SPEAKING AS A PATIENT AT THE ERS INTERNATIONAL CONGRESS – a handbook
1. Introduction to the ERS International Congress

The European Respiratory Society (ERS) International Congress is one of the biggest research conferences in the world. It brings together leading scientists and healthcare professionals from around the globe to hear about the latest research and education in lung health and to discuss lung health issues. The Congress is held in a different European city each year.

The European Lung Foundation (ELF) works with ERS to ensure that the patient voice is heard at Congress and to help health professionals improve their awareness of the patient perspective.

Cover image: An idiopathic pulmonary fibrosis (IPF) patient from the UK sharing his experience
2. Why have you been invited?

Since 2011, patient speakers have been contributing to sessions at Congress with their perspective and real-life experience. Both the patient speakers and healthcare professionals attending the sessions tell us how valuable and insightful they find this input.

Contributing to Congress as a patient speaker will also provide you with experience in representing patients’ concerns at an international level and in helping to shape the future of research and care. It can enable you to network with healthcare professionals, scientists and patient organisations.
3. What is a Congress session?

You have been invited to give a short presentation as part of an ERS Congress session. ELF will have let you know which type of session you will be participating in:

- Symposium – a series of 3–5 different presentations looking at a specific topic related to lung health, such as chronic cough or home mechanical ventilation. The session usually lasts 1.5 to 2 hours. You will be asked to talk about your experience for about 7–10 minutes as one of the first speakers in the session.
- Postgraduate course – a session to educate healthcare professionals on the latest research and procedures for the best clinical practice. Usually 1–2 hours. You will be asked to talk about your experience for about 7–10 minutes.

Each symposium or postgraduate course has at least two Chairs, who are responsible for making sure the session runs on time. They will know and be excited that you will be speaking as part of the session.
The number of people who will be in the audience at a symposium to listen to the presentations varies, but in some cases it could be up to 1,000.

Speakers usually use PowerPoint slides to illustrate what they are talking about, including pictures and graphs.

4. Preparing your presentation

We will already have had contact with the session organisers to discuss how your talk can fit in with the other presentations and any key points they think you should mention.

Once you have agreed to take part you will be sent an official invitation by ERS. This will be online. You will be asked to include any information regarding General and Tobacco Industry Conflicts of Interest, which you will have to submit online to ERS. Instructions will be provided with your invitation.

We will provide you with full details of the session, including the title and aims of the session, the names of the other speakers and the titles of their presentations, perhaps with some suggested points for you to include.

ELF is happy to help you prepare your presentation to put your experience into words, and can help you put together some PowerPoint slides to illustrate your experience.

You will be asked to share your slides with the ERS office using an online system before you arrive at Congress, or you can upload them onto the system at the Congress centre.
5. Getting to Congress

Please make your own travel arrangements, such as booking your own flights/trains and accommodation.

If you need to stay overnight you can book your own accommodation using the Congress hotel booking service (also available on the main Congress website), or by doing your own web searches (e.g. www.expedia.com) or contact any of the local tourist websites. You will need to book your accommodation as early as possible, as hotels close to the Congress centre get booked out very quickly. Please be aware that the Congress centre will not be located in the city centre, so if you want to stay in the city centre you will need to plan for travelling time to reach the Congress centre.

If you would like advice on the timings of when to arrive please contact ELF directly via email (Sarah.Masefield@europeanlung.org).

6. Finances

Speaking at Congress is a voluntary role and you will be reimbursed for travel and accommodation with a bursary of 600 euros if you are travelling from abroad. If you are travelling from within 150 km of the city where the Congress is being held you will receive 300 euros. If you need a carer or wish to be accompanied by a partner or relative, you will need to inform us who you want to accompany you and why. We will provide them with a bursary on the same terms.
You can collect your bursary at the Finance Desk which is located in the main entrance of the Congress centre. You will need to show a form of identification, such as a passport or drivers’ licence, and will receive the bursary in euros in cash. This desk will be open Saturday to Monday 07.30–17.30, Tuesday 08.00–17.30 and Wednesday 08.00–11.00.

7. Support during Congress

During Congress all ELF staff members will have a local mobile number that we will send you, so you will be able to reach us at any time during the Congress.

