

PRAYAS Health Group



Annual Report (April 2007-March 2008)

PRAYAS
Initiatives in Health, Energy,
Learning and Parenthood.

प्रयास
आरोग्य, ऊर्जा, शिक्षण व पालकत्व
या विषयांतील विशेष प्रयत्न

PRAYAS

Health Group

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(April 2007-March 2008)



PRAYAS

Amrita Clinic, Athawale corner building,
Near Sambhaji bridge, Karve Road, Pune - 411 004, Maharashtra, India.
Tel. 91 20 25441230 /65615726, Tel./Fax 91 20 25420337
E mail- prayashealth@vsnl.net, Website- www.prayas-pune.org

Dear friends,

It gives us immense pleasure to present this annual report of PRAYAS Health Group (PHG).

We sincerely thank our donors, funding agencies, friends, and well-wishers.

We are indebted to our patients without whose support, cooperation and profound trust in us, this work could not have grown and taken the present shape.

Amuna
S. D. Kulkarni
M. Gadgil
S. Parbhoo
S. K. Ramesh
S. D. Kulkarni
M. Gadgil
S. Parbhoo
S. K. Ramesh

PRAYAS HEALTH GROUP

Contents

I. Introduction	01
II. Completed projects	03
III. Ongoing projects/activities	06
IV. Overview of the projects	07
1. Training and Awareness Programs	
2. Counseling Center	
3. Child Care Project	
4. PMTCT Project	
5. GCR Project	
6. PRAYAS Amrita Clinic	
7. Prenahstest Project	
8. PRAYAS Health Laboratory	
9. CHAI Project	
10. Pediatric HIV Program	
V. Workshops conducted by PRAYAS Health Group	19
VI. Conferences attended by group members	20
VII. PRAYAS Health Group Publications	20
VIII. Human resource structure	23
1. Board of Trustees (BOT)	
2. Executive Committee (EC)	
3. Group Core Team (GCT)	
4. Other Committees	
5. The Team of PRAYAS Health Group	

I. INTRODUCTION

PRAYAS (Initiatives in Health, Energy, Learning and Parenthood) is a public charitable trust, which was registered in 1994. A group of medical and engineering professionals established this non-government organization (NGO) with a mission to apply their professional knowledge and skills to understand the issues afflicting society and to make efforts to address these issues through appropriate and sensitive strategies especially in the areas of health, energy, resources and livelihood as well as learning and parenthood. The belief behind our efforts is that even the most marginalized people can be empowered to tackle their own problems, if they are provided with sound analysis and appropriate support.

Currently there are three active groups of PRAYAS: PRAYAS Health Group (PHG), PRAYAS Energy Group (PEG) and PRAYAS Resources and Livelihoods Group (ReLi).

PRAYAS Health group works mainly in the area of HIV/AIDS and sexuality.

A Brief History of PRAYAS Health Group

In the context of HIV/AIDS in India almost all the sections of society are deprived of essential information, knowledge and opportunities. In a sense, the whole society seems marginalized. Therefore, reaching out to people from different sectors, e.g. literate and illiterate, men and women, people from slums and from richer strata, students in schools and colleges, street children, children in institutions, school and university teachers, industrial workers, doctors, social workers, workers in organized and unorganized sector, etc. were the initial challenges. Dr. Vinay Kulkarni and Dr. Sanjeevani Kulkarni started the work in the area of HIV/AIDS and sexuality in 1986, as an individual initiative and tried to reach out to all mentioned above.

In 1989, Vinay happened to diagnose his first HIV patient at his private clinic (Amrita Clinic). It was quite surprising and thought provoking to have HIV infected patient at the private clinic in just three years after the first case was diagnosed in India. That patient happened to have got infected through a blood transfusion in rural Maharashtra sometime in early 80's. This was a stark realization of the likely spread of HIV/AIDS by then and depth of its impact in store. Soon many groups started to

feel the need for their training to conduct awareness programs. Vinay and Sanjeevani started conducting numerous trainings for such organizations.

The organization PRAYAS was formally launched in 1994. As the epidemic evolved, other activities like clinical and counseling care center, information center were started at PRAYAS. PRAYAS Health group has expanded steadily. It undertook several projects, which led to its overall development and growth. As work increased so did the outreach and the staff of PRAYAS. The individual efforts of two doctors grew surely and steadily into a big family that would stand firmly in the fight against the HIV epidemic.

Important milestones

- From the year 1995, research projects on the topics that needed systematic exploration and advocacy started taking shape. (Various completed projects are enlisted below.)
- Year 2002, was a turning point for PHG. An intervention program for prevention of mother to child transmission of HIV (PMTCT) was started with support from Elizabeth Glaser Pediatric AIDS Foundation. This was our first full-size project that gave a reasonable shape to the group. The program is now running for 6 years and has grown substantially to become India's largest private sector initiative.
- All these years Amrita Clinic (which was Vinay's private clinic) continued providing clinical care to HIV infected people. Though Amrita clinic and PHG were independent bodies, their work was interdependent. Since same people were working on same issues in two independent structures, the amalgamation of these was inevitable and also beneficial for the organization. In January 2006, Amrita Clinic was merged with PHG to form PRAYAS Amrita Clinic, an independent activity of PHG.

Services Provided by PRAYAS Health Group

These are the services provided by PRAYAS Health Group:

- Conducting training and awareness programs in communities, schools, colleges, industries, and various other groups and organizations.

- Outpatient treatment of individuals infected with HIV, sexually transmitted diseases (STDs), and others issues related to their sexual behavior, sexual performance and other concerns related to sexuality.
- Outpatient treatment for HIV infected children
- Dissemination of the information through establishment of AIDS Networking and Information Center.
- Care, support and resource development services for individuals with HIV as well as their family members.
- Counseling services for the individuals with or with a suspicion of HIV infection and their family members.
- Counseling services for pregnant women regarding ante-natal care, HIV testing during pregnancy and PMTCT services if tested positive for HIV.
- Laboratory testing of all essential tests for HIV diagnosis and monitoring at subsidized costs.

