



COMMONWEALTH OF AUSTRALIA

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: CJD settlement offer

MELBOURNE

Tuesday, 12 August 1997

OFFICIAL HANSARD REPORT

CANBERRA

SENATE
COMMUNITY AFFAIRS REFERENCES COMMITTEE

Members:

Senator Bishop (Chair)

Senator Knowles (Deputy Chair)

Senator Forshaw

Senator Neal

Senator Lees

Senator O'Brien

Senator Lightfoot

Senator Synon

Participating members:

Senator Abetz

Senator Colston

Senator Bob Brown

Senator Faulkner

Senator Bob Collins

Senator Margetts

Matters referred for inquiry into and report on:

- (1) The fairness of the recent settlement offered by the Commonwealth Government to recipients of human pituitary hormones, with particular reference to:
 - (a) whether the Government's response to the Allars Inquiry recommendations has been fair and adequate;
 - (b) whether the Government refused to make certain relevant documents related to the inquiry available to recipients;
 - (c) whether the Commonwealth's offer to the recipients was fair and adequate and gave recipients sufficient time and information to make a considered response; and
 - (d) whether legal aid has been unfairly denied to the recipients, placing them under more pressure to accept the Commonwealth's offer of settlement.
- (2) Whether the Commonwealth Serum Laboratory (CSL) or CSL Ltd, the National Health and Medical Research Council, the Department of Health and Family Services or any other Commonwealth department, agency or employee failed to adequately protect public safety in relation to the Australian Human Pituitary Hormone Program.

WITNESSES

BAKER, Mrs Pamela, 9 Monash Street, Morwell, Victoria 3840	43
BRODRICK, Mrs Geraldine Mary, 13 Kuranda Drive, Robina Island, Queensland 4226	3
BYRNE, Mrs Sue, National Coordinator, CJD Support Group Network Inc., 3 Kristen Close, Frankston, Victoria 3199	3
GLEN, Mr Michael Francis Suttor, Solicitor/Partner, Rennick Briggs, Level 1, 459 Little Collins Street, Melbourne, Victoria 3000	53
LEE, Mrs Eleonore Ellen, 8 Collins Street, Geelong West, Victoria 3218	43
OGILVIE, Ms Samantha, 1/151 Glenhuntly Road, Elwood, Victoria 3184	43
SOLVYNS, Mrs Suzanne Lesley, 13 Araluen Place, Glenhaven, New South Wales 2156	3
STACHLEWSKI, Mr John, 12 Austin Street, St Albans, Melbourne, Victoria 3021	30
STACHLEWSKI, Mrs Gina, 12 Austin Street, St Albans, Melbourne, Victoria 3021	30
WILSON, Mrs Carol, 2399 Gordon River Road, National Park, Tasmania 7140	3

SENATE
COMMUNITY AFFAIRS REFERENCES COMMITTEE

CJD Settlement Offer

MELBOURNE

Tuesday, 12 August 1997

Present

Senator Bishop (Chair)

Senator Forshaw

Senator Lightfoot

Senator Lees

Senator Neal

Other senators in attendance

Senator Harradine

The committee met at 9.36 a.m.

Senator Bishop took the chair.

CHAIR—Welcome to this public hearing of the Senate Community Affairs References Committee. The committee is commencing its hearing into matters relating to the CJD settlement offer, which was referred to the committee for inquiry and report by 31 August 1997.

The program has been arranged to allow the committee to take evidence in public session and also in camera. I should warn the audience that the committee may ask for the room to be cleared to hear evidence in camera if the witnesses request that that be done and the committee agrees. The committee may also decide itself to hear certain evidence in camera. However the committee prefers, as far as possible, to hear evidence in public.

I should point out that the hearing of evidence in camera does not preclude its later publication by the Senate, by the committee or by an individual committee member in a minority or dissenting report. There is a specific resolution of the Senate covering such possible publication.

The committee will commence hearing evidence from witnesses who have agreed to give evidence in public. However, if at any time during the questioning a witness considers that it may be more appropriate for the committee to hear part of their evidence in private session, the committee will give consideration to their request to give further evidence in camera. The witnesses have been provided with the guidelines for witnesses appearing before parliamentary committees, which set out Senate resolutions relating to parliamentary privilege.

[9.37 a.m.]

BRODRICK, Mrs Geraldine Mary, 13 Kuranda Drive, Robina Island, Queensland 4226

BYRNE, Mrs Sue, National Coordinator, CJD Support Group Network Inc., 3 Kristen Close, Frankston, Victoria 3199

SOLVYNS, Mrs Suzanne Lesley, 13 Araluen Place, Glenhaven, New South Wales 2156

WILSON, Mrs Carol, 2399 Gordon River Road, National Park, Tasmania 7140

CHAIR—I welcome representatives of the CJD Support Group Network. In what capacity are you actually appearing today?

Mrs Wilson—I am here as Carol Wilson, not as the state coordinator of the CJD Support Group Network.

Mrs Byrne—I am here as the national coordinator of the support group.

Mrs Solvyns—I am here on my own behalf.

Mrs Brodrick—I am the Queensland coordinator of the support group, but I am here representing myself.

CHAIR—The committee has before it submission No. 24 from the CJD Support Group Network, submission No. 52 from Mrs Solvyns, submission No. 18 from Mrs Brodrick and submission No. 33 from Mrs Wilson. Do any of you wish to make alterations to those submissions? As the answer is no, I now invite each of you to make a short opening statement. At the conclusion of your remarks, I will invite members of the committee to put questions to you.

Mrs Byrne—Firstly, we are all very pleased to be here. We are delighted that the Senate committee of inquiry was established. I know that Senator Harradine was in favour of having one some years ago, but we were not in favour at that time because we thought then that the litigation was actually going to get up. Part of the point of the litigation was to have some sort of public airing of all the issues. We thought that would happen in the courtroom but it has not, so we welcome this hearing, which might well be our last chance to air some of these issues.

The basic point behind the inquiry is the settlement offer that was made by the Commonwealth to recipients, and whether it was fair and adequate. I think almost everybody in the support group would feel that it was neither fair nor adequate, largely

because it completely ignored the grounds on which we were litigating. The litigation was about psychiatric injury due to the nervous shock of finding out about the risk of CJD. It was not about dying of CJD. In lots of ways they are two very separate issues. Those of us who were engaged in the litigation were surprised and shocked when the litigation came to such a screeching halt the day before we were supposed to be in court.

I have gone through the whole chronology in the submission. Just prior to that we had been asked to make a financial contribution. Between us we had put in \$46,000. We were not obliged to do that because of the way the case was set up, but we all felt so strongly about it that, when we were asked for \$750 each, almost all of us kicked in. People made enormous sacrifices—they borrowed from friends and family. People were thinking about cashing in their superannuation or selling cars just to support the litigation and to make sure that it did go ahead.

We found out on 4 April that it was not going ahead, and when we found out the terms of the settlement we were absolutely appalled because, in essence, it gives us absolutely nothing. We had no reason, and we still have no reason, to believe that, if anyone of us contracts CJD tomorrow, we would not be able to get pain and suffering compensation from the Commonwealth. Whether or not you have to go to a lawyer first is neither here nor there, really. The other cases that have already died have certainly had common law damages after they were dead. We had absolutely no reason to think that we would not be able to get that fairly easily.

The husbands did not have to go to court. They were very willing to go to court. They would have liked to have had the issues aired in a courtroom just as we would. They never got that chance because the Commonwealth leapt at the opportunity to settle before they got to the courtroom.

I do not think that any of us fear that the case would be heavily defended if we did in fact come down with CJD. There is nothing in the settlement for us. The only difference the settlement makes, if we accept it, is that we say that we will never take any legal action against the Commonwealth or CSL about any issue to do with CJD ever again. For a lot of people that is the rub, that is the real sticking point. They do not want to sign that release.

About 90 people have signed the settlement agreement already. Many of those 90 people feel very strongly that they were intimidated into doing so and did so very much against their will. I feel that something needs to be done for those people because, even if we are successful in getting a recommendation from the committee that legal aid should be made available to us and even if the Commonwealth decides to act on that and provide legal aid, those 90 people no longer have the capacity to sue the Commonwealth or CSL about anything to do with CSL. They are really out on a limb.

Some of those people are the very people who do have significant psychiatric

injury and who can prove it quite easily. Their lives have been severely damaged by it. Because they are already severely damaged they were probably in the worse position to stand up to the Commonwealth and say, 'You can take your offer and jam it,' which is what a lot of us said.

In the end you had to be reasonably brave or determined to stand up against the intimidation that we received. People were told that the sheriff could enter their homes and seize their goods if the Commonwealth decided to pursue them for costs. For most people that is a fairly terrifying prospect. People will say, 'I don't have anything, we don't own our house, we don't have any savings, so the Commonwealth cannot get anything back from us.' But when you are told that the sheriff can knock on your door and come in and take the stereo, the TV, the kids' computer and all those sorts of things it is very intimidating and lots of people succumb to that sort of intimidation.

I might point out that it did not come from the Commonwealth or the AGS; it came from our solicitors, who abandoned us on the day that the test case settlement was signed. They decided that they were no longer going to act for us. They did not want to know about it. We got virtually no information from them from that date until the time the Senate inquiry was announced. There was no information forthcoming from them except that we had no choice but to settle—the only option was to settle.

If we did not settle then the Commonwealth would come after us for costs. 'You can't do anything else; all you can do is settle.' That was the universal story that everybody got—it was exactly the same reaction. There was no advice as to alternatives. There were no other courses to follow. It was just, 'The only thing you can do is settle. You have no choice. You must sign the release.' Numerous recipients will tell you that that was exactly the story they got whomever they asked at that firm.

Basically, I think we all feel that legal aid should have been available to us. If we do not fit the criteria, then we should because here we have a situation where ordinary Australians feel that a wrong has been done to them by the Commonwealth and its agencies.

The case has been tested. I think there were three preliminary hearings where the Commonwealth tried very hard to have the case struck out, to have it found not good at law. On all three occasions the court found that there was sufficient reason to go ahead with the litigation, that it was worth giving it a run to have it decided on its merits.

So it was not a weak case. It was not a worthless case. It was not a case without merit. It did essentially fail specifically because there was no legal aid. I think a lot of ordinary Australians look around them and see other groups getting legal aid and wonder why people like us cannot.

It is an extraordinarily expensive sort of case to run. I have had estimates of up to

\$1 million to run it. Given all the background work that needs to be done, the overseas witnesses and the case was going to run 15 weeks in the Victorian Supreme Court, it is not a cheap exercise. No Australian—with two possible exceptions, I suppose; Packer and Murdoch—could afford to run a case like that as an individual. You would have to have legal aid. It is not just a case about one person, it is not even a case about 2,000 people; it is a case about all Australians and the way their health system and the way the regulatory system works for them or does not work for them, as the case may be.

I think most recipients would like to see some sort of across-the-board compensation because for us it not essentially about and not only about the risk of dying of CJD. Because of the nature of the disease, because you cannot test for it, because you cannot diagnose it and because we know it is transmissible through organs and there is a suspicion that it might be transmissible through blood, we are treated as a public health risk. Realistically, the vast majority of us will never develop CJD, but for the rest of our lives we are treated as public health risks.

The Red Cross has a list of our names. We cannot donate blood. Even if we do not answer the questionnaire correctly, there is a double check and, if our names come up, then we are turned away. We cannot donate organs. There is a list with all the organ donation agencies so we cannot by any chance get through that one either. We have a special set of infection control guidelines written by the NHMRC which are incredibly worthy and a terrific safeguard to public health, but they certainly make our lives difficult.

You may have read in the support group's submission one of the addenda about the case history of a woman who had a baby in Perth eight months ago and about the horrific things that happened to her. She was treated as though she was high risk. She was treated as though she had CJD. She was treated as though her blood was contaminated. That was an extraordinarily unpleasant way to have a baby. What should have been a really joyful event for her and her family turned into a bit of an ordeal.

She ended up feeling like a leper. She felt as though she had something that everybody was very terrified of catching and that the hospital could not wait to get rid of her, basically. Everything was incinerated. All her blankets were incinerated when she left. It was just a complete over-reaction to those infection control guidelines.

That sort of thing happens to us all the time. We have letters from the health department that we can give to our health professionals. They are very good in their way because they save us from having to go through the whole story again and again. They give the decontamination details that those health professionals need, but people have very unfortunate experiences when they use them.

Again, you may have seen in the submission the case of a woman who had the ghastly experience of having her tooth pulled out by a dentist wearing a glove. He actually did it with his fingers. He said it was a new Japanese method. She was highly suspicious

about the motives for that. Other people have actually been turned away from their dentist. The dentist said, 'No, I can't possibly treat you in the surgery. You'll have to go to the dental hospital.' Other people having surgery or minor procedures in a doctor's rooms have been told, 'No, we can only treat you on Friday afternoon at the end of the list because that's the only time we'll have time to do all the decontamination that we need to do.'

It is not the sort of thing that we can just move on from. If we could move on from this I think a lot of us would. But because of this public health status that we have we cannot move on and we cannot forget about it. We are not allowed to forget about it. I think a lot of recipients feel that some compensation is due for that. Obviously there is no damage in the way that the law sees damage, but I think all of us feel that our lives have been fairly severely damaged just by being in this group, just by having these restrictions placed on us. They are going to stay there until we die. When I finally check into the nursing home at 85, I am going to have to carry that damn letter from the Commonwealth telling them about the decontamination procedures. It is not a lot of fun, believe me. It makes aspects of life which for other people are quite ordinary much less than ordinary for us.

Carol has just reminded me that I had an unfortunate experience yesterday. Yesterday was a very busy day. I was on the radio, and somebody listening to that program recognised the treatment that his son had had. He rang me later in the afternoon. I had the unpleasant task of telling him that yes, I agreed with him. I thought it sounded as though his son had had the pituitary hormone treatment too. This boy is now 25. He is actually at the Australian Institute of Sport, so he has got to the top of his field. He is a very successful young man. He had a brother, but that brother died of leukemia when he was much younger.

This family that went through that tragedy and raised this son to manhood and to success now has this other huge shadow hanging over them. They have to tell their son now. The whole family has to work through it. We all know it is going to be a very painful process. It is a particularly painful process for those growth hormone families because not only does the person who had the treatment have the risk and the anxiety, the parents very often have huge guilt because they were the ones who decided that the child would go on the program. Very often they were the ones who actually gave the injections. It brought it all home having to explain to this man exactly what the ramifications were. Of course he did not know what CJD was, so I had to tell him. That is never a lot of fun. It is not a nice disease to explain to people. They are not looking forward to the task of having to explain it all to their son. You know that you have basically ruined that guy's day and that you are probably going to ruin quite a few months of the family's life. I will stop there and let the others have a go.

Mrs Solvyns—I was a non-litigant—not because this did not have a huge impact on my life, because it has, as I put in my submission but because I found it very hard to

see how I could prove psychiatric injury. I guess I represent the majority of recipients. Out of the 2,000-odd, about 150 were litigants and the rest were not. I have concerns that this inquiry does take into account the non-litigants along with the litigants.

I know through my involvement in the support group that very many of the non-litigants have suffered as much if not more than some of the litigants. I think it needs to be made fairly clear that there are a lot of people out there who have suffered so much that they could not even face the fact of taking on a legal challenge. I think that is a point to make to you.

Of course, I have also had dealings through the support group with litigants. I think the pressure that has been put on those people has been atrocious. Most of those who I have spoken to who have settled are very upset that they have been forced to settle. They do not feel that they have done it by choice. They feel that they have been pushed into it. According to the New South Wales recipients that I have talked to, the risk of the costs that may have been awarded against them was the main motive for signing.

I also feel that those who have not settled have experienced great anxiety with the extension of time and the process of trying to get through each time and wondering what would happen. I guess this inquiry has been the godsend that has probably saved them from having to sign because everybody was quite frightened. Putting their families at risk of huge costs was quite devastating to many people.

Since settlement, the actual impact on the lives of recipients has been quite huge. I also have concerns about non-approved recipients. It has come to pass that no decision has been made on the Commonwealth even in terms of the settlement that has been given to recipients. No decision has been made whether this is available to unofficial recipients—that is, people who were treated by doctors in their rooms with leftover product and that type of thing. A lot of these people have medical evidence that they have been treated and yet at this stage the settlement does not extend to them. That is another concern of mine because many members of my support group are in that position. I want to point that out to the inquiry.

Mrs Brodrick—I thank members for the opportunity to speak in support of my submission to this inquiry. During the years since my HPG treatment I have been concerned and suspicious about the lack of information supplied. These concerns were raised by the media debate that followed the birth of my children. Subsequent events have revealed the risk of CJD and shown why so little was divulged.

In my opinion the settlement offer by the Commonwealth in the APQ test case was an affront to every HPG and every HPH recipient and a complete denial of natural justice. The health minister's statement following the announcement of the settlement was designed to trivialise the whole issue and only served to heighten the stress and the anger of all recipients. It did nothing to extend the measures put in place by Dr Carmen

Lawrence following the Allars report findings and the extension of terms to people treated prior to 1977 is irrelevant.

