

# Turning the Tide

CARE AND SUPPORT TO PEOPLE LIVING WITH  
HIV AIDS



**FXB**  international  
Association François-Xavier Bagnoud  
**FXB India Suraksha**



# Acknowledgments

FXB India Suraksha offers this publication as source and inspiration to those infected or affected by HIV & AIDS in particular and as source of information to the society at large. It documents the experiences of many families affected by HIV & AIDS, who have succeeded in living a life of dignity in a society that ostracizes AIDS affected people.

Our grateful thanks to Dr PSKP Raju, General Manager, Medical who heads the team in Visakhapatnam that made it possible for HIV & AIDS infected and affected persons to lead a 'normal' life. Without his valuable guidance to the community we would not have been able to report success stories. We would also like to express our heartfelt appreciation and gratitude to the donors and our partners who are undoubtedly instrumental in bringing about the change in numerous lives.

This report would not have been possible without the kind support and help of the community and many individuals. We would like to extend our sincere thanks to Neeraja Phatak, Independent consultant on Child Rights, for documenting the whole project.

# ACRONYMS & ABBREVIATIONS

**AIDS:** Acquired Immuno Deficiency Syndrome

**ART:** Anti retroviral Therapy

**ARV:** Anti Retro Viral

**ANC:** Antenatal Clinics

**CD4:** CD4 cells are part of the immune system that are attacked by HIV

**CD4 count:** A test that counts the number of CD4 cells in the blood and shows how the immune system is doing

**CoE:** Centre of Excellence

**ELISA:** The enzyme-linked immunosorbent assay

**HIV:** Human Immuno-deficiency Virus

**HCP:** Health Care Providers

**NACO:** National Aids Control Organisation

**OI:** Opportunistic Infections

**PLHIV:** People Living with 'Human Immuno-deficiency Virus'

**PPTCT:** Preventing Parent To Child Transmission

**PVL:** Plasma Viral Load

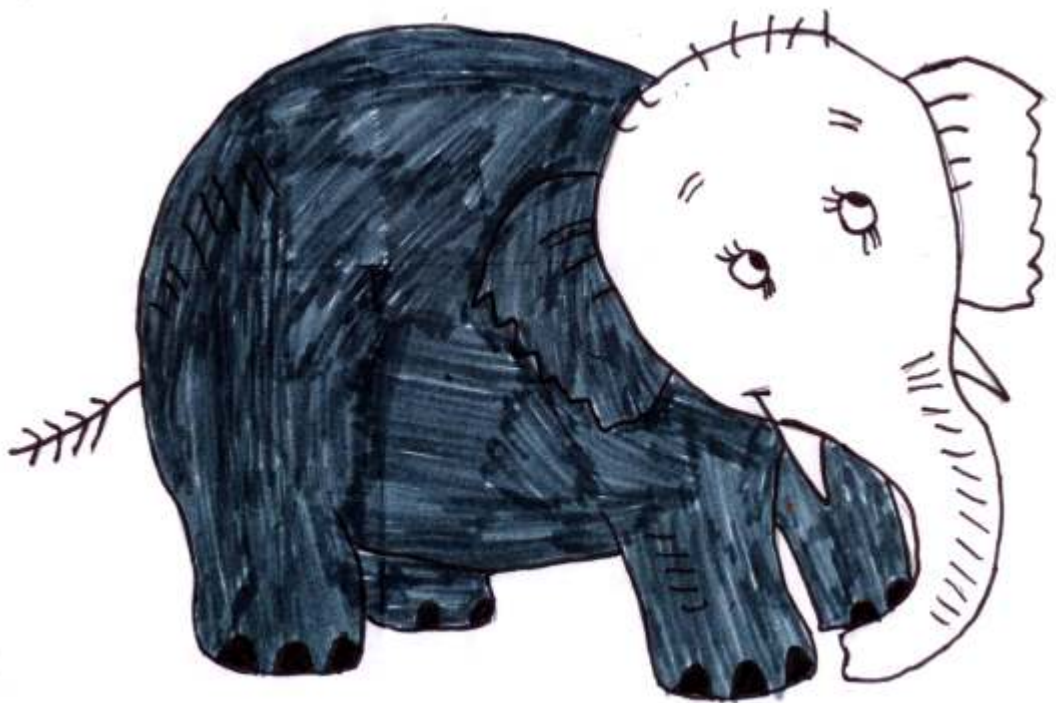
**STI:** Sexual transmitted infection

**STD:** Sexually transmitted diseases

**WPI:** Work Place Interventions

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## WHO WE ARE

We in FXB (François-Xavier Bagnoud) India Suraksha work for the rights of children and their families affected by poverty and disease. We started operations in India in 1991. FXB India Suraksha has now completed nine years registered as an Indian not-profit Section 25 company. The word “*Suraksha* (meaning: “security and protection”) emphasizes our commitment to provide a security net to all children and especially for those specially affected and infected by disease and Poverty.

## WHAT WE DO

We are a result and action oriented field based organisation directly working with the communities across India. We are a group of multi disciplined professionals dedicated and committed to the empowerment of women and children who are stigmatised and abandoned in society. Our specialisations and experiences range from livelihood generation to health, education and prevention of HIV. We build collective capacities of families to enable self-sufficiency through implementation of targeted interventions in health, nutrition, education, hygiene, sanitation and income generation.



