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D1.3 List of EU member registries and their progress on the implementation of GRID

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Organisation: **World Marrow Donor Association (WMDA)**
LEAR: Esther Pustjens
Project coordinator: Lydia Foeken
Tel: 0031 88 505 7900
E-mail: lydia.foeken@wmda.info
Organisation website address: www.wmda.info

GLOBAL
REGISTRATION
IDENTIFIER FOR
DONORS

GRID—

UNIQUE DONOR IDENTIFICATION



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1. Preface

This report, as part of the 2019 work programme of the World Marrow Donor Association (WMDA) for the EU Third Health Programme (2014-2020), details the status of each European Union (EU) member registry in relation to the implementation and use of the Global Registration Identifier for Donors (GRID). This will allow progress to be monitored, and for support to be targeted to those members who are making slower than anticipated progress. It will also enable us to monitor the percentage of donors who have a GRID ID.

Chapter 2 describes background information about the GRID project in addition to the project plan describes in Deliverable D1.2 Progress report GRID (2018). Following, *Chapter 3* displays the whole list of WMDA member organisations within the EU member states that have implemented GRID. It is clear that EU member states are doing exceptionally well on the basis of GRID implementation. Unfortunately, one organisation is lagging behind. Finally, in *Chapter 4* the 4 Third Countries that have not implemented GRID yet, including the reasons and solutions are shown.

On the website **GRID Status: XML Update Dash** on WMDA Share, the complete overview of the GRID implementations statuses of all WMDA member organisations is manifested (*Figure 1*).

Figure 1. GRID Status: XML Update Dash on WMDA Share – last update 13 December 2019

GRID Status: XML Update Dash

Created by [redacted] last modified on Oct 02, 2019

[GRID in WSMS](#)

Check detail track of **GRID status** and survey.

Data is updated every hour.

Overview of GRID update

Orgs with GRID	Orgs no GRID	Orgs Partly GRID	Total Donor records	Total GRID records	Percentage	Last Updated Time
73	5	1	35,872,777	33,982,745	94.73	2019-12-13 09:40:00+01

This page allows progress to be monitored, and for support to be targeted to those members who are making slower than anticipated progress. It also enables WMDA to monitor the percentages of donors who have a GRID ID.

This page is currently only accessible for WMDA members. *Appendix 2* displays the complete list of GRID updates.

2. Background on GRID

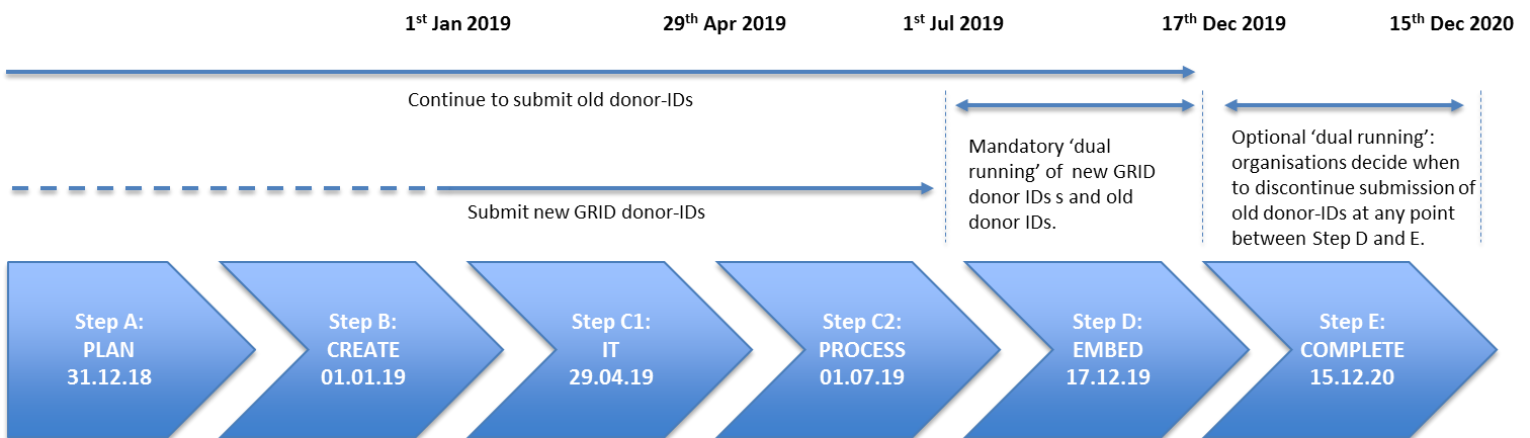
Unrelated hematopoietic progenitor cell (HPC) donor registries and issuing organisations (IO) facilitate exchange of HPC products throughout the world. To improve communication across national and international borders, and to prevent errors in identification of donors, a system to uniquely and consistently identify potential donors on a global scale is needed.

