

# EFA Meet & Greet with the EU training

## Patient involvement in clinical development: practical implications for meaningful engagement

### Date & Time

23 April 2024, 9:30 - 13:00 CEST  
Online event

### Context

The Meet & Greet with the EU series is part of EFA's 2023 Capacity Building Programme.

In 2022 EFA hosted a Meet & Greet with the EU focused on understanding the new EU Clinical Trials Regulation and its impact on patients, with a particular focus on the Clinical Trials Information System (CTIS) overseen by the European Medicines Agency (EMA). To complement these learnings, this year EFA will host an online Meet & Greet with the EU training on '**Patient involvement in clinical development: practical implications for meaningful engagement**', aiming at facilitating patients' access to research and clinical trials as well as provide the EFA Members community with practical knowledge on the new EU guidance on Good Lay Summaries.

The Meet & Greet with the EU event will have a particular focus on **decentralized clinical trials**, to increase patients' access, and the **new EU guidance on Good Lay Summary Practices**, an essential tool to facilitate the understanding of complex medical information for patients and general the public.

The Meet & Greet with the EU is an opportunity to deepen knowledge of patient engagement in research by staying updated on the latest trends and learning practical skills.

### Specific Objectives

Empower EFA Members, young patient leaders linked to the European Allergy and Asthma Youth Parliament, and other patients by fostering new skills and knowledge to facilitate more effective advocacy and engagement in research studies at the EU and/or national level advocacy.

### Target audience

- EFA Members
- Other Patient organisations' representing those living with respiratory or allergic diseases
- Young patients members of the EFA European Allergy and Asthma Youth Parliament

### EFA Objective

INFORM: EFA builds patient evidence, momentum, and capacity for change in prevention, care and participation for people with allergy and airways diseases.

# EFA Meet & Greet with the EU training

## Agenda

### Welcome & Introduction

**9:30 - 9:45**

#### Session Description

This session will kick off the meeting with a brief round of introduction and set the stage for the day with the presentation of the Agenda and Objectives of the meeting.

#### Speakers

- **Marcia Podestà**, EFA President
- **Florian Lasch**, PhD, Biostatistics Specialist, European Medicines Agency (EMA)

#### Moderator

- **Valeria Ramiconi**, EFA Programme Manager

### 01 . Patient engagement in research

**9:45 - 10:15**

#### Session Description

This session will provide a brief introduction to the different levels of patient engagement in research studies, with an overview of the challenges that patients face to be meaningfully involved in research. The session will also introduce topics related to the patient's involvement in clinical trials, including decentralised clinical trials.

#### Speakers

- **Valeria Ramiconi**, EFA Programme Manager
- **Claudia Louati**, Head of Policy, European Patients Forum (EPF)
- **Claire McQuade**, Patient Advocate, COPD Support Ireland

#### Moderator

- **Valeria Ramiconi**, EFA Programme Manager

### 02 . Patient involvement in clinical development and practical implications for (decentralised) clinical trials

**10:15 - 11:15**

#### Session Description

Session 2 will tackle patient involvement in clinical trials. The topic of how patient involvement in decentralised clinical trials could happen is discussed.

#### Speakers

- **Florian Lasch**, PhD, Biostatistics Specialist, European Medicines Agency (EMA)
- **Gill Hayes-Bell**, Senior Director, Patient Science, AstraZeneca
- **François Houÿez**, Information & Access to Therapies Director & Health Policy Advisor, EURORDIS
- **Özlem Ceylan**, President of Living with Allergy Association and EUPATI Fellow

#### Moderator

- **Isabel Proaño Gómez**, EFA Director of Policy and Communications

## Coffee Break

### 03 . EUPATI Workshop: Good Lay Summaries Practice (GLSP) and patient involvement

**11:30 - 12:10**

**Session Description**

Session 3 will provide the participants with the principles of GLSP and the role of patients' involvement in that standard are presented. An overview of practical tools and governance for patient involvement in GLSP will be provided.

**EUPATI Trainers:**

- **Ingrid Klingmann**, MD, PhD, FFPM, FBCPM, GFMD PHARMAPLEX bv, AGAH, EUFEMED, EFGCP, PharmaTrain Federation
- **Tamás Bereczky**, MA, PhD, Research Project Coordinator Research Project Coordinator, Deutsche Aidshilfe

### 04 . Exercise – what is a good GLSP?

**12:10 - 12:40**

**Session Description**

Session 4 will provide the participants with a short presentation, followed by a practical exercise on the qualities of a lay summary.

**EUPATI Trainers:**

- **Ingrid Klingmann**, MD, PhD, FFPM, FBCPM, GFMD PHARMAPLEX bv, AGAH, EUFEMED, EFGCP, PharmaTrain Federation
- **Tamás Bereczky**, MA, PhD, Research Project Coordinator Research Project Coordinator, Deutsche Aidshilfe

### Wrap-up & Closing

**12:40 - 13:00**

**Moderator:**

- **Valeria Ramiconi**, EFA Programme Manager