Witness Name: Charles MacKenzie
Statement No: WIT3939001
Exhibits: WITN3939002- WITN3939060
Dated: 15 May 2020

INFECTED BLOOD INQUIRY

EXHIBIT WITN3939053

P1091

Medically acquired H.I.V. / Parliament of New South Wales, Legislative Council, Standing Committee on Social

1991, English, Article, Report, Government publication edition: Issues. New South Wales. Parliament. Legislative Council. Standing Committee on Social Issues

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CHAIRMAN'S FOREWORD

This Report has been an extremely difficult one for the Members of the Standing Committee on Social Issues.

All social issues require sensitive and careful investigation, because they can have major impact on people's lives, and because they can involve irreconcilable conflicts between different groups, and between hope and feasibility.

Such complexities were fundamental to this Inquiry, and are reflected in the Report. While a minority of the Committee dissented entirely from the recommendations on financial assistance, some Members who supported the majority position believed that the recommendations did not go far enough.

These divisions reflect the divisions within society as a whole regarding the issue of medically acquired HIV, divisions that were evident in the submissions and testimony to the Committee, and that are far too fundamental to be reconciled by any Parliamentary report, unanimous or not.

However, I am confident that the majority of recommendations of this Report represent the best solution that the Committee could find, with all the evidence available to us.

The dissenting voices need to be placed in context, for a number of the recommendations of the report were unanimous. Some recommendations relate to HIV/AIDS generally, rather than just medically acquired HIV/AIDS. In its tragic effects, AIDS creates needs regardless of how it was acquired, and the Committee received sufficient information about these needs to feel qualified to make recommendations concerning them.

For me, it has been particularly saddening to see certain groups, while perhaps acting out of fear of discrimination against themselves, nonetheless projecting what came across as implacable opposition (indeed, on occasion, hostility) towards a group of people suffering terminal and painful illness. Such hostility has even extended to attempts to intimidate Committee Members, unconscionable behaviour under any circumstances.

I am grateful to all Committee Members, both current and former, especially the previous Chairman, now President of the Legislative Council, the Hon. Max Willis, for his leadership throughout most of the period of this Inquiry.

My appreciation also needs to be recorded for the contribution of the staff of the Committee to this Report. Senior Project Officer Tony Pooley and Research Officer Sarah Evans were crucial in the acquisition and compilation of information, and Committee Director Peter Gacs, Committee Officer Heather Crichton and Assistant Committee Officer Andrea Mann were also most important. Without the dedication of the staff, this Report could not have been accomplished.

GRO-C

Dr. Marlene Goldsmith, M.L.C.
Committee Chairman

ACKNOWLEDGEMENTS

The Committee wishes to record its appreciation for the many thoughtful written submissions and evidence received from members of the public and a wide range of organisations, upon which the Report is entirely dependent.

A debt of gratitude is also extended to the many legal and medical professionals who gave much of their time and expertise in explaining the complex issues surrounding this Inquiry.

Our thanks are extended to Dr. Charles Watson from the Western Australian Department of Health and Mr John Mandy, Deputy Clerk, Legislative Council for their assistance with the Committee visit to Western Australia.

Particular thanks are also due to Pam Shipway and Mark Lynch.

We are indebted to David Rubanenko of Maxwell Printing for his advice and assistance in printing the Report.

Finally, but by no means least, the Committee extends its thanks to the staff of the Parliamentary Library, particularly Jan Duncan in the Media Monitoring Section, for their co-operation and assistance.

MEMBERS OF THE SOCIAL ISSUES COMMITTEE

Hon. Dr Marlene Goldsmith, M.L.C. (Chairman), L.P.

Hon. Ann Symonds, M.L.C., (Deputy Chairman), A.L.P.

Hon. Franca Arena, M.L.C., A.L.P. → thats a laugh!

** Hon. Lloyd Coleman, M.L.C., N.P.

Hon. Keith Enderbury, M.L.C, A.L.P.

Hon. Elisabeth Kirkby, M.L.C., A.D.

Hon. Douglas Moppett, M.L.C., N.P.

Rev. The Hon. Frederick Nile, M.L.C., C.T.A.

Hon. John Ryan, M.L.C., L.P.

Hon. Helen Sham-Ho, M.L.C., L.P.

Mr Peter Gacs, Committee Director (until 30 August 1991)

Mr Anthony Pooley, Senior Project Officer (until 13 September 1991)

Ms Sarah Evans, Special Project Officer

Ms Heather Crichton, Committee Officer

Ms Andrea Mann, Assistant Committee Officer

A.D.	Australian Democrats
A.L.P.	Australian Labor Party
C.T.A.	Call to Australia Group
L.P.	Liberal Party
N.P.	National Party

** Joined Committee upon the resignation of the Hon. Richard Bull, M.L.C., Thursday 29 August 1991. The Hon. Richard Bull, M.L.C. was a Member of the Committee from 2 July, 1991 until 29 August, 1991.

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TERMS OF REFERENCE

INQUIRY INTO MEDICALLY ACQUIRED HIV INFECTION

That the Standing Committee on Social Issues report upon as a matter of urgency:

(a) whether persons who have contracted HIV infection through blood, blood products, artificial insemination from a donor, or as a result of organ transplant, are receiving adequate and comprehensive health and welfare services;

(b) whether persons who have acquired HIV infection through secondary transmission from spouses or parents with medically acquired HIV are receiving adequate health and welfare services;

(c) whether the Government should provide financial assistance to those persons described in paragraphs (a) and (b) above.

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EXECUTIVE SUMMARY

The emergence and spread of the HIV virus into the world and Australian community has had devastating consequences at an international, national and personal level for many, many thousands of people. Committee Members, after some nine months of investigation, now have a considerably greater understanding of the huge individual, social, emotional, administrative and indeed financial implications of this epidemic. It is a tragedy of epic proportions.

A number of other countries have chosen to recognise the special nature of this tragedy for those who acquired the virus through medical means. Financial assistance packages of which the Committee is aware have been provided in the United Kingdom, Canada, New Zealand, Germany, Austria, France, Japan and Switzerland.

In Sydney, the first recorded Australian case of what we now know to be the HIV virus came to the attention of medical authorities in 1982. Nine years later over 15,000 Australians are HIV positive and a further 2,500 have already died. With the advantage of hindsight, and advances in medical technology, we are now aware that as many as 350 people in New South Wales and more than 500 Australia-wide contracted HIV through contaminated blood, blood products, organ transplants and artificial insemination by donor.

In May 1985, effective, universal testing of all blood, blood products and human tissue for the HIV virus commenced throughout Australia. The Committee is unaware of anybody in New South Wales or Australia who has acquired HIV as a result of a medical procedure after testing began.

In March 1989, the Haemophilia Foundation of Australia made a submission to the Commonwealth Government calling for the establishment of a Haemophilia Foundation Endowment Fund to "cover additional costs arising from HIV infection on top of the provision of health and welfare services." Acknowledging that a broader cross-section of people had acquired the HIV virus through other medical procedures such as blood transfusions, organ transplants and participation in the artificial insemination by donor fertility program, the Commonwealth Government agreed to the establishment of the fund, known as the Mark Fitzpatrick Trust, and expanded it to allow this broader class of people access to it.

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People with medically acquired HIV are infected with a permanent infectious and sexually transmissible disease, causing extraordinary suffering from multiple symptoms over a long period of time. These factors have a profound impact on the self esteem of this group.

Many people in this group expressed a strong need to keep their condition a secret, even from family members, because of the strong stigma associated with HIV. Others described problems with confidentiality and discrimination because of being HIV positive. Some in this group addressed the need for greater education of health professionals and the general public. People with haemophilia and HIV described themselves as carrying a "double burden".

This group of witnesses strongly supported the granting of financial assistance to people with medically acquired HIV.

The Committee received submissions from and spoke to four broadbased AIDS organisations. They were:

1. The AIDS Action Council (AAC) of the A.C.T.;
2. The AIDS Coalition to Unleash Power, New South Wales;
3. The AIDS Council (ACON) of New South Wales; and
4. The AIDS Council (WAAC) of Western Australia.

Three of these broadbased organisations, the exception being the AIDS Council of Western Australia, opposed the granting of financial assistance, arguing that any assistance should be provided to all people with HIV. ACON points to a number of problems in the area of health and welfare services.

In Western Australia, the Government recently agreed to grant financial assistance to 22 people with medically acquired HIV (average payment of $280,000, total cost $5.4 million). It seems that the decision to grant a settlement payment was based on a weighing up of the potential costs of litigation and the costs of settlement, as well as a consideration of the human costs involved in litigation. WAAC did not oppose this settlement

During the visit to Canberra the Secretariat heard that then Commonwealth Minister for Health was not in favour of awarding financial assistance to people with medically acquired HIV, for the following reasons:

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9. The difficulties for people with medically acquired HIV in pursuing litigation.

The scheme is in many ways similar to the federally funded Mark Fitzpatrick Trust. This was a conscious decision by the Members supporting financial assistance. As the Commonwealth scheme is not deemed to be "income" and as such taxable by the Government it is fully expected that the same criteria will be applied by the Tax Department to this scheme. However, the proposed scheme is focused more on assisting people with medically acquired HIV while they are alive.

The Committee Members supporting financial assistance rejected the arguments placed before it by several of the broad based AIDS organisations because they felt that the factors listed above separated this class of people out from the larger HIV community.

Those Members who opposed the granting of financial assistance did so for the following reasons:

1. Any assistance scheme should be based on need rather than mode of transmission of the virus;

2. This scheme will reinforce, in the minds of the community, the incorrect assumption that some people with HIV are innocent and some others are guilty;

3. That there were insufficient factors which separated this group from the broader HIV community and others with medically acquired diseases and as such it has created a precedent.

The majority of the Committee however do not accept these arguments, holding that:

1. The proposed assistance is based on need: people with medically acquired HIV have had their infection since at least 1985, and some for considerably longer. Consequently they are in the later stages of the illness when need is greatest. Any provisions for all people with HIV would take longer to implement and thus would specifically disadvantage the medically acquired group. In addition, this group is more likely to have dependants, and to be widely dispersed throughout the state away from services, further factors of need.

2. The proposed scheme is not a moral judgement of guilt on the part of HIV positive people. Babies who have acquired the virus from HIV positive parents are just one of a number of categories not covered by the scheme.

- In Australia everyone is entitled to income security (Department of Social Security) and free health care (Medicare) and they do not consider it equitable to give extra benefits to one particular group.
- The Commonwealth has made an assessment that, in general, health authorities were not responsible for medically acquired HIV and, on this basis, Legal Aid may soon cease to fund these cases.
- The Mark Fitzpatrick Trust has been established at the Commonwealth level to provide extra assistance to people with medically acquired HIV.
- People with medically acquired HIV cannot be singled out for special treatment.

The Committee could not help but note the inconsistency of the Commonwealth Government's position. On the one hand, they were prepared to list the reasons why further financial assistance should not be granted, yet they themselves created the precedent, by establishing the Mark Fitzpatrick Trust, in the first place.

Some of the arguments presented to the Committee had characteristics which could be used to either support or reject the granting of financial assistance. However, a majority of the Committee agreed to support the scheme outlined in the List of Recommendations, for the following reasons.

1. The fact that the source of the infection was a Government instrumentality;
2. The extreme physical trauma that is the nature of HIV;
3. The substantial costs involved in caring for someone with HIV;
4. The urgency of the needs of the medically acquired HIV community in that they have all been infected for a substantial amount of time and are in the latter stages of the illness;
5. The double trauma for those who have haemophilia;
6. The "stigma" that the medically acquired community suffers as a result of incorrect assumptions about their sexual orientation or drug use;
7. The fact that many of the medically acquired HIV community have dependent children and or spouses;
8. The adequate precedents for the granting of such financial assistance; and

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LIST OF RECOMMENDATIONS

RECOMMENDATION NO. 1

That people with Medically Acquired HIV be entitled to financial assistance.

Supported by Goldsmith, Arena, Moppett, Nile and Ryan.

Opposed by Symonds, Enderbury, Kirkby and Sham-Ho.

RECOMMENDATION NO. 2

That this financial assistance be restricted to a maximum figure of $50,000 [subject to recommendation no. 6] for a Medically Acquired HIV person with dependants and $25,000 for a Medically Acquired HIV person with no dependants.

RECOMMENDATION NO. 3

That those people who accept financial assistance do not have to waive their right to seek compensation in court but that any amount of assistance granted will be deducted as a disbursement from any compensation agreement awarded by the courts.

RECOMMENDATION NO. 4

That financial assistance be allocated to people with Medically Acquired HIV in the following manner:

Stage of Disease	Dependants	No Dependants
	(Maximum Payment Per Year)	
Stage 3	$ 8,000	$4,000
Stage 4	$12,000	$6,000
Maximum Final Payment[1]	$10,000	$5,000

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[1] If a person with medically acquired HIV dies before they have reached the maximum relevant payment, only this amount will be paid upon notification of death.

RECOMMENDATION NO. 5

That a once only lump sum payment of $10,000 be paid to the dependants of Medically Acquired HIV people who have already died, and that a figure of $5,000 be paid to the carers of Medically Acquired HIV people with no dependants who have already died.

RECOMMENDATION NO. 6

A further once only lump sum payment of $5,000 be paid to recipients of funding under recommendation 4, for each dependant who is HIV positive. This payment shall be in addition to the maximum individual payment of $50,000 (recommendation 2).

RECOMMENDATION NO. 7

That the above assistance be provided quite separately to the current AIDS budget.

RECOMMENDATION NO. 8

That the State initiate discussions with the Commonwealth Government to examine the feasibility of a national no-fault insurance system for people who contract disease or injury with long-term debilitating consequences, through the health care system.

RECOMMENDATION NO. 9

That the Transfusion Related AIDS (TRAIDS) Unit based at Parramatta Hospital receive extra funding to employ another counsellor.

RECOMMENDATION NO. 10

That the following recommendations from the AIDS Bureau of the New South Wales Department of Health Report <u>Planning for HIV/AIDS Care and Treatment Services in New South Wales 1990-1994</u> be implemented:

> "*The AIDS Bureau, areas and regions and AIDS specific volunteer agencies should encourage the involvement of mainstream volunteer agencies in the care of people with aids and their friends and families. This should be achieved through direct approaches to specific agencies and through liaison with the volunteer centre of New South Wales.*"[2]

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[2] NSW Department of Health Report (1990). <u>Planning For HIV/AIDS Care and Treatment Services in New South Wales 1990-1994</u>, p.25.

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[3] Ibid. p.109.

[4] Ibid.

> *"CSN and Ankali should consider jointly providing consultancy services and training to non-AIDS specific voluntary organisations in both metropolitan and non-metropolitan areas."*[3]
>
> *"The Community Support Network should extend training programmes for volunteers to include coverage of the needs of women, children, and intravenous drug using clients."*[4]

RECOMMENDATION NO. 11

That extra resources be provided to assist with the implementation of the above recommendations.

RECOMMENDATION NO. 12

That, in pursuit of the recommendations regarding mainstreaming made in the Aids Bureau of the New South Wales Department of Health Report Planning for HIV/AIDS Care and Treatment Services in New South Wales 1990-1994, where possible, people with HIV should be accommodated in non-identifying areas of the hospital, in the ward most appropriate to their presenting medical problem.

RECOMMENDATION NO. 13

That, where possible, inpatient and outpatient services provided to people with HIV/AIDS be sensitive to the needs of individual patients, taking account of relevant factors, such as sex and age.

RECOMMENDATION NO. 14

That the AIDS Bureau of New South Wales Department of Health continue to implement and develop strategies outlined in the AIDS Bureau Report Planning for HIV/AIDS Care and Treatment Services in New South Wales 1990-1994 to improve the level of services provided to people with HIV by general practitioners.

RECOMMENDATION NO. 15

That the New South Wales Department of Health approach the Commonwealth Department of Health, Housing, and Community Services to request changes to the eligibility criteria for the nursing home subsidy to include people with HIV.

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[3] Ibid p.109.

[4] Ibid.

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RECOMMENDATION NO. 16

That a separate nursing home type facility be established to meet the particular needs of people with HIV/AIDS.

RECOMMENDATION NO. 17

That home based palliative care should be extended to a seven day a week, 24 hour a day on call basis. It is desirable that all New South Wales Health Department areas and regions work toward this goal.

RECOMMENDATION NO. 18

That the following recommendation, contained in the AIDS Bureau of the New South Wales Department of Health Report Planning for HIV/AIDS Care and Treatment Services in New South Wales 1990-1994, be supported:

> *"People with AIDS-related neurological impairment should be managed in the least restrictive environment possible, taking into account the level of their impairment, available health and community resources and the need to ensure the safety of the individual. The provision of longitudinal care in a variety of community, institutional and hospital settings, involving a multi-disciplinary approach is needed for these patients. This should include day programs, domiciliary care, respite care, and access to transport, nursing care and appropriate supervision. In addition, areas and regions will need to be able to provide secure accommodation for patients with particularly significant levels of impairment."*

RECOMMENDATION NO. 19

That a special unit be established for people with AIDS related neurological problems in close proximity to an already established HIV/AIDS unit so that appropriate medical expertise is available for other AIDS-related problems.

RECOMMENDATION NO. 20

That home based nursing care be available on a seven day a week, 24 hour on call basis. It is desirable that all New South Wales Health Department areas and regions work toward this goal, as far as possible.

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RECOMMENDATION NO. 21

That the New South Wales Department of Health investigate the establishment of a bed linen service for people with serious illnesses and a demonstrable need for such a service.

RECOMMENDATION NO. 22

That the New South Wales Department of Health review its policies and negotiate with the Commonwealth Department of Health, Housing and Community Services to alleviate the cost of pharmaceuticals for all people with serious illnesses.

RECOMMENDATION NO. 23

That the New South Wales Department of Health support the efforts of the Commonwealth Department of Health, Housing and Community Services to ensure safe and immediate access to appropriate drug therapies for people with HIV.

RECOMMENDATION NO. 24

That the New South Wales Departments of Health and Community Services liaise with the Commonwealth Department of Health, Housing, and Community Services to increase services provided by the Home Care Service of New South Wales to people with HIV/AIDS.

That the current restrictions of the Home Care Service of New South Wales regarding the provision of personal care to people with HIV/AIDS be lifted.

That funding continue to be provided on a shared basis between the Commonwealth and State Governments.

RECOMMENDATION NO. 25

That the New South Wales Department of Transport review the eligibility criteria for the Taxi Transport Subsidy Scheme to include all people with terminal illnesses who have difficulties using public transport because of the problems not covered in the current eligibility criteria.

RECOMMENDATION NO. 26

That the New South Wales Departments of Health and Community Services ensure the integration of policies and programs regarding the issues of child care, including fostering, adoption, and residential support, for women and children with HIV.

RECOMMENDATION NO. 27

That the AIDS Bureau of the New South Wales Department of Health should implement the following recommendations from the AIDS Bureau Report entitled Planning for HIV/AIDS Care and Treatment Services in New South Wales 1990-1994:

> *"All areas and regions should ensure that agencies providing care to HIV-infected people develop or expand programs to address the needs of HIV-infected women and families."*
>
> *"Areas and regions should consider resourcing mainstream services such as women's health centres to develop services for HIV-infected women."*

RECOMMENDATION NO. 28

That the New South Wales Department of Health should provide additional funds to develop an education program to promote community awareness about the needs of people with HIV and should be designed to reduce public fears and prejudices about the virus. This program should be developed in consultation with members of the Transfusion Related AIDS Unit (TRAIDS, based at Parramatta Hospital, the Haemophilia Society of New South Wales, the Haemophilia Foundation of Australia, and the AIDS Council of New South Wales (ACON).

Note:

A person living in a permanent relationship (married or defacto) or a person with dependant children (whether currently living in a relationship or not) qualifies as a person with dependants for the purpose of recommendations 4 and 5. This definition of dependants attempts to take account of the major financial consequences (e.g. house repayments) for the remaining partner, if one partner dies.

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Voting:

It should be noted that the four Members of the Committee who voted against Recommendation 1 did not participate in the framing of the following Recommendations 2 - 6. However, a majority of the participating Committee (5) supported all of these recommendations. The Hon. Lloyd Coleman was appointed to the Committee after the Hearings had concluded and chose to abstain from all recommendations.

Recommendation No. 2: Rev. the Hon. Fred Nile and the Hon. Franca Arena originally supported a figure much higher than that which was finally recommended.

Recommendation No. 4: Rev. the Hon. Fred Nile and the Hon. Franca Arena supported the proposition that all money up to the maximum respective figures should be paid to the families of Medically Acquired HIV people, rather than the maximum final payment recommended.

Recommendation No. 6: Rev. the Hon. Fred Nile, the Hon. Franca Arena, and the Hon. John Ryan originally supported a figure of $8,000 in this recommendation.

DATES OF SIGNIFICANCE IN THE KNOWLEDGE OF HIV

This is a chronology of some of the significant dates relating to HIV. This list is by no means exhaustive, but it does cover many of the discoveries and issues which are of relevance to the Committee.

1979-1980	Anecdotal reports of Kaposi's Sarcoma in young homosexual men - New York, Los Angeles, San Francisco.
June 5 1981	First published report of Pneumocystis Carinii Pneumonia in Homosexual men in Morbidity and Mortality Weekly Review (MMWR). During the remainder of 1981 there were various reports of homosexual men with unusual opportunistic infections (infections which were usually seen only in people with impaired immune systems).
July 16 1982	First published report of Pneumocystis Carinii and immune deficiency in three people with Haemophilia in MMWR.
July 26 1982	At a meeting held by the American Public Health Service the name Acquired Immune Deficiency Syndrome (AIDS) is given to this new disease.
December 10 1982	First report of transfusion acquired AIDS in MMWR (a 20 month old infant). The editorial of this issue stated:

> "*The aetiology of AIDS remains unknown, but its reported occurrence among homosexual men, intravenous drug abusers, and persons with haemophilia suggest it may be caused by an infectious agent transmitted sexually or through exposure to blood or blood products.*"

	At the press conference, Dr.Joseph Bove, head of the U.S Food and Drug Administration, said, on national (U.S.) television, that there was still no evidence that transfusions spread AIDS.
January 4 1983	Meeting held at the U.S Centre for Disease Control to discuss the link between AIDS and blood products, and surrogate testing. At this meeting there were no decisions made about any form of testing and no decision was made about deferring "at risk" donors from donating blood.
March 3 1983	U.S Public Health Service issues the following guidelines: *"As a temporary measure, members of increased risk for AIDS should refrain from donating plasma or blood."*
March 3/4 1983	Meeting of the Australian National Blood Transfusion Committee resolves to begin study of immune status of haemophiliacs at Royal Prince Alfred Hospital, Camperdown Children's Hospital, Royal Children's Hospital (Melbourne). Dr Archer, the Director of the Red Cross Blood Bank, Sydney, made a request through the media that male homosexuals not donate blood.
May 11 1983	The National Haemophilia Foundation (U.S.A.) newsletter urges Haemophiliacs to continue to accept clotting factor as prescribed by their doctor: *"it has not been scientifically established that AIDS is transmitted by blood products.*
May 1983	Dr Engleman at Stanford University blood bank begins testing blood for signs of the AIDS virus using a T-cell ratio test.

