



Живот со Предизвици / Jeta me Sfida / Life With Challenges

Annual report for 2014

Association of citizens for rare diseases LIFE WITH CHALLENGES

In 2014 Life With Challenges realized many activities for raising public awareness, strengthening patients, cooperation and networking with other organizations on national and international level and communication with the health institutions in Macedonia.

Our most important accomplishment is the new law for financing the Program for Rare Diseases at the Ministry of Health. This is a hope for all untreated patients with rare diseases. On December 16th the Prime Minister of Macedonia Mr Nikola Gruevski gave the following statement:

“The challenge of treating patients with rare diseases is a world challenge. Although they influence 1 in 2000 people they are a challenge for many families and they are before all a life challenge for the patients ... our task is to try and find a way to overcome those challenges and give support to the families, we need to fight together for the health of our citizens. We have a task to find a way to finance the fight with rare diseases in an appropriate way. That is why in Macedonia we found a systematic solution that is in accordance with EU countries, we changed the Law for taxes on cigarettes, and from now on 1 MKD from one packet of cigarettes will go directly to the program for rare diseases in Macedonia. We estimate that 250 million MKD will be gathered to treat the patients. We need to continue working together, the fight of one citizen is a fight for all citizens.”

We expect patient representatives to be included in the Commission of rare diseases and we also expect soon to hear about adopting strategy for rare diseases in Macedonia, and to establish a registry for patients with rare diseases.

For all activities, there is information on our web page, facebook and youtube:

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

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

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Rare Disease Day, 28th of February, 2014

Traditionally Life With Challenges marked the Rare Disease Day, 28th of February, 2014 under the motto “let’s Join Together for Better Care!,”. We are already on the map of Rare Disease Day - <http://www.rarediseaseday.org/event/macedonia-the-former-yugoslav-republic-of/41>. We organized a press conference for media - discussion with patients/families/doctors/ health institutions under the motto of the Rare Disease Day 2014 - let’s Join Together for Better Care!, as we were in preparation of the National Plan for rare diseases. The event was supported by Genzyme –Sanofi Company, Celgene Corporation, EU Info center and Concept marketing and communications.

Also we had sponsors / donors / supporters / volunteer event as we were celebrating 5 years of the existence of the organization. We awarded certificates to all people /companies/ organizations/ institutions that supported us through the years. We had a cocktail afterwards - participants gathering to discuss future improvements in treatment and care in order to improve quality of life, and to share experience on what does it mean to live with a rare disease. We also organised an exhibition: One day of my life with a rare disease as a part of the Rare disease day. This events were organized at the EU Info center and 100 people were present at the event.

Present speakers at the event: Mr Robert Lidl, Minister advisor, manager of the department for political questions, justice and internal affairs, information and communication, EU delegation; Ms Aspazija Sofijanovska, Director of the University Children Clinic, President of the commission for rare diseases; Ms Maja Parnardzieva Zmejкова, Director of the Health Insurance Fund; Mr Momir H. Polenakovik, Macedonian Academy for science and art; Mr Kiro Salvani, State Advisor, Ministry of Health; Ms Katerina Aleksovska, Director of the Bureau for Drugs; Ms Mary Jo Wohlers, US Embassy.

Почитувани,

На 27ти и 28ти февруари, за Денот на Ретки Болести. Здружението на граѓани за ретки болести Живот со Предизвици, ќе организира два настан за одбележување на денот.

Денот на Ретки Болести е годишен настан за подигнување на јавната свест во однос на ретките болести во координација со ЕУРОДИС, за нивна национална и меѓународна свест и Организацијата на пациенти на национално ниво.

Главната цел на Денот на Ретки Болести е подигнување на јавната свест за ретките болести и влијанието кое тие го имаат на квалитетот на живот на пациентите.

За прв пат, Денот на Ретки Болести беше лансиран од ЕУРОДИС во 2009та година, кога повеќе од 1000 настан се организираа во светот, добивајќи достапност и медиумска поддршка. Овај настан има голем придонес во однесувањето на политиката и лобирањето за правата на пациентите со ретки болести и во напредокот на кривична и медицинска промена и законите за ретки болести во многу земји. Иако оваа настан е зборна како и Европскиот настан, сепак во светскиот сценариј 70 земји учествуваа во 2013та година. Се надеваме дека и во оваа година ќе се приклучат оваа година. Целта е Светската Здравствена Организација да го поддржи напредокот на однесувањето на пациентите како официјален Ден на Ретки Болести и да ја подигне јавната свест за ретките болести во целиот свет.

