

# **REPORT**

## **HIV/HCV Co-infection: Planning The Way Forward**

### **1st South and Southeast Asia Regional Community Meeting**

**Bangkok, Thailand  
22 – 23 June 2010**

**7 Sisters, APN+, ANPUD, MSF,  
World AIDS Campaign, Thai AIDS  
Treatment Action Group (TTAG)**



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## **EXECUTIVE SUMMARY**

- The meeting was attended by 26 people, consisting of treatment activists from 6 countries, as well as representatives from regional organizations. Countries represented in the meeting are: Indonesia, India, Nepal, Thailand, China, Viet Nam, as well as regional organizations.
- The current situations of standard of care in 6 countries were presented in the meeting. In general, there is little information available about Hepatitis C compared to information on HIV and AIDS. HCV surveillance needs to be included in the national surveillance program in order to obtain more accurate information about Hepatitis C prevalence in the country.
- Although HCV antibody tests are widely available at an affordable price in every country, the HCV PCR diagnostic tests (including confirmatory tests and genotype testing) are expensive because they are patented. Patents for the reagent kits used in these tests are held by either Abbott or Roche.
- The high cost of Hepatitis C treatment makes it almost impossible for people with Hepatitis C to get the treatment they need. Treatment cost varies from US\$ 14,000 to US\$ 33,000. In Nepal, however, treatment for Hepatitis C is not yet available and Hepatitis C patients are referred to India for treatment. Pegylated Interferon is patented by Roche (Pegasys) and Schering-Plough (PegIntron). Because these two pharmaceutical companies are holding patents, the cost for treatment is extremely high. There is a need to identify specific advocacy campaigns to lower treatment costs.
- Noah Metheny (Thai AIDS Treatment Action Group/ TTAG) presented on the barriers to HIV/ HCV diagnostics, treatment and care in Thailand. Several possible ways he identified to bring down the high cost of Hepatitis C treatment in Thailand are: overriding Roche and Schering-Plough (Merck) patents on Pegylated Interferon by Thai government; issuance of Compulsory Licenses for Pegylated Interferon (or any other new HCV drug); inclusion of Pegylated Interferon and Ribavirin on Thailand Essential Medicines Lists; Thai GPO develop safe and effective generic version of Pegylated Interferon; and price negotiations with pharmaceutical companies for HCV diagnostics and treatment, etc.
- Leena Menghaney (MSF-CAME, New Delhi, India) presented information about the patent situation regarding Hepatitis C treatment. Several ways that Leena has identified to fight against the patent issues are: Preventing patent application for improvement and combinations of drugs used in Hepatitis C treatment and extension of existing patents (basic patents of Pegylation Technology, Pegylated Interferon Alpha 2-a and 2-b will expire in 2015); Develop a pricing guide on Ribavirin and Pegylated Interferon for PLHIV community; Protest against Roche and Schering-Plough (Merck) on high pricing of Hepatitis C drugs; Collaborate with cancer groups, etc.
- The meeting discussed the need to use TRIPS flexibility such as Compulsory Licensing (CL), as well patent oppositions, to drive down the cost of Hepatitis C treatment. It is unclear when the patents for pegylated interferon will expire. Thus, better information about the current patent status of pegylated interferon is needed in each country.

- Although there are a lot of companies producing interferon, there aren't that many companies producing pegylated interferon. This allows the companies to monopolize the market. Pegylated interferon is actually the same interferon, but wrapped in a sugar molecule to slow the absorption of the drug inside the human body, and then sold for 10 times its original price. The fact that pharmaceutical companies would offer "discount packages" indicates that the cost of production for the drugs is not high. However, even with the "discount packages", the overall price for the treatment package is still very high.
- WHA Resolution that recognizes Hepatitis C as a public health issue should be used in advocacy efforts to improve access to Hepatitis C treatment.
- There is a need to learn from the experience of advocacy work in the HIV and AIDS field to avoid the same mistakes.
- Treatment activists from 6 countries developed their work plan, and agreed that due to the lack of awareness about this issue among the general population and the key affected population, the most important activity is to raise this awareness by providing information and education on Hepatitis C through trainings, distribution of IEC materials and public campaigns. For mid and long-term activity, each country agrees that it is important to build partnerships with stakeholders, including government institutions (Ministry of Health in particular) and engage with pharmaceutical companies to reduce the price of drugs so that more people can access Hepatitis C treatment.
- The meeting discussed the possibility of including Hepatitis C in HIV Treatment Literacy programs, while funding is raised to train key people in the region as peer educators on Hepatitis C. The meeting also suggested ensuring that prevention of Hepatitis C infection is a key part of harm reduction programs in each country.
- Els Torreele from OSI's Access to Essential Medicines initiative (AEMI) in New York shared experiences from Eastern Europe. Georgia (where 7% of its general population is infected with Hepatitis C) recently received GF R9 AIDS grant, in which they include provision of Hepatitis C treatment for around 100 people per year. Other countries are also encouraged to access Global Fund grants by ensuring that provision of Hepatitis C treatment is also included in the country proposal. She also clarified the strategic interest of AEMI, in collaboration with OSI's Harm Reduction program (Daniel Wolfe) in increasing Access to HepC treatment, and the opportunity to submit grant proposals to support advocacy and activist activities in that respect.
- Shiba Phurailatpam and Rico Gustav from APN+ shared in the meeting that APN+ is currently developing a multi-country Round 10 GF ATM AIDS proposal with 10 PLHIV country networks (Bangladesh, Cambodia, China, Fiji, Indonesia, Laos, Nepal, Pakistan and Philippines). The proposal aims to fill gaps at country level, by providing services that are needed but are not provided by the government; to strengthen the capacity of PLHIV networks; and to strengthen the capacity of APN+ to manage information, build advocacy and communication platform at the regional level. The proposal will include provision of Hepatitis C treatment for PLHIV in 7 countries with evidence of Hepatitis C infection.

- A Hepatitis C listserv is already in function and will be strengthened to facilitate further discussion and brainstorming sessions related to Hepatitis C response and circulate documents related to Hepatitis C.

## **Minutes of Meeting**

**DAY 1**

Tuesday, 22 June 2010

### **Session I: Welcome, Introductions, Agenda and Expectations**

*Facilitated by: Mr. Giten Khwairakpam (7 Sisters, ANPUD)*

Giten welcomed everyone to the meeting, and asked everyone to introduce themselves. Giten then talked about the objectives of the meeting. The meeting aims to gather information about issues related to HCV/ HIV co-infection at country level, which will be used to develop a proper program planning and produce a Regional policy paper by the end of the meeting. The meeting also aims to obtain information on how regional organizations can support country level advocacy efforts.

Participants were asked to share their expectations of the meeting. Their expectations of the meeting are as follows:

- 1) To have a better understanding of what is being done at country level, the current situation at country level and identify appropriate responses to the issues and barriers.
- 2) To collect information on how regional networks/ institutions like APN+, ITPC, 7 Sisters, MSF and OSI can support country level responses.
- 3) To have a regional advocacy platform to influence country advocacy efforts.
- 4) To push the government to include Hepatitis B and Hepatitis C in the national health insurance scheme and include Hepatitis B and C drug in the essential list of drugs.
- 5) To develop an innovative and clear strategy and see the plans developed in the forum to materialize.
- 6) To learn more about the HIV/ HCV co-infection, both clinical and technical information.
- 7) "Revolution" to start, to end discussions that have taken place. Hepatitis C is disrupting treatment for HIV.
- 8) To have a short term and long term goal.
- 9) To have greater access for Hepatitis C treatment.
- 10) To keep confronting the government about this issue.
- 11) To have a treatment guideline.

The meeting then observed a minute of silence for those who have passed away due to Hepatitis C.

### **Session II: Country Presentations - Situation of Standard of Care**

*Facilitated by: Ms. Karyn Kaplan, Thai AIDS Treatment Action Group (TTAG)*

Karyn thanked the participants for preparing the information and bringing them to the meeting, even though it was not easy to collect the information. Karyn asked everyone to share the experience each country went through while trying to collect the information from the people concerned.

In Indonesia, the doctors wanted the participant to pay some money for the interview or filling out of the questionnaire. This was because the doctor thought he would be giving time to respond to the questionnaire while he could have used that to take care of some patients that could bring him his consultation fees. In India, the process to get information was not so difficult as the country networks

received a good response from doctors in Manipur. The National Nodal officer for ART responded that he does not treat People living with HCV and guided the participant to doctors who treated HCV. The experience in Nepal was similar to India. The situation was a bit different in Vietnam, where the doctors were very busy and it was difficult to get information from them. In China, the country network was able to collect survey conducted by other organizations, namely the Clinton Foundation. In Thailand, there were only few specialists available, who explained that they usually only treated 4 or 5 HIV/ HCV co-infected patients each year.

## **Country Presentations:**

### **1. China**

*Presented by: Ms. Canaria Gaffar, AIDS Care China*

HCV Prevalence in China:

- Estimated number of HCV cases in CHINA is 38 million people (2009).
- HCV prevalence rate is 3.2%. China has one of the highest rates of co-infection, with 56.9% PLHIV co-infected with HCV.
- The highest prevalence of HCV infection is found among injecting drug users (61.4%), followed by the prevalence of HCV infection among PLHIV (56.9%) and plasma donors (27.7 – 63.3 % in China).
- The number of HCV cases in 2009 is 126,817 people. This is six times higher than it was in 2003 (21,145 people).

HIV/ HCV co-infection issues:

- HIV accelerates the progression of HCV and vice versa
- Co-infection slows down immune recovery
- Higher risk of developing chronic infection
- Higher rates and shorter time for developing hepatic cirrhosis
- Much higher rates of mother to child transmission
- HCV-Ab shows false negative

General cost of testing and diagnostics:

- HCV-Ab: US\$ 5.00
- HCV-RNA: US\$ 10.00
- Ultrasonic scanning: US\$ 15.00 – 26.00
- PBH (Ponction Biopsie Hepatique): US\$ 150.00 – 220.00 (Rarely used)
- HCV Genotype: US\$ 330.00 (only available in big cities such as Beijing and Shanghai)
- Liver enzymes (ALT/AST): US\$ 2.00
- Monitoring during HCV treatment: Anemia, neutropenia, thrombocytopenia: US\$ 3.00 every 3 months.

