



EUPATI National Platform Network Annual General Meeting Report

*17th September 2020, virtual meeting
09.00 – 10.55 CET*



On the 17th September 2020, the fourth EUPATI National Platform (ENP) Annual General Meeting was held virtually for the first time. In light of current circumstances, hosting this meeting online was indeed the most appropriate option rather than the regular face-to-face meeting. This year, 40 representatives from 20 countries were in attendance. This figure is slightly lower than 2019's AGM attendance rates of 47 representatives from 23 countries. However, this year new members have joined and it was exciting to have a mix of old and new members at the meeting representing Belgium, Cyprus, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Malta, the Netherlands, Norway, Portugal, Scotland, Slovakia, Spain, Sweden, Switzerland and Turkey.



There are now 23 ENP Networks established all over Europe. Japan has also joined contributing to the fact that EUPATI is going global. With the absence of face-to-face meetings, it was highlighted that connecting and communicating with each other at both a central and local level is still highly important.

The first part of the ENP AGM provided an EUPATI update of the changes happening at a central level. This update was followed by information about workpackage 4 of the EFO-EUPATI project; which has been a culmination of a 2-year study addressing issues discussed at the 2019 AGM. This project outlines the isolation ENP Networks often feel, the difficulty to concisely articulate what an ENP does and the value they bring to the outside world. A discussion then took place focusing on what the ENP Network might look like in 5 years. Finally, there was an update on new ENP representatives, as well as an explanation of the new EUPATI governance structure. It concluded with welcoming the 2 new ENP Network representatives elected to the EUPATI Board as well as the 23 new members of the ENP Network Sustaining Partners Assembly (SPA) Cluster.

ENP Network: What's happened in the past 12 months?

- [EUPATI Foundation](#) has been established in the Netherlands
- New EUPATI Programme Coordinator (Maria Dutarte)
- Development of a new [Governance Structure](#)
- New representatives to the ENP Network
- New ENPs joining the Network (Turkey, Cyprus, the Netherlands, Sweden and Scotland)
- EFO-EUPATI project concluded in September
- Repository of collateral material to use; [flyers](#), [video](#) and [infographics](#)
- Local level work continues with Expert Patient Training courses - 60 Fellows to graduate in early 2021, as well as mini-courses and other training initiatives throughout the Network

Agenda Highlights:

1. EUPATI Programme Update
2. Promoting Your ENP
3. ENP Network Moving Forward
4. Meet Your New ENP Representatives



Highlights 1:

(a) What was covered?

- EUPATI Programme Update (Maria Dutarte, EUPATI Programme Coordinator)

EUPATI Foundation & Sustainability

EUPATI was established as a Foundation on the 11th of August 2020. The Foundation was established to aid EUPATI's sustainability. To assist the 3 main pillars of EUPATI which are; **Patient Expert Training Course; Online Medicines R&D Toolbox** and **National Platforms**

The EUPATI sustainability model is based on the 6 pillars below:

- 1) **Consortium Partners** – 30 support us currently. Full list [here](#).
- 2) **Projects & Grants** – involved in projects such as EFO–EUPATI, and an ongoing EIT Health project
- 3) **Fundraising** – involved in fundraising activities
- 4) **Fee-for-service Training to all Stakeholders** – available in the coming months
- 5) **On-demand Patient Expert Training Course** – ongoing and will support sustainability
- 6) **Matchmaking** – will be formalised and will connect the EUPATI Network with partners

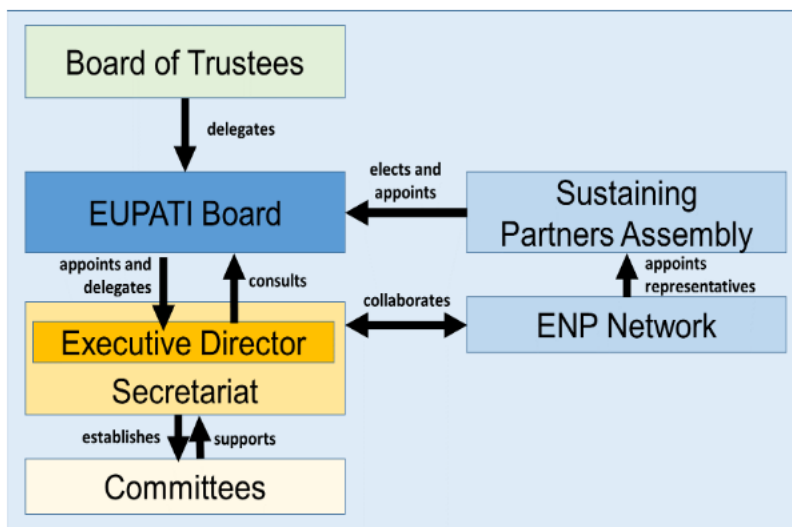
To ensure and allow EUPATI to fully implement this sustainability plan, a legal entity was necessary.

The EUPATI Foundation is a non-profit organisation. The official name is '**Stichting EUPATI Foundation**'. The word 'Stichting' means 'Foundation' in the Dutch language and was necessary for its establishment with Dutch authorities. 'EUPATI Foundation' will be used in all communication with the exception of Dutch authority communication, wherein 'Stichting EUPATI Foundation' will be used. The postal address will be provided by PGOSupport, Netherlands, the same postal address as the Dutch ENP. More information can be accessed [here](#).

The Secretariat team will be operating virtually, working remotely from different countries.



EUPATI Foundation – Governance Structure



Board of Trustees – This governing body is required by Dutch law. This group provide oversight and legal signatories for the Foundation. They are ‘self-appointed’ by law; however, they can receive recommendations by the Board. In the operating rules, the Board recommended representation from different areas and experience. There are 5 members. An odd number of trustees will always be required.

EUPATI Board – this is the body who is elected and appointed by the Sustaining Partners Assembly.

Sustaining Partners Assembly – includes all of the Consortium Partner members such as industry, patient organisations, academia, non-profit partners and ENPs.

The minimum in cash and /or in-kind contributions is defined by the Foundation’s Partnership Policy (not applicable for ENPs).

The Sustaining Partners Assembly sets the priority areas of the Foundation on a 3-to 5-year basis. The first meeting was held on 17th September 2020 and comprised of a workshop focusing on priority areas. This workshop focused on;

- *What should EUPATI do in training for example*



- *Define what our geographical strategy going forward*

The Sustaining Partners Assembly does not have decision-making powers. The different stakeholder groups of the Sustaining Partner Assembly elect their representatives to the EUPATI Board. This board has the decision-making power. The Sustaining Partners Assembly will meet at least once a year.

EUPATI Board

This is the operational, decision-making body of the Foundation. It oversees the implementation of the EUPATI strategy and goals that the Sustaining Partners Assembly have outlined. The Chair and Co-chair have been elected as follows;

- Chair – Anders Olauson, *European Patients Forum (EPF)*
- Co-Chair – Kay Warner, *GlaxoSmithKline (GSK)*

EPF will always provide the Chair position. The Co-Chair has been selected from the industry cluster and will serve a 2-year term.

All clusters (industry, patient organisations, national platforms, academia/non-profit) will have 2 seats each. All representatives were elected in advance of 17th September 2020.

Secretariat

All operational responsibilities are delegated to the Executive Director. There are currently 6 full-time/part-time staff members. Existing positions include;

- *Executive Director* (Maria Duterte)
- *Finance Consultant*
- *HR Consultant*
- *Operations & Grants Coordinator* (TBC)
- *Training & Content Coordinator* (Tamás Bereczky)
- *Training Organisation Coordinator* (Ingrid Heyne)
- *Business Development Coordinator* (Gemma Killeen)
- *IT Coordinator* (Vitalii Luchinskii)



Planned future positions for later this year/and or next year include *ENP Coordinator, Communications (Amanda Lyons recently hired) & Training Intern, Project Management Consultant (Gloria Valencia recently hired), Communications & Marketing Coordinator.*

What is going on in EUPATI central at the moment?

EUPATI central have many ongoing activities.

1) Patient Expert Training Course

Since 2016 there have been 150 graduates. 60 participants are graduating in March 2021.

The EIT Health Project is helping to transform the course online and to an on-demand format. The entire material has been examined and carefully organised into online modules. This allows learners to access the information at their own pace and in their order of preference. It will be free of charge to access the modules and there will be a minimal fee for a certification. By next Spring, all modules will be online and in this on-demand format.

2) Online Medicines R&D Toolbox

The [Toolbox](#) was redesigned in June. The content is available in 9 languages and 4 languages (Portuguese, Romanian, Swedish and Japanese) are work in progress. All 13 languages will be available soon.

3) New website

EUPATI has a new website – www.eupati.eu. There is also a new '[Collaborate with EUPATI](#)' section which invites stakeholders to join forces and submit their ideas. Submissions are received daily through info@eupati.eu. The new online learning section is available [here](#) and we would appreciate if you shared your opinions and feedback with us.

4) Fee-for-service Training to all Stakeholders

Since 2019 EUPATI developed fee-for-service training services to help support the sustainability plan. These comprise of 1/and or 2-day training courses on patient engagement offered to academia and industry. These training opportunities are aimed at professional working in patient engagement.



'EUPATI Fundamentals' was introduced in 2020. It is a course offered to professionals in academia and pharmaceutical industry. Due to demand the course ran 3 times this year. More information can be accessed [here](#).

In-house training is provided for the internal staff of different organisations.

'EUPATI Essentials' is a follow-up course for 'EUPATI Fellows' and is in development. It will be launching in 2021.

In summary, by the end of 2020, it is hoped that there will be 250 trained professionals in patient engagement.

Highlights 2:

(b) What was covered?

- Promoting Your ENP – How to make the best use of your ENP Resources (Caroline Whelan, EUPATI National Platform Officer)

The EFO-EUPATI project has been a multi-partner international effort throughout the past 2 years. The special contributions of Derick Mitchell, the Work Package leader and the Co-lead ABBVIE, all the IPPOSI team, the ENP Network, EPF, Pfizer and the EUPATI central team were recognised.

