SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE INQUIRY INTO HEPATITIS C AND BLOOD SUPPLY, SECRETARIAT'S REQUEST FOR ADDITIONAL **INFORMATION, 17 MAY 2004**

1. The Secretariat sought information about the Mark Fitzpatrick Trust (relating to medically acquired HIV). Key aspects of interest to the Secretariat include the legal structure, seed funding, number of recipients, average quantum of payment, how many years it existed, board structure and membership, assistance eligibility criteria and key stakeholders.

On 7 November 1989, the Federal Government "agreed to provide special financial assistance to people with medically-acquired HIV infection and AIDS" (see press release at Attachment A).

This was in addition to Commonwealth-State arrangements established from March 1986 whereby the Commonwealth and the States shared the legal costs and the cost of damages not recoverable through insurance, for awards in cases where AIDS was contracted through the Red Cross Society's blood transfusion services.

Detailed answers to questions raised by the Committee follow:

Establishment, Legal Structure, Board Structure and Membership

The Mark Fitzpatrick Trust (the Trust) was established as a discretionary trust by the Australian Government in early 1990. The purpose of the Trust was to provide special financial assistance to people with medically acquired HIV infection and AIDS. This special assistance did not represent compensation. Beneficiaries of the Trust were required to meet specified eligibility criteria (see below).

The Board of Trustees comprised the following representatives:

- Chairman- The Rt Hon. Sir Ninian Stephen AK GCMG GCVO KBE, Ambassador for the Environment
- The Hon. Dame Margaret Guilfoyle DBE, Former Victorian Senator and Minister in Fraser Government 1975-1983
- Mrs Pamela Shipway, Coordinator, Transfusion Related AIDS Unit, Parramatta Hospital
- Mrs Jennifer Ross AO, Executive Director, Haemophilia Foundation of Australia Inc
- Dr Valerie McPherson, Senior Lecturer in Medicine
- Mr John Baker, Managing Director, Beneficial Finance Corporation (not in later years)

The Australian Taxation Office accepted the Trust as a Public Benevolent Institution (PBI) and as such its earnings were exempt from tax. Payments made by the Trust were exempt from income tax and exempt for the purposes of social security income assessment.

Seed Funding

The Australian Government provided original seed funding of \$13.2 million with a further grant of \$1 million in 1999. The Trust also earned income from investments. The Trust was wound up in May 2001.

Beneficiaries of the Trust received annual payments during the life of the Trust, with a final payment on the death of a beneficiary to assist with funeral and associated costs.

Number of recipients and average quantum of payments

The Trust's final report dated 30 June 2001 identifies total payments from the Trust of \$20.16 million to 423 beneficiaries.

Assistance Eligibility Criteria

Under the Deed of Trust, a beneficiary was a permanent resident of Australia, approved by the Trustees to be a person who:

- had medically acquired HIV or was a dependent, parent or guardian of a person who had medically acquired HIV; or
- was a dependent, parent or guardian of a person who had died from an HIV related illness as a result of medically acquired HIV.

Medically acquired HIV was defined as:

- HIV acquired by a person in the course of medical treatment from the transfusion of infected blood or blood products before 1 May 1985; or
- HIV acquired from the transplantation of infected human tissue, including but not limited to, bone grafts, organ transplants and semen donation before 1 May 1985.

Key Stakeholders

The key stakeholders described in the Deed of Trust are:

- Beneficiaries of the Trust
- The Trustees
- The Commonwealth of Australia ("the Settlor")

2. The Secretariat sought a briefing on the National Hepatitis C Strategy

The National Hepatitis C Strategy 1999-2000 to 2003-2004 was developed in response to the challenges of the epidemic at that time. The primary aims of the Strategy are to reduce the transmission of hepatitis C in Australia and to minimise the personal and social impacts of hepatitis C infection. An overriding principle of the Strategy is to address the needs of people affected with hepatitis C in all contexts.

The *Strategy* is not a funding initiative. The *Strategy* is a comprehensive framework to guide Australia's response to hepatitis C.

