

EPF Capacity Building Programme in Poland

Sustainable development of patient organisations as stable and reliable partners in the healthcare system

Presentation of the project results

Phase 1: April - November 2017

Participating Patient organisations:

- ❖ Polish Association of Patients with Phenylketonuria and Rare Diseases "Ars Vivendi,,
- ❖ Association fighting against Lungs Cancer - Branch in Szczecin
- ❖ Association helping Patients with Blood Cancers in Zamość
- ❖ Association of Patients with NTM "Uro Conti,,
- ❖ Federation of Polish Patients
- ❖ National Association Patients with Chronic Myelogenous Leukemia
- ❖ ORPHAN Rare Diseases Forum
- ❖ Polish Association for Children with Epilepsy
- ❖ Polish Diabetes Association
- ❖ Retina AMD Poland
- ❖ Society for the Support of Patients with Idiopathic Pulmonary Fibrosis-IPF
- ❖ Association of Families of Patients with Marfan and Other Genetic Syndromes
- ❖ National Association of Young People with inflammatory connective tissue diseases
- ❖ National Federation of Breast Cancer Survivors Associations „Amazonki”
- ❖ Polish Stoma Society POL-ILKO
- ❖ Polish Union of Patient Organizations Citizens for Health

Areas, issues of the implemented support

No.	Thematic scope	Number of beneficiaries
1.	Development of strategy and Implementation Plan	16
2.	Financing workshop	8
3.	Coaching in assertiveness	6
4.	Team coaching in negotiation	1
5.	Team coaching in members activation	2
6.	Team coaching in communication	1
7.	Team coaching in team building	2
8.	Mini projects	5
9.	Tools - Databases	1

No	Organisation	Strategy, 6h plan	Strategy, 3h plan	Coaching	Mini project	Workshop meeting	Support tool
1	Polish Association of Patients with Phenylketonuria and Rare Diseases "Ars Vivendi"	yes				finances	
2	Association fighting against Lungs Cancer - Branch in Szczecin		yes	Assertive communication	educational run	finances	
3	Association helping Patients with Blood Cancers in Zamość	yes		Assertive communication			
4	Association of Patients with UIC "Uro Conti"	yes				finances	
5	Federation of Polish Patients	yes				finances	
6	National Association of Patients with Chronic Myelogenous Leukemia		yes		online information centre about CML		
7	ORPHAN Rare Diseases Forum	yes				finances	
8	Polish Association for Children with Epilepsy		yes	Assertive communication	epileptology training for doctors		databases
9	Polish Diabetes Association		yes	Assertive communication		finances	
10	Retina AMD Poland		yes	Assertive communication	consultancy org.		
11	Polish Society for the Support of Patients with Idiopathic Pulmonary Fibrosis-IPF		yes	Assertive communication		finances	
12	Association of Families of Patients with Marfan Syndrome	yes				members activation	
13	Let's stay together! National Association of Young People with Connective Tissue Diseases	yes				communication finances	
14	Federation of Breast Cancer Survivors Associations „Amazonki”	yes		negotiations			
15	Polish Stoma Society POL-ILKO		yes	team building	consultancy org.	members activation	
16	Polish Union of Patient Organizations Citizens for Health	yes		team building			

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: Federation of Polish Patients

Organisation's Mission:	Federation's Mission is to integrate the community of patients, defend their rights, represent them and to seek to improve the quality of healthcare and medical services. The Federation strengthens the voice of member organisations in various disease areas in front of external bodies, healthcare system administration, foreign organisations and others.
Organisation's Vision:	<ul style="list-style-type: none"> • The organisation thrives due to a large and devoted team of co-workers in the FPP office. • The organisation cooperates closely with its member organisations, acting in a proactive way, it exploits its members' potential. • The organisation is an effective partner in discussions with policymakers. • The organisation is well-known, recognizable and respected both in the healthcare system community and outside it. • The organisation consolidates the community of patient organisations in various disease areas, representing them and strengthening their voice in public debate. • The organisation is a leader in actions aimed at improving situation of Polish patients.
Members / workers / volunteers / range:	<ul style="list-style-type: none"> • 71 member organisations bringing together over 50 thousand patients • 0 employees / 10 volunteers • Umbrella organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none"> • Consulting activities in developing the Strategy and Implementation Plan • Workshop on fundraising for patient organisations
Project results Good practices	<ul style="list-style-type: none"> • Diagnosis and Strategy developed with Implementation Plan 2017 - 2020 • Increase in knowledge and skills in applying for national and EU funding • Increase in knowledge and skills in communication, presentations, negotiations • Increase in knowledge in project management, gaining new members and activating them

