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EmpoweRARE

Empowerment of People with Rare Diseases

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

Newsletter

Issue 2

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Project information:

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Project start date: 01 October 2019

Duration: 18 months

Project manager: Natalia Grigorova

Organization: Bulgarian Huntington Association

Email: info@huntington.bg

Partner: FRAMBU, Norway

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

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

#STRONGERTOGETHER #ЩЕСЕСПРАВИМЗАЕДНО

COVID-19

A state of emergency was declared in the Republic of Bulgaria on March 13, 2020, due to the growing number of people infected with COVID-19. The pandemic changed the reality of billions of people around the world and changed the course of activity not only of our project, but also of many activities related to the goals of civil society organizations in Bulgaria. In order to be flexible

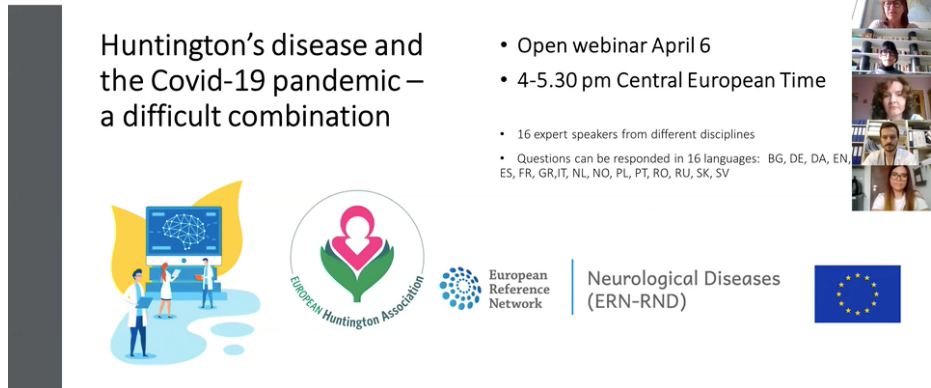


**ЩЕСЕСПРАВИМ
ЗАЕДНО**

and to keep the implementation of the project activities, the team was reorganized into remote work and online team meetings, and the planned first training for project authorization was changed so that it could take place online. In Bulgaria, the campaign #ЩЕЕСПРАВИМЗАЕДНО was quickly organized, in response to the situation. "We will do it together" is the message with which a constantly growing group of civil society organizations in the social sphere called for solidarity, calm and order and called on civil society organizations across the country to think and take action towards the people they care about. to give them hope that no one will be abandoned. The campaign has grown into a call to unite all efforts to overcome the crisis with the Covid-19 epidemic and the only isolation needed. In Europe, EURORDIS called on those affected by rare #STRONGERTOGETHER fighters, and the organization issued several opinions on the significant deterioration in the quality of life of people affected by rare diseases during the pandemic. The possibility of discrimination in triage care for those infected with COVID-19 and recommendations for immediate social support were addressed in open letters and opinions of the largest organization for rare diseases in Europe. As part of our advocacy campaign and in response to current events in the country, we also supported and adapted these recommendations by informing the media and the Ministry of Health in an open letter about the possibility of discrimination against people with rare diseases in providing health care to those infected with COVID -19 people with rare diseases. Our main recommendation was related to the immediate preparation of a Guide for the care of people with rare diseases infected with COVID-19 and the coordination of the treatment of these patients with the Expert Centers for Rare Diseases in Bulgaria. Rare diseases, often chronic, very complex, progressive and severely disabling, give rise to specific care needs. The impact of COVID-19 on health and social systems is enormous and directly affects the care that people living with rare diseases receive during this stressful time, as well as their socio-economic status, education and employment.

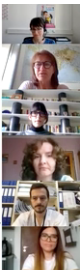




Below you will find information about a large part of the project activities for the period until the end of April 2020.

