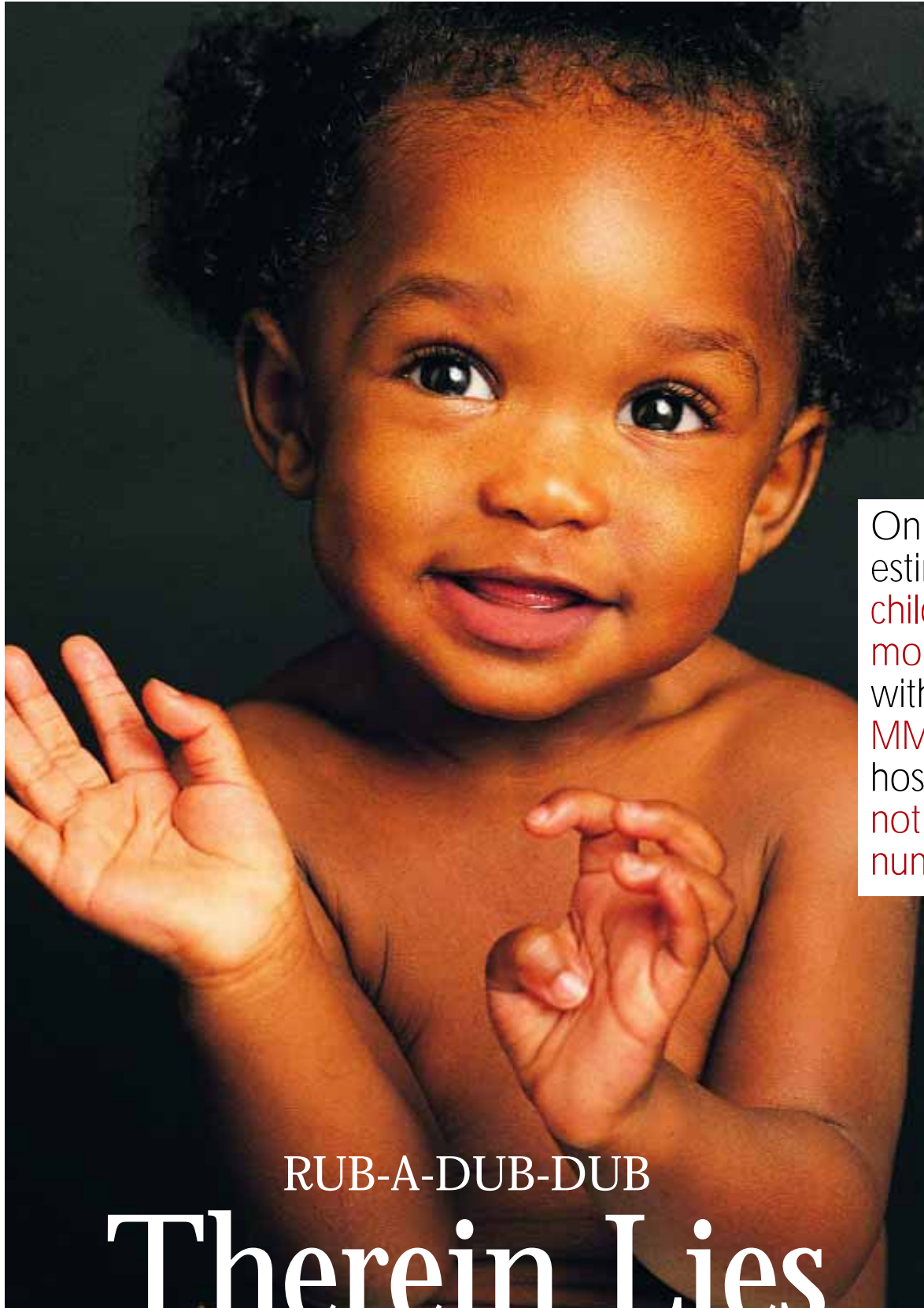


# AIDS BUZZ

New Delhi March 2007



RUB-A-DUB-DUB

## Therein Lies The Rub

Hardly anyone seems to be aware of the possibility of very young children contracting STIs. In some cases, there is no penetration and the molester spreads the disease simply by rubbing contact. Syphilis, warts or sores may get treated with antibiotics that only suppress symptoms and by the time doctors and victims come to know, it may be too late.

By **SADHNA MOHAN** in New Delhi

**D**o adults know anything of the world of children? Or do they simply like to believe that all is well with the little ones? It took a toll of 22 lives in Uttar Pradesh's Nithari village to make the country alive to the issue of child abuse.

And yet, has anyone thought of children suffering from sexually transmitted infections (STIs)? It is a link few of us make. General doctors, paediatricians and obstetricians too aren't sufficiently oriented towards this area of medicine. In fact, paediatricians gathered for the National Conference of Paediatric Dermatologists in Agra recently were shocked to see pictures of kids as small as two or three years of age badly afflicted with STIs.

There was a picture of a two-year-old with an anal wart with an interesting story to boot. The child was treated by Dr N Usman, then Director, Institute of Sexually Transmitted Diseases, Madras Medical College (MMC).

As per usual practice, the child's parents were checked up and questioned on whether they had any extra-marital or pre-marital relationships. The parents did not have any STI nor had they had any sexual relationship outside the marriage.

A month later, a child of the same age from the same village came to the hospital with the same ailment. And a month after that, again a boy of the same age from the same village came with an anal wart.

The cases pointed to one molester. Talking to this reporter, Dr Usman explained the specifics:

"The private parts of the children were too small for penetration. Rubbing had taken place."

"A big wart requires surgery. Injections and medicines don't help. In villages, people often take treatment from quacks. In all likelihood, the molester was seeking a cure by having sex with children."

