

**Report of the First Asia Pacific  
PLWHA Congress  
11 January 2004, Bangkok**

**Organized by Asia Pacific PLWHA Resource Centre in association  
with  
APN+, INP+ and UNDP**

**Report prepared by Asia Pacific PLWHA Resource Centre  
Email: [shiba.p@undp.org](mailto:shiba.p@undp.org)**

## **Contents**

• <b>Background</b>	<b>3</b>
• <b>Introduction</b>	<b>3</b>
• <b>Presentation</b>	<b>4</b>
• <b>Group work</b>	<b>5</b>
• <b>Results of the group discussion</b>	<b>5</b>
• <b>Presentation at the Alternative Community Forum</b>	<b>8</b>
• <b>Summery</b>	<b>9</b>
• <b>Way forward</b>	<b>9</b>

## **I. Background**

As part of the Asia Pacific PLWHA Coalition for Advocacy and Capacity Transfer, the Asia Pacific PLWHA Resource Centre (APPRC) together with Asia Pacific Network of Positive People (APN+), Indian Network for People Living with HIV/AIDS (INP+) and UNDP is tasked with organizing three PLWHA Congresses. The Congresses focus on developing Asia Pacific regional advocacy agendas and strategic action plans based on the issues identified by the Asia Pacific PLWHA Coalition to be implemented by the APPRC in various fora. The Asia Pacific PLWHA Coalition is a network of PLWHA across Asia Pacific Region which is connected through the website of the APPRC and GIPA mailing list for various discussion and information sharing. Each of the Congresses is held in connection with major international HIV conferences in the region to create visibility and facilitate a broad participation of PLWHA. All the Congresses will have three major outputs:

- Endorsement of an Asia Pacific PLWHA Advocacy Agenda
- Discussion and adoption of a Strategic Action Plan to take forward the agenda
- Issuing of a PLWHA resolution to be addressed at the Conference that is held in conjunction with the Congress

The First Congress focused on advocacy for GIPA, Access to treatment/ care and support and Stigma and Discrimination which had been identified by the APN+ General Body Meeting in 2003 as three priority issues. The Advocacy Agenda and Strategic Action Plan prepared by the APPRC were to be endorsed and discussed in order to be taken forward by the Coalition. The delegates for the Congress were representatives of PLWHA groups from countries across the Asia Pacific Region. In addition to the key resource persons for advocacy identified by APPRC, key people from the Coalition were also to be invited as observers.

## **II. Introduction**

The first PLWHA Congress was held on the 11 January 2004 in Bangkok prior to the Asia Pacific Alternative Community Forum . Forty five PLWHA leaders from nineteen countries from the Asia Pacific Region attended the Congress. The participants were from Australia, Bangladesh, Cambodia, China, India, Indonesia, Iran, Lao, Nepal, Malaysia, Philippines, Pakistan, Papua New Guinea, Singapore, Sri Lanka, South Korea, Thailand, East Timor and Vietnam.

Participants were identified through the PLWHA groups who are partners of the Asia Pacific Initiative for Empowerment of PLWHA which is a joint venture of UNDP, APN+, INP+ and APPRC, as well as through other international agencies such as HIV/AIDS Alliance, Australian Red Cross etc. Some of the participants were supported by HIV/AIDS Alliance and Australian Red Cross while UNDP was the main source of funds. The Congress was open to all PLWHA who came for the Alternative Community Forum. Translators were arranged for participants who do not speak or understand English.

## **Objectives of the First Congress**

- To identify the primary issues of PLWHA, which need immediate action in the Asia Pacific region.
- To develop a draft agenda, based on the issues identified, in order to advocate for the rights of PLWHA in the Asia Pacific region.
- To develop a draft strategic action plan to take forward the regional agenda effectively by the APPRC
- To prepare strategies and action plans for the second Congress

The Congress was facilitated by the members of APN+ and the Coordinator of the APPRC. The Coordinator of the APPRC welcomed the participants. He also gave a presentation on the current progress of the Asia Pacific Initiative for Empowerment of PLWHA project which is being implemented in fourteen countries by UNDP in partnership with APN+, APPRC and INP+.

