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## **D3.2 Report on import/export and registry operations within EU Member States**

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## Abbreviations

- BM = Bone Marrow
- CBU = Cord Blood Unit
- DLI = Donor Lymphocyte Infusion
- HLA = Human Leukocyte Antigen
- HSC = Hematopoietic Stem Cells
- PBSC = Peripheral Blood Stem Cell
- WMDA = World Marrow Donor Association

## Executive Summary

Since 1997, the World Marrow Donor Association (WMDA) sends out an annual questionnaire to analyse the global trends in unrelated stem cell and cord blood donation. Approximately 98% of all registries and cord blood bank worldwide participate in this prestigious project. Since 2017, WMDA's Search & Match statistics are also included into the WMDA Global Trends Report.

This WMDA Annual Report describes the 2018 import and export data, trends and insight of unrelated blood stem cell products between the different European Union (EU) member states and third countries. In 2018, almost 1,4 million volunteer individuals were recruited, and HLA typed into unrelated stem cell donor registries within the EU member states and 6,467 cord blood units were added to the inventory increasing the total number of available stem cell donors within the EU member states to 14,515,715 and worldwide almost 37 million.

In 2018: within the EU member states 4,274 adult stem cell products were imported and 4,289 exported and 137 cord blood products were imported and 136 exported.

In 2018, there were 3,801 adult stem cell products exported to 19 countries outside of the EU member states and 1,073 adult stem cell donations imported from these countries. Additionally, 218 cord blood products were exported to countries outside of the EU member states and 129 cord blood products were imported.

This Deliverable D3.2 *Report on import/export and registry operations within EU Member States* is part of the 2019 work programme of the World Marrow Donor Association for the EU Third Health Programme (2014-2020). It is based on the data of the Global Trends Report 2018 and focusses mainly on the export to and the import from EU Member States. It includes current volumes, patterns and trends as well as information relating to quality and safety regulations and related operational processes. This report will be used to baseline and track improvements, as well as a resource to support EU member registries to implement good and best import/export practices that serve to improve efficiency and quality.

The complete WMDA Global Trends Report 2018 is free accessible for WMDA members and available on request for people interested in the data. A screenshot of the Global Trends Report is shown on [page 4](#).

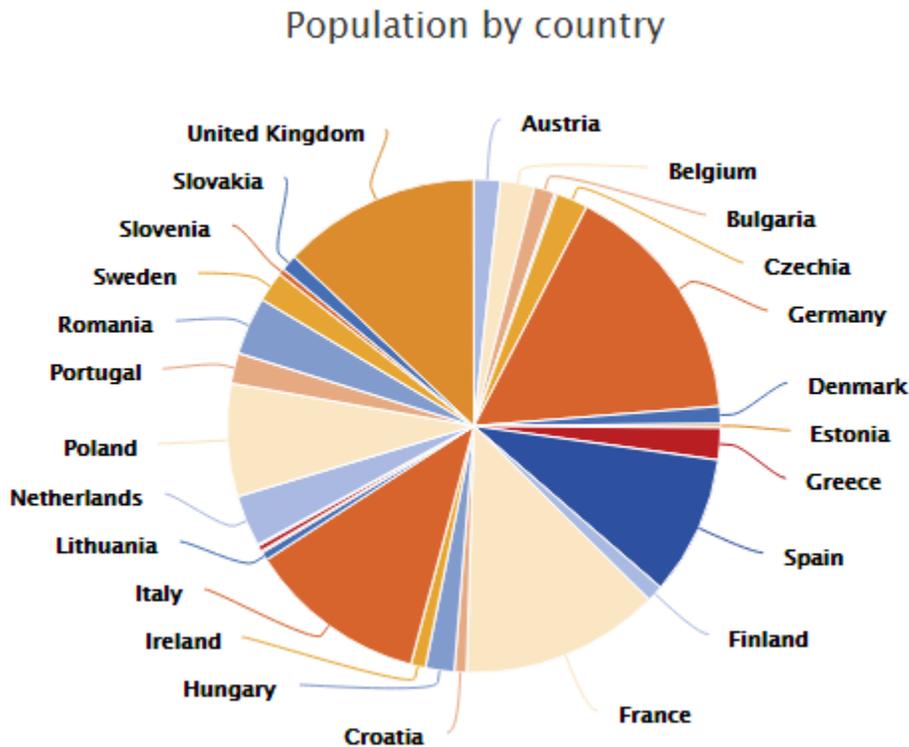
## Introduction

The WMDA is an international collaborative effort of organisations and individuals involved in hematopoietic stem cell donation and transplantation. WMDA’s mission is to promote global collaboration and the sharing of best practices between its members for the benefit of stem cell donors and patients. One of the annual projects of the WMDA is to collect the number of unrelated stem cell products provided by the unrelated stem cell donor registries and cord blood banks (CBB) worldwide. The WMDA office has been collecting these data since 1997 and is proud to distribute the 21<sup>st</sup> edition of the WMDA Global trends report in 2018. A total of 99 organisations from 54 different countries providing hematopoietic stem cell products participated in the annual report 2018. Stem Cell Donor and Cord Blood organisations have voluntarily contributed data on the understanding that publications may result. Each organisation is free to use the data for its own internal use, but any use of the data for publication must receive prior approval of the WMDA Board or its designee.

## EU

The EU covers over 4 million km<sup>2</sup> and has 513 million inhabitants - the world’s third largest population after China and India. By surface area, France is the biggest EU country and Malta the smallest. Germany, France and United Kingdom hold the biggest populations (*Figure 1*).

*Figure 1. Population per EU Member State\**



\*Source: [https://europa.eu/european-union/about-eu/figures/living\\_en](https://europa.eu/european-union/about-eu/figures/living_en)

### Global network

Millions of volunteers have signed up to be a donor worldwide, and tens of thousands of patients receive blood stem cells from a healthy individual every year. Unfortunately, over 30% of the patients is not able to find a potential match. This is more volunteers are needed to sign up as donors. WMDA services the global network by providing a centralised database of all potential donors around the world.

### Import / export

This report shows the importance of global exchange of stem cell products. Nowadays, people have spread all over the world which means that certain populations do not live in the same region anymore as they use to. Unfortunately, not every country has an established network for recruiting donors. Furthermore, smaller countries may not have enough volunteer donors or CBUs themselves. They rely on the international network of blood stem cell donor registries to find a suitable stem cell source.

The list of third countries that export from and import to the EU member states is shown in *Appendix 1*.

## Global Trends Report

The Global Trends Report 2018 (*Figure 2*) is accessible for WMDA members on WMDA Share and for external interested people on request. Please contact [mail@wmda.info](mailto:mail@wmda.info) to request a copy of the Global Trends Report.

*Figure 2. Global Trends Report on WMDA Share*

## Global Trends Report 2018

Created by [redacted], last modified on Sep 16, 2019

WMDA accumulates data as part of its global trends report that includes detailed data on each participating organisation. Participating organisations may use the reports and data included in the reports that are published by WMDA, *other than specific data*, subject to the following terms (limited license agreement):

The organisation may use the data, other than registry specific data, for internal purposes and to communicate with competent authorities, governing boards and sponsors.

Information from the reports may be used in presentations to outside parties provided that WMDA must be acknowledged as the source as follows:

**"WMDA Global Trends Report [YEAR] (a copy of specific editions can be requested via [mail@wmda.info](mailto:mail@wmda.info))".**

The data may not be used for commercial purposes.

The data may not be used in scientific publications without separate permission from WMDA.

Data specific to a participating organisation may not be published in any form without the permission of that organisation.

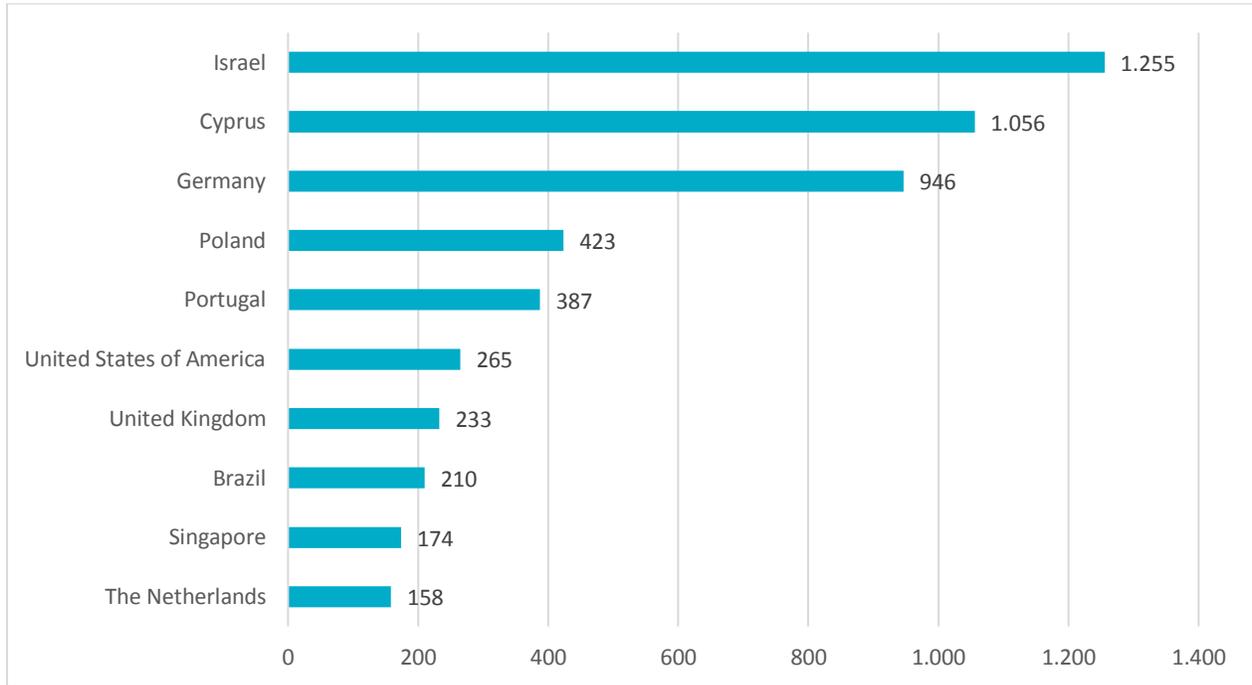
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**Celebrating 20 years of WMDA Global Trends Report. Watch the 'Global Trends in Blood Stem Cell Donation' video infographic**

| File  | Modified ^                                 |
|---|--|
| >  17072019-GTR-Graphs S&M service 2018.pptx | Jul 18, 2019 by <a href="#">[redacted]</a> |
| >  17072019-GTR-Top 5 2018.xls               | Jul 18, 2019 by <a href="#">[redacted]</a> |
| >  17072019-GTR-TNC 2018.xls                 | Jul 18, 2019 by <a href="#">[redacted]</a> |
| >  17072019-GTR-Shipping rates 2018.xls      | Jul 18, 2019 by <a href="#">[redacted]</a> |
| >  17072019-GTR-Factsheet 2018.pdf           | Jul 18, 2019 by <a href="#">[redacted]</a> |
| >  17072019-GTR-Global Exchange 2018.xls     | Jul 19, 2019 by <a href="#">[redacted]</a> |
| >  17072019-GTR-Complete export 2018.xls     | Sep 16, 2019 by <a href="#">[redacted]</a> |
| >  17072019-GTR-Graphs 2018.pptx             | Sep 16, 2019 by <a href="#">[redacted]</a> |
| >  17072019-GTR-Graphs Summary 2018.pptx     | Sep 16, 2019 by <a href="#">[redacted]</a> |

*Figure 3* highlights the number of donors listed per 10,000 inhabitants.

Figure 3. Number of donors listed per 10,000 inhabitants (top 10) (from Global Trends Report 2018)



In general, the growth of the cord blood inventory is lower than the growth of the number of volunteer donors. A trend is observed that the number of cord blood units released for transplantation is decreasing.

Deliverable D3.1 Public webpages with cord blood banking practices (2019) provides more information on this topic. Bone marrow (BM) products and peripheral blood stem cell (PBSC) transplantations are more frequently used than cord blood products.

A shift to more high-resolution typing in adult volunteer stem cell products is observed. This is due to the fact that higher resolution typing is preferable to find a better match and high-resolution typing has become cheaper over the last years.

### Questionnaire

In *Appendix 2* the WMDA Questionnaire is shown with the questions regarding adult donor and CBU numbers and import and export data that were answered by the different registries worldwide.

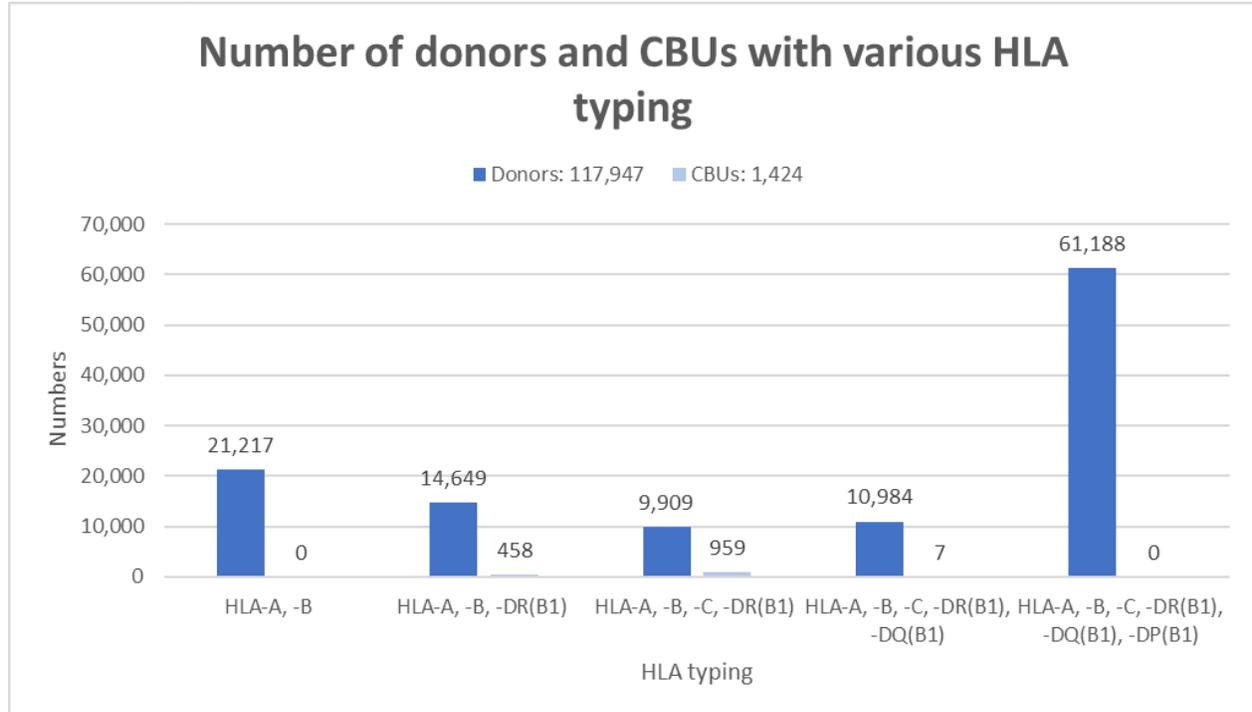
Data from Latvia, Estonia and Malta is missing since these countries do not have a donor registry or a cord blood bank. Estonia has a collaboration with Finland to find their donor matches, so they import stem cell sources from other countries. Lithuania, Luxembourg, Portugal, Romania, Bulgaria, Denmark, Hungary and Ireland do not have a cord blood bank, so they import cord blood products from other countries. Germany is the biggest supplier of all stem cell products.

The following pages show the report per EU member state including the import and export data of the different stem cell products.



