

**ANNUAL REPORT QUESTIONNAIRE 2018**

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: `011155  
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; 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: Laurian Traian Arghisan

Telephone number (including country code, e.g. +44(0)123 456 789: 0040 212 018 806

Telephone number (including country code, e.g. +44(0)123 456 789: 0040 212 018 810  
Fax number (including country code, e.g. +44(0)123 456 789: 0040 212 018 828  
E-mail address : [laurian.arghisan@rndvcsh.ro](mailto:laurian.arghisan@rndvcsh.ro)

**INVOICE ADDRESS****ANSWER**

Name of the registry/cord blood bank: Registrul National al Donatorilor Voluntari de  
Celule Stem Hematopoietice  
Department/contact person: Daniela Niculescu  
Address of the registry/cord blood bank: Str.Constantin Caracas, Nr.2-8, Sector 2

ZIP-code: `011155  
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  
24 h emergency number: 0040 722 751 147

Does your registry have an organisational resiliency program? If yes, which components are described?	Yes
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:

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

No. of marrow collection centres your registry relies on

No. of apheresis collection centres your registry relies on

Note: only for a stem cell product, not DLI

Number of cord blood banks listing their units

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

**STEM CELL DONOR REGISTRIES ANNUAL REPORT QUESTIONNAIRE**

**REGISTRY STATISTICS as of 31st DECEMBER 2018**

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, 2018**  
(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	271
Total number of donors with HLA-A, -B, -DRB1 typing	5,058
Total number of donors with HLA-A, -B, -C, -DRB1 typing	25,304
Total number of donors with HLA-A, -B, -C, -DRB1, -DQB1 typing	4,156
Total number of donors with HLA-A, -B, -C, -DRB1, -DQB1, -DPB1 typing	0
<b>TOTAL</b>	<b>34,789</b>

**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
<b>TOTAL</b>	<b>0</b>
<b>TOTAL of stem cell donors and cord blood units listed and typed:</b>	<b>34,789</b>

**ADULT VOLUNTEER DONORS/CBUs ADDED TO THE DATABASE DURING 2018**

- 2 **Count all new donors/cord blood units recruited and HLA typed during 2018**

Count only the donors who have been registered and HLA typed in 2018	5,883
Count the number of new HLA typed cord blood units added during 2018	0
<b>TOTAL</b>	<b>5,883</b>

**ADULT VOLUNTEER DONORS/CBUs PERMANENTLY DELETED DURING 2018**

- 3 **Total number of donors/cord blood units permanently deleted during 2018**

Donor File Closed, specify the reasons, if possible

Medical reason	32
Death of donor	0
Age limit reached	1
Unable to trace	33
Emigrated	5
Personal withdrawal request	36
Other reason	34
Deleted following stem cell donation	3
Unknown	17
<b>TOTAL</b>	<b>161</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>

**AGE AND GENDER OF ADULT VOLUNTEER DONORS**

- 4-6 **The age and gender of your adult volunteer donors**

	Male	Female	UNK
18 to 25 years old	3,480	2,359	
26 to 35 years old	8,592	5,127	
36 to 45 years old	6,618	4,541	
46 to 55 years old	2,184	1,792	
> 55 years old	39	57	
unknown			
<b>TOTAL</b>	<b>20,913</b>	<b>13,876</b>	<b>0</b>
<b>TOTAL</b>	<b>34,789</b>		

*Check: The total should be equal to question 1; result question 1 is: [34789](#)*