EFO-EUPATI Workpackage 4

The purpose of this was to strengthen the coordination of the ENP network by ***collaboration, exchange of knowledge*** and ***sharing***.

Objective 1: Establish 3 Regional Groups

When the project commenced in September 2018, 3 groups had already been established. The regional structure was revised halfway through the project. There was a decrease in the number of partners in region 2. Slovakia joined region 1 and Poland and Romania joined region 3.

Objective 2: Share Knowledge Between the Regions

After the 2017 AGM in Berlin, work plans were drafted and shared to help regions work together. Subsequently, meetings were set-up including the previous ENP Platform Network



AGM held in Copenhagen and events were organised at regional level. Teleconferences were used most frequently to network and meet. It was highlighted that the number of teleconferences per region did not reflect the work of each region. Regions work together in different ways, all to equal effectiveness.

The number outlined below represents the formal teleconferences organised and with the ENP Coordinator in attendance.

12 teleconferences for Region 1; 3 for Region 2 and 8 for Region 3.

It was also mentioned how meetings were set-up between countries in the various regions without the formal involvement of EUPATI central. Region 2, for example, had a strong working relationship before the project and therefore organised many meetings themselves.

At crucial moments, important meetings discussing budget were held at cross-regional level with the presence of leads and co-leads.

All regions worked on certain common topics, such as the 'Common ENP Message' project. In total, 14 teleconferences were organised in relation to this. More recently, IPPOSI has been in communication with the Dutch and Italians who have run EUPATI-like training courses to help contribute to the Patient Education and Training Initiatives Repository.

To date, there have been 11 EUPATI & National Platform newsletters including the year-end 'highlights' issue.

Objective 3: Develop Patient Training Initiatives

The first action was to understand the activities all ENPs are currently involved in. This objective started 12 months ago with a survey conducted of all ENPs.

A snapshot of the results are as follows:

- *3 ENPs have EUPATI based **Patient Expert Training Courses***
Ireland, Italy and the Netherlands have adapted the course in part or in full to deliver patient education and training programmes. Ireland is launching its third course in 2021. Italy is preparing for its second course and the Netherlands is currently undergoing its first.



- **12 EUPATI Toolbox translations**
The 'EUPATI Toolbox on Medicines R&D' has been translated into English, French, German, Spanish, Polish, Italian, Russian, Dutch, Danish, Portuguese, Romanian, Swedish. For technical reasons, some of the languages outlined are unavailable at present. This issue will be resolved when the website is fully functioning.
- **4 ENPs have EUPATI based mini-Courses**
Belgium, Portugal, Spain and the UK have used EUPATI material to develop and implement mini-courses and workshops.
- **14 ENPs have other training initiatives**
These initiatives exclude Patient Expert Training Courses and mini-courses. Member countries including; Belgium, Denmark; France; Finland; Germany; Ireland; Luxembourg; Norway; Portugal; Slovakia; Spain; Sweden; Switzerland and UK have developed various patient education and training initiatives.

EFO-EUPATI Tasks

As part of the project, there were also specific tasks outlined. The outputs from those tasks are as follows:

Task 4.1 – Boost existing ENP International Network Coordination

A joint workshop with Workpackage 2 (the Sustainability Business Model) was arranged. This WP2/WP4 workshop was held in Switzerland in 2019.

Task 4.2 – Support Regionalisation of the ENP Network

There was a small amount of funding (5,000 – 10,000 EUR) managed by IPPOSI and allocated to the various regions assist in regionalisation. This funding allowed the following:

- **Region 1** – A workshop entitled 'Southern Europe: On the Road to Connecting Patients, Agencies, Industry & Academics' was held in November 2019 in Madrid. Participants from Region 2 and 3 were also invited to attend. This was a highly successful event.
- **Region 2** – Planned to have a face-to-face event in May 2020 which was cancelled due to COVID-19. The group quickly organised a series of webinars on COVID-19 related topics resulting in 2 hours of content which is now publicly available [here](#).



- **Region 3** – Decided to financially support the ‘Common ENP Message’ through slides, [flyers](#), [video](#) and an [infographic](#).

Task 4.3 – Support the implementation of Patient Education Initiatives

- **Status Report** across all ENPs was created in September 2019 and revised in April 2020.
- **Repository** of materials has been created together with an [infographic](#) on how to set up a course.
- **Surveys** of cohorts 1,2 and 3 of the EUPATI Training Expert Course were conducted. In parallel, a survey was conducted of graduates from the national course in Ireland determining their engagement with ENPs.

Common ENP Message History

A common objective in all 3 regional workplans was the need to develop a ‘pitch’ to stakeholders or ENPs. This ‘pitch’ would help explain EUPATI and indeed what an ENP Network is. At the 2019 AGM in Copenhagen, time was dedicated to brainstorming and developing this pitch in the form of a flyer or poster; a set of slides and or a short-animated video and in accordance with budget. Region 3 kindly provided the budget for the short-animation movie.

An infographic entitled ‘TIPS ON HOW TO SHARE THE COMMON ENP MESSAGE’ was developed by Pfizer and IPPOSI, explaining how to use the materials produced. These are available on the website [here](#).

The flyers created by Abbvie, are tailored to suit particular target stakeholders. The [flyers](#) were converted into a PowerPoint deck to enable a user to customize their own slides. Subsequently, the user can then use relevant slides to address the particular stakeholder in which they are presenting to.

There are individual drawings from the short-animated video which can be used. This animated video can be viewed [here](#). It was noted that no voice and little text was used to ensure its international use.

Patient Education and Training – Status Repository & EUPATI Fellow Engagement

The **Status Report** outlines the development and implementation of patient training initiatives in EUPATI member countries.



A **repository** of National Patient Education Training Course material has been accumulated from both the pilot Irish course and indeed the full course in the form of templates, guidebooks and examples. The information was structured and is now being discussed with the Italian and Dutch ENPs who are running similar courses. An [infographic](#) was created to explain the steps that might be undertaken in organising a course.

A **survey** of cohorts 1,2 & 3 EUPATI Fellows & Patient Education Programme was conducted determining their levels of engagement with ENPs. It was reported that while there was a huge appreciation for the training and the quality of training, there was, in fact, a concerning level of disengagement with the ENP Network, particularly for the EUPATI Fellows.

Less than 50% joined or became involved with their local ENP, and 2/3 did not know what their ENPs do and were unable to explain their national ENPs. 60 of the EUPATI Course and 40 graduates from the Irish Course gave detailed responses. An [infographic](#) was created to include their tips on how to improve engagement with local ENPs.

The new exclusive area for ENPs who can log in and access anytime is now available on the website [here](#). All of the repository material discussed will be hosted in this area. This new aspect will hopefully contribute to ENPs efficiency and self-sufficiency going forward.

EUPATI Microsoft Teams space is currently being set up. The purpose of this space is to help ENP Network collaboration. As already mentioned, there is a repository area to access all relevant files. Simultaneously, this '*Teams*' platform will provide a space to share ideas, discuss items and collaborate together. This platform hopes to address the disconnection issue ENPs as well as the inaccessibility of all EUPATI materials when needed. A link will be shared and an explanation of how it works as soon as possible.

Highlights 3:

(c) What was covered?

- ENP Strategy Moving Forward (Derick Mitchell, Co-chair of the ENP Network)

As was discussed that at the beginning of September, a call took place to address the Networks 2020 – 2025 strategy. There were questions of what the Network wants to achieve together and what do they want to look like in 5 years' time? A common concern is members want to feel part of a strong network and do not want to feel isolated.



Points Raised/Key Concerns:

- 1) Translation Mapping – how will the translations and revisions be done?
- 2) Maintaining regions – is this necessary?
- 3) Funding challenges – for admin staff/courses/projects
- 4) Funding from industry – is there a conflict of interest/independence?
- 5) Need to share information on establishing a legal entity for an ENP
- 6) Are we fully optimising the EUPATI Fellow alumni as a resource?

1) Translation Mapping: how will the translations and revisions be done?

EUPATI central are focusing on the new platform and on having all transferred on to this new platform. The mapping of content in all of the languages will be worked on next. There will be an overview of what has been translated so far, and on any further translational needs. By the end of the year, there will be a more complete picture of all translations.

In relation to the Toolbox, it was noted that it is important that ENPs remember to give feedback if they find something new or if they notice updates are needed.

2) Maintaining regions – is this necessary?

It was mentioned that there is no obligation to maintain the regions. Regionalisation stemmed from ENPs expressing interest in working with countries who they perhaps have most in common with. It may be a case that their purpose has been served and they have come to their natural end. It was also suggested that if ENPs want to continue working with a country they have most in common with, they could do so by arranging meetings without EUPATI involvement. Also, ENPs could leave their regions and collaborate with who they wish to in the same manner.

3) Funding challenges – for admin staff/courses/projects

The topic of funding is a common concern amongst all ENPs. It was discussed how some ENPs have the support of administrative staff for certain periods and on certain projects. However, there are general concerns in future funding for staff support. While there are lots of requests from industry, conference organisations and authorities to have patient advocates involved, the lack of back-office support threatens this delivery. Most ENPs



work on a volunteer basis and do all they can to ensure the various activities are organised. However, the need for paid professional support is a common request to help deliver best practice.

It was mentioned that with the help of the repository material available, more funding could be secured as it will contribute to ENPs professionalism.

It was advised that to secure funding, concrete projects should be presented.

EUPATI central is organising 2 fundraising training courses. The first course took place on the 20th of October and the second course ran on the 9th of November. All ENPs were invited to attend.

Based on this discussion, the EUPATI secretariat now plans to address the issue of local ENP support when they approach companies for 2021 funding. It was also highlighted that when EUPATI central is writing project proposals for funding or are considered in a proposal, an evaluation is always made of its suitability for either central's objectives or for ENPs.

4) Funding from industry – is there a conflict of interest/ independence?

It was discussed how in some ENP networks, funding for courses, activities and indeed salaries are largely provided by pharmaceutical companies. For example, in Italy, there are 3 people working in the back-office and are 99% industry-funded. It was recommended that in order for an ENP to progress, support staff is needed.

