

Feature

On the hunt for rogue genes

By Md. Asadullah Khan

MINHAZ Ali became genuinely concerned after his wife got pregnant for the third time. Since they had their first child in 1990, who died in a year afflicted with thalassaemia, Ali had been playing a game of Russian Roulette, but this time medical advances gave some genetic odds in his favour. Ali took his wife to a genetic testing hospital in a neighbouring country. And the hospital genetic testing report relieved him of the tension and fear he had been harbouring since he learnt about his wife's third pregnancy.

Ali now has learnt that somewhere on a stretch of his ancestor's DNA -- the blueprint of the human body -- a genetic command unit called beta-globin gene went awry. The result was that children in Ali's family had died of thalassaemia, a blood disorder that means a lifetime of blood transfusions -- and a life not more than 20 years. Most shocking, his first child born in 1990 was diagnosed as thalassaemic within a year. His second child Kamila has to have blood transfusion every three months. Pressure from his parents was mounting to have a normal baby. So when his wife got pregnant in 1995, Ali shaken with fear and anxiety went to a genetic testing hospital in India to have the DNA of his unborn child tested. Shockingly enough, he and his wife were both carriers of the faulty gene. But now he has learnt that his unborn child has not inherited it. In 1996, Fatema was born and this time God answered to his prayers. Fatema, who had a one-in-four chance of being a thalassaemic, was born normal.

Fortunately for Ali, he is the recipient of the gift of genetic testing, the scientific ability to read the body's blueprints to foresee what they will build or tear apart. He might have been a fortunate one among thousands in the country to have discovered the trauma of living with diseases ordained by defects in their genes. Advances in medical science in recent times have revealed that genetic hand plays the part in many such diseases like Haemophilia, Alzheimer, Marfan Syndrome, Dyslexia, Fragile X-syndrome, Cystic Fibrosis and night blindness.

Some very outstanding personalities and members of the royal families were victims of genetic diseases. Emperor George III (1738-1800) was a victim perfrida disease. Queen Victoria (1819-1901) was a carrier of Haemophilia. Alexy, the only son of the last Czar of Russia, was a carrier of Haemophilia A. President Abraham Lincoln was a victim of Marfan Syndrome and President Ronald Reagan is now learnt to be suffering from Alzheimers.

Most of the diseases, unless the patients come of an affluent family, are crippling and devastating to their families. But, sure enough in recent times, pre-natal DNA tests, explorations of the human genome (the complete genetic text of

human) and the complete screening of communities vulnerable to particular genetic defects hold the promise of a new predictive medicine that could afford the opportunity to avoid, prevent or even treat genetic disorders. It is neither unusual nor rare that a child is born of healthy parents with serious ailments, mostly a result of genetic fault. May be, the defective gene lurking in their parents or even ancestors may suddenly appear at the time of birth. As such the power to look into your future is important because there could be millions in the country with rogue genes. And in a country swept by mass diseases like malaria, tuberculosis, diarrhoea and influenza, caused by all manners of viruses and bacteria, no one really had the time, money, ex-

killings more than 500 a year. Doctors now say that just 10 years ago, the prospects of a girl her age were as bleak as they were inevitable. Doctors in the US further assert that as the combination of chronic infections, clogged airways and digestive problems took their toll, she could not have expected to outlive her teens. But now, says Ramsey, "Brianna has an excellent chance of living into adulthood." In fact, Ramsey says, as things stand today, Brianna and thousands of other babies born with CF in the past few years may even live to see a cure. So says Ramsey, "In the next decade, we are going to see a revolution in treatment for this disease."

In the past few years alone, researchers have reported preliminary success with two sepa-

drug, researchers have now learnt, promises to prevent a protein called elastase, produced in dangerous quantities by the CF patient's own immune cells, from attacking lung tissue. Another synthetic enzyme called DNase instantly dissolves leftover DNA from dead immune cells, one of the bulkiest components of the accumulating mucus. The thinner fluid can then be cleared by the body's own mechanisms.

Further advances have been made to stop the build-up of fluid at its source. In the early 1980s, scientists at the university of North Carolina opened the way for a radically new kind of therapy that would attempt just that. The doctors noticed that cells taken from the lungs of CF patients contain abnormally high levels of

these viruses infect host cells by injecting their own DNA through the target's outer membranes. Crystal hopes to harness this propensity by first disabling the microbes, so that they no longer cause colds, and then inserting a corrected version of the CF gene into the viral DNA.

