

INFORMATION BROCHURE
ACTIVE CITIZENS FUND BULGARIA
EEA Grants 2014-2021

“Empowering people with rare diseases” project



EmpowerRARE

Call for strategic projects (thematic priorities 3, 4 and 6, administered by the Workshop for Civic Initiatives Foundation)

Thematic Priority #3: Empowering vulnerable groups

Specific objectives of the project:

Training of representatives of vulnerable groups in advocacy for the needs of their communities, as well as support for their advocacy campaigns

Project Name: Empowering People with Rare Diseases - EmpowerRARE

Beneficiary: Bulgarian Huntington Association

Partner: Frambu Resource Center for Rare Disorders

Project management team

Nataliya Grigorova - Project Manager, BHA

Vedar Georgiev - Project Coordinator, BHA

Rositsa Sechkova - Project Accountant, BHA

Lisen Julie Mohr - Coordinator of activities and communication with partner organization Frambu

Project Implementation Team

Constantine Economides - Cross-Sector Cooperation Expert, BHA

Øivind Juris Kanavin - Rare Disease Expert, Norwegian partner organization Frambu

Presentation of Active Citizens Fund Bulgaria

Support for civil society is a key priority for the **European Economic Area (EEA) Financial Mechanism 2014-2021 funded by Iceland, Liechtenstein and Norway** in 15 EU Member States in Central and Eastern Europe and the Baltic States. Ten percent of all funding is earmarked for a civil society program in each beneficiary country. The Active Citizens Fund program was created as part of the “Culture, Civil Society and Fundamental Rights and Freedoms” priority sector, one of the five priority sectors agreed between donors and the European Union.

The **Active Citizens Fund Bulgaria** is worth a total of EUR 15 500 000, provided entirely by the donor countries - **Iceland, Liechtenstein and Norway**. The program will operate until 2024 and will contribute to the achievement of the common objectives of the EEA Financial Mechanism and the Norwegian Financial Mechanism, **to reduce economic and social disparities and to strengthen bilateral relations between the beneficiary countries and the donor countries.**

The purpose of the Active Citizens Fund is **"Strengthened civil society, active citizens and empowered vulnerable groups"**. The Fund will support the long-term sustainability and capacity of the civic sector, strengthening its role in promoting democratic participation, active citizenship and human rights.

As part of the Call for Proposals, initiatives will be supported by civil society organizations contributing to:

- Improved democratic culture and civic awareness
- Support for human rights
- Empowering vulnerable groups
- Gender equality and prevention of gender-based violence
- Increasing citizens' commitment to environmental protection / climate change
- Improving the capacity and sustainability of the civic sector, including civic organizations

www.activecitizensfund.bg is the official site of the “Active Citizens Fund Bulgaria” Program. The Fund Operator is not responsible for information and documents related to the implementation of the Program, published elsewhere, unless otherwise stated on the official site of the Program.

Introducing the project partners

Beneficiary of the project - Bulgarian Huntington Association



Established in 2014 as a public benefit non-governmental organization, Bulgarian Huntington Association (BHA), since its foundation, has as one of its main goals the empowerment and support of families affected by Huntington's Disease. Subsequently, having recognized the significant lack of support for thousands more rare diseases, the organization also directs its efforts in providing support and care through social services. Incurable, rare diseases cause severe complex damage that puts the sufferer and his family in extreme mental and physical stress and socioeconomic isolation. Over the years, the organization has provided funding for a number of projects aimed at fulfilling its mission, and in 2017 it built a small Center for People with Rare Diseases, in a space provided by the Sofia Municipality. In 2018, BHA won the First Prize for Innovative Social Service from Sofia Municipality. BHA has a high level of expertise due to the many years of experience in the field, which is also fuelled by the constant exchange of knowledge with NGO from Europe and with experts from the Social Policy Advisory Group at EURORDIS, the largest organization for people with rare diseases in the world. BHA has successfully implemented a number of projects with national and European funding, and through EmpowerRARE will build on what has been achieved so far to bring awareness to the needs of people with rare diseases and facilitate their immediate inclusion in social policy. Empowerment of people with rare diseases is inevitable because of the seriousness of the consequences on society as a whole.

Website: <http://www.huntington.bg>

**Partner in the project - Frambu Kompetansesenter for sjeldne diagnoser
/ Frambu Resource Center for Rare Disorders**



The Rare Disease Resource Center Frambu Kompetansesenter for sjeldne diagnoser, is the national rare disease resource center in Norway. Its mission is to provide world-class expertise, knowledge and services for more than 120 rare diseases.

