UNITED AGAINST AIDS: The Story of TASO

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by Peter Kitonsa Ssebbanja

United against AIDS
Unite and be safe
Get the facts and get to know
What AIDS is all about.

Tony Kasule, TASO Mulago Music, Dance and Drama Group

Foreword by Noerine Kaleeba

Edited by Daniel Kalinaki and Glen Williams

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NOTE: The names of TASO clients 'Eddie' (page 13) and 'Susie' (page 20) have been changed in order to protect their anonymity.

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TASO clients Prossy Nalubowa, Christopher Machika, Ignatius Biryomumaisho, Patrick Olaya, Lucy Lawino and Eve Bashabire Turyamureeba freely shared with us their experiences of living positively with HIV. TASO counsellor, Annet Soobi, shared with us her experience of working for TASO. Numerous other TASO staff provided us with important information whenever asked. The TASO Board of Trustees gave us their guidance and support.

My late wife, Josephine, gave me her unstinting support during the first several years of TASO's existence, when we were just a small group of unpaid volunteers, facing high levels of AIDS-related stigma and discrimination.

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Peter Kitonsa Ssebbanja
TASO, Kampala, Uganda

ABOUT THE AUTHOR

Peter Kitonsa Ssebbanja was one of the 16 founding members of The AIDS Support Organisation (TASO) in 1987. He has worked for TASO in several different capacities, and is currently Director of Advocacy. Married, with eight children, he is a qualified physiotherapist and a former tutor in the School of Physiotherapy at Mulago Hospital, Kampala, Uganda. He also holds a Masters degree in Health Promotion Sciences from the London School of Hygiene and Tropical Medicine, University of London.

ACRONYMS

ABC:	Abstinence, Being faithful, Condom use
ACDI/VOCA:	Agriculture Cooperative Development International/ Volunteers Overseas Cooperative Assistance
AIC:	AIDS Information Centre
AIDS:	Acquired Immune Deficiency Syndrome
ARV:	Antiretroviral (drug)
ART:	Antiretroviral therapy
CBO:	Community Based Organisation
CDC:	Centers for Disease Control
DANIDA:	Danish International Development Agency
DfID:	Department for International Development
GIPA:	Greater Involvement of People Living with HIV and AIDS
HBAC:	Home-Based AIDS Care
HIV:	Human Immunodeficiency Virus
NGO:	Non Governmental Organisation
PEPFAR:	President's Emergency Plan for AIDS Relief
PHA:	Person Living with HIV or AIDS
SCOT:	Strengthening HIV and AIDS Counsellor Training
SIDA:	Swedish International Development Agency
STI:	Sexually Transmitted Infection
TASO:	The AIDS Support Organization
USAID:	United States Agency for International Development
VCT:	Voluntary Counselling and Testing

FOREWORD

As TASO celebrates 20 years of service, people often ask me if I would do things differently if I had the chance. My answer is no. What we did from the start, almost instinctively, without really having any scientific proof of its validity, was to focus our efforts on the person who is infected or affected by HIV. I celebrate the fact that we focused on the quality of life, and on restoring dignity, both in life and in death.

It is easy to look back with hindsight and find some faults with the way TASO evolved, but in fact TASO developed its home-grown philosophy of 'positive living' and exported it to other parts of the world. In addition, long before the principle of GIPA (Greater involvement of people living with HIV and AIDS) became a global rallying call, TASO had instinctively built GIPA into its values and its constitution.

This book captures, in a simple and dignified way, those early days of TASO and what it took to get us off the ground. Twenty years later, TASO has looked after 186,000 HIV-positive people, reaches 56 of the 80 districts of Uganda, has 11 service centres, and has a staff of over 1,000 and an annual budget of over US$20 million. This book is written to help us understand how it all began, and how TASO today is one of the most widely recognized NGOs in the world. TASO led the call for a dignified life for all and we have continued to combine activism with action – a truly potent synergy for change.

When TASO started, our entry point into the family was the HIV-infected person. We focused on counselling the infected person, and counselling the family to care for the infected person. But this approach had one major shortcoming, namely, we failed to offer sufficient support to the children of parents living with HIV. In our culture, children are not given explanations: they speak only when spoken to, and don't ask too many questions. I remember how, when we visited our clients in their homes, we would pass the children on the verandah and go and talk to the adults of the family.

I am, however, pleased that TASO is always learning from its experiences, and this book shows how TASO has both grown and adapted to the environment in which it operates. I am particularly delighted with the increased focus in the last three years on children affected by HIV and AIDS. TASO now has 700 children on ARVs, child care facilities and child counsellors at all TASO service centres, in addition to the traditional school fees support for orphans.

Going forward, TASO will need to develop very comprehensive programmes focused on children, not only orphans, but all children affected by the HIV epidemic. Our aim should not be to just provide them with charity, but to ensure that they have well developed survival skills to cope with the tremendous challenges of growing up in a world marked by poverty, violence and conflict. This is a gargantuan task and can only come to fruition if we pull together in partnership and synergy.

It is a sad fact that global efforts to address HIV and AIDS have often failed to transmit lessons and to hold onto them. The response has often happened in a 'pendulum' fashion, swinging from one extreme to another, emphasising one aspect at a time, forgetting that people's lives, needs and environments are different. We have all lost time debating

the focus of our programmes, for example, HIV prevention OR antiretroviral therapy, OR care and support. Condom use OR abstinence and faithfulness! As a country, we in Uganda recently went down the path of promoting mixed and conflicting messages around abstinence and condom use. While those in the two camps were fighting each other, new HIV infections were still occurring.

Nobody should ever say that Uganda reduced its HIV prevalence simply through abstinence or through condoms. It was a combination of both, and much more – including stigma reduction, gender awareness, HIV counselling and testing and the work of TASO and many others – that gave people with HIV a voice and a face. But we still need to go much further. For example, we need to add property rights for women. In our African context, a woman who doesn't have property rights, especially land, or some other source of income, or a good education, has nothing and is therefore very vulnerable.

There is also a huge amount of scope – and an enormous need – for us to do more in the area of HIV prevention. HIV care and prevention are two sides of the same coin. If you have only 30 people to care for, you can provide a high quality service. But if, with the same resources, you have to provide care for 300 people, the quality of your service is sharply reduced. So it's in TASO's interest that fewer people are infected with HIV, so that those who are infected can receive high quality care.

One interesting thing that has happened in TASO in recent years is the growth in the number of discordant couples, that is, those in which one partner is HIV-positive and the other is negative. Discordance is a reality and we need to acknowledge it. Our message should be that, whether you are in a discordant or a positive relationship, protected sex is the key to health and longer term survival.

I am therefore very pleased to see that TASO in 2007 has focused on 'Scaling up HIV prevention' and has started rolling out the Positive Prevention programme, focusing on safer sex, prevention of mother-to-child transmission, discordance and engaging people with HIV as the voice of HIV prevention, especially for the younger generation, who are most vulnerable.

When we started TASO, we were very clear in our minds that we wanted the organisation to come to an end. We therefore included a dissolution clause in the constitution. Our thinking was that, when the AIDS epidemic came to an end, there would be no further need for TASO. Unfortunately, AIDS is still with us and TASO is still needed. Moreover, the AIDS epidemic is so deeply rooted that in 20 years' time there will still be a need for TASO.

Every day, I ask God to give us a cure – a total cure – for AIDS. I believe that a cure for AIDS is possible, and that eventually we will overcome this epidemic. The ramifications of the AIDS epidemic, however, are far-reaching and will live with us for decades to come.

Let this short history of TASO inspire and invigorate present and future leaders of the struggle against HIV and AIDS, for in the end the story of TASO is the story of how a small band of people did not lie back and wait for others to help them, but instead took up the challenge. Out of the personal loss, pain and confusion of 20 years ago grew TASO - a unique, strong, proud and truly home-grown African institution.

Noerine Kaleeba
Founder and Patron, TASO

TASO SERVICE AND TRAINING CENTRES

CENTRE:	DATE ESTABLISHED:
Mulago (Kampala)	November 1987
Masaka	May 1988
Training centre, Kanyanya (Kampala)	October 1988
Tororo	November 1988
Mbarara	January 1989
Mbale	March 1990
Jinja	March 1991
Entebbe	November 1991
Gulu	January 2004
Rukungiri	August 2004
Soroti	August 2004
Masindi	August 2005

Chapter 1:

Introduction

Early in 1987, I was one of a group of 16 men and women who started meeting in Kampala, the capital of Uganda, to share our experiences of how we were coping with the impact of AIDS on our lives.

Although the first cases of AIDS in Uganda had been identified five years earlier, the epidemic was still shrouded in ignorance. Because of the stigma and fear associated with AIDS, and the myths about how easily it could spread from one person to another, people sought to protect themselves by subjecting those believed to have AIDS to inhumane and degrading forms of discrimination. Traditionally strong family ties, friendships, workplace bonds and community support mechanisms collapsed. Afraid to contract the virus, people refused to shake hands or share plates, cups and other domestic facilities with those living with AIDS. Even people who were not infected with HIV but were affected by having to care for family members and relatives, often suffered from appalling forms of stigma and discrimination.

Our group of 16 individuals who started meeting informally in Kampala in 1987 included both people infected and people affected by HIV. We came together to seek refuge from the stigma and the discrimination we were experiencing, and to find strength in sharing our experiences. We discussed how to care for those living with AIDS. We shared food and offered what little surplus we had to those who had nothing. We visited one another, in our homes or in hospital, to offer prayer and comfort.

As the number of people to visit grew, a structure and a name gradually emerged from our informal meetings. We called ourselves 'The AIDS Support Organisation' – better known by its acronym, 'TASO'. The organisation encouraged its members to 'live positively'. Those living with AIDS should take care of themselves and those around them, and make the best of whatever time they still had left. They should also make preparations so that they could 'die with dignity'.

Twenty years later, TASO still promotes 'positive living', but now works to keep people living with HIV alive and healthy, rather than resigning themselves to a premature death, whether 'dignified' or not. The organisation has also grown at an amazing rate – way beyond the wildest dreams of the 16 founding members. We now operate 11 large service centres in different parts of Uganda, we employ over 1,000 staff, and we provide services to 80,000 people living with HIV and their families.

Since 2003, TASO has also operated a large antiretroviral therapy (ART) programme in rural and urban areas, as well as in camps for internally displaced people in war-torn northern Uganda. We also train counsellors,

we provide social support to our clients and their families, and we assist community responses to HIV. In addition, we carry out HIV education and we advocate, both nationally and internationally, on behalf of people living with or affected by HIV.

In this book I have tried to tell the story of TASO, from the viewpoint of someone who has worked in the organisation, in many different capacities, since its humble beginnings in 1987. I have tried to identify and describe the key milestones in TASO's journey from a small, informal group of volunteers to become one of the largest NGOs in the developing world. In doing so, it is not my intention to celebrate TASO in any way, but simply to tell the story of TASO as I see it, as someone who has been privileged to participate in the development of this remarkable organisation.

It is my hope, however, that this book may serve as a learning tool for the thousands of non-governmental and community-based organisations involved in HIV and AIDS care, support, prevention and advocacy throughout the world.

Chapter Two

History of HIV and AIDS in Uganda

The first cases of AIDS in Uganda were identified in 1982. I remember hearing at that time of a strange new illness that was attacking people in the fishing village of Kasensero, on the shores of Lake Victoria, in Rakai district, southern Uganda. The disease soon became known as 'Slim' because it would often result in dramatic weight loss and wasting away of the body before causing death. Soon, cases were reported in the neighbouring district of Masaka.

Before many Ugandans became aware of AIDS in their midst, the country had become involved in an intense and bloody civil war, which lasted from 1981 until 1986. This caused enormous insecurity and damaged the country's economic and social infrastructure, including the health services. The war might also have contributed to the rapid spread of HIV, as soldiers and civilians moved from one place to another.

Between 1982 and 1986, the number of AIDS cases reported increased slowly but steadily, with the largest increases registered in urban areas. The neighbouring countries of Kenya, Tanzania, Rwanda and the Democratic Republic of Congo were also reporting cases of AIDS, with a high concentration of cases along the main highway that connected these countries to one another.

The true extent of the AIDS epidemic in Uganda was unknown until, in the early 1990s, quarterly surveillance reports were produced. In the 1980s, however, people had very little, if any, accurate information about HIV and AIDS. Instead, they heard – and often believed – rumours attributing the origin of the disease to witchcraft, and to 'God's punishment' for sexual promiscuity and infidelity.

I recall how, in 1984 - 1986, when I was working as a physiotherapist at Mulago Hospital in Kampala, we witnessed an increasing number of patients coming in with AIDS-related symptoms. At the time, we used to talk about 'AIDS' rather than about HIV, the virus which leads to AIDS. HIV testing was still rare in Uganda, so very few HIV-positive people knew they were living with HIV. By the time a person was diagnosed – generally on the basis of clinical symptoms – as having AIDS, they usually had only a short time to live.

In 1986, soon after coming to power, President Yoweri Museveni's government publicly announced that there were many people living with AIDS in Uganda, and that the country needed help in addressing the problem. This was a startling declaration at a time when many other national leaders were denying the existence of AIDS in

their countries. In October 1986, an AIDS Control Programme was established under the Ministry of Health to address the AIDS epidemic. It started an intensive health education campaign, targeting in particular the worst-hit districts of Rakai and Masaka.

In Uganda, and throughout sub-Saharan Africa, heterosexual intercourse is the most common form of HIV transmission. The early HIV prevention messages in Uganda therefore advised people to protect themselves by 'loving carefully', which meant either being faithful to one's sexual partner or using condoms. Other messages, reflecting the fact that many people had more than one sexual partner, called for 'zero-grazing'. This was a term borrowed from the common practice of keeping cows tethered to one spot so that they could eat the available grass without wandering off to eat crops. The message was that spouses should remain faithful to one another, rather than seeking sexual partners beyond their homesteads.

As more information about HIV and AIDS became available, more people living with AIDS came to health units for care and treatment. However, the care provided was inadequate because the medical staff lacked the knowledge and the skills to manage the disease. Morale among medical personnel was also low; health units were understaffed and lacked essential drugs and other basic supplies. In fact many medical staff discriminated against AIDS patients, and left the majority of the nursing, feeding, and cleaning responsibilities to family members, who also knew very little about what to do. Furthermore, in the absence of a cure, many people considered people living with AIDS as 'lost causes' that were 'marked for death', and rejected them.

As a young physiotherapist at Mulago Hospital, I regularly tuned into the British Broadcasting Corporation's *Focus on Africa* programme, which often discussed HIV and AIDS. I followed the broadcasts with keen interest to learn more about this mysterious new disease. What I didn't know at the time was that I would spend more than 20 years of my life trying to contain the spread of AIDS and endeavouring to give a better and more dignified life to those whom it affected.

Chapter Three

The beginnings of TASO

In June 1986, Noerine Kaleeba, who was Principal of the School of Physiotherapy at Mulago Hospital, where I also taught, flew to England to visit her husband, Christopher, who was studying at Hull University. Christopher had been admitted to Castle Hill Hospital, where he had been diagnosed as having AIDS.

At the time, I did not know about Christopher's condition. But one day, Mary Kakeeto Lukubo, a friend and fellow tutor at the School of Physiotherapy, who was a close friend of Noerine, whispered to me that Christopher had been diagnosed with AIDS. Mary insisted, however, that I should not tell anyone else about it. I was shocked and speechless. Later I plucked up the courage to ask: "What about Noerine?" Mary answered: "I don't know."

I had met Christopher at Mulago Hospital, where he worked as a radiographer before going to Hull University. Although not close friends, he and I had always got on well. Noerine stayed with Christopher in Hull for several weeks, until he himself decided he wanted to return home to Uganda, because he was missing his family so much. Christopher returned to Kampala towards the end of 1986, and continued receiving medical care at Mulago hospital. Mary and I regularly visited him on the ward to offer him our moral support and to show solidarity with him and the entire family. Christopher passed away on 23 January 1987.

While Christopher was hospitalised in Kampala, Noerine, who had tested HIV-negative while in England, and the rest of her family experienced the stigma that was routinely directed at people with AIDS and their families at the time. This was in stark contrast to their experience while Christopher was in hospital in Hull, where Noerine and Christopher had received counselling and information about HIV and AIDS from a local support group. While taking care of Christopher in Mulago Hospital, Noerine sorely missed this kind of support. None of the other people living with AIDS patients in Mulago Hospital were receiving such support either.

Before Christopher's death, Noerine started reaching out to some other patients with AIDS in the hospital, and to their families. She brought together a few people who later became founding members of TASO. After Chris died, she asked several friends, including Mary Kakeeto, Jane Mulemwa and me, whether we would join with her in forming a support group.

I was not yet affected – either directly or indirectly – by AIDS, but I had developed

an interest in the disease through listening to broadcasts about it on the BBC, and I had also felt very moved whenever I visited Christopher in hospital. So I did not hesitate when Noerine invited me to join the group – I said 'yes' straight away. I told my wife, Josephine, about my decision to join this new group. She told me that many people with AIDS were coming to the clinic where she worked as a nurse, and she agreed with me that they needed much better care and support.

In April 1987, Dr Elly Katabira started the first AIDS clinic in Uganda at Mulago Hospital, and most of the members of our informal support group were connected with this clinic in some way. The group consisted of Noerine Kaleeba, Dr Elly Katabira, Colin Williams, Rose Ojamuge, Jason Bazebulala, Chanda Williams, Jane Mulemwa, Daniel Etole, Lydia Tamale, Mary Kakeeto, David Lule, Nestor Banyenzaki, Nampologoma, Charles Sentamu and myself. Seven of the members were themselves living with AIDS and were being treated for opportunistic infections at Dr Katabira's clinic.

The group was completely informal, with no name. We came together in solidarity to share information about AIDS and how it was affecting us and our families. We wanted to dramatically reduce the terrible fear, stigma and discrimination that surrounded the disease, which we were seeing daily in the hospital and in the homes of some members of the group. We also took advantage of Dr Katabira's clinic to talk with and comfort those recently diagnosed with AIDS.

The work of our small group soon began to draw attention. Colin Williams, the Country Director of the British development agency ActionAid, arranged for Noerine and Dr Katabira to attend a two-week course in AIDS counselling in the UK. They were also able to visit some of the NGOs and institutions providing HIV and AIDS services in the UK. On their return, Noerine and Dr Katabira shared with the rest of us what they had learned, particularly about counselling.

Noerine kept the group together by holding meetings at her home and in the Department of Physiotherapy at Mulago Hospital. We also visited the sick in their homes and talked to their relatives about how they could offer them better care and support. Soon, the AIDS clinic at Mulago Hospital, which ran once a week on Friday mornings, became the central meeting place for people living with or personally affected by AIDS.

