CHAIN

The Community
Health And
Information Network

HIGHLIGHTS REPORT & PLANS FOR THE FUTURE

Community Partnership initiatives in fighting HIV & AIDS

A REPORT ON THE WORK OF CHAIN AND THE GREAT LAKES NETWORK OF PEOPLE LIVING WITH HIV AND AIDS (GLNPLA)

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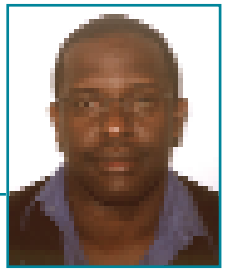


This report summaries the work CHAIN has done over the past years since inception in 1998. CHAIN was started by a group of African treatment advocates right after the World AIDS conference in Geneva. The theme of that conference was Bridging the gap between the North & South. I am proud to be one of the founder members of the organisation and on reflection, I feel that CHAIN has played a significant role in bridging this gap.

Our activities over they years have focused on increasing access to anti retroviral drugs and drugs for opportunistic infections, access to adequate and up to date treatment information. We target both the clients and doctors who prescribe these medications. We have also worked towards building strong institutions of People Living With HIV/AIDS and working closely with policy makers and the pharmaceutical industry.

In 2002 during the World AIDS Conference in Barcelona, we launched the Great Lakes Network For People Living With HIV / AIDS after carrying out a wider consultation with key stakeholders in the region. The network is comprised of national networks of People Living With HIV / AIDS (PLWHA). CHAIN is helping in developing this network which will serve as a strong voice for PLWHA on a regional level. We strongly believe that PLWHA Must be at the centre of all HIV policy making decisions.

CHAIN also initiated the idea of having a bi-annual Great Lakes Conference on HIV / AIDS. This conference brings together policy makers, NGOs, researchers and the pharmaceutical industry to discuss HIV and treatment issues in the great lakes region. So far CHAIN has worked in partnership with the GLIA Secretariat - Great Lakes Initiative on HIV / AIDS and other key stake holders in organising two conferences. The 1st conference took place in Entebbe, Uganda (6-9th Sept 2001) & the 2nd took place in Kigali, Rwanda (16-19th Sept 2003). The 3rd conference is scheduled to take place in Arusha, Tanzania (Sept 2005).

The organisation is also strengthening its capacity in delivering its programmes and we shall be setting up a regional secretariat in Kigali, Rwanda. This will help to coordinate our activities in the region. We are also setting up a sub- office in Uganda. Both offices will be operational by the end of September 2004.

During the next five years, we shall continue to work towards meeting our core objectives which are;

- To strengthen multi agency partnerships and increase the capacity of the voluntary and community sector
- To advocate for increased treatments literacy and access
- To reduce stigma and discrimination.

Let me take this opportunity to thank my fellow board members, our dedicated volunteers and all our funders in particular Merck, GSK Positive Action, Boehringer Ingelheim and Abbott. Without your support this work would have been impossible. Special thanks to Bill Lindsay - Gilead UK for his support in developing and printing this report. We look forward to continue working with you and also to get more partners on board.

William Babumba
Chair - CHAIN

Context

The need for peer-led treatment education in the developing world

Currently there are approximately 40 million people living with HIV in the world. 27 million of them live in sub-Saharan Africa. Four million of those Africans need anti-retroviral drugs right now if they are not to die this year.

Most will not get them. Currently, of the estimated 400,000 people in the world taking anti-retrovirals, only 100,000 live in Africa - coverage of 2.5 per cent.

The World Health Organisation has an ambitious plan, the 3 by 5 Initiative, to provide antiretroviral treatment to three million people with AIDS by 2005.

But in a recent interview, Dr Joep Lange, President of the International Aids Society predicted that the initiative would fail. He told the US PHAs' organisation Positives for Positives:

"I think the bad news about the Bangkok Conference is that...it's going to become clear, if [the WHO is] honest, that the 3 By 5 Framework is not going to be met. And I think we have to be quite critical about that. A decent action plan is still missing."

Why is providing HIV treatment so difficult? No longer is it a question of lack of money. Agreements between bilateral and multilateral donors and branded and generic drug manufacturers have brought the cost of a year's supply of combination therapy down to approximately US$100 a year in the developing world. Even if the price of human resources and distribution were to add $200 to this cost, the amount disbursed by a single donor organization - the Global Fund to fight Aids, TB and Malaria - would be enough to pay for a year's supply of anti-retroviral drugs for three million people by the end of 2004.

The factors holding back access to treatment for HIV infection are fourfold:

- Lack of political will by political leaders to mount effective treatment programmes
- Lack of capacity in Aids service organisations
- Lack of treatment knowledge among both patients and medical staff
- The ever-present burden of the stigma against HIV/AIDS, which makes patients reluctant to come forward for treatment

Once HIV treatment is successfully provided in a setting where patients feel supported and informed, stigma can melt away. This is Matthew Damane, a 25-year-old South African who receives ARVs through the Khayelitsha Clinic near Cape Town:

"In Brazil, I saw a country that is not rich, but everybody there has access to antiretrovirals. That has the effect of reducing the stigma and bringing down the rate of infection. South Africa could do the same."

Dealing with stigma is key. Thailand is a middle-income country with one-tenth the HIV burden of many African countries and three to eight times the per capita GDP. It plans to have 70,000 of its 750,000 people with HIV on antiretrovirals by the end of 2004. But in a recent interview, Kamon Uppakaew, Chair of TNP+, the Thai Network of People Living with HIV and AIDS, commented on the barriers stigma places in the way of treatment:

"The typical new person with HIV in Thailand is now a young married woman who has caught it from her husband. She is the kind of person who will still be ostracised from her village if she presents herself for treatment. TNP+ has a team of 30 people who go to all the 600 support groups round the country educating people on how to use antiretrovirals. But we are still finding that people do not come forward till they are very ill."

As well as infrastructure and training problems and stigma holding back the provision of treatment, psychological and social factors are important too. One of the things holding people back from treatment is the fact that due to its scarcity not everyone can benefit. This creates guilt on the part of the treated person, resentment on the part of those who are not treated, and family rifts. Last year Noerine Kaleeba, founder of TASO in Uganda, told Positive Nation:

"When the singer Bono visited Uganda he met nine people with HIV who needed treatment, and he decided to pay for it But wouldn't take the pills. When Bono asked why they said, 'Because we couldn't stand the guilt'. The global movement has reduced prices so that some people in the south can get antiretrovirals. I have a brother on ARVs, and his wife, who is ill, is not. Oddly, Aids treatments can act as a breaker of solidarity."

Money must be provided by donors and governments. Political will must come from leaders. Medical expertise is the province of doctors and nurses. But it is people living with HIV/AIDS, their carers and families, who are the experts on living with the virus. They can:

- Provide first-hand knowledge of the effects of AIDS, of drug side effects and of barriers to adherence
- Serve as uniquely qualified peer educators of other people with HIV/AIDS and the health workers who serve them
- Combat the stigma of HIV by the simple act of standing up and declaring their status- or the even simpler act of surviving, thereby reducing the fear that is the root cause of the stigma.

It was to help mobilise the energy and expertise of Africans with HIV and the organisations that support and provide a voice for them that CHAIN was founded.

