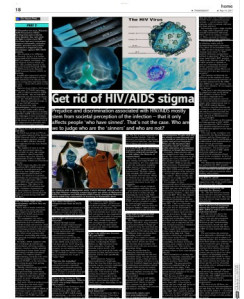


Headline	Get rid of HIV/AIDS stigma		
MediaTitle	The Sunday Post (Kuching)		
Date	14 May 2017	Color	Full Color
Section	Home	Circulation	89,224
Page No	18	Readership	267,672
Language	English	ArticleSize	1460 cm <sup>2</sup>
Journalist	Eve Sonary Heng	AdValue	RM 19,909
Frequency	Daily (EM)	PR Value	RM 59,727



# Get rid of HIV/AIDS stigma

Prejudice and discrimination associated with HIV/AIDS mostly stem from societal perception of the infection – that it only affects people ‘who have sinned’. That’s not the case. Who are we to judge who are the ‘sinners’ and who are not?

By **Eve Sonary Heng**  
features@theborneopost.com

## PART 2

**IN December last year, Malaysia AIDS Foundation (MAF) Kuching Gala patron Datuk Amar Jamilah Anu said while the fight to reduce new HIV infections had seen tremendous progress nationwide, attitudes, beliefs, practices and policies continued to stigmatise and discriminate against HIV/AIDS patients.**

The situation is no different in Sarawak. In fact, it is further compounded by limited access to HIV prevention, treatment, care and support services which are now only available mainly at the Sarawak General Hospital (SGH) or NGOs such as the Sarawak AIDS Concern Society (SACS) in Kuching.

Jamilah also expressed concern over the rising incidence of new HIV infections over the past five years, noting there had been a hike in cases — from 169 in 2011 to 230 in 2015.

Statistics from 1989 to 2015 show there were 2,178 HIV infections — 480 of which resulted in AIDS-related deaths. The current HIV notification rate in Sarawak stands at 8.7 per 100,000 persons — still lower than the national average of 10.9 per 100,000 persons.

In an interview with **thesundaypost**, SACS president Dr Yuwana Podin talked about the role the organisation in dealing with HIV/AIDS-related issues and the challenges it faces in trying to bring about greater understanding

of the disease in order to get rid of the stigmatisation, prejudice and discrimination against patients.

**Q: When was SACS established and why?**

**A:** SACS was set up in 1998 on the recommendation of the Sarawak AIDS Network (SAN), a coalition of government agencies tackling issues on HIV/AIDS in Sarawak. It is supported by the state Health Department.

The number of cases is on the rise and government agencies are not able to carry out certain programmes, aimed especially at reaching out to key affected populations (KAPs) or high risk communities. SACS was formed for the role.

SACS vision can, thus, be said to address HIV/AIDS issues in Sarawak through approaches which are non-judgmental, non-discriminatory and holistic in nature. Its mission is to provide knowledge on preventing sexually transmitted infections (STIs), HIV/AIDS through awareness programmes. The object is to prevent new STI infections and HIV, eliminate stigmatisation or discrimination, provide peer support, promote and protect the rights of people living with HIV (PLHIV).

**Can you name some of the programmes and how they are carried out?**

First, there is harm reduction through an outreach programme with support from the Health Ministry for KAPs such as sex workers or homosexuals.

The programme sets out to increase awareness among these populations and even distribute condoms to high risk persons. Such a prophylactic measure is not meant to encourage permissive behaviour but taken as the lesser of the two evils. SACS social workers offer voluntary counselling and testing and provide treatment and support to PLHIV.

Secondly, SACS organises talks and workshops in schools and communities, allowing students, parents, teachers and the general population to know about sexual reproductive health and related diseases. It’s hoped a greater understanding can help to do away with the prejudice and aversion towards PLHIV, at the same time, preventing people from getting infected themselves.

Thirdly, SACS hopes to provide emotional support to PLHIV through friendship networking by linking up with other agencies or religious bodies that are able to assist in terms of healthcare or welfare services.

And lastly, SACS is in the process of setting up a one-stop centre or a drop-in place to provide information about HIV or AIDS. It also hopes to give counselling and testing as well as acts as a half-way house for PLHIV and their families.

**How many members or volunteers are there in SACS now?**

Over 150 registered members and over 100 volunteers, comprising members and non-members from universities, colleges and the public.

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### How is HIV infection spread in Sarawak?

Mainly through sexual activities of either heterosexuals or homosexuals. In Peninsular Malaysia, the main transmission is through intravenous (IV) drug use.

