

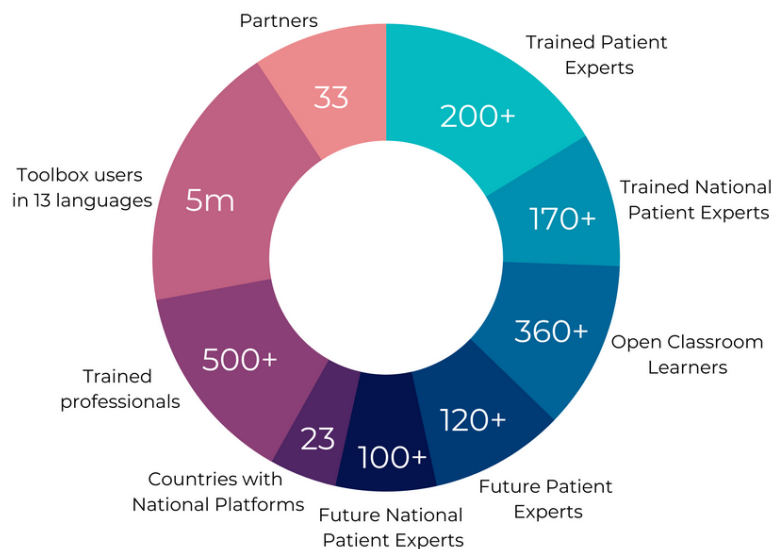


EUPATI

ANNUAL REPORT

2021

EUPATI TODAY



The European Patients' Academy on Therapeutic Innovation (EUPATI) is a patient-led multi-stakeholder public-private partnership originally launched by the Innovative Medicines Initiative (IMI) and today established as an independent non-profit Foundation. EUPATI partnership consists of patient organisations, academic institutions and pharmaceutical companies from all over the world.

EUPATI's vision is to improve health outcomes through the contribution from patients and patient representatives as valued stakeholders in the research and development of medicines and healthcare technologies. It does this by providing accessible, innovative and inclusive education that empowers patients and patient representatives with the right knowledge, skills and competencies to effectively engage and partner with all other stakeholders.

