

Meeting Report

Defining and Organizing a Community-Led Roundtable Process for HIV Treatment and Care

Roundtable Meeting I
Noordwijk, the Netherlands
27–29 March 2007

Sponsored and organized by International Civil Society Support (ICSS)

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About this Report

This report provides an overview of a meeting held 27–29 March 2007 in Noordwijk, the Netherlands. The gathering was organized by International Civil Society Support (ICSS), an Amsterdam-based NGO that seeks to strengthen civil society participation in global, national and local responses to HIV/AIDS.

In 2006, a Dutch NGO, Aids Fonds Netherlands, agreed to finance an ICSS initiative to establish a Roundtable Process to support civil society engagement in the ongoing global campaign for universal HIV treatment access. The initiative is to continue over four years, from 2007 to 2010; the annual funding support for activities totals 100,000 euros (US\$134,000).

ICSS convened the meeting to help identify a structure for the Roundtable Process and what sort of strategies and objectives should be prioritized. Because the primary mandate of the Roundtable Process is that it be civil society–led and –driven, ICSS sought to solicit suggestions, feedback and observations from civil society representatives themselves. The meeting ultimately reflected the global nature of the universal access movement as well. The 31 participants came from 19 different countries—from every

continent except Australia and Antarctica—and represented a total of 25 different local civil society organizations or networks comprising them.

This report includes a summary of the proceedings as well as an overview of the discussions, presentations and strategy proposals identified by participants. ICSS staff and a Core Group of eight civil society representatives will review the information and recommendations obtained during this inaugural meeting as they formalize the Roundtable Process structure and set its priorities. Subsequent meetings of civil society representatives are expected to initiate action plans based on the agreed-upon Roundtable Process.

This report is intended to serve two purposes. It will serve as a record of the meeting proceedings, thereby helping guide internal decision-making processes in the future. In addition, and more broadly, it provides a summary of issues and strategies related to HIV treatment that are considered high priority and particularly important by community-based advocates in different regions throughout the world. Such individuals are well-positioned to recognize and understand the needs of HIV-positive people and members of vulnerable populations. All efforts to respond effectively to the epidemic—whether initiated and implemented by the public or non-public sectors, or by multilateral organizations or local groups with a much narrower focus—should be driven by those needs and careful consideration of how they are being met.

Acronyms and Abbreviations

ART = antiretroviral treatment
ARVs = antiretroviral drugs
CSO = civil society organization
FBO = faith-based organization
GFATM = Global Fund to Fight AIDS, Tuberculosis and Malaria
G8 = Group of Eight
ICSS = International Civil Society Support
LAASER = Linking African & Asian Societies for an Enhanced Response to HIV/AIDS
MTCT = mother-to-child transmission
NGO = non-governmental organization
PEPFAR = U.S. President’s Emergency Plan for AIDS Relief
PLHA = people living with HIV and AIDS
R&D = research and development
STI = sexually transmitted infection
TB = tuberculosis
TRIPS = Trade Related Aspects of Intellectual Property Rights
UNGASS = UN General Assembly Special Session on HIV/AIDS
WHO = World Health Organization

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About ICSS

The main objective of International Civil Society Support (ICSS) is to develop and implement a comprehensive civil society HIV/AIDS agenda that is owned and driven by civil society stakeholders and supports civil society's efforts to strengthen their own response to HIV/AIDS, and to strengthen the response of national governments and international institutions in the global fight against HIV/AIDS.

I. Introduction and Background

In 2002, representatives from multilateral institutions and community-based civil society organizations (CSOs) gathered in Noordwijk, the Netherlands to discuss civil society's role in addressing the critical lack of treatment available for people living with HIV and AIDS (PLHA) in most of the world. By that time, it was clear what worked: The advent six years earlier of triple-combination antiretroviral treatment (ART) and important treatment-support services in the developed world had caused AIDS death rates to decline dramatically in North America and Western Europe, for example. Yet the epidemic raged steadily in poorer parts of the world where such costly medicines and services remained inaccessible to nearly all in need.

This glaring discrepancy was already seen as outrageous, inhumane and unnecessary. Those meeting in 2002 in Noordwijk were part of an increasingly assertive activist-led global push for universal access to HIV treatment. Based on the belief that such a goal was not achievable without the direct, comprehensive involvement of civil society, the community representatives launched the International Treatment Access Coalition (ITAC) later that year. (ITAC, which disbanded within a couple of years, was a network of NGOs, international organizations, donors, developing countries and research institutions with a goal of promoting international cooperation in expanding access to HIV treatment.)

Five years later, in March 2007, many of the same organizations were represented at a similar meeting in the Netherlands, also at Noordwijk. Convened by Amsterdam-based International Civil Society Support (ICSS), the meeting marked the launch of its Roundtable Process, a four-year project to facilitate civil society cooperation and collaboration in the drive for comprehensive, universal access. Participants gathered to take stock of developments since 2002 and to consider strategies and goals to further enhance civil society's engagement and influence.

It is indisputable that remarkable change has occurred over the past five years. For one thing, there has been a sea change in global political and financial commitment. Launched since 2002 to respond to the HIV/AIDS crisis, including lack of treatment access, have been the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), two dedicated World Bank programs and the World Health Organization's "3 by 5" initiative. With the support and prodding of activists, foundations and non-governmental organizations (NGOs) both global and local, these large-scale initiatives have helped increase the delivery of life-saving ART to hundreds of thousands of people in need. Moreover, civil society is now seen as a serious and effective partner in these efforts.

Despite these achievements, however, the ultimate goal remains elusive. An estimated 2 million people in resource-poor settings currently have access to HIV treatment, but that is just a fraction of the 7 million individuals in need. Significant gaps also persist in the quality of treatment offered. For example, treatment preparedness is not seen by governments and other providers as integral to the design and implementation of

comprehensive treatment programs. Women, who bear the brunt of the epidemic in many countries, receive far too little support to help them obtain the full range of necessary treatment services. Major barriers, often related to stigma and discrimination, limit treatment access for members of vulnerable populations such as drug users. Second-line treatment options are often not available or affordable. Programs and policies to monitor resistance and adherence are poorly designed, if they exist at all. Paediatric treatment formulations are difficult to administer widely and effectively. This list goes on.

Clearly there is an almost unimaginable amount of work to be done in both the short- and long-term. Unlike five years ago, few would dismiss the vital role to be played by civil society.

Defining civil society

The term “civil society” has been and continues to be defined in slightly different ways. ICSS and participants of other organizations represented at the March 2007 meeting generally accept a definition provided by the United Nations, which states that civil society consists of “associations of citizens (outside their families, friends and businesses) entered into voluntarily to advance their interests, ideas and ideologies. The term does not include profit-making activity (the private sector) or governing (the public sector).”¹

Understanding civil society in this way helps to clarify its crucial role in responding to HIV. In many countries and regions, government structures—including public-sector health systems—are unable or unwilling to engage appropriately with individuals in need. The opposite is also true. Many individuals view government representatives and institutions with suspicion, distrust or fear because of official or de facto discrimination against those living with or vulnerable to contracting one or more of the diseases. Such concerns are particularly heightened in regards to HIV, given the social, economic and political stigma often attached to injecting drug use, same-sex relations and sex work—all well-known transmission risk factors.

