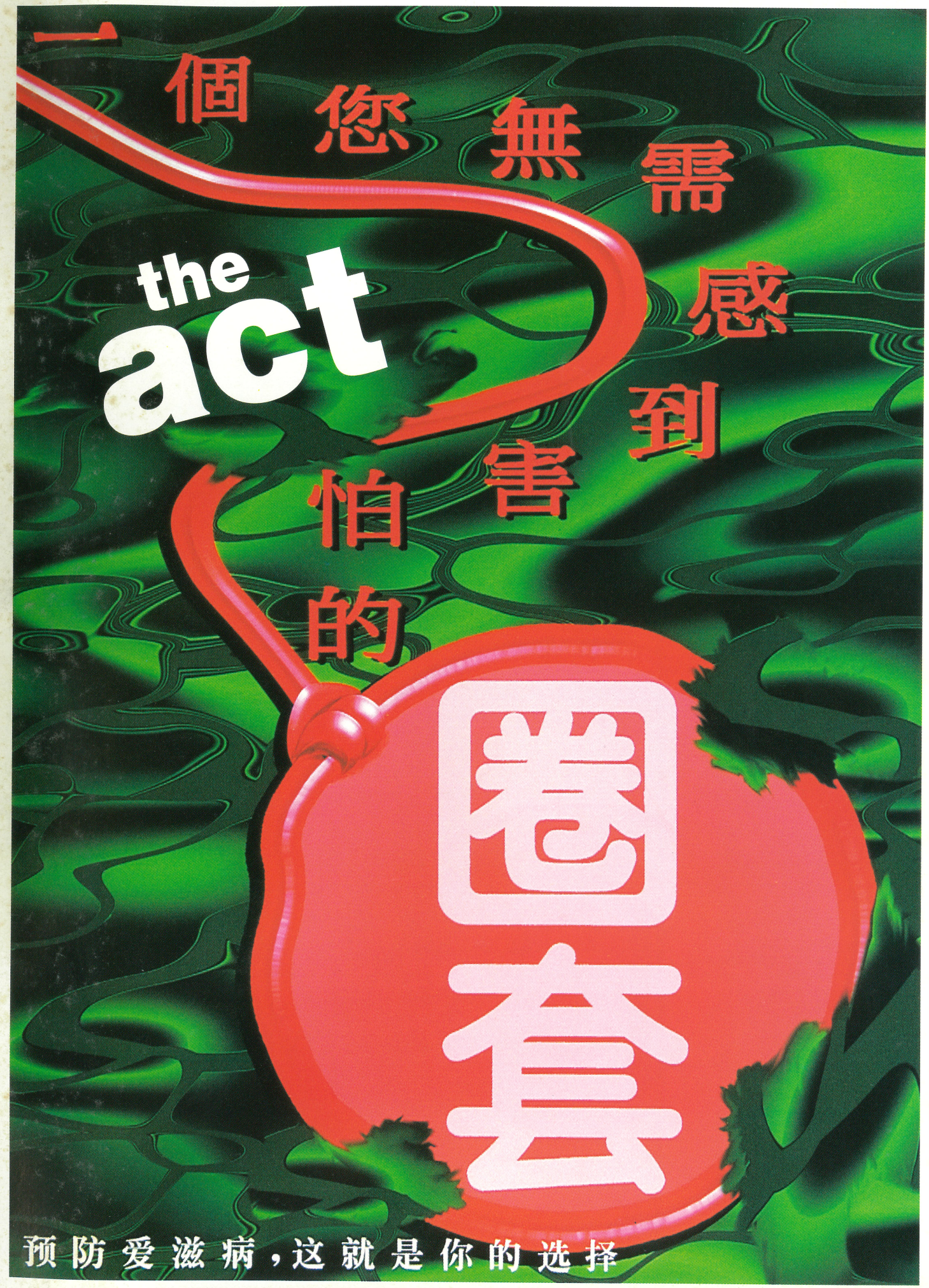
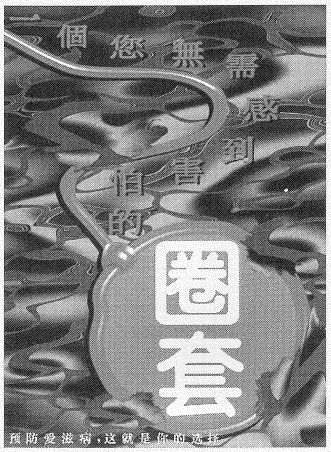


ISSUE NUMBER 22 • MITA (P) NO.051/01/99 • FREE OF CHARGE



EDITOR
Roy Chan

EDITORIAL BOARD
Dawn Mok
Clive Wing
Brenton Wong

CONTRIBUTORS
Dr Vivien Lim
Loo Geok Leng
Azrul Mohd Khalid
Natashya Yong
Feisal Abdul Rahman
Roger Winder

The Act is published by
Action for AIDS (Singapore).
c/o DSC Clinic
31 Kelantan Lane #02-16
Singapore 200031
Tel: 250 9495
Fax: 299 4335
Email: afa@pacific.net.sg
Website: www.afa.org.sg

Designed by Paperclip Communications Pte Ltd and Printed by Robinson Offset Printing Pte Ltd.
MITA (P) No. 051/01/99.

Cover Synopsis:

Quan Tao

Elaine Pang Peck Yin
23 years old
Merit Award,
Student Category
Art Against AIDS 1998

Quan Tao, a trap (condom) to lure the victim (reader's attention) into captivity. The green camouflage environment provides the hunting ground (fear mixed with sadness), while the redness spells danger (AIDS). A cord links the hunter (advertiser) to the trap; enabling control (life/death is in your hands). Use it.

Mission Statement

"Action for AIDS is committed to providing balanced and factual information on AIDS, to providing care and support to persons with HIV/AIDS (PWHAs), and to encourage research into issues related to AIDS in Singapore. We strive to end AIDS-related discrimination and for the acceptance of PWHAs as contributing members of our community."

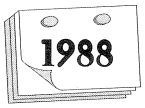
Contents

Dr Roy Chan President, AfA

Action For AIDS Singapore - Significant Dates And Events

Over the years there have been several requests for us to summarise and chronicle the important dates and events since the inception of AfA. Below is such a list of events from 1988 till 1998. It includes major fund-raising and educational events, and dates when the various projects, committees and initiatives of AfA were set up. It is not by any means an exhaustive list, and I apologise if any major event or project has been inadvertently left out.

Not included are overseas conferences attended by AfA volunteers, training programmes conducted, and projects which did not have a definite time frame. This list also does not detail all the activities going on at any one time; it indicates only the new projects and dates when they were introduced.



(1) 30 November 1988 - Action for AIDS Singapore is registered with the Registry of Societies.

(2) 1 December 1988 - Charity Jukebox in Centrepoint. The first ever World AIDS Day (WAD) event here featured many top local entertainers in a fund raising and awareness event, sponsored by The Body Shop.

(1) 18 March 1989 - AFA's first public forum was held to inform and to recruit members for the society. It was sponsored by Wellcome Pharmaceuticals. Over 50 people attended the 3-hour session which featured talks on various aspects of AIDS and HIV infection.

(2) 1st to 15th September 1989 - AIDS and Safer Sex Fortnight. This was the first nation-wide AIDS campaign, and it targeted young, sexually-active people with the aim of disseminating information on "safer-sex" methods and condom use. Over 70,000 educational pamphlets were distributed to members of the public at various night spots, pharmacies, gyms, tertiary institutions, public exhibitions and lectures. A grand draw was conducted for all replies to questionnaires received after the fortnight was over; over 5,000 entries were received. Two pop concerts were held at NUS and NTI and a Lion City Hash Run were also conducted as part of the fortnight's activities.

(3) WAD 1989
- The "Youth, Sexuality and AIDS" forum was held at the College of Medicine Building Auditorium. This featured lectures followed by a lively discussion on topics ranging from birth control measures, HIV antibody testing to sexuality. Over 250 people attended.
- A specially designed T-shirt featuring the signatures of over 30 celebrities from the fields of entertainment, sports and fashion was produced. The T-shirts were sold in department stores, boutiques, hair salons and other private outlets. Over $10,000 was raised from the sale of the T-shirts.
- 23rd November to 3 December - Theatreworks presented the "Safer-Sex" Doublebill, the first ever locally staged drama dealing with AIDS at the Drama Centre.

(1) 22 April - AIDS Mastery Workshop conducted by visiting Australian experts.

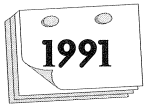
(2) The Outreach Programme targeted the vulnerable male homosexual and bisexual community. These private events were held in an informal and non-didactic fashion to inform the audience on AIDS, and to encourage the group to adopt safe sexual practices. The sessions included tea parties, dance parties, sketches, plays and games, were very well attended. Risk Reduction Workshops worked in tandem with the Outreach programme. The workshop was divided into four once-weekly sessions of 2 hours each.

(3) The Home Visit/Counselling Service (HVS) was started to alleviate the financial and emotional burden of AIDS patients by providing care at home especially for those PWAs who required prolonged hospitalisation. Volunteers made home-visits and hospital visits to needy patients and helped with nursing care and provided emotional support.

(4) Medication Funding to alleviate the financial burden of needy patients and

to introduce up-to-date methods of AIDS-related therapy was started. This project funded aerosolised pentamidine and pneumococcal vaccine.

(5) WAD 1990
- A public symposium on "Women and AIDS" featured six eminent panelists who spoke on the AIDS epidemic - Global and Regional, Women and Sexuality and Control Measures in Singapore. There was also a question and answer session. It was attended by more than 300 people.
- Advertisements on Women and AIDS, and Safer Sex were included in local newspapers, magazines, periodicals and internationally circulated publications.
- Our first AIDS awareness song was composed and recorded by Chris Ho. 10,000 cassettes of the song were distributed free of charge through a weekly entertainment magazine and bookstores.



(1) The AIDS Educational/Awareness Video "Someone I Used To Know". This play was written by local playwright Chay Yue and featured many prominent theatre actors, crew and backstage personnel who contributed their time and efforts free of charge. The drama portrayed the experiences of the family and friends of a young man who has died of AIDS. AFA supplied 300 copies of the video and teaching notes free of charge to schools, colleges, voluntary organisations and other groups. The video was also screened over television.

(2) 19 May 1991 - International AIDS Candlelight Memorial and Mobilisation. Over 100 people attended this first AIDS Candlelight Memorial in Singapore. The programme included short addresses by the AFA coordinators, counsellors, friends and family members of patients who died of the disease.

(3) 15 August 1991 - Fund-Raising Concert by Boy George raised $10,000 for AFA. Three thousand AIDS education postcards bearing photo-art works by 2 prominent local photographers were distributed at the door.

(4) August - NUS Students' Union Orientation Programme 1991 - AIDS was the theme of the year's Orientation Programme of the NUSSU. The NUSSU banquet was attended by BG Lee Hsien Loong, and attracted media publicity when there were plans to distribute condoms at the door.

(5) November 1991 - the Anonymous AIDS Counselling and HIV Test Centre in DSC Clinic, Kelantan Lane starts operation.

(6) WAD 1991 - "Sharing the Challenge".
- 5,000 postcards, buttons, and tee shirts bearing the slogan "My Body Is Responsible", were distributed along Orchard Road.
- The second AIDS awareness song "Only Love" which was written by Mark Chan for the video "Someone I Used To Know" was played on SBC and Radio Heart stations.
- The first issue of the AFA newsletter "The ACT" was launched.

(1) The Malay Language Committee was formed to encourage discussions with community and religious groups, and to provide lectures and counselling sessions to Malay speaking public.

(2) The "HIV in the Workplace" (HEW) committee was started to tackle issues arising from HIV in the workplace, and to produce educational material for workplace education.

(3) "Buddies and Friends" (previously the Home & Hospital Care Service) formed to provide home and hospital visits to needy patients, help with nursing care and emotional support to patients and families. "B & F" grouped together volunteers with appropriate patients. A training course of 10 lectures and 4 workshops was conducted for volunteers from October to December in the Substation.

(4) Advocacy and Legal Aid - AFA's legal volunteers provided help with drawing-up wills, processing insurance claims and other related matters for patients and their families. Our legal advisors pleaded unsuccessfully for leniency for the 2 patients convicted for falsifying their risk factors before donating blood.

(5) Buyer's Club - Our volunteers were able to privately bring in medications from treatment centres in the developed countries. This enabled us to provide our patients with newer drugs not available locally, and medications to be made available at significantly lower costs than if obtained in Singapore.

(6) AFA organised two large fund-raising galas in 1992 viz
- April - the CLAUDE MONTANA fashion show and NAMES Project and Gala

dinner - GOH was Mr Yeo Cheow Tong
- May - the KENZO fashion show and gala dinner - GOH was BG George Yeo

(7) WAD 1992
- The 3rd AIDS awareness song "Save Sex" by Chris Ho was released for WAD 1992.
- WAD Dance Party - 28 November 1992 - This was a first for Singapore. Organised by two individuals at Ding-Dong A-Go-Go in Bugis Village, the party attracted over 400 guests and celebrities.
- "Walk for Life"- WAD Walk - 29 November - Wellcome Pharmaceuticals in its first "Positive Action" programme in Singapore organised a 5 km walk. Over $21,000 was raised.
- "The Rubberball" was a gala evening featuring many of Singapore's top entertainers, musicians and actors in a variety show comprising of songs, dancers and sketches. Over $80,00 was raised. The GOH was Mr Ong Teng Cheong.

(1) "Life Goes On" (LGO) support group for PWAs was set up to encourage PWAs to get together to share solutions to their problems, learn to cope with HIV/AIDS, deal with discrimination, and re-integrate with their families and community.