II. COMPLETED PROJECTS

Sr. No.	Name of the project	Start Date	End Date	Supported by
1.	Perceived Morbidity & Dynamic of Women's Health in Low Income Areas of Maharashtra, India.	1995	1996	Karina Kielmann (of Johns Hopkin's University)
2.	Networks, Language and Sexual Behaviors of Men Who Have Sex With Men in an Urban Setting: A research study	1999	2000	Ford Foundation
3.	Women and AIDS: Issues, concerns, responses and coping	November 2000	January 2001	GTZ India
4.	People with HIV: Stigma, Coping and Support Systems	November 2001	October 2002	NIMHANS (through small grants program of Ford Foundation)

5.	Development of a model for provision of care and support services to HIV infected children attending specialized HIV clinic – as a part of fellowship program of Dr. Ritu Parchure	January 2005	January 2006	CMC, Vellore
6.	Catch them young- Training of Medical Interns	May 2005	Jan 2007	n(o)vib, Oxfam Netherlands.
7.	Assessing the Knowledge Level among Pregnant Women regarding Antenatal Care.	July 2007	August 2007	Kanya Balkrishna (Yale University) (as part of summer training)

Significant events/projects completed in the period from 1994 to March 2007

- In 1995, a **comprehensive slide show** on awareness about HIV/AIDS was prepared with the help of CEHAT, a friendly organization. It consisted of 76 slides. For any program one could choose around 40 slides depending upon the group to be addressed. This tool proved to be extremely effective. It was widely used by various animators. It was prepared to explain the facts about HIV with gender sensitivity and understanding. In 1999, the slide show was translated in 11 Indian regional languages. To facilitate this activity PRAYAS organized a national level workshop, and discussed the complete slide set with special thrust on the linguistic nuances. These slide shows were received very well and were highly appreciated
- **Perceived Morbidity and Dynamic of Women's Health in Low Income Areas of Maharashtra, India** – (Karina Kielmann Ph.D. Research study) – Ms. Kielmann was a Ph.D. student from Johns Hopkins University, Baltimore. Her project was hosted at PRAYAS. Dr. Sanjeevani Kulkarni coordinated and co-worked for the project. Ms. Kielmann received a doctorate for the research.
- A small grant for developing **AIDS Networking and Information Center** was received from Bike-Aid (U.S.). This is a group of students who traveled throughout the country on bicycles and collected money from people to support

activities in developing countries. PRAYAS' information center currently has 1924 books and 282 CDs.

- In 1999 the Ford Foundation funded our efforts for -
 - a) Preparing sensitive learning material for
 1. **Community:** - *HIV/AIDS Vishayee He Mala Mahit Hava*, (Marathi)
 2. **Medical professionals:** - *AIDS Diagnosis and Treatment: Handbook for physicians*
 3. **HIV infected and affected people:** *Pudhe Kay?* (Marathi)
 - b) A research study: **Networks, Language and Sexual Behaviors of Men Who Have Sex with Men in an Urban Setting**. The report is available on the website.
- In 1999 we prepared a set of two booklets for PANOS (South Asia) *Madhyamanshi Maitree* (Friendship with Media) and *Madhyamankarita HIV/AIDS Mhanaje Ahe Tari Kay?* (What is this HIV/AIDS? – For media). These were distributed by PANOS to regional media.
- **Woman and AIDS: Issues, Concerns, Responses and Coping**. A short research project was funded by GTZ India. With the use of qualitative research techniques, the project documented concerns of HIV positive women and the barriers to integrate the issue of HIV into existing reproductive and child health services.
- **People with HIV, Stigma, Coping and Support Systems** – funded by NIMHANS through small grants program of Ford Foundation. The research project dealt with the perspectives of people living with HIV regarding stigma they face, how they cope with it and gain support from family, friends and society. It was a qualitative research conducted among HIV positive men (50) and women (29) attending PRAYAS clinic. Gender differences in the perception and experiences of stigma were striking. Women had less control over disclosure of their status to others. Stigmatization and discrimination from health care providers was a major stressor mentioned by many study participants.
- **Catch them young** – A module for training freshly graduated medical students on HIV related issues and infection control measures. It was supported by

n(o)vib, Oxfam Netherlands. The concept behind designing this module was that mainstreaming HIV in medical field needs beginning early. The problems are both with knowledge and attitudes, the latter not being emphasized in medical curricula at all. The medical curricula do not focus on social aspects, the teachers (most of who not formally trained in HIV) lack perspective, and students before graduating are focused more on examinations. The medical fraternity once in medical practice neither has the time nor inclination to learn more. So, the period of medical internship following graduation was selected for conducting workshops specifically designed. These were participatory, had many activities which made the students think, reflect and shape their attitudes. We conducted 14 workshops in 8 medical colleges for 592 students. The response was overwhelming and many students actually volunteered to work with PRAYAS. We also conducted a 3 days trainers training workshop for teachers from these colleges with a hope that the activity is sustained even after the project ends.

- **Assessing the Knowledge Level among Pregnant Women regarding Antenatal Care-Kanya Balkrishna's Dissertation Project, Yale University**

The objective of this short project was to assess the knowledge level of pregnant women regarding various aspects of antenatal care practices. The study was conducted in five health facilities in and around Pune, implementing the PRAYAS PMTCT project. The knowledge level of the women was assessed before and after ANC counseling. The project was undertaken to understand the impact of antenatal counseling provided in PMTCT project.