Social workers and health workers of the hospital tried to find the abuser but failed. Contact tracing (finding the person who has passed on the infection) is almost zero in the case of children while it is successful in a third of all adult cases at MMC, informs Dr Usman. In 50-60 per cent of the child cases here, 'mama' (maternal uncle) is the alleged assaulter, he adds.

On a rough estimate, two children a month report with STIs to MMC, a referral hospital. Nearly 40 new adults with STIs are seen daily. The number of children seen with STIs is not small; in the context of the fact that MMC has a catchment area of 100,000 people, we could extrapolate the figure to estimate that nationally, a few hundred thousand children are affected by STIs each year.

Giving details of the child patients at MMC, Dr Usman says the youngest kids reporting with STIs have been two years old and one or two kids of this age are seen per year. The maximum number of cases are seen amongst children aged 5-12.

The girl-boy ratio is about the same until age 5 while in the age group 8-12, the number of girl patients far exceeds that of boys.

Mostly, they report with syphilis, warts and gonorrhoea, in that order. Since syphilis and warts are painless and also take time to manifest symptoms, both the child and its parents get to know of these ailments and child abuse pretty late. By then, the abuser has had ample time to escape.

On a rough estimate, two children a month report with STIs to MMC, a referral hospital. This is not a small number

Photo: pealifezine

continued on page 2



Photo: pealidczine

Parents and doctors other than STI specialists need to have a working knowledge of STIs in children

continued from page 1

Generally, children with syphilis come in late – six months to two years after the episode. They come with secondary syphilis, a later stage of the disease. “We hardly ever see a kid with primary syphilis,” asserts Dr Usman.

What happens is this: After sexual assault, the child may get a painless ulcer within 9-90 days. The child may not notice it; the mother might see it but not suspect much amiss or abuse.

If taken to a doctor, the child would probably receive an antibiotic. The ulcer would heal but the organism would remain in the body, leading to the secondary stage of the disease within three months to two years. The child would then have many ulcers around the genitals or rashes throughout the body. And by this time, the disease could have affected several other body systems, such as the heart or brain.

Warts too appear three-four months after a sexual

episode. Even if big, they are painless. A wart is removed surgically but the virus causing it, like HIV and the virus causing herpes, can't be eliminated from the body. The risk of further transmission of the virus to the person's sexual partner and new borns remains.

Gonorrhoea makes its presence felt immediately and painfully. It rears its head within two-five days of a sexual encounter. The child experiences severe burning, discharge and fever. It can't pass urine and walk. It would resist touch during a bath and the mother would definitely see things amiss but may not suspect the presence of an STI.

Usually, in 99 per cent of the cases according to Dr Usman, children are first taken to a general practitioner or a paediatrician, who also doesn't suspect an STI. They try treating with antibiotics and the child is referred to an STI specialist only when it doesn't respond to their treatment.

Clearly, adults, both doctors other than STI specialists and parents, need to have a working knowledge of STIs in children so that kids are provided speedy and effective treatment. This would help reduce the ailments' burden on children and might also help find the abusers because an alert parent spotting the symptoms would immediately raise an alarm and register a case with the police and not delay action until the secondary stage of the disease manifests.

An early visit to the doctor can also significantly reduce the risk of HIV if the doctor is aware of the post-exposure prophylaxis (PEP) to be administered. General doctors, paediatricians, obstetricians and STI specialists must be geared up to understand HIV medicine not only for purposes of administering PEP but also to identify those living with HIV and link them to appropriate care services.

It is critical that children are talked to about sex and given age-appropriate information on STIs and HIV/AIDS.

In addition to the MMC data cited above, evidence of STIs in children comes from NGOs such as Butterflies in Delhi and Karunalaya in Chennai. These NGOs address slightly older children aged 8-18 years. A Butterflies study on 150 street children conducted seven years ago found all of them had been abused at least once. In all, 100 were tested for STIs and 10 of them were found infected, two with Hepatitis B. None had HIV.

A Karunalaya study on street children in 2002 found abuse by peers the most common, followed by abuse by commercial sex workers, women and adult men, in that order.

But we don't hear of comprehensive countrywide statistics on STIs in children and also on how STIs and HIV mutually affect each other's progression in children. Monthly data on STIs in men, women and 'children' (without gender break up) goes from government hospitals to state AIDS control societies. What does it add up to? There's no telling. Even if we had this figure, it would not give a complete picture as many STI patients seek out private practitioners and data from this important sector is not collated nationally.

Importantly, the sexual route of HIV transmission in children is ignored by the national AIDS programme that only talks about parent-to-child transmission. There are no statistics on the issue and there are no policy guidelines on prevention and care (relating to issues like confidentiality, consent, child-friendly counsellors, etc.) for this segment of the population.

\* Children, in this article, refers to kids aged 12 years or less.

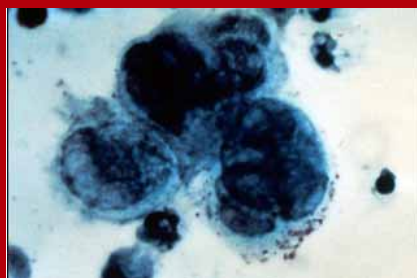
WORLD BYTES

**Herpes Drug Can Control HIV: Study**

**New Delhi:** It's a troublesome duo where the effect of one worsens the symptoms of the other. Now, researchers have found that treating one can help keep the other under control.

A team of scientists, led by Dr Nicolas Nagot of the London School of Hygiene and Tropical Medicine, in the first major study of its kind, has found that treating genital herpes can help keep HIV under control in women with both infections.

