A Report of the State Level Consultation Meeting on Treatment Access & Education - Assam

on

09th & 10th of October, 2006

Managed and Organized by:
Assam Network of Positive People (ANP+)

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In association and supported by Indian Network for People Living with HIV/AIDS (INP+)
Table of Contents

1. Acknowledgement
2. List of Abbreviations
3. Executive Summary
4. Welcome note by Jahnabi Goswami
5. Ice breaking session
6. Expectations of the participants
7. Laying ground rules
8. Presentation on ART by Dr. Nabin Bhuyan (M & E Officer, ASACS)
9. Presentation on Care & Support and Linkage to HIV/AIDS by Dr. C. R. Pathak (ASACS)
10. Presentation on HIV/HBC/HB & OI by Dr. S.I. Ahmed (Chairman, APS)
11. Group discussions to identify issues
12. Summarizing key issues
13. Sharing of experiences by PLHAs
14. Key Recommendations
15. Panel discussion on key recommendations
16. Conclusion
17. Photo Gallery
18. Annexure
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**List of Abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANP+</td>
<td>Assam Network of Positive People</td>
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<tr>
<td>INP+</td>
<td>Indian Network for People Living with HIV/AIDS</td>
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<tr>
<td>DFID</td>
<td>Department for International Development (UK)</td>
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<td>ASACS</td>
<td>Assam State AIDS Control Society</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>AIDS</td>
<td>Acquired Immuno Deficiency Syndrome</td>
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<td>NGO</td>
<td>Non-Governmental Organization</td>
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<td>DLN</td>
<td>District Level Networks</td>
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<td>PLHA</td>
<td>Person Living with HIV &amp; AIDS</td>
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<td>OI</td>
<td>Opportunistic Infections</td>
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<td>ART</td>
<td>Antiretroviral Treatment</td>
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<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>VCTC</td>
<td>Voluntary Counseling &amp; Testing Centre</td>
</tr>
<tr>
<td>PPTCT</td>
<td>Prevention of Parents to Child Transmission</td>
</tr>
<tr>
<td>NACO</td>
<td>National AIDS Control Organization</td>
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<tr>
<td>TI</td>
<td>Targeted Intervention</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>DOTS</td>
<td>Direct Observed Therapy</td>
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<tr>
<td>SHACC</td>
<td>State HIV/AIDS Coordination Committee</td>
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<td>GFATM</td>
<td>Global Fund to Fight AIDS, Tuberculosis and Malaria</td>
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**Executive Summary**

As the HIV prevalence rate is in the increasing trend in Assam due to factors and one important aspect is that two of the high-HIV-prevalence states in India – Manipur and Nagaland are in the Northeast (neighbouring states of Assam) and now feature what epidemiologists call a generalized epidemic with a strong IDU-HIV link. So access to antiretroviral treatment (ART) becomes very essential for the PLHAs apart from other preventive interventions.

ART for those infected with HIV can prolong life. It can also reduce transmission of HIV from parents to infants when antiretroviral drugs are used. ARV can thus, cut by half the rate of parents to child transmission (PPTCT) of HIV. However, access to ARV is extremely limited, especially in resource constrained environments. Affordability and accessibility to ART thus remain as key issues.

WHO’s “3 by 5” initiative set a target of 3, 55,000 PLHA in India to be on ARV by the end of 2005, but on contrary only about 35,000 people were on ARV till February, 2006. So far it has been estimated that more than 23000 people living with HIV and AIDS in Assam. Through the government ARV rollout program till date, only two ARV centers have been set up one in GMCH and second is recently opened at Silchar Medical College and as of August, 2006, only 173 PLHA’s have been enrolled in the ARV roll out center at GMCH and at the same time 5 (five) children were also been registered under the ART program in Assam.

Though the first line regimens are available in the government ARV center but the second line regimens and pediatric formulations as well as dosages/tables are not yet made available in the Government ARV roll out programs which the concerned authorities - Department of Health and ASACS has promised to initiate necessary measures. Apart from the selected treatment adherence and education programs run by the PLHA networks with GFATM-supported project, there are no other specific treatment education or adherence programs for PLHA through the government ARV component in Assam.

As there is no free CD4 testing facility except in Guwahati Medical College and Hospital through MSF so many people who are living with HIV and AIDS are facing lots of difficulties in their treatment procedure. Hence, in order to assess the current situation of treatment education and ARV access in Assam, ANP+ in support of INP+ will be organizing a state level consultation meeting on “Treatment Education and Access” in Guwahati on 9th and 10th Oct’06.

**Objectives:**

- To assess the current situation of ARV treatment education and access in Assam
- To identify the challenges and opportunities to scale up ARV access in Assam
- To improve the treatment education and adherence support to PLHA in Assam
- To enhance the contribution of PLHA networks in improving treatment education/adherence
In order to attain the aforesaid objectives, a two days long state level consultation meeting on ART access and education was held. Prior to the meeting, a pre-designed questionnaire was developed and was sent to the district level networks in order –

- To assess the situation at the respective district level networks
- To gather information on the number of PLHA on ARV in the district and availability of CD4+ testing, etc.

