

ERN-LUNG AT A GLANCE

WORD FROM THE COORDINATOR

While we spend so much time writing proposals and reports and deliverables, we must not forget the aims and vision of ERN-LUNG: to provide valuable cross-border services to patients with rare diseases and to their care teams, and be the European knowledge hub and service and information platform for patients affected by rare diseases of the respiratory system. Improving our grant writing skills is nice and can hopefully be achieved by the Network Coordination Team. But it is far more important to get better with improving care for patients with rare respiratory diseases across Europe and this will only be reached by you and will not happen without your enthusiasm and help.

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DON'T FORGET TO..

- * Send the NCT any content (interesting news in the field, latest research, statistics, infographics, upcoming events, etc) to be added to our social media pages on a regular basis, in order to grow our online presence.
- * Complete the "ERN-LUNG member participation" [survey](#) to let us know how we can improve internal communication within ERN-LUNG, and incentivize members to participate more in the network's activities.
- * Define the relevant clinical outcome measures and minimal criteria for your Core Network, and provide an overview of the numbers reached in 2017 for annual monitoring.

CONNECT IN PARIS

We look forward to meeting many of you in Paris, France at the ERS International Congress on 15-19 September, at the following events (open to all network members):



MON Sept 17, 08h30 to 10h30: ERN-LUNG Symposium

MON Sept 17, 12h30 to 14h00: CN Representatives meet ePAGs

TUE Sept 18, 13h00 to 15h00: Medical Steering Committee meeting

MEMBERS INFORMATION

The Network Coordination Team (NCT) has updated the membership list, members' contact details and Core Network (CN) / Functional Committee (FC) affiliation. Please find this information [here](#). Any member who does not appear on this list or has a classification query may contact the NCT.

WELCOME TO

The ILD Core welcomes new Supporting Partners Dr. Jacobo Sellares Torres from the Hospital Clinic University of Barcelona and Prof. Matthias Giese from the Dr. von Hauner Children's Hospital Munich. The PH Core welcomes Dr. Joern Carlsen from the Rigshospitalet University Hospital Copenhagen. Please note the updated [Standard Operating Procedures](#) on how to accept Supporting Partners.



FOLLOW ERN-LUNG ONLINE

 <https://ern-lung.eu>

 [/rarelungdiseases](#)

 [/ErnLung](#)

MESSAGES FROM THE EUROPEAN COMMISSION

NEW CALL FOR PROPOSALS

A new *call* for ERNs to apply to the Connecting European Facilities Fund (CEF) was published on 28 June 2018, with a submission deadline of 22 September 2018. The grant will fund activities related to the effective use of the Clinical Patient Management System (CPMS) and other IT support for 2019-2020. A maximum amount of €210,000 is available for each ERN (the co-financing element is 25%). The goal is to ensure adequate and efficient use of the ERN Core Services such as CPMS and the ERN Collaborative Platform by members for the ERNs. In response to this, ERN-LUNG is submitting a proposal for the new funding period of the IT-Helpdesk.

EDUCATIONAL WEBINAR SERIES FOR ERN STAKEHOLDERS ORGANIZED BY RD-CONNECT

RD-Connect enables scientists and clinicians around the world to analyze genomics data and share them with other researchers. By making data accessible beyond the usual institutional and national boundaries, RD-Connect speeds up research, diagnosis and therapy development to improve the lives of patients with rare diseases. As part of a close working relationship with EURO-NMD, RD-Connect is organizing a series of highly relevant and informative webinars for researchers that are part of an ERN. Find out more about the upcoming webinars and how you can register [here](#).

OUTCOME OF ERN COORDINATORS GROUP MEETING, 25 JUNE 2018

Prof Maurizio Scarpa (MetabERN, IT) was thanked by all for all his work for the last year as Chair of the ERN CG and Prof. Franz Schaefer (ERKNet, DE) was welcomed as the new Chair. A major issue was planning for UK withdrawal from the EU and the implications this might have, in particular for UK Coordinators and the 114 NHS Trusts involved in ERNs, who deal with an estimated 200,000 patients with rare diseases or complex conditions. The UK ERN Coordinators were asked by the EC to begin plans for switching the coordination function to another Health Care Provider (HCP) within their network in an EU Member State.

