a process, as a maverick process, that I  
17 think we should relinquish it.

18

19 Now, that distrust is being substantiated, I felt I needed to know  
20 in order to take an unpopular line, by the history of things like GM  
21 insulin and the Hepatitis B vaccine. It's been said that although  
22 pig insulin is difficult to tolerate for some people, it's in no way  
23 as difficult and as dangerous as human variety, and unsuspected  
24 comas, fatal accidents while driving are some of the consequences.

25

26 So, in all my research and reading and listening to people, I have  
27 not yet found any reason to trust GM.

28

29 MR FORMAN: I won't go down that particular track because the  
30 Commission has heard quite a bit of information about the insulin  
31 and Hepatitis and genetically modified alternatives to animal based  
32 products, and I think the information they have will suggest very  
33 strongly an alternative view to the one that I have just put  
34 forward. But I'll just come back to the question about, cautions of  
35 the claim about prospective alternatives. What I want to talk  
36 about, with alternative medicines the regulatory authorities already  
37 do exercise precaution. So, if someone says our product did do this  
38 or solve that problem or cure that disease, there is quite an  
39 extensive testing regime which requires them to prove that fact and  
40 to show that it works and that it is safe and that there is a regime  
41 about an appropriate dosage level which will not be harmful to  
42 people. That's the Medsafe and various other organisations which  
43 are in place for that purpose.

44

45 Would you find it acceptable to apply the same sort of rigorous  
46 testing regime to a medicine which comes from a genetically modified  
47 technology? In other words, if the safety can be proved, then it  
48 should be acceptable?

49

50 JOANNA PAUL: I'd like to take that in two parts. First of all, I

1 believe that in the last few years the standards for conventional  
2 medicine have relaxed extremely and that it's no longer requisite to  
3 do extensive trials that, applications for medical release are  
4 granted with the proviso that the trials have been done later,  
5 research later has discovered that in 90% of cases those follow-up  
6 trials have not been done. So, whether or not there's a GM lobby  
7 relaxing the laws, I don't know, haven't got anything to say about  
8 that. But I think that, okay, we can't particularly trust  
9 conventional medicine. Iatrogenic illness accounts for more loss of  
10 life in the United States than road accidents and murder, so I think  
11 Iatrogenic, doctor-generated, medicine-generated illness, would  
12 escalate with genetic modification.

13  
14 MR FORMAN: Is there anyone else on the panel who wishes to offer a  
15 view on this question?

16  
17 JOCELYN THORNTON: I would like to say that, it surely should be -  
18 can't be known that - the safety can't be known until there have  
19 been two or three generations. It seems as though the trials are  
20 very short and especially in the genetic modification there may be  
21 changes in the body that are not apparent for a long time.

22  
23 MR FORMAN: Perhaps it may it might pay to comment here that there are  
24 a number of families within our lysosomal group who are waiting  
25 extremely impatiently for the arrival of potential medicines for  
26 their disorders because regulatory authorities such as the  
27 United States Food and Drug Administration are continuing to insist  
28 on more and more trials, and the delays are put out by another year,  
29 then another year. So, our impression is that in fact that there is  
30 a very intensive testing regime which is in fact frustrating the  
31 arrival of these potentially beneficial medicines.

32  
33 But, having made that comment, I am trying to establish a point at  
34 which we may agree. That, you've said that you think that the  
35 medical research is okay if confined to laboratories and rigorously  
36 monitored. If we then get to the point where someone says, "I now  
37 have a product which we believe is safe", and it is tested to prove  
38 its safety, would you then think it quite appropriate that that  
39 product should be available? I guess in other words, I'm trying to  
40 find out whether your submission is arguing that there should be a  
41 ban on GM medicine or whether it is just an approach about caution  
42 and proof of safety before it is available, and release?

43  
44 JOANNA PAUL: I may note that there was a little clause tucked into  
45 our presentation which said that GM medical research, if it must be  
46 pursued, should be confined and so forth. So, we think - we agree,  
47 we have discussed this among ourselves, we do agree that it is too  
48 volatile, too maverick a technology, to be trusted.

49  
50 MR FORMAN: I then want to comment that, what was stated in your oral

1 presentations was stronger than what is contained in your written  
2 submissions, and I would perhaps have had fewer questions otherwise.  
3 Because, you made a number of statements about alteration of the  
4 physiology of animals to be unacceptable from an ethical point of  
5 view. And, also, that you were appalled at the prospect of living  
6 organisms being tampered with and, that was related back to an  
7 ethical argument.

8  
9 Could I put to you that, if tampering with the physiology of an  
10 animal, such as the insertion of a human gene in order to get the -  
11 that gene back out of that animal's milk, was proved to be an  
12 effective way of solving or curing a particular disease which had  
13 severe and possibly fatal consequences. Would you find it  
14 acceptable that that was done if issues relating to safety were  
15 established?

16  
17 JOANNA PAUL: I wouldn't.

18  
19 JOCELYN THORNTON: I have a problem because I see the very process of  
20 genetic modification as a transgression of nature. It's bulldozing,  
21 overcoming, violating nature's species boundaries and species  
22 integrity, and I can't believe that the right end will come from  
23 using the wrong means.

24  
25 JOANNA PAUL: I would agree.

26  
27 MR FORMAN: If we were to take that argument and apply it to what is  
28 current methods of research involving animals, there is a  
29 substantial use of animals, and some reference was made to it in  
30 your presentation; and the basic approach is that, you test on the  
31 animal to try and determine something which may be safe for  
32 application to humans, rather than start the testing on the human.

33  
34 And, there seems to be a contradiction there, if current research  
35 methods and ethics are acceptable, in saying that is these new  
36 methods would be unacceptable?

37  
38 JOANNA PAUL: There is a movement for medicine without animals, animal  
39 research. There was a convention in 1992 in Israel for that very  
40 purpose, looking at the possibility of science without animal  
41 suffering - without the use of animals, and I think there is still a  
42 movement in England that has that purpose.

43  
44 That being said, I think there are qualitative differences between  
45 trying something out on an animal - I mean, it seems a very crude  
46 way of finding whether that's going to work for a human being - I  
47 mean, we'll leave that aside. There's a qualitative difference  
48 between that kind of thing and actually un-mousing a mouse. You  
49 know, I think that to make something what it is not is a sin and a  
50 crime, you know. I think we have to regard the specificity of

1 things as a sacred trust, you know, this is a new language we have  
2 to talk because it's a new problem.

3

4 MR FORMAN: I guess that then raises the issue that, that type of  
5 activity, the production of transgenic animals for research, has  
6 been something which has been going on since it was possible to do  
7 it, I understand in a decade or two, I'm not sure of the date on  
8 which it first arrived. So, how do we balance the argument against  
9 the production of transgenic animals to derive pharmaceuticals from  
10 them, with the currently accepted practice of developing transgenic  
11 animals in order to do the research on the animal?

12

13 JOANNA PAUL: I don't think we - I mean, if we're not going to use it,  
14 why do it?

15

16 MR FORMAN: Well, I think there will be instances where we do use it.  
17 There are instances now where genetically modified medicines are  
18 available and are in use, besides the insulin and the Hepatitis ones  
19 that you referred to earlier. And, in the lysosomal group of  
20 disorders that we talked about, there is one which has been  
21 available for more than 10 years now which is effective, and there  
22 are several others which are about to arrive, some of which are  
23 derived from such processes, such as altering the genetic make up of  
24 a rabbit for example, and then by the insertion of a human gene, and  
25 then extracting the protein from the milk of the rabbit to apply it  
26 for medicinal purposes.

27

28 JOANNA PAUL: Oh, I just feel really distressed that we human beings  
29 have come to this.

30

31 JOCELYN THORNTON: I find it an object case of the rabbit, it's not -  
32 it's being exploited and its nature is being ignored for itself. I  
33 find it a very difficult concept.

34

35 MR FORMAN: If we look at it from an ethical point of view, and the  
36 choice was either to create a rabbit which is no doubt going to live  
37 the life of Reilly because it will be very precious and very well  
38 cared for, and the alternative was to sacrifice hundreds or  
39 thousands of rabbits or other animals in order to obtain stem cells  
40 or other cells from their ovaries or various other parts of the  
41 body. What choice would you make?

42

43 JOCELYN THORNTON: That's a very difficult question to be responsible  
44 for other's choices. I mean, if I had a lysosomal disease I might  
45 be in the position of looking for a cure too, but it's - I find  
46 this is a very difficult area. This is the most difficult area, I  
47 think, for me and for some of us to - it's so difficult to sort it  
48 out, but we do believe in the sacredness of nature. Now, how do you  
49 treat that which is sacred? Is the rabbit sacred? Is it right to  
50 alter its genetic make up for exploitation?

1

2 PETER HARRISON: I'd just like at this point to express sympathy for  
3 your concerns, that these are very real issues that you ask about,  
4 but the track record does leave room for a great deal of anxiety.  
5 And, I really think there is a need for an overall and major  
6 reappraisal of our whole attitude toward this field. That's a very  
7 broad and general statement and doesn't answer the specific things  
8 of your enquiry, but I think they've got to be looked at in that  
9 context.

10

11 JOANNA PAUL: I've heard from various sources that through gene  
12 therapy there have been a thousand things go wrong, I'm talking  
13 about somatic gene therapy here, you may be talking about something  
14 else. And, with that perspective I am remembering the caution of  
15 Robert Pollack who is a physicist who works with Watson, who  
16 discovered DNA, and he said that, given the fact that no scientist  
17 could say that gene therapy, some intrusion into the stem cell of an  
18 infant, could actually do good, that these sort of things should not  
19 be done; germline therapy and somatic therapy, I think, come under  
20 the same blanket there. They're so risky, they're so dangerous,  
21 that I don't think a kind of hope of cure warrants these kind of  
22 interventions.

23

24 MR FORMAN: If we continue to analyse your responses then around the  
25 concept of the ethics that would be applied to these issues, one of  
26 the statements of the panel was, you know, we must think about the  
27 effects on our children and on our grandchildren.

28

29 Now, one of the lysosomal diseases for which there is demonstrated  
30 effectiveness of the recombinant DNA derived from the rabbit, is a  
31 disease called Pompe disease which has been around for - well,  
32 probably around forever but understood for about 60 or 70 years I  
33 think.

34

35 If a child has an infantile form of that disease, the lack of a  
36 particular enzyme will mean a continuous deterioration in the  
37 condition of their muscles, through to the point where they'll die  
38 from heart failure, probably at about 2 years of age. Now, this  
39 technique of generating that enzyme from the rabbit, has been proved  
40 in the first stage of trials to prevent the deterioration in the  
41 muscle tone.