Under NACP-II as well as in NACP-III (which is yet to be implemented), care and support component was given prime importance for the people living with HIV/AIDS. Emphasis should be given not only on privacy and confidentiality but there has to be a collaboration of relatives, close friends, social workers and medical personnel in rendering supportive treatment as well as combating stigma and discrimination. Apart from these, home based care and multidisciplinary approach is very essential in order to create a linkage of care and support component to HIV/AIDS and TB programs.
**Welcome note by Jahnabi Goswami**

Jahnabi, on behalf of ANP+, thanked all the participants for taking some time in regards of attaining the “State Level Consultation Meeting on ARV treatment Access and Education” and thus, welcomed them in the meeting with an inaugural talk on DFID – Challenge Fund and INP+.

**Ice breaking session**

The facilitator requested all the participants to introduce themselves with their name, favorite fruit and favorite colour and followed by this some games were also played as well. Lastly, all members were asked to sing a song by holding each others hands.

**Expectations of the participants**

All the participants were asked to write in a piece of paper about what they expect from this consultation meeting and accordingly fix it in white board and the idea behind this exercise was to give some space to the participants in order to express their point of view and making them feel as part and parcel of this meeting. The expectations were as listed below:

- More knowledge about positive people
- Services available for PLHA
- Information about HIV and AIDS
- Treatment accessibility
- Recommendations to state government
- Knowing more about ART
- Free medicine/CD4/TA/Nutrition/Vitamins
- Availability of medicines
- Participatory learning
- OI medicines for children
- Updated information of medicines available

**Setting Ground Rules**

Norms and regulations or in other words - ground rules is necessary in order to conduct or carrying out any meeting, workshop, etc and thus, helps in smooth running of any such activity with fewer disturbances and making it more interesting. Some of the ground rules as fixed by the group were:

- Mobile to remain in silent mode
- Respecting each others feelings
- Helping each other in every aspect during the meeting
- Focus/emphasis on the topic every time
- Time bound completion of each sessions
- No tobacco/smoke in the hall
- No cross cutting
- Participation of all
- Managing children/kids by their parent(s)
Antiretroviral Treatment by Dr. N. Bhuyan

Goal antiretroviral therapy is to suppress HIV replication as much as possible for as long as possible. The purpose of any ART is to get the viral load as low as possible and there by, keeping it down. The ultimate goal is to achieve undetectable levels of HIV in he blood.

Thus, Dr. Bhuyan begins his presentation by mentioning that ART can potentially suppress HIV replication, Reduce Opportunistic Infections and Prolong survival. On contrary, he has also said that ART is unable to eradicate HIV, resistance mutations develops and the combination requires at least three agents but again there is limitations.

→ Limitations are: toxicity
interactions
penetration

Figure 1.1
Showing cross section HIV

Dr Bhuyan, than discussed about antiretroviral drugs and how it acts on HIV in different stages of its lifecycle. As we aware that the goal of ART is to suppress viral replication, therefore, it is now recognized that this can be achieved by using a combination of several ART drugs (three or more) at the same time. Some of the ART drugs (2004) are:
1. **Non-nucleoside reverse transcriptase inhibitors (NNRTIs)**
   1.1 Nevirapine
   1.2 Delavirdine
   1.3 Efavirenz

2. **Protease inhibitors**
   2.1 Saquinavir
   2.2 Ritonavir
   2.3 Indinavir
   2.4 Nelfinavir
   2.5 Kaletra
   2.5 Amprenavir
   2.6 Atazanavir

3. **Entry inhibitors**
   3.1 Enfuvirtide (T-20)

4. **Nucleoside Analogues (NRTI)**
   4.1 Zidovudine (AZT, ZDV)
   4.2 Didanosine (ddI)
   4.3 Stavudine (d4T)
   4.4 Lamivudine (3TC)
   4.5 Abacavir (ABC)

5. **Nucleotide RTIs**
   5.1 Tenofovir (tdv)

Dr Bhuyan, then talked about the highly active anti-viral therapy (HAART) which is known to be as powerful anti-viral drugs.

### Price of HAART Generics
(Rupees/month)

<table>
<thead>
<tr>
<th>Company</th>
<th>AZT/3TC/NVP</th>
<th>D4T/3TC/NVP</th>
<th>D4T/3TC/EFV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cipla (India)</td>
<td>1800.00</td>
<td>1602.00</td>
<td>3767.65</td>
</tr>
<tr>
<td>Hetero (India)</td>
<td>?</td>
<td>?</td>
<td>?</td>
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</tbody>
</table>

Though doctors have succeeded in drastically reducing the viral load in the blood of infected persons to virtually undetectable levels using HAART but recent studies have shown that patients receiving HAART, HIV still continues to lurk in cells called “latently-infected CD4” which serve as silent reservoirs of infection that have the potential to inject fresh virus into the bloodstream.
**Recommendations for Initiating Antiretroviral Therapy:**

If CD4 testing is available then document baseline CD4 counts & offer ART to patients with:

- WHO Stage IV disease - irrespective of CD4 cell count
- WHO Stage III disease - with consideration of using CD4 cell counts <350/mm3 to assist decision-making
- WHO Stage I or II disease - with CD4 cell counts ≤ 200/mm3

*If CD4 testing unavailable then ART to patients can be offered with:*

- WHO Stage IV disease - irrespective of total lymphocyte count
- WHO Stage III disease - irrespective of the total lymphocyte count
- WHO Stage II disease - with a total lymphocyte count = 1400/mm3 #

