

# EPF AGM AGENDA

## Background Note to Item 12: Wider Europe and Constitutional Reform

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### 1. Wider Europe

During our last AGM in 2017, EPF members gave the board and the secretariat a mandate to explore further the expansion of EPF geographically: we are currently exclusively an EU organisation. It was recognised during the meeting that all of our European disease-specific member organisations have a wider geographic remit and our 'enlargement' would lead to more coherence in this regard.

An assessment was undertaken, notably with WHO Europe, IAPO and patient organisations from the countries and region in question.

This exercise took on board the implications of BREXIT, our relationship with organisations in the European Economic Area (EEA), the Western Balkans, and the EU Neighbourhood policy East Partnership countries.

Discussions with our members in the UK confirm their desire to remain part of EPF. Further, our talks with patient organisations from the European Economic Areas (Iceland, Norway and Switzerland) also indicated a strong interest in working more closely with EPF. There is, however, an absence of formal national coalitions as such in these countries, but rather looser alliances.

**Countries of the Western Balkans include:** Montenegro, Serbia, Albania, Bosnia and Herzegovina, Kosovo. As Macedonia (FYROM) is an EU candidate country, the Macedonian coalitions is already an associate member of EPF, in line with our current Constitution.

EPF has completed a situational analysis in Western Balkans in 2017, following our capacity building programme (Regional Advocacy Seminar in Croatia in 2014). This exercise indicated an interest in cooperation, primarily from the angle of capacity building/alliance building in the first instance. Several countries are likely to become EU candidate countries in the next few years.

EU East Neighbourhood Countries are:

- Belarus
- Ukraine
- Georgia
- Moldova
- Azerbaijan
- Armenia

## 2. IAPO (International Alliance of Patient Organisations)

The EPF President attended an IAPO board meeting in August 2017 to discuss with IAPO representatives their perspectives. It was established that EPF has a strong and trusted relationship with IAPO based on a Memorandum of Understanding (MoU) signed in 2006. Both EPF and IAPO are active and complementary within WHO Europe.

The meeting confirmed that IAPO has a strategy to concentrate on other regions of the world outside Europe, and collaborate with EPF on addressing the cross cutting unmet needs of patients from the wider Europe. It was agreed that EPF focuses on EU neighbouring countries and the Western Balkans, and IAPO on central Asian countries, which also form part of WHO Europe.

EPF has very informal contacts in some of these neighbouring countries, notably Armenia, where a national patient coalition is at a formative stage, however our knowledge base is extremely limited at this stage. What is clear is that the interests of patients in these countries are not being represented in an international context.

## 3. WHO-Europe

Discussions with WHO-Europe indicated that this is a very timely initiative from their perspective and in line with their priorities, particularly on person/ patient centred care across the region. EPF enjoys a close cooperation with the WHO-Europe office in the context of foresight work and health systems design and strengthening, although we have never applied for membership status. Colleagues there would like to reinforce this cooperation, through the patients' lens in 'neighbourhood countries'.

WHO-Europe cannot support us with funding, but with contacts, meeting opportunities, coordination and a mapping exercise with these countries, and further down the line, policy interaction.

## 4. Next Steps

Clearly EPF has many other challenges to address in 2018 and the board firmly recommends a step- wise approach to this cooperation, not overpromising what we are unable to deliver due to capacity issues (both human and financial). Notwithstanding, positioning EPF as a European-wide organisation, rather than a purely EU organisation also presents exciting political and potentially financial opportunities. Equally importantly, it will provide a platform for many more patient groups to reap the benefit of our work, resources and network.

The next steps should include:

- A wider Europe component of our Constitutional Reform (see below), that reflects the fact that national coalitions do not exist in many of the countries concerned;
- A more in-depth analysis with our UK members, following up on collaborative efforts in the context of BREXIT negotiations;
- A more in-depth discussion and formal agreement with WHO Europe on how we move forward in neighbourhood countries, including a mapping exercise, and acquisition of NGO membership status within WHO.
- Reflection on our potential 'offer' to national coalitions already in existence in the countries concerned, which meet EPF criteria
- An appeal to our European member organisations for contacts in the countries concerned to be able to initiate communications and ensure that they are in receipt of EPF materials, social media networks etc.
- Reflections in 2019 with regard to incorporating 'Wider Europe' within our next Strategic Plan, beyond 2020, and future Capacity Building Programmes.

AGM members are invited to vote on the proposed next steps.

## 5. Constitutional Reform

It was also acknowledged, during the last AGM, that EPF should undertake a constitutional reform process, to revisit our statutes, that were last revised in 2010, and look specifically at the following components:

- A voting seat for a youth group representative on the EPF Board;
- Setting up an ethics committee;
- Integrating EPF's enlarged geographic mandate (see above) and appropriate membership categories and definitions;
- Integrating an effective and constructive modus operandi with on-line patient communities, EUPATI fellows etc as an active part of the 'EPF community';

- Clarity on our relationship with Institutions beyond the EU, i.e. WHO Europe, OECD;
- The development of Internal Rules that will support the governance of the organisation (currently, the internal rules are integrated within the Constitution, however, as the organisation has grown, with new members, new partnerships, and an extended geographic mandate, internal rules will be very useful);
- Other matters that the Constitutional Reform Committee deem necessary to ensure that the EPF statutes are fit for purpose as we move into a new decade and a new EU Programme period and build a new strategy for our organisation post-2020.

## 6. Next Steps

- EPF members are invited to vote on the creation of a Constitutional Reform Committee, composed of 5 members. This committee will meet every other month by TC. Its task will be to develop a revised constitution and internal rules for presentation in first draft form to the EPF board at its last meeting in 2018. The board will then comment, and a revised Constitution will be agreed at the first board meeting 2019, to be circulated to our members for adoption at our AGM 2019;
- The Committee will include the EPF President, one other board member, 3 volunteers from the EPF membership. The EPF Secretary General and one other secretariat team member will be in attendance. The Committee will elect its chair-person at the first meeting;
- The Committee will consult as necessary an independent, pro bono lawyer;
- The youth group will be consulted specifically on wording linked to their representation on the board;
- A complete Terms of Reference for the Committee will be drafted and agreed at their first meeting.

Nicola Bedlington

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