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European Lung Foundation: past, present and future

When commissioned to write this editorial, the *Breathe* Chief Editor suggested the title “What has the European Lung Foundation (ELF) ever done for you?” To avoid offence, he did go on to explain that it was an opportunity to let the *Breathe* readership understand how ELF has developed, the integral and important role it now plays in the life and work of the European Respiratory Society (ERS) and its members, and our vision for the future.

Past

The ERS founded the ELF 12 years ago, with the initial aim of raising money through donations to fund research. This proved difficult for several reasons, not least because people in general prefer to support organisations and projects in their own countries and more closely related to their personal experience. Although fundraising is still a part of what ELF does today, it is certainly not the *raison d'être*.

ELF also began work on the first edition of the Small White Book, which was published in 2003. In a simple tone, accessible style and in multiple languages, the publication ensured that the wider public received key information on lung health.

The Small White Book was well received across Europe and really demonstrated to the ERS, the potential that the society had to better communicate with patients, the public and policy makers.

Following on from the success of the White Book, the ELF website was developed (www.european-lung-foundation.org), in which the content of the publication was showcased and made available to all. The website was developed in eight different languages: English, French, German, Spanish, Italian, Polish, Russian and Greek.

It was clear that there was a greater need for specific patient information; materials that ERS members could use and direct their patients too. With this realisation, ELF factsheets were developed to give disease- and treatment-specific information. ELF continues to produce four such factsheets each year, which are published in *Breathe* and online on the ELF website (www.european-lung-foundation.org/1037).

In 2002, ELF had its first foray into public awareness campaigns when it was tasked with highlighting the importance of lung function testing and raising awareness of chronic obstructive pulmonary disease in the host country and city of the ERS Annual Congress. Working with a range of key sponsors, ELF developed the concept of the “spirometry tent”. This ran for eight consecutive congresses and, on its last event in Vienna, 2009, saw more than 3,000 people have their lungs tested over a two-day period. Consistently, each year in different cities and countries, the ELF referred between 20 and 25% of those tested to their general practitioner for further assessment. This activity

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None declared.

planted the seed for the World Spirometry Day campaign, which is now an international bi-annual event co-ordinated by ELF on behalf of all the international respiratory societies.

Present

ELF went through a strategic review process at the beginning of my mandate in 2010. In this review we looked at what the ELF was doing well and what it had the potential to achieve. Two distinct workstreams evolved.

- Translating, disseminating and advocating the scientific activity of ERS to a lay audience.
- Listening to, involving and engaging patients in the life of ERS.

Translating, disseminating and advocating the scientific activity of ERS to a lay audience

ELF continues to develop relevant and informative patient material and the second edition of the White Book in 2013 will allow the ELF website to be totally redesigned and revamped.

ELF has further strengthened its communication with the wider public, after being invited to be a partner on a number of European Union FP7 research projects, in which it acts as the conduit to inform the public about the work being carried out.

The work of the ERS is also communicated to the media, as the ELF is responsible for the ERS press office. This activity ensures new and outstanding advances published in the *ERJ* or presented at the ERS Annual Congress are communicated to a lay population *via* the media. It also allows the voice of the respiratory professional to be heard in public debates.

Another important way we have provided information to patients is via the ELF Air Travel Database. This online resource allows patients to check the oxygen supplementation policy of different airlines in Europe. As there is no consistent policy between airlines, the database aims to provide one central point of information for patients to check before making travel arrangements.

The first World Spirometry Day was held in 2010 and aimed to encourage the people of the world to care about their lung health and to have their lungs tested. In 2012, the

campaign saw >760 testing and training events being performed in 65 countries across the globe.

Listening to, involving and engaging patients in the life of ERS

The second workstream has been really important to the maturation of ELF and is centred on involving people with lung diseases and the general public in the life and work of the ERS.

In 2010, as part of the revised strategy, we set out a plan to a network, and subsequently an advisory group, of patient organisations from across Europe, covering all respiratory disease areas. The aim was to really get a feel for the patient activities already happening across Europe and to engage with a strong group of patients and carers willing to get involved in ERS activities. We worked from the beginning with our colleagues from the European Federation of Allergy and Airways Diseases Patients Associations (EFA), who represent patient organisations in asthma, allergy and COPD. As this activity grew, we also brought together the voice of all patients with respiratory conditions and ventilatory problems.

This is currently developing rapidly, especially in the field of Task Forces. We are working with ERS Task Force chairs to identify areas in which patients can really help with the development of consensus statements or clinical guidelines: through patients becoming part of Task Force committees, patient-orientated literature searches, online patient questionnaires, patient focus groups and patient versions of the final guidelines.

We have started to get patients actively involved with the ERS Annual Congress. In 2012, we welcomed David Supple and his son Alex to the Congress in Vienna. David spoke at a symposium on improving adherence to asthma medication. He presented the patients' perspective from his experience of raising Alex, who has asthma and a wide range of food allergies. I am delighted to say that during the ERS Annual Congress this year in Barcelona, Spain, three patients will be taking part in mainstream symposia, giving their perspective and input to the debates. The topics for 2013 include patient selection for lung transplantation in cystic fibrosis, the ideals and goals for personalised medicine, and living with interstitial pulmonary fibrosis.

Working together with the ERS Advocacy Department in Brussels, Belgium, the ELF is also encouraging patients to discuss the issues important to them with policy makers. Ensuring the voice of the person living with a respiratory condition is heard in policy debates.

Future

The ELF has a busy agenda over the next few years; ensuring patients are partners in all that the ERS does and making sure the professional and patient voice is in unison and working towards the same goals.

2013 will see the launch of the European Patient Ambassador Programme (EPAP; www.EPAPonline.eu), an online training programme to help patients and carers develop the skills needed to input into research, guidelines, advocacy and media activities at any level. We hope that the EPAP programme will empower and facilitate a pool of patients from all walks of life and with any long-term condition, who are passionate and willing to get involved in healthcare.

We will continue to work with the ERS to ensure that the key messages from the respiratory world are communicated to those that should hear them: patients in need of advice, policy makers who need to adequately address lung health in the 21st century and every member of the public who must care about their lung health and know how to monitor it.

What could ELF do for you?

ELF is your foundation as a member of the ERS, associate of the ERS or attendee at the Annual Congress. There is growing need for patient and public involvement in healthcare, especially with the rising number of people with noncommunicable disease. We invite you to use us, our resources and our network, and to work with us to ensure that professionals, patients and the public are speaking with one voice to improve respiratory health.

So if the ELF has never done anything for you, make sure it does in the future!

- Use our factsheets: download them from our website and give them to your patients or direct your patients to our site
- Suggest a factsheet topic appropriate to your patients or your advocacy efforts
- Help us to raise awareness of lung health and the importance of lung function testing by taking part in World Spirometry Day
- Involve patients in your research or task force: not just as a second thought or an add-on but as integral members of the team.
- Encourage your active and engaged patients to take the EPAP course and to get involved in the future of their healthcare.