Death from CJD is not a totally unlikely event. It has occurred in five known cases and since the settlement was announced another recipient has been provisionally diagnosed. On this basis alone recipients must remain under a very real threat and threatening is the best word I can use to describe the Commonwealth government's actions throughout the course of this issue. Following the announcement of the settlement on 4 April, recipients were offered just 14 days in which to accept its terms or risk potential financial disaster. Bullying tactics of this kind are unacceptable in any situation, more so when they are instigated by one's own government.

Complicit in the exertion of this pressure were Rennick Briggs, the solicitors retained to act on behalf of litigants. Rennick Briggs were allegedly paid \$1,200 for every signature they obtained from recipients to release the government from any future responsibility. Those of us who chose not to be coerced were granted extensions of time. This I feel indicates the government's concern that it might not achieve the same outcome should this case ever be tried again.

Denial of legal aid was clearly the reason why APQ's test case did not proceed. Already the government had mounted, as Sue mentioned, and lost the three appeals. Obviously, they were delaying tactics by a defendant with unlimited resources. Denial of legal aid to recipients with a legitimate recourse to the legal system is, in my mind, unfair to the extreme. Furthermore, I cannot see how I or any other litigant could have been expected to make an informed decision regarding the settlement without access to all the relevant information. We were given little time, no information and just an ultimatum.

No-one from CSL—whose actions in harvesting the pituitary glands under completely uncontrolled conditions must border on criminal negligence—has ever been held to account. Nor have any members of HPAC, who sought kudos and career advancement ahead of prudent medical practice and patient safety.

The Allars report states that it was plainly an abuse of power that allowed HPAC to make special arrangements directly with the director-general of health and the minister, thus circumventing the Pharmaceutical Benefits Advisory Committee and ignoring its recommendations of 1964 and 1967. This resulted in the listing of hormones under section 100, an action which has been found to be legally invalid. If the correct protocol had been followed, it is quite possible that the program would never have been approved for human use without further investigation and stricter controls.

All who conspired to force this terrible legacy on hPG and hPH recipients are now being protected by a government and its officers who would rather see innocent recipients denied justice than admit to the ineptitude and negligence of those involved in producing these treatments and administering this program. The only humane and

commonsense course of action is to now do what should have happened originally, and for the Commonwealth to make a fair, reasonable and voluntary settlement with all recipients.

I am in no doubt that the evidence available supports my belief that the government has a responsibility to make such a settlement with those of us who live with the very real threat that our lives could be shortened, through no fault of our own. This will save further waste of public money in defence of what has been a criminally negligent program that has already been responsible for several unnecessary deaths and has left the remaining recipients with the constant fear that any one of us could be the next victim.

CHAIR—Thank you. Mrs Wilson.

Mrs Wilson—Where do you start? When I first received my letter from the treating specialist, it took a week for the actual words of the letter to sink in. I was just numb. I tried very, very hard to contact this doctor but he was unavailable. I even made out I was a nurse and rang the hospital to try to speak to him. The minute I said, 'I'm Carol Wilson, Doctor,' he hung up. I had not seen him for 25 years and yet, with the things that had occurred in the press and everything, he just hung up on me. And he was the man I needed to talk to, to ask the questions: 'What has happened?' 'Why are you telling me in this letter?' I cannot donate blood; I cannot donate organs. I needed answers and I could not get them, and that is what made us so frustrated. We could not get answers from any of the government departments. It was like butting your head up against a brick wall.

I rang England and America and spoke to professors and other people over there, asking for help and information to ease my mind and my family's mind about what this long medical word was and what it was going to do to me. I went to libraries and I tried to get information. We formed groups and started writing letters to see if we could get some answers. We made some good contacts and got some answers which, when we put them together, scared us a little bit more.

Each recipient knows what the other is feeling because we sat there and had those injections. Nobody else can understand exactly what you feel. You pick up the phone and say hello and there is another recipient at the other end of the phone. You know she is there because she is crying. She has probably just read something in the press or seen it on TV. It sparks it over and over again. Something will happen to you and you think, 'My God, is this the start of this?' You will read of another death. Everything just goes over and over. We get no satisfaction.

Last year, my nephew had Alport's disease and needed a kidney, and everything happened very quickly. He went on to dialysis and all of a sudden we knew that there was a three-to-five year wait for a kidney to save my nephew's life. So the specialist from Melbourne decided that maybe a family member could donate a kidney and they did the

tests.

The boy's father was compatible. So was I and I could not help him. That's what gets to you. I had to watch while my brother gave his kidney to his son to save his life and there was no way I could help either of them by giving an organ or blood. To me that is wrong. Why should I be made to suffer for somebody else's mistake? Why should I be penalised for the rest of my life and put through this garbage? Why can't somebody say to me they did wrong? They should be held accountable and be made to pay and, for God's sake, never ever do it again. Nobody should go through what we are going through, fighting for what we know is right.

I am innocent. I have not done a damn thing. But I am being made to feel so guilty when the lawyers say to me, 'The government will probably come after you for their incurred costs.' Why? I have paid taxes. Why should I have to double dip again? Why should I have to put my family through all this? Many a night you do not sleep. The phone rings through the night. If somebody is upset they will ring. I have got in my car and driven for two hours to go and talk to somebody because I know what they are going through, and I have done that day after day and for the last four years.

Somewhere somebody has to make somebody accountable. The doctors who did it, when did they know? Why didn't they say something? Why was it allowed to continue? I wanted to ask my own specialist did he know. If he did, when did he know? We are told that they all knew in 1985, but they did not tell us for heaps of years after and then all you get is the letter: 'Please do not donate blood. Do not donate organs. You may have this rare disease.' How would you feel if you got a letter like that? Maybe down the track if you have had a child on the program, who knows? They tell us no, it may not happen. How would you feel if you passed it to your child? I might not get it but the child might. You live with that.

Parents gave their children the growth hormone. I have a case down home where the mother and the son are fighting. I have been mediating between the two of them trying to get them to talk, but all of a sudden the son is just so angry. He blames his mother because she signed the paper for him to have the injections. Why should they both be put through it? It makes you wonder where it will all end, but I am damn sure it is not going to get me.

Mrs Byrne—What Carol and Geraldine were saying about accountability is extremely important to recipients. Above everything many recipients will say to you that this is not about money; this is about making people accountable. Reading the Allars report is a chilling experience if you are an Australian who thinks we have a really good health system with lots of checks and balances, that people cannot do things that are unsafe, that all clinical trials are regulated and that the left hand does know what the right hand is doing. Reading Allars is just horrific. It was really Dracula in charge of the blood bank after 1976.

Four people who were intimately involved with the program are actually controlling the program. The regulation of product is being conducted by somebody who works for the organisation who is controlling the product and who invented the process. There were no checks and balances. There was no independent review. There was no scope of expertise. It was a very narrow, a very self-interested group, who were running the Australian human pituitary hormone program.

As to whether they could have or should have known, the English verdict last year, a very conservative verdict, found that after 1 July 1977 those English doctors could have or should have known of the risk that they were transmitting to their patients. If English doctors in 1977 could have known and should have known, so should Australian doctors. If it is in the *New England Journal of Medicine*, if it is in the *Lancet*, if it is in *Science* and if it is in *Nature* then any person in control of the program like that, which is publicly funded, ought to be making himself aware of those pieces of information and putting them together for the protection of their patients.

None of the people on HPAC has ever been given any chastisement or any punishment. They have not lost a thing. Many of them are still in public funded jobs. They have chairs at universities and research institutes. They have NHMRC grants. This was not a long time ago. It was 1988 when they finally realised that they were no longer able to go and play with their pituitary hormones, that they had to put it away for good.

It is incumbent on somebody—presumably the Commonwealth—to bring some accountability to those people. If they are never made accountable, then they will have no reason for changing their ways, and other people in the same position will not have any reason to think that they should not go the merry way that HPAC did.

Senator LEES—I refer to the pressure to sign and to agree. I want to know who the individuals are who were involved in the process. Who were the people who said, ‘You have to sign. There will be problems in reclaiming the costs by the Commonwealth if you do not’?

Mrs Byrne—Up until 15 May we had no direct contact with the AGS. Our only contact was with our own solicitors—Rennick. The only thing that we had which had come from the AGS was one letter which Geoff McDonald had sent to Sean Millard, and it was a very lawyer-to-lawyer letter. It was brief, it was blunt, and it was to the point. It was couched in lawyer language.

That letter was copied and sent round by Rennick to all their clients. It was made out to be some sort of real threat that the Commonwealth would pursue individuals for costs. In my view, all the pressure came from Rennick. People were ringing the office and speaking to the legal secretary, who said, ‘You must settle; you don’t have any choice.’ Michael Glen and Sean Millard were both telling people over the phone, ‘You must settle; you don’t have any choice.’

After 15 May Rennick ceased to act for us. It is intimidating when your lawyer writes to you and says, 'Here you are; you are between a rock and a hard place. We are out of here.' We knew we could not get any other law firm involved quickly. I had numerous conversations on behalf of everybody in the early days after the settlement was offered. Firms were saying, 'This is a very complex thing. We can't pick this up and run with it today. It would take us weeks to get up to speed.' Yes, it would, because it is a very complex case. So there was no way of getting any outside information.

We were very reliant on Rennick; they were the ones telling us. Rennick went to Tasmania and had a meeting with their incipients in Hobart. That was where the sheriff story came from. That was an example that they used. Although many of us realised that the Commonwealth very rarely pursues individuals for costs in cases like this—it is not a good PR exercise really, is it?—that was not the story that people were getting.

It does not seem to be the story that APQ was getting, either. It would seem that part of the reason that she settled—I have this only at second and third hand—was that she was given the very firm impression, by Rennick and by the barristers who were acting for her, that she would be pursued for costs and that she stood every chance of losing everything that her family owned if she did not settle. In my view, there is no doubt as to where the pressure came from. I think that that would be borne out by most litigants.

Senator LEES—I do not remember sighting that letter that was circulated. Is it part of your submission? It is all right; we will track it down.

Mrs Byrne—No, I do not think it was. I think I had a letter that came from Rennick with it but not that particular letter. I do not for a moment think that that letter was intended for our eyes.

Senator NEAL—Mrs Wilson, you were telling us that your first notification was when you received a letter in the post, and you then had difficulty contacting your doctor. I am interested to know how you came to know what the situation was after that point?

Mrs Wilson—After—

Senator NEAL—After you had contacted your doctor, and he was unwilling to speak to you.

Mrs Wilson—In the letter—which I included in my submission—I was told to ring a sister at the hospital. I rang, and I was told that the sister was on sick leave and to ring back in 10 days. I then rang back in 10 days and was told she had now taken annual leave of another three or four weeks. So it took me six to eight weeks before I got to speak to her, and all she could tell me was: 'You can't donate blood, you can't donate organs. Here's the name of a lady who lives in Hobart. Go and talk to her.'

Senator NEAL—And was the lady a doctor or—

Mrs Wilson—No, she was another recipient.

Senator NEAL—I assume you did that?

Mrs Wilson—Yes.

Senator NEAL—Did you ever have someone in the medical profession explain to you what the problem was?

Mrs Wilson—No.

Senator LEES—Has there never been any move on the part of the government to work with you and to go through—particularly in earlier days—what the risks were, once you—

Mrs Wilson—Never in the earlier days.

Mrs Byrne—In the earlier days it was very difficult. Admittedly the health department was in something of a panic. This was a very unusual situation for them to find themselves in. We were basically handed over to the AIDS and communicable diseases section of the health department, which was quite adequate and appropriate in its way because they were used to counselling people about risks to life and they were used to talking to people about transmissible diseases. But it was very ad hoc.

Senator LEES—Could you tell me roughly when that was?

Mrs Byrne—Most of us began to find out in January 1992, so it was pretty ad hoc from—probably—the beginning of 1992 to the end of 1993.

Senator NEAL—How much time was there between when the letter was first sent out saying that there was this problem and when a set-up where you could talk to someone about the risks was organised ?

Mrs Wilson—In 1993.

Mrs Solvyns—It would be 12 months. As I put in my submission, I received a call to ring my doctor, and I was told I had a contaminated batch—a batch that was common with two women who had died. That was all I was told. I knew no more. I said, ‘What does that mean?’ The doctor said, ‘Maybe nothing. You could get run over by a bus.’ And I was left to live with that. That was a second blow—after the first, which was knowing that I had the risk. The second was finding out I had had a contaminated batch. And it took a long time before I even knew what the batch number was or the connection or

anything else.

Senator LEES—Do all recipients now know what their batch numbers were?

Mrs Solvyns—Most.

Mrs Brodrick—I found out on Thursday. I have been fighting for two years to find this out.

Senator LEES—I was about to ask what the process was for finding out the rest of the information you need. After the basic information about what CJD is, then you need to find your own personal information. Could you give me some idea about how many recipients have got to the stage where they are comfortable with the information base they now have—batch numbers, for example, and being able to talk to their own doctors and that type of thing?

Mrs Byrne—Some people do not want their batch numbers. Some people absolutely refuse to have them.

Senator LEES—How many recipients would be comfortable with the information base that they now have?

Mrs Brodrick—Probably about half.

Mrs Solvyns—Infertility recipients can obtain their batch numbers, if they were officially approved and they were not back in the early days of the program. For the growth recipients it is a different story. A lot of them cannot get their batch numbers, and that is very frustrating. Or they were treated over such a long time that they had many batch numbers.

Mrs Byrne—In 1994 and 1995 the department got itself quite well organised. When the CJD task force was up and running, life became much more orderly and we had people we could ring. There was a designated doctor who would be there, and you would always speak to the same doctor; it was a bit disconcerting getting a different one every time you rang—and a different story too. So over that period people did have quite good access. There was a 1800 number, and Graham Maynard was there all day every day, and you could always ring up and talk about anything you were worried about. Most people who have made an effort to access information have got it.

Mrs Solvyns—And there was our group. And we have been the main informants for recipients.

Mrs Byrne—Most people prefer to talk to us if they have something that they are really worried about. There are a lot of people who are not very comfortable about ringing

the department, so they ring us, and then we ring the department and get the information and go back to them. One way and another we have gathered lots of extraneous and varied pieces of information over the years.

Senator NEAL—I am not clear on the response on the time delay between the original letters being sent out or contact and when a system was put in place to provide information about—

Mrs Byrne—Yes, that was a difficulty, but part of the difficulty was that the department was telling the treating doctors that they should notify their patients and the treating doctors were not doing it. I think we got up to letter No. 5 from the department saying ‘Wouldn’t it be a good idea’ before one of them did it. They did it in dribs and drabs, probably from the beginning of 1990 to 1992. The department’s position was that they could not notify us; our treating doctors had to notify us.

Mrs Solvyns—Most of us found out from the *Sydney Morning Herald*, TV shows or the *7.30 Report*.

Mrs Brodrick—Mark found out from the Hinch program.

Mrs Solvyns—Most people knew before they actually got the letters from their doctors, which is quite disgraceful. I guess it was probably 12 months from when the majority of people found out until the department put out a *HPH News*. The first *HPH News* gave some information and then said on the bottom in small print, ‘If you want to continue to receive these, ring and we will put you on the mailing list.’ Most people did not read that small print and wondered why they never got a second copy of the *HPH News*. As they made contact with us in the support group they queried why they had never got a second copy of the *HPH News*.

We finally worked out that it was because of this small print on the bottom that said, ‘Ring if you want to continue to receive *HPH News*.’ They got an initial letter—most of them had not read that—and did not get anything else.

Senator NEAL—Did that newsletter have any further numbers where you could ring for information about your own case or about the disease generally? It was on that?

Mrs Byrne—One of the difficulties all along has been privacy. The health department has a deep and abiding commitment to privacy which I think gets in the way of practical life. One of the Allars recommendations which has never been acted on is that people should be able to get information directly from the department rather than having to go through a GP.

The way the situation works at the moment is that, as with this family I was speaking to yesterday, if they suspect that their son has been treated they have to wait

until this young man comes home because he is over 18, so the department will not tell his parents anything. Then he has to write to the department, tell them who he is and what his date of birth is and give them what other details he has. Then they will have a look a look on the database and see if he is there. He also has to nominate a doctor. The department will then send the information as to whether he was treated to the doctor. There is an on-list and an off-list letter, and that goes to your doctor. You then have to make an appointment to go and see your doctor. Your doctor will tell you what is in the department's letter. Some of us find that incredibly patronising in the circumstances. Some of us would really rather have had the letter ourselves. Some people's doctors just—

Mrs Wilson—Do not tell them what—

Mrs Byrne—Some read the letter, photocopied it and said, 'Here, you'd want to have one of these.' They stick one in their files and give you one. But other doctors have papered over the cracks and have not always told people everything. We would prefer a more direct route. This far down the track I do not think there are going to be many people ringing the department and pretending to be a pituitary hormone recipient. There is not a lot of benefit in it. It would be more direct for all concerned if the information could go straight to the person once they have established who they are. You can do an FOI without the information going back through your GP. I do not see why you cannot inquire about your own medical record.

Mrs Solvyns—Some people have actually had to pay for a doctor's appointment to see the doctor to pick up information about themselves. Some people do not have a set GP, so they do not know where to refer this to. We even asked, through the National Advisory Council, for that to be changed. It was agreed to there, but it has not been done.

Senator LEES—There may be people who at the moment do not know. There must be a number of people who do not know. Have we got any idea how many people are on that list?

