

ANNUAL REPORT QUESTIONNAIRE 2017

Stem Cell Donor Registries

Cord Blood Banks and Registries

These data will be transferred to the global ID number database.

GENERAL DATA

Name of the registry/cord blood bank:

Name of registry representative split into first name and last name:

E-mail address of the registry/cord blood bank representative:

Address of the registry/cord blood bank:

ZIP-code:

City:

Country:

Telephone number (including country code, e.g. +44(0)123 456

789:

Fax number (including country code, e.g. +44(0)123 456 789:

Website:

Name of the person completing this form:

E-mail address of the person completing the survey:

S(P)EAR RAPID ALERTS

Name of the Medical Director:

E-mail address for sending S(P)EAR rapid alerts:

CONTACT INFORMATION FOR SEARCHES

Name search coordinator/department international searches:

Telephone number (including country code, e.g. +44(0)123 456

789:

Telephone number (including country code, e.g. +44(0)123 456

789:

Fax number (including country code, e.g. +44(0)123 456 789:

E-mail address :

INVOICE ADDRESS

Name of the registry/cord blood bank:

Department/contact person:

Address of the registry/cord blood bank:

ZIP-code:

City:

Country:

EMERGENCY CONTACT INFORMATION

Primary contact (first name and last name):

Position:

E-mail address:

Telephone number (including country code, e.g. + 44(0)123 456

789:

Secondary contact (first name and last name):

Position:

E-mail address:

Telephone number (including country code, e.g. +44(0)123 456

789:

ANSWER

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Voluntary Donors

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STEM CELL DONOR REGISTRIES ANNUAL REPORT QUESTIONNAIRE

REGISTRY STATISTICS as of 31st DECEMBER 2017

All sentences in bold are referring to mandatory data to be filled in to be included in the WMDA Annual Questionnaire Report

GENERAL REGISTRY/CORD BLOOD BANK DATA

1 Total number of registered and typed donors/cord blood units as of December 31, 2017
 (please give number of donors with specific HLA typing profile regardless of HLA typing resolution; please roll down to next category if some additional loci are available; list a donor only once)

ADULT VOLUNTEER DONORS LISTED AND TYPED:

Total number of donors with HLA-A, -B typing	196	1%	
Total number of donors with HLA-A, -B, -DRB1 typing	5,017		
Total number of donors with HLA-A, -B, -C, -DRB1 typing	20,985	72%	23,854
Total number of donors with HLA-A, -B, -C, -DRB1, -DQB1 typing	2,869	82%	
Total number of donors with HLA-A, -B, -C, -DRB1, -DQB1, -DPB1 typing	0		
TOTAL	29,067		

CORD BLOOD UNITS LISTED AND TYPED:

Total number of cord blood units with HLA-A, -B typing	0
Total number of cord blood units with HLA-A, -B, -DRB1 typing	0
Total number of cord blood unit with HLA-A, -B, -C, -DRB1 typing	0
Total number of cord blood units with HLA-A, -B, -C, -DRB1, -DQB1 typing	0
Total number of cord blood units with HLA-A, -B, -C, -DRB1, -DQB1, -DPB1 typing	0
TOTAL	0

TOTAL of stem cell donors and cord blood units listed and typed: 29,067

2 Count all new donors/cord blood units activated during the year 2017

Count only the donors who have been registered and HLA typed in 2017	Diferenta	6,777
Count the number of new HLA typed cord blood units added during 2017		0
TOTAL		6,777

3 Total number of donors/cord blood units permanently deleted during 2017

Donor File Closed, specify the reasons, if possible

Medical reason	49
Death of donor	1
Age limit reached	2
Unable to trace	19
Emigrated	
Personal withdrawal request	21
Other reason	
Deleted following stem cell donation	
Unknown	
TOTAL	92

Cord blood units deleted from the inventory POST banking, specify reason if possible

Processing, storage problem	
Medical reason	
Shipped for transplantation	
Used for validation studies	
Used for research	
Unknown	
TOTAL	0

4 The age and gender of your adult volunteer donors

	Male	Female	UNK
18 to 25 years old	3,417	2,187	
26 to 35 years old	7,170	4,106	
36 to 45 years old	5,523	3,717	

Does your registry have an organisational resiliency program? Yes

If yes, which components are described?