## OUR VISION

To facilitate the eradication of poverty for vulnerable and marginalised children and their families through creation of an enabling physical and economic environment to lead their lives with self esteem, dignity and economic self sufficiency.

## OUR PROGRAM AREAS

- Promoting awareness, prevention and treatment of HIV
- Enduring Solutions : Education
- Strengthening Livelihoods : Income Generation & Savings
- Securing clean environment : Water, Sanitation, & Hygiene

## ABOUT THIS STUDY



FXB India Suraksha has been working with PLHIVs (People Living with 'Human Immunodeficiency Virus' ) in Visakhapatnam since 2002, and we had several valuable experiences but the impact of the programme had not been documented. There was therefore an urgent need to document the Care & Support Programme to ensure that valuable experiences were not lost, and the impact of the programme was recorded to enable the organisation to learn and build on this experience.

Two members of FXB India Suraksha and a consultant visited the program in Visakhapatnam in May 2012 with the specific task of documenting this experience through a multi layered participatory approach. We did not want 'answers' to stereotype questions, neither did we want them to evaluate the program; we wanted to know what the people wanted to tell us. The consultant had detailed discussions with people at the Head Office in Delhi, with staff at the Care and Support office in Visakhapatnam but most importantly group discussions and one to one interactions with over 25 PLHIVs . This document reflects experiences of all those who are associated with the Care and Support Program: those receiving support and those providing support.

Over three days the team interacted closely with the members of the programme learning from their lives lessons no university could have taught. As a first step the objective and the process of the documentation were explained to all participants and their informed

consent obtained. Care has been taken to ensure the anonymity of PLHIVs and it has been ensured no quote or information will be traced back. All raw data is in the safe custody of FXB India Suraksha.

The first day, at the World AIDS Orphans Day Event, was just a social meeting and an exchange of pleasantries; what remains in the mind are the smiles and the warmth extended to us. The second day at the FXB India Suraksha Office 35 members participated in a group exercise. They were divided into four groups; and had to find a name for their group and write up two lists of words, one, that would describe their situation and feelings when they found out they were HIV+ and the second would describe their current situation and feelings. The facilitators had to make sure that there was at least one literate member in each group since 95% of the group is illiterate. The members were enthusiastic about the exercise and discussions and laughter ensued, there were also tears; every member participated and then was presentation time. Name for the groups included 'Friends' and *Swarna Kamal* or golden lotus.

There was a great difference in the mindset of the members before and after joining the Care & Support Program. They have moved on in their lives with confidence and compassion.

