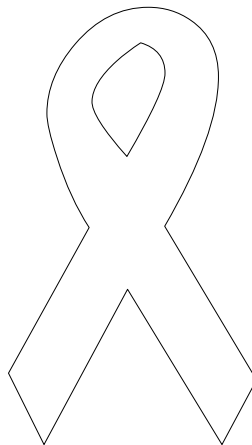


PRAYAS Health Group

Annual Report April 2008 to March 2009



PRAYAS

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Dear friends,

It gives us immense pleasure to present the annual report of PRAYAS Health Group (PHG) 2008-09. It was the first time last year that PHG had published its annual report. Thus, that report contained all the details right from the inception of PRAYAS till the end of financial year 2008. This report is brief and gives the details of our activities between April 2008 and March 2009.

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

We are happy that our patients continue to be with us and give us the strength to carry on and encourage us to venture in new directions.



Contents

I. ONGOING PROJECTS AND ACTIVITIES.....	5
II. OVERVIEW OF ONGOING PROJECTS.....	5
1. Training and Awareness Programs	5
2. Counseling Center.....	6
3. Child Care Project.....	6
4. PMTCT Project.....	8
5. GCR Program.....	9
6. PRAYAS Amrita Clinic.....	11
7. ANRS 12127 - Prenahtest project.....	12
8. PRAYAS Health Laboratory	14
9. Pediatric HIV Program (Supported by Abbott Fund)	15
III. COMPLETED PROJECTS.....	17
1. Children with HIV/AIDS Initiative (CHAI Project).....	17
IV. WORKSHOPS CONDUCTED BY PRAYAS HEALTH GROUP	17
V. CONFERENCES, WORKSHOPS AND OTHER MEETINGS ATTENDED BY GROUP MEMBERS.....	18
VI. PRAYAS HEALTH GROUP PUBLICATIONS	19
1. Papers Presented	19
2. IEC Material.....	20
VII. HUMAN RESOURCE STRUCTURE	21
1. Board of Trustees (BOT)	21
2. Members of Executive Committee (EC).....	22
3. Members of Group Core Team (PHG GCT)	22
4. Other Committees	22
5. The Team of PRAYAS Health Group	23

I. ONGOING PROJECTS AND 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.	Pediatric HIV program	January 2008	Abbott Fund

II. OVERVIEW OF ONGOING PROJECTS

1. Training and Awareness Programs

PRAYAS' initial work consisted of extensive and intensive HIV/AIDS awareness programs. Though the need for such programs has reduced over the years, some people/groups still demand such programs and PHG members continue to conduct them.

With changing times, new issues need to be brought up during such awareness programs. Thus, now issues such as pre-test counseling, HIV testing during pregnancy, prevention of mother to child transmission of HIV, pre marital testing, importance of early testing, availability of treatment, manageability of the disease, etc. are emphasized more.

2. Counseling Center

The counseling center continues to provide support to our patients. In a disease like HIV, mere medicines and clinical check up is never enough to help an HIV infected person to lead normal life. S/he would face and have to deal with social issues such as stigma and discrimination, marriage, bringing up children, adherence to treatment, familial issues and so on. The counselors at PRAYAS are aware of these issues and support our patients for facing these issues and taking the right decisions. One positive aspect that has emerged is that many persons are now seeking help in getting married too. Our counselors are supporting them to find partners.



3. Child Care Project

About 367 pediatric HIV cases are registered at PRAYAS Amrita clinic. Child care project started supporting 65 pediatric patients who could not afford the treatment for their medication (anti-retroviral treatment, ART),

During the year -

- two of these children were shifted to the graduated cost recovery program, as they completed 18 years of age
- 17 children were connected to the government ART center, as part of the CHAI project (Children HIV/AIDS Initiative)
- 3 children expired
- and 7 were lost to follow up

Thus, currently, 36 children are being supported by this project.



Children's library:

Library for children is a very recent venture undertaken by Prayas Health Group. It is developed as a part of Abbott project. Previously, Prayas had conducted various activities for children such as drawing, coloring, puzzles, reading books etc. during their OPD timings. Our basic aim was to keep them involved so that they would not get bored waiting to meet the doctor. Secondly, we also wanted to change their approach/attitude towards the clinic. Such activities reduce their fear towards going to the clinic/to the doctor. In the initial period, these activities were a bit unorganized. In this year, many of us volunteered to spend time with children and also helped in establishing the library exclusively for children in September 2008.