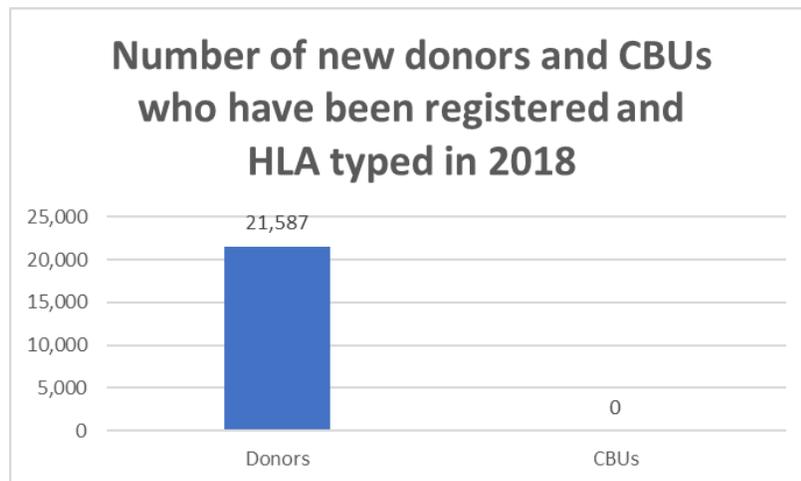
Number of registered and typed donors/CBUs on 31 December 2018:

**119,371**



Adult volunteer donors/CBUs added to the database during 2018:

**21,587**

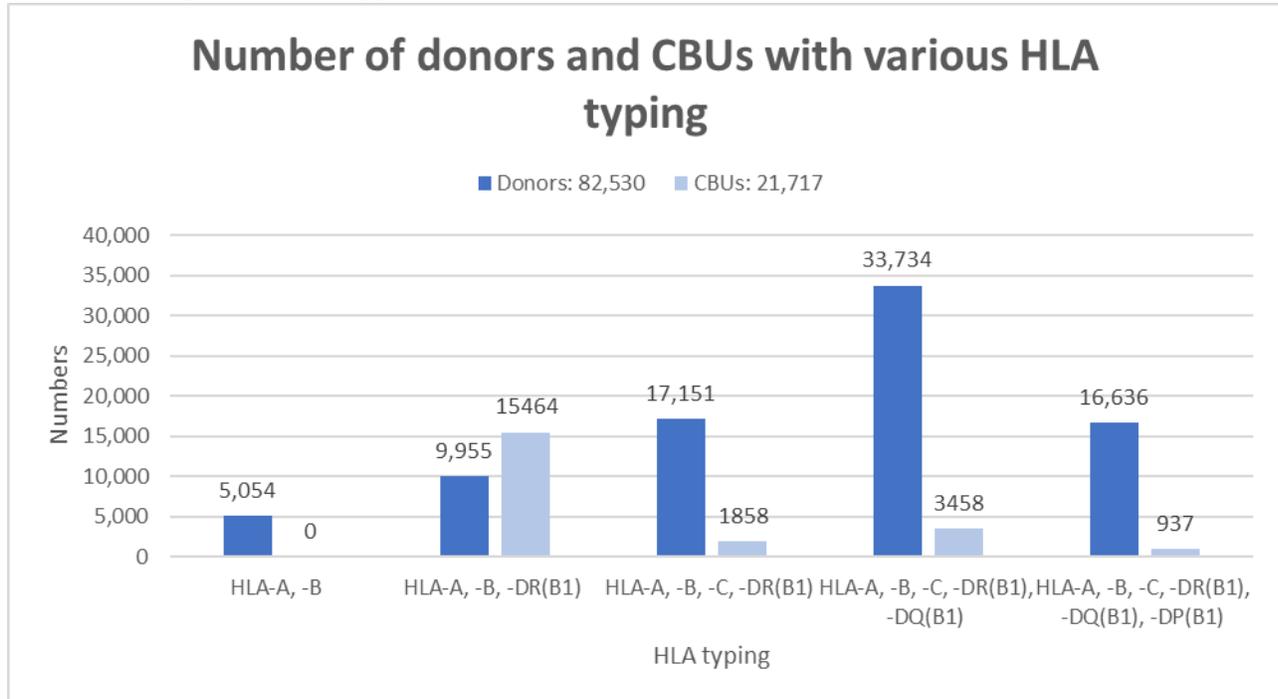


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 1  | 4    | 0   | 1   |
| <b>Export to EU member states</b>   | 4  | 29   | 0   | 1   |
| <b>Export to third countries</b>    | 4  | 14   | 0   | 0   |
| <b>Import from EU member states</b> | 17 | 95   | 3   | 12  |
| <b>Import from third countries</b>  | 1  | 9    | 3   | 1   |



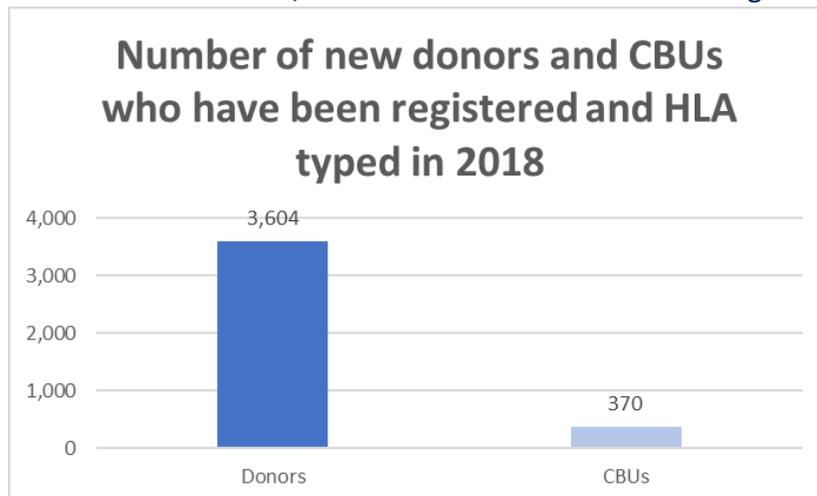
Number of registered and typed donors/CBUs on 31 December 2018:

**104,247**



Adult volunteer donors/CBUs added to the database during 2018:

**3,974**

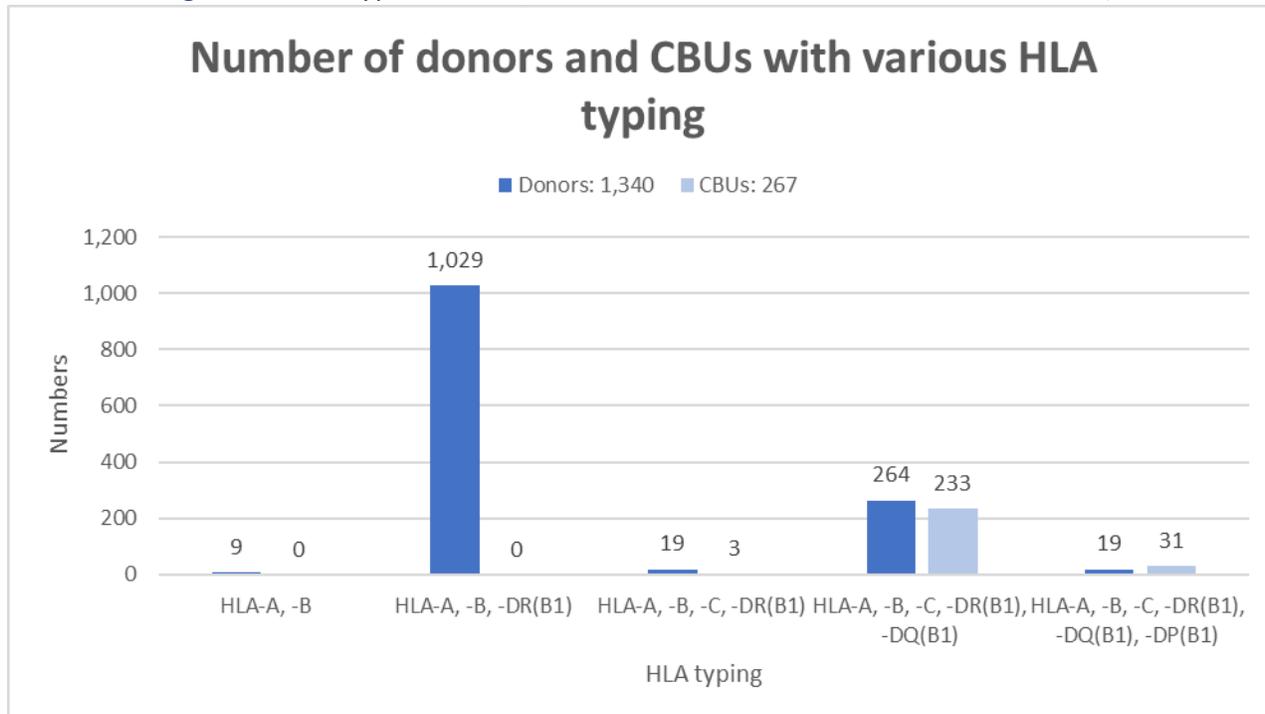


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 0  | 6    | 1   | 0   |
| <b>Export to EU member states</b>   | 3  | 18   | 7   | 2   |
| <b>Export to third countries</b>    | 0  | 6    | 1   | 0   |
| <b>Import from EU member states</b> | 12 | 178  | 2   | 22  |
| <b>Import from third countries</b>  | 6  | 21   | 2   | 0   |



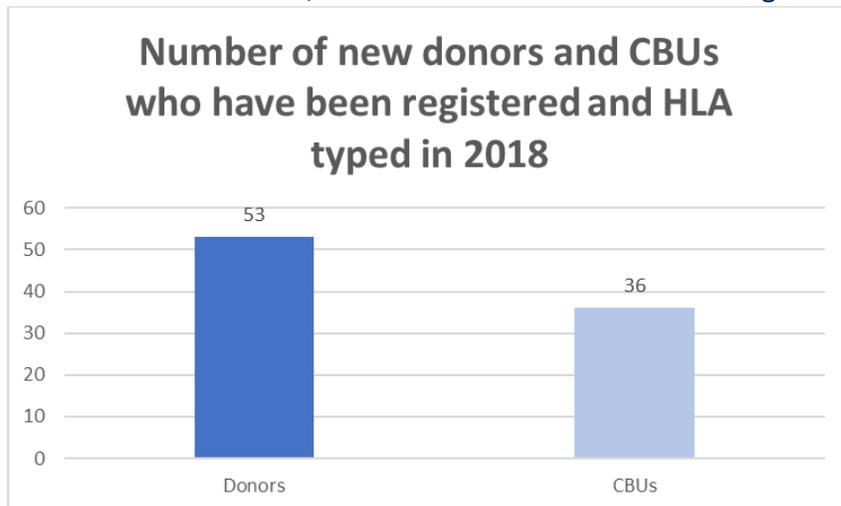
Number of registered and typed donors/CBUs on 31 December 2018:

**1,607**



Adult volunteer donors/CBUs added to the database during 2018:

**89**

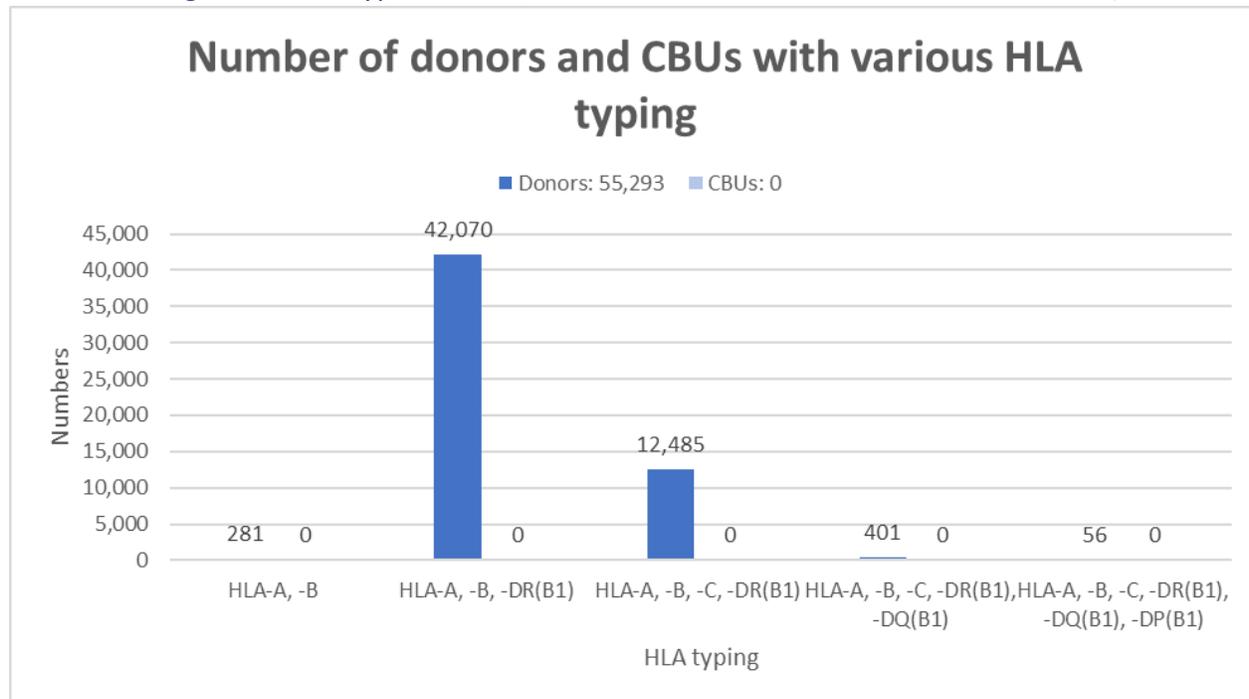


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 0  | 0    | 0   | 0   |
| <b>Export to EU member states</b>   | 0  | 0    | 0   | 0   |
| <b>Export to third countries</b>    | 0  | 0    | 0   | 0   |
| <b>Import from EU member states</b> | 0  | 23   | 0   | 1   |
| <b>Import from third countries</b>  | 0  | 0    | 0   | 0   |



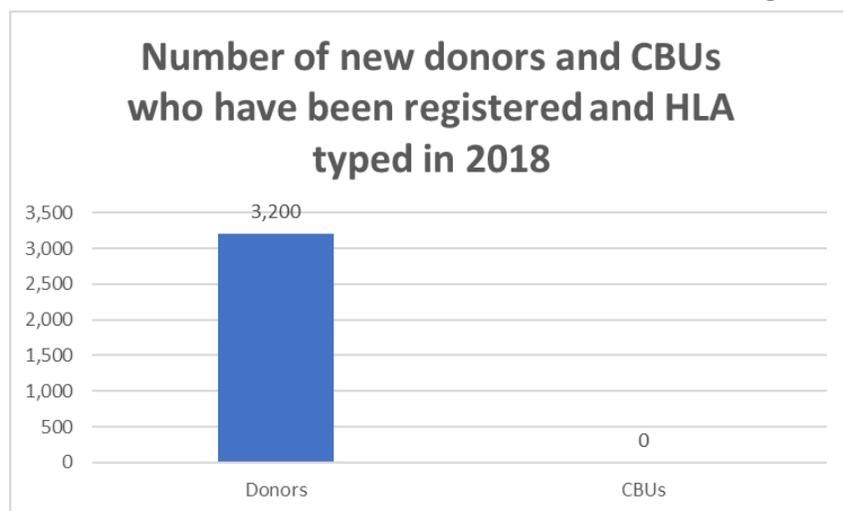
Number of registered and typed donors/CBUs on 31 December 2018:

**55,293**



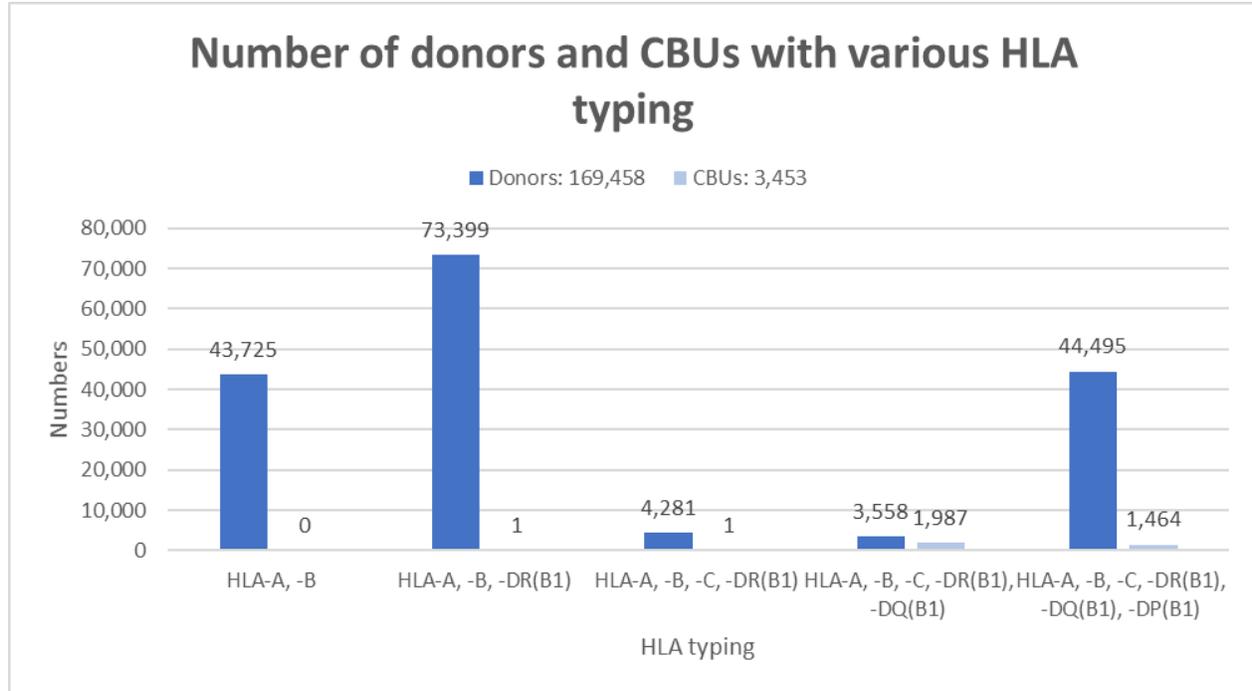
Adult volunteer donors/CBUs added to the database during 2018:

**3,200**

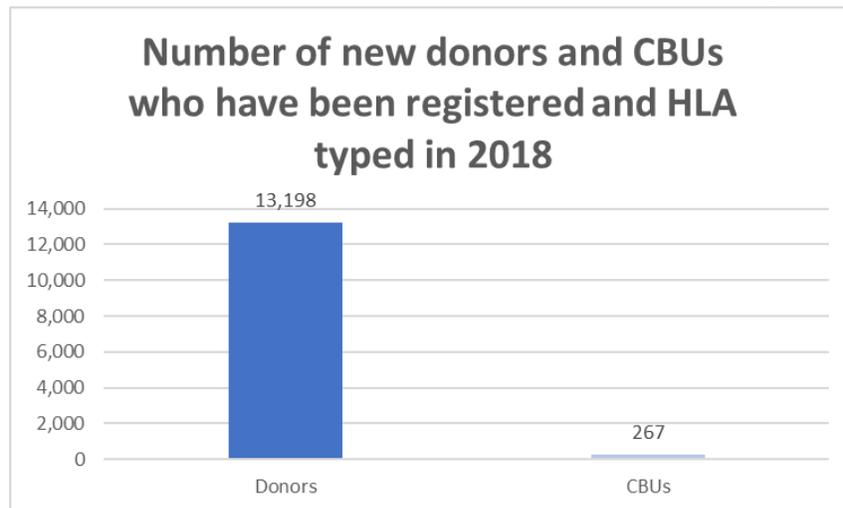


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 3  | 9    | 0   | 3   |
| <b>Export to EU member states</b>   | 2  | 4    | 0   | 0   |
| <b>Export to third countries</b>    | 0  | 0    | 0   | 0   |
| <b>Import from EU member states</b> | 9  | 17   | 0   | 2   |
| <b>Import from third countries</b>  | 3  | 4    | 0   | 0   |

Number of registered and typed donors/CBUs on 31 December 2018: **172,911**



Adult volunteer donors/CBUs added to the database during 2018: **13,465**



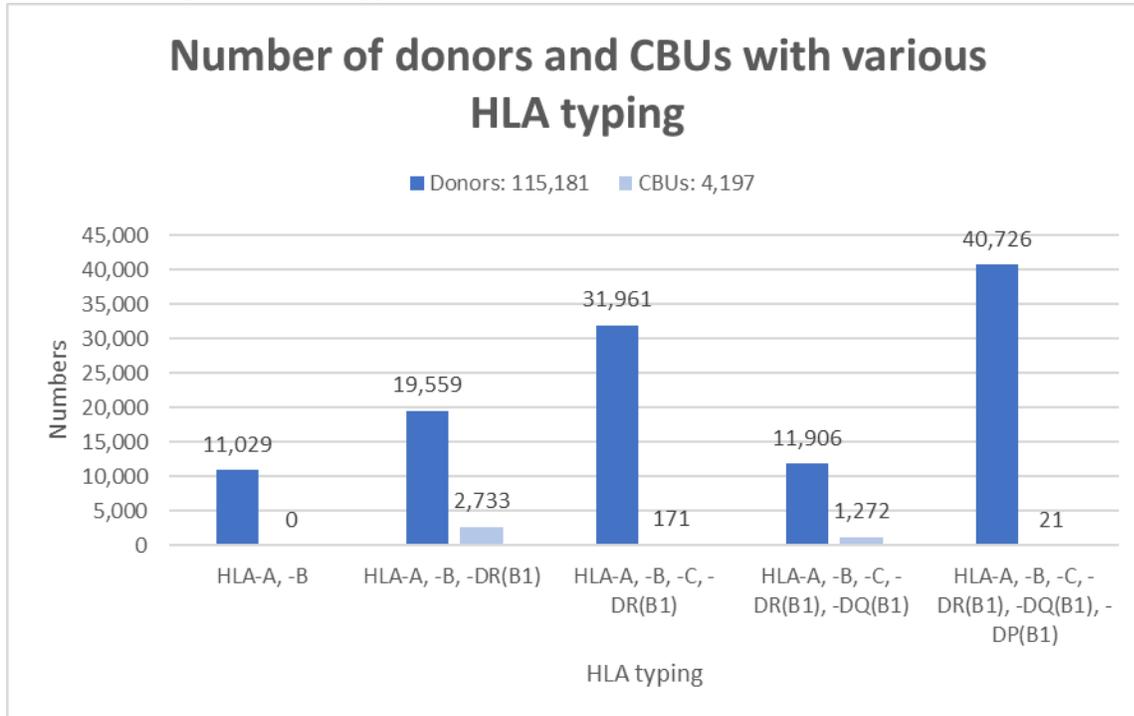
|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 1  | 3    | 0   | 0   |
| <b>Export to EU member states</b>   | 3  | 33   | 0   | 0   |
| <b>Export to third countries</b>    | 1  | 7    | 0   | 0   |
| <b>Import from EU member states</b> | 0  | 0    | 0   | 0   |
| <b>Import from third countries</b>  | 0  | 0    | 0   | 0   |



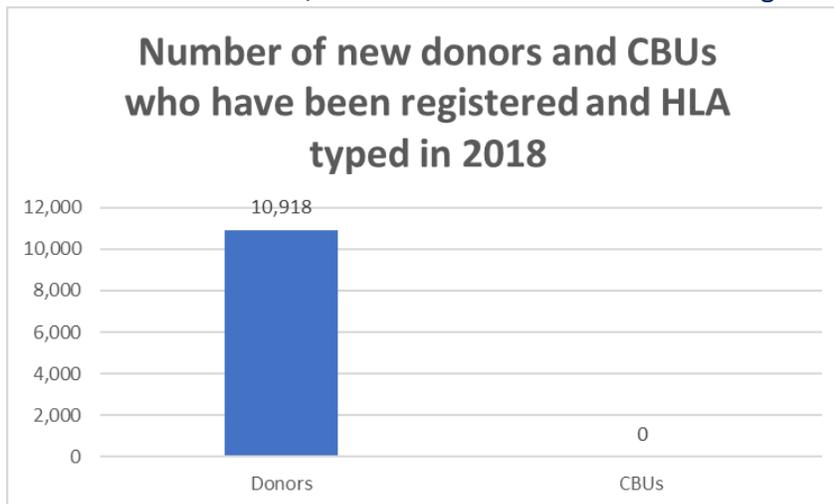
# Czech Republic

10,649,800 inhabitants

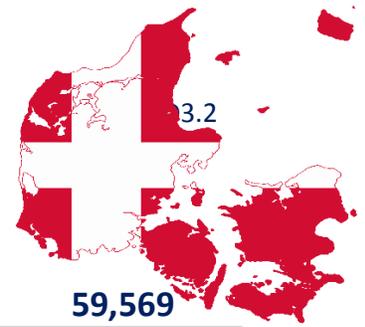
Number of registered and typed donors/CBUs on 31 December 2018: **119,378**



Adult volunteer donors/CBUs added to the database during 2018: **10,918**

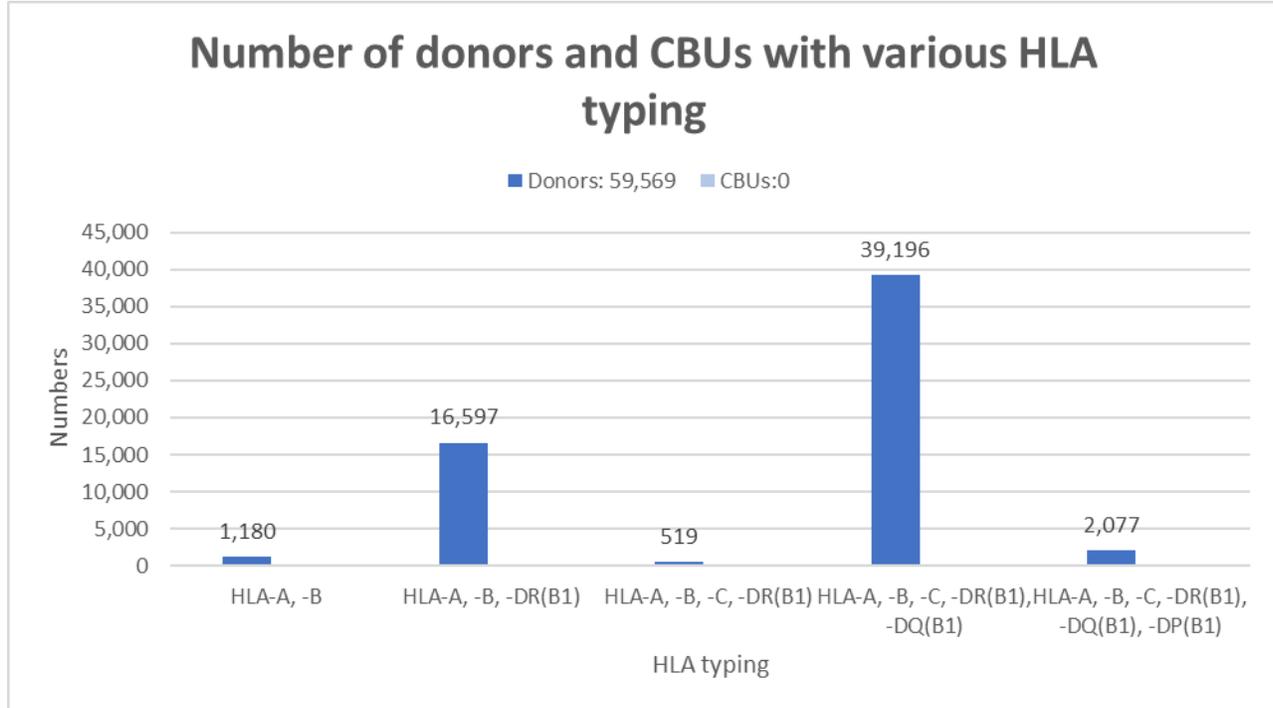


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 2  | 28   | 1   | 4   |
| <b>Export to EU member states</b>   | 4  | 10   | 0   | 1   |
| <b>Export to third countries</b>    | 4  | 3    | 0   | 0   |
| <b>Import from EU member states</b> | 7  | 128  | 3   | 15  |
| <b>Import from third countries</b>  | 0  | 4    | 0   | 2   |



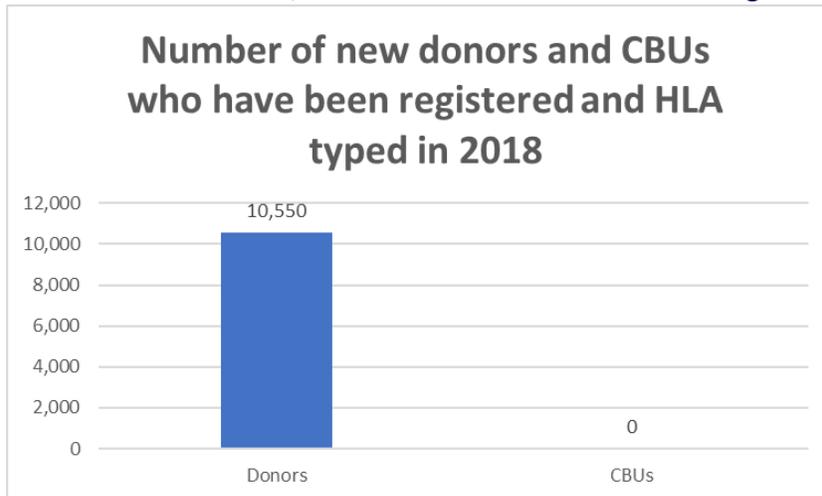
Number of registered and typed donors/CBUs on 31 December 2018:

**59,569**



Adult volunteer donors/CBUs added to the database during 2018:

**10,550**



|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 0  | 1    | 0   | 0   |
| <b>Export to EU member states</b>   | 0  | 2    | 0   | 0   |
| <b>Export to third countries</b>    | 0  | 1    | 0   | 0   |
| <b>Import from EU member states</b> | 22 | 81   | 0   | 8   |
| <b>Import from third countries</b>  | 3  | 13   | 1   | 0   |

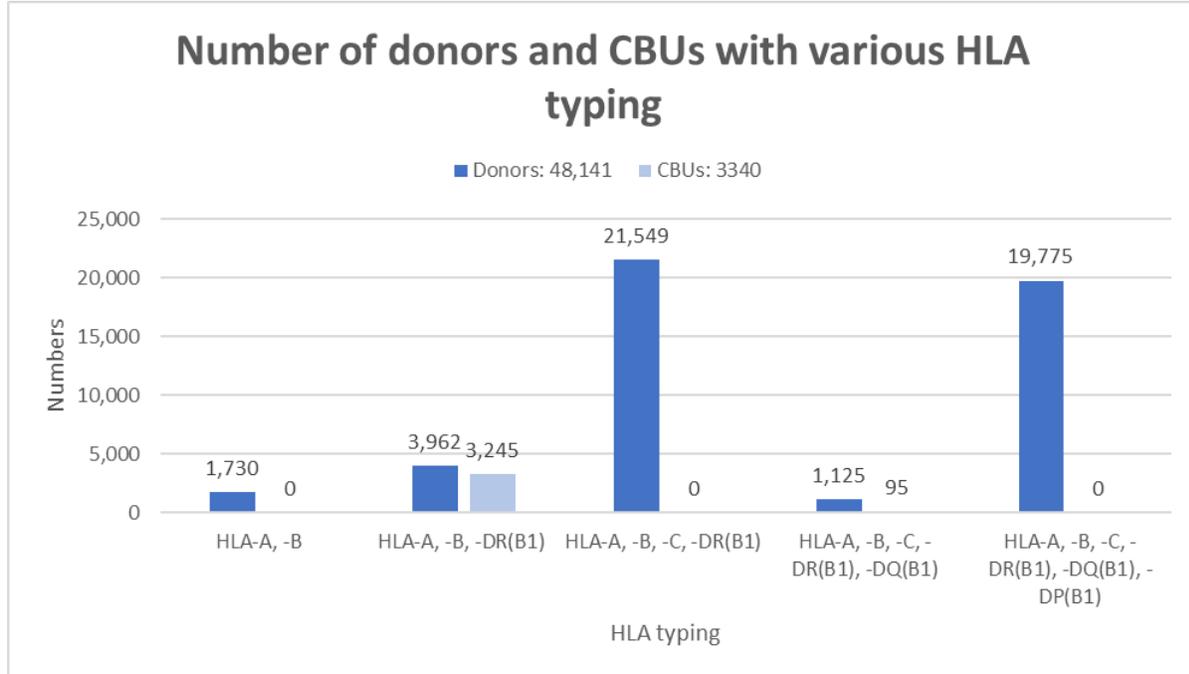


# Finland

5,517,919 inhabitants

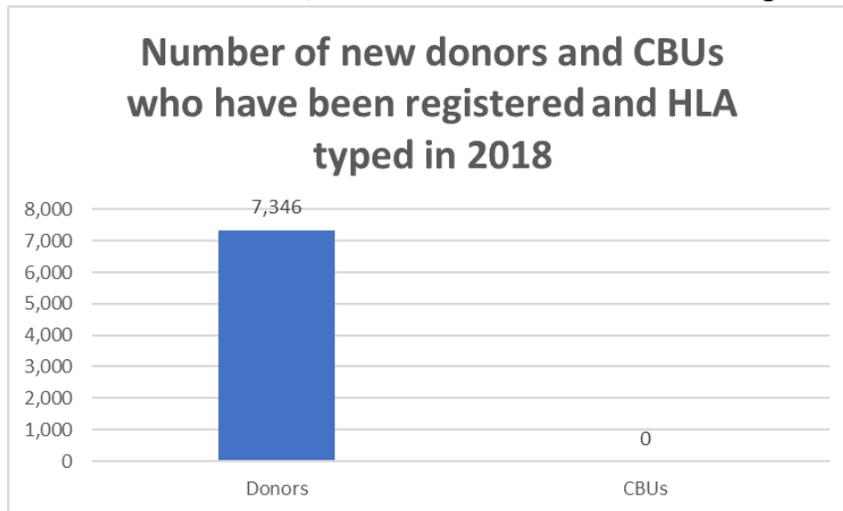
Number of registered and typed donors/CBUs on 31 December 2018:

**51,481**

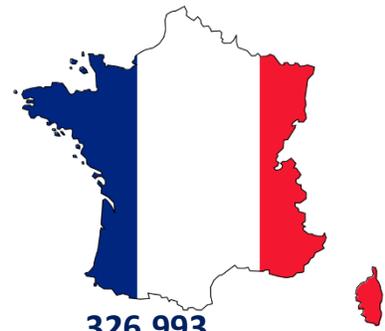


Adult volunteer donors/CBUs added to the database during 2018:

**7346**



|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 5  | 18   | 0   | 2   |
| <b>Export to EU member states</b>   | 0  | 8    | 2   | 2   |
| <b>Export to third countries</b>    | 1  | 5    | 0   | 1   |
| <b>Import from EU member states</b> | 7  | 51   | 2   | 6   |
| <b>Import from third countries</b>  | 1  | 4    | 0   | 1   |

