EUPATI
European Patients‘ Academy
on Therapeutic Innovation

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.

Birgit Bauer
Germany
Trainee at the EUPATI „Patients Expert Course“

MS Patient
Blogger about MS
Speaker / Journalist / Social Media Expert

What is EUPATI?

What is EUPATI?

- **A Public Private Partnership** within the Innovative Medicines Initiative Joint Undertaking*
- **A 5-year project**, launched in February 2012
- **A patient-led project** coordinated by the European Patients' Forum, with EGAN, EURORDIS and EATG in leadership roles
- **A strong multi-stakeholder consortium** of patients' organisations, academia, NGOs and industry – 30 organisations
- **The key pan-European initiative** to build competencies & expert capacity among patients and the health-interested public

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Strong consortium & strong governance

- Coordinated by patients (EPF)
- Leading pan-EU patient umbrella groups involved in all key activities
- 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, AIFA
  - Key experts in bioethics, genetics, HTA, economics, evidence based med, patient advocacy

Reflecting European diversity:
7 languages, 12 countries

7 most frequently spoken languages:

- **English**
- **French**
- **German**
- **Spanish**
- **Polish**
- **Italian**
- **Russian**

12 countries:

UK, Ireland, Malta, France, Luxemburg, the francophone Belgium, Germany, Austria, Switzerland, Spain, Italy and Poland, plus Russian-speaking population in Central and Eastern Europe

EUPATI National Platforms: Partnership on the country level

EUPATI National Platforms will...

- **make sure EUPATI understands educational needs** in R&D on national level
  when developing content
- **disseminate EUPATI's existing training material and information** on the national level
- **To raise public interest about EUPATI** in 12 countries
- **To identify training faculty, logistics and financial support** on the national level

AT
BE
CH
DE
ES
FR
IT
IE
LUX
MT
PL
UK

Areas covered by the European Patients' Academy

1. **Discovery of Medicines & Planning of Medicines Development**
2. **Non-Clinical Testing and Pharmaceutical Development**
3. **Exploratory and Confirmatory Clinical Development**
4. **Clinical Trials**
5. **Regulatory Affairs, Medicinal product Safety, Pharmacovigilance and Pharmaco-epidemiology**
6. **Health Technology Assessment and the economics**

…and *NOT:* develop indication- or therapy-specific information!

Why EUPATI?

There is public distrust and a lack of knowledge about research in the lay public

- **Only 6-12% of cancer patients participate in clinical studies**
- **75% of Phase II-IV studies delayed** due to slow patient recruitment
- Bad image one reason for delayed generation of meaningful clinical data

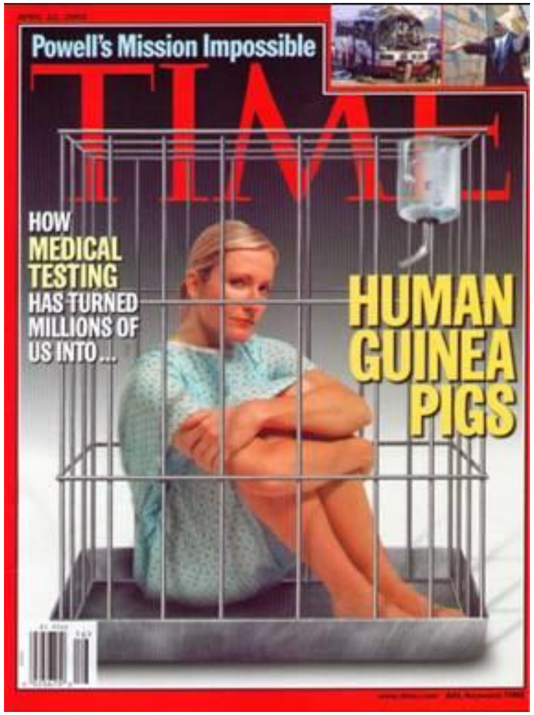
MEDICINE AND THE MEDIA

"We saw human guinea pigs explode"

L Stobbart and colleagues examine newspaper coverage of adverse events in the TGN1412 trial

EMPICS

with death and disfigurement. Science fiction or cinematic imagery is often used to add potency to detailed and gruesome descriptions—although no pictures were printed of the victims' deformities, references such as "his face now resembled that of the Elephant Man" (*Daily Star*, 16 March) were used with effect.



