



WE DELETE BLOOD CANCER



# Question & Answers

**Access to Transplantation**

## Background information

### DKMS State Patient Support, in partnership with Be The Match

A pilot programme to enable South African pediatric blood cancer and blood disorder patients in need of an unrelated blood stem cell donor access to potentially lifesaving therapy.

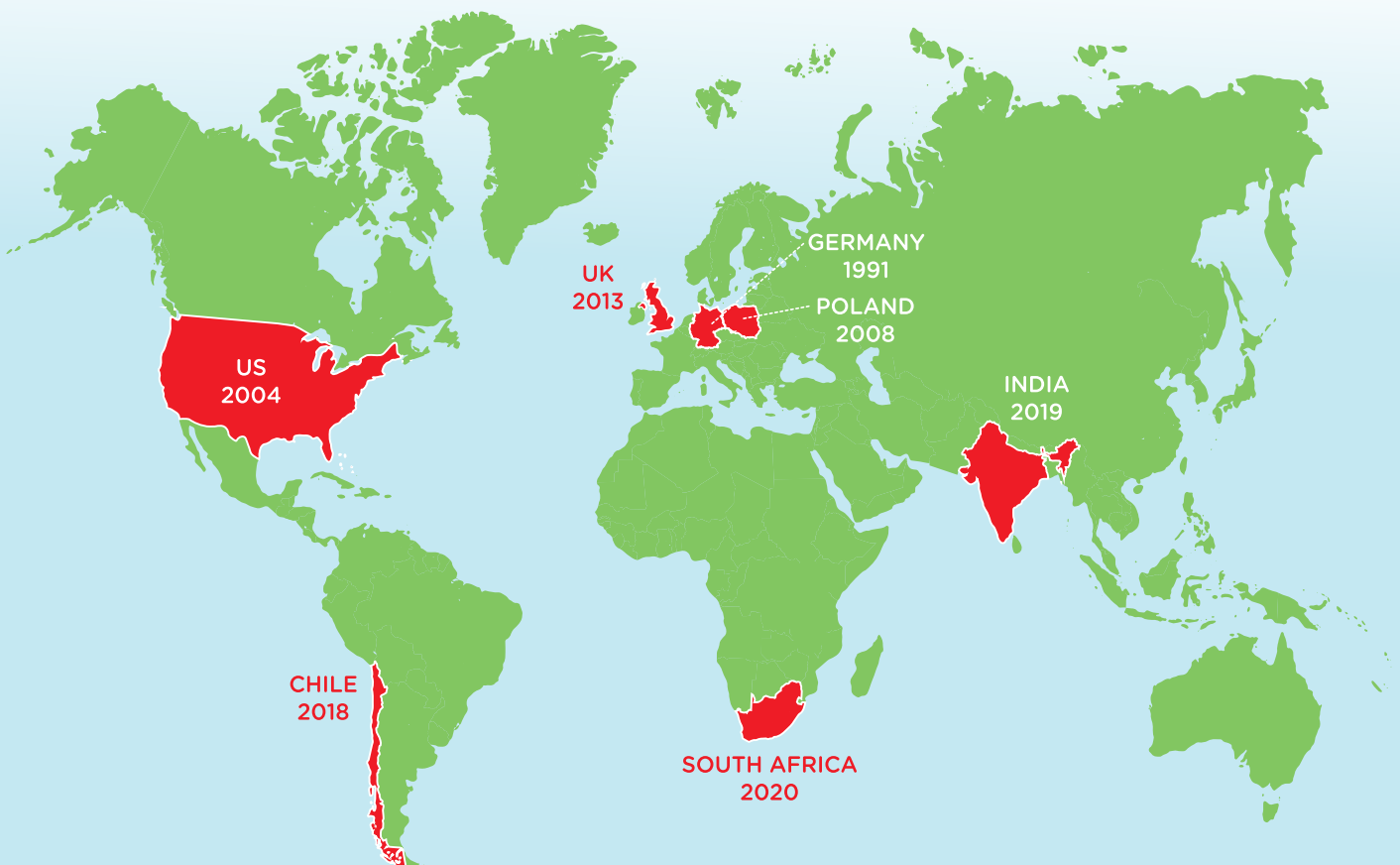
In February 2022 DKMS and Be The Match, USA, launched their joint pilot programme for young patients from South Africa suffering from blood cancer and life-threatening blood disorders such as severe aplastic anemia. With “DKMS State Patient Support, in Partnership with Be the Match” the two non-profit organizations will assist eight state patients aged between 0 and 18 years in need of a blood stem cell transplant from an unrelated volunteer donor with receiving lifesaving treatment.

While South Africa’s public health system fully covers the cost for the blood stem cell transplantation for patients who have found a matching donor within their family, patients who rely on a stranger to donate their cells are faced with major challenges in their journey to transplantation: A matching donor has to be found and they need to pay for the donor related costs such as the search for the best possible match, the (procurement) collection of the blood stem cells and their transport. DKMS and Be The Match will bridge this gap for patients without medical aid who cannot afford those costs to provide them with a second chance at life

#### Why are we doing this ?

DKMS has expanded its mission beyond the registration of unrelated blood stem donors to improve the access to transplantation for patients in low-and middle-income countries. To provide as many second chances at life as possible, it is crucial to remove both socio-economic and infrastructural barriers so that more patients are able to access potentially lifesaving therapy.

