



**10th International Conference  
for People Living with HIV/AIDS**  
27-31 October 2001, Trinidad, Port of Spain

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*celebrating our lives*

POST CONFERENCE REPORT

GNP+

**Amsterdam, The Netherlands  
2002**

# CONTENTS

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## 10<sup>th</sup> International Conference for People Living with HIV/AIDS: Post Conference Report

Acknowledgements .....	3
Definitions of Acronyms .....	4
<b>Background .....</b>	<b>4</b>
About the Coorganizers .....	4
GNP+	
CARE	
CRN+	
Brief Background on the International Conferences for People Living with HIV/AIDS .....	7
Why Hold the Conference in Trinidad? .....	7
<b>Celebrating Our Lives .....</b>	<b>8</b>
Aims of the Conference .....	8
The Conference Program: Introduction and Reflections .....	9
The Global Advocacy Agenda .....	9
The Conference Tracks .....	9
The Conference Theme .....	9
The Opening Ceremony .....	11
Session Highlights .....	11
Positive Living Sessions .....	12
<i>Getting Treatment Access: The Work</i>	
<i>Positive Women's Survival Kits</i>	
<i>Communicating with Children</i>	
Positive Environment Sessions .....	14
<i>Confronting Stigma and Discrimination</i>	
<i>Religion, Stigma and Power</i>	
Positive Engagement Sessions .....	15
<i>Plenary One, UNGASS: From Word to Deeds</i>	
<i>Working with Bureaucrats: The HIV Issue</i>	
<i>Starting Support Groups</i>	
<i>Resource Mobilization</i>	
<i>Creating a Global Fund and Global Fund Workgroup</i>	
<i>Plenary Four, Beyond Principles: GIPA in Practice</i>	
Parallel Forum Sessions .....	24
<i>HIV+ Working in Prevention</i>	
<i>HIV as a Workplace Issue</i>	
<i>UNAIDS/GIPA: A Plan in Progress</i>	
<b>Appendices .....</b>	<b>28</b>
Appendix 1, Listing of Conference Sessions .....	28
Appendix 2, Some Epidemiological Facts about HIV/AIDS in the Caribbean .....	30
Appendix 3, A Historical Précis on the International Conferences for People Living with HIV/AIDS .....	31
Appendix 4, Data on the Delegates .....	32
<b>Afterword .....</b>	<b>33</b>

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# BACKGROUND

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## Definitions of Acronyms

AAN	AIDS Alliance Nigeria	IFRC	International Federation of Red Cross and Red Crescent Societies
ARV	Antiretroviral	ICASO	International Council of AIDS Service Organizations
CARe	Community Action Resource	NACHA	National Action Committee on HIV/AIDS
CAREC	Caribbean Epidemiology Center	NAPWA	National Association of People with AIDS
CCIETS	Centro Nacional de Prevención de las Infecciones de Transmisión Sexual (National Center for the Prevention of Sexually Transmitted Diseases)	PAHO	Pan American Health Organization
CPPS	Centro Provincial de Promoción de Salud	PLWHA	Persons living with HIV/AIDS
CRN+	Caribbean Regional Network of People Living with HIV/AIDS	REDOVIH	Red Dominicana de Personas que Viven con VIH/SIDA (Dominican Network of PLWHA)
GIPA	The Greater Involvement of People Living with HIV/AIDS	SPSTI	Special Programme on Sexually Transmitted Infections
GNP+	Global Network of People Living with HIV/AIDS	SWAA	Society of Women and AIDS in Africa
GNP+ NA	Global Network of People Living with HIV/AIDS, North America	UNAIDS	Joint Programme of the United Nations on HIV/AIDS
HRAG	Health Rights Action Group	UNGASS	United Nations General Assembly Special Session
ICW	International Community of Women Living with HIV/AIDS	ZNNP+	Zimbabwean National Network for PLWHA

## About the Coorganizers

### The Global Network of People Living with HIV/AIDS (GNP+)

GNP+ is a global network operated by and for people living with HIV/AIDS. Its overall aim is to improve their quality of life.

The central secretariat of GNP+ is located in Amsterdam, The Netherlands. The Network has a board of twelve members, two of which represent partner networks in six different regions of the world. The affiliated networks are as follows:

<b>Africa:</b>	Network of African People Living with HIV/AIDS (NAP+)
<b>Asia/Pacific:</b>	Asia/Pacific Network of People Living with HIV/AIDS (APN+)
<b>Caribbean:</b>	Caribbean Regional Network of People Living with HIV/AIDS (CRN+)
<b>Europe:</b>	European Network of People Living with HIV/AIDS (ENP+)
<b>Latin America:</b>	Latin American Network of People Living with HIV/AIDS (REDLA+)
<b>North America:</b>	GNP+ North America (GNP+ NA)

GNP+ seeks to improve the quality of life of people living with HIV/AIDS through its work in three closely interrelated areas: advocacy, capacity building, and communication.

**ADVOCACY:** The Global Advocacy Agenda is the policy platform guiding the advocacy work of GNP+. It consists of three key areas:

- Promoting global access to HIV/AIDS care and treatment
- Combating stigma and discrimination
- 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

**Activities:** Copublishing the Guidelines for Donation of Medications; collaborating with and supporting regional partners on specific campaigns; collaborating with and advising partners, such as the IFRC and UNAIDS, on stigma and discrimination; and participating in the leadership of the UNGASS Special Session on HIV/AIDS and the Global Fund to Fight AIDS, Tuberculosis, and Malaria, respectively.

## Community Action Resource (CARE)

CARE (formerly HIV Anonymous) is a voluntary, non-profit AIDS service organization formed to address some of the needs of persons with HIV/AIDS.

**Mission Statement:** to enhance the quality of life of people challenged by HIV/AIDS

### Guiding principles:

- CARE recognizes that the major challenges facing those infected and affected are lifestyles, priorities and attitudes to life and death.

**CAPACITY BUILDING:** GNP+ works to help people living with HIV/AIDS contribute to the HIV/AIDS response, by providing resources, information, and empowerment.

**Activities:** Making its free manual, Positive Development, available for grassroots organising and training; providing technical assistance to other AIDS organizations.

**COMMUNICATION:** The communication program is based on the principles of linking, sharing, and mentoring. GNP+ links people living with HIV/AIDS to and with each other at various global and regional meetings. These meetings provide a context for them to meet regularly in a safe environment to share personal experiences, day-to-day living with HIV/AIDS, information, skills, and resources. Under the mentoring concept, activists are identified. They are subsequently inspired, encouraged, and trained by other persons living with HIV/AIDS already active in the HIV/AIDS movement.

**Activities:** Coorganizing the International Conferences for People Living with HIV/AIDS and the International AIDS Conferences; supporting meetings of regional networks; and providing an open discussion web forum for members of GNP+.

- CARE is committed to ensuring that people living with HIV/AIDS are central in the organization so that they can influence and contribute to policy development and service delivery.
- CARE is committed to encouraging personal empowerment of all its partners - members, workers, program users, friends and supporters.
- CARE is committed to the confidentiality of the service, and participation by the community will be treated as such.

## Main Objectives:

- To provide emotional support to infected persons and to families affected by HIV/AIDS
- To provide educational support to people living with AIDS
- To provide a buffer supply of medicine for infected persons
- To influence the development of service provision across the public, private and voluntary sector
- To change public attitudes and influence policy

## Services:

- Counselling
- Complimentary health
- Drop-in center
- Information and education
- Community outreach

## Caribbean Regional Network of People living with HIV/AIDS (CRN+)

The Caribbean Regional Network of People Living with HIV/AIDS (CRN+) was formed after three years of involvement of Caribbean individuals at the international level, i.e., the Global Network of People Living with HIV/AIDS (GNP+) and the International Community of Women Living with HIV/AIDS (ICW).

GNP+ and ICW is structured to provide regional representation. Networks had been formed for Asia/Pacific, Africa, Latin America, North America and Europe. HIV/AIDS communities in the Caribbean were required to achieve a similar network, which was critical for increasing the awareness and highlighting the needs of Caribbean people with AIDS both regionally and internationally.

On September 28, 1996, in Trinidad and Tobago twenty-one PLWHA and eleven interested individuals in the region formed CRN+. This network was born out of the need to address the issues of all people living with HIV/AIDS in the Caribbean region. CRN+ now has a growing membership of 27 islands, the ultimate goal being the inclusion of every territory in the wider Caribbean. Seven national networks were formed as a direct result of CRN+, namely Antigua, Bermuda, Dominican Republic, Grenada, Guyana, Jamaica and St. Kitts and Nevis. Subsequent to this plan came the appointment of a Regional Coordinator and the development of a comprehensive plan of action for the Network. It was agreed that the secretariat should be established in Trinidad and Tobago.

CRN+ convenes an Annual Capacity Building Workshop/ Annual General Meeting at which the Regional Board of

CRN+ is elected. Its representatives for the two international PLWHA networks (GNP+ and ICW) are also elected at that time. The Board is a ten member committee (plus three working group coordinators). It meets three times annually and currently comprises members from Antigua, Bermuda, Grand Cayman Islands, Cuba, Dominican Republic, Grenada, Guyana, Haiti, Jamaica, St. Maarten and Trinidad and Tobago. CRN+ accomplishes its activities through three working groups, each of which is headed by a coordinator. These groups are Communication, Financial and Programme.

