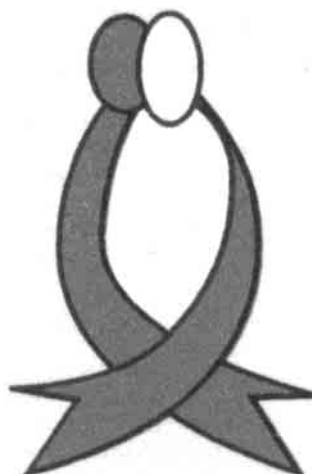


Yayasan Spiritia



Report on Activities 2003/2004

Period of Report: 1 June 2003–31 May 2004

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Prepared: 30 June 2004



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Acronyms and Abbreviations

AFAO	Australian Federation of AIDS Organizations
APN+	Asia Pacific Network of People living with HIV/AIDS
ART	Antiretroviral therapy
ARV	Antiretroviral (drugs)
ASA	Aksi Stop AIDS (USAID-funded AIDS project)
AusAID	Australian Agency for International Development
BP	British Petroleum
Depkes	Ministry of Health (from Indonesian)
GFATM	Global Fund to fight AIDS, TB and Malaria
GIPA	Greater Involvement of PLHAs
GNP+	Global Network of People living with HIV/AIDS
IEC	Information, Education and Communication
IHPCP	Indonesian HIV/AIDS/STIs Prevention and Care Project (funded by AusAID)
KPA	National AIDS Commissions (from Indonesian)
NGO	Non-governmental Organization
PLHA	People Living with HIV/AIDS
PNO	National PLHAs Meeting (from Indonesian)
UNAIDS	United Nations Joint Programme on AIDS
UNDP	United Nations Development Programme
UNV	United Nations Volunteers
UPC	Universal precautions
USAID	US Agency for International Development
VCT	Voluntary counseling and testing (for HIV)

Program Activity Summary

Rationale/Justification

At the Paris AIDS Summit in Paris in 1994, the governments of 42 countries including Indonesia resolved to support the principle of involvement of people living with HIV/AIDS (PLHAs), as a “means to stimulate the creation of supportive political, legal and social environments.” This principle has become known as GIPA (Greater Involvement of People Living with HIV/AIDS). The Paris Declaration became a formal statement by governments of their intent to involve PLHAs in the response to the epidemic at national, regional and global levels.

The Spiritia work plan is designed to turn this principle into practice in Indonesia. All activities have been developed and implemented with the objective of empowering and encouraging PLHAs to play a more active role in the response to the epidemic in Indonesia. It has been proved that such involvement is one of the most effective responses, giving a human face and voice to the epidemic, and showing that those affected are not ‘them’ but ‘us’.

Goal and Objectives

General Objectives

- Improve quality of life of PLHAs in Indonesia.
- Encourage involvement of PLHAs at every level of AIDS control from becoming critical recipients of services, up to active participation in planning, implementation and evaluation of programs and policy.

Specific Objectives

- Support and encourage PLHAs to play their role more effectively as vital stakeholders in AIDS programs and policy.
- Support and encourage PLHAs and organizations in the regions of Indonesia to develop their own support programs which are empathetic, identify the complementary dynamics of care and prevention, and facilitate the meaningful role of PLHAs in their activities.
- Represent Indonesian PLHAs at national, regional and global level; advocate at all levels for increased access to treatment for PLHAs, including both antiretroviral therapy, treatment for opportunistic infections and palliative care.

Results and Success Measures/Achievements

Only a small minority of PLHAs in Indonesia is aware of their HIV status; perhaps 5,000 out of an estimated 100,000 people infected by HIV. Spiritia’s programs are primarily focused upon those who are willing to identify themselves as HIV-positive, and people directly affected by HIV/AIDS (families, partners, etc.). The programs are also designed to encourage those who have been at risk to come forward for testing, to ensure that such testing and the follow-up are non-discriminative and friendly, and to encourage those who test positive to recognize that they are not alone, and that they can benefit from greater openness.

As secretariat of the Indonesian PLHA network, Spiritia is in contact with several hundred PLHAs throughout the country. Almost all agree that involvement in the network has improved their lives: by proving that they are not alone; through ongoing peer support; and by providing them with meaning to their lives.

Spiritia’s program includes ten external activities, together with support functions (secretariat, strengthening human resources and annual evaluation). This report provides a brief review of the results and achievements over the period June 2003–May 2004, followed by a summary of the main barriers faced and strategic changes which are occurring. Selected photographs depicting the main activities may be found in Appendix 2.

Although there continues to be an understanding and acceptance of the principle of greater involvement of PLHAs (GIPA), particularly at the central government level, there remains a challenge in turning this into meaningful participation. The Ministry of Health (Depkes) continues to be proactive in involving PLHAs in national meetings, but few other departments show this concern. On the other hand, the number of PLHAs speaking in public in a wide variety of forums has continued to increase, and the quality of this participation has increased, partly as a result of skills training by Spiritia.

However, the initial objective is to encourage PLHAs to play an active role in their own lives, in their own health. The process of testing for HIV often results in a reduction in self-esteem and a feeling of worthlessness. The process of empowerment of PLHAs must start by proving that they are not alone, and that they have the capability to make a real impact on the epidemic. Skills development is an essential part of this process, and has proved remarkably effective in improving the quality of life of PLHAs.

Although Spiritia coordinates the national network of PLHAs, there is no intention to open branches outside Jakarta. As noted in the previous report, Spiritia's activities are designed to encourage and empower PLHAs in the regions to form local peer support groups, and this has been accelerated by the development and implementation of a new program directed towards development of peer support groups during this period. This has provided additional impetus and resulted in the formation of almost 20 new groups around the country during the year.

National PLHAs Meeting

The national PLHAs meeting (PNO) has become an important event in the national calendar and has played a crucial role as an entry-level introduction to the concept of empowerment. The fourth national meeting of PLHAs was held in Tretes, East Java, in February 2004, attended by 60 people, 80 per cent HIV-positive. As in the past, this five-day meeting was primarily aimed at those who had had little previous involvement, in many cases little if any contact with their peers. Thus the main objective of the meeting was to provide basic information and to encourage sharing of experience, feelings and information among participants. Significant developments and outcomes include:

- The background of participants showed greater diversity compared with earlier meetings, with a greater number of places represented.
- The increase in self-esteem among participants during the meeting was very apparent.
- As many as 80 per cent of participants have since become involved in their home locations, with some participating at the national level.
- This meeting trialed the concept of tracks. On two days participants were offered the opportunity to choose alternative tracks offering a wider range of topics. This was effective and well received.
- Free CD4 testing was offered to participants in cooperation with Yayasan Citra Usadha Indonesia (Bali) and Prodia Bali. Results were available before the end of the meeting. Participants were offered counseling to assist in understanding the significance of the results; those whose results indicated concern particularly appreciated this.
- Most of those attending would have preferred a smaller number of participants.
- The health of at least five participants was poor and this impacted on their ability to participate fully. Three participants died within two months of the meeting, despite efforts to obtain antiretroviral therapy for them.
- Participants released the 'Tretes Statement' (see Appendix 4) following the meeting.
- The local organizing group (Friends+, Surabaya) obtained useful experience.
- Spiritia has yet to develop clear guidelines on selection of participants; priority was given to PLHAs who had yet to be involved and who recently became aware of their HIV status.
- More care is needed in selecting outside presenters, some of whom were assessed as being less than capable. On the other hand, more use could be made of more experienced members of the network/alumni of previous PNOs.

