

Activity 2.21 Genetic screening

Purpose

- To consider the ethical issues raised by genetic screening.

Procedure

Read the section on genetic screening in your textbook and view the video clip that accompanies this activity, then carefully read the article below and answer the question.

Gene screening ‘could cut cystic fibrosis by half’

James Meek, Science correspondent
The Guardian, July 10 2000
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A leading health researcher has attacked as a “scandal” the government’s failure to launch a genetic screening programme which he said could cut the number of children born with the painful, life-shortening disease cystic fibrosis by half.

Howard Cuckle, professor of reproductive epidemiology at Leeds University, said he was angered that last month’s excitement at the deciphering of the human genome glossed over existing, medically important knowledge of our genes which the NHS was refusing to use.

“It’s quite scandalous that there’s been all this hype about the genome project and enormous expectations of how it’s going to change things, and yet we’ve known for more than 10 years the gene responsible for cystic fibrosis and we’re not screening for it,” he said.

Prof Cuckle’s support for screening is controversial because abortion is used to reduce the number of cystic fibrosis cases.

“We should be offering all expectant couples pre-birth screening so they can prevent the birth of a child with cystic fibrosis,” he said. “There have been 11 studies of this and they’ve all shown a high uptake . . . We can’t prevent the disease as such, but we can prevent people being born with this disease.”

Sufferers from cystic fibrosis, which causes a thick build-up of easily infected mucus in the lungs and prevents the digestion of food, have an average life expectancy of around 30 years. They require constant medication and violent physical therapy, experience frequent infections, and, without a life-extending lung transplant, usually die from respiratory failure.

There are around 7,500 sufferers in Britain, with 250 more born each year. Mutations in the gene involved are relatively common – one in 24 people have them – and if two carriers have a child, the chance of it having cystic fibrosis is one in four.

In Edinburgh, the only city in the UK where screening is offered to all expectant couples, the number of children born with the disease has fallen sharply, from an average of 4.6 a year to 1.6.

Not all the fall can be accounted for by terminations – the implication is that couples with affected genes but a healthy baby choose not to have more children together.

Last year the government-appointed national screening committee rejected a report commissioned by the NHS from Prof Cuckle and colleagues which recommended screening.

But the committee will discuss the issue again this year. Its director, Muir Gray, said it supported offering parents an informed choice over abortion, but feared being seen as promoting eugenics – the now discredited pseudo-science of breeding “better” human populations.

Screening for Down’s syndrome is routine, and mass screening for spina bifida, introduced in the 1970s, cut the incidence of the disabling disease by 95% through abortion.

Dr Gray questioned whether it would be so easy to introduce spina bifida screening in today’s social climate. “The eugenic dimension of screening has become more of an issue. Is it right to give people the choice to abort those who are deemed less valuable by society?”

The Cystic Fibrosis Trust, the main charity involved in work on the disease, is a passive supporter of screening but is reluctant to lobby for it because of the link to abortion.

Prof Cuckle said: “In the war against congenital abnormalities, screening is a kind of holding operation. It’s temporary and we hope in the end to have cures, but meanwhile thousands of affected individuals are being born every year.”

Q1 Compose a letter to *The Guardian* either supporting the position taken by Professor Cuckle or opposing it. Your letter should concentrate on the social and ethical issues raised in the article and be no longer than 500 words. When presenting your ideas on the ethical issues you can refer to the ethical frameworks presented in the textbook.