

Indispensable:

People Living with HIV/AIDS and Achieving Universal Access to AIDS Treatment, Care and Prevention by 2010

Donor Consortium Conference

**Noordwijk, the Netherlands
16-17 March 2006**

Hosted by the Global Network of People Living with HIV/AIDS (GNP+),
the International Community of Women Living with HIV/AIDS (ICW)
and the International Treatment Preparedness Coalition (ITPC)
in partnership with UNAIDS and the Netherlands Ministry of Foreign Affairs
and with support of the AIDS Fonds Netherlands.

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The following acronyms are used in this report:

GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	greater involvement of people with HIV/AIDS
GNP+	Global Network of People Living with HIV/AIDS
ICW	International Community of Women living with HIV/AIDS
IDU	injecting drug user
ITPC	International Treatment Preparedness Coalition
MSM	men who have sex with men
MTCT	mother to child transmission
OI	opportunistic infection
PEPFAR	U.S. President's Emergency Program for AIDS Relief
PLWHA	people living with HIV and AIDS

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Foreword

This Donor Consortium Conference has been a historic conference: for the first time PLWHA networks and donors came together to have frank and vital discussions. During the meeting participants all agreed that application of the GIPA principle is of crucial importance to attain universal access, to fight stigma and discrimination and to achieve knowledgeable advocacy. There can be no sustainable long-term response to HIV/AIDS without the meaningful involvement of the networks of PLWHA, since these networks play a crucial role in building local capacity and enabling local, regional and international advocacy.

The meeting also helped to identify the most important issues and bottlenecks for an effective participation of PLWHA within the HIV/AIDS response. Priorities were set both for the networks as well as for donors. The networks need extensive and predictable core funding support. Donors could show their commitment by providing core funding to these networks, applying the GIPA principle and assisting the networks with skills development and strategic assistance.

Donors, on the other hand, would like to obtain more specific and extensive data of the networks on the impact of their activities. The impact and outcomes have to be measured at the country level and at a broader level; these data will ensure better documentation of lessons learned. In addition, networks of PLWHA should explain better and demonstrate to donors why core funding is the best option to finance these networks.

This meeting was a milestone and a first, but crucial, step towards more extensive collaboration between donors and the networks of PLWHA in the worldwide response to HIV/AIDS.

Ambassador Paul Bekkers

AIDS Ambassador of the Netherlands

Overview and Background

The Donor Consortium Conference, held 16-17 March 2006 in Noordwijk, the Netherlands, was organized and hosted by GNP+ in partnership with UNAIDS and the Netherlands Ministry of Foreign Affairs and with support from AIDS Fonds Netherlands. It was structured primarily to broaden donor awareness of the activities of three key organizations run by and for people living with HIV/AIDS (PLWHA): GNP+, the International Community of Women living with HIV/AIDS (ICW), and the International Treatment Preparedness Coalition (ITPC).

More than 50 people from some 20 countries attended the meeting, which featured an opening address by UNAIDS Executive Director Peter Piot. Attendees included PLWHA working with GNP+, ICW, ITPC and their affiliated networks; other HIV treatment and prevention advocates; and representatives from donor entities across the bilateral, multilateral, and for-profit spectrums.

The overall goal of the meeting was two-fold:

- 1) to identify and remove obstacles limiting donors' understanding of the extensive – and growing – role of the three organizations in addressing issues of importance to PLWHA around the world; and
- 2) to provide donors with an opportunity to outline their funding priorities and objectives in regard to HIV/AIDS issues, notably those associated directly with PLWHA networks and community groups. During and after a series of presentations about the organizations, discussion focused on the following areas:

- the challenges that the PLWHA movement faces and how these might best be met;

- the level and kind of support, financial and otherwise, that might enable PLWHA organizations to continue and improve their outreach and advocacy efforts;
- potential strategies to create consistent and sustainable partnerships among PLWHA organizations and donors; and
- the future roles and responsibilities of all partners involved in shaping a meaningful global response to HIV/AIDS.