The question of industry support and if independence can be ensured when salaries are from pharmaceuticals was raised. All agreed that industry companies have the financial resources. It was highlighted that if transparency is ensured to all parties concerned, there should be no issue. It needs to be highlighted that the patient's voice is independent regardless of the industry input.



It was noted that the patients, academics and industry partnerships are working well. It was also remarked that externally, for those people not involved in the work of EUPATI, the industry funds do raise concerns over influence.

It was also noted that though funding comes largely from industry, it is important to include academics and regulatory agencies in the agendas, projects and activities. The mission of the work should reflect all partners involved. Connecting to regulatory agencies and explaining ENPs funding set-up was suggested in helping to achieve acceptance and gain further support.

Italy gave the example which helps their ENP Network to ensure independence from industry. They have a structure in place to protect the content. They have a non-profit association and a profit structure. The non-profit association includes the regulators and a scientific group who are responsible for maintaining the total independence and the profit structure runs the everyday tasks. The decision to divide the structure enables both independence and the management of money. A legal entity was necessary for industries to sponsor their courses, face-to-face meetings etc.

It was suggested that EUPATI have their own regulations that are in line with the industry and with other medical authorities' strict rules within the individual countries. This along with asking for EU grants to help fund the ENPs on an individual basis could also be a way forward.

It was noted that EUPATI central has some industry partners. However, some of these industry partners who have a presence on a national level are committed only to the central operations. It was suggested that having a liaison between the local ENPs and a representative from that company in place might also be useful.

5) Need to share information on establishing a legal entity for an ENP

It was discussed how funding is challenging in many ways. The first challenge, and which has been discussed, is in securing funds from academia or industry and the issues around those contributing the funds. The second challenge is how does an ENP cash in



those funds. ENPs need an entity or indeed a legal entity to have a bank account, in order to cash in the funding.

A request was made for a mapping of all the ENPs who have set up a legal status in their country. This information should include what status is in place, for example; is it a 'Foundation' or an 'Association' etc. This information will help other ENPs who are struggling to set up a legal entity. From this resource, ENPs can then decide which status would work best for them.

It was reminded that when ENPs are asking organisations for support, they should explain that they are a member of a Foundation, which is, in fact, a legal entity.

It was mentioned that some ENPs have been funded for proposals without having a legal entity. There are contracts within a European proposal which provide training and staff who work on the project. This could be an option for an ENP if there is no legal entity in place.

6) Are we fully optimising the EUPATI Fellow alumni as a resource?

There is a general concern that ENPs are not fully optimising the EUPATI Fellow alumni as a powerful resource. Questions were raised, such as are we empowering those who have graduated to make sure they stay connected? Do they find the engagement they wish to have? Are we recognising the spectrum of engagement they could get involved in and do we help them connect to those activities? There was a request for these concerns to be represented in the 5-year vision.

It was stated that perhaps at EUPATI central level, more engagement could be reached informally and more regularly with the alumni. Beyond the traditional communication platforms such as emails and newsletters, it was noted there is difficulty in maintaining and nurturing the EUPATI Fellow alumni relationship. Social media was suggested as an option; however, it was remarked that there is already a heavy online presence. The importance of facilitating this group and helping them to meet, connect and learn from each other is a necessity. The issue is how to put this into operation.



It was suggested that a focus should now be on the current cohort of EUPATI fellows who will graduate next year. Their connection should be strengthened with the ENP Network prior to their graduation. Strategies will be identified to ensure that they are fundamental part of the ENP Network.

It was suggested that successful public/private partnerships running currently and outside of this field, should be assessed to understand how they are operating successfully. This action had been done when EUPATI was first set up.

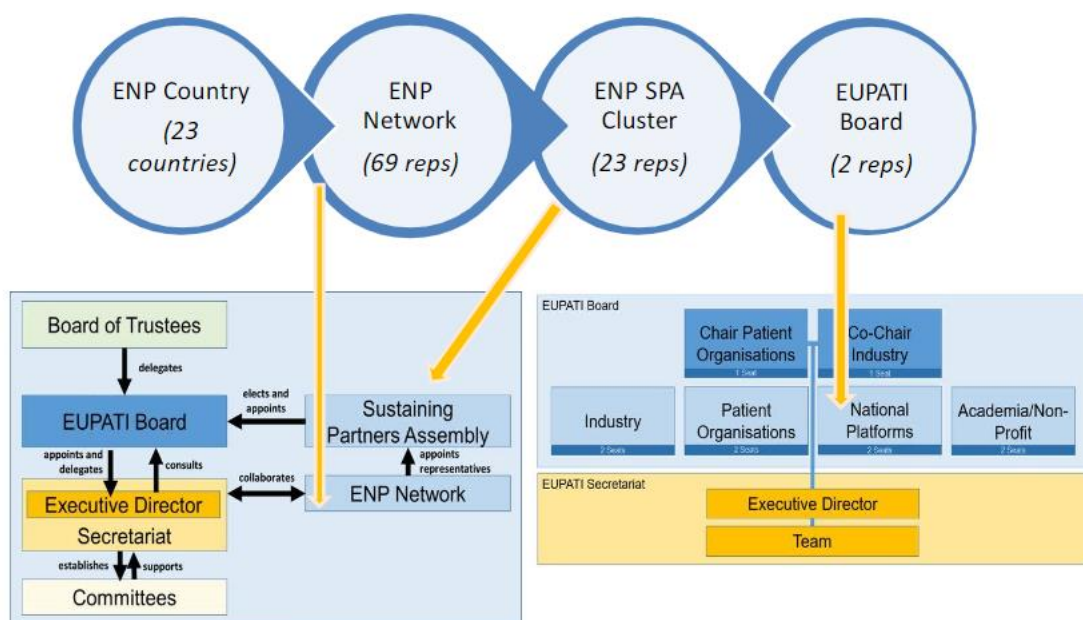
It was noted that the pandemic has made remote working a normal part of life. Subsequently, it was suggested that it may be useful to look at any external models that operate and encourage international remote working. This might be a way in which some ENPs can sustain themselves.

Highlights 4:

(d) What was covered?

- Meet Your New Representatives (Roald Nystad, Co-chair of the ENP Network)

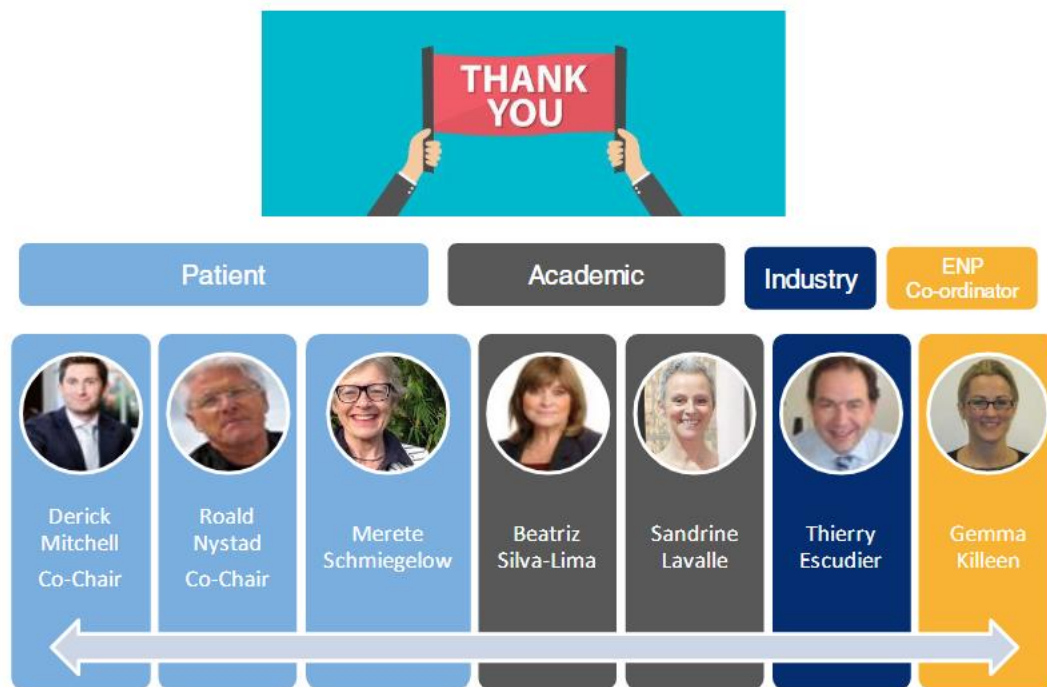
ENP Network Governance Structure from September 2020





This is a very different governance structure from what had been in place previously. ENPs are a central part in this new organisational structure.

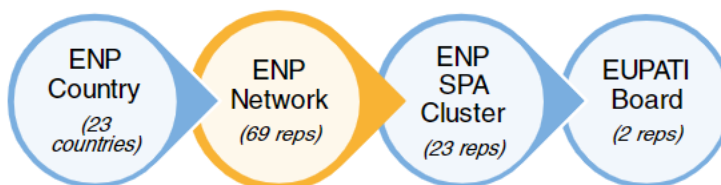
2019 – 2020 ENP Network Executive Committee



There were 7 members in the ENP Network Executive Committee for the past 4 years. This has now come to an end. Roald thanked all the members for their contributions and with a special recognition for Gemma (ENP Coordinator) who has done a fantastic job coordinating the committee.



2020 ENP Network Representatives



Today, the ENP Network consists of 23 ENPs. Each ENP has nominated 1 patient, 1 academic and 1 industry representative, therefore the total ENP Network has now 69 representatives. Each ENP Network then nominated 1 representative to join the Sustaining Partners Assembly Cluster which now comprises of 23 representatives. All clusters were invited to express an interest in becoming a member of the ENP Network Board. There are only 2 positions. Both positions have now been selected and are as follows:

- Sandrine Lavallé (ENP Luxembourg, 1 year)
- Filippo Buccella (ENP Italy, 2 years)

Roald welcomed the 2 new elected members of the Board and hoped there would be some interesting times ahead. He welcomed all members to participate actively.

