

WORD FROM THE COORDINATOR

After almost two years of ERN-LUNG, we are still constantly growing. We are happy to welcome new partners from EU Member States where no centers of expertise have had a chance to join us in the preparation phase. We have such "Affiliate Partners" now from Latvia (n=3) and from Austria (n=3). We keep receiving letters of interest from expert centres throughout the EU to become "Supporting Partners" and expect a new wave of Members as soon as the new call for Membership Applications is out (announced for April this year).

The ERN-LUNG Coordinator together with the Network Coordination Team are so busy liaising with the European Commission (EC) and providing them with reports, deliverables and milestones, grant agreements and other applications, that we have little time to really invest into the content of ERN-LUNG, in activities that show the added value of being organized into a large network and of being a member of ERN-LUNG. But this is exactly what the EC had in mind when designing the ERNs: The Coordinators and their teams are intended to be the facilitator for the Members who are the real assets, who are the ones to drive the evolution and provide the services. Thus, take this as a little reminder that we expect you to bring your ideas and propose them to the other members when you come to our next board meeting – We need you!

Prof. Dr. T.O.F. Wagner

University Hospital Frankfurt, Germany
Editor, ERN-LUNG Newsletter
Email: t.wagner@em.uni-frankfurt.de

ERN-LUNG AT A GLANCE

WELCOME TO




The MSTO Core welcomes Prof. Michael Thomas from the Thoraxklinik University Hospital Heidelberg, Germany as an ERN-LUNG Supporting Partner.

IT-HELPPDESK

The IT-Helpdesk is operational and if needed you may get in contact with Niels Tegtbauer of the Medical Informatics Group (MIG) at Universitätsklinikum Frankfurt. He will help you with registration as a Clinical Patient Management System (CPMS) user and he will be able to support your IT department to clarify technical issues when trying to upload patient data, documents, or X-rays etc. He may be reached at tegtbauer@med.uni-frankfurt.de.



FOLLOW ERN-LUNG ONLINE

-  <https://ern-lung.eu>
-  [/rarelungdiseases](#)
-  [/ErnLung](#)



SAVE THE DATES!

- *Webinar on CPMS Version 17.0 – New features and improvements*
14:00 CET, February 19, 2019
- *International rare disease day*
February 28, 2019
- *8th international meeting on pulmonary rare diseases and orphan drugs*
Milan, March 1-2, 2019
- *ERN-LUNG Annual Board Meeting*
Frankfurt, March 13-14, 2019

ERN-LUNG ACTIVITIES

ERN-LUNG eSUPPORT – SECOND CEF APPLICATION SUBMITTED

The Connecting European Facility (CEF) is a funding programme of the Europe 2020 Strategy in the sectors of transport, energy and telecommunications. ERN-LUNG had won a grant within the telecom call to fund the IT-Helpdesk to ensure adequate and efficient use of the ERN Core Services such as Clinical Patient Management System (CPMS) and ERN Collaborative Platform (ECP). By the end of 2018, ERN-LUNG submitted a second grant application with the acronym “ERN-LUNG eSupport”. This grant will continue the aforementioned support and in addition, will help ERN-LUNG in establishing e-Learning and e-Teaching tools for patients and health care professionals. This application has been submitted together with the European Respiratory Society (ERS), which was not trivial since the ERS headquarter is situated in Switzerland, i.e. outside the EU. Project partners in this application are:

- i. Karin Winter-de Groot , Utrecht, The Netherlands (Core network CF)
- ii. Nazzareno Galie, Bologna, Italy (Core Network PH)
- iii. Antje Prasse, Hannover, Germany (Core Network ILD)

BIOBANKS SURVEY UNDERWAY

Thanks to your support, we were able to finalize most surveys planned during Year 2 and only one more is currently being run. We want to know which biobanks already exist in the rare disease fields covered by ERN-LUNG. Even if you are not primarily involved but know of any biobank where tissue or other bio-samples are stored, please let us know so we can get in contact and hopefully come up with a comprehensive list of biobanks concerning our areas of interest.

PATIENT INVOLVEMENT IN ERN-LUNG

ERN-LUNG has been devised as a patient centered network. Alas, for the time being the network itself has not delivered many services to patients yet. This lies in the nature of our structure where the Core Networks are the main interface between patients and the experts. If we want to participate in a patient satisfaction survey, we certainly will have to organize this via our Core Networks, ideally all Core Networks of ERN-LUNG. There are many cross-border interactions going on in the respective fields of the Core Networks and we therefore have to ask the patients of the Core Networks about their expectations and their experience. We have volunteered to be part of a pilot survey being developed by EURORDIS to start activities in this direction. For those interested in the European and national perspectives of Rare Disease awareness, you may find the Rare Barometer Voices survey [here](#). The objectives of the pilot will be :

- i. Measure the level of patient satisfaction with a) the care received from expert centres that are members of the ERNs and b) the virtual consultation services, targeting patients whose case has been discussed.
- ii. Define the dimensions to be measured and the best tools/questionnaires to measure patient satisfaction.
- iii. Understand how best to operationalize the satisfaction measures and what scores can be used across ERNs and Member States, exploring the limits and challenges of administering the surveys, response rate, data analysis, robustness of the results etc.)
- iv. Provide insights into how to implement this on a large scale in terms of resources, time and budget.

