



# 10 REASONS to be a member of the European Patients' Forum!





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PATIENT MOVEMENT**

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# BE PART OF A STRONG AND UNITED PATIENT MOVEMENT

## WHO WE ARE?

EPF is an umbrella organisation that represents the interests of **PATIENTS WITH CHRONIC DISEASES AND/OR LIFELONG CONDITIONS** to the European institutions in public health and health advocacy.

## OUR MEMBERS

Our members consist of Pan-European disease-specific and national coalitions of patient groups.

They fulfil criteria related to representativeness, legitimacy, democracy, consultation and transparency.



**Through our membership,** we are present in all 28 countries of the European Union!

## OUR VISION



Our vision is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

## OUR MISSION

Our mission is that the patients' community drives the policies and programmes that empower them to be equal citizens in the EU.



## A RIGHTS-BASED APPROACH

We advocate for access to healthcare as a basic human right, and the notion of the patient as an equal citizen.

## AN INCLUSIVE PLATFORM

EPF works with organisations of all sizes and respects the individuality of its member organisations. We recognise and appreciate the diversity of viewpoints among our members and strive to achieve consensus on issues of common interest to us all.



# ACCESS AND CONTRIBUTE EXPERTISE

Our members are the ‘national’ experts from EU countries or ‘European’ experts in the disease area they represent. EPF focuses its actions on cross-cutting topics, which are of interest to all of our members.

We address transversal issues to promote a patient-enabling environment which will help you to put your organisation’s agenda forward and focus on your specific issue, rather than general topics.

Because no one can be an expert in everything, we aim to inform, raise awareness, and serve as a ‘hub’ where expertise is shared.

## HOW DO WE WORK?



### **WE KEEP AN EYE ON WHAT IS HAPPENING AND PROMOTE ISSUES**

**THAT MATTER FOR PATIENTS** – EPF follows closely the developments of EU policy in health and social care and puts forward the issues that you consider important.



### **WE KEEP YOU IN THE LOOP**

– We inform and consult with our members via our member-only “*Weekly Insiders*”. We also draft briefing notes on new pieces of legislation and policies, breaking down the complex subjects and pointing out the issues at stake for patients and where change is needed.



### **WE GIVE OUR OPINION**

– When an important issue comes up, we discuss it within our Policy Advisory Group and our thematic Working Groups in order to develop robust patient-centred positions. As a member of EPF, you too can participate in such groups. We also consult with our wider membership to make sure every member’s voice is heard.

Spelled out in the  
**EPF Strategic Plan  
2014-2020**

## 6 STRATEGIC GOALS FOR 2020



### 1 Health literacy

To promote better access to information and education for patients that will enable them to make informed choices about their health.



### 2 Healthcare access and quality

To improve health systems to ensure equitable access to sustainable and high-quality healthcare.



### 3 Patients' involvement

To advance meaningful participation in the development of health-related policies, programmes and projects in the EU.



### 4 Patients' empowerment

To promote policies, strategies and healthcare services that raise patients' awareness and empower them in the decision-making and management of their conditions.



### 5 Sustainable patients' organisations

To support the development, growth and capacity building of patients' organisations.



### 6 Non-discrimination

To promote policies tackling discrimination in health, social care and education.



# GET LIKE-MINDED ADVOCATES ON YOUR SIDE

## AN AGENDA-SETTING ORGANISATION

EPF is proactive and promotes issues that are key to the patients' community but are not yet visible on the European agenda.

## KEY ACHIEVEMENTS

**Legislation is more demonstrably patient-centred**, thanks in part to our advocacy work:

- The regulation on clinical trials included provisions on informed consent, transparency and patient involvement;
- The cross-border healthcare directive entailed the first commitment to quality information for patients and the creation of 'patient-centred' European Reference Networks;
- The Directive on Pharmacovigilance included direct patient reporting of adverse events.

Our work does not stop in Brussels or Strasbourg: appropriate and effective implementation of the legislation at national level is equally important to us.

**Soft law and policy** – EPF has taken the discussions forward on issues such as patient safety, quality of care, patient empowerment and health literacy. This has in turn created a groundswell of support and ambition to do things differently, and a clearer, more nuanced patients' perspective.



