

INFORMATION BROCHURE



The project

"EmpowerRARE2021"

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

Thematic priority № 3: Empowerment of 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 advocacy campaigns

Project name: "Empowerment of people with rare diseases-2021" - EmpoweRARE2021

Beneficiary: Bulgarian Huntington Association

Partner: Frambu Resource Center for Rare Disorders

Project management team

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Project implementation team

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Iceland 
Liechtenstein
Norway **Active citizens fund**

Presentation of the Active Citizens Fund Bulgaria

Support for civil society is a key priority for the **European Economic Area (EEA FM) 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 funds provided are earmarked for a civil society program in each beneficiary country. The Active Citizens Fund has been set up 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** has a total value of EUR 15,500,000, provided entirely by the donor countries - Iceland, Liechtenstein and Norway. The program will run until 2024 and will contribute to the common objectives of the EEA FM and the Norwegian FM to **reduce economic and social disparities and strengthen bilateral relations between beneficiary and donor countries**.

The aim 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 civil sector, strengthening its role in promoting democratic participation, active citizenship and human rights.

The competitions for project proposals will support initiatives of civil society organizations that contribute to:

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

Website: www.activecitizensfund.bg

Beneficiary of the project

Bulgarian Huntington Association



Founded in 2014 as a non-governmental organization for public benefit, since its inception, the Bulgarian Huntington Association has focused on empowering and supporting families affected by Huntington's rare disease. Subsequently, discovering the significant lack of support for thousands of other rare diseases, the organization focused part of its efforts on providing support and care for more rare diseases. Incurable, rare diseases cause severe complex injuries that put the sufferer and his family in extreme mental and physical stress, social and economic isolation. In 2017, BHA built a small Center for Support of People with Rare Diseases, for which in 2018 it won the First Prize for Innovative Social Service from Sofia Municipality. The organization has serious expertise due to its many years of work in the field, which is fueled by the constant exchange of knowledge with colleagues from Europe, as experts of the organization are part of the group of patient advocates in the European reference networks. BHA successfully implements a number of initiatives with state, European and private funding and through EmpowerRARE2021 will build on what has been achieved so far, to build sensitivity to the needs of people with rare diseases and their urgent inclusion in social policy. Empowering people with rare diseases is inevitable due to the seriousness of the consequences of diseases on society as a whole.

Website: www.huntington.bg

Project partner

Frambu Resource Center for Rare Disorders



Frambu is a private non-governmental organization and provides a meeting place for people diagnosed with rare diseases, their families and professional service providers.

The purpose of Frambu is to enable children, adolescents, adults and their families to cope better with a rare disease and to live in harmony with their conditions, aspirations and needs. The center has more than 25 years of experience in collecting, developing and disseminating knowledge about rare and unknown disabilities. Frambu provides services to more than 500 different rare diagnoses. This is done through an extensive and focused program of courses, counselling and guidance. Frambu is a nationwide center and offers services for people with rare diseases of all ages. The resource center offers summer camps, student internships and study visits. The daily expenses of the Frambu resource center are financed by the state. About 75 full-time employees work at Frambu and represent the most professional groups in the school and healthcare system. The center is large, functional and easy for people with disabilities. It has 72 beds and a fully equipped kitchen with staff who can offer most of the necessary specialized diets. Family courses usually last five days. While parents attend lectures and discussion groups, children are cared for at school and kindergarten. Courses aimed at professionals usually last one or two days.

Website: www.frambu.no

Description of the problem and the context

The European Public Health Commission identifies rare diseases as:

"Life-threatening or chronically disabling diseases that are so prevalent that special combined efforts are needed to address them."

In Bulgaria, more than 400,000 people suffer from rare diseases for which access to health care is unclear and difficult. For those for whom there is no treatment, social support is not provided in any form, despite incurable debilitating diseases. Social isolation is a constant compulsion, not a free choice for people with rare diseases, they are vulnerable and discriminated against, their basic human rights are violated. Rare diseases are not integrated into social and health policy and their specific and urgent needs are not met. Incurable in 95% of cases, these diseases lead to socio-economic instability, complex disabilities, low survival and deteriorating quality of life. Integrating rare diseases into supporting policies and empowering those affected, through access to good practice, training and support, is a way for thousands of people living with rare diseases to receive guarantees and respect for their human rights.

During the implementation of the first part of the EmpoweRARE project, the need to implement the identified good practices for the empowerment of people with rare diseases and the desire of the target group for practical continuation of activities was identified. People with rare diseases continue to be out of the focus of social policy and services, and their vulnerability during the pandemic has worsened due to the neglect of the deepening need for specialized support.

EmpoweRARE2021 aims to achieve continuous civic activation of people with rare diseases, empowerment through the transfer of good practices and upgraded advocacy skills. The project will contribute to solving this problem with training to increase the capacity of people with rare diseases for civic activity, creating of free access resources, building a national network for mutual assistance of people with rare diseases, counselling by "patient assistants", building a virtual resource platform for sharing and counselling, strengthening the connection between those affected by rare diseases and young people with the implementation of Summer camp for people with rare diseases.

Aim of the project

The main goal of the project is to achieve constant civic activity of people with rare diseases by building a network of mutual assistance and training aimed at increasing the capacity for self-advocacy and the implementation of good practices for empowerment.

Project activities

- Adapting experience to implement good practices and building long-term partnerships in the field of rare diseases
- Organizing and conducting a summer training camp modelled on Frambu and establishing a National Self-Help Network for people with rare diseases
- Establishment of a Virtual Resource Center and provision of consultations on the information telephone line by "patient assistants"
- Conducting online trainings for rare diseases according to the Frambu model
- Conducting an advocacy campaign by the established National Network for Mutual Aid of People with Rare Diseases

Expected results

- In the short term it is expected to create a strong, motivated and prepared community of people with rare diseases to meet their unmet needs in Bulgaria
- Long-term change in attitudes, policies and legislation on access to social and health support for people with rare diseases is expected

More information about the project can be found at:

The official website: www.empowerare.eu

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

We work together for a more inclusive Europe

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**Active
citizens fund**

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