## **III. Presentation**

In order to set the tone of the Congress and to highlight an overview of the current situation on the three issues (GIPA, treatment and stigma and discrimination) presentations were made at the beginning of the Congress.

### **( a ) GIPA**

The presentation on GIPA by Mr. Lilabanta from India included the confusion while leveling the affected community. He said that people who are care providers in a professional capacity can be excluded from the affected community. People who are aware of their HIV status and those who are closest to them such as spouse, siblings, parents etc can be given the opportunity to contribute further to GIPA. GIPA means to recognize the important contribution that PLWHA can make in the response to the epidemic by creating space for them and use their experiences. This will also give a human face to the epidemic. The principle of GIPA is not implemented in most countries in the region despite the efforts of many PLWHA groups and other agencies. The government should take more initiative to put the GIPA principle into practice.

### **( b ) Access to treatment and care and support**

The presentation on access to treatment was done by Mr. Rajiv Kafle from Nepal. He said that the current access to treatment is like using internet café by people who can not afford to visit at the café regularly. He also said that even for people who can afford it is not possible to access due to the inconsistent internet facility. He expressed his concerns on the non standard treatment facility and the cost involved. Access to treatment is not

just to get ARV but regular CD4 and viral load should also be included. There are only five trained doctors to treat HIV/AIDS in his country. He also highlighted the overburdened health care system in his country.

### **( c ) Stigma and Discrimination**

Mr. Noel from the Philippines highlighted the stigma and discrimination faced by every PLWHA. He said that despite the global efforts, stigma and discrimination is still accompanied with HIV. In many societies people living with HIV are often seen as shameful. Many people still believe that HIV is associated with minority groups such as MSM, IDU, sex workers etc. Stigma and discrimination can be reduced by developing legislation and laws. One of the priorities to deal with stigma and discrimination is to allocate more funds.

## **IV. Group work**

The emerging issues on GIPA, treatment and stigma and discrimination were prioritized by the participants during the group work. The participants were divided into three groups and worked on the issues. The groups explored methods and action plans based on the identified issues. One person from each group was selected to present the result of group discussion and action plans they developed. There was a question and answer session after each presentation. The groups also worked on the strategies to take the agenda forward.

## **V. Results of the group discussion**

The groups who worked on the three issues came up with the following emerging issues and actions which needs to be taken up immediately.

### **( a ) GIPA emerging issues :**

There were several issues of concerns that emerged out of the Congress. Keeping in mind both the pros and cons, the following ideas were born out of several detailed and multi layered discussions. It was felt that both the policy and program implementation processes did not go beyond the token statement and had not much space for the people living with HIV/AIDS. HIV programs tended to lack sufficient GIPA monitoring and evaluation mechanisms that assess the success and failures of those countries in the region. Linkages and networks of PLWHA at all levels- communities, state, national and regional needs to be strengthened not just by numbers but by commitment, participation and empowerment.

There are several other factors influencing GIPA success in the region, which include inconsistent support to those PLWHA who are active and involved is among the main

issues. Most of the national AIDS council in every country in the region have not yet employed PLWHA in their HIV projects, where their participation will create greater and more meaningful involvement. The training that the PLWHA received for supporters and leaders to take forward the GIPA initiative is insufficient and inconstant. PLWHA can become a vital asset in providing support structures in hospitals with counseling and peer group support systems. The average PLWHA often lacks the basic resources to become a leader, apart from essential reading/writing, language and information system that are lacking, there are no ambitious agendas that will inspire them to succeed not just for themselves but for the community at all levels.

