

# European Patients' Forum eNewsletter

A strong patient's voice, to drive better health in Europe



## SPECIAL YOUTH EDITION



### A WORD FROM EPF PRESIDENT AND DIRECTOR

We are delighted to share with you this special issue of our newsletter dedicated to our EMPATHY seminar "Europe Meets Young Patients", held in Brussels from 8 to 11 July 2013.

This event was our first EPF Youth Project. The focus was on the needs of young patients in EU decision-making processes and through the seminar we established active dialogue between young patients and European policy-makers and stakeholder actors.

We will use the evidence collected through this four-days meeting to shape our policy work with our members.

We hope that EMPATHY will contribute to strengthening young representatives' skills and self-confidence while reinforcing their representation in patient organisations.

We will continue to invest in strong cooperation between young patients and the wider patient community to drive health policies that are more responsive to young patients' needs.

We hope you enjoy this special issue and get a sense of the enthusiasm and passion of our young patient leaders.

Warmest Greetings,

Anders Olauson, EPF President and Nicola Bedlington, EPF Director



A handwritten signature in black ink, appearing to be 'A. Olauson'.

A handwritten signature in blue ink, appearing to be 'N. Bedlington'.

## WHAT DOES 'EMPATHY' MEAN FOR YOUNG PATIENTS?



The EMPATHY project or "Europe meets Young Patients" consisted of a four-day seminar that took place in Brussels on 8-11 July. The EPF Youth Group organised the event with the support of EPF. Policy discussions focused mainly on two major topics: health issues and discrimination.

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## EMPATHY FROM THE PATIENT LEADERS' PERSPECTIVE



Experienced patient leaders attending the EMPATHY Seminar brought their wisdom and guidance to the young audience.

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## EMA GATHERS THE VIEWS OF YOUNG PATIENTS

## EMPATHY FROM A YOUNG PATIENT'S PERSPECTIVE



The EMPATHY Seminar gathered young patients aged between 16 and 25, representing several disease areas and nationalities. The seminar was an exciting learning and networking opportunity.

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## EMPATHY FROM THE EXTERNAL STAKEHOLDERS' PERSPECTIVE



A number of external stakeholders attended the EMPATHY seminar and participated in the different policy debates to contribute to the debate with their experience.

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## EMPATHY: WHAT ARE THE NEXT STEPS?

## UPCOMING EVENTS

**06/09/2013** | ["Best expertise vs conflicts of interests: Striking the right balance"](#)

### London, UK

Our President Anders Olauson will attend this workshop at the European Medicines Agency. The event is intended to elicit the views and concerns from academia, patient organisations, Committee representatives, NGOs, the pharmaceutical industry and the scientific media on the Agency's current conflicts of interests policy.

*EPF speaker:*  
*Anders Olauson*

**12 & 13/09/2013** | [SUSTAINS Steering Committee Meeting](#)

### Lappeenranta, Finland

Review of progress made and decisions on planned activities

*EPF attendance:*  
*Walter Atzori*

**19/09/2013** | [EFPIA Patients' Think Tank September Meeting](#)

### Brussels, Belgium

This quarterly event is the occasion for Patients' organisations and the pharmaceutical industry to have a dialogue on EU policy issues in the area of health and innovative medical research.

*EPF speaker:*  
*Nicola Bedlington*

**20/09/2013** | [EPF Policy Advisory Group meeting](#)

### Brussels, Belgium

The Group supports the policy work of the EPF Secretariat and Board and complements the EPF member consultation process.

*EPF attendance:*  
*Kaisa Immonen-Charalambous, Laurène Souchet*

**25 & 26/09/2013** | [Patients and Consumer Working Party](#)

### London, UK

The PCWP provides recommendations to the European Medicines Agency and its human scientific committees on all matters of interest to patients in relation to medicinal products.



The European Medicines Agency (EMA) was invited to contribute to the EMPATHY Seminar in a session devoted to collecting views on a video and a questionnaire. The exchanges were very fruitful for the Agency which demonstrates the importance to involve young patients in the design of tools that are addressed to them.