## The goal of CRN+

To facilitate access to information exchange, advocacy, lobbying and capacity building of PLWHA in the wider Caribbean.

## Objectives

- Establish an effective communication strategy to ensure the flow of information
- Establish equal access to treatment information for all PLWHA groups in the wider Caribbean
- Involve all countries in the wider Caribbean
- Create a database of expertise within the Network to maximize available capacity and utilization of skills
- Develop strategies for lobbying and advocacy in the wider Caribbean
- Strengthen partnerships with agencies that share similar aims and objectives

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

Begun 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, and the PAHO Directing Council.

It is important to push forward and broaden the scope of the possible outcomes of these conferences. A key way to do so is to focus them on building skills, developing partnerships and strengthening individuals and networks of PLWHA at the local, national, regional, and international levels.

Capacity-building is essential for PLWHA to become full participants and decision-makers in the HIV/AIDS arena. It is not enough to be a full participant, however. PLWHA must be effective in the HIV/AIDS response, which they can only achieve if they are empowered in an enabling, supportive, and non-discriminatory environment.

Even empowered, PLWHA cannot curtail the epidemic alone. The need for many varied and strong multi-sectoral partnerships is essential, and this is certainly as true at the national level as it is at the local, regional, and global levels. According to Dr. Hamza Rafeeq, Minister of Health of Trinidad and Tobago at the time of the Conference, “it is my belief that if all sectors of our society could realize the urgent need to become more involved in preventive and educational activities on HIV/AIDS, we as a nation could escape the full wrath of this disease which has brought about severe economic and social hardships in so many countries around the world.”

PLWHA conferences often generate a new-found activism. As Dr. Hospedales, Director of CAREC, has put it these conferences provide a multiplier effect. Delegates find strength, courage and determination to return home and work with others to improve directly the quality of life of people living with HIV/AIDS. The 10th International Conference for People living with HIV/AIDS was no exception.

## **Why Hold the Conference in Trinidad?**

Until 2001 the International Conferences for People Living with HIV/AIDS had all taken place outside North America and the Caribbean. The Caribbean was a natural choice for the next meeting. The infection rates of the Caribbean are the highest in the Western Hemisphere and fall only second to sub-Saharan Africa. There is thus a great need to take strong action against the epidemic in this part of the world.

As the epidemic has spread throughout the region, the primary mode of transmission has been sexual, shifting from a homosexual epidemic to a predominantly heterosexual one. The epidemic

has also shifted to younger populations, in particular to young females. The future of this epidemic is the growing number of people living with HIV/AIDS and affected families requiring care and support. The changing profile of the epidemic has already begun to impact dramatically, not only on the health sector, but also on life expectancy and on economic resources in the Caribbean, in terms of loss of human potential and productivity.

The generalized epidemic in the Caribbean is affecting both large and small territories and shows no sign of peaking. AIDS has become a

threat to regional development and is no longer solely a health issue. There is a complex mosaic of interwoven factors driving the epidemic, which are related to socioeconomic environments, deeply rooted behaviors and cultural norms, and the biomedical response to the virus. The regional response has been continuous and sustained, and noteworthy achievements have been realized through years of prevention and control efforts. However, some challenges in the response can be solved only through international cooperation for development, to prevent an increase in the magnitude of the HIV epidemic in the region (in terms of morbidity and mortality) and in overall severe socioeconomic impact.

Each of the previous international conferences for people living with HIV/AIDS has successfully brought heightened attention to needs in the host region. With this fact in mind, there was a sense of urgency about having the next meeting in the Caribbean, given the severity of the epidemic in the region. Health organizations and international institutions like PAHO, through CAREC, which it administrates, have a strong presence in Trinidad and would be able to offer the financial and logistical support essential to a large international conference. The choice of Trinidad as the specific venue for the meeting simply made sense.

## **CELEBRATING OUR LIVES**

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### **Aims of the Conference**

The principal aim of this conference was to celebrate our lives!

More specific goals were as follows:

- Raise awareness of the needs and rights of PLWHA
- Inspire PLWHA to become active by enabling them to acquire the skills and confidence to become involved
- Support and strengthen development and capacity of PLWHA networks and organizations
- Enhance collaboration and learning to unite the infected and affected communities, government and business in a multi-sectoral approach to the epidemic
- Widen skills-building initiatives to foster strategic alliances with key institutions and organisations
- Obtain closer collaboration among the global, regional, and country level PLWHA networks, including concrete forms of mutual support
- Reach a consensus for the future priorities and projects of the GNP+ networks
- Share lessons, experiences and new developments in issues pertinent to people living with HIV/AIDS
- Keep the focus on hands-on training, networking and development of skills

# The Conference Program: Introduction and Reflections

## The Global Advocacy Agenda

The 9th International Conference of People Living with HIV/AIDS in Warsaw, Poland, had, as a subset of its extensive program a four-day workshop called “Building a Global Advocacy Agenda”. The collaborative work done in this workshop—over 60 HIV+ people from all over the world participated—produced a policy document, “The Global Advocacy Agenda”, that became the policy platform of GNP+. It focuses on three principal areas of concern for persons living with HIV/AIDS:

1. promoting global access to HIV care and treatment (medications, health care services and treatment information).
2. combating stigma and discrimination against people living with HIV.
3. promoting the greater (and more meaningful) involvement of people living with HIV/AIDS.

## The Conference Tracks

Our goal for the Conference program was to develop the Agenda further and to express it through the dynamic concepts in use in our actual lives as human beings and as persons living with HIV/AIDS. The idea was to make advocacy and policy a living thing, in keeping with the very human and celebratory spirit of this conference. Thus, having access to care and treatment became “positive living”, combating stigma and discrimination became obtaining a “positive environment”, and GIPA (see below for further explanation) became “positive engagement”.

### Positive Living

People with HIV/AIDS can survive when the private or public sectors do not violate their basic right to health care and treatment. We would not have the death rates we have if companies did not reach for large profits and if governments had more courage and commitment. The Global Advocacy Agenda calls for changing the status

quo, this reality with blood on its hands. Sadly, infuriatingly, survival is what we are still fighting for.

But survival is not enough. People with HIV/AIDS must be allowed to thrive. And when they do, it is through their sheer tenacity, ingenuity, and mutual support. It is these elements that allow them to develop and share knowledge and skills for improving their nutrition, making reasoned treatment choices, and for acting responsibly toward themselves and others. Promoting global access to HIV care and treatment is therefore only one key element in the greater context of blooming as a person with HIV/AIDS. The “positive living” track of the Conference was intended to capture this, with workshops not only on treatment access but also on women’s health issues, education, nutrition, and on traditional and non-traditional care alternatives and lifestyles.

### Positive Environment

There are other barriers to flourishing beyond lack of access to care and treatment. Barriers to a decent quality of life for people with HIV/AIDS come from the everyday forms of stigma and discrimination they face. In order to flourish, people living with HIV/AIDS need a positive environment.

If there is to be successful access to treatment and care, stigma and discrimination must be reduced as much as possible. A person living in an area where stigma and discrimination are strong will not be as likely to approach the available health care institutions and associations in his area to seek testing, care, treatment, or support. He might fear, for example, the potentially dangerous repercussions of being seen at an HIV/AIDS care clinic or that health care practitioners would not maintain confidentiality. Yet care, treatment and support begin with access to information on HIV/AIDS and to the freedom to have knowledge of one’s status.

Prevention is also dependent on an environment free from stigma and discrimination. Those rendered unable to access information on HIV/AIDS or the materials to reduce risk of infection are kept ignorant and helpless, and made more at risk of infection, not less so. People must be able to obtain the tools to help themselves and others in this epidemic without having to fear loss of reputation, housing, employment, or physical safety. To prevent them from doing so is to deny them the basic human rights to health and life.

While much must be done at the local level to create a positive environment, there is also considerable work to be done at the national and global levels. There are forms of state-sanctioned discrimination that impact dramatically on basic human rights. Persons with HIV are denied the right to freedom of movement through the discriminatory travel and immigration laws they must confront. Over one hundred countries impose restrictions on the freedom of HIV positive people to visit or obtain residency. The United States government denies HIV positive persons even the right to transit through their country. But lest one think that this sort of discrimination is not as serious because it does not directly affect prevention and treatment, for example, one must not forget that because of travel restrictions HIV positive persons are often unable to attend conferences where they can learn about new methods, treatment and care options, and where they can engage in the networking and social contact they need to be empowered and involved effectively in the response to the epidemic.

### Positive Engagement

The 1994 Paris AIDS Summit recognized the importance of initiatives to strengthen the capacity and coordination of networks of people living with HIV/AIDS and of community-based organizations to support the greater involvement of people living with HIV/AIDS in the response to the epidemic. This idea has become known as the GIPA Principle. Unfortunately, as J. van Roey writes in, “From

Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)” (to be found in the UNAIDS Best Practices Collection),

*“GIPA is not reflected in national policies and programs in any concerted or large-scale way, and there is an almost total lack of mechanisms permitting or encouraging PWHA’s experiences, perceptions or skills to be considered (much less utilized)”*  
(p. 1, 1999).

In order to reverse the situation described above, it is essential to empower persons living with HIV/AIDS so they can build their capacities and skills in a safe environment. In addition, training PLWHA’s in this way can help avoid tokenism, that is, hiring or inviting HIV+ persons to be part of a process simply because their presence can technically fulfill criteria for diversity and community participation. The GIPA Principle is about real involvement, about engagement. With this aim in mind, this track included a variety of workshops on policy, skills-building, and leadership to help make GIPA a reality.

