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Empowering people with rare diseases-2021

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

Project Newsletter

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EmpowerRARE2021

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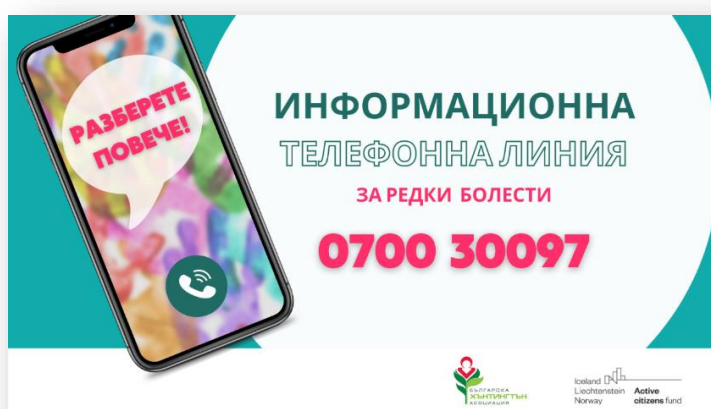
<https://www.facebook.com/empowerare/>

Opening of a National Information Helpline for Rare Diseases

In May 2022, under the EmpoweRARE2021 project, the National Information Line for Rare Diseases was opened, which is part of the European network of EURORDIS support lines. The main aim of the hotline is to contribute to raising awareness of the health services and support available to patients in the country and by contacting it, inquirers can obtain information and assistance on a number of different cases and issues, including:

- General information and guidance
- Information on centers of expertise for rare diseases
- Legal cases related to the rights of people with rare diseases, such as, for example, acquisition of TELK, aids, etc.
- Information on issues related to social and psychological support
- Information on medical cases

In addition to raising awareness about rare diseases in Bulgaria, the hotline also aims to build a mutual aid network for those affected and their families, connecting patients diagnosed with the same rare disease and supporting advocacy.



The information line is open for calls every working day. Currently, the received inquiries are answered by two experienced experts, and the medical cases are

consulted with the Information Center for Rare Diseases and Orphan Medicines in Plovdiv.



Natalia Pamukova is one of the operators on the line, and her desire to engage in this activity is largely connected to her own experience as a patient with a rare disease. Natalia was diagnosed with SLE (Systemic Lupus Erythematosus) in 1991 and PAH (Pulmonary Arterial Hypertension) in 2012. Her long journey in the fight against rare diseases and malfunctions in the Bulgarian health system is a source of valuable experience that Natalia is ready to share with people in the country in need of help and support.

Suzanne Genova is the other operator on the Information Line and also has a



personal touch with the fight against a rare disease, although she herself is not individually affected by one. One of Suzanne's daughters was diagnosed with isovalerian acidemia, which forced the woman to stop practicing her profession as an accountant and devote her time to caring for her child. Familiar with the realities of both rare disease sufferers and caregivers, Suzanne is confident that her mission in life is to help people like her daughter access the right resources and services to lead the best possible lives. - a normal and comfortable way of life and not to allow the lack of

good practices in Bulgarian healthcare to violate their rights.

Promotion of the Information Hotline for Rare Diseases

Various initiatives have been taken to popularize the Information Line for Rare Diseases as a resource available in the country. In addition to increased coverage of the line and related activities in the social networks of the association, the assistance of representatives of all municipalities in Bulgaria, as well as various media, has been sought.

At the moment, several municipalities in the country have supported the initiative and joined the promotion of the Information Line. Among them are Burgas, Stara Zagora, Varna and Smolyan, and the cause receives significant support from the Municipality of Veliko Tarnovo, where - thanks to the assistance of the Chief Expert in the Directorate "Social Activities and Health Care", Radostina Ilieva and the Director of the Directorate, Rositsa Dimitrova - materials with information about the open telephone line are distributed not only in digital format, but also in printed form at the social services provided in the Municipality.

Община Варна - Прессъобщение

Отвориха телефонна линия за съвети за хора с редки заболявания



ОБЩИНА ВАРНА

27.06.2022 15:39

Българската Хънтингтън Асоциация е отворила нова информационна телефонна линия за хора с редки заболявания в Българи - 070030097. Там страдащите от редки заболявания в страната ще могат да получават информация за своето заболяване, права и възможности за лечение от експерти в съответните области, съобщиха от дирекция "Здравеопазване" в Община Варна. Телефонната линия ще бъде част от Европейската мрежа от линии за подкрепа на EURORD

Another initiative for the promotion of the Information Line is the participation of the project manager, Natalia Grigorova, and one of the operators of the line, Suzan Genova, in the program "The Best Doctors" on Darik Radio. In a conversation about empowering people with rare diseases in Bulgaria and the need to create more resources for awareness and support, project team members touch on some of the main issues facing rare disease patients in the country, including:

- The lack of sufficient resources for follow-up care after the diagnosis of a rare disease
- Lack of opportunity to provide medical therapy in 95% of cases of rare diseases in the country
- Access to innovative, life-saving therapy in Bulgaria, which - compared to other European countries - is nearly 3 times more limited for Bulgarian patients



A video of the entire conversation is available on YouTube, for those wishing to learn more about the project's activities, the Information Line and the reality of people suffering from rare diseases in Bulgaria:

https://www.youtube.com/watch?v=hkdw9aF8g38&ab_channel=DarikPlus

Online training “Vigilant parents”

On June 25, 2022, the first of a series of online trainings organized by the association in partnership with the Norwegian resource center Frambu and aimed at raising the awareness of participants on specific current issues affecting coping with the difficulties that life with a rare disease implies, was held.

