



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, December, 2020

Association of citizens for rare diseases "Life With Challenges – Bitola

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Learning about rare diseases

This project was started by Super Radio, Gordana Loleska and LIFE WITH CHALLENGES. In 2020 we started in January with promotion of the project that will lead to Rare Disease Day 2020. The Minister of Health and many doctors supported our campaign.



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.



Join us in raising awareness about rare diseases!

This project is available on the following link for free download of information on Macedonian and Albanian language: [Learning about rare diseases](#)

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Students from Gjorgjija Pulevski, Aerodrom Skopje with the teacher Maja Georgieva Pavlovski, marked a rare disease day asking themselves why is February rare disease day and how can we support patients with rare diseases?



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In Bitola:

Together with HEPAR center from Bitola and the gymnasium Josip Broz Tito, we had a meeting with the mayor of Bitola, Natasha Petrovska. We talked about the activities we had so far and about the stigma regarding rare diseases.



The mayor said that it would be good to make a list or a register of rare disease families in the city of Bitola so that the city can offer more services and support for rare diseases. She stated that Bitola will always be here to support the activities of the patient associations and to offer help for the families.

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At the end of the meeting Ms Petrovka also put her hand impression on the poster from the students supporting the motto – One colored hand for supporting patients with rare diseases all around the world.



The gymnasium Josip Broz Tito, with the leadership of the psychologist Lidija Spoa, Hepar center, and Life with challenges, organized an event to mark RDD. A patient with the rare disease Morpheo-Stefan Vaasikj, told his story in front of the other students in his school. He is a great student and a vice president of the Youth active. The voice of rare diseases needs to be strong and loud.



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Students from the school Todor Angelevski Bitola got involved in support for rare diseases. Their teacher Dragana Sherdenkov shared information with them about what Rare disease are and why we need to support these families.



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“Rêver seul ne reste qu’un rêve, rêver ensemble devient la réalité”; “Siamo tanti, siamo forti, siamo rari”

Under the motto If you dream alone, it will stay a dream and if we dream together we can make it a reality, the students who learn Italian and French, in the school Kliment Ohridski, Bitola, led by the teacher Maja Milevska – Kulevska, organized activities for RDD. Their message was – There are medicines for only 5% of rare diseases, support families who face life with challenges.



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The T-shirts in the picture below are made especially for RDD. We are thankful for the support of the school Taki Daskalo, and the teachers Zhivka Tanusheva Icanoska and Anita Stefanovska. Everyone can contribute to raising awareness on rare disease

#RareDiseaseDay #reframerare #rareisstrong #rarebutnotalone



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In Ohrid the activities were organized with Gordana Loleska, the best from our volunteers, a mother of a child with Alport syndrome

Support from the club for underwater activities



Support from Rotari Club and Interact Club in Ohrid, in hotel Su.



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The school Kocho Racin from Ohrid supported RDD. They had a video presentation on rare diseases and some activities for raising awareness and showing support.



The youth club of Red cross Ohrid Клуб на Млади на ОО Црвен крст – Охрид a year after year supports RDD and a lot of other activities during the year.



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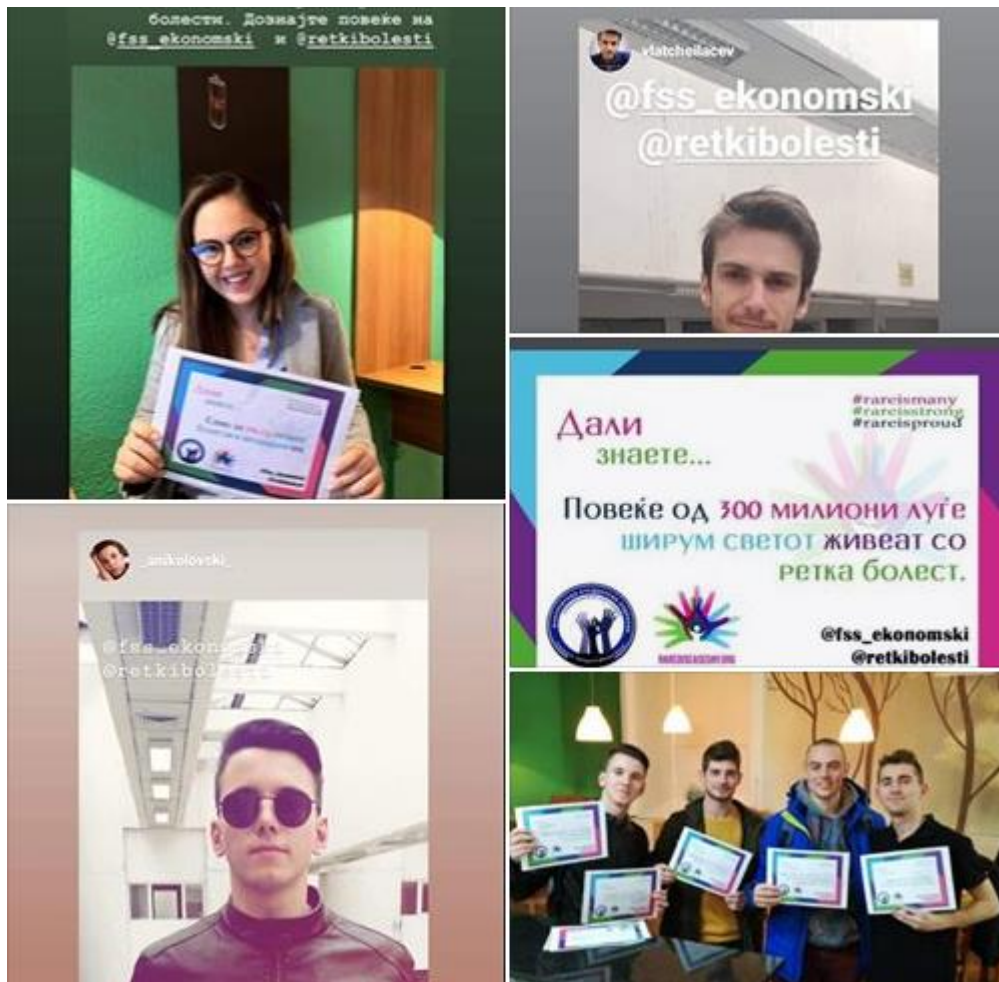
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The student assembly at the Economic faculty in Ohrid also participated in RDD activities. The students were sharing information on rare diseases and they encouraged people to talk about rare diseases.



