### Knowledge...Hope...Strength for Curing TB

Printed by TB/HIV Research Foundation, Thailand and The Research Institute of Tuberculosis, Japan Anti-TB Association

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### Part I Knowledge

Scientists around the world have been spending their endless efforts to help people who are suffering from AIDS. The outcome is quite encouraging. Currently, people with AIDS can expect to live with the HIV virus with a better prospect.



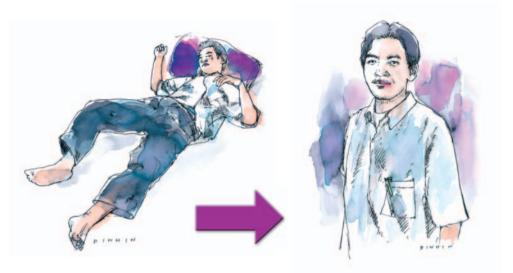
\*Read the true stories of these patients in the section "Hope and Strength for Curing TB" \*

### Living with AIDS and TB with Hope

<u>In the past</u> It was thought that there was not hope for people with AIDS. They suffered for a long time. There was no way to live longer and they were accepting death. People with AIDS suffered a lot not only psychologically but also physically, from AIDS-related diseases

**In the present days.** Many people are living with AIDS in a much better condition by adhering to good health practice, i.e., nutritious diet, regular exercises, and also by receiving psychological and physical care and support.

Many mild symptoms such as diarrhea, common cold and some serious illness likes TB are curable.



**In the past** People with AIDS often suffered from many opportunistic infections, as there were no anti-retrovirus (ARV) medicines. At the early stage of ARV discovery, the medicines were extremely expensive. There were no ways for poor patients to get the treatment.

In the present days. Advanced researches around the world continue to discover and produce new and cheaper ARV medicines which are affordable to poor patients.

**In the past** AIDS used to be perceived as a deadly disease. People thought of death when they heard AIDS.

In the present days. AIDS is now beginning to be considered as a chronic disease. People with AIDS can live with the disease for longer period of time.





Today, people living with AIDS are living with hope! Having good knowledge about the diseases that frequently attack people with AIDS will increase the chances of them live longer and live a better life.

**"Tuberculosis"** (TB) is one of the most important diseases that frequently attack AIDS patients. Although TB is a curable disease, one out of three people with AIDS are sick with, and die of TB.

We can fight TB by giving people good knowledge about TB and also psychologically supporting the patients and their family.



### What is TB ?

- TB is a communicable disease that can be passed on from humans to humans. It is caused by TB bacteria. TB is not the same as asthma, or pneumonia, and it is not a genetic disease.
- TB can attack many parts of the body but the most common site where it attacks is the lung, which can be infectious and transmissible to other people.

### Where do TB bacteria live?

#### How can TB bacteria enter human body?



- TB patients who do not receive treatment carry TB germs. The patients can spread TB germs into the air by coughing, spitting, speaking or laughing.
- TB germs are very tiny, which cannot be seen with naked eyes. After the untreated TB patients coughs, TB germs float in the air, especially in poorly-ventilated settings, such as air-conditioned rooms, rooms with closed windows or closed doors

- TB germs enter the human body through respiration, i.e. people inhale the air contain ing TB germs.
- Although many people have TB germs in their body, they do not have any symptoms because human immunity can control the germs not to be active and not to make people become sick. These people are TB infected persons but they are not sick and they cannot spread TB to others.
- Human immunity can be weakened by many reasons, such as HIV infection, diabetes mellitus, aging. Especially in these people, the TB germs which live silently in human body can become active and attack lungs or other organs, which make these people become sick with TB. These people are TB patients who have TB symptoms. Without treatment, TB patients can spread TB germs to others.

Doctors say that among 100 people who are infected by TB, only 10 of them would become sick with TB. The other 90 people will remain as TB infected persons who are not sick and will not spread TB to others.

# What are the symptoms of lung TB?

Patients usually have persistent or recurrent cough for 3 weeks or cough with bloody sputum, fever, night sweating, chest pain, loss of appetite and weight loss. The ways to prove whether or not a person is sick with lung TB are to use a microscopy to examine the patients' sputum, to culture the sputum and to examine the patient's lung by chest x-ray.

If an HIV-infected person becomes infected and sick with TB, do we have to treat TB? Is there any benefit to treating TB? Isn't it a waste of time?