About CHAIN And GLNPLA

ABOUT CHAIN

CHAIN was founded as a result of African and UK African AIDS activists meeting each other at the Geneva World Aids Conference in 1998.

The theme of that conference was 'Bridging the Gap', but most delegates left with a renewed sense of how large the gap in treatment provision actually was.

For historical and political reasons, the UK has one of the word's largest communities of Africans living with HIV. About 30% of the 60,000 people living with HIV in the UK originate from sub-Saharan Africa, and last year over half of all new diagnoses were from this group.

CHAIN was founded by Africans supporting communities living with or affected by HIV in the UK. Some of CHAIN volunteers had experienced for themselves the lifesaving benefits of the anti-retroviral treatment provided by the UK's National Health Service. Most had lost relatives and friends to Aids back in Africa and had others who were in desperate need of treatment.

The organisation has a board of six members experienced in HIV and treatment issues and supported by three volunteer admin workers in London. Recently it has been able to employ a liaison person for the Great Lakes Network of People Living with HIV/AIDS in Kigali, Rwanda and another in Kampala, Uganda.

CHAIN defines its aims as:

- Lobbying for an effective voice in Africa for people living with HIV/AIDS
- Greater accessibility and affordability of treatments for HIV infection and AIDS-related illnesses
- The promotion of treatment awareness and education
- Capacity building for organisations of people living with HIV in Africa, and in particular in the Great Lakes countries of Uganda, Kenya, Tanzania, Burundi, Rwanda and the Democratic Republic of Congo.

Its implementation strategy is to work in partnership with groups of people living with HIV/AIDS; with existing national and pan-African HIV advocacy networks; with local and global NGOs; with African governments and policy makers; with international treatment advocacy organizations; and with the pharmaceutical industry, doctors and researchers.

It does this by:

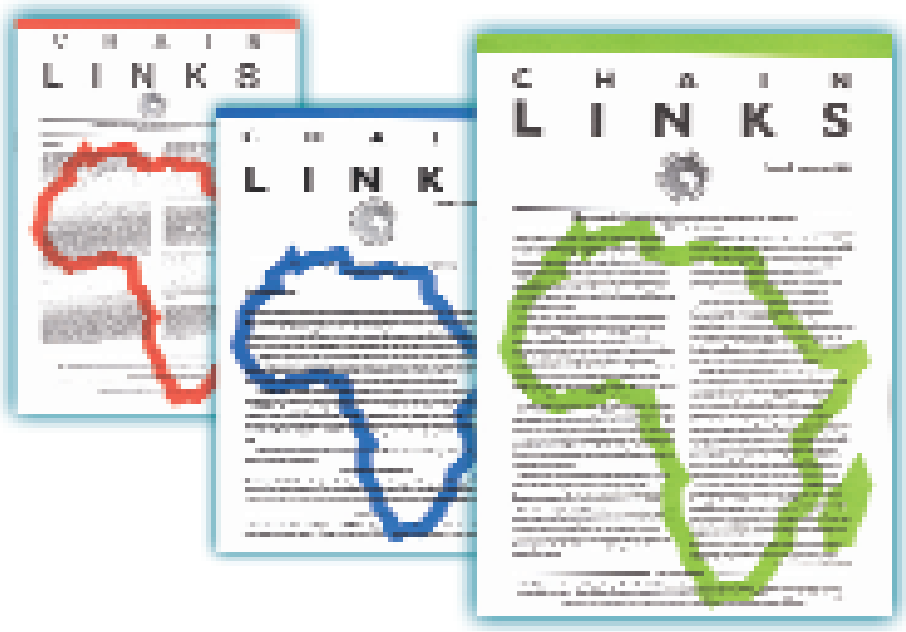
- Organising community symposiums and conferences to provide and discuss issues of treatment education and capacity
- Issuing a quarterly newsletter (see image on next page)
- Helping to set up and capacity build regional and local networks

CHAIN'S MISSION

CHAIN is explicitly a capacity-building organization, lending skills, resources and perspectives gained by Africans living with HIV in the UK and their contacts to other PWAs in Africa to use as 'capital' with which to grow their own initiatives.

Capacity building is best defined as the development of appropriate interventions to address the assessed needs of an organization. Both the capacity builder and the supported organization need to agree on a contract and action plan of what is to be done. Capacity building is a process of enabling, not one of management, and care must be taken not to foster dependency.

Despite over 20 years of HIV in Africa, local governments (with some honourable exceptions) have been slow to foster HIV programmes. However



it was not initially western governments that gave rise to the HIV/AIDS movement in the developed world, and to do so might have fostered a dependency culture.

In developed countries people living with HIV/AIDS have been at the forefront of decision making on prevention strategies, drug trial design, and service development. New HIV advocates are mentored through existing networks.

Although similar mentoring networks exist in certain of the Great Lakes countries, CHAIN identified that local people living with HIV/AIDS still needed help to lobby effectively within their constituencies and be a force for change.

In particular, as the examples from Thailand above show, the input of local people living with HIV/AIDS is essential for the provision of effi-

cient, effective and equitable HIV treatment. Peer education is a proven best-practice method of disseminating treatment information. Local PHAs need to be involved in formulating appropriate ethical guidelines for trials of drugs, microbicides and vaccines, and designing protocols. PHAs need to be centrally involved in advising on the design of appropriate treatment support programmes.

ACTIVITY TIMELINE

From its foundation in 1998 CHAIN has:

- June 1999: Conducted a preliminary needs assessment study in Uganda
- September 1999: Organised an international symposium at the 11th International conference on AIDS and STDs in Africa (ICASA) in Lusaka, Zambia
- April 2000: Conducted a collaborative treatment awareness workshop at Kampala, Uganda
- July 2000: Organised its second international symposium at the Durban World Aids Conference
- September 2001: Organised the first Great Lakes HIV/AIDS Conference in Kampala (see fuller report on page 9)
- April 2002: Commissioned a feasibility study on setting up the Great Lakes Network for People Living with HIV/AIDS (GLNPHA)
- May 2002: launched the Great Lakes Network for People Living with HIV and AIDS at the Barcelona World Aids Conference
- March 2003: Organised the first of six capacity-building workshops (one per Great Lakes country) in Kigali, Rwanda
- August 2003: Organised the second of six capacity-building workshops in Arusha, Tanzania
- September 2003: Organised the second Great Lakes HIV/Aids Conference in Kigali
- March 2004: Organised the third of six capacity building workshops in Goma, Democratic Republic of Congo

The launch of GLNPHA was a landmark in achieving CHAIN's aims. A body already existed called the Great Lakes Initiative on HIV/AIDS (GLIA). Each of the six Great Lakes countries has a national AIDS council (NAC) which is responsible for developing and coordinating a national AIDS response strategy in that particular country. GLIA is comprised of all the NACs of countries based in the GL region, with its secretariat based in Kigali, Rwanda. The intention of GLIA is to co-ordinate the large bilateral and multilateral health programmes directed to the area; not merely HIV/AIDS initiatives but also ones like the poliomyelitis vaccine.

However CHAIN had identified that governmental and inter-governmental bureaucracy was a major obstacle to the efficient functioning of GLIA. GLNPLA was to be set up to augment the inter-governmental effort. A consultation process took an inventory of the numerous existing groups for people with HIV/AIDS in each country, identified their capacity building needs and assessed the feasibility of their contributing to the regional partnership.

