Живот со Предизвици / Jeta me Sfida / Life With Challenges

NARRATIVE REPORT OF ACTIVITIES FOR 2018

ASSOCIATION OF CITIZENS FOR RARE DISEASES LIFE WITH CHALLENGES

1. RARE DISEASE DAY, 2018

This year, the Association of citizens for rare diseases LIFE WITH CHALLENGES, marked 28th of February , RDD, wth many events in many cities: Bitola, Valandovo, Ohrid, Strumica, Skopje, Gostivar ... Rare disease day is international campaign for raising awareness on rare diseases. From 2008, there have been more than 1000 events around the world. The campaign started as an European event and than it became global. The subject for 2018 was research. This day is a possibility for participants all around the world to be a part of the global call towards the creators of politics, researchers, companies and health professionals.

Statement, Vesna Aleksovska, president of LIFE WITH CHALLENGES:

Rare disease day, for us, patients and families with rare diseases, is a day to remind the public about what has been done for us and what is needed in the future so we can have a better quality of life. One of the problems is of course access to new innovative drugs. From 2015 to 2017 there has been 30 new drugs for around 18 diagnosis. Now in 2018 we will get 2 new drugs, one for aplastic anemia and one for Familial Amyloid polyneuropathy. We still have a long list including spinal muscular atrophy, pulmonary fibrosis, systemic sclerosis, muscular dystrophy Duchenne and Becker, rare cancers in hematology and oncology … we also hope for oral therapy to be available for Gaucher patients, and for juvenile arthritis there are only 2 drugs available so we are trying to get one more as there are around 3 patients who are buying the drug themselves. From the social aspect, we expect new social services and training for employees in social centers so that they are aware of the individuality and the difficulty of the rare diagnosis. On our list is also the need for improvement of diagnosis as we ask from the Health insurance fund to provide refund for diagnosis of rare diseases in the country, and if it is not possible than to have a possibility to send appropriate material abroad in laboratories that Macedonia is cooperating with. Without early diagnosis, early treatment is not possible and the quality of life is very low.

Живот со Предизвици / Jeta me Sfida / Life With Challenges

To be rare means to search for diagnosis from couple of months to over 10 years, rare means to know that somewhere else in your neighbor country there is a treatment for your disease but it is not accessible to you in your own country. Rare is when you can't find a person with the same disease in your own city, country, region and you have to search the world to find a person just like you. Rare is when you ask your doctor about your disease, and he starts searching the internet. Rare is when you have to explain your condition to everyone and still no one will understand. Rare is when you fight for every day, when you are happy doing your everyday chores, rare is when you are one in thousands of people and when you find people like you, you feel like you found your other family, rare id when it is not possible for you to plan your future ... because you are rare ... you are not like the others …

From 20 to 25 February, in Gostivar, e othere was an event organized by Josif Mishevski and Nebojsha Petreski. The first picture for support came from the mayor of Gostivar, Arben Taravari. We are thankful for the support of Procam studio and the city of Gostivar.

On 26th of February, in Bitola, Magnolija square, with the support of the city of Bitola, Vino bar Bure and Hepar centre Bitola we organized an event for raising awareness on rare diseases and a press conference. We are thankful to the high school Jane Sandanski and Josip Boz Tito for the support.

With this kind of campaign we showed that everyone an join in and give support to families that face rare diseases.

Живот со Предизвици / Jeta me Sfida / Life With Challenges

On 28th of February in Ohird , Gordana Loleska organized many events for raising awareness. Middle schools and high schools from Ohrid all joined to raise awareness about rare diseases. On the 28th there was a march for rare diseases with many citizens participating and sharing care**.**

Also there was a promotion of a song for rare diseases - We are all the same, that was performed by talents from the show Ohrid Sueprstar. This song is recorded in the studio Kitrozan, the music is from Jovica Karalievski and the text is from Sasho Mitan. The arrangement is from Jovica Karalievski and Dmiche Kitrozoski.

Helen Doron Center also participated in the campaign to support their student Iva Hadjimanova who is fighting with Congenital Muscular Dystrophy. There is no cure or treatment for this disease yet. Also her friends from school joined to support Iva.

Живот со Предизвици / Jeta me Sfida / Life With Challenges

#ShowYourRare #rarediseaseday #MyRare #CureCMD

И основното училиште Ѓорѓија Пулевски, Аеродром, на 21 февруари се приклучи во кампањата и даде поддршка за ретките болести за соученичката Ива Хаџиманова 3-1 одделение.

Strumica and Valandovo also joined for rare disease day under the leadreship of Ljubica Prodanova.