When we started, the group had no name, no organisational structure and no funds. We were just a small group of concerned individuals doing our best to support one another and others in need of help because of the impact of AIDS on our lives. This was our mission, though we did not record it on paper at the time. We had all experienced or observed the rejection and discrimination faced by people living with AIDS and their families. We grew closer, united in the belief that a person with AIDS should receive treatment, care and support, like a person suffering from any other disease. The group stood together against AIDS-related discrimination and stigma, and worked hard to demonstrate to medical staff, the relatives of patients and other community members the kind of compassionate care

Christopher Kaleeba (second, left) is greeted by his wife, Noerine (on left) and relatives on returning to Uganda from the U.K.

Dr Elly Katabira, TASO's first medical adviser, prescribes medication for a mother and her child in 1989.

TASO co-founder members Peter Ssebbanja and Colin Williams.

The room in the former polio clinic building, where TASO had its first office.

and treatment which all patients need and deserve.

On 11 November 1987, we decided to give the group a name – 'The AIDS Support Organisation', or 'TASO' for short. We also started looking for an office where people living with AIDS could receive counselling confidentially. The Medical Superintendent of Mulago Hospital, Dr Edward Kigonya, together with Dr Stella Tibumanywa, who was Deputy Medical Superintendent, responded to our request and allocated a room to TASO in the former polio clinic building, which we used for counselling and as our office.

The 'TASO family spirit'

At first everyone working for TASO did so on a part-time, voluntary basis. We all had jobs elsewhere. As the organisation took shape, however, it became clear that we needed to have a full-time person in the office, in order to meet and talk to the new clients who were coming in for assistance. We chose Jason Bazebulala, one of the founder members, as TASO's first administrator. Noerine Kaleeba was assigned the post of secretary, David Lule became treasurer and I was put in charge of sensitisation workshops and training of new volunteers. Despite these titles and responsibilities, we were all still volunteers, with no formal job descriptions, but we carried out our tasks in a timely manner and in a heart-warming team spirit.

We made decisions quickly, after minimum debate, aware that time was precious. This was especially the case for the people living with AIDS who came to us for help, whom we decided to refer to as our 'clients' rather than 'AIDS patients' – a term we considered stigmatising. In fact, most people were scared of the term 'AIDS', so we felt that using it would lead to people with AIDS suffering even more discrimination. We were all committed to doing our best to assist whoever needed help: one of us could offer counselling; someone else would supply a car to drive the client home; others – sometimes as many as three of us – would escort a client home.

This personal sacrifice and human warmth developed into a culture that would later become better known as the 'TASO family spirit'. We saw the problem of HIV and AIDS as 'our' problem and we regarded one another as 'fellow fighters' in the battle against the epidemic. We all spoke openly about this 'helping culture', and there was always mutual support and a show of solidarity in accomplishing tasks. We regarded our clients as fellow members of the TASO family, and as such they deserved maximum compassion and empathy. We often prayed together, following the biblical saying that a family that prays together stays together. Above all, we were trying to help people living with AIDS to either maintain or to regain their human dignity. Noerine Kaleeba summed it up once:

"We encourage dignity both in life and in death. We encourage living positively and dying with dignity."

'Positive Living'

At first there were clients who were rejected by their families because AIDS-related stigma, based largely on ignorance about the disease, was very high. We welcomed

them into the TASO family, where there was no stigma and no discrimination. While we observed confidentiality with regard to the HIV-positive status of our clients, we strongly rejected stigma against them.

The demand for TASO's counselling and support services increased rapidly. In addition to his Friday morning clinic, Dr Katabira volunteered to run a half-day clinic in the TASO office every Thursday. As the number of our clients increased, we requested – and received – a second room. By then about 30 clients had registered with TASO, and we were starting to realise that TASO might develop into something much larger than we, its founders, had ever imagined. I remember vividly the late David Lule saying to me one day: "Peter, we all have to work very hard because this organisation will help many people". And in the end, that is exactly what has happened.

One of the most important contributions which TASO has made to improving the situation of people living with HIV is the message of 'living positively' (see box opposite). Originally the message was 'Living positively with AIDS'; these days we say 'Living positively with HIV'. This simple message has given hope, purpose and self-respect to many people living with HIV, and to their family members. As this message reached patients and families who, up until then, had been suffering alone and in silence, more and more people started coming to TASO to seek more information and support, and to learn how they too could 'live positively'.

Many people were encouraged by the warm and unique welcome we gave them. At a time when many were shunned by friends and family, they were welcomed to TASO with smiles, handshakes and hugs. Tea and food were provided. Each new member was encouraged to say something about themselves. I remember one early client saying "I feel good when I am with you". Another one said "You are truly a caring family". Some clients did not open up right away, but as they saw the non-judgemental care and support available within the TASO family, they started sharing their experiences, and later they brought friends and relatives who were also living with AIDS.

Home visits

From the beginning, TASO members understood that reaching out and providing home care to people living with HIV and AIDS was essential to fulfilling the group's mission. Home visits by TASO volunteers made a tremendous difference to the lives of individuals and families who could not afford transport costs for frequent hospital visits and admission expenses. It also allowed relatives to stay at home and continue to earn a living to support their patients and families.[1]

Initially we used a car belonging to a TASO volunteer and founder member, David Lule, who was himself HIV-positive, to visit patients in their homes. The TASO volunteers, who were still not being paid for their work, contributed from their meagre resources to buy fuel for the car.

In April 1988, as TASO became busier

[1] In Uganda, as in many other African countries, it is common for hospital patients to be accompanied by relatives, who provide for their physical and material needs.

The tenets of 'Positive Living'

1. Maintain a positive attitude towards yourself and others.
2. Do not blame others.
3. Do not feel guilty or ashamed.
4. Share your diagnosis with a few significant people.
5. Follow medical advice; seek medical care quickly when attacked by infections.
6. Take medicines regularly as prescribed.
7. Eat plenty of food which is rich in proteins, vitamins and carbohydrates.
8. Get enough sleep and do not get overtired.
9. Do not smoke or drink alcohol which further lower the body's resistance to disease.
10. Take enough exercise to keep fit (but not strenuous exercise).
11. Continue to work if possible.
12. Occupy yourself with non-stressful activities such as making crafts.
13. Accept both physical and emotional affection.
14. Socialise with your family and friends.
15. Seek counselling to maintain a positive attitude and talk about your feelings, whether angry, sad, blaming or hopeful.
16. Always use a condom during sex. Even if both partners know they are HIV-positive, using a condom prevents pregnancy and avoids passing on other sexually transmitted diseases, which would further lower immunity to disease.
17. Avoid pregnancy. It may lower the body's immunity and can hasten the onset of AIDS in an HIV positive woman. **(Note: This advice was given before antiretroviral therapy became available. TASO now advises couples where at least one is HIV-positive on how to have children with very low risk of passing HIV on to the child or the uninfected partner.)**

with home visits and volunteers began to feel the pinch of fuelling the car from their own pockets, ActionAid Uganda stepped in and provided a small Suzuki car, and money to pay for running costs. Using the Suzuki within local communities, however, really opened our eyes to the enormous intensity of the stigma attached to AIDS within local the communities.

Initially, many clients were attracted

to TASO because of our sensitivity in handling confidentiality about their HIV-positive status. We fully understood that our clients could not feel free to disclose their HIV status to communities that were not supportive, or were, in some cases, hostile. At the same time, however, we actively and publicly promoted acceptance, care and support for people living with HIV and AIDS, and we felt it was our duty to spread this message in the communities. It became clear to us that two conflicting principles were at work: on the one hand, confidentiality about a person's HIV-positive status, and on the other, the need for much more openness about HIV and AIDS, so that families and communities could offer the required care and support to those infected and affected by HIV.

Matters came to a head over the issue of whether our Suzuki car should be labelled as belonging to TASO or not. Doing so would clearly breach patient confidentiality whenever counsellors went on home visits. Not doing so would mean missing an opportunity to promote greater openness and honesty about HIV and AIDS at community level. We decided to label the vehicle 'TASO COUNSELLING SERVICES', which led to protests from a number of clients, who insisted that we should park the vehicle as far as possible from their homes. Reprieve came in 1989, when we acquired two additional vehicles which we left unmarked; these were used to visit those clients who felt uncomfortable with the labelled car.

Nevertheless, the labelled car that took volunteers on home care visits to the communities informed more people about our services. This meant that an HIV-positive diagnosis was not totally confidential to the person concerned, the clinician and the TASO counsellor. It was, in effect, a statement that a person was living with HIV and might be in need of understanding, help and support from family members and others in the community.

In fact sometimes, when people saw TASO volunteers in the labelled vehicle, they would stop it and tell them that there was someone in the community who was unwell and needed assistance. Sometimes we were stopped and directed to the homes of people who were suspected of living with AIDS but who were hiding in their houses. We interpreted this as an indicator that people recognised the need to provide care and support to members of their community who were living with AIDS. Our volunteers were always ready to approach those suspected to be living with AIDS and to explain the care and support that TASO could provide. Nevertheless, stigma and denial continued to thrive in the communities and within families and individuals.

After increasing community sensitisation activities, our desire to let the public know and get involved in AIDS care and support overtook the fear of stigmatisation. Eventually, all TASO cars were labelled as such. They became, in effect, another means of informing people about the availability of TASO services and of encouraging them to come, or to encourage their loved ones and friends to do so, if they knew or suspected that they were living with HIV.

Eddie:

TASO client

(From: *Living Positively with AIDS. The AIDS Support Organization (TASO), Uganda*, by Janie Hampton, Strategies for Hope no. 2, ActionAid, 1990.)

Eddie is 37, an economics graduate of Makerere University, Kampala. In 1981 he and his wife went to Nairobi for further studies, returning to Uganda in 1985. A year later his wife had a recurrent fever.

"The fevers subsided for a while, but she kept sweating in different parts of her body. She was admitted to Hospital in Kampala with typhoid. Soon after she came out of hospital, still weak, I visited a friend who told me about AIDS. The friend suggested that I should be tested for AIDS. I was found to be HIV-positive.

"I had never heard of AIDS or HIV before and I didn't know what to do. When I went to the doctor for the results, I couldn't believe it. He just said, 'Well there you are, you're positive. You've got AIDS, so there's nothing I can do. Too bad.' I felt like committing suicide.

"I came home after several hours and during supper I told my wife about the test. After that we cried together. Then she was tested and we found out that she had it too. Her relatives wanted to take her to a traditional healer, but we couldn't tell them the truth.

"I was with her all through from the start to the finish. She died a few months ago, at home. I've now lost a lot of weight and my skin is often septic with sores. I am too tired to work. At first I didn't want anyone to know that we had the disease. I even worried about being seen going to the clinic. Then I met two friends there and we talked about it together. Now I don't care who knows. I feel that my experience might help others in showing that hiding is no use.

"The children are my main worry. They are nine, five and three years old now. The young one is always sick, she has a fever and diarrhoea a lot. I'm sure she has AIDS too, but I can't bear to get her tested. We are very close to each other. I know now that I will die before I can bring them up, so what will happen to them then?

"I often wonder who brought the disease into the family. I lie awake at night wondering which one of us is to blame. It might have been either of us I suppose. But now I have joined TASO I am trying not to blame anyone, myself or her. OK, I have the disease, but I am going to use my skills and experience to help other people before the disease gets me."

The need to inform other people, in order to create a support network, led us to adopt the principle of 'shared confidentiality', which we borrowed from the Salvation Army Hospital at Chikankata, Zambia, where Noerine Kaleeba had attended a meeting to share experiences of community-based HIV and AIDS work[2].

The principle of 'shared confidentiality' was meant to help people living with HIV to get the right help by enabling some significant people – especially spouses and other family members – to learn more about HIV and AIDS, and how to care for those who were living with HIV.

As TASO volunteers, we also faced stigma. Many people thought that everyone in TASO was living with AIDS. I used to hear whispers behind me while getting out of the TASO car: "Oh! Look at him; he looks healthy but he must be having the virus". Some people would not even accept a lift in a TASO car. I did not greatly mind their funny comments about me and the other volunteers, because I knew that many people still had inadequate information about AIDS. Nevertheless, I sometimes thought strongly about taking an HIV test myself, just to be sure.

It took me a long time, I must admit, to gather the courage to take the HIV test. There was a fear, naturally, that I could be infected, even though I knew that the risk of being so was low. But the virus had spread out very fast in our communities, and one could not say for sure who was infected and who was not. With the philosophy of positive living, through which we encouraged people living with HIV and AIDS to lead as normal a life as possible, it felt as if anyone and everyone could have HIV. In fact, the volunteers who joined us later did not take HIV tests because it was practically assumed that anyone could have HIV. We also had some fear of finding out the result, even though we were encouraging other people to take the plunge.

It was not until August 1997, therefore, that I finally took the HIV test when, following the death of my first wife, Josephine, on 22 November 1994, I decided to remarry. By then I had enough information about HIV and AIDS, and had found the courage to accept any result. As it turned out, the result was HIV-negative.

Poverty and AIDS

Based on the intensive nature of our interaction with our clients, TASO volunteers were faced with a multitude of issues, many of which we felt almost overwhelmed by. We were worried, for example, by the rapidly growing number of people with AIDS in Uganda, and the poor quality of medical care available to them in our hospitals. Stigma and discrimination continued to be massive problems. AIDS was impoverishing many families. When one or both parents were chronically ill and unable to work regularly, the whole family suffered from lack of income. Parents were unable to pay their children's school fees, so their children dropped out of school. They could not afford the cost of medical treatment, or even basic needs such as food and other basic needs.

[2] See also *From Fear to Hope* and *AIDS Management*, nos. 1 and 3 in the Strategies for Hope series.

At a time when many people with HIV and AIDS were shunned by friends and family, TASO welcomed them with smiles, handshakes and hugs.

TASO's first Suzuki vehicle, donated by ActionAid in 1988.

Sharing a meal has always been part of the TASO family spirit: founder members Jason Bazzebulala, Rose Ojamuge and Nestor Banyenzaki.

Noerine Kaleeba counsels a mother at the first TASO clinic, 1989.

We raised these issues with our donors and visitors to the TASO office, and they responded by providing support for our clients in the form of food, soap, blankets and clothes. Some also provided funds for school fees, uniforms and scholastic materials such as exercise books, pens and pencils. Another way in which we addressed the problem of poor nutrition was by providing a healthy meal to clients and their family members at our day-care centres in Kampala and Masaka. The TASO volunteer staff also participated in this free meal. For a while we provided needy clients with a tray of eggs every month, but this proved to be too costly so we had to discontinue it.

Urgent requests for help

Less than a year after we started TASO, word spread – largely by word-of-mouth – to other hospitals about an AIDS support group based in Mulago Hospital that could help them learn how to respond to the epidemic in a positive and constructive way. In May 1988 we received a request to assist a small group of health and social workers at the government hospital in Masaka, capital of one of districts that had been hit hardest by AIDS.

The group was led by a dynamic young medical practitioner, Dr Sam Kalibala, who a few years later would become the first Chairperson of the TASO Board of Trustees. Their most urgent need was to acquire the necessary counselling skills and to teach medical staff at the hospital how to improve the quality of AIDS care. We responded by sending a small team to train staff at Masaka Hospital, who responded in an extremely positive and creative way. Pre-test and post-test counselling soon became the norm, and a day-care centre was established.

We realised that there was also an urgent need to teach medical personnel in other hospitals about HIV and AIDS. With funding from ActionAid, we conducted three-day AIDS sensitisation workshops for the staff of Mulago and other hospitals around Kampala. About 50 medical staff, of different levels of seniority and specialisation, attended each workshop, which provided accurate information about HIV and AIDS, introduced basic counselling skills and promoted positive attitudes towards people living with HIV. These were not sterile lectures, but highly participatory learning experiences, using role-plays and question-and-answer sessions.

Dr Sam Okware, who at the time was Chairman of the National AIDS Control Programme in the Ministry of Health, attended one of the workshops. His recognition, approval and support for our work, on behalf of the Ministry of Health, was a crucial factor in TASO's development. The medical staff who attended these workshops acknowledged that they were an important eye-opener in their understanding of the AIDS epidemic. Many took the messages to heart and started dealing with AIDS patients with more empathy and compassion. We saw this as evidence that the workshops were successful, and we became even more determined to reach out to other hospitals, not only in Kampala and other urban areas, but in rural areas as well.

At the end of every workshop, we made an appeal for volunteers to join TASO.

However, probably due to the prevailing stigma attached to AIDS, very few people signed up. The few who joined us were mostly nurses who had come across people living with AIDS on the hospital wards. After joining TASO, they attended a one-week orientation course, including an introduction course to counselling.

We also organised one-day sensitisation seminars for community groups that we identified as we visited clients in their homes. The National AIDS Control Committee recognised the importance of what TASO was doing, and invited Noerine Kaleeba to join it as a member. This gave us an opportunity to emphasise the importance of proper care and support for people living with AIDS, despite the absence of a cure, and allowed us to start promoting – within the government health system itself – the TASO message of 'Living Positively with AIDS'.

Because of the growing demand for training, on 1 August 1988 TASO appointed me as its training officer, but I was still an unpaid, part-time volunteer. This was at a time when many health workers were leaving Uganda for better opportunities abroad. I was greatly tempted to join them. My close friend, David Kisuule, had secured me a job in South Africa as a physiotherapy tutor. He was preparing to send air-tickets for me, my wife Josephine, and our two children. Before finally making up my mind, however, I went to Noerine and told her about the opportunity. From her response, I realised that she was disappointed, although she tried not to show it. I went back to Josephine and told her what had happened. After thinking for a short while, she said: "Peter, I don't think we should go. Maybe this new organisation will turn out to be of much help to us and other people." I accepted her advice and went back to Noerine the following day, and told her we were staying. Noerine smiled broadly and thanked me. "I was worried about you leaving at this stage," she said.

Having decided to stay, I happily took on the appointment and worked part-time as TASO's training officer, while still teaching at the School of Physiotherapy. More requests came into TASO from various organisations and hospitals interested in AIDS education and counsellor training. I often travelled around the country carrying out training and community sensitisation about HIV and AIDS. However, I was not yet competent enough to handle all the issues related to counselling. An idea was floated to send me to England to attend a full course in psychosocial counselling, and then come back to train others. Then someone came up with an even better idea, namely, to invite a trainer from outside the country to train counsellors, as well as trainers, and thus build up TASO's institutional capacity.

With support from ActionAid and Save the Children, Jane Lindsay came to Uganda in September 1988, under the Voluntary Service Overseas programme. She worked with me and Dr Jane Mulemwa, an education specialist, on developing a counsellor training curriculum. Noerine Kaleeba and Dr Katabira were constantly consulted for their input, as was Sr Kay Lawler, a social worker at Kitovu Hospital in Masaka district, who had counselled many HIV-positive

patients. Together we developed the first TASO counselling model and curriculum.

Medical personnel in other district hospitals were equally overwhelmed by the number of AIDS patients turning up for treatment. Even those who were sympathetic to the patients tended to avoid them, due to an unfounded fear of contracting the disease through mere physical contact. These medical workers turned to the AIDS Control Programme in the Ministry of Health for help and were advised to draw upon TASO's experience, which the Ministry was aware of by this time. We began to see district hospital medical superintendents approaching TASO for help. The greatest demand was for training in counselling and psychosocial support.

