



European Patients' Academy on Therapeutic Innovation

EPF AGM 2012 – Jan Geissler, EUPATI Director



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Window of opportunity for accelerating medicines R&D

- Personalized & translational medicine
- Increasing development cost
- Duplication and intransparency
- Pressure on healthcare budgets
- Many unmet needs



Patients want to contribute!



- **seek** up-to-date, credible, understandable information about innovation in treatments
- **are unaware** about clinical trials, translational research, personalized medicine, health economics, their key role
- **like to advise on needs**, on protocol design, informed consent, ethical review, marketing authorization, value assessment, health policy
- **lack the education & training** to participate as a partner in medicines R&D



Patients' Academy: a paradigm shift in empowering patients on medicines R&D



- ▶ Truly patient-led:
European Patients' Forum,
4 patient umbrella groups,
29 consortium members.
- ▶ Launched Feb 2012,
runs for 5 years
- ▶ Funded by the
Innovative Medicines
Initiative (IMI)



The European Patients' Academy on Therapeutic Innovation will...



- ▶ **develop and disseminate** accessible, well-structured and user-friendly information and education on medicines R&D
- ▶ **build competencies and expert capacity** among well informed patients and the public
- ▶ **create a public library** on patient information in seven most common languages under public licensing
- ▶ **facilitate patient involvement in R&D** to support industry, academia, authorities and ethics committees

Patients' Academy targets key aspects of medical R&D processes



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

Audiences: advocacy leaders and the public at large



EUPATI Training Programme (→ experts)

- Academic Modular Certificate Programme
- Patient Ambassadors. Patient Journalists, Patient Trainers

100
patient
advocates

EUPATI Educational Toolbox (→ education)

- Tool box with a variety of distributable formats
- Paper-based booklets, presentations, eLearning, webinars, videos etc.

12.000
patient
advocates

EUPATI Internet Library (→ information)

- Wiki” “YouTube” Social Media” Internet Sources (Editorial Board)
- TV films and/or cartoons

100.000
individuals



Reflecting European diversity: 7 languages

- **7 most frequently spoken languages:**

English, French, German, Spanish, Polish,
Russian, Italian

- **Serving 12 European countries:**

UK, Ireland, Malta, France, Luxemburg, the francophone Belgium and Switzerland, Germany, Austria, the German-speaking Part of Switzerland, Spain, Italy and Poland, plus Russian-speaking population in CEE



Strong consortium & strong governance

- Coordinator EPF, 4 leading pan-EU patient umbrella groups involved
- Strong impetus from key academic partners and NGOs
- Industry expertise in medicines R&D
- Advisory bodies & codes to ensure independence, good governance
 - EMA, Swissmedic, MHRA, BfArM
 - Key experts in bioethics, genetics, HTA, economics, evidence based med, patient advocacy



What's next?

Managing expectations:

- First content in mid 2013...

What we're doing just now:

- Project kicked off in February, launch meeting 27 March
- 7-lingual website patientsacademy.eu set up
- “EUPATI Network” being prepared
- “Material collection” ongoing
- Content teams being built
- Ethics Panel, Advisory Boards



EPF members

– please join us and contribute!

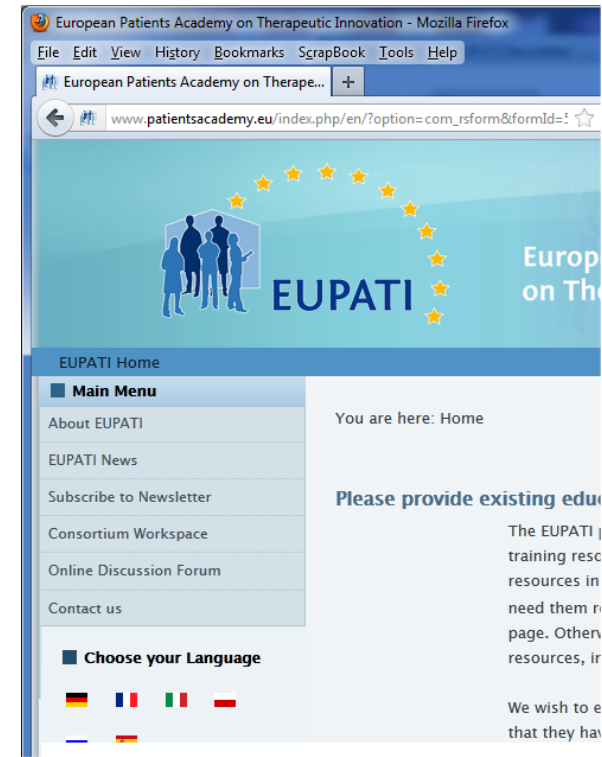


- **Join our network! Spread the word!**
www.patientsacademy.eu/eupati-network



- **Help us not re-inventing the wheel!**
www.patientsacademy.eu/suggest

- **Help us establish patient-led EUPATI platforms**
with representatives of patient org.,
academia, industry



Your ideas are very welcome!



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