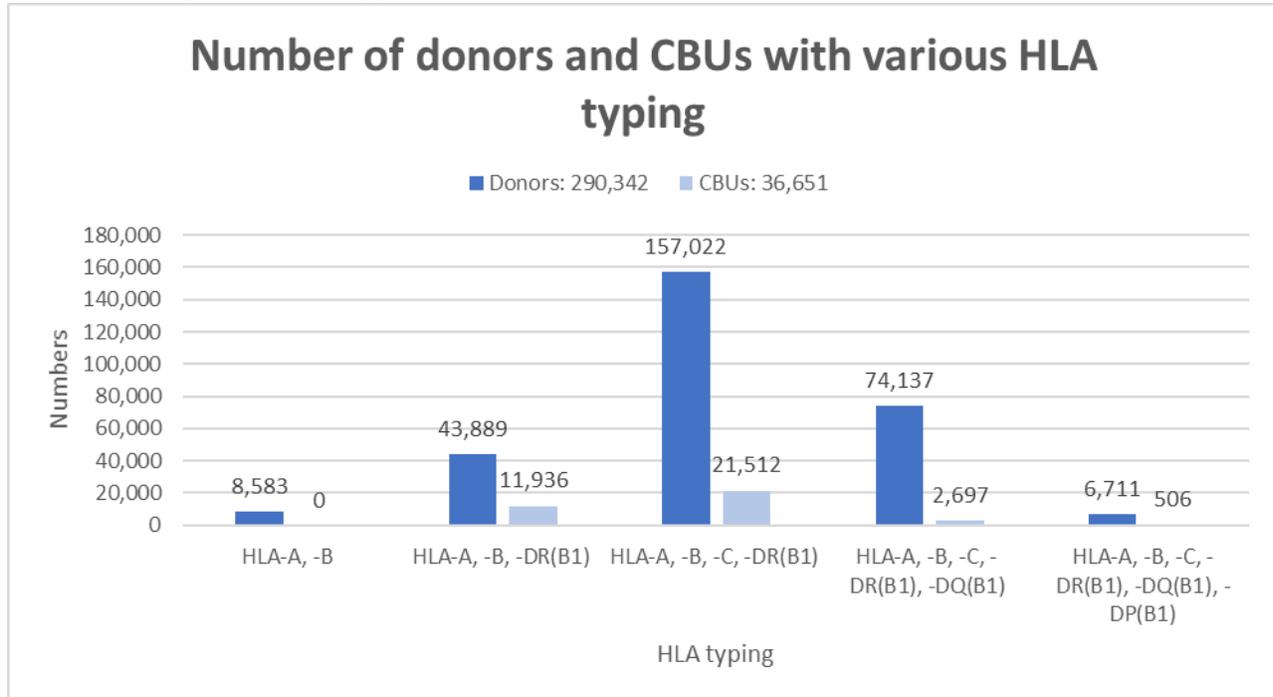


# France

67,028,048 inhabitants

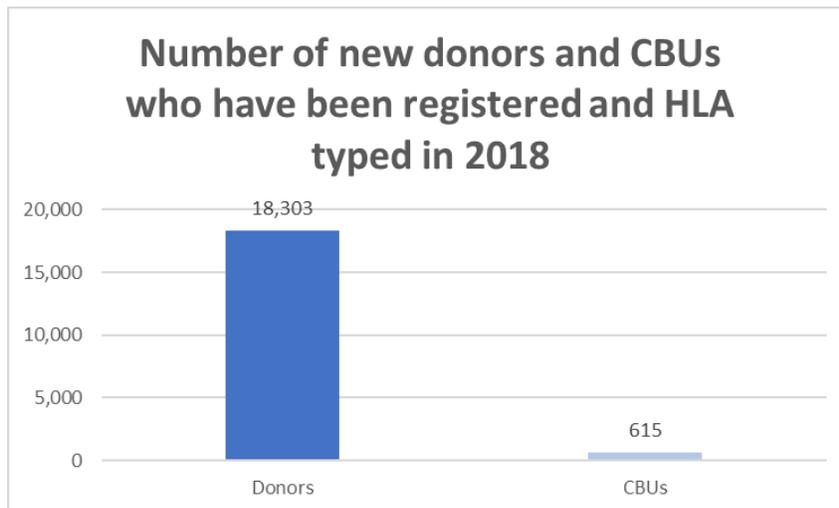
Number of registered and typed donors/CBUs on 31 December 2018:

**326,993**



Adult volunteer donors/CBUs added to the database during 2018:

**18,918**

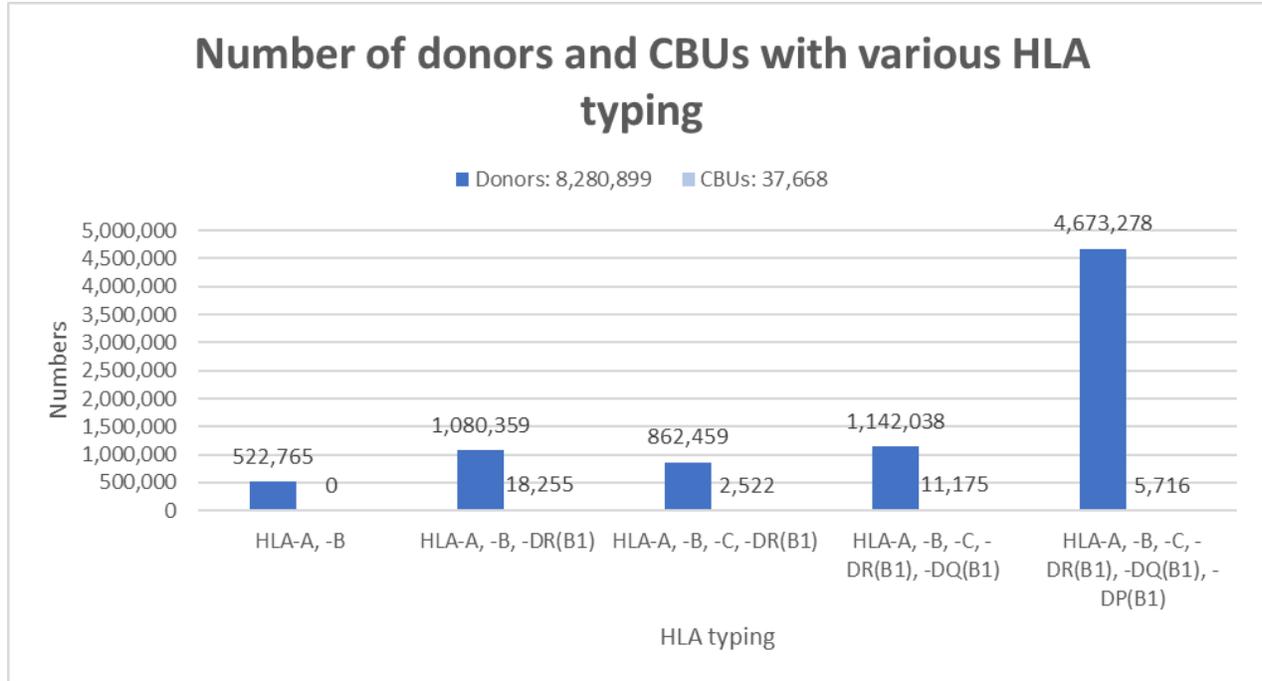


|                              | BM  | PBSC | CBU | DLI |
|------------------------------|-----|------|-----|-----|
| National                     | 9   | 74   | 36  | 11  |
| Export to EU member states   | 7   | 41   | 35  | 8   |
| Export to third countries    | 7   | 21   | 48  | 0   |
| Import from EU member states | 134 | 545  | 36  | 85  |
| Import from third countries  | 23  | 104  | 25  | 17  |



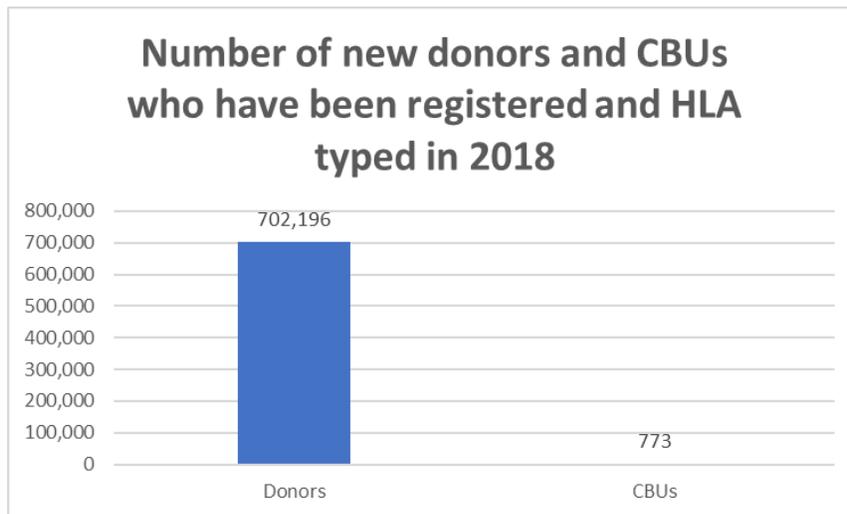
Number of registered and typed donors/CBUs on 31 December 2018:

**8,318,567**



Adult volunteer donors/CBUs added to the database during 2018:

**702,969**



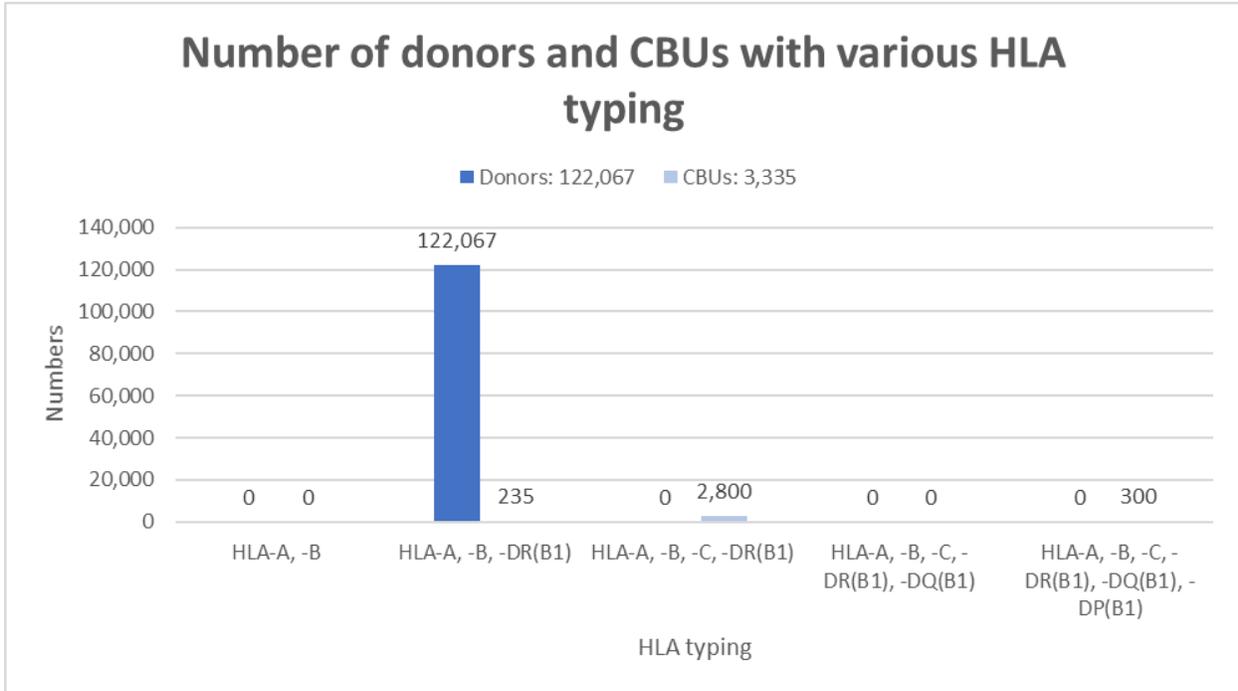
|                                     | BM  | PBSC  | CBU | DLI |
|-------------------------------------|-----|-------|-----|-----|
| <b>National</b>                     | 228 | 1,736 | 0   | 299 |
| <b>Export to EU member states</b>   | 415 | 2,098 | 15  | 232 |
| <b>Export to third countries</b>    | 565 | 2,013 | 23  | 119 |
| <b>Import from EU member states</b> | 40  | 365   | 0   | 52  |
| <b>Import from third countries</b>  | 27  | 176   | 1   | 28  |



Greece | 10,722,287 inhabitants

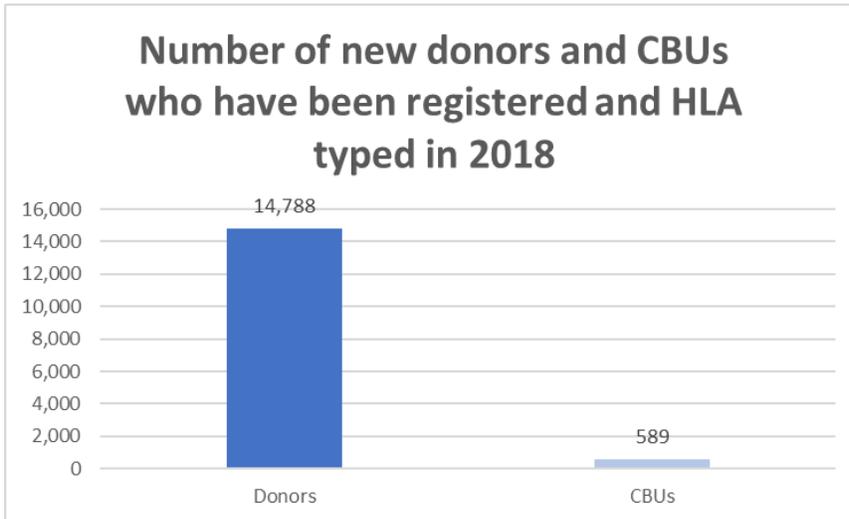
Number of registered and typed donors/CBUs on 31 December 2018:

**125,402**



Adult volunteer donors/CBUs added to the database during 2018:

**15,377**

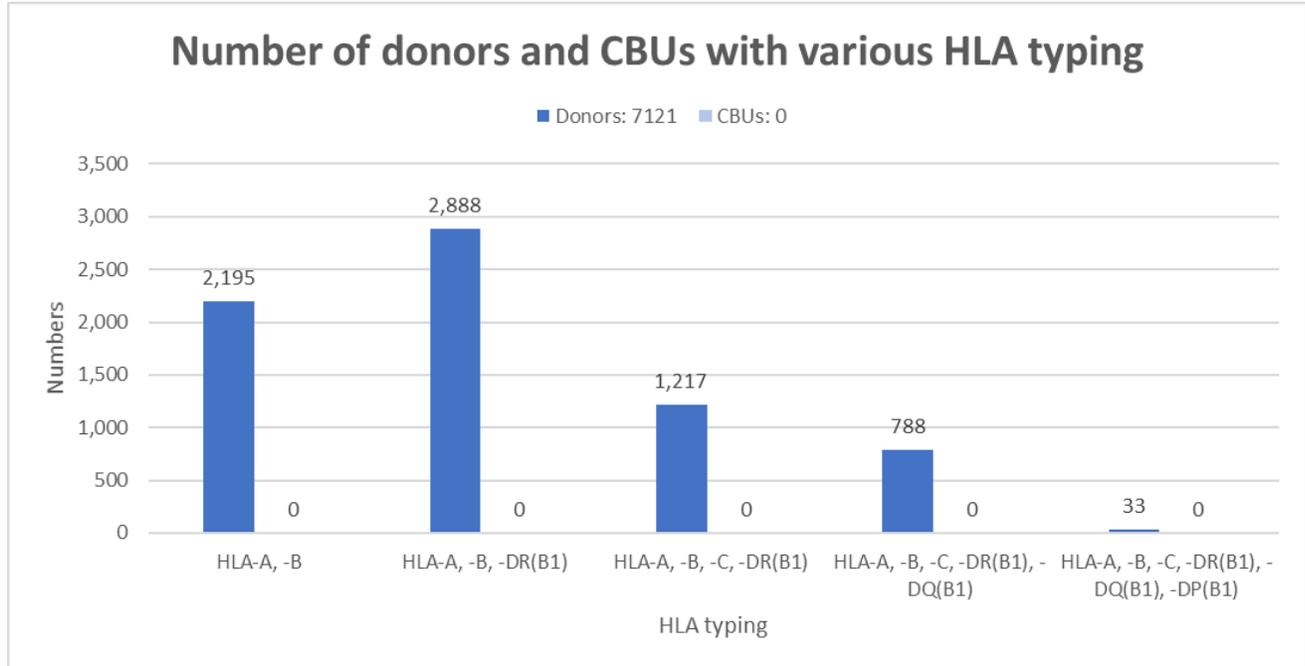


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 13 | 94   | 6   | 3   |
| <b>Export to EU member states</b>   | 0  | 23   | 0   | 1   |
| <b>Export to third countries</b>    | 0  | 12   | 0   | 1   |
| <b>Import from EU member states</b> | 9  | 65   | 5   | 4   |
| <b>Import from third countries</b>  | 3  | 6    | 1   | 0   |



