

ANNUAL REPORT QUESTIONNAIRE 2019

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@ndvcsh.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.ndvcsh.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@ndvcsh.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@ndvcsh.ro**CONTACT INFORMATION FOR SEARCHES****ANSWER**

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@ndvcsh.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@ndvcsh.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@ndvcsh.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:

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 2019

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, 2019**
(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	274
Total number of donors with HLA-A, -B, -DRB1 typing	5,076
Total number of donors with HLA-A, -B, -C, -DRB1 typing	29,749
Total number of donors with HLA-A, -B, -C, -DRB1, -DQB1 typing	5,255
Total number of donors with HLA-A, -B, -C, -DRB1, -DQB1, -DPB1 typing	2,818
TOTAL	43,172

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: **43,172**

ADULT VOLUNTEER DONORS/CBUs ADDED TO THE DATABASE DURING 2019

- 2 Count all new donors/cord blood units recruited and HLA typed during 2019**

Count only the donors who have been registered and HLA typed in 2019	2,162
Count the number of new HLA typed cord blood units added during 2019	0
TOTAL	2,162

ADULT VOLUNTEER DONORS/CBUs PERMANENTLY DELETED DURING 2019

- 3 Total number of donors/cord blood units permanently deleted during 2019**

Donor File Closed, specify the reasons, if possible

Medical reason	7
Death of donor	0
Age limit reached	21
Unable to trace	19
Emigrated	1
Personal withdrawal request	18
Deleted following stem cell donation	0
Unknown	0
Other reason	106
TOTAL	172

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

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

AGE AND GENDER OF ADULT VOLUNTEER DONORS

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

	Male	Female	UNK
18 to 25 years old	3,606	2,658	
26 to 35 years old	10,579	6,647	1
36 to 45 years old	8,132	5,936	
46 to 55 years old	2,994	2,505	
> 55 years old	58	55	
unknown	0	1	
TOTAL	25,369	17,802	1
TOTAL	43,172		

Check: The total should be equal to question 1; result question 1 is: [43172](#)

UNRELATED SEARCH REQUESTS DURING 2019

7 Number of unrelated searches initiated for new patients treated in your country during 2019

Number of patients from your country searching for an unrelated donor

Searches requested for stem cell donors for unrelated national patients	109
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	109

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

3

STEM CELL DONOR REGISTRIES ANNUAL REPORT QUESTIONNAIRE 2019

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

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

9

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

EXTENDED TYPING REQUESTS FROM YOUR DONORS DURING 2019

national patients international patients

10	Total number of HLA-typing requests for donors from your registry	205	25	180
11	Total number of HLA-typing requests performed in 2019			
11a	Typings requested at the end of 2018 and performed in 2019	15	0	15
11b	Typings requested during 2019 and performed in 2019	166	23	143
11c	Typings requested in 2019 that were still in process at the end of 2019	17	1	16
	TOTAL	181	23	158

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?	18	11	7
How many requests have been reported within 8 and 14 calendar days?	37	6	31
How many requests have been reported within 15 and 21 calendar days?	33	3	30
How many requests have been reported >21 calendar days?	93	3	90
Unknown	0	0	0
TOTAL (has to be equal to the answer in question 11)	181	23	158

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

13	Total number of blood samples requested for shipment in 2019	
	Request for patients treated in your country	18
	Request for international patients	102
	TOTAL	120
14	Total number of blood samples effectively shipped to requesting transplant units in 2019	
	Shipment for patients treated in your country	5
	Shipment for international patients	44
	TOTAL	49
	Samples in process (requested at the end of the year and in process)	3

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?	10	0	10
How many requests have been shipped within 8 and 14 calendar days?	19	1	18
How many requests have been shipped within 15 and 21 calendar days?	4	0	4
How many requests have been shipped >21 calendar days?	16	4	12
Unknown	0	0	
TOTAL (has to be equal with the number reported in question 14)	49	5	44

16 **Total number of blood samples cancelled for shipment in 2019** **68** **13** **55**

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

DO = Donor is too old	0	0	0
DD = Donor died	0	0	0
MR= Medical reasons	4	1	3
PR = Personal reasons	16	2	14
TX = After transplantation	1	1	0
MO = Donor has moved	9	1	8
UC = Unable to contact donor	28	7	21
OT = other reasons	1	0	1
UK = Unknown	0	0	0
EX = Expired	2	0	2
MM = HLA mismatch	0	0	0
TOTAL NUMBER BLOOD SAMPLES CANCELLED DUE TO DONOR RELATED REASONS	61	12	49

16b **Patient related reasons (see below the EMDIS definitions)**

BCC = Clinical condition of patient deteriorated (i.e. relapse)	4	0	4
FND = Other/better donor found	0	0	0
LAB = laboratory problem/typing failed/not enough sample	0	0	0
NSP = No sample received	0	0	0
OLD = Sample too old	0	0	0
PDC = Patient deceased before request was completed	1	1	0
STP = Search stopped	2	0	2
TRX = Patient already transplanted	0	0	0
OTH = Other reason	0	0	0
TOTAL NUMBER BLOOD SAMPLES CANCELLED DUE TO PATIENT RELATED REASONS	7	1	6
TOTAL	68	13	55

