

FIRST INTERNATIONAL CONFERENCE  
ON THE IMPACT OF AIDS

BARBICAN CENTRE, LONDON, ENGLAND

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HOLY TRINITY, BANGALORE



Ten days ago I was in Bangalore, India. I was there to attend a conference of judges called to review the remarkable growth of international human rights law. I clutched a few spare hours to visit the fading remnants of British rule to be seen at every turn in that temperate cantonment town. Here, the statue of Queen Victoria, Empress of India. There, the masonic lodge. Nearby, the great parade ground, now overgrown with bougainvillea. As chance would have it, I wandered into Holy Trinity Church - once the bastion of Anglican Christianity - now fallen on harder times. In this crumbling pile I sat in the front pew marked "The Hon'ble The Resident". All about me were the

symbols of yet another foreign empire which India had finally absorbed. Yet this was my empire. And it had passed away in my lifetime.

I looked at the wall plaques which commemorated the servants of Empire. One by one they told the tale of earlier epidemics. A sapper dead at 21 from cholera. Twin brothers dead, within a month of each other, from plague. And so the list went on. The priest dead in two years of service for his flock. Smallpox, dysentery - many forgotten deaths. The encounter of the foreigners with unfamiliar viruses challenged their resistance. And I asked myself, in that quiet place, is AIDS just another infection? Is it simply part of the inescapable cycle of life and death on this planet?

The slightest acquaintance with the history of mankind now shows the importance for human events of these cyclical infections<sup>1</sup>. It demonstrates the frightful havoc and toll of death and suffering of the millions whom disease carries off. Few of the dead are memorialised in the ruined churches of lost empires. They are just more human souls who die in pain and despair. I asked myself if we mortals were so insignificant that epidemics of this kind have no meaning - just something inevitable, to be endured in waves.

As I left the church my eye caught one plaque with a text from the Letter of James.

"Blessed is the man that endures temptation: for when he is tried, he shall receive the crown of life."<sup>2</sup>

We are certainly being tried. But shall we, in the end, receive the crown of life? The trial of AIDS has only just begun. Our scientists and technologists are being tested. International cooperation and world bodies will be extended. Our democratic institution will be put to a test by public alarm and fear. Respect for human rights will be tested - for they matter most when they are hardest to accord. Patients, and their families, in every land will be tested by human suffering, pain and grief. Above all, it will be a test of human ethics. The history of previous encounters with infection has not always been an uplifting one. People panic. Out of panic come irrational and ineffective policies and, worse, harsh and oppressive laws. We must be on guard against the risk of adding to the mounting toll of suffering a burden of ill targeted, ineffective laws.

SACHSENHAUSEN REVISITED

How can we do this? This century has been so full of misery, destruction and cruelty that, near the close of it, we can surely learn some lessons from our earlier mistakes. One of the lessons to be derived from the Nazi holocaust against unpopular minorities - especially the Jews - is the danger of depersonalising human suffering. This is, I am afraid, a growing danger with AIDS. When the problem becomes a matter of statistics, graphs, bar charts, trend lines and the other necessary paraphernalia of modern communication, there is a danger of acceptance of the unacceptable. This, after all, is how civilised and even pious and religious people accepted the horrors of participation, or acquiescence, in Belsen, Buchenwald and Sachsenhausen.

A few weeks ago I read an item in a Netherlands journal. It must be false, I thought. At least I hoped so. A journalist, Suzanne Schneider presented herself as a representative of "Midinvest", an organisation specialising in the building of clinics for incurable diseases. She went, according to the report<sup>3</sup> to a number of mayors in the district of Sachsenhausen. She asked these worthy civic fathers whether they would be interested in the establishment of a closed institution for AIDS patients. She used the old plans of the Schesenhausem concentration camp. Even the watch-towers of the former camp were not deleted. According to the report, eight of the ten mayors interviewed immediately said that they were interested. The idea of a multimillion mark project within the boundaries of their municipalities was too good to resist. One of them said:-

"It is about time something was done about this. The health of the general community is more important than 300 AIDS patients".

