



**FIMATHO**

Filière des maladies rares abdomino-thoraciques



European  
Reference  
Networks

**ERNICA**

# NOUVELLES D'ERNICA

F. GOTTRAND

Belgium

Denmark

Finland

France

Germany

Italy

Norway

Sweden

The Netherlands

United Kingdom

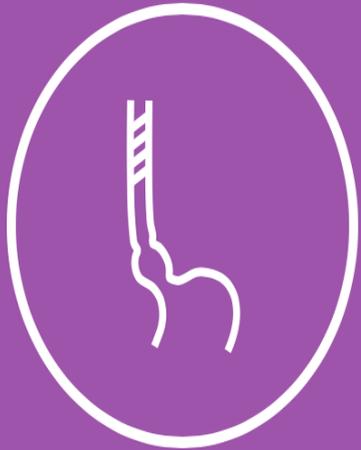
There are 20 European hospitals involved in ERNICA, from 10 member states.

**[HTTPS://ERN-ERNICA.EU](https://ern-ernica.eu)**

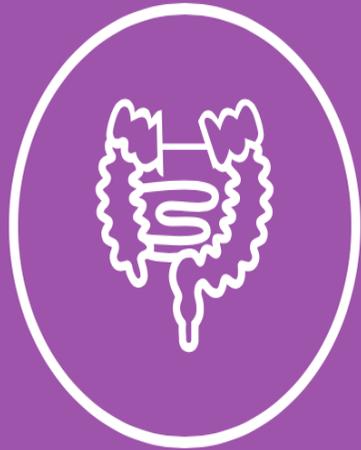
# ERNICA

The European Reference Network for rare inherited congenital digestive disorders

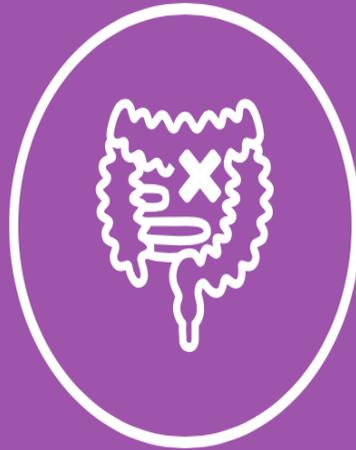
ERNICA



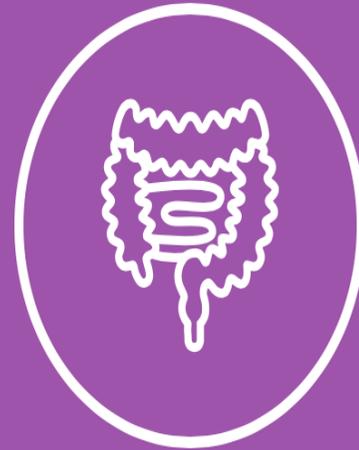
Esophageal  
diseases



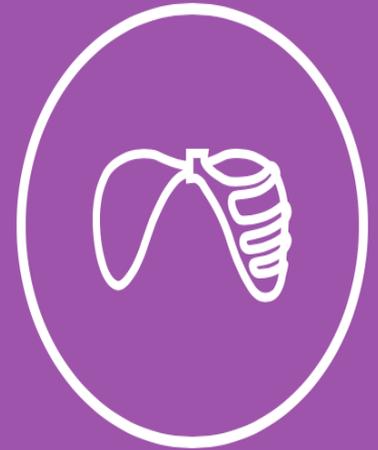
Intestinal  
diseases



Intestinal failure



Gastroenterological  
diseases



Malformations of  
the diaphragm  
and abdominal  
wall

## APRIL 2019

**10th:** Scientific Committee Meeting, Padua

**11th-12th:** ERNICA annual network meeting, Padua

The Clinical Patient Management System (CPMS) is a web-based clinical software application developed by the European Commission which allows healthcare providers from all over the EU to work together virtually to diagnose and treat patients with rare, low prevalence and complex diseases. Follow this link for a video on how to get started: <https://webgate.ec.europa.eu/ern/imgs/CPMS%20Getting%20Started.mp4>

CONSENSUS CONFERENCE ON THE PERIOPERATIVE AND SURGICAL MANAGEMENT OF  
ESOPHAGEAL ATRESIA WITH TRACHEOESOPHAGEAL FISTULA, BERLIN, 25TH-26TH OCTOBER

## Standards of Care

The activities grouped under this work package are linked to the overall objective of ERNICA to improve quality of care, by enhancing diagnosis, treatment and follow-up of patients with rare congenital digestive disorders. Within the different diagnostic groups projects are set up to define core outcome sets, develop guidelines, and to set criteria for multidisciplinary care.

### **ERNICA exchange program**

Within the ERNICA network an exchange program is set up. Both consultants and fellows can make short visits to other member centers. It would be a great opportunity for fellows to gain expertise within the ERNICA centers. Listed below are the specifications for the exchange program.

- Call is open for both consultants and fellows
- Opportunity for medical staff of (non-) member centers to gain expertise within ERNICA centers
- Onsite training by expert professionals within ERNICA
- Period of 1 day - 2 weeks

# MEASURING QUALITY IN HEALTHCARE

An important feature to improve quality of care is to reduce variation and learn from best practices with the best outcomes. Although variation in the way care is delivered can be legitimate, there is evidence that differences in outcomes between providers, and in the cause of an international comparison, are inordinately large. To gain insight in the mechanisms leading to variation in quality of care, measurement of performance is crucial: healthcare deliverers may find out what problems they have, and who else may have solved these problems. Measurement of performance on rare disease treatment makes international auditing crucial since a wider geographical and cultural spread increases variation of quality of care. Moreover, with more patients in the audit statistical analysis becomes viable since the sample size is increased.

The general objective of the EPSA (European Pediatric Surgery Audit) is to set up a pan-European patient registry for different congenital intestinal malformations with the aim to standardise the collection of the scarce data from different EU member states and to achieve a sufficient sample size for epidemiological and clinical research. This will result in improved surgical outcome and quality of life of patients suffering from inherited or congenital intestinal anomalies.