European Patients’ Academy on Therapeutic Innovation

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

The project is receiving support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115334, resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007-2013) and EFPIA companies.
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.
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 user-friendly 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 indication- or 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]
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

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

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 patient advocates
- 12,000 patient advocates
- 100,000 individuals
EUPATI Content: development timelines

Phase 1: October 2014
EUPATI Certificate Training Programme
- e-learning [150+ hours]
- classroom style face to face teaching
  Two 4-day sessions Barcelona: April & Sept 2015

Phase 2: October 2015
EUPATI Educational Toolbox
- repository: video, webcast, pdf, presentation,
  ebook, print ready material (booklets, pamphlets),
  audio

Available: 2015

Available: 2016
EUPATI Internet Library
- WebPages
- Streamed media
- illustrations
Welcome to the EUPATI moodle site

Course Overview
- Discovery of Medicines and Planning of Medicines Development
- Non-Clinical Testing and Pharmaceutical Development
- Exploratory and Confirmatory Clinical Development

Face-to-Face Information
- Clinical Trials
- Regulatory Affairs, Medicinal Product Safety, Pharmacovigilance
- HTA Principles and Practices

First course: started Oct 2014
Second course: starting Sept 2015
EUPATI PATIENT TOOLKIT

The A to Z of how medicines are developed
For patients and citizens by patients and citizens

Search our library of patient focused educational material
For example: How are drugs made?

Or browse our information library

From Laboratory to Patient
- Looking for new Medicine
- Laboratory Testing

Making a Medicine
- Clinical Trials
- Medicines Safety
- Medicine Approval

Effects of Medicines
- Patient involvement
- Value of Medicine

Coming soon: Autumn 2015
Patient Library

Basic Principles of Medicine Discovery and Development

Drug discovery
In the fields of medicine, biotechnology, and pharmacology, drug discovery is the process by which new candidate medications are discovered.

History
Historically, drugs were discovered through identifying the active ingredient from traditional remedies or by serendipitous discovery. Later chemical libraries of synthetic small molecules, natural products, and extracts were screened in intact cells or whole organisms to identify substances that have a desirable therapeutic effect in a process known as classical pharmacology. Natural product drug discovery.

Current techniques
Since sequencing of the human genome which allowed rapid cloning and synthesis of large quantities of purified proteins, it has become common practice to use high throughput screening of large compound libraries against isolated biological targets which are hypothesized to be disease modifying, in a process known as reverse pharmacology. Hits from these screens are then tested in cells and then in animals for efficacy.
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 indication- or 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
## EUPATI NLTs and ENPs

<table>
<thead>
<tr>
<th>Country</th>
<th>Status</th>
<th>Major meetings</th>
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<tbody>
<tr>
<td>Germany</td>
<td>☠️</td>
<td>17 July 2013</td>
</tr>
<tr>
<td>Belgium</td>
<td>☠️</td>
<td>N/A</td>
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| France        | 🟠      | 22 Feb 2012  
               |                              | 21 Jan 2014                 |
| Austria       | 🟠      | 20 Oct 2014  
               |                              | Oct 2015                    |
| Malta         | 🟠      | 30 April 2014                |
| Poland        | 🟠      | 19 Feb 2013                  |

<table>
<thead>
<tr>
<th>Country</th>
<th>Status</th>
<th>Major meetings</th>
</tr>
</thead>
</table>
| Spain         | 🟠      | 9 Jan 2012  
               |                              | 4 Nov 2014                 |
| Switzerland   | 🟠      | 13 Jun 2013  
               |                              | 4 Feb 2014                 |
               |        | 11 Dec 2014  
               |                              | 25 March 2015              |
| United        | 🟠      | 18 Mar 2013  
               | Kingdom                    | 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

** 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?

1st webinar: 05 Nov 2014
2nd webinar: 05 Mar 2015
3rd webinar: May 2015
Further 2015 dates to be announced

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.
EUPATI REGIONAL WORKSHOP

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

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**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 needed locally?

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22 April 2015: Dublin
Get to know us!

EUPATI can make the difference. creating the tipping point for patient engagement in medicines R&D
It's for all of us to make it happen.

www.patientsacademy.eu
1200 Network members

1300 Newsletter subscribers

1300 Twitter followers @eupatients / #EUPATI

900 Facebook friends

550 LinkedIn members