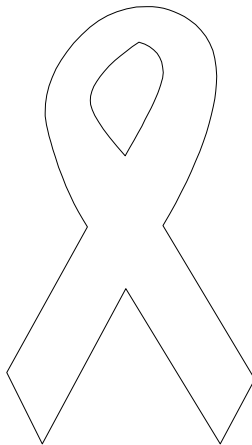


# **PRAYAS**

## **Health Group**

### **Annual Report**

April 2011 to March 2012



#### **PRAYAS**

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*Dear friends,*

It gives us pleasure to present the annual report of PRAYAS Health Group (PHG) 2011-12.

This report gives the details of our activities between April 2011 and March 2012.

We are grateful to our donors, funding agencies, friends, and well-wishers for their continued support.

We are grateful to our patients for motivating us to continue our work in the field of HIV/AIDS.

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## I. LIST OF ONGOING PROJECTS:

No.	Name of the project	Beginning date	Supported by
1.	Training and Awareness Programs	1994	Internal resources of PRAYAS Health Group
2.	PRAYAS Counseling Center	1998	Internal resources of PRAYAS Health Group
3.	Child Care Project	2000	Internal resources 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.	Sakav – Graduated Cost Recovery for ART Program (GCR Project)	October 2005	i. ARCON through grant from Global Fund for AIDS, Tuberculosis and Malaria (till March 2009) ii. Supported by UPS foundation for a period of 1 year (from June 09-May 10) iii. Self supported activity of Prayas Health Group (June 2010 onwards)
6.	PRAYAS Amrita Clinic	January 2006	Self-supported activity
7.	PRAYAS Health Laboratory	April 2007	Internal funds of PRAYAS Health Group
8.	Crucial Transitions – A Research Study	November 2008	Population Research Center, Department of Demography, University of Groningen, The Netherlands and Eric Bleumink Fund University of Groningen, The Netherlands
9.	Linking to Care – A Research Study	June 2011	Internal resources of PRAYAS Health Group and Fellowship of Ms. Mayuri Panditrao
10.	Cervical Cancer Screening and Prevention	November 2011	Self-supported activity Equipment provided by Hirabai Cowasji Jehangir Medical Research Institute

## II. OVERVIEW OF ONGOING PROJECTS AND ACTIVITIES

### 1. Prayas Amrita Clinic (AC) and Counseling Center:

Prayas continues to provide treatment and care to HIV infected individuals through Amrita Clinic. The counseling center provides psychological support to HIV infected as well as affected individuals.

Till March 2012, 5977 patients have been registered at AC. Out of these 5502 were adults and 475 were children. In this year a total of 469 HIV infected individuals were newly enrolled at AC. Out of these, 249 were men, 193 women and 27 children. In this year, 2521 patients are being followed at AC.

Prayas had conducted a sexuality education workshop for HIV infected adolescents and young adults in the year 2010. As a fall out of this, the participants of this workshop formed an informal group of HIV infected peers named 'So What'. The groups started meeting regularly during 2011 to discuss their issues and questions while living with HIV. As a future direction these youth also expressed their wish to work for fellow HIV infected peers coming to AC and eventually for others as well. As an activity, they took up development of a booklet having stories of their experiences around HIV disclosure. This booklet is meant to motivate parents of HIV infected children (who have not yet disclosed the HIV status to their child) to disclose. The members of 'So What' would also help in facilitating further sexuality education workshops for other adolescents coming to AC.

### 2. SAKAV Program

The Sakav program continues to provide antiretroviral treatment (ART) to patients at subsidized rates. This activity is supported using the funds generated through Amrita clinic.

Out of the total patients registered at AC till date, 3345 adults and 305 children were ever started on ART. During these years,

- 202 patients have been reported to be expired,
- 1290 patients have been lost to follow up and
- 205 adults have been transferred to government free ART centers for continuation of ART.
- 1806 individuals are currently taking ART from the Sakav program.

The following table shows the tier wise distribution of patients. These tiers are decided upon the economic status (paying capacity) of the patient. Tier one patients pay the maximum and tier 4 minimum.

Tier 1	Tier 2	Tier 3	Tier 4	Total
1014	222	266	304	1806

### 3. Child Care Project

This project supports treatment for children whose parents cannot afford the treatment. The medicines are given completely free or with some partial support from Prayas (parents put in some amount for the medicines and the rest is supported by Prayas). The consultation fees for these children are also waived. This support is provided till the children enter adulthood i.e. up to 18 years of age.