Не ни биде драго доколку присуствувате и ја дадете својата поддршка за луѓето кои се соочуваат со ретки болести.

Искрено,
Весна Алексоска,
Претседател на Здружението на граѓани за ретки болести Живот со Предизвици

Програмата на настанот е како што следува:

27 февруари, петок, Амбуланта на Деканат на Медицински Факултет, Скопје

10.00 – 13.00ч – Предавање на тема ретки болести – подбора на неа, новости во третман, за студенти на медицина и фармакологија во соработка со Студентски Парламент на Фармацевтски Факултет и Универзитетска Детска Клиника – Скопје.

28 февруари, петок, ЕУИФЦ Центар, Скопје

10.00 ч – 10.30ч. Отворање

Говор – Г-ѓа Весна Алексоска,
Претседател на Живот со Предизвици

Говор – Г-дин Роберт Лидл, Министер советник,
Распоредител на Оддел за политички прашања, правда и внатрешни работи, информации и комуникации

Говор – Г-ѓа Мари Џо Волерс,
Амбасадор на Америка (посетил член на здружението)

Говор – Ас. др. мр. М. Аспазја Софијанова,
Директор на Детска Клиника

Говор – Фонд за Здравствено Осигурување на Македонија

Говор – Министерство за Здравство

Говор – Македонска Академија на Науки и Уметности

10.30 ч. – 11.00 ч. – Доделување на благодарници до поддржувачите на Живот со Предизвици (славне петта година на постоење на здружението)

11.00 ч. – Дискусија / дебата на тема: Моќности за подобрување на третман на ретки болести во Македонија

Доктор од Детска Клиника

Пациенти и родители

Медици

11.30 ч. – 12.00ч. – Изјави за медиуми

12.00 ч. – 13.00ч. – Затворање – мал коктейл

За дополнителни информации слободно контактирајте нб.

Информации за здружението:

Веб страна:
<http://challenges.mk/>

Facebook страна:
<https://www.facebook.com/LifeWithChallenges>

Facebook група:
<https://www.facebook.com/groups/312483895490987/>

Контакт:
Весна Алексоска,
Претседател на Здружението за ретки болести „Живот со Предизвици“ – Битола
e-mail: zivotopredizvici@gmail.com
tel.: +389 70 703 446

* Invitation for Rare disease day

* [Brochure for rare disease day](#) – available for download at our web page

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* **Poster for Rare Disease Day**

* **[Patient stories - poster exhibition](#) – view on web page**

Day before rare disease day (on 27th of February) we had education event for students from the Medicine and Pharmacy Faculty and interested medical professionals (50 people present). This event was organized at the Medical Faculty and supported by the University Children Clinic and the Student parliament of the pharmaceutical faculty.

Lecturers and subjects at the education event: Ms Biljana Coneska Jovanova (Enzyme therapy in Gaucher disease), Mr Samo Zver (Rare haematological diseases and innovation in treatment), Mr Velibor Tasik (Rare diseases in nephrology), Mr Ivan Milev (Pulmonary hypertension), Ms Vesna Grivcheva Panovska (Hereditary Angioedema).

For the Rare disease day we had media coverage from television, radio, newspapers and media portals. Over 30 media covered our story and also it was published on the web page of the Health Insurance Fund.



***Picture from Rare disease day**

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Speakers and subjects at the conference: Borjan Pavlovski, Coordinator of the Program for Public Health and Women's Health at the Association for Emancipation, Solidarity and Equality of Women in R. Macedonia; Mary Jo Wohlers, USA Embassy in Macedonia/ Honorary Member of the Association of Citizens for Rare Diseases Life with Challenges – Bitola; Assoc. Prof. Elena Kosevska, MD, Ph.D. Specialist for Social Medicine, Institute for Public Health of the Republic of R. Macedonia, Head of Department for Health Promotion, Analysis and NCD Prevention; Branko Adzigogov, Advisor of the Director, Health Insurance Fund of Macedonia; Cveta Nakeska, Founder and Member of the Executive Board of HEMOLOG - Bleeding Disorder Society of Macedonia; Davor Duboka, Executive Director of the National Organization for Rare Diseases, Serbia: Presentation of the National Plan for Rare Diseases – Serbia; Vladimir Tomov, President of the National Alliance of People with Rare Diseases, Bulgaria: Presentation of the National Plan for Rare Diseases – Bulgaria; Borislav Djuric, President at the Association for Rare Diseases: Presentation of the National Plan for Rare Diseases - Bosnia and Herzegovina; Vlasta Zmazek, EUROPLAN Advisor: Presentation on EUROPLAN.



