

# EMPOWERING THE PEOPLE LIVING WITH HIV

*A compilation of success stories from the  
Community Care Centre, SPARSH Hospital*

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**The PRIDE  
India**

**in Partnership  
with**

**SPYN Welfare  
Foundation**



## PREFACE

The P.R.I.D.E. India (Planning Rural-Urban Development through Education) is a non-governmental organization, registered in 1982 under Societies Registration Act, 1860. With a mission to facilitate the process of empowering marginalized communities, PRIDE works to develop the capacities of the under-served communities in rural Maharashtra. We believe, for development to be sustainable in an extremely vulnerable background it is imperative to use an all-inclusive model encompassing all constituents.

Therefore, our integrated rural development approach focuses on simultaneously delivering a variety of programmes with the objective of generating sustainable change. Our interventions focus on Early Childhood Care and Development, Education, Health & Sanitation, Women Empowerment, Livelihood Development and developing Ideal Villages. Till date we have reached out to more than 1, 75,000 individuals each year.

Started in 2005 our work for People Living with HIV/AIDS is arranged along the following verticals:



**Community Care Centre (CCC)** a five bedded facility inside SPARSH hospital, Sastur with specialized doctors and in house counselors to provide holistic support. The outreach workers also make regular home visits, conduct individual and family counseling, encouraging loss to follow up (LFU) patients to continue regular treatment and facilitate linkages with social schemes.



**Community Support Centre (CSC)** is a facility set up in three districts of Maharashtra to help communities avail the counseling services nearer to their homes. A CSC consists of a peer counselor, a professional counselor, project coordinator and outreach workers who conduct frequent visits and encourage LFU patients to avail the services.



**Anti Retroviral Therapy (ART) Centre** helps the PLHIV to avail medical services including medicines, diagnosis related to opportunistic infection, laboratory CD4 testing every 6 month each client, community counselor, preventive counseling. The ART centre also provides LFU track back list to CSC for further action and follow up.



**Comprehensive support for orphan children living with HIV/AIDS** - PRIDE also provides care and support to children infected with HIV who have either lost one parent or both parents. The services include nutrition, medical treatment, counselling, linkages for educational support/other government schemes and rehabilitation

We also celebrate festivals such as Diwali and Christmas, and host drawing competitions to spread happiness among the PLHIV & CLHIV, many of who have lost all hope to live. For CLHIV we also celebrate their birthdays and present them with small gifts. We encourage CLHIV to pursue their studies and to encourage them we felicitate them for their academic performance.

## **SPYN relationship**

SPYN Welfare Foundation is supporting 'The PRIDE India for Improving access to Health Care Services for People Living with HIV /AIDS through Community Care Centre and Outreach' for a span of 3 years from 2014-2017. The program supports 5 bedded Community Care Centre for diagnosis, treatment and counseling support exclusively for People living with HIV/ AIDS.

In addition, it supports 100 children who are affected by HIV/AIDS who have lost either or both parents. These children are supported with nutrition, medical treatment, counseling, linkages for educational support/other government schemes and rehabilitation support for an improved future.

## STORY 1

### *Against all odds : A courageous Pradnya fights HIV*

Born and raised in humble farmer family Pradnya went through many difficult times early in life. She became an orphan in 2007 when her parents passed away due to AIDS. Subsequently, when she started living with her grandparents a severe drought in the region rendered the family into financial crisis. The situation made things worse for the 15 year old Pradnya, whose grandparents were not even able to provide her nutritious food which is vital for an HIV+ patient. Her condition became poorer day by day and she started facing medical problems such as weakness, weight loss and her CD4 went low rapidly, she also was irregular in school.

In Oct' 2014 her grandparents became aware of PRIDE India's Community Care Centre (CCC) for HIV patients through our outreach worker, they realised it also provides a customised nutrition programme. After which she was enrolled in the program. One year later with regular treatment they started seeing considerable change in her. Her weight increased from 21 kg to 37 kg; height increased 130 cm to 141 cm and CD4 count from 122 to 591. Today, she regularly comes to visit the CCC for nutrition and ART medicine and undergoes her health checkup periodically.

*"I could have never dreamt to achieve so much and I look forward to a healthy and bright future"*

*- Pradnya ,15 years*

*(on being felicitated for her excellent academic performance)*

Her improved health boosted her confidence and Pradnya successfully completed S.S.C (10thStd) and secured 76% marks. On June'16 PRIDE India SPARSH hospital appreciated her with a trophy and congratulated her for her success. An elated Pradnya says "Thank you for supporting me and changing my life positively. I could have never dreamt to achieve so much and I look forward to a healthy and bright future".



## STORY 2

### *Providing livelihood to Bindu helped her rise*

Bindu and Prakash were diagnosed with HIV in 2001 and unfortunately Prakash passed away leaving the responsibility of the household and three young children on Bindu. Having no support from relatives she struggled to fulfill the needs of the family which led her to depression and further deterioration in health.

PRIDE outreach worker identified Bindu's condition and immediately referred her to the Community Care Centre. The outreach team ensured that Bindu and her children received appropriate medical & financial support, and connected her to a local NGO to provide her a livelihood activity. Bindu now is a proud owner of a goat farm (starting from one goat) which supports her financial needs now. The NGO also supports all her children's education by contributing Rs. 450 per child per month. We see a new Bindu- confident, healthy and empowered who looks forward to a bright future for her and her family.

*"From having no income and no hope in life, I earn enough to meet my family needs and save for future. What more can I ask for?"*  
- Bindu, 45 years



## STORY 3

### *A healthier and bubblier Avinash goes back to school*

Avinash a 13 year old resident of Holi, a village in Osmanabad was diagnosed with HIV 3 year ago. Both of his parents too infected with HIV and his father passed away when he was 10 year old.