Employees in Health home Ohrid supporting RDD.



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The students from the school Kliment Ohridski Ohrid also participated in activities for RDD.



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Studio za tanc “BAH” – Dancing Studio Bah, from Ohrid, this year participated actively in RDD.



Tatjana Uzunoska Treneska is with FA Biseri Ohrid and 2 others at НУ Центар за култура “Григор Прличев” – Охрид. Supporting RDD.



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The school Debrca participated in activities for RDD.



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Why stand aside when we can get involved and share positive energy and acceptance. Learning about rare diseases in the school Grigor Prlichev in Ohrid.



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Advocating for patients in COVID 19

As an active association for rare diseases, we are constantly available for rare disease patients and families. We shared information on rare diseases, and now on rare diseases and COVID 19 recommendations connected to specific rare diseases. We also connected families and find doctors to give advice on different subjects where it is necessary. Having in mind the COVID 19 situation we were available online, e-mail, Facebook and telephone.

We also continued to give free psychological support in many cities in North Macedonia (a list of psychologists is available on our web page and Facebook page). Now in quarantine and isolation time we become aware that there is even more need for this kind of support.

Rare diseases are complex chronic conditions and require multidisciplinary approach in treatment and management. This is why we had a media campaign advocating for the rights of the families with rare diseases. These were the subjects we took a stand on:

- **Rare diseases are not on the list of people of high risk who should be free from work.** We have a lot of patients who receive biological therapy, corticoid-steroid therapy, immunocompromising diseases, patients without spleen, patients with complications of lungs and respiratory distress, heart complications, kidney complications, muscular problems, transplanted patients etc. We think that the Commission for rare diseases should decide on the critical diagnoses and patients that need to be on the list of people free from work.
- **There is a special group of rare diseases with transplanted organs.** Some patients have transplanted kidneys, eyes, bone marrow, liver, heart, lungs .., now the Ministry has only liver and kidneys on the list.
- **There are drugs that patients were buying abroad and can't get to them now.**
- **Parents of children in high risk** should be free of work so they do not put their children in danger.
- There are parents of rare disease children who got **decreased salaries and got fired** because of the situation.
- There are parents of children with **congenital heart defects** who are not able to be at home with their children because they do not go to school so parents can get confirmation that their child is at home and they have to take care of it.
- There is no **special procedure for patients with rare diseases who will become affected by COVID 19**, and it is necessary because of the complexity of rare diseases and the necessity of involvement of multidisciplinary team of specialists' doctors.
- **Home infusion is not available** and treatment is still distributed only in the University clinical center in Skopje.

After less than a month, in April, 2020, the Ministry of health published special recommendations for patients with rare diseases in COVID 19. Unfortunately they were not able to solve the problem of the patients who buy drugs from other countries, but as association we found a pharmacy that was able to get most of them in the country so we supported the patients. Other problem that was not solved was home infusion as doctors are refusing to give patients the right to receive therapy at home, saying that they can't guarantee the conditions for safekeeping and the safety of the patients. We do hope that this situation will change in future. The rest of our requests were in the proposed recommendations of the Ministry of health.

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Meeting with the Minister of health to discuss future plans, August, 2020



Together with 10 other rare disease organizations we had a meeting with the Minister of Health, Venko Filipche to discuss about future plans regarding healthcare services, treatment and other needed for rare diseases. AS an association we asked for neonatal screening for PKU, dispensation of treatment for rare diseases in other cities in North Macedonia, a better system in approving new drugs for rare diseases, improvement of the registry for rare diseases, improved communication and cooperation between the Ministry for social services and labor, Ministry of Health and Health insurance fund. We also asked incentive for pharmaceutical companies to distribute and import drugs that patients need but are not available in the country. We also supported the adaptation and implementation of the strategy for rare diseases on which we worked on last year. As an association we always know that are new ways to improve quality of life of patients and families living with rare diseases.



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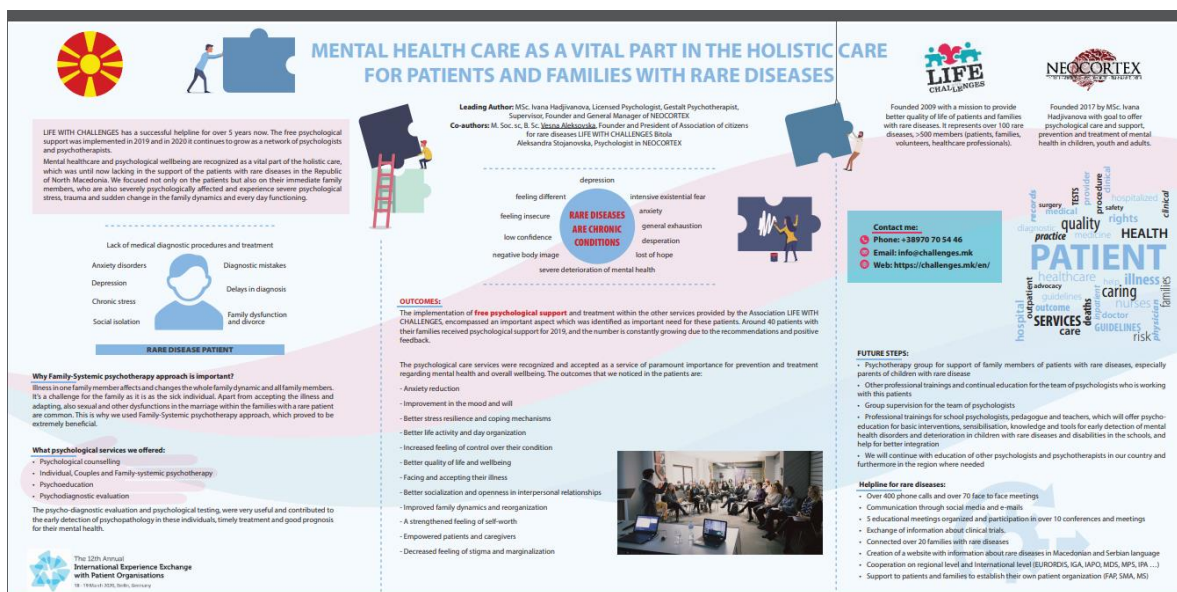
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Helpline for rare diseases, January – December, 2020

