

# EUPATI 2013 CONFERENCE

## EUPATI: A VISION FOR 2020

*19 April 2013, Hilton Rome Airport Hotel, Rome Airport Fiumicino, Italy*

### Introduction

**The EUPATI consortium is delighted to announce its first EUPATI conference entitled “EUPATI: A Vision for 2020”.**

We are looking to the future: 2020 and three years beyond the end of the project, to how tools and knowledge provided through EUPATI could make a difference to patients advocates, patient organisations and the public.

We want this conference to focus on ‘real world’ healthcare hot topics which you, as conference delegates, could relate to.

The conference programme has been structured around three key topics: patient involvement in medicines research and development; building competences and knowledge in medicines R&D; increasing the public awareness of benefits and risks of new treatment development.

Short presentations are designed to inspire a collective vision. Using actual examples we will bring to life existing best practices, discuss future patient involvement and empowerment within medicines development and demonstrate how the Patients' Academy would add value and bring great benefit.

Together, through the EUPATI lens the conference sets out to explore:

- What would patient involvement in medicines development look like in 2020?
- How can we build knowledge & competences for patients' involvement in medicines R&D?
- By 2020 what increase will we predict in public knowledge about development of new treatments?

We want each conference delegate to participate in shaping and building this vision. Throughout the conference you will have many opportunities to voice your opinions and share your thoughts. Open and active dialogue is strongly encouraged.

At the end of the day we hope each conference delegate will:

- understand the value of courses, materials and information currently being developed by EUPATI
- see how these different resources can be applied to shape the future of medicines development
- and have influenced and informed the EUPATI project.

### Programme Committee

<b>Silvano Berioli</b>	European Forum for Good Clinical Practice (EFGCP), Belgium
<b>Virginie Delwart</b>	Janssen, Belgium
<b>Matthias Gottwald</b>	Bayer Pharma, Germany
<b>Ingrid Heyne</b>	European Forum for Good Clinical Practice (EFGCP), Belgium
<b>Ingrid Klingmann</b>	European Forum for Good Clinical Practice (EFGCP), Belgium
<b>Liuska Sanna</b>	European Patients' Forum (EPF), Belgium
<b>Soren Skovlund</b>	Novo Nordisk, Denmark
<b>Kay Warner</b>	GlaxoSmithKline, United Kingdom
<b>Kim Wever</b>	European Genetic Alliance Network (EGAN)/Dutch Genetic Alliance (VSOP), The Netherlands

## Faculty

<b>Nicola Bedlington</b>	European Patients' Forum (EPF), Belgium
<b>Dave Bryant</b>	Luto Research, United Kingdom
<b>Filippo Buccella</b>	Parent Project Onlus, Italy
<b>Virginie Delwart</b>	Janssen, Belgium
<b>Rebecca Dickinson</b>	University of Leeds, United Kingdom
<b>Jan Geissler</b>	European Patients' Forum (EPF), Germany
<b>Michel Goldman</b>	Innovative Medicines Initiative (IMI)
<b>Matthias Gottwald</b>	Bayer Pharma, Germany
<b>Barbara Haake</b>	Die forschenden Pharma-Unternehmen (vfa), Germany
<b>David Haerry</b>	European Aids Treatment Group (EATG), Switzerland
<b>Nancy Hamilton</b>	European Organisation for Rare Diseases (EURORDIS), France
<b>Ingrid Klingmann</b>	European Forum for Good Clinical Practice (EFGCP), Belgium
<b>Svilen Konov</b>	European Aids Treatment Group (EATG), Belgium
<b>Paola Mosconi</b>	Istituto di Ricerche Farmacologiche Mario Negri, Italy
<b>Jennifer Newman</b>	NIHR Medicines for Children Research Network, United Kingdom
<b>Peter O'Donnell</b>	Journalist, Belgium
<b>Anders Olauson</b>	European Patients' Forum (EPF), Sweden
<b>Lucy Simons</b>	INVOLVE /University of Leeds, United Kingdom
<b>Soren Skovlund</b>	Novo Nordisk, Denmark
<b>Bella Starling</b>	University of Manchester - NOWGEN, United Kingdom
<b>Kay Warner</b>	GlaxoSmithKline, United Kingdom
<b>Niels Westergaard</b>	BIOPEOPLE, University of Copenhagen, Denmark
<b>Kim Wever</b>	European Genetic Alliance Network (EGAN)/Dutch Genetic Alliance (VSOP), The Netherlands
<b>Elizabeta Zisovska</b>	University Clinic for Gynecology and Obstetrics, Macedonia

## Workshop Venue

**Hilton Rome Airport Hotel**  
**Room: Salone dei Cesari**  
 Via Arturo Ferrarin 2 Fiumicino  
 00054 Rome - Italy  
 Tel: +39-06-65258 - Fax: +39-06-6525 6525  
 Website: <http://www.hilton.de/romeapt>

## Workshop Language

The language of the workshop will be English.

## Contact EUPATI

For further information about

- **The Project:** please visit [www.patientsacademy.eu](http://www.patientsacademy.eu) or contact the EUPATI secretariat - Tel: +49 89 660 869 68

E-mail: [info@patientsacademy.eu](mailto:info@patientsacademy.eu)

- **Participation in the Workshop and in the EUPATI Network:** contact the EFGCP Secretariat -Tel: +32 2 732 87 83

E-mail: [eupati@efgcp.eu](mailto:eupati@efgcp.eu)

For more information, please click on the following link: [EUPATI: A Vision for 2020](#).