CSOs often are the only entities that can bridge this gap. Local NGOs tend to comprise staff members, volunteers and outreach workers with personal experience in dealing with HIV. Many of them are in fact HIV-positive themselves, a fact that in most cases lends greater urgency and passion to their work. Because they are from and based in a local community, these individuals (and their organizations) are more likely to be trusted by their peers in need. Partly for that reason, CSOs are often directly involved in sponsoring and setting up self-help groups for PLHA. The number of such groups has risen sharply throughout the world; in Ghana, for example, the head of the advocacy group Network of Persons Living with HIV/AIDS (NAP+) recently said that there are nearly 200 self-

¹ This definition was provided in a 2004 UN report, “We the Peoples: Civil Society, the United Nations, and Global Governance”. Online: www.un.org/News/Press/docs/2004/sg2090.doc.htm. (Accessed 1 April 2007.) Some other definitions of civil society include the private (for-profit) sector, but that is considered to be a minority viewpoint.

support groups for PLHA in his country, compared with just one in 2001.² Often such support groups form the core of current and future HIV advocacy efforts, including those related to treatment.

CSOs' close links to the community also mean they are well-positioned to be direct service providers themselves. Many offer their clients high-quality HIV treatment services over a usefully wide range, from ART to prevention assistance. In general, their very existence can help reduce disease-related stigma and discrimination—even in the absence of government initiatives toward those goals or, in the worst cases, outright hostility from authorities.

Creating a forum for increased civil society engagement in treatment access

Although the necessity and value of civil society's involvement are undeniable, it is worth considering how the sector's engagement can be improved and its impact leveraged more efficiently and effectively. That was at the heart of all discussion among participants at the Noordwijk meeting in March 2007. As challenged by ICSS, they sought to establish parameters for a Roundtable Process that would serve as a "neutral space" for consideration and analysis of HIV treatment and civil society's role. Subsequent meetings are expected throughout the four-year term of the initiative, whose activities are supported by an annual 100,000 euro (US\$134,000) grant from Aids Fonds Netherlands.³ The annual activity budget is 100,000 euro's (next to staffing of 1.7 FTE)

ICSS asked those attending the inaugural meeting to help identify the most appropriate and useful guidelines and strategies for the Roundtable Process. Among the broad questions considered were the following:

- As they seek to increase HIV treatment availability and quality, how effectively are CSOs and community groups working together in terms of global and local advocacy, sharing information and resources, and providing support?
- What types of HIV-related activities and strategies might benefit from more coordinated efforts of civil society? How can and should coordination be structured, both within civil society itself and with other sectors (i.e., public and private)?
- What are the most useful civil society roles in activities including service delivery, monitoring, treatment scale up, and global and local advocacy?

² Moresco, Justin, "Once Outcasts in Their Countries, Many Africans with HIV are Finding Camaraderie in Support Groups". *Newsday*, 4 April 2007. See www.newsday.com/news/health/ny-woghan015157910apr04,0,4932362.story. (Accessed 7 April 2007)

³ Aids Fonds Netherlands, a Dutch NGO, is in turn supported by the Dutch Ministry of Development Cooperation. The funds for ICSS's Roundtable Process were allocated under the ministry's LAASER program, which seeks to build capacity to strengthen and improve the quality and durability of HIV/AIDS treatment in Africa and Asia. (LAASER is an acronym for "Linking African & Asian Societies for an Enhanced Response to HIV/AIDS".) Two key objectives of the program are to improve knowledge about new resistance patterns and to support policy makers in undertaking public health action.

- How can civil society ensure that the real needs of PLHA are being addressed and met?

The Roundtable Process is not intended to be a new organization (or a formal organization at all). The concept instead is to create a civil society–owned process that will not duplicate existing efforts, but build on them. As agreed by all participants, by enabling CSOs around the world to engage in more extensive and regular interaction with each other, this process will enhance their ability to advocate more effectively on behalf of people in need of treatment in their own regions. It will also help draw greater attention—and by extension, greater funding—for their activities. These complementary developments will in turn strengthen the role of civil society in the ongoing movement for universal access.

II. Part One: Establishing Roundtable Process Principles

The meeting was structured to elicit as much feedback as possible from all 31 participants regarding how to set up a viable and useful Roundtable Process. ICSS organizers stressed at the beginning of the meeting that they wanted the Roundtable Process to be based on principles, not rules. Therefore an early focus was on establishing some core principles that would help guide the ensuing discussion on strategy and, ultimately, how the Process would work over its four-year lifespan.

Participants gave comments and feedback during an initial plenary session. Among other things, they hoped the Roundtable Process would add the following to their efforts to achieve universal treatment access:

- create a “neutral space” for discussion and information-sharing. It would also be a “safe space” to discuss policy developments and proposals that advocates do not understand or are unsure about;
- enhance the ability of civil society to create its own agenda, and not just respond to other agendas;
- provide an opportunity to improve research and advocacy tools;
- forge new relationships with others involved in similar work, thus leveraging advocacy capacity and strengthening partnerships; and
- increase civil society’s ability to hold governments and multilateral agencies accountable to their commitments; and
- by not being a “closed club”, the Process would encourage consideration of non-mainstream and controversial views.

Based on those comments, participants agreed to group Roundtable Principles into two categories: “Process” and “Working Together”.

“Process” principles include the following:

- the Roundtable Process is not an organization;
- the Process will only engage in activities that provides added value to existing efforts of its members;

- relevance to people living with and affected by HIV is a paramount focus;
- the Process should build on existing structures and processes; and
- prevention = treatment; i.e., one cannot and should not take precedence over another because they are inextricably linked.

“Working Together” principles include the following:

- process & participants should focus on issues they cannot achieve alone;
- existing and potential global strategic agendas should be discussed;
- discussions and proposals should be cutting edge, and participants should not be afraid of being controversial;
- all discussions should be guided by mutual respect;
- the Chatham House Rule should apply;⁴ and
- emphasis should be placed on transparency in sharing information.

III. Part Two: Presentations

To stimulate discussion, five attendees were asked in advance to deliver presentations on key issues regarding HIV treatment access. Their presentations at the meeting centred on stigma and discrimination; sustainability of funding; procurement; treatment preparedness; and gender dynamics. (Although based on objective data, the presentations were mostly subjective in nature, representing the opinions of the presenters.)

Summaries of the presentations follow below.

Stigma and discrimination⁵

Contrary to expectations, ART roll out has not significantly reduced HIV-related stigma and discrimination in most societies. Both continue to be major barriers to the uptake of treatment services. Four quotes from PLHA in South Africa illustrate the type of prevailing attitudes:

- “My husband will kill me if I ever took any kind of medication for HIV because he does not believe that HIV exists.”
- “I have to breastfeed even though I know I am putting my baby at risk. Otherwise, my mother in law will ask why and I am not ready to tell her or my husband [about my HIV status].”
- “I always tell my family that I have some kind of cancer so that they don’t ask what medication I am taking”
- “My husband will kill me if I ever took any kind of medication for HIV because he does not believe that HIV exists.”

⁴ This rule is defined in the following way: “When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed.” The aim of the rule is to provide anonymity to individual speakers so as to encourage openness and the sharing of information. See www.chathamhouse.org.uk.

⁵ Presentation made by Jason Wessenaar from the Centre for the Study of AIDS at the University of Pretoria, South Africa.

