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Participants at the Raising Awareness of Human Rights and HIV/AIDS workshop in Francistown



International AIDS Society meeting in Seattle

HIV Vaccine Trials in Botswana: a brief history



Tonya Villafana with the Maiteko a Tshireletso HIV Vaccine Initiative Team

According to the World Health Organization, the development of a safe, globally effective and affordable HIV vaccine represents the best long-term hope for the future control of the HIV pandemic.

In 2001, the Botswana Harvard School of Public Health AIDS Initiative Partnership (BHP)-a collaboration between the Ministry of Health and the Harvard School of Public Health AIDS Initiative-established the *Maiteko a Tshireletso* HIV Vaccine Initiative. The goal of this collaboration has been to develop the infrastructure to conduct HIV vaccine trials in Botswana, including establishing a clinical trial site, laboratory facilities, assembling a scientific and clinical research team and lastly but most importantly, working with communities in Botswana to gain support for HIV vaccine research.

One of the first things researchers considered when preparing the site for vaccine trials, was the need to engage the community in discussions about this type of research. A National HIV Vaccine Committee, appointed by the Ministry of Health advised researchers on individuals

and institutions considered possible stakeholders in vaccine research and a community advisory board (CAB) was established to help the research team address concerns that the general community may have about the research. Originally, the CAB included religious leaders, human rights activists, people living with HIV, youth, health personnel, and traditional leaders, amongst others. Once vaccine trials were initiated in Botswana, trial participants were invited to join the CAB.

In June 2003, the first HIV vaccine trial was initiated in Botswana in collaboration with the National Institute of Health funded HIV Vaccine Trials Network. The trial was a phase I trial (initial phase in the trial process) to determine, primarily, if there are any side effects and secondarily, the immune responses of the experimental vaccine candidate in normal, healthy HIV negative volunteers. This was the first phase I trial to be initiated in the Southern African region and the first trial to be conducted simultaneously in the United States and in sub-Saharan Africa. HIV vaccine trials were first conducted in Uganda and Kenya. Shortly after HIV

vaccine trials began in Botswana, South Africa and Malawi also began initial phases of other experimental HIV vaccines. Since initiating the first vaccine trial in Botswana, other vaccine related research has been conducted at the BHP, including an HIV Vaccine Preparedness Study to prepare for larger scale vaccine trials (later phases in the HIV vaccine trial process) and to look at the recruitment and retention of certain populations in vaccine studies. A second phase I trial of a different vaccine candidate began enrolling volunteers in May 2005 in collaboration with other research sites in the United States and South Africa.

Since 2001, the CAB has generally met monthly to discuss issues of relevance to the community regarding HIV vaccine research. The CAB has not only advised the research team on the research process but has actively participated in educating the community. In March

2003, the CAB held an ethics workshop to discuss ethical issues in HIV vaccine research. The discussion included deliberations on how researchers would ensure that potential volunteers understood what they were agreeing to do by volunteering to participate in vaccine trials, what would happen to volunteers if there was an injury related to their participation in the research, the need to strengthen groups who review the research process in the country, the need to encourage Botswana to participate and take ownership of the research and how an HIV vaccine could eventually be made available to the entire population. These issues and many others have continued to be debated and addressed by the CAB, the research team and the National HIV Vaccine Committee.

To further address the issue of HIV vaccine development in Botswana, the Ministry of Health and the National HIV

Vaccine Committee organized a workshop in collaboration with the World Health Organisation (WHO) to develop a National HIV Vaccine Plan in December 2004. This was necessary to ensure that HIV vaccine development remains a long-term, sustainable effort in Botswana and that all stakeholders in the country would support and buy-in to these long-term efforts. Most importantly, the plan ensures that the concerns of Botswana continue to be addressed.

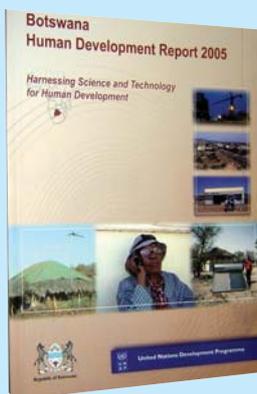
The Botswana Harvard AIDS Partnership plans to continue HIV vaccine efforts, and to participate in trials of several experimental HIV vaccine candidates.

