ASSOCIATION OF PATIENTS
WITH BLOOD DISEASES
IN SLOVENIA

... since 1995

Mengeš 2017
ASSOCIATION OF PATIENTS WITH BLOOD DISEASES IN SLOVENIA

HUMANITARIAN ASSOCIATION OF CHRONIC PATIENTS

ASSOCIATION OPERATING IN THE PUBLIC INTEREST OF HEALTHCARE

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Marjana Božjak – secretary
Mihaela Uhan – treasurer
Jože Uhan, PhD – professional member
Matjaž Jurca and Brigita Avbelj – members
Since 1995, the Association of Patients with Blood Diseases in Slovenia has brought together patients and families of patients suffering from blood diseases – such as acute and chronic leukaemia, lymphomas, disseminated plasmacytoma, aplastic anaemia, MDS, and other rare blood diseases. In addition to patients themselves, members also include patients’ friends and medical professionals. The Association counts over 500 members from all over Slovenia and is a non-profit organisation that operates on the national level in the Republic of Slovenia and actively participates in the operations of similar international organisations.
**Association of Patients with Blood Diseases Slovenia since 1995**

The first and primary purpose for founding the Association was to help patients and their families overcome the problems they faced during treatment and afterwards, especially with bone marrow transplants in Slovenia and abroad. The Association’s activities were especially important for patients who underwent bone marrow transplants abroad, i.e. in London. A permanent link was established with the Slovenian embassy in London at the time, which offered help and support to patients during their treatment. Equally important were the help, support, gatherings with consultations for patients who found themselves on the path that we had already successfully walked. Right from the beginning, another important task of the Association was to provide patients with all the information about their disease, to inform them of the latest methods of blood disease treatment and to inform the public about the problems that patients with blood diseases face.

**Association of Patients with Blood Diseases Slovenia today**

The Association’s mission grew from initial honest ideas about patient gatherings, mutual help and support, selfless participation in the treatment process, spreading provision of information about diseases, and permanent accessibility to patients and their families was complemented and became an essential part of the treatment process. The Association plays an important role in the process of raising awareness about the diseases among the patients and the general public, while it selflessly incorporates its special social programmes into the processes of work, medical, social, and financial rehabilitation of the patients and their families during and after the treatment.

Our aim is to offer the patients all the necessary help to overcome the long-lasting treatments, help them to better understand the situation in which they have found themselves by offering our own experiences, and use the social programmes to provide or at least partially replace what the patients and their families lost during the treatment period.

To ensure continuous and uninterrupted operation of the Association and the implementation of the programmes, the Association has for the last 20 years had its head office in
Mengeš, at the address Slovenska cesta 30. Throughout this time, the patients and their families have had the option of talking individually to a representative of the Association – a former patient – about all the issues you can only talk about with someone who has had the same disease, who has gone through the entire treatment process, and who has beaten the disease. In the 22 years since our foundation, many of our members and members of related haematoma patients’ associations received their first information from former patients in our office.

In 2006, the Ministry of Health of the Republic of Slovenia awarded us the status of a humanitarian organisation of chronic patients and the status of an association operating in the public interest of healthcare for our implementation of our special social programmes. As many as 19 years ago we started participating in the co-financing programme of the Foundation for Financing Disability and Humanitarian Organizations in the Republic of Slovenia (FIHO).

The Association regularly implements special social programmes which focus on supporting patients and their relatives during and after treatment, on informing patients about their disease and treatment options, on ensuring state-of-the-art medications for the treatment of blood diseases, and especially on maintaining newly acquired health. All this is ensured through the implementation of the special social programmes.

**Association’s programmes**

1. Preventative social programmes for maintaining health, improving the quality of life, and prevention of the negative consequences of treatment encompass:
   - co-financing of medical or physiotherapy treatment;
   - special social programmes for patients at social, financial, and medical risk;
   - social assistance.

   Only Association members, i.e. patients and former patients, can benefit from the programme.

   In the 1999–2017 period, a total of 511 members of the Association benefited from the programme for the co-financing of medical or physiotherapy treatment, which means 28.4 members or former patients on average per year.

   From 1999 until 2010 when we discontinued this
programme, we bestowed one-time aid for education purposes to 327 individuals. This programme was used both by the members of the Association and their children.

In the 1999–2017 period, social assistance was granted to 57 members of the Association or former patients in accordance with the applicable Rules on the implementation of the programme.

2. Co-financing the consequences of treatment with stem cell transplant

The aggressive chemotherapy and radiotherapy treatment and the consequences of the stem cell transplant treatment can cause new health complications that significantly lower the patient’s quality of life and which are not entirely covered by the Health Insurance Institute of Slovenia. The services include co-financing of dental, ophthalmological, orthopaedic, endocrinologic, or other medical services at selected outpatient clinics, health resorts, and physiotherapy clinics across Slovenia.

