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D2.2 Resources for registry operations and for import/export to EU Member States

Grant Agreement number: 881553 **Project acronym:** SAVDON **Work Package number:** WP1

Periodic report: 1st □ 2nd □ 3rd X 4th □

Period covered: from 01st January to 31st December 2020

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Co-funded by the Health Programme of the European Union



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1. Preface

This report, as part of the 2020 work programme of the World Marrow Donor Association (WMDA) for the EU Third Health Programme (2014-2020), outlines the online resources provided by WMDA for sharing information and guidance globally with registries that export stem cells to EU member states. It builds on Deliverable 3.1, 2019¹ and Deliverable 3.4, 2019² by giving an update on the status and use of the practical tools and resources that support the efficient import of stem cells to EU member registries. Efficient import includes details of EU safety and quality regulations and the rationale underpinning them.

The resources described in this report are all fully aligned with WMDA's mission to promote global collaboration and the sharing of best practices between its member for the benefit of stem cell donors and patients. Fulfilling this mission in the past year, 2020, has been exceptionally challenging due to the global COVID-19 pandemic. A special chapter (chapter 5) has been added, explaining all the actions undertaken by WMDA to support continuity of care during the pandemic for all our members and the patients we serve and to facilitate the international transport of life-saving products.

The report further consists of chapters, each dedicated to a specific tool/online resource. Screenshots of the different tools and web pages have been added to give a good impression of the information that is presented or requested.

A final chapter describes how WMDA maintains the data and ensures that information is up to date and accurate.





2. Update on Operational Information

As described in Deliverable 3.4, 2019², WMDA provides public webpages with essential information on Stem Cell Donor Registries and Cord Blood Banks. All organisations that are facilitating stem cell donations or cord blood for international patients are obliged to update the information annually.

In 2020, WMDA received feedback that also related donors can be requested internationally. With the increasing globalisation, it may happen that a brother/sister (willing to donate) is living in another country than the patient. Therefore, the operational information provided to international partners has been updated to include a process as well for related donations.

Find here the questions:

Sibling Typing	
Registry is willing to arrange sibling typings	
If yes, procedure to apply for sibling typings	

Members were notified about this change through the WMDA newsletter that issues every three weeks. They were requested to update their operational information accordingly. This is the message that was sent in Stem Cell Matters 61, July 2020³:

Sibling typing service - new operational information

WMDA offers <u>operational information</u> from all WMDA member organisations. One of the WMDA members raised to our attention that the information about sibling typing requests has not been updated since 2003. To avoid this for the future, we decided to add two questions to the operational information, which is reviewed by the registry annually.

Please have your Organisation Profile Administrator check the template and update the information on the following two questions:

- 1. Does your registry provide sibling typing requests? Answer options: yes or no
- 2. If yes, please describe how international registries can request sibling typing service.

Appendix 1 gives an overview of the Donor Registries and Donor Centres in EU Member States that have submitted their operational information. A special column has been added to show if the newly requested data for sibling typing has been added. Currently all 32 organisations from EU Member States have submitted their general operational information, however, only 4 (12,5 %) of those have added the sibling typing service. The registries and donor centres that need to add this information have been contacted in November 2020 with a request to update this information before February 2021. In chapter 6 maintenance of the data is described in more detail.



3. Update on Regulatory Survey

No changes have been made to the content of the Regulatory Survey in 2020.

Appendix 1 shows that 2 (6 %) out of the 32 organisations in EU Member States have not yet submitted their data for the Regulatory Survey. These organisations have been contacted with a request to update this information before February 2021. In chapter 6 maintenance of the data is described in more detail.

4. Update on public webpages with cord blood banking practices

In December 2019 the public webpages for cord blood banks were made available by WMDA. These pages are described in detail in Deliverable 3.1, 2019¹. The data that cord blood banks are asked to submit for these online pages, have been identified as relevant by the WMDA/NetCord Cord Blood Working Group, based on the results of a survey in which 77 cord blood banks from 41 countries participated. The results of this survey were published by Stem Cells' Journals in October 2020⁴.

In May 2020 all registered cord blood banks were contacted to share their information by filling out their data on the public web pages.

This is the communication that was sent:

Dear reader,

This email has been sent to you, because we have you listed as profile administrator for one or more Cord Blood Banks. In the file attached you can see for which Cord Blood Bank(s) you are asked to fill out the data on our public pages on Share.

In this email we explain why we would like you to share your information and we will give you directions how to submit your data.

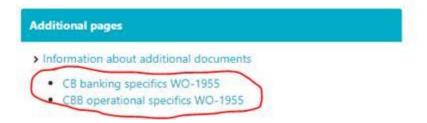
Why share your data?

The WMDA has been working on a valuable tool for patients, donors and organisations worldwide to provide them with readily-accessible data relating to good and best practices for cord blood banking. As a result, we have created two survey pages on Share, our online information and collaboration platform. Each organization has been appointed a designated profile administrator to ensure all information displayed for their Cord Blood Bank is accurate and up to date.



Instructions

Each cord blood bank has two survey pages that need to be filled. You can find these two pages by clicking on the name of an organization in the attached Excel file. On the right side of the page, you can see the links to the survey pages:



Click on the link of the survey page to edit it. Then click 'Edit' in the menu (note that you need to be logged in to Share to see the 'Edit' mode):



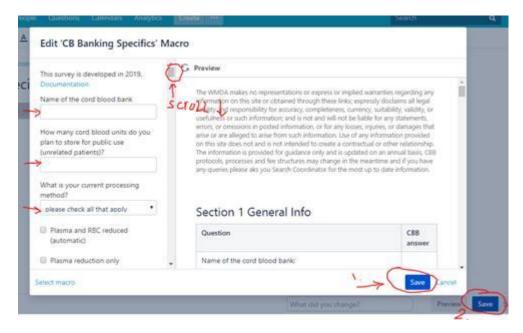
Click on the grey bar to access the survey menu and opt 'Edit' to add/adjust your data:



6



Fill out your data in the left panel and don't forget to press 'Save' when you finish:



Questions?

We hope you will be able to fill out the data for the Cord Blood Banks that have been assigned to you (see attached Excel file) and we thank you for your cooperation. Should you have any questions or suffer problems submitting your data, please send us an email and we'll gladly assist. More information and instructions to edit your pages can also be found on Share here: https://share.wmda.info/x/KYKbEw.

Best regards,

Martine Schuit

Office manager and executive assistant



Appendix 2 shows which cord blood banks in EU Member States have submitted their data for the Cord Blood Banking (Operational) Specifics. Out of the 55 cord blood banks in EU Member States, 9 organisations (16 %) have submitted their data for either or both the public webpages. All organisations that need to fill out information will be contacted before the 30 December 2020 with a request to update this information before February 2021.

WMDA understands that, due to the COVID-19 pandemic, cord blood banks have had other priorities than updating the webpages provided by WMDA. However, the importance of sharing this data publicly will be stressed in the reminder that will be sent out to them in order to have this valuable data available for smooth import and export of cord blood units. In chapter 6 future maintenance of the data is described in more detail.



5. COVID-19: actions and tools

In January 2020, the first news reached WMDA about a virus identified in Wuhan, China, later identified as novel Corona virus SARS-CoV-2/COVID-19. This chapter highlights all actions that were taken by WMDA to ensure continuity of care for her members, patients and donors worldwide.

WMDA first mentioned the virus in the three-weekly newsletter, Stem Cell Matters, that was sent on 30 January 2020. Appendix 3 gives a full overview of all COVID-19 related massages that were shared with WMDA members through the WMDA newsletter in 2020. It gives a clear insight into how WMDA and the international stem cell community were impacted by the pandemic. The most urgent matters for WMDA to tackle were:

- Sharing information on international transportation regulations to ensure stem cells could be transported from donors to patients
- Facilitating international transport by arranging travel vouchers for couriers and by realizing special transfer hubs at border crossings and military airports to ensure international transportation of stem cells.
- Provide operational information on registries, cord blood banks and collection centers to indicate how work-up requests for donors and donor recruitment were being handled
- Sharing information and best practices on cryopreservation of stem cells and other alternative strategies to cope with a constantly changing working field caused by the evolving pandemic

On 12 February 2020 WMDA launched a public webpage⁵ to share important regulatory and operational updates, impacting international collaboration. This is a screenshot of the first version of this webpage:

Coronavirus - Impact on Registry Operations

Created by Lydia Foeken, last modified on Feb 12, 2020

This information page is for search coordinators and transplant coordinators who are performing searches to inform them about the changes in operations of registries that are impacted by the coronavirus outbreak in Asia.

China Marrow Donor Program (ION-2197)

- · Registry operational information available on: https://share.wmda.info/x/mRJcAQ
- · Update February 12th:
 - · Due to the current COVID-19 outbreak in Asia, China Marrow Donor Program would not be able to accept CT and workup requests.

Hong Kong Bone Marrow Donor Registry (ION-4070)

- Registry operational information available on: https://share.wmda.info/x/pxJcAQ
- Update February 12th:
 - Hong Kong Bone Marrow Donor Registry is facing a very difficult situation with risk of a lot of local infections and travel restrictions from/to other countries. At the moment, Hong Kong Bone Marrow Donor Registry will continue to provide hematopoietic stem cell donations for those confirmed cases both local and overseas. As it is uncertain when the infection will be settled, after seeking our hospital authority agreement, Hong Kong Bone Marrow Donor Registry will temporarily suspend to provide CT and work up for overseas patients. At the same time, Hong Kong Bone Marrow Donor Registry advises the Hong Kong transplant centres to consider selecting local donors other than overseas to avoid any delay or disappointment due to travel restrictions. The transplant centres in Hong Kong are also advised to use cord blood units which are readily available.

Please note there is also issue of our donors willingness to attend our facility for work up and donation. They express worries to visit health care facilities. Anyway, it is very challenging to healthcare system, public health, HSC and blood supply. WE are learning everyday. Kindly note: these precautions are implemented to act for the best interest of patients, donors and HSC products. To avoid unnecessary delay and disappointment due to travel restrictuion, alternative strategies though not the best one should be considered.