Mrs Byrne—It would probably be best to ask the department that question tomorrow. About 94 per cent of recipients have been traced. But, as I said, we found one yesterday who had not been traced.

Mrs Brodrick—There are also the IVF people. There are also people who were treated during the IVF program who may not know. They could be out there donating blood and organs.

CHAIR—Would you please speak one at a time? It is difficult for the *Hansard* people to get it down when you are going backwards and forwards.

Mrs Byrne—You have got us going now!

CHAIR—Yes.

Senator LEES—Looking at the time line, I am having difficulty with the fact that the program finished in 1987-88—

Mrs Byrne—It was 1985.

Senator LEES—There was a problem basically and those who were running the program felt it was better if it then finished.

Mrs Byrne—Those who were running the program would have been quite happy to go on. They were told.

Senator LEES—Yes, but the risks were such that finally that was it. But it was not until 1990 that the first attempts were made to contact people.

Mrs Byrne—People died in America in 1985. With the first deaths they put two and two together and I think there were another three deaths quite soon afterwards and all the programs virtually stopped. In France we all know they went on and in some of the Scandinavian countries they went on, but in Australia the program was stopped, against the wishes of HPAC, but they finally considered that they had to stop.

Senator NEAL—You have said a few times that it was not the people who were running the program who actually made the decision to end it. Can you clarify exactly why you believe the program was stopped and who made the decision?

Mrs Byrne—I think they acceded to the necessity of stopping, but they did not stop collecting pituitary glands. They kept right on doing that until 1988 in the hope that they would be able to start using the program again, that the risk would go away. Nobody had died in Australia, so they were quite willing to get up and running again. It was only in 1988 that they finally realised that, no, the risk was too great.

Senator NEAL—But who actually made the decision to stop the program in 1985? Did the people running it say, 'We will put it on hold for a while,' or was there some decision made by the department or some external organisation?

Mrs Byrne—I think from my reading it would have been a combination of CSL, who were extremely worried in 1985 about their legal position, and the Commonwealth, and the doctors who were in HPAC, because, while I say they were unwilling to stop, they did in fact stop using the treatment. But they did not tell anybody why.

CHAIR—Senator Neal, for your own information, in one of the submissions there is a long chronology of events. In the mid-1980s there was a review of the practice in Australia, following the deaths overseas, by a number of committees. It is dated in one

submission.

Senator NEAL—It is not so much the dates, I was just very interested in that view expressed that there was some unwillingness to end the program.

Mrs Byrne—I have been fascinated by the fact that they actually kept on collecting pituitaries for three years afterwards. They obviously had every intention, if they could, to keep on going. They were not sufficiently impressed by the risk.

Mrs Brodrick—It took up to eight years for some people to be notified that they were at risk after they stopped the program.

Mrs Byrne—The beginning of the question was why there was the gap between the program stopping and them notifying people. It was only because Jane Allender died in 1988 and Jenny Halford died in 1990, and pressure was mounting because there were now two families who knew that there was a connection. They only found out about the connection between the fertility program and their wives' deaths after those women had died, which was why they never had pain and suffering compensation. But the connections were being made and the pressure was mounting on the department to make it public, because obviously people knew that CJD was a transmissible disease. Everybody knew there were 2,000 people out there who were also at risk of CJD. Something needed to be done to protect public health and just to find out how many other people had died.

Senator HARRADINE—In your submission, and Mrs Brodrick mentioned it as well, there was mention of quite a number of unofficial recipients of hormones, some 200 I think you mentioned—

Mrs Byrne—It was only a guess. I have got no idea and the department have not told me yet.

Senator HARRADINE—How many of those have been in touch with the support group?

Mrs Byrne—Part of the problem is that we do not really know with any certainty, because until the last few weeks we were not aware that anybody was making a distinction between people who were treated officially and people who were treated unofficially. Again it is in the submission that the database at the department was actually changed to accommodate these unofficial people. If people could basically prove that they had been treated, they were being accepted and put on the mailing list and we were putting them on our mailing lists. There was really no distinction being drawn at all.

We knew that for a few people the department said they had no records of their having been treated. But I guess by the time you get up to—and I am guessing—a couple of hundred unofficial recipients, it becomes less of an issue with the department, they are

not made such a fuss of and, yes, they are just added to the mailing list. We know that they responded to the survey, because when some people who responded to the recipient survey got back their entries on the database it actually said, 'Off-program recipient.' So they were being counted as recipients, but no distinctions were being made.

It seems that both firms of solicitors that had writs going had been informed that the Commonwealth did intend to make some difference when it came to the settlement. But, as I say, we became aware of this only very recently and there does not seem to be very many unofficial recipients who are actually involved in the litigation. We are waiting to have the department clarify exactly how they stand before we really make an issue of it with recipients, because basically if the department is going to say, 'Okay, we'll treat everybody equally,' then there is no point in getting a couple of hundred people very upset. So we are just waiting for the department to give us some sort of clear answer before we go back to recipients.

Senator HARRADINE—Thank you, Mrs Byrne. Mrs Solvyns, you mentioned in your submission a moment ago that more than half of the recipients are not litigants?

Mrs Solvyns—Out of 2,000-odd treated about probably 150 were litigating. The rest of the recipients were not litigants.

Senator HARRADINE—In your case you were not a litigant?

Mrs Solvyns—That is right.

Senator HARRADINE—I ask this simply for information: could you tell us why?

Mrs Solvyns—Because I felt that, although learning of the risk of CJD and particularly learning about the connections with the batches has had a huge impact on my life, I have dealt with the emotions of it myself with my family and I just did not think I could prove psychiatric injury. I have not had any counselling.

Senator HARRADINE—Thank you. I apologise for asking that.

Mrs Byrne—A lot of people had that point of view. A lot of people do not believe in medical litigation. They just do not believe that Australia ought to go down that track and they will not take part for that reason. Some of us can take the psychiatric injury part quite as seriously as Susan. I do not think I could prove it either. But we were there to make the Commonwealth realise that we were serious, that we were not going to go away, that we were prepared to play hard ball to get the issues aired. But, yes, there are only 150 out of 2,000. So it is a long way from being everybody.

Senator HARRADINE—And of course a number of people would have thought that it would be the better to get peace of mind if you were not in an endless type of legal

situation. Really what you are asking us is to make sure that we do take into account those recipients who were non-litigants.

Mrs Solvyns—Yes, because it has had as much impact on their lives.

Mrs Byrne—I have realised since the settlement and since all this has been going on that there are many people who just are not in the position to plead psychiatric injury. As it says in the submission, I was really stunned and surprised by the number of people who said to me, ‘I could not possibly go to a psychiatrist and get a piece of paper that said that I was psychiatrically injured because my ex-spouse would be around for the kids.’ I find that horrifying, but it was a reaction that I had from quite a number of people and that is a very significant reason for not alleging psychiatric injury.

Senator LEES—Were people also concerned about their work prospects if they took that course?

Mrs Byrne—Yes, some people are in jobs where having a piece of paper that says you are psychiatrically injured would not be a good career move.

Senator FORSHAW—It would not necessarily guarantee success in any event, would it? In other words, it can be seen as taking a fatal step, if you like, to seek that declaration, statement or whatever and to put it up in lights that you acknowledge that you have a psychiatric injury and then it does not necessarily end up achieving some compensation anyway and yet it is a thing that you cannot withdraw later.

Mrs Byrne—You can always get another piece of paper that says you are sane now, but we all know how you get those.

Senator FORSHAW—Try giving that to some employers!

CHAIR—Mrs Byrne, in your opening comments you made a number of references to both compensation and accountability—I took down different notes about that at different times. I take it that your prime consideration throughout this inquiry is to have those who were responsible for inflicting misfortune on you and others brought to account, or is it more appropriate to say, on behalf of your members, that you are more concerned with the issue of compensation? I am unclear as to what you are seeking from the inquiry.

Mrs Byrne—So am I, Senator! I think it is both. It is impossible to get people to make that sort of a choice. I think that, if the majority of us had to make a choice, we would go for accountability over compensation, but there are people who very strongly believe that there is some compensation due. There certainly are people who have that psychiatric injury and who do not have a lot of choice about whether they accept it or not. Certainly they are due compensation. It is a question that I have been putting to people, and the answer is far from clear. Most people want both.

Senator HARRADINE—Looking at the question of informed consent, you would suggest that was a complete fiction, generally speaking, for recipients of the HPG treatment. Is that the case?

Mrs Byrne—I think our lawyers concluded that consent was probably better from growth hormone recipients than it was from fertility hormone recipients. Certainly in terms of wide-ranging information there was none. We were not given anything in writing. We were given very scanty information about what it was that we were being treated with. Very little was ever volunteered.

If you asked, sometimes you were told the truth, but I suspect that in some cases the treating doctors did not actually know where this was coming from and they certainly should have. But we did not know. No fertility recipient that I am aware of knew that what she was being injected with came from cadavers. I had been told that it came from human bodies but, being young, naive and fairly obsessed with having a baby, I did not think about whether they were alive or dead, let alone whether anybody had permission to take them. So I would agree with you that consent was much less than informed in the majority of cases.

Senator NEAL—Were you ever aware of any discussion of the risk of disease being passed on?

Mrs Byrne—Oh no, there was no risk! That was my question when I was told that it came from human bodies. I was inquiring about the risk.

Mrs Wilson—It was totally natural!

Mrs Byrne—I was told it was totally natural—‘It comes from human bodies.’

Mrs Wilson—Menopausal mums!

Senator FORSHAW—My question relates to the situation overseas. Obviously you are very critical of CSL, government, the authorities and whomever and we understand that clearly. Have there been any instances of countries or authorities overseas that have taken a more responsive, sympathetic attitude to the sorts of claims that you are now making? I should stress that by that I would not want to suggest that we should do whatever the US or Scandinavia or anyone else would do. Rather, I assume that some of the same issues have arisen and I am interested in knowing whether or not there has been a different attitude adopted in the case, for instance, of paying compensation or officially recognising accountability in similar situations.

Mrs Brodrick—In France they have actually gaoled two doctors on charges of manslaughter and another pathologist who was in charge of their program is in gaol for poisoning, which is a fairly serious crime in France. According to my reading, they have

settled £200,000 in English money on their victims in France.

Senator FORSHAW—Has that been on the basis of a general recognition of recipients—

Mrs Brodrick—Of course, they did have a higher death rate too.

Senator FORSHAW—Yes.

CHAIR—That was for deaths.

Senator FORSHAW—For deaths, was it?

Mrs Brodrick—No, the settlement is on offer. But they had a higher death rate in that country.

Mrs Byrne—To be fair, the French do have a particular situation because, when everybody else stopped, they did not. They thought they had a solution to the problem and they manifestly did not. They have killed more people with growth hormone than any other country has.

Senator LEES—My question follows on from that and you may want to take it on notice: has the Australian group talked together about what they think would be a reasonable level of compensation, across-the-board compensation, considering the impact on the individuals as well as on families?

Mrs Byrne—No, I could not say that we at this point have a formal response to that. The numbers vary. You will get a different answer—

Senator LEES—I realise that in the ways in which it has affected different families. But just looking at a basic settlement both in recognition of the mistake and in recognition—just going through the Allars report—of the lack of support. I am just trying to draw out a bit of the timeline today and the gaps that are there between when knowledge was held by some people and when that knowledge was passed on to others, and in particular to those people that were affected. So acknowledgment of process mistakes as well as the damage to families. Perhaps you might like to do that for us. We have a couple of weeks before we have to actually report.

Mrs Byrne—We had a go last night after dinner but we did not get very far.

Senator LEES—I will leave it with you.

Mrs Byrne—Yes, okay, we would be delighted.

Senator FORSHAW—I do not think it is put on the basis, Senator Lees, that it is like your last chance or anything.

Senator LEES—No, particularly considering what France has done and what a couple of other countries might be looking at.

Mrs Byrne—It is an interesting question exactly what people would consider an acceptable number and what people might consider yet another insult.

Senator LIGHTFOOT—I have a question for Mrs Byrne. You mentioned many things in your submission and in later evidence you gave to the committee you mentioned deaths in the United States from 1985. Do you have any coronial reports on those deaths as to whether they were attributed to CJD; and, if that was the case, was that CJD contracted by the deceased from HGH?

Mrs Byrne—There were certainly autopsies and, yes, the connection was actually made quite quickly. As I was saying before, the knowledge that CJD could be transmitted from one human being to another by various processes was around in the literature from 1977. So when one of the young men who been treated with growth hormone in America came down with CJD, his treating health professionals became highly suspicious because CJD is usually a disease of the over-60s. It is most unusual to get it in your 20s.

Senator LIGHTFOOT—But not unheard of, I take it?

Mrs Byrne—Not unheard of but very unusual. This is prior to BSE and new variant and all those other sorts of things. In those days it was very unusual. Two and two was put together quite quickly and, as I was saying, there were other deaths quite soon after that there and in Europe. It became manifestly obvious that this was what was happening.

Senator LIGHTFOOT—So your evidence from what you have read and from what you have been informed is that the deaths in the United States link CJD to HGH.

Mrs Byrne—I do not think there would be any doubt about that. I think we are now up to 100 cases worldwide where CJD has been linked back to either growth hormone or fertility hormone.

Senator LIGHTFOOT—In the early days, and I must admit that I am about as new as you can get to this committee—this is my first meeting.

Mrs Byrne—I thought you must have been new. You have not been in the Senate for too long, have you.

Senator LIGHTFOOT—You have to forgive me if some of my questions appear

to be pedantic—they are very sincere. I wonder whether you could inform the committee as to the explanation of risk that was given by those administering HGH at any time over that period up to 1988? Was there an explanation by the surgeons, the doctors or the experts with respect to that?

Mrs Byrne—Do you mean in terms of CJD?

Senator LIGHTFOOT—Yes.

Mrs Byrne—Absolutely none.

Senator LIGHTFOOT—In terms of anything—not necessarily CJD but any adverse effect or any negative effect?

Mrs Byrne—We were warned to a greater or lesser degree about the risk of hyperstimulation of the ovaries. Some people had fairly blunt and forthright warnings about that. Other people had none at all. That happened reasonably frequently and sometimes with fairly catastrophic gynaecological effects. I think most of us were warned about the risk of multiple births, but certainly in the place that I was treated you had to agree that if you did become pregnant with more than three that you would have to have an abortion. That took care of the multiple birth risk. There were not very many risks that we were told about. I think they are basically the only two. With the growth hormone, I cannot recall that there were any specific risks that were generally mentioned to people.

Senator LIGHTFOOT—But there may have been?

Mrs Byrne—There may have been, but I cannot recall them at the moment. You are going to hear from some growth hormone recipients later in the day. Perhaps you could ask them that.

Senator LIGHTFOOT—I have gone through some of the submissions but I have been unable to find—I have not exhaustively examined all the submission because they are very extensive and comprehensive—whether there was any cost to the treatment?

Mrs Byrne—Not to most people. This was another one of the ironies of the whole thing. It was presented to us as this magnificent gift that the Commonwealth was giving to you and you were told how terribly expensive this treatment was and how lucky you were to be getting it for nothing. There are some reports of growth hormone people having to pay for it.

Senator FORSHAW—It was put on the PBS list at one stage, was it not?

Mrs Byrne—In a fairly unusual way. It does not really appear to have fitted the criteria dreadfully well.

Senator FORSHAW—Professor Allars actually found that.

Mrs Byrne—Allars had some severe concerns about S100 listing.

Senator LIGHTFOOT—I have a question for Mrs Solvyns. You mentioned in your submission that some of the patients with HGH were treated with—and I think I can quote you correctly—‘leftover product’?

Mrs Solvyns—That is right.

Senator LIGHTFOOT—What did you mean by that?

Mrs Solvyns—What happened was when Mrs Smith got pregnant and there was some product left which had been approved for her to be treated with doctors were taking it back to their rooms and using it to induce mucus and different types of things and treating people in their rooms. One of the Sydney doctors did actually supply the health department with the names of, I think, 11 women who he had treated unofficially in his rooms and notified them of their risks and put them in touch with my support group. It is people who know that they have been treated and the doctor has actually advised the health department about and yet are unofficial who I am concerned about. They are at the same risk. I am also concerned whether or not their names are on the blood bank lists. It only takes one injection to be at risk.

Senator LIGHTFOOT—It is almost a double jeopardy?

Mrs Solvyns—Yes. So that is apparently what was happening. Some doctors have come clean and told the department, others haven’t. This is why there are bound to be a lot of unofficial people out there that doctors have treated like this. The doctors are keeping quiet and these people do not know and will never know of their risk.

Senator LIGHTFOOT—Mrs Brodrick, you mentioned bullying tactics. Could you expand upon that?

Mrs Brodrick—I think the bullying tactics came from the repeated letters from the solicitors, insisting that this was our only option, that we had to pay up.

Senator LIGHTFOOT—These bullying tactics were limited to letters, were they?

Mrs Brodrick—I tried to contact their office. I never spoke to them directly. I could only ever get the secretary.

Senator LIGHTFOOT—My last question—thank you for your indulgence, Mr Chairman—is to Mrs Wilson. I am intrigued as to why your doctor should have hung up—I think one of my other colleagues mentioned this—after 25 years?

Mrs Wilson—I had done some TV programs.

