ERN-LUNG Annual Board Meeting Report
University Hospital Frankfurt, 22/23 March 2023

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1. List of Abbreviations

AATD – Alpha1 Anti-Trypsin Deficiency
ABM – Annual Board Meeting
AP – Affiliated Partner
BEAT-PCD - Better Experimental Approaches to Treat Primary Ciliary Dyskinesia
CEF – Connecting Europe Facility
CF – Cystic Fibrosis
CFE – Cystic Fibrosis Europe
CHAFEA – Consumer, Health and Food Executive Agency
CLAD – Chronic Lung Allograft Dysfunction
CN – Core Network
COST – European Cooperation in Science and Technology
CPMS – Clinical Patient Management System
CRC – Clinical Research Collaborations

CTEPH – Chronic thromboembolic pulmonary hypertension
CTN – Clinical Trial Network
EARCO – European Alpha-1 Research Collaboration
EC – European Commission
EJP-RD – European Joint Programme for Rare Diseases
ELF – European Lung Foundation
ePAG – European Patient Advocacy Groups
ERDRI – European Rare Disease Registry Infrastructure
ERJ – European Respiratory Journal
ERS – European Respiratory Society
ESC – European Society of Cardiology
ETP – Education and Training Programme
EU-IPFF – European Idiopathic Pulmonary Fibrosis and Related Disorder Federation
EURACAN – European Network for Rare adult solid Cancer
EXABO – EXpert Advisory
BOard FC – Functional
Committee
FDA – Food and Drug Administration
HCP – HealthCare Professional
ILD – Interstitial Lung Disease
IPF – Idiopathic Pulmonary Fibrosis
MDT – MultiDisciplinary Team
MS – Member State
MSC – Medical Steering Committee
MSTO – Mesothelioma
nCF-BE – non-Cystic Fibrosis Bronchiectasis
NCT – Network Coordination Team
ORLD – Other Rare Lung Diseases
PCD – Pulmonary Ciliary Dyskinesia
PH – Pulmonary Hypertension
PAH – Pulmonary Arterial Hypertension
PRO – Patient Recorded Outcome
PVRI – Pulmonary Vascular Research Institute
QoL – Quality of Life
RHF – Right Heart Failure
SGA – Specific Grant Agreement
SP – Supporting Partner
WG – Working Group

2. Summary

The 6th ERN-LUNG Annual Board Meeting (ABM) was organized in Frankfurt, Germany on 22nd/23rd March 2023. It was a face-to-face meeting, with a few exceptions which are exposed below. The objectives of the meeting, were to discuss the network's performance with regards to the completion of the first 5-year period (2017-2022), the ongoing gap-period of 18 months, as well as the upcoming 4 - year period (2023- 2027). A new Core Network was created (Sarcoidosis) and the newly launched ERN- LUNG Academy was presented. 90 members of the network were present. We thank them for their time, commitment and valuable contributions.

3. General context

3.1 Network Coordination Team (NCT) report - Thomas Wagner

ERN-LUNG is a patient-centric network of European Healthcare Providers (HCPs) dedicated to ensuring and promoting excellence in care and research to the benefit of patients affected by rare respiratory diseases. As of today, the Network comprises 79 HCPs that are Full Members (from 19 EU countries plus Norway), 9 are Affiliated Partners (from 6 countries), 13 are Supporting Partners, and the network counts also 25 ePAG advocates. Altogether, a total of 26 out of 28 EU member States are currently covered by ERN-LUNG, plus Norway. Updating the list and the contact details is done continuously, but once a year active feedback on contact details will be asked from every HCP.

3.1.1 Attendance of the Board Meetings Years 1-6 (Thazhone Stephy Varghese)

Attendance has increased from 2017 (76 confirmed responses) to 2023 (122 confirmed responses). This increase is continuous since 2019 and has not been haltered by the two pandemic years when the ABM took place virtually only. The attendance of 2023 shows the eagerness to come back to face-to-face exchanges. Almost all countries were represented in 2023, plus the UK and Turkey (Supporting partners).

3.1.2 Evaluation

The European Commission started the evaluation process in February 2023, with the following steps having already been completed:
- Self-evaluation of every Full member HCP, having joined the network from the beginning in 2017 (60HCPs were concerned)
- Self-evaluation of the Network Coordination Team
- Virtual audit of the Network Coordination Team
- Virtual audit of the ePAG

The following steps are ongoing:
- On-site audits on 12 randomly chosen HCPs

Feedback from the HCPs was that the workload was disproportionate. The recently hired member of the NCT (Lisa Gietz) was fully committed to sending out explanatory e-mails, answering questions, and liaising with the Independent Evaluation Body. Thanks to this, but foremostly thanks to the dedication of the teams within the HCPs, 59 out of 60 HCPs sent in their self-evaluation in time. The HCP that has not completed its self-evaluation in time is among the on-site audited HCPs and will be able to exchange directly with the auditors.
The virtual audit of the NCT went very well, and many positive points were singled out, but especially patient participation in research and publications.