Frambu collects, develops and disseminates knowledge about rare diseases and disorders to individuals, with and without rare diseases, to their relatives and families and to the professionals who work with them.

The main purpose of the resource centre's activity is to ensure that children, adolescents and adults with disabilities caused by rare diseases are able to live a harmonious life in accordance with their health, needs and wants.

Website: <http://www.frambu.no>



February 29 marks the World Rare Disease Day, and people and organizations from around the world join in hundreds of events to mark the occasion.

Some data on rare diseases

On 29 February 2016, hundreds of events took place in 85 countries, involving patients and other groups, researchers, healthcare professionals, carers working in the healthcare sector and various institutions, so the voice of sufferers from rare diseases could be heard! The event was organized by Eurordis.

"The fight against rare diseases requires a rare degree of cooperation.

Patients with rare diseases often experience other suffering that can be as damaging as their illness. Isolation. Feeling that no one else knows what they are experiencing, that no one knows how to help them, that they are not investing in finding effective drugs or treatments, because there are not enough people who need them. "

Til Voigtlander, Austria's representative on the Rare Diseases Expert Group and an expert on the Council of Member States on European Reference Networks.

2019 has been marked as the **Year of Rare Diseases in the European Union**, thanks to a strong Eurordis campaign to keep the general public, policy makers and researchers informed about the problems faced by patients with rare diseases.

According to the definition of a rare disease, a rare disease affects no more than 1 in 2000 people. But the nearly 6000 species of rare diseases identified together affect a total of 30 million people in the EU.

In 1999, the European Commission launched its first initiative with the drafting and subsequent adoption by the European Parliament and the Council of Regulation EC 141/2000 on orphan drugs, which provided clear incentives for the pharmaceutical industry to invest in the development of rare diseases drugs. This was followed by further activities and successes, such as the continued support and co-financing of Orphanet, which is currently the world's leading reference database for rare diseases, and facilitating its rapid expansion in practically all EU countries and beyond.

Over time, these initiatives have attracted new and emerging key players for the common purpose of helping people with rare diseases. As a result, the European Commission is currently working closely with Member States, the European Medicines Agency, healthcare providers, patients and stakeholders, including patient organizations, such as EURORDIS, which organizes Rare Disease Day on the last day of February each year to raise awareness. This kind of cooperation is not only taking place outside the Commission, but also within it - DG Food and Food works in collaboration with DG Research and Innovation, both of which cooperate with the Joint Research Center of the Commission.

The latest innovation in connecting many European stakeholders, initiated by the Commission, is the creation of European reference networks. These networks are based on the voluntary involvement of healthcare providers across Europe and aim to help patients more easily access highly specialized care, to promote European cooperation in highly specialized healthcare and to improve diagnosis and diagnosis. services in those areas of medicine where expertise is scarce. Networks will also help Member States with too few patients to provide this type of highly specialized service, contribute to accelerating the penetration of innovation in medical science and health technologies and serve as centers for medical training and research, dissemination and assessing information, ultimately lifting healthcare to a new level of clinical and scientific networking, as has never been the case in Europe or in other parts of the world.

The Rare Diseases Expert Group assists the Commission and its partners by drafting legal instruments and policy documents and providing guidance and recommendations. This group advises the Commission on international cooperation, provides an overview of Union and national policies and organizes exchanges of experience, policies and practices in the relevant field between Member States and various other actors.

On February 29, 2016, hundreds of events took place in 85 countries, involving patients and other groups, researchers, healthcare professionals, carers, working in the health sector and various institutions to hear the voice of those suffering from rare diseases. The event was coordinated by Eurordis.

The European Medicines Agency has launched the PRIME (PRiority MEDicines) scheme, which builds on existing EU regulatory instruments, to better support the speeding up of work on medicines intended to meet unmet medical needs. The document on the current status of so-called 'orphan drugs' for rare diseases describes the incentives provided by the European Union and the Member States to support research into, development of and access to orphan drugs.

Rare diseases - for the patient, his relatives, the community and society

The long wait for a diagnosis of a rare disease

The average time to diagnose a rare disease worldwide is about 5 years. These are years of research, ambiguity, symptomatic treatment and excruciating anxiety for a person suffering from a rare disease. In the meantime, patients are exposed to the symptomatic treatment of the risks of medical errors and severe side effects. On average, patients attend 7.3 specialists, with 40% of patients reporting that delayed diagnosis had a significant or very strong impact on their health status. The WHO estimate is that about 6-8% of the world's population is affected by rare diseases, which means that an improvement in diagnosis procedures would affect more than 460-620 million people worldwide.

