

# Enhancement of Voluntary HIV Counseling and Testing System

## Counselling and Care / Support Services for PWHA: A Major Factor to Make HIV-Test Promotion Policy Effective

Chizuko IKEGAMI

PLACE Tokyo (Positive Living and Community Empowerment Tokyo)

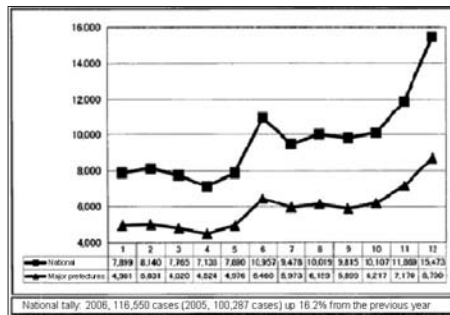
### Abstract

Based on the new guideline of revised AIDS Prevention Policy, Japanese government has started HIV-test promotion campaign since 2006. The purpose of this campaign is to increase the number of people who take HIV test and to decrease the number of newly diagnosed cases of AIDS. The promotion of HIV-test, however, will not automatically lead to decrease the AIDS cases. HIV positive people need various care and support in order to start their new life with HIV. HIV- test should be the start of care and support by community and society for PWHA.

**Keywords:** HIV-Test, PWHA, counselling, care/support, peer

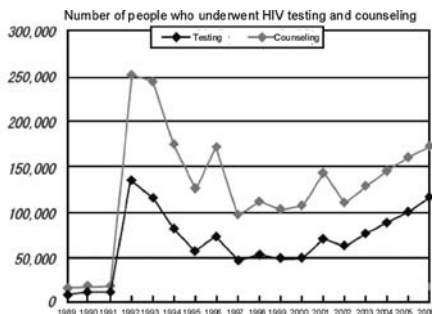
### Introduction

Based on the new AIDS prevention guideline enacted in April 2006, various programs are under way to improve and promote HIV/AIDS testing and counseling support systems. At the national level, since 2006, the central government has designated the first week of June as “HIV Testing Promotion Week”, urging the entire public to undergo HIV antibody tests. Before 2006, the number of tests and counseling cases at public health centers reportedly increased only during the campaign period for World AIDS Day, which is on December 1, and after the campaign period, the number decreased to that during the pre-campaign level. In 2006, however, the number of people who underwent HIV testing and counseling increased during the HIV Testing Promotion Week campaign in June, and although this number somewhat declined, it remained relatively high until the World AIDS Day campaign in December.



**Fig. 1: Monthly Change in the Number of People Who Underwent HIV Testing and Counseling**  
Source: Ministry of Health, Labour and Welfare

At the regional level, various efforts are under way to create efficient and convenient testing systems including measures such as the provision of out-of-hour, nighttime, or holiday tests by public health centers; testing by institutions assigned by public health centers; and the introduction of rapid tests. As a result of such efforts, the number of people who underwent HIV testing and counseling, which continued to decline after peaking in 1993, has started to increase in 2002 and is likely to tie the highest number in 2006, exceeding 110,000 cases.



**Fig. 2: Yearly Change in the Number of People Who Underwent HIV Testing and Counseling at Public Health Centers, etc.**

Source: Ministry of Health, Labour and Welfare

The aims of the HIV testing promotion initiative are (1) to promote the early detection of HIV infection by increasing the number of people receiving HIV antibody tests and (2) to link such early detection to better treatment and thus prevent the development of AIDS, and consequently, reduce the number of cases where infection is detected only after the development of the HIV virus (so-called “sudden AIDS”). The Strategic Research on AIDS Prevention program, initiated in 2006 by Tadao Shimao, chief researcher/president of the Japanese Foundation for AIDS Prevention, has involved the development and implementation of research plans for residents of metropolitan areas and MSM (men who have sex with men) with the goal of “reducing the number of full blown AIDS cases by 25% by doubling the number of people receiving HIV tests.”

The AIDS prevention strategy will be deemed successful only when people who are tested as HIV-positive after receiving HIV antibody tests get appropriate medical care and receive the supports necessary to start their new post-infection lives smoothly. However, merely increasing the number of people receiving the tests will not necessarily lead to an automatic increase in the number of people getting appropriate medical care. There is a possibility that HIV-positives might be “left unattended” unless support and appropriate systems are available to them. As a matter of fact, the “urgent national survey conducted in response to the reported case in which inaccurate HIV test results were given (Jan 23, 2007)” shows that the percentage of cases that were diagnosed as HIV-positive at public health centers stood at 94%, whereas the percentage of cases that received treatment for HIV stood at 60%.

