Designer baby

A US couple used in vitro fertilisation and preimplantation genetics to produce embryos and screen them for a child who could be a stem cell and bone marrow donor for their daughter — the first known instance where the techniques were used both to screen for a disease and to ensure a tissue donor match in a sibling.

The couple's daughter was born with Fanconi's anaemia, a rare, autosomal recessive disease characterised by aplastic anaemia, brittle chromosomes, and the variable presence of skeletal, cardiac and renal anomalies. Untreated, patients do not survive to adulthood. Definitive treatment of the disorder relies on reconstituting the patient's bone marrow via bone marrow transplantation or umbilical stem cell transplantation.

The parents initially hesitated to have more children as they both carried the gene for Fanconi's anaemia and had a 25 per cent chance of conceiving another affected child by conventional means.

They underwent several cycles of IVF and the resultant embryos were tested both for the presence of Fanconi's anaemia and for HLA matching. Only two of 15 embryos were perfect tissue matches **and** free of the disease, and were implanted. One survived the implant procedure. The resultant child was born on August 29, and his umbilical stem cells were transplanted into his sister. If the procedure is successful, Molly will have an 85 per cent chance of recovery.

Dr Jeffrey Kahn, director of the University of Minnesota Center for Bioethics, said: "We've crossed a line here, from protecting the health of a child to selecting for donor traits."

Ruth Macklin of the Albert Einstein College of Medicine, New York, disagrees: "Some would argue that this is having a child as a means to an end . . . but I think that's not a good argument. People have children for lots of reasons and sometimes for no reason at all."

Deborah Josefson: Baby bred to provide stem cells for sister. *BMJ*, October 14, 2000.

India and genome research

The Indian health ministry's decision to pledge £13.3m ($20m) for medical genomics research over the next five years has provoked controversy, coming simultaneously with budget cuts for malaria and leprosy control programmes.

The Indian Council of Medical Research has already approved 20 research projects and is evaluating at least 90 others in an attempt to fund broad areas in medical genomics.

"A major goal of the programme will also be to prepare the country's medical community for the era of molecular medicine," said Dr Vasantha Muthuswamy, head of biomedical sciences at the council, told the *BMJ*. Projects include genetic susceptibility to infectious diseases, the genetics of oral cancer and cancer of the cervix, and the search for new drugs against malaria and tuberculosis.

Leading biologists and policymakers express concern that although India is still grappling with traditional health problems, it may be rushing into medical genomics without a clear focus.

Ganapati Mudur: India invests heavily in genomics research. *BMJ*, March 10, 2001.

Opthalmologist faces criminal case

A paediatrician who lost his eyesight fallowing cataract surgery at Lilavati hospital in Mumbai has filed a criminal case urging a police investigation after attempts to seek justice in the consumer court came to nought.

Dr Vijay Kumar Pradhan and three other patients were operated for cataract on March 10 last year. All four had lost vision in the eyes on which surgery was performed, due to infection. Though the patients maintain that the source of infection was the operation theatre, the institution refuses to accept responsibility.

In his writ petition Dr Pradhan states that the surgery had been performed by Dr Nitin Dedhia, consultant opthalmologist, who claimed the operation was successful. The same day, the surgeon also operated on Jayaram Hegde, Manohar Parekh and A Bhatia in the same operation theatre.

After the bandages were removed from Dr Pradhan's eyes the next day, there was no vision and instead pus had formed, the petition states. A culture taken from the eye showed the presence of E Coli bacteria, a gram negative bacteria of faecal origin. Dr Pradhan was finally discharged from the hospital on March 22 without any improvement. Despite another operation and several consultations, his eyesight has not been restored. The petition claims that the bacteria must have entered the operation theatre either from inadequately sterilised instruments or linen, or through the staff's or surgeon's hands.

When asked, Dr Bhimani said their internal inquiries showed that there was no infection in the OT and the source must have been from outside. However the mater has been referred to the legal department of the hospital, which will be dealing with the court case.

Express News Service: Lilavati in court over failed eye surgery. *Indian Express*, April 7, 2001.

