



Hope and life

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SECOND ANNUAL REPORT

PROJECT TITLE: NETWORK OF PEOPLE LIVING WITH HIV/AIDS
PROJECT NAME: HOPE AND LIFE
PERIOD COVERED: JUNE 2004 TO JUNE 2005
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PROJECT HOLDER: ST. CAMILLUS M. HOSPITAL

MISSION STATEMENT

Hope and Life's mission is to support and empower the people living with HIV/AIDS, reduce morbidity and mortality rates within Migori district, Homa-bay and Suba.

We encourage behavioural change, group therapy and group counselling as we believe this to be the key in preventing the spread of HIV/AIDS.

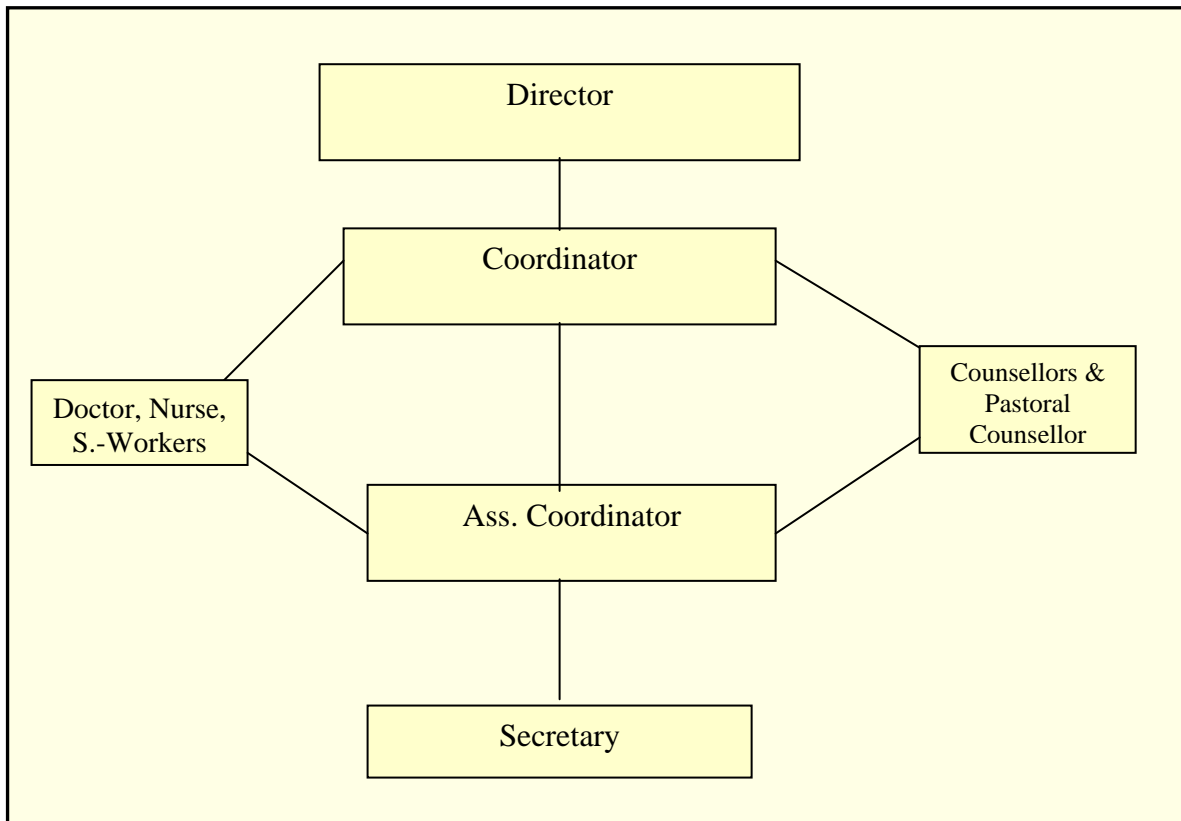
INTRODUCTION

Hope and Life (H&L) supports the involvement of People Living With HIV/AIDS (PLWHA) in HIV/AIDS programmes. We concentrate on the district of Migori, but also operate in some parts of Homa-bay and Suba. The project, which has now been running for two years, creates and sustains networks of PLWHA through the collaboration with the following, and a number of other groups and individuals: church elders, priests, pastors, catechists, chiefs' barazas, community health promoters and pastoral counsellors. These, in turn help to inform the general public on topics concerning the virus and its prevention. Promotion of Antiretroviral (ARV) therapies and Voluntary Counselling and Testing (VCT), as well as education on how to avoid mother-to-child transmission all plays a key role in the matter.

It is rather unusual to find individual PLWHA spontaneously becoming active in the battle against HIV/AIDS. H&L however believes that their involvement and testimonies are crucial when approaching the community.

It therefore assists PLWHA that are willing to come out and serve as positive examples for the rest of the community. H&L encourages them to speak up publicly about their experiences and the way therapy and counselling has improved their lives.

H&L also uses group therapy to restore people's serenity, give them confidence and a sense of belonging. It fights judgemental attitudes towards HIV positive people and instead it offers them love, respect, care and support.



Graph 1 – Management structure

BACKGROUND INFORMATION

The Migori district has the highest rate of HIV/AIDS infection within the whole of Kenya. Yet, both in rural and urbanised areas beliefs and customs still act as major barriers to behavioural and cultural change, which are essential to restrain the diffusion of the virus. The area is situated on the shores of Lake Victoria, close to the border with Uganda and Tanzania.