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: “Let’s stay together” National Association of Young People with Connective Tissue Diseases

Organisation's Mission:	<p>The “Let’s stay together!” Association works in order to help the patients with inflammatory connective tissue diseases to acquire knowledge, tools and psychological support so that they understand their disease, social system they function in and, at the same time, become a conscious, equal partner in negotiations with policymakers in the healthcare system. We believe that only education, in a broad sense, and open dialogue between the communities of patients, doctors and policymakers may lead to quality changes in the area of rheumatology.</p>
Organisation's Vision:	<p>The “Let’s stay together!” Association is an active organisation which is well-known in Poland. It unites people suffering from inflammatory connective tissue diseases and supporting people, by effectively undertaking educational, integration, media and advocacy activities. It is a partner for doctors, policymakers and other European and world organisations.</p>
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 100 members• 0 employees / 30 volunteers• Primary organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Workshop on fundraising for patient organisations• Team coaching in communication skills
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and skills in applying for national and EU funding• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: Federation of Breast Cancer Survivors Associations „Amazonki”

Organisation's Mission:	The Federation of Associations Amazonki’s mission is undertaking comprehensive activities for persons with breast cancer, including supporting women after breast cancer treatment.
Organisation's Vision:	<ul style="list-style-type: none">• Extending educational activities on breast cancer in society and individual persons.• Developing new cycle of trainings for volunteers after recurrence of the disease.• Unique media campaign on the importance of breast cancer prevention conducted with the use of extreme event.• Organisation of the Centre for Oncological Voluntary Services.• Change in social awareness of reputation of breast cancer as a lethal disease for reputation of chronic disease.• Promoting of passing the habit of breast self-examination from generation to generation.
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 207 member organisations bringing together 25 thousand patients• 3 employees / 1300 volunteers (in all member organisations)• Umbrella organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Team coaching in negotiations and presentations for members of the management board
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: National Association of Patients with Chronic Myelogenous Leukemia

Organisation's Mission:	The Association's mission is to help patients, inform on treatment, integrate individual groups of patients, strengthen patients' psyche during treatment, inform about the latest therapies and also raise the level of knowledge through providing trainings and issuing information materials.
Organisation's Vision:	<ul style="list-style-type: none">• The Association supports chronic myelogenous leukaemia patients, their relatives and close friends.• The Association organises trainings and information actions on the disease and latest methods of leukaemia treatment.• The Association takes part in the works of national and international organisations which aim at combating cancer.• The Association undertakes actions designed for patients to have full, equal and free access to the best methods of treatment and to medications that would help them combat the disease.
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 200 members• 0 employees / 10 volunteers• Primary organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Consultancy on mini-project of the Information Centre for Myelogenous Leukaemia (Centrum Informacyjnego Przewlekłej Białaczki Szpikowej - CIPBS)
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them• Developed technical assumptions and layout of the CIPBS project schedule - good practice

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: Polish Diabetes Organisation

Organisation's Mission:	Polish Diabetes Association builds awareness of diabetes among patients and in the society. The most important task of the organisation is education so as the diabetic patients can undertake relevant actions on their disease, diet, physical activity. The Association solicits for the best treatment for patients (drug reimbursement, access to specialists) through negotiations with policymakers in the Sejm (Parliament), and in the Ministry of Health.
Organisation's Vision:	<ul style="list-style-type: none">• Stable financial situation, large surplus on the account and no debts.• The Organisation is known among the citizens - visible in the media, recognisable.• Stable number of members, steady inflow of new members.• Maintained number of local branches - about 400.• No conflicts, cooperation between local branches and activists.• The Organisation is known and trusted by policymakers, it takes part in the legislative process, issues opinions, etc. It is an expert.• Successful introduction of changes in legal regulations, in the interest of patients, real changes for patients.• The Organisation's activists feel that their work has sense.
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 80 thousand of members brought together in 400 local branches• 2 employees / 800 volunteers• Primary organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Workshop on fundraising for patient organisations• Coaching in assertive communication skills
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and skills in applying for national and EU funding• Increase in knowledge and assertive communication skills• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them

