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# EmpoweRARE

Empowerment of persons with rare diseases

*The disease may be rare, but the care must not be!*

**PROJECT NEWSLETTER**

**Issue 6**

**JUNE 2020**

**Project Information:**

Abbreviation: EmpowerARE

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Project Start Date: 01 October 2019

Duration: 20 months

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Partner: FRAMBU, Norway

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

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

#STRONGERTOGETHER

#ЩЕСЕСПРАВИМЗАЕДНО

## EVENTS

### of project EmpoweRARE

The huge challenges which people living with rare diseases face to get the best possible help and for the professionals in the field of diagnosis, treatment and services for people with rare diseases with the huge diversity of their diseases, have formed a specific community of professionals and patients where the people with rare diseases are not only "clients" but also experts in practice.

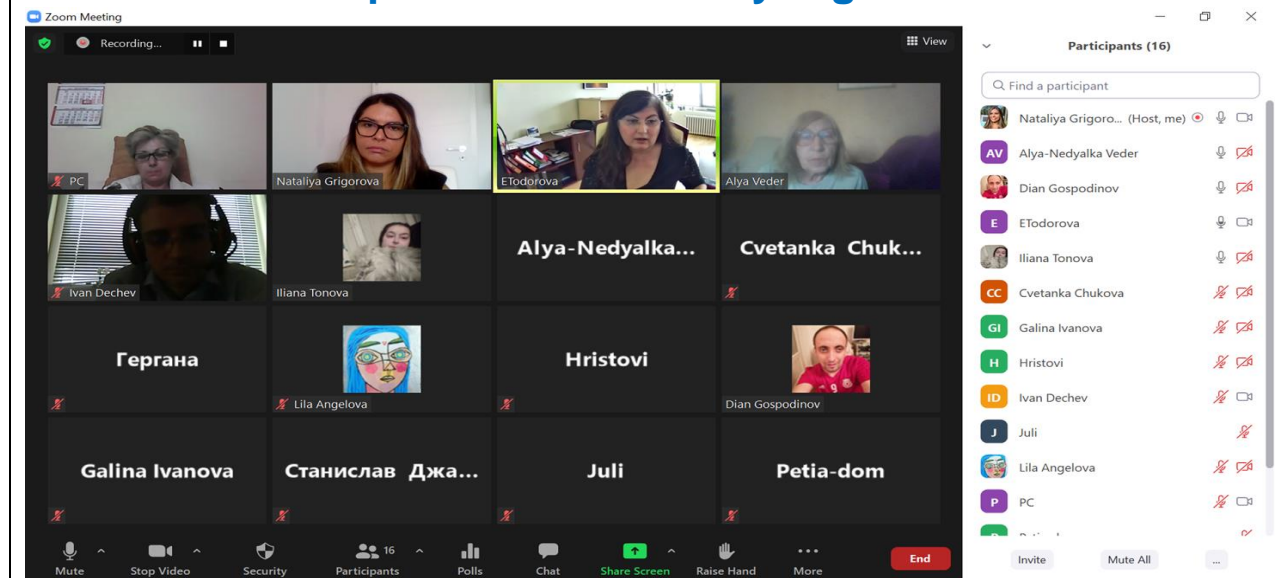
In this community the empowerment of the people with rare diseases by raising their awareness and developing their skills and competencies strengthens their ability to contribute to rare disease research and fight for their right to equal access to support and services, which for them is often a right to life.