In general, participants agreed that as PLWHA organizations become more assertive and knowledgeable about donors' expectations and interests, they will in turn benefit greatly from donors' increasingly proactive engagement. The dialogue initiated at the Noordwijk meeting marks the start of a vital process and potentially heralds new thinking about goals and partnerships involving all entities focusing on HIV/AIDS issues.

This report is not intended to provide in-depth coverage of the entire conference. Instead, it summarizes the following:

- key issues and concerns raised during presentations by representatives from PLWHA organizations, including GNP+, ICW, ITPC and the Collaborative Fund for HIV Treatment Preparedness;
- key issues and concerns raised by donors, especially in terms of what they need from PLWHA organizations in the future to increase the likelihood of extensive, sustainable support; and
- proposed action steps, both short- and longer-term, to build on the momentum established at this initial gathering. Participants agreed to establish a working

group to set a preliminary timeline and to recommend concrete steps and policies to move the process forward.

II ■ Opening Address by Peter Piot

Paul Bekkers, the Dutch AIDS Ambassador, opened the meeting by introducing UNAIDS Executive Director Peter Piot. In his remarks, Piot discussed the genesis and subsequent history – which in his opinion has been far from illustrious in terms of implementation – of the GIPA principles, which were first codified nearly 12 years ago. His overall message was a) there can be no sustainable long-term response to HIV/AIDS without the involvement of networks of PLWHA; and b) these networks' greatest need in terms of financial assistance is more extensive core funding support from donors. Without sufficient core funding, he said, PLWHA organizations find it difficult to consistently and effectively implement the specific projects that donors generally prefer to support.

Excerpts from Piot's speech include the following:

GIPA (greater involvement of people with HIV/AIDS).
“The frustration is that...after so many years we're still trying to make a reality today of what was agreed quite a long time ago. Although there has been some progress toward achieving greater GIPA...I'm not convinced it has been very effective. The general response has been tokenism, not real support. If there had been better progress, I think the AIDS response would have been more advanced. It's really one of the missing links.

“When we talk about universal access and a sustainable response, we focus on long-term funding and health systems. But also important are community capacity and empowerment of PLWHA. I'm convinced that for long-term support this is just as important. I would say

that my first message is that we will not be able to deliver universal access without creative empowerment [and] support for groups of PLWHA. We don't need to be defensive in our efforts, but we need to present the case in a clear way.”

Funding for PLWHA groups. “The second point I'd like to make is that if we accept the first message – that no sustainable large-scale response is possible without PLWHA – then we must provide core funding for organizations run by and organized for them. We have heard from some donors that they can only supply money for projects. But how can you run a project if you don't have the money to establish a system?”

AIDS 'exceptionality'. “Much as I believe that we should aim for integration in provision of health services... AIDS would disappear from the agenda if that were the approach. If we had to wait for health systems to be functioning, we'd all be dead.

“AIDS should not be put in competition with other infectious diseases. We need to fight for the exceptionality of AIDS. We have to be clear: AIDS today is in the league of the major issues of our time, like global warming. That's where and how the discussion must be based. We must define this battlefield ourselves. This is why it's so important to mobilize funds for these three networks.”

III ■ PLWHA Perspectives:

Why Greater Support is Crucial and What is Needed Most

■ 1) First-hand accounts of living with HIV/AIDS in 2006

Three PLWHA attending the conference spoke about the difficulties they and others in their communities face in obtaining *access to vital social, legal, and medical services and assistance*. Some of the major concerns noted from their perspectives were lack of

- confidentiality and privacy;
- core antenatal care;
- funding of community-based activities; and
- research into pediatric treatment.

At the heart of all three speakers' comments was the belief that PLWHA networks play a vital role in providing a way for individuals and communities to make such problems and concerns known to donors who might otherwise have little access to grassroots organizations. Following are excerpts from two of the PLWHA's short presentations:

Loon from India

"I'm an ex-drug user. I got my lovely partner's [HIV] in the 1980s. There have been so many developments since then, many of them good. But I still have many concerns. I have no health care security. I have a job, but what about tomorrow? I have children; I have a family. What will I do to take care of their needs?"