It was agreed that the job of GLNPLA would be to facilitate the flow of information from one group and one community of people with HIV/AIDS to another and to share best practice. It would convene capacity building workshops in each country.

William Babumba explains:

"The idea behind each of these workshops is to help formulate and develop one national network of PLWHA in each country. Once this is achieved, each network will nominate one representative to sit on the board of the Great Lakes Network for People Living with HIV/AIDS (GLNPLWHA). CHAIN's role is to empower the network members and not run the network. The network will be housed at our secretariat in Kigali until they are up on their feet."

The following sections will spell out in more detail the often country-specific conclusions reached by the various conferences and workshops convened by CHAIN/GLNPHA.In September 2001CHAIN co-organised a conference along with the US Aids Healthcare Foundation (AHF) and the Uganda Business Coalition on HIV/AIDS (UBC).

First Great Lakes Conference

6th - 9th Sept 2001

Officially opened by Yoweri Kaguta Museveni, President of the Republic of Uganda (pictured below) receiving an award from CHAIN's William Babumba for his leadership in the fight against HIV and AIDS), the conference was attended by 350 people from 20 countries, including regional international donor and partner agencies such as UNICEF, UNAIDS, Save the Children Fund, Care International and the WHO.

The aim of the conference was to discuss how to overcome barriers to care and support in the African Great Lakes region. The main barrier to effectiveness identified was the lack of communication between all the key stakeholders: clinicians, patients, policymakers, the drug industry, donors and grassroots NGOs in the region.

The major outcome of the Conference was the 'Entebbe Compact Declaration'. This initiative to overcome barriers to HIV/AIDS care in the region committed delegates to strengthening the capacity and resources of existing collaborative mechanisms like GLIA. It set the scene for CHAIN to begin helping local HIV/AIDS organisations to form the GLNPHA.

Soon after the conference UBC and AHF set up an HIV clinic in Uganda to provide free antiretroviral drugs to about 500 patients a year.

William Babumba presenting an award to President Yoweri Kaguta Museveni. Below: CHAIN volunteers - Martin Lukwago Bukulu & Rebecca Lubega, Bukulu manning the information stand.

Rwanda Workshop

March 2003

In the year after the first Great Lakes Conference in 2001, CHAIN was fully occupied helping to set up and launch the GLNPHA and develop partnerships with local groups and stakeholders in order to carry forward the capacity building workshops in each of the six Great Lakes countries, with the aim of using these to set up six national networks of people living with HIV.

The first of the workshops took place on March 20-21, 2003 in Kigali, Rwanda.

The workshop was co-ordinated by the Rwanda National HIV/AIDS Control Programme (CNLS) and the HIV/AIDS NGO Forum. It attended by 96 participants. People from all 12 of Rwanda's provinces travelled to the conference, and delegates from PHAs' organisations in every province attended. This resulted on the second day in the election of a representative urban/rural board of directors for the new Rwanda National Network of People Living with HIV.

The Rwandan Minister for HIV and AIDS, Dr Innocent Nyaruhirira, outlined the remit of the conference.

Dr Nyaruhirira set out the objectives of the conference as support for people with HIV/AIDS (PHAs) to participate in the national struggle against the disease; the creation of a Rwandan PHAs' network and having PHAs represented at all decision-making levels; and to capacity build PHAs organisations.
He noted that issues of particular importance in Rwanda included The number of AIDS orphans and street children; gender-based violence, and women's dependence on partners.
Achievements so far included the Rwanda HIV/AIDS NGO Forum set up in July 1999. This, the national networking and collaborative organisation, would need in particular to work closely in partnership with the proposed PHAs' Network.

Two people living with HIV/AIDS then spoke. Major Rubaramira Ruranga, a veteran AIDS activist from Uganda and Chair of the National Guidance and Empowerment Network there, spoke the lack of strong HIV positive role models in Africa. He said:

"We need to fight the conspiracy of silence. Many generals and leaders have AIDS but because they have enough money to get drugs they keep quiet."

Déo Kalimunda, a Rwandan living with HIV for 16 years, then spoke. He talked of the hard conditions, poverty and homelessness endured by people with HIV/AIDS. He said testing was not universally available and that a large number of people were unable to access monitoring and treatment of any kind. He criticized graduates for not getting involved in supporting PHAs' organisations, which were left to struggle.
He praised the support of Rwanda's First Lady, Jeanette Kagame, and

Right to Left: Limu Limu - HIV Programmes UNICEF Rwanda, Rose Gahire - Swaar Rwanda & Major Rubaramira Ruranga - National Coordinator NGEN+, Uganda.

government recognition of peer-support organisations.
Among his heartfelt recommendations were an end to HIV stigma, the banning of compulsory HIV tests for job applicants, income generation schemes for PHAs, and of course campaigning for cheaper drugs.

The conference then split into four groups which considered the rights and responsibilities in the fight against AIDS of, respectively, government; NGOs and other organisations; funding bodies; and (in the photo, right) PHAs themselves.
The recommendations from these groups are too detailed to list, but noteworthy issues that arose included:

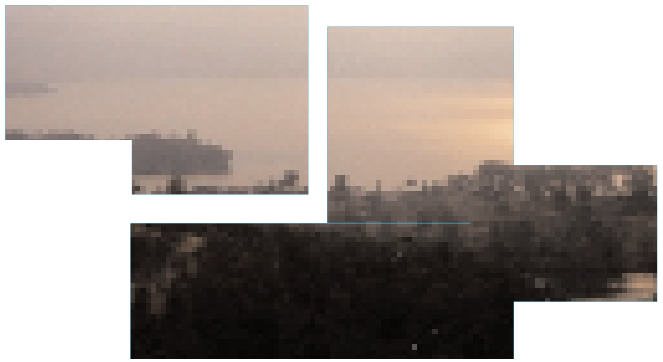
- There should be active backing by politicians for PHAs to come forward and speak publicly
- Faith based organisations, as well as giving psychospiritual support, should not oppose discussion of safer sex and condom use
- Medical facilities were too concentrated in urban areas
- There should be the creation of a police bureau to deal with prostitution
- Donors should back micro-credit unions and income generation for PHAs
- Consideration should be given to specialised housing for outcast PHAs
- PHA organisations should provide PHAs not only with knowledge about HIV, solidarity and social support but also education about health-seeking behaviours such as avoidance of drink dependency

Some of these recommendations occasioned lively debate. There was support from some quarters for decriminalisation of prostitution. It was debated whether separate housing for homeless PHAs would be supportive or stigmatising. There was strong agreement that faith based organisations should stop being ambiguous or hostile towards condom use.

The second day was largely taken up with the election of 13 officers to the board of the new Rwanda Network of People Living with HIV/AIDS. After the election, Thérésie Uwimana, the newly elected Network Chair, thanked delegates and set out her priorities as:

- Strengthening partnerships between provincial PHAs' organisations
- Advocacy for PHAs' needs and right, especially for the most needy
- The protection of PHAs from stigma and isolation
- Treatment, health and safer sex education for PHAs
- Sound and transparent management and decision structures and the drawing up of a constitution.

