



SAATHII / COMPANION



Elizabeth Glaser
Pediatric AIDS
Foundation

CONTENTS

VULNERABILITY 8

AN ORPHAN FACES AN UNCERTAIN FUTURE

SHOCK 14

A YOUNG WOMAN FACES HER NEW REALITY

OPPORTUNITY 18

A MOTHER STEPS INTO A NEW LIFE

FULFILLMENT 22

AN HIV-POSITIVE COUPLE FINDS LOVE AND PARENTHOOD

TO ENDEAVOR 30

A COMMUNITY-BASED ORGANIZATION CREATES A SAFE SPACE

SUPPORT 38

DOOR-TO-DOOR COUNSELORS CARRY HOPE

CONNECTION 48

AN AT-RISK MOTHER IS LINKED TO CARE

COMPASSION 52

AN HIV-POSITIVE COUNSELOR ENCOURAGES OTHERS

HOPE 56

A WOMAN RISES FROM DESPAIR

DIGNITY 60

THE FOUNDER OF A COMMUNITY-BASED ORGANIZATION LIVES WITH DIGNITY

EMPOWERMENT 66

A YOUNG WOMAN FINDS HER VOICE

INTRODUCTION

HIV can be virtually eliminated in children if all families have access to HIV services and if HIV-positive pregnant women follow prevention of parent-to-child HIV transmission (PPTCT) protocols.

With an estimated 2.1 million individuals living with HIV, India ranks third—after South Africa and Nigeria—in number of cases worldwide. About 86,000 new HIV infections occurred in 2015, of which children accounted for 12 percent (about 10,400).¹ In 2016-17, only 48 percent of the 30 million estimated pregnant women in India were reached with HIV counseling and testing. The number of HIV-positive pregnant women was estimated to be 35,255; however only 29 percent of them had been detected.

Founded in 2002, SAATHII is translating the goal of eliminating pediatric HIV into action in partnership with the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF). Between 2002 and 2015, the program received support from Eastman Kodak Company; the Gere Foundation; the Gilead Foundation; Global Fund to Fight AIDS, TB, and Malaria; Janssen Pharmaceutical Companies of Johnson and Johnson; Jewelers for Children; Johnson and Johnson (J&J); M·A·C AIDS Fund; the United Nations Children’s Fund (UNICEF); and individual donors. Since 2009, SAATHII has been partnering with the Government of India through the National AIDS Control Organization (NACO) and State AIDS Control Societies. The partnership has enabled SAATHII to scale up public-private partnerships with government support for test kits, supplies, antiretroviral treatment, and early infant diagnosis.

SAATHII began work with a consortium of nongovernmental organizations (NGOs) in four high prevalence states. Prayas (Pune), Swami Vivekananda Youth Movement (SVYM: Mysore), Bapuji Child Health Institute (BCHI: Davangere), Freedom Foundation (Hyderabad and Bangalore), Asha Kirana (Mysore), Asha Foundation (Bangalore), MGR Medical University (Chennai), and Children AIDS and Research Trust (CART: Mangalore). In 2016, it was implementing the private sector PPTCT program in more than 10,000 private health facilities spread across 14 states and union territories through its own state units and two NGO partners, Prayas and SVYM. As of Dec 2016, SAATHII and its partners have accomplished the following:



Reached **3.3 million** pregnant women with HIV counseling and testing



Reached **6,541** HIV-positive pregnant women with PPTCT services

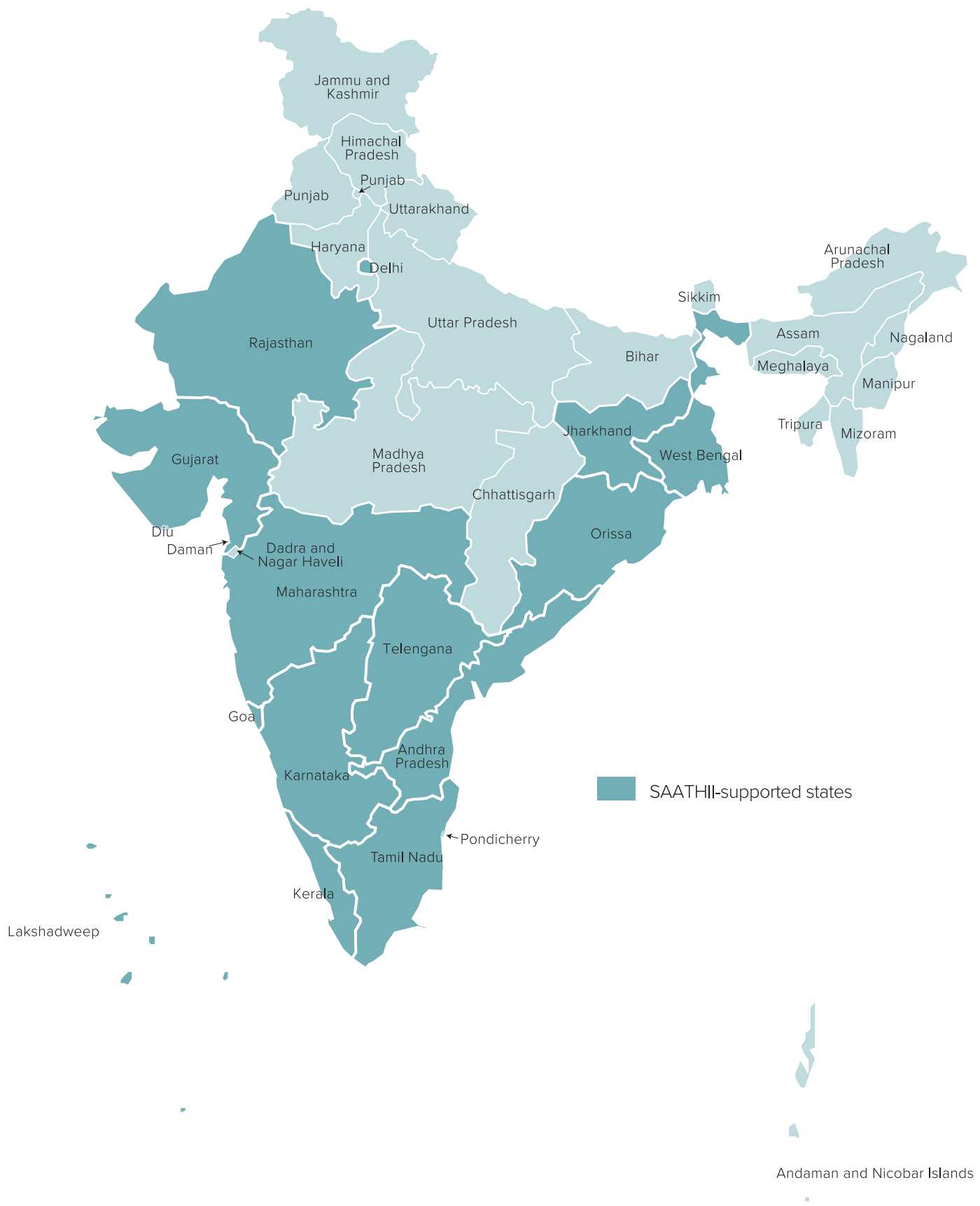


Trained **34,341** health care providers

SAATHII values health responses that are rooted in science and human rights; that directly engage with affected communities; and that address issues of marginalization based on gender, sexuality, and other factors influencing equitable access to quality care.

On the following pages, you will meet some of the individuals whom SAATHII has reached either directly or through partners. You will also meet health workers and volunteers who have dedicated themselves to the vision of an AIDS-free generation in India. These stories were collected from states in which SAATHII has been working on PPTCT and other initiatives. Thanks are due to SVYM, Prayas, and the individuals who have consented to have their narratives included in this book.

¹ Government of India. 2016. Annual Report, Ministry of Health and Family Welfare. Online at <http://naco.gov.in/sites/default/files/Annual%20Report%202015-16.pdf>





PREVENTING TRANSMISSION TO CHILDREN

An HIV-positive infant who is not receiving antiretroviral therapy has a 50 percent chance of dying before his or her second birthday. Therefore, it is important that HIV-affected children (those with an HIV-positive parent) are tested and treated as soon after they are born as is possible. A child living with HIV who adheres to treatment throughout life has a good chance at living a normal life, without developing AIDS.

But the most effective way to end AIDS in children is to block transmission of the HIV virus—so that there is never any risk of a child developing AIDS-related illnesses. Fortunately, the chance of transmission from mother to child can be virtually eliminated if an expectant mother living with HIV adheres to proper care and treatment.

At the center of SAATHII's work is its prevention of parent-to-child HIV transmission (PPTCT)² program. Health workers and peer counselors work with SAATHII to reach the communities in which they work and improve access to and uptake of HIV services, particularly among women and children. Hurdles they must overcome include stigma about HIV, lack of education, and isolation. Personal interaction is a crucial component to supporting mothers and expectant mothers living with HIV—so that their children grow up HIV-free.

SAATHII has tested more than 3 million women since 2002, providing them with PPTCT services, if needed. SAATHII, with the assistance of EGPAF, supports more than 10,000 private health facilities across 14 states and union territories through its own state units and two NGO partners, Prayas and SVYM, providing health care workers and clinicians with HIV-related training and skills. These health workers, in turn, help mothers with the resources and knowledge to be positive that their children are HIV-negative.

² PPTCT stands for prevention of parent-to-child HIV transmission. The Indian government replaced the word *mother* in prevention of mother-to-child HIV transmission (PMTCT) with *parent*, thereby drawing attention to the fact that the overwhelming majority of HIV-positive pregnant women in India are infected by their husbands and to the role of both parents in preventing vertical transmission to children. PPTCT interventions in India are focused on government hospitals and primary health centers. SAATHII is one of the main partners enabling PPTCT interventions in the country's fast-growing private healthcare sector.



