

“One of Sankalp's main goals is to sensitise police and law enforcement to the realities of drug use and to raise awareness about the issues that drug users face” (see page 4)

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VIEWS AND VOICES

Roche Patent on Pegasys Overturned!

On November 2nd the Intellectual Property Appellate Board revoked a patent granted to the Roche pharmaceutical company for Pegasys, a Hepatitis C medication, opening the market for less expensive, generic Hep-C medications and ending Sankalp's five year battle against the patent. The patent, which was granted to F. Hoffmann-La Roche AG (Roche) in 2006, gave Roche a monopoly on pegylated interferon alfa2a (Pegasys) which was being sold at an astounding INR 4,26,000 (USD 8,752) for the 6-month treatment needed to cure chronic Hepatitis C. Even at the discounted rate of INR 3,14,496 (USD 6,313) (not including the INR 47,160 cost of the drug ribavarin which needs to be taken in conjunction with Pegasys) the cost of treatment was unmanageable for the majority of the 10-12 million individuals in India infected with Hepatitis C. Additionally, due to its high cost, the medication has been largely unavailable at government hospitals.

Hepatitis C is of particular concern to Sankalp as many of our clients suffer from the Hepatitis C Virus (HCV) and estimates show that approximately 50% of IDUs in India are infected. HCV is a blood-borne disease that can lead to liver cirrhosis, liver cancer or liver failure and is of particular danger to those co-infected with HIV. Studies have shown that HIV-HCV co-infection can cause increased rates of disease progression.

Concerned about the implications the patent would have on access to the HCV medication, Sankalp, with the aid of the HIV/AIDS Unit of the Lawyers Collective, filed a post-grant opposition challenging the patent in 2007 claiming that Roche's medication did not fulfill India's patentability requirements. When Sankalp's opposition was rejected in 2009, they quickly filed an appeal with the Intellectual Property Appellate Board (IPAB). Roche then challenged Sankalp's ability to file the opposition in the first place,

arguing that because Sankalp was not a researcher or competitor it had no claim to challenge the patent. Sankalp contended that it represented a community directly affected by, and at risk of contracting, HCV and therefore had a stake in the patent.

The verdict on November 2nd not only revoked the patent but also set the precedent that a patients' group can challenge the validity of granted patents. This ruling opens the door for more groups to challenge patents in order to increase access to and affordability of medications.

Our hope now, following the verdict, is that the absence of the patent barrier will spur generic competition and bring down the price of this vital medication for those suffering from Hepatitis C. We also hope that that the government will take concrete steps to start providing access to the medication so that there will be no more needless deaths due to this treatable illness.



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Write to us at sankalp.trust@gmail.com with the subject "Mailing List" to continue to get our newsletter via electronic mail. In our efforts to promote environmentally friendly practices and reduce our usage of paper, we will be transitioning to an electronic format of our newsletter.

A Visit to the International AIDS Conference

By Eldred Tellis, Director

The International AIDS conference held in Washington, DC turned out to be a rather drab affair. The Conference was convened by the International AIDS Society in collaboration with local and international partners. Since the ban on visas for drug users and sex workers was not lifted, the conference felt very one-sided as a large majority of participants in the almost 27,000-strong in attendance were from the lesbian, gay, bisexual, and transgender (LGBT) communities. Strangely, after the long preparation that went into my plan to attend the conference in the U.S., there was a "Satellite" Conference for Injecting Drug Users and Sex Workers in our very own Kolkata!! This must have made it quite difficult for U.S. Secretary of State Hillary Rodham Clinton to address the huge gathering on "Ending the Epidemic: Turning the Tide Together."

The activist in me took a lead role in condemning such discriminating policies by the U.S. administration. There were marches organized to the White House which protested the visa issue and called for ending the War on Drugs. These marches were attended by thousands of participants and luckily got a fair amount of attention

though it was so close to the U.S. elections.

One highlight of the conference for me was a special press conference organised to release a report of a Workshop on Hep C that had been held in India prior to the Conference. I had the opportunity to address the subject of lack of access to Hep C treatment in India which was a concern in many other parts of the world as well.

The overarching thought of the Conference was to encourage scale-up on the global implementation of effective interventions to treat and prevent HIV infections. It was really heartening to notice that there was always mention of treatment and prevention in the same breath rather than one versus the other as it has been in years gone by. It was the moral responsibility of all governments to scale up implementation of scientific interventions which would help us move towards an AIDS-free generation.

