Fighting AIDS in Court
The TREAT Asia Report Interview: Anand Grover

Many of the most important advances in the rights of people living with HIV/AIDS in India can be traced to the work of the Lawyers Collective and its HIV/AIDS Unit, headed by Anand Grover. Mr. Grover’s landmark legal efforts have included arguing the first HIV case in India relating to employment law and the first case opposing patent law related to medicine. In addition, he has litigated with notable success on behalf of marginalized groups such as men who have sex with men (MSM), sex workers, drug users, women, and children. In this interview, Mr. Grover speaks about the centrality of human rights in the fight against HIV/AIDS.

TREAT Asia Report: The Lawyers Collective recently won a major victory for people with HIV/AIDS who rely on generic antiretrovirals (ARVs). What happened in that case and what are its implications for treatment access?

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For Indonesian Drug Users, HIV and Addiction Present a Double Burden

Quietly and destructively, starting in the mid-1990s a low-grade form of heroin known as putaw found a thriving market in Indonesia’s cities. The sharp increase in injection drug use led to a dramatic rise in HIV/AIDS among users. Today, Indonesia finds itself battling twin epidemics of drug addiction and HIV/AIDS.

For HIV/AIDS advocates and activists in this Southeast Asian archipelago, fighting HIV/AIDS among injection drug users (IDUs) takes place in a world of contradiction. “IDUs are the easiest people to work with—and the most difficult,” says Samuel Nugraha, a longtime HIV counselor who is now with the UN Office of Drugs and Crime HIV/AIDS unit in Indonesia and who serves on TREAT Asia’s steering committee. “Compared with other vulnerable groups, they

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HIV and Addiction in Indonesia (continued from page 1)

have less shame, they’re not hidden so it’s relatively easy to reach them. But they are addicts, and the addiction itself is often too much to overcome. When it comes to adherence to medication or responsibility, their priority is their addiction.”

Dhayan Dirgantara has worked closely with IDUs as an HIV treatment educator, first in Bali and now in Jakarta with the Spiritia Foundation, and like Sam he sees the double burden of his clients’ lives. “For IDUs, dealing with HIV isn’t just about HIV,” he says. “To get healthy, they have to go to rehab, change their habits, change their environment, change their friends—it’s so much harder than just taking ARVs [antiretrovirals].”

The number of IDUs in need of HIV treatment is daunting. In 1995, barely one percent of Indonesia’s HIV cases were attributed to injection drug use; today, drug-related transmission accounts for almost half of its HIV caseload, according to the Ministry of Health.

For many years, ARV treatment for IDUs was withheld because of their drug dependence—IDUs who wanted medication had to have been clean for at least six months. In the minds of policy makers, Sam explains, “the issue was treatment adherence. If you’re still using drugs, you’ll never make ARV treatment a priority. But these people need to understand the concept of harm reduction: as long as you can be on treatment and access services, that will reduce the harm. A lot of people cannot accept that concept.”

“Different donors have different agendas,” explains Sam, “so there is competition.”

“For IDUs, the only effective way is to provide options,” he continues. “You have methadone, you have clean syringes, you have ARV treatment, you have rehab, you have drop-in centers.

“People started losing faith in rehab because they thought putting their kids in would be like putting their cars into the garage—they want them fixed.”

“People have started losing faith in rehab over the past couple of years because they thought putting their kids into rehab would be like putting their cars into the garage—they wanted them to come out fixed. But the rate of relapse is really high regardless of the approach. A single methodology will be successful for only about eight percent of addicts. If one approach doesn’t work, maybe they need something different, but many projects don’t offer a comprehensive set of approaches.”

Dhayan agrees, pointing out that different NGO-funded drug treatment projects “don’t even share information or data with each other.”

The solution, they both agree, is strong central coordination. “But it’s hard to get everyone on the same page,” Dhayan notes. “The government cannot impose its ideas on funders because they need their help to save lives.”