The school Jane Sandanski from Strumica supported families with rare diseases and **t**he children from Valandovo also gave their support.

We also got some support from our prime minister - Zoran Zaev as he published a statement on his Facebook page saying that systemic long term solutions are needed to build society where people with rare diseases are integrated and have no challenges in their everyday life.

Zoran Zaev
February 28 at 1:35pm ·

Ретките болести не се избор, како што и системските решенија на една држава не смеат да бидат избор. Ние целиме кон општество во кое лицата со ретките болести ќе бидат интегрирани и нивната различност нема да биде препрека за секојдневно функционирање. Лицата со ретки болести и нивните семејства, се борци од кои сите треба да се инспирираме за тоа како може да се справуваме со предизвици и тоа да го правиме со позитивен елан.

Токму заради ова, Денот на ретките болести (Rare Disease Day) го одбележуваме со 3 нови лекови во Програмата за ретки болести и тоа: еден нов лек за терапија на синдромот „Гоше", еден нов лек за терапија на лица со фамилијарна амилоидна полиневропатија и еден за терапија на апаластична анемија.

Исто така, го надградивме електронскиот информатички здравствен систем, односно овозможуваме евиденција на расположливите количини лекови, со што Министерство за здравство / Ministria e Shëndetësisë може во реално време да ја следи количината и состојбата со лековите и да овозможи континуирано и навремено снабдување на потребните количини на лекови.

On 28th of February, in Skopje in organization of the National Alliance for rare diseases of R. Macedonia there was a press conference in the EU info center. We tried to remind the institutions what have they done until today and what is needed so we can have a better future.

Thanks to everyone who joined in the support for the families that face rare diseases.

2. LIFE WITH CHALLENGES ON SKOPJE MARATHON

The Association of citizens for rare diseases LIFE WITH CHALLENGES continues with the tradition and this year is participating at Skopje Marathon together with the group Skopje Night Running. The motto as the previous years is Running for better life.

On 6th of May, 40 participants on 21 and 42 kilometers will run for rare diseases. Our voice is stronger when we are together.

This activity is dedicated for raising awareness on rare diseases in R. Macedonia. Families with rare diseases face different challenges in their everyday life. We are thankful to everyone who supported this activity from 2013 onward. We hope to further contribute towards the future of people with rare diseases.

Statement: Vesna Aleksovska, President of LIFE WITH CAHALLEGNES

„After the start of the registry for rare diseases and the increase of finance for provision of drugs for rare diseases in 2015, we had around 30 medicines supplied for over 18 diagnosis. The Minister of Health Venko Filipce, this year on rare disease day promised 3 new medicines and he kept the promise as we can see form the new tender for rare diseases that is ongoing at the moment. There is still a need for medicines for newly registered patients and new medicines such as for Pulmonary Fibrosis, Juvenile Arthritis and other rheumatological diseases, Becker and Duchene Muscular Distrophy. We also have a request for oral therapy for Gaucher diseases as it will improve quality of life of patients who can transfer from infusion every 2 weeks on a pill every day. From the Health Insurance Fund we still expect refund for special bandages for Epidermosilis Bulosa that were promised in 2016 in February.

We are also very concerned regarding diagnosis.In the past 2 months we had 3 cases (a baby of 4 months, a child of 10 years and an adult) with difficulties to get the diagnosis. To get tests in other countries it costs from 500 to 5000 EUR depending on the tests needed. Refund is not available for diagnosis. Although the HIF promised to get a new regulative about this nothing is happening. The association will continue to communicate with the institutions to ensure that in future there will be appropriate health and social services for the families that face life with rare diseases. Every person deserves a chance for better life. Only together we can improve all of our lives.“

3. RARE DISEASES ON OHRID RUNNING

On 3rd of June, on Ohird Running, rare diseases were present as 50 people were running for raising awareness about rare diseases. The message is clear – we want timely and free diagnosis, we want access to innovative medicines, we want access to appropriate care, we want a better life! This activity was organized by Gordana Loleska, a member and activist of LIFE WITH CHALLENGES. Also we had support with the municipality of Ohrid. This event was a promotional and there were a few races going on during the day, some professional and some recreational.