**Table 1: Urgent National Survey on HIV Test Systems at Public Health Centers, etc., Conducted in Response to the Reported Case in Which Inaccurate HIV Test Results were Given (Jan 23, 2007)**

Source: Ministry of Health, Labour and Welfare as of March 20, 2007

# of questionnaire responses from public health centers	504/536 centers (94%)
Public health centers informing people of HIV-positive results in 2006	120/501 centers (24%)
# of positive cases	249/86604(% of positives: 0.3%)
# of cases where people were informed that they were HIV-positive	234/249 (94%)
# of cases where people received treatment for HIV	149/249 (60%)
(# of cases where people were informed that they were HIV-negative)	84288/86355 (98%)

The survey indicates that counseling and medical supports for people after they are diagnosed as HIV-positive are indispensable in addition to pretest and posttest counseling. Actually, the course of action from the time of being diagnosed as HIV-positive to the time of receiving treatment varies from individual to individual. Some people seek immediate treatment while others need to make more discreet choices. Merely providing information about the main hospitals may not be sufficient. Appropriate information and supports must be provided on a case-by-case basis.

Based on such facts, this report describes the current scenario with regard to the counseling offered to HIV-positives, based on the counseling services at PLACE Tokyo, and discusses the necessary measures that need to be taken to offer appropriate support and care to HIV-positives.

### 1. Three Reasons Why PGMs (Peer Group Meetings) are Needed by New HIV-Positives

PLACE Tokyo provides counseling services to HIV-positives. The number of people to whom counseling was provided from April 1, 2006 to March 31, 2007 exceeded 2,000. The net number of HIV-positives counseled stood at 439 (including 81 women), of which 174 people (including 11 women) received counseling for the first time. Out of those who received counseling for the first time, PLACE Tokyo conducts “peer group meetings (PGMs) for new HIV-positives” who have been informed about their infection in the past 6 months.

The PGMs began in April 2001. They were conducted for the following three reasons: (1) at that time, the number of new HIV-positives seeking counseling increased sharply to 10 per month, and currently, often exceeds 20 per month (2) after having been informed that they were infected, new HIV-positives were living isolated lives and were facing various personal difficulties without any prospect of medical treatment or future lives, and (3) there were no continuous programs to support the needs of HIV-positives, especially systematic programs to respond to their need to communicate with other HIV-positives.

In view of the above-described scenario, PLACE Tokyo staff and HIV-positive volunteers have jointly developed PGMs. Their purpose is to “provide safe spaces for HIV-positives; enable HIV-positives to share information, knowledge, and experiences with other HIV-positives; and enable them to start new, better lives after being informed of the infection.” Specifically, for new HIV-positives who have been diagnosed as HIV-positive in the last 6 months, the PGMs comprise four 2-hour group sessions conducted every 2 weeks, involving five to seven individuals. Beginning with the orientation, it takes 2 months to complete all the four sessions.

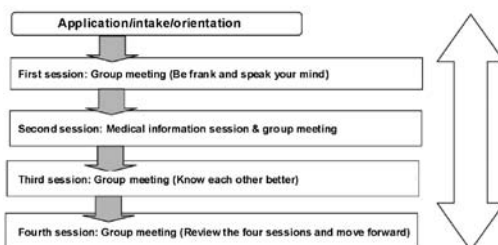


Fig. 3: PGM Flow Viewed from a Participant's Perspective  
Source: PLACE Tokyo

The aims of each session are as follows:

First session: Be frank and speak your mind

To enable the participants to understand the purpose and schedule of the PGMs

To enable the participants to understand and observe the “ground rule”

To enable the participants to feel relaxed through ice-breaking activities and have them introduce themselves

To have the participants discuss the reasons for their participation and expectations from the PGMs

To have the participants share their own situations and feelings based mainly on their experience of being informed that they were infected

To distribute textbooks on basic knowledge for the subsequent sessions

Second session: Medical information session

To understand how each participant obtains medical information

To have medical information staff provide basic lectures and conduct Q&A sessions on medical information

To have the participants share concerns, difficulties, and information about medical care

To provide help to participants in order to enhance their communication with medical practitioners

Third session: Know each other better

To discuss the topics that participants wish to discuss based on the previous two sessions and the results of the questionnaire administered to the participants prior to the session

To have the participants report their current state of mind so as to foster better exchanges and understanding

Fourth session: Review the four sessions and move forward

To discuss the topics that participants wish to discuss

To have the participants discuss any new concerns, difficulties, etc.