# INTRODUCTION AND BACKGROUND



## The Human Immunodeficiency Virus - HIV

HIV attacks and damages the body's immune system, which is the body's defence against infection. As a cure does not yet exist, a person infected with HIV has the virus for life, however Antiretroviral Therapy helps slow or reverse the progression of the infection, thus making living with HIV manageable.

HIV infection is now recognized as a crisis affecting all aspects of a person's life (social, cultural, economic), including the family and community. The response to HIV is framed around the three pillars of 'prevention', 'care and treatment', and 'mitigation'.

PLHIVs can live an absolutely normal life if supported emotionally and medically. People living with, and households affected by HIV/AIDS require a wide range of services, including psychological, social, legal and clinical care.

### The situation of HIV & AIDS in India

In India the first case of HIV infection was diagnosed among commercial sex workers in Chennai, Tamil Nadu in 1986.

Demographically the second largest country in the world, India also has the third largest number of people living with

HIV/AIDS. The total number of HIV-infected is estimated to be 2.39 million (Female 39% and children 4.4%). Children under 15 yrs account for 3.5 percent of all infections, 83 percent infections are prevalent in the sexually active and economically productive age group of 15-49 years. The predominant mode of HIV transmission is through heterosexual contact, the second most common mode being injecting drug use. Previously blood transfusion and blood product transfusion were also major causes, but blood safety measures are now in place to prevent such transmission.

Although HIV/AIDS is still largely concentrated in at-risk populations, including commercial sex workers, injecting drug users, and truck drivers, the surveillance data suggests that the epidemic is moving beyond these groups in some regions and into the general population. It is also moving from urban to rural districts.

Six states of Manipur; Andhra Pradesh, Mizoram, Nagaland, Tamilnadu, Karnataka and Maharashtra account for almost half the HIV burden in the country. "In these states, high HIV prevalence rate among women attending antenatal clinics (ANC) and STI (Sexual transmitted infection) patients is an indication that the epidemic has spread from high-risk groups to the general population (women availing facilities at ANC are considered as surrogate for general population)".<sup>2</sup>

<sup>2</sup> <http://www.nacoonline.org> "Field Impact Study of NACO Campaign"



## AIDS Orphans

India today is home to the largest number of AIDS orphans in the world (UN statistics) and second only to South Africa in the number of people living with HIV/AIDS. While the statistics on HIV infections in India is the subject of ongoing controversy, what is undeniable is that India is expected to become the next epic center of the AIDS orphan crisis. The escalating AIDS crisis is leaving an unprecedented number of children orphaned with little or no adult protection and care. The proportion of orphaned children is expected to double in the next five years and remain exceptionally high until 2020 or 2030.<sup>3</sup>

## Migrants – High risk group

Migration of economically productive sections of the population is a common phenomenon all over India. According to the 2007-08 National Sample Survey in India, 29% of the population had migrated, either within India, to neighbouring countries or overseas.

"Being mobile in an itself is not a risk factor for HIV infection. It is the situations

encountered and the behaviour possibly engaged in during mobility or migration that increase vulnerability and risk regarding HIV/AIDS."

Most of the migrant workers are highly mobile and often live in unhygienic conditions in urban slums. Long working hours, relative isolation from the family and geographical mobility may foster casual sexual relationships and make them highly vulnerable to STDs (sexually transmitted diseases) and HIV/AIDS. Migrant workers tend to have little access to HIV/STD information, voluntary counseling testing and health services. Cultural and language barriers make access to such services as do exist even more difficult. Returning or visiting migrants, many of who do not know their status, may infect their wives or other sex partners in the home community.<sup>4</sup>

<sup>3</sup><http://www.crossroadsinternational.org/news/aids-orphans-in-india.html>  
<sup>4</sup><http://www.aidsonline.org/india>



# About the Care and Support Programme

## Relevance of the Programme

Approximately 20% of the total cases of HIV infections in the country are from Andhra Pradesh. Visakhapatnam district is considered as one of the high prevalence districts. Great demand for labour in the construction sector has resulted in migration of men folk from the rural areas into the city. A majority of the PLHAs in the city belong to the lower socioeconomic strata and are unable to access free ART due to the limited number of Government ART centers in the state.<sup>5</sup> As a result of the stigma and discrimination attached to HIV/AIDS and the lack of comprehensive care under one roof.

