DKMS Registry

EMDIS NATIONAL RULES

DKMS Registry

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Introduction

This document outlines the specific implementation of EMDIS in the DKMS Registry. It is intended for use by EMDIS network partners to understand the processes at DKMS Registry and their effect on message exchange in the EMDIS framework.

Contact Information

- For business related questions or concerns, the e-mail address is: services@dkmsregistry.org
- For workup requests, the e-mail address is: workup@dkmsregistry.org
- For IT questions or concerns, the e-mail address is: emdisadmin@dkms.de
- Our professional homepage: www.dkmsregistry.org
- DKMS Operational User Guide: https://professional.dkms.org/services/operational-user-guide

Level of Implementation

Message	Incoming	Outgoing
ADMIN	n/a	n/a
ALM_REQ	NO	NO
ALM_RES	NO	NO
CBR_REQ	n/a	YES
DONOR_CB	YES	YES
IDM_REQ	YES	YES
IDM_RES	YES	YES
MARR_STAT	NO	NO
MATCH_SUM	YES	YES
MSG_ACK	YES	YES
MSG_DEN	YES	YES
NEW_ADD	YES	YES
NO_RES	YES	YES
PAT_STAT	YES	YES
PAT_UPD	YES	YES
PHEN_LIST	YES	YES
REQ_CAN	YES	YES
RES_REM	YES	YES
RSV_REQ	YES	YES
RSV_RES	YES	YES

SMP_ARR	YES	YES
SMP_REQ	YES	YES
SMP_RES	YES	YES
SMP_INFO	YES	YES
TXT_MSG	YES	YES
TYP_REQ	YES	YES
TYP_RES	YES	YES
WARNING	YES	YES
WOR_REQ	NO	NO

Search Algorithm

The search algorithm used at DKMS Registry is called Hap-E Search (Haplotype-Enhanced Search). Hap-E Search is a probabilistic search algorithm based on haplotype frequencies and was developed by DKMS in 2012. Where only incomplete HLA typing information is available, haplotype frequencies are used to estimate the probability that a specific donor is a match. The algorithm currently uses 29,334 German, Turkish, Polish, Italian, Russian and Indian HLA-A, -B, -C, -DRB1, and -DQB1 haplotype frequencies, depending on donor's and patient's descent. Hap-E Search predicts the 10/10, 9/10 and 8/10 matching probability of a donor, i.e. the probability that there are no, one or two allele-level mismatches between donor and patient. Potential 9/10 and 10/10 matched donors are selected based on antigen recognition site matching (WMDA AI3). Hap-E Search has been validated in the WMDA matching validation project (Bochtler et. al, 2011, 2013, 2016).

Patient Administration

DKMS Registry lists unrelated stem cell donors from India (DKMS Foundation India, ION-9935), Chile (Fundación DKMS, ION-1574), United Kingdom (DKMS Foundation United Kingdom, ION-9968), Poland (Fundacja DKMS, ION-7414) Germany (DKMS Donor Center gGmbH, ION-5525) and South Africa (DKMS Africa, ION-6738).

Please note:

- DKMS requires, that EMDIS partners have processes in place to evaluate the experience and setup of transplant centers to perform matched / mismatched unrelated donor transplantations.
- The grafting physician's identification is not evaluated.
- Serological HLA typing results for patient data are generally not accepted. When registering a patient (PAT_UPD), at least the antigen and/or allele values for the HLA-A, -B, and -DRB1 loci must be provided. Best matching results are achieved when at least HLA loci HLA-A, -B, -C, -DRB1, -DQB1 are provided.
- Before sending a request, HLA data should be provided in high resolution.

Matching Preference

DKMS Registry provides 10/10 and 9/10 matching results only. Mismatches are evaluated according to published WMDA matching criteria on antigen recognition site identical alleles. The direction of mismatches (GvH/HvG) is not evaluated.

Donors with more than one mismatch can be sent via EMDIS upon request to services@dkmsregistry.org .

DKMS Registry always performs a 10/10 or 9/10 search, where the mismatch can be on any locus (A, B, C, DRB1 or DQB1), regardless of the P_MATCH_DR or P_MATCH_AB parameter. In particular, no locus is ignored in the search. Then the requested filter criteria as specified in the P_MATCH_DR string are applied following DKMS Registry implementation (see below) and results are sent out accordingly.

