

DONOR-PATIENT CONTACT

BENEFIT

After donation, the donor and patient are allowed to communicate via anonymous letters. This helps them get to know each other and decide if they would like to remain in contact with their “genetic twin”. Due to years of experience and feedback from patients and donors, we are convinced that contact between donor and patient is not only important for the individuals involved, but also motivates many more people to join a donor registry.

FEATURES

In all DKMS 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 Photos are not allowed and content exchanged must not be published or shared via social media.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 allowed to correspond with family members. DKMS respects all stricter regulations imposed by the country where the transplant is performed.

In Germany, Poland, the UK, Chile, India, and South Africa (DKMS Foundation NPC) exchange of personal contact information is possible two years after the transplant. Inside the US direct contact is allowed after only one year. Donors and patients are able to communicate directly and even meet in person if both agree and provide written consent. In the event of a subsequent donation within the first two years post donation, the period of anonymity will be prolonged depending on the time and the type of subsequent donation. If the patient passes away, the period of anonymity ends immediately.

FUNCTIONS

After donation, DKMS donors can receive information about the approximate age, gender, and country of their patient. DKMS US donors will receive this information (except the patient’s country) at Confirmatory Typing.

It is important that the donor’s and patient’s data are protected and that their identities remain anonymous. Confidentiality must not be violated by actions such as allowing the patient to see the label of the stem cell bag or providing detailed information about the donor, e.g. date of birth.

Adhering to confidentiality guidelines ensures that donors are able to decide independently regarding subsequent donation. Patients are also not obliged to their donors and therefore emotional pressure is reduced for both sides.