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December 1983	Dr Robert Gallo informs the National Cancer Institute that he has discovered the virus which causes AIDS and calls it HTLV III.
June 1984	The Australian Red Cross Blood Bank issues written guidelines to facilitate self-exclusion of high risk persons.
July 12 1984	First case of medically acquired AIDS reported in Australia.
August 15 1984	Dr Archer meets with members of the homosexual community in Sydney to request that homosexual men with multiple partners refrain from donating blood. Some 300 people attended.
August 16 1984	At a meeting of the Blood Transfusion Service Technical Committee it is decided to ask people presenting to donate blood to sign a form stating that they are not a member of an "at risk" group. Several variations of this form were used and soon covered by legislation, the <u>Human Tissue Act 1983</u>(Section 21c.) states that a person shall not donate blood or semen: "*unless the donor has signed a certificate relating to the medical suitability of the donor, being a certificate in or to the effect of the prescribed form, and had the signature witnessed by a prescribed person or a person of a prescribed class, at the time of the removal of the blood, or the obtaining of semen, as the case may be.*"
October 1984	Dr Archer begins using Hepatitis B core anti-body testing at the Red Cross Blood Bank, Sydney.
March 2 1985	Abbott Laboratories HIV anti-body test kit licensed in USA

Chronology

May 1 1985	HIV anti-body testing begins in Australia.
May 31 1987	At the Third International Conference on AIDS the virus which causes AIDS is renamed Human Immunodeficiency Virus.
November 1989	UK Government establishes the MacFarlane Trust with a grant of 10 million pounds. This Trust provides financial assistance to 1226 people with Haemophilia and HIV who are 'in need' (up to 50 pounds per week). The UK government pays 20,000 pounds to each Haemophiliac infected with HIV.
December 1989	Canadian Government announces the establishment of the Extraordinary Assistance Plan to provide financial assistance to people with medically acquired HIV. Approximately 1250 people will each receive $CAN120,000 in four equal payments over four years.
April 1990	Mark Fitzpatrick established in Australia with a grant of $13.2 million to provide financial assistance to people with medically acquired HIV. A single person receives between $1000 and $4000 per annum and a person with dependents receives between $2000 and $8000.
October 1990	Inquiry into medically acquired HIV referred to the New South Wales Standing Committee on Social Issues.
May 22 1991	The Government of Western Australia announces that it is to pay compensation to 22 people with medically acquired HIV - total package $5.4 million, average payout $280,000 per person with medically acquired HIV.
June 10 1991	UK courts give clearance for each person with Haemophilia and HIV to receive between 20,000 and 60,000 pounds in return for waiving their right to litigate.

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CHAPTER ONE

INTRODUCTION

Background

1.1 The emergence and spread of the HIV virus into the world and Australian community has had devastating consequences at an international, national and personal level for many, many thousands of people. Committee Members, after some nine months of investigation, now have a considerably greater understanding of the huge individual, social, emotional, administrative and indeed financial implications of this epidemic. It is a tragedy of epic proportions.

1.2 A number of other countries have chosen to recognise the special nature of this tragedy for those who acquired the virus through medical means. Financial assistance packages of which the Committee is aware have been provided in the United Kingdom, Canada, New Zealand, Germany, Austria, France, Japan and Switzerland. (See Appendix for more details)

1.3 In Sydney, the first recorded Australian case of what we now know to be the HIV virus came to the attention of medical authorities in 1982. Nine years later over 15,000 Australians are HIV positive and a further 2,500 have already died. With the advantage of hindsight, and advances in medical technology, we are now aware that as many as 350 people in New South Wales and more than 500 Australia-wide contracted HIV through contaminated blood, blood products, organ transplants and artificial insemination by donor.

1.4 Little was known about the virus in the early stages. As Professor John Dwyer, Head of the School of Medicine at the University of New South Wales, when giving evidence to the Committee, noted:

> *"The vast majority of people who got infected with HIV, either medically-acquired or otherwise, were infected before they or anybody else knew there was a virus that could cause this disease."*

However, two Members of the Committee disagreed with this opinion.

1.5 With the advantage of hindsight, and advances in medical technology, we are now aware that as many as 350 people in New South Wales and more than 500 Australia-wide contracted HIV through contaminated blood, blood products, organ transplants and artificial insemination by donor (see Appendix for further epidemiological information).

1.6 In May 1985, effective, universal testing of all blood, blood products and human tissue for the HIV virus commenced throughout Australia. The Committee is unaware of anybody in New South Wales or Australia who has acquired HIV as a result of a medical procedure after testing began.

1.7 Because of their dependence on blood products for the treatment of their existing condition, haemophiliacs were particularly vulnerable to the contraction of HIV during the period 1982 to May, 1985, when there was no available test to prove that the blood supply was unsafe. It has been estimated that as many as 60 per cent of "severe" haemophiliacs and almost 30 per cent of "mild" haemophiliacs contracted HIV during this period because of the large number of blood products individually received.

1.8 In March 1989, the Haemophilia Foundation of Australia made a submission to the Commonwealth Government calling for the establishment of a Haemophilia Foundation Endowment Fund to "cover additional costs arising from HIV infection on top of the provision of health and welfare services." Acknowledging that a broader cross-section of people had acquired the HIV virus through other medical procedures such as blood transfusions, organ transplants and participation in the artificial insemination by donor fertility program, the Commonwealth Government agreed to the establishment of the fund, known as the Mark Fitzpatrick Trust, and expanded it to allow this broader class of people, from all states, access to it.

1.9 Since the establishment of the Mark Fitzpatrick Trust an increasing number of people with medically acquired HIV, and their families, have felt that the fund is inadequate and called on various State and Commonwealth Governments to pay them compensation or some form of financial assistance. At least four court cases, in three different states, seeking damages for negligence by Hospitals, the Red Cross or the Commonwealth Serum Laboratories have gone to court with varying results and Justice Wilcox of the Federal Court, in a judgement that rejected the application for compensatory damages (though it may be subject to appeal) called on "Government" to honour its "moral obligation" to these people and organise some form of financial assistance.

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1.10 In response to this increasingly complicated situation, the Legislative Council of New South Wales, on October 11, 1990, debated a motion proposed by the Hon. Franca Arena, MLC. That motion requested:

That the Standing Committee on Social Issues investigate and report on, as a matter of urgency:

(1) whether patients who have contracted HIV infection through blood, or blood products, transfusion, or via artificial insemination from a donor, are receiving adequate and comprehensive health and welfare services;

(2) whether compensation should be paid by the Government to patients who have contracted HIV infection through blood, or blood product, transfusion, or via artificial insemination from a donor; and

(3) whether the decision regarding the suitability of blood and semen donors made by health authorities in 1983/84 was appropriate in light of the information available at the time regarding HIV infection.

Representatives of the government, opposition and minor parties spoke in favour of the motion and it was passed unanimously.

1.11 The Committee immediately advertised for submissions in the major daily newspapers and wrote to 42 organisations and individuals which it felt had some expertise in the HIV area, inviting them to make submissions. The Committee commenced a detailed series of Hearings and visits of inspection early in 1991 and was well advanced on the Inquiry when the Parliament was prorogued and an election called for May 25, 1991. Though the Secretariat continued to collect and analyse information the Committee was effectively dissolved and the Inquiry, for all practical purposes, ceased.

1.12 On the first sitting day of the new Parliament, July 2, 1991, the Standing Committee on Social Issues was reconvened with a majority of the same Committee Members who had commenced this Inquiry and a new Committee Chairman, the Hon. Dr. Marlene Goldsmith, MLC, was appointed.

1.13 Shortly after, the Minister for Health and Community Services, the Hon. John Hannaford, MLC, re-referred the Inquiry into Medically Acquired HIV to the Social Issues Committee with the following, amended, Terms of Reference:

That the Standing Committee on Social Issues report upon as a matter of urgency:

(a) whether persons who have contracted HIV infection through blood, blood products, artificial insemination from a donor, or as a result of organ transplant, are receiving adequate and comprehensive health and welfare services;

(b) whether persons who have acquired HIV infection through secondary transmission from spouses or parents with medically acquired HIV are receiving adequate health and welfare services;

(c) whether the Government should provide financial assistance to those persons described in paragraphs (a) and (b) above.

1.14 The revised Terms of Reference for the Inquiry reflected a feeling among Members that the third question in the original Terms of Reference was beyond the capacity and expertise of the Committee. The Committee is not a quasi-judicial body and it was simply inappropriate to be attempting to lay blame, or apportion negligence where, to date, courts in New South Wales have been unable to do so.

1.15 All documents, evidence, submissions and information gathered in the first part of the Inquiry were "carried over" and utilised under the new Terms of Reference. However, it should be noted that a number of the Hearings were conducted under the original Terms of Reference. (see List of Hearings in the Appendix).

1.16 Unfortunately, but perhaps given the nature of the subject not surprisingly, the Inquiry was subject to much media speculation, inaccurate reporting, claim and counter-claim by various interested parties and passionately held views on all sides of the debate. This did little to assist Committee Members in their attempts to look closely and dispassionately at the evidence before them.

1.17 At the outset, the Committee is keen to stress that this Inquiry is not about discrimination in services for people with HIV and is not about providing two (or more) standards of medical care depending upon how people contracted a particular disease. Indeed, all Committee Members were forthright in their opposition to such suggestions. Most Committee Members were opposed to the suggestion that this Inquiry was about innocence or guilt yet a minority of Members felt that the majority decision to award financial assistance reinforced this notion.

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1.18 What this Inquiry is about, is an investigation of the particular needs of the medically acquired sections of the HIV positive population in this state. Though individuals and organisations have suggested that this is itself discriminatory, a majority of the Committee rejects this view.

1.19 The spread of this disease through the Australian population has automatically divided the HIV community into differing groups. For example, children with HIV have different needs to homosexual men who have different needs than injecting drug users, who have different needs to haemophiliacs who have different needs to women who are HIV positive. Such divisions already exist, and indeed certain services and expertise are designed and allocated to cater for the various distinctive communities who are HIV positive.

Method of Inquiry

1.20 The Committee received submissions from and spoke to individuals and organisations representing the medically acquired HIV community and the haemophiliac community - Transfusion Related AIDS Unit and Support Group (TRAIDS), the Haemophilia Foundation of Australia (HFA) and the Haemophilia Society of New South Wales - both in formal evidence at Hearings at Parliament House and at meetings of both groups at the TRAIDS Unit at Parramatta Hospital and the Haemophilia Centre at Royal Prince Alfred Hospital.

1.21 The Committee also received submissions from and spoke to AIDS related organisations: the AIDS Council of New South Wales (ACON) and the AIDS Coalition To Unleash Power (ACT UP) in Sydney and the AIDS Action Council (AAC) in Canberra.

1.22 Further, the Committee received submissions or evidence from the Positive Women's Group representing women with HIV, people dealing with HIV positive children and the New South Wales Users and Aids Association (NUAA), an organisation representing injecting drug users who are HIV positive.

1.23 The large Canberra-based AIDS umbrella organisations, the Australian Federation of AIDS Organisations (AFAO) and Australian National Council on Aids (ANCA), were both invited to give submissions or send representatives to talk to the Committee but chose not to accept the Committee's invitation.

1.24 The Committee approached a range of professional people with direct contact with HIV sufferers in general and invited them to give evidence. These included solicitors, barristers, doctors and other health professionals with considerable expertise in HIV, social workers and judges. Furthermore, the Committee spoke to people with medically acquired diseases other than HIV and it examined the relevant precedents relating to this issue in New South Wales.

1.25 The Committee received detailed briefings from State Health Department representatives in Sydney, Perth and Melbourne. The relevant office in the Commonwealth Department of Community Services and Health did meet on one occasion with Secretariat staff. However, despite numerous requests, they refused all invitations to place the Commonwealth perspective on this issue before the Committee.

1.26 The Committee contacted the Haemophilia Foundation of Australia and wrote to the Departments of Health in the United Kingdom, France, Canada and New Zealand for advice on how people with medically acquired HIV had been dealt with in other countries (see Appendix for more details). The Committee secretariat conducted a literature search for relevant documentary material in the Parliamentary Library and the State and Commonwealth Departments of Health as well as securing transcripts of the Judgements of relevant court cases. The Committee subscribed to relevant publications, monitored press and electronic media comment, and held informal discussions with eleven people.

1.27 Though the Committee could not speak to every one of the 92 people or organisations who made submissions, every endeavour was made to access a cross section of all available opinions.

The Medically Acquired HIV Population in New South Wales

1.28 As of August 1991 there were a total of 224 identified cases of medically acquired HIV in New South Wales. This figure is made up as follows:

Haemophiliacs	95	- (21 of whom have already died)
Transfusion Related	125	- (60 of whom have already died)
Artificial Insemination	4	- (2 of whom have already died)

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1.29 The National Centre of HIV epidemiology and research and the Red Cross Blood Transfusion Service estimates that there may be as many as a further 100 as yet unidentified cases of medically acquired HIV in New South Wales.

1.30 The New South Wales Department of Health AIDS Bureau notes that:

> *"There have been no new cases of HIV infection occurring in people with haemophilia, blood transfusion recipients and persons enrolled in artificial insemination programs since 1985, following the introduction of screening for donated blood and sperm and new procedures for treating clotting factor."*

1.31 It is estimated that 10 children in New South Wales have HIV which they acquired from a parent who themselves medically acquired HIV. It is estimated that approximately 6 spouses have acquired HIV from partners who themselves have medically acquired HIV.

CHAPTER TWO

REVIEW OF EVIDENCE

Introduction

2.1 The Committee received 92 submissions to this Inquiry, heard evidence from 53 witnesses in 12 hearings and had formal discussions with 26 people in Western Australia, Victoria and the ACT.

2.2 The issue of Medically Acquired HIV is one which arouses a complex range of emotions in the community. This was reflected in the submissions and evidence provided to the Committee.

2.3 The following is a summary of the submissions received and the oral testimony heard by Committee Members. It should be noted that this summary is a review of the arguments presented and that conclusions drawn by witnesses and submittees do not necessarily accord with the views of Committee Members.

People with Medically Acquired HIV, Their Partners and Families

2.4 The Committee received 43 submissions from people with medically acquired HIV, their partners and families. In this group 22 submissions were from people with medically acquired HIV themselves, 7 were from parents, 11 were from partners, 2 were from children and 1 was from another family member. Breaking this down according to mode of transmission there were 18 from haemophiliacs with medically acquired HIV, 14 from people infected through blood transfusions, and 2 from women infected through artificial insemination by a donor. A further breakdown reveals 11 submissions from rural New South Wales and 3 from interstate.

2.5 The Committee heard evidence from 25 people with medically acquired HIV, several of whom were given the opportunity to give evidence twice.

2.6 Not surprisingly, this group was very keen to participate in the Inquiry and this was reflected in the number and detail of their submissions. There was a strong feeling that a decision about their particular needs had already taken too long and so there was a great sense of urgency in the evidence and submissions of this group:

> *"[there has been a] lack of action, or fast enough action by government and those in authority. Is it realised that we are now looking at cases that were medically given their infection up to eight or more years ago? Most of their life expectancy after infection has now passed and in New South Wales, no NSW Government help is forthcoming yet."*[1]

2.7 People with medically acquired HIV and their families provided very moving evidence to the Committee about the circumstances surrounding the contraction of the virus:

> *"I was admitted to hospital on 10th November, 1984, a happy, healthy 32 year old, very excited about the imminent birth of my baby. This was to be the start of a wonderful new family for me and my second husband, his first child, and the beginning of a new phase in our relationship. Our hopes and plans for a long and happy future together ended when I was given an HIV-infected blood transfusion shortly after our daughter's birth. This tragic occurrence has not only devastated my life but the lives of my husband and daughter; our dreams for the future have turned to nightmares and we live in constant fear of the unknown hardships ahead of us."*[2]

2.8 HIV is a terminal illness. Much of the evidence received by the Committee detailed the horrific nature of the disease:

> *"Those affected come from all social and economic backgrounds, yet we are universally in anguish, watching or having watched our loved ones bear such tremendous pain and suffering, slowly seeing them grow spectre thin as their little, twisted bodies are ravaged by disease after disease. We feel such tremendous amounts of bitterness as those that deserve to live are being denied their youth and their life."* [3]

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[4] Evidence. 19.07.

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[5] Submission 69

2.9 People with medically acquired HIV are infected with a permanent infectious and sexually transmissible disease. These factors have a profound impact on the self esteem of this group:

> *"[I am] infectious for life. For life. Not just for one day or one year but for life, sexually and your body fluids. I don't know how any of you would feel but it feels pretty awful. I find that so hard to live with, to know that for life I am going to be infectious. If you are a young child or a young boy growing up how do you tell your child that they have got a sexually transmittable disease, that they can never live a normal sexual life, that they will probably never have children unless we have a cure?"*[4]

2.10 Many people in this group expressed a strong need to keep their condition a secret, even from family members, because of the strong stigma associated with HIV:

> *"The stigma and ignorance surrounding the infection affected our demeanour and affected our family in the deepest and most traumatic way. To have a son, shining with intelligence and life turned into a social pariah was hugely damaging to his intensely fragile ego."*[5]

2.11 Others described problems with confidentiality and discrimination because of being HIV positive:

> *"Discrimination is a real problem. We were accepted onto a waiting list for a Donor Insemination by a major teaching hospital. After anxiously waiting for one year we were told that we had reached the top of the waiting list and to come for an appointment. Just after this we were told that we had been rejected as unsuitable by the Hospital's "Ethics Committee", on the grounds of potential problems with my health. We were not warned in any way that this vetting was normal procedure or that it would be required in our case. Letters were written to my doctors seeking further*

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[4] Evidence. 19.07.91.

[5] Submission 69.

> *medical information without my written or verbal consent. We were not given any chance to present our case nor to protect our identity."*[6]

2.12 Some in this group addressed the need for greater education of health professionals and the general public:

> *" [there is a] need for education with special consideration to Medical Practitioners, Ambulance and Paramedics, Police, Clergy, Hospital Staff, and Social Workers generally, in addition to public education."*[7]

2.13 People with haemophilia and HIV described themselves as carrying a "double burden":

> *"In the case of haemophiliacs, it has become an intolerable and untimely fatal burden for people who were already coping bravely with a severe disability."*[8]
>
> *" The real point is that the AIDS infection coming on top of haemophilia blew our family apart. It was as though someone put a time bomb in our midst which couldn't be diffused and which we were unable to tell anyone about."*[9]

2.14 Because of the relatively constant requirement for treatment over a number of years, families with a member with haemophilia developed into a close community. The advent of HIV has placed a heavy burden on this group:

> *"Soon within our small group, members began dying from AIDS. We slowly began to find out about the sons of friends who were also HIV positive. We were told to stay quiet to protect ourselves from the media. This had a two-fold effect, one - we lost blood donors whom we always actively*

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[6] Submission 57.

[7] Submission 65. Emphasis In Original.

[8] Submission 87.

[9] Submission 60

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[10] Submission 34

[11] Submission 35

[12] Submission 45

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> *encouraged and secondly we became a silent minority unable to speak for fear of discovery and retribution."*[10]

2.15 An added burden is faced by haemophiliacs and other families where there is more than one person infected with HIV:

> *"I had two of my family in the same hospital, dying from the same virus ... My other little girl, ... , has lost her mother and her playmate sister. What do I tell her ? She continually asks me why did my mummy and [sister] die Daddy ? How do you explain to a five year old about this virus ?"*[11]

2.16 People with medically acquired HIV who live in rural New South Wales also claimed to be particularly disadvantaged, because of the lack of medical and other expertise in the country, greater stigma and ignorance about HIV in small rural communities, and the distances which must be travelled to visit specialists in Sydney. A number of families were forced to move to Sydney because of these problems:

> *"We live in a small country town and isolation from the community has always been a threat, but we have been back and forth to Sydney until we're dizzy and suspicion has grown in friends and family. So we have the added worry of realising they must be told and finding the right time to tell them."*[12]

2.17 Almost without exception, this group of witnesses strongly supported the granting of financial assistance to people with medically acquired HIV.

2.18 Many argued for a compassionate response from the State and Commonwealth Governments. Many cited the assistance which had been given in Canada and England, and more recently, in Western Australia.

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[10] Submission 34.

[11] Submission 35.

[12] Submission 45.

2.19 Many felt that money should be spent on the care of people with medically acquired HIV rather than on legal expenses. Many also spoke of the stresses associated with going to court. A feeling was expressed by some people that justice was not available in the courts of New South Wales:

> *"I really believe that these cases shouldn't be settled in court. Lawyers really don't have any medical scientific background and I have sat and listened for so long and honestly, they just play around with words and this is not a humane way of treating these families at all, making them go to court."*[13]

2.20 For members of the haemophilia community the granting of substantial financial assistance could bring an end to litigation and thereby, an end to the "erosion" of haemophilia care. They told the Committee that litigation relating to medically acquired HIV is placing a great strain on health care workers in haemophilia treatment centres in New South Wales and Victoria:

> *"The current situation is creating a climate for people [Doctors, etc.] to move away from haemophilia care and it will be extremely difficult to get anyone interested - Why would they subject themselves to what the doctors and others are experiencing at present. If this were to continue it would produce a crisis in haemophilia care resulting in the erosion of all of the advances that have been achieved in haemophilia care in the past few years."*[14]

2.21 It was stated many times that the State grants financial assistance to the victims of natural disasters and medically acquired HIV should be regarded in this way. In his submission, Professor John Dwyer stated:

> *"Earthquakes, bush fires, flood are common examples where a state endeavours to help the victims of a disaster to put their shattered lives back together again. In any reasonable society, this is regarded as natural justice. The accident has caused suffering, and the state, on behalf of its*

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[13] Evidence. 19.07.91

[14] Submission 29. Emphasis In Original.

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[15] Submission 69.

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[17] Submission 55.

[18] Evidence. 19.07.9

> *citizens, acts on their behalf to help innocent victims of the accident or disaster. This is not a question of legal precedence but one of collective and moral conscience.*"[15]

2.22 Families said that no amount of money could replace the lost loved one, but felt financial assistance could help give them some "peace of mind" and meet some of the many costs associated with caring for someone with AIDS:

> "*In order to overcome many of the problems we have, financial grants are essential. Because of shattered plans, and the dependency on pensions, many [medically acquired] HIV AIDS victims are faced with their financial problems associated with old age, much earlier in their life. Vehicles, vitally necessary for medical treatment, need replacements, and refrigerators, T.V.'s, vacuum cleaners and such capital items need replacement. It is necessary that the victim be able to grasp an opportunity to replace such items when bargains become available, or a break down occurs. The ability to* ***decide to do something*** *is a great feeling and can do a lot to relieve stress.*"[16]

> "*I should be compensated so I can see to these things [mortgage and other debts] before I go and have a bit of peace of mind to enjoy the time I have left with my loved ones.*"[17]

2.23 Witnesses in this group also said they found it degrading to have to 'line up' at government departments to seek assistance. They also spoke of the time involved in organising such assistance:

> "*These people don't want to have to beg. You know, go around to government departments and have to beg all the time and reveal that you have got AIDS and see the girl behind the counter nearly fall over with fright ... I mean this puts a lot of pressure on families and it breaks up families.*" [18]

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[15] Submission 69.

[16] Submission 65. Emphasis In Original.

[17] Submission 55.

[18] Evidence. 19.07.91.

2.24 Many people said that financial assistance would enable them to purchase services that are not available, or not available at the times or for the lengths of time desired.

2.25 People identified several items as being particularly costly - transport (travel to and from clinics and hospitals); pharmaceuticals, especially those not on the Pharmaceutical Benefits Scheme (e.g. mouth washes, bandages, nutritional supplements, etc.); natural therapies, vitamins and home oxygen therapy:

> *"Transport of patients for on-going treatment and-or monitoring of their condition is a major problem. Patients unable to transport themselves need their carer's assistance again because ambulance services are not available for routine pick-up and return of ambulatory patients and will not carry carers. Bed-ridden patients may receive forward ambulance service but have to wait hours for their return journey. Subsidised taxi services or voluntary agencies are sometimes available but this is impractical and uneconomical."*[19]

2.26 Many people said that available services did not meet their needs appropriately:

> *"Accessing health and welfare services has been and still is a major problem. It has been our own experience that the support service guidelines and many working within these services are completely insensitive to the needs of people facing the crisis of HIV."*[20]

2.27 Women with medically acquired HIV said that their particular needs were not met. Many doctors seem to know little about the gynaecological problems associated with HIV and this has led, in some cases, to inappropriate medical responses to their problems. (It should be noted that this suggestion was not restricted to women who had medically acquired HIV. Women who had contracted the virus through other means strongly reinforced the notion that there was a distinct lack of knowledge associated with the specific effects of HIV on women.)