Crisis Response: structures to define threats produced by a preceding incident Yes

Business Continuity: plan to respond to incidents that impact business operations Yes

Disaster Recovery: capacity to quickly return to an acceptable level of business operations after an incident Yes

Is staff trained on a regular basis (e.g. once a year) to face emergencies? Yes

General comments and suggestions

INFORMATION ON WMDA WEBSITE

Please check the registry information page on the WMDA

Website: www.worldmarrow.org

No. of national donor centres collaborating with your registry: 21

No. of national cord blood banks listing their units at your registry 0

No. of marrow collection centres your registry relies on 3

No. of apheresis collection centres your registry relies on 3

Note: only for a stem cell product, not DLI

Number of cord blood banks listing their units 0

Number of transplant units **in your country** having searched 3

Units may be located in the same Transplant Unit (adult patients' unit and paediatric patients' unit)

ATTENTION: you have to fill in eight excel datasheets!

The HPC (Marrow, Apheresis) Questions are marked in BLUE
 The HPC (Cord) Questions are marked in YELLOW
 All HPC products are marked in GREEN

If you only have HPC, Cord, please fill in YELLOW plus GREEN

If you only have HPC (Marrow, Apheresis), please fill in BLUE plus GREEN

If you have all HPC products, please fill in BLUE plus YELLOW plus GREEN

46 to 55 years old	1,570	1,311	
> 55 years old	26	40	
unknown			
TOTAL	17,706	11,361	0
TOTAL	29,067		

Check: The total should be equal to question 1; result question 1 is: [29067](#)

UNRELATED SEARCH REQUESTS DURING 2017

5 Number of unrelated searches initiated for new patients treated in your country during 2017

Number of patients from your country searching for an unrelated donor

Searches requested for stem cell donors for unrelated national patients	85
Searches requested for cord blood units for unrelated national patients	0
Searches requested for both stem cell donors and cord blood unit for unrelated national patients	85
TOTAL NUMBER OF PATIENTS IN YOUR COUNTRY LOOKING FOR UNRELATED TRANSPLANT	85

6 Number of the above new national patients searched via your registry/cord blood bank but transferred to another country for transplantation

1

STEM CELL DONOR REGISTRIES ANNUAL REPORT QUESTIONNAIRE 2017

Please only fill in if you are a HPC donor registry; cord blood banks please go to the next worksheet

All sentences in bold are referring to mandatory data to be filled in to be included in the WMDA Annual Questionnaire Report

**PATIENT RELATED REQUESTS
REQUESTS FOR YOUR HLA-AB TYPED DONORS**

- 7 Total number of pre-existing HLA-AB typed donors from your registry requested for DR-typing during 2017. 163
 Following a formal request by transplant unit - no. DR-typing requests 163
- 8 Total number of DR typings performed following DR-typing requests reported in question 9. 157
- 9 Median time needed to obtain DR-typing results (calendar days) 20 days
 Time (in calendar days) in which you have obtained 50% of the DR-typing results.
 Please calculate from the date that the request arrived at your registry till the date that the report was sent to the transplant unit

**REGISTRY PROSPECTIVE TYPING
STRATEGY TO IMPROVE THE HLA-typing of your donors**

- 10 Number of registered donors that your registry has re-typed to a higher resolution/additional loci typed

	Locus newly typed	Locus higher resolution
A*	0	
B*	0	
C*		
DRB1*	0	
DQB1*	0	
DPB1*	0	

EXTENDED TYPING REQUESTS FROM YOUR DONORS

- 11a Total number of HLA-typing requests for donors from your registry requested to your registry in 2017 375
- 11b Total number of HLA-typing requests for donors from your registry performed in 2017 368
- | | |
|--|------------|
| Typings requested at the end of 2016 and performed in 2017 | 7 |
| Typings requested in 2017 and performed in 2018 | 20 |
| TOTAL | 368 |
- 11c Total number of HLA-typing requests that are in process 1
 HLA-typings requested at the end of the year and not yet performed 1
 HLA-typing requests requested at the end of 2016 and still in process at the end of 2017 0
- 11d In question 11b you have reported how many HLA-typings are performed by your organisation. What is the time (in calendar days) to obtain these HLA-typings? 15
 Please calculate from the date that the request arrived at your registry till the date that the report was sent to the transplant unit.
- | | |
|--|------------|
| How many requests have been reported within 7 calendar days? | 42 |
| How many requests have been reported within 8 and 14 calendar days? | 125 |
| How many requests have been reported within 15 and 21 calendar days? | 53 |
| How many requests have been reported >21 calendar days? | 148 |
| Unknown | |
| TOTAL (has to be equal to the answer in question 11b) | 368 |
- ANSWER of question 11b 368