Group discussion on governance, leadership and resource mobilisation in fighting HIV/AIDS.



Tanzania Workshop

August 2003

The second of six capacity building workshops was held in held in Arusha, Tanzania, on 18-19 August 2003. It attracted 61 people, including 50 living with HIV, who between them represented 31 community and non-governmental organisations.

The workshop was opened by /major-General Herman Lupogo, the Director of the Tanzania Commission for AIDS (TACAIDS). He said that the fight against AIDS in Tanzania, which had been going on since 1983, had been hampered by resistance to behaviour change, low capacity to implement programmes, and disunity between PWAs' groups. He said that the value of working together is not in question. It was a sine qua non of success.
But the main problem had been a history of quarrels and conflicts between organisations, and there had to be openness and peaceful coexistence between PWAs' groups.
He questioned the efficiency of the large number of PWAs groups that had appeared. Most NGOs were based in towns with no interest in visiting the rural areas that some of them claimed to serve. He said that just because one is diagnosed does not make one a trainer, mentor or counsellor of other PWAs, without first being trained oneself.
He then outlined the nine-point National Strategy to fight HIV/AIDS.

Julius Kaaya, Chairperson of the Tanzania Network of People Living with HIV/AIDS (TANOPHA - seen left with Major General Lupogo, on far left) contributed a critical assessment of national HIV policy. He said the National Strategy had yet to have a significant impact and that policies were being implemented by people who know nothing about the communities they served. He said:

"There have been 15 years of concentration on prevention. This has meant workshops, symposia, seminars, placards... usually for the same groups of people and little in the way of treatment and care for people with AIDS."

Women representatives from the Tanzanian Network of PLWHA. Left: Major General (Rtd) Herman Lupogo being greeted by Julius Sabune of EANNASO.

A promised roll-out of anti-retrovirals had not happened. However the scope in services had recently started to widen, increased funds were being devolved to local groups, and activities were becoming “less tedious”.
Stigma remained a great challenge, and the idea of people living openly with HIV/AIDS being involved in running national services was still alien. This non-involvement had led to PHAs setting up their own autonomous groups, with unaccountable founders who tried to ‘own’ their members.

Lucy Ng’ag’a of the East African Nations Network of AIDS Service Organisations (EANNASO) talked about the major role a regional network can have in advocacy, especially for ‘voiceless’ groups like women and children. She said PWAs’ involvement in services was essential: “It’s only the wearer of the shoe who knows where it pinches most.”
In eight months of existence EANNASO had set up a survey of country PWAs’ networks and was planning to set up an info centre where users could communicate and contribute to web forums.

Joseph Katto of Services, Health and Development for People Living with HIV/AIDS (SHDEPHA+) introduced this national network of PHAs. Registered in 1994, its original aims had been mutual support, counselling, and education for behaviour change and positive living skills.
The aim was to help PHAs use local resources to become more “active, hopeful, self-reliant and effective.”
Rose Gahire (left), who is a board member of the Rwanda NGO Forum on HIV/AIDS and also CHAIN GL regional focal point, introduced the Forum as a model of partnership networking. Partnership working was cost-effective, avoided duplication, strengthened capacity, and promoted good practice and social cohesion.
Partnerships should be dictated by service, not funding needs. Honesty of partners at looking at each others’ portfolio of strengths and weaknesses was essential. So was discussion about a steering committee and director, financial arrangements and an exit strategy if one partner wished to leave.
She and William Babumba then introduced principles of strategising to set the tone for group discussions.
The conference then split into two groups (below) which discussed a) how to involve PHAs in meaningful strategy work and b) identifying the capacity- building needs of Tanzanian PHA organisations. The groups came back with these recommendations:

- Greater involvement of PHAs in conceiving, implementing and evaluating HIV/AIDS programmes
- Advocacy for treatment access and treatment information
- A joint Great Lakes nations experience-sharing forum for PHAs
- Greater collaboration among PHAs in Tanzania: they must bury their differences. Come together and work in partnership
- Assistance for PHAs to get access to important stakeholders and partners in various sectors
- Mentoring programmes for PHAs

Workshop delegates during a workshop discussion. Below: Rose Gahire of Swaar Rwanda & CHAIN focal point giving a presentation on effective partnership working.

Second Great Lakes Conference

16th - 19th Sept 2003

This conference took place in Kigali, Rwanda on the 16-18 September 2003. It was organised by the Rwanda National Commission for the Fight against HIV (CNLS) in partnership with CHAIN, the Rwanda NGO Forum on HIV/AIDS, GLNPHA and GLIA.

The theme was **"Building Bridges to Scale up Treatment and Care."** The primary objective was to build a consensus on how to expand access to urgently-needed HIV treatments and treatment information in the Great Lakes region.

The conference would focus on:

- Sharing information on successful pilot AIDS treatment programmes
- Looking at how civil society organisations worked with governments
- Looking at how governments can develop treatment plans
- Representation of PHAs at all levels of decision making
- How to build and support local organisations
- How the private sector could contribute access to treatment, voluntary counselling and testing, education and anti-discrimination work

The first three speakers were **Dr Agnès Binagwaho** (second from left), Executive Secretary of the Rwanda National Aids control Commission; **Dr Innocent Nyaruhirira** (centre), Minister of State for HIV/AIDS and related diseases, and **Dr Abel Dushimimana** (second from right), the Minister of Health, who represented the President of Rwanda, Paul Kagame.

Dr Binagwaho said: "Over four million people in sub-Saharan Africa are in need of anti-retroviral therapy yet only a ridiculously small proportion of these people have access to drugs. We need to work together to combat this scourge."
Dr Nyaruhirira noted that the conference had come at an opportune time, just after the Uganda Business coalition Conference on overcoming barriers to HIV/AID care and support.

Dr Dushimimana, representing the President, said: “Governments have an obligation to protect their citizens. We created GLIA to reinforce national responses. HIV is not a problem of one person, or one country.”

All the following presentations were centred on the importance of treatment and treatment education access. The UNDP Resident Representative in Rwanda, Mr Kamau Macharia, said that treatment for all was a moral obligation, but that it would not be achieved unless the various components were factored into a full-blown treatment plan.

Various speakers then spoke of the role their organisations and companies had in scaling up treatment programmes. Marcel van Soest from the International Treatment Access Coalition said his organisation aimed to be a catalyst in efforts to implement treatment programmes, and Nitya Anand from Ranbaxy laboratories talked about Ranbaxy’s work in manufacturing and ensuring the supply of affordable generic antiretrovirals.

Miriam Scheideman from the World Bank and Jerry van Mourick from the Global Fund talked about their different methods of disbursing funding.