We will agree with you a time and meeting point where your ELF contact or your guide will meet you, answer any questions and take you to the room where your talk takes place. You will usually meet at the scientific programme information desk in the main entrance. At this point you will also collect your day registration badge for Congress.

A meeting of asthma patients and clinicians for the U-BIOPRED project
Your guide will be a local medical student or nurse attending Congress who has volunteered to accompany and support you throughout your time at Congress and will take you to your session. They will be there during the session to support you and help you with anything you might need, such as help with your slides during the presentation.

8. Your requirements

The Congress centre is a large and busy place. Be prepared for thousands of people moving around the building at peak times. Whilst we try to ensure that we limit the amount of walking inside the Congress centre for you, it is not always possible to keep the distances short.

Please let us know about any mobility requirements you might have so that we can provide a wheelchair or allow extra time to get to the room you will be presenting in. It is essential that you tell us about any health or mobility
requirements in the form included in this handbook, and return the form to us as soon as possible by email or fax. It would also be helpful if you could provide information on the form as to whether you require and will bring your own oxygen to the session and any impact this may have on your participation at Congress.

9. Congress registration

Everyone attending Congress, including patient speakers, need to be registered in order to access the Congress centre. We will register you for Congress and an ELF member or a guide (see Section 7) can help you collect your Congress badge from the VIP and speaker registration desk in the main entrance of the Congress centre.
If you have informed us that you need a partner or carer with you, we will also register them, but they will need to collect their Congress badge from the VIP and speaker desk. This is located in the main entrance as well, and we can also help your carer to collect their Congress badge. Everyone at the Congress must wear their registration pass around their necks at all times, so that the security personnel know that you have permission to be inside the Congress centre.

Your badge will include a map of the Congress centre and a small programme of all the events taking place. Please note that your badge will not permit you to enter the exhibition area at Congress. This is because industry representatives (drug companies and companies selling medical equipment) are not allowed to advertise to the public or talk directly with patients. If they break this rule, both the company and ERS will receive large fines. We ask all patient speakers and anyone accompanying them not to enter this part of Congress. This will be clearly signed and easy to avoid. We will be happy to discuss any further questions that you may have about these restrictions.

10. Sorting your presentation slides at Congress

Your guide will meet you when you arrive on site on the day of your presentation. If you are presenting at a symposium or a postgraduate course and have not already uploaded your presentation slides onto the Congress IT system, your guide will take you to the ‘speaker preview room’. You should bring your slides on a memory stick or laptop. Slides must be uploaded no later than 90 minutes before the session.
that you are speaking in is due to start; for example if the symposium starts at 14.00, you must have uploaded your slides by 12.30 that day. If the symposium begins before 10.00 you will need to upload your slides the day before.

In the speaker preview room, you may be asked whether you are happy to have your photo taken for use as part of a webcast and if you agree for the ERS to make your slides available on their e-learning website after your presentation. Only ERS members can access these resources. You will also be asked to sign a “Conflict of interest declaration”.

The speaker preview room is usually open 07.30–17.30 Saturday to Tuesday and 08.00–11.00 Wednesday.

11. Other things to do during Congress

Your badge entitles you to attend other sessions taking place on that day, which you might want to listen to. To make it easier for you we will send you a list of sessions taking place that day relating to your condition or lung health in general, which we think might interest you.

The past ELF Chair speaks about the European Patient Ambassador Programme (EPAP)
You might also want to visit the World Village at the Congress centre, where more than 25 of our national and European partner patient organisations will have stands promoting their role and activities in supporting people with lung conditions. They would be happy to meet and discuss their work and patient representation with you.

Your registration will also include a free public transport ticket for the day, which you can use to explore the city in your free time on your day of Congress attendance.

12. The European Patient Ambassador Programme (EPAP)

ELF has developed a free online course, entitled the European Patient Ambassador Programme (EPAP), to help patients and carers understand how healthcare, research and guidelines work and how to get involved and engage in advocacy and media activities.

Those who register for the programme can choose to become part of a network of patient ambassadors and receive details of opportunities to input into different activities, such as the development of new guidelines on treating a specific condition, or speaking at an event about your condition and how it affects you.