HCV Treatment issues:

- 200,000 people need Pegasys (Pegylated Interferon Alfa-2a) produced by F. Hoffmann-La Roche Ltd.
- High treatment cost (US\$ 18,000 per year per person)
- Patent Protection
- Insurance: social insurance covers only 40% of treatment cost
- Because of patent protection, Chinese pharmaceutical factories cannot produce generic drugs and reduce the price. High treatment cost is the biggest obstacle in treatment access.
- Suggest government to grant Compulsory License for crucial drugs

#### Gaps in care and services:

- Limited information and education provided for high-risk groups. Information and education on Hepatitis B is more widely available than Hepatitis C, usually provided by peer groups or community based organizations.
- Very little mental health care provided during treatment
- Very limited peer support during treatment
- Very few IEC materials developed

#### Existing responses:

- Advocacy-Citizen proposal for two Conferences (i.e. the National People's Congress and the Chinese Political Consultative Conference)
- IEC Development-translating and publishing TRAINING MANUAL FOR TREATMENT ADVOCATES

#### Next steps:

- HIV Collaborative Fund Round 5: Area of focus includes co-infections; Technical assistance should improve the knowledge of grantees about HCV; Promote grantees to raise awareness on HCV among clients; Promote grantees to provide treatment education on HCV
- Develop more IEC materials appropriate for the use of communities

#### **Comments:**

- Canaria explained that US\$ 18,000 is only the cost of Pegylated interferon and Ribavirin, and does not include diagnostic test or treatment monitoring diagnostics that needs to be done during treatment.
- Paul informed everyone about the lack of space for activism in China, and that ITPC China needs to influence policy change on drug patent. China is the only country in the world where 3TC still has some sort of IP (Intellectual Property) protection—3TC is donated to treat HIV but patients have to pay for 3TC as a treatment for HBV.
- Canaria explained that Needle Exchange Program in China has been quite successful; with most injecting drug users have access to sterile needles and syringes. Organizations providing harm reduction services now have a better relationship with the law enforcement. CDC operates methadone substitution therapy clinics.
- Youding explained that there is no national policy on harm reduction yet, only a national condom program. Youding also explained that in some areas, international donors provide free testing for Hepatitis C through the projects they fund.
- Giten raised a question of ease in accessing the 40% subsidy that the national Insurance covers and the process thereof to access the same. Responding to a question, Canaria explained that although the government can cover 40% of treatment cost for Hepatitis C through social insurance, only a few people have access to the social insurance and even then the entire cost of the treatment must be paid personally first and then reimbursed later by the government.
- Gao Qiang added that most of the people with Hepatitis C infection are injecting drug users who do not have social insurance, and even if they do, they would not have any money to pay for the rest of the treatment cost. The social insurance only covers 40% of treatment cost, and it does not cover diagnosis and testing before, during and after treatment. The cost for testing is around RMB 1,400, which may not be much for a mainstream earning person but is a lot of money for most injecting drug users.
- Leena commented on the need to conduct patent search, by first identifying patent application and going to producers to collect information

- about the problem. Afterwards, we need to apply the searches in key producing countries to map the landscapes of patent issues.
- Els explained that OSI has been working with a consultant in Brazil to look at opportunities for local production, which included an analysis of the patent status. They found (to everybody's surprise) that only the Roche patent is valid in Brazil, whereas the Schering Plough one has not been granted, meaning that it would be perfectly legal to locally produce the biosimilar of the Schering-Plough drug. This illustrates the importance of verifying in each individual country what the patent status is of the different drugs, as one often wrongly assumes that the patents are valid.
  - There is no ongoing HCV surveillance in China. You Ding informed everyone that the latest data on HCV surveillance dates back to 1995.

## **2. Thailand**

*Presented by: Mr. Noah Metheny, Thai AIDS Treatment Action Group (TTAG)*

HIV/ HCV prevalence:

- An estimated 32.3 million people living in Southeast Asia have HCV
- An estimated 60% to 90% rate of HCV co-infection among IDU living with HIV/AIDS in Asia
- 610,000 Thais are living with HIV/AIDS, with at least 5-10% contracting HIV from injecting drugs
- At least half (50%) of injecting drug users in Thailand are living with HIV/AIDS
- Up to 90% of injecting drug users in Thailand have contracted HCV

Cost for HCV treatment and diagnostics:

- HCV antibody tests: 200-300 baht (6-9 USD)
- Two-drug combination therapy of pegylated interferon and ribavirin (for a 48-week course): 591,263 baht (17,828 USD)
- Administration and monitoring cost for such a 48-week course: 503,693 baht (15,187.49 USD)
- Total cost for a 48-week course of pegylated interferon and ribavirin: **1,094,956 baht (33,015.49 USD)**

Local organization working on HIV/ HCV issues:

- Thai AIDS Treatment Action Group (TTAG)
- AIDS Access Foundation
- Foundation for AIDS Rights (FAR)
- 12-D
- Thai Network of People Living with HIV/AIDS (TNP+)

Current advocacy efforts:

- Promotion of harm reduction programs
- Education of advocates, patients, healthcare providers, and policymakers about HCV/HIV co-infection issues
- Collection of data on HCV incidence and prevalence among Thais living with HIV/AIDS (both locally and at country-level)

Future advocacy efforts:

- Advocate with NHSO for universal access to free testing for HCV and offer follow-up diagnostic tests on routine basis and to include pegylated interferon and ribavirin on Thai Essential Medicines Lists
- Advocate for price reductions for pegylated interferon with Roche or Schering-Plough

- Increase political support for the GPO to produce generic versions of pegylated interferon, or for the Thai government to exercise legal, TRIPS Flexibilities to gain access to cheaper HCV treatment.

**Comments:**

- Wirat reminded everyone of the importance of capacity building programs on Hepatitis C and HIV co-infections. TTAG have begun disseminating information on compulsory license to their constituents. Aiet added that because the community members now have more information about this issue, campaign efforts have started on compulsory licensing issues.
- Karyn informed everyone that pharmaceutical companies often provide clinical trials and donated drugs through hospitals. Chulalongkorn Hospital is providing free Ribavirin for people accessing Pegylated Interferon treatment. Paul commented that Ribavirin is provided for free because it is cheap, as it is locally manufactured. The real challenge for access to treatment is the high cost for Pegylated Interferon treatment.
- Giten suggested pushing for HCV surveillance by the government, as the antibody test is extremely cheap, especially for people who have a drug use background. This will also allow physicians to prescribe ARVs that are less toxic to liver. The same should/ could be incorporated in the current HIV programming which are mainly (in Asia) supported by the Global fund. This will allow us to have some government supported data after a few years time and once the government realizes that it is costly, after including HCV treatment in the Global fund proposals and providing treatment, they could start price negotiations with the pharmaceutical companies and we will also have enough evidence and data to build our case, which is always asked.
- Responding to Leena's question about what happens when a person is either tested positive or negative on HCV testing, Paul explained that in Thailand HBV vaccination is provided for free for children, following WHO recommendation. In theory, after a person tested positive for HIV, they should be screened for Hepatitis B and offered HBV vaccination if the test result is negative. However, this of course is not the practice.

**3. India**

*Presented by: Mr. Umesh Sharma Hidangmayum - Treatment Activist in Manipur, India*

- Information presented was collected from two different doctors in Manipur. Both the doctors have a great deal of experience treating both people living with HIV and HCV. One of the doctors prescribes Pegasys and the other doctor prescribes only PegIntron. However, both the doctors explained that they do not treat drug users who are still actively using drugs. This includes people undergoing methadone or buprenorphine substitution therapy. The two doctors have a generally good success rate.
- Mostly, doctors provide counseling for patients, though peer counselors also provide some counseling.
- There is a lack of information about Hepatitis C, as most people talk about HIV and there is not much talk about Hepatitis C.
- Cost for HCV RNA testing is around US\$ 40.00
- Cost for treatment (for drugs from both pharmaceutical companies) cost around US\$ 15,000 – 16,000, and the cost continues to increase. The cost of treatment does not include Ribavirin. Discount and free medications are offered if you go through certain doctors who have connections with the pharmaceutical companies.
- Screening for HCV is not included in national surveillance program.

- There is a need to ensure that doctors have the same level of knowledge and capacity in treating people with HIV/ HCV co-infection, as there is different information from different doctors about what ARV drug is “safe” for people undergoing pegylated interferon treatment, as well as the duration of treatment.

**Comments:**

- Paul agrees that a treatment guideline is needed, to ensure that the treatment being provided is the best kind of treatment. The guideline should include information about treatment duration, how to correctly determine the medicine dose for each patient, etc.
- Shiba added that in India, doctors still use standard 800 mg dose of Ribavirin instead of looking at other aspects such as a person’s body weight to determine the dose of Ribavirin.
- Umesh explained that he had genotype 3, which is easier to treat than other genotypes. However, HIV/ HCV co-infection is still an issue, as his CD4 count has often below 200 and doctors have different opinions on ARV regimens.
- Nicolas remarked on the importance of collecting information about the success rate in such small sites of treatment, as well as side effects reported during treatment and ways to cope with the side effects. This can generate the clear evidence that, if treated, this infection could be cured and investment in treatment is worthwhile.
- Loon explained that HCV is a silent epidemic that nobody really ever knows about. There is no ownership on the response against the disease. There is no national data related to Hepatitis C, as the only data available is from northeast part of the country (India). In order to develop an advocacy strategy for provision of free treatment, national data is needed. Currently, data is collected only from community-based organizations, as it is very difficult to get any information from government institutions.
- Leena added that doctors are often being told to suppress data especially on MDR TB and HCV. This is a strategy that the government uses to avoid dealing with a public health issue. To overcome this obstacle, Leena suggested talking to UNAIDS and National Institute of Virology in India, as well as other organizations in order to obtain needed information and data. Information about treatment should be shared not only among HIV/ HCV co-infected people but also HCV infected people without a co-infection. Any research conducted on this issue should be submitted to the National Research Institute, so that the findings can be published and funding for pilot project can be obtained.
- Leena explained that MSF is very keen to treat people with HIV/HCV co-infections, however the treatment has not yet taken place. The first person selected for the first treatment has actually passed away before the treatment was able to take place.
- Paul commented that people need to be on treatment now, to show that it can be done. Otherwise, we will always be waiting because it is too difficult. However, in order to push for better access for treatment we need to first collect data. Both are urgent and needs to be done immediately side by side.
- Rico shared his recent meeting in Cambodia, where WHO was discussing revision of their treatment guideline. HIV/ HCV co-infection treatment guideline will be developed, and a meeting to discuss this will take place soon. APN+ will be involved in the meeting, and everyone is asked to provide input to take to the meeting.