Statement, Gordana Loleska, activist of LIFE WITH CHALLENGES : *„On this marathon we have professional running for rare diseases, but also parents and patients themselves are running for better life. The citizens of Ohrid supported our cause and contributet towards raising awareness about the problems of people with rare diseases. We also have the Minister for Health, Venko Filipce, running for us and the Minister for finance – Dragan Tevdovski, also we had the state secretary for external affairs – Viktor Dimovski.***"**

Statement, Vesna Aleksovska, president of LIFE WITH CHALLENGES: *„Gordana is one of our most active members, and she organized many events for raising awareness on rare diseases. This is one of those events where we share with the media our problems. Rare families help and support each other, as we are aware of the burden of the rare disease that we have to care for the rest of our lives. There are some steps towards improvement of care and treatment but more is needed. We all deserve better health system and health services. As an association we will continue to cooperate with other organizations and institutions towards long term solutions for better health care, treatment and services.“*

4. HELP LINE FOR RARE DISEASES

In the past 3 years we have a functional help line for patients and families with rare diseases. It is not an official free number you can call but it is a hard work to be done. We usually communicate through telephone, e-mail, Facebook page, Facebook group. Usually we have one or 2 calls on a daily basis, not just in work days but also on weekends and holidays. Sometimes we get calls from people who face other kinds of diseases and we try to direct them towards reliable organizations.

With a goal to help more we are in communication with organizations from the region like Croatia, Serbia, Monte Negro, Bulgaria, Bosnia and Herzegovina. We are all enthusiastic and persistent in our work to support patients. We also organize regional conferences, meetings, we share best practices, contacts from medical professionals, we advise and support each other to achieve more for the families who face rare diseases. The requests for help and the questions that we get, are usually similar to these:

- Do I have a rare disease or just ordinary one?
- Where can find information?
- Can you translate information for my diseases?
- Is there a medicine? Is there any other treatment available or not?
- How should I be registered to get a drug?
- Do I have the right to social aid?
- Do you know someone with this diseases?
- Can you connect me with others like me?
- Do you know doctors that can explain about my disease?
- Which institution should I contact?
- How to write a letter to institution?
- Can you take my documents to the institutions in my name?
- Can you help me gathering documentation?
- Is stem cells treatment useful?
- Who in Health insurance is responsible for rare diseases?
- Who in Ministry of health should I contact?
- Is my special food for my disease refunded?
- How can I get refund?
- Is the clinic responsible for provision of my drugs?
- Who decides if I get a drug or not?

We try to answer immediately if we can or in 2-3 days. If do not get an answer until than, we call and say that we need more time. If we are still not able to help we try to connect and communicate with other organizations and institutions.

Also through the help line we managed to help in foundation of 3 new associations. We gather patients with the same disease, they have a meeting and decide on further actions. Of course we helped them in documentation and registration, we help in project writing, in letters to institutions, we give contacts, we arrange meetings and other similar support. For now we supported the foundation of Pulmonary Hypertension, Wilson, Thalassemia, Spinal Muscular Atrophy and Duchenne Muscular Dystrophy. Sometime they do not form an association but an informal group within the association Life with challenges as they do not have the time or means to deal with administrative work. We also invite new organizations to join the national alliance for rare diseases of R. Macedonia. We think that cooperation is very important if we want to achieve our mission and goals.

This year we got a grant from the Foundation Trajche Muaketov. This will be of great help as now we can be of more help for our rare families. We started cooperation with psychotherapist Ivana Hadzivanova, from Neokorteks, as she will be the go to person for rare disease patients and families. She will provide different services based on the needs that patients have.

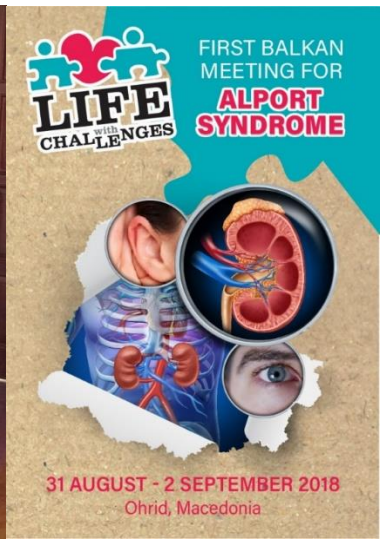
Also we started cooperation with association LIFE from Serbia, as Bojana Milosavljevikj started a web page with information on rare diseases translated into Serbian language. We are going to join forces together and we will put translation into Macedonian language also. On this web site there will be a forum for discussion for patients, families and doctors. Soon Montenegro and Croatia will join this project. We hope to make it a regional web site and use it to exchange experience and knowledge.

5. MAY as MONTH for raising awareness on ICHTHYOSIS

On 29th of May we had a promotion of a video for raising awareness about Ichthyosis. Josif Mishevski made a video with the help of Procam production which was first aired in Gostivar in the coffee bar People, between friends and media. He showed that disease should not be an obstacle to achieve everything you want in your life. The video is available on the following link and it has English subtitles - https://www.youtube.com/watch?v=z_d2CDlvtIg .