- Of course we must treat TB! We should treat TB because AIDS is just one of chronic diseases. There are many ways for people with AIDS to live longer and live a better life, and treating TB is one of them. So treating TB is not a waste of time for people with AIDS!
- Treating TB is also important because by doing so, patients can protecting others from getting TB. After taking 3 weeks of TB medicine, TB patient will no longer transmit TB germs to others

# How do you avoid being attacked by TB?

#### For TB with AIDS patients:

- Patients should understand that TB is curable.
- Patients should have adequate knowledge about the disease
- Patients should be encouraged to treat TB

• Patients have to be patient in taking the TB medicine for at least 6 months. Patients should understand that if they do not complete the medicine, the TB germ will become resistant to the medicine and they bear the chance of being attacked by TB again.

### For HIV infected patients who have never been sick with TB:

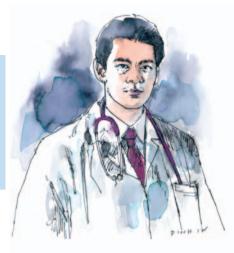
• Avoid being in close contact with persons having chronic cough and TB patients who do not receive treatment or who have only been taking the TB medicine for less than 3 weeks.

• Avoid being in close contact with TB patients in a poorly ventilated and limited space.

• Consult a doctor regarding TB preventive therapy

• Promptly seek medical consultation when TB symptoms are suspected.

### For everyone:



- ► Use handkerchief, tissue paper or your both hands to cover mouth and noses whenever you cough or sneeze. This is a desirable practice not only for the sake of preventing TB transmission but also for help prevent other respiratory diseases, such as common cold and Severe Acute Respiratory Syndrome (SARS).
- Sun light effectively kills TB germs. Living places should be exposed to sunlight with good ventilation.
- Avoid staying long hours in places crowded with people, poorly ventilated, or in dark and damp environment.
- Avoid smoking, drinking, and using drugs because these behaviors weaken your immunity against infectious diseases such as TB and other illnesses.
- Consult health staff or physician when you are coughing for more than 2 weeks or when you are coughing with bloody sputum. Do not buy medication on your own or use medicine offered by other patients.
- People should understand that TB patients who take TB medicine for more than 3 weeks are less likely to spread TB to others. Therefore, people should not shun TB patients who are under treatment.

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# Coughing properly...for everybody's healthy breath

Whenever you cough...please remember that:



This kind of coughing looks polite but it is **NOT SAFE!** If persons have some contagious diseases, they may well be spreading the germs into the air and unintentionally passing them to other people.



This is the best coughing manner which is safe for everyone. Always use a cloth or a tissue paper to cover your mouth and nose when you cough. If you do not have anything, use both of your hands.

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#### Is it true that TB and HIV can be transmitted by eating together? Why did these doctors and nurse dare to eat with these patients?

..Because TB and AIDS do not spread by eating together!



A team of doctors and nurses from Mae Chan Hospital, namely Drs.Sudanee, Nunthana, Chotipong and Ms.Wipaporn joined lunch with several people living with HIV, including a TB patient who were treated a few months ago. The health care team wanted to demonstrate that TB patients (regardless of HIV status) who have been on TB treatment for more than 3 weeks and who show improved clinical symptoms do not transmit TB to others. Therefore, these patients should not be shunned by other people.

These doctors said that TB and AIDS are not transmitted by sharing food but there are several diseases can be transmitted through saliva, such as hepatitis, herpes zoster, and oral ulcer.

Therefore, when people wish to share food with others, (like this photo), "serving spoons" MUST be used and every person MUST have his/her own spoon and a drinking cup. Let's practice this eating behavior no matter who we are eating with...doctors, nurses, patients or general people.

## What will happen if TB germs enter human body?



Breathing the air which contains TB germs

Human bodies without TB germs



Human bodies with T infection



Human bodies v TB infectio

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vithout

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immunity

Poor

Persons continue being in the stage of TB infection, which means:

- **TB** germs are not active.
- **TB** germs live in human body quietly and do not cause any harm.
- These persons are not sick. They do not have TB symptoms and therefore they cannot spread TB to others.
- These persons can take medicine to reduce chance of becoming sick with TB.

#### Persons becomes sick with TB (so-called TB patients)

- **TB** patients suffer from various TB symptoms. They can also spread TB germ to others.
- If patients take TB medicine for at least 6 months, they can be cured. If patients take TB medicine for at least 3 weeks, they will less likely spreading TB germs to others.



### **Medicine reminder systems**

TB patients have to take their medication continuously for at least 6 months. The most common problem is that patients forget to take the medicine, especially when they begin feeling better. The best way to ensure that patients complete this long-term treatment is for a health worker or a volunteer to bring the medicine to the patients' home and to observe them take the medicine everyday. If this is not possible, some sort of a medicine reminder system can help the patient complete his or her medication. For example, several former TB patients kept the medicine or a reminder message in visible locations that were related to their daily activities, such as where they ate, drank, slept or changed clothes. By this way, these patients were able to complete their medication and were treat TB.