VULNERABILITY

AN ORPHAN FACES AN UNCERTAIN FUTURE

MIRYALGUDA

Keshava is a 4-year-old orphan, living in Miryalguda, a rice-cultivating town in southern India. He is HIV-positive, and is being cared for by his 28-year-old cousin, Kodati Ravinder.

Keshava's father had been a truck driver who was living with HIV, but did not tell his family about his HIV-positive status. After his first wife died of AIDS-related illness, he married her sister— Keshava's mother. He did not tell his second wife that he had been infected with HIV and she, too, contracted the virus. Keshava's parents had two children together before both parents died of AIDS-related illnesses.

"[They] were tested but they did not take the ART [antiretroviral] medication reliably because they had not disclosed their status to their family," says a counselor from Jyothi Hospital, which partners with SAATHII.

Because of stigma and misinformation, many HIV-positive people remain reluctant to tell loved ones about their status or adhere to treatment. This increases the possibility that they will spread the virus. SAATHII is engaging healthcare providers from the private sector in eliminating stigma as they provide counseling and testing for the prevention of parent-to-child HIV transmission (PPTCT).

Keshava's mother transmitted HIV to her son sometime during pregnancy, childbirth, or breastfeeding—the main ways that children become infected. PPTCT protocols would have likely reduced the risk of HIV transmission, but the mother was not enrolled in treatment. Keshava's 6-year-old sister is HIV-negative and living in a foster home, but the home will not take Keshava because of his HIV-positive status.

"[Keshava] is eligible for the drugs," says his cousin, Ravinder, "but it is difficult to say what will happen to him."

The Jyothi counselor agrees that Keshava's future is uncertain, explaining that it is difficult for Keshava's family to care of him. Ravinder is a day laborer and poor. He also has children of his own.

 **"THERE ARE A LOT OF ORPHANS LIKE HIM."**

"It is possible that after two or three years he will send him to a foster home," says the counselor. "There are a lot of orphans like him."

ORPHANS AND VULNERABLE CHILDREN

Since the beginning of the HIV pandemic, an estimated 18 million children around the world have lost one or both parents due to AIDS-related illnesses, according to the U.S. Agency for International Development (USAID). Orphans and vulnerable children are less likely to be in school, less likely to have access to healthcare, and less likely to receive regular meals. In addition, they often face discrimination and fewer life opportunities.

Through family-care continuum programs in Tamil Nadu and Andhra Pradesh, SAATHII was able to develop models linking institutional, home and community-based care that included health, educational, and psychosocial support for AIDS orphans and HIV-affected children.









SHOCK



A YOUNG MOTHER FACES HER NEW REALITY

SHOCK

Still a teenager, the young widow sits in the waiting room with her father and infant daughter and weeps. It has only been three months since Badalaboina lost her husband to HIV-related illness and six months since her daughter was born.

Badalaboina only learned that her husband was living with HIV after they were married a little more than a year ago. Now he is dead, and she is HIV-positive.

Fortunately, Badalaboina's daughter, Pavithra, is HIV-free and healthy, according to test results.

The translator says that Badalaboina is crying because her husband passed away, but also that it's more complicated than that. His sisters are in negotiation with Badalaboina about his property. Once they settle all the debts, they will return the property to her.

Maybe.

"It depends on the debts," says Badalaboina through the translator.

"Before I was married, I was always healthy," says the young widow, wiping at tears. "I never had a fever or anything. But now I'm always sick, with a fever and with pains because of the HIV."

Badalaboina's father holds his granddaughter while his daughter quietly cries beside him.

A counselor trained by SAATHII has been assigned to Badalaboina to help her see the positive reality that she is alive and has an HIV-free child. By accepting and adhering to her HIV treatment, Badalaboina will get well and can live a long and healthy life.

**“BY ACCEPTING AND ADHERING
TO HER HIV TREATMENT,
BADALABOINA CAN LIVE A LONG
AND HEALTHY LIFE.**





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OPPORTUNITY

A MOTHER STEPS INTO A NEW LIFE

MIRYALGUDA

Tharangini is willing to talk about her HIV-positive status—but not at her job at a cyber café or around the apartment building where she lives. Her daughter, Renuka, is HIV-free, but the school that the child attends doesn't know about Tharangini's status. She wants to keep it that way

Tharangini asks to meet at her parents' rented house, a half-hour on a dusty road from the center of Miryalguda. Her parents live in a spare two-room structure with a small cottage garden—well-tended tomato bushes and stalks of green onions poking out of the dirt.

"I cried for a week when I found out about her [HIV] status," says Tharangini's mother. "We had a house at that time, but we had just sold it for her dowry.

Tharangini did not find out that she had been infected with HIV until she was in her eighth month of pregnancy.

"I felt very sad when my husband told me he had HIV," says Tharangini. "I was with him only for one year of marriage. He didn't disclose anything before marriage. And then he didn't apologize at all. He still concealed it. He told me to get an abortion, but I wanted to defend the pregnancy.