Organisation: Polish Union of Patient Organizations Citizens for Health

Organisation's Mission:	<p>Our mission is to improve and maintain health of the citizens through representing, supporting and integrating the community of patient organisations and cooperation with other organisations, institutions and community of the healthcare system. We act together - openly, transparently and responsibly.</p>
Organisation's Vision:	<ul style="list-style-type: none">• PUPO is an effective organisation that integrates actions for a patient in the healthcare system• PUPO is an organisation that is perceived by policymakers as a professional partner.• PUPO is empowered in certain structures, recognisable and respected in the community.• PUPO brings together several dozen organisations.• PUPO knows how to motivate patient organisations to solve the most important problems encountered in the Healthcare System.• PUPO brings together experts who support it in substantial matters.• PUPO is getting more involved in the process of designing and changing regulations.• Member organisations have assumed and applied the rules of openness, responsibility and transparency.• Member organisations actively participate in trainings, workshops, conferences and they apply the knowledge acquired this way.• Member organisations' potential increased, allowing them to address the needs of their members in a better way.
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 7 member organisations bringing together 100 thousand patients• 0 employees / 10 volunteers• Umbrella organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Team coaching in team building skills
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase of knowledge and practical skills in team building• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them

Organisation: Polish Stoma Society POL-ILKO - Płock Regional Branch

Organisation's Mission:	The heart of the organisation's activity is to help people who find out they would have a stoma or they have already had the surgery but they cannot cope with the new situation. The organisation integrates and supports the community of people with stomas by offering them participation in integration meetings, workshops, operating equipment bank and engaging in other activities.
Organisation's Vision:	<p>We would like to attract the society's attention to the needs and problems of the patients with a stoma and to help people with a stoma to live dignified and joyful life despite their disability. We make every effort to improve the situation of the people with a stoma through engaging patients, caregivers, doctors, politicians and representatives of the media.</p> <ul style="list-style-type: none"> • The Organisation expands its membership base. • The members are interested in the enterprises and initiatives of the organisation. • Numerous integration trips and meetings are organised. • Good and regular contact of the stoma volunteers with hospital in the Płock region. • The Organisation is active in the media and participates in the life of the city and region.
Members / workers / volunteers / range:	<ul style="list-style-type: none"> • 30 members / 0 employees / 3 volunteers • Primary organisation with a local range (Płock region)
Individual support obtained in the project	<ul style="list-style-type: none"> • Consulting activities in developing the Strategy and Implementation Plan • Team coaching in attracting and activation of members • Team coaching in team building skills • Organizational consulting in the scope of acquiring material assets, including the premises
Project results Good practices	<ul style="list-style-type: none"> • Diagnosis and Strategy developed with Implementation Plan 2017 - 2020 • Increase in knowledge and skills in attracting and activating members • Increase of knowledge and skills in team building • Increase in knowledge in possible actions to acquire premises

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: Polish Association for Children with Epilepsy

Organisation's Mission:	We are an organisation that actively helps people in need, combating their disease, members of the Association and their families and also every person who comes to the organisation. We work to increase social awareness and understanding of the situation of the people with epilepsy.
Organisation's Vision:	<ul style="list-style-type: none">• Creation of the club for young people with disabilities, a place for integration.• The Great Orchestra of Christmas Charity is playing for patients with epilepsy and they obtain medical equipment.• Creation and functioning of a reference centre for epilepsy diagnostics and treatment.• Cyclical social campaigns, including the red cap.• First aid during a seizure as a part of first aid lesson in schools.• Social awareness and getting acquainted with the subject, overcoming fear of epilepsy.• Appropriate medical help.
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 35 members / 0 employees / 4 volunteers• Primary organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Coaching in assertive communication skills• Consulting in the area of the mini project Training on Clinical Epileptology for Doctors• Consulting and creating an online database to contact patients
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and assertive communication skills• Developed online database and increase in knowledge in database support• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them• Designed aims, assumptions and schedule of the Training on Epileptology - good practice