Migration, a high number of commuters, prostitution, wife inheritance and the so-called sex-for-fish culture are just some of the causes linked to the intense augmentation of HIV cases in this already impoverished region.

The year 2004 has been a turning point in the fight against HIV/AIDS as the Kenyan Ministry of Health has approved the importation of generic antiretroviral medication from India and a number of other countries. The prohibitive price of ARV's had until recently lead to congested hospitals and soaring death rates.

H&L has since been able to enrol many more people on antiretroviral therapy, hence improving and saving many lives.

AIMS AND OBJECTIVES

1. Make PLWHA come together to share experiences in order to reduce stigma and discrimination.
2. Empower network leaders on how to support and care for fellow PLWHA.
3. Promote VCT to induce behavioural change.
4. Ensure PLWHA committees have an in-depth knowledge on HIV/AIDS prevention and control.
5. Improve quality of life of PLWHA by improving their nutrition and medical care.
6. Enable PLWHA to sustain themselves through income generating activities.

ACTIVITIES

(See Appendix A for additional information on these activities)

1. Individual and group counselling

- Morally support PLWHA
- Helps to better identify and meet the needs of PLWHA.
- Helps monitor each patient's condition.
- Encourage behavioural change of individual PLWHA.

2. Home visit and assessments

- Visit and talk with individual AIDS patients at least once a week.
- Provide a counselling service for those facing problems at home.
- Weekly follow-ups to monitor health improvements.
- Understand the background of AIDS patients and relatives concerned.
- We also do emergency visits in case of a serious sickness.
- To assess personal and environmental hygiene.
- To assess if the clients are taking their ARV drugs.

3. Group therapy

- Sharing of experiences helps reduce stigma and discrimination.
- Provide information and facts about HIV/AIDS.
- AIDS patients gain more knowledge.
- Helps developing good relations with members.
- Discussion on culture and taboos that fuels the spread HIV/AIDS.
- Discussion on possible side effects of ARV drugs and how they affect each other's daily lives.
- Relationships between members are being fostered during these therapy sessions, so that they can eventually help each other even outside these meetings.

4. Care and support to PLWHA

- Providing healthcare, nutritional as well as material support (for example clothes, mosquito nets, etc) to sick and needy patients.
- Provide medical support and referrals where necessary.
- Provide capacity building on how PLWHA can take care of themselves.

