

Resourcing Patient Organisations for a Strong Patient Movement

Report

5th EPF Regional Advocacy Seminar

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1. INTRODUCTION

1.1 BACKGROUND

Organising Annual EPF Regional Advocacy Seminars is the approach EPF is pursuing to engage and work with national patient organisations and their national coalitions with a view to:

- a) Integrating national perspectives into the European debate to have a stronger patient voice;
- b) Feeding policy information and policy outcomes back into national reality and contexts;
- c) Developing and sustaining the advocacy capacity of patient leaders particularly in new Member States.

The value of this has been strongly confirmed by the success of the advocacy and capacity-building seminars for patient leaders held over the previous four years in Lithuania (2008), Bulgaria (2009), Hungary (2010) and Bucharest (2011).

While the core objective of strengthening patient leaders' advocacy capacity is the key feature of EPF's advocacy seminars, these events also represent an opportunity to address specific issues which we identify in close consultation with our members.

This year's EPF Regional Advocacy Seminar's overarching theme was "Resourcing Patient Organisations for a Strong Patient Movement".

The participants of this Seminar were representatives of national patients' organisations from four Mediterranean countries, namely **Greece, Italy, Portugal and Spain**.

1.2 OBJECTIVE OF THE SEMINAR

The overall objective of the EPF 5th Regional Advocacy Seminar was to explore opportunities with regard to national and EU funding by:

- Identifying the current and future challenges relating to access to national and EU funding for patient organisations
- Raising knowledge and awareness among national patient leaders on how to succeed in fundraising
- Training patient leaders in developing fundraising strategies and skills with emphasis on diversification
- Supporting patient organisations in ensuring sustainability of funding.

The Seminar was an opportunity for the participants and their organisations to establish dialogue and build up partnerships with EPF as well as learn and share experiences about financing of patient organisations in Greece, Italy, Portugal and Spain.

The main outcomes of the Seminar are:

- Increased knowledge of participants of the funding opportunities and environment in the four participating countries
- Enhanced skills of patient leaders to define a fundraising strategy and to be successful fundraisers
- Improved relationship between EPF and national umbrella patient platforms in the region and potential further cooperation

Furthermore, the conclusions and recommendations of the seminar will feed into EPF Annual Work Plan for 2013 and coming years, as well as EPF 2014-2020 Strategic Plan.

1.3 SEMINAR PROGRAMME

During the first day of the Seminar, participants were given a general overview of various sources of funding which can be of use for all patient organisations regardless of the country they are based in. After the introductory session, the day started with a panel session during which participants shared their experiences with fundraising. This was followed up by a presentation of various EU funding opportunities and challenges. Subsequently, two parallel working group sessions took place around three topics: industry and foundation funding, governmental funding and structural funds, and other funding sources such as membership, events, and donations.

The second day of the Seminar had a country-specific focus with regard to funding patient organisations. For the morning session, participants were divided into four groups based on their countries of origin. During the national working group sessions moderated by fundraising experts, the participants analysed various sources of funding in their countries. After this session, two more parallel sessions were organised involving all participants on how to develop an organisation fundraising strategy step by step and how to become a successful fundraiser.

1.4 PURPOSE OF THE DOCUMENT

This document is both the report of the event and a tool for patient organisations interested in improving their fundraising capacities. It summarises the information and knowledge shared during the Seminar, rather than only reporting on the sessions that took place. This document was prepared



with extensive input from the fundraising experts from Greece, Italy, Portugal and Spain who trained the participants of the seminar in terms of developing a fundraising strategy and becoming successful fundraisers.

2. FUNDRAISING FOR PATIENT ORGANISATIONS

2.1 GENERAL OVERVIEW OF FUNDING SOURCES FOR PATIENT ORGANISATIONS

A general overview of funding sources for patient organisations started with a panel session during which **Filipa Palha** (Portugal), **Alfonso Serrano Movilla** (Spain), **Aghela Glytsi** (Greece) and **Erveda Sansi** (Italy) shared their perspective on the situation in their respective countries. The panellists shared good practices in terms of getting national and EU funding for patient organisations, as well as key challenges and some lessons learned. Following the presentations of the panellists, a lively discussion took place during which many participants shared their organisation's experiences.

A prime subject of discussion was the difficulty in keeping a patient organisation running in times of economic crisis during which austerity measures substantially hit healthcare budgets and funding for patient organisations. Besides substantial reduction in governmental funding, there are extensive delays in the actual allocation of these resources as well. Some larger-scale organisations get national funding because of implementing various projects. However there are many challenges such as lack of adequate monitoring of what is achieved with the funding provided, sustainability being at risk, discontinuity of support, great variability of the importance given to patient organisations' activities depending on health problems and disease areas at stake, scarce funding, etc.

The panellists stated that most of their funds come from private funding sources rather than public in Italy, Greece and Portugal, with the exception of Spain. Most patient organisations in these countries receive donations from supermarket chains, banks, and pharmaceutical companies in the framework of their commitment to 'corporate social responsibility'.