The newly elected members Sandrine and Filippo addressed the attendees.

Overall Conclusions:

Despite the fact that this meeting was not face-to-face and was the first AGM held online, it still managed to provide a very useful platform to discuss challenges and solutions faced over the past year. Again, it hoped to ensure a strong level of connectivity between the ever-growing ENP Network.



There have been many exciting developments in the last year. EUPATI is now an established Foundation and it has restructured its governance structure which will provide new faces to the organisation. The Toolbox was redesigned and there is a new website. A repository of material is available to share and *EUPATI Microsoft Teams* space is currently being set up. Both hope to contribute to ENPs efficiency and collaboration in the future.

The EFO-EUPATI project concluded in September and there have been many interesting outputs that will help strengthen the coordination of the ENP Network. Those outputs include the regionalisation meetings, events, webinars and other collective activities which took place. There was a development of patient training initiatives across many countries. A bank of digital assets including an animated video as well as the creation of infographics to help articulate and share what EUPATI is and what an ENP Network does.

There was a discussion about the future 5-year strategy of the ENP Network. It was agreed that funding is another common and challenging factor for most ENPs. This is a constant and multifaceted challenge. For most ENPs securing support with industry provides the financial backbone of their activities. However, transparency with all parties involved is a necessary to ensure independence. More information shared on the legal statuses of all ENPs will help those struggling to overcome funding or sponsorship obstacles. It is hoped that the current cohort of EUPATI Fellows will be targeted prior their graduation in March 2021. This will help in strengthening their connection to their local ENP Network. This group is a vital tool for future sustainability.

Finally, with the new governance structure in place and a larger collection of representatives on the ENP Network, it is indeed entering a new and exciting era. With change comes new opportunities and it will be important for all to contribute in shaping its future.



2020 Suggested Follow Up Actions:

Follow Up Actions	Detail
1. Develop strategies to strengthen connection with EUPATI Fellows	Focus on the current cohort of EUPATI Fellows and look at ways to engage and build connection with them prior to their graduation in March 2021
2. Review all ENPs legal status information	There is data detailing which ENPs have a legal status, but there is no analysis on the types etc. This information to be captured and shared among the ENP Network
3. Funding and core funding information	Share information you have on pan-European networks or alliances which have successfully managed to support their core funding of similar initiatives



EUPATI National Platform Network AGM 2020

17 September 2020

Welcome

Gemma Killeen

ENP Network Coordinator

Today's Agenda



09:00 CET	Welcome and Introductions
09:15 CET	Session 1: EUPATI Programme Update
09:30 CET	Session 2: Promoting Your ENP
09:50 CET	Session 3: ENP Network Moving Forward
10:40 CET	Session 3: Meet Your New ENP Representatives
10:55 CET	Close

ENP Network: Last 12 Months - What's Happened?

New
Coordinator



New
Foundation



New
Governance



ENP
Network



ENPs as
Sustaining
Partners



New
Network of
Reps



EFO EUPATI
Project



New ENPs,
Goodbye
Older ENPs



Local
Training
Courses &
Activity



EUPATI Programme Update

Maria Dutarte
EUPATI Coordinator

EUPATI Foundation and Sustainability



PATIENT EXPERT
TRAINING COURSE

ONLINE MEDICINES
R&D TOOLBOX

NATIONAL
PLATFORMS

SUSTAINABILITY PILLARS



Consortium
Partners



Projects &
Grants



Fundraising



Fee-for-service
Training to all
Stakeholders



On-demand
Patient Expert
Training Course



Matchmaking

**EUPATI Foundation = a legal entity to allow EUPATI
to fully implement the sustainability plan**

EUPATI Foundation – Basic Facts

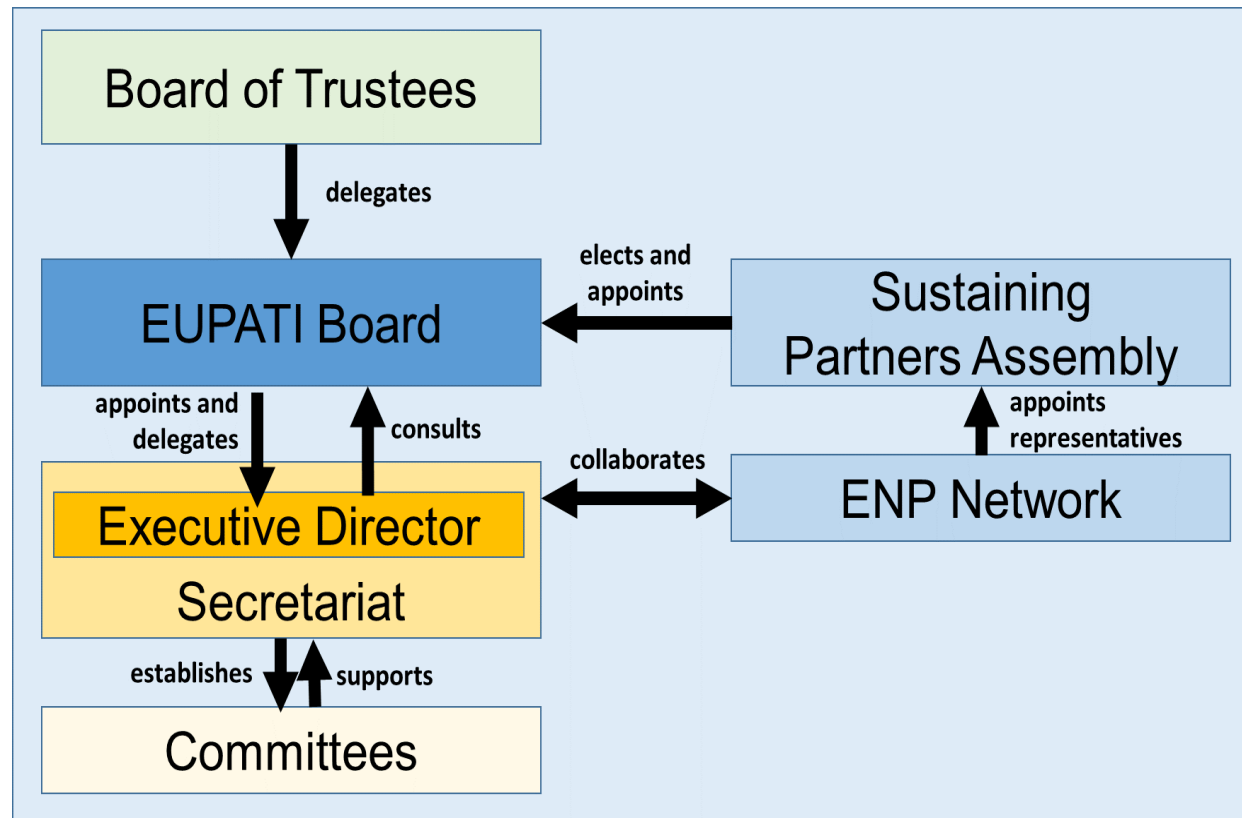


The Foundation's nature is of public interest and **not-for-profit**.

The full official name "**Stichting EUPATI Foundation**" will be used in all official communication with Dutch authorities, while in all other communication, 'EUPATI Foundation' is preferred

The postal address will be provided by PGOSupport, Netherlands

EUPATI Foundation - Governance Structure



Board of Trustees



The Board of Trustees is the Foundation's only governing body prescribed by the Dutch law.

They are 'self-appointed' by law but the recommended composition defined in the Operating Rules and recommendations by the EUPATI Board should be considered.

The recommended number of persons on the Board of Trustees is five.

An odd number of trustees shall always be required.

Sustaining Partners Assembly



The Sustaining Partners Assembly is a committee composed of the main supporters and partners of the Foundation

The minimum in-cash and/or in-kind contribution is defined in the Foundation's Partnership Policy (not applicable for ENPs).

The Sustaining Partners Assembly **sets the priority areas** of the Foundation on a 3- to 5-year basis.

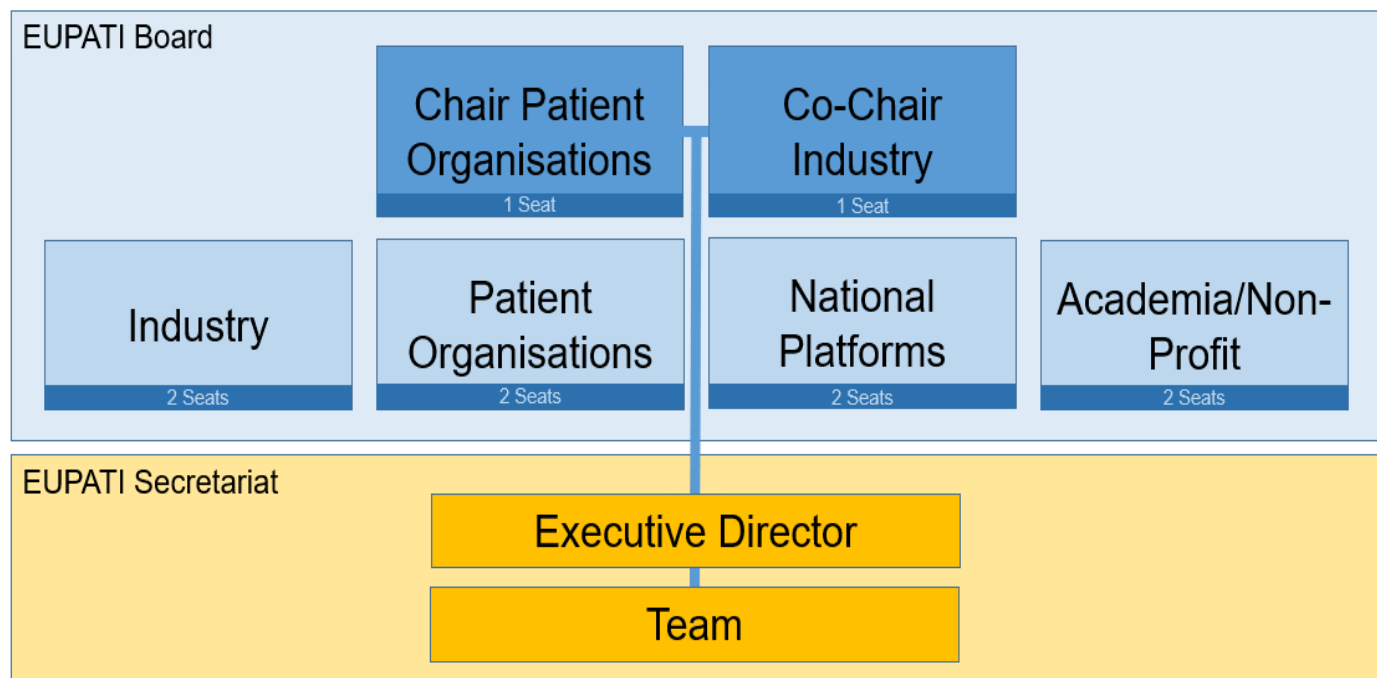
The different stakeholder groups of the Sustaining Partners Assembly **elect their representatives to the EUPATI Board**.

