

LAM patient priorities project - 2016 end of year summary

An international online survey and a joint patient-healthcare professional workshop was held at ERS Congress 2015. The information and priorities that came out of these consultation activities formed the basis for the LAM 'patient priorities' project of which the following has been achieved:

- An **article** was published in *ERJ Open Research* earlier this year, calling for [improved diagnosis, access to drugs and raising awareness of other priorities for people living with LAM](#) based on the findings of the international survey and workshop.
- A **patient advisory group** of 9 women from Denmark, Germany, Italy, Ireland, Netherlands, Norway, Sweden and UK was formed to help guide the development of a new patient information website for women with LAM across Europe.
- The **LAM patient priorities website** will be one of the first to be launched in a family of new patient-centred websites supported by ELF and promoted to ERS members as quality resources for individuals living with the condition.

The website will provide quality LAM information in a number of different languages and include links to support organisations/groups and specialist centres in Europe plus the latest research. The website launch will be in March 2017.

ELF is investing in a new platform to give greater prominence to these new websites (see draft design which shows the first three projects: lung cancer, LAM and bronchiectasis).

- A **LAM factsheet** has been written with input from both patient advisory group members and healthcare experts so that it contains accurate medical information as well as the patient perspective of living with the condition day to day. The factsheet is currently being translated into multiple languages and will be accessed through the new website.

Further updates will be included in the ELF newsletter throughout 2017.