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. The comments that we got from our members is that they are happy not going to the clinic center or the hospital to get this needed support. They were also surprised that their family can also get this support for free as usually, that is not the case. Anonymity is also important. We hope to continue helping people with rare diseases as much as possible. We are happy to be able to support rare disease families and soon we will also share a web page with translated information on many different rare diseases. This is just a small contribution to the improvement of quality of life for people with rare diseases and their families who deserve much more.

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. This was not a surprise for us as we expected this and we made all of our services available on line and via telephone service.

We also managed to make a poster on psychological counselling that was presented at the European Conference on rare diseases (this year it was online platform). This poster was also presented on a IEEPO conference organized by Hoffman La Roche on 23rd of September. An updated version of the poster was also presented on a discussion on helplines and psychological support on the regional conference in (23-24) October. We have a unique way of supporting patients as most organizations have employed psychologist and our organization has agreements with more than 5 psychologists from different cities (they are paid according to number of sessions). This way we can help more people in different regions of our country.



MENTAL HEALTH CARE AS A VITAL PART IN THE HOLISTIC CARE FOR PATIENTS AND FAMILIES WITH RARE DISEASES

Leading Author: MSc. Ivana Hadjivirova, Licensed Psychologist, Geriatric Psychotherapist, Supervisor, Founder and General Manager of NEOCORTEX
Co-authors: M. Soc. sc. B. Sc. **Jasna Aleksandrova**, Founder and President of Association of citizens for rare diseases LIFE WITH CHALLENGES Bitola
Aleksandra Stojanovska, Psychologist in NEOCORTEX

Founding 2009 with a mission to provide better quality of life of patients and families with rare diseases. It represents over 100 rare diseases, >500 members (patients, families, volunteers, healthcare professionals).

Founding 2017 by MSc. Ivana Hadjivirova with goal to offer psychological care and support, prevention and treatment of mental health in children, youth and adults.

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OUTCOMES:
 The implementation of free psychological support and treatment within the other services provided by the Association LIFE WITH CHALLENGES, encompassed an important aspect which was identified as important need for these patients. Around 40 patients with their families received psychological support for 2019, and the number is constantly growing due to the recommendations and positive feedback.

Why Family-Systemic psychotherapy approach is important?
 Illness in one family member affects and changes the whole family dynamic and all family members. It's a challenge for the family as it is as the sick individual. Apart from accepting the illness and adapting, also sexual and other dysfunctions in the marriage within the families with a rare patient are common. This is why we used Family-Systemic psychotherapy approach, which proved to be extremely beneficial.

What psychological services we offer:
 • Psychological counselling
 • Individual, Couple and Family-systemic psychotherapy
 • Psychoeducation
 • Psychotherapeutic evaluation

The psycho-diagnostic evaluation and psychological testing, were very useful and contributed to the early detection of psychopathology in these individuals, timely treatment and good progress for their mental health.

THE 12th Annual International Experience Exchange with Patient Organizations
 16-18 October 2020, Bitola, Macedonia

Future steps:
 • Psychotherapy group for support of family members of patients with rare diseases, especially parents of children with rare disease
 • Other professional trainings and continual education for the team of psychologists who is working with the patients
 • Group supervision for the team of psychologists
 • Professional trainings for school psychologists, pedagogues and teachers, which will offer psycho-education for basic interventions, sensibilization, knowledge and tools for early detection of mental health disorders and deterioration in children with rare diseases and disabilities in the schools, and help for further integration
 • We will continue with education of other psychologists and psychotherapists in our country and furthermore in the region where needed

Helpline for rare diseases:
 • Over 400 phone calls and over 70 face to face meetings
 • Communication through social media and e-mails
 • 5 educational meetings organized and participation in over 10 conferences and meetings
 • Exchange of information about clinical trials
 • Connected over 20 families with rare diseases
 • Creation of a website with information about rare diseases in Macedonian and Serbian language
 • Cooperation on regional level and international level (EURODIS, IGA, IAPQ, MDS, MPS, IPA...)
 • Support to patients and families to establish their own patient organization (FAR SMA, MS)