We considered such requests for help vital in promoting TASO's mission, but we lacked the funds to carry out the training. ActionAid Uganda came to our rescue again, and offered to fund all of TASO's training activities. ActionAid also managed to secure funding for TASO for one year from the charity World in Need, mainly to cater for training activities, home visits and client welfare. However, there was still no salary or any kind of incentives for the volunteers.

In June 1989 Dr Sam Kalibala, from TASO Masaka, and I received funding from ActionAid to attend the Montreal International AIDS Conference. After the conference, we spent five weeks in England, visiting AIDS service organisations such as Mildmay International, the Terrence Higgins Trust, Sussex AIDS Care and London Light House, to learn about their work. We also attended a short course on leadership for voluntary organisations, which enabled us to make improvements to TASO's services.

By October 1988, as TASO carried out more and more training, and as requests to support other hospitals kept coming in, it was obvious that TASO needed larger office premises. We therefore acquired a new office, located on Yusuf Lule Road in Kampala, which became known as the 'TASO Development Unit'. The unit was responsible for defining TASO's activities and guiding the growth and development of the organisation. Requests for training and information about what we were doing were also brought to the Development Unit.

Introduction of a day-care centre

In the middle of 1988 we started the first day-care centre at Mulago Hospital. This was intended as a place where clients could come with their care-givers and other family members to relax, receive counselling and share meals. It was also used for the practical training of volunteer counsellors. The late Kate Nalugya and Margaret Nalumansi were the first to run the centre, which was located in a small room in the former polio clinic building.

Our clients were able to share their experiences and encourage one another to live positively. The joint lunch at the centre attracted many clients and their relatives. TASO staff also ate with the clients, which helped to dispel the myth that people could contract HIV through sharing eating utensils. Yoga classes were also conducted at the

Susie:

TASO client

(From: *Living Positively with AIDS. The AIDS Support Organization (TASO), Uganda*, by Janie Hampton, Strategies for Hope no. 2, ActionAid, 1990)

Susie, 24, attends the TASO day-care centre most days but sometimes she feels very weak. She has been coughing for three months and frequently has diarrhoea and vomiting, with headaches.

She took 'O' levels, then left school and got married. By 1986 she had two children. Her third child died a few days after a premature birth. During her fourth pregnancy she was sick a lot. The baby was born at full term but became sick after a week. Susie was also ill and they were both admitted to hospital. Sickle cell disease was diagnosed shortly before the baby died. Susie recovered but was then readmitted to hospital with typhoid.

"When I found I was HIV-positive, I did not know what to do. My neighbour got AIDS and she tried to kill herself and her children. I too felt like taking poison. I looked so ill. I couldn't walk or do anything. Then I heard about TASO and since then everything has changed. I feel much better now. When I am sick they support me and are kind. They give me medicines and some food. The counsellors never neglect you, they support you through everything. My children are my main worry. The school fees are so high. I am hoping that TASO can help with that. My relatives could look after them, but they need help with food and school fees.

"My husband has gone now. I don't know where. When he knew that both my co-wife and I had AIDS, he just went. He must have it too. I still live together with my co-wife and her children. She has two children alive. Three others died.

"Up to now my parents don't know. I will go and tell them myself soon. I don't want them to find out from someone else, but I have to be strong enough to cope for them as well as for myself. They have paid out so much for me, but now they will get nothing back. I cannot help them in their old age.

"The people we share a house with wouldn't let us live there if they knew. They have said in front of us 'if anyone had AIDS, we would throw them out'. So we can't tell them, but they will suspect eventually. I hope that TASO will help them to realise that it is not a threat. We are suffering more from this disease because of people's ignorance. It is bad enough without ignorance as well. But we have to fight the virus, so we can live longer."

centre to build physical strength and assist in physical and mental relaxation.

The day-care centre quickly became a popular place for many clients to share their experiences of coping with AIDS. It allowed them to express themselves and share their stories of what they were going through, or had already suffered. A number of clients started making memorial quilts, sometimes with help from relatives and TASO volunteers, in memory of their departed friends and colleagues. Each quilt bore around 200 names, and three were displayed to the rest of the world at the Montreal International AIDS Conference in June 1989. The relatives who came to the day-care centre saw their attitudes change, as they acquired knowledge about how to support their sick relatives and how to protect themselves from infection. Many others, seeing the non-judgemental reception we gave to our clients, plucked up the courage to be tested for HIV.

Around the same time another charity, German Emergency Doctors, donated a set of sewing machines to TASO. These were greatly appreciated by the clients, who used them to make clothes for their family members and to generate income by sewing bed sheets, which were included in the patient care kits distributed to TASO clients.

The day-care centre served as an oasis – not just for the clients, but often also for the TASO volunteer counsellors, who developed the self-support mechanism of sitting together and sharing experiences about their work. These sessions, which sometimes had to help resolve misunderstandings and conflicts, were commonly referred to as 'Care of Carers' sessions.

Advocacy for AIDS prevention: personal testimonies

By 1988, cases of AIDS were widespread throughout Uganda and increasing rapidly. Although the Government of Uganda was increasingly vocal about the reality of AIDS, the epidemic was still a very private matter, hidden within individuals, homes, villages and communities. While TASO was reaching out to an increasing number of people, the AIDS epidemic was still shrouded in silence, secrecy and denial.

Things began to change in 1989 when a very popular Ugandan musician, Philly Lutaaya, told a public rally at Makerere University that he was living with AIDS. Although this news was received with shock and disbelief, the reality of HIV now began to register within the population. Aware that his own health was declining rapidly, Lutaaya used his musical talents and his personal experience to highlight the reality of AIDS and the need for action to curb its spread and care for those who were living with it.

The musician visited TASO and identified himself with our clients, thus helping more people to learn about TASO and the work we were doing. Philly's message also had an impact on our clients and volunteers, who started sharing their experiences through personal testimonies in public. The late Henry Ntege, Margaret Nalumansi and Kate Nalugya were the first TASO clients to go public about their HIV-positive status.

This gave other clients the inspiration and courage to accept their HIV-positive status and to share this information with other people.

At the beginning of 1989, ActionAid UK commissioned two British writers, Glen Williams and Janie Hampton, to produce an information booklet and video, *Living Positively with AIDS – The AIDS Support Organization (TASO), Uganda*, as part of the Strategies for Hope series. The book and video documented TASO's work and basic approach, and attracted widespread national and international attention. Although we did not realise it at the time, these two materials raised TASO's international profile sharply and helped to launch TASO on the global stage.

Chapter Four

TASO's mission, values and work ethos

By 1989 TASO was facing rapidly rising demands for AIDS counselling services, and we were still learning about the increasingly complex needs of people living with AIDS. At the same time, TASO staff were still part-time, unpaid volunteers. To maximise the impact of our limited human and material resources, we needed to identify our areas of action, and to agree on strategic objectives that could be incorporated into our programme. We therefore held workshops to decide on the way forward. We invited key stakeholders such as the National AIDS Control Programme, Kitovu Hospital Mobile Home Care Programme, Nsambya Hospital Mobile Home Care, the Catholic Medical Bureau and the Protestant Medical Bureau. As a result, we agreed that TASO would have the following broad objectives:

1. To offer counselling to people with HIV and AIDS, and their family members
2. To train counsellors for TASO and other service organisations
3. To provide complementary medical care to people living with HIV and AIDS
4. To change people's attitudes towards those living with HIV and AIDS
5. Where possible, to minimise the social ills associated with HIV and AIDS, and
6. To support community initiatives and efforts in HIV and AIDS programmes.

We also defined and wrote down TASO's mission and values, as follows:

Mission: "*TASO was founded to contribute to the process of restoring hope and improving the quality of life of persons and communities affected by HIV infection and disease*."

We later expanded the mission to mention what TASO wanted to see done at individual, family, community, national and international levels.

Values:

1. Human dignity
2. Obligation to people infected and affected by HIV and AIDS
3. Equal rights, shared responsibilities, equal opportunities
4. Family spirit
5. Integrity.

At the heart of TASO's mission is our focus on people living with HIV and AIDS and their families. We have always believed that people living with HIV, properly informed and supported, would also become effective

advocates of the behaviour changes needed to help prevent the further spread of HIV. This principle has since been widely accepted by community groups, governments and international organisations throughout the world. At the time, however, it was an untested theory, as Noerine Kaleeba recalls:

"What we did almost instinctively, without really having scientific proof, was to focus our efforts on the person who is infected and affected. Even as early as that time, we were very convinced that the infected person is not a problem, but part of the solution."

Some potential donors whom we approached in the early days did not share our belief that prevention had to involve, at its core, people living with HIV and AIDS. Noerine recalls a conversation she had with Paul Cohen, Head of the USAID Health Office in Uganda in the late 1980s, about the need to focus on those already living with HIV and AIDS:

"I asked Paul what HIV prevention meant to him. He answered: 'Well, to ensure that those people who are not infected don't get infected.' So I asked: 'Where will those people who are not infected get the infection from?', and he replied:

'From those who are infected.' So I then said: 'If we could motivate those people who are HIV-infected to recognise that it is in their interest that some people remain uninfected, we would make a huge difference.'

'I have never looked at it from that perspective,' Paul replied.

So I then said: 'If you can give us just a little bit of money, we can demonstrate that when people who are living with HIV and AIDS are cared for, when their dignities are restored, when they no longer fear that they are going to be persecuted, they will play a much more visible role in prevention than those who are not.'"

In the event, USAID did agree to support TASO's work in Uganda, and it continues to do so. We believe that people living with HIV have made a huge – but largely unrecognised – contribution to HIV prevention in Uganda.

Our services soon outgrew the rooms provided at Mulago Hospital, but the hospital administration and the Ministry of Health agreed that we could construct a counselling centre within the hospital premises. Funds were obtained from World in Need, and the new counselling centre opened its door on 1 June 1989. I was assigned responsibility for the counselling centre, as we waited on funds to recruit a full-time administrator.

Meanwhile, the number of AIDS patients on the wards at Mulago Hospital grew daily. The once-a-week day AIDS clinic (known as the 'Immuno Suppression Syndrome Clinic') in the hospital was not enough to meet the needs. Although we had started TASO to complement the government health units, we ended up taking on greater responsibilities than we had anticipated. The Ministry of Health, for its part, was happy to have TASO as an active partner in the struggle against AIDS and its overwhelming impact on the public health facilities.

We therefore started running two follow-up AIDS clinics a week, and the government seconded doctors to come and attend to patients in the TASO clinic. As we were

located conveniently within the hospital grounds, it was easy for doctors to come in and out of our clinic. The doctor-patient relationship in the TASO clinic was seen as exceptionally good. In addition, drugs to treat opportunistic infections were free and TASO volunteers provided counselling to the patients and their families.

In October 1988 the Ministry of Health, which was planning to set up AIDS clinics in government hospitals, asked TASO to embark on a training programme for clinical doctors. At around the same time, the medical superintendent of Mbarara Hospital, Dr Asiimwe, invited us to go and talk to the staff about AIDS counselling. This led to the opening of the TASO Mbarara branch a few months later.

Voluntary Counselling and Testing

As awareness of HIV and AIDS increased, and as AIDS-related stigma and shame gradually decreased, more people wanted to find out their sero-status, and we began to see a lot more demand for HIV testing.

At the time, HIV testing was not available in hospitals. The National Blood Bank in Kampala and the Uganda Virus Research Institute in Entebbe were carrying out HIV tests, but their capacity was limited and results were made available only after two weeks. These two organisations were also under immense pressure to meet the growing demand for HIV testing.

We realised the importance of increasing access to testing facilities. Once people knew their HIV sero-status, if properly counselled and supported, they would be more likely to take appropriate actions to protect themselves and their loved ones. Those who tested HIV-positive could seek treatment, care and support, and could change their behaviour to ensure that they did not infect others. Similarly, those who tested negative could take appropriate actions to ensure that they did not contract HIV, for instance, by abstaining from sexual activity, by being faithful to their partners, or by practicing safer sex using condoms.

It quickly became clear, however, that in order to meet the increasing demand for HIV tests, a dedicated organisation had to be formed with the specific mandate of offering both counselling and testing. So we sat together with several organisations, including the Uganda Red Cross, Nsambya Home Care, the National Blood Bank, the Uganda Virus Research Institute and the Ministry of Health, and in January 1990 we suggested the establishment of the AIDS Information Centre (AIC). USAID offered to fund the organisation, whose first Director was the late Lydia Barugahare. TASO trained its counsellors until they developed their own curriculum.

The AIC introduced the concept of Voluntary Counselling and Testing (VCT) to Uganda. This was a unique concept, in that people who came to have their blood tested for HIV received counselling beforehand to prepare them to accept the results, whether positive or negative. After the test, they received post-test counselling, in which those who tested HIV-positive were referred either to TASO or to another institution with facilities for providing care and support. Those who tested negative, for their part,

were encouraged to adopt safer sexual behaviour in order to protect themselves from HIV infection.

The AIC also formed a post-test club, in which both HIV-negative and HIV-positive people came together to share experiences. This helped to reduce the stigma and discrimination which was still attached to AIDS. The new organisation also worked to encourage more people to take HIV tests, especially spouses and other sexually active adults.

Establishing staff structures

In January 1990, Noerine Kaleeba requested permission from the Ministry of Health to relinquish her role as Principal Tutor of the School of Physiotherapy, in order to devote herself full-time to TASO. She was then appointed Director of TASO by ActionAid, which was providing administrative support to TASO and was legally responsible for the young organisation until 1991, when TASO was registered with the NGO Board. All TASO staff members were still working for the organisation on a part-time, voluntary basis because we could not afford to give up our full-time jobs.

More volunteers had joined us and were making important contributions to our work. However, seven of the original 16 founder members had passed away. There was always a feeling of tragic loss whenever one of our founder members, or a family member, died. It did not discourage us, however, from continuing our fight against HIV. We would meet and talk about the departed, remembering the contribution they had made to the 'struggle'. Then we would emerge with renewed resolve, convinced that, although AIDS could win battles over the lives of individuals, we would win the war in the end. We particularly celebrated the fact that, although AIDS had killed one of us, they had not passed the virus on to others. In effect, 'their' virus had died with them.

Yet we did not lose sight of the massive challenges that lay ahead of us. On the contrary, we continued the process of creating a formal structure for the organisation, including several posts for full-time, paid staff. ActionAid supported TASO in applying to the UK's Overseas Development Agency (later renamed the Department for International Development) and USAID. To our great delight, these applications were successful, which meant that we could start paying salaries to our full-time staff members. At this point I too decided to devote myself full-time to TASO, in charge of the organisation's rapidly expanding training activities. In January 1991 the Ministry of Health agreed to release me, and I became a full-time, salaried TASO staff member.

Although we still had no formal rules or policies yet with regard to hiring staff, we did have a procedure for assessing applicants for jobs with TASO. For example, after the vacancies were advertised, the short-listed candidates would be invited to a three-day sensitisation workshop about HIV and AIDS, where their attitudes and enthusiasm were observed and evaluated. Those who appeared to have negative attitudes towards HIV-positive people were eliminated. Some decided for themselves that they could not

Graduation ceremony for counsellors trained by TASO in 1993.

The TASO Community Initiative Programme received technical support from Becky Bunnel, a consultant from ActionAid.

Dr Sam Kalibala, newly elected Chair of TASO's Board of Trustees, has a word with Honorary Treasurer, Ian Smith, at TASO's first Annual General Meeting in April 1992.

TASO's first music, dance and drama group, at Mulago in Kampala, perform at the TASO Annual General Meeting in 1993.

fit into the TASO family and withdrew their applications. Those who stayed the course were then given an in-depth interview to determine the best candidates for the available jobs.

TASO expands

With increased funding now coming in, TASO's growth and expansion continued. Between 1991 and 1993, new TASO service centres were opened in the district hospitals of Mbale, Entebbe, and Jinja. Each TASO centre was headed by a manager who was responsible for keeping the Director informed about the activities. The Director also visited each of the centres regularly to orient herself with the work there and provide support and advice where necessary.

We also embarked on training more counsellors as trainers so that they, too, could train others, thus enabling the organisation to handle the increasing workload. Some of those we trained early on to train others included Fred Kagimu Bikande, Mary Kakeeto and Lucy Shillingi. It was also around this time that we started collecting books, journals, scientific papers, videos and other educational materials. These grew into a very rich resource centre with useful materials on counselling and the management of HIV and AIDS.

In 1993, the first 112 AIDS counsellors graduated at TASO Mulago Counselling Centre in a historic and colourful ceremony presided over by the Minister of Health. Each had been trained over a six month period, including 20 weeks of practical work. Some of the trained counsellors were employed by TASO, but most belonged to the Ministry of Health and other organisations.

Community Initiative programme

Between 1992 and 1993 we took a step in another direction, when we introduced the 'TASO Community Initiative programme'. This was done to further sensitise, educate, stimulate, involve and support community members in AIDS programmes, so as to create a conducive environment for individuals and families to live positively. It involved linking up with civic leaders to mobilise members of their communities to join in designing and implementing HIV and AIDS programmes locally, and encouraging them to contribute any resources available. Importantly, members of the community had to identify community volunteers who would be trained by TASO to run the programmes.

We received technical support from ActionAid, led by a consultant, Becky Bunnel. The programme kicked off very well in a number of communities in and around Kampala, before it was expanded into rural areas. However, the programme was not without its challenges, for example, getting people to gather in sufficient numbers and encouraging some to work as unpaid volunteers. In an effort to overcome these obstacles, we scheduled the meetings in the evenings, when most people had finished work, and also introduced some incentives for the volunteers to raise their enthusiasm.

Staff support and development

ActionAid-Uganda's Country Director, Colin Williams, continued to support TASO's

administrative development and fundraising efforts, while helping to build staff capacity in organisational management and administration. He shared his management experience, always with the goal of enabling TASO to grow into a mature and independent organisation. He regularly participated in TASO senior staff meetings and, where necessary, guided the team and offered logistical support. He also linked us to various courses such as the one for senior and middle managers at ActionAid's training centre at Kiboswa, near Kisumu, Kenya, which I attended in April 1993.

After David Lule, treasurer and founding TASO member, passed away, ActionAid seconded one of its staff members, Erisa Lukanga, to help TASO with financial management and accountability. When Colin Williams moved from Kampala to Harare in 1993, the new Uganda Country Director, Ian Smith, continued to support TASO.

At TASO headquarters, an executive committee was established, which consisted of the Director and four senior staff members, and the Treasurer of the Board of Trustees. This sat once a month to examine the running of the organisation.