FXB India Suraksha responded to the 'desperate need' of people with physical, mental, emotional, social and financial support.

## Vision of the Programme

Life and condition of PLHA's and their family members was abysmal due to the alienation of the society, lack of resources and inability to access available services. Care and support program of FXB India Suraksha was started to transform this situation and enable these people to live a qualitative life with pride and dignity in and around the city of Visakhapatnam.

**Aim of the Programme** is to provide comprehensive support and care to PLHIVs.

**Main Objective** is to improve the quality of life and prolong the life span of vulnerable HIV infected and affected families at Visakhapatnam city and adjoining villages in the state of Andhra Pradesh.

*Gomati (name changed) discovered her HIV+ status when her husband died in 2002. He was ill, they thought it was TB but was actually a full blown case of AIDS. Since then Gomati has been 'permitted' to live in her matrimonial home but is kept in isolation. She is not 'permitted' to interact with anybody although she is provided food and shelter. Coming to FXB India Suraksha is like a breath of fresh air for her, she make friends and interact with them. Gomati's CD4 count was 105 cells in 2007 and is 256 cells in 2012. She is on ART and is provided with nutritional supplement from the Centre. A home visit from the counsellors is something she looks forward to. It's a relief from isolation and loneliness.*



## Specific Objectives

- To provide spiritual, emotional and social support to the infected and affected families.
- To provide clinical care.
- To provide socioeconomic support.
- To provide nutritional support in the form of uncooked food items.
- To increase the awareness of the target group to the basic principles of hygiene, sanitation, environmental management, child rights, public health and sustainable community development. Also, sensitizing them with the basic information on risks and safeguards relating HIV-AIDS.
- To create solidarity amongst the members of the community so as to eliminate stigma and prejudice and facilitate the integration of the affected families in the general community

## History of the Programme

In 2002 a small office was set up in Visakhapatnam. One of the first activities initiated was raising awareness on HIV & AIDS in educational institutes. Medicines were dispensed for 'Opportunistic Infection'. FXB India Suraksha made contacts with Chest Physicians, gynaecologists, Blood Banks and 'STI clinics to encourage them to refer patients for counseling. In 2005, 20 persons were initially supported for ART; OI (Opportunistic Infections) medicine and CD4 tests, seeing the success of the programme the support was extended to a total of 60 persons. These 60 beneficiaries started getting free ART from Govt. Centers since the year 2009 with scaling up of ART Centers in the state. FXB India Suraksha now supports 280 infected and affected persons living in and around Visakhapatnam.



*39 year old Narayana (name changed) had come to the centre for a routine visit accompanied by his older brother's wife. Counselling sessions, for him and the family that includes his wife and four children, his parents, older brother and the brother's wife, by FXB India Suraksha has educated and empowered the family to empathize with him and support him. Narayana a diabetic diligently followed the advice of the doctor, "eat well, be careful you don't contract any infection"; and is now back to his profession of gold smithy. He is on ART and from a CD4 count of 35 cells in 2006 his CD4 count in 2012 is 402 cells and has gradually gained weight almost 10 Kilos since 2006 and now weighs almost 58 Kilos – a result of the care and support of his biological family and his newer family FXB India Suraksha.*



## Members of the Care and Support Programme

A majority of the PLHIVs visiting the centre belong to the lower economic strata, are illiterate or barely literate. The adults are in the age group of 28 -39 years and sixty children supported by the programme are between the ages of 8 and 15 years. A majority of the women work as house helps. Some women sell either fish or vegetables. Skills training in making phenyl, candles and tailoring by FXB India Suraksha supplements the income of the women. Of the 89 household currently supported 39 are female headed households.

They are supported in the FXB India Suraksha centre by an experienced physician, a social worker and two peer group counselors.

