Geneticide?

Science has never been about morality, but as its fingers probe deeper into our genetic mysteries, people are going to ask questions

by Margaret Wertheim

There's nothing like big goals to galvanise people. Currently, the biomedical community is engaged in what is probably the biggest research project ever undertaken in biological science — the Human Genome Project (HGP). The biological equivalent of putting a man on the moon, its goal is to work out the chemical content of every single gene that goes to make up a human being. This complete set of genes is called the human genome. It's a mammoth task and thousands of researchers all over the world in universities, government organisations and private research centres are participating. Needless to say, this calls for vast amounts of money. The US government alone has promised $3 billion over the next fifteen years.

Why bother doing this? One reason is undoubtedly the Mt Everest factor: it's an intellectual mountain and people want to scale it for the sheer thrill and glory. But intellectual mountain climbing is rarely enough to convince governments to put in billions of dollars. The publicly touted reason is that it will lead to cures for all sorts of genetic diseases (including genetically linked cancers). And, indeed, a good deal of the work so far has focused on genes that may be linked to diseases.

There are two types of genes that can be linked to a disease: one that categorically is associated with it so that if you have that gene you will get the disease (this is the case with many rare and severe genetic disorders), and another that's called a marker gene. If you have a marker gene, it doesn't mean you will necessarily get the disease, only that you have a predisposition to it. HGP researchers have already identified potential marker genes for Alzheimer's disease, liver and colon cancer and some forms of arthritis. And they are currently hot on the trail of many more.

But if this raises hopes and shouts of jubilation in some quarters, it appalls others. Rupert Sheldrake, the controversial British biologist, is an ardent opponent of HGP. He recently said, "One of the problems with this work is that it doesn't really contribute to curing anything." While finding marker genes may help with early detection of certain diseases, including some kinds of cancers, he believes that this work will not lead to treatments in the foreseeable future. Meanwhile, he points out, it introduces enormous social problems. In particular, he fears that one thing it will lead to is "some sort of eugenics".

In the US, where there is virtually no government health care and people must take out private health cover, insurance companies are now arguing that they should have the right to screen people for all potential problems, and then increase their premiums if they are found to carry any disease-linked genes. But, as was pointed out recently in *Scientific American*, by Neil Holtzman, a professor of paediatrics at John Hopkins University, one of the implications of this is the "increasing pressure to avoid the birth of children who will become costly to insure".

Prenatal genetic screening has already led to a dramatic drop in the number of children born with severe genetic disorders, such as Tay-Sachs disease and beta thalassemia. Many people agree that the pain and suffering these children endure during their usually short lives is not warranted. But where will we draw the line? How will we decide what sort of a life is worth living and what is not?

As HGP researchers identify more and more genes, the choices we have for our offspring will increase. Already in some areas of China and India, the selective abortion of female foetuses is dangerously skewing the sex balance of the population. As we progress, what characteristics will be considered desirable, and what others will be considered undesirable? No longer in the realm of science fiction, these questions will soon be concrete issues that all of us, as individuals and as a society, will have to face. ●