

Capacity Building Programme

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Background and introduction

The Capacity Building Programme was launched in 2012 to respond to needs and concerns which have been identified by our membership during previous activities of EPF.

EPF implemented several capacity building activities during its early years: our annual [Regional Advocacy Seminar](#), workshops linked to EPF's main events, production of toolkits and guidelines for members etc.

However, acknowledging a large variation in levels of skills of patient organisation representatives and also the existence of specific needs, the EPF membership called on EPF to structure its capacity building work in the form of a specific programme.

It should be noted that with this Programme EPF did not want to 'reinvent the wheel' and we are committed to using existing relevant materials and resources where available, while ensuring, at the same time, these are adapted to a 'tailor-made' approach for patient organisations in accordance with their needs. The CBP has been rolled out as a pilot programme over the three year period 2012-2014. An in-depth evaluation of this pilot is currently underway.

Post 2014 strategy and activities will be adapted drawing upon the outcomes of the evaluation in close consultation with the organisations involved and the EPF members who have expressed an interest in joining/benefiting from the programme.

While the evaluation process is still ongoing, our plan for the 2015+ period is to consolidate the programme by means of: a) designing and delivering new training modules at national and European level exploring opportunities to engage more organisations; b) rolling out the programme in new countries providing more resources become available.

Objectives

The overall objective of the programme is to strengthen the capacity of both national and European level Patient Organisations to enable them to be more effective in:

- achieving their objectives and aspirations
- feeding their experiences and expertise into the work of EPF and utilising the outcomes of our collective work in a national, and/ or disease specific context.

Focus

The programme focuses on the improvement of both **organisational capacities** and **advocacy skills** of patient organisations at both national and European level.

The programme was developed according to the needs identified by the patient organisations and their patient advocates. Some of the capacity areas that are included in the programme are:

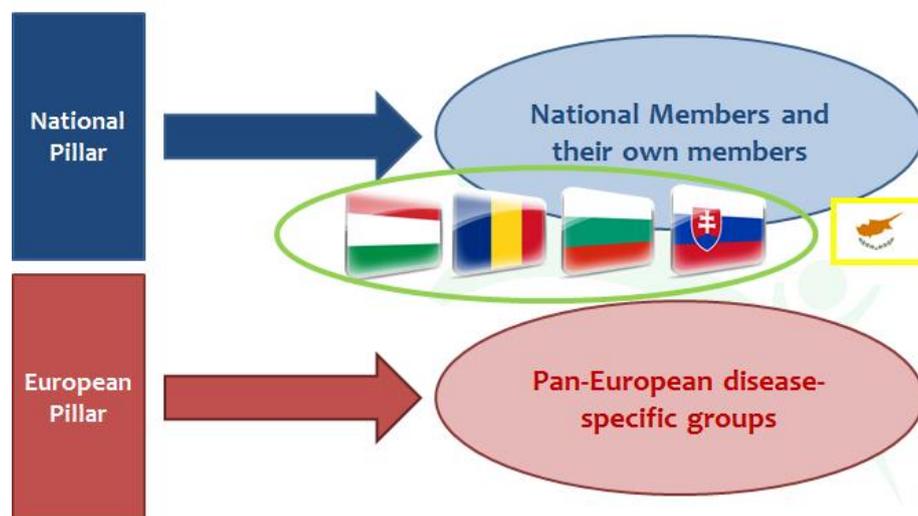
- Strategic Planning
- Operational Planning
- Communication and Media, including social media
- Effective Financial management including principles around transparency and independence

- Fundraising – both public and private
- Good governance and accountability
- Project development and management including partnering in large scale national or EU projects
- Human resources management (both staff and volunteers)
- Networking with other organisations at national and transnational level
- Effective advocacy work, convincing policy makers with strong and well documented evidence, negotiating with decision makers
- Working effectively with national patient coalitions to achieve common goals
- Creating an effective conduit with EPF (harnessing national level information, intelligence and experience to feed into EU policy and utilising the policy outcomes achieved by EPF to the optimum in a national context).

Programme's structure and implementation

The programme consists of two main strands:

1. Capacity Building Programme for National Patient Organisations (national coalitions member of EPF and their own members)
2. Capacity Building Programme for pan-European Disease-Specific patient organisations



Capacity Building Programme for National Patient Organisations

The programme for national patient organisations is currently being rolled out in five countries: Romania, Hungary, Slovakia, Bulgaria, and more recently Cyprus.

