Живот со Предизвици / Jeta me Sfida / Life With Challenges

Report on activities in 2017 of the Association off citizens for rare diseases LIFE WITH CHALLENGES Bitola

In 2017, the Association of citizens for rare diseases organized many activities for raising public awareness on rare diseases, for strengthening patients and families and advocating for patients' rights to treatment and quality of life.

Apart from our activities we managed to maintain a good relationship with media and our presence were in continuation. Almost every month we had a story in media regarding the problems that we face, the challenges that we overcome and the challenges we need to face together with institutions in future.

Also we had many meetings with relevant institutions such as Ministry of Health, Ministry of Labour and Social Policy, Health Insurance Fund, Macedonian Academy for Science and Art, Agency for Drugs etc.

We continue to cooperate with organizations for rare diseases nationally and internationally, working together for the good of the patients and developing our association through networking, exchange of best practices, conferences, help lines, training etc.

Our activities on supporting patients include giving relevant information on rare diseases, translating information, printing brochures, connecting families nationally and internationally, organizing meetings with institutions, organizing patient meetings etc.

We hope to continue the good work further in 2018.

1. Help Line for patients and families with rare diseases 2015-2017

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 request for help are usually those bellow:

- 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 helped, Wilson, Thalassemia, and Spinal Muscular Atrophy. Sometime they do not form an association but an informal group within the association Life with challenges.

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.

1. Rare Disease Day, 28th of February, 2017, R. Macedonia (Skopje, Bitola, Ohrid, Prilep)

The Life With Challenges association, together with the National Alliance for Rare Diseases of the Republic of Macedonia, under the umbrella of the European Association for Rare Diseases – EURORDIS, celebrated the international Rare Diseases Day, February 28, 2017 this year as well under the motto “With Research, Possibilities are Limitless”. In addition, this year we are also focusing on parents of children with rare diseases and the difficulties and challenges they face. Their stories were on display in a poster presentation in the hall of the EU Info Center today and they were shared on social media.

After the new Law on Financing the Rare Diseases Program was passed in 2015, 21 new medicines were procured for approximately 12 rare disease diagnoses, which covered more than 150 patients. According to information available from the Ministry of Health’s public bids, the number of medicines in 2016 has increased by 29, which means that more diagnoses have been covered, so now the number of patients receiving medication has reached approximately 220. There are 46 primary diagnosis in the registry.

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Statement by Professor Aspazija Sofijanova, PhD, president of the National Commission for Rare Diseases: As medical doctors we must be less emotional, however that's not so in our case because we are in direct contact with sick children. When we save a child, it feels like we have saved the world, but when we lose a child, it feels like we have lost the world. This year we will continue to struggle for the patients with rare diseases, and the parents, the patients and the associations offer the greatest help in that struggle – if we join forces with the institutions, there is a lot that can be done. We know the issues. I just came from the clinic and I would like to say that Iskra says hi, that's a child who has spinal muscular atrophy and who is still in intensive care at the clinic. I also know Daniel, who was helped a great deal by the US Embassy in Macedonia, which is Mrs. Mary Jo Wohlers. It is a new medicine, and we will try to find the financial means to bring it to Macedonia, like we bring medicines for other patients.

Statement by academician Momir Polenakovic, Macedonian Academy of Sciences and Arts (MASA): Within MASA we have a small genetics and diagnostics center, but we also collaborate with other countries and we are trying to forge the way ahead in terms of education and to push forward in diagnostics, which is as important as prevention. Early diagnostics is essential for early therapy and for providing timely information to the patients, so that their life quality is improved. The collaboration with the Wilson Disease Association – Macedonia has already resulted in improvement in the education for diagnosing Wilson Disease as well, and they provided us with reagents through a donation. We hope that in the future we will have more funds for providing other reagents in order to boost the diagnosis of a larger number of rare diseases.

Statement by Rashela Mizrahi PhD, Ministry of Health of the Republic of Macedonia: The rare diseases program was launched two years ago with the creation of the rare diseases registry and the increased financial support for medicine procurement. There are many issues in terms of diagnosis, classification and systematization. There's a whole apparatus working in the background at the Ministry and the Rare Diseases Commission, where clinicians work pro bono for the wellbeing of the patients. We have also established criteria and requirements for entering the registry, some 400 patients have been registered with more than 46 diagnoses, and we already have medication for 220 patients.

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Statement by Rebeka Jankovska Risteski, president of NARBM (National Alliance for Rare Diseases of the Republic of Macedonia): This year we are focusing on patients who are yet to receive medicine. Such are patients who have spinal muscular atrophy, children whose only hope is a medicine approved by the American Food and Drugs Administration last year. Then we have the medicines for patients who have rare forms of cancer, such as the MDS patients – two patients who were donated the medicines have already shown signs of improvement in their wellbeing and life. Therefore we believe that innovative medication should be made available in order to allow for a good quality life for the patients and their families. Then we have the medicine for juvenile arthritis – only one of the three that exist is being procured. Finally we would ask the Health and Pension Insurance Fund of Macedonia (FZOM) not to forget that even in 2015-2016 they promised the patients suffering from Chrohn's disease and ulcerative colitis they would provide them REMICADE. Of course, we would also like them to provide patients with medical aids and meet other needs when there are no medicines available. Our vision as an alliance is for nobody to be left behind.

Statement by Anja Bosilkova Antovska, vice-president of NARBM: There is a great variety of rare diseases and anyone may contract them. We carried out research in collaboration with the Wilson Disease Association – Macedonia and we drafted some recommendations for changes in Macedonian legislation so that rare disease patients are not apprehensive of whether there will have a long-term therapy plan available or not. A national rare disease program and systematic, legal solutions must exist for us to ensure a future for the rare disease families.

Statement by Vesna Aleksovska, director of Life With Challenges: No matter how much I speak I am bound to leave something out. On the one hand we are thankful for the understanding that the institutions have shown for us, rare disease patients, in the last two years, but on the other hand I must also say that there is a lot to be done, many people to be helped, and that we will always have new requests and new needs. The rare diseases are very unique, each one has a number of variations and each patient is a different story, with separate challenges, difficulties, issues, happiness and sorrow. Working together as part of the alliance I think that we can achieve much more, and I hope that we will be increasingly vocal and that our voice will be heard more and more. Each family deserves the best chance possible for a happy life. We will continue to meet up with the institutions, we will speak up in front of the media, and we will get the public involved by organizing events… Each patient must be taken care of.

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Other events around Macedonia

Bitola

This year the rare diseases awareness raising campaign began with an event in Bitola on February 24, at 10 a.m. in downtown Bitola, on Sirok Sokak, where with the support of the Hepar Centre for Citizens who have Rare Diseases the Life With Challenges Bitola organized a press-conference and distributed flyers downtown in order to raise public awareness for the rare diseases.