The idea of “positive engagement” goes beyond development of skills to address personal involvement in the response to the epidemic, however. PLWHA’s should not be only clients or receivers of services. They must take an active role in the response and be made to feel their involvement is genuinely needed, and they must progress to become the owners of the process and of the means of the response to the epidemic.

### The Conference Theme

Our lives. It comes down to that. If the Global Advocacy Agenda has to do with anything it has to do with our lives. If this Conference was going to be about the Agenda and the work it involves, it would have to emphasize that fact. During the

planning it struck us we had been through so much to get to this point, it was grossly unfair for our efforts to continue to be shrouded by the negative way being HIV+ is perceived. And

yet here we were to feel this way, in flesh and blood, and glad to be alive. So we thought, “why shouldn’t we change perceptions and...celebrate our lives?”

## The Opening Ceremony

The Opening Ceremony began with the national anthem of Trinidad and Tobago and was followed by an invocation from Pastor Elder Peter Hernandez. Speakers at the Ceremony were Yolanda Simon, Conference Chairperson and Regional Coordinator of CRN+, Stuart Flavell, International Coordinator of GNP+, Dr. Peter Piot, Executive Director of UNAIDS, the Hon. Dr. Denzil Douglas, Prime Minister of St. Kitts and Nevis, the Hon. Dr. Hamza Rafeeq, ex-Minister of Health of Trinidad and Tobago, and Claudette Francis, Executive Director of CARE. The participation of the Honorable Dr. Denzil Douglas in the opening ceremony is particularly noteworthy. His presentation was the first time a head of state has addressed a meeting of the International Conferences for People Living with HIV/AIDS.

The evening continued with entertainment combining comedy, music, singing and dancing. Ms. Patricia-Ann Lamming, an empowerment coach from Trinidad and Tobago, who kicked off the festivities with a comical presentation. She

was followed by a troupe of young girls, called the Vikesh dancers, who gave an inspiring dance show demonstrating that harmony between people from different religions and cultures is indeed possible.

The music continued with Mungal Patasar, a well known jazz musician who has performed at the Montreux Jazz Festival. His combination of both Caribbean and Classical Indian sounds is quite unique. He is a top mandolin player in Trinidad as well as an adept of the harmonium and of the dholak and dhantal, Indian folk instruments, and as can be seen from the photograph, he is also a sitar player. Mr. Patasar is acting director of culture with the Ministry of Culture of Trinidad and Tobago.

The amazing voice of THE calypso diva, Ella Andall, closed the evening. Ms. Andall, famous for her work in the Orisha religion and one of Trinidad and Tobago’s foremost artists, sang, “Celebrating Life”, a song especially written for the Conference. She moved everyone to dance with her electrifying performance of her now classic “Bring Down the Power”.

## Session Highlights

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+ persons and are designed for capacity-building, and to provide a safe environment for presenting issues that, in the opinion of the coorganizers, positive persons would be most comfortable discussing in the exclusive company of other positive persons. Thus, as with past PLWHA

conferences, most of the workshops were open only to HIV+ persons, with some for women-only and others for men-only.

The Parallel Forum sessions, already featured at the 8th Conference for People Living with HIV/AIDS in Chang Mai, Thailand, were given more structure, diversity of topics, and room for participation. They were also more integrated within the daily program. These sessions encouraged regional and national participation and facilitated a positive collaboration with the following target groups:

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

To keep this conference report at a manageable size, and especially, to preserve its usefulness as a capacity-building tool for those who did not attend the conference, we have not provided summaries of each and every one of the sessions. Instead, we have included highlights of key sessions and their conclusions. However, for those interested, a comprehensive listing of the conference sessions can be found in Appendix 1.

## **Positive Living Sessions**

### **Getting Treatment Access: The Work**

Intended not only as a review but also as a rethinking of the global situation with regard to access to treatment, this closed workshop dispelled arguments against implementing treatment programs in poor settings. Facilitators, Stuart Flavell and Naisiadet Mason, NAPWA and SWAA, looked at the arguments some countries have used for not implementing treatment programs. These run from claims to the effect that to treat HIV would deny resources for other uses to claims that the lack of infrastructure in poor countries prevents the possibility of providing ARVs on a continuous basis. These

arguments are inconsistent with what is known about other public health measures in poor settings and reveal deep problems about the response to the epidemic.

First, in almost all countries there are TB control programs. TB requires a long-term treatment regimen. With regard to policy formulation and program implementation, we need to think analogically from other diseases to AIDS when dealing with the AIDS epidemic. There are models we can turn to that exist in even the most resource scarce communities, and where health care is nevertheless provided.

Second, although there is a lack of sufficient infrastructure to provide drugs and ARVs adequately. What is relevant is that there IS an infrastructure, and that it needs to be strengthened. Inadequate infrastructures are not identical with nonexistent infrastructures, and if we are to think correctly about the problem at hand we must not slide from one concept to the other. What the arguments used against implementing treatment programs succeed in convincing us about is that there is a lack of political will in the response to epidemic and that despite the ever increasing global levels of HIV/AIDS-related morbidity and mortality, not all governments have yet realized it is time to prioritize HIV/AIDS.

Facilitators at this workshop also discussed what the response from PLWHA should be. They reminded participants that, although there are 100,000 people on ARV treatment in Brazil, that success came at the price of considerable pressure and advocacy on the part of civil society, and the pressure cannot be released if we are to ensure the Brazilian government continues to provide therapy. There is also a large movement of PLWHA working to ensure that the government of Brazil continues to provide ARVs free of charge. PLWHA need to advocate for governments to realize that it is time to prioritize HIV/AIDS and not to settle for big promises. They need to change. We need real political commitment and willingness to act.

The advocacy work that needs to be done does not begin and end with pressuring governments. Governments have a responsibility to take advantage of compulsory licensing, for instance. All parties need to negotiate with the pharmaceutical companies to reduce the cost of drugs, and PLWHA organizations in particular need to know how to lobby for cheaper drugs. To do all this work PLWHA need to: organize the response; educate people about the fact that there is medication and that they can get it; plan, using allies to support activities; and reach across national borders to bring back examples of successes.

### Positive Women's Survival Kits

Women are among the vulnerable groups most severely, multiply affected by HIV infection. With this fact in mind, the conference program gave considerable space for women's issues. The positive living track alone had three workshops for HIV+ women only. There was a workshop on specific treatment issues as they relate to women, a workshop on communicating with children, and the Positive Women's Survival Kits, which ran over two days and was made available in English, French and Spanish to maximize access and impact. Facilitated by Linda Reed, ICW European Key Contact, this workshop brought forward the reality of what life is like for women who test positive and what they can do in response to their diagnosis. Aspects of the workshop concerned introducing the importance of making a survival kit available to women, and what it can do to help. Currently, ICW publishes a "Survival Kit" in three languages: English, French and Spanish.

HIV is a lonely, isolating disease, and women who test positive often lack confidence, support, and feel a sense of shame. And there is the added stigma of being a woman. Therefore HIV+ women need resources, training and information. Women's survival kits teach women ways of supporting each other, by addressing issues specific to women. They consist in helping HIV positive women: meet each other; form support groups; gain confidence and obtain health care;

have access to education on how the virus is transmitted; learn and teach individuals that there is life after HIV diagnosis, as most people believe HIV=AIDS=DEATH; and decide who needs to know their status, and how to tell a person about it based on the possible consequences of telling.

The issue of telling focused heavily in the discussion that followed the presentation. The fear of rejection and being ostracized are dominant in the period following diagnosis. Participants felt that the hardest task is telling their children and then other family members. Children can react poorly when they find out a parent(s) is/are HIV positive. Therefore, children need support groups.

Despite the fears participants agreed that being able to tell is crucial. They are "worn out from lying and hiding", and feeling dehumanized from having to do so. Participants felt strongly that the problem of having to lie and hide has its roots in the lack of public education about HIV/AIDS.

### Communicating with Children

Although not specifically structured to be a follow-up of the "Positive Women's Survival Kits", this workshop picked up exactly where that one left off. Offering a positive, woman-only environment, it mainly addressed the issues that affect HIV+ mothers with children.

For mothers, a big problem is when to disclose to a child that one is HIV+ and how to deal with a child's finding out about this mother's positive status. Conclusions of the workshop were that the child's age and extent of development would help determine when to tell them, but mothers should educate themselves about the different approaches to telling children about HIV/AIDS. For this education to take place the existence of support groups for women that address dealing with children is crucial. Also, for children to confront the situation appropriately, they need to be educated about HIV/AIDS. To that end, it was suggested that children be brought to conference such as these.

If there were a bottom line, it would be that children need to be shown love and support, and that they need to be told the truth. However, although the focus of concern is often to support the child after he finds out about his mother's positive diagnosis, there is little emphasis on helping mothers with the effects of a negative response from their children. As much as children are affected by their mothers, mothers are affected by their children, and neither is necessarily affected by the same facts in the same ways.

## **Positive Environment Sessions**

### **Confronting Stigma and Discrimination**

This was a two-part, closed workshop, facilitated by Kevin Osborne, Caroline Wills, Musa Njoko and Hugo Thomas of the Policy Project, which took place over two different days. The objective of the first one, entitled "Examining Ourselves, Examining Communities", was to explore the concept of internalized stigma and how it differs from external stigma.

