



# **ACCESS DELAYED** **= ACCESS DENIED**

**TRADE, INTELLECTUAL PROPERTY RIGHTS  
AND PEOPLES' STRUGGLE FOR ACCESS  
TO MEDICINES IN SOUTHEAST ASIA**

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STRUGGLE FOR ACCESS TO MEDICINES IN SOUTHEAST ASIA**



**FOCUS  
ON THE  
GLOBAL  
SOUTH**

**QUEZON CITY 2014**

Published 2014

By **EU-ASEAN FTA CAMPAIGN NETWORK** and **FOCUS ON THE GLOBAL SOUTH**  
with support from **11.11.11** and the **TRANSNATIONAL INSTITUTE**

**EU-ASEAN FTA CAMPAIGN NETWORK**

#19 Maginhawa Street, UP Village

Diliman, Quezon City, 1101

PHILIPPINES

+63 2 433-1676

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Photo Editor: **SONNY YABAO**

Editorial support (photographs): **AL BENAVENTE**

Cover and book design: **J M SANTIAGO**

We acknowledge the support of the following people who helped out with the exhibit and the photobook. Riza Damani, Rachmi Hertanti, Reni Kusumawarani from Indonesia, Ana Maria Nemenzo, Eduardo Manalo (+), Diana Mendoza, Al Benavente, Jess Santiago, Cecilia Olivet, Leticia Boniol, Clarissa Militante, Lourdes Torres, Lyn Ramos and Frances Lo from the Philippines, Charles Santiago and Edward Low from Malaysia, and Jacques-Chai Chomthondi, Chalerm-sak (jockey) Kittittrakul, Kingkorn Naranthirakul, Kannikar Kijtiwatchakul from Thailand, and Pietje Vervest from the Netherlands.

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## INTRODUCTION

"MEDICINES SHOULD BE AVAILABLE ON THE BASIS OF NEED RATHER THAN THE ABILITY TO PAY"

WORLD HEALTH ORGANIZATION (WHO), 2008

**A**BOUT a third of the global population today or around 2 billion people have no access to medicines, according to the World Health Organization (WHO). This figure includes a large number in Southeast Asia.[1]

Governments play a crucial role in ensuring that affordable medicines are made available especially for the poorest sectors. Unfortunately, public health systems across the region are in a state of decline due to lack of resources, political commitment and leadership.[2]

Furthermore, limited and declining budgets for health, poor delivery of infrastructure, and lack of strong public health legislation, make it difficult for governments to ensure that affordable medicines and treatment are made available for the population, especially the poorest sectors. Availability of generic medicines in the public sector has been pegged at only around 43 percent, reflecting a high level of inadequacy.

The WHO notes that such low public sector availability may force patients to purchase medicines from the private sector, where prices are generally higher and are often unaffordable.[3]



This higher private sector participation in the delivery of essential medicines becomes a concern especially in light of what the WHO describes as the private sector's preference for branded medicines.

The WHO says: "(P)ivate sector preference for originator brand products further increases the price and makes treatment even more unaffordable. High private sector prices are caused by high manufacturer's selling prices, taxes and tariffs, and high mark-ups in the supply chain." [4]

Despite the high gross domestic product (GDP) growth in the region, total expenditure for health in Southeast Asia has not grown during the past decade, remaining stagnant at less than 4 percent of GDP.

While there has been a slight increase in government's share from 32% to 34% of total health expenditures from 2000-2010, spending on health still remains largely private in nature, with the private sector contributing from 60 to as much as 75 percent of total expenditures.

Government spending on health in Southeast Asia represents a mere 7% of total public expenditures.

In the case of the Philippines, where total health expenditures account for less than 4 percent of

GDP, "Filipino households bear the heaviest burden in terms of spending for their health needs, with private out-of-pocket (OOP) expenditures reaching 56% of total health expenditures." [5]

It is under these stark conditions that policy makers must examine the impacts of intellectual property rights (IPR) provisions under bilateral free trade agreements on peoples' access to medicines. These so called TRIPS Plus provisions would compel developing countries to provide greater IPR protection including obligations on patents on medicines which would have serious public health implications.

Negotiations for free trade agreements launched by the European Union with Asian countries and the Transpacific Partnership Agreement (TPPA) spearheaded by the United States in particular, have pushed for restrictive patent regulations that have alarmed various sectors across the region because of the possible negative impact of these provisions on public health.

A recent report issued by the United Nations Development Program and UNAIDS on the potential impact of free trade agreements on public health gave a strong warning to leaders against trade agreements that inflate the price of medicines and deny access to lifesaving treatments for poor citizens across the globe.

**OVER THE YEARS, THE RIGHT TO HEALTH AND**

**ACCESS TO MEDICINES HAVE BECOME MAJOR**

**CONCERNS OF NETWORKS MONITORING VARIOUS**

**NEGOTIATIONS FOR FREE TRADE AGREEMENTS**

**ACROSS SOUTHEAST ASIA**

The report concludes that:

“To retain the benefits of TRIPS Agreement flexibilities, countries, at minimum should avoid entering into FTAs that contain TRIPS-plus obligations that can impact on pharmaceuticals price or availability. Where countries have undertaken TRIPS-plus commitments, all efforts should be made to mitigate the negative impact of these commitments on access to treatment by using to the fullest extent possible, remaining public health related flexibilities available.”[6]

Over the years, the right to health and access to medicines have become major concerns of networks monitoring various negotiations for free trade agreements across Southeast Asia.

Various multi-stakeholder platforms that include trade campaigners, health advocates and practitioners, consumer groups, and social movements have emerged across the region spearheading concerted campaigns and actions across to oppose these provisions and assert the right to public health.

As part of our network’s continuing effort to shed light and spur wider public discussions on this issue of free trade agreements (FTAs), IPR and access to medicines, we have initiated an information campaign dubbed Access Delayed,

Access Denied: Peoples Struggles on Access to Medicines.

The campaign aims to document stories and images that shed light on the issue of FTAs and access to affordable medicines across the region.

This publication is also a small effort to help amplify the voices of people and groups who have taken, in many instances, a life and death struggle to promote the right to health and access to medicines.

We dedicate this book to the people on the front lines of this on-going struggle.

**JOSEPH PURUGGANAN**

COORDINATOR, EU-ASEAN FTA NETWORK

NOVEMBER 2013

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## THERE IS HOPE

BY RACHMI HERTANTI

INDONESIA FOR GLOBAL JUSTICE (IGJ)

**T**HE stigma of cancer as a dreaded disease continues. The Indonesian government, however, has not given adequate attention to it. Communities, therefore, have to pay dearly for a glimmer of life that relies on medicines monopolized by multinational pharmaceutical companies.

Lolita (not her real name) is among hundreds of Indonesian children who have cancer. Nested tumor or yolk sac tumor (YSC) has been growing in her ass since she was four months old. Lack of knowledge and unstable economic condition delayed the diagnosis of her disease. It was only when she was seven months old that Lolita was tested positive for stage 4 cancer that has spread to her lungs.

Cancer is one of the three leading causes of deaths in the world after heart disease and stroke. In Indonesia, 13% of the total mortality rate in 2011 was caused by cancer. It is projected that in 2030, there will be 13.1 million deaths in the world due to cancer. About 70% of these deaths are estimated to come from developing and underdeveloped countries.

## THE HIGH COST OF TREATMENT

## INCREASES THE RISK OF DEATH AND

## KEEPS PATIENTS FROM HOPING FOR

## A CURE

The World Health Organization (WHO) predicts that the cause of the high death rate from cancer in developing and underdeveloped countries would be the low quality care for cancer patients. For example, in 2008 about 72% of the deaths due to cancer in developing and underdeveloped countries was caused by delays in diagnosis.

Limited health facilities for cancer treatment in developing and underdeveloped countries are a major problem. In Indonesia, the capital city of Jakarta is the mainstay for patients undergoing treatment for cancer because hospitals in the region do not have adequate tools to treat cancer and other illnesses.

The limitations of the Cilegon Regional General Hospital (RSUD) in dealing with cancer patients forced Lolita to seek treatment in Jakarta. She was then admitted to Cipto Mangunkusumo Hospital (RSCM), the state's biggest hospital in Jakarta. She and her parents had to go back and forth from their house in Cilegon to Jakarta to undergo treatment. Their frequent travels to Jakarta resulted to the loss of her father's job, the family's only source of income.