When laboratory rats had this reconstructed virus sprayed into their tiny lungs, they not only absorbed the foreign gene but actually sprouted, in their airways, the human protein that scientists believe will cure CF. While crystal has yet to try the therapy in humans, he is supremely optimistic. "We now know it works in the test tube and in animals. I can guarantee that we can correct the defective protein in humans."

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Even in India the government is funding genetic studies of Indian communities. Many centres in the private sector have come up throughout the length and breadth of India that offer counselling to families with gene disorders and do tests for the new diseases appearing in the country side.

Take the case of Brianna of Washington who came to hospital for treatment. Brianna had never drawn an easy breath. When she was a baby her tiny chest convulsed at the slightest irritation. Instead of laughing, she would cough, instead of crying, gag. She suffered from an endless string of infections -- pneumonia, a cold bronchitis -- that ordinary antibiotics seemed powerless to curb. Brianna weighed less at one year than she did at six months. Finally, at an age just after the child's third birthday, her anxious parents took her to the University of Washington Pulmonary clinic at Seattle. Chest X-ray revealed that thick bluish mucus had started to accumulate in her airways. "She already had some permanent scarring to the lungs," said Dr. Bonnie Ramsey, Brian's physician and an expert in lung diseases.

Brianna was suffering from cystic fibrosis, the most common inherited disorder among whites and a disease that afflicts about 25000 Americans,

rate therapies that for the first time treat the underlying cellular disorder as opposed to just the symptoms of the disease. More promising still, doctors are closing in on a technique for replacing the defective CF gene, which was discovered in 1989. The discovery has spawned an unprecedented proposal to screen tens of millions of Americans for the defect, so that couples can avoid an affected child. "This is a wonderful place to be right now", says Michael Knowles, a CF researcher at the University of North Carolina. "Just a decade ago, these therapies were abstractions".

For half a century doctors have been treating cystic fibrosis symptom by symptom, doing their best to stem the rising tide of mucus triggered by the disease. As this abnormally thick fluid builds up in the lungs, liver, pancreas and other organs, it not only serves as a fertile ground for damaging infections but also blocks the passage of vital digestive enzymes to the intestine. As a result patients have difficulty breathing, digesting food and even reproducing. "This is a disease that simply wears you down", says Ramsey. Using simple therapies, such as clapping young patients on the back and chest several times a day to clear the lungs or providing a special nutrient, rich diet, scientists have made impressive strides against the ailment, extending the average life span from just five years in 1950s to 28 today. Recent advances in genetic engineering may have improved tactical approach further. One

sodium and chloride-the constituents of salt. This did not come as a complete surprise, since CF patient's sweat is known to be abnormally salty, a sign that their bodies do not handle the mineral properly. But the U.N.C researchers realised that this imbalance in the lungs could explain why thick mucus was accumulating there. An excess of salt within cells was leaching water out of the mucus. This apparently was the basic defect behind the disease.

In the past few years, the U.N.C team concentrated on two drugs that could help repair cellular malfunction. One, a blood pressure medication, called amiloride, slows the uptake of sodium. The other containing naturally occurring substances called AFP and UTP (for Adenosine and Uridine Triphosphate), stimulates the secretion of chloride. Both have proved effective in early trials, although a marketable treatment, researchers say, is still several years away.

Another therapy may be coming along sooner as Knowles predicts. Since Francis Collins and Lap-Chee Tsui discovered the CF gene on chromosome 7 in 1989, researchers from around the world have been struggling to devise a way to bring that finding to the bedside. The challenge: to transport corrected versions of the DNA into the lungs of CF patients. Dr. Ronald Crystal at the U.S. National Heart, Lung and Blood Institute believes the best vehicles are cold viruses, which have a special fondness for the linings of the airways. Ordi-

Another futuristic therapy involves the manipulation of the errant protein itself. The molecule which scientists have already reconstructed using the blueprint provided by the CF gene could conceivably be goaded into working with the right medication. Alternatively, doctors could implant a healthy version of the CF gene in embryonic mice or goats, harvest the resulting protein from the adult animal's milk and then spray the protein into patient's lungs.

