

# Annual report for 2003

AIDS Law Project  
Centre for Applied Legal Studies  
University of the Witwatersrand



## Acknowledgements

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We would like to acknowledge the courage of our clients in taking up and pursuing their cases.

In particular we would like to remember Charlene Wilson, Edward Mabunda, Kamoelo Pitso, Martha Jas and Matomela Paul Ngubane.

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Discrimination against people with HIV/AIDS undermines society's efforts to prevent HIV infection and limit the impact of the HIV/AIDS epidemic on our society. Discrimination is also contrary to internationally accepted principles of human rights. The AIDS Law Project operates according to the principles set out in the United Nations International Guidelines on HIV/AIDS Human Rights, 1998.

## mission statement

In particular, the ALP focuses on removing obstacles that:

- Prevent people with HIV/AIDS from having access to adequate health care and treatment in both the private and public sectors;
- Prevent people with HIV/AIDS from contesting unfair treatment and discrimination and having access to legal remedies to protect their fundamental rights; and
- Deny people with HIV/AIDS access to employment, employee benefits, insurance, education and other services.

### The AIDS Law Project aims to:

- Carry out litigation to counter wrongs that have occurred and, where possible, to establish legal precedents that prevent them from recurring;
- Build capacity within existing legal advice service providers to offer free legal advice that will empower people living with HIV/AIDS to seek legal remedies in response to acts of unfair discrimination;
- Carry out research to support policy formulation and bring about practices that prevent discrimination; and
- Produce media that creates an awareness of rights in government and civil society and promotes effective lobbying and advocacy.

The ALP is committed to a code of professional ethics, to respecting confidentiality and to the principle of the maximum inclusion of people living with or affected by HIV/AIDS. We will oppose all forms of unfair discrimination and promote a culture of human rights and equality for all.

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## Hail Aids Law Project staffers

IN the world of HIV-Aids activism, there is a body known as the Aids Law Project, which is headed by my bosom friend, one of the most committed people I have ever met and one who simply outshines everyone else in the background – an unsung hero, to be more precise, Mark Heywood.

In this edition of my column I wish to give long-overdue acknowledgement and shower unending praise on the exceptional expertise, sacrifice and commitment to the struggle of those of us who are disenfranchised and trampled upon, those of us who have become known as the helpless victims of HIV and also those of us who have even become regarded as the scumbags of the earth by virtue of an almost entirely sexually transmitted infection, one which remains incurable.

Heywood and a host of other equally capable, lesser known group of lawyers, are fighting our battles to regain our lost dignity, respect and legitimacy whenever and wherever any form of discrimination can be traced and eventually thrown into the ... in this case, stinking dustbin of history where it rightfully belongs.

Judge Edwin Cameron remains a great inspiration and a symbol of the legal struggle against Aids and it's subsequent ills of society. He is and will always be, a torchbearer for every person in whose blood veins this parasitic and thankless virus runs amok.

On behalf of those who remain silenced, oppressed and exploited as an unnecessary, preposterous and inhumane result of living with HIV, I will always be grateful to these selfless men and women who represent us and fight the struggle to live on our behalf.

At the moment, the Aids Law Project is dealing with over 50 cases. Some of these are prominent cases, heading for the courts (such as a case the Aids Law Project is preparing against the South African National Defence Force and cases the ALP has against doctors or hospitals who tested people without following proper procedures regarding consent, etc.)

Finally some of them are less public cases, for example, where the ALP is assisting domestic workers and other people who are victims of unfair discrimination.

The ALP has three paralegals,

Chloe Hardy, Nanie Madiba and Mandla Mgogoshe who help people over the phone with problems that they experience and sometimes take up cases directly.

One of the recently recorded victories for the ALP is the favourable verdict against two high profile pharmaceuticals, GlaxoSmithKline (GSK) and Boehringer Ingelheime by recommending that such companies be obliged to permit generic firms to produce generic anti-retroviral treatment affordably. This case was handled by Fatima Hassan and Jonathan Berger.

A successful judgment from the full bench of the Pretoria High Court handed down two weeks ago, where the court made it clear that the Health Professions Council of South Africa must investigate complaints brought by patients against doctors where there is evidence of disgraceful or improper conduct by the doctor, that is to say, they cannot just take a doctor's word.

In this case, the Aids Law Project was acting for VRM, a young woman with HIV who in 1999, was tested without her knowledge during her pregnancy and not told of the positive result until after the stillbirth of her baby.

This case was run by Anita Kleinsmidt and Liesl Gerntholtz, both lawyers at the Project.

A case where ALP acted for three women with HIV who alleged that they did not give permission for their names to be mentioned in a book about a South African politician.

A case where judgment will be handed down today on behalf of the mother of a three and a half-year-old girl who was refused admission to a creche because she had HIV.

This case was handled by Tebogo Motebele and Liesl Gerntholtz, both lawyers at the ALP.

These are just a sample of the matters that the ALP is involved in.

The service provided is free, although it must be obvious that they are stretched well beyond a limited capacity to help those in need.

The real challenge that lies ahead is in making more people aware of their rights, and then in teaching other organisations about how to practise law on behalf of people with HIV.

Hail the Aids Law Project (ALP).

*The Sowetan is South Africa's largest readership newspaper*

*"Just call me Lucky"*

**Sowetan 21st October 2003**

**ACTSA**

Action for Southern Africa

**ARVs**

Antiretroviral medicines

**BI**

Boehringer Ingelheim

**CALS**

Centre for Applied Legal Studies

**CHALN**

Canadian HIV/AIDS Legal Network

**CCMA**

Commission for Conciliation, Mediation and Arbitration

**GRIP**

Greater Nelspruit Rape Intervention Project

**GSK**

GlaxoSmithKline

**HIV**

Human Immune Deficiency Virus

**HPCSA**

Health Professions' Council of South Africa

**HSRC**

Human Sciences Research Council

**NGO**

Non-Governmental Organisation

**NHLS**

National Health Laboratory Service

**NPG**

National Pathology Group

**PEP**

Post-Exposure Prophylaxis

**PLWAs**

People living with HIV/AIDS

**PMBs**

Prescribed Minimum Benefits

**SA**

South Africa

## GLOSSARY

**CHOMP**

Children's Home Medical Outreach Project

**CEPPWAWU**

Chemical, Energy, Paper, Printing, Wood and Allied Workers' Union

**COSATU**

Congress of South African Trade Unions

**CMS**

Council for Medical Schemes

**CSVR**

Centre for the Study of Violence and Reconciliation

**DoH**

Department of Health

**DR**

Doctor

**DTI**

Department of Trade and Industry

**GARPP**

Generic Anti-retroviral Procurement Project

**ICASO**

International Council of AIDS Service Organisations

**LRC**

Legal Resources Centre

**LTAU**

Law and Treatment Access Unit

**MCC**

Medicines Control Council

**MEC**

Minister of the Executive Council

**MRC**

Medical Research Council

**MSF**

Médecins Sans Frontières

**MTCT**

Mother-to-child transmission

**NAPWA**

National Association of People Living with HIV/AIDS

**NEDLAC**

National Economic, Development and Labour Council

**SALC**

South African Law Commission

**SAMA**

South African Medical Association

**TAC**

Treatment Action Campaign

**TRIPS**

World Trade Organisation's Agreement on Trade-related Aspects of Intellectual Property Rights

**UN**

United Nations

**UNAIDS**

Joint United Nations Programme on HIV/AIDS

**WHO**

World Health Organisation

**WLC**

Womens Legal Centre

**WTO**

World Trade Organisation

# Foreword

The AIDS Law Project was founded in 1993. This, its Report for its tenth full year, reminds us not only of what has been achieved in our struggle with the AIDS epidemic since then, but of what we have yet to achieve. Fittingly, despite the lustre the ALP's achievements and activities have rightly earned, this report of its activities vaunts nothing. It is a record of endeavour and application – often highly inventive and painstakingly assiduous, as the pages following show – on the part of the ALP's leaders, lawyers, researchers, administrators and paralegals. A model project, the ALP attracts international support, recognition and acclamation. Its litigation and policy initiatives have been well-directed and influential, while its research has contributed significantly not only to knowledge, but to practical interventions and strategies.

Yet the report's tone of sobriety is right, since our struggle in the epidemic has been as much with the virus and its devastating effects as with ourselves – our conception of truth, our acceptance of the truth, and our readiness to act on its implications. And none of us has been exempt from denial, neglect and insufficient application and imagination. The legal and policy struggles documented here, and the ALP's successes in them, remind us of how much we all have yet to do – how much we all still *can* do – to lessen the toll of suffering and bereavement this epidemic has caused. My hope is that this report, and the dedication and application that it documents, will inspire us to further action.

**Mr Justice Edwin Cameron**

**Supreme Court of Appeal**

**30 April 2004**







aidslaw  
project

## introduction

2003 marked the 10<sup>th</sup> anniversary of the AIDS Law Project, and it is therefore fitting that the foreword to this annual report should be written by the ALP's founder and mentor, Justice Edwin Cameron. The key objective of the ALP remains to empower disadvantaged and marginalized people to use the law to address unfair discrimination, find redress for the violation of their human rights and hold government and the private sector accountable to people's needs.

The ALP conducts research, advocacy and legal action that aim to ensure immediate and short-term remedies, as well as long-term systemic change. Together, such actions give effect to the ALP's aim, which is to use the law to defend and advance the rights of people living with HIV/AIDS.

The ALP uses litigation as a tool to hold government to account in respect of its positive obligations regarding the right

of access to health care services. High quality research is undertaken to support litigation and assist in legislative and policy development. Professional lawyers and paralegals provide quality legal advice and litigation services to people who have experienced unfair discrimination, as well as to individuals and organizations working to advance the rights of people living with HIV/AIDS.

Towards the end of 2003 the ALP embarked on a process of internal evaluation and restructuring. The organization recommitted itself to litigating cases that will have a great public impact both on the judiciary and society generally. The objective is to extend the benefits of legal action from the individual or group that initiates it to as many people as possible.

In 2004 the ALP will restructure itself around two main units. They are the HIV Law and Policy Unit and the Law

and Treatment Access Unit. Despite having two distinct areas of work, these two units will also work collaboratively on projects.

One highlight of 2003 was the receipt of the “Award for Action on HIV/AIDS and Human Rights” bestowed upon the ALP by the Canadian HIV/AIDS Legal Network and Human Rights Watch at a ceremony held in Canada and attended by human rights advocates from around the world. Stephen Lewis, the United Nations Secretary-General’s Special Envoy for HIV/AIDS in Africa, was the keynote speaker. In acknowledging the ALP Lewis said:

*“It is very rare that one has the opportunity to honour an organization that has so effectively represented the*

*uprooted and disinherited in their society. The people in the AIDS Law Project are a principled group of advocates. They forced the Government of South Africa to reverse itself and to champion policies that it might never have championed otherwise.”*

Such a comment from such a distinguished human rights advocate is indeed an honour.

After 10 years the ALP remains strong and committed to further challenging and addressing human rights abuses and developing measures for the eradication of discrimination, in order to empower people living with HIV/AIDS.

The screenshot shows the Human Rights Watch website interface. At the top, there is a navigation bar with the HRW logo and the text "DEFENDING HUMAN RIGHTS WORLDWIDE". Below this, there are language options: PORTUGUÊS, FRANÇAIS, ПУБЛИКАЦИИ, DEUTSCH, ESPAÑOL, 中文, العربية, and OTHER. The main content area features a news article titled "AIDS Law Project of South Africa Honored" with a sub-headline "ALP Fights Human Rights Abuse Driving AIDS". The article text includes a quote from Ralf Jurgens, executive director of the Canadian HIV/AIDS Legal Network, and a quote from Joanne Csete, Director of the HIV/AIDS Program at Human Rights Watch. A "Related Material" section lists a "2nd Annual Awards for Action on AIDS and Human Rights 2003 Program Brochure, 12 pages PDF" and a "Chinese AIDS Activist Honored Despite Ongoing Detention Press Release, September 12, 2002". The left sidebar contains a menu with categories like Home, News Releases, About HRW, Publications, Info by Country, Global Issues, Arms, Children's Rights, HIV/AIDS, International, Justice, Prisons, Refugees, Women's Rights, United Nations, More..., Campaigns, Film Festival, Photo Galleries, Site Map, and Contact Us. At the bottom of the page, there is a URL: <http://www.hrw.org/press/2003/09/aidsaward091203.htm>

# HIV law and policy unit

2003 saw a number of important changes in the HIV Law and Policy Unit of the ALP. A process of discussion of the unit's work commenced in April 2003 and sought to examine whether the current ways of working were still effective. This process eventually linked into a broader evaluation of the ALP that culminated in November 2003. An important decision taken during this process was to refocus on high impact public interest cases, and to find other attorneys and legal organizations to assist in litigating the non-impact, but important cases. In this regard, an extremely fruitful meeting took place with Bowman Gilfillan Incorporated, a prominent private law firm. The firm has agreed to take over four of the ALP's cases. Should this co-operation be successful, it is hoped that similar relationships can be formed with other law firms.

## Paralegal work

The ALP recorded 415 complaints. These included telephonic requests for assistance, e-mail requests and face-to-face consultations. The ALP paralegals gave advice on a wide range of issues, including questions relating to HIV testing, confidentiality and disclosure, insurance and workplace related discrimination, alleged willful HIV transmission and social assistance. The paralegals also dealt with a large number of requests for information.

The paralegals conducted an outreach clinic at Helen Joseph Hospital in Johannesburg, working closely with members of the Infectious Diseases Unit, which provides services to people with HIV. The training is intended to build capacity within the peer support group so that they are able to provide basic advice and information to their members and communities. A similar programme began at the Harriet Shezi Paediatric HIV Clinic at Chris Hani Baragwanath Hospital in the second half of the year.

An important part of the paralegal work is the assistance that is provided to the ALP's attorneys. The paralegals have supported the legal work of the unit by conducting interviews with clients and witnesses, drafting affidavits, serving and filing pleadings and attending court.

## Impact Litigation: major cases in 2003

The unit had a busy and largely successful year, with several important cases either being argued or finalized in the courts. Unfortunately not all cases were concluded successfully, and the ALP intends to take at least one important case on appeal in 2004.

### Member of the Executive Council (MEC) for Health, Mpumalanga Province v GRIP

This matter was first taken up by the ALP in 2000 on behalf of the Greater Nelspruit Rape Intervention Project (GRIP). At the time the ALP assisted GRIP to bring an urgent application against the MEC after she unilaterally locked GRIP out of the rooms it had used in a public hospital to provide services to rape survivors. Following that case, the MEC brought two other cases against GRIP in an attempt to shut it down. The attempts to evict GRIP from the hospital's premises started when it began to assist survivors of sexual violence to obtain antiretroviral drugs to reduce the risk of HIV transmission following rape or other forms of sexual assault. At the time, it was not part of government policy to provide these drugs to survivors who sought care in the public sector.

The case was finally settled on the 5<sup>th</sup> of February 2003 when the MEC withdrew her case. The ALP successfully defended GRIP's right to provide PEP to rape survivors and, as part of the campaign to highlight the misconduct of the MEC, also filed complaints with the Public Protector and the Human Rights Commission.

As part of the settlement, the MEC also tendered to pay the costs of the litigation.