Finally, Dr. Bhuyan concluded his presentation by repeatedly asking the participants to have a close watch in Monitoring Antiretroviral Therapy specially its:

- Clinical aspects
- CD4 cell counts
- Viral load measurements (RT PCR / bDNA)
- Compliance / Adherence
- Adverse drug effects

And when the participants enquired him about the second line regimen, he mentioned that so far NACO hasn’t planned anything about it and as such ASACS haven’t taken any initiative. But as far as the ARV accessibility in Assam is concerned – at present there are two centres one at Guwahati Medical College and Hospital and the second is at Silchar Medical College.
Care & Support and Linkage to HIV/AIDS and TB by Dr. C.R. Pathak

The burden of HIV patients is increasing in India (with more than 5.7 million) and people affected are usually young and in prime productive years of their life. Though there is no cure available so far but the quality of life can be improved and efforts to eradicate stigma and discrimination attached to people living with HIV/AIDS.

On the other hand, tuberculosis (TB) is the leading cause of deaths among the adults in India and is contributing more than 30% of world’s TB burden. TB is known to be the oldest disease in the world. More than two billion people are infected with TB in the world of which 95% are in the developing countries. In 1992, World Health Organization (WHO) declared a “global emergency” and called countries to adopt Direct Observed Therapy (DOTS) as a TB control strategy.

Relation of TB and HIV: The hallmark of HIV infection is a progressive depletion and dysfunction of CD4 cells coupled with defects in macrophages and monocyte function. Because CD4 cells and macrophages have a central role in anti anti-microbial defences, dysfunction of these cells places the person with HIV/AIDS at high risk of developing primary or reactivation of TB. Epidemiological evidences indicate that HIV infection increases the risk of re-infection of latent tuberculosis infection.

Magnitude of TB and HIV in India: India is contributing more than 1/3rd of world’s TB burden and it is estimated that there are 14 million TB cases in India, out of which 3.5 million are sputum positive. There is one TB death in India every minute and kills more women than all cause of maternal mortality

There are an estimated 5.7 million people infected with HIV in India today and approximately 100,000 cases of AIDS may have already occurred in the country. The most rapid and well-documented spread of HIV has occurred in Mumbai and the State of Tamil Nadu. In Mumbai HIV prevalence has reached the level of 50% in sex workers, 36% in STD patients and 2.5% in women attending antenatal clinics. On contrary, drug use is a problem in some parts of the North-East Region, where 55% of drug users are HIV-infected and 1% of women attending antenatal clinics are infected with HIV.

And now HIV is rapidly spreading to rural areas through migrant workers and truck drivers. Therefore, a major international and governmental effort is necessary to respond effectively to this severe epidemic.

Tuberculosis and AIDS: TB accelerates the process of development of AIDS through the following mechanism –

1. Viral replication - may continue in macrophage and acts as a reservoir of HIV. Macrophages are stimulated in TB and thus, HIV infection goes to AIDS disease.

2. M.TB- can augment HIV disease by activation of CD4 lymphocytes.
Suspecting HIV in TB patient if there is:

- Generalized lymphadenopathy
- Candida infection – white patch of fungus in mouth and esophagus
- Chronic diarrhoea > 1 month
- Herpes zoster
- Kaposis sarcoma- small red vascular node on skin, specially palate

There is a long period, even after carrying several years of HIV infection; patients are doing quite well during the period of infection.

Treating tuberculosis through DOTS:

<table>
<thead>
<tr>
<th>Category</th>
<th>Intensive phase</th>
<th>Continuation phase</th>
</tr>
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<tbody>
<tr>
<td>I</td>
<td>2 (HRZE) 3</td>
<td>4 (RH) 3</td>
</tr>
<tr>
<td>II</td>
<td>2 (SHRZE) 3 (HRZE) 3</td>
<td>5 (RHE) 3</td>
</tr>
<tr>
<td>II</td>
<td>2 (HRZ) 3</td>
<td>4 (RH) 3</td>
</tr>
</tbody>
</table>

Thus, early and prompt infection of effective treatment increases the probability that a patient with HIV who develops TB will be cured of this disease. Patients with TB and unknown HIV status should be counseled and offered HIV testing and HIV infected patient undergoing TB treatment should be evaluated for antiretroviral therapy.
Opportunistic Infection, Hepatitis C, Hepatitis B and HIV/AIDS by Dr. Ahmed

Dr. Ahmed, prior to starting his presentation shared some examples of opportunistic infections and followed by this, the former addressed the participants mentioning that human bodies carry many germs - bacteria, protozoa, fungi and viruses and as along as the immune system is working it controls these germs but moment the immune system is weakened by HIV disease or by some medications, the same germs can get out of control and cause health related problems.

And infections that take advantage of weakness in the immune defenses are called "opportunistic" and the phrase "opportunistic infection" is often shortened to "OI".

What are the most common OIs?

In the early years of AIDS epidemic, OIs caused a lot of sickness and deaths. And once people started taking strong antiretroviral therapy only fewer people got OIs though it's not clear how many people with HIV will get a specific OI.

