

# Organisation Information Public Access

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## Organisation types

### Information available for organisation types

To facilitate the exchange of information and to improve business relations, WMDA provides access to contact data of organisations that are listing donors or cord blood products in the global database of Search & Match Service (formerly BMDW).

The following information is available:

Type of organisation	Data available	Maintained by
<p><b>DR Donor Registry</b></p> <p>Definitions as set out in WMDA Standards (version January 1, 2020):</p> <p>An organisation responsible for coordination of the search for hematopoietic stem cells from donors unrelated to the potential recipient.</p> <ul style="list-style-type: none"> <li>The patient registry or requesting registry is the registry that acts on behalf of their transplant centres.</li> <li>The donor registry or providing registry is the registry that provides the hematopoietic stem cell product.</li> </ul>	<p>Contact details</p> <p>Operational information</p> <p>Regulatory survey</p> <p>Documents</p> <p>Personal data <i>only available for WMDA members after login</i></p>	<p>Personal data can be added or deleted by the organisation profile administrator by filling in a request form. The contact details are updated automatically from the WMDA address database.</p> <p>The operational information, regulatory requirements information and (member) documents are updated by the organisations.</p> <p><i>Each organisation has identified an organisation profile administrator who is responsible for updating the information.</i></p>
<p><b>CBB Cord Blood Bank</b></p> <p>Definitions as set out in WMDA Standards (version January 1, 2020):</p> <p>A facility responsible for donor management and the collection, processing, testing, cryopreservation, storage, listing, reservation, release, and distribution of cord blood units.</p>	<p>Contact details</p> <p><b>If the CBB is a listing organisation the following data is also available:</b></p> <p>Cord Blood Bank survey</p> <p>Documents</p> <p>Member documents <i>only available for WMDA members after login</i></p> <p>Personal data <i>only available for WMDA members after login</i></p>	<p>Personal data can be added or deleted by the organisation profile administrator by filling in a request form. The contact details are updated automatically from the WMDA address database.</p> <p>The (member) documents are updated by the organisations.</p> <p>The Cord Blood Bank survey is completed by the organisations. The organisation has provided their information in 2017.</p> <p><i>Each organisation has identified an organisation profile administrator who is responsible for updating the information.</i></p> <p>In case a cord blood bank is missing, it is possible to provide this information. Please contact the WMDA office (<a href="mailto:mail@wmda.info">mail@wmda.info</a>) and ask for the link.</p>

<p><b>DR with CBU Donor Registry that lists both donors and cords</b> that directly provides cord blood units and hematopoietic stem cell (without collaboration with a registry)</p>	<p>Contact details</p> <p>Operational information</p> <p>Regulatory survey</p> <p>Cord Blood Bank survey</p> <p>Documents</p> <p>Member documents <i>only available for WMDA members after login</i></p> <p>Personal data <i>only available for WMDA members after login</i></p>	<p>Personal data can be added or deleted by the organisation profile administrator by filling in a request form. The contact details are updated automatically from the WMDA address database.</p> <p>The operational information, regulatory requirements information, and (member) documents are updated by the organisations.</p> <p>The Cord Blood Bank survey is completed by the organisations. The organisation has provided their information in 2017.</p> <p><i>Each organisation has identified an organisation profile administrator who is responsible for updating the information.</i></p>
<p><b>DC Donor Centre</b></p> <p>Definition as set out in WMDA Standards (version January 1, 2020):</p> <p>An organisation responsible for donor recruitment, consenting, testing, management and the collection of donor personal, genetic, medical data.</p>	<p>Contact details</p> <p>Operational information</p> <p>Regulatory survey</p> <p>Documents</p> <p>Personal data <i>only available for WMDA members after login</i></p>	<p>Personal data can be added or deleted by the organisation profile administrator by filling in a request form. The contact details are updated automatically from the WMDA address database.</p> <p>The operational information, regulatory requirements information and (member) documents are updated by the organisations.</p> <p><i>Each organisation has identified an organisation profile administrator who is responsible for updating the information.</i></p>

## Organisations identify


### Organisations are identified as follows:

- Listing organisations have an ION (Issuing Organisation Number): a globally unique identifier, as issued by ICCBBA, which maintains the authoritative list of ION's. All organisations with an ION are listing donors and/or cord blood units in the global database Search & Match Service.
- All other organisations without an ION are referenced by their WO number, as used by the WMDA internally.

