

Press Release – 10 Sept 2012

PATIENTS INVOLVEMENT IN MEDICAL R&D: MANY VIEWS, VARIED IDEAS, ONE VISION

With its kick-off event on 5th of September 2012, the European Patients' Academy on Therapeutic Innovation (EUPATI) provided an open forum for stakeholders from all over Europe. More than 120 registered participants from 24 countries attended the first public workshop of EUPATI in Frankfurt, demonstrating the broad interest and real need for more patient involvement when new treatments are being developed.

“Everybody recognises that there are many unmet needs for most patients with life-threatening diseases,” said Nicola Bedlington, Executive Director of the European Patients' Forum and project coordinator of EUPATI. *“Patients know their needs best but rarely have the broad know-how on how the highly regulated and complex R&D process works. Our Patients' Academy aims to address this by educating patients about the medicines development processes. We know it can be done.”*

Being an involved, informed, independent and active patient requires substantial knowledge, understanding and ability to question. This is especially true when patients are involved in clinical trials. The European Patients' Academy is taking the challenge of bringing all relevant stakeholders together to make a joint vision happen: to provide top-quality, objective, reliable, unbiased education, training and information to patient organisations and patients at large on all aspects of medicines research and development, in order to get involved and become empowered players in the medicines development process. This creates paradigm shift, making sure that patients' needs and insights are at the centre in all relevant areas of medicines R&D.

In its first 8 months, the Patients' Academy has not only established the structure and initial processes for this 5 year project, but has also achieved first results in its seven work packages which were presented in Frankfurt. The workshop was designed to open up the discussion on these first results, providing a space for gathering, discussing, exchanging and developing ideas and plans. Covering a huge range of perspectives, participants included patient advocates as well as representatives from academic institutions, not-for profit organisations and industry from all over Europe.

“Nothing is set in stone,” Nicola Bedlington emphasized as the break-out sessions began. *“We have a framework and clear ideas, but the input of all participants, being experts with different backgrounds and from different geographical areas, is absolutely vital to shape what we do. The floor is open.”*



The term “OPEN” in this context stood for several aspects:

- **Open minded** – receptive for new ideas, different thoughts, the supporting but also the critical voice
- **Open for involvement** – giving the chance to anybody to become a part of EUPATI, and help developing and spreading the idea of the project
- **Open for discussion** – encouraging a dialogue
- **Open for progress** – not being static but flexible in thoughts and actions
- **Open and transparent in all that we do**

Starting off with initial presentations on the background and the progress of the EUPATI project to date, the workshop in Frankfurt encouraged communication **(1)** on how to raise awareness for EUPATI to maximise collaboration and support, **(2)** on how to best establish and organise National Platforms that will build bridges into the 12 countries served by EUPATI, **(3)** on how to enhance collection of information in this project and **(4)** on how to best deliver the outcomes, to make sure as many patients as possible will benefit from the pool of information developed by the Patients' Academy.

Lively discussions during breaks and in the workshop sessions provided much relevant feedback on all aspects of the project.

“We need to talk to each other to achieve the best outcome”, added Frank Wells, National Research Ethics Advisor, *“communication is the name of the game.”* These are early days for the European Patients' Academy. Yet the workshop has demonstrated that solid foundation work has been done, and much more will follow through meetings like this one.

The overall summary at the end of the day demonstrated very valuable input of ideas and different views, but also many open questions that the project consortium will now follow up.

A more detailed workshop report will be available soon on www.patientsacademy.eu – please register for the EUPATI Newsletter to hear as soon as it is available.

BACKGROUND

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 advisors in medicines research, e.g. in clinical trials, with regulatory authorities and in ethics committees. Started on 1 February 2012, the patient-led academy will develop educational material, training courses and a public Internet library to





educate patient representatives and the lay public about all processes involved in medicines development.

Topics will include personalised and predictive medicine, design and conduct of clinical trials, drug safety and risk/benefit assessment, health economics as well as patient involvement in drug development. EUPATI will provide educational material in seven European languages targeting twelve European countries. Initial educational material will become available after the first 18 months of the project. 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 research and development in medicines. The project is coordinated by the European Patients' Forum.

The **Innovative Medicines Initiative (IMI)** is Europe's largest public-private initiative aiming to speed up the development of better and safer medicines for patients. IMI is a joint undertaking between the European Union and the pharmaceutical industry association EFPIA. IMI supports collaborative research projects and builds networks of industrial and academic experts in order to boost pharmaceutical innovation in Europe. The EUPATI 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' in kind contribution. More information can be found at www.imi.europa.eu

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