A Double-Edged Sword

By Rupert J. and Linda E. Taylor

"Science in the service of society". That's a slogan with a nice ring to it. Images spring to mind of barren landscapes made suddenly fertile, or people ravaged by disease quickly cured. Science performs those miracles and many more

But, science and the way it's used isn't always for the best. This issue has been brought into sharp focus by the decoding of the human genome.

For a decade, more than a thousand scientists worked to unlock the biological secrets held within the roughly 100,000 genes that, together, form the basis of human life. With great fanfare, the completion of the project was announced in June, 2000.

Before the genome project began in 1990 most of the genetic construction of humans was a mystery. It was as though someone had taken the only copy of the instruction manual for making people, stripped each page of its letters, jumbled them up, thrown them into a cellar, and switched the lights off. Scientists then had to grope about in the dark and reassemble the manual without even knowing what the original copy looked like.

The fact that the job was completed in ten years owes more to computer technology than biology. At the start of 1999, scientists in a branch of technology called bioinformatics developed the capacity to sequence 1,000 letters of DNA per second, 24 hours a day, seven days a week. That breakthrough got the project into the fast lane.

The decoding process was a joint effort, involving scientists from the United Kingdom, the United States, China, France, Germany and Japan. Its completion was treated as a great moment in history, so Britain's Prime Minister Tony Blair and American President Bill Clinton jointly made the announcement through a transatlantic telephone hookup. However, understanding the location and function of each gene is only the start. A great deal of work remains to be done.

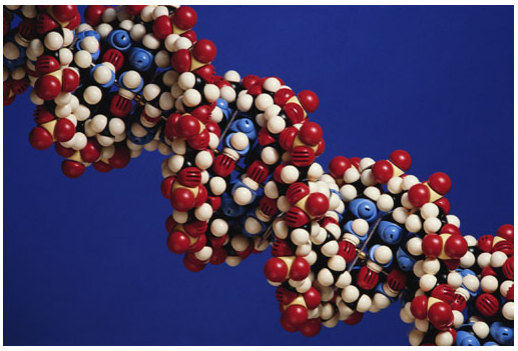
A large number of diseases are caused by genetic flaws, or by the absence of one or more genes. Having the complete instruction manual will help scientists solve many medical mysteries. Within a couple of decades, doctors could be able to cure many cancers that today are usually fatal. Such illnesses as Alzheimer's, Parkinson's, multiple sclerosis, schizophrenia, diabetes, and many others may also be conquered. Dr. Francis Collins is Director of the Human Genome Project (HUGO). He says that by 2040, gene therapy and gene-based drugs will be available for most diseases, and the average human life span will reach 90.

In July 2000, The Economist wrote about a brighter future for medicine. "These days the talk is of a perfect diagnosis, drugs that will work first time and have no side-effects, even of predictive medicine so accurate that it could tell you, should you want to know, when you are going to die and of what."

That's the good news. But, the information coming out of HUGO raises a lot of ethical questions. One of the major ones turns on money.

Jean Paul Getty (1892-1976) put together a vast fortune in the oil business. Recently, one of his grandsons saw that "Intellectual property is the oil of the 21st century." Companies protect the value of their intellectual property (their discoveries or innovations) through patents. A patent prevents anyone else from using the breakthrough without payment to its owner. This protection encourages biotechnology companies to undertake very expensive research because they are assured of a financial payoff if the research proves successful. A patent gives its holder a monopoly in the same way as a right to drill for oil on a particular parcel of land. Without patent protection there would be little reason for commercial interests to begin research.

A Double-Edged Sword (cont'd)



The issue is full of high drama; it involves life, death and big money. To see why, let's look at the story of a bacterium called Staphylococcus aureus. This bacterium causes Toxic Shock Syndrome, an infection that usually proves fatal if untreated. But, Staph aureus is a clever little devil that develops resistance to the ever-more powerful antibiotics that are used against it. In the early 1990s, doctors at Harvard University began the search for a way of attacking the bacterium. They realized the key to an effective treatment was unlocking the Staph aureus genome, but they lacked the funding for such a project.

Then, in 1996, a private company announced that it had decoded the Staph aureus genome. But, the Harvard scientists were denied access to it. Human Genome Sciences Inc., kept the genome secret to ensure that it got all the money out of its discovery that it could before sharing it with anyone else. Three other biotech companies did the same thing.

Harvard pleaded for public funding to help unlock the Staph aureus secret. The project eventually got its money and, early in 1999, the bacterium's genome was sequenced and a vaccine produced. But, how many people died during the two-to-three-year period it took for the public discovery of the genome?

Genome 101

Deoxyribonucleic acid is such a mouthful that most people just call it DNA. James Watson and Francis Crick discovered DNA in 1953 inside tiny X-shaped structures called chromosomes.

Each person has 23 pairs of chromosomes in the nucleus of cells that make up their body. The DNA molecule is two chains of chemical compounds called polynucleotides. The chains are twisted into the form of a coil, called a double helix. Between the twisted strands of DNA are structures that look like the rungs of ladder. These are called bases and they come in pairs. The bases are coded with the letters A, C, G, and T, which relate to their chemical composition. A section of DNA with a four letter combination of bases forms a gene; a single gene can have thousands of base pairs.

The chemical instruction carried by a coded gene determines whether a cell will become part of a toenail or part of an ear lobe, for instance. There are thought to be about 1000,000 genes in each person (nobody knows for sure how many) and this is called the human genome.