6. ALPORT MEETING, 31st August – 2nd September, 2018

The citizen association for rare diseases "Life with Challenges" organizes The First Balkan Meeting for Alport Syndrome in Ohrid, Republic of Macedonia from 31st August to 2nd September. The event is organized by Gordana Loleska, Vesna Aleksovska and Velibor Tasich, MD. The event began with an opening addresses from a mother of a child with Alport syndrome, the Minister of Health and the Mayor of Ohrid Municipality.



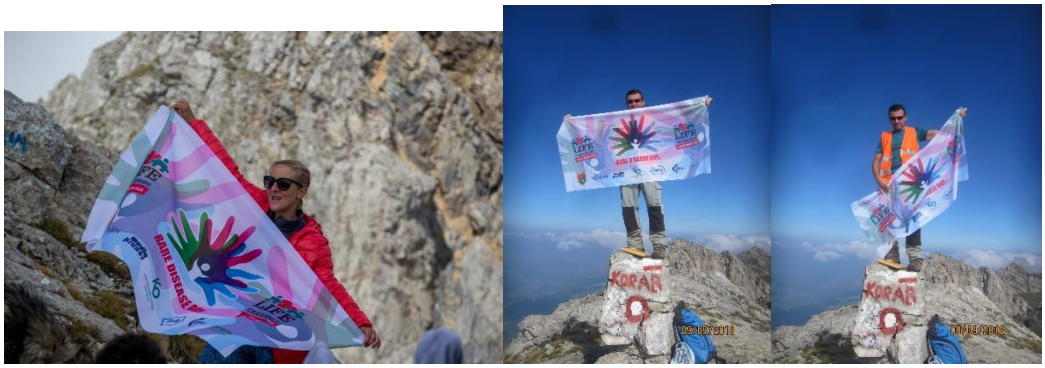
Statement, Gordana Loleska, activist in LIFE WITH CHALLENGES, mother of a child with Alport syndrome, organizer of the conference: *I am glad that we have here present today institutions, patients and doctors, because together we can achieve more for the families that face a rare disease such as Alport Syndrome. I hope that the families will have the*

opportunity to talk and to sincerely ask about all they need to know about Alport syndrome in the course of these 3 days. As a mother of a child with Alport syndrome I know what it feels like when the world crashes upon you when you get diagnosis with which you do not know what to do because there is no cure. It remains for us to bear hope that there will be new clinical trials and medicines that will extend and improve life with Alport syndrome.

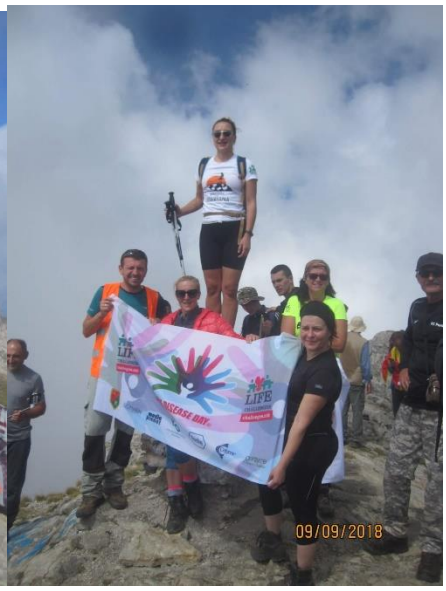
Statement, Venko Filipche, Minister of Health of R. Macedonia: *I believe that only in such meetings where all the concerned parties are present we can jointly do much more and get good results . Doctors and experts should always be at disposal to patients, as well as to institutions. We will try to improve the life of all patients, citizens of our country. We have started cooperating with the rare disease associations a year ago when we had meetings where all the problems and challenges were genuinely discussed. We have completed some of the tasks, and we are still working on others. The electronic registry has been completed, three new medicines have been procured. Now we are working on improving the diagnostic of rare diseases and procuring new medicines. At a meeting with the Minister of Finance we demanded higher budget for health care as well as for rare diseases. Also, we are working on a special fund with the Chamber of Commerce for creating additional means for medicines for rare diseases.*

7. CLIMBING KORAB, 9th of September, 2018

We continued this year with our tradition to have our flag on the highest mountain top in Macedonia, Golem Korab. Following 8th of September – the Independence Day of Macedonia, the association Korab took our flag to the top.