(2) The AfA Research Grant funded the following projects - Developing Negotiation Skills in condom use among female prostitutes - Drs Wong Mee Lian, Roy Chan and David Koh (NUH/NSC); Survey on HIV in the Workplace - Drs Andre Wan and Douglas Ong (AfA); Study on Physician Awareness and Knowledge of HIV infection in Singapore - Drs Lam Mun San, Wong Sin Yew, David Allen and Chew Suok Kai (CDC).

(3) The Women & AIDS Committee was set up to make women more aware of their risks of contracting HIV infection, and not to consider it as a man's disease. We also wanted to assist women who were increasingly faced with the difficult role of caring for family members living with and dying from AIDS.

(4) April - Aerobics Marathon. The first ever AIDS Aerobics marathon was held in the World Trade Centre Expo Gateway.

(5) May - AIDS Candlelight memorial, GOH Kanwaljit Soin.

(6) August - "Rite of the Quilt" Exhibition in the Substation.

(7) September - Informal consultative meeting organised by UNDP/AfA on Law, HIV and Ethics. This first such meeting in Singapore was attended by representatives from the AIDS Task Force, the Attorney-General's Chambers, AWARE, the Law Faculty of NUS, SPPA, the CID, MOH, SAWL, SNEF and the UNDP and AfA.

(8) September - "Never on a Sunday" a carnival at Jiak Kim Street, Zouk Carpark, raised over $12,000.

(9) WAD 1993
- Walk-for-Life" organised by Wellcome Pharmaceuticals along Orchard Road raised over $30,000.
- AIDS Seminars in NTU, PA, SAF
- AIDS Exhibition in Centrepoint

(1) March - Charity Film Premiere "Philadelphia" - raised over $170,000.

(2) 21 April - AfA registered as member of the Health Endowment Fund

(3) May - We rent our first premises at 62B Race Course Road. The premises have been used for meetings, talks, training programmes, as a drop-in centre for LGO, and for the AIDS Counselling telephone service.

(4) 7 October - AfA registered as a charity.

(5) WAD 1994
- AIDS Helpline project was launched. It provides members of the public an information service manned by trained counsellors.
- Island-wide "Charity Treasure Hunt on Wheels"
- Plays cum Talk Shows "Lets Talk 90s" in DBS Auditorium, in English, Malay and Chinese.
- Concert and Party in Zouk.

(1) HIV Education in the Workplace (HEW) had its most active year with training courses and over 20 talks to more than 3000 people.

(2) 14th April - Charity Movie Premiere "Pret-a-Porter", part of the 8th Singapore International film Festival

(3) April - AIDS awareness CD by Dick Lee - Redo Renew

(3) WAD 1995
- AIDS Workshop, Four Seasons Hotel
- Charity Concert, Hard Rock Cafe featured performances by a host of local artistes and auction of celebrity memorabilia

- Charity Movie Premier "The Cure", organised by the Medical Society and Club of the NUS.
  Cathay Cinema, GOH - MP Dr Michael Lim
- AIDS Walk - Ngee Ann City Civic Plaza

1996

(1) The Red Ribbon Awards was a painting competition with the theme "Art Against AIDS". Over 120 entries were submitted in 2 categories. Winning entries were exhibited in the Suntec City Mall, Parco Bugis Junction and the Substation, reaching out to an audience of thousands.

(2) RCS Radio One - AfA was adopted by RCS Radio One as their official charity for 1996. In addition to monetary donations, they also gave us airtime to our volunteers in talkshows and interviews, and provided publicity for our events.

(3) The Outreach Project was restarted with several projects including Karaoke contests, a boat cruise, a concert in Fort Canning Park and parties in the Boom Boom Room, the Velvet underground and in Studebakers.

(4) WAD 1996
- AIDS Walk 96 - Over 2,000 participants registered for the walk which was the most successful to date. The main sponsors were Merck, Sharp and Dohme and Levi Strauss.
- WAD Show, Art Auction and Party at Boom Boom Room
- "True Selves " - WAD Fashion Show and Party in Music World

1997

(1) The Street Walker Project (SWP) was the first collaborative project between AfA and MOH. Volunteers combed the streets of the red light districts and handed out condoms and educational materials to freelance sex workers and streetwalkers.

(2) A full time administrator Benedict Jacob Thambiah was recruited. Since starting work he has been invaluable in running the AfA office, successfully streamlined the use of the office, cleaned out the office space, sorted out our mailing lists and come out with a newsletter for volunteers, giving them up-to-date information of the projects and activities of the society.

(3) May - Women United to Fight AIDS (WUFA) which replaced the Women & AIDS Group, was launched.

(4) September - The Charity Gala in Tribute to Princess Diana raised close to $900,000 and the money has been channeled to the Endowment Fund. The aim of the fund is to assist needy patients with medication subsidies.

(5) WAD 1997
- AIDS Walk - Millennia Walk
- Rubberball 1997 Party - Zouk
- Charity Film Premiere "The Jackal"

1998

(1) Subsidies for anti-HIV medications for patients came online.

(2) The second anonymous HIV testing site was started in mid 1998 operating through a private clinic in Tanglin Shopping Centre.

(3) February - Charity movie premiere - "In & Out"

(4) May - "Passing the Bucks" was the first AIDS charity run. It attracted significant interest from the public, and was flagged off by Senior Minister of Health Dr Aline Wong.

(5) The Juicy Parties at Zouk and Velvet Underground reached out to the younger party going set with AIDS information and free condoms.

(6) WAD 1998
- AIDS Walk 98 - Bras Basah Park
- WAD Parties - Venom
- AIDS Conference 1998 on 12 December at the SICEC in Suntec City was the first multisectorial conference to be held locally. co-organised by both AfA and CDC it was opened by the Ministry of Health Mr Yeoh Cheow Tong. The highlight of the conference was Mr Paddy Chew who gave the first ever public address and press conference by a Singaporean PWA. We hoped that his action would have a deep impact on the perceptions and attitudes of our citizens towards PWAs and AIDS here.

Dr Vivien Lim
Department of Organisational Behaviour
Faculty of Business Administration
National University of Singapore
Singapore 119260

Loo Geok Leng
Research Assistant
Department of Organisational Behaviour

AIDS and its Economic Toll on the Workplace: A Study of Human Resource Professionals in Singapore (Part Two)

In the second part of this study involving a sample of 161 HR practitioners, we focused on respondents' attitudes towards disclosure of HIV health records at the workplace. We also examined whether organisations which participated in the study have health-care programs in place.

Attitudes Towards Disclosure of HIV Health Records at the Workplace

A summary of respondents' attitudes towards the disclosure of AIDS test results at the workplace is presented in Table 3. In general, descriptive statistics suggest that respondents felt that employers have a right to know about both the outcome of AIDS testing as well as the identities of those infected with AIDS.

About 50% of respondents agreed that employers should have access to information only about the outcome of AIDS testing for employees (Item 1), while almost 46% indicated agreement to potential employers having access to such information (Item 2). However, approximately 50% of respondents also felt that workers should not have access to such information (Item 3).

A plausible explanation could be that respondents feel that employers need to be informed in order to make the necessary decisions where an HIV-infected worker, potential or otherwise, is concerned. On the other hand, they may feel that there is no need for other employees to know the HIV-positive individual's health status. They may also feel that revealing such sensitive information will unnecessarily lead to work disruptions that can be avoided.

Sixty-eight percent of respondents agreed that employers should know the identities of employees who have had AIDS tests (Item 4). Another 52% also agreed to the disclosure of the identities of those who have had AIDS tests to potential employers (Item 5). Again, about 48% of respondents disagreed that workers should be privy to such information (Item 6). This is plausibly because they fear that workers, upon knowing the identities of these PWHIVs, may ostracise and shun their HIV-infected colleagues.

Table 3 Attitudes Towards To Aid Health Records At The Workplace+

Items	Disagree (%)	Unsure (%)	Agree (%)
In the context of the workplace:			
1. Employers should have access to information about the *outcome* of employees' AIDS tests, without knowing the identities of these test candidates.	34.8	14.9	50.3
2. Potential employers should have access to information about the *outcome* of employees' AIDS tests, without knowing the identities of these test candidates.	37.5	16.9	45.6
3. Workers who work around HIV-infected employees should have access to information about the *outcome* of employees' AIDS tests, without knowing the identities of these test candidates.	49.7	25.2	25.1
4. Employers should have access to information about the *identities* of employees who have had AIDS tests.	18.2	13.8	68.0
5. Potential employers should have access to information about the *identities* of employees who have had AIDS tests.	30.2	18.2	51.6
6. Workers who work around HIV-infected employees should have access to information about the *identities* of employees who have had AIDS tests.	48.4	22.0	29.6

+N = 161 and missing values have been excluded

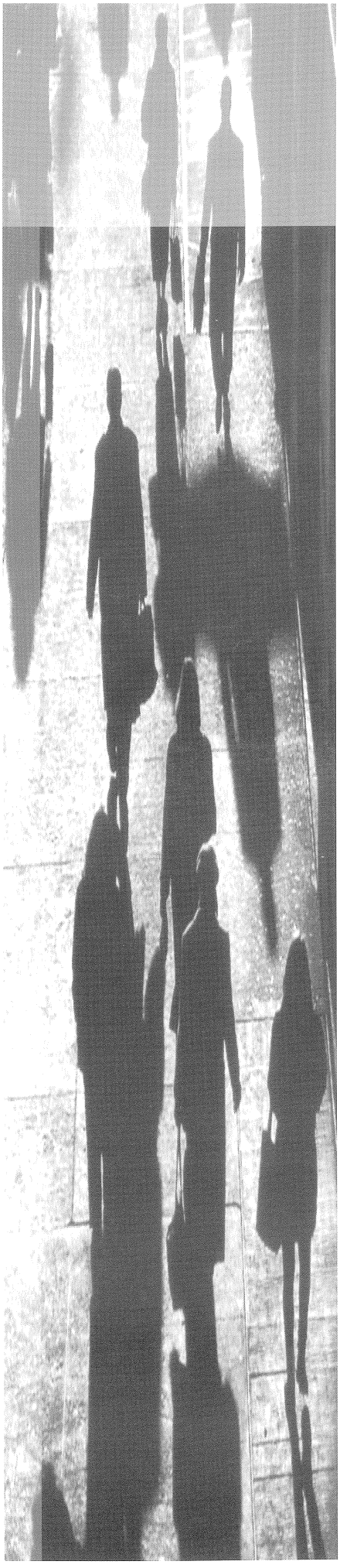


Table 3 Ongoing Healthare Programmes*

Company Type	Ongoing Healthcare Programmes	
	Yes (%)	No (%)
MNC	17.0	39.6
Local	13.2	30.2
Total	30.2	69.8

*N = 161 and missing values have been excluded

Type of Companies and the Healthcare Programmes they have

Table 4 summarises the percentages of respondents who indicated that there is some form of ongoing healthcare programme within their organisation. Majority of companies (70%), regardless of whether they were local or foreign businesses did not have any organisational healthcare programmes for their employees. Almost 30% of companies indicated that they had some form of healthcare programmes periodically. Seventeen percent of companies which reported that they organise healthcare programmes for their employees were multinational corporations (MNCs), while the remaining 13% were local businesses.

Calls were subsequently made to those respondents who had indicated that they had health education programmes going on at their workplace. These calls revealed that the majority of these companies (96%) had programmes typically dealing with stress and time management. Only 4% of respondents revealed that some form of AIDS educational programmes had been organised by their companies.

Thus, this finding may be an indication that many organisations still do not consider AIDS as an important workplace issue.

Implications

Findings of this study suggest the importance and utility of AIDS education in the workplace. Several practical implications concerning AIDS education may be derived from the results of our study.

First, getting organisations involved is critical as the majority of HIV+ individuals contract the disease during their prime working years. Being more aware of AIDS and the ways in which it can be transmitted may mitigate the fear that individuals have regarding the possibility of coming into contact with PWHIV at the workplace.

In selecting and designing organisational AIDS programmes, findings from our study suggest some points that should be kept in mind. It is important to emphasise the point that HIV cannot be transmitted through the casual contact that most likely typifies the form of interactions at the workplace. Past research has found that simply providing dry scientific evidence is insufficient in convincing individuals about how HIV cannot be contracted. Therefore, it may be helpful to use illustrations that create a memorable impact while they convey the message across. For instance, it may be more cogent to say that calculations have shown that mosquitoes can only transmit HIV if 107 of these insects fed on an infected individual and then all of them flew to feed on another person (Booth, 1987).

Second, clear organisational policies pertaining to the treatment of PWHIV will better equip managers in balancing the organisation's needs with those of PWHIV and regular workers. Such policies will also help to lessen the occurrences of unnecessarily draconian measures against PWHIVs.

Anecdotal evidence and findings of extant research suggest that to date, society is still far from accepting PWHIVs as regular societal members. Until such a change is brought about, organisations should seriously consider developing and implementing a workplace policy dealing with the issue of AIDS, even if AIDS has not been encountered at that particular organisation. More costs would have been incurred, in terms of organisational and emotional resources, by the time an organisation is forced to come face-to-face with AIDS. Having an organisational AIDS policy in place and communicating it to all employees conveys the message that management is taking a proactive stance towards a very relevant workplace issue. Employees will not be left to wonder where management stands with regards to AIDS and will also know how management plans to deal with the disease when it is encountered at work.

Before an objective and appropriate AIDS policy can be designed, policy developers should be fully aware of all relevant aspects of the disease and their own possible biases towards PWHIVs. HR practitioners, being in charge of human resource issues, are likely to be in charge of developing or at the very least, participating in the development of such policies. Thus, they should be among the first to be sent for AIDS education programmes. This is because they are likely to be responsible for selecting appropriate external programmes as well as developing and implementing AIDS educational programmes for the other employees subsequently. Therefore, they will need to have a good grasp of AIDS-related information to be able to deal with AIDS and its related issues when it occurs within their organisation.

