



Message from the Coordinator

The first year of ERN-LUNG is almost coming to an end and we still have not had our first CROSS BORDER CONSULTATION.

We have been building the necessary infrastructure to offer services to patients and now we should try to use our capabilities. The European Commission has provided us with a Computerized Patient Management System (CPMS) and we should start using it.

What kind of patients or questions should we discuss in such a CROSS BORDER CONSULTATION?

I remember having seen a patient, a well-known and successful bicycle professional (Tour de France and such events), who after experiencing a significant decrease in his working ability was diagnosed to have severe pulmonary emboli with secondary pulmonary hypertension. The questions of whether he would be able to get back to the racing business and when and with or without continued treatment were not so trivial to me. So I asked the Leads of the Pulmonary Hypertension Core Network and they were able to recommend a “real” specialist to this patient with specific experience with pulmonary embolism in highest level athletic competition.

That might have been a good candidate to be discussed in a CROSS BORDER CONSULTATION.

The reason for this message is to ask you whether you have a patient who you would like to discuss in a CROSS BORDER CONSULTATION? If so, please give us a short info about the patient and the problem and – if you like to – give us some idea of whom you would like to have taking part in such a conference?

If you are not sure, no worries: We have to practice, we have to learn how to use this tool, and we really should get started because this kind of CROSS BORDER EXCHANGE is one of the major purposes of ERN-LUNG!

1. 2nd ERN-LUNG Board Meeting March 7&8, 2018

The Network Coordination Team would like to again remind you of our Board Meeting, which is coming up on March 7&8, 2018. We will be delighted to welcome many participants in Frankfurt, who are engaged in ERN-LUNG.

Please be sure to register online under following link:

<https://www.surveymonkey.de/r/QH9VTSL>



2. New Supporting Partners

The ERN-LUNG Core Networks have been very busy lately with accepting new Supporting Partners into their Core Networks.

We are happy to announce that the Core Network PCD welcomes two new supporting partners to their group: Panayiotis Yiallourous from the Makarios Hospital and Cyprus Institute of Neurology and Genetics, Cyprus, and Sandra Rovira from the University Hospital Vall d'Hebron, Barcelona, Spain.

The Core group Mesothelioma has also welcomed two new Supporting Partners to their Core Network: Arnaud Scherpereel from CHRU Lille, France, and Dean Fennell from the University of Leicester/University Hospitals of Leicester NHS Trust, UK.

And last, but not least, the AATD Core Network has accepted two new Supporting Partners into their Core Network: Gerry McElvany from Beaumont Hospital Dublin, Ireland, and Robert Bals from the University Hospital Saarland in Germany.

3. Definition of “Supporting Partner” (ERN-LUNG specific)

Since there have been frequent questions regarding “Supporting Partners” of ERN-LUNG lately, we would like to give you a general outline of useful facts:

First of all, the candidate has to be supported either by a Core Network (CN) or by a Functional Committee (FC) or by the Network Coordination Team (NCT).

Furthermore, the following points apply:

- a) They did not go through the European Commission application process
- b) They are not endorsed by their national authorities;
- c) They do not need to fulfil the minimum criteria of the CN they want to join;
- d) They do not have voting rights;
- e) If full members want to be involved in other Core Networks than those they have been endorsed and accepted for as full members, they can ask the resp. CN for acceptance as ‘supporting partners’ in which case they have to nominate an extra person to take this role.
- f) It is up to ERN-LUNG to involve supporting partners to foster excellence in rare respiratory diseases across Europe.



4. BaseCamp

The first year of ERN-LUNG is slowly but surely coming to an end and we still have quite a bit of pending tasks that still need to be completed. Though we know that a lot of members are still “struggling” to get acquainted with our Project Management tool BaseCamp, and we understand that everyone on ERN-LUNG is quite tied up with their many work related obligations, it must be said that more and more members have managed to make do with the tool and we appreciate this very much.

In order to get an overview on what’s cooking, we would like to ask you to please log in and click the button “Docs & Files”, which contains all the deliverables we nonetheless managed to complete and report to the EC thanks to your contributions and input, despite the initial difficulties encountered with the project implementation. Currently there are 9 unfinished tasks (deliverables), that are mainly assigned to the respective ERN-LUNG members and we are convinced, that we will be able to manage to complete all tasks by the end of year 1.