Skills Development Training

Effective and meaningful involvement, as experts rather than tokens, requires that PLHAs possess the necessary skills. While many of those who are diagnosed HIV-positive have capability, few have the necessary skills, and many suffer from low self-esteem, often as a result of testing that violates laid-down procedures. Spiritia has continued to address this by offering skills development training for PLHAs, in a way that also attempts to improve self-esteem. Outcomes of this program over the period include:

- Spiritia organized four three-day training courses covering: Public Speaking; Forming Peer Support Groups; Becoming a Peer Educator; and Joining International Conferences.
- Three days is insufficient for some of these courses; in future four days will be allocated for Public Speaking and Peer Support Groups.
- Modules developed for courses on Public Speaking and Forming Peer Support Groups have been used by other support groups for training their own members. The Public Speaking module has been published and distributed widely.
- A formal module and support material for training peer educators have yet to be developed. Those used require simplification followed by field-testing.
- After public speaking training, many participants have spoken out in public with greater effect.
- Following training on the topic, several new peer support groups have been formed, and those already formed have developed clearer direction, including vision and mission.
- All 16 participants in the training on attending international conferences submitted abstracts to the International AIDS Conference 2004 during the training. Of these, seven were accepted, and four of these obtained full scholarships. The biggest challenge faced is inadequate English language capability.
- Spiritia has yet to develop clear guidelines on selection of participants or location of training.
- Training over the period involved a total of 66 participants. At each course, at least one drug user in recovery relapsed or presented discipline problems.
- Three of the four courses were held outside Jakarta (two outside Java), with groups at the location acting as local organizing committees. This helped spread experience and skills.

Local Strengthening Visits

Local strengthening visits have become a very successful method of extending the PLHA network, and of identifying the challenges faced by PLHAs in Indonesia, as well as providing advocacy opportunities. The visits are usually made by teams consisting of two members of Spiritia staff and two or three members of the PLHA network, with usually at least two members openly HIV-positive. The team usually stays for three or four days in each place. The following are the main outcomes of this program over the period:

- The number of visits and places visited was somewhat lower than during the previous period: 13 places in seven provinces. However, several of the visits included districts/municipalities outside the province capitals.
- Concerns noted remained similar to those in the previous year: lack of VCT services; KPADs not playing their role; difficulty accessing care, support and treatment needs; and poor implementation of universal precautions in most hospitals.
- A few places felt sufficient benefit to cause them to invite us back, even covering costs.
- Spiritia's network was further extended, covering stakeholders and allowing better support of local PLHAs.
- Bali Plus, the peer support group in Bali, has taken the initiative to carry out a similar program in Bali, with plans also to visit Lombok.
- The visits carried out over the period involved 22 people as team members, providing valuable advocacy experience. Choice of team members favored open PLHAs; choice of locations was partly based on requests, and partly on the need to extend coverage.

- As more experience is gained with these visits, so more effective ways are being found to achieve their objectives. One particular development is the increasing use being made of local mass media through interviews and TV and radio talk shows.
- In several cases, planning for the visits was hampered by lack of suitable host organizations. As a result, appropriate appointments were not made in advance with resultant waste of time and opportunities.
- Visits always result in a long list of follow-up actions. It must be admitted Spiritia often fails to give these the priority they may deserve, and local groups are often lacking in resources or skills to make sure that all outstanding matters are addressed. This may give rise to loss of opportunities and disappointment among those to whom commitments were made.
- We always attempt to make maximum use of the time available in each place, and indeed we are often swamped with requests for meetings or other activities during the visits. This results in a very crowded schedule and resultant fatigue, which can be very significant after a week or more. Considering that several team members are also living with AIDS and may be in less than excellent health as a result, this may risk more severe sickness, and on one occasion caused brief hospitalization of one team member.
- A report on the visits carried out up to mid 2003, together with ten major recommendations for action, was prepared and disseminated in Indonesian and English. Major stakeholders, including representatives from the National AIDS Commission, the Ministry of Health and other ministries, donor and UN agencies, and NGOs was invited to a presentation of this report in September 2003 at the Coordinating Ministry of People's Welfare. Participants appreciate the detailed information and suggestions, but little else concrete appeared to result from the meeting or the report.

Development of Peer Support

Peer support is the essential next step after PLHAs have started to play an active role in their own lives and in their own health. Initially this may be as a member of an existing group, later as a leader of a group, then extending to involvement in formation of new groups. Spiritia started a new program during this period to support this process.

It had become clear that one of the major barriers to development of such groups was lack of funds. Although the needs are often not great – reimbursement of communication and transportation costs, and provision of small snacks at meetings – without these small amounts, it was difficult to attract members who are often themselves poor. On the other hand, it is difficult for fledgling groups to attract funding. Spiritia therefore requested funds from IHPCP to be able to offer limited startup funds to ten such groups around the country. This program also provided for employment of a manager to take responsibility for this effort, including regular monitoring visits. These elements have allowed a strong start to be made in this program.

- The program was kicked off with a meeting of representatives of 16 existing peer support groups, held in Jakarta in December 2003. This provided useful feedback and ideas on how Spiritia can support new groups.
- Results have become increasingly apparent in a number of areas. Currently 30 peer support groups have been formed around the country, most actively in contact with Spiritia. These have supported around 400 PLHAs and 100 affected people
- Most of the groups are still small and fragile, with main activities supporting and strengthening each other. Around 60 per cent have started to become involved in some form of external activities. All have at least one member who is willing to speak out openly.
- Spiritia assisted several groups to apply for grants from the Australian Federation of AIDS Organizations (AFAO). Although apparently none was successful, it provided useful experience will be of value in the next round of this scheme in August 2004.
- Several groups have started to advocate for the needs of their members, working with doctors, hospital management, local government, etc.
- The biggest challenges most face in development are lack of human and financial resources.