Ohrid

On February 28, 2017, at noon, a march began from the front yard of the Hristo Uzunov primary school. Some 200 students in a line marched along Pitu Guli street, and then along Jane Sandanski street, and then they joined forces with the students of the St. Clement of Ohrid secondary school and

they continued together all the way to the Macedonia quay (in front of the Royal hotel). There, at 1 p.m., the students ran a cross race to the Ss. Cyril and Methodius monument. From there the students went to the city square, where they distributed information leaflets for rare diseases. On February 26 and 27, there were hiking activities organized as well, with the support of ZSH Avantura – Ohrid. The activities in Ohrid were also bolstered by the Animalija association, which supported the idea for rare disease awareness raising with the motto: "Adopt a pet, for some people that's the only free therapy". The event was organized by Gordana Loleska, a mother of a child suffering from Alport syndrome, with the support of the Ohrid Red Cross, the St. Clement of Ohrid secondary school, ZSH Avantura, the Animalija association and the citizens of Ohrid.

Prilep

On February 24, 2017, a group that distributed flyers for rare disease awareness raising joined the Prilep masquerade. There was also a public lecture for rare diseases. The event was organized by Jasmina Hristoska, an acromegaly patient, with the support of SLAP – Prilep.

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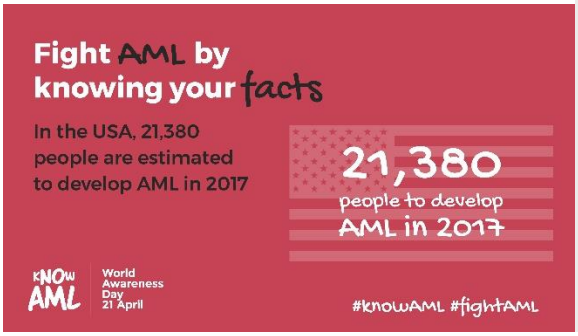
Press Links from Rare Disease Day 2017, R. Macedonia (Skopje, Bitola, Ohrid, Prilep):

1. http://www.mia.mk/mk/Inside/RenderSingleNews/33/133589641
2. http://24vesti.mk/28-fevruari-den-na-retki-bolesti
3. http://sitel.com.mk/kampanja-den-na-retki-bolesti-vo-bitola
4. http://sdk.mk/index.php/makedonija/patsientite-retki-bolesti-se-nevidlivi-pred-zakonite-alarmirashe-zdruzhenieto-vilson-makedonija/
5. http://www.libertas.mk/litsata-so-retki-bolesti-zhiveat-zhivot-poln-so-predizvitsi/
6. http://setaliste.com.mk/vesti/binfo/inovativnite-lekovi-nadez-za-zivot-za-pacientite-so-retki-bolesti/
7. http://press24.mk/istrazhuvanje-na-vilson-makedonija-za-pacientite-so-retki-bolesti
8. http://tvnova.mk/vesti/makedonija/pacientite-so-retki-bolesti-vo-makedonija-nevidlivi-pred-zakonite/
9. http://tvnova.mk/vesti/makedonija/alijansa-za-retki-bolesti-bara-novi-lekovi-na-pozitivnata-lista/
10. http://plusinfo.mk/vest/106323/pacientite-so-retki-bolesti-s%D1%90-ushte-se-nevidlivi-pred-makedonskite-zakoni
11. http://www.ohridnews.com/vesti/103923
12. http://a1on.mk/archives/708586
13. http://www.telegraf.mk/aktuelno/makedonija/ns-newsarticle-den-na-retki-bolesti-pacientite-baraat-lekovi-za-site---navreme-i-bez-ogranicuvana.nspx
14. http://www.time.mk/c/bc4a8c4655/licata-so-retki-bolesti-ziveat-zivot-poln-so-predizvici.html
15. http://tvm.mk/vesti/ohrid/25128-ohrid-go-odbelezha-denot-na-retki-bolesti
16. http://www.webohrid.com/2017/02/28/megunaroden-den-na-retki-bolesti-2017/
17. http://www.telma.com.mk/vesti/predocna-se-postavuva-dijagnozata-kaj-pacientite-so-retki-bolesti
18. http://www.mkd.mk/makedonija/skopje/vilson-makedonija-pacientite-so-retki-bolesti-se-nevidlivi-pred-zakonot
19. http://www.fiskalnatransparentnost.org.mk/index.php/poveke-pari-za-redovna-terapija-baraat-bolnite-so-retki-bolesti
20. http://www.ohrid1.com/vest-statija/45097/denot-na-retki-bolesti-kje-bide-odbelezhan-vo-ohrid
21. http://www.mrt.com.mk/node/38652
22. http://mama365.mk/%D0%BC%D0%B5%D1%93%D1%83%D0%BD%D0%B0%D1%80%D0%BE%D0%B4%D0%B5%D0%BD-%D0%B4%D0%B5%D0%BD-%D0%BD%D0%B0-%D1%80%D0%B5%D1%82%D0%BA%D0%B8-%D0%B1%D0%BE%D0%BB%D0%B5%D1%81%D1%82%D0%B8/
23. http://ohridpress.com.mk/?p=62202
24. http://kanal77.mk/%D0%B8-%D0%B2%D0%BE-%D0%BC%D0%B0%D0%BA%D0%B5%D0%B4%D0%BE%D0%BD%D0%B8%D1%98%D0%B0-%D1%81%D0%B5-%D0%BE%D0%B4%D0%B1%D0%B5%D0%BB%D0%B5%D0%B6%D1%83%D0%B2%D0%B0-%D0%B4%D0%B5%D0%BD%D0%BE%D1%82-%D0%BD%D0%B0/
25. http://hdtvmega.mk/%D0%BF%D0%BE%D0%B4%D0%B8%D0%B3%D0%BD%D1%83%D0%B2%D0%B0%D1%9A%D0%B5-%D0%BD%D0%B0-%D1%98%D0%B0%D0%B2%D0%BD%D0%B0%D1%82%D0%B0-%D1%81%D0%B2%D0%B5%D1%81%D1%82-%D0%B7%D0%B0-%D1%80%D0%B5%D1%82%D0%BA%D0%B8/