# AGENDA

## THURSDAY, 18 APRIL 2013

**19:00 – 22:00** Welcome Dining Reception  
(Giardino dei Consoli Room)

## FRIDAY, 19 APRIL 2013

**07:45** Registration & Welcome Coffee

**08:30** **Welcome and Introduction**  
*Anders Olauson, European Patients' Forum (EPF), Sweden*

**08:35** **Patients at the core of European healthcare research: the IMI perspective**  
*Michel Goldman, Innovative Medicines Initiative (IMI)*

**09:05** Q & A

## SESSION 1:

### Patient involvement in medicines R&D Process in 2020

How to progress the involvement of patients in the process of medicines development has long been debated. The ultimate goal of EUPATI is to provide dedicated training, information and material to equip and empower more patients to become active partners with academia, industry, regulatory agencies, HTA bodies and ethics committees. This session will set the scene for this step change in approach by sharing examples of current best practice and encourage an exchange of views on how EUPATI can be a catalyst for efficient patient involvement in new treatment development processes across Europe.

Co-chairs: *Virginie Delwart, Janssen, Belgium & David Haerry, European Aids Treatment Group (EATG), Switzerland*

**09:15** **Vision – here we are, where we want to be in 2020**  
*Nicola Bedlington, European Patients' Forum (EPF), Belgium*

**09:35** **Best practices**  
'DAWN2 Study' - *Soren Skovlund, Novo Nordisk, Denmark*  
'Collaboration as the best practice: All Together now!' - *Filippo Buccella, Parent Project Onlus, Italy*

#### **Abstract Presentations**

'EATG Advisory Group' - *David Haerry, European Aids Treatment Group (EATG), Switzerland*  
'Young People's Involvement in Medicines R&D' - *Jennifer Newman, NIHR Medicines for Children Research Network, United Kingdom*

**10:05** **Bring to life with EUPATI examples**  
*Jan Geissler, European Patients' Forum (EPF), Germany*

**10:20** **Open discussion on how to achieve the vision**

**11:10** Coffee Break & Posters Presentation

## SESSION 2:

### Building Knowledge & Competences for Patients' Involvement in Medicines R&D

Educating and training patients objectively, efficiently and adapted to their needs in the complex area of medicines research and development requires to take new avenues. Different innovative approaches how to teach a lay audience need to be considered. EUPATI chose the strategic approach of training knowledgeable patient representatives as experts, as well as providing suitable educational material and toolkits for own use with their constituency and local partners. This session will explore best practice examples on patient education pursued by other stakeholders, and discuss which lessons can be learned for EUPATI to facilitate effective and meaningful involvement of patients in R&D.

Co-chairs: *Bella Starling, University of Manchester - NOWGEN, United Kingdom & Nancy Hamilton, European Organisation for Rare Diseases (EURORDIS), France*

**11:30 Vision – here we are, where we want to be in 2020**  
*Ingrid Klingmann, European Forum for Good Clinical Practice (EFGCP), Belgium*

**11:50 Best practices**  
*Svilen Konov, European Aids Treatment Group (EATG), Belgium*

#### **Abstract Presentations**

'Essential principles for training and support for public involvement in research' - *Lucy Simons, INVOLVE /University of Leeds, United Kingdom*

'Patients' perception of the "informed consent"' - *Elizabeta Zisovska, University Clinic for Gynecology and Obstetrics, Macedonia*

**12:20 Bring to life with EUPATI examples**  
*Niels Westergaard, BIOPEOPLE, University of Copenhagen, Denmark*

**12:35 Open discussion on how to achieve the vision**

**13:30** Lunch (& Posters Presentation as of 14.00)

## SESSION 3:

### Public awareness about new medicines development in 2020

Pharmaceutical medicines development is a highly regulated, costly, long and complex process that is largely unknown to the lay public. Benefits and risks of existing and new treatment alternatives are difficult to understand for the general public. In an era of growing demand and emphasis on both quality and sustainability of healthcare, it is critical to address this major gap in public perception and knowledge.

This session will explore how EUPATI can contribute to overcome current barriers through a coordinated approach of all stakeholders involved in this process and to develop reliable and most up-to-date information and opportunities for involvement of the lay patients and citizens.

Co-chairs: *Matthias Gottwald, Bayer Pharma, Germany & Kim Wever, European Genetic Alliance Network (EGAN)/Dutch Genetic Alliance (VSOP), The Netherlands*

**14:30 Vision – here we are, where we want to be in 2020**  
*Peter O'Donnell, Journalist, Belgium*

**14:50 Best practices**  
*Paola Mosconi, Istituto di Ricerche Farmacologiche Mario Negri, Italy*



### **Abstract Presentations**

'The benefits of benefits: A qualitative study exploring opinions on the inclusion of benefit information about medicines in PILs' - *Rebecca Dickinson, University of Leeds, United Kingdom*

'User Testing of an EPAR Summary – Does it meet people's needs?' – *Dave Bryant, Luto Research, United Kingdom*

**15:20 Bring to life with EUPATI examples**

*Barbara Haake, Die forschenden Pharma-Unternehmen (vfa), Germany*

**15:35 Open discussion on how to achieve the vision**

**16:30 Closing discussion: achieving goals**

*Nicola Bedlington, European Patients' Forum (EPF), Belgium & Kay Warner, GlaxoSmithKline, United Kingdom*

**17:00 Networking Farewell Drink**



*The EUPATI project receives support from the European Union (IMI JU) and EFPIA companies*