III. ONGOING PROJECTS/ACTIVITIES

No.	Name of the project	Beginning date	Supported by
1.	Training and Awareness Programs	1994	Internal funds of PRAYAS Health Group
2.	PRAYAS Counseling Center	1998	Internal funds of PRAYAS Health Group
3.	Child Care Project	2000	Internal funds of PRAYAS Health Group

4.	Prevention of Mother To Child Transmission of HIV (PMTCT Project)	September 2002	Elizabeth Glazer Pediatric AIDS Foundation (EGPAF), U.S.A
5.	Graduated Cost Recovery Program (GCR Project)	October 2005	ARCON through grant from Global Fund for AIDS, Tuberculosis and Malaria
6.	PRAYAS Amrita Clinic	January 2006	Self supported Activity
7.	Prenatest Project	March 2007	Agence Nationale de Recherche sur le SIDA (ANRS) and EGPAF
8.	PRAYAS Health Laboratory	April 2007	Ms. Anu Aga's donation and Internal funds of PRAYAS Health Group
9.	Children with HIV/AIDS Initiative (CHAI Project)	September 2007	Clinton Foundation
10.	Pediatric HIV program	January 2008	Abbott Fund

Year 2007-2008 has proved to be very significant for PHG. We undertook various new ventures in this year. This expansion of ongoing activities and new ventures gave rise to the need of having specialized people for specialized tasks. The subsequent increase in the number of employees necessitated the formation of some formal committees so that the organizational structures and systems get formalized and democratized.

IV. OVERVIEW OF THE ONGOING PROJECTS

1. Training And Awareness Programs

The awareness and training programs continue. We are invited to conduct such programs from many places. However we are shifting our emphasis towards creating more animators by training organizations rather than doing awareness programs on our own. The subjects of trainings have also changed over years. Now they have shifted to counseling for ART, adherence counseling, counseling regarding disclosure to children, etc.

2. Counseling Center

The counseling centre continues to provide services to people with HIV and their families. It provides pretest, posttest counseling and ongoing support. In 2006 with the beginning of GCR project many patients started availing the ART (Anti Retroviral Therapy) at subsidized costs. Resultantly, the work of providing support to patients on ART, and maintaining as well as improving the compliance to treatment increased by many folds. ART has helped in increasing the hope for a prolonged and healthy life. More and more people with HIV are now asking questions about having children and about getting married. We are supporting them in the decisions in this matter.



3. Child Care Project

The Child Care project is a self-supported activity, which started in 2000. It evolved because of the felt need to provide care to HIV infected children, which was almost non-existent at that time. At that point of time we decided to provide free treatment to deserving children as in many families it was either the parents or the children could go on treatment at the expense of the other. There was lack of knowledge among health care providers about HIV disease in children and its treatment. We developed expertise in the same and started providing clinical care to HIV infected children.

It is an ongoing activity and most of our funds are from organizational resources and individual donations.

In the initial period, around 20 HIV infected children were accessing clinical care at PRAYAS Amrita clinic. Gradually this number increased and by the end of March 2008 there are more than 150 HIV infected children on the project.

Salient features of the services offered are:

- Guidance for diagnosis of HIV infection among children
- Clinical and immunological evaluation of the child
- Separate OPD for children on Tuesdays and Fridays in the afternoon
- Provision of Antiretroviral treatment as per the standard guidelines

Provision of antiretroviral treatment is an important part of the clinical care provided to these children. Some parents were incapable of paying the cost of treatment for the child in addition to the cost of their own treatment. Under such situation they insisted that we start the treatment for the child and they would stop their own treatment. This 'choice' would certainly prove to be detrimental to the parents as well as to the child. To respond to the situations, we decided to support those children for ART, while parents are linked to the GCR project. More than 150 children are registered in the childcare program. We are providing free antiretroviral treatment for 20 children as of now.

Children's recreational activities

Conducting various recreational activities such as drawing and painting, games, reading, educational games, origami etc for children during child OPD is a routine activity at PRAYAS health group. As a part of the project **Pediatric HIV program**

supported by ABBOTT funds many more educational tools that aid learning in languages and mathematics are bought. We have been collecting number of books such as storybooks, books on various skills like origami, drawing and painting, puppets etc. for children attending the clinic.



Sometimes puppets are used to facilitate the dialogue with children about issues related to disease perception, adherence to medicines, health-promoting activities etc.

More often we involve children in the activity directly so that their role becomes participatory than that of an observer.

Most of the times children are not disclosed regarding their HIV infected status. For children, visiting the doctor even when they do not have any apparent illness may lead to apprehension about clinic, doctor, medicines and testing etc. The recreation activities help in building a child-friendly atmosphere in the otherwise grim environment of clinical care facility. If the children feel that they are welcome at this place, it is more likely that they come there gladly.

4. Prevention of Mother to Child Transmission of HIV Project (PMTCT)

In 2002, we started with implementation of the project in a few private hospitals in Pune district mainly in urban area. Eventually we collaborated with different private obstetric facilities for implementation of the project. The initial hurdle was that most of the private health care facilities were not ready to provide care to women with HIV and did not show interest in implementing the project. Doctors used to be apathetic towards HIV patients and apprehensive about providing care to people living with HIV/AIDS (PLWHA). In such situation awareness, sensitization and training of health care providers were imperative parts of the project activities before starting the actual negotiations with the hospital management.

The needs of HIV non-infected women can not be neglected in a PMTCT program especially when HIV prevalence is less. We therefore integrated PMTCT activities with Reproductive and Child Health (RCH) services and did not provide 'stand alone' HIV care. Provision of comprehensive antenatal counseling and care was one of the important objectives apart from rendering PMTCT services. The issue was not only proved to be essential from public health point of view but it has also helped in fetching good acceptance from hospital management during negotiations.

As a part of project activity we conduct multiple on site and off site awareness and training programs. Take home education material is also developed for pregnant women, health care providers etc.

From our experience and theoretical understanding of the issue we have realized that such project cannot be successful without comprehensive approach. We have also linked it to HIV/AIDS care and support program.