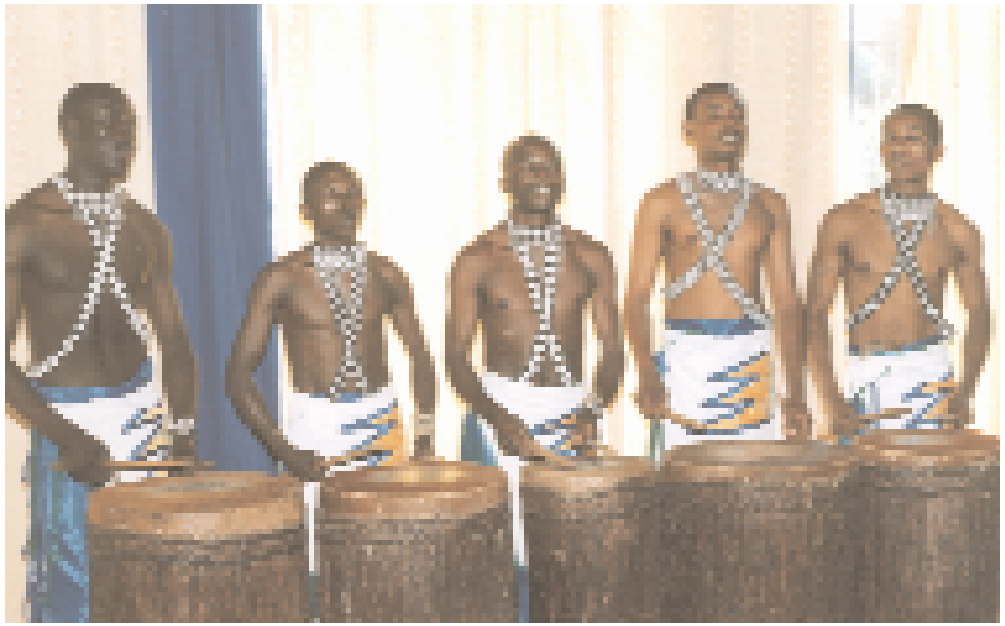
Dr Elisabeth Namagala from the Uganda Ministry of Health highlighted the factors needed to successfully scale up access to treatment. Among them were:

- A national strategic care framework for people with AIDS
- A national programme of antiretroviral therapy (ART)
- Establishment of a national therapy committee to co-ordinate and monitor the ART programme and lead on policy guidelines
- Accreditation of health facilities and pharmacies as dispensing centres
- Scaling up services necessary for the provision of ART
- Strategies to sustain treatment

The second day of the conference looked at practical examples of treatment in action. In Rwanda the primary ART centre is the Biryogo Health Centre, whose 12 staff members provide increasing amounts of treatment and care to about 1500 people, at present mainly concentrating on voluntary counselling and testing and the prevention of mother to child transmission.

Christine Nabiryo from TASO in Uganda talked about that organisation’s experience in providing ART in a resource poor setting. Points that came up, some unexpectedly, included support for the extended family when one person was fortunate enough to star on ARTs (exactly the point made by Noerine Kaleeba above); the fact that people’s appetites improved along with their health and a family suddenly had to find more food; and the problems of staff retention.
She also spoke about the importance of adherence, and said that group counselling had proved to be the best method of fostering adherence to treatment regimens.

The Conference then split into three groups to discuss access to HIV treatment, the role of PHAs in civil society, and the role of national AIDS councils, national ARV programmes, pharmaceutical firms and national medical stores.
At the end of the conference, the recommendations formed the KIGALI DECLARATION, which can be read on pages xx-xx.



Dr Innocent Nyaruhirira, Minister of State for HIV/AIDS and related diseases and Dr Agnes Binagwaho, Executive Secretary of the Rwanda National AIDS Control Commission.

D.R.Congo Workshop 1st - 3rd March 2003

This workshop was held in Goma, North Kivu province, in the DRC (Democratic Republic of Congo), from 1-3 March 2004.

Goma and its province are the area where many refugees fled following the Rwanda genocide and the civil war in DR Congo. The area is still politically unstable with a large transient population of refugees and ex-militias. However the Lac Kivu area (see right) is very beautiful and has tourist potential.
The relationship between Aids and Development was the focus of the workshop, which was attended by 54 participants form all over North Kivu.
The workshop was co-ordinated by ActionAid, CHAIN, the DRC Provincial Inspectorate of Health and the National Programme to Fight HIV (PNLS).

The aims of the workshop were to discuss the capacity-building needs of local grass-roots organisations, to increase understanding of how HIV/AIDS affects development issues, to identify ways to increase access to ARVs and treatment education, and to set up links between North Kivu and adjacent countries, the US and Europe.
Participants stated that they hoped the outcome would be “a strategy for the promotion of development in a society already ravaged by HIV/AIDS.”

In his opening remarks, Edward Kakande of ActionAid said “HIV is a social as well as a medical disaster. It affects life, education, productivity, food, human resources, self-image and self-reliance.”
Joachim FIKIRI, Co-ordinator of ACOLSI, the Association of Aids Service Organisations of Congo, introduced his organisation. This network had been set up as long ago as 1987. But it had been in crisis since WHO withdrew its support. He hoped it could once again become active and the local co-ordinating body; it still had good links with the PNLS and other NGOs.

The conference then split into three groups to brainstorm a ‘wish list’ of interventions urgently needed in the Goma area. Some of the ones delegates suggested were anti-Aids sports weekends, kiosks for condom distribution, role plays and lectures in community settings, exchanges with other organisations, and a treatment and care centre.

On the second day, Jean Jacques Nkhungu, Director of Behaviour Change at the PNLS, gave a stimulating presentation about development. He said that HIV/AIDS could have tragic effects on development potential. It turned political will and civic-mindedness into avoidance and apathy; it turned social and political conscience into alienation; and it turned the ability to choose a strategy for living into powerlessness.
He said that nurturing sustained development in a resource-poor setting was like building a house. The foundations were a strong multisectoral partnership; the walls were capacity building, social mobilisation, and

infrastructure improvement; only once these were built could one could put up the roof of behaviour change.

Delegates then split again into three groups that considered factors contributing to the spread of HIV in the area strategies to combat them. These included sexual abuse and rape and social customs such as polygamy, and levirate and sororate (the practice of a widow or widower marrying their deceased spouse's sibling).
The group considering child and sexual abuse urged the setting up of women's groups, the rehabilitation of street children, outlawing the bartering of jobs for sex, combating provocative fashion, and ensuring that refugees did not have to go too far to get water at night. The group considering cultural issues urged an end to the custom of fathers-in-law trying brides' virginity and of the taboo against sex education. The evaluation group chalked up a set of markers - condom distribution, numbers of trained advocates, financial probity, ARV availability - by which success could be measured.
Two further workshops discussed sex workers, youth and truck drivers.
The delegates then acted out three interesting role plays in which they attempted to educate teenagers and sex workers in condom use, and put themselves in the position of a newly diagnosed man rejected by his family.

At the end the delegates issued the following statement:

"We undertake to promote associations of PHAs and to fight with all our energy against them being dismissed, discriminated against and condemned so that they can participate in the development of our country the DRC. We entreat other organisations to join our efforts to roll back the impact of HIV and AIDS on individuals and communities."

They resolved:
- The urgent creation of a multisectoral network to fight HIV/AIDS
- Proper dialogue between NGOs and the government
- Continuous capacity building of local NGOs
- Making ARVs available, and the opening of VCT and PMTCT centres
- Reorganisation of ACOLSI and election of officers
- Training in counseling and better media coverage

Workshop delegates performing a role play to highlight stigma and discrimination HIV+ people face after being diagnosed.