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[19] Submission 18.

[20] Submission 29. Emphasis In Original

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2.28 Many people were critical of the care of people with medically acquired HIV in hospitals. This included problems with staff being over-cautious and food trays being left outside rooms, although most acknowledged that these problems are no longer so prevalent. The more pressing problem seemed to be that of being accommodated in wards with members of other risk groups:

> *"A great deal of sensitivity is required in this matter because it is difficult for people to share a ward with people from such a group as the gay group whom they may consider were the reason why those with haemophilia have been infected by the HIV virus in the first place."*[21]

2.29 However, this view was not universal:

> *"She has been treated very well by her Doctors and ---- Hospital where she is occasionally an inpatient and attends clinic regularly."*[22]
>
> *"At the ---- Unit, ---- ,has never been isolated or treated differently from any other child on the ward. Every medical service ---- requires has always been available and given with care and compassion from the whole team under Dr ---- ."*[23]

2.30 Some witnesses spoke of the need to have better co-ordinated services. This particularly related to passing on information about the health of the patient (at the patient's request, of course) to relevant support services.

2.31 One father and partner spoke of the particular problems of the person with medically acquired HIV and a psychiatric condition. It appeared that the patient's regular treating hospital, the psychiatric unit at this hospital, and a specialist psychiatric hospital were unable to deal appropriately with this problem. This seemed to be one of the most distressing episodes in this family's experience with AIDS:

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[21] Submission 29.

[22] Submission 54.

[23] Submission 36.

> *"This was the most ghastly event ------'s parents and I have experienced, let alone -----'s own suffering during the episode. I am left with the most chilling, awful memories of this time. I am also left with the knowledge that this should have been prevented. ... More and more AIDS sufferers are being affected by HIV related mental illness."*[24]

2.32 Many of those giving evidence praised community nursing services and the Community Support Network but said they could not provide an adequate service. People expressed the need to have home nursing care available 24 hours per day.

2.33 Most submittees and witnesses were critical of the Mark Fizpatrick Trust (see Appendix for details of Mark Fitzpatrick Trust). One witness saw the amount of financial assistance given as an "insult", there were criticisms of the administrative arrangements of the Trust, and many witnesses said that they would rather receive more of the assistance granted while the person with medically acquired HIV was alive, rather than after they had died.

> *"I though it [$23,000 paid by the Mark Fitzpatrick Trust after the death of witness's partner] was quite an affront actually, and a bit of an insult. For one thing, when --- died, I was granted $23,000. Now surely that money should be given when the person is alive. It just seems to me common sense."*[25]

2.34 Those involved with TRAIDS, the Haemophilia Treatment Centre at Royal Prince Alfred Hospital, the Haemophilia Society of New South Wales and the National Haemophilia Foundation were most appreciative of the support and services provided by these organisations. They also strongly appreciated the opportunity to talk with others with medically acquired HIV and found great support within these groups.

2.35 The submission of the Transfusion Related AIDS (TRAIDS) Unit relates that it provides support to 60 clients, 40 of whom are in regular contact (total number of people with transfusion related HIV is 65). The members of a support group convened by TRAIDS have worked hard in

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[24] Submission 67.

[25] Evidence. 7.8.91.

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lobbying for financial assistance for people with medically acquired HIV. Representatives of this group were in attendance at most of the Public Hearings for this Inquiry.

2.36 The submissions of the Haemophilia Foundation of Australia, the Haemophilia Society of New South Wales, and the Haemophilia Society of Tasmania indicate that these organisations are actively lobbying for financial assistance for their members.

People With Other Medically Acquired Diseases

2.37 The Committee did not actively seek evidence from people with medically acquired illnesses, other than medically acquired HIV, because it was considered that this group of people did not fit within the Terms of Reference of the Inquiry.

2.38 Still, the Committee took formal evidence from one person with medically acquired Hepatitis C and received telephone calls from a small number of other people with Hepatitis B and Hepatitis C, all of whom contacted the Secretariat following an inaccurate article in a Sunday newspaper. This article incorrectly speculated that the Committee would be recommending that people with medically acquired HIV would be awarded a total of $100 million .

2.39 This person was firmly opposed to the idea of compensation for herself, people with medically acquired HIV, or people with medically acquired diseases of any kind.

> "*I would not be in agreement with compensation on either [medically acquired HIV or Hepatitis C] .... I think I know the system fairly well, and the crying need is for care for people and support services .... not to give people financial handouts ...*"[26]

2.40 However, the Committee received extensive testimony on the long term debilitation, suffering and symptoms of AIDS, testimony that for at least some of the Committee members was sufficient to class AIDS as an illness that is unexceeded in its capacity to inflict discomfort, pain and trauma over a long period.

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[26] Evidence, 08.08.91.

Broadbased AIDS Organisations

2.41 The Committee received submissions from and spoke to four broadbased AIDS organisations. They were:

1. The AIDS Action Council (AAC) of the A.C.T.;
2. The AIDS Coalition to Unleash Power (ACT UP), New South Wales;
3. The AIDS Council (ACON) of New South Wales; and
4. The AIDS Council (WAAC) of Western Australia.

The Committee invited the Australian Federation of AIDS Organisations (AFAO) and the Australian National Council on AIDS to give submissions or appear before the Committee but both rejected the offer.

2.42 All of these broadbased organisations opposed the granting of financial assistance. The AAC stated that:

> *"... the committee's distinction between medically acquired HIV and other routes of infection, can only serve to reinforce and strengthen the discrimination directed towards HIV positive people. ... that the resources being spent on a review such as the committee is undertaking, are a waste, considering the enormous needs of HIV infected people, ... [and] the committee should be directing its attention and efforts to improving the services .... [so] that all HIV positive people gain suitable and appropriate access to such services..."*[27]

2.43 The AIDS Council of New South Wales has a policy of attempting to meet the needs of people with medically acquired HIV more effectively through close liaison with organisations such as TRAIDS.

2.44 ACON is opposed to the granting of special financial assistance to people with medically acquired HIV:

> *"ACON recognises that a number of arguments can be mounted for compensation for people with medically acquired HIV, as indeed they can for all people with HIV/AIDS. ACON shares the widespread concerns about the inappropriateness of large amounts of money being spent on unproductive legal battles.*

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[27] Submission 39.

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> *Of even more concern is the extreme stress the people bringing these battles suffer, and the likelihood that in many cases it is substantially affecting their already compromised health.*
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> *Nevertheless ACON believes that compensation is not the appropriate policy response to the effects of this epidemic. We concur with the view set out in the National HIV/AIDS strategy."*

2.45 In support of the above statement ACON refers to the assistance already provided by the Mark Fitzpatrick Trust, concerns about the source of the money for such assistance (i.e that it may come from an already stretched AIDS budget), and concerns about setting a precedent for other groups with medically acquired conditions.

2.46 ACON points to a number of problems in the area of health and welfare services. These include "poor levels of nursing, domestic and personal home or community based care"[28], problems with access to dental and some other health care, lack of support services, financial problems resulting from the costs associated with the care of someone with HIV, and discrimination, and adds:

> *"It is ACON's belief that none of the issues identified are unique to people with medically acquired HIV. All people with HIV suffer from some or all of these issues. The issues are not resolvable by the payment of compensation to a particular group of the infected and affected; only significant improvements in the level of services for all people with HIV and changes to the social and legal climate in which services are provided will resolve them."*[29]

2.47 ACT UP strenuously proposed that the Terms of Reference be expanded to include all people with HIV. In their submission they suggested that AIDS had been "allowed to happen" because it was first identified in a minority group, homosexual men. They further suggested that the Committee's Inquiry perpetuates discrimination against the larger majority of people with HIV - homosexuals and intravenous drug users - and that this is detrimental to the ongoing care of all people with HIV. ACT UP suggests that the focus of the

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[28] Ibid.

[29] Submission 60.

Inquiry's recommendations should be on providing better access to treatments, dealing with HIV related discrimination, and ensuring that there are sufficient acute care beds for people with HIV.

> "*We are not up against a viral disease. We are up against a complex social disease, made up of stigma and discrimination. ... A Parliamentary inquiry into medically-acquired HIV is a perpetration (sic) of this social disease. ... It implies that the needs of people with HIV are different depending on how they acquired HIV.*
>
> *ACT UP maintains that any ex-gratia payments be given solely on the basis of need and that the manner in which a person acquired HIV is irrelevant. The issue of compensation for liability should be left up to the courts. However, ACT UP would like to see the limited AIDS budget go towards issues of treatment and social services rather than compensation.*"[30]

2.48 The Western Australian AIDS Council (WAAC) did not oppose the settlement package awarded in Western Australia:

> "*What happened here was a commercial settlement based upon, I was reassured by [Dr] Charles Watson [Director, Disease Control Branch, Department of Health, Western Australia], reasonable grounds based upon a reasonable estimate of what the cost would be to litigate.*"[31]

Overseas

2.49 The Committee received detailed information about financial assistance available to people with medically acquired HIV in the United Kingdom, Canada, and New Zealand. The Committee also received information from the World Haemophilia Foundation that packages of financial assistance have been granted to people with medically acquired HIV in Ireland, Germany, France, Austria, Japan, Spain and Switzerland.

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[30] Submission 50.

[31] Evidence. 30.07.91.

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[33] Submission 66.

2.50 In March 1988 the British Government established the MacFarlane Trust with a grant of 10 million pounds in response to a "campaign ... led by the Haemophilia Society of the U.K"[32]. This Trust provides financial assistance to 1226 people with Haemophilia and HIV who are considered to be 'in need' (up to 50 pounds per week).

2.51 In November, 1989, the British Government paid 20,000 (approx. $A 40,000) pounds to each haemophiliac infected with HIV. In June 1991 the British courts gave clearance for each person with haemophilia and HIV to receive an additional amount of between 20,000 and 60,000 pounds ($A 40,000 - 120,000), in return for waiving the right to litigate.

2.52 In December 1989 the Canadian Government announced the establishment of the Extraordinary Assistance Plan following formal requests from the Canadian Haemophilia Society in 1988 and from a smaller group of non-haemophilia HIV infected blood transfusion recipients. There has been no contribution from the Provinces to this Plan. This Plan provides financial assistance to 1250 people with medically acquired HIV. Each receives a total of $CAN120,000 in four equal payments over four years:

> *"Our goal is two fold: to ensure that public confidence in our blood supply remains high, and to provide a form of disaster relief to Canadians who are facing extraordinary hardship. With the assistance announced today, I believe we are responding in a way that expresses the fairness and compassion Canadians expect of their government, while recognising the overall objective of fiscal responsibility."*[33]

2.53 In New Zealand, The Accident Compensation Act 1972 (NZ) established a no-fault compensation scheme for:

- medical and surgical misadventure, and
- the mental and physical consequences of such misadventure.

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[32] Submission 60.

[33] Submission 66.

2.54 It is funded through a levy on motor vehicle owners, a levy on employers and the self-employed, and direct Government reimbursement for non-earners and overseas visitors.

2.55 People with medically acquired HIV are entitled to receive $NZ27,000 from this scheme. There are fewer than twenty people with medically acquired HIV in New Zealand.

Other Jurisdictions in Australia

2.56 During the Inquiry, the Committee visited Canberra, Melbourne and Perth.

2.57 The Secretariat made a separate visit to Canberra during the New South Wales election period (May/June 1991) to speak with representatives of the Commonwealth Department of Community Services, Housing, and Health. Representatives of the Department were invited to give formal evidence before the Committee, but this invitation was not accepted.

2.58 The Committee visited Canberra and spoke to representatives of the Mark Fitzpatrick Trust and the AIDS Action Council of the ACT.

2.59 During the visit to Melbourne the Committee spoke with representatives of the Department of Health, and Mr John Gordon of Slater and Gordon (solicitors representing people with medically acquired HIV in Victoria). Slater and Gordon also sent a submission to the Committee.

2.60 During the meeting with the representatives of the Department of Health the Committee heard that the Victorian Government had given some consideration to granting financial assistance to people with medically acquired HIV but was not, at that stage, proceeding with this course of action.

2.61 In Western Australia, the Government recently agreed to grant financial assistance to 22 people with medically acquired HIV (average payment of $280,000, total cost $5.4 million). It seems that the decision to grant a settlement payment was based on a weighing up of the potential costs of litigation and the costs of settlement, as well as a consideration of the human costs involved in litigation. The Western Australian Government was its own insurer.

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The Committee spoke to the Minister for Health, the Deputy Leader of the Opposition and Shadow Minister for Health, representatives of the Department of the Health, the Crown Solicitor's Office, of the medically acquired HIV community, and Slater and Gordon.

2.62 The Mark Fitzpatrick Trust was set up with a Commonwealth grant of $13.2 million in November 1989 following lobbying from the Haemophilia Foundation of Australia. It was designed "as a modestly costed estimate of the additional costs arising from HIV infection on top of the provision of health and welfare services"[34]. Its funds are available only to people with medically acquired HIV. The Commonwealth Government is not considering granting the Mark Fitzpatrick Trust any additional funds. There have been no state contributions to the Trust, despite requests from the Commonwealth Government at the time the Trust was set up.

2.63 A single person receives between $1,000 and $4,000 per annum depending on their health status - and a person with dependants receives between $2,000 and $8,000. After death, the family of a person with dependants receives $23,000 and that of a person with no dependants receives $8,000 (see Appendix for more details). A discretionary fund is available to families "where there is evidence of particular hardship or special family circumstances."[35]

2.64 During the visit to Canberra the Secretariat heard that the then Commonwealth Minister for Health, was not in favour of awarding financial assistance to people with medically acquired HIV, for the following reasons:

- In Australia everyone is entitled to income security (Department of Social Security) and free health care (Medicare) and they do not consider it equitable to give extra benefits to one particular group.
- The Commonwealth has made an assessment that, in general, health authorities were not responsible for medically acquired HIV and, on this basis, Legal Aid may soon cease to fund these cases.
- The Mark Fitzpatrick Trust has been established at the Commonwealth level to provide extra assistance to people with medically acquired HIV.

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[34] Submission 38.

[35] Submission 17.

- People with medically acquired HIV cannot be singled out for special treatment.

2.65 The Committee could not help but note the inconsistency of the Commonwealth Government's position. On the one hand, they were prepared to list the reasons why additional financial assistance should not be granted, yet they themselves created the precedent, by establishing the Mark Fitzpatrick Trust, in the first place.

Health Care Professionals

2.66 The Committee received evidence and submissions from a number of health care professionals working with people with medically acquired HIV.

2.67 Professor John Dwyer, Professor of Medicine and Head of the School of Medicine at the University of New South Wales and physician involved with the care of people with HIV, made a passionate plea for financial assistance for people with medically acquired HIV:

> *"As if it wasn't bad enough to be struggling with a deadly virus, but to be struggling with discrimination, to be struggling with these financial problems, to be struggling with that bitterness that's inside them, that difficulty of understanding, "Why me ?" We could ease so much of that pain, and I would put it to you, ladies and gentlemen, that we're going to spend the money one way or another that we want to spend in coming to a settlement except that unless we act carefully and properly we are going to be spending that money in a way we really don't want to spend that money."*[36]

2.68 Dwyer also presented the argument that people with medically acquired HIV had no choice about becoming infected while those who have acquired HIV through intravenous drug use or sexual activity had some choice about their behaviour:

> *"those people who were engaging in careless sexual activity and who were using intravenous drugs knew*

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[36] Evidence. Professor John Dwyer. 08.04.91.

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[37] Evidence. 08.04.

[38] Ibid.

> *there were health hazards associated with that and freedom of choice was exercised in engaging in these activities."*[37]

2.69 In regard to services, Professor Dwyer said that while the specialist services are very good, they are coming under increasing demand, and there is a need for more mainstreaming of services and increasing the level of awareness of the facts about HIV in the community:

> *"When you talk to individuals you always seem to get the appropriate response, yes, I understand, yes, I would be willing to look after someone with HIV and yet the fact is that many people seem to, even professional people, seem to take their cue from something they have heard in the media, from some exaggerated story about the risk involved in caring for people."*[38]

2.70 The Committee also spoke with the Social Worker and the Nurse Consultant from the Paediatric AIDS Unit at Prince of Wales Children's Hospital. They have a role throughout New South Wales to provide education, research, consultation and policy development regarding children with HIV. They spoke of the problems of finding nurses, baby sitters and other carers with the willingness and expertise to look after children with HIV, and of the need for ongoing community and professional education. They also made some comments about the importance of providing a co-ordinated service when more than one family member is infected with HIV.

2.71 The Committee received submissions from, and spoke to, a number of medical practitioners and a Social Worker from the Haemophilia Treatment Centre at Royal Prince Alfred Hospital. All those working at the Haemophilia Treatment Centre identify several problems in the area of health and welfare services. These include the inadequacy of income support provided by the Department of Social Security, inadequacy of access to public housing, problems with the availability and high cost of pharmaceuticals, access to nursing home beds, and availability of home care and home nursing services. Some of those working at the Centre supported the granting of financial assistance to people with medically acquired HIV, although this was not the official view submitted on behalf of the Central Sydney Area Health Service.

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[37] Evidence, 08.04.91.

[38] Ibid.

The Legal Profession

2.72 The Committee received submissions from a number of people in the legal profession; a cross section of those who represent clients with medically acquired HIV, the defendants (the Government Insurance Office), the Legal Aid Commission, the Anti Discrimination Board and interested observers.

2.73 Representing those with medically acquired HIV were Martin Board, J.M Caruana Kay and Barry (Sydney), John Gordon, Slater and Gordon (Melbourne), and Peter Gordon, Slater and Gordon (Perth). These solicitors were in favour of the granting of financial assistance to people with medically acquired HIV. They were of the opinion that future cases in New South Wales would succeed and would cost the Government substantial amounts of money in compensation payments as well as the actual costs of running the cases and tying up the courts (a summary of approximated legal costs for medically acquired HIV matters is contained in the Appendix). Mr Board suggested that his firm has nine cases in which proceedings have been instituted, three of which have been heard and have not succeeded. He made reference to the case, known as P.Q., who was awarded $870,000 by a jury in Victoria:

> "*P.Q. was a haemophiliac. ... We know that his treatment was changed in March 1984 from cryoprecipitate, which is single donor clotting factor, to lyophilised factor VIII. Which is pool donor clotting factor. ... My reading of the jury's decision in that case was that they were dissatisfied with the treatment given by the hospital in that they failed to warn P.Q. of the additional risks of infection from pooled product as opposed to the single donor product.*"[39] and
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> "*The problem, though, arises in relation to those people who could reasonably expect to succeed in a claim for litigation. Those people, on the basis of the P.Q. decision would have expectations of large awards, large verdicts in their favour. ... So it can be seen from that [the large settlement awarded in P.Q.] the jury have obviously formed a very clear impression what lies ahead for people who are so unfortunate as to contract this virus.*"[40]

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[39] Evidence 6.2.91.

[40] ibid.

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[41] Submission 71.

2.74 The Committee also heard about the case of a six year old girl with medically acquired HIV, known as GRO-A in which an out of court settlement of $300,000 was made in Victoria.

2.75 Slater and Gordon in Perth were extensively involved in negotiating and then distributing the financial assistance granted by the Western Australian Government.

2.76 Representatives of the Legal Department of the Government Insurance Office informed the Committee that they have assessed the 41 cases pending in New South Wales and believe that they will not lose any of these cases.

2.77 The submission of the Legal Aid Commission confines its comments to the issue of the granting of financial assistance to people with medically acquired HIV. The submission states that the Commission has thus far granted $650,000 in legal aid and anticipates future costs of $1 million. The submission supports the granting of financial assistance because of the legal costs and cost of other resources involved and the fact that "none of this money has gone to assist the victims and families who are suffering as a result of medically transmitted HIV."[41]

2.78 Mr Steve Mark of the Anti-Discrimination Board gave evidence before the Committee regarding the implications of granting special assistance to people with medically acquired HIV in relation to anti discrimination legislation in New South Wales. He told the Committee that such assistance may be considered discriminatory under section 49ZG subsection 2A, 2B and 2C of the Anti-Discrimination Act relating to indirect discrimination:

> *"... where an apparently neutral condition or requirement has an adverse impact on one group disproportionate to another, then that can amount to discrimination if it is unreasonable in the circumstances of the case."*

2.79 However, the Government has the power to exempt any legislation from anti-discrimination provisions rights as has happened previously in the case of religious sect schools.

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[41] Submission 71.

2.80 Mr Philip Bates is a barrister and senior lecturer in Law at the School of Health Services Management, University of New South Wales who gave evidence in his capacity as a barrister who has represented people in cases of medical negligence, as a legal academic and as a legal consultant to the World Health Organisation. In regard to litigation in the cases of medically acquired HIV, he said:

> "... *most of these people, I believe, would be unsuccessful in litigation based on what has happened in the H case. It depends on times, but ... Under current law, I think the H case is correct and I think the Queensland case is correct. Under current law, on the whole, I think, most of these patients would be unsuccessful.*"[42]

2.81 Regarding financial assistance for people with medically acquired HIV, Mr. Bates said that the Committee needed to consider the possibility of establishing a precedent for other people with medically acquired illnesses and, further, that when perhaps three out of every 100 patients who go to hospital contracts some kind of condition not caused by negligence it is not appropriate to single out people with medically acquired HIV for special consideration.

New South Wales Department of Health

2.82 The New South Wales Department of Health supplied a submission and gave evidence to the Committee. In that evidence the Department detailed the services currently provided for both medically acquired and all HIV positive people and future plans that the Department has in relation to those services.

2.83 The Department is opposed to the granting of financial assistance:

> "*The health care delivery system is designed to promote and protect the health of the people of NSW. In the discharge of this role all reasonable and foreseeable steps are taken to protect the safety of patients. When cases of medically acquired infection or illness occur the health system is rightly open to scrutiny and is accountable at law. NSW Government policy is that the available civil remedies are an appropriate means of determining the question of liability and quantum of damages in these matters.*"[43]

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[42] Evidence. Philip Bates. 08.08.91.

[43] Submission 77.

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CHAPTER THREE

FINANCIAL ASSISTANCE

3.1 The revised Terms of Reference for this Inquiry required the Committee to decide whether "the Government should provide financial assistance" to:

(a) ".... persons who have contracted HIV infection through blood, blood products, artificial insemination from a donor, or as a result of organ transplant, ..." and;

(b) ".... persons who have acquired HIV infection through secondary transmission from spouses or parents with medically acquired HIV ...".

3.2 The three key questions which formed the basis of the Committee's deliberations on the issue of Financial Assistance to people with medically acquired HIV were:

1. Are there a set of needs, criteria and circumstances which separate this group or groups of people from others within the broader HIV community or the people of New South Wales?

2. If so, are these people entitled to some direct financial assistance as a result of those needs, criteria and circumstances?

3. If these people are entitled to financial assistance, what form should that assistance take?

3.3 The Committee agonised at length over these questions. All Committee Members recognised that the Inquiry was not operating in a vacuum and that different groups would see any decision that the Committee made in terms of qualified support or rejection of their own particular viewpoint.

3.4 What can be stated with certainty is that the HIV virus itself does not discriminate on the basis of how it was acquired. The profound and long-term suffering is tragic for all HIV positive people, and as such the demands on the financial resources and personal support of the family are substantial regardless of the mode of transmission.