Services offered under the project

- Comprehensive antenatal counseling - It offers one to one counseling, guidance and support regarding issues related to pregnancy and necessary laboratory investigations including HIV, pre-test HIV counseling etc.
- HIV screening and confirmation of HIV in suspected cases. Post-test counseling to both HIV uninfected and HIV infected pregnant women.
- Every pregnant woman, who is counseled under the project, is provided take home educational material regarding antenatal care, and HIV awareness.
- Guidance and care to HIV infected women regarding their disease and options available through PMTCT.
- Prophylactic anti retroviral medicines to both mother and child according to the current WHO protocols for PMTCT.
- Obstetric care guidance
- Guidance and support regarding infant feeding
- Facility and support for early diagnosis of HIV infection in the child
- PCP prophylaxis to HIV exposed infants
- Linking HIV infected parents and children to subsidized HIV care programs

Educational material prepared and distributed under this project

For pregnant women

1. An intensely sensitive, simple yet visually attractive booklet has been created for pregnant women. The name given to the booklet is "*Aai Hotana*" (Marathi), It is translated in Hindi as "*Maa Banane se Pahale*" and in English as "*Becoming a Mother*".
2. **Trimester appropriate ANC Cards** are additionally prepared to respond the trimester wise as well as individual complaints and issues. These cards give special importance to the do's and don'ts of a particular trimester.

3. We distribute the booklet '*HIV/AIDS Vishayee He Mala Mahit Have!*' (Marathi) ('I must know this about HIV') to all pregnant women. We believe that spreading awareness about HIV to all irrespective of HIV status is an important aspect of any PMTCT program. It is an important primary prevention intervention.

For HIV infected pregnant women

1. For those pregnant women detected HIV infected and opting to continue with pregnancy we have prepared a booklet '*Tarisudha Aai Hotana*' (Marathi) ('Becoming a Mother, in spite of...'). This is a user friendly booklet written in a style of personal notes of an HIV infected pregnant woman.
2. **Special cards for care during pregnancy and post-partum (for baby care)** for HIV infected mothers have been prepared to keep track of compliance in taking ARV prophylaxis in mother and baby and to monitor the baby's growth, vaccinations and HIV testing schedule.

For health care providers

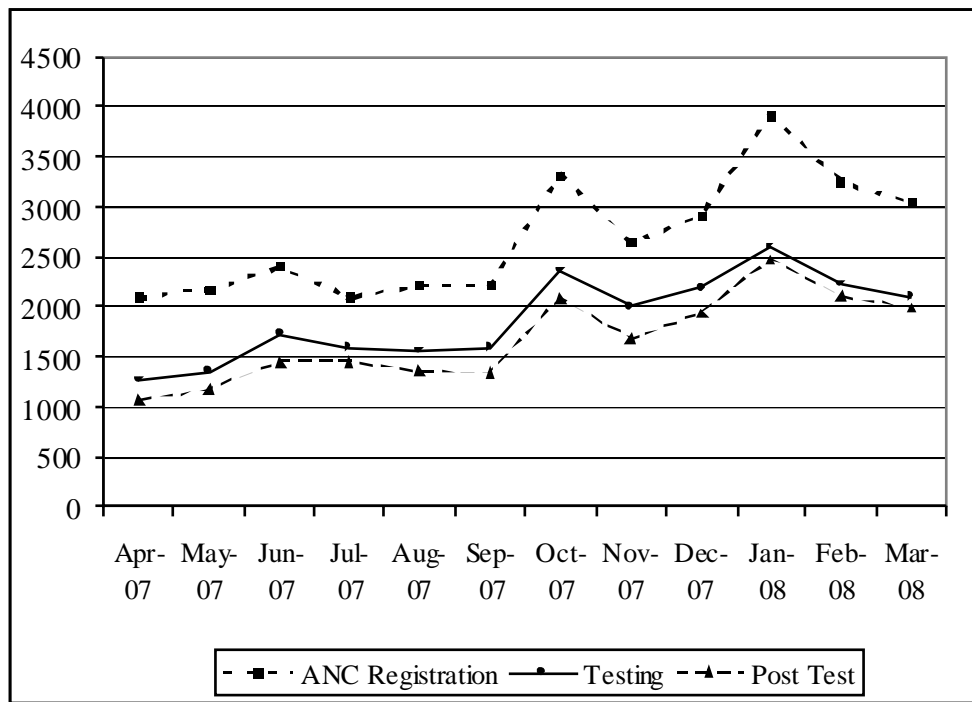
1. **HIV disease in pregnant women and neonates: PMTCT manual about technical information** for doctors at the sites.
2. Understanding the concerns of medical personnel regarding safety, a **short film on Universal Precautions; 'Am I at Risk?'** has been prepared. Some of our EGPAF partners from India are also using the film. They have distributed copies of it to their sites. The film is available in English and Marathi.
3. **A poster in Marathi about universal precautions** has also been prepared to be put up at the sites for ready reference.
4. **Flip Chart for ANC counseling:** The flip chart is useful while conducting group counseling sessions, and for less experienced counselors

Activities conducted by PMTCT project in the year 2007-08

- 20 new sites were started under the PMTCT project during this year. Initial visits, feasibility talks and training of staff from the field were conducted during this process.
- Three of these sites were closed, while one site is on hold.

- A total of 40 training workshops were conducted during this year under the PMTCT program. More than 400 personnel such as doctors, nurses, counselors, and other field staff were trained through these workshops.

PRAYAS' PMTCT program is the largest PMTCT program in private health care sector in India. More than 32,176 women have been provided comprehensive antenatal counseling from April 2007 to March 2008 and about 70% (22525 women) of these have been screened for HIV. Care has been provided to 161 HIV infected pregnant women. Out of the 138 children born to HIV infected mothers only 7 have been infected with HIV.