Senator LIGHTFOOT—On the subject?

Mrs Wilson—Yes. I was trying to get people information, to make people aware of what was happening and to get people together. Whether he saw that as a threat, I don't know.

Senator LIGHTFOOT—Did you subsequently speak to him?

Mrs Wilson—No.

Senator LIGHTFOOT—You have never spoken to him at any length?

Mrs Wilson—No.

Senator LIGHTFOOT—Did you try other phone calls to him?

Mrs Wilson—Yes.

Senator LIGHTFOOT—He refused to take your phone calls?

Mrs Wilson—Yes.

Senator LIGHTFOOT—You were able to get to him directly?

Mrs Wilson—I was able to get to him directly, but as soon as I said, 'Hi, Prof, it's Carol Wilson,' he would just hang up.

Senator LIGHTFOOT—He never had any contact with you by letter?

Mrs Wilson—No, the only letter I got, signed by him, was at the end of May 1992.

Senator LIGHTFOOT—No other indirect means?

Mrs Wilson—No.

Senator LIGHTFOOT—You have never had any second-hand evidence by way of a third person from the professor?

Mrs Wilson—No.

Senator LIGHTFOOT—That is rather extraordinary. How many times did you

see the professor prior to that, prior to your telephone calls?

Mrs Wilson—As I said, I had not seen him for about 24, 25 years.

Senator LIGHTFOOT—In the period of time prior to that 24 to 25 years, how many times had you seen him?

Mrs Wilson—Probably once a week for about two years—probably more.

Senator LIGHTFOOT—So you got to know him quite well?

Mrs Wilson—Yes.

Senator LIGHTFOOT—What was your opinion of him at that time? Was he a decent sort of a caring person?

Mrs Wilson—Yes.

Senator LIGHTFOOT—Would you describe him as that, without me putting words into your mouth?

Mrs Wilson—Yes, he was.

Senator LIGHTFOOT—Did you have utmost faith in him?

Mrs Wilson—Yes, I did.

Senator LIGHTFOOT—You had confidence in him?

Mrs Wilson—Yes.

Senator LIGHTFOOT—You never questioned what he did?

Mrs Wilson—No.

Senator LIGHTFOOT—Then why do you think he would not have wanted to have seen you when you had that relatively close relationship?

Mrs Wilson—I don't know, and that has happened to quite a few other recipients as well.

Senator LIGHTFOOT—What would you guess if you had to guess?

Mrs Byrne—I think a lot of the treating doctors were genuinely shocked and

horrified at what they may have just found themselves up to their necks in. It was not an unusual experience for people to find that their doctors were no longer available, that they could not get through on the phone. A significant number of gynaecologists and obstetricians actually decided to take jobs overseas. I think you will hear from some people later today whose treating doctors found that the opportunities overseas were beckoning just about the time that all this happened. To give them their due, it must have been pretty horrific for them. It would not be nice to think that you might be looking at having to tell this to a whole lot of women that you had treated and made pregnant. A lot of these guys did really enjoy that making families aspect of it; they do like babies and bringing them into the world. It would not be very nice to have to think that you might have to cope with a lot of your patients dying from a disease like CJD. It would be very unpleasant indeed. A lot of them took the easy way out.

Senator LIGHTFOOT—Ms Byrne, I am sure the Chairman is going to indulge me one more question that you have precipitated. With respect to other countries that we sometimes compare ourselves with—the United States, Canada, France, and particularly the United Kingdom—what is their position with respect to funding, through legal aid or other means, recipients of the HGH who now find themselves in this predicament?

Mrs Byrne—The only place I can speak about with any confidence is England. They have started from a different end, I suppose, because they had so many deaths. The case there was brought by the families of growth hormone recipients who had died. They have not yet got to the point of the worried well—which is what they call people like us—but I would have to say that it does not look all that likely that the English courts are going to be terribly accommodating to the worried well.

Senator LIGHTFOOT—So there is no class action in any of these countries that you are aware of?

Mrs Byrne—No, which is amazing, because I think everybody is expecting America to lead the way with some sort of class action. They have had quite a number of deaths and they certainly have a lot of recipients, but for some reason it does not seem to be happening, which is odd.

To give the Commonwealth its due, it certainly has done a lot of good things in terms of providing counselling services—which have had to be revised significantly, but are now quite good—funding support groups and services generally.

CHAIR—Thank you ladies for all of your comments this morning and the help you have offered to the committee. I will ask you now to vacate the chairs, and Mrs Gina Stachlewski and Mr John Stachlewski can come to the table.

[11.00 a.m.]

STACHLEWSKI, Mrs Gina, 12 Austin Street, St Albans, Melbourne, Victoria 3021

STACHLEWSKI, Mr John, 12 Austin Street, St Albans, Melbourne, Victoria 3021

CHAIR—I welcome Mrs Gina Stachlewski and Mr John Stachlewski. The committee has before it submission No. 2. Do you wish to make any alterations to that submission?

Mr Stachlewski—No, we would like to add to the submission in terms of information that has come to light since that submission was submitted.

CHAIR—When you say ‘add’, do you mean in the form of the video?

Mr Stachlewski—The video is part of it. There is other information that will come out during discussion.

CHAIR—How long will the video go for?

Mr Stachlewski—For a few seconds.

CHAIR—Okay, we will come back in due course. I now invite you to make a short opening statement. At the conclusion of your remarks, I will invite members of the committee to put questions to you.

Mrs Stachlewski—Firstly, I would like to acknowledge John Coulter’s attempts to have a Senate inquiry two years ago. I would like to also introduce my husband John, who is a great support to me.

Mr Stachlewski—I would like to thank the committee also for taking the time to listen to the various submissions which are before it. One of the important issues that comes out—and it relates directly to the video—is where we stand, what the terms of reference are of this committee and why we are sitting around these tables. Without wanting to rehash Professor Allars’s statements and the unlawfulness of the program, I think it might be worth while to play a few seconds of this video, which is quite significant in terms of what the gentleman has to say.

CHAIR—Who is the gentleman?

Mr Stachlewski—Dr Tony Adams, the past Chief Medical Adviser for the Commonwealth government.

A video was then shown—

Mr Stachlewski—Dr Tony Adams started saying what I think is a fairly important set of issues regarding the perceptions of the government at that particular time. That program was taped in 1994. The significance of his statements speak for themselves. However, he goes on to say a number of other things apart from the fact that pituitary hormone patients, certainly those in the HGH area, were guineapigs. ‘Medical misadventure’ is used as a term and he goes on to talk about a variety of other areas.

I think the important thing here to stress is that, when you talk about people being guineapigs, it is a rather intriguing little exercise, particularly since they are human guineapigs. I think Dr Tony Adams at that particular stage said what we all thought was the case—that it was an experimental program—and Allars subsequently put that into her paper and into her report.

What does it do? It does not offer any solace to my wife, my family or other recipients. The safety of the program was compromised as shown in Tony Adams’s own transcript that was put to the committee for consideration. That raises a number of fairly critical issues regarding how the program was conducted and, perhaps more importantly, when it should have been stopped. A couple of dates have been thrown around; 1 July 1977 is one of those dates. There is reason to suggest that we could probably trace back, in Australia, to 1965 the fact that the program should not have taken place. But we will never know; we do not have that opportunity at the present time.

So where do we go to from here? In 1993 we presented our concerns to Associate Professor Allars and the inquiry. A number of issues were raised including issues relating to the way the drugs were administered, the treatment process, the inquiry model, privacy and the labelling of recipients—you have already heard that from some of the support group members.

In our particular submission to Allars we also looked at the independence of each of the committee structures so that there was seen to be independence from the government. The reason for suggesting that was that the government was involved, in the first instance, in the program, its development and administration, et cetera. It was also involved in the various committees. Dr Tony Adams goes on to say, and I quote from the transcript of the video tape:

They were over enthusiastic—

‘They’ being the doctors—

so some of the such guidelines that were in place were either ignored or fudged.

To go over it again: the question was asked:

So patients welfare was sacrificed?

The answer was:

Unfortunately yes.

Tony Adams also said:

Here was a situation that should have been corrected earlier than it was and people concerned both in Government and in the Committees who were handing out the hormones were derelict in their duty in not stopping it sooner.

That does not come from my wife, it does not come from a recipient; it comes from a representative of the government. It is a fairly important case when you have the chief medical adviser basically admitting that the program was derelict in the way that it was handled. I place the tape at your disposal for further consideration.

CHAIR—Can you give us the source of the tape?

Mr Stachlewski—It was Channel 7 and the program was called the *Times*. It was in 1994, but I am not sure of the actual month. Paul Barry was the person in the background.

We believe that the report completed by Professor Allars, her executive summaries and Dr Lawrence's speech to the House prove beyond any question that there had been significant breaches of the law as it applies to a wide variety of areas. These include the manufacture of the hormone, including the collection of glands, distribution of the hormone by various agencies, including HPAC, CSL and others as detailed in the Allars report, and non-disclosure of possible side effects. No information was provided regarding the type of treatment to patients. This is a summary, and we will probably pursue it in private session, if we may. It is fairly important to understand the background of the paper.

A chronology of the events shows how little the department had actually done. If we look at the various issues that were raised it may give the committee an idea of what should have been done, I suppose. I would like to read from a memorandum from the US. It is from the Assistant for Bioethics in the Department of Health and Human Services at the National Institute of Health and it is dated 16 July 1985. It reads as follows:

If physicians in positions of responsibility have knowledge about potentially harmful consequences and do not disclose them, they could be blameworthy in an ethical sense. If one reasoned that the risk is remote and the chances of unduly alarming the informees is great, therefore, justification exists for withholding that information . . . then the rejoinder would be, "who are you to decide what will or will not upset me?" The burden of proof in these cases is always on those who argue for non-disclosure, and if you look at the evidence, people normally want to be told these things. I should say, people in our culture want to be told.

Can I table this document, please? It is extra to our submission.

CHAIR—Yes.

Mr Stachlewski—So what did the Australian government do? If we look at the chronological sequence we find that in 1985-86 the US government hired an independent company to undertake epidemiological research into the administration of HGH. This perhaps answers your question, Senator Lightfoot. That research had been on-going for 10 years and it finished last year. The correlation between deaths and HGH has proven within that report.

De-identifiers were applied during the course of any study, and in the United States specifically, maintaining the confidentiality of individuals involved in the exercise. In 1985-86 a pamphlet—if I can dig it out I will show you an original of it—was produced by the United States government, and specifically from NIH. The pamphlet detailed what CJD was, who to contact, what to look out for, what the problems were—any concerns that anybody had would be dealt with. This is the original publication from the US government dated 1986. Can I submit that as further evidence?

CHAIR—The committee will receive that.

Mr Stachlewski—It took the Australian government another 10 years to come up with a semblance of what CJD was—this is the response. The thing that surprises me about this exercise is that if you compare the two in terms of the information, and the availability of that information to people, particularly in the government sphere, it is surprising that we have this—relative to that document. I would have imagined that there would be great discussions, if not changes of information, between each of the government areas and/or departments. I would like to submit that as a relationship to that particular document. Ten years before we start reinventing wheels—why? The question always comes back to, why?

The ethical obligations I read out from that particular piece of paper before are a fairly important issue. Why? Because my wife did not find out for another seven years—and it was not through official channels, it was courtesy of Derryn Hinch and Channel Seven. That is how my wife found out, and I dare say a number of other recipients that you have already talked to this morning. The responsibility of the department—where does it belong in here? In 1991 the department sought legal advice. You have heard people say they have been labelled. They have certainly been labelled in a whole variety of areas. They have had to carry around letters.

Before I talk about this, and I would like to read from two paragraphs from this particular paper, there are two issues which come out. First of all, the department was looking at releasing information on recipients. We have no bone to pick with the department releasing information. The thing that was missing from the exercise was its

communication or ability to communicate with then known recipients and/or putting on extra resources to find those recipients. That is really the issue that comes out of this. If I may, this letter is dated 14 June 1991. It is by George Pikoulas, acting director legal services branch. I will just read the last two paragraphs in terms of what the relevance of this document means. It was a question as to whether they should release names to blood and organ donation agencies:

The simplest means of empowering the department to disclose such information, which it is clearly in the public interest to disclose, is to obtain the consent of the donors to the release of their names and any other information relevant to the purpose of providing all relevant information to relevant organisations. Another, but more cumbersome, means would be the enactment of legislation to empower the department to release such information.

Can I submit that as another addition please?

CHAIR—The committee will receive that document.

Mr Stachlewski—Thank you. The information has been passed on and I think it is an important issue because, as the chronology continues, the department has acted illegally in distributing this information. I ask this question on behalf of my wife and certainly those others who are concerned with the release of the information: can any action be taken against departmental officers who have distributed this information? It goes against the core of the ability to communicate with the recipients and, more importantly, it is dealing with their own personal rights. We do not have a bill of rights in Australia at the moment, which is extremely unfortunate nonetheless.

In 1992, the department started to distribute information without notifying the then contacted list of recipients or attempting to discuss the issue. In our submission to Professor Allars in 1993, we noted major concerns about databases and their management while the department was disseminating data, without informing those recipients what it had found, or adding more resources to find the other recipients. The department notified support group coordinators in February 1995, not recipients directly, regarding the dissemination of information. There is still a question regarding how many recipients actually know. Nobody can give us a straight answer.

During this exercise, the National Pituitary Hormones Advisory Council supported the release of the information. The National Pituitary Hormones Advisory Council is an independent advisory group reporting to the minister. The question of fairness and its reporting procedures have brought it into doubt just based on these issues alone.

Organisations from 1992 onwards were sent information regarding recipients, and that information was not requested. One such organisation is the Australia New Zealand Transplant Society, which in the first instance sent the information back via registered mail and shredded the second set of information. How many other organisations were placed in this situation?

The department maintained, via minutes of the National Pituitary Hormones Advisory Council, that the material and the organisations that had been given that material were visited and told about the sensitivity of the information that they were dealing with. In actual fact, there was no such meeting with the Australia New Zealand Transplant Society at all. How many other organisations are in the same situation? There is a question mark hanging over the questions about visiting and perhaps, more importantly, making the point about whether their perceptions have been seen to be borne out.

In December 1994, a letter from Ms Dunlop, giving an outline of the database structure, was supplied to us. Children's names, birth dates and sex are listed as fields within the database. I ask the question: why? It appears that the department adds fields to the database on an as required basis. What does this mean? Where is the information sent, who collates it and who controls it?

In March 1997, NPAC had studied the implementation of privacy protocols—12 years after the same exercise had started in the United States. It appears that John Coulter's opinion was that, given the fact that the information had already been disseminated, the nature of this exercise may be purely academic. By the looks of things, coding is finally accepted, but the information has already been disseminated.

The department, NPAC and other support structures are reactive rather than proactive. This causes us some fairly major concerns. There needs to be a look at the way that the department has handled information. In a letter regarding APQ, which I will go into in a minute, there are some major concerns in terms of the fairness and the way it is handling it.

The secretariat that was responsible for maintaining support for the National Pituitary Hormones Advisory Council had functional responsibilities of keeping accurate minutes and the provision of formal secretary minute taker for the council. There is a letter dated September 1994 from Ms Dunlop, which can be given to you and tabled along with a letter from Mr Rodger Hughes. The minutes of the meeting of August 14, 1995 are completely inaccurate.

CHAIR—Which meeting was that?

Mr Stachlewski—The meeting of the National Pituitary Hormones Advisory Council—it is in our submission—dated 14 August 1995. There is a subsequent letter, which I will table, if I may, at the end of this meeting.

There is a question of conflict of interest due to the various bodies which are involved in this exercise. You have heard of the traumas, but there are other traumas involved too. One of the things that surprises me, and certainly my wife and other people we have talked to about this situation, is that we have, on the one hand, a government giving money for various things but not accepting blame and, on the other, the secretariat,

made up of government employed people, and the task force, which was employed to look after the recipients' welfare. However, there is a major problem when it comes to the way the department supports—and I suppose the word 'support' is a fairly important issue—recipients and their families. Marion Dunlop sent a letter in September 1995 regarding the granting of legal aid to APQ. Can I read this letter?

CHAIR—Yes, you may.

Mr Stachlewski—Thank you. It is to Mr Frank Tallarita, Director, Legal Aid and Family Services Branch, Attorney-General's Department, National Circuit, Barton, ACT:

I refer to your letter of 31 August 1995 to Mr John Carroll, Assistant Secretary, Legal Services Branch, seeking advice on the request from Rennick, Gaynor, Kiddle and Briggs for legal or financial assistance on behalf of APQ who has issued proceedings in the Supreme Court of Victoria. Mr Carroll has forwarded your letter to the Pituitary Hormones Task Force for comment and reply.

The first question I would ask is why this letter was sent to the Pituitary Hormones Task Force. It was there to support the recipients. May I go on:

I understand that the Australian Government Solicitor's Victorian Office will write to you direct in regard to the legal issues relevant to the RGKB request.

There are also a number of other broader issues which may be relevant to your consideration of the claim by RGKB. These issues concern the level of funding already allocated by the Government to assist the pituitary hormone recipients and the extent of the litigation to date. The relevant points are as follows—

and the question of relevancy is a fairly important one. I go on:

The Commonwealth has already spent around \$900,000 on an independent Inquiry into the Use of Pituitary Derived Hormones in Australia and Creutzfeldt-Jakob Disease. This Inquiry made a number of recommendations to provide ongoing support and counselling to all pituitary hormone recipients and their families as well as recommendations relating to future research and scientific activities.