Function	Description	Number per registry	Access to WMDA Share	Cost implications
Primary Emergency Contact	Only accessible for WMDA members, primary contact point that can be contacted by WMDA members in case of emergency (e.g. workup cancellation, transport problems)  This contact is for information purposes only and does not fulfill a specific role within WMDA.	1	None	None
Secondary Emergency Contact	Only accessible for WMDA members, second contact point that can be contacted by WMDA members in case of emergency (e.g. workup cancellation, transport problem) in case the primary contact does not respond  This contact is for information purposes only and does not fulfill a specific role within WMDA.	1	None	None
Organisation Profile Administrator	Only accessible for WMDA members, person responsible for maintaining the registry organisation profile page on WMDA Share (address, contact person, operational information, regulatory information).	Multiple	Has edit rights to organisational profile on WMDA Share.	None
WMDA registry representative	Only accessible for WMDA members, person eligible to serve as the WMDA organisational representative and to vote on behalf of the organisation.	1	Access to WMDA Share	Included in WMDA membership fee
Medical director	Only accessible for WMDA members, medical director  This contact is for information purposes only and does not fulfill a specific role with the WMDA.	1	None	None
Search coordinator	Only accessible for WMDA members, search coordinator  This contact is for information purposes only and does not fulfill a specific role with the WMDA.	Multiple	None	None
S(P)EAR alert contact	Only accessible for WMDA members, person who will receive the rapid alerts from the S(P)EAR Committee.	Multiple	None	None
WMDA member - free of charge	Only accessible for WMDA members, persons who are appointed by the registry to serve as a WMDA member (there is a maximum of persons a registry can appoint, based on the number of donors/cord blood units listed).	Limited	Access to WMDA Share	Included in WMDA membership fee
Additional WMDA member	Only accessible for WMDA members, persons who are appointed by the registry to serve as a WMDA member (above the maximum of persons).	Multiple	Access to WMDA Share	Annual fee
WMDA annual report	Only accessible for WMDA members, persons who are appointed by the registry to fill in the WMDA Annual Questionnaire.	1	Annual questionnaire web application	None
Search & Match Registry User	Only accessible for WMDA members, person who will have access to the Search & Match Service.	Multiple	Search & Match Service	Each user incurs a fee charged to the registry
IT expert for data submission	Only accessible for WMDA members, person who is responsible for the data upload to the Search & Match Service.	1	None	None

## Navigation tips

### Helpful Navigation Tips

- The "Watch" feature can be clicked for a space which allows automatic emails to be sent to your address notifying you when information has been edited.
- The "Share" feature allows you to send the page to desired people
- The "..." feature allows you to export certain pages on the space to printable documents
- For registered users (WMDA members) additional/restricted information may be accessed by clicking on 

## Permissions

### Permissions and restrictions

- This page is publicly visible
- Editing is restricted to the organisation profile administrators
- Editing is further restricted on page level to specific persons (record owners)

## Profile administrator

### Information about and for the organisation profile administrator

It is each organisations designated organisation profile administrator's responsibility to ensure all information displayed for their organisation is accurate at all times. By compiling, this resource will be a valuable tool for patients, donors, and organisations worldwide.

Type of Edit	Title of Tables/Page	Action for editing
Editable by user on page	Operational information, regulatory requirements information and documents	Follow instructions in Helpful Tips document
Not editable by user on page	Contact details, registry information, affiliated organizations, emergency contact, persons and functions, registry closures on main calendar, CBB survey	Must use 'Edit' button found on registry page main page by clicking key symbol in additional resource title

[Guidance on how to update the profile data](#)

Any omissions, errors or corrections can be communicated by email to [mail@wmda.info](mailto:mail@wmda.info)

## Disclaimer

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