

## THE NATIONAL FORUM OF PLHA NETWORK IN UGANDA



Uganda AIDS Commission Civil Society Fund

(NAFOPHANU)

Vol. 1 Issue No.2, January 2009

The Quarterly Newsletter



Philly Lutaaya Day marked in Tororo

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'Together for a positive difference'

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#### **Empowering HIV+** people very crucial'



For any information please contact us

#### **EDITORIAL TEAM**

Betty lyamuremye - Editor

#### Contributors

Amori Gabriel, Richard Serunkuma, Stella Kentutsi, Florence Nagawa, Raymond Ruyoka, Rose Baryamutuma

P.O BOX 70233 Kampala, Uganda Plot 213 Sentema Road-Mengo Email: nafophanu@infocom.co.ug Fax +256 414 270976, Tel: +256 414 270015

#### **COVER PHOTO:**

Hon. Chris Baryomunsi, The Chairperson HIV Programme Manager, NAFOPHANU during an HIV/ Bill debate at Speke Hotel, Kampala last year

## WELCOME to our new year's edition

ast year The National Forum for People Living with HIV/AIDS Networks ■in Uganda (NAFOPHA-NU) underwent fundamental and rapid changes- restructuring, re-strategic planning and most importantly, striving to make a step forward.

At NAFOPHANU, we recognize the need to provide both coordination and partnership development to strengthen meaningful involvement of the PHAs in HIV prevention and

Our catch for this edition focuses on the recent role NAFO-PHANU was entrusted by other stakeholders to spearhead the campaign against the HIV Control and Prevention Bill, 2008 in its current form. The bill seeks to criminalize the HIV/AIDS transmission and exposure.

The challenge here is to intensify advocacy for increased support, mobilise funds to confront the contradictory clauses that appear in the bill, which otherwise are likely to pose the biggest set back in the continued struggle against the pandemic since the 80's.

Concrete achievements last

year included;

recruitment of highly skilled and professional human resources, a new Board instituted, rejuvenated past collaborations with donors, and strengthened partnership with existing stakeholders, capacity building of PHAs at district and network levels.

Others include; relevant and coordinated information management and dissemination, timely advocacy as well as monitoring and evaluation of activities in the PHA fraternity.

However, the role of all stakeholders in the HIV prevention, Care and support struggles of this year cannot be underestimated.

We take this opportunity to send our condolences to families and friends of our colleagues and partners that have passed on. May their souls rest in eternal peace.

Thank you, as always, for your support. We look forward to a healthier 2009.

'Together for a positive difference'

Editor

#### BY BETTY IYAMUREMYE

ganda is acknowledged worldwide as a leading example in handling the HIV/AIDS problem. The successes of the last 20 years have been built on pragmatic policies, legislation and social and political commitment. It is perhaps the desire to build on these successes that the government through Uganda AIDS Commission, the Parliamentary HIV/AIDS Standing Committee and Uganda Law Reform Commission, have come up with a draft HIV Prevention and Control Bill.

Yet the Bill, in its current form, might unintentionally roll back the achievements of the last two decades. Why? Because by seeking to criminalize HIV transmission and exposure (making one liable to life imprisonment), it ends up focusing on PL-HAS behaviors and not HIV control and prevention! In the end, the eroding stigma that has seen hundreds of thousands of Ugandans go for voluntary counselling and testing and mothers practice prevention of mother-to-Child transmission could be rekindled.

So whereas it is true that Uganda needs a law to guide it in its policy formulation regarding HIV/AIDS, the current draft Bill is not comprehensive and sensitive enough to prevent and care for the PL-HAs and the affected members of the community.

Indeed the draft law may provide an enabling political and legislative framework for the national response to HIV, as well as protect the rights of individual citizens who are affected by HIV. The law, combined with effective implementation and enforcement – for example, in the areas of violence against women, or discrimination against people living with HIV/AIDS and other vulnerable populations – can play an important role in reducing vulnerability to infection.

However, care should be taken on a number of issues in order to achieve a truly effective enabling framework.

- First, this law should be as comprehensive as possible, either including all the necessary components of effective legislation in the context of HIV or referring to relevant laws existing that address these components.
- Secondly, the relationship between provisions of the law and other relevant existing laws should be clear, so there is no conflict and no confusion as to which prevails;
- Thirdly, existing laws should be reviewed, and if necessary reformed, to ensure that they support the HIV law, and more broadly, are consistent with

## Will new AIDS Bill deliver JUSTICE OR HEALTH?



the international human rights treaties that government has ratified;

- Fourthly, judges and other members of the legal community should be appraised of the new legislation, as often they continue to apply earlier laws not being aware of the new laws;
- A lot of infrastructural gaps still exist in the health sector. These would certainly deter it's effective implementation.
- And finally, a budget should be provided to ensure that the law is implemented through the creation of necessary regulations and administration

With regard to other relevant laws, it will be important to audit the existing laws of Uganda (if this has not been done already) to ensure that their provisions are consistent with the provisions of the present draft Bill.

Be that as it may, the process of development and/or reform of HIV-related laws is a valuable opportunity for public discussion and awareness

raising with regard to HIV prevention, treatment, care and support. It is imperative therefore that many people are engaged in extensive and constructive consultations through their respective coalitions on the draft law as it moves towards finalisation and adoption.

