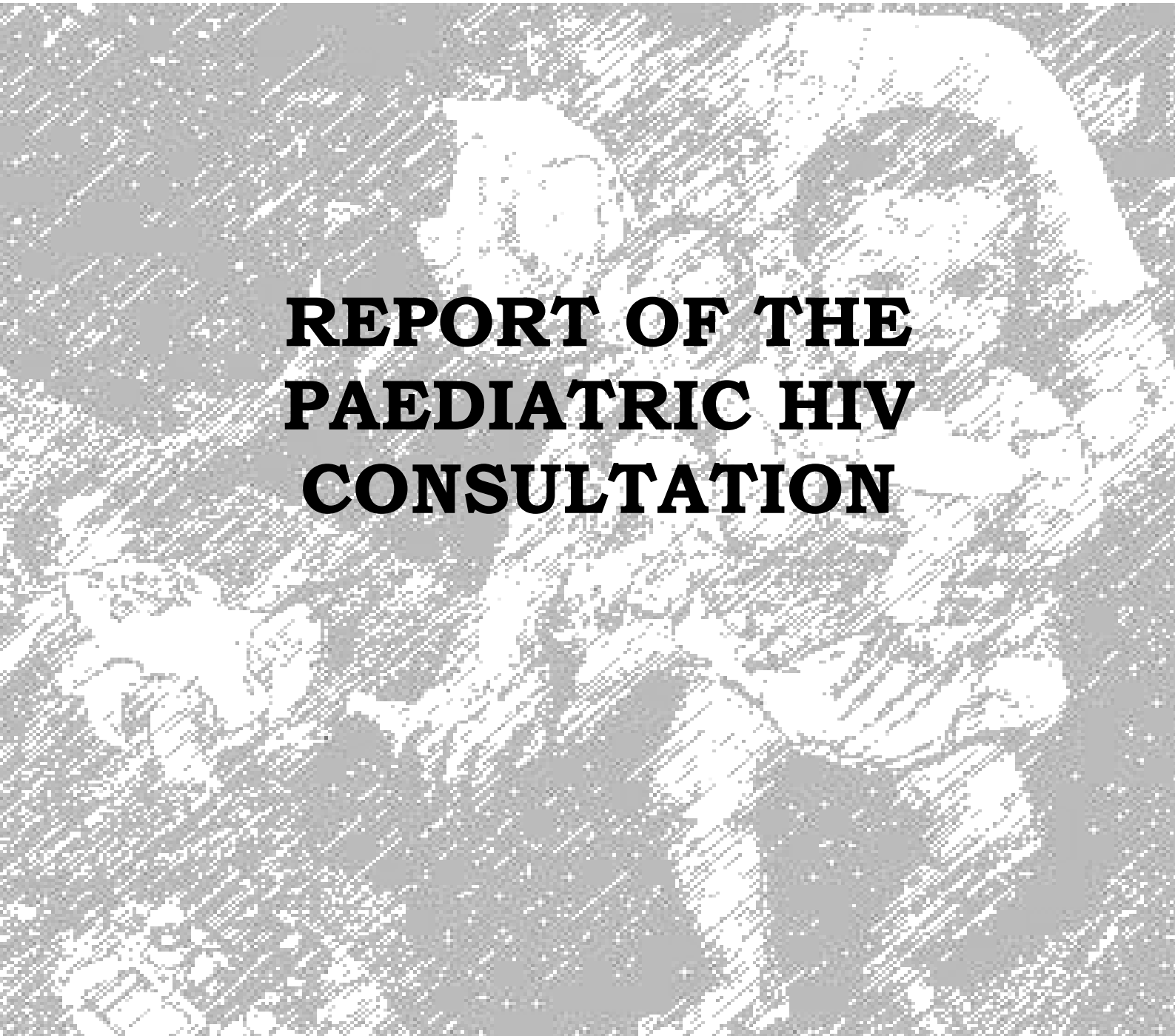


**Consultation on Accelerating Support for Paediatric HIV
Care, Support and Treatment in Thailand and Neighbouring
Countries within the Context of the 3 x 5 Initiative**



**REPORT OF THE
PAEDIATRIC HIV
CONSULTATION**

**Organized by HIV/AIDS Section
UNICEF East Asia & Pacific Regional Office
Bangkok, Thailand, 20th October 2004**

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INTRODUCTION

On October 20, 2004, 29 representatives from three countries and more than a dozen international and supranational organizations and hospitals attended the Consultation on Accelerating Support for Paediatric HIV Care, Support and Treatment in Thailand and Neighboring Countries within the Context of the 3 x 5 Initiative. (For details see the participants list in Annex C)

This important one-day meeting was convened in Bangkok by UNICEF and involved paediatricians along with other doctors, researchers and administrative officials from various countries and organizations.

The meeting was intended to update those working on issues concerning Pediatric HIV/AIDS in the region on progress being made by their colleagues. It also aimed to strengthen communication and cooperation among those working on PMTCT and pediatric HIV/AIDS-related issues in the region through sharing country experiences and technical updates from global experts. Reporting on progress toward reaching the 3 x 5 goals, including increasing access to pediatric antiretroviral treatment, was also a cornerstone of the meeting's agenda.

Also highlighted were:

- Needs and support for paediatricians and other caregivers
- Integrating paediatric HIV/AIDS issues with the larger goals of protecting and improving children's health
- Advocacy required for attention to be paid to pediatric formulations
- Addressing psychosocial problems and needs of children living with HIV/AIDS

SUMMARY OF CHALLENGES, LESSONS LEARNED AND RECOMMENDATIONS ON PAEDIATRIC HIV

Arjan de Wagt, UNICEF EAPRO

HIV disease progresses among young children is more rapidly than in adults and so survival time for children is shorter. But there is also good news as the impact of PMTCT is started being seen, for instance one physician from Thailand said that in the past much fewer cases.

The consultation shared many lessons learned so far on the care, support and treatment for children infected with HIV. Below you can find a summary of the main issues and suggested improvements as presented and discussed during the consultation.