The ERN CG has seven Working Groups, each chaired by a Coordinator, which deal with issues of a transversal nature. The Working Group on Conflict of Interest presented their near-final report. A major issue is that the Board of Member States for ERNs regards ERN collaboration with industry as a risk, whilst the ERN Coordinators regard this as a rather outdated view. Many Coordinators and their HCPs have considerable experience of collaborating with industry in the correct way and see it as vital both to the sustainability of the ERNs and to identify innovative treatments for patients with rare diseases.

The Working Groups of the ERN CG and the Board of Member States for ERNs have merged and the two groups now work collectively on the continuous monitoring process. A set of 18 core indicators applicable to all ERNs has been agreed upon. However, further work will need to be done at individual ERN level as all ERNs need to identify key performance indicators specific to their ERN in the next phase of this work.

Finally, the EC has set up a new Advisory Group of ERN Coordinators or their representatives. They are planning a large publicity campaign to raise awareness of the ERNs and how they can benefit patients. They are looking for stories from patients (or carers of patients) whose case has been discussed on CPMS.

ERN-LUNG ACTIVITY HIGHLIGHTS

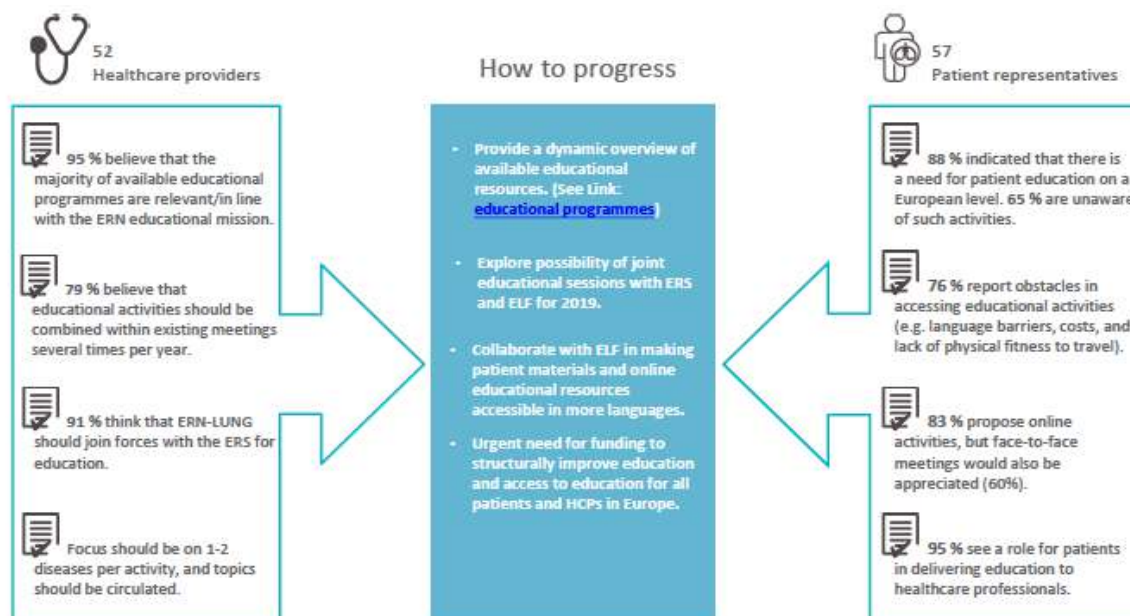
SPECIFIC GRANT AGREEMENT (SGA) APPLICATION UPDATE

The Specific Grant Agreement (SGA) application for years 3 to 5 of ERN-LUNG has been submitted. We are getting better: the final version has been ready and uploaded more than 24 hours ahead of the deadline! We cannot do much now but hope that the evaluators accept the proposal as it is and don't ask for too many changes. We were able to reconcile some of the comments concerning the SGA for year 2 that has not yet been signed.