„Huntington’s disease and the Covid-19 pandemic – a difficult combination“ webinar of the European Reference Network – Neurological Diseases (ERN-RND)



Huntington’s disease and the Covid-19 pandemic – a difficult combination

- Open webinar April 6
- 4-5.30 pm Central European Time
- 16 expert speakers from different disciplines
- Questions can be responded in 16 languages: BG, DE, DA, EN, ES, FR, GR, IT, NL, NO, PL, PT, RO, RU, SK, SV



An open webinar of the European Huntington Association and the European Reference Network - Neurological Diseases ERN-RND was held on April 6, 2020 with 16 panelists from various disciplines.

EmpowerRARE project manager Natalia Grigorova took part in the seminar as one of the presenting experts, while having the opportunity to receive and then share the latest information on the situation of people with rare diseases in the COVID-19 pandemic situation and to disseminate international progress in empowering people with rare diseases in Bulgaria.

Advisory Board of Patients with Rare Diseases of the "Empowerment of People with Rare Diseases" project

True to the motto of the global movement of people with disabilities "Nothing for us without us", the EmpowerRARE project has its Advisory Board of civil activists with rare diseases, who have proven to be "experienced experts" to consult and advise our activities.

Here we present three of the members of our Advisory Board, known and respected by many of you:



Iliana Tonova, President of the National Sarcoidosis Association

Iliana was born in Sofia and has been facing the problems of people with rare diseases and disabilities personally for 14 years. In an effort to help friends, acquaintances - people with disabilities, some of them with rare diseases, he tries to find out about the changes in NME - the Ordinance on Medical Expertise, in order to be aware of the current situation. Participated in proposals for changes in the Ordinance, which were adopted and included in it. Iliana is actively involved in the advocacy campaign of the project, advising and guiding people with rare diseases on issues related to the procedure for the acquisition of TEMC and is a lecturer in the training for empowerment provided by the project.



Desislava Dimitrova, member of the board of the Bulgarian Huntington Association

Desislava was born in Sofia, has two children, whom she takes care of, and also works and is an active advocate for the rights of people with rare diseases and disabilities. She is an extremely strong and combative person, as her younger son was born with a heart defect, due to which he underwent a number of risky operations. Desi goes through the ordeal, as she herself is affected by a rare disease and takes care of her children with a proud head, finding time to defend a number of civic causes. Desislava is also a lecturer in the

trainings for empowerment provided by the project, on the topic of the rights of children with disabilities in Bulgaria.

Lila Angelova, founder of Turner Syndrome Bulgaria



Lila was born in Sofia and grew up during the turbulent years of the new democracy. She would like to live in a fairer and more beautiful world where there is room for everyone. She has been in India for many years and practices yoga. He is the founder of the Facebook support group for parents of children and women with Turner Syndrome, and in his spare time he actively tries to support, provide accessible information and support better medical care for people with rare diseases. She has worked in the non-governmental sector, participating in lifelong learning opportunities programs. Lila is a lecturer in the training for empowerment on the topic of employment of people with disabilities.

Participation in the 10th European Conference on Rare Diseases & Orphan Products 2020 (ECRD 2020)

The image shows a screenshot of the website for the 10th European Conference on Rare Diseases & Orphan Products 2020. The main banner features the conference title and a navigation menu with options like Lobby, Sessions, Exhibit Hall, Posters & Resources, Lounges, Games, Network, and My Profile. A large blue sign in the center reads "THE 10th EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS". To the left, a yellow sign says "THE JOURNEY OF CHILDREN WITH A RARE DISEASE IN 2030 SESSIONS". A navigation bar at the bottom lists "SESSIONS", "EXHIBIT HALL", "POSTERS", "LOUNGE", and "HELP DESK". On the right, there is a section for the "EmpowerRARE" project, including logos for Iceland, Liechtenstein, Norway, Active Citizens Fund, and EmpowerRARE. The text describes the project's goals and partners, such as the Bulgarian Huntington Association and FRAMBU. Logos for the European Union, the Government of Bulgaria, and the Active Citizens Fund are also visible.