Patient organisations also use other possibilities for fundraising such as collecting membership fees or smaller-scale private donations through organising events (charity concerts, marathons, charity bazaars, lotteries, etc.), participating to various events such as birthday parties and baby showers, legacy fundraising, and fundraising online using social media or their websites. On the other hand, panellists mentioned that, especially in Southern European countries there is no tradition of collaborating with NGOs, which makes fundraising harder for patient organisations in these countries.

With regard to EU funding, many organisations are not aware of the opportunities available, and the ones that are aware consider EU funding quite challenging. They especially see the application

submission procedure as very complicated for organisations with limited capacity. This necessitates turning to specialised agencies in order to access these funds, which brings up the problem of resources to do pay for such expertise. Another major challenge is the need for networking to access EU funding, which can be hard in some areas and/or some patient organisations depending on their capacity.

Filipa Palha, the panellist from Portugal, suggested that fundraising activities need to be periodic, such as yearly, so that everyone knows the cause and people become familiar with the routine. She argued that fundraisers should have a great commitment, inspiring ideas, have developed powerful relationships with donors, and should acknowledge the supporters and present results of the fundraising. She also attracted attention to the necessity of marketing skills as well as the opportunities social media present as an untapped source of fundraising for many organisations. Finally, she suggested that **creating win-win situations** as well as negotiating donations instead of walking away after getting a “no” for answer are also important principles to keep in mind.

Alfonso Serrano Movilla, the panellist from Spain, pointed out the fact that NGOs are forced to compete with each other to get more funds, while cooperation among them is needed to share the tools they have for fundraising and good practices. He emphasised the importance of **diversifying sources** of funding for patient organisations in order to achieve financial sustainability, which also necessitates creating an individual donor programme along with a system of communication with the donors. Finally, he stated that patient organisations should abide by the law for protection of personal data in their countries while managing their relationship with their donors. They should not share their database or use their contacts for other purposes.

Mr Serrano Movilla also listed some key challenges his organisation faced in terms of fundraising in general, which were the lack of tools to measure the efficiency of the organisation’s activities, part of the staff not having training/experience in fundraising, and lack of staff specifically dedicated to fundraising. For further information and recommendations from fundraising experts, see sections 2.3 and 0.

2.1.1 PUBLIC FUNDING SOURCES

There are a number of public funding sources both at national and EU levels for patient organisations in the EU Member States. These public funding sources were tackled during the first day of the seminar in both plenary presentations and workshops.

EU Funding Opportunities and their Challenges: Overview of EC Funding Programmes

EPF Director **Nicola Bedlington** introduced the available EU funding opportunities for patient organisations in her [presentation](#). First of all, she explained various EU funding programmes directly and indirectly managed by various directorates-general (DGs) of the European Commission (EC). Many programmes such as the Public Health Programme and FP7 Health Research are directly managed by various DGs in the EC; the Structural Funds that fall under the remit of DG REGIO are funded by the EC but managed by national authorities. Ms Bedlington provided a comparison between these two types of EU funding (Table 1).

Table 1: Comparison between directly and indirectly managed EU funding programmes

Directly-managed EU funding Programmes	Indirectly-managed EU funding Programmes
PHP, FP7, CIP etc..	STRUCTURAL FUNDS
<ul style="list-style-type: none"> • Multi-year EU-level funding programme (2007-2013) • Management level: centralised • Priorities: set at EU level • Focus: all EU countries+other depending on programme • Annual EU-level call for proposals • Competition for funding at EU level • Multi-country partnership (from at least 3 different EU countries) • Project results to be applied in more than one EU country 	<ul style="list-style-type: none"> • Multi-year national or regional level funding programmes (2007-2013) • Management level: decentralised • Priorities: set at national/reg level • Focus: MS and regions with GDP pro-capita < 75% EU average • Calls decided by national authorities • Competition for funding at nat. level • Partnership, when required, includes only local organisations • Project results apply locally

The directly managed programmes are managed in a centralised way by the EC, with priorities set at EU level. Candidates need to form multi-country partnerships with a focus on all EU countries. On the other hand, indirectly managed programmes, i.e. Structural Funds, are managed by the Member States with priorities set at national and/or regional levels.

The general principles for participating in EU projects are the following:

- Co-financing rule (max. 50 to 80% of eligible costs subsidized by the EU)
- Non-profit rule (the grant may not be used to produce a profit)
- Non-retroactivity rule (only the costs incurred after the starting can be eligible)

- The project should have a European dimension, be innovative and add value

Governmental Funding and Structural Funds

Governments disburse funding, at national or regional level, for a number of reasons such as core (operating) grants, delivering various projects, implementing campaigns, organising events, training and capacity building, etc. EPF Senior Programme Officer **Walter Atzori** moderated two sessions on [governmental funding and structural funds](#) for patient organisations. The session covered funding from public sector in general, including regional, national and European level public funding. In these workshop sessions, opportunities, benefits, challenges, strategies and good practices related to governmental funding and Structural Funds were discussed and workable recommendations were formulated for patient organisations that aim at accessing governmental funding and Structural Funds.

