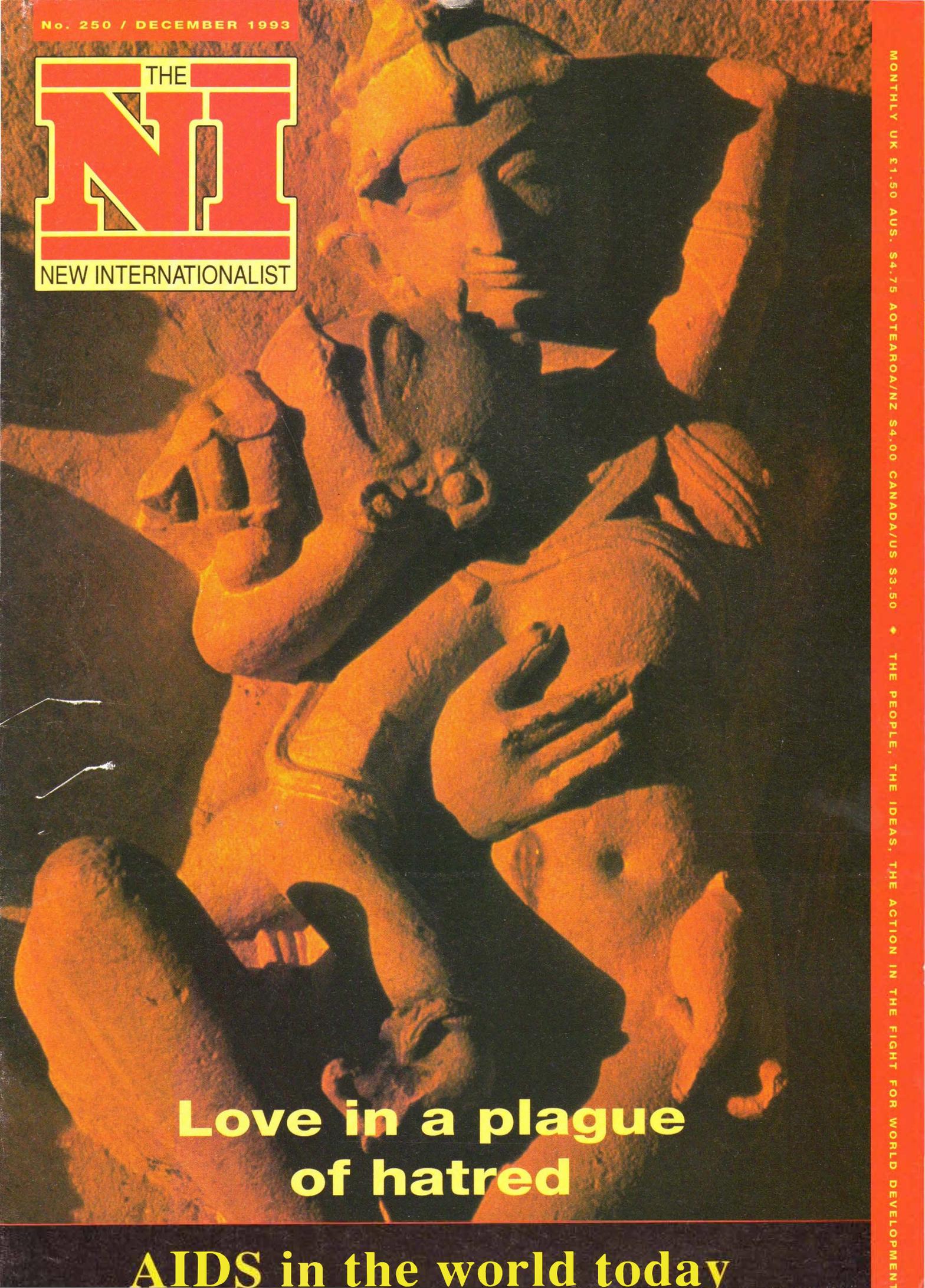
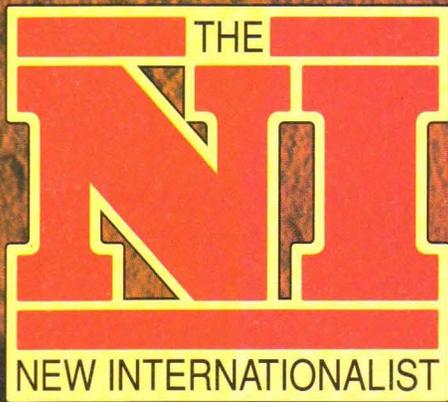