Meets at least once a year.

EUPATI Board



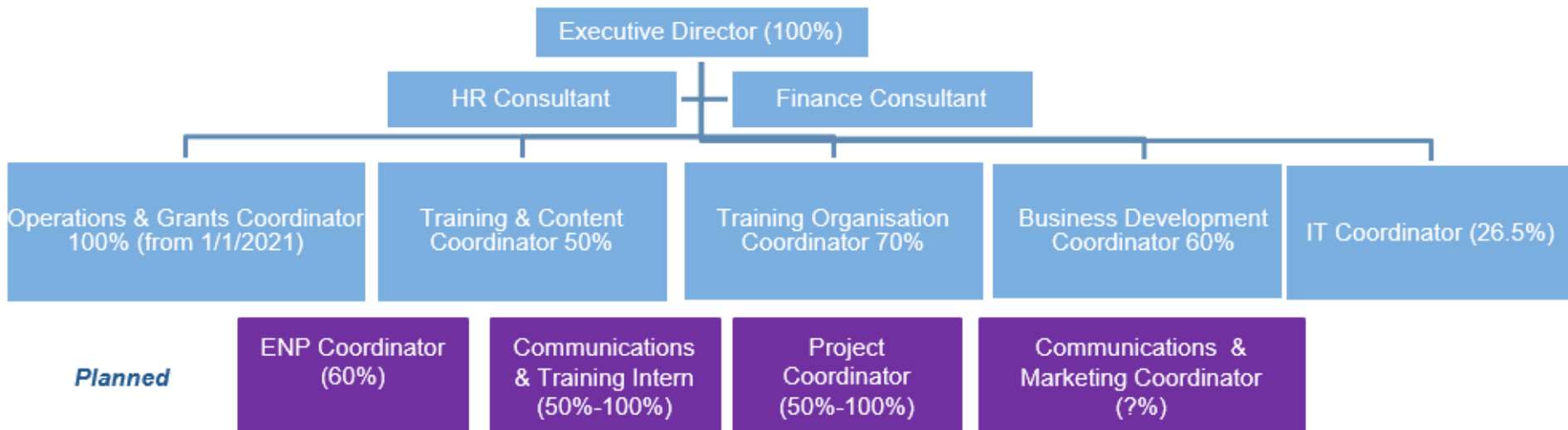
- The EUPATI Board is a supervisory committee, elected by the Sustaining Partners, which **oversees the implementation of EUPATI strategy and goals.**
- Chair – Anders Olauson, EPF
- Co-Chair – Kay Warner, GSK



Secretariat



- All operational responsibilities are delegated to the Executive Director
- The Executive Director leads the Secretariat and appoints staff as necessary to achieve the aims and objectives agreed by the EUPATI Board and Sustaining Partners Assembly in line with the approved budget.



Patient Expert Training Course



learning.eupati.eu

**Expert-level training
on medicines R&D**

Online & Face-to-face

Toolbox



www.eupati.eu

toolbox.eupati.eu

**Freshly designed in
June 2020**

Fee-for-service trainings



**Training on Patient
Engagement**

**Target audience:
academia and industry**

- EUPATI Fundamentals (3 x year)
- EUPATI Essentials (*in development*)
- In-house training

**In 2020: 250
professionals trained
by EUPATI
(estimation)**



EUPATI: Patient Engagement Through Education

Providing patients with accessible and reliable information and training on medicines research and development and other therapeutic innovations. A patient-led partnership working across stakeholders to enhance patient engagement.

[What is EUPATI?](#)

Toolbox

The Toolbox is organised in two main areas: Medicines R&D and Patient Engagement. You can also search by category or keyword. At the next stage you can also refine the search by "tags" (sub-categories). Key introductory topics are highlighted to help you begin to explore medicines research and development as well as patient engagement. Key concepts in the articles are linked to the [Glossary](#) for definitions.

☐ [Medicines R&D](#) [?](#) ☐ [Patient Engagement](#) [?](#)

Not sure what you're looking for?

Try to browse by category:

[Basics of Medicine R&D](#) [?](#)[Clinical Development / Trials](#) [?](#)[Drug Discovery](#) [?](#)[Regulatory Affairs](#) [?](#)[Benefit and Risk Assessment](#) [?](#)[HTA](#) [?](#)[Safety of Medicines](#) [?](#)[Non-Clinical Studies](#) [?](#)[Pharmacoeconomics](#) [?](#)

Welcome to EUPATI Open Classroom!

EUPATI provides patients with accessible and reliable information on how medicines are developed. We are a partnership changing the face of patient engagement through patient education.

[What is EUPATI?](#)

Promoting Your ENP

How to make the best use of your ENP Resources

Caroline Whelan

EUPATI National Platform Officer

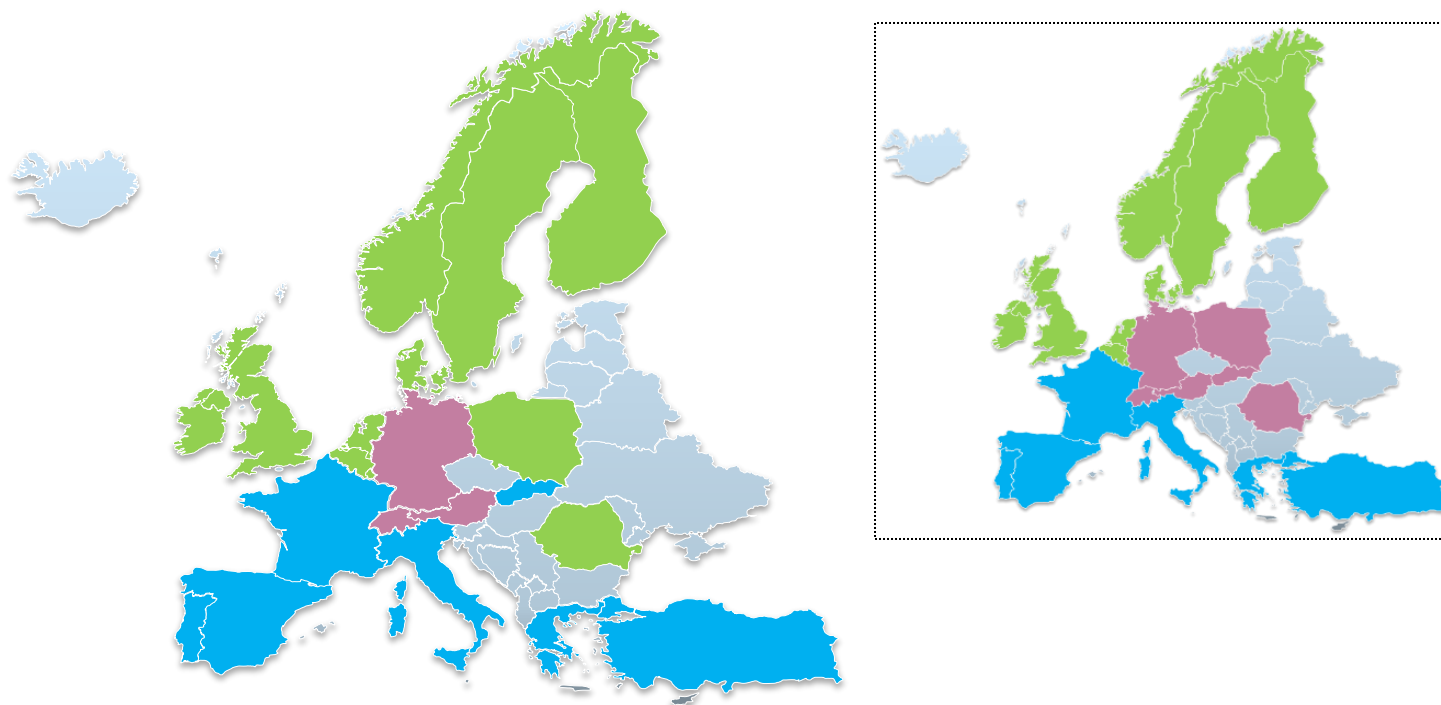
EFO-EUPATI Workpackage 4

Purpose

To **strengthen the coordination** of the ENP network, through:

- Collaboration
- Knowledge Exchange
- Sharing

Objective 1: Establish 3 Regional Groups



- Region 1 (9 countries):** ENPs for Portugal (lead), Italy (co-lead), France, Spain, Malta, Greece, Turkey, Cyprus, Slovakia
- Region 2 (3 countries):** ENPs Germany (lead), Austria (co-lead), Switzerland
- Region 3 (11 countries):** ENPs for Ireland (lead), Norway (co-lead), Belgium, UK (including Scotland), Luxembourg, Denmark, Finland, Sweden, Netherlands, Poland, Romania

Objective 2: Share Knowledge Between the Regions

- **Workplans:** Regional Workplans shared across regions
- **Meetings:** Regional & Cross-Regional meetings
 - 5 face-to-face meetings including an AGM;
 - 42 teleconferences in total;
 - 12 teleconferences for Region 1; 3 for Region 2; 8 for Region 3;
 - 2 teleconferences for Region 1, 2 and 3 leads and co-leads;
 - 14 teleconferences for the 'Common ENP Message' project;
 - 1 teleconferences for the Patient Education and Training Initiatives Repository.
- **Communications:** 11 EUPATI & National Platform Newsletters including year-end 'highlights' issue



Objective 3: Develop Patient Training Initiatives



3 ENPs have EUPATI based **Patient Expert Training Courses**

Ireland, Italy and the Netherlands have adapted the course in part or in full to deliver patient education and training programmes. Greece is currently preparing such a course.