Kigali Declaration

Sept 2003

1. Aware that HIV / AIDS continues to be a leading cause of morbidity, mortality and economic devastation in the Sub-Saharan Africa and the Great Lakes in particular, and aware that provision of anti-retrovirals drugs have changed the trend of HIV/AIDS in the North making it a manageable although chronic disease;

2. In conformity with the theme of this conference which is "Access to all" - Building Bridges to Scale Up on Treatment & Care within the Great Lakes Countries;

3. We feel it is apt and important to demand the commitment of the political leaders and all actors to take immediate action.

4. We the delegates hereby make this declaration at the end of this conference to all National AIDS Commissions in the Great Lakes Countries to commit to the following:

5. Ministers of Health in all Great Lakes Countries should ratify the Great Lakes Initiative on AIDS (GLIA) and conform to its objectives.

6. Ministers of Health and state ministers of HIV/AIDS in the Great Lakes Countries should hold regular consultative meetings to monitor and evaluate GLIA activities in order to keep their government initiatives co-ordinated.

7. The GLIA secretariat must be empowered and functional in order to be able to take charge and appraise the partners on the agreed activities.

8. National HIV / AIDS Programmes must devise a transparent mechanism of accounting to all the stakeholder.

9. GLIA must ensure that the Great Lakes Conference on HIV/AIDS which is a bi-annual event takes place regularly. We must ensure that all the Great Lakes countries are actively involved in the planning and implementation of this conference, and other GLIA activities.

10. GLIA must ensure that the Great Lakes Network of People Living with HIV/AIDS (GLNPHA) is supported to achieve its aims & objectives as was agreed at the Nairobi workshop which was organised by GLIA (16 -17 April 2002). This mandated that a secretariat must be put in place.

11. Capacity building for networks of people living with HIV/AIDS, NGOS & CBOs is paramount. To achieve this national budgetary provisions must of necessity be made.

12. It is imperative that greater involvement of people living with HIV/AIDS is ensured during the development of, and consultation on, National HIV / AIDS Strategies and policies. This is in conformity with UNAIDS policy.

13. National HIV/AIDS strategies and policies must take a bottom-up approach in decision making and implementation of HIV/AIDS programmes as central command approach has not yielded good results. This ensures the communities own the programmes and act upon them.

14. In order to ensure effective management, administration and distribution of ARVS, the following must be done:

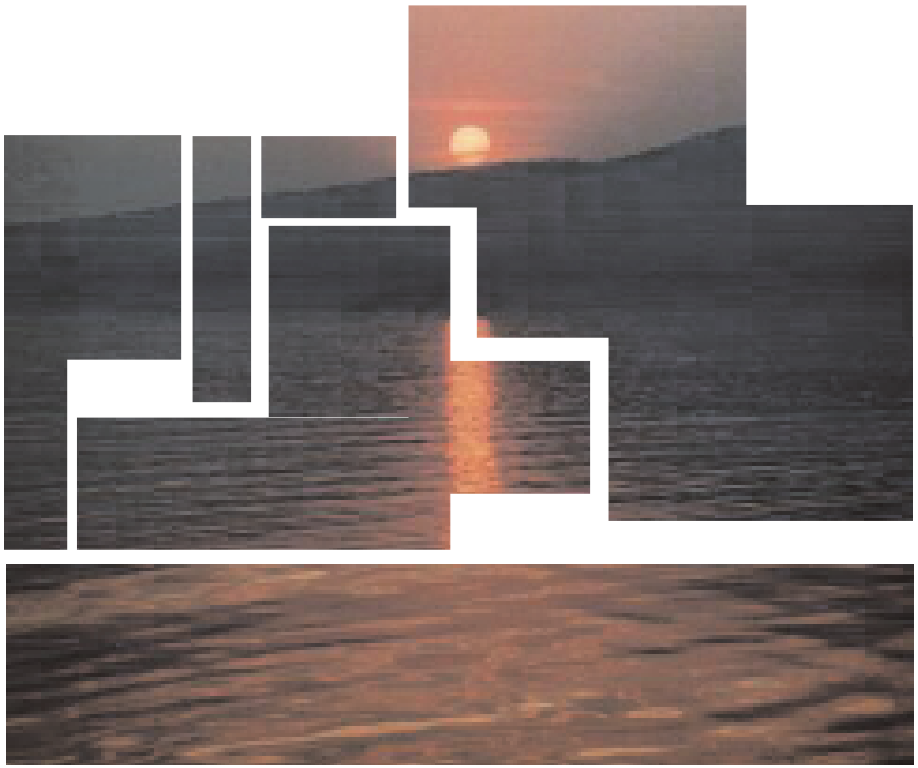
15. National treatment & care policies and implementation plans must be put in place with the participation of all stakeholders.

16. For the accessibility of drugs to succeed, the National Medical Stores within the Great Lakes countries should harmonise and develop standard guidelines on bulk procurements and distribution of ARVs & ensure quality assurance.

17. It is very important that national governments, the private sector, people living with HIV/AIDS, NGOs, CBOs, FBOs, bilateral & multilateral donors work together to achieve GLIA goals.

18. In order to ensure health for all, we must promote and advocate for accessible and fordable treatment for all in need.

19. National HIV/AIDS Commissions should collaborate with other initiatives within the region, such as the sub Saharan African First Ladies Association (OAFLA)



"The world must do more, much more on every front in the fight against HIV/AIDS. The single most important step we must now take is to provide access to treatment throughout the developing world. There is no excuse for delay. We must start now. If we discard the people who are dying from AIDS, then we can no longer call ourselves decent people"

Nelson Mandela, 15 July 2003

IFPMA Reception

Geneva, 16th May 2004

International Federation of Pharmaceutical Manufactures Association (IFPMA)
Reception, Sunday, May 16, 2004
President Wilson Hotel, Geneva

This meeting was organised just before the 57th World Health Assembly (WHA) meeting which took from 17th - 22nd May 2004. The theme of the WHA was global public Health.

The IFPMA reception focused on partnerships in the fight against HIV/AIDS and was attended by about 200 delegates. Several speakers where invited and these included Dr. Harvey E. Bale, Director General - IFPMA, William Babumba - CHAIN, Christopher Murray - Director - Pharma International, Hoffmann - La Roche, Robert Lefebvre - Senior Director - Global HIV Brands, Bristol Myers Squibb and Dr Jeffrey Sturchio - Executive Director, Public Affairs, Human Health, Europe, Middle East & Africa, Merck & Co, in.

During his introductory remarks, Dr Harvey Bale emphasised the importance of building partnerships between NGOs and the pharmaceutical industry particularly around scaling up on ARVs. William Babumba described the community partnerships CHAIN and the pharma industry have developed to fight HIV in the Great Lakes region. The issue of project sustainability must be addressed. Resource mobilisation, good governance and leadership must be tackled if we are to build and maintain effective partnerships.

Christopher Murray gave an update on the HIV/AIDS Accelerated Access Initiative (AAI). By Dec 2003, the number of treatments delivered by the AAI in Africa reached more than 150,000 patients, a 16-fold increase since 2000 when the programme started. If we are to

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scale up on ARVs there is an urgent need of rolling this programme in many other countries.

