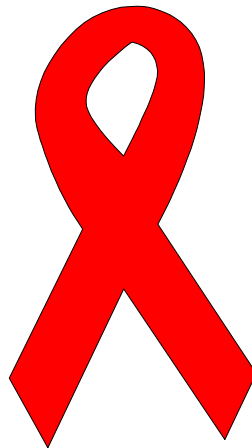


PRAYAS

Health Group

Annual Report
April 2013 to March 2014



PRAYAS

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Dear friends,

It gives us pleasure to present the annual report of PRAYAS Health Group (PHG) for 2013-14.

This report gives the details of our activities from April 2013 to March 2014.

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 and personal donations
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). Partial support for a few components of the program from Oak foundation
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	Adolescent HIV Program	2010	Internal funds of Prayas Health Group and ActionPlus
8.	Cervical Cancer Screening and Prevention	November 2011	Self-supported activity Equipment provided by Hirabai Cowasji Jehangir Medical Research Institute
9	Forum on Child Protection and HIV	2012	Prayas is one of the partner organizations of this forum supported by UNICEF Maharashtra and coordinated by Committed Communities Development Trust (CCDT)
10	Bhavishya Project	Sept 2013	Supported by Keep a Child Alive (KCA)
11	Project UNITE	Nov 2013	Supported by Janssen Infectious Diseases – Diagnostics vBVBA
12	HIV DRDB project	Jan 2014	Supported by National AIDS Research Institute, Pune

II. OVERVIEW OF ONGOING PROJECTS AND ACTIVITIES

1. Prayas Amrita Clinic and Counseling Center:

Prayas continued providing 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 2014, total 6664 patients have been registered at AC. Out of these 6151 were adults and 513 were children. **In this year a total of 351 HIV infected individuals were newly enrolled at AC.** Out of these, 162 were men, 167 women and 22 children. Out of the total patients registered at AC till March **2014**, a total **3967** adults and **343** children were ever started on ART.

2. Adolescent HIV program

The changing context of the AIDS epidemic is posing unprecedented psychological and emotional issues specific to the HIV infected adolescents. The adolescent HIV program works to address these upcoming issues faced by adolescents. The 'So What!' group (a group of HIV infected youth formed to work on 'Concerns of HIV infected and affected children about growing up') is a strong partner in the adolescent HIV program. Almost all activities are done with the active participation of the members of this group.

To address various concerns and stressors about growing up with HIV in HIV infected adolescents coming to Prayas, we conduct a five days residential workshop for youths between the ages of 14 to 24 years. This workshop is organized and conducted by PRAYAS with the help from Aarogya Bhaan (ABHA) - using innovative strategies for health communication. Different tools for communication such as music, singing, drawing, skits, group discussions, using appropriate illustrations while communicating important message or information, etc. are used.

After first workshop in 2010, the 'So What' group was formed and the members of 'So What' group help in facilitating the workshops. Two such workshops were conducted during this year. Adolescents from different organizations like Sahara, Manavya, CCDT also participated along with adolescents from Prayas this year.

'Plus one' workshop –After Prayas had conducted 4 'growing up with HIV and transitioning to adulthood' workshops with HIV infected adolescents and young adults, a next step to these workshops, a 'Plus One' workshop was designed. The HIV infected adolescents got one more member (friend, brother, sister, cousin) along with them who knew about their status. The workshop was designed to facilitate communication between the infected and uninfected peers in order to strengthen their relationships. Bonds of friendship, trust and support were reinforced through different activities. The uninfected peers were provided with information related to HIV in order to eliminate any misconceptions. Through the workshop they realized the stigma and obstacles faced by individuals living with HIV. Concerns and expectations were expressed by both the sides. This was also a very enriching experience for the participants and the facilitators alike.

3. SAKAV Program

The Sakav program continued to provide antiretroviral treatment (ART) to people living with HIV (**PLHIV**) at highly subsidized rates. This activity is supported through the funds generated through Amrita clinic.

