ERN on inherited and congenital abnormalities (ERNICA)

ERNICA addresses congenital malformations and diseases that appear early in life and require multidisciplinary care and long-term follow-up, and examines the transition to adulthood.

The network is organised around two main work streams in line with ORPHANET classifications and ICD10. One work stream deals with malformations of the digestive system and the other deals with malformations of the diaphragm and abdominal wall. In the latter work stream, there are working groups covering malformations of the oesophagus and a group working on gastroenterological and intestinal diseases. This group also includes a sub-group specialising in intestinal failure. Each working group has its own disease-specific task forces.

For some of these rare diseases, mortality rates can be as high as 50 %. ERNICA aims to improve the quality of care that patients receive and to reduce the long-term impact of these rare diseases in infants. The network will facilitate research collaborations with the power to develop evidence-based clinical guidelines. Access to new surgical techniques and treatments will also be improved.

ERNICA is a meeting place for national patients' associations and caregivers, including nurses and other professions committed to improving patient outcomes.

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NETWORK COORDINATOR

Professor Rene Wijnen
Erasmus Medical Center Rotterdam, The Netherlands