

MARINAN

European Patients' Academy on Therapeutic Innovation

http://www.patientsacademy.eu - info@patientsacademy.eu







The Patients' Academy: Paradigm shift in empowering patients on medicines R&D



- Launched Feb '12, runs for 5 years,
 29 consortium members,
 PPP of EU Commission and EFPIA
- will develop and disseminate objective, credible, correct and up-to-date public knowledge about medicines R&D
- will build competencies& expert capacity among patients & public
- will facilitate patient involvement in R&D to support industry, academia, authorities and ethics committees



Project led by 4 key pan-European patient associations





European Patients Forum

- EUPATI Project Coordination
- >50 umbrella patient organisations. Through 'members of members', potential outreach to 150 million patients



European Genetic Alliance Network

 Linked with national and regional patient alliances in Germany, Eastern Europe, Italy, Netherlands, United Kingdom and Ireland, Sweden, Spain, Italy, Greece and Balkan countries



EURORDIS – Rare Diseases Europe

Representing >500 rare disease organisations in >45 countries

European AIDS Treatment Group

More than 100 members in over 30 countries.

Additional partners in other patient organisations and "members of members" via "EUPATI Network"



Strong consortium & strong governance

- Leading pan-EU patient umbrella groups
- Strong impetus from key academic partners and research organisations
- Industry expertise in medicines R&D
- Advisory bodies & codes committed to ensure independence and good governance
 - EMA, Swissmedic, MHRA, BfArM
 - Key experts in bioethics, genetics, HTA, economics, evidence based med, patient advocacy









Within the next 5 years, the Patients' Academy will...



- build expert capacity by training patient advocates, and competencies among patients and the public
- develop and disseminate accessible, well-structured and userfriendly information and education on medicines R&D
- create the leading public library on medicines R&D:
 7 languages, "creative commons" license
- facilitate patient involvement in R&D to partner up with academia, authorities, industry, ethics committees

...and NOT: develop indicationor therapy-specific information!



Why do we need EUPATI?

In 2013, EUPATI set out to measure:

- Knowledge and awareness of medicines R&D
- Interest in learning more in medicines R&D
- Preferences for information formats and providers

7000 people were surveyed across 6 European countries [Spain, France, UK, Germany, Poland and Italy]















PUBLIC VIEWS ON MEDICINES DEVELOPMENT

Exploring attitudes, beliefs, knowledge and interest ACROSS EUROPE

in 2013, we asked 7,000 adults aged 18 years and over in select European countries about their attitudes towards, beliefs about and interest in learning more about the medicines development process as part of the groundwork for EUPATI.

RESEARCH PARTICIPATION



CURRENT KNOWLEDGE

HIGHEST



- 1. Medicines safety 25%
- 2. Drug discovery 22%
- 3. Clinical trials 22%

LOWEST



1. Patients' roles and medicines

regulation 18%

2. Medicines R & D 16%

3. Pharmacoeconomics 15%

INTERESTED IN LEARNING MORE



- 1. Medicines safety 50%
- 2. Personalised medicine 47%
- 3. Predictive medicine 47%

LESS INTERESTED IN LEARNING MORE



- 1. Pharmacoeconomics 33%
- 2. Medicines regulation 36%
- 3. Clinical trials and patients'

roles 39%

INFORMATION SOURCES

TOP THREE







BOTTOM THREE





59%



20%

21%

FAVOURED INFORMATION PROVIDERS

Doctor or other medical practition-

University / academic

organisation



70%





41%

LESS FAVOURED

friend or colleague

Journalist or news organisation

Public-private





20%



15%

The Noun Project (thenounproject.com). Creative Commons - Attribution (CC BY 3.0).

EUPATI Research: public views of medicines R&D across Europe identified

- Low knowledge of R&D
- Poor participation in research
- Support for more information from patient organisations, academia and medical professionals



EUPATI Audiences: advocacy leaders and the public at large



EUPATI Certificate Training Programme

- Academic Modular Certificate Programme
- Patient Ambassadors & Patient Journalists raising awareness
- Patient Trainers for patient communities & networks

100 patient advocates



EUPATI Educational Toolbox

- Educational tools for patient advocates
- Variety of distributable formats: Paper-based booklets, presentations, eLearning, webinars, videos etc.