ERN-LUNG wants to say Thank you! to all those who participated in this exercise, and also wants to encourage those who have the on-site audits not to do or to show anything they do not feel comfortable with.

3.1.3 Application for the next funding period (September 2023 – August 2027)

The funding increases for this 4-year period: approx. 806.250€ per year for ERN-LUNG, without any need for subsidiary funding. This number is to be compared with 200.000€/year for 2017-22, and with 725.333€/year for the gap funding 2022-23. This increase in funds means that there will be fresh money for different purposes: guidelines, CTNs, etc.

The deadline for submitting the new funding application is May 25th.

Marc Humbert (Bicêtre Hospital APHP), currently vice-coordinator, is to be the next ERN-LUNG coordinator from September 2023 on. The NCT is then going to be managed on two sites, Paris and Frankfurt.

The following Work Packages are to be distributed between Paris and Frankfurt: WP 1:

Coordination
WP 2: Dissemination
WP 3: Evaluation
WP 4: Healthcare and CPMS
WP 5: Registries, data management and analysis
WP 6: Training and Education
WP 7: Clinical Practical Guidelines and Clinical Decision Support Tools
WP 8: Clinical Trial Networks
WP 9: Undiagnosed Patients (this is a new WP)

ERN-LUNG wishes to implement a Future Strategy Working Group. The following members have already declared themselves ready to be part of it:
Marc Humbert, TOF Wagner, Helge Hebestreit, Gergely Meszaros, Marjukka Myllärmieni, Kim Nielsen. All CN and FC leads will be members as well.

3.1.4 Ongoing Projects

1. **ERN-LUNG Academy**
   The Academy (more details under 4.6.2) has been built up during the year 2022 and is now up and running. The ERS has been very helpful with hosting the entire content on its own website, at no charge. This is also a call for new modules (Webinars and e-Cases), to be proposed to Elisabeth Humbert-Dorfmüller. Each author is paid individually for this (1.200€ for a Webinar, 600€ for an e-Case, for the next funding period: 1.000€ for a Webinar, 500€ for an e-Case).

2. **Clinical Patient Management System (CPMS)**
   This is functioning in an unsatisfactory way for the moment, because participation of the network is low. Most cases are proposed by University Hospital Würzburg, as Helge Hebestreit is very active in that field. An HCP which proposes a case (panel lead) is paid 200€. If it seems technically complicated to lead a panel, it is possible to indicate the data to the NCT which can then prepare it and set it up in lieu of the proposing HCP. A new technical framework, much more user friendly, is in the process of being developed by the EC. Olivia Steinmann and Helge Hebestreit participate in the elaboration task force on behalf of ERN-LUNG.

3. **EXABO**
   The medical advice platform accessible to patients and care team members is available in two languages (English, German). The Polish version has been prepared and has to be implemented on the Website. More versions in different languages can be prepared and be financed (9.000€ for each “new” language).

4. **ERN-LUNG Registry**
   This registry is to be used as an interface between HCPs and ERN-LUNG. Its data are provided for the continuous monitoring, CPMS and reporting. 150,000 Euros for registries are available. New patients will have to be entered. Consent of patients will of course be needed. Transfer of data to ERN-Lung registry will have to be done before the end of August 2023 for refund purposes.
   Invoices coming later would not be eligible cost and money not spent until then will be lost.

5. **Population registry**
   This is a patient driven registry. The governing body needs the participation of patient representatives and clinicians. The only patient right now is Gergely Meszaros. Volunteers are needed.

6. **Clinical Trial Networks (CTN)**
   Three CNs have implemented Clinical Trial Networks so far: CF, PCD, AATD. Others could follow (PH,BE?), and 9.000€ can be financed for the starting phase.

7. **Guidelines and Research**
   The network has an impressive list of guidelines at its disposal. They can be seen here: https://ern-lung.eu/guidelines/
   ERN-LUNG has endorsed many of them. Funds can be made available for guideline review or grant application preparation.

8. **Network Activity Monitoring System**
   The network wishes to implement a system to assess and to measure the active involvement of member HCPs. A system of "credit points" will show the degree of their involvement: credit points can be given for being a CN, FC or WG lead or co-lead, for providing the Academy with Webinars and to host Academy participants, or for actively participating in CPMS panels for example. The goal is to increase the degree of the HCPs involvement.

9. **European Joint Program on Rare Diseases**
   This European program is not well known and underused. It aims to create an effective rare diseases research ecosystem by funding research, bringing together data resources and tools, providing dedicated training courses and translating high quality research into effective treatments. More on https://www.ejprarediseases.org/

10. **European Joint Action for the Integration of ERNs into the National Health Systems (EJA JARDIN)**
    This is considered very useful for ERN-LUNG. France is a positive example of ERNs being fully integrated into the national expert centers. ERN-LUNG will be involved via TOF Wagner in the undiagnosed patient program.

11. **ERS Monograph 100**
    Rare diseases of the respiratory system, the editors are Marc Humbert, Marlies Wijsenbeek- Lourens, Michael Kreuter, Helge Hebestreit, TOF Wagner. The 28 chapters were all written by ERN- LUNG authors.

