



**ELF** EUROPEAN  
LUNG  
FOUNDATION

## Patient Organisation Networking Day ERS International Congress, 15 September 2018, Paris

### THEME FOR THE DAY

Partners in learning: changing the culture of medical and patient education

### ATTENDEES

85 individuals from 43 organisations and 21 countries attended with 22 posters



## Presentations

Download presentations from the ELF website at <http://www.europeanlung.org/en/news-and-events/news/ers-congress-overview-elf-patient-organisation-networking-day-2018>

**Keynote: Patients as Educators at University of Montreal** - *Annie Descoteaux, Patient Partnership Unit, University of Montreal, Canada*

The model used within the medical education, research and healthcare facilities at the University of Montreal which started as a pilot in 2010 and now has 200+ patients involved.

**Fight ASTHMA: a teenager's game** - *Nona Evghenie, Associazione Respiriamo Insieme, Italy*

A new video game APP for young people which aims to improve the knowledge and therapeutic adherence of the player. The game includes messages of prevention and encouragement. Quality of life data will be collected for studies.

**SarcoidosisUK Nurse Helpline** - *Jack Richardson, SarcoidosisUK*

In response to clinical, emotional and practical needs of patients, a nurse helpline was set up to provide information and support. Nurses directly affected by sarcoidosis and with empathy and experience in this area were recruited. They work remotely using cloud-based technology and receive around 5 referrals a week with 97% positive feedback received.

**Medical and Patient Education: Ukraine-Norway** - *Uliana Malofii, Sister Dalila, Ukraine*

This Pulmonary Hypertension (PH) Association collaborated with the Norwegian Association of PH by visiting their special rehabilitation centre for PH patients and a physiotherapist from Norway visited the Ukraine to run an exercise workshop with patients. Patients also met with a nutritionist and psychologist to ensure that these aspects were included in the development of their own exercise programme which is now up and running.

**Teaching first year medical students together** - *Mr Huub Kooijman, Dr Marlies Wijzenbeek, Erasmus MC, Netherlands*

A partnership between a patient with IPF and a respiratory doctor has the patient's story and description of their symptoms, investigations and feelings about having a deadly disease contribute to medical student education. The impact leads to better remembering, improved recognition of (rare) diseases and acknowledges the emotions of the doctor.

**Continuous professional development for physicians – why does it matter to patients?** - *Professor Daiana Stolz, ERS Education Council Chair*

Continuing professional development (CPD) ensures that professionals remain up to date with current practice. Professionals face medical advances in diagnosis, treatment and management; better informed patients; need for greater reporting and transparency; patient and professional cross-border mobility and decline in the retention of knowledge. Across Europe all physicians do not receive the same level of training as each country sets own standards for training. Example of a Swiss website where you can find out information about your physician - (<https://www.doctorfmh.ch/>).

## **Small table discussions:**

The feedback from discussions and postcards covered: how to improve medical education training and better involve patients, how to ensure better conversations between patients and doctors and the benefits and concerns around the growth of telemedicine and research as well as the importance of raising awareness in schools and with policymakers.

The main points are summarised below followed by some of the things we aim to do in response. See the Appendix on pages 5-8 for a more detailed summary of discussion points.

## **Medical and patient education:**

- Better communication/training for doctors e.g. we need to talk the same language.
- It is essential that patients are involved in healthcare professional training on a regular and not ad hoc basis.
- How to develop a model which reflects the complexities of care (for different disease groups and different socio-economic groups)?
- Patients need to be proactive and educate themselves.
- More discussion tools to empower patients and improve conversations.
- How can patients give feedback to healthcare professionals when there is pressure of time and it feels intimidating?

## **Infrastructure**

- Patients in most countries see less of their doctors and see a reduction in healthcare spending/hospital beds. What can we do to address this?
- How do we put patients into the communications loop for primary-secondary-tertiary care?
- Infrastructure needs to support patients supporting each other. Social media?

## **Raising awareness**

- Raising awareness in schools of respiratory diseases.
- Is a need for national/international awareness days for rare diseases too.
- Campaign for a No Car Day across Europe.
- Telemedicine:
  - Patient data sharing, consent and anonymity and potential impacts – concerns that this does not always happen well
  - Patient organisations have a responsibility to educate patients more about data and the benefits of including their data in research.
  - Patient organisations need to understand data management, sharing and to be more active in sharing data – this will help to change the dialogue patients have with clinicians and lead to more active conversations
  - Is there a role for patient organisations to hold data?