Organisation: Retina AMD Poland

Organisation's Mission:	AMD Poland mission is to support people who are losing their sight due to incurable retinal diseases so that the patients feel they are not alone, that despite the lack of treatment they may live decently, have rehabilitation, gain knowledge and enjoy their lives. We are a professional, competent organisation that represents the interests of people who are losing their sight before policymakers and other interested parties: scientists, rehabilitators, doctors. We acquire and spread knowledge on retinal diseases.
Organisation's Vision:	<ul style="list-style-type: none"> • Equal access to treatment and clear, transparent procedures of treatment. • The Organisation is competent, extends knowledge and qualifications of its leaders. • The Organisation has a regional clubs that locally support patients (at least one or two clubs in each voivodeship). • A strong organisation that is reckoned with by policymakers. • The Organisation has stable financing sources for operating expenses (e.g. office). • Good, honest and friendly relations inside the organisation. • More persons are active in the management board.
Members / workers / volunteers / range:	<ul style="list-style-type: none"> • 417 members / 0 employees / 3 volunteers • Primary organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none"> • Consulting activities in developing the Strategy and Implementation Plan • Coaching in assertive communication skills • Organisational consulting in organisation and activity of the association
Project results Good practices	<ul style="list-style-type: none"> • Diagnosis and Strategy developed with Implementation Plan 2017 - 2020 • Increase in knowledge and assertive communication skills • Increase in knowledge and skills in communication, presentations, negotiations • Increase in knowledge in project management, gaining new members and activating them • Increase in knowledge of organization and activity of the association

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: Association fighting against Lungs Cancer - Branch in Szczecin

Organisation's Mission:	Improvement in the situation of patients with lung cancer, especially direct help to people: information and psychological support, help in obtaining a drug programme, renting equipment, integrating patients, education, information. Familiarising the society with the issue of lung cancer.
Organisation's Vision:	We want to attract the society's attention to the threats influencing increased incidence of lung cancer in Poland and to unite patients, caregivers, healthcare specialists, politicians and representatives of media in the fight against the disease.
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 18 members / 1 employee / 0 volunteers• Primary organisation with local range (West Pomeranian Voivodeship)
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Workshop on fundraising for patient organisations• Coaching in assertive communication skills• Consulting in the mini project "Pogoń Raka" Educational Run
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and assertive communication skills• Increase in knowledge and skills in applying for national and EU funding• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them• Set aims, assumptions and initial schedule of the "Pogoń Raka Run" - good practice

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: Association of Patients with UIC "Uro Conti" – Wielkopolski Branch

Organisation's Mission:	We are an open and supporting community of patients with UIC that voluntarily serves people through educating activities and open solving of problems connected to UIC, helping at the same time to increase the degree of comfort and joy of life.
Organisation's Vision:	<ul style="list-style-type: none">• The Organisation has numerous members and is important and has regional branches (Szamotuły, Wągrowiec and 2 others).• The Organisation works free of charge in a granted office.• There is a prostate section in the organisation.• It offers exercises for women who have delivered babies, which are free of charge.• It performs extensive information and prevention actions.• UIC is a recognised disease thanks to consequent actions of Greater Poland Branch of "UroConti" in cooperation with other branches of UroConti".• Barriers are reduced and there is greater social awareness of UIC.
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 100 members / 0 employees / 0 volunteers• Primary organisation with local range (Wielkopolski / Greater Poland Voivodeship)
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Workshop on fundraising for patient organisations
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and skills in applying for national and EU funding• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them