26. http://www.radiomof.mk/stav-ne-e-fer-pacientite-so-retki-bolesti-da-ostanuvaat-bez-lekovi-i-da-se-diskriminiraat/
27. http://ohrid24.mk/37575-2/
28. http://slobodna.mk/2017/02/24/ohrid-17/
29. http://kanal5.com.mk/vesti_detail.asp?ID=118381
30. http://ohriddenes.mk/%D0%BF%D1%80%D0%B8%D0%B4%D1%80%D1%83%D0%B6%D0%B5%D1%82%D0%B5-%D0%BD%D0%B8-%D1%81%D0%B5-%D0%B7%D0%B0-%D0%B4%D0%B0-%D1%81%D0%B5-%D1%81%D0%BB%D1%83%D1%88%D0%BD%D0%B5-%D0%B3%D0%BB%D0%B0%D1%81/
31. http://gostivarpress.mk/svetski-den-na-retkite-bolesti/
32. http://ohrigani.com/zg-zhivot-predizvitsi-niza-aktivnosti-ke-go-odbelezhi-denot-na-retki-bolesti/
33. http://www.slobodenpecat.mk/drustvo/28-mi-fevruari-svetski-den-na-retkite-bolesti/
34. http://www.dw.com/mk/%D0%BB%D0%B8%D1%86%D0%B0%D1%82%D0%B0-%D1%81%D0%BE-%D1%80%D0%B5%D1%82%D0%BA%D0%B8-%D0%B1%D0%BE%D0%BB%D0%B5%D1%81%D1%82%D0%B8-%D0%B6%D0%B8%D0%B2%D0%B5%D0%B0%D1%82-%D0%B6%D0%B8%D0%B2%D0%BE%D1%82-%D0%BF%D0%BE%D0%BB%D0%BD-%D1%81%D0%BE-%D0%BF%D1%80%D0%B5%D0%B4%D0%B8%D0%B7%D0%B2%D0%B8%D1%86%D0%B8/a-37741954?maca=maz-rss-maz-pol_makedonija_timemk-4727-xml-mrss
35. http://plusinfo.mk/vest/106274/na-mojot-sin-mu-treba-zdrava-majka
36. http://novamakedonija.com.mk/NewsDetail?title=%D0%A1%D0%B5-%D0%BE%D0%B4%D0%B1%D0%B5%D0%BB%D0%B5%D0%B6%D1%83%D0%B2%D0%B0-%D0%94%D0%B5%D0%BD%D0%BE%D1%82-%D0%BD%D0%B0-%D1%80%D0%B5%D1%82%D0%BA%D0%B8-%D0%B1%D0%BE%D0%BB%D0%B5%D1%81%D1%82%D0%B8&id=88912f61-aa91-4c67-8955-741b325c5b2d
37. http://plusinfo.mk/vest/106239/shto-da-se-pravi-koga-deteto-kje-ja-nasledi-tvojata-bolest
38. http://exclusive.mk/articles/26180/shto-i-kako-da-se-pravi-koga-deteto-kje-ja-nasledi-tvojata-bolest
39. http://exclusive.mk/articles/26180/shto-i-kako-da-se-pravi-koga-deteto-kje-ja-nasledi-tvojata-bolest
40. http://www.vest.mk/?ItemID=ED2A821C230C1C43B7D373D8D21ADD80

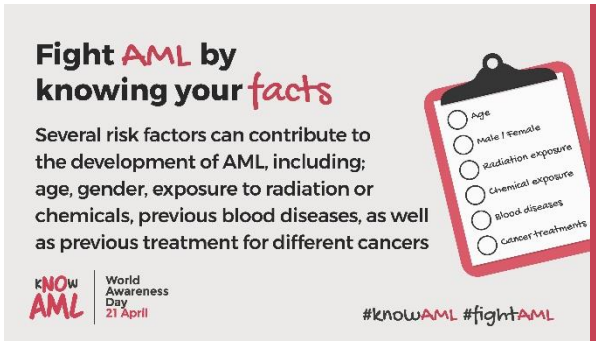
2. Know AML Fight AML

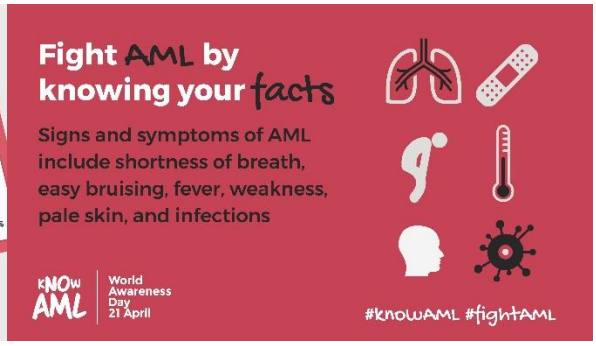
Know AML is the world's first global AML awareness coalition supporting AML World Awareness Day on April 21. The mission of Know AML is to raise awareness and education in AML to patients, carers, families, healthcare professionals and the general public.



In December 2016, during the American Society of Hematology (ASH) meeting, a collective of AML patient Leaders, professional and industry representatives, now named the Know AML Coalition, gathered to agree on how to mark AML World Awareness Day in 2017.

The Fight AML campaign aims to improve education and support in order to empower the AML community in its fight against AML and it is the first of many Know AML awareness and education activities.





More info on – http://www.know-aml.com

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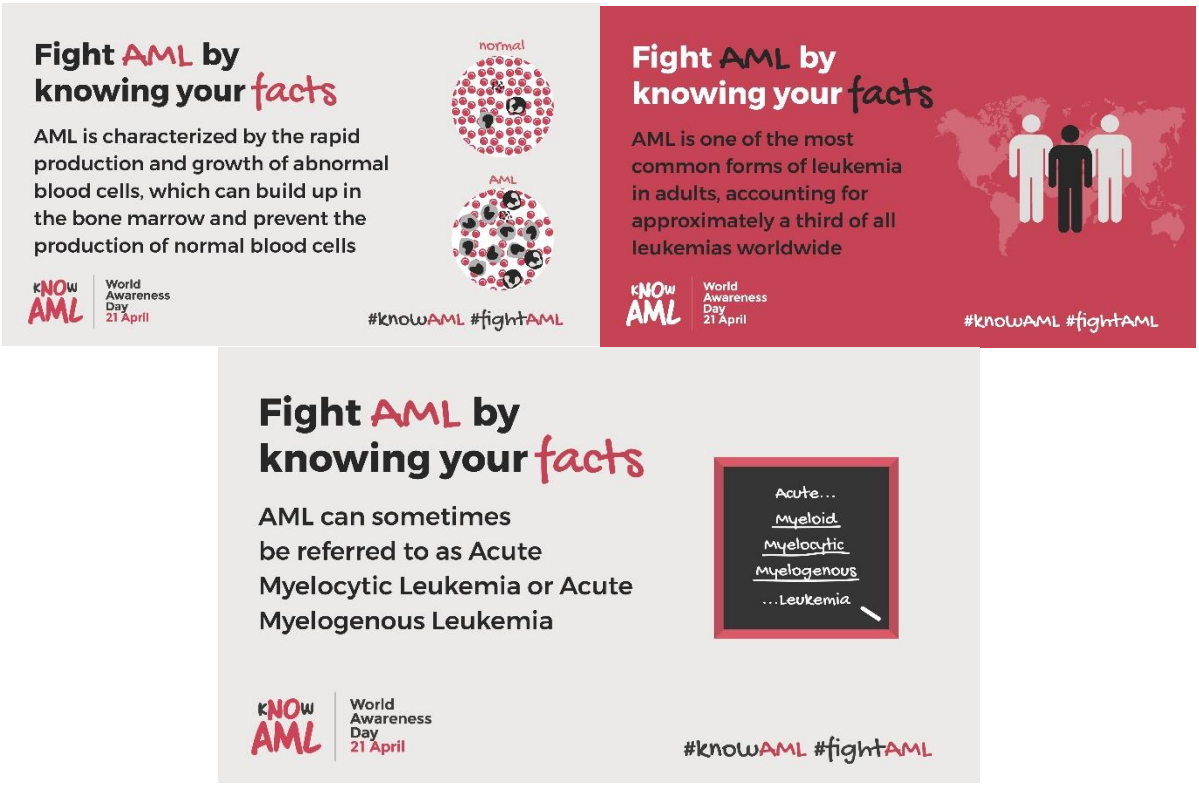

3. Skopje Marathon, May, 2017

The association of citizens for rare diseases LIFE WITH CHALLENGES continued the tradition of participation in the Skopje Marathon. This year together with HAE Macedonia and Skopje Night Running.

This activity is for raising public awareness on rare diseases and their families. We hope to contribute for the future of people with rare diseases to be a future that they want.

