

The short troubled life of a boy called Kumar

Orphaned at 7, Kumar underwent 12 years of HIV treatment, infections, and relapses. **John Dalton** relates the trials and lessons learned from a difficult but spirited youngster

In March 2004 I was asked by my friend Gunasekaran at Vasandham to visit a seven-year-old boy in a distant hill village who was sick. Arriving on a motor bike in this rough and tough village I was surrounded by children by the time I found the house. The villagers had already made the diagnosis. His father had died of it and his mother was harassed and accused of infecting her husband and child. She had poisoned herself the month before, and little Kumar had found her and tried to "wake her up". In those days treatment for HIV infection or Aids was only just becoming a possibility.

There are only two families of his depressed Vannar (dhobie) caste in the village and Kumar had been passed around between them. I asked the Aunts to bring him to Arogya Agam and we would see what we could do. The dominant caste people in the crowd told me to take him then and there and to "bring him back when he is better". I was protesting but prospects of refusal were getting thinner. As a final shot I tried, "in any case he won't come"; the reply was, "ask him". Only when he was happily sitting on the petrol tank in front of me with a small bag of clothes were we allowed out of the village.

And so it was that Kumar came to Arogya Agam. Later we found Muthulakshmi, his sister on the Kerala coast at Cochin. Kumar, always good at directions, led me straight to the house. Muthulakshmi didn't know



Kumar, pictured just after he started antiretroviral treatment

where or when he was born, and said no – she didn't want him "spoiling my own two boys".

His age was estimated by wrist x-ray as seven but it turned out later that he was three years older. We managed to get him into class 2 at a nearby primary school where he fitted in but did not do well. This was a first - the first time we had got a child known to be HIV-infected into school.

Kumar was also the first child in the district to take antiretroviral drugs. In 2004 these

The doctors had never treated anyone this young before

drugs were becoming affordable. VST was supporting Arogya Agam to buy antiretrovirals for around 30 HIV positive activists. The idea was to keep them healthy since they were best placed to advocate for services and against discrimination. Kumar was not eligible for this so I bought them myself. There were some doubts because the doctors needed to consult - they had never treated anyone this young before. Kumar was a sounding board for treating HIV-affected children when government supply drugs came along.

Kumar taught us a lot, and I learned a lot about myself, at the cutting edge of care of an HIV-infected child. It could be frightening, for instance at times when he was bleeding out of both ears.

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Bec runs a marathon raffle



Bec Taylor: raising funds for VST with an auction, raffle and donations. Follow Bec on Facebook

In February 2017 I reach a milestone ... my 40th birthday and so I decided I wanted a fitting challenge to mark the occasion. Most people would opt for a party, a holiday or a trip to a West End show! But not me, I have very graciously been granted a charity place for the April 2017 London marathon through VST.

The aspect that interests me most with VST is their dedication to supporting the LGBT (lesbian, gay, bisexual, trans) community. Living in Brighton as a gay female and having the majority of my circle of friends working or living within the LGBT community, I realise how fortunate and accepting my life is in Brighton. The same fate is not so readily available for those minorities living in South India, therefore the work VST undertakes to support these projects is both important and personal to myself.

I admit, I am currently overweight and unfit, so I'm committing to a six-month training journey to be able to reach the start line and cross that finish line of the London marathon. Throughout my journey, I want to raise as much awareness and money as possible for VST so that the LGBT people in South India can continue their own daily journeys in life.

I will be raising money via three methods:

1. eBay Auctions: Peppa pig voice personalised message left to the winning bidder
A day out in London - Afternoon Tea & Tickets to the West End show Wicked
Celebrity Autographs. Winners name published in Times Best Selling Author C.L. Taylor's latest book.
2. Raffle: In honour of my 40th birthday, I'm holding a £10 per ticket raffle with 40 raffle prizes, ranging from personal training sessions, dinner date meals, a VIP night out, gift vouchers, champagne & edible delights. All donations over £10 will be entered into the raffle.
3. Birthday donations: I'm asking all of my family, friends and work colleagues to donate to VST rather than gifting me a birthday card, drink or present.

You can help Bec's fundraising effort at www.virginmoneygiving.com/BecTaylor

OBITUARY: Sir Nicholas Fenn

A supportive and trusted adviser and patron for VST

Sir Nicholas Fenn, VST's first and so far only patron, has died. He was 80.