Holland and euthansia

The Netherlands became the first country in the world to pass a law decriminalising voluntary euthanasia. Dutch doctors carrying out the practice under strict conditions will no longer be judged automatically as criminals when the law comes into force this autumn.

The legislation will empower the regional committees of doctors, lawyers, and ethicists, to whom doctors must report euthanasia cases, to decide whether a doctor has acted with due care and if so to close the case. Currently that power rests with the public prosecution service: the committees can only make recommendations to the service.

An estimated 3,600 cases of voluntary euthanasia are carried out each year in the Netherlands.

Since members of parliament passed the bill last November senators have been inundated by mail on the topic from the public, but the balance of opinion has been in favour of the bill.

Opposition spokesperson Yvonne Timmerman called for doctors to be given specific legal rights not to cooperate with euthanasia on moral grounds. Health minister Els Borst said professional standards already enabled staff with moral objections to refuse to participate in euthanasia, abortions or in vitro fertilisation, and believes the law will not result in an increase in the annual number of voluntary euthanasia cases.

The new legislation states that doctors must be 'convinced' that the patient's request is voluntary and well considered and that the patient is facing 'unremitting and unbearable' suffering. Doctors must also have advised patients of their situation and prospects and reached a firm conclusion with the patient that there is 'no reasonable alternative solution'. Additionally, the doctor must consult 'at least one other independent physician'. The law also offers legal recognition of written euthanasia declarations and allows minors aged 12 to 16 to request euthanasia with the consent of their parents.

Tony Sheldon: Holland decriminalises voluntary euthanasia. *BMJ*, April 21,2001

Hungary and pharmaceutical ads

A new Hungarian government decree will drastically limit pharmaceutical marketing, in order to bring down the country's drug costs.

The decree will strictly limit the amount manufacturers spend on conferences and other events and will prohibit them from paying for doctors' trips to these events.

Drug companies gifts cannot exceed one per cent of Hungary's monthly minimum wage, currently 40000 forints (£93). The decree also limits the number of free pharmaceutical samples doctors may accept and prevents doctors from receiving drug samples directly from manufacturers or importers. Such "freebies" will instead come through the chief pharmacist's office.

Representatives of drug companies — usually doctors making much more than their practising colleagues — will be prohibited from pushing their products on fellow doctors during office hours.

Drug companies say drug advertising in Hungary is already regulated by advertising and pharmaceutical laws, and the industry code of ethics. Advertising agencies are appalled, contending that the decree is an unlikely remedy for Hungary's ailing healthcare system. A spokesman for one agency called the measures "nonsense" and said the decree would "only give way to more corruption."

Carl Kovac: Hungary curbs drug company advertising. *BMJ*, April 21, 2001.

Corporate hospital rivalry?

Bombay's Jaslok Hospital recently issued a directive to its consultants to stay away from 'large hospitals', a move hospital authorities is only to ensure that consultants give enough time to their patients.

Jaslok's consultants may have only two additional attachments, one a teaching attachment and the other an attachment 'which is not with a large hospital'. The official reason for the policy is that multiple attachments affect patient care. "If a doctor has too many attachments, he or she doesn't spend enough time with patients. One ends up spending time just on commuting from one hospital to another and it is very unfair to patients," says a consultant with Jaslok.

While no one disputes this fact, many doctors also feel that increasing corporate rivalry has a role to play in the formulation of the not-too-many attachments policy. Similar policies exist for almost all the other large hospitals in the city.

Money is the bottom line. "If you lose even one heart surgery to another hospital it could mean a loss of anything above Rs 2 lakh," says one consultant. Besides, many hospitals put pressure on consultants to bring business, says another consultant. A doctor attached to two hospitals might take a patient to the hospital where s/he can charge higher fees.

Deepa A: Doctors debate corporate prescriptions for consultants. *The Times of India*, May 25, 2001.

Missing: the human touch

High-tech gizmos. State-of-the-art operation theatres. The best doctors and the best addresses. Yes, the city's five-star hospitals do seem to have it all. Except that vital factor - human touch - or so say patients.