"I'm also concerned about the lack of treatment availability in my country. It's very sad for me that in a country like India, which makes so many drugs,

only 15,000 people are getting ARVs now – although some 700,000 may need them. It is also almost impossible to get second-line treatment through the government. So I buy my drugs from a buyers' club... this is something we organized among ourselves, within the community, because no one else would help us."

Patricia Asero, from NAP+ in Kenya

"For a long time after I tested positive [in 1990] I was very healthy, but then I started getting sick. I had to breastfeed because I could not afford food to put on the table...and I passed HIV to my baby. This made me very depressed. But thanks to other PLWHA I was able to get back on my feet. And now I take drugs; they have saved me.

"I'm the coordinator of a community-based organization, but I can't be there full time. I want to be there full time, though, because I want to do what I do best. But no one wants to fund small community organizations like mine. Among the problems we have are how to arrange transit to clinics and other sites. Also, it costs \$15 to have a CD4 test done. Most people, including me, cannot afford that fee.

"Many babies continue to die because there are no drugs for them. I've seen mothers breaking up drugs to give to their babies, but they don't know what they are doing."

■ 2) Summary of challenges and gaps to achieving universal access

According to several participants, PLWHA around the world far too infrequently have access to the treatment and prevention services they need for reasons including:

- limited access to accurate and updated information about availability of resources;
- inadequate care and support programs for PLWHA (including lack of treatment literacy, adherence support, and substitution therapy);
- limited funding for achieving universal access; and
- insufficient recognition by donors and government agencies of the important role PLWHA can and should play in increasing access to services and responding to all aspects of the epidemic.

■ 3) Implementing GIPA: The importance of including PLWHA in all responses

Several participants noted that evidence from around the world indicates that the most effective responses to HIV/AIDS are those in which PLWHA and their community organizations are directly involved.

Among the many reasons cited, the direct involvement of PLWHA is important because they

- have first-hand experience with key issues related to treatment and prevention efforts, including side effects and adherence;
- can serve as role models within communities, including efforts to increase testing uptake and reduce stigma and discrimination;
- are less likely to discriminate, in service delivery, based on HIV status or risk behaviors;
- are the most passionate and knowledgeable advocates, as noted by many organizations' frequent and persistent confrontations with governments that have been unwilling to respond appropriately and extensively; and
- are uniquely committed because their lives depend on the results of their work.

4) PLWHA's expectations from donors

To address the challenges and gaps noted previously, PLWHA at the meeting said they seek the following from donors:

- *commitment to fund* the work of PLWHA organizations and networks;
- provision of strategic assistance, notably greater levels of *core funding* for organizations;
- assistance with *skills development*, particularly among new organizations operating in areas and communities that have been poorly served; and
- greater commitment to the *GIPA principles*. This would entail renewed effort to involve PLWHA and community organizations in decision-making processes – including their input and leadership in helping design and fund prevention, treatment, care and support programs.

As noted by one PLWHA participant:

“We’re asking donors to take a leap of faith – to involve us in helping set funding priorities. This is important for community organizations that may otherwise have to rely mostly on governments for funding. If you’re dependent on the government for your funds, you can’t be an advocate and watchdog to make sure that government does the right thing.”

“It is also important for both organizations and donors to ensure that funding is based on evidence. Every single effective response to HIV/AIDS – except for the discovery of the virus and the drugs themselves – has been developed by PLWHA, including home-based care models, peer support, [...], and safer sex. We would not have a UNAIDS, a GFATM, or a good WHO model if we did not have independent advocacy of people living with HIV/AIDS. Unless we have independent funding, we cannot do this work easily and effectively.”

IV Network Presentations

At the conclusion of the initial discussion regarding the importance of GIPA, a representative of each of the three primary PLWHA networks – GNP+, ICW, and ITPC – gave a brief presentation about his or her organization. A representative from an affiliated entity, the Collaborative Fund for HIV Treatment Preparedness, also spoke. All four presentations focused on missions, strategies, goals, and achievements.

The presentations were based on the following overviews of each organization. The overviews for the most part are repeated verbatim from text provided directly by the organizations.