Diagnosis

- Diagnosis before 18 months is difficult without viral load testing capacity available.
- CD4 and VL testing expensive, often not available, decision on when to treat therefore difficult
- Counseling of families on having an HIV infected child is complex

Stigma and discrimination

- Even in Thailand with a well developed HIV/AIDS response there are still deep-seated problems with discrimination and stigma and these can extend to health care workers as well as the general public.
- Because of stigma and discrimination children living with HIV suffer from many psychosocial problems. The four main causes of those problems are misconceptions about HIV/AIDS, lack of knowledge and skill among caregivers, lack of adult care and economic problems. Those conditions can lead to no access to treatment, psychological distress and hopelessness, and not achieving adherence to medication

Psychological and social issues of children

- Psychological and social issues HIV infected children have to deal with receive too little attention in most pediatric HIV programs.
- Sleep problems among HIV infected children are significant. They can cause cognitive impairment in school. The younger and more inarticulate they are, they can't express their problems. When you put that together with HIV and language delay then the problem is much greater.
- Psychological pathology in kids is more severe than in adults and often goes undiagnosed or misdiagnosed. It is hard to determine how much is related to the disease and how much to situational factors.
- Children's problems include illness even after starting ART; physical and psychological trauma from neighborhood discrimination; adherence to ARV; disclosure -- children don't know why they need to take ARVs.
- Telling a child he or she has HIV is very challenging. Guidelines need to be developed to help parents and care givers with deciding when and how to tell the child about HIV and being HIV positive.

Psychological and social issues of older children

- Adolescents need to have better access (incl. legal) to services like testing and treatment
- Because of stigma and discrimination access to schooling for HIV infected children is a major concern.
- An increasing number of HIV infected children are growing up and will become sexual interested and active. They will need guidance and support on sexual and reproductive health, disclosure of HIV and protection of their own health and that of their partner.
- “Our oldest child is 14, and we’re trying to prepare him for the outside world. It will be difficult.”

Psychological and social issues of women

- “People living with HIV should have unrestricted access to solutions that are available and be able to make the choices that are most appropriate to them and not have a choice imposed by doctors and other caregivers. That ability to make a decision is one of the most empowering things that can happen, and gives quality of life to people with HIV. Making decisions helps them regain self esteem and dignity.”
- “Also for the HIV infected woman support needs to go beyond care for illness and symptoms, to looking at identity both as a social and psychological need as mother and wives. Women particularly are stigmatized as being bad women who deserved the disease.”
- HIV affected families have socioeconomic problems and need to take care of children and care givers and this is inadequately included in the services presently provided.

Pediatric ART

- Some of the challenges with pediatric ART include:
 - Uncertain dosing, limited pharma kinetic data available
 - Formulations including simplified dosing schedules are poorly available and expensive and this is in particular the case with second line treatment
 - Palatability of drugs (including bad taste)
 - Prior exposure to NVP and potential resistance: surveillance and management need to be established

Drug supply management

- The difficulties in meeting the needs and demands for drugs are mainly a matter of logistics and is often due to poor supply planning and management
- In principle to supply ARVs is no different than supplying paracetamol. Good to reflect on past performance with other pharmaceuticals.
- Ensuring access to ARVs is one whole big circular chain and it’s as strong as the weakest link.

Management of HIV in children

- High levels of malnutrition is seen among infected children, management is complex and clear guidelines are not available.
- Clear guidelines on micronutrient supplementation among HIV infected children are needed

- Pediatric care and treatment needs to be part of a more holistic family response
- Psychosocial impact and support to families and children is too limited
- Follow-up in PMTCT programs simply isn't happening in many places. Despite clear evidence that children should be put on prophylaxis, they aren't. Programs also must provide entry points for care for the mother.

Prevention

- It is important to ensure that resources for treatment are not being taken from prevention activities
- Better guidance is needed on how to use 3by5 as an opportunity of primary prevention
- PMTCT follow up needs to be improved to ensure a continuum of care including PCP prophylaxis

Program management

- Better guidance is needed on how to accelerate PMTCT as part of 3by5.
- We need to be very efficient with very good PMTCT services first. The problem of HIV infection among young children will decrease with good PMTCT. There is a need for innovative approaches and more efficacious PMTCT services.
- The programming indicators, benchmarks and targets are not there, we don't know how interventions are performing. The dearth of information is quite frightening.

Staffing issues

- Need to strength knowledge and skills on HIV care/treatment among health care workers
- Attitudes / discrimination by health workers are still a major challenge. Many health care workers still fear getting HIV from kids. Some also don't believe these children can get much better, so it's for them hard to be motivated.
- Lack of adequately trained physicians and counselors - both quality and quantity. There are huge needs for training health care workers at various levels of the health care system on pediatric HIV and this does receive inadequate attention in treatment programs.
- What additional support (technical, psycho-social etc.) do health care workers dealing with paediatric HIV cases need, e.g. how to prevent burn out?

OPENING REMARKS

“The issues of children and health go beyond HIV/AIDS to children’s health in general.” – Dr. Stephen Atwood

The meeting opened with remarks by Dr. Stephen Atwood, UNICEF Regional Advisor on Health and Nutrition. In laying out the meeting’s objectives and expected outcomes, Dr. Atwood, who would also serve as moderator throughout the day, noted that the gathering was a meeting of paediatricians and those who are providing care and support for children and families dealing with HIV/AIDS.

Other points made by Dr. Atwood during his opening remarks included:

- The number of pediatric HIV deaths is underestimated especially children under the age of 15 months. This is a reporting challenge.
- There is a lack of simple and cheap screening methodologies.
- There is a need for pediatric formulations; children can’t swallow pills.
- Closer follow-up is needed to monitor drug toxicities.
- HIV infection is a chronic illness.

PRESENTATIONS

1. Approaching Paediatric Care, Support and Treatment; Presented by Dr. Usa Thisyakorn, President – Paediatric Society of Thailand and Deputy Director, Thai Red Cross AIDS Research Centre.

Dr. Usa noted that the one-day meeting was especially important because it was part of the agenda for several organizations such as UNICEF, WHO, UN and the Thai Red Cross Society and Paediatric Society of Thailand. She detailed the history of HIV/AIDS in Thailand and the country's early response to the disease and its early concern for how children would be affected by the epidemic, and spoke about problems she and her colleagues have encountered in combating the spread of the disease.