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Statement, Vesna Aleksovska, president of LIFE WITH CHALLENGES:

With the start of the registry for rare diseases and the new law for financing of the program for rare diseases in 2016 over 29 medicines are provided for over 15 diagnosis. There is still need for new medicines such as FAP, Pulmonary fibrosis, Spinal Muscular Atrophy, Myelodysplastic Syndrome, Duchene Muscular Dystrophy and others ... Also the promised medicines for Chron and Ulcerative Colitis from the Health Insurance Fund are still not provided for the patients. And the patients with Epidermolysis Bullossa are still waiting on the promise of refund for special bandages.

We will continue to communicate with the relevant institutions because we believe that only through mutual cooperation we can achieve better quality of life for patients with rare diseases.

We also want to say that the institutions must not allow the political crisis in the country to become a health crisis. Patients should not be left without medicines. The situation is life threatening.

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Part of the press releases for the Marathon:

1. http://republika.mk/772302
2. http://novatv.mk/otekuvam-no-ne-se-povlekuvam-skopski-maraton-za-retkite-bolesti/
3. http://republika.mk/771764
4. http://www.radiomof.mk/zdruzhenijata-za-retki-bolesti-kje-trchaat-na-skopski-maraton-za-pogolema-dostapnost-na-lekovi/
5. http://sdk.mk/index.php/neraskazhani-prikazni/nie-sme-korisni-chlenovi-na-opshtestvoto-porachaa-litsata-retki-bolesti-posebni-potrebi-na-skopskiot-maraton/
6. http://tv21.tv/mk/%D1%83%D1%87%D0%B5%D1%81%D0%BD%D0%B8%D1%86%D0%B8%D1%82%D0%B5-%D0%B7%D0%B0-%D1%85%D1%83%D0%BC%D0%B0%D0%BD%D0%BE%D1%81%D1%82%D0%B0-%D0%BB%D1%83%D1%93%D0%B5-%D1%81%D0%BE-%D1%80%D0%B5%D1%82%D0%BA%D0%B8/
7. http://www.mkd.mk/makedonija/skopje/pretstavnici-od-skopsko-nokjno-trchanje-kje-trchaat-za-zdruzhenijata-na-gragjani
8. http://vesti.mk/read/article/4487820/zaglavena-terapijata-za-retki-bolesti
9. http://vesti.mk/read/article/4482611/retkite-bolesti-utre-kje-bidat-del-od-skopskiot-maraton
10. http://a1on.mk/archives/736374
11. http://emagazin.mk/vesti/vest/35526
12. http://kanal5.com.mk/vesti_detail.asp?ID=123319
13. http://zdravstvo24.mk/2017/05/06/zdruzenija-na-gragani-za-retki-bolesti-da-nes-e-dozvoli-pacientite-da-ostanat-berz-lekovi/
14. http://reporter.mk/makedonija/%D0%B7%D0%B4%D1%80%D1%83%D0%B6%D0%B5%D0%BD%D0%B8%D1%98%D0%B0-%D0%BD%D0%B0-%D0%B3%D1%80%D0%B0%D1%93%D0%B0%D0%BD%D0%B8-%D0%B7%D0%B0-%D1%80%D0%B5%D1%82%D0%BA%D0%B8-%D0%B1%D0%BE%D0%BB%D0%B5%D1%81%D1%82/
15. http://fokus.mk/skopski-maraton-za-retkite-bolesti-ministerstvoto-za-zdravstvo-da-ne-dozvoli-patsientite-da-ostanat-bez-lekovi/
16. http://plusinfo.mk/vest/113973/otekuvam-no-ne-se-povlekuvam-%E2%80%93-trcam
17. http://vesti.mk/read/article/4482344/zdruzhenija-na-gragjani-za-retki-bolesti-da-ne-se-dozvoli-pacientite-da-ostanat-bez-lekovi
18. http://vesti.mk/read/article/4482872/na-skopski-maraton-kje-se-trcha-i-za-pacientite-so-retki-bolesti
19. http://vesti.mk/read/article/4482576/zdruzhenija-na-gragjani-za-retki-bolesti-da-ne-se-dozvoli-pacientite-da-ostanat-bez-lekovi
20. http://vesti.mk/read/article/4482611/retkite-bolesti-utre-kje-bidat-del-od-skopskiot-maraton
21. http://daily.mk/makedonija/retkite-bolesti-utre-bidat-del-skopskiot-maraton
22. http://daily.mk/auto/dozvoli-pacientite-ostanat-bez-lekovi

4. EURORDIS Membership meeting, May, 2017, Budapest, Hungary

The EURORDIS Membership Meeting in 2017 took place in Budapest, Hungary. Many important topics for the Rare Disease Community were discussed and shared!

There were also different workshops and interactive sessions. EURORDIS is dedicated to empowering patient and patient representatives.

The representative from LIFE WITH CHALLENGES was there to learn and represent Macedonia together with the representative from the National Alliance for Rare Diseases of Macedonia!

5. Rare diseases at Ohrid Running, 4th of June, 2017, Ohrid

A volunteer of LIFE WITH CHALLENGES Gordana Loleska, in cooperation with companies and organizations from Ohrid managed to organize teams who run in support of people with rare diseases in the event Ohrid Running. This was a promotional event with a main goal to support running, sport, quality of life and healthy life.

Statement Gordana Loleska, member of LIFE WITH CHALLENGES

„For the children with rare diseases and special needs on this event we had professionals but also parents and patients involved. The citizens also supported our idea for raising public awareness on rare diseases. People with rare diseases deserve better quality of life, they deserve a chance to do most with what they have. Everyone can be successful if he has a chance to do so.“

Statement Vesna Aleksovska, president of LIFE WITH CHALLENGES

„Gordana is one of our most active members, she organizes many events in Ohrid and we are proud of her. This is just one more event showing support for people facing life with a rare disease. We need to remember that there are many social and health services needed to support families with rare diseases. After the register for rare diseases started in 2015, there are around 450 patients registered and around 40 basic diagnosis (70 different). With the new financing of the program for rare diseases at the Ministry of Health, now there are around 29 medicines for 15 around 15 different diagnosis in Macedonia. There is a need for more medicines for different diagnosis. If there is a drug, patients need to have it so they can have hope for life. We expect that medicines will be covered soon for FAP, Spinal Muscular Atrophy, Muscular Dystrophy – Duchene, Myelodisplastic Syndrome – MDS, Acute Myeloid Leukemia, Pulmonary Fibrosis and others. We also ask for social services such as personal assistants for ALS patients and other patients with severe physical invalidity. We are still waiting on the Health Insurance Fund to approve refunding for special bandages and plasters for Epidermolisis Bulossa and other things that patients need.

We hope that the new Ministers of Health and Social Policy and Labour will find a way to make the Program for Rare diseases better. Institutions need to work together to make life easier on families with rare diseases. "

6. Running, paragliding and sailing for rare diseases, July 2017

Ohrid is again giving a lot of support for rare diseases through different activities in July, 2017. Beach Run is an event in 5 location near water in Macedonia in July, 2017. On 30.07.2017 was the final race in Ohrid. The teams of NRC nike Run Club Skopje and Ark Lotus Prilep were running for support of rare diseases.

The organization for support of rare diseases was in the very capable hands of Gordana Loleska who showed that everyone can do so much more in support of families with rare diseases.


Also there was support from the paragliding club Fly Ohrid and from the club Aqatica Divono who took the flag of rare diseases sailing.