To this end, the World Marrow Donor Association (WMDA) worked in collaboration with International Council for Commonality in Blood Banking Automation (ICCBBA) to develop and implement a Global Registration Identifier for Donors (GRID). The GRID Project is a multi-phase, multi-year effort to achieve implementation on a global basis.

Given the international nature of the work done by the organisations providing blood stem cell products, a system to uniquely identify potential donors on a global scale is needed to facilitate communication and prevent errors in identification of donors.

A GRID implementation timeline - *Figure 2* - was developed in 2018, to let organisations proceed more smoothly into complete implementation. To ease the implementation across organisations, WMDA have extended the implementation plan for step C to allow for changes around the Operational processes within their organisations.

Figure 2. GRID implementation timeline 2018 - 2020



- Get your ION-registration number from ICCBBA.
- Define your plan how you will implement GRID in your organisation.

- Creation of a GRID **field** in your XML data submission to the Search & Match Service (BMDW) is mandatory.
- Where you have assigned a GRID to your donors please, submit it in your XML file and you will see the GRID shown in Search & Match (BMDW).
- If your GRID field is blank it will show as blank alongside the old donor IDs.

- All IT systems (for example your own registry software; EMDIS; Search & Match Service) **must** have a GRID populated for all donors. GRID is visible in all IT systems.
- If you need more time to roll out your operational processes, you have until 1st July.

- Ensure all your operational procedures contain GRIDs (for example labels, paperwork, working instructions) and that all your transplant centres, donor centres, collection centres and other stakeholders are fully aware of your GRIDs.

- You **must** be able to use GRID as the sole donor identifier for all your donors and any incoming donors
- You may continue to use your old donor IDs alongside their GRID as a secondary identifier should you wish to.

- GRID **must** be fully implemented for all listing organisations and will be the only donor identifier to be shown in the Search & Match Service.
- Old donor IDs will no longer be accepted by the Search & Match Service.

- C*1: IT track: The expectation for mandatory GRID implementation is defined as any technical process that involves interaction with other organisations (for example completing the EMDIS IPs), but does not include any technical changes that are entirely internal (e.g. screen changes or internal database changes). GRID as mandatory in IT will remain from the beginning of step C on 29 April.
- C*2: Operational track: The expectation of GRID implementation during this step includes search reports, email communications, documents and forms, blood sample and product labelling, invoicing etc. Operational changes will be mandatory from 1 July 2019.

For more information on the previous and coming steps, please visit [GRID: WMDA Implementation Deadlines](#) on WMDA Share.

Despite all the efforts from both the WMDA office and the GRID Task Force, there are 5 registries that have not implemented GRID yet: one within the EU member states and 4 outside. WMDA office and the GRID Task Force (expert volunteers from across the WMDA community) are doing everything in their power to reach out to those organisations, find out their struggles and offer support to ease the GRID implementation.