In the study, conducted in Africa and published in *New England Journal of Medicine*, women who took the herpes



drug Valacyclovir had less HIV in their blood and in their genital secretions. This finding is significant for India, where a recent study conducted among commercial sex workers in Chennai by YRG Care found 79 per cent of them suffering from herpes.

**The Times of India, New Delhi**

**Omkara Director Ropes in Hollywood Lensman for AIDS Film**

**Mumbai:** Omkara director Vishal Bharadwaj has invited one of Hollywood's top-notch cinematographers, Guillermo Navarro,



to shoot his short film on AIDS.

Coincidentally, Navarro has won an Oscar for his cinematography in *Pan's Labyrinth*.

"I asked him before the Oscars and Guillermo has agreed," Bharadwaj, who is making an 11-minute film on AIDS, said.

Bharadwaj planned to start shooting the film titled *Blood Brothers* in March. The movie's story is credited to Mathew Robbins and is being produced by Mira Nair, who is executive-producing on behalf of Bill and Melinda Gates Foundation.

**Asian Age, New Delhi**

# The Numbers Simply Don't Add Up

Discrepancy in data on number of children living with HIV in India may result in a sizeable portion being left out of medicare and prevention efforts. This article looks at areas of slippage, where there is scope for improvement. By **SADHNA MOHAN** in New Delhi

Photo: pealidzine

**D**ata on the number of children living with HIV in India is confusing. But the fact that we are losing out on sizeable numbers in whom we can prevent HIV comes through clearly when we analyse some of the data put out by National AIDS Control Organisation (NACO).

First, a look at the number of children living with HIV. Each year, a certain number of children are born with HIV; to find the prevalence at a given time, you would add this yearly number to the base prevalence figure.

The yearly add on is determined like this: More than 27 million women give birth in India each year. Since .9 per cent of India's adult population (aged 15-49 years) is estimated HIV-positive (per sentinel surveillance in 2003 and 2004, compiled in 2004 and 2005, respectively), 2,43,000 of them would have HIV. About 25-30 per cent of them would deliver an HIV-positive child. By this calculation, roughly 60,000-73,000 HIV-positive children have been born yearly for the years in question.

Base prevalence, calculated as of 2003 when 5.1 million (51 lakh) Indians were estimated to have HIV, is arrived at by the following logic: On the basis of census 2001 listed distribution of men-women in the population, 17.8 lakh (of the total of 51 lakh) were women infected with HIV. In view of the General Fertility Rate among women being 103.2 per thousand, 1.84 lakh of them were pregnant. If the rate of transmission of HIV from mothers to children was 30

per cent, there would be 55,200 HIV-infected children then (source: NACO web site).

By this token, prevalence in 2006 could be estimated at  $55,200 + 73,000 \times 3$ , that is, 2,74,200, and in 2005 at 2,01,200, and so on. Factoring in deaths would reduce these numbers somewhat.

There could be contentions to this mode of calculation but even going by the logic above has not provided a consistent figure, which is confusing.

Sample this. NACO's web site offering information on Prevention of Parent to Child Transmission (PPTCT) that otherwise lists post 2003 information says, "More than 27 million women, including over 92,000 HIV-infected women, give birth in India every year." The figure of 92,000 varies considerably from 2,43,000 that we got above. By this token, 30,000 HIV-positive children would be born each year!

NACO NEWS Oct-Dec 2006, a newsletter of NACO, says, "using a conservative transmission rate of 30 per cent from mother to child, approximately 56,700 HIV-infected children are born each year (NACO, 2005).

A national newspaper reported Health Minister A Ramadoss as saying, "We estimate there are around 65,000 kids with HIV infection out of an estimated 5.2 million in the country." This report appeared on 30 Nov, 2006.

On 23 Dec, 2006, NACO's Director General K continued on page 4

The logic of calculation and the calculation itself are at odds, leading to immense confusion

## Obese Pre-Schoolers Show Early Puberty

**New Delhi:** Childhood obesity is contributing to a worrying new global phenomenon – a sharp increase in the number of girls reaching puberty by nine years of age. Researchers from the University of Michigan Health System have found that girls who are obese at the age of three are more likely to hit puberty around their ninth birthday.

The study published in the American journal *Paediatrics*, tracked 354 girls from when they were 2 years old till they were 12. Nearly half (168) of them showed signs of puberty by nine years – a majority of them were either obese or

overweight at 36 months.

Researchers said that for every extra point on the girls' body mass index scores at 36 months, the chances of early onset of puberty rose by 44 per cent.

**The Times of India, New Delhi**

## Kids' Book Kicks off Uproar

The word 'scrotum' that appears in a children's book written by Susan Patron, this year's winner of the Newberry Medal, the most prestigious award in children's literature, has shocked some school librarians who have decided to ban



the book from many elementary schools.

Lucky Trimble, the 10-year-old heroine of *The Higher Power of Lucky*, hears the word through a hole when another character says he saw a rattle-snake bite his dog on the scrotum.

The inclusion of the word has reopened the debate over what constitutes acceptable content in children's books. The book has already been banned from school libraries in a handful of states in the United States.

**NYT News Service**

## Phase I AIDS Vaccine Trials Successful

**Pune:** Phase I clinical trials for an AIDS vaccine at the National AIDS Research Institute in Pune have been completed with researchers confirming that the "whole exercise went off smoothly without any safety concerns".

The trials were aimed at evaluating the safety and tolerability of the vaccine at escalating dose levels, as well as immune responses in healthy volunteers.

**Time of India, Mumbai**





Photo: pealidzine

GUARD MY INNOCENCE: A little girl casts a fearful glance behind as many of them fall victim to predators who sexually abuse them and leave them with STIs and other diseases

There is a huge gap in the number of children estimated to be born with HIV and those actually detected with HIV. What is happening on the ground?