*** Pictures from the conference**

We had a lot of media attention at the conference – around 22 media covered our story (television, radio, newspapers, and web portals). At this conference we had around 100 people attending (organizations, institutions, patients, medical professionals, researchers, families etc...).

**“First CEI Conference for building regional network of organizations for Rare Diseases”,
on 23rd – 24th of March, 2014 in Skopje, R. Macedonia.**

First CEI Conference for building regional network of organizations for Rare Diseases is a project that contributed to strengthening of the capacities of the organizations and to increasing networking and communication between the organizations from the CEI region that work in the field of rare diseases. With this conference we contributed towards raising awareness (general public, government institutions, and medical professionals) about rare diseases in Macedonia and the CEI Region. The conference meeting contributed for sharing best practices in advocating for patients' rights and sharing information on implementation of National Plans/Strategies on rare diseases in different countries.

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*Poster from the conference and a picture from speakers



*Invitation and agenda for the conference

* European Regulative and recommendations for rare diseases - brochure available for download at our web page

Countries that participated: Serbia, Slovenia, Croatia, Bosnia and Herzegovina, Bulgaria, Italia.



*Picture from the conference

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Speakers and subjects at the conference: Ms. Maja Ivanova, First Lady of R. Macedonia; Ms. Maja Parnardzieva Zmejкова, Director of the Health Insurance Fund Macedonia; Prof. D-r Aspazija Sofijanovа, Director of the University Children Clinic – Skopje, President of the Commission for Rare Diseases; Prof. Dijana Plaseska Karanfilska, Macedonian Academy for Science and Art; Katerina Aleksoska, Director of the Bureau of Drugs, R. Macedonia; Drancho Apostolovski, Representative from the Ministry of Foreign Affairs, Deputy National Coordinator for Macedonia of the Central European Initiative (CEI): Presentation on CEI; Anja Kladar, Vice-president of the Croatian Alliance for Rare Diseases: Presentation on Orphanet Croatia; Nikolina Covic, Social worker at the Croatian Alliance for Rare Diseases: Presentation on support and social rehabilitation for patients with rare diseases, Croatia; Todor Mangarov, President of the Association for Pulmonary Hypertension, Bulgaria: Presentation on the situation of patients with PH in Bulgaria; Marija Joldic, President of the Executive Board of the National Organization for Rare Diseases - Serbia: Presentation on the situation of patients with rare diseases in Serbia; Jasminka Jezdimirovic, President of Association for Rare diseases and disability in Serbia: Presentation on situation of PKU patients in Serbia; Borislav Djuric, President of the organization for rare diseases in Bosnia and Herzegovina: Presentation on situation of patients with rare diseases in Bosnia and Herzegovina; Viktorija Penova, Patient with FOP: Presentation on Life with FOP disease, R. Macedonia; Vlasta Zmazek, Member of the Board of Directors of European Organization for Rare Diseases (EURORDIS): Presentation on EURORDIS; Irena Znidar, Member of the Board of Directors of European Gaucher Alliance (EGA): Presentation on EGA; Fernanda Torquati, President of the Italian Gaucher Association: Presentation on strengthening patients; Sandra Pavlovic, President of DEBRA, Serbia: Presentation on DEBRA; Polona Zakoshek, President of DEBRA, Slovenia: Presentation on DEBRA; D-r Vukashin Andric (D-r Vulnet Ferati), Genzyme, Sanofi Aventis: Presentation on the Humanitarian Aid Program and Innovation in treatment for rare diseases; Gordana Lenarcic, mag. farm., Medical Affairs Manager, Celgene International: Presentation on innovation in treatment for rare diseases; D-r Vujkovic Bojan: Presentation on Fabry Centar, Slovenia; Ass. D-r Biljana Coneska Jovanovа, University Children Clinic – Skopje, Department for Hematology and Oncology: Presentation on Enzyme Replacement Therapy in Patients with Gaucher Type 1; Prof. Dijana Plaseska Karanfilska, Macedonian Academy for Science and Art: Presentation on Rare Diseases genetics in the era of next generation sequencing; Prof. D-r Zoran Gucev, University Children Clinic – Skopje, Endocrinology Department: Presentation on MPS (Hunter) patients treatment in Macedonia; Prof. D-r Velibor Tasik, University Children Clinic – Skopje, Nephrology Department: Presentation on Rare Diseases in Nephrology; Prof. D-r Aco Kostovski, University Children Clinic – Skopje, Gastroenterology Department: Presentation on Rare Diseases and Tyrosinemia; Ass. D-r Ivan Milev, Special Hospital for Chirurgical Diseases, Filip II, Skopje: Presentation on treatment and situation of patients with Pulmonary Hypertension in R. Macedonia.