**By Tonya L. Villafana, PhD MPH
Site Director, HIV Vaccine Initiative**

For more information on the Initiative, please contact the Botswana HIV Vaccine Trials Unit at: 0 800 600 606 or 391 3579.

BONELA Round-up

- BONELA said goodbye to Human Rights Internet intern Natalie Doyle in March.
- Oratile Kidd, Milikani Ndaba and Kristi Kenyon facilitated two *Stakeholder Consultative Workshops on the BONELA Human Rights And HIV/AIDS National Training Programme* with participants from the Health Sector from 22nd – 25th February 2005 and with Community Groups from 1st to 3rd March 2005.
- Oratile Kidd presented to the Botswana College of Agriculture Peer Counsellors on the ethical and legal considerations regarding HIV and AIDS on 30th March 2005.



- Our Media Relations Volunteer Werani Chirambo attended the launch of the Human Development Report at the UN Place in Gaborone on 31 March 2005
- Christine Stegling presented a talk on *HIV/AIDS and Human Rights in Botswana* to a delegation of German parliamentarians on 18 May 2005 at the German Embassy.
- Our accountant Nana Gleeson attended a breakfast seminar on the *Impact of Changes in Accounting and Auditing Standards* on 20th May 2005 at

the Grand Palm International Conference Centre in Gaborone.

- Our Human Rights Research Officer Kristi Kenyon continued to sit on the Community Advisory Group for the BOTUSA Tenofovir Trial.
- The BONELA team had a staff and volunteers lunch on 3 June 2005.



The BONELA team having a farewell lunch for HRI intern Natalie Doyle

Call for submissions

THE BONELA GUARDIAN is looking for timely, insightful articles on any topic related to HIV/AIDS and human rights, ethics, policy development, or the law.

If you enjoy writing and are passionate about a topic related to HIV/AIDS we encourage you to send us an article! We welcome first-person accounts, opinion pieces, and responses to articles we have published. Alternative topics, including articles about the medical or social dimensions of living positively with HIV, will also be considered. Submission of relevant photographs or other artwork is encouraged.

For further information, or to submit your ideas, please contact Werani Chirambo or Milikani Ndaba at BONELA (tel: 393-2516)
Have your say!

Awareness Raising Workshops Francistown 17th- 26th May 2005

My colleague and I have begun globetrotting to raise awareness on the human rights barriers, challenges and strategies in the approach to HIV/AIDS. So far, we have held workshops with community and health groups in Francistown with good representation from the health sector as well as community based organizations, the defense forces, correctional services and immigration.

Some issues raised included the presence of discriminatory clauses in some employment policies which threaten the work-related rights of People Living with HIV/AIDS (PLWHA), the need to sensitize Francistown community service providers as well as communities themselves on HIV-related stigma and discrimination.

Below are some of the key learnings from the workshops:

1. How underlying beliefs about HIV modes of transmission affect how we treat people. In an exercise where participants were instructed to rate the risk of HIV transmission in different scenarios, some felt that



Participants from the health sector during a workshop at Tati Lodge.

when correct precautionary measures are taken, HIV is generally difficult to catch. On the other hand, other participants felt that any risk, regardless of precautions taken, is high risk and therefore, HIV is always easy to catch. These risk judgments affect how we relate to people living with HIV/AIDS. When we see PLWHAs as highly contagious, we tend to be less sensitive to their needs and feelings whereas when we are less fearful of them giving us HIV and know how to protect ourselves, we tend to treat them with more respect and dignity.

2. Human rights begin at home. Early discussions between intimate partners about their sexual health are the starting point to taking up their responsibility to their right to health.
3. There is a general lack of knowledge about the rights of individuals in the area of HIV testing, confidentiality and employment to name a few. Encouragingly, there is also massive support for this initiative to adopt a human rights approach to HIV and AIDS. There was a general willingness to take up the knowledge and skills learnt from these workshops and to use them in the community work that participants are involved with in different sectors.