No. 250 / DECEMBER 1993



**Love in a plague  
of hatred**

**AIDS in the world today**

MONTHLY UK £1.50 AUS. \$4.75 AOTEAROA/NZ \$4.00 CANADA/US \$3.50 ♦ THE PEOPLE, THE IDEAS, THE ACTION IN THE FIGHT FOR WORLD DEVELOPMENT

C O N T E N T S



**Love in a plague of hatred** 4  
*Aids is in its second decade. Pratap Rughani looks at how – and whether – we are rising to its global challenge.*

**Sex, lies and a certain virus** 8  
*Sue Branford finds out what Brazilian women do when they discover that the virus never lies.*

**Aids myths and theories** 10  
*Bullshit under the microscope.*

**Bringing it home** 11  
*From Zimbabwe, Dr Sunanda Ray tells a story of medicine and morality.*

**The ache of sensuality** 14  
*An intimate portrait of life and death with Aids by Edmund White.*

**Children and mothers** 16  
*Personal stories from the frontline.*

**Hiv and Aids – THE FACTS** 18  
*From body to body politic.*

**When living is a luxury** 20  
*What experts pronounce from their luxury hotels has little to do with reality on the ground in Africa. Maggie Black reports.*

**Simply... Health and humanity** 22  
*A global look at how countries are responding to the HIV/Aids crisis.*

**Bigots take the temple** 24  
*Moralists are encouraging HIV infection according to Ashok Row Kavi and Dinyar Godrej.*

**Positive lives** 26  
*Life with HIV and Aids.*

**Letters** 2  
**Letter from Lagos** 3  
**Updates** 29  
**Reviews:** including Victor Jara classic 32  
**Curiosities** 34  
**Endpiece:** by Luis Sepúlveda 35  
**Country profile:** Guatemala 36

FRONT COVER PHOTOGRAPH: KHAJURHAO TEMPLE BY RAGHU RAI / MAGNUM. MAGAZINE DESIGNED BY CLAIRE PALMER.

THIS MONTH'S THEME

# Aids and HIV

FROM THIS MONTH'S EDITOR

**S**OME people say that once you've been diagnosed the challenge makes life more vital, better even. On other days the same lips speak of devastation – a holocaust in which lovers and friends are lost, children are orphaned and the future is uncertain.

There are at least two different languages about HIV and Aids, public and private. For journalists Aids makes good copy. But editors have their own agenda when turning lives into news. Too often, when reporting HIV, journalists generate panic, then scapegoats. Having built a house of fear they discover a 'plague that never was'.

They have a flirtatious fascination for the virus, almost an obsession with the pandemic of HIV and Aids, mixing more cocktails of sex and death. In truth both are part of any narrative. They are part of this magazine too. So what am I doing adding to the pulp?

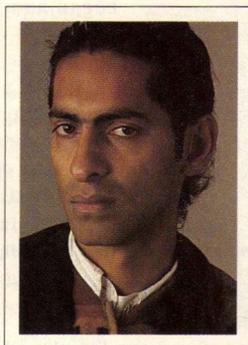
I think there are other stories that don't get heard; perspectives that don't turn patients into deviants.

I didn't go looking for HIV or Aids. Friends had it in their blood. I wanted to produce a magazine that comes more directly from the experiences and priorities of people living with HIV and Aids. It strikes me that their frequent emphasis on grassroots partnership and social change parallels the forces that are tackling North-South inequality.

Responding to HIV and Aids, endemic in North and South, brings the two together.

I wasn't prepared for HIV, just as no parent prepares to bury a child. As Adam Mars-Jones says, 'The virus has a narrative of its own, a story it wants to tell, which is in danger of taking over'. My 'narrative' is the need to believe that those who escaped the virus can enhance the work of so many who have not. I guess it's my way of holding on to friends who, of necessity, learned to let go before I could.

This month, World Aids Day is a chance to remember, to celebrate, to contribute. Part of me can't resist an inward smile at this year's slogan: 'Time To Act'. After many years it continues to be Time To Act. This year, let's take the time.