This very small percentage of the population affected shows why advances in the diagnosis and treatment of so-called 'rare diseases' are of global importance and why any new quality of life support for affected people initiative - like our project - has strong social significance.

Summary of the “Empowering people with rare diseases” project - EmpowerARE

In Bulgaria, people diagnosed with rare diseases suffer from lack of empowerment due to poor awareness, lack of treatment and follow-up care. Social services specializing in the needs of people with rare diseases are completely lacking. Rare diseases are not part of any national or local strategy for developing social services or long-term care. The aim of the project is to contribute to reducing social disparities in the EEA by empowering a vulnerable group of people with rare diseases to participate in social policy reforms, launch an innovative modern social service, and strengthen bilateral relations between donor countries and beneficiary countries. EmpowerARE will achieve civic activation of people with rare diseases, some of them from disadvantaged geographical regions and groups (Roma), to formulate recommendations for improving their social rights in the country.

The project will contribute to solving the problems of people with rare diseases by increasing the capacity of people with rare diseases for civic activity, creating training and information materials, transferring information on good practices of social services from Norway, proposals to the institutions

towards improving and reforming social services and policies, identified 'lessons learned'.

The target groups of the project are: main - public institutions, end users - people with disabilities (with the exception of mental disabilities) and Roma. The direct beneficiaries are people with rare diseases, including Roma and public institutions with responsibilities in the field of social policy and services.

Expected results of the partnership

The expected outcome of the partnership is to familiarize yourself with the experience and best practices of the donor with years of service models and experience in empowering people with rare diseases. In order to achieve the desired project results, it is necessary to work with a partner in order not only to propose the introduction of new specialized services for the target group, which are currently missing in Bulgaria, but also to be judged on the basis of experience and consulting with professionals the portability, effectiveness and efficiency of the support provided.

The partnership will help achieve the specific objective of the priority chosen with the experience and knowledge of donor professionals what works in the process of empowering the vulnerable group. This will save time, effort and money when we take advantage of the lessons learned. In addition to the direct contribution of the partnership to the implementation of the project, we expect to achieve sustainable effects by making the cooperation permanent. Working together on the topic creates the opportunity for long-term partnerships, sharing of knowledge, experience and the initiation of new events for the benefit of the target group.

Establishing a lasting partnership will contribute to broader cooperation in the rare diseases sector, where Bulgaria is still lagging behind in the health and social services offered.

Description of the problem and context

In Bulgaria, over 400,000 people suffer from rare diseases. The National Rare Disease Strategy 2009-2013 states that "patients with rare diseases represent a group with many unresolved medical and social problems that remain unknown and hidden from the public. These people are vulnerable and discriminated against because they have violated one of their fundamental human rights. " At present, rare diseases in Bulgaria are not integrated into social policy and services, and their specific and urgent needs are not met. In 95% of cases incurable, rare diseases lead to social exclusion, socioeconomic instability, complex disability, poor survival and poor quality of life. Integrating rare diseases into social policies and empowering them through access to good practices and training is a way for thousands of people living with rare diseases to receive guarantees and respect for their human rights.

Relationship of the project with the Active Citizens Fund and the selected thematic priority

EmpowerRARE is a long-term project that empowers and activates people with rare diseases, provides sustainable solutions to identified problems with the imperfection of the law. We have chosen the Fund due to compliance with the main objectives. By empowering people with rare diseases and contributing to social policies and services that meet their real needs, the project contributes to reducing economic and social disparities in the European Economic Area. We will achieve the specific goal of mobilizing our expertise and upgrading to the benefit of the target group through a series of empowerment trainings, supporting social policy reforms, integrating innovation in social services, sharing information and good practices with our partner.

Stakeholder involvement and liaison with the needs of the target groups

A problem with the lack of social policies, regulations and laws addressing rare diseases has been communicated and identified. The low number of patients with the same disease is the reason for the lack of capacity to assert rights. We have consulted with rare disease patient organizations and university experts to partner with. We also took into account the needs of people with other disabilities who sought help from us living in remote regions and / or with impeded access to services. The specific needs of that group will be met by contributing to the improvement of legislation. The target groups will be involved by participating in events, submitting an analytical feedback report and civic recommendations, submitting recommendations for the inclusion of rare diseases in the law on social services.