3.5 However, certain characteristics do differentiate the medically acquired HIV group from the broader HIV community. People with medically acquired HIV were infected within the public health system, in which they had faith and from which they must now receive ongoing care. They have to deal with the terrible progression of HIV, changes in life expectations, discrimination, isolation, and sometimes, the stress of involvement in legal action. For many, the fear of discovery is overwhelming - many members of the general public are still ignorant of the true facts about HIV and there is the added fear for these people of being identified with the major risk groups.

3.6 At the risk of overemphasising its dilemma, the Committee felt it was in an irreconcilable position. Some Committee Members, while eager to do what they could for this particular group of people felt constrained by what they saw as sending inappropriate messages to the New South Wales community as a whole. Other Members were concerned at what precedent might be set by granting financial assistance to a small group of people. Other Members felt that justice demanded some financial recognition of people with medically acquired HIV.

3.7 All Committee Members were determined to come to a decision based on principle. However, often individual principles conflict, and most Members felt that it would be irresponsible not to consider the financial implications of any decision it reached. The Consolidated Fund of the New South Wales Government, particularly in the current economic circumstances, is not limitless and the Committee felt constrained to make recommendations which were fair, equitable, but above all, achievable.

Review of the Arguments Presented to the Committee

1) The Nature of the Disease

3.8 The most obvious point to be made about the HIV virus is that, at the moment, it is terminal. The Committee received detailed evidence about its debilitating effects on individuals, and through them, family members.

3.9 Because of the range of opportunistic infections that people with a impaired immune system are liable to pick up, the disease is also particularly expensive in terms of pharmaceuticals, palliative care, nursing and home care. When AIDS becomes fully developed, 24-hour care in the home is an absolute necessity, except for those, often extended, periods of time when the patient is in hospital.

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3.10 Evidence to the Committee would suggest that few, if any, other diseases are the cause of such suffering. The Committee noted however, that for example, Hepatitis C is also incurable, it may cause premature death and until recently was undetectable in the blood supply. On the surface then, these three characteristics might appear to give Hepatitis C sufferers, and indeed other people with medically acquired diseases, the same claim to any financial assistance that may be directed to medically acquired HIV people.

3.11 The Committee however, cannot comment on this issue simply because our Terms of Reference did not allow us to examine in detail these other classes of people. Most Committee Members, on the basis of the limited evidence presented to us, were of the opinion however, that the stress, stigma and massively debilitating nature of HIV placed it in a different "class" to other medically acquired diseases.

3.12 For haemophiliacs, AIDS is doubly traumatic coming on top of problems associated with haemophilia. While haemophiliacs might appear to have a stronger case for special consideration, as a result of their situation, their evidence to the Committee was strongly supportive of assistance for all the medically acquired HIV community.

2) Mode of Transmission

3.13 There can be no doubt that one factor which separates the medically acquired HIV community from the broader HIV positive population is the method by which they acquired the disease. However, not all Committee Members agreed that this was a relevant factor.

3.14 Noting the fact that almost every person who acquired the disease in the early years of the epidemic in Australia, regardless of the mode of transmission, was unaware of the existence of the virus as a virus, most Committee Members reject outright any suggestion that one group is guilty and another innocent.

3.15 The argument was put to the Committee that the medically acquired HIV community attended a public hospital, or used blood products supplied from a public hospital in good faith. That trust in the public health system resulted in the acquisition of a terminal illness. It was further argued that these people had no choice in the utilisation of these medical services and blood products, that this medical treatment was required to save their lives, and as such they had no way to protect themselves against the disease (see also 2.68). Even where there might have been some choice, with the treatment of mild haemophilia for instance, witnesses informed the Committee that they were not given the relevant information to consider such a choice. Evidence from medical experts though, suggests that people were not given the choice because the state of knowledge at the time was insufficient to provide that information and further that even "mild" haemophilia can be quite serious and should be treated.

3.16 Therefore, some Committee Members concluded that while the fact that homosexuals and injecting drug users acquired the HIV virus is lamentable, and there is no question that they deserve the highest level of health care the community can provide, the issue of mode of transmission separates them and other people (such as those infected by their spouses), for the purposes of financial assistance, from the medically acquired HIV community.

3) The Moral Obligation of the Government

3.17 The responsibility that attaches to the State Government because a public institution, in exercising its normal functions, infected a large group of people with a terminal disease, which it was unable to detect, is a complex issue.

3.18 As stated above, the Committee felt it was unable and indeed inappropriate for it to adopt a quasi-legal stance and in some way review the evidence that has been presented in the courts around the country.

3.19 Two conflicting views were, once again, presented to the Committee: firstly, that the whole issue of potential compensation was linked to negligence and such decisions should be left to the courts. However, one Judge, Justice Wilcox of the Federal Court in New South Wales in deciding against the plaintiff "E" in his case against the Australian Red Cross and Others, in effect redirected the issue of financial assistance back to the Government by stating at pages 158 and 159 in the transcript of his judgement that:

> *"... this applicant, and any other people who are in a like position, have a strong moral claim upon the community for some financial assistance in coping with their illnesses. ... In some other areas of activity, in which individuals are sacrificed for the wider public good, the community recognises an obligation to provide some recompense; for example, under war veterans' legislation. Perhaps the same attitude ought to be taken towards those people who contracted AIDS as a result of a*

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> *blood transfusion or haemophilia treatment. I do not have in mind any extravagant award of money, but something to make up for the income which they have lost or will lose - after taking into account any social service entitlements - and their out-of-pocket expenses."*

3.20 In Australia there are two precedents for the suggestion of Justice Wilcox: the Western Australia settlement and the Mark Fitzpatrick Trust. In most situations plaintiffs need to prove negligence in order to obtain compensation, however based on evidence before the Committee, only a minority of the medically acquired community will even have the opportunity to present their case at Court.

3.21 The particularities of the position in W.A. deserve some close examination. Unlike in New South Wales, where the Government Insurance Office as the insurer must defend court cases and incur the costs, in W.A., as there was no insurer, the Government (i.e. Consolidated Revenue) would have been directly responsible for defending the Hospitals and Red Cross etc. Furthermore, the possibility of a group settlement in Western Australia was greatly increased because of the limited numbers of people infected (22) and the fact that if just one of these cases went to Court, then it would cost almost as much as the total settlement. Therefore, it may be concluded that the large financial settlement organised in Western Australia was in response to two key factors, the limited number of people involved and the peculiarities of the Western Australian insurance arrangements.

3.22 Some Members of the Committee disagreed with the foregoing and felt that to suggest that the Government step in and make a moral judgement in favour of, or against these people was inappropriate. The question was asked whether the State should accept financial responsibility for people's misfortune if other avenues are not available, and if so, how far such a responsibility might extend. Mr. Peter Garling, a Barrister, stated in evidence before the Committee that:

> *"The basis on which we have compensated people is if one can establish fault ... We have said, "If you can establish fault then the law either, in accordance with its common law position or in accordance with its statutorily amended common law position has provided damages for it" and I cannot see that there is any special basis for separating the group of medically acquired HIV victims ... from any other group of innocently afflicted people in our society. I think that if this committee was*

> *to recommend that there be, in effect, a special legislative package dealing with this particular group, that it would be very hard logically to resist such a package in respect of a very large number of other groups."*[1]

3.23 However, those Committee Members that supported the granting of some limited financial assistance are at pains to explain that it is not compensation in lieu of a court decision. There is no factor in the recommendation that attempts to replace lost earnings or to compensate for pain and suffering. What it is, is a recognition that this group, as a result of factors listed above, is unique, and as such deserves some special assistance.

4) Urgency

3.24 One reason that the Committee felt that the Government restricted the Terms of Reference to the Inquiry is simply the urgency of the problem. Because of the time frame in which the disease was contracted, most medically acquired HIV people are in stages 3 and 4 of the disease. For financial assistance to have any impact whatsoever, that assistance must be distributed immediately. Similarly, the argument that any assistance should be given to <u>all</u> HIV sufferers is, in practice, an argument against the medically acquired group. Because their infection is so longstanding, any large-scale increase in assistance across the board, would less likely to reach them in time, especially given that larger scale action tend to take longer to implement.

3.25 The Committee is further aware that the Review and Audit Branch of the Commonwealth Department of Health, Housing and Community Services is currently investigating the possibility of creating a national no-fault medical compensation scheme. While such a scheme may benefit all people who medically acquire a disease in the future, it is once again, simply too far away to be a realistic alternative for this group of people.

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[1] Evidence. 08.04.91. Page 23.

5) The Stigma

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5) The Stigma Associated With HIV

3.26 A large range of factors contributed to the development of the stress and stigma associated with this disease. Principally, as it was a new disease, the lack of knowledge about HIV, especially regarding its transmission, aroused a great deal of fear. Secondly there is no cure, and initially, no treatment, a situation at odds with the public expectation that the medical profession could deal with just about every disease. Thirdly the disease did not discriminate on the basis of age, in that it was killing many people during the most productive years of their lives. Finally, because the virus was first identified in homosexuals (and for some people, remains so) it was associated with sexual taboos and was seen by some as a form of 'divine retribution'.

3.27 While these factors combined to create an atmosphere of rejection and discrimination for all HIV positive people, the medically acquired community suffered because of what they perceived as incorrect assumptions about their sexual orientation or drug use.

6) The "Natural Disaster" Argument

3.28 Further argument put to the Committee was that the medically acquired HIV community is no different to those people affected by the Newcastle earthquake or any other natural disaster such as a bushfire or flood. This argument suggests that these people should thus be financially assisted for a disaster which was beyond their control.

3.29 The Committee concluded that there were a number of difficulties associated with this argument, most notably that the provision of individual cash payments as compensation is something which is, to the Committee's knowledge, never given to victims of natural disasters.

3.30 Even in disasters as catastrophic as the Darwin cyclone, the bulk of Commonwealth and Territory expenditure went on infrastructure replacement and short term practical aid such as the provision of free clothing and accommodation. In Newcastle some low-interest loans were negotiated but no substantial cash payments of any kind (except minor payments through welfare agencies for foodstuffs etc.) were made.

3.31 This argument is further diminished by the fact that if the prerequisites for utilising this comparison are that it affects a class of people and that it is a disaster beyond their control, one would expect that these conditions are fulfilled in the Chelmsford Case and for anybody who has acquired Hepatitis B or C or any other disease as a result of a blood transfusion.

7) The Creation of "Classes" Within the HIV Community

3.32 Many witnesses and most Committee Members were concerned about the possible effect that the granting of financial assistance may have on the broad HIV community. While it is acknowledged that the effects of the disease are largely the same regardless of the mode of transmission, some Members were concerned that financial assistance may assist a limited number of families to a higher standard of care than is currently available to others.

3.33 Alternatively, a majority of the Committee agreed that it could be argued that the mode of transmission has already divided the HIV community into classes and it is the feelings of hurt, anger and embarrassment associated with the "betrayed" trust placed in the public health system that forms the basis for this different class perceiving themselves as "innocent victims" and further that as such they deserve some special consideration.

3.34 Further, there are distinctions in the demographic profile between the medically acquired and general HIV populations. While 86.5% of AIDS cases have resulted from male homosexual contact, 2.9% have resulted from blood transfusions, tissue donations or artificial insemination by donor, 1.5% are haemophiliacs. In other words, the overwhelming majority of AIDS cases are adult and male, and tend to be without dependent children. Many - although far from all - of these cases live within the inner city and eastern suburbs. Medically acquired HIV cases, however, are far less homogeneous: widely scattered, with dependent spouses and children, ranging in age from young children to elderly people. A number are mothers with dependent children.

3.35 What a majority of the Committee felt was the key issue, was that sub-groups within the medically acquired community and the general HIV community already exist. The granting of financial assistance is not creating new classes but recognising, as the Commonwealth Government did previously, that one group, those that medically acquired the HIV virus, deserve some special assistance.

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8) Precedent

3.36 The issue of what kind of precedent the payment of financial assistance to medically acquired HIV people would create, was a topic of considerable discussion by Committee Members.

3.37 Those Members supporting financial assistance felt that the medically acquired HIV community was a discrete group. The timing, nature, mortality rate, mode of infection and numbers affected by the disease separate out this class of people from both the broader HIV community and from other people with medically acquired illnesses.

3.38 A precedent for financial assistance has been established by payments made to this class of people in the U.K., Canada, Austria, Spain, Japan, Ireland, Germany,[2] Western Australia, and by the Commonwealth Government. In the USA there has been no Government compensation, however the ability to mount "class actions" by groups of people in similar circumstances and the fact that lawyers will accept actions on the basis of a percentage of the final payout undoubtedly influence this situation. It can be further argued that there are similarities in circumstance between people with medically acquired HIV and Australian soldiers sprayed with Agent Orange in Vietnam, the asbestosis issue in Western Australia and the victims of radiation at Maralinga, though the Committee recognises that not all of these groups have been successful in organising compensation.

3.39 It should however be noted that New Zealand gave assistance only because it has a scheme specifically to cover such situations. In the U.K. and some other European countries none of the transfusion-related people are granted anything under the MacFarlane trust. This facility is restricted to haemophiliacs only.

3.40 The scheme recommended by a majority of Committee Members in New South Wales is not large-scale compensation. It is simply a recognition that the specific circumstances surrounding this group of people deserves some recognition, and as such follows an annual payment model similar to most of the countries listed in the Appendix.

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[2] See Appendix

9) Legal Issues

3.41 It has been suggested or implied to the committee from a variety of sources, that it would in fact be cheaper to settle the claims of the medically acquired community than to allow them to proceed to court. If a large number of cases do proceed there is little doubt that the major beneficiary will be the legal system, and it is argued that it would be better to spend the money on people in need of assistance. Some claims have been made that if a large number of cases are proceeded with, the court system could be "clogged up" for years. Peter Gordon, of the legal firm Slater & Gordon stated in a conversation with the Committee that:

> *"It is impossible to suggest what the community perception of this problem will be after five or six years of litigation where hundreds of people have been compensated [by successful court actions]"*[3]

3.42 The evidence before the Committee was conflicting, there are as many people that can be found to claim that in fact there is little likelihood that many more cases will come before the courts, as those that claim that they will. The Government Insurance Office, legal representatives in the Commonwealth Department of Health, Housing and Community Services, the New South Wales Department of Health and Philip Bates, a Barrister and Senior Lecturer in Law at the School of Health Services Management all claim that a very limited number of cases will proceed. It appears that Legal Aid has largely concluded its funding proposals.

3.43 While it would be reasonable to assume that a few cases of the "PQ" (see 2.73) type may exist in New South Wales, it must be remembered that these do not provide a precedent for others. With no pattern of cases being won in New South Wales by the medically acquired HIV community, it is fair to assume that the Government Insurance Office is unlikely to contribute to any financial assistance package.

3.44 In evidence before the Committee, Philip Bates stated that:

> *"... most of these people, [potential MA/HIV litigants] I believe, would be unsuccessful in litigation based on what has happened in the H case. It depends on times, but ... Under current law, I think the H case is correct and I think the*

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> *Queensland case is correct. Under current law, on the whole, I think, most of these patients would be unsuccessful."*

3.45 Other evidence that the Committee received from legal sources contradicted this point of view. However, the Committee decided that it was impossible to guess what the outcome would be. . More importantly though, it felt that such a determination was unnecessary. The recommendation that a majority of Committee Members made to support financial assistance does not preclude those people who wish to pursue their cases in court from doing so and could not attempt to do so, as the amounts proposed for financial assistance are much more modest than could be expected from a compensation for negligence judgement.

3.46 The Committee also received considerable evidence suggesting that the adversarial legal system which is utilised in this State, and indeed all over Australia, is inappropriate for dealing with illnesses which (a) are terminal, (b) have a particularly stressful impact on litigants[4] and (c) are complicated by the limited amount of information relating to when transfusions occurred, and which "batches" were infected. Even when a case might be strong it involves considerable risks for the litigant, in that our judicial system does not allow for class action suits (where large groups can share costs) or contingency fees (where lawyers are paid only if the case is won by the litigant).

3.47 In New Zealand, medically acquired HIV people were covered under special no-fault insurance, via the Accident Compensation Act (1972). If such a scheme could provide justice without the dangers of the "legal lottery" (huge costs gambled in the hope of a huge payout) the Committee would see this as a positive step.

10) Funding

3.48 Some concern was expressed by some witnesses who were opposed to the granting of financial assistance that its funding would be provided from within the current Government AIDS budget, hence disadvantaging HIV positive people who had not been infected through medical means. The Committee sees a need for all current AIDS funding to continue, indeed be expanded as the recommendation on services (See Chapter 4) show. Sadly, the need for AIDS funding can only increase in the near future, as the number of very sick people grows.

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[4] There is also evidence to suggest that stress contributes to the progression of HIV to AIDS.

11) Conclusion

3.49 All of the arguments presented to the Committee had characteristics which could be used to either support or reject the granting of financial assistance. However, a majority of the Committee agreed to support the scheme outlined below, for the following reasons.

1. The fact that the source of the infection was a Government instrumentality;
2. The extreme physical trauma that is the nature of HIV;
3. The substantial costs involved in caring for someone with HIV;
4. The urgency of the needs of the medically acquired HIV community in that they have all been infected for a substantial amount of time and are in the latter stages of the illness;
5. The double trauma of HIV for those who already have haemophilia;
6. The "stigma" that the medically acquired community suffers as a result of incorrect assumptions about their sexual orientation or drug use;
7. The fact that many of the medically acquired HIV community have dependent children and or spouses;
8. That there were adequate precedents for the granting of such financial assistance; and
9. The difficulties for people with medically acquired HIV in pursuing litigation.

3.50 The scheme is in many ways similar to the federally funded Mark Fitzpatrick Trust. The Mark Fitzpatrick Trust was set up with a Commonwealth grant of $13.2 million in November 1989 following lobbying from the Haemophilia Foundation of Australia. It was designed "as a modestly costed estimate of the additional costs arising from HIV infection on top of the provision of health and welfare services"[5]. Its funds are available only to people with medically acquired HIV. A single person receives between $1,000 and $4,000 per annum depending on their health status - and a person with dependants receives between $2,000 and $8,000. After death, the family of a person with dependants receives $23,000 and that of a

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[5] Submission 38.

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person with no dependants receives $8,000 (see Appendix for more details). A discretionary fund is available to families "where there is evidence of particular hardship or special family circumstances."[6] The Commonwealth Government is not considering granting the Mark Fitzpatrick Trust any additional funds. There have been no state contributions to the Trust, despite requests from the Commonwealth Government at the time the Trust was set up.

3.51 As the Commonwealth scheme is not deemed to be "income" and as such taxable by the Government it is fully expected that the same criteria will be applied by the Tax Department to this scheme. This was an important consideration for some members of the Committee. Evidence was presented to the Committee that people who had received lump sum settlements in Western Australia would lose their entitlements to Social Security and Medicare benefits because the relevant Commonwealth Departments deemed the payments to be compensation or income. To date no decision has been made on these matters. Whilst the Committee could not support such action by the Commonwealth, it is presumed that since the scheme recommended by this Committee is not deemed to replace income in any way it should not be taxable or affect Social Security of Medicare entitlements.

3.52 But the scheme differs from the Mark Fitzpatrick Trust in an important way. Many witnesses (see 2.33) told the Committee that if financial assistance is to be granted it should be provided while the beneficiary is alive, rather than after their death. The scheme devised by the Committee addresses this by granting most of money while the person is still alive. The Committee further felt it was important to make some payment ($10,000) to those families in which someone has already died and also felt such a payment would assist with the payment of funeral expenses.

3.53 The Committee Members supporting financial assistance rejected the arguments placed before it by some of the broadbased AIDS organisations (see 2.42-2.47) because they felt that the factors listed above separated this class of people from the larger HIV community.

3.54 Those Members who opposed the granting of financial assistance did so for the following reasons:

1. Any assistance scheme should be based on need rather than mode of transmission of the virus;

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[6] Submission 17.

2. This scheme will reinforce, in the minds of the community, the incorrect assumption that some people with HIV are innocent and some others are guilty;

3. That there were insufficient factors which separated this group from the broader HIV community and others with medically acquired diseases and as such it has created a precedent.

3.55 The majority of the Committee however do not accept these arguments, holding that:

1. The proposed assistance is based on need: people with medically acquired HIV have had their infection since at least 1985, and some for considerably longer. Consequently they are in the later stages of the illness when need is greatest. Any provisions for all people with HIV would take longer to implement and thus would specifically disadvantage the medically acquired group. In addition, this group is more likely to have dependants, and to be widely dispersed throughout the state away from services, further factors of need.

2. The proposed scheme is not a moral judgement of guilt on the part of HIV positive people. Babies who have acquired the virus from HIV positive parents are just one of a number of categories not covered by the scheme.

3. The catastrophic nature of HIV and multiple long term symptoms separate it from other medically acquired illnesses, while the factors described above along with medical acquisition separate those with medically acquired HIV from others with HIV.

Secondary Infection

3.56 There was extensive Committee deliberation about the relative merits of a claim on financial assistance by people such as:

- Spouses of haemophiliacs or transfusion related HIV positive people who contract HIV;

- Children of parent(s) who have medically acquired HIV who subsequently contract HIV in utero or via breastmilk.

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3.57 As the Committee decided that the broader medically acquired HIV community should receive financial assistance, then on the surface it might seem that nothing should prevent people in the above two classes also receiving assistance, except perhaps that they did not actually receive the disease medically - a quite important point.

3.58 The problem of course arises when attempting to distinguish between the above mentioned categories of people - i.e. spouses and children of medically acquired HIV people - and children and spouses of people who acquired the disease through sexual contact or intravenous drug use. The mode of transmission is not a separating factor in the secondary infection cases.

3.59 It should also be noted that it has come to the Committee's attention that a number of couples have continued to engage in unsafe sex after discovering that one partner is HIV positive for the very obvious reason of trying to have a child. As there is only a one-in-four chance of the child being HIV positive it is considered by some couples to be a legitimate risk. If, in the course of attempting to have a child the spouse becomes HIV positive, should this entitle that person to any financial assistance which is being granted to the primary group? It would appear not.

3.60 Perhaps more importantly, who or how would any person or tribunal be able to determine whether this was the case?

3.61 Other complications also present themselves. Is the child of an HIV positive haemophiliac any more deserving of financial assistance than the child of an injecting drug user who is HIV positive?

3.62 When examining spouses the same difficulty arises. Is the spouse of an HIV positive haemophiliac any more deserving of direct financial assistance than the spouse of a man who contracts HIV in Thailand whilst on a business trip (and who doesn't warn his spouse of the potential risk) or the woman who is unaware that her spouse is bisexual ?

3.63 In any case where negligence was proven in a court, people with proven secondary infection would also have a legitimate claim for compensation. However there is a clear distinction between legal compensation and financial assistance where no legal negligence is in question.

3.64 The Committee concluded that it was unable to recommend the granting of any direct financial assistance to secondary infection people as this could only be a legal matter. However, a majority of Committee Members agreed that having HIV positive dependants was a criterion that should influence the total amount of financial assistance.

RECOMMENDATION NO. 1

THAT PEOPLE WITH MEDICALLY ACQUIRED HIV BE ENTITLED TO FINANCIAL ASSISTANCE.

Supported by Goldsmith, Arena, Moppett, Nile and Ryan.

Opposed by Symonds, Enderbury, Kirkby and Sham-Ho.

RECOMMENDATION NO. 2

THAT THIS FINANCIAL ASSISTANCE BE RESTRICTED TO A MAXIMUM FIGURE OF $50,000 [SUBJECT TO RECOMMENDATION NO. 6] FOR A MEDICALLY ACQUIRED HIV PERSON WITH DEPENDANTS AND $25,000 FOR A MEDICALLY ACQUIRED HIV PERSON WITH NO DEPENDANTS.