1) GNP+

GNP+ is at its core a human rights organization: it was created 20 years ago with the stated goal of helping all HIV-positive people identify common needs and advocacy strategies to fight for their health, legal, and social rights. Prior to 1992, the organization was known as the International Steering Committee of People Living with HIV/AIDS.

Guiding principles of GNP+

The people active in and around GNP+ share basic principles that include:

- a commitment to ensuring that the network is driven by constituencies' needs;
- the understanding that AIDS is a human rights issue;



- an acknowledgement of the need to address gender inequalities; and
- a commitment to solidarity, hope, compassion, inclusion, and diversity.

Global Advocacy Agenda

The work of GNP+ is based on a policy platform, the Global Advocacy Agenda. The Global Advocacy Agenda focuses on:

- promoting global access to HIV care and treatment;
- ending stigma and discrimination against people living with HIV/AIDS; and
- promoting the GIPA principles in the decisions that affect the lives of PLWHA and their communities.

GNP+ seeks to achieve its mission through advocacy, capacity building and communications programs that draw from strategies based on lobbying, linking, and sharing. One of its core activities over the past 20 years has been to organize the International Conference of People Living with HIV/AIDS. The most recent conference, scheduled for October 2005 in Lima, Peru, was canceled due to lack of funds. GNP+ currently hopes to reschedule in Lima in 2007.

Organization structure

In an effort to bridge the gap between global and grassroots advocacy, GNP+ works closely with six affiliated regional networks of people living with HIV/AIDS, one each in Africa (NAP+), Asia/Pacific (APN+), the Caribbean (CRN+), Latin America (RedLa+), Europe (GNP+ Europe), and North America (GNP+ NA). These networks are represented on the board of directors of GNP+, which maintains a central secretariat in

Amsterdam. The regional networks get their direction and mandate from their national and sub-regional member organizations and structures. This structure is intended to ensure that the roots of GNP+ reach directly to PLWHA around the world. (GNP+ is currently working with other groups to establish a network in the Middle East/North Africa.)

Partnerships

GNP+ works in collaboration with UN agencies, global partners, national governments, civil society and the private sector, including:

- International Federation of Red Cross and Red Crescent organizations (IFRC)
- UNAIDS
- Dutch Ministry of Foreign Affairs
- AIDS Fonds Netherlands
- International HIV/AIDS Alliance
- GlaxoSmithKline's Positive Action

GNP+ also works closely with other PLHIV organizations, including ICW, ITPC, the African Network of Religious Leaders living with HIV/AIDS (ANERELA+), and Young Positives.

Strategies

GNP+ is currently in a transition period. One of its main goals is to move away from being perceived only as a group that organizes a conference. Its future short- and long-term strategies will be based on input from regional networks. Among the strategies considered for 2006 are helping to facilitate PLWHA involvement in the GFATM; the June 2006 follow-up meeting of UNGASS; and the 2006 International AIDS Conference in Toronto, in August.

GNP+ also plans to publish a new edition of Positive Development, one of the organization's key advocacy documents for PLWHA; to continue publishing policy position papers on a regular basis; regularly update its CCM handbook; and to undertake a "criminalization scan" that will document where and how people face criminal charges for transmitting HIV.

2) International Community of Women Living with HIV/AIDS (ICW)

ICW is the only global network run by and for HIV-positive women and young women. It was founded in 1992 due to a desperate lack of support, information, and services available to women living with HIV, and the need HIV-positive women felt to influence policy development. The founding members were a group of 56 HIV-positive women from around the world attending the 8th International Conference on AIDS held in Amsterdam in July 1992.



ICW's overall vision is to create a world where all HIV-positive women

- have a respected and meaningful involvement at all political levels – local, national, regional, and international – where decisions that affect their lives are being made;
- have full access to care and treatment; and
- enjoy full rights – particularly sexual, reproductive, legal, financial and general health rights – irrespective of culture, age, religion, sexuality, social or economic status/class and race.