In order to present the project "Empowerment of people with rare diseases" and to fulfil the goals set in the communication plan, as well as to achieve publicity at the international level and the

opportunity to exchange experiences and create partnerships, the project team prepared a poster presenting the project, to participate in the largest event for rare diseases in 2020. ECRD is recognized worldwide as the largest patient-led event on rare diseases, bringing together dialogue and learning to form the basis for future policy-making on rare diseases. Leading, inspiring and engaging all stakeholders to take action, the event is an unbeatable opportunity to network and share invaluable knowledge with all stakeholders in the rare disease community - patient representatives, politicians, researchers, clinicians, industry, payers and regulators.

Recommendations for action on social support for people with rare diseases during the COVID-19 pandemic, call for non-discrimination

On the official website of the project, you can find a translation of an open letter with recommendations for improving policies for people affected by rare diseases to the responsible institutions published by EURORDIS of the Project Team "Empowering people with rare diseases", translated part of the letter in informal partnership with the team of Retina Bulgaria Association. Retina Bulgaria Association is also implementing a project funded by the Active Citizens Fund, aimed at the needs of people with reduced vision due to various degenerative diseases of the retina, some of which are rare eye diseases. Part of the letter aims to make recommendations on social support and holistic care for people with rare diseases. Holistic care covers the full range of health, social and daily needs of people living with a rare disease and their families. The implementation of detention and quarantine measures to prevent the spread of COVID-19 can have a serious impact on the provision of holistic care for people living with rare diseases:

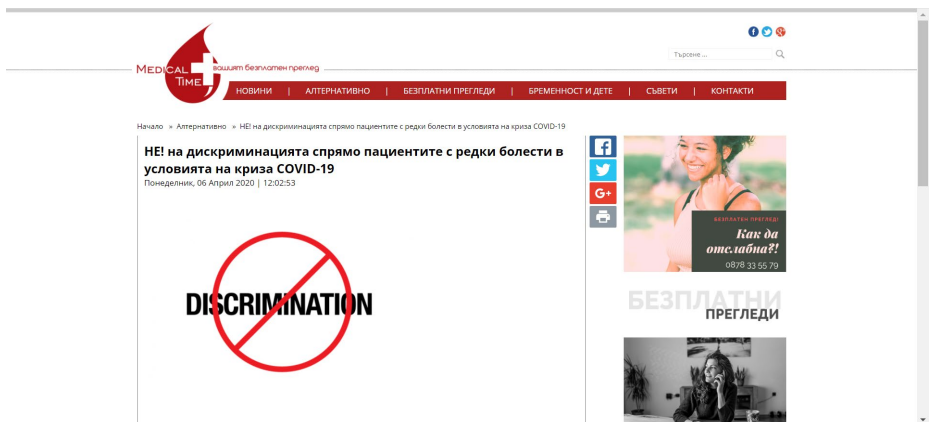
Some of the recommendations in the letter are:

"Ensuring minimum support and personal assistance services for vulnerable populations, including people living with rare diseases, in the same way as maintaining minimum services for children from vulnerable groups in a number of Member States"

"Engage and support patient organizations that are connected to their local communities and can support health services in providing information flows and good communication, partner support and developing innovative solutions to the crisis."

As we know in Bulgaria there is no strategy and plan for social support for people with rare diseases, as well as centers for independent living or resource centers. Therefore, recommendations for action on holistic care cannot be made in their entirety. The translation of the entire open letter of EURORDIS can be found on the official project website: www.empowerare.eu

Our call for non-discrimination of patients in crisis was published by our media partners MEDICAL TIME.