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Sujatha Rao was quoted by Tehelka, a newspaper published from New Delhi, saying that an estimated 1,00,000 children had HIV in addition to India's 5.2 million with the infection. But wait, NACO's web site citing 2003 figures includes 55,145 children in India's total of 5.1 million HIV infected.

UNAIDS, on its part, estimated we had 2,02,000 children with HIV in 2004 (varying considerably from the national estimate for that year that would be derived following the logic mentioned above.)

Leaving estimates alone, if we zoom in on numbers actually found infected by examining PPTCT data on NACO's web site, we find 4,771 mother-baby pairs received nevirapine through Jan '03-June '04 at 273 PPTCT centres in Government hospitals. Assuming 8.5 per cent of

these mothers gave birth to positive children, we find 405 children were born positive during this period.

The gap in the number of kids estimated to be born with HIV and those detected with HIV is huge. What is happening on the ground?

A quick glance at the above PPTCT data provides some pointers. During the period in question, 10,12,144 new women registered at ante-natal clinics (ANCs), where they are given group education that leads to an offer of an HIV test, followed by the test and enrollment for the PPTCT programme.

Of these, 8,24,867 were counselled (nearly 2 lakh less than those registered), 8,04,051 were tested and 5,14,287 came to pick their test results. A major slippage occurs here — nearly 3 lakh don't come to pick their result!

Significantly, in terms of those detected positive (9,650) and how many of them came to pick up their result (5,949), there is a considerable gap of less than 4,000 (little over 38 per cent drop out). Another 1,740 women who came directly for labour without registering at ANC were found HIV-positive.

Total live births to HIV-positive women were 5,643 while 4,771 mother-baby pairs received nevirapine. Why the slippage in numbers here? No answers are offered.

Toxicity with nevirapine was nil. In all, 2,500 HIV-positive mothers chose to breastfeed their babies though breastfeeding carries a risk of HIV transmission.

To beef up detection of HIV in mothers-to-be and prevent its transmission to new borns, the slip ups along the way at PPTCT centres need to be plugged. Services each step along the way need to be improved with the focus being on building women's receptivity to the issue. And the PPTCT programme would need to be expanded to cover many more pregnant women, each year over 43 lakh pregnant women (16 per cent of the total) come to government hospitals alone for delivery as per National Family Health Survey 2.

# CHILD Finds A Home



HOME IS WHERE THE HEART IS: A happy family atmosphere enables them to live with dignity, thanks to support from Project CHILD

Photo: Zishaan Latif

An orphaned HIV-positive child is often left to fend for itself when in dire need of financial and moral support. Project CHILD is performing yeoman service in this respect in Mumbai.

By **FRENY MANECKSHA**  
in Mumbai

There was no one to look after 12-year-old Mangesh, an HIV-positive boy, and his two older siblings, when their parents died of AIDS-related illness.

An aged bedridden grandmother in the house could only provide moral support. Some relatives were willing to look after the older brother and sister, but not Mangesh. The family wanted to stay together so the older brother, then 14 years old, gave up his education and took up a job. Project CHILD helped by providing moral support and taking Mangesh to the hospital when needed and following up on his treatment.

When the grandmother died, the family was forced to split. Mangesh was admitted to a temporary residential home, Ashray, managed by Committed Communities Development Trust (CCDT), which runs Project CHILD.

In a few years, the older brother arranged for the wedding of the sister, hired a one-room tenement and

took Mangesh back to stay with him. The two brothers lived together till Mangesh expired last July.

CHILD is an acronym for Children of HIV-Positive Individuals Living in Dignity. The project began in 1995 following CCDT's work with women in prostitution, several of them HIV-positive, in Kamathipura, the largest red light area in Mumbai. Their children not only faced discrimination, but suffered the anguish of mothers dying and leaving them abandoned or with fragmented families. Most of the children were forced to give up school and assume adult roles and responsibilities. The difficult circumstances in which these children lived, exposed them to abuse and exploitation and put them at risk of HIV/AIDS.

CCDT realised the need for a holistic approach in providing care. The home-based care programme

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## FOOTLOOSE



Illustration: Dhir

This issue of **AIDS BUZZ** focuses on children. We had just about packed off our content to the designer when the front pages of national newspapers spewed alarming news – “every fourth child in India has been sexually abused.”

In a study said to be the world’s largest on child abuse, 17,000 children and stakeholders such as teachers and NGOs in 13 states were interviewed over a year’s period ending in December 2006 and the report was submitted early this year to the Government. Prayas, a Delhi NGO, conducted the study with support from UNICEF and the Department of Women and Child Development. At least 25 per cent of the respondents had been sexually abused – 30 per cent of them by family members or relatives.

According to the newspaper reports, the study also notes that by the Government’s own admission, 35 million homeless children in India need protection. But only 35,000 are actually placed in shelters provided by the Government and NGOs.

There’s more to contend with. A staggering 45,000 children go missing in India each year and cases of child abuse are low on the police’s list of priorities, points out the National Human Rights Commission. Police non-registry of cases of missing children is conceded by Ms Kiran Bedi, Director General, Bureau of Police Research and Development, who says, “the numbers of missing children reported on child helplines are much more than the figures in police records.”

Doctors too kind of turn their back on abused children, either refusing treatment or failing to report the matter to the police. Very often, the family too prefers to cover up rather than confront abuse head on, fearing some kind of moral backlash on the child.

It’s time to blow apart this conspiracy of silence. Our cover story draws attention to the area of STIs in very young children who’ve been sexually abused and brings home the urgency to address this issue.

There’s news from the field too – we bring you reports of NGO work of considerable number of years with HIV infected and affected children.

Read on and write in your thoughts to us.

