



## WHAT IS EUPATI?

The European Patients' Academy on Therapeutic Innovation (EUPATI) is a multi-stakeholder programme led and hosted by the European Patients' Forum (EPF) originally established by the IMI-EUPATI project (2012-2017). It is a successful programme that provides education and training to increase the capacity and capability of patients to understand and contribute to medicines research and development (R&D), and to improve the availability of medical information for the health interested public. It does so by conducting its established Patient Expert Training Course which has trained more than 150 patient experts to date and by providing an open-access multilingual toolbox that has served more than 3 million users around the world to date.

EUPATI is the only dedicated training provider for patients and patient advocates on the end to end process of medicines research and development. Educated patients are the core resource for patient involvement in medicines R&D, regulatory deliberations and other patient engagement initiatives. EUPATI is offering various activities related to patient education and engagement.

## WHAT IS OFFERED?



Patient Expert Training Course



Toolbox



National Platforms



Stakeholder Patient Engagement training



Matchmaking with EUPATI Fellows



Infrastructure for Patient Engagement



# OBJECTIVES 2020-2025

Update existing training programmes to meet the growing demand for flexible and on-demand learning pathways.

Drive towards more solid sustainability by further diversifying funding streams, both permanent and project based.

Grow the training portfolio to offer stratified levels of education that are available for all stakeholders involved in Patient Engagement on both an organisational and individual level.

Establish the necessary infrastructure and governance to ensure EUPATI's continuous sustainability on the European, National and Global level in the mid- and long- term.

## PROGRAMME DETAILS



The **EUPATI Patient Expert Training Course** is an exciting and unique opportunity offering patients and patient advocates expert-level training in medicines research and development. The Course is a blended mixture of e-learning coursework and face-to-face training events over 15 months.

More than 150 patient experts in three cohorts have graduated from the course since 2014. The EUPATI fellows have acquired skills and knowledge to make significant, active contributions in high level processes of patient involvement in medicines research and development in Europe.



The **EUPATI Toolbox** was launched in January 2016. It contains a library of information around medicines research and development. This information is not medicine- or disease-specific.

More than 3 million users have accessed the information on the Toolbox in less than three years. It provides the "A-Z of medicines research and development" from lab bench to approval, drug safety and other topics. Users can utilise the Toolbox information in nine languages with three additional languages in translation (Portuguese, Romanian, Swedish), Japanese).



EUPATI sits at the key interface between **stakeholders looking to engage patients**, and patients with the requisite knowledge to provide expert level input into medicines R&D. We therefore provide an increasingly **active matchmaking** service for members of the EUPATI partnership.



**Training on Patient Engagement** is necessary since there is a lack of understanding of efficient involvement that ensures patients and professionals both have a meaningful engagement that meets everyone's expectations. There is no standardised training for professionals working in patient relations and engagement, or any common rules to enter the field requiring too much on the job learning, diverse approaches and lack of institutional and experiential knowledge transfer. Plus, there is a lack of continuous professional development (CPD) for professionals in this field in order to advance their careers and improve their work practices and processes.

In 2019, EUPATI will launch its first course on patient engagement for industry and academia, and will later expand its portfolio to not only address end-to-end patient engagement but also ensure there are stratified courses at different levels available for all stakeholders who need to engage patients in their work. It will address the current gap of no training being available to professionals working in patient relations/engagement management and operational functions looking to work with patients.



There is a wealth of **initiatives on patient engagement** and EUPATI collaborates closely bringing in the essential education component. True patient engagement cannot exist without quality education, hence our involvement with initiatives at the European and Global level. The EUPATI partnership through its knowledge and experience participates in the development of guidance and best practices for patient engagement as well as other topics. With its **infrastructure for patient engagement**, EUPATI moves the latest developments into practices through education.

