MINISTRY OF
SOCIAL AFFAIRS AND HEALTH

National Advisory >Board on Health Care Ethics (ETENE)
Ritva Halila

MEMORANDUM

Jan. 8th, 1999

OPINION ON THE MEMORANDUM OF THE WORKING GROUP ON GENETIC SCREENING

The Working Group on Genetic Screening of the Ministry of Social Affairs and Health published on 7 May 1998 a memorandum that was sent in the autumn of 1998 for comments to several agencies. The National Advisory Board on Health Care Ethics discussed the memorandum at its meeting on 8 December 1998 and wishes to summarise the discussions as follows:

It should be defined clearly what screenings should be included in the public service system. The Advisory Board is of the opinion that in the first place such gene defects should be screened the diseases caused by which are treatable. Genetic screening for a disease should not be carried out if there are no treatment methods available or realistically expectable for a disease caused by a defective gene.

The Advisory Board also paid attention to adequate access to objective information. This is a prerequisite that people can on the whole choose if they take part in a screening or refuse to do so. Contrary to other screenings at the population level, the outcome of genetic screening is final. Therefore, a person taking part or deliberating to take part in genetic screening should understand fully what is examined in a screening and what is its individual meaning for each person. If a person proves to carry a certain gene, he or she should obtain adequate counselling and support after the screening. Adequate training of health care staff in expert and counselling tasks was considered very important.

Apart from relating to screenings, basic information about genes and genetic research should be given to the citizens also more generally. For instance, the school institution and media are important disseminators of information. The main principles of information prior to genetic screening should also be clarified.

It has to be remembered also that the information that is gained through genetic screening does not only give information on the individual concerned, but at the same information is obtained on whether close relatives possibly carry the same gene. It is not self-evident if these persons want information about their genes and what diseases they are carrying or if these persons want that their close relatives know about their hereditary diseases or what diseases they are possibly carrying. Furthermore, there is reason to remember that a human being is not only the sum of his or her genes and that environmental factors and lifestyles contribute to a person's health.

It should be defined as precisely as possible what is examined in a genetic screening and how, who or what agency examines, to whom a service is offered, and if the

service is a service provided by society or a private agency. It has to be remembered that the activity takes place within the bounds of the available information and continuously changing new information.

On the whole, the memorandum is a good basic piece of work. The Advisory Board however considers that screenings directed at the whole population should not be started on the basis of the memorandum alone, but that the issue should be examined further, at least in regard to the circumstances referred to above.

For the Advisory Board,

Martti Lindqvist
Chairman of the Advisory Board
on Health Care Ethics

Ritva Halila
General Secretary