We had a lot of media attention at the conference – around 20 media covered our story (television, radio, newspapers, and web portals).

At this conference we had more than 100 people attending (organizations, institutions, patients, medical professionals, researchers, families etc...).

For this activity we had financial contribution from CEI, Genzyme – Sanofi Company, Celgene Corporation and Concept Marketing and communications.

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Skopje Marathon, 11th of May, 2014

In May, 2014 we joined the Skopje Marathon under the motto – “We are running for better life”. We had around 150 participants running for the patients and also promoting healthy life style. We are very proud that this year we had a Hantington patient running by pushing a wheelchair of a patient with child paralysis.



Media: over 15 media covered our story.

Financial support: Genzyme – Sanofi Company, Celgene Corporation, Alkaloid Skopje and Concept Marketing and communications.

Volunteer support: HAE Macedonia, Association of Physiotherapists of Macedonia, HEMOLOG, Jane Sandanski – Shtip, Moment Plus and Dajte ni Krilja.

First international Gaucher Day, 26th of July, 2014

We joined the activities of EGA in Gaucher day celebrating the 160th anniversary of Philippe Gaucher’s birth in 1854, with organization of a bicycle ride through Skopje.



**Pictures from the event*

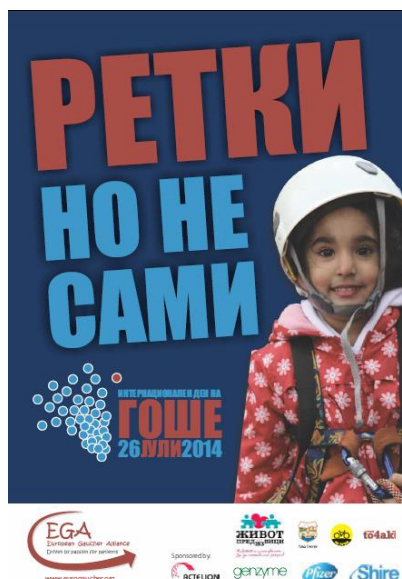
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**Media coverage – collage and poster for the day*

We also organized a patient/ family/ doctor meeting to discuss about life with Gaucher and how to improve quality of life. This meeting was organized on 15th of November because most of the invited participants were on holiday. Also on 15th of November we had a guest – D – r Timothy Cox who was speaking at the Congress for rare diseases of South East Europe organized by Macedonian Academy for science and Art. So we decided that it is a perfect day for a get together and share experience.



**Pictures from the event*

Financial support: Genzyme – Sanofi Company

Other support: Concept marketing and communications, Kontura, associations for other rare diseases, Natocak, To4ak and Municipality of Skopje.

Media support: over 20 media covered the event.

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Climbing Korab, 8th of September, 2014

“To the top for better life” – activity for raising public awareness. Around 70 participants joined this activity, promoting social inclusion and healthy life style. Although the weather conditions were not friendly still a lot of participants made it to the top.



* Pictures from the event

Financial support: Genzyme – Sanofi Company, Celgene Corporation, ONE telecommunications and Concept Marketing and communications.

Volunteer support: Korab mountain climbing club.

Media support: More than 20 media covered this event by publishing a story about it focusing on the problems that patients and families face in their lives.

Education activities, September – December, 2014

In cooperation with Red Cross, we started educational workshops for education of the volunteers in the Red Cross. Volunteers have a possibility to learn about rare diseases in general and specific for different rare diseases that exist in Macedonia directly from patients and families affected by rare diseases. We plan to continue with the education and involve the volunteers in the activities of the association next year.



* Pictures from the event

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Congress for rare diseases of South East Europe organized by Macedonian Academy for Science and Art

Our association cooperated with MASA for successful organization of the congress. Through the EGA, D-r Timothy Cox was supported to attend the congress and give lecture on Gaucher Disease, and D-r Julijan Naskov was supported by Celgene to give a lecture on Value of innovation in the field of rare diseases. D-r Vukashin Andric was supported by Genzyme to present about Eliglustat as a new therapy for Gaucher disease. Also our organization had a presentation on the importance of implementation of National plan for rare diseases in Macedonia for improving quality of life of patients and families that face life with rare diseases. As a patient organization we are aware that the only way we can support patients is to cooperate with all stakeholders in the country and internationally so we will continue communication and cooperation in the next year on a higher level.