Organisation: Association helping Patients with Blood Cancers in Zamość

<p>Organisation's Mission:</p>	<p>The Organisation's activity is based on social work of its members and it is aimed at helping patients with blood cancers and their families. The association was created to help to organise the new Ward of Haematology. The Organisation offers educational and prevention activities among patients and their families and participates in bone marrow donation actions and others. It belongs to PKPO and international structures and wants to be present where issues connected to patients with blood cancers are raised.</p>
<p>Organisation's Vision:</p>	<ul style="list-style-type: none"> • The association will develop and gain new members. • The association will have greater financial support. • The Ward of Haematology will work, the threat of closure (by NHS) is gone. • Appropriate number of specialist doctors will be acquired. • The association will focus on supporting patients and their families. • The association will expand the patient's library. • The association will strengthen its efforts for education and prevention. • The association will undertake actions to include elderly patients (over 70-year-old) and the ones, who, due to their disability, need to commute over long distances or financial difficulties, could not engage into the association's activities. • The Statutes will be changed so as to add patients as supporting members and introduce the possibility of exemption from the obligation to pay membership fees. • The association reaches those most in need and covers them with its support, informative, educational and prevention activities.
<p>Members / workers / volunteers / range:</p>	<ul style="list-style-type: none"> • 31 members / 0 employees / 7 volunteers • Primary organisation with local range (Eastern part of Lublin Voivodeship)
<p>Individual support obtained in the project</p>	<ul style="list-style-type: none"> • Consulting activities in developing the Strategy and Implementation Plan • Coaching in assertive communication skills
<p>Project results Good practices</p>	<ul style="list-style-type: none"> • Diagnosis and Strategy developed with Implementation Plan 2017 - 2020 • Increase in knowledge and assertive communication skills • Increase in knowledge and skills in communication, presentations, negotiations • Increase in knowledge in project management, gaining new members and activating them

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: Polish Society for the Support of Patients with Idiopathic Pulmonary Fibrosis-IPF

Organisation's Mission:	Polish Society for the Support of Patients with Idiopathic Pulmonary Fibrosis-IPF is an organisation that works for the patients and their relatives. It is an active organisation undertaking actions for providing easy access to reimbursed drugs and specialist knowledge of the disease.
Organisation's Vision:	<ul style="list-style-type: none"> • Sharing the knowledge of the disease. • Transparent working methods. • Extensive network of active volunteers working for the patients and sharing the knowledge of the disease. • Thriving central office of the organisation taking care of stability of its functioning. • Attention to the highest level of diagnostics and availability of treatment. • Activity all over the country, gaining ambassadors of the organisation.
Members / workers / volunteers / range:	<ul style="list-style-type: none"> • 57 members / 0 employees / 0 volunteers • Primary organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none"> • Consulting activities in developing the Strategy and Implementation Plan • Workshop on fundraising for patient organisations • Coaching in assertive communication skills
Project results Good practices	<ul style="list-style-type: none"> • Diagnosis and Strategy developed with Implementation Plan 2017 - 2020 • Increase in knowledge and skills in applying for national and EU funding • Increase in knowledge and assertive communication skills • Increase in knowledge and skills in communication, presentations, negotiations • Increase in knowledge in project management, gaining new members and activating them

Organisation Association of Families of Patients with Marfan Syndrome

Organisation's Mission:	Innovative application of unique knowledge, life experiences of families of the patients with Marfan Syndrome and of their potential to increase the quality of life and offer development to each person under the organisation's care in a changing social situation.
Organisation's Vision:	<ul style="list-style-type: none">• Working Marfan Poland Monitoring and Therapeutic Centre that comprehensively uses the experiences of the Association and the world-wide knowledge.• System of elective development of talents of the patients with Marfan syndrome (patronage - comprehensive support in focused development, promotion and use of talents).• Developed website presenting the latest medical and therapeutic treatment guidelines to be used in Poland and abroad.• Access to packages of knowledge and information tailored to the needs of specific groups.• Constant refinement of management of knowledge base availability (intuitive navigation).• Constant cooperation with researchers and practitioners in the areas related to healthcare in order to develop the knowledge base.• Promoting the latest technologies in the areas of ophthalmology, cardiology, traumatology, orthopedics, pulmonology and facilitating access to those technologies.• Developing the passion of joyful life through sharing experiences and information (e.g. through organisation of cyclical meetings and projects).
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 171 members / 2 employees / 13 volunteers• Primary organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Team coaching in attracting and activation of members• Consultancy activities in the Organisation Ambassadors Project
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them• Developing assumptions of the Organisation Ambassadors Project - good practice

