



THE NEWSLETTER OF THE ASIA PACIFIC NETWORK OF PEOPLE LIVING WITH HIV/AIDS (APN+)

WORKING WITH PLHIV COMMUNITIES TO ADDRESS STIGMA AND DISCRIMINATION AND INCREASE ACCESS TO TREATMENT THROUGH ADVOCACY AND EDUCATION

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Message from the Co-chairs of APN+

As we approach the end of our role as APN+ Co-chairs, we take this opportunity to extend appreciation to all our network members, donors and all the other stakeholders for the ongoing support we have received in advocating for the rights of our positive brothers, sisters, children and friends in the region.

The continuation of support is crucial as we confront and challenge a shifting momentum of the global pledge to HIV/AIDS treatment and services. Access to treatment has not been fully achieved, thousands of people in the region continue to live without treatment, prevention tools or basic health care. In addition to this fact is the pending threat of interruption to ARV supplies for those in the region who do have access. Such an event would have devastating consequences for many people and would reverse any progress that has been made so far. Equally important is the action required to urgently address issues around access to Hep C treatment for people living with

HIV/HCV co-infection. Greater attention is needed to enable people to enjoy the same right to health and quality of life. The fulfillment of ongoing commitment and support is more critical now than ever before.

Fundamental to tackling these issues is the full involvement of PLHIV in the response, particularly as we continue to expand and strengthen our advocacy efforts and regional networks.

Finally, we express sincere thanks for having an important opportunity to support growing solidarity for PLHIV networks in the Asia-Pacific region. As our final greeting, we look forward to continuing these efforts in the future and working together with you. Let us also remind ourselves- together we stand, divided we fall.

Thank you

Naoko Kawana and Do Dang Dong
APN+ Co-chair

Farewell Meji

After nearly four years working with APN+, Meji has decided it is time for her to return to her home province to look after her lovely mother. Meji first joined APN+ in 2006 as the APN+ Administrative Officer. Meji helped coordinate many of the day-to-day functions of the APN+ Secretariat. Without Meji's hard work behind the scenes, it would have been difficult to organize our many meetings and workshops. We will miss Meji greatly but we also wish her all the best with a wonderful life at home.



Your voice counts!

We welcome stories from your own networks, letters and other feedback.

If you have comments, suggestions, photos or inquiries, please send to:

info@apnplus.org

APN+ Newsletter Editorial Working Group calling for volunteer

Would you like to join our small friendly team (Robert, Naoko, John, Shiba, Lissa) and help us to deliver future APN+ Newsletter

Please contact Shiba : shiba@apnplus.org

Global Fund Multi-Country Proposal

Despite the crucial role played by people living with HIV in response to HIV prevention and care, positive networks in Asia and the Pacific continue to be unacceptably under resourced. This thereby prevents them from actively and meaningfully participating in delivering much needed services and being in a position to build their individual and organisational capacity. In response to this barrier, APN+ national network members are currently in the process of submitting a multi country proposal to the Global Fund in an effort to fill these gaps in ten countries in the Asia Pacific region. The 10 countries include Bangladesh (Ashar Alo Society in partnership with Mukto Akash), Cambodia (CPN+ in partnership with CCW), China (AIDS Care China), Fiji (FJN+), Indonesia (JOTHI), Laos (LNP+), Nepal (NAP+N), Pakistan (APLHIV), Philippines (Pinoy Plus), and Vietnam (VNP+).

In March 2010 a consultation workshop was organized with representatives from the 10 country networks where all agreed that the proposal will have the following objectives:

1. Expand treatment support and education services by networks of people living with HIV
2. Strengthen networks of people living with HIV to provide services and improve the health of PLHIV through developing expertise in resource mobilisation, program management, financial management, monitoring and evaluation, and reporting
3. Improve and strengthen the AIDS response by expanding information

management, documentation and advocacy with direct involvement of national and regional networks of people living with HIV

A follow up workshop was organized in June 2010 to finalise the workplan and budget with all 10 country networks. The project will reach more than 80,000 PLHIV in 10 countries. The proposal will be submitted to the Global Fund by 20 August 2010 and we will expect to hear the result before the end of the year. Let's keep our fingers crossed.