Today some of the significant challenges facing the global epidemic include implementing treatment as prevention in settings most affected by HIV/AIDS, research towards a cure and using funding efficiently.



Eldred Tellis presenting the Hep C Workshop Report at the 2012 International AIDS Conference

Dance Pure



The house was packed at DancePure on June 27th

The lights were shining on the stage, DJ Pearl was pumping out the tunes and the dance floor was full of revelers showcasing their best moves. Everyone was out to celebrate Dance Pure, a night free of illicit substances, a night of enjoyment through dance and music without drugs, a night to support Sankalp.

Under the fearless leadership of Tara Humphries, and the support of countless others, Dance Pure was a huge success and a true community effort. FBar, located in One India Bulls Centre in Lower Parel, graciously hosted the event. Larson and Tubro, a long time friend of Sankalp, sponsored the evening. Sankalp supporters new and old helped to raise money through advertisements in the souvenir, donations throughout the night and attending the show!

The evening started out with a set from the FBar's resident DJ, DJ Amul. This opening was followed up by DJ Nasha and DJ Pearl, two of India's top DJs. Sankalp was honored to have such big stars featured at Dance Pure. We are truly thankful for the time and energy they dedicated to the organization and to helping Mumbai's drug users. DJ Pearl even spent her birthday night playing for Sankalp a true commitment!

The night was a successful kickoff to our new fundraising initiative. However, the show was not only a fundraiser for Sankalp, but also a chance to raise awareness and

promote clean fun, without the any illicit substances. And Dance Pure doesn't stop at just this night. In face, it's only beginning and we look forward to continuing with Dance Pure to advocate for a life free of drugs.

For all those who supported us, thank you!



DJ Nasha & DJ Pearl rocked the house

Partnership with Police Spurs New Initiative at Detox Centre

Sankalp has recently partnered up with social activist Ms. Pamela Dutta and Senior Police Inspector Damodar Choudhary of the Chunabhatti Police Station in a combined effort to help drug users and curb crime in the area. Through this new initiative, started only this July, Ms. Dutta and Inspector Choudhary have already sent two drug users from Kasai Wada in Kurla to Sankalp's Detox Centre.

"Drug users commit crimes to get drugs. They can do anything when desperate for their drug. If they are helped, then they will come back to their family and society, and naturally, they will leave crime as well," explained Inspector Choudhary.

In Kasai Wada, drug users mainly abuse prescription pharmaceuticals and Iodex, as well as alcohol. Therefore, Inspector Choudhary and Ms. Dutta began by holding a series of meetings with doctors and pharmacists in the area, strongly urging them to stop selling medications without proper prescriptions. Their next step was to find an organisation at which the drug users could receive help.

"I found that Sankalp was the best among all the organisations in this field. Sankalp had a few videos uploaded on its website where I saw ex-drug users speaking about their experiences, and I really liked it... I felt like I was sending the boys to the right place at Sankalp, where there would be a positive result," said Ms. Dutta.

Sankalp Director Eldred Tellis agreed to partner up with Ms. Dutta and Inspector Choudhary and set up a one month programme for their drug-using clients. One of Sankalp's main goals is to sensitise police and law enforcement to the realities of drug use and to raise awareness about the issues that drug users face. An opportunity to work directly with the police in helping drug users was a key step forward in strengthening this advocacy work.

Inspector Choudhary, Ms. Dutta, and Mr. Tellis all attended a meeting held on July 3 at Kasai Wada for drug users, where Mr. Tellis talked about the importance of addressing one's drug use. After the meeting, Inspector Choudhary was contacted by families who wanted their drug-using relatives to receive help and attend Sankalp's programmes for recovery. Two of these users were Salim and Sarvar, both young men from Kasai Wada.

After attending the meeting and seeing drug users in much worse conditions than themselves, Salim and Sarvar both decided to put their drug use to an end for good and signed up for the new one-month programme at the Detox Centre. At the centre, Salim and Sarvar have adjusted to the daily routine, enjoying their schedules and benefiting from the counseling sessions. Both of them have no desire to do drugs, and neither has experienced any withdrawal symptoms, due to the medications they receive.