Transmission through unprotected sex among homosexuals is also on the rise, hence our outreach programmes for the MSM (men who have sex with men) group. As IV drug use is not the main concern here at the moment, we are watching out for designer-drug users who resort to the IV method or chemsex (using drugs to facilitate sex) to get a 'bigger' high.

### What are the remedies?

We need to work harder in our outreach exercises, especially creating more awareness among the target populations and get as many of them as possible tested and treated, if they are found positive.

### There is the Getting to Zero World AIDS Campaign. What is SACS' role to help Malaysia in this respect?

The focus of the Getting to Zero Campaign is to reduce AIDS-related deaths, HIV births and emergence of HIV/AIDS among the population — in other words, to promote the highest awareness (and zero tolerance) of the disease.

In addressing HIV/AIDS issues prevalent in society, it's important to avoid the silo mentality. All parties need to work synergistically. The responsibility does not lie with only one person or one organisation but should be extended to learning institutions and corporations as well. They should make their own arrangements to train new recruits as they do under their Occupational, Safety and Health (OSH) programme.

### What's the difference between HIV and AIDS?

HIV is human immunodeficiency virus that infects the immune system, weakening the body's defence to fight infections from other pathogens. It saps the immune system slowly. Left untreated, the virus in the body will replicate quickly and infect more immune system cells (specifically

CD4 cells).

AIDS stands for Acquired Immunodeficiency Syndrome. When the virus has taken over the immune system, severely weakened by the huge drop in CD4 cells, other opportunistic infections will occur. This results in AIDS, causing the patient's health to deteriorate very quickly as the immune system can no longer fight all these opportunistic infections. Death may occur, depending on the complications.

### Is an HIV infection a universally fatal diagnosis?

Being tested positive for HIV is not a death sentence. There have been cases of PLHIV living a long

life. The key is to get treatment and lead a healthy lifestyle. Take the necessary precautions when having sex to prevent infection. The bottom line is taking care of one's health.

### Is it true PLHIV who undergoing treatment and medication can still live a relatively normal life — and reduce the chances of transmission?

Very true. As mentioned earlier, cases of long-surviving PLHIV are not uncommon. It's very important to take the medication regularly, follow doctor's advice and stick to the HAART (Highly Active Antiretroviral Therapy) regime. Lead a healthy life and take care of the health of loved ones. While it's entirely up to one whether or not to reveal one's health status, it is equally important to not self-stigmatise.

HIV women can get pregnant on consultation with their doctor — previously not possible but can now be done to reduce the risk of passing the virus to the baby. Chances of delivering HIV-negative babies are more than 90 per cent if HIV-positive pregnant mothers are detected and treated early. That's why HIV tests are done for pregnant mothers. Malaysia has been successful in this programme.

### What kind of treatment and medication do HIV patients receive?

The highly active antiretroviral therapy (HAART) drug treatment. Various generations of drugs are available to keep the viral load low.

There is a tug-of-war between the virus and the CD4 cells in the body.

Different drugs are prescribed, depending on how patients responds. It is a must to comply with the drug regime as instructed by the doctor. If not, the virus may become drug-resistant and patients need to be put on second-generation drugs.

Now the medication for Malaysian citizens is heavily subsidised, especially for the first generation drugs. For the second generation drugs, which are more expensive, patients will have to top up a few hundred ringgit per month in addition to government subsidy. Regular CD4 counts are carried out to ensure patients are healthy and their immune systems are fine. Counselling is always available when needed.

As the infection is still highly stigmatised, PLHIV can get peer support from NGOs, if needed. Here, patients can share their experiences, thoughts and concerns and support each other.

### Apparently, many cases have gone undetected due to stigmatisation and

discrimination. People with HIV are afraid to come forward and seek medical attention in both public and private hospitals. What are the measures that should be taken? Is holding public education and campaign sufficient to break this barrier?

Certainly, stigmatisation and discrimination are huge stumbling blocks. We must remember we are fighting the virus, not the people. One needs to open-minded to think of HIV/AIDS as just like any other infections. Stigmatisation and discrimination associated with HIV/AIDS mostly stem from societal perception of the infection — that it only affects people 'who have sinned'. That's not the case. Who are we to judge who are the 'sinners' and who are not?

For example, we have encountered cases of housewives and children who were tested positive for HIV and who died of AIDS. The housewives have not left their homes at all and the children — they were born with HIV. Were they sinners?

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Of course, one should not start blaming the husbands or the men for supposedly infecting their wives with HIV. That's not the point.