We feel the response so far to this initiative has been immensely positive and we would like to thank everyone who has supported this endeavor. From here, we continue our awareness raising workshops across the country so if we have not reached you yet, be on the lookout for us!

By Oratile Kidd

Discrimination and Access to Care Seminar

On 2 April 2005, BONELA with LeGaBiBo¹ organized a morning discussion seminar entitled *Discrimination and Access to Care*. This was enabled by the Democracy and Human Rights grant from the American Embassy.

The seminar draws its rationale from the marginalization gay, lesbian, bisexual transgendered and intersex (GLBTI) people in Botswana face as a result of social and cultural norms and a law that prohibits 'carnal knowledge against the order of nature.' Therefore, the objective of the seminar was to create awareness and stimulate discussion around the health issues affecting GLBTI people with various stakeholders. The seminar brought together about 40 representatives from various government bodies including the armed forces, law enforcement and correctional services, certain representatives of the UN family including the World Health Organization (WHO) and UNAIDS, public and private medical and legal practitioners, other civil society organizations including the media, members of LeGaBiBo and other *straight allies*.



One of the facilitators Thuli Madi – Director of Behind the Mask in South Africa – presenting at the seminar

Experts who facilitated the discussion fora included local attorney Duma Boko, former National AIDS Coordinating Agency (NACA) Coordinator Dr. Banu

Khan and a resource person and Director of Behind the Mask in South Africa, Thuli Madi, to name a few. Their role was to contribute local expertise and assist with local capacity building. The gathering discussed the legal provisions that criminalize same sex sexual behaviour and the human rights implications of such laws on people who identify as non-heterosexual. The seminar also looked at how the current legal provisions impact on access to preventative and curative healthcare for GLBTI people and how such practices increase vulnerability to HIV and other infectious diseases. The group discussed the public Information, Education and Communication (IEC) approach to the HIV epidemic and observed how it not only desexualizes the disease through its clinical approach to HIV/AIDS issues but also how it, in its strategy, excludes people of non-heterosexual orientation. From group work, participants developed recommendations on how best to ensure non-discriminatory provision of health care for GLBTI. One popular recommendation is the adoption of a private morality concept that restricts exercise of the law in sexual

matters between consenting adults. Another outcome of the seminar is an information leaflet on sexual diversity that also captures the recommendations of the seminar.

By Milikani Ndaba

For more information about the seminar please contact the BONELA office for a copy of the seminar report or visit our website. For information regarding LeGaBiBo, please contact Milikani Ndaba at the BONELA office.

¹ Lesbians, Gays and Bisexuals of Botswana (LeGaBiBo) is an informal network of lesbian, gay, bisexual and transgendered people who meet regularly under BONELA's auspices to address the plight of such people in Botswana.

From the Legal Desk

Various cases are at various stages. Of note are two defamation suits lodged at the High Court where our clients are seeking monetary damages. In one case, the Defendant allegedly habitually publicized a client's HIV positive status and discouraged school children from buying fast food from her supposedly because her goods were contaminated and highly infectious. In the other case, a client's HIV positive status was allegedly disclosed by the Defendant to the client's co-workers and friends.

We are also handling two other separate and unconnected labor matters at the Industrial Court in which our clients claim they were dismissed purely on the basis

of their HIV positive status. We are also talking to a rehabilitation centre for the disabled to enroll a five year old HIV positive disabled child who is on anti retroviral treatment in their program for the disabled. The difficulty we are facing is that the centre maintains that they do not enroll children who are on some treatment for chronic illness, particularly ARV treatment, as they do not have trained personnel to administer the drugs to the children and do not have storage facilities for the drugs.

Watch this space for developments.

By Uyapo Ndadi

Tenofovir Desiproxil Fumarate Preventative Trial

The BOTUSA Project (a collaboration between the US Centres for Disease Control and Prevention and the Government of Botswana) is undertaking a trial to determine whether a daily dose Tenofovir Desiproxil Fumarate (TDF) will prevent HIV infection or decrease its severity. The trial will involve 600 participants in Gaborone and 600 participants in Francistown. It is estimated that the trial will begin in July 2005.