- Reach of peer support is still very limited. Many PLHAs in Indonesia have no access to peer support, while others are not yet willing to be involved.
- Most of the groups are open to both those infected by HIV and those affected (family, partners, etc.). Some restrict membership to certain groups, such as injecting drug users (IDU), transvestites (*waria*) or to family members of PLHAs.
- The support Spiritia is providing to most of these groups in the form of meetings, empowerment, skills training, funding, information, and advocacy is seen to be extremely helpful in strengthening the groups.
- Spiritia has committed to visit each group funded through the program every four months, to monitor progress and check use of funds. However, this schedule has often slipped as a result of other commitments. Most groups are submitting reports on time, but some are late.
- Criteria for support have yet to be formalized. The main condition is that they should be new groups facing lack of funds to carry out planned activities.
- Spiritia's vision is of a hierarchy of peer support, with groups (called 'umbrella groups') at regional or provincial level supporting smaller groups in their areas. Bali Plus has started to play this role, and is already supporting three recently formed groups in Bali and another group in Lombok.
- Although Spiritia and other parties can provide support and encouragement to such groups, our experience is that they cannot be forced. Development often takes time, as members become comfortable with each other and develop mutual trust. Patience is required, and sometimes this does not accord with the objectives of donor agencies. In addition, there is risk of misuse of funds, especially in groups with a preponderance of drug users. We must also be willing to accept that some groups may disband, perhaps due to failure, or because members no longer feel the need for peer support.

Information Dissemination

Provision of correct and up-to-date information for PLHAs about HIV and its effects and treatment in Indonesian language has remained an important program for Spiritia. This has included publishing two monthly newsletters: *Senandika*, aimed solely at PLHAs in the network, as a vehicle for strengthening and maintaining the network, offering space for PLHAs to communicate with each other, and to share experience, feelings and information with their peers around the country; and *Sahabat Senandika*, intended as a medium to disseminate information on care and support more widely to individuals and organizations supporting PLHAs. Spiritia continues to publish and expand its series of booklets and fact sheets for PLHAs.

- The two newsletters were published monthly on schedule throughout the period. *Senandika* is now distributed to around 200 subscribers, mostly PLHAs. The monthly print run for *Sahabat Senandika* is now up to 480. Feedback indicates that both are well received and filling an important gap. Both are still produced in simple format. *Senandika* relies strongly on submissions from the network, and it can be difficult to stimulate these submissions.
- The series of booklets was expanded over the period to include a printed version of the booklet on antiretroviral treatment, and a manual for public speaking to support the training module, in photocopy form. Four existing books were revised and republished: *Empowered Patient and Alternative Therapy* in printed form with the larger layout; plus *Home Care* and the translation of UNAIDS' GIPA booklet, still photocopied.
- The depth of information provided by the series of fact sheets, now over 80 sheets, has caused many PLHAs to refer to them as 'the PLHAs Bible'. They are often used to assist those speaking in public to prepare their presentations.
- Peer support groups and other stakeholders routinely request all Spiritia publications. A large number of copies of booklets and fact sheets were purchased by donor agencies over the period.
- Spiritia has also prepared and marketed a CD-ROM with nearly 400MB of key Care, Support and Treatment Documents in English and Indonesian. Almost 300 copies have been sold at a profit.

- Among the major challenges are ensuring that the books get to the hands of those who need them, and limited funds for publishing them.
- A plan to publish information on audiocassette has yet to be realized.

Human Rights

Spiritia was the key implementer of a project for documentation of violations of human rights of PLHAs, carried out in 2001 in four Asian countries under the auspices of the Asia Pacific Network of PLHAs (APN+). The main finding of this project, which involved interviews of 42 PLHAs by HIV-positive interviewers, was that many PLHAs around the country had experienced discrimination by health care providers.

In order to identify trends and (hopefully) improvements, a second phase documentation project was started in late 2003. This aims to have nine trained peer interviewers interview a minimum of 200 PLHAs from a wider range of locations and backgrounds. In order to identify changes, respondents will be limited to those who became aware of their infection after the first phase finished in 2001.

- Progress on this phase II documentation has been slower than planned, because one interviewer fell sick and another with injecting drug background relapsed.
- The questionnaire used for phase II is largely the same as that for phase I to assure comparison, although a few changes were made to correct misunderstandings. Experience in phase II has indicated that additional changes may be needed before phase III, planned for 2006.
- The results of the phase I documentation were discussed with health care providers and health service managers in all local strengthening visits. Initially this came across as overly critical leaving contacts rather defensive, and as a result we made changes to make our approach more supportive.
- Spiritia and several NGOs in Semarang protested reports in two local newspapers that published the identity of a PLHA after death in a local hospital. Similar cases in Medan and Mataram were also taken up.
- In early 2004, we heard reports of plans by the government to apply the contagious infection ('plague') laws to HIV infection, raising the specter of additional discrimination and even quarantine. Spiritia gatecrashed a meeting at the Department of Health discussing this, to ensure that the voice of PLHAs was heard during the process of consideration. Partly as a result, the plan was reconsidered.
- Following reports of apparent discrimination of PLHAs at one of the major private hospitals in Jakarta, Spiritia requested a meeting with the management. Although this did not result in a change in policy, it provided a clearer picture of the attitudes of private health providers, and will assist in future advocacy.

Representation in International and National Forums

Frika Iskandar Chia (a Spiritia staff member) remains the Indonesian representative on APN+, and in addition, was chosen to become APN+ representative on the GNP+ board, acting as International Coordination Supervisor. She has been kept very busy with meetings concerned with these responsibilities. Spiritia is now in process of organizing an election of an alternate APN+ representative who can take over some of the responsibility.

While not directly covered in the work plan, efforts have been made to promote Spiritia's name and credibility in international and national forums. Some highlights from the period:

- Spiritia was credited as providing input to the revised WHO Guidelines on Antiretroviral Therapy, published in December 2003.
- Spiritia provided one community member of the Country Coordinating Mechanism (CCM) of the Global Fund (GFATM).
- One Spiritia staff member is included in the national 2004 World AIDS Campaign.
- Spiritia staff were photographed for a poster exhibition on HIV/AIDS in Australia, and articles in the Australian Women's Weekly.