12 EUPATI **toolbox translations**

The “EUPATI Toolbox on Medicines R&D” translated into many of the languages of member countries including English, French, German, Spanish, Polish, Italian, Russian, Dutch, Danish, Portuguese, Romanian, Swedish.



4 ENPs have EUPATI based **Mini-Courses**

Belgium; Portugal; Spain and the UK have used such material to develop and implement mini courses and workshops.



14 ENPs have **other** training initiatives

Many member countries (including Belgium; Denmark; France; Finland; Germany; Ireland; Luxembourg; Norway; Portugal; Slovakia; Spain; Sweden; Switzerland; UK) have developed various patient education and training initiatives other than EUPATI based patient expert training courses.

EFO-EUPATI Tasks



Task 4.1 - Boost existing ENP International Network Coordination

- WP2/WP4 workshop

Task 4.2 - Support Regionalisation of the ENP Network

IPPOSI Call for Expressions of Interest for funding per region

- **Region 1** Event “Southern Europe: On the Road to Connecting Patients, Agencies, Industry & Academics”
- **Region 2** Series of webinars on COVID-19 topics (2 hours of content)
- **Region 3** ‘Common ENP Message’ – slides; flyers; video; infographic

Task 4.3 - Support the Implementation of Patient Education Initiatives

- Status Report across all ENPs
- Repository & Infographic
- Fellow/Graduate engagement with ENPs Survey & Infographic

ENP Common Message

Common ENP Message History

- Develop a 'pitch' to stakeholders common to all 3 regional workplans;
- 'Common ENP Message' workshop during 2019 ENP AGM
- A flyer or poster; a set of slides; a short, animated movie

Achieved by International, multi-partner, virtual collaboration

Abbvie (WP4 co-lead) led on producing **set of slides and a flyer**;

IPPOSI in collaboration with EUPATI produced a **storyboard & short, animated movie** supported by **Region 3** funding;

Draft materials reworked in close collaboration **with IPPOSI, Regional members, the ENP Executive Committee and EUPATI central**;

Infographic TIPS ON HOW TO SHARE THE COMMON ENP MESSAGE
developed by **Pfizer & IPPOSI**

ENP Common Message Package

<https://eupati.eu/national-platforms/resources/>



EUPATI



The European Patients' Academy on Therapeutic Innovation (EUPATI) is a multi-stakeholder program led by the European Patients' Forum that provides education and training to increase the capability of patients to understand and contribute to medicines research and development as well as to healthcare decision making.

EUPATI [country]



Creates a national platform for collaboration between multiple stakeholders (eg. patients, academia, industry, media, government agencies, regulators)



Provides stakeholders with the opportunity to offer their expertise and resources, and to contribute to training topics



Provides objective, independent information and training in the national language with national content so that patients can meaningfully participate in the national healthcare system



Why Regulators or Health Technology Assessment agencies may want to work with EUPATI



EUPATI [country]

Helps you meet your objective to include patient input in your relevant workstreams and activities



Provides a process by which patients are trained to become increasingly helpful collaborators in their own health care



Patients trained by EUPATI [country]

- Understand the role of your agency in the regulatory process
- Understand the efficiency and sophistication required when delivering patient input
- Understand the limitations and trade-offs that must be made as part of decision making



Offer you an appropriately independent, feasible, and effective way to ensure your decisions are informed by the patient voice



Why Regulators or Health Technology Assessment agencies may want to work with EUPATI



EUPATI [country]

Helps you meet your objective to include patient input in your workstreams and activities



Patients trained by EUPATI

- Understand the role of your agency in the regulatory process
- Understand the efficiency and sophistication required when delivering patient input
- Understand the limitations and trade-offs that must be made as part of decision making

For more information visit: [eupati.eu \[country\]](https://eupati.eu/[country])
To contact your EUPATI representative, please email: <name@email.com>

<https://www.eupati.eu/>

TIPS ON HOW TO SHARE THE COMMON ENP MESSAGE

1 DEFINE KEY AUDIENCE

- Identify key opinion leaders within target audience
- Determine best approaches to connect with them



2 USE THE SLIDE DECK



- Slides provide in-depth detail about EUPATI & ENPs
- Add slides specific to ENP
- Best presented in-person
- Pick individual slides & post to social media outlets such as Instagram and Twitter for quick exposure
- Link websites in captions so readers can learn more

3 SPREAD FLYERS

- Flyers explain why audiences should engage with ENPs
- Share via postal service & in-person during presentations
- Use websites like Canva to customize flyers
- Post to Instagram, Twitter, & Facebook
- Use current & trending hashtags such as #patientsinvolved for greater visibility and consistency across ENPs



4 PLAY THE ANIMATED MOVIE



- Illustrates how patients & various stakeholders can work together
- Best suited for YouTube & Instagram
- Add a voice-over or text layer to the video
- Include links to the video on social media

5 MAKE CONNECTIONS

- Follow influencers & decision makers on Twitter & LinkedIn
- Ensure ENPs follow each other on social media
- Share all content to ENP website & LinkedIn



Patient Education and Training Insights & Tools

Patient Education and Training – Repository & EUPATI Fellow Engagement

- **Status Report**, published in September 2019 and updated in April 2020, on the development and implementation of patient training initiatives in EUPATI member countries
- **Repository** of National Patient Education Training Course material – templates; guidebooks; examples & **Infographic** on How To Set Up A National Patient Education Training Course
- **Survey** of cohorts 1,2 & 3 EUPATI Fellows & Patient Education Programme 2019 Graduates in Ireland; **Infographic** STRENGTHENING ENP & EUPATI FELLOW ENGAGEMENT

STRENGTHENING ENP & EUPATI FELLOW ENGAGEMENT

A SURVEY OF EUPATI FELLOWS REVEALS



WHILE FELLOWS ATTEST TO THE VALUE OF THE TRAINING, MANY EXPRESSED A LACK OF KNOWLEDGE ABOUT THEIR ENP



SO, HOW CAN THE ENP-FELLOW ENGAGEMENT BE ENHANCED?

- 1 Regular communication & meetings between ENP & Fellows
- 2 Mentoring of Fellows including clear membership rules and activities for Fellows within ENPs

ADDITIONAL TIPS FOR ENHANCING ENGAGEMENT:

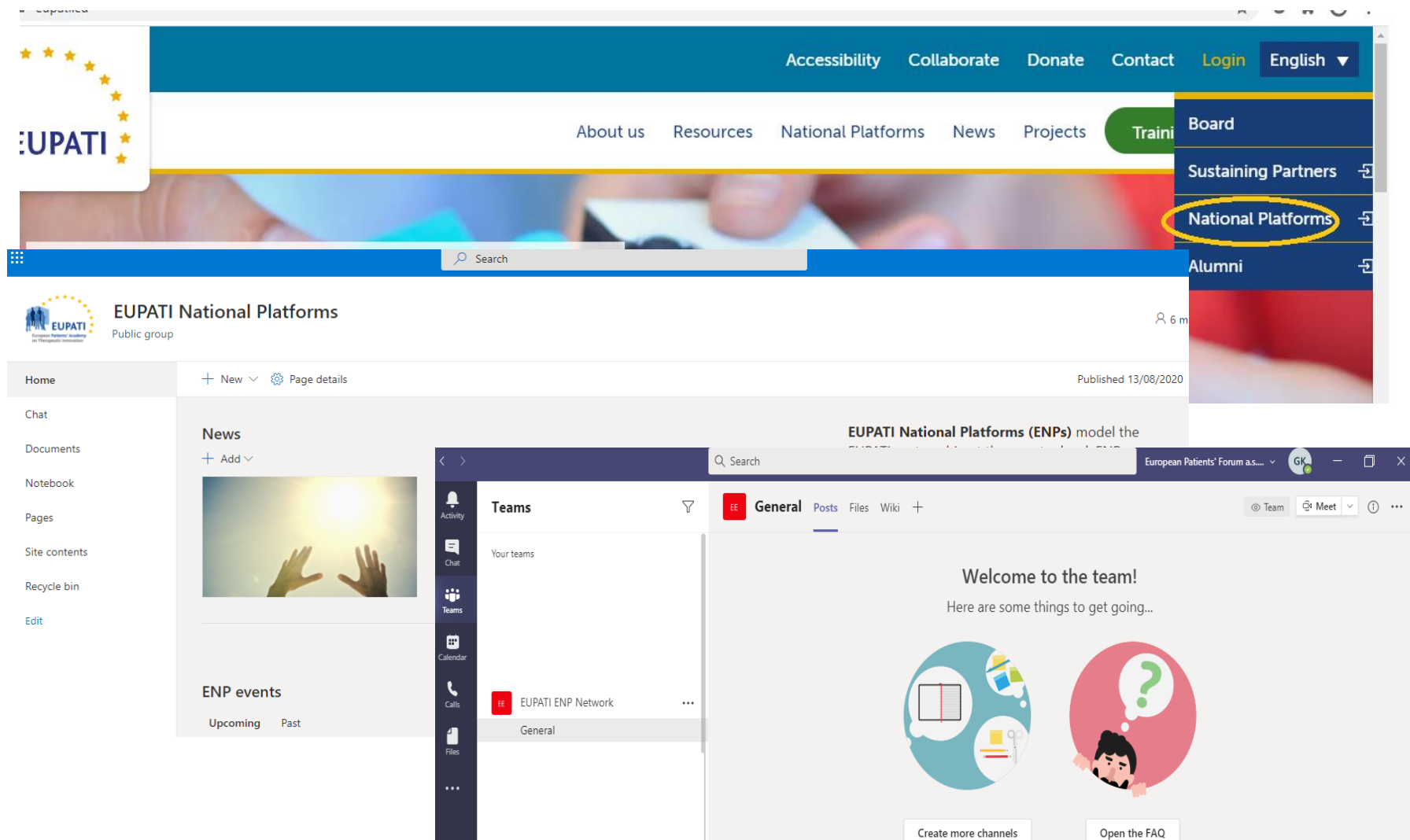
- Financial resources to support Fellow engagement with ENP
- Administrative resources to support Fellow engagement with ENP
- Sharing best practices for Fellow engagement between ENPs
- Create joint work plan for ENP & Fellows



EUPATI Fellows are eager to participate and actively looking for ways to engage with their ENPs
While not all ENPs are at the same stage of development, ENPs and Fellows could mutually benefit from greater engagement

Coming Soon....

