



Bone Marrow Donors Worldwide

Annual Report 2013





Contact address

Bone Marrow Donors Worldwide

Europdonor Foundation

Plesmanlaan 1B

2333 BZ Leiden

The Netherlands

Tel: +31-71-5685300

Fax: +31-71-5210457

bmdw@europdonor.nl

www.bmdw.org

Graphic Design

Martine Dhondt, Rotterdam

Leiden, 2014

Bone Marrow Donors Worldwide

Annual Report 2013

Index

Preface	3
1. Introduction to Bone Marrow Donors Worldwide (BMDW)	5
2. Participating Stem Cell Donor Registries and Cord Blood Banks	8
2.1. Participating stem cell donor registries	8
2.2. Participating cord blood banks/registries	10
3. Number of Stem Cell Donors and Cord Blood Units	13
3.1. Number of stem cell donors	13
3.2. Number of cord blood units	17
4. Distribution of Stem Cell Donors and Cord Blood Units in the World	21
4.1. Distribution of stem cell donors	21
4.2. Distribution of cord blood units	24
5. Number of HLA Phenotypes	27
6. Information Technology	31
6.1. Developments in 2013	31
<i>Change Requests</i>	
<i>Registry / third party support and other topics</i>	
6.2. Use of BMDW	32
<i>On-line services</i>	
7. Financial overview	34
8. Board and Staff	35
9. Advisory Committee	36

Preface

In 2013 the BMDW file has grown with over two million donors and forty thousand cord blood units.

This resulted in an increase of almost twenty thousand new HLA-A, -B, -DR split phenotypes to BMDW. Each year new registries join BMDW, in 2013 six new stem cell donor registries joined and five new cord blood banks.

The annual report of 2013 illustrates the continued need for BMDW. The use of the regular match program, the program that matches for (potential) HLA identical donors, was increased by 15% compared to 2012. The actual utilization of the BMDW data is even higher as several countries download the BMDW data to incorporate this in their own matching programs.

Clearly BMDW is there to stay. However, significant improvements are needed. In the BMDW meetings held in London, April 2014, we have given you a general outline of how we envisage what the new BMDW should look like. We have asked your input and spoken to with many of you and used this to improve our plans. It is now time for real action and the first step, to create a project group and transition board is already on the way. We will keep in touch with you and hope to have a clear plan of action by the end of 2014.

Dr. M. Oudshoorn
Chairman of Bone Marrow Donors Worldwide
July 2014

1

Introduction to BMDW: Bone Marrow Donors Worldwide

Bone Marrow Donors Worldwide (BMDW) started as an initiative of the Immunobiology Working Party of the European Group for Blood and Marrow Transplantation (EBMT) in 1988. In February 1989 the first edition was distributed, which contained the donor files of eight registries with a total of 150,000 volunteer stem cell donors.

The pioneer registries were:

- Anthony Nolan Research Centre (UK)
- France Greffe de Moelle (France)
- National Marrow Donor Program (USA)
- Eurodonor Foundation (The Netherlands)
- German Registry of Bone Marrow Donors (Germany)
- Italian Bone Marrow Donor Registry (Italy)
- Austrian Bone Marrow Donors (Austria)
- Marrow Donor Program Belgium (Belgium)

The original goals of BMDW are still adhered to, but new initiatives have been added.

The main goals are:

- To maximize the chance of finding a stem cell donor/cord blood unit by providing access to all donors and cord blood units available in the world.
- To minimize the effort put into stem cell donor/cord blood unit searches: only registries/banks with potential stem cell donors/cord blood units need to be contacted.
- To provide an estimate of the chance of finding a stem cell donor/cord blood unit for a given patient.
- To provide advanced search programs to identify partially matched stem cell donors and/or cord blood units.
- To facilitate search request advices via Internet.
- To provide relevant general information for the benefit of the patient.
- To provide statistics on the increase of donors of different registries, the number of DNA typed donors etc.

What is BMDW?

BMDW

Bone Marrow Donors Worldwide is a service provided by Eurodonor Foundation. It provides a listing of HLA phenotypes and other relevant data of unrelated volunteer stem cell donors and cord blood units from participating stem cell donor registries and cord blood banks (CBB's) combined with matching programs. The participants pay an operational fee to have the right to have their own data files uploaded in BMDW and to consult those from other registries and cord blood banks in a secure fashion.

BMDW can be used by transplant centres and search coordinators. The procedure for authorisation can be found on www.bmdw.org.

BMDW Office

The office consists of Eurodonor (ED) staff, responsible for keeping BMDW operational, but also to improve the operation as decided by the Editorial Board (EB).

Note: The staff size is flexible, which has meant in practical terms that if necessary, extra staff is provided to BMDW by ED.

Editorial Board (EB) of BMDW

The Editorial Board is a forum of one representative from each of the registries and cord blood banks, which meets at least once a year. It approves the budget and is authorized by the Eurodonor Board to decide on new developments.

Advisory Committee (AC)

The Advisory Committee consists of seven members elected from and by the EB to assist the BMDW Office and the chair of the Editorial Board to select and prepare topics to be discussed and decided upon by the EB.

How is the relationship between the individual registries and/or cord blood banks in relation to BMDW as part of Eurodonor regulated?

The requirements the registries or CBB's must meet in order to participate in BMDW are described in the house rules (see www.bmdw.org). The services to be delivered by the BMDW Office are defined there as well. They are in brief as follows:

- The registries/CBB's will submit their data according to a format as determined by the BMDW Office.
- The clients pay a yearly fee to be agreed upon by the Editorial Board.
- BMDW verifies the submitted data and makes it available on the website together with matching programs.
- The BMDW budget depends on the tasks to be performed and is approved in advance by the Editorial Board.

How is the relationship between the BMDW Office, the Editorial Board, Advisory Committee and Europdonor regulated?

Briefly the following has been agreed upon:

- The Board of Europdonor has authorized the Editorial Board to decide on new features and improvements to be developed.
- The Editorial Board will decide with the BMDW Office as part of Europdonor, the necessary budget to keep BMDW running and to develop the requested new features.
- The Advisory Committee assists the BMDW Office in preparing the agenda of the Editorial Board meeting and the items on which the Editorial Board has to decide. It will report to the Editorial Board not only the opinions of the majority of the Advisory Committee members, but also minority opinions. The Advisory Committee has the option to consult the IT Working Group of the WMDA.

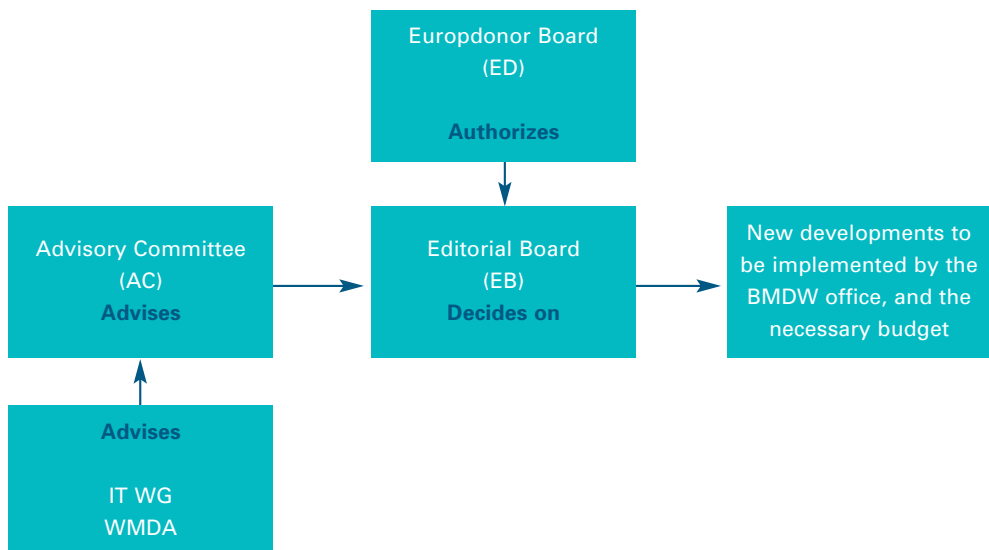


Figure 1
Relationship between the BMDW Office, the Editorial Board, the Advisory Committee and the Europdonor Foundation

2

Participating Stem Cell Donor Registries and Cord Blood Banks

2.1 Participating stem cell donor registries

At the end of 2013, 72 stem cell donor registries from 52 countries participated in BMDW (Table 1).

Six new stem cell donor registries joined in BMDW, Hema-Quebec Stem Cell Donor Registry from Canada, University of Patras Stem Cell Donor Registry from Greece, Korean Network for Organ Sharing (KONOS) from the Republic of Korea, Macedonian Bone Marrow Donor Registry (MBMDR) from the Republic of Macedonia, Saudi Stem Cells Donor Registry from Saudi Arabia and the Delete Blood Cancer UK. Together the new registries supply 262,720 donors to BMDW.

Tabel 1

Participating stem cell donor registries

The Caitlin Raymond International Registry (CRIR) has ceased to exist; the donors have been incorporated into the National Marrow Donor Program (NMDP).

Registry (N = 72)	City	Country (N = 52)
Argentine CPH Donors Registry	Buenos Aires	Argentina
Armenian Bone Marrow Donor Registry Charitable Trust	Yerevan	Armenia
Australian Bone Marrow Donor Registry *	Sydney	Australia
Austrian Bone Marrow Donors	Vienna	Austria
Marrow Donor Program Belgium	Mechelen	Belgium
INCA/REDOME	Rio de Janeiro	Brazil
Bulgarian Bone Marrow Donor Registry	Sofia	Bulgaria
Hema-Quebec Stem Cell Donor Registry	Quebec	Canada
OneMatch Stem Cell and Marrow Network *	Ottawa	Canada
China Marrow Donor Program (CMDP)	Beijing	China
Hong Kong Bone Marrow Donor Registry (HKBMDR)	Hong Kong	China
New Sunshine Charity Foundation (NSCF)	Beijing	China
Croatian Bone Marrow Donor Registry	Zagreb	Croatia
Cyprus Paraskevaudio Bone Marrow Donor Registry (CPBMDR)	Nicosia	Cyprus
Cyprus Bone Marrow Donor Registry (CBMDR) *	Nicosia	Cyprus
Czech Stem Cells Registry (CSCR)	Prague	Czech Republic
Czech National Marrow Donor Registry (CNMDR) *	Plzen	Czech Republic
The Danish Bone Marrow Donor Registry (DBMDR)	Aarhus	Denmark
Bone Marrow Donors Copenhagen (BMDC)	Copenhagen	Denmark
Finnish Stem Cell Registry	Helsinki	Finland
France Greffe de Moelle *	St-Denis la Plaine	France
ZKRD - German National Registry of Blood Stem Cell Donors*	Ulm	Germany
University of Patras Stem Cell Donor Registry	Patras	Greece