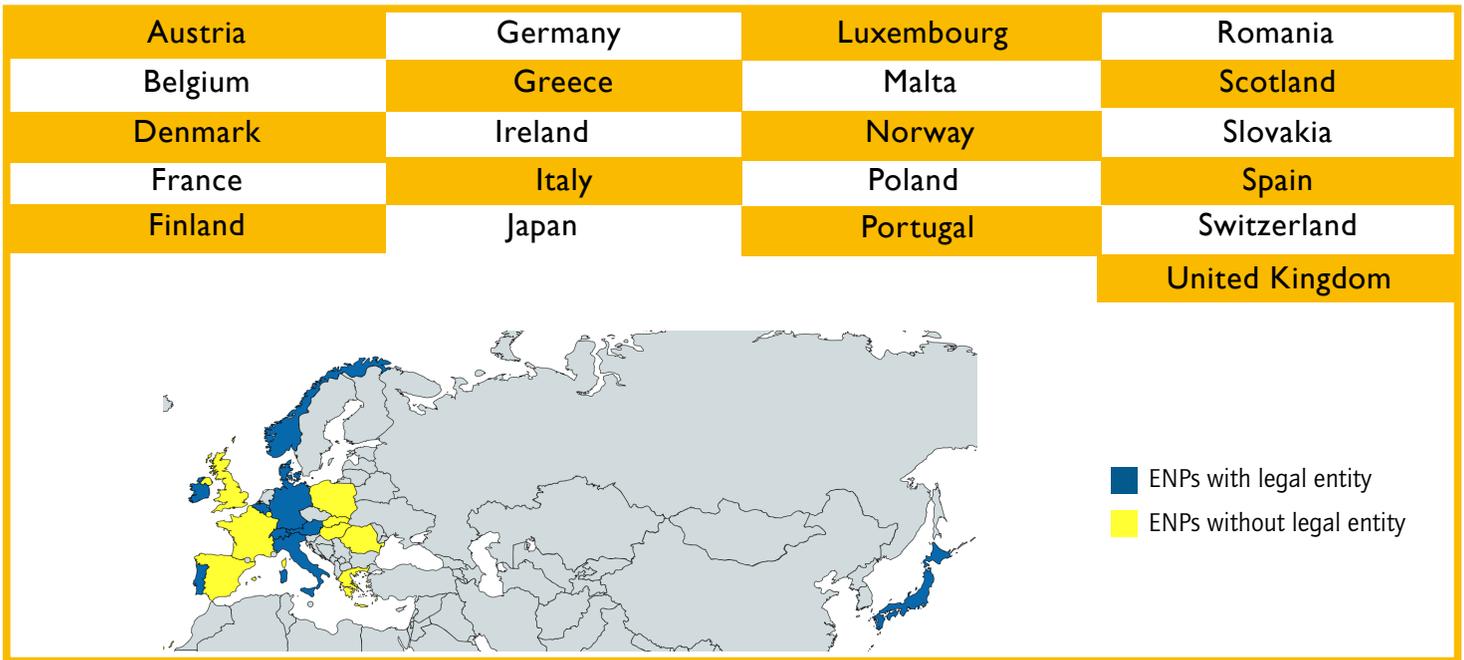


**EUPATI National Platforms (ENPs)** model the EUPATI partnership at the country level. ENP Membership is open to all, but its make-up can vary from country to country. In some countries, ENPs are set up as an informal group run by volunteers, other countries have established legal entities with formal statutes and paid staff in place.

ENPs' work includes establishing national patient education programmes, establishing charters for patient involvement, members speaking internationally at conferences and promoting education by establishing workshops on patient engagement, mini-courses or webinars. National platforms are not disease specific and as a result they bring together individuals across all areas of patient involvement.