***That is why the main goal of the EmpoweRARE project, financially supported by the Active Citizens Fund of the Norwegian Financial Mechanism, is the empowerment of people with rare diseases in Bulgaria through a series of trainings and practical advocacy. We are happy to announce that more than 80 people with disabilities and rare diseases from all over the country participated in our trainings, more than 40 people with rare diseases from all over the country participated in the bilateral workshop, and more than 150 people participated in the project live or online! Many thanks to all participants for your active and valuable participation and feedback! We look forward to seeing you again in September 2021! EmpoweRARE continues!***



## FOURTH TRAINING under the EmpowerRARE project

### Discussion and questions "Disability Rights"



The fourth training was held as the previous ones as online training in Zoom on 30.05.2021 starting at 10:00 AM. All experts from the previous trainings participated in the last group training format in order to discuss and clarify any unclear issues, as well as to encourage and answer questions and work on individual cases. The experts also delivered training on an individual level, working on case studies independently with willing end users of the project. The fourth training brought together all the previous speakers from the EmpowerRARE project to summarize what was learned in the previous events and to answer unresolved case studies and questions of the participants. The event was attended by people with different disabilities from all over Bulgaria, and the main topics discussed were:

- getting aid and support;
- obtaining lifetime TELK;
- re-calculation of pension benefits;
- training and employment programmes for people with disabilities;
- national plan for employment of people with disabilities;
- self-employment programme;
- TELK extension: time limits.

The legal expert Ivan Dechev answered questions related to the basic rights of people with disabilities, the expert Elka Todorova spoke on labor rights and independent economic activity/ Iliana Tonova was an expert on issues related to the renewal and terms of TELK, and Maya Hristova joined as an expert on the rights of children with disabilities.

**Key messages formulated by participants during the training:**

- People with rare diseases usually receive a lower percentage of work ability than their actual condition
- The renewal of TELK Expert Decisions takes longer than the statutory time, during which delay people lose their entitlement to social benefits such as public transport cards for example
- There are absurd cases in the determination of the percentage of incapacity, such as the compulsory renewal for people with irreversible disabilities
- Very often the procedure for appearing before the TOLEC is not clear and disabled people cannot renew their driving licences
- Access to information on starting a self-employed business is difficult, people with disabilities are not aware of what support they are entitled to
- People with rare diseases face a widespread misunderstanding of their illnesses, leading to ongoing cases about TELKs and inaccessibility to basic welfare benefits and entitlements.

***Due to the reduced interest in the online trainings and the increasing number of inquiries on individual cases, the project team decided to implement individual "trainings" instead of another group one, namely the experts employed in the project worked on 8 different individual cases, requested to them, as letters, complaints and documents to the relevant institutions were prepared together with the users who sought individual training. Some of them are presented as good practices in the Empowerment Handbook.***

**THE EXECUTIVE TEAM OF THE PROJECT WOULD LIKE TO EXPRESS ITS GRATITUDE TO ALL THOSE WHO TOOK PART IN THE GROUP TRAININGS AND ASKED THEIR CASES INDIVIDUALLY! WE HOPE WE HAVE BEEN USEFUL!.**

**TOGETHER WE ARE STRONG!**

## ROUND TABLE with Closing Conference



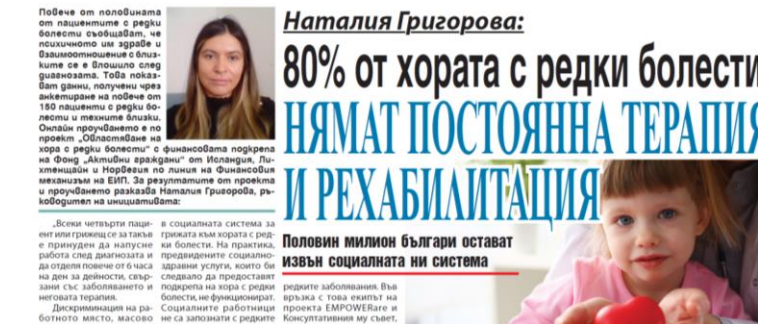
On 31 May at 09:30 the final Round Table of the EmpoweRARE project was held with an accompanying press conference to announce and discuss the results of the project.

This activity, focused on people with disabilities, professionals, civil society organizations in the field, public institutions and journalists in Bulgaria, aimed to inform the participants about the need and good practices to support people with rare diseases.

