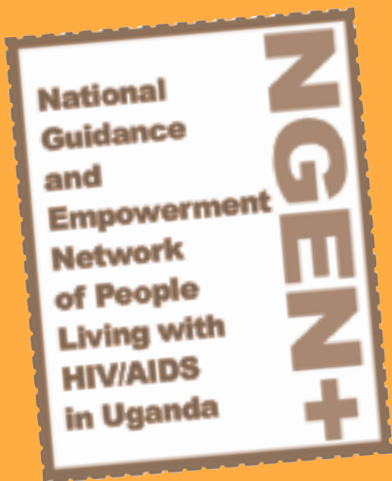




The Dawn of New Positive Leadership Conference Report

11th International Conference for People Living with HIV/AIDS
October 26-30, 2003



Acknowledgements

We would like to thank the Conference volunteers for all their help at the 11th International Conference for People Living with HIV/AIDS. The Conference would not have been possible without them. We are also very grateful to the following agencies, companies, and organizations for their financial support:

Patron of the Conference

The AIDS/HIV Integrated Model District Programme of Uganda (USAID)
Multi-Country AIDS Programme (World Bank), The Uganda AIDS Commission
The Joint United Nations Programme on HIV/AIDS (UNAIDS)
The United Nations Development Programme
Positive Action (GlaxoSmithKline)
The Global Network of People Living with HIV/AIDS

Gold Sponsor

The Dutch Ministry of Foreign Affairs

Silver Sponsors

Latin American Network of People Living with HIV/AIDS
AIDS Non-Governmental Organization Networks in East Africa
(The German Technical Cooperation Corporation)
The Rockefeller Foundation
Dutch AIDS Foundation
The World Health Organization
The Policy Project, The Futures Group International (USAID)
The Department for International Development of the United Kingdom
Development Cooperation Ireland, Department of Foreign Affairs
The Ugandan Ministry of Health
The Core Initiative (USAID)

Bronze Sponsors

Altria Corporation
HIVOS
Merck & Co.
Uganda Red Cross Society

Additional Acknowledgements

We also thank Multatuli Travel, Amsterdam, the Network of African People Living with HIV/AIDS (NAP+), and the International Federation of Red Cross and Red Crescent Societies (IFRC) in Geneva and in Nairobi for their partnership and support. We are grateful to UNAIDS, the World Health Organisation (WHO), and the United Nations Children's Fund (UNICEF) for their post-Conference reports.



Table of Contents

About the Co-organizers	4
The Global Network of People Living With HIV/AIDS (GNP+).....	4
National Guidance and Empowerment Network of People Living With HIV/AIDS in Uganda (NGEN+).....	5
Introduction and Foreword	6
Background on the International Conferences for People Living With HIV/AIDS	7
Why Uganda?	7
Peripheral Events	8
Pre-Conference Leadership Training.....	8
AMICAALL Meeting	8
Health Rights Action Group Meeting on Access	8
Activities of UNICEF MENA Region Delegates	9
Launching of ANERELA+	9
Background on the Program.....	10
Opening Ceremony	10
Session Highlights	12
Positive Leadership	12
A New Paradigm of HIV-Positive Leadership.....	12
Aspects of Leadership	12
Talking to Governments That Don't Listen	13
Public Speaking as a Positive Person	13
Positive Women's Leadership	13
Developing and Sustaining Care and Support Groups	15
The Global Fund: New Hope, New Bureaucracy and the Role of PLWHA	15
Injection Drug Use (IDU) and HIV: Strategies for Survival.....	16
Code of Practice: Supporting Effective NGOs in HIV Work	16
Stigma and Discrimination	17
World AIDS Campaign: Fighting Stigma and Discrimination	17
Religion, Culture, Stigma and Discrimination.....	18
Faith-based Stigma and Discrimination.....	18
Foundation MAMIO Names Project	18
Internalized Stigma.....	18
Militant Media.....	19
The GNP+ and IFRC Partnership: Update and The Way Forward	19
Treatment, Care and Support	20
PLWHA in Prevention Strategies.....	20
Advocating for HIV-Positive Women's Rights to Reproductive Health Care In Ukraine.....	20
Ethical Implications of Programs for the Prevention of Mother to Child Transmission of HIV (PMTCT).....	21
Microbicides and HIV+ Women and Men.....	22
The APN+ Buyers' Club: Mobilizing to Save Our Leadership.....	22
Treatment Activism and Advocacy: Understanding What It Is.....	23
Three Million by 2005! Working With WHO to Keep a Promise.....	24
Family, Youth, And Children	24
HIV+ Youth: A Call for Inclusion of Our New Generation.....	24
Giving A Voice to Orphans and Children Affected By HIV/AIDS In Mali	25
UNICEF Helping Children Raise Their Voices	25
Closing Ceremony	26
Declarations	26
Conference Declaration	26
Women's Declaration to All World Leaders:.....	27
Declaration from REDLA+	28
Declaration from "Injecting Drug Use and HIV Meeting"	29
Voices of Children	29
Appendices	30
Appendix 1 - Conference Statistics	30
Appendix 2 - The Denver Principles	30
Appendix 3 - The Ugandan National Response	30
Appendix 4 - A Historical Précis on the International Conferences For People Living With HIV/AIDS.....	31

About The Co-organizers

THE GLOBAL NETWORK OF PEOPLE LIVING WITH HIV/AIDS (GNP+)

GNP+ is a global network for and by people living with HIV/AIDS (PLWHA). The mission of GNP+ is to improve the quality of life of people living with HIV/AIDS. The central secretariat of GNP+ is located in Amsterdam, The Netherlands.

GNP+ works with six affiliated regional networks of people living with HIV/AIDS, listed below. Each of these networks sends two persons to represent its respective region in front of the Board of GNP+. These twelve AIDS activists and advocates form the governing body of GNP+.

Affiliated networks, per region:

Africa: Network of African People Living with HIV/AIDS (NAP+)

Asia-Pacific: Asia-Pacific Network of People Living with HIV/AIDS (APN+)

Caribbean: Caribbean Regional Network of People Living with HIV/AIDS (CRN+)

Europe: European Network of People Living with HIV/AIDS (ENP+)

Latin America: Latin American Network of People Living with HIV/AIDS (REDLA+)

North America: GNP+ North America (GNP+NA)

FOCUS AND PROJECTS

GNP+ seeks to improve the quality of life of people living with HIV/AIDS through advocacy, capacity building, and communications programs that draw from strategies based on lobbying, linking, and sharing:

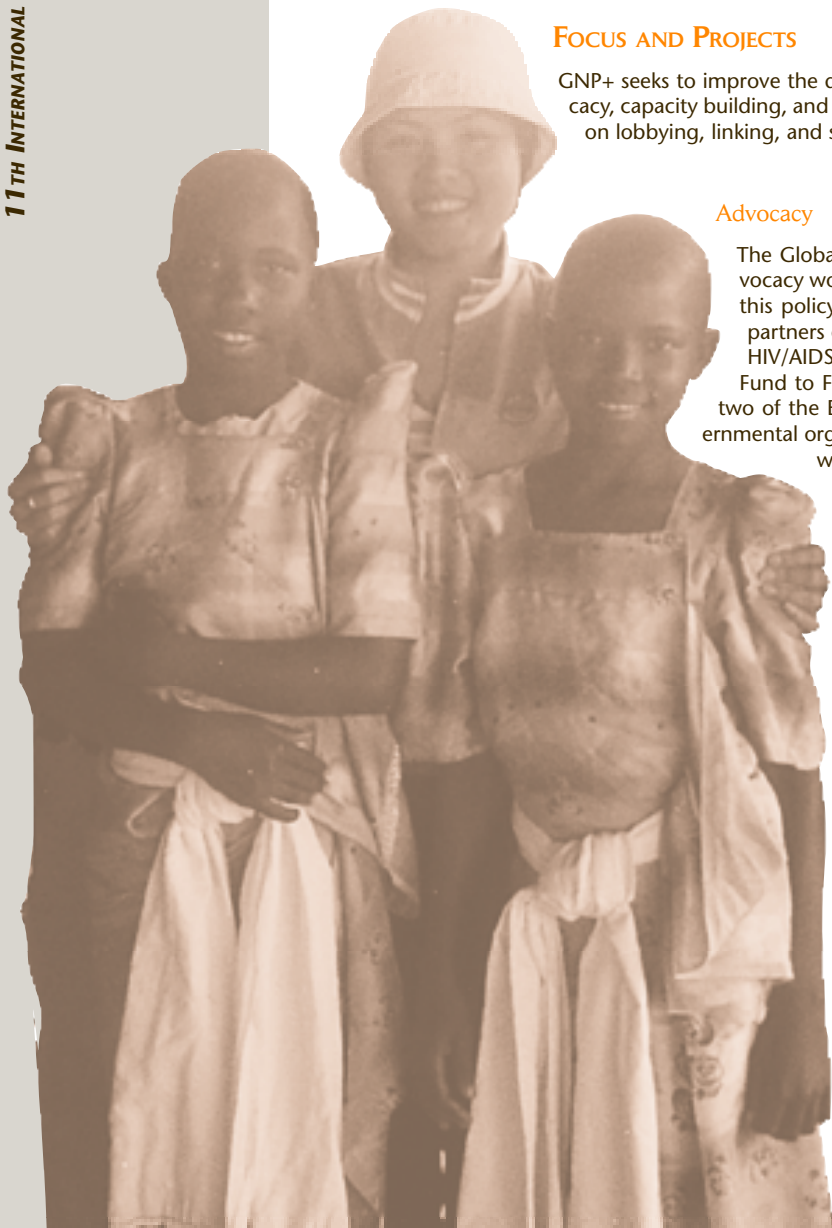
Advocacy

The Global Advocacy Agenda is the policy platform guiding the advocacy work of GNP+. Various activities are undertaken to implement this policy platform. GNP+ collaborates with and supports regional partners on specific campaigns. GNP+ represents people living with HIV/AIDS on the Resource Mobilization Committee of the Global Fund to Fight AIDS, Tuberculosis, and Malaria ("Global Fund"), and two of the Board members of GNP+ represent the sector of non-governmental organizations (NGOs) on the Board of the Global Fund. GNP+ works in close partnership with the United Nations Joint Programme on HIV/AIDS (UNAIDS) and the International Federation of Red Cross and Red Crescent Societies (IFRC), in particular in the fight against HIV/AIDS-related stigma and discrimination. GNP+ also participates in the decision making of the IFRC-led project on developing an NGO HIV/AIDS Code of Practice.

Capacity Building

GNP+ works to help people living with HIV/AIDS contribute to the HIV/AIDS response by providing resources, information, and empowerment. In addition to a number of fact sheets and position papers, GNP+ co-publishes guidelines for donation of medications. It makes its manual, Positive Development, available in multiple languages and free of charge for purposes of grassroots organizing and training.

The sparkle in the eyes of these young special guests shining brightly even after a long day of work.





Communication

GNP+ links people living with HIV/AIDS to and with each other at various global and regional meetings. GNP+ co-organizes and co-sponsors the International Conferences for People Living with HIV/AIDS. These conferences provide a special context for PLWHA to meet in a safe environment and share personal experiences, day-to-day living with HIV/AIDS, information, skills, and resources. Under the mentoring concept, activists are identified at these meetings. They are subsequently inspired, encouraged, and trained by other persons living with HIV/AIDS already active in the PLWHA movement. GNP+ also co-organizes the International Conferences on Home and Community Care for People Living with HIV/AIDS and the International AIDS Conferences, and it supports meetings of regional networks.

In addition, GNP+ is the Communications Focal Point for the Global Fund delegation representing the community of people infected and affected by the three diseases within the scope of the Global Fund. With the involvement of several HIV-Positive experts, GNP+ recently completed a multi-country study on the involvement of people living with HIV/AIDS in the Country Coordinating Mechanisms of the Global Fund.

NATIONAL GUIDANCE AND EMPOWERMENT NETWORK OF PEOPLE LIVING WITH HIV/AIDS IN UGANDA (NGEN+)

NGEN+ is a network of people living with HIV/AIDS in Uganda. It was established in 1996 with the mission to bring together people living with HIV/AIDS, to empower them to take part in HIV prevention and AIDS-care efforts, and to promote their involvement at all levels of the HIV/AIDS response.

SPECIFIC OBJECTIVES

- Mobilize people living with HIV/AIDS in Uganda to join local networks to create a common voice to advocate and lobby for an improved quality of life.
- Empower HIV-positive persons to share experiences, skills and power to promote positive living among themselves and prevention practices.
- Promote self-esteem and confidence and create a sense of belonging among HIV-positive persons in Uganda.
- Work with the private sector, Government departments and non-governmental bodies involved in HIV prevention and AIDS care.
- Training PLWHA on issues like positive living, communication skills, networking, lobbying and advocacy, information on HIV transmission and prevention, and management of the disease.

ACTIVITIES

NGEN+ is involved in prevention campaigns in the Ugandan armed forces, the Ugandan Police, and the Ugandan prison services. By the end of June 1999 ninety-two bodies all the forces mentioned above had been reached with prevention campaigns and message of hope for those infected. NGEN+ continues to push lobbying and advocacy for an improved quality of life to the fore. NGEN+ is engaged in a dialogue with the Ministry of Health to increase access to anti-retroviral (ARV) therapy and to treatment for the most common opportunistic infections.

STRUCTURE OF NGEN+

NGEN+ works through a national task Force with ten volunteers. A national coordinator heads the Task Force with the assistance of a project manager and a secretary. NGEN+ has mobilized PLWHA into groups in twenty-two districts. A district coordinator heads each district network, with assistance of a secretary, and a core group.

Introduction and Foreword

“Silence equals death, break the silence”. These simple messages have been lasting sources of inspiration for the social and political movement of people living with HIV/AIDS. The PLWHA movement has changed, however. People living with HIV/AIDS do not wish to expend all their energy responding to situations. They also want to take a leadership position; they know how important it is for them to be leaders in the response to HIV/AIDS. The challenge for the Conference was, thus, to support PLWHA in developing concrete, lasting, and teachable leadership skills. The Conference Co-organizers made that challenge the principal aim of the only international conference entirely developed by people living with HIV/AIDS for people living with HIV/AIDS.

One should not misunderstand. From the beginning of the pandemic there have been HIV positive leaders, people who have gone beyond every impasse and given themselves intelligently and wholly to serving the needs and interests of other people living with HIV/AIDS, and to working to prevent new infections. But there is a need for many more strong leaders. For this need to be met, existent leaders must have opportunities to transfer their knowledge and skills, to take stock of their responsibilities, and to develop further their own capacities. People new to the PLWHA movement must also be trained and developed.

The theme, “The Dawn of New Positive Leadership”, reflected our shared commitment to use the context given by the Declaration of Commitment of the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS in June 2001 to transform the role of HIV+ people into one of leadership in global, regional, national, and community responses. In addition, we set out to build on our accomplishments and heritage, and to demand of ourselves a new accountability.

