



European Reference Network

for rare or low prevalence complex diseases

Network
Inherited and Congenital Anomalies (ERNICA)

NEWSLETTER

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ISSUE 5: EXTENDED ISSUE



ERNICA COVID-19 STATEMENT

The current situation with the COVID-19 pandemic is a significant global challenge.

ERNICA recognises that patients with rare inherited and congenital digestive (and gastrointestinal) diseases and their families/ carers may have concerns about their health at this time. There may be particular concerns surrounding those disorders with pulmonary involvement. We also understand that ERNICA members may be required to divert their focus to the COVID-19 effort. ERNICA coordinator, Prof. dr. René Wijnen has issued a [COVID-19 statement](#) on the ERNICA website which will be continually updated.

European Commission response - COVID19-CMSS

As part of the European Commission response to this pandemic, a web-conferencing support system for the clinical management of COVID-19 patients (COVID19-CMSS) has been set up to support all EU hospitals treating complex COVID-19 cases. The system provides a fast-tracked route for clinicians to discuss complex COVID-19 cases across borders. Clinical Patient Management System (CPMS) accounts (including 'guest accounts' for non-ERNICA centres) can still be used to virtually discuss rare disease and complex cases, with or without a possible connection to the COVID-19 infection.



Read the [ERNICA COVID-19 statement](#) for more information.

Cancellation of face-to-face ERNICA meetings

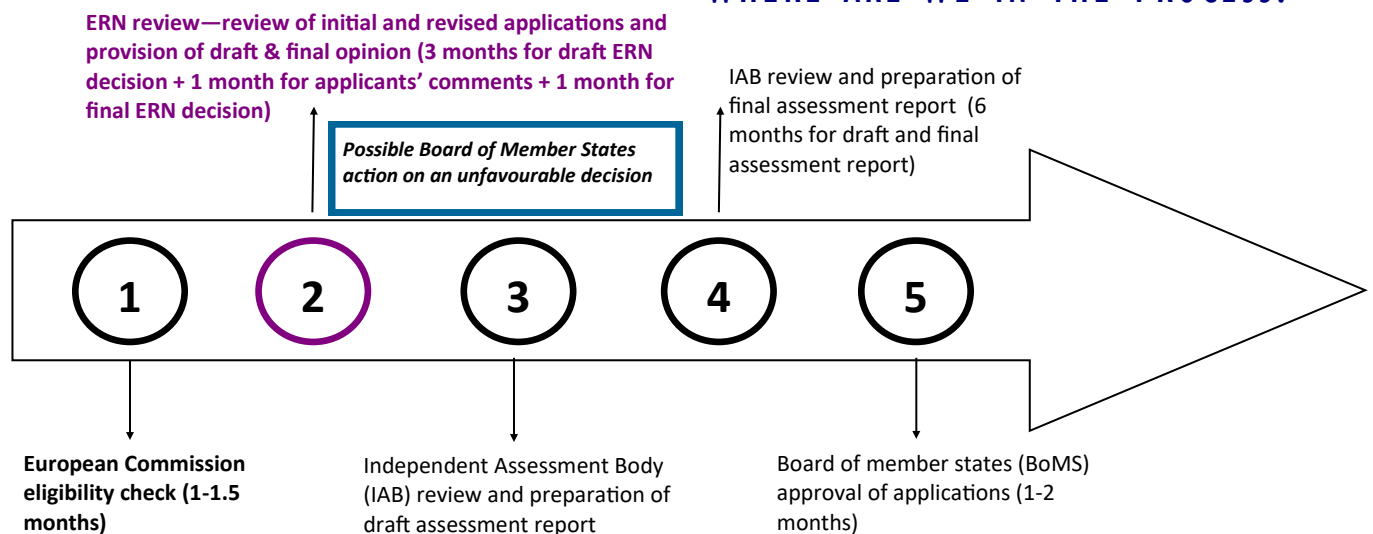
Until further notice, ERNICA will not be hosting face-to-face meetings.

Unfortunately the planned Intestinal Failure working group meeting scheduled to take place at the *Amsterdam University Medical Centre* on 6 March was cancelled due to the outbreak. The group will continue to work on specific projects over video conference and the plan is to postpone this face-to-face meeting to a later date.

The ERNICA 2020 annual meeting due to take place at *Le Centre Hospitalier Universitaire de Lille* on 23-24 April was also unfortunately cancelled. The plan is to postpone this meeting. In its place, a series of online video calls are scheduled to take place on 23-24 April (see page 3).

ASSESSMENT OF NEW MEMBER APPLICANTS:

WHERE ARE WE IN THE PROCESS?



The first step of the assessment process (European commission eligibility check) is now complete. 39 applicants passed the eligibility check and are now being internally reviewed by the ERNICA assessment committee. The deadline for ERN review was originally set at 30 April 2020 but it has now been postponed until 30 September 2020 in light of the COVID-19 outbreak.

WELCOMING NEW AFFILIATED PARTNERS TO ERNICA!



In 2019 a call was open for member states to designate healthcare providers to become 'affiliated partners' of ERNICA. There are two types of affiliated partner: **Associated national centres & National coordination hubs** (Click [here](#) for more information).

ERNICA received a total of 17 appropriate affiliated partnership applications from 10 different member states.
(x 13 Associated national centre, x 4 National coordination hub applications).

