

2013

## Výročná správa EBMT.SK



SLOVENSKÝ KLUB  
PACIENTOV PO  
TRANSPLANTÁCII  
KRVOTVORNÝCH BUNIEK



*Representatives of Slovak Patient and Family Group on the meeting with President EBMT Dr. Alejandro Madrigal and Dr. Jane Apperley during The 7<sup>th</sup> Patient and Family Day in London 2013*



*European Group for **B**lood and **M**arrow Transplantation .*

*Slovak **K**(C)lub of patients after stem cell transplantation*



## 1. ESTABLISHMENT OF THE ASSOCIATION

**Establishing meeting** EBMT.SK was within **4th Patient and Family Day in Vienna 20th March 2010**. Association EBMT.SK is registered as independent non-governmental organization at Home Office SR, nr. VVS/1-900/90-35540, ID Nr: 42073073 since 7th April 2010. Patronage of EBMT.SK by EBMT has been **supported by Prof. Niederwieser, Prof. Gluckman, Dr. Koza** as well as **Mrs. Anita Waldmann**.

### GOALS OF THE ASSOCIATION:

- to **advocate patients** undergoing stem cell transplantation (SCT), to **help to improve patients' quality of life** during the time of hospitalization, treatment and after that
- to improve a flow of **information**, to raise an awareness and to **educate** medical and non-medical society as well as general public about the latest treatment possibilities within SCT and diseases leading to SCT
- to create **co-operational network** of regional clubs for patients post SCT operating by Slovak centers for transplantation
- to organize for patients post SCT and their relatives the **educational, tourist and cultural activities**
- to get **involved in EBMT** (The European Group for Blood and Marrow Transplantation) **activities** under methodical supervision of EBMT Outreach Committee
- to **support a research**, clinical studies and special therapeutical treatment procedures within SCT area in order to provide optimal treatment for all possible patients as well as to defend human dignity and life from the moment of conception

## 2. THE MAIN ACTIVITIES

- » organizing of meetings for patients undergoing SCT and after SCT and their relatives
- » sharing and preparing of guidelines in treatment
- » supporting of education of patients and their relatives,
- » a consultancy with professionals, doctors and specialists
- » organizing of recondition stayings for patients after SCT
- » a research and publication activity
- » supporting of the National register of voluntary bone marrow donors



### 3. PROJECTS REALIZED IN 2013

#### RECONDITION STAYING FOR PATIENTS AFTER SCT

The goal of **recondition** staying was to offer a possibility of **common meeting** for patients after SCT in order to **build up good relations** between them. All participants could get to know each other better and could be an inspiration how to deal with the treatment and period of convalescence for the others. The patients after SCT with the help of professionals could **improve their health**.

Realization: *Our recondition staying took part in Bardejovske Spa in Bardejov from 17<sup>th</sup> September to 22<sup>nd</sup> September 2013. Thirty transplant patients (in the time range 0,5 – 18 years after stem cell transplantation) and their 16 relatives participated in 6 days' staying in spa.*

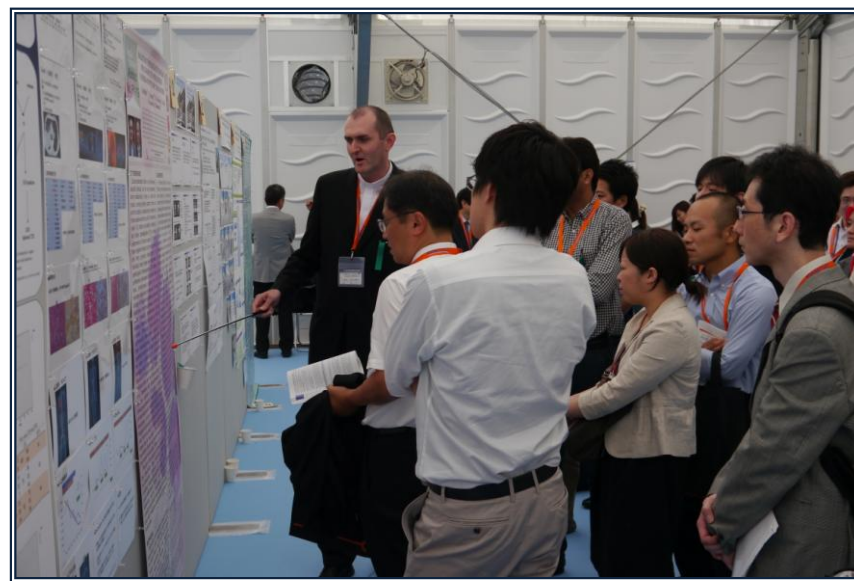
*We started with a dinner and an introduction meeting. Next day all patients after SCT had medical examination and a several medical procedures were suggested to each of them for a whole staying. There was a possibility to take an individual physical training (exercise with fit balls, swimming (individual, group), hydrotherapy, massages, reflex massages, inhalation, drinking cure, salt cave. Except the all medical procedures and catering all participants had also a free time for various sports and cultural activities in surrounding countryside. It was a pleasant time for all because they spent it with the people who passed the same journey after transplantation and they understand each other even without words.*