Governance and organisational structure

In 1991 a Board of Trustees was appointed to look after the interests of TASO. It consisted of nine people who were carefully selected by the TASO management for their sympathy and support to TASO. The Board, which was chaired by Colin Williams, drafted a constitution in preparation for TASO's formal registration as a not-for-profit NGO later in the same year. We then embarked on the process of recruiting members to subscribe to the organisation.

In April 1992 TASO held its first Annual General Meeting, and formally elected the Board of Trustees for the first time. The newly formed TASO Mulago Music, Dance and Drama Group (see box opposite) performed songs which their own members had composed. Dr Sam Kalibala, who a few years earlier had invited TASO to train staff at the government hospital in Masaka, was elected as the first Chairperson of the board. Ian Smith, who had succeeded Colin Williams as ActionAid-Uganda's Country Director, was elected Honorary Treasurer. Annual General Meetings became an opportunity for every subscribing TASO member to vote for the board members of their choice. People living with HIV were always encouraged to participate fully, and had their own representatives on the board. Board members, who came from varied backgrounds and different parts of the country, had two-year terms and could be re-elected only once.

In 1991, three major departments were created within TASO: Programme Planning and Development, Administration, and Training. Each department was assigned a leader. I headed the Training Unit, which had by then moved into more spacious premises. In order to upgrade our knowledge and management capacity, I was part of a group of five staff members who attended a six week course in communication and strategy development at Cornell University, USA, and a two-week course in AIDS epidemiology at John Hopkins University, also in the USA.

Music, dance and drama

In 1992 the day-care centre activities at TASO Mulago uncovered a group of clients who were particularly gifted at music, dance and drama. Inspired by the example of Philly Lutaaya several years earlier, they began putting on performances about 'positive living' and HIV prevention through songs, poems, plays and personal testimonies. They began performing in local communities, where they attracted an enthusiastic following from people of all ages.

TASO decided to support the drama group by providing musical instruments, costumes, transport costs and meals. The communities themselves showed their appreciation by providing the drama groups with funds. Invitations started coming in for the group to perform in other places at special events such as World AIDS Day and the annual Candlelight Memorial ceremony. This was highly encouraging for the members of the drama group, who felt that they were valued by local communities, while also helping TASO itself to fulfil its mission.

Soon, every TASO centre throughout the country had its own drama group, which would meet several times a week to practice and perform. In 2003 we moved a stage further, by hiring professional people to train the drama groups. We also began organising annual competitions to judge the best songs, plays, personal testimonies and messages. These steps have helped to raise the quality and impact of the performances of the groups, and have also been popular with group members.

By 1994 TASO had developed a structure, policies and basic systems. Slowly but surely, we had managed to transform ourselves from a support group of volunteers into a fully-fledged AIDS service organisation, capable of raising funds and accounting to our donors on how these were spent. As we found our own feet, financial and technical support from ActionAid steadily diminished, but we still maintained close and cordial relations with the organisation, which had played such a crucial role in helping us become established.

It was also in 1994 that TASO received an unexpected windfall in the form of the prestigious King Baudouin International Development Prize, which Noerine Kaleeba travelled to Brussels, Belgium, to receive on behalf of the organisation. The Selection Committee awarded the prize to TASO "for the example of solidarity it sets and its effectiveness as an instrument of community development, particularly in the field of AIDS prevention and support for AIDS patients and their families in Uganda".

Growing pains

As TASO continued to grow, the need to evaluate service quality and effectiveness became a matter of critical importance.

Periodic workshops were organised for TASO staff and board members to discuss and reflect on the progress we were making and the challenges we still faced as an organisation. As TASO strived for openness and transparency as an organisation, these conversations were always frank and sincere, allowing for a critical examination of TASO's activities. Challenges were addressed, gaps identified, and solutions were sought through collaborative problem-solving exercises. These methods helped TASO to grow into a robust organisation that was not afraid to accept new challenges, but remained self-critical and vigilant against errors, which we were quick to identify and correct.

In 1994 TASO began to experience difficulty in raising more donor funding in order to continue expanding. We were forced to institute stop-gap measures in order to address this problem. For example, we decided to stop providing lunch at the day-care centre and also halted the distribution of eggs to clients. We resolved not to open any new counselling centres, and to develop the training unit into a self-sustaining entity which would be able to offer training to other organisations on a wide range of topics.

We decided therefore to use our reserves to buy a large piece of land at Kanyanya, on the northern outskirts of Kampala, where we built our main training centre. In the midst of these growing pains, however, we were confronted with a sudden and unexpected challenge: the need to find a new leader to replace Noerine Kaleeba.

Chapter Five

Change and leadership in TASO

In February 1995, after more than seven years of dedicated service to TASO, Noerine Kaleeba announced her decision to retire as Director in May of the same year. She accepted a position with UNAIDS, answering a call to use her experience to strengthen community responses against HIV and AIDS worldwide.

We all felt extremely apprehensive at the prospect of seeing Noerine, the mother of TASO, leave the organisation. In fact we could hardly imagine how TASO could continue. Some of us asked her: "Noerine, can you give TASO a few more years before you leave?" She listened quietly but answered: "When a mother sees her child beginning to walk then she has to let him or her walk. TASO is now grown and can continue well with the support of the local and international community, so please let me reach out to other communities elsewhere to give the message of living positively with HIV and AIDS."

I took over as Acting Director of TASO in February 1995, only three months after I lost my dear wife, Josephine Babirye, to breast cancer on 22 November 1994. This was an extremely difficult time for me. I was still deeply worried about my future and that of our five children, the eldest of whom was 11 and the youngest only three. Here now came the responsibility to head TASO, an increasingly complex and fast-growing organisation.

I saw it as a massive challenge to follow in Noerine's footsteps. Her charismatic leadership and brilliant advocacy skills had brought TASO worldwide recognition. I remembered the speeches she had given at the World Health Assembly in Geneva in 1993 and at the International AIDS Conference in Yokohama in 1994, where she emerged as a gallant and visionary leader in the global fight against the AIDS epidemic. I doubted whether I could reach her lofty levels. Nevertheless, I was not alone; the entire TASO family gave me support and encouragement and held my hand, literally, while I led the organisation during the period of several of months when Noerine's successor was being recruited.

Soon after I became Acting Director, TASO's funding situation became critical due to the delay in remitting promised funds by a new donor. This was an extremely stressful time for me and all staff members. Budget cuts were made and some employees laid-off to reduce the wage bill. The job insecurity increased tensions and stress within the organisation, testing the 'family spirit' to the limit, while we scaled down our activities to within the constraints of

Noerine Kaleeba:

charisma and passion for service

Noerine Kaleeba's charisma and passion for service to the needy were the hallmarks of her leadership style as Director of TASO from 1990 until 1995. Much of the innovative work which TASO carried out – especially in the field of HIV counselling – during Noerine's term of office is now well known and respected internationally. Yet most of her ideas were original, and had not been tried anywhere else in Uganda or in sub-Saharan Africa.

She earned widespread respect among international organisations such as UNAIDS, for whom she worked from 1995 until 2006. She has been a strong and compelling advocate of the rights and dignity of people living with HIV, but she has also stressed the importance of respect and support for the families of those who are living with the virus.

Noerine's views have been accepted and emulated by many other people involved in community-based HIV programmes, especially in Sub-Saharan Africa. In 1992 she was appointed a member of the Uganda AIDS Commission to represent NGOs. She has also been honoured by a series of awards, including the 'It Works' award from NORAD in 1990, the World Health Organisation's Dr C.A.A. Quenum Prize for Public Health in Africa in 1991, and Honorary Doctorates from Nkumba University in 2000 and Dundee University in 2005.

the funds available. However, we remained optimistic about receiving the promised funds, and encouraged the remaining staff members to continue working hard, as this was the surest way of attracting more funding for the organisation.

In September 1995, the TASO Board of Trustees appointed Sophia Mukasa Monico as the new Director of TASO. A qualified and practising lawyer, who had been widowed while living in Italy, Sophia also faced the steep challenge of having

to follow in Noerine's footsteps in leading the organisation into an uncertain future. She, however, was totally undaunted by the challenge: in fact she seemed to relish it. I recall how she spent her early days observing the organisational practices, staff work ethics and attitudes, and the various norms and traits that made up the TASO culture.

When Sophia joined, we were in the process of offering feedback to the TASO centres on the results of a participatory evaluation of the TASO services which we had carried out in 1994. I took Sophia around our seven service centres, giving her an opportunity to meet the staff and the clients, and to see how the TASO service delivery system worked. Sophia told me she was impressed with what she saw, especially the high commitment to the work by both junior and senior staff members, as well as the systems in place. "My major task," she said, "will be to make progress from the high level to which Noerine had brought TASO."

Meanwhile, TASO was still suffering severe cash flow problems. Relief finally arrived in January 1996, when a large grant from the Danish Development Agency, DANIDA, came through. This made it possible for us to re-hire the majority of staff who had been laid off. The ensuing atmosphere was like a good family reunion. However, we now became even more conscious of our heavy reliance on donor funding in order to sustain TASO services.

We decided therefore to make the training unit self-sustaining by running courses for other organisations on a cost-recovery basis. We introduced a counsellor's course and a community trainer course, and moved the training centre to Kanyanya, on the outskirts of Kampala city. Moreover, in order to cut costs, we decided to move TASO's main administrative offices to Kanyanya.

We also embarked on a process of decentralising some of our administrative functions from the headquarters to the service centres. There was a proposal to let the service centres become autonomous and do their own fund-raising. This was rejected by the centres themselves, who argued that they did not have the capacity or the fundraising skills to compete for and attract funding. We decided that donor fund-raising would continue to be done centrally by the headquarters, while the centres would be encouraged to fund-raise locally to complement the central efforts.

Basket funding

In 1996 TASO negotiated successfully with most of its donors to introduce a system of 'basket funding'. Previously, donors gave money for specific programmes and activities of their choice, which left some other activities with little or no funding. Under the 'basket funding' system, however, all money from the donors involved would be pooled in a 'basket' and then allocated to priority activities, according to one strategic plan. This would make planning, accountability and reporting easier, while also making programme funding more predictable.

As a result, our funding grid improved greatly, enabling us to consolidate the services we provided to our clients. USAID

remained outside the 'basket funding' mechanism, but its contributions to TASO were still substantial and very important. Funds from USAID's LIFE programme, for example, enabled us to scale-up our support for orphans and vulnerable children, many of whom received school fees through the programme. In addition, the USAID-funded ACDI/VOCA programme provided TASO clients with nutritional supplements in the form of corn soya blend, beans and fortified cooking oil.

Bringing it all back home

TASO was by now growing rapidly as an organisation, and we also began to see increasing openness about HIV and AIDS amongst individuals, families and communities. But at the level of individual families, HIV was still causing great pain and suffering. In 1997, one of my brothers told me he was HIV-positive. He was my first biological family member to reveal his HIV-positive status, not only to me but also to other relatives. I was very sad, but I also felt that I had the knowledge and skills to help him live positively, since I had been trained as a counsellor. I also realised that, having seen HIV come into my own family, the virus had well and truly settled into our community.

With my encouragement, my brother registered as a client with TASO Jinja branch. Whenever we met, we would spend time together talking, and I would provide him with some financial support. He told me he felt very good when he was warmly received at the TASO clinic, although, as my brother, I imagine he received a little extra warmth. He became firm and regained energy and health, and was able to continue looking after his family until he passed away on 30 April 1998. His wife died two years later, leaving their four orphaned children, aged between three and 10, in my care.

Pressure on the 'family spirit'

Due to the increasing number of new clients registering at the seven TASO centres, staff members found themselves spending less time interacting with individuals. The time for casual interaction amongst staff members also decreased, putting strains on interpersonal relations and the family spirit within the organisation. We therefore began to look for ways of coping with the increasing workload. We paid greater attention to time management and record keeping, and we even introduced stress-management retreats for the staff of all centres. In addition, in 2000 a volunteer from Voluntary Service Overseas, Pete Sketchley, spent a year with us, addressing stress management issues and training TASO staff in how to deal with these.

We were still very concerned, however, about preventing staff 'burnout', as there were a few signs of staff getting tired. We therefore organised retreats and stress management workshops where TASO counsellors and other staff could discuss the challenges of their work in a relaxing physical environment, such as a national park, where they could go on nature walks. This helped to rejuvenate our morale and to revive our enthusiasm to continue working.

As TASO became more professionally run, it was important to maintain the family spirit within the context of an organisation

Noerine Kaleeba, TASO's founding Director, serves a cake to clients at her farewell party in September 1995.

Peter Ssebbanja and his children in 1994. He became Acting Director of TASO in February 1995, only three months after his first wife died.

Sophia Mukasa Monico (TASO Executive Director from 1995-2001) receives a consignment of medicines from the World Health Organization.

TASO staff on a nature walk: excursions and retreats have helped staff to cope with stressful jobs and avoid burn-out.

which, by this time, was quite large and results-oriented. A few staff members misinterpreted and sometimes misused the family spirit as cover for underperformance of their duties, assuming they would not face any form of punishment. This was contrary to the expectations of their supervisors, who insisted on the importance of achieving good performance results.

Our Director at the time, Sophia Mukasa Monico, always stressed the uniqueness and importance of the TASO family spirit. It kept staff members happy and united, and helped them to show more compassion to clients and their relatives. It also narrowed the gap between staff and clients, and encouraged clients to participate fully in the planning and implementation of TASO's activities. However, Sophia also firmly believed in professional conduct, high quality performance and good discipline in the organisation.

The staff Code of Conduct was revised, strengthened and strictly observed. A disciplinary committee comprised of senior staff and some members of the Governance Board was set up to oversee staff conduct and ensure that the family spirit was not misinterpreted or misused. It was now emphasised to everyone that displaying a high commitment to work and achieving set targets was actually part of the family spirit, not in contradiction to it.

Decentralisation of management

In 1998, TASO felt ready to start decentralising its services to the six service centres outside Kampala, so we hired a consultant to plan and guide the process. We opted for a gradual process, in which we periodically increased the autonomy of each centre, including their ability to take some decisions after minimal consultation with the head office. The aim was to improve the performance, efficiency and cost-effectiveness of each centre, allowing the head office to concentrate on policy formulation, guidance, standards and quality control, as well as setting regulations, monitoring activities and fund-raising. We also expected that decentralisation would encourage further public sensitisation and enhance the roles played by local government officials and community leaders.

This meant improving our systems, including our decision-making processes, resource allocation and channels of communication. One of the major strengths identified by the consultant was the link between the centre managers, the community and the district leadership, via the Centre Advisory Committees. These nine-person committees are elected by members of the community within which the centre operates. They are elected during the centre's Annual General Meeting and advise the centre management and the head office. They also play a crucial role in mobilising community awareness of, and support for, TASO.

We also enjoyed close collaboration with other NGOs and community-based organisations in the districts, but we felt the need to strengthen such links and establish new connections with influential members of the private and local government sectors.

The need to improve the job-related skills of personnel at all levels also became a top

priority. The staff training policy was revised and a new position, Human Resources Manager – based at the head office – was created. Each centre manager drew up a personnel development plan, in which they outlined proposals to increase the skills of their staff.

The centre managers and senior staff members at head office all went through in-service training in order to improve their knowledge and skills in areas such as personnel, advocacy, and financial and project management. In October 1998, together with one other TASO colleague, I left for a three-month Project Planning and Management course at Arhus Technical College, Denmark. Unfortunately, this was only two months after I had re-married, to Grace Namwanje, so the separation from my new wife and my family was very difficult for us all. However, the course was very important for me and for TASO, so we accepted the personal hardship involved.

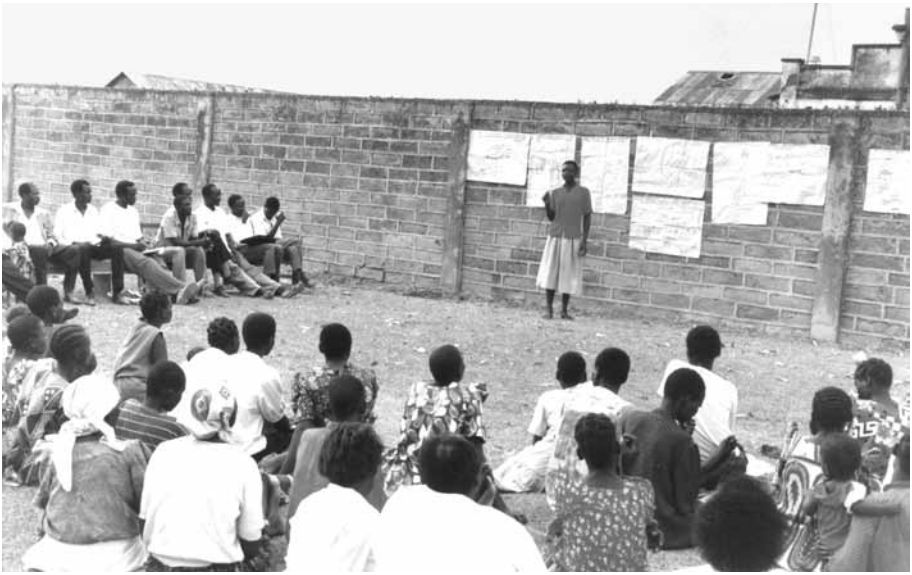
In preparation for the devolution of some powers from TASO head office to the centres, which provided services to our clients, we conducted a series of in-house workshops for all centre managers, heads-of-departments and members of the Centre Advisory Committees. These workshops were to re-define the roles and responsibilities of service centres in relation to the head office. The monitoring and evaluation system was reviewed and improved to ensure the sustainability of quality TASO service delivery in all the centres.

TASO head office remained responsible for ensuring that the mission and objectives of the organisation remained in focus, that targets and technical standards were set, and that all centres adhered to TASO's policies and regulations. Senior staff from the head office periodically carried out management audits at the centres. At the same time, the capacity of the Centre Advisory Committees was strengthened through intensive workshops.

The decentralisation process also included a move to turn the Training Unit into an autonomous entity. However, this did not move at the expected pace due to a number of challenges, particularly the lack of staff and resources to realign and decentralise the administration of the Training Unit. We needed to get more trainers trained and to equip the Training Centre, but the funds required were not readily available. Meanwhile the requests for training continued to arrive, and we had to respond to them.

Despite all these changes and challenges, we kept the doors of the seven TASO service centres open to our clients. Expansion into other districts, however, was halted. Instead, we concentrated on strengthening the existing centres and turning them into 'centres of excellence'. This meant that the centres had to be expanded to provide more counselling rooms and office space. New buildings were therefore constructed at TASO Mbale, Tororo, Entebbe and Mbarara.

Meanwhile, the community education programme on HIV prevention and AIDS care continued in the previously mobilised communities. We regarded this work as a way of sustaining the enthusiasm of the public to combat AIDS. However, due to the slowness with which the communities



TASO's community education programmes on HIV prevention and AIDS care continued throughout the many changes in central management and structures.

Dr Alex Countinho (TASO Executive Director, 2001-2007) presents a certificate to a trained peer counsellor.