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: Polish Association of Patients with Phenylketonuria and Rare Diseases "Ars Vivendi"

Organisation's Mission:	The aim of the Association is to offer comprehensive assistance to patients with phenylketonuria and rare diseases and ultra rare diseases, genetic metabolic diseases and to help the patients' families as well as to act for public benefit, taking into account broad social goals. The association has the status of a Public Benefit Organization (OPP), it represents interests of patients and works for building strong patient movement in order to create the opportunity to influence policymakers and politicians.
Organisation's Vision:	<ul style="list-style-type: none">• The association is engaged in educational activities, trainings and sharing information on the disease, ways of keeping diet, threats and effects of the disease being not treated, access to specialist phenylalanine-free food and purchasing opportunities.• The association organises "working" meetings of patients and parents, where they share their experiences in their fight with the disease and plan their future joint actions.• The association provides leisure and entertainment to children. It organises didactic and leisure events, integration meetings, summer leisure in facilities, where maintaining proper diet is provided.• The association works for greater accessibility of specialist low-protein food necessary for maintaining proper diet.
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 720 members / 2 employees / 18 volunteers• Primary organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Workshop on fundraising for patient organisations
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and skills in applying for national and EU funding• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them

Patient Organisation Charter / EPF Capacity Building Programme in Poland

Organisation: ORPHAN Rare Diseases Forum

Organisation's Mission:	The Organisation works for systemic changes in care over patients with rare diseases. The Forum solicits for creation of consistent system of treating rare diseases that would offer effective model of coordination of treatment process and social care. This system is described in the National Plan for Rare Diseases.
Organisation's Vision:	<ul style="list-style-type: none">• Raising social awareness of the meaning of therapy of severe rare conditions.• Introduction of a long-term policy that would ensure emergency and constant funding of highly-specialised treatment and therapies and proper care for patients.• Our aim is to provide the same medical assistance and adequate social support for patients with rare disease as in the rest of the European Union countries• Creation of consistent system of treatment of rare diseases that would ensure effective model of coordination of treatment process and social care. The model where management of cases of rare diseases from the moment of performing diagnostics, through treatment and rehabilitation is based on a united national system.
Members / workers / volunteers / range:	<ul style="list-style-type: none">• 32 member organisations / 0 employees / 8 volunteers• Umbrella organisation with a nationwide range
Individual support obtained in the project	<ul style="list-style-type: none">• Consulting activities in developing the Strategy and Implementation Plan• Workshop on fundraising for patient organisations
Project results Good practices	<ul style="list-style-type: none">• Diagnosis and Strategy developed with Implementation Plan 2017 - 2020• Increase in knowledge and skills in applying for national and EU funding• Increase in knowledge and skills in communication, presentations, negotiations• Increase in knowledge in project management, gaining new members and activating them

Selected achievements of the implementation phase:

Short after having worked on strategy within the CBP, 6 organisations reported the first successes:

- ✓ IPF – implemented regular meetings of management board
- ✓ 3majmy się razem – succeeded in activating more members to engage in everyday work
- ✓ UroConti got in touch with another NGO with the aim to start cooperating with them
- ✓ Retina – engaged a new volunteer to support their team
- ✓ National Association of Patients with CML – have more members participating in trainings for patients
- ✓ Marfan – started the activity of newly designed Association Ambassadors project

Trainers/coaches from ResPublic:

- ❖ Mr. Jacek Dębczyński (strategy, project management, interpersonal communication)
- ❖ Mrs. Agnieszka Esz (strategy, interpersonal communication, assertive communication)
- ❖ Mrs. Agnieszka Garbolińska (social research, strategy)
- ❖ Mr. Grzegorz Romańczuk (strategy, databases)
- ❖ Mr. Łukasz Wielec (financing, EU funds)
- ❖ Mrs. Edyta Rosińska-Wielec (media communication)
- ❖ Mr. Bartosz Olszewski (communication, negotiations)

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