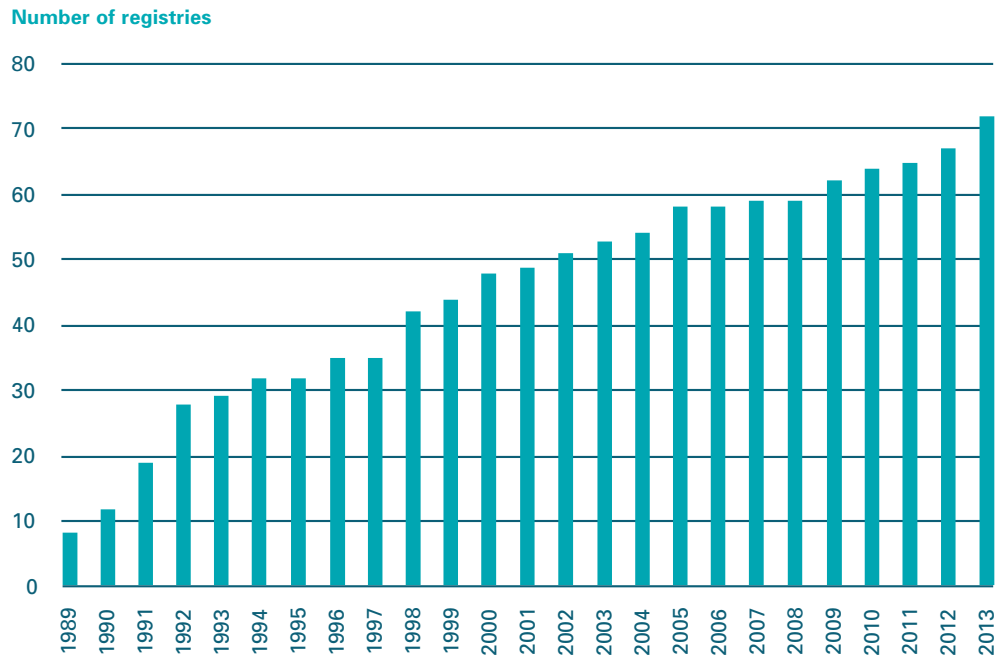
Registry (N = 72)	City	Country (N = 52)
Unrelated Hematopoietic Stem Cell Donor Registry Greece	Athens	Greece
Hungarian Bone Marrow Donor Registry	Budapest	Hungary
Bharat Stem Cells (BSC)	New Delhi	India
DATRI Blood Stem Cell Donors Registry	Chennai	India
Iranian Stem Cell Donor Program (ISCDP)	Tehran	Iran, Islamic Republic of
Irish Unrelated Bone Marrow Registry*	Dublin	Ireland
Hadassah Bone Marrow Donor Registry (HBMDR)	Jerusalem	Israel
Ezer Mizion Bone Marrow Donor Registry (EMBMDR) *	Petach Tikvah	Israel
Sheba Medical Center Donor Registry (SMCDR)	Tel-Hashomer	Israel
Italian Bone Marrow Donor Registry *	Genova	Italy
Japan Marrow Donor Program *	Tokyo	Japan
Korean Network for Organ Sharing (KONOS)	Seoul	Korea, Republic of
Lithuanian National Bone Marrow Donor Registry	Vilnius	Lithuania
Macedonian Bone Marrow Donor Registry (MBMDR)	Skopje	Macedonia
Mexican Bone Marrow Donor Registry (DONORMO)	Mexico City	Mexico
Europdonor Foundation *	Leiden	The Netherlands
New Zealand Bone Marrow Donor Registry *	Auckland	New Zealand
Bone Marrow Donor Registry Nigeria	Enugu	Nigeria
The Norwegian Bone Marrow Donor Registry *	Oslo	Norway
Against Leukemia Foundation Marrow Donor Registry (ALF-MDR)	Warsaw	Poland
Fundacja DKMS Baza Dawcow Komorek Macierzystych Polska	Warsaw	Poland
Central Bone Marrow Donor Registry (POLTransplant)	Warsaw	Poland
Portuguese Bone Marrow Donors Registry (CEDACE)	Lisbon	Portugal
Romanian Nat. Registry of Hematopoietic Stem Cells Voluntary Donors	Bucharest	Romania
Karelian Registry of Unrel. Donors of Hematopoietic Stem Cells	Petrozavodsk	Russian Federation
Bone Marrow Donors Registry Blood Banks of Russia	St. Petersburg	Russian Federation
HPC Registry	Samara	Russian Federation
Saudi Stem Cells Donor Registry	Riyadh	Saudi Arabia
Serbian Bone Marrow Donor Registry	Belgrade	Serbia
Singapore Bone Marrow Donor Programme (BMDP)	Singapore	Singapore
Slovak National Bone Marrow Donor Registry	Bratislava	Slovakia
Slovenia Donor	Ljubljana	Slovenia
South African Bone Marrow Registry (SABMR)	Cape Town	South Africa
REDMO, Jose Carreras International Leukemia Foundation	Barcelona	Spain
DKMS España	Barcelona	Spain
The Tobias Registry	Stockholm	Sweden
Swiss Blood Stem Cells **	Bern	Switzerland
Buddhist Tzu Chi Stem Cells Center *	Hualien City	Taiwan, Province of China
Thai Stem Cell Donor Registry (TSCDR)	Bangkok	Thailand
Ankara University School of Medicine Unrelated Blood and Marrow Donor Registry	Ankara	Turkey
Blood and Bone Marrow Donor Registry of Istanbul Medical Fac.	Istanbul	Turkey
Emirates Bone Marrow Donor Registry	Sharjah	United Arab Emirates
Anthony Nolan *	London	United Kingdom
Delete Blood Cancer UK	London	United Kingdom
British Bone Marrow Registry (BBM) *	Bristol	United Kingdom
Welsh Bone Marrow Donor Registry *	Pontyclu	United Kingdom
National Marrow Donor Program (NMDP) *	Minneapolis, MN	United States of America
Gift of Life Bone Marrow Foundation (GOL) *	Boca Raton, FL	United States of America
SINDOME	Montevideo	Uruguay

*) Registry accredited by the World Marrow Donor Association (WMDA)

**) WMDA Qualified Registry

The number of participating stem cell donor registries is shown in Figure 2.

Figure 2
Participating Stem Cell
Donor Registries



© BMDW

2.2 Participating cord blood banks/registries

In 2013, 47 cord blood banks/registries located in 33 countries participated in BMDW (Table 2).

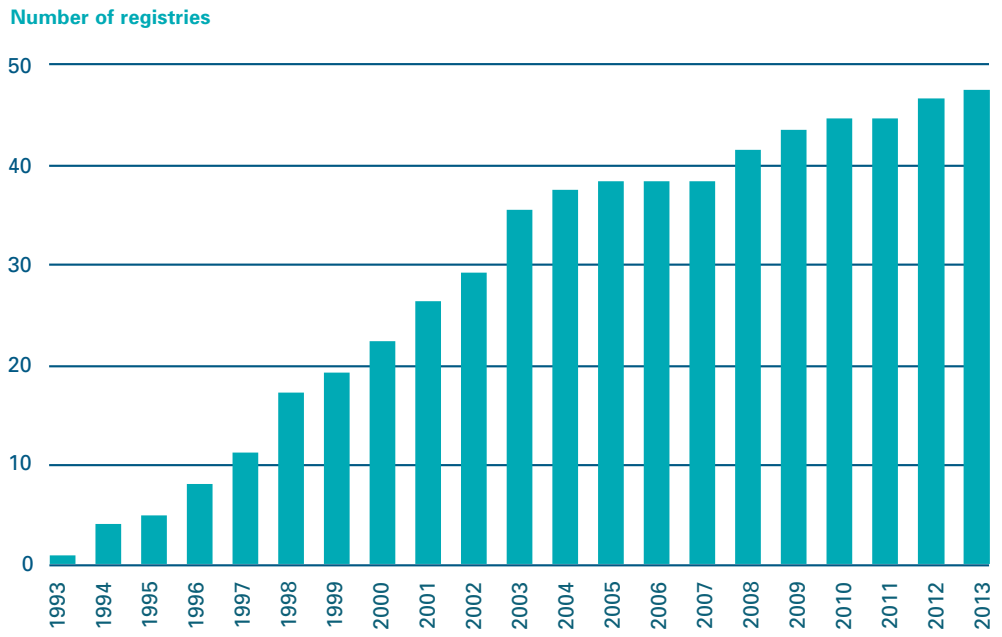
Five new cord blood banks joined BMDW, Cord Blood Bank Linz and Vivocell Cord Blood Bank both from Austria, Redome Cord Blood Bank from Brazil, Chile Cord Blood Bank from Chile and Korean Network for Organ Sharing (KONOS) from the Republic of Korea. These new banks supplied data of 31,659 units to BMDW. The Gift of Life (GOL) Cord Blood Program has temporarily withdrawn its units from BMDW. The New Jersey Cord Blood Bank has ceased to exist, their cord blood units are partly in the National Marrow Donor Program and partly in the Central Cord Blood Registry (POLTransplant). The cord blood units from the Catholic Hematopoietic Stem Cell Bank and the Korea Cord Blood Bank are now in the Korean Network for Organ Sharing (KONOS).

Table 2Participating Cord Blood
Banks / Registries

Registry (N = 47)	City	Country (N = 33)
Argentina National Cord Blood Bank	Buenos Aires	Argentina
Australian Cord Blood Registry	Sydney	Australia
Cord Blood Bank Linz	Linz	Austria
Vivocell Cord Blood Bank	Graz	Austria
Belgium Cord Blood Registry (BCBR)	Mechelen	Belgium
Redome Cord Blood Bank	Rio de Janeiro	Brazil
Hema-Quebec Cord Blood Bank	Quebec	Canada
Chile Cord Blood Bank	Santiago	Chile
Croatian Cord Blood Bank	Zagreb	Croatia
Cyprus Cord Blood Bank	Nicosia	Cyprus
Czech Cord Blood Registry	Prague	Czech Republic
Finnish Cord Blood Registry	Helsinki	Finland
France Greffe de Moelle Cord Blood Registry	St-Denis la Plaine	France
Jose Carreras Stem Cell Bank Duesseldorf	Duesseldorf	Germany
ZKRD - German National Registry of Blood Stem Cell Donors	Ulm	Germany
Hellenic Cord Blood Bank	Athens	Greece
Thessaloniki Public Cord Blood Bank	Thessaloniki	Greece
Hadassah-MDA Cord Blood Bank (H-MDACBB)	Jerusalem	Israel
Sheba Medical Centre Cord Blood Registry (SMCCBR)	Tel-Hashomer	Israel
Iranian Stem Cell Donor Program (ISCDP)	Tehran	Iran, Islamic Republic of
Royan Institute Cord Blood Bank	Tehran	Iran, Islamic Republic of
Italian Cord Blood Bank Network	Genova	Italy
Tokyo Cord Blood Bank	Tokyo	Japan
Korean Network for Organ Sharing (KONOS)	Seoul	Korea, Republic of
Mexican Unrelated Cord Blood Bank (BACECU)	Mexico City	Mexico
Europdonor Foundation	Leiden	The Netherlands
Central Cord Blood Registry (POLTransplant)	Warsaw	Poland
HPC Registry	Samara	Russian Federation
Eurocord Slovakia – Slovak Placental Stem Cell Registry	Bratislava	Slovakia
Slovenia Cord	Ljubljana	Slovenia
REDMO Spanish Cord Blood Registry	Barcelona	Spain
The Tobias Registry	Stockholm	Sweden
Swiss Cord Blood Registry	Bern	Switzerland
AventLife Inc.	New Taipei City	Taiwan, Province of China
BIONET Corp.	Hualien City	Taiwan, Province of China
Buddhist Tzu Chi Stem Cells Center	Taipei City	Taiwan, Province of China
Healthbanks Biotech Co. Ltd.	Taipei City	Taiwan, Province of China
StemCyte, Inc. Taiwan	LinKou, Taipei Hsien	Taiwan, Province of China
Thai National Cord Blood Bank	Bangkok	Thailand
Ankara University School of Medicine Unrelated Blood and Marrow Donor Registry	Ankara	Turkey
Anthony Nolan Cord Blood Registry	London	United Kingdom
British Bone Marrow Registry – Cord Blood Bank	Bristol	United Kingdom
StemCyte Inc.	Covina, CA	United States of America
Celgene Cord Blood Bank	Cedar Knolls, NJ	United States of America
Cleveland Cord Blood Center (CCBC)	Cleveland, OH	United States of America
National Marrow Donor Program – Cord Blood Bank (NMDP)	Minneapolis, MN	United States of America
National Cord Blood Program, New York Blood Center (NCBP-NYBC)	Long Island City, NY	United States of America

The number of participating stem cell donor registries is shown in Figure 3.

Figure 3
Participating Cord Blood
Banks / Registries



© BMDW

3

Number of Stem Cell Donors and Cord Blood Units

3.1 Number of stem cell donors

The number of HLA-A, -B and HLA-A, -B, -DR typed stem cell donors per registry is shown in Table 3.

In Figure 4 the total number of HLA-A, -B and HLA-A, -B, -DR typed stem cell donors per year is given. The number of stem cell donors increased by 2,334,267 from 20,226,863 to 22,561,130 in 2013.

The percentage of HLA-DR typed donors has increased by 2%, from 88% in 2012 to 90% in 2013.

In the total group of donors the percentage of HLA class I DNA typed donors is 78% and HLA class II DNA typed donors is 87%.