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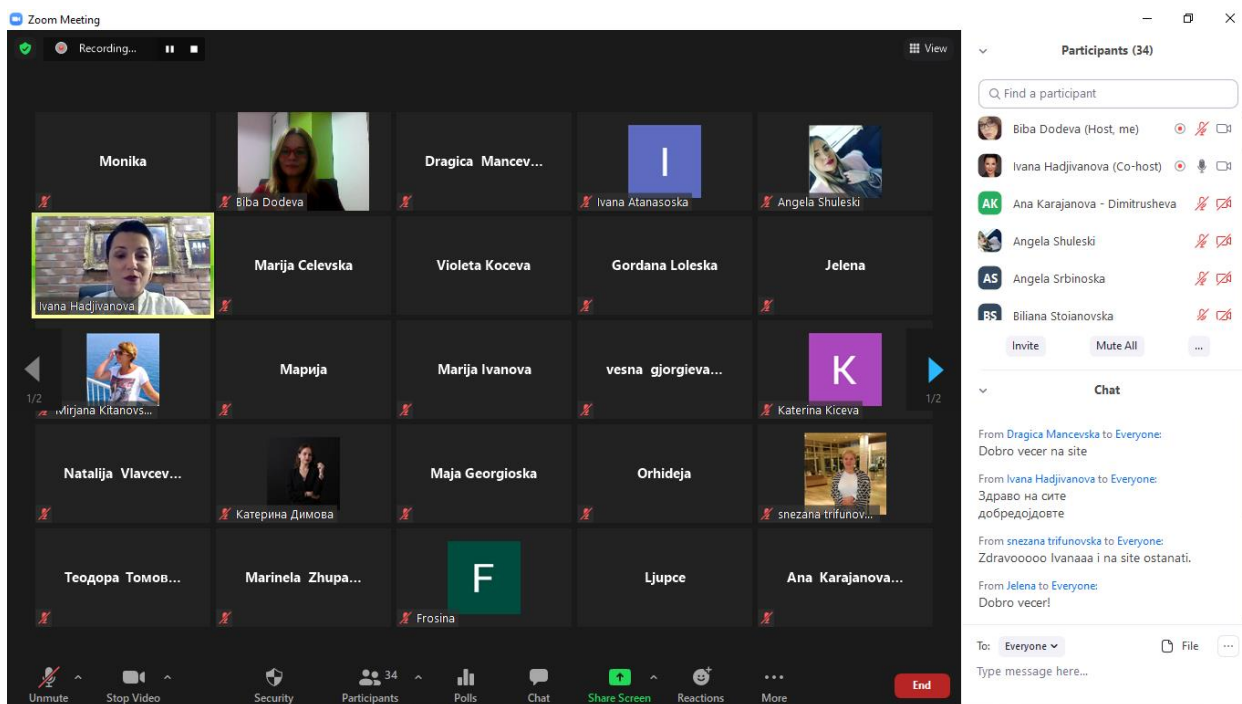
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Activities of the helpline:

- 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).
- Education of patients, families, doctors (webinars, meetings, sending information and new knowledge).
- And other activities connected to family help and support.

Psychological support – online webinars

On 4th of November we also organized online workshop for families that face rare diseases, which were led by a psychologist that we cooperate with as to support group therapy and group support. We planned to do this in a face to face meeting but unfortunately we had to move it online. Another webinar was held in December on how to support children with rare and chronic diseases.



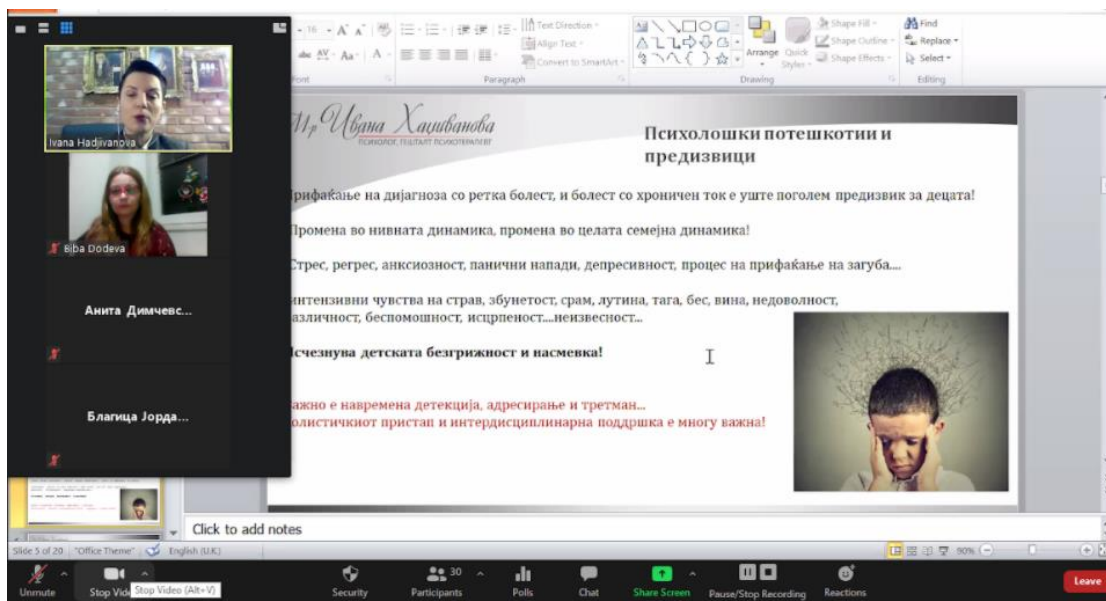
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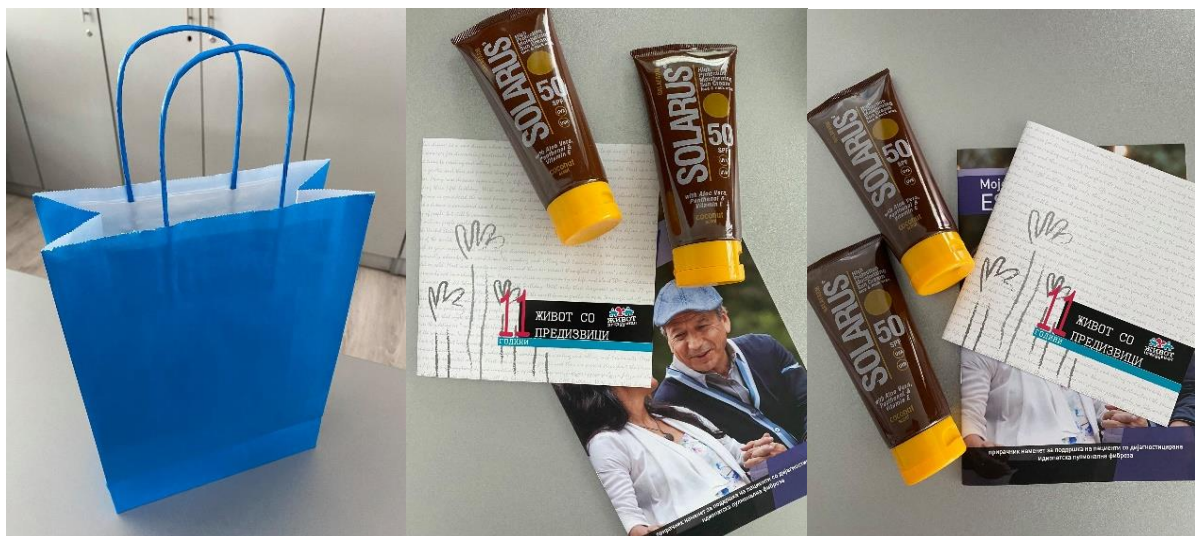
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Supporting patients in cooperation with pharmaceutical industry