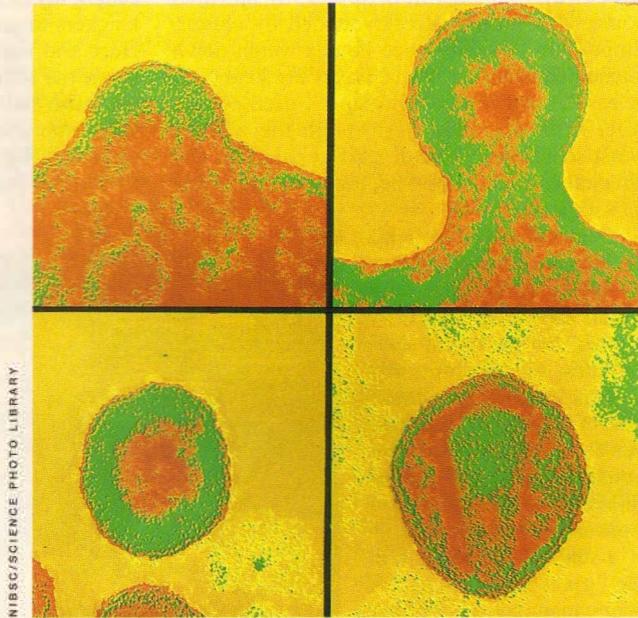


JANE MANN

*Pratap Rughani*

*Pratap Rughani  
 for the New Internationalist Co-operative*

# Love in a plague of hatred



NIBSC/SCIENCE PHOTO LIBRARY

*As the Aids epidemic enters its second decade, Pratap Rughani examines how we are facing up to its challenge.*

**F**LUORESCENT light glinted off their shiny jackets. Their wolf-whistles didn't seem particularly threatening. But still my stomach tensed and my hand slipped out of hers.

'The men's lager-laughter died when they saw what kind of women we were. Fear shrouded my anger as the jauntiest of them swung across the road and blocked our way.

"Don't touch them. You'll get Aids," shouted his friend.

'I didn't tell him that you can't get HIV from touching, and that next to celibacy, lesbian sex is about the safest. We would be more at risk from these straight guys

than the other way around.

'By now, Fawziah, my lover, was wheezing. Then there was a muffled wail as she loosed a cascade of projectile vomit at their Wrangler jeans. As social comment it was perfect, if inflammatory. I grabbed her hand and ran.'

A friend's recent experience shows the power and persistence of the 'gay plague' view of Aids. Even today, despite all we know, homophobia remains in many societies the key way in which HIV and Aids are rationalized.

Add prostitutes and injecting drug users to the list of the first people to die of Aids-related diseases in the North and you have a godsend for Right-wing moralists, unable

to resist displaying their morality by condemning those 'foundering in a cesspit of their own making'.<sup>1</sup>

When haemophiliacs began contracting Human Immunodeficiency Virus<sup>2</sup> (HIV), bigots were forced to pause. They were unused to preaching about the 'unnaturalness' or the 'perversion' of haemophilia. Their solution was a great sleight of hand. Suddenly we had the 'innocent victims of Aids' – thus casting the rest as somehow guilty. The sick were criminalized according to how they contracted the virus.

As so often in the cultural history of disease the answer was to turn disease into 'plague', segregate the dying and bring down the shutters.<sup>3</sup> This obsession with



MIKE GOLDWATER / NETWORK

(Opposite) Birth of a virus: HIV first appears as a bump on the cell surface. Then it 'buds' from the cell and is released into the bloodstream; (above) In memoriam... Ugandan villagers tell their story as part of an Aids awareness campaign.

manufacturing 'high-risk groups' rather than focusing on high-risk behaviour may sound like a semantic nicety. But it led to a social disaster because it made most people think 'I don't belong to this group so HIV's got nothing to do with me'. Others were frightened and isolated – a common experience across the world.

Meanwhile the climate of righteousness and condemnation hampered the work of health educators who were trying to get the message across to all of us that if we have unprotected sex – sex where there is exchange of semen or vaginal fluid or blood – we may be putting ourselves and our partners at risk.

Connected as it is to such potent taboo areas as sex and death, it is not surprising that HIV should have inspired fear. The sudden appearance of a mystery virus with such devastating effects had to be rationalized and finding scapegoats was the easiest way to do it.