On the days of the pediatric OPD, children sit in our meeting room, and enjoy reading till being called by 'doctor uncle' when their turn comes.



4. PMTCT Project

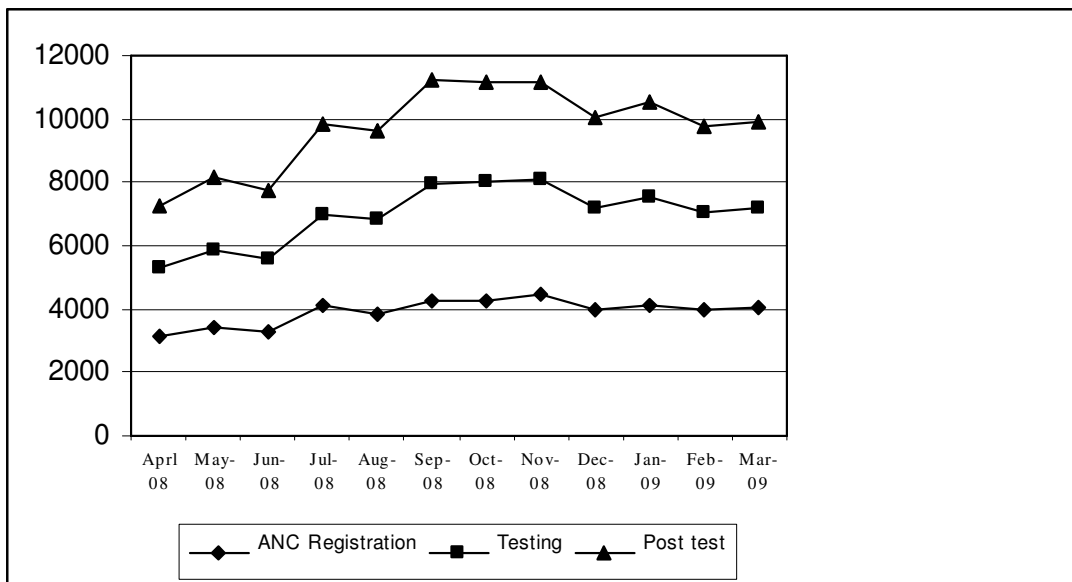
PRAYAS PMTCT program is running for past seven years (since 2002). The program has grown and evolved over these years. High quality of care is given to patients, which reflects through the patient's adherence to treatment and regularity in follow up. We aim at reaching out to more and more number of patients and at the same time try to make the model cost effective and sustainable. The number of cases reached needs to increase so as to achieve this aim. During this year, new activities were designed to increase the referrals for this project. These activities were supported by Abbott fund, which is also supporting the pediatric HIV initiative.

PMTCT Activities 2008-2009

- PRAYAS PMTCT program was operational in seven districts till last year. During this year, it was expanded to 10 districts in Maharashtra.
- From the month of June, we started providing test kits for HIV testing to some of our PMTCT sites as a strategy to increase HIV testing uptake, which increased from 70% in 2007-08 to 77% in 2008-09.
- The XVII International AIDS Conference was organized in Mexico this year. We had sent many abstracts for the same. Out of these, one was selected for oral

presentation, one for poster discussion, one for poster presentation and two were included in the CD. The details of the papers are in the list of publications.

- In January 09, we started networking with different district level networks of people living with HIV. This, helped in reaching out to more number of HIV infected pregnant women. They were given an opportunity to avail better facilities for preventing the HIV transmission to their children or were linked to convenient facilities.
- During this year, 46948 pregnant women were given comprehensive antenatal counseling. About 77% of them (36551) women were tested for HIV. PMTCT services were provided to 165 HIV infected pregnant women. Out of the 140 children born to HIV infected mothers, 5 have been infected with HIV.