Advocacy campaign - Open letter to the Ministry of Health

As part of our advocacy campaign and in response to current events, we sent an open letter to the Ministry of Health. Getting acquainted in detail with the guidelines and guidelines published by the Ministry of Health, including those on the website of the Bulgarian Medical Union, we found that nowhere is mentioned the procedure for admission and care guidelines for patients with rare diseases who are infected with COVID

-19. In this regard, and taking into account the vulnerability of people with rare diseases in this situation, we made recommendations for **immediate** Delegation of the Committee on Rare Diseases to the Ministry of Health to prepare a special guide for prevention and treatment of people with rare diseases infected with COVID-19, and coordinating the actions of health authorities and healthcare providers with recommendations on the care of patients with rare diseases affected by COVID-19 of the Expert Centers for Rare Diseases, members of the European reference networks. A link to the entire open letter can be found at:

FIRST TRAINING SEMINAR of the EmpowerRARE project

Он-лайн обучение

„Права на хората с увреждания в България“

26 април /неделя/ 10:00- 16:00 ч./ ZOOM



- Наталия Григорова: модератор
- Илиана Тонова: учител
- Иван Дечев: учител



Ioeland
Liechtenstein
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**Active
citizens fund**



The first training seminar "**Rights of people with disabilities in Bulgaria**", under the EmpowerRARE 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 **April 26, 2020** in the ZOOM platform.

Familiar with its previous projects with the interests and needs of people with rare diseases, the leading organization of the project Bulgarian Huntington Association (BHA) focuses this first training on providing information on key topics and legal regulation, inviting people with proven experience and practice in the field of the training seminar - **Ivan Dechev**, Chief Expert at the Institute of the Ombudsman of the Republic of Bulgaria, Department for the Rights

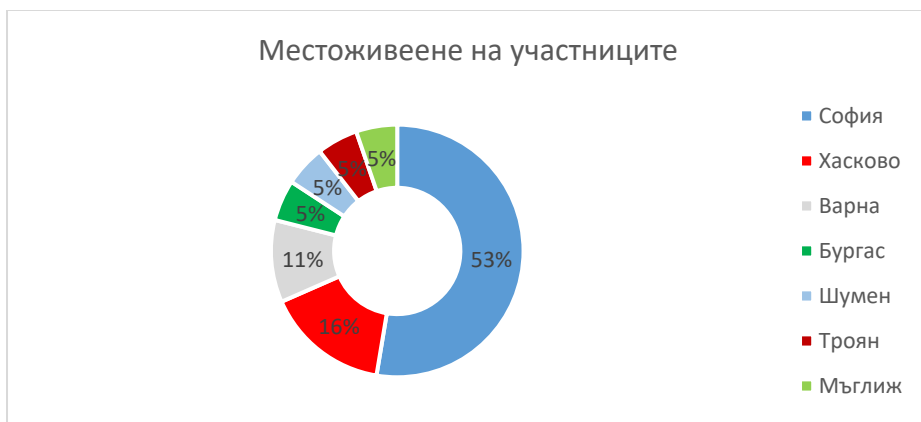
of Persons with Disabilities and Discrimination and **Iliana Tonova**, who is a patient with a rare disease and an expert in practice.

During the training, information was provided on the basic guaranteed rights of people with disabilities in Bulgaria and related cases for discussion. The participants were sent a pre-prepared set of teaching materials, and during the training a wide opportunity was created for discussions, questions and work on specific cases.

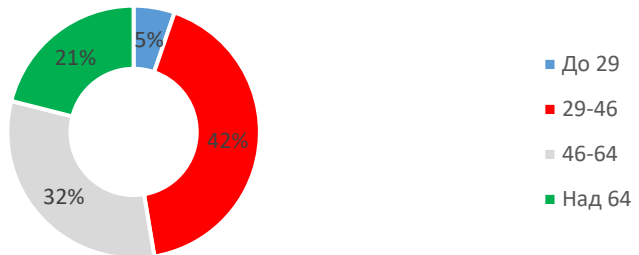
The participants in the training were 30 people. They were invited to fill in a training evaluation questionnaire to check the level of knowledge, old and new, on the relevant topics, as well as to give their opinions and recommendations for the next two trainings. 21 (70%) participants responded to the survey.

**THE PROJECT EXECUTIVE TEAM EXPRESSES ITS
ACKNOWLEDGMENT TO ALL WHO HAVE SPENT FROM THEIR
VALUABLE TIME TO GIVE US FEEDBACK WHICH WE NEEDED TO
PLAN THE MOST USEFUL TRAININGS FOR YOU!**

FEEDBACK ANALYSIS FROM THE PARTICIPANTS IN THE FIRST EmpowerRARE TRAINING



Възраст на участниците



19% of respondents to the feedback survey are **men**, the remaining **81%** are **women**.