Number of women registered for antenatal counseling and HIV testing in PMTCT Project

5. Graduated Cost Recovery Project (GCR)

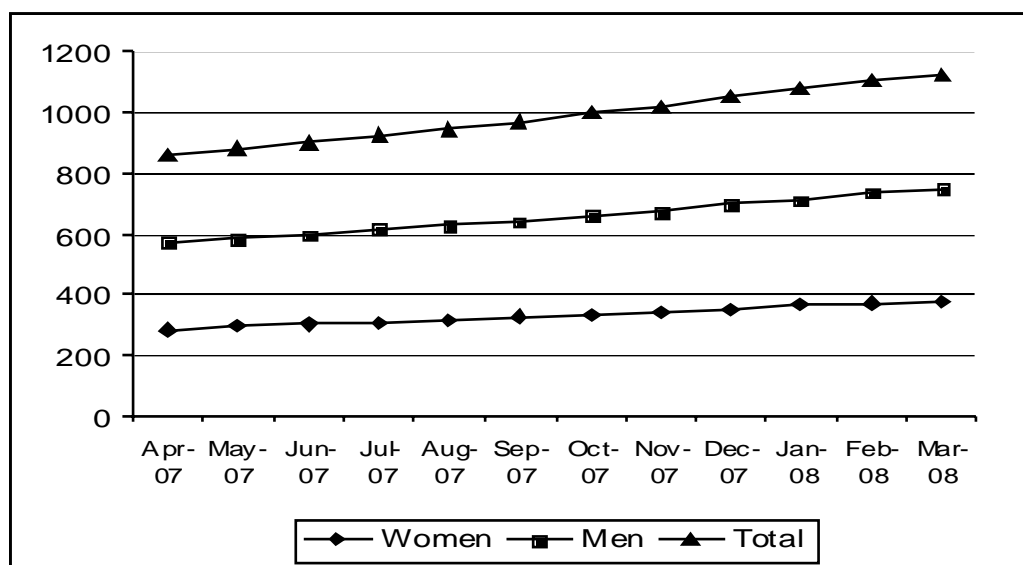
PRAYAS has been providing specialized care to people with HIV since many years and has provided antiretroviral treatment at much cheaper rates by directly negotiating with pharmaceutical companies. However, there was substantial number of people, who could not access the treatment mainly because of economic reasons. To overcome this difficulty PRAYAS started the GCR project with support from

ARCON under GFATM (Global Fund for AIDS, Tuberculosis and Malaria) since December 2005.

The basic concept of the project is that the cost of medicines to the patient is decided as per their economic status. However, all the patients enrolled under the project get medicines at a lower price than in the market. This approach ensures lowest possible cost to the poorest, and the project does not have to bear the cost of medicines.

There are 4 categories (tiers) of proportion of concession for ART medicines. Based on the economic status of the patient, s/he is categorized appropriately.

In-depth counseling sessions are conducted each time the patient comes for follow-up. Pill count, follow up counseling, and check up form an essential part of each visit. Counseling services are provided free to all patients.



Gender distribution of patients in GCR project

Following services are offered under the program

- Clinical care
- Counseling services including pill count for adherence assessment.
- Antiretroviral treatment
- Free CD4 testing (6 monthly)
- Support for some basic biochemistry investigations required for monitoring (Free profile such as LFT, RFT, Hemogram, BSL) is provided once a year.

From Oct 2005 to March 2008

Total no. of patients	Tier 1	Tier 2	Tier 3	Tier 4
1508	551	299	454	204

Till January 2008 the GCR project was being carried out only at Amrita Clinic. We thought of expanding the project in some of the partner institutes such as Nitya Seva Hospital and Waneless hospital, where our PMTCT program is already been implemented. Starting a new site means a lot of work and a long process. Two days training program was conducted for the counselor, lab technicians, and administrators for effective implementation of the project in these institutions. This training was conducted on 22-23 of January. The actual initiation of the sites did not take place till the end of the reporting year.

6. PRAYAS Amrita Clinic

Amrita clinic was merged with PRAYAS in January 2006. Outpatient service to HIV infected people and special OPD for infected children are the important services provided by Amrita clinic.

From April 2007 to March 2008 PRAYAS Amrita Clinic registered about 1157 total new cases. About 25% of these cases were provided free consultation services. A total of 232 patients were registered for HIV treatment in the months of January, February and March 2008.

From its inception till date, PRAYAS Amrita clinic has provided services to about 4400 patients of HIV.



7. Prenahtest Project

Prenahtest project is a multi-centric, multi-country intervention trial supported by ANRS aimed at investigating the feasibility and impact of couple oriented prenatal HIV counseling sessions on the incidence of partner HIV testing. Prenahtest Project was started in March 2007.

Institute of Public Health, Epidemiology and Development, France (ISPED) is coordinating the project and it is funded by the ANRS (Agence Nationale de Recherche sur le SIDA, (ANRS) Paris, France). This intervention trial takes place in four urban areas where HIV prevalence is less than 10% and where PMTCT services are available. Sites from Asia, Africa, Caribbean and Eastern Europe are involved in the project. The partner sites are:

- 1) Cameroon (Yaoundé): The Epidemiology and Public Health Unit of the Centre Pasteur (CPC)
- 2) India (Pune, Maharashtra province): PRAYAS (Initiatives in Health, Energy, Learning and Parenthood)
- 3) Dominican Republic (Santo Domingo): The CENISMI (Centro Nacional de Investigaciones en Salud Materno Infantil)
- 4) Republic of Georgia (Tbilisi): Maternal and Child Care Union (MCCU)

Sane Guruji Hospital at Hadapsar in Pune was chosen as the site to conduct this research. In this hospital, PRAYAS has been implementing its PMTCT project since 2002. The Prenahtest project is going to be carried out in two phases:

- **Feasibility phase:** (Duration 1 year)

To assess the feasibility of integrating the couple-oriented posttest HIV counseling session within pre-existing health services and to evaluate its acceptability.

- **Trial phase:** (Duration 2 years)

To demonstrate the efficacy of the couple oriented posttest HIV counseling session in different operational and socio-cultural setting.

Under the feasibility phase qualitative data were collected from the health staff, pregnant women and their partners. The analysis of this data is currently in process.

8. PRAYAS Health Laboratory

Laboratory investigations are routine activity for HIV infected patients for monitoring the disease. Some of these investigations, such as CD4/CD8, and routine profile etc. are expensive. Thus, PRAYAS felt the need to have its own laboratory where it could afford to give the patients these tests at much reduced prices (only consumable costs.) The laboratory was established with the generous donation from Ms. Anu Aga.

