



# EUPATI 2016 CONFERENCE

## All Aboard to a Better Health Future

14 December 2016 – The Square - Brussels, Belgium

### Introduction

In December, patient experts in the medicines research and development process will graduate from the EUPATI Patient Expert Training Course, another of EUPATI's major milestones. It is our pleasure to invite you to our EUPATI Conference on the 14<sup>th</sup> of December 2016 entitled "**All Aboard to a Better Health Future**" timed to coincide with this ceremony.

Our conference is a very special event for the EUPATI community, as we take this opportunity almost 5 years after the start of our project, not only to reflect on our accomplishments, but to prepare for future growth. It is now time to set off together to define what we mean by a Better Health Future through patient-focused research and development.

We believe that patient involvement in medicines research and development is a major driving force for transformational change in health care and the development of innovative medicines. This is why the EUPATI Project is such an exciting and unique opportunity - offering patients and patient advocates education and information on how new therapies are being developed and regulated.

We also work at national levels, implementing EUPATI initiatives in 18 countries. The national teams offer workshops and tutorials for patient communities, interacting with professionals from clinical research, ethics committees, regulators and the pharmaceutical industry.

The challenge now is to bring all these initiatives and experiences together to create value for everyone. For the patient this means better understanding of research and innovation, leading to better therapies and eventually to improved health and well-being.

This conference will build the foundation for fruitful collaboration between all stakeholders with a role in the medicines development process. We will focus on nurturing an evolving sustainable ecosystem for medical innovation, asking how patients, regulators, academia and industry can continue to work together, how they can further support each other in a trusted and respectful way, while committing themselves to our shared goal of Better Health.

You are invited to join in our 2016 EUPATI Conference to actively engage in this effort. Whether you represent patients, citizens, industry, academia, ethics committees, regulators, medical professionals, policy makers or journalists, we look forward to welcoming you on 14th December 2016 in Brussels to come on board and help us achieve a Better Future in Health!



## Programme Committee

<b>Silvano Berioi</b>	European Forum for Good Clinical Practice (EFGCP), Italy
<b>Rob Camp</b>	European Patients' Forum (EPF), Spain
<b>Barbara Haake</b>	Die Forschenden Pharma-Unternehmen (vfa), Germany
<b>Carole Hagan</b>	EUPATI Fellow, Tuberous Sclerosis Association, United Kingdom
<b>Ingrid Heyne</b>	European Forum for Good Clinical Practice (EFGCP), Belgium
<b>Laura Kavanagh</b>	Irish Platform for Patients' Organisations, Science and Industry (IPPOSI), Ireland
<b>Tanja Keiper</b>	Merck, Germany
<b>Ingrid Klingmann</b>	European Forum for Good Clinical Practice (EFGCP), Belgium
<b>Souzi Makri</b>	EUPATI Fellow, Cyprus
<b>Derick Mitchell</b>	Irish Platform for Patients' Organisations, Science and Industry (IPPOSI), Ireland
<b>Roald Nystad</b>	EUPATI Fellow, Norwegian Melanoma Association, Norway
<b>Ilaria Piuzei</b>	Janssen, Italy
<b>Daphnee Pushparajah</b>	UCB, Belgium
<b>Joanna Robaczewska</b>	EUPATI Fellow, Hasselt University and Collegium Medicum UMK, Poland
<b>Fanny Senez</b>	European Forum for Good Clinical Practice (EFGCP), Belgium

## Graduation Ceremony & Conference Faculty

<b>Amanda Bok</b>	EUPATI Fellow, Belgium
<b>Nicola Bedlington</b>	European Patients' Forum (EPF), Belgium
<b>Richard Bergström</b>	European Federation of Pharmaceutical Industries & Associations (EFPIA), Belgium
<b>Lara Bloom</b>	EUPATI fellow, The Ehlers-Danlos Society, United Kingdom
<b>Filippo Buccella</b>	Parent Project ONLUS, Italy
<b>Jan Geissler</b>	European Patients' Forum (EPF), Belgium
<b>Matthias Gottwald</b>	Bayer, Germany
<b>Marco Greco</b>	European Patients' Forum (EPF), Belgium
<b>Anton Hoos</b>	Amgen, Switzerland
<b>Joan Jordan</b>	EUPATI Fellow, MS Ireland, Ireland
<b>Ingrid Klingmann</b>	European Forum for Good Clinical Practice (EFGCP), Belgium
<b>John Lenehan</b>	Hibernia, Ireland
<b>Rachel Lynch</b>	EUPATI Fellow, NorthsideFibroDublin, Ireland
<b>Souzi Makri</b>	EUPATI Fellow, Cyprus
<b>Pierre Meulien</b>	Innovative Medicines Initiative (IMI), Belgium
<b>Derick Mitchell</b>	Irish Platform for Patients' Organisations, Science and Industry (IPPOSI), Ireland
<b>Isabelle Moulon</b>	European Medicines Agency (EMA), United Kingdom
<b>Roald Nystad</b>	EUPATI Fellow, Norwegian Melanoma Association, Norway
<b>Peter O'Donnell</b>	Politico, Belgium
<b>Sue Pavitt</b>	University of Leeds, United Kingdom
<b>Andy Powrie-Smith</b>	European Federation of Pharmaceutical Industries & Associations (EFPIA), Belgium
<b>Codruta Zabalán</b>	EUPATI Fellow, Romania



## Graduation Ceremony Venue

### Concert Noble

Rue d'Arlon 82  
1000 Brussels  
Belgium  
Tel.: +32 (0)2 737 91 43  
Email: [concertnoble@edificio.be](mailto:concertnoble@edificio.be)  
Website: <http://edificio.be/en/concert-noble>

## Conference Venue

### Square Congress Centre

Rue Ravenstein, 2  
1000 Brussels  
Belgium  
Tel.: +32 (0)2 515 13 22  
Fax: +32 (0)2 515 13 10  
Website: <http://www.square-brussels.com/>

## Conference Language

The language of the conference will be English.