CANCELLATIONS FROM YOUR DONORS OF WORK-UPS REQUESTED

17 **Total number of work-ups requested from your donors in 2019 (no DLIs)** **8** **1** **7**
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)** **4** **0** **4**
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** **0** **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)** **4** **0** **4**
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** **0** **0** **0**
Work-ups requested in 2019 and performed in 2020
 NOTE:
The total number work-ups requested in 2019 minus the cancellations of work-ups requested in 2019 minus the work-ups requested in 2019 that are still in progress plus the work-ups requested in 2018 and performed in 2019 should be equal to the number of stem cell products provided.

22 **Number of international donors deferred at work-up, resulting in harvest cancellation** **6** **6** **0**
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** **0** **0**

**DISTRIBUTION OF UNRELATED STEM CELL DONATIONS
TO VARIOUS COUNTRIES DURING 2019**

25-27 Total number of HPC products provided by your donors shipped to international patients
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	4	0	0
0	1	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 2019. 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 2019 and specify the country</i>	0	4	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		1		
23	Greece				
24	Hungary				
25	India				
26	Iran				
27	Ireland				
28	Israel				
29	Italy		2		
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				
57	United States		1		
58	Uruguay				
59	Venezuela				
	Other countries not specified above:				
	TOTAL	0	4	0	0
	GRAND TOTAL OF HPC PRODUCTS EXPORTED FOR INTERNATIONAL PATIENTS	4			

! Do not forget the subsequent stem cell donations!

**DISTRIBUTION OF HPC PRODUCTS IMPORTED
FROM VARIOUS COUNTRIES FOR URTx DURING 2019**

TYPE OF STEM CELLS

HPC, Marrow	HPC, Apheresis	HPC, Cord	DLI
5	44	0	6

35-37 Total number of HPC products imported by your organisation for unrelated transplantation during 2019

38-40 Number of HPC products imported from various countries for unrelated transplantation during 2019 from the following countries:

List, by alphabetical order, the name of the countries from which all HPC products have been imported in 2019. 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 2019, from various countries</i>		5	44	0	6
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		1		
17	Czech Republic				
18	Denmark				
19	Estonia				
20	Finland				
21	France				
22	Germany	2	23		4
23	Greece		1		1
24	Hungary				
25	India		1		
26	Iran				
27	Ireland				
28	Israel		2		
29	Italy		2		
30	Japan				
31	Jordan				
32	Korea				
33	Lithuania				
34	Malaysia				
35	Mexico				
36	Netherlands				
37	New Zealand				
38	Norway				
39	Philippines				
40	Poland	2	8		
41	Portugal				
42	Romania				
43	Russia				
44	San Marino				
45	Saudi Arabia				
46	Singapore				
47	Slovakia				
48	Slovenia		1		
49	South Africa				
50	Spain	1			
51	Sweden		2		
52	Switzerland				
53	Taiwan				
54	Thailand				
55	Turkey		1		
56	United Kingdom		2		
57	United States				
58	Uruguay				
59	Venezuela				
	Other countries not specified above:				
	TOTAL	5	44	0	6
	GRAND TOTAL OF HPC PRODUCTS IMPORTED FOR NATIONAL PATIENTS	55			

! Do not forget the subsequent stem cell donations!

UNRELATED HPC DONATION PROVIDED BY YOUR REGISTRY DURING 2019

41	TOTAL NUMBER OF HPC PRODUCTS OF YOUR DONORS PROVIDED BY YOUR ORGANISATION FOR UNRELATED TRANSPLANTATION		
42-45	FIRST TIME DONATION	national patients	international patients
	HPC-Marrow	0	0
	HPC-Apheresis	1	4
	TOTAL	1	4
	SUBSEQUENT DONATION; same initial patient		
	HPC-Marrow	0	0
	HPC-Apheresis	0	0
	DLI	0	0
	TOTAL	0	0
	SUBSEQUENT DONATION; another unrelated patient		
	HPC-Marrow	0	0
	HPC-Apheresis	0	0
	DLI	0	0
	TOTAL	0	0

PATIENTS RECEIVED UNRELATED TRANSPLANT

NATIONAL PATIENTS

46 Total number of patients received unrelated transplant in 2019 from your organization (no DLI) **50**

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	1
TOTAL NUMBER OF PATIENTS	1
National cord blood product provided for patient in your organisation	
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 organisation	
Patient received HPC-Marrow transplant from international donor	5
Patient received HPC-Apheresis transplant from international donor	44
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	49

INTERNATIONAL PATIENTS

39 HPC donations facilitated by your registry without interaction of another registry in 2019

(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	4
TOTAL	4
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