

# B. HOPE

## THE NEW COMMUNITY

The Council has grown, changing to fit the different needs of its community. That community has been redefined along the way. In the original organisational structure of the Council, the board was comprised of employees, health professionals and 'community' members.

An ongoing process of reflection for WAAC is the definition of its community. Whilst HIV/AIDS remains a significant health issue for the gay/bisexual men, rising numbers of infections in heterosexual men and women, frequently among Indigenous people, in the last five years is directing changes in the service.

*New diagnoses are about 50% gay men, 45% heterosexual men and women... We have, as a proportion of our population, more HIV+ Indigenous people in Western Australia than the other states. My aim for the agency is to be responsive and we currently have two Aboriginal staff members. It seems so much of Aboriginal culture is the antithesis of how the medical or the health system works in Australia or the world. I will give you an example that has been challenging. Aboriginal people have a culture of sharing. When we're talking about the needle exchange – how do you talk about the non-sharing of needles when there is such a strong culture of sharing? We have got to find a way of working through those differences.*

**TRISH LANGDON, 2005**

The future of WAAC will inevitably include collaboration to work on AIDS as a global issue. With steady rises in infection over the past three years the council now faces the challenge of constantly keeping the message of safe sex and safe injecting fresh for the generation which came of age in the panic of the eighties, whilst bringing home the realities of life with HIV to a generation which has not seen frightening images of people in the final stages of AIDS in the news.

**MARK REID, 2005**

*'So as a worldwide community we have got to embrace the fact that we can work together to change it and it is; it's about humanity. It's about us caring for each other and that we are in a global world now. It's not just "Perth, Western Australia". Everybody is too connected. We're not insular any more. We're connected through the internet and through news and through all of those things so we know what's going on around the world everywhere and so we have got to grab that and we have got to care about everybody and not just ourselves.'*

## NEW AND IMPROVED SAFE SEX

WAAC faces the constant challenge of re-packaging the safe sex message in new ways to maintain the culture of safe sex which it established in Perth. This is very difficult when the people the message is targeted at have heard about safe sex for so long the messages barely register anymore.

**MARK REID, 2005**

*'How do you, after 20 years of health messages, come up with something fresh that is going to engage a population that is over it and that's what they are; they're over it. They're over HIV/AIDS in lots of ways. We're not reminded every day of people living with the virus and I remember being in Sydney 12, 13 years ago and walking down Oxford Street and seeing people with Karposi's lesions walking down the street, people being pushed down the street in wheelchairs. You don't see that any more because in a lot of ways the drugs allow us to live good lives and then when people do get sick they generally tend to go into hospital and you don't see*

*them... There is no room for complacency because if you become complacent we will see an epidemic go through the roof again," and we can't afford for that to happen. Yes, there are drugs available but, yes, people are still dying and the reality is people are still dying and they will continue to die because treatments can only be at the moment effective for so long. And then what happens? When the treatments stop becoming effective you start to get sick and you die and that's still a reality.'*

Current education in schools and the wider community places HIV and AIDS amongst a plethora of other health and safety dangers. The threat and fear of AIDS has certainly diminished in the last ten years.

## BEING POSITIVE IN AUSTRALIA

The experiences of being HIV positive in Australia have changed dramatically since the 1980s. Positive people are living long and healthy lives with and without treatments. The changing public profile of AIDS as one of many significant illnesses one might have but live with for a long time, has removed some of the fear that has motivated people to carry on with safe practices.

**MARK REID, 2005**

*'The scary thing is that after 20 years of the epidemic we have become complacent. People are starting to take risks again and seeing it as a chronic, manageable illness - 'I'll just take some pills and I'll be all right.' They don't understand that when you're on treatments, you're on treatments forever and they do have side effects that you have to deal with.'*

The Council now focuses on providing holistic health services, counselling and financial assistance to HIV positive people. The emerging issues for Australians have been relationships, family, aging and mental health.

**SUZANNE CALVER, 2005**

*'Aging and mental health are the issues facing our clients now. What happens when a nursing home refuses entry to a long term HIV positive person?'*

Balancing peoples need for confidentiality with ease of access is an ongoing issue for the Council. The relevance and accessibility of the name AIDS Council is one possible concern for newly diagnosed people.

**HISTORY FORUM, 2005**

*'Most people coming in are HIV positive but there is counselling and everything else. May be it is time to change the name, if the people you are dealing with are not necessarily people with AIDS. It is generally accepted that they are. There is the other side, that there is an organisation which is not afraid to come out and acknowledge it'.*

# THE GLOBAL PANDEMIC

HIV and AIDS have always been global issues, and communities around the world have formed connections over the virus. The vastly different opportunities for preventing and treating HIV/AIDS in different communities around the world have become more and more obvious in the last five years.

**TRISH LANGDON, 2005**

*'I was in Princess Margaret Hospital one day and I saw this HIV+ Aboriginal child from a remote part of WA and I remember thinking ' How does the same disease that kills Rudolf Nureyev and Liberace end up in a remote Aboriginal community?'*

HIV positive people in Australia are aware of the benefits they receive from Australia's advanced health care system. Many HIV positive people are motivated to extend that quality of care to the developing world where HIV diagnoses are increasing and treatments are not available.



