

Stem cell harvesting – information for parents

This leaflet is for anyone considering stem cell harvesting and storage. It explains what is involved and the Royal Berkshire NHS Foundation Trust's position with regards to this procedure.

Stem cell harvesting is only performed by paediatricians (doctors specialising in the care of children) at the Royal Berkshire Hospital (RBH) when it is to benefit the health of a sick sibling. RBH is not licensed to collect stem cells for storage or for donation. You may ask a private commercial company to collect stem cells but this must be arranged with the Director of Midwifery before you give birth. The reasons for this are explained below.

What is stem cell harvesting?

Technology has been available in the UK since 1996 or haemopoietic (stem) cells to be collected and stored from the blood in the umbilical cord (the cord that attaches the baby to the placenta). Stem cells are cells from which other types of cells can develop and they can be used to investigate new possible treatments for a number of genetic conditions.

The procedure of stem cell harvesting involves removing blood from the umbilical cord after it has been cut from the baby. At least 80-100ml (about $\frac{1}{3}$ of volume in a canned drink) is needed if the stem cells are to be later transplanted into children; more is needed for transplanting into an adult.

Why harvest stem cells?

Occasionally, in a family where a child is suffering from leukaemia or some rare auto-immune diseases, the paediatrician (doctor specialising in the care of children) looking after the sick child may ask for stem cells to be collected from the cord of the newborn brother or sister. These cells are then tested for a 'match' to the sick child, and can be given if the match is close enough in order to possibly benefit the sick child's treatment.

Where is this being carried out and who benefits?

The National Blood Transfusion Service has a scheme where families can donate stem cells for banking that can be later transplanted into patients (not family members) who need this type of treatment. This is similar to bone marrow donations for patients with some cancers or leukaemia. This 'altruistic banking' is only available in a few hospitals, in the UK. The Royal Berkshire NHS Foundation Trust is not involved in any way in altruistic banking of stem cells. Hospitals in the UK who do offer this service include: Northwick Park Hospital in Harrow, Barnet General Hospital, Newcastle Royal Infirmary and the Mater Infirmorum Hospital in Belfast.

The National Blood Transfusion Service does not bank blood from newborn babies for their own or their family's later use. This service is only available from private commercial companies, which can be found using internet search engines.

How is the blood collected if organised privately?

Staff employed by the Royal Berkshire NHS Foundation Trust are not permitted to take samples for parents who wish to 'bank' stem cells as to do so would require an institutional licence from the Human Tissue Authority, and for all practitioners to have completed highly specific training.

Parents must not ask staff to 'help them' as if they do so they will be in breach of their employment contract and will be disciplined.

The blood has to be collected using a special kit supplied by the private commercial company, by a representative from the company who will then take the stem cells with them for storage. Storage of the stem cells can cost around £1,200 for a 20-year term.

Please note companies who offer storage facilities may offer a training session for partners to collect samples. At the RBH we do not allow partners to perform the collection of cord blood.

If you wish to privately arrange stem cell harvesting and are booked to have your baby at the RBH, please write to the Director of Midwifery who will be able to supply you with the necessary documentation required by the Trust.

Director of Midwifery Maternity Unit Royal Berkshire Hospital Craven Road Reading RG1 5AN

How effective is stem cell storage?

These companies often suggest that the stem cells have enormous potential for curing serious and/or life-threatening diseases.

What is the evidence?

The key word here is 'potential' as for many of these conditions, either:

1. there already exists an effective treatment, such as bone marrow transplants
2. there is no current research to suggest that stem cells might be an effective treatment option; or
3. Transplant of stem cells banked at birth is to say the least, unwise, as in some leukaemic conditions the gene predisposing (having a tendency) to the illness is present in stem cells.

Professional opinion

The Royal College of Midwives, American and European professional bodies for doctors and midwives and the Royal Berkshire NHS Foundation Trust **do not support or recommend commercial stem cell banking**. The Royal College of Obstetricians and Gynaecologists issued a document about stem cell banking during 2001, which was updated in 2006. The opinion is

Compassionate

Aspirational

Resourceful

Excellent

that there is little scientific evidence to recommend to families that banking stem cells for possible future use is valuable. The conditions that can be treated using stem cell technology are rare, and it is uncertain whether these cells would work for other conditions. In the USA, one commercial company has only released two stem cell donations for treatment, from a bank of 10,000.

Further information

- Visit the Royal College of Obstetricians and Gynaecologists website
<https://www.rcog.org.uk/en/guidelines-research-services/guidelines/sip2/>
- Visit the Royal college of Midwives website
<https://www.rcm.org.uk/sites/default/files/Joint%20Statement%20-%20UCB%20-%20aug%2011%20%286%29%20v2.pdf>

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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