ICW has adopted a human rights framework for all of its work. It currently campaigns to promote gender equity, universal access to care, treatment and support, and solidarity with and involvement of HIV-positive women at all levels of decision-making affecting their lives. ICW works internationally, regionally and nationally, ensuring worldwide links of mutual support, learning, and advocacy among HIV-positive women and their organizations, and between HIV-positive women and allies and partners. It has a growing membership which currently stands at over 5,000 HIV-positive women and young women from around 130 countries. ICW members engage in activism and advocacy at local, national, and international levels.

Working to support all HIV-positive women as an international network, ICW enables the sharing of experiences, strategies, advocacy messages and strengths globally as a united movement for the rights of women living with HIV and seeks to empower and build the capacity of positive women in advocacy.

In addition to advocacy, awareness raising and public speaking work carried out by ICW members around the world, ICW activities include:

- capacity building and training of HIV-positive women (including young positive women) in research and advocacy skills and practical knowledge of HIV, nutrition, opportunistic infections, access to care, treatment and support, and rights including sexual and reproductive rights;
- working to create spaces for HIV-positive women and girls in HIV/AIDS-related policy-making and planning forums;
- establishing, maintaining, and networking between national, regional and international positive women's structures to support HIV-positive women of all ages and to coordinate global advocacy efforts of HIV-positive women;
- sharing information globally with and between HIV-positive women, including through publications, communications, and e-forums which allow HIV-positive women (including young women) to share experiences and information and support each other across geographical and language barriers;
- conducting research on issues of importance to HIV-positive women, particularly regarding sexual and reproductive rights and access to care, treatment and support for women and girls;
- producing and disseminating publications in a number of languages about the rights, experiences and advocacy messages of HIV-positive women and girls; and
- coordinating and working collaboratively with other organizations, including UN bodies, NGOs, faith-based organizations, AIDS service organizations, positive people's organizations and others.

Governing ICW, a charity registered in the United Kingdom, is an International Steering Committee made up of two HIV-positive women per region, with a future aim of electing one younger and one older woman per region. Seventy-five percent of the members of its Board of Trustees must be HIV-positive.

ICW is working towards decentralizing its infrastructure. Latin-America is the first region to have achieved autonomy. In Africa, where ICW employs 11 staff in 7 countries, its two regional offices are moving towards autonomy. An Asia-Pacific regional coordinator is due to be recruited in the summer of 2006. London is the home of ICW's support office, which supports members and regional staff, as well as its two global advocacy officers (one for sexual and reproductive rights, and the other for access to care, treatment and support).

3) International Treatment Preparedness Coalition (ITPC)

ITPC is a coalition of more than 600 people with HIV/AIDS and their advocates from over 100 countries. Its mission is to promote universal access to comprehensive AIDS treatment through local, national, regional, and global treatment advocacy and literacy projects. ITPC was born out of the 2003 International Treatment Preparedness Summit in Cape Town, South Africa. Its governance structure currently consists of regional advisory committees and an international steering group.



Among the key achievements of ITPC to date have been the following:

- arranging and hosting the first meeting in the history of the epidemic between the Director-General of WHO, the Executive Directors of UNAIDS and GFATM, and a delegation of PLWHA;

- organizing a successful campaign to add two substitution therapies (methadone and buprenorphine) to WHO's List of Essential Drugs and Medicines;
- revising Moldova's drug-procurement policy;
- organizing World Community Advisory Board (World-CAB) meetings with originator and generic pharmaceutical companies;
- planning "Days of Solidarity" with community groups in countries including Russia, South Africa and Thailand; and
- commissioning the publication, in November 2005, of "Missing the Target", a report on WHO's 3x5 campaign. Written by PLWHA and their advocates, the report analyzed the progress of treatment roll out in six countries: the Dominican Republic, India, Kenya, Nigeria, Russia, and South Africa.

Future activities

ITPC's treatment advocacy efforts in the future will include the following:

- preparing "Missing the Target 2", with progress reports on treatment roll out in an additional 20-30 countries. Also included in this report will be extensive information on paediatric treatment, MTCT, OI treatments, second-line therapies, and treatment concerns relevant to specific vulnerable groups including women, IDUs, MSM and commercial sex workers;
- organizing WorldCAB 3, which will focus on improving access to second-line treatment; providing national and community groups with technical assistance on issues such as drug registration and pricing;
- commissioning and publishing a report card on diagnostics;
- commissioning and publishing a report on the top five OI drug needs; and
- improving treatment literacy through the creation of
 - a diagnostic literacy booklet
 - a paediatric treatment literacy booklet
 - an online treatment literacy library (on a publicly accessible website)
 - regional email lists
 - monthly reports from regions to ITPC list

- monthly translations in 4-6 languages of ITPC digest (and emergency translations where necessary).