For instance, while the draft Bill covers a wide range of issues, including HIV testing and counselling, discrimination, protection of confidentiality, prevention, treatment, and HIV-related research, we feel that the Bill does not adequately address a number of critical issues, such as the particular vulnerability and needs of women, young people, prisoners, people with disabilities, migrants, sex workers, and other critical issues such as post-exposure prophylaxis, age of informed consent for HIV-related medical treatment and interventions; access to HIV and sexual education, life-skills training among others.

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# AMURU DISTRICT launches PHA forum

#### BY OUR REPORTER

muru District recently joined other districts in the country by launching the PHA district forum for People Living with HIV/AIDS (PLHAs).

The forum was launched on October 2, 2008.

The successful function was facilited by the Northern Uganda Malaria, Tuberculosis Project (NUMAT), which has been key in the fight against HIV/AIDS in that region of the country.

Frank Rwekikomo, NUMAT PHA representative, noted that Amuru District is blessed with committed and hardworking PHA leaders. Rwekikomo expressed confidence in Amuru PHA leaders whom he said will fulfill their mandate in HIV national response.

While officiating at the launch, Amuru District Health Officer Dr. Patrick Odongo pledged cooperation with the newly elected PHAs leadership to ensure availability of ART services through the AIDS Task Force that was formed at the District.

The National Forum for People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) Information, Education and Communication Officer Betty lyamuremye said networks and district forums are targeted to raise awareness on the roles of the PHAs in the fight against the pandemic.

The district forums also link networks to service providers as well as lobbying both financial and technical support.

Other responsibilities she said include; building capacity of PHAs as rights holders and holding duty bearers accountable, conducting home visits to PHAs and their homes, planning and conducting fundraising drives at local levels, lobbying government mission groups and national NGOs to offer ongoing technical, human resource and financial resources, among others.

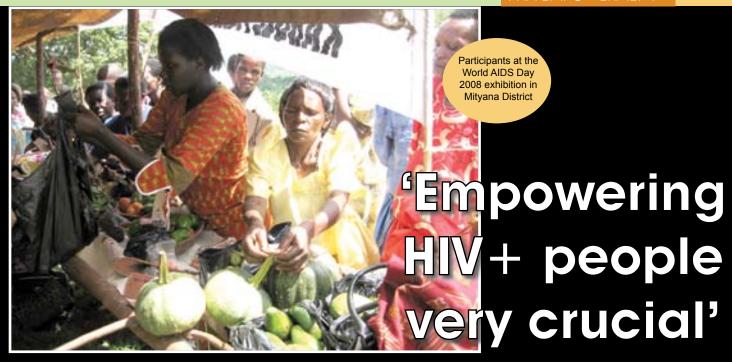
"The forum had office bearers elected to strengthen it throughout the district networks." the officer added.

#### **Elections**

The following were elected for different posts: Forum Coordinator -Jimmy Oloya (Lamogi); Chairperson- Ochaya Geofrey (Alero); Vice Chairperson-Auma Dessuretta (Pabbo); General Secretary- Mohamed Karoli (Lamogi); Vice Secretary- Ogek Sam (Purungo); Treasurer- Alinga Veronica (Anaka); and Tokwaro Ronald (Amuru), as the Mobiliser.

Committee members include; Olwedo Leone (Koch Goma), Ocheng Vincent (Attiak), and Lalam Christine, from Pabbo.

lyamuremye noted that there is great representation of leaders from the 10 sub counties in Amuru, saying it is a sign of continued success. The other PHA forums launched last year included Amolatar, Bushenyi and Isingiro districts.



#### BY ROSE BARYAMUTUMA

n the past 25 years, a lot of progress in terms of mitigating the effects of the HIV/AIDS pandemic in Uganda has been made. People who have contracted HIV can now live longer and enjoy healthier lives, thanks to the advent and increased access to anti-retroviral drugs (ARVs).

Consequently, HIV/AIDS has since significantly evolved from being an automatic death sentence upon being diagnosed and found to be HIV positive to a chronically manageable disease that you can live with for a long time.

This achievement however, is often overshadowed by poverty that characterizes the majority of people living with HIV/AIDS. In Uganda like many other countries where HIV/Aids infection level is high, the majority of people living with HIV/AIDS are among the poorest.

While poverty increases the incidences of the spread of HIV by undermining people, especially women's ability to protect themselves, HIV/AIDS itself escalates poverty levels. It leads to an increase in expenditure on health as households exhaust their meagre resources catering for their relatives living with the virus. Besides, HIV/AIDS mainly affect people in productive age bracket (15-49 yearolds) and who in most cases are the income earners for their households.

For Antiretroviral therapy to be effec-

tive, many issues, including the wellbeing of people living with HIV/Aids, needs to be addressed. Requirements such as good feeding and routine visits to health facilities for review and counseling to reduce stress are all dependant on the availability of money.

Although poverty is not a preserve of people living with HIV/Aids, there is no doubt that it compounds their situation most. Not only do they have to cope with the psychosocial distress of suffering from an incurable disease that also results in their stigmatisation in society, but poor health also compromises their ability to work.

