

### Empathy is key to volunteers' success

The volunteers are all HIV positive women. Most have taken the prophylactic medicines when they were pregnant or have HIV positive children themselves and so they can truly empathise. They are paid for travel and food on the days they work.

When a new HIV positive pregnant women is found the volunteer will meet her discreetly in the village. She will clarify what she understands from the hospital counsellor and clear up any doubts.

Disclosure is a key issue of concern, most importantly if the husband is HIV negative. Other family issues will be discussed – who to tell and who not to.

The volunteer will reinforce the need for her to start on anti-retroviral drugs for the sake of the baby. The volunteer will accompany her to the centre until she is confident enough to go on her own. Often the volunteer will arrange peer counselling from women who have been in a similar situation. They will plan for where the delivery will take place and most often the volunteer will be there at the delivery.



Barefoot counselling: a volunteer in discussion with a positive mother

#### SHIVAKUMAR



Shivakumar is 11 and studying in 5<sup>th</sup> standard. He has a younger brother in nursery school who is HIV negative.

His father and grandmother look after him

as his mother died of TB. The volunteer told us that the father is not very responsible and drinks sometimes and it is only through the assistance and the volunteer's efforts that Shivakumar was first started on TB drugs and then on anti-retrovirals.

Even now he has skin problems and the volunteer has taken him to see the skin specialist recently.

He will go to a different school later in the year and told us: "I am happy about that, because I was ill I am a year behind in school and all my friends are in the school I am going to."

Photo: Shivakumar with his volunteer.

#### SUDHA



Sudha, 25, learned she had HIV when she had a blood test in her fourth month of pregnancy.

"The counsellor tried her best to console me but I still felt fear. I phoned my husband to say that he should come for a test also. He did and he was HIV

positive too. Then he left the house and went off to a distant place and doesn't support me at all.

"Anyhow, I never wanted to marry him, my relations pressured me to do so. I am back at my parent's house now, but I haven't told them about the HIV. I have only told my sister and we have agreed to tell no one. The hospital counsellor asked Natchiammal (the volunteer pictured next to her) to meet me and she has helped a lot. I tell my parents she is from the health centre just to enquire how the pregnancy is going. I have asked her to come at the time of delivery in three months time and I am sure she will.

Photo: Sudha, left, with Natchiammal and another volunteer.



Vinitha with her grandmother: no child should be born with HIV

Photography: Richard Williams

## A life in the balance

Vinitha is 16 and HIV positive. Her parents died from Aids and she lives with her elderly grandparents. She has been on anti-retroviral therapy for the last five years.

Her drugs regime has had to be changed frequently because of complications. She says that if she takes the tablets she feels sick and vomits. The volunteers and staff have tried their best with her and visited often.

Vinitha agreed to come for admission at our partner Arogya Agam after her

school practical exams. When the team recently visited she was in a bad way. She was sitting up but would not or could not speak. She had eaten a little but when asked at least to try and take her tablets she vomited it all out.

With our financial help she subsequently did come for admission with her grandmother but she is very weak and reluctant to take tablets.

We are getting the best medical advice now and there is some hope. Specialists are advising on treatments that will help her tolerate anti-retrovirals. But

we have seen a few children like her who are weak and can't cope with the treatment. We lost a number of such children despite good medical advice and treatment. Vinitha's life seems to be hanging in the balance.

No child need ever become HIV positive and suffer like Vinitha. Today the world knows how to prevent mother to child transmission of HIV. But as we describe in this newsletter, stopping children being born with HIV takes more than just having the right drug treatment.

# Counting down to zero

Counting down to zero is a United Nations project to prevent HIV passing from mothers to their babies. The infection can be passed on during pregnancy, in childbirth, or from breast feeding. Without medication 30% of babies born to HIV+ mothers will be infected. With medication the figure drops to 2% or less.

The aim is to ensure that all children are born free of HIV infection and that their mothers are kept alive.

This is a grand global ambition, and we have a small part of it. Our partner Arogya Agam is working in eight of Tamil Nadu's 32 districts on the Countdown project. It is funded mostly by Positive Action Children Fund – which is financed by ViiV Health Care of UK – but VST contributes 20% of the cost.

The programme has been running for a year. Some 206 positive pregnant women have been identified and started on anti-retroviral drugs. So far there have been 154 deliveries and 148 live births. Early testing is encouraging, very few appear to be HIV infected, but it is only after further testing at 18 months that we can be sure of the all-clear.