- Two Spiritia staff members act as consultants to the AusAID-funded Indonesia HIV/AIDS Prevention and Care Project.
- One Spiritia staff member acts as member of expert advisory panel for the bi-weekly newsletter 'HIV/AIDS Treatment in Practice', published by the National AIDS Manual, UK.
- Spiritia acted as host and local organizer for the Asia Pacific Women's Workshop, held in May 2004 by APN+.
- Spiritia staff participated in the following international and significant national functions:
 - National Seminar on Care and Treatment of PLHAs, Jakarta, Indonesia, August 2004 (one speaker)
 - Jogja Roundtable Meeting, Jogjakarta, Indonesia, September 2003 (one moderator)
 - UNDP Leadership Workshop, Pattaya, Thailand, September 2003 (one facilitator, one participant, plus seven participants from network)
 - 9th European AIDS Congress, Warsaw, Poland, October 2003 (participant)
 - ASHM Conference and NAPWA Conference, Cairns, Australia, November 2003 (speaker)
 - Community Consultation with WHO, Geneva, Switzerland, November 2003 (Asia-Pacific representative)
 - 6th Home & Community Care Conference, Dakar, Senegal, December 2003 (two staff as participants)
 - Asian Church Leadership Consultation on HIV/AIDS, Batam, Indonesia, December 2003 (speaker)
 - Community Forum, Bangkok, Thailand, January 2004, (chair/facilitator)
 - ASEAN GFATM Meeting, Yangon, Myanmar, January 2004 (CCM representative)
 - World Community Advisory Board Meeting, San Francisco, February 2004 (APN+ representative)
 - UNOHCHR Expert Meeting on Human Rights and HIV/AIDS, Bangkok, Thailand, March 2004 (participant)
 - WHO Consultation on Accreditation, Geneva, Switzerland May 2004 (GNP+ representative)
 - Early Warning Rapid Response System in ASEAN, Bangkok, Thailand, May 2004 (community representative)
 - Asia-Pacific Positive Women's Workshop, Bali, Indonesia, May 2004 (one staff plus four network members as organizers and participants)

Although several reports in the local media have referred to Spiritia, exposure has been limited, primarily because many programs involve PLHAs who do not wish their status to become known. This limits our ability to seek media coverage.

Special Funds

Spiritia has continued to develop its two special support funds: Positive Fund, to offer emergency loans or grants to PLHAs in difficulty; and ARV Fund, to pay for antiretroviral treatment for activists who need it.

- Currently some ten people are fully or partly supported by the ARV fund. Most are grateful of the opportunity to stay healthy and continue their activities. All are involved openly to a greater or lesser extent in AIDS activism in their locations.
- Sadly a number have died soon after starting therapy, probably as a result of opportunistic infections, perhaps also partly due to immune reconstitution syndrome. Many doctors managing therapy are still short on experience and knowledge, and thus may not be making the best decisions.
- The ARV fund has received a number of significant donations, mostly from overseas. Some donations are sufficient to pay for a year's therapy; others are smaller donations that still assist in expanding the program.
- As a result of increasing mortality among *waria* in Makassar, Spiritia made a special effort to solicit funds to provide them with treatment. Five private donors, three from Australia and two from the US, responded, and this will allow the fund to support *waria* in Makassar, Jakarta, Jogjakarta and Surabaya. Uptake is however proving slow.

- As prices fall and (hopefully) the promised subsidy is implemented, funds will allow more people to be supported. However, an increasing number of those supported have needed to change therapy to more expensive drugs as a result of side effects or pre-existing conditions, so currently average cost remains more or less the same.
- Much interest has been shown nationally and internationally in the selection criteria and priorities developed for the ARV Fund by Spiritia. These became the basis for a similar program in Bali, and for selection of *waria* to receive treatment in Makassar. Since they are also included in Spiritia's set of fact sheets, they have also provided ideas for others concerned with development of transparent processes for identifying recipients of limited supplies of drugs.

Human Resources/Staff Development

The position of Executive Director remains empty following the death of Suzana Murni in 2002, with the search for a suitable HIV-positive person to fill the position continuing. Strategic direction continues to be determined collectively in staff discussions led by Daniel Marguari, Project Coordinator. All other positions provided for in the work plan have been filled, with a total of ten full-time staff, five of whom are female, and five openly HIV-positive.

Priority for staff development continues to be placed on English language training, to allow more effective participation in international meetings. Courses are arranged in-house.

Annual Evaluation

An annual evaluation was carried out in May 2004, in a two-day meeting with participation by 21 members of the Indonesia PLHA network from 11 towns around the country. A brief report on the results of this evaluation may be found in Appendix 1. The evaluation provided valuable input and feedback, contributing greatly to this report. In addition, many ideas for detailed improvement of elements of the program were identified. Compared with last year's evaluation, participants were less critical, perhaps because most had a shorter experience with Spiritia and few had been involved in more than one Spiritia-organized activity; however, it would be wrong for us to assume that this indicates that improvements are not required.

Additional Activities Not Covered in Original Plan

At the request of IHPCP, Spiritia was asked to design a program aimed at assisting PLHAs to avoid passing on their infection. Following much research of similar programs in other parts of the world (mainly the US), Spiritia developed an initiative called 'HIV Stops Here'. This was kicked off with a brainstorming meeting involving a number of HIV-positive people from around the country, using a highly-qualified facilitator. The main outcome of this was strong support from participants and other members of the Indonesian PLHA community for the concept; this is in contrast to many PLHAs around the world, who view this approach as leading to their additional stigmatization as 'vectors' of the disease. However, PLHAs in Indonesia do understand that they can hope for much greater community support if they are seen to be taking a 'responsible' approach, while admitting to human failings and conditions which may result in occasional failure.

The future of the 'HIV Stops Here' initiative is still under discussion. It is clear that while such a small proportion of people are aware of their infection, its impact on the epidemic may be small. However, this approach is referred to in all Spiritia meetings, and this in itself must have positive impact.

A visit in May 2004 by Ford Foundation information technology experts provided an opportunity to consider our future direction in this management support area. In particular, discussions around accounting systems, software purchase, and security of data were valuable and have provided ideas for future development. There was also discussion around more intensive use of the internet, both for reporting to Ford Foundation, and for maintenance of the national network.

Barriers and Strategic Changes

WHO's "3 by 5" Initiative

In December 2003, WHO launched its strategy to significantly increase access to treatment for PLHAs in the developing world. The aim of this "3 by 5" initiative is to provide antiretroviral therapy (ART) to three million PLHAs in the developing world (estimated to be half of those who need it) by 2005. Indonesia has accepted this challenge, and has set a target of providing ART to 10,000 PLHAs by 2005.

Achieving this target will require massive scale-up in voluntary counseling and testing (VCT) to identify those who are infected with HIV and require ART – it will be remembered that currently less than 5000 people in Indonesia are aware that they are infected, and obviously ART can only be offered to those who know they are HIV-positive. In the process of identifying the 10,000 who need ART, it is estimated that as many as 50,000 people in Indonesia will be diagnosed as infected with HIV.

The impact of this rapid increase in reported cases is only just beginning to be appreciated. But clearly it will result in a massive increase in the need for peer support, together with all of the services currently offered by Spiritia. On the other hand, it will provide a huge new human resource, with many already skilled, some of whom will be willing to participate in the response. The challenge will be to mobilize this resource without increasing levels of stigma and discrimination.

The WHO initiative recognizes the crucial role that must be played by the community, especially PLHAs, in its success. The role they identify includes: advocacy to the government and community to provide financial and other resources including training; involvement in the process of development of policies and plans for implementation; monitoring and evaluation of the success of the initiative; and (crucially) treatment education for PLHAs and families to ensure adherence to treatment. Sadly this community involvement has yet to be realized for many reasons, including: attitude of the medical profession and government officials; lack of people, particularly those with the required skills, who are willing to play this community role; no provision of funding for participation or for training; and unwillingness of many potential players to be open about their status.

