Editorial Board
Executive Editor : Mr WONG Man-kong ACA Secretariat

Vol 10, no.11 – November 2003 (issue no.119)

Calendar

XLV Meeting of the Advisory Council on AIDS (ACA)

2:30 pm 9 January 2004

XXX Meeting of the Scientific Committee on AIDS (SCA)

2:30 pm 16 December 2003

XIV Meeting of the AIDS Prevention and Care Committee (APCC)

5:30 pm 3 December 2003

XII Meeting of the Committee on Promoting Acceptance of People Living with HIV/AIDS (CPA)

2:30 pm 27 November 2003

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We have

The 44th ACA Meeting

It seemed that the after-shocks of the SARS had not completely vanished. The ACA had to give way to the SARS Expert Committee, which revealed his findings and recommendations of the report on 3 October 2003 when the 44th ACA meeting was originally scheduled.

At the rescheduled ACA meeting held on 17 October 2003, members discussed the three main agenda items below. They were (a) Treatment and care of HIV-infected Haemophilia patients in Hong Kong; (b) Planning the core indicators set for monitoring Hong kong's AIDS programme; and (c) Development plan for the Expert Panel on HIV infection of health care workers for 2004 to 2006.

For (a), members noted with concern the treatment and care provided for patients suffered from both haemophilia and HIV and expressed sympathy for their sufferings. A collection of stories depicting the life of some haemophiliacs with HIV infection was tabled at the meeting. To allow readers to better understand the problems faced by these people, the stories have been reprinted on page 46. The Council would continue to keep in view of the development of the matter and explore other alternatives to assist them.

As regards (b), members were supportive to the proposal to produce Hong Kong's own core indicators despite Hong Kong is not a country. The collection of the date would be based on the following three principles: (i) to use existing data; (ii) to modify UNAIDS indicators as appropriate; and (iii) to use same methodology for data collection for allowing longitudinal comparison. The first set of the data would be available at the end of the first quarter next year.

On the subject of the Expert Panel under (c), members unanimously agreed to the proposals for (i) the appointment of a new Panel with a chairman and 4 to 5 members for a 3-year tenure from January 2004 to December 2006; (ii) the establishment of a new set of protocol to enhance the effectiveness of the work of evaluating the referred cases; and (iii) the reprinting of the guidelines to incorporate the modus operandi of the Panel.

The ACA will meet again on 9 January 2004.

Appointment of ACA member

Readers may be pleased to know that Prof. CHEUNG Mui-ching, Fanny, J.P. has been appointed as Member of the Hong Kong Advisory Council on AIDS with effect from 11 August 2003. Her appointment will fall in with the current term of the Council until 31 July 2005.

Prof. Cheung is the Chairperson and Professor of the Department of Psychology, the Chinese University of Hong Kong. Her research interests include Cross-culture personality assessment; Chinese MMPI-2 and MMPI-A; Chinese Personality Assessment Inventory (CPAI); Psychopathology; Community mental health; Somatization and help-seeking behaviour; Gender roles; Violence against women.

The Secretariat is looking forward to working with her.

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Congratulations

Congratulations to Mr Chung TO on winning the Ten Outstanding Young Persons Award this year. As a member of the AIDS Prevention and Care Committee (APCC), Mr TO is also the founder and chairperson of Chi Heng Foundation, a charitable organization based in Hong Kong. Founder in 1998, Chi Heng has been promoting equality for LGBT (lesbians, gays, bisexuals and transgender) through political advocacy, public education media campaigns and community building. Chi Heng has recently expanded its scope of services by moving into Mainland China, focusing on AIDS prevention among the MSM population and care of AIDS patients and orphans in Central China. Prior to moving to Hong Kong in 1995, Mr TO resided in the United States for 13 years, where he received his bachelor and master degrees at Columbia and Harvard Universities respectively. Keep going, Mr TO. Congratulations again on your well-earned award!

In and around Hong Kong

Pediatric AIDS

Prof. LAU Yu-lung, the Chairman of the Scientific Committee on AIDS, will attend the Pre-congress Workshop on Pediatric AIDS, under the theme of "From Prevention to Care and Anti-stimatization", to be held on November 2-3, 2003 at the Sofitel Central Plaza and the Bangkok Convention Center in Thailand. The pre-congress workshop is one of the programmes under the 11th Asian Congress of Pediatrics and the 1st Asian Congress on Pediatric Nursing. The two congresses are organized by the Royal College of Pediatricians of Thailand and the Pediatric Society of Thailand, under the auspices of the International Pediatric Association and Association of Pediatric Societies of the South East Asian Region.

Prof. Lau will present the 'Implementation of PMTCT in the Low Prevalence Areas' during the plenary session on November 2,2003.