3.2 Administrative Business - Thomas Wagner

3.2.1 Changes in teams and team leaders

The Network Coordination Team: Olivia Steinmann, Elisabeth Humbert-Dorfmüller, Thazhone Stephy Varghese, Lisa Gietz, Dorothea Berger. Sabrina Walter has left the team.

New Core Network Leads:
CLAD: Geert Verleden retires, new lead to be determined
Sarcoidosis CN to be founded, new CN lead Francesco Bonella
New Functional Committee leads:
Research and Clinical Trials: Sara Palchetti has stepped down, new lead to be determined
Communication and Outreach: new leads are Gergely Meszaros and Pippa Powell

3.2.2 Upcoming events

ERS Congress in Milano 9-14 September 2023
ERN-LUNG will hold a session on Wednesday morning (Sep 13th)

4. Activities of the Functional Committees (FC)

4.1 Research and Clinical Trials – *Thomas Wagner*

CTNs realized within ERN-LUNG: CF, AATD, PCD (in 2022)
CTNs empower the RD community. They facilitate translation from bench to patient.
They help overcome obstacles in RD, and they are advantageous to patients, scientists, clinicians, pharma industry.
Isablle Fajac, former lead of the FC, held a workshop on that subject in 2021. A new lead for this FC is to be found.
ERN-LUNG will be able to allocate some budget for this activity in the next funding period. BE and PH could think of getting aCTN started.
Sara Palchetti, from University hospital Florence, has done a Clinical Trial Research Projects Survey. The results are:
69 network members from 19 countries have responded to the survey.
On profit Clinical Trials, most PIs have on average fewer than 10 active profit CT in the recruitment phase.
On non profit Clinical Trials, each PI has on average about 5 active non profit CT and 5 in activation. In terms of diseases targeted by CTs, ILD (30) comes first, followed by CF (28), PH (27) and BE (18). Half of the participants would like to receive support in the organization and management of CTs, and particularly in the field of ethical approval and contracting/negotiating with sponsors and in the recruitment of study nurses/coordinators/personnel.
An interesting proposal came from Harm Jan Bogaard (UMC Amsterdam): To build a platform and to design a master protocol for joint studies.

4.2 Quality Management – *Marion Delcroix*

4.2.1 Extending the network

The aim of ERN-LUNG is to expand the network throughout Europe and beyond for the benefit of patients via full memberships, affiliated memberships and supporting members/partners. ERN-LUNG

is inclusive, and wishes to involve partners even if they may not meet all formal criteria to become a full member.

4.2.2 Quality indicators in PH

The European Society of Cardiology has developed a methodology for the assessment of quality indicators for the quantification of cardiovascular care and outcomes.

It aims to classify
1. The Structural Framework
2. The Diagnosis and Risk Stratification
3. The Initial Treatment
4. The Follow-Up
5. The Outcomes

Developing Quality indicators for other diseases covered by ERN-LUNG could be a lead. “Learning from the best” is also an important objective of the network.

4.3 Registries and Biobanks – *Thomas Wagner*

TOF Wagner and his group have published a paper on an undiagnosed patient registry which was the reason they are now in charge of establishing a European Registry for undiagnosed patients. Undiagnosed patient registry will be a topic within the new ERN-LUNG application.

Although ERN-LUNG did a survey earlier, this will be repeated to have more accurate information. Olivier Sitbon (Bicetre Hospital APHP) will coordinate the Registry in the next funding period. All Members will be asked how many patients they are planning to recruit for the ERN-LUNG registry.

4.4 Guidelines and Best practice of care – *Helge Hebestreit*

There are no activities to report for 2022.
There are large number of guidelines reported on the ERN-LUNG website.
Not all of them have been endorsed by ERN-LUNG.
For 2023:
- existing guidelines should be identified for endorsement by ERN-LUNG.
- gaps in guidelines should be identified.

4.5 Patient Recorded Outcomes (PRO) – Simon Gibbs

This presentation was given via Zoom.

ERN-LUNG can use PROs to
- strongly involve patient organisations
- investigate their routine clinical use
- establish their routine clinical use

A survey carried out in 2021/22 by the PH Core Network questioned the use of PROs in 30 ERN-LUNG HCPs. The result is that about 50% of the HCPs use a PRO in routine clinical practice. Further data on frequency, barriers to using PROs and physician's satisfaction with them were also analyzed.

A comparable survey on Mesothelioma carried out in 2023 (with only 6 HCPs) gives similar results. A survey for ORLD should follow. It would be useful if all CNs carried out a survey on the use of PROs.

Question from the public: Could it be the aim to determine one PRO per disease?
Answer: It could be but it is probably unrealistic

Question from the public: How can we force HCPs to use PROs?
Answer: Hard to force, but we could give HCPs who use PROs credit points (see also under 3.1.4.8)

Question: Could ERN-LUNG produce a consensus statement for using PROs?
Answer: Yes, that could be an objective

4.6 Professional Training and Education – *Elisabeth Humbert-Dorfmüller*

Main achievements for 2022:

4.6.1 The ERS/ERN-LUNG Virtual School of Rare Respiratory Diseases in June 2022

Organized by Marlies Wijsenbeek and Michael Kreuter
A very interesting spectrum of presentations, questions, case histories and discussions were offered and participants were very satisfied. This type of activity will be repeated in the future.