The Structural Funds are the Cohesion Policy's key financial instruments.¹ They are EU funding sources managed by governments, and they provide the financial resources to promote economic, social and territorial cohesion across European regions. There are two types of Structural Funds: European Regional Development Fund (ERDF) and European Social Fund (ESF). The three objectives of Cohesion Policy and Structural Funds are:

- Convergence aimed at lagging regions with a GDP per capita 75% lower than EU average)
- Competitiveness and employment for more developed regions
- Territorial cooperation for all regions

Structural Funds list health as one of the priorities for since 2007, and invest in other areas relevant to patient organisations such as social inclusion, anti-discrimination, access to employment, education and training, urban projects and local services, etc. They can be used to prevent health risks and improve health infrastructure. Patient organisations could apply for/participate in various types of projects under different ESF priorities both as individual beneficiaries and as part of consortia.

Public and private entities, NGOs, voluntary sector bodies can all apply for Structural Funds. On the other hand, sometimes national/regional authorities may decide to narrow down the range of entitled entities e.g. only healthcare centres, NGOs or SMEs to apply. This information is published in the call for proposals as well as deadlines and required documents. Since the procedures are

¹ Cohesion Policy is the EU's strategy to promote and support the "overall harmonious development" of its Member States and regions.

country-specific, there is no common or general application process for EU funds.

The health component will be strengthened in the period 2014-2020 as people with chronic diseases are mentioned as a specific target group for the first time. Different opportunities might exist for patient organisations such as projects related to

- access to services, in particular social care, social assistance services and healthcare (including preventive healthcare, health education and patient safety);
- specific actions targeting people at risk of discrimination and people with disabilities and chronic disease with a view to increasing their labour market participation, enhancing their social inclusion, and reducing inequalities in terms of educational attainment and health status;
- support for the transition from institutional care to community-based care services for children without parental care, people with disabilities, the elderly, and people with mental disorders, with a focus on integration between health and social services.

For further information about the workshop content, refer to the [presentation](#) and [report](#) of the session.

2.1.2 PRIVATE FUNDING SOURCES

Private funding sources are frequently used by patient organisations. Companies and individuals as sources of private funding were discussed in the seminar.

Industry and Foundation Funding

EPF Director **Nicola Bedlington** moderated two sessions with regard to [industry and foundation funding](#) for patient organisations. In these workshop sessions, opportunities, benefits, challenges, strategies and good practices related to industry and foundation funding were discussed and workable recommendations were formulated for patient organisations that aim at accessing industry and foundation funding.

Ms Bedlington started with the importance of mapping out all potential sources of funding from industry and foundations. She emphasised the need to pay attention to diversifying the sources of funding across different sectors, being clear about why funding is needed, and being transparent with regard to the sources of funding. She recommended that fundraisers in patient organisations should talk to those who have been successful in this area and also develop a concept note, a plan and a realistic budget.

She argued that reaching a win-win scenario can happen if both parties' short- and long-term objectives are discussed well, areas of common interest are identified and the structure of

collaboration is outlined. In this regard, patient organisations should not compromise on their values of independence, integrity and transparency, i.e. not engaging in joint lobbying with the funders or endorsing the funders' products. She also argued that effective financial and qualitative reporting would improve the organisations' reputation and credibility.

A first step of fundraising is to arrange a face-to-face meeting with the other party, and present the mission and objectives of the organisation. The way the donor wants to work should be discussed in this meeting. The parties should establish and maintain mutual trust and not be afraid to talk about money or other difficult topics. Fundraisers should focus on building long-term relationships with their donors, and agree on a multi-year programme whenever possible. Getting to know the donor's budget planning cycle can also help in this sense.

For further information about the workshop content, refer to the [presentation](#) and the [report](#) of the session.

Other Sources: Donations, Events, Membership, etc.

[EuropaColon](#) Director of Policy **Geoffrey Henning** moderated two sessions on other sources which patient organisations can use to fundraise such as donations, events, membership, etc. In these workshop sessions, opportunities, benefits, challenges, strategies and good practices related to funding sources such as donations, membership, events, etc. were discussed and workable recommendations were formulated for patient organisations that aim at accessing these types of funding.

Mr Henning pointed out to the fact that general population is the main target for this type of fundraising activities and the only way to successfully fundraise is to raise awareness. Raising awareness is the job of everybody working in the organisation, while the specific job of the fundraiser is to turn awareness into a donation using 'emotions' as a marketing tool. Emotions should be used very cautiously to get compassion, sympathy, and empathy from other people in a positive way.

When asked about their most successful fundraising experience, some participants mentioned successful fundraising events. On the other hand, they did not keep track of the people who donated at that time. Mr Henning emphasised the importance of taking contact details of people and including them in the database, as the volume and accuracy of the database of the organisation is crucial for fundraising.

Mr Henning said that organisations can ensure donors to keep donating regularly by having a project

that has their name on it. Various activities such as marathons or lottery raffles can be helpful in terms of fundraising. Advertising in magazines, websites, radio, and TV will also contribute to the visibility of the organisation and the cause. Mr Henning also mentioned collecting investment from celebrities, distributing leaflets, selling goods (e.g. second-hand shop), and encouraging people to donate part of their legacies to the organisation.