The Vigilant Parents training was conducted by Prof. Christoph Jarmesdahl, clinical psychologist and researcher at the Frambu Resource Center, Norway. The main focus of Jarmesdal's presentation are the following topics and questions:

- What does it mean to be a "watchful" parent of a child diagnosed with a rare disease?
- What are some of the main mental health risks for parents of children with rare diseases?
- What are the different types of coping mechanisms for stress, mental strain, and symptoms of depression and anxiety in such situations?
- What advice can be given to parents of children with rare diseases?

Prof. Jarmesdal emphasizes that parents of children with rare diseases are at increased risk of developing mental health problems, particularly depression, anxiety and increased stress levels. He describes dealing with the problems associated with a rare disease and the parental attempt to protect the child from various medical risks concerning physical and cognitive development as a source of high mental stress and negative emotions associated with mental disorders such as anxiety and depression.

The advice that Prof. Jarmesdahl gives is about increasing the quality of care for the child with a rare disease without negatively affecting the mental state of the parent. As examples of such practices, he points out:

- Caring for the parent's physical health (ensuring regular sleep, regular meals, as well as some form of movement even for a short period of the day)
- Openness about the problems and difficulties that the parent encounters in the process of caring for their child with medical professionals and seeking the

possibility of referral to a professional prepared to provide assistance (eg, psychologist, social worker, etc.)

- Join support groups and connect with other parents in a similar situation



A video of the full presentation from the Vigilant Parents online training is available with a Bulgarian translation on YouTube for those interested in learning more about what vigilance means for parents of children with rare diseases and what are some of the good practices they would could implement in their daily lives to increase both their own quality of life and the quality of care for their children:

<https://www.youtube.com/watch?v=zYDKFi8EaAI>

The Vigilant Parents training is the first in a series of online trainings that BHA is organizing to help develop the services and resources currently available to address some of the main challenges facing people with rare diseases:

- The lack of an established network for mutual assistance of people affected by rare diseases and their caregivers
- Lack of sufficient medical, social and psychological support for patients and their families
- It is widespread among people directly and indirectly affected by a rare disease that there is a lack of institutions and persons in Bulgaria who understand their reality and provide them with the necessary support to deal with it.

Summer Camp for people with rare diseases 2022



In July, the planned training camp for the project took place, in which more than 70 people affected by various rare diseases and young people from all over the country and the city of Burgas took part.

The camp had an intensive program aimed at providing training in self-help and home care, and participants had the opportunity to engage in various forms of therapy and rehabilitation and individual consultations with specialists in the field of rare neurological diseases. For another year, specialists in neurology and psychiatry from UMBAL "Alexandrovska" were the participants of the camp free of charge, to support those affected and to provide health care and examinations to people living in remote geographical areas.

"For us, this is an experience of a lifetime, to meet other people affected by a rare disease and to have the opportunity to get information about the ways in which we can live better and properly care for our loved ones. We hope that this event will become a tradition, because the Sreshes help us a lot to deal with the diagnosis in everyday life", comments Zivka Georgieva, aunt of a patient with a rare disease participating in the camp.

A flash mob and a march as a sign of empathy and support for those living with rare diseases took place during the camp, in which not only the patients but also their relatives and residents of the city of Burgas took part.

The camp was also attended by the expert Karsten Barton, from the Frambu

Rare Disease Resource Center, who presented the activities and opportunities for collaboration between the partners in the initiative to empower people with rare diseases.



Visiting partners in Frambu, Norway

Immediately after the conclusion of the Summer Camp, the BHA team left for Norway to implement the planned working visit to the Partners' Resource Center in Oslo, Norway. In July 2022, representatives of the Bulgarian Huntington Association team had the extraordinary opportunity to visit the third edition of the Frambu Summer Camp for this summer. At the time of this visit, the camp was already coming to an end and this gave an opportunity to see the development that the participants undergo during their ten days stay at Frambu. The first steps in the surroundings of the center reveal how important the selection of a place is for the provision of quality and efficient social and health services - the preserved nature in which the buildings of Frambu are located and the rich



resources at its disposal are an indispensable prerequisite for the smoothly running work of the team and causing a lasting change in the mental well-being of the visitors.

And upon entering the building itself, one is immediately impressed by the large Frambu team - despite the short summer season in the country and the expectation that a large part of the staff will be on summer leave, the center is busy with the summer camp.

Actively involved in all activities are the leaders of each camp group, their assistants, the Frambu medical team, as well as the administration that takes care behind the scenes to make the camps possible. We were surprised to discover another small team on the territory of Frambu - the executive director of photography and his assistants, who take care of the center's video productions and ensure that every important event is representatively filmed and shared with the public. On this occasion, a specialized video recording studio and technical office have been developed in the center, accompanying the hall where the Frambu conferences take place.

But the activities at Frambu leave the strongest impressions of the entire encounter with the center. During the visit, we have the opportunity to become part of the audience of one of the most favorite parts of the Summer Camp program for the youth: every year, an official football tournament is held for the participants of the camp. One of the league's champion teams in Norway is taking part in this year's edition.

Read more about the health and social care delivery model in Norway and the full report of the team's visit to the resource center on the project's official website, in the materials section:
<https://bq.empowerare.eu/resources>



Stay tuned!

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

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

YouTube: https://www.youtube.com/channel/UCcZDultF90H_4TZ5hyfigdQ



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