Questions and Answers regarding the Changes in EMDIS for the Listing of DKMS Donors

General

Q: Which are the IONs, that will be used by DKMS Registry in future?

A: Currently, HUB DR (ION-4596) lists three donor pools: 1574 (DKMS CL), 9935 (DKMS BMST IN) and 9968 (DKMS UK). Starting April 21st, 2021, there will be two additional donor pools: 5525 (DKMS DE) and 7414 (DKMS PL).

In *DONOR_CB* messages, REG_SND for all five donor pools will be 4596 (HUB DR). The DON_POOL of the donors will be the respective ION of the DKMS donor pool:

- DE-DKMS donors: 5525 (Please note, that the donor pool of DE-DKMS donors will consist of donors with GRIDs, that start with either 5525 or 6939)
- PL-DKMS donors: 7414
- GB-DKMS donors: 9968
- CL-DKMS donors: 1574
- IN-DKMS BMST donors: 9935

Q: Will DKMS assign a new GRID to DE-DKMS and PL-DKMS donors after the change?

A: The GRID of the donors will not change! The donors' GRID will not be affected by the change of listing of the donors.

Please note, that DE-DKMS donors, newly recruited after April 21st, will have the new ION of DKMS Germany in their GRID (5525). However, donors, who already have an assigned GRID, will keep their existing GRID.

In the *DONOR_CB* messages sent by HUB DR (DKMS), not the GRID field but the REG_SND and DON_POOL fields will be different from the messages sent by ZKRD.

Q: How can you distinguish between DKMS donors, that once have been sent by ZKRD via EMDIS and will be migrated to DKMS Registry AND the other German ZKRD donors, that will remain listed with ZKRD?

A: Criteria to identify DKMS donors, that were sent by ZKRD before April 21st, 2021 and will be migrated to DKMS Registry:

- PL-DKMS Donors: REG_SND = 6939, DON_POOL = 7414
- DE-DKMS Donors: REG_SND = 6939, DON_POOL = 6939, DON_ATTR = DKM

Please note, that the GRID of the donors (e.g. all donors whose GRID starts with 6939DKM) is not a 100% suitable criterion for clearly identifying DE-DKMS donors due to donor transfers. -> If donors are transferred from one registry to another, they will keep their GRID.

DKMS Registry

Examples:

- If a DE-DKMS donor has been transferred from DKMS DE to another German donor center, the GRID will still start with 6939DKM although he no longer belongs to the DKMS DE.
- If a donor has been transferred from another donor center to DKMS DE, the GRID will start with 6939XYZ although he belongs to DKMS DE.

Q: Which requests does HUB DR support via EMDIS?

A: HUB DR supports Typing [TYP_REQ]-, Infectious Disease Marker [IDM_REQ]-, Sample [SMP_REQ]- and Donor Reservation [RSV_REQ]-requests (both incoming and outgoing).

Q: What are the accepted matching preferences of HUB DR?

A: DKMS Registry provides 10/10 and 9/10 matching results only. If an 8/10 or 7/10 donor is of interest, the respective *DONOR_CB* message of this donor can be sent up on request. (services@dkmsregistry.org)

Mismatches are evaluated according to published WMDA matching criteria on antigen recognition site identical alleles. The direction of mismatches (GvH/HvG) is not evaluated.

A restriction of mismatches at specific loci is not possible. If one mismatch is accepted, DKMS Registry will always send the complete set of 9/10 matched donors with mismatches at HLA-A, -B, -C, -DRB1 or -DQB1.

P_MATCH_AB= 0:XX:40:2020XXXXXX/ or 0:XX:41:2121XXXXXX/ and **P_MATCH_DR**= 0:A0:60:20202020/ or 0:A1:61:2121212121/ are the only accepted "HLA difference filter parts" of matching preference strings.

Q: How can it be assured that we will receive the same DKMS donors from HUB DR (DKMS) after the change as we have received from HUB DE (ZKRD) before?

A: This cannot be assured 100% since DKMS and ZKRD use different matching algorithms and haplotype frequencies. Nevertheless, both algorithms provide validated matching results.

Q: Is it possible to send EMDIS requests to DKMS Registry for a donor reported via ZKRD, before April 21st, 2021 / before receiving a *DONOR_CB* message of this donor from DKMS Registry?

A: Please wait with the request until April 21st, 2021. DKMS (HUB DR) will not accept any EMDIS request messages before the respective *DONOR_CB* message has been sent.

However, please make sure, that the patient is already active at DKMS (HUB DR) even before April 21st, 2021. If so, you will automatically receive *DONOR_CB* messages of this donor on the transition day and can proceed with the request immediately.

Q: Will ZKRD (HUB DE) send a *DONOR_CB* message after completion of a Typing request [TYP_REQ], that is running at ZRKD on April 21st, 2021?

A: ZKRD (HUB DE) will send *DONOR_CB* messages together with the TYP_RES, IDM_RES or NO_RES messages, when a running request for a DKMS donor is completed.

Financial transactions

Q: After the change of donor listing, will all financial transactions for the new requests be conducted with DKMS Registry (ION-4596)?

A: After the change, all financial transactions concerning services before a workup request will be conducted with DKMS Registry (ION-4596). However, invoices for PBSC, Bone Marrow or MNC procurement will be conducted with the individual DKMS Donor Centers in Germany, Poland, UK, Chile or India.

Please be reminded, that DKMS Registry will introduce "Free Search", starting April 21st, 2021 with requests for all DKMS donors listed with DKMS Registry.

"Free Search" means, that Extended Full-profile, High-resolution HLA testing, Infectious Disease Marker and Blood Group testing, Confirmatory Typing (CT) requests (also known as Verification Typing) and our Health & Availability Check (HAC) are free of charge.

Cord blood units

Q: How will DKMS cord blood units be listed after the change on 21st April 2021?

A: Contrary to previous announcements, DKMS cord blood units will stay available at ZKRD (HUB DE) after April 21st, 2021. ZKRD (HUB DE) will keep listing the CBUs via EMDIS as before.

Workup Requests

Q: Where should workup requests for DKMS donors be sent?

A: All workup requests for DE-DKMS, PL-DKMS, GB-DKMS, CL-DKMS or IN-BMST-DKMS donors should be sent to <u>workup@dkmsregistry.org</u>. DKMS will confirm the receipt of the workup forms and the request will be transmitted to the responsible DKMS donor center. A DKMS workup coordinator will get in contact with you in order to discuss further details regarding the request.