Preventative HIV trials.

Currently the only known ways to prevent HIV infection through sexual intercourse are to abstain from sexual activity, to be in a mutually monogamous relationship where both parties are HIV negative, or to use condoms every time you have sex. The objective of preventative HIV trials is to find additional methods of prevention. There are three main methods currently being investigated around the world:

- 1) Vaccines (the injection of non-infectious versions of the virus to develop anti-bodies able to fight off the real thing)
- 2) Microbicides (a gel that can be applied to the vagina or anus prior to sex which can kill the virus)
- 3) Pre-exposure prophylaxis (taking a drug prior to exposure which prevents infection by interfering with the virus' ability to reproduce)

The TDF trial

The objective of this trial is to see if one tenofovir tablet a day will help prevent HIV infection. Although researchers do not know if tenofovir prevents HIV in humans, previous

research has indicated that it does work as a preventative drug against a similar virus (SIV) in monkeys. Tenofovir is currently used as an anti-retroviral in conjunction with other drugs. In Botswana, tenofovir is not part of the standard treatment regime and is used only if a patient has developed resistance to other drugs.

Similar trials are or have been undertaken on the same drug in Nigeria, Cambodia, Thailand, the U.S. and Cameroon. Some of these trials have been stopped because they have run into a variety of problems (see article on p6).

In Botswana the trial aims to recruit a total of 1200 participants and monitor them for one year. The trial uses a placebo (a drug that looks and tastes like tenofovir but has no effect) in what is known as a 'double blind.' One half of participants will receive the placebo, and the other half will receive tenofovir. This is done to make sure that the biases, hopes, fears or expectations of the researchers or the participants do not bias the research. Participants will be assigned either the real drug or the placebo through a random process, so that neither the participant nor the clinic staff will know who is taking what drug.

Since it would be unfair and unethical to ask trial participants to put

themselves at risk of HIV infection, trial participants are counseled at regular intervals about prevention strategies and are given male and female condoms free of charge. If every person in the trial used condoms every time they had sex we would not know if the drug worked. We would however, as Principal Investigator Dawn Smith says, have developed the first completely effective method of HIV prevention counseling, which, in itself would be a beneficial discovery. Finding out whether tenofovir works to prevent HIV, however, depends on some people within the trial having unprotected sex.



BONELA's involvement

BONELA is involved, through membership in the trial's Community Advisory Group (CAG) in order to highlight any legal, ethical or human rights concerns that may arise and help to develop solutions to resolve them. We realize that participants are taking a risk and are also acting in service to all when they choose to participate in a clinical research trial. The results of previous trials have helped to develop vaccines and medications that have helped all of us avoid diseases that have killed and disabled many people in earlier generations, such as polio.

By Kristi Kenyon

For more information about the trial contact:
Francistown Clinic 241-0646
Gaborone Clinic 319-1375

Botswana's War Against AIDS - Where Refugees Stand



Refugees at Dukwi camp during the 2004 World AIDS Day commemorations

Today the HIV/AIDS epidemic is distressing the African continent more seriously than any of the armed conflicts. HIV/AIDS is not only a challenge but a humanitarian catastrophe. The United Nations General Assembly Special Session (UNGASS) on HIV/AIDS adopted a Declaration of Commitment in June 2001, which states that "populations destabilized by armed conflict including refugees, internally displaced persons, and in particular women and children, are at increased risk of exposure to HIV infection". Refugees are often double victims of discrimination by virtue of being refugees when host countries falsely accuse them of bringing HIV/AIDS across borders and when they are seen by both their country and the host country as 'not our problem' and the epidemic continues.

Botswana, a country with one of the highest HIV/AIDS prevalence rates in the world, has become a safe haven for refugees from war torn or politically unstable African countries, namely Angola, Namibia, Zimbabwe, Somalia, DRC, Somali, Burundi and Uganda. The Government of Botswana in collaboration with UNHCR has set up a refugee camp, called Dukwi in Tutume sub district, 30 km from Francistown.