During these years,

- **1980** individuals are currently taking ART from the Sakav program.
- **451** adults have been transferred to government free ART centers for continuation of ART.
- **331** patients have been reported to be expired,
- **1571** patients have been lost to follow up and

The following table shows the tier wise distribution of patients. These tiers are decided based upon the economic status (paying capacity) of the patient. Tier one patients pay the maximum amount (which is still highly subsidized as compared to the treatment in other private clinics) and tier 4 the 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 very low socio-economic status.

Tier 1	Tier 2	Tier 3	Tier 4	Special category	Total
1171	237	238	297	37	1980

4. Child Care Project

This project supports treatment for children whose parents cannot afford treatment. The medicines are given completely free or with partial support from Prayas. The consultation fees for these children are waived. Such support is provided till the children enter adulthood i.e. till they become 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	11
50% concession	3
Some concession	4

Out of these- 16 are on 1st line ART and 2 are on 2nd line ART medicines.

On an average the 1st line ART treatment costs about Rs.500-1000/- per month and the 2nd line treatment costs Rs.2000-3000/- per month. We spend around Rs. 2-2.5 lakhs per year on ART medicines for these children. The resources are generated through individual donations from well-wishers.

5. Prayas Health Laboratory

The PRAYAS Health laboratory was established in 2007. All diagnostic and prognostic tests required for diagnosis and management of HIV disease such as HIV testing by antibody detection or by DNA PCR, Hepatitis B and VDRL test, routine hemograms and biochemistry tests, CD4 counts, viral load test are done here. The genotyping test for drug resistance testing is done at another commercial laboratory, at a special concessional rate for Prayas. The biopsies taken for the Cervical Cancer Screening and Prevention project are studied for histopathology at our laboratory. Fine needle aspiration cytology reporting is also done. Reporting of samples from HPV and HIV co-existence study and GSK HPV vaccination study at

Jehangir Clinical Development Center was also done at Prayas Laboratory. The details of number of tests done are as shown in the following table.

Test	Prayas Amrita Clinic	Other projects and tests from other laboratories	HPV vaccination project	Total
Anti HIV	345	109	47	501
CD4	3856	505	0	4361
(Hmg+BSL®+LFT+RFT)	2339	5	--	2344
HbsAg/VDRL	319	--	--	319
Viral load	957	144	27	1128
HIV DNA PCR	8	70	--	78
Cervical Screening	451	--	--	451
Cervical Biopsy	17	67	--	84
Genotyping	30	--	--	30
Fine needle aspiration cytology	4	--	--	4

6. Cervical cancer prevention services:

Cervical cancer can be prevented by primary prevention of HPV infection using HPV vaccination and by secondary prevention by screening women aged 30 to 59 for cervical cancer precursor lesions and its appropriate treatment. India accounts for one fifth of the global burden of cervical cancer however there is lack of awareness among Indian women for this prevention. Prayas has been involved in creating awareness among women free of cost. Cervical cancer screening and treatment facilities (cervical cancer screening services using visual inspection of the cervix using acetic acid (VIA) and Lugol's iodine (VILI), HPV testing, colposcopy, biopsy, treatment using cold coagulation or LEEP. HPV vaccination is also available at extremely reasonable costs at Prayas.

Research study: Cervical cancer prevention in HIV-infected women in Maharashtra

Cervical cancer prevention among HIV-infected women is a major priority, given the high risk of HPV infection, cervical cancer precursor lesions and cervical cancer among them. 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. A large cohort of 1153 HIV-infected women is being followed at Prayas since 2011 to comprehensively address several research questions for cervical cancer prevention. Results from the cross sectional component of the study are published in international journals (AIDS and Vaccine). In our study cohort, about 5% of the women had

CIN 2/3 lesions that were treated appropriately. We also reported that sequential testing with VIA and VILI is the most feasible screening approach for cervical cancer screening in HIV-infected women in low-resource countries. We observed a very high frequency of high-risk HPV and multiple infections in HIV-infected women. Any HPV was detected in 44.8% and high-risk ones in 41.0% women. This cohort is being followed at Prayas for the long-term follow-up of enrolled women to evaluate incident/persistent/new HPV infections, and incident CIN lesions and occult CIN in women with persistent HPV infections. The cross-sectional component of the study received funding from Union for International Cancer Control (UICC) from 2011-2012. After that this study is being continued with the help of research donations received for the study.