"First I went to a private hospital, and there I found out about my status," says Tharangini. "Then I went to a community hospital where they referred me to Jyothi hospital where they deliver [HIV-] positive pregnant women."

"There were no complications in my delivery, Tharangini continues. "And the baby was [HIV-] negative."³

Tharangini's husband eventually died from AIDS-related illness. However, she has managed to keep the virus at bay through the antiretroviral therapy that she receives from the government treatment centre. Jyothi Hospital is a partner in a private-sector PPTCT program supported by SAATHII.

³ After confirmatory testing at 18 months of age



Tharangini explains that she feels safe when she visits her parents, but that life as a single mother with HIV is more challenging in her own neighborhood.

“Here I don’t have any problems with the neighbors. But in the city where I live and work, I do not disclose my status.” Still, with the help of treatment and a 7-year-old daughter to raise, Tharangini remains hopeful, resourceful, and independent. “I don’t want to get married again,” she says. “I want to build up my career. I want to live with my child and to use all my opportunities.”

“I WANT TO LIVE WITH MY CHILD AND TO USE ALL MY OPPORTUNITIES.”

PREVENTION OF PARENT-TO-CHILD HIV TRANSMISSION

The most effective way to end AIDS in children is to block transmission of the HIV virus—so that there is never any risk of a child developing AIDS-related illnesses. Fortunately, the chance of transmission from mother to child can be virtually eliminated if an expectant mother living with HIV adheres to proper care and treatment.

At the center of SAATHI's work is its prevention of parent-to-child HIV transmission (PPTCT) program. SAATHI and its partners have tested more than 3 million women since 2002, providing them with PPTCT if needed. SAATHI supports more than 10,000 health facilities in more than 235 districts, providing health care workers and clinicians with HIV-related training and skills. These health workers, in turn, help mothers with the resources and knowledge to be positive that their children are HIV-negative.





FULFILLMENT



AN HIV-POSITIVE COUPLE FINDS LOVE AND PARENTHOOD

FULFILLMENT

PUNE

Sweta and her husband, Jitendra Kumbhar, represent the sort of success story that helps Prayas⁴ counselors put up with the long hours and heavy caseloads.

Both are HIV-positive while their only son, Sarthak, is HIV-negative.

Sweta's first husband didn't tell her about his condition before they got married—not until he started to get symptoms of AIDS. He died within six months. Sweta soon learned that she had been infected with HIV.

As she tried to cope with the loss of her husband and the new reality of her HIV-positive status, Sweta also had to contend with the relatives of her late-husband, who demanded that she return his property. Her mother-in-law seized the family home and cast Sweta out, so she had to return to her parents' house.

The reception there wasn't much better. Her father is an alcoholic and offered no support.

"Why did you come back?" he yelled at her. "You should have died there!"

Sweta was unsure about what to do next. For her HIV treatment, she was visiting a government hospital where she heard about the local Positive People Network, an association of HIV-positive adults. She went to the Network for advice, and they said she should think about marrying again.

"They told me there was a group of the Positive People who came together for the purpose of marriage. They introduce themselves to each other and see if it's suitable."

That's where Sweta met Jitendra.

"Of course I wanted to get married, and also I wanted a family," says Jitendra. "But [I thought] there was no option because there is no cure for HIV. And I don't want to pass the infection on to someone else. But the days passed and I came to know that we could get married with someone who also has HIV. So I started working with the Network as a volunteer social worker. I found out there was medicine available and I could control the disease and I could live a longer life."

Without the Positive People Network, Jitendra and Sweta would never have met, since they lived in different districts. They decided to meet in a third district—neutral territory. Sweta's mother accompanied her, while Jitendra was joined by a good friend. They got along and decided they would get married.

Sweta quickly got pregnant, but miscarried. This happened twice, and Jitendra became hesitant about trying again.

⁴ Prayas (Initiatives in Health, Energy, Learning and Parenthood) is a nongovernmental, nonprofit organization. Members of Prayas are professionals working to protect and promote public interest in general and the interests of disadvantaged sections of society in particular.



“THE STRUGGLE WHICH WE FACED IN OUR LIVES, OUR BABY WILL NEVER FACE.”

“Why do you want to go for the pregnancy?” he asked her. “Maybe the baby will get infected.”

She understood his reluctance and the uncertainty of trying again for a baby but she was willing to take the chance.

A Prayas counselor in the Sholapur district where they were living began to counsel them about how to prevent transmission of the HIV virus to the unborn child. Convinced that the baby would be HIV-free, Sweta got pregnant again.

At 14 weeks of pregnancy Sweta began receiving antiretroviral medicine. She took her medication regularly and came to the antenatal care clinic every month.

When Sweta began feeling the baby move inside her, she became optimistic. At nine months, she delivered Sarthak without complications and started breastfeeding him. The couple took their son to the clinic every six months for testing. At 18 months, Sarthak was declared HIV-free.