## OUR CAMPAIGNS



### 2014 Election Campaign:

“Patient + Participation =  
Our Vote for a Healthier Europe”

EPF obtained the support of 34 Members of the European Parliament who committed to include a patients’ perspective in their work during their mandate.



### 2015-2016 Patient Empowerment Campaign:

“Patients prescribe E<sup>5</sup> for sustainable health systems”

EPF seeks to take the European discussions on patient empowerment a crucial step forward – towards concrete actions at practical and political levels, led by the patient community in partnership with all relevant stakeholders.

“EPF is a great advocate for patient organisations towards European institutions. The EPF team keeps us informed of the on-going political debate and the key questions where patient representatives need to get active.”

**IPOPI – International Patient Organisation for Primary Immunodeficiencies**



# PROVIDE REAL EVIDENCE FOR REAL CHANGE

Since its creation, EPF has invested in solid project work. We want to provide real evidence for change that is recognised and respected by other healthcare players.

## FEEDING IN THE PATIENTS' PERSPECTIVE IN EUROPEAN PROJECTS

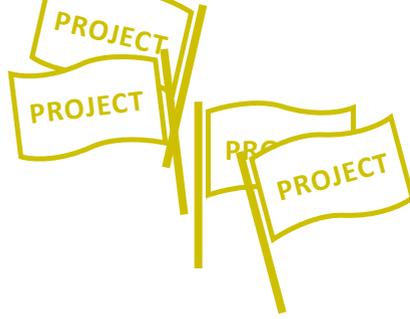
There are innumerable European projects looking at the impact of new healthcare solutions on citizens and patients – we only engage in projects where we can provide a real patients' perspective, and where our contribution is valued. We link up prospective projects with relevant member organisations wherever this is possible.



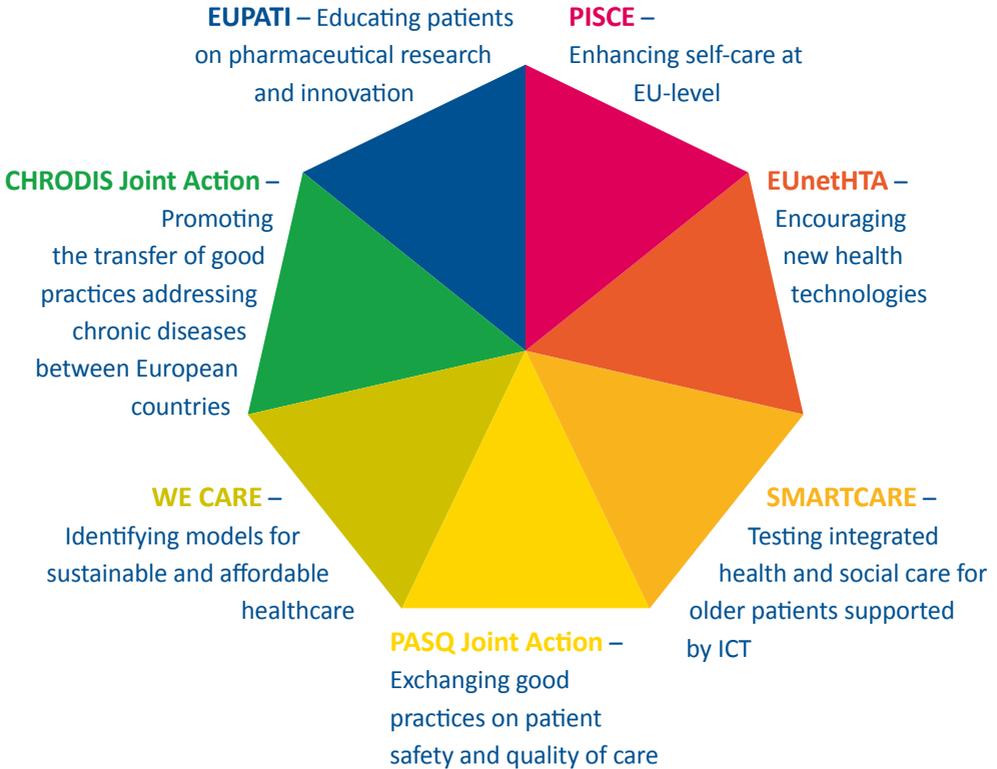
## CALLING ON YOUR EXPERTISE

EPF is present in a number of European projects and Advisory Boards. We share the invitations we receive and relay the opportunities to represent the patients' perspective on specific areas to our members.