PRAYAS Health group's laboratory started in April 2007 with some basic instruments. Space for setting up a laboratory was made available by Dr. Sanjeevani Kulkarni. Basic testing facilities such as HIV screening, BSL, Heamogram etc are available at the laboratory.



Quality control and Quality assurance

At PRAYAS Health laboratory strict quality control checks are followed. PRAYAS has both internal and external quality control systems. Periodically randomly selected samples are sent to external standard laboratory for quality check.

Disposals

Laboratory wastes such as used needles, cotton, used vacutainers; gloves etc. are incinerated thrice a week.

As a preventive measure each staff member who needs to handle blood, is tested for HIV and HBs Ag quarterly. The staff members are vaccinated for Hepatitis B.

9. Children with HIV/AIDS Initiative (CHAI Project)

This project has been undertaken for a period of 1 year and is funded by Clinton Foundation. The objective of the project was to link the children coming to Amrita clinic for treatment to public health care facilities. After coming to Amrita clinic, these children are taken to public health care facilities for routine check-up and testing. Counselor from PRAYAS accompanies them on these visits. While the treatment part is given by the public health facilities, PRAYAS provides guidance, counseling, nutritional support and supportive care. A 5-day workshop for HIV infected children on sexuality education was also organized under this project.

10. Pediatric HIV program (Supported by the Abbott Foundation)

Considering the prolonged duration (life long) of care required and the complex psychosocial issues that are associated with HIV, PRAYAS has evolved and adopted the family centered approach. The advantage of such a family-centered approach is that a support system is created within the family. As the family evolves as a unit of support, it would become self-sufficient in providing psychosocial support to the HIV infected members of this unit.

While working with people living with HIV, the most difficult group to work with was the group of children. This group not only has young ages but is also dynamic. Various challenges come up while working with children living with HIV.

The major challenges are:

1. Maintaining regular follow up
2. Ensuring adherence
3. Proper monitoring
4. Managing intermittent hospitalizations
5. Lack of pediatric HIV related care

In order to deal with these challenges, there is urgent need to have pediatric care facilities at locations which are easily accessible to people. Even the monitoring of pediatric HIV needs strengthening, which currently remains largely empirical with hardly any data on natural history of pediatric HIV in India. Early diagnosis is impossible due to lack of facilities for conducting HIV testing. Treatment decisions are currently done only on clinical and immunological basis. These have not been

supported by virology data as facilities for viral load testing are not freely available and those that are available are extremely costly. This is in contrast to the wide distribution of pediatric HIV all over the places. If, pediatric HIV is to be managed adequately then there is a need for scaling up capacities through development and designing of appropriate curricula and trainings.

Since there are substantial pediatric HIV cases at PRAYAS we are trying to develop such a holistic facility with the support from Abbott Fund.

Objectives of the project

1. To develop a model of ideal family based pediatric HIV care
2. To develop a laboratory facility for
 - a. Early diagnosis by DNA PCR using dry blood spots (DBS)
 - b. Monitoring the disease by doing CD4 counts and HIV viral loads (also testing feasibility of using DBS for the same)
 - c. Routine testing for monitoring children on ART
3. To develop training materials and courses for capacity building of health care providers
4. To develop appropriate IEC material for other care providers
5. To document all relevant data in appropriate formats so that the same could be used to develop future interventions as well as research protocols

Project started in January 2008 and the duration of the project is one year. The establishment of the laboratory and making of a film are still in process.

V. WORKSHOPS/MEETINGS/SEMINARS CONDUCTED BY PRAYAS HEALTH GROUP

- 1) PMTCT training workshops
- 2) GCR – Workshop for training staff prior to starting new sites.
- 3) Sexuality, Reproductive Health and HIV/AIDS workshop
- 4) Universal safety precautions workshops
- 5) Panel Discussions at BMCC on HIV and its Social implications
- 6) Management of HIV: CME at Wanless Hospital, Miraj
- 7) Psychological aspects of patients on ART: CME at Wanless Hospital, Miraj

- 8) Ethics and laws of counseling: Training for nurses and counselors at Sasoon Hospital, Pune
- 9) HIV/AIDS: History, Epidemiology and Social Issues - workshop on HIV/AIDS for interns at Dhondumama Sathe Homoeopathic Medical College, Pune



VI. CONFERENCES ATTENDED BY GROUP MEMBERS IN THE REPORTING PERIOD

- 1) 8th International AIDS Conference on Asia-Pacific held at Sri Lanka in August 2007
Attended by Dr. Ritu Parchure and Dr. Trupti Darak

VII. PRAYAS HEALTH GROUP PUBLICATIONS

Papers Presented

1. Kulkarni, S. and V. Kulkarni, *Women and HIV: Why current RCH programs are inadequate?*, in *6th International Conference of AIDS in Asia and the Pacific 2001: Melbourne*.
2. Kulkarni, S. and V. Kulkarni, *10 years of experience of community based awareness programs in 6th International Conference of AIDS in Asia and the Pacific 2001: Melbourne*.
3. Kulkarni, V. and S. Kulkarni, *Sexual behavior of MSM in an urban setting in 6th International Conference of AIDS in Asia and the Pacific 2001: Melbourne*.