To have the participants discuss their goals and future

To have the participants review and summarize the four sessions by beginning their statements with “in my current frame of mind....”

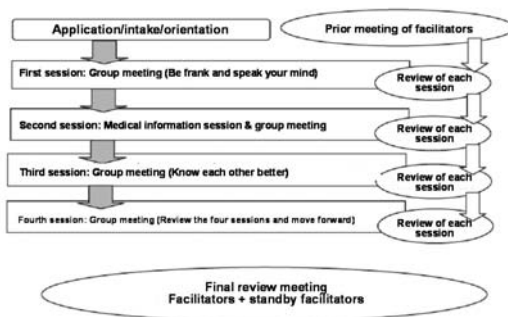
This program consists of the following four major features:

**Table 2: PGM Program Features**

- Group meeting
  - The sharing of experiences and information with others
- Medical information session
  - The provision of basic medical knowledge about HIV
- “Two facilitators”
  - Peer facilitator  
(HIV-positives who have received training and have been informed about their infection at least 2 years earlier)
  - Staff facilitator  
(people experienced in supporting others)
- Ground rule
  - Safe “spaces”  
For example, spaces where privacy is protected, diversity is respected, HIV-positives are not exposed to criticism, etc.

The ground rule is a rule that each participant has to observe to carry out group meetings safely, smoothly, and effectively. Facilitators play important roles in ensuring the implementation of the ground rule. PGMs always have two facilitators (a peer and a staff member). Facilitators hold prior meetings based on participants’ intakes and conduct a review at the end of each session. Further, after the end of the fourth session, they conduct a final review of all the PGMs that also includes the opinions of other standby facilitators.

Ever since PGMs were initiated 6 years ago, 33 terms of PGMs have been completed, serving a total of 650 participants (the net number being 184). Currently, the total number of trained facilitators is 13 (seven peers and six staff members). Further, the number of PGM graduates taking training courses to become facilitators is increasing; thus, they will soon start supporting others rather than being supported by others.



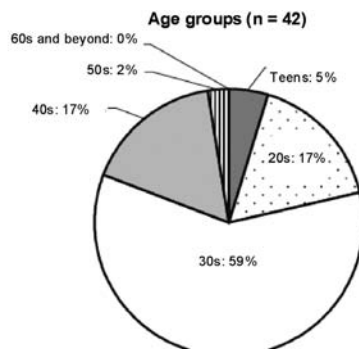
**Fig. 4: PGM Flow Viewed from the Perspective of the Facilitators**  
Source: PLACE Tokyo

## 2. Places Where New HIV-Positives Receive Tests

Looking at the backgrounds of the 42 participants who attended last year's PGMs, it can be observed that most of them were men, 59% of them being in their 30s, followed by those in their 20s and 40s, who accounted for 17% of the total number of participants, respectively. More than half of them were informed of their infection less than 2 months ago. The age distribution of the group resembles that reported by the Committee on AIDS Trends. Of particular note are the participants' motives for taking antibody tests and the places they chose to take these tests. In 50% of the cases, hospitals were the preferred choice, while public health centers and test centers accounted for 46% of the choices, with self-test kits accounting for 2% of them. It is assumed that there is a close relation between places where people choose to get themselves tested and their motives for taking the tests. Of the 42 participants, only 21% took the tests voluntarily while 14% received the tests on a regular basis supposedly at public health centers or test centers. The regular test recipients were supposed to have been diagnosed as HIV-negative in past tests, indicating that taking HIV tests does not necessarily motivate the test recipients to take preventive actions. Five participants responded that they did "not give consent for taking the tests", which raises the issue of informed consent at hospitals. Five participants did not visit hospitals on a regular basis, 40 did not take any medication, and five people were holders of certificates of physical disability. With regard to the sources for finding out about the PGMs, the Internet was the most frequently cited source.