**Your input is essential to our work!**



## OUR PROJECTS' PORTFOLIO



"EPF represents a model entity in pursuit of better conditions and quality of care for patients and their families across Europe. Being part of EPF means for us support in the actions we take for patients and means to have the opportunity to participate in achieving our goals with other European patients' associations, with the conviction that we all work for the good of patients."

**FEP** – Spanish Patients' Forum



# NETWORK WITH YOUR PEERS

EPF is 'the place' to meet other patients' organisations with whom you can build strategic coalitions. Networking and interactivity play a central role during our meetings both physical and online.

## ANNUAL GENERAL MEETING

The Annual General Meeting is our main *rendez-vous*. It provides you with the opportunity to share your experiences and views and reflect on EPF's development and your role therein.

This is also the one occasion in the year for all EPF members to meet, exchange, and celebrate their being part in an umbrella organisation that drives patients' rights in Europe.



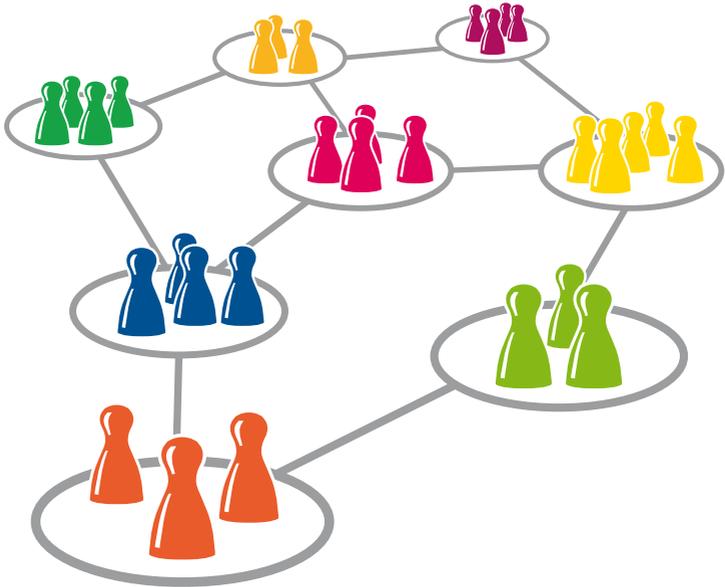
## PATIENTS' COMMUNICATIONS NETWORK

Launched in April 2015, this informal network is made of people in charge of communications (leaflets, website, social media, etc.) within EPF membership and within their own members. Communications Officers working in patient organisations face similar challenges and opportunities: the objective is to support each other to be more successful in our communication activities.



## KEEPING IN TOUCH ONLINE

We are currently developing an online platform to enable EPF members to stay in touch easily between meetings.



"EPF is an organisation that advocates and defends patients' rights, and supports us in our aspirations and objectives. This contributes to create a powerful and influential patient movement, where health and social systems are based on the real needs of patients. It unites us and gives us strength in our work."

**COPAC** – Coalition of Patients' Organisations with Chronic Diseases from Romania



# ENHANCE YOUR ORGANISATION'S CAPACITY

Through our Capacity Building Programme and the training we regularly organise, we support the development of our members' organisational capacities and advocacy skills.

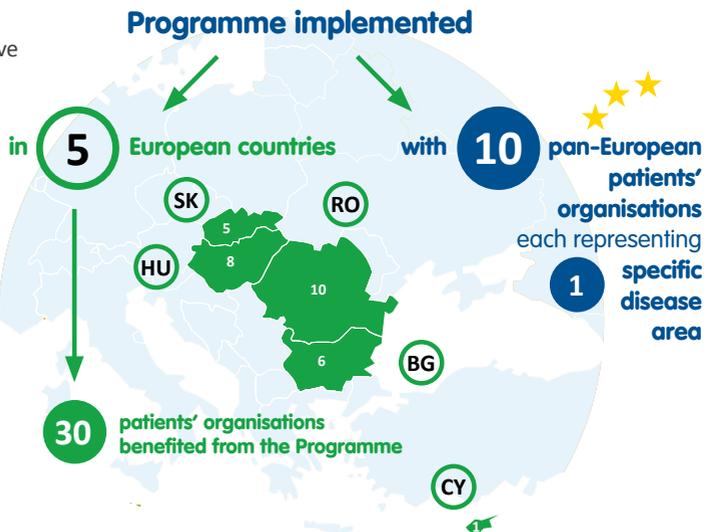
## AT NATIONAL LEVEL

The local pillar of our Capacity Building Programme is targeted at our national members and their own members.