Dr David Matovu (standing), Chairman of the Board of Trustees between 1999 and 2006, oversaw the smooth changeover from Sophia Mukasa Monico to Dr Alex Coutinho in 2001.

Robert Ochai, having spent most of his working life with TASO, became Executive Director in October 2007.

responded to the programmes, and the limited funds available to us, we decided to limit the number of new communities to be mobilised to one per centre, per year.

More changes at the top

In 2001 TASO experienced another change in its top leadership. In January of that year, Sophia Mukasa Monico announced that she would be leaving the organisation. A few months later she was replaced by Dr Alex G. Coutinho, a graduate of Makerere University who had been working as a medical practitioner in Swaziland. We were all very sad to see Sophia leave TASO. She had ably filled the gap left by Noerine Kaleeba's departure, and had helped us realise that TASO had grown into a mature organisation, with its own robust systems and structures. Sophia left to join the International Council of AIDS Service Organisations in Toronto, Canada. We had already worked with ICASO in AIDS advocacy campaigns and felt that, with Sophia there, our link to that organisation could only get stronger.

Over the previous six years, Sophia had successfully consolidated TASO's programmes, ensured that essential management and programme systems were in place and, crucially, negotiated a multi-year, 'basket funding' commitment from our development partners. Some TASO centres had expanded rapidly and our clientele had more than doubled under her leadership. TASO was thus in good shape to launch a new phase that would enable it to continue to grow, supported by commitments at the national and global levels to fund HIV prevention and AIDS care programmes. The change in the top leadership was ably overseen by the TASO Board of Trustees, led by Dr David Matovu, who chaired the board from 1999 to 2006. There was a smooth and orderly handover period from Sophia Mukasa Monico to Dr Coutinho.

My initial impression of Dr Coutinho when he joined TASO was that, as a medical doctor who had been involved in HIV work for nearly 20 years, he would contribute a lot to the treatment side of TASO's work. I also thought he was very dynamic and entrepreneurial. As it later turned out, he had all these skills and more. In fact, I had actually underestimated his abilities! He brought to the job very important management experience, which he had gained while working in the private sector in Swaziland. The corporate mentality which he had acquired would prove decisive in TASO's expansion over the next several years, as he took calculated but ultimately successful risks. At the same time, he was deeply committed to professionalising the way TASO programmes were planned, implemented and evaluated.

While orienting himself to TASO, Dr Coutinho was supported by the existing strong senior management team. Systems continued to function well and activities ran normally. Having realised how much potential TASO had, Dr Coutinho decided to implement changes to help the organisation perform to its potential. He quickly embarked on streamlining the administration, expanding the workforce and mobilising funds. A consultant was hired to review staff job descriptions and salaries, and to review and streamline lines

of command to ensure rapid decision-making and implementation.

Fund-raising was high on the agenda to ensure that there was sufficient money to run programmes. The decentralisation process continued, but was closely monitored and regularly reviewed, while the process of enhancing staff skills and knowledge continued. I was among the beneficiaries of a scholarship to study a Masters degree in Public Health (Health Promotion Sciences) at the London School of Hygiene and Tropical Medicine, University of London, in 2002-2003. This course highly enriched my performance as Director of Advocacy.

Dr Coutinho decided to leave TASO in October 2007, after six years of highly successful service. He was succeeded by Robert Ochai, who had joined TASO in 1991 as a branch manager. Unlike his three predecessors, Robert had spent most of his working life with TASO. Again, there was a smooth handover from the outgoing director to his successor.

Noerine Kaleeba believes that this smooth transition from one leader to the next has been a major factor in helping TASO to grow, while also maintaining high quality services: "In TASO, at every stage there was a very clear succession plan from one leader to the next. No leader has ever come to TASO planning to stay indefinitely. That's very important. Every leader has brought a slightly different perspective but TASO's mission has never changed over the last 20 years".

The period 2001 – 2007 was an exciting one for TASO, marked by growth, development and innovation. It was a period of new programmes and of increased partnerships, establishing TASO in the forefront of AIDS service organisations worldwide. The vision of the founders in 1987 had grown beyond their wildest dreams, but TASO still continued to focus on restoring hope, defending the dignity of HIV-positive people, and bringing life back again to TASO clients and their families.

Chapter Six

TASO services and other activities

Since its establishment in 1987, TASO has provided a range of services to over 180,000 clients and their children. During the course of 2006, TASO provided services to a total of 80,592 clients. The gender distribution of TASO clients is skewed in favour of women: 65 percent of TASO clients are female and 35 percent male.

Counselling

Right from the beginning, counselling has been TASO's area of 'core competence'. In TASO, counselling is a process aimed at enabling clients to live positively, to cope with stress and to make informed decisions about their lives. The counsellor-client relationship is one of mutual trust and confidentiality. Through counselling, clients are supported in taking responsibility for their lives, rather than looking down upon themselves as 'victims'.

TASO continues to excel in the quality of one-to-one counselling. By the end of 2007 there were 250 counsellors working in our 11 service centres. In addition, the TASO Training Centre at Kanyanya, on the outskirts of Kampala, has trained over 2,000 counsellors now working for government institutions and other organisations throughout the country. This is a considerable achievement for an NGO which began as a small group of untrained volunteers.

Due to the changing nature of the AIDS epidemic and the ever-increasing client load, TASO has adapted its approach to counselling, which now includes group counselling, family-based counselling, couple counselling and child counselling (see box, p. 46). Each of these types of counselling was researched, guidelines were prepared and training curricula developed. A particularly valuable resource has been TASO clients themselves, many of whom have been trained as peer counsellors, particularly for group counselling.

Medical services

TASO medical services are designed to improve the quality of life of clients and nuclear family members, particularly children. They include curative, preventive, palliative and rehabilitative therapies, and are provided free of charge.

TASO provides medical care through its 11 service centres, as well as outreach clinics, hospital wards and home visits. Since many clients live far from TASO's service centres, outreach clinics have become a major delivery point for TASO medical services: about 30 percent of medical sessions are

Types of counselling provided by TASO

Pre-test Counselling

Offered to clients before an HIV test to establish their sero-status, and to those interested in information on HIV infection and disease. It aims to prepare a person to make an informed decision about whether to take an HIV test and to consider the implications of the positive or negative results, and ways of living with either result. This type of counselling also helps a person to consider behavioural change as a means of preventing HIV infection and to realise the dangers of having unprotected sex, which could transmit HIV to others and also expose the person to re-infection.

Post-test Counselling

Offered to a client who has been tested for HIV and is willing to receive and learn about his or her test results. It aims to ensure that the person has understood the meaning of the test results, and provides the emotional support needed to cope with the impact of receiving the results (whether positive or negative).

Prevention Counselling

Provides information to clients to help prevent infection and re-infection of HIV and sexually-transmitted diseases. This type of counselling also helps the client to think about the factors that may predispose him or her to opportunistic infections and what they can do to minimise those risks. It also introduces the concept of "positive prevention".

Child Counselling

This form of counselling is designed especially for children, whose emotional needs are not identical to those of adults, and whose problems need to be approached with particular sensitivity and unique communication approaches.

Couple Counselling

This is where two individuals who have had, or intend to have, sexual relations discuss issues concerning HIV infection and disease. Couple counselling enables the two individuals to share and learn more information about HIV infection and other sexually transmitted infections. They share their feelings, anxieties, concerns and worries about HIV infection and other diseases. Couple counselling gives the couple an opportunity to identify factors that can predispose them to HIV and to devise strategies for prevention. It also helps the couple acquire more information about safer sex methods e.g. condom use and non-penetrative sex. It is critical as an entry point to identify discordant couples.

Family Counselling

This is offered to those living in a committed relationship with a client, those

living in the same household as a client and important members of the client's extended family or community. It aims to reassure family members and encourage their positive involvement in the life of the client.

Bereavement Counselling

Offered to spouses, children and close family members in the event of the death of their relative. It aims to help family members develop a positive perspective on death.

Crisis Counselling

This form of counselling helps clients deal with crises that could be sparked off by any of the following: sudden onset of an illness (e.g. herpes zoster, intractable diarrhoea, skin rash); sudden fear of dying, and loss of a spouse or a child; hospitalisation; seeing others who are apparently doing well suddenly die; sudden loss of employment and accommodation; losing a close friend or relative who had promised to provide long-term support for one's family.

On-going supportive counselling

This type of counselling is given to the client, as and when required, for the rest of his or her life. Quite often a client may have issues or problems which require support from a counsellor, for example, stigma or discrimination, economic hardships, property rights or drug problems.

conducted through such clinics. TASO also continues to operate a home-based care programme implemented by community-based health workers.

Two-thirds of TASO clients receive Co-trimoxazole prophylaxis, which has been demonstrated to improve quality of life by reducing the incidence of opportunistic infections. In addition, a total of 18,000 TASO clients have received antiretroviral therapy as part of a 'basic care kit' (see chapter 7).

In 2004, TASO started a Home Based Voluntary Counselling and Testing service, focusing initially on the family members of clients enrolled in the TASO ART programme. In 2006, a total of 25,972 people in 5,376 households were counselled and tested for HIV in their own homes. The overall HIV prevalence rate was 6.4 percent, which is almost identical to the national average.

TASO also provides TB and STI services. In 2006, 92 percent of clients seen at TASO clinics were screened for TB; 4 percent were diagnosed as having TB and received treatment, either from TASO or from other health service providers. Of the 40,003 TASO clients who were sexually active, 97 percent were screened for STIs at least once in 2006; 12 percent were diagnosed as having an STI, of whom 96 percent were treated in TASO clinics and the remainder referred.

Social support

TASO's social support programme aims to mitigate the impact of HIV on TASO clients,

their families and communities. It consists of three main components:

Educational support:
During 2006, 1,710 orphans and children of TASO clients were assisted to attend primary, secondary and tertiary education. TASO support took the form of scholastic materials (exercise books, pens, pencils, mathematical sets, rulers, uniforms, sweaters, school bags and graph books) and fees for attending secondary schools and tertiary institutions. TASO staff members themselves raised funds to cover the cost of supporting 360 school children. In addition, in collaboration with the US-based NGO, Trickle-Up, TASO supported 200 young people with training in business management and start-up capital.

Nutritional assistance:
Many TASO clients are extremely poor and unable to provide sufficient food for themselves and their families. In 2006, with support from four international donor organisations[3], a total of 12,850 TASO clients and over 50,000 of their family members received nutritional support in the form of corn-soya blend, fortified cooking oil, beans and maize flour.

Sustainable livelihoods programme:
This small programme aims to enable TASO clients to become economically self-sufficient. In 2006, 286 individuals were trained in income generating skills and 61 received loans. In three TASO service centres, the Heifer Project provided funds for TASO clients to carry out livestock farming with goats, cows, pigs or oxen.

[3] Agricultural Cooperative Development International/Volunteers Overseas Cooperative Assistance, World Food Programme, Plan International and World Vision.

HIV and AIDS education

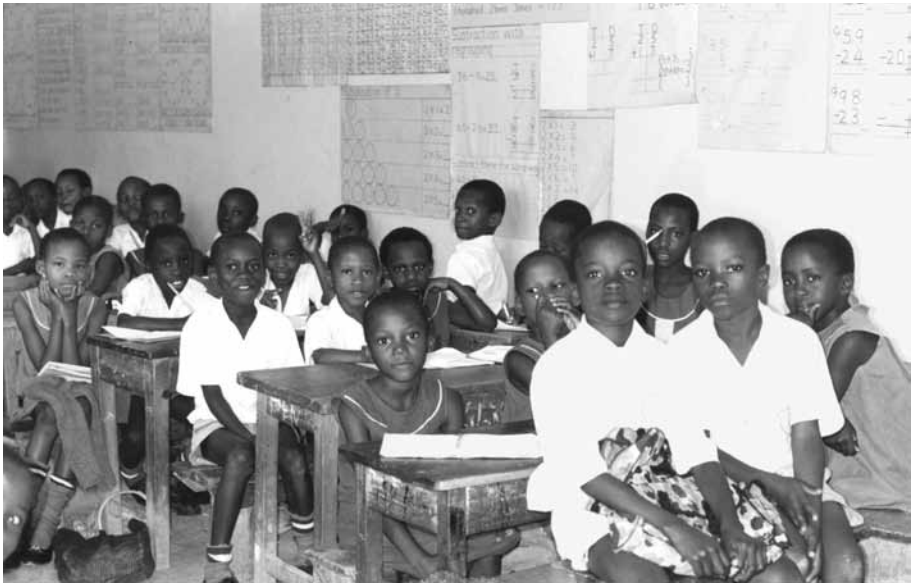
TASO's HIV and AIDS educational activities are designed to disseminate messages about HIV prevention, stigma reduction and living positively with HIV. The main vehicle for this programme is the network of drama groups working out of TASO's 11 service centres. In 2006, these groups staged 957 performances, attended by almost 300,000 people. In addition, TASO used local FM radio stations (516 radio programmes were broadcast in 2006), in local languages, to reach hundreds of thousands of listeners in rural areas.

Community programme

TASO continues to support organised community responses to the challenges of HIV, with the emphasis on providing accurate information about HIV prevention, care and support. TASO support takes the form of training, refresher courses, support visits and provision of facilitation grants. In the course of 2006, TASO supported 76 communities, who in turn reached half a million people through educational activities and distributed nearly 250,000 condoms.

Each of TASO's 11 service centres also has a Centre Advisory Committee (CAC), which is elected at the centre's Annual General Meeting. CACs are responsible for motivating community members to undertake HIV-related activities and for

Presentation of certificates to trained counsellors (from right to left: Peter Ssebbanja, Juliana Nyombi, Miriam Katende).



TASO helps orphans and children of clients to attend school by providing scholastic materials, school uniforms and (for secondary school) paying school fees.

Food distribution to TASO Clients in Kampala.

TASO Tororo Drama, Dance and Music Group perform to a village audience.

Annet:
counsellor

My name is Annet Soobi and I am a counsellor at the TASO Mulago centre. I joined TASO in 2003 as a volunteer before becoming a member of the staff in July 2004. Before joining TASO I was a teacher. I met a friend who worked in TASO and while speaking about the challenges of managing children, she encouraged me to do a counselling course, which I did at the TASO training centre in Kanyanya.

The first thing I saw when I joined TASO was the family spirit. I imagined that maybe people feared those who were living with HIV, but I found people hugging one another, and I was surprised to see clients and staff members using the same facilities. You couldn't tell who the managers were because everyone acted the same.

In my first days in TASO, I would have sleepless nights when I returned home. I used to think about what the clients had told me during the day, and sometimes I would imagine what I would do if the same thing happened to me. For instance, I am married and sometimes clients would come with marital problems, and you begin to wonder whether they are talking about your own situation.

I try not to feel emotional but empathetic, so that I can help my clients cope with their problems. Clients who come to us really need love and when we make them feel like part of a family, they feel welcome. They need someone to speak to, to open up to in a secure environment so they can share their problems. For instance, if a client comes to us with a large family to look after and no partner to support them, there is need for social support, such as food. Most of our clients are very needy.

TASO's biggest contribution to fighting HIV and AIDS has been care and support. We give our clients psychological help through counselling. They also get social support in the form of food. We also have child clients, and TASO makes a contribution to their school fees. We give priority to orphans who have lost both parents.

We also reach out to the community, especially through the drama groups. We reach out to schools, organisations and individuals and give them information about how to live positively if they are already infected and, if they are not infected, how to stay safe and give care and support to those living with HIV and AIDS.

mobilising local resources. They also oversee TASO's activities in the district and advise TASO management on how to ensure that appropriate and quality services are provided by the centres.

Children and adolescents

In 2001 TASO Entebbe started a pilot Child Care and Counselling Centre, which demonstrated that there was a huge need for a place of quiet and safety for child clients of TASO. In the same year, we received a large grant from USAID, through the LIFE Programme, which enabled us to provide formal educational support to 1,500 children each year, and apprenticeship skills training for older adolescents so they could earn a living and support themselves. Through this programme, TASO was able to train nearly 1,000 adolescents and provide them with start-up tool kits. Unfortunately, due to lack of business skills and start-up capital, many apprentices could not sustain their businesses. Currently, through assistance from Trickle-Up, we are providing follow-up support to many of these initially unsuccessful trainees.

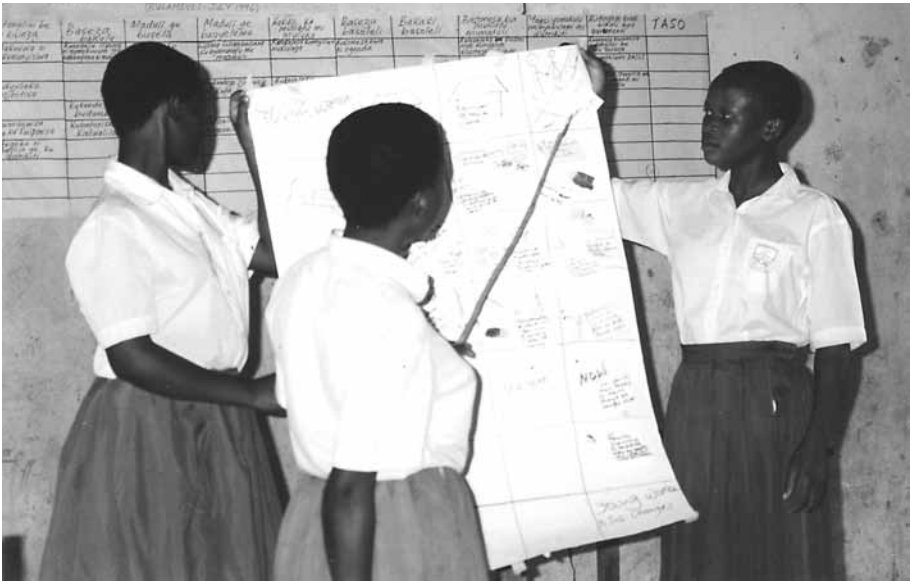
TASO took this experience as a lesson, and decided to leave vocational training to organisations with greater experience and expertise in this area. Instead, we supported HIV prevention programmes focussing on youth, in particular, through the AIDS Challenge Youth Clubs (ACYCs) which were being established in schools. These clubs provide young people with information about how they can prevent HIV infection, and encourage them to resist peer pressure that could entice them into risky sexual behaviour. A total of 55 ACYC clubs are active in schools. Some activities are carried out in partnership with other organisations. For example, in 2006 TASO Tororo conducted ACYC activities in collaboration with the Uganda Family Planning Association.

TASO has also focused on the treatment and care of children living with HIV. In partnership with the Paediatric Infectious Disease Centre at Mulago Hospital, TASO established a model child treatment and training facility at Kanyanya, on the outskirts of Kampala. This centre provides medical care and psychosocial support for HIV-positive children, along with practical training for counsellors and medical staff in child counselling and treatment.