Other points made by Dr. Usa in her presentation were:

- Doctors have been working on PMTCT in Thailand since 1995. The country now has several programs to prevent mother-to-child transmission
- Since 1984, when AIDS first appeared in Thailand, doctors began considering what to do for children. The next consideration was how to gear more programs toward teenagers.
- The spread of HIV/AIDS has left Thailand with an increasing number of orphans.
- The country has introduced PMTCT-plus.
- An important element of Thai programs is to help parents stay alive longer and care for their children, so there will be fewer orphans.

2. 3 x 5; National Responses presented by Dr. Ying Ru-Lo, WHO SEARO, and Siobhan Crowley, WHO Geneva

In a dual presentation, Dr. Siobhan Crowley and Dr. Ying Ru-Lo reviewed progress toward achieving the 3 x 5 goals and obstacles that still remain. 3 X 5 means 3 million people on treatment by 2005 with the ultimate goal being universal access to treatment as a universal right. Nonetheless, even the more modest target of 3 million people on treatment doesn't appear to be obtainable by the deadline considering the levels of support currently being provided by most countries.

Among the important points made by Dr. Crowley were:

- The goal is universal access to treatment as a universal right. The way to achieve that is to scale up national programs for treatment, but also improving prevention. Treatment provides us with a huge opportunity to improve prevention.
- Two key things are to simplify and standardize the tools that are there instead of asking what each country needs and specializing it for them. We need to be supporting countries to meet their goals. Helping them to fill the gaps and do whatever is required.

- A major obstacle in many countries is that the drugs aren't there even if people on the ground are ready to use them.
- Moving to document cases where scaling up of treatment has occurred.
- Moved to a full-stage system which broadly harmonizes with the CDC. Early suggestions are that it stands up.
- Real lack of access to any formulations. Thailand is ahead of the field. Illustrated here is scored pill. With a scored pediatric tablet you're more likely to get the right dosages. With syrups the volume needed is huge.
- Trying to support countries that have been trying to scale up and build capacity.
- The programming indicators are not there, we don't know how they are performing. The dearth of information is quite frightening.
- We must make sure on the ground that national coordination is much better to make a difference.

Points made by Dr. Ying Ru-Lo included:

- The number of children on treatment is not yet known, data has not been validated in Thailand. In Myanmar there is only one site providing ARV therapy. It's run by the FHM, the Fund for HIV/AIDS in Myanmar. Less than 50 children infected are coming to hospital and less than 10 are on ARV. India just started. In Indonesia, no children are on ARV therapy.
- Regional, guidelines are being revised and will have a section on paediatric care and support of HIV/AIDS.
- Lack of trained physicians remains a problem. Even in Thailand there are considerable gaps. Access to schooling for HIV infected children is a major issue even here in Thailand.

3. Paediatric Care and ART for Children with HIV - Dr. Sam Sophan, National Paediatric Hospital, Phnom Penh, Cambodia

Dr. Sam Sophan is the director of Cambodia's National Paediatric Hospital, a modest institution making important contributions in the fight against HIV/AIDS in one of the world's poorest countries. Originally built in 1975, the hospital was open for just two months before the radical Marxist Khmer Rouge took control of the country. The Khmer Rouge shut down the hospital. It reopened after the country was liberated in 1980 and had 75 beds. Today it has 114 and treats between 7,000 and 10,000 patients a year.

Other points made by Dr. Sam were:

- Since 2002 every infected child at the hospital has received VCT service.
- More infections are being reported now because more people understand through education, television and newspapers not to keep quiet about the disease.

- The guidelines from the hospital became the guidelines for the whole country after consultation with partners and NGOs.
- There are two flows for anti-HIV testing and treatment. Less than, and older than 18 months.
- Cd4 testing is so complicated for hospitals in Cambodia because of lack of resources and sophistication of the labs. Some samples are sent to Thailand.
- The hospital set up a malnutrition subunit because treatment can't support malnutrition. The hospital also supports an IMCI program.

Panel discussion / Q&A with previous speakers

During the question and answer session, it was posited that despite the general belief that treatment works to support prevention, there is scant or no evidence to back that up. Dr. Crowley responded that by normalizing HIV management through health services, prevention will be improved, and that the divide between treatment and prevention is an artificial one. Dr. Ying Ru-Lo commented that it is important to ensure that money allocated for treatment isn't being taken away from prevention. One participant asked how can PMTCT and treatment for children work together. Dr. Crowley observed that the problem in this area was that follow-up in PMTCT programs simply isn't happening in many places. Despite clear evidence that children should be put on prophylaxis, they aren't. Programs also must provide entry points for care for the mother. The fact that they haven't been, is resulting in more orphans.

Questions were also raised about when VCT should take place and the role of social and cultural considerations in programming and counseling. Dr. Crowley said that UNICEF is trying to be consistent about how and when VCT being offered. It can be done in different ways in different models in different places but all women should have the offer of knowing their status and receive counseling. That helps prevent infections being passed to children, and the most important thing is to prevent as many infections as possible. Sr. Sam noted that in Cambodian provinces where male partners participate in testing and counseling, the transmission rates are lower. A speaker asked if any countries were providing post-exposure prophylaxis to child sex abuse victims. Dr. Ying Ru-Lo said that that hasn't been specifically built in to any country's ARV guidelines yet, although South Africa has experience with this, and she hoped Asia would be moving towards guidelines for it next year.

4. Khon Kaen Integrated Response - Dr. Pope Kosalaraksa, Faculty of Medicine, Khon Kaen University

Srinagarind is a university hospital in the northeastern Thai province of Khon Kaen, and it also serves patients from neighboring Udon Thani and Nong Khai provinces. The hospital uses a holistic approach model and integrated response as part of a two-year program from UNICEF. It's a two-year program and its objectives are to improve care of HIV-infected children and families and to develop a holistic approach for the entire northeastern

area, the most populous region of Thailand. Another goal is to get adherence up to more than 95% among those taking ARV. Dr. Pope noted that there are still deep-seated problems with discrimination and stigma in northeastern Thailand and these can extend to health care workers as well as the general public.