## RESEARCH ACTIVITY

The target of our research activity is to engage in education and research activity of those fields which can be useful for transplant patients.

Realization: *In cooperation with Comenius University, University hospital in Bratislava and Faculty hospital in Trenčín one of our transplant patients presented the results of the research of the topic: „Malignant proliferative disorder of leukocytes preceded by father-son psychic traumatism and impaired trustworthiness/functionality of a social relationship “father–son” at an international conference - The 11th Annual Meeting of Japanese Society of Medical Oncology in Sendai, Japan on 29<sup>th</sup>-31<sup>th</sup> August 2013.*



## PROJECT PATIENTS TO PATIENTS

The aim of the project is to provide a **support to the patients** from the patients primarily by individual meetings with transplant patients, **in guiding the treatment**, group meetings within the club activities of the association. The patients also have a possibility to share their treatment's story through the Association's web site.

Realization: *In 2013 a several individual meetings of the patients took place in Bratislava, Trenčín, Partizánske, Bardejov and a general Assembly in Bratislava.*

*EBMT.SK bought a part of the equipment for new transplant rooms in Transplant Unit in University hospital of St. Cyril and Method in Bratislava for acquired financials.*



## ASSOCIATION'S WEB SITE

The goal is to run the **information portal**, an online discussion and a **forum for patients and specialists**.

Realization: *Web site [www.ebmt.sk](http://www.ebmt.sk) updates information about bone marrow transplantation, explains the procedure and steps of treatment, informs about goals, mission and activities of association and offers a place for the social, law and psychological consultancy.*

## 4. THE ECONOMY OF THE ASSOCIATION

**Balance** (cash + current account) **at the end of 2012:** **3958,85 €**

**Income of EBMT.SK in 2013:** **7496,42 €**

Finacial donations from individuals	650 €
Finacial donations from other organizations	4000 €
Financials from assign 2% of income tax	2845,93 €
Interests	0,49 €

**Expenses EBMT.SK in 2013:** **7157,03 €**

Realized projects	6424,23 €
Recondition staying 2013	4820,10 €
Recondition staying 2014	1400 €
Participation at conferences (KPO, JSMO)	654,37 €
Overhead costs, post office charges, registration of assign 2%	72,06 €
Account charges	6,37 €

**Balance** (cash + current account) **at the end of 2013:** **4298,24 €**

Scheme of expenses for 2014:

- 5500 EUR (recondition staying for patients, meetings, participation at conferences, overhead costs)

## 5. MEMBERS OF THE ASSOCIATION

The structure of the association in 2013:

**Administration board:** Dr. Martin Mistrík, PhD., Dr. Eva Bojtárová, PhD., Miroslav Hrianka, PhD., Dr. Viera Jarolíková, Dr. Silvia Mikušová, Mgr. Miroslava Harišová, Dr. Juraj Sedláček, PhD., Bc. Ján Tuleja

**President of association:** Mgr. Miroslava Harišová

**Vice-President of association:** Dr. Silvia Mikušová

**Chief controller:** Mgr. Ivana Chudová

EBMT.SK has actually 94 members.



## 6. THANKS

We would like to give thanks to all willing donors and volunteers for their financial and material support of the projects prepared and realized on behalf of the Association EMBT.SK in 2013.

### **Our partners:**

Cancer League (member of The European Cancer Leagues)

Sanofi Avensis

Dr. Miloš Trn M.D.

Mr. Marián Sarňák, ThLic.

Students of Biochemistry of Comenius University in Bratislava

Slovak Nordic Walking Association

**THANKS!**

Miroslava Harišová, President of EBMT.SK



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