Another mayor was even recorded as saying:-

"Once the clinic is in operation we will say that a medicine has been found there."

The prospect of ordinary labouring jobs for the local population attracted others. Only two of the ten would have nothing to do with it.

We should not be surprised at such a report. We have seen it all before. It is there in earlier living memory<sup>4</sup>. Anyone who doubts the stigmatisation of patients during epidemics should read of the way, in Australia in the 19th

Century, that the small Chinese populations were rounded up and put in shocking conditions in haulks off the coast<sup>5</sup>. And if you think that we have now become more civilised - with a heightened international conscience about human rights - remember Sachsenhausen, then and now.

#### THE HUMAN DIMENSION.

In the big cities of the developed world as in the villages of central Africa, the day is not far off (if it has not already arrived) when every person will know someone who has died from AIDS - or be the friend of someone who has died. A problem with these large international gatherings is that the human dimension may be insufficiently focused. Yet that dimension is vital, both to mobilise our energies, whatever our respective expertise, and to toll loudly the bell of ethics. Good ethics in the global fight against AIDS will be derived from good data and from never forgetting that this is a problem of fellow human beings - people like ourselves with families, and with the joys and disappointments of living.

At a conference in Paris last October I announced my isolation of three new mutants of the AIDS virus. To distinguish them from HIV<sup>6</sup>, I called the "HIL"<sup>7</sup> - highly inefficient laws. HIL I represents laws for mandatory testing of the entire population for the presence of HIV. HIL II is mandatory testing of particular groups deemed specially at risk to exposure to the virus. HIL III is mandatory certificates at the frontier. My thesis was that these were ineffective, inefficient and potentially even harmful approaches to the social regulation of AIDS - at least at this time. Until there

is a vaccine and a cure, the whole thrust of effective social policy and lawmaking must be to promote the spread of information and of measures for prevention of infection. Difficult though it will be for some societies to accept a number of the measures of prevention necessary to contain the epidemic, those measures will eventually have to be taken. If we are serious about the protection of life, the sooner this is done, the better.

I suggested in Paris that no AIDS conference should convene without the voice being heard of those who have acquired the virus. True, it will not be the only voice. But it is a voice that should not be silenced.

Mark was at school a few years behind me. He was a good athlete. He showed talent in languages. He went to the university and marked out a career in what seemed to me to be a number of esoteric aspects of foreign literature. I kept contact with him over the years after school days.

Six months ago he asked to see me. He told me that he had been diagnosed as antibody positive to HIV. He was frightened. Would I speak at his funeral, if the worst came to the worst? Of course I would. I laughed, telling him not to worry. The statistics were against his progression to "full blown AIDS". The scientists would find a cure. Jonas Salk even talked of a vaccine for the already infected. Mark smiled with relief and we ate our dinner. But I noticed that he took no wine and chose the simplest of food. Mark was scared.

I returned to Australia from Europe in late January to the news that he had been admitted to hospital. It had all

happened very suddenly. He was without symptoms until mid-January. He had been meditating and dieting. Then suddenly he was too weak to work. He was losing weight rapidly. A mass was discovered in his stomach. He was admitted to hospital for tests. I went to see him at once after my return. Down the long hospital corridor I walked. Throwing a glance to right and left, the scene was the same. Rows of beds. Young men emaciated. Tearful families clustered in the corridors. Retching and coughing the only sounds to break the silence. The epidemic was certainly here.

Mark's concern was how he could tell his colleagues that he would not return next week to work. He had already braved that journey once and told his parents. To the fear of death was added, for him, the hurt of embarrassment and stigmatisation - even of loathing amongst some at the mention of the fearful acronym. I composed a letter for him. It just said, accurately, that he had been diagnosed with cancer and would need chemotherapy. He would probably not be back this semester. It was a great relief for him when he signed the letter. He wanted to act professionally and honourably.