Живот со Предизвици / Jeta me Sfida / Life With Challenges



8. CLIMBING MOUNTIAN TOPS AND RUNNING MARATHONS FOR RARE DISEASES

20th of May, Ohrid night run, and July, 2018, Ohrid Marathon

Живот со Предизвици / Jeta me Sfida / Life With Challenges

30th of June, European competition for mountain running

17th of June, Mont Blanc

Живот со Предизвици / Jeta me Sfida / Life With Challenges

August, 2018, Climbing Triglav, Slovenia

8th of September, Ohrid Marathon, R. Macedonia Independence Day

23th of October, 2018, Ruen mountain

Живот со Предизвици / Jeta me Sfida / Life With Challenges

11th of October, 2018, Korab, Shuplja Stena and 14th of October, 2018, Shar mountain, Plat

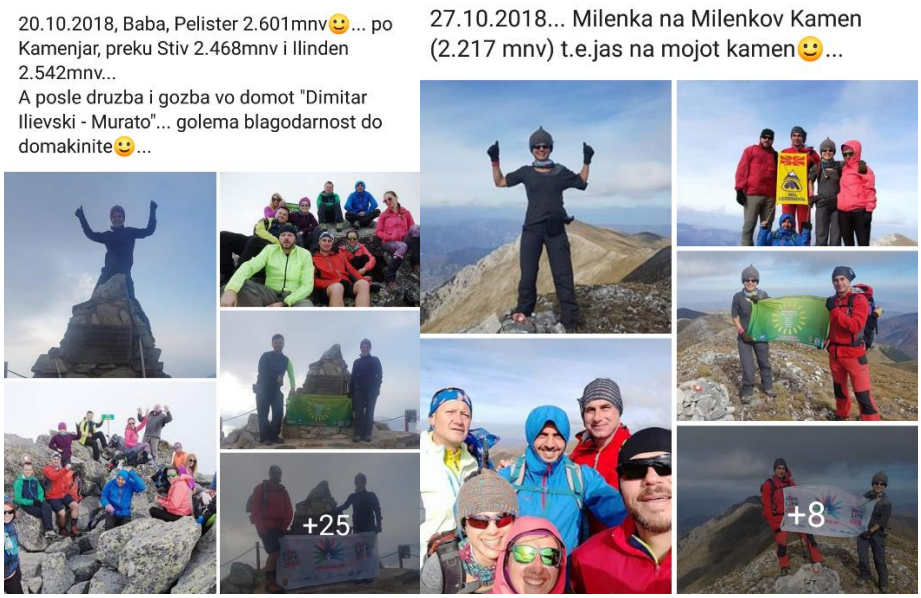
14.10.2018, Sar Planina - Plat 2.398mnv...
Maksimalno da se iskoristi "ciganskoto leto"😊

11.10.2018, Korab, Suplja Stena, 2.442mnv...
Praznicen den kakov samo moze da se posaka...😀