- The report of the Inquiry covers a wide range of information and research relevant to any test case related to the pituitary hormone treatment. All relevant documents held by the Department and CSL were provided to the Inquiry and a large number of both recipients and scientific experts gave evidence to the Inquiry.

The Inquiry reported to Parliament on 28 June 1994 and on 7 November 1994 the Government announced funding of \$10 million to implement the Report's recommendations. This funding includes the setting up of a Trust Fund of \$5 million to provide:

- ongoing funding for support groups for recipients and their families until at least the year 2010 . . .

I would like members of the committee to note the dates; these are fairly important. It goes on:

- ongoing funding of free counselling services to pituitary hormone recipients and their families until the year 2002—

CHAIR—Mr Stachlewski, I do not want to cut you off, but we are very limited for time. There are another seven persons listed in this section to give evidence.

Mr Stachlewski—Can we table the document then, please?

CHAIR—Yes. And could I ask you to bring your introductory remarks to a conclusion so that members of the committee might ask you questions; otherwise others will be denied the opportunity to make their points.

Mr Stachlewski—Absolutely. I think the issues in terms of the opening remarks are these: we do not believe that the settlement has been fair in any sense, shape or form. A number of demonstrable problems with the way that the structures that have been set up to support recipients have been noted, and certainly there are other letters which we would like to table according to those particular comments. Generally, I would say that the question of independence is a question that is very close to our hearts as is a number of other issues that we would like to take up in private session. Perhaps if I leave it at that, that will give you the opportunity to ask your questions.

Senator LIGHTFOOT—Mr Stachlewski, I wonder if you could tell me—I missed it earlier—to whom or what Dr Tony Adams was the chief medical adviser.

Mr Stachlewski—To the Commonwealth government.

Senator LIGHTFOOT—And he still is?

Mr Stachlewski—I think he resigned about two or three weeks ago.

Senator LIGHTFOOT—Why did he resign?

CHAIR—I don't agree with this. That is incidental.

Mr Stachlewski—I do not know. I have absolutely no idea.

Senator LIGHTFOOT—But it would be reasonable to expect that it was incidental to this inquiry?

Mr Stachlewski—It is rather interesting that it has happened at the time that it did.

Senator LIGHTFOOT—You are saying that it is not incidental to the inquiry?

Mr Stachlewski—I am not suggesting that. I am saying that it is rather interesting that it has happened at the time that it did.

Senator LIGHTFOOT—If you had to pick between whether it was or whether it was not, what would be your opinion?

Mr Stachlewski—My opinion would be it is doubtful that he wanted to see this particular committee sit, and he was concerned about it.

Senator LIGHTFOOT—Are you suggesting that there is some sort of protest in Dr Adams's resignation?

Mr Stachlewski—I do not know whether it is a protest or worry but it could be; it could be either.

Senator LIGHTFOOT—It could be either?

Mr Stachlewski—I cannot talk for Tony Adams.

Senator LIGHTFOOT—It is an unequivocal 'maybe', is it?

Mr Stachlewski—It is a 'maybe'.

Senator LIGHTFOOT—In the transcript you spoke of—

Mr Stachlewski—I am sorry, but which one?

Senator LIGHTFOOT—Right in the beginning of the transcript from the Channel 7 program, a program that I am not familiar with because I am from the west, you spoke of 'over-enthusiastic doctors'.

Mr Stachlewski—Absolutely.

Senator LIGHTFOOT—What manifested that over-enthusiasm?

Mr Stachlewski—The support group members who were here before perhaps gave an indication that those people, who are now in very prime areas and leading areas of research—and they are on the leading edge of technology in many cases, had the opportunity to experiment with a large group of both females and people of short stature. I think that is an important issue.

Senator LIGHTFOOT—Okay, thank you. Again, I did miss the years that you

spoke of with respect to those over-enthusiastic doctors. I take it that it was not a contemporaneous statement?

Mr Stachlewski—No.

Senator LIGHTFOOT—And that it was something going back? Was it retrospective to some years ago?

Mr Stachlewski—Can I make the suggestion that in the tape the one comment that Dr Adams did make was that they should have stopped a lot earlier. What he did not quantify was what that ‘lot earlier’ meant, and it would be an interesting question to ask Dr Tony Adams.

Senator LIGHTFOOT—Could you hazard a guess as to what he meant?

Mr Stachlewski—No.

Senator LIGHTFOOT—With respect to the United States memorandum that you spoke of shortly after the tape, I think it was 1986—was that right?

Mr Stachlewski—Nineteen eighty-five.

Senator LIGHTFOOT—Nineteen eighty-five. What brought about that memorandum in the United States? What was the precipitating factor?

Mr Stachlewski—The precipitating factor and the background to this memorandum from the NIH was that the issue and the deaths that were occurring—and I think Mrs Byrne has already alluded to those deaths—were starting to compound; they were getting more deaths in the US. As a result of that, there were questions. They had an experimental program that was labelled as exactly that, an experimental program, so in the first instance the question was put to the bio-ethics committees: should we tell those people in the experimental program that they have the possibility of dying? The answer to that was yes. This is in the following paper.

Senator LIGHTFOOT—When you say ‘those people’, they are the ones who were injected with HGH. Is that so?

Mr Stachlewski—Yes, and they were told that it was an experimental program.

Senator LIGHTFOOT—If I could just extrapolate from that, the deaths from CJD were not all associated with HGH, were they?

Mr Stachlewski—No, certainly not.

Senator LIGHTFOOT—What percentage? Do you have any idea?

Mr Stachlewski—Not off the top of my head.

Senator LIGHTFOOT—Can you hazard a guess? I am completely new to this.

Mr Stachlewski—What I would prefer to do is this: if you want that information, can I take that on notice?

Senator LIGHTFOOT—Can we take that on notice, Mr Chairman? So, yes, we can. Mr Stachlewski, who does control the database that you spoke about?

Mr Stachlewski—That is a very good question. If you can find an answer for me, I would be very happy.

Senator LIGHTFOOT—Where is the database?

Mr Stachlewski—That is also a very good question, because I do not know.

Senator LIGHTFOOT—Who has a copy of the print-out?

Mr Stachlewski—That is also a very good question, because the number of print-outs, depending on who you talk to within the department, varies. Each of the blood and organ donation agencies now have one, but how far that has travelled nobody really knows.

Senator LIGHTFOOT—Who compiled the database originally?

Mr Stachlewski—The task force.

Senator LIGHTFOOT—Would the task force know then where the database was?

Mr Stachlewski—I would certainly hope so; however, there is a caveat on that answer. The caveat is that the task force have said that, once they have taken the information and passed it on, it is not their responsibility to maintain due diligence on the maintenance of that database and the privacy principles.

Senator LIGHTFOOT—I have about 100 other questions, but I will defer. Thank you very much, Mr Stachlewski.

Senator NEAL—You said earlier in your evidence to the committee that you actually found out about the risk from Derryn Hinch.

Mrs Stachlewski—That is right. It was in December 1992.

Senator NEAL—How long after then, if ever, were you advised officially that there was a risk?

Mrs Stachlewski—I rang the number that was flashed on the screen. I was not able to get through until the next day. Even then, they could not tell me. They took my name and address at the time that I had the injections, and they told me to make an appointment with my doctor about a week or so later.

Senator NEAL—It was the department of health number, wasn't it?

Mrs Stachlewski—Yes, it would have been the department of health in Canberra. They told me just to wait and they would send all the information to my doctor, but I could not wait. John suggested calling the doctor whom I was under the program with.

I was not able to get through to him, but I got through to his partner. His partner said, 'Why don't you ring the Monash Medical Centre? They have a Prince Henry's ovulation induction centre there.' He told me to speak to a sister there. The sister took virtually the same details that I gave the health department, and she said, 'I will have to check my files and I will let you know this afternoon.'

About four hours later this big ream of fax came through saying, 'Yes, I was definitely on the program,' and there were all the implications of kuru and Creutzfeldt-Jakob disease. There was so much to take in because about 16 pages came through.

Senator NEAL—Why was the original doctor who was treating you unavailable? Was he not available as in not there, or was it that he did not want to speak to you?

Mrs Stachlewski—At the time, I thought he was not there. It never occurred to me that maybe he just did not want to talk to me.

Senator NEAL—Have you spoken with him since then?

Mrs Stachlewski—No, I have not.

Mr Stachlewski—There was one meeting, however, with the doctor who was looking after the program.

Mrs Stachlewski—There was the doctor who was looking after the program and another doctor whom I was actually under.

Mr Stachlewski—We asked a couple of questions of Professor Henry Burger when we talked with him.

CHAIR—Mr Stachlewski, I apologise but could you wait for a moment while we

change the tapes. Thank you.

Mr Stachlewski—There was a consulting period. At one of the meetings at Monash Medical Centre we were invited to go and have a chat with Dr Henry Burger. That discussion took place and there were a couple of questions which we asked. One of the simplest ones was: why did you use the pituitary derived hormone?

Mrs Stachlewski—We were always told there were two types. There was the hormone from menopausal women that was used and the pituitary hormone. But we found out later that that was not the case, that it was only the pituitary derived hormone that was used, and it was used in both cases for the children of short stature and for infertility. It killed two birds with one stone.

Mr Stachlewski—And that is a quote from Dr Henry Burger, and it was literal.

CHAIR—Thank you for that, Mr and Mrs Stachlewski. You are going to be giving in-camera evidence later, so we will have the opportunity to pursue it further—

Mrs Stachlewski—Could I just make one more comment. I cannot make a fully informed decision until I have all the information concerning my treatment, which would include information on the batches I received, were they contaminated and were they potent.

Evidence was then taken in camera, but later resumed in public—

[12.08 p.m.]

BAKER, Mrs Pamela, 9 Monash Street, Morwell, Victoria 3840

LEE, Mrs Eleonore Ellen, 8 Collins Street, Geelong West, Victoria 3218

OGILVIE, Ms Samantha, 1/151 Glenhuntly Road, Elwood, Victoria 3184

CHAIR—The committee has before it submission Nos 56 and 71. If you do not wish to make any alterations to those submissions, you are reminded that if, during the giving of your evidence, you consider that it may be more appropriate for the committee to hear part of your evidence in private session the committee will give consideration to your request. I now invite you to make a short opening statement. At the conclusion of your remarks I would invite members of the committee to put questions to you.

Mrs Lee—My treatment began in 1983 at Prince Henry's Hospital. After a break I recommenced HPH again in July 1984. At that time, much was being heard about HIV, so I asked my treating nurse if HPH was safe from HIV or any other transmittable diseases. She told me that it certainly was, as they treated the pituitary glands in such a way that HIV and all other diseases were destroyed. I also asked where they got the pituitary glands from and was told that they were donated. On 5 July 1985, I delivered my first child. In 1987, two years after Drs Lordings and Burger stated that they had tried to contact all of us who had been on HPH, I recommenced treatment for a second child.

I sat at a desk opposite Drs Kovaks, Lordings and Burger, who had my history spread out before them, and not once did any of them mention CJD to me. It is safe to say that had my husband and I been informed of the risk we would not have considered a second pregnancy. The treating nurse did explain that they were not using pituitary glands any more but were extracting the hormones necessary from the urine of Italian nuns who were going through menopause. So on 4 March 1988 I delivered my second child.

Early in 1993, while watching a Hinch program on television my world came crashing down around my ears. That was how I found out—a television program with the images of one of the victims in her final months of life. I rang the phone number that was flashed up on the television screen and, after giving a gentleman from the health department very detailed information, I was told I was indeed in the risk group.

I sank into a deep depression, suffering from severe headaches, sleeplessness, stomach ulcers, despair, et cetera. The thought that one day I may also have to tell my daughters that they may be at risk also breaks my heart. I now have to bear the shame of informing doctors, dentists and medical personnel that I am at risk of CJD and suffer their reactions, which vary from genuine concern and sympathy to outright horror, like the reaction I got from a physiotherapist whom I was seeing just this year. She reeled back from me and exclaimed: 'I won't catch it from you, will I?' I must also contend with the

fact that, unless a test for this disease is found, my girls and I will never be free from the fear and worry.

Some time after seeing the Hinch program I rang a number in Canberra to see if they could help me find counselling and was subsequently referred to a psychiatrist, whom I started to see in May of 1993. I have been undergoing treatment with her ever since. I had known for some time that many of my fellow victims were taking legal advice, and planning to take the Commonwealth government and CSIRO to court. However, my husband and I found it difficult to raise the funds required to file suit. Early this year we finally were able to contact Rennick Briggs and were placed in the hands of Mr Sean Millard. He advised us of the upcoming suit of APQ and strongly urged us to file our suit, as he said that it was quite likely that only the people who had already filed prior to APQ's case being heard would be compensated.

On reading in the paper of the settlement we were more than surprised at the outcome. I received a letter from Mr Millard shortly after, advising me of the conditions of the settlement that, should I become affected by CJD at any time in the future and subsequently die, I would be taken care of until my death and that my family would be compensated after my death. Rennick Briggs strongly urged me to sign the document, stating that, should I try to take my case any further, my family and I would be left destitute, as the government had quite clearly stated their intent in taking the case as far as it could go. They also advised me that we would not be eligible for legal aid and that we would quite likely lose everything if we decided to pursue the matter. We assumed that Rennick Briggs was working in our best interests and that we could rely on any advice given by them.

Some days later I received a phone call from Rennick Briggs asking why they had not received my signed and completed forms. They said that speed was of the essence and that if we didn't send the papers off we would miss out on the agreement. So, believing that we had no other options, we signed the documents and sent them to Mr Millard. We most certainly were not given adequate time or information to make a considered response. We do not feel that we have been treated fairly by the government. You only need to look at a few of the facts of the case and think of a few simple precautions that those responsible could have put into place to know this is most certainly true.

It is a fact the pituitary glands were not donated, so no record of the cadavers was ever kept. Ergo there is no way anyone can now go back and find out where the CJD originated. This is reprehensible. In our society grave robbing is illegal, is it not? For what they did was, indeed, grave robbing. When you take something from a dead body that you have not received permission for from the next of kin, and then proceed to exchange money for said body part, what else can it be called? When you harvest a portion of the brain from a patient who resides in a mental institution, when you fail to tell the recipients that the procedure is experimental and falsely state that the glands were donated and assure them of the product's safety, as well as fail to inform of other safer procedures,

isn't that the grossest of neglect?

My safety and the safety of all the other victims in this case were never adequately protected at any time. The definition of 'victim' is a person who is harmed by or made to suffer from an act, circumstance, agency or condition. What is a person who is tricked, swindled or taken advantage of? A dupe. That is what I and all of my fellow victims are—dupes. We trusted and believed what we were told by those whom it is ingrained in us from childhood to trust—our doctors.

So here we are again once more victims by virtue of the fact that we stand against a company which is run by the government. If we were faced with this disease because of the neglect of a private sector company, would we then not expect and receive the full backing of our government and legal bodies of this country? As far as compensation is concerned, how can I put a figure on what my suffering has been during the last four years of my life? One must take into consideration the amount of time lost working, the fact that I am under the care of a psychiatrist, the headaches and ulcer that I have suffered due to the stress of my situation and most importantly the time lost being a mother to my children and a wife to my husband, for surely they have suffered right along with me.

I do know without doubt that I have been caused to suffer due to no fault of my own, that I was caused to suffer due to the neglect of the CSIRO, the government and various individuals who now have escaped retribution and continue on their merry way without ever so much as a slap on the wrist. This fact above all is abhorrent to my mind.

I hope that my submission to you will help you to decide in favour of me and my fellow victims, for without a doubt the recent settlement offered by the Commonwealth government has not been fair and adequate, sufficient time and information for us to make a considered response was not given and the unfair denial of legal aid has placed us under more pressure to accept the Commonwealth's offer to settle. But the Commonwealth Serum Laboratory, the National Health and Medical Research Council, the Department of Health and Family Services or any other Commonwealth department, agency or employee failed to adequately protect public safety in relation to the Australian human pituitary hormone program. Thank you.

Mrs Baker—I was injected with HPG in 1982 by Dr Kovaks at Prince Henry. At no time was I told that the injections given to me were taken from the pituitary gland of a deceased person. As far as I knew I was given hormones for my infertility problems and I also was not aware that the gland was removed from deceased people without their family consent. To get a proper number on your batch number is impossible, because they used what was left over on other people.

I found out about CJD from the media at first and then I contacted my doctor at the time, Dr James Evans, and was told that I was not on HPG. A few months later I received a letter from Professor Burger at Monash Medical Centre. His excuse why it took

so long to notify me was that they could not find my name or address on my medical records. But when I went to Monash to get a copy of them, it was plastered all over my records. I could not get all of my records because there were other ladies names on my records. This is a poor excuse as far as I am concerned.

The Commonwealth Serum Laboratory, the National Health and Medical Research Council, the Department of Health and Family Services and any other Commonwealth department, agency or employee, medical practitioners and any other body involved in the Australian HPG program should be accountable for not protecting my safety when they knew the danger of this treatment could cause CJD.