(Please also see FAQ “Access to Transplantation”)



## Questions & Answers

### 1. What does the programme entail exactly? What is the donor-related costs covered by DKMS and Be The Match?

The pilot programme, organised by DKMS Africa, is designed to cover donor search which includes verification of the donor which includes further tests, high resolution typing of the donor if necessary, blood tests, medical examination (confirmatory typing/CT) procurement (collection of the blood stem cells) and transport costs associated with providing an unrelated stem cell donation for eight state patients in South Africa under 18 years of age who/whose parents are not members of a medical aid/scheme.

The South African public healthcare system will cover the cost of the transplant itself.

### 2. What role does DKMS Africa play?

DKMS Africa is in charge of the programme and coordinates with the two participating state transplant clinics, the Steve Biko Academic Hospital, Pretoria and the UCT, Red Cross War Memorial Children's Hospital, as well as the Academic independent Clinicians Panel which receives all applications and evaluates patients' suitability for blood stem cell transplantation.

DKMS has no influence on any medical decisions such as the patient's medical treatment, the transplantation or similar parameters.

### 3. Who selects the patients for the programme?

Patients will be identified by the participating transplant doctors, Steve Biko Academic Hospital, Pretoria (Prof. D. Reynders); UCT, Red Cross War Memorial Children's Hospital, Cape Town (Prof. A. Davidson). The treating physicians will fill out an application and forward this to the independent clinicians' panel.

The independent clinicians' panel (Dr Theo Gerdener, Dr Jackie Thomson and Dr Candice Hendricks) receives all applications and evaluates the patients' suitability for blood stem cell transplantation.

### 4. What are the criteria for patients to become beneficiaries of the support?

The programem is designed for pediatric state patients in need of a blood stem cell programme from an unrelated donor who/whose parents are not members of a medical aid/scheme.

## 5. Why is the programme supporting children under 18 years of age?

Blood stem cell transplantation is a complex procedure that requires specialised care. We are very pleased that two renowned hospitals and their highly skilled experts are taking part in this programme. Both are pediatric oncologists and thus specialised in the treatment of childhood cancer which is why the pilot programme is supporting children. The Red Cross War Memorial Children's Hospital, in Cape Town (Prof. A. Davidson) exclusively treats children and the Steve Biko Academic Hospital, too houses a Paediatric Oncology Unit. We are confident that the young patients will receive the best possible treatment and care at both facilities.

## 6. Is the support only for blood cancer or other blood disorders patients as well?

This is subject to treatment of hematological malignancies and other blood disorders such as severe aplastic anemia or sickle cell disease. The independent clinicians' panel (Dr Theo Gerdener, Dr Jackie Thomson and Dr Candice Hendricks) which receives all applications, evaluates whether a transplant indication is given along with patients' suitability for blood stem cell transplantation.

## 7. How much do patients/their families usually have to pay for donor-related costs?

The donor-related costs vary depending for example on how many donors need to be verified for the concerned patient. It is for example possible that a matching donor is no longer available to donate, for example due to health reasons. In this case, another donor needs to be verified which usually entails laboratory tests. Further, the work-up process which follows the selection of the donor by the transplant center entails lab tests, physical examinations and the costs for the stem cell collection itself, which vary depending on where the donor is based. A matching donor could come from anywhere in the world. This also means that the donated blood stem cells might need to be transported over a long-distance. The courier costs vary accordingly.

Overall, costs can range from R115,000 (~USD 7,500 / ~ EUR 6,700) for a local donor to about R1 million (~USD 66,000 / ~EUR 58,000) for a non-DKMS donor. This is another reason why it is important that more South Africans register as potential blood stem cell donor as this significantly decreases the costs for patients in need of a transplant from an unrelated matching donor.

## 8. Why are you cooperating with the Steve Biko Academic Hospital, Pretoria and the Red Cross War Memorial Children's Hospital, Cape Town?

Blood stem cell transplantation is a complex medical procedure requiring specialised care. Both transplant centers have state-of-the-art facilities and a team of qualified experts that ensures the best possible outcome for the patients. Further, the transplant centers are public hospitals which treat pediatric patients covered by the public health system.



9.

Are you planning to extend the programme after completion of the pilot?

Together with Be The Match we are starting this programme in South Africa as a pilot with the hope of expanding it soon. However, while many patients depend on a stem cell donation from an unrelated donor, the search for a genetic twin is like finding a needle in a haystack. Donors of South African origin have unique tissue (HLA) characteristics that are severely under-represented in the global database. In this respect, South Africa's rainbow nation is at a distinct disadvantage, requiring a large pool of prospective donors. Thus, it is also necessary to register as many potential blood stem cell donors as possible to increase the likelihood of finding the perfect match for South African patients. Thus, we keep urging people to register as potential lifesavers.