#### 4. **Nepal**

*Presented by: Mr. Nikhil Gurung, HEPA Foundation*

##### Overview of HIV/ HCV in Nepal:

- Number of people who use drugs: 46,309 (Central Bureau of Statistics of Government of Nepal, 2006). 60% are injecting drug users.
- 68% of injecting drug users in Kathmandu are HIV positive (2003)
- Estimated number of PLHIV: 70,000 (UNAIDS)
- HCV prevalence among 118 drug users in Oral Substitution Therapy (OST) is 80.5%, while prevalence among 82 drug users not in OST is 57% (HEPA Foundation Survey, 2009)

##### Available services:

- Cost for HCV antibody test is US\$ 2.00
- A private company has started HCV RNA test, but it is not accessible for the majority of people who use drugs.
- Treatment for HCV is not available in Nepal – most of the patients are referred to India.
- Majority of the doctors are not aware of the treatment guideline
- Low accessibility to HAV and HBV vaccination
- ARV drugs available in Nepal are: AZT, 3TC and Nevirapine. Second line ARV is only recently available, following the availability of HIV Viral Load testing.

##### Local organization working on HIV/ HCV issues:

- Hepa Foundation
- Nava Kiran Plus
- NAP+N
- Sparsha
- Recovering Nepal

##### Current advocacy efforts:

- Lobbying with decision makers
- Treatment literacy programs on Hepatitis C
- Small component has been accommodated successfully in National AIDS Action Plan (2008-2011) – though pledge hasn't been made by any agencies.
- Promotion of Harm Reduction Program
- WHAD commemoration

##### Future advocacy efforts:

- Advocate the government to provide free HCV antibody test and to offer follow-up diagnostic tests on routine basis and to include Pegylated Interferon and Ribavirin on Nepal Essential Medicines Lists.
- More sensitization workshops to policy makers (including CCM members, health ministerial secretary and other institutions) regarding HIV/ HCV co-infection issues to support advocacy efforts.

##### Challenges:

- Donors are mostly focused on HIV treatment, child health, maternal health and climate issues. It is difficult for activists to justify Hepatitis C treatment, especially because most of the activists are people who use/ used drugs.
- Learning from the experience of advocacy for access to HIV treatment, we know that Education and Activism are the best ways to overcome the challenges.

### **Comments:**

- The government conducts national AIDS program in Nepal.
- There is a good opportunity to collaborate with ITPC- HIV Collaborative fund to scale up provision of treatment literacy program, both at national and regional level.
- Rajiv, who is the Vice Chair of CCM Nepal, explained that donors usually do not want to provide treatment for "bad people". Pre-ART Key affected population such as people who use drugs, sex workers, etc are not usually the people to receive attention, not considered as cost-effective.
- Els explained that Global Fund has issued guidance notes ("Harm Reduction Information note") that specify that vaccination, diagnosis and treatment of viral hepatitis C can be included in proposals to the Global Fund. The need of HCV treatment should be articulated in the proposal itself, and it would be advisable to also explicitly express the need to reduce the cost of Hepatitis C treatment as part of the proposal. Consultants who are usually writing the country proposal should be approached so that they include the issue in the proposal. OSI is working on a 2-page summary of the arguments that can be used as a basis by anyone interested (should be available soon).
- Nicolas remarked that policy makers need to be made aware of the dual benefit of providing treatment, not only for people receiving the treatment but also a public health benefit through positive prevention.
- Karyn informed everyone that TTAG has done a cost-effectiveness study supported by Roche, which Noah will share with everyone. The study was not produced as a publication but was done as a poster in a recent liver conference in the US.

### **5. Indonesia**

*Presented by: Mr. Abdullah Denovan (JOTHI/ Indonesia National PLHIV Network)*

#### Hepatitis C Prevalence in Indonesia:

- Estimated 7 million people are living with Hepatitis in Indonesia (Ministry of Health, 2009)
- Estimated 60% to 90% HIV/ HCV co-infection rate among Injecting Drug Users (Yayasan Pelita Ilmu (YPI), Yayasan Harapan Permata Hati Kita (YAKITA), 2007)
- Documentation of Hepatitis C from hospitals and laboratories (123 report units, 99% participation):
  - First Phase (11 provinces): 5,780 out of 6,000 samples are Hepatitis C positive (Oct 2007 to Sept 2008)
  - Second Phase (21 provinces): 15,736 out of 16,000 samples are Hepatitis C positive (October 2008 to June 2009)

#### Cost of HCV Diagnostic and Treatment:

- Hepatitis C antibody test: US\$ 25 – 30 (IDR 225,000)
- Hepatitis C RNA test: US\$ 290-310 (IDR 2,700,000)
- Two-drug combination therapy for a 48-week course:
  - Pegylated Interferon + Ribavirin: US\$ 17,000 – 18,500 (IDR 160,000,000)
  - Conventional Interferon + Ribavirin: US\$ 5,000 – 7,000 (IDR 40,000,000 – 60,000,000)
- Administration and monitoring cost for a 48-week treatment course: US\$ 9,000 – 11,500 (IDR 80,000,000)
- Total cost for a 48-week course of Pegylated Interferon and Ribavirin: **US\$ 14,000 – 30,000** per patient.

Previous Advocacy Work:

- National AIDS Strategic and Action Plan 2010 - 2014 (Including integration of HCV related issues under HIV Prevention and Care, Support and Treatment (CST) work under GFATM grant framework)
- WHA resolution on Hepatitis (coordination with APN+, WHO country offices, and meeting with Indonesian Ministry of Health).
- Hepatitis C campaign (newspaper and online media), as well as during 9th ICAAP.
- National Surveillance on Hepatitis C by Ministry of Health, 2007 - 2009 (with limited resource).

HCV prevalence comparison groups (US Naval Medical Research Unit-2 (NAMRU) on Hep C, 2001 (Supported by Dinabott (Japan) and Abbott (USA)); Injecting Drug User data from YAKITA and YPI, 1999-2001):

- Injecting Drug Users (IDU): 71.0% HCV positive
- Adult Renal Dialysis Patients: 63.7% HCV positive
- Pediatric Hematology Patients: 38.4% HCV positive
- Spouse caregiver: 9.0% HCV positive
- Parent caregiver: 4.0% HCV positive

Qualitative Research of Pegylated Interferon Alfa 2-B non-stavudine treatment for HIV/ HCV co-infected patients, in 3 (three) provinces in Indonesia, 2006 (supported by Scherring-Plough):

- Respondent: 25 PLHIV with HCV co-infection (under non-stavudine treatment; CD 4 count  $\geq$  500; ANA negative). All cost (up to US\$ 15,000) was covered by the research included the socio-economy impact.
- Only 1 PLHIV finished the 48 period of treatment, while 24 people experienced side effects such as leucopenia, trombopenia, oedem and strong depression.
- HIV antibody test for 1 PLHIV who finished the treatment became negative for one year

Denovan explained that the reason why the qualitative research conducted to 25 PLHIV with Hepatitis C co-infection failed because the treatment was not effective and lacked side effects management. Because of this, the majority of the respondents quit the treatment.

Research on treatment access for HIV-infected Injecting Drug User (JOTHI and APN+, 2008-2009):

- 6 Provinces: North Sumatera, DKI Jakarta, West Java, East Java, Bali and South Sulawesi (only in big cities)
- Data collection method: Questionnaire and Focused Group Discussion (FGD). N = 200.
- Lack of information about Hepatitis C caused 50% of HIV-infected IDU to think that liver function test is the same as HCV antibody test. This proves that treatment education program for HIV-infected IDU for the past 3 years is ineffective.

Research on Hepatitis C infection among MSM in Surakarta, August - September 2009 (Biotechnology and Biodiversity Centre, University of Surakarta):

- Method: respondent-driven sampling to test for HIV and Hepatitis C infection from sexual transmission. N = 100 people.
- Result: 8% HIV positive and 10% Hepatitis C positive.

Current advocacy efforts:

- Data collection on Hepatitis C incidence and prevalence among PLHIV (provincial and district level).
- Development of JOTHI – Ministry of Health National Technical Plan for the prevention and treatment of Hepatitis C.
- Provision of information and education on HIV/ Hepatitis C co-infection issues for activists, PLHIV, healthcare providers and policy makers - JOTHI will partner with PKNI (Indonesia Drug Users Networks).
- JOTHI has asked President of Republic of Indonesia, Susilo Bambang Yudhoyono to push the implementation of DOHA Declaration at G20 meeting, **this week**. (Included in the President's agenda that was published in news paper)

Future advocacy efforts:

- Ensuring the availability of Hepatitis C test for at least 200,000 PLHIV and their partners, by 2015.
- Advocate for price reduction of Pegylated Interferon to Roche or Schering-Plough.
- Keep pushing the discussion and process related to HIV/ HCV co-infections issues forward
- At least 10 PLHIV receiving Hepatitis C treatment, by the end of 2010. (JOTHI Development Assistance on Hepatitis 2010 – 2014)

Denovan also shared that 2 major pharmaceutical companies in Indonesia - ROCHE Indonesia and INDOFARMA- are signing an MoU for technical collaboration to conduct Hepatitis C surveillance in order to develop a national policy on Hepatitis C, to provide future direction and evaluation for Hepatitis C management and control.