The programme is currently only available in English but we hope to translate it into other European languages in the future.
Information about EPAP is available at www.epaponline.eu, or email Kerstin Morrison at Kerstin.Morrison@europeanlung.org.

### 12. Appendix: Forms and what to do with them

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<th>Form Description</th>
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<td>Consent form for use of media</td>
<td>Fill in and bring to Congress</td>
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<tr>
<td>Disclaimer for medical equipment health risks</td>
<td>Fill in and bring to Congress if needed</td>
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<tr>
<td>Special requirements form</td>
<td>Return to ELF immediately</td>
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<tr>
<td>Post-Congress feedback form</td>
<td>Do online after Congress:</td>
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<td></td>
<td><a href="https://www.surveymonkey.com/r/patients-speakers-participants-at-congress-feedback">https://www.surveymonkey.com/r/patients-speakers-participants-at-congress-feedback</a></td>
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Photo and media consent form

This form is used to record the written consent for images and/or the spoken word or recorded voice to be used for publicity purposes.

This could be a photograph or video recording that has been taken by ERS/ELF, a photograph or video recording that you have submitted to us, a photograph or video recording taken by another individual at an ERS/ELF event or the content from an interview with the ERS/ELF.

It is your right to refuse photographs or video to be taken of you or used in any related publicity. Please let us know your preferences by completing the form below.

By completing and signing this form I have declared my view towards the use of photography, video recordings or interviews with/of myself. Please tick the statements that you agree with.

1. I am happy for photographs and video of me to be taken for publicity purposes

2. I am happy for photos and video to be used in the following ways:
   • in summaries published either online or in print
   • on the ERS or ELF website
   • future ERS event promotion
   • submitted to the press and media for use in their publications

3. I understand that any images or video taken are the property of ERS

4. I understand that I can request electronic copies of any photos or videos of me taken by an official photographer

5. I am happy for spoken word in the interview I provided to be used in future publicity

Name     Date  Signature
Disclaimer for medical equipment

This form is used to record your written consent with regard to any medical equipment you may bring to Congress with you.

By completing and signing this form I have declared my responsibilities for my own personal medical equipment.

Please tick the statements that apply to you and that you agree with.

- I understand that I am fully responsible for my own wheelchair and that ELF/ERS will not be liable for any damage to it.  

- I understand that I am fully responsible for my own oxygen apparatus and that ELF/ERS will not be liable for any damage to it.  

- I understand that I am fully responsible for other medical equipment/apparatus and that ELF/ERS will not be liable for any damage to it.  

Name    Date    Signature
Patient speaker at Congress – special requirements form

The Congress centre is a very big and busy place. Whilst we take every step to ensure that you will not have to walk long distances inside the Congress centre, it is not always possible to keep the distances short.

We will be able to provide wheelchairs if you need one. It is therefore essential that you tell us about this and any other requirements you have by ticking any relevant boxes below and/or sending us details by email:

1. **Wheelchair:**
   - I will require a wheelchair inside the Congress centre. □
   - I will bring my own wheelchair to Congress. □

2. **Oxygen:**
   - I will bring oxygen with me. □
   - I will require some help with carrying my oxygen. □

3. **Dietary requirements:**

During some sessions, food or light refreshments will be provided. Please indicate any dietary requirements (vegetarian, allergies etc) below.

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Name ___________________________  Date __________  Signature ___________________________
Patient speaker post-Congress feedback

Please take a few minutes to provide us with feedback about your Congress experience. This will help us identify areas which we could change or improve for future patient speakers.

Please either complete and return the form below to us, or fill it in online at: https://www.surveymonkey.com/r/patients-speakers-participants-at-congress-feedback

1. On a scale of 1–5, 1 being bad and 5 being excellent, rate your experience of the following:
   - Contact from ELF before Congress
   - Information about Congress/the handbook
   - Support from ELF with the preparation of my presentation
   - My guide during Congress
   - Getting around the Congress centre
   - Uploading my slides before my session and help with technical issues
   - Being made welcome by the session chair
   - My presentation

2. Did you visit the World Village?
   Yes □   No □

3. What did you find most positive about your experience of being a patient speaker at the ERS International Congress?

4. What, if anything, could have been more positive or improved your experience?

5. What advice would you give to someone else taking part as a patient speaker?