External stigma is stigma oriented toward people living with HIV/AIDS that comes from sources outside the affected person. The media, family, friends, religious institutions, the workplace, the health care system, and so forth, are all possible sources of external stigma. Internalized stigma has to do with how people living with HIV/AIDS stigmatize themselves. It is the shame associated with the illness, and the fear of being discriminated against on account of the illness. Internalized stigma comes about when, for example, the images, thoughts, or prejudices that a person has formed about HIV and AIDS and about people living with HIV/AIDS suddenly become that person's reality upon diagnosis. Suddenly, what was outside that person is now his understanding of himself.

When a person is diagnosed as having HIV, internalized stigma can come in a number of forms, including: an inability to relate to friends, a loss of self-esteem, a fear of approaching

people, thinking one does not have the right to connect with negative people or that one does not deserve the things one has, an expectation of rejection on the part of others, personal blame, mistrust of others, negative feelings about sex, reduced productivity, or (on the contrary) overdoing things to prove oneself. Beyond the sometimes devastating effects on a person, internalized stigma also jeopardizes the response to the epidemic. It has a negative effect on the resolve, commitment and personalized perspective of people living with HIV/AIDS to confront issues that impact on programs and interventions.

The second part of this workshop, "Responding as HIV+ People", concerned the strategies, guidelines and actions that can be taken to address internalized stigma. Participants identified personal examples of internalized stigma and explored ways of addressing them, and workshop facilitators emphasized both working on influences from within and from without. Internal responses concern keeping a healthy mind through alternative therapy, self-empowerment support groups, rehabilitation, and spirituality. They also concern staying aware of the issue and its manifestations within oneself, thus asking oneself, for example, what people living with HIV/AIDS bring to stigma and how they might stigmatize each other.

It also involves being hardnosed about responding to external stigma and documenting workplace incidents and other instances of stigma in the public sphere, advocating for the promotion of the human rights of PLWHA and getting involved in educating others on HIV/AIDS, including challenging others on their conceptions about people living with HIV/AIDS. In addition, a positive process of disclosure is critical and should be promoted. Ongoing, comprehensive support should be available for PLWHA from diagnosis onward to ensure they are empowered to make informed decisions and choices about their lives.

The statements of the UNGASS Declaration of Commitment on discrimination and human rights can inform the direction to be taken on stigma in the response to the epidemic. In two articles it states:

1. By 2003, enact, strengthen, or enforce, as appropriate, legislation, regulations, and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups.
2. By 2003, establish or strengthen effective monitoring systems for the promotion and protection of human rights of people living with HIV/AIDS.

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### Voices from Participants

*“Are there situations where you would fear revealing your HIV status?”*

*“Yes, I fear hurt and rejection from my Islamic community which is remote and AIDS is unknown”*

*“Yes, I fear my friends knowing because they will tell others”*

*“Yes, with my parents and fathers family I feel that they are still getting used to my sexuality so my status is another kettle of fish.”*

*“Yes, when entering new relationships I fear the other person may reject me”*

*“Yes, I believe that due to my work it might create a problem with other workers”*

*“Yes, the backlash to my family and if they can cope with it.”*

*“Yes, I am in fear of people knowing because I will lose my friends.”*

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## Religion, Stigma and Power

This open panel discussion focused on the role of religion in HIV/AIDS-related stigma and discrimination.

Few churches have helped PLWHA or contributed positively to their lives. According to workshop

participants, the stigma that persons affected by HIV/AIDS feel from religious institutions and religious people has its roots in an incorrect perception about HIV/AIDS as a disease of homosexuals and promiscuous individuals. Participants at this workshop agreed there needs to be increased awareness of the reality of HIV/AIDS and knowledge about PLWHA to reverse negative and incorrect perceptions. They also agreed there needs to be accompanying advocacy aimed at religious institutions and religious people for the defense of the rights of PLWHA and for stopping the exclusion of vulnerable groups, such as homosexuals. Indeed, Christian churches have an obligation to support PLWHA and homosexuals, because they of their marginal social status.

Being realistic, however, participants warned that integrating PLWHA with churches would not come easily, as it would touch on very sensitive issues for both groups. The process of harmonizing the relationship requires a recognition of this constraint and that strategies must be developed and implemented to address it. Lest the efforts involved seem overly daunting, participants were quick to call to mind the strong benefits that would be produced. In fact, where religious groups have accepted PLWHA, these PLWHA have gone on to becoming strong advocates for HIV/AIDS-related education. The support of religious groups has a positive impact on the response to the epidemic, and on the involvement of PLWHA within it.

## Positive Engagement Sessions

### Plenary One, UNGASS: From Words to Deeds

This session featured presenters from CAREC, CRN+, GNP+, ICASO, and UNAIDS. They underscored the different approaches and strategies in need of implementation to convert the UNGASS Declaration of Commitment into action.

Richard Burzynski, Director of ICASO, delineated some specific advocacy-oriented strategies, such as the importance of: disseminating the Declaration as

widely as possible, as the Document includes fifty targets; holding governments accountable for the areas addressed in the Declaration; organizations deciding to endorse the Text; and of organizations strengthening their relationships with governments.

Yolanda Simon and Stuart Flavell drew the focus back to PLWHA. Both emphasized key needs for involving PLWHA in putting the Declaration into action. For example, PLWHA must have access to treatment in order for as many as possible to be involved sustainably, and they must have access to training and capacity-building. Furthermore, countries must pass legislation to fight discrimination against PLWHA.

Dr. Bilali Camara, Head of SPSTI of CAREC, spoke about the specific epidemiological implications of keeping the promise of the Declaration, including the need to upgrade laboratories, developing public health measures at a regional level, developing key determinants for successful care, and renewing surveillance guidelines.

Dr. Peter Piot's presentation, of which excerpts are reproduced in the boxed area below, reviews the spirit, political implications, areas of emphasis, and the steps to be taken to convert the Declaration of Commitment into action.

### ***"UNGASS From Words to Deeds"***

#### ***Excerpts from Dr. Peter Piot's presentation\****

*"[T]he UNGASS [was] different from the hundreds of meetings and summits that have been held on the subject of AIDS since the epidemic began...because it was a meeting of all states, acting as governments-not only health ministers - with all that entails in terms of political accountability and national interest.*

*[...] [T]he result, for all its imperfections, commits governments more thoroughly than a thousand passionately argued civil society manifestos could.*

*It was also different because of its declaration of*

*commitment. It is not a treaty with quasi-legal force - agreeing a treaty would have required years of negotiation, out of step with the urgency of AIDS. But the declaration did draw some lines in the sand:*

*One-unequivocal recognition that the fight against AIDS needs resources-7 to 10 billion dollars in developing countries;*

*Two-that the AIDS response must be founded on human rights principles; and*

*Three-that treatment and care for people with HIV are as fundamental to the response to AIDS and HIV as is prevention.*

*Four-that vulnerable groups must be partners in the response - this last line in the sand got a bit fuzzy, but at the very least, the Session challenged all those who think the easy way to avoid a genuine response to the epidemic is by denigrating sex workers or men who have sex with men or injecting drug users.*

*The declaration of commitment [...] is both an opportunity and a challenge: an opportunity because for the first time there is international consensus on the principles, priorities and targets in the fight against AIDS, and a challenge, because what the declaration leaves unsaid is how these targets are going to be met.*

*[...] So far, the signs are good that the Declaration is an effective tool. As we are in the Caribbean I must note that not only was the formation of the Pan-Caribbean Partnership against AIDS one of the most significant lead up events to the UNGASS, but the Caribbean was also the quickest region to take follow-up action, with the Nassau declaration constituting the first concrete resolution of regional action to make good the promises of the UNGASS.*

*One way of keeping the UNGASS promise will be to monitor closely progress on the Declaration as one of its main functions is providing an*

*international instrument of accountability. Already, the UNAIDS Secretariat with all our cosponsoring organizations, has started work on the indicators that will keep track of progress on all the key elements of the Declaration. These indicators will not just be for the UN system[.]*

*Finally, let me say just a few words about some of the most crucial aspects of the Declaration.[...]*

*Obviously care - the commitment to the highest attainable standard of treatment for HIV/AIDS is a wording that leaves a lot of room for negotiation. The trick will be to be specific and strategic in defining attainability-using leading nations to pull others along.Second, human rights. There is a whole human rights infrastructure around the world that includes national human rights commissions, vocal non-governmental organisations, and global instruments. To date this infrastructure has barely begun to realise its potential to redress the discrimination daily faced by people living with HIV. The UNGASS declaration places human rights at the heart of the AIDS response, and now it ought to be used to put AIDS at the heart of human rights responses.*

*Third, the Declaration draws clear attention to the gender dimensions of the epidemic. Gender is about both men and women - it structures both heterosexual relations and relations between men and between women, and promoting gender equality will not only prevent new infections it will lessen the burdens of people living with HIV. Again, the challenge is to turn this into practical action with a real impact of millions of lives.*

*Finally, what will be crucial in turning words into action are as much the quality of alliances website at [www.unaids.org](http://www.unaids.org).as global organizing.[...]"*

*\*A full version of the speech can be found under the rubric "speeches" on the UNAIDS AIDS website at [www.unaids.org](http://www.unaids.org).*

## Working with Bureaucrats: The HIV Issue

This open panel discussion focused on how to include bureaucrats in partnership work aimed to strengthen lobbying efforts.

