



ЖИВОТ СО ПРЕДИЗВИЦИ / JETA ME SFIDA / LIFE WITH CHALLENGES

ACTIVITY REPORT



Association of citizens for rare diseases LIFE WITH CHALLENGES

Skopje, Republic of North Macedonia, 2023

Association of citizens for rare diseases "LIFE WITH CHALLENGES" – Bitola

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Rare disease day, February 2023

In 2023, we worked together with the National Alliance for rare disease to show united voice of patients with rare diseases.

The event in Skopje gathered the First Lady of Republic of North Macedonia, Ms. Elizabeta Gjorgievska, the Minister of labor and social affairs Ms. Jovanka Trenchevska, directors of the clinics in the University Clinical Center in Skopje, members of the Commission for Rare Diseases at the Ministry of Health, patients, families, patient representatives, media representatives and a lot of supporters of the rare disease cause.



At the event we also promoted the start of our project: Analysis of the problems and challenges of families with rare diseases in the Republic of North Macedonia.



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We also supported lectures organized by Macedonian Medicine Student Association dedicated to rare diseases, and events for raising awareness in Ohrid and Bitola.



A lot of pictures are available on our Facebook page where you can see many different activities on raising awareness about rare diseases in different cities in North Macedonia.

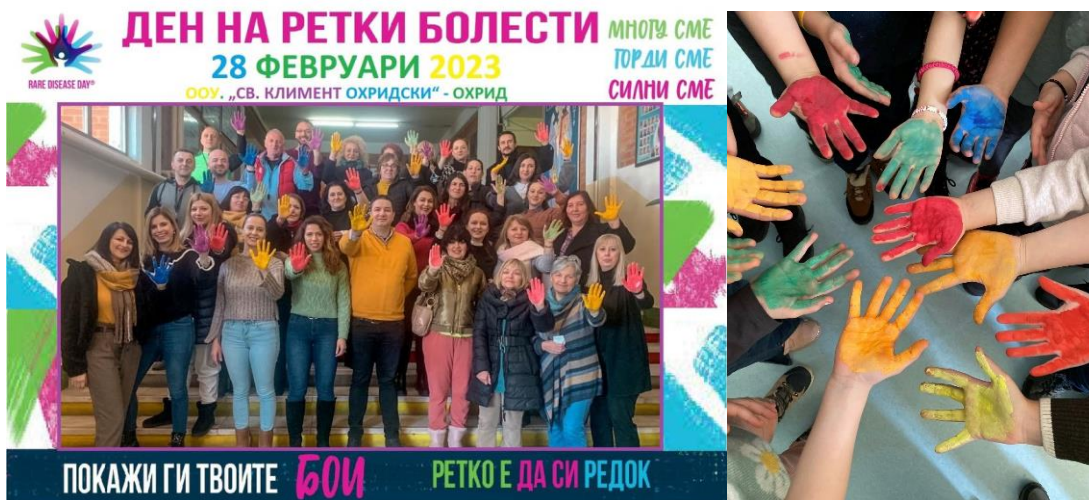


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Learning about rare diseases

This project was started by Super Radio, Gordana Loleska and LIFE WITH CHALLENGES. In 2023 we started in January with promotion of the project that will lead to Rare Disease Day 2023 and continue further. Many doctors supported our campaign. It is amazing to see that new doctors are joining in the fight for a better life for people with rare diseases. Also all information on rare diseases is being uploaded on Wikipedia from the volunteers in Wiki Club Ohrid – Information on Wiki Club Ohrid, so if you write rare diseases in the Macedonian language you will get a lot of information on different rare diseases. This is helpful to spread the information on rare disease in the public and to make the information more accessible and available to families with rare diseases and medical professionals.



Our videos were also shared in Albania and Kosovo as we had translation in Albanian language not just Macedonian language. Join us in raising awareness about rare diseases! Dedicated Facebook page for this project: <https://www.facebook.com/gizapoznavameretkitebolesti>



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Helpline for rare diseases, January – November 2023

In our Helpline, a very special part is the free psychological support for families with rare diseases. During 2019 we saw how important this is for patients with rare diseases and we have been providing this much needed help for 4 years now. We hope to continue helping people with rare diseases as much as possible in the future. We are happy to be able to support rare disease families and now we also have advocacy support, translations and much more. This is just a small contribution to the improvement of the quality of life for people with rare diseases and their families who deserve much more.



In 2021, due to the COVID 19 situation we had increased number of people calling and asking for information, for recommendations, for support and there was also an increased number of people asking for psychological counselling. And in 2022 we got even more people and increased our support with psychologists in 3 cities including Skopje, Tetovo (Gostivar), and Kumanovo. In 2023 we now have psychologists in Skopje, Tetovo, Gostivar, Kumanovo, Bitola, and Prilep.