7. Climbing Korab, 3rd of September, 2017

Life With Challenges continues the tradition of climbing Korab. On 3th of September, 2017 the association KORAB set the flag of rare diseases on the top of the highest mountain in Macedonia, Korab.

Statement, Vesna Aleksovska, President of LIFE WITH CHALLENGES:
After the registry for rare diseases started development in 2015, in 2016 there were 30 drugs procured for around 18 rare diseases. There is still a need for different drugs for new patients and new diseases. At the moment we are asking for drugs for Familial Amyloid Polyneuropathy, for Spinal Muscular Atrophy, Pulmonary Fibrosis, Muscular Dystrophy Duchene, Myelodysplastic Syndrome and others. We

are still waiting on an answer about special bandages for Epidermolysis Bulossa from the Health Insurance Fund. And we are in contact with the ministry of Social politics about personal assistants for people with ALS and other similar conditions. We expect that the Minister of Health will have understanding for the needs of the families with rare diseases, for the necessary treatment that is needed for a normal life. We believe that the promises about therapy not being late will be realized, because a lot of patients were facing problems with not getting therapy for more than 1 month. We hope to cooperate together, all of us, associations, and institutions so that we can improve quality of life of people with rare diseases. Patients cannot wait for politicians to decide for their life, therapy should be procured on time, the health system should work in favour of patients. The Ministry of finance has to find a way to finance the Program for rare diseases in a way that all patients can get necessary treatment. Patients should not beg or ask donations, no matter what kind of disease they are facing.

This is a symbolic activity for raising public awareness about rare diseases in Macedonia, about the challenges that families face in their everyday life. We are thankful to Ljuubomir Kotevski, president of Korab who accepted and supported this idea from the beginning.

We continue to fight further for people with rare diseases. We hope to contribute so that the future is a future that people with rare diseases want to have.

8. Running for rare diseases on International Athletic Ohrid Marathon, 8th of September, 2017

Ohrid is running again in support of rare diseases. On 8th September, 2017 the Independence Day of R. Macedonia the International Athletic Marathon started in Ohrid.

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The organization of the teams for rare diseases was in the capable hands of our volunteer Gordana Loleska, a mother who showed that a lot can be done for raising awareness on rare diseases.

The Minister of finance Mr Dragan Tevdovski, participated in the Marathon in support of rare diseases.

Statement, Gordana Loleska, volunteer of LIFE WITH CHALLENGES:

Ohrid showed that is together with people facing rare diseases. Again we are spreading the message: People with rare diseases, you are not invisible, we are your voice!

Statement, Vesna Aleksovska, President of LIFE WITH CHALLENGES:

We expect that the Minister of Health will have understanding for the needs of the families with rare diseases, for the necessary treatment that is needed for a normal life. We believe that the promises about therapy not being late will be realized, because a lot of patients were facing problems with not getting therapy for more than 1 month. We hope to cooperate together, all of us, associations, and institutions so that we can improve quality of life of people with rare diseases. Patients cannot wait for politicians to decide for their life, therapy should be procured on time, the health system should work in favour of patients. The Ministry of finance has to find a way to finance the Program for rare diseases

in a way that all patients can get necessary treatment. Patients should not beg or ask donations, no matter what kind of disease they are facing.

After the registry for rare diseases started development in 2015, in 2016 there were 30 drugs procured for around 18 rare diseases. There is still a need for different drugs for new patients and new diseases. At the moment we are asking for drugs for Familial Amyloid Polyneuropathy, for Spinal Muscular Atrophy, Pulmonary Fibrosis, Muscular Dystrophy Duchene, Myelodysplastic Syndrome and others. We are still waiting on an answer about special bandages for Epidermolysis Bulossa from the Health Insurance Fund. And we are in contact with the ministry of Social politics about personal assistants for people with ALS and other similar conditions.

The program for rare diseases needs to have more financial support so that everyone who needs a medicine can get one through this life saving program. Every family deserves a chance for a better life. If medicine exists for a certain disease, it should be available as soon as possible.

We will continue as an association of citizens for rare diseases LIFE WITH CHALLENGES to support and fight for patients' rights. In communication with all relevant institutions we will try to improve quality of life of families facing a life with a rare disease, a life with challenges.

9. Work meeting for rare diseases at the government of R. Macedonia, 25.09.2017, Skopje

The Ministry for labour and Social policy organized a meetings with all relevant institutions (Health Insurance Fund, Ministry of Health), and all organizations that represent rare diseases in Macedonia. This meeting was to present the challenges and the problems of people that face rare diseases.

There was a wide discussion about the needs of social and health services for the families with rare diseases. The important challenges that all agreed upon were continuous provision of treatment without delay, appropriate change in regulative to include rare diseases, exchange of information between all relevant stakeholders, transparency in the work of the commission for rare diseases, application for continuous development of the registry for rare diseases and many other subjects of importance for better quality of life for people with rare diseases.

The goal of this meeting was to demonstrate political will and preparedness to agree upon directions towards building an institutional frame for care for people with rare diseases through provision of appropriate information, health and social services.

10.International Gaucher Day, 1st October, 2017, Skopje

The ***International Gaucher Day*** (1st October) is marked in over 40 countries where organisations, members of the European Gaucher Alliance, organize different activities for the patients, families, doctors, researches….In Macedonia, the Citizens' association for Rare Diseases LIFE WITH CHALLENGES…..

Over 10 patients in Macedonia suffer from Gaucher Disease. The disease is manifested in three types, but in Macedonia only Type 1 is present. This type of the disease is manifested with enlarged spleen and liver, bones easily prone to fractures, low platelets count and low haemoglobin, lack of energy, etc. Until 2015 5 patients received treatment through donation via a humanitarian programme of the company Genzyme Sanofi Aventis and one through the programme for rare diseases of the Ministry of Health. Since 2015 enzyme replacement therapy is available for all patients provided by the Programme for Rare Diseases of the Ministry of Health. This therapy is present worldwide since 1991. With this therapy all the symptoms that have occurred in the course of the years decrease and even diminish and patients themselves can have normal life

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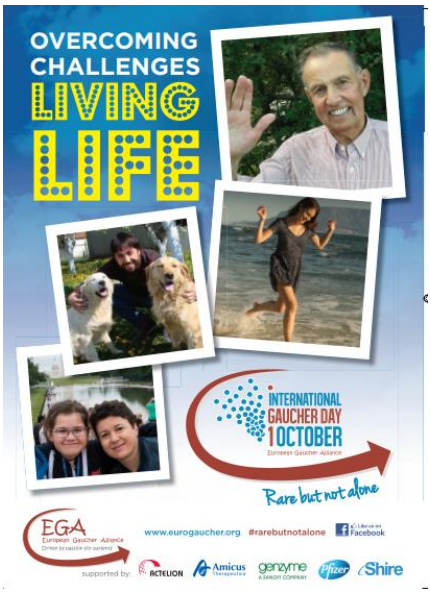

As a Gaucher patient I am thankful for the advancement regarding the patient treatment of Gaucher Disease in Macedonia. Since my diagnosis 23 years ago until today I am happy that all newly diagnosed patients with this disease do not have to fear for their future, on the contrary, with the right diagnosis they will have the opportunity to receive timely treatment which is a gold standard in the world and with this they have the opportunity for a normal life without feeling the symptoms of the disease in the long term. I do hope that all the rare disease patients in Macedonia will have the same opportunity to lead a normal life in Macedonia. With the therapy we can have a family, we can work and we can contribute like any other citizen of Macedonia – Vesna Aleksovska, President of Life With Challenges.