7. Prevention of Mother to Child Transmission of HIV (PMTCT) program

The Prayas PMTCT program entered its 12th year of implementation.

In the middle of this year Maharashtra State AIDS Control Society (MSACS) announced launch of the national guidelines for PMTCT in the state. During this year our major focus was to participate in and facilitate the activities organized by MSACS/District AIDS Prevention Control Unit (DAPCU) in 6 districts (Pune, Satara, Sangli, Kolhapur, Ahmadnagar and Solapur) of the state regarding roll out of these guidelines. In October, MSACS conducted first Training of Trainers (TOT) for new national guidelines at Pune. PRAYAS participated in the TOT. PRAYAS conducted several training sessions in functional districts. The films prepared by PRAYAS; ‘Conducting a positive delivery’ and ‘Universal Precaution’; were screened in all these training sessions organized by MSACS for doctors in public as well as private sector as well as other health care providers.

The program has now expanded to 330 sites through Public Private Partnership (PPP). We have covered all 74 taluks from our operational districts. The PPP model has helped us to share resources, ensure sustainability of the PRAYAS program. This initiative of scaling up of program through PPP and launching of national guidelines in the state would definitely help to serve the national goal of ‘Elimination of pediatric HIV’.

The program performance is summarized below.

Parameters (April 2013- March 2014)	Number
Number of women provided pretest and ANC counseling	56638
Number of pregnant women tested for HIV	56223
Number of HIV infected pregnant women enrolled in the project	190
Number of HIV infected women delivered	161

In this year, in the program, CD4 count uptake was 99%, maternal ARV uptake was 83% and infant ARV uptake was 99%. 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 rapidly, there is still a need for such a program in the health care sector.

This year we have got partial support for a few components of the program from Oak foundation. We will continue to seek support for the program from Oak foundation and other sources.

8. Project UNITE:

Prayas along with Deenanath Mangeshkar Hospital Research center started a research project in November 2013. This is a randomized, controlled, open-label, multicenter trial to evaluate the effect of access to TAMA (Treatment Advice by Mobile Alerts; an IT system with a cell phone interface) on treatment effectiveness in HIV-1 infected individuals initiated on first-line antiretroviral therapy. Primary objective of this research project is to demonstrate superiority in efficacy of a first-line NNRTI-based regimen in the group having access to TAMA versus the control group receiving Standard of Care (SoC). It will be measured by the proportion of treatment-naïve HIV-1 infected subjects with plasma viral load < 50 HIV-1 RNA copies/mL at Week 48. In addition to the current SoC, participants in TAMA group will also receive treatment reminders, health tips on various topics and advice on symptoms by use of a cell phone. The trial will consist of a screening period of 14 days and study period of 48 weeks for each participant. This project is sponsored by Janssen Infectious Diseases– Diagnostics BVBA.

Up till March 2014, total 7 participants were enrolled in this project. Out of these, 3 were in TAMA group and 4 were in Non- TAMA group i.e. control group.

9. Bhavishya Project:

Prayas became a partner of the Bhavishya project in September 2013. Bhavishya is a collaborative effort of 3 organizations- Sahara Aalhad, Sahasee and Prayas; and is being supported by 'Keep a Child Alive'.

The aim of this project is to improve health and wellbeing of women, children and families affected by HIV/AIDS, TB and poverty in Pune.