**Comments:**

- Responding to a question about advocacy strategy with Roche and Schering-Plough, Denovan explained that Kimia Farma currently produces ARV drugs in Indonesia. Indofarma – another major pharmaceutical company – is collaborating with Roche to produce generic pegylated interferon. JOTHI plans to collaborate with the Indonesian Medical Association to advocate for access to treatment.
- Denovan also explained that by advocating provision of Hepatitis C test for 200,000 people by 2015, there would be more data and information to use as advocacy tool for availability and accessibility of treatment in a year or so.
- Karyn informed everyone that the Harm Reduction Coalition in New York has developed a very good counseling guideline for pre and post-test of Hepatitis C testing. There is also a research conducted on creating a less toxic Hepatitis C drug with shorter treatment course. However, the drug is expected to be even more expensive than pegylated interferon.
- Loon complimented JOTHI for doing such an outstanding work, for a relatively new network.
- JOTHI was suggested to approach Roche and INDOFARMA and see if there is any pricing control quotes in the agreements. It could be well that the drugs produced under the license could be sold at the same price. Leena was asked to provide information and collaborate with JOTHI so that JOTHI could use the correct terminologies and issue while writing to the pharmaceutical company.

## 6. Viet Nam

*Presented by: Mr. Dong Duc Thanh, Viet Nam Network of Positive People (VNP+)*

HIV/ HCV Prevalence in Viet Nam:

- Estimated number of PLHIV in Vietnam: 160,019 people (2009, Viet Nam AIDS Administration Control (VAAC)).
- 50.6% of PLHIV are infected through injecting drug use
- Over 50% of injecting drug users in Viet Nam are infected with HIV.
- Up to 90% of injecting drug users in Viet Nam are infected with HCV.

Cost of HCV Treatment and Diagnostics:

- HCV antibody test: VND 180,000 (US\$ 10)
- HCV viral load test: VND 1,600,000 (US\$ 100)
- Cost for liver enzyme test (GOT and GPT) – conducted every three months during Hepatitis C treatment: VND 70,000 (US\$ 4)
- Cost for administration and monitoring cost for 12 months course treatment: VND 300,000,000 (US\$ 16,000)
- Total cost for a 12-months course treatment of pegylated interferon and ribavirin is: VND 522,000,000 (**US\$ 28,000**)

Local Organizations working on HIV/HCV Issues:

- Hospital for Tropical Diseases
- Infectious diseases ward in general hospitals in some provinces;
- Some INGOs and LNGOs that receive funding from PEPFAR;
- Viet Nam Network of People living with HIV/AIDS (VNP+);
- Free ARV programs from PEPFAR

Current Advocacy Efforts:

- Promotion of harm reduction programs;
- Methadone Model Treatment (MMT);
- Promotion of positive prevention programs (PWP);

Future Advocacy Efforts:

- Advocate the availability and integration of free HCV testing, follow-up diagnostic and monitoring tests into national ARV treatment program
- Advocate the price reduction of pegylated interferon
- Increase political support for the GPO to produce generic versions of pegylated interferon, or for the Viet Nam government to exercise legal, TRIPS Flexibilities to gain access to cheaper HCV treatment;
- To encourage and advocate for experiment of alternative medicine that is more affordable for poor people.
- Strengthening advocacy and treatment literacy toward people living with HIV of HCV and harm reduction, PWP.

### **Comments:**

- Duc explained that the data he used in his presentation was collected from public health institutions, as well as from individual interviews.
- Umesh remarked that there are certain time and situation where plain interferon can also work. Umesh asked that the meeting also discuss different options available for treatment.
- Gao Qiang explained that a common issue that has been discussed continuously in the meeting is reducing the cost of Hepatitis C treatment. However, there is also a need to ensure that the rights of injecting drug users are protected. If the rights of injecting drug users are not protected, it would not matter if the cost of treatment is reduced.

## Session III: Panel Discussion

### **3.1. Barriers to HIV/ HCV Diagnostics, Treatment and Care in Thailand**

*Presented by: Mr. Noah Metheny, Thai AIDS Treatment Action Group (TTAG)*

Noah began his presentation by explaining the cost of treatment and diagnostics in Thailand as follows:

- HCV antibody tests: 200-300 baht (6-9 USD)
- Two-drug combination therapy of pegylated interferon and ribavirin (for a 48-week course): 591,263 baht (17,828 USD)
- Administration and monitoring cost for such a 48-week course: 503,693 baht (15,187.49 USD), including the cost of ongoing diagnostic tests
- Total cost for a 48-week course of pegylated interferon and ribavirin: **1,094,956 baht (33,015.49 USD)**

It was concluded that the reason why the cost for treatment and diagnostic is so high is because of patents. Noah then explained that pegylated interferon seems to be under patent in Thailand until 2015, and that any new HCV treatments will also be patented in Thailand. Currently, pegylated interferon is patented by Roche (Pegasys) and Schering-Plough (PegIntron). Because these two pharmaceutical companies have patents, the cost for treatment is extremely high. There is a need to identify specific advocacy campaigns to lower treatment costs.

Although HCV antibody tests are widely available at an affordable price in Thailand, the HCV PCR diagnostic tests (including confirmatory tests and genotype testing) are expensive because they are patented. Patents for the reagent kits used in these tests are held by either Abbott or Roche.

Noah then shared identified ways to bring down the high costs, as follows:

- Override Roche and Schering-Plough (Merck) patents on pegylated interferon by Thai government:
- Pre/ post grant patent opposition cases (example of India)
- Issuance of compulsory licenses for pegylated interferon (or any other new HCV treatments)
- NHSO provide universal access to free testing for HCV and offer follow-up diagnostic tests on routine basis
- Include pegylated interferon and ribavirin on Thai Essential Medicines Lists
- Thai GPO develop safe and effective generic version of pegylated interferon (and any other HCV treatments)
- Price negotiations with pharmaceutical companies for HCV diagnostics and treatment
- Inclusion of HCV treatment in Global Fund proposals
- Research into lower-cost HCV treatment therapies

#### **Comments:**

- Els commented that the ways to bring down the high costs of treatment Noah presented need to be investigated further, maybe in Indonesia or China. Pharmaceutical companies need to be convinced that there is a market needing the medical product they produce.
- Noah explained that more information is being collected about pharmaceutical companies who could produce generic pegylated interferon.
- Responding to a question from Sam, Nicolas explained that no studies have ever been conducted to prove that prophylaxis for Hepatitis C exists.

### **3.2. HCV Treatment – Getting Past the Patent Thicket**

*Presented by: Ms. Leena Menghaney, MSF-CAME, New Delhi*

Leena first explained that inclusion of counseling for Hepatitis B and Hepatitis C test in HIV/ AIDS programs is a key approach. Also, to improve Hepatitis C diagnostic, it would be good to also include HCV viral load/ PCR/ liver function test in HIV treatment programs.

Leena then explained that Roche's monopoly on the reagent kits is the reason why HCV genotype test and HCV viral load tests are very expensive. Research is being conducted to find out how to simplify HCV viral load test by government of India, FIND, MSF.

People who tested positive for HIV should also be offered counseling and testing for Hepatitis B. If they decide to do the test and the test result comes back negative, they should be offered vaccination. If the test result is positive for Hepatitis B, they should be offered TDF/ 3TC based ARV regimens.

In India, TDF as an ARV drug is not patented, because of strong opposition from PLHIV groups that lead to the drug being produced locally. However, Gilead is filing a patent application for 'new use' of TDF, which is for the treatment of Hepatitis B.

New technologies are being developed to diagnose and treat Hepatitis C infection. New forms of interferon and ribavirin and their combinations that are more effective, less toxic and more convenient are now being studied. Studies currently conducted to improve the drugs are as follows:

- Pegylated technology (Enzon)
- Pegylated Interferon Alpha-2A (Roche)
- Pegylated Interferon Alpha-2B (Schering-Plough through Merck)
- Combination therapy of Pegylated Interferon plus Ribavirin
- Improvement of Ribavirin (Taribavirin)

New technology is also being used to develop HCV protease inhibitors:

- Boceprevir (SCH 503034) by Schering Plough through Merck. The study is ongoing and is in its third phase.
- Telaprevir (VX-950/TVR) by Vertex. The study is ongoing and is in its third phase.
- TVR+PEG+RBV
- Boceprevir+PEG+RBV
- HCV Polymerase inhibitors molecules
- Polymerase inhibitors + Pegylated Interferon, with or without Ribavirin

Although there is another (lupin) pharmaceutical company that produces Ribavirin in India, the cost of the drug is still quite high. Ribavirin is currently being studied to reduce one of the side effects of ARV treatment, which is anemia.

HCV patent landscape in India is as follows:

- Patents on Ribavirin in India that dates back to 1970s have expired.
- Pegylation technology by Enzon Inc. US Application No. 08/143,403 filed on 27<sup>th</sup> October 1993. Many more at WIPO and Indian patent office
- Pegylated Interferon Alpha-2A, patented by Roche (US & India). US Application No. 60/018,834 filed May 31<sup>st</sup> 1996. Indian Patent No. IN198952 {1032/MAS/1997}, valid until May 2017.

- Pegylated Interferon Alpha-2B, patented by Enzon Inc. US Application No. 5951974. [Orange book]. Not published in India
- 3 patents were granted to Schering-Plough as follows:
  - IN207233 [IN/PCT/2000/434/CHE] = PCT/US1999/004268
  - IN199135 [INPCT/2001/00647/CHE = PCT/US1999/020900
  - IN206985 [89/CHENP/2003] = PCT/US2001/022678
- Pegylated interferon + ribavirin for eradicating detectable HCV-RNA in patients with chronic Hepatitis C infection: PCT/US1999/021448 = IN/PCT/2001/00520/CHE

Pegylated Interferon cannot be produced locally in India, because patent is held by Roche (US). Aside from patents, another issue is data exclusivity which is being pushed through the Free Trade agreements. Pharmaceutical companies monopolized clinical trial data relating to the use of Pegylated Interferon and Ribavirin in Hepatitis C treatment.

