

ANNUAL REPORT QUESTIONNAIRE 2021

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:	National Registry of Hematopoietic Stem Cells Voluntary Donors
Name of registry representative split into first name and last name:	Aurora Dragomiristeanu
E-mail address of the registry/cord blood bank representative:	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

S(P)EAR RAPID ALERTS

Name of the Medical Director:	Aurora Dragomiristeanu
E-mail address for sending S(P)EAR rapid alerts:	aurora.dragomiristeanu@rndvcsh.ro

CONTACT INFORMATION FOR SEARCHES

Name search coordinator/department international searches:	Laurian Traian Arghisan
Telephone number (including country code):	0040 212 018 800
Telephone number (including country code):	0040 212 018 810
Fax number (including country):	0040 212 018 828
E-mail address :	laurian.arghisan@rndvcsh.ro

INVOICE ADDRESS

Name of the registry/cord blood bank:	Registrul National al Donatorilor Voluntari de Celule Stem Hematopoietice
Department/contact person:	Nicoleta Simion
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

Primary contact (first name and last name):	Aurora Dragomiristeanu
Position:	general director
E-mail address:	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
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

No. of national donor centres collaborating with your registry: 16

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

STEM CELL DONOR REGISTRIES ANNUAL REPORT QUESTIONNAIRE 2021

REGISTRY STATISTICS

*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	Number of registered and typed donors/CBUs/ADCUs on December 31 2021	56,309
	<i>(please give number of donors with specific HLA typing profile regardless of HLA typing resolution; please list a donor/CBU/ADCU only once)</i>	
	1a) Number of adult volunteer donors available for transplantation for unrelated patients	56,309
	1a1) Number of donors with HLA-A, -B typing	56,309
	1a2) Number of donors with HLA-A, -B, -DR(B1) typing	318
	1a3) Number of donors with HLA-A, -B, -C, -DR(B1) typing	5,032
	1a4) Number of donors with HLA-A, -B, -C, -DR(B1), -DQ(B1) typing	7,419
	1a5) Number of donors with HLA-A, -B, -C, -DR(B1), -DQ(B1), -DP(B1) typing	7,624
	1b) Number of fully molecular HLA-A, -B, -C, -DR(B1), DQ(B1) and -DP(B1) typed ADCUs <i>(Adult Donor Cryopreserved Units) available for transplantation for unrelated patients An ADCU is an adult donor product that was collected and cryopreserved.</i>	0
	1b) Cord blood units listed and typed:	0
	1b1) Number of CBUs with HLA-A, -B typing	0
	1b2) Number of CBUs with HLA-A, -B, -DR(B1) typing	0
	1b3) Number of CBUs with HLA-A, -B, -C, -DR(B1) typin	0
	1b4) Number of CBUs with HLA-A, -B, -C, -DR(B1), -DQ(B1) typing	0
	1b5) Number of CBUs with HLA-A, -B, -C, -DR(B1), -DQ(B1), -DP(B1) typing	0
	1c) In the previous question you have reported how many HLA typed CBUs are available for transplantation for unrelated patients. How many of those are available in a hybrid setting before release of the unit for public use? These CBUs are listed in paralel for public AND private use and need consent from the mother	0
2	Adult volunteer donors/CBUs/ADCUs added to the database during 2021 (Registered, HLA typed and available for transplantation for unrelated patients)	8,117
	2a) Count the donors who have been registered and HLA typed during 2021	8,117
	2b) Count the number of new HLA typed CBUs added during 2021	0
	2c) Count the number of new HLA typed ADCUs added/banked during 2021	0
3	Total number of donors/cord blood units permanently deleted during 2021	108
	3a) Donor file closed, specify the reasons if possible	108
	3a1) Medical reason	12
	3a2) Death of donor	0
	3a3) Age limit reached	33
	3a4) Unable to trace	17
	3a5) Emigrated	4
	3a6) Personal withdrawal request	31
	3a7) Deleted following stem cell donation	0
	3a8) Unknown	0
	3a9) Other reason	11