The organisational AIDS policy should state explicitly how the organisation will treat existing and potential employees who become or are already infected with HIV. Relevant HR issues that should be addressed in the policy include health insurance and healthcare costs, job accommodations for the PWHIV, work disruptions, discrimination against and harassment of HIV-infected workers, negative employee and customer reactions and possible declines in productivity and workplace morale. Most importantly, the policy should clearly outline how the company intends to deal with employee confidentiality and privacy.

Findings of our study reflect the ambivalence surrounding the issue of disclosure of outcomes of HIV testing and identities of PWHIVs. While generally agreeing that employers should have access to the outcomes of HIV medical testing and identities of employees infected with HIV, majority of our respondents disagreed that such information should be made available to the co-workers of PWHIVs. This is to prevent co-workers from reacting negatively to PWHIVs should they know the latter's identities.

Conclusion

Despite worrying statistics and worldwide trends, business communities in many countries still appear to adopt a nonchalant attitude towards the issue of AIDS in the workplace setting. AIDS is a disease that is here to stay and organisations must realise that HIV/AIDS issues arouse great fear and anxiety in individuals which will result in counterproductive behaviour.

Business leaders need to understand that AIDS is highly preventable. Organisations will not be able to escape from having to confront the issue of AIDS since it is only a matter of time before PWHIVs become regular members of society and continue making viable economic contributions for as long as advances in medical treatments allow them to do so. Whether businesses choose to work in tandem with the relevant authorities or to spearhead AIDS education and prevention drives themselves, organisations must realise that understanding and acceptance is the key to a productive and efficient workforce in the era of AIDS.

Azrul Mohd Khalid

A Young Person Speaks:

Why HIV/AIDS Information is Not Reaching Young People

"We strongly believe that our energy, idealism and commitment can be used to stop the further spread of the AIDS epidemic that is devastating the social and economic fabric of our countries."

Delegation of young people to the 1993 International Conference on STD/AIDS in Africa

---

"Teenage sex in particular brings a flurry of public comment... more moral and religious education in schools, more TV censorship and special schools for pregnant students so they will not 'corrupt' their peers"

"As Malaysia grows more affluent, its lifestyle more global, it is erroneous and dangerous to say that we will be protected by our 'unique Asian culture and values'."

"Surveys and studies (in Malaysia) on students and school leavers show an alarming gap in essential sexual knowledge together with clear evidence of increasingly early sexual experience."

"To urgently address anticipated problems, we should start by looking out at what is to the rest of the world instead of looking in to homegrown 'Asian' solutions. The threat of the AIDS epidemic in the region makes this even more urgent."

Dr. Choong Sim Poey
Asiaweek, June 13, 1997

"Right now kids are dying because adults are arguing about what to tell them about AIDS"

Miguel Bustos,
contributor to the White House Report on Youth and HIV/AIDS, 1996

Let's be honest about the role of young people and adults in preventing the spread of HIV/AIDS. The entire process of effectively conveying prevention and awareness messages is actually a vicious circle where if the adults don't come up with a youth-friendly approach to AIDS, young people will more or less turn a deaf ear. However, the best and friendliest prevention effort will fail, should young people themselves be indifferent and apathetic to the dangers of AIDS and the impact it has on their lives and decide to instead continue with their practices or behaviour that may cause them to be vulnerable to HIV infection. Therefore, it is fair to say that an effective approach to increasing safer behaviour and successfully working with young people, is one that utilises the energy, enthusiasm and charisma of young people and the resources, experience and guidance of adults.

Initiatives that combine the strengths of both young people and adults, from the planning stage all the way to implementation and evaluation, will be the ones that will make a difference.

However, as young people are often considered by adults to be immature or unable to significantly contribute to any sort of discussion that involves planning and implementation, this need remains as text on a multitude of working papers that have been consistent in constantly re-identifying this crucial element. In fact, in Malaysian society perhaps even in Asian society, a young person would find it hard to contribute and make his/her voice heard, especially if it is amidst older people. We even have a saying that discourages young people from being vocal and putting themselves forward: 'older people have eaten salt first - orang tua terlebih dahulu makan garam'.

But let's be frank: this is old news. We know what works and what doesn't, but we don't do enough of it.

What Doesn't Work in HIV/AIDS Education?

Simply said, what is listed below is only some of aspects of current HIV/AIDS education that doesn't work with young people. I believe in constructive engagement so what I have done is to outline what is wrong and what to do about it.

Language used is not youth-friendly.

In order to communicate better with us and allow us to understand, you need to get down to the language we use. If the young people you're communicating with use slang, then use slang to get the message through. Remember, what is important is that the message of AIDS prevention and awareness gets through NOT how proper it looks or seems. We work and understand best when you get down to our level.

Very directive and doesn't always allow young people to explore for themselves.

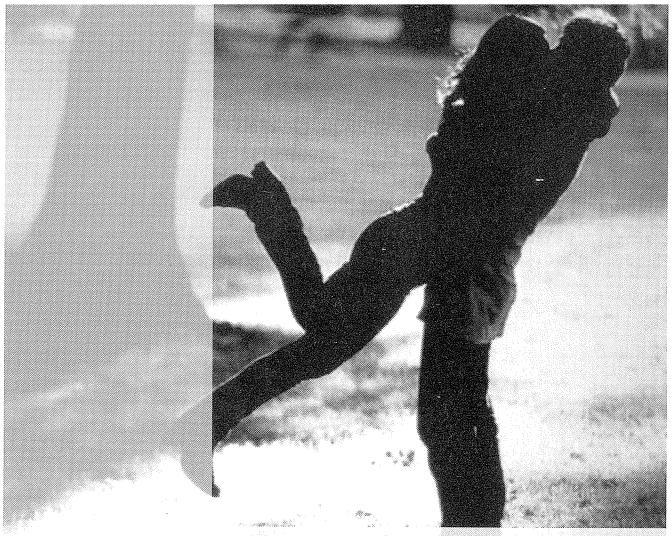
Most of the time, current HIV/AIDS education tends to dictate what young people should or shouldn't do. We know you mean well and that what you say is probably true, but nevertheless you must allow us to think for ourselves and form our own opinions. Ask open-ended questions such as, "What do you think we can do? Why do you think that is so? Questions such as these will encourage young people to talk about their own ideas and take the initiative of the discussion. Allow young people to explore to the limits of their capacity and do what they want to do. Even if the ideas do seem idealistic. Failure has its own rewards.

Being judgmental

Being judgmental with young people will cause them to close up and shut you out. This would definitely make communication difficult, if not impossible. Being judgmental will in turn cause youth to be judgmental of you. Instead of developing a partnership, an antagonistic relationship will develop, that will result in a breakdown in communications between us. In the end, nothing would be able to be done and much effort and goodwill would be lost.

Scare tactics

Using scare tactics or punishment as a way to enforce young people not to do something e.g. have pre-marital sex, doesn't work. Young people will by nature, be curious and tempted to try even though you have attempted to scare them off. You must treat and respect youth as being able to reason and decide what it is they want. To do that youth must be empowered with factual information to enable informed decisions to be made. Telling them, for example, that sex is sinful and that sexual intimacy is punishable by whipping is no good. The "why" is often treated as inconsequential and, more often than not, easily waved off behind the front of religion.



Assuming that young people already know about AIDS

Malaysian HIV/AIDS education often places the onus of finding out and knowing about HIV/AIDS on the shoulders of its intended audience. This is often the case with young people. As such, prevention and awareness messages in the mass media are often vague and has heavy emphasis on innuendo and deduction.

We are left dangling with unfinished and unknown messages concerning HIV/AIDS. Religious and cultural sensitivities in Malaysia tend to pervade and dictate the course of HIV/AIDS prevention and awareness initiatives. As such, young people suffer from the lack of information and the dearth of proper AIDS messages that empower us to protect ourselves.

Being negative and pessimistic when working with young people

Perhaps the main reason behind young people getting involved in programmes for a few years or even months, and then quitting. If adults working with young people tend to be negative from the very start, they will not put their full support behind the project and as a result their decision-making will be biased or clouded. In Malaysia, young people are considered the bane of society and the source of so many social ills and woes.

Facilitators in programmes involving so-called troubled youth, tend to be hostile and judgmental from the very beginning of the programme. As a result, the youth become adversarial and refuse to cooperate. Therefore at the end of the programme, we learn nothing and have but ill feelings and misgivings for any future dealings with adults.

Underestimating the abilities of young people.

A lot of the time we want to have space and allowed to think and design plans for our own needs. We want to be allowed to be creative but our ideas are often brushed aside as being too wild, idealistic or even ridiculous. Never tell a young person that he/she cannot do something. Even if you think they have "idealistic" ideas. You must allow youth to be too ambitious, don't disillusion or discourage their ideas. Allow us to explore our capabilities and we will find our limits.

Not admitting that young people are sexually active and use drugs

Believe it or not, there are many adults involved in the planning of HIV/AIDS prevention and awareness programmes who still cannot accept the fact that young people are sexually active and use drugs. They tend to have their own ideas as to what young people do. In Malaysia, we have been fighting for sexual health education for young people in secondary school for years. Many of those in the education ministry, and I've met quite a few including the Minister, have said "We don't need sex education for young people. Our youth have strong morals and virtues and don't start having sex at such an age."

The facts are that many young people have sex and use drugs. The majority of injecting drug users in Malaysia land in the young people category. Besides this, when people take non-injecting drugs or substances such as alcohol or glue, decision-making becomes impaired and it becomes more likely that they have unprotected sex. Such denial of reality will only harm and expose young people to HIV infection.

What does work ?

Listening and learning from young people

This is probably a tough requirement to fulfill but believe it or not, it works with us. Having an adult listen to our needs and interests goes a long way in developing a working relationship with young people. Having an adult learn from us, makes things happen. Perhaps this is unrealistic. How many adults will want to listen and learn from people younger than them who have "eaten salt" much earlier? If I was asked I would say very few. Nevertheless hearing what young people have to say often gives adults new insight into our wishes and needs, and provides information for programmes to meet them.

Being frank and direct

Many young people get mixed messages and go through their teens not understanding the changes that happen to them. Adolescent sexuality is experienced by everyone and I mean, EVERYONE. But, it is one area that is least discussed and understood. Adults fear discussion of this matter. They resort to being indirect and rather give innuendoes to sexual health questions rather than being straight-forward. Current sex education (that is when we finally get approval for sex education!) gives lengthy explanations yet still fail to answer some of our basic questions. If all else fails, religious and cultural biases are used to evade or make difficult a free discussion of issues relating to sex and sexuality. However, what is convenient for adults to hide from will expose their children to HIV infection. This attitude must change and adults must face their responsibility to educate young people in not only learning about sexuality but also how to protect themselves from infection by loving and knowing about their bodies.

Consulting and supporting young people in education programmes

Let's all own up to the inevitable fact that young people are usually not taken seriously by adults. Nevertheless, it has been proven that young people's participation and contribution to programmes has resulted in a better understanding and cooperation in forming partnerships between young people and adults. Combining the energy, enthusiasm and charisma of young people and the resources, experience and guidance of adults, programmes that promote behaviour change among young people have been both successful and effective.

Adults must accept the fact that young people are a capable and resourceful group of individuals who are able to develop and run programmes independently or as part of smart partnerships with adults.

Involving young people in the formulation, designing and implementation of HIV/AIDS Education programmes

There are many levels of involvement for young people and children in education, prevention and care programmes related to HIV/AIDS. Only young people can relate what it is it that they need, what or means for them to live in a world with AIDS. Enabling smart partnerships with young people will result in proper and effective measures that are tailored to the needs of young people. Encouraging the participation of young people in the development of programmes will also enable young people to learn about co-operation, understanding and social responsibility. This smart partnership between adults and young people will lead towards greater public understanding which may lead to changes in public policies and give youth more protection from prejudice and discrimination.

Using other mediums of communication i.e. the Internet

The Internet is a vast pool of knowledge and resources that is slowly being the main source of information and education for young people around the world. It is unfortunately under-utilised and although there are literally thousands of websites dedicated to HIV/AIDS, many are scientific orientated or not youth-friendly in design and approach. Thousands of young people use the Internet every single day for their emails, chatting, or discussion and research, spanning whole continents and multiple countries. This represents a whole untapped resource or HIV/AIDS awareness and prevention medium that may be specifically targeted and tuned towards young people.

Nevertheless, there are websites already in existence that are easy, friendly and most importantly, effective in communicating HIV/AIDS awareness messages as well as other related issues such as sex education, conception and STDs for young people. However, the numbers of youth-friendly websites are very few. Among these is the **AVERT** website maintained by the **AIDS Education and Research Trust (AVERT)** at http://www.avert.org. The website ***Iwannaknow.org*** by the American Social Health Association (ASHA) at http://www.iwannaknow.org is also good in its approach and

design. I would personally recommend the AVERT website to young people as it makes available not only information and messages concerning AIDS and sexuality but also booklets and posters that are easily read and downloadable online. The ***Iwannaknow.org*** website answers questions pertaining to young people and sexual health in a format that, I believe, is easily understandable and appealing to young people.

Personalising and NOT moralising AIDS

AIDS is often if not always moralised in HIV/AIDS education. For example, the act of teaching the modes of transmission for HIV is always followed up by comments or statements such as 'this is the punishment for sinners', 'people with bad morals or virtues will end up like this' and 'AIDS is God's punishment to homosexuals, lesbians and prostitutes.' AIDS should not be moralised, it must be personalised, as portraying AIDS as a disease of certain people, disillusions young people and doesn't lead to a better understanding of HIV/AIDS. It must be stressed to young people that it isn't a question of whose morals are better and who or what you are but instead that AIDS is unbiased and can infect anybody regardless of social class, standing or even morals.