Moreover, the economic consequences of HIV/Aids usually go beyond the individual living with the disease - its impact stretches to their children, spouses as well as the extended family. It is common to find children from a family where parents are living with HIV/Aids dropping out of school since they (children) usually find it difficult raising basic school requirements even with UPE and USE programmes in place. Such a scenario sustains the cycle of poverty and HIV/Aids.

Like other special groups, people living with HIV/Aids need assistance so as to be able to establish and sustain income generating activities. Programmes such as Bonabagagawale aimed at eradicating poverty in the country should ensure that it involves people living with

Their economic empowerment has a number of benefits; it will enable them to regain independence economically - something that could raise their self esteem.

Empowering them economically can also improve their health conditions.

With improved incomes, people living with HIV/Aids will be able to eat better and afford paying their medical bills as well as transport fare to health facilities for routine check-ups. All these are pertinent to the notion of positive living that is promoted by all providers of HIV/Aids services.

Despite all its benefits, income generation has been neglected as a critical aspect of HIV/Aids care and support by some donors and governments. In the past, the idea of advancing soft loans to people living with HIV/Aids was hampered by high death rates and poor health.

But now with ARVs in place, people living with HIV live longer and healthier lives. For instance, if they get assistance including training in basic business principles, they could contribute significantly to the economic wellbeing of their families, the communities and the nation at large.

> Ms Baryamutuma, SPH-CDC HIV/AIDS Fellow

This article was first published in The New Vision **HIV Counselor services** 

### STRENGTHENED

#### BY BETTY IYAMUREMYE

testing (CT) services has been on an increase since 1980s when the HIV/
AIDS was first identified in Uganda.

However, recently an integration of HCT with Positive Prevention to incorporate the existing individual, family and community prevention efforts and strengthening PHA networks and family support systems was introduced to strengthen counseling and testing services.

Strengthening Counselor Training in Uganda (SCOT) and ACQUIRE (Access, Quality and Use in Reproductive Health) have been jointly implementing the Positive Prevention program over the last one year.

The two projects work together with key stakeholders involved in HIV/AIDS counseling, HIV counselor training, AIDS care and treatment centers as well as People living with HIV and their networks.

On the other hand, Positive prevention (PP) is a program with the goal of contributing to the reduction of HIV/STI transmission in Uganda. This program focuses on empowering and involving PHA's and their networks as key partners in reducing HIV/STI transmission. It also integrates family planning into HIV Prevention, care and support programs.

To achieve the above, SCOT and its

partners have trained 21 and will train more 8 PHA groups in various regions of the country.

Mirro Moses Nsubuga, SCOT PHA trainer says a verification exercise had been carried out in the Northern, Eastern and Central regions and 80 groups were vetted including West Nile and Western Uganda that had not been visited owing to the Meningitis and Ebola scares respectively.

National Forum of People Living with HIV/AIDS (NAFOPHANU) together with other major HIV counselling training institutions' role in this project is to establish the existence of PHA groups in the country, provide technical guidance to the PHA groups as they role out Positive Prevention activities in their communities, provide technical assistance during the trainings, provide support supervision during community Education events, among others.

The selected peer support groups have benefited from training, supplies of IEC

equipment for performing arts, facilitation of Positive Prevention community education activities. From the selected groups, SCOT in collaboration with the members of the selected peer support groups shall identify and orient twenty (20) people living with AIDS to Peer and Community educators' curriculum. Thereafter, the twenty PHA trainers will then roll out the Peer and community education training to at least 250 peer support group members in the different regions.

SCOT certifying

Lugo counseling

club, last year

(Courtesy photo)

Some PHA groups have already been trained in Gulu, Kampala and Mbarara districts.

These districts have been coined for inclusion in the Positive Prevention Peer and community education program because they have 7-8.5% prevalence rates (USBHS 2004/5), have well established AIDS support services for large numbers of PHAs (at least 2000 active clients per organisation) and peer support groups.



#### From Page 3

HIV vulnerability stems from (a) lack of access to HIV prevention information, education and commodities, such as condoms, drugs and clean injecting equipments (b) sexual violence (c) lack of access to treatment for sexually transmitted infections, tuberculosis and AIDS-related illnesses.

The present draft bill also does not include attention to strategies, policies and programmes to address the HIV-related issues in vulnerable groups. If supportive legislation is not found elsewhere, it is recommended that the present draft includes texts along the lines of the National strategies, policies and programmes regarding HIV/AIDS.

However the bill has some positive aspects which include;

- Protection of the confidentiality of information related to HIV status, by requiring that testing and counselling only be performed in spaces where confidentiality can be assured (Article 9(1));
- Requiring pre- and post-test counselling to be carried out only by staff with adequate training in HIV counselling (Article 18);
- Protection of the right to travel to and out of Uganda, without impediment on the basis of HIV status (Article 29(4)); prohibition on quarantine, isolation, denial of entry or deportation on the basis of HIV status (Article 42);
- Protection of the right to a safe working environment, including through the use of universal precautions and access to post-exposure prophylaxis in the event of occupational exposure to HIV (Article 32);

- Prohibition on HIV-related discrimination in schools (Article 41);
- Prohibition on mandatory HIV testing for the purposes of accessing credit, health insurance or life insurance (Article 44):
- The obligation of the Government to take steps, to the maximum of its available resources, to ensure access to essential healthcare services, including essential medicines, by people living with HIV and those at risk of infection (Article 47).