Given the very short time scale for the achievement of this objective, it is clear that action must be taken very urgently. Spiritia is still assessing its role in the response, and how this should be implemented. It is discouraging that at this crucial stage, a hiatus of four months will occur in the funding of Spiritia by Ford Foundation. Efforts are being made to find ways to minimize the impact of this break in funding, but it will clearly be difficult to fill all of the gaps.

Involvement of PLHAs

As noted above, if the "3 by 5" initiative is successful, much larger numbers of PLHAs will be aware of their status. Currently, the number is still limited, and this clearly impacts on their ability to participate in the response. Other barriers include lack of education and skills, and lack of self-esteem, and addressing these challenges with greater numbers will become even more difficult. Spiritia's strategy is to empower local peer support groups to address these challenges through skills development and providing support materials to leverage the responses.

We were reminded several times over the year that infection with HIV does not change the basic character of those infected: people with character defects such as a tendency to misuse funds are not 'cured' by HIV. One case of such misuse of funds by a member of the network became apparent, thankfully before any significant losses had occurred. It is easy (and stigmatizing!) to assume that these problems will occur among drug users, but the person in this case came from a different background. Spiritia cannot choose among PLHAs those we wish to support and those we might prefer to steer clear of. It is clearly essential to put in place systems to minimize such misuse of funds and other negative effects, but it will not be possible totally to prevent them.

National PLHAs Meeting

As noted in the last annual report, there was some concern that we were reaching the limit in numbers participating in entry-level meetings of this nature. As noted, several participants, and most of the organizing committee, felt that the participation of 60 people in the recent meeting seemed to exceed that limit. One main objective of these meetings to date has been to encourage empowerment and participation as a means to stimulating self-esteem; this objective can best be achieved in a more compact group.

As previously noted, Spiritia's future strategy provides for such entry-level meetings to be held as regional or provincial meetings, organized by peer support groups in those areas, initially with support from Spiritia. Such meetings have already been held with some success by Bali Plus in Bali (twice) and by the Papua network of PLHAs in Papua; Spiritia will encourage other groups to follow this lead.

It is planned that the national meeting will be replaced by a congress, directed towards more experienced PLHAs, with larger attendance and more focused programs. It is planned that the meeting will be held every two years, involving initially around 120 participants, of whom about half would be expected to arrange to cover their own costs. In anticipation of this change, as noted this year's PNO successfully trialed the concept of tracks, which will become an important element of a congress-style meeting.

Local Strengthening Visits

One main impact of these visits has been to open minds and motivate stakeholders at the local level play a more active role. Unfortunately few of these stakeholders have taken up the challenge to continue the action and develop teamwork, and the impact soon begins to dissipate; doors opened quickly begin to close.

This program requires considerable investment in time by Spiritia staff, and time is becoming increasingly difficult to allocate to this task. Leadership of visit teams requires a level of maturity and self-confidence that is still limited in Spiritia management. It is clear that these visits provide a very wide range of benefits to many stakeholders; this was confirmed from feedback following dissemination of the report on these visits in September 2003. However, it soon became clear that other parties were not motivated to assist in this program or carry out similar programs. This is sad...

Information Dissemination

Although the books and other publications produced and distributed by Spiritia are directed to people infected and affected by HIV/AIDS, demand for them is great by a much wider community. However, the funds for printing and distributing these publications are limited. As a result, Spiritia has been forced to consider priorities and ration supplies.

As one response to this challenge, Spiritia has successfully encouraged other donor agencies to order bulk quantities for distribution either among their own partners or for specific activities. This strategy must be expanded. In addition, Spiritia must consider other distribution channels, such as through booksellers.

Human Rights

As noted earlier, the scaling up of testing required to achieve "3 by 5" objectives may (and probably will) result in an increase in violations of human rights. Although efforts are being made by the central government to ensure that testing is only carried out with due process, it will be difficult for them to enforce this at local levels.

Should we advocate for "3 by 5" and for scale-up of VCT knowing that this will be one outcome? Spiritia takes the view that having treatment available but not taken up because people are unaware of their HIV status is equally a violation of their human rights. The challenge therefore is to implement the program with minimum increase in cases of stigma and discrimination. It will be

essential that a process be put in place to monitor and address such violations, and to report cases of coerced or inappropriate treatment to achieve targets.

Skills Development Training

Three or four courses per year, with a maximum planned attendance at each of 16 people, can only reach a small proportion of PLHAs and peer support groups. Thus Spiritia's strategy has been to encourage local groups to carry out this training with support from Spiritia. This support has included the development of training modules and offering other resources to assist the training effort.

While this has driven a 'training of trainers' approach, there has been justified criticism that this has been limited to providing technical knowledge on the subjects being trained, while training in training techniques has been somewhat neglected. Spiritia must place more emphasis on this in future training.

Peer Support

As noted above, there has been significant development in the formation of peer support groups for people infected and affected by HIV/AIDS in Indonesia, with more than 30 now in place around the country. However, most of these groups are in very early stages of development, with main focus on members supporting each other. Few have effective outreach programs to attract those newly diagnosed, and even fewer are involved in advocacy or are ready to 'take their place at the table', in accordance with the GIPA principle. Partly this is because few stakeholders are aware of the importance of meaningful involvement on PLHAs in the response to HIV/AIDS.

Spiritia's vision is for the formation of 'umbrella' peer support organizations at provincial or regional levels around the country. Such groups would provide services to PLHAs and small peer support groups in their areas, in a similar way to that provided by Spiritia at a national level. These services would include training, advocacy, and representation. They would also assist small peer support groups by offering space and resource people for meetings.

Although there has been progress in this direction, again it has been slow. Bali Plus is providing a role model for this concept, and is validating the approach. However, this development process is slow, and few groups have yet developed this type of vision.

Among the barriers to this is the fact that it is very difficult for PLHAs and peer support groups to access funding or other resources to support this development process. Funders are more concerned over their own objectives, often focused on numbers or deadlines, which may attempt to force groups and members in directions that are inappropriate or beyond their comfort zone.

The "3 by 5" initiative if successful will result in an explosion in the number of PLHAs who are aware of their status. Clearly Spiritia will not have the capacity to respond to the needs of all of these people. One crucial solution to this must be to encourage more PLHAs to form peer support groups and develop these groups to address the needs of the members. Spiritia will be required to play an even greater role in this process. There is fear that insensitive actions to facilitate this by other parties who do not understand the needs of PLHAs could result in even higher levels of stigma and discrimination.

Spiritia's strategy must develop rapidly to respond to these challenges. It is of interest to note that the work plan developed in 2002 covering the period under review placed major emphasis on empowerment of individual PLHAs; there is no reference to development of peer support groups. In fact it became clear during the first year that Spiritia must move up one level, to encourage and support development of such groups. Now during the second year (that under review), Spiritia has been forced to move up another level, to develop the concept of umbrella groups. Spiritia must continue to show the vision and flexibility to respond to these rapid changes that are affecting the lives of PLHAs in Indonesia.