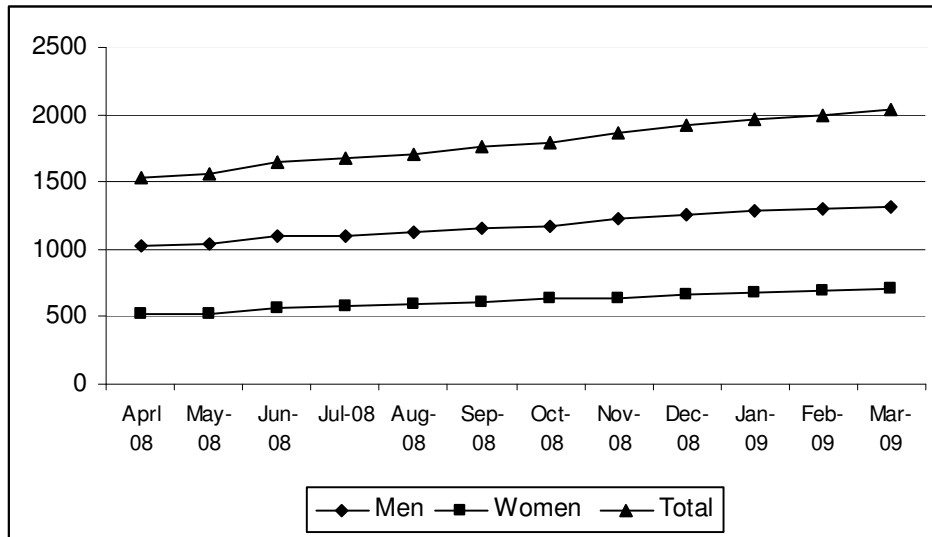


Number of women registered for antenatal counseling and HIV testing in PMTCT Project

5. GCR Program

Our collaboration with ARCON under the GFATM program was terminated at the end of March 2009 by us for lack of any cooperation from them. However, looking at the success and the need of such a support to the patients it was decided that the program would be managed by PRAYAS Amrita Clinic under the same principles of cost sharing for the medicines. The patients would require to pay the laboratory charges which too are

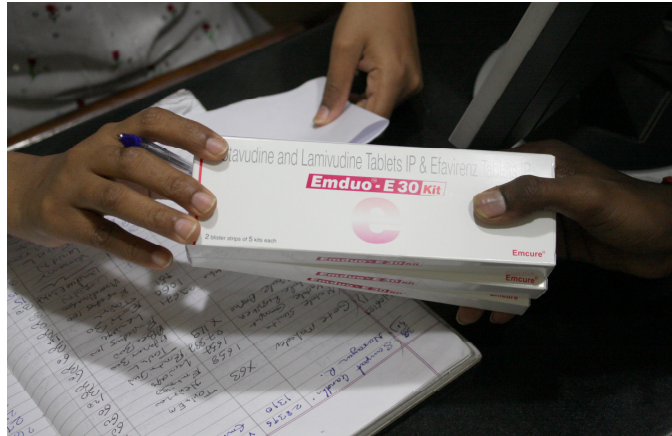
subsidized. The program has been named as SAKAV, meaning bridge. It bridges the gap between HIV infected patients and comprehensive care for HIV.



Gender distribution of patients in GCR project

The following table shows tier wise distribution of new enrollments in GCR Program from April 2008 and March 2009 and total enrollments from October 2005 to March 2009:

	Tier I	Tier II	Tier III	Tier IV	Total
No. of new enrollments from April 2008 to March 2009	218	50	86	169	523
No. of total enrollments from Oct 2005 to March 2009	769	349	540	374	2031



The expansion of GCR program took off at Waneless Hospital, Miraj at the end of April 2008. About 116 patients; 42 women and 74 men were enrolled in their GCR program. However, at the end of March 09, with the end of funding from ARCON, the GCR program at Waneless hospital was discontinued. Services are still provided to patients at Waneless hospital.

