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NON-GOVERNMENTAL WORLD MARROW DONOR REGISTRIES AND WESTERN BALKAN MARROW DONOR REGISTRIES (2021 YEAR)

Abstract

Background: The Western Balkan countries include Albania, Bosnia and Herzegovina, Kosovo, Montenegro, Republic of North Macedonia, and Serbia. The Western Balkan region is the last region to be fully integrated into European Union and many of the indicators classify these countries near the bottom of European countries. From the six countries of the Western Balkan region, only two marrow donor registries are included in the World Marrow Donor Registry (North Macedonia and Serbia), and one is in preparation (North Macedonia).

Aim: We aimed to investigate the current non-governmental world marrow donor registries and marrow donor registries in the Western Balkan countries as of 2021.

Methods: We visited all of the websites at World Marrow Donor Association looking for any information about the organizational structure as of June 2021. The Western Balkan marrow donor registries were identified in the register of the World Marrow Donor Association as of July 2021.

Results: We identified 196 marrow donor registries in total, from which 140 (71%) were governmental and 56 (29%) were non-governmental.

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The number of registries in several countries are 100% non-governmental, in several countries have more than half of the registries are non-governmental or are equal in number between non-governmental and governmental registries, and in few countries there are equal or smaller amounts of non-governmental than governmental registries. The rest of the countries have only governmental registries. There are two functional marrow donor registries included in World Marrow Donor Registries from the Western Balkan: MBMDR - Macedonian Bone Marrow Donor Registry from North Macedonia and Serbian Bone Marrow Donor Registry from Serbia. There is one more marrow donor registry in preparation from Scientific Foundation SPIROSKI as a part of the non-governmental sector in North Macedonia. Currently there are no marrow donor registries in Albania, Bosnia and Herzegovina, Kosovo, or Montenegro.

Conclusion: We can conclude that in most of the Western Balkan countries (Albania, Bosnia and Herzegovina, Kosovo, and Montenegro) there are no marrow donor registries, and only in North Macedonia and Serbia there are governmental marrow donor registries. There is a need to develop more non-governmental and governmental marrow donor registries in the Western Balkan countries.

Keywords: Marrow donor registry; Western Balkan; nongovernmental; governmental.

Introduction

The Western Balkan Countries include Albania, Bosnia and Herzegovina, Kosovo, Montenegro, Republic of North Macedonia, and Serbia. The European Union (EU) has developed a policy to support the gradual integration of the Western Balkan countries into the European Union. Montenegro, Serbia, the Republic of North Macedonia, and Albania are official candidates. Accession negotiations and chapters have been opened with Montenegro and Serbia, and Bosnia and Herzegovina and Kosovo are potential candidate countries [1].

The Western Balkan region is the last area to be fully integrated into the European Union, and many of the indicators classify these countries as near the bottom.

World Marrow Donor Association (WMDA) is made up of organisations and individuals, promoting global collaboration and best practices for the benefit of stem cell donors and transplant patients. WMDA was informally initiated in 1988 by three pioneers in the field of transplantation: John Goldman (United Kingdom), E. Donnall Thomas (United States), and Jon J. van Rood (the Netherlands). This led to the foundation of WMDA in 1994. In 2007, the WMDA became one of the founding members of the Worldwide Network for Blood and Marrow Transplantation (WBMT). WBMT is a non-profit scientific organisation which aims to promote excellence in stem cell transplantation, donation, and cellular therapy. The WBMT has an official relationship with the World Health Organization. The other three founding organisations of the WBMT are the European Society for Blood and Marrow Transplantation (EBMT), the Center for International Blood & Marrow Transplant Research (CIBMTR), and the Asian Pacific Blood and Marrow Transplantation Group (APBMT). In 2017, WMDA took over the activities of Bone Marrow Donors Worldwide (BMDW) and the NetCord Foundation. WMDA is led by the WMDA Board and committees, whose members are all experts in their fields. Day-to-day activities are carried out by the WMDA office by a team of professionals based in Leiden, the Netherlands [2].