APN+ Strategic Plan Review Process

The APN+ Strategic Plan 2006-2010 was developed in 2005/06 during a consultative process with all members of the APN+ Board (member country representatives) and Advisors. It is proposed that the time leading up to the planned APN+ Annual General Meeting (August 2010) will be an opportunity to review the achievements of the current Strategic Plan and provide a basis for the development of our next Strategic Plan (2011-2015).

As you will know our current Strategic Plan has 5 objectives:

1. Advocacy;
2. Network Capacity Building;
3. Growing the Network;
4. Knowledge Sharing;
5. Secretariat Capacity Building.

Please go to the APN+ website www.apnplus.org and click on 'strategic plan' to view our current Strategic Plan.

Assisting this review process is Dr Mark Shepherd, who was the lead facilitator for the development of our current Strategic Plan, along with some APN+ Advisors, Secretariat and members of

the Steering Committee. The review process over the next few months will include consultations with our key stakeholders and key people involved in APN+, such as our ex-Coordinators and ex-Chairs. We are also planning on having a full-day allocated (at the same time as our AGM) for consultations with our current Board Members.

Any enquiries or comments welcome. Contact Robert: tuntablecreek@bigpond.com

HIV/HCV Co-infection: Planning the Way Forward



Participants of the HIV/HCV community meeting

1st South and Southeast Asia Regional Community Meeting

In June 2010, APN+, joined Seven Sisters, Thai Treatment Action Group (TTAG), Asia Network of People who Use Drugs (ANPUD), Medecins Sans Frontieres – Access (MSF Access), World AIDS Campaign (WAC), Open Society Institute (OSI), International Treatment Preparedness Coalition (ITPC) and representatives from PLHIV networks in China, India, Indonesia, Nepal Thailand and Vietnam in Bangkok to identify advocacy strategies for HIV and Hepatitis C Viral (HCV) co-infection treatment in the region.

The two-day meeting was the first forum of its kind in the region. Specifically,

it aimed to provide an opportunity for participants to exchange experiences and develop national and regional-level strategies for a collective response to the challenges faced by people living with HIV/HCV co-infection. The need to advance the issue of HIV/HCV co-infection onto the HIV/AIDS agenda is particularly urgent since the health benefits of anti-retroviral therapy (ART) for those living with co-infection are severely compromised by their inaccessibility to HCV treatment and care.

Addressing the treatment issue of HIV/HCV co-infection requires advocacy around the inclusion of treatment on the WHO essential drug list, raising awareness and

working with the community, medical sector and government at both the regional and international level, developing a pricing guide that will identify the variation of HCV drug prices across the region and using a human rights framework to challenge the inaccessibility and un-affordability of treatment. The forum highlighted common concerns across the region about developing mechanisms for monitoring and ensuring accountability, especially striking a balance between an expansion of ART programs and the need to include services that address the needs of people living with HIV/HCV co-infection.

Welcome Note



We are very happy to welcome a number of new team members to the APN+ Secretariat office in Bangkok, Thailand.

From Left: Jack Arayawongchai (Deputy Director), Thanid Boonridrerthaikul (WAPN+ Program Assistant), Kirenjit Kaur (WAPN+ Program Coordinator), Lissa Giurissevich (AVI Communication & Advocacy Network Liaison Officer) and Dean Lewis (ANPUD)

Access to Services are not So Accessible in Poor Countries.

An experience being eligible to receive ARV: By Sudin Sherchan

I was diagnosed HIV positive 9 years ago in a private clinic and currently, living with Hep C and suspected of TB. In those days, voluntary counseling & testing (VCT) in the Government Health settings were uncommon. Now, VCT in Government health settings have rapidly increased. I was very cautious about going to health check-ups, especially in government health settings because of previous experiences and because private health settings are not affordable.