#### A known quantity

In fact HIV is not such a mystery. We know a lot about it. It's a virus not a bacterium. It works by depleting the immune system until someone is said to have Acquired Immune Deficiency Syndrome. A syndrome cannot kill, nor does HIV, but it opens the door to so-called opportunistic

infections. Diseases normally kept at bay by a healthy immune system now have the chance to flourish. There is no cure. But nor is there for any virus – including the common cold. So any meaningful strategy for treatment must be designed for a long-term struggle, sustained to control the advance of opportunistic infection. Over a varying period – on average 10 years from infection – the overwhelming experience of HIV is that it leads to Aids and death. There is no set pattern for this and quality of life varies hugely. The virus is not contagious. It is both fragile and quite hard to contract, once we know the simple ways of reducing risk. It can't survive outside the body so no one is at risk from casual contact, like shaking hands or from toilet seats. And unlike syphilis it can't pass through a membrane so using condoms is a good protection against transmission.

The World Health Organization estimates that at least 13 million people have HIV today. The scale of the epidemic in Africa is often discussed. It is less well known that South Asia's rate of HIV infection is set to increase exponentially and outstrip Africa's within three years. Yet there are other global pandemics which account for more deaths than Aids-related diseases. Deaths from tuberculosis, malaria, cholera and diarrhoea far outstrip those

linked to Aids. This may suggest that we are paying too much attention to HIV. But it is impossible to separate Aids from other diseases. The path from HIV to Aids makes this clear as HIV prepares the ground for further infection. For example the recent increase in tuberculosis is linked directly in many places to HIV.

Rather than just concentrating on current figures we should also be looking at projections for the future. The World Health Organization predicts that, on current trends, 40 million people will be infected by the end of the century. Different estimates put the figure at up to 110 million.

Even if some of the rhetoric is alarmist, we should recognize that HIV and Aids threaten to reverse recent improvements in health and life expectancy in several developing countries. The World Bank for example, suggests that life expectancy in sub-Saharan Africa could fall from the projected 62 years to 47 by the year 2000.

Many communities face a death toll that has wiped out a whole generation. While most diseases pick off the weakest among the very young and old, HIV strikes the sexually active. This removes people at an age when they usually carry the greatest burden of work and care for other generations. Already some communities are into the



The new crucifixion; lesbian and gay activists argue that HIV is being used to justify homophobia.

second decade of deaths from Aids-related diseases. Many villages in Uganda, Rwanda and Zimbabwe function with grandparents and grandchildren only.

### Mirror to injustice

HIV and Aids have been described as 'misery-seeking missiles', thriving where lack of health care conspires to make people more vulnerable. In the South, as in deprived areas of the North, HIV risk is exacerbated by poverty, poor education, bad housing, malnutrition, lack of clean water and sanitation.

For people like Rani Deva, a village worker in Rajasthan, India, HIV only makes sense if it becomes a tangible risk in her life – a risk that is more immediate than that of getting cholera or typhoid from unclean water. It is unrealistic to expect her to think about protecting herself and her family from HIV so that they do not fall ill some time in the future if she does not have the basic things she needs today. In this sense getting clean water may be more effective in empowering people to care for their health than giving them condoms.

Poverty increases vulnerability to HIV in the North too. HIV holds up a mirror to social injustice. In the US women of colour are the fastest growing HIV-positive group.<sup>4</sup> Once diagnosed they die five to six times more rapidly than men. This also suggests that symptoms in women are not being read early enough. And it implies that Aids education isn't getting through to different communities equally. Prevention and primary health care must go together.

Once diagnosed, however, people have to find ways of continuing. In the early days of the epidemic many people with HIV, their friends and acquaintances started to organize. They were galvanized by bereavement and the knowledge that lifetimes are telescoped by HIV – decades into years. Armed with dignity, compassion and fury at government indifference a small group of committed humanitarians worked for a vision of community based on providing health care and support where needed.

People continuing with high-risk behaviour – like injecting drug users who share needles and syringes – began to get precise information explaining how they may be putting themselves at risk. In Edinburgh for example, stopping HIV became, for the first time, more important than criticizing drug users. Needle exchanges and other facilities were established.

Gradually the obituary columns replaced euphemisms like 'rare blood cancer' or 'long illness' with that four letter word – Aids. The courage it took and continues to take to be open about HIV has been the most powerful contribution to counteracting stigma.

In the worst-hit areas of Africa, many are forced to think up drastic changes to survive. New crop strains that are less labour-intensive are being introduced in areas where most adult farmers are dead or dying. Children's education is also being restructured to enable them to carry out the adult work and caring responsibilities thrust upon them by the epidemic.