Of the six countries in the Western Balkans, only two marrow donor registries are included in World Marrow Donor Registry (North Macedonia and Serbia), and one is in preparation (North Macedonia) [2].

We aimed to investigate current non-governmental world marrow donor registries and marrow donor registries in the Western Balkan countries (2021 Year).

Methods

We visited all websites at World Marrow Donor Association (WMDA), looking for any information about the organizational structure and found many different approaches. Some of the websites are without any information about their organizational structure, some of the websites are only in the local language, some of the websites declare mixed organizational structure (governmental and non-governmental), some websites have traditional non-

governmental organizations (i.e., Red Cross), and are also defined as governmental organizations, and some of the websites state that they have a charitable structure (which was classified as non-governmental organization). We categorized all websites with a clear definition of foundation and/or charity organization as foundations.

Western Balkan marrow donor registries were identified from the register of the World Marrow Donor Association (WMDA) [3] in July 2021.

Results

We identify 196 marrow donor registries in total, from which 140 were governmental and 56 were nongovernmental (Table 1). The number of registries in several countries are 100% non-governmental (Armenia, Lithuania, Luxembourg, Nigeria, United Kingdom, and the United States of America). Several countries have more than half non-governmental registries (India, Mexico, and South Africa). Equal number of non-governmental and governmental registries are in several countries (Australia, Austria, Chile, North Macedonia, Slovakia, Thailand, and The Netherlands). The group of countries with fewer non-governmental than governmental registries are Cyprus, Czech Republic, Germany, Hong Kong, and Spain. The rest of the countries have only governmental registries (Table 1).

Table 1

Current structure of foundations and charity organization (in alphabetical order) of the World Marrow Donor Association (WMDA) (July, 2021)

Country	Governmental	Foundation (Charitable)	Website of the Foundation (Charity) [reference]	N
Andorra	1	0		1
Argentina	2	0		2
Armenia	0	1 (100%)	Armenian Bone Marrow Donor Registry Charitable Trust [4]	1

Australia	2	2 (50.0%)	ABMDR is a public company limited by guarantee under the Australian Corporations Law and a registered charity under the Australian Charities and Not-for-profits Commission Act 2012 (Cth) [5]; Mater Foundation is registered as a charity with the Australian Charities and Not-for-profits Commission ABN 96723184640 [6]	4
Austria	2	2 (50.0%)	Red Cross Blood Transfusion Service of Upper Austria [7]; Geben für Leben - Leukämiehilfe Österreich [8]	4
Belgium	6	0		6
Brazil	8	0		8
Bulgaria	2	0		2
Canada	0	5	Canadian Blood Services Stem Cell Registry. Canadian Blood Services (Charitable Registration No. 870 157 641 RR0001) [9]; Canadian Blood Services' Cord Blood Bank (Charitable Registration No. 870 157 641 RR0001) [10]; Hema-Quebec Public Cord Blood Bank Héma-Québec is a non-profit organization that supplies blood and other biological products of human origin to hospitals for the Canadian province of Quebec. [11]; Hema-Quebec Stem Cell Donor Registry [12]; Victoria Angel Public Cord Blood Bank [13]	5
Chile	1	1 (50.0%)	Fundación de Beneficencia Pública DKMS [14]	2
China	4	2 (33.4%)	The Data Bank of Chinese Hematopoietic Stem Cell Donors, also known as the China Marrow Donor Program (CMDP), is a non-profit organization under the umbrella of the Red Cross Society of China (RCSC). [15]; Beijing New Sunshine Charity Foundation [16]	6
Colombia	2	0		2
Croatia	2	0		2
Cyprus	2	1 (33.4%)	Karaiskakio Foundation is a non – profit organization established with the sole purpose of organizing a volunteer Bone Marrow Donor Registry. [17]	3