Singapore Bone Marrow Donor Programme (ION-3785)

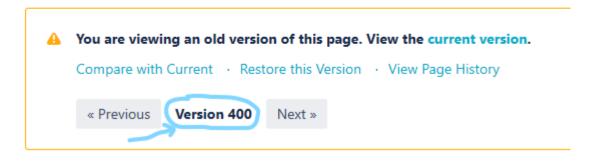
- · Registry operational information available on: https://share.wmda.info/x/TxRcAQ
- · Update February 12th:
 - Due to the current COVID-19 outbreak in Asia, BMDP would not be able to accept the buccal swab for confirmatory typing (CT) in order to protect the safety of our staff and minimize the risks. BMDP will use the blood samples and have them shipped directly to the respective labs. As we adopt this, the fees for CT will change (increase) because of this logistic change.



All member registries were contacted and asked to send in their regulatory updates in order to have these publicly available in one general location. Over the months this webpage has been updated frequently and regularly. Version 400 of the webpage was made on 12 November 2020, exactly 9 months after it was launched:

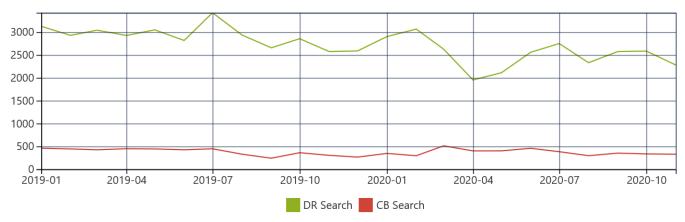
COVID-19 - Impact on Registry Operations

Created by Lydia Foeken, last modified by Martine Schuit on Nov 12, 2020



On 17 March WMDA started a special cord blood service⁶, because donor availability was dropping due to travel restrictions, lockdowns, fear from donors to catch COVID during apheresis, etc. A dedicated team of specialists, consisting of experienced WMDA members was available for consultation on selecting the best alternative cord blood units for patients.

Our statistics show a clear increase in the search of cord blood units in March, after starting this service and then a more stable pattern for the rest of the year. Interestingly, the overall number of Cord Blood Unit (CBU) searches increased in 2020, compared to 2019; breaking the downward trend of that year, which showed a steady decrease of CBU searches and usage in the second half of 2019⁷:



The WMDA has an International Emergency Task Force (IETF)⁸ that provides assistance to WMDA member organisations that request support in responding to incidents, that are not routine, that impact their operations, and are not easily resolved on their own.



The goal is:

- To provide knowledge and expertise to WMDA member organisations to ensure the continued delivery of stem cell products
- To assess impact to operations
- To determine options to assist in averting the issue, that is impacting operations
- To optimize the use of resources in response to large-scale incidents that impact many registries (i.e., chartering one plane for multiple couriers versus chartering one plane for each courier)

The IETF was called together to address the impact of travel restrictions for couriers traveling internationally. They worked together closely with courier companies in the field of hematopoietic stem cell transportation and facilitated the creation of travel waivers for international travel, resulting in various national travel waivers⁹ and a European travel waiver¹⁰. They also pointed out special hubs for the exchange of stem cell products.

On 20 March a special webpage was launched to support the European waiver, which allowed transport of couriers between EU Member States without a delay. On 23 March the EU published a communication on the implementation of the Green Lanes under the Guidelines for border management measures to protect health and ensure the availability of goods and essential services. The SoHO team supported this document with a letter sent to the European Competent Authorities to explain the cross-border shipments of SoHo as essential goods and services. WMDA published a specific webpage for couriers and customs that provided information in case clarification was needed on the purpose of the trip. The webpage provided emergency contact numbers of local persons.

Information for the European waiver for transport of cells between European countries

Three important documents (see links in blue):

HPC are defined under the green lanes for border management to ensure the availability of goods and services. If you request a courier to transport a product, we recommend to fill in, sign A driver of a heavy goods vehicle (road transport)
 A public transport aircraft crew (flight transport)

- . The border control will reach out to telephone number (mentioned below) if they have any questions on the import of cells to your country.

You can find more information on the following website: https://ec.europa.eu/health/blood_tissues_organs/overview_en WMDA has created a certificate for couriers to attest the importance of unhindered and swift travel: WMDA Travel Certificate

Country	Waiver	Importing organisation	No. of imports 2018	No. of exports 2018	Contact information to verify shipment	Couriers allowed to enter the country without quarantine	Handover hub on airport
Austria		Austrian Bone Marrow Donor Registry	122	38	+43 1 515 61 378 +43-676-848191-278.		
Belgium	link	Marrow Donor Program Registry	217	27	+32 473 367 350		
Bulgaria		Bulgarian Bone Marrow Donor Registry	23		+359-887 455 191		
Croatia		Croatian Bone Marrow Donor Registry	33	6	+385 91 5218 026		
Cyprus		Cyprus Bone Marrow Donor Registry		44	+357 9958 6381		
Czechia	link	Czech Stem Cell Registry Czech National Marrow Donor Registry Plzen	139	21	+420 602 250 797 +420 606 311 884		Vaclav Havel Prague Airport is only airport open

The work of the IETF was presented to the members of WMDA through a webinar on 25 March 2020¹¹. This webinar marked the first in a series of nine webinars, given over the course of four weeks. The webinars provided a platform for WMDA members to share information and best practices to ensure continuity of care for patients worldwide in need of a stem cell transplantation.

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Appendix 4 contains screenshots of all the webinars that were given. The following overview of the series can be found on the public WMDA Share page⁵, including the links to see them on YouTube:

- Tuesday, April 14th: Gift of Life Marrow Registry introducing their new Hybrid Virtual Physical Exam for physical exams, by Jay Feinberg and panelists Bruce Lenes MD, Richaele Nichiporenko, DNP, Lindsey Greenberg, RN
- Thursday, April 9th: Singapore BMDP ensuring continuity of care and sharing their experience: In this webinar Charles Loh, Elaine Tan and Louise Cho, from the Singapore BMDP, explain how their registry is ensuring continuity of care. They share valuable and practical information on how to operate as a team during the COVID-19 pandemic.
- <u>Tuesday, April 7th: NMDP ensuring continuity of care and sharing experiences</u>: In this webinar Steven Devine of NMDP-Be the Match shares his experience and talks about all the actions NMDP-Be the Match is taking to ensuring continuity of care for patients and donors worldwide.
- Monday, April 6th (15:00 CEST):How to ensure unrelated donor grafts and CAR-T Cell Products during the Corona pandemic: joint webinar by EBMT and WMDA. View the presentation here.
- Thursday, April 2nd: Italian BMDR ensuring continuity of care and sharing their experience: In this webinar Nicoletta Sacchi, from the Italian BMDR, shares her experience. She tells how IBMDR is ensuring continuity of care and how they managed the last few weeks during the COVID-19 crisis, which has hit Italy so very hard.
- Tuesday, March 31: ZKRD ensuring continuity of care and sharing their experience: In this webinar Fabian Bosbach and Carlheinz Müller, from ZKRD, share their experience. They explain how ZKRD is ensuring continuity of care and how they are coping with this new reality we're faced with.
- Friday, March 27: Donor care medical aspects: Our medical team explains the donor suitability criteria and respond to the questions you may have for donor care. Please note that we suffered a technical issue, resulting in problems with the sound during the first minutes. During the Q&A, after 9:09 minutes', the problem is solved. Find Mirjam's presentation here.
- <u>Thursday, March 26: Cord Blood Selection Service</u>: Irina Evseeva of Anthony Nolan explains what support you will receive from the cord blood selection service and how it works. Find Irina's presentation here.
- Wednesday, March 25: WMDA International Emergency Task Force Transport challenges: Gabi
 Rall of DKMS gives you an update on the work that has been done by the WMDA International
 Emergency Task Force and explore with you how they can support you more in the next weeks.
 Find Gabi's presentation here.



On 25 March 2020 the WMDA staff updated the signatures for all their email accounts with links to the public webpages with COVID-19 updates:

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Office manager and executive assistant



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Mon. Tue. Wed. Thu. Fri.



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2316 ZL Leiden, The Netherlands

Web: <u>www.wmda.info</u>

Email: mail@wmda.info

Coronavirus recommendations from Donor Suitability Committee:

https://share.wmda.info/x/ED6OF

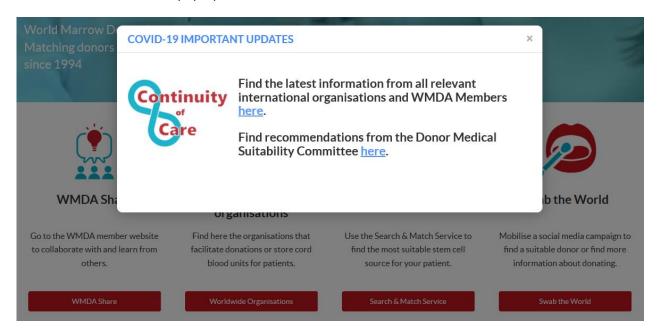
Information from registries whose operations are impacted by Coronavirus:

https://share.wmda.info/x/Yj6OF





On the WMDA website¹² a pop-up with the links was added:



The international travel restrictions also impacted face-to-face meetings. Two major meetings for WMDA, the EBMT Annual Meeting, scheduled for 21 to 25 March 2020 in Madrid, Spain and the Biannual International Donor Registry Conference, scheduled for 23 to 27 June 2020 in Québec, Canada were both postponed.

To compensate, WMDA organised a full week of Virtual Meetings, focusing on the impact of the COVID-19 pandemic from 22 to 26 June. A summary of the full week can be found in a special extra edition of WMDA's newsletter Stem Cell Matters¹³. An overview of the program can be found on WMDA Share¹⁴.