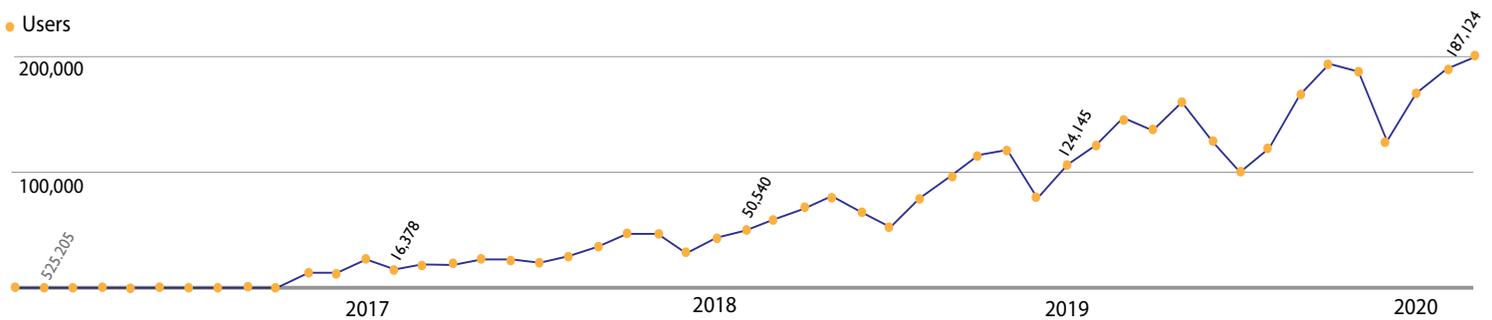


## BY 2020, EUPATI ESTABLISHED PLATFORMS IN 21 COUNTRIES (EU & ASIA)

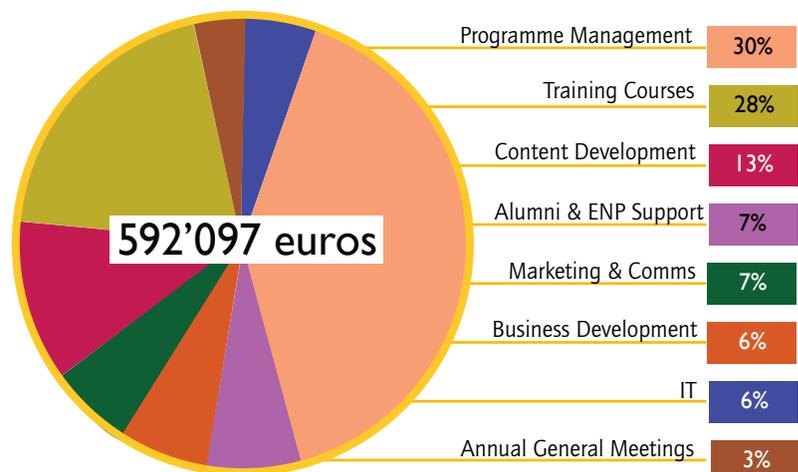


## NUMBER OF USERS OF THE TOOLBOX PER MONTH SINCE JANUARY 2016 TO MARCH 2020

+3 million users worldwide



## WHAT ANNUAL BUDGET IS NEEDED?



EUPATI aims to generate revenue of €61'500 through income from training courses (€58'500) and donations (€3'000). EUPATI will further look to participate or propose projects under relevant funding frameworks which will be in addition to the mentioned figures.

The minimum requested contribution by industry partners is €30'000 (big pharmaceutical companies), and €20'000 for industry associations and medium sized enterprises. In-kind contributions are welcome but are considered in addition to a cash contribution.

The minimum requested contribution by public partners is €5'000 in-kind, the in-kind contribution must contribute directly to an activity defined in the EUPATI 5-year workplan.

Only partners meeting the minimum contribution are eligible for election to sit on the EUPATI Steering Group as representatives of their respective stakeholders. All partners have a voice through the general assembly as sustaining partners.

## WHAT BENEFITS ARE THERE BEING A EUPATI CONSORTIUM PARTNER?

### PUBLIC PARTNERS

- ★ Co-create meaningful resources together with other patient organisations, academia, regulators and industry resulting in a new climate of understanding and trust that goes beyond EUPATI alone.
- ★ Networking and dialogue with other partners across different disease areas and countries.
- ★ Ensure training is reflective of all stakeholders' perspectives.
- ★ Co-design the future of patient education and engagement content.
- ★ Join consortia of future EUPATI driven project proposals.
- ★ Co-define the direction and strategy of educational content of the European Patients' Academy.
- ★ Access all educational resources developed by EUPATI.
- ★ Receive regular updates on developments in patient engagement and training opportunities.