The discovery of CF gene has revolutionised the diagnosis of CF. Some public health experts in the U.S. believe that since doctors can identify the defective DNA (which occurs in 1 out of 25 Americans), they should screen all prospective parents. Men and women who find that they are both carriers might then choose to adopt or conceive with donor sperm or eggs. Only in the recent past, the U.S. National Institute of Health financed a handful of pilot projects to help it decide whether massive screening programme would be worth the considerable cost.

For those already suffering from CF these are exciting. Younger patients have a fair chance of recovery. Brianna Oas' parents are a bit philosophical. "We're fully aware that whatever they come up with may not be in time for our daughter. People around the U.S. are now very hopeful. For the first time in the history of this devastating disease, that hope is warranted."

The author is controller of examinations, BUET

Fasten your seatbelts!

When people are crushed by the wheels of a killer truck or flung about and splattered over a busy highway, the issue of safety plays second fiddle to "catching the culprits". As people take dangerously to moribund awareness, A Maher rides with the commuters to see why safety has lost its seatbelts

“WHEN visibility of speed breakers on the roads is had the driver loses control of his vehicle if he goes over one while executing a relatively accelerated motion. This loss of control, even if only momentary, results in the endangering of a passenger's life".

The echoes of an analyst on road safety? No. This is from a Dhaka baby-taxi driver who has had his road sense jolted by the concept of driver safety. Mohammad Rahman is just a baby-taxi (also called the auto-rickshaw) driver toiling for his livelihood in the clogged streets of Dhaka. But he is a bit different from the rest. Rahman is trying to set a unique precedent for the other baby-taxi drivers of Dhaka in terms of driving safety. He has installed a seatbelt in the driving seat of his three-wheeler and proudly tells the 'tale of the seatbelt' to many an inquisitive customer. But the success story must go to the appropriate levels to make all the other such taxis a safer ride. As commuter life in Dhaka transforms itself from hectic to nail-biting, the issue of commuter safety seems to have gone into a dangerous oblivion.

Frustrated by the grime and dust of Dhaka's worst traffic seasons people have started to accept life without safety, even the most fundamental. The extent to which baby-taxis or any sort of public commuter trans-

port complies to safety standards is an alarming question -- most are not even close to being called safe. Overloaded buses that are reeling dangerously on one side, battered tempus and of course the polluting auto-rickshaws are everyday glaring examples of the risks taken by office-goers.

Safety concerns can include more than just the physical structural protection. Poisonous exhausts from surrounding vehicles, loud whistling horns, unchecked engine noise and the training of the driver himself constitute a safety issue. Many commuters claim the inside of the baby-taxi is not designed properly to protect the passengers during or right before an accident.

"The entrances on either side to the back of the taxi (where the passenger sits) are too narrow and cramped" says Atiq Chowdhury, a daily commuter of these three-wheelers.

"When a person senses a possible collision he cannot scramble out of the taxi quickly enough to avoid serious injury. The driver, on the other hand, has much more space on both sides to jump out."

That brings us back to the issue of how safe the drivers are. Mohammad Rahman, in fact, had driver safety on his mind when he thought of the seatbelt for his baby-taxi. Fortunately he received quite a bit of media

attention for his little innovation. Rahman claims to have been interviewed by a crew from an Italian television channel, journalists and passengers alike.

"I feel very happy to be interviewed by curious people who have never seen a seatbelt on a baby-taxi," smiles a beaming Rahman.

"They are usually amused by its history. I got the seatbelt support from a friend from Singapore (in a gleaming aluminium case) and it cost a lot of money, I tell you."

But he has received little support from the different associations of baby-taxi drivers and owners, mainly on the issue of cost effectiveness and installation charges. Rahman claims that with some persuasion it could be tried out on a pilot sample of scooters; the costs are not that much.

"People also don't have to be afraid of shooting transportation costs. At least for me I will not raise my fares."

Getting a safer ride will no doubt be a bigger investment but for those Dhakaites who are too engrossed in their daily hassles to think better of themselves and others, the issue of commuter safety remains to be hammered in. As people overtake buses and tempus, getting them to their places in one piece will be a sum of the efforts of drivers and passengers alike.

The economics of information

By Syed Abul Basher

How little one is permitted to know about another person. Even if one is very attentive.

RECENTLY, one of my friends has been offered a handsome job in a local firm. He initially thought that he would receive the current market-recruiting price for MBAs as his salary. However, when he actually faced the interview board he asked for much higher and still got the job. One may question how the answer is information, he had inside information regarding what the employer was actually prepared to pay to the prospective employee.