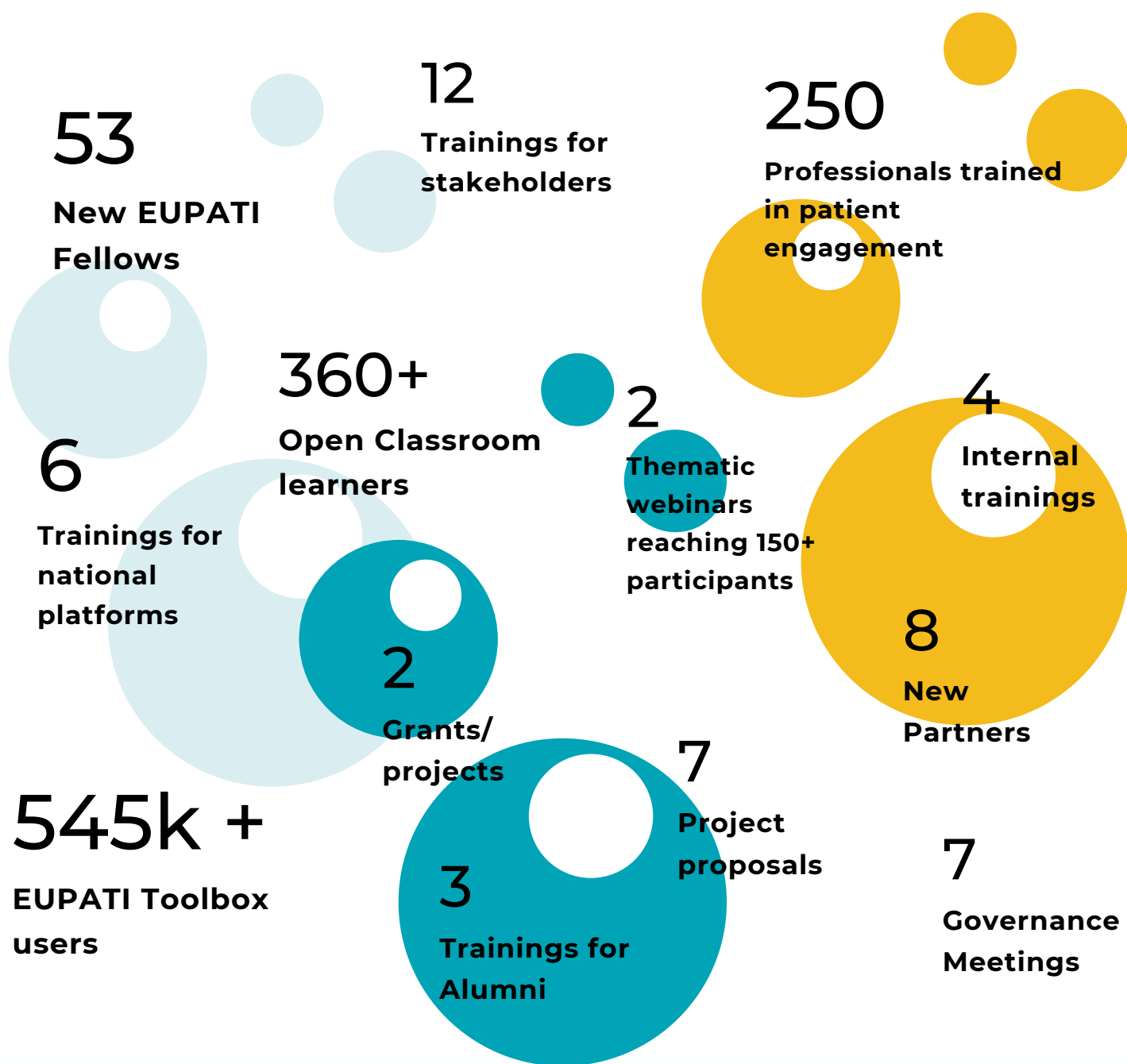
EUPATI is today, via its Open Classroom, the global leading platform for patient education. It has trained more than 200 Patient Experts (EUPATI Fellows), and with more than 360 currently enrolled on the platform. In addition, 170 Fellows have graduated from the national EUPATI trainings in Ireland, Italy and the Netherlands.

EUPATI is active in 23 countries through its National Platforms, and also provides an open-access multilingual Toolbox that has served more than 5 million users in 13 languages around the world to date.

In order to enhance patient engagement, EUPATI also provides general trainings about patient involvement in medicines R&D for professionals working in academia and the pharmaceutical industry. To date, more than 500 individuals have participated in these trainings. A new activity launching soon, 'EUPATIconnect', will also facilitate the collaboration between trained patients and other stakeholders.

EUPATI is committed to offering educational materials and information for patients, patient representatives and the wider public free of charge. This is made possible by financing in form of cash contributions from industry partners and in-kind contributions from public partners, grants (e.g. IMI, European Commission, EIT Health), donations and fee-based trainings & services around patient engagement. EUPATI Foundation functions as a non-profit organisation and all generated income is re-invested in patient education.

EUPATI IN 2021



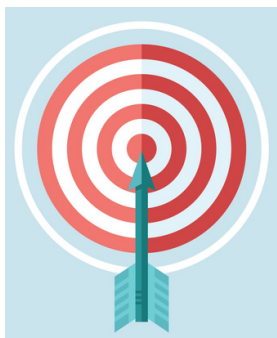
This report summarizes EUPATI's progress from January to December 2021 against the annual work plan goals.

Overall, the EUPATI Partnership, the National Platforms, Alumni, network of Experts and Collaborators were widely successful in enhancing patient education and patient engagement in medicines R&D. A new group of EUPATI Fellows graduated from the Patient Expert Training Programme, an unprecedented number of learners joined the new Open Classroom learning platform, and a growing number of professionals took part in EUPATI patient engagement trainings.

This year has also brought further strength and stability to the governance of the EUPATI Foundation and the coordination between the international core entity and the National Platforms. Special efforts were invested in defining and clearly communicating EUPATI's vision & mission, and its key role as a provider of education, training and information for patients and other stakeholders at the global scale.