### **Actions needed**

For GIPA to succeed several pro active measures needs to be undertaken laterally and horizontally from the individual to community level and effective networks must be establish which include support groups with fund raising built into its agenda. The organizations must be able to work together in establishing successful relationship with NGO, CBO and Government agencies. Every member must be aware of their rights and promote them in their work. They should integrate not just basic skills but also design training program and activities as well as do self-monitoring and assessment. Every PLWHA must be encouraged and supported in decision making and foresee a growth from basic to higher skills which will help them establish a common framework that will be modified in each country by reflecting language, culture and individual needs.

A realistic yet ambitious agenda will strengthen capacity and capability of the PLWHA as well as promote the GIPA initiative clearly in all parts of the communities. There is a need for greater involvement of the members at the Country Coordinating Mechanism ( Global Fund ) and to successfully advocate a funding mechanism that will be beneficial to PLWHA.

### **( b ) Access to treatment, care and support emerging issues**

One of the basic issues in the existing treatment structure is lack of information on treatment of PLWHA. There are only a limited number who have access to ARV and non availability of information is one of the main causes of these. Self-assessment can be the first step to PLWHA needs.

Actual treatment logistics confirmed that CD4 and viral load testing is unaffordable and only a small number of trained doctors are available to treat PLWHA. The decision making of the treatment process is not patient friendly where doctors dominating the decisions. There are insufficient advocacy campaigns for receiving health care services which is compounded by insufficient capacity among the health care providers, lack of ARV supply and a lack of access to quality health services.

Despite the health and treatment angle involved, the drug companies and their marketing strategies influence the production and price of drugs. This problem is heightened by the

non availability of drugs both OI and ARV in all parts of the Region. Government funding does not cover access to ARV for all PLWHA who require them and access to treatment means more than just free ARV. Expensive licenses prevent the drugs being available at more nominal cost and this in turn prevents ARV from being available to all PLWHA.

The facilities related to ARV that exist are insufficient in several counts. ARV related issues are usually under represented and the quality of VCT is often questionable. Ongoing counseling facilities are not maintaining quality and lack resources for peer group support networks. There is a need to promote quality home based care as well as increase the availability of CD4, viral load and other tests.

### **Actions needed**

For the first and most basic part, PLWHA must be involved in all treatment plans that are developed, along with guidelines and looking at long term treatment successes. Legislation must be developed to constantly monitor the rights of PLWHA and ensure that the best practices of treatment are available to all high risk groups ( drug user, MSM and sex workers).

Working with local partner, treatment issues have to be integrated into the work plan and there is a need to look at education for health care providers and the community. Access to ARV and OI drugs as well as testing facilities must be increased and made available both in terms of logistics and information. If PLWHA capacity is developed then pharmaceutical companies can be lobbied through leaders, bureaucrats, government, UN and other agencies. This may help in price reduction and quality control of the drugs, make available more services for women and children and take PLWHA involvement from community to country and regional level.

### **( c ) Stigma and discrimination emerging issues**

The issues of stigma and discrimination are an integral part of the most Asian societies where socially sanctioned violence- both mental and physical affects the vulnerable and marginalized parts of all communities. Within the issue of HIV/AIDS, stigma and discrimination problems exists at several levels. Within the family itself, care and understanding are rarely available while at the community level it can reach its peak. This affects the workspace where jobs become unstable and insecure. Health care services are also affected by stigma and discrimination and without any laws to challenge this, discrimination also influences issues at policy level like funding in the Asian countries.

While prevention programs need to be supported, there appears to be an imbalance of funding towards it, compared to care and support programs. In hospitals there is a need to create sensitization programs for health care service providers to challenge the daily stigma faced by PLWHA.

## **Actions needed**

To tackle the twin issues of stigma and discrimination, multi pronged effort must be undertaken at several levels with many stakeholders involved. Hospital staff require sensitization and education programs and PLWHA must help initiate and be involved as partners in carrying out these programs. IEC materials must be developed and PLWHA trained to carry out positive speaking bureau activities as well as identify gaps on PMTCT and develop special programs for women and children.