The following table gives details of the children enrolled in this project.

No. of children receiving ART through the child care project	
100% concession	19
50% concession	6
Some concession	8

Out of these- 30 are on 1<sup>st</sup> line ART while 3 are on 2<sup>nd</sup> line ART medicines.

On an average the 1<sup>st</sup> line ART drugs cost about Rs.500-1000/- per month and the 2<sup>nd</sup> line drugs cost Rs.1000-2000/- per month. Thus, we spend about Rs. 4.5-5 lakhs per year on ART medicines for children. The resources are gathered through individual donations from well wishers.

#### 4. Prayas Health Laboratory

The PRAYAS Health laboratory was established in 2007. All diagnostic and prognostic tests required for detection and management of the disease are done here. Tests for HIV diagnosis (anti HIV), CD4 testing, pre-treatment profile, Hepatitis B (HbsAg) and Syphilis (VDRL) are done at Prayas health laboratory. Viral load and DNA PCR testing is done at Deenanath Mangeshkar hospital, where Prayas has set up its machines. The genotyping test is done at other commercial laboratories.

The following table shows the number of tests done during this year.

CD4	Viral load	Genotyping	Anti HIV	Pre-treatment profile	HbsAg/VDRL
4213	690	57	697	2111	561

#### 5. Cervical Cancer Screening and Prevention

Prayas had collaborated with Hirabai Cowasji Jehangir Medical Research Institute (HCJMRI) Pune for conducting a research study about cervical cancer prevention in HIV infected women. Cervical cancer is the cancer of the mouth of the uterus. Women infected with HIV are at a greater risk of acquiring cervical cancer.

For this research, HIV infected women from Prayas were sent to Jehangir hospital for cervical screening. The facility was shifted to Prayas in August 2011. The research showed that many women had cervical abnormalities which could later turn into cervical cancer. Women who participated in the study benefitted as their abnormalities were detected in time and treated.

As a limited number of women participated in the study, we felt that these services should be extended to other HIV infected women, who could not take part in the study. Thus, in November 2011, cervical cancer screening and treatment facilities (cervical cancer screening services using visual inspection of the cervix using Acetic Acid (VIA), VILI, HPV testing, Colposcopy, biopsy and treatment) were made available for other women (infected or not infected) coming to Prayas. If any abnormalities are detected and treated appropriately, cervical cancer can be prevented. Till March 2012, 157 women were screened at Prayas.

## 6. Prevention of mother to child transmission of HIV (PMTCT) program

The PMTCT program has entered its 10<sup>th</sup> year of implementation from September 2011. The program has expanded to 50 sites in 10 districts of Maharashtra. The performance is summarized below.

Parameters (April 2011 - March 2012)	Number	Percentage
No. of women provided ANC counseling	35785	-
Total HIV testing in ANC women	35177	98
No. of women tested from outside	20434	58
No. of women tested through the project (free HIV testing)	14743	42
No. of HIV infected pregnant women enrolled in the project	201	-
No. of HIV infected women detected in the project	42	21
No. of HIV infected women referred to the project	159	79
No. of deliveries	170	-

Out of **201** women registered in the program, **170** women delivered. After providing these women with PMTCT services, only 4 babies turned out to be infected by 1<sup>st</sup> DNA PCR testing. Thus, with interventions, one can see that mother to child **transmission rate** can be reduced to as low as **2%** as against 25-30% without intervention.

Elizabeth Glaser Pediatric AIDS foundation (EGPAF) has funded this program from its inception till date. This would probably be their last year of providing funding for this program. Though the government PMTCT program has expanded many folds, there is still a need for such a program to cater to HIV infected women accessing care in the private or not-for-profit health care sector. Thus, the Prayas PMTCT program would continue to provide services even if the funding from EGPAF ceases. Efforts are being made for identifying funders and also for collaborating with the government for public-private partnership.

## 7. Other Research Projects

### i. **Crucial transitions: Life course perspective on reproductive career of HIV infected women in Maharashtra, India (RC Study)** (P.I: Dr. Shriniwas Darak)

This is the Ph.D project of Dr. Shriniwas Darak, a senior member at Prayas. In this research the reproductive career of HIV infected women would be studied through a life course perspective. The data collection of this study which began in November 2010, ended in Dec 2011. Analysis of the data and preparation of manuscripts is in process.