Additional points made by Dr. Pope included:

- Groups on dual therapy showed a lot of resistance and had to move on to protease inhibitors.
- Experience shows that medical therapy in hospital is not enough to provide a happy life. Families still have socioeconomic problems and need to take care of children and care givers.
- When parents are ill, they suffer from fear and depression. Some kids have to take care of their own parents. Some children suffer from over-protection from the family and are not allowed to do anything.
- Children's problems include illness even after starting ART; physical and psychological trauma from neighborhood discrimination; adherence to ARV; disclosure -- children don't know why they need to take ARV; and prevention of sexually transmitted diseases.
- The hospital is still trying to set up a system to produce good workers. Attitude is most important. Some caregivers cause problems. The problems come from fear from not enough knowledge. No confidence to take care of the child. Teamwork is needed.
- Activities; strengthen health care team and network; find out baseline problems of each family; group support, art and play therapy; home visits; HIV camp for children and families.

5. Paediatric ART - Professor Tawee Chotpitayasunondh, Queen Sirikit National Institute of Child Health

The Queen Sirikit National Institute of Child Health is the only children's hospital in Thailand. It has 538 beds and treats 50,000 babies a year. The hospital started HIV activities in 1992. At that time the only drug available was AZT. The hospital has treated 220 patients infected with HIV, 96% of who are on ARV. Only 5% are on dual therapy, most are on triple therapy and a small portion are on protease inhibitors. Because each test costs about \$100, the hospital can't afford viral load assessments. Queen Sirikit National Institute of Child Health is engaged in long-term cooperation with the U.S. CDC and NIH. It has a research program on PMTCT and is working with Sriraj Hospital in Bangkok.

Other points made by Prof. Tawee included:

- Of those infected, 15% are more than 10 years old. Our oldest infected child is almost 16.
- Most PMTCT originates from the paediatricians. Without them it would be a big burden. Some paediatricians are trying to force obstetricians to do it instead.

- The number of patients has decreased because of the PMTCT program. In the past there were more than 300 or 400. Now there are fewer cases because of more protection, less opportunistic infections and more healthy children. People are happier.
- There are still problems. ARV formulations are a big burden. Some pills or capsules are a problem to divide or crush. The second problem is adherence, although it is improving. Patients are surviving longer, getting older. Disclosure is a big problem. They're in a program with the CDC to look at these adherence and disclosure problems.

Panel discussion / Q&A with previous speakers

With most deaths the result of inability to meet the high costs of treatment, participants wanted to know who is picking up the costs and how much is passed on to the patient. Dr. Pope responded that while the government pays for ARV, other costs such as transportation, food, visits and overnight stays for families so they can see doctors, falls on the patient. He said it was the hospital's duty to try and help with those expenses, but the problem is that it receives very few donations. If patients can't meet the costs of travel, etc., then adherence and follow up will be weak or nonexistent. The government also does not pay for protease inhibitors.

Participants also wanted advice on disclosure. What is the proper age? Dr. Kulkanya said that the general feeling was that 10 was the proper age. Most parents, relatives and care givers, however, tend to never think any time is the right time. Dr. Rangsimma said some hospitals are doing a good job on disclosure, including one in Petchburi province that is using a model established by Harvard Medical School. This year Siriraj and Queen Sirikit will assess a disclosure plan and develop guidelines. If they work, then it will scale up to a national model. Disclosure is a process not a one step thing, Dr. Rangsimma added. Concerns include, can the child keep a secret? There is a need to develop guidelines on what to do before disclosing to a child.

Other participants were curious about patients developing resistance to therapies. Dr. Rangsimma said that after 3 years 95% show resistance to dual therapy. They develop nucleotide mutations and can't recycle NRTI anymore. If a patients is on ARV more than six months, there is a high risk of mutation. For that reason, Dr. Pope says his hospital is not doing dual therapy anymore. Dr. Siobhan said that there is a need to see that children will be part of an international network tracking resistance, and they will be.

6. Whistle Home Power of Life Group – Ms. Junsuda Suwanjundee or Khun Oom

In a powerful presentation, Khun Junsudda Suwanjundee told participants the story of how as a drug user she contracted HIV, lost her job and family, but eventually found a positive path in life through founding Whistle Home, an organization dedicated to helping others with the disease. Khun Junsudda began using intravenous drugs as a teenager. She did not realize she was HIV positive until years later when she was tested as part of a job

application. When she revealed to her family she had the disease, they threw her out of the house and didn't want her to use the family name. She and a small group of women in similar circumstances started Whistle Home to help other women suffering from HIV/AIDS and the stigma that accompanies the disease. Through helping others, Khun Junsuda found new meaning in her own life. She has married, adopted one child and given birth to another who is now three years old and is expecting one more in January. So far, her three-year-old child has shown no sign of having contracted the disease.

Other points Khun Junsuda made in her presentation included:

- People living with HIV/AIDS lose their identities as human beings. They must regain self esteem and with this they can work and have the ability to manage their own lives.
- Sometimes when services have been provided they are services not needed or requested. Most important is to develop understanding among other people about people living with HIV/AIDS.
- Support needs to go beyond care for illness and symptoms, to looking at identity both as a social and psychological need as mother and wives. Women particularly are stigmatized as being bad women who deserved the disease.
- Many women find out they are positive when they are pregnant. They are rejected by their husbands and turned out of the home. The government had no services. They had nowhere to turn. They became unemployed. Families were resistant to take them in. As the babies were born, no care services or support were provided for children at that time. So they developed Whistle Home with women in similar circumstances.
- The organization has become interested in research. Mothers are the most highly regarded persons in the family. HIV positive mothers should be regarded in the same way. By participating in research Whistle Home can help improve the living circumstances of mothers and children with HIV.
- The conviction of the organization and its members is that living with HIV should be based on choices. People living with HIV should have unrestricted access to solutions that are available and be able to make the choices that are most appropriate to them and not have a choice imposed by doctors and other caregivers. That ability to make a decision is one of the most empowering things that can happen, and gives quality of life to people with HIV. Making decisions helps them regain self esteem and dignity.
- Family encompasses happiness and sorrow. It's about helping one another. Khun Junsuda was rejected by her family, but now they are much closer than before. By opening doors to helping other people they find more avenues to receive help as well.

