



April 6, 2001

## LETTERS FROM THE WORLD OF AIDS

***Loved ones,***

I am watching the moon— and a full one at that— rise over Fisherman’s Cove in the Bay of Bengal, some thirty miles south of Chennai, formerly known as Madras. Richard, Lee, Craig and I have retreated to this beautiful place for a couple of days to both work and unwind. The work is in a centuries-old fishing village just a beach walk up from the hotel. The images we’ll record are of sons of fishermen wading into the gentle surf to cast their nets for bait; ancient wooden catamarans so low to the water that from the shore the fishermen that ride them seem to be gliding on the sea; and the life of the village itself, in which Hindus, Catholics, and Muslims live in the kind of harmony one can only wish for elsewhere. These and other scenes will serve us well as we attempt to give a feel for the way life is lived here in the southern Indian state of Tamil Nadu, and they will also add to the bank of images we are creating as we carve out a film that is increasingly, I believe, not only about the presence of AIDS in the human family, but also about the family itself: a celebration of dignity and the pulse of life, in the face of injustice and premature death.

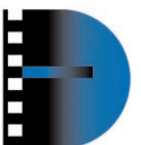
We are unwinding just a bit because when you go to India to document the reality of the AIDS epidemic you run up against some harsh realities, some things that are pretty hard to listen to and to see, particularly since in India you’re looking at the future: sub-Saharan Africa all over again, and then some. The metaphors people use here to describe the present-day reality of HIV/AIDS are “tip of the iceberg”, “smoldering volcano”, and “earthquake”. In other words, a disaster.

I want to describe as best I can what we have found here with respect to the plague, but first, something about India itself.

I traveled throughout India, as you know, for a month late last year to try to figure out what to do here as far as the film is concerned. I spent time in Delhi, Chennai, Mumbai (that’s Bombay), and managed to get up into Nepal as well, for a few days. So between that trip and this one, some six weeks in all, I’m beginning to rid myself of the powerful culture shock— there really is no better term for it— that one feels upon being in this country of a billion people for the first time. I’m beginning to feel comfortable here, and am beginning to understand how and why people fall in love with this place.

For one thing, the Indians themselves— at least the many I’ve met— are very sweet, especially the people here in Tamil Nadu, where we’ve chosen to concentrate our work. With their easy laughter and gracious ways, they seem genuinely warm to me, and I’ve made some good friends already, both in the AIDS work, but also with ordinary people.

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**Robert**  
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For instance, I've been to Fisherman's Cove three times now for brief stays, and was very touched tonight when the lifeguard, who I hang out with on the beach, brought me a shell with my name engraved on it. When he put the shell down on the table I didn't at first see my name, and therefore was surprised, because it's the villagers who sell the shells, not the hotel staff. So I reminded him that I had bought shells when I was here last November. "No Mr. Robert, this is for friendship. See?" Then he turned the shell over and sure enough, there it was, "Robert", engraved along with some elephants, trudging along.

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The cliché about India is that it is a land of contrasts and contradictions and, like most clichés, this one has more than a grain of truth.

India, for instance, has the world's most brilliant and sought-after computer specialists, yet at the same time more than half the country's population— 600 million people— cannot read or write. Poverty is pervasive, and in big city slums like those of Bombay, the inhabitants earn barely a dollar a day. Yet that same city claims that it has more millionaires than any other city in the world. Government-run hospitals offer world-class care— except for HIV and AIDS— at a fraction of the cost of similar care elsewhere in the world, but the rural hospitals, serving the majority of the country's population, frequently run out of aspirin, and have little else to offer. In the land of the Kamasutra, the revered discourse on human sexuality, parents are unable to discuss the subject of sex with their adolescent offspring.

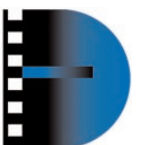
Into this tapestry of human experience in all its contradictions, contrasts, and contrariness, the HIV virus is at present happily and deftly weaving it's many threads. I am pretty well convinced that the virus will do better here than anywhere else so far, if only because Indian society is offering it so many opportunities. (Remember what Jonathan said? "AIDS is taking advantage of the opportunities society offers it.")

It's a sad litany.

- No coordinated or comprehensive or effective national policies or programs to deal with education, awareness, testing, prevention, or care. Nothing. Only isolated programs driven by individual NGO's or government universities acting like NGO's: Anjali Gopalan's



*Indian child (name unknown)*





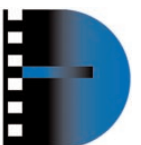
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NAZ Foundation in Delhi; Suniti Solomon's YRG Care here in Chennai; Dr. N.M. Samuel's rural testing and mother-to-child intervention program in Namakkal, deep in the interior of Tamil Nadu. Fine programs all, but unrelated to one another, scrambling for money all the time, and clearly insufficient to stem the coming tide.

- Hundreds of other NGO's taking government money and sitting on their asses in air-conditioned offices in Delhi and Bombay doing nothing, thus creating the illusion of a response, but not the reality.
- No health care structures equipped to deal with the coming millions of infections and but a handful— and I mean a handful— of doctors in a country of a billion people trained to treat HIV/AIDS patients.
- Untrained doctors in private practice are prescribing single-medication protocols based on stuff they read in journals or pick up from ads. These protocols have no relation to their patients' actual needs. This practice will increase as the epidemic worsens. What will happen? These protocols could cause the virus to produce new recombinant strains that are resistant to existing therapies, and so now we start all over again, folks. And we start all over again everywhere, by the way, since we know full well by now that HIV is a frequent flyer and just loves to travel and see the world.
- No money for drugs for the vast majority of the country's population, most of whom are poor. Picture a ladder with ten rungs. If you're not on the single top rung of this ladder in India, high above the crowd, and you're standing hungry and poor on the other nine, and if on top of that you have HIV/AIDS, then you're most likely not long for this world. That's blunt, but that's true. If you have AIDS in India right now and you are not part of the elite economic minority, you will die needlessly before your time, and we now have pictures and interviews to drive home how that is happening, right here, right now, even as I write.
- India is the world's largest democracy, but it is a democracy whose social and cultural foundation remains a caste system that categorizes the country's citizens and institutionalizes marginalization, discrimination, and stigmatization. The HIV virus feeds hungrily on these de-humanizing social categories, and it seems to me unlikely that they will change anytime soon.
- The most dramatic, alarming, and across-the-board example of the socially and culturally-induced vulnerability to AIDS in India is, of course, women, whose lives and experiences in this country have been problematic long before AIDS came along to complicate them even further. Arranged marriages; taboos about sex and

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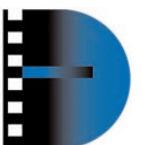
talk about sex; proscriptive and restrictive roles once in marriage; inability and fear to negotiate about safe sex; a pervasive cultural perception that men are rightfully dominant: it's a sad litany. No Woman, No Cry, indeed.

- And then of course there are the huge numbers of men who have casual sex with other men, and then go home and infect their wives who either don't know about AIDS, don't know that their husbands are having sex with other men or with sex workers, and/or can't do anything about it even if they do. Unprotected anal sex on the weekend, just for laughs, then a romp with the missus once or twice during the week. Multiplied by millions. And millions. Every day.

I could go on, but what's the point?

Along with all of India's problems— other diseases, poverty, illiteracy, water and environmental issues to name a few— we have a unique recipe for disaster here, and I worry about it because I know that it's real. The water's boiling, and ingredients are being dumped by the spoonful into the pot. My new, and already dear friend, Dr. N.M. Samuel, ("please just call me Sam") who directs the AIDS program at a university hospital here in Chennai, pointed out to me that our perspective may be unique simply because, as a documentary filmmakers, we are taking the time— that's the key word, time— to be with people, to listen to them, to get to the heart of the problem, and to organize, understand, and then try to communicate what we are seeing and hearing in all these different places and in all these different contexts. "You must, Bob, write a book", Sam said to me more than once during this past week. "I love the movie you're making, but I really want to read your book." OK Sam, no problem. He also said something that took me by surprise. He said that he thought I was becoming an "expert", and that I should expect, accept, and respond to that role as *A Closer Walk* fulfills its purpose and attains the dreams we have all had for this project since Jonathan and I first conceived the film five years ago. While it's true that I've certainly learned a great deal over the last five years— from Jonathan and all the others— "expert" is uncomfortable for me in this context: Peter Piot, Eric Sawyer, Sam, Suniti Solomon, Paul Farmer, Mark Heywood, Sandy Thurman, Nils Daulaire, Jeff Sachs— these are "experts". Like my buddy Paul Farmer— who admittedly wears two hats, if not two dozen— I prefer just to be with the people. That's when I'm happiest. On the other hand, it may well be that what Sam is intuiting is precisely what we have all these years hoped to achieve: a voice. A voice for health, dignity and human rights that is not only Jonathan's and my own, but, more importantly, a voice for all who are marginalized, discriminated against, forgotten, and poor. I'm proud to be an expert for them.

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There have been many revealing, haunting, and magical moments on this shoot, and I will perhaps write more about them in another letter. But the defining moment for me was at the Hospital of Thoracic Medicine outside Chennai. This is a government-run campus and complex that is essentially a center for tuberculosis treatment in India and has now, by default, become a principal HIV/AIDS treatment center as well. So in a very real sense what we saw and filmed at this hospital earlier today is the epitome of AIDS in India: its epicenter, its heartbreaking reality.



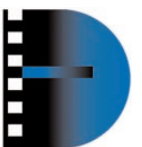
**Nurses at Hospital of Thoracic Medicine**

The hospital was founded in 1928 and has grown from a small institution with 12 beds to a sprawling ten-acre campus with some 20 buildings providing a wide range of services for in and outpatients. Huge Banyan trees provide dappled shade and comfort for those who are able to walk about. On decades-old benches made from thick slabs of stone sit thin men and women with lung disease, in robes of blue and gray. They pay us little mind in the midday heat as we trudge by with our equipment, conversing with the doctors, drinking our bottled water, doing our thing. Our presence notwithstanding, the whole place has a peaceful, quiet feeling that belies the suffering taking place inside the walls of its clinics and wards.

There are about 1,000 HIV/AIDS in-patients at this hospital— children, women, and men. The bed occupancy rate for AIDS in-patients is 130%, meaning that there are not enough beds for all. Hundreds of other HIV patients come to the hospital every day on an outpatient basis. The queues are long, and new patients are presenting themselves to the hospital at an exponentially increasing rate as the virus spreads and the word gets out that this is one of the places in India where some care can be had. This growing pressure is true of other HIV clinics and care facilities we visited as well. Not enough beds, not enough staff, not enough money, not enough drugs, too many people.

We visited three HIV/AIDS wards during the six hours we spent at this hospital. The first was the children's ward, shared by HIV and tuberculosis patients. (Not a terribly good idea, but space is at a premium.) We filmed in this ward by having the doctor stop at the bedside of each child and give me a thumbnail sketch of his or her history. The ages of these children ranged from about 8 months to 5 years. All definitely on the young side.

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"This one is very advanced. We are not hopeful."

"This one the mother and father have already died. This is her grandmother. Her brother is also HIV positive."

"This one has TB. And look at this." (He asked the girl to stick out her tongue. It was mottled with a white and green fungal infection.)

"This one the whole family has died. He is three years old."

"This one" (a tiny thing with huge eyes and jet black hair) "is too young to test. So we can always hope. But her brother has died."

And so on. And so on. And so on. It is perhaps pointless— or is it— to say that each of



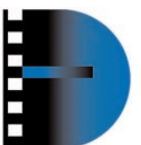
*The Hospital's Children's Ward,*

these children was beautiful, though they were all terribly thin. In each case, AIDS had already set in, and was taking its course. Death in the making. But what really got to me is the simple fact that these children do not need to be where they are; do not need to suffer; do not need to die. Mother-to-child transmission can be prevented. There are easy-to-administer drugs that prevent HIV-positive mothers from passing the virus along to their children

in utero. But where are the programs? Where are the delivery systems? Where are the drugs themselves, particularly for the poor? Where is compassion? Where is the will? Where, for God's sake, is common sense? I agree with Paul Farmer. Stop talking and analyzing and researching and worrying and avoiding and bureaucratizing and just get on with it. Treat the poor. Save your country. Save yourselves. Save the world. Get with the program. It doesn't have to be this way.

The women's ward wasn't much fun either, although it was beautiful because the women themselves were beautiful— they were all in their 20s so far as I could tell— and they were all dressed in colorful sarwals— brightly patterned, loose-fitting pants with a matching knee-length shift for the top. Blues, whites, reds and greens. There were about thirty beds in this ward, upon them all women with AIDS. Some were clearly dying. At the foot of each bed, on bamboo mats, sat other women, also with AIDS, who represented the overflow. Not enough beds, so these women sat on the floor.

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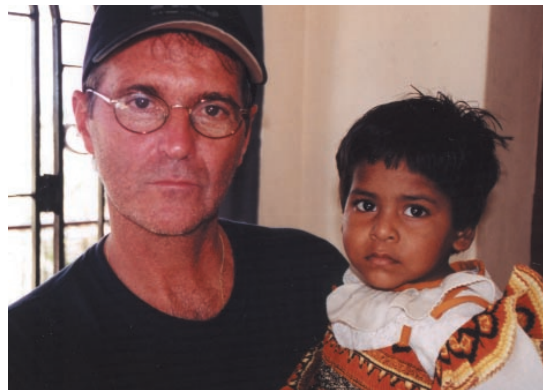
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It's a rotating system, actually, where the sickest women get the beds, but once they do better, then they go to the floor so the new ones can have the beds.

The ward was immaculately clean, and quiet. For the most part, the women just stared off into space, their thoughts and emotions difficult to read. We filmed this scene with the doctor standing in the middle of the ward, among the patients, giving me an overview of what it's like to be a woman with AIDS in India.

It goes something like this.

There are about half as many women infected as men, but that is slowly, steadily changing. (By the way, did I mention that no one really has any idea how many Indians, men or women, actually have HIV at this point in time? The published numbers are around 4 million, but most of the people I talked to are guessing two or three times that many, already. But the key thing is: no one knows. No testing!)

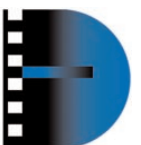


**Robert Bilheimer, Director, with 18 month old Jansi, an AIDS orphan (CHES AIDS Orphanage, Chennai, Tamil Nadu, India)**

Back to the women. More and more of them are coming to the hospital. And their demographics are changing. In the early stages of the epidemic most of the women coming in were commercial sex workers. Now they are seeing more and more "housewives," and when these women come in, they are invariably very, very sick. The reason for this is that unlike the men, who go to the hospital at the first sign of an opportunistic infection, the women, even though they develop symptoms, stay in the home as long as they possibly can. In India, pretty much across all social and economic levels as far as I can tell, the role of the woman is in the home, while the man is the wage earner. This role is so deeply woven into the fabric of Indian society that even when a woman gets very, very sick, she is expected to keep the home fires burning, and make the appropriate sacrifices. And then, to add insult to injury, when the woman is finally diagnosed with a deadly disease like AIDS, she is then shunned, and, for all intents and purposes, deemed to be worthless.

"Do you notice anything different here?" the doctor asked me. (We had already been to the men's and children's wards.) I looked around, and then it struck me. There were no visitors. Sure enough, the doctor told me, whereas the men and children have wives or grandmothers sitting by their bedsides, the women have no one. I asked the doctor if a

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husband had ever set foot in the ward. "Never. Not even one." Even visits by female relatives are relatively rare, he told me, because these women are expected to stay home as well.

So not only are Indian women dying of AIDS in growing numbers, they are dying alone.

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Heartbreaking as were the scenes in the women's and children's wards, it was the men's ward that affected me the most because it so powerfully represented not only the reality of AIDS in India, but the reality of AIDS anywhere.

The men's ward—there are three or four of them at the hospital that are devoted strictly to AIDS—is large: twenty five beds on each side of a room easily a hundred feet long and thirty feet wide. On each of the beds in this room was lying or sitting an emaciated, dying man, stunned, as it were, by the maturation of the deadly virus that had been living in his body—without his knowledge, of course—for the last three years or so, methodically dismantling his immune system.

At the bedside of some of these men were women—mostly mothers as far as I could tell— or other men, brothers perhaps, or cousins, or friends. I didn't see many fathers. The men were all fully dressed, except for shoes. Some slept. Most simply lay still, staring vacantly at a window, a wall, or the man lying in a bed next to him.

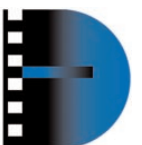


*Patient, in the Hospital's Men's Ward*

Like the others, this ward was immaculately clean, and eerily silent. Wise, immaculate nurses hovered. One dying man was vomiting blood and when he did these angels, dressed in gray with white hats that flared out on the sides like wings, would encircle him. His cough, the rack of tuberculosis, penetrated the room like a crack of thunder.

Beyond the attendance upon this man, there was little activity. Bear in mind that there are no— or only very limited— drugs to treat these patients, so they are usually discharged— sent home to die, basically— after a couple of weeks in order to make room for the new wave of admissions. It's an overlapping, rotating thing, kind of like the trains that brought the Jews to Auschwitz, Belsen, and Dachau. Only this time the genocide is not being committed by an evil lunatic, but by the very world we ourselves have created through our indifference, greed, and neglect. I increasingly feel ashamed to be living in such a world.

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A  
CLOSER  
WALK

A film about AIDS in the world. A film about the way the world is.



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Standing in this ward on the outskirts of Chennai, in the state of Tamil Nadu, in the country of India, on the Asian continent, I felt for the first time in a year and a half that I was smack dab in the middle of the global AIDS pandemic, palpably in its midst. As I stood there looking around, I said to Dr. Sam, who had facilitated our visit, "Sam, I'm feeling something I've never felt before, it's...."

As I hesitated, looking for the right word, he quietly provided it. "The enormity, is that it Bob?" I looked at him. He is such a sweet, gentle man. "That's it, Sam. It's the enormity of it all."

And then I realized that I felt something else, as well. As I walked up and down the ward, looking at the patients, directing the crew, talking to Sam and the doctors and nurses, I realized that I was in a holy place. Holy because of the suffering. Holy because of the care. Holy because of the dignity of these dying men. I can't write any more about this feeling of being in a holy place right now, because the feeling was so powerful that I need to live with it for some time in order to understand it more fully. What I do know is this: in one way or another, I will be in that ward the rest of my life.

When the shoot was over, I could not bring myself to just walk out, so I went to each individual patient, up one row and down the other, and said good-bye to all fifty. I did this by putting my hands together and bowing slightly in the traditional Hindu greeting. As I began to do this and it became apparent to the patients what I was doing, each made an effort to sit up and greet me in return, often with a smile. Though it was difficult at first, I took great care to look each of these patients directly in the eye, and say "thank you." By the time I had gotten to about the thirtieth or fortieth man, the cumulative weight of their sorrow and mine was causing my eyes to fill with hot tears so when I was finished I went out of the ward and stood for a while apart, to collect myself, before moving on.

With much love from India,

Robert

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