

Evaluation of the EPF Capacity Building Programme 2012-2014

Summary of findings

June 2015



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1 Background

The European Patients' Forum (EPF)'s Capacity Building Programme (CBP) was launched in 2012 to support the development of organisational capacities and advocacy skills of national and European patient organisations. It responds to needs and concerns, which have been identified by the EPF membership during previous activities of EPF, especially the Regional Advocacy Seminars EPF has been organising since 2008. The CBP was first launched in Romania and Hungary in late 2012. One year later Bulgaria and Slovakia joined the programme, while Cyprus got on board in late 2014. Thematic training modules are organised for EPF European-level members.

At national level the CBP is implemented stepwise by means of sequential training modules (phases). The first phase of the programme was aimed to support the participating organisations in implementing a strategic planning process and develop a Strategic Plan (Phase I). In parallel to strategic planning a comprehensive needs assessment exercise and SWOT analysis was undertaken for each organisation with a view to identifying further training priorities.

The second phase was dedicated to the development of an Operational Plan (Phase II) that was related and contributed to achieving the long-term goals set out in the Strategic Plan developed in the previous phase, as well as to strengthening patients' organisations ability to develop strategic and annual plans in the forthcoming years. A key feature of these two planning modules was the involvement of organisations' own members and volunteers.

Further to successful implementation of these two planning modules, the participating organisations benefit from thematic training modules designed in order to strengthen key organisational capacity areas, e.g. fundraising, governance, advocacy, communication etc.

In late 2014 Hungary and Romania completed Phase I & II and have just started the first thematic module on fundraising. Bulgaria and Slovakia completed Phase I in autumn 2014 while activities in Cyprus, where EPF is supporting their local member, the Pancyprian Federation of Families and Friends, are on-going. The first thematic training on fundraising for European members was delivered in 2014. The length of each module was between 8 to 10 months and consisted in a blend of face-to-face training and remote coaching.

At national level, except Cyprus where EPF is directly involved in delivering the activities, the programme is delivered by local experts in the areas concerned selected by means of an open call for tenders. This approach proved quite beneficial since it allowed EPF to identify a pool of trainers who possess the right mix of experience and skillset to be able to offer a training programme that is geared towards the specific needs of local patients groups.

The first thematic module for pan-European organisations was delivered by a team of fundraising experts selected by means of an open call for tenders.

2 Evaluation of the EPF CBP: objectives and methods used

An evaluation of the programme activities was carried out between November 2014 and April 2015, except in Cyprus where implementation of Phase I is on-going. An evaluation of the thematic training module on fundraising – European members was also carried out during this period of time. The evaluation focused on the activities that have been implemented and completed in the participating countries as follows:

- Bulgaria and Slovakia, Phase I completed in autumn-2014
- Romania and Hungary, Phase I & II completed in mid-2014
- Thematic training on fundraising – European members, training completed in early-2015

A consultant developed and implemented the evaluation framework, which included conducting focus groups with the participating organisations and skype calls with the local experts (trainers), as well as written evaluation questionnaires.

The objective of the evaluation was to measure the extent to which the programme objectives were attained and the benefits of the activities to the participating organisations, as well as to identify areas for improvement and lessons-learnt. Evaluation reports summarising the findings per country were produced.

The current report brings together the main findings of the individual country evaluations, providing specific examples for each country, and highlighting areas for improvement.

3 Findings of the evaluation in participating countries

Feedback received from participating organisations and trainers from the different participating countries, as well as the thematic training on fundraising – European members, was mostly positive. Overall participating organisations recognise the benefits of the strategic, operational, and fundraising/advocacy planning processes to their organisations and how this has impacted on the way they work. Representatives noted that the strategic and operational plan development process has not only impacted on the way they approach their work, for example how to prioritise activities, but also contributed to increasing their credibility vis-à-vis external stakeholders, including donors.