Presenting A Positive View of People Living With HIV/AIDS (PLWHAs)

Young people tend to have a negative view or perspective of PLWHAs because the images portrayed of them are usually those who are at the terminal stage. These images project negative feelings or vibes rather than caring for people with AIDS. Having HIV/AIDS education that emphasise that PLWHAs can live longer and positively and just as productive as other people, can help promote the positive side of life which is both meaningful and caring for people infected and affected by AIDS. Young people are able to understand better and learn that we need to provide care and understanding to support PLWHAs and to live with them.

Having faith and trusting young people and adults

I would consider the element of trust and faith, the most important ingredient in a smart partnership between young people and adults in promoting prevention, awareness and care with relation to AIDS. Young people must trust on the experience and resources of adults and the latter must have faith and trust in the abilities and energy of young people. This form of constructive engagement will and can result in better HIV/AIDS education for young people based on the bilateral exchange of information and opinions. We are able to make independent and effective decisions as well as empower ourselves with proper HIV/AIDS education that recognises the needs and rights of young people to protect ourselves from infection as well as for the betterment of our well-being.

Together, without mutual trust and faith in a partnership between young people and adults, no programme will be able to fully fulfill the goal of understanding and empowering young people against the spread of the AIDS epidemic.

Finale

I don't want to end this paper as sounding demanding and unrealistic. The whys and hows I have outlined above are in reality, quite possible and achievable. The shortcomings in current HIV/AIDS education must be overcome and done so fast. To do so, requires the co-operation and understanding of both young people and adults. Neither can stand on their own or work independently for the benefit of the other. What is needed is a bilateral relationship that is frank, direct and mutually respectful of each other's capabilities, rights and needs. Impossible? I don't think so.

The clock is ticking and the grains of sand trickles downwards as more and more young people are infected by HIV due to our ignorance and inaction.

Let no more young people die while we squabble and argue on what to tell young people.

Because we are the future and we want to live. Thank you.

Resource Materials

AVERT - AIDS Education and Research Trust
4, Brighton Road, Horsham, West Sussex, RH13 5BA, United Kingdom
Tel: +44 (0) 1403 210202
Fax: +44 (0) 1493 211001
Email : avert@dial.pipex.com
Website: http://www.avert.org

Viewpoint : End The Ignorance on Sex
Asiaweek, June 13, 1997

Force for Change: World AIDS Campaign with Young People
1998 World AIDS Campaign Briefing Paper
Joint United Nations Programme on AIDS (UNAIDS)

Guidelines for Children's Participation in HIV/AIDS Programs booklet
Children and AIDS International Non-Government Organization Network (CAINN)
& Joint United Nations Programme on AIDS (UNAIDS)

5th ICAAP Youth Electronic Forum - Young People: Meant To Be Seen & Heard!
http://talk.to/youngICAAP

Natashya Yong

HIV/AIDS Education: A Young Singaporean's View On Being HIV Positive

Presented at the 5th ICAAP, Kuala Lumpur 23 - 27th October 1999

I have this opportunity to stand before all of you, not only to put a young person's face to the virus, but also to show everyone present that as a young person living and coping with the disease, I am still moving forward and am able to contribute to this worthy cause by being determined to do my bit in warning other young people what they themselves can be subjected to. My concerns for this evening shall be "HIV Education: A young person's view on being HIV positive".

Education - the act or process of imparting knowledge or skill by an external party. Know very well that a simple piece of information can change the rest of one's life totally, before wrong, irrational or rash decisions are made.

In this highly competitive world that we live in, the stress to succeed in everything that we vaguely attempt in is so often emphasised upon, that education is no longer only the responsibility of that of institutions or within the family, but that of society as well. This modern world is dawning upon the new millennium; in retrospect, technology has become advanced beyond recognition. Nevertheless, during this age where information is widely available and propagated through many media, education regarding the Human Immunodeficiency Virus (HIV) and Acquired Immunity Deficiency Syndrome (AIDS) is still not available in the simplest formats in many countries throughout Asia Pacific. There are still too many youths these days that have the wrong concepts and are illiterate and ignorant of how HIV/AIDS could be contracted.

What we young people want of today would be the most simple and basic pieces of information about what HIV is all about, only thereafter can teenagers endeavour to understand and empathise with those infected. Be it the old or the young, everyone should know the only methods that the virus can be transmitted, and I shall stress them again, and they are:

1. Through unsafe sexual intercourse with an infected partner;
2. From a positive mother to her child during childbirth or during breast-feeding;
3. Through contaminated blood during blood transfusions, organ transplants;
4. The sharing of contaminated needles by intravenous drug users.

Once everyone can grasp the concepts of transmission, they will be able to prevent themselves and others from contracting the fatal disease that can eventually lead to AIDS.

There are various mediums where the general public can easily access information regarding HIV/AIDS and I shall begin with: -

Television. Within this century, it has evolved to a medium of not only entertainment and news, but within them lie hidden, or subtle messages about reality, life and moral values that are degenerating rapidly. It is a tool that can prove to be orthodox or otherwise. Although there is information regarding the much avoided taboo subject of HIV/AIDS, what is provided by the media is and never will be good enough, basically because there will never be adequate measures regarding the dissemination of information about this disease. In my country, I do recall that when AIDS was becoming an epidemic, there was much wide spread coverage upon the possible ways of contracting HIV/AIDS, actually if you catch my drift, the ONLY way. From advertisement slots on the tube-box, where it would mostly be a couple inter-locked in a fiery embrace with subtitles reading - "You never know whether he/she has IT, you can't tell"; to the family man rejecting the occasional female onslaught in a pub, because he suddenly has pangs of guilt by just catching a glimpse of his family's picture in his wallet. But the hullabaloo seems to have died down. *And we've come to realise that in reality, these messages are not working anymore.* These may be the most logical and superficial methods of projecting how you could save yourself from contracting the virus, but of course they are never as simple as they seem.

What these advertisements have been doing, and have done, were to subconsciously embed within our conscience that the virus is an extremely destructive force and to unconsciously instil fear within the viewers. To a certain extent the advertisements have pointed out that this epidemic isn't flu, but on the other hand, unjust, erroneous and negative

messages are being sent out. The media constantly stresses that the public should very well be cautious during sexual intercourse or the consequences would be dire, it stops short of demonstrative commercials about the accurate application of condoms.

Although it is true that HIV is most commonly spread through sexual intercourse and that highlighting how it is transmitted could reduce the risks of transmission, however, are the people in conservative Asia truly ready to accept such messages of this nature? Asians are definitely the more reserved and less liberal in comparison to Europeans and Americans, no matter how advanced in technology the country is, especially pertaining messages that are even vaguely or remotely associated with sex. Therefore, whilst the media succeeds in captivating its audience with sex, romance, violence and mystery as entertainment, it succeeds invariably and unconsciously in swaying and subjecting it's audience in singling out the disease and emphasising how it is a mark or token of shame and disgrace, resulting in stigmatism. It cautions one against the contraction of the virus and other Sexually Transmitted Diseases (STDs), but there is no information pertaining how once the disease is contracted, what the consequences are besides death and how life eventually can go on, no matter how wrecked it becomes. That is the power of television, ladies and gentlemen, to not only entertain, but to dishonour and bring out of favour.

What the media and the Government could learn to do would be instead to focus on other aspects of advertising how HIV cannot be transmitted. For there are still so many ignorant of the fact that HIV is not transmitted by the sharing of toilet seats, air, utensils or bodily contact.

Unfortunately, the media has not been able to promulgate widely what the effects and consequences are after contracting HIV. HIV/AIDS does not only bring about a

change in the lives of those infected, but of those affected by it as well. And these messages are best targeted at the younger members of society. Humanity could be incorporated in advertisements. What I am sure would boost teenagers like myself that are positive would be for the mass to learn what the virus does to the human body and how one is still of service to the economy, no matter what one's handicaps are and that we are no different from anyone else on the street. *To present the reality of the disease, while simultaneously creating opportunities for the infected to have easy access to counselling and treatment.*

Brochures and charts in schools no longer do the trick. How many of us in the audience would rather be caught dead than to be reading those stand-up charts and brochures in school? And what else really is there to know about HIV/AIDS that we learn from the charts that we don't already know from advertisements? What could be done would be to provide the leaders of tomorrow, a more interactive and enjoyable method of learning about HIV/AIDS and that there is really nothing to be fearful or disrespectful about those stricken with the disease.

What about **the Internet**? I did a little surfing about within various Asia Pacific countries' search engines, and found that what is offered pales in comparison to what our more advanced counterparts, the Americans and Britons, have to offer. Although the information that is posted on the American websites are very well stocked and sufficient, it would do very well for a change if we are able to see and learn information regarding the disease and how it is being treated and handled on our own countries' websites.

I have come to notice another way that the public could become well aware of HIV/AIDS, and that is through **posters**, yet the posters that I still notice in this age are the ones that warn you against going to bed with a stranger and using a condom if you must. This sends out contradictory messages to the public,

continue on page 16

Rubberball 99

Velvet Underground
World AIDS Day,1 December 1999

Theme - Bombay! P Ramlee does the Kama Sutra in saris and a scinitillating Bindhi.

A fun-filled night of Indian cultural dance followed by frenzied clubbing which raised $8,000 for AFA. The event was supported by Velvet Underground, E33, Alessi and Transit.

THE Eden Hall Fair 1999

The Eden Hall Fair is an annual event organised by the British Association of Singapore. About $70,000 was raised at the fair. $11,300 was donated to AFA and to each of the other 5 recipient charities.

The Eden Hall Fair was started 10 years ago. It progressed from being a Christmas bazaar to a full-fledged fund-raising event in support of local charities. 1999 was the first year that AFA has been picked to be a recipient charity.

The British High Commissioner, HE Mr Alan Hunt, was the host and Guest-of-Honour.

Horizons
- INK & COLOUR ON PAPER

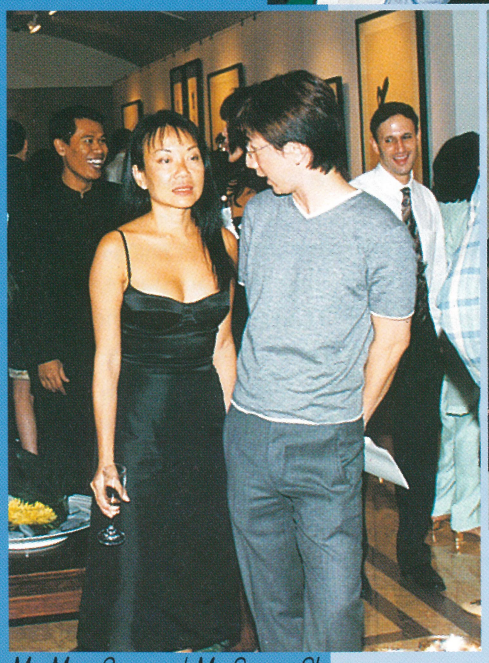
by Katherine Xiao Kejia
18 November 1999

Presented by Pomellato, at the Club 21 Gallery, Four Seasons Hotel. Opened by Mrs Dorothy Green, wife of the US Ambassador, HE Mr Steven J Green. Supported by Christies, Pomellato and Absolut.

Proceeds of the auctioned artwork and part of the sales were donated to AfA.

Left to right: Ms Kathy Xiao and Ms Dorothea Green

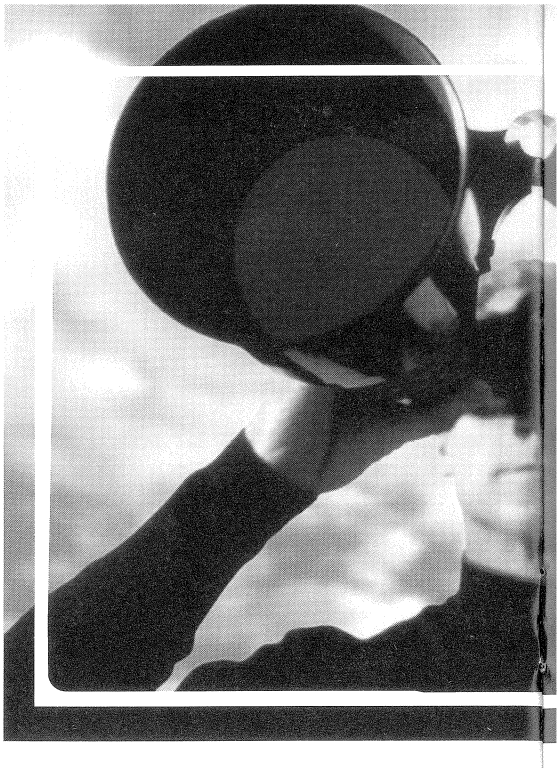
Centre, left to right: Ms Elizabeth Khoo, Ms Irene Lee and US Ambassador HE Mr Steven J. Green



Ms May Oon and Mr Casey Chua.

HE Mr Steven J. Green making a bid at the auction.

continued from page 13



especially teenagers, who are at their peak of exploration. On one hand, it encourages the use of condoms to protect one from contracting STDs, but on the other, it seems to encourage the public to engage in sexual activities. Perhaps more imagination and creativity should go into these posters as well as more information that we do not already know.

After the visual antics that the public is being exposed to, there comes the lack of **audio advertisements**. I have hardly ever heard anything over the radio that warns of caution against subjecting oneself to the possibility of the virus. And this is one important medium, which is neglected. As a teenager myself, I am aware of how much of our time we can spend tuning in to the radio, and we can listen to it about everywhere, when we're on a bus, in a cab, at work, when we do housework and even when we are doing homework. There could be just excerpts of information of the disease that could be included or having talk shows over the air on radio stations that the young tune into that would be extremely helpful.