CHAIR—Would you like to have a break for a minute or so? We have the submission here anyway.

Mrs Baker—I will just go on a bit more.

CHAIR—Okay.

Mrs Baker—I will skip some of mine and I will go to the counselling service that was provided. I live in a country area. For me to come to Melbourne, it takes me 2½ hours. When we first got the counselling service, the only way you had contact with it was by phone. My counsellor was Kevin Zobell. He was in Ballarat, I was in Morwell. So the only conversation was over the phone and it was very unpleasant and did not help me one little bit. It made me worse, actually.

Eventually, I saw Kevin Zobell, and the first thing he actually said to me was that I hated men—which was a joke. Then he stopped being my counsellor and gave me a female counsellor because he reckoned I needed to speak to a female. If I had to see Jane Chapman, I had to come down to Melbourne at my own expense because they could not come to see me, yet we were paying all this money for counselling. I think that was unfair. We got no support from the government, no support from anybody. That is all I have to say.

CHAIR—Thank you, Mrs Baker.

Ms Ogilvie—I was on the human growth program from 1979 until 1985, when the whole program was ceased. At that time, our doctor informed my mother and me that people had died from CJD overseas, but he made it very clear that it would never happen in Australia because the procedures were so completely different.

I was seven years old when I first started the program, so the decision to put me on the program was my mother's. She was also the one who gave me my injections. It never occurred to me—until she mentioned it to me this weekend—that she in fact pricked her own finger on several occasions with the injections when she was going to give them

to me. So that potentially puts her at risk as well.

In regard to batch numbers, I am not sure how other doctors did it in relation to growth hormone, but my doctor was in Sydney and we were living on the mid-north coast of New South Wales for most of the time I was on my treatment. I would come down to see him every eight weeks. At that time, we would take home an eight-week supply of growth hormone. On several occasions, the supplies had not come from Canberra so he would borrow from other children's growth hormone supplies. So all of the batch numbers next to any of the children he treated are wrong. It does not matter if we got hold of them anyway, because they are not the correct numbers.

I also came across several other growth hormone recipients who suffered, along with me, from various other illnesses, particularly different brain tumours. Most of us were not supposed to live anyway. The neurologist, who was the only doctor I was seeing at the time, was the only one prepared to talk to me about it. At the time I was being considered for the program, he suggested that I probably would not be accepted because of the fact that I was expected to die anyway and it was not general practice for the medical profession to put people who were not relatively healthy on programs like this—which makes you wonder if they were not using us just because we were going to die anyway so we were the best ones to experiment on, seeing it was all experimental.

My mother found out before I did. She saw it on the Hinch program in 1992, and it was about six months later that she told me. She chose to wait a while because of events happening in my life. I was about to turn 21 and then I was coming down here to get my guide dog. I know that she found it very difficult to find the best time to inform me and, because I was over 18, the department of health would not give her any information.

At the time that she did tell me, I got in contact with them. They sent the information to one of the doctors I had been seeing at the time. He never got back to us, despite the fact that we tried on several occasions to speak to him. The endocrinologist who was in charge of my growth hormone program conveniently had gone to America and was not expected back at any time. That is about it really.

CHAIR—Thank you, Ms Ogilvie.

Senator NEAL—Mrs Baker, you obviously did not find the counselling very good in the beginning. Has there been any improvement at all?

Mrs Baker—No. Because I felt, 'What is the point?' I was not getting anywhere, I was not getting any help. If you rang the counselling service and you were really on a down, you could not speak to them. They would say, 'I will ring you back', and you could wait four days—and then you had to ring them back. So I have nothing to do with them now, nothing at all.

Senator NEAL—Are any of the three of you using the counselling service at the moment?

Ms Ogilvie—I had a bad experience as well, which I should have mentioned. I was originally in Canberra, and then I moved to Melbourne two and a half years ago. When I was in Canberra there was only counselling over the phone from Sydney. The counsellor I spoke to was quite good. But, being visually impaired, when I moved to Melbourne it took me a lot longer than other people to learn how to get around Melbourne. I had to get instructors from Guide Dogs and what have you to teach me.

I had been informed by the committee in Canberra that part of the money given to the counselling service Relationships Australia was for them to travel to people, if we were not able to travel to them. So, when I rang up to make an appointment with them, I told them that I believed that they were expected to travel to me, at which time they refused to do so. I got back to the committee, and I spoke to Sue Byrne as well. The committee told them that they had to come and see me.

So they sent out Jane Chapman, who proceeded to ask me questions about my family. At first I thought it was just background information about how many brothers and sisters I had and what have you, but then she started asking some really bizarre questions. By the end of her interview she had decided that I had been abused as a child because I had been smacked with a wooden spoon occasionally—which I thought would apply to most Australians anyway—and that my parents had serious problems with their marriage because their only arguments were about their children. All of that is completely irrelevant to the situation anyway.

I did not use them after that. I know that the counselling situation has changed and now it is possible to find your own counsellor or psychologist and get funding for that. I have not used them myself, but I have heard reports that it is far better now.

Mrs Lee—I rang Canberra to request counselling, and I was told that they were planning to set up a counselling service in country areas—I am from Geelong and that is considered a country area—but, if I needed to see someone in the meantime, I could see a lady at the children's hospital in Melbourne, which I was not able to do. I was not able to travel down. So they contacted my GP, who then put me in touch with the psychiatrist I now see.

Senator FORSHAW—How long have you been seeing this psychiatrist?

Mrs Lee—I go and see her roughly every six weeks. I went more often in the beginning. I was on treatment for depression—a drug called Tolvin, I believe. I have been seeing her since 1994, I think.

Senator FORSHAW—Does that involve you in any expense?

Mrs Lee—As far as the drugs are concerned, yes. But, as far as the visits with the psychiatrist, no. She bulk-bills.

Senator FORSHAW—What about other members of your family—have they had cause so far to seek counselling or some assistance?

Mrs Lee—My husband and I are very protective of our daughters. We have not spoken to them very much about it at all. They are still fairly young. The eldest is 12. My husband has been to a session with me, but I think he finds it easier to deal with it in his own way.

Senator FORSHAW—But it must be a concern to you that it has the potential to impact upon other members of the family in a similar way.

Mrs Lee—It is, yes.

Senator LIGHTFOOT—What is the gestation period of the virus?

Mrs Lee—As I believe, it is from 12 to 30 years.

Senator LIGHTFOOT—When was your first injection?

Mrs Lee—My first injections were in 1983.

Senator LIGHTFOOT—It is a long time to wait, isn't it?

Mrs Lee—It is; it is virtually the rest of my life.

Senator NEAL—Are any of you involved in this negotiated settlement?

Mrs Lee—Yes.

Senator NEAL—Are all three of you? Did you find the discussions about your settlement satisfactory?

Mrs Lee—There were no discussions. We were contacted by Rennick Briggs and were virtually told that we had no choice.

Ms Ogilvie—Those of us who have not accepted the offer have basically been accused of being difficult and unreasonable and have been led to believe that we should have all signed the agreement and gone away and felt eternally grateful that the government was even going to offer us any money.

Mrs Baker—We want more than that anyway; we want justice.

Ms Ogilvie—It is not the money that matters. It is the fact that people should be held accountable for what they did to us.

Senator NEAL—Ms Ogilvie, whom did you actually deal with at this firm?

Ms Ogilvie—Sean Millard.

Senator NEAL—So you spoke to Sean Millard about the settlement?

Ms Ogilvie—I rang him when I first got the letter, and I did not even ask him for his advice. They were offering money if we contracted the disease and that they would pay our families money after we died, which just seemed like bloody money to me. Apart from that, the way it was worded was basically that we were not allowed to say anything ever again about it, which was probably the biggest problem for me. So I did not even ask his advice, but I rang him to inform him that I was going to refuse it. He basically told me that there was nothing he could do for me anymore, and he made out that I was just being difficult.

Senator NEAL—Were any of you told that the Commonwealth would pursue you personally for costs if you did not settle?

Mrs Baker—Yes.

Ms Ogilvie—There have been veiled threats in all of the letters that we have received since then that that is what will happen.

Mrs Lee—I was told that my family would be left destitute if we proceeded with the matter—that the government was willing to go as far as it possibly could to make sure that it won the case. I suppose that, along with many of the other recipients of HPH, we cannot afford to fight Big Brother.

CHAIR—Was your solicitor explaining to you the full nature of the government's offer or was he, in your mind, going beyond that and raising other consequences? Was he acting on his behalf or the government's in explaining those things to you?

Mrs Lee—From what I know now—

CHAIR—No, at the time.

Mrs Lee—I felt that the solicitors were acting in our interests at that time.

CHAIR—They were or they should have been?

Mrs Lee—They should have been. I felt that they were acting in our best interests.

That is what they were there for. They were our solicitors and we should follow their advice.

Senator HARRADINE—Mrs Baker, I could not find in your submission the dates of your first and last treatment.

Mrs Baker—My first was in 1982, and at the end of 1983 I finished the treatment.

Senator HARRADINE—And Dr Kovacs was quite definite that there were no long-term effects?

Mrs Baker—I have actually got a letter that he gave us.

Senator HARRADINE—Could we have that letter? Thank you. I will have a copy made of it.

Mrs Baker—It has not got his signature on it, but he did answer it. That letter was actually written by a social worker whom I was seeing at the time. I was having trouble handling infertility, and she wrote that letter.

Senator HARRADINE—That is not signed.

Mrs Baker—No, I said that was not signed.

Senator HARRADINE—You saw him on a number of occasions. How many?

Mrs Baker—Just about every week for 12 months.

Senator HARRADINE—And there was never any indication on his behalf that there was any possible adverse effect?

Mrs Baker—No. I would not be taking it.

Senator NEAL—So this letter is the doctor spoke to a social worker and the social worker wrote it down.

CHAIR—I will circulate it. It is not a letter, it is a series of questions that Mrs Baker asked Dr Kovacs. That is all it is, a series of questions that she put to him with her own handwriting in answer to a number of the questions. There is nothing from Dr Kovacs here.

Senator LEES—In other words, you were comfortable with the answers. They gave you confidence that there was not a problem.

Mrs Baker—I did not actually write that. A social worker wrote that.

Senator LEES—But when you got the answers—

Mrs Baker—I trusted my doctor. I was stupid.

CHAIR—Can I also ask each of the witnesses if you would mind providing to the secretariat a copy of your statement that you were reading from at the outset. That would be helpful for the *Hansard* record.

Ms Ogilvie—I was not actually reading from anything.

Senator FORSHAW—Only if you were reading.

Senator HARRADINE—Who was the social worker?

Mrs Baker—She was from the church medical clinic out there. I could not tell you her name. That is going back a number of years.

CHAIR—Thank you for coming and sharing your evidence with us.

Evidence was then taken in camera, but later resumed in public—

[2.03 p.m.]

GLEN, Mr Michael Francis Suttor, Solicitor/Partner, Rennick Briggs, Level 1, 459 Little Collins Street, Melbourne, Victoria 3000

CHAIR—I welcome Mr Glen to the committee. The committee has before it submission No. 11. Do you wish to make any alterations to that submission?

Mr Glen—Is that the submission regarding legal aid?

CHAIR—Yes, it is.

Mr Glen—No, I do not wish to make any alterations, thank you.

CHAIR—You are reminded that if during the giving of your evidence you consider it may be more appropriate for the committee to hear part of your evidence in private session the committee will give consideration to your request. I now invite you to make an opening statement. At the conclusion of your remarks, I would invite members of the committee to put questions to you.

Mr Glen—I refer to committee submission 1(d), which relates to whether legal aid had been unfairly denied to the recipients, placing them under more pressure to accept the Commonwealth's offer of settlement. I would like to briefly summarise my submission and indicate that 1(d) is a very significant issue as far as Rennick Briggs is concerned.

APQ had applied for legal aid from the Commonwealth Attorney-General's Department in May 1995 under the cases of national importance scheme. APQ's circumstances, in our view, clearly came within the ambit of that scheme. However, that department refused to make a decision on the application until after the federal election in March 1996. Upon the coalition government being elected to office, the scheme was reviewed, and eventually new guidelines were released for the scheme, which is now known as the public interest and test cases scheme. The new guidelines specifically excluded common law actions against the Commonwealth from legal aid funding.

In August 1996, APQ's application for aid was refused, and an appeal was subsequently lodged. However, we were notified on 20 December 1996 that the appeal had been rejected.

In order to expand on my submission, I attached a brief chronology, starting from APQ's initial application for aid on 26 May 1995 to when the final appeal was lost in December 1996. I also attached our letter to Legal Aid and Family Services, dated 23 September 1996. We considered it significant enough that we consulted senior counsel, Mr Graham Uren QC, and Mr Nick Green of counsel, to assist us in drafting that letter. In addition, I attached a response to our office from Dr Margaret Browne, of Legal Aid and

Family Services, dated 4 October 1996 and 20 September 1996 finally.

I must say that we were appalled and dismayed by the respective decisions of Legal Aid and Family Services to deny legal aid, in respect of APQ's action, under one or more of the respective schemes in place. The tenor of part of our letter of 23 September 1996 was to the effect that guidelines ought to have some sort of flexibility attached to them and that the response by Dr Margaret Browne indicated that the guidelines could not have any flexibility and were rigid in the extreme.

Subsequent to final avenues for legal aid funding being closed in late 1996, all further avenues for funding of APQ's trial were explored but were unsuccessful. These avenues included approaching four of the largest law firms here in Melbourne which handle personal injury litigation and making applications to the Supreme Court to avoid having to pay some trial disbursements, such as daily court fees. The final application was to Law Aid—very recently set up under the auspices of the Law Institute of Victoria—which was also unsuccessful.

Consequently, APQ was placed in the intolerable position of having insufficient funds to cover disbursements such as those I have just mentioned—daily court fees—and transcript costs and jury fees for a trial that, at that stage of the government's estimate, would last approximately 13 to 15 weeks.

I refer to the final submission relating to legal aid. We believe that, had proper and adequate legal aid funding been extended to APQ in her action—which was due to commence on 7 April 1997—as was most appropriate in all the circumstances, APQ would have been placed in a fairer position to meet the unlimited resources available to the defendants. It is our strong belief that APQ ought to have been granted legal aid in order for her to prosecute her action in this very sensitive and highly emotive piece of legislation.

I note that, just before parliament rose in March this year, a question—with or without notice; I am not quite sure—was directed by Senator Lees, I think, to Senator Newman. The very last question by Senator Lees to Senator Newman, on 26 March 1997, asked:

Therefore . . . will you now go back to the Minister for Health and Family Services and make a recommendation that the legal aid should be paid and seek his support to make sure that the plaintiffs can continue with their action?

Senator Newman replied:

I will refer the request to the minister and see if I can obtain an answer for Senator Lees.

This was a week before Easter, and the trial was due to start on the following Monday week.

We reiterate our strong sentiments, set out in our letter to Legal Aid and Family Services dated 23 September 1996, as to the reasons why aid ought to have been granted. The lack of legal aid funding in APQ's case, in our view, clearly demonstrates the unfairness of people being left to their own resources and efforts in order to prosecute their rights and seek answers to a precarious situation created by a bureaucracy that takes no responsibility. Finally, we believe that had legal aid been granted APQ would have been, in colloquial terms, on a more level playing field.

CHAIR—Thank you, Mr Glen. Any other comments?

Mr Glen—No. I am happy to answer any questions in relation to—

Senator NEAL—Are you a principal of the firm?

Mr Glen—I am a principal of Rennick Briggs. The action was being handled by Sean Millard of our office, who is a former employee of mine. Sean is still involved in the law and he has sought a different career in the law after the CJD action—most of them resolved. I have a general overview of the whole case and Sean was under my supervision, but he had the nitty gritty day-to-day conduct of the litigation.

Senator NEAL—When you say he sought another career, what do you mean?

Mr Glen—He has gone to work for a solicitor called Damien Smith, in Hawthorn, handling legal seminars. There was insufficient work for Sean to continue and he left by mutual agreement.

Senator NEAL—There was reference by some witnesses to a letter attached to your letter providing the offer of settlement, which was from the Australian Government Solicitor.

Mr Glen—Is that the letter dated 18 April?

Senator NEAL—It is. Do you have a copy we could see?

Mr Glen—Yes, I do. I was going to refer to that letter in my second submission.

CHAIR—Do you have further submissions to make, Mr Glen?

Mr Glen—I did make a submission that Mr Humphrey received last night, but I understand that the committee has not had time to—

CHAIR—That was given to us this morning.

Senator NEAL—Can I move that it be accepted as an addendum to the

submission?

CHAIR—It might more appropriate if you go on to complete all of your submissions, on the entirety of all matters, and then the committee members will ask you questions. Meanwhile, perhaps you could give a copy of that letter to us.

Mr Glen—Yes, certainly. My second submission is in response to a facsimile I received from Mr Humphrey yesterday morning in my office, although the fax was sent on Friday evening and unfortunately was not received until yesterday morning. Mr Humphrey forwarded to me some excerpts from litigants for whom we act, or acted, expressing some dissatisfaction in relation to the service they received after 2 April, which was the date of APQ's settlement. I wish to respond to that submission. I forwarded a written submission to Mr Humphrey by fax yesterday evening and I would like to expand on that if I could. This is a letter from my office dated 11 August 1997. I have copies.

