
The request for advice

On 12 August the State Secretary of Health, Welfare and Sport addressed the following request for advice to the President of the Health Council (letter reference: IBE/E 2399824):

In the “Monitoring Report on Ethics and Health 2003”, which was published by the Centre for Ethics and Health (CEG) on 16 May, the Health Council considered the ‘alerting’ advisory report entitled “Screening of Newborns for Congenital Metabolic Diseases”. The findings of a Health Council-organised workshop on technical, ethical and legal aspects provided a useful platform for this advisory report. It is clear from this report that various new developments are taking place in the field of neonatal screening. Improvements in analytical technology are making it possible to rapidly and reliably detect a wide range of disorders, especially using mass spectrometry. This should pave the way for a considerable scaling up of the heel prick screening programme, which will also make it feasible to screen for non-treatable disorders.

These developments are giving rise to questions from various quarters regarding neonatal screening. Some of these questions come from medical researchers, some from clinicians and others from representatives of patient organisations. The questions relate to screening by mass spectrometry, the changing prevalence of certain diseases, and the extent of the health gain justified by neonatal screening. In many cases, observers are asking whether certain disorders ought not to be included in the screening programme.

In the light of these developments and in response to the above-mentioned 'alerting' advisory report, I would ask you to advise me on the current state of knowledge with regard to neonatal screening.

At the same time, I would like you to consider whether the screening criteria formulated by the Health Council some time ago, as outlined in the advisory reports entitled "Heredity: Science and Society" and "Genetic Screening", are still adequate and whether these criteria are sufficiently specific to be applied to the neonatal screening programme.

An important point to consider in connection with these criteria is the concept of 'treatability'. Following consultation between ourselves, it has been decided that the Health Council will publish a separate advisory report on this topic. You will receive a formal request to this effect in due course. I anticipate that some of the results of that advisory report will prove useful for the advisory report on neonatal screening and that this will be predicated on the basic principle that utmost caution is required when screening for untreatable or unpreventable disorders.

I then ask you to indicate, partly on the basis of your answer to the first question, which disorders should be considered for inclusion in the neonatal screening programme.

Finally, would you kindly explore the ethical, legal and social aspects of this issue? What moral questions will be raised by the expansion of neonatal screening? Will it still be possible to satisfy the requirement of express consent? I look forward to receiving your advisory report in late 2004.

Yours sincerely,
The State Secretary of Health, Welfare and Sport,
Clémence Ross-van Dorp