RECOMMENDATION NO. 3

THAT THOSE PEOPLE WHO ACCEPT FINANCIAL ASSISTANCE DO NOT HAVE TO WAIVE THEIR RIGHT TO SEEK COMPENSATION IN COURT BUT THAT ANY AMOUNT OF ASSISTANCE GRANTED WILL BE DEDUCTED AS A DISBURSEMENT FROM ANY COMPENSATION AGREEMENT AWARDED BY THE COURTS.

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RECOMMENDATION NO. 4

THAT FINANCIAL ASSISTANCE BE ALLOCATED TO PEOPLE WITH MEDICALLY ACQUIRED HIV IN THE FOLLOWING MANNER:

Stage of Disease	Dependants	No Dependants
	(Maximum Payment Per Year)	
Stage 3	$ 8,000	$4,000
Stage 4	$12,000	$6,000
Maximum Final Payment[7]	$10,000	$5,000

RECOMMENDATION NO. 5

THAT A ONCE ONLY LUMP SUM PAYMENT OF $10,000 BE PAID TO THE DEPENDANTS OF MEDICALLY ACQUIRED HIV PEOPLE WHO HAVE ALREADY DIED, AND THAT A FIGURE OF $5,000 BE PAID TO THE CARERS OF MEDICALLY ACQUIRED HIV PEOPLE WITH NO DEPENDANTS WHO HAVE ALREADY DIED.

RECOMMENDATION NO. 6

A FURTHER ONCE ONLY LUMP SUM PAYMENT OF $5,000 BE PAID TO RECIPIENTS OF FUNDING UNDER RECOMMENDATION 4, FOR EACH DEPENDANT WHO IS HIV POSITIVE. THIS PAYMENT SHALL BE IN ADDITION TO THE MAXIMUM INDIVIDUAL PAYMENT OF $50,000 (RECOMMENDATION 2).

RECOMMENDATION NO. 7

THAT THE ABOVE ASSISTANCE BE PROVIDED QUITE SEPARATELY TO THE CURRENT AIDS BUDGET.

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[7] If a person with medically acquired HIV dies before they have reached the maximum relevant payment, only this amount will be paid upon notification of death.

RECOMMENDATION NO. 20

THAT HOME BASED NURSING CARE BE AVAILABLE ON A SEVEN DAY A WEEK, 24 HOUR ON CALL BASIS. IT IS DESIRABLE THAT ALL NEW SOUTH WALES HEALTH DEPARTMENT AREAS AND REGIONS WORK TOWARD THIS GOAL, AS FAR AS POSSIBLE.

4.58 In addition to problems experienced with the availability of home nursing services a number of submittees and witnesses said that they spent a great deal of time and effort in meeting the needs of the person with AIDS for bed linen. Many people with HIV/AIDS suffer from extreme night sweats and bed linen must be changed regularly. The Committee also heard evidence that people with other serious illnesses such as leukemia also suffer extreme night sweats.

RECOMMENDATION NO. 21

THAT THE NEW SOUTH WALES DEPARTMENT OF HEALTH INVESTIGATE THE ESTABLISHMENT OF A BED LINEN SERVICE FOR PEOPLE WITH SERIOUS ILLNESSES AND A DEMONSTRABLE NEED FOR SUCH A SERVICE.

Community Health Centres

4.59 As well as providing home nursing, Community Health Centres provide a range of services which vary from centre to centre and can include counselling, occupational therapy, psychiatric services, relaxation and stress management classes, quit smoking groups, etc.

4) OTHER SERVICES AVAILABLE TO PEOPLE WITH HIV

4.60 People with HIV also have access to a variety of services, provided by other Government Departments, in the following areas - pharmaceuticals, home care, transport, childcare, housing, income support, and medical expenses. These are described below.

Pharmaceuticals

4.61 The Committee heard much evidence about the high cost of pharmaceuticals involved in caring for someone with HIV.

4.62 The Commonwealth Pharmaceutical Benefits Scheme (PBS) provides low cost pharmaceuticals for people in receipt of a pension or sickness benefit at commercial pharmacies. This scheme only applies to pharmaceuticals on the PBS. The Commonwealth has recently removed some expensive drugs from the PBS. Pensioners pay $2.50 for each script and there is a maximum outlay of $130 per calendar year. If a person does not have a health care card, the price of medications is not fixed and there is a maximum outlay of $300 per calendar year.

4.63 The Department of Health in New South Wales has responded to the ever increasing cost of pharmaceuticals, and the increasing number of drugs not available through the PBS, by introducing a fee for medications dispensed through hospital pharmacies. The fee is $2.50 per item for people with a Health Care Card and $15 for all other patients. There is a ceiling (maximum outlay) of $130 for those with Health Care Cards and $300 for all other patients.

4.64 The total outlay for prescribed medications could amount to $260 per year for those with a Health Care Card and $600 for those without.

4.65 The problem for many people with HIV is that they need many pharmaceuticals which are not included in the Pharmaceutical Benefits Scheme. These items include nutritional supplements, dressings and mouth washes.

4.66 Many people with medically acquired HIV and those caring for them suggested that the cost of pharmaceuticals was one of the most constant and high costs of caring for a person with HIV:

> *"The idea of charging for life saving and health maintaining pharmaceutical drugs has caused much distress among HIV infected people generally. The nature of AIDS is such that patients can be, and invariably are, affected by a wide range of life threatening illnesses. These always require prompt treatment. Consequently, AIDS patients are often required to take numerous medications."*[15]

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[15] Submission 47

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RECOMMENDATION NO. 22

THAT THE NEW SOUTH WALES DEPARTMENT OF HEALTH REVIEW ITS POLICIES AND NEGOTIATE WITH THE COMMONWEALTH DEPARTMENT OF HEALTH, HOUSING AND COMMUNITY SERVICES TO ALLEVIATE THE COST OF PHARMACEUTICALS FOR ALL PEOPLE WITH SERIOUS ILLNESSES.

4.66 The Committee also received submissions and evidence from all groups of people with HIV and the professionals involved with their care about the delays in gaining access to new drug therapies.

> "*Access to a variety of treatments for HIV is of major concern to all with an infected family member.... People medically infected with HIV have now been infected between six and ten years. For them it is necessary to see energy being directed towards effective treatment.*"[16]

RECOMMENDATION NO. 23

THAT THE NEW SOUTH WALES DEPARTMENT OF HEALTH SUPPORT THE EFFORTS OF THE COMMONWEALTH DEPARTMENT OF HEALTH, HOUSING AND COMMUNITY SERVICES, TO ENSURE SAFE AND IMMEDIATE ACCESS TO APPROPRIATE DRUG THERAPIES FOR PEOPLE WITH HIV.

Home Care Service of New South Wales

4.67 The Home Care Service of New South Wales is provided through the Home and Community Care Programme. This programme was introduced in 1985, by the Commonwealth Government with the Home and Community Care Act 1985, and was "one of a number of initiatives designed to restructure government assistance for the frail aged, younger people with disabilities, and their carers." (First Triennial Review of the HACC Program, 1988) It is designed to prevent unnecessary institutionalisation. Funding for Home Care is provided by the Commonwealth and State/Territory Governments; in New South Wales the funding ratio is approximately 56% Commonwealth and 44% New South Wales. The total spent in New South Wales is about $73 million per annum. It costs Home Care an average of $25 per hour to provide an hour of service anywhere in the state.

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[16] Submission 4. Emphasis In Original.

4.68 The Committee has heard that Home Care provides services to 80,000 people through 177 service outlets each month. Home Care can provide services 24 hours a day and seven days a week. Pensioners, eligible for Home Care, are charged $2 per hour.

4.69 Home Care provides two main types of care:

- general housekeeping, live-in housekeeping, home maintenance; and
- personal care which may include assistance with bathing, dressing, eating, etc.

4.70 Because HIV is classified as "infectious", people with HIV/AIDS are not able to receive personal care services. The Committee has also heard evidence from community nursing organisations that it is not appropriate for Home Care to undertake personal care for people with unstable medical conditions such as AIDS.

4.71 Home Care provides services to people with HIV/AIDS under its "no growth" category, defined thus:

> *"all those who, although experiencing a crisis in their household which means that they are unable to perform essential daily tasks, are not people who have continual disability which would lead to premature institutional care."*

4.72 The "no growth" category currently comprises 10% of Home Care services. As a percentage of services provided by Home Care this will decrease over time. Home Care acknowledges that there is, and will continue to be, an increasing demand for services from groups in the "no growth" area. Evidence of the level of demand is passed on to relevant planning authorities. There are no plans to amend the "no growth" restrictions in the HACC agreements.

4.73 In 1986, Home Care undertook a training programme to educate its staff about HIV/AIDS and has an infection control policy to protect workers and clients.

4.74 People with medically acquired HIV saw the need for more flexible services available for a greater range of hours. This seemed to apply particularly to Home Care. The Committee is of the view that because of the growing number of people with HIV and the increasing dependence of those already infected the need for this service will

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only increase. Further, an increase in the availability of these services is very important to enable people with AIDS to be cared for at home and to avoid unnecessary institutionalisation.

RECOMMENDATION NO. 24

THAT THE NEW SOUTH WALES DEPARTMENTS OF HEALTH AND COMMUNITY SERVICES LIAISE WITH THE COMMONWEALTH DEPARTMENT OF HEALTH, HOUSING, AND COMMUNITY SERVICES TO INCREASE SERVICES PROVIDED BY THE HOME CARE SERVICE OF NEW SOUTH WALES TO PEOPLE WITH HIV/AIDS.

THAT THE CURRENT RESTRICTIONS OF THE HOME CARE SERVICE OF NEW SOUTH WALES REGARDING THE PROVISION OF PERSONAL CARE TO PEOPLE WITH HIV/AIDS BE LIFTED.

THAT FUNDING CONTINUE TO BE PROVIDED ON A SHARED BASIS BETWEEN THE COMMONWEALTH AND STATE GOVERNMENTS.

Transport

4.75 The Isolated Persons Travel and Accommodation Assistance Scheme is run by the New South Wales Department of Health and subsidises the cost of travel and accommodation for people living more than 200 kilometres from specialist medical treatment.

4.76 New South Wales Department of Transport has established the Taxi Transport Subsidy Scheme for people with severe and permanent disabilities. There are six classes of disability (see Appendix):

- permanent inability to walk;
- dependence on a wheelchair;
- other severe ambulatory problems;
- total loss of vision or severe visual impairment;
- severe and uncontrolled epilepsy; and
- intellectual disability causing behavioural problems.

4.77 Some people with HIV are eligible for this Scheme. Those who qualify receive an identification card and a book of travel dockets, and pay only 50% of the taxi fare (up to $25 per trip).

4.78 The Committee heard evidence to suggest the cost of transport is a major burden to people with medically acquired HIV. Public transport is often not a viable option for people with medically acquired HIV as they may have temporary or intermittent problems with mobility or they may feel uncomfortable using public transport because of other physical problems often associated with AIDS , such as extreme weight loss or facial rashes. Visible lesions can be a particular problem for haemophiliacs, because of bleeding. After examining the eligibility criteria for the Taxi Transport Subsidy Scheme the Committee concluded that they should be reviewed, especially as ACON's transport scheme covers only a limited area (see part 4.37).

RECOMMENDATION NO. 25

THAT THE NEW SOUTH WALES DEPARTMENT OF TRANSPORT REVIEW THE ELIGIBILITY CRITERIA FOR THE TAXI TRANSPORT SUBSIDY SCHEME TO INCLUDE ALL PEOPLE WITH TERMINAL ILLNESSES WHO HAVE DIFFICULTIES USING PUBLIC TRANSPORT BECAUSE OF THE PROBLEMS NOT COVERED IN THE CURRENT ELIGIBILITY CRITERIA.

Childcare

4.79 The New South Wales Department of Community Services is required to provide:

- foster care placements and short and long term substitute care for a child or children from a family in which a person is infected with HIV; and
- financial and other assistance (this could be used to assist with transport, education needs, etc.).

4.80 Problems associated with child care were made clear to the Committee:

> "*With no family or community support, my husband and I have a constant problem finding affordable, quality child care. Between 1987 and late 1989 we*

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> *were forced to pay over $6,000 for child care at a Long Day-Care Centre ... Since our daughter began school in 1990, transporting her to and from school every day and providing care during the holidays has been a constant problem. Although I have been taking the drug AZT since June 1989 and have not suffered from any serious illnesses in the last 12 months, I am constantly plagued by overwhelming fatigue, severe muscle pain and weakness, and blinding headaches which make it extremely difficult to carry out my normal duties as a wife and mother."*[17]

RECOMMENDATION NO. 26

THAT THE NEW SOUTH WALES DEPARTMENTS OF HEALTH AND COMMUNITY SERVICES ENSURE THE INTEGRATION OF POLICIES AND PROGRAMS REGARDING THE ISSUES OF CHILD CARE, INCLUDING FOSTERING, ADOPTION, AND RESIDENTIAL SUPPORT, FOR WOMEN AND CHILDREN WITH HIV.

Housing

4.81 People with HIV have access to assistance from the New South Wales Department of Housing. This may be in the form of Priority Housing Assistance, rental accommodation or mortgage assistance.

Income Security

4.82 People with medically acquired HIV are entitled to receive a range of benefits from the Commonwealth Department of Social Security, depending on their circumstances.

5) WOMEN WITH HIV

4.83 A number of women with medically acquired HIV presented submissions and gave evidence to the Committee to suggest that there is a need for services to be developed to meet the particular needs of women with HIV. These included the need for information and appropriate

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[17] Submission 7.

specialist treatment for gynaecological problems associated with HIV, problems with obtaining child care, and problems with home care. This evidence was strongly supported in evidence given by representatives of the Positive Women's Group.

4.84 While a consideration of the needs of women with HIV does not strictly come within the Committee's Terms of Reference the Committee did considered it relevant to make a recommendation in regard to the needs of women with HIV. As women form a larger proportion of the medically acquired HIV population than of the general population of people with HIV, the Committee thought it important to address the needs of this group.

<u>RECOMMENDATION NO. 27</u>
THAT THE AIDS BUREAU OF THE NEW SOUTH WALES DEPARTMENT OF HEALTH SHOULD IMPLEMENT THE FOLLOWING RECOMMENDATIONS FROM THE REPORT ENTITLED <u>PLANNING FOR HIV/AIDS CARE AND TREATMENT SERVICES IN NEW SOUTH WALES 1990-1994:</u>

> *"ALL AREAS AND REGIONS SHOULD ENSURE THAT AGENCIES PROVIDING CARE TO HIV-INFECTED PEOPLE DEVELOP OR EXPAND PROGRAMS TO ADDRESS THE NEEDS OF HIV-INFECTED WOMEN AND FAMILIES."*
>
> *"AREAS AND REGIONS SHOULD CONSIDER RESOURCING MAINSTREAM SERVICES SUCH AS WOMEN'S HEALTH CENTRES TO DEVELOP SERVICES FOR HIV-INFECTED WOMEN."*

6) EDUCATION

4.85 The Committee also received a great deal of information to suggest that services are not entirely adequate. Public attitudes towards HIV still require a considerable amount of change. The major problems cited were ignorance, fear of disclosure, and discrimination among health professionals, other service providers and members of the general public. HIV positive people living in rural communities spoke of particular problems in this area (see 2.16). Witnesses again and again described the stress and sense of isolation created by discrimination and fear of disclosure.

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> "[People with medically acquired HIV] *are still occasionally confronted with inappropriate reactions from service providers at different levels who may have specific concerns working with HIV infected patients. These incidents can add unnecessary anguish to that which accompanies such serious conditions as HIV infection and may create a cycle of anger which reinforces popular opinion and attitudes.*"[18]

4.86 The Committee came to understand that public attitudes and services for people with HIV/AIDS have improved over the past few years. Committee Members are optimistic that these improvements will continue. The Committee applauds any efforts which enable all people with HIV to have access to a range of services which are sensitive to their needs.

4.87 Ignorance was seen, by the Committee, as a major source of discrimination and continues to be reflected in public attitudes about HIV.

4.88 The Committee recognises the need for a program to educate people about HIV and the needs of people with HIV. While the Committee commends the effectiveness of education campaigns designed to reduce the spread of HIV by way of sexual activity and intravenous drug use, it also recognises the need for another dimension in public education about this disease which has tragically affected the lives of many people.

RECOMMENDATION NO. 28

THAT THE NEW SOUTH WALES DEPARTMENT OF HEALTH SHOULD PROVIDE ADDITIONAL FUNDS TO DEVELOP AN EDUCATION PROGRAM TO PROMOTE COMMUNITY AWARENESS ABOUT THE NEEDS OF PEOPLE WITH HIV AND SHOULD BE DESIGNED TO REDUCE PUBLIC FEARS AND PREJUDICES ABOUT THE VIRUS. THIS PROGRAM SHOULD BE DEVELOPED IN CONSULTATION WITH MEMBERS OF THE TRANSFUSION RELATED AIDS UNIT (TRAIDS) BASED AT PARRAMATTA HOSPITAL, THE HAEMOPHILIA SOCIETY OF NEW SOUTH WALES, THE HAEMOPHILIA FOUNDATION OF AUSTRALIA, AND THE AIDS COUNCIL OF NEW SOUTH WALES (ACON).

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[18] Submission 47.

Hon A Symonds, MLC, Hon K Enderbury, MLC
Hon E Kirkby, MLC, Hon H Sham-Ho, MLC

DISSENTING OPINION

HIV is a virus largely transmitted through blood and semen. Blood and semen are exchanged in medical processes, in many forms of sexual contact and in intravenous drug use. All people infected with HIV suffer terribly.

We, the undersigned, had to ask ourselves why the majority (5 votes to 4) of this Committee has seen fit to categorise people with the same illness according to the means by which they acquired the disease. To grant financial assistance, not on the basis of need, but on the mode of transmission is for us, unjust, inappropriate and unacceptable.

We believe that such a distinction goes against the principles of compassion for people who are suffering and against democratic formal law. Moreover, it is ultimately counterproductive because it will only serve to reinforce the social stigma and prejudice associated with HIV and do nothing to help our society deal with this terrible disease.

No evidence presented to the Committee adequately differentiated between the medical acquisition of HIV and for example, Hepatitis B and C, both of which can be fatal and both of which can be acquired through the blood supply. Indeed, the Committee made no serious effort to compare the relative merits of the different groups of people suffering from medically acquired disease or injury. The claim that HIV is different from other contagious and life-threatening diseases rests on the reputation of the disease, linked as it is to the homosexual and IV drug-using community.

In the last decade, the community and indeed the Government has gone some way in redressing the discrimination that these marginalised groups have suffered by decriminalising homosexuality, introducing anti-discrimination legislation, and needle-exchange programs. The decision to exclude these groups from the proposed settlement and by extension, from the same level of care by instituting a separate response to one group suffering from the illness is clearly discriminatory and therefore cannot be supported. It should also be noted that this group, and this group alone, already has access to the Mark Fitzpatrick Trust.

It is unacceptable to help one community with financial assistance to the exclusion of other medically acquired groups when all of these groups are "victims" of "ordinary risks" that cannot be avoided and where there is no action for damages because there is no negligence. Many people suffer injustice from actions for which they remain uncompensated.

Notwithstanding claims to the contrary, the majority Committee decision has effectively usurped the role of the Courts.

Traditionally, issues of medical negligence have been decided by due legal process but the decision to award financial compensation, yet still allow people in this category to sue for damages destroys the argument that this scheme will entitle people to assistance without the stress associated with Court cases. In fact, what this scheme admits, is that the overwhelming majority of people with medically acquired HIV have no prospect of gaining a successful legal decision.

Mr Garling, a Barrister, summed up the legal position.

> "As a society, we have traditionally provided a level of social benefit to all people who have, for whatever cause or reason, been afflicted by some sickness. The Commonwealth provides the sickness benefit and associated benefits. We can all argue about whether the level of that is adequate; however, that's a different question to the question of principle.
>
> The second basis upon which we have compensated people is if one can establish fault - be it a motor car driver's fault, a fault in the workplace, a fault in the professional relationship, or a fault arising in a public liability sense. We have said: 'If you can establish fault, then the law either in accordance with its common law position, or in accordance with its statutorily amended common law position, has provided damages for it' and I cannot see that there is any special basis for separating compensation in our society. I think that if this Committee was to recommend that there be, in effect, a special legislative package dealing with this particular group, that it would be very hard logically to resist such a package in respect of a very large number of other groups." [Evidence, 8.4.91. p.23]

Another issue of concern to us is that some Members of the Committee have sought to imply that AIDS has a more devastating effect on individuals than any other medically acquired disease. This, as stated above, is very difficult for the Committee to determine. Firstly, a woman with medically acquired hepatitis C testified to the Committee that:

> "People in my situation have died from Hepatitis C, ... as I understand it, my life expectancy is certainly shortened because it [Hepatitis C] is continually damaging my liver, ... the liver does not regenerate." [Evidence, 8.8.91, P.41]

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Secondly, this woman was the only woman with a medically acquired disease other than HIV who appeared before the Committee. Many medically acquired HIV people appeared before the Committee appealing for sympathy and compassion and redress. Unfortunately, other such groups did not have the same opportunity to present their case to the Committee. This majority recommendation sets a dangerous precedent. The Government may be asked to set up a special scheme for every identifiable group who is subject to misfortune.

Ultimately, there can be no justification for the Government to treat people with medically acquired HIV differently from other people with HIV and people with other medically acquired diseases. Financial assistance should be based on compassion and need rather than on a moral judgement that these people are in a unique situation.

Dr Susan Holck, the Chief of Planning and Policy Co-ordination on the WHO Global Commission on AIDS reinforced this notion:

> "As you know, WHO has taken a strong stand against discrimination of HIV-infected persons, without any distinction being made as to the 'source' of the infection. We share your [Justice Michael Kirby][1] concern about such distinctions, as the basis for discrimination. As you know all too well, judgements of this type, and the resulting discrimination, have been generally counterproductive in HIV prevention and care activities."

The scourge of HIV is in itself too contentious and emotive an issue for us to allow the debate to rest on the insupportable assumptions of "innocence" and "guilt".

Our only responses, therefore, should be to ensure that all persons who are disadvantaged or suffering in our society are cared for. Consequently, our recommendations should relate to the extensions of personal support and community services.

It is this firm belief that made it impossible for us to support the financial assistance recommended in this report, but it is also why we supported unanimously the recommendations to improve services and to alleviate the pain, suffering and personal tragedy of all with HIV not just a discrete group.

We must work together to combat the disease - not divide the community.

---

[1] Chief Justice of the Court of Appeal in New South Wales and Australian representative on the WHO Global Commission on AIDS.

DISSENTING OPINION ON CHAPTER ONE

INTRODUCTION

I dissent from the contents of Chapter 1 where it states that "*little was known about the virus in the early stages*", whereas there was sufficient evidence in 1982 to indicate the virus was transmissible through bodily fluids such as blood or semen.

Even though there was a gradual growth in knowledge about the actual nature of the virus itself, the lack of knowledge about the specific nature of the virus should not have prevented prompt action in 1982, to avoid the contamination of the Red Cross Blood Transfusion Service or Blood products for persons suffering from haemophilia.

The excellent submission to the Committee by Robert and Lynette Hatch, factually documents the failure of the Federal or New South Wales Health Departments to take prompt preventative action to stop at least 224 innocent persons in New South Wales from medically acquiring the AIDS/HIV virus, of whom 83 have already died.

I dissent from the Report in that I believe there was gross neglect by the Federal and New South Wales Health Departments and that the medically acquired AIDS/HIV persons still living or their next of kin and/or dependants are morally and legally entitled to generous compensation, as a matter of justice.