“I never thought about having a family, a child,” says Sweta. “My family was very reluctant about me. They said I should leave the house and go join an orphan’s organization. I should die there. People were so bad with me.”

She pauses, eyes downcast. But then she looks up.

“Now we are very happy because we have a family and our baby is [HIV-] negative,” says Sweta. “The struggle which we faced in our lives, our baby will never face because of Prayas—because we got all of the support. We received medicine at the appropriate time. Our baby is negative and we don’t want him to face all the struggle. We are happy!”

Does the baby’s name, Sarthak, mean anything?

“Fulfillment,” they reply in unison.

COMMUNITY-BASED ORGANIZATIONS

Community-based organizations (CBOs) play a vital role in addressing India’s HIV/AIDS epidemic. These include networks of people living with HIV at national, state, and district level, as well as networks of key affected populations such as transgender women, men who have sex with men, and women who sell sex. CBOs provide peer support, link individuals to welfare schemes and benefits, motivate members to seek healthcare and adhere to treatment regimens, and often assist in tracking clients lost to follow-up.







TO ENDEAVOR

A COMMUNITY-BASED ORGANIZATION CREATES A SAFE SPACE

PUNE

VINAY KULKARNI, M.D.

“When the HIV epidemic came to India it landed in major metropolitan cities like Pune. This is one of the places in India with one of the highest levels of HIV infection. We identified the epidemic quite early and we tried a comprehensive response right from the beginning.

“Prayas comes from Sanskrit—it means 'to endeavor.' We started in 1994 and work in health, energy, learning, and parenthood. At first it was only a few patients a year and then they gradually started increasing. In the 1990s, for a while there were no resources available for people with HIV. They were just wasting away, waiting to die.

“The Prayas clinic was one of the first places in India where there was a full-time counselor. People would come from all over the state to this clinic. It was very difficult counseling at the beginning because there was no treatment. Most of the people I counseled in the beginning died.

“It is still difficult, but it is easier now because they don’t have that kind of a bleak future. There was no formal training at that time. We had to learn on our own. We had to approach people who work in social work and knew how to counsel to ask them how to do it.

“Now we have 3,500 patients coming in. People know that this is a place where they can get good service. People coming from outside can walk in, give their blood, see the doctor, see the counselor, collect their medicine and go.

“We also find women who have gone for screening at a private facility. We tell all the doctors that they should screen women because without that we won’t know. Everyone tests. And when they find somebody positive then they link to our care.

“People get counseled before the test and after the test. And there is follow-up counseling when people go on to the treatment. They also have crisis counseling.





“IF THE WOMEN ARE GIVEN THE SPACE AND THEY FEEL COMFORTABLE, THEY SHARE THEIR EXPERIENCES. THEY OPEN UP.”

“The mother-to-child program started in 2002. We trained all our counselors about how to talk to women who are pregnant and look at issues. As we learned from our feedback and experiences, we kept modifying our counseling sessions and creating materials for them.

“In the rural mother-to-child prevention program, if the women are given the space and they feel comfortable, they share their experiences. They open up. It is one-to-one confidential and private.

“We encourage the husband to come to counseling. We tell every infected woman that the partner should get involved. There are betrayal issues, usually on the part of the husband. That’s what the counseling is about, supporting the family, dealing with each other, making decisions.”

ABOUT PRAYAS

Prayas (Initiatives in Health, Energy, Learning, and Parenthood), founded in 1994, is an NGO based in Pune. Members of Prayas are professionals working to protect and promote the interests of disadvantaged members of society. Through its health initiative, Prayas focuses on HIV awareness and training, counseling, care and support, and PPTCT. Prayas covers the districts of Pune, Sangli, Solapur, Kolhapur, Satara, Jalna, and Ahmednagar in the state of Maharashtra.



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SUPPORT

DOOR-TO-DOOR COUNSELORS CARRY HOPE

MYSORE

Manjula and Nagarathna are health counselors for Swami Vivekananda Youth Movement (SVYM), a nongovernmental organization in Mysore. SVYM has built a hospital in Sargur to treat people of limited resources who are living with HIV and other infectious diseases. The two counselors have a caseload of around 400 HIV-positive clients. They start their visits at 9 a.m. and continue until it is dark.

Manjula (*left*) and Nagarathna (*right*) deliver antiretroviral medication to Rathna and her 2-month-old son in their home so that Rathna can stay healthy and continue to breastfeed safely. The counselors visit every client at least once a month, but they visit new mothers like Rathna every week.



Nagarathna explains to Rathna the proper dosing of her antiretroviral medication. Each week Nagarathna will return with a refill.



So far, Rathna's son has tested negative for HIV. Because of Rathna's adherence to PPTCT protocols during pregnancy and breastfeeding, the counselors are hopeful that this child will grow up HIV-free.





Rathna is only one client on a very long list for the SVYM health counselors. Later, Nagarathna (*left*) meets with Meenakshi and her husband Anand. Although both are living with HIV, their daughter, Thangamani, is HIV-free, thanks to a unified effort.



