



1. New Members in the Advisory Board

At the end of May we approached several persons and entities asking them if they would be interested in either becoming a member of the Advisory Board of ERN-LUNG or a stakeholder. We are happy to inform you that we could win three persons for our Advisory Board, namely:

Ingeborg Beunders from Central and Eastern Europe IPF patients' network (CIPFAPANET)

Stephen Holgate from Academia Europaea

Ana Rath from Orphanet

Welcome to the Advisory Board of ERN-LUNG!

2. Questionnaire about "Ongoing Clinical Research"

The Functional Committee "Research and Clinical Trials Committee" (leader: Isabelle Fajac) prepared a questionnaire about "Ongoing Clinical Research" which was put into "SurveyMonkey" by the Network Coordination Team in Frankfurt (special thanks to Olivia).

SurveyMonkey

Preview & Test

ERN-LUNG- Ongoing clinical research

1. Research organisation and facility

Dear Core Network Coordinators and ERN-LUNG Members,

As discussed during the ERN-LUNG kick-off meeting in Frankfurt in April, you will find below a questionnaire intended to get an overview of ongoing research activities in the network. It will allow the network to identify gaps of knowledge and design a plan to develop future ERN-LUNG research activities. All the information below is about your centre's activities within the area of this specific Core Network. Please do not give any confidential information in your answers. In any case, be assured that no individual information will be divulged outside the network. If you belong with more than one Core Network, please fill in appropriate number of questionnaires.

Please make sure to fill in appropriate number of questionnaires corresponding to the number of Core Networks you belong with!

* 1. Address

Name of ERN-LUNG member

Core Network

Healthcare Provider (HCP)

The survey was sent to the 60 official leaders and deputies of each HCP asking them to distribute it to the respective Core Networks (if the HCP is part of several CNs).

Almost 100 questionnaires were submitted! The data will be evaluated by the Functional Committee in the next weeks.



3. Grant Agreement for 1st Year Finally Signed by EU

Although the project ERN-LUNG started officially on March 1 this year we did not have a signed “Specific Grant Agreement” (SGA) until the end of June. We hope to receive the first pre-financing payment soon and will then contact all those who joined the Kick-off meeting in Frankfurt giving further information about how their travel costs can be reimbursed. Thank you for the patience you had.

4. Online Expert Advice Tool (software) for ERN-LUNG

ERN-LUNG will need to establish tools and means for cross border care. One possible step in that direction would be the roll-out of an expert advice system similar to ECORN-CF.*)

Our “Medical Informatics Group” at the University Hospital Frankfurt started with writing a software program for an online expert advice tool for ERN-LUNG. It will certainly still take a couple of months of work but finally we hope to provide you with a tool that can be used for each disease in each language.

*) ECORN-CF: In 2007 the University Hospital Frankfurt started a similar tool for Cystic Fibrosis called ECORN-CF. If you want to learn more about ECORN-CF you can have a look at this paper : D'Alquen D, De Boeck K, Bradley J, Vávrová V, Dembski B, Wagner TO, Pfalz A, Hebestreit H. Quality assessment of expert answers to lay questions about cystic fibrosis from various language zones in Europe: the ECORN-CF project:

<https://cloud.ern-lung.eu/index.php/s/KLMGhWyb8zta0Z>

5. Videos about ERNs from EU

To illustrate the potential of the ERNs the EU has produced **four video reportages, with real-life case studies:**

- of an Italian patient with bone disorders
- a Dutch heart patient
- a Spanish girl who underwent a transplantation and
- a French representative of kidney patients.

Telling their personal stories, we can show different aspects of the ERNs.

A fifth, longer video reportage, brings the full story of the European Reference Networks, with the views of doctors, patients and European Commissioner Vytenis Andriukaitis.

Watch all the videos here: https://ec.europa.eu/health/ern/videos_en, and feel free to promote them through your websites, newsletters, social media channels, stakeholder networks, etc.



6. “Basecamp”- Project Management Tool

The Network Coordination Team in Frankfurt decided to work with “Basecamp” which is a project management tool supposed to help us a lot in dealing with all the work (and hopefully in time).

All those who are responsible for deliverables within the project (e.g. Core Network Leader and Functional Committee Leaders) already received an invitation to join the “Basecamp” of ERN-LUNG. Since Olivia was kind enough to put all input into “Basecamp” she is now the expert in the field and tells us about the functionalities of Basecamp:

What are the basic tools of Basecamp?

Olivia: “There are six different basic tools: The campfire, which is basically a group chat, which you can use to share links and files and have conversations; the message board, which is good for more permanent conversations, to-do-lists, which are for keeping track of all the tasks that need to be completed, the schedule, to keep track of all the important meetings and events, and to-dos with do-dates, which will also appear in the schedule; automatic check-ins, which are short questions asked by Basecamp on a regular basis; Docs & files, where you can write longer documents and upload important files you need.”



