

### Conference organizers:

the Ministry of Health of the Republic of Slovenia, the Association of Patients with Blood Diseases Slovenia and the Clinical Institute of Medical Genetics, UMC Ljubljana. The conference was attended by twelve patient associations that bring together patients with rare diseases, the Minister of Health and representatives of the Ministry of Health of the Republic of Slovenia, representatives of the Clinical Institute of Medical Genetics, UMC Ljubljana, professional medical staff, representatives of governmental and non-governmental organizations, representatives of pharmaceutical companies and the media.



From left - Mrs. Milojka Kolar Celarc and Mrs. Bernarda Kociper – Ministry of Health of the Republic of Slovenia and Mrs. Majda Slapar – Chairperson Association of Patients with Blood Diseases

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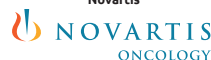
Majda Slapar – Chairperson

### The event was sponsored by:

Celgene, Podružnica v Sloveniji



Novartis



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Pfizer, Podružnica Ljubljana



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REPUBLIKA SLOVENIJA  
MINISTRSTVO ZA ZDRAVJE

20 let  
1995 – 2015



Društvo bolnikov  
s krvnimi boleznimi



## First National Conference on **RARE DISEASES** 2015 SLOVENIA Brdo Congress Centre



DAY-BY-DAY,  
HAND-IN-HAND



EURORDIS  
Rare Diseases Europe

On European Rare Disease Day, 27 February 2015, we organized the First National Conference on Rare Diseases in Slovenia at the Brdo Congress Centre, starting at 10:00.



Mrs. Milojka Kolar Celarc,  
*Ministry of Health of the  
Republic of Slovenia*

Honorary sponsor of the First National Conference on Rare Diseases was the President of the Republic of Slovenia, Borut Pahor.

Since 2008, all Member States of the European Union – on the initiative of the European Organisation for Rare Diseases EURORDIS – organise a conference held on Rare Disease Day, typically the last day of February (28 or 29 February) each year. Until 2012 no joint meetings for rare disease patient organisations had been organised in Slovenia – with the exception of individual meetings within associations of certain groups of patients. Therefore, in 2012 the Association of Patients with Blood Diseases Slovenia decided to independently organize a meeting on European Rare Disease Day, continuing the event in 2013 and 2014. We invited a number of rare disease patient organisations, for which this conference is foremost intended, professional medical staff, representatives of governmental and non-governmental organizations.

This year's slogan for Rare Disease Day "DAY-BY-DAY, HAND-IN-HAND" was published by the European Organisation for Rare Diseases EURORDIS, of which the Association of Patients with Blood Diseases Slovenia is a full legal member. Only in the way our slogan indicates can we overcome the difficulties that patients with rare diseases encounter in the course of treatment and during their everyday life.



In Europe, a rare disease is an illness only affecting up to 5 out of 10,000 people. Treatment for curing most rare diseases is not effective and is therefore aimed primarily at extending and improving the quality of life.

The aims of the First National Conference on Rare Diseases in Slovenia were to inform the general public of the problems associated with rare diseases, work plans and emphasize European initiatives, to present the modern Slovenian diagnostics concept of genetic and rare diseases and the assurance and consumption of medicines for rare diseases treatment, to present rare cancers, the conservation of fertility and the legal rights of patients with rare diseases; and to present in detail one of the rare diseases and the operation of the patient associations.

The following patient associations that bring together patients with rare diseases participated at the First National Conference on Rare Diseases:

the Association of Patients with Blood Diseases Slovenia, the Association of Haemophiliacs Slovenia, the Association of Patients with Lymphoma, Slovenian Lymphoma and Leukaemia Patient Association L&L, the Association of Patients with Gaucher Disease Slovenia, Dystrophic Epidermolysis Bullosa Research Association, Cystic Fibrosis Association of Slovenia, the Association of patients with Fabry's disease, the Association of Patients with Dystrophy, the Association of Slovenian Cancer Societies, Cancer

Patients' Association and the Huntington's Disease Society.

The Association of Patients with Blood Diseases published a booklet to accompany the First National Conference on Rare Diseases: – Rare Diseases – fifth edition, which was distributed to all the participants. The content of the booklet is rich, as it comprises several medical articles, the presentation of conference themes and the associations bringing together patients with rare diseases.

To facilitate the operation of patient associations in the field of rare diseases, it was agreed with the Ministry of Health of the Republic of Slovenia and the representatives of patients with rare diseases that a multiplier organisation, which will be called the Association of Slovenian Patients with Rare Diseases Societies, will be established as soon as possible.

Majda Slapar  
*Chairperson  
Association of Patients with Blood Diseases, Slovenia*