Such was the conceptual and goal-driven framework of the Kampala Conference. Within that framework there were more than seventy meetings on the following themes: leadership; treatment care and support; stigma and discrimination; and family, youth and children. In the report that follows we cover the key events of the Conference, and we highlight sessions from each track.

Our principal goal in producing this report is to provide a useful reference resource for those who did not attend the Conference, but are actively involved in the PLWHA movement. To reduce this report to a manageable size, and especially to preserve its usefulness as a capacity-building tool, we did not provide summaries of all the sessions. Instead, we included highlights of those sessions with content and concrete outcomes that could be readily reproduced, and that addressed the most pressing concerns of current and aspiring PLWHA leaders.

We also covered the opening ceremony, events peripheral to the Conference, the closing ceremony, and the Conference declarations. We hope this report will be useful and help deepen or continue the work done in Kampala. We look forward to your feedback on it.

In solidarity,

Stuart A. Flavell and Major Rubaramira Ruranga

Conference Co-Chairs



Background on the International Conferences for People Living with HIV/AIDS

Began in 1987 with the theme “Caring for Ourselves”, the International Conferences for People Living with HIV/AIDS have proven to be effective catalysts for advocacy and empowerment over the years. These successes have led to the inclusion of persons living with HIV/AIDS at high decision-making levels of international health agencies, such as the Programme Coordinating Board (PCB) of UNAIDS, UNAIDS Heads of Government meetings, the Pan American Health Organization’s Directing Council, and the Board of Global Fund. The International Conferences for People Living with HIV/AIDS are the only international events where the agenda is completely set by the global community of people living with HIV/AIDS. Initially a European gathering to highlight the need for mutual support, the Conference for PLWHA has become a principal hothouse for policy thinking among HIV+ leaders.

In 1999, the focus of the Conferences changed. During the 9th International Conference for People Living with HIV/AIDS in Warsaw, over forty HIV+ activists from across the world hammered out a common platform for their movement. They called this policy platform the “Global Advocacy Agenda”. It focuses on three key areas:

1. promoting global access to HIV/AIDS care and treatment;
2. combating stigma and discrimination; and

3. promoting the greater and more meaningful involvement of people living with HIV/AIDS in the decisions that affect their lives and the lives of their communities.

This Global Advocacy Agenda became the foundation of GNP+’s signature program, the International Conferences for People Living with HIV/AIDS, and of the Network’s advocacy efforts in general. It is thus now also the driving force for the programs of the Conferences.

PLWHA activists took concrete action on the Global Advocacy Agenda at the 10th International Conference for People Living with HIV/AIDS, which took place in October in Port of Spain, Trinidad. At that meeting, working groups synthesized a position paper on the Global Fund, called the “Trinidad Challenge”. This document made recommendations on such key issues as governance, funding eligibility criteria, and accountability. It was submitted as part of the NGO and Civil Society Consultation of the Global Fund. GNP+ then went on to participate in the Transitional Working Group, the body set up to establish the Global Fund. This participation translated into the creation of two positions for NGO representatives on the Board of the Global Fund.

Efforts to roll back the HIV pandemic and to increase treatment, care, and support for those already infected would not go far enough without more leadership from PLWHA. But for that to be possible people living with HIV/AIDS needed to develop their leadership skills. Thus a plan emerged for this 11th Conference.

Why Uganda?

Uganda’s successes in lowering its HIV/AIDS prevalence, in advancing toward HIV treatment, and in the inclusion and development of civil society provided a perfect setting to evoke squarely both the urgency and the importance of collaborative work in the African context. Uganda was among the first sub-Saharan countries to experience a full-blown HIV/AIDS epidemic. As early as 1987, HIV/AIDS was viewed as a national threat, and an HIV/AIDS control program was created within the Ministry of Health. In 1989, Uganda adopted a multisectoral approach to responding to HIV/AIDS, with all sectors involved in carrying out prevention campaigns and implementing support and care programs.

Uganda has been a leader in the development of HIV+ leadership. NGEN+ and the National Community of Women Living with HIV/AIDS in Uganda (NACWOLA) have created a highly visible group of HIV+ activists, working at local, national and international levels. Uganda gave the world an HIV+ positive member to the Board of the Global Fund, and an executive director for the International Community of Women Living with HIV/AIDS (ICW). In a continent where people living with HIV/AIDS are not free to talk about their status in their most intimate

relationships, HIV+ people speak publicly about HIV and sit down on a regular basis with government officials. Major Ruranga, for example, runs a weekly radio program on HIV/AIDS in Kampala.

However, the socioeconomic devastation caused by HIV/AIDS is still evident as the Country struggles to sustain itself despite a declining epidemic and the success of a multisectoral response. According to the Ugandan government’s report to UNAIDS:

“Uganda is a country low in resources, still recovering from years of a dictatorial regime and civil war. The total population is 23 million (2002), with about 50% under the age of 15. The Country is classified as a low-resource country, with 87% of the population living in rural areas and an adult literacy rate of 62% (1995). The average fertility rate is 7.1, and life expectancy has dropped to 42 years due to AIDS, which is the leading cause of death. The country has a total external debt of US \$3.4 billion (2001)...”

Thus despite its successes against a high prevalence rate of HIV, the issues of Uganda remain those of sub-Saharan Africa: poverty, strife, exploitation, denial, and a health gap of enormous proportions.

Peripheral Events

By way of supplemental information and background, we have included below a brief description of key thematically-linked events peripheral to the Conference.

PRE-CONFERENCE LEADERSHIP TRAINING

Thirty PLWHA participants were selected to participate in the two-day leadership pre-conference training seminar funded by the United Nations Development Programme. This seminar was designed by Milly Katana, of the Health Rights Action Group, and Julian Hows, Interim Coordinator of ENP+, and led by Jonathan Love. Love is an expert in knowledge management and motivational speaking. The purpose of the seminar was to sensitize participants to the concept of leadership and to teach them to effect it in themselves. The framework and conceptual background for the seminar was based on a business model oriented toward concrete outputs. One such output was a plan for GNP+ to produce a training program and manual for leadership development.

AMICAALL MEETING

A meeting was organized by the Chairman of the Alliance of Mayors and Municipal Leaders on HIV/AIDS in Uganda, John Ssebaana, with representatives of UNAIDS, Major Ruranga, the Ministry of Health, the AIDS Support Organization (TASO), AMICAALL Uganda and other partners. This meeting provided an opportunity to share information on AMICAALL Uganda: progress and

constraints and to elicit feedback from representatives of people living with HIV/AIDS. While progress is being made, it was noted that in many districts, local authorities had not yet internalized the challenges of HIV/AIDS. Stigma is still a big problem and as a result many people living with HIV/AIDS are still not open about their status and do not seek help. It was noted that local authorities are now beginning to take responsibility and should be actively supported. NGEN+ reminded mayors that the theme of the Conference was the "Dawn of New Positive Leadership" and requested mayors to make this a reality in their communities. For more information about AMICAALL, please visit their website at: www.amicaall.org.

HEALTH RIGHTS ACTION GROUP MEETING ON ACCESS

The Health Rights Action Group organized a meeting on October 26th on "Human Rights and Access to Treatment for HIV/AIDS in Uganda". Professor John Rwomushana, of the Uganda AIDS Commission, opened the meeting and spoke on the HIV/AIDS response in Uganda. Other speakers included activists from Uganda, such as George Muwanguzi of the Health Right Action Group, who spoke on the subject of human rights.

The basis for Muwanguzi's speech began with a basic articulation of the source of human rights: Human rights are inherent and not an entitlement granted to human beings as a favor by the State or an individual. He also spoke about the international standards and enforcement mechanisms that exist on human rights, and how Uganda is bound and affected by them.

Muwanguzi argued that, although health care, and therefore HIV/AIDS treatment, is a human right, Uganda has done little to satisfy respect for that right. Indeed, despite the fall in the price of antiretroviral (ARV) medication, the government of Uganda is still not providing ARV treatment to its people who need it. In addition, there are only two advanced testing facilities for HIV/AIDS in Uganda, and they offer their services on commercial terms. For the poor, they are useless. Furthermore, the government has put little in place with regard to infrastructure, policy, legislation and institutional development to respond to the Pandemic. The conclusion one takes from his powerful speech is that Uganda is violating the human rights of its citizen living with HIV by not providing them affordable access to HIV treatment. And given that, according to Muwanguzi, "...in the context of HIV/AIDS observance of human rights must embrace all rights; i.e., civil and political rights, together with economic, social and cultural rights," one can also conclude that Uganda is also violating the rights of its HIV-positive citizens by not providing them with an equitable economic environment, a full-fledged democracy, and so forth.



Posing with the volunteers on one of the few quiet moments.

ACTIVITIES OF THE UNICEF MENA REGION DELEGATES

UNICEF facilitated the attendance of a number of Middle Eastern and North African experts on HIV/AIDS from the medical, NGO, and media sectors.

Dr. George Ionita, Advisor on HIV/AIDS for the UNICEF Middle East and North Africa (MENA) Region, guided the delegates to various sites and specially arranged meetings when going to closed sessions and workshops was not possible. Journalists from Yemen, Iran and Saudi Arabia, for example, also had the opportunity to attend an open media training session provided by Aulora Stally, UNAIDS consultant.

MENA delegates visited the Mulago National Referral Hospital. This hospital implements interventions for the prevention of mother to child transmission of HIV (PMTCT) in an urban setting. During the visit, delegates had the opportunity to speak with a professor about PMTCT and the change in the testing approach used at the Hospital. HIV testing there has gone from voluntary counseling and testing (VCT) to confidential counseling and voluntary testing (CCVT). Delegates learned about the single-dose treatment used to prevent transmission, and problems with patient follow-up.

MENA delegates also visited the Islamic Medical Association of Uganda (IMAU). Delegates discovered the IMAU has 15 branches in 56 districts, 26 of which are Muslim, and that there are 45 Muslim clinics around the country. They were able to meet with Sheikh Bukunya, an Imam who works in the community. The imam led them on a visit of an Islamic school established in 1994 for Muslim children who have been orphaned due to AIDS. The next day, delegates visited the Mildway Center, a care center that offers counseling and psychosocial care and support for PLWHA, including children. According to Dr. Emanuel Luyirika, the Center cares for 6,780 persons, with 2,000 on ARVs. After next touring the UNICEF Uganda offices MENA delegates went on to visit the Naguru Teenage Center, which the Kampala government runs as a model site for integrated youth-friendly health services, including peer-led information and counseling services, condom distribution, recreation, and voluntary HIV counseling and testing.

Finally, MENA delegates gathered for a special workshop on completing an action plan and budget to support the principle of the Greater Involvement of People Living with and Affected by HIV/AIDS (GIPA) in their countries. Delegates agreed to set up networks within their countries and between countries that would include PLWHA, media representatives, NGOs and health professionals. Delegates from Iran, for example, prepared a workplan for activities costing about USD 380,000.

LAUNCHING OF ANERELA+

The African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS was officially launched at the Conference on the 29th. ANERELA+ delegate attendance was made possible with funding from the CORE initiative (project of USAID) and World Vision International. The members of ANERELA+ said they identify very strongly with all people who are living with HIV or AIDS and with the concept of HIV-positive leadership, and that they chose to launch their network during the Conference for these reasons.

The Network already has more than 20 members from seven countries in Africa. Any religious leader, ordained or lay, who is either HIV+ or personally affected by the disease can be a member. ANERELA+ understands by "personally affected" someone who is either nursing or has lost a child, spouse or parent to HIV or AIDS. Plans are to increase membership to represent at least 12 countries.

ANERELA+ calls for all people of every creed living with or affected by HIV/AIDS to be treated with dignity and respect. "ANERELA+ is there to support, without judgment, all religious leaders living with or personally affected by HIV and AIDS. We hope that our presence in Africa will serve to eliminate stigma, discrimination, indifference and silence around HIV and AIDS. We believe that our active involvement in this area will force the faith community

to pull their heads out of the sand and become the loving response we know they need to be," said the Reverend Japé Heath, ANERELA+ Coordinator from South Africa, during his presentation on religion and stigma and discrimination on the 27th.

Reverend Canon Gideon Byamugisha, Chair of ANERELA+ from Uganda, added that he felt that members of ANERELA+ were at an advantage. As religious leaders living with or personally affected by HIV and AIDS, and speaking openly about their HIV status, they can help overcome the stigma, discrimination and many of the taboos around HIV/AIDS.



Children acting out their dreams.

Background on the Program

The conference program was designed to be as interactive and participatory as possible to allow for a wide range of skills-building opportunities. With these goals in mind, the program was structured to include five types of sessions: plenaries, panel discussions, workshops and parallel fora. These last two are worth some commentary.

The workshops are intended specifically for HIV-positive persons and are designed for capacity-building, and to provide a safe environment for presenting issues that, in the opinion of the co-organizers, positive persons would be most comfortable discussing in the exclusive company of other HIV-positive persons. Thus, as with past PLWHA conferences, many of the workshops were open only to HIV-positive persons, with some for women-only and others for men-only.

The Parallel Forum sessions, already featured at the 8th International Conference for People Living with HIV/AIDS in Chang Mai, Thailand, were a strong feature of the Conference. They allow for people who do identify themselves as HIV positive to attend the conference, and they encourage collaboration between PLWHA and representatives of the following groups:

- Faith-based organizations
- Governments
- Private sector (international agencies, drug companies and business)
- Affected community (partners, loved ones, and NGOs, among others)

Stuart Flavell, international coordinator of GNP+, calling for people living with HIV/AIDS to transform themselves and join the PLWHA movement.

Opening Ceremony

The opening ceremony began with a performance of traditional dance and drum music. The audience was led in singing traditional Ugandan songs and the national anthem.

The first speaker was Dorothy Odhiambo, co-founder of the Network of African People Living with HIV/AIDS (NAP+) and Senior HIV/AIDS Partnership Officer at for IFRC in Nairobi, who also served as the master of ceremonies for the Conference. After speaking eloquently and proudly about the progress PLWHA have made since the beginning of the pandemic, she introduced Major Ruranga.