*Sadhna Motan*

Editor-in-Chief



## LETTERS

I am a medical professional working in the field of HIV medicine for the past 12 years and have just completed my Fellowship in HIV Medicine from the School of Tropical Medicine, Kolkata.

I am attached to a number of organisations providing HIV care. It would be of great help if you could send me **AIDS BUZZ** to the address given below.

**Dr Prasenjit Saha**  
AE-559, Sector - I, Salt Lake City

We have gone through copies of **AIDS BUZZ** and found it extremely useful and interesting. We would like RCSHA to provide us 1,000 copies of the January 2007 issue so that we can include them in the conference kits for delegates to our prestigious 34th National Conference of Indian Association of Preventive and Social Medicine, being held in New Delhi from 22 to 24 February, 2007.

**Dr Bir Singh**  
Professor, Centre for Community Medicine & Conference Organising Secretary  
All India Institute of Medical Sciences  
New Delhi-110 029

I am from the Directorate of Field Publicity, Ministry of Information and Broadcasting,

Government of India, Andhra Pradesh. Recently I happened to see the magazine **AIDS BUZZ** and found it very interesting and useful for our field communication programmes. We do disseminate information on public health at the grassroots levels for about 15 days a month as part of our job. Hence, I request you to send one issue of the newsletter to our field unit in Visakapatnam on the following address:

Door No 38-37-22, Bhaskar Gardens, Marripalem, Visakapatnam-530 018 (AP) and, if possible, 13 copies of the newsletter to our regional office located at Ground Floor, Kendriya Sadan, Sultan Bazar, Hyderabad, for onward distribution to all 13 district-level units in the state.

**Vijayakumar Vedagiri**  
Field Publicity Officer, Visakapatnam

Thanks for sending us copies of **AIDS BUZZ**. It’s a really informative bi-monthly. I have read the article ‘Women in Blue’ and was highly impressed by the

working of the CBO. Kindly give us details of the NGO working with this CBO and the contact person with whom we can interact as we want to go for an exposure visit to understand the activities and formation of the CBO. We are also in the process of forming such a CBO of sex workers, so this would be a good opportunity. Can RCSHA provide us funds for the exposure visit?

**Gumane Rajesh Tarachand**  
Training Officer  
PSU, GSACS, Gujarat

I came across a posting that mentioned that RCSHA has a list of 111 districts in India that have the highest prevalence of HIV. Can you e-mail me that list? By the way, I love your **AIDS BUZZ** magazine!

**Koen Van Rompay, DVM, Ph D**  
Associate Research Virologist  
University of California  
County Road 98 & Hutchison  
Davis, CA 95616, USA

I’m Edward Daniel doing my second year in counselling and guidance in Madras School of Social Work. I need a lot of information about HIV from journals because I believe that such source material gives us the latest updates.

I went through a copy of **AIDS BUZZ** in our college library and found it very useful. But I was unable to access the previous month’s issue.

I have registered myself on the RCSHA web site and would like the newsletter to be sent to me regularly.

**Edward Christopher**  
cedr\_dan@yahoo.com

LEPRA Society – Blue Peter Research Centre is a medical charity in Hyderabad, Andhra Pradesh, treating leprosy, TB and HIV/AIDS patients. We found **AIDS BUZZ** extremely useful and very informative for both medical and paramedical staff and request you to kindly send two complimentary copies every month to our organisation.

**Ramana Babu**  
Director, LEPRA Society – Blue Peter Research Centre,  
near TEC Building, Cherlapally  
Hyderabad-501 301





PAINT A PERFECT PICTURE: A child engrossed in painting a perfect picture feels at home as all her needs have been taken care of

Photo: Zishaan Latif

## Dancing Feat

CCDT, in partnership with The Shiamak Davar Institute for the Performing Arts and seven NGOs in Mumbai, used dance to counsel children at risk of HIV.

They used Bollywood jazz sessions to give out messages on issues of sex and sexuality. Many children would come for dancing and stay on for sessions on life skills. A few public performances were put up for peers, teachers, special invitees and family members.

Dancing on the stage helped the children build their capacity to say "No" to exploitative relationships. It helped build groups that could support and depend on each other. The programme enabled children to understand that HIV was not about death but enjoying life to the hilt.

continued from page 4

The home-based care programme works at keeping children who are infected and affected by HIV/AIDS in a family set up. It is only when there is just nowhere for the child to go, that he/she is taken in for institutional care

restores hope and enhances the quality of life of persons and families infected and affected by HIV/AIDS, especially children. It works at keeping children who are infected and affected by HIV/AIDS in a family set up. It is only when there is just nowhere for the child to go, that he/she is taken in for institutional care. Some 800 children and 500 families in Mumbai, Navi Mumbai and Thane are under its home-based care.

Manisha was a recipient of home-based care four years ago. Today, she is a peer educator, reaching out to other families and children in need and undertaking awareness through street plays. She confidently answers questions from bystanders and has no hesitancy in revealing that she was diagnosed HIV-positive nine years ago. People wonder how she can be so frank and exude health and confidence.

She says she has come a long way since the time she was a nervous wreck. "I wept incessantly and was scared to disclose my status. My husband used to sexually abuse me and had infected me." She wanted to move out with her children but found she did not have the courage to do so.

The moral support and legal guidance that she received from Project CHILD helped her break away from the abusive husband. "I have learnt how to stay healthy and stand on my own two feet. Now no more tears. I have a right to live," she asserts.

Like Manisha, Rajalakshmi too received support from Project CHILD and is now a peer educator. She had been driven out of her home after her husband died, leaving her penniless with two small children, the younger one HIV-positive and very sick.

