

**NHSBT Board
June 2023
Patient Story
An unusual request; one cord transplant for two patients**

Introduction

Donations of cord blood containing lifesaving haematopoietic stem cells have been collected and stored from maternal donors since 1996 at maternity units in areas of high diversity in and around London, building up the NHS Cord Bank to nearly 20,000 readily available stem cell transplants used to treat blood cancers and some non-malignant disorders. There is approximately a 50/50 split between the number of cord transplants we provide to adult and paediatric patients, similarly there is about a 50/50 split between double and single cord transplants. Following the first cord transplant in 1996 for a paediatric patient with Fanconi's anaemia, cord blood increased in popularity as a choice of stem cell treatment as an alternative to adult bone marrow or peripheral blood stem cell transplants and after encouraging results with single cord transplants were published, clinicians began to use two cords to treat one patient. These are carefully selected for their tissue type and cell dose depending on the patient weight; one cord usually acts as a support whilst the other cord fully engrafts in the patient and starts to produce blood cells for their new immune system. However, it is very rare to provide one cord to treat two patients, with this patient story being only the second time in the NHS cord bank's history that we received such a request. Unlike a tissue donation, for example amnion, where several treatments for corneal repair can be made from one amnion, cord blood usually contains enough cells to support one transplant; the cell dose and the HLA match with the recipient being of prime importance for a successful transplant.

The donation

Our story begins some time ago in 2016 with a potential cord blood donor who had expressed an interest in donating their cord blood to our bank during an ante-natal visit to their maternity unit in London, which fortunately was also one of our cord blood collection sites. When they arrived at the delivery suite in the early stages of labour, ten days before their due date, a sticker on their notes flagged to the midwives that should all be well with the birth, the placenta and umbilical cord could be given to our cord blood collectors. Her baby was safely born later that night and we were able to collect enough blood and cells from the umbilical cord to bank what we term an 'A grade' cord. These comprise a small proportion of our cord bank but are the most desirable cords as they contain the highest quantity of cells which are important for successful engraftment and longer-term outcome. Along with the HLA match, the cell dose available for the patient is a primary selection criterion for transplant clinicians choosing which donor or donation is best for their patient. In brief, the greater the cell dose the swifter the cord is likely to engraft in its recipient and remain engrafted. This reduces the danger zone that immediately follows transplantation when a patient is neutropenic and at high risk of infection whilst they await their new immune system to engraft and start working. After processing and testing, the cord was safely stored in liquid nitrogen and made available to transplant centres across the UK and worldwide.

The cord blood transplant

Moving forwards, almost six years to the day later, we received a request from a UK transplant centre asking for more information about this cord blood donation, noting that it would be divided and transfused equally into monozygotic twins who had been recently diagnosed with Hurler syndrome soon after their first birthday.

Hurler syndrome is a genetic syndrome where children lack an enzyme that the body needs to digest sugar, they consequently get a build-up of undigested sugar molecules in their body which causes progressive damage to their brain, heart and other organs. The severity of the symptoms is associated with a life expectancy of about ten years. A haematopoietic stem cell transplant, if carried out as soon as possible after diagnosis, can stop the disease from causing further damage and replaces the blood-forming cells stem cells that are missing the important protein with healthy ones.

The cord donation contained a very good dose of cells, especially for an infant recipient and even for two small patients weighing less than 10kg each, as well as being an excellent HLA tissue match with the twins. The request was received just over a week prior to the cord being shipped to the transplant centre and this activated all the medical review and testing needed to allow us to release the cord for transplant. The Cord Bank work closely with several departments at NHSBT, particularly H&I and Testing and there is a real sense of teamwork when everyone pulls together to turn around requests as quickly as possible. With testing complete, the cord blood transplant was packaged into a cryogenic shipping container and couriered to the stem cell laboratory at the transplant centre prior to the twins starting their conditioning. The twins received their transplant three weeks later and began their wait for the cord stem cells to engraft. This usually takes up to twenty-one days and patients are monitored thereafter to check the stem cells remain engrafted. We receive outcome data several months later, allowing time for transplant centres to review their patients. We were delighted to hear that both twins are doing well. Their donor stem cells had engrafted by sixteen days after receiving their haematopoietic stem cell transplants which is relatively fast for cord blood transplants and they remain disease-free, with no graft versus host disease and with full donor chimerism.

This story highlights our donors, the recipients, the collaborative ways of working with our NHSBT colleagues and transplant centres and the versatility of cord blood as a source of stem cells. There are two cord blood banks in England; the NHS CBB hosted by us and the Anthony Nolan CBB. We are supported by monies from DHSC for the NHS CBB and the British Bone Marrow Donor Registry. Together with the other UK unrelated donor registries they are a key part of addressing health inequalities. Patients from a minority ethnic background have 37% chance of finding an optimally matched donor from international registries compared to 72% chance for patients from a white ethnic background. Cord blood units are an important source of stem cells particularly for patients from ethnic minority backgrounds, usage has increased by 43% since 2019. We are diversifying the donations in the CBB by recruiting 40% of donations from mothersPatient story May 2023 CB for twins v2.docx from a minority ethnic background in our three recruiting hospitals. We have been doing this year on year following the 2014 recommendations from the UK Stem Cell Strategic Forum.

Authors: Alex Ross

Responsible Director: Gail Mifflin