The collaboration between participating organisations and trainers (please see annex 1) was generally felt to have worked well, during both the face-to-face training and the coaching phase, and to have provided participating organisations with an opportunity to re-think their activities, assess the needs of the organisation, set priorities and further the organisation's work. Nevertheless, in some countries, participating organisations noted that more time is needed to assess the long-term impact of the CBP activities into the work of the organisations, as well as the mainstreaming of processes across their work.

3.1 OUTCOMES AND IMPACT OF THE CBP ACTIVITIES IN PARTICIPATING COUNTRIES

3.1.1 CBP APPROACH AND OUTCOMES

The EPF CBP has developed a comprehensive approach to the training of patient organisations. On the one hand, organisations are provided with opportunities to meet face-to-face with their peers and local experts, to share experiences and build their capacity. On the other hand, the coaching phase provides tailored support and training to the organisations, to specifically address their needs. The programme also tried to ensure the inclusiveness of the process by involving, when possible, the organisations' members. However, budgetary constraints have, at times, impacted on the number of representatives that could be involved in the meetings organised under the programme, as well as the number of face-to-face trainings conducted.

40 organisations, (33 national and 7 pan-European patient groups) have received training so far and have successfully completed the CBP activities to date. A small number of organisations decided to withdraw from the programme at different stages for various reasons (see box 1 and annex 1).

A kick-off meeting was organised at the beginning of each phase in each participating country, to initiate the process of developing a strategic and operational plan respectively, for each of the participating organisations. The objective of these initial meetings in Bulgaria, Hungary, Romania and Slovakia was to provide at least one person from each organisation with information on the strategic and operational planning process and the elements needed in order to develop the plans.

'Before we were very disorganised and we would talk about our activities for hours. Now I remind my co-workers about how we worked with FDSC and when we discuss work we do it with our feet on the ground, we are more realistic. The operational plan moved us towards self-assessment'.

Feedback from a representative of one of the patient organisations involved in the CBP in Romania.

The thematic training on fundraising – European members followed a slightly different approach. The process was initiated with an assessment of the fundraising capacity of the organisations, followed by a three-day training and coaching support to develop the fundraising plans. The training aimed not only to provide information on the elements needed in order to develop the fundraising strategy but also to build the capacity of the organisations on fundraising.

The process followed by the organisations to agree on the plans varied according to their structure and consultation procedures. Further support, e.g. coaching and consultancy provision, was provided by local experts to the participating organisations during the process of developing a strategic, operational and fundraising plan.

All strategic, operational and fundraising plans were developed as expected, with few exceptions (please see annex 1 and box 1). The participating organisations that completed Phase I (Bulgaria, Hungary, Romania and Slovakia) & II (Hungary, and Romania) feel that the tools they have received and the process they have been through, provided them with the necessary skills and tools to

develop future strategic and operational plans for their organisations. Nevertheless, representatives would welcome the feedback from an external expert once the plans have been independently developed, to assess whether the plan developed needs further work and meets minimum quality standards. Most of the representatives that participated in the thematic training module on fundraising also felt that the training module had provided them with interesting and useful information to impact and shape their work on fundraising (please see box 1).

3.1.2 IMPACT OF THE CBP ACTIVITIES ON PARTICIPATING ORGANISATIONS

Representatives felt that the strategic and operational plans developed under the CBP helped the organisations to become more professional and increase their credibility vis-à-vis external partners, such as donors, as it shows that the organisations know what they aim to achieve and how. In Romania one representative noted that, following the operational planning process, they felt more ‘courageous’ and applied to more funding opportunities. She went on to say that the plans developed under the CBP had facilitated access to a private project, which was financed. In Hungary, it was noted that the plans are an important tool for applying for funding and approaching new donors. One representative went on to say that the strategic plan developed under the CBP played an important role in a tender application submitted and won by the organization. In Bulgaria, a representative noted that the strategic plan has mainly benefited the work of the organisation with external partners. He went on to say that some of the organisation’s long-term sponsors were happy to see the strategic plan and this gives the organisation an opportunity to safeguard the relationship

Box 1: Outcomes and impacts of the training module on fundraising – European members

Feedback received shows that overall the thematic training module (face-to-face training and coaching) contributed to further the work of the participating organisations. The training provided organisations with an opportunity to re-think their approach to fundraising and donors, to identify new opportunities and, in some cases, to promote a more systematic approach to fundraising.