GRIP continues to assist rape survivors to obtain access to PEP.<sup>1</sup>

### Gazi v The Minister of Public Service and Administration and others

Dr Gazi, a public service doctor working in the Eastern Cape, had been disciplined for making a derogatory comment about the former Minister of Health, Dr Dlamini-Zuma, after she declined to provide antiretroviral drugs to pregnant women to reduce the risk of mother to child transmission. As a result of his comments, Dr Gazi, was called to a disciplinary hearing and found guilty of misconduct. He received a reprimand.

The application sought to review the findings of the magistrate who found Dr Gazi guilty of misconduct, on the basis that his constitutional right to freedom of expression had been violated. The case also dealt with the rights of public servants to make comments in the best interests of their patients and in the public interest.

It was argued in the Pretoria High Court on the 13<sup>th</sup> and 14<sup>th</sup> of May 2003. At the time of writing, judgment had still not been handed down.

### Ex parte Nigel Redman N O; Ex parte Meyers<sup>2</sup>

During 2003, the unit took up three cases dealing with the rights of children without parents to receive medical treatment and HIV tests. The unit

<sup>1</sup> A full account of the history of the conflict over the provision of PEP in Mpumalanga can be found at: <http://www.hrw.org/reports/2004/southafrica0304/4.htm>

<sup>2</sup> Notice of motions, press statement and affidavits are available at [http://www.alp.org.za/view.php?file=/camps/20031205\\_Children.xml](http://www.alp.org.za/view.php?file=/camps/20031205_Children.xml)

worked closely with the Wits Paediatric HIV Working Group, a group of health workers providing services to children in the public sector.

Prior to commencing litigation, the unit drafted a memorandum on behalf of the Childrens Home Medical Outreach Project (CHOMP) on the legal and ethical issues regarding HIV testing of abandoned infants. This was intended to assist the Department of Social Development to grapple with the legal issues associated with HIV testing. The memorandum made recommendations that guidelines be developed to regulate the HIV testing of abandoned infants. The Department agreed to establish a task team, including representatives of the ALP and the Wits Paediatric HIV Working Group, and although the task team met on one occasion, the guidelines were not completed. The ALP then decided to initiate litigation.

In the first case, the unit acted on behalf of four orphaned children who attended the Harriet Shezi Paediatric HIV Clinic at Chris Hani Baragwanath Hospital. The clinic had raised funds to provide antiretroviral medication to ten children in the context of an operational research study. Permission was sought from the Ethics Committee of the University of the Witwatersrand for the children to participate in the study and it was granted on the basis that informed consent was sought and obtained from the parents or legal guardians of each child.

However, there was no person capable of providing legal consent in respect of four of the children. Therefore an urgent application was brought in the Johannesburg High Court, requesting the court, as the upper guardian of all children, to provide consent. The order was granted on the June 10<sup>th</sup> 2003.



**The Star**

**LIFELINE  
FOR AIDS  
ORPHANS**

*Newspaper billboard after the ALP's successful court application to allow children with no legal guardian to be tested and treated for HIV*

A second, similar case, concerning the rights of one child to access antiretroviral treatment, was successfully brought on the 19<sup>th</sup> of August 2003.

A third case, argued on the 5<sup>th</sup> of December 2003, was brought on behalf of eight children who required access to antiretroviral treatment and three who needed to undergo HIV tests. The case was also brought on behalf of the Wits Paediatric HIV Working Group, who requested permission from the court to test and treat other, unnamed children in similar positions, by obtaining consent from their care-givers, even though the law currently does not permit this. The court ordered in favour of the children receiving treatment and HIV tests, and, importantly also permitted the Wits Paediatric HIV Working Group, once they had certified that treatment and/or HIV testing was

in the best interests of the child concerned, to obtain permission from the caregiver, in circumstances where there is no legal guardian present to provide permission. Although this order will significantly assist in protecting the rights of children who receive treatment and care from the health workers associated with the Wits Paediatric HIV Working Group, it will not assist children in other provinces. The ALP intends to examine how this order can be extended to other children in 2004.

### X and two others v S and two others

The ALP is acting on behalf of three women with HIV who participated in a clinical trial organized through the University of Pretoria and a hospital. As a result of alleged unethical practices that occurred during the trial, the defendant intervened and an investigation into the trial was conducted by the University.

Later the full names of the women who participated in the trial, their HIV status and details of their personal circumstances were included in a biography of one of the defendants. None of the women had been approached to give permission for their names and HIV status to be disclosed and none of them had in fact disclosed their HIV status to family members and friends. As a result of the disclosure in the book, all three women suffered detrimental consequences, including being evicted and threatened with assault.

The ALP has brought a case for damages against the authors and their publishers based on the unlawful disclosure and the violation of the right to privacy.

In its summons, the ALP pleaded that the disclosure made by the parties took place intentionally or negligently. South African common law does not provide for a cause of action based on a negligent disclosure and the defendants brought an exception against this aspect of the pleadings. The exception was argued on the 6<sup>th</sup> of August in the Johannesburg High Court and Judge Lewis Goldblatt found in favour of the ALP's clients.

The main claim against the three parties will proceed in 2004.

### VRM v The Health Professions' Council of South Africa (HPCSA)<sup>3</sup>

The ALP acted on behalf of a pregnant woman with HIV. In 1998 during her pregnancy she was tested for HIV without her informed consent and without pre- and post-test counseling. She was also not advised that there were measures she could take to protect the health of her unborn child.

The ALP filed a complaint about the conduct of the doctor with the HPCSA. Its Committee of Preliminary Enquiry declined to refer the complaint to a disciplinary hearing on the grounds that they did not believe that there was misconduct on the part of the doctor concerned. The ALP brought an application to review this decision.

This matter was originally argued in the Pretoria High Court in 2002, and the application was dismissed with costs by Judge Daniels. A number of issues were raised on appeal, including the HPCSA's argument that its guidelines on the management of HIV/AIDS, which provide for informed consent and pre-and post-test counseling, are not binding on doctors.

<sup>3</sup> A copy of the judgment can be found at [http://www.alp.org.za/view.php?file=/resctr/jdgmnts/20020527\\_jvr\\_mvshpc.xml](http://www.alp.org.za/view.php?file=/resctr/jdgmnts/20020527_jvr_mvshpc.xml)

The ALP appealed against the decision and the appeal was argued on the 17<sup>th</sup> of September 2003. In its argument, the ALP dealt with the status of the HPCSA's guidelines for the management of HIV/AIDS and argued that the guidelines were in fact binding on health workers. It also argued that the HPCSA has a duty to act in the public interest and that in refusing to regard the conduct of the doctor as professional misconduct, it had failed to meet its obligations.

Judgment was handed down on the 10<sup>th</sup> of October 2003. In the judgment, the court found that the Committee of Preliminary Enquiry was not entitled to adjudicate on complaints that raise disputes of fact. In particular, the court considered what weight the Committee was entitled to place on the version of the doctors in responding to complaints. In cases where there are disputes of fact, such as in this case, the Committee must refer the complaint to a disciplinary enquiry where appropriate evidence can be led. The judgment represents an important victory for patients who wish to take up complaints against members of the health profession.

As a result of this judgment, the ALP approached the HPCSA and requested that it reconsider several other complaints. All of these complaints had

been referred to the Committee of Preliminary Enquiry and none had been referred to a disciplinary hearing. The HPCSA agreed to reconsider the complaints.

## Karen Perreira v Sr Helga's Nursery School and the Buccleuch Montessori Nursery School<sup>4</sup>

The case dealt with the rights of children with HIV to attend nursery school. The second respondent, the Buccleuch Montessori Nursery School, had refused to admit Tholakele Nkosi, when her foster mother, Karen Perreira, disclosed her HIV status to the school. The

school indicated that it did not consider itself ready to admit children with HIV, none of its teachers having received any training in this regard. It also stated that it was concerned about the risks of HIV transmission through biting, sharing of suckers and scratching of insect bites.

Although it was argued on behalf of Karen Perreira that the school had refused to admit Tholakele, the court found that the school had recommended that the child's enrolment be deferred for at least six months when she would be "past the biting stage". On this basis, the court found that the school had therefore not taken a final decision to exclude the child. The application was dismissed with costs.

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Thursday, April 29, 2004, 16:32 Africa's first online

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**HIV nursery school case comes before court**

Johannesburg

01 January 2002 00:00

A case involving the rights of children infected with the HI virus to attend nursery school will be heard in the Johannesburg High Court on Wednesday.

According to the Aids Law Project (ALP), the Buccleuch Montessori Nursery School in Woodmead declined to admit a two-and-a-half-year-old girl because she was HIV-positive. The girl's foster mother disclosed her daughter's HIV status to the head of the nursery school to ensure that when the girl felt ill, she received the appropriate treatment and care from her teachers, the ALP said in a statement on Tuesday.

The mother had also hoped that the disclosure would ensure that the girl was treated with compassion. However the school declined to admit the child on the basis that it was not equipped to deal with children living with HIV, the ALP said.

In the interim, teachers at the school received training in managing HIV, but the child was once again rejected after the training was completed.

The ALP said it was particularly concerned that although the training had been completed, the school continued to allege that HIV was easily spread through scratching and biting.

"It is clear from the defence of the school that it has consistently failed to engage with critical aspects of HIV and, given the magnitude of the epidemic in the country, this seems not only irresponsible but negligent," it said.

The case will look at the constitutional right of the child not to be discriminated against on the basis of her HIV status.

It would also deal with the failure of the school to take adequate steps to accommodate HIV infected children in its classrooms, according to the ALP. The school has said it was inappropriate to comment before the start of the case.

The hearing will start around 10am. - Sapa

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[www.mg.co.za/Content/13.asp?ao=2872](http://www.mg.co.za/Content/13.asp?ao=2872)

### Sunday's Paper



Location: Sunday 21 Sep 2003 > National news

Pregnant woman's doctor 'did not tell her she had HIV'

Nashira Davids and Sphiwe Maphumulo

An Mpumalanga woman is suing her doctor because he failed to warn her that she had tested positive for HIV during her pregnancy.

The Nelspruit woman is also taking on the Health Professions Council of South Africa after it ruled that her doctor's conduct was not "improper or disgraceful".

The woman, identified only as VRM, appeared in the Pretoria High Court this week to appeal against a court ruling that the council was correct not to censure Dr Elardus Labuschagne for acting unethically and failing to follow medical guidelines on HIV testing and disclosure.

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<sup>4</sup> A copy of the judgment can be found at [http://www.alp.org.za/view.php?file=/resctr/jdgmnts/20040312\\_Bu\\_cclJdg.xml](http://www.alp.org.za/view.php?file=/resctr/jdgmnts/20040312_Bu_cclJdg.xml)

The judgment seems to suggest that it is permissible for nursery schools to use a lack of preparedness as a justification to defer the enrolment of children with HIV. The judgment failed to give any guidance to what nursery schools need to do to ensure that they are able to admit children with HIV and also failed to comment on and deal with the fact that it is unreasonable for any school in South Africa to consider themselves unequipped to admit children with HIV at this stage of the epidemic. The judgment acknowledged that the school had raised concerns about the risks of HIV transmission through biting but failed to deal with the reasonableness of this fear, despite the expert evidence adduced by the ALP that unequivocally indicated that there is a remote possibility that a child will contract HIV as a result of a bite from another child. To date, there are no recorded cases of transmission between children as a result of biting.

The ALP has decided to appeal against the decision and the application for leave to appeal will be argued in 2004.

### Other litigation

The ALP initiated litigation in the following matters in 2003:

***M and another v One Military Hospital*** – the ALP clients were undergoing fertility treatment at the hospital. As part of the programme, they were advised that they were required to undertake an HIV test. One of the clients tested HIV positive. The doctors dealing with the case failed to disclose the results of the HIV test to the clients and the second client, who had tested HIV negative, subsequently contracted HIV as the couple continued to have unprotected sex. The ALP has issued summons against the hospital for damages as a result of the

negligence of the hospital in failing to ensure that the HIV results were disclosed.

***L and another v GaRankuwa Hospital and others*** – the ALP's clients are a son and his mother. The son has a chronic renal condition that required him to have a kidney transplant and his mother agreed to donate her kidney to him. Both were tested for HIV, but the hospital failed to ascertain the results of the HIV test before the transplant took place. The mother has HIV and as a result of the transplant of her kidney into her son, he has contracted HIV. The ALP has issued summons against the hospital for their negligence. This case has been referred to Bowman Gilfillan Incorporated.

***Baby A v The Red Cross Children's Hospital and another*** – a baby contracted HIV during a period of hospitalization; both parents have tested negative and other routes of transmission, including through blood transfusions, breast feeding and sexual assault, have been excluded. Summons has been issued against the hospital.

***X v Connell Instruments*** – the ALP's client was dismissed for wearing an 'HIV-positive' T shirt. The ALP has initiated an action on his behalf in the Labour Court.

## Cases before other tribunals

### Council for Medical Schemes:

#### *FH v Compcare Medical Scheme*

The ALP acted on behalf of FH whose membership of Compcare Medical Scheme had been terminated on the basis that he had failed to disclose his HIV status. FH stated that he was not



aware of his HIV status prior to applying for membership of the medical scheme. A complaint was made by the ALP to the Registrar of the Council for Medical Schemes and a mediation hearing was convened on the 8<sup>th</sup> of August 2002. A hearing took place before the Council on the 28<sup>th</sup> of October 2002. The ruling of the Council was made available on the 4<sup>th</sup> of November 2002 and Compcare was ordered to reinstate FH with immediate effect and also to pay out on all costs that he had incurred during the period that he was not a member of the scheme.<sup>5</sup> Compcare appealed to the Appeal Board of the Council and the appeal was argued on the 24<sup>th</sup> of February 2003.

The Appeal Board found in favour of FH, indicating that Compcare had failed to prove that FH had been aware of his HIV status prior to joining the scheme and stating in its ruling that it was clear from the evidence that Compcare had terminated FH's membership when it became aware of his HIV status. Compcare were ordered to reinstate FH's membership with retrospective effect.

### EL and BB v Discovery Health Medical Scheme

The ALP referred a complaint to the Council for Medical Schemes concerning the capping of AIDS-related hospitalization by Discovery Health Medical Scheme, on the grounds that it unfairly discriminated against members with HIV/AIDS.

The Council instructed Discovery to convene a Disputes Committee hearing, which it did on the 26<sup>th</sup> of May. To date, Discovery Health Medical Scheme has not yet released its ruling.

### Public Health and Welfare Sectoral Bargaining Council:

#### *N v The Department of Health, Mpumalanga*

The ALP acted on behalf of a doctor who had provided assistance to GRIP, another of the ALP's clients, who in turn provided PEP services to rape survivors who sought care at public hospitals. The MEC for Health attempted to prevent GRIP from providing PEP to rape survivors.

As a result of the support offered to GRIP by Dr N, the Department of Health unlawfully dismissed him. The ALP assisted him in challenging the conduct of the Department.

The matter was argued before the Bargaining Council and the decision to dismiss Dr N was upheld. The ALP assisted Dr N to appeal against this decision and the appeal was successfully argued on the 5<sup>th</sup> of August. The matter will be referred back to the Bargaining Council.

### Commission for Conciliation, Mediation and Arbitration:

The ALP took a number of cases to the CCMA during the year, most concerning the rights of domestic workers. Most were successfully conciliated in favour of the ALP's clients.