For the planning of the topics of the future trainings, the feedback from the participants gave us the desired information on which topics they are most interested in and consider them the most useful. To this end, open-ended questions were asked, the answers to some of which we share with you. The full analysis of the surveys, as well as the correct answers, can be found on the official project website: www.empowerare.eu

Answers to Question 8: Which part of your training was the most interesting and why?

19 people gave an answer here (**90.48%** of the respondents).

The most common answer given by 10 people (**47.62%**), which gives us a happy indication of well-planned training, is the **Rights of People with Disabilities - Laws and Institutions**, where 3 people (**14.29%**) explicitly emphasize that the two presentations of the expert to the Ombudsman Ivan Dechev were very interesting and useful.

Everything was interesting and useful to me is an answer given by 8 people, **38%** of the respondents.

2 people (9.52%) emphasize that the **information about TEMC** was very interesting and useful and define it as the **most applicable**.

2 people (9.52%) define the **third part** of the training as the most interesting for them.

The answer (1) that the most interesting to the respondent was the **information about the driver's license** gives us an indication that some details of the legally regulated assistance to people with disabilities are not well known to everyone and such information should not be omitted during the trainings.

2 people (9.52%) found the **Presentation to be very interesting for the financial and social benefits** to which people with disabilities are entitled / the **Law on Integration of People with Disabilities**.

The feedback on the perception of the **discussion parts** as "**very important in order to clarify the matter**" specifically written "**in the regulations and laws**" was very useful for the planning of future trainings. Giving concrete examples helps to clarify insufficiently clear texts."

Answers to Question 10: Do you think that other similar trainings are needed for people with rare diseases and if so - on what issues?

20 people (95%) of the respondents gave a positive answer **that other similar trainings are necessary**.

The most common answers are: "**Yes, they are definitely very necessary**", with very valuable additional explanations "**because people with rare diseases often feel confused and do not know who to turn to. The institutions in Bulgaria do not work uniformly enough and it happens that in order to solve a specific case you have to go around several social services and health specialists and get an answer "you are not for us"**, in variants and

"**Yes, I don't think people know what specialists to go to and they are very late with diagnoses. They spin in a vicious circle.** This is our healthcare system. **Most doctors treat the consequences, not look for the causes of the disease "and" such training is rare and very**

necessary (and concerns not only people with rare diseases, but all people with disabilities)."

In response to this question, more suggestions are given for the inclusion of these in future similar trainings:

Trainings related to employment opportunities, where it is emphasized that one of the major topics to be addressed is employment and motivation of employers to hire such people while providing **appropriate working conditions and remuneration** - 3 people (**16.67%**).

To include information on the situation of people with rare diseases in other countries, formulated as "**acquaintance with all patient organizations and initiatives supporting people with rare diseases not only in Bulgaria but also in the EU.**"

This is a proposal that the project planned to respond to with the involvement of the Norwegian partner FRAMBU Resource Center for Rare Disorders, which is already working to identify their good practices, innovative for Bulgaria and is waiting for this feedback to respond in the most appropriate way. of the needs and expectations of people with rare diseases in Bulgaria.

Training or a short guide with guidelines on what a person with a recently diagnosed rare disease should do step by step - what examinations to perform and where, what documents to collect, which specialists are the most proven in the field, which NGO could help, etc.

Training on discrimination in the workplace.

Trainings on the Social Services Act. The Child Protection Act and the Social Assistance Act, also formulated as "**on the same issues** (as the current training), **including innovations and changes.**"

And the interesting proposal in future training "**to emphasize psychological support, with specific examples of how to deal with a person with a rare disease**, when due to the limitations to which his body has to put much more effort than healthy people, and at the same time it must be fought on an equal footing with them in order to have its place in the labor market or in other endeavors. '

And one of the answers to topics of future training is: "**Medicines. Responsibilities. Providers. Deadlines. Pharmacy tourism. Problems.**"

It is clear that there are many topics on which people with rare diseases need much more information, and within the EmpowerRARE project we will try to meet at least some of their needs.