4.6.2 ERN-LUNG Academy

This is a curriculum for medical staff at any stage of their career, who wish to get a proof of knowledge on rare respiratory diseases. Launched in September 2022, it started in January 2023.
25 Webinars produced by the network's experts, hosted on the ERS Website
43 participants in 2023, coming from 12 EU and 3 non-EU countries
Practical stay of one week in one of the network's HCPs
Travel and Accommodation is reimbursed by ERN-LUNG
Recruitment for 2024 will start in September 2023

4.7 Communication and Outreach – *Gergely Meszaros*

The Website has had numerous updates and additions:

- Patient journeys (more are to come)
- Patient priorities
- Membership categories
- Covid-19 updates
- A sub-Website for the PCD Core Network

ERN-LUNG is active on social media (Facebook, Twitter)
Users of social media should take the habit to mention ERN-LUNG regularly.

Newsletter is sent our quarterly
Editors of newsletters (patient groups, etc.) should include news from the ERN-LUNG Newsletter in their own publications.
The other way round, they should inform ERN-LUNG of their own activities, for publication in ERN- LUNG Newsletter

4.8 Cross-Border Care – *Adam Torbicki*

The year 2022 was still characterized by many turbulences and by the impossibility for patients to move across Europe.

The typical pathway of Cross-Border Care is:
- EXABO : Online consultation accessible to patients and medical staff, but mainly within the nationalborders (language)
- CPMS : Cross-border online consultation among experts of the network via the CPMS panel
- Cross-border referral : prerequisites are that a satisfying solution cannot be found on CPMS level, that the experts form CPMS recommend Cross-border referral, and that the national contact of the residencecountry of the patient has been contacted.

A ESC/ERN Diagnostic algorithm with teleconsultations has shown that this improves early detection of PH/CTEPH, that it helps in differentiating between PH groups, and that it assists in preselection of patients requiring expert center admission.

The new problem in 2022 is the war in the Ukraine. Poland has received about 1 million immigrants from Ukraine in the first 3 months of the war. More than 10% of new PH patients in the expert center ECZ-Otwock are from Ukraine.
The network has been mobilizing effectively to help. Drugs and equipment have been delivered without charge from the pharmaceutical industry and from other stakeholders.

Cross-border care in Europe? It is the Ukrainian patients who need it most right now.

4.9 Clinical Patient Management System – *Helge Hebestreit*

The current CPMS is working and online sessions are being held once a month on Wednesdays 15:00 CET (lasting 30-60 minutes).

However, a “new CPMS” is being developed, with the goals of providing open source, easier access (the current system is tricky, and thus the participation is low) and suitability for mobile phones. Olivia Steinmann and Helge Hebestreit are the network’s members of the business implementation group working on the new version. It is expected to be in place at the end of 2024.

Remark from the public: CPMS should be more Core network focused (e.g., inviting members of one CNonly) in order to be efficient.

Question from the public: Could patients be invited to assist the discussion around their own case? Answer: For ERN-LUNG this is not feasible, since the data protection issue becomes very complex.

5. Activities of the ePAG – *Gergely Meszaros*

5.1 News about the group structure

The ERN-LUNG ePAG has received a number of new applications. The aim of the call launched by EURORDIS was, apart from necessary replacement, to have a more balanced representation in terms of geography and covered diseases.

Three new patient advocates (two from Sweden, one from Switzerland representing a Greek patient organization) have been endorsed.

Liam Galvin from the European Pulmonary Fibrosis Federation (ILD CN) has been elected co-chair, alongside Gegely Meszaros who is the chair of the ePAG. They will both share responsibility for coordinating the group and representing the ERN-LUNG ePAG on the Medical Steering Committee of the network.

5.2 Activities

- Patient webinars
- Patient conferences
- Virtual school on rare lung diseases (see also under 4.6.1): Natalia Maeva from the ePAG contributed as a speaker
- MEP Lung Health Group conference (European Parlement): organized by Gergely Meszaros

5.3 5-year assessment by the European Commission

The ePAG had to undergo an evaluation, just like the NCT and the HCPs. The interview was virtual and involved 5 members of the ePAG. The evaluators pointed out that they were impressed by the ePAG involvement in the network's publications.

Question from the public: Could patients be included in CTNs?
Answer 1: it is difficult to find patients interested in all diseases of a CTN.
Answer 2: There are patient representatives in the PCD CN.

5.4 Future Plans

- ePAG ERN Evaluation (AMEQUIS) task force
- Closer collaboration with the core networks

- Plans for ERS Congress – Milan (September 9-13)

6. Medical Steering Committee Meeting

The meeting was held for the purpose of the creation of a new CN (Sarcoidosis). Francesco Bonella presented the structure of the CN, including its board and the involved patient organizations. The MSC voted unanimously in favour of creating the Sarcoidosis Core Network.