Table 3

The number of HLA-A, -B and HLA-A, -B, -DR and DNA typed stem cell donors per registry

Registry	Country	Total number of donors	Number of HLA-A, -B, -DR typed donors	Percentage of HLA-A, -B, -DR typed donors	Number of class I DNA typed donors	Number of class II DNA typed donors
Argentine CPH Donors Registry	Argentina	34,979	30,887	88	34,979	30,886
Armenian Bone Marrow Donor Registry Charitable Trust	Armenia	22,798	22,797	100	22,798	22,798
Australian Bone Marrow Donor Registry	Australia	175,303	146,748	84	74,928	137,220
Austrian Bone Marrow Donors	Austria	63,081	32,455	51	23,800	23,927
Marrow Donor Program Belgium	Belgium	65,890	58,359	89	29,121	46,367
INCA/REDOME	Brazil	3,161,866	3,154,416	100	3,021,029	3,149,462
Bulgarian Bone Marrow Donor Registry	Bulgaria	692	684	99	585	684
Hema-Quebec Stem Cell Donor Registry	Canada	32,097	20,751	65	13,998	19,504
OneMatch Stem Cell and Marrow Network	Canada	329,103	290,968	88	219,563	285,355
China Marrow Donor Program (CMDP)	China	678,731	677,760	100	678,731	677,762
Hong Kong Bone Marrow Donor Registry (HKBMDR)	China	78,622	65,550	83	41,972	48,676
New Sunshine Charity Foundation (NSCF)	China	2,767	2,614	94	2,767	2,614
Croatian Bone Marrow Donor Registry	Croatia	36,812	36,481	99	36,413	36,410
Cyprus Paraskevaudio Bone Marrow Donor Registry (CPBMDR)	Cyprus	5,638	756	13	3,330	408
Cyprus Bone Marrow Donor Registry (CBMDR)	Cyprus	126,142	79,173	63	104,350	67,596
Czech National Marrow Donor Registry (CNMDR)	Czech Republic	42,670	38,172	89	15,159	38,135
Czech Stem Cells Registry (CSCR)	Czech Republic	22,090	11,459	52	4,324	11,411
The Danish Bone Marrow Donor Registry (DBMDR)	Denmark	28,836	27,774	96	20,041	27,772
Bone Marrow Donors Copenhagen (BMDC)	Denmark	13,594	12,856	95	1,243	12,681
Finnish Stem Cell Registry	Finland	21,354	20,885	98	6,530	7,914

Table 3

The number of HLA-A, -B
and HLA-A, -B, -DR and
DNA typed stem cell
donors Per Registry

Registry	Country	Total number of donors	Number of HLA-A, -B, -DR typed donors	Percentage of HLA-A, -B, -DR typed donors	Number of class I DNA typed donors	Number of class II DNA typed donors
France Greffe de Moelle	France	221,139	208,270	94	152,984	199,209
ZKRD-German National Registry of Blood Stem Cell Donors	Germany	5,164,484	4,268,725	83	3,891,125	4,197,404
Unrelated Hematopoietic Stem Cell Donor Registry Greece	Greece	37,686	21,256	56	2,377	3,402
University of Patras	Greece	3,229	3,226	100	3,229	3,226
Hungarian Bone Marrow Donor Registry	Hungary	6,739	3,989	59	2,083	2,867
Bharat Stem Cells (BSC)	India	198	198	100	189	189
DATRI Blood Stem Cell Donors Registry	India	34,514	33,245	96	34,514	33,388
Iranian Stem Cell Donor Program (ISCDP)	Iran, Islamic Republic of	2,794	2,488	89	2,479	2,488
Irish Unrelated Bone Marrow Registry	Ireland	21,111	20,988	99	14,288	14,877
Hadassah Bone Marrow Donor Registry (HBMDR)	Israel	124,305	94,579	76	122,110	94,539
Ezer Mizion Bone Marrow Donor Registry (EMBMDR)	Israel	699,043	602,058	86	648,473	601,528
Sheba Medical Center Donor Registry (SMCDR)	Israel	1,782	709	40	386	617
Italian Bone Marrow Donor Registry	Italy	342,783	257,704	75	97,937	161,263
Japan Marrow Donor Program	Japan	439,268	439,268	100	317,020	324,310
Korean Network for Organ Sharing	Korea	248,326	247,886	100	0	123,181
Lithuanian National Bone Marrow Donor Registry	Lithuania	9,157	9,155	100	6,901	9,155
Macedonian Bone Marrow Donor Registry (MBMDR)	Macedonia	283	283	100	283	283
Mexican Bone Marrow Donor Registry (DONORMO)	Mexico	12,675	12,675	100	0	12,668
Europdonor Foundation	The Netherlands	44,344	43,118	97	28,906	35,370
New Zealand Bone Marrow Donor Registry	New Zealand	10,960	4,429	40	5,793	4,339
Bone Marrow Donor Registry Nigeria	Nigeria	276	261	95	276	261
The Norwegian Bone Marrow Donor Registry	Norway	30,406	29,561	97	14,496	29,162
Against Leukemia Foundation Marrow Donor Registry (ALF MDR)	Poland	15,145	10,974	72	10,676	10,974
Fundacja DKMS Baza Dawcow Komorek Macierzystych Polska	Poland	375,266	372,897	99	375,264	373,240
Central Bone Marrow Donor Registry (POLTransplant)	Poland	142,086	125,982	89	101,456	125,544
Portuguese Bone Marrow Donors Registry (CEDACE)	Portugal	337,307	335,197	99	336,773	334,853
Romanian Nat. Registry of Hematopoietic Stem Cells Voluntary Donors	Romania	2,721	2,647	97	2,721	2,648
Karelian Registry of Unrel. Donors of Hematopoietic Stem Cells	Russian Fed.	2,792	375	13	2,101	375
Bone Marrow Donors Registry Blood Banks of Russia	Russian Fed.	3,382	349	10	0	50
HPC Registry	Russian Fed.	2,284	2,284	100	2,284	2,284
Saudi Stem Cells Donor Registry	Saudi Arabia	1,110	1,110	100	1,110	1,110
Serbian Bone Marrow Donors Registry	Serbia	2,243	2,217	99	2,243	2,217
Singapore Bone Marrow Donor Programme (BMDP)	Singapore	36,837	36,811	100	36,837	36,811
Slovak National Bone Marrow Donor Registry	Slovakia	4,883	4,715	97	4,337	4,715

Table 3

The number of HLA-A, -B
and HLA-A, -B, -DR and
DNA typed stem cell
donors Per Registry

Registry	Country	Total number of donors	Number of HLA-A, -B, -DR typed donors	Percentage of HLA-A, -B, -DR typed donors	Number of class I DNA typed donors	Number of class II DNA typed donors
Slovenia Donor	Slovenia	15,593	15,584	100	15,024	15,588
South African Bone Marrow Registry (SABMR)	South Africa	65,938	15,651	24	5,012	14,429
REDMO, Jose Carreras International Leukemia Foundation	Spain	128,699	95,990	75	76,425	79,225
DKMS España	Spain	1,371	1,371	100	1,371	1,371
The Tobias Registry	Sweden	41,928	27,303	65	9,153	26,262
Swiss Blood Stem Cells	Switzerland	48,531	48,370	100	33,365	48,160
Buddhist Tzu Chi Stem Cells Center	Taiwan, Province of China	316,060	286,396	91	195,379	285,012
Thai Stem Cell Donor Registry (TSCDR)	Thailand	147,439	142,868	97	146,834	142,756
Ankara University School of Medicine Unrelated Blood and Marrow Donor Registry (TRAN)	Turkey	10,581	9,259	88	7,445	9,163
Blood and Bone Marrow Donor Registry of Istanbul Medical Fac. (BBMDR-IMF)	Turkey	27,460	2,485	9	7,028	2,487
Anthony Nolan	United Kingdom	505,115	446,036	88	321,842	421,275
British Bone Marrow Registry (BBMR)	United Kingdom	328,357	312,797	95	277,509	284,932
Delete Blood Cancer UK	United Kingdom	13,001	12,848	99	13,001	12,985
Welsh Bone Marrow Donor Registry	United Kingdom	50,539	50,539	100	49,134	50,539
Emirates Bone Marrow Donor Registry	United Arab Emirates	45	45	100	0	0
SINDOME	Uruguay	535	535	100	535	535
Gift of Life Bone Marrow Foundation (GOL)	United States of America	233,614	218,322	93	206,965	218,136
National Marrow Donor Program (NMDP)	United States of America	7,301,701	6,736,695	92	5,749,081	6,642,191
Total		22,561,130	20,354,268	90	17,692,415	19,651,175

Figure 4

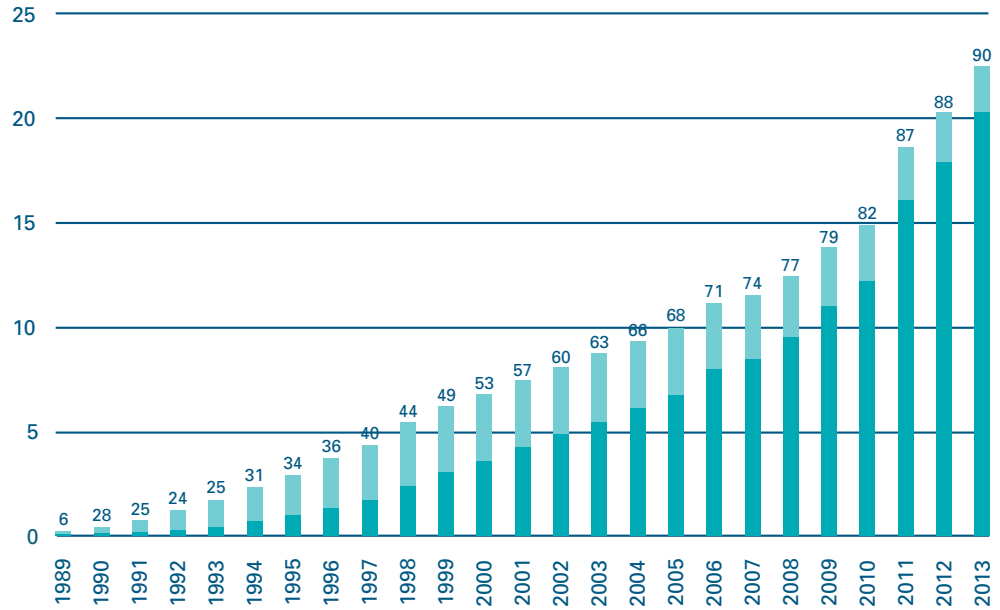
Total number of HLA-A, -B and HLA-A, -B, -DR typed stem cell donors

Number above bars is % HLA-A, -B, -DR typed stem cell donors

■ HLA-A, -B
■ HLA-A, -B, -DR

© BMDW

Number of stem cell donors (x million)



The increase of the number of stem cell donors per year is given in Figure 5. The number of additional donors (2,334,267) in the database in 2013 is more than in 2012 (1,613,741).

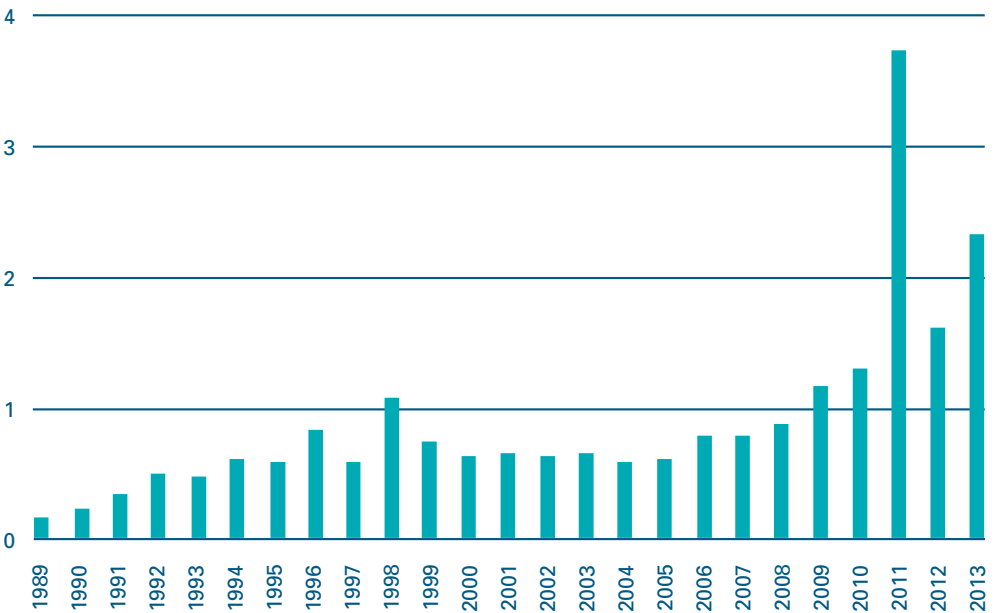
On average there has been an increase of 2,031,087 donors per year over the last five years (2009-2013).

Figure 5

The number of stem cell donors added to the database per year

© BMDW

Number of stem cell donors (x million) added per year



3.2 Number of cord blood units

The number of HLA-A, -B and HLA-A, -B, -DR typed cord blood units per cord blood bank/registry is shown in Table 4.

Table 4
The number of HLA-A, -B, and HLA-A, -B, -DR typed cord blood units per Cord Blood Bank / Registry

In 2013 600,750 cord blood units are listed in BMDW. The cord blood units are practically all fully typed for HLA-A, -B and -DR, in addition 76% is class I DNA typed and 93% of the units is class II DNA typed.

The total nucleated cell count is given for over 99% of the units and for 81% of the units the net volume collected is provided.