12.000 patient advocates



EUPATI Internet Library

- Patients & lay public at large, e.g. on specific aspects of the development process of medicines for patients with low (health) literacy.
- Wiki, YouTube, films and/or cartoons

100.000 individuals

EUPATI Content: development timelines



Phase 1: October 2014

EUPATI Certificate Training Programme

e-learning [150+hours]

Phase 2:

classroom style face to face teaching

October 2015

Two 4-day sessions Barcelona: April & Sept 2015]

English

Available: 2015

EUPATI Educational Toolbox

repository: video, webcast, pdf, presentation,

ebook, print ready material (booklets, pamphlets),

audio

Available: 2016

EUPATI Internet Library

WebPages

Streamed media

illustrations

English
French
German
Spanish
Polish
Italian
Russian



EUPATI PATIENT EXPERT TRAINING



EUPATI

Face-to-face

Forum

Glossary

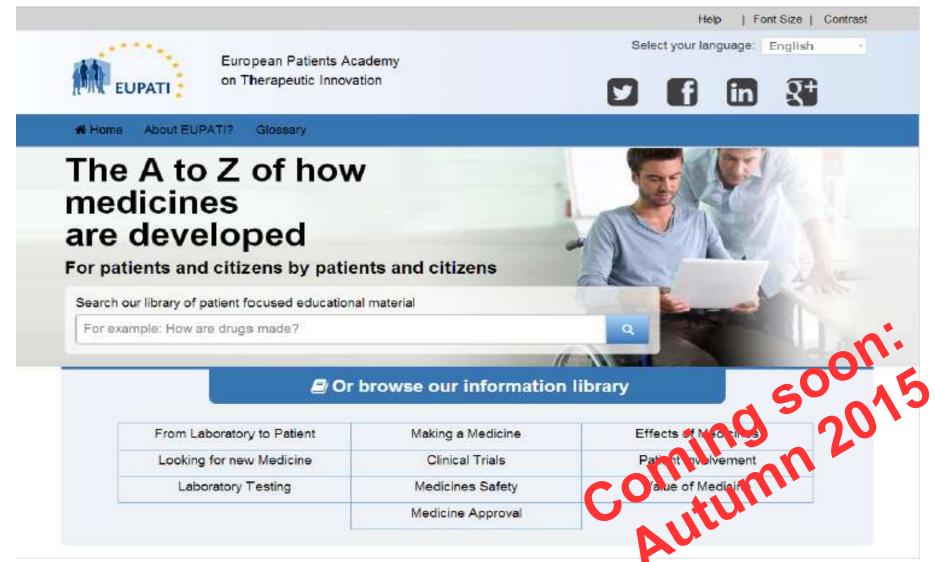
You are not logged in. (Log in)

Welcome to the EUPATI moodle site

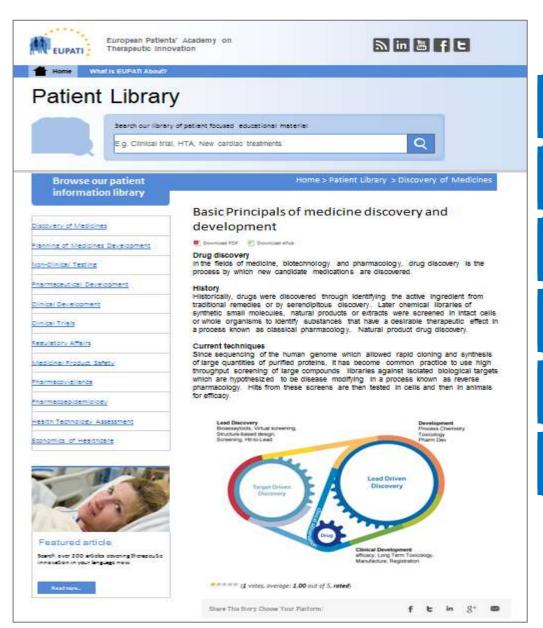
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EUPATI PATIENT TOOLKIT





EUPATI PATIENT LIBRARY





Glossary

Multilingual encyclopedia

Multimedia

Read or save content offline

Multilingual downloads and toolbox resources

Responsive library content for mobile devices



Areas covered by the Patients' Academy



- 1. Medicines development process from research to approval
- 2. Personalized and predictive medicine
- 3. Drug safety and risk/benefit assessment of medicines
- 4. Pharmaco-economics, health economics and health technology assessment
- 5. Design and objectives of clinical trials (& roles of stakeholders)
- 6. Patients roles & responsibilities in medicines development

...and NOT: develop indicationor therapy-specific information!

