

# Danish Stem Cell Donors – West

## DSCDW ION2015

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### *Vision*

To achieve and maintain a position as an internationally recognized hematopoietic stem cell donor registry with respect to high quality of donor data base and HLA typing, individualized, rapid, and reliable services, smooth donor work-up and stem cell donation, and conscientious follow-up.

To achieve and maintain a position of an active participant in national and international collaboration with donor registries and transplant centers.

Through the quickest possible way to identify matched unrelated donors or cord blood units for patients in Denmark waiting allogeneic HSC transplantation with an unrelated donor.

### *Mission*

To maintain a data base of 40,000 – 45,000 or more HLA typed volunteer HSC donors, and to make these donors available for donation of HSCs and other cell types (e.g. lymphocytes) relevant for allogeneic HSC transplantation

To quickly identify, through national and worldwide donor and cord blood units searches, a matched HSC donor or umbilical cord blood unit for domestic patients awaiting an unrelated allogeneic HSC transplantation

### *History and current organization*

DSCDW is one of 2 stem cell donor registries in Denmark. The other, Danish Stem Cell Donors – East is located in Copenhagen. There is a close cooperation between the 2 registries. DSCDW recruits volunteer



HSC donors in cooperation between the blood banks in the North Region of Denmark, the Central Region of Denmark and the Region of southern Denmark. In addition to running the donor registry, DSCDW has since its start performed unrelated donor searches for Danish patients from the North Region of Denmark, the Central Region of Denmark and the Region of southern Denmark on behalf of the transplantation centers at the National Hospital in Copenhagen and Aarhus University Hospital.

DSCDW is a regular service unit within the Department of Clinical Immunology at Aarhus University Hospital. Dept. of Clinical Immunology has functions as a regional blood bank and transfusion service, HLA typing laboratory, Apheresis Centre, cell processing facility and laboratory for Infectious disease markers.

### *Collaboration and certifications*

DSCDW is aiming at complying with standards, recommendations and guidelines of World Marrow Donor Association (WMDA) as well as other international and national regulations.

DSCDW is a member of WMDA. DSCDW regularly submits HLA data of its donors to Bone Marrow Donors Worldwide (BMDW). DSCDW is participating in the EMDIS system (European Matching and Donor Information System). DSCDW is affiliated with the National Marrow Donor Program (NMDP) as a cooperative registry. Further, DSCDW is licensed by the Danish Health Authority as a tissue establishment according to the Danish Tissue Act No. 273 of 01/04/2006 and regulation No. 984 of 02/08/2007 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissue and cells (EU and Commission Directives on human tissue and cells). This licensed tissue establishment also covers functions performed by the Collection Centre (Dept of Clinical Immunology and Dept. of Hematology, Aarhus University Hospital) and testing for Infectious Disease Markers. DSCDW works under the Danish Act of Data Protection and the Act of Public Health.

Department of Clinical Immunology is accredited by the European Federation of Immunogenetics (EFI) for HLA typing and donor-patient transplantation immunology for organ and HSC transplantations and JACIE accredited for collection and processing of PBSC and marrow.

DSCDW has a formal agreement with the blood banks in North Region of Denmark, the Central Region of Denmark and the Region of southern Denmark and the two Transplantation Centers (National Hospital Copenhagen and Aarhus University Hospital)

ABO and RhD typing are performed at the blood banks. They are all approved by the Danish Health Authority according to the Danish Act of Blood. Blood collection, ABO typing and cross-matching for autologous erythrocyte transfusion following a bone marrow donation takes place at the blood bank of Aarhus University Hospital (Dept. of Clinical Immunology).

### *Recruitment of donors in DSCDW and collaboration with blood banks*

Donors are recruited among blood donors in Danish blood banks in North Region of Denmark, Central Region of Denmark and the Region of Southern Denmark. Donors, who are not blood donors are recruited through an online application.

