# Serving blood stem cell organisations worldwide



Leiden, August 10, 2017

Dear BMDW Listing Organisation,

## BMDW Search & Match Service - Phase 2: Important Revisions to Donor Data Submissions

We are writing to update you on some important upcoming changes to the way in which your organisation submits donor and/or cord blood data to BMDW. In September 2016, we have informed you that BMDW Search & Match Service will move to a new file format. This letter gives you a summary of what to expect in the coming months.

### **Background and context**

The global database 'Bone Marrow Donors Worldwide' lists donors and cord blood products and provides donor search capabilities to help professionals find matches for patients in need of a haematopoietic stem cell transplant. The services and database of BMDW have been transferred to the World Marrow Donor Association on January 1, 2017.

During phase 1 of the BMDW Search & Match Service redevelopment, we modernised the user interface and introduced a predictive matching programme. In November 2016, the new service was launched and has been well received by the community and BMDW users.

#### File format and data submission changes

We have recently embarked on a second phase of development. The focus in this phase is to improve data collection and presentation and to further enhance search functionality. In order to improve the data collection, WMDA would like to receive a more extensive data-set from listing organisations and represent these to the users of the BMDW Search & Match Service.

Donor and cord blood unit data is submitted to BMDW on a daily basis. The current method for sending data to BMDW is outdated and increasingly difficult to support. More importantly, the data file format ("DOT20") will not expand to allow additional data fields to be received by BMDW.

In order to improve the quality and relevance of data that can be presented through the Search & Match Service, BMDW is implementing changes to its procedures for data reception and data processing. We are now introducing a new file format based on the Extensible Markup Language (XML), which is considered an industry standard that is extendable, secure, robust and easy to use.

The benefits of these changes for you as a listing organisation are:

- Increased chance that your donors or cord blood products will be selected when your organisation provide additional data;
- A secure platform to upload and download data files that comply with the European data protection regulation and ISO 2700:2016;



- Streamlined web-based data upload service with the possibility to upload data manually or automatically (via API connection) on a daily base;
- Improved reporting of the processed data files and downloading functions of those reports through the BMDW data upload service;

## Why present more data in BMDW Search & Match Service?

For search coordinators and transplant physicians it is important to have more information available when they are in the process of selecting a donor or a cord blood product. The following examples reflect the importance of additional data for the search process for patients in need of a stem cell transplantation:

- Currently, a search coordinator has to request cord blood unit (CBU) reports from cord blood banks for relevant cord blood units that are shown on the BMDW Search & Match Service. After receipt of all the reports the search coordinator / physician decides if a cord blood unit should be requested for shipment. Our new data submission procedure will allow cord blood banks to send all relevant information on cord blood units directly to BMDW as a matter of course. The search coordinator will thus immediately see the details related to the cord blood product in the BMDW Search & Match Service. This will accelerate the overall search time and may increase the chance of survival for severe patients.
- The new data submission procedures will provide search coordinators with information on the status and availability of a potential donor. This will help to prevent requests for verification or extended typing from donors that are temporarily unavailable.

#### Proposed plan and timeline

The BMDW Search & Match Service project team has been testing XML files for the last 5 months. We have received test files from 18 organisations. Based on these test results and the responses we received from the survey that was sent to all listing organisations on May 19, the following timelines has been set in order to migrate from the old data format to the new data format.

Key date	Activities
July 31 - November 15, 2017	<ul> <li>Information, support and guidance to organisations to help transition to the new file format and submission process</li> <li>Organisations send test XML files via the BMDW data upload service and will receive validation results and feedback. (If your organisation would like to upload a test file, an e-mail can be sent to <a href="mailto:support@bmdw.org">support@bmdw.org</a> for details)</li> </ul>
October 1, 2017	<ul> <li>Pilot test phase: NMDP, ZKRD, Anthony Nolan and other selected organisations (previously sent high quality test file) submit data via the new XML file and conduct end-to-end testing to confirm that the new data submission infrastructure is functioning properly</li> <li>All other organisations continue to send data submissions to BMDW via the current DOT20 file</li> </ul>



Key date	Activities
November 1, 2017	<ul> <li>After a successful pilot, BMDW starts accepting XML files from the remaining organisations</li> <li>If your organisation has fixed a date between November 1 and December 15 to move to the new file format, an e-mail can be sent to <a href="mailto:support@bmdw.org">support@bmdw.org</a> to receive a confirmation and further details</li> </ul>
December 15, 2017	<ul> <li>BMDW no longer accepts data submissions via DOT20 format</li> <li>BMDW only accepts XML files</li> </ul>
Annually	<ul> <li>The file format will be reviewed and adjusted, based on feedback and scientific developments</li> </ul>

## Support and guidance

Details on the new XML file format and data schema – including definition of which fields are mandatory or optional – can be found on the <u>BMDW public access pages</u> at WMDA Share.

If your organisation requires clarification of any technical details or lacks the knowledge and IT resources to create an XML file from your inventory, WMDA can offer a support service. You can consult our ICT specialists for investigation of the likely effort and costs that are required to implement the changes. If you would like to request an appointment for a consultation, please contact the WMDA office as soon as possible through <a href="mailto:support@bmdw.org">support@bmdw.org</a>.

We would like to take this opportunity to stress that the move to the new data submission process is a critical milestone in the continuing development of the BMDW Search & Match Service.

If your organisation cannot meet any of the timelines described above, need support or has problems to fulfil the requirements of the new data format, please do not hesitate to contact the WMDA office as soon as possible through sending an e-mail to: <a href="mailto:support@bmdw.org">support@bmdw.org</a>.

We thank you for your attention and cooperation.

Yours sincerely,

Lydia Foeken
Executive director