



European Reference Network

for rare or low prevalence complex diseases

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

NEWSLETTER

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ISSUE 3



THE UPCOMING EXPANSION OF ERNICA!

The second call for new healthcare centres to join the ERNs as full members was launched on 30th September 2019. It will remain open until 30 November 2019. Applications are to be completed online using the new application tool. All information on how to apply can be found via this dedicated webpage:

https://ec.europa.eu/health/ern/consultations/2019_call_membership_en

We have been informed that as there are multiple steps involved in the assessment procedure, successful applicants are not likely to have their membership status confirmed before December 2021.



This call for membership also marked the deadline for **affiliated partner** designations. Prior to this, some member states could designate a centre to become an 'affiliated partner' of an ERN.

What are affiliated partners?

Affiliated partners are not members of an ERN. Affiliated partners are expected to provide a link to the ERN for those European countries without a healthcare provider involved. Therefore, if a member state already had a healthcare provider involved in the network as a full member, they could not designate an affiliated partner. Visit the ERNICA website for more information on affiliated partnership.

This European Commission-led initiative thus addresses concerns related to the geographic coverage of the networks.

Affiliated partners will have the opportunity to use the Clinical Patient Management System. We can also offer our support in regards to strengthening and developing their clinical expertise. Affiliated partners help to increase the profile of ERNICA across Europe and provide more ERN entry points for patients. We can also benefit from their knowledge and skills and gain an insight into the different healthcare systems and infrastructures across Europe.

There are currently 20 European hospitals involved in ERNICA as full members, from 10 member states. In total, we received 21 affiliated partner applications from 11 additional member states. Appropriate applications are currently under review.

ERNs seek to support the provision of high quality care to patients from across the European Union, regardless of where they are located. Affiliated partners can help us on this mission!

ERNICA GUIDELINE FOR TOTAL COLONIC AGANGLIONOSIS: INITIAL DISCUSSIONS

On 27th September 2019, ERNICA members gathered at Erasmus MC, Rotterdam to kick off initial discussions regarding the development of an ERNICA guideline on **total colonic aganglionosis**.

The group discussed key questions to address for the development of this guideline.

Both ERNICA clinicians and patient representatives will be involved.

We look forward to seeing this project develop!



APPLICATION SUBMITTED FOR AN ERNICA RARE DISEASE REGISTRY!

In May 2019 the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) published the annual work programme 2019 for grants under the third programme for the union's action in the field of health (2014-2020). This includes an ERN call for rare disease registries.



5/24 ERNs already received funding from the health programme (annual work programme 2016) and have/are currently developing their own rare disease registry. This call published under the annual work programme 2019 was open for the remaining 19 ERNs, such as ERNICA, to apply for financial support (200 000 EUR per ERN).

A team of ERNICA representatives met in Berlin in June 2019 to start the initial discussions and on 10th October, the application was **submitted!** The registry proposal focuses on the diseases covered by ERNICA. It seeks to standardise data collection across Europe and monitor outcomes to ultimately improve patient care. We propose to build on an already existing registry infrastructure in The Netherlands, the European Paediatric Surgery Audit (EPSA).



STEPS-EA trial

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STEPS EA-TRIAL: ERNICA'S FIRST RCT!

The **STEPS-EA trial** is a multi-centre Randomised Controlled Trial looking at intralesional **STE**roid injections to **P**revent refractory **S**trictures in patients with **E**sophageal **A**tresia.

The trial involves 1:1 randomization to injection with 10 mg/ml TAC (Kenacort-A 10) prior to balloon dilatation and balloon dilatation without any injection.

This will be the first randomized controlled trial within ERNICA and the trial team is excited to announce that they are now waiting for the first eligible patient to include.

The first STEPS-EA trial newsletter is available under the 'news' section of the ERNICA website.

For any questions please email the STEPS-EA trial team at: steps.ea@erasmusmc.nl



SAVE THE DATE! FOR THE 2020 ERNICA ANNUAL MEETING 23-24 APRIL, LILLE

Our soon-to-be affiliated partner representatives will also be invited to this meeting!

OTHER RELEVANT MEETINGS AND EVENTS:

NOVEMBER 2019

13th: ERN workshop for research infrastructures, Brussels

13th-14th: ERNICA consensus conference on the perioperative, surgical and long-term management of patients with long-gap esophageal atresia, Berlin

14th-15th: ERN coordinators meeting, Brussels

15th: Esophageal atresia patient journey workshop, Berlin

DECEMBER 2019

2nd: ERNICA gastroschisis guideline meeting, Rotterdam

ERNICA healthcare professionals and patient representatives: Don't forget to share any ERNICA-related dissemination activities and events with us!