Leena then presented ways to move forward that she has identified, as follows:

- **Basic patents** on Pegylation Technology, Pegylated Interferon Alpha 2a & 2b will expire in the next few years. Patents should not be allowed to go beyond 2015.
- **Prevent** patenting of improvements and combinations.
- **Finding quality producers** and sharing information with them – stimulate production [Brazil, India, Bangladesh].
- Collect information on whether or not resources for **clinical trials** an issue for the generic drugs.
- **Registration** is going to be an issue for generic producers.
- Develop a **Pricing Guide** on Ribavirin and Pegylated Interferon for PLHIV community.
- **Protests** against Roche & Schering Plough [Merck] on high pricing [**common day of action on the first World Hepatitis Day in July**]
- **Cancer support groups** could be potential allies
- **Filing test court cases** to access treatment [**Ukraine case**]

There is no safe haven to produce new drugs, with the globalized TRIPS patent regime. Compulsory Licensing (CL) must be fought for newer treatment to stimulate production in developing countries. Free Trade Agreement (FTA) must also be fought to prevent TRIPS Plus.

#### **Comments:**

- Paul commented that new drugs would be patented, due to globalized TRIPS patent regime. Because of this, TRIPS flexibility must be used to get Compulsory Licensing (CL).
- Noah suggested alternative to Compulsory Licensing, which is patent opposition against Pegylated Interferon.
- Leena explained that resources are needed to hire lawyers to do patent opposition. As the patents will expire in 2015, the battle needs to begin now. Fighting a patent after it is granted is more difficult than fighting it before it is granted. We need to put our minds and resources together if we are to do patent opposition or Compulsory Licensing.
- Paul explained that there are various mechanisms to put pressure to companies. Although pushing for Compulsory Licensing in a country will bring with it huge pressure, it will also bring big results. For example, when Thailand pushed for Compulsory Licensing, they were issued almost immediately. Following that, all middle-income countries also received lower price for the drug.
- Wirat suggested every country to fight against FTA to prevent TRIPS Plus.

- Giten shared that ANPUD and 7 Sister will commit to hold a protest against patent on World Hepatitis Day.
- Paul stressed the importance of collecting information, and while the information is being collected, to advocate for better price for the drugs we need. We need to agree on a broad agenda to allow different groups to come in. This is the only way we can win.
- Karyn remarked that harm reduction group and HIV community are important allies that should be better educated on this issue.
- Responding to Rajiv's question, Paul explained that the reason why pegylated interferon is so expensive is because of the monopoly from pharmaceutical companies. Although there are a lot of companies producing interferon, there aren't that many companies producing pegylated interferon. This allows the companies to monopolize the market. Pegylated interferon is actually the same interferon, but wrapped in a sugar molecule to slow the absorption of the drug inside the human body, and then sold for 10 times its original price.
- Leena added that experience shows that generic production of a drug will reduce the cost of production by 100%, if not more. The fact that pharmaceutical companies would offer "discount packages" indicates that the cost of production for the drugs is not high. However, even with the "discount packages", the overall price for the treatment package is still very high. This just shows how greedy the pharmaceutical companies are. Doctors usually work together with the pharmaceutical companies, and we should have dialogue with them.
- Jennifer informed everyone that there are doctors working with TREAT Asia that we can also have a dialogue with. Dialoguing with the doctors is a better strategy than shaming them or exposing them without substantial evidence.
- Canaria remarked that the problem lies in the health care system; as often doctors are not getting enough payment and the system encourage them to get the bonus offered by pharmaceutical companies.
- Els informed everyone, that in the last World Health Assembly (WHA), there was a resolution put forward by Brazil to recognize viral hepatitis as a major public health challenge and that it was adopted by the assembly. Other country members supported the resolution, and we can use this as an advocacy tool.
- Leena commented that in WHA, it was the government of Brazil that was advocating the resolution, not the communities.
- Rico remarked that this is not true, as prior to the WHA community groups already lobbied their government to pass the resolution. However, community involvement is not seen in the WHA because it is a government event, and producing the resolution itself was a very bureaucratic process.
- Rico also informed everyone that community groups have been in discussion with WHO about Hepatitis C for the past two years. However, it was only after the resolution was passed in WHA that WHO took action. Now, we need to push WHO to integrate the resolution into their strategic plan, so that they can push government into taking action. We need to be involved in WHO Strategic Plan meeting that will take place next month. This is almost the same situation in 1986 when people were advocating access to treatment for HIV, and we need to use the experience we learned from HIV and AIDS advocacy work to avoid repeating the same mistakes.

## **Summary of Day 1**

- Treatment activists from 6 countries presented the current situation of standard of care in their countries. In general, there is little information available about Hepatitis C compared to information on HIV and AIDS. HCV surveillance need to be included in the national surveillance program in order to obtain more accurate information about Hepatitis C prevalence in the country.
- Although HCV antibody tests are widely available at an affordable price in every country, the HCV PCR diagnostic tests (including confirmatory tests and genotype testing) are expensive because they are patented. Patents for the reagent kits used in these tests are held by either Abbott or Roche.
- The high cost of Hepatitis C treatment makes it almost impossible for people with Hepatitis C to get the treatment they need. Treatment cost varies from US\$ 14,000 to US\$ 33,000. In Nepal, however, treatment for Hepatitis C is not yet available and Hepatitis C patients are referred to India for treatment. Pegylated Interferon are patented by Roche (Pegasys) and Schering-Plough (PegIntron). Because these two pharmaceutical companies are holding patents, the cost for treatment is extremely high. There is a need to identify specific advocacy campaigns to lower treatment costs.
- Noah Metheny (Thai AIDS Treatment Action Group/ TTAG) presented on the barriers to HIV/ HCV diagnostics, treatment and care in Thailand. Several possible ways he identified to bring down the high cost of Hepatitis C treatment in Thailand are: overriding Roche and Schering-Plough (Merck) patents on Pegylated Interferon by Thai government; issuance of Compulsory Licenses for Pegylated Interferon (or any other new HCV drug); inclusion of Pegylated Interferon and Ribavirin on Thailand Essential Medicines Lists; Thai GPO develop safe and effective generic version of Pegylated Interferon; and price negotiations with pharmaceutical companies for HCV diagnostics and treatment, etc.
- Leena Menghaney (MSF-CAME, New Delhi, India) presented information about patent situation regarding Hepatitis C treatment. Several ways that Leena has identified to fight against patent issues are: Preventing patent application for improvement and combinations of drugs used in Hepatitis C treatment and extension of existing patents (basic patents of Pegylation Technology, Pegylated Interferon Alpha 2-a and 2-b will expire in 2015); Develop a pricing guide on Ribavirin and Pegylated Interferon for PLHIV community; Protest against Roche and Schering-Plough (Merck) on high pricing of Hepatitis C drugs; Collaborate with cancer groups, etc.
- The meeting discussed the need to use TRIPS flexibility to get Compulsory Licensing (CL), as well as the possibility for patent opposition. As the patent for pegylated interferon will expire in 2015, there is need to gather all available resources now. Patents should not be allowed to go beyond 2015.
- Although there are a lot of companies producing interferon, there aren't that many companies producing pegylated interferon. This allows the companies to monopolize the market. Pegylated interferon is actually the same interferon, but wrapped in a sugar molecule to slow the absorption of the drug inside the human body, and then sold for 10 times its original price. The fact that pharmaceutical companies would offer "discount

packages" indicates that the cost of production for the drugs is not high. However, even with the "discount packages", the overall price for the treatment package is still very high.

- WHA Resolution to recognize Hepatitis C as a public health issue should be used in advocacy efforts to improve access to Hepatitis C treatment.
- There is a need to learn from the experience of advocacy work in the HIV and AIDS field to avoid the same mistakes.

**Recap of Day 1 on Key Issues, Gaps and Challenges**

The second day began with a recap of the first day by Greg Gray, who shared that yesterday's process was very interesting, and that it was crucial to prioritize and identify the needs at country level to see how regional organizations – those who are represented in this room or not - can provide support.

**Session I: Advocacy Strategizing – Country Level Plans**

*Facilitated by: Ms. Karyn Kaplan, Thai AIDS Treatment Advocacy Group (TTAG)*

Karyn explained that each participant is part of a group in each country. The group work that will be conducted in this session is to identify some key issues at country level. Each country is asked to sit together and discuss:

- Issues related to Hepatitis C in their country.
- Possible solutions
- Advocacy targets
- Advocacy tools to change the problem
- Resources needed
- Potential allies

Participants are asked to identify which ones are short-term goal, and which are the long-term goals. Information collected from this exercise will be used to develop an advocacy plan.

