PARTICIPATING 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.
2. Why have you been invited?

Your role as a patient participant is to contribute to sessions by being the patient. This means that you have volunteered to be available to answer questions that the healthcare professionals might want to ask about your condition, treatment, any side-effects of treatments or your disease management. They might also ask you to demonstrate the use of your equipment or carry out some tests on you while you are there.

Please note that the healthcare professionals will not perform any invasive procedures on you without your agreement or cause you physical discomfort. If, however, you do feel discomfort at any point, please tell the healthcare professional immediately.
3. Who is who at Congress?

There are a number of different people that you might have contact with before and at Congress. These include your ELF contact, your guide and the healthcare professionals.

Your ELF contact
A member of the ELF team who will be in touch with you prior to Congress to answer any questions you may have about your participation, and to keep you up to date with the arrangements for the session.

Your guide
A medical student or a nurse, local to where the Congress takes place. They will be your contact for your day at Congress. This means they will meet you in the Congress centre, help you with registration and claiming your reimbursement, and they will accompany you to your session and stay throughout.
Healthcare professionals
Healthcare professionals are the people who will be in the session in which you will participate. They are the doctors, nurses, physiotherapists and other professionals working in the medical field.

4. Preparing for Congress

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.

Your ELF contact will provide you with the details of what, if anything, the healthcare professionals leading the session would like you to bring with you on the day. We will let you know these details well before the Congress, so that you have plenty of time to prepare.

A post-polio patient shares his experience of home mechanical ventilation
5. Support

We will provide you with all the details about your session, such as a timetable for the day, location of the venue, how long the breaks will be, and catering. You will be able to discuss any aspect of your participation with your ELF contact prior to and during the Congress.

Your guide can meet with you at a pre-arranged time to accompany you to your session. You are welcome to bring along a family member or a friend to accompany you for the day.

6. Getting to Congress

Please make your own travel arrangements, such as booking your own trains and any other transport. Some helpful information is provided on the Congress website: www.erscongress.org

If you would like advice on the timings of when to arrive and leave, we will be happy to provide help.
7. Finances

Participating in 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 money 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. You will receive the money 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.
8. Congress registration

Everyone attending Congress, including patient participants, needs to be registered in order to access the Congress centre. We will register you for Congress and an ELF staff member or your guide will help you collect your Congress badge from the VIP and speaker desk in the main entrance of the Congress centre.

If you have informed us that you will bring a partner or carer with you, we will also register them, and they will need to collect their Congress badge from the VIP and speaker desk. Everyone at the Congress must wear their registration badge 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.

9. Your requirements

The Congress centre is a very big and busy place. However, your guide will be able to ensure you can find where you need to be. Be prepared for thousands of people moving around the building at peak times. Whilst we 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 may have so that we can provide a wheelchair or allow extra time to get to the session room. It is essential that you tell us about this in the form included in this handbook. It would also be helpful if you could provide information on the form as to whether you require and will be bringing your own oxygen and any impact this may have on your participation at Congress.
10. 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 the programme is available at www.epaponline.eu, or email Kerstin Morrison at Kerstin.Morrison@europeanlung.org.

12. Appendix: Forms and what to do with them

| Consent form for use of media | Fill in and bring to Congress |
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 subject 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 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?