In women, health problems in the vaginal area may be early signs of HIV. These can include pelvic inflammatory disease and bacterial vaginosis among others. The most common OIs are listed here along with the disease they usually cause and the CD4 cell count when the disease becomes active:

*Candidiasis (Thrush)* is a fungal infection of the mouth, throat, or vagina. CD4 cell range - can occur even with fairly high CD4 cells.

*Cytomegalovirus (CMV)* is a viral infection that causes eye disease and can lead to blindness.CD4 cell range - is under 50.

*Herpes simplex viruses* can cause oral herpes (cold sores) or genital herpes. These are fairly common infections but if anyone carrying HIV, the outbreak can be much more frequent and more severe. They can occur at any CD4 cell count.

*Malaria* is common in the developing world. It is more common and more severe in people with HIV infection.

*Mycobacterium avium complex (MAC or MAI)* is a bacterial infection that can cause recurring fevers, general sick feelings, problems with digestion and serious weight loss. CD4 cell range is - under 75.

*Pneumocystis pneumonia (PCP)* is a fungal infection that can cause a fatal pneumonia. CD4 cell range is - under 200. Unfortunately this is still a fairly common OI in people who have not been tested or treated for HIV.

*Toxoplasmosis (Toxo)* is a protozoal infection of the brain. T-cell range is - under 100.

*Tuberculosis (TB)* is a bacterial infection that attacks the lungs and can cause meningitis. CD4 cell range is - everyone with HIV who tests positive for exposure to TB should be treated.
PREVENTING OIs

Most of the germs that cause OIs are quite common and one may already be carrying several of these infections. But one can reduce the risk of new infections by keeping them clean and avoiding known sources of the germs that can cause OIs. Even if a person is suffering from he/she can always take medications that will prevent the development of active disease and this is known as prophylaxis.

The best way to prevent OIs is to take strong ART. The Fact Sheets for each OI have more information on avoiding infection or preventing the development of active disease.

TREATING OIs

For each OI, there are specific drugs or combinations of drugs that seem to work best. One may always refer to the Fact Sheets of OI to learn more about how they treat. Besides, strong antiretroviral drugs can allow a damaged immune system to recover and do a better job of fighting OIs.

What is Hepatitis C?

Hepatitis C or ‘Hep C,’ is a virus that can damage the liver. Sometimes it can cause scar tissue to build up, making it hard for the liver to work properly. It can take years or even decades for the virus to do any damage. For many people, it may never do any damage at all.

What is co-infection?

‘Hep C’ and HIV co-infection means having both ‘Hep C’ and HIV viruses.

How do you get Hepatitis C?

Hep C is spread by blood so one can get it if s/he comes into contact with the blood of someone who has Hep C. The most common ways that this happens are:

Sharing needles or works, even once. This is the way that most people get Hep C. Sharing anything – needles, cookers, cottons, or rinse water – can put one at risk. And bleach does not always kill Hep C. One can also get Hep C from snorting drugs.

Sharing certain household items such as toothbrushes and razors that might have blood on them (even amounts one can’t see).

One can get Hep C from sex. The more people you have unprotected sex with, the greater your chance of getting it and other STD’s through sex. But, if you’re in a long-term relationship with only one person, the chances of spreading it through sex are low.

Some people have gotten Hep C from even tattoos but it is hard to get it that way, especially if you go to a professional tattoo parlor. It is more risky to get a tattoo someplace where there isn’t sterile tattoo equipment, like in prison or from a friend.

A pregnant woman who has Hep C may also pass it to her fetus but this is rare.
What are the symptoms of Hep C?
Most people with Hep C don’t have any symptoms. That’s why so many people have it without knowing. Things that people sometimes feel include: feeling very tired, belly pain, Swelling, itching. Most people with Hep C don’t get jaundice or yellow skin and eyes.

Why should I worry about my Hepatitis C?
Hep C can be more complicated and more dangerous for people who also have HIV. If you also have HIV, the chances of getting sick from Hep C may be higher. It might not take as long for Hep C to start damaging the liver. Some HIV medicines can hurt the liver, so if you have Hep C, the doctor will ask you to be careful about which pills you take.

Are there special tests that I need?
Most important Hep C tests are blood tests, so the doctor may do them along with whatever blood tests one usually have done. The doctor may also talk to you about getting a liver biopsy. This special test tells how exactly the liver is functioning.

What happens if I get a liver biopsy?
To get a liver biopsy, you have to spend a few hours in the hospital. The doctors may make a video of your belly called an ultrasound in order to see the exact position of the liver is. They will then numb the skin and use a long skinny needle to remove a tiny piece of the liver and see under a microscope.

Is there treatment for Hepatitis C?
Yes! The easiest way to ‘treat’ Hep C is to take some simple steps yourself: Don’t drink alcohol. If you can’t stop completely, cut down as much as you can. Alcohol is like poison to a liver that is already working overtime to fight hep C. If you haven’t already been vaccinated or exposed, get vaccinated for Hep A and Hep B. There is no vaccine against Hep C. If you shoot drugs, use a new sterile needle for every injection and don’t share any of your works. Don’t share needles, cottons, cookers, or rinse water. Doctors at the clinic can give you a prescription for cleaning the needles if in case you need them. See your doctor regularly and keep your HIV under good control.