## 3. Evaluation of PGMs by New HIV-Positives

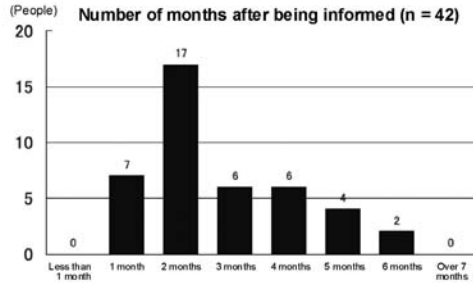
At the end of the fourth session, participants are asked to evaluate the PGMs to help better plan and operate the next round of the PGM program. Let us consider the evaluations of the 2005 PGMs by 21 participants (note that these evaluations are subjective ones that were made by the participants). For "change in awareness" with regard to "image of the disease", "changed for the better" and "changed somewhat for the better" together accounted for about 90% of the responses. Further, 75% of the respondents claimed that they had changed their perceptions in a positive way with regard to the areas of "emotional fluctuations", "human relationships", and "love and sex". For "gains" from the program, "broadened perspective", "time to speak freely about topics that cannot be raised at other places", and "alleviating the sense of isolation" topped the list, followed by "image of future life", "medical- and welfare-related information", "sense of peace", "future prospects", "friends to keep in touch with." "Awareness of capability to help others" was also evaluated highly, and in all likelihood, this is an effect of group work. New HIV-positives who received little support after being informed of their infection could have negative perceptions about themselves. However, becoming aware of their capability to help others



**Fig. 5: Age Groups of PGM Participants (2006)**  
Source: PLACE Tokyo

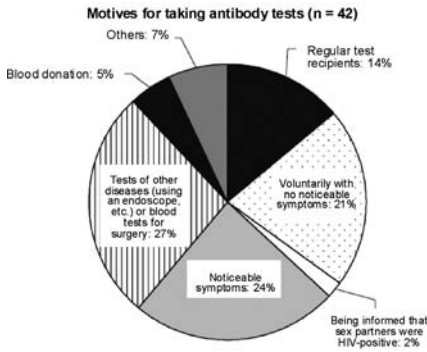
by participating in the group program will be of tremendous help for them in starting their better post-infection lives.

As mentioned earlier, the purpose of the 2-month four-session program is to help new HIV-positives start better post-infection lives by enabling them to overcome their sense of isolation. I believe that this goal has been achieved, at least to some extent. However, we will not be able to respond to the expanding needs as the number of people receiving tests and, as a result, the number of HIV-positives is increasing. It is imperative that support for HIV-positives start at the site of the test as soon as people have been informed of their infection. However, it is doubtful whether all the facilities/infrastructure necessary for the provision of such support are in place. It is likely the case that a budget for testing has been earmarked but that a budget for developing human resources and securing places for support and counseling has not been set aside. However, in the HIV testing process, it is absolutely imperative that the support starts from the moment the test recipient is informed of the infection, and is immediately followed by medical support and other specific support for his/her new post-infection life.



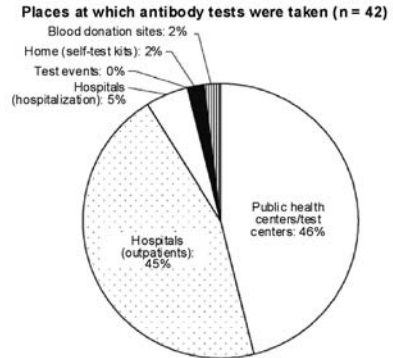
**Fig. 6: Number of Months after PGM Participants were Informed of Infection**

Source: PLACE Tokyo



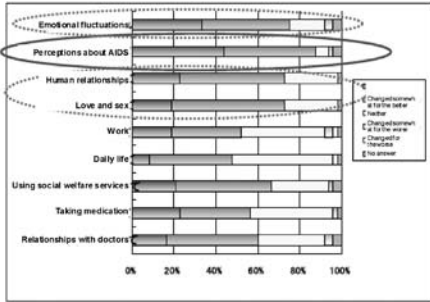
**Fig. 7: Motives of PGM Participants for Taking Antibody Tests**