WMDA Virtual Meetings June 2020

Created by Martine Schuit, last modified by Lydia Foeken on Jun 26, 2020

 $Find your local time via this website: https://www.timeanddate.com/worldclock/converter.html?iso=20200615T100000\&p1=tz_cest. The properties of the propert$

Pillar 1: Search, Match & Connect	Pillar 2: Global Development	Pillar 3: Donor Care	Pillar 4: Quality	Foundation	
June 22	June 23	June 24	June 25	June 26	
Newcomers coffee: Your first time at WMDA? Start the conference with a new set of friends to make you feel at home right away! Link to recording Link to slides	GEMS (Group Medium Sized Registries) Link to recording Link to slides		Ask WMDA: Is it a challenge to prepare your application for Certification. Qualification or Accreditation? Our accreditation coordinator welcomes you to address all your questions. Link to the recording Slides of the meeting	Ask WMDA: WMDA staff members are ready to welcome you and answer your questions about WMDA. Link to the recording	
			Weekly 15-minute webinar Pillar 4: Internal self-evaluations –what reviewers expect to see - by Ingrid Tistl Link to recording Slides of the meeting		
EMDIS User Group & Technical Group Link to recording Link to slides	Global Development Board Committee: registry and cord blood bank challenges during COVID-19 • 12:30-12:35: Welcome - Dunia Jawdat • 12:35-12:55: COVID-survey - responses of the registries - Ann O'Leary	SEAR Annual Report 2019 - lessons learnt Thilo Mengling and Mirjam Fechter will provide an update and share the results and takeaways from the SEAR Annual Report 2019.	Quality Pillar - quality in registry operations 12:30-12:35: Welcome - Nicoletta Sacchi 12:35-12:50: Standards Committee - Dena Mercer	WMDA General Membership Meeting Agenda Minutes of the last meeting Link to the recording Slides of the meeting	
	12:55-13:25: Cryopreservation - future or not - the registry point of view - Heidi Elmoazzen NMDP - Steven Devine Australia - Garth Haeley	Link to recording Link to slides Link to SEAR annual report 2019	WMDA Standards 2020 Crosswalk NetCord-FACT Standards and WMDA Standards Cycle for new version of the	WMDD award ceremony Accreditation award ceremony	
	Germany - Annette Rasche	Link to SEAN unitidat report 2019	WMDA Standards	Honorary membership	



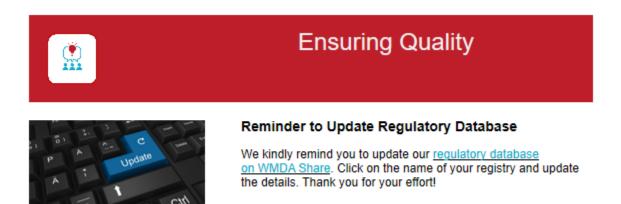
The week was very well attended with the highest attendance for the General Membership Meeting on 26 June 2020 (source: WMDA ZOOM account, attendee report):

Date	Time	Торіс	Webinar ID	Unique View ers 🗈	Total Users	Max Concurr ent Views 🕙
O Jun 26,	2020 12:12 PM	WMDA General Membership Mee	824 0600 12 29	110	156	98

WMDA will continue with virtual meetings in 2021 as long as safe travel is still compromised by the risk of catching the COVID-19 virus. The WMDA community is continuously coping with and adapting to the reality it faced with due to the pandemic.

6. Data maintenance

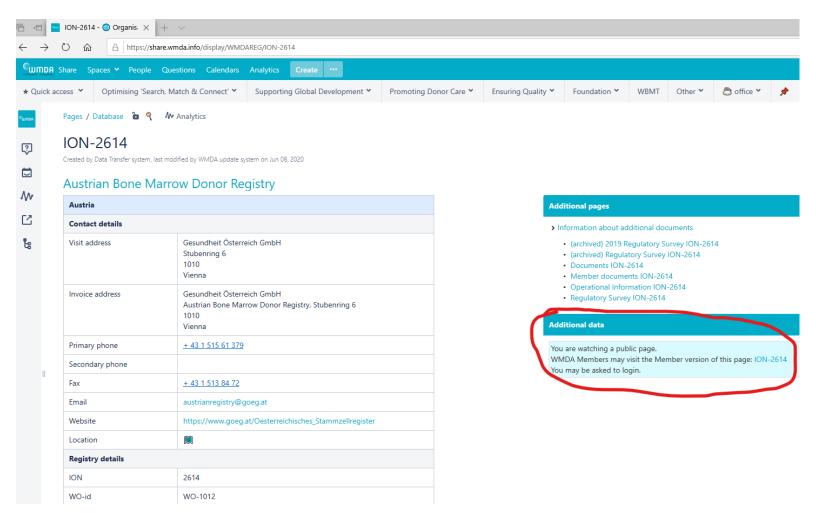
It is imperative that all public data displayed by WMDA is accurate and up to date to ensure the best service for our members and the donors and patients they represent. Part of the data displayed by WMDA can be maintained by the members themselves. Each member organisation has assigned one or more 'Profile Administrators' who have special access and edit rights for the public webpages, displaying their organisation's data. This is the case for the pages with operational and regulatory information, described in chapter 2, 3 and 4 of this report. As part of the WMDA Accreditation Programme, it is mandatory to update the information annually. We remind our members yearly through Stem Cell Matters and a special email to CEO's and the profile administrators to keep their data accurate²¹:



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Part of the publicly available information cannot be edited by members themselves. This is the case for all the data that is extracted directly from the WMDA Customer Relationship Management System (CRM). These data pertain information such as contact details, address and accreditation status. A secure page with additional data, accessible only for WMDA members, also contains data that's uploaded directly from the CRM. This additional data displays persons and functions at the organisation.



Most registries know that they can have their data in WMDA's CRM updated or corrected by submitting the request forms, available on their organisation profile page, or simply by sending a mail with their changes or updates to mail@wmda.info. They are aware that it is mandatory to communicate changes.

Nevertheless, WMDA has developed a dashboard in 2020, that is to be sent to all members yearly, as an extra check mechanism for all registries to verify their data. An example of this dashboard is added as appendix 4. Our goal for the future is to have this dashboard available online for every member to check real time at all times.



Annually WMDA is approached by emerging registries that start up activity in their country. To ensure that the donors and cord blood units that are listed for international search comply with the critical standards for donor care, the WMDA has defined minimum criteria to list donors. Registries that are not WMDA Certified, Qualified or Accredited will have to fill in this form to prove that they adhere to international standards for donor care.

The criteria were developed in2020 and were approved in November 2020. The criteria are developed to ensure data is complete and correct for registries that start listing their donors in the WMDA Search and Match database. The form is added as appendix 5. The form is based on work of the WMDA Search, Match & Connect Board Committee and WMDA members were informed of this in the newsletter Stem Cell Matters 65, September 2020²³:

Criteria to list donors approved

Search, Match & Connect Board Committee has worked on a project to define the criteria for registries that are listing donors and/or cord blood units for international search. The group worked on defining the critical criteria to list donors. The criteria were defined in five areas:

- Legal entity
- · Operational
- · Certified laboratories
- Donor care
- · WMDA specific

Registries that will start listing donors will be requested to provide information how they comply with the defined critical criteria.

Find the criteria here.

WMDA will continue to invest time in data maintenance and will remain striving towards a best practice for sharing and maintaining data of her members.





Appendix 1. Status of information submitted by Donor Registries/Centres in EU Member States

EU Member State	Donor Registry	Operational Information		Regulatory	
	Austrian Bone Marrow Donor Registry	Information	Typing	Survey	
Austria	Verein Geben für Leben				
Belgium	Marrow Donor Program Registry Belgium				
Bulgaria	Bulgarian Bone Marrow Donor Registry				
Croatia	Croatian Bone Marrow Donor Registry				
	Cyprus Bone Marrow Donor Registry				
Cyprus	Cyprus Paraskevaidio Bone Marrow Donor Registry				
	Czech National Marrow Donor Registry Plzeň				
Czech Republic	Czech Stem Cells Registry Prague (CSCR)				
	Danish Stem Cell Donors - East (DSDE)				
Denmark	Danish Stem Cell Donors - West				
Estonia	No registry				
Finland	Finnish Stem Cell Registry				
France	France Greffe de Moelle Registry - FGM				
	DKMS gemeinnützige GmbH				
C	DKMS Registry gGmbH				
Germany	Westdeutsche SpenderZentrale (WSZE)	* see below			
	ZKRD - Zentrales Knochenmarkspender-Register Deutschland				
	Centre of Bone Marrow Donor Volunteers - Save a life, University of Patras	* see below			
Greece	EOM Hellenic Transplant Organization				
	Orama Elpidas	* see below			
Hungary	Hungarian Stem Cell Donor Registry				
Ireland	Irish Unrelated Bone Marrow Registry				
Italy	Italian Bone Marrow Donor Registry				
Latvia	No registry				
Lithuania	Lithuanian National Bone Marrow Donor Registry				
Luxembourg	Luxembourg Marrow Donor Program (LMDP)				
Malta	No registry				
Netherlands	Matchis Foundation				
	Against Leukemia Foundation (ALF), Warsaw				
Poland	Fundacja DKMS				
	Poltransplant				
Portugal	CEDACE/Portuguese BMD Registry				
Romania	National Registry of Hematopoietic Stem Cells Voluntary Donors				
Slovakia	Slovakia Slovak National BMD Registry				
Slovenia	Slovenia Donor				
Spain	Registro de Donantes de Médula Ósea (REDMO)				
Sweden	Tobias Registry				

*lists through parent organisation, same information applies

Caption:	Information has been submitted
	Information needs to be added



Appendix 2. Status of information submitted by Cord Blood Banks in EU Member States