EmpowerRARE is aimed at people with rare diseases, people with disabilities whose needs are mentioned only in the National Strategy for Rare Diseases 2009-2013, which states that their fundamental human rights are violated not only in Bulgaria but also in Europe. Only 5% of rare diseases have treatment, which is accessible in Bulgaria after advocacy campaigns in the media. Rare diseases are unknown, incurable, often sensitized because of their low numbers, those affected cannot effectively assert their rights. The needs of people with rare diseases are not met and as far as their social rights are concerned, rare diseases are not integrated into social policy and social services. Apart from the lack of public policies, people with rare diseases living in remote areas or those with severe disabilities often do not have access to any social services, which puts them in extreme marginalization.

Main target groups: Public institutions (at national and local level) (

Direct beneficiaries: Patients with and close to those with rare diseases

End users: People with disabilities (except mental disabilities)

Project activities:

Sharing experiences and good practices for building a Bulgaria-Norway partnership in the field of rare diseases

The project will explore the Norwegian model of providing support services for people with rare diseases through:

- 1) a working visit of 2 Bulgarian experts and 2 representatives of end users in Norway
- 2) submission of a Report on identified good practices to the partner
- 3) Bilateral Information Seminar in Bulgaria for introducing and thus empowering the target group with practices in Norway with presentations of the Norwegian experience by 3 Norwegian experts
- 4) Presentation of the Norwegian experience and the final Roundtable for presenting the results and discussing project opportunities
- 5) Coordination of the Long-term Partnership Agreement

The objective of the experience-sharing and good practice activity is to contribute to improving cooperation between the two countries in the field of rare diseases and empowering end-users by sharing good practices, learning from experience and acquiring knowledge of existing state models and measures treatment of rare diseases in donor countries.

The activity is for people with disabilities and public institutions in Bulgaria who will be familiar with portable Norwegian good practices in providing services and support for people with rare diseases, experts and activated advocates from the target group, whose capacity to contribute to the introduction of innovative specialized support services for Bulgaria will be increased. The activity also applies to Bulgarian and Norwegian organizations working to support people with rare diseases and who through partnerships will be able to share their experiences and learn from their mistakes and achievements to improve support for people with rare diseases. The Bulgarian participants in the working visit to Norway will be selected by the project teams according to their expertise, and the participants from the target group, which we envisage, by the activity of their involvement in the Advisory Board and in advocacy. Participants in the development of the reports and the proposal to the public institutions will also be selected on the basis of expertise and involvement.

Expected end result of the activity

Strengthening international cooperation between beneficiary countries and donors by building a Bulgarian-Norwegian partnership in the field of rare diseases and connecting active / activated people with disabilities on both sides to share experiences. As the Norwegian partner will be the lead partner

in this activity, the activity will give as a result and improved understanding of the Bulgarian context among the Norwegian resource centers by sharing the identified cultural differences among interested colleagues, which is also valid for the Bulgarian partner. Both partners will increase their cultural competence.

Empowering people with rare diseases through training

This main project activity will be implemented in 5 stages:

1. Consumer Survey: Will prioritize empowerment training topics
2. Identification of good advocacy practices initiated and implemented by vulnerable / unauthorized groups
3. Empowerment through training (offline and online): introduction of good practices from Bulgaria and Norway - 3 training seminars (Sofia, Plovdiv, Varna) with participants from all over the country;

Empowering training topics:

- What are the rights of people with rare diseases in the EU?
- What is the situation in Norway - rights, laws, work strategies? What is the situation in Bulgaria?
- What is advocacy and how does it improve the situation of vulnerable and unauthorized groups to achieve equality?
- Which institutions should we turn to?
- Communication skills - how to express a position?

Practical classes:

- how to relate a case
- how to formulate an opinion and a recommendation

4. Creating a Custom Advisory Board

5. Participation of 2 active users in a partnership meeting in Norway.

Who the activity targets and the involvement of direct users

The activity relates directly to end users, people with disabilities from rare diseases, some of them Roma, and indirectly to public institutions responsible for the care of these people.

End-user participants will be selected according to their degree of disability to allow them to be active after explanatory motivational meetings with them. According to their opportunities for inclusion, they will be included in the

training offline, online and / or blended, and the training will be delivered in three groups of participants from the 6 planning regions of the country to enable the capacity building of the target group in all regions. with a view to further multiplying empowering learning.

