

EFA AGM: EFA Networking Meeting including Event at the European Parliament Brussels, 17th June, 2013 08.30/9.00-17.30 hours – Draft Agenda

Objectives:

- A. Share best practices, projects and ideas by members in particular with relation to the Working Groups on Allergy, Asthma and COPD.
- B. Provide opportunity to collaborate and help to plan for the year ahead
- C. Introduce the new European Parliament to EFA Members
- D. Present the preliminary outcomes and progress made in EU Projects for respiratory diseases in which EFA is an active consortium member
- E. Initiate public discussion of how EU research projects benefit & involve patients now and in the future

Members Working Group Programme:

1. **Parallel Working Groups for Food Allergy and COPD:** EFA Project Briefings, Sharing Best Practices and Planning Ahead (1 hour) *Chairs: Michael Wilken and Roberta Savli*

COFFEE BREAK (30min) – *members can continue discussions while room is reassembled*

2. **Joint Asthma and Allergy Working Group:** EFA Project Briefings, Sharing Best Practices and Planning Ahead (1 hour) *Chairs: Christine Rolland and Lina Buzermaniene*
3. **Feedback and Summing Up:** Reports from Working Groups, Conclusions (20 min)
4. **Introducing the New European Parliament:** Roberta Savli, EU Policy Adviser, (20min)

LUNCH BREAK (1 hour)

EFA EU Programme (14h00 – 17h30)

5. **Does the innovative research for allergy and respiratory disease in the European Union benefit patients and what's new?** EFA event at the European Parliament
→ See page 2-3 for more details

Does the innovative research for allergy and respiratory disease in the European Union benefit patients and what's new?



European Parliament
Tuesday, 17 June 2014 14.00 – 17.30

Draft – Event Programme

Session 1: Updates on innovative research for allergy and respiratory disease in the EU	
14.00	Introduction – MEP Address,
5-10min	Comments on EFA's experience in a diverse range of EU projects – EFA President
10-15min	An overview of the EC's research initiatives for medicines, European Commission Representative (same as Panel)
15min	AirPROM – Project Coordinator, Patient (new ELF chair?)
15min	MeDALL – Jean Bousquet (INSERM - Project Coordinator), Per-Ake Wecksell (EFA Board Secretary)
15min	U-BIOPRED – Louise Fleming (Imperial College), Patient (PIP Representative)
15min	EARIP – Samantha Walker (Asthma UK – Project Coordinator)
Session 2: Panel Discussions concerning the impact of patients on EU research	
30-40min	<p>Panel Session 1: <i>How will the projects shape a better future for patients and healthcare systems with the burden of respiratory diseases?</i></p> <p>AirPROM Project Coordinator MeDALL Project Coordinator European Commission Representative (DG SANCO) European Presidency Rep. EMA Director (OR Association Internationale Mutualité (AIM) Rep. OR IPCRG representative)</p> <p><i>Moderator: David Supple, U-BIOPRED PIP</i></p>
10-15min	Discussion: Q&A
30-40min	<p>Panel Session 2: <i>How could a European Patient Input Platform (PIP) benefit EU projects?</i></p> <p>Louise Fleming (Imperial College) EPF Chair European Commission Representative (DG RESEARCH) Member of European Parliament</p>

	PIP Representative <i>Moderator: Scott Wagers (Bioscientific Consulting)</i>
10-15min	Discussion Q&A
5-10min	Closing Remarks from the MEP
Total :	3.5 hours of educational content

Purpose:

EFA's event at the European Parliament in June 2014 "How does innovative research for respiratory diseases in the EU involve patients? The examples of AirPROM, EARIP, MeDALL and U-BIOPRED" will present four ongoing EU funded projects where patients are actively participating and should stand to benefit from their outputs. The project coordinators from each of these EU projects will have an opportunity to present the ongoing work in their projects and explain how patients have played a meaningful role. Panel discussions will inquire further into describing ways in which European patients, research initiatives and the EU as a whole all stand to benefit from such projects. These benefits will be assessed from the perspectives of the project coordinators, patient representatives and policymakers.

Aims:

The programme above outlines one example of an approach which can aim towards:

1. Educating the public and policymakers on a diverse range of the different EU projects focused on respiratory diseases along with their goals and anticipated outcomes (or actual results if there are any at that time)
2. Demonstrate the utility of EU-funded research projects for patients and how integrating patients into the projects is beneficial
3. Informing relevant stakeholders in attendance of ways project outcomes could assist European healthcare systems and improve patients' quality of life in the future

Outcomes:

1. Establish a precedent for future events for each of the EU projects involved
2. Attraction of interest from diverse groups of stakeholders and increase awareness of the projects among policymakers at the European institutions
3. Clear demonstration of how patient involvement in research is beneficial and how EU funded projects serve the interests of patients and healthcare systems



This programme arises from the EFA 2014 Operating Grant, which has received funding from the European Union, in the framework of the Health Programme (2008-2013).

Disclaimer: The content of this programme is EFA's sole responsibility; it can in no way be taken to reflect the views of the European Commission and/or the Consumers, Health and Food Executive Agency (CHAFAEA) or any other body of the European Union. The European Commission and/or the Executive Agency do(es) not accept responsibility for any use that may be made of the information it contains.