ERNICA /ERN

ERN BOND	European Reference Network on bone disorders
ERN CRANIO	European Reference Network on craniofacial anomalies and ear, nose and throat (ENT) disorders
Endo-ERN	European Reference Network on endocrine conditions
ERN EpiCARE	European Reference Network on epilepsies
ERKNet	European Reference Network on kidney diseases
ERN-RND	European Reference Network on neurological diseases
ERNICA	European Reference Network on inherited and congenital anomalies
ERN LUNG	European Reference Network on respiratory diseases
ERN Skin	European Reference Network on skin disorders
ERN EURACAN	European Reference Network on adult cancers (solid tumours)
ERN EuroBloodNet	European Reference Network on haematological diseases
ERN eUROGEN	European Reference Network on urogenital diseases and conditions
ERN TRANSPLANT-CHILD	European Reference Network on Transplantation in Children

ERN EURO-NMD	European Reference Network on neuromuscular diseases
ERN EYE	European Reference Network on eye diseases
ERN GENTURIS	European Reference Network on genetic tumour risk syndromes
ERN GUARD-HEART	European Reference Network on diseases of the heart
ERN ITHACA	European Reference Network on congenital malformations and rare intellectual disability
MetabERN	European Reference Network on hereditary metabolic disorders
ERN PaedCan	European Reference Network on paediatric cancer (haemato-oncology)
ERN RARE-LIVER	European Reference Network on hepatological diseases
ERN ReCONNET	European Reference Network on connective tissue and musculoskeletal diseases
ERN RITA	European Reference Network on immunodeficiency, autoinflammatory and autoimmune diseases
VASCERN	European Reference Network on Rare Multisystemic Vascular disease

900 « centres de référence » de 300 hôpitaux de 26 pays

EU

IL est suppose que les REN permettent :

- Aider le clinicien a accéder à un grand panel d'expert
- Mettre ensemble des listes de centres d'expertises par pays
- Aider a la comprehension des maladies rares par le biais de base de données et de recherche au niveau européen