The programme is tailored to their needs and focuses on capacity areas such as strategic and operational planning, good governance, effective advocacy strategies and more.

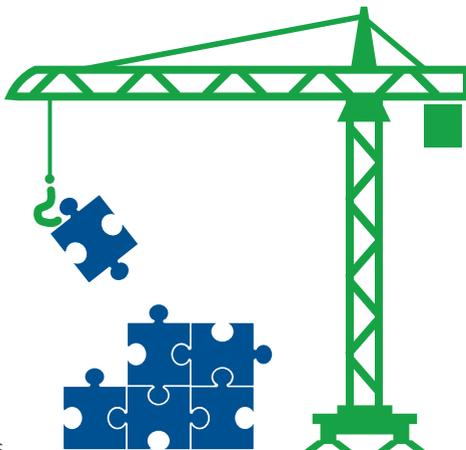
So far, we are active in five countries:

**BULGARIA,**  
**CYPRUS,**  
**HUNGARY,**  
**SLOVAKIA** and  
**ROMANIA,**  
and we hope to grow this programme.



## AT EUROPEAN LEVEL

Our European members benefit from training and dedicated resources too. We organise hands-on exercises, provide individual coaching and publish toolkits on topics that are essential to their development in areas such as fundraising, communication and social media.



## OUR ADVOCACY SEMINARS FOR PATIENTS' ORGANISATIONS

EPF organises advanced and regional advocacy seminars in which we invite patient organisations to share knowledge and experience about ways to interact more efficiently with the EU institutions, national parliaments and the media.

Topics include information on the EU legislative process, advocacy strategies, preparation of project proposals, access to European funds and more.

Apart from the obvious skill and know-how building, we also aim at inspiring confidence and strengthening the awareness of a Europe-wide patient community.





# KEEP UP WITH THE LATEST NEWS FROM EUROPE ON WHAT REALLY MATTERS FOR PATIENTS

## WEEKLY INSIDERS'

This short and easy-to-read email 'news', accessible to members only, informs you about upcoming events, EPF consultations and funding opportunities.



## WEEKLY (VIRTUAL) COFFEES WITH EPF

By setting a regular appointment with our members, EPF aims to collect fresh and first-hand information about what you are doing. This way, we are in a better position to connect your needs and priorities with what is going on at EU level, potential links with EPF's activities, and to get a better sense of how EPF members work.





### “EPF ON THE SPOT”

In order to better understand our members’ perspectives and the context of their work, EPF attends General Assemblies or key events (upon invitation). Our objective is to learn more about our members’ work on the ground and to define our services accordingly.



"Since its foundation, the EPF has successfully strengthened the role of the patients and their associations, by defining health policies and programmes that have impact on their lives. Through educational and capacity building programmes, EPF has also contributed to the development and empowerment of its members. GAMIAN-Europe is proud to be a member of this active, effective and dynamic organisation."

**GAMIAN-Europe – Global Alliance of Mental Illness Advocacy Networks**



# GET MORE VISIBILITY

Your organisation's visibility contributes to your success! EPF is proud of our members' work and shares your successes and achievements.

## NEWSLETTER

Each month, we dedicate one article to the top news of one of our members. You have a special event? Your organisation is celebrating its anniversary? Let us know, and we will help to make it known!

eu-patient.eu



## BLOG – OUR MEMBERS IN THE SPOTLIGHT



[eu-patient.eu/blog](http://eu-patient.eu/blog)

Each month, we ‘home in’ on one of our members by featuring them on our blog. Introduced in 2015, this new **‘SPOTLIGHT’** gives you the chance to introduce your organisation by answering to five short questions.

## SOCIAL MEDIA

EPF is present on many social platforms. We voice your messages and inform you of the latest opportunities for your organisation in real-time.



[/eupatientsforum](https://twitter.com/eupatientsforum)



[/eupatient](https://www.youtube.com/channel/UC...)