Is there medicine for Hepatitis C?
There is medicine for Hep C and at present there are two kinds of medicines available:

1. Interferon, an injection once a week
2. Ribavirin, pills twice a day

In order for the medicines to work best, one have to be on them for six months to one year but there can be side effects, such as tiredness, itchiness, headaches and lowering of blood counts. Another important side effect can be depression and this is why it is very important that if anyone is on the medication, then the doctor/team needs to see that patient.

Does the medicine work?
Even when a person is receiving the treatment through out the year, there is still about 40% to 80% chance that s/he will be cured of Hep C depending upon the type of virus the person is carrying. Even if the person is not cured, the medicine can help the liver to repair itself.
This medicine is not meant for everyone. If person is having certain other medical problems then these medicine could be dangerous. The Hep C team can help you decide if the medicines are right for you.

**Hepatitis B virus (HBV):** is the most common cause of chronic liver disease worldwide. HBV is a DNA virus that is transmitted primarily through blood exposure and sexual contact and from mothers to their children. Because HIV and HBV share transmission routes, up to 90% of HIV-infected patients have evidence of previous or current HBV infection.

Most people who become infected with HBV are able to clear the virus without treatment, and they subsequently become immune to HBV. HIV infection appears to increase the risk of developing chronic HBV infection after HBV exposure. Patients coinfected with HBV and HIV also tend to have faster progression of liver disease, with associated morbidity and mortality.

**Diagnostic Evaluation**

- Assessing the severity of liver disease at the time of diagnosis and once every 6 months with alanine aminotransferase (ALT), albumin, bilirubin, prothrombin time, platelet count, and complete blood count.
- Consider checking the HBV DNA (viral load). DNA levels are usually high in persons with active HBV (in the absence of treatment) and can be used to confirm active disease (in those not taking effective treatment) and monitor the response to treatment (in patients taking HBV treatment). Note, however, that HBV DNA levels apparently do not predict the progression of liver disease.
- Check for HBeAg; this test indicates active infection and infectiousness, as does the HBV viral load.
- Persons with chronic HBV are at elevated risk for HCC. Consider screening for HCC every 6-12 months with the serum alpha-fetoprotein (AFP) level or imaging of the liver (ultrasound, computed tomography, or magnetic resonance imaging). Screening is especially important if the patient is in a high-risk group (eg, patients aged >45 years, those with cirrhosis, or those with a family history of HCC).
- Liver biopsy is the only definitive test to assess the grade (inflammation) and stage (degree of fibrosis) of liver disease. Many experts recommend liver biopsy to guide decisions about therapy, whereas others start therapy based on ALT and HBV DNA, without liver biopsy.

**Treatment**

The optimal treatment strategies for patients with HIV and HBV co infection have not been defined and individual patient characteristics should be used to guide therapy. The patient's need for HIV treatment (ART) should be considered carefully because it will influence the selection of HBV therapy. When ART is indicated, agents that have activity against both
HIV and HBV (eg, lamivudine, emtricitabine, tenofovir) can be considered for inclusion in the ART regimen.

Patients who need HBV treatment but are not candidates for HIV treatment can be given agents that do not have activity against HIV at standard doses (eg, interferon, adefovir, entecavir). Though some experts treat all patients with proven chronic HBV, whereas others consider treatment for patients with both of the following:

Positive HBeAg or HBV DNA >10,000 copies/mL
ALT >2 times the upper limit of normal, or inflammation or fibrosis on liver biopsy

Following table describes the possible treatments for HBV: -

<table>
<thead>
<tr>
<th>Medication</th>
<th>Treatment Regimen</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interferon-alfa 2a or 2b</td>
<td>5 million units (MU) daily or 10 MU 3 times weekly for 4-6 months*</td>
<td>▪ Interferon is contraindicated in patients with decompensate cirrhosis.</td>
</tr>
<tr>
<td>Pegylated interferon-alfa 2a (Pegasys)</td>
<td>180 micrograms per week for 4-6 months*</td>
<td>▪ Expect the CD4 count to drop by 100-150 cells/µL or more during treatment with interferon or pegylated interferon. (The CD4 percentage usually remains stable.)</td>
</tr>
<tr>
<td>Lamivudine (Epivir, 3TC)#</td>
<td>150 mg twice daily or 300 mg daily (dosage as part of ART regimen) for 1 year or more*</td>
<td>▪ Use only as part of an effective HIV ART regimen.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ High rate of HBV resistance occurs after 1-2 years of treatment. Lamivudine-resistant HBV is also resistant to emtricitabine.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Most specialists recommend combination with a second agent (eg, tenofovir or emtricitabine).</td>
</tr>
<tr>
<td>Tenofovir (Viread)#</td>
<td>300 mg daily; treatment duration unknown*</td>
<td>▪ Use only as part of an effective HIV ART regimen.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Active against lamivudine-resistant strains of HBV.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Most specialists recommend combination with a second agent (eg, lamivudine or emtricitabine).</td>
</tr>
<tr>
<td>Emtricitabine (Emtriva)#</td>
<td>200 mg daily; treatment duration unknown*</td>
<td>▪ Use only as part of an effective HIV ART regimen.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Emtricitabine-resistant HBV also is resistant to lamivudine.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Most specialists recommend combination with a second agent (eg, tenofovir or</td>
</tr>
<tr>
<td>Drug</td>
<td>Dose</td>
<td>Duration</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Adefovir (Hepsera)</td>
<td>10 mg daily</td>
<td>treatment duration unknown*</td>
</tr>
<tr>
<td>Entecavir (Baraclude)</td>
<td>0.5-1.0 mg daily</td>
<td>treatment duration unknown*</td>
</tr>
<tr>
<td>Emtricitabine (Emtriva)#</td>
<td>200 mg daily</td>
<td>treatment duration unknown*</td>
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<tr>
<td>Adefovir (Hepsera)</td>
<td>10 mg daily</td>
<td>treatment duration unknown*</td>
</tr>
<tr>
<td>Entecavir (Baraclude)</td>
<td>0.5-1.0 mg daily</td>
<td>treatment duration unknown*</td>
</tr>
</tbody>
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# agents are active against HIV and HBV