42

43 Does that sound like a good ethical basis for pursuing and  
44 continuing with this technology in order to produce this medicine,  
45 with the proviso that I think everyone would have, that every  
46 medicine must be proved to be safe, as well as effective?

47

48 JOANNA PAUL: I think parents now are put under intolerable choices,  
49 you know. There's a choice of two ills here, and these choices are  
50 extremely difficult to make and, as a parent, I found it easier to

1 suffer the death of a child, in the end, than the mayhem of  
2 technological intervention. You know, that's - one has to speak  
3 personally on these issues, but I think it's almost beyond, you  
4 know, it's beyond the human pale in a sense to have to - to have to  
5 make some of these choices, and the way that the more sophisticated  
6 the technology, the more extraordinary the choices we're going to  
7 have to face.

8  
9 MR FORMAN: But when we've considered all of those dilemmas it will  
10 come down to the point of making the decision, shall we do it or  
11 shall we not? Are you saying that we should not do it, but are you  
12 accepting that while you may have personal views about it, you would  
13 be accepting of other people having this medicine from this process  
14 available to them?

15  
16 JOANNA PAUL: I can only say that I feel the process is wrong and that  
17 the decision is something that always has to remain a personal one,  
18 but I would like Barbara to speak.

19  
20 BARBARA MOUNTIER: Thank you, I would like to make a general comment.  
21 I'd like to make a general comment, I'm not familiar with the  
22 diseases you've been speaking about, and I share the sense of  
23 difficulty in responding to that, and I think we've made it clear in  
24 both our written submission and in our oral submission that, we do  
25 accept biomedical, GM biomedical work if it is necessary, and if I  
26 could just read this again from our written submission, "Claims made  
27 about perspective medical benefits of GM technology need to be  
28 viewed with great caution". And our reason for that is that there  
29 are many claims being made now about the efficacy about GM  
30 biomedical research is going to be a courier for this and a panacea  
31 of that, and we think many of those claims are inflated. We further  
32 think that many of them are the basis for the hope to get funding  
33 for a project. So all of those things have to be taken into  
34 account. It can't take away the need in the cases you have put  
35 forward and we do accept that if it needs to be pursued, we accept  
36 that but with the most stringent controls. None of us are prepared  
37 to accept that the controls in place at present are of any value, or  
38 of only very limited value I should say, because our experience of  
39 controlling bodies is entirely disillusioning, in every field.

40  
41 MR FORMAN: My final example is another of the lysosomal diseases  
42 called Fabre disease. Now, the storage in this disease leads to, at  
43 around middle age, kidney failure and heart failure. And, on  
44 average, because it's what is called an X linked condition that will  
45 normally affect males, it will lead to death at an average age of  
46 about 45 rather than a normal life expectancy, and prior to that  
47 there will be issues such as dialysis and possible kidney  
48 transplants and heart disease in its management.

49  
50 Now, one of the companies, probably a multinational, but - well, it

1 will be, I guess, when its product arrives here, has applied for  
2 licensing here in New Zealand just within the last few weeks of the  
3 products which they claim will treat and possibly cure this disease,  
4 in other words, get rid of the storage, the inappropriate storage in  
5 the cells of the body and lead to a normal and healthy lifestyle.

6  
7 Do you see, again looking at it from an ethical point of view, for  
8 all of the issues that you have raised and all of the concerns that  
9 you have raised, that the Commission should be recommending to  
10 Government whether there should be any special restraint or  
11 constraint about the use of that particular therapy, as opposed to  
12 any other medical product which may be put forward for licensing in  
13 New Zealand?

14  
15 BARBARA MOUNTIER: If I could make another general comment. You are  
16 speaking about very specific diseases, and I've already commented on  
17 our view on that. I think, as you say, there's a tendency for  
18 claims to be made for GM biomedical intervention for almost  
19 everything now, and almost anything. And, I'd like to say that, I  
20 believe there are still other approaches. We don't need to go down  
21 the GM track for every medical purpose. And other approaches  
22 involve searching for the origins of the disease, you may feel  
23 already that's been done in the cases you quote, searching for  
24 contributing environmental factors. And, for instance, in the case  
25 of diabetes, we can see the path being shaped now. Everybody with  
26 diabetes is going to be treated with GM medication, and that's going  
27 to increase and increase as the population of diabetic patients  
28 increases, but why is it increasing? That's my sort of question.  
29 Why don't we go back and look why are so many people getting  
30 diabetes; what can we do in the way of preventative work? What is  
31 there in diet and lifestyle that's contributing towards this  
32 ballooning increase in that population?

33  
34 Just to say one last general thing. I listened to somebody in the  
35 last few weeks, and I don't remember who it was, saying that in the  
36 case of sheep genes, it's not necessary to do GM interventions  
37 because, in a big enough population of sheep, if you're observant  
38 sooner or later you will find the sheep with the characteristic that  
39 you want and then you can breed for that. Now, I don't know how  
40 this applies to humans but it's just popped into my mind as a  
41 possible alternative. Somewhere I'm prepared to believe there are  
42 other ways of dealing with this than by a blanket approach of GM  
43 biomedical technology.

44  
45 I can see that GM technology may have important uses in certain  
46 cases, but what I'm trying to contest is the belief that it solves  
47 everything and it's the only way we can go. There are important and  
48 successful alternatives and I think we need to hold to that.

49  
50 MR FORMAN: And I would - my final response, which I would invite you

1 to comment on, is that most people, I'm sure, would be aware of the  
2 importance of improving the environment and everything from the  
3 quality of our water and the air that we breath and the food that we  
4 eat to improve our health and diets and exercise etc. When we have  
5 solved those environmental and other disease causing problems we  
6 will come back to a number of largely rare genetic diseases which  
7 are caused not by environmental factors but by the genetic make up  
8 of the individual, which suggests very strongly that only a genetic  
9 solution will be the answer to that problem. Would you like to  
10 comment on that in response to the use of genetic modification  
11 technology to solve these problems?  
12

13 ANNE MEULI: I don't wish to make a response to your statement, but I  
14 would like to say that we are members of the Quaker Spiritual  
15 Ecology Group, which is a committee of our yearly meeting, and as  
16 Quakers we personally are making these statements, but we wouldn't  
17 dare to presume that all Quakers feel the same way; as someone else  
18 expressed in a submission on Tuesday. We are speaking - I would say  
19 this Quaker says, but I cannot say that all Quakers would speak the  
20 same.  
21

22 CHAIR: Thank you very much. I think that's a good note on which to  
23 finish your cross-examination and we'll take the morning break for  
24 15 minutes. There will be some more questions after that.  
25

26 MR HODSON QC: I wonder sir, if I could just indicate that I wanted to  
27 say something in one sentence and then depart if I may because I  
28 don't wish to cross-examine today.  
29

30 CHAIR: Yes, certainly.  
31

32 MR HODSON QC: My name is Hodson, I'm counsel for the Life Sciences  
33 Network and it will be no surprise to you that we are, in varying  
34 degrees, opposed to the recommendations you put forward. And, you  
35 may be surprised to know that we're not opposed to all the  
36 recommendations you put forward.  
37

38 I would like to acknowledge the sincerity and the thought of your  
39 submission, and the spiritual aspect you have given to the debate.  
40 We respect that. The scientific issues, as you've indicated, have  
41 been well canvassed, and in the context of the acknowledgment I've  
42 given, I really do not think it would be appropriate for us to  
43 question you on the beliefs that you've put forward. But, thank you  
44 very much for doing so, from us.  
45

46 CHAIR: Yes, 15 minutes.  
47

48  
49 Adjournment taken from 11.00am to 11.25am  
50

1

2

CHAIR: Mr Upton, who is Counsel Assisting the Commission, will have some questions.

3

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6

7

MR UPTON: Yes, thank you. My name is John Upton and I'm Counsel Assisting the Commission, the Royal Commission. I just want to pick up some of the topics that we've been talking about this morning. And the first issue I'd like to look at is the issue of ethics. And, there have been various comments there morning such as the sacredness of nature and the need to ensure that one's own happiness is not at the expense of someone else.

10

11

12

13

14

15

Are those seen as absolutes?

16

17

JOANNA PAUL: I think a hill can be bulldozed and trees cut down, and we can feel sorry about it, but we know that trees will grow again, and that some of the ravages will be made good. But I think that we're just conscious that we're talking about the kind of disrepair that can't be made good, when we're entering this field of genetic manipulation.

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MR UPTON: I'll get into the GM area in a minute, but I just wanted to talk about the propositions. And, what I just wanted to explore with you was whether these propositions are absolutes or whether there's room for exceptions?

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29

HILDA DAW: Can I just speak to this one? Going back to the sacredness of life and the interconnectedness of the whole web of life, I think we have felt that the human species has, the last 200 or 300 years at any rate, been the central focus, and we are only a tiny part of this whole web of life. So, in that context that, elaborating that the humans have the right to do this, that and the next thing, we feel they do not have a right in the context of the sacredness of all life.

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MR UPTON: Because there's been a suggestion being put forward at the hearings that we're stewards for future generations?

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41

JOCELYN THORNTON: I would not be happy with the word "stewardship", I would be happy with the word "participation"; we are participators in this universe. Without microbes we would not be here, they are the basis of life. Microbes are the basis of the nutrient cycles. We don't understand these things, and we need to know more about ourselves and about nature, and how nature works so that we don't transgress nature's codes and rules, which we see as sacred.

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MR UPTON: Then we get into the next stage of the debate, it seems to me, that possibly good can result from what you good people would

50

1 see as wrong means. And, I think some of that was implicit in the  
2 discussion that Mr Forman was having with you.

3

4 Are we in a situation where, what you would regard as wrong means;  
5 not necessarily the same as what others might regard as wrong means?

6

7 JOCELYN THORNTON: It would depend on one's world view and one's  
8 perception of things, that's - we all don't have the same view.

9

10 MR UPTON: Of course.

11

12 JOCELYN THORNTON: No.

13

14 MR UPTON: But here's someone, like Mr Forman, saying, "I desperately  
15 want to be able to get this medicine", and you've got a strongly  
16 rooted concern about GM medicines, and that view is entirely  
17 respected. But, at the end of the day, there's got to be some  
18 balancing, doesn't there?