7. What can MCTC-plus programs contribute to paediatric HIV care in developing countries? - Dr. Nittaya Phanupak, Thai Red Cross AIDS Research Centre

Dr. Nittaya told the meeting that as a model of care for HIV families, MTCT-plus initially started as women-centered and multidisciplinary care. In this model, hospitals set up a family clinic where doctors from different disciplines are available at the same clinic on the same day. It's a team. There are five MTCT-plus hospitals in Thailand: Chulalongkorn, Thammasat, Police General, Sriracha and Queen Sirikit. To broaden activities at the Red Cross they have two parallel programs. The first one is funded by Columbia University. The reason there are two is that Columbia would only allow the Red Cross to enroll currently pregnant women. That's not sufficient for the situation in Thailand, so they set up another program. It was delivered five or six years ago from the PMTCT program.

Other points in Dr. Nittaya's presentation were:

- Sriracha hospital has set up a real family clinic. Family doctors and paediatrics are in the same room. Paediatricians take care of the children and an internist takes care of the mother and father the same day. It's a success story.
- There are regular team meetings every week after the clinic hours. It's proven to be a very successful model for dealing with chronic long-term diseases. It has also been successfully used and repeated in other HIV programs in these hospitals. The guidelines are flexible and practical, adapted to the country although they were originally set up for use in African countries.

8. Guidelines for the management of HIV infection in children in resource-limited settings in Myanmar - Dr. Chris Duncombe, HIV-NAT

Treating and preventing the spread of HIV/AIDS is a particularly difficult challenge in countries such as Myanmar which suffer from limited resources. Myanmar is one of the world's poorest countries and was accorded Least Developed Country status by the United Nations in 1987. Of its 48.36 million people it is estimated that 1.2% has HIV/AIDS. Between 20% and 30% of female sex workers have the disease, while anywhere between 10% and 73% of injecting drugs users do. As Myanmar has limited infrastructure, numerous ethnic minorities and some areas are difficult to access, these figures are merely estimates and difficult to confirm.

Other points made by Dr. Duncombe were:

- Approximately 7,600 children up to the age of 13 are living with HIV/AIDS.
- An ART pilot program was launched in 2003.
- Only 100 adults are participating at this stage, and only 10 children.

- Myanmar is currently reviewing its locally-written guidelines on care and treatment and adapting regional guidelines.

9. From PMCT to PMCT+ Experience from the PHPT Network in Thailand - Dr. Gonzague Jourdain, Perinatal HIV Prevention Trial

In a technical presentation, Dr. Gonzague Jourdain outlined the history of the PHPT Network in Thailand and what the trial has discovered to date. The PHPT Network is a group of hospitals trying to identify problems with PMTCT and PMTCT-plus and find solutions. Forty public, provincial and community hospitals are taking part and a center for clinical research is located in Chiang Mai. The center is looking at protocol development, training, data management, monitoring, statistical analysis, and laboratory dedicated to HIV (virology + pharmacokinetics) As of September 2004 the program had 300 children on ARV treatment

Additional points and questions raised by Dr. Jourdain during his presentation included:

- Are we compromising the treatment of children because of PMTCT? If you use Nevirapine alone you have many children infected and resistant.
- We need to be very efficient with very good PMTCT services first. The problem will decrease with good PMTCT.
- There is a need for innovative approaches and more efficacious PMTCT
- Propose care programs for the family: need for coordination and collaboration between specialists and programs.
- Ensure reliable early diagnosis of HIV-infected children.
- There are huge needs for training (health care workers at various levels and PHA)

10. Psycho-social impact on children and how we respond with counseling and art therapy - Ms. Chutima Saisaengjan, AIDS Access Foundation

In her presentation, Ms. Chutima Saisaengjan of the AIDS Access Foundation, a non-governmental organization, talked about the formation of the We Understand Group, which consists of people who work with children infected by HIV/AIDS. Chutima explained that stigma and discrimination against those infected by HIV, even children, is still strong in many communities throughout Thailand. Consequently, children living with HIV suffer from many psychosocial problems. The four main causes of those problems are misconceptions about HIV/AIDS, lack of knowledge and skill among caregivers, lack of adult care and economic problems. Those conditions can lead to no access to treatment, psychological distress and hopelessness, and not achieving adherence to medication.

Other points made by Ms. Chutima included:

- Understanding the psychological world of the child is important.
- Art, play and peers are useful. They help alleviate psychosocial problems.
- Awareness of issues surrounding HIV/AIDS needs to be raised at all levels.
- Responses of the families and communities needs to be strengthened.

Panel discussion / Q&A with previous speakers

The panel discussion began with one participant asking about the cost-effectiveness of CD4 testing among children. Dr. Jourdain responded that because the number of children infected with HIV is still small that doctors should do the best they can for them despite the costs. If children were tested every three months it wouldn't be a major financial burden in Thailand. He added that because CD4 levels can drop very rapidly in children less than one year old, that children be tested before then.

Another participant asked how children are tolerating side effects like sleep disturbance and nightmares? Dr. Jintanat responded that children can tolerate side effects better than adults and that few showed problems sleeping. Some of the discussion also dealt with the question of micronutrients and whether or not they should be a standard part of the treatment regimen. Dr. Nittaya replied that most doctors in Thailand didn't think they were important. Dr. Jourdain added that while there is no evidence additional vitamins help, the feeling he got from many hospitals is that vitamins are needed. Arjan de Wagt of UNICEF EAPRO said that both too little and too much vitamins could cause problems. Because studies have been limited and there are many micronutrients that might help, figuring out how much to prescribe and which ones are very difficult.

Afternoon Sessions

11. Response to Paediatric HIV Care and Support in Thailand TUC [Thailand MOPH - U.S. CDC Collaboration] - Dr. Rangsim Lolekha, CDC Thailand

In her presentation Dr. Rangsim Lolekha gave an introduction to the Global AIDS Program initiated by the Thailand-United States Collaboration. GAP/Thailand provides funding and technical collaboration to pilot new approaches in prevention, care, and surveillance for HIV/AIDS, TB, STD; scale up successful pilot projects to the provincial level and nationally; and strengthen existing programs. It also works to develop province-based networks for prevention, care, training, and surveillance. An important part of the program is to expand care and treatment for women, partners and their children. A key part of this is to focus on adherence.

Other points made by Dr. Rangsimma included;

- The HIVQual-T program has shown very nice results. It's been expanded to 30 hospitals in Thailand this year.
- Right now it's only for adults, but we want to try to expand it to children.