In diverse ways HIV has set a political agenda across the world. For Ugandan feminists, part of fighting Aids involved overturning the patriarchy of inheritance law. As the pandemic advanced, many women who lost their husbands – often after being infected by them – were then faced with their husband's family attempting to 'repossess' the home and children. Feminist lawyers campaigned and for the first time managed to secure inheritance rights for widows.

Aids has also made the need for equality in relationships more urgent. For safer sex to work individuals have to be unafraid to initiate it. This may involve changing the balance of power within relationships – essential if condoms are to make it out of their wrappers without starting a domestic war. When this Pandora's box opens,

women often start talking about 'safer relationships' rather than just safer sex.

There are other positive changes. Out of the shadows of HIV, some gay groups have created a chance to organize and be open about their sexuality. A significant achievement for gay men is reclaiming freedom to express sexuality as a basic right. As the World Health Organization now recognizes, only in this climate can HIV prevention be carried out effectively. Otherwise the risk of transmission increases as gay men are driven underground. Through the experience of HIV, homosexuality was made legal in countries like Russia. They accepted for the first time that men have sex with men whether they identify themselves as gay or not.

Other advances include a gradual shift in doctor-patient relationships. In the North doctors are joined, perhaps for the first time, by an articulate and active patient population insisting on fuller knowledge and a say in the treatment of their illnesses.

Though encouraging, all of these changes are hard-won. Many developments are piecemeal and their successes may prove to be provisional. What they share is a reaction to HIV that recognizes the essential link between health and human rights.

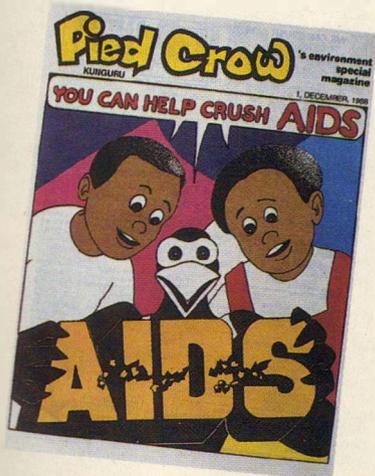
It's a link that we cannot ignore. This is a critical moment in the story of Aids. Some 80 per cent of HIV-positive people are in the South and are often unequipped to respond to this crisis. Some countries like Burma and the US under Reagan and Bush have tried to ignore Aids. Others, like Uganda, have shown the political will to

deal humanely with Aids but lack the resources. Often, cash-strapped Southern governments can't afford to start basic prevention measures. People in many poor countries continue to contract HIV through blood products when a small transfer of resources from North to South could ensure that blood is properly screened. As African researchers Sanders and Sambo argue: 'Economic recession and structural adjustment policies further aggravate the transmission, spread and control of HIV infection in Africa... increasing the population at risk through urban migration, poverty, women's powerlessness and prostitution, and indirectly through a decrease in health care provision.'

Because HIV threatens North and South at roughly the same time it receives more research attention than exclusively 'Southern' diseases like malaria. One worry is that as we learn to ameliorate some of the effects of Aids and HIV, they might be regarded as a condition of the South in the same way that our governments behave as though 'poverty' were an immutable state of being, rather than the result of particular economic and social forces, some of which we help to shape.

**Lessons from Aids**

Responding to HIV and Aids is a litmus test of our values. While the health and medicine industry makes vast profits, hope is only available to those who can pay the price. A short course of the anti-HIV drug AZT for example exceeds the annual earnings of most ordinary people in the South. Meanwhile Burroughs Wellcome made \$100 million profit from AZT in just one year and didn't even incur the research and development costs since AZT has been synthesized before.<sup>6</sup> Why is it that this company, which holds the licence for AZT, have devised a pricing structure that makes it unavailable in places where most patients are?



As yet, too few people make an imaginative leap to see the future of our health reflected in the health of others, whether we naturally identify with those 'other' communities or not. The Aids activist Jon Gates, who died last year, gave his vision to the Canadian Aids Society. He said that governments, drug companies and development agencies should 'delay the release of any new vaccines or a cure for Aids until... the drug or vaccine be affordable, accessible and available world-wide.'