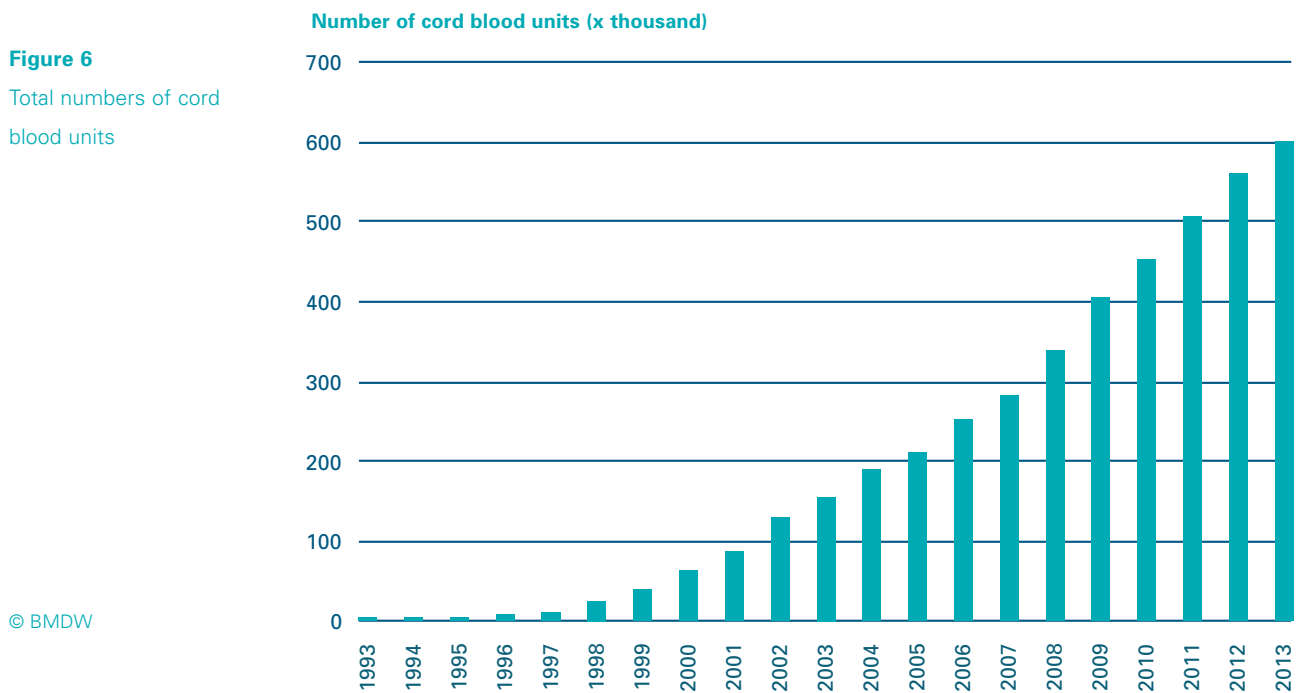
Registry	Country	Total number of units	Number of HLA-A, -B, -DR typed donors	Number of class I DNA typed donors	Number of class II DNA typed donors
Argentina National Cord Blood Bank	Argentina	1,962	1,959	1,962	1,959
Australian Cord Blood Registry	Australia	27,465	27,465	22,215	27,465
Vivocell Cord Blood Bank	Austria	1,134	1,134	1,134	1,134
Cord Blood Bank Linz	Austria	1,471	1,471	1,471	1,471
Belgium Cord Blood Registry (BCBR)	Belgium	17,416	17,411	15,238	17,411
REDOME - Registro Nacional de Doadores Voluntarios de Medula Ossea	Brazil	2,987	2,987	2,970	2,976
Hema-Quebec Cord	Canada	7,937	7,937	7,937	7,937
Chile Cord Blood Bank	Chile	640	640	640	640
Croatian Cord Blood Bank	Croatia	2,447	2,447	2,447	2,447
Cyprus Cord Blood Bank (CCBB)	Cyprus	1,951	1,951	1,951	1,951
Czech Cord Blood Registry (CSCR)	Czech Republic	3,984	3,984	3,870	3,982
Finnish Cord Blood Registry	Finland	3,365	3,365	1,636	3,365
France Greffe de Moelle Cord Blood Registry	France	30,858	30,858	25,654	30,379
Jose Carreras Stem Cell Bank Duesseldorf	Germany	18,508	18,508	14,861	18,508
German National Registry of Blood Stem Cell Donors (ZKRD)	Germany	15,970	15,970	14,604	15,963
Hellenic Cord Blood Bank (HCBB)	Greece	2,103	2,103	2,103	2,103
Thessaloniki Public Cord Blood Bank	Greece	676	676	676	676
Iranian Stem Cell Donor Program (ISCDP)	Iran, Islamic Republic of	1,842	1,828	1,842	1,828
Royan Institute Cord Blood Bank	Iran, Islamic Republic of	1,742	1,741	1,742	1,741
Hadassah-MDA Cord Blood Bank (H-MDACBB)	Israel	8,213	8,211	8,212	8,211
Sheba Medical Centre Cord Blood Registry (SMCCBR)	Israel	2,780	2,361	2,780	2,361
Italian Cord Blood Bank Network	Italy	29,474	29,474	21,321	29,473
Tokyo Cord Blood Bank	Japan	4,698	4,698	0	4,698
Korean Network for Organ Sharing (KONOS)	Republic of Korea	25,427	25,427	0	743
Mexican Unrelated Cord Blood Bank (BACECU)	Mexico	308	308	0	308
Europdonor Foundation	The Netherlands	3,336	3,336	2,741	3,331
Central Cord Blood Registry (POLTransplant)	Poland	3,162	3,162	3,078	3,161
HPC Registry	Russian Federation	5,142	5,142	5,142	5,142
Eurocord Slovakia – Slovak Placental Stem Cell Registry	Slovakia	1,720	1,720	1,167	1,174
Slovenia Cord	Slovenia	245	245	245	245
REDMO Spanish Cord Blood Registry	Spain	57,648	57,648	44,861	53,556
The Tobias Registry	Sweden	3,115	3,115	3,115	3,115
Swiss Cord Blood Registry	Switzerland	4,011	4,011	4,006	4,011
AventLife Inc.	Taiwan, Prov. of China	884	884	0	0
BIONET Corp.	Taiwan, Prov. of China	32,955	32,955	32,955	32,954
Buddhist Tzu Chi Stem Cells Center	Taiwan, Prov. of China	14,202	14,201	12,646	12,718
Healthbanks Biotech Co. Ltd.	Taiwan, Prov. of China	6,507	6,507	6,507	6,507

Table 4

The number of HLA-A, -B, and HLA-A, -B, -DR typed cord blood units per Cord Blood Bank / Registry

Registry	Country	Total number of units	Number of HLA-A, -B, -DR typed donors	Number of class I DNA typed donors	Number of class II DNA typed donors
StemCyte, Inc. Taiwan	Taiwan, Prov. of China	9,466	9,461	9,466	9,461
Thai National Cord Blood Bank	Thailand	2,040	2,040	0	0
Ankara University School of Medicine Unrelated Blood and Marrow Donor Registry	Turkey	765	755	765	755
Anthony Nolan Cord Blood Registry	United Kingdom	2,285	2,284	2,285	2,285
British Bone Marrow Registry – Cord Blood Bank	United Kingdom	18,937	18,937	18,929	18,937
StemCyte Inc.	United States of America	20,081	20,080	20,081	20,080
Celgene Cord Blood Bank	United States of America	3,878	3,878	3,878	3,878
Cleveland Cord Blood Center (CCBC)	United States of America	182	182	182	182
National Marrow Donor Program – Cord Blood Bank (NMDP)	United States of America	135,737	135,737	131,471	135,682
Nat. Cord Blood Program, New York Blood Center (NCBP-NYBC)	United States of America	59,094	59,094	4,814	53,746
Total		600,750	600,288	465,600	560,650

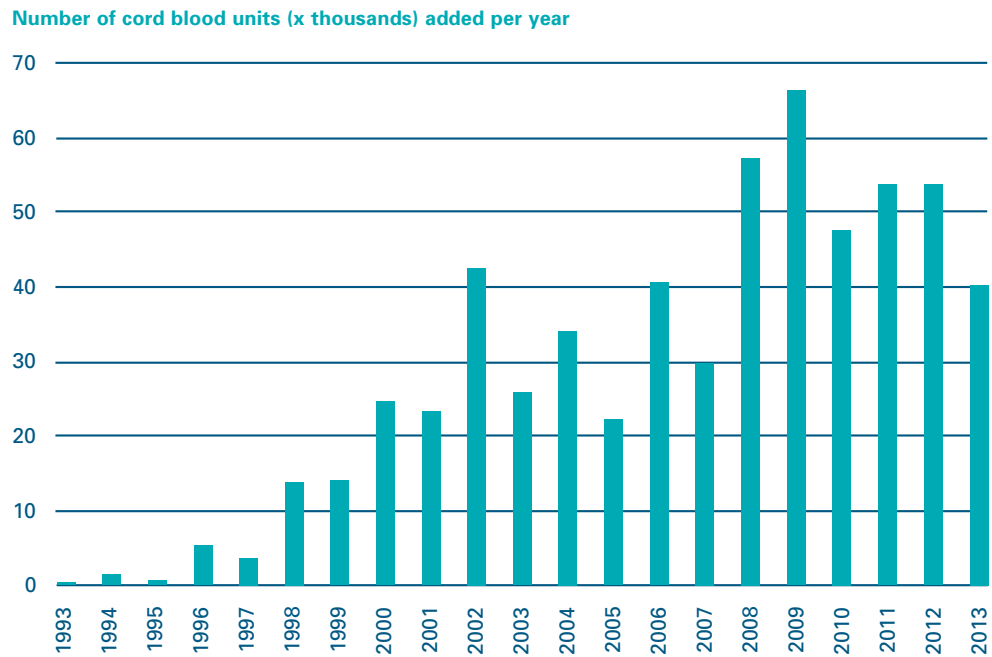
The steady increase of cord blood units in BMDW is shown in Figure 6. The total number of cord blood units at the end of 2013 is 600,750.



The number of cord blood units that have been added per year is given in Figure 7. The number of cord blood units added to the database in 2013 is 40,227.

Figure 7

Number of cord blood units added per year



© BMDW

Table 5

The mean number of total nucleated cells of the cord blood units in the Cord Blood Banks / Registries

In Table 5 the mean number of total nucleated cells (TNC) of the cord blood units in the cord blood banks is given.

For all cord blood units in BMDW the mean number of TNC is 102.7×10^7 and the median of TNC is 101.2×10^7 .

There has been a slight increase in the mean TNC since 2012 but not in the median TNC.

Registry	Country	Total number of units	Mean number of TNCx10 ⁷
Eurocord Slovakia – Slovak Placental Stem Cell Registry	Slovakia	1,720	186.1
HPC Registry	Russian Federation	5,142	166.7
Belgium Cord Blood Registry (BCBR)	Belgium	17,416	135.7
The Tobias Registry	Sweden	3,115	134.7
Anthony Nolan Cord Blood Registry	United Kingdom	2,285	134.6
Cleveland Cord Blood Center (CCBC)	United States of America	182	134.3
France Greffe de Moelle Cord Blood Registry	France	30,858	134.2
StemCyte Inc.	United States of America	20,081	124.8
Chile Cord Blood Bank	Chile	640	124.6
Sheba Medical Centre Cord Blood Registry (SMCCBR)	Israel	2,780	124.3
Italian Cord Blood Bank Network	Italy	29,474	123.1
Czech Cord Blood Registry	Czech Republic	3,984	121.2
Hema-Quebec Cord Blood Bank	Canada	7,937	119.0
REDMO Spanish Cord Blood Registry	Spain	57,648	117.3
Jose Carreras Stem Cell Bank Duesseldorf	Germany	18,508	116.9
National Marrow Donor Program – Cord Blood Bank (NMDP)	United States of America	135,737	115.2
Hadassah-MDA Cord Blood Bank (H-MDACBB)	Israel	8,213	112.9
Swiss Cord Blood Registry	Switzerland	4,011	110.6
Europdonor Foundation	The Netherlands	3,336	110.1
Hellenic Cord Blood Bank	Greece	2,103	110.0
Australian Cord Blood Registry	Australia	27,465	107.5
Cyprus Cord Blood Bank	Cyprus	1,951	105.3
Croatian Cord Blood Bank	Croatia	2,447	103.1