4. Darak, S., et al., *Males but not men*, in *4th International Conference of International Society for Culture, Society and Sexuality*. 2003: Johannesburg.
5. Darak, S., *Disclosure graph: A new tool for data collection* in *National conference for study of sexuality and sexual behavior* 2004: Bangalore.
6. Darak, S., et al., *Burden of being discreditable: Fear of stigmatization and its impact on people living with HIV/AIDS (PLWHA)*, in *15th International AIDS Conference*. 2004: Bangkok.
7. Kulkarni, S., et al., *Integrating comprehensive antenatal care: The only way to upscale PMTCT programs*, in *15th International AIDS Conference*. 2004: Bangkok.
8. Kulkarni, V. and S. Kulkarni, *Men who have sex with men: A study in urban Western Maharashtra*, in *Sexuality in the time of AIDS* R. Verma, et al., Editors. 2004, Sage Publications: Delhi. p. 195.
9. Kulkarni, V., et al., *Role of anti retroviral treatment (ART) in coping with HIV/AIDS*, in *15th International AIDS Conference*. 2004: Bangkok.
10. Pant, R., *Stigma in marital relationship*, in *National conference for study of sexuality and sexual behavior* 2004: Bangalore.
11. Pant, R., et al., *Implementing sustainable and effective PMTCT program: Experience in private health care facilities in Maharashtra* in *1st Asia Pacific Women and Girls Best Practices conference*. 2004: Pakistan.
12. Pant, R., et al., *Experiences of PLWHA with respect to stigma and coping-Gender related differences: An analysis using the disclosure data*, in *15th International AIDS Conference*. 2004: Bangkok.
13. Ramkrishna, J., et al., *Perceptions and experiences of stigma among people living with HIV/AIDS: Qualitative data from two Indian clinic populations*, in *15th International AIDS Conference*. 2004: Bangkok.
14. Darak, S., et al., *Feeling the pulse- Use of software for management of PMTCT programs*, in *1st National Conference of AIDS Society of India*. 2005: Delhi.
15. Darak, S., et al., *Disclosing wife's HIV status to husband: Challenges faced during implementation of a PMTCT program*, in *1st National Bioethics Conference* 2005: Mumbai.

16. Darak, S., et al., *40-40: Advantage women*, in *7th International Conference of AIDS in Asia and the Pacific 2005*: Kobe.
17. Kulkarni, V., et al., *Experiences from PMTCT program implemented in private facilities; Evolving a new model of care*, in *1st National Conference of AIDS Society of India. 2005*: Delhi.
18. Kulkarni, V., et al., *Pediatric HIV: Issues, concerns and possible solutions, review of 150 cases* in *7th International Conference of AIDS in Asia and the Pacific 2005*: Kobe.
19. Pant, R., et al., *PLWHA experiences of stigmatization in healthcare setup and its impact on treatment seeking behavior*, in *1st National Conference of AIDS Society of India. 2005*: Delhi.
20. Pant, R., et al., *Ethical dilemmas in management of HIV infected children* in *1st National Bioethics Conference. 2005*: Mumbai.
21. Kulkarni, V., *Efficacy and safety of a fixed dose combination Lamivudine, Stavudine and Nevirapine in the treatment of HIV/AIDS in Indian patients*. *Indian Medical Gazette*, 2006: p. 158-162.

IEC Material

1. "HIV/AIDS Vishayee He Apalyala Mahiti Hava" this is a general information booklet about HIV/AIDS (Marathi)
2. "Children and AIDS" Compilation of articles dealing with different aspects of HIV/AIDS among children (out of print)
3. A Slide set for AIDS awareness programs along with a handbook for animators
4. "Madhyamanshi Maitree" booklet for sensitizing media personnel (Marathi)
5. "HIV/AIDS Mhanaje Ahe Tari Kay" a handbook on HIV/AIDS for media personnel (Marathi)
6. "Chandrapurchya Janglat" a video film for sensitizing people working in the field of HIV/AIDS (Marathi)
7. "Pudhe Kay?" a booklet for HIV infected individuals and their family members (Marathi)
8. "Prashna Apala, Uttar Aplech" a booklet for HIV infected individuals (Marathi)

9. “HIV/AIDS Diagnosis and Management - Handbook for Physicians”
10. “Doctor Kakankade Gelyavar” a beautifully illustrated book addressing issues faced by children suffering from chronic illness such as HIV (Marathi)

VIII. HUMAN RESOURCE STRUCTURE

PRAYAS has a three-tiered institutional structure. These structures are as per the formal constitution of the organization. It consists of

1. Board of trustees
2. The executive committee
3. Group core team

1. Board of Trustees (BoT)

The top most governing body of PRAYAS is the Board of Trustees, which looks after over all decision making and guides the organization.

Members of Board of trustee (BoT) are

1. Dr. Anant Phadake
2. Dr. Vinay Kulkarni
3. Dr. Sanjeevani Kulkarni
4. Dr. Subodh Wagale
5. Mr. Girish Sant

Dr. Sanjay Mehandale was an active member of the BoT. However, he resigned from the board in 2007.

It has been decided to expand BoT and also improve its gender balance.

2. Executive Committee (EC)

It is the second level organizational structure to coordinate the different autonomous groups of PRAYAS (i.e. Health group, Energy group and Resources and Livelihoods group). The directors of these groups constitute the EC. The EC acts as a link between the BoT and the groups. It monitors and manages the common organizational issues as accounts, FCRA and other statutory requirements.

Members of Executive committee (EC) are

1. Dr. Sanjeevani Kulkarni (PHG)
2. Dr. Subodh Wagale (ReLi)
3. Mr. Girish Sant (PEG)

3. Group Core Team (GCT)

This is the third tier of the institutional structure. This is a group level committee. The entire team of PRAYAS Health Group, through democratic procedure elects members of the GCT. The team is elected for a term of one year. It is responsible for conceptualization, execution, monitoring, and evaluation of projects, approving new projects/budgets, recruitment and promotion of staff members. GCT also has the responsibilities of looking after decision-making at the group level, logistical requirements and execution, organizational culture, developing systems for any new projects and overall monitoring and execution of the projects. The overall functioning of PRAYAS Health Group is managed democratically.

Members of the GCT are

1. Dr. Sanjeevani Kulkarni
2. Dr. Vinay Kulkarni
3. Dr. Ritu Parchure
4. Dr. Shrinivas Darak
5. Ms. Vijaya Jori
6. Mr. Abhay Dhamdhare
7. Dr. Trupti Darak
8. Ms. Sarita Kadam

4. Other Committees

Several committees have been set up at group as well as organizational level to help and sustain the democratic processes in the group, to help determine, maintain and nurture the ethical environment and uphold the basic values that are the founding principles of PRAYAS.

