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2021 EmpoweRARE

Empowering people with rare diseases-2021

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

Project Newsletter

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#Strongertogether

We continue to empower the people with rare diseases

In the period from January to April 2022, the project team is actively working to prepare the implementation of some of the main activities of the project. The opening of an information telephone line is expected very soon, and in the summer of 2022 the Summer Training Camp for people with rare diseases and the long-awaited visit of the partners to Norway will take place. Meanwhile, we celebrated International Rare Disease Day 2022 and participated in a campaign to raise awareness about rare diseases.

Below we will summarize the news from the activities of the national and European organizations for the period.

Rare Disease Day 28 February 2022

Traditionally, on February 28, the world celebrates the International Day of Rare Diseases. Rare Disease Day is a globally coordinated rare disease movement that works for equality in social opportunities, healthcare and access to diagnostics and therapies for people living with a rare disease. Since its inception in 2008, Rare Disease Day has played a crucial role in building an international rare disease

community that is multidisease-related, global and diverse, yet united in purpose.

Rare Disease Day is celebrated every year on February 28 (or 29 in a leap year) – the rarest day of the year.

Rare Disease Day was created and coordinated by EURORDIS and provides the energy and focal point that enables rare disease advocacy work to progress locally, nationally and internationally. Although Rare Disease Day is patient-led, everyone, including individuals, families, carers, healthcare professionals, researchers, clinicians, policy makers, industry and the general public, can take part in raising awareness and taking action today to this vulnerable group that needs immediate and urgent attention.
By sharing your colors through social media, events, lighting up buildings, monuments and homes, sharing experiences online and with friends, calling out politicians and shining a light on people living with a rare disease, we collectively aim to change and improve the lives of 300 million people worldwide.

BHA in a conversation about rare diseases and cahalenges in access to patient care in Bulgaria - interview in the program "100% awake" on BNT1

Two of the members of the BHA team - Nataliya Grigorova (Chairman of the organization) and Regina Gospodinova (clinical psychologist and project coordinator at the BHA) appeared on the air of BNT1 to share with the Bulgarian viewers a little more about the activities of the association and the need for -great support for those affected.

In a conversation with the presenters of the program "100% awake" on BNT1, Natalia Grigorova emphasized the importance of symptomatic therapy for patients diagnosed with Huntington's disease. The president of the organization also added that in cases where patients do not have access to quality care and do not receive the appropriate therapeutic services, the manifestations of the symptoms of the disease become more

serious and could have severe negative consequences on a person's motor skills and cognitive abilities, which in turn affects their ability to care for themselves.

Regina Gospodinova noted another serious problem for people with rare diseases in the country, namely – the degree of their social isolation, which is closely related to the mental health of the patients. Although people with rare diseases can be counted among the social group of people with disabilities in Bulgaria, the chance of them being socially isolated even within it is further increased by the high percentage of patients with rare diseases who do not have access to information about the essence, symptomatology and available therapies for their respective disease.

Gospodinova also added that - according to data from a BHA study - patients with a rare disease in the country, who reported access to social and psychological care, share significant positive changes in terms of their quality of life. Unfortunately, however, the patients who had the opportunity to benefit from such services are only about 10% of the participants in the study, which testifies to a huge shortage of this type of care for people with rare diseases in Bulgaria.

You can watch the entire conversation here:
https://bnt.bg/news/kak-da-se-grizhim-za-stradashtite-ot-bolestta-na-hantingtan-v316055-304103news.html?fbclid=IwAR0X-5he0deVdiCF723yUEV6a8buzC6N0ESumHQnBMLCZqUCT2npKn49gYQ

The "Twentieth Hero" campaign was launched on the occasion of World Rare Disease Awareness Day

In an interview with "Capital: Health", Todor Kesimov, who since 2018 has been the manager of the Bulgarian representative office of Takeda - one of the fastest growing pharmaceutical companies on a global scale - talks about the campaign.

Mr. Kesimov says that behind the name of the campaign are "invisible" patients with rare diseases for the Bulgarian health and social institutions. He emphasizes that - according to statistics of the World Health Organization in Bulgaria - 5% of the population in the country or more, 1 in 20 people, are diagnosed with a rare disease. The Twentieth Hero campaign aims to address the current challenges in the healthcare system that people with a rare disease and their families face on a regular basis. Mr. Kesimov points out some of the following directions of development on which the campaign is focused:

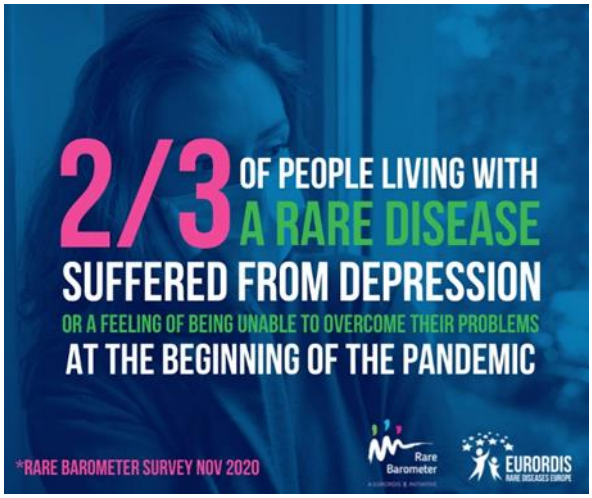
- Improving the quality of access to treatment: Takeda is working hard to expand access to the therapies offered by the company to the largest possible range of affected patients in the country.
- Improving the quality of social support for patients and their families: In almost all cases, people suffering from a rare disease and their caregivers face many difficulties outside of drug therapy (e.g., regarding their professional life or their relationships with others etc.). This testifies to the urgent need to provide appropriate psychological and social support to patients with rare diseases