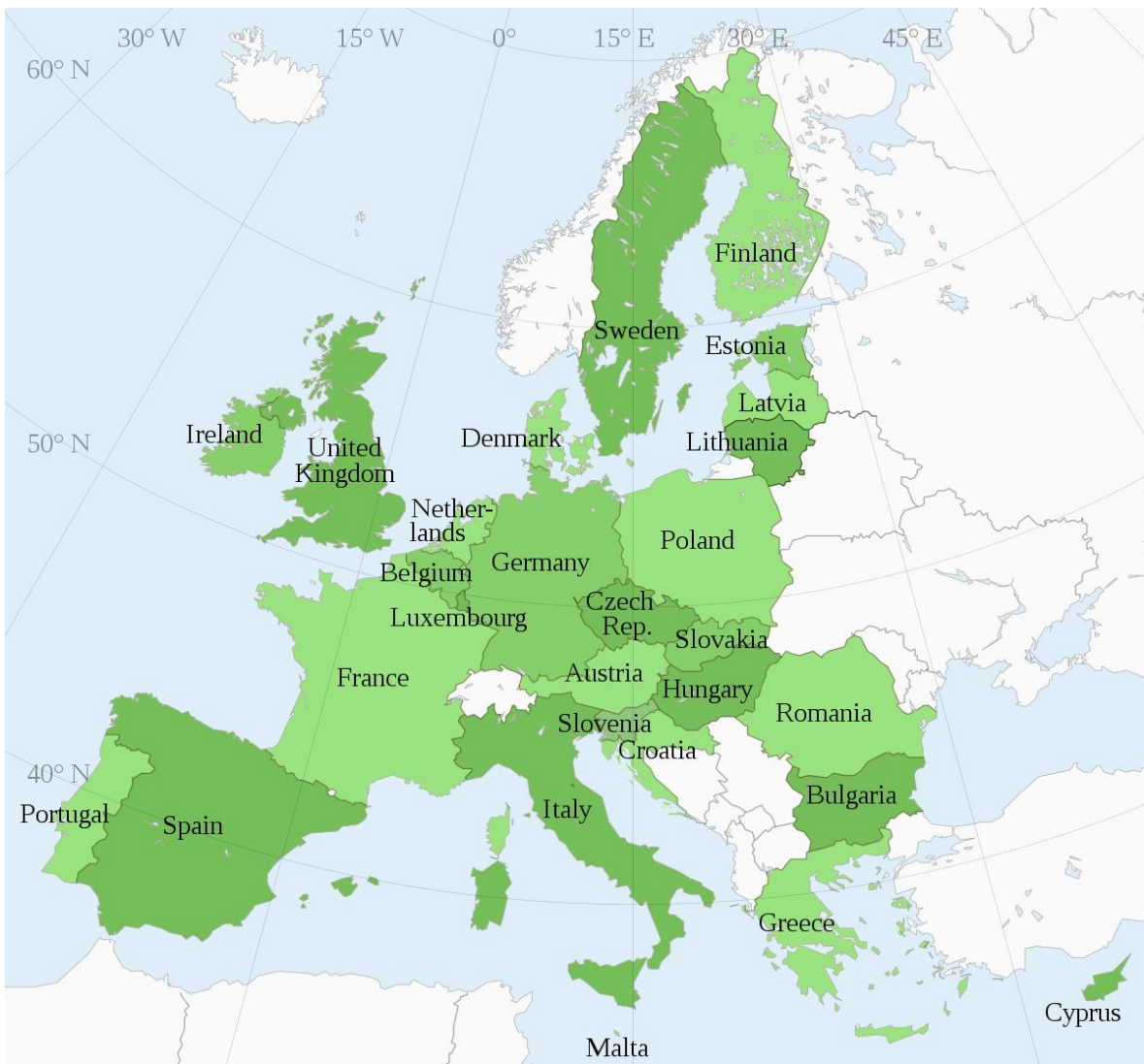
To get a better picture of the GRID implementations in the WMDA member organisations, WMDA office sent out a survey (*Appendix 1*) in the annual GRID newsletter to ascertain the status of GRID implementations of the WMDA member organisations. This was sent out to all WMDA member organisations to check for the GRID implementation status of their organisation.

3. EU Member States - GRID implementation status

In 2019, the European Union (EU) consists of 28 member states. Each member state is party to the founding treaties of the union and thereby subject to the privileges and obligations of membership. Unlike members of most international organisations, the member states of the EU are subjected to binding laws in exchange for representation within the common legislative and judicial institutions. Member states must agree unanimously for the EU to adopt policies concerning defence and foreign policy. Subsidiarity is a founding principle of the EU.¹

Figure 1 displays all countries in Europe that are EU member states. Estonia, Malta and Latvia do not have hematopoietic stem cell organisations.

Figure 1. EU Member states



¹ https://en.wikipedia.org/wiki/Member_state_of_the_European_Union

The last couple of years, WMDA office and the GRID Task Force provided support and guidance to all issuing organisations on all operational matters related to the GRID. In addition, they accommodated recommendations and guidance to support the implementation of GRID in the international stem cell community. These recommendations are approved by the WMDA board members before it being communicated to the wider community.

In 2019, WMDA succeed in almost 100% GRID implementation. Especially the EU member states were successful in the implementation of GRID. On 13 December 2019, **99,83%** of the WMDA member organisations within the EU member states had GRID fully implemented (*Table 1*). That is more than the worldwide percentage.