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EPF will follow-up on the positive outcomes emerging from the EMPATHY seminar. The outcomes of the EMPATHY project will be consolidated in a series of resources targeted to the various audiences involved in the project.

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*EPF attendance:*  
*Kaisa Immonen-Charalambous*

**26/09/2013** | [Lunch Debate on Data Protection and Medical Research](#)

**Brussels, Belgium**

The review of the Data protection directive and its consequences for medical research

*EPF attendance:*  
*Laurène Souchet*

**26 - 29/09/2013** | [3rd Annual Meeting of the Youth Group](#)

**Blagoevgrad, Bulgaria**

Follow-up of the EMPATHY seminar

*EPF attendance:*  
*Walter Atzori, Valentina Strammiello*

**28 & 29/10/2013** | [Save the Date! EPF 6th Regional Advocacy Seminar](#)

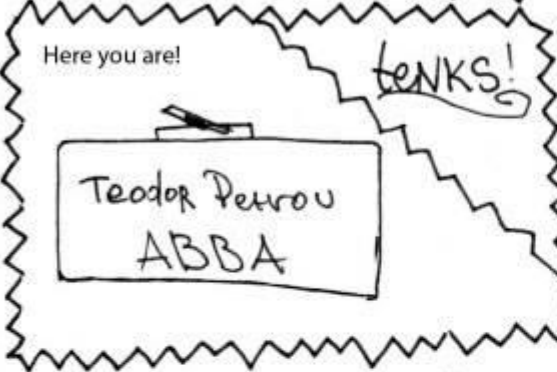
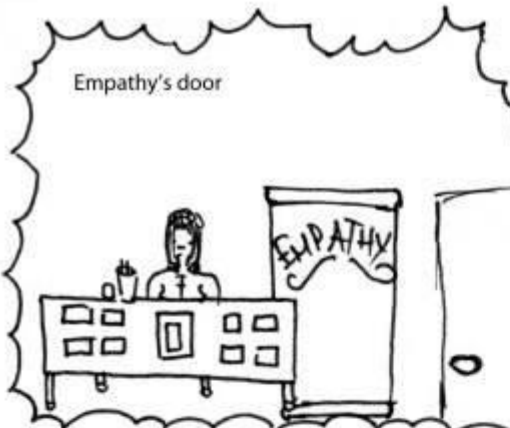
**Zagreb, Croatia**

The event is open to patients organisations' leaders from Croatia, Serbia, Montenegro, Macedonia and Turkey (the EU acceding and candidates countries) and will look at the link between policy-making at EU and member state level and advocacy skills for patient advocates.

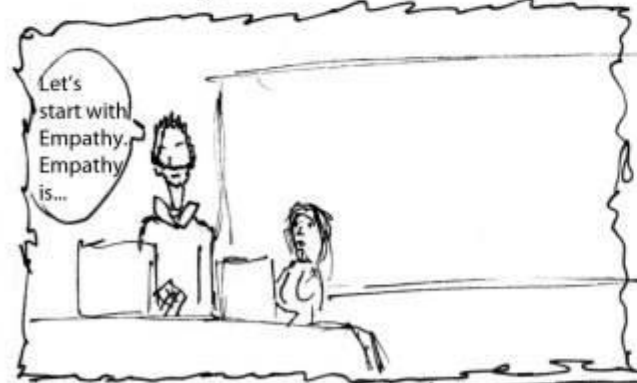
**21/11/2013** | [Save the date! EPF Patient evidence workshop](#)