**Country Presentations:**

**1. Indonesia**

*Presented by: Mr. Samuel Nugraha, Indonesia National Drug Users Network (PKNI)*

|                    |  |
|--------------------|--|
| Issues             | <ul style="list-style-type: none"> <li>• Hep C treatment is expensive</li> <li>• Only few people know about Hepatitis C issues</li> </ul>  |
| Possibly solutions | <ul style="list-style-type: none"> <li>• Make treatment available very low price, start with HIV infected people</li> <li>• Treatment education</li> </ul>   |
| Activities         | <ul style="list-style-type: none"> <li>• Scale-up testing - by Ministry of Health (Short, Mid, Long Term)</li> <li>• Information dissemination, public campaign (Short, Mid, Long Term)</li> <li>• Piloting a project to be used as baseline to support that Hepatitis C treatment is working (Short and Mid term)</li> <li>• Public movement to push availability of Hepatitis C treatment by the government (Mid Term)</li> <li>• Lobbying local pharmaceutical companies, i.e. Kimia Farma, Indofarma, etc. (Mid and Long Term)</li> <li>• Advocate for Compulsory Licensing (Mid and Long Term)</li> <li>• Develop partnership on FTA Indonesia and EU (Mid and</li> </ul> |

|                  |   |
|------------------|---|
|                  | <ul style="list-style-type: none"> <li>Long Term)</li> <li>Strengthen partnership with Ministry of Health (Mid and Long Term)</li> <li>Consultation forums on Hepatitis C treatment with constituents, including cancer support groups and activity groups (Mid and Long Term)</li> <li>Literacy development and dissemination (Short Term)</li> <li>Conduct workshops and trainings on Hepatitis C related information (Short Term)</li> <li>Develop support system for people undergoing Hepatitis C treatment (peer support groups, study clubs, etc) (Mid Term)</li> <li>Conduct M &amp; E on implementation of activities (Long Term)</li> </ul> |
| Advocacy tools   | <ul style="list-style-type: none"> <li>Database on previous Hepatitis C testing conducted</li> <li>National policy and engagement mechanism, including financial resources, content of law and treatment culture (Guidelines)</li> </ul>  |
| Resources needed | <ul style="list-style-type: none"> <li>Total budget of around US\$ 510,000 (for 5 years)</li> </ul>   |
| Potential allies | <ul style="list-style-type: none"> <li>Ministry of Health</li> <li>FHI</li> <li>OSI</li> <li>HCPI</li> <li>WHO</li> <li>UNAIDS</li> <li>Regional networks</li> </ul>  |

## **2. Nepal**

*Presented by: Mr. Nikhil Gurung, HEPA Foundation*

|                    |  |
|--------------------|--|
| Issues             | <ul style="list-style-type: none"> <li>Prevention</li> <li>Access to treatment</li> <li>Patent Regime and its implications to our treatments/ lives</li> </ul>   |
| Possibly solutions | <ul style="list-style-type: none"> <li>Develop IEC on Treatment Literacy of Hepatitis C and HIV/ HCV co-infection</li> <li>Treatment advocacy training, prophylaxis</li> <li>Global action</li> </ul>  |
| Advocacy tools     | <ul style="list-style-type: none"> <li>Education materials, training manual to be adapted in Nepali by the end of December 2010</li> <li>Organize regional training for treatment advocacy</li> <li>Sign-on letters/ Global Day of action</li> </ul> |
| Potential allies   | <ul style="list-style-type: none"> <li>PLHIV/ IDU network</li> <li>TTAG</li> <li>Local networks</li> <li>Global regional networks/groups</li> </ul>  |

### 3. Viet Nam

Presented by: Mr. Dong Duc Thanh, Viet Nam Network of Positive People (VNP+)

|                        |  |
|------------------------|--|
| Issues                 | <ul style="list-style-type: none"> <li>• Stigma and discrimination towards injecting drug users (IDU)</li> <li>• No IDU network</li> <li>• Lack of awareness on Hepatitis C and HIV/ HCV co-infections</li> <li>• No health service facilities providing information on Hepatitis C or HIV/ HCV co-infections</li> </ul>   |
| Possibly solutions     | <ul style="list-style-type: none"> <li>• Establish a national network of injecting drug users under VNP+</li> <li>• Treatment literacy for IDU and PLHIV</li> <li>• Advocacy campaign to reduce stigma towards injecting drug users and build public acceptance for Oral Substitution Therapy (Methadone treatment)</li> <li>• Initiate dialog with Ministry of Health and other government institutions, pharmaceutical companies and donors to discuss options to reduce price of Hepatitis C treatment</li> </ul> |
| Short-term action plan | <ul style="list-style-type: none"> <li>• Develop a work plan based on the priority needs of the constituents</li> <li>• Share work plan with VNP+ steering committee</li> <li>• Get support for advocacy strategy from WHO/ UNAIDS</li> </ul>  |
| Advocacy tools         | <ul style="list-style-type: none"> <li>• Need evidence based data/ country specific research on the actual scale of the problem</li> <li>• Use mass media to support campaign</li> <li>• Translate and adapt existing HCV resources, i.e. from TTAG</li> <li>• Use experience of VNP+ to help set up "Peer Support Network"</li> </ul>   |
| Resources needed       | <ul style="list-style-type: none"> <li>• Human and financial resources</li> <li>• Technical assistance from partners, regional</li> <li>• Partnership with UNAIDS, UNODC</li> <li>• Create opportunities for IDU to raise their voices</li> </ul>  |
| Potential allies       | <ul style="list-style-type: none"> <li>• VNP+</li> <li>• INGOS</li> <li>• UNAIDS</li> <li>• UNODC</li> <li>• PEPFAR</li> <li>• WHO</li> <li>• ANPUD, APN+, 7sisters</li> </ul>   |

#### Comments:

- Duc explained that it was important for Vietnam to work under the umbrella of existing national PLHIV network, VNP+. 60% of VNP+ members are injecting drug users (IDU). After the meeting, Duc hopes to be able to bring back a work plan to his constituents on how to move forward.

#### 4. **China**

Presented by: Mr. You Ding, MSF-CAME, China

|                    |   |
|--------------------|---|
| Issues             | <ul style="list-style-type: none"><li>• CDC system: There are NCAIDS and NCTB available, but there is no specific department in CDC to manage Hepatitis treatment and control.</li><li>• Difficult to provide ART and HCV treatment in closed settings.</li><li>• Lack of awareness on Hepatitis C, among injecting drug users and general public.</li><li>• Lack of well-trained physicians.</li><li>• Unaffordable treatment and testing</li></ul>  |
| Possibly solutions | <ul style="list-style-type: none"><li>• 2<sup>nd</sup> round public health reform: enhance CDC functions, universal social insurance coverage (Including HCV, and increasing reimbursement rate)</li><li>• Mobilize social resources to participate in HCV treatment and control</li><li>• Forging partnership with government at all levels</li><li>• Proposal to two congress</li><li>• Long-term strategy.</li></ul>   |
| Action Plan        | <ul style="list-style-type: none"><li>• Dialogue with government at all levels.</li><li>• Proposals to the two congress/conference</li><li>• Directly raise HIV/HCV issue to PM or president on the World AIDS Day.</li><li>• Compulsory Licensing (CL)</li><li>• Closely monitoring the outcome of National R&amp;D Research Program (RMB 30 billion within 4 years managed by PM office)</li><li>• Capacity building for civil society organizations.</li><li>• HIV/HCV proposal to GF 10</li></ul> |

#### **Comments:**

- Responding to a question from Jennifer Ho, You Ding explained that there are no existing mechanisms to build synergies for Hepatitis C. There has been more focus on Hepatitis B.

#### 5. **India**

Presented by: Mr. Umesh Sharma Hidangmayum, Treatment Activist in Manipur, India

|        |  |
|--------|--|
| Issues | <ul style="list-style-type: none"><li>• Lack of awareness about Hepatitis C among key population groups.</li><li>• Better understanding of Hepatitis C issues and the national body who has this mandate (advises the government on Hepatitis C issues), i.e. ICMR, MOH, AIIMS.</li><li>• Understand how people are paying for their Hepatitis C treatment, either by loans, reimbursement, support from small networks, etc.</li><li>• No data from the government.</li><li>• Patent situation on HCV from lawyers collective</li></ul> |
|--------|--|

|                        |  |
|------------------------|--|
| Short-term Action Plan | <ul style="list-style-type: none"> <li>• Proposal on literacy campaign on Hepatitis C from ITPC India Collaborative Fund</li> <li>• "Sign on" to provide education, counseling and testing for HCV before initiating ART (initiated by Leena)</li> <li>• Train and encourage activists to start protest and campaign in local set-up (12 NGOs x US\$ 5,000 = US\$ 60,000)</li> <li>• GF Round 10 Proposal Call for Interest</li> </ul> |
| Resources needed       | <ul style="list-style-type: none"> <li>• Funds to document, mobilize, human resources</li> </ul>   |
| Potential allies       | <ul style="list-style-type: none"> <li>• Lawyers collective</li> <li>• PLHIV networks</li> <li>• Harm reduction implementing organizations (NGOs)</li> <li>• VIRCHOW (Hyderabad) – produce Hepatitis C medicine products for export to Ukraine</li> </ul>  |

## 6. Thailand

*Presented by: Mr. Noah Metheny, Thai AIDS Treatment Action Group (TTAG)*

|                                    |  |
|------------------------------------|--|
| Issues                             | <ul style="list-style-type: none"> <li>• Lack of access to treatment: treatment is available but the cost is too expensive, since it is patented. Universal Healthcare Scheme doesn't cover Pegylated Interferon or the testing and follow-up diagnostics.</li> <li>• Limited health care providers and laboratory resources</li> <li>• Few doctors to treat People Living with HCV</li> <li>• Few laboratories available (with most of them at large research institutions)</li> <li>• No information or knowledge about HCV, especially among high risk groups</li> <li>• Limited knowledge among key leaders</li> <li>• Lack of support services, including for those who are co-infected</li> <li>• Lack of policy on harm reduction (clean needle exchange, etc) by the Thai government</li> <li>• Attitude toward IDU, among policy makers, healthcare providers, etc</li> <li>• Lack of national data on HCV, co-infection etc</li> </ul> |
| Short Term Action Plan (1-2 Years) | <ul style="list-style-type: none"> <li>• NHSO Forum (Negotiations of HCV treatment with pharmaceutical companies)</li> <li>• Improve local knowledge (educate community) to become better advocates</li> <li>• Screening for HBV/ HCV</li> <li>• Information for injecting drug users and their families</li> <li>• Develop harm reduction collaboration/ involvement</li> <li>• Education key organizations/ key leaders (networking/ partnership)</li> <li>• Conduct a workshop for health care providers</li> </ul>   |
| Mid Term Action Plan               | <ul style="list-style-type: none"> <li>• CCM (GF)</li> <li>• GPO dialogue to develop HCV treatment/ diagnostics (capacity)</li> <li>• Negotiate for drugs</li> <li>• Standard for HCV treatment</li> </ul>   |

|                                  |  |
|----------------------------------|--|
| Long Term Action Plan (20 years) | <ul style="list-style-type: none"> <li>• Getting around patents</li> <li>• Develop HCV treatment/ diagnostic capacity</li> <li>• Donations/ Clinical Trial</li> <li>• Government policy on harm reduction</li> <li>• Develop treatment guidelines</li> </ul>   |
| Advocacy targets                 | <ul style="list-style-type: none"> <li>• GPO</li> <li>• 12-D</li> <li>• TTAG</li> <li>• MSF</li> <li>• FTA Watch</li> <li>• Ministry of Health</li> <li>• NHSO (National Health Security Office)</li> <li>• Thai Patent Office</li> <li>• Thai FDA</li> <li>• CCM</li> <li>• Pharmaceutical companies</li> <li>• Local doctors aware of IDU issues</li> <li>• HIVNAT</li> <li>• Scientific researchers</li> <li>• IDU support community (religious, family, local, etc)</li> </ul> |
| Advocacy tools                   | <ul style="list-style-type: none"> <li>• Local and national trainings on HBV/HCV</li> <li>• Policy brief/ targeted educational information on HBV/HCV (leaflets, newsletters brochures, etc)</li> <li>• Education about HCV/HBV status and rights</li> </ul>   |
| Resources needed                 | <ul style="list-style-type: none"> <li>• Trainers (TTAG, regional TNP+, etc)</li> <li>• Better HCV/HIV surveillance</li> <li>•</li> </ul>  |
| Information to collect           | <ul style="list-style-type: none"> <li>• Situation (evidence based, prevalence)</li> <li>• Local situation (hospital level: HCV and HIV)</li> <li>• Situation in every Thai region</li> </ul>  |