Some participants stated that organising events and campaigns drained their resources. For this reason, the importance of evaluation was discussed in order to keep track of costs and revenues. Even though organising events could be a major source of funding for many organisations, fundraisers should make sure that they do not spend more than they can get back from the audience.

For further information about the session, refer to the [report](#) of the session.

2.2 FUNDRAISING IN THE MEDITERRANEAN EUROPE

Acknowledging the diversity and specificities existing in each country, four separate national working groups were established and each group analysed funding sources in their country. Professional fundraisers from those same countries moderated each national working group and guided participants in getting a clear overview of current and upcoming funding opportunities for patient organisations, exploring the most suitable funding sources for the organisation, and identifying the challenges and barriers with regard to fundraising for patient organisations in different countries and with different type of sources.

Each moderator identified different needs of and recommendations by the participants they interacted with from their particular perspective. The country-specific examples given below are not limited to the specific national working groups but apply to all participants in the seminar. The classification is made to show the group in which discussion has started.

2.2.1 GREECE

Maria Moudatsou, moderator of the Greek national working group, reported that both the opportunities in the EU-level and how to approach them as well as specific foundations and private fundraising in Greece and how to approach them were discussed. Various tools were presented to the participants to help them when designing their requests for funding. Three key issues Ms Moudatsou highlighted are:

Organisation's strategy: It is important to have a specific strategic plan in the organisations about (1) where the organisation is and (2) where it wants to be in the short and long terms. Both the funding request and fundraising strategy as whole have to “answer” to these two questions. Finding a funding source and applying for funding without considering how that funding source can help to take the organisation's strategy one step further will only be a temporary solution and not a permanent one. Patient organisations should build a strategy and follow it step by step while also having the necessary flexibility.

Results-based methodology: The key points below should be explained also in ‘numbers’ when organisations apply for various projects or funding sources:

- Thorough analysis of financial condition of the organisation
- Specific target beneficiaries
- Outcomes of the initiative
- Services to be delivered
- Human resources allocation to ensure efficiency
- Tools to control, measure and evaluate the project
- Full grid of tools ensuring effectiveness and success
- Detailed budgeting to formulate the needs for the initiative

Fundraising is a win-win situation where both parties, the organisation as well as the donor/foundation/company win. The fundraiser should not ‘beg’ but create a clear and trusting relationship through which both sides can win. It is important to also identify what the donor can win by engaging in this relationship.

Some key issues common for all participants from Greece with regard to fundraising are as follows:

- Lack of knowledge about managing programmes
- Lack of specific skills in project planning, project implementation, monitoring and evaluation procedures
- Good practices are not shared enough among patients' groups
- Lack of basic knowledge on funding opportunities (EU-level, national, private, etc.)
- Lack of knowledge in using tools when writing a request for funding

- Need for networking at a national, EU and international level
- Lack of communication strategy planning
- Lack of personnel dedicated to fundraising
- Limited human resources in general

Participants in the Greek national working group decided on the following as recommendations:

- An “umbrella” organisation should be established for each disease
- A statutory mixed participation body (all stakeholders involved; from public, private and civil society sector) should be established in each organisation
- Public funds should be easily accessed and understood by patient groups
- There is a need for extra social marketing training as well as for FR strategy training, recruiting, motivation and we planned to continue in Greece
- There is a need for more social media involvement

For more information on the content and results of the Greek national working group, refer to the [presentation](#) and the [report](#) of the session.

2.2.2 ITALY

Simona Biancu, the moderator of the Italian group, identified three most notable areas that need attention and recommendations related to these.

Training: Lack of specific training paths in fundraising has clearly emerged as a challenge. There are very few courses and seminars aiming to support NGOs to acquire fundraising techniques and tools, compared with the real need of them. Ms Biancu mentioned CRM (customer relationship management) systems to map contacts and donors, database for fundraising and donors profiling, online communication plan and Internet as examples on which training programmes may be prepared. Another subject might be the theory of fundraising, which is not used much by NGOs. Ms Biancu stated that training on this would help with the switch from a charity-based approach to a relationship-based system in order to create long-term and stable links between organisations and donors.

Approach to Fundraising: Ms Biancu argues that there is a “Mediterranean way” of fundraising – which is based on the emotional side of fundraising instead of techniques – unlike the way fundraising is handled in Northern European countries with a more consolidated tradition of raising

funds as a shared responsibility within the community. Thus, Mediterranean countries are more based on 'charity' and empathy, rather than 'care' and responsibility-based approach in Northern Europe. For this reason it is even more important for the patient organisations based in the Mediterranean region to address the hearts of people as well as heads.

Organisation: Another common point between Italy, Portugal, Spain and Greece is the high number of organisations with the same cause, addressing the same donors and asking for the same things as their needs are the same. It is quite difficult to link similar organisations to an umbrella organisation that centralises resources and has a general overview on the whole situation. The only exception to this is Spain, as it has an umbrella patients' organisation. A national patients' organisation could provide training and analysis, support needs and campaigns, search further opportunities in terms of funding, etc.

