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WE CAN WIN!

KWAZULU-NATAL CABINET AIDS INITIATIVE UPDATE

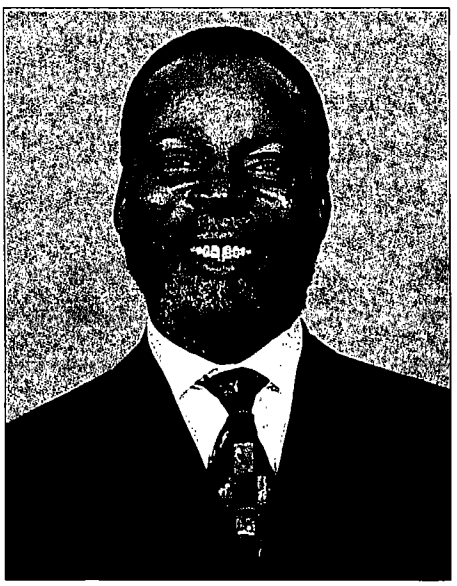
SPEAKING OUT

All over South Africa, Africa and the world, people are speaking out about AIDS. People with HIV and AIDS are bravely disclosing their status, proving to their friends, relatives and their communities that it is not a sin to be HIV positive.

Leading politicians, as well as King Goodwill Zwelithini have taken up the AIDS cause. Their message is simple: we have to rid ourselves of the stigma against people with AIDS. As our Minister of Health, Dr Zweli Mkhize says, AIDS is not a disgrace. We should not discriminate against or blame people with HIV or AIDS. To do so is to violate their human rights.

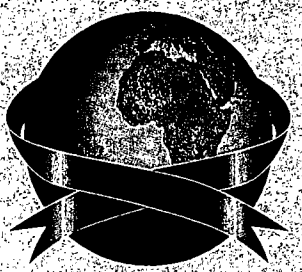
Instead, we should be open and frank in our attitudes towards this disease. People who are living positively with HIV and AIDS deserve our help and support. As Minister Mangosuthu Buthelezi says, an HIV positive person is as reliable a father, mother, worker or friend as anyone else.

People who have the courage to disclose their HIV positive status are the frontline soldiers in our struggle against HIV/AIDS. You will be introduced to many such people in the pages of this publication. They are all members of NAPWA, the National Association of People Living with HIV/AIDS. Their willingness to stand up honestly and confront their disease is a demonstration of their courage and commitment to the struggle against AIDS.



King Goodwill Zwelithini calls for a return to the values of Zulu culture, as a way to combat HIV/AIDS (see page 3).

WORLD AIDS CAMPAIGN



YOUTH: A FORCE FOR CHANGE

Each year the Joint United Nations Programme on HIV/AIDS, (UNAIDS) chooses a theme around which people all over the world can unite. This year, the theme focuses on Youth: A Force For Change.

This theme calls upon young people the world over to join together in the fight against HIV/AIDS, because young people are the people most at risk of getting AIDS in the world today. More than half of the new HIV infections recorded worldwide occur in the 10-24 age group.

Young people are the people to whom the future belongs. They are the ones who will be inheriting the world of the 21st century. They are the leaders of tomorrow and it is they who will lead our world to a future free of AIDS and HIV. They therefore have a special responsibility to ensure that they do not put themselves or their sexual partners at risk.

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RED HOT NEWS

Volume 4 Number 3 November/December 1998

Sectors pledge their support to the Partnership Against AIDS

From the Editor

Welcome to the revamped *Red Hot News* which has been redesigned to provide more detailed information about the epidemic. *Red Hot News* will:

- keep you informed about programme implementation at national level
- create a platform for networking
- provide a national perspective to events and hopefully, align disparate activities to one purpose – curbing the spread of HIV/AIDS in South Africa.

This development will continue for sometime and an evaluation of the publication will take place about eight months down the line. We hope you will participate in that process.

This edition focuses on the Partnership Against AIDS (A copy of a special edition of the Red Hot News dealing with this campaign is included in case you did not receive it).

A special letters page is also being introduced for your comments, your queries and concerns – please use it. Looking forward to hearing from you.

We would like to take this opportunity to welcome Dr Nono Simelela, who will be replacing Rose Smart as Director of the HIV/AIDS and STD Directorate. We also welcome Partnership Against AIDS Campaign Manager, Mtholephi Mthimkhulu, and Campaign Co-ordinator, Thami Skenjana.

Eddie Mohoebi
Editor

Deputy President Thabo Mbeki delivering his declaration on AIDS at the Salvation Army's Ethembeni Children's Home. The home cares for abused and abandoned children including HIV-positive children

OCTOBER 9th marked a historic day for the AIDS movement in South Africa with the delivery of the declaration on AIDS by Deputy President Thabo Mbeki, on behalf of President Nelson Mandela.

President's Call for Partnership

In 1997, in Davos, Switzerland, Nelson Mandela, in his capacity as Honorary President of the Global Business Council on AIDS, called for AIDS to be brought under control and said – "Let us join hands in a caring partnership for health and prosperity as we enter the new millennium."

That "Partnership" has now become a reality in South Africa,

Continued on page 2

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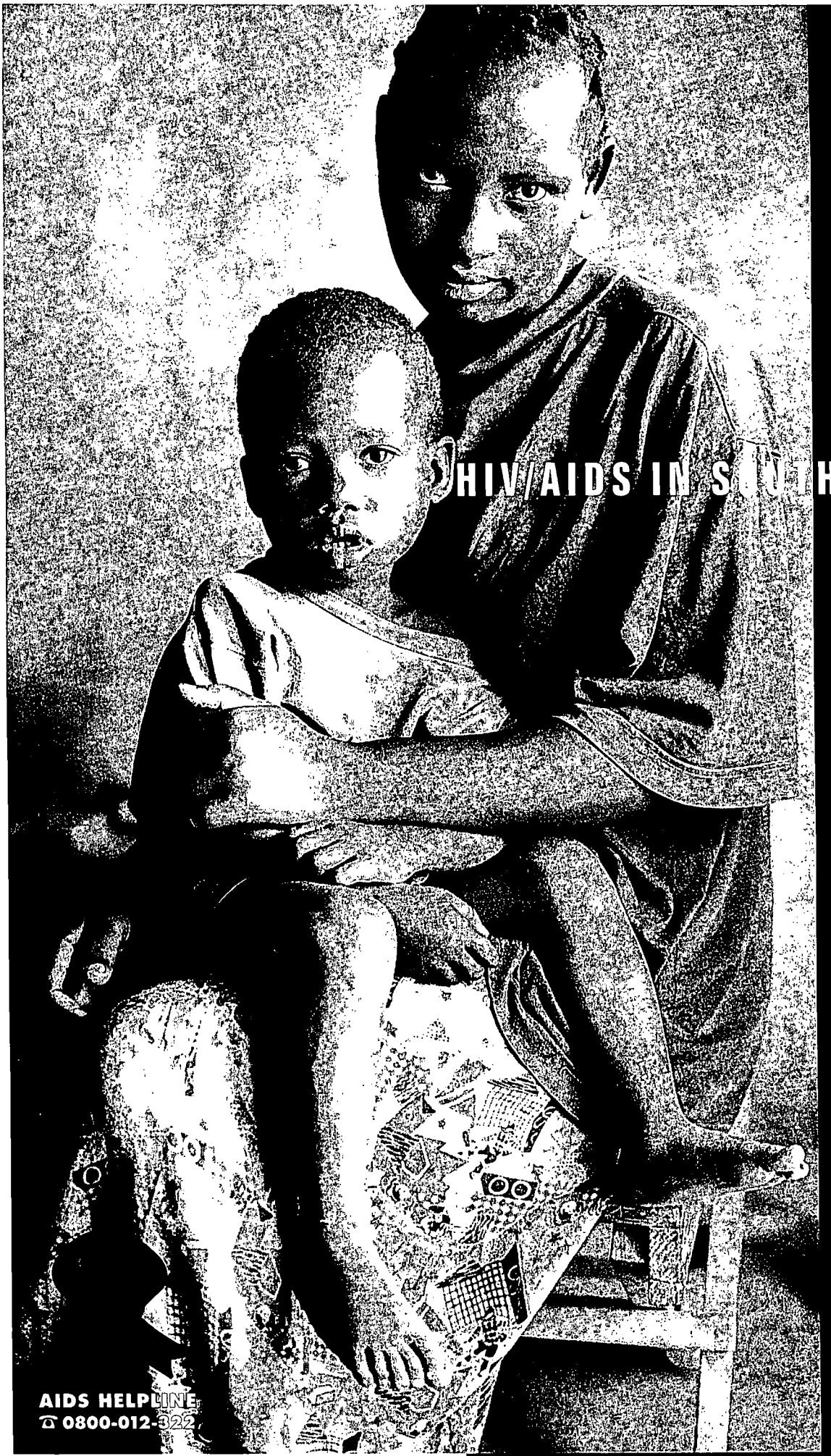


HIV/AIDS IN SOUTH AFRICA:

AIDS HELPLINE
☎ 0800-012-322

DEPARTMENT OF HEALTH

REMARKS BY
THE VICE PRESIDENTOF THE UNITED STATES AL GORE
AND
DEPUTY PRESIDENT OF SOUTH AFRICA THABO MBEKI

PRESS CONFERENCE
KIRSTENBOSCH GARDENS
FEBRUARY 18, 1999
CAPE TOWN, SOUTH AFRICA

* * * *

April Ryan, American Urban Radio Network: Vice President Gore and Deputy President Mbeki, you're both wearing lapel pins dedicated to the fight against AIDS. How can you effectively fight the spread of the disease when many people here and in the United States run from issues of AIDS testing and prevention techniques?

Mbeki: Well, what we are trying to do in this country is to engage in as widespread and sustained as possible a campaign of AIDS awareness. It's a very major challenge to educate the entirety of the South African population about this issue to make sure everybody knows what's involved, what's at stake, what preventive measures to take and so on. And we are quite certain, and I think universal experience around the world, shows, including Africa, shows the critical importance of that kind of campaign. Of course, you need also to keep a very close watch on this as to practically what is happening in the society on rates of infection and all of these kinds of questions. And, these are areas in which there is cooperation between ourselves and the United States to be able to keep an eye on this. But, as I say, we are quite convinced that the most effective way to deal with this is continuously, at all levels of society, the entirety of the society, the entirety of its leadership, business, labor, politicians, religious people, everybody, artists, sports people, and so on; to engage this thing in a way that makes its impact. And that's the direction in which we are setting.

Gore: If I could respond also. In the United States of America, the AIDS epidemic really began to hit home around 1981. Our national leaders did not really raise the alarms at that time. There are many reasons for it; I won't go into it lest my comments be misinterpreted. The point I'm trying to make is a simpler point; we did not ring the alarm bells. Our national leadership did not raise the roofs in trying to alert people to what was going on. It took some time before that happened. Now, finally, we have begun to see a little bit of progress, but we're not out of the woods yet. Here in South Africa this epidemic, which is really a pandemic, has hit with hurricane force. South Africa is blessed with a leader in Thabo Mbeki who has been speaking out forcefully, boldly and often. In order for South Africa to turn the corner, his leadership must be joined with leadership from every sector of society. Please forgive me, as a non-South African, for speaking in this way about a matter affecting your country. I'm wearing this pin because my friend, Thabo Mbeki, gave it to me this morning after a very lengthy conversation we had about HIV/AIDS last night. This is a crisis for South Africa. Listen to what Deputy President Mbeki is saying and ask the leaders of entertainment and sports and business and labor and every sector of society: Why aren't you also adding your voice to that of the Deputy President? Minister Zuma has been leading the way. Our Surgeon General, David Satcher, engaged in a very interesting and illuminating discussion with her in our Commission meeting today. Secretary Shalala, from the United States, has been actively involved in the health committee's work as well. This is a problem that must be faced at a new level of urgency. And by the way, it is not only in South Africa. South Africa keeps good statistics. Neighboring countries may not in the same way. This is a regional epidemic and a worldwide pandemic that must be faced with the kind of urgency that Deputy President Mbeki has been bringing to it.

HIV/AIDS

I. ISSUE SUMMARY

A. There are currently 3.5 million people infected with HIV in South Africa. South Africa has one of the fastest growing epidemics in the world, with over 1500 new infections every day.

B. By the year 2010, USAID estimates that there will be 2.6 million children in South Africa orphaned by AIDS.

> NOTE: Sandy Thurman, Director of the Office of National AIDS Policy has recently returned from a preliminary fact-finding mission to South Africa on the issue of children orphaned by AIDS. She will return to South Africa in April with an official congressional delegation.

C. AIDS is not only causing unfathomable human suffering, but will have far reaching ramifications for the economy, stability, and civil society as well. Projections of economic impact suggest that AIDS is reducing the South African GDP by 1% per annum. And while Mbeki is focused on crime as the number one issue in the upcoming elections, recent reports in SA have linked the growing number of children orphaned by AIDS (street youth) to future increases in crime and civil unrest.

II. DESIRED OUTCOME

A. To increase the political leadership behind the implementation of the SA National AIDS plan and the Partnership Against AIDS (a prevention initiative that you recently applauded Mbeki for launching -- see letter). To reduce the stigma of AIDS and to ensure an effective response to this burgeoning crisis, strong leadership from the top is essential. In addition, while Mbeki has established an inter-ministerial commission on AIDS, his leadership is needed to make this broad-based multi-sectoral response real.

B. To affirm that the US strongly supports the Partnership Against AIDS and the SA National AIDS plan, and stands ready to be an active partner in the implementation of these worthwhile efforts.

C. As Mbeki prepares to assume the Presidency, securing his commitment to continue and intensify his leadership on this issue would be extremely helpful.

III. CURRENT STATUS

A. USAID is currently spending $10 million on public awareness, STD control, capacity development, advocacy training, and support for vaccine trial preparation. They have had a number of successes working with unions and mines, and have helped to integrate HIV/AIDS into broader health care systems development. In addition, $11 million is being considered which would focus on supporting non-governmental organizations (NGOs) and community-based care. There are also funds being spent on tuberculosis, multi sectoral work, and reproductive health.

B. The CDC has worked with government and NGOs on prevention, surveillance, and training. The NIH has conducted collaborative research in the area of prevention and have established sites for vaccine trials.

C. As a result of the $10 million that the President set-aside for children orphaned by AIDS, and as a follow-up to Sandy Thurman's recent trip to SA, it looks likely that SA will receive $1.5 million for community-based projects in Soweto, Capetown, and KwaZuluNatal.

D. The cooperation between the US and SA around AIDS has generally been positive. However, Dr. Zuma, the Minister of Health, has become embroiled in a series of high profile controversies (on AIDS and other issues) that have consumed considerable time, attention, and resources. Therefore, Zuma has been seen by many as an obstacle to the formation and implementation of a clear and cohesive national response. However, she does remain close to Mbeki.

E. SA has gone through an extensive process of planning and consensus building on AIDS. It is now time to move from paper to practice -- by translating good policies into effective action. In addition, the recent stoning to death of a woman who was open about her HIV status to help educate the public, highlights the need for high level and ongoing leadership in reducing stigma.

IV. SA PERSPECTIVE

The SA ministry of health does not support the delivery of AZT to pregnant women. They believe that, given limited resources, investments in broad-based prevention programs are more cost effective. In addition, they believe that, after years of the benefits of government going only to a select few, that interventions provided by the government of the new SA should be universal.

V. US PERSPECTIVE

A. Among the various agencies currently involved in SA (AID, ONAP, NIH, CDC), discussions are still being had about the ethical issues involved in providing pregnant women with AZT just long enough to reduce HIV transmission to their children, but not thereafter to prolong their lives. USAID offers the possibility of limited funding for a research project if the SA government would agree to permit research in this area.

B. The French have proposed the creation of a Therapeutic Solidarity Fund to help pay for the delivery of anti-retrovirals in developing countries. In addition, former Congressman Dellums is proposing a "Marshall Plan" for Africa which mirrors the french plan in large part. While the US applauds their active interest in increasing access to services for people living with HIV and AIDS in SA, we believe that investments in antibiotics treatments for opportunistic infections and aggressive STD and TB treatments are far more realistic given the resources and infrastructure available.

VI. PROPOSED STRATEGY

A. Reiterate our support for the SA National AIDS Plan and the Partnership Against AIDS and our desire to cooperate with Mbeki in his enhanced leadership role in the battle against AIDS.

B. Reiterate our desire to work with SA and others to move forward with a realistic and responsible approach to prolonging lives of people living with HIV and AIDS in SA.

C. Affirm out plans to work closely with SA to respond to the growing number of children orphaned by AIDS through new funding and ongoing dialogue. Request that Mbeki meet with the congressional delegation that plans to visit South Africa (among other sub-Saharan nations) during the April congressional recess.

D. Offer our willingness to work with SA and multinational corporations in SA on public-private partnership regarding AIDS activities. We believe that Ford Motor Company and Levi Strauss are strong possibilities.

E. Uganda, the AIDS success story in Africa, became engaged in the AIDS issue because of the large percentage of HIV+ members in their military. Many believe that SA has a significant and growing problem in its military as well. Surgeon General Satcher will be meeting with the medical officials in the SA military during your visit. For AIDS and security/stability reasons, additional attention to this issue is important.

Summary results of the eighth national HIV survey of women attending antenatal clinics of the public health services in South in 1997

Background

HIV/AIDS continues to be an important public health concern in South Africa. South Africa is considered to have one of the fastest growing HIV epidemics in the world.

In 1997, the Department of Health (DOH) undertook the eighth in a series of annual unlinked, anonymous HIV surveys. The latter have been conducted since 1990 amongst women attending antenatal clinics of the public health services in South Africa.

Methods

In 1997 the HIV survey protocol was revised through workshops and consultation with the Medical Research Council (MRC), the National Institute of Virology (NIV) and the South African Institute for Medical Research (SAIMR) , the South African Blood Transfusion Services (SABTS) and provincial AIDS and Health Information officers. The review resulted in more rigorous sampling and laboratory methodology being uniformly applied throughout the country, using a standardised and national protocol. A specified number of routine antenatal blood specimens consecutively received during October/November were serologically screened for HIV antibodies and syphilis.

Following data entry in each province, the data were verified by being re-analysed at the national office and comparing these statistics. At the national office the data were analysed and reanalysed by the responsible directorate. For further verification of these data, independent analysis by MRC statisticians was conducted.

Results

Out of the 12 522 specimens received, 12 343 specimens were screened for HIV and syphilis. Based on the 12 343 blood samples tested, it is estimated that **16.01%** of the women attending antenatal clinics of the public health services nationally were infected with HIV by the end of 1997. This represents a 12.99% increase in the prevalence level of HIV infection since 1996.

The tables and graphs below give details on provincial and age distribution.

HIV infection in the provinces was estimated as follows: KwaZulu/Natal - 26.92 %, Mpumalanga - 22.55 %, Free State - 19.57 %, North West - 18.10 %, Gauteng - 17.10 %, Eastern Cape - 12.61 %, Northern Cape - 8. 63 %, Northern Province - 8.20 % and Western Cape - 6.29 %

Taking into consideration that the survey was limited to women of child-bearing age, estimates are available only for 15-49 year-olds. Since fertility sharply decreases after 40 years, the estimates of these groups are based on small numbers and should be interpreted with caution. In all age groups under 40, HIV prevalences have increased since 1995, reflecting the same pattern as before (Table 1). Women in their twenties have the highest rates of HIV infection at 19.67 % and 18.18% for the 20-24 and 25-29 year old groups respectively. The rates in the older groups are slightly lower at 14.49% in the 30-34 year group, 9.47% in the 35-39 year group and 7.52% in the 40-44 year old group (Figure 2). As seen before, HIV infection is clearly present in older women with a rate of 8.82% found in the 45-49 year group.

Information on population group was available for 9 436 of the 12 522 specimens. Of the specimens from known population groups, 65.0% came from Blacks, 9.2% from Coloureds, 0.3% from Whites, 0.1% from Asians and 25.4% unknown. As already mentioned sampling from the public sector facilities has been found to be an under representation of race groups other than African since the number of White and Indian subjects using these facilities has been found to be typically small. Consideration for the future is to target the private sector as well.

Levels of HIV infection have increased in eight of the nine provinces except the North West where statistically significant decreases in the estimates were found. KwaZulu/Natal continues to be the province with the highest prevalence which has shown an increase from 19.90 % in 1996 to 26.92 % in 1997.

Acknowledgements

The participation of provincial co-ordinators, South African Blood Transfusion Services, SAIMR laboratories, Virology Departments of Cape Town and Natal Universities, the NIV, Medical University of Southern Africa (MEDUNSA) Mankweng Provincial laboratory of the Northern Province and MRC is greatly appreciated.