Not all settings for the matching preferences (P_MATCH_AB / P_MATCH_DR), which are possible according to EMDIS semantics, are accepted by DKMS Registry:

- The first position of the string will be ignored (=HvG mismatches are not ignored).
- For mismatches at antigen recognition sites of the loci, a maximum of one mismatch is accepted. A higher number is automatically reset to one.
- DKMS Registry accepts all possible values for the value filter part (HLA-C, HLA-DQ, HLA-DPB1, gender, CMV-status).
- The third part of the MP string is not processed.

Examples for P_MATCH_DR

Incoming P_MATCH_DR	Outgoing P_MATCH_DR
0:XX:61:**2**1**2**1**X**X**2**1**X**X**/**	0:11:11:**1**1**1**1**1**1**1**1/
0:XX:61:**2**1**2**1**X**X**2**0**X**X**/**	0:11:11:1111111011/
0:XX:60:**2**0**2**0**X**X**2**0**X**X/	0:11:00:**0**0**0**0**1**1**0**0**1**1/

P_MATCH_CB is silently ignored and is not processed as DKMS Registry does not list any cord blood units.

If P_MATCH_AB / P_MATCH_DR are missing or are blank, the following default values are used:

P_MATCH_AB= 0:11:10:1010111111/ and

P_MATCH_DR= 0:11:10:1010111011/.

Repeat Search Program

Search updates for patients with status active (ACT) are performed daily (overnight, Central European Time). Remote registries are requested to set the status of registered patients to suspended (SUS) or stopped (STP) once regular search updates are no longer required. For cases, which are inactive for longer than 185 days, the repeat search is stopped. However, any patient related message via EMDIS re-activates the daily repeat search for the patient.

Donor Administration

KIR typing

In our lab the typing of KIR loci 2DL5A and 2DL5B cannot be separated. Sometimes it is known that only one locus is present, but it cannot be determined which one. In this situation, we send POS for both loci.

Number of Transfusions and Number of Pregnancies

According to the EMDIS semantics, the field length for the number of transfusions and the number of pregnancies is limited to one. Therefore, whenever there are more than nine transfusions or pregnancies, the number nine is reported.

Requests

Incoming Sample Request [SMP_REQ, SMP_RES, SMP_ARR, SMP_INFO]

- The amount of blood samples requested for verification typing (SMP_REQ) must not exceed 50 ml. If more than a total of 50 ml is requested, the amount will be adapted to 50 ml.
-
- It cannot be guaranteed that the blood samples will be delivered exactly as requested. The number, volume of tubes and, in rare cases, the anticoagulant may vary from the order placed due to the availability of certain types of tubes. Since available tubes also vary depending on the donor pool, the total amount of anticoagulant is considered while the number and volume of tubes are not.
- Requests for tubes with Citrate Phosphate Dextrose (CPD) as anticoagulant are not be processed as CPD cannot be provided.
- The shipping address of the blood sample (INST_SMP_SENT) is only processed if the institution has the type LAB or TRA.
- Once the request has been received, the donor is automatically reserved for this patient for six weeks.
- Once the date of blood draw has been scheduled, reservation period is adapted and the donor is automatically reserved for this patient for another 90 days.
- In case of ongoing interest in the donor (DON_ACCPT=Y), the donor is reserved for this patient for 90 days from the submission of the sample testing results. However, the donor reservation can only be extended up to a maximum of nine months after the blood draw date. If a reservation is required for a longer period than nine months, a reservation request must be submitted.
- In case of no interest in the donor (DON_ACCPT=N), the donor is released.
- Cancelations are not possible once IDM results have been sent. However, the donor will be released, if a cancellation is received after the IDM results have been sent..
- Result reminders are sent four weeks after the IDM results have been shared in case the results of the sample request have not been sent. The process continues in a biweekly rhythm until the reservation expires.