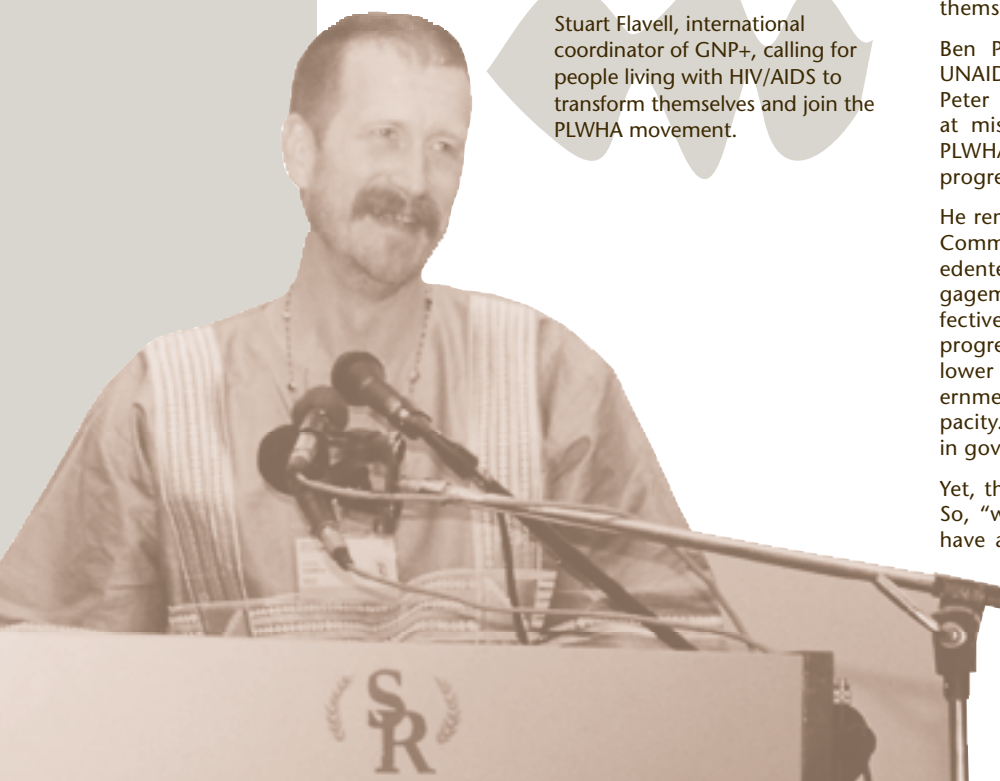
Major Ruranga explained the history of his personal involvement with the International Conferences for People Living with HIV/AIDS and then spoke about the theme of the Conference, emphasizing the legitimacy of PLWHA leadership. "No one understands this disease better than us," he said. He went on to define what he believes are the appropriate conditions and character for positive leadership. He spoke out against tokenism, proclaiming that people living with HIV/AIDS "are not owned". But he warned that PLWHA leadership is not a platform for power.

Next, there was a moving performance of Ugandan children singing about their wishes and dreams for the future. After this inspiring break, Stuart Flavell addressed the audience. He admonished business, governments and institutions for not taking their responsibilities toward the pandemic, but being overly concerned about money. "Proper care is not a budget line but a birth right", he stated passionately. He balanced this message interestingly with a call for people living with HIV/AIDS to transform themselves to become enrolled in the Movement.

Ben Plumley, Chief of the Executive Office of UNAIDS, next took the floor. He first excused Dr. Peter Piot's absence, extending Dr. Piot's regrets at missing his first International Conference for PLWHA. Plumley then went on to describe the progress made in the response to the Pandemic.

He reminded the audience that the Declaration of Commitment and the Global Fund were unprecedented steps forward in obtaining political engagement and financial responses to activate effective programs in the field. He also described the progress made in lowering the prices of ARVs. With lower prices for ARVs we can better pressure governments to scale up and boost manufacturing capacity. He also spoke positively about the increase in government spending for HIV/AIDS.

Yet, there is not enough access to HIV treatment. So, "where do we go from here?", he asked. We have an UN-wide goal: "3 by 5" (project led by the World Health Organization to support scale up of ARV treatment such that three million people will be on medication by





2005). He argued that 3 by 5 will help pool sustained technical and development support. "We also need to build on what we know works", he added, rationally.

Milly Katana next took the floor. Her speech was a personal appeal to the President of Uganda to address, among other things, the continued problems of stigma and discrimination against people living with HIV/AIDS and lack of access to HIV treatment. In her call for her government to take a strong stance against stigma and discrimination, she described some of the ways in which the rights of people living with HIV/AIDS are commonly violated: "people living with HIV/AIDS are denied opportunities for further education on the account that they are sick and therefore will die soon. Many employers quietly screen new recruits, and those they find HIV/AIDS positive are denied employment opportunities." She reminded the President that such acts of discrimination are against the constitution of the Republic of Uganda, and they contravene international human rights. She then called upon the President to take the lead in changing people's attitudes, norms and beliefs about people living with HIV/AIDS.

Katana then addressed the problem of lack of access to HIV treatment in the developing world. She called upon the government of Uganda to take advantage of the provisions of the agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). "In Uganda, we have the Patent Law of 1991, which gives powers to patent holders to determine prices of patented goods including drugs. However, under the same law, the government of Uganda retains the right to declare states of emergency and to issue compulsory licenses where similar products, like patented products, can be manufactured locally or imported from other countries at reduced prices. Your Excellency, despite the fact that two million of your people are living with HIV/AIDS, one million have already perished to AIDS, and over 1.7 million children are orphaned by AIDS, your government has not declared AIDS an emergency...", she admonished.

Katana closed her speech by asking the President to use his new role as Chair of the Inter-Governmental Authority on Development to enroll other heads of state in the Region in scaling up the response to HIV/AIDS. She also called for him to press the connection between HIV and development problems, and for him to fight for a better response to HIV/AIDS on the grounds of this connection.

Dr. Kihumuro Apuuli, the Director General of the Uganda AIDS Commission, then spoke. As if he wished to begin by providing a counterweight to Ben Plumley's speech, he began with this statement: "The world has nothing to congratulate itself." One million people have died of AIDS in Uganda, and more are orphaned due to AIDS. African countries are facing economic collapse. He listed various urgently needed interventions, include the need for more investment and research in microbicides and vaccines. But he, like other speakers, came back to lack of HIV treatment as the

most immediate, pressing issue. He pointed out the vicious inequity that exists between rich and poor countries. He added that partnerships are needed to harness competencies, reiterating Ben Plumley's view of the direction the response to the Pandemic must take. And people living with HIV/AIDS must remain central to the response to HIV/AIDS as it moves forward.

The Minister of Health of Uganda, Jim Muhwezi, next addressed the delegates. He focused mainly on the transitions of the Ugandan response from the beginning of the Pandemic to today, describing it as initially using a medical approach, then a public health approach, and then a multisectoral approach. He extolled the virtues of this collaborative and participatory way of addressing problems, arguing that through continued advocacy, it has given people living with HIV/AIDS the opportunity to be partners. He then went on to describe some of the concrete steps his office would be implementing in the near future, such as increasing HIV-related diagnostic tools available at district health care centers and obtaining financing from the Global Fund.

The president of Uganda, Yoweri Museveni, was the last speaker as he officially opened the Conference. He spoke about the beginning of the epidemic in Uganda, and how Uganda responded to it and succeeded in bringing down prevalence. He described five strategies used. The first one was to sound the alarm and warn the population about HIV. The second strategy was to advise, counsel, and rebuke "reckless" behaviors." In other countries they pander to the mistakes of the population in order to get [political] support", said President Museveni. But not in Uganda, he implied. The third strategy was to give encouragement to those infected: "We told people living with HIV/AIDS there was hope for treatment." The fourth strategy was to ensure the safety of the blood supply and to provide disposable syringes to hospitals. Anti-natal care was also given special attention in order to lower the risk of vertical transmission from mother to child. The fifth strategy was to have high placed people talk about HIV/AIDS. The lack of communication from governments about HIV/AIDS has indeed been one of the strong barriers to an adequate response to the Pandemic.

President Museveni then spoke about his conception of the future of the Ugandan response to the Pandemic. He said that African research needs to be encouraged, and Uganda must develop generic drug manufacturing. Even if it cannot hope to create an export industry, as Brazil has, Uganda can hope to treat its own people for cheaper. Uganda cannot continue to rely on the big pharmaceutical companies. In addition, President Museveni called for more political leadership and government commitment, greater global resources and poverty reduction, and vaccine development. Then, President Museveni opened the Conference, and delegates had the opportunity to enjoy more traditional singing and dancing.

Session Highlights

POSITIVE LEADERSHIP

“Strategies to combat the disease only have succeeded when PLWHAs took the lead”, said Kofi Annan, United Nations Secretary General, in a special video-recorded message shown at the opening of the first plenary of the Conference. This comment captured the essence of the logic behind the Conference and serves as a perfect lead in to this section.

A NEW PARADIGM OF HIV-POSITIVE LEADERSHIP

In her plenary speech on the first day, Milly Katana articulated a new paradigm for HIV-positive leadership. She defined leadership as “an act of courage that moves a community out of a current difficulty to an anticipated difficulty.” According to Katana, each and every person living with HIV/AIDS must be willing to take such risks. But to bring about that willingness, there must be a transformation at the level of each person.

Katana argued that personal transformation requires new beliefs, new partnerships, and new relationships. In particular, new ways of sustaining partnerships must be developed, if we are to ensure large scale up of sustainable treatment, care and support. New ways of thinking and acting require that the individual identify what is at stake and what the challenges are within his or her community. It also requires that he or she map out a plan for a desirable future. PLWHA should not rely on others. They must make the efforts themselves.

Katana urged participants to reexamine the history of the PLWHA movement and to build on its legacy. She referred participants to the Denver Principles. These were first pronounced publicly by a small group of PLWHA at a health conference in Denver in 1983. They call for the respect,

non-discrimination, involvement and empowerment of PLWHA. They gave structure to PLWHA activism and became the reference point for the PLWHA movement (Please see appendix for the Denver Principles).

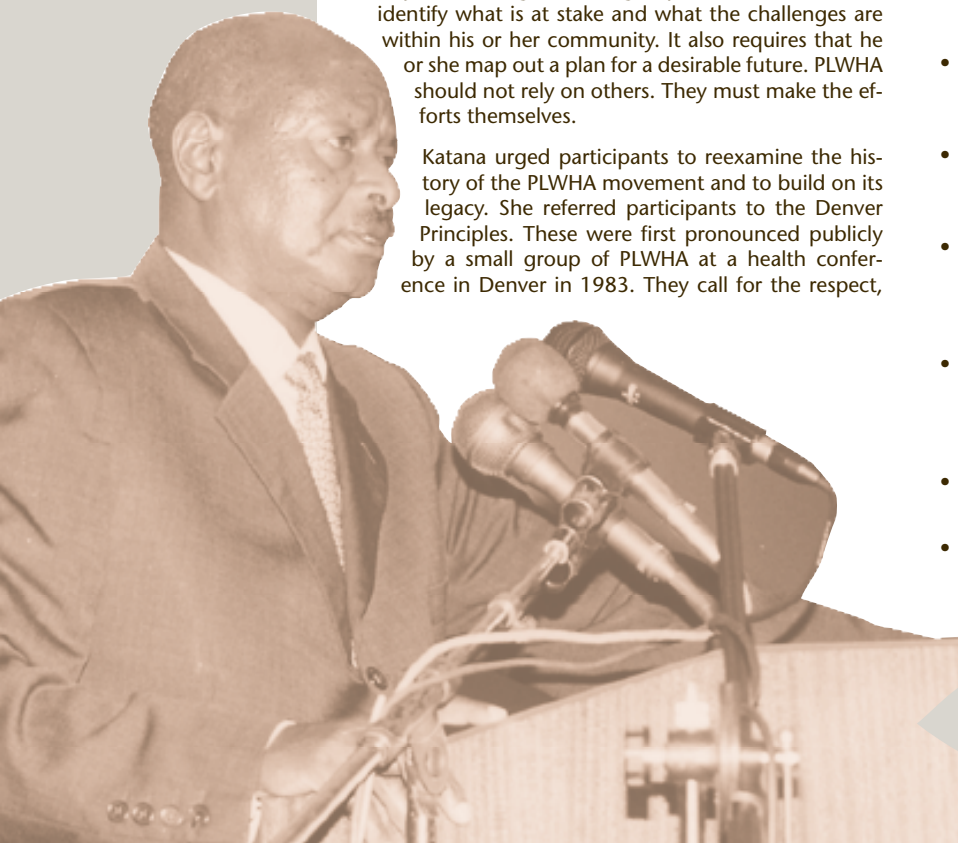
Katana declared that PLWHA are ready to take on the necessary personal transformation. They understand the needs and beliefs of their immediate community, as well as those of the broader communities. They are able to design strategies that take the key issues into account, and they can assert themselves as true leaders.

ASPECTS OF LEADERSHIP

There are other types of leadership relevant to PLWHA. If one accepts that the best way to respond to HIV/AIDS is to do so as a united front, then strategic, organizational leadership becomes of capital importance for PLWHA. According to Helene Badini, of NAP+ and Yawo Gouna, GNP+ Board member for Africa, who gave a presentation, the effective, strategic, organizational leader is:

- Courageous and prepared to take risks and make difficult decisions and sacrifices, including on a personal level.
- Avoids useless controversy.
- Trustworthy and has moral integrity, including with regard to finances and transparency.
- Charismatic and able to inspire, motivate, influence, reassure, and guide others.
- Imbued with good common sense and is able to foresee consequences.
- Thinks creatively, in general, but also in meeting the needs and interests of constituents.
- Able and willing to engage others in team work and share in a common vision.
- Supportive of the mission and goals of the organization, and actively pursues goals in relation to these.
- Able and willing to share leadership with others, and permits all members of the organization to reach their full potential.
- Able and willing to share information, and creates an environment that generates confidence, and facilitates communication and mutual respect for individual ideas and contributions.
- Able and willing to facilitate positive relationships between staff members at all levels, and forges relations that ensure a continuous engagement toward common goals.
- Able to have a global vision and does not concentrate only on immediate problems.
- Able to position the organization to bring about effective advocacy, in a way that favors implementation of the GIPA Principle and the improvement of the quality of life of people living with HIV/AIDS.

President Museveni addressing the audience at the opening ceremony.



- Attached to having diversity—with regard to women, youth, ethnic groups, and sexual orientation.
- A good manager of relations with partners and makes maximum use of partnerships.
- Able to mobilize and manage resources; and collaborates with funders while understanding the greater environment that dictates the levels of performance and responsibility donors require.
- A consensus builder who reconciles expectations with political and financial constraints.

TALKING TO GOVERNMENTS THAT DON'T LISTEN

If one is trying to change things at the government level and one is dealing with a government that turns a deaf ear to its constituents, all of one's best intentions for advocacy can fall flat. In the opening plenary session, Sunil Pant, of the Blue Diamond Society, an organization in Kathmandu that fights for the rights of Men who have Sex with Men (MSM), discussed problems of dealing with complacent governments. According to Pant, it may not be enough to fight for the visibility of issues or better access to information; it depends on the context. Sometimes one needs to advocate for changes at the legal or legislative level.