"There is no time for me to work. Even if I go home, there is no job. For the cost of travels back

and forth from Cilegon to Jakarta, we've been supported by my parents," said Lolita's father.

## ASSISTANCE

Cancer treatment requires intensive therapy with sustained intensity, which requires a big amount of money. Lolita's treatment process costs Rp 120 million to Rp160 million (USD12,000-US\$16,000) per protocol. (USD1=10,000 Indonesian rupiahs (Rp)

The result of her CT scan required Lolita to undergo surgery before starting chemotherapy. After the surgery, she went through 12 cycles of treatment. Lolita was to undergo three more cycles of treatment before her cancer could be considered clean. She has been undergoing treatment for more than 1 year.

Patients hope to survive, but they become pessimistic because of the high cost of treatment. In the end, most cancer patients surrender in the face of a disease that eats away at their bodies.

The high cost of treatment increases the risk of death and keeps patients from hoping for a cure. Many of them expect compassion and help to pay for their treatment. Cancer foundations as social assistance institutions, like the Indonesian

Child Cancer Foundation (YKAKI) are usually a way out.

Lolita and her family were finally helped by YKAKI, which is managed by Ira Soelistiyo.

The foundation shoulders their living cost in Jakarta. By paying Rp 5,000 (USD 0.5) per day, Lolita and her family gets to have a place in a shelter owned by YKAKI to sleep on, and meals, until the treatment process is completed.

Although YKAKI is not really the central factor in helping pay for Lolita's medical expenses, it has greatly eased the burden of her father, who has to survive in Jakarta while accompanying his child for treatment.

"The issue of parents with cancer children is not only about the cost of treatment, but more about survival. When parents find out that their children have cancer, they sometimes resign from their jobs to take care of their sick children," said Soelistiyo.

## EXPENSIVE DRUGS

The high cost of cancer treatment is caused by the high price of cancer drugs. Drugs are the biggest needs in cancer therapy to help reduce the spread of cancer. Therefore, the dependence of

TABLE 1. MULTINATIONAL PHARMACEUTICAL COMPANIES DOMINATING THE ASEAN MARKET

	Country of Origin	Representative Office in ASEAN	Net Income (US\$ million, 2008)	Total Number of Workers (2008)
Pfizer	US	Malaysia, Singapore, Philippines, Thailand	14,111	137.127
Johnson & Johnson	US	Philippines, Thailand, Vietnam, Indonesia	10.576	119.200
GlaxoSmithKline (GSK)	UK	Cambodia, Indonesia, Malaysia, Philippines, Myanmar, Singapore, Thailand, Vietnam	10.432	103.483
Bayer	Germany	Singapore, Indonesia, Malaysia, Philippines, Brunei Darusalam	6.448	108.600
Roche	Switzerland	Philippines, Thailand, Vietnam, Cambodia, Malaysia, Indonesia, Myanmar, Singapore	8.135	78.604
Sanofi-Aventis	France	Thailand, Vietnam, Singapore, Malaysia, Philippines, Indonesia	7.204	99.495
Novartis	Swiss	Philippines, Vietnam, Thailand, Indonesia, Malaysia, Singapore	11.946	98.200
Astra Zeneca	UK/Sweden	Indonesia, Malaysia, Singapore, Thailand, Philippines, Vietnam	5,969	67.400
Abbott-Laboratories	US	Indonesia, Malaysia, Singapore, Thailand, Vietnam	4.880	68.697
Merck & Co.	US	Malaysia, Philippines, Singapore	7.808	74.372

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the cancer patient on drugs is very high and they have to use them continuously.

An example is 'Glivec' manufactured by Novartis that costs about USD2,400 (Rp 24 million) for one-month's dose. It definitely makes the access of the poor to this drug very limited. WHO stated that of the 61% cancer patients in developing and underdeveloped countries, only 5% use cancer drugs.

Lolita must rely on expensive cancer drugs. She also has to be operated on before starting the chemotherapy which requires a lot of money. With a father who has no job, there is no way Lolita's treatment can be paid.

For one cycle of treatment, she has to consume intravenous fluids for three days and go through 15 cycles of one treatment. The average cost per cycle is 5 to 7 million Rupiahs (USD55-700). If a complication occurs during the treatment process, it will require more drugs. This condition eventually forced Lolita's father to seek help to buy the drugs.

It turned out that she was lucky and she got a waiver for her treatment. The Jamkesmas or health insurance of Lolita's parents, were able to finance the entire treatment process, including the costs of surgery and the expensive drugs.

However, this relief was not always enjoyed by Lolita, because the drugs that had be redeemed were often not available in the hospital thus forcing her father to buy them from private pharmacies.

Jamkesmas has shown its limitations in providing public access to medicines. Medication cannot always be provided by the government, especially when the demand increases along with the increasing number of cancer patients in Indonesia.

This leads to more burden on the state's budget and makes it more inefficient. Jamkesmas is still not the state's right solution to address the challenges in cancer medication. An effective mechanism is needed to open the access to affordable medicines, especially for cancer.

This also happens with the Jakarta Health Card (KJS) program issued by Jakarta Governor Jokowi. The program, which has a budget of Rp1.2 million from the Jakarta government, provides access to healthcare for 4.7 million poor of Jakarta.

However, the Jakarta government has run short of funds because the actual expense has exceeded the budget that has now reached Rp2 trillion. And because the provincial government can no

longer pay the hospital bills, 16 partner hospitals in the KJS program have threatened to resign.

This is not to mention the problem in data collection of the poor who are entitled to Jamkesmas. The inadequate information system in Indonesia has caused difficulty in updating data. Since March 2013, Lolita's father's Jamkesmas has expired. When he was about to extend it, the National Team for Acceleration of Poverty Reduction (TNP2K) said Lolita's father's data disappeared from the government database. This resulted in the loss of free healthcare for Lolita and created uncertainty in her treatment process.

"Thank God, with Jamkesmas everything was covered including bed, surgery costs, and medicines. But when our Jamkesmas is no longer available, we have to buy medicine from outside (the hospital) which is very expensive. It has been 5 months now (that Lolita) is not being covered," Lolita's mother said.

#### **PATENT, PRICE CONTROLS**

One factor affecting the high cost of cancer medicines is the patent owned by giant pharmaceutical companies as the inventor of the drugs. The patent gives its holder the right to capitalize it. In the case of pharmaceutical companies, they can capitalize the medicines they produce. The

**ONE FACTOR AFFECTING THE HIGH COST OF  
CANCER MEDICINES IS THE PATENT OWNED  
BY GIANT PHARMACEUTICAL COMPANIES AS  
THE INVENTOR OF THE DRUGS**



patent has control over drug prices which are essential for public health.

The state gives the patent-holder the exclusive commercial right to the invention and innovation in science, including health, for a specific period of time. A patent excludes others from using, making, or selling the products without the permission of the copyright holder.

Patent rules are adopted from the WTO governing the Agreement on Intellectual Property Rights (IPR) and the Trade Related Intellectual Property Rights (TRIPS). This rule has to be implemented by all WTO members. Indonesia is one of the founding members of the WTO which was established in 1995. Indonesia ratified the Agreement to Establishing the World Trade Organization through Law No. 7/1994. Indonesia officially adopted the TRIPS principles on the right to patent to the national law through Law No.14/ 2001.

The TRIPS Agreement in the WTO is driven by the interests of developed countries like the United States and the European Union, the base of giant pharmaceutical companies, with high technology innovation.

This interest is based on the view that first, technology and science have become important

factors in the trade of goods and services in the world to reap profits. Second, industrial companies of the developed countries, particularly the pharmaceutical industry, which have been dominating the market, have to compete with similar products from Asian countries. Third, leading companies from developed countries are keen on maintaining their positions as market leaders. Fourth, the monopoly of knowledge and technology through the strengthening of IPR protection, have opened up opportunities for multinational companies to expand its market in developing countries.

The TRIPS requires all WTO members to apply high standards for the protection of intellectual property rights compared to protection standards given by developed countries. In patent protection, the TRIPS gives exclusive rights of up to 20 years.