Table 1. EU member states vs. Global data

EU member states		
Total Donor records	Total GRID records	Percentage
15,598,534	15,571,651	99,83
Worldwide		
Total Donor records	Total GRID records	Percentage
35,872,777	33,982,745	94.73%

Only the Against Leukemia Foundation MDR (ALF), Warsaw Registry has not implemented GRID yet despite several attempts from WMDA office to offer support. The overview in *Table 2* includes the name of the listing organisation, the country, ION, number of total donor records, last update, shipments (both national and international), the reason for delay and if they are a paying WMDA member.

Table 2. EU member state organisation - record and reason

Name	Country	ION	Record	Last updated	Shipments National	Shipments International	Reason	Membership paid
Against Leukemia Foundation MDR (ALF), Warsaw	Poland	3918	26,883	2019-01-03	16 (2018)	4 (2018)	Political	✓

The official list of total donor records and GRID records of WMDA organisations within the EU member states is specified in *Table 3*.

*Table 3. EU member states - WMDA member organisations**

Organisation	Total Donor records	GRID records	Percentage
Austria			
Austrian Bone Marrow Donor Registry	80,947	80,947	100
Verein Geben für Leben	58,306	58,306	100
Belgium			
Marrow Donor Program Registry Belgium	83,305	83,305	100
Bulgaria			
Bulgarian Bone Marrow Donor Registry	1,592	1,592	100
Croatia			
Croatian Bone Marrow Donor Registry	56,770	56,770	100
Republic of Cyprus			
Cyprus Bone Marrow Donor Registry	172,311	172,311	100
Cyprus Paraskevaïdio Bone Marrow Donor Registry	5,003	5,003	100
Czech Republic			
Czech Stem Cells Registry Prague	32,562	32,562	100
Czech National Marrow Donor Registry Plzeň	86,934	86,934	100
Denmark			
Danish Stem Cell Donors - West	42,265	42,265	100
Danish Stem Cell Donors - East	19,897	19,897	100
Finland			
Finnish Stem Cell Registry	50,889	50,889	100
France			
France Greffe de Moelle Registry	307,860	307,860	100
Germany			
Zentrales Knochenmarkspender-Register Deutschland	8,923,596	8,923,596	100
Greece			
EOM Hellenic Transplant Organization	155,332	155,332	100
Hungary			
Hungarian Stem Cell Donor Registry	7,075	7,075	100
Ireland			
Irish Unrelated Bone Marrow Registry	21,603	21,603	100
Italy			
Italian Bone Marrow Donor Registry	442,115	442,115	100
Organisation	Total Donor records	GRID records	Percentage

Lithuania			
Lithuanian National Bone Marrow Donor Registry	12,101	12,101	100
Luxembourg			
Luxembourg Marrow Donor Program	12,457	12,457	100
Netherlands			
Matchis Foundation	305,094	305,094	100
Poland			
Against Leukemia Foundation MDR	26,883	0	0
Poltransplant	258,123	258,123	100
Fundacja DKMS	1,505,823	1,505,823	100
Portugal			
CEDACE/Portuguese BMD Registry	398,694	398,694	100
Romania			
National Registry of Hematopoietic Stem Cells Voluntary Donors	39,517	39,517	100
Slovakia			
Slovak National BMD Registry	15,036	15,036	100
Slovenia			
Slovenia Donor	19,142	19,142	100
Spain			
Registro de Donantes de Médula Ósea (REDMO)	398,189	398,189	100
Sweden			
Tobias Registry	230,371	230,371	100
United Kingdom (UK)			
Anthony Nolan London	777,358	777,358	100
NHS Blood and Transplant - BBMR	375,397	375,397	100
DKMS United Kingdom	608,997	608,997	100
Welsh Bone Marrow Donor Registry	66,990	66,990	100

*There are no stem cell donor registries in Estonia, Malta and Latvia

4. Third Countries - GRID implementation status

In addition to the WMDA organisations that are part of the EU Member states, 4 other registries outside the EU have not yet implemented GRID. With 3 of those 4, WMDA office is in close contact. Due to different reasons (*Table 4*), they are not up to date with GRID implementation. However, we do expect them to keep up by the end of 2020. Therefore, we extended their deadline to December 2020.

The overview in *Table 4* includes the name of the listing organisation, the country, ION, number of total donor records, last update, shipments (both national and international), the reason for delay and if they are a paying WMDA member.

