

PRAYAS Health Group

Annual Report
April 2012 to March 2013



PRAYAS

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Dear friends,

It gives us pleasure to present the annual report of PRAYAS Health Group (PHG) 2012-13.

This report gives the details of our activities between April 2012 and March 2013.

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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1. Papers Presented at conference
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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 (Through SAATHII, India)
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 of PRAYAS Health Group
7.	PRAYAS Health Laboratory	April 2007	Internal funds of PRAYAS Health Group
8.	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 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 2013, 6314 patients have been registered at AC. Out of these 5822 were adults and 492 were children. **In this year a total of 337 HIV infected individuals were newly enrolled at AC.** Out of these, 176 were men, 144 women and 17 children. **In this year, 2553 patients are being followed at AC.**

To address various concerns and stressors about growing up with HIV in HIV infected adolescents coming to Prayas, we had conducted a four days residential workshop with 10 boys and 5 girls between the ages of 14 to 24 years in October 2010. The participants of that workshop have formed a support group under the name "So What!" **A similar workshop was again conducted in October 2012 with 17 new participants.** All of them were aware of their HIV status. This workshop was organized by PRAYAS and co-facilitated by Aarogya Bhaan (ABHA) - a group which uses innovative strategies for health communication. The members of 'So What' group also helped in facilitating this workshop.

The objectives of the workshop were

1. To create an open and free environment so that participants are able to talk and ask questions about their sexuality.
2. To help participants understand their sexuality positively.
3. To create a platform for communication during and after the workshop.
4. To demonstrate that the ethos of celebration about sexuality can be maintained even with HIV infected adolescents.

Different tools used for communication were music, singing, drawing, skits, group discussions, using appropriate illustrations while communicating important message or information, etc.

Increasingly enthusiastic participation from the children and their intense discussions affirmed the need for such an intervention.

We also published a book "Kalala tevha" (When I came to know) which is in the form of stories of children from 'So what' group members about their experience of disclosure of HIV status and its impact on them. This book is meant to motivate parents who have not yet disclosed the HIV status to their child to disclose.

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 March 2013, 3651 adults and 321 children were ever started on ART. During these years,

- 297 patients have been reported to be expired,
- 1493 patients have been lost to follow up and
- 418 adults have been transferred to government free ART centers for continuation of ART.

- 1813 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. There is also a special category in which two of the combinations of ART which are not covered under Sakav program are provided at subsidized cost to patients from low socio-economic status.

Tier 1	Tier 2	Tier 3	Tier 4	Special category	Total
1120	147	239	285	22	1813

2. 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	12
50% concession	6
Some concession	6

Out of these- 23 are on 1st line ART while 1 is on 2nd line ART medicines.

On an average the 1st line ART drugs cost about Rs.500-1000/- per month and the 2nd line drugs cost Rs.1000-2000/- per month. Thus, we spend about Rs. 3-3.5 lakhs per year on ART medicines for children. The resources are gathered through individual donations from well wishers.

3. Prayas Health Laboratory

The PRAYAS Health laboratory was established in 2007. All diagnostic and prognostic tests required for detection and management of the HIV 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 another commercial laboratory. In collaboration with Jehangir clinical development centre, Cervical Cancer screening & prevention study is ongoing project at Prayas & reporting of biopsy samples taken under the study is done at laboratory. Fine needle aspiration cytology reporting is also done at the Prayas laboratory. Processing of samples from HPV and HIV co-existence study & GSK HPV vaccination study at JCDC was also done at Prayas Laboratory & the details of number of tests done are as shown in the table.

The following table shows the number of tests of routine follow up patients and of participants enrolled in different studies done during this year.

Test	Prayas	HPV and HIV co-existence study in FSW	HPV vaccination project	Total
Anti HIV	496	246	11	753
CD4	4063	100	75	4243
Profile (Hmg+BSL®+LFT+RFT)	2181	--	--	2181
HbsAg/VDRL	337	300	--	637
Viral load	736	100	77	913
HIV DNA PCR				
Cervical Screening	286	--	--	286
Cervical Biopsy	40	24	--	64
Genotyping	29	--	--	29
Fine needle aspiration cytology	1	--	--	1

4. 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.