Reported HIV/AIDS Statistics (updated 30 June 2003)

		HIV		AIDS	
		total	**/ Q2 2003**	**total**	**/ Q2 2003**
Gender	male	1715	40	554	10
	female	401	9	87	4
Ethnicity	Chinese	1469	36	501	11
	non-Chinese	647	13	140	3
Transmission	heterosexual	1199	20	426	11
	homosexual	406	11	111	2
	bisexual	97	3	30	0
	injecting drug use	56	2	10	0
	blood/bl products	68	0	20	0
	perinatal	15	0	6	0
	undertermined	275	13	38	1
TOTAL		**2116**	**49**	**641**	**14**

NOTE: The "total" refers to the cumulative total number reported since 1984, under the voluntary HIV/AIDS Reporting System. Q2 refers to the period from April to June 2003. The "AIDS" number is a subset of the "HIV numbers" and the two should not be added.

SOURCE : Special Preventive Programme, Department of Health, Hong Kong SAR Government

The 29th SCA Meeting

The 29th meeting of the Scientific Committee on AIDS (SCA) was held on 30 September 2003 as scheduled. There were three main items on the agenda: (a) prevention of transmission of HIV in health care settings guidelines and practices; (b) a proposed template and protocol of pediatric management of infants born to HIV infected mother; and (c) a review of the HIV/AIDS surveillance system in Hong Kong.

In the matters arising, members were in pursuit of the recommendations on HIV antibody rapid testing. They saw the need to provide some sort of protocol for the use of the rapid test of HIV infection. They resolved to circulate the document for members' endorsement after suggested amendments had been made to the original draft.

For (a), the discussion was put off until next meeting because the review of the guidelines had not been fully completed. For (b), members welcomed the protocol and agreed to develop standard treatments for babies exposed to ART but not HIV infected. After discussion, the meeting proposed to bring the matter to the Hong Kong College of Pediatricians for its deliberations. For (c), members were updated the existing HIV surveillance system in Hong Kong, which comprised voluntary HIV/AIDS reporting, seroprevalence studies, STD surveillance and behavioural surveillance. After discussion, members agreed to strengthen the collection of STD data by involving private clinics and private laboratories in the surveillance system. After the usual review of the progress of the action plan, the Chairman announced that the 30th meeting would be held on 16 December 2003.

The Council Chairman hosted a reception at the Red Ribbon Centre on 17 October 2003 to welcome new members. See many new faces you can recognize!

These are the true stories of some haemophiliacs with HIV infection in Hong Kong

The Case of "T"

36 year-old T is a haemophiliac living with his mother and younger brother. The family relies on T's income for a living. Ever since he was in primary school T had been a frequent visitor to Queen Elizabeth Hospital for treatment. With hard work and perseverance T finally got through his secondary education and gained employment as a Warehouse Attendant. The job did involve working long hours and much physical activities; nonetheless T overcame and gained the admiration of his superior, and was promoted to the position of Warehouse Clerk. T had wanted to further his education and scale higher grounds in his career.

Alas, fate did not treat kindly. In the 1980s T was found to have infected with HIV through transfusion of virus-contaminated blood factor. Ever since the trauma T had been living under **fear** – the fear of being discovered an HIV carrier and suffer discrimination and the fear of passing the virus onto relatives and friends. He led a very secluded life, taking anti-retroviral drugs in the lavatory so no one would notice. To make matter worse, after treatment with anti-retroviral medicine, haemophiliacs tend to suffer neurological disturbances, causing deterioration of muscular functions and bones, making it so much harder to accomplish everyday tasks. With difficulty even in walking, T was forced to give up his job in 2002. The livelihood for T's family was thus thrown into turmoil, even traveling to and from clinic became a financial liability, let alone any hope of furthering T's education to prepare for a better future. Ever since infected with HIV, T's has been afflicted with problems relating to liver, skin and vision, to name but a few. What little resources T had left were spent on traveling to hospital, treatment and accessories.

It is particularly distressing in times like mid-autumn when family and friends are supposed to gather and rejoice. T could only sit by himself and ponder on the grim future ahead of him, with little prospect of having his own family, career, studies or even a more bearable life. Even when being invited by friends, T had to decline for reasons of health and financial constraints. It is indeed not a predicament other people can easily appreciate.

The case of "Y"

Y is 26 years old and has been diagnosed with haemophilia since the age of 3. Y felt very frustrated for being haemophiliac and not being able to participate in more competitive sports, and felt life had been utterly unfair on him. In the mid 1990s, through an examination of the bleeding in the joints, Y was diagnosed to have infected with HIV. While he was angry to have inherited haemophilia from birth, he was totally devastated to have learnt that he was also infected with HIV. He suffered near nervous breakdown and totally incapable of controlling his emotions, believing that he could die any time. Ever since, he gave up for striving for a better future. Without any counseling or assistance, Y and his mother felt aggrieved to be inflicted with the worst tragedy imaginable in life. They lost all confidence in the public health system and refused even to visit any hospital for treatment. Whenever Y suffered pains in the joints, he would go for the Chinese chiropractor practitioner or bandaged the joints himself until the bleedings stopped rather than visiting hospitals for treatment.