Activities of the helpline:

- Providing psychological and social support for families with rare diseases in North Macedonia.
- Organization of patient gatherings and webinars.
- Connecting families with same diseases (email, Facebook, telephone).
- Connecting patients with institutions (arranging meetings, writing requests).
- Gathering information on current problems and challenges (advocating for change).
- Publishing brochures for patient support (sharing online for free download and printed version in clinic center in Skopje).

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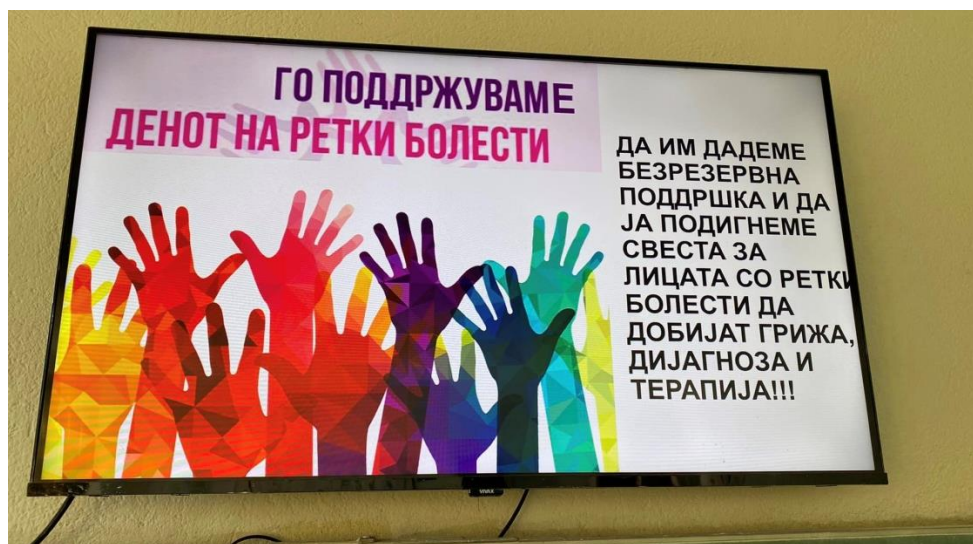
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- Education of patients, families, doctors (webinars, meetings, sending information and new knowledge).

Results in 2023:

- We have increased the number of psychologists in our network and now we cover 6 cities in different regions, and they are available online so that families do not have to travel to get the support they need.
- We organized 3 group gatherings in 3 regions of our country so that families could meet and talk to each other. Also, when they are together it is easier to get support from the municipalities, they live in.
- We estimated that we have around 40 calls a month for different problems, issues, questions, information, support and much more.
- We connected over 50 patients during the year, nationally and regionally, with families and patients with the same rare disease, or with organizations in other countries.
- We gathered information about current problems and issues and prepared analysis that will serve as a tool to advocate for better solutions and better lives of people with rare diseases.
- We had communication with institutions on getting new patients and new medicines in the program for rare diseases, according to the information we have gathered.
- The Helpline is a crucial project of paramount importance for our organization and our community. With this we can gather and disseminate information, we are able to advocate better as we are in direct contact with the families, with those in need. We do hope to continue our activities in the future, especially now that we are well established organization with high integrity and credibility.



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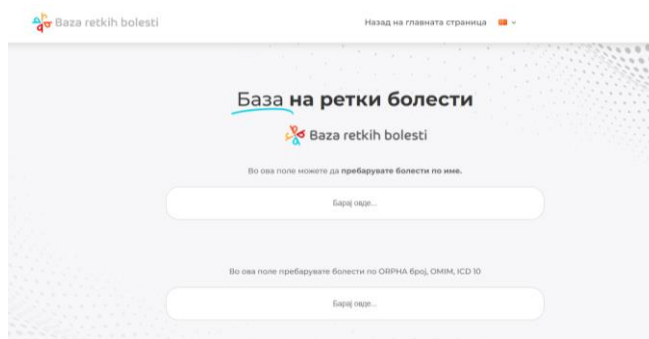
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Regional rare disease database

The Rare Diseases Database is a unique regional project that we are involved in for the past years. It is aimed at shortening the time to diagnosis and providing broad support to patients suffering from rare diseases, their families, and doctors.

LIFE WITH CHALLENGES is involved since the beginning of this project. At this moment included countries are Serbia, North Macedonia, Monte Negro. Republic of Srpska, Croatia. We hope others will join too.