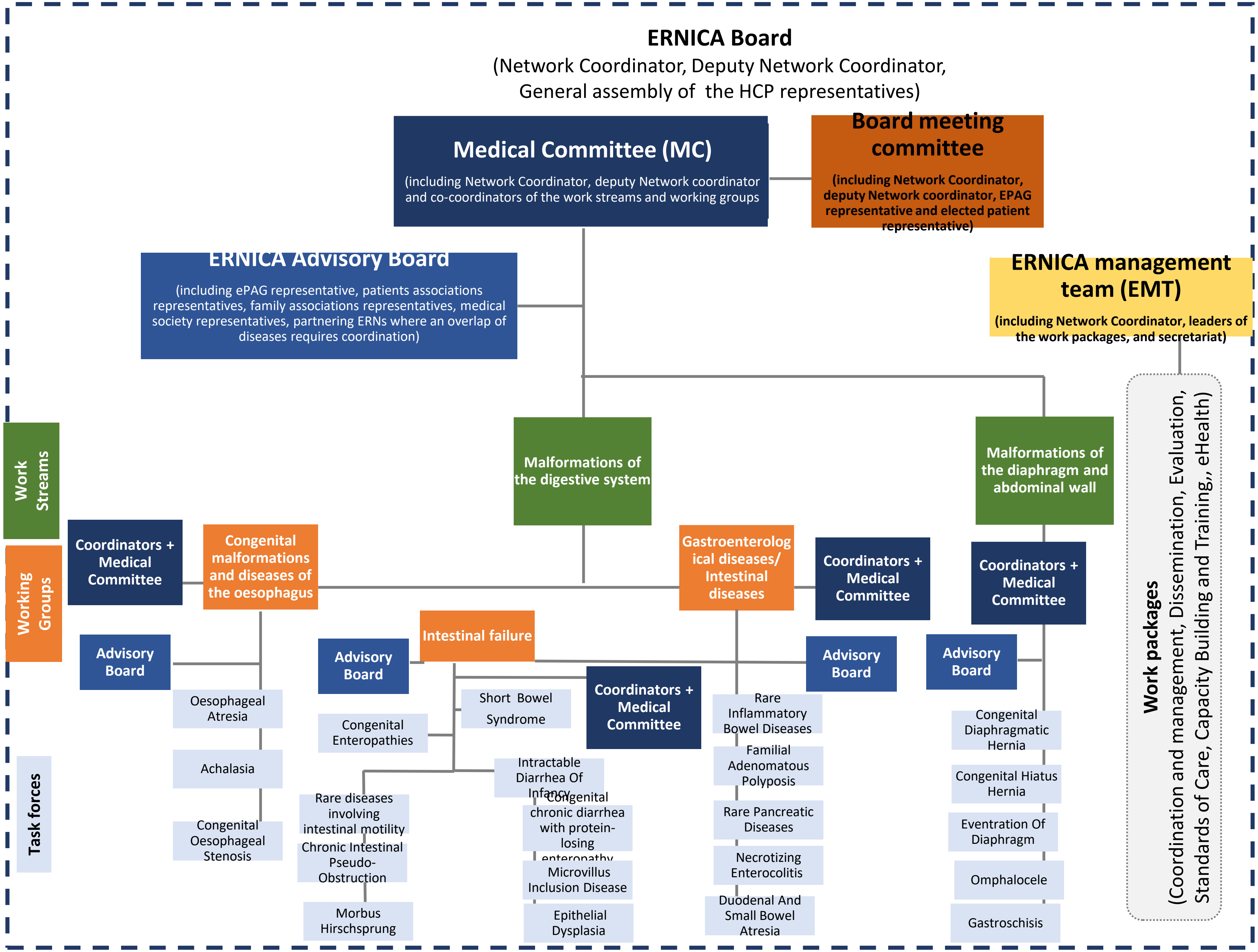
Les ERN doivent aider :

- Au développement de guidelines, programmes d'echanges et de formations
- Mise en place de large étude
- Le developpement de nouveaux medicament et de nouvelles technologies
- Le developpement de nouveux outils de soins, eHealth, IA

European Reference Network for rare Inherited Congenital Anomalies (digestive) ERNICA

https://ERN-ERNICA.EU

- 20 hôpitaux européens, 10 pays membres
- Belgique : Louvain
- Danemark : Copenhague
- Finlande : Helsinki
- France : Beaujon, Marseille, Lille, Robert Debré, Antoine Béclère, Necker
- Allemagne : Hanovre, Mannheim
- Italie : Padoue,
- Norvège : Oslo
- Suède : Stockholm
- Pays bas :Amsterdam, Rotterdam, Utrecht et Nijmegen,
- Angleterre : GOS



ERNICA Board

(Network Coordinator, Deputy Network Coordinator, General assembly of the HCP representatives)

Medical Committee (MC)

(including Network Coordinator, deputy Network coordinator and co-coordinators of the work streams and working groups

Board meeting committee

(including Network Coordinator, deputy Network coordinator, EPAG representative and elected patient representative)

ERNICA Advisory Board

(including ePAG representative, patients associations representatives, family associations representatives, medical society representatives, partnering ERNs where an overlap of diseases requires coordination)

ERNICA management team (EMT)

(including Network Coordinator, leaders of the work packages, and secretariat)

Work packages

(Coordination and management, Dissemination, Evaluation, Standards of Care, Capacity Building and Training,, eHealth)