Sir Nicholas was the UK High Commissioner to India from 1991 to 1996. During that time he met Dora Scarlett, founder of the work that VST supports, to ask if she would accept an MBE.

That was the start of his involvement with VST, first as a donor and supporter and later as our patron. By coincidence we later found out he knew one of our trustees, Richard Garforth, a former teacher at Kingswood School, Bath, which Sir Nicholas and subsequently his children attended.

VST was lucky to have the perfect patron: an interested and informed adviser who was always willing to help with whatever we asked. Over the years Nick helped us with talks to our supporters, articles on India, hosting a meeting at his club and attending various events, the last one being our conference on caste and development.



Sir Nicholas: deep affection for India

Sir Nicholas's 37-year career as a civil servant and diplomat included serving as UK ambassador in Burma (twice), the Republic of Ireland, and India. He also worked for the United Nations, the Foreign Office and as press secretary to Lord Carrington. During his time in Ireland Margaret Thatcher awarded him a knighthood for his contribution in a fraught political arena. It has been said of him that he earned the rare distinction of making many friends and no enemies!

Born in London, the son of a Methodist minister, he went to Peterhouse, Cambridge, where he achieved a first class degree in medieval history.

In 1995 while UK High Commissioner in India, he took time out from a holiday in Kodiakanal to visit nearby Theni District so that he could meet Dora Scarlett at her Seva Nilayam clinic. Sir Nicholas travelled widely within India, acquiring a deep affection for the country and a shrewd understanding of its problems and complexities.

Sir Nicholas was involved in several charities. He was for five years chief executive of Marie Curie Cancer Care, and also chair of trustees of Sightsavers. His interest in the latter stemmed from a rare condition that left him partially blind in later life. He also served as a governor of his old school, Kingswood.

A talented and principled member of his generation, with infectious good humour, he will be greatly missed.

Challenge of three decades at the forefront of innovative HIV programmes

John Dalton describes the importance of working with stigmatised communities

VST's partner Arogya Agam was one of the first to start work on HIV and Aids in the late 1980s and continues to take up challenges that the mainstream ignores or is unaware of.

Early on Arogya Agam managed to do a good deal of HIV education in schools including condom demonstration. It covered most of the schools in Theni

District and trained a number of NGOs in four states to do the same.

Soon Arogya Agam began work with women in prostitution. These women have stories that, when advocating for their rights, can make hardened policemen cry. This work has been variously supported by VST, Oxfam, Christian Aid, Bill and Melinda Gates Foundation and now is funded by the Indian government's National Aids Control Organisation.

The rationale of working with sex workers and others is that HIV is driven more by the pattern of unprotected sex than the number

of sexual encounters. Infection rates accelerate when there are "key populations" who have large numbers of sexual partners.

Sex work is common in India where casual sex is harder to find. Theni District, with a population of one million, has around 900 women and 200 men/transgender who are selling sex.

It was hard at first. For instance police arrested women if they had condoms on them which is very counter-productive. Arogya Agam was one the leading organisations in getting this practice

changed. Police would arrest, rape, torture and tondre sex workers. When sex workers became organised with our help, they would gather around and shout at offending police officers and shame them in the street. These malpractices are largely a thing of the past now and condom use (except with "regular partners") is high.

Arogya Agam was also at the forefront in promoting the "peer educator" model where volunteer condom users distributed condoms and persuaded their associates to use them. In addition a clinic was set up for the sex workers (now transferred to the

government hospital) since regular medical check-up and treating sexually transmitted infections is another intervention shown to reduce HIV transmission.

Reduced HIV transmission in sex workers reduces the HIV burden in adults and children in the population at large. In the past we have assisted children of sex workers, girls in particular, to finish school and to go to college. The women however are now very determined to keep their girls out of the trade. There are a few that have taken it up later but it is very hard to

find girls and young women under the age of 20 as sex workers in Theni District.

Another group with high HIV rates is "men who have sex with men" including transgendered, bisexuals and gays. Arogya Agam is one of very few organisations that work with this high risk group whose existence is barely acknowledged in India. The work involves identifying and training "peer educators" to promote safer sex through use of condoms.

Read more about HIV and Aids work at www.villageservicetrust.org.uk and www.arogyagam.org

Kumar

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There was good support, however, especially from our staff who remained supportive to the end, despite Kumar's tendency to be difficult. Problems started when he had to change school to go to class 6. We had suspected from the way he behaved that he was three years older. He began to truant: we fought, but in the end he won. It is always difficult to keep children in school when they are two years or more behind. He would have been 14 by now, a difficult age in any case, and having to mix with children three years younger. So he was one of the first HIV-infected children to drop out of school.