**BLOOD SAMPLES REQUESTED FROM YOUR DONORS
FOR CONFIRMATORY (VERIFICATION) TYPING**

- 12 Total number of blood samples requested for shipment in 2017
- | | |
|--|------------|
| Request for patients treated in your country | 24 |
| Request for international patients | 98 |
| TOTAL | 122 |
- 13 Total number of blood samples effectively shipped to requesting transplant units in 2015
- | | |
|--|-----------|
| Shipment for patients treated in your country | 6 |
| Shipment for international patients | 36 |
| TOTAL | 42 |
| Samples in process (requested at the end of the year and in process) | 1 |

14	In question 13 you have reported how many blood samples were shipped by your organisation. What is the time (in calendar days) to ship blood samples? Please calculate from the date that the request arrived at your registry till the date that the blood sample was sent to the transplant unit.	
	How many requests have been shipped within 7 calendar days?	10
	How many requests have been shipped within 8 and 14 calendar days?	7
	How many requests have been shipped within 15 and 21 calendar days	7
	How many requests have been shipped >21 calendar days?	18
	Unknown	
	TOTAL (has to be equal with the number reported in question 13) Answer of question 13	42

15	Total number of blood samples cancelled for shipment in 2017 Donor related reasons (see below the EMDIS definitions)	79
	DO = Donor is too old	0
	DD = Donor died	0
	MR= Medical reasons	1
	PR = Personal reasons	10
	TX = After transplantation	0
	MO = Donor has moved	1
	UC = Unable to contact donor	47
	OT = other reasons	0
	UK = Unknown	8
	EX = Expired	0
	MM = HLA mismatch	1
	TOTAL NUMBER BLOOD SAMPLES CANCELLED DUE TO DONOR RELATED REASONS	68
	Patient related reasons (see below the EMDIS definitions)	
	BCC = Clinical condition of patient deteriorated (i.e. relapse)	0
	FND = Other/better donor found	0
	LAB = laboratory problem/typing failed/not enough sample	0
	NSP = No sample received	0
	OLD = Sample too old	0
	PDC = Patient deceased before request was completed	0
	STP = Search stopped	11
	TRX = Patient already transplanted	0
	OTH = Other reason	0
	TOTAL NUMBER BLOOD SAMPLES CANCELLED DUE TO PATIENT RELATED REASONS	11
	TOTAL	79
	Percentage of the requested blood samples cancelled because of donor related reasons	56% %

CANCELLATIONS FROM YOUR DONORS OF WORK-UPS REQUESTED

16	Total number of work-ups requested from your donors in 2017 (no DLIs) Count all work-up requests from your donors for unrelated patients that are requested by transplant units	5
17	Total number of donors from your registry deferred at work-up, resulting in harvest cancellation (from the work-ups requested in question 16) Percentage of cancellation rate at work-up The reasons of the work-up cancellations must be related to the donors themselves	1 20%
18	Total number of work-up cancellations of your donors made by your national transplant units (from the work-ups requested in question 16) The reasons of the work-up cancellations must be related to the patients themselves The concerned donors belong to your registry	0 0
19	Number of work-up cancellations of your donors made by international transplant units (from the work-ups requested in question 16) The concerned donors belong to your registry The reasons of the work-up cancellations must be related to the patients themselves	0 0
20	Work-ups requested of question 16 still in progress Work-ups requested in 2017 and performed in 2018 NOTE: The total number work-ups requested in 2017 minus the cancellations of work-ups requested in 2017 minus the work-ups requested in 2017 that are still in progress plus the work-ups requested in 2016 and performed in 2017 should be equal to the number of stem cell products provided.	0 0
21	Number of international donors deferred at work-up, resulting in harvest cancellation The reasons of the work-up cancellations must be related to the donors themselves	0 0
22	Number of work-ups requested without preceding verification/confirmatory typing request for respective donor/patient pair	0 0

**DISTRIBUTION OF UNRELATED STEM CELL DONATIONS
TO VARIOUS COUNTRIES DURING 2017**

34 Total number of products of your donors shipped to international patients
Total number of products of your donors shipped to national patients

TYPE OF STEM CELLS			
HPC, Marrow	HPC, Apheresis	HPC, Cord	DLI
1	2	0	0
0	1	0	0

35 Number of stem cell donations provided by your registry/cord blood bank for the benefit of patients

List, by alphabetical order, the name of the countries to which all stem cell products have been exported in 2017. Precise the number of products per country and the type of stem cells provided.

