

Health professionals, researchers and patient representatives gathered in Padua, Italy on 11-12 April 2019 for the 3rd ERNICA annual network meeting. On 11 April the meeting took place at the beautiful University of Padua and began with some updates from the ERNICA management team. Information was provided on current initiatives, anticipated funding calls, the expected call for new network members, the impact of Brexit on the ERNs and planned dissemination efforts. Francesco Fascetti Leon (e-health coordinator) and Rebecca Pulvirenti (ERNICA CPMS helpdesk officer) from Padua AOP followed with a presentation on the use of CPMS within the network. The CPMS is a web-based clinical software 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. For this purpose, ERNICA clinicians were encouraged to set up 'panels of experts' within each workstream. After this session the workstream leads and patient representatives presented on projects relevant to each of the ERNICA workstreams.

Esophageal Atresia: Benno Ure promoted the use of machine learning and consensus conferences to improve the management of patients with esophageal atresia when the evidence base is lacking. He voiced the need to obtain varied 'evidence' by initiating multicentre trials, developing registries, holding consensus conferences and by using new methods such as machine learning. The consensus statements on *perioperative and surgical management of esophageal atresia with trachesophageal fistula* are due to be published for use throughout Europe in the European Journal of Pediatric Surgery. Graham Slater and Anke Widenmann-Grolig, two of ERNICA's patient representatives, also introduced the 'patient journeys' concept to the group and their work to date within the esophageal atresia workstream. The development of patient journeys asks patient representatives to reflect on their personal experiences with the rare or complex disease they represent and map what their needs were against what would have been considered the 'ideal' standard of care at each stage.

Intestinal Diseases: Mikko Pakarinen, Ivo de Blaauw and Annette Lemli, patient representative for intestinal diseases, outlined the newly formed working group with the eUROGEN network for Hirschsprung Disease and Anorectal Malformations. With eUROGEN primarily focusing on the urological outcome of such malformations, ERNICA would be able to offer expertise in regards to the intestinal impact. In coming years this group will focus on defining aims and setting up collaborations. Kristiina Kyrklund presented on development of the Hirschsprung Disease guideline, that is nearly completed and due to be published by the end of the year.

Gastroenterological Diseases: Jean-Pierre Hugot gave an overview of planned activities within the gastroenterology group and made a proposal to initially focus on polyposis.

Intestinal Failure: This new workstream that is coordinated by Merit Tabbers and Cécile Lambe started their activities in January 2019 when the ERNICA IF expert meeting took place. Merit Tabbers presented the top ten research topics in the field of paediatric chronic intestinal failure that were identified by the group. These relevant research topics will be addressed by subgroups and will inform future projects. Henrik Arnell will be coordinating the development of an IF-registry and shared some interesting survey results on registries. Two patient representatives from The Netherlands, Sylvia Griffioen and Nadine van Gent, together with Roel Bakx, then presented a new initiative to promote access to specialist care abroad.

Fetal Therapy and CDH: Within the coming year it is planned that this group will start setting up training days for pre-natal assessment for diaphragmatic hernia. The programme was presented by Jan Deprest and Alexandra Benachi. There will be two training sessions a year in Paris/Leuven. The proposal for the development of a Core Outcome Set for CDH was also presented and interested ERNICA members were

invited to participate. Over the coming year continued efforts will be made to set up a prenatal network involving specialists from all ERNICA centres. Lucas Wessel provided an overview of research activities within the CDH/AWD workstream and proposed the development of consensus statements for abdominal wall defects. Beverley Power, patient representative for CDH/AWD, presented the newly established 'Alliance' for international CDH charities. This was promoted as a potential blueprint for other diagnostic groups. The IDEA alliance is a group of patient organisations from around the world who strive to support patients with Congenital Diaphragmatic Hernia, Congenital Hiatus Hernia, Eventration of the Diaphragm, Gastroschisis and Omphalocele and improve outcomes and patient experiences by increasing awareness, improving education and stimulating research: <https://www.idea-alliance.org/>

Beverley also presented the results of a survey she circulated to patient representatives prior to the meeting. The responses provided an insight into the experiences of patient representatives within the network and many ideas were given in regards to strengthening patient involvement. These results will help to inform future ways of working.