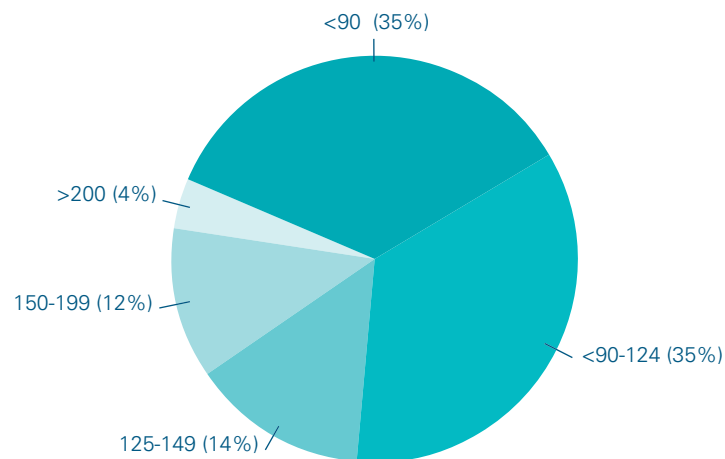
Table 5

The mean number of total nucleated cells of the cord blood units in the Cord Blood Banks / Registries

Registry	Country	Total number of units	Mean number of TNC x 10 ⁷
Korean Network for Organ Sharing (KONOS)	Republic of Korea	25,427	101.2
National Cord Blood Program, New York Blood Center (NCBP-NYBC)	United States of America	59,094	100.9
British Bone Marrow Registry – Cord Blood Bank	United Kingdom	18,937	99.2
Central Cord Blood Registry (POLTransplant)	Poland	3,162	98.9
StemCyte, Inc. Taiwan	Taiwan	9,466	97.5
REDOME - Registro Nacional de Doadores Voluntarios de Medula Ossea	Brazil	2,987	97.2
Finnish Cord Blood Registry	Finland	3,365	94.6
Argentina National Cord Blood Bank	Argentina	1,962	94.4
ZKRD - German National Registry of Blood Stem Cell Donors	Germany	15,970	91.6
Cord Blood Bank Linz	Austria	1,471	90.0
Slovenia Cord	Slovenia	245	88.4
Royan Institute Cord Blood Bank	Iran, Islamic Republic of	1,742	83.4
Iranian Stem Cell Donor Program (ISCDP)	Iran, Islamic Republic of	1,842	82.4
Thessaloniki Public Cord Blood Bank	Greece	676	82.1
Vivocell Cord Blood Bank	Austria	1,134	79.7
Ankara University School of Medicine Unrelated Blood and Marrow Donor Registry	Turkey	762	76.2
Celgene Cord Blood Bank	United States of America	3,878	75.3
BIONET Corp.	Taiwan	32,955	73.7
Buddhist Tzu Chi Stem Cells Center	Taiwan	14,202	73.2
Mexican Unrelated Cord Blood Bank (BACECU)	Mexico	308	71.1
Thai National Cord Blood Bank	Thailand	2,040	69.1
Tokyo Cord Blood Bank	Japan	4,698	68.9
AventLife Inc.	Taiwan, Province of China	884	64.7
Healthbanks Biotech Co. Ltd.	Taiwan, Province of China	6,507	–

Figure 8

The percentage of cord blood units in the different range of TNC (x 10⁷)



© BMDW

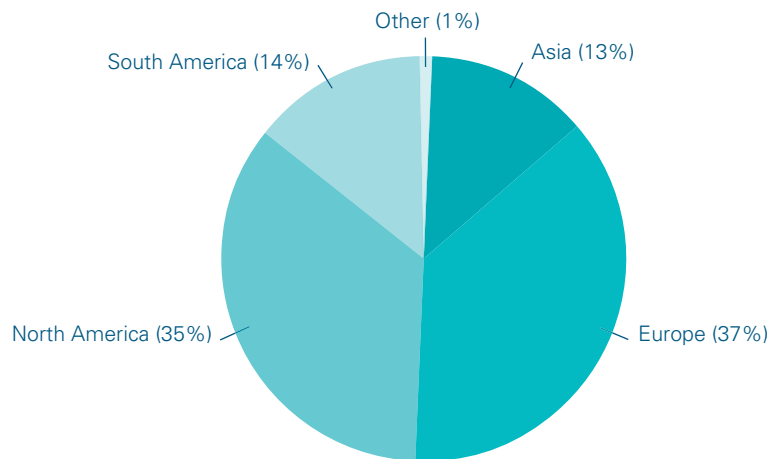
4

Distribution of Stem Cell Donors and Cord Blood Units in the World

4.1 Distribution of stem cell donors

As shown in Figure 9, 35% of the donors reside in North America, 37% in Europe, 14% in South America, 13% in Asia and the remaining 1% originates from other continents (Africa and Australia/Oceania).

Figure 9
The distribution of stem cell donors per continent



© BMDW

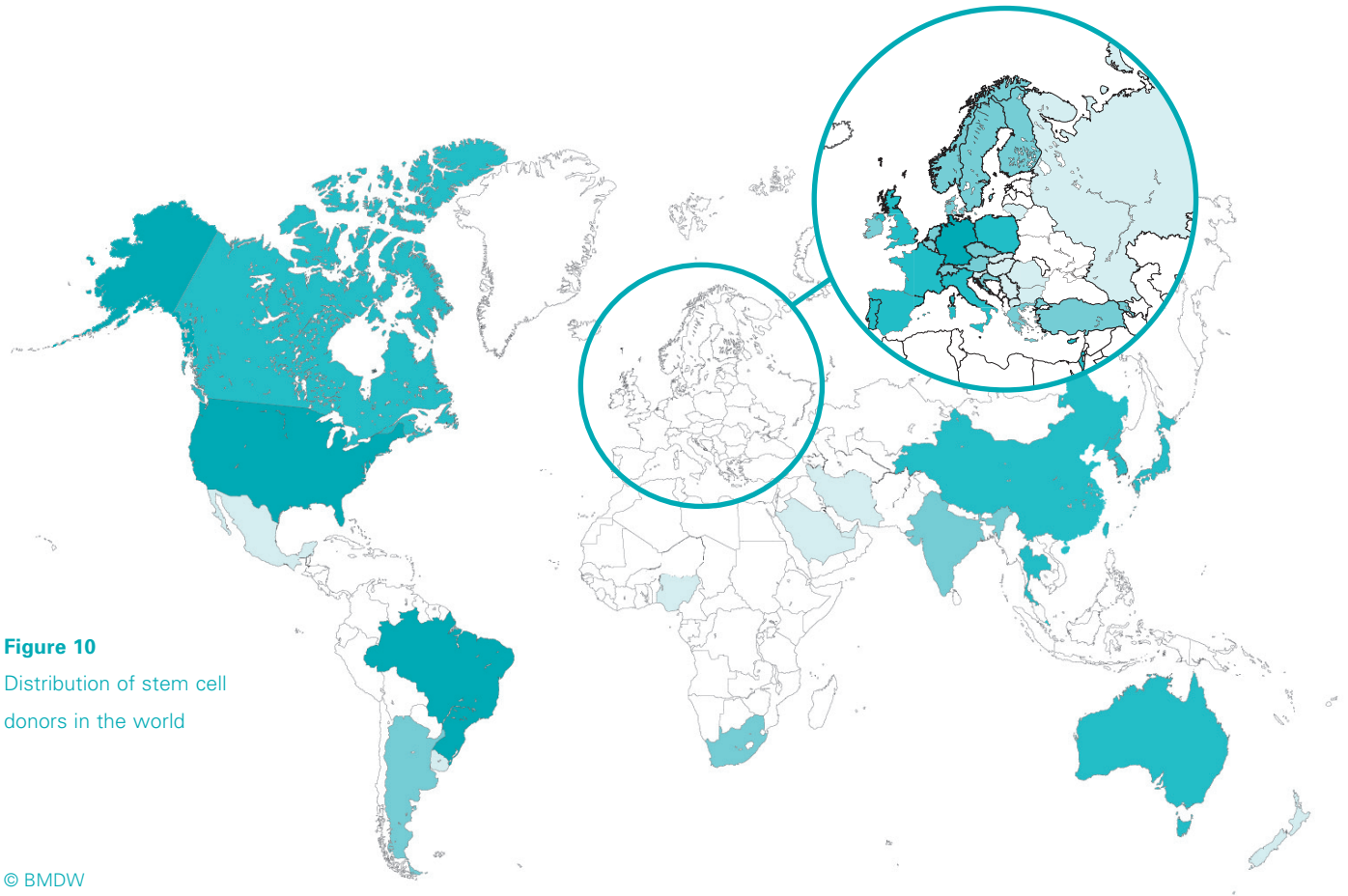


Figure 10
Distribution of stem cell
donors in the world

© BMDW

- < 20,000 donors**
 Bulgaria, Hungary, Iran, Lithuania, Macedonia, Mexico, New Zealand, Nigeria, Romania, Russian Federation, Saudi Arabia, Serbia, Slovakia, Slovenia, United Arab Emirates, Uruguay
- 20,000-100,000 donors**
 Argentina, Armenia, Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, Greece, India, Ireland, Norway, Singapore, South Africa, Sweden, Switzerland, The Netherlands, Turkey
- > 100,000-1,000,000 donors**
 Australia, Canada, China, Cyprus, France, Israel, Italy, Japan, Poland, Portugal, Republic of Korea, Spain, Taiwan, Thailand, United Kingdom
- > 1,000,000 donors**
 Brazil, Germany and United States of America

Table 6 contains the number of stem cell donors per 10,000 inhabitants sorted by HLA-A, -B, -DR.

The mean number of HLA-A, -B, -DR typed donors per 10,000 inhabitants in the participating countries is 85.1 and median is 34.5; for HLA-A, -B plus HLA-A, -B, -DR typed donors the mean is 103.5 and median is 34.0.

It is obvious that there are still large differences in the number of donors per 10,000 inhabitants between countries. Of the world population 0.3% is registered as a hematopoietic stem cell donor.

Table 6

The number of stem cell donors per 10,000 inhabitants (sorted by HLA-A, -B, -DR per 10,000 inhabitants)

Country	Number of inhabitants x 10 ⁶	Number of stem cell donors		Number of donors per 10,000 inhabitants	
		ABDR	Total	ABDR	Total
Israel	7.7	697,346	825,130	904.8	1,070.6
Cyprus	1.2	79,929	131,780	691.8	1,140.6
Germany	81.1	4,268,725	5,164,484	526.0	636.4
Portugal	10.8	335,197	337,307	310.4	312.3
United States of America	316.4	6,955,017	7,535,315	219.8	238.1
Brazil	201.0	3,154,416	3,161,866	157.0	157.3
Poland	38.4	509,853	532,497	132.8	138.7
United Kingdom	63.4	822,220	897,012	129.7	141.5
Taiwan, Province of China	23.3	286,396	316,060	122.9	135.7
Canada	34.6	311,719	361,200	90.2	104.5
Croatia	4.5	36,481	36,812	81.5	82.3
Slovenia	2.0	15,584	15,593	78.2	78.3
Armenia	3.1	22,797	22,798	74.4	74.4
Denmark	5.6	40,630	42,430	73.1	76.4
Singapore	5.5	36,811	36,837	67.4	67.5
Australia	22.3	146,748	175,303	65.9	78.7
Switzerland	8.0	48,370	48,531	60.5	60.7
Norway	5.1	29,561	30,406	58.1	59.8
Belgium	10.4	58,359	65,890	55.9	63.1
Korea, Republic of	49.0	247,886	248,326	50.6	50.7
Czech Republic	10.6	49,631	64,760	46.8	61.0
Ireland	4.8	20,988	21,111	43.9	44.2
Italy	61.5	257,704	342,783	41.9	55.8
Finland	5.3	20,885	21,354	39.7	40.6
Austria	8.2	32,455	63,081	39.5	76.7
Japan	127.3	439,268	439,268	34.5	34.0
France	66.0	208,270	221,139	31.6	33.5
Sweden	9.6	27,303	41,928	28.3	43.5
Lithuania	3.5	9,155	9,157	26.0	26.0
The Netherlands	16.8	43,118	44,344	25.7	26.4
Greece	10.8	24,482	40,915	22.7	38.0
Thailand	67.5	142,868	147,439	21.2	21.8
Spain	47.4	97,361	130,070	20.6	27.5
New Zealand	4.4	4,429	10,960	10.1	25.1
Slovakia	5.5	4,715	4,883	8.6	8.9
Argentina	42.6	30,887	34,979	7.2	8.2
China	1,349.6	745,924	760,120	5.5	5.6
Hungary	9.9	3,989	6,739	4.0	6.8
South Africa	48.6	15,651	65,938	3.2	13.6
Serbia	7.2	2,217	2,243	3.1	3.1
Uruguay	3.3	535	535	1.6	1.6
Turkey	80.7	11,744	38,041	1.5	4.7
Republic of Macedonia	2.1	283	283	1.4	1.4

Table 6

The number of stem cell donors per 10,000 inhabitants (sorted by HLA-A, -B, -DR per 10,000 inhabitants)