19

20 JOCELYN THORNTON: We, yes, I would like to say that -

21

22 MR UPTON QC: There are no absolutes in this particular area, are there?

23

24 JOCELYN THORNTON: That would be right, I think, from my point of  
25 view. Who am I to stand in the way of someone else getting some  
26 help, if this is the way? But, it's a matter of compassion, I  
27 think.

28

29 MR UPTON: But you see, if you go back to the proposition that I  
30 think one of you good folks said this morning, that one's own  
31 happiness shouldn't be at the expense of someone else. How do you  
32 relate that to Mr Forman's situation?

33

34 ANNE MEULI: May I? I think it was I that read this piece, that it  
35 seemed to me to be quite clear, biomedical GM technology, if it must  
36 be pursued, should be rigorously monitored by an impartial body.  
37 This body should be independently funded and provide information for  
38 public debate. I think that's a real recommendation - a recognition  
39 that we need to understand other people's needs by saying, if it  
40 must be pursued. There are some Friends who would not - some  
41 Quakers who would feel that that is being a little wider than their  
42 own thought, but it's recognising.

43

44 MR UPTON: The situation that we're talking about with Mr Forman?

45

46 ANNE MEULI: Yes, I think that's quite clear.

47

48 MR UPTON: Could I move on then to this question of - I'll just get  
49 the right word - could I move on then to this issue of an impartial  
50 body to monitor GM technology for biomedical purposes.

1

2

Are you people aware of the existing structures that are in place to deal with ethical issues relating to human gene technology or animal welfare, which is used for GM purposes?

5

6

JOCELYN THORNTON: We're not really au fait with all of that, but I do have some knowledge of medical ethics through somebody I know who's on it, and I must say, I have a very, I don't know, sceptical view or not trusting view, because of the risk benefit that's applied so much these days. It's not rooted in anything that is most valuable.

11

12

To me, ethics must be rooted in that which is vital and cannot be done without. I'm thinking of nature, I think, and ecology, because without the well-being of nature none of us would survive. And, to me, that must --

16

17

MR UPTON: I think we'd all endorse that?

18

19

JOCELYN THORNTON: -- must be included in ethics.

20

21

MR UPTON: But there's a whole raft of ethical structures in place at the moment which we've heard a lot about in recent weeks, both in the human research area and in the animal research area.

24

25

JOANNA PAUL: Yes. I wonder if I can say - I know I've said too much, but --

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28

MR UPTON: No, you haven't.

29

30

JOANNA PAUL: -- I'd like to say a word or two here

31

32

MR UPTON: This is your opportunity.

33

34

JOANNA PAUL: I feel quite intimately involved with these regulatory bodies, having been a submitter on two or three occasions. Interestingly enough I think that they may slow things down a bit, but I don't think they regulate it - they don't provide any ethical framework whatsoever. Even though I think the Act has no - the HSNO Act, does allow for cultural and ecological considerations which are ethical. However, I don't think those considerations had been taken seriously by bodies such as ERMA. To give a specific example, I was very concerned about animal welfare, but when putting in a submission in about the myostatin knockout sheep, we were told first of all that our - any misgivings about the technology weren't appropriate, only information was wanted, and that if we had animal welfare concerns we should refer them to MAF. In spite of this, 80 submitters did question the principles and the processes, and did have animal welfare concerns.

49

50

I think only those who were actually interested parties supported

1 the submission. I took ERMA's suggestion literally and wrote to MAF  
2 and cited the new Animal Welfare Act that said an animal should be  
3 allowed to express its own nature. I was told that, that Act did  
4 not apply to experimental animals.

5

6 So, they did then suggest that if I had concerns I should have  
7 referred them to the Royal Commission. So, as far as I'm concerned,  
8 this is the Ethics Committee.

9

10 MR UPTON: Well, just staying with this idea of technology being  
11 monitored by an impartial body, I take it then that you regard the  
12 existing structures as, quite bluntly, inadequate.

13

14 [All ladies agree]

15

16

17 MR UPTON: But as I understand it, you don't, I'm going carefully  
18 here, I understand you haven't looked at the structures in detail?

19

20 JOANNA PAUL: There have been a few glimpses. For example, when  
21 wondering how AgResearch managed to put up this proposition, in  
22 spite of having an animal welfare Ethics Committee, we were given a  
23 little glimpse of the proceedings; they simply used the cost-benefit  
24 analysis and decided that the hypothetical benefits for some reason  
25 outweighed the damage to the animals. So, I don't see an ethical  
26 paradigm working there at all.

27

28 MR UPTON: Well, if we leave that discussion, and thank you for that.  
29 Can I move to a totally separate topic just for a moment, and it  
30 relates to organic foods. And, I'm looking at your written  
31 submission at the moment, and you say there that organic foods are  
32 commanding premium prices. Are you aware why they're containing, or  
33 commanding premium prices?

34

35 JOCELYN THORNTON: Is it not because people don't want to eat GE food,  
36 and their labelling is so inadequate or nonexistent, that nobody can  
37 trust food, except organic food?

38

39 MR UPTON: Have you looked at the cost involved in producing organic  
40 foods?

41

42 JOCELYN THORNTON: I produce it myself. It doesn't cost any more.

43

44 MR UPTON: No, but are you doing it for commercial purposes?

45

46 JOCELYN THORNTON: No.

47

48 MR UPTON: Have you looked at the cost involved in producing organic  
49 foods for commercial purposes?

50

1 JOCELYN THORNTON: No, but I know we pay more for organic food because  
2 there are added - they can't grow in such mass-production, so they  
3 have to charge more.

4  
5 MR UPTON: Do you think it is also a factor that is being sold into  
6 niche markets?

7  
8 JOCELYN THORNTON: I think that has been the case but I don't think  
9 it's so much now. For instance, Affco did a survey of New Zealand  
10 farmers and they found that 70% of them favoured organic production  
11 for New Zealand in the future, and I have that paper with me.

12  
13 MR UPTON: And I think the figure is 70% favoured organic over  
14 genetically modified foods?

15  
16 JOCELYN THORNTON: That's right, yes.

17  
18 MR UPTON: Do you know if the survey - addressed conventional  
19 farming? Or was it simply looking at GM versus organic?

20  
21 JOCELYN THORNTON: I don't know, but I do have the paper with me.

22  
23 MR UPTON: Are you suggesting that New Zealand should move totally  
24 into organic production?

25  
26 JOCELYN THORNTON: I would like that, but I can't see it happening.  
27 But slowly perhaps. But, in the meantime, non-GE food is desirable  
28 in - rather than GE food.

29  
30 MR UPTON: If we move towards organic production, and organic foods  
31 command premium prices, where does that leave the lower paid people  
32 in New Zealand? Do they have to pay those premium prices?

33  
34 JOCELYN THORNTON: I have heard that, as organic production increases,  
35 the prices may be lowered. It is a problem, because we do not care  
36 for those on low income sufficiently in this country. We --

37  
38 MR UPTON QC: That's why I'm asking the question.

39  
40 JOCELYN THORNTON: Exactly. I think if there was Government support  
41 and Government research and - it could be - there could be all sorts  
42 of input that would make it more available, I'm sure there's a way  
43 where there's a will.

44  
45 PETER HARRISON: I'd just like to comment and I can't speak  
46 authoritatively, but I was in conversation recently with a scientist  
47 from Massey who is from Austria, and he said that in that country  
48 they are predominantly organic and benefitting greatly by the fact.

49  
50 JOCELYN THORNTON: And Denmark is hoping to be totally organic by

1 2020.

2

3 HILDA DAW: I know the prices in England, in France, while I've been  
4 recently in touch with friends, the prices of food has come down  
5 markedly as the prices increased all over Europe. I think we feel  
6 very strongly that as an island nation which, if we can prevent the  
7 fallout from contamination from GM crops to our Organic Industry,  
8 we're in an extremely strong position of being a very strong trading  
9 export trader for organic agriculture.

10

11 BARBARA MOUNTIER: Could I make another comment which is a little to  
12 the side, but I agree with you that it's out of the reach of people  
13 on low incomes, and that is a serious disadvantage of the situation.  
14 But, if there were the political will to ban GE food from our  
15 supermarkets, then people in any sort of income would have access to  
16 relatively safe food and they would then have a choice between  
17 uncontaminated food produced by ordinary agriculture, industrial  
18 agricultural means and organic foods, and it would be a much fairer  
19 situation.

20

21 MR UPTON: Thank you very much, that covers all the points I wanted  
22 to discuss, thank you sir.

23

24

25 \*\*\*

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27

28 [12.43pm]

29 CHAIR: Can I just take up with you Mr Forman's debate and take that a  
30 step further?

31

32 How do Quakers solve that kind of problem when it affects them  
33 personally? I imagine there may well be Quaker families that,  
34 unfortunately are subject to one of these rare genetic diseases. We  
35 know, of course, of groups with beliefs that prevent them from  
36 accepting blood transfusions, or even medical treatment. How do  
37 Quakers, or how would a hypothetical Quaker, if you like, face the  
38 situation where it was discovered that their family was subject to  
39 one of these rare genetic diseases and there was a GM treatment that  
40 afforded at least some hope?

41

42 HILDA DAW: I think, again, we're back to Quakers speaking  
43 individually. Each one of us would have an individual response to  
44 that, and as Quakers we do have a wide tolerance and respect for  
45 individual choice within the framework of our overall beliefs. So,  
46 it would be a question for the individual.

47

48 CHAIR: Thank you, that answers my question precisely unless any other  
49 member of the group wants to differ from that?

50

1 JOANNA PAUL: I'd just like to say that, once people used to say,  
2 "This is the will of God". I think that's probably, you know, it -  
3 maybe it seems a little pat, it seems a little pious, but it enabled  
4 people to perhaps come to grips with the fact that they might have a  
5 child that might not live very long, and that's what I want to say.

6  
7 CHAIR: So you disagree with the question of individual choice?

8  
9 JOANNA PAUL: I think I said before that I think the choices are  
10 becoming painfully difficult. I mean the kind of background reading  
11 that I've done suggests that patients might not even be able to  
12 tolerate the cure for Cystic Fibrosis for example, I mean this was  
13 from Peter Wills. You know, there's a big question mark over some  
14 of these therapies. As an individual, for myself, I would - I hope  
15 I would be allowed to refuse.

16  
17 DR FLEMING: Yes, I just have come clarification. You've mentioned an  
18 independent body to monitor GM development, should it have to  
19 happen. Can you comment a bit more about what you mean by  
20 "independent"? There's been a lot of views expressed about not  
21 trusting scientists, not trusting commerce, not trusting Government.  
22 Who is independent and how would this body be appointed?