Dr. Frank Guni, ZNNP+, spoke about his country's laws on non-discrimination in employment based on HIV status and on its national HIV/AIDS policy and strategic framework. Based on his experience, he argued that the key in working with bureaucrats is to build partnerships and alliances with the interest of people living with HIV/AIDS at the heart of their visions. Suggestions on how to effectuate this centered around: interventions aimed at the executive branch of government that include diplomatic engagements and dialogue, strategic confrontations, and targeted advocacy; the importance of knowing the issues from the government's perspective; and facilitating the harmonization and main-streaming of HIV/AIDS in national governance.

He gave concrete, candid recommendations on how to "normalize" and incorporate HIV/AIDS work at the country government level:

- Formulate a policy.
- Push for meaningful participation at all levels of decision-making.
- Do not wait to be invited, and make your presence felt.
- Ensure that they understand you as partners.
- Target women in leadership.
- Identify those who relate to PLWHA.
- Build blocks from the few who know you.
- Remain focused and keep pushing.
- Do not be bought and betray the people you represent.
- Remain apolitical.
- Use them to get what you need.
- Above all do not become a bureaucrat yourself.

Dr. Guni underscored that many challenges have to do with the tendencies of bureaucrats, which he described as follows:

- Political suspicion of civic leaders
- Political manipulation for their political interest
- Failing to personalize HIV/AIDS
- Assuming the eminent death of advocates with AIDS and therefore have the tendency to harbor negative attitudes
- Assuming that advocates are there for money
- Taking long to make decisions
- Needing reminders and pushing

Bob Mills of GNP+ NA also gave specific tips:

- Need to access information to know what is needed.

- Need to know what the government thinks of PLWHA.
- Need to know what is relevant information for the government.
- Need to know the sources of information.
- Need to know the issues from the government's perspective.
- Need to be informed to enhance the organization's credibility.

- What's important?

- Seeing a minister, because mid-senior bureaucrats are key.
- Getting your case heard rather than just seen.
- Receiving feedback rather than sending feedback.
- Using grass-roots workers, proxies and lobbyists.
- Knowing how your organization is perceived and its reputation.

- Know your issues well.

- Understand the issue and get all the facts.
- Find out whose voice you carry and what they want (e.g., do you represent employees, patients, consumers, etc.?).
- Identify decision-makers in government and their motives.
- Identify detractors/opponents and their motives.
- Identify the influential and their motives.

- Build your issues and be realistic.

- Identify the undecided and how can you gain their support.
- Identify the media who might be willing to help.
- Develop many and various strategies, both public and private (e.g., letters, protests, meetings, demonstrations, etc.).
- Implement chosen strategies strategically and consciously.
- Evaluate strategies before campaigns, asking questions like, "will these strategies achieve the identified goal?"
- Evaluate strategies after campaigns, asking questions like, "is each party pleased with the results and/or process?", "am I satisfied with the strategies chosen?", "would I have chosen a different route?", and "has the implementation of strategies been consistent in relation to my goals?"

## Starting Support Groups

This closed workshop addressed the importance of having PLWHA support groups and how to get one off the ground, including the tactics and challenges for doing so. Participants also shared their views on the characteristics of a good support group.

Participants agreed that support groups give a sense of belonging, which is a precious feeling to have in the context of a lonely disease. Support groups give strength and help to empower people.

PLWHA need to know about similarly situated individuals and that there are people to whom they can turn for help in coping and dealing with being HIV+. Support groups address: learning how to deal with stigma and discrimination; how to deal with marital conflicts; how to tell family members; how to obtain access to medications; where to obtain financial resources; learning where to turn to help orphaned children; and how to obtain gainful employment.

Key elements in setting up a group:

- Define for whom the group is intended
- Know the goals and objectives of the group
- Determine who will be in the group: positives or negatives, or infected and affected
- Establish the level of anonymity and confidentiality
- Recruit the appropriate members with confidentiality as a guiding principle
- Establish a group identity
- Give the group a name
- Do a needs based assessment to determine what sessions to set up

Challenges to setting up a group:

- Finding a safe place to meet
- Difficulties for members to attend meetings
- Some individuals are more comfortable in one-to-one contact
- Need to know which support groups work best in which country
- Politics and bureaucracy might hinder people from joining
- Lack of government funding

What makes a good group? A good support group does not necessarily have to be formal, but it should have *certain basic characteristics*:

- Give a feeling of non judgmentalism and acceptance
- Confidentiality
- Engender trust
- Openness and cooperation
- Organization and rules
- Have a facilitator, direction and goals
- Be empowering
- Have energy, enjoyment, and humor
- Equality among all members
- Provide feedback
- Have and/or provide resources

## Resource Mobilization

The objectives of this workshop facilitated by the International HIV/AIDS Alliance and some of its Latin American partners were to gain a clear understanding of: the difference between resource mobilization and fundraising, the steps to follow to mobilize resources strategically, and how to ask resource providers for what is needed. The workshop was also a way of introducing and getting feedback on a draft of the Alliance's toolkit on "Raising Funds and Mobilizing Resources for HIV/AIDS Work" (published in June 2002), currently available on the Alliance's web site at [www.aidsalliance.org](http://www.aidsalliance.org).

Resource mobilization concerns an organization's obtaining the resources needed to do the work it has planned. It differs from fundraising because it has to do with obtaining a range of resources (rather than just money, for instance) from a wide range of resource-providers via a variety of different mechanisms. Resources, of course, can include money but they can also include technical assistance, human resources, material goods, and free services and facilities.

The mechanisms involved in resource mobilization are the different ways of directly getting resources. These can be: to provide services to gain resources, to sell products to gain money, to hold resource mobilization events and on-going campaigns, and to solicit resources or contributions.

Resource providers are those entities that give the resources, such as international agencies, bilateral and multilateral agencies, NGOs, businesses, individuals, and religious groups.

Planning for resource mobilization. There are nine steps that help to mobilize resources strategically:

- Create a strategic plan.
- Link strategic plans to resource mobilization.
- Review current resource positions and identifying gaps.
- Research and collate information about potential resource providers.
- Identify different resource providers.
- Create a priority-based resource action plan.
- Meet resource providers.
- Develop and follow up a winning proposal.
- Maintain relationships with resource providers.

It is also necessary to include some type of evaluation in order to ensure that both the strategic and resource plans do not remain static.

In preparing the strategic plan be: Realistic, organized, and strategic.

Pitching to resource providers means targeting them and planning specifically for them. To do this you need to:

- Know their needs regarding programmatic and geographical areas of interest.
- Use their Language, i.e., the key words and phrases they use, find out the language they don't like and understand why they use the language they do.

- Understand their motivations, because their motivations affect how they perceive the role of NGOs/CBOs and PLWHA. These might be promoting human rights, poverty reduction, reproductive health, or facilitating academic research.
- How they work with the national governments.
- Above all, demonstrate confidence and offer human contact about how you feel about your work. Show a good track record by documenting what you do. This is very important. It allows the funder to share with colleagues and justify why they should give you money.

### Creating a Global Fund and Global Fund Workgroup

This workshop took place over two different days. The first session provided background on the Global Fund to Fight AIDS, Tuberculosis, and Malaria (the “Global Fund”) as well as a review of the history of the Global Fund from July 2000, with the G8 summit’s endorsing action of a global fund, to October 2001, with the first meeting of the Transitional Working Group (TWG), the administrative organ in charge of setting up the Global Fund.

In the second session, working groups were established to develop recommendations on the Global Fund. The results of the meetings of the working groups were synthesized into a position paper on the Global Fund called the “Trinidad Challenge”. Representatives of GNP+ submitted this document, reproduced below, at the NGO and Civil Society Consultation of the Global Fund, which took place shortly after the Conference.

## **“The Trinidad Challenge to the Global Fund”**

*A position paper developed at the 10th International Conference of People Living with HIV/AIDS, Port of Spain, Trinidad*

### **Conclusions of Working Groups**

*Through the Global Fund Workshop, delegates to the 10th International Conference of People Living with HIV/AIDS convened a number of working groups to make recommendations concerning critical issues of the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria.*

*These recommendations are a challenge to decision makers concerning the operational aspects of the Fund to include and encourage transparency and broad participation of civil society and especially persons living with HIV/AIDS in key areas of policy.*

### **Considerations:**

*Understanding that the Fund will include all three diseases, AIDS should be the top priority because:*

- *The other diseases are curable.*
- *AIDS deaths are often hidden - deaths are recorded as TB in the HIV+ population.*
- *The social stigma attached to AIDS is much greater.*
- *Controlling AIDS has a direct impact in controlling TB, rather than the other way around.*

### **Governance:**

*People living with HIV/AIDS (PWAs) must be represented on the governing body of the Fund as well as other representatives of civil society.*

### **Overall Eligibility Criteria:**

*All countries who are eligible to receive funding should meet the following criteria:*

- *A comprehensive strategic plan must be in place.*
- *PWA's must be included in the proposal process.*
- *A well-defined implementation plan is necessary.*
- *A monitoring mechanism must also be included.*

### **Country Eligibility Criteria:**

*The Fund must not only take into account country income but also issues of incidence and prevalence of AIDS in making funding decisions. This can only be done on a country by country basis.*

### **Characteristics of the Epidemic to be Considered:**

- *Priority in funding should go to countries based on high prevalence of HIV infection.*
- *Incidence should also be considered as deciding criteria.*
- *Country proposals must reflect the nature of their specific epidemic in terms of vulnerable and affected populations.*