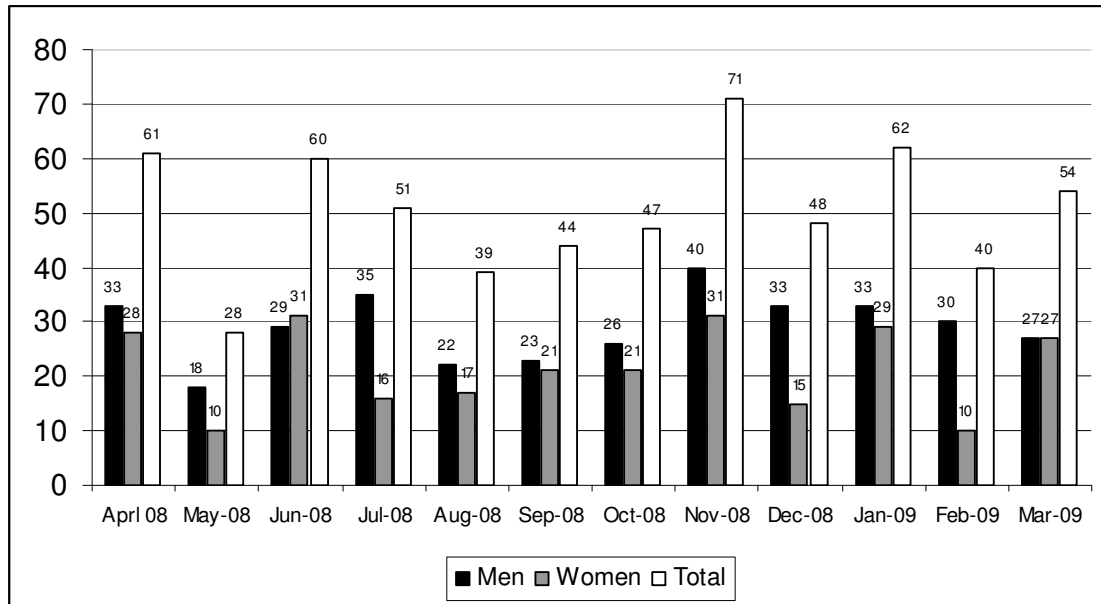
The following table shows tier-wise distribution of patients at Waneless hospital's GCR program –

	Tier I	Tier II	Tier III	Tier IV	Total
No. of total enrollments from April 2008 to March 2009	21	56	30	9	116

6. PRAYAS Amrita Clinic



Amrita Clinic continues to provide clinical care to patients infected with HIV. From April 08 to March 09 Amrita clinic registered 635 new cases. Out of these, 30 were children.



Gender distribution of patients at PRAYAS Amrita Clinic

7. ANRS 12127 - Prenahtest project

A multi country trial to evaluate the public health impact of couple oriented counseling in low to medium HIV prevalence countries

Objective of Prenahtest Project

To investigate the feasibility and impact of a couple-oriented prenatal HIV counselling session on the incidence of partner HIV counselling and testing and couple HIV counselling and on the attitudes and behaviours related to sexual and reproductive health of the couples.

End of feasibility phase

Data collection for the feasibility phase and its analysis was completed in April 2008. A two days workshop of all four sites was organized by ISPED at Bordeaux in April, which was attended by local country coordinators and qualitative interviewers from each country. The purpose of this workshop was to discuss the feasibility phase results, and to plan for the trial phase. This meeting was very fruitful in order to have consensus on various logistical and methodological issues crucial for the trial phase. Even after having rigorous and extensive discussion during these two days some issues remained pending.

It was decided that discussion on these pending issues would be continued through e-mails in following months. A daylong meeting was organized with all Prenahtest study members in August 2008 in Mexico preceding the International AIDS conference. The pending issues were discussed and decisions were made on these issues during this meeting.

Preparation for trial

After this meeting feasibility phase was officially concluded and preparations for trial began. This included

- Dissemination of the findings of feasibility phase to the medical and administrative staff of Sane Guruji hospital where the trial is being conducted in India
- Finalization of trial procedures and protocols
- Finalization of consent forms and tools for data collection and its approval from the ethics committee
- Training of personal to conduct recruitment, interviews and to deliver couple oriented counseling
- Development and printing of study information leaflet, study cards and other material

A computer generated list of random numbers was prepared centrally at ISPED and was given to each site. Similarly, the database was centrally designed and installed at each site for data entry.

Beginning of The trial

The trial started on 26th February 2009 in Sane Guruji Hospital, Pune. Among the four participating countries PRAYAS site was the first one to start the recruitment of women. In the first week of initiating the trial, the central coordinator of ISPED visited PRAYAS and reviewed all the procedures and protocols. During these days, many logistical and methodological issues which were not anticipated were discussed and resolved and appropriate changes in the research procedures and data collection tools were made. Eighty-one women were recruited in the project by the end of March 2009. On an average 3 women were recruited in the project on each working day. Total sample size for the project is 434 women and it is expected that the recruitment would be completed

by the end of July 2009. However, the follow-up data collection would continue for next two years.