Seeing her plight, a doctor referred her to Project CHILD. She learnt to be self-reliant. Tired of scouting for temporary shelter, she defied slumlords' threats and built her own small dwelling where she now lives with her children. Rajalakshmi says, "When a compounder at a government hospital refused to give me the drugs I needed, I went straight to the doctor and threatened to go to higher ups. I am HIV-positive. So what? I enjoy life. My brothers and sisters insist I attend all festive occasions because they say I add to *maja-masti* (enjoyment)."

This spirit of celebration and positive attitude is the underlying linchpin of Project CHILD. Counsellors link the

children for medical help with government hospitals and get them enrolled into schools in the neighbourhood. Referrals to other civil society organisations are provided in case they need financial support.

School authorities are sensitised to issues related to children affected or infected by HIV. For example, an infected child felt breathless while climbing the stairs to her classroom. The counsellor spoke to the staff and she was placed in a classroom on the ground floor.

The counsellors also educate the families on nutrition. A comfort bag containing grains, sugar and other groceries is provided to families in need. Legal guidance is provided to deal with cases of property and rights and access to children.

The project brings together people with HIV, caregivers, youth groups and those on anti-retroviral therapy (ART) and educates them on issues of hygiene, nutrition and palliative care.

Says Vaijyanti Bhagwe, project manager, "Sometimes we see families in which there is no middle generation. The mother and father have died and so there are only grandparents and grandchildren. Support groups organise activities like picnics and visits to the temple so that their emotional needs are fulfilled."

CCDT Director Sara Lizia D'Mello says, "When we began 12 years ago, the situation was scary. The government didn't want to accept that AIDS was here and stressed only on prevention and awareness programmes targeting high-risk populations. But we were the first to see how the general population had been affected and to take a holistic view of the problem by moving into care and support work."

"We had seen how the family, traditionally viewed as a strong support system, was breaking up with HIV/AIDS. We saw single mothers dying, leaving children abandoned," she says. "The attitude of the medical professionals then was not exactly welcoming or positive, particularly towards women from Kamathipura," she adds.

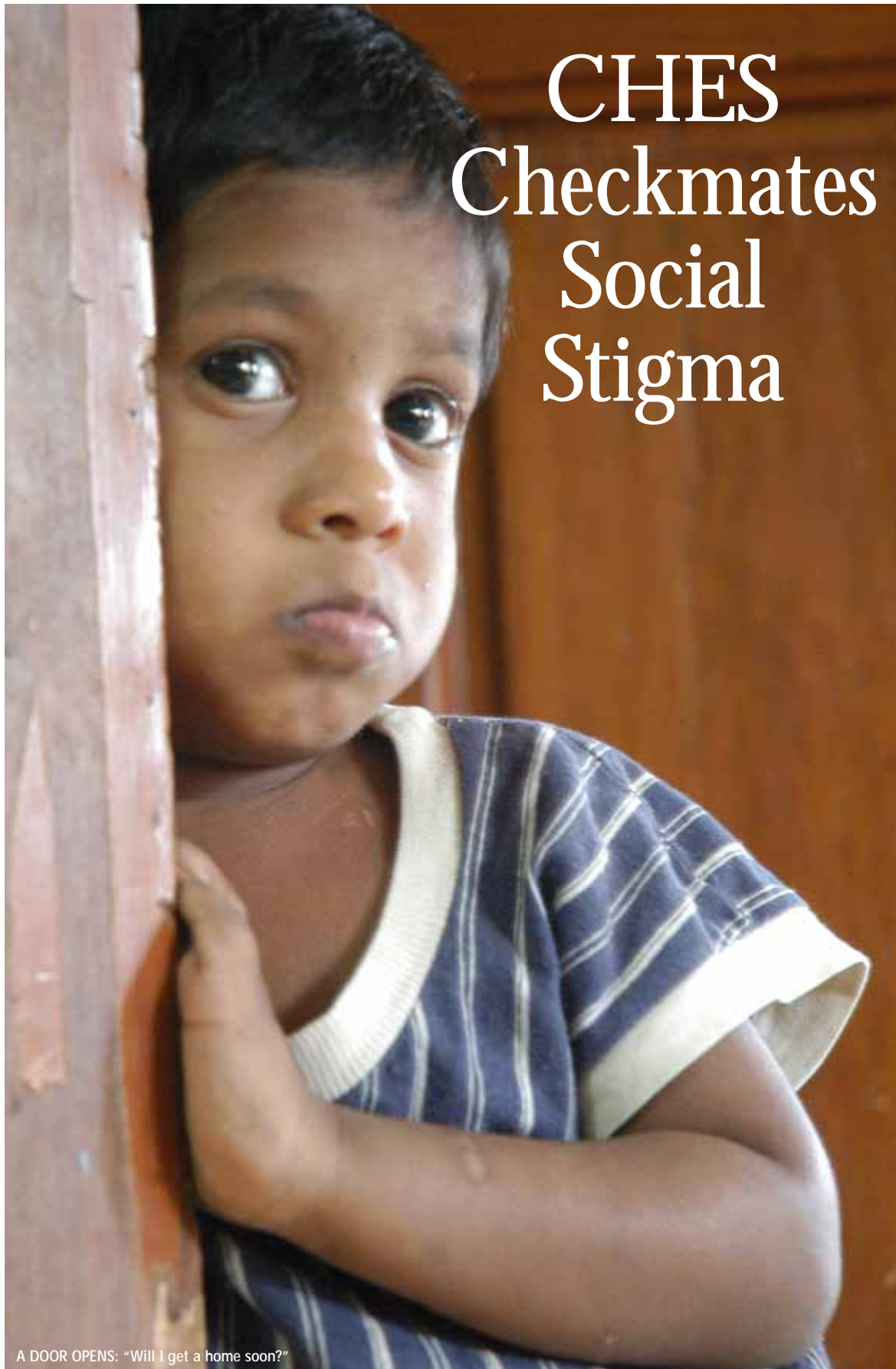
Today, the scene is far different with many more informed people. People Living With HIV/AIDS (PLHA) groups are growing and reaching out effectively to others like them. But, says D'Mello, civil society has to play a far more active role and support them in more concrete ways.

\* Names of HIV-positive persons have been changed in the article.

## Ground Wisdom

Sara Lizia D'Mello suggests we have:

- Adequately trained and sensitised counsellors for children who face trauma, not only in having tested positive but also in accessing treatment and disclosing their status and that of their parents
- Government providing a means of livelihood or pension to poor women whose husbands die of AIDS
- A special medical insurance that is practical and within reach
- A public distribution system that looks after their special needs
- HIV/AIDS linked with the primary health system, particularly to provide access to ART, proper counselling and follow-ups. PLHA given all information to ensure drug adherence and also told about the side effects of drugs
- People knowing ART is not the only solution. Many people lead quality life with good nutrition and a standard of hygiene, timely management of opportunistic infections and with the support of the family and community.
- More temporary crisis centres for women and children



A DOOR OPENS: "Will I get a home soon?"

Photo: V Ramesh

# CHES Checkmates Social Stigma

Community Health Education Society (CHES) in Chennai runs an orphanage that takes in HIV-positive children abandoned due to social stigma and gives them away for adoption after convincing parents about the non-infectious nature of the malady and the need for finding them good homes.

By **SHOBHA MATHUR** in Chennai

remote possibility of getting HIV by sucking infected blood in a small quantity.

The couple had adopted Celine when she came into Ashram with HIV infection six years ago. Now they give their example to bring home the point that an HIV-positive child poses no danger to others.

CHES has been in the forefront in Tamil Nadu trying to raise awareness about HIV issues in the community and bettering the lot of children infected and affected by the virus. It was following a CHES community awareness programme that Soorya, a slum dweller, came forward to adopt an infected baby, Shubha. The mother of two boys who ran a small sari-selling business in the slum, heard about the baby during the programme, visited the orphanage, took a liking to her and wanted to provide her with a home. The fact that her husband was a daily wage labourer and the family was just about able to meet their basic needs did not deter her. Little Shubha, now four and free of HIV, is happily settled in with the family that has given her much love. Seeing Soorya, 25 other slum-dwelling women have queued up for adopting HIV-infected children.

Dr Pinagapany Manorama, a paediatric gastroenterologist, set up CHES in 1993. She was working at the Institute of Child Health when some HIV-positive children were brought to her for treatment from a local orphanage. Seeing the social stigma they faced, Dr Manorama set aside her lucrative career and decided to work for the children.

Today, Ashram located at Valasaravakkam, houses 42 children, aged as young as 3 months to 18 years. Of them, 23 have tested HIV-positive while 7 have yet to undergo the test. Chitra points out, "Seven to eight children are of single parents, mostly sex workers, who brought them in as they could not take care of them." The others are orphans sent in by the Child Welfare Committee (CWC), a government body, which is approached by other orphanages for onward placement of HIV-positive children. At Ashram, they get a healthy diet and are looked after well. As you enter the Ashram hall, you find them giggling and laughing while watching a Tamil film. Some are computer savvy and enjoy using e-mail.

Currently, 20 of the children attend school. Ten of them go to government schools in the neighbourhood, while others, from pre KG to Class IV, are tutored by a teacher who comes in daily. "The children are very bright. One of them stood first in class IX," says Dr Manorama proudly.

"The school managements have been informed of

continued on page 8

our-year-old Harini's parents were very worried. The little girl had sucked the blood flowing from the injured finger of her 10-year-old adopted sister, Celine (name changed), who was HIV-positive. Various tests later, Harini's blood report stated that she was still HIV-negative. The relieved parents, R Muthu Pandian, administrative officer at Community Health Education Society (CHES), an NGO in Chennai, and mother M Chitra, housekeeper at the CHES orphanage 'Ashram', say, "After the incident we are sure that HIV can only be transmitted through blood transfusion or sex and do not fear that Harini will get infected from her elder sister or by playing with children at the orphanage." Doctors say there is only a

## All the right moves

Dr Pinagapany Manorama recommends the following:

- A separate section in the Child Protection Bill to fix minimum standards of care and training of caregivers and doctors
- Guidelines for orphanages on caring for HIV-infected children. Someone to be authorized to take decisions on testing of children in private orphanages to prevent needless testing
- Guidelines for immunisation against diseases, routine paediatric care, nutrition, management of opportunistic infections like tuberculosis, and

mainstreaming of orphans

- A data system on the number of affected and infected children in the state
- Strengthening the capacity of the family to deal with an HIV-positive child in terms of health, hygiene, nutrition and anti-retroviral therapy
- Building the capacity of children and adolescents for self-care, and also the family's capacity, with paediatricians involved at all levels in this effort
- There have been cases of relatives usurping the property or insurance of HIV-positive children. Panchayats could function as watchdogs in rural areas, while in the urban areas, the Social Welfare Department and NGOs could link up with the birth and death registry to smooth out property matters for children.

Becoming a doctor, pilot or engineer when they grow up, the dreams of HIV-positive children are no different from those of other children. But they are pained at the discrimination shown to them by the society. They gave vent to their dreams, expectations and experiences at a recent national consultation.

By **NITIN JUGRAN**  
**BAHUGUNA** in Manesar,  
Haryana



BEHIND A CLOSED GATE:  
A little girl awaiting the day when she would break free of all barriers and fly high like other children

Photo: Zishaan Latif

# Yearning for a 'Normal' Life

With the cheerfulness that characterizes children, they fantasize about glory and wealth, saving lives as doctors, designing high-rise buildings as architects, seeing the world as pilots or spreading awareness as teachers.