Information is an invaluable asset. From ancient times to the present, information is with us in some form or the other, helping us in innumerable ways. However, distribution of information is not always unique. Some seem to have more information than others do, either because the former may have superior access than the latter or the market for information may be imperfect. Information of this type is known as asymmetric (or imperfect) information in

which one agent has more information than the other.

When information is imperfect, resources may be misallocated causing welfare loss to the society. In economics a voluminous amount of literature has been devoted towards discussing this welfare loss when asymmetric information exists.

Having known the need for (perfect) information, this article will primarily discuss some adverse consequences of imperfect information in the light of Bangladesh's economy.

Goerge Akerlof (1970) first discussed the characteristics of asymmetric information in economics. Using a classic example he showed that usually, a seller of a product has superior knowledge about the product than the buyer. He mentioned about the automobile market where the seller actually knows better as which one is a good car and which is bad (a lemon). A buyer with scanty information regarding the quality of the product couldn't distinguish between the good and lemon car and ended up underestimating the true quality of the good car. Notice how information asymmetry in this case misallocates the true product causing welfare loss thereby.

Imperfect information is a universal phenomenon but it is of particular interest for developing countries as the cases of market failure is severe in the latter. Consider for example, the flamboyant growth of stock markets in Bangladesh in the last quarter of 1996. One could, without any hesitation, conclude that the growth of the market in 1996 did not follow the fundamentals of trading rules rather it was revealed by the enquiry committee that it was a case of manipulation among the stock brokers, members of stock exchange, and some unscrupulous owners of private institutions. The innocent investors who sold their utmost in the hope of gaining some windfall were trapped by the myriad of vile practices of unscrupulous bodies. Truly, the individual investors should have been more cautious, unfortunately information regarding the true value of a stock was unidirectional where one party gained at the cost of the other. As much as Tk. 380 crore flew out from the country causing huge losses to the local investors. We all know the hypotheses of an efficient market. Perhaps information symmetry is one of the prime criteria. From this standpoint, it is no wonder that the capital markets in Bangladesh are inefficient.

Perhaps the most acute case of asymmetric information exists in the manpower business. Often we see newspapers carrying captioned photographs of hundreds of Bangladesh workers in foreign jails suffering inhuman pains. How has this happened? These workers are innocent people who have paid the market price for the job and yet are being exploited by the venal traders. Had they (the

workers) been aware about the venality of the contract, the future unpleasantness that they have to endure could have been greatly avoided. Once again, imperfect information is seen causing misallocation of resources.

In Bangladesh we often see people die after drinking rectified spirit or other alcoholic drinks. People who have the habit of drinking such products obviously do not drink to die; rather they drink to temporarily escape from reality (as they define it). What happens is due to the dishonest practice of the sellers in this business. Sellers having perfect information regarding the actual state of the products keep the buyers completely unaware causing loss of valuable lives. Recently it was revealed that a particular type of consumer item (Dal, to put it specifically) that used to be imported from Australia has been found to be inedible. We often hear discontent among buyers after purchasing a particular good; either an apparel or an electrical good. Disputation regarding pesticides used in farming that are really killing insects or hampering the environment, still remains a burning question. Often we get pathological lab reports that are hard to believe, or we may be stuck in a nasty traffic jam without notice. Even the government employer is unsure about the capability of a potential employee during the recruiting phase.

All these are unwanted outcomes of asymmetric information and of course there could be many more. The aim of this article is to identify the consequences of asymmetric information in the Bangladesh economy. There is no intention to provide any concrete solutions. However, once the problems are precisely identified, solutions become clearer. For example, while information asymmetry has been identified as one of the key hindrances towards an efficient capital market, the roles of concerned bodies in the dismantling of such defects become imminent. The government knows what the SEC has to do in this regard and what else could be done to ameliorate the existing situation. Similarly, it is the sole duty of the labour ministry to stop faulty manpower business and administer things in an appropriate manner.

The Bangladesh economy is in transition from a centrally planned economy during the 80s towards a market-oriented one in the 90s. However the old problems seem to be remain with us. One can not expect to meet the new century's challenges with so many innate defects. However failure in correcting the evils will continue to push us back no matter how many words are wasted in worthless speeches.

The author is a teaching assistant at North South University

Prescription for health or just healthy profits?