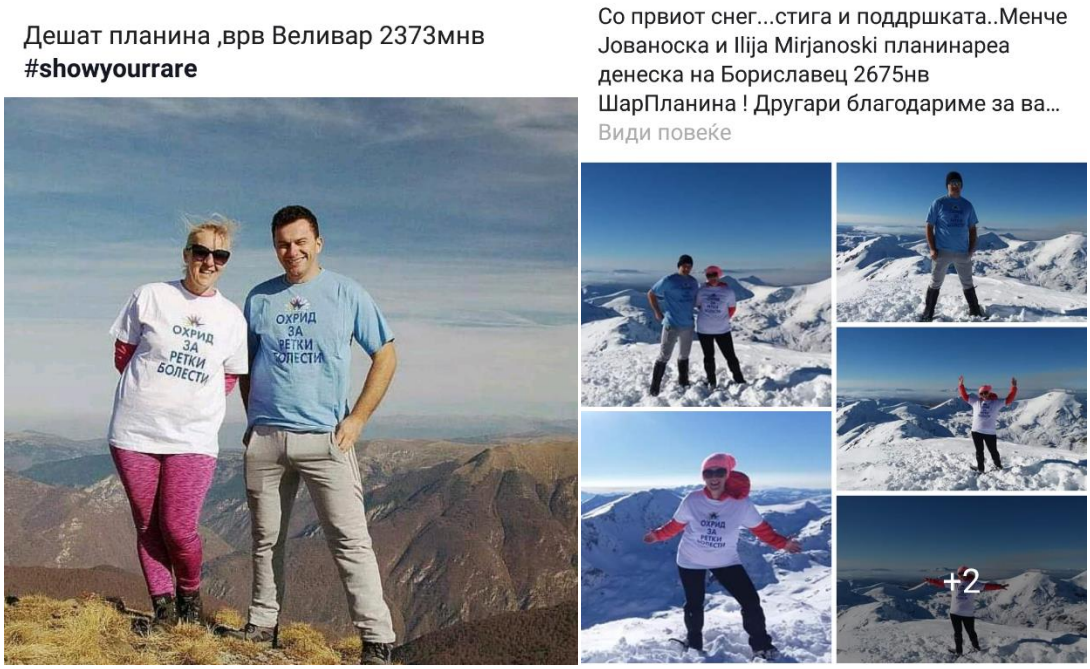
Prilep Marathon, 25th of November, 2018

Живот со Предизвици / Jeta me Sfida / Life With Challenges

20th of October, Baba mountain, Pelister and 27th of October, Milenkov Kamen



Deshat and Shara mountain



9. PROMOTION OF A RARE DISEASE FILM – FACES OF LAFORA

On 16th of October the Bosnian Embassy in Macedonia organized a promotion of the movie “The faces of Lafora”, which is a film about rare diseases. As organization for rare diseases we supported this event and we were included in the organization. We had opportunity to talk in front the audience on the problems and challenges of rare diseases. We are thankful for this support, and we hope now in 2018 to show the film in Bitola and Ohrid.

Живот со Предизвици / Jeta me Sfida / Life With Challenges

10.INTERNATIONAL GAUCHER DAY, 28th of November, 2018

Although it was 1st of October as International Gaucher day, we managed to organize a lecture on Gaucher disease for the doctors in the hospital in Tetovo in November, because there were some political crisis during October.

We had 2 lectures one from Prof. D-r Zlate Stojanovski about Gaucher Disease (diagnosis and treatment) and one from Prof. D-r Velibor Tasik about Innovative technologies in diagnosis of rare diseases. Also we presented the association and how we can support patients and families with rare diseases.

11.DUCHENNE MUSCULAR DYSTROPHY MEETING, 16TH December, 2018

The meeting was organized from Life with challenges with the support and help of the members of the new organization for Muscular Dystrophy. As a guest speaker we had Prof. D-r Natalija Angelkova who is treating the children with Muscular Dystrophy at the University Children Clinic, department of neurology. She explained about the registry and the program of rare diseases, about treatment, clinical studies and she shared her contact information so that families can be in contact with her.

Orce Nikolov as one of the founders of the association, father of a child with DMD, shared his experience from conferences on DMD that he attended this year.

Through Facebook we also had Dimitris from Greece, who is the president of the association for neuromuscular diseases. As we cooperated with him through the EUPATI project and EURORDIS, we started to work closely so that we can support DMD patients in Macedonia.

12.MEETINGS AND CONFERENCES

Meetings with institutions

In this year almost every month we had meetings with the Minister of Health and/or people from his cabinet to discuss on progress regarding treatment and care of people with rare diseases. For now we got 3 new medicines in the program and we are expecting at least 2 more until the end of this year and for next year we expect increased budget for more innovative drugs. Also the register will be in electronic form and easier to manage until the end of 2018. In the beginning of June, we initiated an analysis for diagnosis of rare diseases.

This will start as a list of diagnosis to see what and where is available for testing and then continue with search for funds for diagnosis in Macedonia and abroad. Also we talked about getting new medicines in the program for Pulmonary fibrosis, for secondary pulmonary hypertension (they only provide medicines for primary at the moment), for additionally registered patients with FAP, ALS, Gaucher, Juvenile Arthritis and others, oral therapy for Gaucher … Also we talked about the provision of biological medicines for patients at the children clinic, gastro clinic and rheumatology clinic. A lot of patients are on the list of waiting to get drugs, everyone who is diagnosed during 2018, are on the waiting list for 2019. We agreed that this is not good for the patients, as the condition is progressing and for next year we expect as promised to have urgent public biddings to cover the newly diagnosed patients.

We also had a meeting with the Ministry of Labor and Social policy and a meeting with the Health Insurance Fund. We expect some changes regarding how rare disease families are being treated from the social system and how can we improve that further. Also it is very important to mention orthopedic devices (especially for ease of breathing and other necessary equipment for neuro-muscular diseases) for which we had a meeting with the commission for orthopedic devices at the Health Insurance Fund and they will see what can be implemented in 2019. With the Ministry for social policy we talked about managing an info center for rare disease as we plan to fully provide this service for the families in Macedonia next year.

In **March, 2018** at the **public debate for the changes of the law for medicines** (more specific about the parallel import of drugs) **at the parliament of Macedonia** we had a representative (Vesna Aleksovska) stating that the best thing to do for the patients, the citizens and our future is to adopt EU laws and with that exclude Turkey, Japan and Russia as countries on the list of allowed import. Our statement was clear that we only want to have EU countries on the list of allowed import of drugs. This law was changed and they added certificate of quality from the manufacturer, certificate from a laboratory, and documents for transport of the drugs from the manufacturer to the end user. With this we believe that there is increased security and decreased chances of getting falsified drugs and drugs with suspicious quality as it was the case before. We have to wait and see if this will work.