IN CASE YOU MISSED

ERN-LUNG CLINICAL TRIALS NETWORK DEVELOPMENT WEBINAR

The ERN-LUNG Research and Clinical Trials Functional Committee, along with the Network Coordination Team (NCT), successfully organized the network's first educational webinar on how to setup a Clinical Trials Network (CTN), illustrating the example of the pre-existing well-established CTN of the European Cystic Fibrosis Society, on 20 November 2018. The webinar was attended by about 25 participants, and you may access the recorded video and slides [here](#).

ERN-LUNG AT ERS INTERNATIONAL CONGRESS, SEPTEMBER 2018

Many ERN-LUNG members re-connected at the annual ERS International Congress in Paris on 17-18 September 2018. At the Medical Steering Committee meeting, members, along with the Network Coordination Team, reviewed the progress made by the Core Networks and Functional Committees in Year 1, and discussed the network's objectives and priorities for the upcoming year. The MSC meeting report can be found [here](#). At the ePAGs patient representatives meeting, the procedure for the election of Core Network patient representatives was outlined, and ERN-LUNG was confirmed by EURORDIS as one of four ERNs to participate in the pilot project to test the Rare Barometer Voices survey as a patient satisfaction monitoring tool.

4TH CONFERENCE ON EUROPEAN REFERENCE NETWORKS « ERNs IN ACTION » NOVEMBER 2018



The 4th ERNs conference was held in Brussels on 21-22 November 2018. ERN-LUNG was represented by 9 delegates. The conference highlighted the fact that ERNs are entering the next stage of their life cycle: the deployment phase. The main clinical and organizational outcomes of the networks were presented, and the main challenges and opportunities for the improvement of the functioning, management and sustainability of the networks were identified. Some key topics covered included: geographical expansion of ERNs and closure of expertise gaps, integration of ERNs into national healthcare systems, funding in the short and longer term to ensure sustainability, and raising the visibility and awareness of ERNs.

As part of an ERN awareness campaign, a new set of communication products (video clip/flyer/brochure) have been developed by the EC, targeted to hospitals, patients and doctors alike, which may be disseminated by ERN members mainly to explain the functioning of ERNs and the CPMS principles to them. Links to these communication products, as well as the conference presentations, videos and final summary reports can be found [here](#). For a more general presentation of the ERN initiative (towards a broader audience), you can still use the videos and publications which were produced earlier and are available in the communication toolkit [webpage](#).

MESSAGES FROM THE EUROPEAN COMMISSION

CLINICAL PATIENT MANAGEMENT SYSTEM (CPMS) UPDATE

You may find the latest ERN Status Report [here](#), illustrating the activity of ERN members on CPMS as well as the ERN Collaborative Platform (ECP). At the moment, only 35 ERN-LUNG members are authorized CPMS users, and to our knowledge, besides dummy panels, no real Panels have been created and used for patient consultations on CPMS. Every member is encouraged to use the system to enroll patients, discuss cases via panels, and schedule meetings within the system. If you need any help, don't hesitate to contact us!

We would like to emphasize here that the use of CPMS continues to be one of the main parameters by which ERNs will be evaluated. The lack of usage will lead to de-activation of the accounts of inactive users in the short run, and eventually termination of insufficiently operating and performing ERNs in the long run. As keeping the CPMS accounts open for all users goes with a cost, EC Europa are considering de-activating the accounts of those users that have been inactive since at least one year on 28 February 2019. Reminders will be sent to the users concerned one month and one week before the accounts are de-activated. Should there be a need to re-activate a de-activated user account, the ERN Coordinator or users with administrator rights can unlock this user in SAAS to activate his or her CPMS account again.

A new version of CPMS (Vers.17) will be released at the beginning of March, including new tools for scheduling meetings and agenda settings, generating a PDF of the patient consultation form, assessing the usefulness of CPMS and satisfaction of panel participants, to name a few. A dedicated webinar to introduce CPMS 17.0 will be held for all ERN Members on WebeX on 19 February 2019. You may find details of the webinar, information regarding WebeX as well as the list of new CPMS features and improvements [here](#).

CONTINUOUS MONITORING AND ASSESSMENT OF ERNs

The first phase of the ERN monitoring system prepared by the ERN Continuous Monitoring working group was approved by the ERN Board in September 2018 and presented at the 4th ERN Conference in November 2018. The final version of the 18 indicators can be found [here](#). Using these indicators, the European Commission has now established a Monitoring System for ERNs. Starting from February 2019, we will have to collect and retrospectively input data for the first two years and then we will have to continue to do so for the upcoming years.

It is important to emphasize that ERNs could be terminated by the European Commission if they have not achieved the common ERN indicators. Similarly, membership of a specific ERN may be terminated if a member centre has not achieved the specific indicators. It may also be important and relevant to note that many of the common and specific indicators focus on the use of the Clinical Patient Management System (CPMS) by ERNs to discuss patients.