Partnership with Collaborative Fund

Furthermore, ITPC will continue its work as operational partner with the Tides Foundation in the Collaborative Fund for Treatment Preparedness. To this end, ITPC will distribute \$4 million in small grants in 10 regions for local/regional mobilization, treatment literacy and advocacy. The grant program will expand to cover HIV/TB and potentially the expansion to two additional regions (Middle East/North Africa and South Eastern Europe).

4) Collaborative Fund for HIV Treatment Preparedness

Founded in 2003, the Collaborative

THE COLLABORATIVE FUND FOR HIV TREATMENT PREPAREDNESS

Fund is a community-driven funding mechanism that provides:

- small grants to community organizations around the world for treatment education, mobilization, and advocacy projects;
- funding for regional coordination and networking to share information and advocacy strategies;
- funding for technical assistance to support grantees; and
- program evaluation.

The Fund divides its work into 10 categories: nine separate regions and one demographic group (Women in Africa). In alphabetical order, the nine regions include Caribbean, China, CIS/Baltics, East Africa, Latin America, South Asia, Southeast Asia, Southern Africa, and West/Francophone Africa.

Each region conducts a planning process, including a workshop to develop a treatment preparedness agenda. ITPC regional members lead this process. Workshop participants then select members of Community Review Panels (CRPs); these panels are geographically diverse,

have appropriate gender balance, and the majority of members are PLWHA. The CRPs set funding priorities based on workshop discussion, develop an RFP, review grant applications, and decide which projects to fund. The Tides Foundation, which provides administrative services for the overall Fund, collects organizational information and disburses funds.

In less than three years of operation, the Collaborative Fund has funded some 200 projects in 60 countries. Of the entities receiving grants, more than half are PLWHA organizations. Over half of the funds dispersed have been used to build support groups, peer associations, and peer resource networks with the goal of providing education and improved literacy about HIV/AIDS treatment options. Among the specific populations targeted are women, drug users, MSM, migrants, children, ethnic minorities, sex workers, and prisoners. Furthermore, over 50% of projects are based in rural areas or small cities.

Because the funding mechanism is based on GIPA principles, PLWHA are involved in every aspect of the process and all funded programs.

The Collaborative Fund's plans for 2006 include the following:

- a minimum of \$200,000 in treatment preparedness grants in each of the 10 regions/demographic groups;
- \$100,000 per region for network support and technical assistance;
- \$60,000 for regional coordination and CRP support;
- \$10,000 per region for program monitoring;
- grant making for HIV/TB advocacy and education;
- start of operational research to evaluation treatment literacy programs; and
- strengthening partnerships with ICW and GNP+.

In addition to the Tides Foundation, there are nearly 20 other contributing partners to the Collaborative Fund, including WHO, the Rockefeller Foundation, the Ford Foundation, the Pfizer Foundation, AIDS Fonds Netherlands, and UNAIDS.

During the Noordwijk meeting, a Collaborative Fund representative from the CIS/Baltics region provided an example of how local grantees are using the Fund's assistance to increase treatment awareness and availability. In 2004, access to ARVs was practically non-existent in Kaliningrad, a region with one of the highest levels of HIV prevalence in Russia, and authorities had no apparent interest in changing the situation. Activists from FrontAIDS, a Russian NGO and Collaborative Fund grantee, traveled to Kaliningrad from all over Russia and held a demonstration during which they demanded treatment.

The action was highly publicized throughout Russia, including when activists were seized and taken away by special police forces. Soon thereafter, according to the speaker in Noordwijk, treatment became much more available in Kaliningrad.