5. Education on safer sex

- We provide demonstrations and education on how to use condoms correctly.
- We stress on family life education and faithfulness and the importance of abstinence before marriage especially to youngsters.

6. Disclosure of patient's HIV status to close family members

- Helps PLWHA accept their status.
- Helps getting support from loved ones.
- Helps fighting stigma and discrimination.
- As a result, will make the patient stronger and more willing to fight the illness
- Will reduce the spread of HIV/AIDS.

7. Collaboration with other organisations

- Exchange of knowledge and practices with groups such as:
 - MMAAK (Movement of Men Against Aids),
 - WOFAK (Women Fighting Aids In Kenya), and
 - MICOBA (Migori Community Based Aids Orphans).
- H&L has since adopted some of practices of these organisations. It has for instance created more sub-support groups within its team.

8. Sensitisation

- We have also been invited by a number of different organisations to provide sensitisation. These included:
 - C.D.C (Centre of Disease Control),
 - MMAAK (Movement of Men against Aids in Kenya),
 - CACC (Constituency Aids Control Committee Meeting),
 - WOFAK (Women Fighting Aids in Kenya).

Hope and Life Member's Statistics: Comparison Year 1 and Year 2

Period	Children		Widows		Widowers		Married Couples		PLWHA on ARV		PLWHA not on ARV		HIV related Deaths	
	03-04	04-05	03-04	04-05	03-04	04-05	03-04	04-05	03-04	04-05	03-04	04-05	03-04	04-05
Nr.of PLWHA	5	12	47	150	5	59	39	39	78	180	78	80	78	10
Sex	F:3	F:3					F:18	F:22	F:59	F:132	F:59	F:30	F: 59	F:4
	M:2	M:9					M:21	M:17	M:19	M:48	M:19	M:50	M:19	M:6

Table 1 – H&L Member's Statistics

ACHIEVEMENTS

1. Numbers of H&L members has risen to 260

- So far 260 PLWHA have registered with us (compared with 96 at the end of year 1). We consider this a notable number, given the resistance to change we have encountered over the past two years.
- We have been using the testimony of PLWHA who have joined H&L in the previous year to recruit more members.
- Out of these 260, 180 are on ARV treatment, compared to 78 from year 1. (See p.4, Table 1)

2. Higher sensitisation

- More members mean higher sensitisation on HIV/AIDS and related issues.
- Higher sensitisation means are more willing to openly discuss the subject.
- Higher sensitisation means more potential H&L members.

2. Formation of more group therapy teams

- The network of group therapy is growing increasingly.
- During group therapy session people learn and practice how to disclose their status and seek assistance.
- To this day 13 groups, all of which have their elected representative, have been formed in different locations.