The screening for infectious disease markers is included in a sample request (SMP_REQ). It comprises routinely:

- HBsAG, Anti-HBc, Anti-HIV, Anti-HCV, Anti-CMV (IgG + IgM) and STS (Lues), as well as the testing of the ABO blood group and Rhesus factor.
- For individual additional markers such as EBV, a note must be included in the REMARK field of the SMP_REQ, e.g. "Plus EBV testing". The EBV testing result will then be sent as an IDM_RES message along with the other IDM markers that are tested during the sample request.
- For donors from India (ION-9935) a test for Malaria QBC is performed in addition.
- For donors from Chile (ION-1574) antibodies to Trypanosoma cruzi (IgG, Chagas) are tested in addition.

  The results of Malaria and Chagas tests are shared via text message or within the IDM results.

Incoming Typing Request [TYP_REQ, TYP_RES]

- All requested loci are typed in high resolution by molecular methods. Loci can be requested individually.
- Once the request has been received, the donor is automatically reserved for this patient for six weeks.
- Requests for donors having a high resolution in all loci are denied.

Incoming Request for Infectious Disease Markers [IDM_REQ, IDM_RES]

The following markers can be requested individually or in combination::

- ABO, rhesus factor, CMV IgG/IgM, HBc Ab, HBs Ag, HCV Ab, HIV-1 Ab, HIV-2 Ab, STS, Toxoplasmosis, EBV.
- For donors from India (ION-9935) testing for Malaria QBC can also be requested.
- For donors from Chile (ION-1574) testing of antibodies to Trypanosoma cruzi (IgG, Chagas) can also be requested.
- CCR5 will not be tested, if the donor is already typed for CCR5.
- Additional markers can also be tested. Please see our specification of services for more details.

- Once the request has been received, the donor is automatically reserved for this patient for six weeks.
- Requests for individual markers not mentioned above will be rejected.
- For requests that combine available and unavailable markers, the request will be adjusted accordingly and only the available markers will be tested.
- An IDM results message may contain more markers than were requested.

Incoming Reservation Request [RSV_REQ, RSV_RES]

- Reservation requests without a previous sample or HAC request for the same donor/patient pair are not possible.
- Reservation requests for a donor with a previous completed sample request for the same patient that was less than 6 months ago, will result in a reservation extension for 3 months unless otherwise specified.
- Reservation requests for a donor with a previous completed sample request for the same patient that was more than 6 months ago, will end up in an automatically generated Health and Availability Check (HAC).

Workup Request

Messages related to workup requests are not dealt via EMDIS. Workup requests have to be sent to the DKMS Registry for all donor pools (ION-9935, ION-1574, ION-9968, ION-7414, ION-5525 and ION-6738).

Contact: workup@dkmsregistry.org or send a fax to +49 7071 943 2299.

Cord Blood Units (CBUs)

DKMS registry does not provide CBUs. Messages relating to cord blood units are not processed.

Adult Cryopreserved Donor Units (ADCUs)

As ADCUs cannot be shared as search result directly, a text message is sent whenever there is one or more ADCUs within the patients' search results. The text message will

provide information whether ADCUs are a 10/10 or 9/10 match. More information about the corresponding ADCUs can be shared upon request to services@dkmsregistry.org.
For more general information about ADCUs see: https://professional.dkms.org/about/stem-cell-bank .

Invoicing

Invoicing address is

DKMS Registry gGmbH
Kressbach 1
72072 Tübingen
Germany

Invoices received from DKMS Registry must be paid within 30 days, otherwise dunning charges may apply.

References

Bochtler W, Maiers M, Bakker JNA, Oudshoorn M, Marsh SGE, Baier D, Hurley CK, Müller CR on behalf of the Information Technology Working Group of the World Marrow Donor Association. (2011) World Marrow Donor Association framework for the implementation of HLA matching programs in hematopoietic stem cell donor registries and cord blood banks, Bone Marrow Transplantation, 46:338-343.

Bochtler W, Maiers M, Bakker JNA, Baier DM, Hofmann JA, Pingel J, Rist HG, Oudshoorn M, Marsh SG, Müller CR, Hurley CK, Information Technology Working Group of the World Marrow Donor Association. (2013). An update to the HLA Nomenclature Guidelines of the World Marrow Donor Association, 2012., Bone Marrow Transplantation, 48:1387-8.

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