I will summarise that submission. As the committee knows, we acted on behalf of two groups of recipients. The first group was those families who had lost a family member to CJD. These writs were issued in the first half of 1993 and settled in December 1994. There were four death claims. The second group was the pituitary hormone recipients who, while not demonstrating any signs of CJD, live in the fear that one day they may contract the disease.

The novel facts of CJD raised new legal questions which, to all intents and purposes, made APQ a test case. The defendants argued that the law did not recognise a duty of care in the circumstances where recipients who had been treated with hormone manufactured between 1967 and 1985 then alleged the suffering of psychiatric injuries after the disclosure by the government of the risks of CJD in the early 1990s. By about May 1993, it became evident that those who were not demonstrating the signs of CJD but who feared they might one day contract the disease might have a claim, even though the facts of CJD were novel and there was no established precedent at law which would give a determinative indication of entitlement to compensation. The Allars inquiry was then announced by the then Labor government, and in May 1993 Professor Allars began interviewing recipients. In June 1994 her report became available, and it was generally fairly damning of the government in relation to the program.

The first writs on behalf of those alleging psychiatric injury were issued in about May 1993. At this time there was a fear that one or two of these people might be demonstrating early symptoms of the disease. Hence it was thought tactically better to issue, in case the symptoms became full-blown. This did not eventuate. We were also concerned about proceedings becoming statute barred.

As the number of inquiries grew, we visited groups of recipients in various states of Australia in order to inform them of what we had learned about CJD and the hormone program and about their legal rights. Further writs were issued progressively from that

time. We conducted a number of meetings in various states, updating our information and advice as the litigation progressed. We were buoyed by the government's decision to attempt to settle, and we did settle the four death claims in December 1994. A further death claim was settled approximately a year later.

The only way of funding the litigation was to seek the cooperation of counsel, advisers and experts, on the basis that invoices would be rendered but payment of the same would not be demanded unless the litigation produced a result which included the recovery of legal costs and disbursements. Initially we anticipated that APQ's trial might run for six weeks. In late 1994 it was evident that the defendants were going to vigorously defend APQ's action. The defendants' application to strike out APQ's cause of action clearly demonstrated the defendants' intention of challenging the legal basis of her claim. The defendants indicated to the Supreme Court that one way or another APQ's action would end up in the High Court because of the legal issues concerning liability for psychiatric injury that the litigation raised. The defendants put an estimate on the trial not of six weeks but of a likely 17 weeks at that stage.

In May 1995, as I have indicated, the then Attorney-General, Mr Lavarch, announced the Justice Statement, which included a component of funding for cases of national importance. I have already referred to that in my earlier submission—No. 11. With all avenues of appeal exhausted for obtaining legal aid from the Commonwealth Attorney-General, in December 1996—little more than six months ago—we sought, as I have indicated, alternate funding from other large law firms but to no avail. We even had to regretfully write to our clients and ask them for a donation of up to \$750 to go towards disbursements in relation to the case. The outcome of that request was extremely positive amongst most of the recipients who could afford to pay. A lot of recipients paid by instalments, and a sum of about \$46,000 was raised. However, our estimate of the amount needed for daily transcript, daily trial fees and jury fees over a 13-week to 15-week trial came to some \$167,000. In the end there was no way that the amount of \$46,000, while much appreciated, was going to suffice.

The points I would like to raise in relation to the APQ's litigation and the litigation of the other recipients, as I said in the middle of page 5 of my letter, is that the conduct of APQ's litigation was made extremely difficult by the following: firstly, the issues of negligence law relating to the novel facts of psychiatric injury in the CJD and the hormone program; secondly, the costs and logistics of conducting group litigation on behalf of the 133 people located in various states of Australia of individual proceedings issued in the Supreme Court of Victoria; thirdly, the difficult scientific and medical material and the personal agendas of certain people concerning peripheral issues to the strict legal issues raised by the litigation of APQ's Supreme Court proceedings; fourthly, the forum of the Supreme Court was not that of a royal commission or an administrative inquiry such as that undertaken by Professor Allars; fifth, as I have alerted to in my earlier submission No. 11, the question of legal aid was of paramount importance.

For a small practice such as Rennick Briggs it was necessary for the practice to fund the overseas trip in April-May 1996 for Mr Jack Rush QC, Mr David Beach, Mr Sean Millard and me to partake in viewing part of the UK trial in London and also to interview potential expert witnesses not only in London but in the United States of America. In relation to this latter submission with regard to the terms of reference and those inferences raised by parts of the submission provided to me by Mr Humphrey in his facsimile yesterday, we say that we have provided all available information and advice to our clients as to when it becomes available by way of circular letter and visits interstate at no cost to those litigants during the years prior to settlement of the litigation. We were satisfied that we had obtained sufficient information from the defendants to prove negligence from about 1975 onwards. The discovery process between ourselves and the defendants was voluminous and carefully structured.

Counsel for the defendants conveyed to our council on Good Friday 1997 the basic outlines of a settlement proposal, which was not provided to us in writing until after Easter, by which time we had organised for APQ to come to Melbourne to discuss the offer once we had it in writing from the defendants on 2 April 1997. Of the 133 people we acted for like APQ, approximately 20 people had fairly frequent contact with our office. The balance, for their own reasons, rarely contacted our office, nor sought further advice or elaboration on the content of our circular letters.

As APQ's trial was to commence on 7 April, the proposal of settlement had to either be accepted or rejected within that period, otherwise the trial would commence. Those clients who were contacting our office during the period to 7 April were advised of the progress of settlement negotiations as far as it was possible at that time when negotiations were being conducted on a confidential basis.

On 4 April 1997, the defendants dropped their requirement of confidentiality and we were in a position to elaborate on the terms of settlement to those clients other than APQ who were inquiring. The court was also informed on 4 April 1997 that the matter had settled. While it was unfortunate, the media were present and reported the matter had settled on 4 April 1997. Our letters to all our clients of 4, 7 and 28 April 1997 clearly set out the events and reasons surrounding APQ's acceptance of the settlement and that those same terms of settlement were then being extended to all litigants for whom we acted. If the committee requires copies of that correspondence and correspondence exchanged between ourselves and the Government Solicitor the same will be provided.

CHAIR—We would like copies of those, Mr Glen.

Mr Glen—All available information and advice was provided to our clients who requested clarification of matters described in our letters. The threats by the defendant that they would pursue recovery of legal costs of those not settling was clearly conveyed in the Australian Government Solicitor's letter dated 18 April 1997 and was in response to inquiries made by some of our clients.

Prior to trial, we sought to negotiate a better offer than that put by the defendants but to no avail. The only option to not accepting the settlement was to proceed to trial. Neither APQ nor the group of 133 recipients or ourselves could fund the trial disbursements, let alone the costs, which have to be met if the trial proceeded. We absolutely refute any allegations that our clients were badly served by us after 2 April 1997. Our files will stand any scrutiny by both objective and qualified persons.

Further, we refute any suggestion that clients were bullied into acceptance of any settlement offer. All our clients had was the choice to accept or reject the offer. The offer was the best we could obtain for our clients, for the reasons set out in our detailed letter dated 4 April 1997. In addition, I would be prepared, with the consent of a particular client, to render to the committee for their perusal a typical file of one of our clients.

The only other thing that I would like to say is that I am dismayed by, take exception to and find offensive some comments made in relation to some submissions that I received yesterday that plaintiff litigants of ours were, for purposes of financial gain to Rennick Briggs, bullied into settlement or cajoled in some way into accepting the defendants' offer. Nothing could be further from the truth and I refute it categorically.

CHAIR—Thank you.

Senator NEAL—I want to clarify two things. Some evidence we took today indicated that your firm advised that they were withdrawing from the proceedings at the time this settlement offer was made. Can you clarify that?

Mr Glen—Withdrawing from the proceedings?

Senator NEAL—Yes, indicating that you were not going to act any further if the matter did not settle.

Mr Glen—No. The situation is this. We were placed in an impossible position. On Good Friday eve, the Thursday, we received the one and only offer that was going to come from the Commonwealth.

Senator NEAL—Why do you say that? How can you be so confident that it would be the one and only offer?

Mr Glen—Our counsel, Jack Rush, went back to Mr Stanley and they had discussions amongst themselves about whether that was it. Mr Stanley made it perfectly clear that that was the one and only offer that was going to be made in relation to APQ.

Senator NEAL—So it was on advice provided by Mr Stanley?

Mr Glen—As I understand it, Mr Stanley informed Mr Rush that that was the one

and only offer that was going to be made in relation to APQ's case. We are quite convinced of that.

Senator NEAL—Did your firm, or Sean Millard, advise any of your clients that they would withdraw if it was not settled?

Mr Glen—We had indicated in correspondence that we had had no luck with legal aid and that we might be forced to abandon the proceedings at some time if legal aid was not forthcoming. We were desperate in that last week. We had a letter faxed to Senator Harradine dated 26 or 27 March. I have a copy here. We had a letter hand-delivered to Dr Wooldridge over the Easter break—we knew of a relative of his who was going to see him over that Easter break—'Please reverse your decision on legal aid.' We were absolutely desperate.

Senator NEAL—The legal aid decision had been resolved some time before. You knew you were not going to—

Mr Glen—Yes, but we were lobbying at the last minute. In the meantime, of course, we had consulted other law firms to try to make the action work.

Senator NEAL—Essentially, what you are saying is that, because of the situation with legal aid and because other firms were not prepared to come and share the risk, as it were, you had indicated to people that you would have to withdraw if it was not settled.

Mr Glen—We had indicated to people that we may have to abandon the action, not necessarily if it did not settle. Obviously, if it did not settle we would have to. We had an expert witness from London. We had interviewed him and he was ready to give evidence. We had APQ in Melbourne. Obviously, she came on the 2nd because of the offer but we would have had her in Melbourne. If no offer had been forthcoming on Monday, 7 April we would have had to negotiate our way out of the proceedings because it was impossible to continue without legal aid.

Senator NEAL—Why do you say it was impossible? Was it because of your own costs, outgoings or what?

Mr Glen—We just did not have the funds to continue. The firm Rennick Briggs did not have the funds, APQ did not have the funds, we were without legal aid and the application for trial disbursements to be waived in some part was refused.

Senator NEAL—I thought you said that you had made agreements with third parties to render their accounts but not to demand payment until the matter was finalised?

Mr Glen—We had in the initial part of the action, that is right—I indicated that in my letter—but I am talking about trial disbursements more specifically, which over a 13-

to 15-week trial would have been significantly more than \$150,000. All we had in the kitty was \$46,000 kindly donated by our clients.

Senator NEAL—So when you say ‘disburse’, are you including counsellors’ fees?

Mr Glen—Counsellor fees were in addition to our scientific advisers. Part of that \$167,000 was an allocation of \$25,000 for expert witness fees in Australia and our expert witness from the UK.

Senator NEAL—Did that \$160,000 you are talking about include expected counsellors’ fees?

Mr Glen—No, over and above counsellors’ fees. That was set out in our letter to our clients dated 4 March 1997—jury fees, \$49,500; transcript fees, \$850 a day, \$72,250; court filing fees, \$20,475; and witness expenses and overseas experts, \$25,000.

Senator NEAL—We will see that letter shortly. We have not seen it yet, but you have handed it over. I have had a look at this letter of 18 April and I notice that the last paragraph says:

In the event that the Commonwealth is successful in defending the action or the plaintiff discontinues the action, the Commonwealth will pursue recovery of its legal costs.

A lot of the people involved in the action who rang up your firm after they had received your circular letter, as you call it, about settlement said that it was strongly impressed upon them that the Commonwealth would personally go out and seek legal costs from them and they would send a sheriff around to sell their goods.

Mr Glen—I really do not think that we pressed it that far. There is a precedent for the Commonwealth pursuing its legal costs in that celebrated case of Cooper. It is in black and white in the AGS’s letter dated 18 April. Obviously, after the clients received our letter of 4 April, certain queries were made. They rang us, we answered their queries and we had to clarify certain things of the Government Solicitor. It was made quite clear and it is in black and white here in that last paragraph.

Senator NEAL—I saw that paragraph. Was there anything in discussions with the Australian Government Solicitor or any further correspondence which elaborated on how far they intended to go to recover those costs?

Mr Glen—No.

Senator LEES—If I could just go back for a moment: you acted on behalf of the four families that had lost a family member.

Mr Glen—Correct.

Senator LEES—And you were successful?

Mr Glen—We settled those actions in December 1994, having issued proceedings in May 1993.

Senator LEES—And later there was an additional family?

Mr Glen—Yes, there was an additional family of an HGH recipient who had died.

Senator LEES—So, in your legal opinion, if there were another family—and we certainly hope that there is not—looking at your success in 1994 and your success in 1995, do you believe that you could say that it is very likely that following your processes in 1994-95, putting all the legal action we have just been talking about to one side, you could also be successful, unfortunately not until after a family member has been lost, but that you could get through the processes and get compensation?

Mr Glen—If someone had died between 1994 and 1997?

Senator LEES—Yes, initially.

Mr Glen—The four women who died, I understand, died between 1988 and about 1991 and the HGH recipient died in 1991. If someone had died between 1994 and 1997—is that what you are asking?

Senator LEES—Yes, initially.

Mr Glen—We would have issued proceedings like we did in the other five cases. We would have served proceedings on the Government Solicitor and we would have attempted to negotiate a settlement.

Senator LEES—Looking at your previous results, do you think that would have been reasonably successful?

Mr Glen—I would hope that it would be successful. The only thing is that, after March 1996, we had a different government. They might adopt a different view.

Senator LEES—Also, let us look at what is happening overseas in terms of payment to families there. If we had not had a settlement from the government in this particular instance—I am looking here at the letter that you have circulated to us, which I guess you described previously is what you thought was their final offer—do you think it would have been highly likely that you could have continued after the fact to try to get compensation for a family who had lost a family member?

Mr Glen—Sorry. Can you just repeat that, Senator?

Senator LEES—If you put the final offer to one side—we will just leave that as not accepted and move on into the future, perhaps next year or the year after, and we unfortunately have another family that loses a family member—given past history and the potential you see, maybe even as late as last year, in still successfully getting some compensation—and we will not worry about whether or not it is adequate for the family—do you think that is possible? I am putting aside the acceptance of that.

Mr Glen—Yes, I do.

Senator LEES—So, when we look at what has been accepted, isn't that basically what you had already got for people?

Mr Glen—Yes and no. Let me elaborate on that. We had issued proceedings on behalf of the families of the five people who had died. We issued them in May 1993. In December 1994, some 18 months after, the government wanted to settle them with us. We were preparing those cases for trial. Then, just before the end of 1994, the government said, 'Well, let's talk settlement.' We settled them very quickly. It is not a difficult task to settle those types of wrongs act claims. Then we had another claim with slightly different medical circumstances, but that was settled some time later. I am not quite sure when.

Senator LEES—But in all cases the government was quite keen to settle?

Mr Glen—Yes, but in the initial four claims not until 18 months after. You never know whether a different government, a coalition government, might take a different view. We were hopeful, but we could not say it is a lay down misere.

Senator LEES—No, but in terms of timing did you advise your clients that the offer they were being given was only that little bit better than what you had already got for people in 1994 and 1995?

Mr Glen—In my view it was a fair settlement. When I say fair, I mean fair in another context. I do not mean outstanding; I do not mean excellent; I do not mean good; I do not mean bad. I mean it was a fair settlement in all of the circumstances. In all of the circumstances relating to no legal aid, the government had us over a barrel.

Senator LEES—Let us put legal aid aside. We were on this particular claim. I am just looking for the advice that you have given your clients as to the actual status of this offer compared with your previous experiences as a law firm in 1994 and 1995 and the equivalent type of offer that they were getting.

Mr Glen—The offer was to all recipients, whether or not they were clients of ours. It has now been established to all recipients on the program.

Senator LEES—But effectively not until they die or they are actually suffering from a fatal disease?

Mr Glen—Suffering from a fatal disease.

Senator LEES—Which is the same situation as the five people for whom you acted.

Mr Glen—Yes, that is right, but the five people whom we acted for were all deceased when we issued proceedings. Now, although it is a dreadful thing to talk about compensation in the last year or two of one's life, if they do come down with CJD, at least those matters can be settled prior to their demise.

I might also draw the distinction between the Australian situation and the UK situation. With the Australian situation, the APQ settlement achieved a result for all litigants no matter when they were treated or with what substance. If they were treated in 1966 or 1984 with HPG or HGH, they are still entitled to full common law damages without having to issue proceedings. So it was a step forward.

Senator LEES—Thank you.

CHAIR—I want to go back to the nature of the offer that was put by your solicitor to the various litigants. There were a range of comments made in submissions and this morning to the effect that there was undue influence, duress, pressure, and your own correspondence refers to bullying. That was the thrust of the submissions we received this morning as to the actions of Mr Millard on behalf of your firm.

In particular, a range of persons commented that Mr Millard said that, if the offer from AGS was not accepted, the government could and would pursue legal costs and would pursue costs in terms of forcing the sale of homes and forcing the sale of private properties to pay its costs. The evidence was that Mr Millard put that to the people who attended this morning.

What I am interested in knowing is, from your position as principal in the firm, was that put? Was it authorised? If it was put and was authorised in such language and in such a framework, how do you classify it as fair and reasonable?