5. Meeting the European Commissioner for Health and Food Safety Vytenis Andriukaitis

Earlier this month some ERN Coordinators had a chance to meet the European Health Commissioner Vytenis Andriukaitis who has always been very supportive for the ERNs. The meeting took place in Berlin and together with ERN-LUNG there were four different ERNs represented. Doris Staab and Carsten Schwarz from the Berlin Charité (Christiane Herzog CF Centre Berlin) agreed to represent and present on behalf of ERN-LUNG. The general impression was that the Commissioner is enthusiastic about ERN. From the ERNs a clear message was delivered: The participating Health Care Providers need some financial support if one really wants the ERNs to become a lively and helpful infrastructure. No promises were made but at least all agreed that this discussion has to go on and has to lead to some results.



6. Endorsement of ERC ARIANE IPF metaregistry

The ERS is funding a Research Collaboration which aims to establish a metaregistry for all existing European Pulmonary Fibrosis Registries. The project is called ERC ARIANE which is coordinated by Vincent Cottin, Lyon, and Bruno Crestani, Paris. At the last ERS conference Antje Prasse and Michael Kreuter, ILD Core Network Leaders have learned about this project and contacted Vincent in order to coordinate ERS and ERN activities in this field. Participants had a meeting at ERS headquarter at Lausanne and got informed about current activities and schedules of ERS-ERC ARIANE-IPF. Antje Prasse and Michael Kreuter both think that ERS ERC ARIANE-IPF is a well-organized project ready to start beginning 2018 which should be supported by ERN-LUNG: "We think that it makes a lot of sense to combine ERS and ERN efforts and with regards to the outlined metaregistry and the ERS task force appears to be quite advanced. Of note, there is a substantial overlap of people involved in this project on ERS side and ERN-lung ILD-group side. So, we would like to join and support the ERS ERC-ARIANE-ILD as ERN-LUNG ILD-group and kindly ask for your endorsement as the coordinator of ERS-LUNG."

7. ERN-LUNG Specific Grant Agreement for Year 2

The network coordination team has submitted a grant proposal for the budget of year 2 for ERN-LUNG. The degree of freedom was low because of the fact that we had to stick to the five-year plan and its objectives. The budget is almost the same as during the first year since the EU contribution has remained at a maximum of 200.000€.

This is a very short summary:

ERN-LUNG's Year 2 programme will now focus on using the established structures to offer services to patients and medical professionals throughout the European Union. ERN-LUNG will start using and improving the CPMS to the best of patients and colleagues. In accordance with the five-year plan the Network will add more supporting partners, associated partners and – if the next call should be published during this year – to add more members to the network as to cover all Member States of the EU. The network will continue to seek funding possibilities to improve the quality of care offered in the area of rare diseases of the respiratory system.



6. European Joint Program (EJP)

The next rare disease research program is being written by a large writing group. ERN-LUNG has volunteered to contribute to Pillar 2 (registries) and Pillar 4 (clinical trial networks). The scope of the project (with a possible volume of 50 to 55 Million €) is summarized in the call <http://ec.europa.eu/research/participants/portal/desktop/en/opportunities/h2020/topics/sc1-bhc-04-2018.html>

The drafting process seems to be extremely complex with so many people involved that it is hard to see what ERN-LUNG really will be able to do within this huge activity.

Here is a short passage from there:

“The research and innovation programme should encompass various aspects of rare diseases, such as development of new means for diagnosis and screening, improved annotation and interpretation of genetic variants, functional analysis of candidate variants, animal and cellular models for human conditions, natural history studies with improved, scalable and participants-centred registries, preclinical research for new therapies, development of new methods for clinical trials, clinical trials for new and/or repurposed therapies including advanced therapies, discovery and validation of robust biomarkers, basic research into pathomechanisms and molecular pathways, social, economic and healthcare oriented studies including burden of disease studies, and health services research to improve patient outcomes and healthcare systems. The calls should be implemented on the basis of the standards and good practice for calls implemented under ERA-NET Cofund actions (international peer review, Horizon 2020 evaluation criteria, proposal selection according to the ranking list etc.)”.



European
Reference
Network
for rare or low prevalence
complex diseases

Network
Respiratory Diseases
(ERN-LUNG)

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