According to Pant, governments in Southern Asia still find it difficult to sit at the same table with sex workers, injection drug users, MSM and other members of marginalized communities, and letting them have an equal 'say' and 'vote'. Furthermore, according to Pant, we talk about a multi-sectoral response to HIV but ministries and policies in place still work against each other. In countries like Nepal and India, health ministries acknowledge the need to work with marginalized communities and allocate funding and technical support for that work to be accomplished, and ministries of justice, which have a more powerful and decisive profile, criminalize sex work, MSM or drug use.

Pant then went on to describe an example in India in which the offices of two organizations working on issues related to the sexual health of MSM were raided and their workers jailed in 2001. This incident and continued harassment have happened despite the fact that national and state AIDS agencies are well-acquainted with the programs, and that they prioritize the need to work with the MSM community. The National AIDS Control Organization has gone so far as to issue a written statement to the effect that working on MSM issues is a priority. All to no avail.

According to Pant, there is an urgent need to work collectively towards framing anti-discrimination legislation to combat the above attitudes and discrimination. Indeed, "homosexual" behavior remains illegal in India. Recognition of the need for changing things at the legal level in Nepal has led to the formation of the Anti-Discrimination Legislation Advocacy Group (ADAG). ADAG is to lobby and draft anti-discrimination legislation for Nepal.

PUBLIC SPEAKING AS A POSITIVE PERSON

In the large two-part workshop she led, Susan Paxton, of APN+ addressed issues around the lack of visibility of PLWHA and public discussions around the experience of being HIV-positive. She also covered how these create barriers to PLWHA leadership, activism and advocacy. The impact of efforts to change social attitudes and influence decision-makers, for example, cannot be anything but weak if the efforts are anonymous or mediated via the intervention of others. In addition, the lack of visibility of PLWHA impedes HIV prevention efforts. It is important that everyone view himself or herself as vulnerable to HIV infection. One of the key ways for that to happen is if the distance between those with and without the virus is reduced. For that to be the case people need to see people living with HIV/AIDS face-to-face to confront the fact that they are just like them, and that it is incorrect to think that only certain types of people become infected with HIV.

Another barrier to PLWHA leadership is the social stigma that people living with HIV/AIDS confront. Speaking it out in public about one's experience of living with HIV can help to break down the discrimination and prejudice against HIV-positive people. This can happen, in part by showing that people living with HIV can lead positive and productive lives for many years.

In response to these issues and the need to support and help guide PLWHA who decide to speak out publicly and give a face to HIV, APN+ produced a manual and a training module for leading workshops. They are called, respectively, "Lifting the Burden of Secrecy, a Manual for HIV-Positive People Who Want to Speak Out in Public", and "Lifting the Burden of Secrecy, a Training Module for HIV-Positive Speakers". The manual and training module are based on interviews with 76 HIV-positive speakers from Asia, the Pacific, Australia and Africa.

We will not cover the contents of the manual and training module here as it is available for free through APN+ and on-line via the GNP+ website. However, it may be useful to know that the documents cover a broad range of issues: from how to do public education without going public to one's family and local community, and when to seek the support of a counselor, to how to find out about one's rights. The manual gives key tips on: telling one's story, structuring a talk, soliciting questions, dealing with emotions, preparing to give a talk (voice exercises), dealing with the media, participating in an interview, and avoiding burnout, among other topics.

POSITIVE WOMEN'S LEADERSHIP

Some groups of people living with HIV/AIDS face special problems in taking leadership in the PLWHA movement. One such group is women. There were several presentations at the Conference on how to increase and improve the leadership of women living with HIV/AIDS. Here we focus one from Latin America, a second from South Africa, and another from Central African Republic, but as we shall see much of what was learned from the presenters applies to positive women everywhere.

Violeta Ross, of the Bolivian Network of People Living with HIV/AIDS, argued in her presentation entitled, "Increasing and Improving Leadership of Women Living with HIV/AIDS in Latin America", that gender roles are responsible in large part for the lack of positive women leaders in HIV/AIDS advocacy. In Latin America, these roles are taught and learned, and they determine in large part the character of women. There is a strong "Marianist" influence in Latin America, which is promoted by the Catholic Church. The term refers to an idea of the woman as embodied by the Virgin Mary. The woman who does not fit this ideal is placed at another socially constructed extreme, that embodied by the "prostitute".

There are other factors that play a role in denying HIV-positive women leadership in advocacy. These are the fact that political roles are delineated for men and that even those women who would like to take on more leadership-oriented roles simply cannot do so because they must sustain their households. The daily concern of poor women is "what can I get to eat today?" This economic situation means that many women lack access to education and thus lack the skills to assume leadership roles.

What can women living with HIV/AIDS do to become leaders? Ross interviewed a woman leader on her experience and presented the results of her interview during the session she led. This woman leader said that what drove her to take on a leadership role is that she saw some of the male leaders were not acting courageously. She decided to fill that leadership gap. She argued that, practically speaking, the best context in which a woman can exercise her leadership is in a full and crowded space in which everything is functioning and there is no doubt that she will be able to participate in that space. In other words, no man will be able to make her feel small and insignificant, causing her to become silent. The social pressure becomes too great for him to take the liberty to act oppressively. Ross's interviewee also declared that women must not serve just to legitimize discourse by their mere presence.

Women will at times have access to power but their participation will be contingent on the needs of her allies. Women's leadership has its conditions. A key element of success in the experience of the above leader was having many male leaders who supported her. It is also important to have the support of other women.

Ross argued that it is very important for women to be more visible and succeed in no longer being ignored. It is not easy.

Women need to work hard. A big challenge for the visibility of HIV-positive women to become leaders is that around a woman there are series of persons affected by what she says and does. This is especially true for women with children.

Women's leadership must not be sporadic or interventionist but planned out in the long term, and women must work collaboratively and closer to the communities in which women are not leaders. They must learn from previous successes of women's movements. What applies to groups in general also applies to women's groups, there need to be evaluation systems established to see if actions are being realized and if goals are being met, and women's groups need to rely on technical assistance. Finally, women need to demand to have their capacity built.

But as Johana Satekge argued in her presentation on the work of the Positive Women's Network for Women Living with HIV/AIDS in South Africa (PWN), concrete supportive activities need to be undertaken to facilitate skills building in resource poor countries. Women need information on nutrition, elementary counseling, peer support, basic education and ability to ply a trade. They need support to help them talk and negotiate abstinence, faithfulness and condom use. Because of their limited social power women have very little room to express and act on their wishes to protect themselves and others. HIV/AIDS prevention messages do not tend to help as they do not target HIV+ women and female-focused prevention tools, like female condoms, are not emphasized.

In addition, logistical conditions for working to empower women are very weak in poor areas. Many villages in South Africa do not have electricity. Newspapers, the internet, telephones, and radios are often not available.

Patricia Outiama, of the Network of People Living with HIV/AIDS in Central African Republic, presented the work of a program called, "The National Congress of Young HIV+ Women" (Congres national des jeunes femmes VIH+). She pointed out that the prevalence in CAR, in 2002 was 14%. Young people are more affected than adults and young women between the ages of 15 and 35 are five times more vulnerable than young men. Thus it is crucial to focus on young women, and especially, to help them build solidarity among themselves. She presented. The objectives of this young women's group is to: mobilize and sensitize young positive women; create a link of solidarity with them; support them in living positively; ensure that they receive psychosocial care in their communities; and sensitize pregnant women about early testing and vertical transmission of HIV.

The Group has established satellites organizations in districts and this has gone along with specialized training of those women in charge of the satellites. The group also does door-to-door sensitization and in churches. One of their other activities is prevention counseling. A key activity is giving a face to HIV and speaking out in public about being HIV+.

The results obtained are impressive. The group has created 16 satellite groups in the districts of Bangui, the main city in CAR. Fifty-six members have been trained. There have been 200 sensitization sessions accomplished in one year with 350.000 persons impacted. In addition there is one counseling session every week for pregnant women.



Treatment activists in Uganda during the Health Rights Action Group Access meeting.

DEVELOPING AND SUSTAINING CARE AND SUPPORT GROUPS

Pauline Mouton, of the Association of Active and United Women (Association des Femmes Actives et Solidaires, AFASO), described how she helped start a new women's support group. The title of her presentation was "Women who have lost their husbands confronting HIV/AIDS in Cameroon". Women from AFASO who had lost their husbands felt they needed support group to discuss their unique experiences and challenges. So, they decided to try to find other women like them who would be interested in forming a support group.

The women of AFASO went to hospitals to find other women who had lost their husbands and introduced them to the support group concept. Twenty-five women accepted to constitute a support group. Through group discussion they decided to center their activities around HIV/AIDS, access to ARVs, and problem solving on family and work difficulties.

The Project has met with considerable success. The women's support group has had twelve meetings addressing such topics as discrimination within the family, pressure to remarry, the desire to have children, and difficulties in registering children in school. There have also been two discussions for the express purpose of holding discussions with children orphaned due to HIV/AIDS.

According to Mouton, experience shows that organizing women who have lost their husbands is a worthwhile and useful endeavor, and that it should be encouraged. Cultures that strongly emphasize marriage and that define a woman's identity in terms of marriage often isolate or exclude women who have lost their husbands. In such cultures, it is difficult for "widowed" women to receive the consideration or care they deserve. Matters are made even more difficult when community members know AIDS was the reason for a woman's loss and that she, perhaps, is also HIV-positive. Support groups can help women confront the challenges of tradition, stigma, and discrimination, and break the silence on HIV/AIDS. Support groups can also help improve the quality of life of women who have lost their husbands by helping them better respond to life challenges.

THE GLOBAL FUND: NEW HOPE, NEW BUREAUCRACY AND THE ROLE OF PLWHA

The Global Fund to Fight Tuberculosis and Malaria and especially the Country Coordinating Mechanisms (CCMs) process were topics in several sessions in the Leadership track, including one session which served to introduce the Global Fund and two closed sessions for Global Fund Secretariat staff, CCM members and consultants.

The Global Fund had contracted GNP+ to conduct a 13 country study (in Asia, Africa, Eastern Europe and Latin America) to gain information on the participation of people living with HIV/AIDS in CCMs to get a clear understanding of the role of PLWHA in CCMs and in the national response to HIV/AIDS, to examine the working relationship among PLWHA and other

stakeholders, to look at the challenges of the various actors involved, and to make recommendations to effect positive change with reference to the role of PLWHA in the CCMs.

We have combined below the general results of the presentations Kate Thomson, Civil Society Relations Manager at the Global Fund, Augustine Chella, of NAP+, and Rodrigo Pascal, Global Fund alternate Board member representing the infected and affected communities.

According to those interviewed:

- Up until November 2002 only 5% of the CCMs included PLWHA in the decision-making process.
- CCMs make themselves inaccessible and may refuse to discuss politically uncomfortable topics like MSM and IDU.
- There is more representation from the government sector and very little civil society representation.
- There is token participation of people living with HIV, who have a seat but no vote.
- People living with HIV/AIDS and NGOs are not sufficiently included in CCM processes.
- There is not enough communication.
- There is insufficient training at the CCM level for PLWHA members to do their work.
- People living with HIV/AIDS do not always have the opportunity to participate in proposal preparation or to assume implementing roles.
- There was an attempt to use non-formal selection criteria that left out community representatives.

What can be done to enhance meaningful participation?

- Build the capacity of networks of people living with the diseases through technical assistance and other forms of support.
- In the large countries, create sub-national CCMs or working groups to facilitate wider representation of members from all parts of the country.
- Do ongoing evaluation of CCMs to enhance understanding of what facilitates and what impedes meaningful participation.
- A system could be created to enable sharing examples of good practice across CCMs.
- High-level political commitment should be echoed throughout all levels of government.
- Honest dialogue and relationships based on trust between all stakeholders need to be fostered.



Asian delegates smiling during a break from the work and hub-bub.

- Put in place guiding principles in an effort to provide a CCM evaluation and monitoring framework at different phases of the process, i.e., at pre-approval and implementation phases.
- Global Fund proposals should be sent twice to respective CCMs, but if there is still no response, then they should be sent directly to the Global Fund with all the supporting evidence.

INJECTION DRUG USE (IDU) AND HIV: STRATEGIES FOR SURVIVAL

Rajiv Kafle, founder of Nava Kiran Plus and Act-Up Kathmandu, and Steve Garrett, Executive Director of Planet Poz in New Mexico, USA, facilitated a workshop on IDU. There was a working group of more than thirty people from different parts of the world and backgrounds. Rajiv and Steve led the discussion with a brief introduction of themselves. Then they collected stories from other participants in the room. Participants compared ideas on harm reduction efforts—what has worked and what has not worked. They also discussed challenges for doing harm reduction, including the problem that governments refuse to help injection drug users.

Participants concluded that a more global response to injection drug use and HIV is needed. If the spread of HIV throughout the world is to be curbed, injection drug users must make themselves heard. This can only be accomplished through extensive communication between the people on the streets doing the field work and those creating policy at the government level. All major organizations need to help build the bridges necessary for this dialogue to take place.

At the end of the session Steve promised to create a database of fields workers living with AIDS who are or have been injection drug users. The purpose of the database is to communicate and compare notes on the problems existing in the regions in which the different fields works live, in the hope of replicating the strong programs that exist. To read about more about the outcomes of the workshop please see the attached declaration (see Annex).

CODE OF PRACTICE: SUPPORTING EFFECTIVE NGOS IN HIV WORK

The first part of this workshop on the IFRC-led NGO HIV/AIDS Code of Practice was an overview of the purpose and current status of the Project, and of the opportunities for involvement. The aim of the Code is to develop a guide to help ensure that lessons learned guide allocation of resources and development of new programs and services in the HIV/AIDS work of NGOs.

The second part of the session was devoted to structured small group discussions. To guide the discussion session Julia Cabassi, Project Manager of the Code project, who facilitated this workshop, handed out a fact sheet that gave examples of the kinds of standards the Code would outline in each of key areas: prevention, access to treatment, care and support, preventing stigma and discrimination, impact mitigation and scaling up. Julia asked groups to choose to discuss one or two of

these topics. A second fact sheet provided an overview of the process, suggested approaches for discussion and sought views on the consultation phase.

Below is a summary of the key issues raised in the workshop discussions.

Input from participants on the guiding principles of the Code was highly positive. They expressed strong support for the idea that human rights principles should provide the overarching framework for the Code. However, they warned that it important to recognize the constraints of living up to those principles in contexts where government support for human rights is weak or unsupported. The Code and its use would need to be consistent with an approach that emphasizes progressive realization of human rights protections in such contexts.

Participants provided some input on the key areas for developing standards of work. In the area of prevention, there was some concern expressed that vague standards would be too open to interpretation. The trouble is that greater specificity makes global application difficult. With regard to treatment, care and support, participants supported suggestions for standards on testing and treatment advocacy; Participants agreed that the Code would provide an important check list for PLWHA to use in treatment advocacy. In addition, they pointed out that standards would need to place strong emphasis on treatment access. According to the group discussions on the area of discrimination, standards developed for the Code need to help NGOs develop and implement workplace policies to prevent discrimination and to scale up GIPA within their own organizations.