The presentations at the closing Round Table included a presentation by two end-users summarizing their benefit from the project activities and giving recommendations for follow-up activities, including highlighting the important role of the Users Advisory Board established under the project, a brief presentation of the findings of the analytical reports developed under the project, an introduction to the discussion between the Bulgarian and Norwegian partners on their field of activity and their interests in finding common ground and the formulation of a Partnership Agreement between the two project partners BGA and the Norwegian Resource center FRAMBU.

The online brochure "Lessons Learned", the printed materials Compendium of Legal Materials and Institutions and Empowerment Handbook were presented, published and available online.

After the Round Table, a press conference was held with journalists, where participants were available for interviews and questions. Media publications on the conclusion of the project and interviews with members of the Advisory Board can be found on the project's official website, under News: <https://bg.empowerare.eu/publikacii>



## Advocacy campaign - seeking solutions to provide the missing social support and health care for people with rare diseases

During the implementation of the project activities, the project team together with active end-users of the project and members of the Advisory Board drafted a number of letters, statements and requests to government institutions, which aimed to present current problems of people with rare diseases and propose their solution.

As part of an advocacy campaign and in response to current events, we sent several letters and statements to public institutions, the topics of which were initiated by members of the Project Advisory Board according to the needs of end users and their feedback on needed reforms. The periodic consultation with the Advisory Board members on necessary changes has led to fruitful collaboration and increased activity among this vulnerable group, with many of the needed reforms being prioritized and clarified.



The main theme of the requested changes and actions in the last months of the project were:

- Update missing information on COVID-19 vaccination for people with rare diseases and facilitate access to vaccination for people with rare diseases.
- Changing the Methodology for conducting individual support needs assessment for people with disabilities
- Request for updating the list of chronic diseases under Article 95, paragraph 3, of Regulation No. 10/01.09.2016 of the Ministry of Education on the organization of activities in school education, with rare diagnoses affecting persons up to 18 years of age

In a letter to the Ministry of Health, we requested that information regarding the vaccination recommendations made by the European Reference Networks for Rare Diseases, of which

Bulgarian hospitals are members, be made public for Bulgarian patients. In response from the Chief Health Inspector, we were referred to the Single Information Portal, where information on rare diseases and COVID-19 is not available, and so the problem of the lack of any information from the beginning of the pandemic to the present, concerning one of the most at-risk groups - people with rare diseases, was again neglected.

Two separate opinions, formulated by the end users in connection with the public discussion of the Draft Decree on the amendment of the Methodology for the Individual Assessment of Support Needs for People with Disabilities were sent, and as a separate recommendation to the MLSP to change the assessment sections included in the Individual Needs Assessment, as it does not correspond to the needs of people and children with rare diseases and cannot objectively and adequately assess their needs. The opinion on the draft decree amending the methodology was not adopted during the public hearing, and we have not yet received a response to the separate recommendation and request to modify the Individual Assessment in line with the needs of people with rare diseases. A letter has also been submitted to the Ministry of Education, the Ministry of Health and the Ombudsman. 95, paragraph 3, of the Ordinance No. 10/01.09.2016 of the Ministry of Education and Science on the organization of activities in school education, as the list of rare diseases affecting persons under 18 years of age, adopted in the List of Rare Diseases periodically updated by the Minister of Health, has not been updated.

We believe that there are serious legislative and executive gaps concerning the health and social care of people with rare diseases, including neglect of the problems of people with rare diseases during the pandemic. The lack of social care for people with rare diseases, the lack of awareness among those involved in the social care system, the inadequacy of individual needs assessment in relation to the real needs of people affected by rare diseases, the lack of information on rare diseases and COVID-19, and the serious gaps in the definition of personal assistance, to the detriment of thousands of people living with a rare disease, remain serious and still unresolved problems. The education system also discriminates against children living with a rare disease.