I also dissent from the change of Reference from "Compensation" to "Financial Assistance", when the Committee had already taken the bulk of its evidence under the original Terms of Reference.

DISSENTING OPINION ON CHAPTER TWO

REVIEW OF EVIDENCE

I record my dissent from the Committee's decision to take evidence from radical homosexual organisations such as ACT-UP (AIDS Coalition To Unleash Power - NSW), which is based on direct physical action, even to the extent of conducting a demonstration during an actual Hearing of this Committee.

Such radical homosexual organisations were already on record as opposing our Inquiry as well as compensation or treatment of the medically acquired AIDS/HIV persons as a unique group with special needs.

Their participation and attitude only added hurt and a further sense of injustice to the Medically Acquired AIDS/HIV persons, who in the majority of cases were infected by blood donated by AIDS infected homosexuals.

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DISSENTING OPINION ON CHAPTER THREE

FINANCIAL ASSISTANCE

I strongly supported the Western Australian Government's resolution of the Compensation issue for medically acquired AIDS/HIV persons, whereby an average amount of $280,000 was made available for each person on the basis of forgoing any further litigation in the Courts. (Total $5.4 million for 22 persons).

I dissent from the Committee's decision not to adopt this Western Australian policy and reluctantly agreed to the much lower amount of $50,000 without any waiver concerning future litigation, so that these long suffering medically acquired AIDS/HIV persons, who I truly regard as a unique tragic innocent group in our society should at least receive some financial assistance for themselves and/or dependents.

I believe the larger amount of compensation ie. financial assistance could have been found by the NSW Government from it $14 billion dollar budget in cooperation with the Government Insurance Office (GIO). Such a compensation policy would have saved these persons going to court and suffering additional stress, heavy legal costs as well as disrupting the NSW Health Service with doctors etc., giving stressful evidence over a long period of time.

DISSENTING OPINION ON CHAPTER FOUR

SERVICES

I dissent from the Committee's Recommendations that moved beyond the Committee's Terms of Reference, which clearly stated whether medically acquired AIDS/HIV persons or secondary transmission persons, who were infected through their medically acquired AIDS/HIV parents or spouses, are receiving adequate and comprehensive health and welfare services.

I dissent from those Recommendations which simply refer to HIV persons, as we did not investigate their areas of need or current services or care.

In dissenting, I am not saying that HIV persons should not received adequate or comprehensive services, which could be the basis of another Inquiry.

However, by broadening the Recommendations in this way to cover all HIV persons, the Committee may have inadvertently reduced the improvement of services to the primary group in its Inquiry, who should receive priority in the available services and care.

The wider AIDS/HIV group (see Appendix B) which mainly comprise homosexuals have been infected with AIDS/HIV, by knowingly engaging in high risk STD activities such as anal sex (sodomy). The medically acquired AIDS/HIV group are truly innocent as they were infected through no fault of their own by the NSW Public Health Services and its agencies.

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ORGANISATIONS WHICH SUPPLIED SUBMISSIONS

AIDS Council of New South Wales (ACON), Mr Don Baxter

AIDS Coalition To Unleash Power (ACTUP), Mr Lyle Chan

Anti-Discrimination Board of New South Wales, Mr Steve Mark

The Australia Federation of the Festival of Light, Dr Kevin Hume

Australian Red Cross Society, Mr John Smith

Central Sydney Health Service, C S Scarf

Commins Thompson Solicitors, Mr G J Potter

Commonwealth Department of Community Services & Health, Ms Mary Scott

Department of Family & Community Services, Mr William Hartley

Extraordinary Assistance Plan, Health & Welfare Canada, Mr Greg Smith

Government Insurance Office (GIO) Australia, Ms Audrey Lee

Haemophilia Foundation of Australia Inc, Mr Mike Barry & Ms Jennifer Ross

Haemophilia Society of New South Wales, J N Flinn & Ms Barrbara Volk

Haemophilia Society of Tasmania Inc, Ms Robyn Farr

Home Care Service of New South Wales, Ms Beryl Jamieson

J. M. Caruana Kay & Barry, Solicitors, Mr Martin Board

Legal Aid Commission of NSW, Mr Mark Richardson

Longterm Survival Working Group For People Living With AIDS, Mr Mahoney

MacFarlane Trust - London, Mr John Williams

Mark Fitzpatrick Trust, Mr Brendan Kelly

New South Wales Department of Health, Dr Bernard Amos

New South Wales Users & AIDS Association Incorporated, Ms Susan Morgan

New Zealand Accident Compensation Corporation, Mr J T Chapman

Organisations

People Living With AIDS (ACT), Mr Kenn Basham

Prince of Wales Children's Hospital, Ms Patricia Langdon

Royal Prince Alfred Hospital, Dr Kevin Rickard

Slater & Gordon, Solicitors

St Vincent's Hospital, Ms Roberta Lachlan

Therapeutic Goods Administration, Mr Alex Proudfoot

T.R.A.I.D.S, Ms Pam Shipway

T.R.A.I.D.S, Support Meeting Group Committee

University of New South Wales, School of Medicine, Professor John Dwyer

Venereology Society of New South Wales, Dr Stephen Davies

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LIST OF WITNESSES

NAME	CAPACITY IN WHICH THEY APPEARED
WEDNESDAY 6 FEBRUARY 1991	
[redacted]	Parents of a 16 year old [redacted] a haemophiliac who died from AIDS.
Mr Martin Board	Solicitor, J.M Caruana Kay and Barry.
[redacted] [redacted]	A person with Medically Acquired HIV.
THURSDAY 7 FEBRUARY 1991	
Dr John Ziegler	Immunologist, Prince of Wales Children's Hospital.
[redacted]	A person with Medically Acquired HIV
FRIDAY 1 MARCH 1991	
Dr R J Garsia	Director, Clinical AIDS Services. Chairman, AIDS Co-ordinating Committee, Central Sydney Area Health Service.
Four witnesses in camera	
Mr Steve Mark	President, New South Wales Anti-Discrimination Board.
MONDAY 18 MARCH 1991	
[redacted]	Husband of a person with Medically Acquired HIV.
A witness in camera	
A witness in camera	

List of Witnesses

NAME	CAPACITY IN WHICH THEY APPEARED
MONDAY 8 APRIL 1991	
Mr Lyle Chan	AIDS Coalition to Unleash Power (ACTUP)
Mr Gerard Thomas	AIDS Coalition to Unleash Power (ACTUP)
A witness in camera	
Professor John Dwyer	Professor of Medicine. Head of Department, School of Medicine, University of New South Wales
Mr Peter Garling	Barrister who has represented the Government Insurance Office in matters relating to Medically Acquired HIV
MONDAY 15 APRIL 1991	
Two witnesses in camera	
GRO-A	Husband and Father of two people who died from Medically Acquired AIDS.
GRO-A	Mother-in-law and Grandmother of two people who died from Medically Acquired AIDS.
GRO-A	Sister-in-law and Aunt of two people who died from Medically Acquired AIDS.
A witness in camera	
MONDAY 29 APRIL 1991	
Ms Regis McKenzie	Director of Nursing, Sydney Home Nursing Service.
Ms Beryl Jamieson	General Manager, Home Care Service of New South Wales.

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NAME	CAPACITY IN WHICH THEY APPEARED
WEDNESDAY 19 JULY 1991	
A witness in camera	
[redacted]	A person with Medically Acquired HIV.
Ms Patricia Langdon	Social Worker, Paediatric AIDS Unit, Prince of Wales Children's Hospital.
Ms Marilyn Cruikshank	Nurse Consultant, Paediatric AIDS Unit, Prince of Wales Children's Hospital.
TUESDAY 23 JULY 1991	
Ms Ann Malcolm	Community Services Manager, AIDS Council of New South Wales (ACON)
Mr Paul Van Reyk	Executive Assistant/Policy Writer, AIDS Council of New South Wales.
Mr Rolf Petherbridge	Vice President, AIDS Council of New South Wales (ACON)
A witness in camera.	
FRIDAY 26 JULY 1991	
[redacted]	Foster sister of a person with Medically-Acquired HIV & Researcher into HIV & Women's issues.
[redacted]	A person with Medically Acquired HIV.
Dr Neil Burich	Psychiatrist, Caritas, St Vincent's Hospital.

List of Witnesses

NAME	CAPACITY IN WHICH THEY APPEARED
WEDNESDAY 7 AUGUST 1991	
Mr David Lowe	Director, AIDS Bureau, New South Wales Department of Health.
GRO-A	Partner of a person with Medically Acquired HIV.
GRO-A	Father of a Haemophiliac who died from Medically Acquired HIV.
Mr Mark Richardson	Director, Legal Aid Commission of New South Wales.
GRO-A	Parents of a 16 year old haemophiliac "H" who died from AIDS.
THURSDAY 8 AUGUST 1991	
Mr Philip Bates	Barrister and Senior Lecturer in Law, School of Health Services, University of New South Wales.
A witness in camera	
GRO-A	Husband of a person with Medically Acquired HIV.
Three witnesses in camera	

Discussions

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CANBERRA 14

Ms Kerin O'E

Mr Kenn Basl

Mr David Ph

Ms Stephani

Mr Mark Fit

Mr Jim Arac

Mr Brendan

Ms Pam Bowe

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NAME	CAPACITY IN WHICH THEY APPEARED
CANBERRA 14 FEBRUARY 1991	
Ms Kerin O'Brien	Executive Officer, AIDS Action Council (AAC).
Mr Kenn Basham	People Living With AIDS (PLWA).
Mr David Phillips	People Living With AIDS & Finance Manager, AIDS Action Council.
Ms Stephanie Buckle	Counsellor, AIDS Action Council & Member of Haemophilia Association.
Mr Mark Fitzgerald	Volunteer Coordinator, AIDS Action Council.
Mr Jim Arachne	Founding Member, AIDS Action Council.
Mr Brendan Kelly	Executive Officer, Mark Fitzpatrick Trust.
Ms Pam Bower	Mark Fitzpatrick Trust.
MELBOURNE 23 APRIL 1991	
Dr Robert Simpson	Chief Medical Officer, Department of Health, Victoria.
Ms Bebe Loff	Manager, Legislative Review Section, Department of Health, Victoria.
Mr John Hayes	Director, Finance Division, Department of Health, Victoria.
Mr P Gordon	Slater & Gordon, Solicitors.
Ms A M Farrell	Slater & Gordon, Solicitors.
Ms L Mudge	Social Worker, the Alfred Hospital.

NAME	CAPACITY IN WHICH THEY APPEARED
PERTH 29 JULY 1991	
The Hon. Mr Kevin Minson MLA	Deputy Leader of the Liberal Party & Shadow Minister for Health.
Dr Charles Watson	Director, Disease Control Branch, Department of Health, Western Australia.
Mr John Young	Senior Assistant, Crown Solicitor, Crown Law Department, Department of Health, Western Australia.
Ms Liza Newby	Principal Consultant & Director, Legislation & Legal Branch, Department of Health, Western Australia.
Mr Nigel McBride	Acting Senior Legal Officer, Legislation & Legal Branch, Department of Health, Western Australia.
Mr & Mrs Tippett	Secretary and President, Haemophilia Society of Western Australia.
Mr Jeff Soo	Medically Acquired AIDS Support Group.
Mr & Mrs Verneet	Medically Acquired AIDS Support Group.
PERTH 30 JULY 1991	
The Hon. Keith Wilson, MLA	Minister for Health, Western Australia
Mr John Gordon	Solicitor, Slater & Gordon.
Ms Diedre Young	Social Worker, Haemophilia Treatment Centre, Fremantle Hospital.
Ms Michelle Kosky	Executive Director, AIDS Council of Western Australia.
Mr Neil Roberts	President, AIDS Council of Western Australia.

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14 DECEMBER 1
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NAME	CAPACITY IN WHICH THEY APPEARED
<u>14 DECEMBER 1990</u> Ms Pam Shipway	Coordinator, Transfusion Related AIDS (T.R.A.I.D.S.) Group.
Dr John Kaldor	Director, National Centre for HIV Epidemiology and Clinical Research.
GRO-A	A person with Medically Acquired HIV.
Mr Ken Barker	Executive Director, Finance and Administration, New South Wales Department of Health.
<u>CANBERRA - 10 MAY 1991</u> Ms Mary Scott	Assistant Secretary, AIDS Policy & Programmes Branch, Commonwealth Department of Community Services, Housing & Health.
Mr Brian Chandler	Legal Services Branch, AIDS Policy & Programmes Branch, Commonwealth Department of Community Services, Housing & Health.
Ms Helen Watchirs	Legal Secretariat, Commonwealth Department of Community Services, Housing & Health.
Ms Fiona Tito	Audit & Review Branch, Commonwealth Department of Community Services, Housing & Health.
<u>22 MARCH 1991</u> Haemophilia Society Meeting	
<u>30 APRIL 1991</u> Transfusion Related AIDS Group (T.R.A.I.D.S) Meeting	
<u>1 AUGUST 1991</u> Mr Justice Michael Kirby	Judge of New South Wales Supreme Court. Member of Global Commission on AIDS of the World Health Organisation.

APPENDIX

WORLD-WIDE FINANCIAL ASSISTANCE FOR PEOPLE WITH HIV[1]

AUSTRIA

The "Support Fund for Persons and Relatives Who Have Been Infected with HIV Through Medical Treatment or Activity" was unable to assume payments in February 1989. The following payments are now being made:

OS 1,000 monthly for HIV-infected without symptoms
OS 3,000 monthly for haemophiliacs with full-blown AIDS
OS 30,000 single payment for burial expenses

Over OS 1,200,000 has been paid out of the Fund so far.

The Austrian Haemophilia Society advised that anyone planning to sue in court should do so before the 3 year statute of limitations is ended. To ensure the possibility of suing one can request an extension in the form of a disclaimer not to use the statute of limitations on the part of the firm/party involved. If this is denied, quick legal action is recommended.

Status data:	1990	
Haemophiliacs:	635	
VWD:	1	
Total:	636	
HIV-Infected:	over 150	(over 50% of severe)
AIDS cases:	26	

Status data:	July 1990	
Haemophiliacs:	3000	
VWD:	300	
Total:	3300	(est. 6000)
HIV-Infected:	1172	of 2476 tested (47.3%; 61% of sev.)
AIDS cases:	437	

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[1] From the World Federation of Haemophilia. Information Letter No 5. February 1991, supplied by the Haemophilia Foundation of Australia Inc.

FRANCE

After the meeting on October 24, 1990, the Committee for the Distribution of Public and Private Funds released the latest statistics on financial assistance that had been allocated:

HIV-infected haemophiliacs having received financial assistance averaging FF 100,000 from the Public Fund 188.

HIV-infected haemophiliacs and their infected spouses having received financial assistance from the Private Fund 1074.

Status data: July 1990
Haemophiliacs:
VWD:
Total: 5000 (est.)
HIV-infected: 1067 (47% of tested); (1500 est.)
AIDS cases: 150 (over 200 est.)

JAPAN

The program of HIV Financial Assistance for haemophiliacs with AIDS in Japan has not been changed from the original program which was outlined in the HIV Financial Assistance Committee's Status Report from May 1990. Over the last three years the amount of compensation was as follows:

1988 - US$ 82,921.00
1989 - US$ 1,443,530.00
1990 - US$ 655,376.00 (as of July 31, 1990)

The government is planning to increase the budget in the expectation of an increase in the number of haemophiliacs with HIV/AIDS. As of December 31, 1989, 68% of all known HIV-infected individuals were haemophiliacs.

Status data: June 1990
Haemophiliacs:
VWD:
Total: 3081 (reg.) (est. 5000)
HIV-Infected: 1209 (40%-45% of tested) (est. 2000)
AIDS cases: 207 (17%)

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AIDS cases:

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There had been considerable confusion in New Zealand as compensation for HIV-infected haemophiliacs could be attained under two different aspects under the Act from the Accident Compensation Corporation (ACC):

- Section 78 covers loss of bodily function granting a maximum of NZ$ 17,000
- Section 79 covers loss of enjoyment of life and pain and suffering granting a maximum of NZ$ 10,000

The ACC explained that once a person has been diagnosed as HIV positive, their lifestyle would be affected in the sense of Section 79, and therefore a payment of NZ$ 10,000 would be granted. As the immune system is affected in any way the ACC would recognise that the disease is progressive to the point of loss of bodily function as described in Section 78, and would grant a further NZ$ 17,000. In some cases people would be receiving a sum of NZ$ 27,000 in one payment whereas others would be receiving NZ$ 10,000 initially and NZ$ 17,000 at a later date.

Status data:	Apr. 1988	
Haemophiliacs:	453	
VWD:	200	
Total:	653	
HIV-infected:	28	(4.29%)
AIDS cases:	3	

SPAIN

By a Decree from April 16, 1990, the foundation "Royal Foundation Victoria Eugenia" was classified as an individual beneficence of a welfare nature. Assets of the Foundation amount to Ptas. 15,125,000. The patronage of the Foundation consists of governmental organisations, haemophilia and haematology societies. The objectives are to assist all HIV-infected haemophiliacs in needs of all kinds.

Status data:	Mar. 1988
Haemophiliacs:	2160
VWD:	441
Total:	2601
HIV-infected:	86%
AIDS cases:	95

SWITZERLAND

Early in 1990 the Swiss Red Cross and the firm Immuno AG each gave SFr 250,000 to the Swiss Haemophilia Society toward the Fund for assistance to HIV-infected haemophiliacs. The last report was that about SFr 300,000 were still available. Both the Swiss Red Cross and Immuno have pledged further financial assistance, with the Swiss Red Cross guaranteeing SFr 1 million for emergency purposes.

By the first quarter in 1990

- 4 applications had been processed and payments were made
- 14 further applications were being processed
- 25 additional applications had arrived

Since 1988 the Haemophilia Society has been lobbying to secure governmental assistance of SFr 50,000 for HIV-infected haemophiliacs and on March 12, 1990 the Federal Council publicised a plan for assisting HIV-infected haemophiliacs and blood transfusion recipients. In August 1990, the Commission of the National Council recommended the plan in an overwhelming majority. It was hoped that the National Council and the Council Board would vote positively so that payments could begin in early 1991.

Although there are still many misunderstanding as to the criteria for eligibility, HIV-infected haemophiliacs and HIV-infected blood transfusion recipients are being encouraged by the Swiss Haemophilia Society to continue sending in applications even if the final governmental decision has not been made.

Status data:	Oct. 1989
Haemophiliacs:	
VWD:	
Total:	400 (est.)
HIV-infected:	63 of 289 tested (22%, 33% of severe)
AIDS cases:	21

UNITED KINGDOM

In March 1990 an additional L 34 million was granted to the Macfarlane Trust. As of that time, 1184 people had registered with the Trust and a further 19 applications for registration were being processed.

- 1132 people received L 20,000 as ex gratia payments by March 31, 1990
- 600 people received regular payments totalling L 999,449
- 600 people received single grants totalling L 786,395
- 975 people received special "Winter" payment of L 400 per person

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In spite of the payments 962 people were suing in court in October 1990. In view of this fact, Prime Minister Major increased the Fund's assets by L 42 million, which seemed to mark a reversal in government policy. In January 1991 most of those suing were expected to accept this out-of-court offer by the government:

- Single men received	L 23,500
- Children	L 21,500
- Childless married men	L 32,000
- Married men with children	L 60,500
- Infected intimates	L 23,500
- Divorced men with dependants	L 32,000
- Wives not infected	L 2,000

Status data:	Dec. 1990
Haemophiliacs:	6104
VWD:	1773
Total:	7877
HIV-infected:	1217
AIDS cases:	228

APPENDIX

HIV/AIDS EPIDEMIOLOGY[1]

Cases of AIDS by sex and exposure category, cumulative to 30 June 1991, and for two previous yearly intervals of diagnosis.

Adults/adolescents (13 years and older at diagnosis of AIDS)

EXPOSURE CATEGORY	1 Jul 89 - 30 Jun 90		1 Jul 90 - 30 Jun 91		Cumulative to 30 Jun 91			
	Male	Female	Male	Female	Male	Female	Total	%
Male homosexual/bisexual contact	502	-	463	-	2317	-	2317	86,5
Male homosexual/bisexual contact and ID use	13	-	6	-	66	-	66	2.5
ID use (female and heterosexual male)	8	5	6	3	25	16	41	1,5
Heterosexual contact:	5	3	15	4	27	20	47	1,8
Sex with ID user	*0*	*0*	*1*	*0*	*1*	*1*	*2*	-
Sex with bisexual male	-	*0*	-	*1*	-	*6*	*6*	-
From Pattern-II country	*2*	*1*	*1*	*0*	*6*	*4*	*10*	-
Sex with person from Pattern-II country	*0*	*1*	*2*	*0*	*5*	*2*	*7*	-
Sex with transfusion recipient	*0*	*0*	*0*	*1*	*0*	*2*	*2*	-
Sex with HIV-infected person, exposure not specified	*3*	*0*	*4*	*2*	*8*	*3*	*11*	-
Not further specified	*0*	*1*	*7*	*0*	*7*	*2*	*9*	-
Haemophilia/coagulation disorder	11	0	8	0	39	0	39	1.5
Receipt of blood transfusion, blood components, or tissue	8	5	6	2	44	34	78	2.9
Other/undetermined	21	2	17	1	63	6	69	2.6
Total Adults/Adolescents	568	15	521	10	2581	76	2657	99.2

Children (under 13 years at diagnosis of AIDS)

Mother with/at risk for HIV infection	1	0	2	2	3	4	7	0.3
Haemophilia/coagulation disorder	2	0	0	0	4	0	4	0.1
Receipt of blood transfusion, blood components, or tissue	0	0	0	0	9	1	10	0.4
Total Children	3	0	2	2	16	5	21	0.8
TOTAL	571	15	523	12	2597	81	2678	100

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[1] Figures from National Centre in HIV Epidemiology and Clinical Research. Australian HIV Surveillance Report, July, 1991.

Number of new diagnoses of HIV infection (in States and Territories other than NSW), by sex and exposure category, cumulative to 30 June 1991 (SA to 18 May 1990), and for two previous calendar intervals.

Adults/adolescents (13 years and older at diagnosis)

EXPOSURE CATEGORY	16 Jun 90 - 31 Dec 90		1 Jan 91 - 30 Jun 91		Cumulative to 30 Jun 91			
	Male	Female	Male	Female	Male	Female	Total	%
Male homosexual/bisexual contact	208	-	185	-	3643	-	3643	74.7
Male homosexual/bisexual contact and ID use	6	-	6	-	115	-	115	2.4
ID use (female and heterosexual male)	8	2	9	2	108	38	146	3.0
Heterosexual contact:	7	14	11	9	81	53	134	2.7
Sex with ID user	*1*	*1*	*1*	*0*	*7*	*4*	*11*	-
Sex with bisexual male	-	*1*	-	*1*	-	*8*	*8*	-
From Pattern-II country	*1*	*0*	*1*	*0*	*2*	*1*	*3*	-
Sex with person from Pattern-II country	*0*	*1*	*1*	*3*	*2*	*4*	*6*	-
Sex with person with haemophilia	*0*	*0*	*0*	*0*	*0*	*1*	*1*	-
Sex with HIV-infected person, exposure not specified	*0*	*1*	*0*	*0*	*0*	*1*	*1*	-
Not further specified	*5*	*10*	*8*	*5*	*70*	*34*	*104*	-
Haemophilia/coagulation disorder	0	0	0	0	174	4	178	3.6
Receipt of blood transfusion, blood components, or tissue	5	0	1	0	24	14	38	0.8
Other/undetermined	68	7	67	4	525	79	604	12.4
Total Adults/Adolescents	302	23	279	15	4670	188	4858	99.6

Children (under 13 years at diagnosis of HIV)

Mother with/at risk for HIV infection	1	0	0	1	2	2	4	0.1
Haemophilia/coagulation disorder	0	0	0	0	4	1	5	0.1
Receipt of blood transfusion, blood components, or tissue	0	0	1	0	9	0	9	0.1
Other/undetermined	1	0	0	0	1	2	3	0.1
Total Children	2	0	1	1	16	5	21	0.4
TOTAL	304	23	280	16	4686	193	4980[1]	100

[1] Includes 101 people whose exposure category and sex were not reported.