From the beginning of this year, 2010, my health started to become unfit. I already had most of the OIs that one with HIV positive encounters (including WHO stage 3-4). Being HIV positive in a poor country means accessing services at clinics provided by NGOs, which are partially free. As of Nov, 2009, my CD4 was 257 and viral load as of Dec, 2009 was more than 1,79,142 copies/ml. According to current Nepal ART guidelines, I am not eligible for ART.

At the end of March, 2010, I decided to do a health check-up. I had information about the doctors who specialised in AIDS in Nepal as I had been working in this field. I planned to visit Tribhuvan University Teaching Hospital (TUTH) which was one of the ART sites and just a km away from the place I stay. TUTH had most of the facilities but I came to know that it had been closed because of strike for the past 17 days. I enquired of the TUTH doctor's availability, he specialised in AIDS and also had a private clinic, however was told that he was already booked up for a week. I had to go for other options and called another known specialist on AIDS. I made an appointment, visited the clinic and went for tests according to his suggestions.

By the 30th March, 2010, I had done most of the pathological tests that were available in the clinic laboratory and had to then go to National Public Health Laboratory (NPHL) to do FNAC test. I went to NPHL, the next day, took the coupon and stayed in line for over half an hour to receive the necessary papers.

I was referred to room no. 11 where I waited many hours. I hadn't eaten since 8am and wanted some answers about the doctors availability so that I could be sure not to miss the doctor or the FNAC test. I made numerous enquiries about the doctor's whereabouts to no avail. I had no option but to wait, and at 1:45 pm, over 4 hours after arriving, I made one last request at which point the angered assistant transferred me to another room. I asked for his name as he helped me a lot but he did not reply and asked me why I need his name. I waited until he returned with the doctor. She offered no introduction, apology and did not answer any of my questions.

I saw the doctor take out a syringe (must be 10 ml) and told me she has to prick my lymph node and take out some pus. I said please go ahead. The testing process was painful and I experienced electric shocks throughout my whole body. The doctor said she was trying not to cause me pain, but there was little comfort and much pain, and following a number of attempts, some inspection and discussion with her assistant, the doctor told me that I might have to return for another test if this one does not produce results. I thought ohh noo.....again electric shocks, but do I have a choice?

On the 2nd April 2010, I returned to the NPHL to receive my report only to find out I must re-do the FNAC test. The same routine began again in Room no. 11. I was informed that the doctor was available after 11:00 am. I felt happy and secure that today I knew about the doctor's availability, so I went out for some snacks and visited some colleagues in a nearby hospital. I hurried back by 11 for my FNAC re-test only to discover the doctor was still unavailable. 3 hours passed, with the same difficulties experienced when I sought help or information. I eventually requested to be taken to the doctor immediately, and again following hostile encounters, I was taken to another room where I waited for 20 minutes until the doctor showed up. When I asked about the previous test and whether the doctor was familiar with FNAC testing, I was not provided any response. The testing procedure involved a repeat experience of pain and electric shock.

I consulted my physician and he said it is ok, that I could start ARV but to my surprise the report had mentioned that "I did not have TB bacilli". To re-check the test validity of the report, I went to TUTH to do my FNAC and there, I was provided with the right information and I did not experience any electronic shocks. I wondered why there was shock in my body while doing FNAC in NPHL and why not in TUTH. I went to receive my report on 9th April and was told that I had to do the test again. It was fast and easy. The doctor inquired about my health in which I answered and she did not ask anything except to come for the report on Monday after hearing that I am HIV positive and had been in touch with the senior doctor and focal person for HIV at TUTH hospital. When I returned for the report, it said the same as before. "I did not have TB Bacilli."

I went with all the reports to the Government ART hospital. I queued for an hour to receive out-patient's ticket. I went to the clinic and waited for my turn. There were requests for me to be in first place but I waited as the clinic was crowded. As my turn came up, I saw familiar face and the doctor was also familiar. I had met her in a meeting and at that time did not know she was a doctor.