Health research & policy is changing

Innovation transforms the lives of patients with serious, lifelong conditions:

- Molecular targets/pathways
- Genome sequencing,
- Translational research
- Personalized medicine
  - Small trial populations
  - Biomarkers, companion diagnostics
- Need for post-marketing data
- Health Technology Assessment, endpoints, comparators
- BUT long term pressure on health budgets – here to stay

Window of opportunity

- trial design
- relationship between researchers, regulators, industry, **patients**

Patients have a key role in all aspects of health-related research

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EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH
BfArM
MHRA
swissmedic

Competent authorities

Public

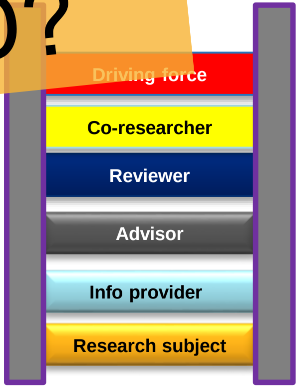
Policy makers /Research Policy

Trial protocol design, informed consent, ethical review, marketing authorization, value assessment, health policy

Are there enough patient advocates to engage in R&D?

Research Ethics Committees

HTA agencies & committees



Driving force
Co-researcher
Reviewer
Advisor
Info provider
Research subject

Clinical Research

EUPATI is needed because…

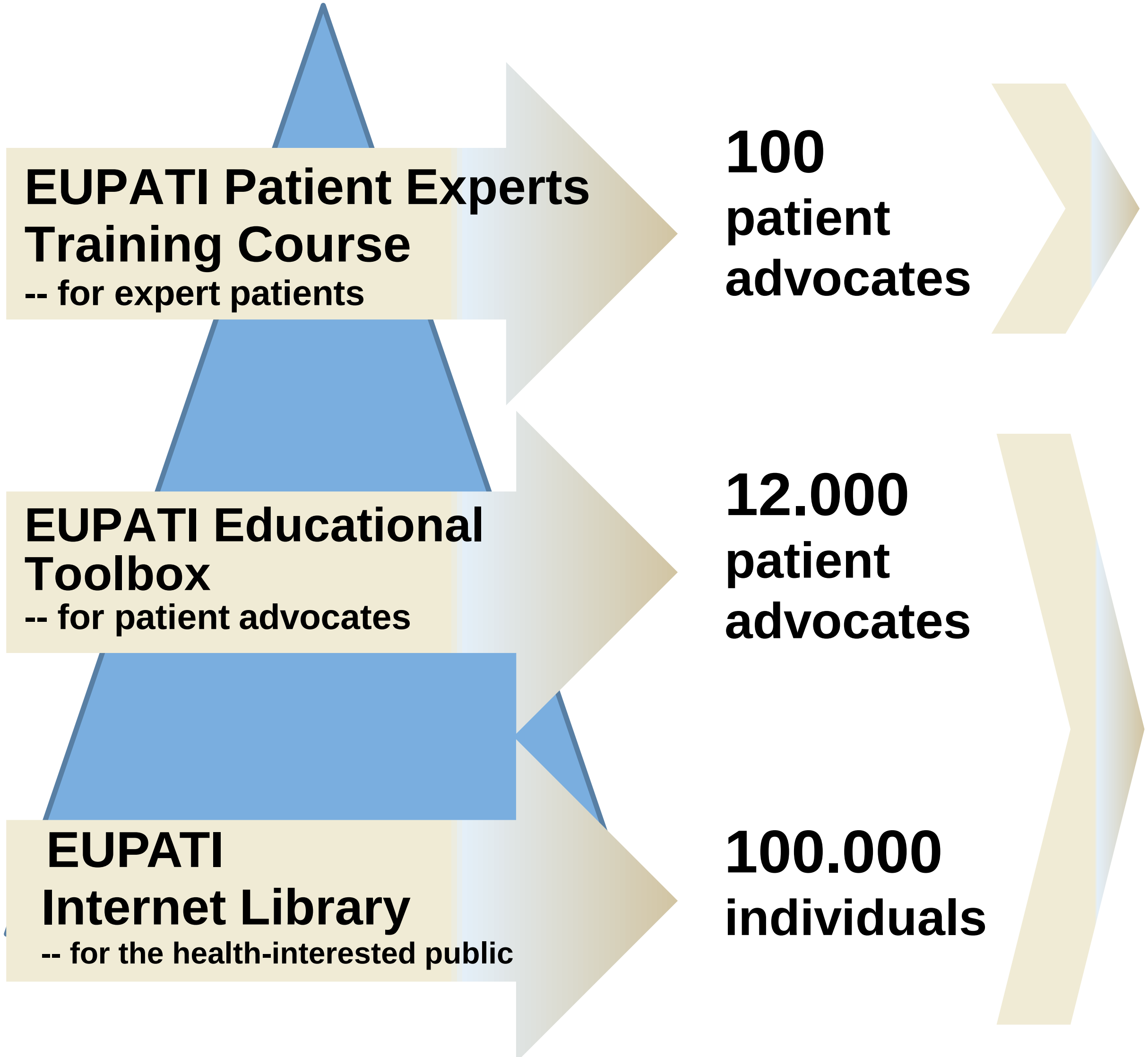
- **Patients…**
  - seek up-to-date, credible, understandable information about innovation in treatments
  - are largely unaware about clinical trials, translational research, personalized medicine, pharmaco-economics etc and their key role

