

## REGISTRATION FOR HAP-E SEARCH® ACCESS

(To use Hap-E Search® please complete and sign this registration form)

### Organization

#### ORGANIZATION DETAILS (in block letters)

Organization:	
Abbreviation:	
Address:	
ZIP Code:	
City:	
Country:	
Phone: (Including country code)	

#### CONTACT DETAILS (in block letters)

Gender:	Male <input type="checkbox"/>	Female <input type="checkbox"/>	Diverse <input type="checkbox"/>
Last name:			
First name:			
Title:			
Position:			
Phone: (Including country code)			
Email:			

For the Login to Hap-E Search® a two-factor authentication method is used. In order to get access to the web application you have to provide two factors to verify your identity: your **password** and your **passcode**.

During the registration process you will receive your initial **password** from DKMS Registry. The **passcode** is provided by an authentication app. Therefore, we ask you to install an authentication app on your smartphone or another mobile device you want to use.

We recommend to use one of the following authentication apps:

- Google Authenticator (Google)
- FreeOTP Authenticator (RedHat)
- Microsoft Authenticator (Microsoft)
- Twilio Authy (Authy)

I confirm that I have successfully installed an authentication app on my smartphone or other mobile device.

Herewith I apply for registration for Hap-E Search® by DKMS Registry gGmbH.  
With my signature, I confirm that the information given above is accurate and complete and I declare that I agree on behalf and with the full authority of the organization mentioned above (hereinafter: 'Organization') to the *terms of use* below.

Date:

(yyyy/mm/dd)

Signature:

## **Disclaimer**

**Please note that Hap-E Search® is a service to find unrelated donors of hematopoietic stem cells (HSC, i.e. peripheral blood stem cells / bone marrow):**

- The search for a matching donor should always start in the patient's family by typing parents, siblings and optionally the extended family.
- In case no family donor is available, a search for an unrelated donor is recommended.
- Hap-E Search can be part of this unrelated donor search; a worldwide search, for example via WMDA Search and Match Service (formerly BMDW), should always complete the search process.
- Hap-E Search shows potential donors from donor centers / registries. The currently listed donor centers / registries are displayed in the software. Click the question mark in the header of any page and select 'Listed Organizations' to see the list.

**In case you need assistance with your donor selection:**

- The help of an expert for Human Leukocyte Antigens (HLA) is a prerequisite that you do not miss the best match for your patient regarding HLA but also other markers, like blood group, cytomegalovirus (CMV) or killer cell immunoglobulin-like receptor (KIR). For this purpose, you may rely on assistance by the DKMS Registry Search Unit. This assistance can be accessed through Hap-E Search.

## **Terms of Use:**

**Welcome to Hap-E Search®, a web-based service ([new.hapesearch.org](http://new.hapesearch.org)) to find unrelated donors of hematopoietic stem cells (peripheral blood stem cells / bone marrow).**

When you access and / or use Hap-E Search, you agree that you and your Organization are bound by the terms of use given hereinafter. These terms of use explain your and your Organization's rights and legal obligations pertaining to the use of Hap-E Search.

### **1. Privacy Policy**

With registration for this service you agree that your organization details and contact details are collected, processed and used by DKMS Registry gGmbH for (a) the purpose of your access to and your use of Hap-E Search and (b) for the purpose of communication by any means of communication between you and the other actors involved in the coordination of the donation and transplantation (e.g. Transplant Centers, Search Centers, Registries) globally. Furthermore, you agree, that your organization and contact details can be shared with other DKMS donor centers globally for the purpose of process related communication.

To enable a search for an unrelated donor you will be required to submit all relevant personal data of an individual patient for whom the search shall be performed, subject to that person's written consent according to applicable laws and regulations [1]. Required personal data covers at least: Patient ID number, name and surname of the patient, date of birth, gender, country, weight and diagnosis, the acceptable level of matching and HLA typing results (minimum: HLA-A, HLA-B, HLA-C and HLA-DRB1 DNA-based typing). Any personal data of the patient entered in the system as well as their accuracy is under the full responsibility of the user.

Personal data of the individual patient sent to Hap-E Search will be used by Hap-E Search exclusively for the purposes of identifying a suitable donor of hematopoietic stem cells from peripheral blood and / or bone marrow for immediate therapeutic treatment of this patient, for the arrangement of a stem cell donation subsequent to your order for this patient, for patient follow-up on the efficacy of the therapeutic treatment, and for data analyses aimed at improving Hap-E Search.