I do know **talks and seminars** are being held in schools, but from my experience, I was more interested in the live videos that they had about abortions than the information that the speakers went on monotonously about regarding sexual transmitted diseases. I am sure that if this information could be organised to be as interactive, as humorous and as enjoyable as possible, more people would listen. However, *they still have to drive across, stress and inculcate to the young that HIV/AIDS is not a myth that occurs only to adults, but that HIV/AIDS could happen to teenagers who engage in drugs or unsafe unprotected sexual consummation as well.* However, my point would be that although transmission of STDs or HIV is the deterrent of unprotected sex, the young should not engage in any course of action regrettable unless they are ready to deal with the consequences. For this to happen, many countries in Asia Pacific should first realise and admit that for advances to be made and for improvements for the patients to be achieved, the government must accept, co-operate and give full support to research and issue medical benefits to the younger PLWHA that honestly cannot afford to keep themselves alive unless they regrettably rely on their parents.

The escalating cases of increasingly younger HIV positive patients must be brought to the attention of the governmental bodies and they must accept that HIV is not primarily and no longer just a disease that the adults are subjected to. It is also important for the government to understand that more care, concern and assistance should be issued to the younger patients. We are after all the "leaders of tomorrow", or so they say. Governmental assistance towards young infected patients leaves very much to be desired. Especially in most countries of Asia and the developing world, where approximately 90% of the patients are diagnosed HIV positive. I notice every time I pay a visit to the doctor's that there are all those life-saving drugs gathering dust on the shelves of the pharmacies; owing to financial and economic factors less than a third of the patients actually can afford any anti-HIV medications, much fewer can afford to be treated with optimal therapy as in other developed countries. I therefore pose a question to all present, how can a student of perhaps 14-24 years of age be able to afford the medication and blood tests? I know for myself, I have to rely upon my parents, and it is already taking a toll on their financial situation.

Problems that are encountered by young patients are numerous. There are so many implications that have to be considered, both emotionally and physically. One physical aspect that could plague them through life would be job stability and living costs. There are of course job scopes that require one to be HIV free, and if it is an occupational hazard, I certainly agree that it is unreasonable to put others at risk. However if it is just a preference of the company, I find it totally uncalled for and unfair. There definitely should be legislation and laws to protect the interests of HIV patients that are about to step out into the fast-paced working world. While these problems can be solved in the long run, what will remain an obstacle would be the emotional aspects.

This include the guilt of having to burden your parents with the responsibilities that you did not shoulder and having to put them and other loved ones through this ordeal. Or there could be that possibility of finding that one person out there that you truly love and want to spend the rest of your life with, but you are hindered because of obvious reasons. And then there is marriage and procreation. Sure, it is possible for HIV positive mothers to be impregnated and give birth to healthy uninfected babies; yet ethically is it right to subject the child to the lifestyle of either positive parent?

The involvement of young PLWHAs would definitely be of assistance to the production of HIV/AIDS messages because it brings out human faces behind HIV/AIDS and not the dark shadows, but how many of us are willing to step out and face the harshness of society? For like racism, the stigmatisation of being HIV positive can go to extremes even in countries that favour non-revolutionary progress and reform. We

desperately need human faces behind HIV/AIDS. *Those infected should not live behind the shadows and wallow in self-pity, but step out and take control of the situation and be in-charge, for the possibilities of making the environment around us a more comfortable place to live in lies in our own hands.*

I was diagnosed HIV positive 2 weeks after I had donated blood in an annually held blood donor's drive in my College, but never in my wildest dreams would I ever be ready for what a submicroscopic entity could ever do to change the rest of my life. I am sure I speak on behalf of many of us whom are on the verge of adulthood and have not been exposed to the gruel of society. The deliverance of such news would invariably leave many of us previously full of vitality, dreams, hopes and ambitions, bitterly and cruelly crushed. I would have to admit that it did just that to me for a period of time, because I was just 4 months away from my 'A' levels when I was informed, my results leaves much to be desired and I know that under different circumstances I could have excelled. But I do not look back. Now I stand at the juncture where I am given opportunities by several Australian Universities, for they have accepted my applications, yet my parents are reluctant to send me abroad on the basis that they are worried about my health and that it really an added financial burden because of my treatment. I stand here now, appealing for help. Be it donors, sponsorships, scholarships, grants or any other form of moral support, I would be eternally grateful.

I am thankful that after I was diagnosed with the disease, not only did I have the unwavering support of my parents, but I gained the support of a group of wonderful friends as well. But how many youths would be as lucky or realistically optimistic as I am? At that point of realisation, I believe that the most important thing besides taking stock of your health, would be to have the emotional support at the time when one would be the most frail and shattered emotionally.

These days, I still get affected by perhaps insignificant objects or situations that remind me that life will never be the same and even after coming to terms with myself and for accepting the sacrifices that I would have to make in life. The feeling of helplessness still gnaws at me on occasions when I watch a movie with a death scene in a hospital, because I realise that could well likely be how things will eventually turn out for me, but *I carry on being strong because people around me depend on me to be and I do not want any more disappointed faces around me. That would be taking stock and moving forward, knowing things that we cannot change, accepting them and changing the things that we can.*

For those affected by it, unfortunately, it is because of the shame and disgrace associated with the disease that not many of us are willing to be identified being associated with the disease and seeking help in the form of support groups or counsellors, and stepping forward and extending a helping hand. Everyone should know that the disease is not only subjected to the uneducated, the sex-workers, homosexuals or drug-addicts. I should know, for many others and I do not fall into any of the above categories.

Being HIV positive can be an extremely terrifying ordeal to go through, particularly when one can be so young, but it is no longer a death sentence. The market these days supplies countless forms of medications that can suppress the virus in our bodies to undetectable levels and slow down the process of it's replication (as long as we can lay our hands on it). Therefore, newly diagnosed young people no longer have to fear death, because we are able to live long, healthy and successful lives before the symptoms start to show. And honestly, there is a better chance of dying from a stray bullet or a reckless bus driver than HIV, for you can help yourself by taking your medication regularly or keeping a positive outlook on life.

As the AIDS epidemic enters its 3rd decade, practitioners in private practice and agency settings should be prepared to competently address those with and affected by HIV, it does not take much to acknowledge that all in all, the Human Immunodeficiency Virus is not the greatest enemy of all, it is the malevolent and corrupting force: the virus of stigmatism of this disease that we have to overcome and empower before life begins anew for us.

On a more personal note, naturally my life has been affected to some extremes by this entity, but I look forward to each new day with trepidation and because I am HIV positive, I have finally learnt how to cherish life much more than I ever did. I have no regrets about how my life is right now, except for the fact that I could very well be happier if I knew I did not have to put my family and friends through all the hurt, pain and disappointment. As I endeavor to start on the path that I am paving the stones for in education, I implore those amongst you that are HIV positive to try to keep a positive outlook on life, because, looking at me, you know that you are not alone.

Kirsty Machon
Reprinted from the HIV Herald,
Vol. 9 No. 1 1999,
Australian Federation of
AIDS Organisations

Is It ever safe to stop?

Drug breaks in the spotlight

More than three years on from what US activist Erte Rofes dubbed the Protease Moment, the wears and tears of combination therapy are beginning to show. It might have been easier to 'adhere' to complicated regimens, and to suffer side effects, if the scientific optimism of the protease prophets had been borne out.

The early enthusiasm for triple therapy was partly fuelled by speculation that HIV could be 'eradicated' from the body through drug combinations containing protease inhibitors. Initially, it was estimated that this process would take about three years. This figure, rather like a tax, has been creeping up steadily ever since. The latest research suggests it might take anything up to 63 years before 'latent' cells infected with HIV and resting in the body's lymph nodes actually decay and die. So even if antiviral drugs could wipe out all the HIV in the bloodstream, there would still be replication-competent virus in lymph nodes and other "reservoirs" which would be capable of eventually causing damage to the immune system if the cells should ever become activated. And this virus is now thought to hang around for a long time: much longer than the amount of time most people would care to be on antiviral treatments.

So should we be surprised then, that one of the most pressing of the emerging issues facing people living with HIV relates to the question of whether or not and under what conditions it might be safe to stop taking HIV antivirals - even for short periods of time. That there be some public debate about this has now become a matter of urgency. There is no agreement within the medical community as to whether breaks from antiviral therapy should ever be sanctioned for any reason. Most doctors, if quizzed, will refer to studies which show how quickly viral load can rise after stopping drug treatment. However, it is also the case that people are deciding for themselves (and sometimes on the basis of limited or even incorrect information) to stop taking their drugs - and in some cases, not telling their doctors about this for fear of repercussions.

The term '*drug holiday*' now has a widespread currency among PLWHA and doctors, but it is in fact, quite misleading. The term was initially coined to describe the not-uncommon practice of stopping treatments for short periods, in order to better, enjoy special events like Mardi Gras weekends or camping trips. However, it has now become a "catch-all" term used to describe breaks from therapy in general: whether these breaks occur in a 'structured' way (after discussion with a doctor), or a person simply decides to "go off their drugs" for a day, a week, "a while". Structured interruptions to ongoing treatment are more accurately referred to as 'pulse therapy'.

Treatment breaks in early infection

It is important at this point to make a distinction. Most of the limited research about treatment breaks has involved people who started taking antiviral drugs at seroconversion, or during primary infection. However, these people are in a very different immulogical position compared to people who began treatments at a later stage in HIV infection. It is thought that people treated during primary infection, and who have managed to keep the virus suppressed at consistently undetectable levels, have maintained the potential for some of the key immune responses to HIV. As with other viruses and infections, the body does mount an initial immune response to HIV. This includes the production of antibodies, and of cells which specifically seek and kill other cells if they are infected with HIV. If antiviral treatment is able to drive viral load down and maintain this at extremely low or undetectable levels, these immune responses to HIV will not occur, because there will not be enough HIV protein around for the immune cells to respond to. However, in many people who treat HIV very early, the virus has not had the opportunity to cause any of the damage to the immune system found in later stages of infection. So some researchers believe that the body will maintain certain important elements of an immune response to HIV.

The theory behind structured interruptions to therapy in people treated early is this: if therapy is stopped for a short period, the virus will begin to replicate, and the immune system, recognising the virus, will respond, and mount an attack against HIV-infected cells. If viral load begins to rise again, antiviral therapy will then used to suppress virus again. Over a long period of time, the immune system may become so effective at fighting HIV on its own that the need for antiviral drug suppression become less and less. However, while research continues, there is not nearly

enough evidence to 'prove' that preserving these immune cells will necessarily lead to long-term suppression of HIV in the absence of antiviral treatment.

Evidence for this approach

It seems there is some flimsy evidence to support this theory, some of it presented at the Chicago retroviruses conference earlier in 1999. Dr Marty Markowitz, from the Aaron Diamond AIDS Research Centre in New York, reported on a small study of people who had discontinued treatment after an average of about 18 months on treatment. There are two critical caveats to this study. Firstly, it was very small (just four people), and secondly, all four people had been treated very early, and all had undetectable virus (below 400 copies). When therapy was stopped, two of them were able to maintain virus below 400 copies after stopping therapy: one for 14 months, and one for 21 months. However, the other two saw their virus rise back to baseline (pre-treatment) levels. This study is at best suggestive, and it would be impossible to draw any meaningful conclusion from the experience of the two patients who stayed undetectable for 14 and 21 months.

A second study from Chicago was presented by Dr France Lori, who looked at the case of three people taking AZT, 3TC and ritonavir. All had high viral loads (between 16,000 and 720,000copies), and started treatment within one year of infection. They were put on a 'structured' series of breaks from therapy. Three weeks of treatment was followed by a complete break (or interruption), which continued until viral load rose to 5,000 copies. The patients then began treating again (with the same combination). After three months, treatment stopped again. The researchers noted that following each successive interruption to treatment, the time in which it took for viral load to rebound to 5,000 increased: from one week after the first break to an average of 37 days third time round.

As with the Markowitz study, this is far from "evidence" that structured interruptions to treatment, or pulse therapy, have a role in managing HIV. It is Dr Lori's view this approach may only be applicable in people who actually start treatment in the window period before seroconversion has actually occurred. He was moved to warn that the data was experimental, and should not be used to justify changes to current treatment strategies.

The 'Berlin patient' hype

Most discussion about stopping therapy is likely to touch on the so-called Berlin patient. The case of this one man has garnered an enormous amount of attention worldwide, and has been frequently held up as exemplifying the argument that early treatment of HIV can lead to eradication, or at least to ongoing successful viral suppression without therapy. The 'Berlin patient' was treated close to the time of his seroconversion with a combination of hydroxyurea, indinavir and ddI. At the time he commenced therapy, he had a high viral load (90,000) but was antibody negative. The triple combination therapy was immediately effective in suppressing his viral load to below 500 copies (undetectable). After a few months, the man stopped his anti-HIV medications due to an infection (for which he took antibiotics), and, as might be expected, his viral load increased. He re-started the same combination of drugs, and then stopped again after experiencing another infection. This time, however, his viral load did not rise. It remained well below the level of detection, and only through the most high-tech analyses of his lymph nodes have doctors yielded any evidence of HIV whatsoever in this man's body. More recent reports indicate the Berlin patient also maintains one of the critical immune responses against HIV: the production of immune cells called cytotoxic T-lymphocytes, which can kill cells infected with HIV.

