

ERN-LUNG AT A GLANCE

ERN – LUNG NEWSLETTER

WORD FROM THE COORDINATOR

The upcoming ERN-LUNG and European Respiratory Society (ERS) joint symposium together with the ERN-LUNG Medical Steering Committee Meeting (open to all Members, Affiliated Partners and Supporting Partners) in Madrid on October 1st will be the ERN-LUNG highlights of the coming weeks. We expect you all to come and join us in lively discussions. The symposium will show-case some of the most important issues and principles of our networking. Isabelle Fajac (Paris) will give an overview on “How to accelerate bringing new drugs to patients: role of clinical trials networks” and this will be seconded by Laura Fregonese (Amsterdam) who for a long time had been involved in the Alpha-1-AntiTrypsin Deficiency (AATD) registry before moving to the European Medicines Agency. She will talk on “How to assist bringing new drugs to patients: role of the European Medicines Agency”. The pivotal role of patients in our network becomes evident with the talk on “The future of treatment for interstitial lung diseases: the patient’s and physician’s perspective”, which will be presented jointly by Michael Kreuter (Heidelberg) and a patient of his, Klaus Geissler (Bietigheim-Bissingen). Last but not least, we will have Joachim Aerts (Rotterdam) talk on “How to improve diagnosis and care for mesothelioma patients in Europe” which, like the other contributions, will give almost all of us the chance to “learn from the best”. Hope to see you in Madrid!

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NEW ERN-LUNG MEMBERS

In addition to the 60 Full member HCPs, we are now delighted to welcome 12 Affiliated Partners from Austria, Croatia, Estonia, Hungary, Latvia, Lithuania, Malta and Slovakia. We also welcome the new CF Supporting Partner from Poland. You may overview reference centres by country [here](#).

GAP ANALYSIS OF ERN-LUNG GEOGRAPHICAL COVERAGE

The Network Coordination Team (NCT) recently analysed the needs of ERN-LUNG prior to the call for new members to join existing ERNs in order to gather an estimate of the additional HCPs needed in those countries where ERN-LUNG has no representation. This gap analysis showed that 7 countries (in the European Union and EEA) do not have any representation at all. In liaison with ERS, we intend to close these gaps in expertise with further membership in the form of full members, Affiliated Partners, Supporting Partners or National Contact Points.



SAVE THE DATE

Join us for the following sessions at ERS2019 in Madrid on Tuesday, 1st October:

- ERN-LUNG / ERS [Joint Session](#) on Rare Lung Diseases, Tuesday 1st October 08:30 - 10:30
- ERN-LUNG Medical Steering Committee [Meeting](#), Tuesday 1st October 12:00 - 14:00

Please block your calendars for the ERN-LUNG Annual Meeting, taking place in Frankfurt on 26th and 27th February 2020.

ERN-LUNG ACTIVITIES

YEAR 3 REPORTING TO THE EUROPEAN COMMISSION

The Annual Dissemination report, outlining all communication and outreach activities carried out in the past year, was submitted by the NCT this summer. Following a request from the Commission, the NCT also clarified the diseases to be covered by ERN-LUNG under the existing minimal clinical criteria.

ERN-LUNG WEBSITE

The network website has been updated to include more detailed information about our [organisation](#), as well as listings of the member HCPs ([full members](#) and [Affiliated Partners](#)), [reference centers](#) and [patient organizations](#). Other sections detailing the network activities and services offered are still under construction. We thank all members for their contribution to the website content wherever needed. We also invite you to use the patient-centric flyer (available [here](#) in 8 languages) and curated [patient resources](#) for dissemination purposes within your organizations / networks.

PATIENT SATISFACTION PILOT SURVEY UPDATE

ERN-LUNG is one among 4 ERNs that is working together with EURORDIS to develop a common patient feedback mechanism (pilot survey) that measures patient experience with the care received at ERN reference centres. Following a systematic literature review by EURORDIS to investigate existing validated scales, it appears that no validated questionnaire has yet been designed specifically for patients with rare diseases and complex conditions, hence giving us the opportunity to design a first of its kind. Two existing questionnaires have been narrowed down – EUROPEP (European Project on Patient Evaluation of General Practice Care) and PACIC (Patient Assessment of Care for Chronic Conditions) – for potential modification and adaptation to the specific experience of rare disease patients.

