Iceland Liechtenstein Norway **Active citizens** fund

Working together for inclusive Europe

EmpoweRARE

Empowering people with rare diseases

The disease is rare, but the care must not be!

Project Newspaper

Issue 4

December 2020

Project information:

Abbreviation: EmpoweRARE

Ref. №: ACF-231

Thematic area: SEC-12-FCT-2017

Project start date: October 1, 2019

Duration: 18 months

Project manager: Nataliya Grigorova

Organization: **Bulgarian Huntington Association**

Email: info@huntington.bg

Project Partner: FRAMBU, Norway

Webpage: https://www.empowerare.eu/

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

#STRONGERTOGETHER

Trainings under the project "Empowerment of people with rare diseases"

The EmpoweRARE project trainings are one of the main activities for empowering people with rare diseases, by raising their awareness of their legal rights and regulations and good practices to ensure a good quality of life and equality in the partner country Norway.

With each training, the awareness and understanding of people with rare diseases about their rights to support and the new provisions of the legislation, the legally regulated mechanism for receiving the support they need according to their individual needs, orientation to which institution in which moment of the request for support should be addressed, are there any restrictions on their individual choice and which institution may impose it.

The chosen model for forming a training team with the participation of experts from practice, people with rare diseases, as well as planning the trainings in accordance with the expressed wishes and recommendations in the feedback of the target group proved its effectiveness.

One of the great challenges of the trainings is to be organized in an interesting and understandable way according to the large age range of the participants - from 15 to over 70 years and to select topics of interest and usefulness for the various rare diseases.

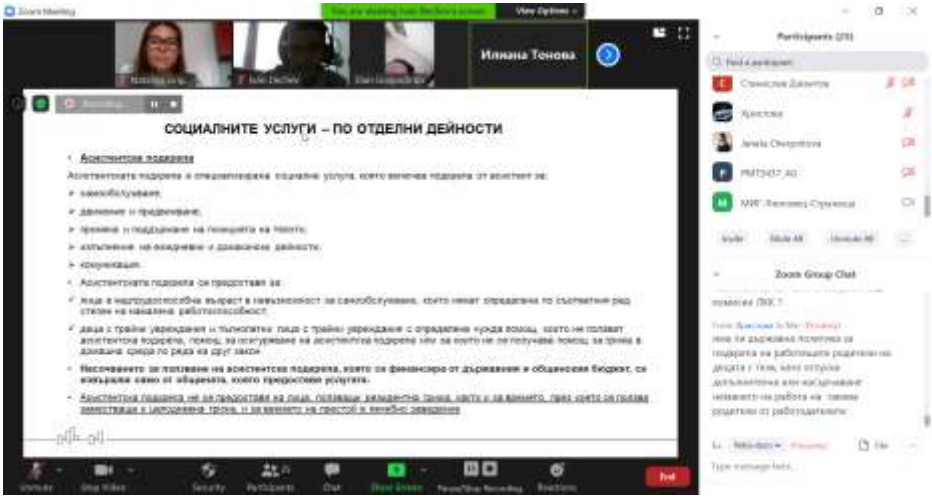
A positive trend that the project implementers try to maintain in the inclusion of participants in the project trainings is the expansion of the geographical scope of the participants' place of residence, which will increase the dissemination of information in the country.

With the outbreak of the COVID-19 pandemic, the topics of the information provided expanded with the presentation of current news related to the situation of the COVID-19 pandemic, and the third training, as well as this issue of the bulletin, offer specific, much needed for people with rare diseases. information selected by the trainer - expert in practice Iliana Toneva, about the advantages and disadvantages of different types of vaccines - nucleoid vaccines (RNA and DNA) in people with rare diseases.

Practical information was provided to the third training and is presented here, prepared by the trainer Ivan Dechev, an expert in the team of the Ombudsman of the Republic of Bulgaria for the issuance of a sick leave in quarantine - the requirements and rights, and the economic sectors in which workers can receive compensation for closure due to COVID-19 on the basis of an Order issued by the Minister of Labor and Social Policy.

THIRD TRAINING under the EmpoweRARE project.

Rights of people with disabilities in Bulgaria - Social services and rare diseases.



The third training seminar "Rights of Persons with Disabilities in Bulgaria", held under the EmpoweRARE project, funded by the Fund for Active Citizens of the EEA Financial Mechanism, was held online in the context of the COVID-19 pandemic on 20 December 2020.

As in previous trainings, people with proven experience and practice in the field were invited as lecturers - Ivan Dechev, Chief Expert at the Institute of the Ombudsman of the Republic of Bulgaria, Department for the Rights of Persons with Disabilities and Discrimination and Iliana Tonova, Patient with Rare Disease and Expert in practice.

During the training the expert Ivan Dechev presented the Law on Social Services (LSA) and what is new in this law compared to the Law on Social Assistance, the bodies responsible for the implementation of social services, who and under what conditions is entitled to social services, the grouping of social services in ZSU according to different

criteria, the general rules for using social services, the social services for separate activities were presented,

important information on social services for 2021 was announced, the National Program "Provision of care in the home environment", the specialized transport service for people with disabilities in Sofia, the social services of the municipalities in support of people with disabilities during COVID- 19 - purchase of the necessary medicines, food and payment of their household bills.