### **General Comments:**

- Paul commented that the guideline developed by TTAG can also be used in another country, and suggested putting a local perspective about the situation in each country and not just to translate the guideline into a local language. Paul also suggested making a summary about key information from TTAG guideline to raise awareness on Hepatitis C issue, particularly to encourage PLHIV to get people tested on Hepatitis C and B, and to inform them what they should do after receiving the test results. For example, if they are HBV negative, they should be offered vaccination and if they are HBV positive to ask for ARV that can treat both HIV and HBV.
- Shiba suggested including Hepatitis C in HIV treatment literacy program, while fund is raised to conduct capacity building programs to specifically train people as peer educators on Hepatitis C. This will also ensure cost-effectiveness of treatment literacy programs. Providing basic information on Hepatitis C is very important and should be done as soon as possible, as there is obviously a lack of information and awareness about this issue. We need to start doing something, now.
- Umesh remarked on the need to also focus on preventing further HCV infection, and suggested collaborating with organizations providing harm

- reduction programs for injecting drug users to improve prevention programs.
- Rico remarked on the fact that there hasn't been any honest evaluation of harm reduction program carried out in South East Asia that collects real evidence based data without it being influenced by anyone's agenda. Rico also agreed that immediate action needed to be taken, one of which is including Hepatitis C into HIV Treatment Literacy program while also training key people from community groups in the region as peer educators on Hepatitis C.
  - Leena suggested identifying key stakeholders and discuss Hepatitis C issues with them as one of the first step we take upon returning to our countries. Aside from getting us access to high-level policy making meetings, this will also make it easier for us to access Hepatitis C related information and data.
  - Responding to a question from Umesh about whether or not someone who has started treatment with pegylated interferon can go back to conventional interferon, it was explained that pegylation is not a drug but is a technology used to make interferon make it more efficient and to reduce side effects. Pegylated interferon is absorbed at a slower rate in the body, which means that the drug does not have to be injected as often as conventional interferon (injection is only done once every week instead of 3 times per week with conventional interferon. Pegylated interferon is therapeutically more effective and has fewer side-effects than non-pegylated interferon.

## **Session II: Experiences from Eastern Europe**

*Presented by: Ms. Els Torreele, OSI, New York*

Els explained the three elements of building an effective advocacy strategy to increase Access to Hepatitis C treatment: 1) Knowing the medical need and articulating the demand; 2) ensuring a sustainable supply (affordable, effective, quality medicines); 3) Have a relevant Hepatitis C control Policy in place (national, international), which also addresses the need for adequate funding. While there is a need for Hepatitis C treatment, there isn't really a demand because most people are not yet tested, and maybe unaware of the disease (both within risk groups and within the health system).

There is a need to ensure the availability of affordable and safe drugs at the country level. There is also a need to convince pharmaceutical companies that there is a demand for treatment, and that they need to provide the supply of drugs used in the treatment. Lobbying the government to put pressure to pharmaceutical companies is something we need to do in our countries. Regarding funding for Hepatitis C programs, Els suggested looking into the Global Fund guidance note and other document which talks about Viral hepatitis Testing and treatment and at the same time country proposals that have been already been funded for HCV treatment.

Simultaneous work on all three elements is needed to ensure progress on Access to Hepatitis C treatment, and community groups need to have a better understanding of the situation in order to develop a better advocacy plan. Community groups should also collaborate with lawyers group, particularly to fight against patent issues.

In Georgia, there is a high prevalence of Hepatitis C, with almost 7% of the population is infected and the method of transmission is not only through injecting drug use. Georgia received GF ATM Round 9 AIDS grant to provide

Hepatitis C treatment for 110 people per year. The Georgian government seems committed to develop a national control program on hepatitis, and OSI is currently supporting civil society groups to be involved in advocacy to ensure this becomes a reality, and that all risk groups have equitable access to the available treatments.

In Ukraine, the local WHO office took the initiative to organize a stakeholder meeting to commemorate National Hepatitis Day on May 19<sup>th</sup>, including Ministry of Health, OSI, infectious disease research institutes, MDs involved in Hepatitis C, and NGOs (HIV/AIDS groups, harm reduction groups, Hepatitis C patient groups, etc). The next day, OSI convened a separate meeting with the civil society groups to strategize about advocacy to increasing Access to Hepatitis C treatment. The groups concluded that there is a lack of knowledge about Hepatitis C among risk groups and the health care providers, and that there is a lack of treatment providers and no Access to the too expensive treatment. After the meeting, the groups committed themselves to begin raising awareness about the disease, and mobilize the community to advocate for better treatment access.

In Brazil, where there are a lot of Hepatitis C cases, 25,000 people receive treatment every year. The government pays the treatment, and because they have to allocate a large sum of money to purchase Pegylated Interferon, the government has started to look into ways to reduce the cost. One approach could be to produce the drugs locally, and efforts are underway to build capacity to this end. It is expected that Pegylated Interferon Alpha 2-b could be produced locally and might be available within the next 2 years. There is also collaboration underway with Cuba to develop a new form of Pegylated Interferon, but this may take a couple of more years to deliver. The Brazilian government and the manufacturers were very interested to hear that there actually is a big demand for the drug from other parts of the world.

### **Session III: Global Fund Round 10 Multi-Country Proposal**

*Presented by: Mr. Shiba Phurailatpam, Asia Network of People Living with HIV (APN+)*

Shiba informed everyone that APN+ and 10 PLHIV country networks are developing a multi-country proposal for Global Fund Round 10, which will be submitted on August 20<sup>th</sup> of this year. The proposal development process has begun since March 2010. On 28<sup>th</sup> – 29<sup>th</sup> June, there will be a meeting with country focal points to produce a proposal draft. The proposal draft will be shared with CCMs in 10 countries to avoid duplication of activities in the country proposal.

The 3 objectives in APN+ multi-country proposal are as follows:

- 1) Expand treatment support and education services by networks of people living with HIV. (Country networks to fill gaps at country levels, by providing treatment education programs and provide services that complement those provided by the government)
- 2) Increase the capacity of networks of people with HIV to provide these services through developing expertise in resource mobilization, program management, financial management, monitoring and evaluation, and reporting. (The budget allocated for this objective is around 40% of the total budget in the proposal. This objective aims to strengthen the capacity of PLHIV networks, and is the heart of the proposal)

- 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. (This objective aims to strengthen APN+ capacity in managing strategic information at regional level, build advocacy and strengthening communication platform at the regional level)

The nominated PR for the proposal is APN+, with the 10 PLHIV country networks as potential SRs.

Provision of Hepatitis C treatment for HIV/HCV co-infected people will be included in the first objective of the proposal. Following a request by Indonesia PLHIV country network (JOTHI), the proposal team decided that it would be a good idea to also include provision of Hepatitis C treatment in countries that have evidence of Hepatitis C. The target is to provide Hepatitis C treatment for a total of 100 PLHIV in five years. Although the amount of requested fund for this activity will be huge, APN+ wish to use this opportunity as part of advocacy efforts to push the provision of Hepatitis C treatment.

Rico explained that there is some trouble finding a document from Global Fund that actually states that HCV treatment in the HIV proposal to Global Fund. Although the proposal development team is aware of the letter from Michel Kazatchkine -Executive Director of The Global Fund – but the team have yet to find any guidelines, fact sheet or other documents to support this fact.

Giten informed everyone that there are actually 3 documents that will support the inclusion of Hepatitis C treatment in GF AIDS proposal. The documents are: a letter from Michel Kazatchkine, GF Round 10 Guidance Sheet and AIDS country proposals from Belarus and Georgia.

Els suggested looking at the GF Round 9 Country Proposal from Georgia, as the provision of Hepatitis C treatment was not framed in a harm reduction program. Els also informed everyone that civil society in Ukraine is pushing to include in the Round 10 Proposal a plan and budget to provide Hepatitis C treatment for 6-8,000 people for five years. While it is still uncertain whether the CCM will accept this in the proposal (or a sized-down version of it), it is useful in terms of advocacy to include Hepatitis C activities based on the real need in proposals to Global Fund, so that Global Fund not only realizes how big the needs are, but also can start pushing pharmaceutical companies to reduce the price of drugs and also push country governments to improve their health system in order to ensure that they have the capacity to provide the treatment.

Leena suggested including Hepatitis C counseling and testing in country proposals, to encourage people to get tested for Hepatitis C.

Rico explained the need to develop a fact sheet for each country to use as an advocacy tool for Hepatitis C. The fact sheet can also be used to advocate to CCM.

Shiba explained that ITPC Collaborative Fund is a small grant that can also be accessed for Hepatitis C related programs, such as capacity building activities, data collection, etc.