At National level, with the exception of Cyprus where the programme has so far been delivered by EPF ourselves, the programme is delivered by local experts who have been selected further to an open tender process.

The national pillar consists of three consequent phases:

Phase I - Strategic Planning and organisational needs assessment: the objective there is to develop a strategic plan and conduct a needs assessment for each patient organisation and teach them how to design and implement a strategic planning process

Phase II - Operational Planning: the objective is for each organisation to develop their first annual plan in line with the strategic plan through face to face training and remote coaching

Phase III - Thematic Training: the objective is to deliver training programmes on selected thematic areas such as fundraising, advocacy, project management, etc. through face to face training and remote coaching.

In Romania, Hungary, Bulgaria, and Slovakia, the Programme involves EPF local member plus a cross-section of their own members who have expressed an interest in this programme and fulfil all eligibility criteria set out for participating therein.

In Cyprus the programme has so far been targeting EPF member “the Pancyprian Federation of Patients and Friends” in response to an ad-hoc request from the new leadership of the organisation to receive support in implementing a strategic planning process with the involvement of the wide membership of the organisation (16 members in total).



Capacity Building Programme for European Patient Organisations

The programme for European organisations focused initially on a comprehensive needs assessment involving a cross-section of our pan-European Organisations to identify main strengths, weaknesses and critical needs. This phase of the programme was delivered directly by the EPF Secretariat in 2012-2013.

Following that exploratory phase a proposal for training priorities was made and with the first thematic training on fundraising was delivered in 2014.

Programme's progress update

National patient organisations

Romania and Hungary are the CBP's' pioneer' countries, where the programme kicked off in mid-2012 with the implementation of a 12-month strategic planning and organisational capacity assessment process for 20 patient organisations, 10 in Romania and 20 in Hungary.

By autumn 2013 each organisation had developed their first ever strategic plan and benefited from a comprehensive needs assessment of their current capacity and prioritisation of training needs. By autumn 2014 all organisations had completed the second phase of the programme on operational planning.

In Slovakia and Bulgaria the programme kicked off in late 2013 further to the evaluation of the first phase of the programme in Romania and Hungary. 7 organisations in Slovakia and 10 in Bulgaria embarked on the first phase of the programme on strategic planning and organisational capacity assessment. The first phase of the programme was completed in both countries in late 2014.

In Cyprus, where, as mentioned above, the programme was launched in autumn 2014 further to an ad-hoc request by the new leadership of EPF member the Pancyprian Federation of Patients and Friends. A strategic planning workshop took place in Nicosia on 17 January 2015. This workshop, which was facilitated by EPF, saw the participation of 25 representatives of the members of Federation and resulted in the development of a first draft of the strategic plan. A working group has been set up to carry on the work on the strategic plan with a view to having a final document endorsed at the Federation AGM in April 2015. The strategic planning process is part of a broader strategy aimed at raising the profile of patients in the country and ensuring the meaningful involvement of patients in health-related decision-making process in Cyprus.

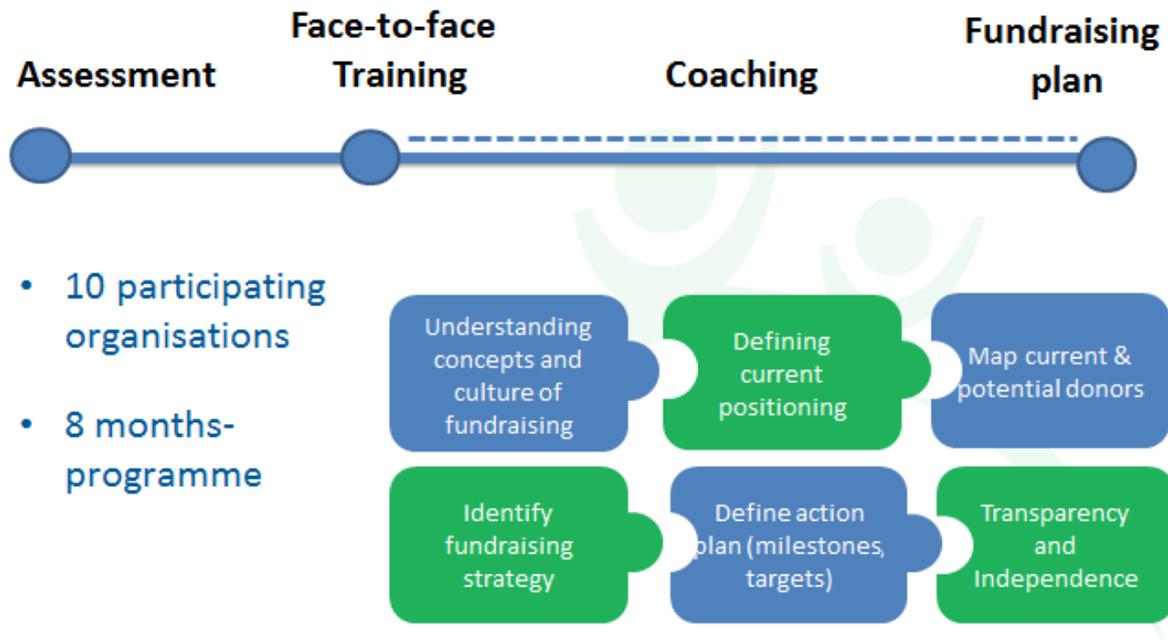
Two organisations have dropped out from the programme in Hungary, one in phase 1 and one in phase 2. Two organisations have dropped out during phase 1 in Slovakia, while four organisations from Bulgaria have decided not to start the programme after having attended the kick-off meeting. In Hungary and Slovakia drop outs are largely due to either challenges in terms of internal capacity to sustain the involvement in the programme or high turnover in the leadership of the organisation resulting in de-commitment/low buy in from new-coming board members/chairperson. In Bulgaria the four organisations that decided to step down after having expressed an interest in the programme belong to EPF member KZZ – there are two national coalitions who are full members of EPF in the country – while all organisations associated to the other national coalition NPO, including NPO themselves, all remained committed to the programme and completed phase 1 in late 2014.

