

**ANNUAL REPORT QUESTIONNAIRE 2016**

Stem Cell Donor Registries

Cord Blood Banks and Registries

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

**GENERAL DATA****ANSWER**

Name of the registry/cord blood bank: National Registry of Hematopoietic Stem Cells  
Voluntary Donors

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

E-mail address of the registry/cord blood bank representative: [aurora.dragomiristeanu@rndvcsh.ro](mailto:aurora.dragomiristeanu@rndvcsh.ro)

Address of the registry/cord blood bank: Str.Constantin Caracas, Nr.2-8, Sector 2

ZIP-code: 11155

City: Bucharest

Country: Romania

Telephone number (including country code, e.g. +44(0)123 456 789: 0040 212 018 800

Fax number (including country code, e.g. +44(0)123 456 789: 0040 212 018 828

Website: [www.rndvcsh.ro](http://www.rndvcsh.ro); [www.registru-celule-stem.ro](http://www.registru-celule-stem.ro)

Name of the person completing this form: Dragomiristeanu Aurora

E-mail address of the person completing the survey: [aurora.dragomiristeanu@rndvcsh.ro](mailto:aurora.dragomiristeanu@rndvcsh.ro)

**S(P)EAR RAPID ALERTS****ANSWER**

Name of the Medical Director: Aurora Dragomiristeanu

E-mail address for sending S(P)EAR rapid alerts: [aurora.dragomiristeanu@rndvcsh.ro](mailto:aurora.dragomiristeanu@rndvcsh.ro)

**CONTACT INFORMATION FOR SEARCHES****ANSWER**

Name search coordinator/department international searches: Luminita Marina Jieanu

Telephone number (including country code, e.g. +44(0)123 456 789: 0040 212 018 804

Telephone number (including country code, e.g. +44(0)123 456 789: 0040 212 018 828

Fax number (including country code, e.g. +44(0)123 456 789: 0040 212 018 828

E-mail address : [luminita.jieanu@rndvcsh.ro](mailto:luminita.jieanu@rndvcsh.ro)

**INVOICE ADDRESS****ANSWER**

Name of the registry/cord blood bank: Registrul National al Donatorilor Voluntari de Celule Stem Hematopoietice

Department/contact person: Carmen Valentina Mesu

Address of the registry/cord blood bank: Str.Constantin Caracas, Nr.2-8, Sector 2

ZIP-code: 11155

City: Bucuresti

Country: Romania

**EMERGENCY CONTACT INFORMATION****ANSWER**

Primary contact (first name and last name): Dragomiristeanu Aurora

Position: general director

E-mail address: [aurora.dragomiristeanu@rndvcsh.ro](mailto:aurora.dragomiristeanu@rndvcsh.ro)

Telephone number (including country code, e.g. + 44(0)123 456 789: 0040 212 018 810

Secondary contact (first name and last name): Irina Monica Dutescu

Position: HLA expert

E-mail address: [monica.dutescu@rndvcsh.ro](mailto:monica.dutescu@rndvcsh.ro)

Telephone number (including country code, e.g. +44(0)123 456 789: 0040 212 018 800

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](http://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 Note: only for a stem cell product, not DLI	3
Number of cord blood banks listing their units	0
Number of transplant units <b>in your country</b> having searched Units may be located in the same Transplant Unit (adult patients' unit and paediatric patients' unit)	3

**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**

# STEM CELL DONOR REGISTRIES ANNUAL REPORT QUESTIONNAIRE

## REGISTRY STATISTICS as of 31st DECEMBER 2016

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, 2016

(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	296
Total number of donors with HLA-A, -B, -DRB1 typing	5.031
Total number of donors with HLA-A, -B, -C, -DRB1 typing	15.183
Total number of donors with HLA-A, -B, -C, -DRB1, -DQB1 typing	1.872
Total number of donors with HLA-A, -B, -C, -DRB1, -DQB1, -DPB1 typing	0
<b>TOTAL</b>	<b>22.382</b>
<b>CORD BLOOD UNITS LISTED AND TYPED:</b>	
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
<b>TOTAL</b>	<b>0</b>
<b>TOTAL of stem cell donors and cord blood units listed and typed:</b>	<b>22.382</b>

#### 2 Count all new donors/cord blood units activated during the year 2016

Count only the donors who have been registered and HLA typed in 2016	9.415
Count the number of new HLA typed cord blood units added during 2016	0
<b>TOTAL</b>	<b>9.415</b>

#### 3 Total number of donors/cord blood units permanently deleted during 2016

Donor File Closed, specify the reasons, if possible

Medical reason	122
Death of donor	1
Age limit reached	3
Unable to trace	4
Emigrated	
Personal withdrawal request	34
Other reason	76
Deleted following stem cell donation	1
Unknown	32
<b>TOTAL</b>	<b>273</b>

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	
<b>TOTAL</b>	<b>0</b>

4 The age and gender of your adult volunteer donors

	<b>Male</b>	<b>Female</b>	<b>UNK</b>
18 to 25 years old	2.938	1.766	
26 to 35 years old	5.446	3.036	
36 to 45 years old	4.256	2.908	
46 to 55 years old	1.095	894	
> 55 years old	16	27	
unknown			
<b>TOTAL</b>	<b>13.751</b>	<b>8.631</b>	<b>0</b>
<b>TOTAL</b>	<b>22.382</b>		