Czech Republic	2	1 (33.4%)	The Umbilical Cord Blood Bank of the Czech Republic was established as a non-profit donor project of the Institute of Hematology and Blood Transfusion in Prague. Its mission is to ensure the collection, processing, examination and freezing of donated umbilical cord blood. [18]	3
Denmark	2	0		2
Finland	0	2 (100%)	The Blood Service is a part of the Finnish Red Cross. We are a not-for-profit organisation, and our prime concern is what is best for the patient. [19]; Stem Cell Registry [20]	2
France	4	0		4
Germany	8	2 (20.0%)	The DKMS Stiftung Leben Spenden (Foundation for Giving Life) exclusively and directly pursues non-profit and charitable purposes. [21]; DKMS Registry gGmbH [22]	10
Greece	6	0		6
Hong Kong	2	1 (33.4%)	The Hong Kong Red Cross began its voluntary, non-remunerated blood donation programme in 1952. [23]	3
Hungary	1	0		1
India	1	7 (87.5%)	Be The Cure Registry by Jeevan Stem Cell Foundation [24]; DATRI is a Not-for-Profit organization that was founded in 2009 with a mission to save lives of those suffering from life threatening fatal blood disorders like Blood Cancer, Thalassemia, Leukaemia, Aplastic Anaemia, Sickle Cell Anaemia etc. [25]; DKMS BMST Foundation India [26]; GENE BANDHU is a not for profit Non-Governmental Organization (NGO) located in New Delhi, India. [27]; Jeevan Stem Cell Foundation [28]; The MDR(I) is India's first NGO which maintains computerised database of voluntary, -unrelated stem cell donors and facilitates blood Stem Cell transplants for patients with life-threatening blood diseases. [29]; The Arjan Vir Foundation [30]	8
Iran	5	0		5
Ireland	1	0		1
Israel	6	0		6
Italy	19	0		19
Japan	13	0	In preparation	13

Korea	3	0		3
Lithuania	0	1 (100%)	Since 2002 a non-profit, non-government organization COHP 'Kraujas' unites patients with oncohematological diseases, their relatives, medicine specialists and everyone who supports the ideas of organisation's activities, volunteering as well as bone marrow and blood donation [31]	1
Luxembourg	0	1 (100%)	The Stefan Morsch Foundation, based in Birkenfeld in Rhineland-Palatinate, is Germany's first stem cell donor center. It is named after Stefan Morsch, son of the two founders Hiltrud and Emil Morsch, who was the first European to have a stem cell transplant with a non-related donor. [32]	1
Malaysia	1	0		1
Mexico	2	3 (60%)	Be The Match®, operated by the National Marrow Donor Program® (NMDP), is a non-profit organization that's dedicated to helping every patient get the life-saving transplant they need. [33]; Mexican BMDR – DONORMO [34]; Mexican BMDR - DONORMO (CORD) – BACECU [35]	5
New Zealand	1	0	New Zealand Bone Marrow Donor Registry [36]	1
Nigeria	0	1 (100%)	The Bone Marrow Registry in Nigeria ("BMRN") is a not-for-profit organization based at the College of Medicine, University of Nigeria Teaching Hospital, Enugu. [37]	1
North Macedonia	1	1 (50%)	Scientific Foundation SPIROSKI, in preparation [38]	2
Norway	1	0		1
Paraguay	1	0		1
Peru	1	0		1
Poland	3	2 (66.7%)	Against Leukemia Foundation (ALF), Warsaw [39]; Fundacja DKMS [40]	5
Portugal	1	0		1
Qatar	1	0		1
Romania	1	0		1
Russian Federation	7	0		7
Saudi Arabia	4	0		4