Even in countries with high HIV prevalence, such as South Africa, there are few positive images of PLHA or high-profile individuals who are open about their status. Stigma and discrimination are entrenched at many healthcare facilities as well, such as when clinics have separate entrances for HIV services and when healthcare workers do not respect patients' confidentiality. Stigma remains persistent in the most unexpected places; for instance, it is considered a main reason that ART uptake is slower than expected in Botswana, a country regularly touted as a success story because all national leaders strongly support the effort and it is fully funded.

Combating stigma is difficult because of its complexity: It is embedded in cultural issues, religious issues, upbringing and moral judgments. The effort to win hearts and minds requires a multi-pronged approach.

Guiding principles for strategies to address stigma and, by extension, HIV-related discrimination, are that they should be based on evidence; be multi-level, multi-sectoral and holistic; use a gender lens; use a rights approach; be sustainable; be mainstreamed; and involve PLHA. Strategy should consider the following:

- providing legitimate information,
- advocacy and lobbying,
- promoting human rights/legislation/policy,
- focusing on the needs of PLHA,
- reaching communities through civil society, and
- conducting research and M&E (monitoring and evaluation).

Selected comments during discussion

“In general, these objectives are important. However, I think the problem remains that such strategies are not specific enough. What are the concrete things we can do to address stigma and discrimination, that can be put into national plans and then costed? If we don't have concrete steps, then everything remains amorphous.”

“It is important to recognize legislative developments when considering how and why stigma and discrimination persist. For example, many countries in my region are considering laws to protect PLHA. Yet these laws also mention HIV-positive people's 'responsibility'—and this in turn leads to the possibility and likelihood of criminalizing the transmission of HIV. I think we need to address this development now. In too many countries the trend toward prosecuting PLHA for transmitting the virus is moving forward, and not just in developing countries (as seen with recent cases in France and Canada). It is important to recognize that HIV-positive people may not have the ability and capacity to resist such efforts if it's necessary to spend so much time and energy proving 'we are good people' and don't really want to hurt others.”

“The main thing is to have more information about stigma and discrimination. At the ground level, we need to determine and specify which populations are affected and why. This can help us support national and global efforts to reduce stigma and discrimination.

Strategies initiated top down, at the global level, won't lead to effective policies at the local level. Positive steps can only really be made by starting in local communities.”

“Part of the problem is that PLHA and their advocates don't have the capacity or ability to engage effectively in issues that directly affect discrimination. In my country, for example, the parliament passed an HIV prevention bill without any input from PLHA. This law contains numerous provisions that criminalize HIV transmission. How can we take action in situations when PLHA are already being dragged into courts, and there are very few people willing and able to fight with and for them? We need to support the mobilization of PLHA to fight for their rights and resist these discriminatory laws.”

“I think it's important to consider issues that are not only HIV specific, but also those that criminalize behaviours and attitudes regarding vulnerable populations, such as sex workers, MSM and drug users. Stigma and discrimination related to these individuals should be considered jointly in relation to PLHA.”

“We must not forget healthcare workers. Stigma among them is very high, and they are scared. This is because they often do not have as much information as they need to care effectively for PLHA. Where we have targeted education and information programs at the community level, the levels of stigma and discrimination have gone down, including among healthcare workers.”

Sustainability of funding

The major donors of HIV/AIDS programs, including those related to treatment, are PEPFAR; GFATM; the World Bank; and some bilateral agencies (notably the UK Department for International Development). Most donor countries (including Canada, the United Kingdom, the United States and the European Union) are not meeting what would be considered their fair share, however, based on their wealth and available resources. The same can be said about the private sector in general, as companies around the world record profits but rarely allocate a significant share to pressing health concerns.

The result is that although there has been a rapid increase in spending on HIV, the need continues to far outweigh the assistance provided. The funding gap is even greater throughout the overall health sectors in developing countries.

In addition, the high cost of drugs and pharmaceutical companies' resistance to breaking patents mean that a disproportionate share of HIV funding is spent on procurement. More than 40% and 45% of PEPFAR and GFATM funds, respectively, are spent on purchasing medicines, for example. The costs likely will increase even more sharply to meet the growing demand for second-line ART and drugs to treat multi-drug resistant tuberculosis (MDR-TB) and hepatitis.

Some useful new initiatives, such as UNITAID, an international drug purchase facility launched in September 2006 by six countries,⁶ are working to reduce the price of medicines. In the long run, however, the sustainability of HIV treatment programs may depend on identifying and implementing new R&D models and bring down the costs of development and drug prices in general.

Among the questions advocates might consider regarding funding issues:

- How effective and valuable are existing programs and policies to provide technical support?
- How can treatment support be expanded (to increase adherence, bolster prevention efforts, reduce stigma and increase community mobilization)?
- How can we improve GFATM? Options might include increasing its size and scope, as well as increasing its commitment to including civil society in all aspects of funded projects.
- There are currently about 40 costed national AIDS plans around the world. Are these plans properly costed, i.e., epidemiologically appropriate? Is civil society monitoring their implementation? How are they being funded, and how sustainable are current funding sources?
- How can civil society prompt increases in domestic spending on HIV programs, particularly in countries such as India that are experiencing rapid economic growth?
- What advocacy priorities should be set by civil society to increase funding and its likely sustainability? For example, should focus be on improving PEPFAR and GFATM? Advocating for governments to meet their fair share of assistance? Lowering drug costs by pressuring pharmaceutical companies and governments? Focusing on the development of innovative financing mechanisms? A combination of some or all of the above?

Selected comments during discussion

“We shouldn’t forget funding for health systems strengthening. There’s a role for us to play in advocating with the World Bank and IMF, for example. They’re working on these issues.”

“We also need to consider accountability, both among governments and NGOs. Corruption at all levels remains a problem that greatly affects the effectiveness of funding.”

“Sustainability also depends on the strength and capacity of civil society. For example, GFATM pays for first-line ART in both my country and a neighbouring one, which is roughly at the same level economically. Yet in my country, civil society groups have a long-term strategy to lower prices and we have been advocating for this for many years.

⁶ Additional information about UNITAID may be found online at www.unitaid.eu/EN-Inutaid-unis-pour-soigner.html.

Such a situation does not exist in our neighbour, where civil society is much weaker. As a result, drug prices are several times higher next door.”

Procurement

As evidenced by the large share of resources allocated for medicine purchases by leading HIV care initiatives (such as GFATM and PEPFAR), issues related to procurement of HIV medicines are extremely important to HIV treatment. Years of advocacy and pressure have forced down prices of many drugs, but some therapies remain unaffordable in the developing world. With notable exceptions, leading multinational pharmaceutical companies resist lowering prices on brand-name drugs or accepting the breaking of patents. They usually claim that they need to make significant profits from drug sales in order to fund R&D for new drugs—an assertion that many advocates reject based on analysis of most firms’ high profit margins and budget priorities skewed toward advertising.

Two high-profile patent-related conflicts highlight the problems inherent in contemporary procurement efforts. Both cases indicate the tenacity exhibited regularly by some companies in upholding patents and resisting pressure to lower prices. In Thailand, Abbott Laboratories is fighting the government’s efforts to introduce compulsory licensing as part of an effort to reduce the cost of Kaletra. And in India, Novartis has filed a legal challenge against a section of the country’s national patent law that aims to restrict certain kinds of patents. Many HIV advocacy groups, including those providing HIV treatment services, argue that a change in the Indian law could strengthen the ability of companies to seek greater patent protection for existing and future antiretroviral drugs (ARVs). Such a development would restrict generic competition and raise medicine prices significantly.