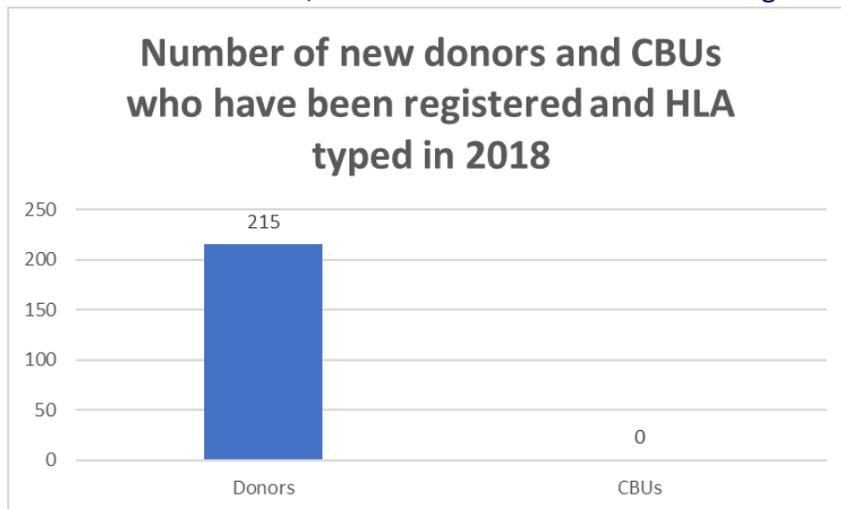
Number of registered and typed donors/CBUs on 31 December 2018:

**7,121**



Adult volunteer donors/CBUs added to the database during 2018:

**215**

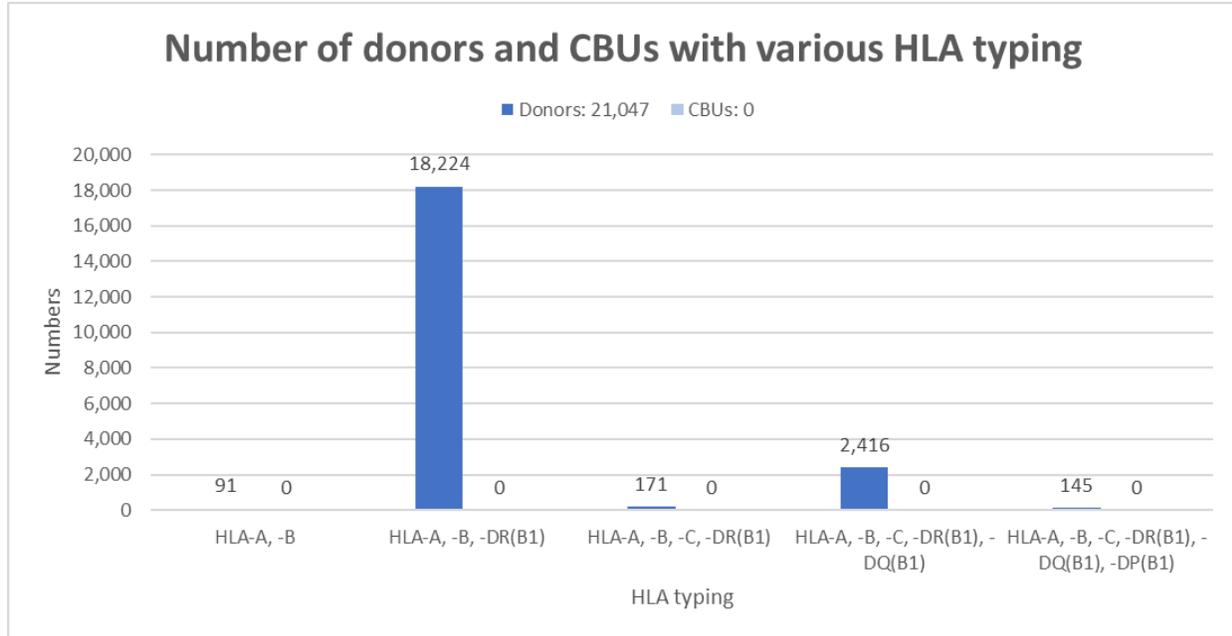


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 0  | 0    | 0   | 0   |
| <b>Export to EU member states</b>   | 0  | 1    | 0   | 0   |
| <b>Export to third countries</b>    | 0  | 0    | 0   | 0   |
| <b>Import from EU member states</b> | 15 | 45   | 2   | 2   |
| <b>Import from third countries</b>  | 4  | 8    | 0   | 0   |

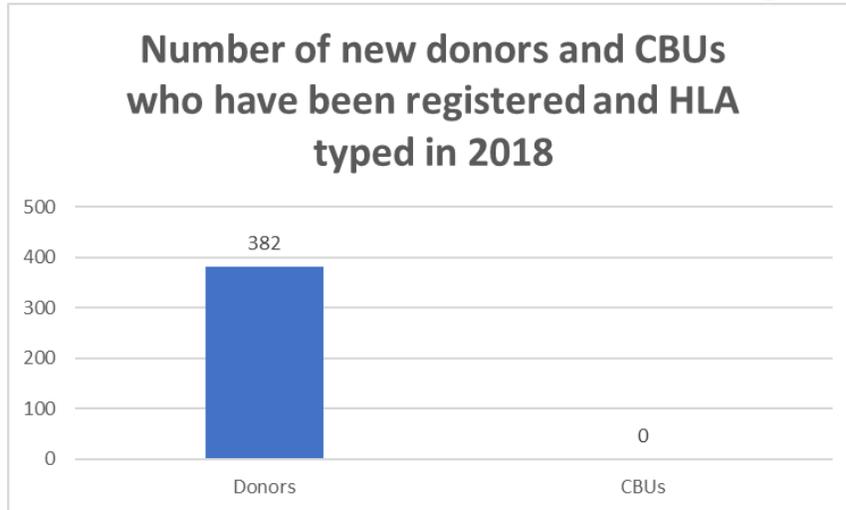


Ireland | 4,904,226 inhabitants

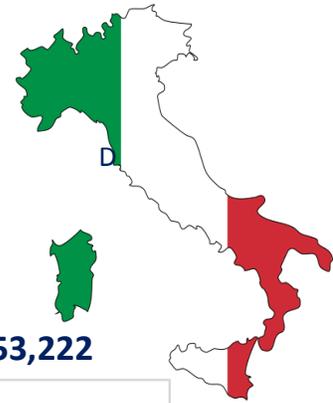
Number of registered and typed donors/CBUs on 31 December 2018: **21,047**



Adult volunteer donors/CBUs added to the database during 2018: **382**

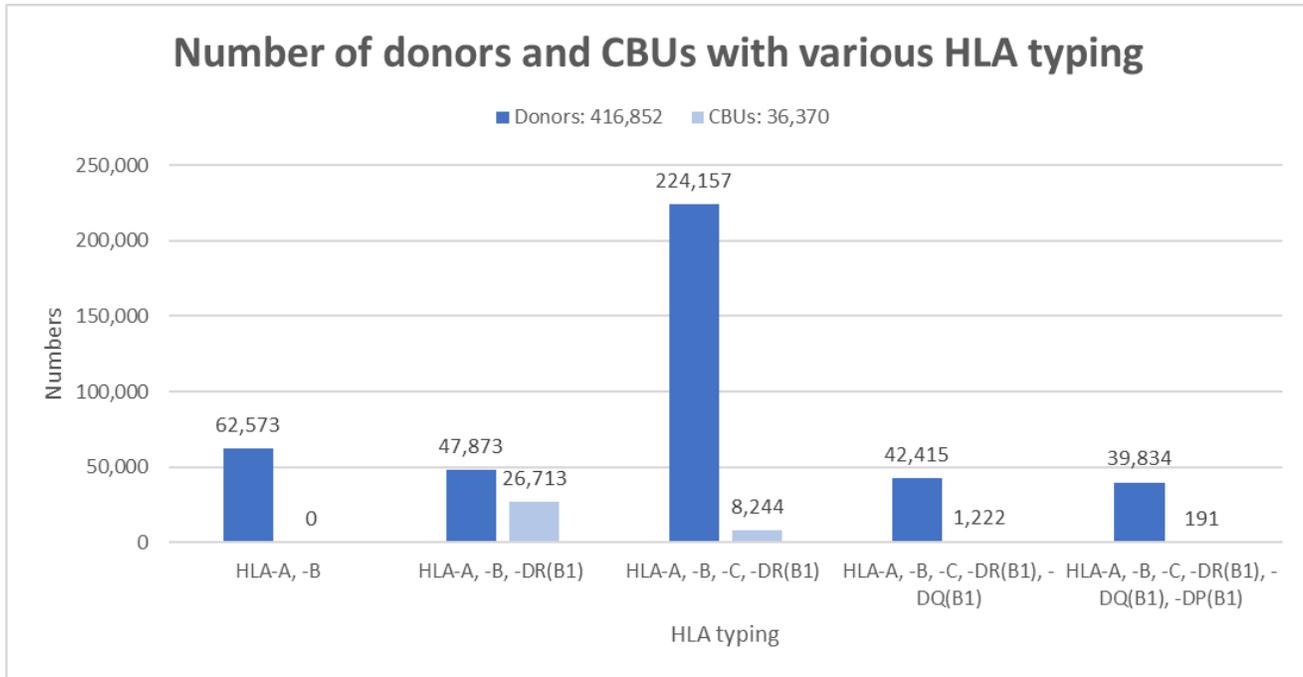


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 1  | 2    | 0   | 0   |
| <b>Export to EU member states</b>   | 0  | 1    | 0   | 0   |
| <b>Export to third countries</b>    | 0  | 0    | 0   | 0   |
| <b>Import from EU member states</b> | 22 | 27   | 0   | 4   |
| <b>Import from third countries</b>  | 5  | 5    | 0   | 1   |



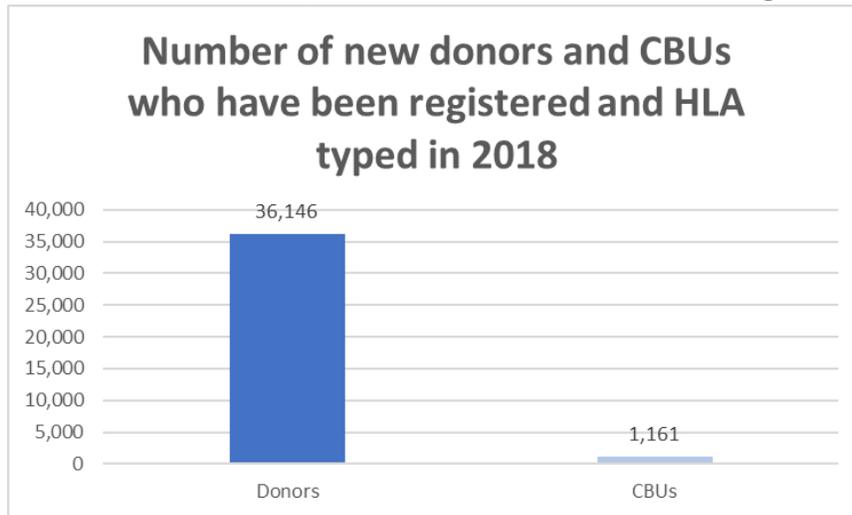
Number of registered and typed donors/CBUs on 31 December 2018:

**453,222**



Adult volunteer donors/CBUs added to the database during 2018:

**37,307**

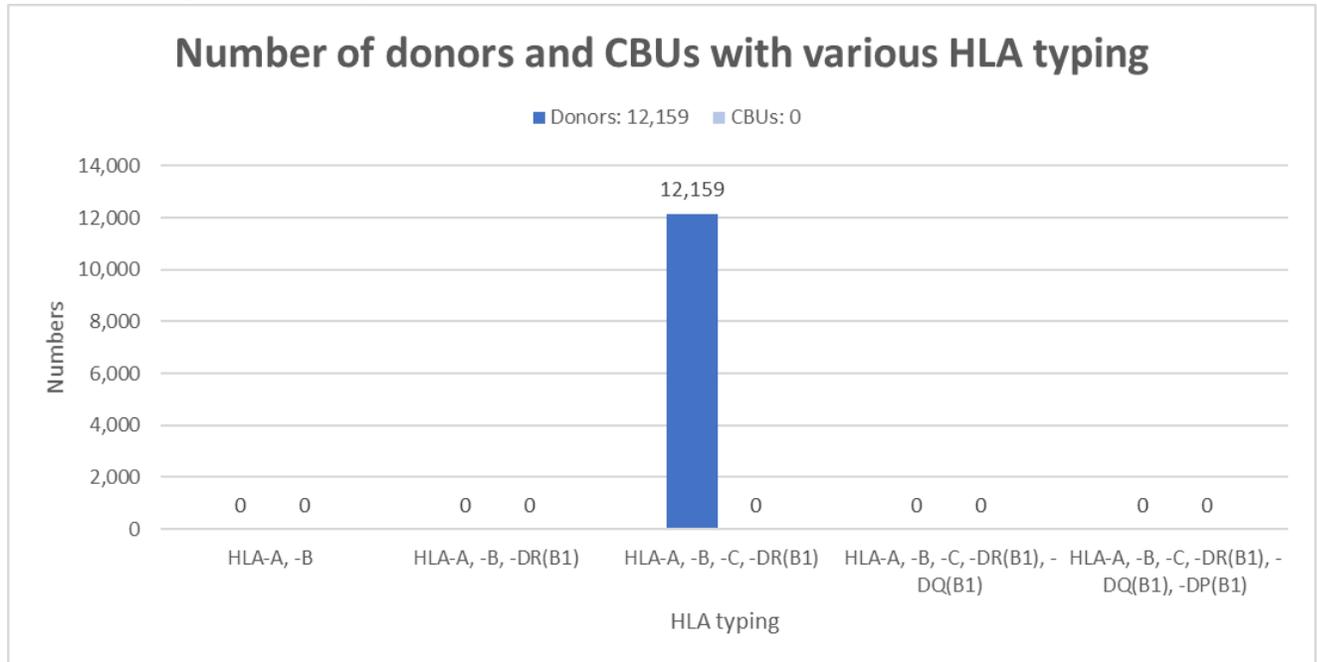


|                                     | BM  | PBSC | CBU | DLI |
|-------------------------------------|-----|------|-----|-----|
| <b>National</b>                     | 53  | 114  | 6   | 21  |
| <b>Export to EU member states</b>   | 13  | 37   | 17  | 5   |
| <b>Export to third countries</b>    | 6   | 9    | 15  | 1   |
| <b>Import from EU member states</b> | 111 | 372  | 7   | 38  |
| <b>Import from third countries</b>  | 38  | 142  | 19  | 6   |



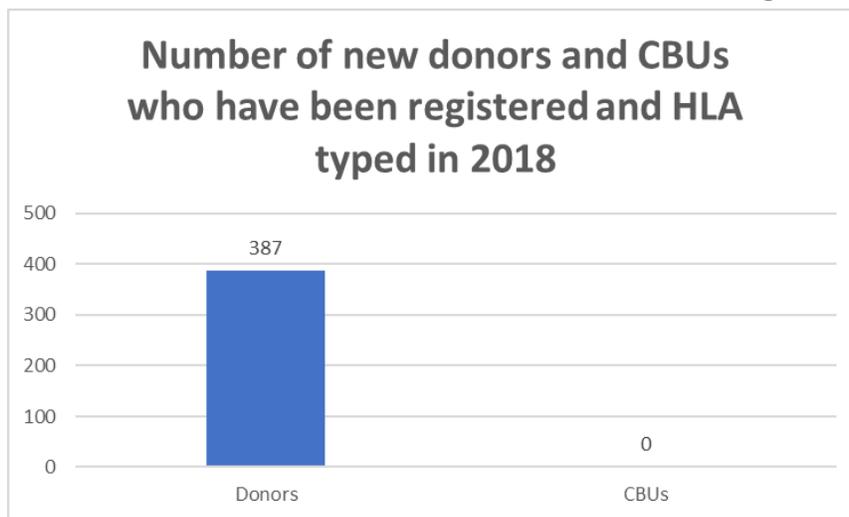
Number of registered and typed donors/CBUs on 31 December 2018:

**12,159**



Adult volunteer donors/CBUs added to the database during 2018:

**387**

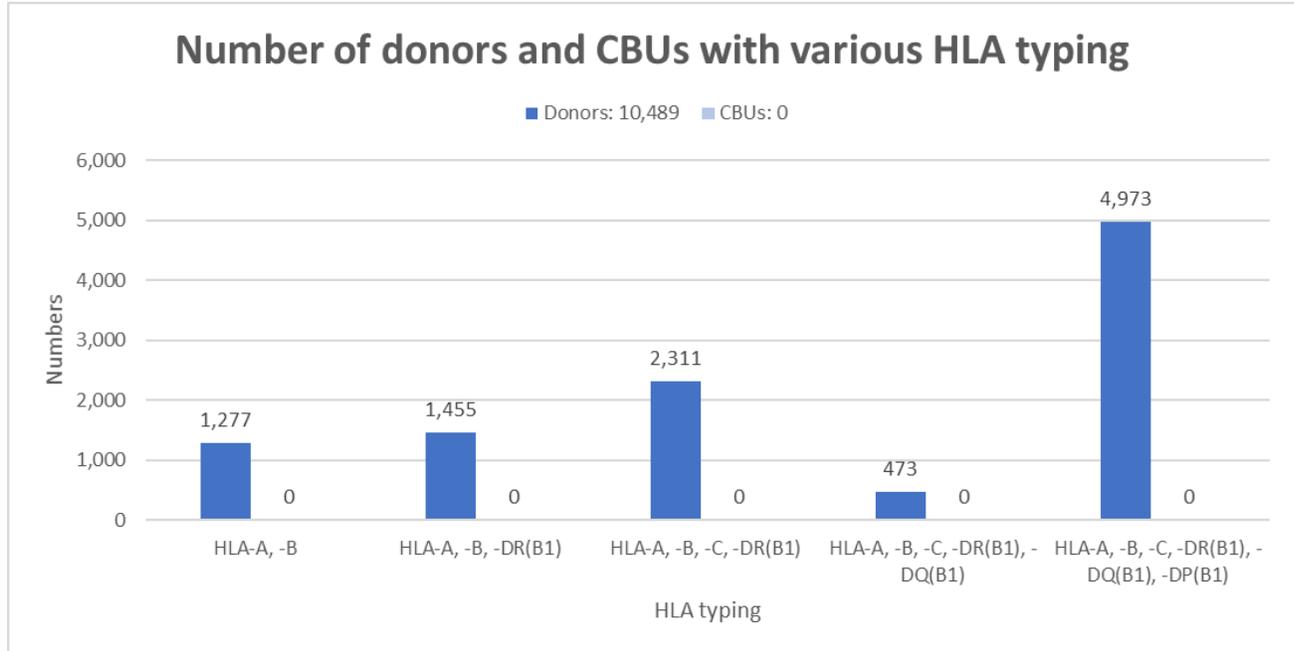


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 0  | 7    | 0   | 0   |
| <b>Export to EU member states</b>   | 0  | 0    | 0   | 0   |
| <b>Export to third countries</b>    | 0  | 1    | 0   | 0   |
| <b>Import from EU member states</b> | 3  | 40   | 0   | 1   |
| <b>Import from third countries</b>  | 0  | 0    | 0   | 0   |



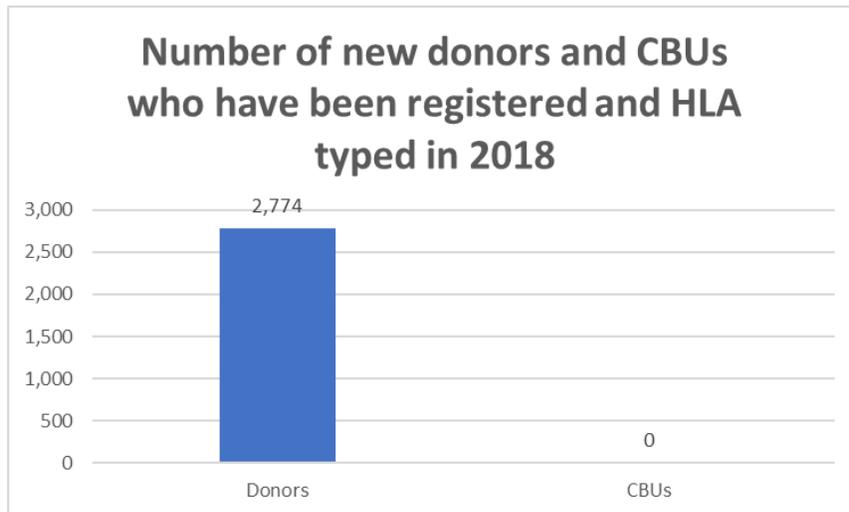
Number of registered and typed donors/CBUs on 31 December 2018:

**10,489**



Adult volunteer donors/CBUs added to the database during 2018:

**2774**

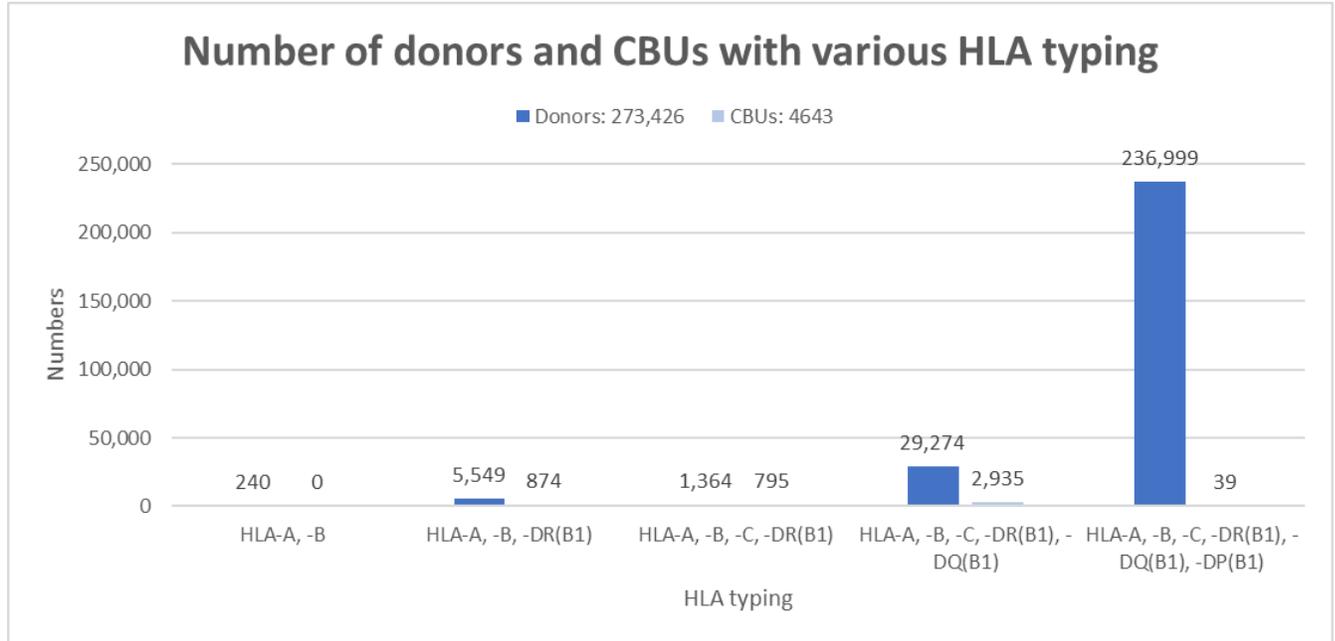


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 0  | 0    | 0   | 0   |
| <b>Export to EU member states</b>   | 0  | 1    | 0   | 0   |
| <b>Export to third countries</b>    | 0  | 2    | 0   | 0   |
| <b>Import from EU member states</b> | 0  | 0    | 0   | 0   |
| <b>Import from third countries</b>  | 0  | 0    | 0   | 0   |



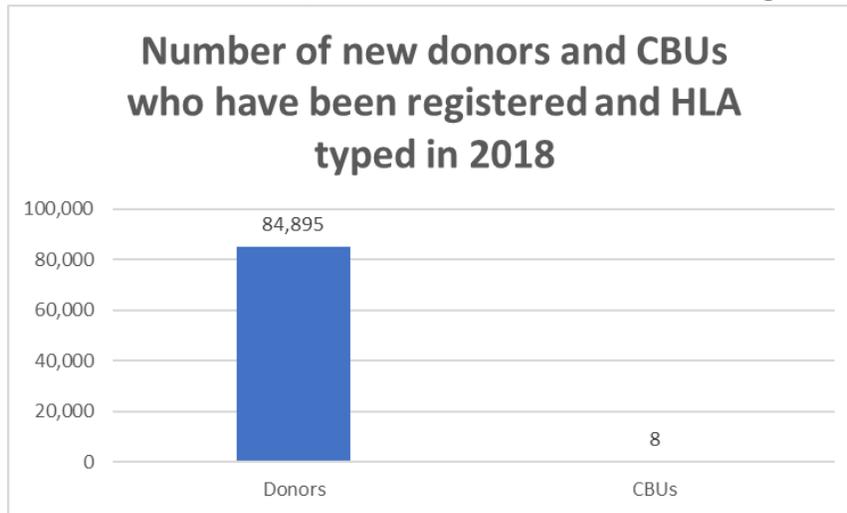
Number of registered and typed donors/CBUs on 31 December 2018:

**278,069**



Adult volunteer donors/CBUs added to the database during 2018:

**84,895**

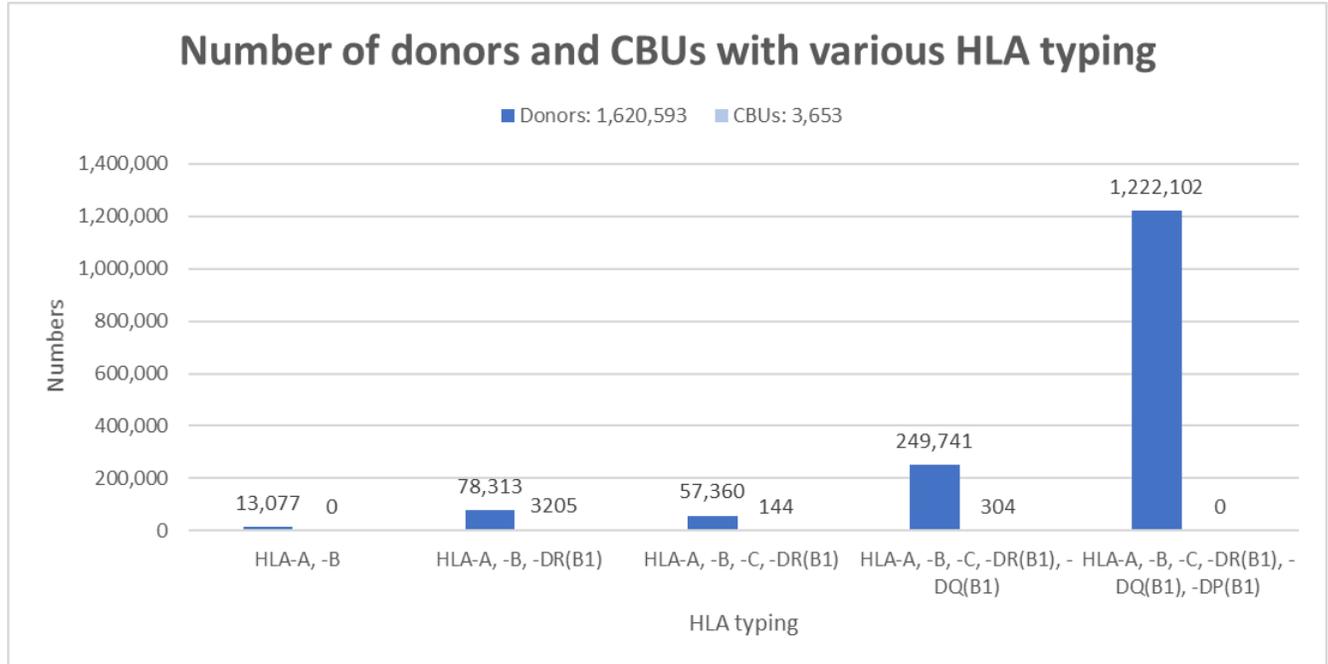


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 6  | 34   | 2   | 7   |
| <b>Export to EU member states</b>   | 10 | 39   | 1   | 4   |
| <b>Export to third countries</b>    | 5  | 40   | 0   | 2   |
| <b>Import from EU member states</b> | 21 | 257  | 45  | 48  |
| <b>Import from third countries</b>  | 12 | 49   | 26  | 9   |



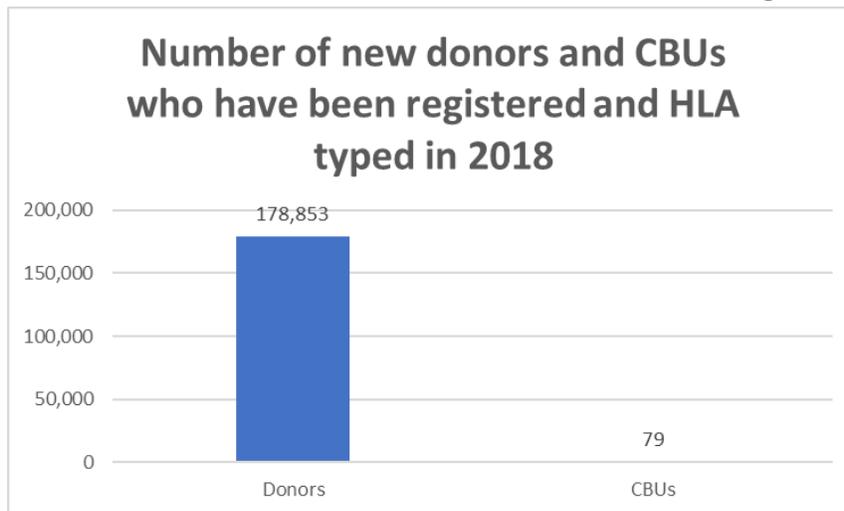
Number of registered and typed donors/CBUs on 31 December 2018:

**1,624,246**



Adult volunteer donors/CBUs added to the database during 2018:

**178,932**



|                                     | BM  | PBSC | CBU | DLI |
|-------------------------------------|-----|------|-----|-----|
| <b>National</b>                     | 22  | 296  | 0   | 13  |
| <b>Export to EU member states</b>   | 80  | 606  | 0   | 87  |
| <b>Export to third countries</b>    | 103 | 364  | 1   | 23  |
| <b>Import from EU member states</b> | 16  | 117  | 0   | 4   |
| <b>Import from third countries</b>  | 2   | 12   | 0   | 0   |

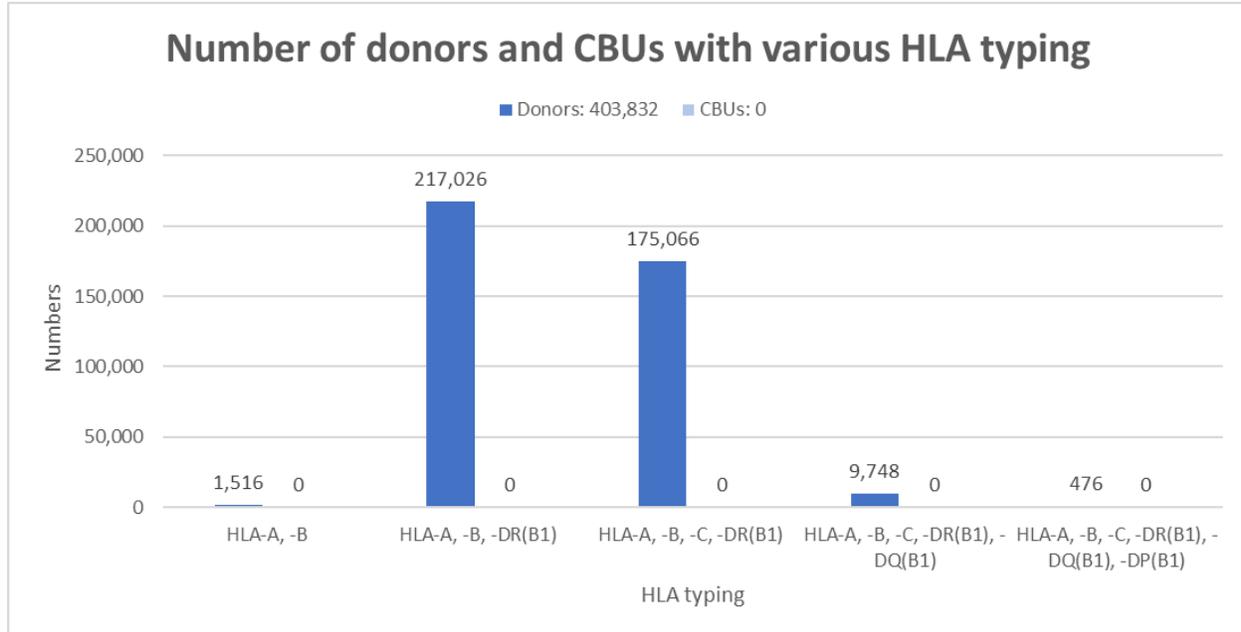


# Portugal

10,276,617 inhabitants

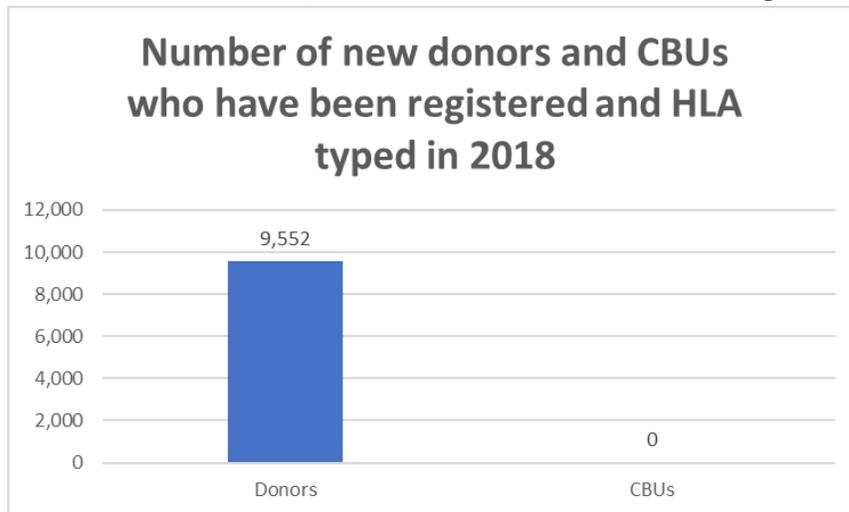
Number of registered and typed donors/CBUs on 31 December 2018:

**403,832**



Adult volunteer donors/CBUs added to the database during 2018:

**9,552**

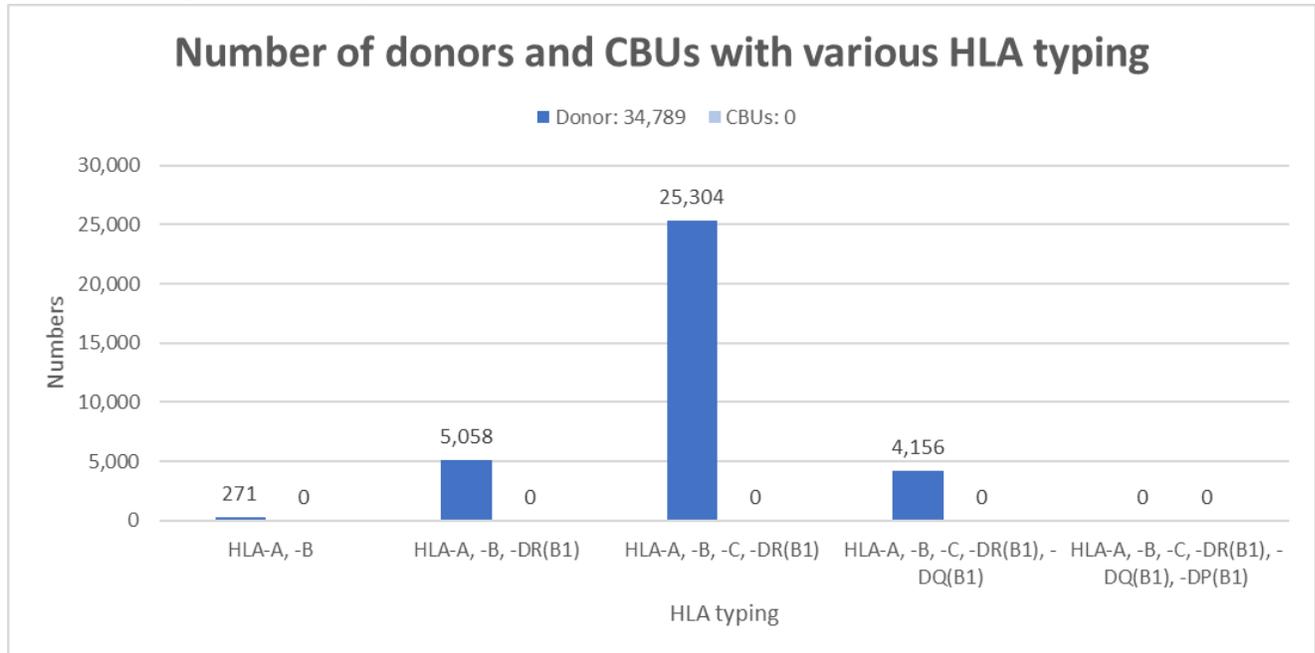


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 4  | 23   | 0   | 1   |
| <b>Export to EU member states</b>   | 5  | 34   | 0   | 3   |
| <b>Export to third countries</b>    | 2  | 9    | 0   | 0   |
| <b>Import from EU member states</b> | 8  | 40   | 1   | 0   |
| <b>Import from third countries</b>  | 3  | 8    | 1   | 0   |



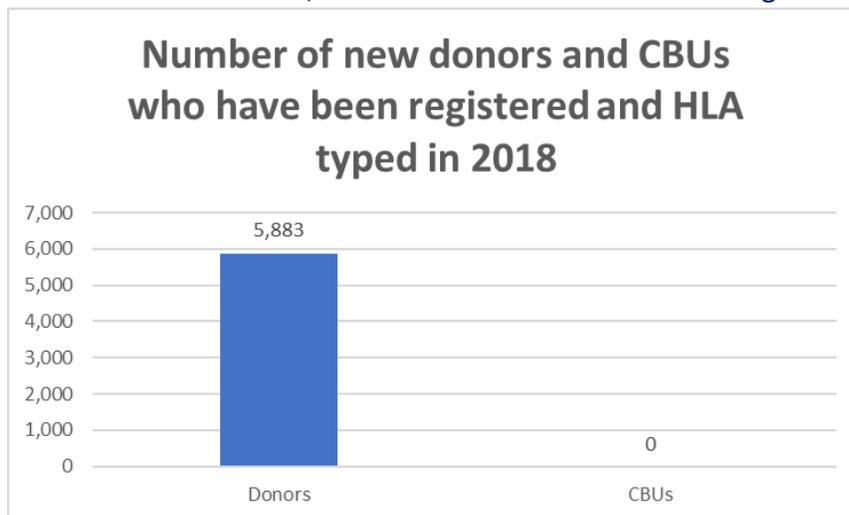
Number of registered and typed donors/CBUs on 31 December 2018:

**34,789**



Adult volunteer donors/CBUs added to the database during 2018:

**5,883**

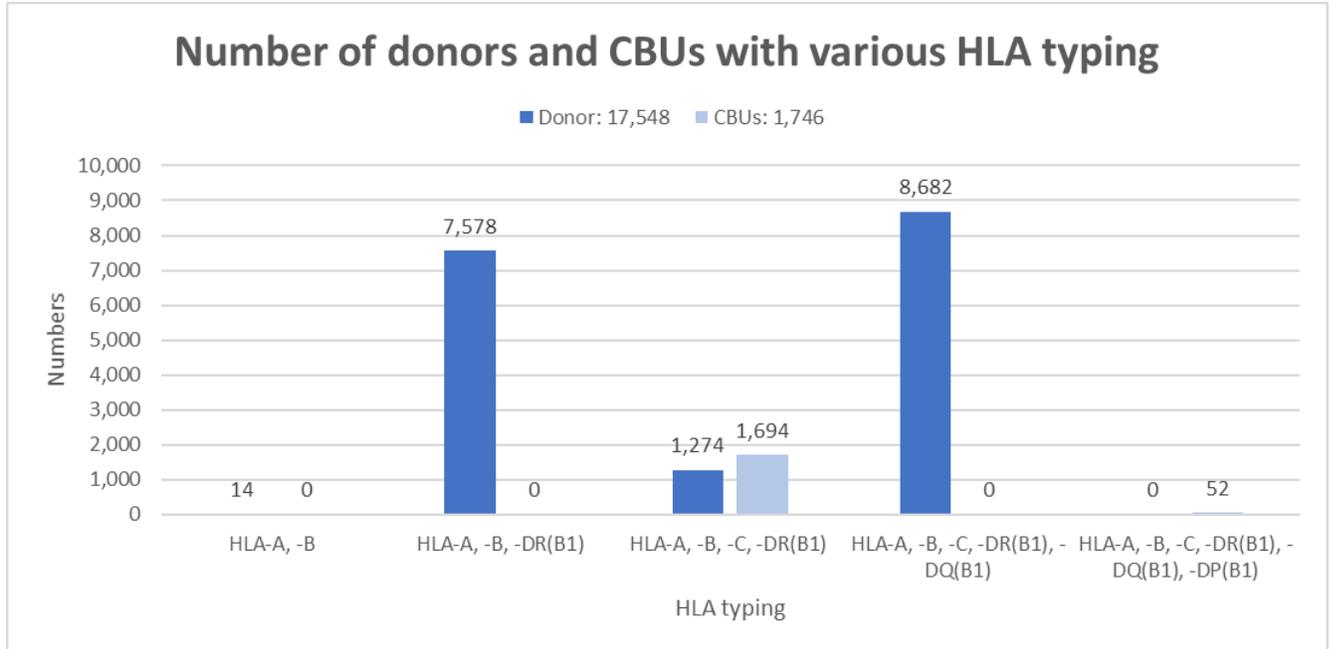


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 0  | 2    | 0   | 0   |
| <b>Export to EU member states</b>   | 0  | 1    | 0   | 0   |
| <b>Export to third countries</b>    | 0  | 0    | 0   | 0   |
| <b>Import from EU member states</b> | 3  | 34   | 0   | 4   |
| <b>Import from third countries</b>  | 0  | 1    | 0   | 1   |



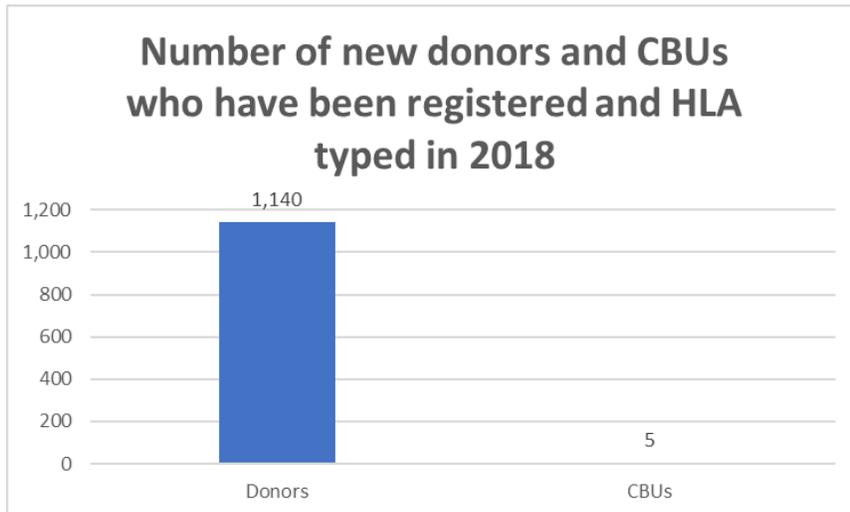
Number of registered and typed donors/CBUs on 31 December 2018:

**19,294**



Adult volunteer donors/CBUs added to the database during 2018:

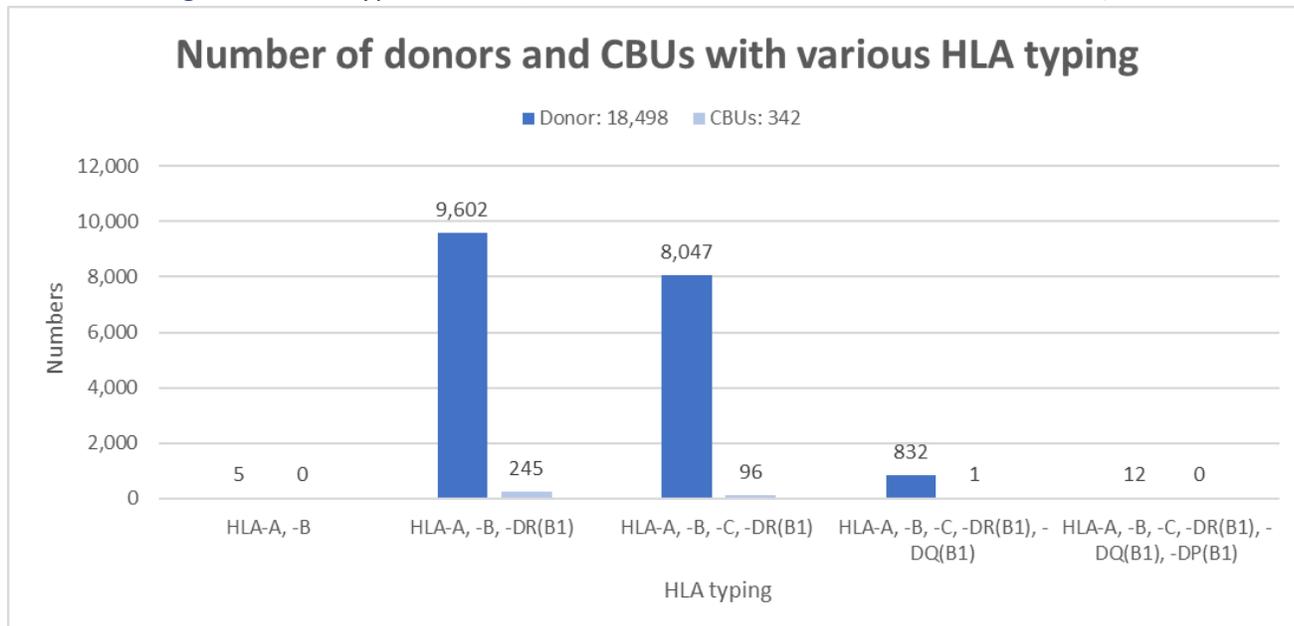
**1,145**



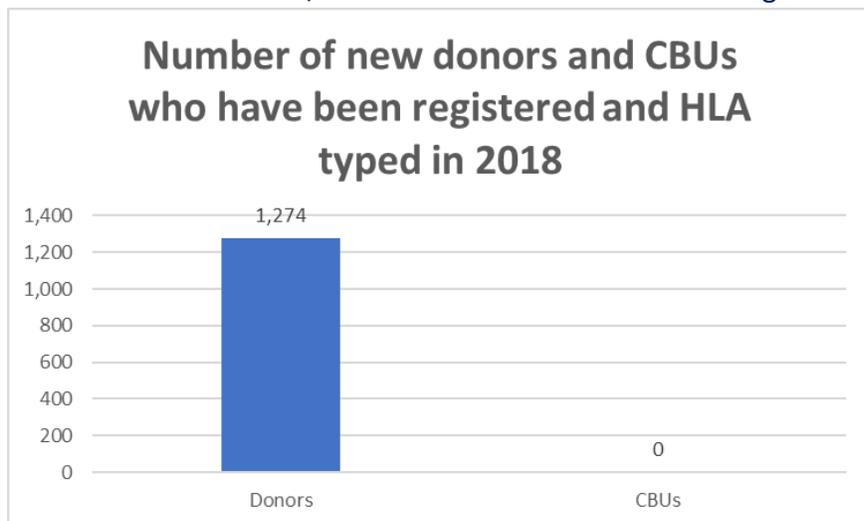
|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 1  | 6    | 0   | 0   |
| <b>Export to EU member states</b>   | 0  | 3    | 1   | 0   |
| <b>Export to third countries</b>    | 0  | 2    | 0   | 0   |
| <b>Import from EU member states</b> | 7  | 30   | 0   | 0   |
| <b>Import from third countries</b>  | 0  | 3    | 0   | 0   |



Number of registered and typed donors/CBUs on 13 December 2018: **18,840**



Adult volunteer donors/CBUs added to the database during 2018: **1,274**



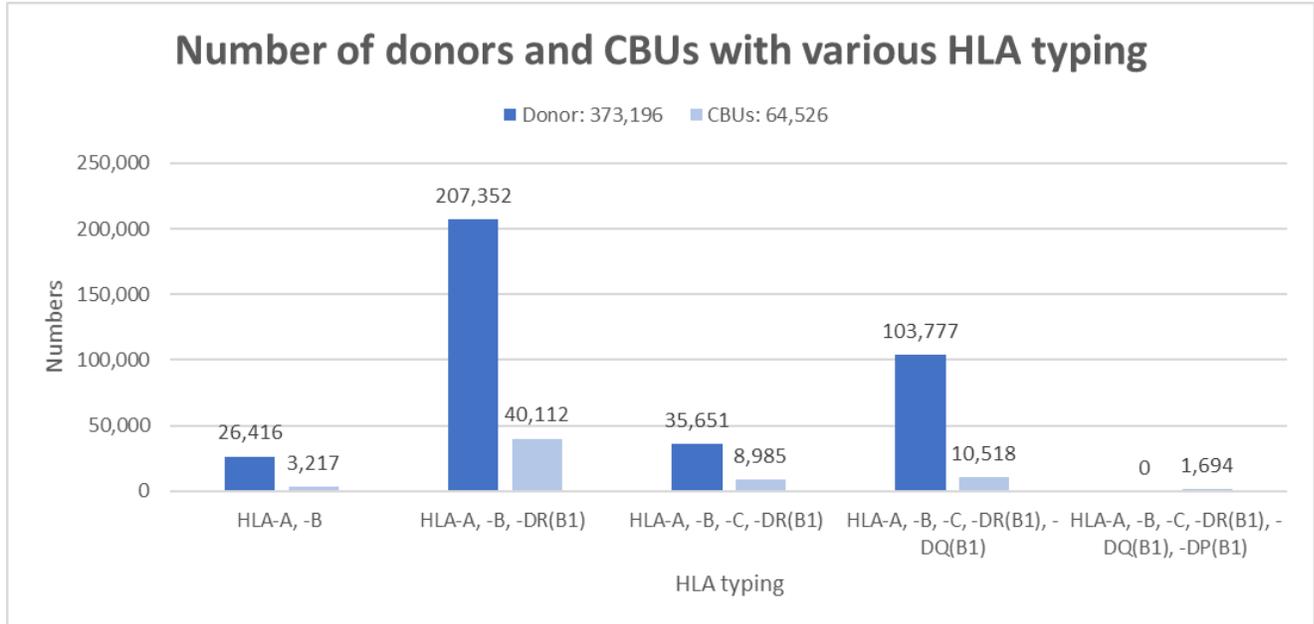
|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 0  | 4    | 0   | 1   |
| <b>Export to EU member states</b>   | 0  | 2    | 0   | 0   |
| <b>Export to third countries</b>    | 0  | 0    | 0   | 0   |
| <b>Import from EU member states</b> | 2  | 22   | 1   | 1   |
| <b>Import from third countries</b>  | 0  | 1    | 0   | 0   |