There are approximately 3194 refugees residing in this camp. 52% of them are adults. The exact rate of HIV prevalence in the camp is unknown, but the Tutume district rate of 37.7% is also applied to the Camp. In 2004, AIDS related deaths in the camp were recorded at 17. Out of the 18 patients who are currently on Home Based Care, 13 are people living with HIV/AIDS (PLWHA). The Home Based Care in the camp is organized by Botswana Red Cross Society to provide care and support for patients, including PLWHA; however, the facilities and support provided to them is inadequate. There are more than 104 orphans in Dukwi, many of them heads of their households. Being left alone without the protection and guidance parents provide makes them more vulnerable to HIV/AIDS.

There is a health clinic in the camp administered by the government. NGOs functioning in there are Red Cross, TCM and the Botswana Christian Council. The UN HIV/AIDS theme group runs an HIV/AIDS project with support from UN agencies, BOTUSA, Tebelopele and the Office of the President, among others. There are 90 trained refugee volunteers, called Peer Educators, in the camp. Twice a week they visit the families assigned to them, they visit all zones of the camp, except the fastest growing zone - the camp cemetery.

Mavis Matenge, UNHCR's officer for HIV/AIDS at Dukwi says "If HIV is still spreading, it is not for lack of information". A situation analysis showed that current interventions need to be enhanced. Cultural taboos and myths about sex are the major obstacles faced by health workers in this camp. The supply of Information Education and Communication (IEC) material is inadequate in languages appropriate for the camp. Even though refugees are secluded by virtue of living in a settlement, interactions between refugees and the local population persist. Marriages between refugees and locals and ongoing casual sexual relationships between the camp and beyond cannot be discounted. These close interactions and their repercussions on HIV/AIDS, therefore, should not be ignored.

Today, Botswana is taking progressive steps to curb the epidemic's impact. The Presidential directive dated 17 April 2002, states that refugees at Dukwi Refugee camp should continue to be provided with public medical services.

Unfortunately Botswana's current response of providing free antiretroviral (ARV) treatment and Prevention-of-Mother-to-Child-Transmission (PMTCT) services has not been extended to the refugees. In July 2004, the national PMTCT program was withdrawn from Dukwi as a result of a policy decision by the government. Even though the testing facilities are available, refugees in the camp prefer not to know their status rather than finding out they are HIV positive and knowing that they have no access to treatment.

This policy of exclusion raises a number of questions often with moral implications. What good is protecting them from war if we do not protect them from HIV/AIDS? The government may be afraid of what will happen to those who would get on ARVs after they are repatriated, to countries where treatment is not available. A cross border approach may answer this issue. The World Bank is attempting to address this issue by funding a unique program with six African governments called the Great Lakes Initiatives on HIV/AIDS.

Excluding the refugees from national ARV and PMTCT programs is highly discriminatory and epidemiologically counterproductive. A successful HIV/AIDS initiative in Dukwi can be achieved by incorporating the refugees in the national ARV and PMTCT programs, developing more IEC materials, providing more awareness raising activities, improving the incentives provided to peer educators and more importantly by supplementing more financial and technical support.

For Botswana to achieve its vision of an AIDS free nation by 2016, intensive efforts have to be carried out at Dukwi, which has the potential of spreading the epidemic further if left unattended. An integration of the HIV/AIDS programs by different stakeholders with UNHCR and a comprehensive monitoring and evaluation is needed. It is true that the financial obligation is high, but together we can succeed in the battle against HIV/AIDS. Refugees, as long as they are in our country, will be our liability, and must live free from any form of discrimination.

By Vanisree T. Ramanathan

ON THE INTERNATIONAL FRONT

International AIDS Society- Seattle Meeting



The Botswana country group during the International AIDS Society meeting at the Hotel Monaco in Seattle

From May 18-20 the International AIDS Society convened a meeting to address the controversies that had been brewing internationally over various preventative HIV drug trials using the anti-retroviral tenofovir. The meeting was attended by principal investigators from the various sites, activists and civil society representatives as well as members of the agencies funding the trials.

