

# Organisation Information Public Access

## Information

- Organisation definitions
- Data available
- Roles defined
- Helpful Navigation Tips
- Responsibilities organisation profile administrator
- Disclaimer

Go to organisation information database



## Organisation definitions

### Organisation definitions

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:

Organisation definitions	Data available	Maintained by appointed organisation profile administrator
<p><b>DR Donor Registry</b></p> <p>Definitions as set out in WMDA Standards (version January 1, 2020): 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>	<ul style="list-style-type: none"> <li>Contact details</li> <li>Operational information</li> <li>Regulatory survey*</li> <li>Documents (e.g. price lists)</li> <li>Personal data <i>only available for WMDA members after login</i></li> </ul>	<ul style="list-style-type: none"> <li>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.</li> <li>The operational information, regulatory requirements information and (member) documents are updated by the organisation profile administrator</li> </ul>
<p><b>CBB Cord Blood Bank</b></p> <p>Definitions as set out in WMDA Standards (version January 1, 2020): A facility responsible for donor management and the collection, processing, testing, cryopreservation, storage, listing, reservation, release, and distribution of cord blood units.</p>	<ul style="list-style-type: none"> <li>Contact details</li> <li><b>If the CBB is a listing organisation the following data is also available:</b> <ul style="list-style-type: none"> <li>Cord Blood Bank survey</li> <li>Documents (e.g. forms, price lists)</li> <li>Personal data <i>only available for WMDA members after login</i></li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>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.</li> <li>The (member) documents and cord blood bank operational and technical information are updated by the organisations.</li> </ul> <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 WMDA to set up the webpages of this cord blood bank.</p>
<p><b>DR with CBU Donor Registry that lists both donors and cords</b></p>	<ul style="list-style-type: none"> <li>Contact details</li> <li>Operational information</li> <li>Regulatory survey*</li> <li>Documents (e.g. price lists)</li> <li>Personal data <i>only available for WMDA members after login</i></li> </ul>	<ul style="list-style-type: none"> <li>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.</li> <li>The operational information, regulatory requirements information and (member) documents are updated by the organisation profile administrator</li> </ul>
<p><b>DC Donor Centre</b></p> <p>Definition as set out in WMDA Standards (version January 1, 2020): An organisation responsible for donor recruitment, consenting, testing, management and the collection of donor personal, genetic, medical data.</p>	<ul style="list-style-type: none"> <li>Contact details</li> <li>Operational information</li> </ul>	

## Data available

### \* Regulatory Questionnaire import practices EU Member States

The EU has a common set of standards to ensure the quality and safety of:

- Organs for transplantation, and
- tissues and cells for human use, including reproductive cells

For EU registries to import cells into a EU Member State, the EU Member States must be able to ensure that cells imported under their licences meet the quality and safety requirements set out in the EU tissues and cells Directive 2004/23/EC and its implementing Directives, including 2006/17/EC and 2006/86/EC.

This questionnaire will be sent out in 2019.

## Roles Defined


### Roles defined

- Listing organisations or donor centres (if approved by the registry) have an ION (Issuing Organisation Number): a globally unique identifier, as issued by ICCBBA, which maintains the official list of ION's.
- All other organisations without an ION are referenced by their WO number, as used by the WMDA internally.

Function	Information presented on WMDA Share	Access to
Primary Emergency Contact	Only accessible for WMDA members, primary contact point that can be contacted by WMDA members in case of emergency (e.g. work-up cancellation, transport problems)	
Secondary Emergency Contact	Only accessible for WMDA members, second contact point that can be contacted by WMDA members in case of emergency (e.g. work-up cancellation, transport problem) in case the primary contact does not respond	
Organisation Profile Administrator	Only accessible for WMDA members, person responsible for updating the registry and/or cord blood information on WMDA Share (address, contact person, operational information, regulatory information, cord blood operational information, cord blood technical information).	Responsible for updating operational and regulatory information
WMDA voting member	Only accessible for WMDA members, person eligible to serve as the WMDA organisational representative and to vote on behalf of the organisation.	
Medical director	Only accessible for WMDA members, medical director	None
Search coordinator	Only accessible for WMDA members, search coordinator	None
S(P)EAR alert contact	Only accessible for WMDA members, person who will receive the rapid alerts from the S(P)EAR Committee.	None
WMDA member	Only accessible for WMDA members, persons who are appointed by the WMDA member organisation to serve as a WMDA member	Access to WMDA Share
WMDA global trend report	Only accessible for WMDA members, persons who are appointed by the WMDA member organisation to fill in the WMDA Global Trend Report (annual questionnaire)	Access to annual questionnaire web application
Search & Match Registry User	Only accessible for WMDA members, person who will have access to the Search & Match Service.	Access to Search & Match Service
IT expert for data submission	Only accessible for WMDA members, person who is responsible for the data upload to the Search & Match Service.	Access to data upload facilities of WMDA

## 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 

## Responsibilities 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	Please read more details, <a href="#">here</a> .
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

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