Personal data concerning this patient will be provided to third parties (e.g. international registries, donor centers, collection centers, courier companies) only to the extent necessary to perform unrelated donor searches, to prepare and perform HSC donation and patient follow-up on the efficacy of the therapeutic treatment with the cells supplied for this patient. You are solely responsible for obtaining informed consent for these purposes from this patient in accordance with all ethical and legal requirements relevant for this patient.

## **2. Use of Cells**

Cryopreservation of cells prior to infusion must be specifically requested and authorized by the donor and the donor center / registry holding the donor's data. If authorization is granted, the transplant center obtaining the cells is responsible for the correct process of cryopreservation so that cells can be transplanted in the patient they were requested for without undue delay. Excess cells shall only be stored for future therapeutic treatment of this individual patient; no other use of these cells is permissible without the specific consent of the donor and the donor center / registry. In case cells are infused by a transplantation center which is a third party, you shall oblige such a transplantation center by a written agreement which includes the same obligations as contained in this point 2.

## **3. Registration**

### **3.1. Registration to Hap-E Search®**

- a) By registering to Hap-E Search, you agree that you will provide accurate, current and complete organization and contact details. In case of changes, you shall maintain and update this information promptly either via the website or by email to [hapesearch@dkmsregistry.org](mailto:hapesearch@dkmsregistry.org). In case of inaccurate, not current or incomplete information, DKMS Registry may discontinue your access to Hap-E Search.
- b) You are responsible for keeping your password confidential and agree not to allow anyone else to use your user name or password to access Hap-E Search. You are responsible for any activities that occur under your user name and password. You agree to immediately notify DKMS Registry of any unauthorized access or alteration of your user account or any other security problem you noticed.
- c) Your user name will be provided by DKMS Registry and cannot be changed. You are requested to change your initial password immediately when you first access Hap-E Search.
- d) DKMS Registry reserves the right to access, use, preserve and disclose your personal Hap-E Search account if required to do so by law or if DKMS Registry in good faith believes that the information is reasonably necessary to:

- provide requested customer service or service related to the search of a potential donor;
  - comply with law, regulation, legal process or enforceable governmental requests;
  - enforce these terms of use;
  - respond to issues including detection, prevention or investigation of fraud, security or violation of rights of DKMS Registry or others; and
  - protect the rights, property or safety of DKMS Registry, the users of Hap-E Search or the public.
- e) You agree that DKMS Registry may prevent you from using Hap-E Search, without prior notice, if DKMS Registry believes you have violated these terms of use or for any other misuse. You agree that DKMS Registry is not liable to you or any other third party if access to any part of Hap-E Search or Hap-E Search in full is denied.

### **3.2. Use of RSA Token**

- a) You are responsible for keeping your RSA token under lock and seal, and agree not to allow anyone else to use your RSA token to access Hap-E Search. You are responsible for any activities that occur while Hap-E Search is accessed using your log in and RSA token. You agree to immediately notify DKMS Registry of the loss of your RSA token or any unauthorized access or alteration of your user account or any other security problem you noticed.
- b) You agree that DKMS Registry may prevent you from using your RSA token, without prior notice, if DKMS Registry believes you have violated these terms of use or for any other misuse. You agree that DKMS Registry is not liable to you or any other third party for denying the use of your token.

### **4. Security**

DKMS Registry is committed to ensuring the security of your information. To prevent unauthorized access, maintain data accuracy and ensure the appropriate use of information, we have put in place appropriate and reasonable physical and electronic procedures to safeguard and secure the information we collect online.

### **5. Data Protection**

It is your responsibility to ensure that you confirm to the data protection policies within your organization and country. DKMS Registry has no liability of data that might have been printed or extracted from the site.

### **6. Changes to Hap-E Search®**

DKMS Registry reserves the right to alter, add or remove Hap-E Search in part or entirely at any time and without prior notice to you. Whenever reasonably possible, we will try to notify you of any discontinuance of services. You agree that DKMS Registry is not liable to you or to any third party for any change, limitation or discontinuance of Hap-E Search.

### **7. Liability**

Irrespective of point 7.2. DKMS Registry shall be liable within the limits of the statutory provisions if a claim for damages or for reimbursement of expenses is based on willful misconduct or gross negligence or if DKMS Registry commits a material breach of a contractual duty in a culpable manner, as well as in the cases of a

culpable injury to life, body, or health.

