




# European Reference Network

for rare or low prevalence complex diseases

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

# NEWSLETTER

MAY 2019  
ISSUE 2



## 3RD ERNICA ANNUAL MEETING, PADUA 2019



On the 11th and 12th of April 2019 the ERNICA network had its 3rd annual meeting in the beautiful city of Padua, Italy. Healthcare professionals and patient representatives gathered from all over Europe to discuss key network updates and make plans for the future. Discussions began on 10th April, with a pre-meeting dedicated to research. This meeting focused on formalising the role of the scientific committee, discussing ERNICA's current multi-centre research projects and exploring possibilities for future research collaborations.

On Thursday 11th we welcomed all meeting attendees to the University of Padua. The day featured updates from the ERNICA management team, the CPMS helpdesk and each of the work stream groups. The work and perspectives of both healthcare professionals and patient representatives within the network were presented. Friday's meeting was held at Padua University Hospital. Here we discussed the development of a registry and had the opportunity to participate in a live CPMS simulation. Workstream specific projects were discussed in separate sessions organised for the different diagnostic groups. A full meeting report will be circulated soon.

Whilst in Padua we also had the opportunity to visit the famous anatomical theatre and attend a lecture on the anatomical history of Padua. Thank you to everyone who contributed to this productive meeting and special thanks to Francesco Fascetti Leon, Piergiorgio Gamba and Rebecca Pulvirenti for all your organisational support. We look forward to reuniting in Lille for the 4th annual meeting on 23rd - 24th April 2020. [Save the date!](#)



## WELCOMING ANNE-LAURE ASLANIAN!

### PATIENT ENGAGEMENT MANAGER SUPPORTING ERNICA

You may have met Anne-Laure at the recent annual meeting in Padua! Anne-Laure joined EURORDIS in March 2019 as Patient Engagement Manager. She is managing and supporting 8 out of the 24 European Patient Advocacy Groups (ePAGs): ERN EYE, SKIN, ITHACA, VASCERN, EPICARE, EUROGEN, ENDO and ERNICA. Anne-Laure also leads all the communication and knowledge management activities to support the 24 ePAGs' work and facilitate the exchange of good practice and access to information.

Anne-Laure has several years of experience in research and innovation project management and development of international research project proposals. Prior to joining EURORDIS, she has been working for 4 years in the Research Institute of the Vall d'Hebron Hospital and in the Centre for Genomic Regulation (both based in Barcelona).

Anne-Laure is a native French speaker, she also speaks English, Spanish, Catalan and basic Portuguese.

Please do not hesitate to get in touch with her: [anne-laure.aslanian@eurordis.org](mailto:anne-laure.aslanian@eurordis.org)

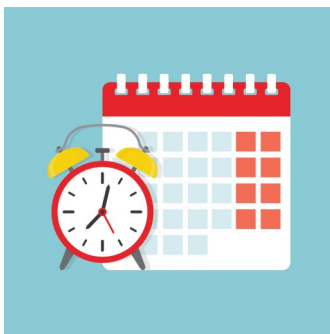


## NEED SOME PROJECT MATERIALS TRANSLATED?

The ERN coordinators and project managers now have access to the eTranslation tool set up by the European Commission. This can be used to support your translation needs. This tool can be used to exchange information across languages in the EU, Iceland and Norway.

The tool can translate text in a large variety of formats (doc, pdf, jpg, excel, powerpoint...).

If you have any project-related materials that you would like translated please make contact with the ERNICA project managers Olivia Spivack and Renée de Ruiter: [o.spivack@erasmusmc.nl](mailto:o.spivack@erasmusmc.nl) & [r.deruiter.1@erasmusmc.nl](mailto:r.deruiter.1@erasmusmc.nl)



## UPCOMING MEETINGS AND EVENTS:

### JUNE 2019

**5th-8th:** 52th Annual meeting of the European Society for Pediatric gastroenterology, hepatology and nutrition, Glasgow

**7th:** ERNICA registry meeting, Berlin

**24th:** 8th ERN Coordinators meeting, Brussels

**24th-28th:** INPAT-INoEA esophageal atresia joint meeting, Rome

**26th:** Focus group meeting, WP17 of the European Joint Programme on rare diseases – development of the ERN research programme, Leiden



### JULY 2019

**3rd-6th:** 16th International Congress of the Intestinal Rehabilitation & Transplant Association, Paris

### SEPTEMBER 2019

**17th-19th:** European Joint Programme on rare diseases general assembly meeting, Gdansk

## A CALL TO OUR MEMBERS- PATIENT REPRESENTATIVES AND HEALTHCARE PROVIDERS:

**Please let the ERNICA project managers know of any relevant meetings and events so that we can share these on our newsletter and on our other dissemination platforms!**