Globally, most tenofovir trials involve vulnerable and marginalized groups as their target population. Medical trials using these groups are ethically more challenging than trials targeting the general population because researchers need to be especially careful that participation in the trial will not increase participants' vulnerability or hardship. In situations where that group is criminalized (for example drug users, commercial sex workers) there is the added risk that being known as a trial participant further identifies an individual as someone who participates in illegal activities.

Issues concerning vulnerable groups arose in two trials. In **Thailand**, the trial targets intravenous drug users. This is a highly stigmatized group vulnerable to arrest and extra-judicial execution. The main dispute is over the provision of sterile syringes. In Thailand, it is legal to sell or distribute syringes; however, a law exists illegalizing the facilitation of drug use. On the donor side, the US government prohibits the provision of injecting equipment. This is an issue because the ethical standard in other trials has been to provide prevention equipment for the main mode of infection such as condoms for sexual transmission.

In **Cambodia**, the trial targets commercial sex workers. The controversy in this trial was over the level of care that would be provided if participants became infected with HIV during the trial. In countries without national ARV programs this is a common challenge. Should participants be provided with the standard of care available to the general population? Or with the standard available in the donor country? Or a third standard? The difficulty here, apart from the cost of care, is that providing a standard of care that is significantly better than the local standard could be an undue incentive to participate in the trial and might compromise informed consent. On the other hand, denying care fails to recognize the important role that participants play in the discovery of an effective method of HIV prevention.

Cameroon had a wide range of issues, and misunderstandings. The trial was intended to target commercial sex workers; however, civil society representatives at the meeting said many of the participants were young women who did not fit this profile. Many young women had heard that if they participated in the trial they would get a free medical check-up and participated for this reason. Other problems included the fact that materials and consent forms were in French not local languages; female condoms were not provided; there was a low level of trust of counselors; and access to care and ARVs in case of seroconversion was not provided. Worryingly, some participants did not understand the trial and falsely believed that they had been vaccinated against HIV making them vulnerable to high risk behavior and infection.

In **Nigeria** the trial was terminated due to poor performance with respect to laboratory standards and clinical procedures by trial staff, meaning that the data obtained could not be trusted to be accurate.

Looking Ahead

As the Botswana trial has not yet begun, this was an excellent opportunity to learn from the mistakes of other trials. In comparison with other countries, Botswana is already in an advantaged position in several respects. The existence of a national health care program and, particularly, a national ARV program means that accessing care for those who seroconvert is much simpler. The fact that the Botswana trial targets sexually active young adults, rather than a vulnerable group, means that the burden of participation does not fall on those already disadvantaged. The BOTUSA staff has been conducting training on protocol adherence for months, and all materials are available in both Setswana and English. Male and female condoms are provided free of charge to trial participants.

The Botswana group, however, went beyond trying to avoid problems in other sites, and sought to develop general recommendations for medical trials that would increase community involvement and input and ensure clear communication. Some of the recommendations were:

- to pursue the development of national guidelines for community involvement in research trials.
- to build community capacity in research literacy and researchers' capacity in community literacy.
- to keep some element of the

community involved at every stage of the trial process.

- to develop a system to monitor informed consent

It is important to realize that prevention research is a human rights issue. It is through successful research in this area that we are able to protect the right to health and the right to life. In seeking this goal, however, we must also remain cognizant of the rights of trial participants and the contribution that they are making. Without them, research such as the tenofovir trial would not be possible. It is in the best interests of civil society, activists, researchers and society at large that community involvement be integral from the outset of a trial. It is only in achieving this constructive cooperation that we can have research that is supported and understood by the community, that is fair to participants, and that achieves accurate, relevant results that are socially, culturally and medically useful to the communities that participate as well as those in other parts of the world.

By Kristi Kenyon

BONELA Welcomes a New Volunteer

I am **Vanisree. T. Ramanathan**. I joined BONELA in early April 2005 as a Research Volunteer.