### **Income Considerations:**

- *Developed countries should be excluded from receiving funds.*
- *The focus should be on the poorest countries.*
- *Low-income countries (UNDP list of Least Developed Countries) could receive unmatched funding from the Fund and should take priority.*
- *Middle-income countries or economies in transition could apply for funding, but would need to match the funding they receive with additional matching resources of their own (quantifiable in monetary terms) in order to show political commitment.*
- *In certain instances, there should be a mechanism for NGOs to receive funding directly, such as conflict situations, government instability, corruption or in the case of refusal to match funding (middle-income).*

### **Country Level Process:**

- *PLWHA must be involved in all aspects of proposal development and implementation and it should be noted that PLWHA would require technical support to do this.*
- *The Fund should take responsibility itself to ensure both transparency and PWA involvement in the country process.*
- *There is a need for a central facilitator to involve all different stakeholders within the country, sometimes this facilitator could be the UN System, other times it could be the government.*
- *There should be a two-stage proposal process whereby a country first develops a framework of how it will construct the proposal with the various different stakeholders and the second stage that involves the proposal itself.*
- *There must be a completely open proposal review process - for example, six weeks posted publicly on the web, with comments made directly available to the Fund's technical reviewers.*
- *Some funds must flow directly to NGOs as part of the overall country proposal through some in country fiduciary agent.*
- *Country projects with a commodity component must use best value procurement (least cost/best quality) system.*

### **Technical Review:**

- *The proposal development process should be transparent and broad-based and verifiable by the Technical Review Panel.*
- *The members of the Technical Review Panel should be appropriately remunerated to ensure their full and active participation.*

- *Keeping in mind the critical nature of the AIDS epidemic, countries should be allowed to resubmit proposals after receiving specific recommendations or adaptations from the Technical Review Panel or to allow approval of a part of the proposal and resubmission of another part.*
- *In addition to being an eminent technical expert, the Technical Review Panel should be convened by someone who is well respected, a good facilitator and group leader.*
- *PWA representation must be included on the Technical Review Panel.*

### **Accountability:**

- *The Fund must be accountable first to keep all stakeholders included and involved in the proposal development process*
- *The Fund should consider its accountability within the context of assisting in the achievement of the goals of the Declaration of Commitment of the United Nations Special Assembly on HIV/AIDS (UNGASS).*

### **Plenary Four, Beyond Principles: GIPA In Practice**

Salvatore Niyonzima, UNAIDS, was the first presenter at this fourth plenary. He explained the GIPA principle and the work UNAIDS is undertaking in promoting and implementing GIPA. However, far from being a lecture on the meaning of GIPA or a didactic précis on the activities of UNAIDS\*, his presentation was first and foremost a moving call to action for PLWHA.

In his speech he explained that GIPA is the recognition that the direct and personal experience of PLWHA adds value to the global response against the epidemic. However, he is realistic about the fact that not all PLWHA will be willing or able to be recognizably involved in the response. In consequence of this reality, he argued

that GIPA requires leadership: someone to take the lead and to take risks, to bear the burden of prejudice, stigma, discrimination, hostility and even violence. Today, more and more PLWHA have unleashed the power to raise their voice and break the conspiracy of silence and denial that surround HIV/AIDS. In exchange for the risks taken, GIPA builds on courage and generosity. Those who decide to step up and participate turn a personal tragedy into a positive energy to fight the epidemic.

GIPA calls for the creation of an environment that enables the active and meaningful involvement of PLWHA in the response to the epidemic at all levels, and the fostering of their individual and collective development. Direct experience of living with or being affected by the virus can be considered a kind of expertise if it is complemented by certain skills. Active PLWHA provide a reality check to HIV and contribute to reduce stigma, changing the perception of the epidemic in the world.

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*“When decisions are being made, we want to be part of the process right from start. We want to be there because this is about our lives and the lives of those we love. We want to be there because we know what our needs are better than anyone else. We want to be there because we have a substantial contribution to bring. An era has come to an end: we want to do more than just “giving the epidemic a human face and voice” because we are not just faces to showcase and voices to hear. We are people; no more but no less! We are resources! This is our commitment, this is our work, we can do it, we will do it!”*

*-Salvatore Niyonzima*

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Yolanda Simon’s presentation followed. She further emphasized Mr. Niyonzima’s point with the idea that PLWHA are not asking for pity or handouts but for a paradigm shift to true partnership with the PLWHA community. She also brought a perspective on GIPA involvement that draws on the experience in the Caribbean region, including the work CRN+ has done to sensitize governments. Myrna Villalon, CCIETS (Cuba), spoke of how GIPA has been approached in Cuba, with PLWHA forming mutual

assistance networks and handling education, including advocacy training. Last but not least, John Ibikwe, AAN, elaborated on the situation in Nigeria, where the NACHA was set up by the government and did not include PLWHA until they were included through advocacy. PLWHA are now represented on a presidential committee.

*\*For further information on UNAIDS activities related to GIPA please allow us to suggest consulting the “UNAIDS Report” (1999), “Enhancing GIPA in sub-Saharan Africa. A UN response: how far have we gone?” (2000), and “The faces, voices and skills behind the GIPA Workplace Model in South Africa” (2002).*

## Parallel Forum Sessions

### HIV+ Working in Prevention

This open session focused on the involvement of PLWHA in HIV prevention. Andrew Doupe of UNAIDS gave the first presentation. He addressed whether PLWHA should get more heavily involved, and if so how, in prevention work. PLWHA have survival on their own agendas, given how much work there is to do in terms of treatment access. PLWHA involvement, however, is key in helping realize an approach to HIV/AIDS that follows the prevention-to-care continuum. To better understand Mr. Doupe’s point, one should consider that, for example, reducing stigma encourages people to seek testing, care and support, and that it can encourage communities to be more supportive. It has been demonstrated repeatedly that PLWHA have a crucial role to play in reducing stigma, be it by putting a human face to HIV/AIDS, demystifying the disease, or by showing that having HIV/AIDS is not a death sentence or that any type of person can contract it.

Carlos de Leon gave the second presentation. His main points were as follows: For PLWHA to participate directly in prevention there must be a commitment to prevention on the part of the PLWHA community. PLWHA need to be more visible members of society if they are to take part in prevention more directly. Sexual health work must be productive, and for that PLWHA must be remunerated for the services they render.

Promise Mthembu, ICW, spoke next on the factors that affect women negatively in the context of the epidemic, and in particular on the fact that women's issues are not addressed in HIV prevention programs. She argued that AIDS programs tend to be generalized and don't address prevention for women. Ramón Acevedo of REDOVIIH spoke next. He further emphasized the point that prevention starts with reducing stigma against people infected with HIV or affected by HIV/AIDS. Lastly, Yoire Ferrer of CPPS, Cuba, spoke about PLWHA involvement in prevention work in Cuba, describing the specifics and degrees of that involvement.

Finally, this session asked some hard questions. Participants argued that prevention efforts are failing because the HIV infection rate continues to rise. There is, therefore, a need to be realistic and honest with ourselves: "Are our prevention programs failing because we do not want to address failure?" Frank discussions of failure are lacking when dealing, for example, with issues of how HIV positive people came to be infected.

## HIV as a Workplace Issue

Terje Anderson, NAPWA and GNP+ NA, and Mohammed Farouk Auwalu, AAN, both gave presentations on labor issues as they relate to HIV in their respective countries of employment, and Michele Jankanish, ILO Caribbean, gave a presentation on the ILO code of practice on HIV/AIDS and the workplace.

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*"Beyond the suffering it imposes on individuals and their families, the epidemic is profoundly affecting the social and economic fabric of societies. HIV/AIDS is a major threat to the world of work: it is affecting the most productive segment of the labour force and reducing earnings, and it is imposing huge costs on enterprises in all sectors through declining productivity, increasing labour costs and loss of skills and experience." (ILO, 2001, p. iii)*

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Since a copy of the ILO code can be found readily on the ILO web site at [www.ilo.org](http://www.ilo.org) or by contacting them directly, we will not reproduce Ms. Jankanish's introduction to the Code here or the ILO guidelines which that introduction covered, but we will include the part of her presentation that addressed specific questions on HIV/AIDS and workplace issues, as it contains educational components.

### ***"HIV as a Workplace Issue: The ILO Code of Practice"***

***Edited excerpts from Michele Jankanish's presentation***

#### ***Should job applicants be required to be tested?***

*No. Any testing for fitness should not include mandatory HIV testing.*

#### ***What if the employer doesn't require a test, but insurance companies will not provide coverage without a test?***

*Insurance companies should not require HIV testing. Employers should not facilitate testing for insurance purposes. Information they have should remain confidential.*

#### ***Should workers be subject to periodic testing?***

*Doing so is unnecessary, and it imperils human rights and dignity. Anonymous testing for epidemiological purposes is allowable as long as it follows the ethical guidelines established for scientific research, professional ethics, and the protection of individual rights and confidentiality. Employers and workers must be informed and consulted when such research is undertaken.*

#### ***What about voluntary testing?***

*Normally, voluntary testing should take place away from the workplace, by suitably qualified personnel, and meeting strict confidentiality and disclosure requirements. There must be the*

written informed consent of the worker, with advice of the worker's representative if requested. Pre and post counselling should be part of the procedure.