23  
24 BARBARA MOUNTIER: Could I begin this? One of our difficulties has  
25 been seeing regulatory and advisory bodies composed of people who  
26 have connections with the biotech industry, and that is not  
27 independent. So, that's just a start.

28  
29 DR FLEMING: Any more comments?

30  
31 JOCELYN THORNTON: I think funding is an important matter that we all  
32 know, that those who work for a particular organisation find it very  
33 difficult to speak out against anything that they find abhorrent or  
34 not right. And, I would hope that the funding could be independent.  
35 I think that's -

36  
37 DR FLEMING: Government funding?

38  
39 JOCELYN THORNTON: Well, I suppose so but that's difficult - yes, I  
40 think Government funding rather than private or corporate. That's  
41 tax payer after all, isn't it?

42  
43 HILDA DAW: A body like yourselves for instance, which is an  
44 independent, hopefully, overall, but without any specific tie to any  
45 industry.

46  
47 DR FLEMING: Do you want to make a comment?

48  
49 PETER HARRISON: Yes, I just wanted to say that I think we've heard  
50 sufficient to show that there is a need for this matter to be

1 addressed.

2

3 DR FLEMING: Sure.

4

5 PETER HARRISON: And what the answer is might not be all that evident,  
6 but there are some suggestions that have come forward.

7

8 DR FLEMING: May I then ask you if any of you have read the evidence  
9 from UNESCO and their model for, if you like, an independent policy  
10 advisory ethical body?

11

12 BARBARA MOUNTIER: I just saw a newspaper report of it.

13

14 DR FLEMING: Okay, if you're not aware of it, that's fine, I won't  
15 make any more comment. Thank you.

16

17 JOCELYN THORNTON: Could I just say that I think this setting up of an  
18 independent ethical body is really really important to be done  
19 quickly as it can be, because I expect you will be aware of the  
20 report about Klebsiella planticola, a bacterium which was  
21 genetically modified -

22

23 CHAIR: Yes, we have heard of it.

24

25 JOCELYN THORNTON: That it could spread right around the world and  
26 turn the plants into slime. Now, that is so drastic that surely we  
27 should take note of that and think well, how - it was only  
28 discovered in the nick of time before the field trials were made.  
29 So, it really is extremely urgent.

30

31 BARBARA MOUNTIER: May I express another anxiety about finding  
32 independent people? There's a culture developed, it seems to me, to  
33 be paralleled to that in the 80s of, "there is no other way". And  
34 it seems that, there's pressure on people to fit into this paradigm  
35 of approaching research from a GM point of view, and it's very hard  
36 in that case for people to speak and behave independently if there  
37 are pressures of all sorts to make them fit into the mould, and we  
38 saw that in the 80s, and I'm afraid that that is something that's  
39 being repeated now, in a different context.

40

41 JOANNA PAUL: Perhaps it might be worth mentioning, or picking up on  
42 an Anglican comment about the necessity of Maori representation.  
43 Equal, equal Maori representation.

44

45 JOCELYN THORNTON: Yes, I would support that wholeheartedly.

46

47 BISHOP RANDERSON: Thank you for your submission, but I have no  
48 further questions.

49

50

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1 CHAIR: Thank you very much for your submissions, for the way that  
2 you've presented them, and for coming along today to discuss them  
3 with us, we've valued that, and we're going to take a break now  
4 until 1 o'clock.

5

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8 Adjournment taken from 11.50am to 1.05pm

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1 PRESENTATION BY NEW ZEALAND CATHOLIC BISHOPS CONFERENCE

2

3

4 BISHOP CULLINANE: Thank you Sir Thomas and members of the Commission,  
5 and thank you for the opportunity to present ourselves. I bring  
6 with me an apology from Cardinal Thomas Williams. I have with me on  
7 the far right - this is Mrs Anne Dickinson, who is the director of  
8 Caritas New Zealand, which is the Catholic Church's Aid Agency, and  
9 currently chair of the Independent Biotechnology Advisory Council,  
10 and then also Dr Michael McCabe who is in parish ministry in  
11 Wellington and who is the director of the Nathaniel Centre which is  
12 the Catholic Church's Bioethics Centre. Oh, and I'm Peter  
13 Cullinane. I'm the Catholic Bishop of Palmerston North and  
14 currently Chairman of the New Zealand Catholic Bishops' Conference.

15

16 Sir Thomas and Commission we are under no illusion concerning the  
17 complexity of the matters that you have some responsibility for, and  
18 we certainly aren't here to present you with any so-called simple  
19 solutions.

20

21 But, it seems to us that the underlying issues are not entirely new.  
22 The technology is, but ever since humans took their place on the  
23 planet they've always needed to explore the laws of the universe and  
24 harness its energies and creatively put these at the service of the  
25 human race, and we see technology as a tool in the service of that  
26 deep human need.

27

28 There is another deep human need, that is the need to experience  
29 certain stability and predictability in the universe and to respect  
30 a certain harmony. But our position fundamentally is that both  
31 these human needs are valid concerns, they both have their rightful  
32 place, and the problems really only arise when either of these human  
33 needs is presented from an extreme point of view, or when one is  
34 pitched against the other.

35

36 For example, a focus on economic benefits of genetic modification to  
37 the exclusion of other human values, would impoverish rather than  
38 enrich us as a people. Likewise, so would blanket opposition to  
39 genetic modification on the grounds that we're not wise enough to be  
40 trusted with it.

41

42 In our submission we've stated that while we don't see the  
43 technology of genetic modification to be in conflict with ethical  
44 values, we are, of course, very aware that there are some uses of  
45 that technology which could be unethical and unwise and offensive to  
46 some people.

47

48 Many of the uses of genetic modification have been tabled, with  
49 potential uses only being hinted at, or simply unknown at this  
50 stage. And while, as a Commission, you make decisions about known

1 uses of genetic modification, it's our hope that you might also put  
2 in place a means of ethically evaluating new uses as they arise in  
3 the future.

4  
5 We recognise the role the Environmental Risk Management Authority  
6 currently plays in evaluating environmental health and safety  
7 aspects of the uses of genetic modification. However, we believe  
8 that this needs to be complimented by a broader evaluation, based on  
9 a framework of ethical principles. And, it's to address that that I  
10 would ask Dr Michael McCabe to continue.

11  
12 \*\*\*

13  
14 [1.10pm]

15 DR MCCABE: Thank you Bishop Peter.

16  
17 Sir Thomas and members of the Royal Commission, we argue that we do  
18 not need new ethical principles to evaluate the uses of genetic  
19 modification. There are already fundamental and accepted ethical  
20 principles that underpin much of our legislation and the work of  
21 ethics bodies in New Zealand; for example, I sit on the Health  
22 Funding Authority Ethics Committee in Wellington and those  
23 principles have been clearly established and work with the  
24 Cartwright Report in New Zealand, in evaluating health research and  
25 the use of innovative treatment.

26  
27 Ethical principles are powerful guides in thinking about the ethical  
28 dimensions of many diverse situations, including genetic  
29 modification.

30  
31 The first of these ethical principles from the Hippocratic tradition  
32 is that of non-maleficence; first, do no harm. Essentially this is  
33 a principle about safety. First, do no harm involves more than  
34 ensuring physical or environmental safety.

35  
36 We believe that too much is being asked of the HSNO Act in its  
37 current form, because it does not provide a sufficient framework for  
38 balancing ethical, cultural and spiritual beliefs with scientific  
39 information.

40  
41 The case-by-case approach of the regulatory process needs to be  
42 guided by policy, which incorporates wider concerns and defines the  
43 boundaries in our use of genetic modification.

44  
45 We are supportive of recommendations which recognise that  
46 applications of genetic modification lie along a continuum of risk.  
47 Low risk research activities of the type carried out in New Zealand  
48 safely in containment for the last 25 years, are now routine and do  
49 not need the same high level of regulatory and community scrutiny as  
50 new uses which have potentially irreversible effects.

1

2 There has been much said about the Precautionary Principle in the  
3 Commission's hearings. We support the application of this principle  
4 to uses of genetic modification in a form which recognises that  
5 human activities always involve some degree of risk, however slight.

6

7 Understanding of the degree of risk is often a function of time, the  
8 risk increasing or decreasing with advances in knowledge. This is  
9 particularly so for certain milestone events in the use of genetic  
10 modification. For example, a first release of a GMO into the  
11 environment.

12

13 For this type of use, the competitive element of human nature needs  
14 to be tempered by the virtues of caution and patience. There are  
15 some complex and potentially irreversible uses of genetic  
16 modification which we simply don't know enough about and where there  
17 is the possibility of serious or irreversible damage. In such cases  
18 the burden of proof should fall on those who wish to carry out the  
19 activities in question.

20

21 There is wisdom in delaying these types of decisions for a period of  
22 time in order to carry out further research, not only into the  
23 science but also into the ethical, cultural and economic aspects of  
24 the application.

25

26 The second fundamental principle to be included in an ethical  
27 framework is that of beneficence, to do the good. The potential of  
28 an action to provide a good or a benefit. Those who will benefit  
29 from a particular modification should be clearly identified, and  
30 their need for such benefit evaluated to ensure that it is not  
31 achieved at the expense of the well-being or the benefit of others.

32

33 We recognise the value to the community of economic benefit, but  
34 strongly believe that it should not be the key driver in  
35 decision-making. Improvement of the human condition, respect for  
36 our environment, for the gift of life and other life forms, are less  
37 tangible, and longer term benefits are all equally important  
38 considerations.

39

40 Evaluation of the potential of a particular genetic modification to  
41 do harm or provide benefit, depends upon the acceptance by all of a  
42 third fundamental principle, that of veracity or truthfulness.  
43 Sound decisions depend upon the availability of information which is  
44 honest, unbiased and comprehensive.

45

46 As we said in our submission, this debate has been characterised by  
47 polarisation and the use of carefully selected information to  
48 support particular viewpoints.

49

50 Truthfulness requires that all information be available and

1 verifiable, and that research be open to all possibilities rather  
2 than designed to support particular stances.

3  
4 Competitive advantage, or a personal philosophy are not reasons for  
5 obscuring truth, because there is too much at stake for all of us.

6  
7 Our western society is based on respect for individual freedom which  
8 carries with it an acceptance of responsibility for one's actions,  
9 and for their contribution to the common good. These concepts are  
10 reflected in the principle of respect for autonomy, the fourth  
11 principle to be included in any ethical framework.