Number of ne
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EXPOSURE C

Homosexual/I
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TOTAL

1. In the interv
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2. In the interv
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ther than NSW),
May 1990), and

to 30 Jun 91	
Total	%
3643	74.7
115	2.4
146	3.0
134	2.7
11	-
8	-
3	-
6	-
1	-
1	-
104	-
178	3.6
38	0.8
604	12.4
4858	99.6

4	0.1
5	0.1
9	0.1
3	0.1
21	0.4
1980[1]	100

Number of new diagnoses of HIV infection in New South Wales by sex and exposure category, cumulative to 30 June 1991, and for two previous calendar intervals.

EXPOSURE CATEGORY	16 Jun 90 - 31 Dec 90[1]		1 Jan 91 - 30 Jun 91[2]		Cumulative to 30 Jun 91			
	Male	Female	Male	Female	Male	Female	Sex not reported	Total
Homosexual/bisexual contact	164	2	182	0	3716	15	128	3859
Homosexual/bisexual contact and ID use	3	0	3	0	70	2	4	76
Heterosexual contact and ID use	0	1	2	1	14	16	0	30
ID use not further specified	11	2	10	2	141	40	15	196
Heterosexual contact	21	10	17	6	110	52	4	166
Haemophilia/coagulation disorder	0	0	3	0	60	0	0	60
Receipt of blood transfusion, blood components, or tissue	2	2	4	2	46	36	1	83
Child of mother with/at risk for HIV infection	2	1	0	1	7	6	4	17
Other/undetermined	138	15	125	15	3564	227	1806	5597
TOTAL	341	33	346	27	7728	394	1962	10084

1. In the interval 1 July - 31 December 1990, HIV infection was diagnosed in 60 people whose sex was not reported.
2. In the interval 1 January - 30 June 1991, HIV infection was diagnosed in 37 people whose sex was not reported.

AIDS and HIV in the WHO Western Pacific Region by country; based on reports available at 1 July 1991.

COUNTRY/ AREA	CUMULATIVE AIDS CASES Male	Female	Children <15 Years	Total	AIDS Rate[1]	Cumulative Diagnoses HIV	Ratio HIV/AIDS
American Samoa	0	0	0	0	0.0	0	-
Australia	2597	81	24	2678	15.7	15064	5.6
Brunei	2	0	0	2	0.7	6	3.0
Cambodia	0	0	0	0	0.0	0	-
China	6	0	0	6	0.0	493	82.2
Cook Islands	0	0	0	0	0.0	0	-
Fed. S. Micronesia	1	0	0	1	1.0	5	5.0
Fiji	1	2	0	3	0.4	7	2.3
French Polynesia	20	5	1	25	13.9	96	3.8
Guam	7	1	0	8	6.7	26	3.3
Hong Kong	44	1	2	45	0.8	212	4.7
Japan[2]	366	12	-	378	0.3	1663	4.4
Kiribati	0	0	0	0	0.0	0	-
Korea	5	2	0	7	0.0	131	18.7
Laos	0	0	0	0	0.0	0	-
Macao	1	0	0	1	0.2	3	3.0
Malaysia	25	3	0	28	0.2	1042	37.2
Marshall Islands	1	1	0	2	4.9	2	1.0
Nauru	0	0	0	0	0.0	0	-
New Caledonia	15	1	1	16	9.4	50	3.1
New Zealand	265	9	4	274	8.1	658	2.4
Niue	0	0	0	0	0.0	0	-
N. Mariana Islands	0	0	0	0	0.0	0	-
Palau	0	0	0	0	0.0	0	-
Papua New Guinea	23	14	1	37	0.9	85	2.3
Philippines	40	11	2	51	0.1	240	4.7
Samoa	1	0	0	1	0.6	1	1.0
Singapore	23	0	0	23	0.9	62	2.7
Solomon Islands	0	0	0	0	0.0	0	-
Taiwan	28	2	0	30	0.0	186	6.2
Tokelau	0	0	0	0	0.0	0	-
Tonga	2	0	0	2	1.7	3	1.5
Tuvalu	0	0	0	0	0.0	0	-
Vanuatu	0	0	0	0	0.0	0	-
Vietnam	0	0	0	0	0.0	0	-
Wallis and Futuna	0	0	0	0	0.0	0	-
TOTAL	3473	145	35	3618	-	20035	5.5

1. AIDS cases per 100,000 total current population.
2. Dashes indicate that counts were unavailable.

Incidence o
diagnosis, f
30 June 1991

STATE/ TERRITORY
ACT
NSW
NT
QLD
SA
TAS
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WA
TOTAL

Table 3.3
Cases of AI
1991, and fo

Cases[2]

AGE GROUP (YEARS)
0 - 12
13 - 19
20 - 29
30 - 39
40 - 49
50 - 59
60 +
TOTAL

Deaths[3].

0 - 12
13 - 19
20 - 29
30 - 39
40 - 49
50 - 59
60 +
TOTAL

1. Populatio
(Australia
2. Cases ar
3. Deaths a

ased on reports

ulative gnoses HIV	Ratio HIV/AIDS
0	-
64	5.6
6	3.0
0	-
93	82.2
0	-
5	5.0
7	2.3
96	3.8
26	3.3
12	4.7
63	4.4
0	-
3	18.7
0	-
3	3.0
42	37.2
2	1.0
0	-
50	3.1
58	2.4
0	-
0	-
0	-
85	2.3
40	4.7
1	1.0
62	2.7
0	-
86	6.2
0	-
3	1.5
0	-
0	-
0	-
0	-
35	5.5

Incidence of AIDS per million current population by sex and State/Territory of diagnosis, from 1 January 1982 to 30 June 1991, and for two yearly intervals prior to 30 June 1991[1].

STATE/ TERRITORY	1 Jul 89 - 30 Jun 90		1 Jul 90 - 30 Jun 91		1 Jan 82 - 30 Jun 91		
	Male	Female	Male	Female	Male	Female	Total
ACT	83.4	7.1	54.9	0.0	240.1	7.0	124.7
NSW	119.2	1.7	104.1	2.4	553.1	16.3	283.7
NT	12.2	0.0	48.5	0.0	85.0	0.0	44.2
QLD	35.0	1.4	23.1	0.7	128.9	5.5	67.4
SA	34.9	1.4	26.3	0.0	123.4	4.1	63.5
TAS	26.5	0.0	17.6	0.0	61.5	4.3	32.7
VIC	46.9	1.4	58.9	1.4	242.7	5.4	123.2
WA	33.9	3.7	25.2	1.2	139.3	9.8	75.2
TOTAL	66.9	1.8	60.9	1.4	302.2	9.4	155.6

Table 3.3

Cases of AIDS and deaths following AIDS by sex and age group, cumulative to 30 June 1991, and for two previous yearly intervals.

Cases[2]

AGE GROUP (YEARS)	1 Jul 89 - 30 Jun 90		1 Jul 90 - 30 Jun 91		Cumulative to 30 Jun 91			
	Male	Female	Male	Female	Male	Female	Total	%
0 - 12	3	0	2	2	16	5	21	0.8
13 - 19	6	1	1	0	14	3	17	0.6
20 - 29	118	3	107	4	529	23	552	20.6
30 - 39	227	8	197	2	1081	15	1096	40.9
40 - 49	160	1	155	1	690	9	699	26.1
50 - 59	48	2	45	1	211	12	223	8.3
60 +	9	0	16	2	56	14	70	2.6
TOTAL	571	15	523	12	2597	81	2678	100

Deaths[3].

0 - 12	2	0	0	2	10	3	13	0.8
13 - 19	3	1	2	0	6	2	8	0.5
20 - 29	69	4	62	2	252	9	261	15.6
30 - 39	203	2	144	4	668	9	677	40.5
40 - 49	121	0	131	2	465	7	472	28.2
50 - 59	45	3	48	0	173	10	183	10.9
60 +	6	0	12	1	46	12	58	3.5
TOTAL	449	10	399	11	1620	52	1672	100

1. Population estimates by sex, State/Territory and calendar period from *Australian Demographic Statistics* (Australian Bureau of Statistics).
2. Cases are classified by age at diagnosis.
3. Deaths are classified by age at death.

APPENDIX

THE MARK FITZPATRICK TRUST[1]

ADVICE TO REGISTRANTS

This newsletter sets out to achieve a number of goals, the most important of which is to provide information about the operations of the Trust to date and how it will operate in the future.

WHO IT WILL COVER

As most of you know, the Trust was established by the Federal Government with a seeding grant of $13.2 million to provide financial assistance to people with medically acquired HIV infection, their dependants and carers. Medically acquired HIV infection is, in terms of the Trust Deed, an infection acquired by a person in the course of medical treatment from the transfusion of infected blood or blood products or from the transplantation of infected human tissue, including but not limited to, bone grafts, organ transplants and semen donation between 1 January 1979 and 1 May 1985. Under the terms of the Trust Deed created by Government only cases within that description can benefit under it.

WHAT HAS HAPPENED SO FAR

Presently an initial payment of $2,000 is being made to living persons as soon as their registrations are accepted while payments of $10,000 (if single)/ $30,000 (if with spouse/dependants) are being made in respect of those who were deceased at time of registration.

These payments were set as an interim measure until sufficient registrations had been received to enable the health status of the entire eligible group and thus the likely demand on the Trust's funds to be determined.

Up to 14 September 1990, 228 registrations had been accepted and initial or retrospective payments totalling over $1 million paid out. These registrations have been "staged" for payment purposes having regard to the medical reports provided by the treating doctor. This staging seeks to reflect health status in terms of quality of life, as well as the clinical and immunological factors brought on by the HIV infection.

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[1] Newsletter from the Mark Fitzpatrick Trust sent on 11 February 1991.

THE REGULAR PAYMENTS PROFILE

An actuarial study related this data to the limited amount of money available to the Trust in order to establish a regular payment profile. Based on this information the Trust has decided on the following profile. All Trustees would very much prefer to make higher payments but this is all that can be afforded within the amount of money available.

	Single $ per annum	With Spouse/Dependants $ per annum
. Stage 1	1,000	2,000
. Stage 2	2,000	4,000
. Stage 3	4,000	8,000
. Final (once only)	8,000	23,000

Stage 1 payments will be made once a year on or about 1 November while Stage 2 and 3 payments will be made twice a year, on or about 1 November and 1 May, at half the rates shown.

In response to the strong feelings of registrants the stage payments have been increased at the expense of the final payment. As a result the Trust has decided that for the time being no further advances will be made against the final payment except in exceptional circumstances. Requests for advances will be subject to the same scrutiny as discretionary assistance.

PLEASE NOTE. PAYMENTS ARE NOT PROVIDED TO COMPENSATE FOR LOSS OF EARNINGS. THEREFORE, THEY DO NOT HAVE TO BE DECLARED FOR INCOME TAX OR SOCIAL SECURITY PURPOSES.

These regular payments are determined solely on the basis of health status and whether the individual has dependants, without necessarily intrusive means testing.

The first regular payment will be made on or about 1 November 1990 in accordance with the information provided in the registration forms. In other words, where a registrant has indicated that he/she is married, in a defacto relationship or has dependants, the spouse/dependant rate will be

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Before the second payment is made, however, the Trust will require evidence of the relationship or the existence of dependants. This could include:

- a copy of the marriage certificate;
- evidence of joint financial commitment such as joint bank accounts, rates notices, mortgage commitments, or other evidence of an established relationship including acceptance of the relationship for social security purposes, or possibly a statutory declaration witnessed by a Justice of the Peace.

Similarly, for dependants:

- copies of birth certificates for those under 18; and
- where appropriate, copies of birth certificates and evidence of full time study for those under 25,

will be required.

Following the 1 November 1990 payment, the single rate only will be paid until this information is provided to the Trust Office. No retrospective adjustments will be made between the single and spouse/dependant rate.

Stage payments will also be determined having regard to the most recent medical report provided by the treating doctor. Generally, these reports will be sought in February and August each year. However, more frequent reassessment is possible if the treating doctor thinks it necessary.

Quite apart from changes in health status, the Trust Office should be advised of any other changes eg marriage, that will affect payment entitlements. Next of kin should advise the Office in cases of death of the registered person and provide a copy of the death certificate.

Except where the minor completes the Registration Form, payments in respect of dependants will be made to the parent/guardian until the child reaches 18 years of age. Thereafter, payments will be made direct to the registrant.

For accounting purposes, registrants accepted by:

- 1 May of each year in respect of Stage 1; and
- 1 February or 1 August of each year in respect of Stage 2/3,

will be entitled to the immediately preceding regular payment. Those registering after these dates will receive their first payment on the date when the next regular payment is due.

To make things easier, each payment cheque will have attached to it a checklist for return to the Trust where there are changes in personal circumstances affecting payments or the ability of the Trust to keep track of health status, for example, change in treating doctor or change of address.

DISCRETIONARY ASSISTANCE

Discretionary assistance can be provided where there is evidence of particular hardship or special family circumstances. Limited funds only are available for this purpose. The following factors are taken into account:

- Assistance to be available only in extreme circumstances.
- Assistance to be generally of a one-off nature.
- Size of family (numbers, ages and whether single parent).
- General family financial situation - income, employment, commitments, etc.
- Stage of infection of registered person.
- Health of other members of family.
- Advice of counsellor and doctor.
- Assistance will not be available in cases where retrospective or final payments have been made, except under extreme circumstances.

Requests for discretionary assistance will be considered promptly. However, it will save time if all of these points are covered in the original request.

Those who have already sought discretionary assistance will be contacted shortly.

1 NOVEMBER 1991 - THE TARGET DATE

1 November 1991 is the target date for all eligible persons to be registered with the Trust. On that date the current initial and retrospective payments will cease.

Eligible persons can register after this date but will go straight onto the regular payment profile. For example, a Stage 2 person with spouse/dependants whose registration is accepted on 10 April 1991 will receive $2,000 at that time and a further $2,000 on or about 1 May 1991. The same person registering after 1 November 1991 would receive only the half-yearly Stage 2 payment of $2,000 as the first payment.

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CHAIRMAN

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CONTACT WITH THE TRUST OFFICE

There may be many other aspects that individuals may wish to have explained to them. If you have any concerns at all, please contact the Trust Office on PO Box 1299, WODEN, ACT, 2606, or by phone (06) 287 1215. It is always better to know the facts than be upset by rumour.

Finally, the Trust is very sensitive to the fact that many registrants want to retain their privacy. You may be assured that the Trust Office will at all times preserve the confidential nature of its relations with registrants.

NINIAN STEPHEN
CHAIRMAN

APPENDIX

COST OF LITIGATION IN AUSTRALIA IN MEDICALLY ACQUIRED HIV MATTERS

Victoria

Slater and Gordon estimate that the total cost of the case of P.Q was $10 million.

Chris Slattery from the Policy and Legislation Branch of the Victorian Health Department estimates that the cost of P.Q was $9 million, plus the $870,000 in settlement payments, and the costs involved in B.C are estimated to be $ 2.5 million.

New South Wales

Arthur Payne, Liability Manager of the GIO, estimates that the costs of defending the Red Cross Blood Transfusion Service and the Hospitals involved in the cases run in NSW are as follows:

"H"	$ 440,142.47
"E"	$ 871,056.32
Holly Johnson	$ 742,023.82

Martin Board in submission outlines other costs in these cases :

"H" $ 240,000 (total cost to Applicant, funded by Legal Aid)

[Board estimates total cost to all involved: "would have significantly exceeded one million dollars"]

"E" $ 450,000

Holly Johnson $180,000 (total cost to Applicant, funded by Legal Aid)

[again Board estimates total cost to all involved: "would have significantly exceeded one million dollars"]

TOTAL	"H"	$ 680,142.47
	"E"	$ 1,321,056.32
	Holly Johnson	$ 922,023.82

APPENDIX

ELIGIBILITY CRITERIA - TAXI TRANSPORT SUBSIDY SCHEME

Many permanently disabled persons may not be sure that they are eligible to participate in the Taxi Transport Subsidy Scheme. To assist persons to decide whether they should apply, the following information has been prepared to supplement details shown in the main brochure.[1]

Disabilities covered by the Scheme fall within the following groups:

1. Permanent inability to walk.
2. Total permanent dependence on a wheelchair.
3. Severe permanent ambulatory problems.
   - (a) necessitating permanent use of large complex walking aids, e.g., walking frame, crutches or splints. Walking sticks or "quad" sticks do not qualify.
   - (b) necessitating constant assistance of another person for mobility.
4. Total loss of vision or severe permanent vision impairment.
5. Severe and uncontrollable epilepsy.
6. Intellectual disabilities causing behavioural problems.
   - (a) resulting in socially unacceptable behaviour.
   - (b) requiring the constant assistance of another person for travel on public transport.

The scheme is intended to assist persons who are permanently disabled and whose quality of life and mobility is limited by one of the six classes of disability shown above.

It should be noted that the restrictions mean that some persons, although unable to use public transport because of some other severe and non-qualifying disability, will not be eligible to participate in the Scheme.

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[1] Information supplied by the Department of Transport.

Appendix

To qualify for the subsidy the applicant's disability must be PERMANENT. The subsidy is not available for persons receiving treatment or undergoing rehabilitation with the expectation that in due course the extent of their disability will not then be such as to qualify for participation in the Scheme.

The above has been prepared to alert more persons to the scope of the Scheme and to help people understand the restriction imposed on eligibility.

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Government To Set Up $13.2m AIDS Trust. SYDNEY MORNING HERALD. November 8, 1989.

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Sperm Donor Case May Be Dropped SYDNEY MORNING HERALD November 27, 1990.

RECOMMENDATION NO. 8

THAT THE STATE INITIATE DISCUSSIONS WITH THE COMMONWEALTH GOVERNMENT TO EXAMINE THE FEASIBILITY OF A NATIONAL NO-FAULT INSURANCE SYSTEM FOR PEOPLE WHO CONTRACT DISEASE OR INJURY WITH LONG-TERM DEBILITATING CONSEQUENCES, THROUGH THE HEALTH CARE SYSTEM.

Note

A person living in a permanent relationship (married or defacto) or a person with dependant children (whether currently living in a relationship or not) qualifies as a person with dependants for the purpose of recommendations 4 and 5. This definition of dependants attempts to take account of the major financial consequences (e.g. house repayments) for the remaining partner, if one partner dies.

Voting

It should be noted that the four Members of the Committee who voted against Recommendation 1 did not participate in the framing of the following Recommendations 2 - 6. However, a majority of the participating Committee (5) supported all of these recommendations. The Hon. Lloyd Coleman was appointed to the Committee after the Hearings had concluded and chose to abstain from all recommendations.

Recommendation No. 2: Rev. the Hon. Fred Nile and the Hon. Franca Arena originally supported a figure much higher than that which was finally recommended.

Recommendation No. 4: Rev. the Hon. Fred Nile and the Hon. Franca Arena supported the proposition that all money up to the maximum respective figures should be paid to the families of medically acquired HIV people, rather than the maximum final payment recommended.

Recommendation No. 6: Rev. the Hon. Fred Nile, the Hon. Franca Arena, and the Hon. John Ryan originally supported a figure of $8,000 in this recommendation.

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ESTIMATE OF COST - FINANCIAL ASSISTANCE

Haemophiliacs - Total Number: 75

Estimated 50 with dependants	= $2,500,000
Estimated 25 with no dependants	= $ 625,000
Estimated 15 (now deceased) with dependants	= $ 150,000
Estimated 5 (now deceased) with no dependants	= $ 25,000
sub-total	= $3.3 million

Transfusion Related Cases - Total Number: 65

Estimated 45 with dependants	= $2,250,000
Estimated 20 with no dependants	= $ 500,000
Estimated 50 (now deceased) with dependants	= $ 500,000
Estimated 10 (now deceased) with no dependants	= $ 50,000
sub-total	= $3.3 million

Artificial Insemination - Total Number: 4

Two people with dependants	= $ 100,000
Two people (now deceased) with dependants	= $ 20,000
sub-total	= $ 120,000

HIV Positive Dependant Children

Estimated 10 children	= $ 50,000
sub-total	= $ 50,000

Plus up to 100 yet to be identified

Estimated 60 with dependants	= $3,000,000
Estimated 20 with no dependants	= $ 500,000
Estimated 10 (now deceased) with dependants	= $ 100,000
Estimated 10 (now deceased) with no dependants	= $ 50,000
sub-total	= $3.65 million

TOTAL COST = UP TO $10.42 MILLION [1]

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[1] These costs will be spread over a number of years.

CHAPTER FOUR

SERVICES

4.1 In its Terms of Reference the Committee was asked to consider:

> "Whether persons who have contracted HIV infection through blood, blood products, artificial insemination from a donor, or as a result of an organ donation are receiving adequate and comprehensive health and welfare services," and
>
> "Whether persons who have acquired HIV infection through secondary transmission from spouses or parents with medically acquired HIV are receiving adequate and comprehensive health and welfare services."

4.2 The Committee received a substantial number of submissions and heard a great deal of evidence to indicate there are many services available to people with medically acquired HIV.

4.3 The Committee received a substantial body of evidence about the special needs of people with medically acquired HIV. Some of these have already been outlined in the Evidence chapter. When considering making its recommendations, the Committee took into account factors such as geographic isolation, experiences of discrimination, and the devastating social, economic and psychological costs of HIV. People with medically acquired HIV were infected in a public institution and feel betrayed by the system from which they must now receive ongoing care.

4.4 The Committee also recognised that all people with HIV, and indeed, all people with terminal illnesses have many needs in common. The Committee was not able to address all these issues within its Terms of Reference, but in view of the considerable information received on these needs, felt that some recommendations were relevant to all people with HIV, not just the medically acquired group.

4.5 The Committee believes that all people with HIV should have access to comprehensive health and welfare services of a high quality.

4.6 Services available to people with medically acquired HIV include services established specifically to meet the needs of people with medically acquired HIV, services established for all people with HIV, and services available to all people who are ill.

4.7 Specific services for people with HIV are funded on a 50:50 basis by the Commonwealth and State Governments' AIDS Program, amounting to a total of $18 million in New South Wales per annum. This money is spent on care and treatment outside hospitals, education and prevention, blood and blood donor screening, and the HIV Study Grants Programme. Areas with a low prevalence of HIV cases are able to set aside some of their AIDS Program funding to purchase extra services for people with HIV/AIDS as they are needed.

4.8 The planning and establishment of HIV/AIDS services in New South Wales is carried out by the AIDS Bureau of the Department of Health. In 1990 the AIDS Bureau wrote a report, <u>Planning for HIV/AIDS Care and Treatment Services in New South Wales 1990 - 1994</u>. In this report the AIDS Bureau identifies several "service planning principles" which include the following:

- *"People with HIV/AIDS should have access to quality health care on an equitable basis with other persons requiring the services of the health system. ...*
- *"Service delivery models need to be responsive to the health care needs and socio-economic variables of particular groups of patients/clients. ...*
- *"Greater use needs to be made of mainstream health care resources to provide a comprehensive range of services and to deal with the increasing prevalence of AIDS. The merits and mix of specialist and mainstream services should reflect local needs and the prevalence of HIV/AIDS within each area and region."*[1]

4.9 Also included in this Report are a range of recommendations, a number of which the Committee has chosen to support, and are outlined below.

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[1] Pages 1 & 2.