A donor can be recruited to DSCDW when the following requirements are met:

- The donor has either been accepted as a blood donor and meets the national standards for blood donors according to the EU directive for blood transfusion and national Standards for Transfusion (TMS) in Denmark developed and maintained by the Danish Society of Clinical Immunology. Or the donor has passed an online health screening questionnaire ensuring that the donor is healthy and fulfill the basic requirements of WMDA.
- The donor is between 18 and 55 years old at time of recruitment (donors up to age 60 can occasionally be accepted)
- A donor has given written informed consent to participate in DSCDW

A donor is removed from the data base when:

- A donor's health condition is listed in the exclusion criteria of the WMDA Guidelines for donor eligibility
- The donor is older than 60 years
- The donor cannot be traced
- The donor wishes to be removed
- The donor is for other reasons not eligible for donation

### *Personal data security and informed consent for donors in DSCDW*

Donors are requested to provide an informed written consent when joining DSCDW, when blood samples are shipped for Verification Typing and when asked to donate HSC or lymphocytes. All participation in DSCDW is voluntary and the donors are informed that they can withdraw at any time without explanation. Donor's name, date of birth, social security number, and blood group are revealed by the blood banks to DSCDW. These data are together with the HLA typing data and donor unique identification (ID) number, filed in the DSCDW data system. ID number, HLA types, ABO types, gender and age is the only information in communication with registries around the world.

DSCDW is a regular entity of Aarhus University Hospital. The DSCDW personnel, as well as the personnel at the Collection Center and other collaborating units are working under confidentiality. All personnel have only access to the computer system through a secure log in procedure. In addition only DSCDW personnel have access to the data file and DSCDW data system through an additional secure log in procedure.

### *Characterization of donors in DSCDW*

All donors recruited in blood banks and they meet the criteria for blood donors according to the EU directive for blood donation and the national Standards for Transfusion (TMS) in Denmark developed and maintained by the Danish Society of Clinical Immunology. Donors recruiting donors from the general population fill in an online health screening questionnaire, and are only accepted to the registry, if they fulfill the requirements by the WMDA.

At recruitment, the donor is further characterized by:

- Age (year of birth) and gender
- ABO and RhD blood typing (performed by local blood banks)
- HLA typing data

New donors are HLA typed by histogenetics with high resolution genomic typing for HLA-A, -B, -C, -DRB1, -DQB1, DRB3, DRB4, DRB5, DQA1 and DPB1 low and high resolution typing.

In addition, infectious disease marker analyses and ABO and RhD typing are always provided at time of verification typing and pre-donation workup. Infectious disease marker and other analyses are performed according to a standard list available on WMDA share. Further, additional analyses may be performed, if specifically requested.

All donors are recruited for both bone marrow and peripheral blood HSC donation, as well for lymphocyte donation in case of need for a donor lymphocyte infusion. The Collection Center can collect and provide all cell products.

A stem cell donation can be requested according to the DSCDW Guidelines for request for donation and subsequent donations. Please see the document at the WMDA Share web site.

### *Donor search and request on donors*

DSCDW performs search for unrelated donor or cord blood for Danish patients on behalf of the 2 transplantations centers (National University Hospital in Copenhagen, and Aarhus University Hospital). Patients are included for donor search only after approval by the Group for Allogeneic Stem Cell Transplantation according to national criteria published by the Danish Society of Hematology.

Request for search for an international patient, may come through EMDIS or via e-mail/fax. All forms are accepted, but we recommend WMDA forms. If the search request is via e-mail or fax, a subsequent search is not performed. If the patient is activated through EMDIS repeated search are being done until the patient is suspended or inactivated.

Request for Extended Typing (ET), Verifying Typing (VT), Infectious Disease Marker (IDM) analyses etc. can be received by EMDIS. DSCDW also accepts request by fax and e-mail for these services. For non-EMDIS requests, we recommend the usage of WMDA forms ([www.worldmarrow.org](http://www.worldmarrow.org)), but do accept other forms and free text messages as long as they contain the information needed to perform the request task.

IDM-testing, health screening and ABO-typing is regularly performed at VT-stage as part of the VT service.



Request for donor work-up can be forwarded to DSCDW by fax or e-mail. For this purpose, it is strongly recommended to use the WMDA forms, but other forms will be accepted as long as relevant information is provided. See also the document "Guidelines for request for donation and subsequent donation".

### *Time limits for reservation of donors from DSCDW*

A donor requested for Extended Typing (ET) is routinely reserved for the specific patient for four weeks from the reporting of the results. After four weeks the donor will be released without further notification to the requesting center. The reservation may be prolonged if requested by the requesting center and accepted by DSCDW.

A donor requested for Verification Typing (VT) is reserved for the specific patient for 3 months after sample shipment. After 3 months a form asking if the donor can be released will be sent to the requesting center. The reservation may be prolonged if requested by the requesting center and accepted by DSCDW.