EUROPEAN RESPIRATORY SOCIETY-CLINICAL RESEARCH COLLABORATION (ERS-CRC) APPLICATION II (REGISTRY INTEROPERABILITY)

Registries are one of the most important resources for clinical research. Especially in rare diseases, but not restricted to these, it is of crucial importance to know where the patients are and who might be recruited for observational studies or clinical interventions. Patient registries are also crucial for improving clinical trial feasibility and recruitment processes. Building on the expertise gained in developing and establishing pan-European interoperability across all rare respiratory disease registries, Thomas Wagner (Frankfurt) and Olivier Sitbon (Paris) prepared a CRC application proposing to make this know-how readily available to all respiratory research groups and to make their registry data findable, accessible, interoperable, and reusable (FAIR) and – if necessary – migrate the data to an internationally accepted open source registry program (OSSE). More information will be provided soon and related educational webinars & hands-on training activities will be organized for interested clinical researchers.

IN CASE YOU MISSED

EUROPEAN JOINT PROGRAM-RARE DISEASE (EJP-RD) SURVEY RESULTS

EJP-RD recently conducted a survey for ERNs aimed to map our research data, research translation, clinical trial challenges and training needs. Thanks to ERN-LUNG members for their massive participation! Please find the survey results [here](#).

PAST WEBINARS AND MEETINGS

Chronic ThromboEmbolic Pulmonary Hypertension (CTEPH) in focus: Meeting our patients' expectations, 8 May 2019 - This [webinar](#) is routinely organised by the European Pulmonary Hypertension Association (PHA Europe) and ERN-LUNG, as part of the World Pulmonary Hypertension day celebration. At this year's edition, endorsed by EURORDIS and European Lung Foundation (ELF), patient testimony was provided and the 2 ERN-LUNG member speakers (Gergely Meszaros, Olivier Sitbon) concluded with an overview of ERNs.

ERN-LUNG CPMS [webinar](#), 26 June 2019 - The Network Coordination Team (NCT) of ERN-LUNG, the Medical Informatics Group of University Hospital Frankfurt and Helge Hebestreit (CF) successfully organised a webinar last month on how to use the Clinical Patient Management System (CPMS), focusing on how to request authorisation to CPMS and how to subsequently create a "Panel" for patient case discussion.

Webinars on the ERN Monitoring system, [19 July](#) & [12 September](#) 2019 - To help ensure more clarity around the 18 common ERN indicators that are part of the Monitoring process, DG Sante organised 2 webinars. The main aims were to go through each indicator to explain them in detail to the ERN community, to discuss any issues with data collection at local level and to try to identify common solutions.

A Registries Task Force (RTF) was formed within the ERN Research Working Group for the purpose of enhancing synergies, common needs and requirements to optimize the tools for developing patient registries. Holger Storf, Head of The Medical Informatics Group, Universitätsklinikum Frankfurt and lead of the meta data registry project WorkPackage within the EJP, represented ERN-LUNG at the [first RTF meeting](#) on 18 July 2019.

ERN Hospital Managers [meeting](#), 16-17 May 2019 - Organised by DG Sante with the aim of consolidating the role of Hospital Managers in the ERNs system.

8th Coordinators Group [meeting](#), 24th June 2019 - Reports from each of the ERN Working Groups were presented, with the Monitoring Working Group identified as a key priority. A range of other topics were discussed such as the extension of disease areas, the enlargement of the Networks with the designation of the Affiliated Partners by Member States, the call for registries for the 19 ERN without registries, and UK withdrawal from the EU.

ERN UPDATES

CALL FOR MEMBERSHIP TO THE EXISTING ERNs

The European Commission will launch in the coming weeks the first call for new members to join the existing 24 ERNs, following the adoption of the Commission Implementing Decision (EU) 2019/1269 of 26 July 2019 amending Decision 2014/287/EU. The Commission has published an additional document in the form of an [FAQ](#) responding to common questions about the ERNs and the application procedure. Please note that the FAQs will be updated on a regular basis. You will find more information about the imminent call to join ERNs [here](#).

TWO STATEMENTS ADOPTED ON ERNs INTEGRATION INTO THE NATIONAL HEALTH SYSTEMS AND COOPERATION WITH INDUSTRY

The ERN Board of Member States adopted updated guidance principles to frame collaboration between the ERNs and the industry, through a revision of its 2016 statement on the matter. It also adopted a new statement concerning recommendations and good practices to foster integration of the ERNs in national healthcare systems. For more information please visit [the website of the European Commission](#).

ERN ACKNOWLEDGEMENT POLICY

Any publications, clinical trials, educational activities or clinical guidelines arising from the collaborative work of ERN-LUNG members, linked to ERN activities, are encouraged to acknowledge ERNs using the [definitions](#) developed by MetabERN.

SUBSCRIBE TO THE NEW ERN NEWSLETTER

The European Commission Communications Unit has initiated a new tri-annual publication of an ERN newsletter that will highlight activities and programmes of interest within the ERNs, often including at least one highlight per ERN. At the moment, only the Network Coordination Teams (Coordinator, project managers, communication officers) of all ERNs have been included in the mailing list by default. So please subscribe directly to the newsletter [here](#).