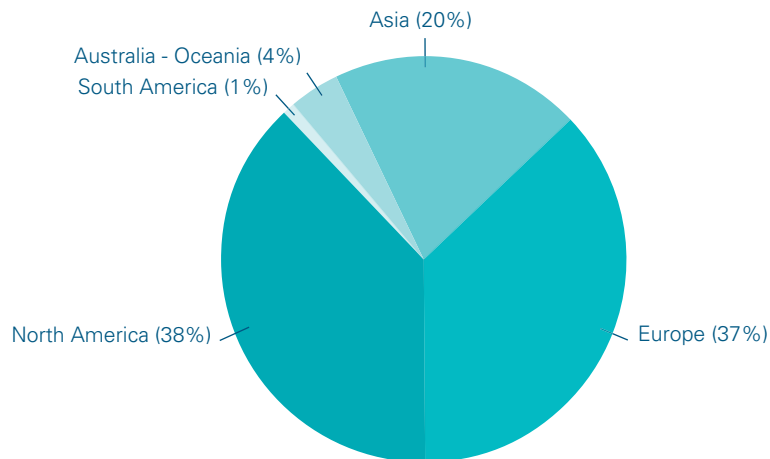
Country	Number of inhabitants x 10 ⁶	Number of stem cell donors		Number of donors per 10,000 inhabitants	
		ABDR	Total	ABDR	Total
Romania	21.8	2,647	2,721	1.2	1.2
Mexico	118.8	12,675	12,675	1.1	1.1
Bulgaria	7.0	684	692	1.0	1.0
Saudi Arabia	26.9	1,110	1,110	0.4	0.4
Iran, Islamic Republic of	79.9	2,488	2,794	0.3	0.4
India	1,220.8	33,443	34,712	0.3	0.3
Russian Federation	142.5	3,008	8,458	0.2	0.6
United Arab Emirates	5.5	45	45	0.08	0.08
Nigeria	175.5	261	276	0.02	0.02

4.2 Distribution of cord blood units

As shown in Figure 11, the majority of the cord blood units is stored in North American (38%) and European (37%) cord blood banks. The remaining cord blood units are from Asia (20%), Australia/Oceania (4%) and South America (1%).

Figure 11

Distribution of cord blood units per continent



© BMDW

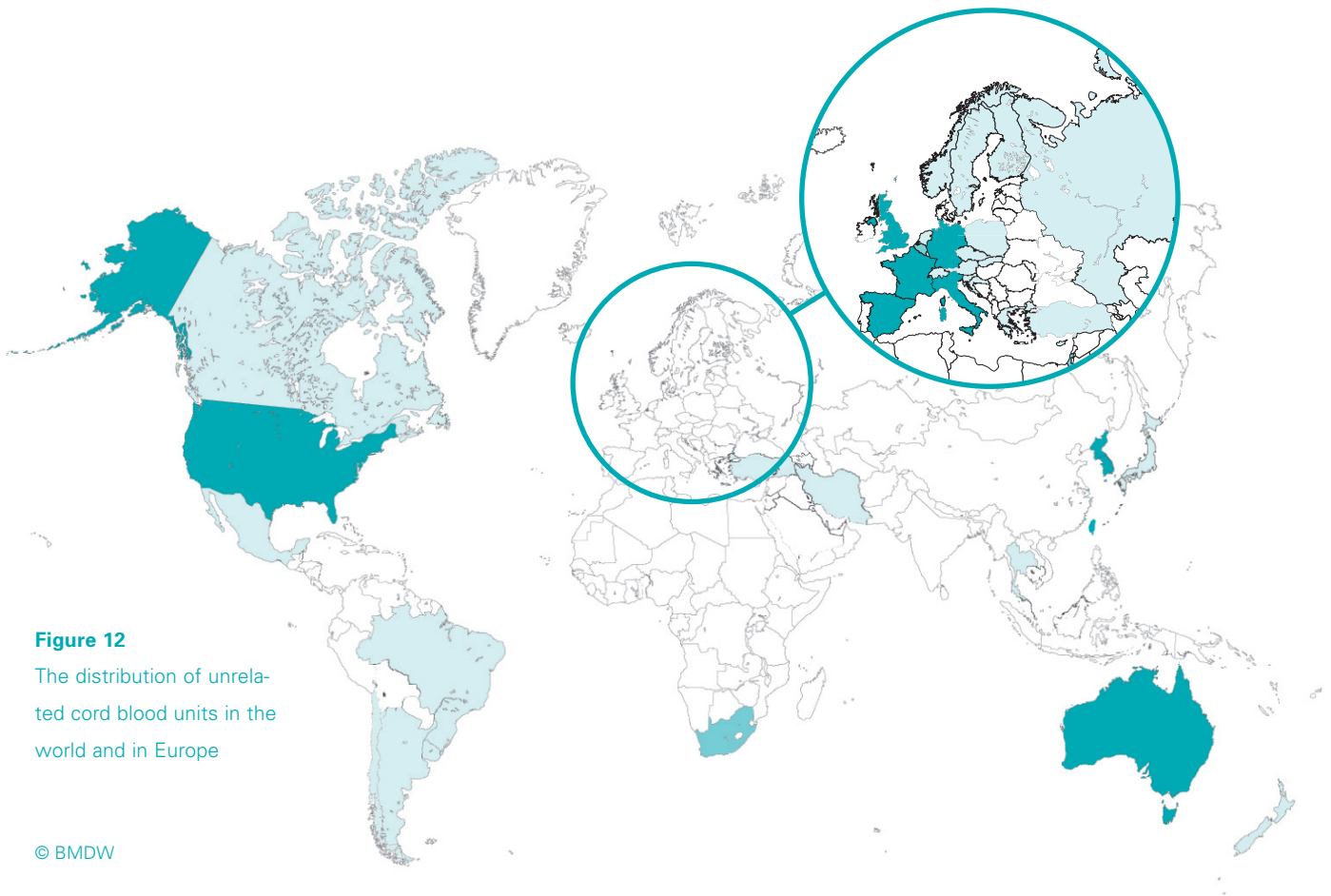


Figure 12

The distribution of unrelated cord blood units in the world and in Europe

© BMDW



The number of cord blood units per 10,000 inhabitants per country is given in Table 7. The data is sorted by the number of cord blood units per 10,000 inhabitants, starting with the highest number.

The mean number of cord blood units per 10,000 inhabitants in the participating countries is 5.2 and the median is 3.2.

Table 7

The number of cord blood units per 10,000 inhabitants per country

Country	Number of inhabitants x10 ⁶	Number of cord blood units	Number of cord blood units per 10,000 inhabitants
Taiwan, Province of China	23.3	64,014	27.5
Cyprus	1.2	1,951	16.9
Belgium	10.4	17,416	16.7
Israel	7.7	10,993	14.3
Australia	22.3	27,465	12.3
Spain	47.4	57,648	12.2
United States of America	316.4	218,972	6.9
Finland	5.3	3,365	6.4
Croatia	4.5	2,447	5.5
Republic of Korea	49.0	25,427	5.2
Switzerland	8.0	4,011	5.0
Italy	61.5	29,474	4.8
France	66.0	30,858	4.7
Germany	81.1	34,478	4.2
Czech Republic	10.6	3,984	3.8
United Kingdom	63.4	21,222	3.3
Sweden	9.6	3,115	3.2
Austria	8.2	2,605	3.2
Slovakia	5.5	1,720	3.1
Greece	10.8	2,779	2.6
Canada	34.6	7,937	2.3
The Netherlands	16.8	3,336	2.0
Slovenia	2.0	245	1.2
Poland	38.4	3,162	0.8
Argentina	42.6	1,962	0.5
Iran, Islamic Republic of	79.9	3,584	0.4
Chile	17.2	640	0.4
Japan	127.3	4,698	0.4
Russian Federation	142.5	5,142	0.4
Thailand	67.5	2,040	0.3
Brazil	201.0	2,987	0.2
Turkey	80.7	765	0.1
Mexico	118.8	308	0.03

5

Number of HLA Phenotypes

Figure 13 states the number of stem cell donors and cord blood units typed for HLA-A, -B, -DR split antigens, the number of different HLA-A, -B, -DR split phenotypes and the number of unique phenotypes.

Unique phenotypes are defined as occurring only once in the BMDW database. In 2013 there were 13,789,060 HLA-A, -B, -DR split typed stem cell donors and cord blood units representing 1,526,060 different phenotypes.

Forty-five percent of these were unique phenotypes (691,199). These donors were mainly typed at low resolution DNA typing.

The number of unique phenotypes rises even more, if typing is performed on the allele levels for the HLA-A, -B, -C, -DR and -DQ loci.

Figure 13

Number of stem cell donors and cord blood units per year

■ HLA-A, -B, -DR split typed stem cell donors and cord blood units

■ HLA-A, -B, -DR different phenotypes

■ HLA-A, -B, -DR unique phenotypes

© BMDW

Number of stem cell donors and cord blood units and phenotypes (x million)

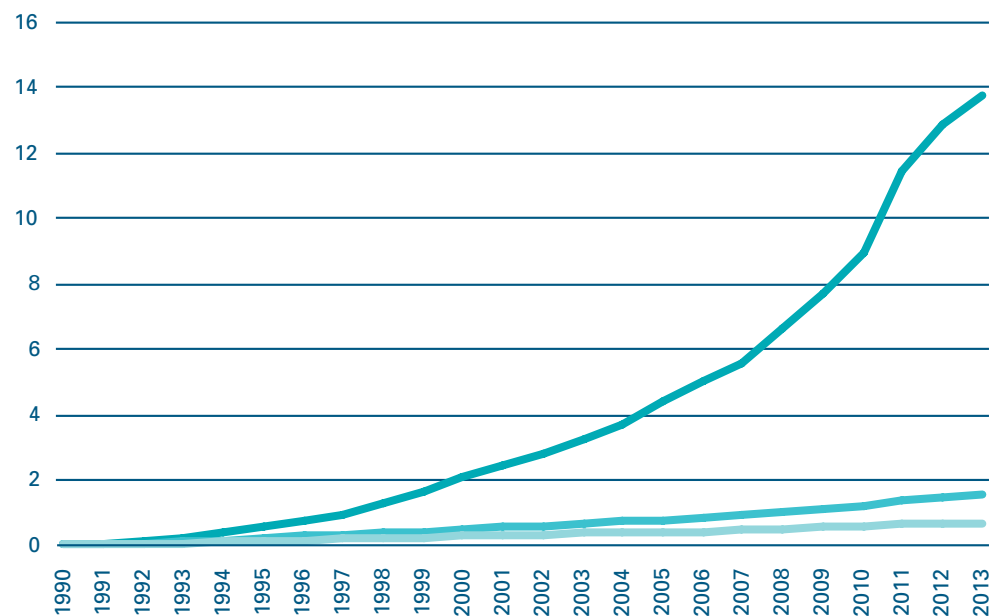
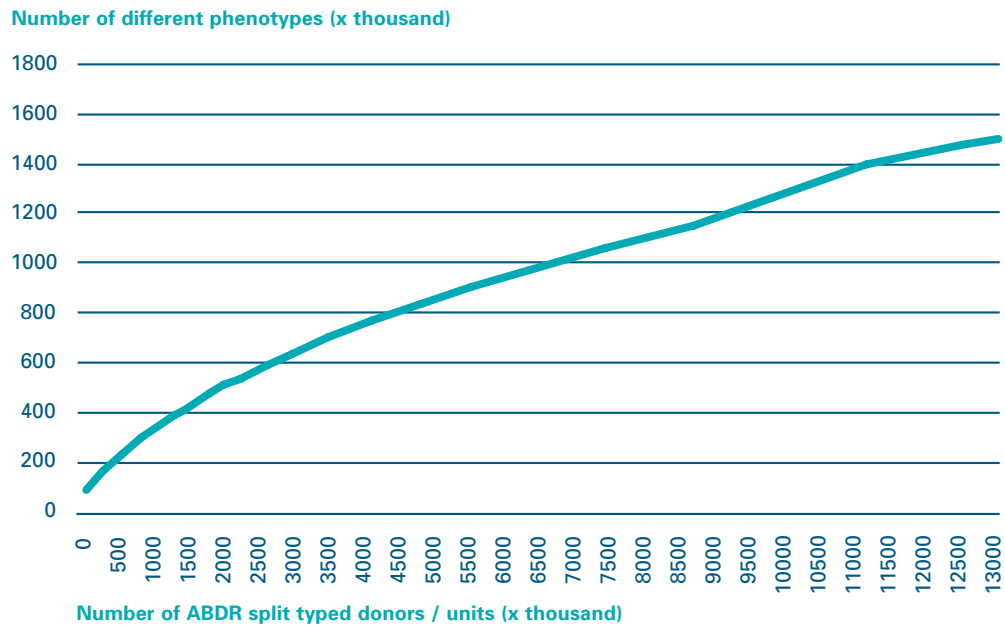


Figure 14 shows that new stem cell donors and cord blood units still add new HLA-A, -B, -DR split phenotypes to the BMDW database.