"It feels very good here. I want to thank all the people who help me here. Today even if you put a bottle of alcohol in

front of me, I will not take it," said Salim.

"When I heard about the other drug users' stories during group sessions, I got scared and decided that I want to quit drugs before I ever get in such a horrible condition," said Sarvar.

Both Salim and Sarvar hope to bring their friends to Sankalp so that they too can realize the harms of drug use and change their lifestyles.

After visiting Salim and Sarvar at Vithalwadi, Inspector Choudhary and Ms. Dutta were appreciative of Sankalp's efforts.

"I found the Detox Centre to be very nice. I appreciate the work that Sankalp is doing," said Inspector Choudhary.

"When I saw them [Salim and Sarvar] at the Detox Centre, they looked very fresh and energetic, which was not there initially. They also looked very healthy," said Ms. Dutta.

Seeing the positive results, Inspector Choudhary and Ms. Dutta continue their efforts to motivate drug users to go to Sankalp and involve the community. They have already received interest from others in the area. Once Salim and Sarvar are finished with their programme, they plan to hold a meeting where the two can talk about their experiences, so that other users will be encouraged to go to Sankalp. In addition, Inspector Choudhary and Ms. Dutta plan to follow-up and secure jobs for these individuals to ensure that they do not relapse.

By holding meetings, conducting home visits, and spreading the word about Sankalp's services, Inspector Choudhary, Ms. Dutta, and our Director Mr. Tellis hope to mobilize the community against drug use and crime.



A Sankalp Doctor oversees the management of withdrawal symptoms at Project Disha

The Sankalp Family

By Rebecca Stern, AJWS Volunteer

I stood in the kitchen doorway of Sankalp's Charni Road office watching the machine-like assembly line of chapatti production. A few Project Hunar participants, as part of their shared-living obligations within the sustainable livelihood training programme, were working together to make nearly one hundred fresh chapatti for dinner that night. Raju was forming small rounded balls from the big bowl of dough, breaking off a small segment and maneuvering it quickly in his hands. Abdul then flattened each piece into the flour-covered newspaper, skillfully rolled it out into an even perfect disk, and tossed it into a stack waiting for the stove.

I had been working at Sankalp for a little under a month and was still getting to know the "Sankalp family:" my coworkers; Eldred Tellis, the director; the Sankalp clients; and the many other volunteers. I was hanging back shyly on the sidelines as I tried to find my own place within the family. Tonight, I was staying late at the office to observe Project Hunar's data-entry work, which happens long after normal work hours. I wanted to get to know the Hunar guys. But I hardly spoke Hindi, I had never been a drug user, and I surely couldn't cook Indian food.

Raju saw me out of the corner of his eye and motioned for me to come in and join. I found a spot on the ground in front of the newspaper workspace as Abdul handed me a rounded ball of dough and demonstrated how to flatten and roll it out. My first try was lumpy and the chapatti's shape vaguely resembled a map of India, which wasn't exactly what I was going for. But Raju just smiled, I laughed, and we started again.

One of the most meaningful parts of working at Sankalp for me was the ability to interact with our clients on a daily basis. This was especially true of the dozen participants in Project Hunar, Sankalp's sustainable livelihood training programme. The Project Hunar participants lived and worked in the Charni Road office, which meant that I got

the chance to really get to know them. I sat in on their morning meetings, joked around with them in the hallway, and was able to practice my horrible Hindi through our conversations. Through these clients, Sankalp's work became human and real. I saw how hard they worked to learn computer-based data entry and was amazed by their commitment to recovery, peer education, and self-improvement. Their strength was contagious and motivated me every day.

Yet it wasn't until I accompanied Sankalp's peer educators during their daily outreach work in the streets of Mumbai that I fully understood the path that my friends in Project Hunar had taken, how far they had come and how important Sankalp had been in that process. The users that I met during outreach have been pushed out by society and then kicked while they were down. They were weak and in obviously poor health, many with protruding bones and abscesses waiting to form. Raju and Abdul and the rest of the Hunar guys were physically healthy and mentally strong. They fought their addiction daily in individual and group sessions with the social worker. They had access to necessary medical care both at Charni Road and through referrals. Most importantly, they had been able to reclaim their dignity and their humanity.

