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# EmpoweRARE

**Empowerment of People with Rare Diseases**

*The disease may be rare, but care shouldn't be*

**Newsletter**

**Issue 1**

**January 2020**

## Project information:

Project abbreviation: EmpowerARE

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Duration: 18 months

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Partner: FRAMBU, Norway

Official project website: <https://www.empowerare.eu/>

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



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[rarediseaseday.org](http://rarediseaseday.org)

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## Welcome

Dear Reader,

### **Welcome to the first newsletter of the EmpoweRARE project!**

The 'Empowerment of People with Rare Diseases (EmpoweRARE)' project is an 18-month EEA Active Citizens Fund funded project, which commenced in October 2019.

In this first issue, we introduce you to the EmpoweRARE project. The EmpoweRARE project aims to contribute towards addressing the challenges people with rare diseases face in Bulgaria by employing comprehensive measures, targeted specifically at empowering people with rare diseases. The measures aim to facilitate civic engagement for reforms in social policies and strengthen bilateral relations between the donor states and Bulgaria.

Our work in the field of rare diseases, networking with other stakeholders in the country and abroad and conducted research have revealed that empowerment of people with rare diseases and their care givers makes a difference. The partners of this project intend to contribute towards the empowerment of Bulgarians affected from rare diseases also by transfer and adaptation of good practices from Norway.

Empowered by information and training, people with rare diseases will have the knowledge and skills to exercise their democratic right for participation in decision making, lobbying for the necessary legislation that can ensure a decent life for them, and consult and advise national policies and strategies that affect them.

The project is being coordinated by the Bulgarian Huntington Association and implemented together with our Norwegian partner FRAMBU – Resource Centre for Rare Disorders.

*We hope you will enjoy reading our newsletter!*

## Introduction to the EmpoweRARE project

The EmpoweRARE project is a Bulgarian-Norwegian project which aims to contribute to reducing the social disparity in Bulgaria by empowering a vulnerable group of people to participate in civil society, to initiate social policy reforms and to strengthen bilateral relations between donor countries and beneficiary countries.

This will be achieved by transfer of good practices from Norway and bilateral collaboration towards empowerment of Bulgarians affected by rare diseases, so that they can more effectively exercise their human right for citizen participation in decision making for achieving equality in health and social services and thus improve their quality of life despite their diseases.

The 18-month long project started in the autumn of 2019. It is financially supported by the Active Citizens Fund of the Financial Mechanism of EEA and Norway as relevant to its thematic priority 2 – Empowerment of vulnerable groups.

The services developed through the EmpoweRARE project will be based on proven good practices, on the experience of the Norwegian Resource Centre for Rare Disorders, while the delivery of pertinent information to various stakeholders will be tailored to their needs and interests.

*The EmpoweRARE solutions encompass:*

1. Dissemination of information about proper legislation and good practices to beneficiaries, stakeholders and the general public.
2. Empowerment of people with rare diseases and their care givers through training.
3. Transfer of good practices from Norway to Bulgaria.
4. Collaboration between Bulgarian and Norwegian organizations active in the field of delivery of services and support to people with rare diseases.

The expected outcome of the partnership as added value, is to familiarize Bulgaria with the experience and best practices of the project partner, which has many years of experience in effective

service models and experience in empowering people with rare diseases. 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 between our respective organizations permanent. Working together on the topic creates an opportunity for long-term partnerships, sharing of knowledge, experience and 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.

The EmpowerRARE project will meaningfully enhance the awareness of the directly affected and the general public, through identification, interpretation and correlation of policies, strategies and good practices from multiple data sources, as well as their delivery via different media.

EmpowerRARE will adopt a user-driven approach with strong involvement of end users in the implementation and evaluation of the project and in the formulation of recommendations to institutions and policy makers. It will help people with rare diseases achieve civic engagement and to formulate, based on their experience and needs, recommendations for desired national reforms and development of new services.

## **Project Coordinator – Bulgarian Huntington Association**

The Bulgarian Huntington Association began as an effort to create a community of support, understanding and care for families affected by Huntington's Disease in 2014. Shortly after, the association expanded its support and services to people with other rare diseases, when the experts of the association assessed that there was also a striking lack of care and support available to people with other rare conditions.

With the years of experience of many initiatives undertaken, Bulgarian Huntington Association kept growing and evolving, so that it can offer

more specialized help and support to the many families affected by rare diseases in Bulgaria.



## **Partner - Frambu Resource Center for Rare Disorders, Norway**

Frambu is a private nongovernmental organization and provides a meeting place for people diagnosed with rare diseases, their families and professional service providers. The goal of Frambu is to enable children, adolescents, adults, and their families to better cope with a rare disease and to live in harmony with their conditions, aspirations and needs.