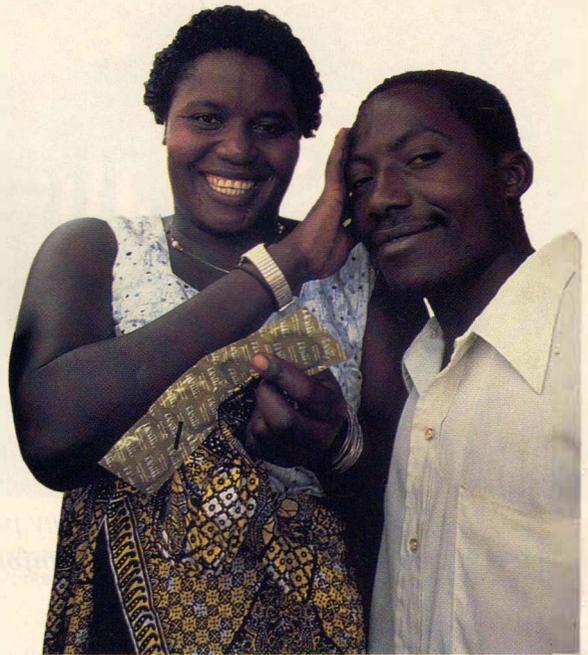
Gates was willing to refuse drugs if that helped avoid what he felt to be a worse nightmare than his own suffering – the nightmare that Aids (like leprosy) would be wiped out in the North yet allowed to flourish in the South.

Double standards also produce some curious twists in medical ethics. Professor Ron Desrosiers, a leading vaccine researcher at Harvard University suggests that his proposals for experimental HIV vaccines should be tested on people in the Third World, despite the risk that those vaccinated might contract HIV. Desrosiers argues that 'a few thousand lives lost now is preferable to the death toll ahead'. It seems that what would be unthinkable in the North is given full consideration when the risk would be borne by 'disposable' people.

Aids gives us a painfully clear view of how deprivation and discrimination damages people and their health. Discrimination harms people with Aids, restricts their access to health care and therefore encourages HIV infection.<sup>8</sup> Recognizing discrimination when we see deprivation would be a major shift for the medical establishment. Doctors are generally uneasy about this view – often articulated by feminist and black critics – and are nervous that it draws them inevitably into tackling political injustice.

In the charged atmosphere of HIV and Aids it's a thin line between complacency and scare-mongering. Currently it's fashionable to play down the significance of the pandemic. Part of this response is habitual denial; part is concerned with conflicting anecdotal reports of the true scale of HIV infection, particularly in central Africa. Both aim to reduce our responsibilities.

The truth is that HIV is spiralling out of control. Even the most conservative esti-



TOP: MIKE GOLDWATER / NETWORK; BOTTOM ROB COUSINS / PANOS

With a stroke and a smile; safer sex gets people talking in Uganda (above); Aids Education poster from Kenya (below).

mates suggest that the number of people infected will triple within six years. No community in the world can claim to have stopped HIV infection – few have begun to meet their sustained needs for health care. And as the virus advances, stigma and violence continue to plague many people with HIV and Aids.

Some hope can be drawn from small measures. Where we can protect ourselves from the virus we generally do. Individual changes in the way we have sex help to reduce HIV risk, which cuts the chances of transmission significantly. Aids may not be an inevitable disaster. Much suffering is preventable and depends on our humanity. If we tackle the discrimination that restricts health care, we can slow down the rate of infection. Stopping HIV will take more than a handful of condoms. It demands political will to tackle the inequalities that let HIV flourish.

1 From a speech by James Anderton, the former police chief of Manchester, UK. 2 Like other viruses, HIV mutates. Two strains of HIV, HIV-1 and HIV-2 have been identified. HIV-2 is less common, found mainly in West Africa. For the purposes of this magazine HIV-1 and HIV-2 are not distinguished. 3 For a discussion of the history and effects of 'plague language' on disease, see *Illness as Metaphor & Aids and Its Metaphors*, Susan Sontag, Penguin 1991. 4 *The Invisible Epidemic: The Story of Women and Aids*, Gena Corea, Harper Collins. 5 Quoted in *The Hidden Cost of Aids*, The Panos Institute, London 1992. 6 For a fuller critique of Burroughs Wellcome and AZT see *American Journal of Public Health* 81 (1991): 250. 7 From Jon Gates' speech to the Canadian Aids Society, May 1992. A documentary of his work is available from Harvey McKinnon Associates, 2524, Cypress St, Vancouver BC, Canada V6J 3N2. 8 Dr Jonathan Mann mapped out the interconnections between health and human rights in a lecture to the Terrence Higgins Trust on 14 October 1993.