[/europeanpatientsforum](https://www.facebook.com/europeanpatientsforum)



# SHARE OUR NETWORK OF PARTNERS AND ALLIES

EPF places a strong emphasis on forging alliances and good working relations with European organisations with which we have a common agenda.

## PUTTING YOU IN CONTACT WITH THE RIGHT INTERLOCUTOR

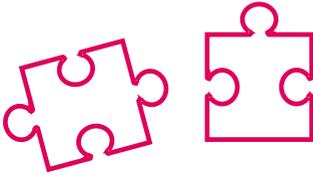
As a member of EPF, you have access to a comprehensive database of health stakeholders.

We are happy to connect you with our contacts when you are looking for a partner for your project, or for specific insight on a topic.



## WHO ARE OUR PARTNERS?

- **Health stakeholders:** for example, International Alliance of Patients' Organization (IAPO), European Public Health Alliance (EPHA), World Health Organisation, European Health Policy Forum, European Network on Patient Empowerment (ENOPE), European consumers' association BEUC...
- **EU institutions and Agencies:** for example, European Commission (DG SANTÉ and DG ENTR), European Parliament, European Medicines Agency (EMA), the European Council and EU Presidencies...



→ **Health professionals:** for example, European Standing Committee of Doctors (CPME), Royal College of Physicians, European Pharmacists' organisation (PGEU), European Federation of Nurses (EFN), the European Health Managers' Association (EHMA), the European Hospitals and Healthcare Federation (HOPE), European Union of Medical Specialists (UEMS)...

→ **Cooperation with the industry:** for example European Federation of Pharmaceutical Industries and Associations (EFPIA), European Generics Association (EGA), the medical devices industry MEDTECH EUROPE...



→ **Academia and related NGOs:** for example the Imperial College, LSE, the European Forum for Good Clinical Practice, DIA Europe, ISPOR...

"As a member of the EPF since it was founded I have watched it steadily grow in confidence and influence on behalf of patients. More to the point it has not subsumed the role of other voluntary organisations but rather augmented and facilitated their work. The net result is a strong, independent, influential overarching voice combined with an enhanced input at the National and local level. It is impossible to overstate the effect this has had on policy makers and thus potentially on the lives of people we represent."

**EMHF – European Men's Health Forum**



# IT'S AS EASY AS A CLICK

## WANT TO JOIN EPF?

Can you answer positively 2 out of the 3 following affirmations?

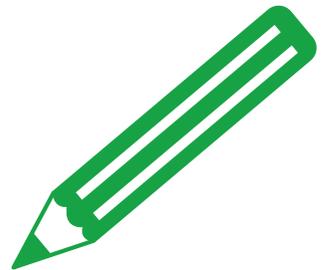
My organisation represents several patient organisations

My organisation is active at national level and represents several disease

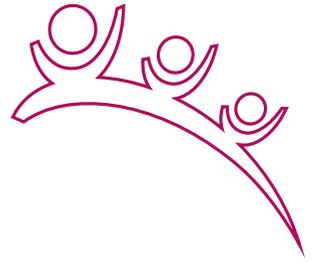
My organisation represents one specific disease area and is present in several European countries

Yes

No



Then **you may wish to consider EPF membership!**



## WHAT DO WE NEED FROM OUR MEMBERS?

EPF is the ‘sum’ of our members’ engagement. We can only be effective and strong with the active support of all our member organisations.

- ➔ **Keep us updated!** Keep the Secretariat updated with your activities, contact details and health policy developments in the countries you are active in, or in your disease area.
- ➔ **Work on national and disease-specific level:** our members play a crucial role in adapting and implementing the policy and campaign work carried out at EU level, making it work for patients ‘on the ground’.
- ➔ **Represent EPF!** Our members are EPF ambassadors and act as bridge builders between EPF and European and national politicians, institutions and organisations.
- ➔ **Membership Fees** – We provide extensive information and support for a modest membership fee that is proportionate and based on your annual turnover. By paying your fee regularly you express your commitment to our work.



# CONTACT US!

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 [www.eu-patient.eu](http://www.eu-patient.eu)

 [www.facebook.com/EuropeanPatientsForum](https://www.facebook.com/EuropeanPatientsForum)

 <https://twitter.com/eupatientsforum>

 [www.eu-patient.org/blog/](http://www.eu-patient.org/blog/)

 [www.youtube.com/user/eupatient](https://www.youtube.com/user/eupatient)



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