Cooperation with other organizations and meetings with different stakeholders

Meeting with the Minister of Health, Fatmir Medziti



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Meeting for the Rare Disease National Strategy of the Republic of North Macedonia



Meeting with the Municipality of Bitola and the families with rare diseases from Bitola



Cooperation with Macedonian Association of Young lawyers


We continued cooperation with the Macedonian Association of Young lawyers. This was the first project that provides free law support for the patients who are on treatment in the hospitals and clinics. As the problem of public bidding and procurement of medicines continues, we agree that this will be the right step forward to support our families who face life with rare diseases. We are grateful to Roche as they supported this project. The web page for this project is the following: www.pravnaapteka.mk. At the end of 2023, the beginning of 2024, we expect published guidelines for patients and families, so it is easier for them to seek support and fight for their rights.

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Кои се моите права како осигурано лице во однос на пристапот и добивање на редовна терапија - лекови кои се даваат во болница поради природата на болеста (пример, онколошки, ретки болести)?



Како осигурано лице во ФЗОСМ вие имате право на пристап и навремено и континуирано добивање на редовна терапија/лекови кои се даваат во болниците и тоа согласно Уставот на РСМ, Законот за здравствено осигурување, Законот за здравствена заштита и Законот за заштита на правата на пациентите



Initiative for joined forces among patient organizations

Together with other active organizations we managed to continue working together to advocate for solutions to problems that are of concern to all citizens in our country. Each patient group has its own individual problems and challenges, but a lot of them are mutual and we decided to stand together and advocate for change. We will continue to work together on this initiative in 2024 and we do hope to form a national platform for rare diseases.



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Meeting with the Doctor's Chamber of the Republic of North Macedonia

We had a meeting with the chair of the doctor's chamber in October, together with other patient representatives to discuss how we can act together to resolve some of the many problems in the health system. One of our propositions is to work on decentralization of health services and treatment as now everything is concentrated in Skopje in the University Clinic Center.



Conference for genetic and rare diseases, October 2023

At the conference we were able to attend and speak about the problems of families with rare diseases at the opening of the conference. We managed to realize a couple of meetings with a promise for cooperation soon.



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Press conference for focusing on the problems of rare and chronic diseases, October 2023

At this conference together with the chairs of the associations of Multiple Sclerosis, Juvenile Arthritis and the Institute for social sciences and humanities we gave statements about the mutual problems we all face, starting with the need of decentralization of medicines and health services and furthermore the long-term problem with tendering and procurement of drugs which leads to waiting lists, late procurement, lack of medicines from 2 to 4 months and more. We hope to continue working together to resolve the current issues that have been with us for more than 15 years. Our citizens deserve a better life.



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Working meeting for focusing on the problems in the healthcare system, November 2023

Together with a couple of active patient associations we organized a working meeting between patient representatives and institution representatives to discuss the current issues in the health system and the possibilities of solutions as some of the problems exist for years now and the change is crucial for better quality of life, especially for chronic diseases (lifelong diseases, including rare diseases).

Associations included apart from ours were: Hepar Center (liver diseases), Stronger Together (AIDS), Nefron (kidney diseases), Alliance for diabetes, Hema (cancer organization), MS association (Multiple Sclerosis), CML association. From the institutions we had representatives from the Ministry of Health, the Program for rare diseases and the program for diabetes, Health Insurance Fund, Agency for Medicines, Bureau for procurement. Also, we had a representative from the World Health Organization.



We had a lot of discussions connected to many different challenges such as the positive list of medicines, the process of direct negotiation for procurement of medicines, the process for procurement and how can it be better, the waiting lists of patients (to get a medicine they need), the ways to get new medicines to the patients who need them, financial situation, doctor expertise, and much more.

We decided that there are many ways in which we can cooperate and improve the health system in North Macedonia to improve the quality of life of patients, especially for those with lifelong conditions. Next year we will form an Alliance of patient organizations as we know that is important to stand together on the issues that we are all facing together. We expect to improve cooperation with institutions and health professionals.



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International conferences, workshops, and work groups

Caring for Rare, Belgrade, September 2023

We participated in a workshop for planning future mutual activities and cooperation between the organizations in the region. We agree that working together helps us in building better health systems and support more the families with rare diseases in our countries.



Regional Gaucher Meeting, September-October 2023

At the regional Gaucher meeting, 15 patients and family members from North Macedonia attended the lectures and workshops. Unfortunately, the doctors were not able to join us this time. The program was made according to the current needs of the families with GD, and it was great that we could meet again after a very long time. Regional cooperation is very supportive for families who face similar challenges.