#### **Session IV: Discussions – The Next Steps**

*Facilitated by: Ms. Karyn Kaplan, Thai AIDS Treatment Advocacy Group (TTAG)*

- Karyn asked everyone to discuss the next steps that will be taken after the meeting. Possible follow up actions include: getting a letter of support from the Brazilian government (government to government approach); continue pushing the agenda forward in other meetings; conduct Hepatitis C counseling and testing during Hepatitis Day this year on July 28<sup>th</sup>.
- Giten suggested using the momentum of Hepatitis Day on July 28<sup>th</sup> to launch a Regional policy paper on Hepatitis C. However, Karyn felt that it was too soon for a policy brief and suggested developing a press release instead. Leena proposed a sign-on letter to push for counseling and testing of Hepatitis C before circulating a press release.
- Paul remarked that there is no need to do a common action on July 28<sup>th</sup>, as there are other things that also need our attention. The most important thing now is to ensure that more people have basic information on Hepatitis C. Leena and Paul will draft this basic information document, using existing data that we already have. Aside from basic information about Hepatitis C infection, treatment and other related issues, Leena also suggested including a testimony from an HIV/ HCV co-infected person who has received treatment for his or her co-infection. This is a longer-term project that will take around 2-3 months to complete. We should be prepared with enough information and data for the journalists, as they will ask for information on even the smallest of detail.
- Rajiv remarked that in six months' time, there isn't anything more that we can find out about Hepatitis C aside from the information that we have already collected. We can already develop a document containing basic information that is necessary for this stage of the process.
- Giten commented that the whole point of the meeting will be defeated if we say that we do not have enough information to produce a press release. We have enough information to start something, and if people ask for more data we should also explain why collecting data has been a challenge. We need is to release a 1-page document that contains basic information that we already have on 28<sup>th</sup> July. The press release needs to address the fact that people are dying from lack of access to Hepatitis C treatment and one of the strongest reasons is due to the extreme high costs of the drugs.
- Leena explained that it is better to gather senior journalists that will take the issue forward, instead of just doing a press release. We should do a press release that people cannot ignore. We need to ensure that the journalists fully understand the issue; otherwise they will not report on it.
- Rajiv suggested confronting pharmaceutical companies like Roche during International AIDS Conference that will be held in July of this year in Vienna, which will be attended by a number of treatment activists from different countries.
- Loon explained that ITPC South Asia is almost finished with its research on Hepatitis C, and that by the end of the project a working group focusing on Hepatitis C will be established.

- Leena suggested that the next meeting discussing HIV/ HCV co-infection issues should also include a session on basic information of Hepatitis C infection and treatment and patent issues, to ensure that everyone have the same basic understanding of the issue.
- Paul will look at how to move these issues forward within MSF. As part of the MSF campaign team mid-year review in 3 weeks in Geneva this will be an issue that will be brought forward in the meeting, to raise awareness within MSF. Meeting has been useful.
- Wirat remarked that we are here to advocate for access to treatment, and that it was too fast to think about our next steps because each country has different situation and health system in place. The most important thing we can do after the meeting is to educate our friends about this issue, while also collecting information from them about what action we should take. This doesn't mean that we are not doing anything.
- After the meeting, it would take 2 weeks to 3 months for country activists to discuss with their constituents what the next step should be and how regional networks can provide assistance. This is important, as it will ensure that the initiatives come from grass root at country level and not from the regional level. Regional networks/ organizations will provide any type of support needed by country activists.
- Giten suggested creating a thank you letter from regional level forum to thank the government of Indonesia (including CCM members) for pushing the Hepatitis C resolution at the World Health Assembly and also for all the work that are being done to include HCV related issues in the Round 10 proposal.
- Wirat remarked that although we did not come to an agreement in the meeting on what the next actions should be, we have already received more information about country situation and patent system from the 2-days meeting, and that means that the meeting was not useless.
- Shiba commented that the discussion in the meeting has been great, as we begin to understand more about the urgency of this issue and how the disease is slowly killing people. Shiba also commented that donors have countries that they prioritized when funding a program, which contributes to the lack of resources for Hepatitis C. Although community mobilization will need resources, there are things that we can begin to do without any funding.
- Els informed everyone that OSI is really keen to support any activities related to advocacy and activism around improving Access to Hepatitis C treatment. Els also expressed that she was very impressed with everyone's commitment in the meeting, and looks forwards to building collaborations together.
- Karyn suggested using a designated Hepatitis C listserv to help facilitate the brainstorming of ideas and circulate documents related to Hepatitis C, as there was still no agreement on what the next action should be.
- Karyn then thanked everyone for participating in the meeting and for a great discussion that have taken place the past two days. Karyn also reminded everyone that it was important to maintain communication after the meeting to keep the network established in the meeting strong.

## **Summary of Day 2:**

- Treatment activists from 6 countries developed their work plan, and agreed that due to the lack of awareness about this issue among the general population and the key affected population, the most important activity is to raise this awareness by providing information and education on Hepatitis C through trainings, distribution of IEC materials and public campaigns. For mid and long-term activity, each country agrees that it is important to build partnership with stakeholders, including government institutions (Ministry of Health in particular) and advocate pharmaceutical companies to reduce the price of drugs so that more people can access Hepatitis C treatment.
- The meeting discussed the possibility of including Hepatitis C into HIV Treatment Literacy program, while funding is raised to train key people in the region as peer educators on Hepatitis C. The meeting also suggested ensuring that prevention of Hepatitis C infection is a key part of harm reduction programs in each country.
- Els Torreele from OSI New York shared experiences from Eastern Europe. Georgia (where 7% of its general population is infected with Hepatitis C) recently received GF R9 AIDS grant, in which they include provision of Hepatitis C treatment for around 100 people per year. Other countries are also encouraged to access Global Fund grants by ensuring that provision of Hepatitis C treatment is also included in the country proposal.
- Shiba Phurailatpam and Rico Gustav from APN+ shared in the meeting that APN+ is currently developing a multi-country Round 10 GF ATM AIDS proposal with 10 PLHIV country networks (Bangladesh, Cambodia, China, Fiji, Indonesia, Laos, Nepal, Pakistan and Philippines). The proposal aims to fill gaps at country level, by providing services that are needed but are not provided by the government; to strengthen the capacity of PLHIV networks; and to strengthen the capacity of APN+ to manage information, build advocacy and communication platform at the regional level. The proposal will include provision of Hepatitis C treatment for PLHIV in 7 countries with evidence of Hepatitis C infection.
- A Hepatitis C listserv is already in function and will be strengthened to facilitate further discussion and brainstorming sessions related to Hepatitis C response and circulate documents related to Hepatitis C.

### **ANNEX 1. List of Participants**

| <b>No</b> | <b>Name</b>                     | <b>Country</b>          | <b>Contact details</b>   |
|-----------|---------------------------------|-------------------------|--|
| 1         | Mr. Samuel Nugraha              | Indonesia               | National Coordinator<br>Persaudaraan Korban Napza Indonesia<br>(Indonesia National Drug Users Network)<br><b>sam.nugraha@gmail.com</b> |
| 2         | Mr. Abdullah Denovan            | Indonesia               | National Coordinator<br>JOTHI (National PLHIV Network)<br><b>denov11@gmail.com</b>   |
| 3         | Mr. Henminlun                   | India                   | Regional Coordinator<br>Collaborative Fund (South Asia)<br><b>Loon_gangte@yahoo.com</b>  |
| 4         | Mr. Umesh Sharma<br>Hidangmayum | India                   | Treatment Activist<br>Manipur, India<br><b>husharma@gmail.com</b>  |
| 5         | Mr. Rajiv Kafle                 | Nepal                   | President<br>National Association of PLHA in Nepal (NAPN)<br><b>rajhiv2002@yahoo.com</b>   |
| 6         | Mr. Nikhil Gurung               | Nepal                   | HEPA Foundation<br>Passport no. 4758384<br><b>nikhilgurung@gmail.com</b>   |
| 7         | Mr. Wirat Phurahong             | Thailand                | Thai AIDS Treatment Action Group (TTAG)<br><b>wirat.wiratpurahong@gmail.com</b>  |
| 8         | Mr. Aiet Prommet                | Thailand                | Thai Drug Users Network<br>Thailand  |
| 9         | Mr. Gao Qiang                   | China                   | Honghe Addicts Service Network<br><b>gq1974@gmail.com</b>  |
| 10        | Mr. Pham Van Cuong              | Viet Nam                | Vietnam Network of Positive People (VNP+)<br><b>pncuongqnnplus@gmail.com</b>   |
| 11        | Mr. Dong Duc Thanh              | Viet Nam                | Vietnam Network of Positive People (VNP+)<br><b>dongdodang@yahoo.com</b>   |
| 12        | Ms. Leena Menghaney             | MSF- CAME, New<br>Delhi | <b>leena.menghaney@gmail.com</b>   |
| 13        | Ms. Els Torreele                | OSI, New York           | <b>etorreele@sorosny.org</b>   |
| 14        | Mr. Nicolas Durier              | FHI, Bangkok            | <b>nicolas.durier@hotmail.com</b><br><b>ndurier@fhi.org</b>  |
| 15        | Mr. Youding Chen                | MSF- CAME China         | <b>youdingchen@gmail.com</b>   |
| 16        | Mr. Shiba Phurailatpam          | APN+                    | <b>shiba@apnplus.org</b>   |

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|----|------------------------|----------------------------|--|
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| 20 | Mr. Noah Metheny       | TTAG                       | <a href="mailto:noah.metheny@gmail.com">noah.metheny@gmail.com</a>           |
| 21 | Mr. Giten.Khwairakpam  | 7 Sisters/ ANPUD           | <a href="mailto:giten@7sisters.org">giten@7sisters.org</a>                   |
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| 23 | Ms. Lawan Sarovat      | PSI, Thailand              |  |
| 24 | Ms. Lissa Giurissevich | APN+                       |  |
| 25 | Ms. Cariana Gaffar     | AIDS Care China            |  |
| 26 | Mr. Rico Gustav        | APN+/ ITPC South East Asia |  |