3b) Cord blood units deleted from the inventory POST banking, specify reason if possible	0
3b1) Processing, storage problem	0
3b2) Medical reason	0
3b3) Shipped for transplantation	0
3b4) Used for validation studies	0
3b5) Used for research	0
3b6) Unknown	0

3c) ADCUs deleted from the inventory POST banking, please specify the reason if possible	0
3c1) Processing, storage problem	0
3c2) Medical reason	0
3c3) Shipped for transplantation	0
3c4) Used for validation studies	0
3c5) Used for research	0
3c6) Other	0
3c7) Unknown	0

**Age and gender of your adult volunteer donors
(Registered, HLA typed and available for transplantation for unrelated patients)**

4-6 The age and gender of your adult volunteer donors	Male	Female	UNK
18 to 25 years old	2,986	2,525	0
26 to 35 years old	13,128	9,103	0
36 to 45 years old	10,988	8,187	0
46 to 55 years old	4,978	4,200	0
> 55 years old	109	102	0
unknown	2	1	0
TOTAL	32,191	24,118	0

UNRELATED SEARCH REQUESTS DURING 2021

7	Number of unrelated searches initiated for new patients treated in your country during 2021	130
	Number of patients from your country searching for an unrelated donor	
	7a) Searches requested for stem cell donors for unrelated national patients	130
	7b) Searches requested for cord blood units for unrelated national patients	0
	7c) Searches requested for both stem cell donors and cord blood unit for unrelated national patients	0
8	Number of the above new national patients searched via your registry/cord blood bank but transferred to another country for transplantation	0

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	Total number of registered donors that your registry has re-typed (unrelated to requests) to a higher resolution (RE-typed) or typed for additional loci (NEWLY-typed)	
	9a) Number of donors RE-typed on HLA-A	174
	9b) Number of donors RE-typed on HLA-B	191
	9c) Number of donors RE-typed on HLA-C	148
	9d) Number of donors RE-typed on HLA-DRB1	820
	9e) Number of donors RE-typed on HLA-DQB1	27
	9f) Number of donors RE-typed on HLA-DPB1	12
	9g) Number of donors NEWLY-typed on HLA-C	8,166
	9h) Number of donors NEWLY-typed on HLA-DRB1	8,163
	9i) Number of donors NEWLY-typed on HLA-DQB1	4,818
	9j) Number of donors NEWLY-typed on HLA-DPB1	3,499
	TOTAL	8,785

10	Total number of health and availability check requests for your donors during 2021	132
	10a) Request for patients treated in your country	7
	10b) Request for international patients	125

11	Total number of alternate samples / information requests for your donors (e.g. CMV status from swab)?	0
	11a) Request for patients treated in your country	0
	11b) Request for international patients	0

EXTENDED TYPING REQUESTS FROM YOUR DONORS DURING 2021

12	Total number of HLA-typing requests for donors from your registry	173	36	137
13	Total number of HLA-typing requests for donors from your registry performed in 2021	168	34	134
	13a) Typings requested at the end of 2020 and performed in 2021	14	0	14
	13b) Typings requested during 2021 and performed in 2021	154	34	120
	13c) Typings requested in 2021 that were still in process at the end of 2021	11	0	11
	TOTAL	179	34	145

14	In question 13b you have reported how many HLA-typings are performed by your organisation. What is the time (in calendar days) to obtain these HLA-typings?			
	<i>Please calculate from the date that the request arrived at your registry till the date that the report was sent to the transplant unit.</i>			
	14a) How many requests have been reported within 7 calendar days?	28	4	24
	14b) How many requests have been reported within 8 and 14 calendar days?	54	13	41
	14c) How many requests have been reported within 15 and 21 calendar days	52	10	42
	14d) How many requests have been reported >21 calendar days?	33	7	26
	14e) Unknown	1	0	1
	TOTAL (has to be equal to the answer in question 13)	168	34	134

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

15	Total number of blood samples requested for shipment in 2021	122	32	90
	15a) Request for patients treated in your country	32	32	0
	15b) Request for international patients	90	0	90
16	Total number of blood samples effectively shipped to requesting transplant units during 2021 (blood samples requested from your donors during 2021)			
	Shipment for patients treated in your country	14	14	0

Shipment for international patients		37	0	37
	TOTAL	51	14	37
Samples in process (requested at the end of the year and in process)		7	1	6

17 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.