3. Increasing disclosure rate

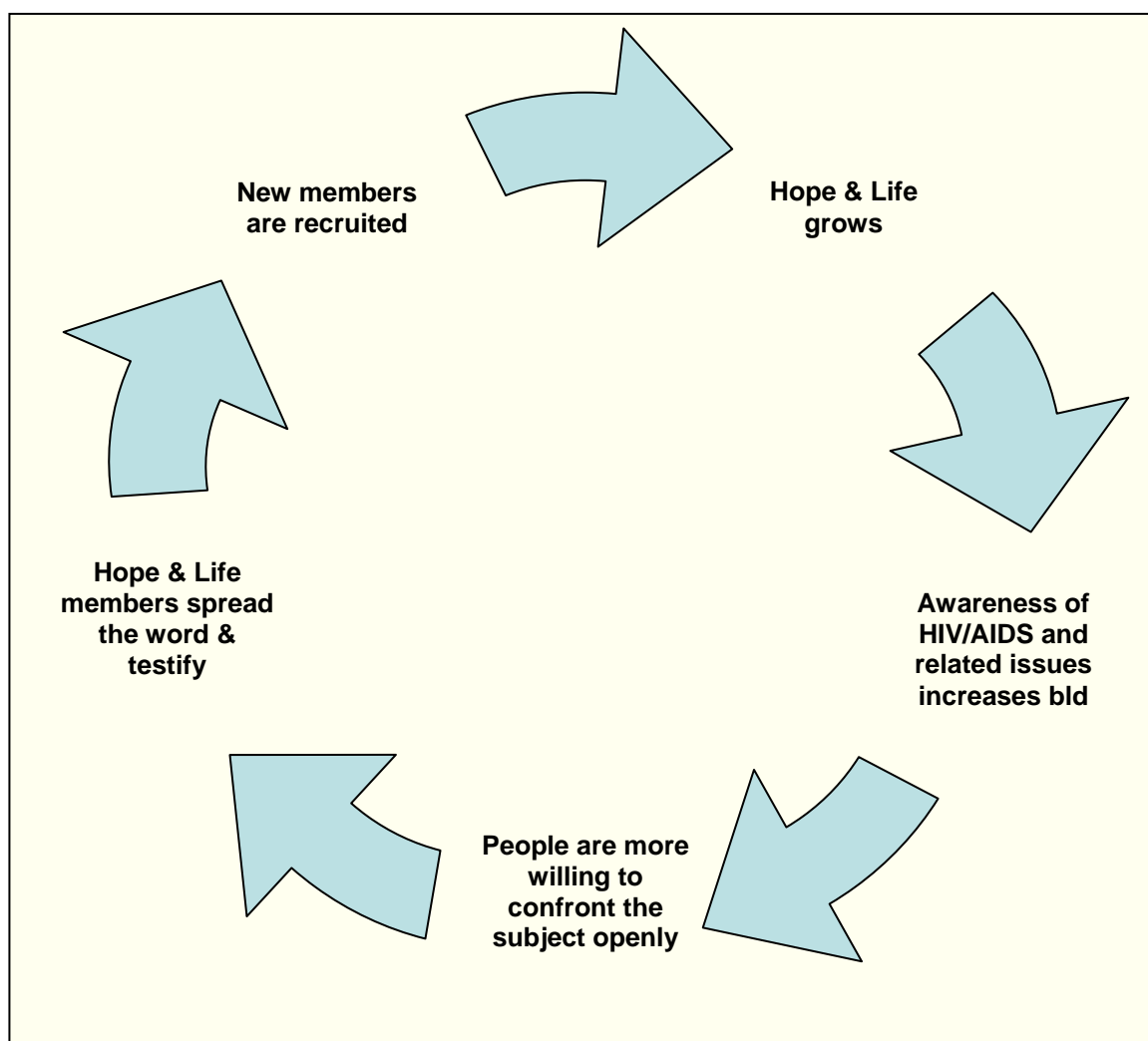
- As people are growing more aware of the issue, they are slowly more willing to disclose their positive HIV status.
- This once again helps fighting stigma and discrimination.
- This can bring a number of advantages for the PLWHA:
 - Prevents further dispersion of the virus,
 - PLWHA can seek help and support from relatives, friends and acquaintances,
 - Family members can assist in correct intake of ARV medication.

4. Lower death rate

- The number of HIV related casualties has decreased significantly in the community (See p.4, Table 1).
- Over the past year the percentage of deaths caused by AIDS within H&L members has dropped from almost 16% down to less than 4%.
- Higher sensitisation, behavioural change and the sudden decrease in ARV prices have all had a significant input.

5. Assistance to HIV positive orphans has increased

- The number of HIV positive orphans who are receiving ARV therapy supported by the Dala Kiye orphanage has risen from 2 to 12.
- 5 of these are now permanently living at the centre. They are receiving free nursing, clinical, as well as psychosocial and nutritional care. Health and formal education, up to and including secondary schools are also part of the programme these children have been enrolled on.