The Twentieth Hero campaign is one of a variety of initiatives aimed at increasing civic engagement with social issues of social development importance. The work of specialists in the field is complex and affects numerous directions, covering a much wider range of activities than the above-mentioned activities, but at its core, it boils down to one fundamental principle, which, according to Mr. Kesimov, is the manifestation of understanding towards people suffering from a rare disease.

You can read the entire article on the conversation with Todor Kesimov here: *https://www.capital.bg/politika_i_ikonomika/zdraveopazvane/2022/06/03/4346776_todor_kesimov_upravitel_na_takeda_bulgariia_ne_prosto/*

#MentalHealt in Rare Diseases

Mental health is often overlooked when talking about rare diseases. However, most research shows that people affected by rare diseases have significantly worse mental health compared to the general population. 2/3 of people living with a rare disease suffered from depression or feeling unable to overcome their problems at the start of the pandemic, according to a survey by the Rare Barometer. Vital care and treatment for people living with a rare disease is interrupted, and the stress and anxiety of daily life increases.

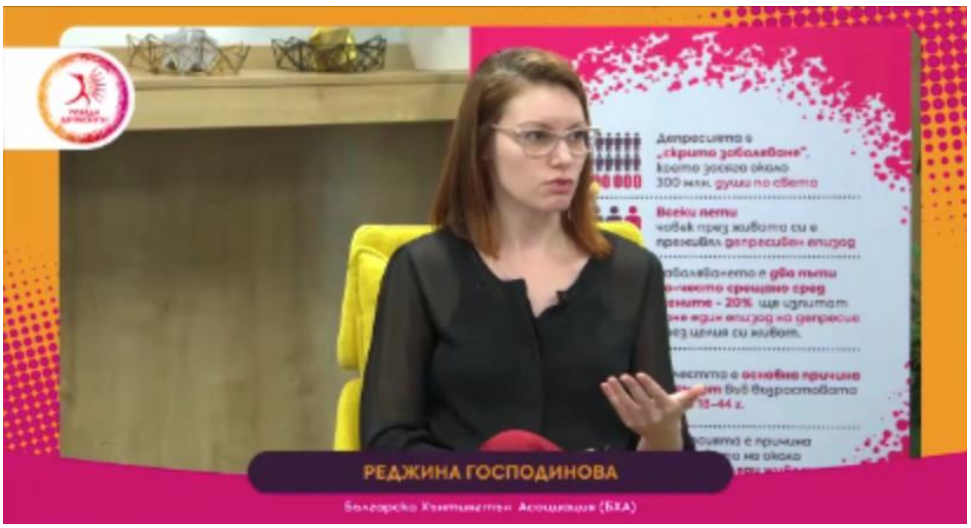


Knowing these challenges, the Bulgarian Huntington Association organized a webinar on the topic "Mental health and rare diseases" in November 2021, as an interview with psychiatrist Vasya Vutova on the topic, you can read here: *https://zdrave.to/saveti-ot-spetsialisti/d-r-vasya-vutova-trevozni-i-depresivni-sstoyaniya-sptstvat-redkite-bolesti*

Within the framework of the forum "Picture of mental health - with a focus on depressive states", part of the BHA team, Regina Gospodinova and Iva Ivanova talked about the challenges related to mental health in people with rare diseases.

- People with rare diseases suffer from depression and anxiety disorders at times higher than the general population
- People with rare diseases report that the first area affected by diagnosis is their social life and mental health
- People with rare diseases report that when they have access to psychosocial support, it significantly impacts and improves their quality of life
- Shock, anger, guilt are the first feelings accompanying the diagnosis, and fatigue from the chronic illness and mental problems are an invariable part of the subsequent daily life
- Built-in psychosocial support mechanisms and a strong community that provides a coping model are key to improving the mental health and quality of life of people affected by rare diseases

You can get acquainted with the recording from the Discussion Studio here: https://www.youtube.com/watch?v=eQPjskypz3Q



Animated film raises visibility of challenges facing those affected by Huntington's disease

"She's home, but it doesn't seem like she's really there."

Children whose parent is affected by Huntington's disease may become frightened and confused by a sudden change in their mother or father's behavior. It is important to help them understand what is happening to their parents. Who can find better words than a toy?

In The Broken Doll - A Huntington's Disease Story by Noah Huntington and Lega Italiana Ricerca Huntington-LIRH, a toy lion explains why parents living with the disease behave differently and how to deal with it.

You can see the whole movie here:
https://www.youtube.com/watch?v=GeafJq2vOwg

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/UCcZDuItF90H_4TZ5hyfigdQ

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