Independent Ethics Committee for Research (IECR)

As PHG started undertaking various forms of research through national and international collaborations and as most of the research was likely to involve human subjects, that too from a highly vulnerable population (HIV infected individuals) it was decided that PRAYAS would have its own independent ethics committee to strengthen and institutionalize ethical practices in conducting research. PRAYAS constituted its Independent Ethics Committee for Research on 1st of March 2007.

Members of the IECR are

1. Dr. Sidhivinayak Hirve (MS MPH, Director, Vadu Rural Health Program, KEM Hospital, Pune)
2. Dr. Sanjay Mehendale (MD MPH Deputy Director [Senior Grade], Epidemiology, National AIDS Research Institute (NARI), Pune)
3. Dr. Nandita Kapadia Kundu (PhD, IHMP)
4. Mrs. Manisha Gupte (M Sc, founder trustee and Co-Convener of MASUM)
5. Dr. Jaya Sagade (PhD, Associate professor, ILS Law college, Pune)
6. Dr. Shanta Sathe (PhD, eminent worker in the field of sexuality education)

Dr. Siddhivinayak Hirve was elected as the chairperson of the committee. All research projects undertaken by PRAYAS Health group are reviewed and approved by the committee. It has very strong recommendatory powers and it would suggest modification and advice as and when necessary. The recommendations are binding on PRAYAS Health Group. The decisions are taken generally by a broad consensus, or otherwise by a vote of majority after quorum requirements are fulfilled.

Anti-Sexual Harassment Committee

The committee has been formed, as a statutory requirement for non-governmental organizations in view of providing support that is accessible to people in the organization in case of possibility of any sexual exploitation. This committee is common for all four groups of PRAYAS. Each group has a representation in the committee.

Representative of Anti-Sexual Harassment Committee from PRAYAS Health Group:

- Mrs. Shruti Bhide

Sexual harassment grievance will be dealt on the basis of the related Supreme Court guidelines and judgment on sexual harassment.

Grievance Redressal Committee

An informal group has been set up within the group to handle issues and misunderstandings among personnel to make the working atmosphere more comfortable. Issues beyond this could be referred to the grievance redressal mechanism.

Grievance Redressing

The GCT or EC (in the case of organizational level issues) will address and resolve the grievance and problems arising out of employee's dissatisfaction towards decisions made by the supervisors or organization, or the policies or rules of the organization.

Any employee who feels aggrieved due to rules, policies, and decisions made by any authority or the organization, as a whole, should first approach the concerned GCT or EC (in the case of organizational level issues) for its resolution.

If the employee is not satisfied with the recommendations of the GCT and EC, he/she may approach the 'Board of Trustee'.

5. The Team of PRAYAS Health Group

1. Dr. Sanjeevani Kulkarni (Director)
2. Dr. Vinay Kulkarni (Medical Director)
3. Dr. Ritu Parchure (PMTCT Project Manager)
4. Dr. Shrinivas Darak (PMTCT Project Manager) – (discontinued from August 2007 to pursue his Masters degree from University of Groningen, The Netherlands)
5. Ms. Vijaya Jori (PMTCT Field Coordinator)
6. Ms. Asha Khengare (PMTCT Field Assistant)
7. Mrs. Smita Apte (PMTCT Data Manager)
8. Ms. Amruta Bahulekar (PMTCT, Assistant Field Coordinator)
9. Mrs. Mukta Gadgil (Qualitative Interviewer)
10. Mr. Abhay Dhamdhare (Office Administrator and Data-entry Operator)
11. Mr. Ganesh Khambe (Group Administrator)

12. Mr. Sandeep Jadhav (Driver)
13. Dr. Neeta Gokhale (Senior Clinical Assistant)
14. Dr. Manasi More (Clinical Assistant)
15. Dr. Jaydeep Gangal (Clinical Assistant)
16. Mrs. Shruti Bhide (Lab Technician)
17. Mrs. Seema Khambe (Front Desk Manager)
18. Mrs. Santoshi Ranpise (Amrita Clinic Receptionist)
19. Mr. Rhushikesh Pophale (Accounts Assistant)
20. Mr. Manik Pardhe (Amrita Clinic Counselor)
21. Mrs. Aparna Gagendragadkar (Amrita Clinic Counselor)
22. Mrs. Vaishali Dudhgaonkar (Counselor)
23. Dr. Trupti Darak (Clinical Assistant and Counselor)
24. Dr. Shobha Patil (Counselor)
25. Mrs. Pradnya Edke (Counselor)
26. Mrs. Aparna Joshi (Accountant)
27. Mr. Rakesh Memane (Office Assistant)
28. Ms. Vrushali Kulkarni (Office Assistant)

Personnel discontinued during reporting period:

1. Dr. Aparna Babar (Clinical Assistant)
2. Dr. Sonali Kurlekar (Clinical Assistant)
3. Dr. Bhalachandra Rawal (Clinical Assistant)
4. Ms. Sarita Kadam (Counselor)
5. Ms. Rekha Ramteke (Data Entry Operator)
6. Ms. Renuka Wagh (Assistant of ANRS Project Coordinator)
7. Ms. Nidhi Sharma (Block Coordinator)
8. Mr. Sangramsingh Jadhav (PMTCT block Coordinator for Sangram, Sangali)
9. Mrs. Vaishali Rahane (Field Coordinator)
10. Mr. Nilesh Jadhav (Office Assistant)
11. Mr. Sunil Raut (Office Assistant)
12. Mr. Amol Gaikwad (Office Assistance)

In general, the turnover of clinical assistants is more as most of them are recently passed out medical graduates joining such jobs for the need of experience.



प्रयास

आरोग्य, कर्पा, शिवाण व पालकव
या विषयांतील विशेष प्रयत्न

PRAYAS

Amrita Clinic, Athawale corner building,
Near Sambhaji bridge, Karve Road, Pune 411 004, Maharashtra, India.
Tel. 91 20 25441230 /65615726, Tel./Fax 91 20 25420337
E mail- prayashealth@vsnl.net, Website- www.prayaspune.org