## How ELF plans to address some of these issues:

1. Develop an ERS communications training session for healthcare professionals at ERS Congress 2019 – developed with patients and professionals.
2. Currently in discussions for developing school resources to raise awareness in schools during ERS Congress 2019 which could then be adapted for wider use.
3. Contact any European No Car Days and link our Healthy Lungs for Life campaign. Also see how rare lung diseases can be covered in World Lung Day.
4. Potential to develop a new EPAP (European Patient Ambassador Programme) module on data sharing.
5. Ensure that next year's ELF Day theme focuses on important and relevant issue for patient organisations. Some themes suggested by you: Personalised health care and management; Prevention and behaviour change; Data registries; Quality of life from psychological view; How to work together for common interests.

If you have any other ideas for actions arising from the discussions or themes for next year, please email [jeanette.boyd@europeanlung.org](mailto:jeanette.boyd@europeanlung.org)

## Your feedback

- We received 34 completed feedback forms (40%) and saw an average rating score across all questions between 4 and 5 (Good to Excellent), which was great feedback.
- The most popular aspects of the day were the sharing of interesting ideas, making new contacts and the table discussions. The round table layout worked well, the quiz was a fun start to the day and having a theme worked very well.
- Suggestions made for improvements included: more videos, some translations, more time for posters and discussion, more healthcare professionals participating in the day, making sure the day meets the needs of both new and established organisations. The catering was not as good as last year and the room was too cold.
- Around 20 topics were suggested as themes for next year and 16 people offered to help with the planning – so we will be in touch!

## Appendix: Detailed discussion points made on the day and links to articles

Communication and conversations	
Patients and caregivers are experts in their own right – our stories are important	How can we ensure doctors listen?
We need to talk the same language	Healthcare professionals need to simplify their vocabulary and listen to patients
Discussion tools to improve these conversations are very important so are not one-sided. See links below:	Mechanisms are needed for getting better outcomes from appointments
<b>Tools from Allergy, Asthma Network:</b> <i>Severe Asthma, Shared Decision Making &amp; Checklists:</i> <a href="http://www.allergyasthmanetwork.org/education/severe-asthma/">http://www.allergyasthmanetwork.org/education/severe-asthma/</a> <a href="http://asthma.chestnet.org/patients/">http://asthma.chestnet.org/patients/</a> <i>Other Asthma tools:</i> <a href="http://www.allergyasthmanetwork.org/education/asthma/management-tools/">http://www.allergyasthmanetwork.org/education/asthma/management-tools/</a>	
Empower patients with tools e.g. pre-appointment questionnaires and helping patients to think more strategically about their conversations with doctors	Support patients to think about the questions they ask - Patient associations could provide questions that patients with a specific condition want answering
Patients with rare diseases seem to have better conversations with doctors – why? E.g. have more time; patients are more prepared and specialists in rare conditions may be more prepared to talk for longer about their subject?	COPD Giving intervention – developed 3 conversations with patients evaluated scientifically in clinical trials to find out how patients found the interventions – ADD LINK
Some organisations bring HCPs/researchers and patients together in a setting that is outside of the consultation room where different and more equal conversations can be had. See recently published article: <a href="https://rdcu.be/9gMM">https://rdcu.be/9gMM</a>	Patients in most countries both see less of their doctors and see a reduction in healthcare spending and hospital beds – there is less time for conversations. Would be useful to have a conversation with ERS about how we can address this?
How do we put patients into the communications loop (primary-secondary-tertiary care)?	Aim is for patients to be empowered through the process of shared decision making
Infrastructure needs to support patients supporting each other. Social media?	There should be top-down from doctors and bottom up from patients with a meeting in the middle which then helps patients to find solutions to their problems
Research in Netherlands showed the benefit of interventions to help nurses develop their communication skills. Nurses have more time than doctors. University of Utrecht study: The effectiveness of a nurse-led illness perception intervention in COPD	Conversations need ‘yeast’ to be 2-way e.g. conversation starter, question prompts = shared decision-making

patients: a cluster randomised trial in primary care (S Weldam)	
Patients need to be proactive and educate themselves e.g. Associations for expert patients (Patient Universities in France) – but it is a challenge	Doctors need to be more empathetic and patients need to become better experts in the questions they ask