### Part II Hope and Strength

### The true stories...not fictions! "Having Strength... Having Hope"

Having the correct knowledge about TB and HIV/AIDS can give lives to many tuberculosis (TB) patients, who may have initially felt hopeless and discouraged because of the disease. The following stories are patients' real experiences (the names are in pseudonyms). These patients were not only suffering from TB but also from HIV infection and several complications related to AIDS. **Yet, they all managed to successfully overcome TB!** 

There were many difficulties. Most of these patients were poor and jobless, and some patients were socially isolated and were forced to live alone. Anti-retro virus medicines for AIDS were not yet available at that time. So why were these patients cured from TB? Don't you think there is much to be learnt from these patients' stories?

We are extremely grateful to these patients who kindly allowed us to publish their stories and photos. We admire their courage and good wills. They told us that they simply wanted to help other patients experiencing the same difficulties overcome them.

Lastly, they wished to convey one message to other patients: **"So long as you hold on to courage...your life will be brightened with hope".** (We hope that this book will...)

#### Ms.Nita...."No matter what diff treatment, I was pa



Before TB treatment



After completing the treatment

#### Ms.Nita (pseudonym) 28 years old

Nita got her HIV infection from her husband, who passed away 5 years ago, leaving Nita and their two young children, a son and a daughter, to struggle on with their life. After her husband's death. Nita moved back to her hometown to live with her parents. The daughter lives with Nita while the son lives with her husband's relative Soon Nita developed fever, fatigue, short breath and massive coughing. The coughing were so severe that she could not even sleep. When she finally went to the hospital, the doctor told her that she had a TB in her lung. Three weeks after she started her TB treatment. Nita was feeling better. Her coughing subsided and her short breath disappeared. Yet she strictly stuck with the treatment and never forgot to take the medicine on any one single day. She remembered that when she was firstly admitted to the hospital, she saw a TB patient being given an injection everyday. She remembered the doctor

saying that if TB patients start taking medicine inconsistently, the chances of drug resistance developing will be high and when that happens, patients will have to start a new treatment course including daily injection.

Nita is an excellent example of a TB patient with HIV infection who successfully completed the TB treatment, despite being attacked by other opportunistic infections such as oral thrush and meningitis during the TB treatment course. She told us that she held her moral high and put all efforts to treating her TB. She wanted to live in order to take care of her children. She told us that when she had the oral thrush, it was so painful whenever she tried to swallow the medicine. It was so painful she found it even hard to drink water, let alone eat. During

the 5th month of her TB treatment course, she suffered from severe headache and repeatedly vomited, often falling unconscious afterwards. At that time, whenever she tried to swallow the TB medicine, she vomited it out. She said that she really thought she was going to die. But in the end, she did not give into those physical pains. She survived and she successfully cured her TB.

Nita told us that she would like to convey her good will and best wishes to other patients who are suffering from TB and AIDS. She said that she will be more than happy if her story can encourage and support other patients.

### Ms.Suda: "It took me an hou but I was patient for the sake

Photo after completing TB treatment

#### Ms.Suda (pseudonym) 34 years old

Suda got her HIV infection and TB from her husband. Three months before her husband passed away, Suda developed serious coughs, short breath, persistent fever, and fatigue. she felt that she was going to die. She was admitted for 3 nights in a hospital, where a doctor told her that she had TB with HIV infection. The doctor said she had to take TB medicine for at least 6 months. After being discharged from the hospital, Suda moved back to her home to live with her parents. According to Ms. Suda's memory, she was taking a medicine for the first time since she became an adult. At the beginning of the TB treatment, Suda spent an hour to take the total 10 tablets of TB medicine every day.



### r to swallow the medicine... of my beloved parents".

"Not only TB, but I was also suffering from fungal infection in my mouth and my throat. I felt very sick, I could not eat and I was so weak. I felt I was going to die. But I was encouraged to take all medicines. My mom cheered me up every night. It was so painful whenever I swallowed the medicine and water. Many times, I was depressed when I thought about the 6 month treatment but at last I completed it!"

Suda cured her TB and her body weight increased from 33 to 39 kg.. She was able to resume her work. Suda said that she was able to complete her TB treatment because of the following reason:



"I know AIDS is not curable. I will die anyway. But I love dad and mom. Doctors told me that if I take TB medicine I will not spread TB to the others. I was determined to take medicine not for myself but because I was afraid my parents and others would get TB from me. I was concerned for my parents. I do not want them to be infected with TB. I know how terrible it is to have TB."