****Pictures from the event***

****Program of the event***

Macedonian Academy of Arts and Sciences (MASA), Skopje , 3RD RARE DISEASE IN SEE MEETING, SKOPJE, MACEDONIA, (EAP, UEMS Section of Paediatrics)

1. Welcome and opening

- Mrs. Maja Ivanova, First Lady of the Republic of Macedonia, Honorary Patron of the Association of citizens for rare diseases "Life with Challenges"
- Mr. Vlado Kambovski, President, MASA
- Mr. Nikola Todorov, Minister of Health, Macedonia
- Mrs. Maja Parnadjieva, Head, Health Fund of Macedonia
- Mr. Momir Polenakovic, Director, Research Center for Genetic Engineering and Biotechnology "G.D.Efremov"
- Mrs. Aspazija Sofijanovska, Director, University Pediatric Clinic

2. Invited Speakers

- Zvi Laron, Israel
- Martin Savage, UK
- Gorazd Rosoklija, USA

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- Christiane Zweier, Germany
- Timothy Cox, UK
- Vukasin Andric, Croatia
- Julijan Naskov, Slovenia
- Vladimir Lozanovski, Germany
- Stephan Storch, Germany
- Tatjana Zorcec, Macedonia
- Zoran Gucev, Macedonia
- Velibor Tasic, Macedonia
- Aco Kostovski, Macedonia
- Vesna Aleksovska, Macedonia

Wilson disease gathering – 6th of December, 2014

We organized a gathering for patients, families and doctors about Wilson disease since a lot of patients were in bad condition because of lack of treatment and expertise. Also we invited the Bulgarian association for Wilson disease – patient representatives and doctors to help families and doctor regarding support in treatment and advice for living with Wilson disease.

At this gathering there were presentations from doctor about Wilson disease and patients shared their stories regarding the challenges they face living with Wilson disease.



***Pictures from the event**

***Program of the event**

- Introduction from the president of Life with challenges
- Introduction from patients and patient representatives from Bulgaria
- Discussion on treatment and way of life
- Conclusions and appointing a leader of the Wilson group

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Participation at conferences and meetings - January – December, 2014

- World Symposium for Lysosomal Diseases, 9th to 14th of February, 2014, Sand Diego, USA
- Go With Gaucher, 23rd to 25th of March, 2014, Frankfurt, Germany
- EUPATI workshop on reaching a public audience on medicine development, 2nd of April, Warsaw, Poland
- DITA task force – EURORDIS meeting, 3rd of April, 2014, Warsaw, Poland
- Caregivers workshop and Gaucher Patient Advisory meeting, 28th and 29th of April, Amsterdam, Netherlands
- EURORDIS Membership meeting, 8th of May, 2014, Berlin, Germany
- European Conference for Rare Diseases (ECRD), 8th to 10th of May, 2014, Berlin, Germany
- European Federation of Neurological Associations training course on Pharmaceutical policy, pricing and reimbursement, at London Schools of Economics and political science, 13th to 14th of May, 2014, London, UK
- European Gaucher Alliance and European Working Group on Gaucher Diseases Membership meeting, 22nd to 28th of June, 2014, Haifa, Israel
- Partners for progress, workshop, 1st and 2nd of July, Prague, Czech Republic
- ICORD (International Conference for Rare Diseases and Orphan Drugs), 7th to 9th of November, 2014, Ede, Netherlands
- Gaucher conference, 21st of October, Belgrade, Serbia
- EUnetHTA Training course and conference – HTA 2.0 Europe, Teaming up for value, 29th to 31st of October, 2014, Rome, Italy
- Congress for rare diseases of South – East Europe, 15th November, 2014, Skopje, R. Macedonia
- Rare Disease conference, 10th to 11th of December, 2014, Sarajevo, Bosnia and Herzegovina
- International rare diseases meeting – Eurasian Alliance – Exchanging experience , 13th to 14th of December, 2014, Sofia, Bulgaria

Financial support for travel, accommodation and attendance: grants, EGA, EURORDIS, Genzyme Sanofi Company, Celgene Corporation, EFNA, EUnetHTA, EUPATI.

Thank you for your attention,

Vesna Aleksovska,

President of the Association of citizens for rare diseases,

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