7.1. Except for cases where DKMS Registry has committed a willful or grossly negligent breach of duty or has inflicted a culpable injury to life, body, or health, all claims for damages and for reimbursement of expenses shall become statute-barred within twelve months and liability for damages shall be limited in its amount to the foreseeable, typically occurring damage. In the event of a loss of data, DKMS Registry shall be liable at most for the expenses that would be necessary for reconstruction if you had made data backups in due manner.

7.2. Any further liability for damages or for reimbursement of expenses beyond the scope provided for under this point 7 shall be excluded, regardless of the legal nature of the asserted claim. DKMS Registry shall insofar in particular not be liable for any consequential damages resulting from the content, function, reliability or service offered on Hap-E Search, especially, but not limited to financial losses.

7.3. To the extent that liability on the part of DKMS Registry is excluded by this point 7, this exclusion shall likewise apply to the liability of the representatives of DKMS Registry as well as persons employed for the fulfilment of its obligations and its vicarious agents, especially but not limited to staff members.

7.4. The liability of DKMS Registry for malware, hacker attacks or other harmful actions performed by users or a third party is limited to intent and gross negligence.

## **8. Links to Other Websites**

Our service may contain links to third-party websites or services that are not owned or controlled by DKMS Registry.

DKMS Registry has no control over, and assumes no responsibility for, the content, privacy policies, or practices of any third-party websites or services. You further acknowledge and agree that DKMS Registry shall not be responsible or liable, directly or indirectly, for any damage or loss caused or alleged to be caused by or in connection with use of or reliance on any such content, goods or services available on or through any such websites or services.

## **9. Waiver and Severability**

If DKMS Registry does not enforce one of these terms described here, DKMS Registry does not waive that right or provision to do so at any later point in time. If any of these terms is found not enforceable, then you and DKMS Registry agree that all other terms are not affected and that the respective term shall be replaced by a new, enforceable term closest to the original intent.

## **10. Changes to Terms of Use**

DKMS Registry reserves the right to change these terms or add new terms of use at any time. Any changes will be posted on the website. Changes to these terms of use become effective as soon as they are posted and after you have accessed Hap-E Search confirming these changes to the terms of use. If you do not agree to the modified terms of use further access to Hap-E Search will be denied automatically. The most current version of these terms of use at each time automatically replaces and supersedes any prior terms of use or any other understandings, written or oral, that were made between the parties concerning the use of Hap-E Search.

## **11. Termination**

If a user wants to terminate his or her access to Hap-E Search, DKMS Registry must immediately be informed via email to [hapesearch@dkmsregistry.org](mailto:hapesearch@dkmsregistry.org). DKMS Registry will then deactivate the account. In case the account shall be used by a new user within the same organization DKMS Registry must be informed as well, so that new log in data can be provided for the new user according to the standard procedures of DKMS Registry.

If the organization wants to terminate the Hap-E Search access in full, DKMS Registry must immediately be informed via email to [hapesearch@dkmsregistry.org](mailto:hapesearch@dkmsregistry.org). DKMS Registry will then deactivate all user accounts within that organization. DKMS Registry reserves the right to terminate access of any user or organization to Hap-E Search at all times, in particular but not exclusively in cases of infringement of these terms of use.

## **12. Indemnification and Holding Harmless**

You shall indemnify and hold harmless DKMS Registry including, as applicable, its representatives, members, directors, employees, and agents against any and all losses, costs and damages (including reasonable legal fees) suffered by DKMS Registry in connection with any demands, actions or proceedings that arise or are commenced against these entities due to injuries to persons (including death), property or financial loss as a result of negligence, willful misconduct or breach of these terms of use by the Organization including, as applicable, its representatives, members, directors, employees, and agents.

## **13. Applicable Law and Place of Jurisdiction**

Access and / or use of Hap-E Search are subject to German law. Disputes that may arise in conjunction with access and / or use of Hap-E Search shall be reconciled in advance through negotiations between the Organization and DKMS Registry. If it is not possible to reach an out-of-court agreement, then the exclusive place of jurisdiction is the court in Tübingen, Germany, responsible for the substance of the dispute.

## **14. Contact us**

If you have any comments or questions about these terms, please send them to this email:  
[hapesearch@dkmsregistry.org](mailto:hapesearch@dkmsregistry.org).

### **Notes:**

[1] For South Africa: patient informed consent for data transmission to DKMS Registry must comply with the National Health Act, 2003 and the Protection of Personal Information Act, 2013.