The significance of this one patient remains unclear, and it is not clear that we should expect such results to ever be widely duplicated. What's abundantly clear is that the situation of the Berlin patient, whose case is most unusual, should not be taken to mean that stopping therapy is generally safe, or even beneficial. But frustratingly, the Berlin patient's case has been widely claimed as evidence in support of both treatment breaks, and of the benefits of hydroxyurea (an anti-cancer drug sometimes used to treat HIV).

Reality bites: what if you want to stop?

The reality is, most people taking, or contemplating, so-called "drug holidays", are not seroconverters. Practitioners seem divided on the question of whether breaks from therapy - for any reason - should be countenanced in people who begin treating HIV at a later stage of infection. Many doctors insist that any breaks from treatment at all are dangerous: an open invitation for the virus to reopopulate and cause havoc (and perhaps develop drug resistance at the same time). Nonetheless, many doctors who see lots of people with HIV have experience in managing people who have come off therapy.

HIV is certainly capable of replicating very quickly, and the principles of combination antiviral treatment are based on a philosophy of getting viral levels as low as possible, and keeping them there. If viral load remains extremely low, so too does

the level of damage to the immune system. Generally (though perplexingly, not in 100 percent of cases), if viral load is very low or undetectable, CD4 counts remain higher, and effective viral control can even lead to CD4 count rises: good news in terms of staving off opportunistic illness and AIDS.

The other important thing about keeping virus at really low levels is that it dramatically decreases the likelihood of developing drug-resistant virus. HIV becomes drug-resistant relatively easily because it is prone to changes in its genetic makeup each time it replicates. Over a period of time, these changes may allow the virus to escape the control of certain anti-HIV drugs (or in some cases, whole groups of drugs). This resistant virus eventually starts to multiply unchecked, and so you get the now-familiar rises in viral load and potential for immune damage associated with drug resistance.

However, if viral load is low or undetectable, and is staying at that level, it means very little, if any, viral replication is happening. If HIV is replicating at negligible levels (or not at all), then there is little opportunity for the mutations than can lead to drug resistance. One of the great concerns about interrupting treatment is that this may lead to drug resistance, and limit or drastically foreshorten ongoing treatment options. The third factor is evidence about HIV itself, which shows that after stopping therapy, viral load can rebound incredibly quickly, with the level of virus in some cases doubling every two days.

When you'd rather drink sump oil than take another pill

This 'round-up' of medical evidence gathered in laboratories and the rarefied world of studies and trials ignores one obvious point: the reasons for which people might want to take breaks from treatments. To name but a few: lipodystrophy; nausea; diarrhoea; kidney stones; drug interactions; double-digit pill regimes; treatment fatigue.

If you want to stop treatments because of intolerable side effects, it may be worth investigating whether switching to a different drug or combination with fewer side effects would be an appropriate first step. Some side effects (like diarrhoea) can be managed with a range of handy tricks and tips, some of which are quite simple, natural and non-invasive. However, changing treatments is not the answer for everyone. It could well be that there is simply nothing to 'change to', and if your drugs are working, you could be unnecessarily 'using up' options. Besides, the argument to "just change your drugs" is hardly useful or comforting if your reason for wanting to stop therapy is not physical, but psychological. Maybe you're feeling well, and finding the treatments a general imposition on your busy life. Or maybe you just feel as if, with all the pills you have to swallow, you might as well walk down the street rattling: you'd frankly rather drink sump oil.

Things to consider before any break

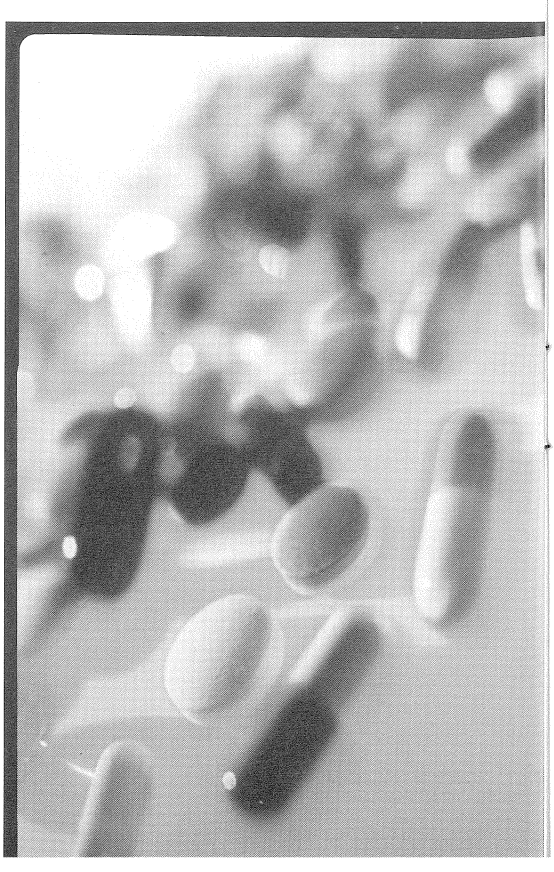
One of the critical factors overlooked in all the sermonizing and lecturing about treatments break is this: if you are taking your current combination erratically or irregularly, this is potentially more problematic than stopping altogether for a break. The reason why it's important to take HIV therapies pretty much to the letter is that suboptimal drug levels in your blood create the perfect situation for resistance to emerge.

Dr David Butcher, a well-known HIV clinician from the USA, says that when his patients report problems adhering to a particular drug regimen, and these problems cannot be resolved, he prefers to pull the patient off all treatments altogether, and work on the adherence issues. He has sometimes done this for periods of up to six months.

If you are considering a treatment break, it may be best to stop all drugs at the same time, rather than just stopping the drug which is causing you trouble or side effects.

Monitoring and prophylaxis

Treatment breaks are something that you really need to do in close consultation with your doctor. This is important because of the capacity for viral load to rapidly rise. It would be best to have your viral load and CD4 counts checked regularly during any interruption to treatment, so that if either reaches a level at which you feel uncomfortable, or at risk, you can consider whether to go back on treatments. For some people, however, part of the psychological importance of a treatments break is precisely about not seeing a doctor or undergoing any motoring. Though most medical practitioners would be likely horrified by this prospect, some people report that this is part of 'freeing' oneself (if only for a short time) from the tyranny of checkups, appointments, blood tests and the relentless white noise of health maintenance.



If you are in this position, there are a couple of things to think about. The first is to be generally aware of your state of health, including the potential symptoms of any opportunistic infections or illness you may be at risk of, especially if you stopped treatments with a high viral load or low CD4 count. One of the realities of stopping treatment is that it might well put you at risk of an OI. OIs can be better managed and treated if diagnosed early. You may also want to think about starting or continuing prophylactic drugs (for example, the antibiotic Bactrim to prevent PCP). Some people may find this idea defeats the entire philosophy of a 'treatments break'. But this relatively low-maintenance intervention could prevent a much more serious, debilitating and invasive medical interventions down the track.

The 'great experiment'

Many HIV-experienced GPs understand that so-called drug holidays are a fact of life in managing HIV - and one that isn't going to go away by ignoring the issue. On the basis of the medical evidence alone, drug holidays are at best a risk and at worst, dangerous. There is a feeling that clinical research in this area needs to be urgently conducted, and some trials are likely to begin shortly in Australia.

However, test-tube understandings of HIV are million miles from the daily reality triple (or more) therapy. If your GP is absolutely adamant that he or she will not discuss your wish to stop treatment, seek advice elsewhere. It may be your doctor doesn't endorse it, but I'd be worried if they refused to entertain a discussion. It seems clear that what is more dangerous than a well-planned and monitored break from your treatment is to take drugs in an erratic or sporadic manner, or to stop therapy cold without advice, support or plans for contingency.

Treatment breaks: the lowdown

Reasons you may be considering a break from treatment

- Side effects
- Holidays, Mardi Gras, 'having a life'
- Exhaustion of treatment options
- Illness
- Treatment fatigue
- Intolerable pill burdens
- As a planned medical strategy to boost your immune response

What we know about stopping treatment

- A limited amount of research has been conducted.
- Much of this focuses on people treated at seroconversion or primary infection; it is difficult to draw firm conclusions, or assume that what happens in some individuals will be the experience shared by all - especially for people who started treatment later in the course of infection.
- Even in these seroconversion studies, people did not have uniform or predictable responses on stopping therapy.
- Viral load can 'rebound' very quickly after stopping drugs, often doubling every two days, and CD4 T-cells can sometimes quickly fall.
- For many people, virus can be controlled again once treatment is resumed.
- There is a greater difference between structured interruptions to treatment in the setting of clinical trials, and erratic adherence, or random 'drug holidays'.
- It may be best to stop all drugs at once, rather than just stopping the drug in your combination with which you are having the most trouble. Some drugs stay around in your body longer. If you are taking a break, ask your doctor whether you should come off the longest-acting drug first.
- A carefully planned interruption to all therapy for a limited time, but at least a month, is probably 'better' than erratic and frequently missed doses, or very short breaks of only a few days.
- A lower viral load and higher CD4 count at the time of starting therapy may suggest a better outcome on any treatment break.

But we don't know...

- if HIV can be eradicated from the body through long-term ART, or how long this might take;
- whether long-term suppression of HIV is possible without antiviral therapy;
- the optimum time frame (if any) for a structured treatments interruption;
- whether seroconverters and people treated in primary infection really do preserve durable immune responses which are enhanced by interrupting treatments;
- the exact relationship between planned drug holidays and the risk of resistance.

Things to consider if you want to stop treatments

- If side effects or difficulty adhering to a particular drug or regimen is the problem, is there an alternative combination which could be easier or more viable for you? Can your side effects be managed in other ways (eg. with complementary therapies)?
- It's advisable to undertake any treatments breaks with guidance from a doctor. If he or she will not support you, or talk you through the issues, see someone else who will.
- You will be strongly advised to monitor your viral load or CD4 cells, so that you know when and if you should consider going back on treatments.
- If you want a break from medical interventions full stop (including monitoring), be aware that you could be at risk of opportunistic infection or illness, seek medical advice if you have any symptoms or problems.
- If you are stopping treatments with a low CD4 count or immune damage, consider taking prophylactic medications to prevent OIs. This intervention could prevent serious illness.

Feisal Abdul Rahman

Islam & HIV/AIDS: A Tradition of Compassion & Action

AIDS is simply a disease. Like all diseases, we should therefore do all we can to prevent it, and do our best to cure it when it occurs. That seems so obviously right, and in the end, that is exactly what Islam - and many other religions - teaches its followers. But the road to that point is often tortuous, mainly because AIDS is often viewed as one of those controversial "taboo" topics that most Muslims prefer to avoid. So if you ask some Muslim leaders about AIDS in their community, they would often reply, "Muslims don't have AIDS."

Many Muslims appear to take solace in the widely accepted belief that Islamic values provide a sufficient degree of protection against HIV/AIDS. However, as evidenced by the growing number of Malay/Muslim HIV/AIDS cases here and in other parts of the world, it is clear that while Islam does help to promote a line of behaviour for HIV/AIDS prevention, moral/religious theory is not necessarily being put into practice. More significantly, such denial does a disservice to those persons who are suffering from the disease - regardless of how they contracted it.

The Islamic tradition

The Islamic tradition has as its centre, the Holy Quran and the documented life and example of the Holy Prophet Muhammad of 6th century Arabia. In order to become a Muslim, one takes the Shahada, which means bearing witness that: There is no God but Allah and Muhammad is his final Prophet. This declaration of faith, in essence, means that a Muslim believes that there is only one God, one Supreme Being whom they call "Allah", and that Muhammad Ibn Abdullah of Arabia, is the last and final Prophet, or Messenger of Allah. Inherent in this declaration is the act of submission to the Supreme Being, the Creator of the Universe, who has the exclusive authority to prescribe a way of life, which guarantees success in this life and the promise of paradise in the hereafter.

The faith of a Muslim is confirmed by five obligatory acts of worship:

i) belief in the oneness of God;
ii) prayer five times a day;
iii) giving of alms to the poor;
iv) fasting during the month of Ramadan; and
v) performing the haj, or pilgrimage to Mecca, at least once in a lifetime.

Muslims believe that God has prescribed these tenets in order to assist human beings to develop the spiritual strength necessary to practice virtuous conduct and avoid sin. So, the foundation of a Muslim's belief and worldview is teleological, i.e. they see the world in terms of a divine will or plan, with a distinct purpose.

Disease as divine punishment

Muslims see belief in God and obedience to God as an essential element of salvation and reward, achieved through prayers and righteous conduct. In addition, they see disbelief and disobedience as actions and behaviour that earn God's wrath and punishment in this world and the hereafter.