17a) How many requests have been shipped within 7 calendar days?	12	4	8
17b) How many requests have been shipped within 8 and 14 calendar days?	13	3	10
17c) How many requests have been shipped within 15 and 21 calendar days?	14	5	9
17d) How many requests have been shipped >21 calendar days?	12	2	10
17e) Unknown	0		
TOTAL (has to be equal with the number reported in question 14)	51	14	37

18 Total number of blood samples cancelled for shipment in 2021

	64	16	48
18a) Donor related reasons (see below the EMDIS definitions)			
18a1) DO = Donor is too old	0	0	0
18a2) DD = Donor died	0	0	0
18a3) MR = Medical reasons	6	2	4
18a4) PR = Personal reasons	22	7	15
18a5) TX = After transplantation	1	0	1
18a6) MO = Donor has moved	6	3	3
18a7) UC = Unable to contact donor	25	4	21
18a8) UK = Unknown	0	0	0
18a9) EX = Expired	0	0	0
18a10) MM = HLA mismatch	0	0	0
18a11) OT = Other reasons	0	0	0
TOTAL number blood samples cancelled due to donor related reasons	60	16	44
18b) Patient related reasons (see below the EMDIS definitions)			
18b1) BCC = Clinical condition of patient deteriorated (i.e. relapse)	0	0	0
18b2) FND = Other/better donor found	1	0	1
18b3) LAB = laboratory problem/typing failed/not enough sample	0	0	0
18b4) NSP = No sample received	0	0	0
18b5) OLD = Sample too old	0	0	0
18b6) PDC = Patient deceased before request was completed	0	0	0
18b7) STP = Search stopped	0	0	0
18b8) TRX = Patient already transplanted	0	0	0
18b9) OTH = Other reason	3	0	3
TOTAL number blood samples cancelled due to patient related reasons	4	0	4
TOTAL	4	0	4

Work-ups requested from your donors during 2021

19 Total number of work-ups requested from your donors in 2021(no DLIs)	9	7	2
(Count all work-up requests from your donors for unrelated patients that are requested by transplant unit)s			
20 Total number of donors from your registry deferred at work-up, resulting in harvest cancellation (from the work-ups requested in question 16)	2	1	1
(The reasons of the work-up cancellations must be related to the donors themselves)			
21 Number of work-up cancellations of your donors made by your national transplant units	1	1	0
(the reasons of the work-up cancellations must be related to the patients themselves, the concerned donors belong to your registry)			
22 Number of work-up cancellations of your donors made by international transplant units	0	0	0
(the reason of the work-up cancellations must be related to the patients themselves, the concerned donors belong to your registry)			
23 Work-ups requests still in progress	2	1	1
24 Work-ups requested in 2020 and performed in 2021	2	1	1
25 Number of work-ups requested without preceding verification/confirmatory typing request for respective donor/patient pair	0	0	0
(verification/confirmatory typing performed at work-up)			
26 ADCUs shipped by your organisation for unrelated patients during 2021	0	0	0

**DISTRIBUTION OF UNRELATED STEM CELL DONATIONS
TO VARIOUS COUNTRIES DURING 2021**

	TYPE OF STEM CELLS					
	HPC, Marrow	HPC, Apheresis	ADCUs	HPC, Cord	DLI	CAR-T cells, NK
31-35 Total number of HPC products provided by your donors shipped to international patients	1	1	0	0	0	0
36-40 Total number of HPC products provided by your donors shipped to national patients	0	4	0	0	0	0

41-44 Number of HPC products provided by your donors shipped to the following countries for unrelated transplantation:

Count all HPC products for international patients (have been exported) in 2021; Precise the number of products per country and the type of stem cells provided.

	TYPE OF STEM CELLS; include also the subsequent donations!					
	HPC, Marrow	HPC, Apheresis	ADCUs	HPC, Cord	DLI	CAR-T cells, NK
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		1				
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		4				
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						
Other countries not specified above:						
TOTAL	1	5	0	0	0	0
GRAND TOTAL OF HPC PRODUCTS EXPORTED FOR INTERNATIONAL PATIENTS	2					

! Do not forget the subsequent stem cell donations!