Through this project, Prayas would extend its expertise to Sahara Aalhad for capacity building of the staff in pediatric HIV care, managing psychosocial issues faced by children and adolescents living with HIV, conducting 'growing up with HIV and transitioning to adulthood' (GUWHATTA) workshop for adolescents living with HIV and forming and mentoring adolescent peer support group.

In year 1 of the project:

Clinical services -

- 4 children living with HIV were provided critical in-patient clinical care.
- 51 children living with HIV received outpatient clinical consultations.
- Viral load tests were conducted for 34 children living with HIV.

Quality improvement of clinical services and psychosocial support

- 6 clinical mentoring sessions conducted for the clinical staff at Sahara Alhad.
- 6 training workshops conducted for non-clinical staff on psychosocial care.
- 47 adolescents participated in 2 GUWHATTA workshops.

- 20 participants attended a 'Plus One' workshop for HIV infected adolescents and their non-infected friends/siblings.
- Peer support group was formed. 7 peer support group meetings were held.
- 40 adolescents participated in the Annual Meet.
- 26 parents/caregivers participated in 2 workshops for guardians.

10. FORUM ON CHILD PROTECTION AND HIV:

This forum was formed in the year 2012 as a civil society initiative to strengthen the advocacy on behalf of the vulnerable children infected / affected by HIV/AIDS. Objective of this forum is to move beyond sheer survival- related programming to more comprehensive efforts towards ensuring quality of life for children infected and affected by HIV/AIDS. Prayas is one of the partner organizations of this forum. It is supported by UNICEF and coordinated by Committed Communities Development Trust (CCDT).

On **29th - 30th October 2013**, Prayas as the lead organization, the forum convened a 2 days state level consultation on 'Adolescence and HIV' in Pune. The broad areas covered in the consultation were perspective building on adolescents and HIV; current interventions with adolescents with focus on good practices, programming challenges, lessons learnt; unfolding issues related to disclosure, transitioning to adulthood; mainstreaming as well as policy imperatives and way forward.

11. HIV DRDB Project:

Objective: Development of a National HIV Drug Resistance Database by Generating and Utilizing Clinical, Genotypic and Phenotypic Characterization Data of the Prevalent Drug Resistant Strains of Indian HIV-1 Clade C

As very limited data on HIV drug resistance is available in India, generating HIVDR sequence database for Indian HIV-1 Clade C is of prime importance. The proposed study attempts to establish a network of ART sites and centers where genotypic drug resistance assays are being done to develop a database on *pol* gene sequences and mutations, to collect the clinical data to link it with genotyping data and to carry out phenotypic resistance assays to assess the association of novel mutations with HIV drug resistance. The technological tools will be developed for phenotypic drug resistance and replication fitness studies of a subset of Indian HIV-1 Clade C resistant viruses and develop a preliminary database for phenotypic drug resistance in India. The national HIV drug resistance database in the form of web resource will be developed for submission, analysis and retrieval of genotypic and phenotypic data related to HIV drug resistance in the country. It is a multi-centric study in which 20 blood samples will be collected from each center for the genotypic drug resistance and phenotypic test. Prayas is one of the centers for this study. National AIDS Research organization (NARI) is conducting this study. Prayas started sending the blood samples to NARI from Jan 2014. Till the end of March 2014, total 10 blood samples were sent for genotypic and phenotypic test.