The merger that has created what has been termed "the Microsoft of the pharmaceuticals industry" has investors enthusing at the potential for cost-saving and profit-making. But the real test of the new giant will be whether it delivers cheaper, more appropriate drugs to millions of people who cannot at present afford them, writes John Madeley

THE managements of drug giants SmithKline Beecham and Glaxo Wellcome are pleased with their mega-merger, but bigger may not mean better for people who cannot afford essential medicines.

The merger will make the offspring of the two Britain-based companies, Glaxo SmithKline, the biggest global pharmaceutical, with a 7.3 per cent share of the world market for medicines. And it will greatly increase their power over the setting of prices as well as over national drugs policies.

In the past two decades, large drug companies, often backed by the government of the country in which they are based, have used their clout to try to dissuade governments from introducing national drugs policies aimed at improving health rather than profits.

Bangladesh, the first developing country to introduce such a policy almost 20 years ago, was lent on heavily by pharmaceutical companies. They wanted the Dhaka government to abandon its proposed strategy of manufacturing a relatively small number of generic medicines (which do not carry a trademark) and restricting some of the more expensive brand-name patented products made by the pharmaceutical giants.

The government persisted and the policy proved to be a life-saver for millions who were able to buy essential medicines previously beyond their reach. Bangladeshi companies increased their share of local production from 35 per cent to 60 per cent, and the country saved around \$600 million in foreign exchange on imported drugs in the first 10 years of the policy.

The concern now is that the new mega-sized companies will have more power to persuade governments to drop policies that the companies do not see as in their interests.

Three years ago, the then South African president Nelson Mandela was sued by drugs companies after his government announced that it would buy essential drugs as cheaply as possible as part of the fight against HIV/AIDS.

"The companies involved in this mega-merger, along with many of the other drugs companies, have been shamelessly trying to prevent South Africa from dealing with its own problems. They've done that because they're worried about their profits," claims Andrew Simms of the London-based New Economics Foundation.

South Africa's 'crime' was to pass a law allowing domestic companies to make generic

drugs to treat emergency illnesses. Even though the law still allowed for royalty payments to the patent-holders, the pharmaceutical companies argued that it threatened their intellectual property. The lawsuit has been suspended, but not lifted.

Patents on new drugs can be taken out for 20 years, "which makes the production of generic equivalents very difficult," says Mohga Smith of the international development charity, Oxfam.

Mohga Smith is concerned that the current round of mega-mergers will boost the ability of the new conglomerates to raise rather than lower prices, and put essential medicines further out of the reach of the poor.

"We are worried about this," warns Mohga Smith. "In some countries, and over certain

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products, the new company could have a monopoly. On the other hand, it will have lots of money for lots of research. The question is whether it will develop low-cost drugs to treat tropical illnesses."

Glaxo SmithKline's research and development budget will be around \$4 billion a year -- more, for example, than Britain's entire development aid budget last year. Pharmaceutical companies argue that profits and prices need to rise in line with the rising expense of bringing new products onto the market.

In the United States, prices of essential drugs have been rising by 12 per cent a year, with many companies getting extensions on the patents for their drugs.

Glaxo Wellcome chairman Sir Richard Sykes dismisses fears that the company will be able to charge what it likes.

"In the European Community, the price of a medicine is decided by the government not by the company. Companies like ours have been driving big programmes to make sure that the Third World can get access to medicines," he says.

But governments of developing countries are in a weaker position to fix prices than their European counterparts. "If companies don't like the terms of an agreement a government offers, it can threaten to pull out altogether," notes Mohga Smith.

Medicine merger



* Merger of Glaxo Wellcome and SmithKline Beecham will produce the world's biggest drugs group: Glaxo SmithKline

● It will have a market value of \$190bn, 7.3% of the global pharmaceutical market, and global sales of \$25bn

* Glaxo has 59,000 employees, SmithKline Beecham 47,000. Managements say the merger will achieve \$1bn in cost savings, including about 10,000 job losses

● Half the world's top 25 drugs companies have announced mergers since 1998

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As for the "big programmes", the facts hardly bear out Sykes' claim.

"Out of 1,233 new drugs brought onto the market worldwide between 1975 and 1997, only 13 were for tropical diseases," points out Bernard Pecoul of the Nobel Prize-winning organisation, Médecins Sans Frontières (Doctors without Borders).

John Madeley is the author of 'Big Business, Poor Peoples: The Impact of Transnational Corporations on the World's Poor'.