Since I had some time to receive my report I decided to attend a meeting organized by PLHIV volunteers in the ART clinic. I went to listen to what it is all about. There were discussions about current issues affecting access to treatments. It was quite interesting. There were discussions about all the daily issues that PLHIV volunteers and the ART clinic were facing. There were also discussions about the availability of Viral Load testing (Viral Load test is only available at NPHL in the whole Nepal). Before, viral load tests used to be available once a week but now they have reduced to once a month, for 20-25 persons at a time. That was a discussion issue which attracted me. People had to come from all parts of Nepal and once a month testing was not enough. There were discussions on what can be done so that people have access to viral load testing. Participants did not have any conclusion as the discussion took shape on, identifying why it was not available, government does not have

APN+ Positive Capacity Development Initiative

money, GFATM is not providing money etc etc. I was asked to speak about it. I shared with them, that I am also unfit these days and want to do viral load test but don't have access. I told them that according to our context, we know how our health care workers are, so it is better to be literate and be prepared about treatments that we, who are living with HIV, will sooner or later need. I said that we can't totally rely on our available health care workers so it doesn't matter if government has the money or not, GFATM is paying or not, we need the service. Even when thinking about people who come from other parts of the country for a viral load test, what happens when there is no test available?. How long can they afford to stay here in this expensive city, people who often do not have enough to eat at their own place. So I suggested to the advocates at the ART clinic to make viral load testing more accessible to PLHIV.

Formal exchanges of information took place and she studied my reports, made notes in the ART clinic card and asked me to do a biopsy to test if my lymph node had bacilli. I told her, I want to start ARV, and she referred me to another person in the table and that person told me "you are not eligible". I told him my viral load is going to be around two hundred thousand and CD4 is low but he just murmured and I could not hear him clearly as the clinic was crowded. Amazing clinic, asking me all sorts of confidential information in the presence of around 8-13 people surrounding me while I do my minor health check-ups. I asked her, where I can do the biopsy. She recommended me two places but I knew both places only had the equipment to do microscopic investigations, and that for a biopsy a minor operation is needed. I conveyed this information but she resisted. I again went to the NPHL and got the answer I already knew, that they only do microscopic investigation. I went to GENTOP, same answer. This is my experience.



LNP+ TNP+ Positive capacity development initiative project



The APN+ Positive Capacity Development Initiative funded by AusAID is entering the last year of its program (March 2009-June 2011). Work has been conducted in the following countries, identified by AusAID as their 'focus countries', Cambodia, China, Indonesia, Lao, Myanmar, Timor Leste, Vietnam and the Pacific (Fiji, Solomons, Tonga and Samoa).

Activities have focused on institutional and organisational strengthening, and skills building, according to the identified needs of each national group or network. In many cases networks have implemented activities themselves (China, Indonesia and Vietnam). In some cases there have been useful cross border collaborations such as between TNP+ (Thailand) and

LNP+ (Laos), and between Estrela+ (Timor Leste) and Indonesia.

All those involved so far have felt that this is a very useful project in contributing to the capacity development of positive groups and networks. The project is supervised by Shiba, as Executive Director in consultation with the Steering Committee, and implemented by the three Australian Advisors, Robert, Susan and John.

APN+ thanks AusAID for funding this project and AFAO (Australian Federation of AIDS Organisations) for auspicing APN+ to be the only non Australian organisation to receive direct funding through the HIV Consortium.



LNP+ Committee Leadership Training with TNP+



JOTHI - Positive Capacity Development Project Team, Indonesia

Now You Can Hold Your Governments Accountable on Treatment Targets

Despite all of the self congratulation about getting more of us on treatment the fact is that there are still huge gaps. Against the new WHO guidelines of starting treatment at a CD4 count of 350 or less the percentage of people on treatment of those estimated to need it in the Asia Pacific Region is probably only 25-30%. Furthermore in many countries there are not adequate second line regimens, there are problems for rural PLHIV in accessing ARVs, and in many countries there are no regular CD4 count checks let alone viral load measurements.