The Centre has more than 25 years of experience to gather, develop and disseminate knowledge of rare and unfamiliar disabilities to persons with a rare disease, their families and professionals. Frambu provides these services to more than 500 different rare diagnoses. This is done through a comprehensive and targeted course program, consultations and guidance, documentation, research and developmental work. Frambu is nationwide and offers services to people with a rare disease of all ages.



## **Active Citizens Fund of the Financial Mechanism of EEA and Norway**

Support for civil society is a key priority for the EEA Grants 2014-2021, funded by Iceland, Liechtenstein and Norway in 15 EU Member States in Central and Southern Europe and the Baltics. Ten percent of the total country allocations is set aside for a programme for civil society in each beneficiary state. The Active Citizens Fund is established under the priority sector 'Culture, Civil Society, Good Governance and Fundamental Rights and Freedoms', one of the five priority sectors agreed between the donors and the European Union.

The allocation to the Active Citizens Fund Bulgaria, is EUR 15 500 000, provided by the donor-states Iceland, Liechtenstein and Norway. The Program will operate until 2024 and shall contribute to the overall objectives of the EEA and Norway Grants, to reduce economic and social disparities, and to strengthen bilateral relations between the beneficiary and donor states.

The objective of the Active Citizens Fund is: “Civil society and active citizenship strengthened and vulnerable groups empowered”. The fund shall seek to develop the long-term sustainability and capacity of the civil society sector, strengthening its role in promoting democratic participation, active citizenship and human rights. The following Areas of Support are eligible:

- Democracy, active citizenship, good governance and transparency
- Human rights and equal treatment through combating any discrimination on the grounds of racial or ethnic origin, religion or belief, gender, disability, age, sexual orientation or gender identity
- Social justice and inclusion of vulnerable groups
- Gender equality and gender-based violence
- Environment and climate change

[www.activecitizensfund.bg](http://www.activecitizensfund.bg) is the official website of the Active Citizens Fund Bulgaria Programme.

## **The teams behind the EmpowerRARE project**

### **Project management and coordination team**

**Nataliya Grigorova** – Project manager, BHA

**Vedar Georgiev** – Project coordinator, BHA

**Rositsa Sechkova** – Project accountant, BHA

**Lisen Julie Mohr** – Coordinator activities and communication of the partner, Frambu

### **Project implementation team**

**Constantine Economides** - Expert intersectional collaboration, BHA

**Øivind Juris Kanavin** – Expert rare diseases, Norwegian partner  
Frambu





## **EmpoweRARE meeting with final beneficiaries**

On 25 November 2019 the managing and implementation teams of the coordinator held a meeting with the final beneficiaries of the project to inform them about the planned project activities and its expected results.

## **EmpoweRARE kickoff Meeting with Press Conference**

On 23 December 2019 the official introduction meeting of the EmpoweRARE project was held.

30 participants took part in the opening meeting and its' Press Conference, held in the Bulgarian Telegraph Agency.

Journalists, health professionals, representatives of NGOs working in the field of rare diseases came together to share information about new steps towards better services to people with rare diseases and planned activities for their empowerment that the EmpoweRARE project will implement.

The meeting provided an opportunity to outline the proposed work frame, to hear expectations and through media outlets to inform the general public about the project and its support from the Active Citizens Fund of the Financial Mechanism of the EEA.

The project press conference brought good media coverage with published articles in news.bg, two articles in Medical Times, ZDRAVE.NET, Bulgarian National Radio, DARIK NEWS, Health Navigator and NAPRD.



## The project Informational brochure

The first product of the EmpoweRARE project – its Informational Brochure – was produced in Bulgarian and English and disseminated to inform the project beneficiaries, the stakeholders and the general public about the project goal, aims, planned activities and expected results.

Additional information about the project can be found at the project's official website: <https://www.empowerare.eu>

## Keep up to date

To subscribe to the newsletter or to receive more information please visit the project website: [www.empowerare.eu](http://www.empowerare.eu)

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

Instagram: <https://www.instagram.com/huntington.bg/>

To see video coverage from the press conference, please visit the project's YouTube channel:

<https://www.youtube.com/watch?v=C1PObhRwjZU>

[https://www.youtube.com/watch?v=\\_L3JyW7M7Ks](https://www.youtube.com/watch?v=_L3JyW7M7Ks)

***If you are involved in a project or initiative, which you believe could collaborate with the EmpowerARE project, please contact the Project Manager.***



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