Work Streams

Working Groups

Task forces

Malformations of the digestive system

Malformations of the diaphragm and abdominal wall

Coordinators + Medical Committee

Congenital malformations and diseases of the oesophagus

Advisory Board

Oesophageal Atresia

Achalasia

Congenital Oesophageal Stenosis

Intestinal failure

Advisory Board

Coordinators + Medical Committee

Short Bowel Syndrome

Congenital Enteropathies

Intractable Diarrhea Of Infancy

Congenital chronic diarrhea with protein-losing enteropathy

Microvillus Inclusion Disease

Epithelial Dysplasia

Rare diseases involving intestinal motility

Chronic Intestinal Pseudo-Obstruction

Morbus Hirschsprung

Gastroenterological diseases/ Intestinal diseases

Coordinators + Medical Committee

Advisory Board

Rare Inflammatory Bowel Diseases

Familial Adenomatous Polyposis

Rare Pancreatic Diseases

Necrotizing Enterocolitis

Duodenal And Small Bowel Atresia

Coordinators + Medical Committee

Advisory Board

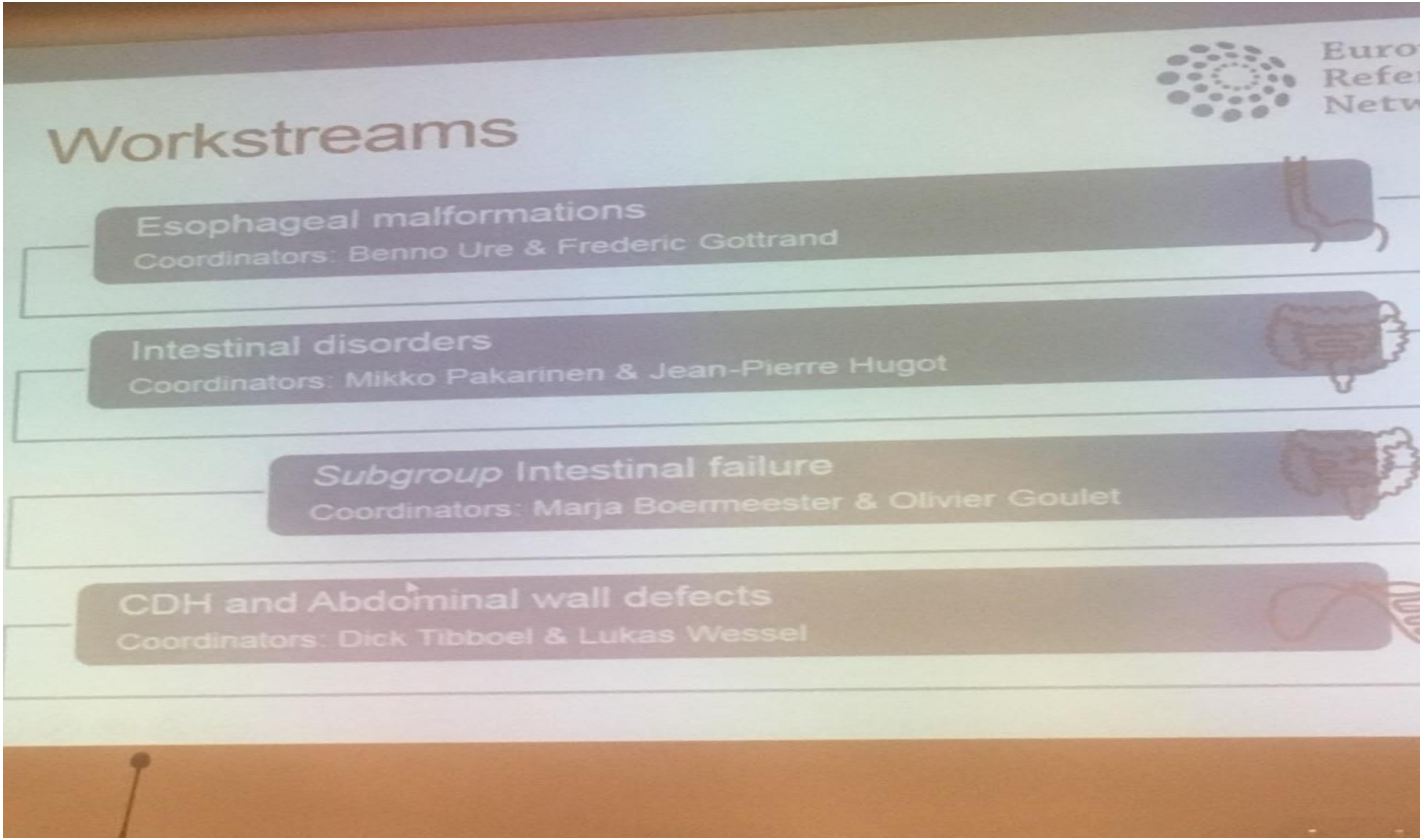
Congenital Diaphragmatic Hernia

Congenital Hiatus Hernia

Eventration Of Diaphragm

Omphalocele

Gastroschisis



Euro
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Workstreams

Esophageal malformations
Coordinators: Benno Ure & Frederic Gottrand

Intestinal disorders
Coordinators: Mikko Pakarinen & Jean-Pierre Hugot

***Subgroup* Intestinal failure**
Coordinators: Marja Boermeester & Olivier Goulet

CDH and Abdominal wall defects
Coordinators: Dick Tibboel & Lukas Wessel

JANUARY 2019

24th: ERN coordinators research capabilities meeting, Brussels 24th-25th: Intestinal Failure expert meeting, Amsterdam

FEBRUARY 2019

1st: One day workshop: Patient journeys (Esophageal Atresia work stream), Hannover 18th: ERN coordinators working group on knowledge generation, Brussels

MARCH 2019

5th: ERN project managers meeting, Brussels
25th: 7th meeting of the ERN coordinators group, Brussels

APRIL 2019

10th: Scientific Committee Meeting, Padua 11th-12th: ERNICA annual network meeting, Padua

CPMS

- CPMS : 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