V ■ Donors' Perspective:

Needs and Expectations from PLWHA and Networks

Donors, PLWHA and network representatives also engaged in extensive and frank discussions about the needs and expectations of donors. In general, donors stressed the importance of recipients' **clarity of vision**; streamlined and efficient **structures and operations**; ability to obtain measurable results; and submission of **"realistic" funding requests** based on a more thorough understanding of donors' resources, methods and objectives.

Donors said that PLWHA networks could increase their chances of obtaining more extensive funds by improving the quality of their requests. Among the donors' recommendations to the networks were the following, many of which are accompanied by direct quotes from comments made at the meeting:

Provide more specific, extensive data about problems and issues to be addressed. Donors said they would be more inclined to respond affirmatively to requests that include relevant, up-to-date numbers and information – and not just rhetoric and anecdotes. For example, donors said, they were more likely to be receptive to a funding request stating, "This is a real issue because 80% of people are affected..." instead of language along the lines of, "This is a real issue because we see that it is..." , etc.

Focus more extensively on impact, outcomes and documentation. Donors need more data from networks and organizations providing evidence of policy changes, if relevant, and showing how funds ultimately affect the

lives of PLWHA and other members of their communities. Among the examples given by donors were the following:

- If a network says that funds will be used by local organizations to reduce stigma and discrimination, it would be useful to provide details about the advocacy strategies being employed and how their effect might be measured successfully.
- For requests for harm reduction funding, "We'd like to see more than just, 'we want to provide services'." How many PLWHA are receiving the services? Do they have a sense of being represented and encouraged to participate in organizations' work within the community? And if so, what exactly is it that they are doing, and to what extent? How has this changed their lives, if at all?
- The International Conference of People Living with HIV/AIDS, which is organized and hosted by GNP+. The conference costs up to \$2 million, according to GNP+ – a large amount of money that donors say is difficult to justify unless there is more extensive post-meeting documentation provided to donors.

As one donor stated, "Focus is important. What I as a donor am trying to do is evaluate whether the money I give you has been effectively used. What is the impact and what is the outcome of the funding that I am going to give? You need to provide me with this information. I think this is especially hard with international organizations that are trying to be coalitions and networks – it's hard because you want to be all things to all people. Yet at the same time we still need some

evidence of actual outcomes, and we often do not get it." *Create a more unified approach.* Donors urged the networks to collaborate more thoroughly and efficiently when strategizing for funding. According to one donor, such a step would "help me decide who and what to fund, and why."

Provide better rationale for core funding requests. As one donor asked, "Why is it that organizations for PLWHA think they should receive core funding, when most other organizations don't? We generally provide money for programmatic funding and you can take a percentage for overhead. You need to explain to me why I should fund core funding and, equally importantly, what this means. If you're saying you need funding for additional staff and rent, etc., then to me that's overhead, not core funding. Furthermore, we need to know how we can monitor and know what happened to the money we gave away; what's the measurable outcome?"

Improve quality of presentations. Several participants noted that the four network presentations varied extensively in terms of specificity and quality of content. The most ineffective ones, they said, were those that came across as vague and muddled. At the conclusion of one presentation, for example, one non-donor, non-network partner said, "If I were a donor and listened to that presentation, I would not be convinced as to why I would fund you. I didn't get a coherent vision and couldn't see where you're going. What I felt I got was a list of things, things you're doing because there is money. From a donor perspective, you have to be convinced that there is a clear vision, a valid vision. I wasn't convinced by the presentation; we need to work on this, we need to make this more clear."

Donors agreed that the most persuasive funding requests were those accompanied by clear and precise information about projects, achievements, and plans for the future that detail exactly how they will be attained. What are the steps that will be taken? How will they be taken, and why is it likely that these steps

will be the most appropriate and efficient? Donors added that information about an organization's structures and staff is less relevant.

Provide thorough evidence of impact in countries. Donors want more evidence that funds provided for the activities of community organizations are actually reaching these local groups – and how quickly and reliably they get there.