Table 1: National HIV surveys of women attending antenatal clinics of public health services in South Africa, 1996-1997

	1997 Est (HIV+) 95% CI	1996 Est (HIV+) 95% CI
South Africa	**16.01** (15.37; 16.67)	**14.17**(13.45; 14.89)
Provinces		
Western Cape	**6.29** (5.20; 7.52)	**3.09**(2.34; 3.84)
Eastern Cape	**12.61**(10.93; 14.44)	**8.10**(6.92; 9.28)
Northern Cape	**8.63**(6.39; 11.34)	**6.47**(5.05; 7.89)
Free State	**19.57**(17.11; 22.21)	**17.49**(15.57; 19.41)
KwaZulu/Natal	**26.92**(24.91; 29.01)	**19.90**(17.68; 22.12)
Mpumalanga	**22.55**(20.45; 24.75)	**15.77**(14.34; 17.20)
Northern Province	**8.20**(6.87; 9.68)	**7.96**(6.24; 9.68)
Gauteng	**17.10**(15.11; 19.22)	**15.49**(13.58; 17.40)
North West	**18.10**(16.19; 20.11)	**25.13** (22.31; 27.95)
Age Group		
<20	**12.70**(11.32; 14.19)	**12.90** (11.45; 14.35)
20-24	**19.67**(18.38; 21.00)	**17.74** (16.49; 18.99)
25-29	**18.18**(16.80; 19.62)	**15.33** (14.04; 16.60)
30-34	**14.49**(12.92; 16.18)	**12.20** (10.73; 13.67)
35-39	**9.47**(7.72; 11.46)	**9.71** (7.89; 11.53)
40-44*	**7.52**(4.44; 11.77)	**10.16** (5.95; 14.36)
45-49*	**8.82**(1.86; 23.68)	**5.83** (2.24; 9.40)

Figure 1. HIV Prevalence in antenatal clinic attenders, in South Africa 1990- 1997 *(1991-1993 figures exclude the former Bophuthatswana.)*

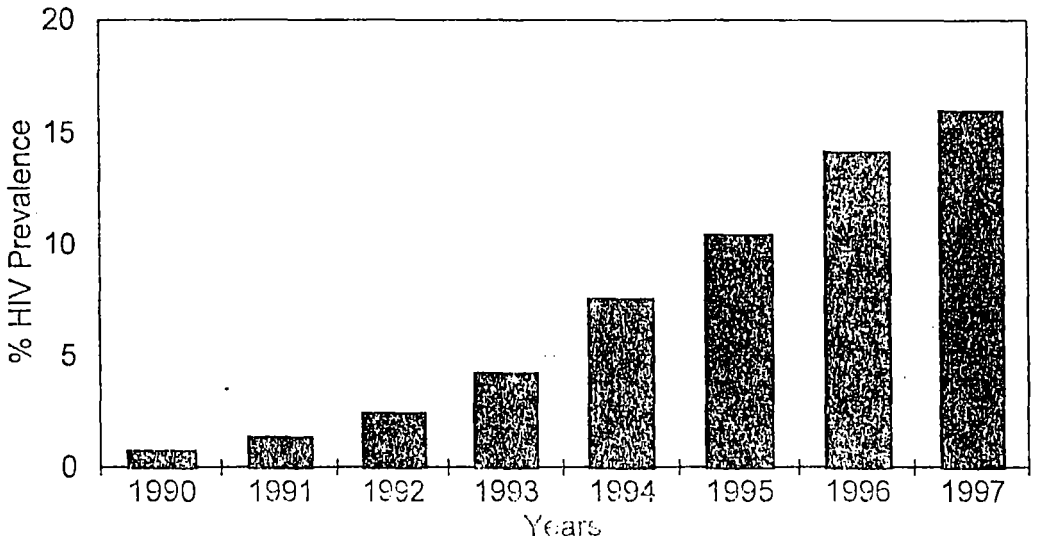


Figure 2: HIV distribution by age group, 1991-1997

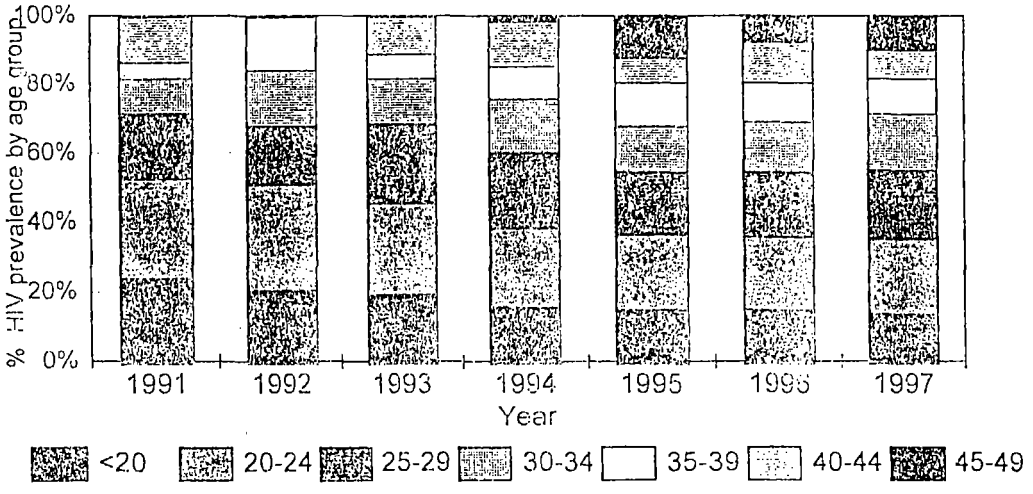
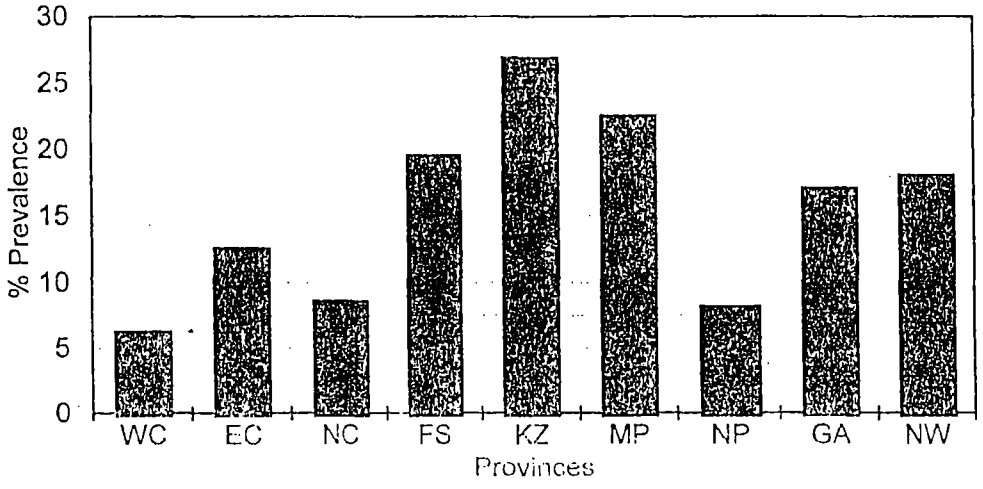


Figure 3: 1997 HIV Prevalence for antenatal clinic attenders by Province



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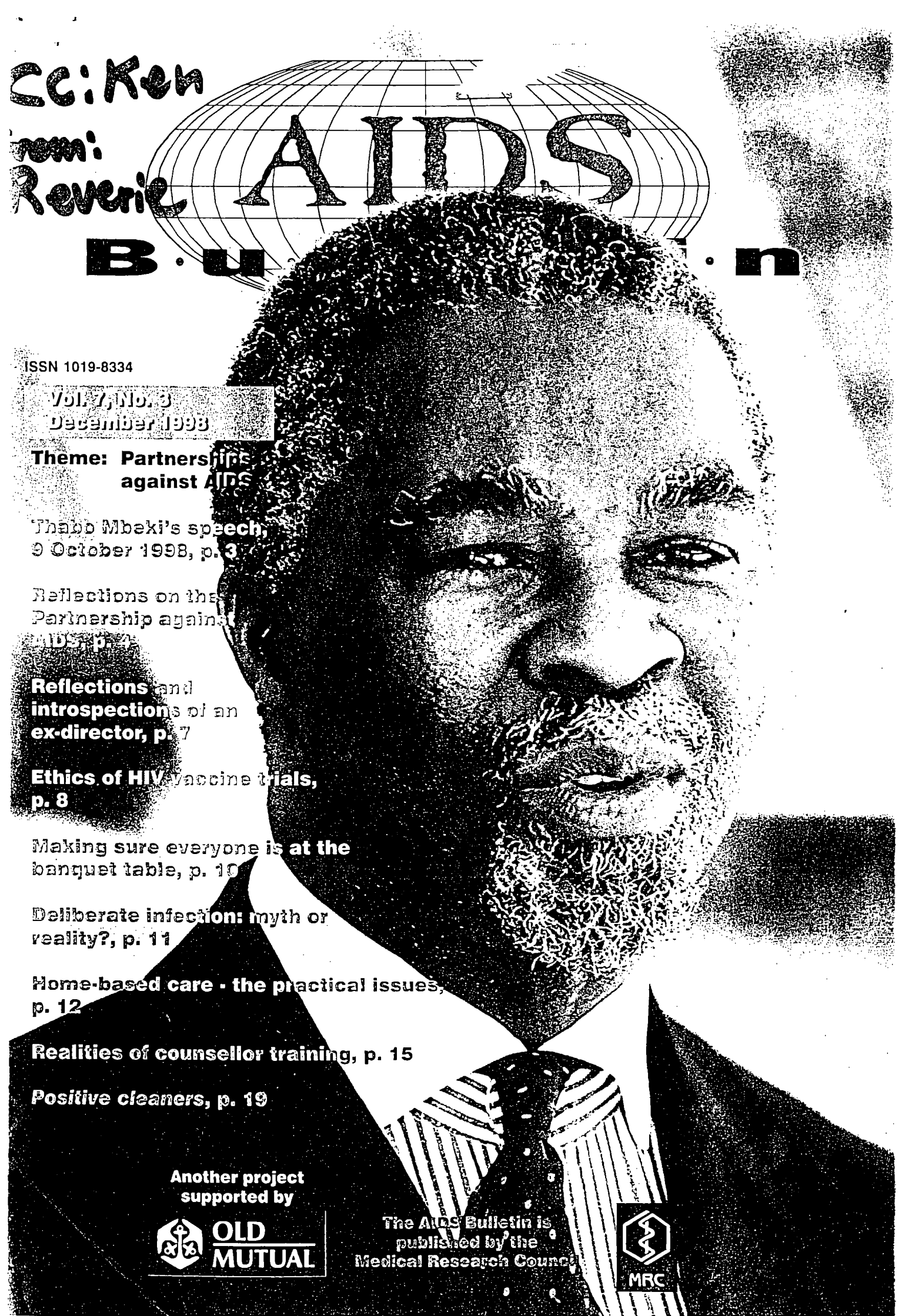

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Theme: Partnerships against AIDS

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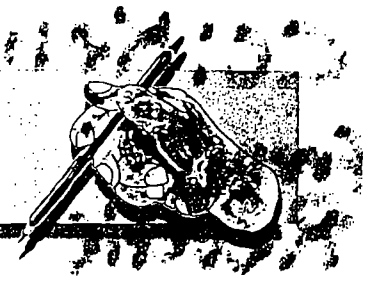
EDITORIAL



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The Corporate Communication Division, MRC, PO Box 19070, Tygerberg 7505.
Telephone: +27 (0) 21 938-0205
Fax: +27 (0) 21 938-0395
e-mail: mgallow@eagle.mrc.ac.za

Editorial adviser - Leverne Gething
Art Direction - Iulius Toma

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The photos of Deputy President Thabo Mbeki and President Nelson Mandela were supplied by the *Cape Argus*.

Partnerships against AIDS

It's been a busy few months for the AIDS world. What with the much-heralded launch of the ***Partnership against AIDS*** and the on-going controversy surrounding AZT, not to mention the endless reminders of the fact that South Africa has one of the fastest-growing epidemics in the world, it's been a time when HIV/AIDS has been in the news and in the limelight. By media standards it's been a good time - whether for good or bad reasons - the public is being forced to pay attention.

AIDS activists from across the spectrum have been calling for high-level political commitment for many years. Until now these cries have gone unheard. Now the Deputy President has publicly stated his intention to fight HIV/AIDS in a countrywide television and radio broadcast on 9 October entitled "*Ten minutes to save the nation*". But is this a case of too little too late? As in many other African countries, our government is finally confronting our AIDS problem when it has become too severe to ignore. Certainly, the 3 million South Africans already infected and the estimated 1500 South Africans newly infected each day will regard this epidemic as having been worthy of much earlier attention.

So, what exactly did Deputy President Thabo Mbeki promise the nation and how are these promises and pledges being interpreted by people in the frontline? To answer these questions, we publish a transcript of Mbeki's speech as well as a commentary and critique of the process and the substance of the government's response.

It seems unfortunate that despite this renewed commitment to prevent HIV and AIDS, an announcement that AZT would not be provided to pregnant women with HIV was made. Whether one agrees or not with the Health Minister, this must have been an extremely difficult and heartrending decision to make. AZT can reduce the transmission rate of HIV to babies by half and it is estimated that it would cost approximately R500 per patient for the treatment (excluding HIV testing and provision of formula feed). Yet the government has decided to commit its limited resources to prevention campaigns instead. Minister Zuma points out that, "*I have to look at the whole picture. If you have limited resources, you may decide to put your resources into preventing mothers getting infected in the first place. These are difficult issues we have to face.*" (*Mail & Guardian*, 16 - 22 October 1998, p. 12) AIDS groups have challenged this decision in light of the long-term cost of caring for an HIV-positive child and the AIDS Law project will be challenging the decision in court. No doubt it is an issue which will dominate 'AIDS news' for some time.

Another issue which should receive our attention is the search for a vaccine for the South African population. It is generally accepted that a vaccine is the only possible long-term solution to HIV prevention. However, the development of a vaccine requires an equal partnership between policy makers, scientists/researchers and the community. Vaccine trials are a difficult and complex issue and we require both adequate information and high-level advocacy. Some of the ethical dilemmas of vaccine work were the subject of a meeting in September which is summarised on p. 8. We are also privileged to feature an interview with Steve Wakefield of the US AIDS Vaccine Advocacy Coalition (p. 10) who shares a wealth of experience on the subject.

In light of the government's current focus on 'partnerships' we have adopted this as the theme of this issue. We look at a range of partnerships or relationships, ranging from those between government and other sectors through to those between patients and carers, and counsellors and counsellor trainers. The relationship between so-called 'deliberate infectors' and their 'victims' is also explored.

We are pleased to publish Rose Smart's retrospective on her term as head of the HIV/AIDS Directorate. We thank her for her contributions to the Bulletin over this period and wish her well in her future endeavours.

Finally, for a change, we feature a wonderfully uplifting story of changing adversity to challenge (*Positive Cleaners*, p. 19).

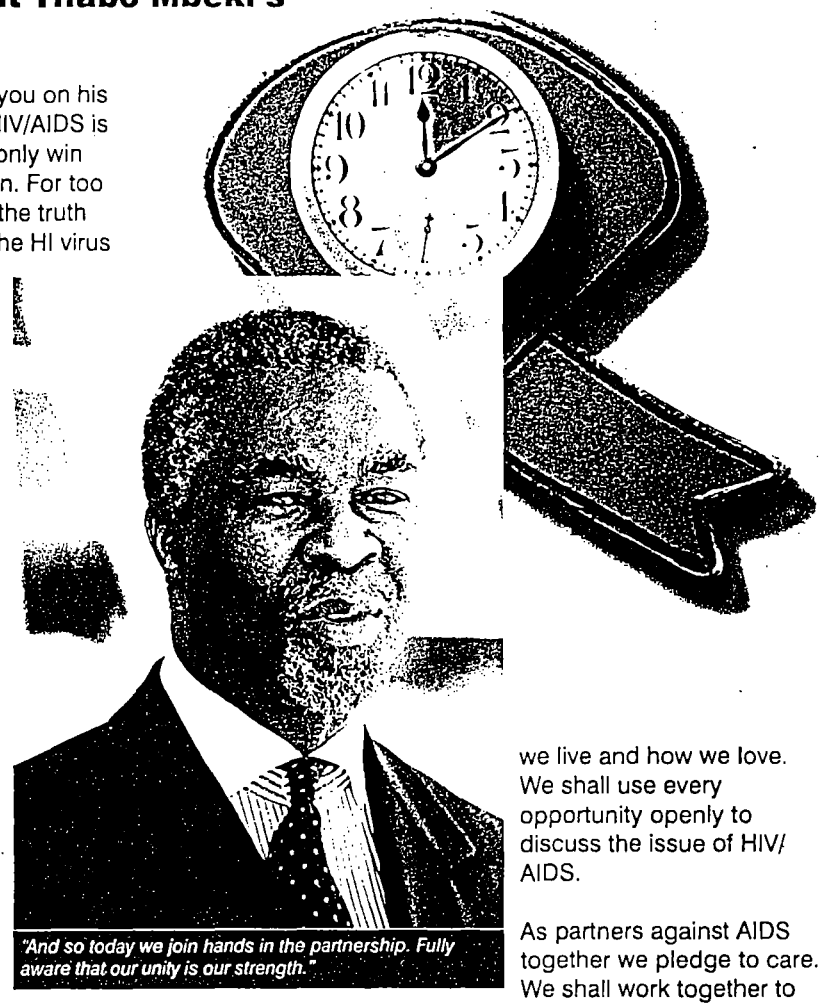
As yet another World AIDS Day comes and goes perhaps it is time for all of us to reflect on what we have achieved thus far and how we too can form a partnership at every level to change the bad news about HIV/AIDS to good!

The Editors

Partnership against AIDS - for the life of the Nation

A transcript of Deputy President Thabo Mbeki's speech - 9 October 1998

President Mandela has asked me to address you on his behalf. I am honoured to be able to do so. HIV/AIDS is among us. It is real, it is spreading. We can only win against HIV/AIDS if we join hands to save our nation. For too long we have closed our eyes as a nation, hoping the truth was not so real. For many years we have allowed the HI virus to spread and at a rate in our country which is one of the fastest in the world. Every single day a further 1500 people in South Africa get infected. To date more than 3 million people have been infected. Many more face the danger of being affected by HIV/AIDS. Because it is carried and transmitted by human beings, it is with us in our workplaces, in our classrooms and our lecture halls. It is there in our church gatherings and other religious functions. HIV/AIDS walks with us. It travels with us wherever we go. It is there when we play sport, it is there when we sing and dance. Many of us have grieved for orphans left with no one to fend for them. We have experienced AIDS in the groans of wasting lives. We have carried it in small and big coffins to many graveyards. At times we did not know that we were burying people who had died from AIDS. At other times we knew but chose to remain silent.



"And so today we join hands in the partnership. Fully aware that our unity is our strength."

And when the time comes for each one of us to make a personal precautionary decision we fall prey to doubts and false confidence. We hope that HIV/AIDS is someone else's problem. HIV/AIDS is not someone else's problem, it is **my** problem, it is **your** problem. By allowing it to spread, we face the danger that half of our youth will not reach adulthood. Their education will be wasted. The economy will shrink. There will be a large number of sick people whom the healthy will not be able to maintain. Our dreams as a people will be shattered.

HIV spreads mainly through sex. You have the right to live your life the way you want to, but I appeal to the young people who represent our country's future to abstain from sex for as long as possible. If you decide to engage in sex use a condom. In the same way I appeal to both men and women to be faithful to one another but otherwise to use condoms.

The power to defeat the spread of HIV and AIDS lies in our partnership - as youth, as women and men, as business people, as workers, as religious people, as parents and teachers, as students, as healers, as farmers and farm workers, as the unemployed and the professionals, the rich and the poor - in fact, all of us.

Today we join hands in this partnership against HIV/AIDS, united in our resolve to save the nation.

As partners against AIDS together we pledge to spread the message - every day, every night, wherever we are we shall let our families, our friends, our peers know that they can save themselves and save the nation by changing the way we live and how we love. We shall use every opportunity openly to discuss the issue of HIV/AIDS.

As partners against AIDS together we pledge to care. We shall work together to care for those living with HIV/AIDS and for the children orphaned through AIDS. They must not be subjected to discrimination of any kind. They can live productive lives for many years. They are human beings like you and me and when we lend a hand we build our own humanity and we remind ourselves that like them each one of us can become infected.

As partners against AIDS together we pledge to pool our resources and to commit our brainpower. There is still no cure for HIV and AIDS. Nothing can prevent infection except our own behaviour. We shall work together to support medical institutions to search for a vaccine and a cure. We shall mobilise all possible resources to spread the message of prevention, to offer support to those infected and affected and to destigmatise HIV and AIDS, and to continue our search for a medical solution.

And so today we join hands in the partnership. Fully aware that our unity is our strength. Simple but practical action that we take today is tomorrow's insurance for our nation. Accordingly we pledge that wherever we meet and study, work and sing, play and enjoy one another's company, we will protect ourselves and our partners against HIV and AIDS.

Together as partners against HIV and AIDS we **can** and **shall** win. I have asked for your time to listen to this urgent message because there is no other moment but the present to take action. I thank you for your attention and urge you to act now!

AIDS

Reflections on the Partnership against AIDS

Mary Crewe, GJMC AIDS Programme

Part one: Athletics is more important
11 September 1998


Mary Crewe

There has been a growing demand in recent months for an increasing commitment from the government and politicians to the campaigns in South Africa to combat HIV and to ensure that people with HIV and AIDS suffer no discrimination.

That South Africa has not seen such political commitment seems odd. For the first time there is a government committed to equality and non-discrimination. Many people newly appointed to the government have come from 'the struggle' and are acutely aware of the effects of social discrimination and neglect. The Minister of Health and other parliamentarians played a significant role in the writing of the NACOSA AIDS Plan. The cabinet, in one of its first actions, adopted the NACOSA AIDS plan as the National AIDS plan, and the Department of Health (DOH) has allocated a generous budget and strengthened the AIDS Directorate. The constitution recognises AIDS as a disability.