Philosopher Alex Wellington and political scientist Ted Schrecker summed up the dilemma in a March 2000 article in the Globe and Mail. "Questions remain," they wrote, "about the appropriate balance between private returns…and the public interest. Fairness dictates that the inventors and investors should benefit from their commitments of money and scientific knowledge. But their returns should not be determined only by what the market will bear."

Many people - scientists, religious leaders, philosophers, ethicists, and others - question whether or not a life form can, or even should be, patented. Dr. Gert-Jan van Ommen of Leiden University in the Netherlands says, "A mere DNA molecule…cannot constitute an invention." However, by April 2000, an estimated 40,000 genetic patents were pending at the U.S. Patent and Trade Office.

Canadian law is beginning to catch up to this challenge. The Canadian Patent Act says that intellectual property rights may be asserted over "any new and useful art, process, manufacture or composition of matter." There's no mention of life forms. But, in simple terms, a patent application only has to pass three tests; is the invention new, useful and non-obvious?

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In the case of the Harvard mouse the Canadian Court of Appeal answered "yes" to all three. In August 2000, the Court ordered that a patent be issued on the mouse which has been genetically tweaked to make it more prone to cancer, making it valuable to medical researchers. It took 15 years for the case to get this far, and the court ruled only on whether the mouse met the tests for patentability.

The Court of Appeal judges said that there might well be good reasons that living things should not be patented. But, that's an issue for elected officials to decide, not the courts. To which politicians will say under their breath, "Thanks a lot." It'll be a monster for legislators to tackle, because no matter what decision is made somebody will be ticked. Environmentalists and a large portion of the general public are very suspicious of genetics and biotechnology. But, multi-national companies are very gung-ho to push the science forward.

Some experts get nervous about genetic technology for other reasons. One is genetic screening. This can be done today for some conditions and it will become more commonplace in the near future. Careful study of a sample of DNA can reveal how likely a person is to succumb to certain illnesses.

One of these ailments for which a screening test is already available is Huntington disease. It is a genetic brain disorder that affects one in 10,000 people. If one parent of a child has Huntington's disease and the other does not, the child has a 50% chance of inheriting the disease. Once transmitted, it is almost certain to develop and it is always fatal.

If Huntington's occurred in your family would you have the genetic test done? In Canada, only one in five at risk people wants to know if the Huntington gene has been transmitted to them. There's nothing sinister about the personal choice of whether to know or not know. Where the moral dilemma creeps in is whether anybody else should know; and this applies to all genetic screening.

People applying for jobs today usually fill out an application form in which they reveal some personal information - age, marital status, previous employment, etc. Companies choose whom to hire based, to some extent, on this information. What if employers could add genetic screening to the hiring process? This would inevitably lead to genetic discrimination. Given two equally qualified applicants would a company hire the one whose genetic screening revealed a likelihood of developing schizophrenia? Probably not.

Genetic screening information could also be used to deny someone insurance. But, why would that be a problem? Insurance companies already delve into a person's medical history when writing life or health coverage. A person who has suffered a heart attack is going to have trouble getting life insurance. Concealing an existing heart ailment would probably make the insurance invalid. Genetic screening would simply give insurance companies more accurate information than they have now.

Another concern is the possibility of creating "designer babies." Today, when a sperm and an egg unite, chance plays a major role in how the life thus created will turn out. The embryo will get half its genes from its mother and half from its father. Whether it inherits its father's tallness or its mother's blue eyes pretty much depends on a roll of the dice. But, genetic engineering holds within it the promise of overcoming the random nature of heredity.

We might be able to fix the problem with chromosome 21. Most people have an identical second copy of chromosome 21, but occasionally a third copy appears. This extra chromosome 21 is the cause of Down's syndrome, a form of mental retardation. It's possible that the third copy of chromosome 21 could be removed and the baby born without Down's syndrome.

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Most people would agree that eliminating Down's syndrome is a positive development. The same with thalassemia and Tay-Sachs disease. Both illnesses usually kill victims before adulthood and both are inherited. A blood test can determine the odds of a couple having affected children. A screening project for thalassemia and Tay-Sachs disease has been underway in Montreal since the 1970s. Researchers say the program has reduced the incidence of the diseases by 95%.

But, suppose you are a carrier of thalassemia and you fall in love with another carrier. Do you call off the wedding because any children you might have together are more likely to die young? The tests can also be done on an unborn fetus. If it's positive do you have an abortion? These are troubling questions for many people.

The questions get even more troubling when we confront the possibility of creating "designer babies." Germ-line manipulation is the scientific term for this and it's done soon after an egg has been fertilized. It involves taking the very early-embryonic cells apart to see what the genetic lottery has delivered to them. (This process destroys the cells and puts new focus on the question of when life begins.) Any genetic material that is seen as defective - presumably, the parents decide what's good and what's bad - can then be snipped out and replaced. At present, this is a very difficult trick to pull off, but it will become easier and accurate.

We know that certain human characteristics will be preferred: tall over short, male over female, good looking over average, smart over dumb. Will society go along with a concept that allows parents to order up a child with options in the same way as they can order up a hamburger or a car today?

On the other hand, who wouldn't want to get a pet unicorn for a birthday present?

Taylor, R. "Social Concerns", Canada and the World Backgrounder, Volume 66, No. 2, October 2000.

From Both Perspectives

"Private companies should be allowed to protect their genetic discoveries in order to reap adequate financial rewards for the costly research they have undertaken." (Taylor, 2000)

Reasons why I agree ….	Reasons why I disagree ….