There is a need to target advocacy to the decision makers of health care services. Community must be responsible to ensure that there are sufficient funds to address this problem. Establishing partnerships with multiple stakeholders and documenting stigma and discrimination incidents are important priorities.

On the legal front, legislation, law and policies to fight stigma and discrimination at the workplace and changing laws that prevent PLWHA entering other countries must be of targeted to enable change. Mandatory testing for migrant workers and rethinking national AIDS policies will also go a long way in addressing stigma and discrimination.

Communities must stop the negative portrayal of PLWHA in all forms and develop culturally sensitive programs to address their needs. Counseling and health care services must be made more sensitive. The media must be educated and encouraged to publish positive and informed articles. The programs to fight stigma and discrimination must be an ongoing effort, that should not be limited to World AIDS Day events and must encourage all HIV related activities to contain messages to combat stigma and discrimination.

## **VI. Presentation at the Alternative Community Forum**

The findings of the First Congress were presented on the first day of the Alternative Community Forum by Mr. Shiba Phurailatpam, the Coordinator of the Asia Pacific PLWHA Resource Centre. The presentation included the need to establish strong, effective and sustainable networks for a meaningful GIPA implementation. Developing skills for PLWHA is essential and creating an opportunity for involvement of PLWHA at all levels is a must in order to put the GIPA principle into practice. PLWHA do have a meaningful role to play in adherence, compliance and ensuring effective management of ARV drugs. There are a lot inputs and commitment needed in the 3x5 advocacy plan and PLWHA can play a major role to make the plan success.

As highlighted by the Asia Pacific Network of People Living with HIV/AIDS peer led research, stigma and discrimination in the workplace and within the health care system exist in most parts of the region. Having effective laws and legislation that can be implemented will help to fight with stigma and discrimination. Documenting stigma and discrimination related incidents will help to mitigate the problems faced by PLWHA.

***“Strategies to combat the disease ( HIV/AIDS) have only succeeded when people living with HIV/AIDS took the lead” – Kofi Annan***

## **VII. Summary**

The Congress has given an opportunity to identify the issues together which will help to build a common platform for the PLWHA in the Asia Pacific Region by networking and learning on issues concerning them. This was the first PLWHA Congress in the Asia Pacific Region which was planned, organized for and by PLWHA. One of the biggest achievements of the Congress was the identification of issues related to PLWHA in the region.

The Congress also gave a clear picture that access to HIV/AIDS treatment is still the biggest problem for most PLWHA in the Asia Pacific Region. Combating stigma and discrimination needs to be taken seriously in the political agenda of all countries. Promoting and putting the GIPA principle into practice will help to achieve successful HIV/AIDS programs. The need of the hour is to respond with effective strategies to the urgent and emerging issues of PLWHA. It is important to understand and be familiar with the history and current issues of the PLWHA while responding to HIV/AIDS. The Congress strengthened PLWHA networking and helped to set the agenda for action in the Region and helped PLWHA prioritize strategies for future action.

## **VIII. Way forward**

Based on the results of the first PLWHA Congress APPRC will now develop an advocacy agenda and action plan together with PLWHA groups to be implemented effectively in the areas of Greater Involvement of PLWHA, Access to Treatment and Stigma and Discrimination in the Asia Pacific Region. The agenda and action plans will be used as guidelines to Greater Involvement of PLWHA for them to effectively advocate for their rights. The agenda and action plans will support the National, Regional and International organizations in their advocacy work.

The second Congress will be held in July 2004 in conjunction with the International AIDS Conference in Bangkok. It will evaluate the results of the Action Plan formulated at the first Congress. An advocacy agenda and strategic action plan will be endorsed and a resolution addressing the issue of GIPA, Treatment and Stigma and Discrimination will be presented at the International AIDS Conference. The International AIDS Conference will be used as a major venue for the Congress to further strengthen the Regional collective voice.