Understand and respond to the guidelines and policies of specific donors. Potential recipients were encouraged to more fully research the donors' policy histories, objectives, and restrictions. A representative from PEPFAR noted, for example, that various earmarks in his program mean that 55% of funds must be allocated to treatment and that 75% of those funds must be spent on drug provision. In addition, he said, one-third of prevention funds must go to abstinence programs.

VI ■ Changing the Dynamic: Joint Goals and Next Steps

Meeting participants agreed that although PLWHA networks and donors share the same overall goal – responding quickly and forcefully to the HIV/AIDS epidemic by increasing access to essential treatment and prevention services – they often fail to effectively communicate their strategies and policies. Substantial work therefore needs to be done to improve collaboration and partnership among PLWHA networks and donors. Participants identified several objectives designed to achieve this goal and also determined a series of short- and longer-term action steps.

■ 1) How do we work together?

Participants agreed that collaboration between donors and network recipients could be enhanced by greater consideration of the following:

- involving both donors and PLWHA in the planning of future meetings like this one – and ensuring that the participating donors increase both in number and variety;
- reducing the use of “us vs. them” language, which can sound confrontational and uncompromising;
- learning from what works well in other partnerships;
- strengthening linkages between people at different levels of donor and network organizations;
- defining common objectives;
- defining and developing rules of partnership to guide future processes (including the joint identification of important milestones and how they should be evaluated); and
- conceptualizing networks as intermediaries, not necessarily as primary recipients.

■ 2) Next steps

Follow-up meeting.

Participants agreed that among the next steps should be at least one additional meeting in 2006 to build on the progress begun in Noordwijk. That meeting would include a more substantive policy debate on the issues and recommendations raised, with the goal of moving toward an environment in which donors are more fully prepared to support the networks’ work. Donors and network representatives would collaborate in planning the agenda and identifying potential participants.

Some participants recommended having the follow-up meeting during UNGASS, in late May/early June 2006, or during the International AIDS Conference in Toronto, in August 2006. Both of these options also engendered significant opposition, however, based on the assumption that few participants at those two gatherings would have the time or resources to attend a separate meeting. Furthermore, according to one donor, it is unlikely that many of the relevant individuals from donor organizations – those with direct responsibility for reviewing grants – would be attending UNGASS or the International AIDS Conference. *(As noted below, a working group was established to recommend the location and timing of a follow-up meeting.)*

Network representatives also agreed to consider holding a separate meeting among themselves to more clearly identify and articulate the overall objectives and goals of the networks. Among the questions to consider: What does it mean to be a global network of PLWHA? What should these networks be expected to do? How

should they be structured? These questions also need to be addressed with the understanding that the three PLWHA networks – GNP+, ICW and ITPC – have very different histories and processes. Network representatives agreed to discuss the possibility and timing of this separate meeting, which should be held prior to the larger follow-up meeting involving donors.

Representatives from donor organizations also agreed to meet separately, at the very least on an informal basis, to discuss various issues in greater detail prior to the next joint meeting. Among the issues donors vowed to consider are application processes; the provision of core funding; monitoring and evaluation; and expectations from recipient networks and community organizations.

Working group

Participants agreed to create a working group that would be charged with:

- establishing an ongoing process, including the identification of individuals and/or organizations to play leadership roles;
- determining logistics, including the timing, location and preliminary agenda of a follow-up meeting; and
- recommending additional specific steps.

The initial working group will consist of two individuals, one from a PLWHA network (Kevin Moody from GNP+) and one from a donor organization (Els Klinkert from the Dutch foreign ministry). Moody and Klinkert agreed that their first task, over the next few weeks, would be to establish a timeline to help guide the process forward over the next several months, along with suggestions for next steps. These suggestions will be circulated for feedback to meeting participants and others who were not able to attend.

A final plan for future engagement between PLWHA networks and donors will be widely distributed.

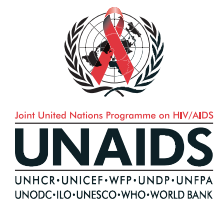
Appendix I: List of Participants

The following individuals attended the Donor Consortium Conference held 16-17 March. Clarifications and questions about names, spellings, affiliations, and contact information should be obtained by contacting individual participants directly. Participants are listed alphabetically by last name.

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