With this in mind, Spiritia will continue to develop this peer support program to reach more PLHAs and support groups. This will include expansion of provision of funding to groups to allow

them to develop and grow stronger. It will also include clearer focus on the concept of training of trainers, so that peer support groups can take over several of the roles currently played by Spiritia, including skills building, provincial or regional PLHA meetings, strengthening visits to district/municipality levels, information dissemination, and advocacy.

As Spiritia moves up to these new levels of response, the challenge will be to retain contact with the grass roots – with the needs and feelings and worries of individual PLHAs around the country. One participant at the annual evaluation commented that Spiritia's focus on groups had reduced the concerns with individuals. Ways to address this must be discussed and developed.

Representation in International and National Forums

Spiritia continues to be inundated with invitations/requests to take part in meetings, workshops, seminars, etc. at the national and local levels. While this represents a degree of success in promotion of the GIPA principle, it is often beyond our capacity to respond. It is essential to maintain focus, and place priority on those functions in which we can contribute meaningfully. Again, the strategy is where possible to involve local groups and PLHAs, but it remains important that involvement should be meaningful, not just tokenism.

An effort has been made to widen the potential for representation at the regional level, by arranging nomination and voting by members of the network for an alternate representative to APN+. It will be important to provide the new representative with the skills to participate meaningfully, and ensure feedback to members of the network. It is also important that these representatives are given the opportunity to meet with as many members of the network as possible, preferably in their home environments, in order for them to understand and appreciate the problems they face. One approach is to include them in the teams on strengthening visits, but it is frequently difficult to schedule these visits without conflicting with other commitments.

Human Resources/Staff Development

As Spiritia programs expand, the need for professional staff to organize and manage them also increases. Spiritia has prioritized employment of infected people, but it continues to be a challenge to identify and attract those who are qualified. Secondary priority is given to people affected by HIV/AIDS, but again it may be necessary to spread our net more widely. However, it remains crucial that Spiritia staff should be client-centered, retaining the 'soul' or vision of the founders.

Universal Precautions

In the previous annual report, it was noted that the concept of universal precautions (UPC) is poorly understood, and worse implemented, in almost all medical facilities around Indonesia. Little progress has been made in addressing this challenge. Perhaps surprisingly, it appears that private health facilities may be at least as bad as government health centers. They maintain that 'other' patients are unwilling to pay the cost of precautions that they view as unnecessary. The result is even wider use of mandatory testing for HIV on admission to private hospitals. Strategies to address this challenge are still being considered.

Access to Antiretroviral Therapy

There have been major developments in access to antiretroviral therapy (ART) over the period. Although definite figures are not available, it is estimated that 1300-1500 people are now receiving ART. Prices have reduced significantly, and alternatives of those unable to tolerate the 'standard' regimen have become available. Local production of one combination is seen by many as a breakthrough, but few appreciate that this is in fact a backwards step. Local production saves no costs – in fact it often increases them, and has resulted in prices still almost twice that of those available on the international market. Part of this is a result of 30 percent import duty, but other factors also raise the costs. In addition, supply is less flexible, and since the local producer is not prequalified by WHO, local products cannot be used for GFATM purchases.

A 50 percent subsidy promised by the Minister of Health almost a year back has yet to be implemented. In any case, Spiritia is convinced that subsidies are not the solution, since few

PLHAs can afford even the subsidized price; drugs for treatment of HIV must be free-of-charge, in the same way as those for TB and leprosy.

It is not only the subsidy that is taking an inordinate time to implement: we still await release of the government (Depkes) policy and plan of action supporting the “3 by 5” initiative. The Communicable Diseases Directorate of Depkes (P2MPL) continues to be the main player directing the response. There is now greater involvement by other elements of Depkes such as Medical Services (Yanmed) and Drug Services (Yanfar), but the KPA is playing only a very minor role.

Empowerment

In the last report, it was noted that Spiritia was working with UN Volunteers (UNV) on a proposal to enhance GIPA in Indonesia. Although the money has been approved, this program has yet to be blessed by UNDP. However as noted the situation now is vastly different from that at the time the original proposal was developed, almost two years ago. This has required a rewrite of the proposal, but this remains inflexible. It also appears to assume a level of involvement by Spiritia that is beyond our capacity, while providing very limited funding for increasing that capacity.

Conclusions

During the second year of funding by Ford Foundation, Spiritia has been able to reach higher levels of achievement. Spiritia’s main aim has been to support and empower PLHAs, to facilitate their access to care and treatment, and to encourage their involvement so that they play an active role in the response to HIV/AIDS in accordance with the GIPA principle. These aims have been more widely achieved with more PLHAs and in more places.

The wishes of PLHAs to meet and support each other has provided Spiritia with a larger role in encouraging the formation of peer support groups in more areas, and in facilitating a variety of activities to develop and strengthen those that exist.

Several peer support groups have now developed and become stronger, so that they have potential to coordinate the activities of smaller groups in their area as these are formed. With support from Spiritia, several of these groups have started to play a role as umbrella groups.

Spiritia’s concept of supporting PLHAs as individuals has been strengthened by this focus on groups and umbrella groups. Infected and affected members of the national network of PLHAs have also welcomed the concept of training of trainers as an effective strategy to support and empower more of them throughout Indonesia. This approach also anticipates the imminent explosion in the number of people who become aware of their HIV status as a result of the “3 by 5” initiative that is being promoted by many parties.

Spiritia has continued the pace of development, moving from a local peer support group to become a significant national and regional player, and responding to the increasing needs of a growing number of PLHAs and support groups. In the process, the pressures on Spiritia’s management organization have also grown, and shortcomings have become more apparent. These must be addressed, and management professionalism improved, if Spiritia is to respond to the needs of its client population.

Support from Ford Foundation has been one important factor in the achievement of these aims. Similarly the support from the Indonesia HIV/AIDS Prevention and Care Project (IHPCP) has increased Spiritia’s reach, particularly through funding the peer support group development program. Several programs also received specific support (mainly to fund additional participation) from the ASA project, MSF-Belgium, UNAIDS, BP and GNP+.