Robert Lefebvre updated members on the BMS Secure the Future programme. This initiative covers Southern Africa - South Africa, Lesotho, Namibia, Botswana & Swaziland. The programme was launched in May 1999 and committed $100 million for five years. It was launched in West Africa in November 2001 and covers Senegal, Mali, Burkina Faso & Cote d'Ivoire. $15 million was committed for five years to help countries in West Africa. The key objectives of the programme are; prevent HIV/AIDS & STD transmission, reduce the impact of HIV/AIDS on individuals by empowering infected and affected women and children and expand access to treatment by informing public health policy.

Dr Jeff Sturchio emphasised the importance of public - private partnerships in scaling up on ARVs. For example the African Comprehensive HIV/AIDS Partnerships (ACHAP) is a collaboration between the Government of Botswana (GOB), the Bill & Melinda Gates Foundation, and The Merck Company Foundation/Merck & Co., Inc., to prevent and treat HIV/AIDS in Botswana. ACHAP, established in July 2000, supports the goals of the GOB to decrease HIV incidence and significantly increase the rate of diagnosis and the treatment of the disease, by rapidly advancing prevention programmes, healthcare access, patient management and treatment of HIV/AIDS. The Bill & Melinda Gates Foundation and The Merck Company Foundation have each dedicated US$50 million over five years towards the project. Merck & Co., Inc., is also donating two antiretroviral medicines for appropriate treatment programmes developed by the GOB for the duration of the initiative. Dr Jeff Sturchio also announced the new partnership between Merck, Gilead and BMS in developing a once-daily, fixed-dose combination of three anti-HIV drugs and are also considering certain co-packaging options for the individual products. The three companies welcomed comments by U.S. Secretary of Health and Human Services Tommy Thompson on the need for increased treatment options for people with HIV/AIDS in the developing world.

This collaboration - a multi-company effort to create a fixed-dose product with three patented HIV/AIDS medicines - would be the first partnership of its kind in the field of HIV. The parties also agree on the importance of the task - to support the need for simplified treatment regimens, particularly in resource-constrained settings.

This potential three-drug, fixed-dose combination would include two Gilead drugs, Viread(r) (tenofovir disoproxil fumarate) and Emtriva(tm) (emtricitabine).

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CHAIN's Strategic Plan 2004 - 2009

There has been a momentous shift in the international response to HIV since mid 2001, which has had an impact on the way in which national governments, the voluntary and community sectors address HIV work. The 2 significant international initiatives have been:

A. United Nations General Assembly Special Session on HIV (UNGASS)

The 2001 Declaration on HIV and AIDS at the United Nations General Assembly Special Session (UNGASS) in Abuja is being implemented under 5 international strategic objectives. The pillars of UNGASS are:

1. To empower leadership for an effective response at country level
2. To mobilise and empower country-level public, private and civil society partnerships
3. To promote and strengthen country management of strategic information
4. To build capacities to track, monitor and evaluate country responses
5. To facilitate access to technical and financial resources at country level

B. Treating 3 Million by 2005 (3 by 5 Campaign)

On 22 September 2003 the Director General of World Health Organisation (WHO), the Executive Director of UNAIDS, and the Executive Director of the Global Fund to Fight AIDS, Tuberculosis and Malaria jointly declared the lack of access to antiretroviral drugs to be a global health emergency. WHO and its partners launched the global target of treating 3 million people with antiretroviral therapy by the end of 2005. WHO's strategic framework for the emergency scaling up of antiretroviral therapy falls under 5 pillars.

1. Global leadership, strong partnership and advocacy
2. Urgent, sustained country support
3. Simplified, standardised tools for delivering antiretroviral therapy
4. Effective, reliable supply of medicines and diagnostics
5. Rapidly identifying and reapplying new knowledge and successes

Under each pillar are key UNAIDS and WHO actions and targets that the organisations hope to achieve by set dates, working with Governments, the voluntary and community sectors. CHAIN is committed, and indeed excited to work within the frameworks of this unprecedented international effort. CHAIN's future programmes will be developed to complement and support the principles of international frameworks and country responses to them.

CHAIN'S VISION

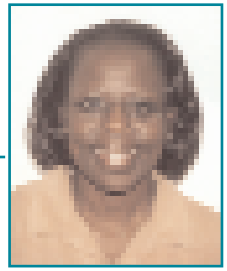
"People living with HIV having choices and opportunities to make decisions about their health, social and economic circumstances"

OBJECTIVES

CHAIN intends to focus on 3 objectives over the next 5 years and has set clear targets for their achievement.

1. **Promoting Multi Agency Partnerships and Increasing the capacity of the voluntary and community sector in the Great Lakes Region.**

- CHAIN will firm up partnerships at international level, in support of international programmes such as UNGASS and GFATM.
- CHAIN will firm up its partnerships with state agencies in each coun-



try, especially in ministries of Education, Health and Social Services, including co-operation with the Country Co-ordinating Mechanisms.

- CHAIN will firm up existing partnership with voluntary, community and faith based local groups and roll out expanded programmes of organisational development support
- CHAIN will increase its partnership work with the international pharmaceutical industry to support closer working between the industry and communities living with HIV.

2. Promoting Treatments Advocacy in the Great Lakes Region

- CHAIN will provide programmes of treatments literacy training in conjunction with institutions of learning
- Treatments access will increase with treatments literacy, in addition to work supporting the World Health Organisation targets of reaching 3 million people by the year 2005.
- CHAIN will advocate for further reductions in the price of treatments as affordability is key to increasing people's choices and opportunities in health.

3. Addressing Stigma and Discrimination

- CHAIN will promote and support HIV information sharing programmes addressing stigma
- CHAIN will work with grassroots faith groups to challenging discrimination
- CHAIN will monitor and seek redress for human rights violations in partnership with other agencies.