***If there has been a possible exposure at work, what should the employer do?***

*The worker should be immediately counselled about the medical consequences, the desirability of testing, the availability of post-exposure prophylaxis, and referred to appropriate medical facilities. Further guidance should be given as to the legal rights of the worker and information on the eligibility and procedures for obtaining workers' compensation.*

***What should happen to information about a worker's HIV/AIDS status?***

*With regards to results of voluntary testing and medical data relating to workers, privacy and confidentiality must be maintained. The information must be kept strictly confidential and only in medical files and access must be restricted only to medical personnel.*

*Should an employer dismiss a worker who is HIV positive to protect the rest of the workforce?*

*HIV infection is not a cause for termination of employment. Where a worker is too ill to work, the employment relationship may cease in accordance with anti-discrimination and labor laws respecting general procedures and full benefits. Employers must engage in risk reduction and management and take up additional protective measures where there is contact with blood and bodily fluids.*

***What kind of adaptation at work might be necessary for someone with AIDS-related illnesses?***

*In consultation with workers and their representatives the following can be reasonably accommodated: rearrangement of working time; availability of special equipment; rest breaks; time off for medical appointments; part-time work; and return to work arrangements.*

## **UNAIDS/GIPA: A Plan in Progress**

Savaltore Niyonzima, UNAIDS, and Lisette Mendosa, REDOVIIH, spoke in this open panel discussion about what makes PLWHA involvement difficult. PLWHA hesitate to publicize their status or to advocate in the HIV/AIDS movement in part because of stigma, marginalization, and ignorance, all of which also make coping with HIV/AIDS difficult. Mr. Niyonzima also discussed lack of involvement when it arises from PLWHA themselves. For example, some people feel they cannot become involved because of their responsibilities to their families. They might fear for the safety or wellbeing of their partners or children, if they publicize their positive status. In addition, some PLWHA misconceive GIPA as a United Nations project or program rather than as a strategy. This is in part because UNAIDS has been implementing pilot projects in different countries in order to evaluate how best GIPA can work and to help develop policies built around GIPA.

Milly Katana, HRAG, presented a project called the "Analytical Review of HIV/AIDS Initiatives targeting communities in Uganda", that concerns the status of human rights as they relate to PLWHA in Uganda. She also set about to address the question, "How can you move from the principle of GIPA to practice of it?". Let us consider her answer below.

***"Involvement of PLWHA in the AIDS Response and Plans in Progress"***

***Edited excerpts of Milly Katana's presentation***

*[...]The involvement of PLWHA in the Western developed world set a record in history when people who are affected by a problem came out to spearhead the efforts to look for a solution. Today we owe HIV/AIDS activism and all the fruits that have arisen from it to the fearless endeavors made by these PLWHA. They were the first people to break the silence about a disease branded shameful.*

*We now know that one's life does not necessarily have to be changed because one has HIV... We are now moving into an era where PLWHA should be integrated into normal life as much as possible.*

*Since the early years of the involvement of Western activists, a few policy makers realized that the involvement of PLWHA is crucial in management of the disease, and in the developing world a few people who have come out to identify themselves as being HIV positive are being brought into implementation efforts. For example, the GIPA effort of the United Nations (UNAIDS) has developed a Pyramid of Involvement:*



*As what happened in the developed world, any improvements in the magnitude of involvement of PLWHA has taken considerable effort. In some countries, where PLWHA have been encouraged and supported to make a contribution towards the national AIDS responses, the levels of infection are levelling. The disease has been demystified and levels of stigma and discrimination are considerably lowering. This can be attributed to many factors including: The community of people infected with HIV being supported to appreciate their position in the spread chain and prevention effort; the uninfected being brought to realize how vulnerable they are to infection; the momentum being kept for young people to*

*realize personal vulnerability to infection; and getting equipped with prevention knowledge on top of having the information.*

*As we look into the future, we need to humble ourselves as people living with HIV/AIDS and policy makers, decision makers, and implementors. We need to acknowledge the fact that many of the strategies that have been employed in the past, especially in Africa and other developing countries, have had very minimal impact on the disease. Many countries are registering increases in the infection rates to unacceptably high rates. What then is going to make an everlasting impact? We must make vertical and horizontal expansion on the Pyramid of Involvement, but how?*

- 1. Get more people to identify themselves as PLWHA and therefore seek services to support them. It is the availability of services that is the greatest incentive for people to get involved. We have been talking about access to care and treatment since the conference started.*
- 2. Obtain more people identifying themselves as PLWHA, and support them in their involvement in implementation of AIDS interventions, decision making, and policy formulation.*

*How can this be achieved?*

- 1. Skills-building for PLWHA*
  - Leadership*
  - Advocacy*
  - Human rights observers*
  - Political commitment monitors*
  - Treatment educators*
  - Care givers, etc.*
- 2. Lobbying and advocacy with stakeholders.*
- 3. Changing the dimensions in activism. With this goes a need for renewed activism, especially in the developed world, where the epidemic has matured and there is a fear that many long term activists are getting burnt out.*

# APPENDICES

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## Appendix 1. Listing of Conference Sessions

### Saturday, October 27, 2001

Registration  
Community Forum  
Opening Ceremony  
Opening Reception

### Sunday, October 28, 2001

#### Positive Living:

HIV Disease: Our Bodies, Our Communities  
Open panel: beginners

Positive Women's Survival Kits  
English, closed workshop: HIV+ women

Positive Women's Survival Kits  
French, closed workshop: HIV+ women

Living Well/Nutrition  
Closed workshop: HIV+, pros

Getting Treatment Access, the Work  
Closed workshop: HIV+

#### Positive Environment

Legal Discrimination and Stigmatization  
Closed workshop: HIV+

Human Rights, Monitoring Training  
Closed workshop: HIV+

Women's Lives and Responses in the HIV Epidemic  
Open panel: women, beginners

#### Positive Engagement

Plenary One, Ungass: From Word to Deed

Working with Bureaucrats  
Open panel: pros

Creating a Global Fund  
Open panel: beginner

Starting Support Groups  
Closed workshop: HIV+

### Parallel Fora

Red Cross/Red Crescent: Working in HIV  
Closed workshop: HIV+

HIV+ Working in Prevention  
Open panel: pros

### Monday, October 29, 2001

#### Positive Living:

Plenary Two, Treatment, Care and the Quality of Life

Youth and Prevention  
Open workshop: pros

Communicating with Children  
Closed workshop: HIV+ women

MSM, Safer Sex, Barebacking and Sex w/o Condoms  
Closed workshop: HIV+ MSM

Positive Women's Survival Kits  
Spanish, closed workshop: HIV+ women

Treatment Education, Informing Ourselves  
Closed panel: HIV+, beginner

#### Positive Environment:

Serodiscordant Couples: Let's Talk about Being Positive  
with Negative Partners  
Closed workshop: HIV+

ID & Substance Use, Selfcare and Empowerment  
Closed workshop: HIV+

#### Positive Engagement:

Resource Mobilization  
Closed workshop: HIV+, pros

Participatory Community Assessment and Project Design  
in HIV Prevention  
Closed workshop: HIV+

Global Fund Workshop  
Closed workshop

## Parallel Fora:

**Treatment Access: Progress & Battles. Progress on the Balance of Access to Treatment in the Caribbean**

Open panel

**Vaccines**

Open panel: beginner

**Microbicides**

Open panel: women, beginner

**Building Blocks of Care**

Open panel

## Tuesday, October 30, 2001

### Positive Living:

**Women's Specific Treatment Issues**

Closed workshop: HIV+ women

**Treatment Education, Lower Resources Model**

Closed workshop: HIV+, pros

**Grief and Loss**

Closed workshop: HIV+

### Positive Environment:

**Plenary Three Defeating Stigma and Discrimination**

### Religion, Stigma and Power

Open panel

**Confronting Stigma I: Examining Ourselves, Examining Communities**

Closed Workshop: HIV+

### Positive Engagement:

**Making More HIV+ Leaders**

Closed workshop: HIV+

**Outreach and Politics in Sex Work**

Closed workshop: HIV+

**Causing Change, Lobbying/Organising as HIV+ People**

Closed workshop: HIV+

## Parallel Fora:

**HIV as a Workplace Issue**

Open panel

**From Durban to Barcelona: XIV International AIDS Conference**

**Positive and Negative Working Together**

Open panel: pros

**Regional Events: Caribbean, Latin America, North America, Asia/Pacific, Africa, and Europe.**

## Wednesday, October 31, 2001

### Positive Living:

**Women's Sexual and Reproductive Health**

Closed workshop: HIV+ women

**Men's Sexual and Reproductive Health**

Open panel: pros

**Grief and Loss**

Closed workshop: HIV+

### Positive Environment:

**GNP+ The Future**

Closed workshop: HIV+

**Confronting Stigma II: Responding as HIV+ People**

Closed workshop: HIV+

### Positive Engagement:

**Beyond Principles, GIPA in Practice**

**MSM at the Margins: Outreach and Organization**

Closed workshop: HIV+

**Exploring Microfinance for Resources**

Closed workshop: HIV+, pros

## Parallel Fora:

**UNAIDS/GIPA: A Plan in Progress**

Open panel: pros

**Closing Plenary, Celebrating Our Lives: A Summary**

## **Appendix 2.**

### **Some Epidemiological Facts about HIV/AIDS in the Caribbean**

According to the 2002 UNAIDS *Report on the Global HIV/AIDS Epidemic* some 420,000 individuals have HIV/AIDS in the Caribbean. The Caribbean region has the highest HIV prevalence rates after sub-Saharan Africa, and AIDS is now the leading cause of death among adult (15 to 44 age group) men and women in several Caribbean countries. HIV/AIDS models developed by CAREC, in collaboration with the Health Economics Unit at the University of the West Indies, suggest that if there is not more success with prevention efforts, AIDS will have a very significant impact on mortality in the coming two decades, including expenditures of 3-5 percent of GNP on AIDS.