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. This research project got completed, but we are following this cohort for next few years. For year 2012-13, the funding for this project was extended by Union for Cervical Cancer Control (UICC), Geneva, Switzerland. We are seeking additional research grants as well as donations for continuation of the (India's largest) cohort.

Understanding the importance of cervical screenings, as was seen from the results of the study, we felt that these services should be extended to other HIV infected women, who could not take part in the study, as well as to even HIV uninfected women. 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. If any abnormalities are detected, they are treated appropriately, so that cervical cancer can be prevented.

Till March 2013, 406 women were screened at Prayas. Out of these 406 women 41 women had revisited to Prayas for 2nd follow up. There were suspected lesions in 21 women. On histopathology report 4 out of 21 women were detected with CIN 3 lesion and others were diagnosed to have CIN 1 or acute/Chronic cervicitis. All were treated with cold coagulation.

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

The PMTCT program entered its 11th year of implementation.

From the beginning of year 2012, our focus was to sustain PMTCT activities at existing hospitals in all districts and to provide quality PMTCT services to pregnant women enrolled in the project.

This year Maharashtra State AIDS Control Society (MSACS) entrusted PRAYAS the responsibility of facilitating partnerships with private sector in Maharashtra to scale up PMTCT program through Public Private Partnership (PPP) in 6 districts. This change would help to share resources, ensure sustainability of the PRAYAS program as well as would help to serve the national goal of ‘virtual elimination of pediatric HIV’.

The program has now expanded to 57 sites in 6 districts of Maharashtra.

The program performance is summarized below.

Parameters (April 2012 - March 2013)	Number
Number of women provided pre test and ANC counseling	35996
Number of pregnant women tested for HIV	35398
Number of HIV infected pregnant women enrolled in the project	188
Number of HIV infected women delivered	159

CD4 count uptake was 97%, Maternal ARV uptake was 89% and Infant ARV uptake was 99% in the program. Only 3 babies turned out to be HIV infected by 1st 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 could probably be their last year of providing funding for this program. Though the government PMTCT program has expanded many fold, there is still a need for such a program in the health care sector. We will continue to seek support for the program from other sources.

6. Collaboration with other Research Projects

During last year there were no new research projects undertaken by Prayas Health group. However PHG collaborated with Jehangir Clinical Development centre (JCDC) by providing infrastructure to its research projects on ‘Oral, anal and vaginal HPV among Female sex workers’ and ‘Feasibility and cost effectiveness of a second HIV test in pregnant women’.

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 (agencenationale de recherchessur 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 has been completed and the findings were published in peer reviewed journal.

2. 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

3. Cervical Cancer Prevention among HIV infected Women in Pune, India.

Hirabai Cowasji Jehangir Medical Research Institute (HCJMRI) and Prayas; in collaboration and guidance from the International Agency for Research on Cancer (WHO) completed a research project to prevent cervical cancer in HIV infected women during 2011-12. This study intended to comprehensively address early detection and prevention of cervical cancer in HIV-infected women in low and medium resourced settings. It 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. The findings of this first phase of the study are published in a peer reviewed journal.

All women enrolled in this study are being followed regularly for continued cervical cancer screening every year. For year 2012-13, the funding for this project was extended by Union for Cervical Cancer Control (UICC), Geneva, Switzerland.

A grant (Cervical Cancer Prevention in HIV infected Women in Pune, India-Part II.) was submitted to NIH for consideration of funding (RO3) to enable follow up of 1153 women enrolled in the ongoing study in HIV infected women. The proposal was revised based on the comments received from NIH and has scored well. The revised comments were approved by Prayas. The final decision of funding from NIH is awaited.

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. Yearly cervical screening is performed for the women. From November 2011 to March 2013, 406 women were screened at Prayas. Suspected lesions were found in 21 women. Further investigation in these 21 women revealed CIN 3 lesion in 4 women and CIN 1 or acute/Chronic cervicitis in the remaining. All the women were treated with cold coagulation.