**DISTRIBUTION OF HPC PRODUCTS IMPORTED
FROM VARIOUS COUNTRIES FOR URTx DURING 2021**

	TYPE OF STEM CELLS					
	HPC, Marrow	HPC, Apheresis	ADCUs	HPC, Cord	DLI	CAR-T cells, NK
Total number of HPC products imported by your organisation for unrelated 45-49 transplantation during 2021	0	46	0		9	

Number of HPC products imported from various countries for unrelated 50-53 transplantation during 2021 from the following countries:

		TYPE OF STEM CELLS					
		HPC, Marrow	HPC, Apheresis	ADCUs	HPC, Cord	DLI	CAR-T cells, NK
<i>Count all HPC products have been imported in 2021 T1. Precise the number of products per country and the type of stem cells imported.</i>							
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		26			5	
23	Greece		2			1	
24	Hungary						
25	India						
26	Iran						
27	Ireland						
28	Israel		1			1	
29	Italy		1				
30	Japan						
31	Jordan						
32	Korea						
33	Lithuania						
34	Malaysia						
35	Mexico						
36	Netherlands						
37	New Zealand						
38	Norway						
39	Philippines						
40	Poland		14			2	
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		1				
53	Taiwan						
54	Thailand						
55	Turkey		1				
56	United Kingdom						
57	United States						
58	Uruguay						
59	Venezuela						
	Other countries not specified above:						
	TOTAL	0	46	0	0	9	0
GRAND TOTAL OF HPC PRODUCTS IMPORTED FOR NATIONAL PATIENTS		46					

! Do not forget the subsequent stem cell donations!

UNRELATED HPC DONATION PROVIDED BY YOUR REGISTRY DURING 2021

		PRO	PST	
54	Number of HPC products of your donors provided by your organisation for unrelated transplantation	6	4	2
55	First time donation			
	HPC-Marrow	1	0	1
	HPC-Apheresis	5	4	1
	ACDUs	0	0	0
	TOTAL	6	4	2
56	Subsequent donation	0	0	0
57	Subsequent donation; same initial patient			
	HPC-Marrow	0	0	0
	HPC-Apheresis	0	0	0
	DLI	0	0	0
	ACDUs	0	0	0
	TOTAL	0	0	0
58	SUBSEQUENT DONATION; another unrelated patient			
	HPC-Marrow	0	0	0
	HPC-Apheresis	0	0	0
	DLI	0	0	0
	ACDUs	0	0	0
	TOTAL	0	0	0

PATIENTS RECEIVED UNRELATED TRANSPLANT

PRO PST

59	Total number of patients received unrelated transplant in 2021 from your organization (no DLI)	6	4	2
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60	Number of national patients transplanted during 2021			
	HPC-Marrow	1	0	1
	HPC-Apheresis	5	4	1
	ACDUs	0	0	0
	TOTAL	6	4	2

61	Patients received unrelated transplant in country without national registry during 2021 <i>(e.g. HPC transplants facilitated to countries where no registry exists)</i>			
	HPC-Marrow	0	0	0
	HPC-Apheresis	0	0	0
	ACDUs	0	0	0
	TOTAL	0	0	0

PATIENTS RECEIVED RELATED TRANSPLANT

62	Total number of patients in your country received related transplant during 2021 with HPC donations facilitated by your organisation (no DLIs)			
	HPC-Marrow	0	0	0
	HPC-Apheresis	2	0	2
	HSC Cord	0	0	0
	TOTAL	2	0	2

62	Number of patients in your country received related transplant during 2021 facilitated by your organisation from an pediatric donor (<18yr)			
	HPC-Marrow	0	0	0
	HPC-Apheresis	0	0	0
	HSC Cord	0	0	0
	TOTAL	0	0	0

64	Number of patients in your country received related transplant during 2021 facilitated by your organisation from an adult donor			
	HPC-Marrow	0	0	0
	HPC-Apheresis	2	0	2
	HSC Cord	0	0	0
	TOTAL	2	0	2