Policy making, advocacy and networking

As one of the leading HIV organisations in Uganda, TASO is often invited to participate in meetings on policy issues at national and international levels. As long ago as 1988, for example, the Director of TASO was appointed a member of the National AIDS Control Committee, which gave us a chance to participate in formulating guidelines and policies on how to handle HIV and AIDS in Uganda. When the Uganda AIDS Commission was formed in 1990, TASO was chosen to represent the views of non-government organisations fighting HIV and AIDS. We also contributed to the formulation of the first National Strategic Framework, which aimed to reduce HIV prevalence by 25 percent every five years, mitigate the health and socio-economic impact of the epidemic,

Community Programme members receive bicycles (Noerine Kaleeba on the right).



A TASO-supported workshop for school children, Kampala.

Children's clinic at Katabira Centre, Kanyanya, Kampala.

Reflexology session at a TASO service centre: all TASO centres provide reflexology and aromatherapy, which are administered by specially trained TASO clients.

and strengthen national capacity to respond to the epidemic. More recently, at the UN Special Session on HIV and AIDS in New York in 2001, TASO was one of the NGOs asked to represent the views of civil society organisations from throughout the world. TASO was also one of three global NGOs that participated in the process of establishing the Global Fund in late 2001.

At a national level, TASO continues to play a leading role in annual events such as World AIDS Day, the Candlelight Memorial ceremony, the International Vaccine Awareness Day and the Philly Lutaaya Day.

Over the years, TASO has helped in the creation of several other HIV prevention, advocacy, care and support organisations. These include, for example, the AIDS Information Centre, the National Community of Women Living with AIDS (NACWOLA), Traditional Healers and Modern Practitioners Together Against AIDS (THETA), the Uganda Network of AIDS Service Organisations (UNASO), the Africa Regional Section of the International Council of AIDS Service Organisations (AFRICASO), Positive Men's Union (POMU) and the Regional AIDS Training Network (RATN) in Nairobi, Kenya.

People living with HIV and AIDS

The involvement of people living with HIV and AIDS (PHAs) is recognised internationally as a key component of HIV care, support and prevention. In fact this strategy was pioneered by TASO: seven of our 16 co-founder members were themselves HIV-positive. TASO continues to be a forthright advocate of the rights of people living with HIV, and provides them with facilities and capacity-building support. Each TASO centre has a day-care centre, organised by and for people living with HIV. In addition, TASO continues to assist groups such as the Maama's Club in Kampala, which brings together HIV-positive mothers and their children so they can encourage and support one another, share their experiences and help one another to deal with problems such as economic hardship, and getting food and clothing for their babies.

TASO also assists the Positive Men's Union (POMU), which brings together HIV-positive men to share experiences, encourage one another to overcome stigma, support one another in addressing common problems, and also encourage other HIV-positive men to seek appropriate care and support.

Within TASO, HIV-positive clients continue to contribute to the organisation as staff members, volunteers and as members of the governance bodies, including the Board of Trustees. They make important inputs into programme planning and implementation, using their personal experiences to promote what is most appropriate and beneficial to the users of TASO's services. Dr Lydia Mungerera, who herself is HIV-positive, is TASO's HIV Advocacy Training Officer and carries out training in advocacy issues and approaches for TASO staff, clients and volunteers. Dr Mungerera has also represented TASO at many national and global meetings, including the Board of the Global Fund for AIDS, Tuberculosis and Malaria.

The involvement of people living with HIV in TASO has been a very effective way

of fighting the stigma which still surrounds HIV, and the discrimination which still affects many people living with the virus. The TASO clients' drama groups, for example, have become semi-professional, to the point of being able to raise money by performing at weddings and other social events. Only 10 years ago, people living with HIV would either not have been invited to such events, or would have been cold-shouldered by relatives and friends if they had attended.

The TASO clients' drama groups offer a double-pronged message. On the one hand, they fight HIV-related stigma and enable more people to reach out and care for people living with HIV. At the same time, their music, songs, dances and drama performances carry educative messages on HIV prevention, care and support. The song, *United Against AIDS*, for example, composed by Tony Kisule from TASO Mulago, has become widely known and popular outside TASO.

Twenty years ago, when TASO was still a small group of volunteers meeting to pray together and to support one another in facing the daunting challenges of the HIV epidemic, we did not imagine that our efforts would lead to such a wide range of activities, on such a large scale. Nor could we have predicted that, due to new medical approaches that were in the pipeline during the 1990s, future TASO clients would no longer face the almost certain prospect of premature death.

Chapter Seven

New medical approaches

When we started TASO in 1987, the people who came to us living with AIDS knew, as we did, that they were likely to die in the near future. We encouraged them to live positively, and we provided them with treatment for opportunistic infections. Yet the lack of an effective treatment for HIV infection meant that their death was almost always inevitable, either within a few weeks, a few months or, in some lucky cases, a few years.

This left us to look around for alternative remedies like the traditional herbs that would bring relief of some symptoms. Many people in Uganda, as in many other parts of Africa, relied on traditional healers to treat any ailments they had, resorting to 'modern' health facilities only when traditional medicine failed. With modern science offering no cure for the new disease, we began to see more and more Ugandans resorting to traditional healers, including some who claimed to possess cures for AIDS.

I remember a lady called Nanyonga, who, some time in early 1988, claimed she had received a vision from God that eating soil from a spot within her compound could cure AIDS. Thousands of desperate Ugandans flocked to her home in vain. Some of our clients urged us to try out this and other remedies. In fact we received samples of some of these remedies but soon realised that they did not cure AIDS.

The Ministry of Health also emphasised that these and other claimed cures of AIDS were hoaxes. However, that did not stop more people from flocking to traditional healers in an elusive and desperate search for a cure for AIDS. Other supposed cures came from Nairobi in Kenya and from Kinshasa in the Democratic Republic of Congo. In 2001, a clinic in Kampala claimed it had a herbal cure for AIDS, which also turned out to be fake.

Antiretroviral therapy

In the mid-1990s, the prognosis for people living with HIV began to change. Information became available about antiretroviral drugs (ARVs) which suppress the virus, allowing the body's immune system to fight off opportunistic infections, and enabling HIV-positive people to live longer, healthier, more productive lives. For several years, however, the cost of antiretroviral therapy (ART) was prohibitive, so neither TASO nor our clients could afford it. In addition, health professionals in Uganda lacked training in how to administer ARVs and how to deal with their side-effects. Moreover, our health services did not have a system to ensure the sustainable delivery of these drugs.

At the turn of the millennium, there were

increasingly insistent calls to increase access to ART, particularly among poor people in the developing world. However, this did not translate into widespread access overnight. Before 2004, a few of our clients had started accessing ART as participants in research projects, or, as the prices started falling, by purchasing ARVs from providers such as the Joint Clinical Research Centre in Kampala.

In 2001 the rock star, Bono, visited TASO and made a commitment to provide 25 members of TASO Mulago's drama group with ARVs for three years. In addition, through a research project between TASO Tororo and the Centers for Disease Control, 1,000 TASO clients were selected to start ART on a home-based delivery model. The success of this project provided a template which TASO would later use for the scale-up of ART in other parts of the country.

It was wonderfully uplifting to see our clients regain their health after starting the ART regime. We realised, however, that we could not rely indefinitely on the generosity of other providers to keep supplying our clients with ARVs. Sooner or later, we would have to have our own, fully scaled-up ART programme.

Hence, in 2004, with funding from PEPFAR and technical support from the Centers for Disease Control, TASO started its own ART programme, which aimed to provide ART to all TASO clients in need of this treatment. Starting the programme, however, was the easy part. We also had to convince all stakeholders – especially the government – that TASO was capable of delivering ART on a large scale. Fortunately, we were able to achieve that, although not without difficulty.

Over the next three years, we recruited and deployed 500 new staff, revamped medical and counselling guidelines to take account of ART, and procured large volumes of HIV test kits, supplies of ARVs, four-wheel vehicles, motorcycles and computers. We also trained over 1,000 staff and volunteers to carry out their functions in the roll-out of ART through our 11 service centres.

The results were remarkable. By the end of 2007, a total of 18,000 TASO clients had received ART from TASO and another 8,000 from other providers. The impact of ART on the lives of our clients was dramatic and heart-warming (see boxes: Christopher, opposite, and Prossy, p. 63). Moreover, the ART adherence rate has been consistently above 95 percent, which compares favourably with that in any other country in the world.

Consequences of ART

ART has completely transformed the prospects of our clients to live longer, healthier lives. In the absence of ART, these people would probably be either dead or very ill, and there would be as many as 80,000 more orphans and other vulnerable children in need of care and support.

On its own, however, ART has not resolved old problems, such as poverty, lack of employment and insufficient food. It has also brought new challenges, particularly the desire to be loved, to start or resume sexual activities and to have children. We have responded to these challenges by incorporating them in the training of our counsellors, to ensure that the better

Christopher:
farmer

Christopher Omoit Machika's wife died in 1998, leaving him with six children. When he remarried. his sister-in-law encouraged him to visit TASO and take an HIV test, which was positive. His new wife, however, tested negative.

Christopher soon fell ill with diarrhoea and his CD4 cell count dropped to 16. "I was tending towards the grave," he says. In 2003 the Centers for Disease Control started funding an ART programme through TASO, and Christopher was one of the beneficiaries.

Under TASO's Home Based AIDS Care programme, Christopher has also received insecticide-treated mosquito nets to prevent malaria, a basic water purification kit to prevent diarrhoea and other water-borne diseases, Co-trimoxazole (Septrin) to ward off opportunistic infections, and condoms to protect his wife from contracting HIV. Christopher's health has improved dramatically and his CD4 cell count has risen to 270.

"I have moved from the graveside to normality," he says. "In the last 6 months I have not gone to the clinic and I have not fallen sick.

"The condoms have really benefited us because my wife is negative and I am positive. We have been using condoms consistently and her latest results, carried out last year, show that she is still negative," he adds.

With his health improving, Christopher is able to work and support his family. He grows millet and maize, as well as groundnuts, rice and onions.

After starting ART in 2003, Christopher met with other TASO clients in the area and formed a support group to share experiences and encourage one another to adhere to the treatment, and also adopt safe and responsible sexual behaviour.

"The purpose of forming the group was to educate members so they can abstain, or they can play it safe by zero-grazing with one partner."

The members of the group also support one another financially and materially to ensure food security. The Centers for Disease Control provided the group with a grant through TASO in the form of ox-ploughs, groundnut seeds, pesticides and a spray pump. The group has already harvested and sold its first crop of groundnuts and is now using some of the money earned to run a revolving loan scheme.

health that ARVs make possible does not undermine the personal responsibilities that belong to positive living.

In addition, since people on ART also need good nutrition, we have also boosted our nutritional support programme with assistance from the World Food Programme.

New 'Basic Care Kit'

Between 2001 and 2007 the medical services provided by TASO were greatly enhanced by ongoing research, much of it involving TASO clients and staff, in collaboration with the Centers for Disease Control and the Medical Research Council in Entebbe, Masaka, Jinja and Tororo. The research helped in the processes of revising and improving some policies in health care for people living with HIV, in particular, the development of a 'basic care kit' for all TASO clients, comprised of:

- Antiretroviral drugs for those who require them
- Septrin (Co-trimoxazole) taken to prevent opportunistic infections
- A plastic vessel for storing drinking water hygienically
- Water purification solution
- Condoms
- Two insecticide-impregnated mosquito nets to provide protection against malaria
- Health education materials to ensure that clients and their families understand how to use the elements of the basic care kit.

Overall, the introduction in August 2004 of ART to the medical services available through TASO has greatly improved the lives of our clients and enhanced the professional knowledge and skills of TASO health providers. Thanks to our donor partners, TASO has been able to acquire the health care personnel, drugs and laboratories which are needed to provide these services. However, we continue to refer complicated cases and patients that require admission to the hospitals which host our centres.

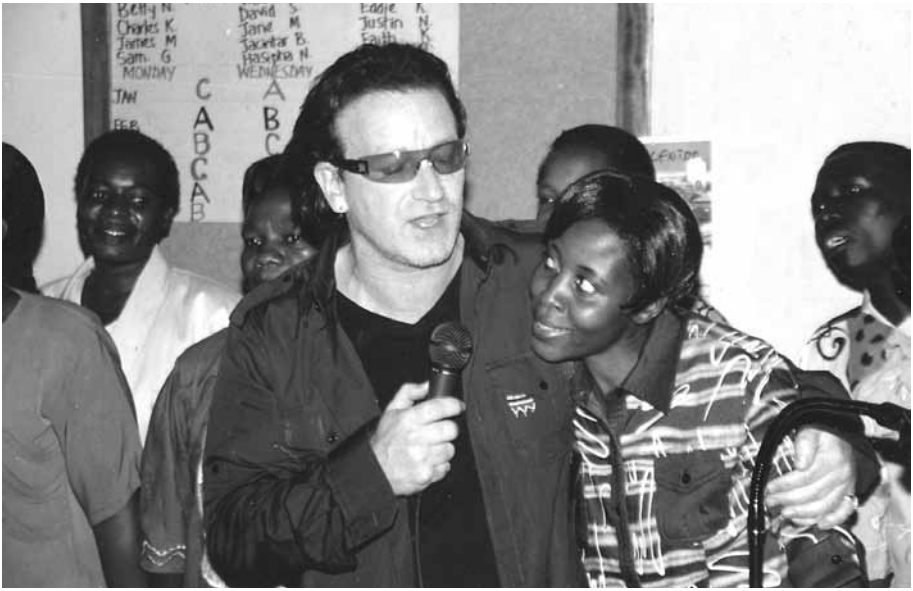
Community involvement

In order to support our clients receiving ART, TASO trained 1,000 HIV-positive clients to become 'Community AIDS Support Agents' (CASA). Each CASA was allocated 10-20 clients in the community whom they regularly visited to encourage adherence to the ART regime, to reinforce HIV prevention messages and to encourage disclosure of one's HIV-positive status within the family.

This was followed by the introduction of home-based HIV testing, through the entry point of existing clients (with their consent). This enables the spouse and the other members of the household to know their own HIV sero-status. Those who test HIV-positive are encouraged to register with TASO and to start receiving care and support, including ART, if their CD4 cell count is very low.

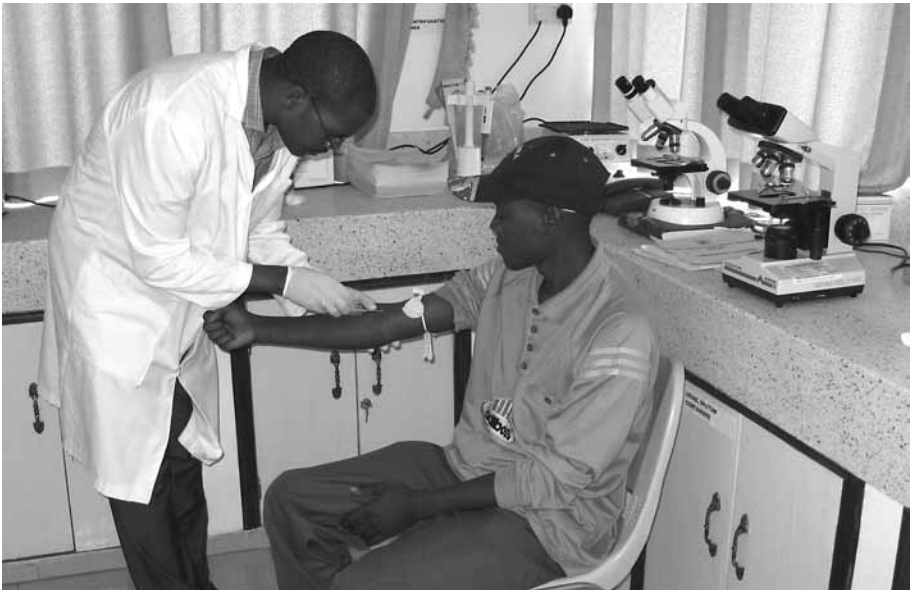
Through this programme, we learned that amongst TASO clients there are many couples – as many as 64 percent according to a recent study[4] – living in discordant

[4] "High discordance rates among ART Clients in The AIDS Support Organisation", by Mohamed Mulongo and Francis Wasagami, presentation to PEPFAR HIV/AIDS Implementers Meeting, Durban, South Africa, June 2006.



Rock-star Bono visits the TASO Mulago Music, Dance and Drama Group in Kampala in 2003.

A TASO doctor explains how to use antiretroviral drugs: 18,000 TASO clients receive ARVs from TASO.



A laboratory technician takes blood for testing at a TASO service centre.

TASO counsellor and client: home visits are part of a counsellor's responsibilities.

Prossy:

TASO client and peer educator

When Prossy Nalubowa, 50, started falling sick in 1997, members of her family and community in Kiboga, about 100 kilometres northwest of Kampala, accused her of contracting AIDS through promiscuity. She was admitted to a local hospital, where herpes zoster was diagnosed.

The health workers at the hospital asked Prossy's relatives to pay to have her transferred to Mulago Hospital in Kampala for better care. The family members refused.

"They said that since I was about to die, they would rather buy a coffin for me than waste money on treating me," Prossy recalls. With the help of a community member, Prossy was transferred to Mulago Hospital, where she was admitted for four months and joined the TASO Mulago day-care centre, where she received counselling and psychosocial support.

The stigma, however, continued. After Prossy's discharge from hospital, her late husband's family threw her out of the room where she was staying, in a suburb of Kampala. Her relatives in the village ransacked her property after she was assumed dead, and her 14-year-old daughter was married off to a 45-year-old man to help pay the bills for Prossy's three other children.

In December 2001, Prossy was one of the 25 members of the TASO drama group who received free antiretroviral drugs, with financial support from the Irish rock star, Bono. Her eldest son, who is also HIV-positive, joined an antiretroviral drug trial run by the Joint Clinical Research Centre in Kampala. He also returned to school, with financial support from TASO, and is now set to enter university.

Prossy's health has improved; her CD4 cell count has risen from 101 to 484 and her weight has increased from 53kg to 80kg. She is now a peer educator and assistant supervisor of the day-care centre at TASO Mulago.

Prossy uses her experience to fight stigma in society. She once travelled with a TASO drama group to her community in Kiboga, astounding those who had declared her dead, and teaching them how they too can live positively with HIV. She also appears on local FM radio stations, and campaigns against stigma and discrimination towards people living with HIV.

"I try to help others the way TASO helped me," she says.

relationships. The HIV-negative partner in these relationships is obviously at high risk of contracting HIV, unless the couples take preventive measures, such as the use of the condom, which we encourage. This realisation led to the development of the Positive Prevention programme (see Chapter 8), which will form a major focus of TASO's HIV prevention work in future years.