### Legal advice:

The ALP Legal Unit continues to assist a number of key AIDS organizations by providing them with legal advice on a range of issues, including internal, organizational issues.

<sup>5</sup> A copy of the judgment can be found at [http://www.alp.org.za/view.php?file=/resctr/jdgmnts/20031030\\_CompOct02.xml](http://www.alp.org.za/view.php?file=/resctr/jdgmnts/20031030_CompOct02.xml)

**SETTLEMENT AGREEMENT**

entered into between, on the one hand,

the twelve COMPLAINANTS, named below,  
in the complaint submitted by them ("the complaint")

to the Competition Commission in South Africa

in terms of the Competition Act,

under and in connection with case no 2002Sep226,

and, on the other hand,

BOEHRINGER INGELHEIM (PROPRIETARY) LIMITED,  
INGELHEIM PHARMACEUTICALS (PROPRIETARY) LIMITED,  
BOEHRINGER INGELHEIM GmbH,  
BOEHRINGER INGELHEIM PHARMACEUTICALS INC,  
BOEHRINGER INGELHEIM PHARMA KG,  
BOEHRINGER INGELHEIM INTERNATIONAL GmbH and  
DR KARL THOMAE GmbH

(together defined herein below as "BOEHRINGER INGELHEIM").

JOHANNESBURG

2003

Signed on behalf of  
BOEHRINGER INGELHEIM  
PHARMACEUTICALS INC,  
BOEHRINGER INGELHEIM PHARMA  
KG, and  
BOEHRINGER INGELHEIM  
INTERNATIONAL GmbH

by:

Full name: ROBERT LEE APPELBAUM

Designation: Power of Attorney

Signature: 

DULY AUTHORISED

ARDS

Lawburg

03

Signed on behalf of  
INGELHEIM PHARMACEUTICALS  
(PTY) LIMITED

by:

Full name: PAUL BRUCE STEWART

Designation: Chairman

Signature: 

DULY AUTHORISED

Signature: 

Signature: 

Signature: 

Thus done and signed at JOHANNESBURG

on 09 DECEMBER 2003.

Witness:

Signed on behalf of the  
complainants by:

Full name: JONATHAN BERGER

Full name: FATIMA HASSAN

Designation: ATTORNEY

Signature: 

Signature: 



# law and treatment access unit

A critical issue in the HIV/AIDS epidemic is the legal and human rights question of access to essential medicines for preventing and treating HIV infection and AIDS-related illnesses. The law, both at national and international level, has generally been used by governments and the pharmaceutical industry to restrict access to such medicines. In light of this, the Law and Treatment Access Unit (LTAU) was set up in January 2002 to address this crucial issue as well as additional barriers that limit access to treatment for HIV/AIDS.

Since its inception, the LTAU has made numerous written and oral submissions to Parliament, the Department of Health, other government departments and statutory bodies on a range of health policy issues; assisted individuals and organisations in South Africa and elsewhere with legal advice on access to medicines; and provided legal education, advice, litigation and research services to a range of civil society organisations, most notably the Treatment Action Campaign (TAC).

## **Access to essential medicines, medical products and diagnostic and monitoring services**

### **Hazel Tau and Others v GlaxoSmithKline and Boehringer Ingelheim**

The highlight of the LTAU's work in 2003 was the successful conclusion of negotiations with two major pharmaceutical companies that will ensure better access to three key antiretroviral (ARV) medicines throughout sub-Saharan Africa. The settlement agreements would not have been reached without the formal complaint to South Africa's Competition Commission that the LTAU lodged in September 2002 on behalf of four people living openly with HIV/AIDS, four health care workers, the TAC, COSATU and its affiliate CEPPWAWU.<sup>1</sup>

<sup>1</sup> In February 2003, two further complainants joined – a police officer living openly with HIV/AIDS (who subsequently passed away on the 16<sup>th</sup> of June 2003) and the AIDS Consortium (representing more than a thousand individual and organisational members).



Alleging that GlaxoSmithKline (GSK) and Boehringer Ingelheim (BI) were acting unlawfully by charging excessive prices for certain of their ARV medicines to the detriment of consumers, the complaint argued that the prices charged by the groups for their essential and life saving

medicines were directly responsible for the premature, predictable and avoidable deaths of women, men and children living with HIV/AIDS.

The complaint assembled the testimonies of people living with HIV/AIDS and health care workers who treat people living with HIV/AIDS. It also assembled a range of expert evidence by collaborating with leading doctors, nurses, scientists, economists, lawyers and actuaries. In essence, the complaint showed that even when allowance is made for the costs of research and development, higher profits, licensing fees and the incentive to develop new drugs, the prices of these ARV medicines were excessive.<sup>2</sup>

On the 16<sup>th</sup> of October 2003, the Competition Commission announced that it had decided to refer the complaint to the Competition Tribunal for adjudication. As a result of its year-long investigation, the Commission had found sufficient evidence to support the referral on the basis of prohibited excessive pricing as well as two

additional grounds, both of which deal with the failure of GSK and BI to licence generic manufacturers in certain circumstances. Simply put, the Commission found that GSK and BI were using their patent monopolies to deny appropriate licences to other manufacturers, whilst simultaneously keeping their own prices high.

By December 2003, within two months of the Commission's announcement, GSK and BI entered into separate settlement agreements with the complainants and the Commission respectively.<sup>3</sup> In short, the two groups of companies have agreed to open up the market for these drugs to generic competitors.

The matter received local and international attention, being a world-first in terms of the licensing of generic companies to supply essential medicines to both public and private sectors in countries where such medicines are still protected by patent.

### Generic Anti-retroviral Procurement Project and TAC Treatment Project v Boehringer Ingelheim

In a second matter dealing with the issue of access to essential medicines, the LTAU formally approached BI in September 2003 on behalf of the Generic Anti-retroviral Procurement Project and the TAC Treatment Project, seeking non-exclusive voluntary licences for the two not-for-profit projects to import and distribute generic nevirapine products.

<sup>2</sup> The LTAU published a report on the complaint entitled "The Price of Life – Hazel Tau and Others v GlaxoSmithKline and Boehringer Ingelheim: a report on the excessive pricing complaint to South Africa's Competition Commission". The report is available in hardcopy and online at [http://www.alp.org.za/view.php?file=/resctr/pubs/20030813\\_PriceCover.xml](http://www.alp.org.za/view.php?file=/resctr/pubs/20030813_PriceCover.xml).

<sup>3</sup> The settlement agreements with the ALP's clients are available online at [http://www.alp.org.za/view.php?file=/camps/20030910\\_PatRights.xml](http://www.alp.org.za/view.php?file=/camps/20030910_PatRights.xml).

In this case, the LTAU worked within the framework of patent legislation, threatening a compulsory licensing application in the event that the voluntary licence requests were denied. While separate from the Competition Commission complaint, the combination of the two matters helped to bring BI to the negotiating table. By December 2003, the LTAU had successfully secured royalty-free voluntary licenses for nevirapine on behalf of the two projects.<sup>4</sup>

While the Generic Anti-retroviral Procurement Project may only import and distribute nevirapine products to its members (not-for-profit treatment programmes), the TAC Treatment Project is able to supply individuals in need of access, including beneficiaries of medical schemes. In addition, the TAC Treatment Project is able to import generic nevirapine products for patients who receive treatment that it funds.

### Treatment Action Campaign v National Pathology Group

Early in 2003, the LTAU began consulting with key pathology industry role-players as part of its own investigation into private pathology practices. In the LTAU's view, the private pathology industry continues to act in anticompetitive ways that serve to limit access to necessary laboratory monitoring and diagnostic services. Through its representative body, the National Pathology Group (NPG), the industry ensures that the high costs of such services are artificially maintained.

With the knowledge that the Competition Commission was investigating various private health care

practices on the grounds that they were violating the provisions of the Competition Act, the LTAU submitted a report in June 2003 containing the key findings of its investigation. By September 2003 the Competition Commission requested that the LTAU convert the report into an official complaint.

In September 2003, LTAU lodged a formal complaint on behalf of the TAC against the NPG. The Commission has until September 2004 to conduct an investigation into the allegation that the NPG operates as a cartel, engaging in prohibited price fixing and other restrictive practices.

### Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa

In the second half of 2003, the LTAU participated in the development of the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa in two key ways.

First, the LTAU met with senior treasury officials to discuss strategic options for accessing a sustainable supply of affordable medicines. Following the meeting, the LTAU followed up by providing treasury with information and legal memoranda on the issue.

Second the LTAU participated in the drafting of the civil society submission to the National HIV and AIDS Treatment Task team, working on three legal memoranda: legal aspects of reducing drug prices; the constitutional requirements for developing and implementing a treatment plan; and informed consent and patient confidentiality. The first two of these three memoranda were co-drafted by

<sup>4</sup> The settlement agreement is available online at [http://www.alp.org.za/resctr/other/pdf/20031215\\_GSKBI4.pdf](http://www.alp.org.za/resctr/other/pdf/20031215_GSKBI4.pdf)

the Legal Resources Centre (LRC). The LTAU also drafted and assisted with the drafting of the following sections of the submission: drug registration and supply; diagnostic and monitoring services; national patient register and data collection.

### Complaint to the Council for Medical Schemes on Substandard HIV/AIDS treatment

In response to the findings of a study conducted by the Centre for Actuarial Research and the TAC on the provision of HIV/AIDS benefits in Medical Schemes, the LTAU submitted a complaint on behalf of the TAC to the Council for Medical Schemes (CMS) calling for an industry-wide investigation into the provision of substandard HIV/AIDS treatment. The complaint requested that the CMS develops appropriate medical treatment protocols for use by schemes.

The CMS completed its investigation towards the end of 2003 and will be publishing its findings shortly. In addition, the CMS has used its findings to motivate for the inclusion of ARV treatment as a prescribed minimum benefit (PMB) for medical scheme beneficiaries. This is likely to come into effect by early 2005.

### Implementing the World Trade Organization's Declaration on the TRIPS Agreement and Public Health

In terms of international law and in the light of the *Declaration on the TRIPS Agreement and Public Health* adopted by the World Trade Organisation in November 2001, South Africa is permitted to make active use of existing as well as to introduce new legislative provisions to facilitate the early market entry of generic essential drugs and medical products. Such executive and

legislative actions, however, have yet to be taken.

With this in mind, the LTAU hosted an international seminar in March 2003 entitled "Implementing Doha, Increasing Access: Rethinking Patent Law in the Context of a Right of Access to Essential Medicines". The purpose of the seminar was to:

- Explore the regulatory options available under international law to reduce the prices of essential medicines that are under patent protection; and
- Explore the implications thereof for the state's positive constitutional obligations in respect of the right of access to health care services.

Seminar participants represented a wide range of bodies, including government departments, civil society organisations, organised labour, academia, funders and the media. Speakers and chairpersons were also drawn from a diverse range of South African bodies - including the Department of Trade and Industry; the Medicines Control Council; the University of Durban-Westville, University of the Western Cape and the University of the Witwatersrand; the TAC and the LRC - as well as internationally from Brazil, India, Namibia and the United States.<sup>5</sup>

## Holding Civil Society to Account

At the end of 2002, allegations of irregularities relating to the state funding of an organisation of people living with HIV/AIDS (the National Association of People Living with HIV/

<sup>5</sup> A copy of this report can be found at [http://alp.org.za/view.php?file/camps/20030910\\_PatRights.xml](http://alp.org.za/view.php?file/camps/20030910_PatRights.xml)

AIDS, or NAPWA) came to the fore. In 2003, the LTAU instituted its first case under the Promotion of Access to Information Act (on behalf of the TAC), by submitting formal requests asking about financial and funding information relating to NAPWA as well as government funding of NAPWA.

These requests were submitted to the Department of Health and NAPWA. When it was clear that neither NAPWA nor the Department of Health were prepared to comply with the requests, the LTAU prepared legal papers to proceed against both in the High Court, seeking orders to compel them to hand over the requested information.

An internal appeal against the Department's initial decision to refuse the request resulted in records relating to the information requested being made available to the LTAU. In light of this, the LTAU was instructed by the TAC not to proceed with the legal case. Instead, the LTAU compiled a dossier and report of its findings, largely based on the documents accessed through the Department, for the purposes of a submission to the Auditor General. At the time of writing, the submission had not yet been made.

## Legislation and policy watch

The LTAU participated in three important legislative and policy processes in 2003.

In February, in collaboration with the ALP's HIV Law and Policy Unit, the LTAU drafted a submission on the Compulsory HIV Testing of Alleged Sexual Offenders Bill.<sup>6</sup>

In June, the LTAU drafted a written submission and participated in the Portfolio Committee on Social Development's public hearings on the social development aspects of the *Report of the Committee of Inquiry into a Comprehensive System Of Social Security for South Africa*.

In June 2003 government published its National Health Bill. The LTAU made an extensive written submission on the bill as well as making an oral presentation to Parliament's Health portfolio committee.<sup>7</sup>

## Opinions, memoranda and legal advice

Aside from the various legal opinions and memoranda drafted in preparation for legal action, the LTAU continued in 2003 to provide an advisory service to a range of organizations and bodies, including the Medicines Control Council, the TAC, the TAC Treatment Project, the Generic Anti-retroviral Procurement Project, the Terrence Higgins Trust and Oxfam GB.

In addition, the LTAU continued to provide legal advice on treatment-related matters to a range of individuals and companies. In particular, the LTAU advised and assisted on various aspects of workplace treatment programmes, medical schemes matters (including limits on AIDS-related hospitalisation, condition-specific waiting periods and the extent of HIV-related benefits) and overcoming obstacles in the way of accessing cheaper generic medicines.

<sup>6</sup> A copy of this submission can be found at [http://www.alp.org.za/view.php?file=/restr/subs/20030328\\_SOB.xml](http://www.alp.org.za/view.php?file=/restr/subs/20030328_SOB.xml)

<sup>7</sup> A copy is available at [http://www.alp.org.za/view.php?file=/restr/subs/2002028\\_subnhbl.xml](http://www.alp.org.za/view.php?file=/restr/subs/2002028_subnhbl.xml)

## Regional and International Work

The LTAU concentrated on two areas of regional and international work.

The LTAU met with Xavier Carim (South Africa's chief trade negotiator) to discuss the potential implications of the United States/Southern African Customs Union Free Trade Agreement negotiations for access to essential medicines and health care services more broadly. In addition, the LTAU began work on producing a memorandum detailing the concerns of the LTAU and the TAC in this regard.

The unit also advised the Canadian HIV/AIDS Legal Network (CHALN) on its approach to the amendment of Canadian patent law regarding access to generic medicines for developing countries. In addition, the LTAU drafted a press release welcoming the Canadian government's commitment to increasing access to essential medicines, and participated in a press teleconference with Médecins Sans Frontières and the CHALN.

The LTAU also participated in the CHALN/ICASO/ALP expert consultation in Montreal (Canada) entitled "HIV treatments, vaccines and microbicides: developing an agenda for action", as well as a number of regional training and advocacy workshops on legal aspects of access to treatment for HIV/AIDS.