The participants will be people with rare diseases, among which members of the Consumer Advisory Board will be selected based on activity, communication skills, organizational and leadership skills, and will seek to have one representative due to the specificity of the target group. and the Roma community.

Methods used and resources required for implementation

The needs study will be conducted through surveys and in-depth interviews conducted at consumer meetings during 3 regional tours, combined with a motivating campaign for readiness to participate in seminars and advocacy. An end-user Advisory Board will then be set up, with work schedules and communication channels. Empowerment through training we will use the blended learning method (offline regionally and online), with flexible involvement of consumers due to their health status. Some will only join online with additional advice. The training will also include hands-on skills for expressing positions. Knowledge of good practices will be made during the visit to the partner. Based on the collected material, a Compendium of Good Practices will be prepared and published online. The necessary resources for the implementation of the activity are expert researchers trainers, facilities and financial resources to cover the costs of necessary external services and hard work.

Outcome of the activity:

With the successful implementation of the activity, the expected result is the achievement of empowerment and activation for civic participation of end users. To achieve this, the following interim results will be achieved: submission of an end-user needs study in a report; the establishment of a User Advisory Board, training materials and a Compendium of Good Practices from Donor Countries; conducting 3 empowerment trainings; launching an offline and online advocacy campaign to realistically meet consumer awareness needs of the institutions and the general public.

Empowering people with rare diseases through an advocacy campaign

The activity envisages activation of people with rare diseases in an advocacy campaign for their rights to equality, initiated and implemented by them, with the support of the project team for further development of their capacity for social activity and supporting motivation in the face of difficulties.

Main sub-activities:

1. Initiating an Advocacy Campaign. As a consequence of the trainings that have developed the communication skills with the institutions and the

motivating activity of the team during the visits, and the ideas of advocacy formulated by the participants-participants during the trainings, the Advisory Board, supported by the necessary material base, will initiate an advocacy campaign for the rights of the participants. people with rare diseases.

2. Advocacy for institutions: Submitting opinions on (in) accessibility and quality level of accessible social services, formulating recommendations for improvements, lobbying for desired new services.

The activity is directly related to end users, people with disabilities of rare diseases, some of them Roma, and indirectly to all people with disabilities and public institutions responsible for the care of these people. All direct participants in the project from the target groups will be invited to join the advocacy campaign. The main organizer and

Advocacy Campaign Coordinator will be an Advisory Board composed of project end-user representatives, who will maintain communication with people with rare diseases and encourage their participation in the advocacy campaign by contacting the project team when advice or other legal support is needed. consultation. Parents, young people - children of people with rare diseases, other relatives and NGO activists will be invited to join the campaign.

The advocacy campaign will be prepared with a motivating activity of the project team for visits of people with rare diseases, with trainings for capacity building and building of a Consumer Advisory Board as an organizational center of the target group. Following the training, the Advisory Board, assisted by the project team, will develop a work schedule for the advocacy campaign and specify the communication channels. According to the views expressed by people with rare diseases regarding the access, quality and availability of the necessary and desired social services, opinions and recommendations will be submitted to institutions, publications and media will be prepared. Presentations by people with rare diseases for the Final Roundtable will summarize their activities and recommendations. Necessary resources for the implementation of the activity are the built expertise of people with rare diseases, a financial resource for paying the labor of consumers from the Advisory Board.

Outcome of the activity

The expected outcome of the advocacy campaign is two-way: (1) to increase the capacity of consumers to disseminate information about a problem, build support / find allies, influence others for support, influence the desired support. Consumers will practically learn the skills of the 5 advocacy steps: identifying, exploring, planning, acting and evaluating and how to build a support coalition after identifying stakeholders as opponents, neutrals or opponents of their cause. (2) to provide useful feedback to public institutions.

The outcome of the advocacy campaign is expected at the end of the project, after its evaluation, for which users will also be trained and supported - to

evaluate whether the campaign objectives have been achieved, whether the messages have been delivered, the data found and used. were correct and timely decisions taken, was a coalition built to support it, what was the quality of governance? In addition to the consumer self-assessment of the campaign will be evaluated by the project team.

Analytical activities - studies and reports

Provides support for guaranteed access for people with rare diseases to specialized social services. In addition to the initial needs study, the project will periodically collect, summarize, analyze and submit to public institutions at national and local level, a Report with Recommendations on the Integration of Rare Diseases into the Law on Social Services and Social Policy such as whole. The aim of the activity is to contribute to improving access to innovation in social services and mainstreaming rare diseases in social policy.