They had diagnosed a lymphoma. He was going to have chemotherapy. But he told me:- "I must face the fact that I probably have only eighteen months to live. My life has telescoped". I looked at him - his grey face and frightened eyes. I shared his fear. I tried to encourage him. But it was hard. We both knew that he was on a short journey from which there would be no return.



Mark seemed just a little bitter. "The rules changed", he said, "But they didn't tell us quickly enough". The words kept recurring. The "rules" for "safe sex" for Mark had taken too long to save him. He was the kind of person who would have obeyed the rules - if only he had known them.

I saw Mark a few days later. He had undergone surgery. He was trembling and shaking uncontrollably. I grasped his hand. "Hang on", I told him. He could not talk. He could not stop shaking. But he nodded to me. It was the last time I saw him. I had to leave Sydney and travel to Bangalore. In Bombay I received word of his death. I never spoke at his funeral, as I had promised him I would. But I speak for him now and I dare to speak for all those like him. I speak for their families; for their doctors and nurses; for their loved ones and for their fellow citizens who care.

If we see the problem of AIDS as a problem of statistics then we may face the dangers of the new Sachsenhausens. If we continue to deny its existence and call it by other names we will prolong grieving and diminish our resolve to act. If we content ourselves with treating the ill and refuse to face the necessities of education and counselling we will have the deaths of many on our collective conscience. But if we see this calamity as the problem of Mark and of men, women and children in every land, we will surely redouble our efforts to find a cure and to develop a vaccine. And meanwhile we will guard ourselves against the danger of laws and policies that are ineffective and yet damaging to human rights. There is, of course, no human right to spread infection - AIDS or

otherwise. The central human right is the right to life. Close behind is the right to the pursuit of happiness which subsumes most other rights. As we bring to a close a century of so many mistakes and of unprecedented suffering and destruction, we should seek to redeem ourselves by at least tackling this problem efficiently and ethically.

That means a global approach - for no hidden corner of the world exists that will be immune from AIDS. It also, at the moment, means prevention. Unless we learn from the errors of the past we will repeat its mistakes. The surest way to guard against that danger is to keep steadily in mind the human dimension of AIDS. First and always it is an illness. People are suffering and dying. Their families and friends are grieving. No law and no policy, no rule and no judgment that concerns this topic should, even for an instant, forget those central facts. To the burden of illness, fear and even despair, we must certainly not add the burdens of stigmatisation, shame and discrimination. To do so would not only be immoral. It would be seriously counterproductive<sup>8</sup>. At least at this time, the effective global attack on AIDS requires urgent behaviour modification of those specially at risk. No other strategy holds out hope of containment to protect the uninfected. Spreading urgently and clearly the word of the changed rules to the Marks of this world - not their confinement in new Sachsenhausens - is the way of the moment.

FOOTNOTES

\* President, Court of Appeal, Supreme Court, Sydney. Former Chairman, Australian Law Reform Commission; Commissioner, International Commission of Jurists, Geneva. The views stated are personal views only.

1. W H McNeill, "Plagues and Peoples", Anchor, New York, 1976.
2. The General Epistle of James, I, 12.
3. "Sachsenhausen herleeft", reported in "The Gay Krant", Amsterdam, Netherlands, October 1987, No. 10, p9.
4. R Plant, "The Pink Triangle", Henry Holt, New York, 1986.
5. P H Curson, "Times of Crisis", Uni of Sydney, Sydney, 1985.
6. HIV - Human Immuno-Deficiency Virus.
7. See M D Kirby "The New AIDS Virus - Ineffective and Unjust Laws", unpublished paper delivered at the Symposium International de Reflexion sur le SIDA, Paris, France, 23 October 1987, reprinted, The Washington Post, 2 February 1988 p 12.
8. Cf T Mangold, "The Plague mentality makes victims of us all" in The Listener, 2 July 1987, 546.