**Check:** The total should be equal to question 1; result question 1 is: [22382](#)

### UNRELATED SEARCH REQUESTS DURING 2016

5 Number of unrelated searches initiated for new patients treated in your country during 2015

**Number of patients from your country searching for an unrelated donor**

Searches requested for stem cell donors for unrelated <b>national</b> patients	91
Searches requested for cord blood units for unrelated <b>national</b> patients	
Searches requested for both stem cell donors and cord blood unit for unrelated <b>national</b> patients	91
<b>NUMBER OF PATIENTS IN YOUR COUNTRY LOOKING FOR UNRELATED TRANSPLANT</b>	<b>91</b>

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

	0
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## STEM CELL DONOR REGISTRIES ANNUAL REPORT QUESTIONNAIRE 2016

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 2016.  
Following a formal request by transplant unit - no. DR-typing requests 105
- 8 Total number of DR typings **performed** following DR-typing requests reported in question 9. 93
- 9 Median time needed to obtain DR-typing results (calendar days) 11 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*	<del>XXXXXX</del>	
B*	<del>XXXXXX</del>	
C*		
DRB1*		
DQB1*		
DPB1*		

### EXTENDED TYPING REQUESTS FROM YOUR DONORS

- 11a Total number of **HLA-typing requests** for donors from your registry **requested** to your registry in 2016 204
- 11b Total number of **HLA-typing requests** for donors from your registry **performed** in 2016 202
- Typings requested at the end of 2015 and performed in 2016 2

Typings requested in 2016 and performed in 2017 7

**TOTAL**
- 11c Total number of HLA-typing requests that are in process 0  
HLA-typings requested at the end of the year and not yet performed 0  
HLA-typing requests requested at the end of 2015 and still in process at the end of 2016 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?  
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? 41

How many requests have been reported within 8 and 14 calendar days? 116

How many requests have been reported within 15 and 21 calendar days? 27

How many requests have been reported >21 calendar days? 20

Unknown 0

**TOTAL (has to be equal to the answer in question 11b ANSWER of question 11b)** 204

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

- 12 Total number of blood samples **requested** for shipment in 2016 82
- Request for patients treated in your country 27

Request for international patients 55

**TOTAL** 82
- 13 Total number of blood samples **effectively shipped** to requesting transplant units in 2016 34
- Shipment for patients treated in your country 15

Shipment for international patients 19

**TOTAL** 34

Samples in process (requested at the end of the year and in process) 10

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?	5
	How many requests have been shipped within 8 and 14 calendar days?	13
	How many requests have been shipped within 15 and 21 calendar days?	8
	How many requests have been shipped >21 calendar days?	8
	Unknown	0
	TOTAL (has to be equal with the number reported in question 13)	34
	Answer of question 13	

15	Total number of blood samples cancelled for shipment in 2016	
	<b>Donor related reasons (see below the EMDIS definitions)</b>	
	DO = Donor is too old	0
	DD = Donor died	0
	MR= Medical reasons	2
	PR = Personal reasons	4
	TX = After transplantation	0
	MO = Donor has moved	1
	UC = Unable to contact donor	31
	OT = other reasons	0
	UK = Unknown	0
	EX = Expired	0
	MM = HLA mismatch	0
	TOTAL NUMBER BLOOD SAMPLES CANCELLED DUE TO DONOR RELATED REASONS	38
	<b>Patient related reasons (see below the EMDIS definitions)</b>	
	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	0
	TRX = Patient already transplanted	0
	OTH = Other reason	0
	TOTAL NUMBER BLOOD SAMPLES CANCELLED DUE TO PATIENT RELATED REASONS	0
	TOTAL	
	Percentage of the requested blood samples cancelled because of donor related reasons	%

**CANCELLATIONS FROM YOUR DONORS OF WORK-UPS REQUESTED**

16	Total number of work-ups requested from your donors in 2016 (no DLIs)	2
	Count all work-up requests from your donors for unrelated patients that are requested by transplant units	
17	Total number of donors from your registry deferred at work-up, resulting in harvest cancellation (from the work-ups requested in question 16)	0
	Percentage of cancellation rate at work-up	%
	The reasons of the work-up cancellations must be related to the donors themselves	
18	Total number of work-up cancellations of your donors made by your national transplant units (from the work-ups requested in question 16)	0
	The reasons of the work-up cancellations must be related to the patients themselves	
	The concerned donors belong to your registry	
19	Number of work-up cancellations of your donors made by international transplant units (from the work-ups requested in question 16)	0
	The concerned donors belong to your registry	
	The reasons of the work-up cancellations must be related to the patients themselves	
20	Work-ups requested of question 16 still in progress	0
	Work-ups requested in 2016 and performed in 2017	0
	<b>NOTE:</b>	
	The total number work-ups requested in 2016 minus the cancellations of work-ups requested in 2016 minus the work-ups requested in 2016 that are still in progress plus the work-ups requested in 2015 and performed in 2016 should be equal to the number of stem cell products provided.	
21	Number of international donors deferred at work-up, resulting in harvest cancellation	0
	The reasons of the work-up cancellations must be related to the donors themselves	
22	Number of work-ups requested without preceding verification/confirmatory typing request for respective donor/patient pair	0