There is a strong belief that once the politicians get involved, once they make AIDS a priority then 'the people' will begin to see that the campaigns against HIV and AIDS are serious. They will recognise the need for, and practice, safer and more responsible sexual behaviour. They will have compassion for people with HIV and AIDS (PWAs) and their families. PWAs will be able to reveal their status secure that a political climate will have been created for them to do so. While this is overstating the case, there seems to be something of an AIDS malaise while people wait for high-level political commitment to kick start a new campaign and to redirect the nation's efforts.

In part, the call for this high-level political commitment came from the work of NACOSA. NACOSA had developed its campaign around lobbying and advocacy and this has meant that difficult questions requiring complex answers were being asked, not only of Government departments, but also of the Minister of Health and the HIV/AIDS Directorate. These answers were seldom satisfactory and fed into the sense of a government paralysed by AIDS and unable to generate an effective response.

At the recent Geneva International AIDS conference, a number of South African speakers criticised the response of the South African government and its President to AIDS and made calls for them to recognise the consequences of this neglect.

On the 11th September the Deputy President, Thabo Mbeki, hosted and launched what was billed as a **Partnership against AIDS** and hailed as the beginning of a new campaign to stem the spread of the virus and to care, at all levels, for those who are infected and affected.

Two hundred leaders in their fields were invited. It is unclear who drew up the guest list but it contained the same faces that are seen at all AIDS gatherings. Certainly few new 'partners against AIDS' were present. If the captains of industry were there, they kept a very low profile. Sports administrators may have been there, there may even have been some famous players, but they were not visible. A few cabinet ministers were scattered around, but they too kept a low profile. While there were dozens of bishops, the input of religious groups was unimpressive. Despite this, it was a large and committed gathering of people.

At 14h30 the Deputy President arrived. The Minister of Health was nowhere to be seen. Mbeki announced the commitment of the government to combatting HIV and AIDS and welcomed the participants. He went on to announce that he would not be attending the rest of the gathering as he had to go to Johannesburg to open the World Athletic championships as Mandela was in Mauritius. He assured the gathering that the more than 3 million viewers of the Athletics opening would be told about the partnership against AIDS meeting. Minister Zuma, he added, was late because she was flying back from Mauritius.

This seemed the point at which NAPWA should have asked to speak. Something had already gone wrong in the planning. Neither the Athletics nor the SADC meeting was an impromptu event, calling for Mandela and Mbeki at short notice.

Why was the 11th September chosen if Mbeki's diary could not accommodate the full 2 hours? Why was Zuma's travel itinerary not more carefully co-ordinated so that she could be there on time? And why was it not possible for the Minister of Sport to open the Athletics and explain, to 3+ million people, that Mbeki could not be there because he was hosting the most important AIDS meeting of the present government's AIDS campaign?

The moment passed. The absence of Mbeki and the lateness of Zuma was acceded to and sanctioned.

The Minister of Welfare spoke next. HIV/AIDS has, of course, huge implications for her department and her vision about how she intended leading the department in its response to HIV and AIDS would have been welcome. Instead, she gave a competent overview of AIDS in South Africa. Her speech writer should have done better. During this speech, candles were lit, in a rather tossed away recognition of the immense suffering and death that this epidemic has, and will continue to, cause.

The Minister of Health was next. She did not outline her new vision for her Department. She did not say how she hoped the new Chief Director and his or her staff would operate. She did not give any indication of where she hoped the country would be by the year 2000. As ever, she was friendly, even charming, but she inspired no great hope about a dynamic new response.

No leadership

What was significant and disheartening about all the government speakers was their total lack of leadership, inspiration and vision. There was no critique of our society, of why we have failed so dismally to address this most perplexing of epidemics. There was no enthusiasm, no vitality and no excitement. The room was not carried

"The government gave no vision, no inspiration, no plans and no leadership. Nothing beyond vague generalities that have been placed on the agenda for over a decade."

forward on a surge of new hope and enlightened optimism; nor was it caught up in the partnership or the challenge. The 200 leaders were given no context in which to place their commitments or their pledges. There was not even a basic attempt to show what the new role of the government would be in this new call to action.

In fact, the message that came through very clearly was a passive one. This epidemic is beyond the role and scope of the government, so we have called you all together to tell you this. It is now over to you. We will work with you, even alongside you, but we will not, in any meaningful or accountable way, take responsibility for this epidemic any longer. It was a disingenuous twisting of the recognition that AIDS is not just a health issue.


Health Minister, Dr Nkosazana Zuma

Of course AIDS is a health issue. Of course the primary responsibility for curtailing this epidemic lies with the government. Of course the private sector and communities must be involved but someone must take responsibility – someone must give leadership, someone must drive it. A Health Minister who jets in late, a Welfare Minister who gives no vision about how she will structure her department's response, a Deputy President who gives an athletics meeting more credibility than a crucial AIDS consultancy do not appear to have grasped this.

Almost as distressing was the silence of the other ministers present. If the Department of Transport is going to address HIV/AIDS we do not know – the Minister did not reply to two public challenges. If the Minister of Finance is going to pursue good deals with drug companies we do not know – he sat sphinx like.

The people from NAPWA, as ever, spoke eloquently about their experiences. They must be tired of all these gatherings, at which people clap each point each time they make, even weep. It is unfortunate that there was little challenge from NAPWA to the government - although they did challenge the media as well as companies about employment practices and benefits.

Question time was appalling. It was chaired by a deputy minister who clearly had little understanding of even the mainstream AIDS debates and dilemmas. All opinions were represented – the anguished liberal white PPHC, the confusion of clerics dealing with homosexuality and the infection of 'non deviants', the commitment from COSATU a union grouping notable by its silence on AIDS, the Youth promising Cuban type 'each one teach one' AIDS brigades, and the questions of concern by people working in the field. The room seemed to move from a kind of predictable activism to acquiescent populism. Neither was helpful. It was as if the failure of the government to offer any analysis as to why we are in this position made people feel almost sorry for them – and they hastened to make their pledges.

Of course this partnership is important and requires congratulations. For many NGOs it seemed to herald a new partnership away from acrimony, and for that it was supported.

In the current PC language – whose process is this? Who owns it? The groups that were allegedly represented are too divergent, lack consensus and are too unfocused to naturally act together. Who will take the lead?

The government gave no vision, no inspiration, no plans and no leadership. Nothing beyond vague generalities that have been placed on the agenda for over a decade. Where do we go? What is being expected of this partnership? What is different now?

Probably nothing, except that the Government has neatly and skilfully shifted the locus of blame from itself should we not contain the epidemic. It is outrageous that the Deputy President of the country with the fastest-growing epidemic in the world did not have a major new government policy vision statement. It is outrageous that he placed athletics ahead of AIDS. It is outrageous that the Minister of Health could be so late and that the government can be quite so passive, so pedestrian and so uncreative.

The moment came, the moment passed. If this was a preview of what Mandela was to say on the 9th October, it was depressing. If Mandela can pull a surprise on the 9th, let's hope the colleagues who stay in government when he has left are capable of halting this slide into organised mediocrity.

Part 2: The President fails to make it
9 October 1998

For some time the country had been seeing advertisements saying 'lend me your ears' and other mysterious things like '10 minutes to save the Nation'. This 10 minutes were those that would place the newly launched partnership firmly into the hearts and minds of the population. In these 10 minutes, the President would use his considerable charm and power to situate HIV and AIDS in our lives and his leadership to make AIDS the national priority it should have been for the past 4 years.

By Monday the 5th October, it was known that he was not going to be there and Deputy President, Thabo Mbeki, had been given the task of inspiring the nation to take action against AIDS. There are a number of disturbing questions. Why was the President not pre recorded? It would not have been too taxing to film him at home, with no crowds and none of the pressures of live TV. If this was not possible then why was it not possible to have a phone link so that he could still give his message – or, at the very least, a message of support to that being read by Mbeki. Both a pre-recorded message and a live input could have been very short – a couple of sentences.

But most incomprehensible of all – why did he fail the nation? His failure to participate in any form, made the whole initiative seem uninspired and second rate.


President Nelson Mandela

His presence at a farmers' meeting the following day, served to highlight this failure. He has never made AIDS a national priority and his failure to participate in the 10 minutes to save the nation undermined the whole exercise. Why should the sceptical population take AIDS seriously, when the President doesn't?

The role fell to Mbeki. He does not have the Lady Di touch. There he was surrounded by a posse of small children desperate for his attention. He came over as the 'Wooden Man'. He had seen the speech before the broadcast – indeed we had heard him rehearsing it. He must have known the text well enough to relax, even digress, a bit. Instead, he read the speech from the teleprompter, as if for the first time, rather like a nervous newsreader auditioning for the SABC. His eyes did not waver, he did not look at the children, and he showed no emotion, no personal expression or that this is an epidemic about which he has any feelings at all.

Certainly he did not convey to the public that people with HIV and AIDS need love and support – not once did he even touch the children – no hand on a head, no caress, no hug. This was an automaton speaking – not a politician who has grasped the complexities of AIDS and taken them on with personal understanding and compassion.

He gave no programme direction, no promises of action, no direct strategies. He gave a number of general statements, at least mentioned condoms, and made AIDS everyone's issue. But there was no leadership, no vision and no inspiring call to arms! Was this really worth asking the country to come to a halt for 10 minutes? The feeling of anticlimax was perhaps best summed up by a member of the audience watching the broadcast from another room at Entembeni who had heard his repeated practising of the speech; " Is that it?" she asked, "Is that all we are going to get?". That's all. And judging by the reaction of the rest of the group watching, they shared her sentiments. High-level political commitment let us down. The President failed to participate, the Deputy President was awkward and wooden and the orphans were neglected.

What did he pledge?

One – to spread the message – every day, every night. He pledged to use every opportunity to openly discuss the issue of HIV/AIDS. Yet since then there has been very little said about AIDS – as far as I know it was not mentioned at the farmers' meeting, nor at the job summit.

Two – he made the pledge to care – to care for those living with HIV/AIDS and for the children orphaned. What a pity that at that moment he did not see fit (as I suspect Mandela or Lady Di would have) to pick up one of the children and hold her on his lap – showing powerfully that people with AIDS need love and human comfort.

Three - he pledged a pooling of resources and brainpower and support for work towards a vaccine or a cure. What a pity that the Minister of Health chose the same moment to announce that the pilot tests to monitor the efficacy of AZT in preventing maternal transmission would not go ahead as planned, and as budgeted for in three provinces.

Four - he pledged to mobilise resources to prevention, support and destigmatisation. To this end, he could have announced the intention to implement the SA Law Commission's recommendations on HIV and AIDS and changes needed in the law. He didn't.

So we are left with a few well-phrased generalities which are, in essence, no different from what government has been saying since the start of the epidemic. As a moment to save the nation it failed, as a moment to inspire us all to greater action I fear it failed again. As an election ploy, it may be sufficient.

Peter Busse showed how eloquently people can speak about HIV and AIDS. He could have given a hint or two to Mbeki, on how to use TV as a powerful medium to give out the message. But, of course, there is a powerful difference – Peter speaks as a person living with HIV, he speaks from direct experience and with a passion that having the virus and experiencing the social and personal consequences generates.

The groups who pledged support at the 11th September meeting reiterated their pledges and commitment. Significantly the NGO sector was not asked to pledge – nor were any of the major HIV/AIDS NGOs and CBOs, with the exception of NAPWA, invited to the broadcast.

Mbeki did not stay long after his speech – he held a press conference and left – he did not mingle with the people – he did not hear what they thought, or how they deal with HIV and AIDS in their every day lives. The

Peter Busse of NAPWA

Ministers of Health and Welfare were more accessible and curious.

In the end it was a failure of planning. Instead of creating a sense of partnership between the government representatives and the people, the two groups were largely separate. It could as easily have been filmed in a studio, without the guests. It was unclear why anyone else had been invited.

Would it have been any different had Mandela been present? The message in all probability would have been the same – but the delivery would certainly have been different. Warmer, more moving, expressing greater conviction perhaps and certainly would have led to a greater acceptance of the message by 'the people'.

If our political leaders find it this difficult to talk about AIDS, if they find it this difficult to be relaxed and empathetic with the issues, then this is the message that the public will pick up. Some people have expressed their belief that Mandela did not make the broadcast because he finds it embarrassing to talk about sex and HIV/AIDS. In the absence of an plausible explanation for his non appearance, what do we believe?

Political commitment to HIV and AIDS in terms of helping to raise awareness and generate behaviour change can only be effective if the political leaders themselves are prepared to be relaxed, sincere and informed. If not, we have once again, tokenism on our hands.

This does not mean that the Partnership will fail. But we are still left with the question as to who is driving it, who will ensure that the pledges are upheld, who will continue to breathe life and enthusiasm into it? With the lacklustre performance from the government, it is more crucial than ever to have well-funded, critical and vigilant NGOs. They must ensure that having launched this Partnership against AIDS, the government acts as a partner should.

AIDS

Reflections and introspections of an ex-director

Rose Smart


Rose Smart

As I approach the end of my tenure as Director of the National AIDS Programme, it is appropriate to reflect on the past 2 years and on the goals which I set for myself and for the Programme.

In a press release following my appointment in December 1996 I described a vision for 1997 and it seems fitting to begin my retrospection with a review of that vision. I saw the year ahead as a year of unprecedented growth, expansion and acceleration, based on participation and consultation and the building and strengthening of partnerships. A year heralding a new human rights culture and unequivocally exposing discrimination and abuse.

The reality has been a mixture of significant and not so significant successes as well as some failures. I choose to believe the comments of friends, colleagues **and** critics who acknowledge what we have achieved rather than the 'anonymous official' who, in Andy Duffy's article in the *Mail and Guardian* of July 1998, stated that *"the past two years have been incredibly bland"*! Anonymous official, let me describe for you the highlights of the past 2 years.

The National Review of South Africa's response to the AIDS epidemic in mid-1997, must be counted as one of the most significant highlights. It brought together representatives from across the spectrum of AIDS organisations and, in describing the strengths and weaknesses of the response, provided an invaluable baseline for future planning as well as a powerful advocacy platform.

The emergence of the Inter-departmental Committee with its committed membership has resulted in strong, vibrant HIV/AIDS programmes in many national government departments and is only rivalled by the fledgling Civil Military Alliance which represents a unique partnership to address AIDS in situations of extreme risk.

Another breakthrough which is worthy of congratulation is the trade union initiative which has been embraced by all the major unions. The conviction and dedication with which the representatives who have completed our training have taken on this significant additional responsibility is worthy of the highest praise.

The traditional healer consultants performed miracles with their counterparts from all major organisations and in all provinces. Their partnership with the National AIDS Programme, and their position as a crucial component of the continuum of care, must now be consolidated and expanded.

Our programmes for groups at increased risk have been focused and, I believe, relevant. I inherited a strong sexually transmitted disease (STD) programme which more recently has embarked on addressing STD management in the private sector. The life skills programme in secondary schools is finally reaching maturity, despite a sometimes stormy adolescence.

Projects with which the national office is privileged to be associated include the Lesedi Project in the Free State which provides vital services to women at high risk and the South Coast Hospice Outreach Project in KwaZulu Natal which cares for infected and affected clients in their communities.

The fact that people both within and outside of the AIDS Programme speak of *beyond awareness* and know about the AIDS Help Line are tributes to the 'Beyond Awareness I' campaign. Under the able guidance of the National Communications Forum, 'Beyond Awareness II' is already well under way. Traditionally the National AIDS Programme has had huge responsibilities in respect of NGO funding and condom procurement. It is with a real sense of pride that we can speak of the systems which have been developed and refined, systems which provide for accountability and optimal resource utilisation.

Internally, the past 2 years have seen the restructuring of the Directorate, with the Sub-directorates assuming management of their respective portfolios. Externally, the stronger relationships which were born during the Review have, with only one or two exceptions, flourished. This has resulted in broader ownership of the Programme, evidenced, for example, by such events as noisy ATIC training workshops on the 17th Floor of Hallmark Building.

Let us not forget that, at the heart of all our work are people who confront this epidemic from a very personal perspective. The FACES, who taught us so much, and who, each in their own way, left a legacy which will survive long after all our other achievements have been forgotten. In a small way, we were also able to support the establishment of the *Women Alive National Network*, a critical mass of courageous women who, against all odds and often at substantial risk to themselves and their families, turned their individual silences into a chorus of conviction.

I am cognisant of the difficult gap which must be breached between policy and implementation. The care policies which are currently being finalised have to be given effect if they are to translate into improvements in the quality of life of and care for people with symptomatic HIV disease. It is possible - the success of the HIV/TB initiative is apparent in the now-frequent reference to the two in policies, planning and projects.

Yes, there have been failures, particularly if judged against original goals. The lay counsellor project had as its goal the appointment of 270 persons for 2 years, 30 in each province. This did not materialise in most instances and there is little evidence that counselling is more accessible than it was 2 years ago. There is, however, evidence that significant strides have been made in establishing counselling as a valuable intervention with the setting of minimum standards for training and mentoring.

The quilt hanging on the wall at the Ethembeni Children's Home marking the all too short lives of the many babies who have died of AIDS is a powerful reminder that reducing mother-to-child transmission must remain on the Department of Health's agenda, and new developments in this regard must be constantly monitored.

And the new Government AIDS Action Plan, with its ambitious public awareness campaign? It was a recommendation from the Review, which within a few short months has almost eclipsed our other activities. So, while I share the concerns expressed about how to sustain the valuable momentum which has been generated, this must be marked as a genuine 'turning point' in our response. If I could have one wish it would be that 12 months from now, we could look back on this ***Partnership Against AIDS*** and celebrate its coming of age.

In conclusion, I humbly record my deepest appreciation to the staff who have unfailingly risen to every occasion. I constantly marvel at their tenacity and dedication. We shared more laughs than tears. We did our best. Salani Kahle - you will forever people my memories of the past 2 years. To my successor, I wish you wisdom, strength and perseverence - good luck.

The complicated ethics of HIV vaccine trials

Michelle Rotchford Galloway
Corporate Communication Division
Medical Research Council

A group of AIDS activists, researchers, clinicians, scientists, vaccine advocates, ethicists and the media met in Durban on 1 and 2 September 1998 for a Workshop on *Ethical issues in the conduct of HIV vaccine trials*. The workshop was sponsored by HIVNET, the International AIDS Vaccine Initiative (IAVI), the Fogarty AIDS International Training and Research Program and the Medical Research Council, and was attended by nearly 100 delegates.

Dr Walter Prozesky (left), MRC President, with Dr Seth Berkley, President of the International AIDS Vaccine Initiative (IAVI).

Advances in vaccine development

It is generally accepted that while traditional prevention efforts (including information provision, education, condom use and treatment for other sexually transmitted diseases) can slow the spread of HIV it is only the development of an effective vaccine that can bring an end to the epidemic. Until recently, vaccine development had not received the funding and attention it requires. Despite extensive laboratory research that has led to the creation of candidate vaccines, it is only recently that the first full-scale efficacy trial commenced. Some of the candidate vaccines currently in various stages of development include: live attenuated, whole killed, canarypox vector, recombinant envelope (gp 120 and gp 160), peptide, recombinant subunit, particle and DNA vaccines. However, these candidate vaccines were developed from the clade B subtype of HIV which is predominant in the developed world and not from the clade C subtype which accounts for 90% of infections in the developing world. Commercial interest is low in the developing world and, to date, there has been no champion to further the cause of vaccine development for the poorest countries where the need is greatest.

Which clade?

A critical issue involving science, community perception and ethics featured strongly in the discussions: Should South Africa become involved in testing a B clade vaccine (which is immediately available) when C clade infection predominates in the region or do we wait the estimated 2 - 3 years for a clade C-specific vaccine? On a purely scientific level the decision is difficult. There is evidence of cross-clade reactivity - CTL epitopes are highly conserved between clades and there is some evidence that a clade B vaccine would offer some protection against clade C although it is not clear how much. The closer the vaccine is to the circulating virus, the greater the level of protection but even within a clade the level of protection can vary - even if a person were immunised against clade C and then challenged by another version of clade C they may not be protected. There is also the danger that if a clade B vaccine didn't work in trials in South Africa we wouldn't really be sure if this is because of the clade difference or because of an ineffective vaccine design. On a political and social level things become even more complex. It would be very hard to explain to politicians and the community why we are testing a vaccine that has not been developed from the virus affecting South Africans. We would be seen as guinea pigs being used to test a vaccine for the developed world.

The participants of the workshop debated this issue extensively and decided that the national effort should prioritise a clade C vaccine ("a vaccine for our people") but that individual researchers could study clade B or C vaccine candidates with the aim of acquiring more data on cross reactivity and on the immune response in the South African population.

Ethical dilemmas

Several ethical issues were discussed in depth:

How does one get informed consent from poorly educated individuals?

Issues:

- How do you explain complicated scientific methods such as randomisation, placebos, vaccine inefficiency, the fact that participation in one trial may exclude future participation in trials of more effective vaccines and discrimination linked to participation? How does one explain that trials are a reiterative process and that a vaccine which is tested in trials will not immediately (if ever) be available in clinics?
- How do you equalise the power gap between researchers/doctors and subjects/patients?
- How do you ensure respect for cultural, familial and social customs

and for the hierarchy of decision making in different cultures? If participation in a trial is a benefit in terms of the vaccine itself or because of the accompanying counselling and treatment then respecting social authority may infringe individual rights.
- Should pregnant women/women who may become pregnant be allowed to participate? If we decide that they should not, this would constitute a barrier of access of women to the benefits of trials.
- Should teenagers (currently the group at high risk but not of a legal age to give informed consent to trial participation) be allowed to participate?