**Patient Education**

- Most patients with HBV will remain asymptomatic for several years. However, ongoing injury to the liver occurs during this time, and can culminate in liver failure. Patients can slow the damage by avoiding alcohol and any medications (including over-the-counter drugs and recreational drugs) that may damage the liver. Instruct patients to call their pharmacist or health care provider if they have questions about a specific medication or supplement.

- As with HIV, patients must avoid passing HBV to others. Instruct patients not to share toothbrushes, dental appliances, razors, sex toys, tattoo equipment, injection equipment, or personal care items that may have blood on them. Emphasize the importance of safer sex to protect themselves and their partner(s).

- Tell patients to discuss HBV with their sex partner(s), and suggest that partner(s) get tested for HBV.

- Certain antiretroviral drugs are more likely to cause problems with the liver because of HBV. Advise patients that if they start an ART regimen, their liver function tests should be watched carefully to determine whether the body is able to process the medicines.
- Patients, who have not been vaccinated against HAV, will need to receive 2 vaccinations 6 months apart. HAV can cause severe illness, liver damage, or even death, in people with HBV.
- Patients who have not been tested for HCV should be tested for this virus
- HCV can worsen liver function greatly if it is acquired in addition to HBV. Patients with HCV should use safe sex practices (latex barriers) to avoid exposure. Patients who use injection drugs should not share needles or injection equipment
- If children were born after women were infected with HBV, consider having them tested. Even though their risk is low, they should be screened for HBV
- HBV treatments may cause adverse effects. Most of these are treatable with medications. Patients should contact their health care provider know right away if they experience adverse effects or new symptoms

Finally, Dr. Ahmed has come to the end of his presentation by making some recommendations for the PLHAs, i.e., they have to choose their own doctor or government of Assam must decide on their behalf and second, Hep B vaccination need to provided by government at free of cost.
Group discussions to identify issues

All the members were asked to form five groups according they were given a topic in order to identify all relevant issues in regards to ARV treatment access in Assam.

<table>
<thead>
<tr>
<th>Group</th>
<th>Group Leader</th>
<th>Topic</th>
<th>Issues Identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Herojit</td>
<td>ART</td>
<td></td>
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<tr>
<td>02</td>
<td>Sabir</td>
<td>O I Medicine</td>
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<td>03</td>
<td>Prashanta</td>
<td>Testing facility</td>
<td></td>
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<tr>
<td>04</td>
<td>Usha Dey</td>
<td>VCTC &amp; PPTCT</td>
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<tr>
<td>05</td>
<td>Narzary</td>
<td>Stigma &amp; Discrimination</td>
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The groups after carefully discussing all possible issues related to ARV treatment access jotted down the list as stated below:

**Issues identified for ART by Group 1**
- Inaccessibility of ART centres (in all district)
- Nutritional needs not been provided to parents (spl to children)
- At present there is no proper waiting room available for ART seekers
- No spacious room for ART
- Insufficient awareness program for enrolling PLHA in ART centres
- There is no uniformity of ART medicines (as provided by doctors)
- Vitamins not provided along with medicine
- No TA/DA available for ART seekers except Golaghat district
- PLHA’s not been involved to supervise ART services
- Second line regimen not yet introduced
- No ART specific IEC materials developed
- Though parliamentary forum was formed on 19 Nov’05 but nothing much has been done in concrete for HIV/AIDS
- At present there is no separate ART centre for children
- No child specialist readily available in ART centre
- No treatment facility available for Hepatitis C/B/A

**Issues identified for O.I. by Group 2**
- OI medicine not readily available in govt hospitals & doctors ask to purchase the same from outside
- Vitamin not available in civil hospitals
- Local doctors to be trained for OI treatment
- Confidentiality not maintained
- Most of the doctors are not available during office hours

**Issues identified for Testing facilities by Group 3**
- No testing facilities available in all district hospitals though VCTCs are operating/functioning
- No free testing (Hep B & C, LFT) available in govt hospitals
- No trained doctors, nursing support, counselors (must possess technical knowledge of counseling), health care workers available in govt hospitals
- No availability of HIV kits (CD4) in all hospitals
**Issues identified for VCTC & PPTCT by Group 4**