3. Patient to Patient: Psychological Help and Support programme

To ease the troubles of patients and their families when coming to face the disease during hospitalisation and based on the approval from the management of the Department of Haematology at the University Medical Centre Ljubljana (UMC Ljubljana), we have been implementing the Patient to Patient: Psychological Help and Support programme since 2008. The programme is implemented at the Department of Haematology of UMC Ljubljana once a week throughout the entire year, on Thursdays between 4 PM and 8 PM. In that period, all the patients being treated at the department and their families can talk to a former patient about all the non-medical questions that arise during the treatment process. The programme is implemented by four members of the Associations, former patients who suffered from one of the blood diseases and who successfully completed the entire treatment process.

In 2016, an increase in patients seeking this kind of help spurred us to extend the implementation of the programme to the Novo Mesto General Hospital and UMC Maribor. At the Novo Mesto GH, the programme is implemented once
a month by a member of the Association (former patient), while the programme is implemented at UMC Maribor twice a month, i.e. also by a member of the Association who is a former patient.

Since the foundation of the Association and until 2014 when the patients being treated at the old Department of Haematology on the sixth floor of UMC Ljubljana moved to new medical facilities, we always opened our ears and our hearts to the requests by medical professionals at the Department of the Haematology of UMC Ljubljana as well as the needs of their patients. Subject to our financial abilities, we donated the most urgently needed medical devices and technical equipment to ensure better quality of treatment and ease the patients’ stay at the hospital during treatment.

4. Publication of professional literature and Association’s publications

In the 22 years of its operation, the Association collaborated with many medical and other experts to publish numerous guides for patients dealing with different blood diseases and their treatments. We published proceedings of lectures held on the international Day of Rare Diseases and on the Patients’ and Families’ Day, pamphlets on international conferences on rare diseases in Slovenian and English, an Almanac on the occasion of the 15th and 20th anniversary of the Association, a book of patients’ stories: Stories from the Sixth Floor, and presentation posters in Slovenian and English for international cooperation purposes.

The purpose of the programme is to give patients and their families as much information as possible about the blood diseases, the course and method of treatment, the use of modern medications and the consequences of the treatments, about living with the diseases, psychological support and a suitable and healthy diet. By publishing our publications, we attain our goal of raising the patients’ awareness and helping improve their medical, social, and work rehabilitation after the treatment.

Such guides and manuals for patients are not published by any public institutions or publishing houses, which makes them a very important information source for patients and their families during the treatment process, in addition to information they receive from medical personnel.
### Overview of the publications of the Association of Patients with Blood Diseases in Slovenia from 1999 to 2017.

<table>
<thead>
<tr>
<th>Year</th>
<th>Title of publication</th>
<th>Type of publication</th>
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<tbody>
<tr>
<td>2017</td>
<td>Patient to Patient – Psychological Help and Support</td>
<td>Guide for patients</td>
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<td>2017</td>
<td>Chronic Myeloid Leukaemia, Revised edition</td>
<td>Guide for patients</td>
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<td>2017</td>
<td>Third National Conference on Rare Diseases 2017 Slovenia – Brdo Congress Centre</td>
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<td>2017</td>
<td>Rare diseases 2017 – 7th edition</td>
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<td>2016</td>
<td>Stem Cell Transplant</td>
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<td>2016</td>
<td>Second National Conference on Rare Diseases 2016 Slovenia – Brdo Congress Centre</td>
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<td>2016</td>
<td>Rare diseases 2016 – 6th edition</td>
<td>Guide for patients</td>
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<td>2016</td>
<td>Rare Diseases Day 2016</td>
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<td>20 years 1995 – 2010</td>
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<td>2015</td>
<td>First National Conference on Rare Diseases 2015 Slovenia – Brdo Congress Centre</td>
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<td>2013</td>
<td>Acute leukaemia and stem cell transplantation – Completed instructions for patients</td>
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<td>2013</td>
<td>Stories from the sixth floor</td>
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<td>2013</td>
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<td>2012</td>
<td>Patients’ and families’ day, October 2012</td>
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<td>2012</td>
<td>Less common diseases 2012</td>
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<td>15 year of the “Association of Patients with Blood Diseases” 1995–2010</td>
<td>Proceedings</td>
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<td>2009</td>
<td>20 years of stem cell transplantations in Slovenia – Patients’ Day 2009</td>
<td>Guide for patients</td>
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<td>Presentation of the Association of Patients with Blood Diseases</td>
<td>Proceedings</td>
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<tr>
<td>1999</td>
<td>Treatment with stem cell transplantation from an unrelated donor</td>
<td>Guide for patients</td>
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<td>1999</td>
<td>Stem cell transplantation in adults – Instructions for release</td>
<td>Guide for patients</td>
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<tr>
<td>1997</td>
<td>Presentation of the Association with application form</td>
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We are very proud to have published the ALMANAC OF THE ASSOCIATION OF PATIENTS WITH BLOOD DISEASES IN SLOVENIA in 2010, on the Association’s 15th anniversary, and in 2015, on the Association’s 20th anniversary. The Almanac served to present our successful work in text and images. In 2013, we also published a book of patients’ stories called Stories from the Sixth Floor. The sixth floor of the Department of Haematology at UMC Ljubljana is the floor where patients with blood diseases were treated until 2014, when they were finally relocated after long years of hard work by the Association of Patients with Blood Diseases in Slovenia to the newly equipped rooms on the ground floor of UMC Ljubljana. The book contains stories of patients who were prepared to share their experiences of successfully beating their disease with all those who face such diseases today. It is a valuable book that should also be read by many doctors and other medical personnel to help them understand what the patients go through when diagnosed with cancer.
How to access our publications