# advocacy, research and public education

## **The campaign for a National Treatment Plan and access to antiretroviral treatment**

During 2003, the ALP continued its work promoting and protecting the human rights of people with HIV through research and advocacy. The ALP's human rights advocacy covered numerous issues but, as in previous years, there was a particular focus on campaigning for a comprehensive response to the HIV epidemic that included access to ARV treatment for people with AIDS. This involved a continued close collaboration with the TAC throughout the year.

The ALP's 2002 annual report spoke positively about the developments at the end of 2002 and, in particular, the process taking place within the National Economic Development and Labour Council (NEDLAC) to draft a "Framework Agreement for a National treatment and prevention plan" agreement between business, labour, government and communities. Unfortunately, 2003 began with an unnecessary controversy over the status of this agreement, with President Mbeki and the Minister of Health initially denying that there was a document at all. Although by February 2003 the business, labour and community

sectors at NEDLAC had reached agreement on the text, government refused to return to the negotiations before a Cabinet decision had been taken on the use of ARV medicines. This stymied the NEDLAC process for many months, with meetings only resuming in June 2003.

The deadlock over a Treatment Plan led to a political conflict between the TAC and government dominating the early part of 2003. On the opening day of Parliament, the 14<sup>th</sup> of February 2003, TAC led an historic march of 15 000 people to Parliament, calling on people to 'Stand Up for Our Lives'. On the 21<sup>st</sup> of March 2003, Human Rights Day, TAC was forced to launch its 'Civil Disobedience' campaign. The ALP lent its support to both of these activities; ALP members joined the 'treatment train' taking activists to Cape Town from Johannesburg and in February and March, the ALP presented training workshops on the basic tenets and philosophy that underlie civil disobedience and non-violent social change. ALP lawyers also trained TAC activists in Gauteng about their legal rights in the event of being arrested on demonstrations. On the days of civil disobedience demonstrations, the ALP had lawyers on stand-by to assist the demonstrators if needed.

The TAC civil disobedience campaign lasted from March to April 2003 and involved a number of high-profile but disciplined demonstrations. Despite the USA's war against Iraq dominating media, it led to a national debate on the issue of ARV treatment and demonstrably elicited broad public support for TAC's demands. In mid-April, the campaign was suspended after a meeting between TAC leaders and the Deputy President, Jacob Zuma. This led to a meeting between TAC and six Ministers who are members of the South African National AIDS Council (SANAC) in June 2003, and a promise by the Ministers of urgent resolution of the issue of an antiretroviral treatment programme.

This promise was kept in August 2003, when the Cabinet published the report of a joint task team of the Health Department and the Treasury, which had been set up as a result of the NEDLAC process, and recommended the speedy introduction of an ARV treatment programme in South Africa. Soon after this, the ALP co-ordinated the research and writing of a civil society 'shadow report', making a number of concrete proposals to the government on the detail of implementation. This included a number of papers prepared by the ALP.<sup>1</sup> In the final 'Operational Plan' which was published by the government in November 2003, as well as in the Health/Treasury report, it seemed as if the South African government had absorbed the lessons of the litigation over the provision of services to prevent mother-to-child HIV transmission and was now more sensitive to fashioning public policy on access to health care that directly takes account of its legal duties and the decision of the Constitutional Court in the TAC case.

## Applied research and advocacy: Children, PEP and Insurance

The ALP conducts a great deal of research. Some of this is published in academic journals and presented at conferences. For example, at the first South African AIDS conference, held in July 2003, four ALP staff had abstracts accepted and made oral presentations at the session on law and human rights. However most of the ALP's research is immediately applied to support advocacy around policies, legislation and emerging issues. Thus, in addition to treatment advocacy, throughout the year the ALP continued to be involved in a range of other legal and human rights issues.

Some of these are described briefly below:

- **Children's rights:** The growing number of deaths of parents due to HIV/AIDS has led to the issue of children's rights and needs assuming more importance. As a result the ALP began advocacy around the need for a better policy allowing bona fide care-givers to consent for HIV testing and treatment of children without legal guardians. This led to both litigation (see HIV Law and Policy Unit report) as well as collaboration with the national Departments of Social Development and Health on the drafting of guidelines.<sup>2</sup>
- **PEP for rape survivors:** The ALP remained actively involved in monitoring the provision of post-exposure prophylaxis (PEP) services

<sup>1</sup> A copy of the submission can be found at <http://www.tac.org.za/Documents/FullSubmissionToTaskTeam-Draft-20030919.doc>

<sup>2</sup> A copy of the presentations can be found at [http://www.alp.org.za/view.php?file=/resctr/cpaprs/20030910\\_DbnConf.xml](http://www.alp.org.za/view.php?file=/resctr/cpaprs/20030910_DbnConf.xml)

to survivors of a rape through the public health service. Before April 2002, PEP was not available to rape survivors in the public health system outside the Western Cape. PEP involves the use of ARV medication that can reduce the risk of contracting HIV after rape or sexual assault. After a range of advocacy initiatives and pressure from civil society, Cabinet announced the roll-out of PEP on the 17<sup>th</sup> of April 2002. The ALP decided to conduct a study on the extent of roll-out of PEP in order to assess the level and degree of policy implementation. In May 2003 findings of the extent of roll-out after 12 months were presented at the Medical Research Council (MRC) 'Gender-based Violence & Health Conference'. The study was extended to include a situational analysis after 18 months which was presented at the 'Reproductive Health Rights Priorities' conference in October. The study generated particular interest and requests for presentations on the topic came from civil society and government. 40 000 additional copies of the ALP booklet entitled "*Preventing HIV after Rape – Steps you can take to protect your health*" were printed and distributed.<sup>3</sup> The ALP also assisted *GenderLinks* – an NGO that focuses on gender and the media – in their 'PEP Talk' campaign. This campaign involved fieldworkers doing spot-checks on the availability and quality of sexual assault services in various clinics and public hospitals throughout South Africa. An educational and information workshop for civil society was conducted with the Centre for the Study of Violence and

Reconciliation. Together- with the CSVR, the ALP has developed a manual, "*Health and Hope in Our Hands – Addressing HIV and AIDS in the aftermath of rape and woman abuse*". This comprehensive manual aims to strengthen service provision to survivors of sexual violence by ensuring that health care workers have access to accessible and appropriate information. The manual locates the provision of PEP within a continuum of services that should be provided to survivors of sexual violence and attempts to explain the dynamics surrounding the provision of services. The manual includes sections on rape and domestic violence and the myths that surround these crimes. The text of the manual will be finalized in early 2004.

**Mpumalanga:** At the beginning of 2003, the ALP and TAC had started litigation against the MEC for Health in Mpumalanga, alleging that she was acting in contempt of the court order in the TAC case on the prevention of mother-to-child HIV transmission. A complaint against the conduct of the MEC was filed with the Human Rights Commission.

In addition, the ALP acted in a number of cases to defend doctors and NGOs against the conduct of the MEC (described more fully in the Legal Unit report).

These actions, and the ALP's collaboration with several investigative journalists, turned a spotlight on the misgovernment of the Health Department in this province. This contributed to an investigation into the running of the Department and eventually to the removal of Ms Sibongile Manana from the post of MEC.

<sup>3</sup> Information on PEP is available at: <http://www.alp.org.za/view.php?file=/camps/20020917 cmpgnpep.xml>

· **Insurance:** The ALP continued to receive cases dealing with insurance-related HIV discrimination. Although no cases have been taken up in courts yet, the unit has worked with the AIDS Consortium and other civil society organizations to raise awareness of key issues. A campaign protesting HIV exclusion clauses in funeral policies led to one major insurer, Avbob, changing its policies. The ALP also developed a partnership with the Life Offices' Association who, at the suggestion of the ALP, agreed to publish a series of information advertisements dealing with the rights of consumers in relation to HIV and insurance. These are being published monthly in popular newspapers at a cost to the LOA of over R1 million. The

advertisements are intended to educate people who wish to purchase insurance products to know and understand their rights.

### Teaching, public education and work with the media

Where possible, staff write up the experience and lessons of these engagements for articles that are published in a range of media. 16 articles were published in 2003. These are listed in appendix B and many can be found on the ALP's web-site.

As in previous years almost all ALP staff made public presentations on HIV/AIDS, the law and human rights. In 2003, the ALP made oral presentations on aspects of its work at 276 conferences, seminars and workshops. The table below breaks this down in greater detail:

## Presentations made by ALP Staff members by sector

| Government | NGO | Education | Religious | Health | Other | International | Total |
|------------|-----|-----------|-----------|--------|-------|---------------|-------|
| 25         | 114 | 44        | 2         | 17     | 62    | 12            | 276   |

Many of these presentations are made in response to invitations requesting the ALP to provide a speaker. However, in 2003 the ALP began to try to develop more systematic training courses. Thus, in early 2003, ALP staff lectured at the University of the Witwatersrand's LLB course on HIV/AIDS and the Law. In August the ALP designed and presented a course on 'The politics and Law of HIV/AIDS: Human Rights and Public Responsibilities' for African post-graduate students from 22 countries, under the auspices of the United Nations Development Programme (UNDP) and the University of SA (UNISA).

## Advocacy and Human Rights Training in Africa and internationally

The ALP's work, although focused on South Africa, is respected internationally. The ALP continues to work closely with UNAIDS and the WHO, sometimes providing technical expertise. During 2003 ALP staff presented papers or provided training in the United States, Canada, Nigeria, Lesotho and Zambia.



### The AIDS & Rights Alliance for Southern Africa (ARASA)

The ALP is a founding member of the AIDS & Rights Alliance for Southern Africa (ARASA).<sup>8</sup> This organisation serves as a regional network that assists human rights activists in Southern African countries in drawing the important links between human rights and HIV/AIDS, and aims to increase the capacity of NGOs and CBOs to conduct work on HIV/AIDS and human rights. The ARASA co-ordinator is based in Windhoek, Namibia, at the AIDS Law Unit of the Legal Assistance Centre. A steering committee made up of people from a number of Southern African countries plans and implements activities.

In February 2003 the ALP, AIDS Consortium and Southern African AIDS Training Programme (SAATP) co-hosted a regional training workshop on AIDS advocacy. This was attended by people from 10 countries in Southern Africa, and led to the development of the first draft of a regional Code on Gender and HIV/AIDS. In July the ALP provided training at an ARASA leadership workshop held in Johannesburg and in October the ALP assisted an ARASA workshop on AIDS and human rights that was held in Lusaka, mainly for people from Zambia, Zimbabwe and Malawi.

<sup>8</sup> <http://www.ac.org.na/arasa/>

## LONG-TERM INSURANCE – THE IMPORTANCE OF COUNSELLING WHEN UNDERGOING AN HIV TEST.

This article, part of a series about HIV/AIDS and the long-term insurance industry, covers aspects relating to pre-test and post-test counselling and discusses why it is very important to use this free service.

In previous articles, we gave you an idea of what you can expect when applying for risk long-term insurance and explained that you will be asked to undergo certain medical tests including an HIV test.

As part of the HIV testing process, you will be handed an information sheet on HIV which is available in the 11 official languages. You will also be advised that personal pre-test counselling is available on request. This service is offered free of charge with the aim of helping applicants to discuss and thoroughly think about the personal implications of agreeing to an HIV test. Before you give permission for the HIV test to be done we advise that you should read through, understand the information and receive face-to-face counselling. This allows you to give your "informed consent" for the HIV test.

this information, not even your intermediary.

If you have tested negative and there are no other medical conditions to be considered, your policy will be issued.

However, if the test is positive, the chief underwriter of the insurance company will write to you and your nominated doctor or specified clinic who will contact you for an appointment. A personal post-test counselling session will also be offered free of charge. Again, it is strongly advised that you make use of this counselling session.

### POST-TEST COUNSELLING

The long-term insurance industry...

test counselling session by positive or other medical post-test counselling if you people who test HIV negative opportunity to get further to re-commit yourself to

plays during HIV/AIDS

based at the University his subject matter and do not agree with

in, dedicated to the

## LONG-TERM INSURANCE What you can do if your HIV test is Positive

THIS ARTICLE FORMS PART OF THE CONSUMER EDUCATION PROGRAMME ABOUT HIV/AIDS AND THE LONG-TERM INSURANCE INDUSTRY AND LOOKS AT WHAT YOU NEED TO DO IF THE MEDICAL TEST YOU TAKE WHEN APPLYING FOR LONG-TERM INSURANCE RISK COVER INDICATES THAT YOU MIGHT HAVE HIV.

As mentioned before, you will be asked to undergo certain medical tests if you apply for long-term insurance risk cover. This will include

However, if the test is reactive (positive), two more tests need to be done.

- If both these tests are non-reactive, your policy will still be granted, but your doctor will also be notified of your results and asked to contact you in this regard. It is the responsibility of you and your doctor's to determine if this test result was only an irregularity, or if you have HIV.



counselling session with your doctor. This session is paid for by the insurance company and will not cost you anything. Your doctor will be able to explain the test results and its health implications to you. You would also have the chance to discuss options about anti-retroviral (ARV) treatment and whether and how you disclose your status to your sexual partner and family and friends.

Nowadays, HIV infection is perceived as a treatable disease if you can get

a certain stage. The insurance environment is also changing regularly and developments regarding products needs to be monitored.

It is also important to know that having HIV only impacts on risk insurance and not investment products.

In the next article we look at what options you have and actions that can be taken when you test negative for HIV.

### AIDS Law Project

The AIDS Law Project of the Centre For Applied Legal Studies based at the University of the Witwatersrand has provided input on the choosing of this subject matter and the contents thereof. However, it should be noted that we do not agree with mandatory HIV testing for long term insurance.



OFFICES' ASSOCIATION OF SOUTH AFRICA

## LONG-TERM INSURANCE – THE ROLE OF THE INTERMEDIARY

This article, part of a series about HIV/AIDS and the long-term insurance industry, discusses the role that the intermediary plays during the application process and the information to be provided regarding HIV/AIDS.

You will often deal with an intermediary when you want to take out long-term insurance. An intermediary is a representative of an insurance company who has vast knowledge about insurance products and the processes involved in obtaining them.

When you take out risk long-term insurance, your intermediary will tell you about the process and the medical test, including an HIV test you have to undergo. You should also be told that you have the right to refuse to undergo an HIV test. However, if you do so, you will be refused insurance cover or certain exclusion clauses will apply.

Also, your intermediary must tell you exactly what will happen if the HIV test is positive. Although long-term insurance is available to people living with HIV/AIDS it is expensive and your intermediary would be able to discuss this in detail. It is important to get detailed information from your intermediary prior to making a decision.

Your intermediary also needs to let you know about the long-term insurance industry's life register. The life register is a list kept by the long-term insurance industry of all persons who are applying for or already have long-term insurance, and have a serious medical condition that is relevant to their policy.

Your intermediary should explain that if you test HIV posi-

itive, your name will appear on this list. Also, that you must give permission for this to happen. The list does not note your medical condition in detail and the results are totally confidential to the insurance industry. However, all insurance companies have access to the information that is contained on the register.

You also need to get information on the nature of the HIV test. Your intermediary should be able to tell you more.

Further information you need to get relates to the various counselling processes available. This includes pre- and post-test counselling. Your intermediary will tell you about them. If not, ask.

Also important for you to find out is the specific processes to be used for medical testing. There is a specific process in place for HIV testing so as to ensure confidentiality and other aspects. Please ensure that your intermediary discusses these in detail. You must know that your HIV test result is confidential and may not be discussed to a third party without your permission.