Recruitment cascade till 31st March 2009

Women informed about the project	262	
Women accepting recruitment session	232	88.55%
Women seen in recruitment session	162	69.83%
Women eligible	134	82.72%
Women accepting participation in the study	102	76.12%
Women recruited	81	79.41%
Women refused participation	32	23.88%
Women randomized to couple oriented counselling group	40	49.38%
Women randomized to standard post-test counselling group	41	50.62%

8. PRAYAS Health Laboratory

Development of laboratory facility:

The objective of setting up the lab was to provide all essential investigations to our patients 'at cost'.

The process started with a study of available technologies for the purpose. Several options were short listed after taking inputs and technical assistance from various experts in the field for assessing quality of the machines. Then quotations were invited and the prices were negotiated. An internal review committee then reviewed all these instruments and those which would provide best output for money were selected. Machines were purchased in April 2008 after completing all the necessary formalities.

- For DNA/RNA PCR: ABS GeneAmp Gold Block System Thermal Cycler and for HIV VIRAL LOADS: Biomerieux NuclisensEasyQ systems were purchased in May 2008. As PHG does not have sufficient laboratory infrastructure to install the PCR machines, we collaborated with Deenanath Mangeshkar Hospital (DMH). We have collaboration with DMH for past many years with respect to PMTCT program as well as for hospitalization of our patients. Space, manpower and paraphernalia required to set up the PCR machines was provided by the hospital. All tests for PRAYAS are been done at the cost of consumables only.

- For setting up CD4/CD8 laboratory PRAYAS has invested from its own resources in a BD FacsCallibur. It was set up in the current site of PRAYAS laboratory. These facilities help us to provide above mentioned tests at much reduced prices.



Currently we are offering the CD4/CD8 test to our adult patients at a minimal cost (approximately @ US \$ 8 per test), lower than anything available in and outside Pune. We are offering the tests at no cost to HIV infected children under our care and intend to extend the same facility to women detected in our PMTCT program. As an attempt to increase out reach and detect more children we are offering **HIV screening of children of HIV infected mothers at no cost.**

9. Pediatric HIV Program (Supported by Abbott Fund)

Development of data management system

Prayas had collaborated with Indian Institute of Technology (IIT), Kharagpur, to develop a high quality and easy to use software. The collaboration did not go through. There were difficulties in using it, as it was a web based online system. There were also problems regarding possibility of access to and analysis of PRAYAS data from the centralized data sharing. We explored other avenues and are currently collaborating with Plural Soft solutions to upgrade their software termed Clinicio to meet our requirements.

Workshop for parents about disclosure HIV status to children:

Dr. Sanjeevani Kulkarni, while working in the field of HIV counseling, especially in pediatric group of patients observed some issues about disclosure to children regarding their HIV status. Parents always had a problem in disclosing. She handled many cases of pediatric disclosure. The shocking fact about the disclosures she handled was that almost all children were above the age of 14. Disclosing at such a late stage could lead to severe consequences. Fortunately, none of her cases resulted in a negative outcome. However, there always remained a possibility of risk in such late disclosures. Even while counseling parents she always emphasized on disclosing to the children themselves. This also meant starting the process of communication about the disease/disclosure at an early age. However, in spite of her endless efforts parents were circumventing the issue. It was felt that the parents ought to take responsibility of the disclosure.

A film 'Dhusar' prepared by Prayas in August 2008, was an effort in the same direction; to convey to parents the importance of disclosure and the possible consequences if, it did not happen in time. The workshop on disclosure was another concrete step in making parents realize the importance of disclosure and to help them to understand how and when to do it. The parents were taken through a gradual process from a point where disclosure was not even there concern to a point where they felt the importance of disclosing and felt the need to take steps towards it. One such workshop was also conducted in Ratnagiri for parents of HIV infected children associated with an NGO named Guruprasad.

Training workshops for NGOs working in the field of HIV/AIDS

With good quality care being provided through the PMTCT program, different efforts were undertaken to reach out to more and more people. One such effort was to network with organizations already working in the field of HIV/AIDS. The objectives of these training were -

To inform about and clarify some concepts of participants about

1. mother to child transmission of HIV and its prevention
2. care and support of HIV infected children
3. diagnosis of HIV in children
4. disclosure and confidentiality

5. HIV testing and treatment
6. locally available care and support services

These trainings helped in capacity building of NGOs and network with them to provide quality care to HIV infected pregnant women and their children.

III. COMPLETED PROJECTS

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

The project was undertaken for a period of 1 year. The objective of the project was to link the children coming to Amrita clinic for treatment to public health care facilities. While the treatment part is given by the public health facilities, PRAYAS provided guidance, counseling, nutritional support and supportive care. The project was terminated in April 2008 due to some technical issues.