As noted in the presentation, the four strategic objectives of pharmaceutical procurement, regardless of sector, are the following:

- procure the most cost-effective drugs in the right quantities,
- select reliable suppliers of high-quality products,
- ensure timely delivery, and
- achieve the lowest possible total cost.

Achieving these objectives can be difficult and complicated for a variety of reasons, ranging from substandard infrastructure to funding shortfalls. The quality of procurement at both national and international levels can be greatly enhanced by the following:

- minimizing stock outs (which might require buffer stocks, improved lead times, and sufficient storage capacity and conditions);
- creating reliable inventory mechanisms (especially for accounting purposes);
- establishing appropriate management information systems to ensure smooth and consistent flow of products;
- prioritizing parallel procurement for other essential medicines and health commodities (such as condoms); and

- ensuring that medicines are safe, effective and acceptable to the patient (hence the importance of quality-control mechanisms, drug registration, and WHO pre-qualification standards).

Supplying drugs is one thing; affording them is another. The World Trade Organization's agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS) was designed to provide national governments with a mechanism to override patents by declaring a national health emergency. This would enable them to purchase lower-priced generic drugs from abroad or to license the manufacture of generics domestically. Many countries are reluctant to take such a step in the face of pressure from brand-name drug makers and national governments, notably the United States, that insist on strict compliance with international patent regulations. As a result, the availability and flow of lower-priced HIV medicines remain limited in some countries where a significant number of PLHA need them desperately.

The current imperfect situation begs for new strategies to improve access to quality medicines and commodities at the national and international level. Several have been initiated in recent years, including the establishment of UNITAID (see previous presentation on "sustainability of funding"); a special levy on air tickets that is allocated to HIV drug-purchasing schemes; the Clinton Foundation HIV/AIDS Initiative's Procurement Consortium, which purchases AIDS medicines and diagnostic equipment at reduced prices; and efforts to initiate pooled procurement. All of these have achieved important results, but even taken together they have yet to change the current system as radically as might be necessary.

Selected comments during discussion

"Some civil society groups, notably MSF [Médecins Sans Frontières] have managed to lower prices significantly on the drugs they purchase for their treatment initiatives. So there are examples of how costs can be reduced through the work of civil society actors."

"I think an issue that we also need to consider is what kind of alternative models and approaches we can take at the national level. We need to strategize about what to do if the drug companies do not register, as has happened in Thailand. Perhaps, too, if we had monitored the situation more closely we could have anticipated this outcome and moved more quickly to respond to it."

"What appeals to me most is supporting alternative models of R&D [research and development]. Drug companies are using R&D as a sham for raising prices."

"We must not forget to focus our attention on governments as well as pharmaceutical companies. The big buyer in our region is governments, and there is so much corruption in the process. Far more people could be receiving medicines if corruption weren't so widespread."

Treatment preparedness

The term “treatment preparedness” refers to efforts to ensure the direct involvement of PLHA in all aspects of HIV treatment. According to the Collaborative Fund for HIV Treatment Preparedness:

Ultimately, the effectiveness of HIV treatment access efforts will depend on the ability of people living with HIV to overcome the stigma associated with HIV disease, access medicines and healthcare services in their communities, and understand how to make and follow through on treatment decisions. These activities, broadly defined as treatment preparedness, are as essential to success as the drugs themselves. They include national and regional advocacy; community-based advocacy; treatment literacy; and integration of services for HIV treatment.⁷

Founded in 2003, the International Treatment Preparedness Coalition (ITPC) is a prominent civil society-based force in the expansion of HIV treatment. It comprises 800 PLHA from more than 125 countries and seeks to promote universal access to comprehensive AIDS treatment through local, national, regional and global treatment advocacy and literacy projects.

Among ITPC’s achievements to date have been arranging the first meeting in the history of the epidemic between a delegation of PLHA and a WHO director-general, and initiating a regularly updated report card, called “Missing the Target”, on steps toward universal treatment access in selected countries.⁸ Future activities will include expanding “Missing the Target” to additional countries and including comprehensive information about paediatric treatment, MTCT, second-line therapies, treatment access among vulnerable groups, and access to diagnostics (such as laboratory tests for CD4 counts and resistance). ITPC also plans to produce treatment literacy booklets for use by community groups around the world.

In general, ITPC and other groups engaged in HIV treatment preparedness seek to identify challenges toward achieving universal access and work to address them. Among the obstacles noted are

- lack of harmonization among multilateral initiatives (such as GFATM and PEPFAR) in terms of strategy and funding;
- insufficient tapping into civil society/community resources;
- lack of baseline data and accurate statistics, which would help better prioritize resources;
- insufficient monitoring of quality treatment;
- insufficient emphasis on treatment literacy; and
- the increasing burden and cost of second-line treatment.

Selected comments during discussion

⁷ See www.hivcollaborativefund.org.

⁸ See www.aidstreatmentaccess.org.

“More emphasis needs to be placed on paediatric treatment, including diagnostic tests for children. We need to do a better job of diagnosing HIV in children and getting them on appropriate regimens as early as possible, before they get too sick.”

“On this whole issue of targets—such as achieving universal access by 2010—I don’t think we should get too bogged down. There is a value on targets because it gives you something to work for, but they should not be set in stone. Having said that, I’m depressed because we’re coming up to the middle of 2007, and we haven’t really achieved close to what we need.”

“Our organization is very concerned about all the issues raised in this presentation. We have five key areas we’re focusing on to help address them: 1) using HIV resistance data to advocate for availability to second-line treatment, both at government level and among pharmaceuticals; 2) educating the community so that resistance testing is used to improve quality treatment and does not turn out to be an argument against the roll out of treatment; 3) evaluating the extent of undocumented sporadic first-line treatment (e.g., obtained from friends and the black market, etc.) as a risk for resistance, thereby jeopardizing the effectiveness of first-line therapy; 4) evaluating and educating for adherence as part of a link to treatment programs on a community level; and 5) collecting better data by facilitating community outreach and access to study population for surveillance purposes.”

“I’d like to highlight the implementation issue. We’re seeing large amounts of money going to things like training, etc. Yet probably we should also focus on building capacity and sustainability of program implementation at the ground level.”

Gender dynamics

Gender inequalities can constrain HIV-positive women's access to care, treatment and support as well as their ability to use treatment, information and advice to improve the quality of their lives. For one thing, women are less in control with most things that happen in their lives. They are often less mobile than men, often because they are primary caregivers for their family, which means they have fewer opportunities to travel for care and support services. Moreover, the care, treatment and support needs of HIV-positive women often are different than those of men.

In addition to those faced by men, women in many societies face numerous additional obstacles to obtaining comprehensive HIV treatment services. Among them are the following:

- lack of decision-making power because of cultural, political or legal norms. For instance, a woman may have to ask relatives for permission to access services;
- gender-related stigma, discrimination and violence perpetrated by family members, healthcare workers, and authorities;

- limited healthcare provider knowledge about the health needs of HIV-positive women, including those related to sexual and reproductive health matters, including treatment of sexually transmitted infections (STIs);
- insufficient awareness, information and treatment for gender-specific illness;
- lack of information and advice on MTCT; and
- limited ongoing support (preferably in the form of counselling) regarding healthy pregnancy and motherhood;

The following are among the recommendations for addressing the existing barriers and improving the quality and scope of HIV treatment for women:

- improved client data reporting, both on drugs and on other aspects of care and treatment. This step would help further identify gender-specific gaps and shortfalls;
- more research into opportunistic infections specific to women and HIV-related conditions such as cervical cancer, and more research into screening and treatment options for these; and
- greater understanding of the challenges facing women and girls in gaining access to treatment, especially those related to stigma and discrimination. Responses might include improved confidentiality in service delivery coupled with more extensive support groups that enable women to feel more comfortable in being open about their status.