LIFE WITH CHALLENGES in cooperation with Roche Macedonia (<https://www.facebook.com/rochemacedonia>), prepared a little surprise for the patients with Idiopathic pulmonary fibrosis who are treated at the clinic for pulmonary diseases in Skopje. This little care package is just a reminder that the families are not alone and that we are here to support their physical and mental health even in COVID 19 situation. We will continue further with our activities to improve quality of life of families that face life with rare diseases. Together we are stronger.



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Raising awareness on rare diseases

Although it was not easy to organize activities during COVID 19 pandemic, still we managed to get support to organize a couple of activities to raise awareness on rare diseases, to support the patients and to raise the spirit of the families.

Paragliding for rare diseases, Ohrid, July, 2020



Climbing the highest mountain top in North Macedonia, Korab, 6th of September, 2020



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Ohrid running, 30th of August, 2020

During the Ohrid marathon the team for rare diseases dedicated their efforts to the people with rare diseases who do not have therapy available in the world. Only for 5% of rare disease there is some kind of therapy but no cure. While there is ongoing research for treatment, families with rare diseases need support regarding health and social services and the focus is on physiotherapy, rehabilitation and psychological counselling. We need our institutions to provide better conditions and improve quality of life of people living with rare diseases.



Struga kayaking, 30th of August, 2020

This event was possible with the Sport recreation club and hotel Bograd apartments and lounge station from Struga with the support from Gordana Loleska leading Rare diseases Ohrid. The event was organized to support people with rare diseases by raising awareness about what it means living with a rare disease.



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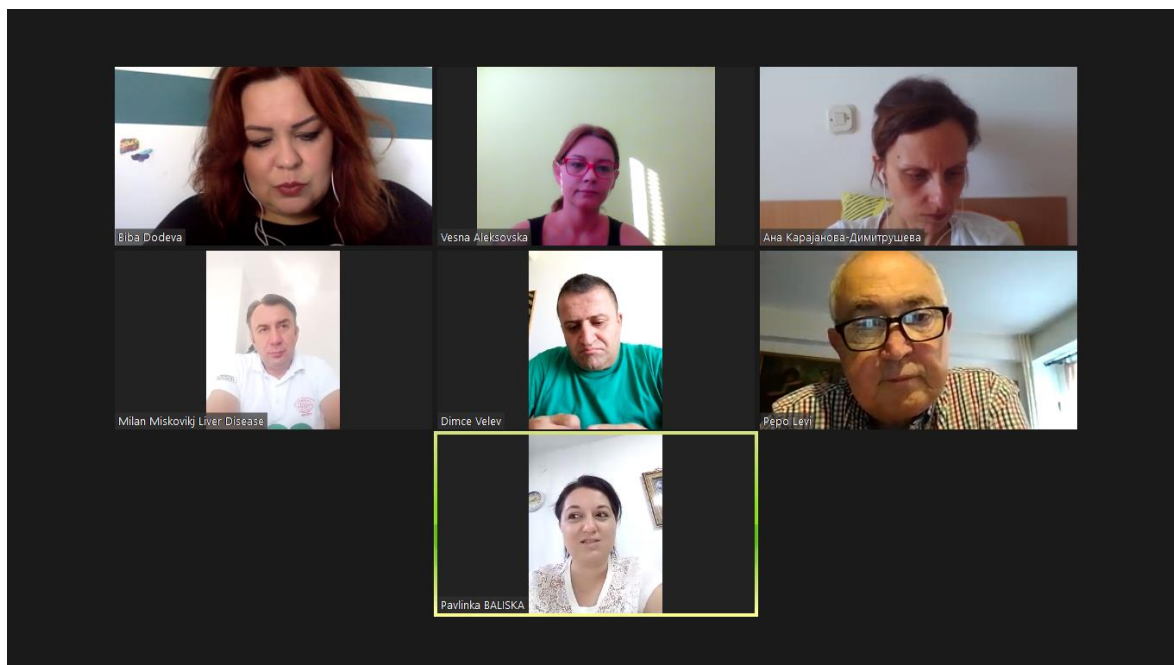
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Advocating for chronic diseases, September 2020

As in September the government decided to change all the measures about chronic diseases that were due to COVID 19 we called an urgent meeting of couple of strong patient associations to agree on requests to the Ministry of Health.



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After the patient representative meeting we agreed on requests and we sent them to the institutions and to the media. The reaction to our requests was immediate and we had a meeting with the Minister of Health to agree upon criteria and difficulties in the recommendations for going back to work. Once again we proved that working together is something that shows success.