Mr Glen—To answer your question, certainly in response to the Government Solicitor's letter of 18 April, those last two very important paragraphs and detailing our knowledge of the Cooper case, we had to and felt it our duty to advise our clients of the situation regarding that very important letter.

If I could go back a bit, when we wrote our letter of, I think, 4 April we sent every letter out express post to our clients. I think we had a return date of 24 April, which we

felt was sufficient time to come back to us. We have had constant phone contact with our clients. They do not have a problem in relation to that. Neither do we. We are always on the phone to them. The situation is that, if Sean is busy, I will take a call.

There was some concern that this period of time fell within the school holidays. A lot of clients sent back the authority to accept with no attachment, nothing. That was okay. Other clients rang and expressed a concern that they did not have enough time. There was no problem with that. The dates were extended. Then the government imposed two dates—one some time in May and the other on 30 June. They have now delayed any further date until the results of this committee inquiry.

I worked very closely with Sean on this matter in the settlement stages and he would never have used those alarmist type tactics, such as ‘The sheriff is going to come in and sell your property.’ It may have been that, in response to statements such as, ‘I can’t afford to pay for it,’ or ‘Does my house go?’ he said, ‘Probably not, but do you have any other assets?’ It would have been a conversation along those lines. Sean would not deliberately—and I know him extremely well—say something that would unnecessarily alarm or place fear in someone along those lines.

CHAIR—If Mr Millard had used language of that type—deliberately causing concern or pressure—would you regard it as an unreasonable method of persuading a client to accept what, in all of the circumstances, you have said to be a fair offer?

Mr Glen—If Mr Millard had said, ‘If you don’t accept the offer, I can tell you they are going to pursue you for costs’—which is true, because they have said it—‘they are going to sell your home. The sheriff is going to come around. They are going to sell your assets,’ and all those sorts of things, he would only have said that in response to certain questions. If he had said that without referring to the fact that they were going to pursue them for costs, that would be unreasonable, but I am sure he did not say that in that context or in those terms.

CHAIR—So you say, if it were said, it was in response to direct inquiries by litigants?

Mr Glen—Exactly. Sean would spend sometimes half an hour or an hour on the phone to clients. He gave them the time of day. There is no doubt about that. He had very, very lengthy conversations with clients from all over Australia.

Senator LIGHTFOOT—Mr Glen, what level of compensation do you think your clients would have accepted, and perhaps your current clients who have not accepted? I would like to tie that in in respect of notice that your clients may have been given on the British line where, prior to 1 July 1977, those people treated with HGH have been denied any form of compensation due to, I assume, the statutory limitation of time.

Mr Glen—Both of those are very good questions. If I may deal with the second one first, the situation—put very briefly—regarding the UK trial, which I was at myself so I am able to expand on that, was that the Hon. Mr Justice Morland ruled that the Department of Health in Britain was not negligent in relation to the deaths of those who had died from CJD before 1 July 1977 upon the basis that the state of knowledge prior to that date did not amount to negligence. For all those who were treated after that date, the government was liable, and for those families who had lost loved ones to CJD as a result of human growth hormone—one must remember that there is no HPG outside Australia—the government was liable. We are not talking about psychiatric injury; we are talking about deaths.

Our clients were advised of that by way of letter when we arrived back from the UK. I have got the letter here. On 14 June 1996 we wrote a detailed letter to our clients. It opens with these words, ‘We now report to you on our trip to the UK and the USA,’ and it was a three-page letter. We did not know the result of the decision then, of course, because the judge had reserved his decision. Senator, does that answer the second part of your question?

Senator LIGHTFOOT—If you are saying that, yes, your clients were notified.

Mr Glen—Yes, we did notify them then. After the decision had been announced—I think it was in August 1996—we notified them of the decision.

Senator LIGHTFOOT—Shortly after the decision had been brought down?

Mr Glen—That is right. We understand that parts of that judgment of the Hon. Mr Justice Morland are now under appeal by the plaintiff and the defendants. The first part of your question is also a good question because we believe the strongest part of our case against the government was on the issue of negligence in the running of the program as per the Allars report—that they owed our clients a duty of care and that there was a subsequent breach of that duty. The most difficult part of our claim was establishing psychiatric injury as a result of the government’s negligence. That, as I have indicated before, involved novel questions.

Senator LIGHTFOOT—Have you advised your clients to accept damages for psychiatric injury?

Mr Glen—Have we advised our clients?

Senator LIGHTFOOT—Yes.

Mr Glen—Our clients have been offered nothing for psychiatric injury.

Senator LIGHTFOOT—But that was not my question.

Mr Glen—Sorry.

Senator LIGHTFOOT—I asked you: ‘Have you advised your clients to accept damages for psychiatric injury?’

Mr Glen—No, we had alerted them. The whole aim of the litigation was to obtain damages for psychiatric injury for our clients.

Senator LIGHTFOOT—But, on that point, were your clients aware that once they accept—and you can correct me if I am wrong—damages for psychiatric injury, if CJD develops at a later stage that nullifies the claims they may have?

Mr Glen—Yes, they were, and I can read you paragraph 3 from our letter of 14 June:

Another client has raised the issue of what happens if a psychiatric injury claim is settled and that person then subsequently falls ill with CJD. Will that person’s family then have a claim as dependants against the Defendants?

This is our answer:

If that client succeeds at trial for the psychiatric injury, neither that client nor that client’s family will have any further claim for compensation in the instance that a client falls ill with CJD thereafter.

So we did advise them.

Senator LIGHTFOOT—You only have to answer then, if you can, the question of what damages would be acceptable.

Mr Glen—That depends upon whether, in our view, a particular client has suffered a psychiatric injury. We ran with APQ because she was treated late—in 1980—when we say the state of knowledge was obvious and evident. We also ran with APQ because she was treated with HPG because it was a known alternative in HMG.

Importantly, we also ran with APQ because we truly believed, and had medical evidence to support the fact, that she had a recognisable psychiatric injury. You have to be more than shocked, upset and angry. You must have a recognisable psychiatric injury. There is no doubt that some of our clients did not have a recognisable psychiatric injury. A lot did; some did not. Some had not bothered to consult with psychologists or psychiatrists; they dealt with it within their family. If we did have a group settlement, there would obviously have to be plateaus of compensation for various people.

Senator LIGHTFOOT—What would that average be?

Mr Glen—It is very hard to say. Juries are notoriously conservative in relation to awarding damages for psychiatric injury in that Supreme Court. It might be anywhere between a low of \$5,000 and a maximum of \$75,000 to \$80,000—just to give you a broad spectrum.

Senator LIGHTFOOT—That is better than what we were doing.

Senator FORSHAW—I want to take up some of the issues that Senator Lightfoot has just raised. As for the settlement offer that is on the table now and as I understand the position of your firm, you believe there is no scope for further improvement through negotiation. What steps did you try to take to seek to negotiate an improvement particularly in relation to this issue of the psychiatric injury? I ask this because the settlement offer clearly recognises the position of people who ultimately contract CJD, and it recognises in some part the issue of costs and so on but an essential part of what you were seeking to litigate is not covered at all in the settlement. One of the major complaints of recipients is that, if they accept this offer, they waive any rights for any further litigation in the future.

Mr Glen—I am not quite sure of the date but we had written to the Australian Government Solicitor saying that we would recommend a group settlement for all our clients of \$2 million inclusive of costs. That offer was never responded to.

Senator FORSHAW—How many clients would that have covered?

Mr Glen—It would have covered all those clients who had a recognisable psychiatric injury in some way, and obviously there would be some sort of assessment in a plateau-type way of determining psychiatric injury. That is one way of doing it, or the government would have said, 'Okay, we will agree to that,' or would have come up with some counter offer. We never received a response to our letter. The only response we received was senior counsel talking to senior counsel on Good Friday eve.

Senator FORSHAW—Can you provide us with a copy of the letter that you sent?

Mr Glen—Yes, but I do not know if I would have a copy here.

Senator FORSHAW—If you would provide a copy to the committee when you can. I hear what you say. You say your firm was put in an unenviable, impossible situation: seeking to mount litigation with no or insufficient funds to cover the cost. One can appreciate the concerns of the individuals and families involved in that they saw a whole range of issues being litigated, including accountability and also including, hopefully, a recognition of the position that they had been placed in even if they did not contract the disease and possibly even if they did not suffer a recognisable psychiatric injury, but there was the very fear of contracting it.

The question I now want to ask you is: what do you say to the committee now? One of our terms of reference is whether the Commonwealth's offer to the recipients was fair and adequate? Do you have a view to put to us as to what we may say to the parliament about this other category, if you like, of people who do not get anything out of the settlement offer?

Mr Glen—Let us hope nobody gets anything out of the settlement offer in relation to contracting CJD.

Senator FORSHAW—But that means no-one gets anything.

Mr Glen—That is true, but at least they are covered for the future—it is a cast-iron guarantee—should they come down with CJD. There has not been a death since 1991.

Senator FORSHAW—No, but what I am getting at is: if the litigation were on foot, there would still be the belief by the clients that the action being taken on their behalf by the firm seeking to achieve a result would provide compensation and potential accountability in terms of findings against individuals. It appears that the position of your firm is that, because that litigation is no longer continuing, that opportunity has been lost through the courts at this point in time for those people.

We now have a Senate inquiry. What do you say that we should do? Should we make some recommendations to deal with that issue to satisfy, if you like, the clients you originally had and on whose behalf you were taking that action?

Mr Glen—You are talking about whether another action is possible?

Senator FORSHAW—I am asking you whether you think we should put a suggestion to the government about compensation.

Mr Glen—My strong recommendation fits fairly and squarely within my first submission—that is, there is no more deserving case of legal aid funding than those cases. I am absolutely convinced of that. It was a mortal blow to us that the government revised its guidelines.

Senator FORSHAW—So your position is that we should at least recommend that the opportunity be given through legal aid for litigation to continue?

Mr Glen—For someone to continue a piece of litigation.

Senator FORSHAW—I was wondering whether or not you were also taking that a step further and putting to us that, whereas for all sorts of reasons you were not able to succeed in the settlement for people who are here today, we should put forward some proposition along those lines.

Mr Glen—APQ's claim is settled and their other claims have settled. For those who have not accepted the government's offer, the opportunity exists. As I understand it there is a Western Australian woman who is pursuing a claim by her solicitors and wants to be another 'test case'. She may be clearly deserving of legal aid.

Even the champions of the no-win no-fee solicitors Slater and Gordon have put a memo on the Internet saying that they cannot fund this action in the absence of legal aid—'We are not prepared to do it on the no-win no-fee basis because of the legal and novel issues involved regarding psychiatric injury.'

Senator FORSHAW—Another proposition that could be put to even avoid the trauma of a test case and further litigation, the trauma that may put individuals through and potentially the chance of no result—and I was wondering whether you were going to put this—is that there should be some global compensation settlement offered to all of the people involved in the program.

Mr Glen—I would support that 100 per cent. No question about it. We had even suggested to the government earlier on in these proceedings as they had settled the five death claims with us—clearly we thought that that put them behind the eight ball on the issue of negligence—why don't we run this trial as six-week psychiatric injury trial rather than a 13- to 15-week trial on all issues when we believe and they probably suspect, appreciate and acknowledge that they would lose on the primary argument.

Senator LEES—Regarding this letter from the Attorney-General, had you ever seen anything like this before, particularly part (d)—

Mr Glen—Had we ever seen anything like this before?

Senator LEES—Had you ever received something like this as a result of an action you were taking, and I particularly refer to (d):

In the event that a plaintiff does not accept the offer of the settlement the Commonwealth will commence action to take the required steps as pursuant to the Supreme Court Rules to have the matter prepared and set down for hearing.

In the event that the Commonwealth is successful in defending the action or the plaintiff discontinues the action, the Commonwealth will pursue recovery of its legal costs.

Mr Glen—I must say that every other action I have taken against the Commonwealth has either settled or proceeded to verdict, but I have never seen a letter like that. That letter does not surprise me, because all lawyers are aware of the Cooper case.

Senator LEES—Yes, but your firm had never come across this before?

Mr Glen—I do not believe our firm has come across that. I might be wrong. I have never come across it personally.

Senator LEES—So did you advise your clients of that, that this really was a step beyond anything your firm had ever come across before?

Mr Glen—We knew that the Commonwealth are a formidable opponent. We also knew that in the case of Cooper they pursued Mrs Cooper for their legal costs. They might have wanted to make an example out of it; I am not sure. But we knew that and we knew that a precedent had been established and therefore they were not kidding, they were not just mucking around. We felt that we had a legal as well as a moral obligation to indicate to our client in very strong terms the last two paragraphs of that letter.

Senator LEES—Regarding the actual recovery process, if your clients had said, ‘No, we do not think this is fair,’ or whatever, would you have been able to recover any of your costs? Were there any avenues for you to recover costs?

Mr Glen—If the government had made no offer, there would have been no recovery—

Senator LEES—No, but if this offer had been made but your client said, ‘We do not think that we want it’ or ‘We do not think it is reasonable,’ for whatever reason, was there any other avenue for you to at least recoup what you had expended?

Mr Glen—Are you talking about individual plaintiffs or APQ?

Senator LEES—Any costs that you had incurred as a result of this action.

Mr Glen—If clients do not accept the offer, and there are about 44 who have not accepted it, about a third, then we do not recover any costs. We only recover the costs of the clients who have accepted the offer and APQ. There are no other avenues of recovery.

Senator NEAL—You did recover some costs as part of this settlement. what was the offer for your clients?

Mr Glen—We have not received any costs yet and our cost consultants are negotiating at this very moment in relation to the question of costs.

Senator NEAL—But essentially it is a verdict in your favour, so you are entitled to have your costs taxed and recovered from the Commonwealth in the usual way?

Mr Glen—If we cannot agree on costs then we have liberty to go back to the court to apply for an order that costs be taxed.

Senator NEAL—I understand it is fairly clear-cut recoverable damages where someone has died as a result of catching a disease.

Mr Glen—Yes.

Senator NEAL—You said that there has to be a circumstance where there is a real psychiatric illness before damages can be recovered. Is it that certain? If you can prove on the facts that there is a psychiatric disorder arising from the stress of possibly having CJD, is it absolutely certain you will receive damages, or is it not a clear principle in law?

Mr Glen—It is not a clear principle because not only must you have had a psychiatric injury but you have to relate that suffering of a psychiatric injury to having found out in the early 1990s that you may be at risk of contracting CJD as a result of the government's program in which you may have received an injection in 1969. So it causation, remoteness of damage, all intermingled together. The principles of the case—

Senator NEAL—Sorry to interrupt you, but if on the facts you can prove that there is causation, are the principles clear that you can receive damages?

Mr Glen—Well, if you can prove causation and you have suffered a recognisable psychiatric injury, the celebrated case of Rogers and Whittaker would assist a recipient in relation to informed consent. So the answer is probably yes, even though it is novel. But we see it as an extension of the existing law rather than creating new law. That is an important distinction.

CHAIR—Senator Neal, we are coming to the close of the session. One further question?

Senator NEAL—Yes. I suppose it varies from client to client but, in terms of the test case you had, had you received advice from counsel about the likelihood of success?

Mr Glen—Yes, we received that advice from Mr Jack Rush—just very skeleton advice—on the prospects of success.

Senator NEAL—Is that something you would be able to provide access to for us?

Mr Glen—I believe I could provide it.

Senator NEAL—We would appreciate that because—

Mr Glen—It is a short three-page advice.

Senator NEAL—Good.

Senator LEES—I have one final issue: why psychiatric illness? Was there any alternative—for example, the question of negligence? At least post-1977 the knowledge base was there and the warning bells were ringing but no-one was taking any notice within the program. My particular reason for asking is that issues were brought up this morning relating to the risks that people were taking if they put in as a plaintiff—for example, the risk to their job if they were compensated for psychiatric illness and what that would do for their prospects of promotion. What about the prospects if, say, a Family Court battle or Family Court case were going on and the woman was indeed compensated for psychiatric illness? Could she, for example, lose access to or perhaps care of children? Were those issues discussed with your clients?

Mr Glen—They may have been broadly discussed, but I do not think that that would create a real issue unless someone had so suffered a psychiatric illness to the extent of not being a balanced person, and therefore could not be a carer for their children. But I think in the vast majority of cases the people we are dealing with and who were on the program are regular, good hardworking Australian men and women who are certainly pretty level-headed but have had this dreadful trauma to live with.

Senator LEES—But is there any other way that the case could have been run—for example, a negligence case?

Mr Glen—It was a negligence case against the Commonwealth and the CSL alleging duty of care, breach of—

Senator LEES—Yes, but looking at both the written evidence and what we had this morning, many people have apparently not even become part of the case because of their concerns about a successful process and not wanting to fight those battles with employers, former spouses or whatever.

Mr Glen—That may be a peripheral issue, but it is something that we have not really turned our minds to.

CHAIR—Thank you, Mr Glen, for coming along and giving evidence. I propose to adjourn the committee now until 3.20 p.m. When we resume we will be going to in camera evidence, so persons in the public gallery will not be able to attend that in camera evidence. All the remaining evidence this afternoon is in camera evidence.

Evidence was then taken in camera—

Committee adjourned at 4.20 p.m.