



Живот со Предизвици / Jeta me Sfida / Life With Challenges

Dear members and supporters,

For Rare Disease Day, the Association of citizens for Rare Diseases „Life With Challenges“ is organizing two events to mark the day.

Rare Disease Day is an annual event for raising public awareness in coordination with EURORDIS on international level and from National Alliances and patient organizations on national level. The main goal of this day is raising public awareness about the influence that rare diseases have on quality of life of patients and families.

For the first time, Rare Disease Day was launched by EURORDIS in 2008th when more than 1000 events were organized all over the world. This event has great contribution in advocacy and lobbying for patients rights and towards progress in developing national plans and regulative for rare diseases in many countries.

Although the campaign started as a European event it grew into world event with above 70 countries participating in 2013th. We hope that more countries will join this year. The goal is to raise public awareness for rare diseases in the world.

Program:

27 February, Thursday, Amphiteater - Medicine Faculty, Skopje

10.00 h. - 13.00 h.- Lecture on subject Rare Diseases - better care, innovation in treatment.

28 February, Friday, EU Info Center, Skopje

10.00 h. -10.30 h. Opening speeches

- Ms Vesna Alesksovska, President of Life With Challenges
- Mr Robert LIDDELL, Minister Counselor, Head of Section for Political & Justice and Home Affairs Issues, Information and Communication, EU Delegation
- Ms Mary Jo Wohlers, USA Embassy (Honorary member of the association)
- Ms Aspazija Sofijanova, Director of the Children Clinic
- Health Insurance Fund of Macedonia
- Ministry of Health of R. Macedonia
- Macedonian Academy of Science and Art

10.30 h. - 11.00 h. Awards (5 years of existence of the organization)

11.00 h. - Discussion - Debate: Possibilities for improvement of treatment of patients with rare diseases in Macedonia

11.30 h. - 12.00 h. - Media statements

12.00 h. - 13.00 h. - Closing (coctail)



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Please contact us for additional information

Sincerely,

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In cooperation with:



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Информации за здружението:

Web page: <http://challenges.mk/>

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

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