TRAINING

EUPATI4PATIENTS



- Increase the reach of EUPATI patient education and strengthen the ENP Network's training capacity
- Provide continued education opportunities for the EUPATI Alumni

Latest Cohort of EUPATI Fellows

- 53 New Fellows graduated in April
- 28 Countries represented
- 6 Training Modules, 16 Months, 300 Hours of online study
- 8 Days of online training events with 33 Faculty members

EUPATI Open Classroom (learning.eupati.eu)

- EUPATI Patient Expert Training Programme transformed onto a new format: Online - On-demand - Open to all
- Full EUPATI Fellow Programme made available (6 Modules containing 27 courses)
- 360 registered learners, 120 enrolled in Fellow Programme
- New Modules on Digital Health and Medical Devices developed, containing 8 courses (publication early 2022)

ENP Patient education

- Three new cohorts of EUPATI national patient expert training programmes launched by ENPs in Italy, the Netherlands and Ireland, total of 120 trainees
- A working group established for these three ENPs sharing best practices & experiences

ALUMNI training

- 3 webinars organised for EUPATI Fellows on Patient Preferences and PROs, HTA and Good Lay Summary Practice, 150 participants

+34% increase
in number of
Fellows

+44% more
new learners
than initially
targeted

3 National Patient
Training
Programmes



CONTENT CREATION



- Expand the EUPATI training and Toolbox materials

Medical Devices & Digital Health

- Two new Training Modules for Open Classroom developed (publication early 2022)
- Supported by EIT Health EUPATI Reload project consortium
- Authoring groups included a variety of new partners and stakeholders

Translational & personalised medicine

- Update and expansion of existing toolbox articles conducted (publication early 2022)

Patient preferences & PROs

- New content developed and added onto Open Classroom Module on HTA

Thematic webinars

- Diversity & Clinical Trials, 70 participants
- Cross-Border Healthcare, 70 participants

2 New areas:
Medical Devices &
Digital Health

2 New Toolbox
articles

New publicly
available
educational
content



TRAINING

EUPATI4PROFESSIONALS



- Further develop the EUPATI Fundamentals (for industry and academia) to meet the training needs of different stakeholder groups and consortia
- Solidify the delivery and promotion of EUPATI In-House Trainings and explore new target groups
- Strengthen the EUPATI Trainer Pool and provide Training of Trainers

EUPATI Fundamentals

- 3 trainings, 36 hours, 54 participants

EUPATI Essentials

- Module 1 developed and piloted for 6 participants

EUPATI In-House Trainings

- 8 tailor-made trainings, 40 hours, total of 210 participants

EUPATI4Professionals Promotion campaign

- New leaflet published
- Special newsletter disseminated

Trainer pool

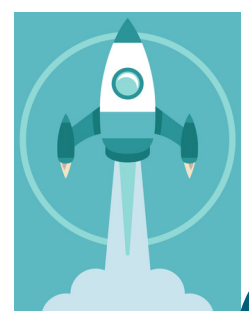
- 2 new trainers identified and introduced to the training portfolio

+250 professionals trained in patient engagement

All trainings co-designed and co-delivered by patients

Wide dissemination reached via partners and networks

Training capacity enhanced



COMMUNICATIONS



- Strengthen EUPATI's external and internal communications

General

- Communication strategy developed
- Branding guidelines established

EUPATI Toolbox (toolbox.eupati.eu)

- 5,223,897 visitors
- 13 languages
- Promotion campaign conducted
- User experience improved

EUPATI main website (www.eupati.eu)

- 43.304 unique visitors
- New 'look' and enhanced information

ENP Websites

- 8 ENPs new websites launched

Patient engagement communications

- Patient Engagement Open Forum (PEOF) 2021, in collaboration with PFMD and EPF: 16 sessions, 2.3k participants, 70+ speakers, engagement 52k, total reach 1,397k
- Observer role at the EFPIA Patient Think Tank

Over 5 million
Toolbox visitors
since launch!