Australian Government expenditure on hepatitis C education and prevention initiatives

In the 1999-2000 Federal Budget, the Government allocated \$12.4 million over four years for the Hepatitis C Education and Prevention Budget Initiative. Of the \$12.4 million, \$6.6 million was allocated to State and Territory Governments to develop and implement hepatitis C education and prevention programs. The remaining \$5.8 million was allocated to national hepatitis C education and prevention activities administered by the Department of Health and Ageing.

State and Territory funding allocation for the 1999-2000 Hepatitis C Education and Prevention Initiative.

Period	NSW (\$)	Vic (\$)	Qid (\$)	(\$)	SA (\$)	Tas (\$)	ACT (\$)	(\$)	Total (\$)
2000-01	\$589.378	\$443,820	\$346,913	\$221,697	\$186,635	\$84,772	\$75,753	\$67,032	\$2,016,000
2001-02	\$599,006	\$450,256	\$355,062	\$226,078	\$188,498	\$85,109	\$76,318	\$67,673	\$2,048,000
2002-03	\$609,589	\$457,374	\$363,831	\$230,822	\$190,580	\$85,502	\$76,937	\$68,365	\$2,083,000
Total	\$1,860,473	\$1,413,950	\$1,128,306	\$741,097	\$628,213	\$317,883	\$291,508	\$265,570	\$6,647,000

In the 2003-04 Federal Budget, the Government allocated \$15.9 million over four years for the continuation of the Hepatitis C Education and Prevention Initiative. Of this allocation, \$8.8 million will go to State and Territory Governments to develop and implement hepatitis C education and prevention programs. The remaining \$7.1 million will be allocated to national activities to be administered by the Department of Health and Ageing.

The State and Territory funding allocation for the 2003-04 Hepatitis C Education and Prevention Initiative

Period	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
	(\$)	(\$)	(\$)	(\$)	(\$)	(\$)	(\$)	(\$)	(\$)
2003-04	625,300	459,100	385,000	240,900	183,300	86,600	75,600	75,300	2,131,100
2004-05	640,000	468,900	396,200	247,000	186,000	87,300	76,400	76,300	2,178,100
2005-06	655,000	478,800	407,700	253,200	188,700	87,900	77,100	77,300	2,225,700
2006-07	670,300	489,000	419,600	259,600	191,500	88,500	77,900	78,400	2,274,800
Total	2,590,600	1,895,800	1,608,500	1,000,700	749,500	350,300	307,00	307,300	8,809,700

Help for people with medically-acquired HIV

The Federal Government has agreed to provide special financial assistance to people with medically-acquired HIV infection and AIDS.

Minister for Community Services and Health, Neal Blewett, said that the Government had recognised the particular case of individuals who had become infected with HIV as a consequence of medical procedures, and had extended financial assistance to them to assist in the costs associated with their illness.

"The Government will provide a seeding grant of \$13.2 million to establish a Trust Fund to provide payments to eligible people. The Trust will invest and manage the seeding grant to generate the funds necessary to meet the needs of people eligible for assistance," he said.

Dr Blewett said that in 1985, the Commonwealth and State Governments had moved jointly to screen all blood donations and to require self exclusion of individuals at risk for AIDS from donating blood. As a consequence, the blood supply and blood products had been protected since this time and were now safe.

"To be eligible for assistance from the Trust, individuals must show that they have become infected as a consequence of medical procedures prior to the protection of the blood supply and blood products.

"Those eligible include people with haemophilia and people infected as a result of blood transfusions or tissue/organ transplants.

"The Government intends to establish a Board of Trustees, which will include representatives of affected groups, to administer the Trust," he said.

Dr Blewett said that should recipients of assistance from the Trust be successful in claims for damages through the courts, they would be required to repay any assistance to the Trust.

"The provision of special assistance to this group of people recognises their particular hardships and needs resulting from HIV infection on top of existing medical conditions," he said.

Canberra: November 7 1989