



# Children with Anencephaly

the babies, their parents and professional support



## CLINICAL FEATURES

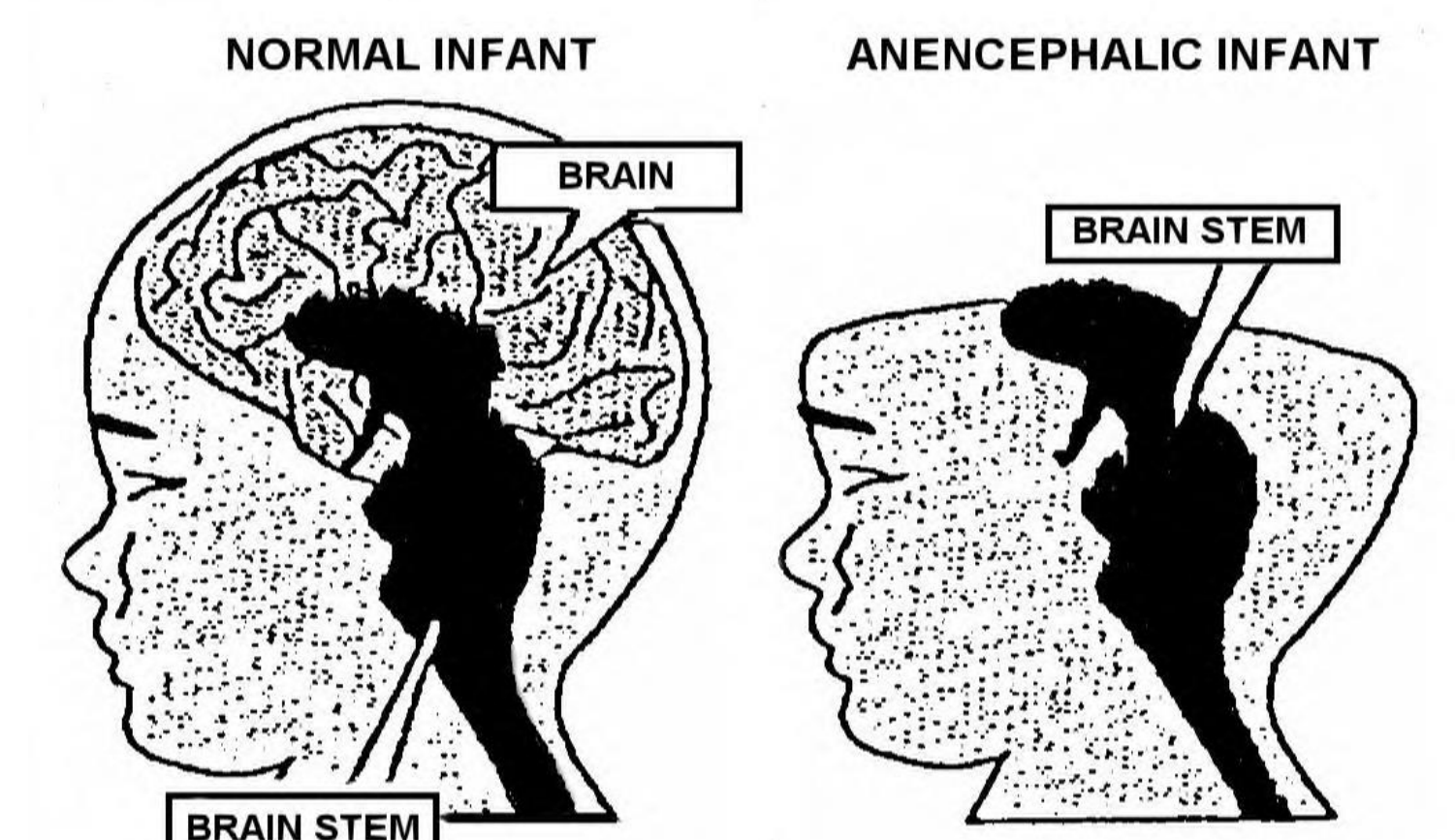
Anencephaly results from a failure of fusion of the cranial portion of the neural tube, with resultant absence of all or part of the brain, neurocranium, and skin.

- The cerebral hemispheres are usually absent;
- the brainstem and portions of the midbrain are usually present.
- ICD-10 Code: Q00.0 Anencephaly

Moore, C. A. (2006): Classification of neural tube defects. In: D. F. Wyszynski (Ed.): Neural tube defects: From origin to treatment (66-75). Oxford: University Press

## EPIDEMIOLOGY AND PROGNOSIS

- Anencephaly is the most frequent developmental malformation of the brain (1:1000 newborns).
- There is no cure.



Pschyrembel, W. (2002): Pschyrembel Klinisches Wörterbuch. Berlin

www.asfhelp.com

## LIFE EXPECTANCY

- 25% die during pregnancy or delivery
- 50% live between a few minutes and one day
- 25% live up to 10 days
- Very few live longer, e.g.: - Faith Hope: 3 month, 4 days, - Vitoria de Christo: 2,5 years (after surgery).

Jaquier M., Klein A. & Boltshauser, E. (2006): Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly. In: BJOG – International Journal of Obstetrics and Gynaecology, 113, 951–953

## RESEARCH PROJECT

The „Anencephaly Network“ exists at the University of Erfurt (Germany) since 2003. Participants come from different fields (e.g. medicine, philosophy, theology). Parents are valued members of the research team. To date, 11 interdisciplinary conferences on the situation of children with anencephaly and their families took place. Acquisition of international experts in different scientific disciplines is planned for the future.

Research objectives are:

- anthropological and ethical questions of personhood,
- questions on awareness, perception and emotion, and
- development of adequate programs to serve parents and children.

## LITERATURE

- Goll, H., Jaquier, M. & Römelt, J. (Eds.) (2009). Kinder mit Anenzephalie und ihre Familien. Bad Heilbrunn: Klinkhardt
- Merker, B. (2007). Consciousness without a cerebral cortex: A challenge for neuroscience and medicine. Behavioral and Brain Sciences, 30, 63–134
- Jaquier M., Klein A. & Boltshauser, E. (2006). Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly. BJOG – International Journal of Obstetrics and Gynaecology, 113, 951–953

## PHYSICIAN'S OPINION: "INCOMPETENT"

„Infants born with anencephaly are usually

- blind,
- deaf,
- unconscious and
- unable to feel pain.“

Parker, J.M. & Parker, P.M. (Eds.) (2002): The official parent's sourcebook on anencephaly: A revised and updated directory for the internet age. San Diego

## PARENT'S OPINION: "COMPETENT"

"Katie would search with her one beautiful blue eye for me, her daddy, and her sister when she heard our voices. She would startle when there was a sudden loud noise, whether it was from a toy her sister was playing with or laughter. She was not supposed to feel but she loved being held and hated being put down.“

<http://www.anencephaly.info/e/katie.php>

## SITUATION OF THE PARENTS

- An increasing number of parents decides to continue the pregnancy.
- They experience togetherness with their unborn child, say good-bye and let their child go in a more personal and peaceful way.
- Carrying to term is an internationally observable trend.

further information: [www.anencephaly.info](http://www.anencephaly.info)