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1) SERVICES ESTABLISHED FOR PEOPLE WITH MEDICALLY ACQUIRED HIV

4.10 During the Inquiry, the Committee became aware that there are a number of services which have been specifically established to meet the needs of people with medically acquired HIV. These include the Transfusion Related AIDS Unit, the Haemophilia Treatment Centre (Royal Prince Alfred Hospital), and programs at the Red Cross Blood Transfusion Service.

Transfusion Related AIDS Unit (TRAIDS)

4.11 The Transfusion Related AIDS Unit (TRAIDS) based at Parramatta Hospital was established in December 1986 and is the only service of its kind in Australia. TRAIDS was set up in response to the large number of people with medically acquired HIV in New South Wales. TRAIDS provides the following services to all people with transfusion related HIV in New South Wales:

- pre and post-HIV antibody test counselling;
- ongoing support and counselling for people with medically acquired HIV, their families and friends;
- education;
- group support;
- information, liaison and assistance with organisations such as Social Security, Department of Housing, and other organisations;
- health and welfare services to ensure access to appropriate resources; and
- liaison with other health care professionals (hospital social workers, general practitioners, etc.).

4.12 The staff of TRAIDS consists of a full-time co-ordinator, who has welfare training, a part-time psychologist, a full-time secretarial assistant and a part-time counsellor, who also works at the Red Cross Blood Transfusion Service.

4.13 All the people who are clients of TRAIDS and who provided submissions and gave evidence were very appreciative of the services provided by TRAIDS:

> *"the [TRAIDS] Unit has provided excellent counselling and information services for a large number of people, myself included, as well as help with a wide range of practical problems. Mrs Shipway has worked tirelessly to improve conditions and make life more comfortable for people with medically acquired HIV and their families."*[2]

4.14 After speaking with staff, representatives of the New South Wales Department of Health and clients, the Committee concluded that TRAIDS is under resourced. The demand on the services of TRAIDS will increase as the people with medically acquired HIV become increasingly unwell. The Committee has also taken into consideration geographic dispersement, social isolation and the needs of dependants in making this recommendation.

RECOMMENDATION NO. 9

THAT THE TRANSFUSION RELATED AIDS (TRAIDS) UNIT BASED AT PARRAMATTA HOSPITAL RECEIVE EXTRA FUNDING TO EMPLOY ANOTHER COUNSELLOR.

The Haemophilia Centre, Royal Prince Alfred Hospital

4.15 The Haemophilia Centre at Royal Prince Alfred Hospital provides specialist comprehensive treatment and care for people with haemophilia and people with haemophilia and HIV.

4.16 After hearing from members of the Haemophilia Society of New South Wales and some of the staff at the Haemophilia Centre it seems that the Centre has sufficient resources to meet the present needs of haemophiliacs with medically acquired HIV. The importance of the treatment of haemophiliacs with HIV being carried out in a haemophilia treatment centre was continually emphasised:

> *"People with haemophilia who were receiving ongoing treatment through their Haemophilia Treatment Centre have been able to maintain a natural link with their treating hospital for the treatment of HIV. There is a strong need for treatment of*

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> *haemophilia to be given alongside the treatment of the person's haemophilia. Haemophilia and HIV complicate each other medically and socially."*[3]

Red Cross Blood Transfusion Service Programs

4.17 The Red Cross Blood Transfusion Service receives $2.4 million for the Donor Welfare Service and for blood donor screening and counselling.

4.18 In 1988, $260,000 was provided to conduct the Look Back Programme - 6,000 people who had received blood transfusions between 1980 - 1985 were tested and 17 new HIV positive recipients of infected blood product were identified (0.28%)[4]. The Look Back programme is ongoing and the Donor Welfare Service has three staff who follow up HIV infected donors and the recipients of infected blood products (the Co-ordinator spends ten hours per week working at TRAIDS).

4.19 The Committee visited the Red Cross Blood Transfusion Service and received many documents relating to the Blood Bank's early efforts in screening blood and blood donors. The Committee received conflicting submissions about the effectiveness of these efforts.

2) SERVICES ESTABLISHED FOR ALL PEOPLE WITH HIV

4.20 Other services have been established for all people with HIV. These also assist people with medically acquired HIV and include HIV Study Grants, specialist community AIDS nursing staff, the Paediatric AIDS Unit at Prince of Wales Children's Hospital, the AIDS Council of New South Wales, and Ankali.

HIV Study Grants

4.21 In 1990/1991 $600,000 has been made available to enable professionals and volunteers involved in providing hands-on care and support to people with HIV/AIDS to undertake practical training and study. There is an expectation that those involved will transfer skills to people they are working with. This programme will continue until 1993.

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[3] Submission 4. Emphasis In Original.

[4] Submission 77. NSW Department of Health.

Specialist Community Nursing Staff

4.22 The Eastern Sydney Health Service, the area with the highest prevalence of HIV infection in New South Wales, receives special funding to employ six community nurses and two clinical nurse consultants. They provide a service seven days a week until 9.00 p.m. liaising between the hospitals and community services and provide consultation and education to community nurses in both Sydney and rural areas.

Paediatric AIDS Service, Prince of Wales Children's Hospital

4.23 A Community Social Worker and Clinical Nurse Consultant are funded from the AIDS program to provide support and counselling to children and families with HIV, and education and consultation in schools and other community settings. The goal of the Unit is to:

> *"help the referred child and his/her family maintain as normal life as possible within parameters set by the physical condition of the child as well as to provide the child with opportunities to reach his/her maximum potential."*[5]

4.24 The Committee wishes to acknowledge the importance of the work being done by the Paediatric AIDS Unit at the Prince of Wales Children's Hospital. The Committee supports all efforts to enable children with HIV to reach their maximum potential.

AIDS Council of New South Wales (ACON)

4.25 The AIDS Council of New South Wales was established by the "gay community" in Sydney.[6] ACON now provides a wide range of HIV related education programmes and services, as well as lobbying for rights and services for all people with HIV, its objectives are:

> "1. *To minimise the transmission of the Human Immunodeficiency Virus (HIV).*

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[5] Submission 33. Paediatric AIDS Unit, The Prince of Wales Children's Hospital.

[6] Evidence. 23.07.91.

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> 2. *To ensure that provision is made for the adequate effective and appropriate education, support, care and treatment of people affected by HIV/AIDS."*[7]

4.26 ACON has an evolving policy of extending the scope of its services to meet the needs of more people with HIV through liaison with organisations such as TRAIDS.

4.27 The Committee received information in submissions and evidence that people with medically acquired HIV have utilised and appreciated many of the services provided by ACON. However, the Committee also heard that many people with medically acquired HIV do not feel comfortable with the services provided by this organisation.

4.28 Members of the Committee acknowledged the valuable work being done by the AIDS Council of New South Wales, particularly in the prevention of the spread of the virus and the provision of services to homosexual men with HIV. The Committee also acknowledged that, given the history of ACON and the number of homosexual men with HIV, it is not appropriate to expect one organisation to meet the needs of all people with HIV.

4.29 ACON is the umbrella organisation for a number of services described below. These include the Community Support Network, the Bobby Goldsmith Foundation and a transport scheme.

4.30 <u>The Community Support Network (CSN)</u>

The Community Support Network is a group of trained volunteers who care for people with AIDS at home. The volunteers come from all walks of life. Those wanting to join CSN must first attend an information night (these are held twice a month) and then complete a detailed application form. Suitable applicants are then interviewed. Those chosen to be volunteers undergo an initial 45 hour training programme and are then involved in an ongoing support and education programme.

4.31 The Community Support Network has trained over 800 volunteers since 1984. There are currently 200 active volunteers working with 100 clients. Volunteers work with community nurses and perform a range of tasks including gardening, child care, shopping, and transport.

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[7] AIDS Council of NSW. 1989/1990 Annual Report.

They can also provide 24 hour physical care. Training courses have been held in Newcastle, the Blue Mountains and Wollongong.

4.32 <u>The Bobby Goldsmith Foundation (BGF)</u>

The Bobby Goldsmith Foundation provides direct financial assistance to people with AIDS, irrespective of the mode of transmission. It assists with small grants towards the payment of rent; telephone and other important accounts; the purchase of small electrical appliances, such as heaters and blenders; some child care and transport costs; and also assists with the costs of nutritional supplements, vitamins, and imported drugs. BGF is funded through donations. A number of people with medically acquired HIV have accessed this fund.

4.33 <u>Transport Scheme</u>

ACON runs a transport service for all people with HIV/AIDS covering an area from Burwood to Cronulla. This service is accessed by people with medically acquired HIV, particularly those attending the Haemophilia Treatment Centre at Royal Prince Alfred Hospital.

<u>Ankali (Sydney Hospital)</u>

4.34 Ankali is based at the Albion Street Clinic and is funded by the New South Wales Department of Health through Sydney Hospital. Ankali (an aboriginal word meaning friend) is a group of trained volunteers who provide emotional support to people with AIDS. The volunteer and the client are matched by trained social workers or psychologists. Volunteers are involved in ongoing support groups. There are currently 6 part-time staff, 160 volunteers and 130 clients.

4.35 The Committee heard of the valuable contribution made by volunteers in the care of people with HIV and AIDS. People with medically acquired HIV have received support from the Community Support Network and Ankali. The Committee strongly supported the involvement of mainstream volunteer organisations in the care of people with HIV. Such involvement was seen as an effective way to increase general community awareness about HIV and the needs of people with HIV.

4.36 However, the Committee does not see volunteers taking the place of health care professionals involved in the care of people with HIV. The needs for all kinds of support and assistance for all people with HIV will only increase.

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RECOMMENDATION NO. 10

THAT THE FOLLOWING RECOMMENDATIONS FROM THE AIDS BUREAU OF THE NEW SOUTH WALES DEPARTMENT OF HEALTH REPORT <u>PLANNING FOR HIV/AIDS CARE AND TREATMENT SERVICES IN NEW SOUTH WALES 1990-1994</u> BE IMPLEMENTED:

> *"THE AIDS BUREAU, AREAS AND REGIONS AND AIDS SPECIFIC VOLUNTEER AGENCIES SHOULD ENCOURAGE THE INVOLVEMENT OF MAINSTREAM VOLUNTEER AGENCIES IN THE CARE OF PEOPLE WITH AIDS AND THEIR FRIENDS AND FAMILIES. THIS SHOULD BE ACHIEVED THROUGH DIRECT APPROACHES TO SPECIFIC AGENCIES AND THROUGH LIAISON WITH THE VOLUNTEER CENTRE OF NEW SOUTH WALES."*[8]

> *"CSN AND ANKALI SHOULD CONSIDER JOINTLY PROVIDING CONSULTANCY SERVICES AND TRAINING TO NON-AIDS SPECIFIC VOLUNTARY ORGANISATIONS IN BOTH METROPOLITAN AND NON-METROPOLITAN AREAS."*[9]

> *"THE COMMUNITY SUPPORT NETWORK SHOULD EXTEND TRAINING PROGRAMMES FOR VOLUNTEERS TO INCLUDE COVERAGE OF THE NEEDS OF WOMEN, CHILDREN, AND INTRAVENOUS DRUG USING CLIENTS."*[10]

RECOMMENDATION NO. 11

THAT EXTRA RESOURCES BE PROVIDED TO ASSIST WITH THE IMPLEMENTATION OF THE ABOVE RECOMMENDATIONS.

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[8] NSW Department of Health Report (1990). <u>Planning For HIV/AIDS Care and Treatment Services in New South Wales 1990-1994</u>, p.25.

[9] Ibid p.109.

[10] Ibid.

3) MEDICAL SERVICES FOR PEOPLE WITH HIV

4.37 In conjunction with the AIDS Bureau, the New South Wales Department of Health provides medical services for people with HIV/AIDS as described below. These include inpatient and outpatient services, step-down care, respite care, long term care, palliative care, mental health services, home nursing and community health centres. General practitioners also provide care and Medicare meets most of the costs to individual patients.

Medicare

4.38 People with medically acquired HIV are entitled to free medical care under Medicare. Thus, the Commonwealth spends about $31,000 per year on a person with AIDS. This amount is separate to the matched funding for HIV/AIDS.

Inpatient and Outpatient Services

4.39 Inpatient and outpatient services are provided by a number of teaching hospitals. There are six such hospitals in New South Wales, namely Prince Henry Hospital, St. Vincent's Hospital, Royal Prince Alfred Hospital, Royal Newcastle Hospital, Westmead Hospital, and Royal North Shore Hospital. Services for children are provided at Prince of Wales Hospital, Royal Alexandra Hospital For Children, and the Haemophilia Centres at Royal Prince Alfred Hospital and the Mater Hospital in Newcastle.

4.40 The Committee received a lot of evidence to suggest that people with medically acquired HIV do not feel comfortable in AIDS wards and clinics with people from other risk groups:

> "*There is a discomfort for many people with haemophilia and HIV (and their families) in being treated in general AIDS units for either in- or out-patient care. Stress caused by the double life threatening conditions of haemophilia and HIV should not be increased by adding the anxiety of receiving health care in an environment where the person and his family do not feel comfortable*".[11]

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[11] Submission 4. Emphasis In Original.

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RECOMMENDATION NO. 12

THAT, IN PURSUIT OF THE RECOMMENDATIONS REGARDING MAINSTREAMING MADE IN THE AIDS BUREAU OF THE NEW SOUTH WALES DEPARTMENT OF HEALTH REPORT PLANNING FOR HIV/AIDS CARE AND TREATMENT SERVICES IN NEW SOUTH WALES 1990-1994, WHERE POSSIBLE, PEOPLE WITH HIV SHOULD BE ACCOMMODATED IN NON-IDENTIFYING AREAS OF THE HOSPITAL, IN THE WARD MOST APPROPRIATE TO THEIR PRESENTING MEDICAL PROBLEM.

RECOMMENDATION NO. 13

THAT, WHERE POSSIBLE, INPATIENT AND OUTPATIENT SERVICES PROVIDED TO PEOPLE WITH HIV/AIDS BE SENSITIVE TO THE NEEDS OF INDIVIDUAL PATIENTS, TAKING ACCOUNT OF RELEVANT FACTORS, SUCH AS SEX AND AGE.

General Practitioners

4.41 Ongoing patient care is also provided by general practitioners. The Committee heard of many problems encountered in locating health personnel, other than those specialist doctors who deal particularly in HIV medicine, able to deal appropriately with their HIV related problems:

> *"It seems a pity that general practitioners who are interested in this field are not encouraged to participate more in the treatment of their patients --- a situation that would take some pressure off the overcrowded public hospitals, would cut down the need for patients to constantly make long, tiring journeys to public hospitals and would improve doctor/patient relationships."* [12]

4.42 Although the HIV Study Grants Program (see 4.25) and other programmes have been utilised to increase the number of general practitioners familiar with problems associated with HIV, the Committee recognises that more needs to be done in this area, particularly in rural areas, where the range of medical services is limited.

4.43 The AIDS Bureau in its report planning for HIV/AIDS Care and Treatment Services in New South Wales 1990-1994 makes a number of recommendations which encourage greater involvement of general practitioners in the care of people with HIV which the Committee supports.

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[12] Submission 7.

RECOMMENDATION NO. 14

THAT THE AIDS BUREAU OF NEW SOUTH WALES DEPARTMENT OF HEALTH CONTINUE TO IMPLEMENT AND DEVELOP STRATEGIES OUTLINED IN THE AIDS BUREAU REPORT PLANNING FOR HIV/AIDS CARE AND TREATMENT SERVICES IN NEW SOUTH WALES 1990-1994 TO IMPROVE THE LEVEL OF SERVICES PROVIDED TO PEOPLE WITH HIV BY GENERAL PRACTITIONERS.

Step-Down Care

4.44 After a person with AIDS has been treated for an opportunistic infection they may require skilled medical, paramedical (social work, occupational therapy, physiotherapy, dietitians) and nursing care to regain strength and adequate functioning ability. Step-down care is usually provided in facilities adjoining AIDS units, or can be provided in separate facilities.

Respite Care

4.45 Respite care provides relief to carers by taking over care of the person with AIDS for a short period of time. This can be provided:

- in the home by organisations such as Home Care (see below) or the Community Support Network (see above);
- in a day care centre; or
- in an institution such as a palliative care unit (see below). Nursing homes do not currently provide this service for people with HIV as they do for the elderly and disabled.

Long Term Care

4.45 A small number of people with HIV/AIDS require long term nursing home style care. The number will increase as drugs, such as AZT, prolong life. People with medically acquired HIV may be in particular need of long term care as many of them are older than people with non-medically acquired HIV and may therefore have other medical problems for which they require such care.

4.47 The provision of long term care can involve a range of activities, from assistance with activities such as eating and bathing, to skilled medical and nursing care. Nursing homes are the usual providers of such care for the elderly.

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4.48. Up to now, nursing homes, most of which are operated by private organisations or individuals, have been reluctant to accept patients with HIV/AIDS for the following reasons:

- people with HIV/AIDS do not generally qualify to receive the Commonwealth nursing home subsidy. The scheme is designed to provide care for the frail aged;
- training in infection control procedures and facilities for adequate infection control are not always available in nursing homes;
- general community ignorance and prejudice against people with HIV means that many nursing homes are reluctant to accept people with HIV as residents;
- the fluctuating health status of people with AIDS means that they may have to be transferred from nursing home to hospital regularly and this is disruptive to the continuity of their care and to the operation of the nursing home; and
- nursing homes are generally designed to meet the needs of the frail elderly and may not be the most appropriate way of providing long term care to people with HIV.

4.49 The New South Wales Department of Health is currently looking at a number of options in this area:

- utilising existing nursing homes;
- utilising state run nursing homes;
- establishing long term care beds in existing AIDS Units; and
- establishing a separate nursing home-type facility for people with HIV/AIDS, which may be more appropriate to their needs.

4.50 The Committee received evidence from the AIDS Bureau, those involved with the direct care of people with medically acquired HIV, and representatives of the haemophilia community that there is a need for the provision of long term care for people with HIV:

> "*There have been major problems with <u>access to nursing homes</u> for some of our (Haemophilia Foundation of Australia) members in New South Wales.*"

> *"(One particular incident involved a man with haemophilia and HIV, who was in every other respect eligible for nursing home care. He occupied a bed at Royal Prince Alfred Hospital for three years before an appropriate nursing home would admit him. This was despite the best efforts of the RPAH staff team, the Haemophilia Society of New South Wales, the HFA, and representatives of the State and Federal Governments.)"*[13]

RECOMMENDATION NO. 15

THAT THE NEW SOUTH WALES DEPARTMENT OF HEALTH APPROACH THE COMMONWEALTH DEPARTMENT OF HEALTH, HOUSING, AND COMMUNITY SERVICES TO REQUEST CHANGES TO THE ELIGIBILITY CRITERIA FOR THE NURSING HOME SUBSIDY TO INCLUDE PEOPLE WITH HIV.

RECOMMENDATION NO. 16

THAT A SEPARATE NURSING HOME TYPE FACILITY BE ESTABLISHED TO MEET THE PARTICULAR NEEDS OF PEOPLE WITH HIV/AIDS.

Palliative Care

4.51 Palliative care services provide care for people who are dying. This can be provided in the home, with the help of family and friends, a community palliative care team, community nurses, the Community Support Network, Home Care, or in a palliative care unit such as St. Vincent's Sacred Heart Hospice, Eversleigh, Greenwich Hospital, or Calvary Hospital.

4.52 The Committee recognises the benefits, both to the patient and their families and to the health care system, of enabling a person with AIDS to die in their own home if this is their choice and if it is possible.

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[13] Submission 18. Emphasis In Original.

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RECOMMENDATION NO. 17

THAT HOME BASED PALLIATIVE CARE SHOULD BE EXTENDED TO A SEVEN DAY A WEEK, 24 HOUR A DAY ON CALL BASIS. IT IS DESIRABLE THAT ALL NEW SOUTH WALES HEALTH DEPARTMENT AREAS AND REGIONS WORK TOWARD THIS GOAL.

4.53 There are a range of other services provided by the New South Wales Department of Health which include Mental Health Services, Home Nursing Services, and Community Health Centres.

Mental Health Services

4.54 It is estimated that 20% of people with HIV/AIDS will develop neuro-psychiatric abnormalities (due to infection of the brain with HIV or opportunistic infections in the brain). Some will have mild symptoms such as loss of concentration while others will suffer from psychotic episodes or dementia.

4.55 However there is currently no specialist unit to deal with such patients. They have to be placed in mental institutions or dementia wards of hospitals. In the latter the patients are geriatric and in the former, there can be an incapacity to deal with AIDS, whether through ignorance, fear or inappropriate resources. This can result in considerable suffering, the Committee has been told by witnesses. The Committee felt that a range of options is needed to deal with these problems.

RECOMMENDATION NO. 18

THAT THE FOLLOWING RECOMMENDATION, CONTAINED IN THE AIDS BUREAU OF THE NEW SOUTH WALES DEPARTMENT OF HEALTH REPORT PLANNING FOR HIV/AIDS CARE AND TREATMENT SERVICES IN NEW SOUTH WALES 1990-1994, BE SUPPORTED:

> *"PEOPLE WITH AIDS-RELATED NEUROLOGICAL IMPAIRMENT SHOULD BE MANAGED IN THE LEAST RESTRICTIVE ENVIRONMENT POSSIBLE, TAKING INTO ACCOUNT THE LEVEL OF THEIR IMPAIRMENT, AVAILABLE HEALTH AND COMMUNITY RESOURCES AND THE NEED TO ENSURE THE SAFETY OF THE INDIVIDUAL. THE PROVISION OF LONGITUDINAL CARE IN A VARIETY OF COMMUNITY, INSTITUTIONAL AND HOSPITAL SETTINGS, INVOLVING A MULTI-DISCIPLINARY APPROACH IS NEEDED FOR THESE PATIENTS. THIS*

> *SHOULD INCLUDE DAY PROGRAMS, DOMICILIARY CARE, RESPITE CARE, AND ACCESS TO TRANSPORT, NURSING CARE AND APPROPRIATE SUPERVISION. IN ADDITION, AREAS AND REGIONS WILL NEED TO BE ABLE TO PROVIDE SECURE ACCOMMODATION FOR PATIENTS WITH PARTICULARLY SIGNIFICANT LEVELS OF IMPAIRMENT."*

RECOMMENDATION NO. 19

THAT A SPECIAL UNIT BE ESTABLISHED FOR PEOPLE WITH AIDS RELATED NEUROLOGICAL PROBLEMS IN CLOSE PROXIMITY TO AN ALREADY ESTABLISHED HIV/AIDS UNIT SO THAT APPROPRIATE MEDICAL EXPERTISE IS AVAILABLE FOR OTHER AIDS-RELATED PROBLEMS.

Home Nursing Services

4.56 Home nursing is provided by a number of organisations in New South Wales, including local councils, palliative care units (specialised palliative care nurses), the Sydney Home Nursing Service (covering five areas in Sydney) and community health centres. Each service has a designated geographical area, or areas. Some home nursing services have received extra funding to provide care for people with AIDS and have developed a great deal of expertise in caring for people with AIDS. The availability of such services is limited by the level of funds allocated to the nursing service and the number of clients seeking care.

4.57 People with medically acquired HIV, health care professionals and the New South Wales Department of Health see a need for home nursing services available for a greater range of hours to people with HIV:

> *"People with HIV/AIDS require ad hoc 24 hour care. Many people with haemophilia and HIV infection would prefer to spend as much of their remaining days and months as possible in the familiar surroundings of their family home. At present there is no 24 hour 'mobile' health care service designed to provide a comprehensive range of services to these people. It has been my experience that families who wish to care for a loved one with HIV infection at home, without outside support, risk family breakdown as a result of the enormous stresses involved."*[14]

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[14] Submission 47.

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