

# Erfurt Project on Children with Anencephaly

## Condition of the children

Anencephaly means the absence of the cerebrum. It is the most frequent developmental malformation of the brain (1:1000 newborns). There is no cure. The children survive for a few hours or days only at the most.

## Situation of the parents

An increasing number of parents decide to continue the pregnancy after prenatal diagnosis. They consciously use the time afforded by carrying to term to experience togetherness with their unborn child. Now they are able to say good-bye and let their child go in a more personal and peaceful way. Carrying to term is a trend observable in the international context.

## Research Questions

Profound brain impairment and very limited lifespan lead to anthropological and ethical questions of personhood as well as questions on awareness, perception and emotion. The development of adequate programs to serve parents and children is another aspect of the project.

## Research methods

Methodologically, three elements are essential: (1) access through cultural studies, (2) interdisciplinary team structure and (3) integration of parents as experts.

## Research project

Since 2003 there has been ongoing research cooperation at the University of Erfurt (Prof. Dr. Harald Goll, Prof. Dr. Josef Römelt) and parent groups (Monika Jaquier). Nine international conferences on the situation of children with anencephaly and their parents have been held. An interdisciplinary "anencephaly network" with participants from the fields of medicine, philosophy, psychology and law emerged from this activities. The acquisition of international experts in different scientific disciplines is planned for the future.

## Publications

Goll, H. (2011): Anenzephalie. In: M. Dederich, W. Jantzen & R. Walthes (Hrsg.), Sinne, Körper und Bewegung (292-296). (Enzyklopädisches Handbuch der Behindertenpädagogik Bd. 9). Stuttgart: Kohlhammer

Goll, H., Jaquier, M. & Römelt, J. (Hrsg.) (2009): Kinder mit Anenzephalie und ihre Familien. Bad Heilbrunn: Klinkhardt.

Jaquier, M. (2009): Sich verbinden und loslassen. Deutsche Hebammen Zeitschrift 8; 15-18

Jaquier, M., Klein, A., Boltshauser, E. (2006): Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly, BJOG; 113:951-953

Römelt, J. (Hrsg.) (2005): Spätabbrüche der Schwangerschaft. Überlegungen zu einer umstrittenen Praxis. Leipzig: St. Benno Verlag.