III. CONFERENCES, WORKSHOPS AND MEETINGS ATTENDED BY GROUP MEMBERS

1. IAS Kuala Lumpur, 5th International Workshop on HIV Pediatrics, June 2013
2. What is New in Pediatric Guidelines, Vadodara, August 2013
3. Training of Trainers (TOT) for new PMTCT national guidelines, conducted by MSACS, October 2013
4. **'Positive Growing...The Way Ahead': State level consultation on Adolescence and HIV** Forum on Child Protection and HIV (CP-HIV), Oct 2013, Pune.
5. CPHIV Forum, Case study Presentation, Mumbai, December 2013
6. Pre- exposure prophylaxis (PrEP), ASICON2013, Mumbai, December 2013
7. Pediatric HIV & Adolescent Counseling for private practitioners organized by IMA , Nagpur, December 2013
8. Neonatal ART for private practitioners organized by IMA, Nagpur, December 2013
9. CME on sensitizing private sector Gynecologists on new national guidelines for PMTCT launched by NACO, December 2013. Nagpur FOGSI and DAPCU, Nagpur. December 2013
10. CME on sensitizing private sector Gynecologists on new national guidelines for PMTCT launched by NACO, December 2013. IMA Satara, Pediatric Association, Satara and DAPCU, Satara. December 2013
11. CME on sensitizing private sector Gynecologists on new national guidelines for PMTCT launched by NACO, December 2013. Pune FOGSI and DAPCU, Pune. December 2013
12. HIV Science symposium. Chennai, January 2014
13. Cervical Cancer Prevention in HIV infected women, HIV Congress, Mumbai, March 2014,
14. HIV-HPV conference Kolkata, March 2014

IV. REPRESENTATION ON COMMITTEES

1. Dr. Sanjeevani Kulkarni is a member of community advisory board of NARI, Pune.
2. Ms. Vijaya Jori is a member of community advisory board of B.J. Medical College, Pune.
3. Dr. Vinay Kulkarni is in the consultancy services of Emcure Pharmaceuticals Ltd. to provide scientific advice not limited to development of new products /treatment regimens and ARV guidelines in the area of HIV/AIDS

V. PRAYAS HEALTH GROUP PUBLICATIONS

A) Papers Presented at conference

- **Biliary Tract Malignancies in HIV infected persons- A case series** Vinay Kulkarni, Ritu Parchure, Prasad Bhoite and Harshal Gadhikar. ePoster, 2nd International Symposium on HIV and Infectious Diseases (HIV Science 2014), Chennai, India 30th Jan -1st Feb 2014
- **Will It Matter When We Start?- Age At Start Of Anti-Retroviral Therapy (ART) And Reversal Of Stunting**, Poster abstract, IAS Kuala Lumpur, 5th International Workshop on HIV Pediatrics, June 2013

B) Papers published in peer reviewed journal

1. **HIV risk perception among pregnant women in western India: Need for reducing vulnerabilities rather than improving knowledge!** Darak S, Gadgil M, Balestre E, Kulkarni

M, Kulkarni V, Kulkarni S, Orne-Gliemann J; ANRS 12127 Prenahtest Study Group. AIDS Care. 2014; 26(6):709-15.

2. **Human papillomavirus infection among human immunodeficiency virus-infected women in Maharashtra, India.** S Joshi, J M Babu, D Jayalakshmi, V Kulkarni, U Divate, R Muwonge, T Gheit, M Tommasino, R Sankaranarayanan, M R Pillai; Vaccine. 2014 Feb 19;32(9):1079-85

C) IEC material, other literature and media prepared by Prayas Health Group:

- **Phukani:** This book was prepared for the training of ASHA workers and Aanganwadi workers on issues related to PMTCT. It is in the form of a module in which a very effective tool of storytelling by using pictures is used.
- **Growing with HIV... So What! : A case study on engagement with adolescents:** This case study documents our journey together with the adolescents living with HIV to find answers to various questions they were facing while growing up with HIV.
- **Positive Growing ... The Way Ahead :** This is a report on Adolescent and HIV Maharashtra State- level Consultation convened by Prayas as a leading organization on behalf of Forum on Child Protection and HIV on 29th-30th October 2013 in Pune
- **A Film on ‘Conducting a positive delivery’:** This film is prepared for medical personnel’s and discusses issues related to conducting deliveries of HIV positive women. It is based on interviews with doctors who do conduct delivery of HIV infected women. It also contains dos and don’ts and about universal precautions to be taken while conducting deliveries.