Iceland
Liechtenstein
Norway
Active
citizens fund

Working together for an inclusive Europe

EmpoweRARE

Empowerment of People with Rare Diseases

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

Newsletter

Issue 3

July 2020

Project information:

Project abbreviation: EmpoweRARE

Project number: ACF-231

Call Topic: SEC-12-FCT-2017

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/

FRAMBU

RESOURCE CENTRE FOR RARE DISORDERS

Online work meeting of the partners of the "Empowerment of People with Rare Diseases" project

The COVID-19 pandemic prevented a live workshop, but in order to continue the work on the project and coordinate the activities of the partners, an online meeting was held to discuss the progress of the project and plan the next steps in its implementation, in accordance with the consequences of the current pandemic.

On the Bulgarian side, the meeting was attended by the project manager Natalia Grigorova and the expert Constantine Economides, as well as two members of the Advisory Board to the project - Iliana Tonova and Lila Angelova. Lisen Julie Mohr - coordinator of activities and communications of the partner and Øivind Juris Kanavin - expert in rare diseases, took part on behalf of the Norwegian partner FRAMBU. The Norwegian partner was introduced to the first training with the target group of people with rare diseases and the analysis of the feedback from the participants as a focus on their interests and identification of their needs and desires for further training and awareness raising. The experts from the Norwegian Resource Center had prepared and presented a brief history of their development by increasing the expertise and covering a constantly growing volume of services provided to families with various rare diseases, which the FRAMBU team provides services to. It was decided that the planned visits of the partners to each partner's respective country should be postponed and carried out in future time, according to the developments with the global pandemic. In the meantime, the implementation of the project will continue with online coordination of the things being implements between the partners.

GOOD PRACTICES – Activities of FRAMBU Resource Center for Rare Disorders, Norway

The FRAMBU centre was established in 1955:

- With significant volunteer initiative and work by the members of the Post-War Workers' Union,
- As a Health Center focused on rare diseases in 1975,
- As a meeting place for people with rare diseases, family members and professionals since 1994.

From the very beginning, the center has been working to empower people with rare diseases by actively involving them in the discussion and planning of activities.

The center is large, functional and fully accessible for people with disabilities. It's responsible for working with **over 450 rare**

diagnoses - using a diverse interdisciplinary approach to support families.

Basic principles of work in the center: Family-oriented care, practice based on knowledge, salutogenesis and empowerment (health pedagogy) and user participation.

The Ministry of Health and Social Welfare allocates funding to the Center, and the diagnoses for which the Resource Center is responsible are determined through NAURD. The focus and framework for the work and services provided by the Center are determined by national law.

FRAMBU works with 72 permanent staff (70% of them professionals directly involved in providing services) and with 200 intermittent staff (for summer camps).

The regular activities of FRAMBU consist of**:**

- **Courses**
- **Summer camps**
- **Orientation and development of expertise**
- **Information and communication**
- **Research and innovation**
- **National and international visits and cooperation**

The courses organized by the Resource Center for Rare Diseases FRAMBU are:

- Courses for patients, family and local service providers
- Courses for professionals
- Internet-based courses - eLearning
- Webinars
- Mini seminars and courses organized for the visitors of the Center
- Summer camps

Summer camps organized by FRAMBU are more training courses than a holiday service. They offer:

- Holiday experiences in a safe and inclusive environment,
- Training activities and opportunities that promote better coping and strategies for overcoming challenges related to everyday life,
- An inclusive arena where participants can meet others in similar life circumstances and with the same diagnosis.

The purpose of the summer camps is:

- To build a personal image, empowerment and useful social networks for the participants,
- Encouraging participation in social activities and spending free time by encouraging increased participation in a home environment.