Figure 14

Increase in the number of different phenotypes added to the BMDW database

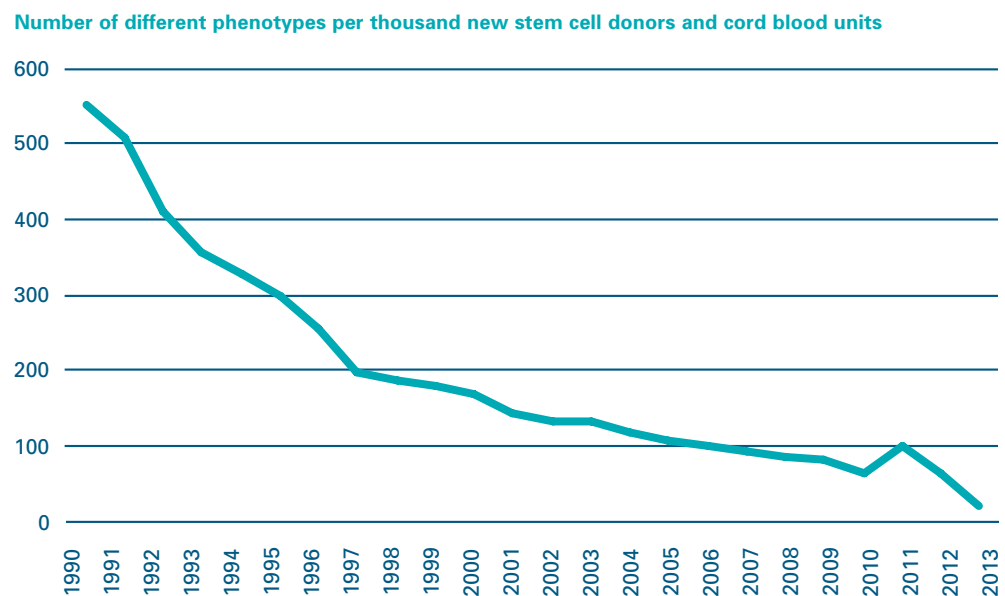


© BMDW

The number of different new HLA-A, -B, -DR phenotypes per 1,000 new stem cell donors and cord blood units is given in Figure 15. In 1990 more than half of the new donors and cord blood units had an HLA-A, -B, -DR split phenotype that was not yet present in the BMDW database. In 2013 one out of forty-seven donors and cord blood units add a new HLA-A, -B, -DR split phenotype to the database. In 2012 this was one out of fifteen.

Figure 15

Number of different new HLA-A, -B, -DR split phenotypes per thousand new stem cell donors and cord blood units



© BMDW

The relative contribution to BMDW of stem cell donors per country with an HLA-A, -B, -DR split phenotype is shown in Figure 16. There are large differences between the countries; countries on the left-hand side of the curve such as Nigeria, Saudi Arabia and South Africa have a relatively high contribution of new HLA phenotypes to BMDW, while countries on the right-hand side such as Ireland, Slovenia and Norway added relatively few new HLA phenotypes to BMDW. This means that many of the

phenotypes of those countries are already in BMDW, which is of course good news for the patients in those countries.

Figure 16

The relative percentage of unique HLA-A, -B, -DR split phenotypes of stem cell donors per country contributed to the entire database in BMDW

Remark

Republic of Macedonia and United Arab Emirates had too few HLA-A, -B, -DR split typed donors to be depicted in Figure 16

© BMDW

Relative percentage of unique phenotypes in 2013

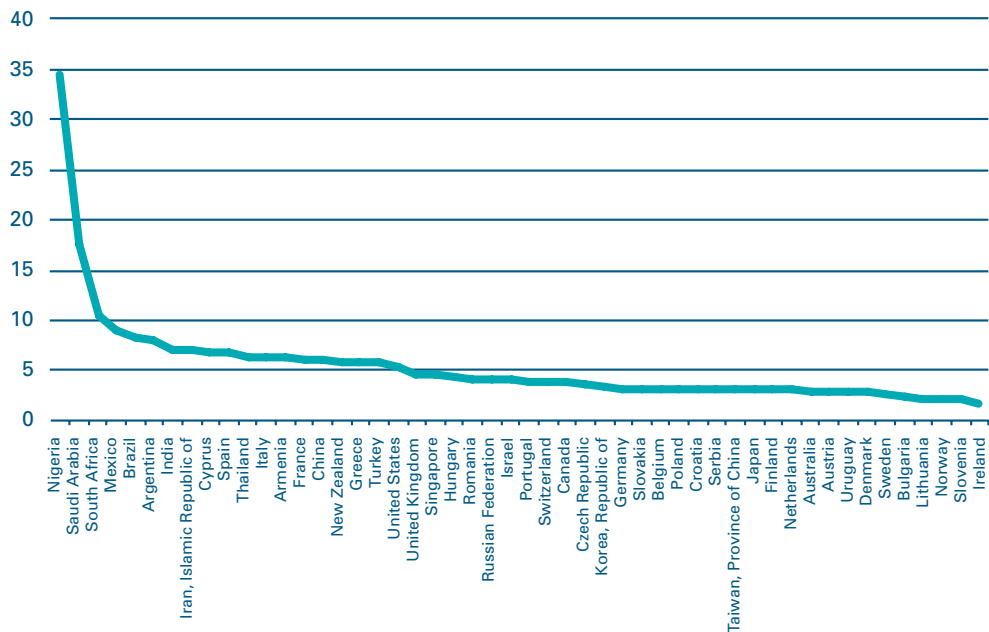


Figure 17 depicts the relative contribution of cord blood units with new HLA phenotypes in the entire BMDW database. Figure 18 shows the percentage of unique HLA-A, -B, -DR split phenotypes of stem cell donors contributed to the donor BMDW file (excluding cord blood units). The difference between Figure 16 (entire BMDW database) and Figure 18 (only the stem cell donor data in BMDW) is minimal. In virtually all countries the cord blood units have a much higher relative contribution of new HLA phenotypes to BMDW than the stem cell donors of the same country, indicating the success of the cord blood banks in recruiting cord blood units from minority groups.

Figure 17

The relative percentage of unique HLA-A, -B, -DR split phenotypes of cord blood units per country contributed to the entire database in BMDW

Remark

Slovenia had too few HLA-A, -B, -DR typed cord blood units to be depicted in Figure 17

© BMDW

Relative percentage of unique phenotypes in 2013

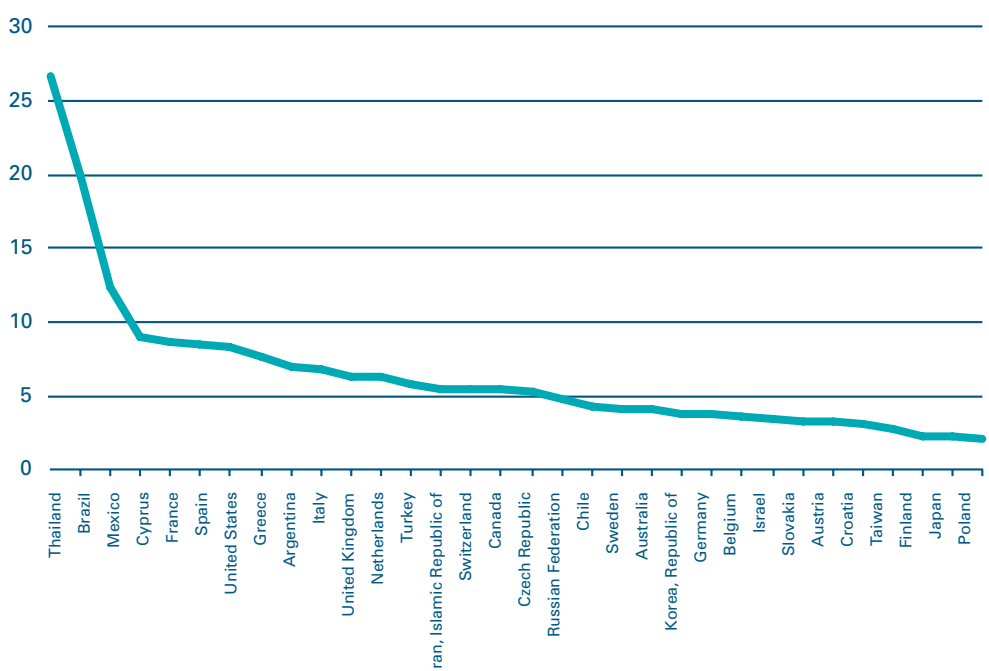


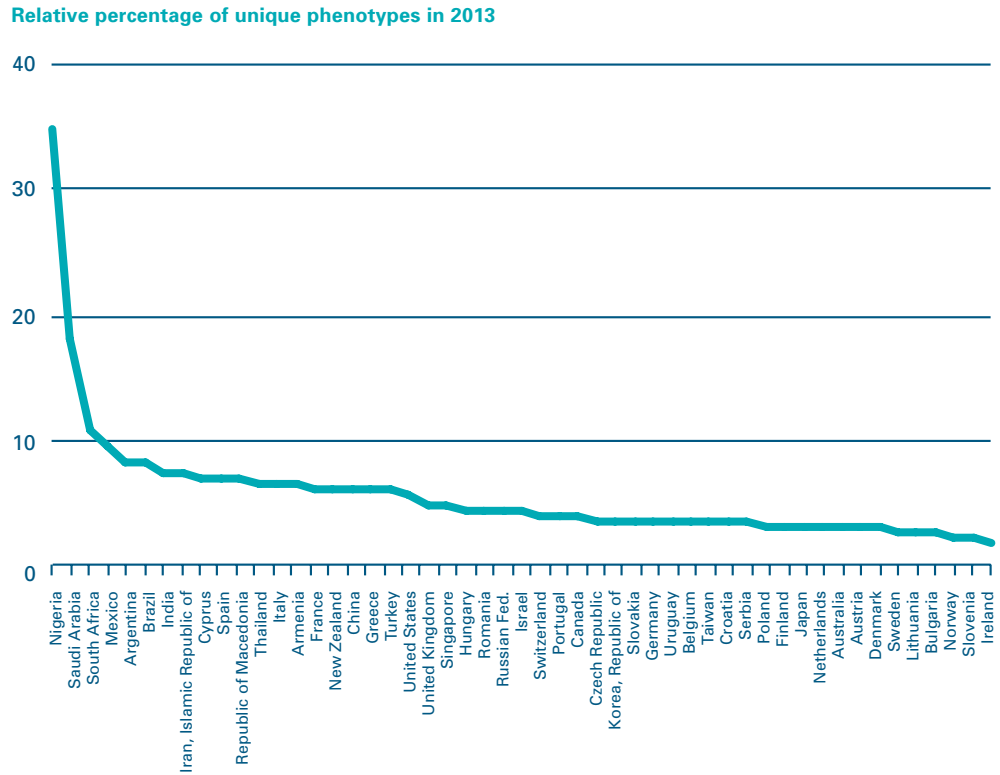
Figure 18

The relative percentage of unique HLA-A, -B, -DR split phenotypes of stem cell donors per country contributed to the stem cell donor database in BMDW

Remark

Republic of Macedonia and United Arab Emirates had too few HLA-A, -B, -DR split typed donors to be depicted in Figure 18

© BMDW



In Figure 19 the percentage of unique HLA-A, -B, -DR split phenotypes of cord blood units contributed to the cord blood unit data only (excluding donors) is given. The large difference between Figures 17 and 19 indicate that the number of phenotypes of the cord blood units within BMDW is still limited.