Answers to Question 11: What actions do you think should be taken to empower people with rare diseases?

There are 14 specific answers to this question in the survey, while the non-respondents most often give the answer "**I have no suggestion**" or "**I do not think I am competent to answer.**"

Some of the answers given also indicate that the meaning of "empowerment" is not understood and therefore here we will give the interpretation of the **European Patients' Forum** about what is **empowerment** of patients:

POWER IS: a process that helps people gain control of their own lives and increase their capacity by acting on issues that they themselves consider important.

ASPECTS OF EMPOWERMENT are:

- self-efficacy,
- self-awareness,
- confidence,
- coping skills,
- health literacy

The main goal of empowerment is to **strengthen the capacity and resources** of the vulnerable group.

In order to achieve empowerment, it is necessary to inform, train, advocate, achieve equal cooperation / partnership with the current authorities to participate in the decision-making concerning the empowered decisions.

The specific actions proposed by the respondents are:

To prepare a program to support people with rare diseases and to monitor its implementation - proposed by 3 people (21.23%).

Wider participation in the meetings of the Committee on Rare Diseases with an advisory vote - submitted a proposal by 2 people (14.29%).

Instead of under Ordinance 16, to accept all RARE DISEASES FROM WHO TO BE ON THE LIST - proposed by 2 people (14.29%).

“Raising awareness about these diseases”

Non-profit associations, such as organizations of people with rare diseases, have the opportunity to contribute to the establishment of a disease registry, as well as to receive information related to the disease they represent.

Informing the general public about the difficulties such people are experiencing and what anyone could do, if they wish, to support them. **By activating the victims and the society to put additional pressure on the relevant structures of the state to introduce favorable changes.**

Continuing training, including advocacy and civic activism.

Proposals to be lobbied for are:

Expanding the possibilities for free genetic research, for their early detection and possible treatment.

Opportunities for state-paid treatment abroad, if there are none.

Establishment of an institution familiar with all the rights of people with rare diseases and disabilities, to which the person or his relatives can turn and it can give specific guidelines and recommendations according to the individual case of the person, to be explained step by step the sequence and institutions to which the sequence and specificity of the documents can be addressed.

Creating a document that summarizes the information from all legal provisions and indicates the specific institutions and the order to which people with rare diseases or their relatives should turn.

Study of the needs of people with rare diseases and assistance in introducing legislative changes.

Specific commitment of doctors to people with rare diseases.

Social services and support, specialized according to the needs of people with rare diseases.

ACTIVITIES OF OUR NORWEGIAN PARTNER



The answers of the participants in the First EmpowerRARE project training seminar provided a valuable contribution to their interests and the need for additional information about our Norwegian partner FRAMBU Rare Disease Resource Center.

The experts involved in the EmpowerRARE project are actively working to identify good Norwegian practices and innovations that can be transferred to Bulgaria and create a basis for sustainable cooperation in the field of rare diseases between our countries. Unfortunately, the activities of the resource center were severely affected by the pandemic. All courses and visits to Frambu have been canceled since March 13, 2020. All summer camps in July-August are also canceled, which is a precedent in the history of the center. Most of the staff work from home. All contact with patients and professionals is done online. E-learning courses are open and accessible to all, but only in Norwegian. Questions and inquiries from patients and specialists are sent by phone or e-mail. When consultations are needed, they are performed online by the center's professionals. Webinars, group discussions and seminars on videoconferencing are organized. Frambu is constantly updating its website with information about the virus and rare diseases. The center updates links to various medical institutions such as the Norwegian Institute of Public Health and the Norwegian Directorate of Health, both of which are responsible for deciding the situation.



Additional information about the project, goals, activities and achievements can be found on the official website of the project: <https://www.empowerare.eu>



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

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