Despite these relatively positive aspects bearing in mind the recent number of prosecutions around the world, the Bill does not address the core issues of HIV prevention and control and it contradicts the national and international policy documents such as the recently launched National Strategic Plan and various sector policies.

#### BY RICHARD SERUNKUMA

ganda Health Marketing Group (UHMG) has joined efforts to improve the social, economic and health welfare of Ugandans, including those living with HIV/AIDS (PHAs).

This will be achieved through partnership with NAFOPHANU and other HIV organizations to promote better quality of life for the PHAs.

UHMG is an amalgamation of AFFORD Health Marketing initiative, a USAID funded project implemented by a consortium of partners. The group is completely indigenous and fully committed to improving the quality of life of Ugandans.

The goal of the partnership is to ensure that PHAs in Uganda access affordable wrap around health services provided by UHMG.

When this takes off, it will improve service uptake for Family Planning, palliative care, Malaria prevention and hygiene and sanitation for the PHAs in northern Uganda.

NAFOPHANU is expected to coordinate the activities implemented by its member organisations. The National PHA networks like Uganda Young Positives (UYP), Positive Men's Union (POMU) and NACWOLA and others will do the activity implementation.

Selected district PHA forums will also complement the implementation process.

The partnership will be operational for an initial phase of one year with a possibility of extension.

### **UHMG** joins

#### struggle against HIV



The UHMG
Managing Director
Dr. Magumba (C) and
his team un-veil the
re-branded
Protector Condom
to the media
last year

Previously, UHMG has worked closely with PHAs through partnership with POMU. So far, POMU has implemented its mandate to supply good life products in Mbarara, Rukungiri, Wakiso, Arua and Gulu districts.

UHMG envisions a Uganda where families and communities are empowered to pro-

tect and improve their health; markets for health services are vibrant and expanding and consumers access affordable products.

The author is the cordinator of Positive Men's union (POMU)

#### Workplace policy vital in HIV advancement

#### BY BETTY IYAMUREMYE

t has been realised in the recent past that the nature of certain jobs inadvertently increases the vulnerability and susceptibility of workers to contract, or spread of HIV amongst their spouses and sexual partners.

According to the 2006 INTRAC study, the pandemic increased staff costs by 7 per cent and reduced output and performance by 10 percent in workplaces.

The debilitating effects of AIDS at the workplace come in the form of loss of skilled workers, absenteeism (related to HIV/AIDS morbidity and mortality), conflicts at workplaces that result from stigmatisation and discrimination of PHAs.

Other costs of HIV/AIDS to organisations include depression and low staff morale associated with emotional grief; rising bill on medical expenditure, recruitment and training; which leave organisations struggling with increasing overheads and declining output. This in turn limits organisations' ability to deliver effectively on their mandates, targets and deadlines.

In the case of CSOs, the effects of HIV/AIDS ultimately constrain their relationships with donors and other key stakeholders and threaten the organisation's very survival.

However, two years ago, a coalition of organisations started a project that sought to contribute to reduce spread and better management of HIV/AIDS issues in workplaces among participating organisations in Uganda. This project was a brainchild of four Dutch cofunding Agencies (CFAs).

This pilot project utilised a unique model of being hosted by the organisation, ACORD, which is widely experienced in HIV/AIDS programming.

While ACORD in headquarters in Kampala host this project, a committee of eight organisations constituted the Local Project Group (LPG), with a cardinal role of giving strategic direction to the project.

Ellen Bajenga, the in-charge of HIV/AIDS at ACORD, says the project has a membership of 76 participating organizations, which are linked to the secretariat by four regional 'Lead Organizations (Los).' The Los, she says, are part of the 76 but play a role of being project implementation satellites in their respective regions.

Bajenga who recently addressed a committee meeting in Soroti said that one of the most striking achievements of the pilot project was the impressive progress made towards having participating organisations initiate and implement workplace programs.

Out of 76, 27 organisations, have drafted their Workplace Policies (WPPs) and await feedback from the SAN/WPP review committee. Health Need Uganda (HNU) is one of the organisations that have implemented the workplace policy.

Richrad Ochen, the Executive Director of HNU, said that since its inception, there is free sharing of information regarding HIV/AIDS; counseling and testing has been embraced by staff and their family members. Stigamtisation also reduced, he added.

As the mandate of the pilot project draws nearer, (December 2008), Partnership to Stop AIDS at the workplace (PAST) is envisaged to sustain what has already been started under the project.

The achievements of the pilot project would be laid to waste if such a pilot project was not transformed into a fully-fledged project.

PAST will build on the networking success of SAN! The existing skills of internal mainstreaming that it has built, and generally on the best practices and achievements it has registered.

Louise Van Deth, Director of STOP Aids Now, Netherlands says SAN will continue to give advise and technical support to PAST once it kicks off.