EU Member State	te Cord Blood Bank		CBB Operational Specifics
Acceptation	Red Cross Blood Transfusion Service of Upper Austria		
Austria	Vita 34 Gesellschaft für Zelltransplantate mbH		*see below
	Banque de Sang de Cordon, Cliniques Universitaires Saint Luc		
	CHU de Liège - Liege Cord Blood Bank (Sart Tilman)		
Belgium	Cord Blood Bank UZ Leuven		
	Institut Jules Bordet - ULB Cord Blood Bank		
	UZ Gent Cord Blood Bank		
Bulgaria	Bulgarian Cord Blood Bank		
Croatia	Public CBB Ana Rukavina		
Cyprus	CYCORD PACBB		
Czech Republic	Cord Blood Bank Czech Republic		
Denmark	No Cord Blood Bank		
Estonia	No Cord Blood Bank		
Finland	Finnish Cord Blood Bank		
	Banque de Sang Placentaire du CHRU de Montpellier		
France	Besancon Cord Blood Bank		
	Bordeaux Cord Blood Bank		
	Bayerische Stammzellbank GmbH		
	Deutsche Stammzellspenderdatei Nabelschnurblut		
	DKMS Stem Cell Bank gGmbH		
Germany	José Carreras Cord Blood Bank Düsseldorf-Universitätsklinikum Düsseldorf		
	Norddeutsches Knochenmark- und Stammzellspender Register gGmbH		
	Universitaetsklinikum Erlangen Stammzellbank		
	Hellenic Cord Blood Bank		
Greece	Public Cord Blood Bank Crete		
	Thessaloniki Public Cord Blood Bank		
Hungary	No Cord Blood Bank		
Ireland	No Cord Blood Bank		
	Banca Del Sangue Cordonale Di Cagliari (Ccbb)		
	Banca del Sangue Cordonale di Treviso (Treviso Cord Blood Bank)		
	Banca Del Sangue Del Cordone Ombelicale Di Sciacca		
	Banca Del Sangue Di Cordone Ombelicale Di Verona		
	Banca Di Tessuti E Cellule Regione Toscana Pisa Cord Blood Bank		
	Banca Sangue Placentare Regione Abruzzo Pecb		
	Calabria Cord Blood Bank		
	Campania Cord Blood Bank		
Italy	CBB Roma Azienda Policlinico Umberto I		
italy	Emilia Romagna Cord Blood Bank		
	Florence Cord Blood Bank		
	Liguria Cord Blood Bank		
	Milano Cord Blood Bank		
	Padova Cord Blood Bank		
	Pavia Cord Blood Bank		
	Puglia Cord Blood Bank		
	Torino Cord Blood Bank		
	Unicatt Cord Blood Bank		





Cord Blood Bank	CB Banking Specifics	CBB Operational Specifics
No Cord Blood Bank		
Sanquin		
Diagnostyka Bank Komórek Macierzystych		
The Public Stem Cell Bank, Regional Science and Technology Center		
No Cord Blood Bank		
No Cord Blood Bank		
Slovenský register placentárnych krvotvorných buniek- Eurocord-Slovakia (SRPKB)	*see below	
ESPOK Cord Blood Bank Slovenia		
Andalucia Cord Blood Bank (Malaga)		
Banc de Sang i Teixits - Barcelona Cord Blood Bank		
Basque Country Cord Blood Bank		
Galicia Cord Blood Bank		
Ivida Cord Blood Bank		
Madrid Cord Blood Bank		
Valencia Cord Blood Bank		
Swedish National Cord Blood Bank		
	No Cord Blood Bank No Cord Blood Bank No Cord Blood Bank No Cord Blood Bank Sanquin Diagnostyka Bank Komórek Macierzystych The Public Stem Cell Bank, Regional Science and Technology Center No Cord Blood Bank No Cord Blood Bank Slovenský register placentárnych krvotvorných buniek- Eurocord-Slovakia (SRPKB) ESPOK Cord Blood Bank Slovenia Andalucia Cord Blood Bank (Malaga) Banc de Sang i Teixits - Barcelona Cord Blood Bank Basque Country Cord Blood Bank Galicia Cord Blood Bank Ivida Cord Blood Bank Ivida Cord Blood Bank Valencia Cord Blood Bank	No Cord Blood Bank Sanquin Diagnostyka Bank Komórek Macierzystych The Public Stem Cell Bank, Regional Science and Technology Center No Cord Blood Bank No Cord Blood Bank Slovenský register placentárnych krvotvorných buniek- Eurocord-Slovakia (SRPKB) *see below ESPOK Cord Blood Bank (Malaga) Banc de Sang i Teixits - Barcelona Cord Blood Bank Basque Country Cord Blood Bank Galicia Cord Blood Bank Ivida Cord Blood Bank Madrid Cord Blood Bank Madrid Cord Blood Bank Valencia Cord Blood Bank Valencia Cord Blood Bank

*Not applicable: this bank has its own ION and has filled the Operational Information and/or Regulatory Survey

Caption:	Information has been submitted
	Information needs to be added





Appendix 3. COVID-related messages via WMDA Newsletter

Source: Stem Cell Matters 53, January 2020¹⁵

Novel Coronavirus and substances of human origin safety

The potential transmission of the novel Coronavirus is unknown. WHO has provided a risk assessment and a series of technical documents regarding the novel Coronavirus 2019-nCoV and is sharing updated information regarding this cluster on its website. In addition, the European Centre for Disease Prevention and Control (ECDC) provides a daily update on its website.

Source: Stem Cell Matters 54, February 2020¹⁶

Dear <<First Name>>,

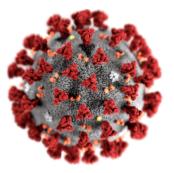
With all the media and messages being published around the Coronavirus, we urge you to read the changes/updates on the WMDA Share Coronavirus - Impact on Reqistry Operations. We strive to update all the changes on the impact of the Coronavirus on registry operations. More on the background of the virus you can read here on Coronavirus-2019-nCoV.

If you have any concerns or need help regarding the impact of the Coronavirus, please do contact WMDA office.

Best regards, Lydia and the WMDA Team



Promoting Donor Care



Important messages - Coronavirus (2019-nCoV)

- Any changes and/or updates from registries impacted in their operations will be published on WMDA Share page Coronavirus – Impact on Registry Operation.
- If your registry would like to share an update with international partners, please contact <u>WMDA office</u>.
 We will update the information page on WMDA Share.
- The donor suitability committee has published donor suitability recommendations, which you can find on the WMDA Share page: <u>Coronavirus - 2019-nCoV</u>.
- If your registry needs advice or support, please contact WMDA office.



Source: Stem Cell Matters 55, March 2020¹⁷

The Spanish authorities do not allow medical conferences, therefore the WMDA Search Coordinators Training Day has been postponed to Sunday, 30 August 2020.



Dear <<First Name>>,

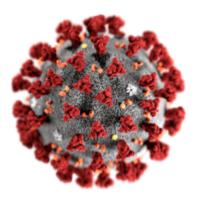
These times are challenging, especially for WMDA colleagues from regions that are impacted by the spread of COVID-

19 or registries facing changing landscapes per hour. WMDA is offering two public webpages to facilitate the community. Donor Suitability Committee is regularly meeting to explore if the donor suitability criteria are fit-for-purpose or require an update. Global Develop Committee offers a webpage where you can find details about registry operations.

The Emergency Task Force is in close contact with the courier companies. The Cord Blood Working Group is offering a cord blood selection service. We value your continued support during these challenging times as we seek to wisely move as an association through what is a very unique time for our world.



Promoting Donor Care



Update COVID-19

- Any changes and/or updates from registries impacted in their operations will be published on WMDA Share page Coronavirus – Impact on Registry Operation.
- If your registry would like to share an update with international partners, please send your update to <u>WMDA</u> <u>office</u>. We will notify the community through the information page on WMDA Share. If you would like to receive the updates from your colleagues automatically, you can sign up as a 'watcher' of the webpage.
- The donor suitability committee publishes updates regarding donor suitability recommendations, to read here: <u>Coronavirus - 2019-nCoV</u>.
- If your registry needs advice or support, please contact the WMDA International Emergency Task Force.



Cord Blood Service

COVID-19 is challenging our community

To assist you in the donor selection process, WMDA has introduced a new service. If you need urgent help in the selection process because of problems finding a suitable and available unrelated adult stem cell donor, the WMDA has established a cord blood support team.

Cord blood may be a good alternative if there are complications in the search process as cord blood is quickly available, was collected before the COVID-19 outbreak and can be shipped by cargo flights or by car.

How to connect to this service?

Send an e-mail with the above-mentioned information to <u>Lydia</u> <u>Foeken</u>. You will receive a confirmation with the name of the cord blood specialist who will assist you in the selection of the cord blood unit.



Onsite inspections adjusted to the COVID-19 situation

WMDA Accreditation Steering Committee will reschedule the two onsite audits due to COVID-19. WMDA office works closely with the reviewers and registries impacted to adjust the planning to the situation.



Interesting reads



Interesting reads concerning COVID-19::

- · World Health Organization
- US Food & Drug Administration
- · Centres for Disease Control and Prevention
- Actual global cases by Johns Hopkins CSSE



Source: Stem Cell Matters 56, April 2020¹⁸



Sign up for the EBMT/WMDA webinar on Monday, April 6, 2020. The webinar will be at 15:00 CET. Register here!



WMDA offers the possibility to participate in COVID-19 webinars. The webinars provide practical information on how to manage COVID-19 in your registry. The webinars are short, 15-30 minutes, on specific topics. You can watch the YouTube recording in case the webinar is at an inconvenient time.

Register here for these webinars!

Dear <<First Name>>,

These times are challenging and at WMDA we are doing all we can to ensure continuity of care for transplant patients around the world and for all our members. In the last month two waivers were obtained from the European Commission and the US Center for Disease Control and Prevention to facilitate international transport of stem cells.

While getting transports organised and finding new alternatives (e.g. cargo), EBMT invited WMDA to inform European transplant centres how to ensure unrelated donor grafts during the Corona crisis. You are welcome to join coming Monday.

To stay connected and wellinformed, WMDA organises short webinars twice a week to share experiences in managing your registries during the pandemic. For those who are not able to attend, a recording is available on the Share homepage.

Unfortunately, the WMDA/IDRC meeting will be postponed till 2021. Together with the pillar leaders we are working on a plan how to stay connected in 2020. If you have any ideas or suggestions, feel free to reach out to us.

Stay healthy and take care.

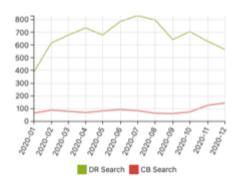
Best regards, Lydia and the WMDA team



Corona changing the search landscape

Are you interested to see the trends in the searches done in the Search & Match Service? Have a look at the graph. In week 7 829 searches were done. This dropped down to 564 searches in week 12.

On the other hand, the number of cord blood searches increased from 82 to 142 searches a week. We are happy to provide specific information about your region if you wish to receive this; drop a note with your request to Zhihong He (support@wmda.info).



.....

Cord Blood Selection Support Service

WMDA has launched a cord blood selection support service. Click here-to-the-recording-of-the-webinar-explaining-the-service. Some cord blood banks have units available to practice thawing of the unit in your centre.

