




# European Reference Network

for rare or low prevalence complex diseases

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

# NEWSLETTER

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## ERNICA ANIMATIONS FOR PATIENTS, PARENTS AND FAMILIES

ERNICA is busy with the development of animation videos for patients, parents and families. ERNICA is working with an animation company in The Netherlands, called [Informed](#).

The first ERNICA animation video **CAN EAT**—**C**are and **N**utrition in **E**sophageal **A**tresia is complete and will be disseminated in due course (in English) via the [ERNICA YouTube channel](#). This animation was prepared for by a dedicated team of patient representatives and clinicians.

We are looking to provide subtitles in as many languages as possible - *French, German and Dutch translations are already underway.*

We also plan to disseminate this video alongside a feedback survey, in order to capture the user experience.

**Thank you and congratulations to all those involved in creating this animation video!**



Co-financed by the Connecting Europe Facility of the European Union

Additional animation videos for parents, patients and families are also in development including explainer videos on:

- ◇ ***What is pediatric intestinal failure?***
- ◇ ***What is Hirschsprung's disease?***
- ◇ ***What is congenital diaphragmatic hernia?***

**We look forward to working with Informed to finalise these videos and disseminating the videos to patients and their families across Europe.**

## CROSS-ERN PREGNANCY AND FAMILY PLANNING WORKING GROUP

A transversal cross-ERN Pregnancy and Family Planning working group now exists.

This is an area of relevance to ERNICA.

In this group, ERNICA is represented by René Wijnen as ERN coordinator, Alexandra Benachi as clinical representative (from Hôpital Antoine-Béclère, Paris) and Beverley Power as patient representative (from CDH-UK).



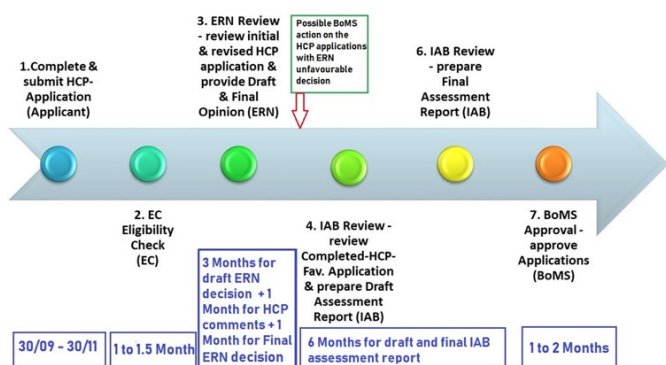
## CONGRATULATIONS ANKE!



Anke Widenmann-Grolig, patient representative for Esophageal Atresia within ERNICA (Representing KEKS, part of the Federation of Esophageal Atresia and Tracheo-Esophageal Fistula Support groups [EAT]) has been accepted to be part of the **Advisory Body of the European Reference Network Clinical Practice Guidelines Programme**.

Anke has been actively involved in the development of ERNICA consensus statements for Esophageal Atresia and her experience will bring huge value to this cross-ERN programme. We are very proud that ERNICA will be represented and we congratulate Anke for her successful application!

## ASSESSMENT PROCESS FOR NEW ERN MEMBERS; WHERE ARE WE?



\*\*Due to the COVID-19 pandemic, the ERN review period was suspended by the European Commission from April - September 2020

Step 3 of the assessment process (the ERN review process) is now complete.

The Independent Assessment Body (IAB) review will now take place, followed by approval from the ERN Board of Member States representatives.

We expect new members to join ERNICA in 2021.

## EJP-RD JOINT TRANSNATIONAL CALL 2021 ON SOCIAL SCIENCES AND HUMANITIES RESEARCH: PRELIMINARY ANNOUNCEMENT



Open to ERN members and affiliated partners

**Topic:** Social sciences and humanities research to improve health care implementation and everyday life of people living with a rare disease.

**Dates & Deadlines:** 2-stage submission process: pre-proposals (Deadline : 16th February 2021) and full proposals (Deadline : 15th June 2021). The call is scheduled to open in early December 2020. The maximum duration of the project is three years.

**More information?** Click [here](#).

*Please let the ERNICA coordinator and project managers know if you do have an idea and plan to submit a proposal*



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