12  
13 Respect for autonomy acknowledges our right to our own choices,  
14 opinions, values, goals and freedoms to act in a way which is  
15 respectful of others and respectful of self.

16  
17 An autonomous person makes choices after careful consideration of  
18 alternatives. Which means that respect for autonomy must operate in  
19 tandem with the principle of veracity or truthfulness.

20  
21 In the health field, the provision of good information to patients  
22 as the basis for personal decision-making, has long been accepted.  
23 Likewise, the provision of neutral and non-judgmental information  
24 about the risks and benefits of genetic modification is a key  
25 component of respecting the autonomy of individuals.

26  
27 The labelling of foods with a GM component is an example of  
28 providing information which allows people informed choice.

29  
30 The fine detail of how the principle of respect for autonomy is to  
31 be applied will be one of the most challenging aspects of developing  
32 an ethical framework. Labelling food is one of the simplest  
33 solutions. The growing of food and the modification or use of  
34 copies of human genes, give rise to more difficult issues.

35  
36 It is in this area of respect for autonomy, that issues of concern  
37 to Maori need to be worked out so that their spiritual beliefs are  
38 respected without imposing a veto on GM work within New Zealand.

39  
40 In relation to genetic modification, the teasing out for respect for  
41 autonomy requires a commitment to dialogue with a multidisciplinary  
42 and multicultural approach being essential.

43  
44 Such a dialogue challenges all groups engaged in the debate to stand  
45 in the shoes of others, rather than simply dismissing perspectives  
46 which differ from their own.

47  
48 A fifth principle, that of justice, must also be included in an  
49 ethical framework. Application of the principle of justice would  
50 bring into focus questions about the sharing of the benefits and

1 risks of genetic modification, and issues about human rights.

2

3 In this new context there is the possibility of starting afresh and  
4 seeking to make social justice a reality, taking account of the poor  
5 in our midst, and remembering that as a nation we consume far more  
6 than our fair share of the earth's resources. Our use of this new  
7 technology has the potential to exacerbate further the inequalities  
8 that subject many Third World countries and developing countries to  
9 injustice and marginalisation. This is especially so if we use it  
10 in an exploitative way or to gain wealth for others at the expense  
11 of others - of some others.

12

13 As a nation, we can decide to use this technology, not only to  
14 benefit ourselves, but also to respond to the needs of the poor. In  
15 New Zealand we have a particular responsibility to provide  
16 leadership in the use of this technology to benefit and protect our  
17 Pacific neighbours.

18

19 Is it too much to require that the needs of the poor take priority  
20 over the desires of the rich in determining how we will use genetic  
21 modification?

22

23 We noted in our submission that many of the issues in genetic  
24 modification have arisen from a non-Maori world and have their  
25 origins in a different cultural perspective. The Treaty of Waitangi  
26 requires respect for the world view of Maori, their spirituality,  
27 culture and traditions.

28

29 We draw your attention to the witness brief of Dr Mere Roberts  
30 presented on behalf of the Maori advisory group to ERMA. Members of  
31 this group are highly qualified in scientific disciplines, and they  
32 identify a number of serious issues for Maori in the regulatory  
33 process and state that they are concerned that until these issues  
34 are addressed and resolved, there would appear to be no  
35 circumstances available under the HSNO Act, "Within which Maori's  
36 spiritual and cultural concerns will ever be considered of  
37 sufficient significance to lead to the decline of an application".

38

39 They consider that the Act in its present form is failing Maori, a  
40 statement that deserves our attention.

41

42 These issues may be better worked out within an ethical framework  
43 through the principle of respect for autonomy and the other  
44 principles in tandem, than on a case-by-case basis in a regulatory  
45 system.

46

47 In conclusion, we believe that developing and applying a framework  
48 of ethical principles to uses of genetic modification is essential,  
49 but acknowledge that this will be a challenging task. It will  
50 require dialogue across disciplines and between groups with strongly

1 held views.

2

3 However, it has the potential to bring about a deepening of the  
4 ethical wisdom needed to handle, not just this scientific advance,  
5 but others that are yet to come.

6

7 If this debate could be described as having sides, namely a pro-GM  
8 lobby and an anti-GM lobby, then we need to understand the values in  
9 both perspectives. The very focused innovation and creativity of  
10 science is balanced by the perspective of those who look at the  
11 impact of potential change on the less tangible aspects of our  
12 lives. This is not a matter of one side winning, it is about how we  
13 go forward together with a greater understanding of one another, and  
14 with the ability to make decisions for our common good. Thank you.

15

16

17 \*\*\*

18

19 [1.23pm]

20 MRS DICKINSON: In putting forward a case for an ethical framework,  
21 we're very aware that raises immediately a question where in the  
22 structure for dealing with GM would such an ethical framework fit?  
23 We are not in favour of multiplying the bodies that one has to  
24 approach to get approval for the use of genetic modification. Nor  
25 are we in favour of making the process more cumbersome where there  
26 is low risk involved.

27

28 It is our belief that the ethical framework would be best  
29 incorporated at the level of a national policy which guides the  
30 operation of the regulatory bodies, and it sets boundaries to the  
31 uses of GM.

32

33 It's a very large ask to ask applicants, who want to use genetic  
34 modification techniques, or genetically modified organisms, to go  
35 through several different bodies to receive that approval.

36

37 Currently we ask, via the HSNO Act, is it safe, is it of benefit?  
38 And that's the sort of focus, the ethical focus, that the HSNO Act  
39 has. Somehow we need to put into the process the question, is it  
40 acceptable to the community? And, tie up in that question, or  
41 incorporate into that question all the other social, ethical,  
42 cultural factors which have been such a major force in this debate.

43

44 If this ethical framework that we've proposed can define the  
45 boundaries at a policy level, then the regulatory bodies can operate  
46 within that policy. The policy can be quite specific, and because  
47 it's policy rather than regulation or legislation then it will be  
48 amenable to change and keep up with the rapid developments in the  
49 scientific field.

50

1 I guess this sort of also raises the question, where does such  
2 policy come from? And I would expect that much of that policy would  
3 be determined by you, the Royal Commission. That the policy  
4 directions will be somehow contained in your report, and when you  
5 report to Government, that from that report the initial policy  
6 directions would be quite easily drawn out by those people who are  
7 skilled in policy writing.

8  
9 Now, at the moment ERMA for example acts in a case-by-case basis  
10 without that broader framework within which to base its decisions.  
11 And, I think personally that that has been quite a dilemma for them,  
12 how to handle these particular issues.

13  
14 In the background have been the medical advisory bodies who also  
15 have the same dilemmas, about the boundaries to their action.

16  
17 If we had some sort of national policy framework where the community  
18 could express its wishes, if you like, clearly, and through putting  
19 in place of this policy, could influence the pace at which GM  
20 develops or the use of GM develops, then I think it will go a long  
21 way to resolving many of the issues that we've faced. And we have,  
22 as Dr McCabe just mentioned, said that it may be at this level, at  
23 this policy level, that it is better to work out some of the issues  
24 raised by Maori that are currently trying to be dealt with on a  
25 case-by-case basis. Thank you.

26  
27 CHAIR: Now, is that your presentation?

28  
29 DR MCCABE: Yes.

30  
31 CHAIR: Thank you.

32  
33  
34 \*\*\*

35  
36 CHAIR: Mr Forman, unless there are some new matters you wish to  
37 raise, the Commission doesn't wish to hear a repetition of the  
38 debate that you've conducted on more than one occasion.

39  
40 [1.27pm]

41 MR FORMAN: Surely, yeah, and I don't intend to either. There was just  
42 one issue that I want to discuss with the group, and that is the  
43 issue of germline therapy.

44  
45 The submission you have made is something which I have, I guess,  
46 substantial agreement with, or to put it the other way around, agree  
47 substantially with the position we have adopted on a number of  
48 issues.

49  
50 There is the issue of germline therapy which you have referred to,

1 and concluded that there should be a ban for a period of time. And,  
2 in respect of some other submitters, they have proposed an absolute  
3 ban for all time on the basis that it is totally and utterly  
4 unacceptable. I would just like to tease out a few issues around  
5 this to see if there may be some common ground that we could reach  
6 about other possible aspects of germline therapy which may be of  
7 less concern.

8  
9 And that is the fact that, as you have said, all technology can be  
10 either good or bad, the idea that some germline therapy may be  
11 beneficial and helpful and have no perceived risks or negative  
12 consequences.

13  
14 Do you envisage, under your scenario, or how would you envisage that  
15 such issues would be dealt with?

16  
17 DR MCCABE: With great caution. But, I would defer to Anne to answer  
18 that.

19  
20 MRS DICKINSON: We have suggested caution and patience as being  
21 important in a number of areas, and in particular in relation to  
22 certain milestone events, and we mentioned the release of - a  
23 commercial release of a genetically modified organism as being one  
24 of those events that is more significant than a lot of others. The  
25 "first use", if you like, in inverted commas, of germline therapy  
26 would come into that category.

27  
28 In principle, if it's therapeutic, we are not opposed to it, but  
29 what we are saying at the moment is that we are not convinced that  
30 the safety of it can be assured, that because of its potential to -  
31 if there's a mistake, to harm those who cannot give their consent to  
32 it, that is generations yet to come, that when we get to that point  
33 - and I would - this is a personal opinion, be reasonably sure that  
34 at some point we will, that we need to be very sure. And we are  
35 simply saying, no, absolute bans have a funny way of backfiring on  
36 you. We say, ban it for a period of time. Now, we haven't named  
37 the period of time. But we're saying, yes, we've been around for  
38 hundreds, thousands of years; we can afford to wait for this one  
39 because of the consequences for future generations.

40  
41 MR FORMAN: So it's about understanding technology better and it's  
42 also, I suppose, as you referred to in your submission, avoiding the  
43 sorts of uses that would be about selection for characteristics,  
44 which I imagine most people would find unacceptable?

45  
46 MRS DICKINSON: We would find that excluded by the term. Germline  
47 therapy is therapy, not enhancement. It is for a therapeutic use.

48  
49 For example, a family that carries a gene which is devastating, you  
50 know Huntington's or something like that, it's a therapeutic use,

1 not an enhancement use. So the word "therapy" is important to us.

2

3 MR FORMAN: Maybe we're talking the same language but using different  
4 words here. I wanted to use the example, well to distinguish  
5 germline therapy from the issue of enhancement or selecting for  
6 characteristics, but to talk about the avoidance of disease.