7. Activities of the Core Networks (CN)

7.1 Alpha1-Antitrypsin Deficiency

The network did not do any presentation, despite the presence of several members of the group. It was decided to hold an Online meeting in the next weeks.

7.2 Cystic Fibrosis – *Inez Bronsfeld*

The presentation revolved around the following questions which were submitted to the ERN-LUNG CF Centers by different countries (Sweden, Norway, Germany, Belgium, Lithuania, Slovenia, France, Portugal, Spain and Hungary):

- Which are the diagnostic tools available?
  Sweat test and genetic screening are available in all countries. Sequencing in some countries and started with next gebneration screening. In 1 or 2 countries NPD, ICM, nasal epithelium and organoids in Belgium and the Netherlands. Possibilities of sending difficult cases to countries that do have diagnostic tools. Possibility of emailing and consulting us.

- Is there a newborn screening and when did it start?
  There are 4 countries that do not have newborn screening yet and are negotiating with the ministry of health. Some of the reasons in certain countries mention that if CFTR modulators are reimbursed earlier in life, then it would be feasible to introduce newborn screening.

- Do you have inhalation antibiotics available, from which age, for everybody?
  Inhalation antibiotics are covered in almost all countries even special ones like Vancomycin and MRSA colonization. The only one not available in all countries is Quinsair (which is not used often); mostly because patients do not like the taste of it. It stopped due to Cuff 3.0 introduction.

- Do you have availability of CFTR modulator treatment, from which age, since when?
  The availability is different in these countries. In a lot of countries there are negotiations with Vertex and insurance companies to set a certain price. The price per European country is higher in some but a lot lower in others as each country has its own rules for insurance. Lithuania is also at the discussion point and not having the possibility to prescribe CF modulator treatment and negotiating with government and ministry of health.

Vertex Cestor should be a compassionate use program for patients without right mutations for modulators. In France there is a program done with doctors and ministry of health on compassionate use for non-delta F patients.

CF registry: The network prefers not to enter data in more than one registry, the only one which should beused is ECFS registry which is advanced.

7.3 Chronic Lung Allograft Dysfunction – *Jens Gottlieb*

- *Aims*:
  a) Sharing interest in CLAD epidemiology, phenotyping, and natural history
  b) Increasing knowledge in management and transborder counseling.
  c) Collaboration between major European lung transplant centres to tackle CLAD as a major obstacle to long term survival after Lung transplant.
  d) Establishment of platform for clinical trials.

- *Activities of the CN in the past year*:
  a) included the publication of an ERS monograph, articles endorsed by ERN-LUNG, Webinars, two contributions to the ERN-LUNG Academy, as well as studies on the effect of Covid-19 on the disease. Provided talks in the ERS Virtual school on Lung transplantation.
  b) Transborder Counselling – established network of European Lung transplant centres and regular on-site visits (hospitations) from other centers (pre pandemic). Forum of the international Society of Heart and Lung Transplantation (ISHLT). Discussion of difficult cases and transborder care limited due to ethical barriers (declaration of Istanbul, CoE). First multicenter trial of antifibrotics in CLAD sucessfully performed in Europe (EPOS trial)

CN would like to get more financial benefit from its ERN-LUNG affiliation. The ways of achievingthis have to be discussed.

7.4 Bronchiectasis – *Felix Ringshausen*

First, the group has decided to change its name from non-CF Bronchiectasis to Bronchiectasis.

- EMBARC is presented: The EMBARC (European Multicentre Bronchiectasis Audit and Research Collaboration) registry is a prospective, pan-European observational study of patients with bronchiectasis. It describes microbiology and disease burden across Europe.
  EMBARC 2 → EMBARC 3 (2022-25) has the objectives to
  - link data with large scale translational research
  - understand inflammation and the microbiome.
  - do interventional studies including clinical trials
  - involve genetic studies.
  - include early Bronchiectasis.
  - generate educational and patient resources and empowerment.
- The CN counts many publications in 2022 and submitted for 2023. One of which is published in Lancet Respiratory medicine including 17,000 patients from 28 European countries showing.

distribution of Pseudomonas Aeruginosa in Europe. The findings are stimulating and important for providing care in Europe according to the aims of ERN-Lung.

- World Bronchiectasis Day in July 2022 was an important event, as well as the Patient conference organized by ELF, and an EMBARC Webinar series.
- Outcome of BE CN meeting – a) intercalation between ERN-Lung – ERS and the European registry. b) to be more integrative to pediatricians. c) Pediatric Bronchiectasis registry: CHILD-BEAR could be an area where ERN-Lung could support patients (not recognized as pediatric or adult).

Future plan:

- Provide Pan-European support; for example, Indian network of Indian Bronchiectasis Registry, African Bronchiectasis registry (abstract given to ERS Congress with data from EMBARC bridge) etc.
- Felix Ringhausen wishes to resign from CN lead and requests for replacement, also from the pediatric side. A CTN for specific aspects, including pediatric populations, is to be set up, financial support from ERN-LUNG as well as manpower is needed.