#### **BY LULE JAMES**

he commemoration of Philly Bongoley Lutaaya Day started five years ago with the aim of raising awareness of HIV/AIDS pandemic in Uganda.

This was in recognition of the late Pop star musician who declared his serostatus; publicly announcing he was HIV positive.

After 19 years since he passed on, Lutaaya's music remains very touching to our lives more so due to the fact that he gave a human face to the HIV/Aids scourge.

Amidst discrimination and rejection, Lutaaya was determined to unveil and reveal the truth that "AIDS was the killer and it was spread through SEX, and blood contact."

Since then, there's a nationwide AIDS awareness campaign supported by all stakeholders who have joined efforts to fight the epidemic.

However, there are concerted grassroots awareness campaigns spearheaded by religious and cultural leaders in deep in rural Uganda.

This year, Philly Lutaaya's day was commemorated on November 7, at Tororo Children's Park in Tororo District.

The theme for the day was "prevention with positives".

The function brought many people including; Government organizations/departments, Non Government Organiza-

tions, Uganda People's Defense Forces (UPDF), Schools especially primary schools, The occasion kicked off with a procession on the streets of Tororo town.

The Deputy Resident District Commissioner, also Guest of Honour, Mr. Richard Gulume put emphasise on the fact that HIV/AIDS is still a big challenge and something must be done.

The disease has not only affected the communities but even the country's economy is affected, where by many young productive people have died, others are bed ridden leading to low productivity among the general public, orphans every where you go etc.

Other speakers said policy makers should avoid bringing in policies that undermine the rights of PHAs because HIV/AIDS has affected all Ugandans including policy makers.

'The habit of do as you're told not as we do should stop" stressed Mr.Gulume.

As we commemorated the day, the guest of honour said "it's upon us all to continue with educating the community about HIV/AIDS, some communities' response to HIV/AIDS is characterized by witch craft and superstition hence turning to traditional healers and fortune tellers for solutions".

Philly Lutaaya is remembered as one the first Ugandans to disclose his status publicly and for he deserves to be a hero. In his song "alone and frightened" he said these very important words that we should also always not forget, "Out

there some where alone and frightened, days are long no more making new friends, life is hiding, I am tired and lonely, give me love give me hope, all I need is love and understanding. Lets us fight up to end, let's save some lives save the children of the world. Advise the young ones a new generation, protect and love".

In times of sorrows and joy let us continue the fight he started and let us fight together. As we commemorate Philly Lutaaya day we sing this song and it's now an Anthem but when singing it as a public what do we learn? What messages do we get or we sing for sake of singing?

The theme for this year "prevention with positive" ogres well with the Positive Prevention (PP) strategy that enhances skills and knowledge of the community educators and peer counselors in promoting PP at the community level. However, people living with HIV/AIDS have got a big role to play in HIV/AIDS and Sexually Transmitted Diseases STIs prevention and they must be on the fore front in struggle.

The Philly Lutaaya Day was coordinated by Uganda Aids Commission and other HIV/AIDS Non Government Organisations (NGOs) with support from Aids Development Partners- the UN and Bilateral Agencies.

The writer is the Coordinator KADFO+

NAFOPHANU Newsletter | January 2009

#### **COMPILED BY RAYMOND RUYOKA**

959: HIV infection first traced in a man from Liverpool, England, who died of what is now recognized as AIDS related infection.

**June 1981:** Researchers from UCLA report the first cases of what we know as AIDS in an article that appears in the center for disease control's morbidity and mortality weekly report on June 5, 1981.

**Dec 1981:** The number of reported cases of AIDS reaches 259. UCLA researchers publish an article about this deadly new disease syndrome in The New England Journal of Medicine.

1983: Discovery of lymphadenopathy virus (LAV) by Dr. Luc Montagnier and colleagues of the Pasteur institute in Paris. This virus is identified as the cause of AIDS. In April, Dr. Robert Gallo and colleagues at the National Cancer Institute announce the discovery of the same virus, which they call human T-cell lymphadenopathy virus 111(HTL-111). Montagnier and Gallo are later declared the co-discoverers of the cause of AIDS.

**1985:** LAV/HTLV-111 is re-named Human Immuno Deficiency virus (HIV)

May 1985: The first anti-body test is licensed. It is now possible to test individuals for HIV infection, although no treatment is yet available. It is also possible to begin screening the blood supply, to prevent inadvertent transmission of HIV through transfusions and through the blood-clothing factor used by hemophiliacs.

**Feb. 1986:** The food and drug administration approves the first drug to treat HIV infection. The drug is known as nucleoside analog, is called zidovudine but is popularly known as AZT. It inhibits viral replication in the body, slowing the rate at which an infected individual's immune system is destroyed. Unfortunately, the drug's effects wear off in a year to 18 months, as the virus mutates into a form that is less susceptible to the drug's effects.

**Nov 1990:** The CDC estimates the number of cases of HIV infection in the U.S has reached approximately one million.

1991: Several new drugs are added to the anti-HIV arsenal, among them an entirely new class of anti-HIV drugs called the non nucleoside analogs, which are more quickly activated in the bloodstream than older drugs.