Representatives noted that the training increased their understanding of the value of developing a fundraising strategy and that the work initiated during the training module provides the basis to build on and further develop the work of the organisations on fundraising. Due to time constraints, some organisations were not able to complete or completed only partially their fundraising plans. However, some of the participating organisations reported that developing a fundraising strategy was not the most important element and/or outcome of the training module to their work.

Some of the participating organisations have continued to use the work developed during the training module activities, as well as the knowledge acquired, to further their fundraising work. For example, the ‘case for support’ developed during the training was considered a useful exercise, which organisations have used as a basis for funding applications, to approach donors and to prepare communication materials and update websites. Other organisations are exploring different approaches to fundraising and one organisation set up a fundraising committee to further the work of the organisation.

with its donors.

In addition, participating organisations noted that the process they went through provided them with skills and tools to further their work. Some organisations reported becoming more organised and realistic about their work. It was also noted that the needs assessment provided the organisations with an external perspective, identifying prospects and opportunities that are sometimes missed by the organisations engrossed in their day-to-day work. In Romania, one representative noted that the strategic and operational planning process contributed to better structure ideas, which helped the organisation better communicate its work to others, such as donors. The process also provided organisations with a methodology to implement activities. In Bulgaria, one representative reported that the strategic planning processes helped not only to identify objectives for the organisation but also to reorganise the team in order to make the work of the organisation more effective. In Slovakia the trainers felt that some of the participating organisations started to think more about how to better implement their work e.g. where to get additional resources, how to better market themselves etc, following the CBP activities.

'... members [of the organisation] now want to work together and they have common objectives and that is partially because of the programme.'

Feedback from the representative of a patient organisation involved in the CBP in Hungary.

Representatives also reported that CBP activities contributed, in most cases, to increase collaboration and involve more members into the work of the organisations. In Romania, organisations were able to identify new leaders and involve more volunteers into the work of the organisation as part of the strategic and operational planning process. In Slovakia, the trainers noted that the activities helped to generate the right frame of mind within some of the participating organisations, as it provided the leadership and members with an opportunity to meet, discuss and work together. In Bulgaria, one representative reported that the organisation's work was advanced as the members had an opportunity to get together to jointly write the strategic plan. In Hungary, the programme also provided leaders with an opportunity to meet and network, and to develop a common language on how to set up an organisation. This was felt to benefit the recently established National Patient Coalition.

In spite of that, representatives noted that they would have welcome additional opportunities to involve more of their members and volunteers, not only the leadership, into the CBP activities. Shorter training periods and more face-to-face meetings would make this possible and/or easier, particularly in Hungary. Participating organisations would also have welcomed more opportunities to meet with their peers, to facilitate collaboration, exchange experiences and to create synergies between the organisations.

The funding available for the programme implementation poses some limitations to the expansion of activities. However, Phase III of the programme (thematic training) accommodates the feedback received during the evaluation and more face-to-face training (two face-to-face trainings instead of one are planned) and increased participation of representatives of the participating organisations in the programme activities are foreseen.

3.1.3 IMPACTS OF THE EPF CBP BEYOND PARTICIPATING ORGANISATIONS

The impact of the CBP activities was not limited to the participating organisations. In Hungary, it was reported that one participating organisation invited a partner association to take part in the strategic planning process, as there are some synergies between the work of the two organisations. The partner association was so motivated by the process that it adopted the CBP templates and planning process and later asked the trainers to provide feedback on the plans developed. In Romania, one representative from a participating organisation reported that a younger organisation requested their support to develop its strategic and operational plans. The support was provided and the representative from the CBP participating organisation clarified the different aspect of the strategic and operational planning process herself. One other representative noted that they have also tried to involve public health authorities into the strategic and operational planning process of their organisation.