**UNRELATED SEARCH REQUESTS DURING 2018**

**7 Number of unrelated searches initiated for new patients treated in your country during 2018**

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

Searches requested for stem cell donors for unrelated **national** patients 112

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 0

**TOTAL NUMBER OF PATIENTS IN YOUR COUNTRY LOOKING FOR UNRELATED TRANSPLANT 112**

**8 Number of the above new national patients searched via your registry/cord blood bank**

**but transferred to another country for transplantation 7**

## STEM CELL DONOR REGISTRIES ANNUAL REPORT QUESTIONNAIRE 2018

*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**

### REGISTRY PROSPECTIVE TYPING STRATEGY TO IMPROVE THE HLA-TYPING OF YOUR EXISTING DONORS

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

	Locus newly typed
A*	<del>0</del>
B*	<del>0</del>
C*	0
DRB1*	0
DQB1*	0
DPB1*	0

### EXTENDED TYPING REQUESTS FROM YOUR DONORS DURING 2018

10 Total number of **HLA-typing requests** for donors from your registry **requested** to your registry in 2018

**217**

11 Total number of **HLA-typing requests** for donors from your registry **performed** in 2018

11a Typings requested at the end of 2017 and performed in 2018

6

11b Typings requested during 2018 and performed in 2018

157

11c Typings requested in 2018 that were still in process at the end of 2018

54

TOTAL

**163**

12 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?

31

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

23

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

27

How many requests have been reported >21 calendar days?

82

Unknown

0

TOTAL (has to be equal to the answer in question 11)

**163**

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

13 Total number of blood samples **requested** for shipment in 2018

Request for patients treated in your country

18

Request for international patients

106

TOTAL

**124**

14 Total number of blood samples **effectively shipped** to requesting transplant units in 2018

Shipment for patients treated in your country

6

Shipment for international patients

44

TOTAL

**50**

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

18

15 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?

21

How many requests have been shipped within 15 and 21 calendar days	9
How many requests have been shipped >21 calendar days?	15
Unknown	0
TOTAL (has to be equal with the number reported in question 14)	50

16 **Total number of blood samples cancelled for shipment in 2018** 40

16a **Donor related reasons (see below the EMDIS definitions)**

DO = Donor is too old	0
DD = Donor died	0
MR= Medical reasons	2
PR = Personal reasons	1
TX = After transplantation	0
MO = Donor has moved	1
UC = Unable to contact donor	48
OT = other reasons	2
UK = Unknown	0
EX = Expired	0
MM = HLA mismatch	0
TOTAL NUMBER BLOOD SAMPLES CANCELLED DUE TO DONOR RELATED REASONS	54

16b **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	2
TRX = Patient already transplanted	0
OTH = Other reason	0
TOTAL NUMBER BLOOD SAMPLES CANCELLED DUE TO PATIENT RELATED REASONS	2
TOTAL	56

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

17 **Total number of work-ups requested from your donors in 2018 (no DLIs)** 12  
*Count all work-up requests from your donors for unrelated patients that are requested by transplant units*

18 **Total number of donors from your registry deferred at work-up, resulting in harvest cancellation (from the work-ups requested in question 16)** 10  
*The reasons of the work-up cancellations must be related to the donors themselves*

19 **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*

20 **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*

21 **Work-ups requested of question 16 still in progress  
Work-ups requested in 2018 and performed in 2019** 0  
NOTE:  
*The total number work-ups requested in 2018 minus the cancellations of work-ups requested in 2018 minus the work-ups requested in 2018 that are still in progress plus the work-ups requested in 2017 and performed in 2018 should be equal to the number of stem cell products provided.*

22 **Number of international donors deferred at work-up, resulting in harvest cancellation** 1  
*The reasons of the work-up cancellations must be related to the donors themselves*

23 **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 2018**

25-27 Total number of HPC products provided by your donors shipped to **international** patients  
28-31 Total number of HPC products provided by your donors shipped to **national** patients

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

**32 Number of HPC products provided by your donors shipped to the following countries for unrelated transplantation**

List, by alphabetical order, the name of the countries to which **all** HPC products have been exported in 2018. 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
	<i>Count all donations for international patients in 2018 and specify the country</i>	0	1	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				
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		1		
51	Sweden				
52	Switzerland				
53	Taiwan				
54	Thailand				
55	Turkey				
56	United Kingdom				
57	United States				
58	Uruguay				
59	Venezuela				
	<b>Other countries not specified above:</b>				
	<b>TOTAL</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>
	<b>GRAND TOTAL OF HPC PRODUCTS EXPORTED FOR INTERNATIONAL PATIENTS</b>	<b>1</b>			