**Dec 1992:** The CDC issues a new definition of AIDS, which is henceforth used to refer to anyone whose CD4 count-a measure of immune function- has dropped from a range of cells 1000 cells per milliliter of blood to 200 or less. Individuals who have been diagnosed with one or more of the opportunistic infections associated with advanced HIV infections are also said to have AIDS, irrespective of what their CD4 count may be.

**June 1993:** For the first time the CDC reports that more women are being infected through sex than through injection-drug use.

## TIMELINE of the HIV epidemic



**Aug. 1993:** The CDC, NIH, FDA declare that condoms are highly effective in preventing HIV. When used consistently and correctly, condoms are almost 100% effective.

Jan. 1995: The CDC reports AIDS as the leading cause of death for Americans between the ages of 25-44.

**Jan. 1995:** More than 440,000 AIDS cases of HIV infection were diagnosed in the United States, up from a mere 259 cases 14 years earlier.

**Dec. 1995:** The first of a potent new class of anti-HIV drugs, the protease inhibitors, receives FDA approval for us in combination with older drug classes. The approval which took only 97 days is the fastest in FDA history and reflects pressure brought on the agency by AIDS activists. This pressure leads to the creation of also-called "fast track" approval process that makes drugs available much more rapidly to those who need them- an advance that benefits those suffering from a range of diseases in addition to AIDS.

**July 1996:** The FDA approves the marketing of the first test that measures HIV levels in the blood. This "viral load" test becomes an effective way of measuring how well a given individual is responding to a given combination of drugs: if the is combination is working, the viral load falls; if it is falling, the viral load rises. This test allows doctors to switch drug regimens when

a particular combination loses its effectiveness.

**July 1996:** At the international AIDS conference in Vancouver , researchers report that HIV drug regimens that include a protease inhibitor and other drugs can reduce the levels of HIV in many treated individuals to bellow the level of detection of commercially available viral load tests.

**Nov. 1996:** The UN estimates that there are more than three million cases of HIV infection worldwide.

**Feb. 1997:** The CDC reports the first significant drop in AIDS deaths – a 13 per cent decline in the first half of 1996. This drop in mortality is attributed to the new combination drug therapies. Worldwide, however 6,400,000 people are estimated to have died of AIDS and 22,000,000 are thought to be infected with HIV.

**Nov. 1999:** The UN reports that more women than men are infected with HIV in Africa. As the world's attention shifts to the epidemic in Africa, efforts are launching to develop cheap generic versions of standard HIV drugs for distribution in resource-poor settings.

Jan. 2000: A UN Security Council session is called to the AIDS crisis in Africa. It is the first time a health-related issue is recognized as a threat to global and national security.

May 2000: Five pharmaceutical companies offer to negotiate steep cuts in the price for Africa and related issue is recognized as a threat to global and national security.

**July 2000:** The 13th International AIDS Conference is held in Durban, South Africa, where South African president Mbeki stirs a furor by questioning the assumption that HIV causes AIDS.

Jan. 2000: By the 20th anniversary of AIDS, more than 700,000 Americans have been diagnosed with the disease and more than 420,000 have died. Worldwide, more than 36 million people have HIV, and more than 14,000 to 16,000 new infections occur each day.

**Feb. 2000:** Scientists from the Los Alamos national laboratory trace the origin of the AIDS epidemic as far back as the 1930s.

**June 2000:** U.S Surgeon General Satcher releases a report saying that some 40,000 new HIV infections occur in the United States every year, despite decades of prevention efforts, and an estimated 800,000to 900, 000 Americans are living with HIV.

**June 2005:** Despite these reassuring trends, a resurgence of the HIV epidemic cannot be ruled out. Increases in HIV incidence have recently been reported by the Uganda AIDS Commission, up from 70,000 cases in 2003 to 130,000 cases in 2005.

#### August 2008:

1.5 million Ugandans live with HIV/AIDS

The author is a member of Uganda Young Positives

## "Begin at your



#### **BY Gabriel Amori**

eligious leaders are key players in the reduction of stigma associated with HIV and AIDS beginning at their congregations. "Sometime early June 2004, a friend of mine Rebecca the wife of a Reverend contacted me and said there is a meeting for religious leaders hosted by the organization that she represents called ANERELA+. She hesitated to explain the whole detail of what this ANERELA+ actually stands for, possibly because she was not sure I would easily accept the idea she was floating for my attention", was one Fred's opening statement as he stood up to give his testimony of how he encountered HIV in his life as a deacon of his local Pentecostal church in Jinja.

This turned to be a Retreat for religious leaders who are living with or affected by HIV and AIDS. The 42 leaders came from Islam, Catholic Church, Church of Uganda, Bahai faith, Seventh Day Adventist Church and some Pentecostal Churches all over the country.

It was very unique in that for the first time religious leaders of all faiths came together for an agenda that seems all encompassing - HIV and AIDS.

"I hesitated to say yes to my friend at the same time I did not want to embarrass her;" Fred continued; "I decided to leave her in suspense saying I will get back to her. Her persistence paid off and I reaistered to attend this Retreat".