Source: PLACE Tokyo

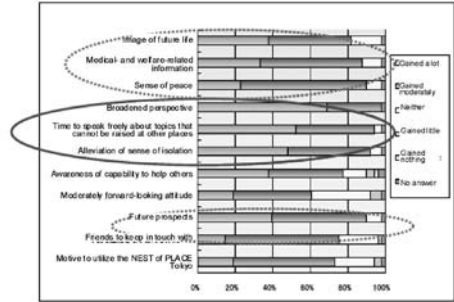


**Fig. 8: Places at Which Antibody Tests were Taken by PGM Participants**

Source: PLACE Tokyo



**Fig. 9: Evaluation by PGM Participants**  
—Change in awareness

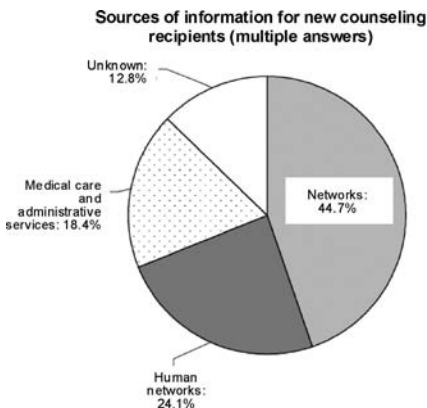


**Fig. 10: Evaluation by PGM Participants**  
—Gains

HIV tests are usually performed at public health centers, test centers, or general hospitals, and the site of the test is not necessarily the place at which medical care is provided. New HIV-positives receive information about the main hospitals; however, such information is not necessarily provided in an appropriate and adequate manner. Further, many test recipients are not fully mentally prepared to accept the test results. Moreover, under the current social situations, HIV-positives cannot disclose their condition immediately to their family, friends, or colleagues, and therefore, tend to refrain from seeking social support. Further, a strong stigma is attached to being HIV-positive, and AIDS is viewed differently from the other diseases even though from a medical point of view, it is one of the many chronic diseases. Moreover, in many cases, HIV-positives themselves nurture the stigma. If after having been informed of their infection, HIV-positives are left unattended in society, where the negative perceptions and misunderstandings about HIV/AIDS still remain intact, it could result in them going untreated, and even lead to them developing mistrust in medical care. Therefore, to further improve the convenience and effectiveness of HIV testing, support and counseling systems in addition to testing need to be improved. There is also the risk of capacity shortage at special medical institutes if the number of those infected continues to increase at the current rapid pace.

Regular test recipients account for no small portion of the total number of PGM participants. The fact that even regular test recipients require PGMs suggests that testing does not necessarily entail opportunities for preventive actions. More importantly, this also suggests that tests neither increase the recipient's understanding of HIV nor do they prepare the recipient for the results.

**Fig. 11: Sources of Information for New Counseling Recipients of HIV-Positive Counseling Services**  
Source: PLACE Tokyo



**Table 3: Counseling Services for HIV-Positives by PLACE Tokyo (2006)**

# of counseling and contact cases (Unit: cases)			
Telephonic counseling		709	
Face-to-face counseling		534	
Online counseling		815	
Background of counseling recipients (Unit: cases)			
Total	548	467	81
HIV-positives	439	404	35
Partners	43	35	8
Family	20	2	18
Friends, etc.	46	26	20
Background of new counseling recipients (Unit: cases)			
New counseling recipients	241	204	37
HIV-positives	174	163	11
Partners	26	21	5
Family	11	1	10
Friends, etc.	30	19	11

#### 4. Counseling Needs of HIV-Positives in Terms of Their Lives

The number of HIV-positives seeking counseling at PLACE Tokyo has been increasing sharply in the past 3 years. The number of counseling recipients in 2006 was 548, exceeding 500 for the first time. Out

of these 548 recipients, 241 were seeking counseling for the first time. The counseling service for HIV-positives started in 1997, and now, counseling requests from their families, partners, friends, colleagues, etc., are accepted in order to meet the diversifying needs. The major information sources through which people find out about the counseling service include the Internet and human networks (such as introduction by other HIV-positives, partners, friends, acquaintances, etc.). The percentage of recipients that got to know about the service through medical and administrative bodies was 18.4%.

The major counseling topics are as follows (multiple choice items):

- (1) Specific problems related to everyday life: 642
- (2) Concerns and anxieties over the disease and changes in the condition of the disease: 405
- (3) Medical support and care: 370
- (4) Partners of HIV-positives: 309
- (5) Psychological and mental problems: 229
- (6) Problems in interpersonal relations caused by HIV infection: 224

With regard to “Specific problems related to everyday life”, employment (229) ranked first from among all the problems, followed by the welfare system (100), economic problems (97), privacy (61), housing (53), legal problems (52), etc. With regard to “Concerns and anxieties over the disease and changes in the condition of the disease”, medication/side effects (80) topped the list, followed by counseling after being informed of infection (77), which is also the main topic of this report. The list also included inconclusive test results (8). With regard to “Medical support”, communication with medical staff (184) ranked first, followed by choices of hospitals (85) and inter-departmental efforts (43). With regard to “Partners”, admission about the disease to partners (62) ranked first. With regard to “Psychological problems”, depression/anxiety (114) ranked first.