Graph 2 – H&L's growth strategy

ISSUES AND CHALLENGES

1. Cultural practices, local customs and myth belief

- Deeply rooted and very hard to change, notwithstanding our efforts.
- Wife inheritance, circumcision, witchcraft and polygamy are just some of the factors which assist the proliferation of HIV/AIDS.

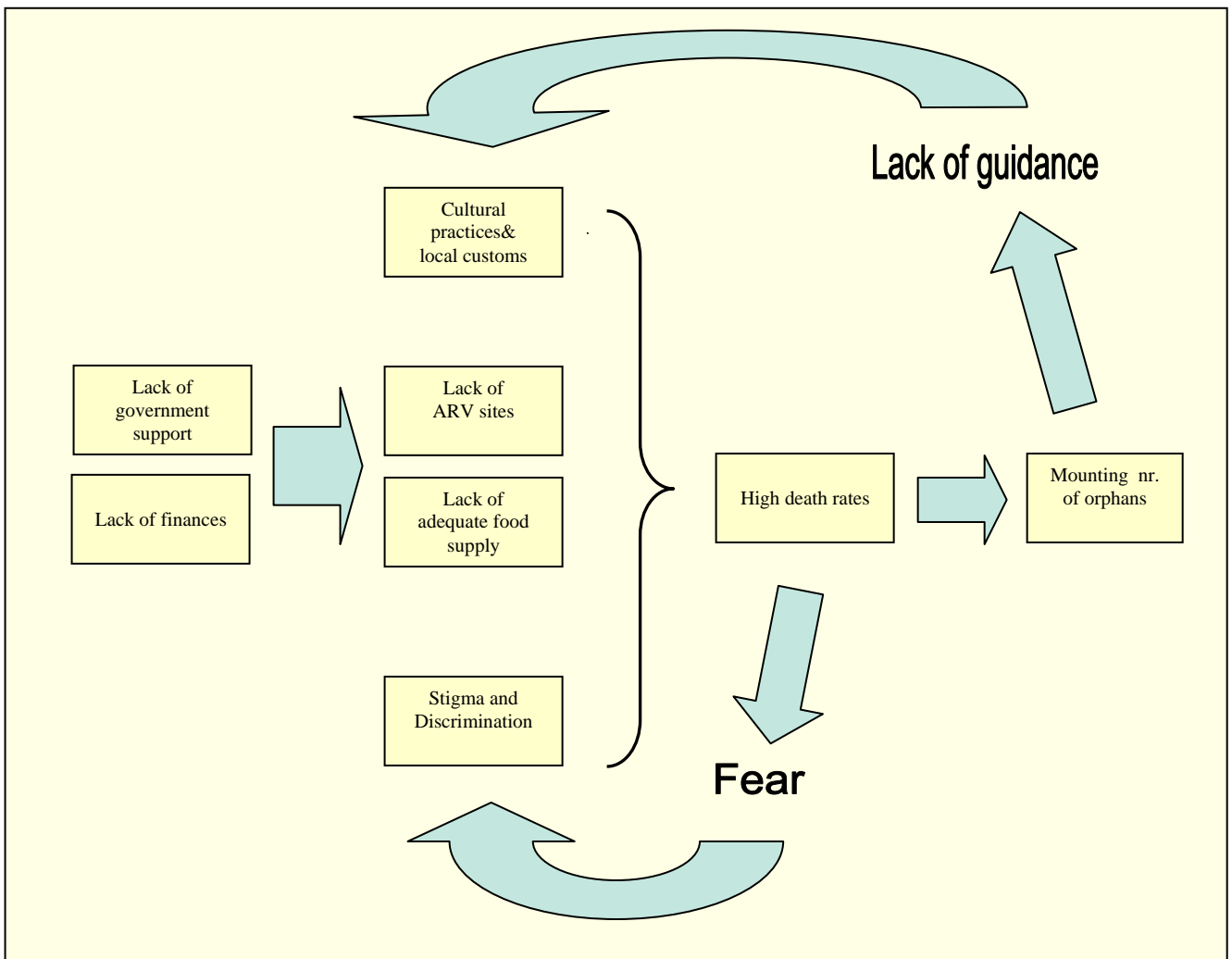
2. Stigma and discrimination

- Although they are reducing, stigma and discrimination are still strongly embedded in the local community and still the main cause of insufficient disclosure rate (especially within men)
- Even if we are witnessing change, many infected people still refuse to access ARV treatment.

3. Lack of support by government

- Does not provide satisfactory funding for HIV/AIDS projects.
- Government intervention usually occurs in cities and towns. Smaller villages, which are often the worst affected are frequently neglected.

- Lack of HIV/AIDS programmes in school.
 - Lack of proper strategies in support of orphans and widows.
- 4. Lack of finances**
- We are now receiving funds, though limited. This does not allow us to run all of our activities efficiently and effectively.
- 5. Few adequate health institutions**
- Adequate health institutions, such as sub district hospitals or even dispensaries, are still not available in most rural areas.
 - This will make it increasingly difficult for us to adequately meet increasing demand for drugs.
 - PLWHA often have to travel relatively long distances in order to collect ARV drugs, thus making it an expensive and fatiguing affair.
- 6. Lack of adequate food supplies within the community**
- Mainly caused by:
 - The government failing to provide adequate capacity building for farmers. This leads to mismanaged farming and consequent poor food supplies.
 - Seasonal droughts which affect crop production.
 - Given the potency of the drugs, PLWHA on ARV treatment need sufficient nutrition, in order to perform daily tasks.
- 7. Death rate within HIV/AIDS patients**
- Even though diminished, the number of HIV related casualties is still significant.
 - Many people are still refusing to accept the gravity of the problem. These are the ones turning down treatment and dying as a result.
 - 10 H&L members have died so far.
 - Fear and discouragement are still present, due to high number of people who have died in the past.