Chapter Eight

Scaling-up and sustaining TASO

In 2001, when Dr Alex Coutinho became Executive Director of TASO, there was a strong surge in the demand for TASO services such as counselling. This might have been due to the success of efforts by the Government of Uganda, TASO and many other organisations to reduce HIV-related stigma and discrimination. Whatever the reasons for this increase in the demand for TASO services, we felt we had to respond positively. Obviously, TASO could not be physically present throughout Uganda. At the time we had only seven service centres: in Kampala, Masaka, Tororo, Mbarara, Mbale, Entebbe and Jinja. We therefore had to devise a strategy to scale-up our capacity to respond to the demand for TASO services.

Scale-up strategies

First, we were able to mobilise funds from international donors to start up four new TASO service centres: in Gulu, Soroti, Rukungiri and Masindi. The decision to work in Gulu, in the North of Uganda, was made at a time when insecurity was still rampant in the region and there were many fears about TASO's ability to operate there. According to the Uganda AIDS Commission, the level of HIV infection in the north was higher than that of the rest of the country, yet services were poor due to the insecurity and the difficult living conditions in the camps for 'internally displaced people'. Stigma and discrimination were also rife, as was war trauma. We therefore had to train our counsellors to deal with these psychosocial challenges. Thankfully, the security situation has since improved, and we have been able to provide services to a growing number of clients, most of whom are still living in the camps.

Our second scale-up strategy was that of regionalisation. We established four regional offices, which have the capacity to support TASO services in all 80 districts in Uganda. As part of this strategy, we also selected 15 government and non-government hospitals to become TASO 'franchises' – or 'mini-TASOs' – through the provision of counselling, medical and community services. TASO then supported these hospitals by training their staff in counselling and in the management of HIV and AIDS, as well as other sexually transmitted diseases, and in antiretroviral therapy. TASO also provided the mini-TASOs with grants and other forms of support and supervision.

The concept of mini-TASOs was well-received and has led to more clients registering for TASO's services. In 2006

TASO supported eight mini-TASOs, which counselled a total of 45,569 people and provided medical care to 29,401 people. In 2007, TASO supported another seven mini-TASOs. The mini-TASO concept has become so popular that there have been several requests to turn them into fully fledged TASO centres. Due to lack of funds, this has not yet been possible.

The regionalisation strategy also involved providing support to community-based organisations (CBOs) which showed potential for performing well. TASO trained the staff of these organisations and also provided seed money for purposes such as renovation of their offices and the purchase of office equipment. The TASO-supported CBOs have also been successful and popular. In 2006, TASO supported eight CBOs, which counselled 18,054 people and provided medical services to 7,599 people.

The combined effect of these strategies was a sharp escalation in the number of new clients registering with TASO: from 6,000 in 2001 to over 20,000 in 2006. This surge in TASO clients can be attributed, in large part, to the availability of antiretroviral therapy, free of charge, in our service centres from the year 2003 onwards.

The surge in demand for TASO services also meant that the number of TASO staff had to be dramatically increased and facilities expanded. By the end of 2007, the organisation had over 1,000 staff, compared with 352 in 2001. In addition, all the existing buildings were extensively renovated and 19 new buildings were added. All TASO centres acquired fully functional laboratories and pharmacies, child-care centres, day-care centres, and sufficient counselling and medical rooms.

Scaling-up HIV prevention

TASO has developed a new Five Year Plan for 2008-2012, its most ambitious plan ever. It reflects the collective wisdom of the last 20 years and puts particular emphasis on scaling-up HIV prevention. Dr Coutinho, TASO Executive Director from 2001-2007, is often quoted as saying: "If you find a flooded house due to a tap of water which was left on, you cannot concentrate on wiping up the water on the floor before you turn off the tap. Otherwise you will easily get frustrated."

There is, therefore, an urgent need to scale-up our approaches to preventing new HIV infections, so that we can continue to provide high quality services to those requiring care and support. The TASO National Annual General Meeting in September 2006 paved the way for this new programme emphasis by adding the words 'preventing HIV infection' to the TASO Mission Statement, which now reads:

"TASO exists to contribute to a process of preventing HIV infection, restoring hope and improving the quality of life of persons, families and communities affected by HIV infection and disease."

TASO chose 'Scaling up HIV prevention' as its theme for 2007, and many of its programmes now address HIV prevention issues. The TASO drama groups, for example, have developed sketches and songs on prevention, home-based counselling and testing. In addition, couple counselling has been intensified

Patrick and Lucy: shopkeepers

Patrick Olaya and his wife, Lucy Lawino, live in a camp for people displaced by the 20 year-long conflict between government forces and the Lord's Resistance Army rebels in northern Uganda. When Patrick fell sick and was bed-ridden for several weeks in 2004, close friends and relatives advised him to take an HIV test, which he did at Gulu Main Hospital. The result was positive. Patrick was instantly concerned about how to break this news to his wife Lucy.

"I was given enough counselling by TASO and became strong in the heart," recalls Patrick. "At first I did not tell her and went back to the counsellor and asked if he could go with me to deliver the story. He advised me to come back to the hospital together with my wife."

Lucy recalls: "I was very devastated when I got the news. I was pregnant and thought of aborting. I went to the TASO counsellor and he told me that if you are pregnant and you are HIV- positive, there are drugs to keep you alive and help you produce a health baby."

Lucy was tested for HIV and found to be positive. Her newborn baby died after two days, but she and Patrick are both receiving ART at the TASO centre.

Patrick has recovered his strength and rides a bicycle several kilometres to Gulu town each day, returning with merchandise for the small shop which they opened in the camp. The couple sold off part of their land to pay school fees for their children, and say that joining TASO has transformed their lives.

"TASO has helped us very much; it saved my life, and it is still continuing to give me counselling," says Patrick. "This has made me strong, and encouraged me to live a happy life. I want TASO to train me in counselling so that I can also help other people in the camp. If they come to my shop I can share my experience with them and encourage them to go for testing."

Patrick and Lucy are now trying for another baby. When Lucy's labour pains set in, she will be given Nevirapine, a drug that reduces the risk of mother-to-child transmission of HIV during childbirth.

"TASO has helped many people in Uganda who would have died of AIDS," says Lucy. "If you don't go to the hospital and get tested you keep leading a hopeless life. You should always go for testing and counselling so that you are assisted to live a happy and healthy life, even with HIV."

Dr Sam Okware, Commissioner for Community Health, Ministry of Health, lays the foundation stone for TASO's new head office building in Kampala, to be called the 'House of Hope', November 2005 (Dr Alex Coutinho on left).

TASO's National Headquarters, Mulago, Kampala, was built in 2004.

and discordant clubs have been started at TASO centres throughout the country.

'Positive Prevention'

In 2006, TASO initiated a new project known as 'Positive Prevention', which seeks to increase the participation of people living with HIV and AIDS (PHAs) in addressing the challenges of HIV prevention. This project is particularly important for the many TASO client couples who live in discordant relationships. Having regained their health through antiretroviral therapy, many discordant couples wish to resume a normal sex life and to have children, which may place the HIV-negative partner, or a new-born baby, at high risk of contracting HIV. The Positive Prevention project is training TASO counsellors and peer educators in education and support for discordant couples, disclosure to spouses or partners, sex and sexuality, family planning, safer sex, and prevention of mother-to-child HIV transmission. The project has begun by developing a curriculum and the training of trainers who, in turn, will train hundreds of TASO staff and volunteers.

Sustaining TASO

TASO would not have been able to manage the rapid growth in its staff, funds, facilities and activities since 2001 if it had not been sustained from within by a number of key factors. Dr Alex Coutinho summarises these factors as the 'Six Ps', as follows:

Purpose:

TASO's purpose is summarised very clearly in its mission statement, which was updated in September 2006 (see p. 66) to include HIV prevention. TASO's government partners and international donors are very clear about what TASO stands for and is trying to achieve.

Principles:

TASO's principles are the five TASO values (see p. 23), which have served the organisation well over the past 20 years.

Product:

Right from the outset, TASO defined its 'product' as 'positive living', a term coined by TASO, which has resonated throughout the world, giving hope and meaning to the lives of many HIV-positive people who otherwise might have given up on life.

Proof:

TASO is meticulous in collecting and presenting evidence of the effectiveness and the efficiency of the work it does. We monitor activities in our service centres and provide progress and financial reports to our donors on a regular basis. We have established systems for ensuring proper financial controls and accountability. This has been necessary to cope with the huge growth in TASO's annual budget: from virtually nothing in 1987, to over US$20 million in 2007. TASO is always willing for all aspects of its activities to be inspected by its funding partners and stakeholders.

Partnership:

TASO is well aware that it does not work in isolation, but in partnership with many different institutions and organisations: with families, communities, government bodies,

civil society organisations, other NGOs, and international donor organisations (see Appendix).

Posterity:

TASO is committed to HIV work in the long term, for as long as its services are needed. We have systems in place to ensure sustainability into the future.

For my part, I would suggest that there is another very important 'P', for 'People'. As we shall see in the next chapter, TASO has always made a point of investing in people.

Chapter Nine

Investment in people

One of the main reasons for TASO's growth from a small group of individuals into a large organisation that reaches out to several thousand people every day is our investment in people – not only our clients, but also the staff and volunteers who provide them with counselling, treatment, information, care and support.

We have tried, right from the onset, to empower people within the organisation to face the challenges of living with HIV and managing their situation with courage and dignity. One of the key components of this empowerment process has been the creation of a governance structure that allows everyone, right down to the grassroots, an opportunity to participate in policy formulation and decision-making.

Structure of TASO

TASO is a membership organisation: about 6,500 people from throughout the country pay a membership subscription, which entitles them to have a say in how the organisation is managed. At the apex of the organisation is the Patron and TASO founder, Noerine Kaleeba. Although Noerine is not involved in the day-to-day running of the organisation, she continues to inspire us all and to guide the organisation to ensure that we never lose sight of our original mission, our values and our goals.

The top governing body of TASO is the Board of Trustees, whose members are elected by TASO clients and individual members for three-year terms, renewable only once. This gives policy guidance to the TASO management to ensure that they steer the organisation towards its strategic goals. The Board of Trustees includes two client representatives to ensure that the voice of our clients is heard right at the top of the organisation's decision-making process. The Board also includes representatives from each of TASO's regional centres, ensuring that decisions are informed by local realities, and are therefore owned by our staff and clients, not simply handed down to them.

The day-to-day running of the organisation is in the hands of the Executive Director, who is assisted by two Deputy Executive Directors, one of whom is in charge of Finance, Administration and Human Resources, and the other in charge of Programmes. TASO also has six directorates, namely, Advocacy, Human Resource and Administration, Finance, Training and Capacity Building, Programme Management, and Strategic Planning and Information.

At TASO's 11 service centres, the Board of Trustees is represented by the Centre Advisory Committee, which includes client

TASO
Annual General Meeting

Ever since 1992, TASO has been holding Annual General Meetings to review the organisation's progress and chart the way forward. The year 2007 is no different. More than 2,500 TASO clients, staff, donors, board members and well-wishers meet in Lugogo, on the outskirts of Kampala City. In a large hall, usually used to display wares during an annual trade fair, the TASO clients display hope, courage and heart-warming camaraderie.

Although each of the 11 TASO service centres have designated seats, the delegates mingle freely, greeting one another with big hugs. Drama groups from the different centres bring the hall to its feet with catchy songs and jumpy dances. Many people are wearing T-shirts with slogans like 'Anybody can catch AIDS' and 'Together we shall overcome AIDS'.

The chairperson of TASO's Board of Trustees, Juliet Tembe, captures the essence of the AGM in her opening remarks: "This is the time we come together as a family, to interact, share our experiences, take stock of our achievements and failures, and plan for the coming months."

The minutes from the previous AGM are circulated to the clients and discussed. Clients, staff and volunteers are all free to comment on their accuracy or to highlight issues that need to be discussed before the minutes are adopted. Action points agreed upon in the previous AGM are revisited, and the TASO management are asked to show that these have been carried out. The dialogue is open and honest. Jesse Musobozi, a client representative from TASO Masindi, calls for more effort in encouraging 'positive prevention'. Esther Agali, the team leader for TASO's Positive Prevention programme, responds immediately, with details of how this is being done.

The Honorary Treasurer presents his report, and the keynote address is delivered by Esther Kisaakye, Executive Director of the Uganda Network on Law, Ethics and HIV and AIDS, on the rights of people living with HIV to treatment, employment and non-discrimination. The address, delivered in English, is translated into Luganda for non-English speaking clients.

The Executive Director of TASO, Dr Alex Coutinho, greets the delegates in at least six local languages – a testimony to the great diversity within the organisation – and proceeds to give his sixth and last report. Flanked by the incoming Executive Director, Robert Ochai, and other senior TASO managers, Dr Coutinho

says: "Nothing that TASO has achieved has been achieved as an individual. It has been achieved as a team. As I leave, I leave as an individual but the team will remain. I can attest that the family spirit is alive and kicking. Working for TASO is like no other job in the world, as TASO becomes intricately a part of your life and your soul. Parting from TASO is one of the most difficult things I have had to do."

Dr. Coutinho highlights TASO's successes as well as the challenges it faces. Such duality, of success and failure, threats and opportunities, life and death are ever-present in TASO. Midway through the speech, the names of 10 clients from each service centre who have died since the last AGM are read out, representing the hundreds who continue to die each year. Yet at the end of the speech, Dr Coutinho ends with a celebration of life.

"I want to call on all our clients in the hall to stand up and join me in celebrating life, for surely, without TASO services and in particular antiretroviral therapy, your names would have been on that list." More than 2,000 clients rise to their feet. The treatment, care and support that TASO provides to its clients show how thin the line is between life and death.

representatives and other elected community members. Their role is to give advice to the management of each centre to ensure that our services reach the people who need them, and with the quality they have come to expect from TASO. Each centre is headed by a manager whose staff includes counsellors, medical and clinical officers, nurses and support staff. The day-care centre in each TASO service centre is managed by a member of staff living with HIV in order to provide peer support to clients.

Clients also elect representatives from their communities to represent them on a Clients' Council, which meets the Executive Director at least twice a year to discuss clients' views on the services provided by TASO.

Decision-making

Each level within TASO has clear roles and responsibilities to ensure smooth and quick decision-making. The Board of Trustees makes policy decisions on funding, approves the budget, authorises certain levels of expenditure and procurement, and recruits the Executive Director and Directors. Above all, the Board maintains TASO's mission and values.

Directors and their deputies make up the senior management team at TASO headquarters, where decisions are usually made through regular consultations, including fortnightly meetings to review progress and plan ahead. Although the Executive Director can take some decisions without consulting the Board or the senior management team, major decisions are taken only after such consultations.

TASO has four administrative regions, each headed by a Regional Manager in charge of three service centres. The manager is supported by a Regional

Eve:

evangelist

Bashabire Eve Turyamureeba, 37, and her husband joined TASO Mbarara in February 1994, two years after they had both tested positive for HIV. After the death of her husband in October 1994, Eve continued to visit TASO for treatment, care and support. In 2002, she joined the TASO drama group to help spread messages about HIV prevention in her community.

Between 2003 and 2007, Eve was a member of the Clients' Council at TASO Mbarara, whose role it is to suggest ways in which the organisation can improve the quality of its services to its clients. Clients' Councils are one way in which TASO clients are involved in the running of the organisation. Each of TASO's 11 service centres elects six members and sends two of them – one of whom must be female – to sit on the Clients' Advisory Council at national level. Two clients are then elected from the Clients' Advisory Council to sit on the TASO Board of Trustees.

"As clients, we ask staff to improve on any areas that we think would help us get a better service, such as treatment and the counselling they provide," says Eve. "By listening to what we say, the TASO leadership shows that it is concerned about the welfare of its clients."

Like other TASO clients, Eve has a lot to thank TASO for. Her allowance from the drama group enables her to look after her four children aged between 13 and 18, and TASO also pays school fees for her daughter, who is in the first year of secondary school. Under the home-based care and treatment programme, a team from TASO recently visited Eve's home and tested her four children for HIV. They all tested negative.

"It was my greatest worry that my children might also be infected," Eve says. "I was very relieved and happy to learn that they are free from HIV and I pray that it remains that way. I am an evangelist and I continue going around the community, using my personal testimony to advise people to protect themselves from HIV."

Although Eve no longer sits on the Clients' Council, she continues to share any views she has when the clients meet at their service centre, or during the TASO Annual General Meeting.

"TASO is open; anyone who has something to say can say it and they will be listened to," she says.

At TASO Annual General Meetings, all delegates vote to elect the Board of Trustees.

The TASO Annual General Meeting in 2001.

Staff discuss a report. Every quarter the Management Committee reviews TASO's programmes and administrative systems.

Role play during counsellor training: TASO trains more than 3,000 people a year in skills related to HIV care, support and prevention.

Council comprised of representatives from the Centre Advisory Committees of all the service centres in the region concerned. At each TASO service centre, the manager has considerable autonomy to make decisions without having to consult with the Executive Director, the Regional Manager, the Centre Advisory Committee or the Centre Heads of Departments, although most major decisions are agreed upon through regular departmental and staff meetings.

Every quarter, a Management Committee Meeting, comprising of the directors and their deputies at the headquarters, heads of sections, regional managers and centre managers reviews TASO's programmes and administrative systems. This meeting allows the views from the bottom to the top, to be debated, adopted and implemented.

The role of training

TASO believes passionately in the importance of training to develop the skills and capacity of its staff members and volunteers, as well as members of the communities where TASO works. In 2006, TASO trained a total of 3,623 people (1,828 females, 1,795 males) at its Training Centre in Kanyanya, Kampala, at its four regional centres, and through the TEACH and SCOT programmes. During the past 20 years, TASO has trained well over 30,000 people in a wide range of HIV-related care, support and prevention skills.

Originally, whenever new volunteers joined TASO we would induct them into HIV and AIDS issues, and train them in 'helping skills' to use when interacting with TASO clients. In October 1988 we started developing a curriculum for training AIDS counsellors, mainly in order to produce trained staff for TASO's own clinics. Very soon, however, government institutions, NGOs and other organisations also expressed an interest in having their staff trained by TASO – and not only in AIDS counselling. In fact we often developed new courses as we went along, based on emerging needs. By the end of 2007, TASO offered 14 different training courses on a range of topics including various types of counselling, peer education, home-based care and the clinical management of HIV and AIDS-related conditions. Training for community volunteers is carried out, free of charge, by staff at the 11 TASO service centres. These courses are much sought-after by people and organisations within and outside Uganda.

Some of these courses have been developed in collaboration with other training institutions such as the Regional AIDS Training Network (RATN) in Nairobi, CONNECT in Zimbabwe, and Nkumba University and Mildmay International in Uganda. TASO has also carried out training on a contract basis for United Nations agencies such as UNICEF and international NGOs such as ActionAid International.

Apart from TASO itself, participants in these courses have come from the Uganda People's Defence Forces, the National Electoral Commission, Ministry of Education, Ministry of Agriculture, Ministry of Gender, Labour and Social Development, Ministry of Internal Affairs, private sector agencies and road construction projects, local and international civil society

Ignatius:
Board Member

Ignatius Biryomumaisho, 55, is one of the two client representatives on the TASO Board of Trustees. He joined TASO in December 1998, after testing positive for HIV at the AIDS Information Centre in Mbarara. He had already lost his job in the Resident District Commissioner's office after he revealed his HIV-positive status.