Although quite different among themselves, people suffering from rare diseases and their families have equal difficulties that stem precisely from the rarity of their disease. The problems are numerous, from setting the final diagnosis and access to proper treatment to social exclusion and life on the margins of society.

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Despite everything, strength, optimism and the belief in better tomorrow are the main "weapon" of the patients and their families in the fight for a long life of good quality. It is up to us to give them hand and ease their journey…

11. Promotion of a postal stamp – Children with rare diseases, 4th October, 2017, Skopje

The citizens' association for rare diseases LIFE WITH CHALLENGES from Bitola in cooperation with Macedonian Post promoted a post-stamp titled Children with Rare Diseases on 4th October at MASA.

Loran Kufalo is the author of the post stamp with nominal value of 48 denars, which has been published in print of 6000 copies.

Statement by Vesna Aleksovska, President of the Association:

To live with a rare disease means to live with a friend, not with a foe. Simply we get to know the rare disease and learn how to live best with it. We face many challenges, starting with the diagnosis, then the search for information, medicines, health and social services. The reality is that it is necessary for all the institutions to work together with the associations in order to have advancement. Together we are stronger and we can do more. When we have help we can work and have families, we can lead a normal life as everybody else who does not face a rare disease. We deserve to be part of the society and make our contribution.

The post-stamp is the first in the world dedicated to rare diseases and we are proud that our member Gordana Loleska, employed at Macedonian Post, has initiated this process and Macedonian Post has realized it as such. With this initiative we want to raise the public awareness about rare diseases and the challenges that families face.

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Statement, Iva Petrevska, patient with rare disease Epidermolisis Bulosa

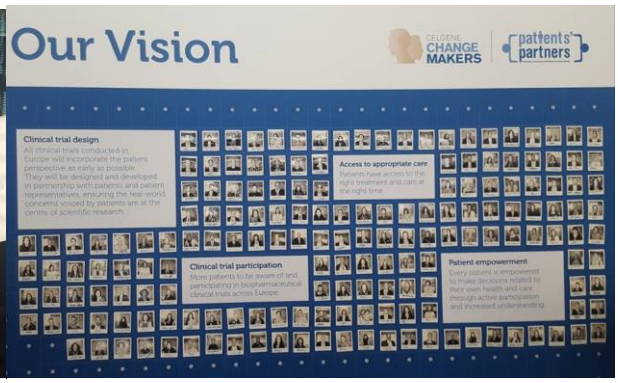
I wish that they invented a therapy for all rare diseases, for some there is, for others there isn't. For me there isn't, but I can live without therapy. I've got my mum and dad who are always here with me. A big thank you to Macedonian Post who have thought of us, the children with rare diseases.

Statement, General Manager of Macedonian Post Office, Fadis Rexhepi:

All the institutions in Macedonia, all the greater companies should make everything possible to improve the life of families facing a rare disease. We should help raising the awareness for these diseases in Macedonia. This post stamp dedicated to the Children with Rare Diseases is but a small gesture that we could offer, let's hope that we'll be able to do much more.

12.Patients as partners, 18-20 October, 2017, Boudry, Switzerland

This meeting is organized by Celgene, and as participants are patient representatives from all over the world. At this meeting patient representatives had an opportunity to share best practices, to network and build cooperation. There were presentations on capability building, goal workshops, and best practice sharing by 18 organizations. Also at the event there was an inspirational speaker.



In the picture below are the change makers from the Balkan. We always acknowledge the importance of the Balkan cooperation.

13.EUROPLAN Conference, Systemic solutions for rare diseases – Building a future for people with rare diseases, 10th November, 2017, Skopje

The first EUROPLAN conference in Macedonia on the topic of rare diseases was held on the 10th November 2017 from 10:00 am to 2:30 pm in the hotel Holiday Inn in Skopje. Experiences and examples from the area of the rare diseases from Europe and the region were shared at the conference, as drive towards discussions and identification of possibilities for the improvement of the situation in Macedonia. Through discussions this conference works toward the possible solutions to provision of secure future and good-quality life for the patients and families facing a rare disease in our country.

For the first time at such a conference were present the institutions (Health-care committee, Government of RM, Ministry of Finance, Ministry of Health, Ministry of Labour and Social Policy, Health Insurance Fund of R. Macedonia, The Macedonian Academy of Sciences and Arts, Agency for Medicines), health-care workers (Committee for rare diseases , University Children's Clinic, University Clinical Centre Skopje) representatives of pharmaceutical companies , representatives from associations form Macedonia and the region and EU, patients and parents facing a rare disease.

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Statement by Rebeka Jankovska- Risteski, President of the National Alliance for Rare Diseases of R. Macedonia: In 2015 as a result of our loud endeavours, the wider community became aware of our sufferings and problems- the difficult diagnostic for rare diseases in Macedonia, the unavailability of medicines for treatment, and even more the price of treatment. A dedicated team of people some of which, to my great pleasure, I see here today and that causes a sense of debt towards them and my entire respect, have taken up the challenge to establish and to give life to the Rare Disease Programme. The Programme has encompassed several medicines, namely 29 medicines for 18 diagnoses, for which we as a non-governmental sector suggested, and the professional health-care workers decided that they should inevitably be covered in the regular treatment for rare diseases.

The problems are many and we often reacted to the responsible ministries for changes in the laws, bylaws, rulebooks … Many things are necessary, such as defining the notion of a rare disease, with this many patients will become visible and recognized as a special category of people for whom a special treatment and therapy is needed; defining proper procedure for timely procurement of medicines, a centre for rare diseases, even a virtual one, which will have a team of its own, responsibilities and a manner of working and, of course, bigger budget for the procurement of medicines and other kinds of medical interventions.

Statement Anja Bosilkova Antovska, Wilson Macedonia: As persons with rare diseases we live in a miserable condition, invisible in front of the law. The treatment of rare diseases is regulated only on the surface. The Programme is a big step forward, but there remains much more to be done. We call upon the system to work regardless of the political situation. Patients must not be left without medicines, as it is still the case, for more than 4 months. Today we are here to talk about solutions not only the problems. We fight for early diagnosis, early treatment, for the availability of social and health care services, for independence and quality of life.

Statement Vesna Aleksovska, President of the Citizen Association for Rare Diseases Life with Challenges: Today we are here to create future for the people with rare diseases. Today, you present here at this conference are here because you work to save human lives, to make the future possible for people with rare diseases. Together I think we can make many people happy, together we can help the families with rare diseases to have better quality of life, to get the independent future they deserve. We have several priorities to discuss today regarding the proposed National Plan for Rare Disease. We don't want to discuss the problems, we want to discuss solutions, concrete actions that should be undertaken this year, the following year and further on.

Rachella Mizrahi, Committee for Rare Diseases stated that it had been a real challenge to work on the rare disease program. From the beginning we had to discuss for a definition, approach and solutions.