Suggestions:
- that increased training, money and effort is put into the process of acquiring informed consent;
- that people be trained as intermediaries to work between the researcher and potential participant to reduce the power gap and ensure language and cultural divides are addressed;
- that previous study participants be used to share experiential knowledge;
- that researchers are honest and open and provide adequate, detailed information.

What obligations do researchers have to promote known HIV-prevention strategies among trial participants?

Issue:
- Should prevention interventions be offered to trial participants even if this may affect the outcome of the trial? - i.e. it would not necessarily be clear if the reduction in infection was due to vaccine efficacy or behaviour change.

Suggestion
- that the following basics of HIV prevention be provided:
  - comprehensive, on-going sexual health education
  - voluntary HIV testing and counselling
  - free condoms
  - free sexually transmitted disease (STD) services

What obligations do researchers have to provide care to trial participants?

Issues:
- What about individuals who become seropositive due to their participation in trials - what care will they expect to receive and what arrangements will need to be made to reduce discrimination against them, ensure continued employment, access to medical aid and insurance and eliminate restrictions on international travel?
- What about the issue of the promise of care in settings where it isn't available in any other way and may therefore constitute undue inducement to participation? Should trial participants be offered HAART (Highly Active Antiretroviral Therapy) when this is not available in the country setting? Should the standard of care offered be the best available in the country or should it be the (higher) standard of care available in the sponsoring country?
- Who will finance such treatment? Is it the responsibility of the pharmaceutical companies and, if so, will they not use this as an excuse to avoid testing in developing countries?

Suggestion:
- that four basic elements of care should be available, namely:
  - effective pre-, post- and on-going counselling
  - baseline screening to detect disease (e.g. syphilis serology, pap smears, tuberculosis skin tests, assessment of signs and symptoms) and immune status (CD4 or lymphocyte counts)
  - effective prevention/prophylaxis (e.g. on-going contraception, pneumococcal vaccine shots)
  - treatment for common morbidity

Despite extensive laboratory research that has led to the creation of candidate vaccines, it is only recently that the first full-scale efficacy trial commenced.

Conclusion

All of these issues as well as the macro ethical issues such as inequality between countries and the collapse of emerging markets, which are major factors in the uneven distribution of HIV/AIDS, were extensively discussed by workshop participants. It became very clear that on-going dialogue will have to occur at all levels in society and that, although we can use the combined wisdom of international experience, solutions have to found by South Africans for South Africans. There is also an urgent need for a high-level advocacy programme which aims to encourage partnerships at all levels and convince the public and politicians of the value of science and of the urgent need for a vaccine in order to avoid the devastation that the HIV epidemic will cause for our population and economy.

Making sure everyone is at the banquet table

Interview with Steve Wakefield of the AIDS Vaccine Advocacy Coalition, USA

Michelle Rotchford Galloway

Can you tell us a bit about the coalition - its aims and functions and what activities it has been involved in both in the USA and internationally?
The AIDS Vaccine Advocacy Coalition (AVAC) was founded in December 1995. AVAC's mission is to speed up the development of preventive HIV vaccines by analysing obstacles to HIV vaccine development and advocating to remove these obstacles. AVAC is committed to achieving this mission without taking resources away from basic HIV research, drug development or prevention efforts.

Individual members have been involved in every major US scientific meeting and several international meetings since the organisation's inception with the goal of ensuring information is shared with those most in need of and affected by vaccine development. In May of 1998 AVAC published its second major report, *Nine Years and Counting*. This report, as in AVAC's December 1996 report, *Industry Investment in HIV Vaccine Research*, seeks to provide an independent, honest, well-informed critique of current efforts toward developing an HIV vaccine. AVAC hopes that its reports further both dialogue and progress in the many organisations whose missions relate to public health and eradication of disease throughout the world.

Ethics meetings participation has included member travel to Brazil, Switzerland, Thailand, Uganda, Abidjan and South Africa. *(Ed's note: Steve Wakefield was one of the participants at the Workshop on ethical issues in the conduct of HIV vaccine trials, held in September, see p. 8)*

What is the rationale for promoting HIV vaccine development?
With 16 000 people becoming infected with HIV every single day, the consequences of a world without a vaccine or action to develop one are dire. AVAC believes that every year we move up the discovery of an AIDS vaccine, we'll save millions of lives around the world.

What progress have you made thus far?
We have affected public policy at the US National Institutes of Health; we consult with major scientists in government and industry (internationally); we have provided leadership to US Community Advisory Board members and community groups such as Vaccine Advocates in their efforts on behalf of trial participants; we have gotten a phase II US trial to ensure the highest quality behavioural interventions for volunteers, a valid and thorough informed consent process, and compensation for medical expenses.

"Black participation in vaccine clinical trials can create a community which assures we will not only be at the table, but will help determine the menu and type of service available."

Can you tell us a bit about the trials currently under way in the USA?
There are Phase I, II and III trials currently enrolling or providing research products to persons willing to help develop a vaccine. Most of your readers will be most interested in a Phase III trial designed to enroll 5000 persons in the US and 5000 persons in Thailand. Trial subjects are persons at high risk for the virus, including homosexual men and heterosexual women with infected partners. Intravenous drug users are not included in the trial. The volunteers will have seven injections over a 3-year period; they will be compensated $225 over the course of the trial. About one-third of the volunteers will receive placebo injections. The AIDSvax vaccine is the first potential vaccine to reach large-scale testing.

Do you see the situation in SA regarding a vaccine initiative as being very different from the USA? If so, in what ways?
There are several ways SA is different and therefore more adept at finding out if a vaccine product works. A primary way is persons in SA are more likely to be interested in a vaccine and could be more convinced than their US counterparts that vaccines are a way to fight this virus. South Africa has a much higher seroprevalence rate, particularly in rural areas. This provides a different understanding of the urgency in finding an answer about the effectiveness of a vaccine product. Drugs which treat HIV infection are only available on a limited basis in SA. More than other African nations, SA has the technology to conduct clinical trials.

You've done a lot of work with vaccine trial participants. Can you describe what the process is like?
In most communities it is a matter of getting those with some scientific interest, some with research expertise to join those interested in the needs and rights of human research subjects. Using community organising principles, community advisory boards (CABS) have been created in major US cities. The purpose of a CAB is to formulate recommendations and strategies regarding the scientific research agenda and to assess community impact and assure that community concerns are considered. CAB also serve as a voice for the communities and study participants.

What are the most common concerns/issues which affect people in deciding to participate and during the course of the trial itself?
Will I suffer any social discrimination or harm as a result of trial participation? Is there any social harm? How will my family and employer react to my participation? Are there medical risks? What if I am sick a day or two from being injected? If my arm is sore from the injection, can I complete most other tasks I had in mind? Many participants will experience a vaccine-induced seropositivity. Will many understand that there is not a simple way for one's MD to distinguish seropositivity which is vaccine induced from actual HIV infection?

Do you believe the SA population is ready for vaccine trials?
While closer than many other locations - community education and community consent to conduct trials must be obtained. Failure to have community understanding about vaccine trials may allow fear or myths to later interrupt participation for a number of persons.

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Deliberate infection with HIV: Myth or reality?

Pierre Brouard

The arrival of HIV on the world stage in 1981 heralded a series of rumours and myths. In Johannesburg in the early 1990s we were told someone in Smal Street mall was spiking people with HIV needles, later that oranges sold by hawkers had been injected with HIV. But the one that has persisted is the notion of the deliberate infecter, the evil, unpredictable, maverick, murdering man (usually) who is deliberately and knowingly trying to kill with his HIV, usually through sex with his unsuspecting 'victims'. I propose to examine the purpose of these myths and fears, to discuss the possibility that there might be some people who want to infect others, why they might do so and, lastly, what can be done about it.

Good pre- and post-test counselling enables people to 'own' and accept their results.

Deliberate infection, it needs to be said, is very hard to quantify. There are no statistics, no surveys that I have read, no real debate even on the reality of the phenomenon. But it is probably the most talked about issue in all the years of counsellor training I have conducted. I suggest, firstly, that it is a projection of the fears, anxieties and impulses (perhaps the Jungian idea of shadow) of 'the community' onto people with HIV. If we can make them the repository of our worst qualities, we rid ourselves of these dark thoughts. Secondly, it confirms widely held beliefs that people with HIV are morally weaker and untrustworthy. In other words, they are 'other', not like us and therefore we can treat them like inferior human beings. We can blame them for the spread of the epidemic and distance ourselves from co-responsibility. In creating this split between good and bad, we are able to take the moral high ground, to demonise people with HIV and diminish personal responsibility for epidemic control and safer sex. So myths serve the purpose of maintaining the status quo, dealing with an 'intruding' dark force and perpetuating the punishment of the infected. The one truth about HIV infection is that most of it occurs unknowingly by people who are unaware of their own HIV infection. But if deliberate infection were to occur (and I believe that it does, but on a much smaller scale than we imagine), what could motivate the person who does this? The simple answer? Almost anything. But let me speculate.

I imagine firstly that a person who was diagnosed without proper pre- and post-HIV test counselling might feel the result has been imposed on him ("I arrived at the hospital negative and left positive.") and in a sense that result is not accepted and integrated into the psyche. Here, I feel, the result is 'left behind' at the hospital. This denial could lead to a kind of 'unconsciously deliberate' infection where the person with the virus is aware of what he is doing but does not quite believe his HIV-positive status. Is this deliberate? Or a newly infected woman might intend to tell her partner but not quite pluck up the courage because she fears the consequences. How culpable is she?

"But given the general lack of respect for human life in South Africa today, the legacy of years of institutionalised violence, the brutalisation of apartheid, is it surprising that deliberate infection occurs? I think not."

Antisocial tendencies

Some people with HIV might, before infection, have had antisocial tendencies and so their deliberately infecting is part of an existing and on-going process and personality. Or the receipt of a diagnosis might trigger off a massive rage in the infected person, rage which may have its roots in family dynamics, crippling poverty, or humiliating and infantalising racism during apartheid. But most importantly, this rage could be prompted by the climate of intolerance and stigma that has existed around HIV ever since the first known infections occurred in the untouchables of our times; gays, sex workers and drug users. Knowing that your community is hostile and that you face degradation, discrimination, and even death, if you reveal your status is hardly likely to engender social responsibility in a person with HIV.

I think it is possible, too, that a person with HIV might feel that he was not given the choice about being infected and therefore is not prepared to give his next sexual partner the choice either. Who knows why some might choose this route? When it comes to heterosexual transmission, the answer to this question might be found in the amount of suspicion that exists between the sexes. Many men see sexually transmitted infections as women's diseases and a man who finds he is positive might want to infect women as a part of his misogyny, his sexism and, indeed, his patriarchy. Men sometimes feel women are out to trap them, that they have conniving ways. This victim relationship with women (ironical given the status of men in South African society) could, I believe, lead to a basic fear of women. Once this construction has been made, it is not too far fetched to imagine a man wanting to punish all women for who they are, fearful objects.

Cry for help

All of us go about our daily lives 'hurting' the ones we love for all kinds of imagined slights and injuries. Insulting, belittling, humiliating, even hitting. Often this is the legacy of our relationships with our parents. Even though we would not want to infect our partners, it is possible that we want to hurt them, to make them feel our pain. In this context I could see infection of the partner as a cry for help from a wounded person, a desperate act even. Of course, it is a terrible thing to do, but I wonder how often the intention is to kill? This is impossible to answer. But given the general lack of respect for human life in South Africa today, the legacy of years of institutionalised violence, the brutalisation of apartheid, is it surprising that deliberate infection occurs? I think not.

What can be done? Firstly, what is needed is an attempt to understand the psychology of deliberate infection and to offer excellent counselling to those who might be identified as

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Home-based care

Interview with Pauline Molefe of t

Michelle F

You are involved in home-based care programmes for the Esselen Street Clinic. Can you outline for us the work you do?

What happens in the home-based programme is that we visit people who are not in hospital. As you know, hospitals are not able to take people just on the basis of their HIV-positive status. So people are cared for in their homes and we visit them. Mainly we aim to educate the families. This is made easier if the client has already told them about their status - not necessarily the whole family but a member they have chosen. This happens around counselling - we don't actually push clients to tell, but as we work with them we encourage them so that when they become sick and are unable to cope then there is someone in the family who understands what is happening and is able to give care and support within the family structure. Our lives are made easier if the person is

"We don't carry Panado, we don't carry soothing ointment but by just being there when a person needs you you can give a lot of relief."

introduced in good time so that we can create a relationship with the caregiver. It gives the caregiver time to get used to the idea that there is someone that they are going to look after and gives them time to look at their own attitude about HIV/AIDS - how they feel about being close to the person and how they feel about the responsibility. If they are not comfortable then we will rediscuss it with the client. Most often the client's choice remains the best.

Once we have established a relationship, we usually visit the place where the person lives - to assess the environment and see what resources are available nearby like clinics and transport for emergencies. We need to make plans if there is no transport available so that the caregiver won't panic. It's a process to get used to people. What I have found is that the closer you get, the more people open up and you begin to understand the family. You understand the dynamics and culture which makes life easier. You don't want to do things contrary to the family's beliefs. Often people don't say what they don't like, you have to judge their reactions. Families are not the same - each has its own issues.

What sorts of clients and communities do you work with?

We get people from different social backgrounds. The demands are not the same. Some just come in for information - they can afford their own paid caregiver and they want information and guidance on what to do when. Sometimes a family may come in with questions and concerns and they want counselling as a group or want you keep in touch by phone when they need support.

However, the majority of clients I deal with come from very different situations - many are from city flats, squatter areas within the inner city and from the townships. They come in from the townships because they may have a problem of being stigmatised in their communities and they don't want anyone to know. Strictly speaking, the townships are out of our prescribed area but we don't deny people help. Even if we can't see them often, we keep in touch by phone. I do a lot of phone contacts and I'm often called in when the client's condition changes and they need to be transferred to a hospital or to a home. In some cases you go in to give some respite if the family is exhausted or depressed. Often families don't share the responsibility and it's loaded onto one person. So we look for signs of exhaustion. We make the people aware that there are alternative care facilities and we invite them to talk to the staff. It all helps to get the family to agree and be comfortable with a particular home. Then we assist with arrangements.

Home-based care takes place in a variety of to overcrowded inner city high-rise building

Can you describe the sort of home set up that you usually deal with?

It varies. In informal settlements it may be a tin shack with a bed, a primus stove and a table. Water is fetched from the communal tap, the toilet is shared - usually a pit latrine. It's difficult because the whole family may share this structure and there is no privacy and space. Most of the time the client has to be moved to a home or back to the rural areas - because often this type of set up is utilised by people from rural areas.

The second type is inner city flats like in Hillbrow. Sometimes you find these are well organised with some privacy - a kitchen, a bedroom, flushing toilets, hot water. However, there is also overcrowding and lack of privacy, communal sharing of toilets and bathing facilities. Often you find people sharing a small room - not relatives. They rent a space. Often there isn't much respect.

Of course, you get the other extreme. People in a township with a 4-room house in their own yard, toilet, bathroom, etc. It's easier to visit and be able to discuss with them what they can and can't do. In a communal set up it's much more difficult.

Another example is people staying in their employer's houses - maybe in their own room. They may be living with a partner or child.

What is the usual relationship between caregivers and patients? Are they family members/friends/ partners?

It's a combination. Many people in the

"You still find that pe tend to deny the exist own sexual behaviou

e practical issues

C AIDS Programme, Johannesburg

d Galloway

ral settlements where facilities are shared

cities don't have families with them - they stay with friends or partners or flatmates. Often these people are prepared to care for each other. But there are limitations - people work, they can't be around all the time. Clients often end up spending a lot of time alone. That's when you see a lot of depression. During the day, even if they aren't actually sick and can do things for themselves they are alone and that's depressing. So we give out telephone numbers and encourage them to call whenever they need to talk. They don't have to make appointments - they can just pop in. We always make time for our clients. Anything can happen at any time. They can speak to me at any time. I don't like to limit things. On Fridays I usually check in with people to see how they are doing. I also check in on Saturdays and Sundays. If I get any signals that things aren't good I'll arrange to visit them. We don't carry Panado, we don't carry soothing ointment but by just being there when a person needs you you can give a lot of relief. Sometimes people complain of a physical pain when it's really an underlying social or psychological problem. Often our clients keep their own medications including pain killers. The support role is very important. People often have questions for which they can't really find any help. If they at least have access to us it helps.

What are the major practical issues and problems that your home-based care clients face - from the point of view of both the caregiver and their patients?

Caregivers face a lot of depression. Especially when you go from house to house and face different situations. What I have found is that your mind has to switch off quite quickly because you can't carry all the problems. You can't carry them to the next client - you have to be fresh and ready to help. At the end of the day you have to deal with it emotionally - it is depressing. It's frustrating because in some cases there is very little you can do. You may get a person into hospital. If the doctor decides there is no need for admission then you can't afford to panic - you have to help the person

very sexually active because of their

"I didn't learn about AIDS in a book. I didn't see AIDS in a video. I saw AIDS for what AIDS is."

back at home. You also need to be there to reassure them that they aren't being rejected by the health system because they have HIV/AIDS.

The usual things we deal with is getting access to help for social problems. They don't have information about resources or about preparing for retirement and providing for their families. I find it very useful as a caregiver to have that kind of information. People are not well conversant about their rights. Even when they have worked for a company for a long time - they still tend to look up to the employer and believe that whatever he does is right. "Whatever he gives me is what is due to me." As a caregiver you have to have the right information to be able to lead them - to educate them about their rights and benefits. People tend to think that if they apply for a medical boarding or disability grant they will lose their benefits. If the caregiver has the information, can explain it and can actually do something about it like writing referrals and following up - it helps a lot. So it's not just information about exercising and feeding - that's very important - but in other issues you need to be informed about available resources - because that is what you deal with daily. It includes things like who to hand insurance over to. You watch all the clinical reports and speak to the doctor. When the condition deteriorates you have to interest yourself in the other issues. You must be able to help people to plan their future.

What should the health services be offering people in such a home-based care set up? How far can it actually go?

I'm not sure if the health services have enough capacity. It's demanding - in terms of time and limitations. People sometimes tell me that I'm involving myself in areas that are not my responsibility. I do refer my patients on to social workers, the Department of Welfare, spiritual support groups, bereavement groups, etc. Always being there demands time. I keep contact after hours so I'm not really sure that the health services could do that. They have to look at budgets, staff, etc. There is no prescribed procedure - it's something you develop as you work with people. It becomes part of you. They start to look at you as someone who gives them what they need. I share information with my co-workers so that there is always someone who knows the case and can assist. If the patient is in need and I'm not available there is someone around. In that way you decrease dependency on one person.

How many clients do you see at any one time?

It varies. Particularly people who live in city flats. You may see them once or twice and then they are taken home to the rural areas or elsewhere. There are also foreigners who sometimes go back to their countries. When things are not working the family comes to take them home. So the numbers are not stable. We try to maintain at least 20 to 30 people. Obviously we don't see them every day. Of course, people also die. We build up clientele by going to the HIV clinic at Hillbrow on a Wednesday where I assess the people. Some are referred to me by the doctors. Families call and

say that they have a crisis and I take that opportunity to go in and start working with them. Once I transfer a person to a home I don't work with them any more. I may visit them to see how they are doing but I leave it to the home staff to handle things.

Is home-based care really a viable option in a country where ignorance and discrimination about HIV/AIDS still predominates? How can we increase real acceptance at community level?
I don't really know about awareness. A lot of things are going around aimed at making people aware. It's hard to say why we still have these barriers. What I have noticed is that people believe when it is on their doorstep. Otherwise generally saying it's happening doesn't work. You still find that people who are very sexually active tend to deny the existence of AIDS because of their own sexual behaviour. You still find people making jokes and so on. But once it hits them, and I don't necessarily mean personally but people close to them, then it drives the point home. It sounds cruel but the more people who are affected, the less discrimination we will get. Even in the community you still find discrimination which is why most people don't want to be cared for in their own communities. Despite the TV talking about AIDS and World AIDS Day - it's the converted who attend these gatherings, they don't reach the people in the street. You can stand on a street corner and hand out pamphlets and people will throw them away in front of you. Even in the clinics people pick up things and you find them in the bins outside. I don't know if it's the culture of reading or the culture of accepting things - but it is difficult to get to some of our people.

Have you ever had any incidents of people being thrown out of flats because the landlord found out they were receiving care for HIV/AIDS?
People usually don't know when there is someone ill with AIDS in a flat because the family and friends tend to cover it up. Often not even the person next door knows. When you go for a visit this sometimes causes problems. Often the flats have buzzer systems or security guards. If the person isn't able to come down to let you in it's a problem because you can't break the confidentiality to get in. Sometimes you sound the buzzer and the person doesn't respond and there is nothing you can do - you don't want to alarm the whole block. The security guards in flats are not trained in dealing with health issues - they want to know everything. In some instances when we go to a flat we have to leave our ID books and tell them we are doctors or social workers - it's a problem if you can't remember what you said the last time. They sometimes question you on why you are visiting a family and if you say it's confidential they won't allow you in.