Spain | 46,934,632 inhabitants

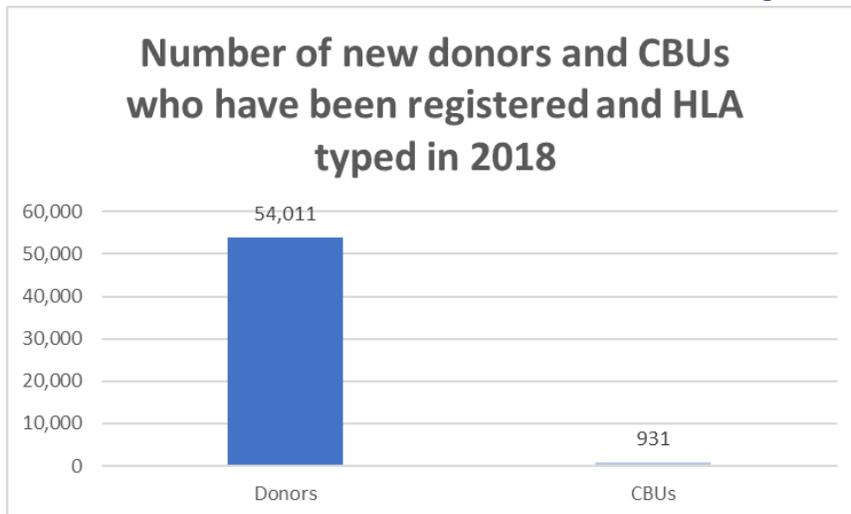
Number of registered and typed donors/CBUs on 31 December 2018:

**437,722**



Adult volunteer donors/CBUs added to the database during 2018:

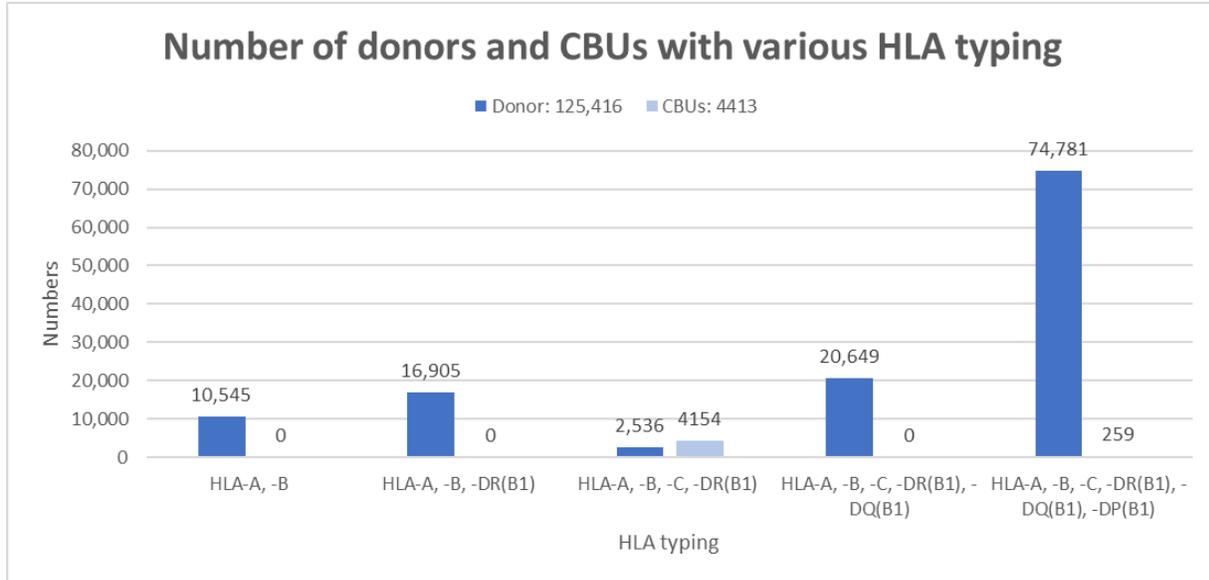
**54,942**



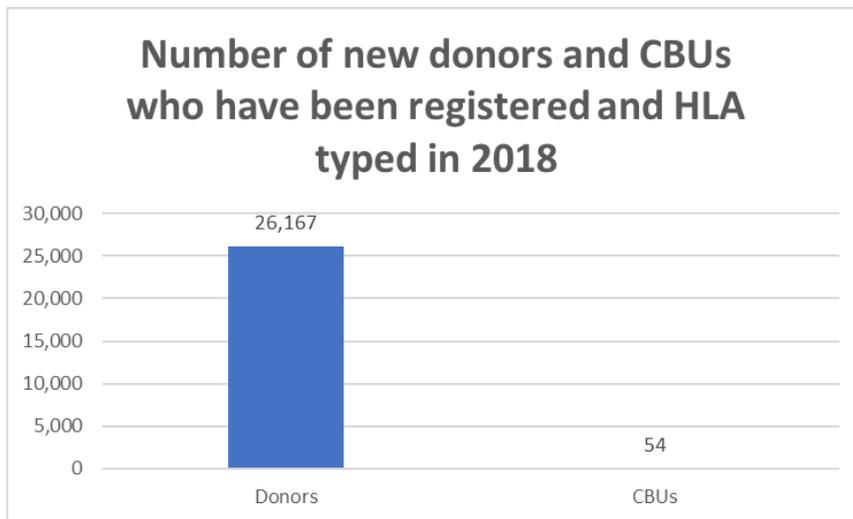
|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 8  | 93   | 23  | 3   |
| <b>Export to EU member states</b>   | 8  | 54   | 46  | 5   |
| <b>Export to third countries</b>    | 6  | 23   | 94  | 1   |
| <b>Import from EU member states</b> | 54 | 219  | 5   | 10  |
| <b>Import from third countries</b>  | 13 | 75   | 13  | 7   |



Number of registered and typed donors/CBUs on 31 December 2018: **129,829**



Adult volunteer donors/CBUs added to the database during 2018: **26,221**

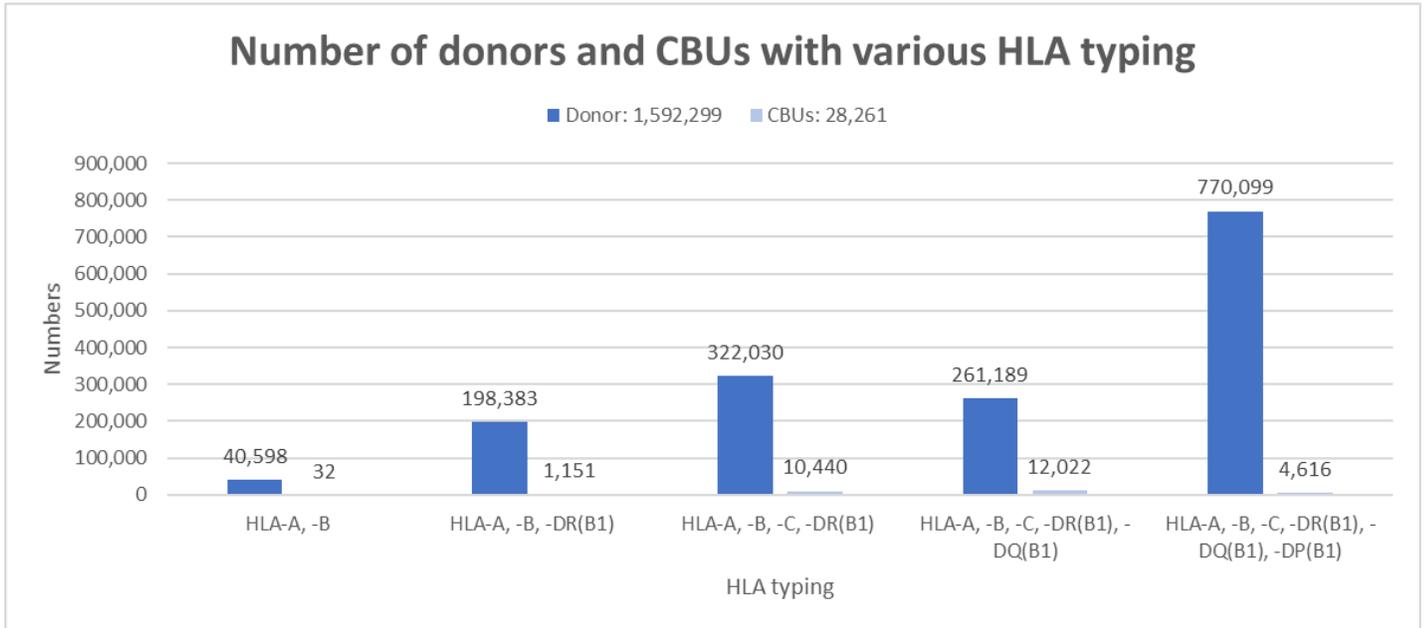


|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 4  | 30   | 1   | 3   |
| <b>Export to EU member states</b>   | 2  | 23   | 2   | 3   |
| <b>Export to third countries</b>    | 6  | 20   | 0   | 1   |
| <b>Import from EU member states</b> | 28 | 111  | 1   | 11  |
| <b>Import from third countries</b>  | 3  | 22   | 2   | 1   |



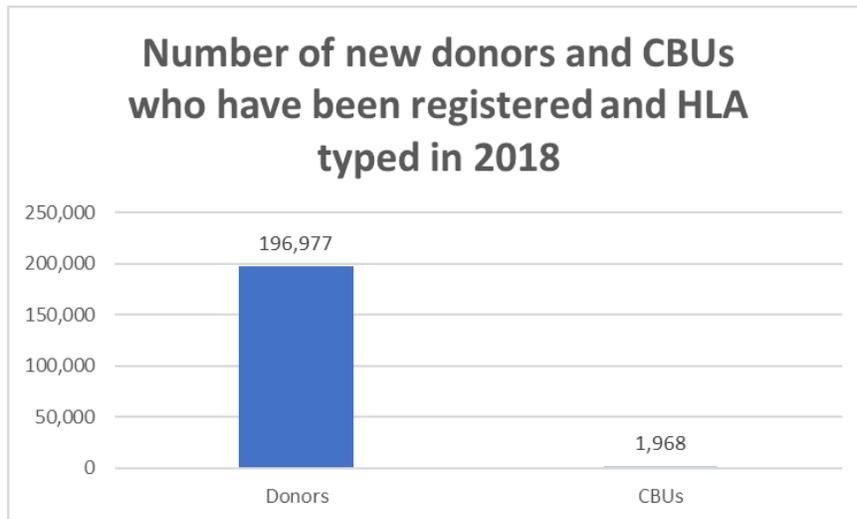
Number of registered and typed donors/CBUs on 31 December 2018:

**1,620,560**



Adult volunteer donors/CBUs added to the database during 2018:

**198,945**



|                                     | BM | PBSC | CBU | DLI |
|-------------------------------------|----|------|-----|-----|
| <b>National</b>                     | 48 | 362  | 21  | 57  |
| <b>Export to EU member states</b>   | 38 | 273  | 10  | 24  |
| <b>Export to third countries</b>    | 72 | 314  | 36  | 17  |
| <b>Import from EU member states</b> | 47 | 441  | 24  | 47  |
| <b>Import from third countries</b>  | 32 | 142  | 35  | 11  |

## Appendix 1: List of countries that export to EU member states

- Argentina
- Australia
- Brazil
- Canada
- China
- India
- Iran
- Israel
- Japan
- Korea
- Norway
- Russia
- Singapore
- South Africa
- Switzerland
- Taiwan – province of China
- Thailand
- Turkey
- United States of America

## Appendix 2. WMDA Annual Questionnaire

Logged user: admin  
Your account 

[? QUESTIONS](#) [EXPORT](#) [QUESTIONNAIRE](#) [USERS](#) [SETTING](#) [LOGOUT](#)

**QUESTIONS** QUESTIONS CATEGORIES

[QUESTIONS](#) → QUESTIONS

Insert new question

Category: \* Question: \* Headline: Code: \*  *necessary, is used as a key*No. in REG form: No. in CBU form: Order: Answer wanted: Text in answer: Display: Display from year: Display to year: Sum subquestions:  (separate by ; eg.: 2a;2b)Validation rule:  (eg.: 8<7a)For register type: 

Inserted questions

**GENERAL REGISTRY AND CORD BLOOD REGISTRY/BANK DATA**

| <u>Code</u> | <u>Question</u>  | <u>Answer wanted</u> | <u>Display</u>      | <u>Type</u> | <u>Action</u>   |
|-------------|--|----------------------|---------------------|-------------|---|
| 1           | Number of registered and typed donors/CBUs on December 31 2018 (please give number of donors/CBUs with specific HLA typing profile regardless of HLA typing resolution, please list a donor/CBU only once) | ✓                    | ✓ from 1997 to 2018 |             |   |

**ADULT VOLUNTEER DONORS/CBUS ADDED TO THE DATABASE DURING 2013**

| <u>Code</u> | <u>Question</u>   | <u>Answer wanted</u> | <u>Display</u>      | <u>Type</u> | <u>Action</u>   |
|-------------|---|----------------------|---------------------|-------------|---|
| 2           | Count all new donors/CBUs recruited and HLA typed during 2013 | ✓                    | ✓ from 1997 to 2018 |             |   |
| 3           | Total number of donors/CBUs permanently deleted during 2013   | ✓                    | ✓ from 1997 to 2018 |             |   |

**AGE AND GENDER OF YOUR ADULT VOLUNTEER DONORS**

| <u>Code</u> | <u>Question</u>       | <u>Answer wanted</u> | <u>Display</u> | <u>Type</u> | <u>Action</u>   |
|-------------|-----------------------|----------------------|----------------|-------------|---|
| 4a          | Males, total number   | ✓                    | ✓              | REG         |   |
| 4b          | Females, total number | ✓                    | ✓              | REG         |   |
| 4c          | Unknown, total number | ✓                    | ✓              | REG         |   |

**UNRELATED SEARCH REQUESTS DURING 2013**

| <u>Code</u> | <u>Question</u>  | <u>Answer wanted</u> | <u>Display</u> | <u>Type</u> | <u>Action</u>   |
|-------------|--|----------------------|----------------|-------------|---|
| 5           | Number of unrelated searches initiated in 2013 for new patients in your country  | ✓                    | ✓              | REG, CBU    |   |
| 6           | Number of the above new national patients searched for via your registry or cord blood registry/bank but were transferred to another country for transplantation | ✓                    | ✓              | REG, CBU    |   |

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

| <u>Code</u> | <u>Question</u>   | <u>Answer wanted</u> | <u>Display</u> | <u>Type</u> | <u>Action</u>   |
|-------------|---|----------------------|----------------|-------------|---|
| 7           | Total number of HLA-AB typed donors from your registry requested for DR typing during 2013  | ✓                    |                | REG         |   |
| 8           | Total no of DR typings performed following a request from transplant unit   | ✓                    |                | REG         |   |
| 7a          | Number of pre-existing HLA-AB typed donors from your registry requested for DR-typing during 2013 (following a formal request by transplant unit)   | ✓                    | ✓ to 2017      | REG         |   |
| 7c          | Number of DR-typings performed following DR-typing requests reported in the previous question   | ✓                    | ✓ to 2017      | REG         |   |
| 7d          | Median time needed to obtain the DR-typing results (median: time in which you have obtained 50% of the DR-typing results, please use calender days and please calculate from the data that the request arrived at your registry till the date the report was sent to the transplant unit) | ✓                    | ✓ to 2017      | REG         |   |