Coming Soon...ENP Network Collaboration Space & Microsoft Teams



The image displays a composite of two digital interfaces. The top portion shows the EUPATI website, which has a blue header with navigation links: Accessibility, Collaborate, Donate, Contact, Login, and English. Below this is a secondary menu with links to About us, Resources, National Platforms, News, Projects, and a green 'Traini' button. A vertical sidebar on the right contains links to Board, Sustaining Partners, National Platforms (highlighted with a yellow circle), and Alumni. The main content area features a search bar and a section titled 'EUPATI National Platforms' with a 'Public group' label. The bottom portion of the image shows a Microsoft Teams window. The left sidebar lists navigation options: Home, Chat, Documents, Notebook, Pages, Site contents, Recycle bin, and Edit. The main area shows a 'Teams' view with a list of teams, including 'EUPATI ENP Network'. The right pane displays a 'Welcome to the team!' message with instructions and icons for creating channels and opening the FAQ.

ENP Strategy Moving Forward

Derick Mitchell

Co-Chair of the ENP Network

Discussion: ENP Strategy 2020-2025



Question:

What should the ENP Network look like in 5 years time?

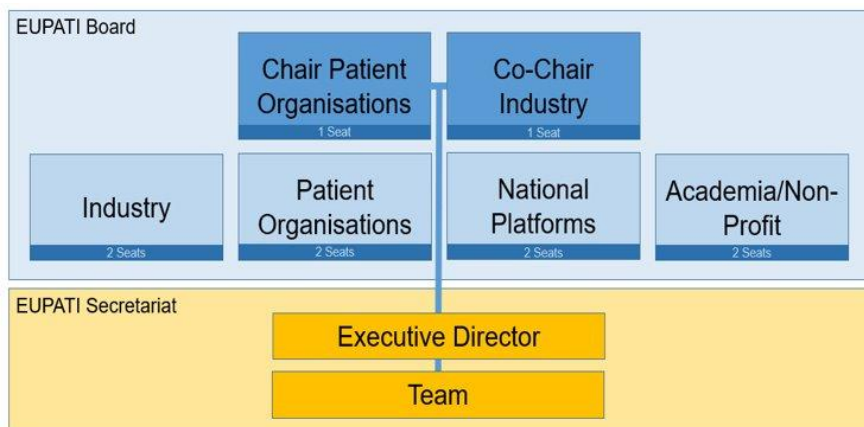
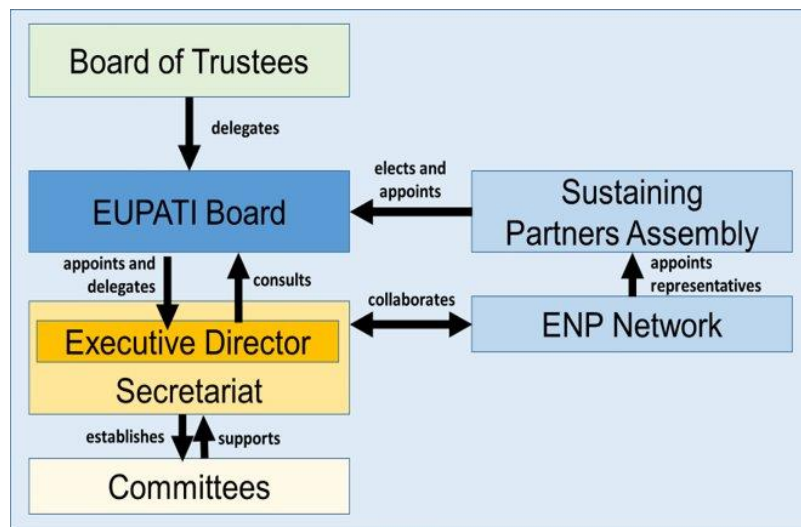
- **Feel Connected:** Not feel alone. To feel part of a strong network.
- **Consolidation:** To consolidate what has been done at the European level with what is being done national level.
- **Joined Up Thinking re Funding:** Local and central funding to be linked.
- **Collaboration:** Encourage Cohort 4 and future trainees' collaboration with ENPs.
- **Translation Mapping:** What are the needs for further translation and revisions?
- **Future of the Regions:** Should we maintain the regions?
- **How can EUPATI Central Assist?** Given current resources.

Meet Your New Representatives

Roald Nystad

Co-Chair of the ENP Network

ENP Network Governance Structure from Sept 2020



2019 - 2020 ENP Network Executive Committee



Patient

Academic

Industry

ENP
Co-ordinator



Derick
Mitchell
Co-Chair



Roald
Nystad
Co-Chair



Merete
Schmiegelow



Beatriz
Silva-Lima



Sandrine
Lavalle



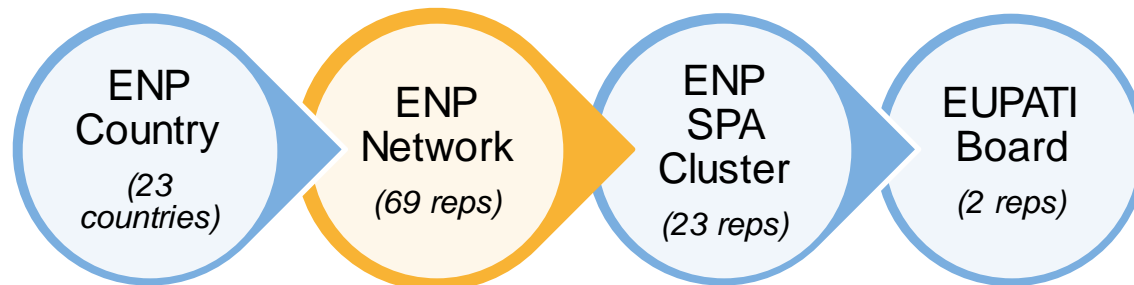
Thierry
Escudier



Gemma
Killeen



2020 ENP Network Representatives

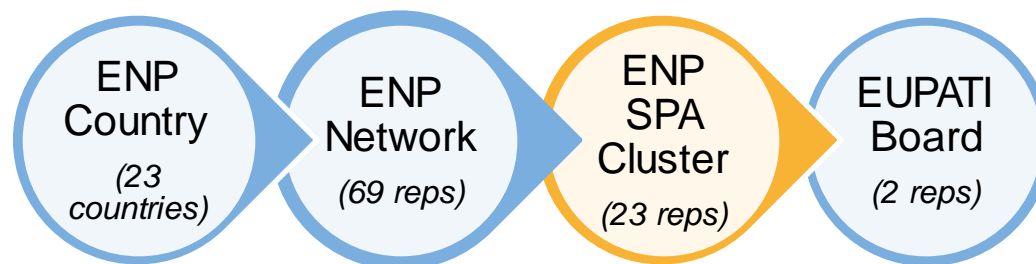


- You can now find your full list of ENP Network Representatives here
<https://bit.ly/3gJNccu>