I believe that you recently held a "Weep In" at Esselen Street - what was the intention and outcome? Was it a useful exercise for you and your clients?
The group I brought in was families of people who have died. I called the meeting because after a client has died I keep in touch for quite some time particularly with the person who was the caregiver because they may not be able to share with anyone else in the family the pain that my child or my lover died of AIDS. To the rest of the family it's death and they deal with it in a certain way but the one who actually knew that it was AIDS may be afraid that they could be infected or because they don't know who infected their relative. So it's a long-lasting pain because they can't share it. A lot of these people are going through pain they can't get rid of. So I decided to bring them together so that the ones who are struggling to cope can learn from others who may be coping better. Bringing them together helped us because I found that even the people I thought were coping were going through a great deal of pain. I don't know what impression I had in my head to think that some were coping better than others. I found they had a lot of pain. They wanted to tell about their hurt, things they are going through, things they can't deal with - to share. We all cried which was a healing process to me. The opportunity to cry with each and every family in one go sort of took away my pain for a week. But you put on another load.

The overall aim was to develop a support group for bereaving families. We don't have the skill and expertise to do that but I thought it would give them a chance to link up so that they could speak to each other at times when they feel depressed. They shared telephone numbers - things like that. We are still hoping to bring more on board. Now we are thinking of including people who are still nursing others.

The types of things that came out included the attitude of health workers, the attitude within the family, problems at work like not getting time off when it's needed, "running around asking doctors to get me AZT cheaper so that my daughter could benefit - I couldn't afford the money but I wanted to get AZT". It was really surprising to hear how some of us treated them without sensitivity. The remarks that we as health care workers pass - it was horrible.

Was it a valuable experience? Would you do it again?
I would do it again but differently. We didn't record anything that people said which would have been very useful. The stories they were telling could be used in many ways. We could use them to generate discussion without mentioning names. Playing that tape in a family counselling group, for example, would be very useful. People would hear what others had gone through. It would help people to plan better. Secondly, we didn't have any organisation dealing with bereaved families there - they couldn't make it. Next time we would definitely include them - the information would be very useful. It was a good learning experience. The next one will get input from the people - to open it up. If they want to come that's fine - it's healing to help.

What is your personal background and how did you become involved in this work?
I'm a registered professional nurse. I also have a primary health care certificate. I came on board because they wanted a nurse with primary health care skills. I was working in an ordinary primary health care clinic but I really wanted to become involved in AIDS work. I felt I didn't have enough time to be in touch with people. I was just seeing them at a distance. I wondered how I could contribute and fortunately this post became available.

How long have you been doing this work?
Four years now. For the first 2 years I was learning what was happening in the AIDS field and developing my own skills. I didn't come in as briefed as I am today. It happened bit by bit. I was a scared at first. When people started crying I would retreat. Going into people's homes helped a lot. I didn't learn about AIDS in a book. I didn't see AIDS in a video. I saw AIDS for what AIDS is. The other aspects of AIDS - what it does to the family, to the children, to the community. There is very little that you can read in a book - you can't imagine the reality. But when you get out and become involved and learn to differentiate between families and their needs it helps a lot. The most enriching thing about this programme is to know and be aware of family dynamics. My family is not the same as someone else's - you learn to deal with family structures. In each family you'll find a character who is difficult to handle - disruptive, maybe too protective and obstructive. You still have to get by and give the client the information you think is due to them. Family members will often tell you they are coping and you know they are not telling the truth but you have to respect them and give them

an opportunity to make decisions. As long as they don't abuse the client and make decisions for him/her.

Is there a support mechanism for you?
Yes, we have opportunity to share - counselling support. You talk your load out and it's fine. Once I start, I can't stop talking.

Is there anything you would like to add?
I would like to add one thing - if only the larger population could have have access to this kind of information. We need people to co-operate. Co-operate in the sense of being supportive, co-operate in the sense of being sensitive and co-operate in the sense of being helpful. We are getting stuck with orphans - grandmothers are having to take over. For some people unless an orphan comes with a package they are reluctant to take on the added responsibility. If they do, the children are often in an abusive situation. They get secondhand treatment and I don't know how we can counter this. It's all part of the process of preparing - documents need to be signed and the person needs to make agreements regarding their children, write wills, etc. - after their death it becomes difficult. Especially when there is no money. If a granny takes on the children there is also the worry that they may not have long to live. It's another blow to the child to lose a second parent. Another thing we don't have is services to prepare the orphans. Often the parents are not able to inform the children that they are going to die.

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The realities of counsellor training

Pierre Brouard

Earlier issues of the *AIDS Bulletin* and many other publications have featured articles on the "do's and don'ts" of counselling and we continually hear that the standards of HIV/AIDS counselling could be improved. However, counsellors are only as good as the training they receive, and often this vital aspect is not given the attention and respect it deserves. I have been involved in training counsellors in Gauteng, KwaZulu/Natal and the Northern Cape and would like to share some of my experiences of the realities of and constraints to effective counsellor training.

What is training really like at provincial and local level?

The level of training varies depending on the capacity of each province. Usually the bigger and better staffed provinces have more access to trainers of quality and experience both at provincial and local level, but the smaller ones struggle. The dynamics of the epidemic in each province is also an important factor: the most hard-hit provinces have tended to respond sooner and have got their training into gear. KwaZulu/Natal, for example, has more depth and variety in its training programmes, offering, for example, refresher courses, advanced counselling courses and specialised courses. It also has better supervision networks.

The ATIC (AIDS Training and Information Centre) network in a province will also affect training capacity as they have traditionally done a lot of the counselling training. But recent budget constraints, the increasing tension between the provincial AIDS programmes and the ATICs, the varying capacities of local authorities to fund the ATICs and support their work, have made staffing levels and enthusiasm drop in the ATICS and I think training capacity has dropped somewhat. For example, in some centres so many posts have been frozen that training capacity is almost halved. Some provinces have tried to call in other training organisations like Lifeline and hospice but these charge for their services and budgets don't allow this.

I recently did some training in the Northern Cape where there appeared to be somewhat limited training capacity. While there is an attempt to bring in trainers from the Mental Health Directorate to assist with training and supervision, my concern is whether these trainers have been adequately exposed to HIV training issues and dynamics. So, the question remains, how effective and relevant is this training?

I think staff who are appointed to run counselling in the provinces are often too junior (at the level of salary and power) and lack the necessary professional background to train or manage such programmes. They are also too few. For example, Gauteng, which is one of the strongest provincial directorates, needs to use external trainers to meet its training needs.

The ideal person to train is a social worker or psychologist with a training background and the minimum should be a psychiatric nurse with lots of counselling and training experience. I don't believe these people are being appointed to counselling posts and this reflects, perhaps, the lack of status of counselling. Linked to this is the difficulty of 'proving' that counselling works. While it is accepted internationally, and to some extent nationally, that counselling is an essential component of the support for people with HIV, the 'hard' scientists, mainly doctors, want proof of its usefulness. Counselling is seen as one of the 'soft' sciences and therefore has a lower status, priority and funding. I wonder if there is a genuine commitment to establishing counselling networks in the provinces because the time and effort that need to be put into setting this up is enormous.

Political infighting

Political infighting within health departments is problematic and sometimes appointments are made which are not popular and co-operation within, for example, a Communicable Diseases Directorate, may be poor.

If the mentorship/lay counsellor project is examined, it is evident that some of the provinces were given money to get these projects up and running but simply absorbed the money into other projects, or in some cases gave it back because they said there were no organisations with sufficient capacity to use the money. In the case of the Northern Cape, people who have been paid to provide HIV counselling have been working as health advisors because they were not trained in HIV counselling skills. This has been rectified but there are concerns about sufficient and on-going funding for this lay counsellor project. What are the ethics of keeping people on contract posts with no assurance of future employment and how is a provincial counselling network built and sustained with contract workers? One also hears repeated stories of people at district level saying that too much fuss is being made of AIDS. We therefore need to ask whether all levels of staff in provinces are really committed to AIDS.

What are the main issues?

- *Standards*
  There is a lack of understanding of the intensity and difficulty of counsellor training and a superficial commitment to the minimum standards process, which stipulates that counsellors must be selected, properly trained, evaluated and supervised and that you need one trainer for at most 12 trainees. I have provided *advanced* counsellor courses for trainees who had not completed a *basic* course. Trainers end up with courses with far too many participants so the quality of the training drops, as well as the necessary individual attention to trainees.

- *Time constraints*
  With the ever-growing need for HIV/AIDS counselling services, getting sufficient trainees who can get 10 days off work to be trained is very difficult, if not impossible.

- *Selection*
  Trainees are often informed that they must attend courses without assessing their interest in doing HIV counselling.

- *Commitment*
  This varies from province to province and certainly in the hospital sector there is still quite a lot of resistance to counselling and counselling training.

- *Advocacy*
  There needs to be major work done to raise the status of counselling and counsellor training: it is a rare skill and too many people are being asked to do training without the requisite experience and background.

- *Funding*
  Training costs money and money is tight. Health does not always seem to be a priority and is a junior department in many provinces.

- *Space*
  Proper training venues, facilities and equipment are needed to do justice to this work.

- *Capacity*
  There are very few experienced and competent HIV counsellor trainers available to do such training.

In summary, there are major problems with counsellor training in the country. Advocacy around counselling is essential before there are appropriate, accessible and functioning HIV counselling and training networks in place. There are pockets of excellence and some real commitment to proper training and counselling. But, until there is an equal political commitment across all provinces to the minimum standards process, matched by on-going funding and appropriate appointments, the process will stall.

Post Net Suite 184
Private Bag X04
Berea Road
4007
e-mail: pierre@dbn.lia.net

AIDS

Results of the 8th national HIV survey of women attending antenatal clinics of the public health service in South Africa in 1997

Michelle Rotchford Galloway

South Africa has one of the fastest-growing epidemics in the world with an estimated 1500 new infections per day in men, women and children. According to the results of the 8th national HIV survey of women attending antenatal clinics of the public health service in South Africa it is estimated that 17,04% of the women were infected with HIV at the end of 1997. Levels of infection have increased in 8 of the 9 provinces. KwaZulu Natal continues to be the province with the highest prevalence with an increase from 19,9% in 1996 to 26,92% in 1997. The breakdown per province is given in Table 1.

Taking into consideration that the survey was limited to women of child-bearing age, estimates are available only for 15 - 49 year olds. Since fertility sharply decreases after 40 years, the estimates of these groups are based on small numbers and should be interpreted with caution.Women in their 20s have the highest rates of infection at 19,67% and 18,18% for the 20 - 24 and 25 - 29-year-old groups respectively. The rates in the older groups are as follows: 14,49% in the 30 - 34-year group, 9,47% in the 35 - 39-year group, 7,52% in the 40 - 44-year group and 8,82% in the 45 - 49-year group.

Tuberculosis (TB) remains the most common opportunistic infection and the biggest killer. Due to the effect on the immune system, HIV infection makes persons 30 times more likely to progress from TB infection to TB disease. It is estimated that 25% of the 160 000 TB cases in South Africa in 1996 were attributable to HIV.

Figure 1: The growing number of HIV-positive women
HIV prevalence in antenatal clinic attenders in South Africa based on the national surveys conducted in October/November each year

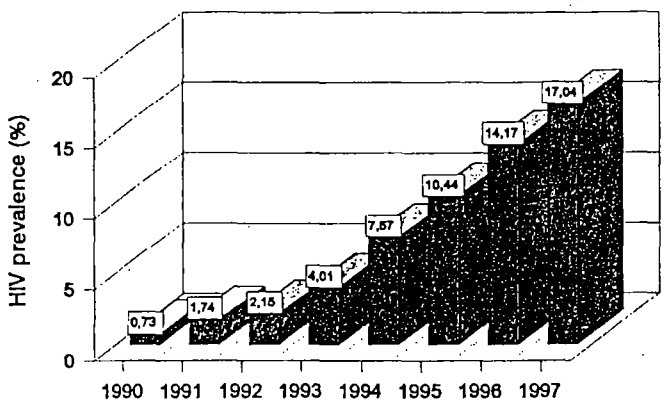


Table 1: HIV prevalence by province for women attending antenatal clinics of the public health sector in South Africa 1996 - 1997

Province	Est (HIV+) 95% CI 1997	Est (HIV+) 95% CI 1996
KwaZulu Natal	26,9 (24,9; 29,0)	19,9 (17,7; 22,1)
Mpumalanga	22,6 (20,5; 24,8)	15,8 (14,3; 17,2)
Free State	20,0 (17,1; 22,2)	17,5; (15,6; 19,4)
North West	18,1 (16,2; 20,1)	25,1 (22,3; 28,0)
Gauteng	17,1 (15,1; 19,2)	15,5 (13,6; 17,4)
Eastern Cape	12,6 (11,0; 14,4)	8,1 (6,9; 9,3)
Northern Cape	8,6 (6,4; 11,3)	6,5 (5,1; 7,9)
Northern Province	8,2 (6,9; 9,7)	8,0 (6,2; 9,7)
Western Cape	6,3 (5,2; 7,5)	3,1 (2,3; 3,8)

Facts

- South Africa has the fastest-growing epidemic in the world
- Estimated 3 million were infected by the end of 1997
- Estimated 1500 new infections a day
- 14-fold increase in HIV prevalence over the last 6 years
- Highest prevalence in KwaZulu Natal with 27% of pregnant women testing positive for HIV
- Youth most at risk with 60% of infections occurring in the 15 - 25 age group
- Projected 20% of the South African workforce will be HIV positive by 2000
- Projected 2,7 million adult infections by the year 2000 (4,5 million by 2005)

AIDS

Launch of Stepping Stones in South Africa

Rachel Jewkes (MRC), Lunah Ncube (PPASA), Janet Fröhlich (MRC)

What is Stepping Stones?

Stepping Stones is a workshop series designed to promote sexual and reproductive health. It addresses questions of gender, sexual health, HIV/AIDS, gender violence, communication and relationship skills. In doing so it recognises that sexual relationships always are situated within a broader context of relationships with sexual partners, families and the community or society in which people live. These influences substantially determine how people behave. It is relatively easy to give people knowledge that they should make changes in their lives, e.g. using condoms, but, often, people find that they are not able to make such changes because they do not communicate well with their partner, fear violence or abandonment, or think their culture or religion does not allow it. If we are to improve health, it is necessary to modify and improve our interpersonal relationships. If we are successful in reducing interpersonal violence and frustrations arising from poor communication people will feel healthier.

Stepping Stones' adaptor Rachel Jewkes from CERSA (second from right), with Audrey Elster, Director of PPASA (second from left), with the three trainers Janet Fröhlich, MRC (left), Lunah Ncube from PPASA (middle), and Matthew Shaw from The Gambia. The Stepping Stones programme is being disseminated in South Africa through a partnership between the MRC and PPASA.

What do the workshops provide?

Stepping Stones workshops provide opportunities for participants to examine their values and attitudes towards gender and relationships, to build on their knowledge of aspects of sexual health and HIV/AIDS, and to develop skills to help communicate with others, so as to ensure that other people know exactly what they want. The workshops are based on participatory learning approaches as people learn better when their knowledge is affirmed and they are able to discuss and decide things for themselves.

How can the manual be used?

The manual is intended to be used in its entirety with a group of participants who work through all the sessions, each building on previous ones. It is designed for use in peer groups, with people of any age and both genders, who are prepared to meet together for the workshops and share aspects of their lives. It was originally developed for use in small, rural communities in Uganda, but has been adapted for South Africa. In making the adaptation we recognise that many South Africans live in cities; community change may be achieved if communities are seen as, e.g. people from a neighbourhood, from a school, a women's group, a football club or a church group. All the exercises are designed so that they can be used in rural and urban settings, with literate and non-literate people.

Stepping Stones manual contents

The Stepping Stones workshops are designed to be held with two or more peer groups drawn from

a community at the same time (although this is not essential). They consist of 14 sessions held with separate peer groups, three meetings of the peer groups together and opening and closing meetings for the whole community.

The 14 sessions for the separate peer groups cover the following topics:

- Introduction and development of group skills
- Images of men and women: exploration of ideals and realities
- Images of sex and sexual health problems
- Exploration of love: what we look for and expect to give
- Exploring our sexuality: problems and concerns about sex and reproductive health
- Conception and contraception
- STDs and HIV
- Safer sex
- Gender violence
- Let's look deeper: Why we behave in the ways we do
- Assertiveness skills: Part 1
- Assertiveness skills: Part 2
- Dealing with loss
- Let's prepare for the future: future decisions and changes

The original Stepping Stones manual has been adapted for use in South Africa by a partnership between the Women's Health Group of the MRC's Centre for Epidemiological Research in Southern Africa and the Planned Parenthood Association of South Africa (PPASA). The launch of the adaptation was held at the Medical Research Council on the 8 September 1998 and this event was followed by the first Training of Trainers course which was held for 26 participants from every province. Funding is currently being sought for further dissemination of the manual including Training of Trainers courses.

If you would like further information about the Stepping Stones manual (for sale, price R100) and Training of Trainer courses, please contact: Rachel Jewkes or Janet Fröhlich, CERSA - Women's Health, Medical Research Council, Private Bag X385, Pretoria 0001. Tel: +27 (0) 12 339 8526, e-mail: rjewkes@mrc.ac.za or jfrolic@mrc.ac.za or Lunah Ncube, PPASA, PO Box 1008, Johannesburg 2109. Tel: +27 (0) 11 482 4601.

AIDS

Obituaries

Jonathan M. Mann and Mary Lou Clements-Mann

Prominent AIDS researchers Jonathan Mann and Mary Lou Clements-Mann died on 2 September 1998 in the crash of a Swissair flight off the coast of Canada. They were on route to a United Nation's AIDS Vaccine Conference in Geneva.

Jonathan M. Mann, born in Boston, was educated at Harvard College and was awarded a medical degree in 1974 by the Washington University School of Medicine. Postgraduate work included an internship in medicine at Beth Israel Hospital, Boston, and a Master of Public Health degree from Harvard University in 1980.

His international career started in 1984 when he founded Projet SIDA in Zaire, the most comprehensive AIDS research effort in Africa at the time. In 1986, he joined the World Health Organisation to lead the global response against HIV/AIDS, and became the first Director of the WHO Global Programme on AIDS (WHO/GPA).

Known as a leading advocate for the importance of human rights and its role in world health, Mann was a tenured professor at Allegheny; founder and director of the Francois-Xavier Bagnoud Center for Health and Human Rights at Harvard; director of the International AIDS Center, Harvard AIDS Institute; and chair of the Global AIDS Policy Coalition. He also edited two of the seminal reports on the status of AIDS, *AIDS in the World* (Harvard University Press, 1992) and *AIDS in the World II* (Oxford University Press, 1996).

Mann's international experiences in AIDS policy led to his interest in the effects of health policies on human rights, the health effects of human rights violations and the inextricable connection between promoting and protecting health and human rights. Based on his suggestion all graduates of the Harvard School of Public Health receive a copy of the Universal Declaration of Human Rights.

In 1996, he married Mary-Lou Clements.

Raised in Longview, Texas, Mary Lou Clements-Mann graduated from Texas Tech University and received a medical degree from the University of Texas (Southwestern) Medical School in 1972. In 1975, she was awarded a DTMH from the University of London, London School of Hygiene & Public Health. She received a Master of Public Health degree from Hopkins in 1979. In addition to her former position as head of the Division of Vaccine Sciences, Clements-Mann held joint appointments in the Department of Molecular Microbiology and Immunology in the School of Public Health and in the Department of Medicine, Division of Infectious Diseases, in the School of Medicine at Johns Hopkins. She also served on the medical staff of Johns Hopkins Hospital and Bayview Medical Center.

She devoted most of her life to developing and testing vaccines to combat the tragic illnesses brought on by bacterias and viruses and was involved in the conduct of trials of candidate HIV vaccines. In 1992, she spent a sabbatical year assisting WHO/GPA in the development of its international HIV vaccine activities. She was a member of the UNAIDS Vaccine Advisory Committee.

At the time of her death, Clements-Mann was principal investigator for NIAID research projects titled *AIDS Vaccine Evaluation Unit* and *Operation of a facility for the study of infectious agents, vaccines and antimicrobials in adult and pediatric human subjects.*

AIDS

From page 15

It could be an added benefit to a teenage child to know that their parent is dying from AIDS so that when we introduce AIDS education they have that firsthand experience and can be peer educators. Children are often left out - even in bereavement sessions. We are not able to explore their pain, to allow them to express anything. I've only had one family who told their teenage daughter what they were going to die from. At the funeral I found that child was stronger than others because she knew what was happening and where she was going to live. We still need these services for teenage children and young adults who are going to be left alone through AIDS. Hopefully their own behaviour can be modified as well. Not to make them afraid of relationships but to make them aware - it's young people who are becoming infected every day. In some families now we have 3 or 4 young people infected in one household. There's a problem somewhere. The adults don't want the rest of the family to know what they are dying from - it's a secret forever. They can't talk about it.

AIDS

Positive cleaners – a positive way of living with HIV

Mary Crewe, GJMC AIDS Programme (better known as 'Esselen Street')

This is a happy story about HIV and AIDS, from a centre where there are not many happy stories. It is about two women who are a real inspiration to other people with HIV and AIDS and who offer a great deal of support to the many people who feel that infection with HIV lands them in a world of reduced opportunity and very little hope.

The Greater Johannesburg Metropolitan Council (GJMC) AIDS Programme is run out of the Community AIDS Centre at 17 Esselen Street. It is housed in the old Colin Gordon Hospital, which is an architecturally famous building being one of the few remaining buildings designed by Pabst. Years of neglect, and uncertainty about who is responsible for the maintenance of this building, have made the outside look as run down as the worst inner city slum building, although the inside is still quite respectable. It is a very large building, housing both the AIDS programme and an STD/Family Planning clinic, and each day many, many members of the public walk through it – seeking clinic services, counselling, advice or support.