- 8. Mounting number of orphans**
- Almost one third of the children living in area are either partial or total orphans.
 - Besides often living in total poverty, this whole new generation is receiving little or no parental guidance. If not controlled it will lead to more poverty, followed by an ever-increasing diffusion of the virus.
 - Most of these children do not reach beyond primary level education due to the inability of paying school fees.



Graph 3 – Main factors contributing to local HIV/AIDS epidemic

EXPERIENCE GAINED

1. Disclosure of HIV status

- Even though a number of members are practising disclosure of their HIV status either publicly or privately, it is still very low especially within couples. This can lead to further dissemination of the virus and a number of other complications, such as potential immunity to ARV-drugs by one of the partners.

2. Support for young PLWHA

- It is crucial to assist the younger members of families as they are often the caretakers of the PLWHA.
- Most young people fear to come out due to stigma

3. Women are more susceptible to HIV/AIDS than men

- This is due to a number of reasons:
 - Sex-for-fish trade, prostitution and rape,
 - Widow inheritance,
 - Weaker immunity system, due to high number of pregnancies.

4. Adequate nutrition for ARV patients

- PLWHA show tremendous improvement, when ARV drugs are combined with a proper diet.
- However, given the strength of the medication, patients are often so weak they are unable to perform even the simplest tasks, if not provided with adequate nutrition.

5. Behavioural change has led to better quality of life

- Generally, PLWHA who have started practicing either abstinence or safer sex, through regular use of contraceptives and have taken ARV's regularly and correctly have improved their health and their quality of life significantly.

6. Side effects

- Now that a wider pool of ARV patients is available, we are noticing that different PLWHA react differently to ARV medication. Types and acuteness of side effects can vary greatly. They may include: dizziness, swellings, exhaustion, tremor, depression, anorexia, insomnia and potentially life threatening rash.
- PLWHA can discuss, give and seek advice on side effects during group therapy sessions.
- We provide medical referrals where possible.