The Personal Assistance Act (PAA) was presented, in force since January 1, 2019, and the amendments to the normative act adopted on December 4, 2020, in force since January 1, 2021, and Ordinance № RD-07-7 of 28 June 2019 for inclusion in the mechanism of personal assistance issued by the Minister of Labor and Social Policy. The possibilities for using assistant support under the Personal Assistance Act were also explained.

Practical expert Iliana Tonova presented information in connection with the current challenges facing people with rare diseases in the context of the COVID-19 pandemic and the very valuable information for the vulnerable group of people living with rare diseases from a reference made by Dr. Svetozar Sardovski. advantages and disadvantages of the available 4 types of vaccines against COVID-19, enough for everyone to make their informed choice for the most appropriate, in people with rare diseases and in individual additional consultation with their doctor or doctors to take into account all possible reactions of the specific organism in its current state. Information was also given about a sick leave in quarantine, as well as explanations by order of the Minister of Labor and Social Policy, confirming the economic activities in which workers can receive compensation due to restrictions imposed by a state authority in the period from November 27 to December 21, 2020, for targeted assistance for families with children under 14 who study remotely, as well as for electronic prescriptions and referrals.

As in the previous trainings, a pre-prepared set of training materials was sent to the participants for the third training, and during the training an opportunity was created for discussions, questions and work on specific individual cases.

The participants in the training were invited to fill in a questionnaire for evaluation of the training, with which to check the level of knowledge, old and newly acquired, on the relevant topics, as well as to give their opinions and recommendations for the next two trainings.

Main messages formulated by the participants during the training:

- The individual care patients with rare diseases are closed.
- Patients with rare diseases are undesirable in COVID wards.
- Before getting a vaccine, consult the specialist treating your specific disease.
- Planned infusions and therapies for rare diseases have been stopped, which endangers their lives.
- Patients are waiting for electronic prescriptions to be able to get the medicines they need.
- Electronic prescriptions and extension of protocols do not work in cities outside the capital. People with rare diseases are forced to travel between dozens of institutions to receive their medicines.
- There are electronic signatures, there are no services for people with disabilities to use.
- People with disabilities do not have access to institutions in difficult weather conditions, but are punished for not meeting deadlines.
- Parents of children with rare diseases do not have access to health and social services information to help their children. Social assessments do not cover the problems of people and children with rare diseases.

THE EXECUTIVE TEAM OF THE PROJECT EXPRESSES ITS ACKNOWLEDGMENT TO ALL WHO HAVE TAKEN FROM THEIR VALUABLE TIME TO GIVE US THE FEEDBACK THEIR VALUABLE TIME TO GIVE US THE FEEDBACK

How has COVID-19 impacted people with rare disease?

Latest data from the EURORDIS survey.

The COVID-19 pandemic has exacerbated the many challenges facing people living with rare diseases.

During the first wave of COVID-19 in Europe, access to the care and treatment that patients rely on was disrupted and the stress and anxiety of everyday life among this vulnerable group of people intensified. The pandemic has changed the attitudes of people living with a rare disease with the health system, opening the door to more digital health opportunities.

This was shown by a EURORDIS study on COVID-19 through the RARE Barometer platform, which was conducted between 18 April and 11 May 2020, among 6945 participants from all over Europe, in 23 languages, with 1250 different rare diseases from 36 countries.

COVID-19 caused a serious impairment of care for people living with a rare disease.

- 84% of European patients with rare diseases surveyed have experienced some form of disturbance in their care due to the COVID-19 crisis.
- 64% of respondents stated that they feared that this had negatively affected their health or the health of the person they cared for.
- 3 out of 10 respondents report that this is likely (2 out of 10) or will definitely be life-threatening.

Among those reporting an interruption of care:

- 6 out of 10 did not have access to diagnostic tests
- 6 out of 10 could not receive therapies such as chemotherapy or infusion
- At 6 out of 10 respondents, their surgery or transplant was postponed or canceled

Because rare diseases are often life-threatening, delayed diagnostic tests or medical interventions can lead to serious worsening of patients' symptoms.

In addition, these interruptions in care and isolation resulted in serious impacts on the mental health of people living with rare diseases, with almost 6 out of 10 experiencing discontinued psychiatric care, while two-thirds of respondents suffered from depression and / or depression. or a feeling that they cannot overcome their problems since the onset of a pandemic.

EURORDIS underlines the recommendations made during the first wave of the pandemic:

- the need to ensure continuity of care and access to medical advice for people living with rare diseases by channeling resources and efforts to health systems to strengthen the medical workforce and equipment;
- the adoption of specific measures / protocols justified by the complex needs of rare diseases in the provision of emergency health care;
- the need for a minimum support service and personal assistance service for vulnerable populations, including people living with a rare disease;
- encourage and facilitate practices such as virtual consultations or the application of certain therapies at home;

The results of the study also highlight the need to move to more sustainable health systems that do not exacerbate the vulnerability of people living with rare diseases across Europe, as observed during the first wave of the pandemic.