It's also not the point to dig up one's past but it's important to be responsible for our action to ensure we will not harm ourselves and our loved ones. People must be sensible and go for voluntary testing (and counselling) if they have been involved in risky sexual activities such as unprotected sex with multiple partners of unknown status or sharing needles.

They ought to take similar action if they suspect their partners or spouses to be high risk. Their identities will be kept confidential. Help comes in the form of pre-testing and post-testing, counselling, treatment (if tested positive), peer support, if needed, and medical care. One is never alone. And no one should be there to judge where or how a person gets infected.

What essential is to erasing the stigma is education, education and education. Message transmitted must be positive rather than judgmental. The general public need to be reminded this is an infection like any other. They need to understand HIV cannot be spread through touches or by just sitting next to PLHIV.

The flu virus or EV71 that causes Hand, Foot and Mouth Disease (HFMD) is spread even more easily than HIV. A flu-stricken person can just cough and sneeze to spread the virus to people in the same room or possibly on the same flight. HIV cannot be spread in this way. So there's nothing to be scared of. In fact, PLHIV should more scared of the general public than the other way round because PLHIV have weakened immune systems — a mere sneeze from someone with a common cold may get them infected.

Sarawak has quite a high number of young adults diagnosed with sexually transmitted infections. They can be as young as 13 and 14. Thus, we need to increase awareness among the youths here.

The media should help by playing a major role in disseminating positive messages. Very often we see headlines such as 'HIV-positive drug user caught stealing scrap metal' or 'HIV-positive drug user among those nabbed in operation'. What has the scrap metal thief's HIV-positive status to do with the crime? Why is HIV-positive a clickbait or used as a sensational keyword? Or the questionnaire in blood donation forms asking 'Have you been involved in a gay sexual act recently?'

The statistics in Sarawak are different as the majority of cases involved heterosexual activities. It was first announced in the 1980s that AIDS was a 'gay disease', but this is now obsolete. It's no longer a 'gay disease'.

Then there's also discrimination by employers who avoid hiring HIV-positive workers. Even insurance companies have discriminatory policies and will not cover the medical expenses of clients with complications due to HIV/AIDS-related illnesses.

There is a need for educational workshops or dialogues to get rid this misconception and allay the fears of these companies so that they will not be discriminatory towards PLHIV.

A Code of Practice on Prevention and Management of HIV/AIDS was introduced in 2001 to ensure HIV-positive employees are not discriminated against but not many adhere to it.

This code in the workplace was prepared by the Human Resource Ministry and the Department of Occupational, Safety and Health in collaboration with representatives from various government agencies, NGOs and international organisations. The purpose is to reduce the spread of HIV/AIDS and assist employers and employees in managing related issues in the workplace. In 2012, a total of seven workplaces adopted the code.

The Malaysian Medical Council has guidelines for HIV-positive doctors to continue working as long

as they take their medication and adhere to safety precautions when dealing with patients.

#### **Can HIV be cured?**

There have been recent studies suggesting some drugs could reduce the infection rate of HIV.

#### **Is it true mosquitoes can transmit the disease?**

No. The fact that it's a human virus and not a mosquito-vector-borne disease says it all. The virus does not survive long outside the human body.

#### **How is the level of awareness among the general public of HIV-AIDS as well as prevention and intervention?**

It's still very low due to the stigma associated with disease. There's also the misconception that it's the disease of sinners. Without proper understanding and education, people can also believe in the rumour that there is HIV in some imported canned fruits.

For prevention, the common sense approach is abstinence from unprotected sex and avoidance of sharing needles. Sex workers must insist their clients use condoms and not be tempted to give in by the offer of more money. They must convince their clients protection is for their own good. This is, of course, not easy as there is a clear inequality in bargaining power — the sex worker needs to earn a living and cannot always do what she wants whereas the client can always get the service of another sex worker who is willing to have unprotected sex.

As for intervention, people must understand the concept of harm reduction. The main purpose is to reduce the risk of HIV transmission through various protective measures, education and awareness programmes.

But when we do all these, we may be accused of encouraging free sex and drug use. But the question that should be asked is — if nobody takes up the gauntlet to deal with this social scourge, is it not going to get worse?



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Dr Yuwana with a Malaysian actor Fahrin Ahmad, who is one of the Red Ribbon celebrity supporters who are allies of Malaysian AIDS Foundation and Malaysian AIDS Council, during the National AIDS Day celebration in Kuching in December 2016.



## The HIV Virus