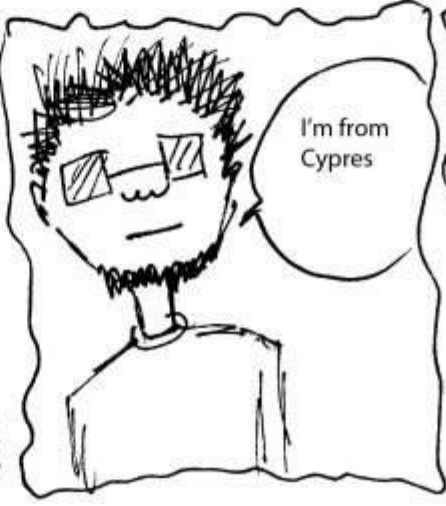
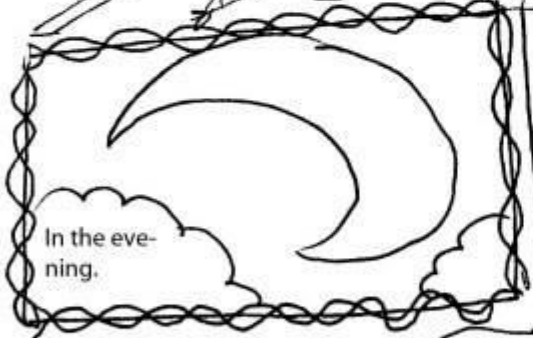
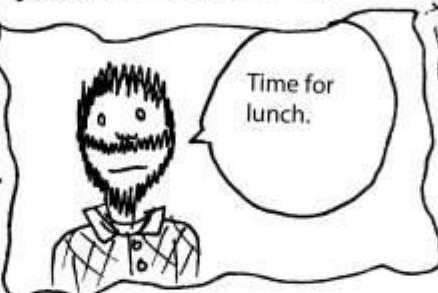
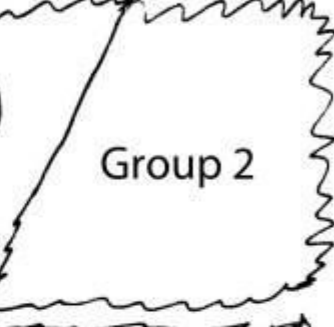
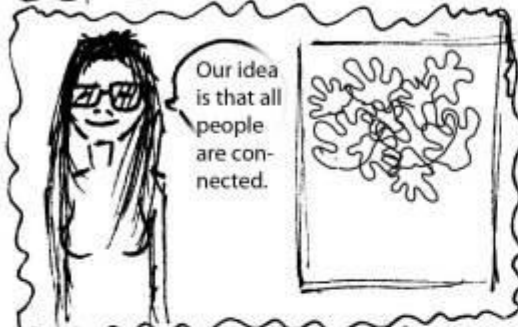
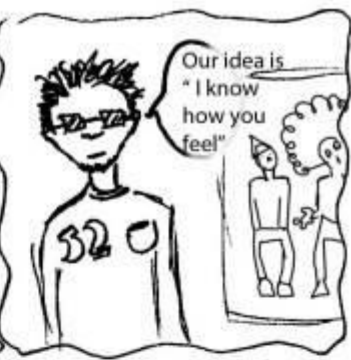
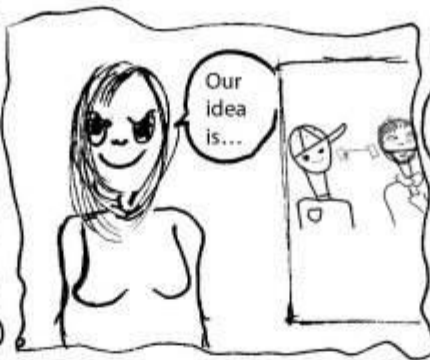
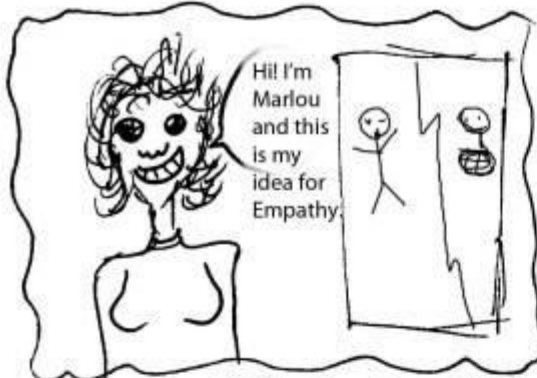
**Brussels, Belgium**