Dorothy Mukasa
Strategic Planner & Policy Advisor - CHAIN

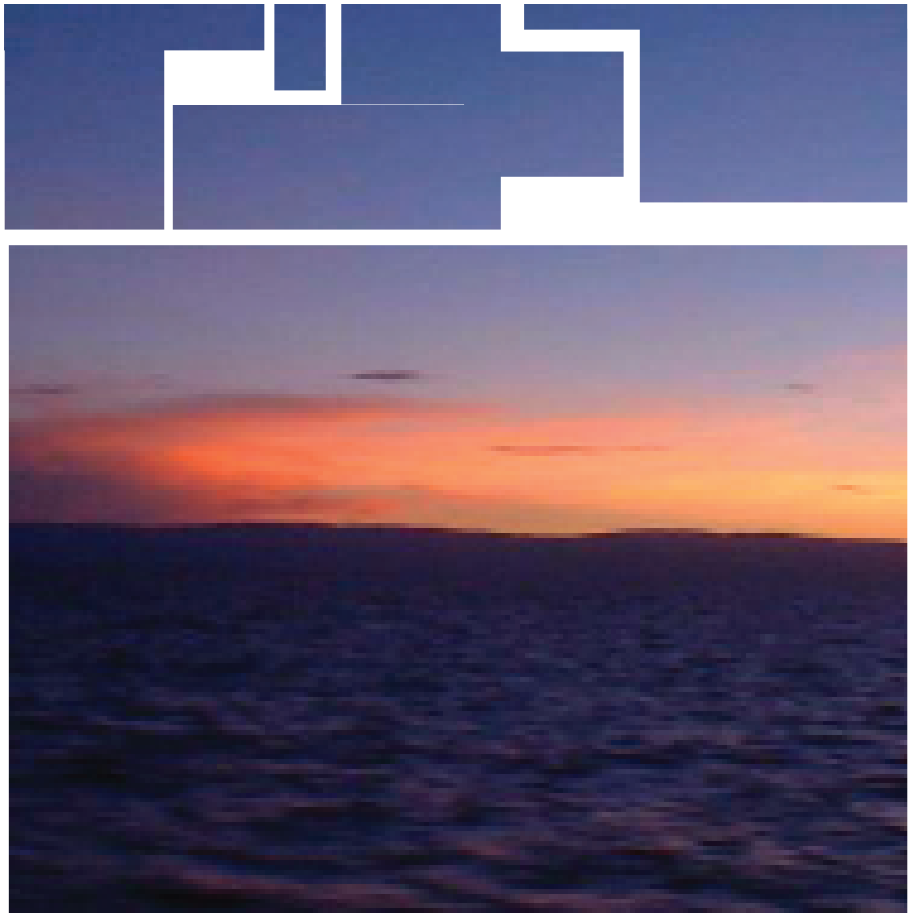


Photo: Peter Birch

List of CHAIN's of Networking Partners

GL REGION:

RWANDA:

1) Rwanda NGO Forum on HIV/AIDS
Contact: Regis Ruhanga
Tel: 0851 13857
Email: Ruharegis@yahoo.fr

2) Rwanda National Network of People living With HIV/AIDS
Contact: Immaculate Gatesis
Tel: 0847 2631 or 08536255
Email: rrpsidavk@yahoo.fr

3) Great lakes Network on HIV/AIDS (GLIA)
Contact: Dr Eugene Rurangwa
Executive Secretary
P.O. Box 1855
Kigali
Rwanda
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Fax: 00250 502633
Email: eugrur@yahoo.fr

4) Commission Nationale De Lutte Contre Le Sida
Contact: Dr Agnes Binagwaho
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Rwanda
Tel: 00250 582018
Fax: 00250 583325
Email: abinagwaho@yahoo.fr

5) Action AID Rwanda
Tel: 0250 08300 006
Fax: 00250 86800

6) Protection & Care of Families Against HIV/AIDS (PACFA)
Initiative of the 1st Lady of Rwanda
Contact: Jacqueline Mukangira
Projects Manager
P.O. Box 7141
Kigali
Rwanda
Tel: 00250 59062048
Fax: 00250 511620
Email: mukangira@yahoo.co.uk

UGANDA:

1) Uganda AIDS Commission
Contact: Prof Romushana
Deputy Director General
P.O. Box 10779
Kampala
Uganda
Tel: 00256 41 273538 / 273231
Fax: 00256 41 258173

2) Ministry of Health
Contact: Brigadier Jim K. Muhwezi MP
P.O. Box 7272
Kampala
Uganda

3) TASO - The AIDS Support Organisation
Contact: Peter Sebanja
Community mobilisation and policy
P.O. Box 10443
Kampala
Uganda
Tel: 00256 41 567637
Fax: 00256 41 566704 / 530412

4) The National Forum Of PHA Networks in Uganda
Contact: Capt Stephen Talugende
P.O. Box 28814
Kampala
Uganda

5) National Guidance And Empowerment Network of PLWHA (NGEN+)
Contact: Major Rubaramira Ruranga Coordinator
P.O. Box 10028
Kampala
Uganda

6) AGOA - Uganda
Contact: Susan K. Muhwezi
Special Presidential Assistant on AGOA & TRADE
Export Led Growth Strategy Unit
Incorporting AGOA (USA), EBA (EEC) Canada
& Japan (GSP)
Country Responses
State House
P. O. Box 25497
Kampala - Uganda
Tel 256-41-343222,343252
Fax 343277

TANZANIA:

1) EANNASO - Eastern African National Networks of AIDS Services Organisations
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Executive Director
Njiro Road
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Tel: 00255 (27) 2507521
Fax: 00255 (27) 2508224
Email: eannaso@eannaso.org

2) Tanzanian Commission for AIDS (TACAIDS)
Contact: Major General Lupogo (Rtd)
Executive Secretary
Tel: 00255 022 2122651

3) TANOPHA - Tanzanian National organisations of People Living With HIV / AIDS
Contact: Julius Kaaya
Chairman
C/o TACAIDS

4) East African Community Secretariat
P.O.Box 1096
Arusha
Tanzania
Tel: 255 - 27 - 2504253/8
Fax: 255 - 27 - 2504255
Email: eac@eachq.org
Web: http://.each.org

5) Service Health & Development For People Living Positively With HIV/AIDS (SHDEPHA+)
Contact: Executive Chairperson
National Headquarters
P.O. Box 13713
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Tanzania
Tel: 255 - 22 - 2181849/50
Fax: 255 - 22 - 2181849

KENYA:

1) Association of People Living With HIV / AIDS in Kenya
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Niamery Lane, off Muthaiti Avenue
P.O. Box 30583 - 00100
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Fax: 254 - 2 - 603421
Tel: 254 - 2 - 603421
tapwak@kenyaonline.com

2) Centre For African Families Studies (CAF)
Pamstech House, Woodvale Grove
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Tel: 254 - 2 - 448618
Fax: 254 - 2 - 448621
Email: info@cafs.org

3) Kenya AIDS NGOs Consortium (KANCO)
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Fax: 254 - 2 - 2714837
Email: kenaids@iconnect.co.ke

BURUNDI:

1) Association Nationale De Soutien Aux Seropositifs Et Sideens Du Burundi
28 Avenue Moso
Rohero II
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Fax: 257 - 241501
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DEMOCRATIC REPUBLIC OF CONGO:

1) ActionAid Goma
Contact: Edward Kakande
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2) Medecins Du Monde France
Republic Democratique du Congo
Contact: Dr Almouner Talibo
Coordinaeur Programme VIH / SIDA Goma
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Email: mdmfgoma@hotmail.com

EUROPE & AMERICA

1) African HIV Policy Network (AHPN)
Contact: Dr Max Sesay - Chief Executive Officer (CEO)
New City Cloisters
196 Old Street
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EC1V 9FR
Tel: 0044 (0) 207 017 8910
Tel: 0044 (0) 207 017 8919
Email: max.sesay@ahpn.org
Web: www.ahpn.org

2) European AIDS Treatment Group (EATG)
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B-1050 Brussels
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Fax: +32 2 644 33 07
office@eatg.org

3) American Foundation For AIDS Research (AmfAR)
Contact: Kevin Frost - Executive Director
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120 Wall Street, 13th Floor
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(212) 806-1600 (tel)
(212) 806-1601 (fax)
WASHINGTON DC
amfAR
1828 L Street, NW, #802
Washington, DC 20036-5104
(202) 331-8600 (tel)
(202) 331-8606 (fax)

4) HIV i-Base
Third Floor East
Thrale House
44 - 46 Southwark Street
London
SE 1 1UN
TeL: 0044 (0) 7407 8488
Fax: 0044 (0) 7407 8499
Web: http://www.i-Base.info

5) International Federation Of Pharmaceutical Manufactures Association (IFPMA)
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Secretary General
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Photo: Peter Birch

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