The ERNICA clinical exchange programme was presented by Janne Suominen. This training programme will be launched in summer 2019 and will be open for fellows to apply for short stay visits in ERNICA centres. ERNICA will also start hosting educational webinars over the coming year. Dick Tibboel then outlined the roles and responsibilities of the Scientific Committee and promoted research collaborations within ERNICA. Gunnar Aksnes (new coordinator for Standards of Care) closed the meeting with an overview of planned efforts regarding the implementation of ERNICA developed/revised/adopted guidelines within ERNICA centres.

Friday's meeting took place at Padua University Hospital. The morning began with an initial discussion on registry development within the network. This prompted the ERNICA management team to organise a follow-up meeting dedicated to the development of an ERNICA registry (June, 2019). Friday's session also featured a live interactive CPMS simulation session, delivered by Francesco Fascetti Leon and Rebecca Pulvirenti. This provided attendees with the opportunity to practice using the platform on the CPMS training environment. Attendees were also supported with CPMS registrations.

Following this, the group split up into **separate work streams**:

- 1) **Esophageal diseases** –chaired by Benno Ure and Frédéric Gottrand
- 2) **Intestinal Diseases** – chaired by Mikko Pakarinen and Kristiina Kyrklund
- 3) **Intestinal Failure**– chaired by Merit Tabbers and Cécile Lambe
- 4) **Malformations of the diaphragm and abdominal wall** (with a focus on Fetal Therapy) – chaired by Lucas Wessel

Discussions were led by the workstream leads and they will follow up on planned activities with all workstream members. For 1) Esophageal diseases and 3) Intestinal Failure meeting minutes/slides can be found on the ERN Collaborative Platform.



Meeting agenda, powerpoints and minutes:

The meeting agenda, available powerpoint presentations, available sub-group meeting minutes and photographs will be made available on the ERN Collaborative platform.

Please follow the following instructions to access these:

1. Click on this link: <https://webgate.ec.europa.eu/ern/>
2. Log on with your EU log in
3. ERNICA → access network → **'Library tab'** → **'ERNICA Annual Network Meetings'** folder → **'Padua Meeting April 2019'** folder

The ERN Collaborative platform will be the central platform to store ERNICA documentation. The ERNICA management team is aiming to increase the use of this platform. An EU log in is required for access. This EU log in is also required in order to register on the CPMS. Please make contact with the ERNICA project managers if you have any queries about using this platform.

Six key action points for the ERNICA network

1) Do you have an idea for an ERNICA activity? Let the ERNICA project managers know.

If you have a proposal for an ERNICA activity (for example; an e-learning idea/consensus conference/training initiative) please send the ERNICA project managers a clear plan and budget proposal. This will be reviewed by the ERNICA management team and a decision will be made in regards to whether or not it can be endorsed and funded by the ERNICA network.

2) Need some project materials translated? Get in touch!

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

Each proposal for translation is assessed on a case by case basis by the ERNICA management team. **If you have any project-related materials that you would like translated please make contact with the ERNICA project managers.**

Please note: We've been informed by the Commission that whilst we are permitted to use this tool, the system is not 100% accurate. We've been told that '*any translation done by the ERNs with this tool on clinical aspects should be considered as not clinically binding*'. In these clinical cases, the tool could be used to aid human translation.

3) Monitoring and Evaluation – Defining disease specific indicators and disease definitions.

The ERN Coordinators working group on monitoring have proposed 18 core (ERN-wide) indicators to monitor the ERNs. Over the coming years, we will be requesting this data from all healthcare centres involved in ERNICA. The frequency of such collection is still being defined. The purpose of this data collection is to help build a quality improvement system, define appropriate outcomes of the ERNs, identify areas of success and potential pitfalls and demonstrate the value of the ERNs, ultimately learning from the experience.