TYPE OF STEM CELLS; include also the subsequent donations!

From your country to -----> Name of the country:	HPC, Marrow	HPC, Apheresis	HPC, Cord	DLI
Count all donations from your donors for national patients in 2017	0	1	0	0
Count all donations for international patients and specify the country	1	2	0	0
1 Argentina				
2 Armenia				
3 Australia				
4 Austria				
5 Belarus				
6 Belgium				
7 Brazil				
8 Bulgaria				
9 Canada				
10 Chile				
11 China				
12 China Hong Kong				
13 Colombia				
14 Costa Rica				
15 Croatia				
16 Cyprus				
17 Czech Republic				
18 Denmark				
19 Estonia				
20 Finland				
21 France				
22 Germany		2		
23 Greece				
24 Hungary				
25 India				
26 Iran				
27 Ireland				
28 Israel				
29 Italy				
30 Japan				
31 Jordan				
32 Korea				
33 Lithuania				
34 Malaysia				
35 Mexico				
36 Netherlands				
37 New Zealand				
38 Norway				
39 Philippines				
40 Poland				
41 Portugal				
42 Romania				
43 Russia				
44 San Marino				
45 Saudi Arabia				
46 Singapore				
47 Slovakia				
48 Slovenia				
49 South Africa				
50 Spain				
51 Sweden				
52 Switzerland				
53 Taiwan				
54 Thailand				
55 Turkey				
56 United Kingdom	1			
57 United States				
58 Uruguay				
59 Venezuela				
Other countries not specified above:				
TOTAL	1	3		
GRAND TOTAL OF INTERNATIONAL PATIENTS	3			
Please check GRAND TOTAL with Question 35 (has to be equal)	3			
GRAND TOTAL OF INTERNATIONAL PATIENTS				

! Do not forget the subsequent stem cell donations!

HPC PRODUCTS PROVIDED BY YOUR REGISTRY

36 Number of HPC products of your donors shipped to national patients

FIRST TIME DONATION

	HPC-Marrow	0
	HPC-Apheresis	1
	TOTAL	1
SUBSEQUENT DONATION; same initial patient		
	HPC-Marrow	0
	HPC-Apheresis	0
	DLI	0
	TOTAL	0
SUBSEQUENT DONATION; another unrelated patient		
	HPC-Marrow	0
	HPC-Apheresis	0
	DLI	0
	TOTAL	0

37 Number of HPC products of your donors shipped to international patients

FIRST TIME DONATION

	HPC-Marrow	1
	HPC-Apheresis	2
	TOTAL	3
SUBSEQUENT DONATION; same initial patient		
	HPC-Marrow	0
	HPC-Apheresis	0
	DLI	0
	TOTAL	0
SUBSEQUENT DONATION; another unrelated patient		
	HPC-Marrow	0
	HPC-Apheresis	0
	DLI	0
	TOTAL	0

TOTAL NUMBER OF HPC DONATIONS PROVIDED BY YOUR REGISTRY		4
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PATIENTS RECEIVED UNRELATED TRANSPLANT

NATIONAL PATIENTS

38 Number of patients in your country received an unrelated transplant in 2017

National donor helping patient in your country

National patients received HPC-Marrow transplant from national donor	0
National patients received HPC-Apheresis transplant from national donor	1
TOTAL NUMBER OF PATIENTS	1
National cord blood product provided for patient in your country	
HPC-Cord, single transplant from national cord blood bank	0
HPC-Cord, multi cord transplant (HPC-Cord solely from national cord blood banks)	0
HPC-Cord, multi transplant (one cord from your country/one from another country)	0
TOTAL	0
International donor helping patient in your country	
Patient received HPC-Marrow transplant from international donor	1
Patient received HPC-Apheresis transplant from international donor	34
Patient received HPC-Cord, single transplant from CBB outside your country	0
Patient received HPC-Cord, multi transplant from CBB(s) from outside your country	0
TOTAL	35

INTERNATIONAL PATIENTS

**39 HPC donations facilitated by your registry without interaction of another registry in 2017
(e.g. HPC transplants facilitated to countries where no registry exists)**

HPC-Marrow facilitated by your registry for international patient	1
HPC-Apheresis facilitated by your registry for international patient	2
TOTAL	3
International patients receiving single CB transplant from your CBB	
International patients receiving multi CB transplant from your CBB	0
International patients receiving multi CB transplant from several CBBs	0
No information known if the patient received a single or multi CB transplant	0
TOTAL	0