During the complex period of 'transforming' Greater Johannesburg, the cleaning staff at Esselen Street were deployed elsewhere. In line with the stringent budget cuts, these posts were not replaced. This meant, in effect, that one of the largest and busiest inner city clinics as well as the AIDS programme were responsible for their own cleaning of the building. This was done through a staff cleaning roster, and soon the inside of the building started to resemble its outside, as staff legitimately refused to move from counselling to cleaning the toilets and back to counselling!!

About 3 months into this slide into squalor, the building was visited by two NAPWA members, who expressed their dismay at the state of the building and offered to clean it, in "recognition for the way they got support and felt at home". Initially, it was possible, through devious means, to pay them a daily rate and they came in once a week. Included in this rate was tea and coffee and lunch. It was clear that this system could not last – the AIDS programme officially has no petty cash and so could not pay in this way for very long and clearly the building required more sustained cleaning.

The clinics in the building are under the control of the Eastern Metropolitan Local Council (EMLC), while the AIDS programme rests in the Metropolitan Council. The two NAPWA members were cleaning both the clinic and the rest of the building. The EMLC were able to put the cleaning of the building out to tender, but only to companies. In response to this the two women formed themselves into a company called: ***Positive Cleaners and Maintenance.*** The company was formed under the auspices of NAPWA, backed by the GJMC AIDS Programme and solely for the purpose of giving employment to people with HIV and AIDS. While the company was formed to secure the cleaning contract, they were also able to offer maintenance services such as gardening, basic painting and repairs to the clinic buildings. The building is impeccably maintained.

They were awarded the tender for 6 months and at the same time the AIDS programme had managed to secure contract appointments for them for one year. The clinic tender paid well, but the contract posts were bound by the Metropolitan Council salary scales. After being unemployed for a long time, both women found that they had sufficient money to open cheque accounts, and were able to employ other NAPWA people to do basic maintenance at the centre or at other clinics as required. They also were able to make long-term saving investments. Essentially they could live off the GJMC salary and invest the money from the tender.

Personal development

But the creation of ***Positive Cleaners*** was of greater significance than just forming the company. The health of both women has improved significantly, as has the general health of their children who are now receiving sufficient food and are able to be in day care and at school. The women have developed greatly in their personal confidence and have become accomplished speakers about living positively with HIV.

They no longer do the cleaning of the clinic – the EMLC decided to award one tender for the entire area and ***Positive Cleaners*** were unable to compete. They have submitted a proposal to the AIDS Foundation for a one-off grant to purchase essential equipment so that they can tender competitively when other tenders are published. They are training other people with HIV and AIDS so that when they are able to expand their operation they will have a group of well-trained staff able to start work immediately.

But perhaps the most significant part of the story lies in the fact that they no longer feel ashamed or guilty about their status. In fact, it is their HIV infection that opened this opportunity to them, coupled with the employment and support they have received from the EMLC and the GJMC AIDS programme. They are able to be proud and assertive within their families, able to be confident about their children's futures and are able to think about whether they wish to openly declare their status to the community in which they live. They recognise that while people with HIV who are open about their status contribute to prevention efforts, it is also equally acceptable that people with HIV have no need to declare their status beyond a close circle of friends or counsellors.

They represent a source of inspiration and hope to the many other people in NAPWA who are looking at creative and innovative ways to earn a living and ensure that HIV is a source of opportunity rather than a cause for despair and hopelessness.

Positive Cleaners can be contacted at: Tel: +27 (0) 11 725 6711/2/3 or Fax: +27 (0) 11 725 5966.

AIDS

Deliberate infection, from page 11

at risk of deliberately infecting, perhaps through referral to specialised counselling services. Secondly, we can stress that rights go with responsibilities. The right to confidentiality goes with the responsibility to protect our partners. But similarly, the right to be told our partner's HIV status goes with the responsibility to protect ourselves during sex with someone who is unaware of his HIV positivity (sexism, abuse and rape notwithstanding). The responsibility to limit the epidemic is not so much with the infected but the uninfected - it is a shared responsibility. Thirdly, we can continue to promote a human rights culture around HIV and AIDS and to encourage communities to be open and accepting. Destigmatisation of HIV would go a long way towards promoting greater openness in the HIV community. Fourthly, we can make sure that we give the very best pre- and post-HIV test counselling possible to help people 'own' and accept their results and to support them through their lives. Lastly, we can try to research this phenomenon so that we know its extent. This could allow us to separate myth from reality, develop perspective and a rational response.

Post Net Suite 184
Private Bag X04
Berea Road
4007
e-mail: pierre@dbn.lia.net

AIDS

Interview, from page 10

Do you have any ideas on how one prepares people for HIV vaccine trials?
SA must start developing a systematic, multi-faceted community education plan that will include activities at the national and local site levels and a needs assessment for community education materials and strategies. The only way to answer the up-front ethical and social concerns communities may bring is to offer public information until there is consensus in a community to move forward with the trial.

What about trial participants who become HIV positive due to their participation? What care should they be offered? Who should finance such care? How can we reduce/ prevent discrimination against them? What about the risk of people participating in trials because they believe they will receive a better standard of care than that which is generally available (particularly in a setting like SA where HAART and other treatment options are not generally available)?
It is not probable that most persons would receive any treatment that is not readily available in SA. Informed consent should help eliminate those who would sign up for a trial in order to obtain better medical care. Trial participants should be made to understand just what is available to them before enrollment - a risk-benefit profile of trial participation.

During the informed consent process, prospective participants should be warned of the specific areas in which there is a potential for social harm. Easy-to-use pamphlets should be prepared to help participants anticipate possible social harm situations, and deal with them once they occur. Participant ID cards with an 800 number for special assistance have already been used in Phase I and II trials and should be available in Phase III trials as well.

"The only way to answer the up-front ethical and social concerns communities may bring is to offer public information until there is consensus in a community to move forward with the trial."

Can you tell us a bit about your personal background - what prompted you to become involved in this kind of work?
The personal loss, health care systems growth and change, struggles with ethical dilemmas and experience of reacting to changing priorities of the HIV/AIDS epidemic have encouraged me to devote life energy to mounting an HIV-prevention response. I also work daily with populations who do not have the resources to adapt safer sex behaviours or sometimes want to make changes in their lives. A vaccine is the only way to ensure their protection against the virus. I am an African American male who has the vision to do this work rather than use my talents in the for-profit industry. I have the ability to translate my care for the world and acumen into leadership in making the changes necessary to begin to address this pandemic. At least I have a willingness to try.

Health care advocate, public health activist, consumer health ally are some of the self-imposed titles which I have employed during my 11+ years of not-for-profit work. I sincerely believe that system change occurs as issues are brought to existing constituencies in a manner which engages them in finding solutions which meet shared objectives.

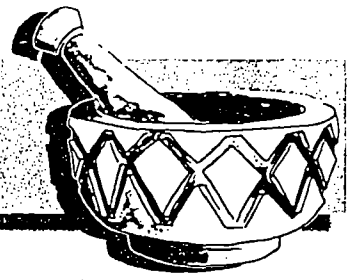
Is there anything else you would like to add/discuss?
The vaccines that are currently available for testing on human subjects are aimed at providing protection against the clade B strain of HIV. This strain is most common in North America, and is found in South Africa among men who have sex with men. However, the most common strain of HIV in South Africa is clade C virus. Participants at the resent SA ethics conference presented arguments for starting trials with a clade B vaccine, based on evidence for cross-clade reactivity. Others suggested that laboratory research on correlates of protection (that is, which of the measurable immune system responses actually provide protection from infection?) continue until a clade C vaccine is available for testing. South Africans clearly want to provide leadership in a scientific agenda that has development of a clade C vaccine as its first priority. The scientific leadership in SA is appropriately ready to take on vaccine research.

ALSO:
The number of HIV/AIDS-related deaths are down dramatically for white Americans. Blacks have seen the same result only when barriers to care make it possible for Blacks to have access to these drugs. Today's HIV treatments are as accessible to most of the world as a formal black tie dinner. The chef has prepared a sumptuous banquet, her assistants have created flawless presentations, wait staff are prepared to ensure an unrivalled dining experience...yet most of the world will not be allowed in the banquet hall. As a matter of fact, they cannot imagine what it is like to watch the guests arrive. Black participation in vaccine clinical trials can create a community which assures we will not only be at the table, but will help determine the menu and type of service available.

AIDS Vaccine Advocacy Coalition
1948 West Evergreen
Chicago USA
e-mail: BMWHRD@aol.com

AIDS

RESEARCH FLASHES



Sassan-Morokro M, Wiktor SZ, Abouya L, *et al. Significant reduction in mortality attributable to cotrimoxazole prophylaxis among HIV-infected tuberculosis patients in Abidjan, Cote d'Ivoire*. Abstract presented at the 12th World AIDS Conference, Geneva.

Seven hundred and sixty HIV-1 or HIV-1/2 dually infected patients with sputum-smear positive pulmonary tuberculosis were randomised to cotrimoxazole 960 mg daily or placebo. This was commenced after 1 month of conventional short-course anti-TB therapy. Prophylactic cotrimoxazole was well tolerated and compliance was excellent. There was a 44% reduction in mortality in patients taking cotrimoxazole (P = 0,006). Hospitalisation was also reduced. The effect was greatest in patients with the lowest CD4+ lymphocyte counts.

This study is important as it is the first to evaluate the efficacy of prophylactic cotrimoxazole in sub-Saharan Africa. This intervention is recom-mended in patients with evidence of immune suppression either on clinical (AIDS-defining illness, oral candidiasis or hairy leuoplakia, or unexplained weght loss, chronic diarrhoea or fever) or on laboratory assessment (CD4+ lymphocyte < 200/ul). Low dose cotrimoxazole prevents *Pneumocystis carinii* pneumonia. Because this is relatively uncommon in sub-Saharan Africa, prophylactic cotrimoxazole is not widely used here. However, cotrimoxazole also reduces other HIV morbidity such as toxoplasmosis, bacteraemia, bacterial pneumonia and some causes of diarrhoea all of which are common in Africa. Offering cotrimoxazole to every TB patient co-infected with HIV is probably not warranted in view of the fact that only immune-suppressed patients benefitted in the Cote d'Ivoire study. If CD4+ lymphocyte counts are unavailable then the presence of other clinical features of immune suppression or the type of TB (extrapulmonary or disseminated) could be used as indications for administering cotrimoxazole. Other studies have shown that lower doses of cotrimoxazole (480 mg) are as effective.

This is a cheap and effective intervention which will prolong life, improve the quality of life and reduce health care utilisation. It deserves to be implemented widely.

Prepared by Gary Maartens, Department of Medical Microbiology, University of Cape Town.

Johns Hopkins international Initiative for tuberculosis control

Through training, operational research and intervention studies, the Johns Hopkins School of Public Health is launching an international initiative to improve TB control in Haiti, Honduras, Brazil, Peru, South Africa, and Russia with its partners, the University of Alabama at Birmingham and the Gorgas Institute. With funding from USAID, the initiative plans to provide regional and national assistance to improve surveillance for disease and drug resistance, to foster operational improvement in local and national tuberculosis control programmes, and to evaluate new and innovative approaches to community-wide interventions to reduce tuberculosis incidence. The initiative aims to improve:

- Success of WHO's Directly Observed Therapy, Short Course (DOTS);
- Control of multi-drug resistant strains of TB, and
- TB control in HIV-epidemic areas.

Personnel involved in the initiative have a broad array of experience in tuberculosis control and research, including laboratory-based studies of drug-resistance and diagnostic methods, research on tuberculosis-HIV interactions in developing countries, and clinical trials of new preventive agents. If you would like further information about tuberculosis control, please contact Laura M. Kelley at: Tel: + 410 614-5439, Fax: + 410 955-7159, e-mail: lkelley@jhsph.edu http://www.ih1.sph.jhu.edu/chr/chr.htm or http://www.hopkins-id.edu

Margaret Johnston moves to NIH

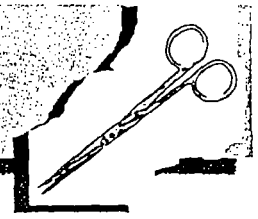
Margaret Johnston has left the International AIDS Vaccine Initiative (IAVI) to assume the positions of Assistant Director for HIV Vaccines, National Institute of Allergy and Infectious Diseases (NIAID), National Institutes of Health (NIH) and Associate Director for Vaccine and Prevention Research, Division of AIDS, NIAID, NIH. In these capacities she will oversee NIAID's extramural HIV vaccine and prevention research efforts, help ensure co-ordination and integration of these efforts with intramural efforts, and represent NIAID to other institutes, agencies, communities and organisations in the field of HIV vaccine and prevention research. Dr Johnston was the first employee of IAVI and conceptualised and implemented IAVI's scientific programme. In her new position she aims to remodel and unify NIAID's clinical vaccine research programme, foster new prevention research activities; and strengthen NIHs collaborative interactions with other domestic and international agencies and organisations, the private sector, developing country scientists and communities. Dr Johnston can be contacted at: tel: + 301 496 8200, fax: + 301 402 1506, e-mail:pjohnston@mercury.niaid.nih.gov

Useful MMWR Report

The CDC Morbidity and Mortality Weekly Report (MMWR) Recommendations and Reports of 25 September 1998, Vol. 47, No. RR-17 is entitled: *Management of possible sexual, injecting drug-use, or other nonoccupational exposure to HIV, including considerations related to antiretroviral therapy.*

AIDS

SNIPPETS FROM THE PRESS



The CDC National Center for HIV, STD, and TB Prevention makes available this information as a public service. We publish these in the interests of information provision - this does not constitute endorsement by the CDC or by *AIDS Bulletin*.
Source: *CDC NCHSTP Daily News Update*, 1997, Information, Inc., Bethesda, MD
Accessed via World Wide Web
http://www.cdcnac.org/summary.txt

Zuma defends AZT policy

Africa News Service **(10/15/98); Barrell H; Hess S.**

South African Minister of Health Nkosazana Zuma is defending her decision not to make AZT generally available to HIV-positive pregnant women because of expense and the possibility of low success rates. Zuma says she is more interested in putting South Africa's resources into preventing HIV in the first place and plans to encourage a serious proposal from some of the country's top medical researchers, who are developing a vaccine to counteract one of the strains of the virus more prevalent in Africa. According to Zuma, it would cost R8 million to treat mothers known to be HIV-positive and that if 100 HIV-positive pregnant mothers are treated with AZT during pregnancy they would still produce about 15 HIV-positive children, compared to 30 HIV-positive children without the AZT treatment. Doctors and HIV-positive people are angered by Zuma's decision, especially because the pharmaceutical company Glaxo Wellcome announced this week that it was willing to cut the prices of drugs such as AZT and 3TC to benefit poorer countries with fewer economic resources.

Post-Exposure Prevention (PEP); What to do if the condom breaks?"

AIDS Treatment News **(09/04/98) No. 302, p. 1; James JS.**

While the Centers for Disease Control and Prevention has published guidelines on the use of post-exposure prophylaxis (PEP) for possible inoculation with HIV through needle-stick accidents in health care workers, no such guidelines exist for people similarly exposed through sexual contact or intravenous drug use. PEP treatment involves the four-week administration of antiviral drugs immediately after needle-stick in order to prevent HIV infection. The drugs involved can be prescribed by any physician; however, few doctors currently know about prescribing PEP for possible HIV infection via sexual exposure. Still, there are some programs designed for people who are possibly exposed in non-health care environments. A PEP trial in San Francisco, for example, will provide treatment for people who qualify as having 'significant' risk of exposure. This includes intravenous drug use, receptive or penetrative anal intercourse, or receptive oral intercourse with ejaculation. Unprotected sex or sex with someone who is HIV-positive also constitutes significant exposure risk. The treatment also includes counseling on risk reduction, sexually transmitted disease screening and treatment, hepatitis B and C screening, hepatitis B vaccination or referral, and pregnancy testing. About 150 people have been tested thus far, with no reported cases of infection. Researchers are unsure if the lack of infections is due to the treatment or not. They are also unsure if the treatment encourages risky behavior, since the evaluation period has been short.

Progress of HIV found to be faster in women

Washington Post - Health **(08/04/98) p. 5; Boodman SG.**

HIV-infected women develop AIDS quicker then men, according to a study of 650 intravenous drug users by researchers at Johns Hopkins University. The study also reports that HIV-infected women with the same viral load as men will generally be much further along in the progression toward AIDS. Homayoon Farzadegan, lead author of the study, says that the results will affect what recommendations doctors are given as to when they should begin drug treatment. The National Institute on Drug Abuse funded the study.

HIV, tobacco are biggest killers worldwide

Reuters **(09/07/98); Reaney P.**

Epidemiologist and medical statistician Richard Peto of Oxford University in Britain announced Monday that HIV and tobacco use are the leading causes of death worldwide. He noted that the best way to reduce mortality rates is to target these two problem, noting that more lives can be saved by moderately reducing major causes of death than by greatly reducing lesser causes of death. According to Peto, while smoking is responsible for more deaths worldwide than anything else, those who quit still have a good chance of avoiding increased risk of mortality. In regards to HIV, Peto said that different populations have to be addressed and that prevention is currently the best method to deal with HIV.

Socioeconomic status does not influence AIDS survival

Reuters Health Information Services (08/03/98)

Researchers studying more than 18 000 diagnosed with AIDS between 1985 and 1995 have found no relationship between socioeconomic status and survival. In the August 1 issue of the *American Journal of Epidemiology*, the researchers report that the median survival time was 22 months for individuals in impoverished or working-class neighborhoods and 23 months for those in 'higher income' or 'predominantly professional/managerial neighborhoods'. Median survival was 23 months for all patients when the neighborhoods were characterized by patients' educational levels.

Doctors blast South Africa for withdrawing AIDS campaign money

Boston Globe Online (10/11/98)

Physicians have spoken out against a decision by the South African government to cut funding for a treatment program serving HIV-infected pregnant women. Five pilot programs supplying AZT to HIV-positive pregnant women were shut down, and Health Minister Nkosazana Zuma announced that the $14 million campaign would be better spent on public education. Glenda Gray, director of an HIV research unit at Chris Hani Baragwanath Hospital, argued that the treatment programs are "a real way we can prevent transmission and the government is not intervening." As many as 200 HIV-infected infants are born in the country daily, with up to 46 percent of infected mothers passing the virus on to their children. The treatment was estimated to cost up to $131 per patient.

AIDS

INFORMATION SERVICES

AIDS Consortium Resource Centre

The AIDS Consortium Resource Centre is situated in Braamfontein, and serves the broader HIV/AIDS community in South and southern Africa. Initially established to support human rights and legal issues at the University of the Witwatersrand, it has grown into an information service aimed at providing information support to all people involved in HIV/AIDS, i.e. community organisations, nursing training, scholars, students, lobbyists, AIDS education programmes, prevention strategies, home-based care, trainers, etc.

Contact: Valerie Fichardt, AIDS Consortium Resource Centre, PO Box 31104, Braamfontein, 2017, South Africa.
Tel: +27 (0) 11 403 0265, Fax: +27 (0) 11 403 2106,
e-mail: resource@global.co.za

Health advocacy training course

Is your voice being heard?
Enhancing your advocacy skills for the current health policy context in South Africa.

Convenors: Mr Kevin Osborne (The Policy Project); Ms Judi Nwokedi (Advocacy Initiatives); Ms Julie Oyegun (The Gender Equity Project, UWC); and Ms Nikki Schaay (Public Health Programme, UWC).

The terms advocacy and lobbying are frequently referred to by health workers, development activists and policy makers. The subtle art of advocacy and the skills involved are the focus of this course which will provide participants with an opportunity to develop their capacity to pro-actively engage with the dynamic advocacy process. While aspects of the programme focus specifically on HIV/AIDS-related matters, the skills learnt are applicable to any health issue.

At the end of the course participants: will have an overview of some of the past and current health advocacy initiatives in the country; will have a practical grasp of the advocacy process which will enable them to influence change in the health sector by developing, orchestrating and implementing a successful advocacy initiative; be able to constructively work with the media; will be familiar with - and be able to network with other local advocacy initiatives; and, be able to work in collaboration with others in developing an advocacy campaign.

Training sessions are co-facilitated and developed to allow participants to work practically on a particular advocacy campaign. Presentations on current health advocacy initiatives are incorporated and an advocacy manual/ workbook is provided.

The course content includes:

- An introduction to the history of health advocacy in South Africa;
- An introduction to the key elements of an advocacy campaign (e.g. identifying key policy issues, designing advocacy goals and objectives, selecting the primary and secondary target audience, and ensuring effective networking and collaborative partnerships).
- An introduction to key advocacy approaches and methods used in working with the media. This will include the development of media briefs and statements, the organisation of a press conference, writing press releases and blurbs, etc. in order to ensure that the press, radio and television give adequate coverage to the issues that you would like highlighted.
- A critical assessment of some current advocacy initiatives, such as the campaign to seek inter-ministerial support for HIV/AIDS programmes; the HIV notification debate; the initiative to prevent violence against women, the 'Women can make it Happen' cancer initiative; and the anti-tobacco lobby.

Target group: The programme is designed for a diverse audience, e.g. managers with responsibility for health policy and education in government departments and private corporations; human resource and personnel managers; trade union officials; health workers at district, regional or provincial level involved in the management of health programmes or institutions.