An important FRAMBU activity is the **Orientation and development of expertise**, which is organized in a way where patients and their families must apply for the provided guidance services (by filling in an application form). The main characteristics of this activity are:

- Multidisciplinary approach, built around knowledge-based practices
- Complementing the local services, not a substitute
- Participation and cooperation between local service providers is required and facilitated (medical, educational, work, housing, social services, etc.)
- Family-oriented approach to services and care

The general criteria for orientation are:

- Topics and issues to be covered are related to a specific diagnosis
- Local professionals may not be able to offer this service
- This service has not been provided before

The criteria for local orientation are**:**

- The purpose of the service is to build a knowledge base
- Education / training of employees providing local services
- Newly diagnosed patients and rapidly progressing diagnoses
- Complex cases

Professionals as well as local and regional service providers can also apply for guidance services (with a completed application form)

Increasing the knowledge base at the local level related to the diagnoses to which services are provided. Helping to facilitate the work of the local network of professionals. Usually local / regional professionals and service providers apply, but also consumer associations.

FRAMBU also contributes to the dissemination of knowledge about rare diseases among schools and students at all levels of the education system.

RESEARCH AND INNOVATION

The hope for a longer and better quality of life for people with rare diseases is linked to new advances in science and medicine. As a rich source of expertise in the field, FRAMBU is actively involved in research and innovation.

Over the last 10 years, FRAMBU has significantly increased its own contribution to research and innovation in the field. The number of staff members with doctoral degrees has increased significantly and the focus has been on research in the field of rare diseases. Clear guidelines and rules related to research and development projects have been introduced. Every year FRAMBU directs funds for possible internal financing of projects.

External funding, for which it regularly applies, is also a means of carrying out research projects.

FRAMBU is also linked to stimulating national research networks and maintains active collaboration with external researchers and institutions.

Information and communication

FRAMBU Resource Center creates and disseminates knowledge about rare diseases, which are:

- Modern and based on the principles of knowledge-based practice
- Understandable to a wide audience
- Related to topics and issues that are relevant to patients / primary target group

Rated as the most important channel: the FRAMBU website / https://frambu.no/om-oss/, but also:

Facebook, Vimeo, Twitter, Youtube, web - Chat and various other media, also meeting the needs of customers, communication channels.

FRAMBU uses and encourages the use of a series of media tools and methods to better reach the target audience and adapt the Center's products.

Summary of FRAMBU knowledge being disseminated:

- Description of diagnoses for which the Center is responsible,

- Description of topics that correspond to a wide range of diagnoses

SECOND TRAINING SEMINAR of the EmpoweRARE project

The second training seminar titled "**Rights of People with Disabilities in Bulgaria - Part II**", part of the EmpoweRARE project, funded by the Fund for Active Citizens of the EEA Financial Mechanism, was held online due to the COVID-19 pandemic on **08 August 2020**.

Он-лайн обучение
„Права на хората с увреждания
в България – II част“

08 август / събота/ 10:00- 16:00 ч./ ZOOM

- Наталия Григорова: модератор
- Лила Ангелова: обучител
- Елка Тодорова: обучител
- Диана Савова: гост

BULGARIAN HUNTINGTON ASSOCIATION

Iceland
Liechtenstein
Norway

Active citizens fund

The lead organization of the project, the Bulgarian Huntington Association (BHA), had received and analyzed the feedback given through the evaluation forms after the first training. The needs and desires of the participants in the training of the target group were taken in consideration and the second training focused on the opportunities for people with rare diseases to be included in the labor market. The lecture was on the legal regulation of the inclusion of people with disabilities in the labor market and the challenges they may face in this process.