IV. WORKSHOPS CONDUCTED BY PRAYAS HEALTH GROUP

Several workshops were conducted between April 2008 and March 2009. The workshops were conducted for doctors, nurses, counselors, parents, social workers and so on. About 2500 individuals were trained on different subjects. The workshops were conducted on the following subjects –

Sr. No	Subject	No. of Workshops conducted
1.	PMTCT workshops	18
2.	Universal Precaution	3
3.	HIV/AIDS Awareness	18
4.	HIV/AIDS Management	3
5.	HIV/AIDS and Sexually Transmitted Diseases (STI)	7
6.	Anti Retroviral Therapy	4
7.	Sexuality	4
8.	Reproductive health	2
9.	Disclosure Workshop	2



V. CONFERENCES, WORKSHOPS AND OTHER MEETINGS ATTENDED BY GROUP MEMBERS

- 1) Prenahtest Project workshop held at ISEPD, Bordeaux, France on 2-3 April 2008
- 2) 17th International AIDS Conference, Mexico from 2-8 August 2008
- 3) Arogya Sauvaad Melava, Sangali in January 2009
- 4) CROI conference, Montreal, 2009.
- 5) Dr. Vinay Kulkarni is a member of the Technical Resource Group (TRG) for ART of NACO.
- 6) Dr. Sanjeevani Kulkarni is a member of community advisory board of NARI, Pune.
- 7) Ms. Vijaya Jori is a member of community advisory board of B.J. medical college, Pune.



VI. PRAYAS HEALTH GROUP PUBLICATIONS

1. Papers Presented

1. Patterns of Disclosure in HIV infected women, detected during pregnancy, their consequences and experiences of stigma. Apte S., Kulkarni S., Kulkarni V., Parchure R., Jori V., and Darak S
2. Providing PMTCT services in private health care sector, in resource limited settings – a comparison of different models. Kulkarni S., Parchure R., Kulkarni V., and Jori V. prepared the presentation.
3. Effect of experiences and/or fear of stigma in HIV infected pregnant women on infant feeding choice and its compliance. Jori V., Parchure R., Kulkarni S., Kulkarni V. and Darak S.
4. Challenges faced by parents in public private partnership program for children with HIV and AIDS (CHAI): Case study of CHA taking treatment from PRAYAS linked to district level public ART center. Bahulekar A., Kulkarni S., Parchure R., Kulkarni V., Darak T.
5. Prevalence and trends of HIV drug resistance mutation in a cohort with known treatment histories. Kulkarni V., Parchure R.

2. IEC Material

a. 'Dhusar' (Blur – Improvising Disclosure)

Considering the potential of audio-visual medium we prepared a film on issue of HIV disclosure in HIV infected children. The film is meant for caregivers of the HIV infected children. To develop the theme, concept & script etc we organized a day's workshop of the fresh and upcoming artists in the field & discussed the basic issue of HIV/AIDS and the complexities of the problem in case of infected children.

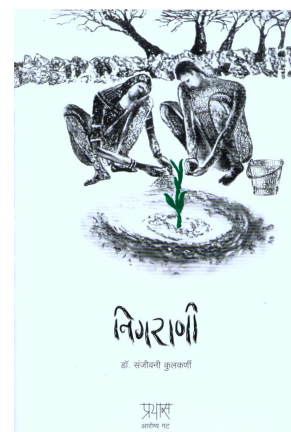
Many of them gave their proposals. Out of these the best proposal was selected for making the film. The theme was formulated and conceptualized by Mr. Vaibhav Abnave. The film was released in August 2008. The film is in Marathi with



English subtitles. 'Dhusar' (Blur – Improvising Disclosure)

b. Nigrani (Nurture with Love)

We have developed the booklet for care providers. It is aimed at parents or institutional care providers looking after HIV infected children. The booklet is in Marathi, gives messages in a simple but appealing language. It would inform about importance of early diagnosis, care of HIV infected child – nutrition, immunization, growth monitoring, importance of ART and adherence, issues around disclosure, etc.



c. Aushadha Suru Kartana (When Starting Medicines)

This book has been written for HIV infected individuals who need to start ART or are already on ART. The book has been written in a form of a narration by a person, who now needs to start ART. It covers all the questions which generally asked by patients while starting ART. It describes the need and use of ART, importance of adherence, resistance to drugs, importance of tests to be done routinely, side effects of ART and home based care for the same.