  - Facilitate greater interoperability of ICT systems in the healthcare field
  - Support patient access to eHealth applications
  - Avoid duplication of effort
  - Mutual recognition or adaptation of [..] standards
  - Provide a better evidence base for optimal use of new technologies
  - Practical facilitating of cross-border provision of healthcare by health professionals

CPMS Key Functionalities

- Secure exchange of data
- Crossover between ERNs
- Database/Reporting
- KPIs
- Customised datasets
- Data transfer for research
- IHE – data transfer from hospitals
- Medical Image Viewer
- Real-time & off-line communication

All patients in Europe with rare disease

- have access to **early and correct diagnosis** supported by experts on CPMS
- are guided early to therapeutic interventions based on **European guidelines to secure better quality of life and improved survival!**
- Have **access to therapeutic standard of care and innovation as indicated by expert panels**
- Have essential disease and therapeutic data captured in **adequately linked registries with CPMS being a resource to create evidence** and reach oversight on progress being made in Europe

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

Work Package 6
Research Framework

Quality of Life Measure

for Patients with Esophageal Atresia –*Dingemann / Sfeir*

Team “Clinical Sciences”/Pediatrics
Gothenburg / Sweden

Team “Pediatric Surgery”
Gothenburg / Sweden

Team “Pediatric Surgery”
Hannover / Germany

Team “Medical Psychology”
Hamburg / Germany

Team “Pediatric Gastroenterology”
Lille / France

Consensus Meeting 2018 Novenbre

on Perioperative and Surgical Management of EA – *Carmen Dingemann*

Concept:

Experts (19) in the field of EA / representatives of ERNICA institutions and members of the workflow including a pediatric gastroenterologist, a methodologist and a representative of patient support groups / EAT

Preparation of a list including all relevant aspects (members of the Workflow EA / Hannover team)

Provision of relevant literature (level 1 evidence) as a basis for the conference in advance (Hannover team)

Lille 23,24 April 2020