In general it is important to know that your intermediary is required by law to advise on certain issues:

- You need to be informed about the terms of the contract and that these terms are dependent on the result of your HIV test. You will also be informed about the premium that you will be paying and the nature and extent of benefits you are to receive.
- You need to be advised as to whether it is necessary to undergo another HIV test if you want to replace an existing

policy. You also need to be shown the costs and implications of such a decision.

It is very important that you are sure that the product meets your requirements and that you have all the information you need before making a final decision on the purchase of a long-term insurance product.

In the next article we look at what rights you have in terms of the HIV test and procedures.

### AIDS Law Project

The AIDS Law Project of the Centre For Applied Legal Studies based at the University of the Witwatersrand has provided input on the choosing of this subject matter and the contents thereof. However, it should be noted that we do not agree with mandatory HIV testing for long term insurance.

The AIDS Law Project is an NGO, not for profit organisation, dedicated to the elimination of discrimination against people living with HIV/AIDS.

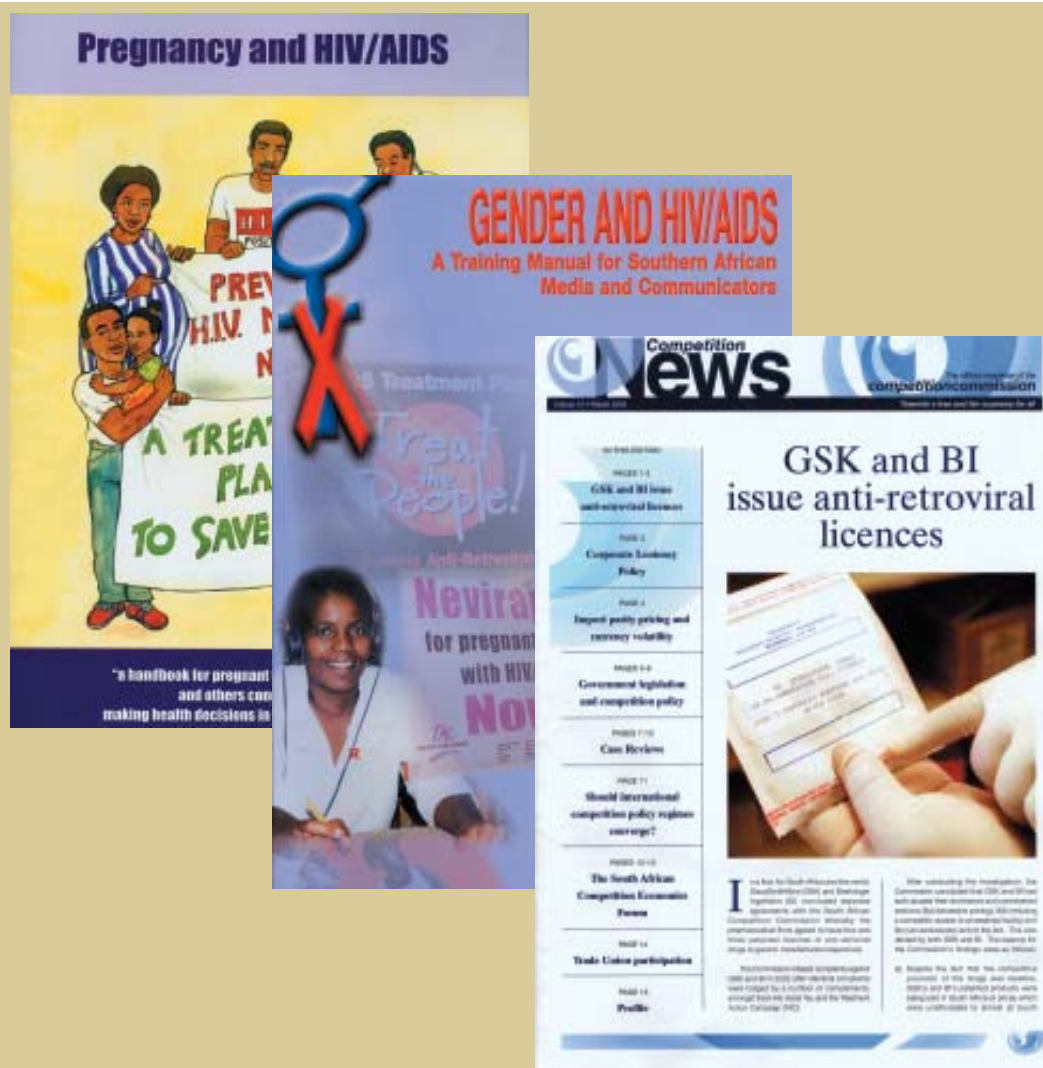
For further information on HIV/AIDS and insurance issues, the ALP can be contacted on 011 717 8600.

### The Life Offices' Association (LOA)

The Life Offices' Association (LOA) can be contacted for information on HIV/AIDS and the long-term insurance industry by writing to them at P.O. Box 5023, Cape Town, 8000, faxing them on 021 421 2599, or e-mail them at [info@loa.co.za](mailto:info@loa.co.za)



As a result of pressure by the ALP, the Life Offices Association (LOA) agreed to embark on a campaign to educate consumers about HIV/AIDS and insurances. Prominent adverts were placed in Sunday newspapers and dealt with a range of issues. The ALP approved the content of each advert before publication



# publications: research and legal literacy

The ALP puts a prime on increasing legal literacy on HIV/AIDS issues among people and organizations affected by HIV/AIDS. Easy-to-read pamphlets in a number of languages are published, as well as research reports and academic articles.

In early 2003 the ALP undertook the publication of the third edition of the *HIV/AIDS and the Law: Resource Manual*. The 2001 edition of the manual was updated and slightly expanded. A further 3,500 copies were published in May and demand for the manual remains great.

## Distribution of the third edition of the AIDS and the Law Resource Manual by Sector

| Sector                    | # donated | # sold | Total |
|---------------------------|-----------|--------|-------|
| Legal                     | 17        | 1      | 18    |
| Academic Institutions     | 54        | 25     | 79    |
| Govt Departments          | 126       | 4      | 130   |
| HIV NGOs                  | 233       | 1      | 234   |
| NGOs general              | 46        | 238    | 284   |
| International NGOs        | 42        | 1      | 43    |
| Trade Unions              | 5         | 0      | 5     |
| Medical practitioners     | 2         | 3      | 5     |
| Donor organisations       | 18        | 36     | 54    |
| Business                  | 4         | 119    | 123   |
| Staff (Project)           | 19        | 0      | 19    |
| Faith Based Organisations | 5         | 1      | 6     |
| Individuals               | 5         | 3      | 8     |
| Book Stores               | 5         | 78     | 83    |
| TOTAL                     | 581       | 510    | 1091  |

In August two new ALP publications were officially launched at the South African AIDS Conference held in Durban. These were:

- 1) *Gender and HIV/AIDS: A Training Manual for Southern African Media and Communicators* (joint publication with Gender Links) and
- 2) *The Price of Life: A report on the excessive pricing complaint to South Africa's Competition Commission* (joint publication with the TAC).<sup>1</sup>

In October two further joint publications with the TAC were launched:

- *HIV in our lives: A book of information sheets for people living with HIV, support groups and clinics.*

- *Pregnancy and HIV/ AIDS: A handbook for pregnant women, their families, and others concerned with making health decisions in the context of HIV/AIDS.*

In July the TAC requested the ALP to develop a research report on the state of traditional healers and traditional medicines in South Africa. This report was finalised in November and is available on the ALP website.

In 2003 work started on a manual that aims to empower a wide range of users of the South Africa's health system with information on health law and policy that will allow them to take advantage of their rights. A manual on these issues has become all the more necessary in the light of recent shifts in government

<sup>1</sup> This report is available on the ALP website at [http://www.alp.org.za/view.php?file=/resctr/pubs/20030813\\_PriceCover.xml](http://www.alp.org.za/view.php?file=/resctr/pubs/20030813_PriceCover.xml)



policy regarding treatment of HIV/AIDS. A range of writers from the ALP and other organisations working in the field will contribute chapters to the manual. It is envisioned that the manual will be completed in 2004.

The ALP's publications are provided free on request and distributed in large quantities around the country to government departments, NGOs, CBOs, the private sector and learning institutions.

### ALP publications distributed in 2003:

|   |               |
|---|---------------|
| HIV/AIDS Current Law and Policy: Women, HIV and AIDS  | <b>3 400</b>  |
| HIV/AIDS Current Law and Policy: Your Rights in the Workplace   | <b>4 410</b>  |
| HIV/AIDS Current Law and Policy: Your Rights to Healthcare  | <b>3 680</b>  |
| Preventing HIV after Rape   | <b>15 760</b> |
| Guidelines on HIV/AIDS and the law for advice and legal office workers  | <b>3 870</b>  |
| The Price of Life: Hazel Tau and others vs GlaxoSmithKline and Boehringer Ingelheim. A report on the excessive pricing complaint to South Africa's Competition Commission | <b>2 820</b>  |
| HIV in our lives: A book of information sheets for people living with HIV, support and clinics  | <b>131</b>    |
| Pregnancy and HIV/ AIDS: A handbook for pregnant women, their families, and others concerned with making health decisions in the context of HIV/AIDS                      | <b>74</b>     |

The ALP continues to have a very good relationship with both the SA and international media. ALP staff are frequently interviewed on the radio and television, or quoted in newspapers. In addition, ALP staff are often contacted

by journalists to provide background briefings and explanations about issues. Staff keep a record of media interviews in their monthly reports. These are summarized in the table on the following page.

**Television interviews with ALP staff**

|               |    |
|---------------|----|
| National      | 24 |
| International | 5  |
| Total         | 29 |

**Radio interviews with ALP staff**

|               |     |
|---------------|-----|
| National      | 151 |
| International | 23  |
| Total         | 174 |

**Occasions when ALP staff are quoted in print media**

|               |     |
|---------------|-----|
| National      | 126 |
| International | 29  |
| Total         | 155 |

**ALP Resource Centre**

During 2003 the ALP Resource Centre moved to bigger premises to allow for greater access to staff members and visitors, and to make space for the increasing volume of materials housed by the Centre. The usual work of the Resource Centre involves information gathering and distribution, filing, maintenance as well as updating of the Centre database. The ALP website was further developed. Most of the ALP's publications, articles and research papers by staff members can now be downloaded from the website.

# Project management and administration

2003 saw the consolidation of the ALP's administration unit, with better internal management systems being implemented. The appointment of a project manager has helped to strengthen the administration and management of the ALP. The ALP introduced an internal management committee in 2003, comprising the project head, the project manager and the two unit heads. This committee meets on a monthly basis, which has also improved communication and management.

Throughout 2003, the administration unit convened monthly staff meetings at which staff members were able to discuss and debate key issues affecting the ALP as a whole. These meetings also afforded the various units of the project with opportunities to provide

regular updates on current areas of work. In addition, the project's two units met on a regular basis. Minutes of all these meetings were taken.

Each ALP staff member provides a monthly report. The heads of the various units submit quarterly reports to the project manager. The project manager compiles the reports according to the specification of each donor. Liaising with donors and regular reporting continues to be a priority for the project. In addition, all staff members are assessed at yearly performance appraisals in terms of university policy. Key performance areas are identified for each staff member and they are appraised according to these areas.

The ALP's finances are managed according to the financial management procedures of the university. The project head and manager are responsible for monitoring budgetary expenditure, with the project administrator being responsible for processing requests for payment and the procuring of services. The ALP receives support from the CALS financial administrator and CALS bookkeeper. An external auditor audits the project at the end of the financial year. One of the areas the ALP would seek to strengthen in the next year would be the implementation of a more efficient financial system.

The project's restructuring and consolidation arose out of an internal evaluation and assessment process that began with a review meeting in the first half of the year, followed by a series of follow-up meetings, with the aim of

strengthening the project and clearly defining the future of the ALP. Out of this process came the decision to restructure the ALP on the basis of two key units – the HIV Law and Policy Unit and the Law and Treatment Access Unit – as well as to focus more attention on public impact legal action and to conduct research proactively to identify emerging legal issues.

As part of the project's restructuring, the ALP decided to rethink its approach to its paralegal work. Instead of providing direct legal advice services to a limited number of people, the ALP would instead focus on capacity building within university law clinics and legal advice offices so that they are better able to provide legal advice and information on HIV/AIDS. A more detailed plan for this programme would be formulated early in 2004.

**The Star**

**GOVT  
SHIFTS  
AIDS  
STANCE**

**The Star**

**GOVT'S  
PLEDGE  
ON AIDS  
DRUGS**

*In August 2003, after years of advocacy, government announced its intention to develop a plan to provide anti-retroviral treatment to people with AIDS*

# appendix

## APPENDIX A

### PRESENTATIONS AND PAPERS AT WORKSHOPS, SEMINARS AND CONFERENCES

#### Jonathan Berger

- 21 January. AIDS Law Project (ALP) paralegals, University of the Witwatersrand, Johannesburg. Training on patents and access to medicines.
- 28 January. AIDS Consortium general meeting, Johannesburg. Briefing on *Hazel Tau and Others vs GlaxoSmithKline and Boehringer Ingelheim*.
- 30 January. Peer counsellors, WITS Positive Campaign, Johannesburg. Interactive training session on advocacy and activism.
- 6 February. Regional HIV/AIDS Advocacy workshop, Centurion. "International trade, patents and access to essential medicines".
- 6 February. Gordon Institute of Business Science, Johannesburg. "Politics, access to treatment and the Treatment Action Campaign (TAC)".
- 18 March. AIDS Law Project seminar: Implementing Doha, Increasing Access: rethinking patent law in the context of a right of access to essential medicines, Johannesburg. "Implementing Doha: what should government be doing?"
- 25 March. Public Health 2003 Conference, Cape Town. "Understanding health systems development and health policy in a constitutional context".
- 29 March. TAC paralegal training, Cape Town. "Role of law and human rights in the epidemic".
- 31 March. CIPRO/ARIPO/EPO/UKPO regional forum on industrial property, Johannesburg. "Implementing Doha, Increasing Access to Essential Medicines".
- 12 April. TAC paralegal training, Cape Town. "Healthcare rights, social assistance and workplace rights".
- 30 April. AIDS Consortium training workshop, Johannesburg. "Access to treatment as a human right".
- 6 May. Pharmaceuticals 2003 conference, Cape Town. "Implementing Doha: towards an appropriate regulatory framework"
- 8 May. Panos Southern Africa workshop, Livingstone, Zambia. "International trade law, patents and access to treatment".
- 14 May. Infectious Diseases Society, Midrand. "Access to affordable medicines for HIV: examining the possibilities for generic antiretroviral medication".
- 24 May. World Bank meeting: *The Role of Generics and Local Industry in Attaining the Millennium Development Goals in Pharmaceuticals and Vaccines*, Washington, DC, USA. "Generic medicines policy and law: the South African experience".
- 10 June. World Education Ntinga/Khula Enterprise Finance workshop: AIDS and