New member of the Advisory Board of Patients with Rare Diseases under the project "Empowerment of people with rare diseases"

Here we present the new member of our Advisory Board: Maya Hristova, mother of a child with a rare disease.

Maya Hristova is a specialist in public finance, but in 2012 she was diagnosed with her daughter Sylvia - post-vaccine immune deficiency and secondary immune thrombocytopenia, a rare immune disease acquired after vaccination. This puts her in an unequal struggle with institutions and legislation in an effort to provide a better life and opportunities for her daughter's development. Maya is actively involved in activities concerning the rights of children with disabilities in Bulgaria, and in recent years has been fully dedicated to the care of her children and is a personal assistant to her daughter Sylvia.

Here is what Maya made in a press release on social support for children with rare diseases:

„*We are forced to adapt to the rules of the various institutions. An endless cycle in which we do not receive adequate support and understanding from social workers or employees of institutions in Bulgaria, because there are procedures and rules to which we cannot respond. The social assessments that have been updated under the new law on social services do not in any way cover the specific problems of people with rare diseases, because they cannot be framed or standardized, there is a lack of individual approach and flexibility. There is no easy and uniform access to information about all services and facilities, parents rely mainly on mutual assistance with each other."*

Advocacy campaign - seeking solutions to provide the missing social support for people with rare diseases.

The project team prepared an Opinion on the implementation of a Draft Action Plan for the implementation of the final recommendations to the Republic of Bulgaria, addressed by the UN Committee on the Rights of Persons with Disabilities (2021-2026) to the Ministry of Labor and Social Policy.

As part of our advocacy campaign and in response to current events, we sent an Opinion on the implementation of the Draft Action Plan for the implementation of the final recommendations to the Republic of Bulgaria addressed by the UN Committee on the Rights of Persons with Disabilities (2021-2026) to the Ministry labor and social policy.

The main topic of the Opinion was the examination of Article 25 (54) of the final recommendations where, "The Committee recommends that the State party provide access to diagnosis, health care and medical rehabilitation for persons with disabilities, especially those with chronic, genetic and rare diseases.

Implementation: One of the principles enshrined in the Health Insurance Act is equality in the use of medical care by compulsorily insured persons, including people with disabilities… (..)

We consider the measures cited as implementation of the recommendations of the Committee for the Implementation of the Convention on the Rights of Persons with Disabilities to be absolutely insufficient and not meeting the needs of people with rare diseases in Bulgaria. We believe that Member States should provide recognition and adequate compensation for the disabilities experienced by people living with a rare disease. Bulgaria must implement the UN Convention on the Rights of Persons with Disabilities, taking into account the specific needs of people living with rare diseases.

The Law on Health Insurance, cited as a basis for implementation of the recommendations, does not meet the recommendations for providing

access to diagnostics, health care and medical rehabilitation for people with rare diseases, due to the fact that the practical access of people with rare diseases to diagnostics, health care and medical rehabilitation is carried out through the National Register of Rare Diseases, which is updated by decisions of the Minister of Health following proposals by the Commission on Rare Diseases.

This procedure is laid down in ORDINANCE № 7 of 6.11.2015 of the Ministry of Health on the criteria for determining the diseases for whose home treatment the National Health Insurance Fund pays in full or in part for medicinal products, medical devices and dietary foods for special medical purposes, where we cite in in Art. 2. it shall be indicated that "The National Health Insurance Fund shall pay in full or in part medicinal products, medical devices and dietary foods for special medical purposes for the rare diseases included in the list under Art. 2, para. 1 of: *Ordinance № 16 of 2014 on the terms and conditions for registration of rare diseases and on the expert centers and reference networks for rare diseases (SG, issue 67 of 2014), for which: 1. home treatment is applicable, including and combined with outpatient treatment; 2. the criteria under Art. 1, para. 1, item 2 and para. 2, items 1, 4 and 5 ".*

In view of this Ordinance, of the existing thousands of different rare diseases in the National Register of Rare Diseases, as of 31.12.2020, only about 80 diseases are included. This excludes hundreds of thousands of people with rare diseases from access to diagnosis, health care and medical rehabilitation. In addition, for 95% of rare diseases there is no medical therapy, and they need specialized and permanent medical and social rehabilitation. That is why, in order to serve the needs of people with rare diseases, the construction of integrated health and social services, enshrined in the Health Act and the Social Services Act, should be implemented.

A link to the entire Opinion to the MLSP can be found on the official website of the project: www.empowerare.eu

BULGARIAN HUNTINGTON ASSOCIATION

Keep yourself informed!

To subscribe to the newsletter or get more information, please visit the project website:www.empowerare.eu

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

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

You tube: https://www.youtube.com/channel/UCcZDuItF90H_4TZ5hyfigdQ

Iceland Liechtenstein Norway

Active citizens fund

This document was created with the financial support of the Active Citizens Fund of Bulgaria under the UIC Financial Mechanism. The entire responsibility for the content 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 Financial Mechanism of the European Economic Area and the Operator of the Active Citizens Fund Bulgaria. www.activecitizensfund.bg