The theory seems simple enough: ensure HIV mothers-to-be receive anti-retroviral drugs in pregnancy and while breast-feeding. In practice it is more complicated. Pregnant women may try to keep their HIV status secret and forego treatment, or they may not fully understand the need for treatment. They may not find it easy to get to a treatment centre. They may have taken anti-retroviral drugs and stopped because of unpleasant side effects.

Our strategy is to work through volunteers and make use of small but highly effective cash grants.

In each district we have formed groups of HIV positive women. These groups draw on volunteers who advise, encourage and accompany HIV positive pregnant women to go to hospital HIV centres where the government provides free treatment. They also make checks on HIV infected children to ensure they are regularly tested, and treated with anti-retroviral drugs and for life-threatening opportunistic infections.



## DASHINI

When Selvi was nine months pregnant with Durka Dashini (now 3 years old) her husband left her. Selvi had slipped through the net and only tested HIV positive when in labour at the hospital where she went for delivery. Durka Dashini also tested HIV positive, confirmed at 18 months. But Selvi never came to collect the result, she was fed up with being pressured to bring her husband for HIV testing which she could not do. So both mother and child were lost to follow-up. A volunteer was looking through counselling records and noticed the case sheet. She and another volunteer went to the address given, not knowing what to expect. Selvi came out with all her fears about the hospital and was assured that it would be OK. The volunteers explained the situation at the hospital and everything was regularised and both mother and daughter are now well and on anti-retrovirals. Selvi says: "If the volunteer had not taken the trouble to come and persuade me I wouldn't be like I am now, taking responsibility for Dashini and my own health."



## KISSORE

Kissors is a happy, outgoing and very cheeky four-year-old. He is an orphan but well looked after by his uncle and aunt who have a girl of their own. Sanmugapiriya, a volunteer who lives in the same village takes care of the medical side of things bringing him to the hospital which she visits frequently because of her work.

It is obvious that she is a second mother to him, she has no living children of her own. In three visits all the investigations were over and here he is seen with his first month's supply of tablets. The financial support was used for scans not available at the government hospital. He is fine now.



## MARUTHAN

Maruthan is 10 and lives with his father and grandparents. His mother died two years ago. His younger brother Kartick is HIV negative because for his birth his mother followed all the medical advice. Both he and his father are on anti-retroviral drugs but they have to cycle 10 km and then take four buses to reach the treatment centre. Because of this they both became irregular in collecting their tablets. A volunteer, Masila, came to see what was wrong. Maruthan was in a bad way with serious skin problems and his father was taking him to a nearby private hospital without telling them that he was HIV infected. Now, with enough motivation and some financial support for bus fares, father and son are visiting the centre regularly. Maruthan has become a normal healthy boy, happy on his father's cycle and wants to be a policeman. His father says: "I now know that missing doses can cause these sort of problems. Despite the difficulties I am determined that we will both take regular treatment in future."



## DEEPA

Deepa is 11 and in 6<sup>th</sup> standard. Her father is healthy and is a bus driver. All the family are taking anti-retrovirals. After Deepa was born there was a little brother, but he died shortly after. It was only then that the parents were tested and found to be HIV positive. No one thought to test Deepa as she looked well. But later she was diagnosed with TB and HIV and took treatment for both. Deepa was irregular in attending for tablets – she thought her skin problems were caused by the tablets.

The volunteers persuaded her and her mother to keep up the treatment. The assistance paid for bus fares and some prescribed medicines.

## £20 - kickstarting life-saving change

In addition to the Positive Action programme, VST funds another life-saving low-cost intervention. We make grants of 500 rupees per month (£5) for three months or more to families with HIV positive children who are not being properly followed up or who are sick. HIV positive children are supposed to go to a government treatment centre at least every six months for routine testing. Those started on anti-retroviral drugs should collect and take these drugs every month.

All children should take early treatment for any infection or other problem. The government services are free but some children do not access them for lack of bus fare or money for food or because the guardian has to work or does not realise the importance of adherence to these principles. Many of the guardians are infected with HIV or are elderly grandparents.

We find that this very small grant can make all the difference. Three months at £5 a month and we calculate another £5 for the volunteer's travel to follow them up for three months. This is a truly life-saving intervention. There are other advantages too – it attracts families with HIV positive children to come forward for help, it popularises the positive women's groups and ensures the best collaboration with the government health centres.

Some 710 needy children were supported in this way in the past year. A total of 62 children who had stopped attending the government system were identified and brought back to follow-up. They were all tested and when eligible started on anti-retroviral drugs and given other treatment and nutritional supplements as required.

The majority had other medical complaints, and quite a number had tuberculosis. The small grants helped with bus fares, food during travel or admission in hospitals, for tests which had to be done in private clinics or for special drugs not stocked by government hospitals. The £20 over three months often made all the difference.