




European Reference Network

for rare or low prevalence complex diseases

 **Network**
Inherited and Congenital Anomalies (ERNICA)

NEWSLETTER

JANUARY 2019
ISSUE 1

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

The mission of the ERN on rare Inherited and Congenital Anomalies (ERNICA) is the promotion of optimal patient care, providing high quality and improving clinical standards across Europe. Many aspects of the current management of patients with esophageal atresia (EA) and tracheoesophageal fistula (TEF) are still controversial, and there is only little evidence for best diagnostic therapeutic practice. As a consequence, the members of the *ERNICA Esophageal Workstream* agreed to perform a conference to establish consensus based on the latest evidence from the literature and expert opinion. Twenty representatives from ERNICA institutions who are extensively experienced in the treatment of patients with EA were invited. The group of participants included pediatric surgeons, a pediatric gastroenterologist, a methodologist and representatives of patient support groups.

The consensus conference took place on Thursday, the 25th October and Friday, 26th October 2018 in the Aesculap Academy in Berlin, Germany. After an extensive literature search and preparation, relevant aspects with regard to diagnostic, pre-, intra-, and postoperative management as well as regarding follow-up of patients with EA/TEF were discussed, and consensus was reached on 60 items important in the care of patients with EA/TEF after an anonymous online voting process. The consensus statements are about to be published for further use throughout Europe in the European Journal of Pediatric Surgery. This consensus paper will facilitate dissemination of evidence, standardisation and improvement of patient care, and will contribute to reducing the morbidity in patients with EA/TEF.

Meeting co-ordinators:

Carmen Dingemann

Hannover Medical School, Hannover, Germany

Simon Eaton

UCL Great Ormond Street Institute of Child Health, London, United Kingdom

Benno Ure

Hannover Medical School, Hannover, Germany

Patient representatives involved in this meeting: Graham Slater, Anke Widenmann-Grolig and JoAnne Fruithof from the patient support group EAT: <http://www.we-are-eat.org/>



4TH ERN CONFERENCE, BRUSSELS, NOV 2018

On 21st and 22nd November, the 4th Conference on European Reference Networks took place in Brussels, Belgium.

12 ERNICA representatives attended on behalf of the network. Prof. dr. René Wijnen, ERNICA coordinator, chaired the plenary round table session on *'The integration in healthcare systems'*. He also co-presented at the *'Patient-Healthcare professional partnerships in ERNs: sharing successes and challenges'* parallel session, alongside Graham Slater, one of ERNICA's patient representatives.

Click on the following link for the conference agenda, powerpoints and video recordings from the day, the conference report and ERN exhibition posters (including a poster specific to ERNICA): https://ec.europa.eu/health/ern/events/ev_20181121_nl



NEED SOME HELP WITH CPMS? ASK FRANCESCO AND REBECCA!



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>

We would also like to take this opportunity to inform you that **Francesco Fascetti Leon** and **Rebecca Pulvirenti** from Padua are now responsible for running ERNICA's internal CPMS helpdesk.

They can help you with CPMS-related queries and you can reach them both by email (francesco.fascettileon@aopd.veneto.it and rebeccapulvirenti@gmail.com).

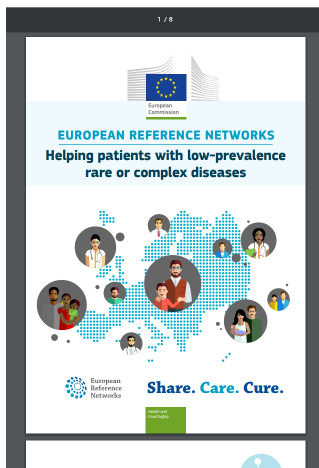
ERNICA IS NOW ON TWITTER AND LINKEDIN!

ERNICA is now on **Twitter!** We will be tweeting key updates, so follow us and keep a look out!

https://twitter.com/ernica_ern

ERNICA is also now on **LinkedIn!** Follow us and connect with other network members:

<https://www.linkedin.com/company/ernica/>



RELEASE OF AN INFORMATIVE VIDEO AND FLYER TARGETING PATIENTS AND HEALTHCARE PROFESSIONALS

The European Commission has released an informative video clip on ERNs, which is targeted at patients and healthcare professionals.

It can be accessed here: https://ec.europa.eu/health/ern/videos_en

A flyer has also been produced: https://ec.europa.eu/health/sites/health/files/ern/docs/2018_patientsflyer_en.pdf

Please share these materials with your patients and colleagues.

They are currently being translated into other European languages so keep an eye on the weblink! https://ec.europa.eu/health/ern_en

MEETINGS CURRENTLY ARRANGED FOR THIS QUARTER:

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