- No qualified/well trained Counselors & Technicians appointed (should know local language)
- Improper counseling
- So far no PLHA’s appointed as peer educator in all VCTC centres
- No PLHA’s involved in all HIV trainings
- Most of the Counselors not available during office hours (10 AM to 4 PM)
- No female & male counselors appointed in VCTCs
- Unsafe counseling environment (spacious room, comfortable furniture, etc)
- PPTCT & VCTC centres have to remain open from 10 AM to 5 PM
- Some IEC materials are giving wrong impression – leading to discrimination
- No proper post test counseling provided
- No telephonic counseling available except few districts
- Most of the doctors of (in Silchar) medical colleges/govt hospitals refused to treat HIV (+ve) people once knowing their status
- NGOs implementing ASACS’s programmes not providing information and leading to further exploitation of PLHA’s
- Frequent change in component’s name is leading to confusion (e.g. VCTC is now known as ICTC)

**Issues identified for Stigma & Discrimination by Group 5**

- Limited positive speakers on HIV/AIDS leading to further stigma/discrimination
- Though sensitization programmes are going on but only in name but not in deeds
- No employment policy for PLHA so far
- Misusing the meaning of GIPA
- PLHA’s to be appointed as Peer Counselors in all VCTC
- Enrollment of PLHA in any institution without discrimination
**Sharing of experiences by PLHAs**

One of the PLHA has shared that she was not allowed to use the lavatory in the Guwahati Medical College and Hospital by one of the doctor’s working there as because the former’s status was HIV positive. This made her very upset and disappointing but she was totally helpless.

Another PLHA (from Silchar) mentioned that she was not provided with any information or services from the doctor present in the VCTC rather he latter has asked her to avail the services including the medicines from outside (private clinic/pharmacy).

These incidents are happening very now and then and are quite common. Almost all PLHA’s in Assam has encountered with these kinds of experiences from government people (in particular) and other organizations etc and are being exploited in one or another form.

Considering these types of issues and taking into account other relevant things Assam Network of Positive People has taken an initiative for forming committee (named SHACC) in order to ensure effective implementation of all the PLHA related activities in the state of Assam and this will be only possible when Indian Network for People Living with HIV/AIDS (INP+) extend its cooperation and support.
Key Recommendations

After threadbare discussions as well as the presentations on all the identified issues, the members of each group tried to find out the best possible solutions and accordingly prepared the final draft recommendations after receiving the verbal consensus of the panel which consists of Commissioner and Secretary (Health, Govt of Assam) and Project Director, ASACS, as well as all the other participants including the PLHAs, NGOs and the media agencies. The recommendations are as stated below:

Recommendations on ART

1. Awareness programmes for enrolling PLHAs in ART centers using ART specific IEC materials & emphasizing strong linkages with VCTC Centres
2. Ensure Accessibility of ART centres in all district with standardized treatment in a user friendly comfortable environment by ART trained medical specialist both for adults & children.
3. Ensure nutritional support & second line regimen need to be introduced

Recommendations for O.I.

1. O.I medicine to be made readily available in all govt hospitals
2. Vitamins also need to be available in all civil hospitals
3. Capacity building training for local doctors for O.I. treatment
4. Confidentiality should be given top priority
5. Concern authority must make sure that doctors should available at least during office timing
6. O.I. medicines for children must be available
7. Treatment facilities for Hepatitis C/B/A need to be available
8. Establish linkage with RNTCP
9. Ensure availability of MDR TB regime

Recommendation for Testing Facility

1. Testing facilities to be introduced in all VCTCs
2. Free testing for Hepatitis B & C as well as LFT must be available in govt hospitals
3. Well-trained doctors, proper nursing support, counselors with technical knowledge of counseling and health care workers should be available in govt hospitals
4. Availability of HIV kits in all hospitals

Recommendation for VCTC & PPTCT

1. Well-trained qualified counselors (with knowledge of local language) and technicians must be appointed
2. Rendering proper counseling services
3. PLHA’s should be appointed as peer educators in all VCTC centres
4. PLHA’s to be involved in all HIV/AIDS related trainings
5. Counselors must be available during office hours (10 AM to 4 PM)
6. Both male/female counselors to be appointed in VCTCs
7. Safe counseling environment with spacious room, comfortable furniture, etc
8. PPTCT & VCTC centres have to remain open from 10 AM to 5 PM
9. Proper IEC materials to be developed (specifically for VCTC)
10. Post test counseling must be given emphasize
11. Telephonic counseling to be introduce in all districts
12. NGOs implementing ASACS’s programmes need to provide all kinds of information (related to HIV/AIDS) to PLHA without any exploitation
13. Frequent change in component’s name is leading to confusion (e.g. VCTC is now known as ICTC)

**Recommendation for Stigma & Discrimination**

1. Introducing a legal policy for safeguarding the rights of PLHA and against discrimination
Panel discussion on key recommendations

During the panel discussion the Sri B.S. Bhaskar, Commissioner & Secy. Health as well as Shyamal Rao, Project Director, ASACS, graced the meeting with their presence and discussed all the recommendations in regards to treatment access and education in the state of Assam. Finally, the former has agreed to all the recommendations as stated above except one i.e., introducing a legal policy for safeguarding the rights of PLHA and against discrimination for which the Commissioner (Health) has mentioned of placing the same to the Hon’ble Health Minister, Govt of Assam for his kind perusal.