Legal protection entitles patent holders to monopolize its use, including price monopoly. The use of the patent by parties other than the owner requires royalty payment to the rights holder. Therefore, when a drug is patented by a pharmaceutical company, the company is free to set the price of the drugs, they produce. The patent holder also has the right to determine the number and distribution of the drug without pres-

sure from any party. It gives manifold profits for multinational pharmaceutical companies. Below is the list of multinational pharmaceutical companies practicing price monopoly and have gained great profits:

Therefore, the application of intellectual property protection in the TRIPS rules, particularly related to patent ownership by multinational pharmaceutical companies, has been very detrimental for they are encouraging first, the high price of drugs, second, the elimination of public access to affordable health care, and third, the weakening of the national pharmaceutical industry in developing and underdeveloped countries.

#### **AFFORDABLE DRUGS**

The debate around patent exemptions to pharmaceutical products and drugs has been going on since 1997 when the United States asked to amend the rules on drugs in South Africa. This has sparked concerns of developing and underdeveloped countries which then encouraged the TRIPS to not be applied to the health sector.

In the 4th WTO Ministerial Conference in Doha in 2001, it was agreed that the TRIPS should not preclude the state from implementing measures to protect public health and reaffirmed the right

**TECHNOLOGY AND SCIENCE HAVE**

**BECOME IMPORTANT FACTORS IN**

**THE TRADE OF GOODS AND SERVICES**

**IN THE WORLD TO REAP PROFITS**

of developing and underdeveloped countries to exercise the exemption set in the TRIPS (flexibility provision) for the interest of public health.

The provision of flexibility provides an opportunity for developing and underdeveloped countries to produce their own supply of medicines with affordable price without the permission of the patent holder.

Some rules of flexibility that can be used are: first, government use, which is the use of patents by the government without the consent of the patent holder for the interest of the public (non-commercial); second, parallel import, which is an act of re-importing or selling the patented product without the consent of the patent holder. This is because the patent holder cannot prevent resale of the product because their rights on the product has been depleted by the act of selling; third, compulsory license, the license granted by administrative or law agency to a third party to use the invention patented without the consent of the patent holder on the ground of public interests.

With TRIPS flexibilities implemented by the government, the medicine is expected to be affordable to the community. This will have an impact on the reduction in mortality due to cancer or other critical illnesses. As was the case in Thai-

land, after implementing the government use policy, the Thai government managed to reduce the number of breast cancer patients by 97% and the number of patients with lung cancer by 98%. The death risks by the diseases were decreasing.

#### INDONESIA

There is still hope. If only the government implements the TRIPS flexibilities to address the issues of cancer treatment as it had been implemented on human immunodeficiency virus infection/acquired immunodeficiency syndrome HIV/AIDS), Lolita and all cancer patients in Indonesia would have a better future. Currently, patients and health advocates await the government's action to put cancer as one of its priority programs.

The government's experience with HIV/AIDS is proof that the state is able to provide access to affordable medicines for People Living with HIV AIDS (PLWHA). The price of anti-retroviral drugs (ARVs), which work to restore the immune system, has been reduced from Rp10 million to only about Rp650,000 per 60 tablets.

Since 2000, the HIV/AIDS epidemic phase has changed from a low to a concentrated number because in some areas, the spread has reached to above 5%. With that condition, the government eventually decided to use the provisions of

the TRIPS flexibilities to produce anti-retroviral drugs (ARVs) of generic versions to lower the price of drugs in Indonesia.

The decision was stipulated in Presidential Decree No. 83/2004 on the implementation of patents by the government against ARVs. In the subsequent implementation, through the Ministry of Health, the government pointed at Kimia Farma to carry out a patent on behalf of the government during the period of patent protection and pay 0.5% fee of the net selling price of ARV drugs.

At that time, the Ministry of Health committed to produce generic ARV drugs intended for public purposes and not commercial purposes. The state budget set an allocation for this purpose. This means, the political will of the government has a significant role in opening people's access to affordable medicines, particularly for chronic illness. Moreover, Indonesia already has a national regulation to implement the TRIPS flexibilities through government regulation No.27/2004 on the Procedures for the Implementation of the Patent by the Government.

"... cancer is still not a priority of the government. Today, the government is still busy taking care of nutrition and infection issues. If it is possible, the cost should be lowered," said Prof. Dr.

dr. Iskandar Wahidiat, SpA (K) in an interview with IGJ.

WHO reported in 2010 that from 64 percent of Indonesia's mortality rate which are caused by non-communicable diseases, 13 percent are due to cancer and 30 percent are due to heart disease. Both critical illnesses are very dependent on expensive drugs.

Based on data reported by Prof. Dr. dr. Iskandar Wahidiat, Sp.A (K), a pediatrician in RSCM, said that in 2012, there were 319 cancer patients in RSCM, with 134 people suffering from solid tumor and 185 people suffering from leukemia (blood cancer). He also predicted that the number of cancer patients in Indonesia will grow bigger every year. Moreover, the environment and food can trigger the development of cancer and heart disease so quickly.

It is never too late to start. The government's commitment will open a new hope for Lolita, so she could fill it with a sheet of colorful life with smiles and laughter. Her father and mother will also have the opportunity to see Lolita grow and make her dreams come true. Currently, the little baby has grown into a beautiful princess and waiting for a glimmer of hope to live a bright future. \*\*\*



## INTERVIEW WITH HIV-AIDS AND ACCESS TO MEDICINES ACTIVIST EDWARD LOW

BY JOSEPH PURUGGANAN

*What were the circumstances that led you to spearhead the campaign on FTAs and access to medicines?*

First of all, as a patient I came across in 1998, a treatment model in Brazil that provides free anti-retro viral medicines for all in their public health care system that I thought could be a good model to replicate in other developing countries seeking to ensure greater access to medicines for patients. I was then motivated to participate and became actively involved in various AIDS Conferences.

Over the last decade, I also have heard about free trade agreements (FTA) and how they impact on health and access to medicines. My country is now facing pressures from two super powers—the United States and the European Union, both wanting to secure trade agreements with Malaysia. Malaysia is part of the negotiations for a Trans-Pacific Partnership Agreement (TPPA) which is being spearheaded by the U.S., and there are also on-going bilateral FTA talks with the EU.

*In your many presentations around the world, you have consistently presented a patients perspective on the issue, can you relate to us why this campaign to stop FTAs like TPP is so important to you and why should it matter to patients everywhere?*

In fact, from a patient's perspective the TPP for example, is a human rights concern. It is about protecting the right to health and right to live. I was described as a "champion patient" when protesting in the public and for showing that people living with HIV-AIDS are at the forefront of campaigns to ensure that our rights protected.

As you know the big pharmaceutical companies ('Big Pharma') are playing with the rules to influence the trade negotiation process by developing and accessing the draft text for corporate input. It is unfair trade which will only benefit them creating another type of monopoly. This will kill market competition and prevent life saving affordable generic medicine market entry for longer periods. .

*Do you think Government's are listening to your message and the demands of various movements and global institutions against these FTAs? What has been the response of the Malaysian government to your demands?*

It is more a question of whether governments are doing their job properly. Recently, our Trade Minister has taken a more open stance, listening to our issues and concerns on to access to affordable medicines. The government has announced at a Cabinet level meeting that higher priority would be given to protecting the public interest



in trade negotiations. The government of Malaysia has given assurances to the public and its approach to negotiations can be quite convincing but without real transparency in these talks, and without genuine public consultations people will lose confidence in government and its ability to defend the public interest in the negotiations.

*What can be done to strengthen the voices of those struggling to secure access to affordable and quality life-saving medicines?*

For me community mobilization is the most important aspect of the campaign through which we are able to strengthen the voices and increase the pressure. We have various strategies in our advocacy work. The frequent meetings and having a working relationship with people in government are other effective approaches to ensure that public interest is advanced in these talks.

*On a more personal level, how are you coping with your own struggle for treatment?*

I am living with HIV for 15 years now and have gotten used to living in the AIDS stage before treatment was initiated.

I have been on first line combination therapy for 9 years now and living a normal life. I am lucky because I am educated about treatment and I

have knowledge of reproductive health and rights. My wife Helen is also HIV positive and undergoing treatment. We have two children that fortunately tested negative.