Meenakshi (*left*) is from a nomadic tribe and her husband Anand is a traveling salesman. Lack of a fixed location complicates adherence to HIV treatment and can make the work of the counselor more difficult. Regular contact with Nagarathna is keeping this family on track with its antiretroviral therapy.

SUPPORT

SAATHII counselor Manjula (*left*) delivers antiretroviral medication to Indramma, a mother living with HIV. Indramma's daughter, Jeevita, is HIV-free thanks to Indramurra's adherence to PPTCT treatment during pregnancy and breastfeeding. If Indramma continues her own antiretroviral therapy, she can live a healthy life as she raises Jeevita.



Along with field visits, Nagarathna meets clients at the Vivekananda Memorial Hospital, which is run by SVYM. Here, Nagarathna counsels a new client on recommended breastfeeding practices.







ABOUT THE SWAMI VIVEKANANDA YOUTH MOVEMENT

Swami Vivekananda Youth Movement (SVYM) is a nonprofit development organization working in the areas of health, education and community development in Mysore, Karnataka. Since 1994, SVYM has offered a range of HIV services, focusing on all modes of transmission of HIV infection and providing comprehensive preventive, curative, and linkages to rehabilitation centers. The organization is helping scale up PPTCT services in the private sector across all districts of Karnataka.



CONNECTION

AN AT-RISK MOTHER IS LINKED TO CARE

Rathna, 22, lives with her infant son in a poor village in southern India, 60 kilometers from Mysore. The village is surrounded by fields of sugar cane and corn. Electrified fences border the fields because otherwise a herd of elephants will come out of the forest at night and destroy the crops. They sometimes come 80 or 90 at a time. The elephants present a constant threat, but the fences have been effective.

Throughout her recent pregnancy, Rathna worked hard in those fields, stopping only right before she delivered her baby.

It was a fast delivery at home, followed by a visit to the Vivekananda Memorial Hospital in Sargur, which is run by the Swami Vivekananda Youth Moment (SVYM), a nongovernmental organization, founded in 1984 by medical students. SVYM provides medical care to people with limited resources, particularly serving people like Rathna who have been dispossessed of their homes in the forest by development projects.

Rathna laughs easily, despite having been recently diagnosed with HIV. She only learned about her HIV status during her fifth month of pregnancy. Fortunately, counselors working with SVYM and SAATHI were able to provide Rathna with the information, antiretroviral medication, and emotional support that she needed.

The young mother doesn't yet know for certain that her son is HIV-free—but so far he has tested negative, so she is hopeful. He will be tested again at six months, 12 months, and 18 months to make sure.

Following tradition, Rathna and her husband will not give their boy a name until he is 9 months old. "You come next time and I will tell you the name," she beams.

Names are important here, says Hemanth, the program manager for the prevention of parent-to-child transmission (PPTCT) project implemented by SVYM. He explains that Rathna means "like a jewel."

Every week, counselors Nagarathna and Manjula visit Rathna,



**“WHATEVER YOUR PAST
EXPERIENCE HAS BEEN ...
AT LEAST IN THE FUTURE YOU
SHOULD PRACTICE SAFER SEX.”**



bringing Rathna antiretroviral medications from the Vivekananda Memorial Hospital. The counselors also give Rathna money so that she can travel to the hospital for follow-up testing and treatment.

Rathna is of particular interest to the counselors because they worry that she may not have enough social support. Her husband is also married to Rathna's older sister, which has made for a strained family situation. To further complicate matters, Rathna's husband has tested negative for HIV, which makes them a discordant couple—one is living with HIV, while the other is not.

Rathna has no other family in the village.

"The older sister did not know [about the relationship], and then when she did find out, they quarreled, and the older sister left," says Hemanth. "Eventually they came to an understanding ... and [the husband] is living in two places, three days with each."

Hemanth explains that a situation like this—jealous partners, a discordant couple—is potentially lethal, with husbands murdering their wives. So alongside HIV treatment and education, counselors also "work at a subconscious level" to defuse potential risks.

According to Hemanth, the counselors advise clients: "Whatever your past experience has been ... at least in the future you should practice safer sex." This will be particularly important for Rathna's husband so that he does not become infected.

"Whenever they [counselors] speak with her they will be speaking with a smiling face and with supportive words," says Hemanth. "If they scold her or tell her that what she is doing is wrong, then she will never come back to the hospital. If she sees them she will go and hide. So they are dealing with very delicate things.

"They have to convince the client that she has been supported. They are nonjudgmental."

So far, Rathna has been diligent about following the HIV prevention and treatment protocols that her counselors have provided. When asked how she feels, Rathna replies, "Good ... I take my medicine regularly."

Today, despite the constant threat of HIV attacking her body, Rathna has taken effective precautions and remains healthy and happy. Prospects for her son are good.