'...Before [our work] was a little disorganised and the decisions were made on a task-by-task basis. The plan gives the organisation a good focus and [shows] which goal to pursue. It will makes us work better ...'

Feedback from a representative of a patient organisation involved in the CBP in Bulgaria.

In addition, the trainers in Hungary and Romania reported that the CBP activities also benefited their organisations. The Fundatia pentru Dezvoltarea Societatii Civile (FDSC) – the organisation in charge of delivering the programme and an important funder in Romania - noted that the coaching and training pushed staff to learn more about the organisations and their activities, as well as to follow-up and look for ideas to continue to provide support to the patient organisations in Romania. In Hungary, increased understanding of Hungarian patient organisations needs has led the trainers to identify opportunities for future work and to continue to work with the recently established National Patient Coalition.

During the evaluation of Phase I, organisations in Romania also noted that policy makers and other health stakeholders really appreciate the effort Romanian patient organisations are making to become more professional through the EPF CBP and are gaining more recognition as equal partners in healthcare. A number of representatives from various participating countries also noted that they take the plans with them when attending meetings with other organisations and that the plans have been well received by partner organisations.

3.2 CHALLENGES FACED BY BOTH PARTICIPATING ORGANISATIONS AND TRAINERS DURING THE IMPLEMENTATION OF THE CBP ACTIVITIES

Both participating organisations and trainers encountered some challenges during the implementation of the CBP activities (phase I & II and thematic training on fundraising). The challenges did not prevent the implementation of the activities, except in Slovakia where difficulties to gather the necessary information from the organisations and to secure the required availability from the representatives to implement the programme activities were faced. The length of the programme, the complexity of the issues and limited resources and availability i.e. skills and capacity

of the organisations to contribute sufficient time to the programme activities , as well as the specificities of working with patient organisations, were some of the contributing factors to the challenges faced. Despite the difficulties, in most countries representatives felt that the strategic and operational planning, as well as the training module on fundraising, process was useful and provided organisations with a more realistic and structured approach to their work.

3.2.1 CHALLENGES FACED BY THE ORGANISATIONS

The CBP activities in Bulgaria, Hungary and Romania were implemented without any major hurdles. However, participating organisations were confronted with challenges mainly linked to the length and complexity of the process, as well as the tools provided, particularly the needs assessment tool. In some cases, the relationship with trainers posed some initial difficulties. However, these were eventually overcome, except in Slovakia where participating organisations reported challenges related to the process and coordination of work with the trainers.

In Bulgaria, the participating organisations reported some difficulties linked to the applicability of some of the tools provided, as well as examples used during the training, to the local context and the situation of patient organisations in Bulgaria. In Hungary, the nature and complexity of the work also contributed to the difficulties faced by the organisations to complete the activities. The strategic and operational planning process is complex and sometimes the organisations did not have the capacity and/or resources, to use the tools provided and complete the work. The length of the process also made it difficult to keep representatives motivated. In Romania, organisations found it particularly difficult to develop a plan that was realistic given their organisational capacity and the unpredictability of the external environment.

In relation to the training module on fundraising – European members, the main challenge faced by the participating organisations was related to time availability to complete the training module work. Some lack of clarity about the timeline of the process and amount of work required to complete the training module activities was felt to have contributed to the challenges faced. In addition, some representatives also found somehow difficult to translate the knowledge acquired in theoretical sessions into practice, and to understand how these could be applied or fitted into the work and fundraising needs of the organisation.