A link to the Institutional Recommendations Report, containing all letters, opinions and requests to institutions produced during the project, can be found on the official project website: [www.empowerare.eu](http://www.empowerare.eu)

**THE EMPOWERARE PROJECT TEAM ONCE AGAIN EXPRESSES ITS GRATITUDE FOR THE VALUABLE FEEDBACK WHICH WE WILL BE EXPECTING AGAIN!**

## **RESULTS OF A CONDUCTED SURVEY ON HEALTH AND SOCIAL SUPPORT NEEDS OF PEOPLE WITH RARE DISEASES**

Within the project, a survey was conducted to examine the needs for health and social support of people with rare diseases in Bulgaria. Here are some of the more important results of a survey of the responses of 150 people who completed the survey:



- **80% of people with rare diseases do not receive the ongoing therapy and rehabilitation they need**
- **More than half of rare disease patients report that their mental health has deteriorated since diagnosis**
- **One in four patients or caregivers is forced to leave work after diagnosis and spend more than 6 hours a day on activities related to the disease and its therapy.**
- **Discrimination at work**
- **Inconsistency of work capacity rates assessed in the TEC**
- **Receiving care only from relatives**
- **Lack of services at local level**
- **Ignorance of rights as a disabled person**
- **Lack of sufficient information in English about illnesses**
- **Reduced quality of life**

These are just some of the problems outlined by the survey and individual meetings with representatives of the vulnerable group, which require urgent reform in the social system for decent care of people with rare diseases. In practice, the envisaged social and health services that should provide support to people with rare diseases are not functioning. Social workers are not familiar with rare diseases and do not have the necessary knowledge and techniques to objectively assess the support needs of children and adults with rare diseases

Despite reforms in the social system and the new law on social services, half a million Bulgarians affected by rare diseases remain outside it. The Individual Needs Assessment, which assesses the need for personal assistance and social support and services, is not designed for people with disabilities as complex and chronic as rare diseases. To read the full Rare Disease Needs Report, visit the Materials section of the project website: <https://bg.empowerare.eu/resources>

## **Useful information materials**

Dear friends, we are happy to announce that we have developed two informational materials - a ***Compendium of Useful Legal Materials and Institutions*** and an ***Empowerment Toolkit*** - to be of use to you, and in which you can find useful materials and guidance on how to take action to protect your rights. You can find a copy of the printed versions with us and at each of our events, and you can download an online copy from the official project website, under Materials: <https://bg.empowerare.eu/resources>

In the Compendium you can find comprehensive information on the rights of people with disabilities in Bulgaria, the institutions they can turn to and the services they can use, and the Handbook is intended for all who want to be active citizens and achieve positive changes in their lives and those of others with similar problems.



**Сборник  
полезни правни материали и  
институции**

*Работим заедно за преобладване Европа!*



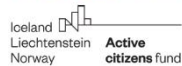
Овластяване на хора с редки болести  
*Болестта може да е рядка, но ориската не!*

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**НАРЪЧНИК ЗА ОВЛАСТЯВАНЕ**  
EMPOWERARE: ОВЛАСТЯВАНЕ НА ХОРА С РЕДКИ БОЛЕСТИ

БЪЛГАРСКА ХЪЛТИНИТЪН АСОЦИАЦИЯ

2022



**WE STAY TOGETHER!**



**DEAR FRIENDS, WE ARE HAPPY TO ANNOUNCE THAT THE  
PROJECT CONTINUES!**

**STAY TUNED FOR NEWS ABOUT NEW ACTIVITIES OF  
EMPOWERARE-2021  
IN SEPTEMBER!**

## **Stay informed!**

To subscribe to the newsletter or get 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/>

Youtube: [https://www.youtube.com/channel/UCcZDuItF90H\\_4TZ5hyfigdQ](https://www.youtube.com/channel/UCcZDuItF90H_4TZ5hyfigdQ)



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