Table 4. Third Country organisations - records and reasons

Name	Country	ION	Records	Last updated	Shipments National	Shipments International	Reason	Membership paid
Japan Marrow Donor Program	Japan	4364	523,465	2019-07-09	1209 (2018)	5 (2018)	Political	✓
Korean Network for Organ Sharing	Korea	8405	344,603	2019-02-25	550 (2017)	3 (2017)	Unclear	✓
Chinese Marrow Donor Program	China	2197	993,145	2017-11-09	766 (2017)	35 (2017)	IT	✓
Chaim Sheba Medical Centre	Israel	4068	1,796	2015-05-06	-	-	Unclear	✗

Please find below the different organisation chapters, including more detailed information concerning the reasons for no GRID implementation yet and additional email conversations between WMDA office and the various organisations.

Japan Marrow Donor Program

In September 2018, the CEO of WMDA office had a meeting with the CEO of Japan Marrow Donor Program (JMDP) during the Worldwide Network for Blood & Marrow Transplantation (WBMT) in Beijing (China). The organisation was – again – notified about the importance of worldwide GRID implementation. In addition, they were informed that WMDA is prepared to assist the JMDP in any way they see necessary to further our common aims and goals. JMDP informed WMDA that they have to discuss this with their Ministry of Health, Labor and Welfare as well as the Japanese Red Cross Society.

It turns out that in Japan the law has to be changed in order for the organisation to make it possible to implement GRID.

Korean Network for Organ Sharing

In October 2019, the CEO of the WMDA office went to Korea for a conference and had the option to speak to representatives of the organisation. Also, this organisation was notified about the importance of worldwide GRID implementation. Up until now, they did not implement GRID yet, but they indicate that they are going to have some difficulties but they will cooperate with the WMDA.

Chinese Marrow Donor Program

The organisation first needs time to update their IT systems and upload their XML file data. After this is finished, they will start implemented GRID. At the moment, there is no specific time schedule available for this. WMDA's data specialist, originally from China, is in close contact with China to help them wherever is needed.

Chaim Sheba Medical Centre

This registry has very limited resources. In addition, this organisation did not pay their recent WMDA membership and did not report their shipment numbers. listing their donors in the WMDA Search & Match service.

Partially GRID implementation

In addition, there is one organisation that has implemented GRID for almost 100%. This is the Serbian Bone Marrow Donor Registry, with 95.90% GRID records of their total donor records (*Table 5*).

Table 5. Organisations who partly implemented GRID

Name	ION	Records	GRID records	Percentage	Last update
Serbian Bone Marrow Donor Registry	4650	3,417	3,277	95.90	2019-07-18

Currently, WMDA's IT experts are in close contact with this registry and offering support. WMDA office is expecting this issue will be solved soon.

Appendix 1. Survey GRID - Status

GRID - what is the status?

GRID - what is the status

The GRID Task Force would like to set up a page where all WMDA Member Organisations can monitor how far their international colleagues are with the implementation of GRID in their organisation.

Please fill in the questionnaire below and let us know.

1. Are you on track with the implementation timeline?

(the next deadline is on December 17th, when organisations can discontinue submission of old donor-IDs at any point)