3.2.2 CHALLENGES FACED BY THE TRAINERS

The trainers also faced some challenges in implementing the CBP activities (phase I & II and thematic training). These were mostly related to the local context and the specificities of patient organisations i.e. these often being volunteer-based organisations. The identified difficulties did not pose a major hurdle in implementing the activities, except in Slovakia; but it did require trainers to follow-up more on the work that needed to be done and to mediate between EPF and participating organisations.

The limited availability of the participating organisations to complete the CBP related work was a challenge faced by the trainers in all participating countries. Most of the patient organisations participating in the programme are small with limited resources available. This made it difficult to implement and complete the activities after the face-to-face training. In some cases, the length and

complexity of the work being done also made it difficult to keep organisations engaged in the activities and motivated. In some countries the trainers also found challenging to mobilise the participating organisation's membership, and to ensure its involvement in the programme activities, given the nature of the organisations and local context.

The trainers in Slovakia faced a number of challenges in developing and implementing activities with some of the participating organisations. It was felt that these difficulties were related to internal discussions/difficulties within the organisations i.e. disagreements, lack of members involvement, lack of availability to answer to the trainers' requests etc., as well as the external environment e.g. some of the organisations not wanting to attract attention to themselves due to public perceptions. Another challenge was to ensure the adoption of the outcomes resulting from discussions and the collective work of members, after the meetings had taken place and reports had been written, by some of the organisation's leaders.

Other challenges faced by the trainers in all countries included:

- The applicability of the tools and curriculum to the local context: The trainers found it challenging to adapt the curriculum and tools provided to the local context. It was felt that the programme should be more flexible and contextual e.g. the tools should be more adapted to the local situation, as well as the needs of participating organisations.
- The level of development of the organisations: this also contributed to the challenges faced. Participating organisations are at different levels of development and require different levels of training and coaching. Trainers had, in some cases, to adapt the outputs to the capacity of the organisations.
- Limited understanding of the programme: In most countries the trainers felt that not all organisations were fully aware of the opportunities presented by the programme and what the latter really entails, e.g. the work that needed to be done, posing additional challenges to the implementation of activities.

Finally, some trainers noted that it would have been helpful to have received some additional guidance on the processes to follow, expected standard of outputs, forms and templates, as well as examples of good practices at an earlier stage.

4 Lessons learnt and areas for improvement

The EPF CBP was launched in 2012 in two countries, Romania and Hungary, and it has since then been expanded to include activities in Bulgaria, Cyprus and Slovakia. A thematic training module on fundraising has also been implemented for EPF European full members, which are pan-European disease-specific groups. As a result, the experiences from both the trainers and participating organisations that have so far participated in the CBP activities provide an initial insight into what went well and/or less well in the delivery of the training, as well as during the process to develop strategic, operational and fundraising plans for the participating organisations. Their experience also

provides and opportunity to identify some potential areas for improvement, to increase the impact of the CBP activities and to ensure that the CBP activities meet the needs of its beneficiaries.

Taking into consideration the feedback received the following areas could be addressed in order to strengthen the impact of the CBP activities:

- *Clarify the different roles of the parties involved in delivering the programme and expectations at an early stage:* The different roles of the organisations i.e. EPF, contractors, and participating organisation, as well as their different expectations and requirements regarding outputs and reporting templates should be clarified at an early stage, to build a common understanding of the work being done and expected outcomes. The involvement of the trainers in the early planning stage of the activities, could also contribute to building a common understanding of the context, expectations and management of the project between EPF and the trainers. Reporting templates and working tools should also be provided well in advance to allow both participating organisations and trainers to become familiar with the information.
- *Adapting the training curriculum to the local context and simplification of tools:* The different nature and levels of skills of each organisation, as well as the different cultural and political situation of each participating country, should be taken into consideration when developing and delivering the training curriculum, to ensure that the latter meets the needs of the programme beneficiaries. The tools developed to conduct work e.g. needs assessment, strategic plans templates etc, should be easy to use and be adapted to the organization's capacity to improve both quantitative and qualitative input. Organisations should find it easy to use the tools and templates provided. Trainers should also be provided with the necessary flexibility to adapt the tools and the training to match the level of development of the organisations.
- *Flexibility with the approaches used and expected outcomes:* The different nature and level of skills of the participating organisations should also been taken into consideration when providing feedback to the work done and discussing expected outcomes. Some participating organisations are more developed and more resourceful, e.g. staff, level of skills, than others. Thus, outcomes might vary significantly from one organisation to another and there should be some flexibility to accept these variations across organisations and countries. In addition, a standard pre-defined output might not be the most beneficial outcome of the training to the work of the organisations.
- *Length of the programme activities:* The duration of the training has an impact on the motivation and engagement of representatives in the long-term development of the organisations. Changes within the organisations, sometimes resulting in changes of attitudes towards the programme, are also more likely to happen during long coaching periods. Shorter training periods could also help involving more members into the programme activities. The length of the programme and its objectives should take into consideration the local capacity. A programme that is too complex and long might face implementation

challenges. Shorter training periods (up to 6 months) might benefit organisations and strengthen the implementation of the programme activities.

- *Facilitating joint meetings between participating organisations and increasing practical sessions and face-to-face training:* Providing an opportunity for the organisations to meet during the strategic and operational planning process would allow them to share experiences, discuss difficulties and challenges faced, as well as potential solutions. More regular face-to-face support and practical sessions could also contribute to strengthening learning of key concepts, provide participants with more time to complete activities and improve outcomes of the process. Coaching and face-to-face support is a long-term process, which is more effective when regular opportunities to meet exist.
- *Building a greater understanding of the programme and increasing EPF presence during the activities:* In general, there is a feeling among trainers that the participating organisations do not always seem to be fully aware of what the CBP entails and what they are committing to when joining the programme. Building a greater understanding of the opportunities provided by the programme and what this involves might strengthen the impact of the programme activities. EPF provides feedback and maintains contact with the trainers during the programme implementation. Increasing EPF presence and contact with both the trainers and organisations might contribute to build a greater understanding of the programme and strengthen commitment to the implementation of activities.

5 Conclusions

EPF has designed and implemented an ambitious programme to develop the capacity of patient organisations, which often have limited capacity in selected countries. Capacity building and organisational development/change is a long-term process that requires a tailored approach to the individual needs of each organisation. A key strength of the programme is to provide this much needed tailored approach to each of the participating organisations, through the coaching phase.

The evaluation findings show that most participating organisations have achieved some important milestones in the development of their organisational capacity, both in terms of the plans developed and acquired organisational skills. These are likely to benefit not only representatives and participating organisations but also partner organisations and coalition members in the long-term.

However, expected outputs from future activities, as well as the tools provided to the organisations during the training, should take into consideration the capacity and resources of the participating organisations. In the future, EPF should try to strike a balance between achieving meaningful results and what is possible for the organisations to achieve given their capacity. This would not only contribute to increase quantitative and qualitative input during the training but also strengthen the implementation of the activities, at the same time that it might provide organisations with a higher sense of achievement and fulfilment.

The third phase of the programme, focusing on thematic training modules on fundraising and communication, is currently being implemented across the participating countries, except in Cyprus where the implementation of Phase I is on-going. In Bulgaria and Slovakia, following the evaluation and discussions with participating organisations, it was decided to move from Phase I (strategic planning) directly to thematic training as this was felt to be more beneficial to the organisations' work.

EPF has developed an implementation approach for Phase III that already takes into consideration the issues raised during the evaluation of the programme, despite the limitation posed by the funding available to expand activities. Opportunities for the organisations to meet face-to-face with their peers and the local experts will be increased from one face-to-face training to two training, and shorter practical, hands-on training are planned. EPF tailored approach to the needs of each organisations will also be strengthened in Phase III. The thematic trainings provide the organisations with the opportunity to identify and develop a project that is meaningful to the work of the organisation, with the support of local experts.