You can reach out to the team that is providing this service by going to this WMDA Share page.



Moving to virtual World Marrow Donor Day 2020

This year, the pandemic is challenging our and your WMDD preparations. Therefore, we are working on a virtual celebration of the World Marrow Donor Day for 2020.

The WMDD task force is exploring to organise a global online donor recruitment campaign. If your registry is unable to facilitate online registrations, please contact us and we will try to find solutions. We are dedicated to make this campaign accessible to all our members.

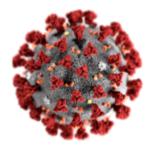
WMDA is proud of the commitment of our members during this pandemic to ensure 'business as usual'. We would like to point out that, especially now during these challenging times, organisations have a unique opportunity to tell the stories of the dedication of donors, staff, medical personnel and couriers to care for our patients. If you wish to share any of these stories with WMDA/WMDD we will be honoured to share them on our platforms and website, now and during WMDD.

We hope together we can make this virtual WMDD edition as successful as the previous ones!



Sept 19 2020 @ Virtual edition





COVID-19

- WMDA publication in Bone Marrow Transplantation: https://www.nature.com/articles/s41409-020-0873-x
- If you have medical questions regarding COVID-19, do check our webinar about <u>Donor care – medical aspects</u> of 27 March. Our medical team explains the donor suitability criteria and responds to some questions regarding donor care.
- Any changes/updates from registries impacted in their operations is published on our WMDA Share page <u>Coronavirus – Impact on</u> <u>Registry Operation</u>.
- The donor suitability committee publishes updates regarding donor suitability recommendations here: <u>Coronavirus - 2019-nCoV</u>.
- If your registry needs advice or support, please contact the WMDA International Emergency Task Force.



WMDA accreditation programme

The pandemic situation is also challenging the ongoing WMDA accreditation programme. The Accreditation Steering Committee is reviewing solutions how to overcome that reviewers are not able to travel and registries do not have time to prepare their applications. For each registry and each reviewer the situation might be different, therefore we ask you to contact Matilde Lartagegui (accreditation@wmda.info) in case you have specific questions.

Cargo plane pilots will ferry vital stem cells as Covid-19 hits cancer treatment

Cancer specialists are preparing to use cargo plane pilots instead of couriers to deliver life-saving stem cells to patients in need as global travel bans and border closings have created a "logistical nightmare" for the delivery of bone marrow and organ donations.



Read more here in the Guardian.



Source: Stem Cell Matters 57, April 2020¹⁹



Dear <<First Name>>,

As challenging times go on, WMDA strives to provide information via webinars and online information pages. Stay connected, check out our recorded webinars available on <a href="https://www.wmba.check.org/wmba.check.o

On 1 May 2020, WMDA office will send out the call for nominations for the vacant WMDA positions. Check out your email soon. The deadline for nominating candidates will be 15 June 2020.

We are working on a plan, how to stay connected in 2020 without having a face-to-face meeting. During the original planned week form 23 to 27 June 2020, we will organise a daily webinar to inform you about the projects from the pillars.

Stay healthy and take care! Lydia and the WMDA team

Find the links to all our recorded COVID-19 webinars on the <u>public page</u> of WMDA Share. The links to our educational webinars you can find here on WMDA Share.



WMDA Webinars

Check out the recordings of our past educational webinars on <u>WMDA Share</u>.

COVID-19 Webinars

WMDA has had webinars on COVID-19, where different registries shared their experience. In case you missed them we highly recommend you to watch the webinars, <u>click here</u> for the recordings. Thank you to those registries that have shared their experience.

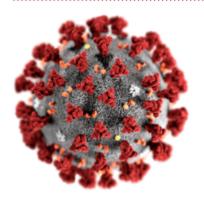


S(P)EAR reporting in times of COVID-19

Thank you so much for your continued reporting during these times of crisis. So far we have received four reports that are directly related to the adjusted procedures in these Corona times. We welcome all reports about quality and transport incidents e.g. concerning cryopreservation or cryopreserved products, transport issues but also the risk of harm situations, for instance on donors that were infected shortly before donation or during mobilization. Even situations that had a good outcome, but could teach us about the measures you took or about the effect that COVID-19 had or did not have on donation or mobilization procedures are very important to report.

Joining efforts in gathering these important data will allow us to evaluate our actions and to improve them if needed. You can expect the WMDA to share the results of the evaluation and possibly recommendation as soon as we are able to. To report Serious (Product) Adverse Events and Reactions, go to the S(P)EAR page on our website.





Update Donor Suitability Criteria

With the staggering amount and pace of change brought by pandemic, the donor suitability criteria in the guidance on COVID-19 have been updated on WMDA Share.

The guidance from the WMDA Donor Suitability Committee has been driven not only by the progression of the global pandemic but also by important questions relating to testing, routine cryopreservation and quarantine of product.



WMDA Board decisions on the Accreditation Programme due to COVID-19

The outbreak of COVID-19 has seriously affected our community in different ways. The availability of all parties involved in the accreditation program, together with the travel restrictions and the security measures, have made it almost impossible to continue with the scheduled timelines for both registries, reviewers and for WMDA as a Certification Body.

Under these extraordinary circumstances, WMDA Board has taken the following difficult decisions effective as of 14 April 2020:

- The current ongoing reviews (applications already received) will be completed with the exception of the onsite visits which will be postponed by 1 year.
- All future applications for WMDA accreditation or WMDA re-accreditation will be delayed 1 year (regardless of the year of submission).

Read the letter and more information in the appendix.





Association News



SAVE THE DATE for virtual meetings WMDA

As the WMDA meeting and IDRC meeting will not take place face to face, we will organise virtual meetings in June 2020.

Mark your calendar for the coming meetings:

- 22 June: 12:30 CET Pillar 1
 23 June: 12:30 CET Pillar 2
 24 June: 12:30 CET Pillar 3
 25 June: 12:30 CET Pillar 4
- 26 June: 12:30 CET WMDA General Membership Meeting

WMDA COVID-19 Webinars

Watch the recording by clicking on the link

- · 25 March: WMDA international emergency task force
- 26 March: Cord Blood Selection Service
- · 27 March: Donor care medical aspects
- 31 March: ZKRD-ensuring continuity of care and sharing their experience
- · 2 April: Italian BMDR-ensuring continuity of care and sharing their experience
- 6 April: Joint webinar by EBMT and WMDA: How to ensure unrelated donor grafts and CAR-T Cell Products during the Corona pandemic
- 7 April 2020: <u>NMDP-Be The Match ensuring continuity of care and sharing their</u> experience
- 9 April 2020: Singapore BMDP ensuring continuity of care and sharing their experience
- 14 April 2020: Gift of Life Marrow Registry ensuring continuity of care and sharing their experience

Source: Stem Cell Matters 58, May 2020²⁰



Survey Cord Blood Donor Eligibility and COVID-19

The Cord Blood Working Group is wondering what is being done in the community handling cord blood donor eligibility and COVID-19. It would be great if you could spare a few minutes to fill in this survey before 25 May 2020 to allow us to benchmark what is done in the community.





WMDA COVID-19 Pages

Do keep an eye on your registry information on our COVID-19
pages on WMDA Share.

S(P)EAR Rapid Alert

Thank you so much for your continued reporting during these times of crisis. Please take note of the <u>S(P)EAR Rapid Alert</u> drawn up by the WMDA S(P)EAR Committee. If you have an incident that you would like to report to the S(P)EAR Committee, related to COVID-19 pandemic or other issues, you can report via our <u>new online application platform</u>.



Possibility of Remote On-Site Audits Survey

WMDA is considering a pilot for conducting a remote "on-site" audit. This would be an audit conducted entirely over the internet. It would replace an on-site audit in situations where the on-site audit cannot be performed due to situations like the Covid-19 pandemic or civil unrest. Please help us to fill in this survey to help guide the development of this pilot.



Results Stem Cell Product Demand Survey

We are proud of our members' efforts to provide continuity of care during these challenging times. WMDA has asked its members in a short survey how they comply with stem cell products demand during COVID-19 pandemic.

Find the summarized main results in the infographic.

Note: the infographic is displayed on the next page.

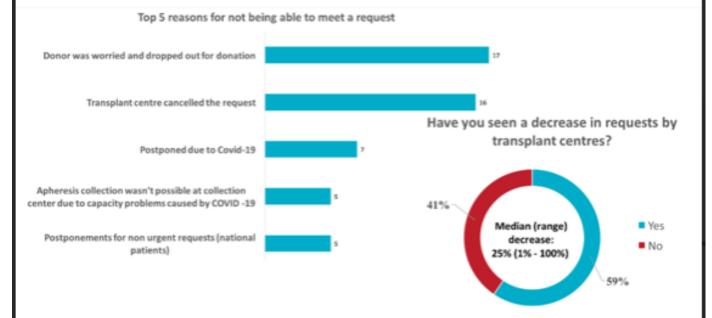
Complying with stem cell product demand during COVID-19 pandemic



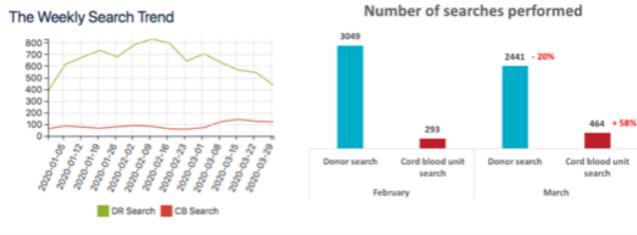


30% survey response rate











Source: Stem Cell Matter 59, June 2020²¹

Pillar 2: Virtual webinar Global Development Board Committee

The Global Development pillar will be dedicated to the COVID-19 pandemic. The pillar is working on two questionnaires to monitor the registry operations during the pandemic (lessons learnt, changes compared with 2019). We encourage you to fill in the first short survey before June 15th, so we'll be able to share the preliminary results with you during the webinar week. After the virtual meeting we will share a more detailed survey. In the meeting the pillar will also address cryopreservation, the registry and donor side. Three registries will share their experience and their view on the future of cryopreservation. We will ask their opinion on:

- Experienes
- · Immediate challenges
- Benefits
- Future challenges

Donor recruitment during pandemic

On 23 June from 15:00 till 16:00 CEST you will be able to join a workshop on donor recruitment during the COVID pandemic.The workshop will be hands-on. You will be assigned to a break-out room to share experiences on how donor recruitment strategies have been redefined in the last months. What worked? What did not work?