- 1) Study the needs of the target group presented in the analytical report;
- 2) Report to the concerned public institutions at national and local level with recommendations regarding the integration of rare diseases in the law on social services and social policy in general;

The activity concerns the empowered target group, the public institutions and other stakeholders and the general public, who, through online submission of the reports and the direct evaluation of the users for their satisfaction with the provided digital social service, will become acquainted with the possibilities for introducing digital services. to remote places and will hear the voice of people with disabilities in advocacy for access to their desired services. The participants in the implementation of this activity will be selected according to their expertise - for the participants from the executive team; for the participants from the users - by their activity and the ability to analyze feedback information proven during the consultation period. End-users will have the opportunity to contribute to lobbying for desired new services by outsourcing a summary end-user evaluation, assisted by an expert from the executive team.

Project communication plan, including description of results dissemination and publicity measures

A communication strategy and plan have been developed that will be enriched to the best of our ability. The dissemination of the results in Bulgaria and Norway will be ensured according to a prepared list of relevant target audiences - public institutions and organizations of people with rare diseases and other disabilities. Communication channels - own media (applicant and partner website and project bulletin in Bulgarian and English), social media, 3 information materials and a set of training materials (printed and online) Key messages: Show your rare. Show you care, Nobody Will Be Left Behind, The disease is rare, but the care shouldn't be. Language of communication -

according to the target audience and the channels used, with the presentation of true stories.

Monitoring indicators - timing and frequency reporting, degree of timely coverage, level of use of different communication channels and their compliance; quantitative: number of media events, participants, publications, project bulletin; Quality: End-user involvement in formulating messages, stories and recommendations.

Sustainability of the project

The sustainability of the project is guaranteed by the capacity built and the activation of end users for social participation and motivation to contribute. The innovative service created in the project has a prospect of sustainability as it responds to a social need not covered by such a service, will be created in consultation with end users on how to provide it and will be submitted for budget financing approval together with an external evaluation from a university expert team on its quality, effectiveness and efficiency.

The project has:

1. Human resilience - capacity built

2. Institutional sustainability - the structures that allow the continuation of the activity (expert team with capacity building) will be maintained after the end of the project

3. Sustainability at policy level - the result of empowerment of end-users in a particular area of disability is subject to multiplication among people with other disabilities

The results of the project correspond to the four areas of sustainability:

-Human resilience: to maintain and improve the human capital of society;

-Social sustainability: preserving social capital through the creation of services;

-Economic Sustainability: Improving social equality and living standards through efficient use of environmental resources. In capacity building training, trainees will be informed how natural resources can be saved.

Monitoring and evaluation plan

Objects of monitoring and control are: activities, publicity and visualization, budget, resources, goals and results (according to set indicators), quality of performance, risks and problems. Monitoring tools: implementation reports, on-site visits to events and activities, verification of technical and financial documentation, meetings with stakeholders, collection of side information, project progress evaluations. Based on the monitoring data, periodic assessment of compliance, efficiency (cost, speed and managerial efficiency and quality of results achieved), effectiveness (contribution of the results to

the achievement of the project objective), impact, viability and sustainability of the project will be made. the context of its goals. The steps in the project evaluation follow the hierarchical structure of the project design. The project participants will get involved by completing questionnaires, reports, documentation, specific tasks, informal communication, active feedback.

More information about the project can be found at

The official website: www.empowerare.eu

Facebook: <https://www.facebook.com/empowerare/>

If you have any suggestions or want to get involved in any of the project activities you can contact the project manager Natalia Grigorova by sending an email to: natalia.grigorova@abv.bg

This document was created with the financial support of the Active Citizens Fund Bulgaria under the Financial Mechanism of the European Economic Area. The sole responsibility for the contents of the document lies with the Bulgarian Huntington Association and under no circumstances can it be assumed that this document reflects the official opinion of the European Economic Area Financial Mechanism and the Operator of the Active Citizens Fund Bulgaria.



Iceland
Liechtenstein
Norway

**Active
citizens** fund

Working together for an inclusive Europe



EmpowerRARE

The EmpowerRARE project is implemented with financial support from Iceland, Liechtenstein and Norway under the EEA Financial Mechanism. The main goal of the EmpowerRARE project is to empower people with rare diseases in Bulgaria.