12. Antiretroviral Therapy in Children - Dr. Kulkanya Chokephaibulkit, Siriraj Hospital

In a technical presentation, Dr. Kulkanya talked about research and findings on when to start ARV in children and what combinations of drugs should be used. She noted that the disease progresses more rapidly than in adults and so survival time for children is shorter. She added that she believed Thai guidelines about when to start and what to use should be revised. Some of the problems of ARV therapy for children include unpalatable drug formulation, limited PK data and clinical trials. Also, some children are very difficult medicine takers and so long-term adherence depends upon the caregiver. It's difficult for most families as ART may disrupt normal family life.

Dr. Rangsimma noted that problems still remain, and they include:

- Lack of knowledge
- Chaotic family settings
- Care-givers not available to feed/F/U.
- Side effects
- Poor formulation/bad taste/complexity/etc. of the drugs
- Difficult drug taker children

13. Paediatric projects at HIV-NAT and treatment of orphans with HIV at Baan Gerda - Dr. Jintanat Ananworanich, HIV-NAT

Dr. Jintanat Ananworanich told participants about a unique program in Lopburi, a central province of Thailand that strives to provide a caring family and community atmosphere for children living with HIV/AIDS. Called Baan Gerda, it is eight homes with seven to nine children each. The caregivers also have HIV. They come from Wat Prabat Namphu, a nearby Buddhist temple that has an AIDS hospice. Dr. Jintanat said there are many stories of children who come to Baan Gerda and with love and care they do very well. She said that among the caregivers, coping was quite good. Few used anti anxiety-medicines and none used alcohol. But they aren't well prepared, don't know what to say and are afraid they will harm the child's mental health if he asks what's wrong with him.

Dr. Jintanat also pointed out that:

- When we did pill counts we saw non-adherence more than through the questionnaire.

- It's hard to find these people who are dedicated and willing to stay and take care of these children. When someone dies, all 55 children go to temple for the cremation.
- Our oldest child is 14, and we're trying to prepare him for the outside world. It will be difficult.
- In the future we hope there won't be a need for this and children can live in their communities.

Panel discussion / Q&A with previous speakers

An important topic raised during the discussion was the problems health care professionals and workers have in accepting and working with children living with HIV. One participant asked why 20 years into the epidemic there is still reluctance to provide service, and are there any systematic or institutional attempts to respond to the reluctance. Is it getting worse, or better? Dr. Rangsimma responded that Thailand has had a program in place in which guidebooks and other tools have been provided to health care workers for treating children living with HIV, yet many physicians were still reluctant to treat them. Dr. Kulkanya added that commitment from a hospital's administration is important. Many physicians would like to take on treating children with HIV but it means a lot more work, and if they don't have nurses or health care workers to help then the entire burden is on them. Dr. Jintanat said that lack of knowledge is still a major reason. Many health care workers still fear getting HIV from kids. Some also don't believe these children can get much better, so it's for them hard to be motivated.

14. Access to paediatric formulations - Helene Moller, UNICEF Supply Division, Copenhagen

The difficulties in meeting the needs and demands for drugs are mainly a matter of logistics. It's also extremely difficult to deduce from the information she receives how much a particular drug a hospital will need, and so planning remains complicated. Nonetheless, she said that progress has been made as far as access to drugs, although there is still a long way to go.

Ms. Moller also noted that:

- There are 42 formulations in 75 doses and 30 to 40% can be used for children. That is good news, it means we have something at least.
- In principle to supply ARV is no different than supplying paracetamol. Good to reflect on past performance.
- We've learned that access is one whole big circular chain and it's as strong as the weakest link.

15. Gaps in responses in Thailand - Kathleen Casey, Family Health International

Thailand's response to the HIV/AIDS epidemic has been held up as a model for other developing nations to follow. While more than a million people have been infected with the virus that causes AIDS since it was first detected in

Thailand in 1984, that's an estimated 400,000 people less than projected thanks to prevention programs. Nonetheless, as the disease has progressed through different sectors of society – finally reaching women and children – new challenges have become apparent, and those working on HIV/AIDS issues are struggling to fill in the gaps where needs aren't being met. A big part of that are the psychological needs of the infected children. Often this is left to NGOs, but Ms. Casey and FHI believe health care workers need to become more involved in this, and that care has to be balanced between the physical and psychological.

Other points made by Ms. Casey included:

- It's important to examine what we're asking often untrained caregivers to manage.
- Psychological pathology in kids is more severe in kids than adults and often goes undiagnosed or misdiagnosed. It is hard to determine how much is related to the disease and how much to situational factors.
- Sleep problems are significant. They can cause cognitive impairment in school. Cognitive problems are a burden for caregivers. The younger and more inarticulate they are, they can't express their problems. When you put that together with HIV and language delay then the problem is much greater.
- There are often beliefs around medicating kids that lead to a lack of adherence. Parents say that when I see my kids having side effects or symptoms it reminds me I infected my child.

Panel discussion / Q&A with previous speakers

One participant said that the Thailand's Government Pharmaceutical Office can't produce Nevirapine because they can't get the ground materials to manufacture it. They asked if WHO or UNICEF can help supply them with the necessary chemicals to make it. Siobhan Crowley from WHO said that UNICEF will hold a meeting in December and will try to find things to change the landscape of formulations, making them easier to use and pushing for development of a couple of new products.

Another participant asked if anything could be learned from the experiences with stigma and discrimination suffered by children infected with other diseases or afflicted with handicaps and applied to children living with HIV. Kathleen Casey of FHI answered that there are linkages. She sees close parallels in the lack of disclosure by parents. It can be very disturbing for children when they don't know what's wrong. And they come up with their own explanations. And that changes balance of relationships within the family, she said, adding that children operate in a vacuum, and when they hear bits and pieces of information, then their understanding of what is happening becomes distorted and they end up being more disturbed.

GROUP WORK

Participants at the meeting formed two working groups to brainstorm on particular issues and come up with solutions. Each group appointed a facilitator and a rapporteur. The groups were tasked with identifying key concerns / issues / challenges coming from the presentations and discussions, and identifying key steps and actors for addressing the issues.