Upcoming events:

- World Bronchiectasis Day – 1st July 2023 in New York, USA – Agenda: basic treatment, research, BE through different life stages, pediatricians awareness in earlier recognition of patients at risk of developing BE etc.
- World Bronchiectasis Day – 1st July 2024 in Dundee, UK.

7.5 Interstitial Lung Disease – *Antje Prasse*

- The group has elected itself a new leadership after the departure of Michael Kreuter:
  Antje Prasse remains lead.
  Elena Bargagli (University hospital Siena, Italy) becomes co-lead
  Vincent Cottin (Hospices civils de Lyon) becomes co-lead.
- Due to the creation of the Sarcoidosis CN, ILD CN is now focusing more on *fibrotic ILD*.
- The group has set minimal criteria for HCPs who want to become members:
  400 patients, 20 children.
  150 new patients per year, 4 children (is this right?)
  However, these minimal criteria are not totally fixed
  Substantial number of procedures like biopsy, lung biopsy (either cryobiology or surgical lung biopsy), VATS procedures – atleast 50 per year.
  There are also criteria on visibility in ILD international conferences and participation in clinical trials in ILD.
- One goal is to connect all existing registries, local ILD registries into a meta-registry for analysis and otherprojects.
- CTN is not a feasible goal, there are too many centers, there would never be a unified action. Worldwide initiative (funded by Guiseley Jenkins, UK) initiated with adaptive trial design where ERN-Lung ILD members like to endorse. It can be a solution for unified expertise to provide the pharmaceutical industry trying to do clinical trials.
- Establishing quality indicators is another goal, and funding would be welcome.

7.6 Mesothelioma – *Thomas Wagner on behalf of Joachim Aerts*

- Members have participated in the evaluation process of the ERN.
- There are 2 joint publications on behalf of ERN-LUNG (1 published, 1 under way).
- The (only) patient representative stepped down, there is no replacement yet.
- There is one Academy participant planning to do his practical stay in one MSTO center.
- The PRO FC has done a survey in the group about use of PROs in the HCPs. The findings, although with far less centers involved, are similar to the findings with the PH CN (see also under 4.5).

7.7 Sarcoidosis – *Francesco Bonella*

The newly elected board of the newly established CN is as follows:
Francesco Bonella (DE) – lead
Jacob Sellares (ES) – co-lead
Paolo Spagnolo (IT) – co-lead
Filippo Martone (IT) – pat rep lead
Bernd Quadder (DE) – pat rep co-lead
Two working groups are established, the leads are Nadia
Nadia Nathan (FR) – pediatric patients.
Jelle Miedema (NL) – adult patients

8 patient associations and 13 HCPs are included already in this new group; more are expected. Minimal criteria are: 500 cases/year, 100 new patients/year, as well as other criteria (e.g. number of diagnostic procedures/year, or participation in clinical trials).

Future Plans:
- The CN wishes to start soon its activities and would like to be included in the ERN-LUNG Website and have a webpage for patient journeys and pathways; For example, also containing the list of the CN members will soon be circulated, as well as info material and list of centres who joined the CN.
- The CN will start with a survey on existing registries and biobanks specifically for Sarcoidosis.
- The group is also in search of specific Sarcoidosis registries and wishes to produce a clinical trial finder.

Question: Number of minimal criteria is too high, some “small” countries will never be able to join
Answer: The number is not that high.

7.8 Primary Ciliary Dyskinesia – *Petra Pennekamp*

The presentation was given via Zoom.

- Achievements of last 5 years:

- Number of patients - The CN has experienced a substantial increase of diagnosed patients in the past 5 years – 687 new patients (2013-2016) and 1298 new patients (2017-2021); which means it has increased upto 260 patients/year. The network has grown accordingly.
- Guidelines – published with help of ERS task force.
  New clinical decision-making tools present like a) consensus guideline for reporting transmission electron microscopy b) International BEAT-PCD consensus guideline for infection prevention and control fro PCD in collaboration with ERN-Lung – PCD CN c) Technical guideline on how to measure the nitric oxide in children.
- Activities - the PCD CN has installed regular meetings (BEATPCD, CILIA2022 etc) and participated in workshops (ERN-Lung – ERS). During COVID, the CN had 10 online meetings and met physically during the last ERS congress in Barcelona.
- Many educational and training activities such as:
  Participation in the ERS/ERN-LUNG Virtual School of Rare Respiratory Diseases.
  BEAT-PCD conference and PCD training schools organized through cost action in Portugal (2018) and Poland (2019).
  Contributions to the ERN-LUNG Academy with 5 Webinars.
  Onsite Training in PCD expert centers. E.g.: Münster hosted 8 healthcare professionasl between 2017-2023. Talks by PCD experts – 12 talks done out of which 10 are in youtube.
- Activities with various patient organizations and good connections with Italian patient association, Kartagener Syndrom und Primäre Ciliäre Dyskinesie e.V., US PCD foundation and breathing together.
- Registries – need to look for clinical outcomes. International PCD Registry is growing. Both number of individuals and number of centres participating in PCD registry have increased in the last 3 years.
- Clinical Trial Network - was established last year: it was the milestone of the PCD CN in 2022.
- Homepage - A PCD subcategory on the ERN-LUNG Website was created (it is the only CN who did that)

Future plans:

- Genetic information – need to increase entry of genetically diagnosed PCD patients for purpose of developing gene specific therapies.
- Clinical studies – 7 are finalized and 8 are ongoing.
- Improvement and contributing more e-cases and e-webinars.
- Associating with international PCD foundations around the world through ERN-Lung.