All patient representatives agreed that it will be more beneficial for all of if we work together more and focus on important health initiatives that are affecting all citizens and not just one group of patients. We will continue with increased number of member organization in the Alliance of patient organizations – APO. Together we can change more for the better.

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International Gaucher Day, 1st of October, 2020

This year we are celebrating International Gaucher Day with online campaign about home therapy. The importance of quality of life especially with the COVID 19 situation is focused on home therapy and the convenience of the patients who are afraid to go to the hospital for their infusions every two weeks.

HOMES NOT HOSPITALS

Improving patients' quality of life by campaigning for home therapy

Patients featured: Gustavo, Irena, Ali, Claudia, Jade, Aimee-Kate, Michaela, Jennie.

Quote: "To me, home therapy means freedom..."

supported by: AVROBIO ORPHAZYME Pfizer Prevail Takeda

#IGD2020 #RareButNotAlone #HomesNotHospitals

INTERNATIONAL GAUCHER DAY 1 OCTOBER
International Gaucher Alliance

gaucheralliance.org

Regional conference for rare diseases – Caring for rare, 23rd – 24th of October 2020

The regional conference was not a face to face conference but we had to transfer and realize the program in an online platform. The program for the meeting was 2 days and all organizations from the region participated in the development and realization of the program. The following subjects were discussed:

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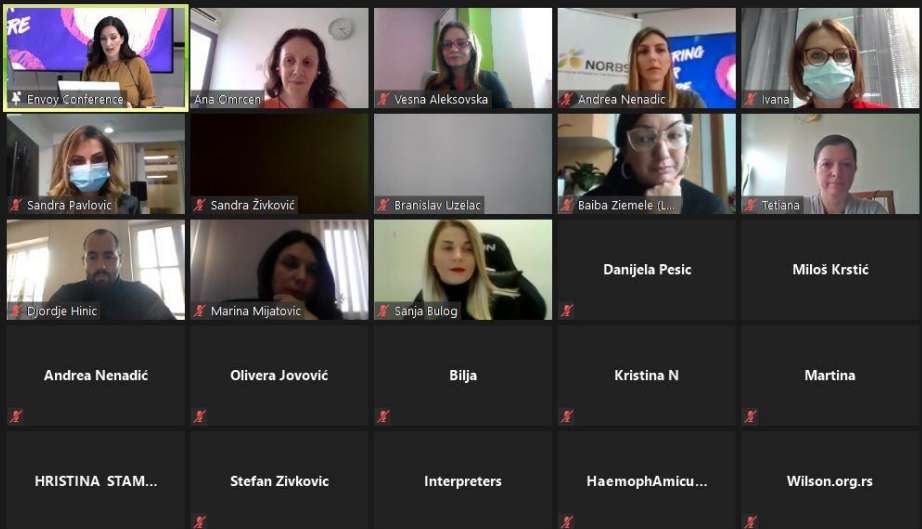
Живот со Предизвици / Jeta me Sfida / Life With Challenges

AGENDA		AGENDA	
FRIDAY, 23 OCTOBER 2020		SATURDAY, 24 OCTOBER 2020	
10:00 - 11:00	OPENING CEREMONY	10:00 - 11:00	ACCESS TO TREATMENT / ACCESSTO OMP
11:00 - 12:00	NATIONAL PROGRAMMES FOR RARE DISEASES IN CENTRAL AND EASTER EUROPE	11:00 - 12:00	THE ROLE OF PATIENTS, PATIENT AND UMBRELLA ORGANISATIONS
12:00 - 12:30	COMFORT BREAK	12:00 - 12:30	COMFORT BREAK
12:30 - 13:30	HOLISTIC CARE AND RARE DISEASES	12:30 - 13:30	NEWBORN SCREENING IN RARE DISEASES
13:30 - 14:30	HELP LINES AND ITS IMPACT	13:30 - 14:00	CLOSING CEREMONY

LIFE WITH CHALLENGES presented the helpline with the outcomes and challenges, participating in the discussions.

Zoom Meeting

Recording



Participants (55)

Q. Find a participant

- Vesna Aleksovska (Me)
- EC Envoy Conference (Host)
- AO Ana Omrcen
- I Interpreters (interpreter)
- A Alex
- AN Alexandru Nita
- AS Andjelka Stupar
- AN Andrea Nenadic
- AN Andrea Nenadić
- AD Andrija Djuranovic
- B Babovic
- Baiba Ziemele (Latvian Alliance ...)
- B Bilja
- BK Biljana Kotur
- BM Bojana Miroslavjevic

