

NETWORK MEMBERSHIP

ERN-LUNG welcomes three new **Affiliated Partners** from Latvia, Austria and Estonia, and we look forward to collaborating together in the various Core Networks. You may find the policy document outlining the ERN general principles on the integration of affiliated partners [here](#).

A new “Project” has been created on **BaseCamp** for **Year 3**, where we can exchange information and documents with all network members about various activities, upcoming events and meeting reports to be submitted to the European Commission. You may also find important documents for your reference (such as SOPs, members’ list and affiliations, etc) in “Docs & Files”.

ONGOING AND UPCOMING ACTIVITIES

Christiane De Boeck (CF Core) has been nominated on behalf of ERN-LUNG to the Task Force on Clinical Research Networks (CNR) of the Interdisciplinary Scientific Committee (ISC) of the **International Rare Diseases Research Consortium (IRDiRC)**. Having been the first director of the ECFS CTN (European Cystic Fibrosis Society Clinical Trial Network), she has been involved in all crucial steps of setting up and managing this very successful example of a CTN bringing therapies to patients in the field of rare diseases (RD), therefore we expect her to be able to give extremely valuable input to this task force.

Thomas Wagner (CF Core) and ePAG representative Gergely Meszaros have been nominated to the **Rare 2030 Panel of Experts**. A continuation of the policy-related activities of RD-ACTION, the European Joint Action for RD, Rare2030 is a new strategic participatory foresight study to reflect on the long-term future of people living with a rare disease in Europe and to provide policy recommendations through 2030 and beyond. You may find more information about this initiative [here](#).

Petra Pennekamp (PCD Core) will be representing ERN-LUNG at the focus group meeting of Workpackage 17 of the **European Joint Programme Co-fund on Rare Diseases (EJP-RD)**. The objective of this meeting will be to develop the ERN research training program based on the results of an EJP-RD survey on preferences, needs and resources from the ERNs ecosystem. You may access the survey [here](#) if you haven’t already taken it.

Thanks to ePAG representative Liam Galvin, we have received the support of the European Idiopathic Pulmonary Fibrosis and Related Disorder Federation (EU-IPFF) for the **development of a pathway project** on the topic of “undiagnosed patients with respiratory problems/symptoms - from GP to ERN”. At the moment Helge Hebestreit (ILD Core), Annick Clement (AATD Core), Thomas Wagner (CF Core), Liam Galvin and Keerthana Iyer are participating. More active partners are needed, so please [contact](#) the Network Coordination Team if you are interested.

DG Sante is organizing a **CPMS webinar** on Frequently Asked Questions and issues faced by users on 23rd May, 2019 at 14h CET. You may find more information [here](#).

PAST ACTIVITIES

ERN-LUNG has successfully obtained another **Connecting Europe Facility (CEF) grant**. This will be used towards eLearning/eTeaching tools to disseminate knowledge relevant to rare respiratory diseases and at the same time these tools will be used to communicate SOPs and guidelines for cross-border services of giving advice, care and/or referral within the network and to an outside audience.

To know more about the main developments of the **ERN community** as a whole, you may access the reports on the past meetings of various ERN Working Groups this year:

- ERN Research Working Group meeting on 24th January, 2019 [here](#)
- ERN Knowledge Generation Working Group meeting on 18th February, 2019 [here](#)
- ERN Project Managers meeting on 5th March, 2019 [here](#)
- ERN Coordinators meeting on 25th March, 2019 [here](#)
- ERN Board of Member States meeting on 26th March, 2019 [here](#)

WHAT WE NEED FROM YOU

- Let us know if you are participating in any **conference** where you will be presenting ERN activities and results
- Let us know if you have **published** anything recently (2019) so that it can be highlighted on the ERN-LUNG website
- Send us back the **Conflict of Interest** Disclosure [forms](#)
- Send us your **monitoring data** for the first half of 2019, corresponding to the indicators defined by the ERN Coordinators Group (only for healthcare providers)