Worldwide reach
for website -
top countries:

1. US
2. France
3. Germany
4. UK
5. Italy



VISIBILITY

LinkedIn

+ 1.202 followers
239 posts
7.901 total engagement
115.284 total impressions

Facebook

+ 700 followers
156 posts
3.163 total engagement
41.801 total impressions

Twitter

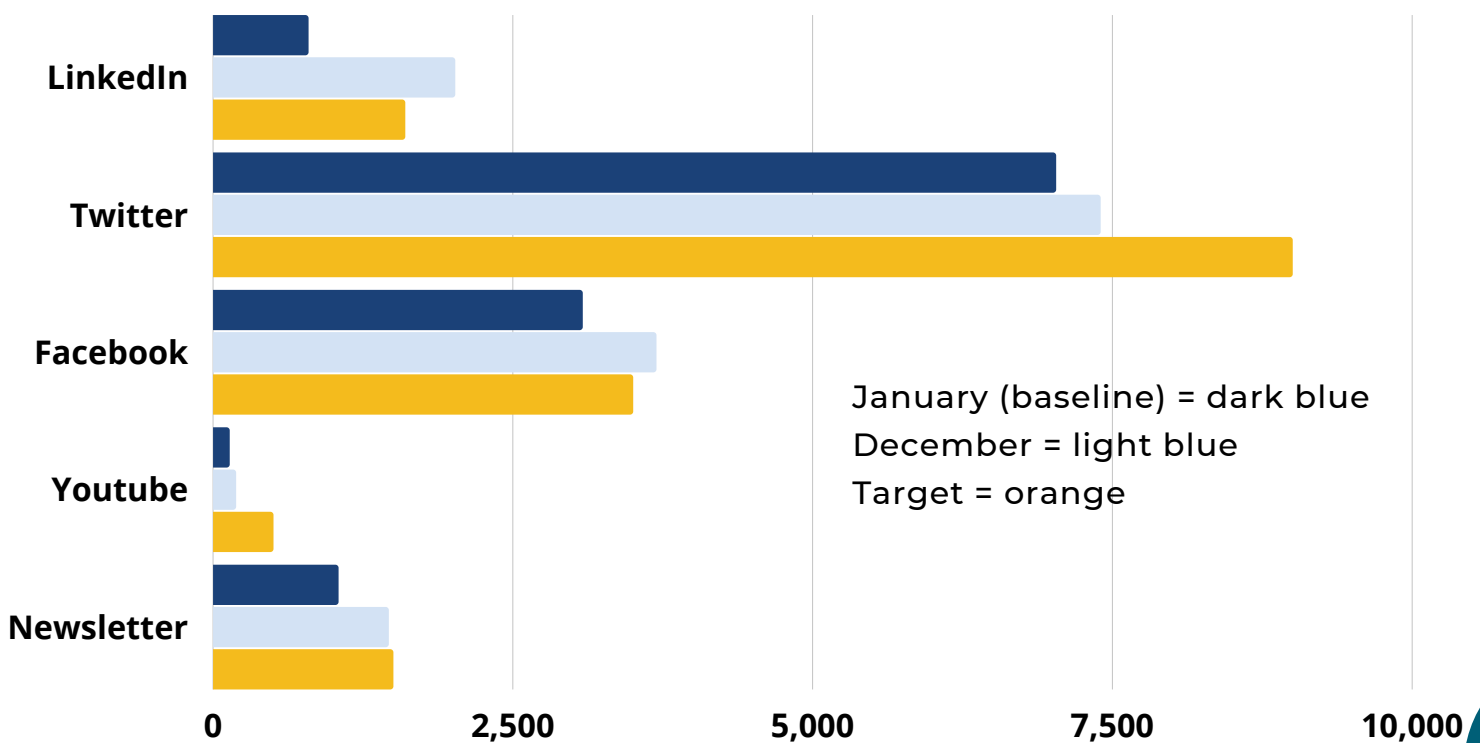
+ 367 followers
287 posts
649 total mentions
334.260 total impressions

Newsletter

1.462 contacts
12 campaigns

YouTube

+ 53 subscribers
3.730 views



SUSTAINABILITY



- Implement the EUPATI Foundation's Sustainability Plan
- Drive towards a balanced contribution of public and private funding

Partner contributions

- Cash contribution levels by industry partners revisited based on the prospective of a balanced 50-50 public-private funding by 2025 (levels decreased as of 2022).
- A new model for in-kind contribution for public partners developed (implemented as of 2022).