- Yes
 No

2. Did you update your local software to accommodate GRID? If not, when is that scheduled?

- Yes
 No, please provide a date

3. Did you update your local standards, forms, labels?

- Yes
 No

4. Did you share the goals and timelines with your national network (transplant centres, collection centres)?

- Yes
 No

5. Did you organise your registry staff?

- Yes
 No

Submit

0%

Appendix 2. Overview of GRID update WMDA member organisations

Name	Listing Org	Records	ION	GRID records	Percentage	Created_at
JMDP - Japan Marrow Donor Program	4364	523,465	4364	0	0	2019-11-20 04:46:05
KONOS - Korean Network for Organ Sharing	8405	344,603	8405	0	0	2019-02-25 06:34:50
Against Leukemia Foundation MDR (ALF), Warsaw	3918	26,883	3918	0	0	2019-01-03 12:20:47
Chaim Sheba Medical Centre	4068	1,796	4068	0	0	2018-04-06 07:09:47
Chinese Marrow Donor Program	2197	993,145	2197	0	0	2018-04-06 02:35:05
Serbian Bone Marrow Donor Registry	4650	3,417	4650	3,277	95.9028387474393	2019-07-18 17:11:21
Fundación de Beneficencia Pública DKMS by intermediary of DKMS Registry	4596	37,687	1574	37,687	100	2019-12-13 05:21:24
DKMS BMST Foundation India	4596	37,246	9935	37,246	100	2019-12-13 05:21:06
Finnish Stem Cell Registry	9738	50,843	9738	50,843	100	2019-12-12 19:07:38
Tobias Registry	5285	231,635	5285	231,635	100	2019-12-12 19:07:08
Danish Stem Cell Donors - West	2015	42,176	2015	42,176	100	2019-12-12 19:05:29
South African Bone Marrow Registry	8118	73,571	8118	73,571	100	2019-12-12 19:05:03
Norwegian Bone Marrow Donor Registry	7214	35,540	7214	35,540	100	2019-12-12 19:04:17
Ezer Mizion Bone Marrow Donor Registry	4987	1,004,104	4987	1,004,104	100	2019-12-12 19:03:56
Slovenia Donor	4565	19,496	4565	19,496	100	2019-12-12 18:50:58
Lithuanian National Bone Marrow Donor Registry	2073	12,099	2073	12,099	100	2019-12-12 18:50:37
Hungarian Stem Cell Donor Registry	1695	7,091	1695	7,091	100	2019-12-12 18:50:24
Armenian Bone Marrow Donor Registry Charitable Trust	5019	30,433	5019	30,433	100	2019-12-12 18:31:55
Czech Stem Cells Registry Prague (CSCR)	4753	33,018	4753	33,018	100	2019-12-12 18:31:42
Saudi Stem Cells Donor Registry	2107	70,437	2107	70,437	100	2019-12-12 18:31:18
Austrian Bone Marrow Donor Registry	2614	80,699	2614	80,699	100	2019-12-12 18:21:17
Gift of Life Marrow Registry	1033	363,048	1033	363,048	100	2019-12-12 16:54:49
Matchis Foundation	8139	310,317	8139	310,317	100	2019-12-12 15:25:04
Ankara University Faculty of Medicine/TRAN Ankara	3893	15,465	3893	15,465	100	2019-12-12 09:10:35
DATRI Blood Stem Cell Donors Registry	8486	415,747	8486	415,747	100	2019-12-12 04:45:26
Welsh Bone Marrow Donor Registry	1726	67,494	1726	67,494	100	2019-12-12 02:08:17
Canadian Blood Services Stem Cell Registry	5103	456,872	5103	456,872	100	2019-12-11 14:15:22
NHS Blood and Transplant - BBMR	2731	376,020	2731	376,020	100	2019-12-10 12:12:01
Be The Cure Registry by Jeevan Stem Cell Foundation	4460	8,256	4460	8,256	100	2019-12-10 11:20:30
Italian Bone Marrow Donor Registry	7450	445,241	7450	445,241	100	2019-12-09 09:15:46
France Greffe de Moelle Registry - FGM	1804	309,836	1804	309,836	100	2019-12-09 02:11:25
ZKRD - Zentrales Knochenmarkspender-Register Deutschland	6939	8,970,440	6939	8,970,440	100	2019-12-08 19:28:04
Verein Geben für Leben	6939	58,745	4961	58,745	100	2019-12-08 17:47:50
DKMS United Kingdom	6939	619,284	9968	619,284	100	2019-12-08 17:47:19
Luxembourg Marrow Donor Program (LMDP)	6939	12,681	3099	12,681	100	2019-12-08 17:40:20
Fundacja DKMS	6939	1,524,791	7414	1,524,791	100	2019-12-08 17:40:13