Serbia	1	0		1
Singapore	2	0		2
Slovakia	1	1 (50%)	It was founded in 1997 as a civic association. Based on the permission of the Ministry of Health of the Slovak Republic, it operates laboratories authorized to process and store stem cells from umbilical cord blood, umbilical cord tissue and bone marrow. [41]	2
Slovenia	2	0		2
South Africa	1	2 (66.7%)	Registered as a non-profit company and a Section 18A Public Benefit Organisation (Reg No 2013/152553/08, 004-003 NPO), the SABMR is governed by a dedicated Board of specialist professionals. [42]; DKMS Africa is the trading name of DKMS Foundation NPC registered in South Africa. Reg. No: 2000/008979/08; VAT Reg. No: 4350236958; Non-Profit Organisation Reg. No: 020-728-NPO; Public Benefit Organisation (section 18A) Ref. No: 130000158 in Terms of Section 18A (2) of the Income Tax Act, No. 58 of 1962. [43]	3
Spain	6	2 (33.4%)	Andalucia Cord Blood Bank (Malaga). Registered at the Registro de Fundaciones Privadas de la Generalitat de Catalunya with number 424. Classified by Order of the Justice Counselor on 10th April 1989. NIF: G-58734070 [44]; Spanish Bone Marrow Donors Registry (REDMO). Registered at the Registro de Fundaciones Privadas de la Generalitat de Catalunya with number 424. Classified by Order of the Justice Counselor on 10th April 1989. NIF: G-58734070 [45]	8
Sweden	2	0		2
Switzerland	4	0		4
Taiwan	7	0		7
Thailand	1	1 (50%)	Thai National Stem Cell Donor Registry [46]	2
The Netherlands	1	1 (50%)	Matchis is a Dutch foundation that enables patients with leukaemia and other severe blood disorders to receive stem cell transplantation, by finding a matching donor as quickly as possible. [47]	2
Turkey	4	0		4

Ukraine	1	1 (50%)	Charitable Foundation "Ukrainian Register of Bone Marrow Donors" - created to help find a non-family donor for patients with leukemia and other serious blood diseases that require bone marrow transplantation. [48]	2
United Kingdom	3	3 (100%)	Anthony Nolan. Anthony Nolan is a registered charity no 803716/SC038827 and a registered company no 2379280. Registered address: Royal Free Hospital, Pond Street, Hampstead, NW3 2QG [49]; Anthony Nolan Cord Blood Bank [50]; DKMS United Kingdom [51]	6
United States of America	14	14 (100%)	Bloodworks NW ARC unit. We're an independent, non-profit organization harnessing donor gifts to provide a safe, lifesaving blood supply to 95% of hospitals in the pacific northwest. [52]; Bloodworks NW Cord Blood Services [53]; The C.W. Bill Young Department of Defense Marrow Donor Recruitment and Research Program, also known as Salute to Life [54]; Caribbean Bone Marrow Registry [55]; Supported by The Abraham J. and Phyllis Katz Foundation and Dr. Donald J. and Ruth Weber Goodman Philanthropic Fund. [56]; DKMS United States of America [57]; The Carolinas Cord Blood Bank (CCBB) [58]; ITxM Clinical Services Cord Blood Lab. The Vitalant Cord Blood Services is a not-for-profit umbilical cord blood donor bank serving Pennsylvania and New Jersey area hospitals. [59]; The J.P. McCarthy Cord Stem Cell Bank at the Karmanos Cancer Institute is a public, non-profit stem cell bank with over 1,200 umbilical cord blood units in its inventory. [60]; LifeCord/LifeSouth Community Blood Centers. Our parent organization, LifeSouth Community Blood Centers, Inc. was founded in 1974. LifeSouth is a 501(c)(3) non-profit community blood supplier for hospitals in Alabama, Florida and Georgia. [61]; New York Blood Center (NYBC) is one of the largest independent, community-based, non-profit blood centers in the United States. [62]; NMDP-National Marrow Donor Program/Be The Match [63]; San Diego Blood Bank is an independent, 501(c)(3) non-profit that serves hospitals in San Diego, Orange, Imperial and Los Angeles counties with blood transfusion products and reference laboratory services. [64]; St. Louis Cord Blood Bank [65]	28
Uruguay	1	0		1
Vietnam	1	0		1
WMDA	140	56		196

The total number of non-governmental registries included in the World Marrow Donor Association is 56 (29%) and the other 140 (71%) registries are governmental (Figure 1).