FUTURE PLANS

1. Increase number of members to about 700

- Continue our sensitisation and mobilisation campaign using existing members to spread the word and recruit new ones.
- Keep revisiting same places as people are growing more aware to H&L.

2. Provision of prophylaxis and ARV treatment to approximately 400 members

- We can provide treatment for many more people, as prices of ARV drugs have dropped and are likely to drop even further in the future.
- All of these people also need prophylaxis treatment prior to starting the ARV treatment.
- We also need to provide them with information on the treatment and its side effects.

3. Provide training in form of Home Based Care (HBC) and drug adherence

- This will teach PLWHA on how receive treatment at their home,
- HBS should contribute to a decongestion of some hospitals, and lower costs for the patient.

4. Expand group therapy network

- Form more groups as number of members is increasing.
- Elect more representatives for better management of groups.

5. Increase number of volunteers

- More volunteers are needed, as H&L and the number of self-help groups are growing,
- Their duty will be to oversee a certain area and to act as an intermediate between H&L head office and PLWHA.

6. Increase volunteer's level of preparation

- Volunteers should receive training on organisational, motivational and leadership skills, as well as regular information on HIV/AIDS related issues.

7. Raise money for means of transportation

- It is becoming increasingly difficult for us to regularly visit each member, as the number is rapidly growing,
- A means of transport, such as a motorbike, would save time, increase efficiency and effectiveness

8. More income generating activities

- Expand types of income generating activities by teaching them how to make bead jewellery.

CONCLUSION

This year has undoubtedly been a defining moment in the battle against HIV/IDS. Thanks to the government's decision to import much cheaper generic antiretroviral drugs, H&L is now able to not only lecture people, but also to effectively provide many of its members with the necessary medication. This combined with a reduction in stigma and the constant presence of our team, has led to a significant augmentation of members, a reduced death rate and a great deal of much needed hope.

Our aim over the next twelve months is to keep growing, both in numbers and efficiency, and at the same time properly co-ordinate the rising numbers, without ever losing sight of our objectives.

APPENDIX

Appendix A - Activities June 2004- June 2005

N°	ACTIVITY	RESPONSIBLE PARTIES	PROCESS	DURATION (from - to)	COMMENTS
1	Individual and group counselling	Counsellors, pastoral care, H&L team.	To promote VCT as a behavioural change strategy	June 2004 - June -2005	For more involvement and concern for individual behaviour change
2	Home visits & assessments	Social workers and H&L team & Community Health workers	Understand the background of members and their environment.	July 2004 - May 2005	126 homes of PLWHAS have been visited. We identify their homes and their challenges surrounding them.
3	Group Therapy	Project team with PLWHA	Empowering PLWHA to safeguard their rights	May 2004 - May 2005	Helps foster good relationship with members. 13 sub-support groups organized.
4	Care and Support	Project team	Identifying the problems and needs of PLWHA	Nov 2004 - Jan 2005	Provision of medical care, capacity building and material support.
5	Education on safer sex	Project team with PLWHA	All infected and youth aged	March 2004 - April 2005	We provide information and education on correct use of contraceptives, as well as promoting faithfulness and abstinence.
6	Disclosure of HIV status to other family members	Group leaders and H&L leaders	Through group therapies and speaking publicly	Mar 2004 - March 2005	Through this activity PLWHA grow more confident about disclosing their status.
7	Collaboration with other organisations	Project team, ministry of health and other concerned organisations	Through visits and sending brochures	July 2004 - Jan 2005	To gather more knowledge, to improve our work and receive external help.
8	Sensitisation	Project team and other organisations	We help in providing sensitisation to the communities through other NGOs.	June 2004 - June 2005	Reach a greater number of people in other areas to give people clear information of our activities and to teach them how to live with the virus in a correct way.