But the children also have other urgent demands: "I want to have a lot of good food", "I want my mother always healthy", "I want good orphanage homes to be opened in different places for HIV affected children", "I need to earn money for my younger sister's education", "I want a good education", and "We need good counsellors and regular treatment". These are just some of the yearnings of over 60 children affected and infected with HIV/AIDS across India who participated in a recent National Consultation, organised by Positive Women Network (PWN+) in Manesar.

In a first of its kind meeting, the children shared their experiences of feeling isolated from the community, facing stigma and discrimination at schools and the lack of good, nutritious food and child-friendly medical services in hospitals. "Why don't we get seats in good schools?" "Why aren't we being treated like other children?" "Why are we thrown out from the society?" "Why are they separating us from our relatives?" "Why can't we live with our brothers and sisters?" These were their anguished questions.

"I am an orphan," says 12-year-old Chingkheihunbi of Manipur matter-of-factly. She stays with her aunt and uncle. "My aunt, who is my father's sister, is kind to me, but my uncle is always scolding me," she says with a shrug. She wants to escape her present surroundings and put as much distance as possible between her uncle and herself. "I am studying in class VI. I hope to become a doctor one day."

Murugesh, 16, of Bangalore, remembers his uncle taking him away from his native Suryanalli village near the Kerala - Tamil Nadu border and placing him in an orphanage after his parents died. At the orphanage, he began to get severe headaches and fever. "After a blood check, it was discovered that I was HIV-positive. Soon afterwards, the orphanage threw me out," he says.

Shunned and homeless, he had his first stroke of luck two years later in 1999 when a Bangalore-based NGO learnt of his plight and offered him a home. At Freedom Foundation, an organisation providing medical and other livelihood support to people living with HIV/AIDS, Murugesh

got another chance at life. "They got me enrolled into school and I am now in class IX," he says proudly.

But the new life is not without its challenges. "Only my teachers and the principal know of my HIV status. I'm scared to tell my friends, in case their parents force my eviction from the school," he says.

The teachers have been very supportive and now he wants to study law. "I want to fight for the rights of HIV-positive people. I also dream of going abroad for higher studies," he shares with a smile.

The objective of the consultation was to get the children to talk about their situation and listen to their recommendations for their future welfare for incorporation in the third phase of the Government's National AIDS Control Programme.

The meeting recommended having child-friendly hospitals with sensitised medical personnel and child counsellors, drugs for all opportunistic infections, children support groups at the district level and the setting up of an expert committee to monitor the quality of facilities for orphan children.

According to UNICEF, every day over 1,700 children become infected with HIV. Worldwide, an estimated 2.1 million children under 15 years of age are currently living with HIV.

"We now plan to establish services in all states for children of women living with HIV/AIDS, including crèches, clubs and sponsorships for children's primary and higher education," states Kousalya.

PWN+ will also be advocating with the Department of Education, schools, colleges, parent and teacher associations and youth groups to protect children against discrimination and sexual abuse. A start has been made in Sangli district in Maharashtra with teachers of classes IX and XI in all government schools getting awareness training on HIV/AIDS in collaboration with UNICEF, states Shabana, who had accompanied the children from the state.

But the immediate need is to provide a safe and secure space for orphans to grow up healthy and happy. "Most state and NGO orphan homes refuse to accept these children because of their HIV status," observes Kim of the Manipur branch of PWN+. "Although inclusion is essential and ideal for these children, in the present circumstances they need to have separate orphanages which can cater to their special needs," she states.

"Child-friendly hospitals and drugs for all opportunistic infections are needed"

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the children's HIV status and they have no objection to our children attending classes in their schools. The need to inform parents of other children has not been felt by the management as HIV is not infectious," she adds.

CHES also runs a home care and follow-up programme. It has demarcated the city into five zones and assigned two social workers to each zone. They visit affected families and counsel them on health, nutrition, education and legal support, help them access medical treatment in government hospitals and provide linkages to programmes such as the widow pension scheme.

CHES has 1,070 children under its follow-up and home care programme. Dr Manorama says 70 per cent of them are likely to become orphans, losing their parent/parents to HIV.

"Every year 6,000 children are added to the state's affected and infected list," says Dr Manorama. "Of them about a third are infected. There is urgent need for guidelines for testing and treating the children. Even the Child Protection Bill has no guidelines to be followed by orphanages and NGOs on handling children who have been sexually abused and would need to be put on paediatric formulations to prevent HIV," she points out.

CHES receives Rs 16 lakh per year from Tamil Nadu AIDS Control Society for running the orphanage, which falls short of its growing requirements. "Healthy children have different needs than those of babies and sick children. You can't impose the same discipline for both the healthy and sick. We plan to set up our own building with recreational facilities for healthy children and require financial support from corporates and the public," Dr Manorama adds.

## SHIC

Sexual Health Information Centre (SHIC) plans to serve as a one-point source of reliable and relevant information related to HIV/AIDS in India. This centre has developed a knowledge repository on sexual health and HIV/AIDS that is accessible physically as well as on the web: <http://shic.org.in/index.aspx>

SHIC regularly disseminates information through various initiatives and is also capable of providing customised information services. The centre is currently set up as part of the RCSHA project and is fully supported by DFID.

We have multiple copies of reports related to HIV/AIDS for dissemination. You can send in requests for hard copies to [rama@rcsha.org](mailto:rama@rcsha.org) and [gurpreet@rcsha.org](mailto:gurpreet@rcsha.org). We would also encourage you to share your work and publications with SHIC for wider dissemination.



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