The countries in the region affected the worst are Haiti, with a national adult HIV prevalence of over 6%, and the Bahamas, with a national HIV prevalence for the same population segment of 3.5%. Adult national HIV prevalence rates in some other countries are as follows: Barbados 1.2%, Cuba < 0.1%, Dominican Republic 2.5%, Jamaica 1.2%, and Trinidad and Tobago 2.5%.

What is perhaps even more worrisome than prevalence rates is that there are no signs that the epidemic is slowing in the Caribbean. With regard to the risk of multiplying the infections through mother-to-child transmission, the situation in the Caribbean appears very serious. For example, according to UNAIDS, 13% of anonymously tested pregnant women were found to be HIV-positive in some areas of Haiti. According to CAREC, approximately 3,000 children are born per year to mothers infected by HIV in CAREC Member Countries (CMC)\*.

Assuming fairly steady levels of reporting, statistical analysis shows a worsening trend in the number of reported AIDS cases in the region from 1982 to 1999. The number of reported AIDS cases has steadily risen from the mid 1980's. In the mid 1990's, to the optimist, it might have seemed the epidemic was beginning to level off. There were

only small increases in reported AIDS cases between, roughly, 1994 and 1997. But then there was a significant jump between, roughly, 1997 and 1998 and a sharp rise of around 500 cases from 1998 to 1999 (CAREC). The situation in the region is particularly striking when compared to its neighboring regions, North America and Latin America. While the number of new AIDS cases was decreasing significantly in Latin America and dramatically in North America toward the end of the last century, they were on the increase in the Caribbean.

With these rates, and according to a low case scenario, the macroeconomic impact in 2005 could be highly negative. A drop of 4.2% in GDP is expected in Trinidad and Tobago and of 6.4% in Jamaica, with dramatic increases in HIV/AIDS expenditure. The epidemic's continual spread in the region will devastate its economies and various sectors, including education, health, agriculture, and business.

According to CAREC, the following factors are driving the epidemic:

#### **Economic and developmental**

- Poverty and inequitable income distribution
- Lack of skills and poor socialisation
- Urbanisation and ghetto formation
- Migration
- Lack of a genuine inter-sectoral response

#### **Social, Cultural and Behavioral**

- Dysfunctional gender relations
- Lack of life-skills for sex education
- Cultural and religious taboos
- Discrimination against and stigmatization of people with HIV
- Sexual norms e.g., insufficient condom use
- Commercial sex work due to poverty
- Criminalization of sex work and homosexuality
- Substance abuse, resulting in risky behavior

### Bio-medical, Ethical, and Access to Care

- Lack of access to care for some populations
- Lack of standards and systems of care and support for PLWHA's
- Attitude of Health workers to people with HIV
- Lack of legal and ethical frameworks for issues surrounding living with HIV

According to UNAIDS the epidemic in the region is mainly fueled by heterosexual intercourse, in combination with early sexual activity and frequent partner exchange among young people. In Trinidad and Tobago, in a large survey of men and women in their teens and early twenties, fewer

than a fifth of the sexually active respondents said they always used condoms, and two-thirds did not use condoms at all. Age mixing (younger women having sex with older men) also drives the Caribbean epidemic. HIV rates are five times higher in girls than in boys aged 15-19 in Trinidad and Tobago. At one surveillance center for pregnant women in Jamaica, girls in their late teens had almost twice the prevalence rate of older women.

\*Bahamas, Turks and Caicos, Bermuda, Barbados, Trinidad & Tobago, Dominica, St. Vincent, St. Kitts and Nevis, Guyana, Antigua & Barbuda, Jamaica, Grenada, British Virgin Islands, Belize, St. Lucia, Cayman Islands, Anguilla, and Montserrat.

## Appendix 3. A Historical Précis on 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 on 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".
- The Fifth International Conference in London in 1991, where 530 people from 53 countries gathered under the subject, "HIV and Human Rights-From 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 in September 1993, which took place in Acapulco, Mexico. 270 delegates attended 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. 357 delegates from 53 countries attended the conference.
- “Uniting for Equality” was the theme of the ninth conference and again was co-organized by GNP+ and ICW. It was held in August 1999 in Warsaw, Poland, with 470 delegates in attendance.

## Appendix 4. Data on the Delegates

### Total Number of Participants: 418

#### Number of Participants per Country:

Antigua 6	Germany 7	Peru 3
Argentina 1	Ghana 3	Philippines 1
Australia 3	Grenada 5	Puerto Rico 1
Bangladesh 1	Guatemala 5	Russia 1
Barbados 13	Guyana 16	Rwanda 1
Belgium 5	Haiti 11	Samoa 1
Belize 2	India 4	Singapore 1
Benin 1	Indonesia 3	South Africa 11
Bermuda 2	Israel 2	Spain 1
Bolivia 1	Italy 10	Sri Lanka 1
Brazil 6	Jamaica 14	St. Kitts & Nevis 2
British Virgin Is. 5	Japan 1	St. Lucia 3
Cambodia 2	Kenya 3	St. Maarten 2
Cameroon 1	Latvia 2	St. Vincent & the Grenadines 5
Canada 10	Malawi 1	Suriname 5
Cayman Is. 2	Malaysia 5	Switzerland 4
Chile 9	Mauritius 1	Trinidad & Tobago 57
Colombia 5	Mexico 7	Turks & Caicos Is. 3
Costa Rica 3	Namibia 3	Uganda 3
Cuba 25	Nepal 1	United Kingdom 28
Czech Rep. 1	The Netherlands 7	United States 33
Denmark 2	New Zealand 1	U.S. Virgin Is. 4
Dominican Rep. 3	Nicaragua 1	Venezuela 3
Ecuador 2	Niger 1	Zambia 1
El Salvador 1	Nigeria 5	Zimbabwe 8
France 1	Papua New Guinea 3	

## Afterword

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*The 10th International Conference was a miracle. After committing to an event with two global partners in 1999, CRN+ and CARE discovered in July 2000 that GNP+ would be their only International partner. Then, ten months before the conference GNP+ experienced a change in directorship. The successful execution of the conference and the participation of scores of HIV+ Caribbean people in the presence of these complications is evidence of the great commitment and perseverance of these two organisations.*

*GNP+ is greatly indebted to both Claudette Francis, Conference Co-ordinator, and Yolanda Simon, Conference Chair, for their marathon of work. One of the myths this conference dismissed was that a 'developing country' setting must rely on solely northern resources to stage such an event. The large number of Trinidadian and Caribbean supporters of this conference is a real victory for the Local Organising Committee and the people of Trinidad and Tobago.*

*The professionalism, initiative and enduring performance of the Local Organising Committee was a brilliant demonstration of how one community, HIV+ people and their supporters, can come together and make something happen. HIV, while an everyday reality in Trinidad and Tobago, is not an everyday topic. The courage and dedication of this team was inspiring. It was a joy and a privilege to work with each and every one of them. When I think of Trinidad, I think of them.*

*A very special mention must be given to Wendy Francis, the Conference Administrator. Wendy came from outside of the HIV/AIDS sector and graciously went well beyond the call of her job description to take care of each one out of the hundreds of us-with our health issues, our travel dramas-coming to Trinidad.*

*The bank of local volunteers made this conference happen. From the Local Organising Committee and the Scholarship Committee, obligated to read scholarship applications in three languages and to address the challenges of transportation and three hotels, to the crack medical team, we were lovingly cared for throughout the conference experience.*

*There were shortcomings. The most heart-rending was the last-minute cancellation of many scholarships as anticipated funds were, in the end, not available to pay for the travel and hotels needed. We deeply regret the disruption and disappointment caused, and GNP+ is committed to restoring confidence.*

*The Board and Regional Co-ordinators of the Global Network of People of People Living with HIV/AIDS came together to perform diligently in Port of Spain. Their support and hard work created the programme, the heart of the conference. This conference is also their triumph, a team of dedicated leaders having emerged.*

*The last acknowledgement is the writing of this conference report. Jennifer Bushee, the GNP+ Communications Coordinator, drafted the document. She made use of the large body of material generated from the conference to craft a faithful representation of our time together, and pushed all of us who attended to contribute. This document is the fruit of her tireless and dogged research and synthesis. We cannot thank her enough. Many thanks to the team of rapporteurs from the University of the West Indies for their records of the work of each session. Thanks also to Mark Ladd for his finishing work on both the web and print versions of this report.*

*When I think of the 10th International Conference, I simply marvel at some of the magical moments. The glorious voice of Miss Ella in the Opening Ceremony, calling to "Bring Down the Power of Love" on our gathering; the salsa sessions of Cuban delegates; the sometimes funny, sometimes heart-rending, but always inspiring sharing of personal life and work in the sessions; the late night meetings of the Programme Committee, dealing with the last-minute changes in the programme; and dancing out of the conference closing.*

Warmly,

Stuart A. Flavell, International Co-ordinator  
The Global Network of People Living with HIV/AIDS  
Amsterdam, 27 October, 2002