The above data indicates that HIV-positives face various problems in their lives. Unfortunately, however, there are very few institutions and places for HIV-positives to disclose their feelings and receive adequate counseling. Medical services for HIV-positives tend to concentrate on few main hospitals that staff experienced doctors, thus making it difficult for HIV-positives to consult the doctors and obtain details about their medical care and, needless to say, their concerns and anxieties. The number of physical disability certificate holders is much smaller in regional areas than in Tokyo probably because of privacy concerns, in other words, concerns that people’s infection may become known in their local communities. A PLACE Tokyo survey shows that only 20% of the HIV-positives have been able to see doctors on a regular basis or continue medication upon gaining acceptance from colleagues and other people after disclosing their infection with the aim of seeking long-term medical treatment. Many people “do not reveal” their infection for a long time (or indefinitely), thereby causing stress to build up within them, and this stress, in all probability, is much stronger than that caused by medication. They tend to blame themselves for their failure to disclose their infection. However, the current scenario is more of a social problem than a problem within these people because they (inevitably) tend to think that they would be rejected by the community if they disclosed their infection. Further, people, in general, are not fully prepared to accommodate and support HIV-positives. Such social ill preparedness is the first and foremost barrier in the lives of HIV-positives. I believe that creating a society where HIV-positives can continue living in their communities even after being informed of their infection can help reduce public burdens on medical care and welfare. From this point of view, counseling support after the person is informed of his/her infection is crucial not only for HIV testing but also for effective AIDS control measures as a whole.

## **5. Making Posttest Support (Counseling and Support) a Broad Regional Service**

Twenty new people sought the counseling services provided by PLACE Tokyo in the month of May, just prior to the writing of this report. Of them, seven were from outside the Kanto region (three were from the Tokai region, two were from the Kansai region, one was from the Kyushu region, and one was from overseas). Two cases were related to concerns and anxieties over inconclusive test results. The number of cases where face-to-face counseling was conducted was 50 and so were the number of cases wherein online counseling (via email) was conducted; the number of cases undergoing telephonic counseling was 66. The needs for such counseling services are expected to increase further as the testing service is to be further promoted in the future. It will be necessary to closely relate the posttest counseling and support services with the testing service. Testing and informing the individual of the infection should not be restricted to “discovering and informing” HIV-positives but should also act as a starting point for the continuous and adequate social and medical supports for HIV-positives.

Considering the needs for counseling at PLACE Tokyo, it is obvious that the current counseling support at HIV test sites is insufficient. Further, medical institutions and local governments do not have enough counseling support know-how or the capacity for the human resources development needed to create the support system. I would like to emphasize that such support services should be based on broad regional systems. HIV-positives do not necessarily live, work, take tests, and receive medical care in the same area. Thus, support services will be ineffective if they are provided at a narrow local government level, making any inter-local governmental efforts difficult. Broad regional efforts are important and necessary to guarantee the adequate availability and accessibility of counseling and support services. In other words, the commitment of the central government to counseling support systems along with testing services is crucial.

Last year, the Review Conference of the United Nations General Assembly Special Session on HIV/AIDS adopted a political declaration. The declaration emphasized not only the goal of “universal access to medical treatment” expressed 5 years ago but also the importance of each country putting a plan into action with the specific goal of “universal access to prevention, medical treatment, and care/support.” The Japanese government sent a delegation led by former Prime Minister Yoshiro Mori and became a signatory to the declaration. With this declaration, the importance of AIDS prevention and care/support was internationally confirmed. Each signatory country is responsible for reporting its progress in 2008. International contributions to AIDS control measures by Japan should not only provide assistance to developing countries. If a system of care/support that is closely related to testing is created in Japan, we can present other countries a model case including know-how regarding such system. In other words, Japan’s AIDS control measures, themselves, can become one of Japan’s major international contributions.

## **Reference**

2006 Annual Report, NPO PLACE Tokyo

Report on the Review Conference of the United Nations General Assembly Special Session on HIV/AIDS, Naoko YAMAMOTO, as reported in the PLACE Tokyo NEWSLETTER 2006, No. 50

*The above was excerpted from “Journal of National Institute of Public Health, 56(3) : 2007”.*