

The flagship of patient education sails on!

The European Patients' Academy on Therapeutic Innovation, EUPATI, has been registered as an independent Foundation in The Netherlands. While EUPATI remains in close partnership with the European Patients' Forum (EPF), this change opens up new and exciting avenues of development for the leading non-profit organisation in education for patients and on patient engagement in Europe.

The European Patients' Academy on Therapeutic Innovation (EUPATI) has been in the forefront of patient education and training on patient engagement provided to different stakeholders since its inception by the European Union's Innovative Medicines Initiative (IMI) in 2012. After operating as a special project hosted by EPF for 8 years (a leading patient umbrella organisation in Europe), EUPATI has now become an independent Foundation registered in The Netherlands. The registration is a result of more than one year of preparation and careful development and will also involve some changes in the organisational setup and operation of EUPATI.

"This is a really important milestone, which not only allows EUPATI to gain more autonomy and independence but also opens up new possibilities for fundraising, development of training events and the promotion of patient engagement in medicines research and development. Solid educational resources for patients, researchers and the pharmaceutical industry are essential to keep up with the growing demand for patient engagement", says Maria Dutarte, Executive Director of the EUPATI Foundation.

These last eight years of EUPATI were anything but uneventful.

- One of EUPATI's most important achievements, the online, <u>multi-lingual Toolbox on</u> <u>medicines research and development</u> reached more than 4 million individual users by May 2020.
- The Patient Expert Training Course of EUPATI has already trained almost 160 patient experts, with an additional 50 currently in training.
- In the last 18 months, **EUPATI** has delivered 7 different training events for more than 250 participants in academia and the pharmaceutical industry who work or plan to work in patient engagement with another 4 trainings planned until the end of the year.
- The network of <u>EUPATI National Platforms</u> covers more than 20 countries, in Europe and worldwide.
- EUPATI Alumni are present in a wide array of research projects and patient organisations, taking the lead in the theory and practice of meaningful patient engagement.

A rigorous and consistent quality assurance process makes sure that all contents developed and released by EUPATI are unbiased, scientifically reliable, and carefully checked by representatives of all stakeholders: regulators, HTA representatives, patient organisations, the pharmaceutical industry, and academia.

The long-term strategy and plans of EUPATI envisage ambitious development.

 The Patient Expert Course will be rolled out as an online, on-demand, modular course with an integrated e-learning system that allows remote and self-paced learning towards the coveted EUPATI certificate.



- The EUPATI Toolbox is being updated and enlarged with additional languages and new relevant contents about medical devices, novel trial designs, big data, and other emerging topics.
- EUPATI will formalise, develop, and roll out its already successful "matchmaking" service
 that brings together research and development projects with well-trained and reliable
 patient experts.
- The successful series of EUPATI Fundamentals training on patient engagement will
 continue, while the new EUPATI Essentials training course will add depth and breadth to
 the training series.
- The EUPATI network of **National Platforms is being redeveloped and enlarged** with bold plans to grow beyond Europe.

Anders Olauson, Honorary President of EPF and Chair of the EUPATI Foundation is optimistic and enthusiastic: "EUPATI is one of the pinnacles of the patient advocacy movement that we started at EPF and other local and European organisations many years ago. The establishment of the EUPATI Foundation will secure flexibility and the proper structure to grow and flourish".

Along with the registration of the 'Stichting' EUPATI Foundation in the Netherlands, the governance structure of the European Patients' Academy has been revisited. This new governance structure has been thoroughly constituted to ensure the effective execution of EUPATI's activities in short- and long-term.

A <u>Board of Trustees</u> has been formed and the new <u>EUPATI Board</u> elected by the <u>Sustaining Partners</u> <u>Assembly, now also including the EUPATI National Platforms</u>. The new EUPATI Board is led by Anders Olauson from the European Patients' Forum (EPF) as the Chair and Kay Warner from GlaxoSmithKline (GSK) as the Co-Chair. Both Anders and Kay have a long track-record in patient engagement and patient education and have contributed to EUPATI since the start. They are picking up the baton from Nicola Bedlington (EPF) and Matthias Gottwald (Bayer) who have successfully steered the EUPATI ship for the past 8 years. For more information about the governance, <u>please see here</u>.

About EUPATI - The European Patients' Academy on Therapeutic Innovation provides scientifically reliable, objective, comprehensive information to patients and the public on the research and development process of medicines. It aims to increase the capacity of patients and the lay public to be effective advocates and advisors, e.g., in clinical trials, with regulatory authorities and in ethics committees. EUPATI is a public-private partnership of more than 25 organisations made up of a unique combination of patient organisations, academia, and not-for-profit organisations expert in patient and public engagement, along with European pharmaceutical companies working in research. EUPATI aims to make a visible difference to all stakeholders involved in medicines research and development.

European Patients' Academy on Therapeutic Innovation (EUPATI) Stichting EUPATI Foundation

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For further information, please contact us or visit our website.

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PGO Support P.O. box in Utrecht (Netherlands) where the EUPATI Foundation is registered at.



Maria Dutarte (EUPATI) and Annemiek van Rensen (PGO Support).