Some areas for improvement with regards communication with participating organisations remain. The feedback received shows that more could be done to build a greater understanding of the opportunities provided by the programme and what the latter entails; as a greater understanding of the programme and contact with participating organisations has the potential to increase input from the participating organisations into the CBP activities and strengthen the implementation of the programme.

Annex 1: List of participating organisations and expert teams per country

BULGARIA

In Bulgaria, *Skills Consult Bulgaria* provided training, coaching and support to the CBP participating organisations. The following organisations participated and completed the activities of the programme:

- National Patients' Organisations of Bulgaria (NPO)
- 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
- Transplant Union Bulgaria
- Alzheimer Bulgaria

Four organisations that had initially expressed an interest in participating in the programme decided to withdraw their participation after the kick-off meeting, but two more were recruited thereafter. Different expectations and perceptions of the relevance of the programme to the work of the organisations, as well as other issues inherent to the local context and the patient community in Bulgaria, were identified by both the trainers and participating organisations as some of the contributing factors for the organisations to withdraw from the EPF CBP.

HUNGARY

In Hungary, *Civil Support* provided the training and coaching support to participating organisations. The following organisations participated and completed the activities of the programme:

- National Association of People with Multiple Sclerosis
- Hungarian League of Patients with Rheumatic Diseases
- Hungarian Osteoporosis Patient Association (HOPA)
- Hungarian Coeliac Society
- Hungarian Federation of People with Rare and Congenital Diseases (HUFERDIS)
- Hungarian Organization for Patients with Immunodeficiency's (HOPI)

- Delta Hungarian Parkinson Association
- National Stroke League

One organisation left the programme half way through Phase II, following a change in the leadership of the organization.

ROMANIA

In Romania, the CBP activities were delivered by the *Fundatia pentru Dezvoltarea Societatii Civile* (FDSC). The following organisations participated and completed the programme activities:

- Coalitia Organizatiilor Pacientilor cu Afectiuni Cronice din Romania
- Uniunea Nationala a Organizatiilor Persoanelor Afectate de HIV/SIDA
- Asociatia Transplantatilor din Romania
- Alianta Nationala pentru Boli Rare Romania
- AP Talasemie Majora
- Asociatia Antiparkinson
- Asociatia pentru Spijinirea Pacientilor cu TB MDR
- Asociatia Romana de Hemofilie
- Asociația Română de Cancere Rare
- Asociatia de Scleroza Multipla din Romania

SLOVAKIA

In Slovakia, the *Open Society Institute* provided participating organisations with training and coaching. The following organisations participated and completed the CBP activities:

- Association for the Protection of Patients' Rights
- Slovilco Slovak Ostomy Association
- Association to help diabetics
- Open the doors, open the hearts
- Society Parkinson Slovakia
- Slovak Crohn Club
- Multiple Sclerosis Association of Hope

Two organisations did not complete all programme activities.

TRAINING MODULE ON FUNDRAISING – EUROPEAN MEMBERS

The training module on fundraising was delivered by *ENGAGEDin & partners*. The later also provided coaching and support to the participating organisations during the development of the fundraising plans. The following organisations participated in the training module:

- Association of European Coeliac Societies
- EFA - European Federation of Allergy and Airways Diseases Patients' Associations
- European Federation of Crohn's and Ulcerative Colitis Associations
- European Liver Patients' Association
- European Multiple Sclerosis Platform
- European Network of (Ex)-Users of Psychiatry
- European Parkinson's Disease Association
- European Federation of Families and People with Mental Illness
- GAMIAN Europe - Global Alliance of Mental Illness Advocacy Network
- PHA Europe
- IDF Europe

Four organisations participated partially in the coaching phase of the training module and developed some elements of a fundraising strategy. Two organisations did not complete the coaching phase and the activities of the training module.