The Association’s publications are available at the Department of Haematology, UMC Ljubljana, as well as at the haematology clinic and day hospital at the Polyclinic, Njegoševa 4, Ljubljana, and in all hospitals in Slovenia where patients with blood diseases are treated. All printed materials are also available at the Association’s office in Mengeš and can be ordered by phone or by e-mail. All the above publications are also available in electronic form on the Association’s website.

5. Active participation and collaboration in similar international organisations

The programme allows us to keep track of international positions on working with and providing information to patients in the field of haematology, and to better inform the patients with blood diseases of the latest treatment options and support options for dealing with current issues.

Since 2010 we have regularly and actively participated at Patients’ and Families’ Days at EBMT (European Group for Blood and Marrow Transplantation) congresses.

Since 2011 we have also been actively participating at the Partners for Progress congresses.

Since February 2014, we have been a full member of the EURORDIS, Rare Diseases Europe Association.

We are also a member of the Myeloma Euronet – European Network of Myeloma Patient Groups.

At the initiative of the European Patient Forum with head office in Brussels, the Association is also registered with the European Registry of Patients with Blood Diseases.

6. Information system, internet, FB, website, personal consultations – by phone, by e-mail, talks with patients and their families at the Association’s office

The Association of Patients with Blood Diseases in Slovenia shares information through personal consultations, phone conversations, and electronic correspondence, as well as through talks with patients and their families at the Association’s office. There, the patients and their families can talk to a member of the Association, who is also a former patient, and access all the Association’s publications.

In 2014, we set up a new, updated website. In addition to basic information about the Association’s activities, our
website, www.drustvo-bkb.si, also contains information about all the events organised by the Association, news and professional articles on blood diseases. We also have a special section *Ask a doctor*, where the patients can find all the necessary information on their disease and its treatment.

In 2014, we also opened a Facebook page for the Association.

We also set up our stands and notice boards at the Department of Haematology, UMC Ljubljana, and at the haematological day clinic at the Polyclinic in Ljubljana to improve the dissemination of information and access to our publications. All other hospitals in Slovenia treating patients with blood diseases also have access to all the information.

7. Organised gatherings and promotion of a healthy lifestyle

In all our years of existence, we paid special attention to socialising between patients, which is of great importance for improved psychophysical well-being of our members. We organised 45 excursions in Slovenia and abroad and 20 New Year’s gatherings.

In September 2015, we introduced monthly hikes under the motto *For health*. All organised meetings are always well-received by the members of the Association.

We also support the participation of individual members of our Association at international athletic competitions of transplant patients and help them financially.
8. European Day of Rare Diseases – 28 February

In 2012 on the European Day of Rare Diseases, which is celebrated every year on 28 or 29 February, the Association of Patients with Blood Diseases in Slovenia first organised an independent meeting of representatives of all associations of patients with rare diseases. The meeting was attended by numerous representatives of patients’ associations, representatives of medical experts, governmental and non-governmental organisations, pharmaceutical companies, and the media. The first meetings were held at the Cankarjev dom conference hall in Ljubljana. Similar meetings on the Day of Rare Diseases are always organised in all member states of the EU. We continued to organise the meetings in 2013 and 2014.
The 3rd National Conference on Rare Diseases was held in Ljubljana, on February 28, 2017. The conference was organized by the Ministry of Health of the Republic of Slovenia and the Association of Rare Diseases Slovenia and held under the patronage of Slovenian president, Mr. Borut Pahor.

The meeting was attended by the members of various organizations, including together rare disease patients, representatives of professional medical staff, representatives of governmental and non-governmental organizations, representatives of pharmaceutical companies, as well as media.

