



1. Infos and messages from the EC

Dear ERN-LUNG Members,

Info from the EC (Plaza in ECP): „We are happy to inform you that on Tuesday 15 May a new collaborative space called 'Plaza' had been added to the ERN Collaborative Platform (ECP). 'Plaza' is the Spanish word for city square and this is exactly what we want it to be: a vibrant, central place in a community where people can come together, meet, connect and collaborate. So, Plaza offers you the ideal forum for the whole ERN community. It will be the forum where ECP users from Member States, different ERNs, patient organisations and the European Commission can enter and exchange information. It will be the place where messages can be posted across the ERN community. Access to Plaza will be automatically granted during your next connection to ECP and this new network will appear on your main ECP dashboard. As Plaza is a common collaborative platform for the ERN Community we expect you to publish posts that are of relevance for the whole ERN community, or a large part of it. The specific collaborative spaces are still there for exchanges on information strictly related to their activities. But if, for example, you want to share information related to a survey conducted by a working group, you can post that on Plaza. As a representative of a Member State you may want to use Plaza, for example, to announce cross-border health initiatives by your Ministry. From the Commission side we will inform through Plaza on our activities which concern the ERN community (e.g. press release, ERN videos available in all EU languages). Also news on the publication of calls for tenders or calls for proposal could be posted on Plaza. Note however that we will continue using e-mail communication via the well-known DG SANTE functional mailboxes. We hope that Plaza will prove to be useful in the sharing of information between ERN stakeholders. On our side we are happy to help you or answer any questions you may have. Certainly at the start it may be useful to coordinate with us a specific folder“.

2. Next coordinator's group meeting

The next coordinators group meeting is scheduled for June 25, 2018 in Brussels, BE. We will keep you informed on any new information and updates.

3. First anniversary of ERNs

The EC has published a press release looking back on Rare Disease Day and a 1 year anniversary of the ERNs.

Please read the full article below: [Press Release](#)



4. Basecamp: new tasks and deliverables for year 2

We are pleased to inform you that the EC has confirmed our work plan with the new deliverables and we are now **in the process of** setting up the second year on our Basecamp (which is named “ERN-LUNG year 2” on Basecamp).

Similar to the way we did in the first year, we will list all tasks and deliverables in the to-do list. By clicking on each task, they will unfold and be described in more detail.

Members that have not been assigned any particular tasks or deliverables, yet, remain in the inactive member group for now.

If you should see tasks or deliverables that you find interesting and feel like contributing to, please let us know and we will assign you these tasks. The members that have already contributed and completed corresponding tasks in the first year, will be re- assigned the same tasks again by us. However, if this is no longer desired, we kindly ask you to let us know. Once you have found a task you feel you would like to carry out, you will no longer remain in the inactive member group on Basecamp.

After choosing a task, please consider the deadline for the deliverable you have decided to contribute to. These deadlines are given by the EC and should be met.

Once you have completed a deliverable, please click on the white box with the check mark on the left hand side of the task in question. This box will turn green, indicating that the task is completed. We would like to ask you kindly not to check off any deliverables you are not assigned to.

Below, please find a link to some how-to guides that will help you get started. If you should have any further questions though, please send them our way!

<https://3.basecamp-help.com/category/116-working-in-projects>

We hope you find an interesting task and look forward to your project contributions!

5. Authorization access to the CPMS

Please note that in order to obtain access to the CPMS, it is necessary for you to both inform Thomas that you have applied for access AND confirm that you are Healthcare Professionals (HP), as the EC requires him (as the coordinator) to verify this information before granting access to the CPMS.



6. Monthly virtual video conferences

As we have discussed at our Boad Meeting in March, we have started with our video conferences for the CNs, FCs, their deputies as well as patient representatives. The first CN and FC meetings have taken place in April and May ([CN minutes](#)). The FC meeting minutes will follow shortly.

The next CN video conference call is planned for June 27, 2018, followed by the FC video conference call a week later. Invites will be sent in due time.

7. ERS award for Marc Humbert for lifetime achievement in PAH

We are happy to inform you that Marc Humbert has received the 2018 ERS Award for Lifetime Achievement in PAH.

He will receive

- A certificate
- 10,000€ as a research grant to your institution, as well as the invitation to the ERS Speakers' Reception on Sunday 16 September 2018.

Congratulations from the Network Coordination Team!

8. Rare Disease Registry Data Warehouse

The Project funded by the European Commission started April 1st. There was an official kick-off meeting of several of these registry-projects and the Frankfurt group (Holger Storf, Johanna Schäfer, TOF Wagner) as well as Olivier Sitbon (Paris) and Abilio Reis (Lisbon) attended this meeting. The most interesting part was the presentation by Simona Martin, who presented the European Rare Disease Registry Infrastructure (ERDRI) which is a comprehensive system of patient data registration tools. A significant part of these tools have been developed in Frankfurt as well, i.e. we will have no problems in getting our ERN-LUNG elements integrated on a European level.

The project group is in the process of preparing the consortial agreement. As soon as we are ready with this we will share a condensed summary of the different project elements and this will give an idea of the challenges and chances the project bears for ERN-LUNG as a whole and for each single HCP.



9. ERN-LUNG symposium September 2018 (ERS)

The ERN-LUNG session is planned for Monday 17 from 8:30 to 10:30.

Please click on following link to view the agenda:

<http://k4.ersnet.org/prod/v2/Front/Preview/Session?e=90&session=7564>

Above that, the European Lung Foundation has also scheduled a meeting for Core Network leads and patient representatives from ePAG for Monday, from 12:30 to 14:00.

Our ERN-LUNG Medical Steering Committee will have a meeting in the framework of the ERS and it is scheduled for Tuesday, September 18, from 13:00 to 15:00 in Paris.

Please note that also non-MSD ERN-LUNG members are welcome to attend the meeting as audience.

10. CPMS

ERN-LUNG is somewhat slow in getting the Cross-Border Teleconferences going. From the start, the CPMS Working Group (Helge Hebestreit et al.) has had a problem with the local data protection officer who refused the right to use the system provided by the European Commission. The reason was unattended access to the medical data of patients from other ERNs within the same Health Care Provider. In Würzburg, Germany, where Helge and his group are involved in ERN-LUNG via their Cystic Fibrosis program, there is more than one ERN. Care team members from the other ERNs would be able to get access to the ERN-LUNG patient data which is not acceptable to the data protection rules. We have addressed this with the European Commission but have not received any answer from there, yet. In the meantime, Helge Hebestreit together with the data protection officer have developed a work-around which has been accepted. This being settled that first patients to be discussed can be entered into the system.

In parallel to these activities Adam Torbicki has tried to manage a cross-border consultation within the Pulmonary Hypertension Core network. There were some technical problems but from all of this we can be optimistic that we will soon have the technology set-up so we can start to offer these consultations as a service.



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