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2021 EmpoweRARE

EmpoweRARE2021

The disease may be rare, but not the care!

Project Newsletter

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Project information:

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Official website: https://www.empowerare.eu/

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#wecontinuetogether

We continue empowering people with rare diseases trough EmpoweRARE2021

The second part of the project continues with the implementation of the identified good practices for support together with the partners from Frambu, the opening of an information and consultation service and the establishment of a National Self-Help Network.

- **For the Bulgarian Huntington Association**

The Bulgarian Huntington Association has existed since 2014 and works hard to protect the right of people with rare diseases to receive the social support they need. Through donations and projects, the provision of free rehabilitation and psychological support to people with rare diseases in Sofia is supported, and when necessary, they are provided in the homes of those affected.



- **About Frambu Resource Center, Norway**

FRAMBU is the largest resource canter for people with rare diseases in Norway, established in 1956. The canter works with over 500 different rare diagnoses, offering both multidisciplinary care and training for families and professionals involved in rare diseases.



Project EmpoweRARE2021

The project continues the initiative "Empowerment of people with rare diseases", whose activities began in November 2019, and a number of good practices identified during the first part are to be implemented.

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

Main project activities:

- Conducting specialized online training courses for people with rare diseases
- Construction of a Virtual Resource Center
- Launch of an Information Telephone Line
- Conducting a Summer Training Camp modeled on the Norwegian Frambu Resource Center
- Establishment of a National Network for Self-Help of People with Rare Diseases
- Support for an advocacy campaign in the field of social care

Expected results of the project:

• **in the short term**: creating a strong, motivated and prepared community of people with rare diseases to address unmet needs

• **in the long run**: achieving change in policies and legislation on access to social and health support for people with rare diseases

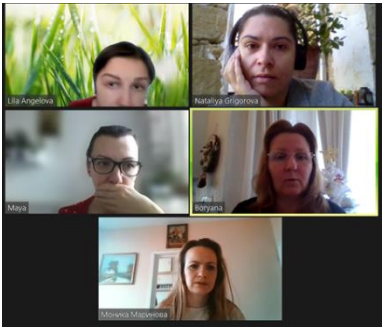
Opening Press conference for the project EmpoweRARE2021

The opening press conference on the project "Empowerment of people with rare diseases-2021" took place on September 2 in the press center of BTA. The press conference was attended by project manager Natalia Grigorova and President of the National Alliance of People with Rare Diseases Vladimir Tomov. Despite the extraordinary situation, the event was attended by representatives of other organizations of people with rare diseases, patients and specialists.

During the press conference was presented the project and its activities, as well as some serious problems related to health and social care for patients with rare diseases in the country. In addition to active civil society organizations, the empowerment of those affected by rare diseases must be supported by a number of national institutions.

Here is what the participants in the press conference said in general:
*"We will realize the first summer camp bringing together families with various rare diseases and specialists involved in their therapy, as well as young people from helping professions. An information line will be launched to help people with diseases and a virtual resource center will be set up with the necessary comprehensive information that a patient would need. The formation of a National Self-Help Network will provide an opportunity to train and motivate more patient advocates to defend the rights of those affected in the health and social spheres"*said Natalia Grigorova, head of the initiative.
To summarize the health situation and the absurdities to which patients with rare diseases are exposed, the press conference was attended by Vladimir Tomov, chairman of the National Alliance of People with Rare Diseases, who said:
"Severely ill people have to deliver protocols for medicines from one institution to another in order to receive the life-saving medicine they need. All this in a pandemic and under the stress of increased risk of infection with COVID-19. A patient familiar with the specifics of the disease refused therapy for COVID-19 offered by doctors, from which she could die, patients have to explain to doctors about their conditions, but even then they often misunderstand. Relatives are crying in front of the wards, begging to be allowed to their relatives because the health workers do not know the nature of the diseases.
The consequences of the dysfunctional health system are visible in all areas of difficulty for this vulnerable group. The lack of a working register for patients with rare diseases leads to the impossibility to analyze their number and needs for social support, which hinders the development of specialized social services for these patients.

Regular meetings of the project management team and the members of the Project Advisory Board.



Two more members joined the Project Advisory Board - Boryana Stoyanova and Monika Marinova, who will be presented one by one in our newsletters. Regular meetings with the members of the Constitutional Court started with the start of the project. The participants discuss the implementation of the activities, as the main topics of the first meetings are:

- guidelines for the main message and theme of an advocacy campaign led by people affected by rare diseases
- start the preparation of a strategic plan for advocacy campaign, incl. identifying potential partners and target groups
- guidelines for the implementation of key activities, including the identification of strengths and risks in implementation
- the commitments of the members of the Advisory Board in their role of monitoring body of the project.

It was identifying the main theme for the advocacy campaign, namely **the need to support the mental health of people with rare diseases**. Work continues to identify key messages, activities and partners of the campaign. The participants also discussed already submitted signals for changes in regulations, advocacy campaigns conducted at European level, opportunities for informal partnerships with other stakeholders to improve the visibility of community issues.