7.9 Pulmonary Hypertension - *Marc Humbert*

- Relationship with ERS is paramount. a) ERS has created an Assembly for Pulmonary Vascular Diseases, chaired by ERN-LUNG members. b) clinical research collaboration
- Multi-dimensional committee for guidelines published in 2022; endorsed by ERN-LUNG.

Quality indicators should be considered while the guidelines are being developed. It was done with experts through the Delphi rounds and published in the European Journal of Heart failure. ESC Quality indicators (see also under 4.2.2).

- Lay summary: patients are unable to understand the guidelines. Hence, lay summary is needed and Gergely would try to develop translations into all European languages.
- Survey on the use of PROs in 30 ERN-LUNG PH Centers (see also under 4.5). PROs are a priority for the PH CN.
- PH patient organization – Gergely Meszaros and Pippa Powell would be helping with communication and patient organization collaboration.
- ERN-Lung Academy: Contributions to the ERN-LUNG Academy with 8 Webinars
- Call to action at the European Parliament (see also under 5.2)
- Numerous publications, among others on Covid-19 and PH; endorsed by ERN-LUNG
- On establishing a CTN, there is appetite, and possibly an initiative will be taken soon.

7.10 Other Rare Lung Diseases – *Helge Hebestreit*

The meeting revolved around three topics:

- On the question of which diseases ORLD should cover, the CN suggests establishing an inter-ERN Workinggroup. An example of a possible cooperation wih another ERN (ERNICA) would be esophageal atresia.
- The list of diseases covered by ORLD should also be transmitted to the other ERN-LUNG CN, with a subsequent joint discussion to finalise which conditions are covered by their CN.
- During the next Online meeting (before summer):
  - The newly established BPD Working group could present its pathways for reflexion. a) evaluate existing errors in guidelines and for endorsement. b) start case discussions c) Registry and CTN in children and adults with BPD.
  - A survey on the use of PROs should be configured, even though due to the multiplicity of ORLD, this isnot that easy.

8. General Discussion

Question: Could ERN-LUNG finance open access to journals?
Answer: The EU says no, but we should insist

Question: Is an EU-Login enough to access CPMS?
Answer: No, the CPMS-login is a different one, but a EU-Login is still needed

Question: What is the ERN-LUNG registry composed of?
Answer: It has not been filled out with data so far, a revised data set will be sent out in the next weeks

Question: Could patients access the ERN-LUNG Academy?
Answer 1: Has to be dicussed and decided. It seems straight forward to have specific subset of offereings for patients (will be discussed with ELF).
Answer 2: Patient journeys are the right format for patients.

Question: Do UK hospitals still have to monitor their data?
Answer: The EU does not want them to do it anymore, but some UK hospitals still report them to us

Question: Is there any tool of patient satisfaction?
Answer: There has been a EURORDIS survey for patients in which ERN-LUNG participated, there should be a next coming up. The result was that the patients of ERN-LUNG centers were more satisfied than the non-ERN-LUNG center patients.

Question: How can patients work to help doctors in research?
Answer: There are multiple ways. Either listening to what we have to say, identifying errors and then educating your patient colleagues or getting the information from your fellow patients and get them to us and we can try to respond to that.

9. List of participants

#	SURNAME	NAME	INSTITUTION	COUNTRY
1	ALDECO	Malena	University Clinical Centre Ljubljana	SI
2	ANAGNOSTOPOULOU	Pinelopi	University of Cyprus	CY
3	BAKKEHEIM	Egil	Oslo University Hospital	NO
4	BALESTRO	Elisabetta	University Hospital of Padua	IT
5	BARGAGLI	Elena	Siena University	IT
6	BERGER	Dorothea	Frankfurt am Main University Hospital	DE
7	BOGGARD	Harm Jan	Amsterdam UMC	NE
8	BONELLA	Francesco	University of Essen	DE
9	BOOMARS	Karin	Erasmus University Medical Center	NE
10	BONTEMPO	Piero Enrico	Associazione Nazionale Alfa1-AT ODV	IT
11	BORIE	Raphael	BIchat	FR
12	BORRELLI	Melissa	Department of Translational Medical Sciences, Pediatric Pulmonology, Federico II University	IT
13	BOYD	Jeanette	European Lung Foundation	UK
14	BRONSVELD	Inez	University Medical Centre Utrecht	NE
15	BRUSSEL	Guy	Ghent University Hospital	BE