	Numbers	Percentage
Total number of women assessed for eligibility for enrollment in the project.	1032	-
Total number of women eligible for enrollment in the project.	827	80
Total number of women introduced about the project.	815	99
Total number of women willing to participate in the project at the first visit.	693	85
Total number of women not willing to participate in the project at the first visit.	52	6
Total number of women with pending decisions about participation in the project at the first visit.	70	9
Total number of women interviewed.	623	82

**ii. Linking to Care - A study to identify the coverage, timeline, and impact of access to continued care in HIV-infected women enrolled in prevention of mother-to child transmission (PMTCT) program and their families. (PI: Ms. Mayuri Panditrao)**

PRAYAS health group initiated a new research study to identify the coverage, timeline, and determinants of access to continued care in HIV-infected women enrolled in prevention of mother-to child transmission (PMTCT) program in India and their families. The study will investigate the association between socio-demographic, health related, and family related factors with access to continued HIV-related care.

This is a panel study of all consenting HIV-infected women who had previously been enrolled in the Prayas PMTCT program. The data collection for this study went on from June 2011 to January 2012. Analysis of the data and preparation of manuscripts is in process.

	Number	Percentage
Total number of women assessed for eligibility for enrollment in the project	1196	-
Total number of women eligible for contacting (women who had provided with consent for contacting)	696	58
Total number of women introduced about the project	374	53
Total number of women willing to participate in the project	323	86
Total number of women not willing to participate in the project	51	14
Total number of women interviewed	323	100

### III. COMPLETED PROJECTS

**1. Prenahtest Project ANRS 12127 (Support by: (ANRS) Agence Nationale de Recherche sur le SIDA, Paris, France & EGPAF, USA) (2007-2012)**

*The Public Health Impact of a Couple-Oriented Prenatal HIV Counselling in Low and Medium HIV Prevalence Countries*

Prevention remains a key intervention for mitigating the HIV/AIDS epidemic, even in the era of anti-retroviral treatments. To achieve this prevention involvement of male partner is crucial. The efficacy of a simple intervention contributing to improve couple HIV counseling and testing in the context of PMTCT, within different programmatic and socio-cultural contexts, has not been assessed to date.

ANRS 12127-The Prenahtest study was a multi-centre multi-country intervention trial which was conducted within four urban areas where HIV prevalence was below 10%, but where PMTCT services were available: Yaounde (Cameroon), Pune (Maharashtra province, India), Santo Domingo (Dominican Republic) and Tbilisi (Republic of Georgia).

During the feasibility phase of the study, the acceptability of the intervention among women and the health staff was assessed which contributed to defining an intervention adapted to the local operational and socio-cultural context. Within the intervention trial, women attending prenatal care were randomized to receive either standard prenatal HIV counseling only, or standard and couple-oriented HIV counseling. Willing partners were also recruited in a partner sub-study towards the end of the trial to get men's perspective. Standardized quantitative questionnaires were administered at inclusion, six months and 15 months post-partum.



This study was supported by ANRS (agence nationale de recherches sur le SIDA) and Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) and is being carried out in collaboration with ISPED, Université Victor Segalen Bordeaux, France

The findings of the feasibility phase are published in a peer reviewed journal. The analysis of trial data is currently in process.

## **2. Cervical Cancer Prevention among HIV infected Women in Pune, India.** (March 2011 – February 2012)

Hirabai Cowasji Jehangir Medical Research Institute (HCJMRI) and Prayas; in collaboration and guidance from the International Agency for Research on Cancer (WHO) have completed a research project to prevent cervical cancer in HIV infected women. This project received funding from the Union for Cervical Cancer Control (UICC), Geneva, Switzerland.

Invasive cervical cancer is an AIDS defining illness. Observational studies in different regions of the world indicate that HIV infected women are at higher risk for oncogenic Human Papilloma virus (HPV) infection and at 5 to 10 fold increased risk of developing cervical cancer. In spite of large burden of both HIV infection and cervical cancer, there are very few studies in India that have addressed the association between them and the ways and means to control the disease. This study intended to comprehensively address early detection and prevention of cervical cancer in HIV-infected women in low and medium resourced settings.

The study assessed the clinical utility of different screening tests (Cytology, VIA, VILI and HPV DNA test) and effectiveness of different treatment methods, cold coagulation in particular, for preventing the progression of high-grade cervical lesions to invasive cancer in 1153 HIV infected women between the age group of 21-60 years.