My first degree is in History from the University of Calicut, India, and I graduated from the University of Pune, India in 1996 with a Master of Arts in Sociology. I also acquired a Master of Arts in Population Studies from the University of Botswana in October 2004.

I have worked as a lecturer in Sociology in India and also taught at Maru-a-Pula school in Botswana.

I was actively involved in the Women's cell and participated in the community education programs depicting women's rights in Pune, India. In Gaborone, I have been involved in charity activities to support HIV/AIDS programs.

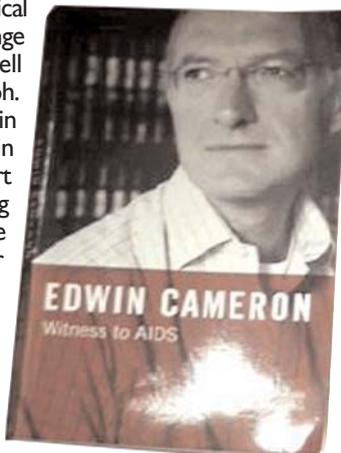
I would like to work in the area of HIV/AIDS, human rights, health, women and children and population policies and programs.

I am eagerly looking forward to working here because I believe in what BONELA strives for.



Book Review: *Witness to AIDS*

Witness to AIDS is an intrinsic blend of memoirs and spellbinding analysis describing how a South African judge faces life with AIDS, how a country grapples with the disease and how Africa is trying to deal with the HI virus and AIDS. It reads like a typical tale of a survival with a tinge of survivor's guilt well highlighted in the epigraph. The author, Edwin Cameron, is a judge in South Africa's highest court and a South African living with HIV/AIDS, a disease that is one of the major challenges the African continent is facing. He is trying to explain why he has been given a second chance, why he has survived an epidemic which is claiming so many lives, not only in South Africa but the whole continent.



Cameron was born in Pretoria on 15 February 1953. After completing high school he was awarded the Anglo-American Open Scholarship to attend Stellenbosch University where he did his BA in Law and Latin. He then went to Oxford University and obtained a BA in Jurisprudence. He later obtained an LLB from the University of South Africa and

was awarded the medalion for best law student. Cameron started practicing law in 1983. He has also been involved in HIV/AIDS policy formulation since the 1980's. He has co-authored books and has delivered several key note addresses including one at the XIII International Conference on HIV/AIDS in Durban, South Africa. Perhaps his biggest achievement so far is that he is the only public office bearer in South Africa to have chosen to go public with his HIV status.

The reason Cameron decided to write this book is well emphasised by Primo Privi in the epigraph; he is a survivor for whom remembering is a duty. He does not want to forget, and above all, he does not want the world to forget that stigma, access to care, race, sexual orientation and HIV/AIDS are still enormous challenges that need to be acknowledged and dealt with.

Witness to AIDS gives a face to HIV/AIDS and its implications not only in South Africa but the whole continent. For those living with AIDS, especially those receiving ARV treatment, they might share with Cameron the survivor's guilt and ask themselves why they have survived. They will also share

with him and others living with HIV/AIDS the inner terror, inner sense of contamination, external fear of stigma and the fact that they are all living with HIV/AIDS.

Cameron admits that he was able to publicly declare his HIV status because he is a Judge and has support from friends and relatives. Other people without support and his socio-economic position find it more difficult to publicly declare their status and often have no access to the life giving drugs. Botswana is one of the countries in the world with a high HIV infection rate, political commitment to fighting HIV/AIDS and ARV's are provided in the public health sector. However no politician, judge, univeristy lecturer or doctor has gone public with their HIV status. The book makes you wonder what it would take for Botswana to have her own witness to AIDS.

This is a must read. Nadine Gordimer actually said; "If truth is beauty then this relentlessly brilliant and hopeful book is beautiful. It is a text to live by..." Reading it is an experience that touches your soul, and after reading it your approach to HIV/AIDS will never be the same. It can be found at any Exclusive Books shop.