7

8 And, for example, if we had two parents who were both carriers and,  
9 instead of dealing with all of the issues about either treating the  
10 disabled child when it is born, or the other issues about testing,  
11 prenatal testing, to deciding whether the child will be carried, or  
12 going to the earlier level of determining whether the first cells  
13 are affected or not, coming right back to an earlier point even  
14 prior to conception, of determining some process perhaps where we  
15 can ensure that the child was a healthy child because it inherited  
16 the good genes from the parents rather than inherited the bad genes.

17

18 Now, would that be germline therapy in your view or would that -

19

20 MRS DICKINSON: No, it's not. Basically what you're taking there, I  
21 mean if you go back preconception, you're talking about selecting a  
22 gamut, an egg or sperm and using the particular one without the  
23 characteristic, the gene that's been carried that's disadvantageous.  
24 Alteration of the embryo after it's formed is, I guess, germline  
25 therapy in relation to that particular individual, but I guess in  
26 theory you could alter it prior to conception. Could you also  
27 select prior to conception, because in a carrier situation you're  
28 not going to actually have all of the eggs or sperm necessary to  
29 carry the particular gene you're concerned about.

30

31 MR FORMAN: Right. So, if we had - and I accept at this stage it is  
32 bound to be at the stage of hypothesis rather than any practical  
33 reality that anyone was working on, but two people who discover  
34 before they consider having children that they are both carriers for  
35 the same condition which would lead to a high risk of a very severe  
36 disease in their child, something which treats them so that there  
37 can be some certainty as to the health of the child. Would that be  
38 the sort of thing that you would envisage banning for a period of  
39 time, or would you allow that under your proposals as therapeutic  
40 applications which should be allowed to proceed?

41

42 MRS DICKINSON: Do you mean in treating the parents, not dealing with  
43 the embryo? .

44

45 MR FORMAN: Yes.

46

47 MRS DICKINSON: I think you're getting pretty hypothetical here.

48

49 MR FORMAN: I'm probably talking about both, but I'm putting in about  
50 treating the parents as a hypothetical extension of where we might

1 be at some stage in the future.

2

3 MRS DICKINSON: I don't wish to appear nitpicking, it would depend on  
4 what form of treatment the parents meant, and it would be the same  
5 in relation to dealing with embryos, if you're talking about  
6 selecting or screening out embryos because of potential defects,  
7 then we would have some moral questions about that as well.

8

9 MR FORMAN: I understand the moral dilemma from the church's  
10 perspective, but I think in terms of the issues relating to the  
11 technology, is the proposal for a ban for a period of time intended  
12 to, and that type of application of the technology?

13

14 MRS DICKINSON: I tend to say, yes. To be quite frank, we haven't  
15 thought through that particular one you talk about, of treating the  
16 parents. But I still think that's got a genetic consequence for the  
17 generations to come. So, in our way of seeing things, then my first  
18 answer to that would be, yes. I mean I think really in terms of  
19 carrying a disadvantageous genetic conditions, the biggest hope  
20 immediately for GM is in relation to medicines and so on that will  
21 treat those conditions. And I think if we can deal with that issue  
22 first, okay, in parallel you may have some - you know, there may be  
23 research going into the germline area, but in animals other than  
24 people. Just think we need to grow in wisdom in this respect, and  
25 not rush.

26

27 MR FORMAN: Coming back to one of the earlier points I made, it is  
28 about trying to distinguish what could be seen as a purely good and  
29 beneficial application of germline therapy, from what is regarded as  
30 a, perhaps a negative or an unacceptable application of the  
31 technology. So, it's trying to suggest perhaps that there could be  
32 some way in which the proposal for a ban on germline therapy could  
33 be qualified to the extent that it should not immediately apply to  
34 things which are perceived or accepted as being beneficial or good?

35

36 DR MCCABE: I think the significant risk of the inherit ability of  
37 mistakes for future generations, that really is the paramount  
38 caution, and that's why a lot needs to be worked through before we  
39 would just say a wholehearted "yes" to this therapy. And we'd have  
40 to be clear that it was therapeutic as you suggest.

41

42 MRS DICKINSON: I think I'd be quite concerned with the wording that  
43 you just used. Because, the beneficial effect of dealing, for  
44 example, with just one gene or one particular characteristic when,  
45 just in the last couple of weeks we've seen that we have fewer genes  
46 than we thought we had, which means that the interreaction between  
47 genes is very important and the control and so on of genes is  
48 important, means that we may be dealing with one gene but not know  
49 that in the process there are connections with others. So, that's  
50 why I would even be cautious about what appears to be a therapeutic

1 intervention until we fully understand the connections and the way  
2 in which all of our genes interact together as opposed to the action  
3 of a single gene.

4  
5 MR FORMAN: I realise now that I didn't actually introduce myself  
6 properly and the organisation that I represent. My name is  
7 John Forman, and one of the organisations I represent is Lysosomal  
8 Diseases New Zealand, and what we are talking about in that context  
9 is diseases which are essentially single cell defects, and while I  
10 appreciate that there are many diseases where you have combination  
11 reactions and various other things, that for the majority of these  
12 it always seems to come back to one particular defect in one  
13 particular gene, which leads to the catastrophic consequences.

14  
15 Can I just ask one final question in that, would it be perhaps an  
16 acceptable alternative, or perhaps why should it not be an  
17 acceptable alternative, to have all of these issues dealt with  
18 through the ethical process which you are proposing? Rather than  
19 say, "We'll have an overarching policy which says we will pick out  
20 one group or one area and ban it for a period of time", when  
21 everything else is to be dealt with by the application, I guess, of  
22 a more stringent ethical analysis and oversight? Could not these  
23 same issues be dealt with, without a ban but with strict ethical  
24 oversight and guidelines?

25  
26 MRS DICKINSON: I think in respect to that I would simply say, human  
27 beings are not the same. I mean, we are part of the network of  
28 life, if you like, but we are not in the same category as animals  
29 and plants, and that, it's important that in this particular area,  
30 given that we have, no, as individuals we can consent to something  
31 but generations to come can't; now, that's a unique, if you like a  
32 unique facet of human beings, that we can give our consent to what  
33 is happening to us, it's not a characteristic of the animal and  
34 plant world.

35  
36 So, in relation to that I'd simply say that, we would prefer to see  
37 a ban on this form of genetic intervention, for a limited period of  
38 time; in other words, subject to review, not absolute, because we  
39 are not the same as some of the other forms of life that we're  
40 dealing with, and because of the consequences for other generations.

41  
42 MR FORMAN: Perhaps, given Father McCabe's experience in a medical  
43 Ethics Committee, he might like to comment on whether he believes  
44 those Ethics Committees, or some enhanced ethical body may be able  
45 to give appropriate oversight to those particular questions around  
46 germline therapy?

47  
48 DR MCCABE: Certainly, I would feel very comfortable that the  
49 regulatory body that we're proposing, and the specific principles  
50 that we are proposing, would work in practice, but I take Anne's

1 point about not adding to the dinosaur, you know, and making  
2 research unduly burdensome.

3

4 In my experience of looking at healthcare research protocols, the  
5 Capital Coast Health in the use of innovative treatment, I think  
6 that the system we have of our Ethics Committee, half the members  
7 being medical healthcare professionals and half the members being  
8 qualified and representative - lay people and representative of the  
9 community and our multicultural society, I think it does work. We  
10 work on consensus, and I think once we approve a research protocol  
11 as being ethical, it has gone through quite a lot of scrutiny, and I  
12 feel confident in this case that a similar system could work. I  
13 might have misunderstood your question.

14

15 MRS DICKINSON: Let's get this right. I think you're asking  
16 Father McCabe whether that system would be sufficient, rather than  
17 asking for a ban in relation to germline therapy?

18

19 MR FORMAN: Yes.

20

21 DR MCCABE: No, it wouldn't be sufficient.

22

23 MR FORMAN: And the suggestion for the ban, basically because it's so  
24 new and because there's such debate, we need to ease it in slowly  
25 and then at some point in time the system which we currently have,  
26 or an enhanced system, would be able to manage the debate and  
27 processes about it. Is that the overall picture that perhaps you  
28 are suggesting?

29

30 DR MCCABE: You may well need, given the need for caution and prudence  
31 here, you may well need an analogous system, that the same system we  
32 have could not deal with that adequately, because it's a slightly  
33 different brief.

34

35 MR FORMAN: Thank you very much. I have no further questions.

36

37 CHAIR: Mr Wevers, do you want to ask some questions?

38

39 MR WEVERS: Sir Thomas, I just want to acknowledge what the Life  
40 Sciences Network believes is an extremely good submission, and we  
41 have no trouble with the Royal Commission adopting that which we  
42 believe is consistent with our views.

43

44

45 \*\*\*

46

47 [1.43pm]

48 MR UPTON: You told us you're on the Medical Health Ethics Committee  
49 for Wellington, and presumably that covers the Kapiti Coast?

50

1 DR MCCABE: That's correct.  
2  
3 MR UPTON: I just wanted to chat with you a little bit about that  
4 committee. How many people on that committee?  
5  
6 DR MCCABE: 10 to 12, I'm a little bit blank, and it's half and half.  
7  
8 MR UPTON: On how long have you been on it?  
9  
10 DR MCCABE: Four years, this is my fifth year. So, I'm becoming a bit  
11 of a kaumatua now.  
12  
13 MR UPTON: Tena koe.  
14  
15 DR MCCABE: Ole.  
16  
17 MR UPTON: And you say it's a 50/50 mix of?  
18  
19 DR MCCABE: Professionals and lay members.  
20  
21 MR UPTON: Can I ask how you got on to the committee?  
22  
23 DR MCCABE: Good luck. There was just a vacancy after I had returned  
24 from my studies overseas, and I applied for the position. So, there  
25 is a selection process in the community.  
26  
27 MR UPTON: And it's an area, we know, you have a specific interest  
28 in?  
29  
30 DR MCCABE: Yes.  
31  
32 MR UPTON: There's been a suggestion put forward by some people that  
33 the lay members of such committees get overawed by the  
34 professionals. What's your comment from your work with the  
35 Wellington committee?  
36  
37 DR MCCABE: I think, when you are taking on new responsibilities and  
38 you come into a new field for the first time, you can be overawed by  
39 the dynamic and/or the jargon within the group, and the nature of  
40 the work. But, I think - I personally find it one of the most  
41 stimulating meetings that I go to, and I'd put church meetings in  
42 there too. Because it's - may be I shouldn't say this in front of  
43 the Bishop, but I think it's free of personality, and it works on  
44 consensus, and there is just a thorough debate of the issues. If we  
45 are considering the Treaty of Waitangi, for example, we would look  
46 at the principles of partnership and protection and participation  
47 and equity. And, we would have great trouble with researchers, as  
48 they do, who say that's not applicable to their research. I think  
49 it's very applicable. Or informed consent or the question, is this  
50 good research? Has it been done before? Can we understand what

1 they're proposing? What are the burdens and benefits, risks and  
2 benefits?