European patient organisations

Six European-level EPF member organisations benefited from a comprehensive organisational capacity and needs assessment in 2013. One organisation, Fertility Europe, also expressed a strong interest in getting support in conducting their first-ever strategic planning process. EPF Secretariat facilitated that process in 2014.

Drawing on the outcomes of the needs assessment the first thematic training module on fundraising was designed in late 2013 and eventually rolled out in 2014 with the participation of 10 pan-European Patient Organisations member of EPF. This module has been delivered by a team of fundraising experts as a blended face-to-face training and remote coaching.

A four-day face to face training took place in late August 2014 in Brussels followed by a three-month coaching programme whereby the experts provided individual coaching to the participants in order to support them with the development of their organisation's initial fundraising activities.



Evaluation of the 2012-2014 Programme

As the end of the “pilot phase” drew near, EPF undertook to conduct a thorough evaluation of the programme.

The evaluation work started in November 2014 and has been conducted with the support of an external evaluator. The objectives of the evaluation are as follows:

- Measure the extent to which the specific objectives established for each phase of the CBP at both national and European level have been achieved, as well as their expected and unexpected effects and impact
- Measure benefits and relevance of the CBP from the perspective of the participating organisations
- Identify successful strategies for extension/expansion/replication/modification of current approach in other countries.

At the time of writing the evaluation of the Programme in Romania has been completed. Evaluation of the Programme in the other countries (except Cyprus) as well as of the fundraising module for European organisations is currently on-going and due to be completed in March 2015.

Strategy for the consolidation of the CBP in 2015+

As mentioned already our strategy for the delivery of the programme in 2015+ activities revolves around the consolidation of the programme by means of:

- a) designing and delivering new training modules at national and European level exploring opportunities to engage more organisations
- b) rolling out the programme in new countries providing more resources become available.

National pillar

While the evaluation process is still ongoing, there is already good evidence from mid-term evaluation in Romania and Hungary (2013) which is quite indicative of the need to continue to invest in strengthening the capacity of patient organisations especially in Central and Eastern Europe.

As far as the countries that joined the programme during the pilot phase are concerned, our plan is to continue to provide support in developing the capacity of the organisations by means of thematic training modules on areas of primary concerns as identified during the needs assessment exercise carried out as part of phase 1 (strategic planning).

The strategy and concrete steps in each country as well as in respect of the European programme will be worked out based on evaluation findings in close consultation with the participating organisations.

In Romania where, the evaluation has been completed in late 2014, a consultation workshop was held in December 2014 with all 10 organisations to gather needs and expectations for the next phase of the programme which is set to kick off already in spring this year with a first thematic training on fundraising and financial management.

Meetings with local organisations will take place in March in Bulgaria, Hungary, and Slovakia to gather qualitative insight to inform the evaluation process and gather needs and expectations on the next phase of the programme.