- Enterprise Development: Confronting the Challenge, Johannesburg. "NEDLAC Framework Agreement on a National Prevention and Treatment Plan on HIV/AIDS".
- 3 July. TAC stakeholders' briefing meeting, Johannesburg. Report back on SANAC, NEDLAC, civil disobedience and *Hazel Tau and Others vs GlaxoSmithKline and Boehringer Ingelheim*.
  - 4 July. Annual Labour Law Conference, Johannesburg. "Workplace HIV/AIDS treatment programmes: what are the legal issues that arise?"
  - 11 July. School of Public Health, University of Pretoria, Pretoria. "Understanding Public Health Policy and Health Systems Development within a Constitutional Framework".
  - 19 July. TAC Gauteng Provincial Congress, Vaal. Facilitated commission on the TAC constitution.
  - 29 July. AIDS Consortium general meeting, Johannesburg. Report back on NEDLAC, possible deregistration of nevirapine and the treatment plan.
  - 30 July. AIDS and Rights Alliance of Southern Africa (ARASA) workshop: training of trainers, Johannesburg. "International trade, patents and access to treatment for HIV/AIDS".
  - 2 August. TAC National Congress, Durban. Proposed amendments to the TAC Constitution.
  - 4 August. South African AIDS Conference, Durban. "Using the law to increase access to treatment: *Hazel Tau and Others vs GlaxoSmithKline and Boehringer Ingelheim*".
  - 16 August. TAC paralegal training, Cape Town. "Providing paralegal services".
  - 21 August. UNISA/UNDP winter school, Johannesburg. "Access to treatment for HIV/AIDS".
  - 29 August. Centre for the Study of AIDS, University of Pretoria, Pretoria. "Using the law to increase access to treatment: *Hazel Tau and Others vs GlaxoSmithKline and Boehringer Ingelheim*".
  - 1 September. University of the Witwatersrand School of Public Health: Masters of Public Health students, Johannesburg. "Implications of the Constitution for Public Health Policy"
  - 6 September. TAC Leadership School, Cape Town. "The World Trade Organization and the TRIPS Agreement".
  - 15 October. Briefing for *People to People International*, University of the Witwatersrand, Johannesburg. "Work of the LTAU".
  - 20 October. Canadian HIV/AIDS Legal Network & MSF Canada press conference (via teleconference). "Amendments to the Canadian Patent Act implementing the August 30<sup>th</sup> WTO decision on generic medicines".
  - 28 October. Workshop for Health-e News Service reporters and editor, Cape Town. "Access to essential medicines".
  - 5 November. TAC Treatment Project, Johannesburg. "Work of the TAC Treatment Project Gauteng Selection Committee".
  - 14 November. University of the Witwatersrand, Johannesburg. Proposed settlements in *Hazel Tau and Others vs GlaxoSmithKline and Boehringer Ingelheim*. Complainants in *Hazel Tau and Others vs GlaxoSmithKline and Boehringer Ingelheim*.
  - 19 November. McGill University, Montreal, Canada. "Politics, access to treatment and TAC".
  - 21 November. Faculty of Law, University of Toronto, Canada. "The Price of Life: A Legal Challenge to the Cost of Antiretroviral Therapies in South Africa".
- ## Liesl Gerntholtz
- 21 January. Central Methodist Church, Johannesburg. "HIV and Education".
  - 30 January. Centre for Palliative Learning, Johannesburg. "HIV and the workplace".
  - 25 February. AIDS Consortium, Johannesburg, "HIV testing and disclosure".
  - 7 March. University of the Witwatersrand Law Students, Johannesburg. "The TAC judgement".
  - 10 March. Gender Links, Johannesburg. "Gender, HIV and human rights".
  - 20 April. CSV and ALP, Johannesburg. "Provision of PEP to rape survivors".
  - 23 April. St Matthew's School, Soweto. "The work of the ALP".
  - 9 May. Gender Links, Botswana. "HIV, gender and the media".
  - 14 May. Soul City, Johannesburg. "Update on HIV and the law".
  - 11 June. CSV and ALP, Pretoria. PEP manual workshop.
  - 24 June. Youth Power, Kagiso. "Children and HIV".
  - 27 June. Ethics Committee, University of the Witwatersrand, Johannesburg. "Informed consent for orphans".
  - 27 August. Parklane Clinic, Johannesburg. "HIV and gender".
  - 2 September. Department of Bioethics, University of the Witwatersrand, Johannesburg. "PEP".
  - 25 September. Departments of Health and Social Development, Pretoria. "Informed consent for children".
  - 12 November. Children's homes, Soweto. "Consent and HIV testing".
  - 18 November. Metropolitan Life, Johannesburg. "New development in the workplace".

- 27 November. HIV Clinicians Society. "Overview of legal developments".

## Chloe Hardy

- 12 March 2003. AIDS Legal Network training for Mpumalanga stakeholders, Witbank. "HIV and insurance" and "The right to health".
- 14 March 2003. Rape Crisis Centre at Leratong Hospital, Kagiso. "Legal issues concerning counselling for PEP".
- 27 March 2003. Helen Joseph Hospital HIV support group, Johannesburg. "HIV and the law".
- 2 April 2003. Wits Law Students LSC HIV programme, Johannesburg. "HIV and social security".
- 7 April 2003. Rape Crisis, Kempton Park. "PEP and new legislation on rape".
- 25 April 2003. Community AIDS Response, Johannesburg. "HIV and the law".
- 7 May 2003. Doctors at Helen Joseph Hospital, Johannesburg. "Legal and ethical issues concerning PEP".
- 12 May 2003. AIDS Legal Network training for Limpopo stakeholders, Polokwane. "Access to health rights".
- 23 – 24 June 2003. Youth Power Conference, Kagiso. "The right to health care" and "Making legal referrals".
- 31 July. Rosebank Union Church, Johannesburg. "HIV and the law regarding domestic workers".
- 5 August 2003. Harriet Shezi Clinic, Chris Hani Baragwanath Hospital, Soweto. "HIV and insurance".
- 12 August 2003. Life Line East Rand, Benoni. "PEP and new legislation on sexual offences".
- 22 August 2003. CALS Labour Project Labour Law Up-date, Johannesburg. "HIV in the workplace".
- 11 September 2003. Life Line, Johannesburg. "HIV in the workplace".
- 30 September 2003. Harriet Shezi Clinic, Chris Hani Baragwanath Hospital, Soweto. "Social assistance grants".
- 22 October 2003. DRAMAID, Vereeniging. "HIV and your rights in the workplace".
- 11 November 2003. Township AIDS Project training for counsellors, Johannesburg. "HIV in the workplace".
- 18 November 2003. Legal Resources Centre training for paralegals, Johannesburg. "HIV and the law".

## Fatima Hassan

- 20-24 January. Women and AIDS Support Network (WASN) Training the Trainers, Treatment Literacy Workshop, Nyanga, Zimbabwe. "Treatment Access - Human Rights Issues".
- 20-24 January. Women and AIDS Support Network (WASN) Training the Trainers, Treatment Literacy Workshop, Nyanga, Zimbabwe. "The battle for treatment in SA".
- 20-24 January. Women and AIDS Support Network (WASN) Training the Trainers, Treatment Literacy Workshop, Nyanga, Zimbabwe. "Legal and ethical aspects of treatment".
- 20-24 January. Women and AIDS Support Network (WASN) Training the Trainers, Treatment Literacy Workshop, Nyanga, Zimbabwe. "The role of medical professionals and volunteers in providing treatment".
- 25 January. Bread for the World HIV/AIDS and Human Rights workshop on 'Access to Treatment', World Social Forum (WSF), Porte Alegre, Brazil. "Treatment Access in Africa – the case of SA".
- 26 January. Oxfam, Action AID, MSF AIDS Seminar, World Social Forum, Porte Alegre, Brazil. "The TAC and access to treatment struggles".
- 28 January. AIDS Consortium general meeting, Johannesburg. Briefing on *Hazel Tau and Others vs GlaxoSmithKline and Boehringer Ingelheim*.
- 6 February. Regional HIV/AIDS Advocacy Workshop, Centurion. "Law as an advocacy tool in SA".
- 22 February. Evening plenary, Ditsela Labour Law Summer School, Braamfontein. "The role of trade unions in the struggle for access to treatment".
- 25 February. ESSET People's Budget Week Conference, Cape Town. "AIDS Orphans – South Africa's time bomb?".
- 17-18 March. Seminar on patent reform: "Implementing Doha, Increasing Access: rethinking patent law in the context of a right of access to essential medicines", Johannesburg. "Competition Law and Policy in South Africa".
- 23 April. Globalising Resistance, Panel discussion with Arundhati Roy, FXI, PSC, University of the Witwatersrand, Johannesburg. "Globalising resistance – the struggle for treatment".
- 13 April. Training workshop for TAC paralegal volunteers, University of Cape Town Branch, Cape Town. "Workplace rights, health care rights and social assistance".
- 30 April. AIDS Consortium Training workshops, Johannesburg. "Access to Treatment and Human Rights".
- May. IIR Pharmaceuticals Conference 2003, Cape Town. Panel discussion with Nathan Geffen from TAC and Jonathan Berger on access to medicines as a human right – Implications for the pharmaceutical industry. "The right of access to health care services".

- May. Training workshop – Institute for the Advancement of Journalism (IAJ), Johannesburg. “The role of the media in relation to HIV/AIDS and the media, reporting, confidentiality and the role of civil society”.
- May. SAHRC round table discussion on HIV / AIDS and Insurance, Johannesburg. “HIV/AIDS and the Insurance Sector”.
- May. IIR Conference on Human Resource Strategies for Managing HIV/AIDS in the Public Sector, Johannesburg. “Ensuring compliance with HIV/AIDS related labour legislation”
- May. Guest Lecture, HIV/AIDS and the Law Course, University of the Witwatersrand Law School, Johannesburg. “How the law and regulatory mechanisms can be used to bring the prices of medicines down and increase access to medicines: the Competition Commission case”.
- 24-25 June. Generic Medicines Market Conference, Volkswagen Conference Centre, Midrand. “The legalities of introducing generic competition to increase access to essential medicines”.
- 28 June. Western Cape TAC Provincial Congress, University of the Western Cape. Facilitated Commission on the Constitution of the TAC.
- 2-4 July. 16<sup>th</sup> Annual Labour Law Conference 2003, Sandton. Plenary session: ‘New issues in HIV/AIDS: testing, the provision of ARVs and Medical Aids’. “Medical Schemes, Employee benefits and HIV/AIDS”.
- 4-7 August. South African National AIDS Conference, Durban. Presented paper on “Treat the People Now: Constitutional Issues Relating to Access to Treatment” (Panel discussion with Jonathan Berger, Liesl Gertholtz, Lisa Forman).
- 27 September. AIDC Evening meeting on the WTO, Cape Town. “Doha, the WTO and Access to ARV medicines”.
- 3 September. Phantsi WTO Coalition Teach In, Cape Town. “How ordinary people experience the impact of the WTO” Case studies.
- 6 September. TAC Leadership School, Cape Town. “The European Union (EU)”.
- 28 October. Health-e News Service Round Table, Cape Town. “Access to Essential Medicines” (with Jonathan Berger).
- 3 November. TAC Health and Districts Development Workshop for TAC Branch leaders, Cape Town. “The Legislative Health Framework – Promotion of Access to Justice and Information Acts”.
- 14 November. Briefing workshop on GSK and BI settlement proposals in Competition Commission case, University of the Witwatersrand, Johannesburg. Presented on settlement proposals.
- 1 December. COSATU/ TAC World AIDS Day Rally, Cape Town. “Your rights as a worker”.
- 3 December. Basic Income Grant (BIG) – Reducing Poverty Conference, Johannesburg. “BIG and HIV/AIDS – Reducing Poverty”.
- 5 December. Southern African AIDS Training and HIVOS Conference, Harare, Zimbabwe. “Theoretical Steps in planning an advocacy campaign”.
- 17 January. Doctors at Chris Hani Baragwanath Hospital, Perinatal HIV Research Unit, Soweto. “Overview of responses to the HIV/AIDS epidemic”.
- 3 February. ALP/SAT/AIDS Consortium Workshop, Pretoria. “Advocacy Strategies in Southern Africa”.
- 5 February. Johnnic trainee journalists, Johannesburg. “The Ins and Outs of AIDS in South Africa”.
- 19 February. Department of Social Development national conference on HIV/AIDS, Midrand. “Improving access to social grants for PWAs”.
- 26 February. SASLAW seminar, Johannesburg. “Labour Law and HIV – from Joy Mining to HIV”. Co-presented with J Joni.
- 27 February. Durban Chamber of Commerce & Industry, Durban. “The NEDLAC Agreement and responsibilities of business”.
- 27 February. Durban Chamber of Commerce & Industry, Durban. “Workplace programmes and the challenges of treatment”.
- 27 February. Treatment Action Campaign, KwaZulu-Natal. “Civil disobedience”. Co-presented with M Richter.
- 14 March. TAC Gauteng Treatment Literacy School, Johannesburg. “Barriers in access to essential medicines”.
- 15 March. SA Parastatal and Tertiary Institutions (SAPTU), Pretoria. “The challenge of HIV for trade unionists”.
- 17/18 March. ALP ‘Access to Medicines’ seminar, Johannesburg. Opening and closing comments.
- 26 March. Rhodes University/IAJ workshop on ‘public journalism’, Johannesburg. “Hearing community voices in the media”.
- 27 March. Centre for Civil Society, University of Natal, Durban. Presented Harold Wolpe Memorial Lecture “The Silence of the Lions : Denialism in the ANC and the AIDS epidemic”.
- 16 April. WISER/Department of Sociology, University of the Witwatersrand, Johannesburg. “The