To make the optimum use of resources FXB India Suraksha ensures that only those who have no support systems are included in the programme. While no one is away turned away those persons who fit into the following criteria are included full time in the programme:

- High Degree of vulnerability (health status / stage of the disease).
- Low socioeconomic condition.
- Large number of family members infected.
- Capacity and willingness shown by recipients to achieve the program objectives

To avoid duplication of services FXB India Suraksha works closely with the administrative authorities, hospitals and positive network groups.

*Andal (name changed) encourages as many people as she can to come to centre and once they come ensures that they remain engaged with the centre. She is not illiterate but recognises 'word pictures' as she points out some information on the chart. What strikes one, is her happy face, her response to any question is first a happy smile.*

*The couple was childless and so adopted a girl child. Suddenly Andal's husband fell ill and wouldn't get better, the diagnosis was never right and he steadily lost a lot of weight and he could barely work for a couple of hours a day. The doctors then asked him to get checked for the HIV virus and unfortunately he tested positive, subsequently when Andal was tested she too tested positive. Their world collapsed around them, what were they to do, they had no idea what this was all about, whether there was a cure for this dreaded 'disease' was it infectious, would they die of this disease? They were full of questions, apprehensions, doubts and despair when they were directed to the FXB India Suraksha Care and Support Program Centre. 'Entering the door was like walking into a new life,' she says.*

*The couple were counselled and put on ART and provided supplementary nutrition. Their CD4 counts began to rise. Andal's husband was soon able to get back to work. Seeing Andal's instant rapport with people and her potential to counsel, she was taken on into the program as a full time staff. Andal says that the love, respect and acceptance at the centre is responsible for everybody to feel well and better.*

*One day as Andal husband was at work, he heard a baby's wail; it seemed to come from the garbage dump nearby. It was an incessant and insistent wail, when he investigated he discovered a three week old baby boy dumped in the garbage. He picked up the baby and brought him to the Care & Support Centre. At the Centre the doctor took charge and was instrumental in saving the baby. Andal and her husband took care of the baby and nursed him back to health. When they could not find his biological parents they decided to adopt him.*

*Today this is a happy family of four, but Andal and her husband believe that had it not been for the FXB India Suraksha Care & Support centre they would have just wasted away their life.*

## Medical Support & Clinical Care

280 persons belonging to 89 families are being supported at the Care and Support Centre. 39 of these are widows and 13 children have lost both their parents are being cared for by a relative most often grandparents. PLHIVs are referred to FXB India Suraksha either by another PLHIV or the Private/Government Hospitals. Persons who have been brought by a friend have generally not confirmed with ELISA (The enzyme-linked immunosorbent assay) test.

FXB India Suraksha does a complete baseline physical evaluation and provides Pre Test Counselling before facilitating a test. Thereupon if necessary initiates ART after 3 sessions of therapy counseling. Follow up counseling is provided during monthly visits to the patients on ART to ensure optimal adherence to the drug regimen; other activities include:

- Prophylaxis and management of opportunistic infections
- Management of HIV/AIDS-related illnesses
- Management of Sexually transmitted infections
- Management of tuberculosis with assistance from Dist. TB Centers
- Palliative care
- Health education



Number of PLHIVs at the Care and Support Centre in May 2012

	Adults			Children 0-18 yrs			Total Number
	Male	Female	Total	Male	Female	Total	
HIV Infected	37	78	115	15	12	27	142
HIV Affected	1	19	20	51	67	118	138
<b>Total</b>	<b>38</b>	<b>97</b>	<b>135</b>	<b>66</b>	<b>79</b>	<b>145</b>	<b>280</b>

ART STATUS of HIV+ Persons							Total Number
	Adults			Children 0-18 yrs			
	Male	Female	Total	Male	Female	Total	
Pre ART	08	36	44	02	01	03	47
On ART	29	42	71	13	11	24	95



## Psychological & Psycho-Social Support

Being affected or infected by HIV & AIDS is not purely a medical problem. It is a social and emotional problem and has ramifications on the economic status of every family. By virtue of the fact that persons infected or affected by HIV & AIDS are completely ostracized by society and the family, 'psychological support' is key to their well being. On being informed of their HIV+ status almost all persons report to have suicidal tendencies and are in despair and are depressed because of the stigma and the misinformation in society regarding the spread of the virus. Poor health prevents people from carrying out tasks associated with their livelihood and at the same time medical expenses deplete their meager savings.