In Hungary, where a new coalition BEMOSZ was set up in 2014 - also thanks to the CBP, the next phase of the programme will be jointly coordinated by EPF and the coalition themselves, who joins the programme as the ninth organisation. The fact that a large number of people who sit on the board of the coalition have been participating in the programme in 2012-2014 on behalf of their own organisations is a distinctive advantage that will ensure optimal cross-fertilisation of learning within and across the coalition.

As far as Cyprus is concerned, priority is to complete the needs assessment process with the Federation by April 2015. It has already been agreed that EPF will continue to support the Federation in developing their 2016 operational plan in close consultation with the full membership.

Regarding involvement of new countries, there is an ongoing dialogue with our Polish member the Federation of Polish Patients who had expressed an interest in joining the programme already in 2013. The ongoing evaluation of the 2012-2014 programme offers a new window of opportunity to roll out the programme in Poland. As the FPP general assembly recently appointed a new leadership a meeting with FPP is scheduled in March this year to assess the feasibility of launching the programme in the country already in 2015. Should that be the case additional resources will have to be identified. It is likely that the same approach followed in Cyprus will apply to Poland as well as to any new country joining the programme in the future. This approach, which is largely backed up by emerging evidence from the evaluation, calls for consolidating capacity within the national coalition in the first place with a view to then putting in place effective mechanisms to ensure knowledge and learning is optimally passed on to the all members.

European pillar

Regarding the European pillar, our plan is to offer our European member shorter training modules on a more frequent basis (twice a year). This is based on emerging evidence from evaluation and feedback received from the various organisations involved as well as challenges faced in delivering

the first training module on fundraising, where the coaching phase proved quite demanding for patient leaders, given their on-going heavy workloads.

Further to consultation with our European members the focus in 2015 will be on strengthening the capacity of 10 EPF European Full Members in Communication and Advocacy.

Annex I - ORGANISATIONS PARTICIPATING IN EPF CAPACITY BUILDING PROGRAMME

National level

Hungary

- BEMOSZ National Patient Coalition
- National Association of People with Multiple Sclerosis
- Hungarian League of Patients with Rheumatic Diseases
- Hungarian Osteoporosis Patient Association
- Hungarian Coeliac Society
- Hungarian Federation of People with Rare and Congenital Diseases
- Hungarian Organization for Patients with Immunodeficiency's
- Delta Hungarian Parkinson Association
- National Stroke League

Romania

- The Coalition of Patients' Organisations with Chronic Diseases from Romania
- Romanian Association of Rare Diseases
- Romanian Association for Rare Cancers
- Romanian Association for Major Thalassaemia
- Anti-Parkinson association
- Romanian Multiple Sclerosis Society
- UNOPA - National Union of people living with HIV
- Romanian association of transplant patients
- Association of Multidrug resistant Tuberculosis patients
- Romanian Haemophilia association

Slovakia

- Association for the Protection of Patients' Rights – including amongst its members:
- Slovilco Slovak Ostomy Association (Colostomy, ileostomy, urostomy)
- OPEN THE DOORS, OPEN THE HEARTS (mental health)
- Slovak Crohn Club
- Multiple Sclerosis Association of Hope

Bulgaria

- National Patients' Organisations of Bulgaria (NPO)
- National Alliance of People with Rare Diseases – NAPRD
- Bulgarian National Patients' Organization – Youth Group
- Association of the Patients with Facial Anomalies and their parents (ALA)
- Bulgarian Haemophilia Association
- NET +: I Foundation (I), Varna; Hope Against AIDS Foundation (HAAIDS), Sofia and Positive Choice Foundation (PC), Plovdiv

Cyprus

- Pancyprian Federation of Patients and Friends with the involvement of all 16 members

European organisations

Organisations involved in the Needs Assessment Phase

- Fertility Europe
- International Diabetes Federation - Europe
- European Liver Patients' Association
- European Heart and Lung Transplanted Patients Federation
- European Cleft Association

Organisations involved in the Fundraising Module

- Association of European Coeliac Societies – AO ECS
- European Federation of Allergy and Airways Diseases Patients' Association – EFA
- European Federation of Crohn's and Ulcerative Colitis Associations – EFCCA
- European Liver Patients' Association – ELPA
- European Multiple Sclerosis Platform – EMSP
- European Network of (Ex)-Users of Psychiatry – ENUSP

- European Parkinson 's Disease Association – EPDA
- European Federation of Families and People with Mental Illness – EUFAMI
- Global Alliance of Mental Illness Advocacy Network – GAMIAN Europe
- European Pulmonary Hypertension Association - PHA EUROPE