There are two functional marrow donor registries included in World Marrow Donor Registries (WMDA) from the Western Balkans: MBMDR - Macedonian Bone Marrow Donor Registry from North Macedonia and the Serbian Bone Marrow Donor Registry from Serbia. There is one more marrow donor registry in preparation from Scientific Foundation SPIROSKI as a part of the non-governmental sector in North Macedonia. Currently, there are no marrow donor registries in Albania, Bosnia and Herzegovina, Montenegro, or Kosovo (Table 2).

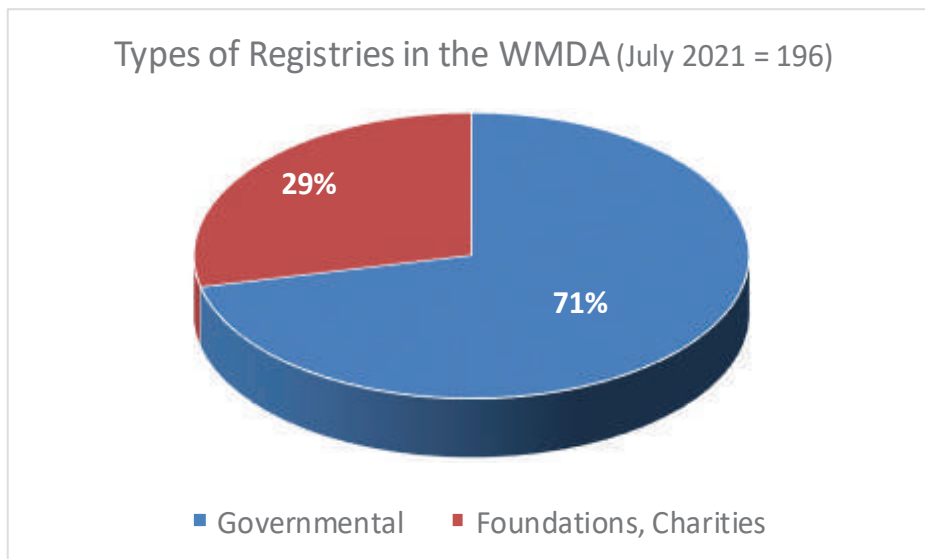


Figure 1 – Organizational structure of the marrow donor registries included in the World Marrow Donor Association (WMDA) (July 2021). From the total of 196 registries (71%), 56 registries are in the group of foundations and/or charities (29%).

The total number of marrow donors in MBMDR - Macedonian Bone Marrow Donor Registry is 2349 with 99.5% ABDR typed samples. In the Serbian Bone Marrow Donor Registry there are 6923 marrow donors with 99% ABDR typed samples (Table 2).

Table 2

Marrow Donor Registries in the Western Balkan countries (in alphabetical order) included in the World Marrow Donor Registries (WMDA), July 2021

Western Balkan Country	Marrow Donor Organization	WO	ION	Total	ABDR	ABDR% Typed	DNA Class I	DNA Class II
Albania	No							
Bosnia and Herzegovina	No							
Kosovo	No							
Montenegro	No							
North Macedonia	MBMDR - Macedonian Bone Marrow Donor Registry	1252	4307	2349	2338	99.5	2349	2344
	Scientific Foundation SPIROSKI – Marrow Donor Registry, in preparation	2117						
Serbia	Serbian Bone Marrow Donor Registry	1078	4650	6923	6852	99	6923	6854

Discussion

In this paper we present the current status of non-governmental vs. governmental marrow donor registries in the World Marrow Donor Association (WMDA). Most of the registries are governmental (71%), but a significant number of registries are found in the non-governmental sector (29%). It should be mentioned that the WMDA is a non-governmental organization and, as one of the founding members of the Worldwide Network for Blood and Marrow Transplantation (WBMT), aims to promote excellence in stem cell transplantation, donation, and cellular therapy.