3

4 So, I think it goes through quite a good process and a very  
5 interdisciplinary process, and a good process.

6

7 MR UPTON: And presumably from what you're saying the researchers  
8 take part in the debate?

9

10 DR MCCABE: They can formally present, there is a provision for them  
11 to come and formally present. Most of them write in. If we have  
12 difficulty, or if it's something particularly on the cutting edge,  
13 we would ask to see them to talk it through.

14

15 MR UPTON: How many applications would you have to look at in a year?

16

17 DR MCCABE: We can average 20 protocols per meeting. A couple of  
18 hundred.

19

20 MR UPTON: Per year?

21

22 DR MCCABE: Yes, for Wellington. So much so that sometimes we have to  
23 have sub-committees just to get through the workload.

24

25 MR UPTON: Thank you.

26

27 DR ALLAN: Can I just ask, Mr Upton, to clarify something? Do you deal  
28 with other things in research, like the hard questions, like some of  
29 the diseases that Mr Forman is talking about, the treatment's very  
30 very expensive. Do you deal with the questions of what gets funded  
31 and what doesn't within Capital Health because that's separate from  
32 Pharmac?

33

34 DR MCCABE: That's Pharmac and also allied to that is SCOTT approval.  
35 But, we do deal with the hard questions, and, for example, the  
36 storage of tissue, and the sending of blood samples and tissue  
37 overseas. As you know, for Maori, that's a particularly sensitive  
38 issue because that, even the embodies their whakapapa. So, that  
39 would be one, and then Huntington's disease, for example, I think  
40 has been quite well researched, we've had several protocols. So,  
41 yes, we have some very hard questions.

42

43 And then a case recently of a tissue bank where people gave consent  
44 for their samples to be stored, but with the development of  
45 technology, new protocols come in; can you use that tissue bank for  
46 a new protocol? So, the difficult question of informed consent in  
47 that case.

48

49 DR ALLAN: For somebody on the ground, how do you find these overarching  
50 protocols that have been developed as national guidelines? Are they

1 helpful? Do you have a role in developing them?

2

3 DR MCCABE: Yes, we do, and we have a role in reviewing them too. I  
4 think it works quite well at the moment, and it's a national system,  
5 and there are parts that need review and are modified, because the  
6 experience of the various committees around the country is that this  
7 or that application is not quite working well, or is making the job  
8 unduly difficult.

9

10 DR ALLAN: One of our witnesses in front of us, Father McCabe, said that  
11 you got caught up in the micro-ethics, and didn't have a chance to  
12 look at the macro-ethics.

13

14 DR MCCABE: I think in part that's true. You know, the macro issue  
15 and healthcare issue in ethics would be, say, the allocation of  
16 healthcare resources, for example. And certainly that's outside our  
17 brief as an Ethics Committee, and it may be in treatment in clinical  
18 ethics that underpinning that, say dialysis for example, the Maori  
19 and Pacific Island population, although Maori make up say 15%,  
20 they're among 50% of people in renal failure, renal condition. So,  
21 it becomes a macro issue in that instance of allocation. But,  
22 that's - we've been told that's outside our brief, and we're unable  
23 to - so there is a frustration there.

24

25 DR ALLAN: Right, that's what I was trying to get at. Because, we've  
26 had a call that - this week particularly - to think of a bigger  
27 committee that was able to, if you like, not get caught up in the  
28 day-to-day things that come up in front of your committee, and look  
29 at the things as a whole. Now, you know, I'm not talking about so  
30 overarching we're talking about a theocracy, but I mean somewhere  
31 down a little lower than that within our system. And you'd find  
32 that quite helpful if there was some sort of bigger picture group?

33

34 DR MCCABE: Yes, I think so. I would agree with that, yes.

35

36 MR UPTON: There was a point that Dr Allan raised about funding  
37 issues, some of the more expensive funding?

38

39 DR MCCABE: And cardiac drugs.

40

41 MR UPTON: You're not involved?

42

43 DR MCCABE: No.

44

45 MR UPTON: You're not involved in that. Presumably when you're  
46 working as a committee you're applying the current National Standard  
47 that's been approved by the Ministry of Health?

48

49 DR MCCABE: Yes.

50

04000

1 MR UPTON: Can I move then to a, we'll call it a "macro" question.  
2 You talked about a national ethical body, as I understand it, that  
3 could deal with policy issues. Can I just explore that one a little  
4 bit further with the panel. Are you visualising that being limited  
5 only to ethical questions arising out of GM applications, or are you  
6 looking at it having a wider potential than that?

7  
8 MRS DICKINSON: I would say that that is a really core issue. The  
9 community has separated GM out as an issue, but at the same time  
10 there are issues about stem cells and many other things.

11  
12 MR UPTON: That's right, assisted reproduction, or whatever?

13  
14 MRS DICKINSON: Exactly. If we create a body that is specific to GM  
15 then you're going to have to multiply it every year with another  
16 body. We didn't actually push the case for a body, we said a  
17 policy. For a national policy framework.

18  
19 MR UPTON: But logically you could have someone or some group  
20 actually involved at that national level, because that would give a  
21 uniformity?

22  
23 MRS DICKINSON: Yes.

24  
25 MR UPTON: And a leadership?

26  
27 MRS DICKINSON: But I think it would have to deal - it would have to  
28 be - I hate to use the word "cost-effective", but it would have to  
29 be a group that could deal with the multiple issues in the genetic  
30 area. I mean the downstream applications of the human genome  
31 project, there's so many of them that we can't afford to multiply  
32 endless bodies. When I say "can't afford", I should say there, not  
33 in terms of money, possibly we could, but in terms of people to be  
34 involved in them. I mean, do we have that many people in  
35 New Zealand who could afford to sit on all of these bodies?

36  
37 MR UPTON: Quite. But you could easily visualise, I imagine, some  
38 sort of policy making level, some sort of policy making group or  
39 body at the national level, and then the existing type of structures  
40 making the individual decisions at the ground floor, as it were?

41  
42 MRS DICKINSON: Yes.

43  
44 MR UPTON: This is perhaps my idea rather than yours, but could you  
45 give any view on who might be members of such a policy making body?

46  
47 DR MCCABE: I think something similar to the HFA Ethics Committees  
48 now. So, a committee that embodied the wisdom needed to make  
49 informed choices about this or that research, so that means an  
50 interdisciplinary committee.

1

2 MR UPTON: Sorry, I'm talking about someone making policy issue,  
3 dealing with policy issues, and you're saying that the HFA model  
4 could be appropriate. I'm not talking about individual  
5 decision-making.

6

7 DR MCCABE: Yes, I think the HFA model could have insight.

8

9 MR UPTON: Can I take you back please to HSNO because Father McCabe  
10 mentioned earlier in his presentation that perhaps we're asking too  
11 much on HSNO. Could you elaborate on that a little bit please?

12

13 DR MCCABE: It was picked up also by Anne, that at the moment the only  
14 ethical basis is a consideration of harms and benefits. So  
15 therefore, you know, the primary focus of safety is too narrow.

16

17 MR UPTON: Right, and you want an ethical dimension to it?

18

19 DR MCCABE: Yes. I think the ethical questions beyond benefit and  
20 harm must have a way of being considered.

21

22 MR UPTON: Absolutely.

23

24 DR MCCABE: And that's where we suggest the need for a framework so  
25 that the wider issues from the community can emerge and be  
26 considered.

27

28 MR UPTON: Thank you. Can I conclude by moving to a topic that has  
29 not been addressed, and can I give you opportunity to address it,  
30 and that is what is the church's attitude to the work involving the  
31 use of animals? For example, a mouse or a sheep, or a cow, or  
32 whatever, and we can just address it in terms of sentient animals,  
33 because you made the comment that - you made the comment earlier  
34 about humans not being on the same level as plants and animals, and  
35 I just want to pick that topic up and explore it a little bit  
36 further?

37

38 MRS DICKINSON: I think I take issue with the point you say there  
39 about humans not being on the same level. I said, we are different;  
40 nature is different. If we can reflect about what we do, think  
41 about what we do, and we can make, you know, reasoned decisions.  
42 And in that respect I'm not sort of down-playing the whole web of  
43 life, if you like, at all because we're an integral part of that.

44

45 MR UPTON: Of course.

46

47 MS DICKINSON: In terms of animals, I don't think the church has really  
48 opposed the use of animals in research unless that is disrespectful  
49 of the animals, and there are many codes and ethics in place in  
50 New Zealand to cover those issues and we would be in accord with

1 those.

2

3 MR UPTON: It goes without saying that my question to you assumes  
4 appropriate care for the welfare of the animal?

5

6 MRS DICKINSON: It assumes appropriate care for the individual animal  
7 being used in the research, and it also assumes appropriate care for  
8 the species. So that, we don't do something - we may do something  
9 to the individual animal, but we don't do something that causes the  
10 whole species, if you like, to become extinct. So, there's a subtle  
11 difference there. I mean, you might have, you know, three of animal  
12 X in a pen, but altering the genetic composition of an entire, of  
13 all the animals of that type, is a different dimension to dealing  
14 with, you know, several of them.

15

16 I think also there, it would be important to realise that research  
17 which is simply directed at what is possible in terms of, that may  
18 create sort of freak type situations, you know, for animals, there  
19 has to be a good reason for doing it. And, it's not just a case of  
20 open slather on, what can we play around with as if they were toys?

21

22 MR UPTON: Quite. No doubt you're aware that there are Animal Ethics  
23 Committees?

24

25 MRS DICKINSON: Yes.

26

27 MR UPTON: In terms of our animal welfare legislation?

28

29 MRS DICKINSON: Yes.

30

31 MR UPTON: Which hopefully deal with the types of issues you're  
32 raising?

33

34 MRS DICKINSON: I'd also bring into play there the question about the  
35 boundary bit. Between humans and animals we have Ethics Committees  
36 like the one Father McCabe sits on, and we have Animal Ethics  
37 Committees. Now, we're now dealing in areas where there's an  
38 overlap between the two and it may be that we need to look closely  
39 at those boundaries. Are there things that slip between two  
40 different boundaries of two types of Ethics Committees?