Group 1 looked at strategies for putting children on the care and treatment agenda; and strategies for fostering partnership and coordination among all involved in the issues of children and HIV/AIDS.

Entry points:

Professional organizations

They can lobby, communicate, and effectively advocate society

NGOs/other networks

Often offer communication strategy

Ensure that MOPH identifies paediatric indicators/targets

This has been done in India and Cambodia.

Political parties. Should these issues be part of a political party's platform?

What can be done to raise these issues as part of national elections in

Thailand next year? What would be the platform's message?

Partnerships

What/who already advocates for paediatrics? Treat Asia, MSF? Need to gather info on what organizations are active in this area.

Need for cross border TA/exchange

Lessons learned/study tours/some cultural similarities between countries in the region

When we think about partnerships it can go beyond HIV-infected children to HIV-affected children and women. Identify other departments and stakeholders aside from MOPH that can help those affected by HIV.

Laboratories as centers of excellence

Collaboration

Is it possible to stockpile of drugs in a central location so they are available quickly when there are shortages in the region?

Group 2 looked at strategies for ensuring program intelligence; and strategies for accelerating country level support.

There needs to be rationalization of program indicators. (We have different organizations funding different programs and parts of programs. Service delivery has not been the focus, reporting has, and that has led to evaluation fatigue)

- Interagency – donor
- Meeting on development of core data sets
- Interagency – government meetings on data collection needs
- Projections on burden of paediatric care
- rapid appraisals of entry points for services
- entry points for paediatric services
- unified resistance monitoring
- core program indicators needed
- development of core national survey data
 - -women testing positive
 - -orphan burden
 - -orphan burden from HIV/AIDS
 - -children with HIV

(Depends on what can be collected, that has to be taken into account: Aussie, collecting data is distracting people from the job and taking up funding. Thailand has set up fairly sophisticated data collecting, as different donors come in they have different reporting demands and its' distracting and is a major problem)

Closing remarks
Robert Bennoun

ANNEX A: Consultation on Accelerating Support for Pediatric HIV Care, Support and Treatment in Thailand & neighbouring countries within the context of 3x5

Bangkok, Thailand, 20 October 2004 [Immediately after Country mission for the National HIV/AIDS Access to treatment programme]

Objectives

1. Identify ongoing initiatives and expertise in the region with regards to pediatric HIV care, support and treatment – projects, guidelines development, and studies.
2. Identify region specific challenges and opportunities.
3. How to explicitly strengthen the linkage between paediatric care, support and treatment, PMCT Plus, and community care for children interventions [IMCI and ECD]
4. Promote improved coordination and collaboration between regional partners.
5. Preparation for the November 3-4 Geneva meeting on paediatric formulations and diagnostics

Outcomes

1. Suggestions for joint action to address regional specific challenges and use region specific resources and opportunities for the acceleration of pediatric HIV care, support and treatment.
2. Agreement on regional coordination mechanisms and suggestions for strengthening collaboration among regional partners.

Background

Most children with HIV infections need a more intensive course of treatment compared to infected adults and therefore need unique care and support measures. Without care and antiretroviral treatment, a significant proportion of children living with HIV in resource limited settings will die before age five; as many as 30 percent dying before their first birthday and 50 percent before age 2. HIV/AIDS ravages children in a way that is even more overwhelming than observed in adults. Despite most children following a more ravaging course, with sustained care and support these children have a good chance of growing and developing to their full potential. Prospects for expanding access to care and treatment are improving as a result of:

- Global and national efforts to mobilise resources and increase financing of care programmes, including health delivery systems and championing of new innovations WHO 3x5 Initiative, Global Fund; US President's Emergency Plan for AIDS Relief (PEPFAR); private foundations and sector initiatives; World Bank MAP Funds and multilateral and bilateral donors and civil society;
- Reduction in the cost anti-retroviral drugs (ARVs);
- Growing availability of generics.

Children are part of the WHO 3x5 agenda at global regional and country levels. The challenge is to translate this reality into feasible, practical and sustainable actions. At the Bangkok International Conference, the Elizabeth Glaser Paediatric AIDS Foundation recently issued a call to action for paediatric HIV treatment. They reiterated that “each day, more than 8,200 people die of AIDS, most as a result of inadequate care and treatment. Of those, 1,400 are children

Programme issues specific to children

Caring for children born to mothers living with HIV has many challenges, and the care approach will need to overcome some of the issues specific to children and build on existing experiences and approaches:

1. *Quantification of burden of disease.* Although UNAIDS estimates the number of children infected annually and those living with HIV, most programmes have used an estimate of 10 percent of the adult estimates. Further elaboration of this estimate will be needed to guide planning.
2. *Lack of simple and cheap screening methodologies for identifying infected children early to facilitate care planning.* Antibody tests, available in resource limited settings, can only identify infection in children over 15-18 months. The PCR test is expensive and requires specialised laboratories and technical expertise. WHO has developed new guidelines for laboratory diagnosis and staging of HIV in children. These guidelines will soon become available to countries to guide programming.
3. *Difficulty of identifying children and providing them with basic health care* due to parental and caregiver consent issues and lack of systematic and comprehensive follow up systems despite knowing the mother’s HIV status.
4. *Limited expertise in treating children living with HIV with ARVs.* Health care providers at all levels of care need to develop their skills in order to identify children living with HIV, provide ARV treatment and other care services, monitor their progress, and offer psychosocial support.
5. *The youngest children cannot swallow pills and require liquid and simplified formulations currently not widely available.* Some of the formulations also require refrigeration and clean water to mix and have a short shelf life. There are currently no fixed dose combinations for paediatric use; they require dosing guidelines specific to certain age groups. These guidelines are not available for many of the ARVs. MSF, Baylor, PMTCT Plus and the Medical Research Council have developed some guidelines to help with the dosing issue but these will require standardisation.
6. *Children will require closer follow up to monitor drug toxicities and resistance,* which might be different from what is observed in adults and in the different co-morbidities frequently seen in children in resource limited settings. Children, because their bodies are still growing, respond differently to drugs than do adults. Special consideration should be

afforded to children who may not have a primary caregiver because of orphaning or illness in the parent.

7. *HIV infection in children is a chronic illness* requiring a team and ambulatory approach to care. Mechanisms for ensuring other support points (households, schools, community care points) are part of the care and psychosocial support plan, and will need to be defined.