EARLY INFANT DIAGNOSIS

India's PPTCT program mandates early infant diagnosis (EID) through DNA PCR testing, beginning at 6 weeks of age. This method is more accurate than conventional antibody-based tests that may be misleading as they can pick up the mother's antibodies in the infant's blood. The EID protocol in India mandates testing at 6 weeks, 6 months, and 12 months, followed by confirmatory testing at 18 months.



“I AM THE ONLY ONE LEFT”

COMPASSION

AN HIV-POSITIVE COUNSELOR ENCOURAGES OTHERS

One of the peer counselors supporting Jyothi Hospital is a woman living with HIV. Bomm Anitha's job as an outreach worker with the government PPTCT outreach program is to counsel pregnant women and describe the services that are available to them. Anitha explains, listens, sympathizes, and advocates. She may make follow-up home visits, traveling in buses for hours, then spending time with the mother, counting pills, asking questions.

Anitha also presents her own experience as a lesson and as encouragement. "It's very difficult to convince them to come to the follow-up services. Whenever I visit the home of pregnant women, I relate my lifestyle. I tell them 'I am supporting you, and I am living very healthy because I'm taking my medicine. You have many services available to you. If you avail yourself of the services you will become healthy.' In this way, I motivate them."

At 19, Anitha has become the head of the family after the deaths of her father, mother, and brother, all of whom were HIV-positive.

"My father died three years ago," says Anitha. "My mother died when I was very young. I also lost my brother who was HIV-positive. I have one more brother and he is [HIV-] negative. I'm not thinking about getting married for now because I have to take the family responsibility. I am the only one left."

Nobody in Anitha's village knows her HIV status. Only her aunt, her father's sister, is aware. Anitha says that she is fortunate to have a cooperative and helpful family member.

"I was very afraid when I came to know about my status," says Anitha. "I thought about committing suicide, but the people at the government center gave me good counseling and supported me with everything."

She looks around at the group of mothers listening to her.

"Because of them, I'm still alive. And I'm happy about that."







HOPE

A WOMAN RISES FROM DESPAIR

Bommu Anitha counsels a suicidal woman, Panga, helping her see some hope for living. Panga did not want her picture taken, but she did share her story.

“I came to know about my status in the fifth month of my pregnancy when I came for an antenatal checkup,” says Panga. “At that time, my husband also was tested and he was [HIV-] positive.

“At first, when I came to know about my status, I decided to kill myself. But the outreach worker motivated me to live.

“When the counselor disclosed my status to me, I left the reports behind; I just got up and left, thinking I would commit suicide. I went home crying, and my husband was there. He consoled me and said ‘I’m also [HIV-] positive, and if you want to commit suicide, I will join you. Otherwise we will live together.’

“And then the counselor [Bommu Anitha] visited and everything changed. She said to me: ‘I am living with HIV. Why don’t you also?’

“She found my address on the reports and came to my house. She explained all the services, and she came with me for the CD4 testing and for the delivery [of my baby]. I had gone to many hospitals, but nobody had agreed to conduct the delivery.

“[Anitha] told me: ‘Don’t worry. We will give you all the information about the services available.’ And she went with me to get my delivery at a government hospital.

“We had a good relationship after that. She also told me about the medicine which will protect the baby from HIV.

“She said ‘I assure you that you will have a negative baby. I will do everything to help.’”





DIGNITY

THE FOUNDER OF A COMMUNITY-BASED ORGANIZATION LIVES WITH DIGNITY

Pravasini Pradhan was one of the community activists who participated in SAATHII's leadership development program through the Coalition-based Advocacy Project, supported by DFID-UK and Interact WorldWide. SAATHII has been partnering with KNP+ on a European Union-supported initiative to increase access to government social benefits for people living with HIV and most-at-risk populations in Odisha.

"In 2003, my husband tested HIV-positive," says Pravasini. "It was the 15th of the month. By the 30th he died.

"After that it was quite obvious I had to be tested. I was found positive. I felt lonely. I felt like the world had come to an end.

"I had one daughter. She is negative. She was one year old at the time and my in-laws drove me out of the house, with my daughter. I had to go live at my mother's house. But that also wasn't easy. They wouldn't even let their small children play with my child.

"In 2006 we felt the need of a network that would help the people living with HIV in getting their day-to-day needs. At the time people were not very aware about the antiretroviral therapy centers. People were not aware about the service delivery⁶ points—even some of our friends. That scenario compelled us to form a network to provide information as well as direct service to those who are in need.

⁵ Pravasini Pradhan was one of the community activists who participated in SAATHII's leadership development program through the Coalition-Based Advocacy Project. SAATHII has been partnering with KNP+ on interventions to increase access to government social benefits for people living with HIV and most-at risk populations in Odisha.

⁶Service delivery points are the government and private facilities available for people living with HIV. They include counseling and testing centers, delivery sites where positive women need to have their infants initiated on Nevirapine, ART Centers where CD4 testing is carried out and individuals initiated on ART, and sites where infant blood is collected for early infant diagnosis.





“A BEAUTIFUL LIFE IS WAITING FOR YOU.”