Participants agreed the Code could play an important role in promoting standards for services and programs. Participants also felt the Code had potential as a lobbying tool for PLWHA groups to utilize in their negotiations and partnerships with international NGOs, NGOs in country and governments. For example, in relation to the Global Fund, some felt the Code could be utilized by PLWHA in advocating for a role or improved involvement in their CCM. Some participants worried, however, about whether the Code could be used by international NGOs to control smaller NGOs. Many felt that the real value of the Code was in its bringing together, in an accessible form, a range of standards to which they already adhered and worked toward, and that the Code could be adapted for regional and in-country use.

Participants made several comments about the difficulties of PLWHA to access and participate in NGOs. They felt that as a result of these difficulties, it would be important for the Code to articulate GIPA clearly, and for it to help build the capacity of PLWHA to support their effective involvement in the work of NGOs. Some argued that this lack of accessibility is connected to there being a pressing need for greater accountability of NGOs.

Participants also expressed concerns about the lack of clarity regarding the audience for the Code. They argued that it would not be feasible or appropriate to seek to develop a Code which tries

to speak to such a broad audience, NGOs, CBOs, FBOs and PLWHA organizations at international, regional, in-country and local levels. The time frame also was an issue, given the scope of the project. Twelve months, they argued, was not enough to do all the work.

Participants also gave their views on the process for developing the Code. They placed strong emphasis on making sure it is not a top down process. There need to be effective consultations in the development of Code, and they should include particularly vulnerable groups such as sex workers, men who have sex with men, and injection drug users. They also called for including a capacity building approach into the process so that NGOs are then able to use the Code within their organizations and externally as an advocacy tool.

Participants also argued that the Project would need an implementation strategy to build stronger commitment to and use of the Code in-country. There were strong views expressed about how implementation will flow from signing on to the Code. Indeed, what follows from agreeing to follow the Code and upholding its standards?

According to Julia Cabassi, to address the concerns participants expressed, the project will focus on international NGOs in the first stage of the project, through to October of 2004. They will focus on the development of a Code directed towards engaging international NGOs in the development of the Code with the aim of encouraging international NGOs to become signatories to the Code, thereby agreeing to hold themselves accountable against the principles and standards outlined in the Code.

National NGOs, PLWHA organizations and global NGO networks will be involved, through the Steering Committee, on commenting on the draft Code as it applies to international NGOs. This will provide opportunities to explore the interest in, and feasibility of, in-country adaptations of the Code as a possible second stage of the Project. This approach would not preclude national NGOs from becoming signatories to the Code in the first stage if they wished. Information about the project and opportunities to participate are available on the Federation's website www.ifrc.org.

STIGMA AND DISCRIMINATION

WORLD AIDS CAMPAIGN: FIGHTING STIGMA AND DISCRIMINATION

Andy Seale, UNAIDS Advocacy Officer, facilitated a session on the World AIDS Campaign, as part of the parallel forum segment of the Conference.

Seale began by discussing the vicious cycle that people living with HIV/AIDS face that progresses from prejudice, through stigma and discrimination, to denial of human rights. Andy identified four entry points for breaking the cycle, focus-

ing on the one that specifically concerns the UNAIDS initiative: highlighting the harm that stigma and discrimination cause the individual. Andy also drew attention to the constraints of broad educational and informational programs, particularly the difficulty in dealing with specifics.

Seale then solicited input from participants on the role PLWHA played in the context of the 2003 campaign. This opened the door for bringing into the open feelings of frustration at levels of perceived tokenism in the involvement of PLWHA in planning campaigns at a national level.

Perhaps the problem of tokenism can be addressed by shifting the emphasis of the Campaign towards civil society. This is one of the proposals from UNAIDS on the future of the World AIDS Campaign. Participants at the session were receptive to the idea of strengthening the role of civil society in the World AIDS Campaign and appreciated the opportunity it would offer to increase pressure on both the United Nations system and national governments. Indeed, given what we learned at the Conference about PLWHA advocacy and activism, by letting the community have more of a say in the structure and content of the the World AIDS Campaign it may be possible for the World AIDS Campaign to take shape as an advocacy tool. It remains to be seen whether this can be done without losing the Campaign's overall educational value, however.

Participants shared their national and local plans for World AIDS Day 2004 and the World AIDS Campaign. It is initiatives at the national and community levels, shaped by broad principles such as those promoted by UNAIDS, that appear to offer the best solution. Delegates confirmed this view by sharing details of local initiatives. Participants from Namibia presented impressive plans for giving HIV-positive persons a voice through the media and public appearances. Also impressive was the plan from Mali for month-long national events organized around the UNAIDS theme. Additional examples from Kenya demonstrated that at ground level at least, various actions were bringing about empowerment of people living with HIV/AIDS. Indeed, several of the examples reinforced the overall message of positive leadership.

At the end of this parallel forum session there was an opportunity to get feedback on the idea of launching a program in 2004 that would focus on asking people to make a personal pledge to stop AIDS. The pledge idea was well received by participants. Some suggested linking the pledge to existing similar initiatives running at national levels. Many made useful suggestions about the best wording for the pledge. Of the options proposed, participants preferred the pledge: "Stopping AIDS is my responsibility."

Milly Katana denouncing her government's failure to declare HIV/AIDS a public health emergency.



RELIGION, CULTURE, STIGMA AND DISCRIMINATION

Faith-Based Stigma and Discrimination

In his presentation, Harry Walsh, a PLWHA expert on the socio-cultural impact of Catholicism, argued that through extensive grassroots level penetration of communities religion has been used and distorted, from a position of ignorance, to reinforce or justify stigma, and to create conditions of inequality and exclusion that can aid destructive and oppressive power to flourish. As a result, the silence, denial, and shame around sexual relations and HIV infection were reinforced, making it more difficult to do HIV-prevention work and to care and treat the infected. Thus, ultimately, faith-based stigma and discrimination have contributed to increasing HIV spread rather than curbing it.

According to Walsh, discrimination against HIV+ people or those assumed to be is a violation of fundamental human rights. Not only does it, obviously, violate the right to be free from discrimination, but it also violates virtually every other human right, such as the right to health-care, freedom of movement, education, employment, or freedom from inhumane or degrading treatment. The denial of rights is realized through rejection, victimization, isolation, and despair of HIV positive individuals, sometimes to point of violence, murder or suicide.

Walsh called for putting in place a new framework of thought in which faith-based communities are essential players. The model must be based on love, mercy, solidarity and compassion. Faith-based communities and organizations are called to proclaim the value, dignity and rights of each individual, to protect and defend the vulnerable, and to renew society through community mobilization, dispelling fear, destroying ignorance and breaking the silence. This new framework calls for the involvement of HIV+ leadership—all in the creation of a more just, more accepting, and more loving society that confronts HIV with all its capacity.

Foundation MAMIO Names Project

Ethel Pengel showed how one organization can take up concrete actions to counteract the effects of HIV/AIDS-related stigma and discrimination. She presented the work of the Foundation MAMIO Names Project (Stichting MAMIO Namen Projekt), founded in August 1990. According to Pengel, in Suriname doctors and health care workers do not provide good care to HIV/AIDS patients. Some of them are even unwilling to treat them at all, because they fear becoming infected as a result of treating patients. The socio-cultural context, in general, also presents serious challenges.

In Suriname, there are at least ten different ethnic groups, and that creates all sorts of cultural and linguistic barriers to caring for people living with HIV/AIDS and doing HIV prevention work. For examples, in some communities people do not speak about sex, and women are highly disempowered. And in all communities gay relationships are not tolerated.

SMNP takes up a number of different peer-based activities to counteract the effects of HIV/AIDS-related stigma and discrimination. SMNP sends HIV-positive counselors to hospitals to give care and support to patients, thus helping with the logistics of obtaining medical care and of living with HIV. SMNP also takes an active role in sourcing funding for medicine for those who cannot afford it.

INTERNALIZED STIGMA

No approach to fight HIV/AIDS-related stigma can hope to be successful unless it also targets internalized stigma. Anuar Luna, Executive Director of the Mexican Network of People Living with HIV/AIDS, facilitated a workshop that explored the concept of internalized stigma, and how to address it.

Luna asked participants to describe the meaning of "internalized stigma". They defined it as the feelings of fear (about stating their status and the probable negative reactions of others), shame and culpability they have as a result of living with HIV/AIDS. Participants also explored how these feelings affect their abilities to lead normal lives.

Workshop participants also explored the causes and consequences of internalized stigma. According to participants, the following lead to internalized stigma: stigma and discrimination from others; self-imposed fear and moral judgment; and the feeling of bearing a taint. They defined stigma and discrimination from others as part of a complex, diverse, dynamic, and collective social process that produces and reproduces hierarchy and power relations, social exclusion, and transforms difference into inequity. The feeling of bearing a taint is related to the fact that HIV/AIDS, like other stigmatized diseases, has the characteristics of being incurable, contagious, disfiguring, and it is associated with stigmatized behavior. According to participants, different people will experience internalized stigma depending on their sexuality, gender, economic and racial or ethnic background.

Internalized stigma leads people to isolate themselves, and to allow denial of services and rights. It results in further feelings of shame, isolation and culpability.

The workshop then explored the different ways in which PLWHA, partners and friends, and HIV/AIDS programs can combat internalized stigma. According to participants, HIV/AIDS programs, for example, can work to identify the incidents and categories of stigma: when it arises, which groups or individuals are targeted, how the stigma is being attributed, and how the stigmatizing response is initiated and developed.

Workshop participants also developed a list of stigmatizing metaphors and similes to be avoided. These are: HIV/AIDS equals death; HIV/AIDS is punishment (for moral behavior); HIV/AIDS is a crime (with victims and innocents); HIV/AIDS is synonymous with war (a virus against which we must fight, i.e., persons we must fight); HIV/AIDS is a horror (perceiving persons with HIV as fright-

ening); HIV/AIDS is something alien; HIV/AIDS is shameful; and HIV/AIDS is synonymous with ignominity (in relation often to the behavior of MSM).

MILITANT MEDIA

One way for PLWHA to eliminate stigmatizing metaphors and similes is to initiate change in the way information and news about HIV/AIDS are communicated. In her presentation, Janice Dayle, Board member of GNP+NA, discussed how to infiltrate mainstream media, how to create and use alternative media, and how to become aware of effective communication strategies for changing how people perceive and respond to HIV/AIDS.

Dayle asked participants how they conceive of stigma, and its relationship to discrimination. Then Dayle argued, and participants agreed, that stigma is in part cultivated and perpetuated through irresponsible media. The media perpetuate ignorance and misinformation, and these are at the roots of stigma and discrimination. It is possible to change the way the media address HIV/AIDS. According to Dayle, mainstream media reach a large audience, and so the wise thing for PLWHA is to get noticed within mainstream media. The problem is that, as workshop participants indicated, mainstream media tend to align themselves with the ideas and ideals of governments and big business, given the fact that the media sector is itself "big business".

If infiltrating the mainstream media proves too difficult, one solution to obtaining public attention on HIV/AIDS in a constructive and non-stigmatizing way is to generate alternative sources of news and information, through newsletters, university or community radio, novels, film, entertainment journals, community newspapers, or cable television, among other means. Janice offered some tips on making a good newsletter: use catchy and varied topics and headlines, provide interesting and necessary information, treat a newsletter as a way to facilitate organizational transparency, provide lots of contact information, and publish an events page with a (pull out) calendar outlining upcoming activities.

Another way to fight the negativity around PLWHA and HIV/AIDS in the media is to set up "watchdog" committees that can comb through daily news looking for discriminatory or stigmatizing language. The types of negative phrases to look out for are labels like: AIDS victim, AIDS sufferer, AIDS patient, or innocent AIDS victim (in reference to persons who contracted HIV through non-drug use related or sexual means).

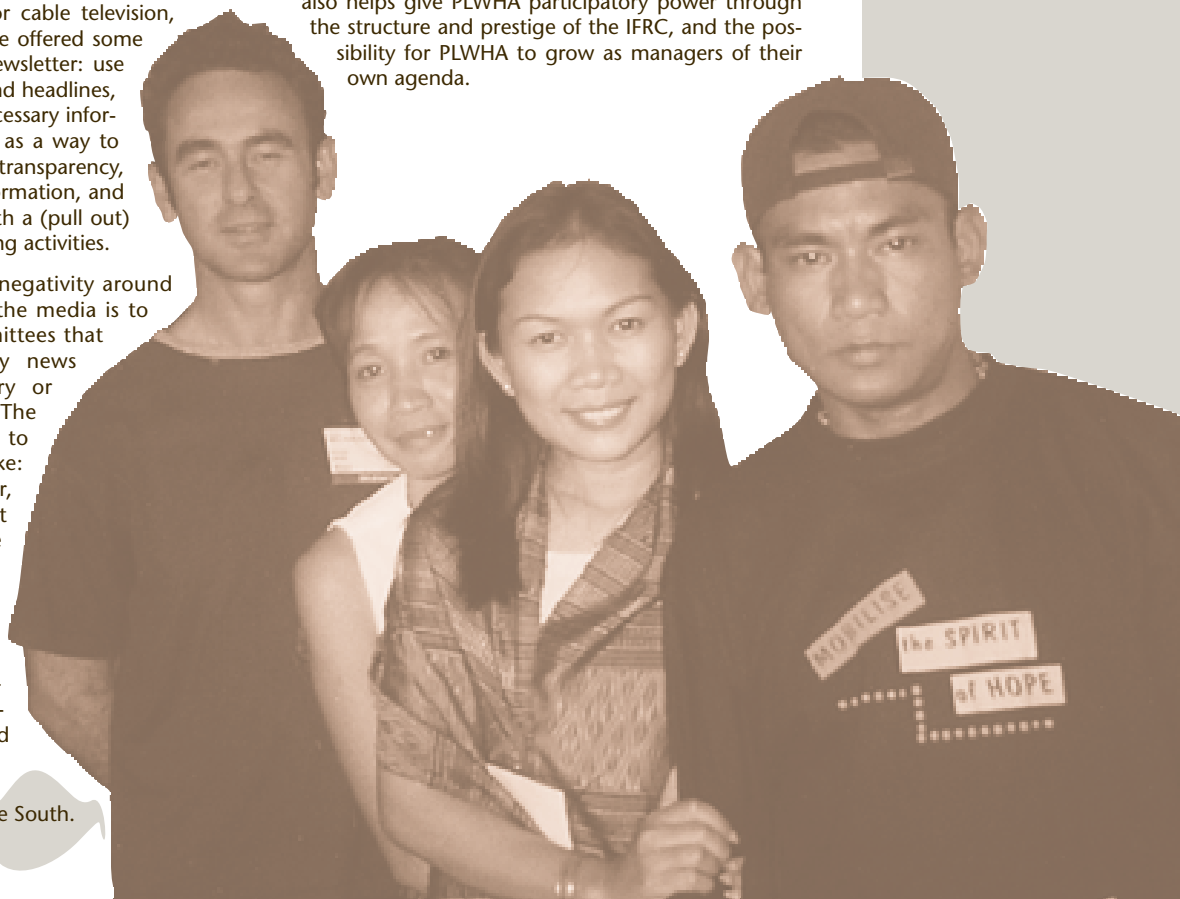
Organizations and individuals can also send rebuttals to journals, send

commentary pieces, write letters to editors, publish press releases, invite journalists to interview PLWHA, and/or hold press conferences around issues. Possible press conference topics can include announcing the loss or gain of organizational funding, completion of a project (in a way that displays achievements), the opening of new facilities, or the launching of a new journal or program.