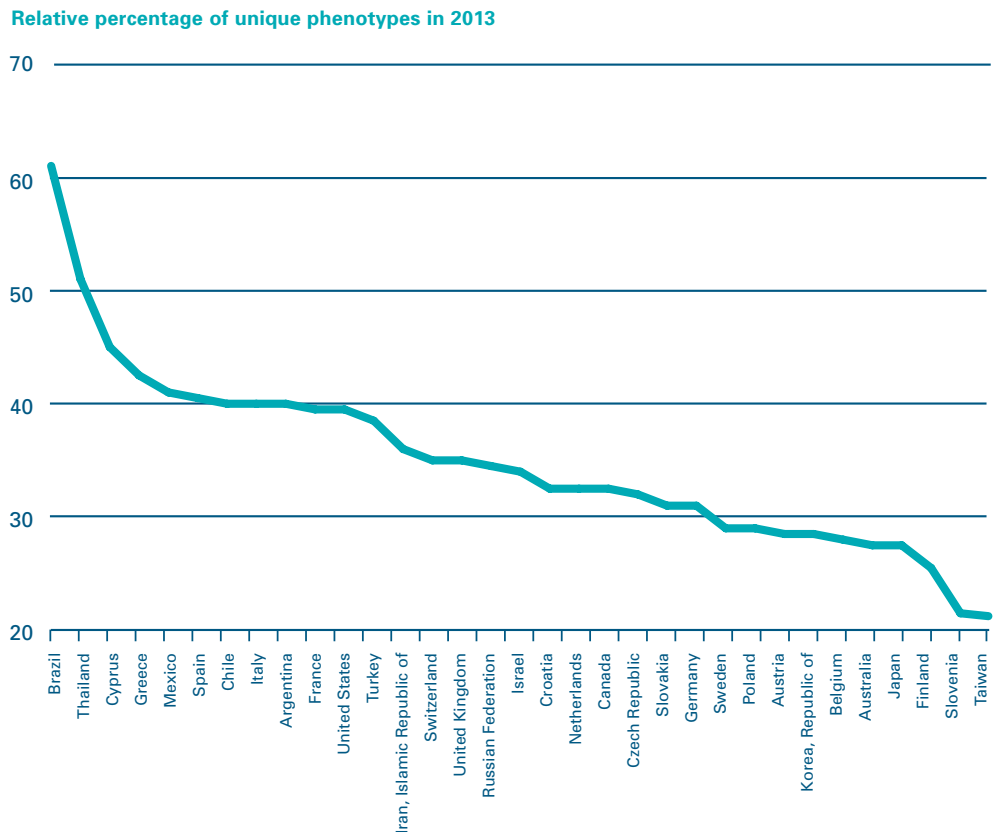
Figure 19

The relative percentage of unique HLA-A, -B, -DR split phenotypes of cord blood units per country contributed to the cord blood unit database in BMDW

Remark

Slovenia had too few HLA-A, -B, -DR typed cord blood units to be depicted in Figure 19

© BMDW



6

Information Technology

6.1 Developments in 2013

In 2013 the handling of deleted alleles has changed conform the WMDA guidelines.

The CRF's which were implemented in 2013 are:

- CRF032: Remote access via Web service to the BMDW Match program
- CRF033: NIMA Match: 2 mismatches/1 NIMA match category.
To make this possible the match algorithm was re-implemented. The new implementation is validated for WMDA Match validation set 1 and the validation with WMDA Match validation set 2 is started.
- CRF040: Remove split MM donors from regular match results.
The split mismatch donors are now included in the corresponding mismatch option.

Also a start was made to combine the cord blood match and the NIMA match program.

These changes in the match program are in beta test and will become available in 2014.

Change Requests received

The BMDW Office welcomes feedback and suggestions for improvements. Change requests may be submitted to the BMDW Office using the BMDW Change Request Form¹. The BMDW Office will evaluate the change requests received, and if needed consult the Advisory Committee, and ask the Editorial Board for approval.

In 2013 the following new change requests have been received:

- **CRF038 – WMDA accreditation status in donor match list**
On donor search result form it should be made clear which of the donors are from a WMDA accredited registry. Suggest using colour for this. List of WMDA accredited registries can be found on www.worldmarrow.org
- **CRF039 – Selected units to separate report**
It should be possible to select donors or cord blood units from the BMDW match results on a separate report which the user can use to send to its transplant centre.
- **CRF040 – Remove split mm donors from regular match results**
Remove split mismatched donors from regular match results and include them in the mismatch results.
Note: this CRF is implemented in 2013.

¹ Available on the BMDW website, in the Downlands section

- **CRF043 – NETCORD-FACT status in CBU match list**
Indicate those cord blood units that come from a NETCORD/FACT accredited cord blood bank. Indicate by using colours? Information must be provided by the cord blood bank.
- **CRF044– No BMDW export of derived search determinants-serology**
No BMDW export of derived search determinants/serology:
BMDW needs to derive serological data/search determinants for matching.
 1. These derived data should not be exported.
 2. Existing data should not be replaced by derived data.
- **CRF045 – BMDW should export maternal HLA data**
BMDW should export maternal HLA data if available.

CRF040 was already implemented and the other change requests will go through the process of approval.

6.2 Use of BMDW

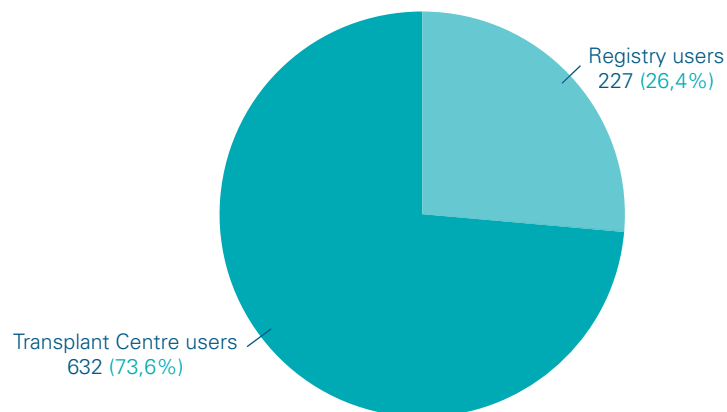
On-line services

At the end of 2013 859 users were authorized to access the on-line services of BMDW (Figure 20).

Transplant centre users remain the largest group of users of BMDW (73.6%).

Figure 20

The users of on-line services (in total: 859)



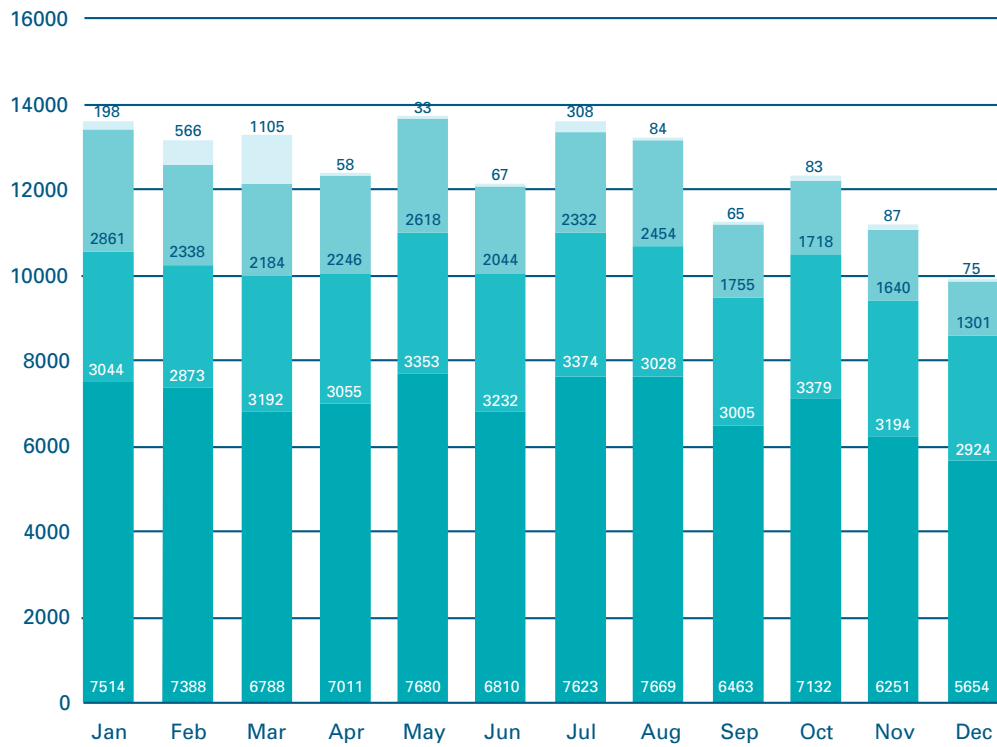
© BMDW

Figure 21 shows the monthly usage of the BMDW online match programs for 2013. The number of regular matches and mismatches was higher than in 2012, but the cord blood matches and NIMA matches were slightly lower. But as shown in Figure 22, the overall number of matches was slightly higher in 2013.

Figure 21

The monthly usage of new BMDW on-line match programs in 2013

- NIMA match Program
- Cord Blood Match Program
- Mismatch Program
- Regular Match Program

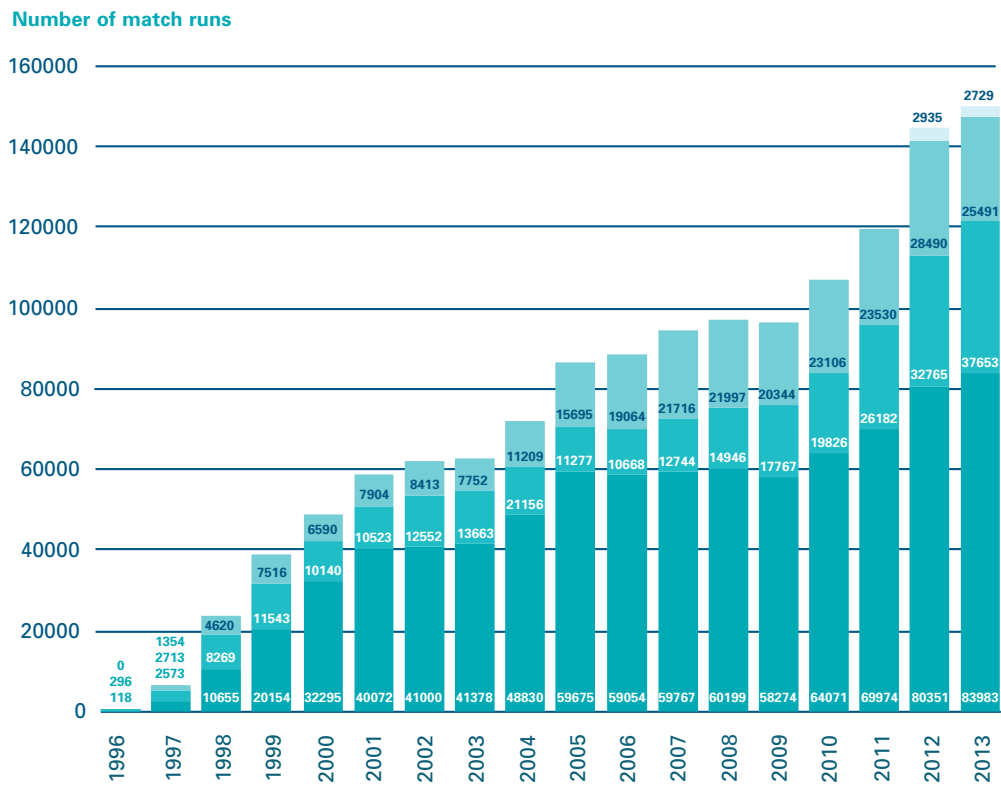


© BMDW

Figure 22

Usage of BMDW on-line match programs per year

- NIMA match Program
- Cord Blood Match Program
- Mismatch Program
- Regular Match Program



© BMDW

7

Financial overview

	Adjusted 2013 Budget	2013 Realisation
Staff office	€ 250,046	€ 249,079
Travel expenses	€ 7,210	€ 8,669
Hardware components	€ 1,550	-
CRF's	-	€ 12,750
Tel/sdsl/fax/annual report	€ 5,956	€ 7,910
BMDW consultancy	€ 21,216	€ 15,496
Debt write off	€ 5,000	€ 6,570
Total costs	€ 290,978	€ 300,444

Annual fees	€ 252,914	€ 275,696
From Transplant Centers	€ 3,703	€ 2,680
From download	€ 30,375	€ 23,250
CRF's	€ 11,000	€ 12,720
Total revenues	€ 297,992	€ 314,346
loss/gain	€ 7,014	€ 13,902

Realisation 2013

The revenues in 2013 increased and ended € 16,354 above plan mainly caused by the increase of annual fees due to increase in number of registries/CBB.

The download fees decreased in 2013.

Staff office costs ended in line with budget. No hardware costs were necessary in 2013. Mainly due to the CRF's costs, the 2013 costs ended € 9,466 above plan.

The 'accountant driven' debt write off ended € 1,570 above budget.

The total result of € 13,902 was € 6,888 above budget. This result will be added to Europdonors BMDW reserves that are available for IT and other investments.

The ultimo 2013 reserve amounts € 42,581.

8

Board and Staff

Editorial Board

The 110 participating stem cell donor registries and cord blood banks/registries
(see Table 1 and 2)

Chairman of the Editorial Board

Machteld Oudshoorn, PhD

Office

Renée J.H. Bouwens-van der Klaauw

Staff

Carine J. Mijnaerends, MSc, Managing Director

Atjan J. Hop, Finance

Angelo E.E.A. Melis, BSc, IT

Leo J. Ebeling, MD, Consultant

9

Advisory Committee

Torstein Egeland, MD, PhD (chair)

Dennis L. Confer, MD,

Jeremy Chapman, MD

Steven Marsh, PhD

Cristina Navarrete, PhD

Hans-Georg Rist,

Edward K.L. Yang, MD