Furthermore she explained the work of the Committee, the creation of the registry, the challenges and the solutions that were reached in the period between 2015 and 2017. For the first time statistical data was presented regarding the number of registered patients, and the road which a patient travels was explained, from registration to receiving treatment.

The present guests from the region and EU talked about their experiences regarding dealing with and managing the problems and challenges which rare diseases carry. The focus was on successful stories in terms of regulative and the importance of the existence of a National Plan for rare diseases.

Ariane Winman, EURORDIS talked about the EUROPLAN project in the EU countries: Why are National Plans Important?

Marie-Pierre Bichette from the French Alliance for rare Diseases explained the achievements of the French national plan for rare diseases: Methodology, monitoring and implementation of national plans

Davor Duoboka, National Alliance for Rare Diseases – Serbia presented the advancement regarding rare diseases in the past five years in Serbia.

Sanja Perich, National Alliance for rare diseases – Croatia presented the Help line for patients and families with rare diseases.

Vlasta Zmazek, Debra Croatia addressed the innovations in social care for patients with rare diseases

Vlado Tomov,National Alliance of people with rare diseases, Bulgaria, presented the work of the Centre for Rare Diseases in Bulgaria and the advancement with the national plan for rare diseases.

Borislav Gjurich, Association for rare diseases in Bosnia and Herzegovina presented the advancement regarding rare diseases in the past five years in Bosnia and Herzegovina.

The conference continued with the working groups for priorities regarding rare diseases in Macedonia, namely:

- Legislation about rare diseases in RM
- Committee and Registry for Rare Diseases
- Diagnostics and Treatment (medicines, orthopaedic devices)
- Centre for rare diseases and social services

The conclusions from the conference together with the proposal of the national plan for rare diseases will be delivered to all the relevant institutions in Macedonia in order to find a long-term solution for the challenges with which people with rare diseases and their families face.

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Media coverage: CONFERENCE ON RARE DISEASES
Source: Internet-online services of national TV houses, daily newspapers, weekly magazines, news portals
Language of original articles: Macedonian

Source and title of news	Brief information and link
Sitel television - Conference for rare diseases in MASA	The Macedonian Academy of Sciences and Arts organized today the sixth conference for rare diseases. The conference is aimed at paediatricians, internists, neurologists, nephrologists, doctors of family medicine, geneticists, biochemists, biologists, medical doctors from Macedonia and South-East Europe link to source
24 Vesti television - The patients with rare diseases complained that they do not have enough medicines and treatment	There aren't enough medicines for patients with rare diseases, the treatments are late for months because of tender procedures and each delay of treatment is a dangerous threat to their lives - complained the associations of people with rare diseases. link to source
Alsat television - Rare diseases, medicines needed for patients	People with rare diseases should not be discriminated and the medicines that they use should be put on the positive list. This is demanded by the representatives of the associations "Give us wings" and "Life with Challenges". According to them, the prices of the medicines used by patients with rare diseases are very often unbearable for the family budget link to source

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Press 24 - Patients with rare diseases - not enough medicines	Not enough medicines for patients with rare diseases, treatments are late for months because of tender procedures, and each delay of treatment is a threat to their lives. link to source
Fokus MK - Patients with rare diseases do not have enough medicines, treatments are late because of tender procedures	Not enough medicines for patients with rare diseases, treatments are late for months because of tender procedures, and each delay of treatment is a dangerous threat to their lives - complained the associations of people with rare diseases link to source
PlusInfo web portal - Associations for rare diseases demand that medicines are procured for the patients	Medicines which are urgently needed by some patients with rare diseases in order to live should be procured, to continue their introduction on the positive list and the suggestions for the programme for rare diseases to be put in a law, demand the associations for rare diseases and the National Alliance for rare diseases link to source
A1 On web portal - Conference for rare diseases organized by MASA	The Macedonian Academy of Sciences and Arts (MASA) organized the sixth conference for rare diseases, supported by the Macedonian association of medical doctors and the Macedonian Medical Chamber. link to source
Akademik MK web portal - Conference for rare diseases: The procurement of medicines for the treatment of rare diseases should be a priority	The associations for rare diseases and the National Alliance for rare diseases of Republic of Macedonia have demanded from the responsible institutions the proposals for the Programme for rare diseases to be put in a legislative framework, i.e. this topic to be legally regulated. link to source
Lokalno MK web portal - CONFERENCE FOR SYSTEMATIC SOLUTIONS FOR RARE DISEASES	The first EUOPLAN Conference in Macedonia on the topic “Systematic solutions for rare diseases” will take place today in Skopje link to source
Republika web portal - EUROPLAN: A Centre for rare diseases is necessary, even a virtual one	It is necessary to define the notion of rare disease with which these patients will become visible and recognized as a separate category of people for whom special therapy and treatment is needed link to source
Meta MK web portal - Conference for rare diseases in MASA	The Macedonian Academy of Sciences and Arts organized today the sixth conference for rare diseases. The conference is aimed at paediatricians, internists, neurologists, nephrologists, doctors of family

	medicine, geneticists, biochemists, biologists, medical doctors from Macedonia and South-East Europe link to source
SakamDaKazam web portal - 70 PERCENT OF PATIENTS WITH RARE DISEASES ARE CHILDREN, THE PATIENTS DEMAND THAT THE STATE PROVIDE MEDICINES	Without therapy are about 40 percent of the registered patients with rare diseases in the country, according to the statistical data from the Ministry of Health. Until 1st January of this year in the registry run by the Ministry 347 patients have been registered with 46 diagnosis of rare diseases, of which 68 are children, that is to say under 16 years of age. link to source
MRT national television - Patients with rare diseases four months without treatment	Regulative for rare diseases and for expensive medicines is demanded by patients and associations. They have complained about the lack of many medicines, but also about the high prices. There is not a law from the field of medicine where the term rare disease is mentioned, claim from the associations... link to source
Samo Zdravje web portal - A CENTRE FOR RARE DISEASES IS NEEDED, AND PATIENTS SHOULD NOT BE INVISIBLE!	People suffering from a rare disease in Macedonia live in extremely difficult conditions, invisible to the law. It is necessary to define the notion of rare disease with what these patents will become visible and recognized as a special category of people for whom special treatment and therapy is needed, as well as defining the appropriate procedure for a timely procurement of medicines, a centre for rare diseases even a virtual one. link to source
Alfa television - No medicines for rare diseases, the patients - angry	The empty minister chair has enraged the patients with rare disease. They say that they need continuous need of treatment that should not depend of the political events and staff changes. link to source
Kanal 5 television - Conference for rare diseases in MASA	The number of rare diseases is huge and they represent 3-5% of each population. According to professor Guchev what is necessary is continuous... link to source
Mreza MK - In MASA big scientific conference for rare diseases	In MASA big scientific conference for rare diseases link to source
MKD web portal - Conference for rare diseases in MASA	The Macedonian Academy of Sciences and Arts organized today the sixth conference for rare diseases. The conference is aimed at paediatricians, internists, neurologists, nephrologists, doctors of family medicine, geneticists, biochemists, biologists, medical doctors from Macedonia and South-East Europe link to source

MakedonskiMediaServis(Macedonian Media Service) In MASA big scientific conference for rare diseases	In MASA big scientific conference for rare diseases link to source

14. 6th South East European Meeting on Rare Diseases, Macedonian Academy for Science and Art, 11th November, 2017, Skopje, Macedonia