## Mark Heywood



- politics, economics and moral questions around ARV treatment”.
- 24 April. American Women Health Workers, Johannesburg. “AIDS in South Africa”.
  - 5 May. Botswana Training of Trainers, Gender, HIV/AIDS and the media, Gaborone, Botswana. “The epidemiology of gender and treatment of HIV/AIDS”.
  - 9 May. LLB students, University of the Witwatersrand Law Faculty, Johannesburg. “The PMA case and legal issues around SA drug policy”.
  - 21 May. CIDA, Canadian High Commission staff, Pretoria. “Current priorities and issues for funding HIV/AIDS in South Africa”.
  - 28 May. Journ-AIDS Roundtable, Cape Town. “Legal considerations in media reporting on HIV/AIDS”.
  - 6 June. Presentation to Health Workers, Chris Hani Baragwanath Hospital, Soweto.
  - 10 June. Presentation to Coca-Cola Africa Communications & Public Affairs staff forum, Johannesburg.
  - 24 June. Gauteng Department of Social Services, Johannesburg. “HIV, Disability and Legal Issues”.
  - 26 June. Youth Power Conference, Johannesburg. “TAC civil disobedience campaign”.
  - 27 June. Ford Foundation HIV/AIDS Roundtable, Johannesburg. “Advocacy and policy”.
  - 27 June. Airports Company of South Africa, Senior Executives, Kempton Park. “Legal issues in the workplace”.
  - 4 July. Chaired plenary session on HIV, Labour Law Conference, Johannesburg.
  - 5 July. Keynote speaker at TAC Eastern Cape Provincial Congress, Mdantsane.
  - 11 July. Facilitated workshop on HIV and workplace issues for team leaders BMW, Pretoria.
  - 18 July. Facilitated workshop on HIV and workplace issues for team leaders for BMW, Pretoria.
  - 19 July. Keynote speaker at Gauteng TAC Provincial Congress, Evaton.
  - 27 July. Opening address at ARASA Regional Leadership Training, Johannesburg.
  - 2 August. Presented National Secretary’s report at TAC National Executive Committee Meeting, Durban.
  - 18 August. UNISA/UNDP course for African post-graduate students, Johannesburg “HIV/AIDS, Discrimination and Human Rights”.
  - 19 August. UNISA/UNDP course for African post-graduate students, Johannesburg. “HIV/AIDS and civil society”.
  - 20 August. Gave speech at Wits ‘Positive’ public meeting (with Khabzela, YFM DJ), Johannesburg.
  - 20 August. Foreign Affairs Institute, Pretoria. “HIV/AIDS in South Africa, perspective of an activist”.
  - 28 August. Department of Social Development, Pretoria. “HIV and Children with Legal Guardians”. Co-presented with L Gertholtz.
  - 6 September. Gauteng Midwives Association, Krugersdorp. “HIV/AIDS and Treatment”.
  - 10 September. Gauteng Social Services Department/ CRC workshop, Johannesburg. “HIV and the law regarding children”.
  - 19 September. Department of Health ARV Task Team and Clinton Foundation, Pretoria. Civil Society submission.
  - 26 September. CALS/Community Law Centre Seminar, Johannesburg. “Public Impact Litigation – Lessons and Tips”.
  - 30 September. ‘Opening Remarks’ to TAC/Traditional Healers Organisation workshop on shared strategies.
  - 1 October. Action Aid International, Johannesburg. “Work of the ALP and TAC”.
  - 2 October. Planning workshop for HIV/AIDS, Health Economics & Research Division (HEARD), University of Natal, Durban. Facilitated day on legal issues linked to HIV/AIDS.
  - 7 October. TAC NEC, Johannesburg. Presented report on settlement talks with GSK.
  - 10 October. Doctors and nurses from Northwest Province Department of Health, Klerksdorp. “Rolling out ARV treatment – Human Rights Issues”.
  - 15 October. University of Pretoria workshop on ‘Litigating Children’s Rights’, Pretoria. “Public impact litigation”.
  - 22 October. Conference on Corporate Strategic Responses to HIV/AIDS, Johannesburg. “Legal issues in the workplace”.
  - 23 October. Inwent Southern Africa Seminar, Durban. “Implementing HIV programmes in the workplace”.
  - 29 October. COSATU, Johannesburg. Panellist on Gender Studies debate re ‘Achievements after 10 years of government’.
  - 13 November. CALS Conference, Johannesburg. “TAC’s Legal Strategy”.
  - 25 November. COSATU Central Executive Committee, Johannesburg. Settlement proposals in *Tau v GlaxoSmithKline and Boehringer Ingelheim*.
  - 27 November. Durban Chamber of Commerce HIV/AIDS Symposium, Durban. “ARVs in the Workplace”.
  - 3 December. British Embassy and DFID, Pretoria. Overview of the AIDS situation, politics and treatment plan.
  - 5 December. DCI Lesotho, Lesotho Government and NGOs, Maseru, Lesotho. Training programme on key aspects of HIV/AIDS.

## Jennifer Joni

- 17 January. Johannesburg Development Agency, Johannesburg. "HIV in the workplace – Development of HIV workplace policies".
- 21 January. TAC Peer Educators, TAC JHB office, Johannesburg. "HIV and the law,"
- 22 January. ALP paralegal interns, University of the Witwatersrand, Johannesburg. "HIV in the workplace".
- 6 February. US Peace Corp volunteers, Mogwase, Sun City. "HIV and the Law".
- 13 February. Managers of International Health Distributors (IHD), Johannesburg. "HIV in the workplace".
- 26 February. SASLAW Seminar, Johannesburg. "HIV testing in the workplace".
- 28 February. Bronkhorstspuit Netcare Hospital Health Care workers, Mpumalanga. "Confidentiality & HIV testing".
- 1 March. Bambanani Support group members, Residencia, Vaal Triangle. "Confidentiality and disclosure".
- 6 March. Senior management at IHD, Johannesburg. "HIV in the workplace".
- 15 March. Health care workers at Garden City Clinic, Johannesburg. "Confidentiality and HIV testing".
- 27 March. Annual Inhouse Legal Congress on HIV in the workplace, Rosebank, Johannesburg. "In-house legal counsel's legal obligations towards employees living with HIV/AIDS".
- 29 April. De Beers Venetia Mine, Mosina, Northern Province. "HIV in the Workplace".
- 10 May. Bambanani Support Group members, Sebokeng, Vaal Triangle. "Confidentiality and disclosure".
- 30 May. Team leaders at BMW SA, Rosslyn, Pretoria. "HIV in the workplace".

- 6 June. Team leaders at BMW SA, Rosslyn, Pretoria. "HIV in the workplace".
- 20 June. Team leaders at BMW SA, Rosslyn, Pretoria. "HIV in the workplace".
- 23 June. Presentation to representatives from various NGOs in Kroonstad on HIV in the workplace, Kroonstad, Orange Free State.
- 26 June. Johannesburg. Presentation to employees of the AIDS Charities Foundation. "HIV in the workplace-development of HIV policies".
- 27 June. Team leaders at BMW SA, Rosslyn, Pretoria. "HIV in the workplace".

## Teboho Kekana

- 28 January. DENOSA, Pretoria. "HIV/AIDS and legal issues".
- 3-7 February. AC/ALP/SAT regional training, Pretoria. "Elements of an advocacy strategy".
- 3 March. Matho-Mayo Development Information, Education and Communication. "Women's rights in relation to HIV/AIDS and abuse".
- 4 March. VSO. "Women and HIV/AIDS".
- 7 March. Population Unit Uniwest. "Population development and HIV/AIDS".
- 9 April. National Union of Mineworkers, Johannesburg. "HIV/AIDS and legal issues".
- 12 May. CARE International, Johannesburg. "TAC Advocacy work".
- 23-25 June. Youth Power, Johannesburg. "Brainstorming on HIV/AIDS and law, confidentiality and disclosure".
- 4 July. BMW, Pretoria. "Impact of HIV/AIDS in business and how to plan as a team-leader".
- 25 July. BMW, Pretoria. "Impact of HIV/AIDS in business and how to plan as a team-leader".

- 2 October. HIV Clinicians' Society, Johannesburg. "HIV/AIDS and ethics".

## Manana Madiba

- 29 May. Kendal Power Station, Witbank. "HIV/AIDS and the law in the workplace".
- 25 June. Youth Power, Kagiso. "Social Assistance".
- 11 September. Lifeline, Braamfontein. "HIV/AIDS and the law in the workplace".
- 11 November. Township AIDS Project, Braamfontein. "Rights to Healthcare".
- 25 November. Harriet Shezi Children's Clinic, Chris Hani Baragwanath Hospital, Soweto. "Rights to Healthcare".

## Teboho Motebele

- 27 January. ALP Paralegals, Johannesburg. "HIV, Insurance & Medical Aid".
- 28 January. NEDCOR (on behalf of HIV Management Solutions), Johannesburg. "HIV & Employment".
- 10, 13 & 19 February. NEDCOR (on behalf of HIV Management Solutions), Johannesburg. "HIV & Employment".
- 10 March. Eskom, Johannesburg. "HIV & Human Rights".
- 14 March. NEDCOR (on behalf of HIV Management Solutions), Johannesburg. "HIV & Employment".
- 7 & 11 April. NEDCOR (on behalf of HIV Management Solutions), Johannesburg. "HIV & Employment".
- 25 April. JOHNNIC Media House (on behalf of HIV Management Solutions), Johannesburg. "HIV in the workplace".
- 11,13, 23 June. NEDCOR (on behalf of HIV Management Solutions), Johannesburg. "HIV in the workplace".
- 25 June. Youth Power, Johannesburg. "HIV and Insurance".

- 8 & 17 July. NEDCOR (on behalf of HIV Management Solutions), Johannesburg. "HIV in the workplace".
- 9 July. University of the Witwatersrand, Johannesburg. "HIV & Human Rights".
- 5 August. Oxygen For Life (Pty) Ltd, Johannesburg. "HIV Workplace Policy".
- 26 August. Eskom, Johannesburg. "HIV in the Workplace".
- 28 August. Paralegals (ALP & TAC), Johannesburg. "HIV & Workplace Issues".
- 3 & 4 September. NEDCOR (on behalf of HIV Management Solutions), Johannesburg. "HIV/AIDS & Employment".
- 27 November. Vista University, Pretoria. "HIV & the Law".
- 4 December. Vista University, Pretoria. "HIV & the Law".
- 3 March. School of Practical Excellence, Johannesburg. "Management of HIV/AIDS in Programmes".
- 11 March. TAC Gauteng, Johannesburg. "Philosophy and Principles underlying Civil Disobedience".
- 14 March. TAC Treatment Literacy, Johannesburg. "Access to health care".
- 28 March. "HIV/AIDS and the Law" course at the University of the Witwatersrand law school, Johannesburg. "HIV/AIDS legislation in 6 SADC countries".
- 8 April. Gender-based Violence & Health Conference, Johannesburg. "Roll-out of PEP services by the Department of Health: Taking stock of the progress made (April 2003)".
- 8 April. Gender-based Violence & Health Conference, Johannesburg. "Young Women's Access to Support services following sexual assault or rape".
- 12 April. CARE International, Johannesburg. "HIV/AIDS & Human Rights".
- 21 April. ALP/CSVR PEP workshop, Johannesburg. "Roll-out of PEP services by the Department of Health: Taking stock of the progress made (May 2003)".
- 24 June. Youth Power, Kagiso. "HIV/AIDS & Gender".
- 25 June. TAC Treatment Literacy, Krugersdorp. "HIV/AIDS and the Law".
- 28 July. AIDS & Rights Alliance for Southern Africa Train-the-trainer workshop, Kempton Park. "HIV/AIDS and Gender".
- 4 August. South African AIDS Conference, Durban. "Customary law, gender and HIV/AIDS".
- 12 August. University of Pretoria 'Good Governance' course, Pretoria. "HIV/AIDS, Human Rights & Workplace policies".
- 15 August. RAISA VSO, Pretoria. "HIV/AIDS and Human Rights".
- 19 August. UNISA/UNDP Winter School, Johannesburg. "AIDS denialism".
- 20 August. UNISA/UNDP Winter School, Johannesburg. "Customary law and HIV".
- 27 August. ALP paralegal training, University of the Witwatersrand, Johannesburg. "HIV/AIDS & Gender".
- 2 September. Steve Biko Bioethics Discussion Forum, Johannesburg. "Roll-out of PEP services".
- 11 September. Department of Social Services – Sexual assault services workshop, Johannesburg. "Roll-out of PEP services".
- 9 October. HURISA Human Rights Camp, Lagos, Nigeria. "HIV/AIDS & Human Rights".
- 15 October. Reproductive Health Rights Priorities conference, Johannesburg. "Roll-out of PEP after 18-months".
- 21 October. Department of Environmental Affairs & Tourism, Johannesburg. "The South African Legal Framework on HIV/AIDS".
- 23 October. ARASA/ZARAN workshop, Lusaka, Zambia. "HIV/AIDS and Human Rights".
- 23 October. ARASA/ZARAN workshop, Lusaka, Zambia. "HIV/AIDS and legal frameworks".
- 25 October. ARASA/ZARAN workshop, Lusaka, Zambia. "Civil Society and Advocacy skills".
- 3 November. GenderLinks Workshop on Media and Gender, Johannesburg. "PEP roll-out after 18 months".
- 20 November. GenderLinks 'PEP Talk' meeting, Johannesburg. "Overview and status of PEP in the public sector in South Africa".
- 26 November. Traditional Healers Collective, Alberton. "Overview of

## Marlise Richter

- 15 January. Department of Health, Pretoria. "AIDS Discrimination".
- 20 January. ALP Paralegal Interns, University of the Witwatersrand, Johannesburg. "AIDS discrimination"
- 5 February. ALP/AIDS Consortium/SAT Advocacy Workshop, Centurion. "Role of law in discrimination".
- 5 February. ALP/AIDS Consortium/SAT Advocacy Workshop, Centurion. "Civil Disobedience: History, Philosophy & Strategies".
- 13 February. Treatment Action Campaign train, Johannesburg, Cape Town. "Philosophy and Principles underlying Civil Disobedience".
- 23 February. TAC, Cape Town. "Philosophy and Principles underlying Civil Disobedience".
- 28 February. TAC, Durban. "Philosophy and Principles underlying Civil Disobedience"

Traditional Healing in South Africa and Clinical trials of traditional medicines”.

- 29 November. HSRC/Kellogg Foundation “HIV/AIDS in Southern Africa” Colloquium, Johannesburg. “HIV/AIDS legislation in 6 SADC countries”.
- 29 November. Gauteng, Johannesburg. Department of Health “Extent of PEP roll-out after 18 months”.
- 30 November. UNOHCHR, Pretoria. “HIV/AIDS legislation in 6 SADC countries”.

# appendices

## APPENDIX B

### PARLIAMENTARY SUBMISSIONS AND BRIEFINGS

#### Jonathan Berger

- 6 February. Compulsory HIV Testing of Alleged Sexual Offenders Bill. Co-drafted submission (with Liesl Gerntholtz and Marlise Richter)
- 21 February. Briefing on HIV/AIDS: Portfolio Committee on Health, Cape Town. Work of the Law & Treatment Access Unit (LTAU) (with Fatima Hassan and Teboho Motebele).
- 4 June. Report of the Committee of Inquiry into a Comprehensive System Of Social Security for South Africa. Drafted submission on the social development aspects of the report (on behalf of the ALP and TAC).
- 31 July. National Health Bill. Drafted submission (on behalf of the ALP and TAC).
- 18 August. Presented joint ALP/TAC submission to the Portfolio Committee on Health, Cape Town. "National Health Bill".
- 18 August. National Health Bill. Drafted edited version of submission for public hearings (on behalf of the ALP and TAC).

#### Liesl Gerntholtz

- 5 February. Portfolio Committee on Justice, Cape Town. Presented ALP submission on compulsory HIV Testing for alleged sex offenders.

#### Fatima Hassan

- 21 February. Briefing to Parliamentary Portfolio Committee on Health, Parliament, Cape Town. The history of the ALP 1993 – 2003 – The ALP

past, present and future – Successes and future challenges (with Jonathan Berger and Teboho Motebele).

- 10 June. Parliamentary Portfolio Committee on Social Development - Public hearings on the Taylor Report (Report of the Committee of Enquiry on Comprehensive Social Security), Parliament, Cape Town. Presented submission on behalf of TAC/ALP.
- 22 September. Parliamentary Portfolio Committee on Social Development Joint Civil Society Submission on Social Security Bill, Cape Town. Presented on HIV/AIDS section.
- Draft Social Assistance Bill. Assisted with joint civil society submission on the Draft Social Assistance Bill on behalf of TAC / ALP and a number of other civil society organisations.

#### Teboho Motebele

- 21 February. Parliamentary Health Portfolio Committee, Cape Town. "Insurance & HIV/AIDS" (with Jonathan Berger and Fatima Hassan).
- 8 August. Parliamentary Portfolio Committee on Finance, Cape Town. "Discrimination against people living with HIV/AIDS in the Insurance Industry".