Health Minister Milojka Kolar Celarc has highlighted the concerns of the Ministry for rare disease and announced an even more active implementation of their work goal in the future, which will be supported by an active working group, composed of medical experts and patient representatives, the aim of which is to achieve a common goal – a satisfied patient that is an active and valued member of society; we need a comprehensive system of treatment of rare diseases, which can only be achieved through cooperation and understanding of difficulty of the rare case.

Following the opening speech by representatives of the Ministry of Health and the president of the Association of Rare Diseases Slovenia, the first part of the conference consisted of various presentations. A list of the lectures were the following: classification of rare diseases, psychological support and "Patient – Patient" counseling is presented as one of the most important tasks ahead.

The event was moderated by representatives of the Ministry of Health and the president of the Association of Rare Diseases Slovenia, prof. Jože Faganel and Ms. Majda Slapar. The conference was closed by the panel discussion, which highlighted the importance of the slogan "Patient – Patient counseling". Speakers agreed with the opinion, shared by the president of the Association for Rare Diseases Slovenia, prof. Janez Fage, who pointed out that "the engine of progress lies deeply in the thought of not giving in to the disease, but bringing the experiences of patients on the area of rare disease to the general public in the best possible manner.

With this in mind, and together with numerous participants, he firmly endorsed the slogan of the Rare Disease Day 2017 – "Research, possibilities are limitless."”

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In 2015, we organised the 1st National Conference on Rare Diseases in collaboration with the Ministry of Health of the Republic of Slovenia and the Clinical Institute of Medical Genetics of UMC Ljubljana, which was held on 27 February at the Brdo pri Kranju Congress Centre.

In 2012, the honorary sponsor of the meeting was Barbara Miklič Türk, then-president’s wife, who also attended the meeting.

In 2016, the 2nd National Conference on Rare Diseases was held on 29 February at Brdo pri Kranju. It was organised by the Ministry of Health of the Republic of Slovenia and the Society of Rare Diseases of Slovenia. Our Association actively helped prepare the programme and organise the meeting as a co-founder of the Society and its member with the status of vice-president. In 2017, the 3rd National Conference on Rare Diseases was held on 28 February at Brdo pri Kranju.

Every year, on the occasion of the Rare Diseases Day meeting, the Association publishes a booklet entitled *Rare Diseases* to present the lectures that were given at the conference, publish a list of the latest medications for treatment of rare diseases, and present the patient associations that participated in the annual conference.

The honorary sponsorship of the meetings in 2013, 2014, 2015, 2016 and 2017 was taken on by the President of the Republic of Slovenia, Borut Pahor.

*Day for patients and their families*

Every year at the beginning of organised gatherings, we organised or participated in a meeting of patients on Patients’ and Families’ Days within the scope of the Haematology and Transfusion Doctors Section organised by the Haematoma Association and the Transfusion Medicine Association of the Slovenian Medical Society. However, over the last few years we have come to the agreement that the meeting will be organised by a different association each year. The programme of the meeting includes experts’ lectures in the fields of blood diseases, treatments, treatment of consequences of chemo- and radiotherapy, diet, fertility, psychological support for patients, patients’ rights under health and pension insurance, and other topics of direct interest to patients with blood diseases.
Organisation of lectures

Every year, we organise several professional and general lectures as part of the regular programme of our Association.

Association’s goals:

– continued implementation and extended scope of all our regular programmes, with the focus on implementation of the special social programmes;
– active collaboration with medical professionals on solving current problems of the patients with blood diseases;
– publication of guides for patients and papers about blood diseases and latest treatment options as well as other materials produced by the Association;
– informing patients about the latest developments in the field of blood disease treatment in Slovenia and abroad;
– informing patients of their rights under health and pension insurance;
– consultations and support in obtaining the status of a patient after stem cell transplantation;
– supporting campaigns to increase the number of volunteer stem cell donors;
– signing the petition for equal personal income compensation for stem cell donors and blood donors;
– active participation and collaboration in similar international organisations;
– active participation in the Society of Patients with Rare Diseases of Slovenia, where we hold the vice-president function;
– annual collaboration in the organisation of the meeting at the European Day of Rare Diseases;
– active participation in the Coordination Work Group for ensuring coordination and implementation of the Work Plan in the Field of Rare Diseases in Slovenia under the auspices of the Ministry of Health of the Republic of Slovenia;
– collaboration with the Oncology and Haematology Department of the Paediatric Clinic at UMC Ljubljana;
– active participation at experts’ consultations and round tables in the field of oncological diseases, their treatment and health policy;
– active collection of donations and sponsorship funds for the implementation of all regular programmes of the Association and its continued operation;
– collection of funds based on calls for tenders of the foundation and ministries, and preparation of reports on the use of the funds received.

The Association of Patients with Blood Diseases will follow all the set goals, supplement its programmes and activities and ensure successful continuation of our long-standing humanitarian path in order to support the members of our Association, their family members and patients who are being treated for one of the blood diseases.