We will also define a set of disease-specific indicators relevant to the ERNICA network so that we can work towards these goals within our network specifically.

A task for workstream leads – We would like you to begin discussions on this within your workstream. As part of this we would also like you to discuss the 'disease definitions' within your workstream. This will provide clarity for those collecting the data.

Tomas Wester, ERNICA vice coordinator is leading on Monitoring and Evaluation of the ERNICA network. If you have any questions do not hesitate to contact Tomas: tomas.wester@sll.se

4) Call for new ERNICA members and affiliated partners – can you help?

We will inform you when we receive more information about the expected call for ERNICA full membership. When we do we invite you to share the information with other centres you think may be interested in applying.

In the meantime, centres from a country without a healthcare provider already involved can apply to become an ‘affiliated partner’ of ERNICA: <https://ern-ernica.eu/news-and-events/news/affiliated-partnership-with-ernica/>

This initiative has been launched to address the problem of geographic coverage.

Are you aware of any healthcare providers who may be interested in applying for affiliated partnership/full membership? Particularly in...**Bulgaria, Greece, Hungary, Luxembourg, Malta, Romania, Slovakia, Slovenia**? Please let the ERNICA project managers know!

5) Dissemination efforts and relevant events – let us know!

Please let the ERNICA project managers know of any relevant meetings, updates and events so that we can consider sharing these on our newsletter and on our other dissemination platforms (social media, website).

Please keep us informed of any presentations you deliver or posters you present on aspects related to ERNICA. We keep track of this as we are required to report to the European Commission on these dissemination efforts at the end of each project year.

6) CPMS use and CPMS panel creation

The CPMS was set up to facilitate the exchange of information and expert knowledge, to ultimately improve the quality of care provided to patients. With this as the goal, we feel it is important that the platform is used and we are here to provide you with any support you may need to do this. We encourage you to register if you haven’t already: <https://cpms.ern-net.eu/login/>

Follow this link for a video on how to get started

<https://webgate.ec.europa.eu/ern/imgs/CPMS%20Getting%20Started.mp4>

If you have any queries please contact Rebecca Pulvirenti, ERNICA’s CPMS helpdesk officer:

cpmshelpdesk@ernica.ern-net.eu

The primary purpose of CPMS is to carry out clinical case discussions with panels of experts. To get this started we would also like to ask the ERNICA workstream leads to take responsibility for creating diagnosis-specific panels within their workstream.

Do you need help with using the CPMS?

The CPMS online training environment allows you to view how the CPMS would work in practice. It also provides you access to user manuals, training videos and webinars. If you would like access to this environment, please email Rebecca. Rebecca can also help with any CPMS-related queries and can provide additional training if required.

Despite not being able to access the CPMS, patient representatives can also access the training environment for learning purposes.

To access the training environment:

- Follow this link <https://cpms-training.ern-net.eu/>
- Click 'To use non-eulogin users, click here (test only)'- (below where it says 'Login via EU login')
- Enter your log in details (which will be provided to you by Rebecca on request)

A reminder: *No real patient information is to be uploaded to the training platform/sent to Rebecca.*

Staying up to date

ERNICA website

Please keep an eye on the ERNICA website for key network updates; <https://ern-ernica.eu/>

ERNICA social media

Twitter [@ernica_ern](https://twitter.com/ernica_ern)

https://twitter.com/ernica_ern

We will be tweeting key network updates, so follow us and keep a look out! Follow us/Retweet us

LinkedIn!

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

Follow us for key network updates!

Points of contact:

You can contact the ERNICA project managers for ERNICA-related queries:



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CPMS support

Please email **Rebecca Pulvirenti** (ERNICA CPMS helpdesk officer) for any queries regarding the CPMS platform: cpmshelpdesk@ernica.ern-net.eu [new email address]

Other relevant points of contact:

IDEA Alliance Website

As mentioned on page 1 the IDEA Alliance website is now live: <https://www.idea-alliance.org/>

If you identify any papers or information that you consider to be relevant for the website, please email idea@cdhuk.org.uk

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