# appendices

## APPENDIX C

### PUBLICATIONS BY STAFF MEMBERS

## Jonathan Berger

### Other

10 January. TAC Treatment Project. Drafted opinion on legal issues raised by the formation of the Project.

24 February. Medicines Control Council (MCC). Drafted opinion on copyright issues relating to patient information leaflets and package inserts.

8 March. Generic Antiretroviral Procurement Project (GARPP). Drafted opinion on legal implications of accessing generics in defiance of patent protection.

17 April. Q&A, Mail & Guardian. Drafted response to questions dealing with the anniversary of the April 17<sup>th</sup> 2002 Cabinet Statement on HIV/AIDS.

7 July. Oxfam. Drafted briefing note for Oxfam on trade and intellectual property issues in preparation for President Bush's visit to South Africa

21 July. Asylum seeker in the United Kingdom. Drafted report on access to treatment in South Africa

2 August. Competition Commission complaint: *Hazel Tau and Others v GlaxoSmithKline and Boehringer Ingelheim*. Co-edited report entitled "The Price of Life" (with Mark Heywood and Fatima Hassan)

30 August. National Treasury. Drafted opinion on legal options available to the state for reducing the prices of antiretroviral drugs.

5 September. Mail & Guardian. "WTO drugs agreement trips up poor countries". Drafted opinion piece on implications of WTO's August 30<sup>th</sup> decision regarding generic drugs.

8 September. Civil Society Submission on the Operational Plan for the Rollout of an Antiretroviral Programme. Co-drafted the annexure on drug procurement for the civil society submission to the National HIV and AIDS Treatment Task Team (with Fatima Hassan and Geoff Budlender (Constitutional Litigation Unit, Legal Resources Centre)).

29 October. Medicines and Related Substances Act and Regulations. Drafted submission for the MCC on the parallel importation of generic medicines (on behalf of the TAC Treatment Project).

29 October. ThisDay. "Drugs ruling: A blow for or against public health?" Drafted opinion piece on Competition Commission decision to refer excessive pricing complaint to the Competition Tribunal for adjudication.

17 December. ThisDay. "AIDS drugs for the price of a cup of coffee". Drafted opinion piece on implications of settlement agreements reached in Hazel Tau and Others v GlaxoSmithKline and Boehringer Ingelheim (co-authored with Fatima Hassan).

## Liesl Gerntholtz

### Academic

"HIV testing and treatment and AIDS orphans", ESR Review, Vol 4 no, 3. September 2003.

### Other

"HIV/AIDS, children and the Buccleuch Montessori Nursery School Case - where to from here?" The Teacher, October 2003.

Homes Medical Outreach Project on "Legal and Ethical issues surrounding HIV testing of Abandoned Infants - the need for government guidelines" - prepared in June.

"Gender violence and HIV/AIDS" and "Gender, human rights and HIV/AIDS" in "Gender and HIV/AIDS Training Manual for Southern African Media and Communicators".

## Fatima Hassan

### Other

March. The South African Competition Commission Case: Hazel Tau and Others v GlaxoSmithKline SA (Pty) Ltd and Others", Canadian HIV/AIDS Policy and Law Review (with Jonathan Berger).

July. The Price of Life. Booklet on the Competition Commission

complaint lodged by Hazel Tau and others against GSK and BI (Co-edited with Jonathan Berger and Mark Heywood).

November. Submitted first draft: The role of the amicus curiae in Constitutional jurisprudence. For Constitutional Law in South Africa, Chaskelson et al Ed.

17 December. This Day. "AIDS drugs for the price of a cup of coffee". Implications of settlement agreements reached in Hazel Tau and Others v GlaxoSmithKline and Boehringer Ingelheim (co-authored with Jonathan Berger).

Access to Information. Memorandum of legal options available to the TAC re allegations of mismanagement of funds by NAPWA.

Access to Information. Memorandum on Access to Information Act and requests by TAC relating to mismanagement of funds by NAPWA.

Private pathology practices. Submission to the Competition Commission of South Africa regarding private pathology practices and the role of the National Pathology Group (NPG).

Civil Society Submission on the Operational Plan for the Rollout of an Antiretroviral Programme. Co-drafted annexures on constitutional law; drug procurement; confidentiality and patient information systems for the civil society submission to the National HIV and AIDS Treatment Task Team (with Jonathan Berger and Geoff Budlender (Constitutional Litigation Unit, Legal Resources Centre)).

## Mark Heywood

### Academic

Contempt or Compliance? The TAC case after the Constitutional Court judgment, ESCR Review, 4: 1, March 2003.

Preventing Mother to Child HIV Transmission in South Africa: Background, Strategies and Outcomes of the TAC case against the Minister of Health, *South African Journal on Human Rights*, Vol 19 part 2, 2003.

AIDS Analysis Africa, Vol 14 (4) Dec 2003/Jan 2004. "TAC Builds Civil Society Support for a Successful ARV roll-out".

### Other

13 February. Business Day op ed article. "Treatment framework must be signed".

March. "Policy and law around HIV/AIDS and human rights". Wits Alumni.

23 March. Sunday Times op ed article. "The right to be angry".

6 April. Sunday Tribune op ed article. "The Silence of the Lions".

8 April. The Star op ed article. "The death of Kebareng Moketsi".

16 May, Op ed in the Sowetan, "TAC Story Hogwash".

May. New introduction for 3<sup>rd</sup> edition of HIV/AIDS and the Law Resource Manual.

June. Wrote draft SADC Heads of Government Declaration on HIV/AIDS.

Case Study 11, 'South Africa: The TAC case and the Right to Medicines' interview in 'Litigating Economic, Social and Cultural Rights: Achievements, Challenges

and Strategies', Centre on Housing Rights and Evictions, Geneva.

Co-edited, 'The Price of Life', ALP/TAC Publication.

Co-edited 'HIV in Our Lives', ALP/TAC publication.

Chapter introduction and 5 reprinted articles from past editions of AIDS Analysis Africa in *Still Everybody's Business, the Enlightening Truth about AIDS*, Metropolitan Group, November.

March. Wrote TAC briefing on the Civil Disobedience campaign, 'Dying for Treatment'.

May. Wrote TAC memo for Growth and Development Summit (GDS).

July. Wrote National Secretary's report for TAC National Congress.

September. Wrote memo on duties of employers to employees on ARV treatment in the event of dismissal or resignation (assisted by Liesl Gertholtz and Jonathon Berger).

September. Edited and coordinated TAC submission on a 'Peoples' ARV programme' to Dept of Health ARV Task Team.

October. Wrote ALP memo on issues related to HIV testing of children and privacy for HIV Clinicians Society Paediatric discussion group (with Liesl Gertholtz)

December. Wrote memo for SANAC on operational plan for Law and Human Rights sector in 2004.

## Jennifer Joni

### Academic

April 2003. Case note on *Irvin & Johnson v Trawler & Line Fishing Union & Others* (2003) 24 ILJ 771-773.

June/July. HIV testing in the

workplace: developments since the implementation of the Employment Equity Act. Labour Law Updates.

### Other

June. HIV testing in the workplace- Legal obligations towards employees living with HIV. Shield Magazine.

## Teboho Motebele

### Academic

October. "Medical Aid Schemes, HIV Status and Material Non disclosure". South African Medical Journal.

### Other

July. "HIV & Insurance - Discussion Document".

## Marlise Richter

### Academic

"The UNGASS Declaration of Commitment on HIV/AIDS: A Review of Legislation in Six Southern African countries" *Canadian HIV/AIDS Policy & Law Review* Vol.8, No.1, April 2003.

"Medical aid schemes, HIV status and 'material non-disclosure'" *South African Medical Journal* Vol.93, No.10, October 2003 (co-authored with Teboho Motebele).

February. The South African Law Commission report on "Compulsory HIV Testing of Persons in Sexual Offences Cases".

June. "Combat, stress and HIV; Psycho-neurology and Immunology".

### Other

"Traditional Medicines and Traditional Healers in South Africa". Discussion Paper prepared for the Treatment Action Campaign and

the AIDS Law Project, 27 November.

"Roll-out of PEP services by the Department of Health: Taking Stock of the Progress One Year on" *Women Health Project Review* Winter.

"AIDS-specific legislation in six Southern African countries". *AIDS Analysis Africa* Vol.13 (5) February/March.



# appendix

## APPENDIX D

### POSITIONS HELD BY ALP STAFF

#### Jonathan Berger

Member of Gauteng Selection Committee, TAC Treatment Project.

Member of the board of the Lesbian and Gay Equality Project.

#### Chloe Hardy

Member of the Executive Committee of the AIDS Consortium.

#### Fatima Hassan

Election Officer for TAC elections (overseeing election process, delegate list, nominations, voting, volunteers and results in collaboration with the IEC), TAC National Congress Durban (1-3 August).

#### Mark Heywood

TAC National Secretary (until August).

TAC National Treasurer (from August).

Member, UNAIDS Global Reference Group on HIV/AIDS and Human Rights.

Member, Johannesburg AIDS Council.

Legal and Human Rights sector representative, SA National AIDS Council (from October).

Steering Committee member, AIDS and Human Rights Alliance of Southern Africa (ARASA).

Board member, Amandla AIDS Advisory Fund.

Member Wits HIV/AIDS Research Institute Steering Committee.

Wits HIV/AIDS and Human Rights "Research Champion".

#### Jennifer Joni

Executive Committee Member, AIDS Consortium (Until February 2003)

Member of the Trade Union Task Team (Solidarity Centre) (Until June 2003)

Member of the South Africa Society of Labour law (SASLAW) (Until June 2003)

#### Marlise Richter

National Reference group of the *Siyam'kela Stigma Project*.

Advisory member of the Canadian Institutes of Health Research/Queen's University Project on "Transforming violent gender relations to reduce the risk of HIV/AIDS among South African young women and girls".

Steering Committee member, AIDS and Human Rights Alliance of Southern Africa (ARASA).

# INFORMED CONSENT, HIV TESTING AND ABANDONED INFANTS



LEGAL GERTHOLTZ, BA (LLB), Head of the Legal Unit, AIDS Law Project, Centre for Applied Legal Studies, University of the Witwatersrand, Johannesburg, [WWW.ALPOREZA](http://www.alp.org.za)  
 GAYLE SHERMAN, MScD, DCh (SA), DTM&I, MRCP (UK), Department of Molecular Medicine and Haematology, Johannesburg Hospital, National Health Laboratory Service and the University of the Witwatersrand, Johannesburg

## THE LAW



**SOUTH AFRICAN LAW** REQUIRES THAT INFORMED CONSENT FROM A PARENT OR LEGAL GUARDIAN BE OBTAINED BEFORE AN INFANT CAN UNDERGO AN HIV TEST OR RECEIVE ANY MEDICAL TREATMENT.

THE CHILD CARE ACT MAKES PROVISION FOR CONSENT TO BE GIVEN BY PERSONS OTHER THAN PARENTS AND LEGAL GUARDIANS, IF THE CHILD HAS BEEN LAWFULLY PLACED IN A PLACE OF SAFETY OR A CHILDREN'S HOME.

THE HIGH COURT IS THE UPPER GUARDIAN OF ALL CHILDREN IN ITS JURISDICTION AND APPLICATION CAN BE MADE TO THE COURT TO APPOINT A GUARDIAN.

## THE CONTEXT



**SOUTH AFRICA** IS ESTIMATED TO HAVE APPROXIMATELY 300 000 AIDS ORPHANS. RESEARCH SUGGESTS THAT THE FIGURE WILL INCREASE TO 2 MILLION BY 2015. SYSTEMS IN PLACE TO ENSURE THAT AIDS ORPHANS ARE APPROPRIATELY CARED FOR ARE OVER-BURDENED AND MANY CHILDREN DO NOT FIND THEIR WAY INTO THE SYSTEM AT ALL. THEY LIVE WITH MEMBERS OF THEIR EXTENDED FAMILIES, WITH CAREGIVERS IN THEIR COMMUNITIES, ON THE STREETS AND IN CHILD HEADED HOUSEHOLDS. MANY CHILDREN ALSO LIVE IN UNREGISTERED HOMES THAT HAVE BEEN ESTABLISHED AS A RESULT OF THE LARGE NUMBERS OF CHILDREN NEEDING CARE.

FOR THESE CHILDREN, THERE IS IN FACT NO PERSON WHO IS LEGALLY ABLE TO GIVE INFORMED CONSENT TO HIV TESTING AND MEDICAL TREATMENT.

## ABANDONED INFANTS



ANECDOTAL EVIDENCE SUGGESTS THAT THERE HAS BEEN A LARGE INCREASE IN THE NUMBER OF INFANTS THAT ARE BEING ABANDONED. MANY OF THESE CHILDREN ARE NOT LIVING IN REGISTERED CHILDREN'S HOMES, OR ARE INFORMALLY PLACED IN CHILDREN'S HOMES WHILE AWAITING PLACEMENT IN TERMS OF THE CHILD CARE ACT. THEY FALL WITHIN THE CATEGORY OF CHILDREN FOR WHOM THERE IS NO-ONE TO PROVIDE LEGAL CONSENT TO HIV TESTING.

## WHY IS HIV TESTING FOR ABANDONED INFANTS IMPORTANT?

- MANY ABANDONED INFANTS ARE IN FACT RECEIVING HIV ELISA TESTS AT THE INSTANCE OF HEALTH WORKERS, DESPITE A LACK OF CONSENT; HIV ELISA TESTS ARE UNRELIABLE FOR CHILDREN BELOW THE AGE OF 18 MONTHS AND CONSEQUENTLY MANY OF THESE CHILDREN ARE WRONGLY LABELED AS HIV POSITIVE;
- ACCURATE KNOWLEDGE OF HIV STATUS IS IMPORTANT TO FACILITATE APPROPRIATE MEDICAL CARE;
- HIV STATUS IS ALSO RELEVANT TO PERMANENCY PLACEMENT, EITHER BY WAY OF ADOPTION OR FOSTER CARE.

## RECOMMENDATIONS

- THE DEPARTMENTS OF HEALTH AND SOCIAL DEVELOPMENT SHOULD URGENTLY DRAFT GUIDELINES THAT REGULATE HOW HIV TESTING OF ABANDONED INFANTS TAKES PLACE;
- THE GUIDELINES SHOULD SPECIFY THAT HIV TESTING CAN ONLY TAKE PLACE IF IT IS IN THE BEST INTERESTS OF THE INFANT AND WITH INFORMED CONSENT;
- THE GUIDELINES SHOULD WIDEN THE DEFINITION OF WHO MAY PROVIDE INFORMED CONSENT TO INCLUDE CAREGIVERS, AS DEFINED IN THE DRAFT CHILDREN'S ACT;
- THE PERSON WHO IS PROVIDING INFORMED CONSENT ON BEHALF OF AN ABANDONED CHILD MUST RECEIVE PRE- AND POST-TEST COUNSELING;
- THE RESULTS OF THE HIV TEST WILL BE DISCLOSED TO THE PERSON WHO PROVIDED CONSENT AND TO ANY STAFF MEMBER OF THE CHILDREN'S AND HEALTH WORKER WHO IS RESPONSIBLE FOR THE PRIMARY CARE AND MEDICAL TREATMENT OF THE CHILD.

Poster presentation at the first South African AIDS Conference, Durban, August 2003



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