

*Embargo: Involve HIV Positive People in AIDS Decisions Urges Kirby*

Saturday 22 October 1994.

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**EMBARGO: Saturday 22 October 1994, 9.00 a.m.**

## **INVOLVE HIV POSITIVE PEOPLE IN AIDS DECISIONS URGES KIRBY**

People living with the HIV virus should "act positively" to ensure that their interests and concerns are taken fully into account by governments and society in responding to the AIDS epidemic.

This was urged today by Justice Michael Kirby. He was addressing the Fifth National Conference of People with HIV/AIDS (PWHAs) held in Sydney.

Justice Kirby is the President of the New South Wales Court of Appeal. He formerly held a position as a member of the World Health Organization's Global Commission on AIDS and was a trustee of the AIDS Trust of Australia.

Justice Kirby said that Australia had enjoyed greater success than most countries in the battle against the spread of HIV/AIDS. However, he warned against complacency:-

*"There is a risk that all the Australian talk about how well we have done will breed a feeling of complacency. It could spread the myth that the epidemic is over for Australians and that the need for extreme vigilance has passed. It is vital that all people realise the toll of this epidemic."*

But Justice Kirby said that it was also important that people with HIV/AIDS (PWHAs) should take active steps to insist upon the protection of their own legal and other rights and the consideration of their special interests in the design of strategies to respond to AIDS.

*"Upon the devastating news of seroconversion, there is an understandable tendency of some PWHAs to resort to denial or to retreat into a private world. But it is vital that PWHAs act positively, particularly when they are well, to protect themselves and to stand up for the rights of others in the same position."*

- *PWHAs must be more closely involved in government decision-making about the response to the AIDS epidemic. They, above all, know what HIV/AIDS means on the human level in daily life. In short, they must empower themselves and protect their own interests;*
- *PWHAs must be fully involved in the design of clinical trials involving the testing of new drugs. Consultation is not enough. Involvement at every level is vital;*

- PWHAs must insist that educational messages and strategies to combat HIV/AIDS in our society are not confined to the uninfected – important as that educational strategy is. PWHAs must get a fair slice of the educational spending. They must have a say in posters and media messages, which should not just write them off as "lost causes". They need to be educated about the risks of infection with STDs, about new drugs and their legal rights;
- PWHAs and their supporters must also raise their voices to ensure reform of the law and administrative policies in areas of special concern to them – such as the law of insurance, superannuation, de facto relationships, euthanasia, etc. The report of the Anti-Discrimination Board of New South Wales (1992): Discrimination – The Other Epidemic; Report of the Inquiry into HIV and AIDS Related Discrimination, showed the need for further law reform. Some of the recommendations of the report had been implemented. This was laudable. But most had not. PWHAs should lobby hard for Federal and State laws, including in States which have not done as much as New South Wales has done. In this age of new constitutional rights and constitutional implications, they should not overlook the possibility of arguing that the Australian Constitution itself, s 117, forbids unwarranted discrimination against PWHAs;
- PWHAs must take an active role in creating guidelines for the media in the presentation of HIV/AIDS-related stories so that a more realistic, positive and considered image of PWHAs is made available to the public at large;
- PWHAs must be encouraged to speak out against discrimination and not accept it as inevitable, especially in the health care system where enforced unnecessary HIV antibody testing and breaches of confidentiality are still a constant threat; and
- PWHAs must inform themselves and others of the legal, social security, housing and other benefits and relief available that make everyday living with HIV/AIDS easier." Justice Kirby said.

Justice Kirby also stated that it was important for PWHAs to involve in their activities women, ethnic and other minorities living with HIV/AIDS:-

"Women have often been overlooked in Australian campaigns about HIV/AIDS. Yet in the United States the epidemic is now increasingly falling upon women. In developing countries women have always been in the front line. PWHAs in rural Australia often need special help to combat isolation. There is a good outreach to vulnerable Asian-Australians. Indeed, Asian Australians, including those living with HIV/AIDS, should take a lead in the Asia/Pacific region to teach the lessons we have learnt in Australia. I can think of few more vital messages that we could bring to the countries of our region with their huge populations. But I do not underestimate the cultural

*impediments to exporting Australia's candour and radical policies to socially conservative Asian and Pacific countries."* Justice Kirby said.

Justice Kirby concluded by saying that Australia had done better than most developed societies in the strategies to reduce the toll of AIDS. But, he said, the biggest challenges of the epidemic lay ahead. On present trends, the toll of the epidemic would increase at the end of the decade. This would put enormous pressures on health services, health care workers, families and especially PWHAs.

*"PWHAs constantly make the point that they do not seek charity. They demand respect for their dignity as human beings, regard for their fair legal rights, a removal of unwarranted discrimination, support for their careers and for the medical science which one day will overcome HIV/AIDS."* Justice Kirby concluded.

NOTE ON ADDRESS:

The above address will be delivered at 9.00 a.m. or Saturday 22 October 1994 at the Oxford Koala Hotel. For contact with the organisers of the PWA conference, telephone Mr Russell Westacott (02) 231.2111. For Justice Kirby telephone (02) 230.8202. He will be at the hotel from 8.30 a.m.

Other speakers at the Conference will include David Barr, Treatments Officer, Gay Men's Health Crisis, New York; Eric Sawyer, Global Network of People with HIV/AIDS, New York; Ross Duffin, Treatments Officer, AIDS Council of New South Wales; and Martine Cornlisse, Netherlands Euthanasia Society.