What is the most important feature of Basecamp in your opinion?

Olivia: “I guess the most important feature is the to-do-system, where we are in the process of setting up to-dos for each project deliverable with deadlines and assigning them to people. You will get an email notification once you’ve been assigned and these dates will also appear on your calendar. The calendar is a great feature because it allows you to take a look at what’s going on (save and add different events, make them a multi-day event), by the way. Once you’ve completed a to-do, you can click the checkbox next to the to-do to mark it as complete.”

What other advantages to you see?

Olivia: “We are working with Basecamp now basically to keep track of the project and keep infos in different messages and threads so that you are not tracking things down through a group of people by email.”



7. Activities of the ERN-Coordinators (by Thomas Wagner)

There are numerous activities going on at the level of the ERN Coordinators which mostly are activities of the ERN team working at the European Commission (EC) and some activities driven by one or more of the ERN Coordinators.

The ERN Coordination team led by Enrique Terol has been very active from the start and has proposed quite a number of activities, most of them trying of getting the many voices coming from the ERN Coordinators sorted out.

The ERN IT platform may serve as an example: This IT platform is far from being ready. There is a file management system but ERN-LUNG e.g. has not yet started using it. The IT platform will eventually serve as the interface to allow patient data exchange for cross border consultations but this feature is not ready yet. The IT company developing this platform has a contract where all interactions with input, amendments, changes, etc. have to be with the EC and not with the ERNs or the ERN coordinators. The expectations and needs of the ERNs are diverse and it is easy to understand that the EC wants to avoid the IT company serving to many masters. The EC though is aware of the fact that the IT platform eventually will have to fit to the needs of the ERNs. This is why they have started setting up an IT working group. This WG will funnel all proposals and will work as the ERN EC IT interface.

The ERN Coordinators have met several times. The last meeting of the BOARD OF COORDINATORS (ERN-BC) was held in BRUSSELS 21 JUNE 2017. A protocol is available. The major topics were:

1. Governance of the ERN-BC and nomination of the leading structure
There will be a chair (Maurizio Scarpa) and a vice chair
2. Organization of ERN Working groups
I have voted to have ERN-LUNG included in the IT and in the Research Working groups. Working groups (and their resp. leaders) will be:
 - IT and data sharing: Chair Ruth Landestein, ERNPaedcan
Members: ERKNET, EPICARE, BONDERN, TRANSPLANTCHILD, EURONMD, **ERN-LUNG**, ERNSKIN, METABERN, ERNRITA, ITHACA, RARE LIVER, VASCERN. ERNEYE
 - Research: Chair: Eduardo Lopez Granados, Transplantchild
Members: EURACAN, ERKNET, **ERN-LUNG**, METABERN, ERNPEDCAN, BONDERN, ENDOERN, RECONNET, ERNSKIN, ERNRITA, VASCERN, EUROBLOODNET, GENTURIS, GUARD-HEART, ERNEYE
 - Knowledge generation: Training, education, capacity building; guidelines development
 - *Data protection, ethics, informed consent*
 - *Crossborder healthcare (organisation, provision etc)*
 - *Brexit*
 - *Monitoring, assessment and quality improvement*



7. Continued... Activities of the ERN-Coordinators

We will have to see how much work will be done in these working groups. My impression is that we have enough work trying to get our ERNs going but if we can avoid doing things over and over again these working groups might help. We will see whether the IT Working group will be able to manage support for the CEF call INEA (see below).

3. Discussion on the CEF call INEA
A call is out to ask for support with IT implementation. Sounds like we are not ready for this, since the IT platform is not ready yet but the coordinators have proposed to submit similar applications on behalf of all ERNs.
4. Discussion on the EJP
There has been a meeting held in Paris on the topic of the European Joint program where the ERNs hope to participate and achieve some research funding. A report on that meeting is pending.
5. Next call for Members
The group of ERN coordinators have expressed that they think it is necessary to stick to the rules established for the first call and it has been decided to create a task force to liaise with the Board of Member states.

One recent activity of the ERN Coordination team is an invitation addressed to the hospital directors of the ERN coordinators. This means they hope that the medical and the administrative directors of my University Hospital would be willing to attend a one-day meeting in Brussels to learn how to better support me in my function as a ERN Coordinator.

This seems to be a good example though for the whole range of activities: all of them seem worthwhile but I do not see how to attend and address all of these many activities. I hope that the protocols and the communication will be good enough to stay up-to date and not miss anything important.



European
Reference
Network

for rare or low prevalence
complex diseases



Network
Respiratory Diseases
(ERN-LUNG)

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