



Живот со Предизвици / Jeta me Sfida / Life With Challenges

Activities of the Association of Citizens for Rare Diseases

LIFE WITH CHALLENGES – Bitola – Annual report for 2013

Association of Citizens for Rare Diseases LIFE WITH CHALLENGES – Bitola, in 2013 focused on activities of strengthening of the association, growth and development and raising public awareness in the field of rare diseases. All the activities are directed towards finding long-term solutions needed for the patients to have better quality of life. Part of our activities are also in support of other associations, cooperation with other associations, support of patients and families, sharing information and best practices and networking, all and all focused to improve management of rare diseases and different complications.

One of our regular activities is maintain communication with the Ministry of Health and the Health Insurance Fund of Macedonia in order to find solutions for improvement of the treatment conditions for the patients with rare diseases.

The program for 2013 is a project with different activities leading to raising public awareness in the area of rare diseases in Macedonia. Life with challenges, won the PAL award from Genzyme, Sanofi Company, that supports this project.

Mrs. Mary Jo Wohlers, the wife of the Ambassador of USA in Macedonia, got involved in our campaign, supporting our cause in improving quality of life of patients and raising public awareness.

Concept, Marketing and Communications is a PR company that also got involved in our campaign, supporting us with design of products for our activities as brochures, posters, t-shirts, logo, web page etc.

We also had support from: Pelisterka (beverages), Herbalife (volunteers), InterBB (print), Association for physiotherapists from Macedonia, Kontura (print and design), Mountain Club Korab, Skopje Marathon, Hemolog (Hemophilia Association), ESE - Association for Emancipation, Solidarity and Equality of Women in the Republic of Macedonia, HAE (Hereditary Angioedema Association) Macedonia, and we had over 300 volunteers supporting our activities.

In January, 2013, Life with Challenges created a brochure with personal stories of patients and parents that face life with rare diseases. The same is available for download on our web page (<http://challenges.mk/wp-content/uploads/2013/04/Brochure.pdf>). On our newly developed web page we publish information about our activities for transparency and publicity of our work (<http://challenges.mk/>).

Also we started to communicate more using the social media:

- <https://www.youtube.com/user/lifewithchallenges>,
- <https://www.facebook.com/LifeWithChallenges>
- <https://twitter.com/ZivotPredizvici>

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On **23rd of February, 2013**, in City Mall, Skopje we realized an activity prior to Rare Disease Day. Volunteers from the Faculty of Pharmacy, Skopje, joined us in the realization of this activity. On a promo stand in the Mall we were sharing balloons and badges with our logo, and we informed the citizens about rare diseases. During this activity we gained more volunteers, more members and we met two parents who have children with rare diseases that previously were not informed about our organization.



Further we continued with organization of a press conference and round table on **Rare Disease Day, 28th of February, 2013**, at the Amphitheater of the Medical Faculty, Skopje. For the first time in Macedonia we gathered in one place 30 patients and parents, 30 doctors and medical nurses. The round table discussion was opened by Mrs. Mary Jo Wohlers, D-r Aspazija Sofijanov (Director of the University Children Clinic and president of the Commission for rare diseases) and Tanya Collin Histed (EGA Director). The PR was supported by Concept and we had publications and statements about the event in all national televisions, radio, daily news papers, and web portals.

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February is also the month we achieved reformation of the **Commission for rare diseases** at the ministry for Health which was very important because before that this commission was not working very well (in 4 years they had 2 meetings). Now the president of this commission is D-r Aspazija Sofijanova and vice president is D-r Arben Taravari. They both stand by the patients in their fight for treatment and they started advocacy and lobbying for the patients with rare diseases through provision of different reports to the Ministry of Health. They both participated in conferences and congresses for different rare diseases with a goal to learn more about rare diseases and gather information about treatment and care.

In March, 2013 the president of the association, Vesna Aleksovska, participated as a presenter in the **Gaucher Patient Advisory Meeting in Waterford**, Ireland, presenting the campaign for raising public awareness about rare diseases and participating in discussion for improvement of quality of life of patients with Gaucher disease and improvement of treatment.



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In **April, 2013**, Life with Challenges was one of the associations that organized the **First Balkan Meeting for Lysosomal Diseases and the Second Balkan Meeting for Gaucher in Sarajevo, Bosnia and Herzegovina**, together with organizations from Slovenia, Serbia and Bosnia and Herzegovina.



During **April, 2013**, 4 representatives of Life with Challenges participated at the **Second Balkan Conference for Rare Diseases, in Sofia, Bulgaria**. Vesna Aleksovska, presented the situation in Macedonia regarding rare diseases. Participants had opportunity to share experiences and create plans for further activities in the Balkan Region regarding rare diseases.



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In **May, 2013**, Life with Challenges together with HAE Macedonia (Hereditary Angioedema Association) and HEMOLOG (hemophilia association) joined the traditional **Skopje Marathon**. Through social networks and cooperation we gathered 100 volunteers that were running for our cause under the motto – **“We are Running for Better Life”**. Our T-shirts were printed with the help of Concept and HERBALIFE. Also as participants we had representatives from the Association for Physiotherapy and the Medicine High school from Shtip, Jane Sandanski.



