A national disgrace

In the section entitled *Vox Populi* in this issue we have reproduced seven extracts from news items entitled *The first Indian porcine xenotransplant*. This episode raises vital issues.

Our understanding on the use of a pig's heart for transplant into a human being is that it is yet to pass trials in animals and has not been cleared by any authorised agency for use in man anywhere in the world, including India.The consideration of use of a pig's heart in man is justified only when the pig has been so bred that it carries genes identical to those in the patient in whom it is to be transplanted. Such a heart, it is proposed, is less likely to be rejected by its recipient. The entire operation of establishing genetic identity between the donor pig and recipient human, ensuring that the surgeon does not transfer infections (especially those by viruses hitherto unidentified) within the pig to the recipient in the process of transplantation; and other attendant problems have proved so formidable that to date no surgeon elsewhere in the world has dared to perform such a transplant. Indeed, the United Kingdon has banned any such transplant, pending further research.

And here we have a surgeon in poorly developed Assam, who has twice claimed to have carried out such a transplant without any enquiry into his credentials, experimental work, organisational facilities, laboratory expertise, peer review and official sanction! Were it not for its tragic aspects, such a claim would have verged on the ridiculous. The least that is expected of the regulatory agencies is an immediate halt to all of Baruah's activities. The Medical Council of India and that in Assam should have investigated all aspects of his activities **before** he started his transplantations. Instead, even **after** the events, we see no signs of any activity on their part.

The statement by the Health Minister of Assam, Kamla Kalita, to the Assam State Assembly — that the Government 'was examining all legal possibilities so that adequate action can be taken against him for trying to sensationalise the issue.' — is even more pathetic. This bureaucratese is easily translated: 'We have decided to do nothing for the present as regards the scientific aspects of Baruah's acts. At best we may administer a gentle tap on his knuckles for promoting himself.'

Baruah has compounded his felony by flouting all tenets of medical ethics. The news reports state that the patient, Purna Saikia, sought treatment from Baruah after reading advertisements inserted in local newspapers. Everything that Baruah does is shrouded in secrecy. The reports also suggest that truly informed consent was not obtained. There was no debate or discussion in any medical forum before undertaking this sensational surgery. No details on surgery and progress of the patient after surgery have been provided to the medical fraternity or the lay public. The only information avail able 1s that ferreted out by journalists and this has been horrifying. Heart, lungs, liver, pancreas were transplanted with abandon and even the pig's blood was transfused into the doomed Saikia. We are yet to learn the findings at autopsy.

To add insult to injury, the laws of the land have now permitted release of Baruah on bail. He has been directed not to perform any further transplant without permission of our national medical agencies. Presumably, he may continue other forms of surgical adventure.

No authority has, as yet, seen it fit to investigate Baruah's antigen-suppressing agent. Indeed, to the best' of our knowledge, no statutory body has investigated the earlier artificial valves designed by him though the four phases prescribed for any clinical trial appear not to be have been completed. The fact that the authorities in Hong Kong found the -use of these valves by Baruah and Ho a matter of questionable ethics and of grave concern should have awakened our own authorities. Certainly, this should have resulted in alarm bells ringing wildly when Baruah made his first announcement on the proposed transplant of a pig's heart into man.

Far from being repentent in any manner, Baruah now brazenly announces his plans for further such operations. In the same breath he speaks of an international conspiracy against him and plans for presenting his 'achievements' before experts in Barcelona and Sydney!

If, as some suspect, Baruah is a victim of psychosis, why is he allowed to roam the land, free to impose his deranged will on the hapless poor? Shouldn't he be behind bars in an asylum, kept out of harm's way? And if psychiatric assessment finds no evidence of insanity, shouldn't he be kept permanently behind a similar barred portal in gaol in the interest of public safety?

As pointed out by Dr. M. K. Mani in an earlier issue of this journal, our watchdogs continue to snore in bliss!'

Who will **regulate** when regulatory bodies have proved hopelessly incompetent?

When such problems are posed to those whose business it is to solve such conundrums — legislators and bureaucrats one gets answers similar to those provided by the Health Minister of Assam. Catch-22 is very much in evidence. Here are three examples we have often encountered:

'There has been no complaint, so how can we investigate?'

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And there cannot be a complaint, for those who should be registering it do everything possible to turn away the complainant.

'We are appointing a committee to look into this matter.' the eternal refuge of the procrastinators! The committee report is never presented to the public and actions taken on it are shrouded in secrecy. Certainly this expensive exercise results in no punitive action against the rich, mighty and politically well-connected and no improvement is evident.

'Do what you like. If you wish, you can even go to court.' When multi-million-rupee corporations do all they can to avoid any appearance in the court of law, knowing of the delay not of months or years but of decades, how is the average citizen, with meagre funds, to fight against individuals or organisations (such as hospitals) with immense resources?

Well-meaning individuals have pleaded for society-at-large to take matters into its hands by forming power-groups. Thus far this has not borne fruit as the widely disparate groups that make up our society does not make such a coming together of dedicated minds easy.

The fundamental question

But all this bypasses the fundamental question that begs an answer.

Why do those in power — governments, bureaucrats, the judiciary — permit the continuation of regulatory agencies that do not deliver? Why are the functionaries in these statutory regulatory agencies never hauled up and severely penalised? Why are hopelessly inefficient and apathetic medical councils permitted to survive? Why are they not scrapped or recreated in such a manner that their existing failings are never allowed to prevail?

Instead, newer regulatory agencies are created. The National Human Rights Commission — in its role as regulator of health care malpractice — is an example. We are driven to the state where we draw consolation from the occasional dig the Commission has against the Medical Council of India. That the pinprick may not even penetrate epidermal layers protecting the Council members does not seem to worry anyone.

And, as you might expect, the government that does not feel it important to ensure that its original watchdogs do their duties efficiently, cannot be expected to nurture this new watchdog. Writing in *The* Hindu on 24 December 1996, senior journalist Kuldip Nayar referred to the deliberate neglect of the National Human Rights Commission by the Government of India and those in the States.

'The Centre and States have not taken human rights seriously.

'It has become a fashion to talk about human rights in drawing rooms. The elite probably consider them part of economic liberalisation, giving another edge to their entertaining life. Most functions held in Delhi on the Human Rights Day were at posh places, followed by sumptuous tea. Participants were in their- best attire. Foreigners and Indians mingled with one another, talking and laughing, as if it was a cocktail party hosted by an embassy, or an industrialist.

'The Centre believes that it has done its duty by setting up the National Human Rights Commission. So deliberate is its neglect that even the Commission members, who were carefully **chosen** for their pro- establishment record, have felt let down. None at the Centre has the time either for the Commission's protests or its recommendations. Most of its Commission members have not been able to meet even the Joint Secretary in the Home Ministry, not to speak of the Minister. The Commission, despite the fact that it is headed by a former Chief Justice of India, has been devalued like the Commission for the Scheduled Castes and the Scheduled Tribes or the Commission on the Linguistic Minorities.'

Kuldip Nayar goes on to comment on autopsies, especially those on individuals who die in police custody: 'It is an open secret that doctors bow to police pressure when writing the report. Often, there is a long time gap between the post-mortem and the report. Facilities in many mortuaries are rudimentary. A 'suggestion that the postmortem examination be video-filmed has not been accepted by many States. They hate transparency.'

Sunil K. Pandya

Reference

 Mani MK: Our watchdog sleeps and will not be awakened. Issues in Medical Ethics 1996;4:105-107

The creatures outside looked from pig to man and from man to pig, and from pig to man again; but already it was impossible to say which was which.

George Orwell, Animal farm New York: Penguin Books. 1946.