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Collaborate meeting, Pfizer, Lisbon, October 2023

This meeting had a focus on ageism and how older people are not treated the same when it comes to rare diseases. Some of the conclusions showed that it is difficult for elderly people to get early diagnosis and early treatment, and the social and health care services are not easy to get. Together we decided on activities to support elderly people with rare diseases in a way that would be more helpful.



Rare Disease conference, Sarajevo, December 2023

In a 2-day conference in Sarajevo the focus was on the quality of life of families with rare diseases in Bosnia and Herzegovina and the Republic of Srpska. There were discussions about the center of rare diseases, the financing of medicines for rare diseases, the social services and much more. As participant from North Macedonia, Vesna took part in the panel discussion on sharing best practices and experiences in the countries from the region. We made plans on future cooperation and shared additional materials after the conference.



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Sport activities for raising awareness, 2023

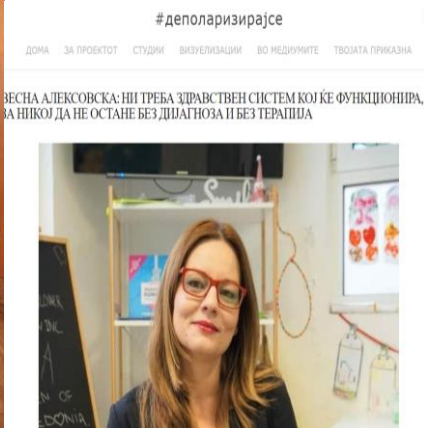


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Rare diseases in the media, 2023



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НАСЛОВНА КАТЕГОРИИ ВЕСТИ ТВ ПРОГРАМА ЕМИСИИ СЕРИИ ФИЛМОВ

Насловна > Македонија > Се зголемува бројот на пациенти со ретки болести

Се зголемува бројот на пациенти со ретки болести

Адијана Митевска Момирска 01.02.2023 235



Бројот на пациенти со ретки болести во земјата е се поголем. Поставувањето дијагноза знае да трае и до една деценија. Ништо пократко не трае набавката на потребните лекови за дел од пациентите.



1 февруари 2023

Охрид, (САКАМДАКАЖАМ.МК)

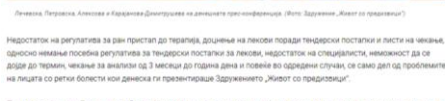
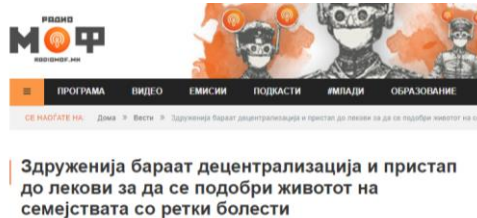


Приоритет е здрав човек, здраво дете, рекоа организаторите на националната кампања „Ги запознаваме ретките болести“ во Охрид. (Фото: СДК МК)

Медицината треба да напредува, а државата мора да ги препознае потребите на болните со ретки болести. Терапијата е скапа, тендерските постапки долги и треба да се бара системско решение оти приоритет е здрав човек, здраво дете, рекоа организаторите на националната кампања „Ги запознаваме ретките болести“ на денешната прес-конференција во Охрид на почетокот на официјалната петта сезона на кампањата.



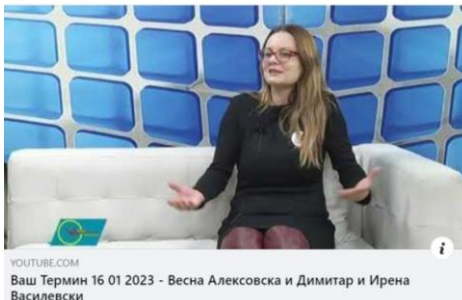
24 анализа - Ќе се набави ли навреме лекот за болните од цистична фиброза?



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Додека надлежните институции си ја префлаат топката кој е одговорен да се реши проблемот за лекот трикафта за болните од цистична фиброза, на многумина од нив им зависи и животот и квалитетот на живот. А доцнежето пак на тендерот за лекови за ретки болести секоја година исто така го загрозува здравјето на многу пациенти кои зависат од терапијата за својата дијагноза на ретка болест.



LIFE WITH CHALLENGES realized all the above activities with the support from sponsors, donors, volunteers and members. We are thankful for their contribution in realization of our projects:

The work of LIFE WITH CHALLENGES is supported by:



Thank you for your support,

Vesna Aleksovska

President of the Association of citizens for rare diseases,

Life With Challenges - Bitola

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Information about the association:

- <http://challenges.mk/>
- <https://www.facebook.com/LifeWithChallenges>
- <https://www.facebook.com/groups/312483895490987/>

Life With Challenges is member of:



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