For more information on the content and results of the Italian national working group, refer to the [presentation](#) and the [report](#) of the session.

2.2.3 PORTUGAL

The three most important issues that were addressed during the sessions were the following according to **Madalena Alves Pereira**, the moderator of the Portuguese group:

How to ask for support from potential donors: The participants were worried about the way they should ask, as they have been experiencing a lot of rejections which led them to frustration. Interestingly, while the need to create strong and committed relationships was being discussed, the same participants admitted that they had not been investing in building these relationships as they should have. Fundraising takes a lot of time, and this often clashes with the urgency to secure funds.

Main issues important to communicate: Different ways to communicate to potential and actual donors were analysed during the sessions. Participants did not know whether they should write long or short documents, or how to present the Case for Support. The Case for Support was one of the main issues in all workshops, as the main document that organisations need to finalise before starting fundraising. One of the conclusions was that having the support of professional advertising agencies could make huge differences in the results of a communication plan. Another thing which was discussed is that patient organisations were more advantageous than many other NGOs in terms of communication as the causes are specific and addressing to emotions. Patient organisations should use this to their advantage and clearly express what they stand for and how they can contribute to patients as well as society in general.

Successful fundraising depends on creating relationships: It is more profitable to create relationships with current and potential donors. If this is not done, donors will donate and go away. Fundraisers should create strong relationships and invest in donors in order to keep them for a long time. It is proven that with a good database of regular donors, organisations can be more financially sustainable. On the other hand, most participants do not know how to create sustainable relationships systematically. Clearly, patient organisations need more support and training about this aspect of fundraising.

For more information on the content and results of the Portuguese national working group, refer to the [presentation](#) and the [report](#) of the session.

2.2.4 SPAIN

Three key issues that arose from discussions in the Spanish national working group according to **Carmen Netzel** are:

Understanding why patient organisations need to fundraise today: As a result of the workshops, it was clear that participants need to learn successful fundraising urgently. Government funding is decreasing, and diversification from pharmaceutical companies as sole major donors is desired. Organisations need to focus on explaining their purpose (mission and vision) to society and go a step further and report on what they offer to society and how they deliver them. Participants recognised the need to diversify and open up to society at large. Some small organisations have already successfully explored many different sources to finance their activities and projects. Sharing this experience may encourage other organisations to follow.

Identifying different approaches to fundraising when it is addressed to private sources: Finding out who (individuals, corporate foundations, private foundations) can become potential donors for patient organisations is crucial. Defining donor profiles, developing strategies and using different channels for communicating with donors are the basics of fundraising.

Developing new skills and enacting new roles: Creative oral and written communication is needed together with learning to use social media and crowd funding platforms. Patient organisations need to start strategic thinking and learn to formulate causes to get support from civil society. Learning how to network in the community and build relationships with stakeholders are also very important.

For more information on the content and results of the Spanish national working group, refer to the [presentation](#) and the [report](#) of the session.

2.3 HOW TO DEVELOP A FUNDRAISING STRATEGY

During the parallel sessions moderated by the professional fundraisers focusing on developing an organisation fundraising strategy, participants were trained on how to develop a clear and step by step fundraising strategy for their organisations depending on their specific needs (capacity, staff, constituency, objectives, etc.), shared best practices and lessons learned, and formulated workable recommendations for an effective fundraising strategy for patient organisations.

Ms Biancu stressed that no matter their size or number of donors or partners, each organisation needs a fundraising strategy. This strategy should be based on a clear idea about the present situation (SWOT analysis),² and a projection of the organisation in the forthcoming future. Ms Netzel also supports the idea of carrying out a SWOT analysis, which could be done with external help.

The path fundraising experts recommend patient organisations to take is the following:

1. SWOT analysis: This will help the organisations' representatives and their teams to acknowledge and evaluate the internal and external factors to take into account in the fundraising process for the organisation. By performing a SWOT analysis, fundraisers can also analyse the strengths, weaknesses, opportunities and threats for their organisations in many areas including the number of volunteers, funds, and communication.
2. Strategic planning: Think about what the organisation would like to become in the mid- and long-term. According to Ms Moudatsou, in addition to the strategic plan, the organisation should have the following: communication plan, visibility plan, human resources plan, geographical coverage plan, clear/concrete strategic goals and objectives, range and type of services offered, frames of investment and barriers, business strategy, 'unique selling proposition', organisational structure, credibility, capacity building, corporate identity of the organisation, advocacy, etc.
3. Set operational goals leading to achievement of strategic goals: Identify the ways and plan the activities (e.g. organise a campaign) to accomplish these strategic goals.
4. Set monetary values for each of the strategic and operational goals of the organisation. This

² SWOT analysis (alternatively SWOT Matrix) is a structured planning method used to evaluate the Strengths, Weaknesses, Opportunities, and Threats involved in a project or in a business venture. A SWOT analysis can be carried out for a product, place or person. It involves specifying the objective of the business venture or project and identifying the internal and external factors that are favourable and unfavourable to achieving that objective. (http://en.wikipedia.org/wiki/SWOT_analysis)

will help you measure your success in terms of fundraising later on.