“I work with families: men, women, children. It’s all about knowledge, setting up information. The typical man may not be aware of the facilities and confidentiality provided by the government. Once he is informed of that and everything that you can get for free of cost without breaching your confidentiality, then people are taking an interest. They say “We should go to get tested” or “We should go get medicine.” People now regularly visit the drop-in center⁷ to get adequate information.

“Since we are HIV-positive and we are dealing with people who have tested positive, who else is a better role model for the client? We tell them, ‘Look, I am HIV-positive. I can live a healthy life with dignity. Confidentiality is a matter of choice. Your choice.

“Now I am welcome in the family again. Because I am a visible leader my family is more willing to accept me and now even my in-laws are welcoming me. There is now a better relationship with them than existed when my husband was alive. And they are also welcoming my daughter back.

“I tell the people living with HIV: Never get frustrated, never get tense. A beautiful life is waiting for you. Be strong. I am confident and getting stronger. I have to boost my child. I have to make myself mentally strong.”

⁷ Drop-in centers are spaces such as large halls or reception areas of the positive people’s network office, where individuals can drop by for information, support, and sessions such as peer counseling, information on nutrition, treatment, and government schemes and benefits.





EMPOWERMENT

A YOUNG WOMAN FINDS HER VOICE

Despite the strides that the world has taken since the beginning of the HIV epidemic, all too often, stigma toward HIV-positive women continues. HIV-positive women in India frequently face rejection from their families and ostracization from their communities. Their children may be taken from them. As a result, many HIV-positive women fall into depression and some commit suicide.

One young woman once at risk of that fate is Banita Jena, a 26-year-old living near Bhubaneswar, India, a commercial hub on the Bay of Bengal. In 2009, Banita got married and two years later was happily pregnant. She looked forward to welcoming the new child into the home that she and her husband shared with his parents. Unfortunately, the delivery did not go smoothly. Banita started bleeding badly during labor and was given three separate transfusions. Despite the frightening situation, both mother and infant daughter survived the delivery.

However, after Banita and her new daughter were discharged, the infant became chronically ill. A counselor at the care center referred Banita to another hospital where a doctor suggested that the infant might be infected with HIV and advised Banita that she and her husband should be tested for the virus. The test results showed that Banita was HIV-positive while her husband was not. It is likely that Banita was infected from the blood transfusions.

Banita's husband assumed that his wife had been unfaithful; he abandoned her and their baby in the hospital.

"He had the notion that [Banita] might have done something wrong, [that] she is not good, and so she has got HIV," said Chandan Kumar Nayak, an officer with SAATHII.

When Banita returned home with her infant daughter, her in-laws refused to let them into the house. Banita's husband refused to see her.



“MALE COUNSELORS CAN'T GO WHERE SHE GOES.”

Fortunately, Banita found support with the Kalinga Network for People Living with HIV/AIDS (KNP+), a partner with SAATHII that helps negotiate day-to-day struggles. In this case, KNP+ tried to reason with Banita's in-laws and open a dialogue. But they were unsuccessful.

“[The in-laws] were very clear in their intentions not to take her back,” says Chandan. “We made a second visit, asking them to take her back but in the meantime her child had died. And this visit also was a failure.”

The legal team working at SAATHII helped Banita file a claim for her property. In the end, her dowry was returned. She also received some money for her daily maintenance. It wasn't as much as she had expected but it was something to help her live during this transition.

Now Banita works at an HIV treatment center as a counselor with KNP+.

“I can show that HIV-positive people can lead a good life,” she says. “I went to live a healthier life with my message to the positive people and to society: never lose hope. That is my message. Nobody knows about HIV; they only know about AIDS,” says Banita. “They don't know about the treatment processes ... how you can live long ... what is home-based care ... what is positive living?”

“Since we are [HIV-] positive—and we are dealing with people who have tested positive—who else is a better role model for the client?” asks Pravasini Pradhan, the president and founder of KNP+. “We tell them, ‘Look ... I am HIV-positive. I can live a healthy life with dignity.’”

Banita has helped conduct village meetings of up to 100 participants to stop “whispering campaigns” by informing both genders about the realities of HIV and AIDS.

“I was nervous,” Banita admits, but she quickly adds that through her KNP+ support groups she has learned to express her feelings and is now confident speaking in public. She says that education is the key to removing the stigma of HIV.

“Banita has become empowered” since she started working with KNP+, says Chandan. “Male counselors can't go where she goes.”





SOLIDARITY AND ACTION AGAINST THE HIV INFECTION IN INDIA (SAATHII)

34 (old 46), MG Ramachandran Road
Kalakshetra Colony, Besant Nagar
Chennai 600 090

P +91 44 2440 3947/3663

E info@saathii.org

WWW.SAATHII.ORG

ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION (EGPAF)

1140 Connecticut Avenue NW, Suite 200
Washington, DC 20036

P +1 202 296 9165

F +1 202 296 9185

WWW.PEDAIDS.ORG