"My doctors did not even ask me how I was doing after the surgery," recalls K Khan, who recently underwent a hernia operation at a prestigious south Mumbai hospital. Unable to control his nervousness, Mr Khan himself broached the question. But the doctor's curt reply - "you are not a medical person to understand that" - was the most bitter pill he had to swallow during his stay.

Patients are reportedly deprived of basic rights like their right to know why a particular treatment is being given to them or why they need to go through a battery of tests. "It is the doctor's duty to explain everything to the patient, including the side-effects of medicines. But they just don't seem to have the time," says Asha Inani, chairperson of the Consumer Guidance Society of India.

One patient recollects how she was told to vacate the room as soon as her mother (the patient) was shifted to the ICU. "My mother was sinking and I didn't know whether to collect our belongings from the room or accompany her to the ICU," she recollects. She later found out that no one had occupied that room for the next two days.

Furthermore, patients have in some cases had to spend money without reason. Hema Kartik, for instance, had to settle for the most expensive room as the cheaper ones were not available. "We booked the room in advance but were later told the cheaper ones were being occupied by emergency case," she says.

"Cheaper rooms are invariably not available," says Ms Inani. The entire cost of the patient's stay multiplies according to the type of room he or she is staying in. "Besides, even if the patient is given two capsules, he or she will be charged for the whole packet."

Dr K G Nair, medical director of Breach Candy Hospital, describes these as stray incidents. "It is like going to an excellent restaurant where the food you get is good 80 out of 100 times." He says that hospitals thrive on 'customer delight' and cites that as one big reason why generations have patronised their hospital.

Roli Srivastava: At high-tech hospitals, service is great but the smile is not. The Times of India, June 4, 2001.

Travelling for transplants

Canadian patients desperately seeking kidney transplants are travelling to India, China and the Philippines to get new organs, even though it is an offence in their country. Canadians pay between $50,000 and $145,000 for a kidney transplant.

According to the Canadian Organ Replacement Register, 536 Candadians died between 1997 and 1999 waiting for organ transplants.

Dr Jeffrey Zeltzman, a Toronto-based kidney specialist and director of St Michael's hospital's renal transplant programme, is quoted as saying, "(It is) like a black market underground economy. We've had lots of patients who have gone. Some tell us and some don't tell us — they just come back with kidneys."

Dr Zeltzman also has horror stories to tell. He examined a patient who had returned from India a six-inch scar on his abdomen after a kidney transplant. An ultrasound revealed no transplant had taken place.

A Canadian businessman in partnership with a man in Shanghai allegedly charges $5,000 for registering the names of people looking for transplants. These people are then shipped to Shanghai where they get organs from Chinese who have been involved in accidents. To them, China is the source for the 'largest supply of organs that are available'.

Buying and selling organs is illegal in all provinces and territories in Canada, but it is only a breach of provincial regulations, not a criminal offence, and is subject to a maximum fine of Canadian $1,000 and six months in jail.

Ajit Jain: Kidney bazaar lures Canadians seeking transplants. *The Times of India*, June 5, 2001.

Australian disabled are sterilised

A report from the Australian Human

Rights and Equal Opportunity Commission reveals that many disabled girls are being illegally sterilised, some without their knowledge.

Parents usually make applications for sterilisation to the Family Court or Guardianship Tribunal and about 45 per cent of the girls are 14 years old or younger and 13 per cent have not begun menstruating at the time of the application. Also, more than half have some form of physical and/or sensory impairment.

According to the report's author, Susan Brady, "It is impossible to say how many sterilisations are being performed because they are being done illegally and the data is unreliable. Since the mid-1980s, adults with decision-making disabilities have not been allowed to have sterilisations without the consent of a specialist and community-based guardianship tribunal. The same, however, cannot be said of children."

While the states of New South Wales and South Australia have legislated to prohibit sterilisation of children without the consent of a Guardianship Tribunal, there are no such laws in the other states. This compels people to go to the Family Court or Supreme Court for authorisation, which is expensive and traumatic for families. As a result, many people are going outside the law and sterilising children anyway. While there is not much data on the long-term health effects of sterilisations performed on pre-pubescent girls, it is known that it can cause an early onset of menopause, osteoporosis, heart disease and depression.