5. Identify activities, their targets, the resources needed (e.g. staff, finances, etc.)
6. Identify the current and potential funding sources for the organisation
7. Start fundraising for these activities
8. Try to keep everything under control, regularly check whether the organisation is on the right path

Key aspects of success in fundraising are leadership, adequate staffing, thorough planning, organisational structure (e.g. roles and responsibilities), coordination, references/contacts, budgeting, supervision, and evaluation according to Ms Moudatsou. Moreover, patient organisations should also take the following into account with regard to fundraising: geographical coverage, current social, economic, and political environment, visibility, having volunteers/partners, sustainability, dedication.

Ms Alves Pereira gives some specific tips about fundraising:

- Improve your relationship with the current donors
- Learn from the experiences of similar organisations to yours outside and inside your country
- Make a good list of current and potential donors: individuals, corporates, foundations, etc.
- Investigate a lot about your current and potential donors, try to know everything that is possible to know about them – this will contribute to your success in creating and developing the best relationship with them
- Study in detail everything you do, and carefully identify the return on investment, amounts raised, lessons learned, etc.
- Do not be afraid of using new technics and formats; innovation and creativeness are the best sources of success
- Develop objectives for each donor, activity, etc.
- Develop a clear plan to raise funds and guide fundraisers through the fundraising cycle
- Never forget to THANK all your donors a lot of times
- Never forget to evaluate your fundraising plan

“If you don’t have too much experience in fundraising, don’t be afraid; start now and begin to have experience.” –

Madalena Alves Pereira

- Ensure you make the changes needed in the fundraising plan to maximise your success

Besides developing a fundraising strategy, Ms Netzel emphasises the importance of joining forces for patient organisations, dividing roles and tasks among/within organisations, having passion and drive about the mission, and being donor-centred:

“Joining forces with similar organisations, particularly for the small or very small ones, could allow for resource sharing in the implementation of campaigns, events, etc. Exploring alliances and partnerships with other closely related type of organisations (i.e. hospitals, primary care networks, research centres) might result in gained expertise, visibility and exposure to new sources of funding.

Joining forces also is directed towards having ‘one voice, one cause’ for organisations dealing with the same disease in a given country. If patient organisations are to turn to society in general to ask for donations, it is necessary that the message is one for all. It would also be desirable that recommendations be issued to national and local organisations to join efforts on a given day – international or world anniversary dates for diseases in order to launch their fundraising campaigns together.

At the same time, it would be advisable that roles and tasks be clarified – and perhaps also distributed – between different levels. Local level patient organisations (provincial, regional) seem to be the best positioned to approach individual donors. Their presence in society is an advantage to ask for support, because they are close to patients and can find people who are sensitive to the disease. On the other hand, umbrella organisations at national, European or even international level could provide managerial support and marketing & communication resources across to all the organisations involved in the same disease.”

Finally, fundraising is about the donor. The fundraiser should make the donor feel that he/she would make a difference by donating and gain satisfaction from doing a good deed. For this reason, the fundraiser should be donor-centred and focus on donors’ expectations from donating.

For more information on the content and results of the sessions, refer to the related presentations ([A](#), [B](#), [C](#)) and reports ([A](#), [B](#)).

2.4 HOW TO BECOME A SUCCESSFUL FUNDRAISER

Finally the fundraising experts trained seminar participants on how to become a successful fundraiser. They went through the essential characteristics of a successful fundraiser as well as the DOs and DON'Ts in the search for funding and formulated concrete recommendations.

Ms Biancu lists certain elements of being a successful fundraiser as follows:

- **Cultivate relationships** with people, other organisations, in general with the rest of the world. Organisations need to focus your approach firstly on people, then on money. To do it, it is important to track every single contact (individual, company, foundation, etc.) you receive as an organisation; try to deepen the type of interest and the opportunity to work together. Have a **proper database** to map contacts, donations, volunteers – there are useful open source tools suitable for this (e.g. www.civicrm.org)
- “... And, last but not least, be passionate about your cause: try to keep in mind numbers, measures, goals and ‘return on investment’, but inject the passion that brought you working with your*
- Since fundraising is a **mix of emotion and mind**, fundraiser should think as they were a potential donor to the organisation. It is an effective way to check whether one is a “proper requestor” or “too pushy”.
 - As **training** is an important point to learn technical skills, another suggestion is to search for courses and opportunities to learn to practice fundraising. As a simpler and more immediate solution, fundraisers are encouraged to read blogs and books about fundraising to understand what others do.

Ms Moudatsou added to this list the need to think about the different groups of donors, capacity to plan, being able to promote financial sustainability and continuity of funding, having the knowledge

“Good fundraising is always about the donor, providing the opportunity to join an organisation that is driven to make a change, a difference. People give to have a better world in any possible imaginable way! Learning how to tell your donors a story and make them feel they can be part of it.”

