

1. ERN-LUNG is an officially accepted ERN

The awarding ceremony of the 24 Certificates took place in Vilnius on March 9, 2017 (see pictures on last page).

2. Kick-off meeting of Medical Steering Committee

On March 10, 2017 the first meeting of the Medical Steering Committee (MSC) of ERN-LUNG took place in Vilnius.

Participants in alphabetical order:

Elisabetta Balestro (on behalf of F. Bonella), Annick Clement, Nazzareno Galiè, Jens Gottlieb (on behalf of G. Verleden), Marc Humbert, Gergely Meszaros, Heymut Omran, Jan Stolk, Kors van der Ent, Marie Louise van Melle (on behalf of J. Aerts), Thomas Wagner

Outcomes: See below

3. New Members

The Commission told us that there will not be a call for new members of the ERNs before the end of this year (the call will then be open for six months to give Member States and HCPs a chance even if they should not be able to respond quickly).

4. Supporting Partners (SP)

We have a group of participants in our by-laws we call *supporting partners*. We have agreed that there are situations that can be thought of where the Core Network Coordinator (CNC) might want to include new partners in their Core Network (CN) although there is no way foreseen by the Commission for inclusion. In such a case, we might want to have them as a SP in our network. At the same time we do not want to dilute quality and/or accept groups which cannot be expected to substantially contribute to the Core Network or the ERN as a whole.

Proposed procedure: The decision concerning SP will be with the CN.

Action Point: CNC will consent generic rules for CN-specific SP to be agreed by MSC.

Responsible: Marc Humbert will start with a short generic preamble which can be used by all CNs in combination with their existing CN-specific criteria.

5. New patients / patient representatives (PR)

The Members of the MSC discussed the need to have rules of how to accept new patient representatives (PR). There are several ways:

- a. Via Eurordis -> ePAG -> Patient board; will be accepted;
- b. Via CN: -> CN Executive Committee -> Patient Board; will be accepted;
- c. Third party or self-declared: will be evaluated by PR the MSC and the respective CNC; if then both come to a positive conclusion -> accepted. If they disagree -> mediation by Coordinator; if both come to a negative conclusion -> denied.

For this, rules will have to be found. Arguments for adding a new PR could be: Country not in the ERN or in the CN yet; disease not in the ERN or in the CN yet.

Proposed procedure: Rules will be prepared to be decided in April (Kick-off in Frankfurt)

Action Point: MSC will consent generic rules new PR

Responsible: TOF Wagner will start by adding a paragraph to the by-laws

6. New Core Networks

There is no limit to the number of Core Networks but it has to be kept in mind that we do not know how manageable the ERN-LUNG is now and if there should arise some problems whether they would be related to size or number of the CNs. It seems therefore reasonable not to want to much by starting new CNs. For the first year, we have the feeling that no new networks should be encouraged. The Other Rare Lung Diseases (ORLD) CN though is the place where such activities and plans should be hedged.

7. Overlap with other ERNs

We have already identified some overlap with other ERNs: Mesothelioma with rare lung malignancies; a1-ATD with ERN-Liver. We have now realized that there is more overlap (PH with ERN-Heart; any other?).

Proposed procedure: CN check whether it will be feasible to have a member from another ERN as a born member in the CN Executive Committee

Action Point: CNCs will actively seek contact with the resp. other ERNs

Responsible: All CNCs; please inform NCT that you have done or need not get in contact (CC... us will be sufficient).

8. Overlap of CNs within ERN-LUNG

There is of course some overlap between CNs within ERN-LUNG (i.e. PH in Fibrosis or CF and CLAD etc). Fringe benefits are obvious, so no specific action point is needed.

9. How to quote affiliation/membership with ERN-LUNG?

Frankfurt signed a contract allowing them to use the logo and name etc. All HCPs can obtain a sublicense as soon as the template will arrive in Frankfurt.

10. Endorsement by ERN-LUNG

It might be nice to be able to state that an activity you have is in collaboration with ERN-LUNG. Any such statement would have to be done by the MSC.

11. Financial support of activities by ERN-LUNG

ERN-LUNG has a very limited budget. No other activities than those stated in the first-year work program (board and some committee meetings) can be financially supported by ERN-LUNG. But: it is safer to not expect any financial contribution.

12. ERN brochure for download

There is a brochure about the ERNs (44 pages) which can be downloaded here:

https://ec.europa.eu/health/sites/health/files/ern/docs/2017_brochure_en.pdf

On page 29 there is a fact sheet (1 page) about ERN-LUNG that you might already know because it can be found here:

http://ec.europa.eu/health/ern/toolkit_en

13. Pictures from the 3rd ERN meeting in Vilnius (Mar 17)



Responsible for the content of this newsletter:

Coordinator of ERN-LUNG
Prof. Dr. T.O.F. Wagner
University Hospital Frankfurt / Germany

Email: t.wagner@em.uni-frankfurt.de