The individual resolve of each Sankalp client is undeniably integral to the empowerment I observed but Sankalp's impact is equally evident. By virtue of reaching out to street based drug users and caring for each individual, Sankalp fights for our clients' human rights and reaffirms their self-worth. Focusing on these multiplicatively marginalized clients and working to improve their lives and their health, Sankalp truly makes a difference for our clients, for their families, and for society at large. I feel lucky and honored to have been involved in this work, to have become a part of the Sankalp family, and to even have learned to roll a nearly round chapatti.

Names of clients in this article have been changed.



Rebecca with some of the Sankalp family

Selvaraj's Story

"All my life I was a slave to my addiction. I lost relationships, friends, ruined my marriage, my passion and my career."

The Rising Star

Captain of the Trombay Sports Club Cricket team and winner of the inter club cricket league at 16, for a person without any formal training, Selvaraj showed excellent talent and leadership on the field, especially for a man who lost his father due to alcoholism at a young age, and whose mother worked day and night to make ends meet for him and his sisters.

The Addiction, the Abstinence

A strong willed, determined young man, Selva had no reason to succumb to peer pressure. He tried brown sugar for the first time with his friends at a local bar. What started as a little adventure, a graduation from cigarettes, turned out to be the biggest game changer in his life and promising cricketing career.

One year hence, Selva was completely addicted to brown sugar. Having sensed something unusual in her son's behavior, Selva's mother, Rajeshwari, took him to see a doctor, much to his resistance. Instead of prescribing him to a rehabilitation/detoxification program, the doctor told him that the only way of going back to normalcy was to quit brown sugar.

But abstinence does not suit everyone as a treatment option. And as it turned out, in Selva's case going 'cold turkey' did no good. In days his health deteriorated, physically & mentally. Frightened that his condition would worsen, Selva secretly bought brown sugar. Shockingly, Rajeshwari took no objection when she found out. Having seen her son in a helpless and desperate, unfit state, she gave Selva the money required to purchase the drug.

Bollywood Dreams and Reality

Selva's uncle got him a job on the sets of a Bollywood movie as a camera technician. Initially, uncertain about his new job, Selva gave this new innings his best. To everyone's surprise, in little time he won the reputation of being one of the top technicians in the industry and personally received plenty of movie offers.

However, nothing lasts forever and unable to give up his addiction, Selva found it increasingly difficult to manage his busy schedule with his addiction. During the same time, Rajeshwari also got Selva married. In her attempt to restore her son's life back to normalcy, Rajeshwari felt marriage would help him get back to a life free of drugs. The mistake she made, however, was not to disclose his problem while arranging the marriage.

But as time passed, Selva found it increasingly impossible to keep up with his work commitments and personal life. His condition was deteriorating. Lacking the determination, his enrollment in various detoxification programs was also unsuccessful. Eventually, he lost his job and his wife left him, too.

Down the Barrel

Disappointed with his life and with himself, Selva boarded the Churchgate local from Mumbai Central. En route, he plunged out of the running train. However, other than a few bruises, Selva was left unharmed. But having set his mind, there was no way he was accepting defeat. In his world, his defeat to addiction had left him shattered. Lost for hope, he attempted suicide a second time over. But what happened was unthinkable...

This time, to leave nothing to chance, Selva jumped in front of an approaching train. He lost both his legs and his right hand but he lived. The man, who once boasted of a successful cricket innings and a promising career on the sets of Bollywood, was left crippled.

The Redemption and Mission

Selva, in a wheelchair, rolls towards a group of addicts. Selva, now clean for 8 months, counsels them to adopt a drug-free life. Thanks to Sankalp's Harm Reduction program and other services for drug-users, he is now able to assist other users in their struggle to quit drugs.

'Banane wale ne bhi kya cheez banayi he' (what a thing the creator has created), Selva says, referring to the architect of brown sugar. 'It reduces a person to such helplessness - he steals, begs, lives on the streets. It not only destroys him but his entire family.'

'I am the captain of my ship; I am the master of my soul.' Selva's mission is to spread awareness amongst the youth about the dangers of substance abuse. He wants to reach out to as many people as possible around the world, especially to those most vulnerable and marginalized, the street drug users.

As narrated by Selvaraj, with inputs from Uroi Gupta volunteer at Sankalp.



Selvaraj at Sankalp

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