16	BURGEL	Pierre-Régis	Paris Descartes University / Cochin Hospital APHP	FR
17	CARR	Siobhan	Royal Brompton Hospital	UK
18	CERRI	Stefania	Center for Rare Lung Disease - AOU Modena	IT
19	CONFALONIERI	Paola	ASUGI, University Hospital of Trieste	IT
20	CONSTANT	Carolina Arez	Centro Hospitalar Universitario Lisboa Norte	PT
21	CORSICO	Angelo Corsico	Fondazione IRCCS Policlinico San Matteo	IT
22	COTTIN	Vincent	University of Lyon	FR
23	CRESTA	Federico	IRCCS Giannina Gaslini Institute	IT
24	CROWLEY	Suzanne	Oslo University Hospital	FI
25	DELCROIX	Marion	University Hospital of Leuven	BE
26	DUIJTS	Liesbeth	Erasmus MC	NE
27	FERRAROTTI	Ilaria	Pavia University	IT
28	FROIDURE	Antoine	Cliniques universitaires Saint-Luc	BE
29	GALL	Henning	University of Giessen Lung Center	DE
30	GALVIN	Liam	European Idiopathic Pulmonary Fibrosis and Related Disorder Federation	BE
31	GARTNER	Silvia	University Hospital Vall d'Hebron	ES
32	GENTON	Celine	European Respiratory Society	CH
33	GIBBS	Simon	Hammersmith Hospital	UK
34	GIETZ	Lisa	Frankfurt am Main University Hospital	DE
35	GIL	Wirtz	CHL Luxembourg	LU
36	GJERUM	Kim Nielsen	Copenhagen University Hospital Rigshospitalet	DK
37	GOHY	Sophie	Cliniques universitaires Saint-Luc	BE
38	GOTTLIEB	Jens	Hannover Medical School	DE
39	GOUBAU	Christoph	Cliniques universitaires Saint-Luc	BE
40	HAARMAN	Eric	VU University Medical Centre Amsterdam	NL
41	HALASZ	Adrien	Korányi National Institute of Pulmonology	HU
42	HATZIAGOROU	Elpis	Aristotle University of Thessaloniki	GR
43	HEBESTREIT	Alexandra	University Hospital Wuerzburg	DE
44	HEBESTREIT	Helge	University Hospital Wuerzburg	DE

45	HOCHREITER	Johann	Lungenfibroseforum Austria	AT
46	HUMBERT	Marc	Hopital Bicetre – Paris Sud, APHP	FR
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48	JANSA	Pavel	General University Hospital Prague	CZ
49	KOUDSTAAL	Thomas	Erasmus MC	NE
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53	MALAKAUSKAS	Kestutis	Hospital of Lithuanian University of Health Sciences Kauno klinikos	LI
54	MANGIAPIA	Mauro	Universita' di Torino	IT
55	MARTONE	Filippo	Amici Contro la Sarcoidosi Italia Onlus, Italy	IT
56	MC CARTHY	Cormac	St. Vincent's University Hospital	IE
57	MERKUS	Peter	Radboud University Medical Centre	NE
58	MESZAROS	Gergely	PHA Europe	HU
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62	MORANDI	Anna	Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico	IT
63	MORENO-GALDO	Antonio	University Hospital Vall d'Hebron	ES
64	MÜLLER	Veronika	Semmelweis University	HU
65	MUSCATO	Giuseppe	University Hospital Policlinico G. Rodolico - San Marco	IT
66	NOORDEGRAF	Anton vonk	Amsterdam UMC	NE
67	OLSCHEWKSI	Horst	Medical University Graz	AT
68	OMRAN	Heymut	Universitäts Klinik Münster	DE
69	PAGLIETTI	Maria Giovanna	Bambino Gesù Children's Hospital	IT
70	PAUL	Pia	University Hospital Würzburg	DE
71	PAVANELLO	Stefano	Unione Trapiantati Polmone di Padova	IT
72	PENNEKAMP	Petra	University Hospital Muenster	DE
73	POWELL	Pippa	ELF	UK

74	PRASSE	Antje	Medizinische Hochschule Hannover	DE
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86	SOTER	Szabolcs	National Koranyi Institute of Pulmonology	HU
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88	STEINMANN	Olivia	University Hospital Frankfurt	DE
89	TELLO	Silke	University Hospital Giessen	DE
90	TEMPELS	Petra	Ks & pcd Organisation	DE
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94	VARGHESE	Thazhone Stephy	Frankfurt am Main University Hospital	DE
95	VASAKOVA	Martina Koziar	Thomayer Hospital Prague	CZ
96	WACHTER	Elke de	UZ Brussel	BE
97	WAGNER	Thomas OF	Frankfurt am Main University Hospital	DE
98	WESTHOFF	Michael	Lungenklinik Hemer	DE
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100	WUYTS	Wim	UZ Leuven	BE
101	YIALLOUROS	Panayiotis	Archbishop Makarios III Hospital	CY