## Twitter Café

EUPATI Twitter Ambassadors have been selected from the EUPATI Training Course and will be on hand to tweet on your behalf if you have ideas or information to share with the conference audience and the world wide web. They will also be at your disposal during coffee breaks and lunch at a EUPATI Twitter Café to help you learn how to use this social media by yourself with your own device (set-up of account, etc.)

## Contact EUPATI

For further information about

### Participation in this Conference and in the EUPATI Network:

Contact the EFGCP Secretariat at Tel: +32 2 732 87 83 – E-mail: [eupati@efgcp.eu](mailto:eupati@efgcp.eu)

**The Project:** please visit [www.patientsacademy.eu](http://www.patientsacademy.eu) or

contact the EUPATI Secretariat at Tel: +49 89 660 869 68 – E-mail: [info@patientsacademy.eu](mailto:info@patientsacademy.eu)



# GRADUATION CEREMONY & DINING COCKTAIL RECEPTION – Programme

(Concert Noble - Rue d'Arlon 82, 1000 Brussels)

TUESDAY, 13 DECEMBER 2016

- 18:00**                      **Welcome & Keynote Speeches**  
*Pierre Meulien (IMI)*  
*Richard Bergström (EFPIA)*  
*Marco Greco (EPF)*  
*Lara Bloom (EUPATI Fellow)*  
*Rachel Lynch (EUPATI Fellow)*
- 19:00**                      **Certificate Distribution**  
Announcement: *Nicola Bedlington (EPF) & Barbara Haake (vfa)*  
Distribution of certificates: *Pierre Meulien (IMI) & Richard Bergström (EFPIA)*
- 20:00**                      **Close of the Ceremony**
- 20:00 – 22:30**            **Dining Cocktail Reception**



# 2016 CONFERENCE – Agenda

(Square Congress Centre - Rue Ravenstein 2, 1000 Brussels)

## WEDNESDAY, 14 DECEMBER 2016

**08:00**      *Registration & Welcome Coffee*

**08:30**      **Welcome**  
*Marco Greco (EPF)*  
*Pierre Meulien (IMI)*  
*Roald Nystad (EUPATI Fellow)*

### Plenary Session 1 – Setting the Scene

Chairs: *Pierre Meulien (IMI) & Joan Jordan (EUPATI Fellow)*

**08:50**      **Introduction to the Conference & EUPATI Update**  
*Jan Geissler, EUPATI Director (EPF)*

**09:15**      **Key note speech “The Future of medicines developments and the supporting role of expert patients”**  
*Anton Hoos (Amgen)*

**10:00**      *Coffee Break (EUPATI Toolbox Demo and Twitter Café)*

**10:30**      **Interactive EUPATI Toolbox Session**  
Facilitators: *Jan Geissler, EUPATI Director (EPF) & Derick Mitchell (IPPOSI)*

### Plenary Session 2 – EUPATI implementation strategies and plans from the project stakeholders

Chairs: *Ingrid Klingmann (EFGCP) & Souzi Makri (EUPATI Fellow)*

**11:30**      **What can Industry do in its environment to improve involvement of patient?**  
*Matthias Gottwald (Bayer), representing the joint view of the Consortium*

**11:50**      **How can Academia integrate patients in its own research and teaching?**  
*Sue Pavitt (University of Leeds)*

**12:10**      **How do we prepare patients for this collaboration taking into consideration their competing activities?**  
*Filippo Buccella (Parent Project ONLUS)*

**12:30**      **Panel and Open Forum Discussion**  
*Session speakers*

**13:00**      *Lunch (EUPATI Toolbox Demo and Twitter Café)*



## **Plenary session 3 - Stakeholder groups supporting EUPATI: strategies and plans to maximise the effect of EUPATI**

Chairs: *Andy Powrie-Smith (EFPIA) & Amanda Bok, (EUPATI Fellow)*

- 14:00** Introduction: How the EUPATI website can support your efforts  
*John Lenehan (Hibernia)*
- 14:10** Strategies and plans to facilitate journalists' use of the EUPATI Toolbox and Fellows' expertise  
*Peter O'Donnell (Politico)*
- 14:30** How to maximise the impact of EUPATI's patient knowledge capacity building for patients' as partners in medicine development?  
*Richard Bergström (EFPIA)*
- 14:50** Paving the way for EUPATI Fellows into regulatory authority committees  
*Isabelle Moulon (EMA)*
- 15:10** Questions and Answers
- 15:30** Coffee Break (*EUPATI Toolbox Demo and Twitter Café*)

## **Plenary session 4 – All Aboard for a Better Health Future with EUPATI**

Chairs: *Derick Mitchell (IPPOSI) & Codruta Zabalán (EUPATI Fellow)*

- 15:45** Panel Discussion on 'The Role of ENPs in the Future of EUPATI'  
*Representation from some ENPs*
- 16:30** EUPATI plans for ensuring sustainability after 2017  
*Nicola Bedlington (EPF)*
- 16:45** Close of the Conference