Neena Bhandari: ***Women's Feature Service***

Ethics and orphans

In the late 1930s, Dr Wendell Johnson, a professor at the University of Iowa, USA, experimented with 22 children at a state-run orphanage to test his theory that stutterers are not born but made — by putting psychological pressure on children so they would stutter. Several children suffered lasting damage.

Johnson got a student to test the theory as her graduate thesis: 22 stutterers and normal speakers were randomly assigned to an experimental or a control group. Children in the control group were labelled normal speakers and got positive therapy. Children in the experimental group were labelled stutterers and given negative therapy. The labels were reinforced by the orphanage staff long after the experiment was over.

By the end of the study, speech had deteriorated for five of six normal speakers and three of five stutterers subjected to negative therapy. In the control group, only one child suffered more speech interruptions at the end of the experiment. The graduate student, Mary Tudor, returned to the orphanage two more times to attempt reverse therapy — unsuccessfully.

The news of Nazi experiments created a predicament for Johnson. Publishing his theory could help millions of children as well as elevate his status in the world of speech pathology. But using the experiment as direct evidence could destroy his career. So he forwarded his theory citing other, indirect evidence. By the late 1940s, his "diagnosogenic theory" became the most widely accepted theory on the cause of stuttering.

A small circle of speech pathologists have been aware of the 'Monster Study' for many years., and most agree that it provided direct evidence for Johnson's theory, which changed the way people regarded stutterers and opened the door to effective therapies.

Twenty of the 22 orphans have been traced, of whom at least 13 are still alive. They had never heard about the experiment.

This was just one of many studies conducted by the university on orphanage children; another was a decades-long study to see if developmental retardation was more common among children in the overcrowded and unstimulating orphanage than among children placed in a special new preschool.

Jim Dyer: Ethics and orphans: the 'Monster Study' ***Mercury News*** **June 6, 7, 2001.** http://www0.mercurycenter.com/special/experiment/experiment.htm

Consumer fora and medical negligence

President of the Maharashtra state consumer redressal forum, MS Rane, assured medical professionals that cases of medical negligence that come up before the forum are heard in detail and that all precautions are taken before the final judgement is delivered.

At a symposium organised by the Association of Medical Consultants on 'the functioning of consumer courts vis-a-vis the medical profession', Mr Rane said he agreed with medical professionals that at times it is difficult for the court to decide on a case without any medical knowledge but that the court's intervention is necessary to pass a judgement.

The financial difficulties faced by Mr Rane when he took over as president of the forum in February 2000 have been addressed, he said, and the forum's proceedings have been systematised. Complaints with documents supporting the case are sent to the other party for response. The complainant is given an opportunity to answer, after which the forum delivers its judgement. If the arguments on both sides are almost equally balanced, the forum tends to lean on the consumer's side, Mr Rane admitted.

He stated that doctors are a "vulnerable lot because their patients have a lot of expectations from them, and want every treatment to be successful. Even though people do file complaints against doctors, this number is very small, and the percentage of doctors being held guidlty is almost negligible."

Earlier, Dr Lalit Kapoor, spokesperson of the AMC, described the Consumer Protection Act as a progressive piece of legislation enacted to give consumers a fair deal. At the same time there is need to exercise caution in its day-to-day proceedings. Doctors work in difficult circumstances and there are factors which are beyond their control, like ill-equipped ambulances, shortage of qualified paramedical staff and poor blood bank facilities. These factors also need to be taken into account when deciding cases of medical negligence. Also, errors of judgement are sometimes termed as negligence.

Rane also assured medical professionals that no false complaints would be entertained at the consumer courts. It would be a good idea to increase the penalty in such cases from the present Rs 10,000.

He also admitted that there is sometimes a trial by the media even before the case is decided, but there are no rules to curb this.

Express News Service: Medical negligence cases are dealt with fairly'. *Indian Express*, June 13, 2001.