At the end of the retreat, members agreed and decided to form a Uganda version of this ANERELA+ which stands for "Africa network of Religious leaders living with or personally affected by HIV and AIDS". This was founded initially as an Africa Network by Rev. Canon Gideon Byamugisha, the first Anglican priest to openly declare he was living with HIV way back in 2002 still in Mukono.

"During the testimony time, I realized all these religious leaders in the meeting are either HIV positive, or are nursing a spouse, child or parent or have lost close relatives. I realized I was not alone and that is how I was prompted to stand and give my testimony."

"I had lost my wife early 1997 and within two weeks also lost my five year old son in circumstances similar to those associated to a person with AIDS. Because No testing was done I cannot conclusively say they died of AIDS. What confuses me most is the fact that I am not positive and have since remarried to a woman who is negative and we now have two children who are healthy" Fred concluded.

This turned out to be the retreat culminating into the birth of UNERELA+ with the following objectives

#### **Objectives**

- To empower religious leaders living with and or personally affected by HIV and AIDS with appropriate knowledge, attitudes and skills to defeat HIV and AIDS related Stigma and Discrimination:
- To facilitate and support religious leaders living with and or personally affected by HIV and AIDS in their efforts to champion hope and to serve as agents of change at family, congregational, community, institutional and national levels.
- To advocate for the development and implementation of people living with HIV and AIDS supportive policies and practices with adequate resources and within an enabling environment and congregational community and national levels.

Thus UNERELA+'s strength is in engaging religious leaders from all religious backgrounds in the fight against Stigma, Shame, Denial, Discrimination, Inaction and Misaction associated with HIV and AIDS beginning from respective congregations as an entry point into the communities they represent.

This UNERELA+ was formed with a national Steering Committee chaired by Bishop Zebedee Masereka with a mandate to establish UNERELA+ as a national

## congregation"

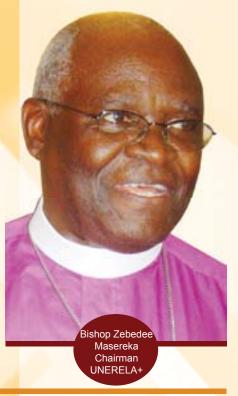
program, register it and call a general meeting to pass all documentation.

From inception UNERELA+, working closely with partners like PSI, World Vision, Action aid, Mildmay center, IRCU carried out stigma reduction programs in all five Regions of Uganda. Structures were established in the process that took up to 2008 for the first general meeting to finally be called. The general meeting was held in October combining it with a review of the UNERELA+ activities since it was formed. A new Board was elected and Bishop retained the chair.

#### **Current UNERELA+ activities include:**

- Congregational prevention of HIV infection,
- Stigma reduction activities,
- Alliance model referral system with health units for treatment, care and support of PHA and OVCs mainly in West Nile and outskirts of Kampala.
  - Youth program started in the Bahai faith Kampala.

The author is the cordinator of UNERELA+



#### Myths and Facts for Fighting the AIDS Pandemic

#### MYTH ONE

Myth: AIDS is mostly an African problem. Fact: Of the 42 million people around the world who live with HIV/AIDS, 70% are in sub-Saharan Africa. But AIDS is not an African problem:

- HIV/AIDS exists and is spreading in Africa in a socioeconomic context created by western colonialism and, more recently, western trade and economic policies.
- HIV/AIDS continues to spread in the rest of the world, especially in countries or communities within countries where poverty, inequality, and conflict are prevalent. Eastern Europe and Central Asia have the fastest rates of spread, followed by countries in Asia and the Pacific, the Caribbean, and Latin America.

#### MYTH TWO

Myth: To stop the spread of HIV, people simply need to give up promiscuous sex and drug use.

Fact: Socioeconomic structures around the world constrain many people's ability to make free choices regarding the behaviors that put them at risk for contracting

HIV/AIDS. Economic insecurity, gender and racial inequalities, labor migration, and armed conflict all limit people's ability to avoid exposure to the virus.

#### MYTH THREE

Myth: Money for AIDS in developing countries goes into the pockets of corrupt officials.

Fact: Corruption exists in countries throughout the world. But it should not slow donor contributions:

- Individual citizens, groups, the media, and government officials world-wide have shown increasing awareness of and commitment to fighting corruption in recent years.
- New international institutions and initiatives, such as the Global Fund to Fight AIDS, TB, and Malaria, have stringent selection and monitoring mechanisms that ensure accountability among funding recipients.
- Many countries with long histories of corruption have established successful HIV/AIDS programs; examples include Thailand, Uganda, and Brazil.

#### Internet

## PHA rights should be priority for HIV activists

#### By Nagawa Florence

n 1986 when the NRM Government took over power, AIDS was rampant in most parts of the country. By that time most of the Africa Nations were in denial about the disease. However, Uganda courageously chose to confront the situation. As a result, Uganda turned the epidemic around, prevalence rate dropped down from 18% to 6.7% currently. Uganda has also been cited as a role model for other countries to draw lessons from in their fight against the epidemic.

Despite the trend taken so far and the success Uganda has achieved in recent years as far as the fight against HIV is concerned, people living with HIV AIDS are still being stigmatized and discriminated. They have been denied their rights either due to ignorance or intentional by some persons or groups of people. These rights are meant for all persons; men, women, people with disabilities and other marginalized groups.

