

DONOR-PATIENT CONTACT

BENEFIT

After donation, donors and patients are able to communicate via anonymous letters. This allows the donor and patient to get to know each other and decide if they would like to remain in contact with their “genetic twin”. Social media and other outlets have publicized meetings between donors and patients, popularizing stem cell donation. We believe contact between donors and patients is important and motivates many individuals to become part of the worldwide donor search by joining the registry.

FEATURES

In Germany, Poland, the US, the UK, and other countries, contact via anonymous correspondence is possible right after transplant. Letters can be sent via DKMS and must not contain any identifying information such as names or addresses. Photos are not allowed and content exchanged must not be published or shared via social media. If a patient passes away, the donor may still be able to correspond with family members. DKMS respects and abides by all regulations imposed by each patient’s home country.

In Germany, Poland, and the UK, exchange of personal contact information is possible two years after transplant. Donors and patients are able to communicate directly and even meet in person if both agree and provide written consent. In the US, if the regulations of the patient’s home country align, direct contact is allowed after only one year. In the event of a subsequent donation, one year of anonymity post donation is required. If the patient passes away, the period of anonymity ends immediately.

FUNCTIONS

After donation and if allowed by the patient’s country, DKMS donors will receive information about the age, gender, and country of their patient. DKMS US donors will receive this information after Confirmatory Typing.

It is important that the donor and patient’s data is protected and that their identities remain anonymous. Confidentiality must not be violated by actions such as allowing the patient to see the label on the stem cell bag.

Adhering to confidentiality guidelines ensures that donors are able to make independent decision regarding donation, patients are under no obligation to their donors, and emotional pressure for all is removed.