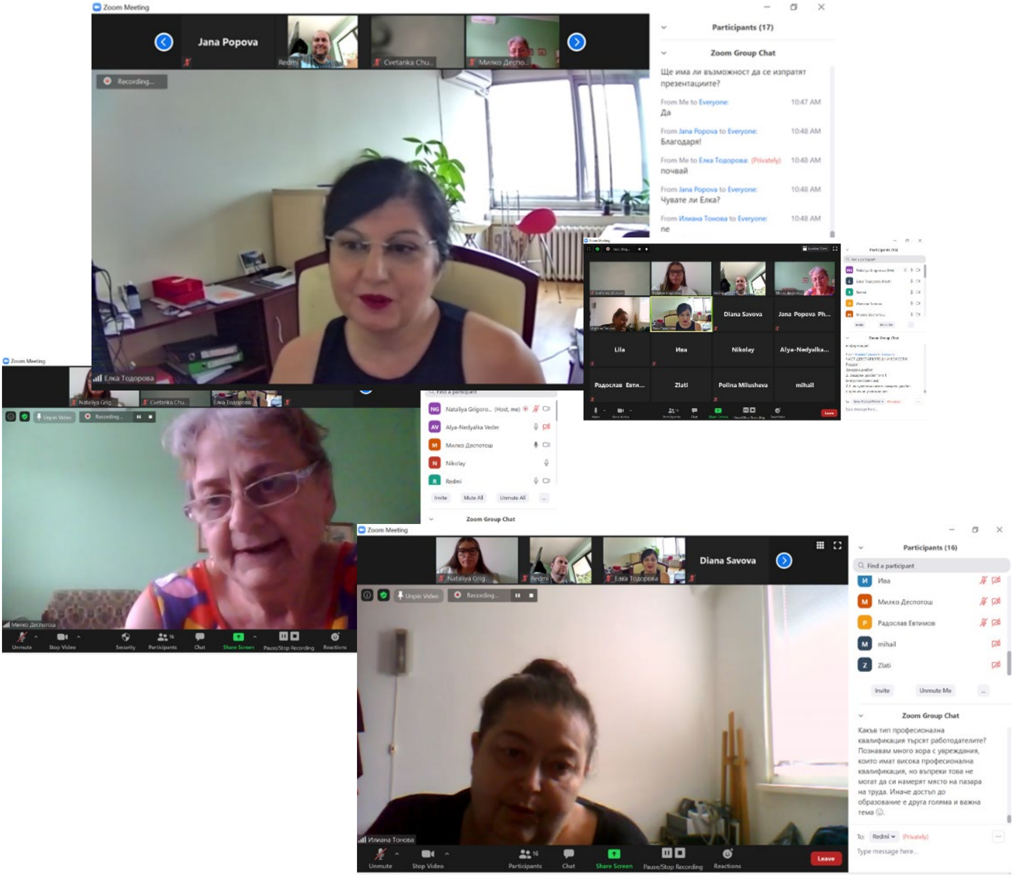
People with proven experience and practice in the field of the training seminar - **Elka Todorova**, President of the National Federation of Employers of the Disabled (NFRI), **Lila Angelova** - expert from experience with a rare disease and **Diana Savova** – expert in JAMBA Bulgaria, were also invited as trainers for this training seminar. The training was moderated by the project manager Natalia Grigorova. Both the first and the second training under the project "Empowerment of people with rare diseases" provided participants with the opportunity to increase their awareness and participate in case studies.

The Chair of the NFRI presented the opportunities, legislation and working programs for employment and entrepreneurship for people with disabilities and measures improving the employment of people with permanent disabilities targeted at employers.

The expert with experience with a rare disease shared her personal experience of professional realization and cases concerning patients with rare diseases.

The innovative practice of JAMBA Bulgaria, an organization representing social innovation, aroused great interest among the participants in the training. JAMBA's mission is to promote equal access to education, the acquisition of key skills and competencies, and the start of careers for people with different abilities. Offering vocational training suitable for people with disabilities and the opportunity to register for the JAMBA online platform to gain access to jobs strictly based on the skills available and those for which you are qualified was a new opportunity for many participants.

As in the first training (which was assessed very positively by the participants) before the second training the participants were sent a set of training materials, and during the training a wide opportunity was created for discussions, questions and work on specific cases. The participants in the second training were 19 people, but the other participants in the first training, who were not present this time for various reasons, expressed a desire to be acquainted with the training, which was made possible through video and audio recording. Participants were invited to fill in a training evaluation questionnaire to check their level of knowledge, old and new, on relevant topics, as well as to give their opinions and recommendations for further training.



Zoom Group Chat

Ще има ли възможност да се изпратят презентациите?

From Me to Everyone: 10:47 AM
Да

From Jana Popova to Everyone: 10:48 AM
Благодаря!