**DISTRIBUTION OF UNRELATED STEM CELL DONATIONS  
TO VARIOUS COUNTRIES DURING 2016**

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
0	1	0	1
1	0	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 2016. 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
<b>Count all donations from your donors for national patients in 2016</b>	1	0	0	0
<b>Count all donations for international patients and specify the country</b>	0	1	0	1
1 Argentina	0	0	0	0
2 Armenia	0	0	0	0
3 Australia	0	0	0	0
4 Austria	0	0	0	0
5 Belarus	0	0	0	0
6 Belgium	0	0	0	0
7 Brazil	0	0	0	0
8 Bulgaria	0	0	0	0
9 Canada	0	0	0	0
10 Chile	0	0	0	0
11 China	0	0	0	0
12 China Hong Kong	0	0	0	0
13 Colombia	0	0	0	0
14 Costa Rica	0	0	0	0
15 Croatia	0	0	0	0
16 Cyprus	0	0	0	0
17 Czech Republic	0	0	0	0
18 Denmark	0	0	0	0
19 Estonia	0	0	0	0
20 Finland	0	0	0	0
21 France	0	0	0	0
22 Germany	0	1	0	1
23 Greece	0	0	0	0
24 Hungary	0	0	0	0
25 India	0	0	0	0
26 Iran	0	0	0	0
27 Ireland	0	0	0	0
28 Israel	0	0	0	0
29 Italy	0	0	0	0
30 Japan	0	0	0	0
31 Jordan	0	0	0	0
32 Korea	0	0	0	0
33 Lithuania	0	0	0	0
34 Malaysia	0	0	0	0
35 Mexico	0	0	0	0
36 Netherlands	0	0	0	0
37 New Zealand	0	0	0	0
38 Norway	0	0	0	0
39 Philippines	0	0	0	0
40 Poland	0	0	0	0
41 Portugal	0	0	0	0
42 Romania	1	0	0	0
43 Russia	0	0	0	0
44 San Marino	0	0	0	0
45 Saudi Arabia	0	0	0	0
46 Singapore	0	0	0	0
47 Slovakia	0	0	0	0
48 Slovenia	0	0	0	0
49 South Africa	0	0	0	0
50 Spain	0	0	0	0
51 Sweden	0	0	0	0
52 Switzerland	0	0	0	0
53 Taiwan	0	0	0	0
54 Thailand	0	0	0	0
55 Turkey	0	0	0	0
56 United Kingdom	0	0	0	0
57 United States	0	0	0	0
58 Uruguay	0	0	0	0
59 Venezuela	0	0	0	0
<b>Other countries not specified above:</b>				
<b>TOTAL</b>	1	1	0	1
<b>GRAND TOTAL OF INTERNATIONAL PATIENTS</b>	1			
Please check GRAND TOTAL with Question 35 (has to be equal)	1			
<b>GRAND TOTAL OF INTERNATIONAL PATIENTS</b>	1			

**! 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	1
	HPC-Apheresis	0
	TOTAL	1
<b>SUBSEQUENT DONATION; same initial patient</b>		
	HPC-Marrow	0
	HPC-Apheresis	0
	DLI	0
	TOTAL	0
<b>SUBSEQUENT DONATION; another unrelated patient</b>		
	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	0
	HPC-Apheresis	1
	TOTAL	1
<b>SUBSEQUENT DONATION; same initial patient</b>		
	HPC-Marrow	0
	HPC-Apheresis	0
	DLI	1
	TOTAL	1
<b>SUBSEQUENT DONATION; another unrelated patient</b>		
	HPC-Marrow	0
	HPC-Apheresis	0
	DLI	0
	TOTAL	0

TOTAL NUMBER OF HPC DONATIONS PROVIDED BY YOUR REGISTRY	2
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**PATIENTS RECEIVED UNRELATED TRANSPLANT**

**NATIONAL PATIENTS**

**38 Number of patients in your country received an unrelated transplant in 2016** 46

**National donor helping patient in your country** 1

National patients received HPC-Marrow transplant from national donor	1
National patients received HPC-Apheresis transplant from national donor	0
TOTAL NUMBER OF PATIENTS	1
<b>National cord blood product provided for patient in your country</b>	
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
<b>International donor helping patient in your country</b>	
Patient received HPC-Marrow transplant from international donor	7
Patient received HPC-Apheresis transplant from international donor	38
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	45

**INTERNATIONAL PATIENTS**

**39 HPC donations facilitated by your registry without interaction of another registry in 2016**  
 (e.g. HPC transplants facilitated to countries where no registry exists)

HPC-Marrow facilitated by your registry for international patient	0
HPC-Apheresis facilitated by your registry for international patient	0
TOTAL	0
International patients receiving single CB transplant from your CBB	0
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