



*Presidenza del Consiglio dei Ministri*

**NATIONAL BIOETHICS COMMITTEE**

**THE ANENCEPHALIC NEWBORN CHILD AND ORGAN DONATION**

(21st June 1996)

*abstract*

The opinion deals with the issues of the newborn baby with anencephalic malformation at a biological, anthropological and ethical level. First of all the document considers the fundamental biological aspects relative to this problem, with the margins of uncertainty still existing and, later on, the anthropological and ethical aspects linked to the donation of the organs. The NBC considers that the condition of the anencephalic child is common to other categories of sick people: it suffices to think of the terminally ill, who have unsuccessfully tried all possible treatment, or the patients who have lost the use of their intellectual functions or contact with the surrounding environment. Therefore, just as it is not considered licit to shorten the existence of these subjects, nor to bring about their death, for similar reasons to behave in such a way towards an anencephalic baby is unacceptable. Considering that the anencephalic baby has the same dignity as any other human being, the necessary condition for the donation of its organs is the ascertainment of death. Death cannot be defined in a utilitarian way.

Even though born with a very serious neurological malformation, it is improbable that the anencephalic newborn goes into a state of cerebral death in a short lapse of time, given that death is for the most part due to respiratory causes. This means that for the purposes of making the organs available for transplant, the anencephalic baby must undergo intensive care treatment until cerebral death has been certified. However, the use of extraordinary therapy in order to preserve the organs of the anencephalic baby belongs to a series of cases of non-routine use of intensive therapy (it suffices to think of pregnant women in cerebral death, in order to let the foetus reach a gestational age that permits survival), that is, the cases of the inevitable and imminent death of a permanently unconscious patient. It is evident that the exceptional nature of the condition of the anencephalic subject is not such as to make the doctor fail in his obligation to give reanimation, favoured by the cardio-circulatory conditions which are usually satisfactory. This obligation to give medical assistance is compatible with the possibility of organ donation, which is made feasible thanks to such therapeutic support, as happens in the case of a minor or an adult who are in the condition to be able to donate their organs for transplant, once their death has been ascertained. In these cases a series of elements should be safeguarded such as the validity of the proposed transplant in particular, the proper procedure carried out by the medical team and the parents' consent. The distress that the diagnosis of anencephaly can create, not only for the parents but also for the doctor, justifies adequate psychological support, which is usually given in specialized centres, but which according to the NBC would be of great bioethical value to institutionalise on a wider scale.