By Werani Chirambo

From the director's desk

This issue of the BONELA Guardian has highlighted several aspects of HIV prevention as an important part of our human rights work in order to safeguard the right to life and the right to health. However, as the articles in this issue show, clinical trials with human subjects involve complex ethical and human rights considerations which need to be part of our public debate in Botswana, especially since we do not have much experience with such trials. We hope that our readers and members will actively get involved in discussing these issues and provide BONELA with feed-back and ideas as to how we can possibly address gaps in the national and/or international debate about clinical trials on preventive methods.

This year, much of our time at BONELA has been spent on completing the training manual. Many readers may wonder whether this manual will ever be finished since we have been working on it for so long. We hope that in the next edition we will be able to report on the launch of the manual. We have definitely learned a very valuable lesson as to how involved the in-house production of such a training programme is. At several stages of the project we considered outsourcing the final part of the production but always came to the

conclusion that we would like to see it through to the bitter end without fearing that the involvement of a third party may compromise the quality of the end-product. As you will have realised, we have nevertheless started training with the manual regardless of the fact that the final product has not yet left the printers. All those who have been trained so far have been assured that we will issue them with a beautiful copy of the manual immediately it comes from the printer. Bear with us and watch this space.

As I have pointed out in the BONELA Guardian before, BONELA would not be able to exist and run as efficiently (we like to think that we are efficient) as we do if it was not for the assistance of the many volunteers who undertake a good part of our programme work. Thank you to our new volunteer, Vani, who has been helping with our research work and has so effectively filled Tebogo's place as the Administrator while Tebogo is on maternity leave. Nthabiseng has joined us again after successfully completing her degree at the University of Botswana. We are happy that she has decided to help with our research and training programme as much as with the coordination of our fundraising activities. Last but not least is this year's Social Work Intern from the University of

Botswana, Lingi, who is mainly assisting with our training activities. As always, we are grateful for the time and energy that volunteers are willing to spend at BONELA. While we agree that some part of the work of any non-governmental organisation will always have to be undertaken by volunteers, it also points towards the fact that we find it increasingly difficult to attract sufficient funding to cover our operational costs. While there is an increasing amount of funding available to support HIV/AIDS work, there seems to be a great reluctance to fund human rights programmes with regard to HIV/AIDS, regardless of the fact that the creation of an ethical and supportive legal environment has been identified as a national priority in the National Strategic Framework on HIV/AIDS. At BONELA we are watching this lack of funding with great concern and will continue to appeal to donors, including the Botswana Government, to make funding available in order to make the implementation of a human rights approach to the HIV epidemic a reality.

Christine Stegling

On the road

- Oratile Kidd presented to Goodhope Sub-District Council Social Workers on the Human Rights of Children in Botswana on 31st March 2005.
- Oratile Kidd and Milikani Ndaba went to Francistown from 26 to 28 April 2005 to hold *Stakeholder Briefs* in preparation for awareness raising workshops commencing in May 2005.
- Oratile Kidd and Milikani Ndaba ran two *Raising Awareness of Human Rights and HIV/AIDS* workshops with community and health groups in Francistown on 17-19 May 2005 and 24-26 May 2005 respectively.
- Kristi Kenyon attended the International AIDS Society meeting held in Seattle U.S.A from 18 to 20 May 2005.
- Oratile Kidd and Milikani Ndaba ran another *Raising Awareness of Human Rights and HIV/AIDS* workshop with PLWHA in Kanye from 7 - 9 June 2005.



Participants after one of the Raising Awareness of Human Rights and HIV/AIDS workshops at Tati Lodge in Francistown



BONELA is...

The Botswana Network on Ethics, Law and HIV/AIDS (BONELA) is a non-governmental organisation committed to integrating an ethical, legal, and human rights approach into Botswana's response to the HIV/AIDS epidemic. To know more, visit us on the web at www.bonela.botsnet.co.bw

...interested in becoming a member? We welcome members from the legal community, academia, community-based organisations, support groups, and public and private sectors, as well as people living with HIV/AIDS and concerned individuals. Contact us today!

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