- **Patient advocates…**
  - have an increasingly complex and professional task of advising on protocol design, informed consent, ethical review, marketing authorization, value assessment, health policy
  - are often self-taught and have gaps in the education and training required to participate as an equal partner in medicines R&D

- Prior to EUPATI the FP7-funded PatientPartner project demonstrated a **clear need & willingness of patient advocates to be an active partner in medicines research and development**

Patients Education –
The Patients Expert Course,
Library

EUPATI develops education targeted at different levels



EUPATI Patient Experts Training Course
-- for expert patients

100
patient advocates

English

EUPATI Educational Toolbox
-- for patient advocates

12.000
patient advocates

EUPATI Internet Library
-- for the health-interested public

100.000
individuals

English
French
German
Spanish
Polish
Italian
Russian

Patient Expert Training Course

Online self-learning

+

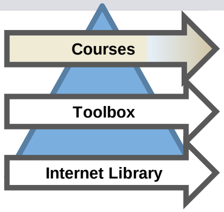
2 Face-to-face events

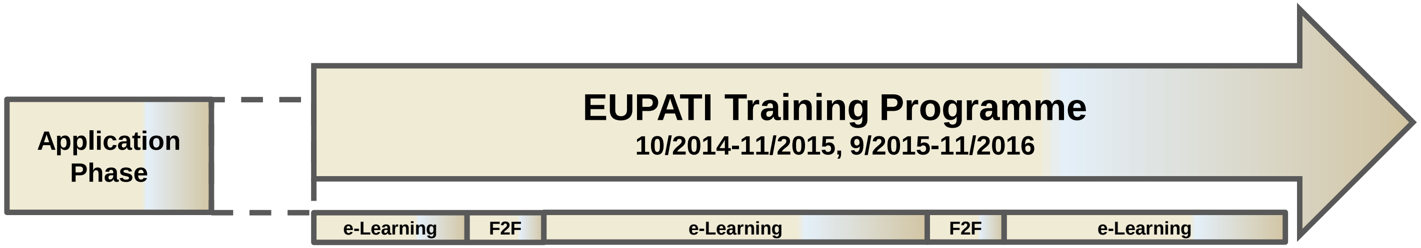
+

Patient involvement forum

150-175 hours of e-learning
and 8 days for two Face-to-Face meetings
over a period of 14 months

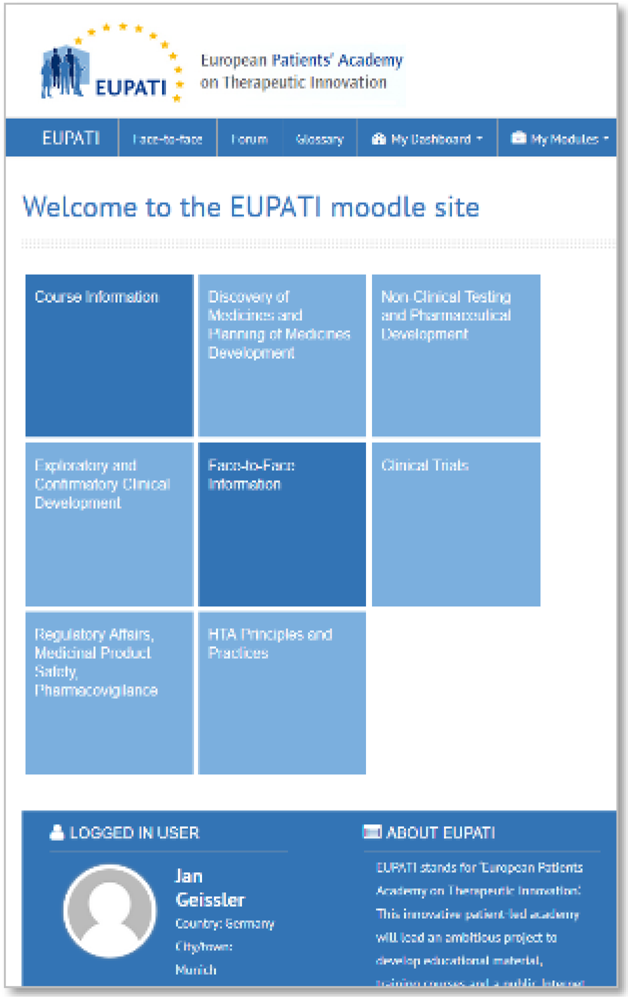
First EUPATI's Patient Experts Training Course kicked off on 6 Oct 2014