So the question is 'How can we push our governments to do better?'. Is there a way we can try and hold them accountable? In fact there is. Each country has to set indicators on treatment as part of the process initiated by the UN in the 2001 UNGASS (United Nations General Assembly Special Session on HIV/AIDS) declaration. Reporting against targets has taken place approximately every two years starting in 2003, with the most recent country reports released March 31st 2010. No government likes

to look bad in a public international forum so they set 'reasonable' targets. And then they report against their performance on them to the UN.

Do they tell the truth, all the truth, about how well they have done? And do the current indicators tell the whole story? Well, no, not necessarily. But there is a process by which civil society, and we as PLHIV in particular, can question them. UNAIDS strongly backs the in-country involvement of PLHIV in what is called 'UNGASS Reporting'.

There are two ways that we can get involved. Ideally the government should involve PLHIV in putting together their reports, in other words they should be part of the official UNGASS country reporting. This has already happened in Indonesia and Thailand. Where this has not happened to date we should continue to push for our official involvement.

If this is not possible then a parallel report, sometimes called a shadow report, can be provided and taken into consideration

along with the official report. It is not expected that PLHIV alone would produce this report but as the lead along with other civil society partners. It is hard sometimes for us to challenge the raw numbers, but there is a more narrative part of the report, called the National Policy Composite Index, where we can more easily put our views.

So what do you do? It is best for PLHIV to be involved under the banner of their PLHIV National network. You can work with the local UNAIDS office to find out what is happening in your country, and then together with other community players start to try firstly to engage with your government in UNGASS reporting, and if that does not work start preparing a shadow report.

APN+ has initiated work in this area with training, funded through the AusAID HIV Consortium, in Bangkok in April 2010 for PLHIV from Cambodia, Indonesia, Lao, Philippines, Timor Leste and Vietnam on how to get involved. We hope to include more countries and expand this work shortly.

MSM Focus Group Discussion Training Workshop

In February 2010, the APN+ positive MSM working group conducted a 3-day skills building workshop in Bangkok, Thailand. The workshop "how to conduct qualitative research by and for community" was developed as an activity for network members interested in developing skills in these areas. All 15 participants from 10 countries learned about key aspects of the Focus Group Discussion process including fundamentals of research: topics, tools and processes, how to collect information, important aspects of context, applying techniques to finalize research agendas, research protocols and interpreting and analyzing qualitative data.

This workshop was a continuation of research activities conducted in India, Indonesia, Malaysia, Myanmar and Papua New Guinea in 2007, with a specific focus on MSM in those 5 countries. By utilizing peer led approaches we are able to gain

information about the impact of HIV on the lives of MSM, their health care, social, economic, sexual behavior and HIV status disclosure.

Understanding more about the needs of MSM will allow us to improve policies targeting MSM and to develop advocacy agendas that are important to them. APN+ later expanded these workshop activities to include MSM in 5 other countries including China and countries of the Greater Mekong Region (Cambodia, Laos, Thailand and Vietnam). These activities increase the involvement of positive MSM in both research design and research outcomes as promoted by



Positive MSM FGD Workshop Participants

the principles of GIPA. These activities were conducted and supported by UNAIDS Technical Support Facility (for the workshop), Alliance Technical Hub (for the consultant), in-country activities from USAID via PACT Thailand and coordination by APN+ secretariat.

APN+ Access to Treatment Research Dissemination Workshops



Myanmar participants at the IDU & MSM research dissemination workshop and AGM.



Chinese participants during IDU research dissemination and TRIPS workshop



Participants at the IDU & women's forum in Vietnam



Participants at the TRIPS and IDU research dissemination workshop in Manipur, India

During 2008-2009 APN+ conducted a multi country research project to identify challenges faced by positive IDU, MSM and women while accessing HIV related treatment and care across 10 countries in the region. A regional treatment summit was organized in June 2009 to disseminate

the findings of the research and plan next steps. Workshops were also organized to share the country specific findings of the research. They were conducted in China, Cambodia, India, Indonesia, Myanmar, Malaysia, Nepal, Thailand, Singapore and Vietnam. During these workshops part of the training component included raising

awareness about and de-mystifying issues that impact on access to treatment such as drug patents, TRIPS and Free Trade Agreements. The findings of the study will be used by the country network partners to further address the issues of access to treatment in all countries.

Updates from the APN+ Working Groups

The three working groups of APN+ have been working hard and continue to expand their activities in the region.

Our positive MSM working group has just published its multi country study report on access to treatment at the 2010 International AIDS Conference in Vienna. Country specific findings of the research were disseminated in all countries (except for India). The working group has also conducted Focus Group Discussions (FGD) in 10 countries and a report will be published soon. A FGD facilitation and skills development training was also organized for all country team leaders of the study. In the coming years the working group will follow up on the findings of the focus groups and treatment access research with country partners. The working group will continue developing capacity in treatment literacy and advocacy, facilitate skills transfer among positive MSM and mentoring. The working group has also recently established an interim core group whilst a TOR is being drafted.

The positive IDU working group continues to be engaged in addressing the issues of HIV and Hepatitis C co-infection in the region. A mapping of the Hepatitis C treatment costs around the region was conducted to help lend a lens into the cost differences of treatment between the different countries. Research findings from the "Access to HIV treatment and related services for HIV-positive drug users" research project were disseminated in the six countries

where the research took place. In the coming years the working group will work closely with country networks and groups to maintain advocacy efforts that address the issues of positive IDU in the region. A training module on HIV and Hep C co-infection will be developed by the working group to increase knowledge among positive drug users in the region.

To continue developing the capacity of positive women in treatment literacy and advocacy, WAPN+ will organise a series of workshops for its positive members. The workplan and activities are mostly focused in China, India, Indonesia, Vietnam, Cambodia and Thailand. A womens health scheme project in Vietnam and China will specifically focus on addressing livelihood challenges faced by many WLHIV in rural areas. The "Diamonds" book and DVD were well received during its launch at ICAAP last year and many agencies continue using it as a tool to support their advocacy campaigns. WAPN+ also successfully launched its multi country treatment access research report during ICAAP, Bali. Country specific findings of the research have so far been disseminated in Cambodia, Indonesia, Thailand and Vietnam. In the coming years WAPN+ will implement activities to address challenges faced by positive women while accessing treatment and other health care services, and develop the organizational capacity of positive women groups in the region. A new core group to support the work of the coordinator was also established. If you are a positive woman and would like to be a member, please send us an email at wapnplus@gmail.com.



Field trip to visit self help women's group in Tha' Binh province, Vietnam



Positive MSM training workshop

ABOUT APN+

APN+ was established in 1994 to create a collective voice for HIV positive people in the Asia Pacific region. We are committed to improving the quality of life of people living with HIV/AIDS (PLHIV) and to overcome the isolation of PLHIV in Asia and the Pacific Region by extending the network into all countries in the region.

During the past fifteen years the network has worked closely with PLHIV and various partners such as AusAID, UNAIDS, UNDP, UNIFEM, WHO, Ford foundation, Levi Strauss Foundation, Alliance, PACT, USAID, TREAT Asia, GNP+, ITPC among others to bring about improved access to treatments, care, support and lobby for equal representation of PLHIV on all relevant decision making bodies.

In addition, APN+ has worked to provide support with information exchange and skills development for PLHIV. APN+ is the regional network partner of the Global Network of People Living with HIV/AIDS (GNP+) and currently works closely with 29 national networks of PLHIV in the region

APN+ Steering Committee

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Mr Do Dang Dong (Vietnam)

Treasurer:

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