Invite Unmute Me Raise Hand

Association of citizens for rare diseases "Life With Challenges – Bitola

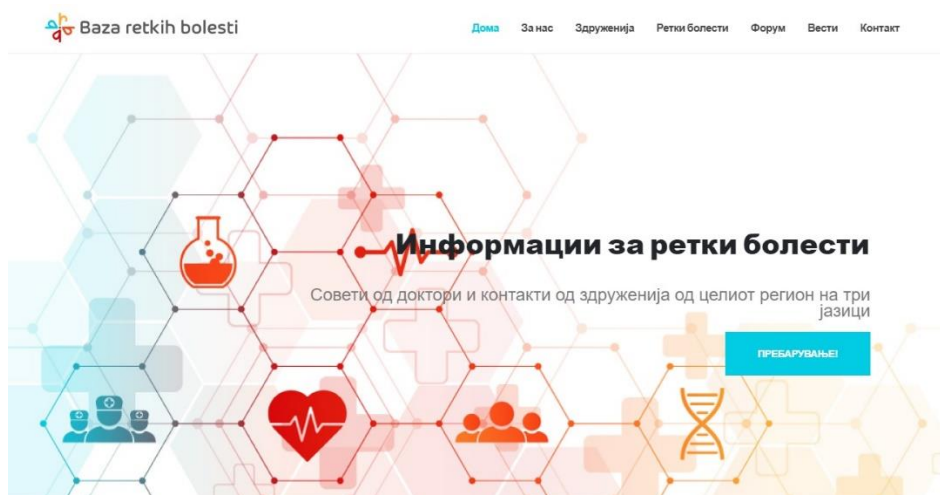
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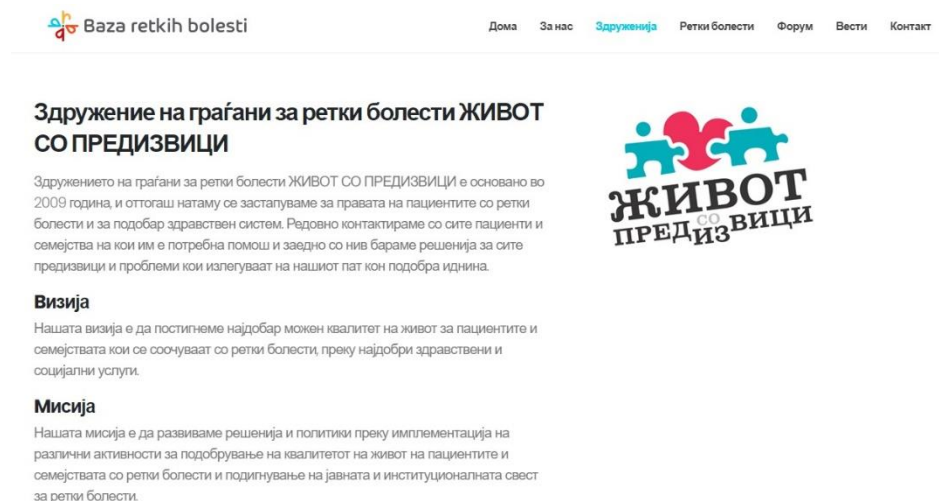
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Regional rare disease database

The Rare Diseases Database is a unique regional project 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.



By entering any term in the search box, the database gives you an insight into the rare diseases that encompass that term.

By clicking on an individual disease, a description of the disease is obtained and additional data, if any, are displayed, also with the contact of association, if there is any.



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info@retkebolesti.com Македонски Пријавување

Baza retkih bolesti

Дома За нас Здруженија Ретки болести Форум Вести Контакт

PRETRAGA

Baza retkih bolesti

Unesi termin...

PRETRAŽI BAZU PRETRAŽI ABECEDNO

☐ Ime bolesti ☐ Orpha broj ☐ OMIM ☐ ICD 10

Subscribing to the forum, you can exchange information and experience with people from around the whole region. **There are two forums: for patients and medical professionals. We call everyone to join the platform and start connecting with people.** More about the base on the web site: <https://www.retkebolesti.com/mk>.

We like to thank everyone who participated in translation: Goce Kalcev, Maja Tankoska, Hristina Stojmirova, Dejan Jakimovski.

Baza retkih bolesti

Дома За нас Здруженија Ретки болести Форум Вести Контакт

БАЗА НА РЕТКИ БОЛЕСТИ

Базата на ретки болести претставува единствен регионален проект со цел скратување на времето до дијагноза и давање на широка поддршка на лицата кои имаат ретка болест.

Базата се ажурира периодично и со своите предлози, информации и знаење може да придонесе кон унапредување на содржината во соодветните делови од базата.

4300+ ретки болести

5 држави

3 јазици

Мисијата на базата на ретки болести е да помогне на докторите и пациентите, но и да ја подигне јавната свест во однос на ретките болести.

- ✓ Важни информации
- ✓ Психолошка поддршка
- ✓ Контакти на здружението
- ✓ Известувања на електронска адреса
- ✓ Вмрежување
- ✓ База на знаење

We call everyone to join us and make this base a center for sharing knowledge, best practice, and communication between people in the region interested in rare diseases.