### PRIVATE PARTNERS

- ★ Collaborate under a public-private partnership ethos of co-creation is the way to collaborate with patients and other stakeholders.
- ★ Co-create and contribute to the education of stakeholders to bring about meaningful and systematic patient engagement.
- ★ Join a truly transformational process for patients and contribute to a major global impact in the patient engagement.
- ★ Access to facilitated discussions and debates on medicines R&D issues in Europe with patient leaders, scientists and industry representatives.
- ★ Networking opportunities with patients, patient organisations, scientists, academics and industry representatives.
- ★ Co-create meaningful resources together with other stakeholders, academia, regulators and industry resulting in a new climate of understanding and trust that goes beyond EUPATI alone.
- ★ Receive regular updates on developments in patient engagement and training opportunities.
- ★ Access to EUPATI personnel for one-to-one or multilateral briefings.

## WHAT HAVE EUPATI FELLOWS DONE?



Dimitris Athanasiou, EUPATI Fellow



*Being nominated a Member of the EMA Pediatric Committee.*



Roald Nystad, EUPATI Fellow



*Founding the Melanoma Patient Association in Norway (Board Director and Manager for 3 years). Establishing the Norwegian ENP.*



Marleen Kaatee, EUPATI Fellow



*Being the first patient to speak at the annual College Day of CBG/MEB, the Dutch Medical Evaluation Board.*



Paola Kruger, EUPATI Fellow



*Media articles, interviews, being nominated Patient Expert in my hospital (MS Centre), 2 scientific publications*



\*this list does not include all of the organisations/initiatives in which the EUPATI Fellows have been active since their graduation.

## TESTIMONIALS



Joan Jordan, EUPATI Fellow

EUPATI opened up my world beyond my own disease area. I understand how the medicines R&D process works from end to end. If you want to get involved, EUPATI is a huge benefit.

Kay Warner, GSK

Founding member & Industry partner

Being able to work with so many fantastic people who share the same passion as you; but more importantly having the privilege of seeing patients go through a training course, growing in confidence, having more exposure, building their expertise and then taking that knowledge and making a difference in so many ways. I am truly grateful for the opportunity to work on EUPATI, personally I have learnt so much not only about patient involvement but also about myself during this 7-year journey; the experience has been immense and so worthwhile – thank you! Long live EUPATI

Nadia Naaman, ISPOR

Founding member & Public partner

ISPOR has been a consortium partner and supporter of EUPATI since its inception in 2012. Our collaboration with EUPATI is part of our Society's long-standing commitment to the engagement of patients in health economics and outcomes research (HEOR). EUPATI has provided ISPOR with the opportunity to connect with its "patient experts;" many of whom have become an integral part of the global HEOR community by attending and presenting at ISPOR conferences, participating and contributing to our global Patient Representatives Roundtables, and partnering with researchers in our scientific working groups, to improve healthcare decision making globally.



Estelle Jobson, EUPATI Fellow



The EUPATI tools and training are very suitable for patient advocates who are intellectually curious about science and wish to develop a wide range of advocacy skills. The EUPATI model calls for more diplomacy and perhaps less flag-waving activism, as the EUPATI ethos is to sit at the table with all key players, including pharmaceutical companies, admitting that we need one another, and trying to broker fallout from the past. We patient advocates have to learn to read and speak in scientific terms, without forgetting the daily reality of living with diseases. This also requires a certain mental agility. I am now less focused on my own disease and more on the bigger picture — the patient movement.



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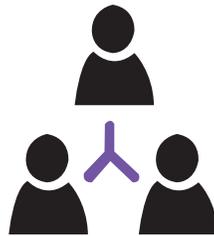


# EUPATI

European Patients' Academy  
on Therapeutic Innovation



**3+ million**  
TOOLBOX USERS



**28**  
CONSORTIUM  
PARTNERS



**5.0**  
FTE  
MANAGEMENT  
TEAM



**154**  
FELLOWS



**95**  
TRAINING  
TOPICS



**4**  
COHORTS



**21**  
ESTABLISHED  
NATIONAL  
PLATFORMS



**9** LANGUAGES OF  
THE TOOLBOX  
**+**  
**4** IN DEVELOPMENT



**4**  
GUIDANCE  
DOCUMENTS  
PUBLISHED



**4'000+**  
ENTRIES



**217**  
COUNTRIES

**1**  
PARTNERSHIP



CHANGING THE FACE OF  
PATIENT ENGAGEMENT  
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