Main messages formulated by the participants during the meetings:

- People with rare diseases need psychological help immediately
- Mental health and social support are first aid for 95% of patients with rare diseases for which there is no treatment
- The community must unite and grow the group of patient advocates for the needs of those affected by rare diseases
- Education-related reforms are needed to improve access to desirable education for children with rare diseases

New members of the Patients Advisory Board under the project EmpoweRARE2021

Here we present a new member of our Advisory Board:

Boryana Stoyanova is one of the founders and a member of the Management Board of the National Association of Patients with Mitochondrial Diseases. Boryana graduated in Law from Sofia University "St. Kliment Ohridski ", works as a lawyer in commercial and corporate law with over 20 years of experience. Married, with 2 children, one of whom has a very rare mitochondrial disease.

Through her participation in the association Boryana actively contributes to:

Membership of the association in the international organization International Mito Patients from 2020, as well as for the first participation in 2021 of the association in the international initiative Light up for Mito (lighting of public buildings in green to support patients with mitochondrial diseases

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

In addition to the topics identified by the Advisory Board, the project team is actively working to synchronize the actions of European advocacy organizations with those in Bulgaria, as well as with specifically identified gaps and problems in national legislation. This is done through signals from those affected, members of the Advisory Board and monitoring of legislative changes open to public consultation.

As part of our advocacy campaign launched in the first part of the project, we renewed communication with the Ministry of Health and the Ministry of Education in connection with the proposal to update Ordinance 10 of 2016 on the organization of activities in school education. soon, including all the rare diseases that occur in children.

After discussions with our Advisory Board, we submitted a proposal to the Ministry of Education and Science and we were promised the formation of an interdepartmental working group with the Ministry of Health to prepare a draft regulatory amendment to Ordinance 10 of 2016 so that rare diseases included in the List, to be included in it immediately and for children with rare diseases to be no longer discriminatory. Ordinance 10 of 2016, on the organization of activities in school education, concerns the approval of lists on which referral of students with chronic diseases, physical and sensory disabilities for admission to documents for profiles and specialties from professions that are not contraindicated in their state of health.

#SOCIALSUPPORT
First meeting with representatives of the Ministry of Labor and Social Policy on presenting the needs for social support to people affected by rare diseases

РЕПУБЛИКА БЪЛГАРИЯ
Министерство на труда и социалната политика

On December 26, 2021, our team represented by the project manager Natalia Grigorova met with Marin Baychev, Head of the Department for Integration of People with Disabilities at the MLSP on the challenges facing people living with rare diseases and their families. The main topics related to the need to provide specialized social services for people living with rare diseases were discussed at the meeting. Mr. Baychev expressed readiness for further discussion of possible actions to improve access to support services for people with rare diseases, and made a proposal for conscientious work during upcoming meetings with civil society organizations on the preparation of changes and actions concerning the Low for social cervices.

Synchronization of advocacy actions
As a member of EURORDIS, Bulgarian Huntington Association regularly supports efforts to unify policies on rare diseases in all European countries.

In this regard, we present the following actions:

- ***Communication with Bulgarian MEPs representatives in the European Parliament on the Debate in the European Parliament on a European Plan for Rare Diseases.***

A debate on the European Action Plan on Rare Diseases took place in the European Parliament on 24 November 2021. Two Bulgarian MEPs

expressed their sympathy and readiness to attend the debate - Radan Kanev and Petar Vitanov in support of more than 400,000 Bulgarian families affected by rare diseases. Unfortunately, neither of them was given time to speak, but Bulgarian politicians have clearly stated their support.

Thanks to the large-scale advocacy campaign led by EURORDIS - European Rare Diseases Organization, each Eurordis member organization had the opportunity to use prepared materials to communicate this crucial community event and to engage its national MEPs to participate in the debate on 24 November and so as to support the Plan and people with rare diseases.

The European Action Plan on Rare Diseases aims to bring Member States towards the same measurable goals in order to improve the survival, quality of life and social inclusion of people with rare diseases. In addition, it has the potential to make a significant contribution to meeting the UN's sustainable development goals.

If implemented in different sectors and countries, the action plan will work to achieve measurable goals for: Diagnose each person within 6 months instead of the current average of 5 years;

● Reduction of premature death due to rare diseases;

● Reducing the economic, social and psychological burden of rare diseases;

● Help discover more than 1,000 new medicines, including gene and cell therapies, based on European research.

- ***Communication with Bulgarian institutions regarding the adoption of the First UN Resolution on People Living with Rare Diseases.***

Coordinated with EURORDIS representatives, we sent several letters to Bulgarian institutions, including the Ministry of Health, the Ministry of Labor and Social Policy and the UN Office in Bulgaria, on the need for our country to adopt and sponsor the UN Resolution on People Living with Rare Diseases.

The UN General Assembly Resolution on Tackling the Challenges of People Living with Rare Diseases and Their Families was adopted by all Member States on 16 December 2021. It consists of 5 key appeals that include:

• Human rights and inclusion: participation and inclusion of people living with rare diseases and their families in society and respect for their human rights

• Appropriate care: improving health and social resources with appropriate care and support within existing resources

• National strategies: promoting national strategies and measures so that no one is left behind - includes promoting the preparation and implementation of National Strategies and Plans, legislation on the rights of people with rare diseases in accordance with international human rights obligations and commitments; implementing policies and measures to address the social development challenges faced by people affected by rare diseases that may need assistance in accessing benefits and services (education, employment, health) and encouraging their participation in society.

Stay informed!

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Youtube: https://www.youtube.com/channel/UCcZDuItF90H_4TZ5hyfigdQ

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BULGARIAN HUNTINGTON ASSOCIATION

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