THE GNP+ AND IFRC PARTNERSHIP: UPDATE AND THE WAY FORWARD

This session reviewed the history, current status and future of the partnership between the IFRC and GNP+ which, begun with the support and encouragement of UNAIDS, was formally launched at the UNGASS on HIV/AIDS in 2001. The partnership has resulted, for example, in joint missions to encourage concrete cooperation, such as creating self-support groups and cooperation between National Societies and PLWHA groups. One such recent mission was to the Sudan, where as result a new national association for Sudanese people living with HIV and AIDS was formed in cooperation with the Sudanese Red Crescent Society.

The twinning of the two key international organizations builds on their strengths to accelerate the global response to HIV/AIDS, but it also helps fills gaps and address problems. HIV positive persons involved in the work of the IFRC who were attending the session expressed that the partnership helps formally identify people with HIV/AIDS as vulnerable communities in need of assistance, but in a way that does not turn them into victims. This is the case in part because the Partnership facilitates the engagement of HIV positive people in staff and volunteer posts. It also helps give PLWHA participatory power through the structure and prestige of the IFRC, and the possibility for PLWHA to grow as managers of their own agenda.



East meets West - in the South.

Dorothy Odhiambo told participants that the partnership has added value to the networks of people living with HIV/AIDS in many East African countries. She argued that critical opportunities have been opened that would otherwise not be there, and that a partnership like this can guide future leaders among the positive community.

For the IFRC, the expertise of people living with HIV/AIDS helps reduce stigma and discrimination in the daily work of the IFRC, be it in-house or outside; Some 200,000 staff and volunteers of the IFRC all over the world are living with HIV. It also helps the IFRC tailor its HIV/AIDS work more strategically and efficiently. This is the case, in part, because the partnership helps tie National Societies to the communities in which they work.

Julian Hows told conference participants he hopes the International Federation's engagement in the Partnership will be a sound, lasting one—that it will not be a case of people with HIV/AIDS being the “flavor of the month” or that the Federation is not working with PLWHA just until it finds other less “tiresome” and more “grateful victims” with whom to collaborate. Nevertheless, he felt the partnership was showing great promise. “It has created new resources for many of our regional organizations. It has changed the lives of many individual persons living with HIV and AIDS. The partnership has also sensitized many within the Federation to issues faced by those living with HIV/AIDS,” he said. The result, he stated was that people with HIV have become part of the Federation's activities as partners, not ‘patients’.

TREATMENT, CARE, AND SUPPORT

PLWHA IN PREVENTION STRATEGIES

According to Chama Musoka, of the Kara Counselling and Training Trust in Zambia, PLWHA are the key partners in preventing the spread of the epidemic. Musoka presented the work of his organization, and gave an overview of the situation in Zambia. Sixteen percent of Zambians are thought to be infected, but under ten percent of the population has been tested. One of the main reasons for the lack of people who know their HIV status relates to stigma. Stigma remains the principal barrier to effective HIV prevention.

Disclosure and sharing information and experiences with HIV help put a face on HIV. They also help people realize that everyone is vulnerable to HIV infection. These results help fight HIV/AIDS-related stigma, as we saw from Susan Paxton's presentation, which in turn helps prevent further spread of HIV. But in order to have the catalyzing activities of disclosure and sharing, it is important to support the involvement of PLWHA in local support groups.

However, supporting the involvement of PLWHA should not be just letting them be “extra volunteers”, Musoka warned. PLWHA should be involved in all levels of decision-making within an organization, and they should receive training

and support to build personal and organizational capacity. The way forward for prevention programs is to target and involve PLWHA.

Prevention programs must not be narrow in scope, Musoka added. They must address age and gender issues, human rights, poverty, and unequal access to treatment and healthcare, as socio-economic factors impact on prevention programs. This means that HIV must be linked to human rights. The fight for socio-economic equality needs to be integrated into all HIV/AIDS programs, including those focusing on prevention.

ADVOCATING FOR HIV-POSITIVE WOMEN'S RIGHTS TO REPRODUCTIVE HEALTH CARE IN UKRAINE

Natalya Leonchuck began her presentation with a review of the epidemiological situation in the Ukraine. The most salient features of this part of her presentation concerned the fact that the Ukraine has one of the fastest growing HIV/AIDS epidemics in the world, and about 65-80% of the cases of HIV transmission are via injection drug use.

She presented the work of the All Ukrainian Network of People Living with HIV/AIDS, the mission of which is to improve the quality of life of PLWA in Ukraine. One of the key activities of the Group since its inception four years ago, has been advocating for antiretroviral treatment for 4,000 PLWHA.

One of the key goals of the Group is to improve the policies and remove the operational policy barriers to improve access to quality reproductive health services for HIV-positive women in the Ukraine. In this effort the Group takes a human rights approach, in part by collecting data on the problems HIV positive women face accessing reproductive health (especially maternal health services), reviewing laws and comparing them to international human rights treaties and reviewing and initiating policy dialogue and advocacy.

One of the projects taken up involved doing research on the access of positive women to reproductive health services. Forty HIV+ women and fifteen health care providers were interviewed in three oblasts with low, medium and high prevalence, respectively. Preliminary findings shows serious problems: testing is often neither voluntary or provided with counseling; some women were pressured to abort, confidentiality of HIV status is often not maintained; both health care providers and PLWHA lack knowledge of rights; and there is stigma and discrimination.

According to initial recommendations, standards are needed to ensure women have the right to reproductive decision making, and to ensure they have access to information and informed consent. Ukrainian law on when terminating pregnancy must be reviewed. Confidentiality must be ensured. Health care providers need training in pre- and post-test counselling. PLWHA need training to better understand their rights, and there must be continued work to increase PLWHA participation in policy development and decision-making.



The research results were reviewed for the development of the national PMTCT program and for accomplishment of a targeted legal review that would focus on issues around reproductive choice, such as family planning, access to information to make an informed choice, access to “appropriate” health-care services, acceptability of services, and sexual rights. Further recommendations and actions included developing dialogue and advocacy on reproductive health policy that includes PLWHA, decision makers, and other key stakeholders.

ETHICAL IMPLICATIONS OF PROGRAMS FOR THE PREVENTION OF MOTHER TO CHILD TRANSMISSION OF HIV (PMTCT)

Jennifer Bushee, Communications Coordinator for GNP+, and Promise Mthembu, Global Advocacy Officer for ICW, led a large two-part workshop on the ethical implications of PMTCT programs. The purpose of the workshop was to create an international working group of positive women to develop a guiding document on ethical issues related to PMTCT programs. The first half of the workshop covered the core components of PMTCT programs and the ethical problems related to them. The second half was given to participants to compare and contrast their experiences with the ethical problems initially discussed. They were also asked to develop suggestions for how to address the ethical problems that affect PMTCT and to delineate what they thought would be key interventions for which ICW and GNP+ should advocate in relation to PMTCT.

The content of the first half of the workshop was based on a discussion paper distributed before the session. Bushee presented some core facts around transmission of HIV from mother to child. She stated that transmission of mother to child can occur when the fetus is developing in the womb, during birth, and after birth through breastfeeding. In 2002 alone, two million women and 800,000 children became infected with HIV, and over 90% of all infected children acquire HIV vertically from their mothers. On average 15% of babies breastfed for two years acquire HIV through breast milk, and a substantial amount of postpartum transmission occurs in the first six months of infancy.

Bushee then went on to describe what are considered the core components of PMTCT programs: voluntary and confidential counseling and testing, modified/substituted infant feeding, administration of antiretroviral drugs, and obstetric care. She then reviewed some of the key ethical issues related to PMTCT program.

The ethical issues discussed were as follows:

- The moral obligation for women to participate in PMTCT programs should be balanced against the social and health burdens women must bear to participate in such programs. It is the responsibility of PMTCT program designers to create programs that minimize the burdens to participating mothers as much as possible.
- By not providing sustained HIV treatment to enrolled HIV positive women, PMTCT programs are valuing the lives of babies over the lives of their mothers, thus violating principles of justice.
- By not providing sustained HIV treatment to enrolled HIV positive women, PMTCT programs are contributing to the deterioration of family and community that ensues when children are orphaned. In 2002 the number of children orphaned because of AIDS was 13 million, and according to UNICEF by 2010 it will be 25 million.
- By not providing sustained HIV treatment to enrolled HIV positive women, PMTCT programs violate principles of equal distribution of social goods, in this case health care.
- By not providing sustained HIV treatment to enrolled HIV positive women PMTCT programs are reaffirming the reductionistic view of women as baby machines. The problem matters in part because of the challenge the lower social position of women presents for HIV prevention.

Mthembu asked participants to review the above ethical issues and to list some additional ones they could think of after comparing and contrasting what they heard with their experiences with PMTCT.

According to participants’ experiences with PMTCT: the time allotted for women to accept their traumatic situation is too short; choices available are not sufficiently explained to mothers; there is strong stigma around not breastfeeding; there is a lack of understanding in the home as hus-

MENA delegates listening to the plenary speakers.



bands do not always know the status of the mother; there is not enough money to purchase ARVs; and there is considerable emotional satisfaction from giving birth.

In addition, they considered the following to be key ethical issues:

- By not providing sustained HIV treatment to enrolled HIV positive women, PMTCT programs risk further burdening the health of mothers by making them resistant to ARVs due to temporary exposure to the medication.
- Health care systems do not promote or facilitate family planning. Women therefore lack choice in reproduction; and there is no encouragement to help women address social and familial pressures to have children.

These were the interventions suggested:

- Encourage pregnant women to be tested for HIV during antenatal period
- HIV testing to be done at clinics for sexually transmitted infections (STIs)
- Make femidoms available
- Continued prevention, care and ARV treatment for both mother and child after birth
- ICW to circulate current information/updates on women's issues
- Enhance ongoing counselling for pre and post natal mothers
- Monitor and evaluate VCCT and PMTCT
- Put in place mentorship programs with PMTCT
- Build capacity among women living with HIV/AIDS for counseling others within the maternity sector
- Policies should accommodate implications with disclosure to partners
- Advocate for women's protection within households and communities
- Better access to good quality caesarean section
- Develop a multisectoral approach for PMTCT

MICROBICIDES AND HIV+ WOMEN AND MEN

Promise Mthembu and Bobby Ramakant, rapporteur from Health and Development Networks, were co-facilitators. Mthembu said that although microbicides still do not exist over-the-counter, there are many promising candidate products in the research pipeline. Microbicides are substances that can substantially reduce transmission of sexually transmitted infections including HIV when applied in the vagina and rectum.

For the HIV positive woman, Mthembu argued microbicides hold immense promise. She can to reclaim her right to sexual pleasure while practicing safer sex. Microbicides can reduce the risk of re-infection with other HIV strains and enable a woman to protect her male partners. Microbicides can also substantially reduce the risk of other STIs including

yeast and bladder infections. And above all, they could increase the chance of conceiving and delivering with HIV-negative babies.

There was a discussion about why big pharmaceutical companies are keeping away from research and development of microbicides. Because of perceived low profitability, liability concerns, lack of in-house expertise and an uncertain regulatory environment, microbicides research is currently being funded by private foundations and university research grants apart from other small sources. For the last 20 years funding for contraceptive related research and development has come from government and private foundations (and not big pharmaceuticals).

Regional and international bodies need to invest more in microbicides research and development. We need more government and political commitment and resources. Increased public and PLWHA's meaningful participation in research and development of microbicides is also important to ensure compliance with ethical requirements.

Mthembu further argued that in addition to advocating for microbicides we need to take the opportunity to improve the discussion on sex-related matters for men and women. We also need to advocate for existing female-initiated methods, like the female condom, and we need to lobby for more allocation of funding to accelerate microbicides research and development.

Participants argued that PLWHA need to contribute to ethical debates around microbicides clinical trials. Mthembu agreed and expressed that we need to work hard to mainstream microbicides in the broader treatment advocacy agenda. PLWHA can also play a key role in keeping a check on ethical compliance in microbicides trials. Responding to a question about when microbicides would be available, Mthembu said that it depends upon raising sufficient investment and political will to accelerate research and development. Unfortunately, it could still take up to four years to get them in the market.

THE APN+ BUYERS' CLUB: MOBILIZING TO SAVE OUR LEADERSHIP

Greg Gray, Coordinator of APN+, gave a plenary speech on the Buyer's Club of APN+. China, India and Indonesia all produce generic medications yet the availability of these is still reaching less than four percent of those who need it. Greg pointed out that Asia is home to two thirds of the population on the planet with some of the richest countries in the region and also some of the poorest. In Thailand, the National Network of People Living with HIV/AIDS, TNP, in partnership with Médecins Sans Frontières, Belgium, took matters into their own hands. They have put into place a cooperative buyers' club.



Gray then explained how the buyers' club works. The Club is fully managed and operated by PLWHA. It serves to purchase and distribute essential medications for HIV/AIDS. It resells the medication at a low price that includes a five percent surcharge to cover administration costs. In addition, it provides a small fund to assist those who may run into financial difficulties.

The key to the success of the Project even if it is only relatively small scale in view of the demand in the Country is its ability to function efficiently, transparently, and effectively. Also important is having strong PLWHA groups with a solid background and knowledge on HIV that can educate and raise awareness on treatment literacy, including on compliance and adherence. It is also important that they have the capacity to work in meaningful partnerships with the health care sector, policy makers and NGOs.

TREATMENT ACTIVISM AND ADVOCACY: UNDERSTANDING WHAT IT IS

According to the delegate from Latvia (who preferred to remain anonymous), who gave this presentation, one first needs to understand the concept of activism if one is to be a leader in treatment activism and advocacy. Activism is making positive change through increased knowledge and understanding, a raised level of communication and power to argue and fight, and a heightened self-confidence and awareness. Activism means investing hard work and time toward interesting, creative, and timely approaches.