Islamic tradition has long viewed plagues and natural disasters as being manifestations of God's wrath. There is no denying the fact that although AIDS may have originated in Africa among heterosexuals, in North America and elsewhere, however, the disease is still deeply connected in the common mind with gay men, for they were among the first people who contracted AIDS in large numbers before its global spread. Consequently, AIDS, when viewed through the prism of "sin," is seen to be brought on by risky behaviour that displeases and disobeys God, and that will certainly result in punishment. The Holy Quran emphasises over and over again the importance of obedience to God:

To Allah belongs all that is in the heavens and on earth; so that He rewards those who do evil according to their deeds and He rewards those who do good with what is best. (Holy Quran, 53:3)

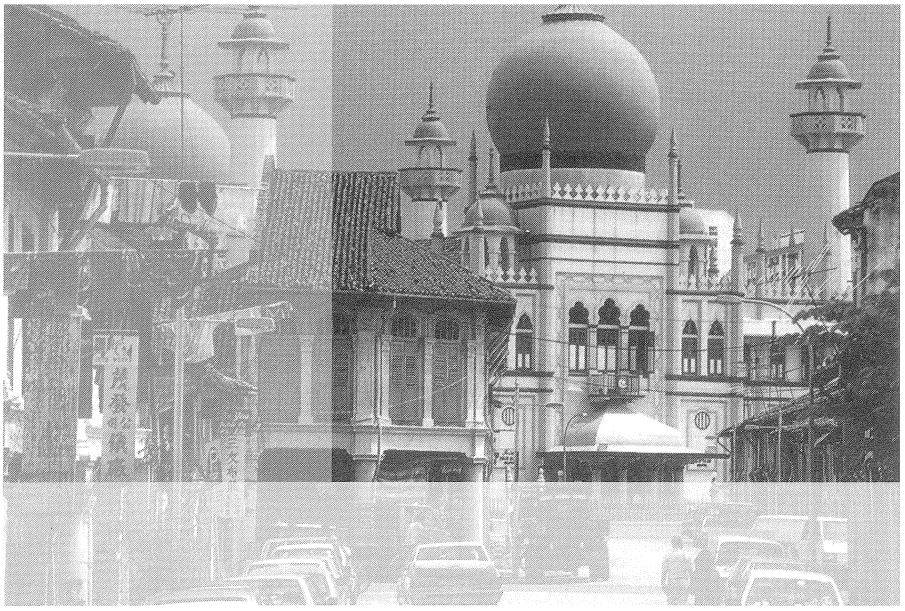
Fear the fire, which is prepared for those who reject Faith: and obey God and the Apostle; that ye may obtain mercy. (Ibid, 53:131-132)

In fact, the identity, position and status of a Muslim are primarily determined by his/her performance of good deeds.

Another critical point to understand is that Muslims are not only required to obey God individually and collectively, but they are also required to enjoin others to engage in righteous conduct:

Let there arise out of you a band of people inviting all that is good and enjoining what is right and forbidding what is wrong, they are the ones to attain felicity (Ibid, 3:104)

You are the best of people evolved for mankind, enjoining what is right, forbidding what is wrong and believing in Allah. (Ibid, 3:110)



So in actuality, Muslims consider themselves among the best and most righteous people, so long as they adhere to the dictates of God's instructions and conform their behaviour in accordance with His divine instructions. Conversely, AIDS is often seen as not just a confirmation of God's promise to punish those who disobey Him, but also an affirmation that God keeps His promise.

From Moral Judgement to Empathic Support

Despite this seemingly intractable quagmire, many Muslim AIDS activists and Islamic scholars believe that we can still establish a way in which Muslims can engage in the struggle to rid the world of the scourge of AIDS while maintaining their religious and moral world view, without compromising their religious beliefs. This paradigm of engagement remains deeply embedded within the traditions and ethical teachings of Islam and operates within the Islamic conceptual framework.

Drawing from the sources of the Holy Quran, Muslims can be urged to focus on that aspect of God which is Most Compassionate and Most Merciful, i.e. to focus on Allah's mercy and forgiveness, rather than His wrath:

Say, O my servants who have transgressed against their souls; despair not of the mercy of Allah: for Allah forgives all sins: for He is oft-forgiving, most merciful. (Ibid. 39-53)

By calling on Muslims to reflect on the essence of Allah's message, which focuses on the all-forgiving nature of God, and which commands them to help those that are less fortunate, Muslims can therefore be urged to view persons with AIDS as fellow human beings who are simply ill. And when a person is sick, the overarching concern should be that the patient deserves all the medical aid and social support that the community can muster, rather than on how he or she contracted the disease.

Muslims can also be persuaded to support and become advocates for an increase in funds for HIV/AIDS research. This is supported by the teachings of Islam which state:

It was reported that the Prophet said: "Verily, Allah has not let any malady occur without providing its remedy. Therefore seek medical treatment for your illnesses." (Hadith reported by Anas ibn Mas'ud and documented by Ibn Majah)

Support of more health care and education can also be mobilised within the community. One need only ask that they recount the famous words of the Prophet Muhammad who stated:

I heard the Messenger of Allah saying: "He who amongst you sees something abominable should modify it with the help of his hand - and if he has not strength enough to do it, then he should do it with his tongue (i.e. speak out against it) and if he has not strength enough to do it, then he should hate it in his heart, and that is the weakest of faith." (Hadith 365, reported by Abu Sa'id al-Khudri)

Islam: A Message of Compassion, Care, and Hope

The message that emerges from the Islamic tradition about AIDS is the simple truth with which I began this essay. AIDS is a disease. We should therefore do all we can to prevent it, and, failing that, we should we do all we can to cure it. Until a cure is available, we owe it to AIDS patients to provide them with compassion, comfort and whatever social and personal support we can provide, including whatever medical ministrations that will help them cope with the disease.

In other words, we must do our best, to remind ourselves and AIDS patients that no disease removes a person from the community. Instead it is precisely when one is in need, that the community has the greatest obligation to function as a supporting community.

For Islam, this is not only what a compassionate human community should do; it is what God commands and what the Holy Prophet himself does. After all, Muslims need only remember what the Quran says about Prophet Muhammad:

" We have sent you O Muhammad as a mercy to the worlds. "

We must therefore come to the aid of the sick, in order to model ourselves after the Holy Prophet, and in accordance with God's divine instructions.

In closing, the discourse on AIDS must be re-framed if we are to fully engage the religious community in this battle. We cannot afford to leave anyone out. We need all of the support that we can get to eradicate this disease and, God willing, we will be victorious. *Insha Allah!*

Anak Melayu Islam Melawan Penyakit Unik HIV/AIDS (AMPUH)

AMPUH is a group of Malay/Muslim volunteers under the auspices of Action for AIDS. It was set up to tackle the rising number of Malay/Muslims infected with the HIV virus or suffering from AIDS.

The objectives of AMPUH are:

i) To enhance awareness about HIV/AIDS within the Malay/Muslim community;
ii) To promote active community participation and involvement in HIV/AIDS education and awareness; and
iii) To enhance community support for Malay/Muslim PWAs.

AMPUH intends to achieve these objectives through the following activities:

i) Research: Conduct periodic research to assess knowledge, attitudes, and practices (KAP) within the Malay/Muslim community with regard to HIV/AIDS.
ii) Partnership: Establish and foster partnerships with local Malay/Muslim organisations, community and religious leaders in our effort to fight the disease;
iii) Education: Establish education programmes to raise the community's awareness about HIV/AIDS;
iv) Support: Run special programmes to enhance community support for Malay/Muslim PWAs.

Those who are interested in becoming volunteers, please contact AFA at 2540212.

we are Moving!

The administrative and volunteer coordination office of Action for AIDS at 62B Race Course Road will move to larger premises at

36A, Kim Keat Road
Singapore - 328812
Tel : 2540212
Fax : 2565903
E-mail address : afa@pacific.net.sg
from 1 February 2000

Please note that the following will remain the same:

Mailing address :
31, Kelantan Lane, #02-16,
DSC Clinic, Singapore 200031
Web site address : www.afa.org.sg

There are no changes to the Anonymous Test sites at the DSC Clinic on Saturday afternoons and at Tanglin Shopping Centre on Wednesday evenings. • Please call us or e-mail us should you have any queries. • Please have a great New Year 2000 and do continue to support our anti-HIV efforts.

AIDS

Candlelight Memorial 2000

Venue : Bras Basah Park
Date : Sunday, 21 May 2000
Time : 7.00 pm

Admission is free

Prayers will be led by representatives of the Inter Religious Organisation, Singapore

The **Candlelight Memorial Party**,
Sunday 21 May 2000, 9pm onwards at Venom.
Heartstrings: The Show at 11pm.
Featuring an all-star volunteer cast.
Entry charges apply.

Condom-shy Teens at High Risk of HIV- Government Fears Disease Level could reach Alarming Proportions

Piyanart Srivalo, The Nation, January 6, 2000

THAI teenagers as young as 13 are at risk of HIV infection because they have unprotected sex with multiple partners, says Dr Somsong Rakphao, director-general of the Public Health Ministry's department of communicable-disease control. She fears instances of HIV among teenagers could reach alarming levels. Somsong told reporters after attending a meeting of the National Committee on AIDS Problems Prevention and Solution that the committee was worried by the sexual behaviour of teenagers as young as 13. This made them vulnerable to HIV infection, which causes AIDS. Only 20 per cent of sexually active teenagers used condoms, which put them at even higher risk, said Somsong.

A study had revealed that fishermen and young people were most at risk. The study also found that some young people began having sexual relationships as early as 13 and that a high proportion of women between 15 and 25 were having sexual relationships with multiple partners. This was more obvious among female factory workers. In a survey of 5,000 female factory workers, about 60 per cent of the respondents said they had had sexual experience, with 22 per cent having had sex men other than their boyfriends.

According to Somsong, the latest official figures show that a million people in Thailand are infected with HIV, 150,000 people have developed full-blown Aids, and 40,000 have died from AIDS. The number of HIV-infected people continues to rise, Somsong said. The rate of HIV infection among blood donors and pregnant women had increased by 0.44 per cent and 1.76 per cent respectively. Most people with HIV were intravenous-drug users. They constitute 51.14 per cent of all HIV carriers.

Somsong said Prime Minister Chuan Leekpai, who chaired the committee meeting yesterday, expressed his concern about the spread of HIV and encouraged all agencies involved to make a concerted effort to control it.

Korn Dabaransi, Deputy Prime Minister and Public Health Minister, who also attended the meeting, pledged that his ministry would accelerate its AIDS-prevention programme. The Public Health Ministry was working on the development of nine HIV-related vaccines, Somsong said. The vaccines research is part of a cooperative programme between Thailand and China to study the feasibility of using herbs in the treatment of AIDS.

The World Health Organisation estimates that 2 per cent of all Thais between the ages of 15 and 49 are HIV-positive, a rate of infection believed to be the highest in Asia. Over the years, the government and the private sector have cooperated in efforts to combat AIDS and provide health care for the victims. AIDS-awareness campaigns have been conducted in villages and all provinces to educate people about safe sex. But the economic crisis of the past two years efforts has cut the amount of money available to meet the health-care needs of people living with HIV/AIDS. According to official statistics released by the Public Health Ministry, 780 people died of AIDS in 1998 and 158 between January and November 1999.

Sex in the Classroom is never Easy

Sanitsuda Ekachai, Bangkok Post, January 6, 2000

Do our children need sex education? Of course. The more important question, however, is how to do it - how to change the conservatism of teachers and how to make sex education part of an overall change in cultural attitudes to tackle the root causes of unequal and exploitative gender relations. It's one thing to think up a good policy. It's another to make it work.

Last year, the Education Ministry announced a policy on independent curriculums for schools, a revolutionary step in the Thai education system. It quickly fell flat because of internal resistance and leadership change. Once the policy initiator is transferred, his/her projects tumble. The new leadership then thinks up his/her own pet projects. That's how the Thai bureaucracy operates.

So don't get excited yet over the new policy push for a sex education overhaul. The odds against it are very high when the enemy is deeply-ingrained sexism and authoritarianism in our own culture. Unless the teachers undo their sexist attitudes and stop top-down teaching, sex education in the school system will never work.

continue on page 26

US Vice President Gore's Remarks on AIDS to UN Security Council

Vice President Al Gore announced January 10 that the Clinton Administration plans to spend $325 million in the coming year to help prevent and treat AIDS in Africa, Asia and other regions of the world.

Addressing a meeting of the UN Security Council on AIDS in Africa, Gore said that the threat of AIDS is real for everyone and every nation, everywhere on earth. "No border can keep AIDS out; it cuts across all the lines that divide us. We owe ourselves and each other the utmost commitment to act against AIDS on a global scale - and especially where the scourge is greatest," he said.

Emphasizing that "AIDS is a global aggressor that must be defeated," Gore said that the Clinton Administration's Fiscal Year 2001 budget will include an increase of $100 million over the current budget to assist efforts to combat AIDS and contribute to international infectious disease prevention efforts. The plan also includes another $50 million to help fund the research, purchase, and distribution of vaccines against other diseases that ravage poor nations including hepatitis B, yellow fever, TB, and malaria.

Gore said that it is important that the Security Council was putting the AIDS crisis at the top of the world's security agenda.

"We must talk about AIDS not in whispers, in private meetings, in tones of secrecy and shame. We must face the threat as we are facing it right here, in one of the great forums of the earth - openly and boldly, with urgency and compassion," the Vice President said. "Until we end the stigma of AIDS, we will never end the disease of AIDS."

Gore emphasised the need for more research and commitment to finding a vaccine to prevent AIDS. He also said that he will convene a meeting of U.S. business leaders active in Africa to develop a set of voluntary principles to make the workplace an effective place for education and prevention of AIDS.

"We here in this room - representing the billions of people of the world - we must become the promise of hope and of change. We must become the promise of life itself... We must make the promise and keep the promise to prevail against this disease - so that when the story of AIDS is told to future generations, it will be a tale not just of human tragedy but of human triumph," the Vice President said.

---

continued from page 25

AIDS educators long ago encountered this stumbling block to sex education. With the outbreak of the AIDS pandemic, many public health and educational agencies want to educate youths on AIDS prevention. The teachers, however, rarely question male promiscuity, which mainly accounts for the spread of AIDS in Thailand. Instead, they focus on the girls by telling them to say no to premarital sex or to insist on the use of condoms.

This is so because teachers are blind to the sexist culture that paralyses women from initiating protection for fear of being seen as sexually experienced, thus bad women. Furthermore, by putting the burden of protection on women, it follows that women must bear the blame if they fail to protect themselves. Condemning premarital sex also forces sexually active teenage girls and women to keep mum about it for fear of being seen as loose, thus preventing them from getting help.

It's not surprising why these gender-insensitive programmes fail miserably. Many AIDS educators have thus opted for peer education as a more effective way to prevent the spread of AIDS. Whether sex education in schools will work or not also depends on how the educational authorities perceive the problem. The effort to improve sex education stems from recent media coverage of commercial sex in colleges and the alarming increase in unwanted teen pregnancies. The coverage puts the Education Ministry on the spot, forcing it to come up with remedies.