41

42 MR UPTON: That takes us back to the earlier proposition that there  
43 should be room for an overarching national body that deals with all  
44 these ethical - lays down guidelines for all of these areas that  
45 we're talking about. Anyway, that completes my questioning. Thank  
46 you all very much.

47

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1 [2.00pm]

2 BISHOP RANDERSON: Could I just clarify one or two things about the  
3 Medical Ethics Committees? Am I right in thinking that currently  
4 germline therapy is not something that's currently practiced in  
5 New Zealand because we don't have a sufficient knowledge yet of that  
6 technique?

7

8 DR MCCABE: There is a moratorium on it in New Zealand at the moment.

9

10 BISHOP RANDERSON: I think what I'm wanting to - I mean, suppose an  
11 issue of that sort, or we might think of others - a new issue came  
12 up. Now, currently, would it come to a committee such as the one  
13 that you sit on, Father McCabe, and, if so, what would you do with  
14 it if it came up? And, leave aside the question of the moratorium,  
15 it's a new issue that's come on the scene, and would it come first,  
16 for example, to one of your committees?

17

18 DR MCCABE: It may do. Perhaps an example might help. We did - the  
19 Health Research Council, I think two or three years back, had a  
20 discussion paper out on xenotransplantation. So, it didn't come, as  
21 such, as a new issue, but it was a discussion paper for ethics  
22 committees to consider and then to pass back to HRC. So, I would  
23 suspect that something new, such as xenotransplantation, or germline  
24 therapy, would go through that route initially.

25

26 BISHOP RANDERSON: So it's sort of, at that point then, it's coming at  
27 a national level? I'm just trying to think -

28

29 DR MCCABE: Yes.

30

31 BISHOP RANDERSON: You couldn't have a scenario where an issue of that  
32 sort was coming up independently in two different regional  
33 committees and they're each making different decisions about it  
34 without reference to some overarching policy?

35

36 DR MCCABE: No. No, I don't think that would happen at the moment.

37

38 BISHOP RANDERSON: So that something in this case which came through  
39 the HRC, if there were some national body or framework, that would  
40 perhaps give greater focus to this particular example?

41

42 DR MCCABE: Yes, and I see that as part of their brief.

43

44 BISHOP RANDERSON: Thanks. And then, just shifting to another topic.  
45 I realise that you've focused very much on the sort of medical  
46 issues, and haven't really commented on other areas such as crops  
47 and fields and forage grasses and organics and some of those sorts  
48 of things, which is perfectly acceptable not to have done that, but  
49 is it a subject that the Catholic Church has considered and has a  
50 view on?

1

2 MRS DICKINSON: I wouldn't say we haven't commented on it. It would  
3 be our belief that that would have to be also worked out in relation  
4 to things like respect for autonomy. I mean, the rights of organic  
5 farmers to preserve their livelihood, and of conventional  
6 agriculture, if you like, to not be affected by GM agriculture, that  
7 is why we put forward the framework of principle, because we believe  
8 that those crop issues, the agricultural issues, if you like, would  
9 be best worked out taking account of those principles.

10

11 BISHOP RANDERSON: And then my final question is really to do with the  
12 principles. I looked for a principle perhaps more along the lines  
13 of sustainability of the environment, and it's not one of the five  
14 that you mention, and I did notice that the reference to the  
15 environment, you depended fairly heavily on Maori views. I'm just  
16 wondering, where within western traditions, or Christian traditions,  
17 or non-religious traditions, you know, you would see parallels for  
18 what you've outlined about whakapapa and the Maori world view?

19

20 DR MCCABE: I think for us in the Catholic tradition, we would see  
21 that meshing in very much with our stewardship of creation, and  
22 we're aware that other churches this week have spoken about that  
23 principle. So, for us, life is a gift given in trust, and that  
24 includes the environment, and so that means protecting and nurturing  
25 and - I think at heart I see the Treaty principles as deeply  
26 spiritual and expressions of our Catholic belief in the universal  
27 sense.

28

29 BISHOP CULLINANE: And we would see that, not as an end in itself, so  
30 much as a way of being human. As you know, the whole Judaic  
31 Christian sees the world as the human habitat, it's the place given  
32 for the human being for their life, for their ends. So what we do  
33 within that human habitat, whether that's the way in which our  
34 activities depend on animal life, or vegetable life, or whatever, is  
35 something we're actually doing to ourselves and it becomes a  
36 statement about whether we're in the business of making life more  
37 human or less human. And everything we touch in some way does that,  
38 including all these different dimensions of the human habitat.

39

40 BISHOP RANDERSON: I take the point that Anne Dickinson made about  
41 human beings being different from animals, but I think some would  
42 query a view that perhaps suggested that the environment existed in  
43 order to enhance the human dimension of it. Now, I'm not sure if I  
44 quite picked up what you were saying, but is this really saying that  
45 humans are at the apex of the environment and the rest of the  
46 environment exists for their benefit, or not quite that?

47

48 BISHOP CULLINANE: I'm certainly not wanting to put down the  
49 environment, the world has, you know, the world has its own  
50 splendor, but at the end of the day we're making a statement about

1 the dignity of persons. And to state that the habitat is for human  
2 beings, is a statement about human beings, isn't it? I would think  
3 that we would be taking away from human dignity if we didn't see it  
4 as the summit of God's creation.

5

6 MRS DICKINSON: Could I just, I see you mentioned my comment there,  
7 because I feel a little misinterpreted on that in some of the  
8 questioning that's followed it. It's simply that human beings are  
9 the only form of life capable of stewardship and that in itself  
10 makes us different, that we are the only life form that can actually  
11 act in a stewardship role to the rest of the planet. And throughout  
12 both our written submission and also in this one, we have also  
13 included respect for the environment. We would not necessarily see  
14 it as an separate principle, but we would see it threaded through  
15 all of the ones that we have mentioned. And if we appeared to be a  
16 bit human-centered, if you like, then that's possibly a bit of a  
17 misrepresentation of that stewardship aspect, which we do hold quite  
18 strongly.

19

20 BISHOP RANDERSON: I think the issue is whether the environment has  
21 some intrinsic value in its own right in a sense of collectivity, or  
22 whether the value of the environment is measured in terms of how  
23 much it contributes to human well-being and, therefore, giving a  
24 lift to human beings as being of greater significance than the  
25 environment of which they are a part? I think that's the sort of  
26 debate we've been having over various weeks. Thank you.

27

28 DR FLEMING: No, just like to say how useful your submission has been  
29 and thank you for it. Thank you very much.

30

31 DR ALLAN: I just wanted to go back, teasing out something, because  
32 there's a bit in it that fascinates me, and that's this issue of  
33 germline. Now, first, I just wanted to comment a couple of things  
34 that we've heard here in the Commission. One was Dr Steven Hughes  
35 from the Nuffield Council on Bioethics. He said that he could never  
36 justify germline therapy. Another one was Dr Ingrid Winship and  
37 Dr Joanne Dixon, who - one's my age and one's younger, so I can  
38 assure you they are not very old. They said that in their lifetime  
39 they would never see germline therapy, they couldn't imagine it. In  
40 fact, one of them called it science fiction, and yet on the other  
41 hand I see some desperate families that it gives hope to.

42

43 Now, in that background I am still curious why you came up with the  
44 five year moratorium? Why five years?

45

46 DR MCCABE: No, we didn't.

47

48 MRS DICKINSON: We didn't. That was a misquote of what we said, and  
49 that's - you'll not find this in our written, or in anything that  
50 we've said "a five year". We've said that we believe there should

1 be a ban on it for a period of time and we haven't - then the  
2 question comes back, "What happens at that end of that period of  
3 time? Does it get reviewed when new technology comes available?"  
4 Because, unfortunately, we find these reviews come after the  
5 technology, not before. In fact yesterday a comment was made that  
6 GTAC only came into existence after some work had been done in  
7 Auckland. Sorry about throwing them hard at you Father McCabe,  
8 they're difficult questions.

9  
10 DR MCCABE: They're absolutely difficult questions, and as the group  
11 this morning, you know, we would want to acknowledge at the outset  
12 the suffering from inherited diseases which can confer significant  
13 disadvantage and obstacles and a cross for the families.

14  
15 However, we make the point in our submission, and using the  
16 guidelines of Pope John Paul in 1983, and we think the strength of  
17 that quote has stood the test of time. Because, it's looking at the  
18 philosophy beneath it, and he says, "A strictly therapeutic  
19 intervention whose explicit objective is the healing of these  
20 various maladies, such as those stemming from deficiencies from  
21 chromosomes and/or genes will in principle be considered desirable,  
22 but it's a big, provided - provided it is directed to the true  
23 promotion of the personal well-being of men and women and does not  
24 infringe on the integrity or, I think importantly, worsen their  
25 conditions of life". And that's the big risk for us, so we're not  
26 anti - because Pope John Paul was very clear that this intervention,  
27 a therapeutic intervention, falls within the logic of the Christian  
28 moral and healing traditions, and where there is the strong image of  
29 being co-creators with God in the use of our technology. But the  
30 significant risk and the danger of the inheritability of mistakes,  
31 personally I'd want to see ironed out just a little bit more before  
32 we went ahead and did it and then had to go backwards.

33  
34 BISHOP CULLINANE: It's a kind of double statement, isn't it? It  
35 acknowledges risk and the need to obviate risk, but it's also  
36 declaring an openness to human activity of this kind. And, I think  
37 we'd be unwise to place our prior limitations on what might turn out  
38 to be authentic genuine human progress, and the church has made  
39 mistakes in this respect in the past, and, I mean, it's been  
40 premature in obstructing scientific progress at times. I hope we've  
41 learned something.

42  
43 MRS DICKINSON: I think the statement, "limitation not in my lifetime"  
44 is a very dangerous one to make. I mean, I'm sure somebody said it  
45 10 years before the Wright brothers flew, or before somebody opened  
46 up a human body to act in that way.

47  
48 DR ALLAN: My favourite one is Bill Gates, "640 megabytes should be  
49 enough for everybody".

04007

1 DR MCCABE: Not to mention his salary.

2

3 CHAIR: Well, thank you very much for coming along, and we all want to  
4 express our appreciation of your considered and well-thought-out  
5 written submission. We've enjoyed reading that.

6

7 Well, that concludes our session for today. Tomorrow we - the  
8 Commission is in Christchurch so, we adjourn until 9.30 tomorrow in  
9 Christchurch.

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13 Hearing adjourned at 2.15pm

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