EUPATI National Platform Network Country Representatives 2020

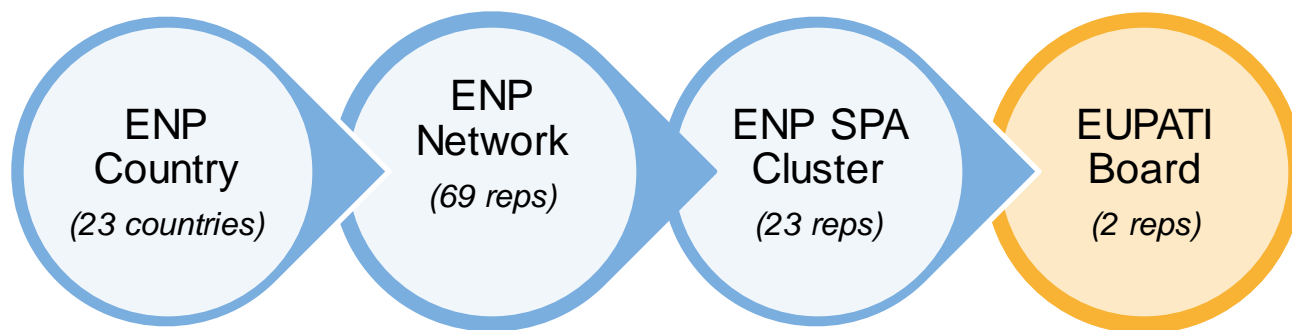
No	Country	Main Coordinator	Email Address	ENP SPA Cluster Rep	Patient representative	Email	Alternate Patient Rep	Email	Academic representative	Email	Alternate Academic	Email
1	Austria	Oleas Rühl	oleas.ruehl@spinder.at	Oleas Rühl	Oleas Rühl	oleas.ruehl@spinder.at	Benoventura Ikedia	benoventura.ikedia@gmail.com	Martin Bauer	martin.bauer@medunivie.ac.at		
2	Belgium	Mitchell Silva	mitchell.silva@gmail.com	Mitchell Silva	Mitchell Silva	mitchell.silva@gmail.com			Lyndee Grino	lyndee.grino@vaxsent.be		
3	Cyprus	Savazi Makri	savazimakri@vaxsent.com.cy	Savazi Makri	Savazi Makri	savazimakri@vaxsent.com.cy			Karantinnaris Perparis	karantinnaris@vaxsent.com.cy		
4	Denmark	Maroto Schmiegelow	Marotoschmiegelow@gmail.com	Maroto Schmiegelow (TBC)	Maroto Schmiegelow	Marotoschmiegelow@gmail.com	Charlotte Harquard	harquardc@gmail.com	Per Spindler	per.spindler@hospitals.dk	Suzanne Kase	suzanne.kase@vaxsent.com
5	Finland	Mirjami Tran Minh	mirjamitransminh@vaxsent.fi	Jenni Tamminen	Jenni Tamminen	jennitamminen@vaxsent.fi	Rima Strömberg	rima.stromberg@vaxsent.fi	Tuuli Lahti	tuuli.lahti@helsinki.fi	Mikka Airavara	mikka.airavara@helsinki.fi
6	France	Allen Wilderf	allen.wilderf@vaxsent.fr	Anno Huqen	Olivier Boleydiar	olevierboleydiar@gmail.com	Gilliane Spurrier	gilliane@melanomafrance.com	Anno Huqen	anne.huqen@vaxsent.fr	Allen Wilderf	allen.wilderf@vaxsent.fr
7	Germany	Tamara Borczyk	tamara@vaxsent.de	Jan Guizler	Jan Guizler	jan@smldvaxsent.net	Tamara Borczyk	tamara@vaxsent.eu	Welf See	welfsee@vaxsent.de		
8	Greece	Dimitris Athanasios	dathas@gmail.com	Dimitris Athanasios (TBC)	Dimitris Athanasios	dathas@gmail.com	Christina Georgiadou (TBC)	christina.georgiadou21@gmail.com	Panagiotis D. Banić (TBC)	panagiotis.d.banic@gmail.com		
9	Ireland	Caroline Whelan	cwhelan@vaxsent.ie	Virginia Minaque	Virginia Minaque	vminaque2017@gmail.com	Derrick Mitchell (TBC)	derrick.mitchell@vaxsent.ie	Jaran Lart (TBC)	jaran.lart@vaxsent.ie		
10	Italy	Silvia Starika	sstarika@vaxsent.it	Filippa Buccella	Filippa Buccella	filippa.buccella@gmail.com	Paola Kruger	paola.kruger@vaxsent.it	Dominique Van Damme	dominique.vandamme@gmail.com		
11	Japan	Satarhi Miki	SatarhiMiki@vaxsent.jp	Satarhi Miki	Satarhi Miki	SatarhiMiki@vaxsent.jp						
12	Luxembourg	Sandrine Lavallé	SandrineLavalle@gmail.com	Sandrine Lavallé	Sandrine Lavallé	SandrineLavalle@gmail.com	Anne Weydert	anneweydert@vaxsent.lu	Manon Gantenbein	Manon.gantenbein@vaxsent.lu	Aurilia Fischer	Aurilia.fischer@vaxsent.lu
13	Malta	Gertrude Buttigieg	info@malta.vaxsent.org	Mark Mallia	Gertrude Buttigieg	gertrude@malta.vaxsent.org	Mary Vella	maryvella@malta.vaxsent.org	Pierre Mallia	pierre.mallia@vaxsent.mt	Raymond Galea	raymond.galea@vaxsent.mt
14	Netherlands	Anamiek van Ronzen	anamiek.van.ronzen@vaxsent.nl	Anamiek van Ronzen	Anamiek van Ronzen	anamiek.van.ronzen@vaxsent.nl						
15	Norway	Raeld Myrstad	raeld@vaxsent.no	Raeld Myrstad	Raeld Myrstad	raeld@vaxsent.no	Elza Motow	elza.motow@vaxsent.no	Ingrid Fieldheim Bønne	ingrid.fieldheim@vaxsent.no		
16	Poland	Marzona Holkon	marzona.holkon@vaxsent.pl	Marzona Holkon (TBC)	Marzona Holkon (TBC)	marzona.holkon@vaxsent.pl	John Patan	john.patan@vaxsent.pl	Aneta Staszko-Habert (TBC)	aneta.staszko-habert@vaxsent.pl		
17	Portugal	Elza Motow	elza.motow@vaxsent.pt	Inês Alvor	Inês Alvor	ines.alvor@gmail.com			Bruna Gago	bruna.gago@vaxsent.pt		
18	Scotland	Lucia Slajeková	luciaslajekova@vaxsent.sk	Irena Oldfather	Irena Oldfather	irena.oldfather@alliance-rcatlon.org						
19	Slovakia	Lucia Slajeková	luciaslajekova@vaxsent.sk	Lucia Slajeková	Lucia Slajeková	luciaslajekova@vaxsent.sk						
20	Spain	Rab Camp	rabcamp@vaxsent.es	David Triquer	David Triquer	dtriquer@vaxsent.es	Ruberto Saldaña	ruberto@vaxsent.es	Janez Glara	janez.glara@vaxsent.es		
21	Sweden	Raehen Tafiqhi	raehen.tafiqhi@vaxsent.se	Raehen Tafiqhi	Raehen Tafiqhi	raehen.tafiqhi@vaxsent.se						
22	Switzerland	Coacilla Schmid	c.schmid@vaxsent.ch	Iva Schwauecker	Iva Schwauecker	iva.schwauecker@vaxsent.ch						
23	Turkey	Soma Erdem	soma.erdem.tr@gmail.com	Soma Erdem	Soma Erdem	soma.erdem.tr@gmail.com						
				21	20		13		17		6	

2020 ENP SPA Cluster Representatives



No	Country	Representative	No	Country	Representative
1	Austria	Claas Röhl	13	Malta	Mark Mallia
2	Belgium	Mitchell Silva	14	Netherlands	Annemiek van Rensen
3	Cyprus	Souzi Makri	15	Norway	Roald Nystad
4	Denmark	Charlotte Norgaard	16	Poland	Marzena Nelken
5	Finland	Jenni Tamminen	17	Portugal	Inês Alves
6	France	Anne Hugon	18	Scotland	Irene Oldfather
7	Germany	Jan Geissler	19	Slovakia	Dominik Tomek
8	Greece	Dimitrios Athanasiou	20	Spain	David Trigós
9	Ireland	Virginia Minogue	21	Sweden	Roshan Tofighi
10	Italy	Filippo Buccella	22	Switzerland	Caecilia Schmid
11	Japan	Satoshi Miki	23	Turkey	Sema Erdem
12	Luxembourg	Sandrine Lavallé			

2020 ENP Network EUPATI Board Representatives



Sandrine Lavalley
ENP Luxembourg
1 Year



Filippo Buccella
ENP Italy
2 Years

Close & Photo!

Gemma Killeen
ENP Network Coordinator



Appendix

Responsibility of the Board of Trustees



By legal stipulation, the Board of Trustees is legally and fiscally responsible for the Foundation.

The Board of Trustees' responsibility is to ensure that:

- The future of the Foundation is never jeopardised.
- The Foundation is run in accordance with the Statutes and Operating Rules.
- The Operating Rules are compliant with the Statutes of the Foundation.
- The tax exemption status is not jeopardised.
- No breach of national or international laws occurs.
- The Financial Audit and Annual Report of the Foundation is conducted, completed, and submitted as defined in the Statutes.
- The EUPATI Board and the Secretariat has the required legal mandate to represent the organisation and undertake all representative and operational tasks.
- The EUPATI Board and Secretariat has completed its duties as defined in the Statutes and Operating Rules at the end of each year.

The Board of Trustees have no external representational or operational role over and above the responsibilities listed above. The Board of Trustees delegates all other representational, supervisory and executive functions to the EUPATI Board and the Secretariat.

Board of Trustees



The composition of the Board of Trustees should be balanced and include:

- one member who is experienced in medicines R&D (industry representative);
- one member who is experienced in R&D in academia (academia representative);
- one member with experience in patient advocacy (patient representative);
- one member experienced in medicines regulation;
- one member experienced in finance.

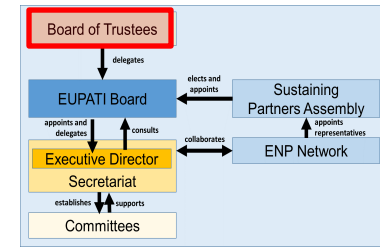
Further facets of the Board of Trustees are considered as helpful:

- Knowledge about patient engagement in research;
- Social entrepreneurship experience;
- Business experience;
- Wide geographic scope and gender balance;
- Dutch nationality and residency for one member.

A Trustee should not be a member of the EUPATI Board, the Sustaining Partners Assembly or the Secretariat.

Board of Trustees

1. Birgit Fischer, Germany
2. Ivett Jakab, Hungary
3. Jytte Lyngvig, Denmark
4. Clayton Hejman, Netherlands
5. Günter Stock, Germany



Role of the EUPATI Board



- Safeguards the Foundation's mission.
- Define and supervise organisational values.
- Ensure the Foundation has adequate resources.
- Approve EUPATI's policies and procedures.
- Approve the Foundation's budget plan.
- Suggest the auditor or auditing company to the Board of Trustees, and supervise auditing is conducted appropriately by the Secretariat.
- Promote the Foundation by serving as a link with members, donors, beneficiaries and other stakeholders.
- Adopts Advisory or Operational Committees.
- Appoint an Executive Director.
- Evaluate the performance and remuneration of the Executive Director.

Elections and SG handover to new EUPATI Board



Board elections June – September 2020

Outcomes:

Chair – **Anders Olauson**, EPF, 2y

Industry Co-Chair – **Kay Warner**, GSK, 2y

Patient Organisations - **Brian West**, EATG, 2y

Patient Organisations - **Derick Mitchell**, IPPOSI, 1y

Industry - **Lasse Funch Jacobsen**, LEO Pharma A/S, 2y

Industry– **Donatella Decise**, Novartis, 1y

Academia/Non-Profit - **Ingrid Klingmann**, EFGCP, 2y

Academia/Non-Profit – **Anne-Charlotte Fauvel**, EATRIS, 1y

ENPs – **Filippo Buccella**, ENP Italy, 2y

ENPs – **Sandrine Laval**, ENP Luxembourg, 1y