d. Anavaran (Disclosure)

We have prepared a booklet for counselors that explore the topic of disclosure in case of HIV. It deals with the complexity and multiple issues related to the topic of disclosure. The booklet talks about disclosures of many kinds such as disclosure in the health care set up, partner disclosure, disclosure to the infected children etc. The booklet also explores other issues related to the process of counseling of HIV infected adults and children. It is prepared in *Marathi*. The booklet is written by two young members of PHG- Ms. Maitreyee Kulkarni and Amrita Bahulekar.



VII. HUMAN RESOURCE STRUCTURE

1. Board of Trustees (BOT)

- a) Dr. Anant Phadake
- b) Dr. Vinay Kulkarni
- c) Dr. Sanjeevani Kulkarni
- d) Dr. Subodh Wagale
- e) Mr. Girish Sant
- f) Ms. Sadhana Dadhich
- g) Ms. Medha Kotwal

2. Members of Executive Committee (EC)

- a) Dr. Sanjeevani Kulkarni (PHG)
- b) Dr. Subodh Wagale (ReLi)
- c) Mr. Girish Sant (PEG)

3. Members of Group Core Team (PHG GCT)

- a) Dr. Sanjeevani Kulkarni
- b) Dr. Vinay Kulkarni
- c) Dr. Ritu Parchure
- d) Ms. Vijaya Jori
- e) Mr. Abhay Dhamdhare
- f) Mr. Ganesh Khambe

4. Other Committees

a) Independent Ethics Committee for Research (IECR)

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. Dr. Shanta Sathe (PhD, eminent worker in the field of sexuality education)
5. Dr. Nilangi Sardeshpande (MSc. Health Sciences, Senior Research Officer with Sathi-Cehat, Pune)
6. Advocate Asim Sarode (BA, LLB)

b) Anti-Sexual Harassment Committee

Mrs. Shruti Bhide continues to be representative of Anti-Sexual Harassment Committee from PRAYAS Health Group.

c) Grievance Reddresal Committee

All trustees are a part of the Grievance reddresal committee.

Members of internal Grievance reddresal committee of PHG

1. Dr. Sanjeevani Kulkarni
2. Mr. Ganesh Khambe
3. Ms. Asha Khengare
4. Ms. Amruta Bahulekar
5. Mr. Sandeep Jadhav

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 (ANRS Project Manager) – (discontinued from August 2007 to pursue his Masters degree from University of Groningen, The Netherlands and joined back in November 08)
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 (ANRS Qualitative Interviewer)
10. Mr. Abhay Dhamdhare (Office Administrator and Data-entry Operator)
11. Mr. Ganesh Khambe (Group Administrator)
12. Mr. Sandeep Jadhav (PMTCT, Driver)
13. Dr. Neeta Gokhale (Amrita clinic, Senior Clinical Assistant)
14. Dr. Manasi More (Amrita clinic, Clinical Assistant)
15. Dr. Madhura Dadekar (Amrita clinic, Clinical Assistant)
16. Mrs. Shruti Bhide (PRAYAS Health Laboratory, Lab Technician)
17. Mrs. Vaishali Dongre (PRAYAS Health Laboratory, Lab Technician)
18. Mrs. Seema Khambe (Amrita clinic, Front Desk Manager)
19. Mrs. Santoshi Ranpise (Amrita clinic, Receptionist)
20. Mr. Rhushikesh Pophale (Accounts Assistant)

21. Mr. Manik Pardhe (Amrita clinic Counselor)
22. Mrs. Aparna Gagendragadkar (Amrita clinic Counselor)
23. Dr. Trupti Darak (Amrita clinic, Clinical Assistant and Counselor)
24. Mrs. Aparna Joshi (Accountant)
25. Ms. Neha Vaidya (Pediatric HIV Program, Training Coordinator)
26. Mr. Prakash Ghanekar (Office Assistant)
27. Ms. Sarita Jadhav (PMTCT, Counsellor)
28. Ms. Maitreyi Kulkarni (ANRS Qualitative Interviewer)
29. Mr. Vitthal Gogate (Accountant)
30. Ms. Sulabha Waghmare (ANRS Introducer)
31. Mrs. Archana Kulkarni (ANRS Data entry operator)