Fee-for-service trainings

- Patient engagement trainings pricing structure revisited

Projects & grants

- Completed: EIT Health 'EUPATI Reload', Development of EUPATI Open Classroom and new modules on Medical Devices & Digital Health
- Launched: HTAi 'Patient involvement in HTA', Research on current practices of patient involvement in HTA for future recommendations
- Granted: IMI 'FACILITATE', Returning Clinical Trial Data to study participants within a GDPR compliant and approved ethical framework
- Submitted: 7 funding proposals

Fundraising

- A fundraising strategy developed
- A pilot fundraising campaign initiated

EUPATIconnect

- An internal tool to provide a quality fee-based matchmaking service between EUPATI Fellows & industry and academic partners developed (launch early 2022)

Sustainable
business model
implemented

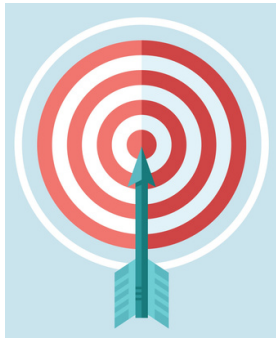
2 new
European
projects

Fundraising
initiated

Matchmaking
tool developed



GOVERNANCE



- Strengthen the infrastructure and governance of the EUPATI Foundation
- Seek new partnerships, especially with Patient Organisations, Academia and the medical technologies and devices industry

Secretariat

- Increased resources, 7.1 FTE
- Payroll established in 4 countries
- Internal training programme established, 4 trainings conducted

+80%
strengthened
Secretariat

Board of Trustees

- Regular meetings held
- Role as legally responsible body overseeing the EUPATI Board and the Secretariat fully executed

Foundation
governance
structure
established
and fully
implemented

EUPATI Board

- Regular meetings led by the Co-Chairs
- Revised Vision, Mission and Value statement established
- Role as guiding the work of the Secretariat fully executed

Sustaining Partners Assembly

- Half of the EUPATI Board seats replenished in elections
- Online General Annual Meeting in September providing input for workplan of 2022
- 8 new partner organisations, representing patient organisations (2), academia (4) and industry (2)
- Regular cluster-specific meetings organised

ENP Network

- Quarterly meetings
- New mode of functioning proposed in 2020 put into action

Committees

- Editorial Board active in reviewing new patient education and patient engagement training materials.
- Advisory Committee and a new Patient Expert Training Committee established
- EUPATI Friends launched (informal forum for individuals who have been previously active in EUPATI)



NATIONAL PLATFORMS



- Further define and establish long-term goals for EUPATI's role in the global arena of patient education and patient engagement
- Strengthen existing and explore new collaborations globally to expand the reach and impact of EUPATI
- Maintain the existing ENP Network, supporting the translation or materials and activities at National Level
- Seek to maintain the EUPATI Brand and quality of the materials while managing growth of the ENP Network

Strategy

- A strategy of expansion established: Focus on existing ENPs while carefully exploring new collaborations

Global collaborations

- Collaboration initiated with IAPO
- Wide reach through existing and new Sustaining Partners (e.g. in North America)

ENP Network

- Support for coordination of existing ENPs, communications and information
- New mentoring system launched. In 2022, pairs will be formed so mentors can coach mentees to build up their local activities : e.g building a training programme, updating a website and communication channels, organising webinars, etc.
- SharePoint tool with valuable ressources (replays of trainings, tutorials...) made accessible to all ENP network
- Quaterly meetings with ENPs representatives to discuss current projects, challenges and solutions

New ENPs

ENP plans initiated in Hungary, Czech Republic, Romania and India.

Trainings

Discussions with partners and ENP representatives to suitable trainings throughout the year, for both the ENP and the EUPATI Fellows audiences.