RARE, BUT NEVER ALONE

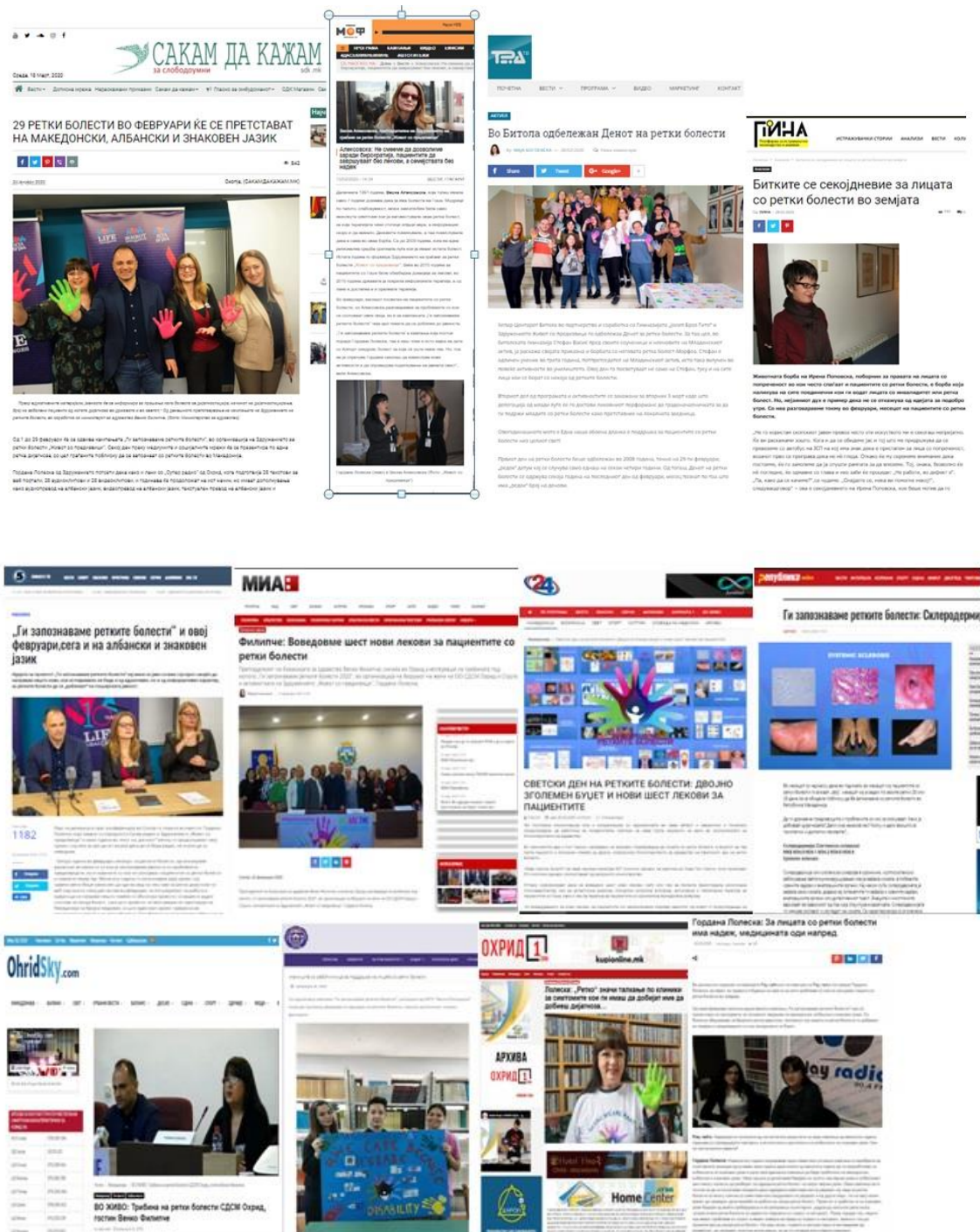
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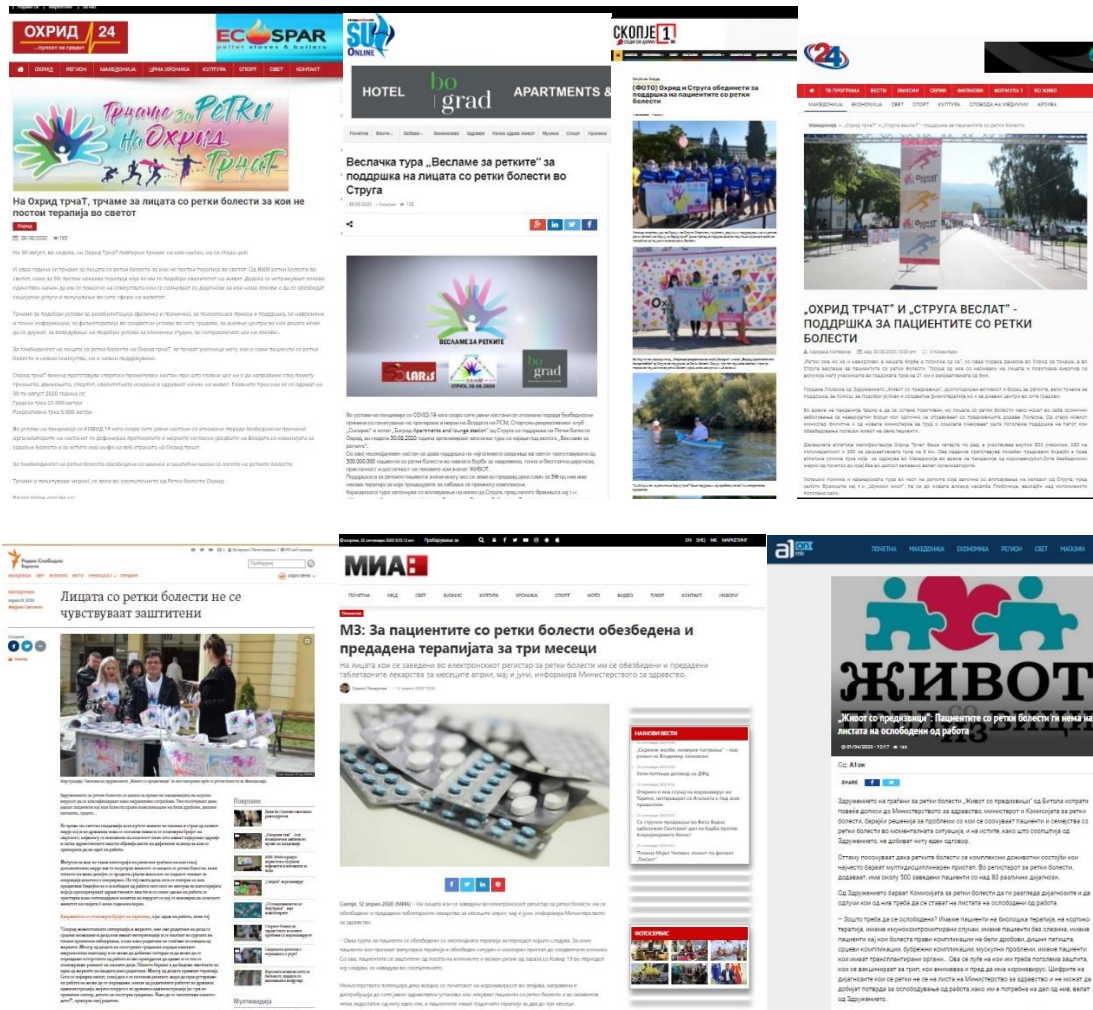
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LIFE WITH CHALLENGES in the media





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

SANOFI GENZYME



B:OMARIN

RECORDATI RARE DISEASES GROUP



ALKALOID SKOPJE Health above all



MEDIS

NOVARTIS

MEDIJA PLANET



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