

Partners in spirit

Created 15 Aug 2004 - 6:00am

With more than a hundred thousand people living with HIV, Indonesia faces an uphill struggle to roll out treatment, education and care programs. But an inspirational and dynamic national network of positive people is playing its part.

Rosy was in rehab when she was diagnosed. A drug user since she was a teenager, she'd ended up in the rehabilitation centre after a long spiral which took from being top of her class in high school to stealing whatever she could to secure her next hit.

She admits she didn't know anything about the risks when she started using: "as a young person, I had no information about drugs." There were no drug education programs in Bali in those days, no needle exchange programs, no harm minimisation. So when friends introduced her to drugs, she didn't realise how far they would take her.

When the staff in the rehab centre suggested she have an HIV test, Rosy says it was strikingly similar to the first time she was offered drugs. She didn't know much about HIV as she'd never been given any information.

"There was no counselling, nothing," Rosy says about her test. When the results came back, eight of the 16 people in the rehab centre were HIV-positive, and she was one of them.

Today, Rosy is a healthy, busy AIDS educator, no longer using drugs and working with Burnet Indonesia, an extension of Australia's Burnet Foundation. She was one of a group of three representatives of Spiritia, the Indonesian Network of People Living with HIV/AIDS, who visited Australia in August.

Spiritia was founded in 1995 by Suzana Murni, an Indonesian woman who had recently been diagnosed with HIV. Originally set up as a peer support group in Jakarta, Spiritia soon expanded to become a national organisation, linking smaller [PLWHA](#) [1]Person (or People) Living with HIV/AIDS. groups in several of Indonesia's 27 provinces. In 1998, Spiritia organised the first national meeting of Indonesian positive people, bringing together 16 people from around the country.

Since 2001, Spiritia has been closely involved in prevention and care projects funded by the Australian government's overseas aid agency, [AusAID](#) [2]Australian Agency for International Development. Australian Government agency responsible for managing the Australian Government's official overseas aid program. . One of Spiritia's handful of staff, Chris Green, Hendrianto Primarendra (Prima) from the Yogyakarta Network of People Living with HIV/AIDS (JOY), and Rosy came to Australia to thank AusAID and the Australian people for their assistance and build closer links with Australian HIV/AIDS groups.

In a country with more than 200 million, estimates of the number of people living with HIV/AIDS range between 100,000 and 130,000, although only a few thousand cases have been officially reported. Widespread stigma and discrimination against people with HIV, and the limitations of the health system, mean that few people come forward for testing.

Battling that stigma and discrimination is one of Spiritia's main aims. Attitudes towards HIV are changing, Prima says, especially in the media. "In the first days, they just wrote about the person with the disease," he says. The media would use sensational language and the individuals would be ostracised. "Now they give the information about HIV, not just the story of the person."

Stigma within the health system is a central concern. Until 2001, no hospital in Yogyakarta would admit people with AIDS, Prima says. With just 13 members, his organisation has worked with health workers and administrators so that there are now three hospitals who will take AIDS patients, and the group is working with the provincial social welfare department to secure access to social programs for positive people.

Building community understanding is the key to bringing about change, and people living with the [virus](#) [3]A small infective organism which is incapable of reproducing outside a host cell. are in the forefront of projects to shift

community attitudes by giving a human face to HIV/AIDS in Indonesia.

Spiritia's role in providing peer support to people working on the front lines is important, says Chris. "The feeling that they're not alone, that they're part of a bigger family, makes a difference," he says.

Spiritia is supporting the involvement of positive people by organising training, resources and information, something which is tremendously important in a country as large and diverse as Indonesia.

"In Sumatra, for example, there is still high discrimination," Rosy explains, "but when I start to change the situation in Bali we can share our experiences."

Because many people with HIV in Indonesia were infected through unsafe drug injecting, positive people often face multiple layers of discrimination and marginalisation.

"If you're a drug user, people will not trust you to hire you," Rosy explains. Ironically, people infected through sex are more likely to get support from their families and communities.