From **9 to 12 of May,** 2018 Vesna Aleksovska attended the **European Conference on Rare Diseases** in Vienna, Austria. These kind of conferences are very important for cooperation, exchange of information, knowledge and best practice. She met with representatives from the region (Bulgaria, Serbia, Croatia, Slovenia …) and also from EU. 800 representatives were

at the conference. Vesna also attended the E-pag meeting and the Rare disease international meeting to make more connections and use them to help policy making and advocacy in Macedonia.


As around 10 Gaucher representatives were present at the meeting, we also had a Gaucher dinner to have time to discuss and support each other on different challenges. Conferences are great place to meet with colleagues and collaborators.

On **31st of May, 2018** Vesna Aleksovska was invited as a speaker at the **Forum for Innovative Medicines** organized by Farma Brend Nova – Organization of pharmaceutical companies for innovative drugs. There were guests speakers from the region and the Minister of Health was also present as he opened the conference.


Живот со Предизвици / Jeta me Sfida / Life With Challenges

Vesna Aleksovska , as board director of EGA and as a president of LIFE WITH CHALLENGES attended **rare disease meeting in Albania** in May, 2018. She gave a presentation about EGA and about the situation in Macedonia and also talked to patients and doctors about the situation in Albania regarding rare diseases and how things can get better for the families. Cooperation between doctors, patients, institutions and organizations is very important to achieve progress in quality of life of patients.

As an association we try to support other organizations in their fight for better life so we attended the events organized for Hemophilia, Cancer, Multiple Sclerosis and other.

Vesna Aleksovska continued to volunteer in the **DITA task force at EURORDIS** and attend regular teleconference meetings and face to face meetings. The Drug Information, Transparency and Access (DITA) Task Force closely follows the work done by patients and consumers at the European Medicines Agency (EMA) and in the European Network of HTA agencies (EUnetHTA) in the areas of product information, transparency of the regulatory process and access to medicines. There are 18 volunteer members of DITA, from EURORDIS member patient organisations, led and supported by EURORDIS staff members Francois Houÿez, Director of Treatment Information and Access, Health Policy Advisor and Anne-Mary Bodin, Operations Assistant. DITA volunteers bring invaluable knowledge of their own rare disease and national health system. Many are patients themselves living with a rare disease. DITA works and gives input into several EU projects that EURORDIS is involved in and that concern the rare disease patient community. The task force meets twice yearly with regular telephone conferences and email correspondence to maintain the workflow.

Живот со Предизвици / Jeta me Sfida / Life With Challenges

In **September, 2018** we had a representative at **the National plan for rare diseases conference in Zagreb, Croatia** to support the Croatian alliance for rare disease, and also to have a meeting on regional level with Croatia, Serbia, Republika Srpska and Macedonia on further cooperation about new policies and services for people with rare diseases.

In **October, 2018,** we participated in the International **Gaucher Alliance membership meeting.** Our representative Vesna Aleksovska is now the vice chair of IGA. We hope to continue cooperation and work with organizations all over the world.

In October we participated in the rare disease meeting in Kustendil, Bulgaria, that was focused on rehabilitation and social services for people with rare diseases.

Живот со Предизвици / Jeta me Sfida / Life With Challenges

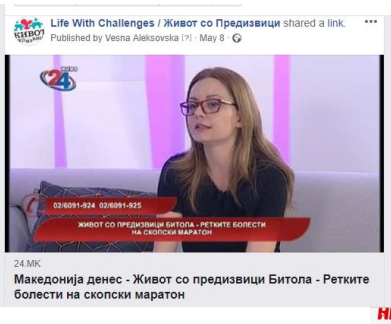
10th of December, 2018, Vesna Aleksovska participated in the **Gaucher Advisory Board** of Genzyme Sanofi Aventis. Participants from different countries discussed on bone involvement in Gaucher disease. It is good to know that the opinion of patients matters.