HERBALIFE joined us with 50 participants. We had group running on 5km and another group on 21km. We won 1st place in women group on 5km, 2nd place in 5km in men group and 1st place for being the largest group at the Skopje marathon. We also gained new volunteers from the Commercial Bank Pension Fund from Macedonia, Skopje. This event was also covered in the media, not only by journalists that cover health, but also by journalists that cover sport and entertainment which was a big success.

In May, we also supported the organization of a **HAE day** with an open concert in Skopje. We had 20 bands and signers, dance groups and a lot of audience and media coverage. This was another activity for raising public awareness and it got a lot support from the Youth Educational Forum Association.

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In **May - June, 2013** we participated at the **EURORDIS Membership Meeting in Dubrovnik, Croatia**, where we managed to expand networking and communication with other relevant bodies and associations in the area of rare diseases.



In **June, 2013**, with cooperation with the Association for Physiotherapy and the Medicine High school from Shtip, Jane Sandanski, we organized a **lecture about rare diseases** in front of 100 students. Most of them become our members and volunteers.



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On 7th of September, we had a **working meeting** with the **National Alliance for rare diseases from Bulgaria**, discussing about support, possibilities for cooperation, exchange of experience and best practices for improving quality of life of patients and families that suffer from rare diseases.



On 8th of September, we gathered a group of 50 people and we participated at the climbing of the highest mountain top in Macedonia, Korab under the motto – **To the top for better life!** This activity helped in raising public awareness about rare diseases and promoting healthy life.



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In **October**, Vesna Aleksovska, became a member of the **DITA Task Force**, EURORDIS and in December she participated at the DITA Task Force Meeting in London.



On **29th of October** we had a meeting with the **Health Insurance Fund of Macedonia** discussing about the possibilities for providing treatment for patients with rare diseases and about National Plan for rare diseases in Macedonia.



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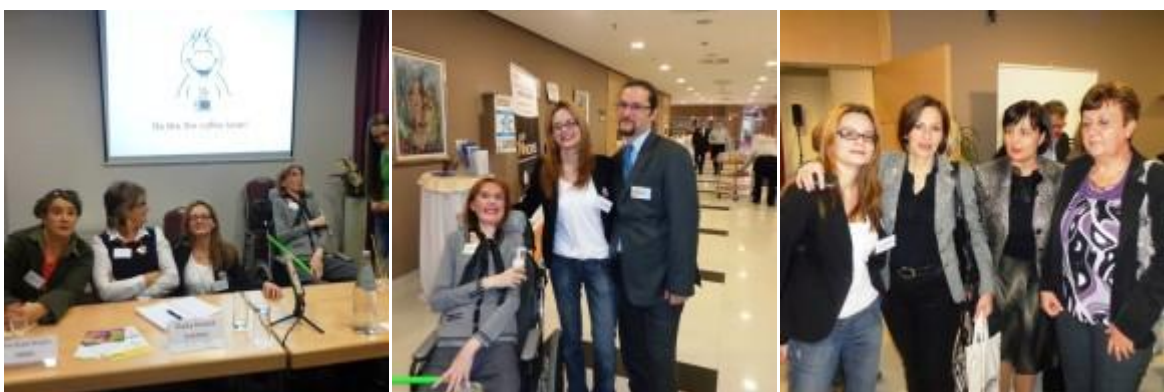
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At the Macedonian Academy of Science and Art on **16th of November, 2013**, Life With Challenges participated in the **Congress for Rare Diseases of South-East Europe**, in organisation of the Research Center for genetic engineering and biotechnology "G.D. Efremov". Patrons of the congress were the European Academy of pediatrics, MASA and the Doctor Chamber of Macedonia.



From **5 - 7 December**, we participated at the **National Plan Conference organized from the National Organization for Rare Diseases – Serbia**. Vesna Aleksovska was one of the leaders of the workshop for strengthening patients.



On **7th December** we participated at the **Second International Summit – When is it fair to say no?** - Healthgrouper, Skopje, Macedonia, where we raised the question of reimbursement for treatment for rare diseases in front of international experts and representatives from relevant Macedonian Institutions.



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In December we prepared information brochures regarding some rare diseases in Macedonian, since there was no available information about rare diseases in Macedonian language. They are available for download on our web page <http://challenges.mk/?p=1712&lang=en>, and they will be additionally promoted on Rare Disease Day, 2014.

We continue to negotiate with the Ministry of Health and the Health Insurance Fund in Macedonia. In November, 2013, a 12 year old girl with Gaucher in critical condition started with treatment provided from the Ministry of Health of Macedonia, which was one step forward, and we expect to see more progress in 2014.

We hope to achieve financing of the treatment for patients with rare diseases.

Thank you for your attention and let me express my gratitude for your support and cooperation and your involvement in advocacy and lobbying for improvement of quality of life of patients with Rare Diseases.

Vesna Aleksovska,

President of the Association of Citizens for Rare Diseases

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***Note:**

For all activities there is more information on our web page and social media. Most of them are translated in English.

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