Women were counseled by trained counselors and demographic and medical information was obtained following a written informed consent. Women were screened using visual inspection with 5% acetic acid (VIA), visual inspection with Lugol's iodine (VILI), cytology and HPV DNA testing using hybrid capture 2 (HC2) tests. All screened women underwent colposcopy, directed biopsy and treatment using cold coagulation for precancerous lesions during a single visit. Women with precancerous lesions not suitable for ablative treatment with cold coagulation were referred for excisional treatment using loop electrosurgical excision procedure (LEEP). Those women with cancers were referred for appropriate cancer directed treatment.

All women are being followed regularly for continued cervical cancer screening every year and we plan a long term follow up of this HIV infected women's cohort.

## **IV. CONFERENCES, WORKSHOPS AND MEETINGS ATTENDED BY GROUP MEMBERS**

1. Conference on Translational Research in HIV/AIDS, Goa, India, 12-14 January 2011.
2. 6<sup>th</sup> IAS Conference on HIV Pathogenesis, Treatment and Prevention, Rome, Italy, 17-20<sup>th</sup> July 2011.
3. The 10th International Congress on AIDS in Asia and the Pacific, Busan, Korea, 26-30<sup>th</sup> August 2011.
4. Course on VIA, Colposcopy and Treatment of Cervical Neoplasia at Nargis Dutt Memorial Cancer Hospital (NDMCH), Barshi, India jointly organized by NDMCH and the International Agency for Research on Cancer from 7-10<sup>th</sup> November 2011.

5. ASICON, Lucknow, India, 16-18 December 2011.
6. Dr. Vinay Kulkarni is a member of the Technical Resource Group (TRG) for ART of NACO.
7. Dr. Sanjeevani Kulkarni is a member of community advisory board of NARI, Pune.
8. Ms. Vijaya Jori is a member of community advisory board of B.J. medical college, Pune.

## V. PRAYAS HEALTH GROUP PUBLICATIONS

### 1. Papers published in peer reviewed journals

- i. **Acceptability of Male Circumcision for HIV prevention among High-Risk Men in Pune, India.** P. Madhivanan, K. Krupp, V. Kulkarni, S. Kulkarni and J. Klausner, Sexually Transmitted Diseases, June 2011.
- ii. **Declining HIV prevalence among women attending antenatal care in Pune, India.** V. Kulkarni, S. Joshi, N. Gupte, R. Parchure, S. Darak and S. Kulkarni, Transactions of the Royal Society of Tropical Medicine and Hygiene, June 11.

### 2. Papers presented at conferences

- i. **Predictors of treatment failure in HIV infected children-a long term follow up study.** Vinay Kulkarni, Shrinivas Darak and Trupti Darak. Conference on Translational Research in HIV/AIDS, Goa, India.
- ii. **Operationalizing rapid implementation of changing WHO protocols for PMTCT: Experience of a private health sector initiative in India.** Vinay Kulkarni, Vijaya Jori, Ritu Parchure, Shrinivas Darak and Sanjeevani Kulkarni. 6th IAS Conference on HIV Pathogenesis, Treatment and Prevention, Rome, Italy.
- iii. **Going Beyond Counselling: Addressing the Needs of Perinatally HIV Infected Adolescents.** (SaPE008) Manik Pardhe, Sanjeevani Kulkarni, Shrinivas Darak, Mohan Deshpande and Neha Vaidya. The 10th International Congress on AIDS in Asia and the Pacific, Busan, Korea.
- iv. **Operationalizing Roll-out of Option 'A' of WHO Guidelines for PMTCT with Respect to NVP Supply Chain and Adherence: Field Experience of PRAYAS PMTCT Project, Maharashtra, India.** (SuPC038) Vijaya Jori, Smita Apte, Sanjeevani Kulkarni, Ritu Parchure and Vinay Kulkarni. The 10th International Congress on AIDS in Asia and the Pacific, Busan, Korea.
- v. **Perinatally HIV infected adolescents and young adults: The emerging face of AIDS epidemic.** (SaPA017) Vinay Kulkarni, Shrinivas Darak and Trupti Darak. The 10th International Congress on AIDS in Asia and the Pacific, Busan, Korea.
- vi. **Treatment Outcome Among Women With Previous Exposure to AZT Monotherapy for PMTCT and Who Were Later Started on ART.** (SaPB022) Trupti Darak, Vijaya Jori and Vinay Kulkarni. The 10th International Congress on AIDS in Asia and the Pacific, Busan, Korea.
- vii. **Unique problem seeking unique strategies: HIV status disclosures to adolescents.** Vinay Kulkarni, Sanjeevani Kulkarni, Shrinivas Darak, Manik Pardhe, and Neha Vaidya. ASICON, Lucknow, India.