Every month our outreach worker gets a list from the ART centre of all cases of HIV who are Loss to Follow Up (LFU), Avinash was one of them. The outreach staff visited his house and found the boy underweight (25 kg) and very weak. His family was counseled and Avinash was immediately enrolled with CCC in Dec 2014. At the time of admission his CD4 count was found to be 115 and was put on ART treatment.

After receiving counseling service, supplementary nutrition, ART and continuous home visits , a marked improvement was seen in Avinash. The well designed nutrition plan which consist of *rajgirachikki* (nutrition bar), *sujiladoo* (semolina balls), *chinda* (spiced flattened rice) and protein powder in appropriate quantity helped in a significant increase in weight and improvement in CD4 count from 115 to 835. We see an active Avinash who looks forward to going to school every day and also participates in various school activities, especially sports enthusiastically.



*"I love to eat the ladoos and chikki given by the CCC team, I never thought medicines could be so tasty"*  
- Avinash, 13years

## STORY 4

### *Chandrakant vows to never stop ART*

Being an HIV/ AIDS patient, Chandrakant a 45 years old resident of Turori village knew that his days will not be trouble-free. He registered himself in CCC in 2014 and was regularly taking ART treatment. Being the only earning member of his family the severe drought lead him to migrate to Mumbai in search of some work where he worked as laborer for 3 months. Feeling better, he eventually stopped taking ART treatment regularly.

Soon he realized that his health condition started deteriorating and he could no longer work and returned back to the village. The CCC outreach worker learnt about him and counseled him to come back to the program.

The professional counselor provide him special counseling on drug adherence and side effects of stopping ART treatment. After continuing medication his health condition improved and he promised to adhere to ART.

Chandrakant is very grateful to PRIDE and SPYN Welfare foundation for all the support which makes him feel at home for communicating his fears and problems with the program staff.



*“Thank you for standing with me like a family member and providing all the required help and services on time.”*

*- Chandrakant, 45 years*

## **STORY 5**

### *Discriminated and stigmatized at every stage but Babita never gave up*

Babita, a 27 year old resident of Toramba District Osmanabad was diagnosed with HIV post marriage. Four years ago her husband succumbed to HIV infection leaving her all by herself. In rural India a widow has to face tough times after the demise of her husband and is stigmatized at every stage, adding to that she was HIV positive, which increased her vulnerability further.

Adding to her affliction her father refused to accept her back into the family because of her HIV status due to the fear of social stigma.

The growing discrimination and hopelessness even made Babita think of committing suicide. Through her neighbor Babita came to know about the CCC services. She reached SPARSH in a weak and depressed condition where she was

admitted for eight days availing of quality medical services and psychological counseling. The program provided her a ray of hope to give life a second chance.

The counselor communicated Babita's case to the outreach worker and informed him to visit her family. After a number of follow ups and home visits, her family finally got convinced to accept her. The family counseling sessions helped them to understand the importance of a support system and emotional needs for Babita. Today Babita is empowered, leads a happy and healthy life with her family, and regularly visits SPARSH.

*"Any time I feel stigmatized or discriminated CCC is my second home, the CCC team strengthens me to face my struggles."*

*- Babita , 45 years*





## STORY 7

### *A brighter and energetic Ishwar*



14 years old Ishwar a resident at Narangwadi village, Osmanabad lives with his uncle after the demise of his parents from HIV/AIDS infection. Two years back in 2013 he was admitted in a hospital with complaints of diarrhea and fever and post examination he was diagnosed with HIV. After diagnosis his uncle brought him to SPARSH CCC centre.

Ishwar received medical treatment, counseling and nutrition support at the CCC.

Ishwar's uncle said "after receiving CCC service and nutrition support, we have seen that Ishwar's health status improved and he is going school regularly". The specially designed diet plan helped Ishwar gain his weight to 25 kg and

his CD4 increased from 326 to 560.

The regular home visits by the outreach team, counseling and behavior change communication activity helped him overcome his fears and myths about HIV/AIDS. Ishwar's uncle is impressed with the work the CCC team did and is motivated to take full responsibility of Ishwar. We see a bright and energetic Ishwar ready to go to school and taking regular treatment. The CCC team undertakes regular follow up visits to his house to ensure that Ishwar is taken care of by his family. We are happy to see that his uncle is supportive and confident that one day Ishwar will grow up and support him.

*"I am so happy I am able to go to school again , thank you PRIDE"*

*- Ishwar, 14 years*

## **STORY 8**

*Akash is playing cricket again, thanks to the CCC team*

Akash Baliram Jadhav is a 13 years old native of Shirgur, Bidardist in Karnataka state. Akash became orphan at the age of 5 years when his parents passed away due to HIV infection leaving Akash with his grand mother.

‘After his parents demise Akash feels very lonely and always misses his mother’ says Akash’s grandmother.

The financial conditions at his grandparent’s house were also not so positive. They struggled to make ends meet but ensured that Akash is taken care off. In the month of April, 2015 little Akash was bought to CCC by his grandmother with complaints of weakness and other health problems. His CD4 was 52 and weight was 34 kgs when he was enrolled on special nutrition diet program. The professional counselor counseled his grandmother on his current health status and importance of nutrition for Akash.

After the intervention positive changes have been witnessed in the Akash’s health status and his CD4 has increased to 500 and he gained weight by 5 kgs. His family thanks PRIDE CCC team for providing comprehensive support and are happy to see Akash healthy, attending school and engaging in his favourite sport – Cricket.

*“Yay, I can play cricket again, I feel so much more stronger and healthier ”*  
- Akash, 13 years



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