

EPF Patient Advocates' Seminar

CONCEPT NOTE

1. General background information

1.1 PATIENT ADVOCATES' SEMINAR (PAS):

The PAS will enable patient advocates to improve their advocacy skills, their knowledge about European health policy debates and integrate national perspectives into the European debate to have a stronger patient voice.

The value of this approach has been strongly confirmed by the success of the advocacy and capacity-building regional seminars for patient leaders held over the previous years, for example in Romania (2011), Portugal (2012), Croatia (2013), Sweden (2015) and The Netherlands (2016) as well as the National Coalitions' Meeting (2017). In 2018 EPF would like to refresh the format of the Regional Seminar and the National Coalitions' Meeting and open the participation to its whole membership and beyond.

While the core objective of strengthening patient leaders' advocacy capacity is the key feature of EPF's patient advocacy seminar, the event also represents an opportunity to work in close consultation with our members on the EPF 2019 European Parliament Elections Campaign.

1.2 PURPOSE AND SPECIFIC OBJECTIVES OF EPF PATIENT ADVOCATES' SEMINAR

The EPF Patient Advocates' seminar will take place as a one-day and a half hackathon where participants will work in cross-functional teams with mentors to find innovative solutions to a common and given challenge in the field of patient advocacy.

The topic of the PAS 2018 is to solve this challenge: **“How could we make health a priority for the European Union post-2020 and position the patient community as a key stakeholder in the EU health policy debates?”**

The Seminar has four specific objectives:

- Developing knowledge about the European Union, its institutional structure and its policies in the field of health;

- Raising knowledge and awareness of how to get involved in policy-making, transposition and implementation of key EU health-related policies;
- Training patient leaders to develop effective advocacy skills to influence national and European health policies;
- Building mutual understanding and cooperation among national patient organisations.

1.3 OUTCOMES

Through addressing the specific objectives mentioned above, this meeting should ultimately make a valuable contribution towards fostering better health policy and health outcomes on a national and European level.

The meeting should have the following outcomes:

- Patient representatives have a stronger knowledge of European decision-making processes and health policies;
- Patient representatives have enhanced advocacy skills that enable them to increase their impact in decision-making at national and European level;
- Increased cooperation between patient organisations across the participating countries;
- Strengthened relationship between EPF and patient representatives, and identification of opportunities for further cooperation and membership engagement.

Furthermore, the conclusions and recommendations of the meeting will be integrated into EPF policy and membership work as well as in our current and future projects.

1.4 PARTICIPANTS / TARGET GROUP

The event is addressed to patient representatives' members of EPF from across Europe and to selected representatives of National Coalitions and European umbrella organisations in countries or disease areas where EPF is currently not represented. EPF is looking for maximum 30 participants from across Europe.

Applicants must be either a:

- Staff member or a volunteer of an EPF Member organisation active at European or national-regional level mainly based in but not only in EU countries;
- Staff member or a volunteer of a cross-section of EPF Member organisations' membership;

- Other European or national-regional patient organisation not affiliated with EPF who have expressed an interest in participating in this event.
- Applicants' organisations must be a legally registered association/NGO working for the direct benefit of targeted, disease-specific population and or a specific geographical scope.

Other selection criteria: Knowledge of public health, interest in developing advocacy skills, willingness to use the learning in practice.

Time Commitment:

Applicants must be able to commit to actively participate in the 1,5-day training (20-21 October 2018).

Language: the entire training will be in English. To successfully take part in this training course, participants must have a minimum working knowledge of English, at least the Upper Intermediate level (B2 of the Common European Framework of Reference for Languages).

1.5 STRUCTURE OF THE MEETING

The meeting will follow the structure of a hackathon aiming at building on the knowledge of participants, and to be an occasion for experience-sharing and peer to peer learning. The seminar will take place over one day and a half. It will include plenary sessions and group work.

Participants will be divided in teams and work towards the creation of a presentation to be addressed to a Jury that will provide feedback and assign prizes to the best 3 teams. During the seminar participants will receive the support of mentors, hints and source documents to proceed in their work.



2. Agenda

When? 20-21 October 2018

Where? Crown Plaza Le Palace, Rue Gineste 3, 1210 Bruxelles, 1000 - Brussels

Day 1 – Saturday, 20 October 2018

09:30-10:00	Registration and welcome coffee
10:00-11:30	Introduction: briefing on the challenge <i>How could we make health a priority for the European Union post-2020 and position the patient community as a key stakeholder in the EU health policy debates?</i>
11:30-12:00	Coffee Break
12:00-13:00	The good the bad and the ugly in patient advocacy EPF will present the do and don't in patient advocacy to support you in creating your own project to solve the challenge
13:00-14:00	Networking Lunch
14:00-18:00	Cracking the challenge in teams part 1
16:00-16:30	Coffee break
16:30-18:00	Cracking the challenge in teams part 2
18:00-19:30	Free time
19:30-21:00	Networking Dinner

Day 2 – Sunday, 21 October 2018

08:30-09:30	Finalising team presentations
09:30-11:00	Team work presentation in front of a Jury part 1
11:00-11:30	Coffee Break
11:30-12:30	Team work presentation in front of a Jury part 2

12:30-13:00	Discussion and Feedback
13:00-14:00	Networking Lunch
14:00	End of Event