*How expensive is your own treatment?*

Although our country provides free first line combination therapy but for second and third line the cost would be around USD 4,500 to USD 7,800 per year. Patients would largely need to pay for this out of their own pockets.

*What keeps you going in the campaign?*

The never ending cooperate driven trade negotiation is keeping me in the campaign. While we may expect losses on our side, I will never give up the struggle because our fundamental human rights are at stake and we need to challenge the claims of Big Pharma that they are serving the public interest because it is clear that their medicines are inaccessible to the poor.

**EDWARD LOW** was diagnosed HIV positive in 1998. He is married to Helen Chan, who is also HIV positive and undergoing treatment as well, and together they are raising two children Janice and Wayne. Together with 7 other 'people living with HIV', Edward established the MTAAG+ in 2004 after a regional treatment workshop in Pattaya, Thailand. MTAAG+ was formed to mobilize the Positive Community to take ownership of their lives and circumstances.

Edward's photograph by **CECILIA OLIVET** of Transnational Institute; photos on next two pages courtesy of Edward Low.





## THE PHILIPPINES: ACCESS TO MEDICINES AND RIGHT TO HEALTH

BY DIANA G. MENDOZA

**S**OLITA Lim took her five-year-old daughter to the San Lazaro Hospital for anti-rabies injections after the child was bitten on the leg by a neighbor's dog. A long queue forced Lim to spend an hour at the outpatient section. She was told that her child was not considered an emergency case because the location of the animal bite was far from the brain.

Physicians say that depending on the location of the dog bite, the rabies virus travels to the brain and affects the central nervous system. A rabies-infected individual can die within hours of developing symptoms. It is essential that post exposure prophylaxis or immediate treatment after the bite exposure is administered to prevent the onset of symptoms of the disease.

While waiting in line, Lim learned from other patients that the normal practice is to share the vaccine ERIG

with other patients so they share in its cost. Her daughter was given one injection each per arm. Each injection cost her 950 pesos (around USD22), or a total of 1,900 pesos (USD44). The hospital ran out of stock due to the number of patients, so Lim was asked to buy additional shots from a pharmacy outside for 1,500 pesos (around USD35).

The 35-year-old Lim, who has two other children, is a housewife living in Sta. Cruz, Manila. She and her husband, a jeepney driver, consider the rabies shots a big disruption in their expenses. On a daily basis from early morning to sometimes midnight, her husband earns from 300 pesos to 1,000 pesos (USD7-25).

Because they struggle to make both ends meet, daily budgeting does not include medicines. "We have three meals a day, but it's difficult to also mind expenses for milk, clothes, and utilities," she told an interview.

She was hoping that the dog's owner, their neighbor, would help with expenses because that is the usual practice. But she recoiled because her neighbors are "loudmouthed thugs who might pick a fight with us."

Lim was advised by the hospital to bring back her daughter four more times at different intervals with two injections each time. She was

assured that in the next visit, she would shell out a "cheaper" 800 pesos (USD19) per injection. She was reminded to have her daughter injected after one year. She was also assured that even if the bite location was far from the head, which makes the child safe for now, it is crucial that she undergo the injections to flush out the virus.

The price of the next shots is just too much for Lim. She decided that the child's next injections will depend on her money. If she wouldn't have the amount by then, she would not take her child to the hospital. "I was assured anyway--the leg is far from the brain," she reasoned out.

When asked if she has ever considered applying for medical care insurance under the state-run Philippine Health Insurance Corp. (PhilHealth or PHIC) that has a program for indigents who can access medicines, she said she had no knowledge about it, except that she sees its advertisements on television.

#### **POVERTY AND PURCHASING POWER**

Lim is one of millions of Filipinos who, owing to their poverty and lack of education, are not conscious about health and health-seeking behavior.

Her situation is not much different from Margot Singson, 28, whose terminally ill father diagnosed with stage 4 lung cancer, was on his sec-

ond week of confinement and had just slipped into a coma at the intensive care unit of the Jose Reyes Memorial Medical Center when she was interviewed for this report.

Singson has spent 45,000 pesos (a little over USD1,000) since January 2013, two-thirds of it in medicines and medical supplies, and the rest in doctors' fees and room charges.

When interviewed, Singson said the cheapest medicine from her list of expenses was a tablet costing 200 pesos (USD5) and the most expensive costing 1,500 pesos (USD35). She has never spent this much for a capsule or tablet since buying a 40-peso pain reliever for her menstrual cramps.

"It's a huge spending when something like this happens in the family," she said. "It drained my savings, and it is impossible now to even consider where to source the next expenses."

The only single member of a family of four siblings, Singson said she had to ask her siblings for money, even if they are hard-up with expenses themselves. But at their last family meeting, they were considering the advice of hospital doctors to pull their father's life support and take care of him at home while he is dying. This way, the expenses are diminished.

**WHILE THE POOR ARE THE MOST LIKELY TO**

**HAVE NO ACCESS TO MEDICINES, THEY ARE**

**ALSO THE MOST EXPOSED TO DISEASES FROM**

**UNSANITARY CONDITIONS AND COMPROMISED**

**IMMUNITIES FROM EATING LESS NUTRITIOUS**

**FOOD AND IMPROPER HEALTH HABITS**





Although they have two different conditions--rabies infection and terminal cancer--both Lim and Singson are two Filipinos encountering health disorders that, even if they are not the ones directly getting sick, affect their lives because of the expenses they have to shell out for health care.

Dr. Anna Melissa Guerrero, program manager of the National Center for Pharmaceutical Access and Management (NCPAM) in the Department of Health (DOH), said that while the poor are the most likely to have no access to medicines, they are also the most exposed to diseases from unsanitary conditions and compromised immunities from eating less nutritious food and improper health habits.

Citing rabies infection, for instance, when children, especially during summer, are exposed to unvaccinated dogs while at play, Dr. Guerrero said a family has to cough out 20,000 pesos (USD463) to be able to complete six shots even if some state hospitals offer two free shots in the entire treatment.

"The DOH has a budget that provides free shots to those who really cannot afford treatment, and even to a few cancers, but the situation is still very far from ideal," she said in an interview.

She cited, however, that there is the PhilHealth that offers an animal bite treatment package to defray the costs to members.

Dr. Guerrero said that since the passage of the Generics Acts in 1988, the government had made certain that medicines have improved in terms of affordability and access, and that Filipinos receive medicines with the least toxicities and risks, at times manufacturing generic medicines from natural and indigenous materials to ensure efficacy.

The World Health Organization (WHO) has noted in a report that the number of Filipinos who spend for their health is increasing, with out-of-pocket expenditures now representing 56 percent of total health expenditures, which is above the 30%-40% range prescribed by the WHO to move towards universal coverage.

In most of South East Asia, the WHO estimated that 60% to 75% of total health expenditures occur in the private sector and the same is true in many Arab countries. This means that households bear a substantial proportion of health costs while having little protection in the event of major illness or injury.







#### THE GENERICS LAW

But 25 years after the passage of the Generics Law, Filipinos are still used to purchasing branded drugs because they believe these are more effective. "It will take time [before] people's confidence in generic medicines [increases]," says Dr. Guerrero, "but we are seeing improvements."

She says the lure of the multinational pharmaceutical industry, with its constant advertising, marketing and sponsorships in all forms of media, is a giant against the government's steady efforts to offer equally effective drugs at lower prices. "In reality, the large market held by multinational companies is still strong. It is difficult to fight that culture."

Compared with other countries in the region like India and Thailand that aggressively campaign to implement programs that put controls on drug prices and are able to offer cheaper medicines to people, the Philippines is still struggling in this area.

In India, for example, Insulin is priced at an equivalent of only 30 pesos (USD0.69) while pricing in the Philippines is still pegged at 200 (USD5).

Dr. Virginia Ala, director of the NCPAM-DOH, explained further that the improvements, how-



ever gradual, are certain. Government hospitals rely on the availability of medicines for their supply and as procured by the health department through the Philippine National Drug Formulary, the list of essential medicines for Filipinos' primary health care and a guide for government procurement of medicines.

Only recently, the Generics Law was strengthened by the Cheaper Medicines Act of 2008 that further ensures a policy environment to enable the DOH to improve access and to institutionalize transparency and good governance in the pricing and procurement of medicines.

An ongoing effort is the rationalization of outlets and pharmacies and the rational use of medicines by prescribers, dispensers and patients.

There are generic franchises around the Philippines such as the "botika sa barangay" (BsB--village pharmacy) or "botika ng bayan" (BnB--town pharmacy) and other DOH-allowed drugstores that have basic medicines and over-the-counter drugs and two antibiotics – amoxicillin and cotrimoxazole –that are available, with the addition of drugs for non-communicable illnesses like diabetes and hypertension.

As of September 2010, the DOH-NCPAM said there were 16,087 BnBs nationwide.





Dr. Ala said the botika sa bayan/barangay are given by the Food and Drug Administration (FDA) under the DOH special licenses to operate “not just to ensure affordability and access but to break the monopoly of medicine distribution and to provide the market with low-cost essential drugs and medicines.”

Also gradually, the government is transforming the BnBs into “not just drug dispensing units but health promotion centers” as well.

The FDA strictly implements Good Manufacturing Practice (GMP) for manufacturers, good distribution practice for importers and distributors and good storage practice for health and medicine establishments. It also capacitates local manufacturers such as Pascual Laboratories, Unilab and Pharex to be in the same market as the multinationals, provided they also comply with regulations.

There is also the state-supported local manufacture of the medicinal herb “sambong,” mainly a diuretic that eases kidney problems, and the herb “lagundi” that relieves fever and respiratory disorders. These two herbal and medicinal plant-based medicines have been tabletized by the laboratories.

FDA deputy director Nancy Tacandong said regular audit inspections are conducted by food and drug regulation officers. Companies that do not comply with requirements are issued cease-and-desist orders or their license to operate suspended if they are in violation. The FDA has applied for membership by next year in the Pharmaceutical Inspection Cooperation Scheme (PICS) to enhance its capacities. The agency was ISO-certified in April 2010.

Tacandong said a number of drug manufacturers have been producing generic products since the enactment of the Generics Act. “Even importers of generic products have grown to a large number. It is noteworthy that all of the imported products comply with the prescribed labelling requirements.”

In medical practice, more medical and dental practitioners offer generic products as an option to their patients and comply with generic prescribing, she said.

“Our food and drug regulation officers include in their monitoring the prescriptions both in hospitals and drug outlets such as pharmacies. Warnings and letters are sent to erring doctors, whose licenses can be suspended on third offense,” she explained.

## DOH ComPack Program List of Medicines

- 1<sup>st</sup> to 3<sup>rd</sup> tranche delivery completed
- 4<sup>th</sup> tranche delivery started June 21, 2012

Name of Medicines	Dosage Form	Estimated Unit Cost (PhP)
<b>Antibiotics</b>		
Amoxicillin (as trihydrate)	500 mg capsule	23.52
Amoxicillin (as trihydrate)	250 mg/mL granules/ powder for suspension, 60 mL	14.58
Cloxacillin (as sodium salt)	500 mg capsule	59.85
Cloxacillin (as sodium salt)	125 mg/5 mL powder for suspension, 60 mL	17.80
Cotrimoxazole	800 mg sulfamethoxazole+ 160 mg trimethoprim, tablet	13.72
Cotrimoxazole	200 mg sulfamethoxazole + 40 mg trimethoprim per mL suspension, 60 mL	9.98
Cotrimoxazole	400 mg sulfamethoxazole +80 mg trimethoprim per mL suspension, 60 mL	12.33
Erythromycin (as stearate)	500 mg tablet	81.90
Ciprofloxacin (as hydrochloride)	500 mg tablet	18.06
Doxycycline	100 mg capsule	11.20
Metronidazole	500 mg tablet	12.18
Mebendazole	500 mg/mL suspension, 10 mL	18.20
<b>Diabetes Drugs</b>		
Metformin (as hydrochloride)	500 mg tablet	56.70
Glibenclamide	5 mg tablet	8.10
Glicazide	80 mg tablet	76.68
<b>Hypercholesterolemia</b>		
Simvastatin	20 mg tablet	24.90
<b>Hypertension and Cardio Drugs</b>		
Amlodopine	10 mg tablet	99.00
Aspirin	80 mg tablet	27.92
Enalapril (as maleate)	10 mg tablet	35.40
Hydrochlorothiazide	25 mg tablet	43.70
Losartan (as potassium salt)	50 mg tablet	24.90
Metoprolol (as tartrate)	50 mg tablet	39.77
<b>Asthma</b>		
Fluticasone + Salmeterol	50 mcg/25 mcg x 120 doses in-haler) for 4-12 y/o	100.00
Fluticasone + Salmeterol	125 mcg/25 mcg x 120 doses inhaler) for adult	100.00
Salbutamol	100 mcg/inhalation x 20 doses	100.00
<b>Bronchodilator</b>		
Lagundi	300 mg tablet	42.84
<b>Diuretic</b>		
Sambong	250 mg tablet	91.80

**UNIVERSAL HEALTH CARE**

President Benigno Aquino III, in one of his statements, said four out of 10 Filipinos die without ever encountering a healthcare professional in their lifetime. The number, he said, is “simply too high.”

But in providing access to medical attention and proper nutrition, the government is implementing the Universal Health Care, which the President said is “within sight from a mere afterthought and impossible dream.”

He said 86% of Filipinos are now enrolled in PhilHealth, with the lowest quintile of the population already benefiting from the “No Balance Billing” policy that allows them to get treated in government hospitals without shelling out a single peso.

Dubbed Kalusugang Pangkalahatan in Filipino, part of the Universal Health Care program is the partnership of DOH with the Department of Social Welfare and Development (DSWD) in identifying the poorest of the poor, who will be given basic needs, including medical help. The DSWD calls this program Conditional Cash Transfer (CCT) that lists municipalities where the poorest of the poor families reside.

Currently, the lowest two quintiles number 5.2 million families or 25 million individuals. These families have been enrolled automatically to PhilHealth.

Included in the provision of services is the requirement for rural health units (RHUs) to do a registry of the families who will be visited monthly for health monitoring, to take the blood pressure of family members who are 18 years old and above, and periodic examinations to those 25 years old and above.

Among the 86% of Filipinos who have health coverage are 4.26 million families from the informal sector.

Dr. Ala of DOH-NCPAM said the RHU is one of the gatekeepers of the government’s medicine access program because it handles health care at the primary level. Its responsibilities include intensive health promotion to ensure family health and provide basic but crucial nutrition advice. One of them should be: “If the food you eat is right, you will not get sick.”

Currently, the RHU is receiving 500,000 pesos from the PhilHealth in tranches: 40% for medicines, 40% for supplies and 20% for administrative costs and physician’s honorarium.





In 2012, the DOH distributed free medicine kits called Complete Treatment Pack (ComPack) to 1,020 CCT municipalities. The ComPack is a complete medicine kit for the most prevalent disorders and conditions like high blood pressure, high cholesterol, diabetes and common infections. They also include medicines not in the DOH programs to cover pneumonia, diarrhea, urinary tract infection, and asthma. (See table on List of Medicines)

The DOH-NCPAM is increasing its target to distribute and upgrade the ComPack to 1,387 CCTs and will include free geriatric medicines in state hospitals with geriatric care. It will also expand the availability of lower-priced drugs for cancer and leukemia to hospitals outside of Metro Manila.

Dr. Ala said the DOH delivers medicines to RHUs every quarter. A total of 540 million pesos (USD12.5 million) has been earmarked for this program, and 240 million pesos (USD5.5 million) has been awarded for bulk purchase of medicines.

The bulk purchases are mostly vaccines and drugs in the DOH's medicines list, and majority are bought from India. Most of the medicines are generics and some are branded. The government used to do parallel drug importations in 2001

when it imported medicines for village pharmacies. But this was not repeated because it was able to purchase cheaper medicines from India, which are all quality-assured.

"We tell the RHUs to comply with PhilHealth requirements because the ComPack is direct government subsidy. If families are empowered, they can tell PhilHealth if they were not given medicines," she said. "In time, health financing will be shifted to PhilHealth which will find ways to procure medicines more efficiently."

Dr. Ala further said municipal health officers have been directed to tell physicians to see to it that each patient gets well so that medicines are dispensed accurately. They will then report treatment outcomes to the DOH-NCPAM.

#### **FREE FOR THE POOR, AFFORDABLE FOR THE MAJORITY**

While the government strives to provide health coverage for the poor with zero out-of-pocket expenses, there are more things that still need fixing in the health care system.

The DOH-NCPAM's Dr. Guerrero said drug prices in the Philippines even surpass other countries in Asia with higher levels of income. She cited an example in 2010 where one government hospital was still procuring mostly branded

medicines, at costs higher than in Malaysia, Vietnam and Thailand when compared in terms of GDP per capita in purchasing power. (See table on Comparative Prices in 4 ASEAN countries)

Dr. Guerrero said the Philippine National Drug Formulary that lists essential medicines for the primary health care of Filipinos and a guide for government procurement of medicines is being reviewed, a result of which may be the inclusion of new medicines. (see table on 2010 Medicines Access Program)

“Cost-effectiveness is essential in listing drugs, but forecasting and purchasing them is very tricky,” she said. “Therapeutic committees need to be capacitated in order to do this.”

She also said the government has yet to fully exercise its right under the law to control drug prices to make them free to the poorest and affordable to many Filipinos.

For now, PhilHealth can only reimburse drugs in the essential drugs list. There ought to be new measures that cover all medicines to health insurance holders.

In 2011, Dr. Guerrero said the DOH adopted a policy to cooperate with the PhilHealth and other relevant government agencies to look for more and better strategies that will provide

free medicines to the poor, or a population of patients that addresses priority diseases such as tuberculosis, HIV, malaria, cancers and non-communicable diseases.

In 2010, the budget appropriation for medicines reached 1 billion pesos after the DOH adopted expert recommendations that it should at least have 1% share of the market to impact drug prices. Part of the improving budgetary considerations was the policy to provide support to local government units that are chronically underfunded in terms of medicines and in covering their poor and vulnerable populations.

A recent GTZ-European Commission study found that 85% of BnBs that have been operating for at least two years remain functional and serving around 500 patients per month per outlet. They also can offer up to 40 essential medicines and are allowed to sell eight prescription preparations, and the medicines passed through the Quality Control and product registration standards of FDA. On the average, medicines were 62% cheaper. The DOH targets to have one botika (pharmacy) for every three adjacent barangays (villages).

In the course of providing accountability and transparency, the DOH is improving its website to include electronic data price monitoring system

**2010 Comparative Procurement prices of selected drugs in four ASEAN countries in terms of average GDP per capita in purchasing power parity prices (in US dollars)**

Medicine	Philippines (USD 3,500)	Vietnam (USD 3,100)	Malaysia (USD 14,700)	Singapore (USD 62,200)
Amoxicillin+ Clavulanic acid	0.8192 (BG)	0.2830 (BG)	0.2160 (BG)	0.1918 (BG)
Ciproflaxin	0.4096 (BG)	0.0310 (BG)	0.0986 (BG)	---
Ceftriaxone	11.3771 (BG)	3.8666 (BG)	3.3690 (B)	0.9927 (BG)
Atenolol	0.4869 (B)	0.0340 (BG)	0.3225 (BG) 0.0177 (G)	0.0069 (G)
Simvastatin	0.2207 (BG)	0.1430 (BG)	0.0873 (BG)	0.0180 (BG)
Atorvastatin	0.6765 (B)	1.3000 (B)	0.2834 (BG)	1.2117 (B)
Insulin isophane	0.7964 (B)	1.4880 (BG)	0.0650 (BG)	---
Metformin	0.0569 (BG)	0.0303 (BG)	0.0120 (BG)	0.0093 (G)
Methotrexate	0.1925 (BG)	0.1020 (G)	0.0934 (BG)	0.0694 (BG)
Hydrocortisone	3.3587 (B)	1.0647 (B)	0.5239 (BG)	1.3100 (B)
Ranitidine	0.2275 (BG)			

**Legend:** G = Generics, B = Branded, BG = Branded Generics

**Medicines Access Program: The Department of Health (DOH)'s access program for priority diseases for 2010**

Activity	Target Population	Access Points	Budget Allocation in Php
1. Vitamin A	Pregnant mothers	Basic Emergency Obstetrics and New-born Care (BEMONC) facilities/ Regional Health Units (RHUs)	70 M
2. Children with ALL2	Indigent leukemic children (500)	10 government hospitals	27 M
3. Breast Cancer	Stage I,II, some IIIa (795)	DOH-retained hospitals (8)	55M
4. Insulin	Diabetics	DOH-retained Hospitals	3M
5. Fluids	DOH Hospitals	DOH-retained Hospitals	13 M
6. Valsartan	Hypertensive Patients	DOH-retained Hospitals	14M
8. BEMONC	Women of reproductive Age	BEMONC facilities/RHUs	100M
9. HIV/AIDS	All patients in HIV registry	San Lazaro Hospital (SLH)/Research Institute for Tropical Medicine (RITM)	19 M
10. Rabies	Animal bite victims	High morbidity provinces with ordinances on responsible pet ownership	50 M



that requires all drugs outlets to upload the selling price of medicines to consumers for them to have options. This transparent data sharing also includes the Drug Price Reference System that provides an agency budget ceiling with options to offer medicines to all local government units who want to buy medicines.

Recently, the Philippine Pharmacists Association, in partnership with private health organizations, has started upgrading the training of pharmacy operators and supervising pharmacists. The upgraded training involved expanded services beyond drug dispensing with health promotion and patient counseling.

Besides the provision of medicines for the poorest of the poor, the 100-peso (USD2.3) policy, which allows the reimbursement of 100 pesos worth of medicines as take home medicines as part of out-patient benefit for PhilHealth members, has been in place since 2009 for public sector facilities.

In the same year, municipal and provincial health officers conducted workshops to expand the policy to hospitals in their localities. Discussions with the private sector are also being done to expand the program beyond government services and facilities.



As of June 2010, there were a total of 72 government hospitals in 16 provinces that were implementing the program. Affordable complete treatment packs for common diseases at the amounts of 50, 150, 200 and 300 pesos have been piloted in public health facilities in 2009.

All these packages offer savings to the public of 58 pesos to 2,000 pesos (USD1.3-46) compared to

when they buy leading brands of medicines.

The government plans to implement the 100-peso system through a central procuring hospital for each region in the country that will serve as the procuring and distribution entry in their catchment area. The system will also expand to offer 44 generic medicines and 33 new medicines.

Dr. Ala said there has been a steady growth of the generics industry where patients have access to more affordable medicines. The industry has an increasing share in the market and there is a mushrooming of hundreds of private generic outlets.

After 25 years of implementing the Generics Law, the DOH will also continue to strengthen



efforts to make sure quality generic products are available in the market and are sought by doctors, patients/consumers. Some of these are further working with the FDA on providing a fast lane to hasten the entry of generic drugs into the market; implementing a generics-only policy in the public sector; providing a generics menu card in retail drug outlets; and generics substitution.

In May and June 2013, the health department will conduct a seminar-workshop with the dispensers consisting of DOH pharmacists, district hospitals and community health pharmacists. In August, it will conduct a scientific forum with the prescribers composed of the therapeutic committees of DOH and private hospitals and provincial chapter presidents of municipal health officers.

#### CHANGING THE PHARMACEUTICAL LANDSCAPE

Dr. Guerrero of the DOH-NCPAM said the program of parallel drug importation and the series of drug price reductions in 2009 and 2010 that affected multinational and local pharmaceutical markets' annual growth from 11-12% to just 3% were helpful, but she said these were insufficient in meeting the real objective of making drugs accessible to the poor.

While generic drugs that are made affordable and accessible are now in the local market, they are not readily available in public health facilities. She said surveys still place the mean availability of key essential medicines in public hospitals and primary health care centers at only 25%, and this leads indigent patients to buy medicines from commercial outlets that restrict their purchasing abilities.

She said the price of generic drugs which may cost only 30-70% of innovator drugs may have to be evaluated especially if the prices charged to patients seem higher than actual production costs would justify.

The Cheaper Medicines Law (Republic Act No. 9502) and the Food and Drug Administration Act of 2009 (RA No. 9711) gave the government additional powers to apply TRIPS (Uruguay Round Agreement on the Trade-Related Aspects of Intellectual Property Rights) flexibilities for medicines still under patent and in ushering in an environment for the government to participate in trade deals.

She recalled that in 2006 at the height of the bird flu pandemic, the DOH raised in a WHO regional meeting the issue of patents and allowing the patent protection of the drug oseltamivir,

the generic equivalent of Tamiflu, an antiviral medicine, with then Health Secretary Francisco Duque asking its producer, the Swiss drug maker Roche, to relax its patent on the drug and allow generic companies to make oseltamivir.

Roche at that time could not commit to supply the quantity of the medicine that the DOH wanted to stockpile. Duque warned the drug company that it might be putting many Southeast Asian countries at risk if it blocks generic companies from producing the drug by insisting that its patents be honored.

Health officials later learned that Tamiflu was not patented in the Philippines, so they asked the WHO to compel Roche to allow the country to produce the drug under a compulsory licensing scheme, which Roche opposed, even if it immediately applied for a patent. But due to the dire need for the drug at the time, the government asked United Laboratories, Inc. (Unilab), a local company, to manufacture under the name of the DOH to prevent legal issues. Roche cooperated and provided the active pharmaceutical ingredient to Unilab.

Unilab provided 500,000 capsules of oseltamivir to the DOH in the following year without charging the government. The donated drugs were worth USD1.25 million.

**WHILE GENERIC DRUGS THAT ARE MADE**

**AFFORDABLE AND ACCESSIBLE ARE NOW IN**

**THE LOCAL MARKET, THEY ARE NOT READILY**

**AVAILABLE IN PUBLIC HEALTH FACILITIES.**

The local company was praised for its deed in what was considered a case of standing up to an industry dominated by multinationals. The company has had a couple more brushes with patent battles when it also produced Versant, the generic version of the anti-hypertensive drug Felodipine manufactured by Astra Zeneca although it is still facing patent infringement issues. It is also importing and distributing the generic version of Viagra, an erectile dysfunction medicine, even against the agreement of Pfizer.

The government is banking on local companies that continue to produce generic versions of off-patent drugs to make pharmaceuticals more available to poor Filipinos, as well as cooperation between local and multinational pharmaceuticals such as Unilab and Roche.

Dr. Guerrero said the challenge for the government is formidable as it faces not just drug prices, but lack of financing and fragmented supply and distributions systems.

This is not to mention having to face old and emerging infections and rising non-communicable, lifestyle diseases such as diabetes and hypertension.

But it continues to develop generic alternatives to patented medicines, simplify the processes of

registering generic drugs, and correct the misuse of patent regulations that restrict competition in the industry and cause drug prices at high costs, all finally being able to assure quality generic medicines for Filipinos.









## LIFE AND STRUGGLE

BY SUDJAI TAPHA

THAI NETWORK OF PEOPLE LIVING WITH HIV/AIDS

WHEN I learned that I was HIV+ at the beginning of 1996, many questions entered my mind: How will my life change from now on? Will anyone know I am HIV+?

But the thought that filled me with dread was that very shortly, I will die. I was in a state of confusion. I had to face more fears and worries than at any time of my life up to then. But I got through it.

At the end of 1996, I had the chance to join the activities of the Thai Network of People Living with HIV/AIDS (TNP+). I was able to meet new friends, and to talk with and listen to them.

I found that each was facing a similar problem—being shunned by their families and their communities. Some have been thrown out of their family homes, others expelled from the community entirely. Some had found huts to live in, out in the rice fields.

### EXPENSIVE MEDICINES

Some were ill, but were not able to get treatment because they didn't have money. Some didn't have rice to eat, and skipped meals. Meeting with the group once a month meant I was able

WE WOULD TELL EACH OTHER  
ABOUT ALTERNATIVE HEALTH,  
LIKE USING HERBAL MEDICINES,  
BECAUSE EVEN IF DRUGS FOR HIV  
WERE AVAILABLE IN THAILAND,  
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COULDN'T AFFORD THEM





to meet new members. But many of my friends have died. What I could do to help during that time was to keep people's spirits up and encourage sharing. So whoever had rice or anything useful would bring them from home to share with friends who had none.

We would tell each other about alternative health, like using herbal medicines, because even if drugs for HIV were available in Thailand, they were expensive and we couldn't afford them. While we could dream of getting medicines to treat various diseases, access to medicines for HIV was beyond any possibility at that time.

#### HEALTH INSURANCE

Most of those living with HIV did not have health insurance. Thus, if they didn't have money, they would not be treated. Everyone who became ill expected to die. Those of us who joined the group had to attend a funeral of one of our friends almost every day. This was a stark reminder that we were unlikely ever to be able to get the medicines we needed to survive.

People had to cope with diseases, even if they were not life threatening. Luckily, some not so expensive medicines were available for some illnesses, so people could survive.

But for other diseases, even though medicines were available, they were so expensive that we couldn't access them.

One example was infection by CMV (cytomegalovirus) an opportunistic virus, which can affect your eye, causing blindness, or your intestines, which can cause stomach ache, diarrhea and bleeding. This virus caused many of our friends to lose their eyesight, which compounded their sufferings.

From the beginning of 1998, I became one of the leaders of the Network of People Living with HIV/AIDS. I was able to participate in the Network's 2nd Assembly in Nong Khai province. During that meeting, we agreed that, apart from the problem of being despised and shunned, another important problem was the lack of access to medicines.

One example of this was not having access to the drugs to protect against inflammatory lung disease, PCP, which was one of the primary causes of death amongst HIV patients.

From a survey of leaders of the network who came to that meeting, less than 50 percent had been allowed prescriptions to protect against PCP, even though the drugs were available in the hospitals at an inexpensive price. Each pill



was only 0.5 baht (USD 0.02) per pill, but people who were HIV+ were not able to access them. Given that context, the possibility of accessing anti-HIV drugs was almost unimaginable.

This meeting was an important turning point. We began to put our hands together to work on the issue in earnest. Otherwise, things would never change. “We had to watch as our friends with HIV/AIDS died, day by day, and had to admit to ourselves that this would keep on happening...”

However, after taking a stand on this issue, the path was not so smooth and scattered with rose petals. We had obstacles to surmount, such as having to negotiate with doctors and nurses, make demands from the state, and mobilize support, for example, for our proposal for a National Health Insurance Act which would allow everyone equal access to medical treatment.

These actions were carried out at a time when people were afraid and prejudiced against

people with HIV. However, we were able to overcome this and gradually show what we were capable of. These days, the TNP+ network is recognized as one of the strongest civil society networks in Thailand.

In 1999, having developed links with NGOs, pharmacists, academics and lawyers, we learned about another issue. It was a difficult issue, but one that had a direct impact on our access to medicine: patents and intellectual property rights.

It was during that same year that we heard that there might be a drug that could work against the HIV virus, called DDI. However, it was very expensive. That’s when we learned that under the law on patents (section 51), Thailand was permitted to issue a compulsory license (CL), by which the state can import patented medicines from other countries that are selling them at a price lower than that in Thailand, or else it can produce its own medicines and make them available for the public.

On Dec. 22-23, 1999, around 100 people from TNP+ gathered around the flagpole of the Ministry of Health, and set up camp, calling it “Section 51 DDI Development Community” or the DDI village. From there, we called on the Minister of Health, Mr Korn Thappharangsi, to declare the use of CL. We consider this the first day of our struggle for justice for patients. This became big news throughout the country.

This event was the first step in the campaign of the Network of People Living with HIV/AIDS, which led to public pressure and on-going learning about intellectual property rights and patents over medicines.

On May 9, 2001, the AIDS Access Foundation together with two people from TNP+ lodged a case in Thailand’s Central Intellectual Property and International Trade Court, against Bristol Myers Squibb (BMS), an American company, 1. It called for the modification of the license for DDI (“Thai patent license 7600”) because it was evident that the patent was issued illegally.

The patent claim was expanded. The text referring to the pharmaceutical composition “from around 5-100 milligrams per dose” had been deleted by the Department of Intellectual Property, according to a request submitted by the company.

In the end, we were victorious, according to the Court’s judgment (red case no: 93/2545) on Oct.

1, 2002. This meant that the Thai patent for DDI was revoked.

But even if we won that case and the patent for DDI was cancelled, people with HIV were still not able to access medicines. This is because, mostly people in Thailand, including those with HIV, who were ill and needed treatment had to pay for health treatment themselves.

Those who had HIV/AIDS, but who were not civil servants or employees with welfare benefits, had to pay more than 20,000 baht (USD644) per month including the cost of treatment for diseases. This is why we began to think of pressurizing for a universal health insurance system. After several years, and the loss of many lives, the universal health care scheme was finally established in 2002.

During that time, Médecins Sans Frontières (Doctors Without Borders) either with the Thai Network of People Living with HIV/AIDS and the AIDS Access Foundation proposed to pay for antiviral medicines for 10 activists in the network.

The network’s committee, including myself, met together to set up the criteria to provide antiviral drugs for network activists who had worked with the movement. But not one person in that room asked for the antivirals for themselves even though some of them had begun to be ill from diseases. Everyone in the meeting reasoned out



ใครจะเป็น  
จะตายข้างมัน!!

ส่งออกต้องได้ 15%  
นะพี่

Give us GSP!  
I'm ready  
to trade off  
PATIENTS' LIVES.

ขอเรียนให้ทราบว่า  
กรุณาอย่าลืม  
ห้ามต่อสาย

ห้ามต่อสาย



AS A RESULT OF OUR STRUGGLE,  
THE GOVERNMENT BEGAN TO  
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TO 100 PEOPLE WITH HIV IN THE  
FORM OF A RATIONED ALLOCA-  
TION TO TRAINED HOSPITALS  
THROUGHOUT THE COUNTRY



that their friends and others who were not sitting there, did not have any access to medicines, and what would they think of us?

In the end, none of the committee members asked for the antiviral medicines for activists, even though many met the criteria. Subsequently, many leaders in the struggle became ill and later died. “They are my inspiration, they give me the will to work on and be committed to the network today.”

As a result of our struggle, the government began to provide antiviral medicines to 100 people with HIV in the form of a rationed allocation to trained hospitals throughout the country. However, there are still many limitations in the provision of antiviral medicines in hospitals in Thailand.

A big number of people with HIV still have not had any antiviral drugs even though they met the criteria to access these drugs. The hospitals use a random draw method to decide who will be lucky to get access to the antiviral drugs each

time. Many people lost hope because they didn’t succeed in the draw. Many people were not able to wait for the next round of the draw, and died.

Those who got the virus were not always lucky. During that time, none of us knew about the side effects of these antiviral drugs. Not even the doctors or nurses had much information about it. Many of our friends, who were not able to bear the side effects, had to stop taking them. Some died while taking the antiviral drugs. This led us to develop information for network leaders about diseases and the antiviral drugs, so they would know how to use them, and could advise their friends and coordinate their work with doctors and nurses in the hospitals. We in the network used to call them the “barefoot doctors.”

We mobilized to demand that the government increase the quota of antiviral drugs, but it took a long time to get a response each time. It wasn’t easy. The government claimed that its budget wasn’t enough to provide antiviral drugs for everyone, because the drugs were expensive. This

is why we began to fight to mobilize for a compulsory license to import cheap antiviral drugs from India. We were successful in 2006.

At present, I am using an antiviral medicine prescription of TDF+3TC+EFV. I switched to these because I also have Hepatitis B. Many of my friends have to use the same prescription as mine, as well as other necessary medicines.

One issue of the government’s ongoing Free Trade Agreement (FTA) negotiation policy that I and the network have always monitored and kept our eyes on is our insistence that the state must not use the issue of medicines and intellectual property rights as bargaining chips to obtain other concessions on trade.

My friends and I have participated in many large mobilizations, such as the protest in Chiang Mai against the negotiations for an FTA between Thailand and the United States. Many people from different networks have joined in this mobilization, including over 3,000 people from TNP+. Eventually the government was forced to stop the negotiations.

Our struggle continues to this day. In particular there is a strong push from the European Union to negotiate an FTA. They have shown their clear intention to increase their control over intellectual property rights and establish patent monopolies, by extending the lifetime of patents under an agreement called TRIPs+.

If the Thai government under Prime Minister Yingluck Shinawatra, accepts this agreement, as it has threatened to do, they will be agreeing to impacts that could be fatal for us. If I or other friends with HIV ever need to change our prescriptions, we will no longer be able to access these medicines.

Those with other illnesses could suffer the same fate.

In the end, the circle of illness and death will return quickly. The government will spend more from the national budget buying more expensive medicines. Our contribution to the fight for a system of health insurance will have meant nothing. But worst of all, such an agreement will mean that our people must lose their lives.



## ABOUT THE AUTHORS

**DIANA G. MENDOZA** is an independent journalist contributing to the Women's Feature Service, Inter Press Service, and Rappler.com. She covered health and social development, and until today, specializes in social and human development issues. She was recognized for Best Individual Reporting Effort from the US Population Institute's Global Media Awards for Excellence in Population Reporting and Second Best News-feature in Print given by the AIDS Society of the Philippines. She has co-authored and co-edited 11 books and publications on media, gender, sexuality, reproductive health, and HIV and AIDS.

**RACHMI HERTANTI** is Research and Monitoring Manager of Indonesia for Global Justice (IGJ), an organization that works on free trade issues. She has been active as a paralegal assisting workers with legal cases in the courts. She graduated from Trisakti University Law School. In 2010, she obtained her Master of Law degree under the International Trade Law Program of the University of Indonesia, with specialization on WTO and ASEAN.

**SUDJAI TAPHA** started his work on HIV and AIDS in 1996 as a leader of a people living with HIV/AIDS (PLHIV) group, known as "Puen Sampan Baan Rom Yen". The group had an aim to provide assistance to the other PLHIV in the community. He helped the group to support other PLHIV - providing information of prevention and treatment, giving counseling, conducting home visit, etc.

The Thai Network of People Living with HIV-AIDS is comprised of over 1,000 PLHIV groups throughout the country. It has an active role in fighting against HIV & AIDS in aspects of raising awareness, prevention, promotion of access to affordable anti-retroviral treatment (ART), advocacy on inclusion of ART in the universal coverage scheme, campaigns against Free Trade Agreements with the TRIPS plus provisions undermining access to essential medicines.

## PHOTO CREDITS

**SONNY YABAO**

Cover photo; pages 6, 8, 30, 34, 36, 38, 40, 42, 44, 46, 48, 52, 54, 59, 60, 62, 67, 68, 70

**JL BURGOS**

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**KARNT THASSANAPHAK □**

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**CHALERMSAK KITTITRAKUL**

Pages 72, 74, 76, 78, 80, 86

## ABOUT THE PHOTOGRAPHERS

**SONNY YABAO** is a former photo editor at Newsday. He was named Photojournalist of the Year by the Press Photographers of the Philippines and the National Press Club in 1995. That same year, his pictures were part of *The Philippines: A Journey Through the Archipelago*, a book which takes readers on a visual voyage via the works of 35 of the world's best lensmen. He was also lead photographer for other Philippine travel and culture volumes including *Tagaytay: Town on the Ridge* (1996); *Philippine Christmas: Art & Form* (2002); *Memory of Dances* (2002, authored by award-winning journalist Shiela Coronel); *Cagraray: a Bicol island-world* (2005); and *Iloilo: A Rich and Noble Land* (2007). More about Sonny and his work at [www.sonnyyabao.com](http://www.sonnyyabao.com)

**JL BURGOS** is an independent filmmaker/visual artist based in the Philippines. A fierce and staunch advocate of human rights, Burgos unfortunately lost a brother to state terrorism. His brother Jonas Burgos, a farmer/activist, was taken by force and made to disappear in broad daylight on the 28th April 2007. Burgos now channels his creativity to artworks that keep the memories of the disappeared alive in the hopes of encouraging people to join in search for justice.

**RIKA FEBRANI** is campaign and international networking staff of Indonesia for Global Justice. Her interest in the issue of trade, investment and the practices of multinational companies influence her photography.

**KARNT THASSANAPHAK** is a freelance artist and activist in Thailand. His work has been exhibited in the Philippines, South Korea, Chiangmai and Bangkok in Thailand.

**CHALERMSAK KITTITRAKUL** is Campaign Coordinator for Access to Medicines, AIDS ACCESS Foundation in Thailand.



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