IV. Part Three: Developing Objectives and Targets for Roundtable Process

The presentations and discussion following them yielded a wide range of possible strategies and objectives. All participants agreed, however, that it was necessary to select a small, manageable number for three reasons: 1) to be realistic in light of the Roundtable Process's annual budget of 100,000 euros, 2) to maximize the efficiency and effectiveness of the Process, and 3) to supply the type of specific guidance requested by the meeting's conveners.

Subsequent discussion concluded that the potential focus areas could be grouped into two main categories:

- Short-term strategy development and planning. Included in this category are time-sensitive issues that would benefit from an action-oriented, coordinated response. Examples might include campaigns to do the following:
 - counter Abbott's threat to withdraw Kaletra from the Thailand market;
 - influence changes in PEPFAR as it comes up for U.S. government reauthorization in 2008;
 - urge and advocate for compliance with universal access targets set for 2010 and beyond;
 - organize an expert meeting as soon as possible to hammer out action steps to maximize civil society's influence in all issues related to universal access;
 - expand access to and affordability of second-line (and beyond) treatment;

- monitor global institutions, such as GFATM and PEPFAR, on a more intensive and regular basis, beginning immediately; and
- pressure the G8 to re-commit, at its 2007, to the pledge it made in 2005 to sharply increase financial support to fight the HIV epidemic. This campaign would also seek greater monitoring and evaluation of the commitment.

All of these campaigns, which might be characterized as “action” or “reaction”, would be time-limited and relatively brief in duration.

- Long-term policy analysis. Included in this category would be efforts to create strategies to achieve positive change in complex social and economic issues that persist in hindering HIV treatment access. Examples might include:
 - considering how to make progress in reducing HIV-related stigma and discrimination;
 - quantifying the impact of gender-oriented disparities;
 - developing alternative models for drug R&D, including patent systems and structures;
 - identifying major gaps in universal access;
 - developing potential strategies to encourage adherence and reduce drug resistance;
 - preparing for UNGASS 2011; and
 - evaluating global institutions from a long-term strategic perspective. For example, how could civil society participate more meaningfully in GFATM and UN agencies, especially in regard to treatment access issues?

All of these efforts, which could be characterized as “reflection”, would benefit from greater civil society engagement and analysis, as could be prioritized through the Roundtable Process.

ICSS members reminded participants that regardless of category, the ultimate goal of the Roundtable Process—to contribute to, complement, improve and enhance the drive to universal access—would remain the same. Furthermore, they added, none of the potential focus areas would be undertaken in a vacuum. Members of the Roundtable Process would seek to build strategic alliances with other organizations, networks and entities engaged in similar efforts—such as multilateral agencies (WHO, UNAIDS, World Bank), private-sector supporters, and representatives from donor and recipient governments. In such contexts, the added value of the Roundtable Process would be that it would help crystallize some key areas of concern to civil society and, by extension, increase its clout and influence in addressing them.

Working group meetings

The final third of the meeting was devoted to narrowing down the big list of potential focus areas within each of the two categories (short-term strategy development and planning; and long-term policy analysis). A key objective of this exercise was to identify

concrete action steps for both ICSS and other civil society representatives involved in the Roundtable Process.

Separate working groups were created to consider issues related to the following three overarching focus areas: **procurement; funding; and gender/stigma**. In addition to determining whether the issue would benefit from the development of a short-term advocacy strategy or longer-term analysis, each working group was charged with proposing priority actions and strategies that addressed four key questions directly relevant to the Roundtable Process:

1. What can and should each of us (current and potential members of the Roundtable Process) do on this issue?
2. Who already works on this issue and how do we evaluate and monitor their work?
3. Who should work on the issue, but is not currently doing so?
4. What is the added value of the Roundtable Process being involved in this issue?

Working group members were also asked to consider the following additional questions, which refer more specifically to developing a work process:

- What kinds of background materials might need to be compiled in order to put everyone on same page (data collection from the field, research surveys, etc.)?
- What kinds of representation and expertise might be needed at the table? Different people will likely be needed for different issues, such as intellectual patent issues and harm reduction, for example.
- What type of structure should be established, and what would it entail (in terms of process and work flow, for example)?
- What are the best possible outcomes that could result from discussion in the Roundtable Process? For example, might the most appropriate outputs be a policy paper, a fact sheet, a structured advocacy strategy?
- What would be the optimal (or necessary) timeline and work processes? This would depend on whether a key date (i.e., a meeting of government leaders) is imminent or several years in advance, for example.

Summaries of reports from the three working groups follow below. The summaries do not have a consistent structure because each group approached its mandate in a different way.

Working group one: procurement

Members of the procurement working group identified several obstacles to appropriately comprehensive, efficient, and affordable procurement of HIV drugs. They include the following:

- Resistance to first-line regimens and poor adherence (among some patients) have greatly increased the need for second-line therapies. The high cost of these therapies limits their availability in most lower-income countries, however.
- Supply chain problems and inefficiencies persist.

- Systems to ensure the quality of drugs remain limited or of poor quality, even when the medicines are pre-qualified by WHO.
- Many trade policies and agreements conspire to bolster patent protection and, consequently, limit access to affordable medications. For example, many countries (such as India, Morocco and Thailand) have been or are being pressured to sign free trade agreements (usually with the United States) in which they renounce their rights to issue compulsory licenses in the case of public health emergencies. These potentially destructive free trade agreements are known as “TRIPS Plus”; they are designed to limit poorer countries’ ability or inclination to utilize provisions under existing WTO TRIPS provisions, as agreed to in November 2001. (Issuing compulsory licenses would allow the importation or production of lower-cost generic medicines.).
- In many countries, civil society has limited capacity to influence issues related to procurement, including trade policy.
- Co-infection with other potentially fatal disease, such as tuberculosis and hepatitis, limits the effectiveness of many HIV treatment regimens.

After discussing each of these issues, members of the working group recommended three issues for consideration as focus areas by the Roundtable Process. One was categorized as a short-term issue (strategy development and process), and the other two would more properly be considered longer term (policy analysis):

1) *Taking on Abbott and Novartis*. The goal of the short-term issue would be to pressure Abbott and Novartis to stop their current efforts to force Thailand and India, respectively, to recognize and honour restrictive patents on key HIV medicines. If successful, the companies’ recent actions would make their drugs more expensive and, consequently, limit the countries’ ability to purchase adequate supplies for those in need.