Cord Blood Eligibility Survey

The Cord Blood WG is meeting on a monthly base. Last meeting the results of the survey, that has been sent out have been discussed. You can download the results of the survey here.

Update from GEMS

The Group European Medium-Sized Registries (GEMS) is having a virtual meeting on June 23 from 10:00 till 12:00 CEST

Virtual Transplant Coordinators Day at EBMT

The Transplant Coordinator Day will be virtual. The WMDA organising committee has changed the programme. Our sessions will be focused on: Lessons learnt in the first months of 2020 - COVID-19.

The plan is to cover three areas:

- Continuity of care how to ensure provision of stem cells
- Transport crossing borders in Corona pandemic
- Cryopreservation reality for the next 18 months?

Pillar 3: Virtual webinar Donor Care Board Committee

The Donor Care pillar meeting will be dedicated to the COVID-19 pandemic. The committee has put together a programme to discuss the impact of COVID-19 on the donor side (donor attrition, donor drop-out, donor concerns and donor testing on COVID-19). In addition, a presentation will be given on cryopreservation and the impact on the patient. Of course, the donor suitability committee and the S(P)EAR Committee will provide updates as well.

Report your COVID SEAR and SPEAR reports to WMDA

In case you have an incident that you have experienced related to the pandemic situation, we encourage you to report a SEAR or SPEAR report to WMDA. You can easily report by clicking on this link: https://wmda.knack.com/spear#welcome/

WBMT survey

The WBMT Donor Issues Committee has made a survey to gather data about the influence of G-CSF mobilization on the clinical presentation of Covid-19 in patients or related donors who were subsequently found to be infected. If you are knowledgeable on this topic, we ask you to fill out the survey on behalf of your organisation. This is the-link

to the survey. The deadline for filling in the survey is the 8th of June.

Read more about the study in this letter.

Thank you for your help, also on behalf of Nina Worel and Bronwen Shaw, co-chairs of the Donor Issues Committee.



Risk management

To support global efforts in dealing with COVID, ISO has some standards freely available for consultation in readonly format. One of these standards is ISO 31000:2018 Risk Management. If you are interested, here is the link: https://www.iso.org/covid19

WMDA guidance on cryopreservation

Most of the WMDA member registries are facing an increase in the requests for cryopreserved products, because of the COVID-19 pandemic. Cryopreservation has different aspects that need to be considered carefully. The quality of the product, the care for the donor and the point of view from a transplant physician. A group will be starting up to work on WMDA recommendations in the area of cryopreservation. In case you are interested to join this group, you can contact the WMDA office.

Source: Stem Cell Matters 63, August 2020²²

Impact of COVID-19 on registry operations

Thank you again to all the regsitries that responded to our call to fill out the survey on their operations during the second quarter of this year. Find the link to the results below, in case you want to review them. The results were also presented during our <u>virtual meeting</u> in June. A more elaborate survey, comparing data from the same period in 2019, will be sent to all CEO's late this month and we will share the link to participate in the next issue of Stem Cell Matters.

➡ Find the results to the survery here

Source: Stem Cell Matters 65, October 2020²³

Follow up survey on Registry Operations during the pandemic

The pillar Global Development worked on a second edition of the registry survey. The first edition was completed in June 2020 and results were shared at the WMDA virtual meetings. Find here the link to the presented results.

As announced, we have developed a more in-depth survey to provide detailed data about the impact of COVID-19 on our activities to international organisations. We value and welcome your input.

→ This is the link to the survey.



Source: Stem Cell Matters 66, October 2020²⁴

Survey on registry activities during the pandemic

The donor registries working group has worked on a second edition of the registry survey. The survey is an in-depth survey that will provide detailed data about the impact of COVID-19 on the activities within registries. We've noticed that gathering the data to fill out the survey takes time and our survey tool doesn't allow for saving in between sessions. To help fill out the survey at your own pace, we're adding a download of the questions, which you can use to gather all the information before filling out the survey online.

- → The link of the PDF with all the questions can be found here.
- → The link of the online survey can be found here.

Interesting Reads on SARS-CoV-2 positive donors

In the field of organ transplantation, some articles have been published recently, which we would like to share with you for your information.

- · Emerging evidence to support not always "just saying no" to SARS-CoV-2 positive donors
- <u>Utilization of deceased donors during a pandemic: argument against using SARS-CoV-2</u>
 positive donors
- No transmission of SARS-CoV-2 in a patient undergoing allogeneic hematopoietic cell transplantation from a matched-related donor with unknown COVID-19.

33



Source: Stem Cell Matters 67, November 2020²⁵

Dear <<First Name>>,

After many months of quarantine, our Australian WMDA President, Jeff Szer, can go out of his house again. Also, in South Africa, the rules are becoming more relaxed.

Unfortunately, in other parts of the world we are facing an increase in the number of COVID cases, more stringent restrictions and strong social distancing advice.

The WMDA Share page with international COVID information is updated daily, because governments are changing their border control. I highly recommend that you set the page to "watch" so that you are automatically notified when a country or registry changes its policies or procedures.

Find here the link to the

page: https://share.wmda.info/x/Yj6OF.

In addition, we invite you to participate in the WMDA Survey on registry operations during the pandemic. The Global Development pillar welcomes your feedback before November 9.

Find here the link to the survey:

Lydia and the WMDA team



WMDA Important message
Fill in the survey on your registry
operations during the pandemic. The
deadline is November 9, 2020. Find the
link here.

Optimising 'Search, Match & Connect'

Supporting Global development

Promoting Donor Care

Ensuring Quality

Association News

Community News

Interesting reads





Submit your SEAR reports - WMDA is working on a publication on COVIDrelated adverse events

The WMDA SPEAR committee is preparing a publication to inform the wider community about adverse events and reactions related to SARS-CoV-2 and the Corona crisis and what we have learned from them. For this publication we will focus on the first period, or the so called 'first wave'.

Therefore, all SPEAR reporters are requested to submit their SARS-CoV-2 and Corona crisis related reports that have occurred before October 1st before the deadline of December 1st. Examples that we expect to be reported are:

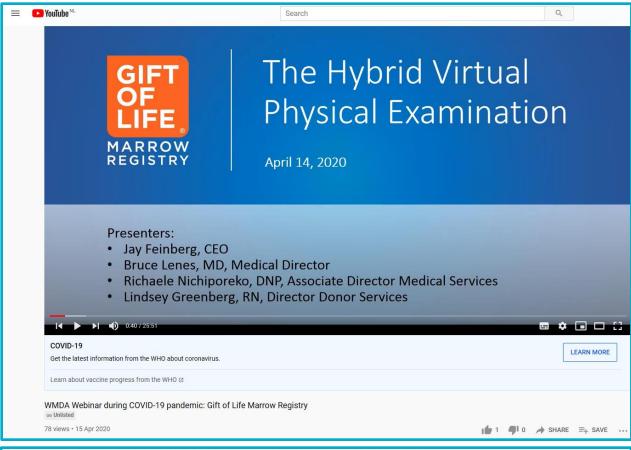
- (suspicion of) COVID-19 with donor or recipient up until 30 days after donation;
- · (suspicion of) SARS-CoV-2 transmission to or from a donor, recipient or staff;
- transport-related issues; please do not forget to mention either Corona, COVID-19 or SARS-CoV-2 in the report.
- cryopreservation issues, also if the same deviation could have occurred regardless of the
 reason for cryopreserving including higher than expected losses of viability or cells as
 well as transfusion reactions; incorrect donor selection and evaluation;
 miscommunication. Please do not forget to mention either Corona, COVID-19 or SARSCoV-2 in the report if cryopreservation would otherwise not have been requested or
 performed.

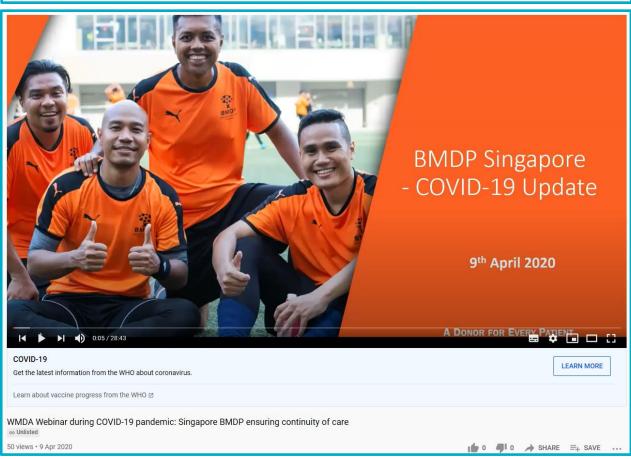
If you are unsure if your report fits into these categories, please contact us at sear@wmda.info for more information.

→ Find here the mail address in case you have any questions, mail here.

