



For the purpose of this year's event we published a booklet Rare Diseases – Third Edition that was distributed to all the participants. The booklet comprises several medical and pharmaceutical articles as well as presentations of all the associations that participated at the event and support and encourage the development of medicine for treating rare diseases. Associations of patients are an important source of valuable information about difficulties that rare disease patients deal with. Therefore, one of the main goals of associations of patients in collaboration with medical workers is to ensure better availability and adequate variety of medicine for treating rare disease patients.

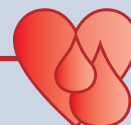
The event was sponsored by Celgene, Novartis, Genzyme in Aleksion. We kindly thank our sponsors.

Majda Slapar
Chairperson



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Blood Diseases**

Slovenia



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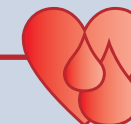
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28th February 2013
Cankarjev dom Ljubljana

**Association of Patients with
Blood Diseases**

Slovenia



RARE DISORDERS WITHOUT BORDERS 2013

Rare Disease Day has been marked with awareness-raising events in the countries of the European Union as well as outside Europe since 2008. For the second time in a row, the Association of Patients with Blood Diseases organised an event where the representatives of eleven different rare disease associations, professional medical workers and the representative of governmental organisations gathered. The event took place at the CD Club at Cankarjev dom on 28th February 2013 – the day also known as Rare Disease Day.

The honorary patron of
this year's event was the

President of the Republic
of Slovenia,
Mr Borut Pahor.



RARE DISEASES
WITHOUT BORDERS

RARE DISEASE DAY




Despite the fact that there is no umbrella organisation in Slovenia that would join and connect different associations of patients with rare diseases, we have decided to host the event of the European Rare Disease Day. The following is a list of participating associations:

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- Društvo bolnikov s krvnimi boleznimi
(Association of Patients with Blood Diseases),
- Društvo hemofilikov
(an association of patients with haemophilia),
- Društvo bolnikov z limfomom
(an association of patients with lymphoma),
- Združenje bolnikov z limfomom in levkemijo
(an association of patients with lymphoma and leukemia),
- Društvo bolnikov z gaucherjevo boleznijo
(an association of patients with Gaucher's disease),
- Društvo pljučnih in alergijskih bolnikov Slovenije
(Pulmonary and Allergic Patients Association of Slovenia),
- Društvo DEBRA Slovenije
(Dystrophic Epidermolysis Bullosa Research Association),
- Društvo bolnikov z redkimi tumorji prebavil GISTNET
(an association of patients with rare intestinal tumours),
- Društvo za cistično fibrozo Slovenije
(Cystic Fibrosis Association of Slovenia)
- Društvo bolnikov s fabryjevo boleznijo
(an association of patients with Fabry's disease),
- Društvo distrofikov Slovenije
(an association of patients with dystrophy),

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In Europe, a disease is defined rare when five or less out of 10,000 people are affected by it. There is no known cure for the majority of them, however, the treatment enables a longer life span and better quality of living.

The purpose of this year's event was to inform the representatives of the associations as well as the general public of the problems associated with rare diseases, managing rare hematologic diseases, medicine availability, placing rare diseases in the system of financing in our country and the directive about treatment abroad.

The event was divided into two parts. The first part was comprised of lectures as written on the invitation. They were introduced by one of the members of our association, Mrs Martina Mlakar. The second part enabled the representatives of the associations as well as other participants to pose relevant questions to all the lecturers regarding this year's theme.

Among the questions asked by the representatives of the associations of patients were the following:

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- What are the options for treating blood disease patients abroad?*
- What is the procedure of home treatment?*
- How to ensure a holistic treatment of rare disease patients?*
- How to ensure a long term financial support and interest of industry for rare diseases?*
- How far under way are the preparations for the national strategy on rare diseases?*
- How can the means from the national budget be obtained for associations to carry out their programmes?*
- When will a national centre for rare diseases be established, since it would enable patients as well as medical workers to obtain information about diagnostic procedures, about possible means of treatment and all other information concerning treatment?*
- How to ensure better awareness of GPs about rare diseases?*

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The questions were answered by doctors from the Department of Haematology, University Medical Centre Ljubljana and the representatives of the Health Insurance Institute of Slovenia.