"I had heard TASO looked after its clients and their families," says Ignatius. "I joined immediately because I knew that, even if I died, TASO would look after my eight children, the youngest of whom is 14."

As one of two TASO client representatives on the board, Ignatius says it is his responsibility to inform the organisation about how its work is affecting the lives of its clients.

"Our main job is to find out what clients feel TASO should do for them, how they would like TASO to treat them, and about the changes taking place in our lives. For instance, after the introduction of ARVs, many young girls want to marry, and many women now want to have babies. It is our responsibility to inform the board about these changes so that TASO can respond appropriately."

Ignatius says the TASO Annual General Meeting brings together clients from across the country and enables them to share their experiences.

"In our individual centres we have no chance to see clients from other parts of the country. This is an opportunity to meet and compare notes. When we see clients who look well, we ask them to tell us what they are doing to stay healthy, and when we see clients who don't look healthy, we speak to them and try to advise them on better ways to take care of themselves."

Ignatius says he would like to see TASO support its members to start more income-generating activities so that they can stop being dependent on the organisation for their basic needs. He also says that TASO needs to encourage more voluntary counselling and testing to prevent new infections.

"HIV and AIDS awareness is very high but we are seeing little behaviour change," he says. "We need to encourage more testing so that people know their status and make informed decisions about their lives and those of their loved ones."

organisations, and individuals sponsoring themselves. In 2006 TASO received an income of US$235,000 from its training courses. These funds have been used to cover deficits in the budgets for other TASO activities.

Despite the huge gains achieved in HIV counselling in Uganda, there are still gaps and shortcomings in the quality of counselling available, and access to counselling services is uneven. In 2005 TASO, in partnership with the Ministry of Health, the Centers for Disease Control and other partner organisations, established the Strengthening HIV and AIDS Counsellor Training (SCOT) project. The purpose of SCOT is to develop properly accredited, high quality counsellors with the skills to respond to the current and changing needs of the epidemic. In 2006, SCOT reviewed four training curricula, and trained 64 trainers and 364 service providers from various partner organisations throughout the country.

The TEACH (TASO Experiential Attachment to Combat HIV and AIDS) project, which began in 2005, is a programme which places trainees with TASO programmes for hands-on, interactive, practical experience for one month at a time. Funded by SIDA, TEACH equips trainees with the knowledge, attitudes and practical skills they need to meet the ever-increasing demand for professional staff trained in HIV-related care, support and prevention. In 2006, TEACH provided experiential training to 186 trainees from 21 African countries.

We also build the capacity of our own staff by organising refresher courses, workshops on various topics, and enabling some to attend courses in universities and other institutions of higher education on a part-time, correspondence or distance-learning basis in order to improve their skills and acquire new knowledge.

Human resources and staff welfare

TASO has a transparent and well-structured staff recruitment policy, which enables it to select competent and suitable persons for its staff, and to deal with staff concerns when they arise. Human resource staff are employed for each TASO service centre and in the national office, thus ensuring that this aspect of TASO's activities is handled in a professional and responsible way.

We often assess the staffing needs within the organisation, and either redeploy staff to areas where their skills are better suited, or recruit more personnel when funds permit to fill any gaps. Many of the people who are recruited as staff members started out as volunteers in TASO, acquiring extensive experience as well as the family spirit that embodies the ethos of the organisation.

To help maintain high staff morale, TASO offers its staff a package of benefits including medical care for staff members and their immediate family, bonuses, gratuity, training opportunities, compassionate leave, study leave, annual leave and bereavement support in the case of death of staff, their parents or their children.

Many staff members have upgraded their education in institutions and universities, with part of their fees paid by TASO. TASO

staff members have also created a Staff Welfare Scheme through which they save money jointly every month. The scheme is administered by a committee comprised of staff members, and is elected at an Annual General Meeting. The committee meets once a month to review the accounts and approve loan requests from members.

Through this scheme, many staff members have been able to borrow money for projects such as buying plots of land, constructing houses and starting income generating activities. Others have been able to pay schools fees for themselves and their children, buy a car, or deal with some pressing domestic issue. Anyone in TASO, from the highest staff member to the lowest-ranked, can join the scheme and can continue investing in it until they leave the organisation.

Chapter Ten

The future of TASO

When Robert Ochai became TASO's fourth Executive Director in October 2007, the organisation had developed into one of the largest NGOs in sub-Saharan Africa, working in two-thirds of Uganda's 80 districts.

Over the past 20 years, TASO has counselled, treated, cared for and supported more than 180,000 clients and their family members. It is estimated that, overall, at least one million people in Uganda have benefitted directly from TASO services. In addition, several million more have been educated about HIV and AIDS through TASO drama groups, radio programmes or talks by TASO staff. The ART programme that we introduced in July 2004 has enabled 18,000 of our clients to extend their lives and has ensured that, from helping our clients die with dignity in the past, TASO is now helping them live positively and in dignity.

Looking back

Looking back at TASO's humble origins, it is amazing to see how large the organisation has become and how many lives we have touched or changed over the last two decades. Although TASO as an organisation has grown beyond our wildest imaginations, the people within TASO – the staff and the clients, the volunteers and the supporters – have remained one family, looking out for one another.

In my time here, I have seen people come to us on the brink of death, only to regain their health a few months later after receiving the treatment, care, support and compassion that TASO offers to all its clients. I have seen people come to us fleeing stigma and discrimination from their friends and family members, only to return to the same communities, empowered by the love and acceptance we give them, using their personal testimonies to triumph over stigma, and helping other people to protect themselves against HIV.

When TASO began, we planned and operated in an atmosphere of great uncertainty because the exact nature and the full consequences of the AIDS epidemic were not yet clear. There was no cure for HIV infection, and apparently no prospect of one on the horizon. Public fear of AIDS led the government and international organisations to prioritise HIV prevention, while care for those already infected and affected received far less attention.

In TASO, however, we decided to prioritise care and support for people living with or affected by HIV and AIDS, because we were convinced that this was a high priority area that was being largely neglected. Our

advocacy efforts focused on issues such as the importance of educating the public through full and accurate information about HIV and AIDS, combating HIV-related stigma and discrimination, enabling people living with HIV to be treated for opportunistic infections, and helping families cope with the psychosocial and economic consequences of HIV and AIDS. As the epidemic has unfolded, its nature and consequences have become clearer, and we have modified our strategies and programmes accordingly.

TASO has always aimed to complement the government's efforts in combating the HIV epidemic. We have never wanted to set up health services in parallel to those of the government. We therefore linked our service centres to government hospitals, establishing them either within, or just outside, government hospital premises. This has made collaboration with government health services easy to implement.

Future priorities

Looking ahead, it is clear that, despite the gains made in Uganda's fight against HIV and AIDS, many challenges remain. Our health and social support systems are not sufficiently geared towards taking care of the needs of people living with HIV, and their families, through counselling, social support and medical care. We need to build the capacity of our country to provide these services. TASO realises that it will never reach everybody. We cannot put our service centres everywhere, so we work with partners – with the Ministry of Health, faith-based hospitals, NGOs, community groups, young people's associations, local government authorities, schools, artists and musicians, and many other sections of society. This is what we mean by being 'United against AIDS', in the words of one of TASO's most popular songs.

The number of new infections has risen over the last three years to more than 130,000 per year. Although an estimated 90,000 Ugandans can now access ARVs, these life-prolonging drugs are still too expensive or inaccessible for the rest of the estimated 200,000 Ugandans who need them. Over one million Ugandans are living with HIV, but many of them have not tested and do not know their sero-status. The epidemic itself is evolving; more and more infections are taking place within marriage and other stable relationships: nearly two-thirds of TASO client couples who were tested in a recent study[5] were discordant, with one partner infected while the other was not.

Uganda has also had a distracting debate in recent years in which the different aspects of the ABC model – Abstinence, Being faithful and Condom use – were presented as mutually-exclusive and competing modes of HIV prevention. The reality is that all three options have contributed to the reduction of HIV prevalence in Uganda. People, especially the youth, need to be given accurate information so that they

[5] "High discordance rates among ART Clients in The AIDS Support Organisation", by Mohamed Mulongo and Francis Wasagami, presentation to PEPFAR HIV/AIDS Implementers Meeting, Durban South Africa, June 2006.

U.S. President George W. Bush and his wife, Mrs Laura Bush, visit TASO Entebbe in 2003.

Dr Alex Coutinho with Dr Elizabeth Madraa (HIV/AIDS Programme Manager, Ministry of Health) and Dr Christine Nabiryo (Director of Planning and Projects, TASO). TASO's aim has always been to complement, and not compete with, government health services.

TASO drama group member gives her testimony during a public performance. TASO is scaling-up its efforts to prevent new HIV infections.

The music group at the TASO Mulago Day-Care Centre, Kampala. Each TASO service centre has a day-care centre, organised by and for people living with HIV.

can make informed choices about their sexuality and lives.

In order to address the changing nature of the epidemic, TASO is evolving from an organisation that predominantly provided treatment, care and support to those living with HIV, into an organisation which accords equal priority to preventing new HIV infections.

Robert Ochai, TASO's new Executive Director, notes: "We will never fight and defeat AIDS if we say we are just going to treat those who fall sick; we've got to stop people from getting infected because once they are infected, they are infected for life. The key to winning the fight against AIDS is in preventing new infections, which is why everyone has to be involved in this fight."

Strategic Plan

TASO has drawn up a Strategic Plan (see box, p. 86) to guide its activities through 2008 to 2012. The overall goal of the plan is to contribute to the national and international efforts to achieve universal access to quality and comprehensive HIV prevention, care, support, treatment and impact mitigation services in an equitable and sustainable approach through enhanced partnerships. Through the Plan, TASO will seek to achieve the following goals:

1. Provide access to comprehensive HIV prevention services to affected families and communities.

2. Provide access to high quality comprehensive care, support, treatment and impact mitigation services for HIV-infected people and their affected families.

3. Contribute to the human resource requirements of the national HIV response through institutional and community capacity-building.

4. Contribute to a process of informing and influencing the global and national HIV response through operational research, modelling, documentation, policy development, advocacy, mobilisation and sensitisation.

5. Develop and promote partnerships and collaborations in HIV service delivery for prevention, care, treatment and impact mitigation.

6. Contribute to enhancement of gender mainstreaming in HIV prevention, care and support services through a rights-based approach by TASO and partner AIDS service organisations.

7. Contribute to enhancement of HIV and AIDS prevention, care, support, treatment and impact mitigation services in conflict and post-conflict areas through appropriate service-delivery models.

8. Enhance and mainstream the GIPA principle in all forms of HIV service delivery by TASO.

9. Ensure adequate financial, human and other resources and systems required for the successful implementation of the 2008-2012 Strategic Plan.

Strategic Plan, 2008-2012

The underlying principles of TASO's Strategic Plan for 2008 - 2012 are:

Evidence-based programming

TASO programming will be informed by research, information systems and best practices within TASO and other national and global stakeholders. These will include the use of the ABC+ prevention approach, appropriate counselling models, a basic care kit, home-based ART and home-based HIV testing, nutritional supplementation and the GIPA principle, and other proven interventions identified in the period.

Greater focus on the family

TASO shall continue to use its clients as an entry point to mobilise, sensitise and provide services to the other family members. This will improve the welfare of people living with HIV, address stigma and discrimination, and contribute to the general efforts to scale-up services.

Empowering communities

TASO will enhance community empowerment programmes to contribute to overall HIV targets and priorities. TASO will use experiences, lessons, findings and best practices by TASO and other key players to enhance community programmes to contribute in addressing critical emerging HIV needs and challenges.

Greater Involvement of People Living with HIV (GIPA)

Through interventions such as Positive Prevention, TASO will continue its pioneering work in putting PHAs at the forefront of its activities, particularly creating awareness about HIV and AIDS in order to prevent new infections and fight stigma and discrimination.

Enhancing partnerships

Our training programmes will enable us to help other organisations improve their services, while the mini-TASOs will help other health facilities adopt our treatment, care and support package.

Quality assurance

TASO will consolidate this strategy to cater for emerging HIV issues, new interventions and to fill gaps pointed out by reviews.

Enhancing accountability

TASO has developed strong and transparent accountability measures that it intends to maintain by ensuring that accountability is true and fair, backed with agreed qualitative and quantitative outputs, clear and agreeable to key stakeholders and implemented at a fair cost.

Value addition

The choice of activities and services to be implemented in 2008-2012 will be based on their potential to add value to the lives of TASO clients, their families and communities. Value-adding activities will include social support, organisational capacity building, stigma reduction, advocacy and activism and sub-granting funds to various groups fighting the epidemic.

Consolidating gains

Throughout its first 20 years, TASO has experienced cycles of growth and consolidation. The first period, between 1987 and 1990, saw the organisation take shape as we volunteered, without pay, to create a support system for the distressed and suffering people we saw around us and in our homes every day.

Between 1991 and 1995, as the structure took form and funding became available to enable us devote more time to the organisation, TASO grew rapidly and spread out beyond Kampala, resulting in seven service centres across the country. This was followed by a period of consolidation, between 1995 and 2001, when the organisation took stock of its achievements and started developing its capacity as a training organisation.

Between 2001 and 2007, we experienced another period of rapid growth and expansion through the opening up of four more service centres, 15 mini-TASOs and partnerships with eight community based organisations across the country. Moreover, we began working in northern Uganda, where years of war had decimated whatever health and social support networks had previously existed.

The new Executive Director, Robert Ochai, has indicated that, between 2008 and 2012, TASO will seek to consolidate its programmes to ensure that the quality of services we provide to our clients remains consistently high:

"TASO realises that it will never reach everywhere and everybody," he says. "We cannot put our centres everywhere so we work through partners; for instance, we work through the Ministry of Health to build their capacity to provide the services that we do. The health system is not yet sufficiently geared towards taking care of the needs of all people living with HIV and AIDS such as counselling, social support, ART and home-based care; we need to work together to build capacity to provide these services."

TASO is also widening and deepening its partnerships with communities through its service centres, mini-TASOs and centre-advisory committees, so as to involve as many people as possible in preventing new HIV infections and providing the best care, treatment and support possible for those people living with HIV.

Despite the emphasis on consolidation, TASO will also seek to play a larger role in preventing new HIV infections, especially through discordance and infection rates among married people. Robert Ochai says: "We need to strengthen our prevention messages, to remind people that HIV is still with us and is real, and strengthen our interventions. There are certain drivers of the epidemic right now – especially the issues of discordance and multiple sexual partners. We need to target our messages to those issues that are driving the epidemic."

Challenges ahead

In his last speech as Executive Director at the 2007 Annual General Meeting in Kampala, Dr Alex Coutinho highlighted

TASO client and counsellor: from the start, counselling has been TASO's 'core competence'.

TASO Mbarara Drama Group: The TASO clients' music, dance and drama groups help to combat HIV-related stigma and at the same time their performances carry educative messages on HIV prevention, care and support.

the challenges TASO faces as it embarks on the next phase of its life. These challenges include, for example:

- Managing the increasing demand for our services and empowering clients, families and communities to take care of their day-to-day health care and counselling needs.

- Ensuring that TASO has a strong HIV prevention programme, so that we are not just a counselling and care organisation but a key player in preventing further infections.

- Continuing as a world leader in developing innovative models of prevention, counselling, care and treatment that can be scaled-up, that can be reproduced in other settings and which can be adopted in other countries.

- Maintaining and expanding our current donor pool and remaining accountable in the four areas of governance, financial, programmatic, and cost-effectiveness.

- Maintaining our volunteers, staff, infrastructure and systems to enable us to deliver services to as many clients as we can, and

- Retaining our brand, reputation, style, soul, values, our concern for the downtrodden, and "to remain humble but ambitious and to never forget that ours is to champion the rights, the dignity and the welfare of HIV-positive people, their families and loved ones".

Leaving TASO, but not the struggle

I remain confident that we have, within the TASO family, the right people, the appropriate systems and the best partners to help us address these challenges and continue to make a difference in people's lives. It is particularly important that we evolve from an organisation that only provides treatment, care and support to those living with HIV, to pay more attention to preventing new infections.

I will leave TASO at the end of 2008 to set up a physiotherapy centre, where patients can come and where students can carry out their practical training. Several of TASO's founder members came from the School of Physiotherapy at Mulago Hospital, and I feel that setting up this centre is one way of giving something back to the profession.

I have led a very busy life in TASO right from the start. I have grown in mind and spirit during my time here and acquired skills in administration, management, community mobilisation and leadership. I have met many people and made numerous friends, both within and outside Uganda, many of whom I am still in contact with.

It is not easy to leave an organisation that one has been part of for 20 years, and one that is as close, warm and welcoming as TASO. Yet, it is important that, as TASO grows we, the founder members, allow in younger and more vibrant people to drive the organisation forward as it enters a new chapter in its life.

My message to all members of the TASO

family is to stay true to the TASO spirit. Remember the TASO mission and values. Never forget that TASO is there for our clients – whether old or young, male or female, and regardless of class, creed or political allegiance.

While I am retiring from TASO, I am not quitting the struggle. I will remain a member of the TASO family, and I share the optimism of all my colleagues in TASO that, united against AIDS, we shall finally win the war against this epidemic.

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APPENDIX

TASO Donors, 1988-2007

ActionAid

Agricultural Cooperative Development International/Volunteers Overseas Cooperative Assistance (ACDI/VOCA)

AusAID

CAFOD

Caritas International

Centers for Disease Control

CELTEL Uganda

DANIDA

Department for International Development (UK)

Development Cooperation Ireland

Elton John Foundation

European Union

German Emergency Doctors

Government of Uganda (Ministry of Health)

Global Fund to Fight AIDS, Tuberculosis and Malaria

Heifer Project International

Japanese International Cooperation Agency/Japanese Embassy

Johnson & Johnson

Medical Research Council (UK)

OXFAM

President's Emergency Plan for AIDS Relief (PEPFAR)

Pfizer Foundation

Rockefeller Foundation

Save the Children Fund

Swedish International Development Agency

Mrs Sally March (late)

TASO UK

Terre des Hommes Netherlands

Trickle-Up

USAID (through AIDSCOM/DISH/ Experiment in International Living / John Snow International/UPHOLD/ World Learning Incorporated)

UNICEF

UNDP

UNAIDS

Voluntary Service Overseas

World in Need

World Food Programme

World Health Organization

World of Hope

The **STRATEGIES FOR HOPE TRUST** produces and distributes books and videos that promote good practice in HIV and AIDS work by civil society organisations in developing countries, particularly in sub-Saharan Africa.

Founded in 1989, **STRATEGIES FOR HOPE** has produced 21 books, five films and the 'Stepping Stones' training package. These materials are used for information, education, training, planning and advocacy purposes in over 160 countries.

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