A bilateral agreement is signed by both the affiliated partner's chief executive officer and the ERNICA coordinator. This defines areas for collaboration and is tailored to each affiliated partner's capacity and level of experience.

Bilateral agreements have now been signed for the following centres and we are delighted to welcome them to the network:

- ◆ **University Hospital Gratz** (Austria) - Associated National Centre
- ◆ **Kepler University Hospital Linz** (Austria) - Associated National Centre
- ◆ **General Hospital of Vienna [Medical University of Vienna]** (Austria) - Associated National Centre
- ◆ **Sozial Medical Center East, Wien** (Austria) - Associated National Centre
- ◆ **La Paz University Hospital, Madrid** (Spain) - Associated National Centre
- ◆ **Hospital Clinic of Barcelona** (Spain) - Associated National Centre
- ◆ **Vall D'Hebron University Hospital, Barcelona** (Spain) - Associated National Centre
- ◆ **Hospital de Sant Joan de Déu, Barcelona** (Spain) - Associated National Centre
- ◆ **Vilnius University Santaros Clinics** (Lithuania) - Associated National Centre
- ◆ **Hospital of Lithuanian University of Health Sciences Kauno Klinikos** (Lithuania) - Associated National Centre
- ◆ **University Hospital Centre Zagreb** (Croatia) - Associated National Centre

A videoconference call with these centres is scheduled for 24 April to discuss next steps and the remaining bilateral agreements will be finalised.



CLINICAL GUIDELINE DEVELOPMENT

At a meeting held in Brussels on 6 February 2020, the European Commission announced the provision of technical assistance to the ERNs for the development, appraisal and implementation of clinical guidelines and clinical decision support tools.

This assistance will be provided by a consortium led by [Fundacion Progreso y Salud](#), who obtained the 4– year contract following a European Commission tender.

What assistance will the consortium provide?

The consortium proposes to support ERNs to adopt a common methodology and deliver training activities. They also propose to support each ERN with the production of two new clinical practice guidelines and review of five clinical decision support tools.

Support provided by the consortium will be ERN-led and adapted to the diversity of the networks.

LAUNCH OF ERNICA'S CLINICAL EXCHANGE PROGRAMME AND COOPERATION WITH EUPSA **NOW ON HOLD BUT TO BE CONTINUED..**

The ERNICA clinical exchange programme was officially launched in January 2020.

The programme provides fellows and consultants the opportunity to apply for a travel grant to visit an ERNICA centre for clinical training purposes.

The programme is currently on hold due to the COVID-19 pandemic and it is our intention for this to be resumed when deemed safe to do so.

The programme will be open to fellows and consultants both within and outside of ERNICA. The programme is accredited by the European Pediatric Surgeons' Association (EUPSA). ERNICA and EUPSA will continue to jointly publicise the programme.

Seven ERNICA centres have offered specialised programmes. Visit the [ERNICA website](#) for more information on the exchange programme, the centres and the application procedure. So far, four individuals have been granted a travel grant. We intend to follow up on the provision of these grants when appropriate to do so.

ERNICA REGISTRY; AN UPDATE

In 2019, ERNICA responded to a call published under the [European Commission Consumers, Health, Agriculture and Food Executive Agency \(CHAFEA\) annual work programme \(2019\)](#) and submitted a proposal to receive financial support for the development of an ERNICA patient registry (200 000 EUR).



A team of ERNICA representatives met in Berlin in June 2019 to start the initial discussions. Following this, a smaller group of ERNICA representatives put together a proposal for submission in October 2019.

The registry proposal focuses on the diseases covered by ERNICA and aims to standardise data collection across Europe and monitor outcomes to ultimately improve patient care. It seeks to build on an already existing registry infrastructure in The Netherlands, the European Paediatric Surgery Audit (EPSA).

ERNICA was successful in obtaining this financial support. It is now the intention to put this proposal into practice. An online meeting dedicated to the ERNICA registry will take place on Thursday 23 April to kickstart discussions on implementation.

MORE ERNICA UPDATES COMING SOON...

In place of the scheduled ERNICA 2020 annual meeting in Lille, a series of dedicated video calls have been scheduled for 23-24 April. The full programme is outlined below:

Thursday 23 April:

- 10.00-11.00 ERNICA board meeting
- 12.00-13.00 Intestinal failure working group meeting
- 12.00-13.00 Hirschsprung disease patient journey meeting
- 14.00-15.00 Esophageal diseases working group meeting
- 16.00-17.00 EPSA/ERNICA registry meeting

Friday 24 April:

- 10.00-11.00 Scientific Committee meeting
- 12.00-13.00 CDH/Abdominal wall defects /Fetal meeting
(for work stream & work package leads)
- 14.00-15.00 Affiliated partners meeting
- 16.00-17.00 Esophageal atresia patient journey meeting
- 16.00-17.00 Total colonic aganglionosis guideline meeting

Relevant updates from these meetings will be shared with the wider network.

We also encourage you to regularly check our website and follow the updates on our [Twitter](#) & [LinkedIn](#) pages...

OTHER ONLINE EVENTS...

As a result of the COVID-19 pandemic, the **10th European Conference on Rare Diseases & Orphan Products (ECDR 2020)** will now take place ONLINE on 14 - 16 May 2020.

Click [here](#) to find out more and follow the [LinkedIn page](#)!



If you become aware of any other relevant online events/initiatives please let the ERNICA project managers know.

Sending you all our well wishes at this difficult time.