From Me to Елка Тодорова: (Privately) 10:48 AM
почвай

From Jana Popova to Everyone: 10:48 AM
Чувате ли Елка?

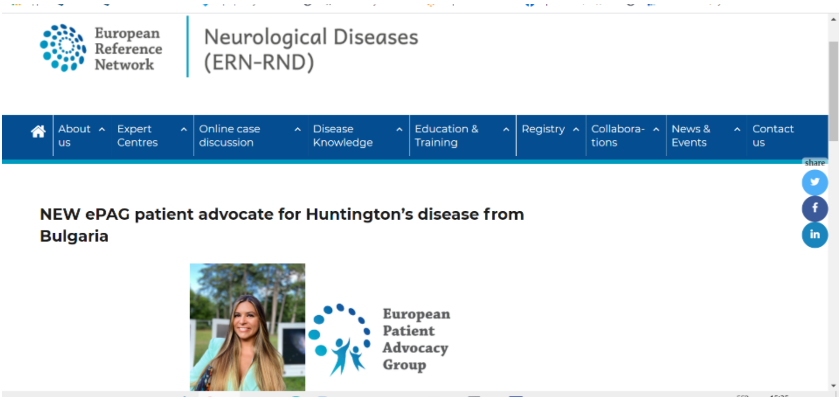
From Илиана Тонова to Everyone: 10:48 AM
пе

Zoom Group Chat

Какъв тип професионална квалификация търсят работодателите? Познавам много хора с увреждания, които имат висока професионална квалификация, но въпреки това не могат да си намерят място на пазара на труда. Иначе достъп до образование е друга голяма и важна тема ☺.

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

THE BULGARIAN HUNTINGTON ASSOCIATION IS PART OF THE EUROPEAN REFERENCE NETWORKS FOR RARE NEUROLOGICAL DISEASES ERN-RND



NEW ePAG patient advocate for Huntington's disease from Bulgaria

Project manager Natalia Grigorova is already part of the European reference network for rare neurological diseases as a patient representative in the group of patient advocates. Here is what Natalia says about her motivation to join the group of patient advocates:

"My motivation to join ERN-RND is to be part of the network, to collaborate, share and learn from the experience of others and therefore to provide the best possible knowledge and support for Bulgarian families affected by Huntington's disease and other rare neurological diseases. At the same time, I feel that I would make a valuable addition to ERN-RND by contributing to the experience gained in empowering people with rare neurological diseases, and I can also provide input on what it is like to work in this sector in an Eastern European country, along with the many challenges people with rare neurological diseases face in Bulgaria."

Link to the full presentation of the organization in the ERN-RND:

http://www.ern-rnd.eu/new-epag-patient-advocate-for-huntingtons-disease-from-bulgaria/?utm_source=mailpoet&utm_medium=email&utm_campaign=ern-rnd-newsletter-september-2020

SOCIAL FRIDAYS

Participation in the working group "Social Fridays" to discuss the law on social services

In July, the project team also took part in a working group to discuss the law on social services initiated by NGOs working in the field. Project leader Natalia Grigorova participated in the online working group to discuss the new law on social services. Here is what the organizers say about the initiative: "As civic organizations, we believe that civic participation is the best way to create social policies and solutions. Social Fridays is an initiative with which we propose every Friday in the coming months to discuss important issues for the good and adequate implementation of the law on social services.

We all want to create a well-functioning system, correct shortcomings and offer effective solutions. We are sure that the most adequate answers are those that have been discussed, debated and analyzed from as many points of view as possible. If it is important for you to share your opinion on how the Social Services Act should be applied, join Social Fridays. "

Initiators: Maria's World Foundation, Bulgarian Center for Non-Profit Law, National Network for Children, International Social Service Bulgaria, Bridges Community Association, Institute for Social Activities and Practices.

The reports from the meetings can be found on the NGO portal, in the Library section:

https://www.ngobg.info/bg/documents.html

Additional information about the project, goals, activities and achievements can be found on the official website of the project: 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

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

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

This document was created with the financial support of the Active Citizens Fund in Bulgaria under the Financial Mechanism of the European Economic Area. The sole 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 in Bulgaria.