Psychological support is provided which includes initial and follow-up counselling services to patients and their families. Counseling on issues of disclosure. The patients visit the centre once in a month where they meet others like themselves which is an important 'therapy' in building confidence and hope. The Social worker and the peer counselors make regular home visits to all patients to understand the situation of each family and provide appropriate support.

Regular picnics are organized for the groups, it is here that the beneficiaries can be relaxed, enjoy themselves and be true to themselves, they do not have to 'pretend' they are accepted for who they are.

Meetings like these provide the women an occasion to dress themselves. It is these events and these opportunities where they develop confidence in themselves and live each day the best they can.

*Ramya (name changed) described how abusive the doctors were when her test confirmed she was HIV+, 'they shouted at me at asked me to get out, I was afraid and cried', then somebody suggested I should visit the FXB India Suraksha Centre. Here she is supported for ART and provided supplementary nutrition. More importantly, she say, "here people listen to what you want to say.*



### Supplementary Nutrition

Majority of the families and in particular women and children are undernourished and this affects their ability to deal with their already compromised immunological status due to HIV +ve status . When they join the FXB India Suraksha Care & Support Centre their Body Mass Index (BMI) is measured and updated during subsequent monthly medical checkups. The programme ensures minimal nutritional levels to HIV affected families. Dry rations are provided to the most vulnerable families on a regular basis as well as to tide over a crisis. In addition awareness programs on nutrition and balanced diet are conducted to sensitize HIV affected families on the basics of balanced nutritional diet in the context of local food habits.

## Socio-economic Support

In over 60% of the cases the women have become the sole breadwinners, who when they joined the center had no livelihood skills. Livelihood training programmes have been conducted for them on stitching and tailoring, fabric painting, candle making, phenyl making, paper bags and grinding batter for dosas and idlis. Today many of the women have been trained on more than one of the skills and have multiple sources of income. They are also linked to health insurance schemes.



*13 children within the programme are orphans. Although AIDS Orphans are a great source of concern at National Level, FXB India Suraksha counsels and supports the extended family to take care of orphaned children.*

*13 year old Anuradha (name changed) who is taken care of by her aunt. Her parents died in 2003 leaving behind two children. Unlike Anuradha, her older sibling is not HIV+. Her CD4 count was 449 cells when she first came to FXB India Suraksha and is now 630 cells. Anuradha's aunt takes care of both the children like her own. She comes to the centre and interacts with the network meeting with other PLHIVS she get the courage and compassion to take care of her HIV+ niece, Anuradha gets medical, educational nutritional support at the centre.*

*Rakesh (name changed) was brought by a neighbour to the FXB India Suraksha Centre when his father died and his mother was ill, Rakesh's CD4 count was 446 he is on ART and nutritional support from FXB India Suraksha in 2012 his CD4 count is 728. He is looked after by his grandmother.*

*Suraj's (name changed) grandfather takes care of him, when he was referred to the FXB India Suraksha Centre after his parents died in 2007 his CD4 count was 68. He was immediately put on ART, he was also provided nutritional support and his grandfather counselled on the need of adherence, ensuring adequate nutrition and more importantly loving the child. Today Suraj's CD4 count is 1170.*





### **Educational Support To Children Infected or Affected With HIV/AIDS**

The greatest cause of concern for HIV+ mothers is the future and security of their children. They rightly believe that education will empower and enable their children to be independent. 60 children are provided school fee, uniform, books every year. Children's academic performance is monitored by peer educators and social workers.

#### **Participation**

All the members are involved in the planning and delivery of comprehensive care to ensure that HIV/AIDS Care, treatment and support programme intended for them addresses their needs of reinforcing adherence, prevention and care and promoting health-seeking behavior.