ANNEX B: Agenda

Consultation on Accelerating Support for Paediatric HIV Care, Support and Treatment in Thailand and Neighbouring Countries within the Context of the 3 x 5 Initiative

Date: 20th October 2004

Venue: Pathumwan Princess Hotel, Jamjuree II Room, M Floor

Time	Session/Topic	Speaker
Chair[morning]: Dr. Stephen Atwood - UNICEF Regional Adviser Health & Nutrition		
08.00-08.30	Registration	
08.30-08.40	Introductions	Dr. Atwood
08.40-08.50	Meeting objectives and expected outcomes	Dr. Atwood
08.50-09.00	Approaching paediatric care, support and treatment	Dr. Usa Thisyakorn, President – Paediatric Society of Thailand & Deputy Director, Thai Red Cross AIDS Research Centre
09.00-09.20	Presentations – 3x5; National Responses ▪ “3 x 5” Initiative & responding to paediatric needs	Dr. Ying Ru-Lo, WHO SEARO & Dr Siobhan Crowley, WHO Geneva
09.20-09.35	▪ Pediatric Care and ART for Children with HIV	Dr. Sam Sophan, National Paediatric Hospital, Phnom Penh
09.35-09.50	Discussion / Q&A	
09.50-10.05	Presentations – Thailand health services ▪ Khon Kaen integrated response	Dr. Pope Faculty of Medicine, Khon Kaen University
10.05-10.20	▪ Paediatric ART	Prof. Tawee Chotepitayasunon, Queen Sirikit National Institute of Child Health, Department of Medical Services,

Time	Session/Topic	Speaker
10.20-10.35	To be advised	MOPH Ms. Junsuda Suwanjundee, Power of Life Organisation
10.35-10.50	Discussion / Q&A	
10.50-11.10	MORNING BREAK	
11.10-11.25	Presentations – specialised responses What MTCT- Plus programmes can contribute to paediatric HIV care in developing countries?	Dr. Nittaya Phanupak, Thai Red Cross AIDS Research Centre
11.25-11.40	Guidelines for the Management of HIV infection in children in resource limited settings, Myanmar	Dr. Chris Duncombe, HIV-NAT
11.40-11.55	From PMCT to PMCT + Experience from the PHPT network in Thailand	Dr. Gonzague Jourdain, Perinatal HIV Prevention Trial
11.55-12.10	Psycho-social impact on children and how we respond with counselling and art therapy	Ms. Chutima Saisengjan, AIDS ACCESS Foundation
12.10-12.30	Discussion / Q&A	
12.30-13.30	LUNCH BREAK	
Chair [afternoon] Dr. Scott Bamber – Project Officer HIV/AIDS UNICEF Thailand		
13.30-13.45	"TUC [Thailand MOPH-U.S. CDC collaboration] response to pediatric HIV"	Dr. Rangsim Lolekha, CDC Thailand
13.45-14.00	Antiretroviral Therapy in Thai Children	Dr. Kulkanya Chokephaibulkit, Siriraj Hospital
14.00-14.15	Pediatric projects at HIV-NAT and treatment of orphans with HIV at Baan Gerda	Dr. Jintanat Ananworanich, HIV-NAT
14.15-14.30	Discussion / Q&A	

Time	Session/Topic	Speaker
14.30-14.45	Presentations – specialised responses Access to paediatric formulations	Helene Moller, UNICEF Supply Division, Copenhagen
14.45-15.00	Gaps in responses in Thailand	Kathleen Casey, Family Health International [FHI]
15.00-15.15	Discussion / Q&A	
15.15-15.30	Summary of key points from presentations	Arjan de Wagt
15.30-15.40	Introduction to group work	Scott Bamber & Greg Carl
15.40-16.40	Group work – Program strategy inputs	
16.40-17.00	<i>AFTERNOON BREAK</i>	
17.00-17.15	Group work presentations	
17.15-17.45	Plenary	

ANNEX C: List of Participants

	Name	Organisation
1.	Ms. Helene Moller Technical Officer PMTCT and HIV/AIDS	Technical Services Centre UNICEF Supply Division, Copenhagen hmoller@unicef.org
2.	Ms. Sedtha Chin Project Officer - HIV/AIDS	UNICEF Cambodia schin@unicef.org
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4.	Dr. Ying Ru-Lo Medical Officer (HIV/AIDS)	WHO, SEARO loy@whosea.org
5.	Dr. Siobhan Crowley Medical Officer HTM/HIV/PRV	WHO, Switzerland crowleys@who.int
6.	Ms. Junsuda Suwanjundee	Power of Life Organisation whistle@ksc.th.com junsuda@yahoo.com
7.	Ms. Chutima Saisaengjan Project Coordinator	We Understand Group AIDS ACCESS Foundation ouichutima@yahoo.com
8.	Ms. Namphung Plangraun Manager	AIDS Access Foundation Chiang Rai accesscr@aidsaccess.com
9.	Dr. Gonzague Jourdain Senior Research Scientist	Perinatal, HIV Prevention Trial - Harvard University - PHPT, Chiang Mai gjourdai@hsph.harvard.edu gonzague@phpt.org
10.	Dr. Pope Kosalaraksa Associate Professor	Department of Pediatrics Faculty of Medicine Khon Kaen University pkosalaraksa@kku.ac.th pkosalaraksa@yahoo.com

	Name	Organisation
11.	Dr. Rangsimma Lolekha Medical Research Scientist, Care and Counseling Section	Thailand MOPH-U.S. CDC Collaboration (TUC) rangsimal@tuc.or.th
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19.	Dr. Jintanat Ananworanich Pediatrician, Clinical Trials Co- ordinator	HIV Netherlands Australia Thailand Research, Collaboration (HIV-NAT) jintanat.a@chula.ac.th
20.	Dr. Josephine Anne Sauvarin Adviser on Reproductive Health Family Planning Programme, CST	UNFPA/CST sauvarin@un.org
21.	Mr. Scott Bamber Project Officer - HIV/AIDS	UNICEF Office for Thailand sbamber@unicef.org
22.	Ms. Wanda Krekel Regional Adviser - Supply	UNICEF EAPRO wkrekel@unicef.org

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