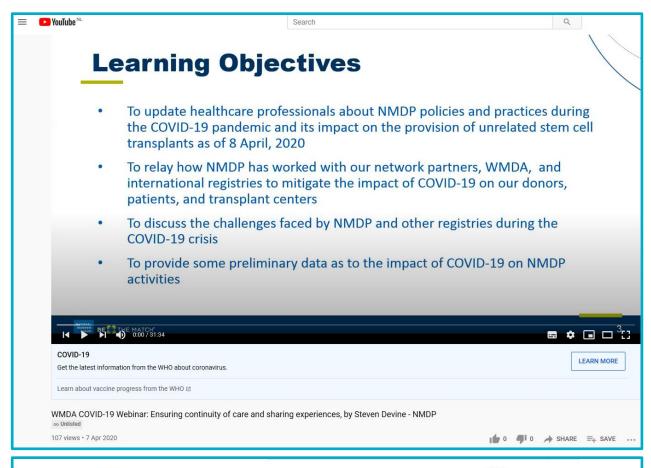


Appendix 4. Screenshots of COVID-19 Webinars







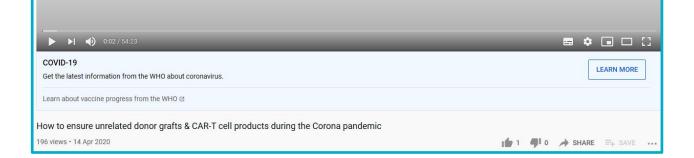




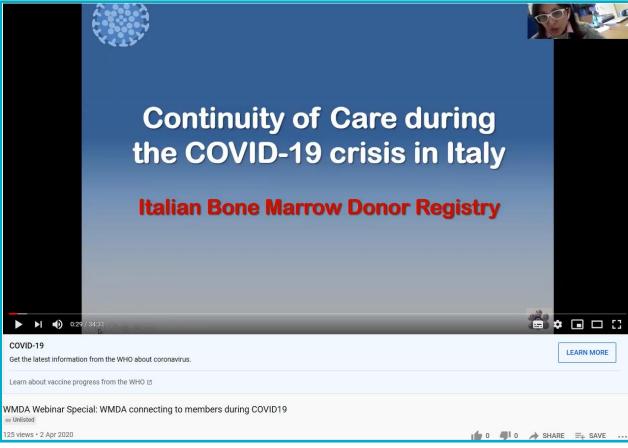


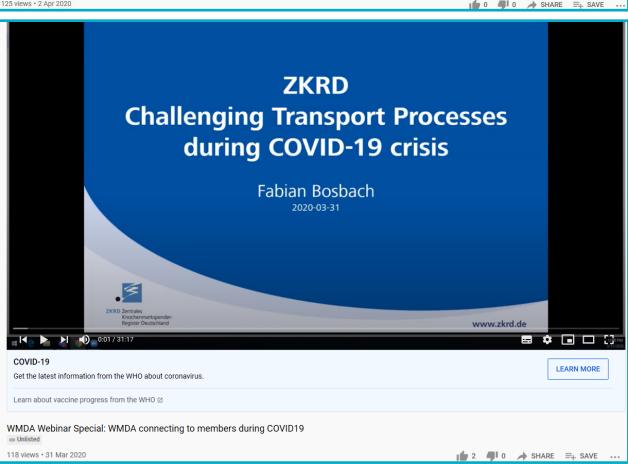
Welcome to the EBMT/WMDA webinar

How to ensure unrelated donor grafts and CAR-T Cell Products during the Corona pandemic

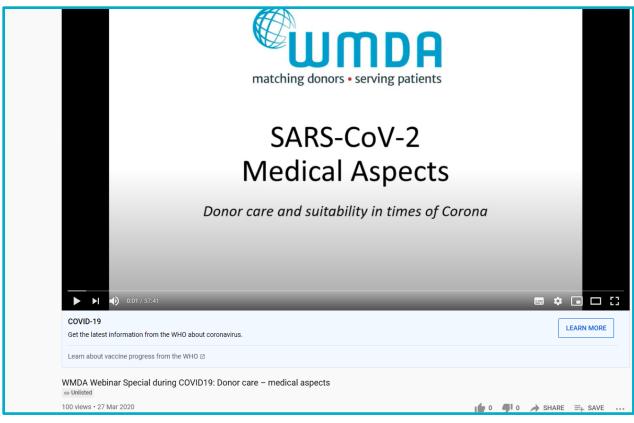


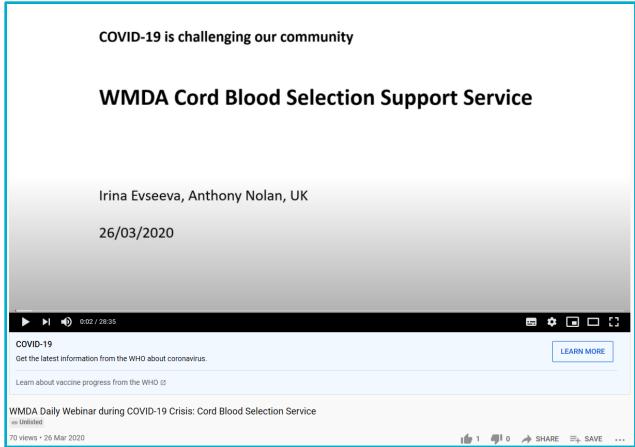




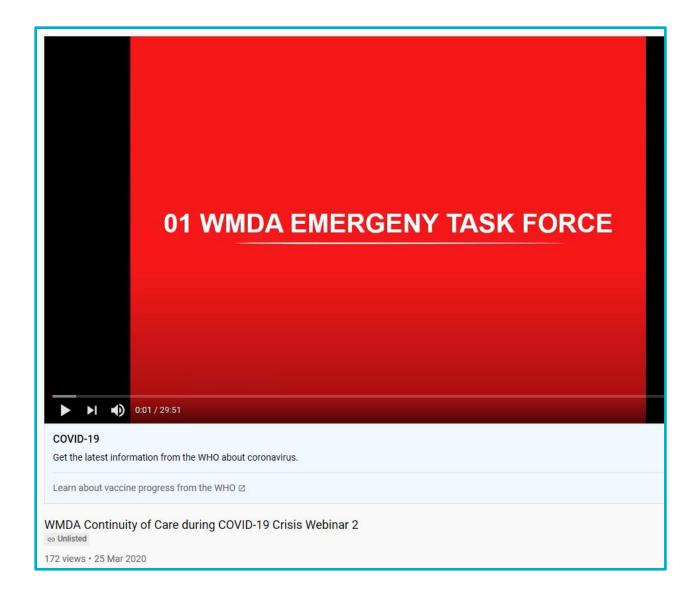












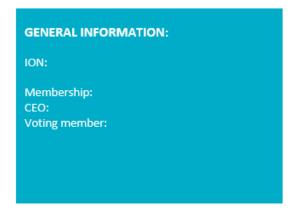


Appendix 5. Dashboards for Registry Information

WMDA DASHBOARD

This is the first edition of the WMDA Dashboard in which you can see the overall activity of your registry in relation to WMDA. Our goal is to send out this dashboard annually to keep you updated and on track. Please provide any feedback you might have to us, so that we can improve our future edition of the dashboard.

- A green box means that your registry complies with WMDA defined common practices
- An orange box means that your registry is recommended to work on improvement
- A red box means that your registry needs to take action



PILLAR 1: SEARCH, MATCH & CONNECT

PRESENTATION ON WMDA SHARE, Organisation Information Public Access:



DATA USE AGREEMENT

WMDA has established two data use agreements for international collaboration. The first data use agreement is signed with WMDA. The second data use agreement can be used for collaboration with other registries. WMDA provides an overview of the signed data use agreements on WMDA Share: https://share.wmda.info/x/HznkEw

	SIGNED?	STATUS
Data Use Agreement with WMDA		
Data Use Agreement with registries		

In case there is a data breach at WMDA or at one of the WMDA member organisations, an alert will be sent out to all WMDA data protection officers. Your registered data protection officer is:

Data Protection Officer:	



GRID:

On December 15th, all registries will stop using the donor-ID number in their communication and GRID will be the sole identifier to communicate with.

The registered GRID officer is:

GRID Contact Person	
---------------------	--

	Percentage	Status
GRID in donor file	%	

DATA UPLOAD:

WMDA is moving to real time data to facilitate the search coordinators in their daily job. Ideally, a registry submits its donor file daily or at least once a week to WMDA. A cord blood file is submitted at least once a month. On WMDA Share you can find the upload frequency of WMDA member organisation: https://share.wmda.info/x/TwfkEw.

The number of donors and cord blood units listed, are presented on https://statistics.wmda.info/.

File Source	Last Upload Date	Status Frequency:
Donor File	Daily	
Cord Blood File	Not applicable	

Link to the WMDA Data Quality Report:

CONTACT PERSONS REGISTERED AT WMDA:

Data uploader(s):

Persons who have access to search for potential matches in Search & Match Service:

INTERESTING WEBINARS TO SHARE:

Title	Weblink
Data Dictionary & <u>Differential</u> Uploads	https://youtu.be/c_i03V11QvI
Search, Match & Connect	https://youtu.be/jCyWnm3X5vY

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PILLAR 2: GLOBAL DEVELOPMENT:

EMERGENCY CONTACT DETAILS:

24 H Emergency Number	
Primary Emergency Contact	
Secondary Emergency Contact	

DONOR CRITERIA:

WMDA has an online tool on the WMDA website for potential donors, that can guide them to the registries in their country. The donor criteria of all registries are visible on WMDA Share:

https://share.wmda.info/x/x8KbEw. These data will be used for the virtual global donor drive on September 19, 2020.

For your registry, we have registered the following criteria:

Chronic diseases	Minimum Age	Maximum Age	BMI minimum	BMI maximum	Other

ORGANISATION CLOSURE AGENDA:

WMDA provides a google calendar on the website, presenting when each registry is closed due to national holidays.

Please check if all dates are correct for your <u>organisation</u> and let us know if additional days need to be added:

https://wmda.info/professionals/optimising-search-match-connect/organisation-closure-agenda/

GLOBAL TRENDS REPORT 2019:

WMDA has received the information from your registry. This information will be used to prepare the 2021 membership invoice. The data for your registry are provided by:

WMDA Global Trends Report	
---------------------------	--

2019 data	National	International
Bone Marrow		
PBSC		
Cord Blood		

OPERATIONAL AND REGULATORY INFORMATION

WMDA Standard 1.04 requires that registries update their operational and regulatory information once a year. Your registry has registered xxx as organization profile administrator, who has access to these webpages and can update them.

	Link	Update	Status
Operational information			
Regulatory information			
Membership documents			

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CORD BLOOD STATUS:

According to our records your registry is collaborating with XXX cord blood banks.

	Link	Update	Status
CB banking specifics			
CB operational specifics			

WORLD MARROW DONOR DAY

Join us on Saturday, September 19th with our virtual celebration of World Marrow Donor Day.

Contact person for World Marrow Donor Day	
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INTERESTING WEBINARS TO SHARE:

Title	Weblink
World Marrow Donor Day 2019 Prize Winners	https://youtu.be/UGGVMGPeMTA
Global Trends Report 2018	https://youtu.be/ctCDXgQUNUk
Donor Selection	https://youtu.be/kl2tIAqRgPU
World Cord Blood Day	https://youtu.be/4-1EwK2BLzE
COVID-19 webinars	https://share.wmda.info/x/Yj6OF

PILLAR 3: DONOR CARE

In case there is a rapid alert, the WMDA will send out a notification to all registered medical directors. Your registry's medical director is:

Medical director

The following persons are registered as SEAR reporters:

REPORTS SUBMITTED BY WMDA:

	Reports submitted to WMDA	Reports in draft
Number of reports in		
2018/2019/2020		

INTERESTING WEBINARS TO SHARE:

Title	Weblink
Serious Adverse Events and Examples	https://youtu.be/wLzWbcHYoCQ
WMDA S(P)EAR Educational Webinar	https://youtu.be/ctCDXgQUNUk

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PILLAR 4: QUALITY

WMDA ACCREDITATION PROGRAMME:

WMDA is maintaining an accreditation programme for registries. Being either WMDA certified, qualified or accredited is evidence that your registry is compliant with the WMDA Standards and international practices.

The status of your registry is:

	WMDA	Source	Status
Status		Donor/Cord Blood	

KEY PERFORMANCE INDICATORS (KPIs)

		KPI 2019
1	High resolution requests performed <14 days	
2	Blood samples shipped for CT < 14 days	
3	Donor availability at CT stage	
4	Donor availability at WU stage	
5	Participation in HLA discrepancy survey	

INTERESTING WEBINARS TO SHARE:

Title	Weblink
Accreditation Program-Reviewer Update	https://youtu.be/6KhjbWH5K9o
WMDA IT Standards 2020	https://youtu.be/kEIJUZSPqb8
WMDA Standards 2020	https://youtu.be/M290V9DT0B0
Weekly 15 minutes webinars	https://share.wmda.info/x/QwlgFQ

WMDA is striving to keep information accurate for all members, in order to facilitate the search coordinators in their daily job and to assist the reviewers with their reviews. If data are not correct, feel free to contact the WMDA office. We can make an appointment with you correct the data together.







Appendix 6. List with Criteria to list donors in WMDA Search and Match System

	Checklist: Critical Criteria to List Donors			
WMDA	Document type	Checklist	Approved by	
30111211	Document reference		Approval date	
	Version	1	Pages	Page 1 of 5
	Pillar	Pillar 1-WSMS — Listing Donors	Status	Public

Checklist: Critical Criteria to List Donors

Contact details	
Organisation	
Company address	
Country	
Billing information	
Organisation	
Company address	
Country	
VAT (optional)	
Financial e-mail address	

Area	Requirement	Description	How to comply when registry applies for listing	Check: 'yes, 'no' or 'pending'
1. Legal Regulatory	1.1 Legal entity	The registry meets the local regulatory standards.	 Certificate of local health authorities In case there is no legal framework, a recommendation of recognized physician supporting the development of the registry Regulatory information provided on WMDA Share: https://share.wmda.info/x/DAAwBw 	☐Yes ☐No ☐Pending ☐Yes ☐No ☐Pending ☐Yes ☐No ☐Pending ☐Yes ☐No ☐Pending
2. Operational	2.1 Year-round operations	The registry must be able to respond to requests in a timely manner and have English speaking staff and emergency (24hx7) telephone number available	Name of CEO, medical director, search coordinator, DPO published on WMDA Share Name of English-speaking person Operational information provided on	☐Yes ☐No ☐Pending If answered 'no', please state the following names: Name of CEO: Name of medical director: Name of search coordinator: Name of DPO: Name: ☐Yes ☐No ☐Pending
			WMDA Share: https://share.wmda.info/x/DAAwBw	Lifes Lino Erending
	2.2 Expertise staff	The registry has access to physicians who can assist in making medical decisions and to HLA consultants	Name of physician working with the registry Name of HLA expert working with the registry	Name: Name:
	2.3 System to track search activity and product provision	The registry has the capacity to facilitate requests. The registry should be prepared to fulfil requests coming from other countries for blood samples, verification typing or infectious disease marker (IDM) testing or shipping cord blood units on a timely basis. The provisional member should also be	Statement that it is allowed to ship blood samples and stem cell products internationally Experience in provision of stem cells (number of searches, number of verification/extended typing requests and number of workup requests)	□Yes □No □Pending □Yes □No □Pending



	2.4	prepared to collect and transport adult stem cells and/or cord blood products to other countries on a timely basis. The registry has a computer,	Statement of confirmation	□Yes □No □Pending
	Communication	printer, phone, internet, phone and e-mail		
3. Quality	3.1 Testing	The registry has a collaboration with an HLA lab and an IDM lab. The registry makes sure that it complies with quality indicators such as standards of testing and HLA typing.	Name of the HLA lab Name of the IDM lab Provide accreditation certificate of the HLA lab Provide certificate of the IDM lab	Name: Name: □Yes □No □Pending
			Provide certificate of the IDIVI lab	□Yes □No □Pending
4. Donor care	4.1 Informed consent	The registry meets certain ethical requirements, particularly in the consenting of donors and mothers.	 Provide a translated copy of the informed consent. 	□Yes □No □Pending
	4.2 Donor Education	The registry has documents on donor education (informed consent, data collection, donor testing and screening, product collection, adverse events).	Provide donor education materials	□Yes □No □Pending
	4.3 Donor protection	Financial responsibility in place to protect the donor (in case of injury or death) during the collection and recovery process	Written commitment	□Yes □No □Pending
	4.4 Donor protection	The registry collaborates with a collection centre that meets the minimum criteria defined in WMDA Standards	Written commitment	□Yes □No □Pending
	4.5 Adverse	Procedure in place to report	Name of SPEAR reporter	Name:
	events	serious adverse events and reactions to requesting organisations and WMDA	Confirmation that SPEAR reporter has viewed the WMDA SPEAR webinar	□Yes □No □Pending
5. WMDA specific	5.1 ION	The registry needs to register an ION at ICCBBA or through WMDA	Provide ION number registered at ICCBBA (or WMDA)	□Yes □No □Pending
	5.2 XML test file	Registry submits a test file in XML file format to check if the	Provide GRID donor ID-number in XML test file	□Yes □No □Pending
		data are according to WMDA data standards.	Confirmation from WMDA IT staff that the test file is correct Registered contact person for data upload	□Yes □No □Pending □Yes □No □Pending
	5.3 Data use	The registry has signed the data	Signed DUA with WMDA visible on:	☐Yes ☐No ☐Pending
	agreements	use agreements implemented by WMDA member organisations	https://share.wmda.info/x/HznkEw Signed registry-to-registry agreement visible on https://share.wmda.info/x/HznkEw	□Yes □No □Pending

Status of items pending

Requirement	Status



References

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https://ec.europa.eu/transport/sites/transport/files/legislation/2020-03-23-communication-green-lanes_en.pdf

https://mailchi.mp/54c3d80e738a/wmda-virtual-week-2020-special?e=%5BUNIQID%5D

archive.com/?u=9d6a603ef6bd5e9b7f89852e5&id=3b8df37154

¹ Pustjens E, Foeken L. D3.1 Public webpages with cord blood banking practices. 2019 SAVDON, WP3, Grant Agreement number 837354.

² Pustjens E, Foeken L. D3.4 Webpages with information for organisations importing hematopietic stem cells to EU Member States. 2019 SAVDON, WP3, Grant Agreement number 837354.

³ Stem Cell Matters 61, July 2020. WMDA newsletter: https://mailchi.mp/2663745c1619/wmda-stem-cell-matters-61?e=%5BUNIQID%5D

⁴ Jöris M, Paulson K, Foley L, Duffy M, Querol S, Gomez S, Baudoux E. Worldwide survey on key indicators for public cord blood banking technologies: By the World Marrow Donor Association Cord Blood Working Group. Stem Cells' Journal, Stem Cells Translational Medicine, October 2020 https://doi.org/10.1002/sctm.20-0246

⁶ Cord Blood Selection Service. A public webpage provided by WMDA: https://share.wmda.info/x/ EmOF

⁷ Data Upload Dashboard. A secure webpage provided by WMDA for internal use:

⁸ WMDA International Emergency Task Force. A membership webpage provided by WMDA: https://share.wmda.info/x/dQAOEw

⁹ Information for the European waiver for transport of cells between European countries. A public webpage provided by WMDA: https://share.wmda.info/x/X0uOF

¹⁰ European Commission. Communication from the Commission on the implementation of the Green Lanes under the Guidelines for border management measures to protect health and ensure the availability of goods and essential services. Brussels, 23.3.2020, C(2020) 1897 final.

¹¹ Webinar: WMDA International Emergency Task Force – Transport challenges. Gabi Rall, 25.3.2020: https://youtu.be/ccutfk0o448

¹² WMDA website: https://wmda.info/

¹³ Stem Cell Matters 60, June 2020. Special Edition WMDA Virtual Meeting:

¹⁴ WMDA Virtual Meetings June 2020. A membership webpage provided by WMDA: https://share.wmda.info/x/uwEgFQ

¹⁵ Stem Cell Matters 53, January 2020. WMDA newsletter: https://mailchi.mp/5246d82a850c/stem-cell-matters-53

¹⁶ Stem Cell Matters 54, February 2020. WMDA newsletter: https://us13.campaign-

¹⁷ Stem Cell Matters 55, March 2020. WMDA newsletter: https://us13.campaign-archive.com/?u=9d6a603ef6bd5e9b7f89852e5&id=753558e14b

¹⁸ Stem Cell Matters 56, April 2020. WMDA newsletter: https://mailchi.mp/27f1ff721951/stem-cell-matters-56?e=%5BUNIQID%5D

¹⁹ Source: Stem Cell Matters 57, April 2020. WMDA newsletter: https://mailchi.mp/3142baf1b57d/stem-cell-matters-57

²⁰ Source: Stem Cell Matters 58, May 2020. WMDA newsletter: https://mailchi.mp/de7a09d28153/stem-cell-matters-58

²¹ Stem Cell Matter 59, June 2020. WMDA newsletter: https://mailchi.mp/0f8b43646b46/stem-cell-matters-59?e=%5BUNIQID%5D

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²³ Stem Cell Matters 65, October 2020. WMDA newsletter: https://mailchi.mp/373550fb6d75/stem-cell-matters-65?e=%5BUNIQID%5D

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