Before TB treatment



After 3 months of TB treatment

### Mr.Sano...Because of their

#### Mr.Sano (Pseudonym) 42 years old

Sano lived with his father and elder sister in an urban community. Sano didn't realize that he was infected by HIV until he became very sick and his family brought him to the hospital. After knowing about his HIV blood test result. Sano decided to leave the hospital and went back home with some supportive medicine. After he left the hospital, other test result showed that Mr. Sano also had TB in his lung. Therefore, the home health care nurses visited Sano and brought the TB medicine to serve him at his home. The nurses instructed Sano's sister and father to take care of Sano and ensure that he took his medications. One week later, the nurses visited Sano's home and found him sleeping alone in his room, depressed and hopeless.

Sano took the anti-TB medicine for a few days but he felt the medicines made his symptoms worse. He thus stopped taking the



### r encouragement...I could stand again!

anti-TB medicine. He had nausea and vomiting. He could not eat and he felt so weak. The nurses found out that Sano was not motivated to take the medicine because he had AIDS. He felt discouraged and hopeless and just wanted to die. He even appeared to accept that he was going to die. He did not feel that he wanted to stand again, or that he could stand again. His father and sister also appeared to accept the situation and just followed Sano's wishes to do nothing and wait to die. However, the home health care nurses eventually managed to convince Sano and his family to resume to the TB treatment. And how worth it was! Sano was cured from TB and he could stand again! He could even return to earning income by riding his rickshaw (tricycles). He also ended up encouraging his neighbors who

had suspected TB symptoms to visit the hospital and to get the treatment like him did.

Sano and his family were encouraged by the power of the message from the nursing team that although AIDS was not curable but TB was curable, and also that treating TB was not only important for the patient but also for the patient's family and friends, who otherwise might have caught the TB from the patient.



### Ms.Patty...The little



'Despite being isolated ... I survived'

#### Ms.Patty (pseudonym) 11 years old

Patty is an eleven years old girl, whose parents passed away due to AIDS. Patty was also infected by HIV. After her parents died, she was invited to live in her relative's house. One day, Patty became sick; she had persistent fever and rash, she was feeling very weak, and she lost appetite. These symptoms lasted for one month. At last, Patty went to the provincial hospital. The doctor told her that she had TB. Her relative was afraid of catching TB from her. Therefore her relative built a small hut for her to live in and provided foods for her to eat in the hut.

Being isolated from others, little Patty became determined that she had to cope with the illness alone. However, she was determined not to let fate take control of her life. She was determined to cure her TB because she did not want to spread TB to others. She optimistically thought that life can always be filled

#### with hope.

"I took the TB medicine by myself everyday. I never forgot to take because the doctor said that if I took the medicine inconsistently, the TB germs will become resistant to the medicine and TB will not cured., I wanted cured TB...so I always reminded myself to take the medicine. Sometimes my relative reminded me as well. Doctor said that if I take the TB medicine for 6 months I will be cured. Doctor also said that HIV-infected persons can be treated for other opportunistic diseases and can then live longer. I believed the doctor because I see an elder child in my village (who is HIV infected)...he is quite strong now."

Three months into her TB treatment, Patty started taking anti-retrovirus together with TB medicine. At first, her body reacted to the anti-retro virus badly and she suffered stomachache, nausea and felt sick. But gradually, her body adjusted to the medicine.

Now, little Patty is a healthy and a lively girl who likes to talk with other children similar to her age. Patty is living with her relative, who now understands that she should no longer be afraid of getting TB from Patty. She completely understands the doctor who told her that after 3 weeks of TB treatment, patients are less likely to spread TB to others.



### Mr.Chai...Just think the



Before TB treatment



After TB treatment

#### Mr.Chai (pseudonym) 34 years

When Chai's relatives brought him to the hospital, everybody thought that Chai was going to die! At that time, he was severely sick, he had short breath, severe coughs and he was very weak. The doctor said Chai had TB in his lung. To make matters worse, the blood test result showed that he was also infected with HIV! At that time, no poor patients, like Chai, could afford the anti-retro virus medicine for HIV. Chai decided to accept the TB treatment. He did not think that his life became hopeless because of HIV. He optimistically thought that persons with HIV still had the chance survive. He was determined to cope with TB and HIV.

Chai was discharged from the hospital with TB medicine. The doctor emphasized that he must not forget to take medicine and that he must complete it. He must be patient with himself for the long term TB



treatment. Chai found that it was not easy at all to complete the TB medication. During the treatment course, he suffered several undesirable symptoms. Whenever he took the TB medicine, he felt sick. He had skin rash and itching, nausea and vomiting and he could not eat. He felt very weak and many times he wanted to quit TB treatment and just die.