### **Training for medical students – and patients**

Essential that patients are involved in healthcare professional training – and not just on an ad hoc basis – it needs to be regular	Should involving patients in medical education be regulated across Europe? One view was that we cannot generalise about this – there is a difference between rare diseases and more well-known conditions
Communication skills and learning from patients must start at University level – it is too late if this only happens at hospital level	Educating HCPs in how to communicate with patients still has a long way to go – they need to know about the general, social, psychological impacts on patients
Talk from NL Huub and Marlies- a great example of imparting the full impact of the condition – physical and social and builds on the medical and emotional knowledge of the student	Patients need to give feedback to healthcare professionals but there is pressure of time and it is intimidating
<p>Research articles referenced from Carolin Sehlbach of Maastricht University:</p> <ul style="list-style-type: none"> <li>• <a href="#">Certified – now what?</a> (Jan 2018)</li> <li>• <a href="#">ERS Congress highlight: educational forum on continuing professional development</a> (June 2018)</li> </ul>	

### **Barriers**

We all mostly agree that communication with healthcare professionals is paramount – but how to make it happen? How to translate it to real world with the whole medical community of healthcare professionals at ERS for instance and beyond?	Time pressures restrict
Communication is a varied experience and dependent on each doctor	How to develop a model which can face the complexities of care (for different disease and for different socio-demographic groups?

**Raising awareness in schools**

Raise awareness to support students with rare/chronic conditions so they are not excluded and there is less stigma	ELF is currently discussing with Madrid city whether there are any activities we can with schools during Congress 2019.
Raise awareness with students with condition, other students, teachers and parents	Lovexair has validated training in schools in Barcelona and Madrid with younger age group by providing online tools – this could be a good starting point.
Use art and creativity - allow children with respiratory conditions to express their emotional and practical needs and teachers other children how to become a ‘hero’ and be understanding and helpful	Key facts and messages about conditions in young people are needed to help them understand the emotional needs of children affected
Important for parents to encourage their child rather than limit them (out of fear) – patients can often do a lot more than others think they can	Education also needed for schoolmates to normalise respiratory conditions and to encourage inclusion and prevent bullying or teasing; and to show them how they can help their friends.
In Italy, some students are excluded from activities due to health conditions, but this is because teacher are not prepared/trained appropriately. If we give them the tools they can support students.	

**Raising awareness with politicians and decision makers**

Asthma Ireland leaflet to help when campaigning with politicians to raise awareness about what is important and creates a useful conversation started. They created 6 personas of individuals with asthma and provided 10 changes they needed – created as a visual life cycle	Campaign for ‘No Car Day’ which happened in Paris would be great to make happen throughout Europe to address impact of pollution
The ‘soft power’ of lobbying of some disease groups – genetic or rare diseases that make some disease at the very focus of interest of industry versus others that are completely neglected – we need national/international days for these diseases.	

**Telemedicine - Concerns**

Many individuals using telemedicine are not informed about what is sent from their machines to a central data point and not aware of what happens to their data once sent.	It is important for patients to understand why telemedicine is being used e.g. for cost reduction purposes; and how it will be used.
Data sharing and consent – many issues - around this – patients are not always asked for consent	

**Benefits**

Telemedicine is not just about cost savings but also about access to care e.g. for those who may find it hard to access a specialist regularly. It can also aid self-management from home – which is more convenient for some people and systems are struggling with chronic diseases and this can help with daily care management.	We have to embrace telemedicine – it has huge potential to reduce waiting lists but there also needs to be standards so that there is good quality across the board.
Patient organisations have a responsibility to educate patients more about data and the benefits of including their data in research e.g. it may result in better care packages, they may get other resources.	Patient organisations need to understand data management, data sharing and to much more active in sharing data – this will change the dialogue patients have with clinicians – and will lead to more active conversations about the future of ‘my healthcare’.

**Should anonymous data be made available for research purposes?**

Some patients are against this e.g. it could endanger access to private health insurance; others feel generally this is a good thing	Need to create a trusting environment to reassure patients that their data will remain anonymous
Even if data is used anonymously, patients should be informed as to how it will be used and when they can give informed consent. They need to know about data, what their data means, what involvement in research means, data management, data sharing etc	Is there a role for patient organisations to hold the data? Meaning that doctors have to apply to access our data? This would strengthen our position