Recommended Actions for the Future

As a result of experience from the 2002-2004 work plan, together with feedback and input from the annual evaluation, plus the changing environment particularly resulting from the “3 by 5” initiative, several evolutionary changes are planned in Spiritia’s 2004-2006 work plan. These include:

- Current national PLHA meetings to be developed to become a national biennial PLHA congress with wider participation; regional or provincial meetings will replace entry-level meetings for PLHAs.
- Encourage the formation of support groups in all areas, providing limited financial support to assist their development.
- Encourage stronger peer support groups to develop and extend their programs. Act as a go-between to other donor agencies and grant-makers to provide funding. Encourage and support further development to become umbrella groups.
- Additional strengthening visits to provinces and towns not yet visited. Encourage local groups to follow up on previous visits and extend visits to district/municipality levels. Invite other national level stakeholders, such as journalists, health care workers, and activists from other AIDS Service Organizations to join the visit teams.
- Develop the concept of treatment educator, identifying suitable candidates and developing training curricula.
- Develop new training modules, with special emphasis on treatment education. Increase the number of training courses, and encourage and assist local groups to carry out training, for example in public speaking and peer education.
- Develop the ‘HIV Stops Here’ program as a means to prevent HIV spread.
- Hold an annual meeting of peer support groups.
- Enhance the capability and skills of Spiritia staff and network members to become professional consultants, speakers and trainers, worthy of an appropriate fee.
- Develop the ARV Fund, particularly to cover costs not covered by government subsidy or other funds. Extend the Positive Fund to ensure that those who are not able to access antiretroviral therapy receive appropriate care, including palliative and end-of-life support. Extend the use of Positive Fund for micro credit to support income generation.
- Play a more active role in the process of policy making by stakeholders, and enhance national level advocacy.
- Examine and develop programs to provide indigent PLHAs can receive nutritional supplements.
- Spiritia operations must become more professionally managed and implemented, with attention given to development of standard procedures and guidelines. Training must be provided to improve supervisory and management skills.
- Plans must be developed to migrate away from the Ford Foundation-provided dedicated accounting program to a more generic program which can be used for reporting to all donor agencies.
- Develop fundraising plans, to allow Spiritia to become more independent.

Appendix 1: Annual Evaluation 2003-2004

Background

Spiritia held its annual evaluation for the year 1 June 2003–31 May 2004 on 2nd–3rd May 2003. Besides all Spiritia staff, 21 members of the national PLHA network from 11 provinces attended representing the clients of Spiritia's programs. The two-day meeting at the Hotel Gran Alia in Jakarta was facilitated by Simplexius Asa of IHPCP.

Assessment Questionnaire

Prior to the meeting, all members of the PLHA network had been asked to complete a questionnaire of 28 questions, which had been sent to 155 members of the network, both infected and affected, in 33 towns in 21 provinces. A total of 79 questionnaires have been returned completed, 76 per cent by members who had been involved in the network for less than two years. This perhaps suggests that 'older' members are losing some interest in Spiritia activities, although it is certainly due in part to the rapid scale-up in membership over that last two years.

The most significant results were:

- All agreed that they had received moral and information support from Spiritia
- 80% have become involved in AIDS programs in their areas, with 95% of these reporting Spiritia had played a role in this involvement
- All but one who had been involved in Spiritia activities felt that they benefited from this participation; the one exception noted concerns with the Phase II human rights documentation program
- 81% found the newsletter *Senandika* interesting or very interesting
- 13% remain confused about Spiritia's role as secretariat of the network (down from previous 20 per cent)
- 85% felt empowered (a slight fall off compared with 90% of 30 respondents to the last annual questionnaire), with almost all acknowledging that Spiritia had played a role in this empowerment

The questionnaire also provided space for respondents to indicate the needs that they hoped could be met by Spiritia or the network. A wide variety of responses were received; some are beyond the means of both Spiritia and the network, but others will provide ideas for future development.

Evaluation Agenda

- Results of questionnaire
- Description of Spiritia program
- Goals and main objectives
- National PLHAs meeting
- Skills development training
- Local strengthening visits
- Peer support group development
- Information dissemination
- Other programs
- Lessons learned

Summary and conclusions

For each of the main topics, the Spiritia staff member responsible first described the program. This was followed by a brainstorming session, and finally the discussion points were classified for later inclusion into the lessons learned.

Discussion Sessions

A wide range of matters was raised in the brainstorming sessions. Although there was an attempt to ensure the comments were balanced, perhaps because most of the participants were only recently involved and most had only participated in only one Spiritia activity, few 'negative' comments were received. However, with some effort to stimulate critical responses, some useful lessons were brought out.

Main Lessons Learned

The following were the main lessons learned from the evaluation. Some will be immediately implemented or incorporated into Spiritia's program. Others will require additional funding, and will be the subject of supplemental proposals. Efforts will be made to address all points in the coming year.

General

1. Spiritia's programs have had a major impact on support and empowerment of members of the network, and have stimulated involvement
2. The National PLHAs Network has increased in strength with the formation of an growing number of peer support groups in the regions
3. Spiritia does not have the capacity to address all of the aspirations of all infected and affected members of the network
4. Spiritia has not promoted its program sufficiently clearly
5. Communication has been uneven
6. Occasionally there has been an impression that Spiritia has been more concerned over the needs of groups rather than individuals

National Meeting of PLHAs

1. Very useful, increased self-esteem and knowledge of participants
2. Follow-up requires more attention
3. Most felt that there were too many participants, but most also felt that more PLHAs needed to be able to attend
4. Some of the outside speakers were lacking in empathy
5. 'Older' members of the network/participants at previous meetings should be more involved

Skills Building

1. Effective in increasing skills and self-esteem
2. Need more focus on building skills as trainers
3. Selection criteria for participants unclear
4. Only elementary skills covered; consideration must be given to development of higher skills
5. Most network members are still dependant on training by Spiritia or other support groups; need to take advantage of outside courses

Local Strengthening Visits

1. Effective at opening doors for local groups
2. Determination of visit targets not based on mapping
3. Reports on visits not disseminated to those visited
4. Selection criteria for team members unclear

Peer Support Group Support

1. Peer support groups activities more focused
2. There is no means for addressing overall financial needs of groups
3. Possibility for funds received from multiple sources with overlap

Information Dissemination

1. Major impact on empowerment of PLHAs
2. Dissemination only in printed form; need consideration of other media
3. The card 'Ketika Temanku AIDS (If my Friend has AIDS)' has great untapped potential for wider advocacy purposes, but need to be update

Positive Fund/ARV Fund

1. Able to sustain efforts of several PLHAs
2. Not well publicized; procedure for requesting support unclear

HIV Stops Here

1. Concept accepted and supported
2. No follow-up or concrete activities yet carried out, only campaign

Human Rights

1. PLHAs more aware of their rights
2. There is an impression that some of those interviewed feel they are treated as objects
3. Participants often seem to expect immediate improvements
4. Coordination with the regions could be improved

APN+

1. Participants not fully aware, did not feel they are members of the Asia-Pacific Network

Involvement in National Forums

1. Criteria for involvement unclear
2. Lack of feedback on activities

SWOT

As part of the evaluation process, participants were asked to brainstorm regarding their views of the network. In summary the results were:

Strengths

- We are cohesive
- There is active networking
- We have many partners

Weaknesses

- Lack of skills
- Lack of human resource

Challenges

- Lack of funds/lack of salaries for network activists
- Local AIDS Commissions (KPADs) unempowered/ineffective
- Reaching PLHAs from different backgrounds
- Stigma and discrimination
- Increasing number of infected people

Hopes

- More cooperation with other NGOs and government
- Turn words into action
- Access to treatment

Appendix 2: Photographs of Activities



4th National PLHAs Meeting, February 2004



Skills Development Training, October 2003 — Batam: Peer Educator



Skills Development Training, March 2004 — Makassar: Peer Support Groups



Skills Development Training, January 2004 — Jakarta: Attending International Conferences



Local Strengthening Visit, April 2004 — Ambon, Maluku: Interview by TVRI



Local Strengthening Visit, August 2003 — Tanjung Pinang, Riau: Presentation to Convicts in Prison



Brainstorming Meeting, September 2003 — Jakarta: “HIV Stops Here”



National Meeting of Peer Support Groups, December 2003 — Jakarta



Annual Evaluation, May 2004



USAID/FHI/ASA Visit, June 2003



Spiritia Staff Members Retreat, March 2004

Appendix 3: IEC Material Published 2003/2004

Spiritia published the following books and other information materials over the period. Copies of each are attached:

- Pasien Berdaya (The Empowered Patient) — revised printed version
- Terapi Alternatif (Alternative Therapy) — revised printed version
- Pengobatan untuk AIDS: Ingin Mulai? (AIDS Therapy: Want to Start?) — revised printed version
- Dari Prinsip ke Praktek – Keterlibatan Lebih Besar Orang yang Hidup dengan HIV/AIDS (From Principle to Practice – Greater Involvement of People Living with or Affected by HIV/AIDS – GIPA) — revised photocopy version
- Merawat Odha di Rumah (Home Care of PLHAs) — revised photocopy version
- Mengangkat Beban Kerahasiaan: Pedoman Berbicara di Depan Umum untuk Odha (Manual on Public Speaking for PLHAs) — photocopy version
- Mengangkat Beban Kerahasiaan: Modul Pelatihan untuk Pembicara HIV-Positif (Training module for above manual) — photocopy version
- Berdayakan Diri Menghadapi AIDS (Self Empowerment to Face HIV/AIDS – Spiritia Profile) — revised photocopy version
- Self Empowerment to Face HIV/AIDS in Indonesia – Spiritia Profile — revised photocopy version in English and Indonesian
- Lembaran Informasi tentang HIV/AIDS untuk Orang yang Hidup dengan HIV/AIDS (Odha) (over 80 Fact Sheets on HIV/AIDS for PLHAs) — photocopies, many sheets updated
- “Tretes” Statement (Declaration by participants of 4th National PLHAs Meeting) — photocopy version in English and Indonesian
- Report on Local Strengthening Visits November 2001 – August 2003 — photocopy version in English and Indonesian
- Report on Activities 2002/2003 — photocopy version in English and Indonesian
- Newsletter Senandika – 12 issues
- Newsletter Sahabat Senandika – 12 issues
- ARV Fund Brochure — photocopy version in English and Indonesian

Appendix 4: “Tretes” Statement

Declared by Participants at the 4th Indonesian Meeting of People with AIDS – 2004

In the “Cikopo” Statement, which represented one output of the 3rd Indonesian Meeting of People with AIDS (PNO) in February 2003, participants noted that too many of those who took part in the 2nd PNO (September 2001)—including our supreme warrior, Suzana Murni—had passed away. They agreed and promised not to allow such losses to recur before this 4th PNO.

Have we fulfilled this promise? Sadly, three of the 50 participants of the 3rd PNO are no longer with us. Although this figure is somewhat better than before, we admit that our struggles have yet to achieve the results expected.

We promise that that we will strengthen our efforts to reduce this death rate, in addition to working hard to reduce the number of people who become infected with HIV in Indonesia. Specifically, we will:

- Support to the best of our abilities all HIV/AIDS programs implemented both by government and by the community;
- Endeavour not to infect anyone else (especially our partners);
- Be prepared to learn about HIV and its treatment so that we can be more fully involved in our own health, and to provide information and counselling to other people with HIV/AIDS (PLHAs); and
- Involve ourselves in providing voluntary counselling and testing (VCT), and endeavour to persuade those close to us to be ready to be tested for HIV.

We also urge much greater effort by government, both national and local, particularly as noted below:

- All HIV/AIDS control efforts must involve PLHAs, in accordance with the principle of Greater Involvement of People with AIDS (GIPA). Of prime importance is the involvement of PLHAs in provincial and district AIDS commissions (KPAD).
- We urge the provision of antiretroviral drugs (ARVs) to 10,000 people in Indonesia by 2005, in accordance with the WHO’s “3 by 5” initiative.
 - This programme must fully involve PLHAs in the process to select recipients of therapy.
 - ARVs must be distributed equitably to all provinces, and to rural areas, not just towns.
 - In order to identify these 10,000 PLHAs, there must be greatly increased efforts to scale up provision of VCT services throughout the country.
 - There must be continued efforts to reduce the price of ARVs, including government policy to exempt the drugs or raw materials from import duties.
 - We urge the scale up of programs to train doctors and nurses about ARV therapy (ART), as well as the development of a communication network among health care workers, to disseminate up-to-date information necessary to manage their patients.
 - Correct and usable information about treatment must be widely available. The role of peer treatment educators is crucial to ensure that therapy is correctly managed, and to promote adherence. Efforts must be made to recruit and train such educators, and provide them with a living income.
- Much greater efforts must be made to ensure that people with AIDS who are not provided with ART can be provided with prophylaxis and treatment for opportunistic infections.
- We most strongly urge that surveillance programmes be halted if they cannot be carried out in accordance with the laid-down procedure and accompanied by free VCT services offered to all members of the sentinels surveyed.
- Much greater efforts are required to enforce universal precautions in all health care services, especially in dental care.
- Community understanding about HIV/AIDS must be increased, with strengthening of programmes to disseminate basic information, including about treatment, in forms that can be understood and accepted, including in local languages if required.

- We urge the provision of integrated and accessible health services for injecting drug users (IDUs), covering all elements of harm reduction including needle exchange, substitution therapy as well as the provision and use of condoms.
- We warmly welcome the promise made in the Sentani Commitment to “make efforts to reduce stigma and discrimination against PLHAs”. However, we urge that this is not just empty words, but is actually realized. We will evaluate this commitment in part by the efforts made by the government to ensure that no hospitals continue to claim to be “unprepared” to accept AIDS patients, an “excuse” that is totally unreasonable and unacceptable.

We commit to use this Tretes Statement as an advocacy tool at national, provincial and district levels, in communications with all parties related to HIV/AIDS control, be they governmental, private sector or community-based and religious organizations.

[Note: This Statement was signed by all 61 participants of the 4th PNO]