Human rights observance can lead to elimination of gross inequalities in wealth and oppression hence better living standards.

#### Some of the rights include;

- Right to treatment,
- Right to protection,
- Right to work
- Right to own and inherit
- properties,
- Right to education
- Right to privacyRight to freedom of worship,
- Right to political participation,
- Right to immunity from arbitrary,
- Right from torture,
- Right to life, liberty and security.
- Right to marry and have a family

These rights are universal and have to be enjoyed by everyone irrespective of ones

Government and stakeholders should endeavor to advocate and implement strategies and policies to see that these people are not stigmatized and discriminated. If all this is achieved, people living with HIV AIDS will continue to play a leading role in the fight against this deadly epidemic. We should be loyal to our country and its citizens, we should not participate in activities which will harm our country or rob fellow citizens of their rights and or properties. We should not accept anything which is unconstitutional and participate in the process of bring democracy. We need to be democratic to others but being bully and defend our rights.

The writer is Advocacy Officer- NAFOPHANU

# East Africa set to rout HIV/AIDS pandemic

**BY STELLA KENTUTSI** 

ast year, I visited the Burundi Forum of PHAs (Reseau Brundais De Personnes Vivant Le VIH/SAIDA- RBP+). This visit coincided with the Great lakes Initiative on AIDS (GLIA) training for the Anglophone countries; Uganda, Kenya, Tanzania and Zanzibar (which is literally taken as a separate entity). As part of information sharing and networking, the visit was paramount to all countries but specifically for NAFOPHA-NU-Uganda.

The RBP+ is located in a quiet Quartier Kigobe with 101 staff and numerous volunteers spread across the country. The Forum that was officially registered in 2002 has grown into a formidable forum of PHAs. It is a non-for profit NGO and members are grouped into 129 communes. The cardinal objective for the founding was that all PL-HAs are both providers and receivers of HIV/AIDS services.

Like NAFOPHANU, the governing body is the General Assembly which meets once a year. The 5 members of BOD meet monthly but each of the 17 provinces has a committee of 6 members with a monthly assembly. For coordination purposes, information is passed on from top-bottom and bottomup. At each province level, there is a Focal Point person but activities are carried out at Commune level (like sub-county in Uganda).

The Forum has numerous funders e.g. NAC, GLIA, FHI, PSI Burundi, Global Fund, CNLS, ONUSIDA, PNUD, GIP ESTHER, ACORD, OXFAM-NOVIB, TIDES Foundation among others. Support to lower level networks at commune level includes capacity building through training, IGAs, referrals, reimbursements of fees paid in health centres, care and support, telephone counseling, resource mobilization.

For advocacy, it is done through the media, lobbying, meetings, campaigns, targeting important persons and visiting them, IEC materials production among others.

The Forum has some specific activities such as:

**LIGNE SOS TELEPHONE (Telephone Hotline)** SOS services started in February 2008. The



government provided and supports it as an information centre. Information is collected from all over the country. On average, there are 1300 calls received per month. The collected information is put in databank. Information is categorized into sex, sero status, province, commune. The forum improvised toll free telephone service which has boosted the traffic, and usually the frequently asked questions are on the basic facts of HIV/AIDS, care and support, and counseling.

#### Legal and advisory services

The Forum provides legal services. They have a waiting room for people seeking for care and support, and legal advice. The legal advisor comes on appointment in the afternoons. He/she helps prepare legal documents.

#### Voluntary Counseling and Testing (VCT)

In the mornings, it is normal activity of counseling, testing, care and support. They receive clients, advise and refer them to the relevant health units since the Forum does not run a clinic. Arrangements and contracts have been made with health providers where members go for free treatment then claim a medical refund.

#### Other services outside VCT

In case of loss of employment or school dropout, PHAs are helped to train in IGAs and loan acquisition. OVCs have no programme yet but a small group of 40 children are referred by social service and assisted by a French NGO. But the Forum is now mapping to know exact number of OVCs.

#### Membership

Members register either as individu-

als or groups; a PHA produces a testing certificate to register and is issued a registration card. Members pay annual subscription fee of 1000Burundi Francs (BF). Membership card is 500 BF. By end of 2007, approximately 20,000 members had been registered. Though registration is done by individuals or groups, funds are given to only organized groups.

#### Sustainability

Besides membership and annual subscription fees, the forum has established a café/canteen for income generating. It also acts a training centre as well. Profits generated help in sustaining the Forum especially with delay in release of funds by their funders.

#### **Lessons for NAFOPHANU**

- Membership is very crucial and therefore should be mandatory for NAFOPHANU and district Forums for sustainability.
- Need for income generating activities for sustainability purposes in case donors pull out or during credit crunch.
- Need for funds to directly support PHAs access care and treatment
- SALT activities can be expanded under Forum guidance to create a database.
  - Plan to have own premises.
- Expand staff; have paid regional coordinators and a team of volunteers
- Need for direct government funding.
- Direct involvement of the Forum in psycho-social support, counseling, referrals, legal service for the oppressed/vulnerable.

The author is the Programme Manager - NAFOPHANU