#### **Respect For Human Rights and Legal Needs**

Services are provided or facilitated to address stigma and discrimination in health facilities, in communities and in the workplace and promote equal access to care. Further necessary legal assistance is facilitated / provided for PLHS's those who are in need.



# PARTNERSHIPS & ALLIANCES

The Care & Support project would not have come this far without the support of a range of alliance and partnership. FXB India Suraksha's first partner at all times is the community along with them other alliance and partnerships include:

**Aids Ark:** Aids Ark provide funds for Medical, Nutrition and Income Generation Activity components of the program.

**AmeriCares India:** Have donated medicine for the care of PLHIVs.

**Cipla:** Provides 40% discount on ARV medicines.

**Vijaya Medical Center:** Visakhapatnam Provides 20% discount on Investigations.

**Pure Medicals:** Visakhapatnam Provides 30 to 40% discount on generic medicines.

**District Aids Prevention Control Unit & Visakha Aids Control Society: ( DAPCU & VACS)** Provides support for the events.

**Hindustan Construction Company(HCC):** Has donated sewing machines, wet grinders and carts to the women providing support for income generation.

**Population Services International (PSI):** Supports Integrated counselling and testing center.

**Jan Sikshan Samsthan (JSS):** Provides training for over 30 types of IGA training programs including Art Drawing & Painting, Beauty Culture and Health Care, Cooking, Baking Confectionery and Food Processing; Cutting, Tailoring, Dress Making & Designing; Handicrafts, Cottage Industry Course include making: Detergent Powder, Washing Powder & Cleaning Powder; Phenyle, Liquid Blue & Candles, Papads, Paper Covers and File Pads.

**Individual donors:**

Concerned citizens have provided support for children's educational needs.





# EVENTS







# IMPACT OF THE PROGRAMME

## Health

Patients who came to FXB India Suraksha were bedridden or very weak with CD4 counts as low as 3. Most of them have regained their health and are able to earn their livelihood. They all have access to ART and most important they have 'hope' to be able to live their lives with dignity.

## No Cases of LFU (Last for Follow Up)

Last for follow-up is a term used by government for those people who do not come for follow-up for treatment. They are the population that discontinues ART indicated by not collecting ARV or accessing other ART services and fieldworkers are usually sent to identify those and bring them back.

The LFU rate at Government run ART centres is estimated at 10.5% for adults and 5% among children, whereas at FXB centre there is no last for follow-up case reported till date.



Children take part in the candlelight march to mark World AIDS Orphans Day

## Deaths

Till 2012 there there have been two deaths due to resistance to first line drugs reported among our beneficiaries. But, in general the HIV related deaths in the state is reported as 11.4% for adults and 7.3% for children.

## Social Change

Women who earlier had not thought of earning nor had the space to decision are now either key bread winners or supplementing family income, they earn on an average INR 1500 to 2000 per month. As active members of the programme, they socialize with others beyond their immediate family and neighbours; they support each other and have become vocal and more confident in their new roles, as peer group leader, counselors and often as head of families. FXB has played a key role in establishing this strong women's' group. The FXB India Suraksha provides them with a safe social space, where they are not discriminated. The women say, this is their maternal home, and the members are their family. They know no other family nor another home – FXB team is their family.



# CHALLENGES

**Society's Attitude-** Despite awareness raising programmes the greatest challenge is over coming negative and demeaning attitude of society at large and the medical fraternity in particular with regard to HIV & AIDS. Every person in the programme reported the demeaning attitude of the Health Care Providers (HCP) when informing them of their status. Health Care Providers took the high moral ground and made moral judgments on patients' character. Dealing with the impact of the result of the test was one matter, but being at the receiving end of the HCP character judgment has been a devastating experience. Patients report that even if they cough in the clinic they are sent out, conspicuous by its absence is respect and this is so across the board at Government Centres.