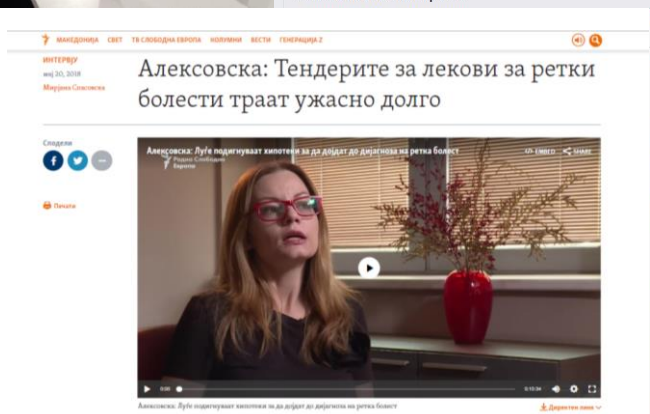
In **December, 2018,** we participated at the **East European Conference on Rare Diseases**, organized by the National Organization for Rare Diseases of Serbia. Participants talked about national plans, social services, access to treatment, and much more as we discussed on many challenges and problems. We agreed to form a council for Balkan rare disease organizations and together to work on improving lives of patients with rare diseases in our region. We will meet again at EURORDIS membership meeting in May, 2019 and in June, at the regional conference for rare diseases in Struga, Macedonia. We hope to achieve change together.

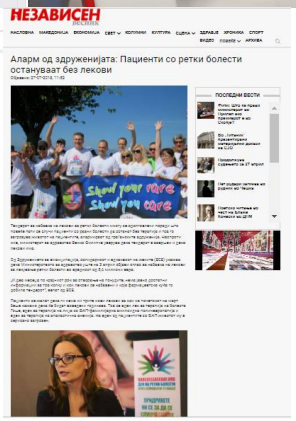
Живот со Предизвици / Jeta me Sfida / Life With Challenges

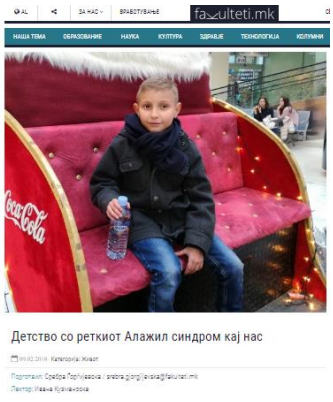
MEDIA COOPERATION

Just a small part of the media coverage that we had through the year talking about problems and challenges of families with rare diseases.

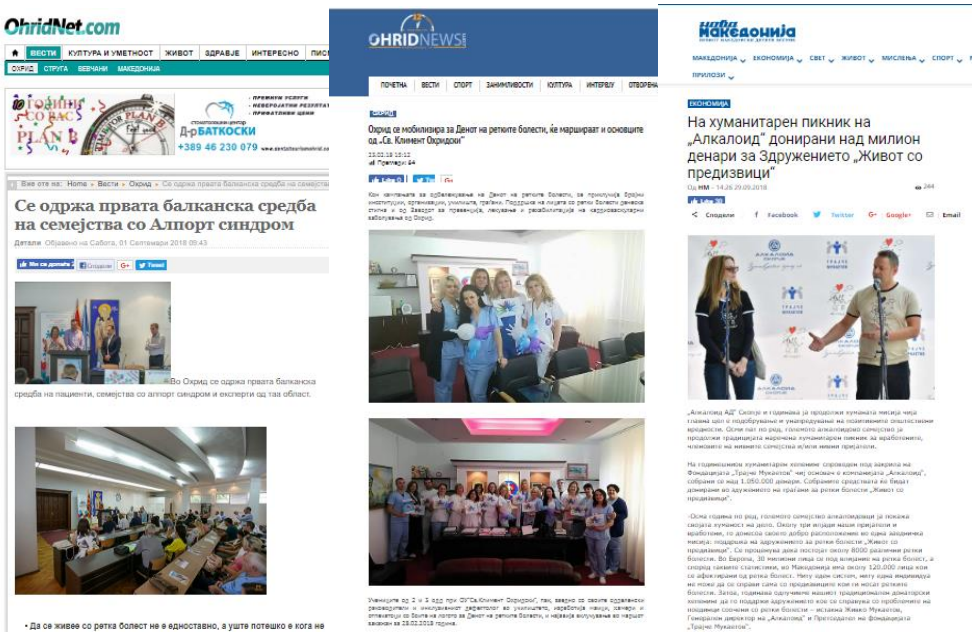








Живот со Предизвици / Jeta me Sfida / Life With Challenges



All events were supported by:

For additional information do not hesitate to contact us,
Sincerely,
Vesna Aleksovska
President of the Association of citizens for rare diseases,
Life With Challenges - Bitola
Tel: +389 (0)70 70 54 46
e-mail: zivotsopredizvici@gmail.com ; vesna.stojmirova@gmail.com

Information about the association:

- http://challenges.mk/
- https://www.youtube.com/user/lifewithchallenges
- https://www.facebook.com/LifeWithChallengesi
- https://www.facebook.com/groups/312483895490987/
- https://twitter.com/ZivotPredizvici

Life With Challenges is member of: