Does the reality of ERNs live up to our hopes and dreams?

Case Study: ERN-Lung ePAG

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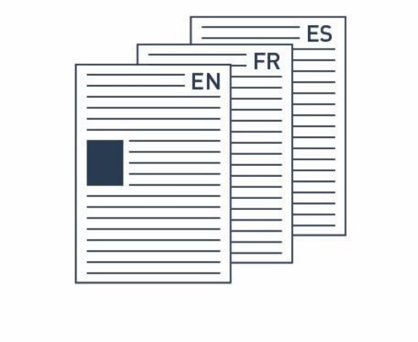
Patient involvement and engagement

ERS ELF

“Bringing together patients and the public with respiratory professionals to positively influence lung health”

- **Reliable information** for patients on all lung diseases, translated into **range of languages**
- Novel ways to **educate patients** & **raising awareness** of lung health
- **Shaping respiratory news** with latest scientific developments
- Growing network of **trained and engaged patients**
- **Involving** and **engaging** patients in the **life of European Respiratory Society** (ERS)
- Strengthening the **patient voice** for lung disease at **EU level**



Hopes and dreams for ERN-Lung

- Care
- Expertise
- New treatments
- Clinical trial participation
- Improved understanding of biology and progression

Hopes and dreams for ERN-Lung

- Raise awareness
- Make EU policies ‘work’ for rare disease community
- Research collaborations

“Current systems aren’t working properly and it is costly for patients to access treatment. Through the ERN-Lung, patients will have better access not only to treatment, but also expertise in their disease. This is really important.”

– Gergely Meszaros,

European Pulmonary Hypertension Association and ePAG member

Hopes and dreams for ERN-Lung

Is there an established treatment?

What are the standard guidelines for diagnosis & management?

Patients from different disease areas have **different priorities**

Are there more studies needed to understand disease mechanisms?

Is access to treatment variable across Europe?

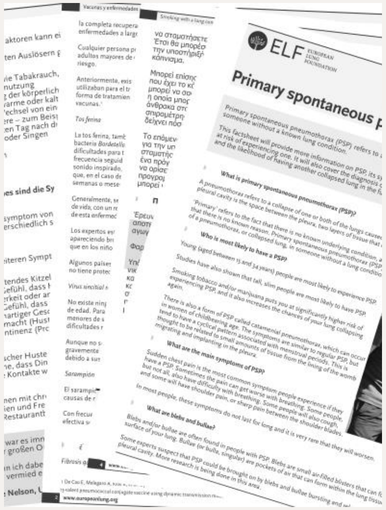
Can patients take part in clinical trials?

What are the challenges?

- Time and funding
- Representativenness
- Patient and professional knowledge
- Ways of working

Can we deliver our ambition?

- Tap into existing infrastructure & resources
- Build collaborative networks, well-placed to apply for funding
- Power in numbers, power in patients!



ERN-Lung experience to date

- ELF approached by ERN-LUNG to join advisory group
- EURORDIS ask ELF to help recruit to ePAG
- Patient representatives from all rare lung conditions
- ELF's patient organisation network, newsletter & social media
- **Huge enthusiasm and commitment to deliver for the benefit of patients**

“ERN-Lung will allow us to build collaborative networks to drive future research into new and emerging therapies, and allow more patients to access clinical trials. Through the network, we can build research capacity, which is especially important for the rare disease community”

– Kate Hill, June Hancock Mesothelioma Research Fund and ePAG member

Let’s not forget the ultimate goal!

Improve understanding, diagnosis and treatment of rare lung diseases for all patients in Europe!

Thank you and any questions?

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