The first step would be a quick review of efforts currently under way with similar objectives. Among the advocacy and health groups likely to be involved are MSF, Oxfam, ActUp, the Stop AIDS Campaign, DNP+⁹ and INP+¹⁰—not all of which were represented at Noordwijk. Advocacy coalitions could be built with these organizations based on their activities to date and what still seems to be missing. Beyond that, among the possible strategies for the Roundtable Process to consider are the following:

- influence shareholders by raising awareness among them of the consequences of the companies’ actions. Possible actions would include protests at shareholders’ meeting in the next several months and a campaign to sway public opinion (through newspaper editorials and articles, for example);
- commission and/or create a media or film piece that would communicate the advocacy message clearly and concisely. This piece could be distributed and aired

⁹ DNP+ = Delhi Network of Positive People

¹⁰ INP+ = Indian Network of People Living with HIV/AIDS

both in the countries affected and in the firms' home nations (the United States for Abbott and Switzerland for Novartis);

- organize a Global Day of Action involving civil society groups in as many countries as possible (notably Brazil, India, and Thailand, all countries facing pressure from the pharmaceutical industry). The goal would be to hold rallies in places (drug companies' local headquarters or government trade offices) to demand resisting the companies' demands. Fact sheets and advocacy material could be distributed during the rallies. Similarly, a targeted protest could be held in Switzerland, where Novartis is based; and
- initiate a campaign to bring on board healthcare providers. In most countries, for example, doctors are among the most respected professionals. Their evidence-based criticism of Abbott and Novartis could sway policymakers.

2) *Helping governments resist TRIPS Plus*. The goal of one of the longer-term efforts would be to determine how to make it easier for governments to resist pressure, while negotiating free trade agreements, to utilize "TRIPS Plus". This provision limits the legal ability of governments to defy international patents so as to import or manufacture lower-priced generic drugs. As agreed in November 2001, the original TRIPS allows governments to take such actions in the case of public health emergencies (such as HIV epidemics).

Participants at the Noordwijk meeting acknowledged that many civil society groups lack sufficient in-depth knowledge of international and national trade law. Therefore, a key initial step in this long-term effort would be to commission a fact sheet or paper that spells out the key issues concisely and clearly, paying particularly attention to why they are important across the civil society sector. This publication could be translated and distributed to as many countries and regions as possible. This step would help create a coordinated, global civil society advocacy movement with concrete goals and objectives.

Other parts of the process might consist of holding training sessions, possibly organized and chaired by experts in the field (such as individuals who work for Oxfam). The Roundtable Process would focus on sharing information across its members and, by extension, their networks and members. A coordinated advocacy strategy to resist TRIPS Plus would be useful not only in countries currently facing pressure, but in nearly every other country at some point in the future as the extent and breadth of free trade pacts proliferate.

3) *Help develop alternative R&D models*. The idea behind this focus area is that the current system of R&D for HIV drugs is too opaque, slow and expensive. Civil society should thus inform itself of alternative models, some of which are already being discussed (i.e., by Jamie Love at the Consumer Project on Technology, and by Imperial College in London), and then support those deemed most worthwhile. It should also consider developing their own, based on its members' specific priorities.

The first in this longer-term process should be the commissioning of a policy brief to examine alternative models being created. What are the potential benefits and liabilities of such models? How might they increase access to HIV treatment? What would their impact be on the role of civil society in treatment access issues? And conversely, how could civil society create a united front and be involved from the very beginning?

Working group two: gender/stigma

Of the myriad potential focus areas that fall under gender and stigma, working group members said that the issue of **criminalization of PLHA** stood out in particular. They agreed that it was imperative for civil society to begin setting the agenda for this issue in a coordinated, supportive way—instead of being reactive on a local basis.

In the view of working group members, policies and legislation to criminalize transmission of HIV (and, by extension, to isolate PLHA from the general population), violate established human rights norms and expectations. By creating climates of fear, anxiety and retribution, such steps also increase HIV-related stigma and discrimination, thereby limiting treatment uptake and access. Not only are such policies discriminatory to the health and human rights of individuals directly affected, but they are irrational from a reasonable public health standpoint in general.

The following were among the action areas proposed by working group members to better understand and establish a common civil society agenda (through the Roundtable Process) on criminalization:

- *Map the situation, perhaps by commissioning a report.* This would focus on identifying existing and proposed laws and policies that criminalize HIV transmission or otherwise violate their basic rights. It is also important to know what people are experiencing on ground; for instance, where and under what pretext are HIV-positive individuals being locked up or forced to leave their homes? How are issues related to criminalization and rights initiated and responded to within different cultures and societies? Those surveyed in the mapping exercise could include PLHA and their networks, activists, lawyers, government officials and academic researchers.
- *Reach out to legal and human rights organizations that support efforts to reverse the trend toward criminalization.* What should the end goal(s) be? What strategies and advocacy tools do these organizations recommend, both globally and in specific local contexts? For instance, would it be useful (and timely) to push the International Criminal Court to consider a case that could lead to a positive ruling on issues related to criminalization?
- *Hold a meeting through the Roundtable Process that focuses specifically on criminalization issues.* The goal would be to develop, for the first time, a comprehensive set of strategies for civil society. Specific steps could also be proposed in a number of local, national or global contexts.

Several members of the working group linked criminalization with HIV testing. Their argument was that policies and drives to encourage testing often are focused primarily on identifying those who are HIV-positive so they can be isolated and discrimination against. In this view, policy makers' emphasis on testing as many people as possible has potentially sinister consequences.

Other participants argued, however, that it is important to separate criminalization from testing. As one stated, "The first is always bad, but the second can have good consequences." For example, more extensive testing means that more people become aware that they are living with HIV and are subsequently able to receive treatment, care and support. This would include information on steps on how to protect their own and others' health, such as by using condoms. When initiated properly—in a confidential manner and with ready information about and access to appropriate services—HIV testing is a necessary and useful part of treatment.

The gender/stigma working group also identified one other potential focus areas for the Roundtable Process: **accountability**. This effort could have both short- and long-term elements. Through the Roundtable Process, civil society could initiate more extensive monitoring of progress toward treatment access targets, including those outlined by the G8 and through the UNGASS process. Comprehensive, collaborate efforts in these areas would help civil society set the agenda more forcefully, both in terms of holding governments to their promises and in working to identify future targets.

Working group three: funding

The central goal of the funding working group was to increase financing for HIV treatment, care and support initiatives at all levels, from global to local communities. The working group examined the following potential focus areas for the Roundtable Process:

1) *Influencing PEPFAR reauthorization*. The legislation establishing PEPFAR is up for reauthorization in 2008 in the United States. The program has notched important achievements in recent years, including the provision of funds and support services to provide treatment to hundreds of thousands of PLHA. Yet most advocates, particularly those from civil society, agree that PEPFAR could and should be improved—by, among other things, adding more countries, increasing total program resources, and removing particularly onerous and impractical restrictions on use of funds.¹¹

2) *Influencing ongoing efforts aimed at health systems strengthening*. According to WHO's World Health Report 2006, there is a shortage of more than four million

¹¹ Nearly all PEPFAR funds are allocated to 15 target countries; as a result, many high-burden nations that could benefit greatly from additional resources to fight HIV are largely excluded from receiving funds. The biggest criticism of PEPFAR is that under U.S. law, one-third of the program's prevention-related funding must be spent on abstinence-only initiatives. Public health authorities and advocates in recipient countries are among those arguing that such a provision is impractical, unrealistic and judgemental. They would prefer that local implementing agencies have more leeway in designing PEPFAR-funded prevention and treatment programs based on the realities of epidemics in their countries and regions.

healthcare workers in 57 developing countries, many of them struggling to respond to HIV epidemics.¹² Other obstacles to the provision of essential health services, including HIV treatment, are substandard and poorly funded healthcare facilities, lack of medicines and support services, corruption, and resource-allocation decisions that fail to make health care a major domestic priority.