The Macedonian Donor Registry Foundation (MKDR) was established on 03.02.2002 as part of the ICGEB project (CRP/MAC03-01) "Ambiguities resolution of HLA genotypes in Macedonian population" [66]. The

Macedonian Bone Marrow Donor Registry (MBMDR) was jointly established on February 28, 2013 by the Institute of Immunobiology and Human Genetics (IIBHG) and the Macedonian Donor Registry foundation as a combination of a governmental institution and a non-governmental foundation. The division of activities was such that blood was taken by the IIBHG (DNA was isolated and HLA-DNA genotyped), and the MKDR foundation created the Marrow Donor Registry, organized lectures, organized donation activities, and established international communications. In September 2013, the functions performed by MKDR foundation were undertaken by the IIBHG and, to date, the registry functions only as a governmental bone marrow donation registry of IIBHG, without cooperation with the MKDR Foundation [67].

On July 30, 2018, the Macedonian Donor Registry Foundation (MKDR) expanded its activities and changed its name to the Scientific Foundation SPIROSKI. Most of the work of the foundation involves publishing scientific journals, the most famous and extensive of which is the scientific journal *Open Access Macedonian Journal of Medical Sciences* [68]. Following the name change, activities began in order to establish a non-governmental Marrow Donor Registry (in addition to the existing state Bone Marrow Donor Registry of the IIBHG) as an additional potential for treating patients with blood cancer with marrow transplantations.

The Serbian Bone Marrow Donor Registry was created on January 31, 2012, as governmental institution at the Blood Transfusion Institute of Serbia in Belgrade, Serbia. The Blood Transfusion Institute of Serbia (BTIS) was founded on the 24th of October, 1944. BTIS started as a Federal military establishment on the 24th of October 1944, and later became a Federal Civilian institution in October 1945, and in March 1946, it became a civilian institution of the Republic of Serbia. The HLA Tissue Typing Laboratory was founded in 1972 and the PCR Laboratory was founded within the HLA Tissue Typing Department in 2003. The current medical director of BTIS is Glorija Miletic. The organisation's top administrator, CEO/director regular or provisional member organization, and WSMS Registry user is Zorana Andric [68].

The absence of marrow donor registries in the most of the Western Balkan countries (Albania, Bosnia and Herzegovina, Kosovo, and Montenegro) is a consequence of low development and has hindered many

patients who need stem cell transplantation to be cured. There are several alternatives that could be used to include citizens from these countries so that they will be included in the World Marrow Donor Association. The best approach is to create marrow donor registries in countries, which is a slow and expensive process, but including citizens in the neighboring countries could be a more efficient approach.

In the last 5 years, the number of registered potential hematopoietic stem cells donors in Poland increased by more than 4 times, from about 146,000 to over 750,000. During the same period, the number of patients qualified for hematopoietic stem cell transplantation from unrelated donors increased from 557 in 2010 to 817 in 2014. A striking change in the percentage of transplantations performed in Polish centers was observed. The material that was collected from national donors jumped from 24% to 60%. This shift was also evident in the number of search procedures closed with acceptance of Polish donors – from 27% in 2010 to 58% in 2014. Another consequence of the Polish registry growth is the increasing number of donations from Polish donors for international patients. Between 2010 and 2014, the percent of donations for non-national patients increased from 33% to 76%, placing Poland in 6th place in the ranking of the HSC “exporters” worldwide [69].

Authorities involved with an HCT donor registry establishment will have to balance the advantages and costs of such a project and accommodate the emerging alternatives, such as cord blood or related haploidentical transplants. Miscalculations and an incomplete understanding of the various aspects of the process can have a tremendous impact on the optimization of a HCT donor registry, especially in developing countries [70].

The main limitation of this study is the classification of the marrow donor registries. We suppose an underestimated number of non-governmental organizations in this paper, and we expect more organizations to be included going forward.

We can conclude that in most of the Western Balkan countries (Albania, Bosnia and Herzegovina, Kosovo, and Montenegro) there are no marrow donor registries and only in North Macedonia and Serbia there exist governmental marrow donor registries. There is a great need to develop more non-governmental and governmental marrow donor registries in the Western Balkan countries.

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