**CIPRI MARTINEZ, 2005**

*'I feel an enormous obligation to my international brothers and sisters who have no access to drugs or who can't afford them. I know what it was like to not have treatments and be very ill and then what a difference the treatments made – they turned my life around. For other people not to have those opportunities just because they can't pay for them – is awful. In comparison we are 'sitting pretty' and so that's where the national focus is*

CIPRI MARTINEZ

*now – trying to solve that problem. And you don't have to go all the way to Africa – you just have to look north!' That's why NAPWA Australia (National Association for People Living with HIV/AIDS) works in Papua New Guinea to help develop the community representative organisation for people living with HIV/AIDS – Igat Hope (the name means 'there is hope' in Tok Pisin)'.*

People in Australia sometimes talk about HIV and AIDS as an 'invisible epidemic' – perhaps this is true of Australia where health care is provided, but the devastating effects of AIDS can be seen very clearly in other parts of the world.

**MARK REID, 2005**

*'It's not a visible epidemic any more in this country. It certainly is in the developing countries. It's very visible. It's still right out there because it's still killing millions of people... we've got to stop being so insular. We have got to see this is a global health epidemic that we all need to embrace and that we all need to find answers for. We need to ensure the drug companies get the generic drugs into the developing countries – that they supply them through their billions of dollars of profits that they make every year and get them out there to enable people to have good lives. But first of all we've got to go out there and we've got to make sure they've got running water and roofs over their heads and food to put on the table every night'.*

Staying motivated about global change is difficult in the face of powerful political, social and religious obstacles. In particular, the denial of condoms as acceptable practice for Catholics poses a large problem for Africa.

**MARK REID, 2005**

*'We're going to battle in places like Africa where Catholicism is huge. Where some man in his sixties, pampered by subordinates, tells them that it's God's will that they don't use condoms. 47 million people are infected with HIV in the world and most of those are in the developing countries where they're not using condoms. It hasn't moved and while we have – whilst we have just had the change in the Vatican where you have got somebody who is, I think, even more conservative than the previous bloke, we're going to battle in places like Africa where Catholicism is huge. We're really going to battle with getting that notion of condoms and what those risks are associated with not using them. We're just going to struggle. It's going to be an uphill battle.*

## COMMUNITY CONTEXT

Staff and community members are constantly looking to the future, preparing for changes and reassessing the role of the Council as the trends in HIV and AIDS change. As AIDS is preventable and the virus is contracted largely through behaviours which continue to be controversial, the sense of responsibility and blame for new infections is a strong motivator.

### HISTORY FORUM, 2005

*'WAAC is blamed for not doing enough, not spending the money in the right place. In the past it has been one of our significant problems. The Cancer Council does not get blamed when someone gets diagnosed with cancer'.*

Increasingly it seems clear that HIV/AIDS in WA cannot be considered solely in the local context, but as part of a global issue.

### MARK REID, 2005

*'I think until we can control what is happening in the developing world AIDS will stay being one of the most devastating health problems in the world I think we have got unless we can reaffirm with our community in Australia that they really still need to be taking care, we will continue to see increases in infections and we don't want – you know, as somebody who has worked in the area for a long time, no, I don't want to see that happen but it's very hard sometimes to know what to do to make those changes happen'.*



# REMEMBRANCE, REFLECTION, CELEBRATION

The WA community continues to respond to rising numbers of HIV diagnoses across the state. Weighing up the needs and priorities there will be difficult decision making ahead. The support of government authorities, organisations and the diverse community associated with the Council will be paramount.

**SALLY ROWELL, 2006**

*'I hope one day there is no need for WAAC – that HIV/AIDS has a cure – until that time I hope that WAAC continues to grow and assist people to improve not only their quality of life but also their desire to engage in the world. That we maintain the integrity that exists and are able to look back and feel that we did make a difference.'*

At the end of 2005 WAAC community members took time to look back at the difference they have made, celebrating their 20th Anniversary. The occasion was marked by a historical and art exhibition curated by Jo Darbyshire. Art works were commissioned and members of the community gathered to reflect on the history of HIV and AIDS in Western Australia.

Amongst the struggle and the deaths and the difficult memories, there were some moments for joy, for pride and for celebration.

It is the spirit of celebration that brings the WAAC community together. Perhaps it is the difficult experiences of the past which make the people in this organisation so willing to celebrate themselves and their community.

**SALLY ROWELL, 2006**

*'Ultimately though there have been so many times that have brought me to tears either through sadness or through laughter.'*

Research into the human immunodeficiency virus continues around the world, including Australia, with new information coming to light every year. Meanwhile Australian AIDS councils look to the developing world with a sense of responsibility and shared purpose. Exchange and cooperation between Australia and other countries has fostered refreshing ideas about prevention strategies and services for positive people.

In Perth, whilst HIV and AIDS are no longer the focus of public panic, a growing awareness of the global impact of AIDS has motivated some creative projects led by Western Australians to help community centres in Africa and South East Asia.

The early story of AIDS was represented with the fairytale villains, victims and heroes, but present perceptions about the illness are far more diverse, reflecting many varied understandings and experiences of the virus. There are no victims and no villains, and the heroes we imagine are here everyday – the staff, the volunteers, the positive people and the community of the WA AIDS Council.



**CATHERINE SWIFT, 2006**

*'My first Pride parade in 2005 was one of the funniest nights of my life... riding on the back of the truck with thousands of people cheering was the most amazing feeling – I couldn't stop smiling and laughing the whole*

CATHERINE SWIFT

*parade. Before the parade, as we were walking around some drag queens were checking us out and thought I was a drag queen too – I still haven't decided if that's a good or a bad thing!'*

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## DEDICATION

We dedicate this book to the memory of those people who lost their lives as a result of AIDS over the past 21 years, those who are living with HIV and all those people who have contributed to Western Australia's response to the HIV/AIDS epidemic.



## THANK YOU TO:

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