The timing is a little complicated: We have to submit the proposal for years 3 to 5 before having a signed contract for year 2, although we are already in the middle of Month 7 of this funding period. It is only a few weeks ago that we – for the first time – got some feedback on the deliverables of year 1. This means that at the very moment three balls have to be kept in the air at the same time: a) Revise the deliverables of year 1 according to feedback from CHAFAEA b) Amend the SGA for year 2 according to requests and c) Get the SGA for years 3 to 5 ready.

EDUCATIONAL ACTIVITIES SURVEY OUTCOME

A survey was sent to ERN-LUNG HCPs and patients to gauge the extent of awareness of existing educational programmes, with the objectives of understanding the current educational needs and further developing educational programmes of interest to the respiratory community. The following infographic conveys the main results of the survey. You can find more details [here](#).



PATIENT PASSPORT

The nCF-BE Core Network has created a « patient passport » to promote guidelines-concordant care for bronchiectasis patients, with the objective of generating added value for patients and patient representatives. The Core Lead James Chalmers has provided the current print version of the passport, and intends for it to be developed further and adapted to local requirements. The ERS and other European organizations have already endorsed this nice patient aid. For more information on this, we encourage you to get in touch with [James Chalmers](#).

TECHNICAL ASSESSMENT AND AUDIT BY ANDALUSIAN AGENCY FOR HEALTHCARE QUALITY (ACSA)

The Andalusian Agency for Healthcare Quality (ACSA) has been selected as an Independent Assessment Body (IAB) to perform the technical assessment of a sample of ERN members' applications received under the framework of the call for Interest for European Reference Networks (March-June 2016). The choice of centers has been done independently by the EC, taking into account the size of the network and the country distribution. The ERN-LUNG HCPs that have been selected for this year's assessment are 1) Antwerp University Hospital, Belgium 2) Meyer Children's Hospital Florence, Italy 3) University Medical Center Utrecht, Netherlands 4) Hospital Clinic de Barcelona, Spain. The HCPs have so far been successful in keeping up with the timeline and instructions, and we are confident that they will have positive reports in each phase of the assessment.

WHAT TO EXPECT

CROSS-BORDER CARE GUIDELINES

We would like to collect information regarding the existence of Standard Operating Procedures, guidelines and bilateral agreements for cross-border referral and clinical care pathways, with the intention to publish it on the ERN-LUNG website. This information will be collected through a questionnaire that will shortly be sent to all ERN-LUNG HCP Representatives and Patient Representatives, in order to learn whether there is a gap between the understanding of HCPs and patients.

OUTCOME OF MEETING WITH EUROPEAN RESPIRATORY SOCIETY (ERS) MANAGEMENT, 4 JULY 2018

Thomas Wagner and Marc Humbert had a very fruitful meeting with Tobias Welte, President Elect of the ERS, together with Celine Genton, Head of Scientific Activities of the ERS, and Werner Bill, Executive Director of the ERS. The most important result of the meeting is that the ERS is willing to take responsibility in making our network a sustainable joint activity of the ERS and ERN-LUNG. This will not only help us meet our financial needs, but being fully interconnected with the ERS and being accepted as an important partner in the field of respiratory diseases cannot be emphasized enough. ERN-LUNG plans to cooperate closely with the ERS in preparing its next grant applications and this meeting has confirmed our belief that the ERS is the ideal partner for ERN-LUNG.



SAVE THE DATES!

- ERS International Congress, Paris, September 17-19, 2018
- "Working with a customized data set in CPMS" Webinar, September 18, 2018
- "How to set up a Clinical Trials Network" Webinar, November 20, 2018
- 4th Conference on European Reference Networks, Brussels, November 21-22, 2018

UPCOMING EVENTS