The course runs from 8 - 12 February 1999 as part of the Public Health Programme, University of the Western Cape Summer School, Bellville. Cost: R950,00 (includes manual and course notes). For information contact: Ms Nikki Schaay Tel:+27 (0) 21 788-9015 or e-mail: nrschaay@iafrica.com

Future Positive - Financial Planning with HIV/AIDS

Southern Life has launched *Future Positive*, a booklet designed to provide information to people living with HIV, their families and their doctors about how best to manage the financial impacts of HIV/AIDS and plan for living positively into the future with HIV and AIDS. The booklet covers financial planning, planning for health care needs, planning for retirement and "how will my family get by after I die?". For more information contact Southern Life at Tel: +27 (0) 21 658 0911.

Pupils rewarded for anti-AIDS efforts

Schoolchildren from all over the country have recently been rewarded for their anti-AIDS efforts as part of Old Mutual's *I have hope* Peer Group Project. The countrywide project is run by Christo Greyling, an Old Mutual Consultant who has been living with HIV for the past 11 years, and his wife Liesl. The programme consists of a 3-day workshop, followed by monthly meetings aimed at encouraging the pupils to embark on AIDS awareness projects reaching out to their peers, their communities and people living with HIV/AIDS. After 6 months each school submits a progress report and does a short presentation depicting their activities.

Some of the recent winners include: Strelitzia Secondary in KwaZulu Natal, Rhenish Girls High in the Western Cape and St. Andrews High School in the Free State.

According to Greyling: "Peer leaders are key to creating an awareness of AIDS - they accept responsibility for their own sexual behaviour and act upon their understanding of AIDS and in their unique way, bridge the communication gap caused by cultural differences."

For more information on the *I have hope* programme contact: Desiree Daniels, Old Mutual, AIDS Focus Area, PO Box 66, Cape Town 8000, Tel: +27 (0) 21 509 3412, Fax: +27 (0) 21 509 5193, e-mail: ddaniels@oldmutual.com

Meanwhile 4 pupils from Mathew Goniwe High School in Khayelitsha in the Western Cape have found that getting enthusiastic about safe sex education can have unexpected benefits. The 4 won the top prizes in a poster competition run by the Society for Family Health (SFH). The pupils attended skills-building workshops and went on a week-long camp where they were taught media and drama skills. They were then supplied with materials to develop posters that would reflect messages about safe sex. About 5000 of the posters will be circulated in Eastern and Western Cape schools.

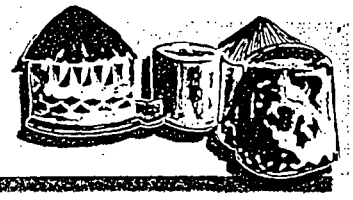
For more information contact SFH at tel: +27 (0) 21 448 7303 or fax: +27 (0) 21 448 8075.

HIV ethics guidelines available soon

A set of ethical guidelines for HIV researchers in South Africa will be available shortly. They were commissioned by the Department of Health and the MRC and are intended as a supplement to the MRC's existing ethical guidelines. Watch the *AIDS Bulletin* for further information.

AIDS

CONFERENCES



International

1998

International Conference on the discovery and clinical development of antiretroviral therapies
13 - 17 December, St. Thomas, West Indies
Contact: International Medical Press
2989 Piedmont Road
Atlanta GA 30305 USA
Tel: +1 404 233 6446
Fax: +1 404 233 2827
e-mail: ICDCD@intmedpress.com

7th SWAA Conference on Women and AIDS in Africa
14 - 17 December, Dakar, Senegal
Theme: Expanding the response: Enhancing the participation of men
Contact: Chairperson 7th SWAA Conference
BP 7504 Medina
Dakar, Senegal
Tel: +221 823 8847
Fax: +221 824 3722
e-mail: swaa@telecomplus.sn

1999

AIDS impact: 4th International Conference on the Biopsychosocial Aspects of HIV Infection
15 - 18 July, Ottawa, Canada
Contact: Canadian Psychological Association
205-151 Slater Street
Ottawa K1P 5H3 Canada
Tel: +1 613 237 2144
Fax: +1 613 237 1674

South Africa

1998

Overcoming the impediments to the strategy against HIV and AIDS
26 - 27 November, Bloemfontein
Contact: Prof. Dingie van Rensburg & Prof. Charles Ngwena
Tel: +27 051 401 2181
Fax: +27 051 448 0370
e-mail: svr@rs.uovs.ac.za

1999

Neurology Congress
4 - 6 March, Cape Town
Contact: Ms Sally Elliott
Postgraduate Conference Division
UCT Medical School
Observatory 7925
Cape Town
Tel: +27 21 406 6381
Fax: +27 21 448 6263
e-mail: sally@medicine.uct.ac.za

The Southern African development scenario
Challenges for the New Millennium
7 - 8 April, Johannesburg
Contact: Adene Pringle Conference and Seminar Planning
PO Box 2163
2125 Randburg
Tel: +27 (0) 11 787-8690
Fax: +27 (0) 11 789-5021
e-mail: adene@icon.co.za

Critical care congress
17 - 21 May, Cape Town
Contact: Ms Sally Elliott
Postgraduate Conference Division
UCT Medical School
Observatory 7925
Cape Town
Tel: +27 21 406 6381
Fax: +27 21 448 6263
e-mail: sally@medicine.uct.ac.za

AIDS

Comment

10 December 1998

AIDS battle should involve all

SA needs political leadership to avoid the effects of the HIV epidemic, writes Alan Whiteside

SOUTH Africans were bombarded with data on the AIDS epidemic on December 1, World AIDS Day. This year the global focus was on southern Africa. This was partly because Peter Piot, the head of the United Nations (UN) AIDS body, was in SA, but also because President Nelson Mandela, at last, made a public pronouncement on the issue.

This day also saw the release of two important new publications. The first was from the health department; the second was the UN Development Programme's SA National Human Development Report, which focused on HIV/AIDS. Both publications warn of a looming crisis for SA and call for urgent action.

The problem is that most people in SA are not seeing evidence to suggest that AIDS is an issue for the country. The reason is that most of the data relates to the HIV epidemic, not to AIDS. People with HIV can lead normal, productive lives and cannot, except by testing, be distinguished from those who are not infected.

It is estimated that the period between infection and illness is between five and eight years. There are an estimated 3,2-million people in SA who are infected, but that does not translate into 3,2-million South Africans falling ill and dying - yet. Furthermore, most of those with HIV have no idea that they are infected.

The reality is that SA is experiencing one of the most serious HIV epidemics in the world. In 1990 fewer

than 0,5% of the adult population was infected. By this year the estimation rose to 13%. There is wide variation between and even within provinces.

The data on HIV prevalence comes from the antenatal surveys carried out every year by the health department. Last year, the most recent year for which figures are available, HIV prevalence indicated in these surveys ranged from 6,3% in the Western Cape to 26,9% in KwaZulu-Natal. However, in the Cape metropolitan health region, HIV prevalence was 8,4% while Empangeni in KwaZulu-Natal recorded a prevalence of 34%, the highest level in SA.

The message is that, in some parts of the country, a concerted prevention campaign could significantly reduce the level at which the epidemic peaks. That is not to say that prevention should not be a priority throughout SA. Even in the areas with the highest levels of HIV infection, the majority of people are uninfected and there are always new cohorts becoming sexually active.

Clearly, given the current levels of HIV prevalence, prevention activities to date have not been successful. It appears that, since 1990, HIV has spread without check. The result is that millions of South Africans are condemned to death or to being orphaned.

The apparent bankruptcy of prevention efforts to date have resulted in government calling for new initiatives and the latest theme is Partnership against AIDS. This was the call of Deputy President Thabo Mbeki on October 9, when he addressed SA on behalf of the president and it has been echoed by many others since.

However, the problem is that AIDS is only beginning to be among us and it is not clear what the arguments are for everyone to get involved.

The question that really needs to be answered is what effect an increase in AIDS will have in terms of illness and death and how that should influence our response.

It is clear why government needs to respond. Preventing AIDS is in the public interest. Dealing with illness and death will be the responsibility of government.

The health departments will have to provide care, which is expensive and means that resources have to be diverted from other uses. The welfare departments will be called on to provide care for the many hundreds of orphaned children. Yet for those not directly affected the question is why and how should

we respond, apart from feeling very sorry for AIDS-hit families.

Furthermore there are actually two responses being asked of South Africans - the first is to support prevention efforts and the second is to deal with the inevitable increase in illness and death the country faces.

Research shows that, at the moment, AIDS is not seen as an issue by most of the private sector. With a few exceptions, they are either ignoring it or taking steps to reduce their exposure to the disease. This is done by reducing the impact (excluding HIV positive people from employment is illegal and impractical, but is still being done); however, firms can resort to multiskilling, casualisation of labour and downsizing.

All is being driven by the new labour legislation and it may stand the companies in good stead as the AIDS epidemic gains momentum. Companies can reduce or shift the costs of the disease. Medical benefits can be reduced or restricted and it is certain that insurance premiums will rise or payouts decrease.

At the level of the national economy, it is uncertain what impact AIDS will have. It is possible that, because SA has a more sophisticated economy with a well-developed financial sector, it may be vulnerable, but the reality is that the actions of international currency speculators or the European Union negotiators may have a greater effect in one day than AIDS has in 10 years.

The real impact of the disease is felt at the household level. It is the poorest families and above all women, who will bear the brunt of AIDS. This will be seen in some development indicators.

For example, it is projected that life expectancy in SA has already fallen from 65 to 55 years and this decline will continue. Both infant and child mortality rates will rise and it will be the poorest communities that will suffer most

The human cost aside, there is one very serious result of the epidemic which has not been quantified and is only now becoming evident. This is the effect on society in general.

There is growing evidence to suggest that in the countries where the governments try to cover up or ignore the problem and there is discrimination and stigma, the fear of the disease and the belief that "everyone is infected" may lead to political and social instability.

Also, in nations with a strong civil society, the epidemic is less likely to spread rapidly. There is also evidence that where the epidemic has led to reassessment of basic human relations, including womens' rights and powers, there is more chance of prevention working.

SA is once again at a crossroads. Our society is already wracked by divisions, AIDS has the potential to widen them. On the other hand, political leadership, openness, an honest attempt to address the problem, with a realisation of what it may cost if we do not deal with AIDS, could make SA stronger.

As we end the decade, we face the challenge of AIDS and so far it is the most important issue to confront our new society. That is why we all need to become involved and for a new partnership. If this works we will benefit in many ways that go beyond the epidemic.

Whiteside is a professor with the University of Natal's health economics and HIV/AIDS research division.

MILLENNIAL MEGABOMB

One of the most shocking aspects of the growing AIDS epidemic is the inability of the media and many others to see and portray it properly, writes **Lesley Lawson.**

ABOVE

A patient with AIDS at Edendale Hospital in Kwazulu Natal. Because she had been rejected by her family and community after they discovered that she had AIDS, she did not want to be identified.

Twenty-one-year-old Nat Khumalo (not his real name) discovered that he was HIV positive after a routine but compulsory blood test at his workplace. On the day he got this news he was also dismissed from his job. Knowing only that HIV meant certain death, and being too afraid to talk to anyone about it, Nat joined a gang and took to life on the streets.

"I couldn't sleep at night," he says, "and I wanted to kill myself, but I thought that it would make people suspicious. So I decided to live a risky life in the hope that other people would kill me."

It took Nat six years to realise that he could live a normal healthy life with HIV. Today he is a trained counsellor at an Aids testing centre in Johannesburg. He devotes his energies to convincing infected youths that they too can live positively with HIV, and that by doing so they can extend their healthy years.

Nat is one of three million, mainly young, South Africans who are HIV positive. His story is unusual, not only because it has a happy ending, but also because he is one of the few who know of their infection long before it turns to illness. This asymptomatic period in the HIV/AIDS cycle is thought to be an average of eight years for most South Africans. Babies and children become sick sooner than adults because their immune systems are immature.

For over a decade the HIV epidemic has been working its way silently across South Africa, thriving on the fear, ignorance and apathy which is shared by the power brokers, mass media and civil society at large.

Since 1990, an anonymous annual survey has been conducted at South African antenatal clinics. The results show an almost exponential rise in infection, leading UN Aids researchers to describe South Africa's epidemic as one of the fastest growing in the world. Commenting on the 1997 survey, Dr Thomas Muhr, the Metropolitan Group's Aids researcher, says that the worst-affected areas of the country are "reaching heights that were considered to be pessimistic scenarios in the early projections of the epidemic."

The survey has shown that the rate of HIV infection among pregnant women has risen from under 1% in 1990 to 16% in 1997. Large regional variations exist - from nearly 27% in KwaZulu-Natal to under 6% in the Western Cape. These figures are aggregates, and mask the fact that certain communities and workplaces are experiencing levels of HIV which are equivalent to those in the worst-hit African countries.

The impact of HIV/AIDS is already clearly observable at hospitals, hospices and testing centres around the country. For example, a study conducted in the paediatric department of Chris Hani Baragwanath hospital shows that the prevalence of HIV-related admissions between 1992 and 1996 increased from 2.6% to nearly 30%. HIV-infected children were more likely to die than uninfected children, leading the researchers to conclude that "HIV infection is threatening the advances that have been made on child survival in South Africa over the last few decades."

Most areas of South Africa have only recently begun to move from the asymptomatic HIV phase of the epidemic to the AIDS phase, where death is a common visitor. In simple terms, the people who are visibly ill today are of the 0.82% who were infected in 1990 - not the 16% who were infected last year. The implications for the future are obvious.

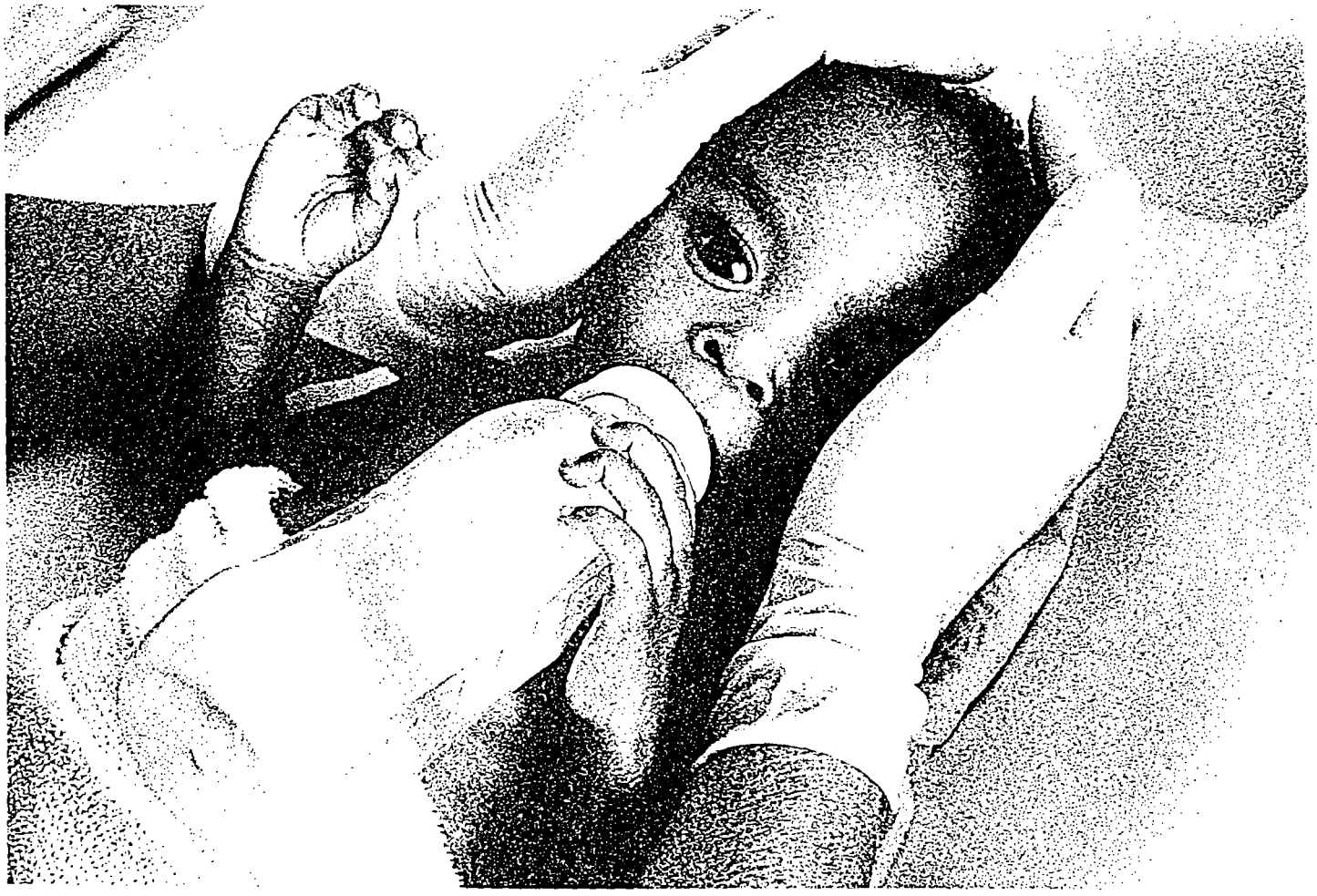
Human tragedy aside, this epidemic will have a serious impact on the new South Africa. Unlike other diseases, HIV/AIDS targets young adults in their prime - the parents and the workers of the nation - leading to a loss of human resources as well as an unprecedented wave of orphaned children. The economic implications of the epidemic have been spelt out by President Mandela himself. Addressing the World Economic Forum in Switzerland in 1997 he said: "It is anticipated that if current trends continue, then AIDS will cost South Africa 1% of our GDP by the year 2005; and that up to three-quarters of our health budget will be consumed by direct health costs relating to HIV/AIDS. Even creative low-cost alternatives to hospital care will leave us with a significant impact on our health-care budget."

That South Africa should have one of the worst HIV epidemics in the world is not surprising when one looks at the deep causal factors (co-factors, in AIDS parlance) behind the spread of HIV. Poverty, social disruption, violence - all are important co-factors for HIV, as is the low status of women in patriarchal societies. New research presented at the 12th World AIDS conference in Geneva showed that forced migration creates a major HIV risk. Speaking of population migrations caused by war and famine, Manuel Carballo, co-ordinator of the International Centre for Migration and Health in Geneva, said: "The experience disorganises and disperses families, breaks down much of the social cohesion that characterises stable societies, and increases the vulnerability of people."

Deep structural features of our society, like the migratory labour system, and the social devastation caused by the recent civil war in KwaZulu-Natal, have created a fertile breeding ground for HIV. Evidence of this can be seen in the above-average HIV infection rates among miners (estimated to be 30%), and among the general population of KwaZulu-Natal (27%).

The most surprising aspects of the HIV/AIDS epidemic in South Africa are not its force and ferocity, but the disinterest with which it has been greeted by the populace. Like Nat on the day before his HIV test, most of us live in happy oblivion of this appalling state of affairs. The big question is, will we as a nation have to go through years of annihilation before we respond constructively to the epidemic?

Dealing as we are with a middle-income country which has embarked on a radical



ABOVE

Josaphat who came to Nazareth House, Cape Town, in the last stages of AIDS after being abandoned in hospital. Here he is enjoying a massage from a volunteer aromatherapist. She wore gloves as his whole body was covered in a fungal infection. Because AIDS and HIV are not spread by casual contact the infected children at Nazareth House are given as much physical contact as possible without the use of gloves.

process of democratisation, one would expect a level of concern and concerted action which would at least match that in other African countries. In Uganda, for example, public health campaigns and intelligent political leadership have led to a 25% decline in HIV infection during this decade. Senegal and Tanzania have also had significant successes in bringing down the infection rate in particular communities.

In 1994 South Africa's new government did show a commitment to fighting the epidemic by adopting a coherent National AIDS Plan drawn up by an expert team and based on local and international experience. AIDS was also declared to be one of 20 "Presidential Lead" projects. But from there on, things began to go wrong.

The National AIDS Plan was not implemented as intended, and several of the government's Aids strategies became surrounded in controversy. One of the Department of Health's (DoH) biggest challlenges has been the reluctance of government leadership to take up the issue in a convincing way. The fact that the Mandela speech quoted above was made to an international audience, not at home, is a good example.

Rose Smart, director of HIV/AIDS and STDs (sexually transmitted diseases) in the DoH believes South Africa's failure to deal with the epidemic is a product of bad timing. "The

need for greatest action came at the time when we were trying to transform. And it has been particularly difficult to prioritise AIDS in the context of other legitimate priorities."

Though it may be argued that funding for the National AIDS Plan was inadequate, it was not until Smart's appointment in 1997 that the HIV/AIDS Directorate managed to spend its full budget allocation. The following year the HIV/AIDS Directorate was asked to draw up a budget for R100m, then got only R50m - out of a total health budget of over R5 billion.

A critical recommendation of the AIDS Plan was that it should be located in the President's office. It arose out of the experience of Uganda and Thailand, where HIV/AIDS programmes began to succeed once they were given credibility and authority by top political leadership. This recommendation was rejected. Instead, responsibility for the HIV/AIDS strategy was located in the DoH and it was August 1997 before the first inter-departmental meeting took place.

It took another whole year before the government came up with Partnership Against AIDS - a high profile multi-sector sector initiative launched by Deputy President Mbeki in a live address on national television and radio on October 10, 1998.

The HIV/AIDS Directorate has a range of creative programmes planned for its R50m - including a life skills programme for youth and a R12m mass communication strategy. Director Smart has played a big role in kick-starting these initiatives and her recent resignation raises fears about their continued progress. But the ultimate responsibility for implementing HIV/AIDS programmes rests with the provincial health departments. And here there is a strange lack of urgency; a lag between knowledge, policy and implementation which can only spell suffering and death to large numbers of people.