I felt discouraged...I felt terribly sick...and I thought that I was going to die. It was so hard to tolerate these symptoms. It was so hard to complete the 6 month TB medicine. Doctor said that it must be 6 months...that I must not forget taking the medicine and I must not miss any single dose otherwise TB germs will become resistant to the medication. But my family and friends warmly supported me. They said that I have to be patient and told me to just imagine that I am in a prison for 6 months.

Chai was encouraged to continue with the TB treatment. He gradually gained body weight. He was only 40 kg when he started the TB treatment and his body weight returned to 47 kg when he completed the TB treatment.



#### Ms.Amporn..."Don't worry...Do



Before TB treatment



After TB treatment

#### Ms. Amporn (pseudonym) 29 years old

Amporn was born in the northern region. She followed her husband to the southern coastal region where her husband worked as a fisherman. One day, Amporn became seriously sick. She had fever, cough with short breath, tiredness. and lost sevenkilograms. Yet, where she lived with her husband, nobody took care of her. Therefore, she moved back to her hometown in the northern region, where she could rely on some financial support of her mother. There she visited a community hospital. The sputum examination and chest x-ray showed that Amporn had TB in her lung.

Amporn was actually also infected with HIV. But she knew about her HIV infection before she became sick with TB. Unlike most people with HIV, Amporn was not depressed with her HIV infection.



She always thought that she was not the only person infected with HIV. She did not care if other people looked at her or thought about her in a bad way. She thought that every human being would die any way, whether infected with HIV or not. If people shunned her, she just ignored them. Amporn felt that having less stress and less worry about HIV and about life were good to her health.

"I took medicine everyday. Doctor told me to take the medicine, so I just followed the doctor. The health staff gave medicine to me and I just took them. I was not discouraged with the treatment. I did not think of anything. I just kept thinking...I will be cured...I will be cured...OR I must cure myself...I must cure myself...."

By having hope and encouragement, Amporn was eventually cured from TB and she could resume to her many daily activities.

## If your story mirrors those that you have just read...please remember that:

- You have hope as long as you have strength.
- TB is curable. You should have knowledge and determination to cure TB.
- AIDS cannot be cured but can be treated, just like any other chronic illnesses.
  We wish you all the best in having TB knowledge, having hope and having strength to fight against the diseases.



The following individuals, organizations and institutes kindly contributed to the development and production of this book:

- The patients and their family kindly agreed to publishing their stories and photos. These patients have also dedicated themselves to supporting other patients.
- Japanese Foundation for AIDS Prevention (JFAP) supported the financial aspects of printing.
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Credibility of this book should honor to the above list. The chief editor alone bares comments, criticism and legal responsibility of this book.

Jintana Ngamvithayapong -Yanai Chief Editor June 2004



**TB/HIV Research Foundation (THRF)** Global Wisdom and Local Participation to Fight Against TB and HIV/AIDS **Registered in Thailand # 222/2545** 

#### Who are we?

Tuberculosis and HIV/AIDS are global health emergencies and Thailand is not spared. In 1992, a group of Thai and Japanese doctoral students carried out their multi-disciplinary dissertations on tuberculosis and HIV/AIDS in Chiang Rai, the northernmost province in Thailand. They soon realized the importance of research in providing knowledge as an effective tool for prevention and control of the diseases. After having worked in the field for more than 10 years in close collaboration with the Research Institute of Tuberculosis, Japan Anti-TB Association, they firmly believe that successful prevention and control programs require not only research but also human resources development and technical collaboration at community, national and international levels.

The *Foundation* was officially registered in Thailand in June 2002 as a non-profit organization, with the aim to drive research on tuberculosis and HIV/AIDS forward. It has since been conducting and supporting biomedical, health and social sciences research on tuberculosis, HIV/AIDS, and other related problems. It has also supported human resources development and provided consultations in the fields of tuberculosis and HIV/AIDS.

Found	ation N	Iembers

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### Give knowledge as an Ultimate Gift

This book was developed, we hope, to fill the knowledge gaps on tuberculosis and HIV/AIDS. We believe that correct knowledge and sharing experiences about tuberculosis and HIV/AIDS will help combat stigma and fatalism, encourage and empower patients, and help healthcare workers cope with enormous pressure and burden of their work.

If you share similar beliefs and want to help disseminate this book to others who need it, you can request copies of this book from the Foundation.

#### You can also help support the Foundation through donations:

 Direct contact with the Foundation at: TB/HIV Research Foundation (THRF) 1050/2 Satarnpayabarn Road, Muang District Chiang Rai. 57000. Thailand.
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