*! Do not forget the subsequent stem cell donations!*

**DISTRIBUTION OF HPC PRODUCTS IMPORTED  
FROM VARIOUS COUNTRIES FOR URTx DURING 2018**

TYPE OF STEM CELLS

HPC, Marrow	HPC, Apheresis	HPC, Cord	DLI
3	38	0	5

35-37 Total number of HPC products imported by your organisation for unrelated transplantation during 2018

38-40 Number of HPC products imported from various countries for unrelated transplantation during 2018 from the following countries:

List, by alphabetical order, the name of the countries from which all HPC products have been imported in 2018. Precise the number of products per country and the type of stem cells imported.

*include also the subsequent donations!*

	To your country from -----> Name of the country:	HPC, Marrow	HPC, Apheresis	HPC, Cord	DLI
	<i>Count all HPC products imported for your national patients during 2018, from various countries</i>	3	38	0	5
1	Argentina				
2	Armenia				
3	Australia				
4	Austria		1		
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	3	19		2
23	Greece		3		
24	Hungary				
25	India				
26	Iran				
27	Ireland				
28	Israel		1		
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		10		2
41	Portugal		1		
42	Romania				
43	Russia				
44	San Marino				
45	Saudi Arabia				
46	Singapore				
47	Slovakia				
48	Slovenia				
49	South Africa				
50	Spain		2		
51	Sweden				
52	Switzerland		1		1
53	Taiwan				
54	Thailand				
55	Turkey				
56	United Kingdom				
57	United States				
58	Uruguay				
59	Venezuela				
	<b>Other countries not specified above:</b>				
	<b>TOTAL</b>	<b>3</b>	<b>38</b>	<b>0</b>	<b>5</b>
	<b>GRAND TOTAL OF HPC PRODUCTS IMPORTED FOR NATIONAL PATIENTS</b>	<b>46</b>			

*! Do not forget the subsequent stem cell donations!*



**UNRELATED HPC DONATION PROVIDED BY YOUR REGISTRY DURING 2018**

	<b>TOTAL NUMBER OF HPC PRODUCTS OF YOUR DONORS PROVIDED BY YOUR ORGANISATION FOR UNRELATED TRANSPLANTATION</b>	<b>3</b>	
41		<b>national patients</b>	<b>international patients</b>
42-45	<b>FIRST TIME DONATION</b>		
	HPC-Marrow	0	0
	HPC-Apheresis	2	1
	<b>TOTAL</b>	<b>2</b>	<b>1</b>
	<b>SUBSEQUENT DONATION; same initial patient</b>		
	HPC-Marrow	0	0
	HPC-Apheresis	0	0
	DLI	0	0
	<b>TOTAL</b>	<b>0</b>	<b>0</b>
	<b>SUBSEQUENT DONATION; another unrelated patient</b>		
	HPC-Marrow	0	0
	HPC-Apheresis	0	0
	DLI	0	0
	<b>TOTAL</b>	<b>0</b>	<b>0</b>

**PATIENTS RECEIVED UNRELATED TRANSPLANT**

**NATIONAL PATIENTS**

**46 Total number of patients received unrelated transplant in 2018 from your organization (no DLI)** **43**

**National donor helping patient in your organisation**

National patients received HPC-Marrow transplant from national donor	0
National patients received HPC-Apheresis transplant from national donor	2
TOTAL NUMBER OF PATIENTS	2
<b>National cord blood product provided for patient in your organisation</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 organisation</b>	
Patient received HPC-Marrow transplant from international donor	3
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	41

**INTERNATIONAL PATIENTS**

**39 HPC donations facilitated by your registry without interaction of another registry in 2018**

(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