– Carmen Netzel

of all fundraising possibilities (e.g. EU, national, governmental, members, etc.). She added that a successful fundraiser knows clearly that fundraising is a question of **building relationships** and creating **win-win situations**, and does not get disappointed easily.

Being passionate about the cause and making the donors feel good about their contribution to society should not be underestimated either as traits of a good fundraiser. Ms Netzel explains as follows:

“Fundraisers are passionate individuals who are driven

without shame to ask money for their organisations. They feel strongly about their cause and have the ability to express it to others. They do not act as free-lancers and need the support and

commitment of the president and board members of the organisations. Setting up a fundraising strategy and the needed resources to implement it is not a current expense, but an investment with medium and long-term return.”

Finally, Ms Alves Pereira provides a DO/DON'T list for patient organisations that want to become successful fundraisers (Table 2).

Table 2: DOs and DON'Ts of Fundraising

DO	DON'T
<ul style="list-style-type: none"> ✓ Be a donor yourself ✓ Plan ✓ Study the donor ✓ Adapt your communication to different audiences ✓ Strong fundraising plan ✓ Identify all the sources of funding ✓ Investigate all potential donors ✓ Cultivate relationship with donors ✓ Ask ✓ Show the benefits ✓ Thank ✓ Give feedback ✓ Evaluate continuously 	<ul style="list-style-type: none"> ❖ Ask everyone you know ❖ Ask everyone you don't know ❖ Ask in the first contact ❖ Ask without creating a relationship ❖ Forget to thank ❖ Ask with fear ❖ Ask without confidence ❖ Ask without enthusiasm ❖ Be shy ❖ Be anxious ❖ Ask for just the amount of money you need ❖ Ask just the number of donors you need to have ❖ Speak too much and listen too little ❖ Don't ask for support ❖ Don't involve ❖ Don't ask for new contacts – prospects

For more information on the content and results of the sessions, refer to the related presentations

(A, B, C) and reports (B, C).

2.5 ONLINE RESOURCES

In order to complement this document, along with the presentations used in the seminar, we provide some online resources where patient organisations can find more information on fundraising.

2.5.1 EUROPEAN & INTERNATIONAL

- SOFII: www.sofii.org
- 101fundraising: www.101fundraising.org
- The Chronicle of Philanthropy: philanthropy.com
- Nonprofit Tech 2.0: nonprofitorgs.wordpress.com
- The Agitator: www.theagitator.net (The Toolbox Features Ideas, Applications, Tools, Processes and Case Studies of Breakthrough Solutions in Fundraising)
- European Fundraising Association (EFA): www.efa-net.eu
- Beginners' guide to EU funding : ec.europa.eu/budget/biblio/publications/publications_en.cfm#new_funds
- The Value+ Toolkit: www.eu-patient.eu/Documents/Projects/Valueplus/Value+%20Toolkit.pdf

Some specific programs:

- EEA & Norway Grants: www.eeagrants.org
- Executive Agency for Health and Consumers: ec.europa.eu/eahc/health/index.html
- Community Research and Development Information Service: cordis.europa.eu/fp7/health/home_en.html
- Health-ncp-net: www.healthncpnet.eu (to better understand FP7)
- Innovative Medicines Initiative: www.imi.europa.eu
- Competitiveness and Innovation Programme: ec.europa.eu/information_society/activities/ict_psp/index_en.htm
- PROGRESS Programme: ec.europa.eu/social/main.jsp?catId=630&langId=en

2.5.2 GREECE

- Eurocharity: www.eurocharity.gr
- Hellenic Network for Corporate Social Responsibility: www.csrhellas.org
- CSR in Greece: www.csringreece.gr
- ESPA/NSRF: www.espa.gr

Some foundations in Greece that provide private funding:

- Stavros Niarchos Foundation: www.snf.org
- Bodossaki Foundation: www.bodossaki.gr
- Onassis Foundation: www.onassis.gr
- John S. Latsis Public Benefit Foundation: www.latsis-foundation.org
- A.G. Leventis Foundation: www.leventisfoundation.org

A list of pharmaceutical companies in Greece: www.medinfo.gr/?cat_id=313

2.5.3 ITALY

- Vite non-profit: www.vita.it/non-profit/index.html
- Fundraising: www.fundraising.it
- Sodalitas: www.sodalitas.it
- CSVnet: www.csvnet.it
- Uidu: blog.uidu.org
- Assifero: www.assifero.org
- Simona Biancu: www.simonabiancu.it/materiali

2.5.4 SPAIN

Spanish Association of Fundraising (AEFR): www.aefundraising.org

CAUSES that change the world: causes.cat

3. CONCLUSION

3.1 RECOMMENDATIONS

Strategic plan of the organisation: It is crucial for patient organisations to have a clear strategy and well-defined goals. In this regard, the organisations should define their purpose, legitimise their *raison d'être*, explain how they can help patients in that area, etc. Preparing such a plan will increase the chances for patient organisations in accessing various funds.