The Organizing Committee for this meeting is: Momir Polenakovic, President, Felix Unger, Co-President, Zoran Gucev, Secretary, Nada Pop-Jordanova, Ilija Filipche, Zivko Popov, VeliborTasic, Katarina Stavric, Vesna Aleksovska


The AGENDA was following:
Rare Diseases in SEE
Moderators:Nada Pop-Jordanova, Zoran Gucev

09.00-09.15 Welcome and opening

Session I
09.15-09.25 Momir Polenakovic, Skopje, Macedonia
Introdcutory remarks

09.25-09.40 Vesna Aleksovska, Anja Bosilkova Antovska, Skopje Macedonia
National plan for rare diseases an regulative for rare diseases in Macedonia - challenges and solutions

09.40-10.05 Ria Schönauer, Leipzig, Germany
Intrafamilial variability due to genetic modification in ADPKD

10.05-10.30 Mirko Spirovski, Skopje, Macedonia
Rare-diseases genetics in the era of next generation sequencing: Single Center experience

10.30-10.55 Johannes A. Mayr, Salzburg, Austria
Next generation sequencing reveals new treatable diseases. Are we entering a new era of preventive medicine?

10.55-11.20 Zoran Gucev, Skopje, Macedonia
Rare diseases, new genes, molecular mechanisms and treatments

Discussion

11.45-12.10 Oliver Bartsch, Mainz, Germany
Clinical update on preimplantation genetic diagnosis

12.10-12.35 Martin Magner, Prague, Chech Republic
Mucopolisaccharidoses

12.35-13.00 Velibor Tasic, Skopje, Macedonia
Pediatric nephrology in the next generation sequencing era

13.00-13.25 Ramush Bejiqi, Prishtine, Kosovo
Klippel-Feil syndrome associated with congemital heart disease

Discussion

13.25-14.10 Lunch and e-poster session

Session II
Moderators: Mirko Spiroski, Velibor Tasic

14.10-14.35 Ruthild Weber, Hanover, Germany
Genetics of renal malformation: new insights through next generation sequencing.

14.35-15.00 Dieter Haffner, Hanover, Germany
Complications and management of X-linked hypophosphatemia

15.00-15.25 Julia Hoefele, Munchen, Germany
Impact of genetic modifiers in female patients with Alport syndrome

Discussion

15.50-16.10 Milosevic Danko, Zagreb, Croatia
Atypical hemolytic-uremic syndrome (aHUS)-Croatian experience

16.10-16.30 Adrijan Sarajlija, Belgrade, Serbia
Clinical spectrum of mitochondrial disorders in childhood

16.30-16.50 Vjosa Kotori, Prishtine, Kosovo
Hyperinsulinemic hypoglycemia

16.50-17.10 Mensuda Hasanhodžić, Tuzla, Bosnia and Hercegovina
Lipid storage disorders (single centre experiance in Bosnia and Hercegovina)

Discussion

Conclusion remarks: Zoran Gucev, Velibor Tasic, Momir Polenakovic

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There were also ELECTRONIC POSTER SESSIONS

First e-poster session (Panel A) 11.20-11.45
Moderators: Ana Momirovska, Svetlana Cekovska, Danko Milosevic

1. Stajkovska A et al. IN THE HEART OF THE MATTER: EXOME SEQUENCING FOR DIAGNOSTICS OF ARRHYTHMIC SYNDROMES AND OTHER CARDIOVASCULAR CONDITIONS
2. Stamatova A et al: FAMILIAL FORM OF CONGENITAL UNILATERAL MICROMASTIA

Second e-poster session (Panel B) 11.20-11.45
Moderators: Nada Pop-Jordanova, Katarina Stavric, Stojka Fustik

1. Ambarkova V et al. PATIENT WITH CLEFT LIP AND PALATE- A CASE REPORT
2. Jovanovski-Srceva M et al . ANESTHESIA FOR PATIENT WITH LOUIS BAR SYNDROME

Third e- poster session: (Panel A) 13.25-14.10

Moderators: Vesna Ambrakova, Ramush Bejiki, Adrijan Sarajlija

1. Stamatova A et al. ECTODERMAL DYSPLASIA IN TWO BROTHERS
2. Bogevska I et al. TISSUE SPECIFIC CREBBP MOSAICISM IN A PATIENT WITH RUBINSTEIN-TAYBI SYNDROME
3. Janchevska A et al. A 9.5 YEAR OLD BOY WITH FAMILIAL MALE CENTRAL PRECOCCIOUS PUBERTY
4. Simic I et al. ANESTHETIC CHALENGES IN A CHILD WITH ARTHROGRYPOSIS MULTIPLEX CONGENITA PRESENTED FOR LIMB SURGERY
5. Fustik S et al. THE IMPORTANCE OF AN INTERNATIONAL REGISTRY FOR PATIENTS WITH CYSTIC FIBROSIS

Fourth poster session (Panel B) 13.25-14.10
Moderators: Vladimir Avramoski, Goran Kungulovski, Rubens Jovanovic

1. Alili Ademi L et al. MYASTHENIA GRAVIS IN A GIRL WITH HASHIMOTO'S THYROIDITIS
2. Markovska-Simoska S et al. GIRL WITH 22q11.2 DELETION SYNDROME MANIFESTING PSYCHOTIC SYMPTOMS: CASE REPORT
3. Momirovska A et al. WILSON DISEASE, MUTATION c.3207C.A (p.His1069Gln) IN ATP7B GENE, IN PATIENTS IN REPUBLIC OF MACEDONIA
4. Mehandziska S et al. RARE IS NOT A DIAGNOSTIC SCARE: EXOME SEQUENCING FOR DIAGNOSTICS OF RARE DISEASES

15. Everyone for Jane, Raising awareness on SMA, December, Ohrid, 2017

In December, in Ohrid, the citizens organized by Gordana Loleska, managed to realize an event for raising awareness on Spinal Muscular Atrophy. As there is a drug approved and available but it is still not accessible for children in Macedonia. We hope that new medicines for different rare diseases will be available in 2018.



16. Football Game, elementary school, Skopje, December, 2017

The children from an elementary school in Skopje, Dimitar Miladinov, organized a football game to raise awareness on the problems and challenges of children with rare diseases. In the game there were also children with rare diseases, who played together.

17.Rare Disease Day Flag under water for New Year, December, 2017, Ohrid, Macedonia

For the 16th time, the members of the Dicing centre Amfora, and the Club for under water activities Ohrid, in cooperation with the Alliance for under water activities of Macedonia, decorated the Christmas tree under water in Ohrid lake, Macedonia. Traditionally as every year they decorated the tree in the lake at the Bay of Bones. Even the youngest members of the diving club participated in this activity.

This year the Ohrid divers dedicated the decoration to the children with rare diseases in Macedonia. This cooperation was made possible with the efforts of our member Gordana Loleska from Ohrid.

18.Santa Clause race, Ohrid, December, 2017

In December, 2017 in Ohrid there was an event for New Year – a race of Santa Clause. Gordana Loleska made a cooperation with the organizers and at the end of the race people could take picture with the participants and the rare disease day flag to raise awareness on rare diseases.

Живот со Предизвици / Jeta me Sfida / Life With Challenges

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The activities in this report were supported by:

Information about the association:

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