Even so, nationwide efforts to slow the spread of illegal drugs in Indonesia—and limit the spread of HIV among IDUs—have begun to bear fruit. Seven years ago there was little talk or action about drugs, says Dhayan, but between Indonesia’s tough drug laws and the efforts of its AIDS control programs, current projections show the epidemic easing away from IDUs by 2010.

Still, the two advocates admit that they can be discouraged. They’re both young, but they’ve been fighting HIV/AIDS for years and the progress can seem achingly slow. Nonetheless, they remain committed. “There’s always hope that we can make a small advance,” says Dhayan. “The willingness is there, the money is there, but the challenge is how we get it together. We must work together.”
I was born in a poor village in Kien Xuong district of Thai Binh province. I got married to a classmate when I was 19 years old. We were farmers; our life was simple but full of happiness. Five years later, we had two daughters and my husband moved to the city to earn money. In 2003, we decided to try to have a son. When I was six months pregnant, I went to a free program for pregnant women and got a blood test.

A month later, I received an HIV-positive result. I was so shocked that I nearly became unconscious. I was crying and protesting to my husband, and I asked my in-laws whether I should keep the unborn baby. Soon, our HIV status was known throughout the whole village.

My husband started to get sick and I had to take care of him, though I was still very angry. At the same time, I had to suffer the curious and fearful looks of villagers. I tried to sell my vegetables and fruits in the market but no one bought—not even my best customers. My in-laws even asked us to use separate cups and bowls. I used to think about death at that time, but the unborn baby moved inside me and I dared not kill myself.

To protect the baby, I went to the local health station to access the PMTCT [prevention of mother-to-child transmission] program. After two months of sickness without any treatment, my husband passed away, and I delivered my third child 10 days after his death. Everyone felt compassion when they saw me holding the baby and sitting beside my husband’s altar. But I didn’t know what my future would be. I had to bring up three children and face stigma and discrimination from relatives and neighbors.

After a while, I was invited to attend a meeting for the wives of migrant workers where I asked the doctors from the district health department about HIV transmission and how to prevent it. I brought back the materials to my mother-in-law and neighbors. I also saw something on TV about the outpatient clinic in Thai Binh. At that time, I didn’t know anything about antiretrovirals and opportunistic infections. The doctor told me that I only needed to register and I would get free medication so I was very happy.

Once I began to learn more about HIV and speak out publicly about my status, things began to change. In December 2004, Viet Nam TV invited me to appear on “Happy Home Builders,” a program about people who have overcome great difficulties such as poverty, illness, and stigma, and have managed to keep their families strong. When I traveled to Hanoi and met other people who had lived with HIV for years, I began to hope that I would live a few more years myself.

Then I thought of establishing a support group in our village. So the other seven PLWHA in my commune asked for help from the leaders of a self-help group in Hanoi called Bright Futures. Our monthly meetings helped group members monitor and manage their health, and our group activities attracted many people seeking spiritual and physical care and support. And with 27 members of our group receiving free ARVs from the national program, the death rate among us decreased significantly.

Many people in the community, even the local leaders, realized the effectiveness of our activities and began to support us. We were invited to training courses on treatment, leadership, communication, and drama performance. I even had a chance to participate in courses to train trainers on treatment literacy, and learned how to become a facilitator. I feel that what I am doing is so meaningful.

Now my support group is big, my children are growing up, and I have a chance to participate in many activities. Thinking back to five years before I was first diagnosed, I could never have imagined I would have such a bright future. In a small way I have participated in breaking the barriers of stigma and discrimination and have helped PLWHA be confident to disclose their status and get treated.

Many PLWHA still need our support and I hope our activities will help them to think positively, get out of the dark, and integrate into the community. I hope that the local authorities will partner with us in these programs.

Looking back, I am happy with what I have done. In the future, I hope to strengthen self-help groups in Thai Binh, educate a trainers team for each group, and update information and knowledge so we may form a collaborative, home-based care team in our province.
Try would have been adversely affected and the low-priced generic ARVs they manufacture would not have been available when patent protection kicked in. Not only would low-priced generic ARVs been undercut in India, but also in other developing countries, where India supplies 50% of the drugs required. We argued that Indian law was not only perfectly within the TRIPS mandate, but that it did not violate the equality clause of the Indian constitution. The Novartis case was decided in our favor.

Apart from patent law, there is an immediate question of how long Indian pharmaceutical companies will remain “Indian” and how long they will remain generic. Matrix is already not an Indian company, it’s controlled by a US company, and Ranbaxy has now been taken over by a Japanese company, Daiichi Sankyo. So there is a concern over whether these companies will remain truly generic. Unless we have Indian companies to produce generic drugs, our efforts are not going to be very successful in the long run.

**TA Report:** You’ve spoken about bulk procurement of ARVs as a way for middle- and low-income countries to afford the medications they need. How would that work?

**Grover:** For example, right now second-line ARVs are not in demand in India—the government is financing second-line ARVs for only 3,000 patients. Even if we push that number up to 10,000, it’s not an economically viable project for the generic or brand drug companies.

But if you bring India, Thailand, Malaysia, South Africa, and Brazil together into a cartel for bulk purchase—which is not anti-competitive at all—then you can actually create a market that is large enough and economically viable for drug companies in India to benefit. The drug companies are looking for economies of scale, and unless that’s proactive-ly done by the government, it will be too late.

Currently the procurement of second line ARVs is done through, and the price is set by, the Clinton Foundation. But they go for small purchases and the companies bid for the drugs individually. Right now there’s no such thing as a commodities market for drugs. We should be able to create such a market in Asia where people need those drugs that are not under patents so you can move towards economies of scale.

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There’s no problem with bulk purchasing itself, it’s just that the governments of these countries have to start thinking in a collective manner. Individual ministries of health are quite agreeable to this idea but it’s not progressing because of various bureaucratic hassles. I’m keen on pushing this as a major step forward.

**TA Report:** The Lawyers Collective has drafted a national HIV/AIDS bill. What approach does the bill take to rights issues and what is its status?

**Grover:** A few years ago, the Indian government asked the Lawyers Collective to draft a comprehensive HIV bill to protect the rights of people with HIV/AIDS and to prevent transmission. That bill is currently under review by the Law Ministry before it will be presented to Parliament. I’m a bit worried because it is taking a long time. However, we have the full support of NACO [the National AIDS Control Organization], the Health Ministry, as well as civil society.

If we get the HIV/AIDS bill passed, it will protect and promote the rights of HIV-positive people and, in our opinion, help facilitate the curtailment of HIV transmission to the general population. When rights of vulnerable groups are protected, people are empowered and then they’re more responsible. The bill we drafted outlaws discrimination against people with HIV/AIDS across the board, both in the public and private sector. In addition, it addresses access to treatment—including first-line, second-line, third-line, and all other drugs and diagnostics, free of charge. With a statute conferring the highest attainable standard of health as an established right, it will help us push universal access forward.

The proposed bill also addresses risk reduction, including safe havens for clean needle and syringe exchange, and condom promotion among MSM and sex workers. It also tackles nondisclosure of confidential information and
Of course, the most important aspects of the HIV/AIDS bill are the antidiscrimination clauses because there is a lot of stigma attached to HIV. Preventing that requires not only understanding but legal recourse, which the bill provides.

**TA Report:** Your office is also representing a challenge to India’s anti-sodomy law, which essentially makes homosexual behavior illegal. Where does that case stand?

**Grover:** The matter is being heard in the Delhi High Court right now, if it actually starts on time. By the end of the year we should have a verdict. Initially the matter was dismissed by the Delhi High Court, but the Supreme Court remanded it back, saying they should decide afresh and not summarily dismiss it. If we win, the law that criminalizes what it calls “unnatural sex” (sodomy or oral sex) would no longer be in force.

“A lot of the most successful human rights interventions in health have been exemplified in HIV”

**TA Report:** Where do harm reduction efforts stand in India?

**Grover:** One of the major lines of our work in the Lawyers Collective involves concentrated HIV epidemics among marginalized groups, such as drug users, sex workers, and MSM. As these groups are the most vulnerable to HIV, they need to be protected, so we are working to develop their rights concretely. One of the primary ways we’re trying to do this is by fighting for harm reduction measures. We’re doing a lot of advocacy with the Health Ministry and they’re totally convinced about the wisdom of harm reduction. They’re also convinced about changing the laws relating to homosexuality, sodomy, and sex workers. Recently, some of the ministers in the government have come out in support of decriminalizing sodomy and same-sex relations, which the proposed HIV bill does. While the proposed bill provides safe havens, it does not legalize drug use.

Harm reduction is being pushed as policy but currently it is not protected by law, so someone can just turn around and say, “Why are you doing all this nonsense? We’re going to stop it because you’re not allowed to do it under the law.” So we have to give them protection and that’s what the proposed bill does. It’s still a huge political battle to be fought in the mainstream.

**TA Report:** You were recently appointed by the UN Human Rights Council to the post of the Special Rapporteur on the Right of Everyone to the Highest Attainable Standard of Mental and Physical Health. What will the position entail, and how does your work on HIV influence your approach to this mission?

**Grover:** As the new Special Rapporteur, I will be in a position to address serious violations of the right to health worldwide. Basically, the aim is to advance the cause of human rights and health, not only in relation to HIV but also with other major diseases such as tuberculosis [TB], malaria, and hepatitis.

As the new Special Rapporteur, I will be in a position to address serious violations of the right to health worldwide. Basically, the aim is to advance the cause of human rights and health, not only in relation to HIV but also with other major diseases such as tuberculosis [TB], malaria, and hepatitis. A lot of the most successful human rights interventions in health have been exemplified in HIV—particularly the rights-based approach and the involvement of affected communities, which have made a big difference in terms of whether you treat health as a human right. These have to be replicated in other areas. As an example, access to treatment is a big issue everywhere, not only with HIV. In other countries, the treatment of TB and malaria is becoming a rights-based issue. So the rights-based approach is something we have to carry beyond HIV.

Treatment isn’t only from the top down—it’s actually about implementing rights and empowering people. A lot of countries think, “What have rights got to do with health?” But if you motivate and activate the community to demand its rights, whether it’s the deployment of resources or access to treatment, that means that the community is not dependent on healthcare professionals alone. Healthcare is then more of a team effort, from patients to healthcare workers to the government.

As Special Rapporteur, I hope to address gross and serious violations of the right to health by holding regional consultations with affected communities. Women and children, sex workers, people with HIV, drug users, historically oppressed groups such as natives and indigenous peoples, even health professionals—the voices of these communities have been unheard, and they need to be at the forefront of decision making. Our experience with HIV has shown that community input is extremely important.

It’s a big challenge for the Special Rapporteur, especially because this is about health. It’s easy to understand the rights-based approach to political rights. With health, people still question it. But that message has to be understood and replicated and implemented across the board.
At Bangkok’s Ramathibodi Hospital, a TREAT Asia site since 2003, the benefits of expanded access to antiretroviral therapy (ART) are evident—more patients are surviving and follow-up rates are high. But physicians there are also confronting the new realities of the epidemic, including a shortage of doctors to treat increasingly long-lived HIV patients and the threat of resistance to common first-line anti-HIV medications.

According to Dr. Somnuek Sungkanuparph, an attending physician in Ramathibodi Hospital’s division of infectious diseases and the principal investigator for TREAT Asia research projects at the hospital, his country’s successful expansion of access to treatment has given his patients the opportunity to live longer and better lives. However, the reality of extended lives means that treatment needs to be extended, too, which requires more staff at major hospital centers like Ramathibodi Hospital. Like other large teaching hospitals in Thailand, Ramathibodi Hospital attracts patients from around the country seeking treatment from its HIV specialists; indeed, the hospital’s HIV/AIDS caseload currently numbers more than 2,000 people.

“We have to see them all,” said Dr. Somnuek, explaining that some patients choose to travel to Bangkok and pay for treatment there rather than use their local hospitals.

In addition to ART, Ramathibodi Hospital provides prophylaxis and treatment for opportunistic infections, HIV testing and counseling, HIV education for patients and healthcare providers, and advanced laboratory testing. Despite the demands of managing a large caseload, Dr. Somnuek noted that the hospital is able to treat so many people successfully because of the increased availability of generic ART.

“Seven or eight years ago, we had almost all the medicine that was available in the U.S., but 90 percent of our patients could not pay for it,” he said. “We had about 10 or 20 patients each day who were hospitalized with HIV and opportunistic infections.” Now, he explained, 90–95 percent of his patients who need ART can receive treatment with generic drugs, which are largely subsidized by the national AIDS program. “Our patients can go back to work and be with their families; they can get a job and can function in society,” he continued. “I think that’s a really big change here in Bangkok and in Thailand, and it’s also something that inspires doctors, nurses, and other medical personnel to help us, because they can see how much they can change the patients’ quality of life.”

One complication doctors in Thailand and around the world are encountering is resistance to first-line ART regimens—a factor that is threatening the long-term success of treatment scale-up efforts. To address this issue, Ramathibodi Hospital participates in numerous research studies, including the TREAT Asia Studies to Evaluate Resistance (TASER). This research project was established to create a system for monitoring the emergence and spread of drug resistance throughout Asia, which is crucial to identifying effective second-line treatments.

Ramathibodi Hospital, which has been participating in TASER since 2006, has enrolled more than 120 patients in the study so far and plans to enroll up to 200, approximately 10 percent of its patients. By studying this sample, doctors are gaining insight into how many patients are resistant. “We’ve never seen that picture before,” said Dr. Somnuek. In addition, participation in TASER means that the hospital’s lab is now part of the TREAT Asia Quality Assurance Scheme, which is helping to standardize the performance of labs across the region.

About five percent of the clinic’s patients show signs of drug resistance 24 months after the initiation of treatment, according to Dr. Somnuek. Most treatment failure, he said, results from imperfect adherence to the most commonly used ART in Thailand—an NNRTI-based regimen—which is inexpensive, easy to take, and causes few adverse effects but must be taken correctly at least 95 percent of the time in order to work effectively. Other patients who have been referred to Ramathibodi Hospital experience treatment failure after taking a suboptimal first-line regimen prescribed by physicians who lack experience and knowledge of ART.

In addition to contributing data to TASER, Ramathibodi Hospital is part of the TREAT Asia HIV Observational Database (TAHOD), and has contributed data to TAHOD’s published research. The hospital’s participation in the database not only helps TREAT Asia develop a more accurate picture of epidemic trends in the region, but also allows doctors to share experiences with other TREAT Asia sites. Learning from other physicians in the region, said Dr. Somnuek, “inspires us to do better and to develop goals that we may be able to achieve in the future.”
TREAT Asia Participating Sites

National Centre for HIV/AIDS, Dermatology, and STDs
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Queen Elizabeth Hospital
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www. qeh.org.hk

Tangdu Hospital, The Fourth Infectious Disease Hospital
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Institute of Infectious Diseases and Foundation for Research in Infectious Diseases
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www.imc.go.jp

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www.ym.edu.tw/english/ History.htm

TREAT Asia Supporting Organizations

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New Hope for Cambodian Children
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www.pmc.edu.my/hospital.html

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www.hivnat.org

Siriraj Hospital
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www.si.mahidol.ac.th/siriraj

Chiang Mai University, Pediatric Department
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www.cmu.ac.th/web8/index48.php

Harvard School of Public Health Program for HIV Prevention and Treatment, Thailand
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www.phpt.org/?lang=en

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TREAT Asia at the XVII International AIDS Conference

TREAT Asia was well represented at the XVII International AIDS Conference in Mexico City, from 3–8 August. Dr. Adeeba Kamarulzaman, chair of the TREAT Asia steering committee, delivered a plenary address on harm reduction for injection drug users. Jack Arayawongchai, TREAT Asia’s MSM program coordinator, spoke at a pre-conference event on HIV among men who have sex with men (MSM), sharing best practices from Asia that have helped to strengthen MSM advocacy and have encouraged many national governments in the region to support the development of MSM programs.

In addition, TREAT Asia’s director of research, Jeffery Smith, presented a report on the progress of LAASER, a collaborative effort supported by the Dutch Ministry of Foreign Affairs to build capacity for the monitoring and surveillance of HIV drug resistance in developing countries in Asia and Africa.

TREAT Asia also presented research data from the TREAT Asia HIV Observational Database in two poster sessions. A third poster described the activities of the TREAT Asia Quality Assurance Scheme to standardize HIV genotypic resistance testing. In addition, representatives of the TREAT Asia-affiliated Purple Sky Network presented two posters detailing aspects of their work with MSM and summarized their experience with peer outreach.

News Briefs

CHINA
One hundred thousand condoms and HIV/AIDS prevention pamphlets were distributed to athletes participating in the Beijing 2008 Summer Olympic Games via medical centers in the Olympic village. “There are many young, strong, single people in the athletes’ village and, like everywhere, some will fall in love or other things, so we need to make condoms available,” said Ole Hansen, a spokesperson for UNAIDS China. The Beijing Health Bureau also distributed 400,000 condoms and 250,000 pamphlets during the games in more than 90,000 rooms in 424 hotels in the city. The materials were provided by UNAIDS, the Beijing organizing committee, and the International Olympic Committee. (Reuters, 12/8/08; Xinhuanet, 15/8/08)

PAPUA NEW GUINEA
Despite significant progress in scaling up HIV testing and counseling services and access to antiretrovirals (ARVs), Papua New Guinea has the highest prevalence of HIV/AIDS and STIs in the Asia-Pacific region, said Michel Kazatchkine, executive director of the Global Fund to Fight AIDS, Tuberculosis and Malaria. The number of people who have accessed HIV testing and counseling has increased five-fold this year, reaching almost 82,000, and the number with access to ARVs has risen from fewer than 200 in 2005 to 2,800 as of March 2008. But the country’s overall prevalence is 1.28 percent among adults 15-49 and rising, with the greatest increases coming in rural rather than urban areas, and among young girls and older men, according to recent research. (Papua New Guinea Post-Courier, 17/1/08; PACNews/Islands Business, 7/1/08)

Amnesty International has also reported that violence against women in Papua New Guinea is contributing to the spread of HIV. AIDS-related deaths are “sometimes believed to be the result of sorcery,” for which local women, accused of practicing witchcraft, are tortured or murdered. Researchers at the Centre for Independent Studies in Australia estimate that there have been 500 such attacks in the past year. (Australian Associated Press, 30/5/08)

PHILIPPINES
The Philippine Department of Health will now actively promote condoms to fight the spread of HIV, despite opposition from the local Roman Catholic Church, which strongly opposes all forms of artificial contraception. “The use of condoms to prevent the spread of HIV/AIDS is different from their use for birth control. The church’s position is detrimental to public health,” said Health Undersecretary Mario Villaverde. “We cannot really prevent people, regardless of their religious belief, from engaging in high-risk behavior, and so we must educate them and we must provide some preventive and control measures for them.”

Although the Philippines is considered a low-prevalence country, with less than 0.1 percent of the population HIV-positive, the number of people living with HIV/AIDS rose nearly 25 percent in the last five years. In 2007, the Philippine Department of Health and the World Health Organization estimated that 7,490 people were living with HIV/AIDS in the Philippines, up from the 6,000 in 2002. (Agence France-Presse, 28/8/08; Philippine Star, 29/9/08; Philippine Daily Inquirer, 28/8/08)