EUPATI at the National Level – 12 countries

EUPATI NATIONAL LIAISON TEAMS are

temporary task forces of three members:

1) patients 2) academia 3) industry



Teams establish **EUPATI NATIONAL PLATFORMS**

- •ensure EUPATI understands and responds to the educational needs at a national level
- •disseminate EUPATI educational and training material to increase the number of patient advocates
- raise general public interest and media interest in EUPATI
- •support national initiatives to encourage greater patient involvement in medicines research and development

UK ΙE CH **ES FR** AT DE MT PΙ

EUPATI NLTs and ENPs

Country	Status	Major meetings			
Germany	•	17 July 2013			
Belgium		N/A			
France		22 Feb 2012 21 Jan 2014			
Austria		20 Oct 2014 Oct 2015			
Malta		30 April 2014			
Poland		19 Feb 2013			

Country	Status	Major meetings			
Spain		9 Jan 2012 4 Nov 2014			
Switzerland		13 Jun 2013 4 Feb 2014 11 Dec 2014 25 March 2015			
United Kingdom		18 Mar 2013 26 Sept 2013 6 March 2014			
Luxembourg		3 April 2013 23 Oct 2013 17 Dec 2014 17 March 2015			
Ireland		30 April 2014 16 Sept 2014			
Italy		19 Feb 2013 14 Oct 2014 10 April 2015			

Red: no NLT available

Yellow: NLT established, 1st meetings took place, 1st work in common has started

Green: NLT well advanced in preparing the establishment of the ENP

Implementing EUPATI at a national level

The **UK EUPATI National Platform** meeting on 06 March 2014 attracted a fantastic response on social media with 12,000 tweets across Europe and even beyond, as well as a retweet by the Association of British Pharmaceutical Industries (ABPI) which has over 4000 followers!

The **Irish EUPATI National Platform** meeting in Ireland on 16 September 2014 was supported by IPPOSI, the Irish Platform for Patient Organisations, Science and Industry with more than 400 members. National Radio personality and journalist, Aine Lawlor gave the keynote presentation during which she described her experience of clinical trials in her fight against cancer and stressed the importance of patient involvement.

The **Italy EUPATI National Liaison Team** on 03 July 2014 signed a Memorandum of Understanding with the Italian Medical Agency (AIFA) to work together to maximise the number of Italian patients who are able to access EUPATI educational and training resources. On 10 April 2015, the Italian National Platform was launched in Rome at an event attended by more than 200 patient, academic and industry partners.

EUPATI NETWORK MEMBERS



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Login	You are here: Home	Registration			
Some areas of this website are accessible to registered members only.	Registration				
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** Access to EUPATI Network area

** Copies of EUPATI Newsletters

** Invites to EUPATI Network webinars

** Invites to EUPATI Workshops

Register to join the EUPATI Network at

www.patientsacademy.eu

EUPATI NETWORK WEBINAR

Webinar - Enabling meaningful patient contribution to ethical review?



Our upcoming EUPATI webinar "How to enable meaningful patient contribution to ethical review?" will provide an opportunity to hear current experiences and expectations and to discuss your questions and suggestions on the 5th of March at 17:00 hours until 18:30 CET.

You need to be a Network member to join in. If you already are, please register here.

If you are not yet a Network member (free and easy!), please sign up here.

Last Updated: Thursday, 05 February 2015 16:35 / 🔚 Print



1st webinar: 05 Nov 2014

2nd webinar: 05 Mar 2015

3rd webinar: May 2015

Further 2015 dates to be announced

EUPATI REGIONAL WORKSHOP





Save the date! - Our 2015 Workshop



- "Taking off on a national level An interactive workshop on implementing EUPATI in your country"
- 22nd of April 2015 in Dublin
- > How can you get involved what is neel ev locally?

**Travel and accommodation costs for registered network patient & academic representatives are fully covered by EUPATI

EUPATI LinkedIn Group







EUPATI Twitter Tweets





@eupatients

@EUPATI_Lux @EUPATI_UK @EUPATI_CH @EUPATI_ES @EUPATI_IT @EUPATI_FR



EUPATI Facebook Posts





Patients' Academy

EUPATI Spain
EUPATI Luxembourg
EUPATI France

Get to know us!





www.patientsacademy.eu

1200 Network members

1300 Newsletter subscribers

1300 Twitter followers @eupatients / #EUPATI



900 Facebook friends



550 LinkedIn members IIII