Fundraising strategy: In addition to their strategic plan, the organisations should also have a fundraising plan. This document should clearly indicate the budgetary needs, the sources of funding, and how the funds will be used in a transparent way. The donors will be more willing to contribute if they see a clear plan and how the organisation makes itself accountable for the use of this funding.

Diversifying funding sources: Patient organisations should avoid becoming dependent on only one or a very limited number of funding sources. In this way, they can overcome financial difficulties more easily especially in today's financial environment where sustainability is at more risk.

Focus on long-term relationships: Organisations should realise that successful fundraising needs time and strong relationships. For this reason, fundraisers should focus on establishing long-term relationships based on mutual trust and understanding.

Address hearts as well as heads: Fundraising with individuals necessitates moving people and touching their hearts. Especially in the Mediterranean countries where people act with their emotions more than Northern European countries, it is important to establish a connection with individuals, touch their hearts, and trigger empathy.

Emphasising win-win approaches: While addressing the hearts is crucial for individual fundraising and collecting donations, when it comes to corporations, foundations and public bodies, it is important to show how helping the organisation will benefit the donor. Fundraisers should be aware of the benefits their potential donors want to make and convince the other party to contribute in this way.

Database and donor profiling: It is crucial to have a database for both individual and corporate donors – current and potential. Patient organisations should aim at growing this database continuously with new potential donors while continuing their relationships with the existing ones. Right profiling of these donors and establishing the right way of communication with them will

increase the chance of getting donations from these sources.

Establishing an umbrella organisation: Having a disease-specific umbrella patient organisation (or a national-level umbrella patient organisation) will contribute enormously to the visibility of the related patient organisations and the greater cause. Instead of establishing many small organisations aiming to do the same things, patient representatives should focus more on uniting their forces and helping each other.

3.2 FEEDBACK FROM THE PARTICIPANTS AND THE MODERATORS

All participants evaluated the Seminar in a very positive way. They thanked EPF for having organised the event and stated that they had learned a lot during those two days. The audience was also pleased with the networking opportunities and having met people with whom they could work in the future. Most participants found the time very limited to discuss the issues in-depth.

The four fundraising experts who moderated the sessions on the second day concurred that the seminar was very well received by the audience. The moderators stated that the participants were from diverse backgrounds in terms of the size of their organisations as well as their knowledge on

“I regard the seminar as a highly positive initiative, because it provided the opportunity to open up a dialogue between patients’ organisations previously unknown to each other, and discovering EPF as a source of knowledge. The issue of fundraising seems a natural ingredient to strengthen the organisations, but perhaps it is also an opportunity to tell society about their purpose and to gain visibility and social support.” – Carmen Netzel

fundraising. On the other hand, it was clear that the vast

majority of participants did not have much knowledge and/or experience on fundraising. The moderators saw that there is a great interest towards fundraising in general.

The moderators think that the participants showed a strong motivation to take action in their respective organisations by the end of the Seminar. Peer-to-peer relationships were initiated amongst patient

“I would really like to thank you for offering me the opportunity to participate in the seminar as an expert and I must say that, I really liked the seminar as I had the chance to share my knowledge with other people, exchange and learn from the other experts, have the chance to meet very important people and organisations and also exchange knowledge among different expertise and countries.” – Maria Moudatsou

representatives and possibilities for cooperation between countries were explored. Finally, finding out about EPF and the expertise of its Board and Secretariat as a source of support was also a plus.

3.3 IMPACT OF THE SEMINAR

Both participants and moderators expressed the need for further seminars and trainings in terms of fundraising and recommended EPF to organise more events with the same theme. On the other hand, the participants from Greece also took the initiative to further improve their skills with the help of Maria Moudatsou, fundraising expert from Greece. Approximately one month after the seminar, this group met in Athens, in the office of Praksis – an NGO fighting against social and economic exclusion of socially vulnerable groups.

The topic of their discussion was how to develop a project proposal as the participants had very limited knowledge on it. The group decided to have another meeting in the future. Ms Moudatsou reports that a network was developed during the Seminar and this small network has been exchanging emails for specific matters ever since to help each other.

Below, there are comments that were sent by two participants after this meeting in Athens:

"I find it very useful to keep our network and organize meetings from time to time. I was very happy to meet the people I got to know in Portugal, some very interesting people who have a lot to share on funding opportunities. I feel that we all want to make our organisations work effectively and this kind of meetings are empowering. Electronic communications are not enough. I hope we will keep in touch."

"Maria thank you for accepting to continue what we've already started in Lisbon. Thank you Spyros for organising this meeting. Following EPF's Lisbon Seminar this meeting was critical for us, because Maria actually explained how to put fundraising knowledge into practice step by step. The guidance Maria gave us was very useful and valuable. We intend to follow these meetings whenever Maria is available. It was also a great pleasure to meet some of the Seminar's participants and exchange information. 31 years after the establishment of Child's Heart, it is the first time that we are able to reach this kind of information."

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Disclaimer: The content of this letter reflects only the author's views and the Executive Agency is not responsible for any use that may be made of the information contained therein.