Since the problem is viewed as arising from women, the underlying motive of the new programme is to control women's reproductive health. Given this bent, the new sex education policy will most likely end up targetting women again similar to state policies on birth control, abortion and AIDS. To be fair, it's wrong to blame the educational system alone for the rise in youth problems. And it's useless to continue the good girl dogma. In the information age, parents and schools must join forces to fight the media and its endless bombardment of youngsters with sexist images and messages that perpetuate the culture of sexual exploitation. If we view gender bias - not women - as the culprit, we'll try to help our children decode the complex layers of cultural sexism. By undoing those oppressive values, both male and female youths will understand their own sexuality and enjoy healthy relationships. In short, we must help our children learn to think and take control of their lives.

If the new sex education policy is aimed only at improving on the good girl dogma, it's doomed to failure right from the start.

Dear Makchik

Why did Paddy Chew die? Presumably he was on the triple drug anti-AIDS therapy?

Paddy Chew was the first person in Singapore to publicly announce that he had AIDS, and therefore put a face to AIDS. In recognition of his courage and sense of public service, AfA agreed to pay for his antiretroviral (HIV) medications. Anti-HIV drugs are expensive and are unaffordable for most persons with HIV/AIDS (PWAs). While this drug therapy can have remarkable results and prolong the lives of patients, some PWAs do not respond to medication. This happens especially in patients with very advanced infections. Such was the case with Paddy - a brave man with a big heart who will be missed.

Is HIV passed from women to women? If so why don't we hear about it?

Women can get HIV from other women. The most obvious route is through unprotected oral sex between women, viz. licking the vagina of an infected partner. To become infected, the "licker" has to have cuts on her tongue or in the mouth that come into contact with infected vaginal fluids. HIV can then pass into the bloodstream causing infection. We do not hear about it because HIV transmission by this means is difficult and extremely rare.

For how long will anti-AIDS drugs continue to be so expensive?

The answer is simple - for as long as pharmaceutical companies don't lower their prices or allow the drugs to be manufactured under license and sold at a fraction of their current prices. It is a tragedy that we have effective drugs that are beyond the reach of the vast majority of persons infected with HIV, even in Singapore. The net result of this is that millions of people are dying of AIDS because they are poor or their governments will not provide the drugs free or subsidize them. But changes may be ahead. Some organisations are discussing the manufacture of these anti-AIDS drugs in developing countries under the "compulsory licensing" scheme. This will make the drugs available to the PWAs in the country of manufacture.

How can we be sure that Singaporeans with HIV don't continue to have unprotected sex?

We can't. Infected Singaporeans are counselled about their responsibilities to others but nobody except themselves can police their behavior. Under Singapore law, a HIV-infected person must inform their partner that they are infected before they have sex. If the partner agrees to have sex, then no law would have been broken. If the PWA does not inform the partner, the penalty is a fine and or imprisonment - regardless of whether the infection is transmitted or is not.

But what if an HIV-infected person subsequently contracts syphilis, gonorrhoea, or some other sexually transmitted disease (STD)? Logic dictates that this new STD must have been the result of unprotected sex with another person. However for the law to be applied this partner must be found and it must be ascertained whether or not the information of HIV was given to the partner before sex. Laboratory tests must also be performed. Therefore even if the authorities suspect that a HIV-infected person is still having unprotected sex, it will be very difficult to prosecute them if their partner(s) cannot be traced.

I'm an expatriate in Singapore with HIV. Where can I get treatment?

While the answer is easy, the consequences are not. Anyone in Singapore needing treatment must first take an HIV test. A Singaporean with a positive result will be offered counselling and treatment at the CDC. A foreigner testing positive will be offered treatment if they have an acute HIV-related complication. In asymptomatic cases, and after this acute episode is treated, he or she will be required to leave the country often by the time their work permit or employment pass expires.

Are there any alternatives? First would be to return to their country of origin and seek treatment there. An alternative is to find a doctor in the region, in Thailand or Hong Kong for example, who is able to offer treatment. But this is only practical if one can travel frequently.

I picked up a "working girl" in Serangoon Road and had sex with her. What are my chances of getting HIV?

Anyone who has unprotected casual sex is at risk of contracting HIV and other STDs. Picking up a prostitute on the street is riskier still because only registered prostitutes working out of designated brothels are regularly counselled and tested for HIV and other STDs. The best advice Makchik can give is to take an HIV test at the AfA anonymous testing clinics at DSC, Kelantan Road, every Saturday 1-4pm and at the Tanglin Shopping Centre, every Wednesday, 6.30-8.30pm, call 2540212 for more information.

Where did HIV come from?

There are many theories, some of them very amusing. For example, that HIV was manufactured by a mad scientist, or by a foreign secret service. Until very recently the most plausible explanation was that the virus was transferred from monkeys to man in Africa. This may have happened when hunters catching monkeys for food, were exposed to a virus that adapted itself to live in man. But recently, there has been a new theory that in the 1970s HIV was spread in Africa by a polio vaccination campaign that used monkey serum. This theory says that HIV was not destroyed during vaccine production. However, there are many scientists who do not accept this explanation. So the debate continues.

Action For AIDS Singapore (AFA)

Projects & Programmes

AFA was formed in 1988 in order to -

i. provide general and targeted HIV/AIDS information, and raise awareness of the disease
ii. provide support and welfare to persons living with HIV/AIDS (PWHAs), their families and loved ones
iii. fight discrimination against PWHAs
iv. encourage research in HIV/AIDS and related issues in Singapore

AFA is a private non-governmental organisation and a registered charity.

Activities are planned, implemented and coordinated by volunteers and a small number of staff.

AFA is entirely privately funded, through the generous donations of private individuals and organisations.

In order to realise our objectives the following are some of our main activities.

1 EDUCATIONAL PROGRAMMES

The ACT

This publication has articles dealing with medical, social, cultural and personal issues. It also reviews and updates AFA's activities. It is distributed free to members and volunteers, to schools, libraries, community organisations, medical and dental clinics and hospitals.
Editor - Roy Chan
charo@pacific.net.sg

www.afa.org.sg

Online since 1 January 1997, the webpage contains information on HIV/AIDS and AFA activities, the latest HIV/AIDS statistics, a Q & A page, and links to other AIDS web pages local and foreign.
Webmaster - Roy Chan
charo@pacific.net.sg

HIV Education and Workplace (HEW)

Education is the most important strategy to prevent the spread of HIV. We have trained educators who can speak to groups and organisations to help raise AIDS awareness. They are also trained to help organisations develop workplace policies relating to HIV and HIV-infected workers.
Coordinator - Douglas Ong
Pager - 92050225
DouglasOng@sgh.gov.sg

MSM Outreach Programme

This programme is designed to reach out to and educate homosexual and bisexual men to adopt and maintain safe sex practices.
Coordinator - Brenton Wong
brenton@pacific.net.sg

Streetwalkers Project

An outreach programme to increase AIDS/STD awareness and safe-sex practices among freelance sex workers.in the red light areas. Volunteers distribute information packages and condoms, and to provide on-the-spot advice and counselling in the field.
Coordinator -Amy Tan
evenus@pacific.net.sg

AMPUH (Anak Melayu Islam Melawan Penyakit Unik HIV/AIDS)

AMPUH is a group of Malay/Muslim volunteers under the auspices of Action for AIDS. It was set up to tackle the rising number of Malay/Muslims infected with the HIV virus or suffering from AIDS. It hopes to enhance awareness about HIV/AIDS within the Malay/Muslim community; to promote active community participation and involvement in HIV/AIDS education and awareness; and to enhance community support for Malay/Muslim PWAs.
Coordinator - Feisal
Telephone - 96751517
feisal@cyberway.com.sg

II PATIENT SUPPORT AND WELFARE PROGRAMMES

Endowment Fund for Medications

The AfA Endowment Fund subsidises anti-HIV medications for needy PWAs. These medications are not subsidised by any other fund or organisation in Singapore.
Coordinator - Roy Chan
charo@pacific.net.sg

The Buddies Programme

Volunteers are trained to provide counselling to PWHAs, care for terminally-ill patients, crisis counselling, advice on sexual problems, and therapies. Volunteers are assigned to work in home-care teams or as personal counsellors to PWHAs.
Coordinator - Roger Winder
Telephone - 8360445
rwinder@pacific.net.sg

Life Goes On (LGO) and Club Genesis (CG)

LGO and CG are self-help patient support groups funded and supported by AfA. They also network with self-help groups regionally and share experience and information that are mutually beneficial. Through LGO and CG, PWHA interests and rights are represented in all of AfA's activities, at both organisational and participatory levels, with confidentiality preserved.
LGO caters to heterosexual men and women, while CG caters to homosexual men and other sexual minorities. AfA currently employs two PWHAs to plan, coordinate and execute hospital and home support and welfare activities, and also to assist in other AfA activities.
LGO Coordinator - Roger Ang
Pager - 93241659
rogerang@cyberway.com.sg
CG Coordinator - Benedict
Telephone - 2540212
bennijt@pacific.net.sg

Survivors

This support group helps network relatives and friends of PWHAs who have passed on. Survivors help each other come to terms with their losses and move on to help others learn to live with AIDS in their families and relationships.
Coordinator - Iris Verghese
Pager - 95131591
Telephone - 3577918
Iris_Verghese@notes.ttsh.gov.sg

If you would like to make a donation, please make your cheque out to "ACTION FOR AIDS SINGAPORE", and post it to Action for AIDS, c/o DSC Clinic, Block 31, Kelantan Lane #02-16, Singapore 200031. All donations are tax deductible.

If you would like to be a volunteer, do write to us at the above address, or via our website at - www.afa.org

Alternatively, you may call or email Benedict at 2540212 and afa@pacific.net.sg respectively.

III CLINICAL SERVICES

Anonymous HIV Testing & Counselling Centres

These are the only places where anonymous tests are available in Singapore. Experienced counsellors are on-hand to provide pre- and post-test counselling for our clients.
Immediate HIV tests are available. Instead of waiting a few days for the result, it only takes 30 minutes at these 2 test sites.

The DSC Clinic
Blk 31, #02-16 Kelantan Lane
Saturdays from 1 to 4 pm.
Coordinator - Lalitha
Telephone - 2939716
lalitna_dsc@hotmail.com

Tanglin Road Site
Wednesdays from 6:30 to 8:30 pm. (Call 2540212 for details)
Coordinator - Sheung
sheung@pacific.net.sg

AIDS Information & Counselling Hotline (tel - 2540212)
The Hotline provides information and counselling services on all aspects of AIDS. Phone lines are manned by trained volunteer counsellors between 6.30-9.30 pm on Tuesdays, Thursdays and Fridays.
Coordinator - Yang Oi Kwok
Pager - 96034847

IV OTHER PROJECTS

Research

We have funded behavioral and intervention studies on various groups with high-risk activities, and prevention/intervention programmes in Singapore.
Coordinator - Roy Chan
charo@pacific.net.sg

Legal Assistance

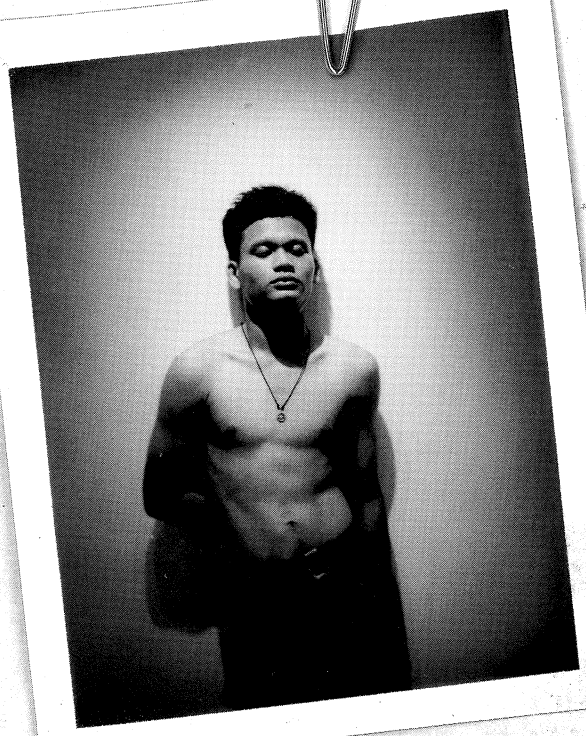
We provide free legal advice and assistance to PWAs and their families on how to deal with difficult employers and workplace issues, draw up wills, and advice on issues related to the Advanced Medical Directive.
Legal advisors - Wilfred Ong & Lin Shiu Yi
Telephones - 2491815 & 96864860 respectively
shiuyi@pacific.net.sg

The Candlelight Memorial

This is an annual international event held to remember those who have died from AIDS. For them there are no funeral service and no time for relatives and loved ones to mourn and grieve. The Memorial provides them this opportunity, to come to terms with death and AIDS.
It has become a powerful symbol of the presence of AIDS in Singapore, and a timely reminder for the community to renew its commitment to fight AIDS discrimination. The memorial is held every last Sunday in May.
Coordinator - Daniel Tan
Pager - 94098302
afa@pacific.net.sg

AIDS Conference

The first multisectorial conference on AIDS was successfully organised in conjunction with CDC/TTSH in December 1998. Over 400 delegates from government and non-govt organisations, volunteers, the press, and businesses attended. We hope that this conference will be a biannual event.



This man died from discrimination in his workplace.

Employers need a positive attitude to AIDS

ACTION FOR AIDS SINGAPORE

It's safe to work with people with AIDS and HIV.