The delegate from Latvia then defined the following as the key elements and actions involved in doing activism and advocacy for treatment education and access:

First, one needs to be aware of who the stakeholders are. There are a host of potential stakeholders, beyond PLWHA and AIDS service organizations. These include health care providers, scientists, pharmaceutical companies, journalists, human rights advocates, state AIDS commissions, and political leaders, among others.

Second, in order to work effectively PLWHA must have access to information. Having the right kind of reliable information is crucial. It is important to be informed about the disease at all levels. Information can be obtained from a variety of sources, not just from printed material and doctors. Other sources are peers conferences, the internet, and treatment advocacy groups. Before using some information, it is important, first, to determine its credibility.

One can educate others in a variety of contexts: in a group; at the in/out patient hospital, and at a drop-in centre. It can be done countrywide, regionally, and internationally. Peer education can be done around clinical trials to inform trial participants, and medical personnel, for example. Discussions about informed decisions, adherence, and effective therapy are key.

Third, treatment advocacy can be done for all sorts of issues, not only for access to affordable medication. One can advocate for the best standard of care, clinical trial monitoring, development of treatment guidelines, more PLWHA representation, and so forth.

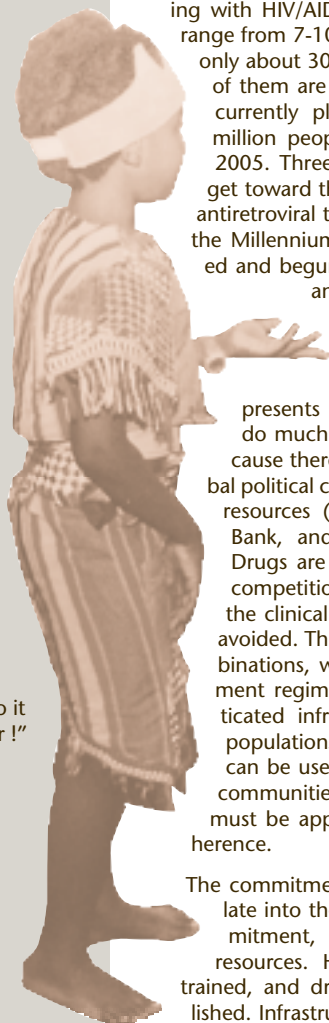
Treatment advocacy can be done to target a number of different entities. These include governments, courts, pharmaceutical companies, and the media.

Fourth, when advocating for a cause it is important to tailor one's language to the audience. For example, when addressing government officials advocates should emphasize that studies show it is cheaper to treat than not to treat! When addressing pharmaceutical companies, the most important element upon which to focus is their capacity to make profit.

Fifth, treatment advocacy can be done through a variety of means. Public actions, printed materials, media presence, internet presence, staffed e-mail services, hotlines, films, theatre and watchdog activities are all viable means of conversing with, educating, and influencing an audience.

North American activists during a session.





"Let's do it together!"

THREE MILLION BY 2005! WORKING WITH WHO TO KEEP A PROMISE

Ian Grubb, Policy Adviser for the Department of HIV/AIDS of the World Health Organization, gave a presentation on the plan to scale up access to antiretroviral therapy worldwide and have three million people on antiretroviral therapy (ART) by 2005. The "3 by 5" session was attended by over 200 people. Alongside there were individual meetings held with regional and national delegations.

Ian explained the roots of the "3 by 5" target. He appealed to the Declaration of Commitment on HIV/AIDS, which sets the conditions for the plan. He also spoke of the renewed political commitment and need for financial resources, USD 10 billion for prevention and care, trained personnel, drug supplies and other commodities, infrastructure, and communities needed to implement the Declaration of Commitment.

The target also comes from the fact that the need for a treatment scale-up is tremendous and urgent. There are six million people in need of ARVs. The WHO 3 by 5 plan aims to treat 50% of them by 2005. This amounts to approximately 7% of all people living with HIV/AIDS, and estimates of those in need range from 7-10% of all PWHA. There are currently, only about 300,000 people on treatment and half of them are in Brazil. If we only implement the currently planned programs, fewer than one million people will receive ART by the end of 2005. Three million by 2005 is an interim target toward the overall goal of universal access to antiretroviral therapy. He reminded participants of the Millennium Development Goal to "have halted and begun to reverse the spread of HIV/AIDS and other major infectious diseases by 2015."

Grubbs's presentation emphasized that the need for ART presents both a crisis and an opportunity to do much more. The opportunity is there because there is currently an unprecedented global political commitment, and there are increased resources (from the Global Fund, the World Bank, and the United States government). Drugs are now cheaper, and there is generic competition. He added that it is important that the clinical mistakes made in rich countries be avoided. There must be standardized drug combinations, with fixed doses. This enables treatment regimens to be followed without sophisticated infrastructure and by treatment-naïve populations. Indeed, he further argued, ART can be used to strengthen health systems and communities. He warned, however, that there must be appropriate support for long term adherence.

The commitment and involvement required translate into the need to consolidate political commitment, and quickly mobilize additional resources. Health care providers need to be trained, and drug supply systems must be established. Infrastructure needs to be built or adapted. Communities must participate, and results need to be measured and lessons learned quickly applied.

The contribution from the WHO includes:

- Emergency response teams in countries to help ministries of health organize themselves. Governments need help and capacity building to implement ARV programs.
- Improving AIDS drugs and diagnostic facilities.
- Helping simplify ARV regimens.
- Providing monitoring and evaluation tools for tracking progress.
- Emergency expansion of training.
- Building community capacity for treatment education and support, especially to help ensure adherence to medication.
- Setting up an international "3 by 5" advisory group with NGO and PLWHA participation.

How did participants react? They showed strong support of 3 by 5, but felt they needed to be told more about how it would be implemented at country level. Those involved with the WHO also wanted to understand better the implications 3 by 5 would have for the work of the WHO country missions.

Participants were particularly interested in knowing how they could use 3 by 5 to do advocacy. For instance, it was suggested that '3 by 5' targets could be used to pressure governments to do more. To do this advocacy work, however, and to be involved in 3 by 5 more generally, community organizations and PLWHA groups would need to have their capacity built. Many are still working as small groups of volunteers with limited resources, and require financial and technical support.

On the basis of the discussions at the Conference here are some of the recommendations made to involve PLWHA groups and treatment advocates more effectively: Establish a Community Advisory Committee at WHO headquarters and regional offices; establish a community-based advocacy and capacity building grants fund; promote models of community-based care, support, and community participation in operational research and program evaluation; and engaging in further building of links between WHO member states and civil society groups working toward the '3 by 5' target.

FAMILY, YOUTH, AND CHILDREN

HIV YOUTH: A CALL FOR INCLUSION OF OUR NEW GENERATION

In the plenary on the first day of the Conference, Raul Fransen, of AIDS Fonds and Young Positive (Netherlands), asked crucial questions often asked about youth involvement in the HIV/AIDS response: "Youth are the future: but where are the youth? Where are the many strategies and interventions that concern the support of young people infected with HIV?" Part of what people get wrong in try-

ing to answer these questions is that there is no such thing as “youth”. We generally define them as under 30, but young people do not make a neat category. Differences in gender, class, skills, education, cut across this swath of population. What unites youth are common interests and goals that revolve around building and shaping one’s life. Indeed, as such, young people face difficult decisions, including employment choices and the exploration of personal sexualities. When these mesh with HIV-positive status the implications are enormous.

The involvement of young people in the HIV/AIDS response can bring improvement of the effectiveness of an intervention, program or project. It can also help adapt these to specific needs, followed by more effective outreach. Furthermore, involvement of young people can help empowerment them. The skills obtained in return for this empowerment can benefit an organization. In addition, a new generation can freshen an agenda.

“We cannot just expect the new generation to come forward and start participating,” he warned. Young people need to be offered something before they will come forward and become involved. To work with young people, we must make sure that young people are given the opportunity to formulate their own opinions, that they feel they are being taken seriously and that there is a sense of equality between generations. Young people also need to be involved in making significant decisions, and they need to be able to contribute at all levels, from activism to policy and advocacy. According to Fransen, “real participation doesn’t only take place at the level of implementation, but also at the level of determining the route to follow and the destination at which to arrive.” If young people are not involved in all these steps of the process, there is a real risk that strategies developed will be “about” young people rather than “of” young people.

At the same time, Fransen argued, youth have limitations that need to be recognized. For example, professionals do generally have more of a certain type of information and skill, and most young people will not have much money. And young people do not stay young forever! Therefore, there is a need for a good system of training and knowledge management to ensure continuation of activities.

He closed his speech with a passionate call for new and strong leaders. “Lack of leadership kills people with HIV and that is unacceptable. The new generation has to take on this responsibility...We all have a role to play in shaping our future, let’s all work together to make it a good one.”

GIVING A VOICE TO ORPHANS AND CHILDREN AFFECTED BY HIV/AIDS IN MALI

Modibo Kane, Coordinator of the Association for People Living with HIV/AIDS in Mali (AMAS/AFAS) and President of NAP+, began with an introduction about the epidemic in Mali. He stated that predictions are that unless the epidemic is controlled in his country, by 2010

there will be about 500,000 HIV-positive persons. This will result in a six-year drop in life expectancy and about 150,000 orphans.

The organization AMAS/AFAS was often being called upon to address children’s cases. Due to infection or death of parents because of HIV/AIDS, children confront problems at home, at school, or with their peers. So the Organization decided to start a discussion group for orphans and children affected by HIV/AIDS. The goal of the discussion group is to allow children 10 to 18 years old to better understand and address HIV/AIDS as it relates to the illness or death of their parents. It also seeks to give them information on HIV/AIDS, create space for discussion of problems and solutions, and to give them skills to care for sick parents.

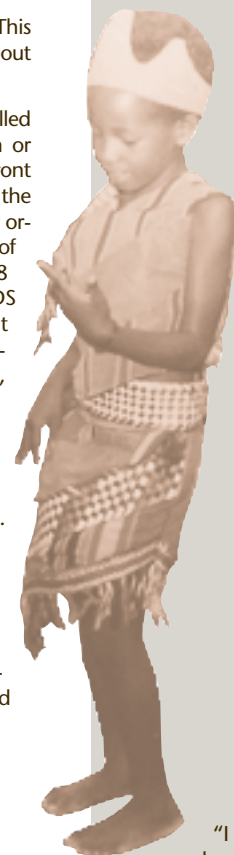
The group of about 30 children meets every first Sunday of the month at the organization’s headquarters. Activities include training on HIV/AIDS and group discussions of a child’s concern. As a result of the program, some children have gone on to become peer educators at school. The children also worry less about their parents. The goals for the group are to decentralize the satellite groups, obtain representation at the Children’s parliament, improve training for adolescents and young boys, increase access to ARVs, and put young PLWHA at the center of the response.

UNICEF HELPING CHILDREN RAISE THEIR VOICES

On October 29th the Conference held an entire day of workshops that focused on young children, adolescents and young adults. That day’s UNICEF-led sessions brought together over 60 young participants, all of whom were living with HIV/AIDS. Some had lost one or even both parents to HIV. This was the first time that HIV positive children have ever been invited to be delegates at an international HIV/AIDS Conference. The goal was that the children would gain, through discussion, exposure to new ideas and support from other participants, confidence building, and development of new skills. They would be able to go on to live positively, lead more aware lives, and contribute to improving the response to HIV/AIDS in their communities. The program’s ultimate, specific goals were to teach children about:

1. committing policymakers on issues regarding rights, services and meaningful participation;
2. developing skills for advocacy, communication, assertiveness, negotiation, and leadership;
3. appreciating positive living and the greater involvement of people living with HIV/AIDS and accessing services;
4. appreciating the need for children to develop a consciousness of the opportunities within their reach.

The facilitators created a multifaceted program built on a high level of interactive activity among the children, to maintain interest and enthusiasm while helping the children open up and share comfortably about their experiences, wishes, dreams and concerns. Split into groups, children prepared presen-



“I have at least two things I can do for you !”

tations that ranged from testimonials and declarations to debates and examples of peer motivation. Creative facilitation methods were used, including visualization, debate, drama, poetry writing, and problem solving exercises.

The children often expressed themselves without a sign of hesitation or fear, talking as if used to public speaking. Beginning with the common words "I want to talk about," the children discussed their concerns about human rights, the right to schooling, the right to health care services, and the right to privacy. They also discussed issues around women and children, death, sex and sexuality, and antiretroviral therapy. The children presented their issues simply yet clearly, and with a healthy portion of humor, sending a clear message to communities and leaders that they know their rights, and they expect these to be respected.

Children shared their dreams, in the form of drawings, notes and letters. These dreams were presented as a symbol of trust, for safekeeping, and in the hope not only that they would be heard, but that action would be taken to help them come true. The program closed with an assurance from the UNICEF country representative in Uganda, Martin Mogwanja, that all that was expressed would be communicated to world leaders, the UN system, policy makers, and community workers to ensure that delegates' concerns are taken into account in future plans.

He concluded by thanking "the children for sharing their dreams, hopes, fears, pain and, specifically, their views". "This has been the most important thing that has happened in the Conference," he added.



Major Ruranga, founder and director of NGEN+, smiling for the camera.

Closing Ceremony

Different speakers highlighted the outcomes of each of the tracks, and then presented the declarations. Prudence Mabele, of the Positive Women's Network in South Africa, and James Kamau, of the Kenya Treatment Access Movement, for example, read the main Conference Declaration. The children who participated in the special UNICEF-sponsored sessions read their wishes for the future and gave a special performance. The Declarations from the Conference are included below.

DECLARATIONS

CONFERENCE DECLARATION

This declaration of the 11th International Conference of People Living with HIV/AIDS was made in Kampala Uganda on the 30th of October 2003.

The declaration represents the collective voice of the international community of women, men, children and young people living with HIV/AIDS.

This conference is the largest ever international gathering of people with HIV, from all regions of the world, over 80 countries and more than 300 organizations representing the diversity and strength of people living with HIV/AIDS around the world.

The Conference has succeeded in bringing together the largest ever gathering of Africans living with HIV/AIDS.

The Conference is held in Uganda to express solidarity with the efforts of the Ugandan government and its people in the fight against HIV/AIDS.

The aim of the Conference is to consolidate leadership of people living with HIV/AIDS and to support the new leaders who will take our struggle forward.

Since the early days of the epidemic people living with HIV/AIDS have worked courageously, tirelessly, and often at great cost to support each other, and as active partners in prevention, care and support. We as a global community call on our governments, the international community working in HIV, faith based organizations, private sector and all stakeholders, to listen and act on the voice of people living with HIV/AIDS as expressed at this conference.