Health systems strengthening refers to efforts to improve and expand poorly funded and capacity-restrained national and local healthcare systems. GFATM has recently begun accepting applications that including funding for health systems strengthening. Civil society should also develop a coordinated strategy to address the problem, which remains a major impediment to effective HIV treatment, care and support. The number of countries in dire need of additional resources and support continues to grow every year.

3) *Increasing the amount and scope of GFATM assistance.* With greater resources available to dispense, GFATM programs could increase the number, size and quality of grants awarded each round. Civil society could be more directly engaged in this process by advocating for more extensive funding of appropriate forms of technical assistance that helps to achieve increased and better expressions of demand from all sectors, including civil society. It could also seek to allay concerns about poor oversight of national-level implementation by increasing GFATM monitoring and evaluation efforts and the establishment of appropriate mechanisms for strengthening grants in trouble, especially those implemented by civil society.

4) *Setting and monitoring national costed AIDS plans.* A growing number of countries have national costed plans to respond to their HIV epidemics; in nearly all cases, these plans include funding for treatment. With improved capacity, perhaps obtained through a viable Roundtable Process, local civil society groups could be more directly involved in setting and monitoring these plans' targets and budget allocations. Civil society also has an important role in determining if the plans are epidemiologically appropriate, especially in terms of the goal of achieving universal treatment access.

In order to efficiently and effectively address one or more of these four focus areas, members of the working group recommended organizing a meeting to discuss potential strategies and concrete steps in greater depth. Civil society representatives could be joined at that meeting by a group of experts from relevant organizations, governments, and academic institutions. Preparatory work for the meeting could include a concept paper laying out the likely benefits and liabilities of each area from the perspective of the Roundtable Process. Outputs from the meeting could include a discussion paper and/or an action paper outlining specific steps to be taken by members of the Roundtable Process to leverage civil society engagement and influence in the selected focus area(s).

Subsequent meetings could be organized to consider progress in achieving objectives. They would also provide a forum for additional strategic thinking on how to improve efforts and set additional goals.

¹² See www.who.int/whr/en/.

V. Next Steps

Because it was the first meeting to discuss a unique and potentially innovative initiative, organizers of the March 2007 gathering in Noordwijk did not expect to leave with a specific blueprint or plan of action. Instead, they were seeking input from a wide range of civil society representatives to help establish a working structure for the Roundtable Process and to guide the development of its strategic focus. They were rewarded with a plethora of interesting, important and powerful ideas and models to consider.

The next step will consist of a series of discussions involving ICSS personnel and members of the Roundtable Process's Core Group. They will make decisions on structure and focus areas based on proposals identified at the March 2007 meeting. Their decisions will be released in a final report that includes action steps, roles and responsibilities for both organizers and members. The goal is to have the Roundtable Process moving forward toward achieving its strategic objectives by the middle of 2007.

Appendix 1 Participating Organizations

The **XX** individuals at the meeting represented a total of **XX** different organizations, the majority of which are community-based organizations or networks of such entities. Several of the organizations represented (in addition to ICSS, the Amsterdam-based NGO that organized the meeting) are listed below, in alphabetical order, along with a brief description of their focus and activities.

Aids Fonds Netherlands

AIDS Fonds is the primary fundraising entity for HIV/AIDS services in Netherlands. It focuses on advocacy and support (financial and otherwise), but is not directly involved in project implementation. The funds it raises are earmarked for scientific research, information and prevention, individual assistance and care, vaccine development and international projects.

Additional information is available online (in Dutch only) at www.aidsfonds.nl.

Alliance Nationale Contre le SIDA (ANCS)

Based in Dakar, Senegal, ANCS is an NGO that seeks to build and reinforce the capacity of civil society organizations to respond to HIV. In that role, it provides technical support regarding financing and service delivery, among other things. It also helps establish self-support groups for people living with and affected by HIV.

Additional information is available online (in French only) at www.ancs.sn.

Asia Pacific Network of People Living With HIV/AIDS (APN+)

APN+ was established in 1994 at a meeting in Kuala Lumpur, Malaysia of 42 PLWHA from eight countries. It was created in response to the need for a collective voice for PLHA in the region, to better link regional PLHA with the Global Network of People Living with HIV/AIDS (GNP+) and positive networks throughout the world, and to support regional responses to widespread stigma and discrimination. APN+ currently has 27 different country members. A peer-based organisation, all of its representatives must be HIV-positive.

Additional information is available online at www.apnplus.org.

Association de Lutte Contre le SIDA (ALCS)

With 17 offices in cities across Morocco, ALCS offers a wide range of services for people living with and affected by HIV (including members of vulnerable populations) in the country. It focuses on treatment education and prevention and defending the rights of

PLHA and those at risk (notably MSM and sex workers). It also seeks to increase the availability of diagnostics and treatments for opportunistic infections.

Additional information is available (in French only) at www.alcsmaroc.org.

Central and Eastern Europe Harm Reduction Network (CEEHRN)

Based in Vilnius, Lithuania, CEEHRN focuses on the provision of treatment and care for PLHA and drug users in Russian-speaking countries of Eastern Europe and the former Soviet Union. It supports, develops and advocates for harm reduction approaches in the field of drugs, HIV, public health and social exclusion by following the principles of humanism, tolerance, partnership and respect for human rights and freedoms. CEEHRN also helps boost service providers' capacity to provide comprehensive harm reduction services and supports changes aimed at implementation of more effective drug policies and integration of topics related to the work conducted in the field of drugs.

Additional information is available online at www.ceeHRN.org.

Centre for the Study of AIDS

The Centre for the Study of AIDS is based at the University of Pretoria in South Africa. It was established in 1999 in response to a) a call by then Deputy President Thabo Mbeki for a Partnership Against AIDS, and b) to mainstream HIV/AIDS through all the activities of the University of Pretoria. To that end, the Centre seeks to ensure that the university as a whole is able to plan for, and cope with, the impact of the HIV epidemic on the institution. More broadly, the Centre seeks to create new and innovative ways to address HIV and AIDS, human rights and development in southern Africa.

Additional information is available online at www.csa.za.org.

Coalition of Asia Pacific Regional Network on HIV/AIDS (“Seven Sisters”)

Seven Sisters is a broad-based alliance bringing together seven regional networks: AIDS Society of Asia Pacific (ASAP), Asia Pacific Council of AIDS Service Organisations (APCASO), Asia Pacific Network of People Living with HIV/AIDS (APN+), Asia Pacific Network of Sex Workers (APNSW), Asia Pacific Rainbow (APR), Asian Harm Reduction Network (AHRN) and Co-ordination of Action Research on AIDS and Mobility in Asia (CARAM Asia). Bangkok-based APN+ is host the coalition, for which treatment access is a rapidly growing focus.

Collaborative Fund for HIV Treatment Preparedness

The Collaborative Fund for HIV Treatment Preparedness is a nonprofit, community-driven funding mechanism to support HIV treatment advocacy and education efforts in Africa, Asia, the Caribbean and Latin America, and NIS/CIS/Baltics. In each funding region, the Collaborative Fund provides:

- grants for community-based organizations for HIV treatment advocacy and education projects; and
- support for regional networks to share information, implement collaborative strategies, and provide technical assistance to grantees;

Additional information is available online at www.hivcollaborativefund.org/.