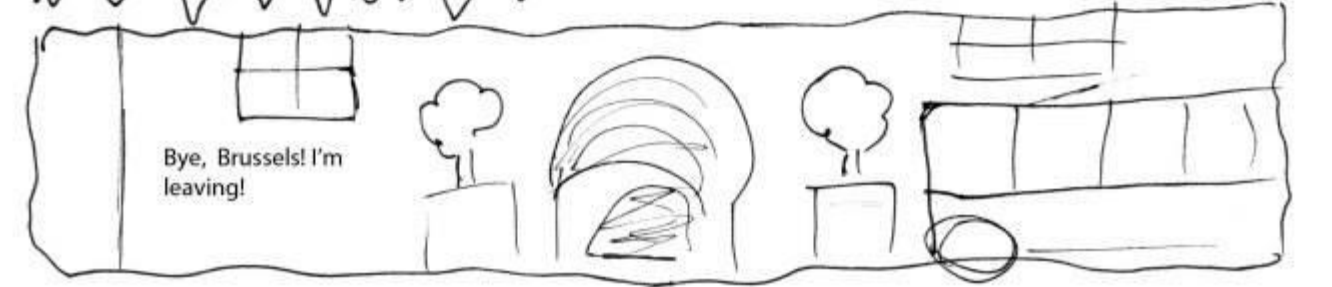
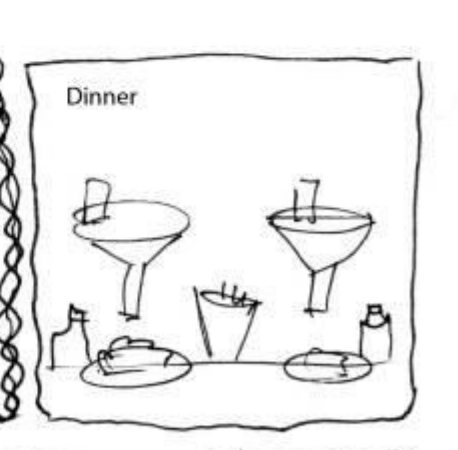
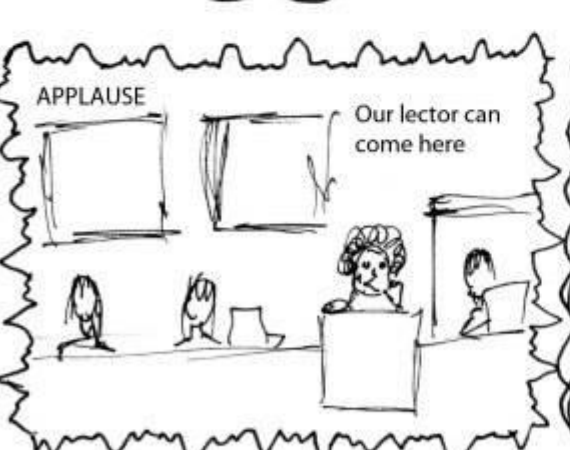
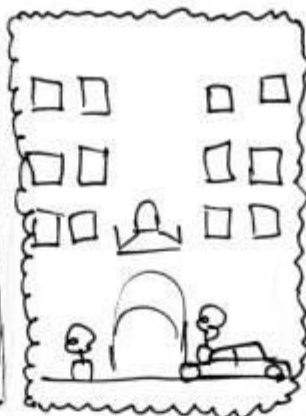
The event is open to EPF member organisations and focuses on shaping EPF contributions to EU-level actions in the Patient Safety area, emphasizing on patient involvement in patient safety.



# EMPATHY









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**A STRONG PATIENTS' VOICE,  
TO DRIVE BETTER HEALTH IN EUROPE**

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Disclaimer: The content of this e-newsletter reflects only the author's views and the Executive Agency is not responsible for any use that may be made of the information contained therein.



Education and Culture DG

### 'Youth in Action' Programme

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