Blutspende SRK Schweiz AG	9341	142,857	9341	142,857	100	2019-12-08 16:09:09
Registro de Donantes de Médula Ósea (REDMO)	7813	402,211	7813	402,211	100	2019-12-08 10:26:32
Thai National Stem Cell Donor Registry	8362	232,886	8362	232,886	100	2019-12-08 02:16:07
New Zealand Bone Marrow Donor Registry	8261	12,536	8261	12,536	100	2019-12-08 02:13:48
Australian Bone Marrow Donor Registry	7748	170,080	7748	170,080	100	2019-12-08 02:13:45
Poltransplant	5391	258,123	5391	258,123	100	2019-12-08 02:11:29
Singapore BMDP	3785	108,863	3785	108,863	100	2019-12-08 02:08:46
Iranian National Stem Cell Donor Network (INSCDN)	4993	49,350	4993	49,350	100	2019-12-06 17:30:53
Anthony Nolan London	6354	779,723	6354	779,723	100	2019-12-06 10:31:29
Beijing New Sunshine Charity Foundation	6681	2,819	6681	2,819	100	2019-12-06 06:07:55
NMMP-National Marrow Donor Program/Be The Match	3553	8,851,765	3553	8,851,765	100	2019-12-06 04:01:52
Sindome	6517	1,220	6517	1,220	100	2019-12-05 15:50:28
Marrow Donor Program Registry Belgium	4201	83,187	4201	83,187	100	2019-12-04 14:13:55
Buddhist Tzu Chi Stem Cells Center - BTCSCC Hualien	3458	377,594	3458	377,594	100	2019-12-04 02:12:16
REDOME - Registro Nacional de Doadores Voluntarios de Medula Ossea	8766	4,688,210	8766	4,688,210	100	2019-12-03 16:48:13
Karelian Registry of Hematopoietic Stem Cells	8256	5,040	8256	5,040	100	2019-12-03 15:50:31
The Sunflower Fund	6738	1,787	6738	1,787	100	2019-12-03 09:00:32
Hong Kong Bone Marrow Donor Registry	4070	119,515	4070	119,515	100	2019-11-27 07:41:56
Czech National Marrow Donor Registry Plzeň	5440	89,505	5440	89,505	100	2019-11-26 14:08:29
Cyprus Bone Marrow Donor Registry	9751	173,113	9751	173,113	100	2019-11-26 09:42:50
Croatian Bone Marrow Donor Registry	5712	56,770	5712	56,770	100	2019-11-21 13:41:09
Hema-Quebec Stem Cell Donor Registry	6912	49,312	6912	49,312	100	2019-11-20 02:10:16
Argentine HSC Donors Registry	5117	164,371	5117	164,371	100	2019-11-20 02:09:35
MBMDR - Macedonian Bone Marrow Donor Registry	4307	1,878	4307	1,878	100	2019-11-13 14:40:22
Danish Stem Cell Donors - East (DSDE)	7484	19,897	7484	19,897	100	2019-11-01 13:01:11
EOM Hellenic Transplant Organization	4979	155,332	4979	155,332	100	2019-10-29 10:12:29
Mexican BMDR - DONORMO	1671	14,174	1671	14,174	100	2019-10-24 02:12:17
Bone Marrow and Cord Blood Bank Registry Hadassah University Hospital	5239	214,457	5239	214,457	100	2019-10-17 18:09:51
National Registry of Hematopoietic Stem Cells Voluntary Donors	1372	39,517	1372	39,517	100	2019-10-14 09:20:43
GeneBandhu New Delhi	2824	7,802	2824	7,802	100	2019-09-26 07:50:24
CEDACE/Portuguese BMD Registry	7358	398,694	7358	398,694	100	2019-09-17 15:34:54
Cyprus Paraskevaudio Bone Marrow Donor Registry	4278	5,003	4278	5,003	100	2019-09-16 13:00:23
Iranian Stem Cell Donor Program (ISCDP)	6887	27,832	6887	27,832	100	2019-09-01 06:07:48
MDR Marrow Donor Registry India Mumbai	4131	38,598	4131	38,598	100	2019-08-12 08:07:23
The Arjan Vir Foundation	8196	709	8196	709	100	2019-08-08 19:50:26
King Faisal Specialist Hospital & Research Centre Stem Cell Donor Registry (KFSH&RC;-UDR)	1810	20,358	1810	20,358	100	2019-07-26 11:50:31
TURKOK - Turkish Stem Cell Coordination Centre	3503	424,999	3503	424,999	100	2019-07-15 18:12:19
Bulgarian Bone Marrow Donor Registry	7197	1,592	7197	1,592	100	2019-07-12 14:06:56
Irish Unrelated Bone Marrow Registry	5590	21,603	5590	21,603	100	2019-06-07 13:20:34
HPC Registry (Samara)	9778	3,190	9778	3,190	100	2019-05-30 08:40:37
Bone Marrow Registry Nigeria	3034	924	3034	924	100	2019-05-20 11:50:17
Slovak National BMD Registry	1005	15,036	1005	15,036	100	2019-03-06 10:07:28
Blood and Bone Marrow Donor Registry of Istanbul Medical Faculty	5509	26,724	5509	26,724	100	2019-02-20 07:41:13