Helen Schneider of the Centre for Health Policy, University of the Witwatersrand writes: "Provincial co-ordinators have the task of implementing a programme through district staff over whom they have no line authority.

"AIDS policy implementation in South Africa is now characterised by multiple and unconnected spheres of activity in which coherence and continuity - over time and between levels of government - is missing."

One example here is the delay over implementing the "Thai regimen" - a short course of treatment for pregnant HIV-positive women which has been shown to reduce dramatically the chance of a baby being born infected.

This treatment was described by UNAIDS as having cost and health benefits similar to that of childhood immunisation.

According to Dr Glenda Grey at the CH Baragwanath peri-natal research unit, the treatment, at R200 per woman, is clearly cost-effective when compared with the expense of hospitalising a child with HIV-related illnesses. (The hospital bed, drips and medication cost at least R650 a day.)

According to Grey, DoH personnel publicly committed themselves to exploring the use of this treatment, with the promise that "we will not let the grass grow under our feet on this one." Now, five months later, the Gauteng government is the only provincial government to be piloting the treatment.

Rose Smart explains: "The actual implementation issues are far from simple. It's not just a matter of making anti-retrovirals available. It's having in place a system that can make testing and counselling available to women. There are a number of complex and difficult decisions to be made and obviously the provinces have to be convinced of the benefits of this, and cognisant of the costs that it will imply."

Health Minister Zuma, speaking on SAfm radio on October 10, has confirmed that the provinces are not ready to implement the regimen because of financial constraints.

Grey says: "What better thing can a government do than give a child life? But no, the wheels turn slowly and there is no action. The AIDS programme is a showpiece, and I get the feeling that nobody takes it seriously. What we need is political muscle. I expected a lot more from Zuma than she has delivered. When Zuma was appointed we were excited because we knew her from her AIDS background. We thought, 'Wow, we have a minister who cares!' But we've just seen flop after flop after flop."

In the chaos which has surrounded the implementation of the National AIDS Plan, essential human rights aspects have been diluted or lost. The Centre for Health Policy's Helen Schneider writes: "In the worst-hit province of KwaZulu-Natal, senior government officials have recently announced that certain diseases associated with AIDS would no longer be cared for in the public sector. Calls for the re-introduction of traditional public health measures such as notification and removal of confidentiality have become increasingly common and have found support among senior policy makers in the Department of Health."

The saga about pre-employment HIV testing is one such example. Like Nat Khumalo, many South Africans are denied work because of their HIV status, even though they may have a decade of healthy life ahead. Human rights aspects aside, pre-employment testing has long been recognised by the international community as being both impractical and unworkable. At current rates of infection, all employees would have to be tested on a regular basis to ensure that they remained HIV negative.

Discussions around legislation to prohibit pre-employment HIV testing began in 1995. According to Mark Heywood who heads the AIDS Laws Project at the University of the Witwatersrand, "there has been a lot of opposition within organised big business

like Business SA and SACOB to the idea of a binding prohibition on pre-employment testing. This is despite the fact that most big business organisations are not involved in it at this time. They recognise that we are moving quite rapidly to an epidemic where there is visible mortality and large-scale illness and think they have to shift back to testing."

The SA Law Commission studied the issue and agreed that it should be dealt with in the Employment Equity Bill. But despite the Commission's recommendation, the clause included in the bill makes no specific mention of HIV testing. (This was being contested by an alliance of AIDS NGOs at the time of writing.) Although the trade union federation Cosatu has pushed for the ban on pre-employment testing, and is itself a signatory to the Code Of Good Practice (HIV/AIDS and employment), it has been slow in acknowledging the serious implications of the epidemic.

For example the September Commission Report of 1997, which examines the broad forces on the trade union movement in the future does not factor HIV/AIDS into its scenarios for the year 2005. Chief commissioner and Cosatu vice president, Connie September, denies that this omission means that the federation is neglecting HIV/AIDS. She says that Cosatu dealt with the issue at the 1997 congress and that many affiliates have new HIV/AIDS projects. But the fact remains that the big thinkers of the union federation were unwilling to rank HIV/AIDS along with crime, violence, poverty, unemployment as future issues for its membership.

Heywood believes that this denial may be rooted in fear. He says "When conducting workshops in the trade unions, one gets a strong sense that people are bringing it all home to themselves. They think about the unsafe sex encounters that they have had and realise that if there are three million HIV-positive people in South Africa, they could easily be infected."

"It is the greatest human tragedy. It is the closing story of the millennium and the newspapers, the television, are just not seeing it."

Even the NGO sector, traditional ally of the poor and marginalised, has failed to relate to the epidemic constructively. For most NGOs the big struggle of the day is to survive funding cuts and the haemorrhaging of their leadership into government. Peter Busse, director of the National Association of People Living with HIV and AIDS (NAPWA) has been working with the NGO funding consortium Interfund in an attempt to move them to action. He says: "The idea was that NGOs in various fields like education and rural development have a unique advantage in working against HIV because of their contacts in the community. But integrating the HIV message has not been easy. Most NGOs can not see the links and impact on their work. And even if they do, they do not have the conceptual ability to address them."

As the HIV/AIDS epidemic gains momentum, activists in the field become increasingly despondent - not because it is unstoppable, but because there are few signs that South Africans will ever be able to take the issue seriously. For people living with HIV and AIDS (PWAS) the mass media fails to provide a mirror to their understanding of the epidemic. Says Busse: "The media have been extremely irresponsible. They have focused on the most sensational and shallow stories like Virodene and Sarafina. Remember the classic story in a popular women's magazine about a child's nanny who was diagnosed HIV positive - "the anguish of a mother"?

A recent example is the cursory way in which the media treated the results of the 1997 ante-natal survey. The revelation that nearly one-fifth of young South African women were HIV positive was not seen to be a big issue. In the same week, the same newspapers headlined Thabo Mbeki's spat with the Medicines Control Council over Virodene.

Journalists in the field agree that coverage on HIV/AIDS has been less than satisfactory, but say they have real difficulties with the subject. Editors fear that people will flip over depressing subjects that they feel that have read before. A former Health writer for The Star, Dave Robbins, says: "News is all about controversy. It's not admirable, but that's the way it works. How do you say to your press you have a moral responsibility to cover this subject? Their original responsibility is to their shareholders. The only other way is for there to be state control of the media."

Another serious obstacle is the lack of journalists with adequate background and training in the subject. Robbins says: "Young journalists are asked to write about AIDS and they don't understand the issues, they may not even understand what a virus is. There is no specialisation, and health is very low on the list of priorities for our media."

For those who live and work in the world of HIV/AIDS, who can see clearly to the years when large numbers of young people are falling ill and dying of AIDS-related diseases, these explanations are not enough. Says Busse "It is the greatest human tragedy. It is the closing story of the millennium and the newspapers, the television, are just not seeing it." ▲

Presidential Mission to Zambia, Uganda, and South Africa

March 27 to April 5, 1999

Office of National AIDS Policy
Department of State
US Agency for International Development

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Rep. Carolyn Kilpatrick, Foreign Operations Subcommittee, Appropriations, Congressional Black Caucus
Rep. Barbara Lee, Africa Subcommittee, International Relations, Congressional Black Caucus
Rep. Sheila Jackson Lee, Founder & Chair, Congressional Children's Caucus, Congressional Black Caucus

CONGRESSIONAL STAFF

Bruce Artim, Health Staff, Senator Hatch
Mary Lynn Qurnell, Legislative Assistant, Senator Helms
Stephanie Robinson, General Counsel, Senator Kennedy
Carolyn Bartholomew, Legislative Director, Rep. Pelosi
Minority Staff, Foreign Operations Subcommittee, Appropriations

NON-GOVERNMENTAL PARTICIPANTS

William Harris, President, Children's Education and Research Institute
Bishop Felton May, General Board of Global Ministries, United Methodist Church
David Dinkins, Chair, Black Leadership Coalition on AIDS
Dr. Jacob Gayle, World Bank
Rory Kennedy, Documentary filmmaker
Nick Doob, Documentary filmmaker

ADMINISTRATION OFFICIALS

Sandy Thurman, Director, Office of National AIDS Policy
Michael Iskowitz, Consultant, USAID
Dr. Paul DeLay, Director, HIV/AIDS Programs, USAID
Maria Sotiropoulos, Protocol Officer, State Department
Phil Drouin, Africa Bureau, State Department

MILITARY PERSONNEL

Lt. Commander James Erskine
Dr. Anthony Barile
Brenda Geist, Director Congressional Travel

March 27, 1999

Saturday

March 1999

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April 1999

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6 am

7 00

8 00

9 00

10 00

11 00

12 pm

1 00

2 00

3 00 — 3:00pm Assemble, Distinguished Members Lounge (Andrews Air Force

3:00pm Baggage call

4 00 — 4:00pm-11:59pm Depart Andrews en route Sal Amilcar Cabral Airport, Cape Verde

5 00

6 00

7 00

8 00

9 00

March 28, 1999

Sunday

March 1999

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April 1999

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LUSAKA, ZAMBIA

6 am 5:15am-3:50pm Depart Sal Amilcar Cabral Airport en route Lusaka, Zambia

7 00

8 00

9 00

10 00

11 00

12 pm

1 00

2 00

3 00

4 00 Arrive Lusaka, Met by Ambassador Re

4:15pm-4:45pm Press Conference. Lusaka Internatl Airport

4:45pm-5:15pm Travel to Pamdozi Hotel

5 00

6 00

7 00 7:00pm-9:30pm Optional evening cultural event TBD

8 00

9 00

12:00am - 4:00am 12:00am-4:00pm Continuation of flight en route Lusaka

March 29, 1999

Monday

March 1999

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April 1999

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LUSAKA, ZAMBIA

6 am

7 00

7:45am-8:00am Pick up from Pamodzi Hotel (Travel to American Embassy)

8 00

8:00am-9:00am Briefing from Ambassador Render & USAID Health Team (Media Room, American Embassy)

9 00

9:15am-9:20am Depart Embassy. Travel to State House

10 00

9:30am-10:30am Meet with President Chiluba, Minister of Health; Prof. Nkandu Luo; GRZ HIV/AIDS Coordinator Dr. Moses Sichone, and other

10:30am-10:45am Travel to site

11 00

10:45am-11:45am Drop in center for street children and other children in special circumstances (Fountain of Hope, Kabwata)

11:45am-12:30pm Travel to USAID

12 pm

12:30pm-2:00pm Working lunch with HIV/AIDS activists and select donors (USAID)

1 00

2 00

2:00pm-2:15pm Travel to site

2:15pm-3:15pm SWAAZ, Society of Women Against AIDS Zambia - Community based income generating activities (Mutendere)

3 00

3:15pm-3:30pm Travel to site

4 00

3:30pm-4:30pm Family Health Trust, Northmead - Community school and day care for children in need

4:30pm-4:45pm Travel back to Pamodzi Hotel

5 00

6 00

7 00

7:15pm-7:30pm Travel from Pamodzi Hotel to Ambassador Render's Residenc

8 00

7:30pm-9:00pm Dinner at home of Ambassador Render, with government officials, NGO representatives and others

9 00

9:30pm-9:45pm Travel back to Pamodzi Hotel

March 30, 1999

Tuesday

March 1999

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April 1999

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KITWE, ZAMBIA

6 am

7 00

7:30am Baggage pick up (Pamodzi Hotel)

8 00

8:00am-8:30am Pick up and travel from Pamodzi Hotel to Lusaka Internationa

8:45am-9:45am Travel from Lusaka International Airport to Ndola (Met by government officials, mission staff and project concern international staff)

9 00

10 00

10:00am-10:15am Travel to site

10:15am-11:15am St. Anthony's Compound - Visit income generating activities, talk with community representatives, see service provision

11 00

11:15am-11:30am Travel to site

11:30am-12:30am Mulenga Compound - Visit community activities

12 pm

12:30pm-12:45pm Travel to site

12:45pm-1:45pm Lunch with government officials, NGO staff and others (Sherbourne Guest House)

1 00

1:45pm-2:00pm Travel to site

2 00

2:00pm-3:00pm Twapia Widows Group - Meet with widows, review community activities

3 00

3:00pm-3:15pm Travel to site

3:15pm-4:00pm Press Event (Ndola Airport)

4 00

4:00 pm-7:30pm Travel from Ndola to Entebbe

5 00

6 00

7 00

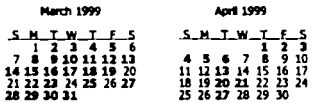
7:30pm-8:00pm Proceed to Sheraton Hotel

8 00

9 00

March 31, 1999

Wednesday



MASAKA, UGANDA

6 am	
7 00	
8 00	8:00am-8:35am Briefing - Ambassador, DCM, AID Director, HIV
9 00	8:45am-10:10am Travel to Mukungwe, Masaka
10 00	10:20am-11:30am Welcome (local leaders, dancers, singers) & Briefing (jointly, UWESO/FINCA)
11 00	G1: 11:30am-12:30pm Kyalisowe - UWESO client visits
12 pm	G2: 11:30am-12:30pm Kalagala - UWESO client visits
1 00	12:50pm-1:05pm Travel to Brovad Hotel
2 00	1:05pm-2:00pm No host buffet lunch (Brovad Hotel)
3 00	G1: 2:00pm-3:00pm FINCA businesses - W
4 00	G2: 2:00pm-3:00pm FINCA businesses - W
5 00	2:45pm-2:50pm Travel t
6 00	3:05pm-4:05pm Travel to equator
7 00	4:05pm-4:35pm Equator - Rest stops, craft shops
8 00	4:35pm-5:20pm Travel to Sheraton Hotel
9 00	6:30pm-6:45pm Travel to reception
	6:45pm-8:00pm Reception (Ambassador's Residence)
	8:00pm-8:15pm Travel back to Sheraton
	8:45pm-10:15pm Dinner (optional, details to follow)

April 1, 1999

Thursday

April 1999

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May 1999

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KAMPALA, UGANDA

- 6 am
- 7 00
- 8 00 — 8:00am-8:15am Travel to site
- 8 00 — 8:15am-9:55am AIDS Info Center (AIC) Program - HIV testing/counseling
- 9 00
- 10 00 — 10:05am-10:20am Travel to site
- 10 00 — 10:20am-12:00pm The AIDS Support Organization (TASO) meeting
- 11 00
- 12 pm — 12:15pm-12:45pm Travel to site
- 12:45pm-1:45pm Lunch (AID Director's Residence)
- 1 00 — 1:45pm-1:55pm Travel t
- 1:55pm-2:50pm Natl. Community of Women Living With AIDS (NCWOLA) site visit
- 2 00
- 3 00 — 3:00pm-3:30pm Travel to meeting
- 3:30pm-4:40pm Meet with President Museveni; Ministers of Health, GLSD
- 4 00 — 4:50pm-5:00pm Travel to hotel
- 5 00
- 6 00 — 6:00pm-6:50pm Travel to Entebbe
- 7 00 — 7:00pm-7:15pm Press Conference - Selected delegates (VIP Lounge)
- 7:30pm-10:30pm 7:30 pm-10:30pm Travel from Entebbe en route Johannesburg
- 8 00
- 9 00
- 10:30pm - 10:30pm Arrive Park Hyatt Hotel

April 2, 1999

Friday

April 1999

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May 1999

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JOHANNESBURG, SOUTH AFRICA

6 am	
7 00	
8 00	8:00am-9:00am Breakfast Briefing at Hotel
9 00	
	9:30am-10:00am Travel to site / 9:30am Baggage Call
10 00	10:00am-11:00am Ethembeni Centre
11 00	
	11:30am-12:30pm Hope Worldwide - Jabavu Clinic, Soweto
12 pm	
1 00	1:00pm-2:30pm Lunch - Wandie's Shebeen
2 00	
3 00	3:00pm-4:00pm Bethesda House, Soweto
4 00	4:00pm-5:00pm Travel to airport
5 00	5:00pm-6:00pm Travel from Johannesburg en route Durban, KwaZuluNatal
6 00	
	6:30pm-7:00pm Travel to Edward Hotel
7 00	
	7:30pm-9:00? Evening event TBD
8 00	
9 00	

8

April 3, 1999

Saturday

April 1999

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May 1999

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DURBAN, SOUTH AFRICA

6 am		
7 00		
8 00	8:45am Baggage Call	
9 00	G1: 9:00am-10:00am Travel to site	G2: 9:00am-10:00am Visit McKenzie TB Hospital
10 00		
11 00	G1: 10:30am-12:30pm Site visit to Grey's Hospital & Edendale Hospital	G2: 10:30-11:30am Visit to Edith Benson Babies' Home
12 pm	G1: 12:30pm-1:30pm Lunch, TLC	G2: 12:00pm-2:00pm Visit to Makaphuthu Childrens Home/Lunch
1 00	G1: 1:30pm-2:30pm Visit to Street Wise Shelter	
2 00	G1: 2:30pm-3:30pm Visit to Highway Hospice	
3 00	G1: 3:30pm Depart Piertermartizburg	G2: 3:00pm-4:00pm Lily of the Valley
4 00	4:00pm-4:30pm Travel to Durban Airport	
5 00	5:00pm-6:00pmTravel from Durban to D.F. Malan Airport, Cape Town	
6 00		
7 00	7:00pm-7:30pm Travel to Table Bay Hotel	
8 00		
9 00	8:30pm-10:00pm Evening Event (TBD)	

April 4, 1999
Sunday

April 1999

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May 1999

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CAPE TOWN, SOUTH AFRICA

6 am
7 00
8 00
8:30am-8:45am Meet in Hotel Lobby
8:45am-9:00am Travel to Mass
9 00
9:15am-10:45am Mass (St. George's Cathedral)
10 00
11 00
11:30am-11:45am Return to Hotel
12 pm
1 00
2 00
3 00
4 00
4:45pm Baggage Call
5 00
5:00pm-5:30pm Travel to Cape Town Internatl Airport
6 00
6:00pm-6:30am Travel to Andrews Air Force Base, US
7 00
8 00
9 00

April 5, 1999

Monday

April 1999

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May 1999

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6 am	6:00pm-6:30am Travel to Andrews Air Force Base, US
7 00	
8 00	
9 00	
10 00	
11 00	
12 pm	
1 00	
2 00	
3 00	
4 00	
5 00	
6 00	
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9 00	

Zambia

Render, Arlene
Ambassador to Zambia

(260)(1) 250-955 (Bus)
(260)(1) 252-225 (Fax) (Fax)

Whitehead, Robert
Deputy Chief of Mission

Department of State
U.S. Embassy Lusaka
Independence & United Nations Ave.
Lusaka
Zambia

USAID

North, Walter ← *trip liason*
Mission Director

(260)(1) 254-303 (Bus)
(260)(1) 254-532 (Fax)

Clay, Robert
Health Officer

Zeitz, Paul
White, Mark
HIV/AIDS Advisors

U.S. Agency for International
Development
351 Independence Ave.
Lusaka
Zambia

Uganda

Powell, Nancy
Ambassador to Uganda

(256)(41) 259-792 (Bus)
(256)(41) 259-794 (Fax)

McKinley, P. Michael
Deputy Chief of Mission

Department of State
U.S. Embassy
Parliament Avenue
Kampala
Uganda

USAID

Liberi, Dawn
Mission Director

(256)(41) 235-879 (Bus)
(256)(41) 233-417 (Fax)

Anderson, Jay ← *trip liason*
Health Officer

U.S. Agency for International Devt.
42 Nakasero Road
Kampala
Uganda

South Africa

Joseph, James
Ambassador to South Africa

(27) (12) 342-1048 (Bus)
(27) (12) 342-2244 (Fax)

Pringle, Robert
Deputy Chief of Mission

Department of State
U.S. Embassy Pretoria
877 Pretorius Street
Arcadia 0083
South Africa

Engle, George
Consul General
Department of State
U.S. Consulate
1 River Street
Johannesburg
South Africa

(27)(11) 646-6900 (Bus)
(27)(11) 646-6913 (Fax)

USAID

Rhodes, Stacey
Mission Director

(27)(12) 323-8869 (Bus)
(27)(12) 328-4412 (Fax)

Yamashita, Ken ← *trip liason*
Health Project Director

Gqwaru, Nellie
HIV/AIDS Advisor

U.S. Agency for International Devt.
524 Church Street
Sancardia Building
Pretoria
South Africa

HOTEL CONTACTS

Lusaka, Zambia

Pamdozi Hotel
463 Church Road
P.O. Box 35450, Lusaka

260-1-254-455 (Bus)
260-1-254-005 (Fax)

Kampala, Uganda

Sheraton Kampala Hotel
Ternan Avenue
Kampala, Uganda

256-41-344-590 to 9 (Bus)
256-41-256-696 (Fax)

Johannesburg, South Africa

Park Hyatt
191 Oxford Road Rosebank
P.O. Box 1536
Saxonwold, 2132

27-11-280-1234 (Bus)
27-11-280-1238 (Fax)
parkhyatt@hyatt.co.za (Email)

Durban, South Africa

Karos Edwards Hotel
Marine Parade
P.O. Box 105
Durban, 4000

27-31-337-3681 (Bus)
27-31-332-1692 (Fax)

Cape Town, South Africa

Table Bay Hotel
Victoria and Alfred Waterfront
P.O. Box 50369
Quay 6, Cape Town, 8002

27-21-406-5000 (Bus)
27-21-406-5656 (Fax)