Despite very regular tablet taking Kumar became sick again and was diagnosed with TB. The drugs were no longer working: so another very unfortunate first – the first child from Theni to be started on second line antiretroviral drugs. We had to admit him in Chennai and then take him every month to get his tablets.

Then more heartache. We called him and his local friends "Kumar's criminal gang". They stole from everybody – serially – including myself. At this time Kumar started to make trips to his village and do some goat herding but he always came back. Eventually he could go to Chennai to collect tablets on his own, but when he started to use the travel money for drinking and smoking ganja things came to a head.

He went off to work in a cinema as watchman. I visited him there a few times – he said that he felt 'free', now he didn't have to go to hospitals and take tablets. I suppose Kumar was in the first cohort of difficult adolescents who were rejecting drug treatment despite so much education, counselling and advice.



Kumar's life and times: clockwise from top left, early days on the beach, with non-HIV schoolfriends, on a trip to the hills, ready for the new school term, the goatherd, and with John last year



Kumar became sick and came back. I had a long session with him and the next day he asked our staff if they could help him to re-start the treatment, now available nearby in Madurai. He said he was willing to do this because "Appa was so sad and crying".

Although this period was short-lived, we came to an arrangement with Kumar. He went back to live with his aunts. When he had problems, mainly skin infections, he would come and be admitted into Arogya Agam's hospital for a few days.

We would all at least mention tablet taking but to no avail. I would go and visit him: it was great being out in the hills and forests with

the goats. Kumar was good at it and never lost a goat and had built up a small herd of his own. I was thinking that when he became really ill again we would treat him, and perhaps the second line drugs would still work, and it would be all right again. When you are personally involved it is easy to 'forget about' other fatal complications. What happened next was an aggressive glandular cancer as a result of destroyed immunity.

Kumar was admitted in our hospital again, really sick now. He was staying in a room with two bunks. For years he

had very rarely asked me for anything. But he did ask me to stay with him at night which I did for the next month.

When the pain was really bad we looked around for morphine. Our friends in the Theni Hospice have a licence for it, but he would have to be admitted there. He refused, saying he wanted to be with us or else he would do away with himself. Our medical staff had to combine the strongest painkiller available mixed with sedatives. So we had a lesson in palliative care.

We talked of all the forest walking we had done, trips to the sea and to the hills. We had had many good times over the years.

He knew he was dying and the end, when it came, was ugly. I was there. Kumar made it just 17 hours into 2016.

Someone said that eulogies were about what people had done and asked, what would have been in Kumar's? Well, as I have said, he taught us a lot – about HIV, treatment, troubled HIV-infected adolescents and more. Right from the start I was told I was letting myself in for a lot of grief and sorrow. That was only too true, and it is still going on. Even if I had known, on that day 12 years ago, the full extent of the sorrow to come I like to think that I would still have taken Kumar - sitting on my motor bike tank and smiling.

HIV compounds teenage angst

When Kumar was asked why he no longer wanted to take treatment he famously said: "Now I am free." That meant he no longer had to go to hospitals, have tests and take pills.

HIV-positive adolescents invariably have a concern about their marriage and future life. Some develop love affairs with those in their social circle most of whom are HIV-negative. The majority have low self-esteem when they compare themselves to their HIV-negative friends. Many are angry with their parents for infecting them, but at the same time feel dependent and worry about their support if the guardian dies.

Some of the antiretroviral drugs do have visible side effects, for instance AZT causes skin darkening which is very unwelcome especially for girls. On the other hand the drugs are blamed for things they don't cause which make them more unpopular still. Late development and puberty is a problem, and seems to affect boys more.

There is an impression that boys more than girls hide their HIV status, certainly they are harder to persuade to attend for treatment, welfare measures and group meetings. On the other hand symptoms of depression seem to occur more in girls. Girls have an additional problem with menstruation with relatives shunning them and difficulty in accessing toilets if their status is known at school.

HIV-infected children underperform in school due to HIV itself, to mental worries, sickness and poor attendance. Adolescence doesn't help and pressure to score high marks increases when public examinations are getting close. It is certainly hard to keep the children in school as the desire to drop out becomes intense from the age of 15.