One of the ways in which Balinese people are learning about HIV is through small community meetings. Rosy and her colleagues disseminate information in the banjar, or community, bringing positive people, drug users and medical practitioners into the village to talk directly to locals, answer questions and distribute educational materials.

For many people, these meetings are the first time they have had the opportunity to talk openly about HIV or drug use, and their first experience of meeting a positive person or drug user. Like the positive speakers' programs which operate around Australia, the program is beneficial both for the speakers and the communities.

Often after the meetings individual villagers will confide in the speakers about their own families' experiences, many speaking up for the first time. In a society where drug use and illness are considered shameful the opportunity to talk can be liberating.

It was at one of these meetings that Rosy realised she needed to become an activist. Just two weeks after being diagnosed with HIV, she was asked to come a meeting called by the local government as an observer.

"When they discussed drug use and HIV it seemed so far from reality," she says. "Then a doctor at the meeting said 'a drug user is someone who is mad since birth', and I said, 'what?'"

The doctor's opinion was so far from Rosy's own story that she knew she had to speak up. "That's not my experience and my friends' experience," she says.

"I thought, my god, I've got to tell people about drugs and HIV."

Now Rosy takes her message to the banjar, to schools, hotels and prisons.

Working in Bali's prisons is something Rosy was eager to do at the outset, but it took time to convince funders of the merits of the idea.

"Many drug users are in prison, and many of them are my friends, so it's personal," she says. "They are in the same situation as me before rehab."

Drug use within the prison system is rife, and HIV spreads easily. It costs just 10,000 rupiah (A\$1.50) to buy a small bag of heroin in jail. Another 25,000 rupiah will allow you to rent a used syringe.

From a standing start, Rosy's prisons project has been spectacularly successful. Previously, people with HIV were marginalised and shunned in prison. Just 18 months later, an AusAID report found that "stigma and discrimination has disappeared from the Kerobokan Prison," Chris says.

Visiting the prison and meeting with positive prisoners in the canteen, Chris was told that six months earlier, the canteen would have emptied if a positive person walked in. Now the prison doctor runs a regular "quiz show" with questions about HIV, and there are regular "positive chat" support meetings for prisoners with HIV.

“The positive people have played a huge role in that,” Chris says.

Visiting Australia gave the group an opportunity to see how positive people are involved in the response to HIV/AIDS in this country, and they’ve taken back many ideas. They say that visiting Positive Women Victoria, the state AIDS Councils, and Melbourne’s Positive Living Centre have been especially inspirational.

But the Melbourne Sexual Health Centre made the biggest impact. The experience of visiting a clinic where HIV testing, counselling, treatment and CD4 and [viral load](#) [4]A measurement of the quantity of HIV RNA in the blood. Viral load blood test results are expressed as the number of copies (of HIV) per milliliter of blood plasma. tests were all available, confidential and free left them dumbfounded.

By comparison, in Indonesia viral load testing is only available through one laboratory in Jakarta, and the tests are prohibitively expensive for average income earners. Basic generic [antiretrovirals](#) [5]A medication or other substance which is active against retroviruses such as HIV. are now being produced domestically within Indonesia and while they’re cheap by Australian standards at 400,000 rupiah (\$A60) a month, for most Indonesians that represents more than two-thirds of their income.

But progress is being made. As part of the World Health Organisation’s ‘Three by Five’ initiative, the Indonesian government plans to have 10,000 people on antiretrovirals by the end of next year. That represents about half the number who need them, Chris says.

In the meantime, Spiritia is continuing its work, battling discrimination, distributing information and supporting HIV-positive people and AIDS activists. The increasingly strong links between PLWHA organisations in the region are a valuable part of this, the group says, as is the financial support provided by AusAID.

“We want to say thanks to Australia,” Rosy says.

- [discrimination](#)
- [involvement of positive people](#)
- [recreational drugs](#)
- [stigma](#)
- [Indonesia](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/119>

[2] <http://www.napwa.org.au/glossary/term/383>

[3] <http://www.napwa.org.au/glossary/term/125>

[4] <http://www.napwa.org.au/glossary/term/416>

[5] <http://www.napwa.org.au/glossary/term/122>