WE NOTE WITH CONCERN THAT:

Six million people need HIV treatment immediately

Access to affordable HIV treatments remains beyond the reach of the vast majority of people with HIV/AIDS who need it urgently

International statements and commitments (e.g. GIPA 1994, Abuja 2001, UNGASS 2001) to increasing our involvement and leadership in the global response have not been translated into meaningful involvement



Stigma and discrimination remain the outstanding barriers to an effective response to the global epidemics. This is particularly evident in the provision of appropriate health services and in the workplace

HIV/AIDS continues to disproportionately affect vulnerable and marginalized communities and sectors of society including sex workers, married women, injecting drug users, men who have sex with men and migrant workers

Women continue to bear the multiple burdens of providing care and support, lack of access to information and services, disproportionate stigma and emotional, economic, legal, sexual and physical abuse

The response is failing to ensure the safety and security of the millions orphaned by the epidemics

Young people lack the information, tools services and support necessary to empower and protect them against HIV

Our communities and organizations are still starved of the resources they need to effectively fulfill their potential and perform the role that is being demanded of us

WE DEMAND THAT

The international community and our governments take all necessary steps to immediately and urgently ensure the following:

That donor countries contribute 10 Billion dollars annually to fight HIV/AIDS in poor countries and fully fund the Global Fund

That all governments and international agencies immediately collaborate with us to ensure the rapid expansion of access to ARV in line with the WHO goal of 3 million people in less economically developed countries by 2005

That the World Trade Organization declarations regarding patent rights be as flexible as possible and that our governments take full advantage of them to import and export affordable generic treatment and ensure maximum coverage

That we are supported in our efforts to building capacity to effectively contribute as equal partners in the response

That people living with HIV/AIDS are meaningfully included in all national and international HIV/AIDS policy making bodies and structures, including the Global Fund, Country Co-ordinating Mechanisms and national AIDS programs, and that the Global Fund be more aggressive in seeking donations from rich countries

That community delegations have full voting rights on the Global FundBoard

WE MAKE THESE DEMANDS

In the knowledge that the epidemics of HIV are devastating our communities, families and societies, our survival and the wellbeing of millions of people are at stake. We as people living with HIV/AIDS are pledged to continue the fight, we are essential to the solution and it is only through solidarity with us that the tide of the epidemic can be turned.

WOMEN'S DECLARATION TO ALL WORLD LEADERS

- Governments
- Businesses
- The United Nations
- Pharmaceutical companies
- Religious groups and
- Civil society organizations

AIDS is killing the world's workers and leaders-women, men and our children.

Commitment statements are not enough.

Take up your responsibilities as leaders.

Now is the time for global united action.

Our demands are affordable & must be resourced. We are ready—you just need to act.

We women of the world want human rights upheld.

TREATMENT FOR ALL NOW

This declaration was issued by many of the women of the attending the 11th international conference of HIV positive people, Kampala, Uganda, October 2003. For more information about how HIV affects women and girls worldwide, visit www.icw.org.

STATEMENT FROM THE INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS (ICW)

The 11th International Conference of People Living with HIV and AIDS taking place in Kampala is a first in many ways. Our conferences have never seen such democratic representation from any country, have never seen so many women, have never seen so many young people – and have never seen such a gulf between those of us on antiretrovirals (ARVs) and those of us without them.

Uganda, in preparation for this conference, developed a process of regional democratic elections, whereby each district of the country is represented by one HIV positive man, one HIV positive woman and one HIV positive young person. Uganda, with its progressive constitution, its high involvement of women in government, its commitment to the convention on the rights of the child and its regional youth parliaments, puts many Western countries to shame.

As a result of this exemplary process, this conference has seen a higher representation of women and young people than ever before—and so has truly moved forward in involving women, younger people and children in all sessions, both as participants and as facilitators. Today's memorable plenary was chaired by a 10 year old Ugandan young woman, Sophie, who is already a force to be reckoned with.

It is most commendable that the conference organizing committee took such great care to involve so many new faces and this has been very warmly received by all conference participants. At the same

time, this high proportion of newer participants has highlighted the key areas for attention at our next positive people's conference.

Many participants have felt that sessions could have been more useful if they had addressed more basic issues. Others have felt that sessions needed to grapple with highly complex issues which are perhaps more the terrain of longer-term activists. We would like to propose that some consideration be given to parallel tracks again, as in the Warsaw conference, so that the needs of all participants be more effectively addressed through separate parallel tracks.

Secondly, and most importantly, the reality of the divide between OECD and non-OECD countries is reflected in the high numbers of participants who have attended the on-site health centre. The centre has received a constant stream of participants who are from countries where ARVs are not yet available, whilst those participants on ARVs are marked by their absence from the centre. Some participants have had to be admitted to hospital, others have had to fly home. The joy of joining with eight hundred positive people from all continents of the world continues to be marred by the deep political stalemate which renders so many of our sisters and brothers sick.

As we come to the end of this conference, the International Community of Women Living with HIV/AIDS (ICW) would like to thank GNP+, NGEN and all the other contributors for their enormous efforts in making this wonderful event on the shores of Lake Victoria happen. Ugandan hospitality is world-renowned and the efforts of the Ugandan Red Cross volunteers especially were quite wonderful.

As ICW members we have very much enjoyed our involvement at this conference and feel more united than ever in our commitment to global activism.

Thank you Uganda.

La lucha continua.

DECLARATION FROM REDLA+

We are thankful to the Organizing Commission, the Major Rurunga President of this Conference, to all the volunteers of the Red Cross and of course to Milly Katana.

Within the framework of 11th International Conference of People Living with HIV/AIDS, carried out between the days 26 and 30 of October, in the city of Kampala, Uganda, activists met, of whom 60 are leaders of the Network of Latin American People Living with HIV/AIDS, and expose:

That according to all the delegates of the different countries from the African continent in the different exhibitions and roundtables in which they participated, we see with much impotence the situation that affects them with respect to the lack of antiretroviral treatment, analysis, education, feeding, discrimination and

lack of public policies on health, and that people living with the virus undergo constant, permanent violations of their human rights.

This situation repeats itself in each encounter, and we do not see advances in any of the commitments assumed in the sessions of the countries members of UNGASS. We realize that the inequity continues. It is not the same to be infected in Europe or North America, than to be a person living with the Virus in Africa, Latin America, the Caribbean, or Asia. This is reflected in the high levels of mortality that take place in these continents, and this situation is the product of the non-access to antiretroviral treatment, testing, feeding, education and adequate housing.

On the basis of the above declares:

- A) It is not possible and permissible to continue maintaining the theory of the lack of economic resources to implement national and international policies that cover what is lacking, as described above.
- B) Directing more funds must be the top priority to create and to fortify public policies directed to promote and to guarantee the provision of antiretroviral medication of high quality and effectiveness, integrated health, specific studies, modified breast-feeding, prophylactic medication, and everything that directly and indirectly can improve the quality of life of all the people living with the HIV.

By way of conclusion from this 11th Conference, the Latin American Network of People Living with HIV/AIDS is motivated to pursue its demands and mobilization activities, supporting all PLWHA of Africa and the world. We feel the necessity to express our demands so that developed countries direct more funds to save lives and step out of "politicking".

This fight is not negotiable and we will persist in the fulfillment of our reclamations until reaching our goals.

The slogan of this year is "The Dawn of a New Positive Leadership". For that reason, we call all world leaders to multiply information, to mobilize and to build awareness in all communities so that forceful actions are generated, which answer to our necessities with force. In the conviction that we are saving and fortifying the lives of all the people living with the virus, we also demand the unrestricted fulfillment of all the human rights of all the PLWHA of the world.

From this document, the Latin American Network of People Living with HIV/AIDS continues with its plan to fight and vindicate in the Region.

Finally, the more than 60 delegates from the Latin American countries represented propose the next International Conference for People Living with HIV/AIDS be in Peru.

Thank you.

Document of REDLA+ read in the closing session of the 11th International Conference of People Living with HIV/AIDS, Kampala, Uganda, by René Roa Flores, Delegate from Argentina.



DECLARATION FROM "INJECTING DRUG USE AND HIV MEETING"

The only IDU-focused workshop during Kampala conference is proud to present to you our "emergency action plan" in regards to IDU issues.

We noted with great concern...

There is a great need for us to address this in a global fashion. As we worked through this project we became aware of the many differing needs of the diverse cultures affected by IDU. Our conclusion: We need to act now.

Injecting Drug Users are at high risk for HIV infection. IDUs are people with family and lives. A growing number of countries around the world and especially in the Asian Region are facing the threat of high HIV prevalence among IDUs. However, many are just beginning to realize HIV/AIDS is a threat to all. The problem is no longer only a problem of IDUs.

We also noted that...

There is very little IDU involvement in the overall response to the AIDS epidemic.

IDU issues are not a national priority in many countries.

We all felt that...

Harm Reduction is still a struggle for us no matter if it is in the East or West.

There is no effective policy as a whole and/or conflicting policies exist within the different ministries of governments in regards to IDU programs.

And have identified a few problems...

HIV and Hepatitis C co-infection is growing rapidly resulting in even fewer chances for IDUs to qualify for ARV therapy.

Lack of funding from government and donors to provide treatment for drug users and harm reduction interventions.

TB is very common among IDUs living with HIV exacerbating the problem.

We call upon all...

All IDU activists to continue advocating for ensuring IDU rights..

To seek solidarity from all communities to address all IDU issues. including GNP+, international organizations, networks, human rights advocates and activist around the globe.

Global Fund to ensure that it funds IDU programs as their main objectives is to fund identified gaps.

We are committed and propose to take this forward by:

Follow-up e-mail discussion with the participants of the meeting/conference.

Follow-up with GNP+ and partners to prioritize IDU issues in their advocacy agenda and work plans.

Discuss and plan for a global IDU consultation meeting next year.

If you are committed and interested in joining the discussion write to us at tagg24@spinn.net or join the discussion on the Web Forum.

ACTION is the Magic Word.

VOICES OF CHILDREN

We dream that we:

Will be strong enough to speak out and help make solutions for our pain.

Will know and understand everything we need to know about HIV/AIDS.

Will have a future.

Will learn how not to infect others with HIV.

Will learn how to stay safe from re-infection with HIV.

Will learn and build courage to encourage others to speak out and live positively.

Will be winners against AIDS.

Will live long.

Will always be treated as human beings.

Will learn how we can help teach others about prevention of HIV.

Will be good advocates for non-discrimination of people living with HIV/AIDS in all communities.

Will always be able to share and learn new ideas and skills with other children.

Will always be welcome in schools.

Will always be able to access advice to help us stay confident and happy.

Will have a bright future.

Will always have the freedom to talk.

Will complete our studies.

Will always have hope.

Will always be confident.

Will grow to be leaders.

Will always be surrounded by friends.

Will always feel valued.

Appendices

APPENDIX 1

CONFERENCE STATISTICS

The approximately 800 attendees can be grouped as follows:

Gender

Male 57%
Female 42%
Transgendered 1%

Vulnerable populations

IDU 7%
MSM 30%
Tribal people 19%
Sex workers 3%
Youth 19%

Region*

North America 7.5%
Caribbean 10%
Africa 42%
Asia Pacific 7.3%
Europe 11.5%
Latin America 21.5%

*Ugandan applications in Kampala are not included in calculations.

APPENDIX 2

THE DENVER PRINCIPLES

We recommend that all people:

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact. (Remember that HIV and the first proof that AIDS was an infectious disease would not be discovered for two more years.)
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

We recommend that people with AIDS:

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda, and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be involved in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low-risk sexual behaviors for those that could endanger themselves or their partners. We feel that people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

Rights of People with AIDS

People with AIDS have the right:

1. To as full and satisfying sexual and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision without discrimination of any form based on sexual orientation, gender, diagnosis, economic status, or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment, and to make informed decisions about their lives.
4. To privacy, confidentiality of medical records, to human respect, and to choose who their significant others are.
5. To die and to LIVE in dignity.

APPENDIX 3

THE UGANDAN NATIONAL RESPONSE

As of 2001 the overall adult prevalence of HIV in persons 15-49-years-old was 5.0%. Across Uganda double-digit prevalence rates are now rare (UNAIDS, "AIDS Epidemic Update", December 2003). Budget allocation from the Ugandan government towards the response to HIV/AIDS (National Strategic Framework) was USD 5.6 million in 2001-2002 and USD 9.6 million in 2002-2003. In addition, Uganda contributed USD 2.5 million to the Multisectoral AIDS Program (2001) and pledged USD 2 million to the Global Fund (UNAIDS, National Responses, 2004). Despite talk from the Government of building some generic medication manufacturing capacity, access to antiretroviral medication remains very difficult.

APPENDIX 4

A HISTORICAL PRÉCIS OF THE INTERNATIONAL CONFERENCES FOR PEOPLE LIVING WITH HIV/AIDS

- In 1987 the International Steering Committee of People Living with HIV/AIDS (ISC) organized the first international meeting. It took place in May 1987 in London with 50 participants, primarily from Western Europe. The theme of the meeting was “Caring for Ourselves”, and its main focus was self-empowerment and international networking.
- The second meeting was held in Munich, Germany, in May 1988, and was called the Second European Meeting for People with HIV. Two hundred participants from all over Western Europe attended with a few representatives from Eastern Europe. The theme was “Encouraging Ourselves”.
- In May 1989, the Third European Meeting for People with HIV took place in Copenhagen, Denmark, with 230 people attending. Although most participants were from Western Europe, a delegation from the United States and from Costa Rica also attended. The theme was “HIV-Lights and Rights”.
- The Fourth International Conference for People Living with HIV/AIDS took place in 1990 in Madrid, Spain, with 500 participants from 42 countries. This was the first truly international conference. The topic was “Another face of HIV”.
- For the Fifth International Conference in London in 1991, 530 people from 53 countries gathered under the subject “HIV and Human Rights: sFrom Victim to Victor”.
- GNP+ (The International Steering Committee had been renamed “The Global Network of People Living with HIV/AIDS” in 1992) organized the Sixth International Conference. It took place in September 1993, in Acapulco, Mexico. There were 270 delegates from 48 countries. The topic was “Communication and Solidarity for a Better Quality of Life”.
- The Seventh International Conference for People Living with HIV/AIDS took place in Cape Town, South Africa, in March 1995, under the theme “Positive Power to the Global Community”. It brought together over 476 people from 84 countries.
- “Basic Needs Basic Rights” was the theme for the Eighth International Conference for People Living with HIV/AIDS. This was the first jointly organized conference by GNP+ and ICW. It took place in November 1997 in Chiang Mai, Thailand. There were 357 delegates from 53 countries.
- “Uniting for Equality” was the theme of the ninth conference, and again, it was co-organized by GNP+ and ICW. It was held in August 1999 in Warsaw, Poland, with 470 delegates in attendance.
- The 10th International Conference for People Living with HIV/AIDS was to “Celebrate Our Lives”. It was held in October 2001 in Port of Spain, Trinidad, with 418 participants from 79 different countries.



Proud delegates from all over the globe showing their unity.