- Open to patients, carers, patient advocates and volunteers
- Two cycles of 50 participants
  - Oct 2014-Nov 2015 (1st 53 trainees), First f2f training course held in Barcelona in March 2015
  - Sept 2015-Nov 2016 (2nd ~50 trainees)
  - Selection carried out by multi-stakeholder selection panel based on solid criteria
- First course 2014-2015:
  - More than 300 applications for first course were received. Great demand from the community!
  - 55 trainees from 21 countries were selected
  - 46 trainees met in Barcelona after 6 months of e-learning

The EUPATI e-Learning platform is already in use with the course launch



Welcome to the EUPATI moodle site

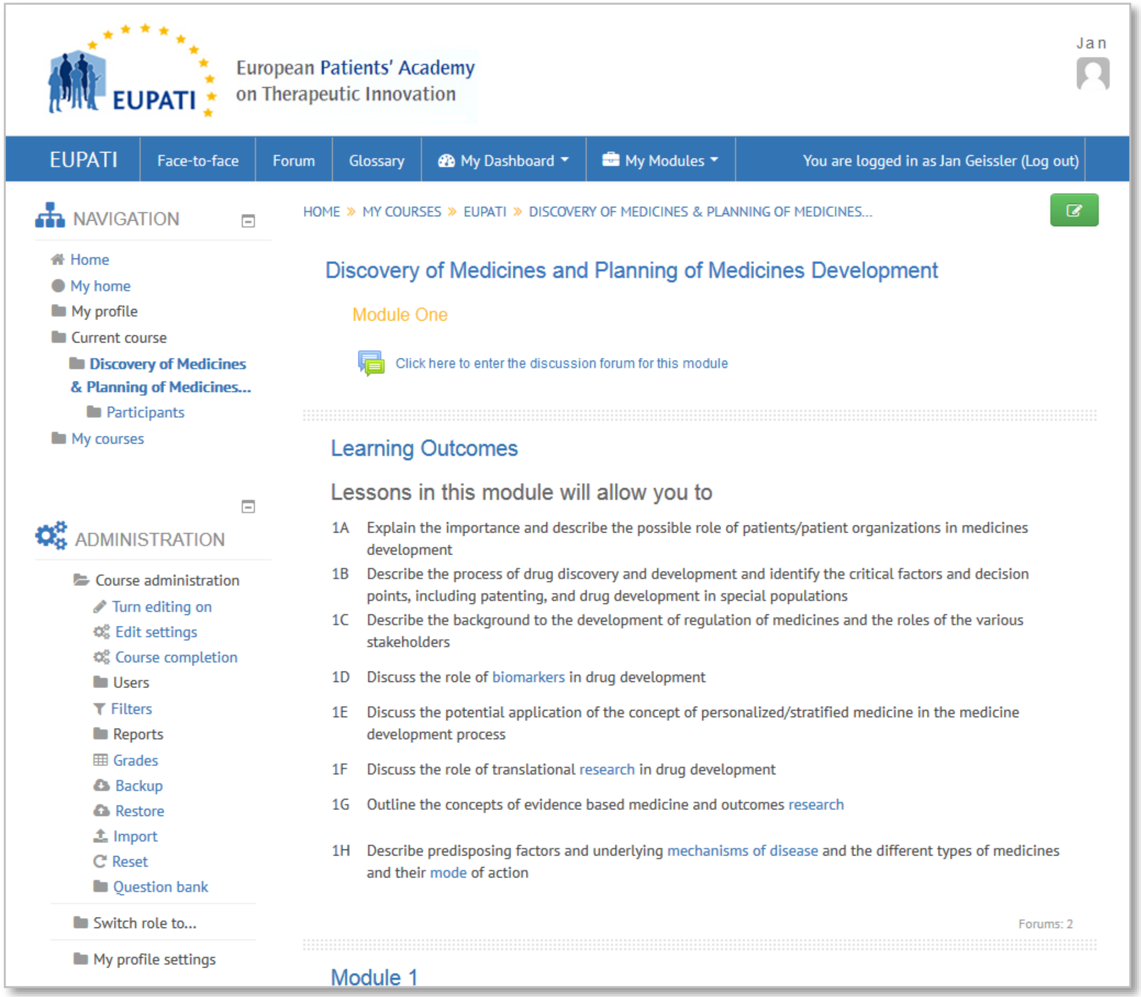
Course Information	Discovery of Medicines and Planning of Medicines Development	Non Clinical Testing and Pharmaceutical Development
Exploratory and Confirmatory Clinical Development	Face-to-Face Information	Clinical Trials
Regulatory Affairs, Medicinal Product Safety, Pharmacovigilance	HTA Principles and Practices	