ENPs maintained in 23 countries:
Austria, Belgium, Cyprus, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Japan, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Scotland, Slovakia, Spain, Sweden, Switzerland and Turkey



WE ARE THE PARTNERS



New Sustaining Partners

Patient Organisations:

ELPA - European Liver Patients Association
EORTC - European Organisation for Research and Treatment of Cancer
GlobalSkin - International Alliance of Dermatology Patient Organizations

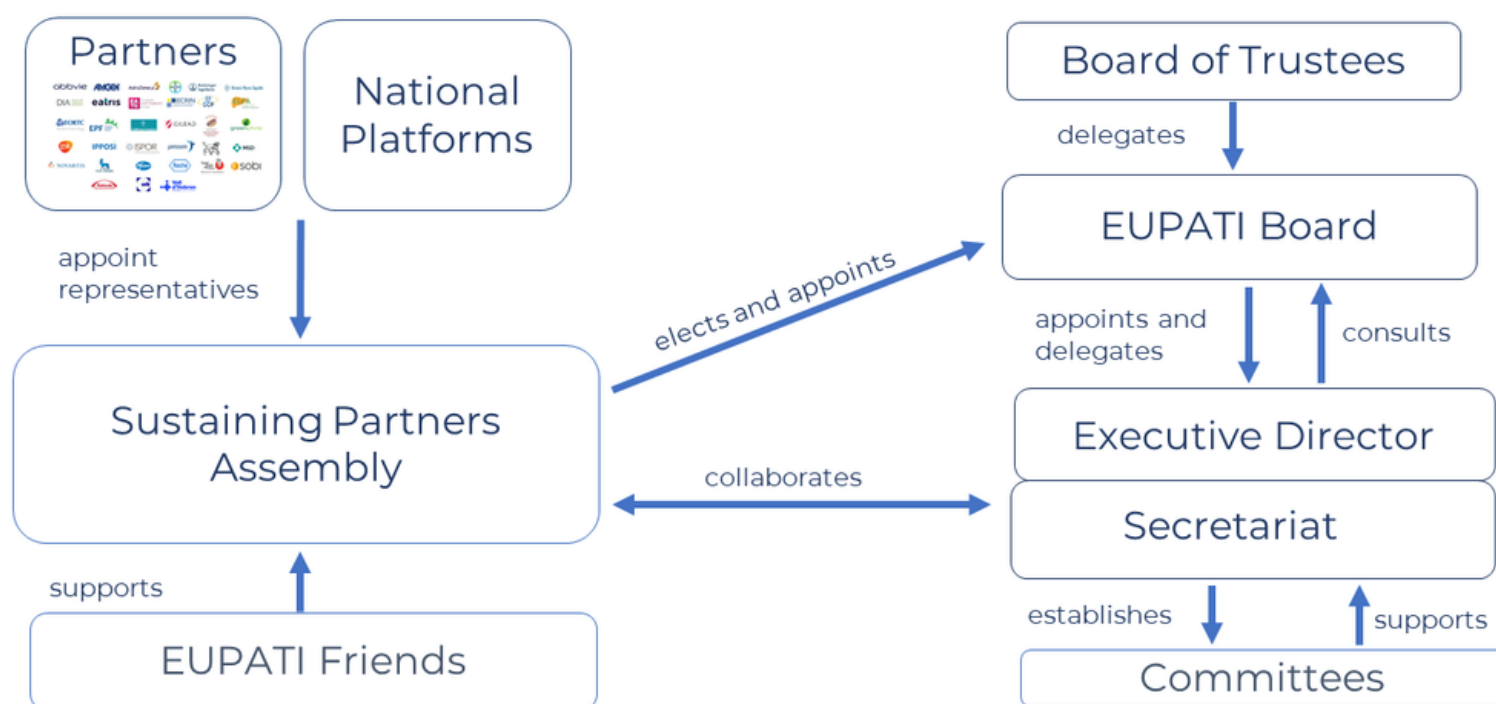
Non-for-profit and Academic Institutions:

Sant Joan de Deu Research Institute
ECRIN - European Clinical Research Infrastructure Network
VHIR - Vall d'Hebron Research Institute

Industry Partners:

Sobi
Greenphire

WE ARE THE GOVERNANCE



The Board of Trustees

Jytte Lyngvig, Denmark (Chair)
Ivett Jakab, Hungary (Vice-Chair)
Clayton Heijman, Netherlands (Treasurer)
Birgit Fischer, Germany
Günter Stock, Germany

EUPATI Board (as of September 2021)

Anders Olauson, EPF (Chair)
Kay Warner, GSK (Co-Chair)
Brian West, EATG
Derick Mitchell, IPPOSI
Daniel de Schryver, Janssen
Donatella Decise, Novartis
Ingrid Klingmann, EFGCP
Anne-Charlotte Fauvel, EATRIS
Filippo Buccella, ENP Italy
Sandrine Lavalle, ENP Luxembourg

WE ARE THE COMMITTEES

EUPATI Editorial Board

Magdalena Ankiersztejn-Bartczak, EATG

Birka Lehmann, BfArM

Wolf See, Ruhr University of Bochum

Léa-Isabelle Proulx, Roche

EUPATI Training Committee (as of September 2021)

Donatella Decise, Novartis

Bruno Gago, University of Aveiro

Ilaria Galetti, FESCA, GILS, ePAG ERN ReCONNET

Ingrid Klingmann, EFGCP

Birka Lehmann, University of Bonn

Jeanette Ryan, GSK

Wolf R. See, Ruhr University of Bochum

Thomas Smith, EUPATI Fellow

Carla Torre, University of Lisbon

Natacha Vaz Liti, EUPATI Fellow

EUPATI Advisory Committee

Chairperson: David Haerry, Patvocates/EATG

Co-Chairperson: Wolf See, Ruhr University Bochum

Regulatory arm:

Birka Lehmann, ex BfArM - Lead

Gabriela Zenhäusern, Swissmedic

Heather Rogers, MHRA

Daniel O'Connor, MHRA

Fokaline Vroom, MEB

Leon Bongers, MEB

Juan Estévez Álamo, AEMPS

Christa Wirthumer-Hoche, AGES

Katharina Prenner, AGES

HTA arm:

Neil Bertelsen, independent - Lead

Karen Facey, independent

Ethics arm:

Ingrid Klingmann, EFGCP - Lead

Hugh Davies, independent

Uta Wernke, DLR

Future topics arm:

Nicola Bedlington, EPF - Lead

Jan Geissler, Patvocates

Matthias Gottwald, Independent

Tony Hoos, PFMD

WE ARE THE SECRETARIAT

Maria Duterte, Executive Director

Ingrid Heyne, Training Organisation & Alumni Coordinator

Jana Popova, Patient Engagement Training Coordinator

Gemma Killeen, Business Development Coordinator

Amanda Lyons, Networks & Communications Coordinator
(temporarily replaced by Coline Guiol since November)

Bojan Cigan, Partnerships & Operations Coordinator

Vitalii Luchinskii, IT Coordinator

Ieva Lukase, Open Classroom Coordinator

Silvia Scalabrini, Project Coordinator

+ Jarik Albers, Raluca Siska & Helena Kissiova, Interns

100%
remote
team

7.1 full
time
equivalent

7
countries

ACKNOWLEDGEMENTS

In addition to its Sustaining Partners, EUPATI collaborates with a wide range of stakeholders within the patient education and patient engagement landscape. The different collaborations strengthen EUPATI's multi-stakeholder public private partnership. We would like to thank the following organisations for their collaboration during this calendar year (in alphabetical order):

Alliance of Patients' Organizations (IAPO)

European Connected Health Alliance (ECHAlliance)

European Federation of Pharmaceutical Industries and Associations (EFPIA)

European Institute of Innovation and Technology (EIT Health)

European Organisation for Rare Diseases (EURORDIS)

European Medicines Agency (EMA)

Health Technology Assessment International (HTAi)

Innovative Medicines Initiative (IMI)

MedTech Europe

Patient Focused Medicines Development (PFMD)

Patvocates

PGOSupport

Studies & Me

Trinity College Dublin

University of Copenhagen

University of Oxford

VMLY&Rx (previously known as WPP Health)

and the many more institutions who contributed to enhancing patient education!



THE EUROPEAN PATIENTS'
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INNOVATION

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