Friendship Group

The Friendship Group is a self-support group in Ho Chi Minh City, Vietnam. Its overall mission is to facilitate continuum of care for PLHA and to improve their lives. As part of a network in southern Vietnam, it also links with other self-support groups in provinces including An Giang, Can Tho, Ca Mau, and Vung Tau to help PLHA live more self-confidently. Among its specific activities are to:

- provide information and counselling to PLHA about issues such as harm reduction, transmission prevention, how to confront stigma and discrimination, and where to go and how to do when their rights are violated;
- provide home-based care for HIV/AIDS patients and educate for family members how to take care of their relatives;
- refer PLHA to social and medical support services such as free ART and OI treatment sites; and
- raise awareness about HIV/AIDS in the community, including through education programs in factories, hotels, and rehabilitation centres.

Gestos

The mission of the Brazilian NGO Gestos is to strengthen the human rights of PLHA and vulnerable populations; to mobilize intervention by communities in public policies; to develop educational and communication strategies; and to increase awareness of gender equity and social justice. More specifically, Gestos focuses on increasing access to prevention, treatment and care services for people living with and affected by HIV, especially those living in poor and under-served communities.

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

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

Additional information is available online at www.gnpplus.net.

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

Based in London, ICW is the only international network run for and by HIV-positive women. It advocates and seeks to build capacity for women in all areas related to treatment, care and support. ICW's vision is 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 or race.

Additional information is available online at www.icw.org.

International Council of AIDS Service Organizations (ICASO)

Based in Toronto, Canada, ICASO is a global network of non-governmental and community-based organizations. Its mission is to:

- mobilize communities and their organizations to participate in the response to HIV/AIDS;
- articulate and advocate the needs and concerns of communities and their organizations;
- ensure that community-based organizations, particularly those with fewer resources and within affected communities, are strengthened in their work to prevent HIV infection, and to provide treatment, care and support for people living with and affected by HIV/AIDS;
- promote the greater involvement of people living with, and affected by, HIV/AIDS in all aspects of prevention, treatment, care and support, and research; and
- promote human rights in the development and implementation of policies and programs responding to all aspects of HIV/AIDS.

Additional information is available online at www.icaso.org.

International HIV/AIDS Alliance

Based in the United Kingdom, the International HIV/AIDS Alliance is a global partnership of nationally-based organizations working to support community action on AIDS, especially treatment access. It currently is active in 32 countries.

The national organizations are supported by technical expertise, policy work and fundraising carried out at the UK-based international secretariat and across the Alliance. In addition to community and country-based programmes, the Alliance also has extensive regional programmes and works on a range of international activities such as support for South–South cooperation, operations research, training and good practice development, as well policy analysis and advocacy.

At the March 2007 meeting in Noordwijk, the Alliance was represented by personnel from the head office and its Zambia office.

Additional information is available online at www.aidsalliance.org

ITPCru

ITPCru is the Russian branch of the International Treatment Preparedness Coalition (ITPC). It focuses on increasing access to HIV treatment, care and support as well as bolstering community members' ability to advocate for high-quality and consistent services. Among the most pressing issues in Russia are a poor quality national treatment program—characterized by regular medicine stock outs and similar severe problems—and rampant co-infection with TB and hepatitis.

Additional information is available online (in Russian only) at <http://itpcru.org>.

Latin American and the Caribbean Council of Aids Services Organizations (LACCASO)

LACCASO is the regional secretariat of ICASO. It focuses on fighting the HIV/AIDS epidemic in Latin America and the Caribbean by promoting and defending human rights through coordination, integration and capacity building of civil society organizations. The goal is to achieve an articulated and effective community and multi-sectoral response to the epidemic. Among the specific focus areas are advocacy, procurement and monitoring (especially of multilateral processes such as UNGASS).

Additional information is available online at www.laccaso.org.

NAP+ and IFRC (partnership in Nairobi, Kenya)

Initiated in 2000, the partnership between the International Federation of Red Cross and Red Crescent Societies (IFRC) and the Network of African People Living with HIV/AIDS (NAP+) aims to strengthen the contribution of PLHA in the fight against the pandemic. More specifically, it works to ensure that PLHA in Kenya receive appropriate care, have access to affordable drugs and can live full and useful lives in their communities. It also organizes joint training initiatives to build the advocacy and networking capacity of local civil society organizations; has introduced a campaign to reduce HIV-related stigma; and has sought to ensure the greater involvement of PLHA's in all HIV-related interventions.

Nava Kiran Plus

Nava Kiran Plus is an NGO in Kathmandu, Nepal that is run by and for PLHA. Its mission is to improve the quality of lives of PLHA and to enable them to live their lives with dignity. It provides services for numerous clients and advocates on their behalf for greater access to treatment, care and support. The overall goal of Nava Kiran Plus is that by 2010, all people living with HIV in Nepal will

- have access to ART, if they need it;
- have access to easily accessible and affordable treatment and care programs;
- have the means to support themselves and those who depend upon them; and

- be able to live in an open society without fear of stigma and discrimination

Philippine NGO Support Program, Inc. (PHANSuP)

From an early and committed focus on HIV/AIDS, PHANSuP has expanded to cover a wide range of public policy initiatives that attempt to integrate HIV/AIDS with reproductive health. Its current overall goal is to build the capacities of community-based leaders and partners in the implementation of reproductive health management projects in the Philippines. PHANSuP is

- the linking organization of the International HIV/AIDS Alliance in the Philippines;
- the national focal point of the Asia Pacific Council of AIDS Service Organizations;
- affiliated with the Philippine NGO Council for Population, Health, and Welfare; and
- a working partner of the Philippine National AIDS Council-Department of Health, the Boy Scouts of the Philippines, and the Girl Scouts of the Philippines.

Additional information is available online at www.phansup.org.

Royal Tropical Institute (KIT)

KIT is a not-for-profit organization that works for both the public and the private sector in collaboration with partners in the Netherlands and abroad. It positions itself as an independent centre of knowledge and expertise in the areas of international and intercultural cooperation, operating at the interface between theory and practice and between policy and implementation. The Institute contributes to sustainable development, poverty alleviation and cultural preservation and exchange. Among the activities it has undertaken in regards to HIV/AIDS are a program focusing on the qualitative aspect of adherence in Mali and Burkina Faso.

Additional information is available online at www.kit.nl.

TREAT Asia (Therapeutics Research, Education, and AIDS Training in Asia)

TREAT Asia is a network of clinics, hospitals, and research institutions working with civil society to ensure the safe and effective delivery of HIV treatments throughout Asia and the Pacific. Facilitated by amfar, TREAT Asia seeks to strengthen HIV care, treatment, and management skills among healthcare professionals through education and training programs developed by experts in the region.

Additional information is available online at www.amfar.org/cgi-bin/iowa/asia/index.html.

UN Children's Fund (UNICEF) Indonesia

While HIV/AIDS affects all of Indonesia, it has hit especially hard in Papua, in the country's east. In that province, the proportion of people living with AIDS relative to the total population is well over 10 times the national rate.

To stem the tide of transmission, a UNICEF Indonesia-supported programme is educating young people in Papua about the dangers of HIV. The goal of this campaign is to promote awareness in the classroom and train young people to serve as peer educators.

Additional information is available online at www.unicef.org/Indonesia.