**Lack of 2nd line ARV drugs-** Second-line treatment is needed by patients when resistance is developed towards first-line medication. It currently costs about Rs. 4,000 - 8,000 per month in the private market, making it unaffordable to several patients. Currently second line ART is available at 10 Centre of Excellence (CoE) wherein nearly 2000 patients are receiving free second line ART. It is being further extended to 8 ART plus centres now and another 13 centres in this year. The second line drugs are almost ten times costlier than first line drugs and hence there are huge financial implications on the Government.<sup>6</sup>

**Lack of Plasma Viral Load(PVL) test-** At present patients are monitored for immunological improvement with CD4 test once in 6 months. PVL once in 6 months can identify failure to ART early and reduce accumulation of resistant mutations.

**Lack of sensitivity tests for ARV drugs-** Government ART Centres do not have the facilities for sensitivity tests. These tests are used to ensure that the patient is not infected with a transmitted resistant virus and determine the line of treatment antiretroviral resistance.

**Treatment denied in Government and private health care settings-** Patients are denied treatment for normal ailments, particularly surgical treatments in private healthcare settings and also face discrimination at Government hospitals healthcare settings when they disclose their HIV+ status, this has led, in some cases to non-disclosure to avail of treatment.

**Children infected or affected by AIDS-** Children like women are infected by the HIV virus for no fault of theirs. In addition to social isolation and economic deprivation they must deal with the emotional trauma of losing parents..Children in HIV/AIDS affected households begin to suffer even before a parent or caregiver has died as income plummets; schooling is often interrupted and many children are forced to drop out either to care for a sick parent or to earn money. Care and Support for children is therefore more complex and resource intensive, both in terms of skilled personnel and material resources.

**Adherence-** Adherence to the drug regimen of ARV is of vital importance. Often patients go through depression or find it stressful to comply and stop taking their ARV drugs. With children, the care giver must physically give the medicine to the child and the child needs to cooperate and take the medicine.

## Story of Chaitanya (name changed)

Chaitanya says that had it not been for FXB India Suraksha he would not have survived and nor would he have had the will to live; now he says “the longer I live the more I will be able to give society”

A welder by profession he provided his services free of cost to make a training shelter at the FXB India Suraksha Care and Support Centre.

Chaitanya gets Rs.200 pm from the Government ART Center to enable him to adhere to ART, he can access this money with an ATM card. He has handed over his ATM Card to the Centre for them to use the money whoever may need it. He can earn enough he says. His generosity and gratitude does not end here. Chaitanya's village has poor connectivity to public transport. He saw an opportunity and bought an auto rickshaw and employed a driver. He earns ferrying people from the village to the bus stop. But in the earning opportunity Chaitanya has found an opportunity for welfare of his people. He provides free transportation to pregnant women, patients & school going children.

In 2009 he discovered he was HIV+. He had been ill for a long time suffering from diarrhoea and had lost a lot of weight. At 5ft 6inches, he weighed only 44kgs. The doctors had been asking him to test himself for HIV in 2003 but he had put it off. When he did finally undergo the test his CD4 count was only 3 and he was given a hope of 6months to live. He was on the verge of committing suicide when his grandmother prevented him.

The doctors at the Government Hospital referred him to FXB India Suraksha where ART was commenced immediately and he was put on high protein diet; the protein supplement that the FXB India Suraksha provides are two eggs, ½ litre of milk, fish and leafy vegetables. Chaitanya responded well and began to feel better within 2 weeks. He was counselled at the centre and was included in a group where there were others like him, at the centre he could discuss his worst fear with other, find comfort and was given confidence and the will to live. He has not disclosed his status to his parents and brothers they believe he suffered from Tuberculosis. In 2012 his CD4 count has increased to 371 and he weighs 53 kilos. He is now attached to a Government Centre for ART. He is particular about adherence and his diet.

These days he is dealing with another situation! His older brothers think that at 38 he should now get married, as they are unaware of his HIV+ status the situation is complicated, Chaitanya does not mind getting married to an HIV+ girl but finding one in this web of secrecy is difficult. He has left the decision of marriage to the Doctor and FXB India Suraksha, the doctor at FXB is mother, father, brother all rolled into one for the member of Care and support program.





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