Y refused to accept the reality of his HIV infection, and grew resistant to any treatment as such. Due to the lack of treatment, Y's body resistance deteriorated and suffered from pneumonia and pulmonary tuberculosis, and had to be hospitalized, putting his life in constant danger.

Even though Y has returned to anti-retroviral treatment, its side effects and psychological burden of the disease weighed on Y heavily, adversely affecting his work and social life. He frequently lost jobs due to the effects of the disease. To hide his HIV status, whenever he meets any new friends or colleagues, he dares not venture to get closer to them for fear of being found out one day. His life is rather like a lonely traveler in a story book, never having any close friends whom he can confide in. As a single mother, Y's mother could not help worrying about her son's conditions but with very little she can do. Y's mother is under no loss stress having to look after Y and not being able to share her feelings with the outside world at the same time, causing her health to deteriorate and constantly suffering from depression. Y's mother had been receiving psychiatric treatment.

The Case of "S"

S was born a haemophiliac passed on by his mother and at the age of 8, S was diagnosed to have contracted HIV through transfusion of virus-contaminated blood factor. S's mother, out of love of her son and the effect on S if found out, tried to shut S from the outside world, practically isolating him from everyone, even the closest of neighbours. It is not difficult to imagine how this kind of upbringing impact the psychological development of a young child, depriving S of a normal environment which any child of his child would take for granted.

S is now 25 years old, yet his ability to communicate and socialize resembles that of a 12 or 13 year old child. With the lack of proper education and work experience, S was once introduced to work in a fast food chain. However, under the treat of haemophilia, it would be difficult to carry out cleaning jobs which require climbing on objects, not to mention S having to sneak into the lavatory every time he had to take anti-retroviral medicine. Under this pressure, S found himself increasingly unable to cope and finally gave up this only job in his life. Three years ago S got another job as a messenger, but unfortunately he could not make it through probation as he did not have any knowledge of street names.

With difficulty making a living, S had to endure the severe side-effects brought on by anti-retroviral treatment. His body was progressively weakening, experiencing vomiting and frequent fainting, body aches and loss of memory, particularly the bleeding in the joints. For a person in his twenties, these conditions have contributed to his very low self-esteem.

His father had been the only financial support in his family. With his death in 2001, the remaining three family members had no alternative but to reply on government assistance. Being the elder son, S naturally blamed himself for not being able to carry the burden of the family. On the other hand, his deteriorating health can only add to the burden on his family. S is at a loss in trying to improve his life in any way, seeing that most recreational activities available for his age are inappropriate for him to participate. For him, he has been deprived of the life and hope that befits a person of his age.

The Case of "H"

H is 35 years old and lives alone. As a haemophiliac, H had to receive transfusion of blood factor to treat his condition when he was in primary school. His mother loved H dearly and withheld the truth from H that he had been infected with HIV through virus-contaminated blood factor until H is 17 years of age, when H was eventually told the brutal truth. Before he learned of his HIV condition, the young H was till active and full of life. He was keen in school and his school work had been above average. Ever since he learned of his HIV infection however, his mind had been very troubled and lost all self confidence. His studies then went downhill and managed poor results in his university entrance examinations.

H felt that his being infected with HIV was totally unfair, unwarranted and frustrating. This even affected his trust and willingness to receive anti-retroviral treatment for HIV. On the one hand, he realized anti-retroviral medicine might save (or at least prolong) his life, and yet on the other hand, not knowing what the medicine might do to his haemophiliac conditions in the long run. Apart from causing bleeding in the joints through the use of anti-retroviral treatment, he was diagnosed with bleeding in the brain in 2001. He went into a coma and was on the verge of death. Although recovered now, his power of memory, intelligence, and bodily function co-ordinations have been greatly impaired, affecting his everyday life, even to the point of having to give up his job as a graphic designer, which he had worked very hard for over the years, thus resorting to government assistance to help him get by. With body resistance falling gradually and haemophiliac condition aggravating, H's visits to the hospitals become more and more frequent. H did not give up. To improve his ability, he enrolled for distance learning over the internet with the hope of a better future ahead. Unfortunately, government assistance amounts to bare subsistence hardly enough to pay for any form of tuition after payments of rent and everyday expenses had been taken care of. That dashed any hope of H in upgrading himself to be a more useful member of society. What was already a double tragedy of haemophilia and HIV infection had worn out one's body and health, the lack of financial assistance makes life even more unbearable, sinking one's self-esteem further. Without any end in sight and comfort from any friends, this for a down-and-out patient is a never ending tragedy in play.