Sri Bhaskar, during his sharing of thoughts with the PLHAs that the Government of Assam has decided to provide the following facilities to the Assam Network of Positive People for effectively carrying out their activities among PLHAs:

1. A vehicle to ANP+ will be provided
2. Free transportation will be given to all PLHAs for their treatment
3. Bank finance will be provided to PLHAs who had lost their employment

Besides, Sri Bhaskar has also promised of looking into the matter of non-functioning of the ART centres, transportation facilities for PLHAs in all the districts, supply of ART and OI medicines to all district level hospitals. He also emphasizes on telephonic counseling services and its availability at all VCTCs. Apart from these, he has mentioned that the department of Health and Family Welfare, Govt of Assam, will also organize a counseling and leadership building training for the PLHAs and ANP+ will be financed for coordinating the same.

Project Director, ASACS, said that the problems and issues raised by the PLHAs are very much genuine and ASACS will look into the matter very soon. Sri Rao also mentioned that people like PLHAs can provide ASACS about the ground realities which they as government representatives some time unaware of. He also promised of looking into the matter for the availability of viral load testing facilities.

The panel also agreed to form a State HIV/AIDS Coordination Committee (SHACC) during the consultation meeting which will be Chaired by Minister of Health, Assam and Commissioner Health will be its Vice-Chairperson and Jahnabi Goswami will be the convenor of the committee.

This committee will be coordinating throughout the state in order to ensure the effective implementation of all HIV/AIDS programmes concerning the People Living with HIV and AIDS of Assam.
The committee structure of SHACC:

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Designation</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Health Minister, Assam</td>
<td>Chairman</td>
<td>Ministry of Health &amp; FW</td>
</tr>
<tr>
<td>2</td>
<td>Commissioner Health</td>
<td>Vice-Chairman</td>
<td>Deptt. of Health</td>
</tr>
<tr>
<td>3</td>
<td>Project Director</td>
<td>Co-Vice Chairman</td>
<td>ASACS</td>
</tr>
<tr>
<td>4</td>
<td>Jahnabi Goswami</td>
<td>Convenor</td>
<td>ANP+</td>
</tr>
<tr>
<td>5</td>
<td>M S Janti Patgiri</td>
<td>Member</td>
<td>DLN, Morigaon</td>
</tr>
<tr>
<td>6</td>
<td>Sabir Rehman</td>
<td>Member</td>
<td>DLN, Nagaon</td>
</tr>
<tr>
<td>7</td>
<td>Nabanita Chetia</td>
<td>Member</td>
<td>DLN, Golaghat</td>
</tr>
<tr>
<td>8</td>
<td>Soteshini Devi</td>
<td>Member</td>
<td>DLN, Cachar</td>
</tr>
<tr>
<td>9</td>
<td>Saya Das</td>
<td>Member</td>
<td>DLN, Barpeta</td>
</tr>
<tr>
<td>10</td>
<td>Prashanta Kalita</td>
<td>Member</td>
<td>DLN, Kamrup</td>
</tr>
<tr>
<td>11</td>
<td>Sibu Dey</td>
<td>Member</td>
<td>DLN, Dibrugarh</td>
</tr>
<tr>
<td>12</td>
<td>Dr. S I Ahmed</td>
<td>Member</td>
<td>APS</td>
</tr>
<tr>
<td>13</td>
<td>Digambar Narzary</td>
<td>Member</td>
<td>Nedan Foundation</td>
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**Conclusion**

Antiretroviral treatment for those infected with HIV can prolong life and can reduce transmission of HIV from parents to child transmission when antiretroviral drugs are used during pregnancy and delivery. However, access to ARVs is extremely limited in Assam due to one or another reason.

Though Assam State AIDS Control Society has made strategic planning towards warding off the epidemic and the challenges of making ART available for the PLHAs (of Assam) to those resource limited settings are gradually improving but there still exist a daunting challenge – as out of 27 districts of Assam only Guwahati and Silchar (new) Medical Colleges are having one ART centres each.

Besides, the WHO and its partners launched “Treat 3 million by 2005” in short 3 by 5 initiative and the goal is to prolong the survival and restore the quality of life of individuals with HIV/AIDS by providing universal access to ART to those who need it as human right. At present, it is estimated (by ASACS) that there is more than 23000 people living with HIV and AIDS but as per the monthly report of Aug’06 (available from ART centre, GMCH) only 173 PLHAs have been enrolled so far.

Thus, effectively halting the HIV/AIDS epidemic requires altering individual, group and social behaviours. Finding ways to enable families and communities to cope with the devastating local impact of the disease requires time and intensive efforts to engage individuals’ ad communities in the response. And lastly, emphasizing more on community – based programmes as it has always found to be effective in enhancing prevention, care, support and treatment for those infected and affected by HIV/AIDS

Living apart all these, Assam Network of Positive People (ANP+) has a firm believe that this consultation meeting on treatment education and access was very fruitful and effective and has educated the People Living with HIV/AIDS in Assam not just on the services available for them like ART, O.I., testing facilities, VCTC, PPTCT as well as stigma and discrimination but also has empowered them as a whole.
Photo Gallery

Presentation on HIV/HCV/HBV and OI

Participants of Assam State Consultation Meeting
Presentation on Care & Support and Linkage to HIV/AIDS

Commissioner & Secy, Dept. of Health, Govt of Assam and PD, ASACS
Presentation on TB and linkage to HIV/AIDS

Group picture with Commissioner & Secy, Health and PD, ASACS
Facilitating Team (first from right: Abhijit Medhi)