

## The Patients' Academy - a paradigm shift in empowering patients in medicines R&D

The consortium project "European Patients' Academy on Therapeutic Innovation" (EUPATI), funded by the Innovative Medicines Initiative, will provide scientifically reliable, objective, comprehensive information to patients on medicines research and development. It will increase the capacities and capabilities of well-informed patients and patient organisations to be effective advocates and advisors in medicines research, e.g. in clinical trials, with regulatory authorities and in ethics committees.

During the course of the project, the Patients' Academy will:

- develop and disseminate accessible, well-structured, user-friendly, objective and credible educational material on therapeutic innovation
- o establish a public library on medical innovation in seven most common European languages
- build competencies and expert capacity among well-informed patients and the public
- o facilitate patient involvement in R&D to support researchers and authorities

The project was launched in February 2012 and will run for five years.

### Please contact us!

We are looking forward to hearing from you! The Patients' Academy has been set up for, and with, patients all across Europe and will be developed by a consortium of all stakeholder groups. We are keen to collaborate with all groups interested in the education about medicines R&D.

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### **EUPATI Project Secretariat**

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Educating patients on therapeutic innovation

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# The Topics and Audiences

The Patients' Academy will develop educational material in the following areas:

- Medicines development process from research to approval
- Personalized and predictive medicine
- Drug safety and risk/benefit assessment of medicines
- Pharmaco-economics, health economics and health technology assessment
- Design and objectives of clinical trials, including roles of stakeholders
- Patients roles & responsibilities in innovative medicines development

The Patients' Academy will target specifically patient organizations, advocacy leaders and the lay public in the countries speaking English, German, Spanish, Polish, French, Russian and Italian.



## The Partners

The Consortium includes pan-European leaders in patient advocacy, academia, not-for-profit organisations and EFPIA member companies, bringing in key expertise in patient advocacy and processes for R&D in medicines.

#### Patient Advocacy Groups



European Patients' Forum (Project Coordinator), European AIDS Treatment Group (EATG), European Organisation For Rare Diseases (EURORDIS), European Genetic Alliance Network (EGAN).

#### Academic Partners



University of Manchester (Nowgen), University of Copenhagen (Biopeople) and Hibernia College in Dublin.

### Not-for-Profit Organizations

DIA Europe, European Forum For Good







### **EFPIA Members**



Amgen, AstraZeneca, Bayer, Boehringer Ingelheim, Chiesi, Eli Lilly, Esteve, Farmaindustria, GlaxoSmithKline, Janssen, Merck, Novartis, Novo Nordisk, Roche, Sanofi incl. Genzyme, UCB Pharma, VFA.

# **Ensuring Objectivity, Transparency** and Independence

The Patients' Academy is a highly collaborative project with partners from very different fields including patient organisations, academia, not-for-profit organisations and pharmaceutical companies. Objectivity, transparency and independence are vital to ensure EUPATI achieves its goals.

A robust governance structure, led by major umbrella patient organizations, includes also a multidisciplinary Project Advisory Board, a Regulatory Advisory Panel and an Ethics Panel, comprising renowned experts in ethics, law, drug development and patient advocacy. EUPATI's Ethical Framework and the EUPATI Code of Conduct set the ground rules for anonymity, confidentiality, informed consent, social research, ethical review, professional integrity, publication ethics, transparency, independence and trust.

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