LOGGED IN USER

Jan Geissler
Country: Germany
City/town:
Munich

ABOUT EUPATI

EUPATI stands for 'European Patients Academy on Therapeutic Innovation'. This innovative patient-led academy will lead an ambitious project to develop educational material,



Discovery of Medicines and Planning of Medicines Development

Module One

Click here to enter the discussion forum for this module

Learning Outcomes

Lessons in this module will allow you to

1A Explain the importance and describe the possible role of patients/patient organizations in medicines development
1B Describe the process of drug discovery and development and identify the critical factors and decision points, including patenting, and drug development in special populations
1C Describe the background to the development of regulation of medicines and the roles of the various stakeholders
1D Discuss the role of biomarkers in drug development
1E Discuss the potential application of the concept of personalized/stratified medicine in the medicine development process
1F Discuss the role of translational research in drug development
1G Outline the concepts of evidence based medicine and outcomes research
1H Describe predisposing factors and underlying mechanisms of disease and the different types of medicines and their mode of action

Forums: 2

Module 1

EUPATI – Contact

EMail: info@patientsacademy.eu

Web: www.patientsacademy.eu

Twitter: @eupatients

LinkedIn: EUPATI

Facebook: www.facebook.com/eupati.eu

Google+: gplus.to/eupati

„The Patients Expert Course“ from my point of view!

10 years ago … 21.01.2005

- Problem with the optic nerve on my right eye.
- 4-Day stay in the hospital
- A lot of exams
- 10 Minutes with the doctors
- Diagonsis: **Multiple Sclerosis**
- What? MS?
- No information, but had to decide for a treatment. ASAP!

- **Miss Trulla came into my Life.**

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Started my Research ….

- Answers
- Useful, understandable and transparent information.
- Sources: On – and Offline!
- Built my network to find more information
- Because: I wanted, and still want, to be empowered!

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Started blogging! Or: Knowledge Sharing!

- 2007: started on the online Platform of Brigitte
  (Big Womens Magazine in German speaking countries)
- since 2012 on my own label (Living and Working with MS!)
- share my experiences as Patient
- provide Information in „Patient Language“, writing about events, news, ideas, thoughts.
- bring People together

- <u>My Diagnosis: A big Gap between Patients and understandable, transparent Information!</u>

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Wanted? More information!

- Offer to participate in a clinical trial.
- Stopped. (to less information, bad informed consent etc.)

Challenge: Find out more information!

- 2012 Health Technology Assessment / London School of Economics (LSE)
- 2013 – Pharmaceutical Pricing and Reimbursement / LSE
- Since Oct. 2014 – Trainee „Patients Expert Course“ EUPATI

Today: Still learning a lot and currently sharing my knowledge to my community.

Future: I offered support for the German EUPATI Team, want to share more useful information thru the media, support other patients and work in ethic committees.

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Thank you!

My Blog about Living and working with MS:

http://leben-arbeiten-mit-multiple-sklerose.blogspot.de/

Find me in Social Media:

http://about.me/birgit.bauer

Email:

Birgit.Bauer@manufaktuer-fuer-antworten.de

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