

given informed, voluntary consent; they trusted the investigators because they had no other health care.

A 1995 article- in the journal *Science* notes that establishing institutional review boards and obtaining meaningful consent are acknowledged to be two major problems in ensuring ethical human research. This issue will become even more important in the future, as developing countries, particularly those with large burdens of "interesting" diseases, are seen as ideal research settings. For example, HIV infection is so prevalent in a country like Nairobi that a study that would take 15 years in the US can be done in 18 months, and for a lot less.

Especially if you don't have to use AZT.

### References/ related reading:

- Unethical trials of interventions to reduce perinatal transmission of the Human Immunodeficiency Virus in developing countries. Peter Lurie and Sidney Wolfe, *New England Journal of Medicine*. September 18, 1997. 337; 853-6.
- The ethics of clinical research in the third world. Marcia Angell. *NEJM*. September 18, 1997. 337; 847-9.
- Ethical complexities of conducting research in developing countries. Harold Varmus, David Satcher. *NEJM* October 2, 1997. 337; 1003-S.
- Placebo orthodoxy in clinical research. Part 1: Empirical and methodological myths. Freedman B, et al. *Monash Bioethics Review*. Vol 16, No. 4, October 1997. Special supplement: 12-26.
- Top US health officials defend third-world HIV research. Sheryl Gay Stolberg. *The New York Times*, October 2, 1997.
- Staging ethical AIDS trials in Africa. Rachel Novak. *Science*. Volume 269, 8, September 1995.
- WHO International ethical guidelines for biomedical research involving human subjects, Geneva: Council for International Organisations of Medical Sciences, 1993.
- Indian study of women with cervical lesions called unethical. Ganapati Mudur. *British Medical Journal*. 7087, Vol 314, April 12, 1997.
- Human guinea pigs. Meetu Jain. *Pioneer*. December 6 and 7, 1997. Action against ICMR doctors sought:
  - 'People should not have to pay with their lives for science'. Meetu Jain. *Pioneer*. December 11, 1997.
  - ICMR admits flouting norms: use of humans as guinea pigs. Meetu Jain, *Pioneer*, December 17, 1997
  - The ethical dilemmas of a good doctor. Radhika Sachdev. *The Times of India*. December 17, 1997.

*Readers are invited to send reports and comments for our April issue on the ethics of clinical trials in India.*

### **"I will feel reassured only after I get my job back"**

A recent Bombay high court judgement affirmed the HIV-positive individual's right to employment. Separately it also held that HIV-positive people can approach the court without disclosing their identities. The court directed that the public sector corporation which had employed the petitioner, MX, give him work as long as he was able, and also pay him Rs 40,000 for the four years that he was unemployed.

MX is among the millions of unsung heroes of our times, courageous and resilient in the face of crippling adversity. It is no passing irony that his employer who kept him dangling first as a contract worker then as a casual worker and finally fired him just before he was to be made permanent, is a public sector corporation. We reprint his story, with his consent.

I ran away from home when I was 12. There was always a shortage of food. I used to work as an agricultural labourer and earn some money but there was only grinding poverty to be faced each day. I ran away from poverty. . .

"A lorry driver took me to a refinery where I was put to work painting drums I slept wherever I found some shelter. Later I joined the company as a contract worker. That was in 1982. I used to load 205-litre drums on to a truck...

"I went back home for the very first time after 12 years, after getting a telegram saying my parents had died. They of course had only used it as a way of getting me there to get married. Thereafter I went home each year that I was working with the company...

"In 1993 I was given a letter saying I was to be made permanent. The company doctor sent me to a private clinic for what I later understood was the HIV test. The doctor at the private clinic told me I had tested positive but I should reconfirm the findings at JJ hospital. I took both reports to the company where the doctor told me that though I had tested HIV positive I was fit enough to work and that I would be made permanent. However, I still worked as a casual employee for the next three months after which I was given a letter telling me that I was suspended from work as I was HIV positive...

"I approached whoever would hear me and pleaded my case specially as I had a wife and two children to support. Many officers told me they could not help and directed me to another official. The doctor at JJ hospital gave me a lot of courage and sent a letter to the management to absorb me but that did not work either. Another senior doctor even wrote to the company director... Finally, this doctor referred me to the advocate who fought my case...

"The first time I went to court I felt I would get justice there but then again I wasn't so sure. Though I was told that I could have as many as 15 years before the virus actually took its toll I never felt ill or tired. I have accepted that I have the virus. It does not frighten me except that I want to provide for my family.. .

"When I lost my job, my wife sold her jewellery and I eventually began driving an autorickshaw. I haven't gone home since I was removed from the company. I can't afford it. When my only sister got married I did not attend the marriage as I could not afford to take anything home for the family or for her.. .

"I will feel reassured only after I actually start working at the company and use the back wages to repay some of my debts. Providing for my children's education is my major task. . . . Life has been a harsh struggle. I cannot bear to see the suffering of poor people on the street. My friends laugh at me when I weep in films that show the disparity between the rich and the poor. I don't see movies anymore."

*Excerpts from 'MX tells his story'. H. Rustomfram. From The Lawyers Collective 12(5), 1997.*