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

This is the Ph.D project of Dr. Shrinivas 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

5. Ethical Issues in the Delivery of Prevention of Mother-to-Child Transmission of HIV interventions in South India

In order to increase HIV testing of pregnant women and to enhance uptake of PMTCT services, the Government of India is seeking to combine vertical HIV programs with general maternal health services and routinely offer HIV testing. Several small research studies suggest that routinizing HIV testing may be compromising the rights and welfare of women since many providers do not inform their patients about HIV testing or seek informed consent for PMTCT interventions. This study explored current practices of healthcare workers providing HIV testing services in community and facility-based settings concerning confidentiality, counseling and consent for HIV testing and treatment. The study investigated the views of both providers and women about current PMTCT programs in India.

The study was conducted in collaboration with Public health research institute, (PHRI), India. It received financial support from Dr. Purnima Madhivanan's Ethics Fellowship from Fordham University. The data collection was completed at PHRI in Mysore and Prayas in Pune during 01/10/2012 to 30/11/2012. Analysis of the data is in the process.

IV. CONFERENCES, WORKSHOPS AND MEETINGS ATTENDED BY GROUP MEMBERS

1. 2nd National Conference on Bringing Evidence into Public Health Policy (EHPH 2012), October 2012, Bengaluru, Karnataka, India
2. Dr. Sanjeevani Kulkarni is a member of community advisory board of NARI, Pune.
3. Ms. Vijaya Jori is a member of community advisory board of B.J. medical college, Pune.

V. PRAYAS HEALTH GROUP PUBLICATIONS

A) Papers Presented at conference

1. Factors related to loss to follow up among HIV infected children seeking clinical care: Experiences from a private health care facility from India. R. Parchure, T.Darak, X. Lu, S. Darak, S. Kulkarni, V. Kulkarni, P. Emmanuel. 4th International Workshop on HIV Pediatrics, Washington DC, USA, 2012.
2. Transition to 'positive motherhood': pregnancy rates after becoming aware of HIV infection among HIV infected women from Maharashtra, India. Shrinivas Darak, Fanny Janssen, Neha Vaidya, Trupti Darak, Vinay Kulkarni, Sanjeevani Kulkarni, Inge Hutter. XIX International AIDS Conference Washington DC, USA. 2012.
3. Barriers associated with access to continued care in HIV-infected women who had previously enrolled in a large-scale private sector PMTCT program in Maharashtra, India: preliminary results from the "Linking to Care" study. Mayuri Panditrao, Shrinivas Darak, Vijaya Jori, Sanjeevani Kulkarni, Vinay Kulkarni. XIX International AIDS Conference Washington DC, USA. 2012.

B) Papers published in peer reviewed journal

1. Systematic review of public health research on prevention of mother-to-child transmission of HIV in India with focus on provision and utilization of cascade of PMTCT services. Darak S, Panditrao M, Parchure R, Kulkarni V, Kulkarni S, Janssen F. BMC Public Health, 2012.
2. Effect of Highly Active Antiretroviral Treatment (HAART) During Pregnancy on Pregnancy Outcomes: Experiences from a PMTCT Program in Western India. Shrinivas Darak, Trupti Darak, Sanjeevani Kulkarni, Vinay Kulkarni, Ritu Parchure, Inge Hutter and Fanny Janssen. AIDS PATIENT CARE and STDs Volume 27, Number 3, 2013
3. Screening of cervical neoplasia in HIV-infected women in India. Smita Joshi, Rengaswamy Sankaranarayanan, Richard Muwonge, Vinay Kulkarni, Thara Somanathan and Uma Divate. AIDS 2013, 27:607–615
4. Increasing HIV testing among male partners. The Prenahtest ANRS 12127 multi-country randomized trial. Orne-Gliemann J, Balestre E, Tchendjou P, Miric M, Darak S, Butsashvili M, Perez-Then E, Eboko F, Plazy M, Kulkarni S, Loû AD, Dabis F; for the Prenahtest ANRS 12127 Study Group AIDS. 2013 Jan 22.