

A close-up photograph of a woman with long brown hair and large hoop earrings, smiling and looking down at a baby she is holding. The baby is looking up at the woman. The background is softly blurred, suggesting an indoor setting with light coming from a window.

# NEX+ B10SCIENCES

Netcells Stem Cell Banking

Frequently asked questions





#### QUESTION

# 01



### What is stem cell banking?

Stem cell banking is a form of medical insurance.

When your baby is born, their umbilical cord blood and tissue is saved so that it can be used in the future, potentially, to help in the treatment of a number of blood or immune disorders – should your child ever need it.

Like all insurance, you hope you never have to use it.

But if you do, you know that you have given your child the instant possibility of treatment, rather than adding their name to a donor waiting list.

#### QUESTION

# 02



### What are stem cells?

We like to think of stem cells as the original building blocks of life. They are the cells that make up the embryo and develop into different cell types in your body.

Umbilical cord blood and tissue is an excellent source of stem cells, because: saving them at birth is easy, painless and a lot less invasive than harvesting stem cells later in life. These stem cells are usually discarded as medical waste, which means that collecting them does not come with any moral, ethical or religious concerns. Scientists believe that treatment results are better when you use stem cells collected at birth because they are at the very beginning of their life span and do not show any age-related changes.

QUESTION

03



### What is the difference between cord blood and cord tissue?

Your baby's umbilical cord blood is high in blood-forming stem cells, which can be used to help treat over 80 blood-related diseases.

These stem cells are used in the regeneration of bone marrow as they can replace diseased or damaged cells with healthy new cells. They make it possible to rebuild a person's blood and immune system.

Your baby's umbilical cord tissue contains the type of stem cells which form the connective tissues in our bodies, such as skin, bone, muscle, cartilage, nerve and fat. These stem cells hold considerable potential in treating a wide variety of medical and aesthetic conditions, such as treating potential in treating burns or wounds that are battling to heal. They are currently being used in a number of clinical trials.

While these cells are found in most of our tissues or organs, they can be difficult to harvest. Collecting them at birth is best because the cells are 'young' and have better regenerative potential. Cord tissue is easily collected with no pain or discomfort to you or your child.

QUESTION

04



### What are the steps to take if I would like to bank my baby's stem cells?

Register online via the easy-to-use online registration platform and pay for the registration fee.

We will deliver a collection kit to you and one of our client services teams will take you through the process to ensure you are properly informed.

You take the collection kit with you to the hospital for your gynaecologist or midwife to do the collection.

Members of selected schemes administered by Discovery Health can get up to 20% off the stem cell banking fee when they register to store their baby's stem cells with Netcells.



QUESTION

05



### Who can make use of the stem cells?

The stem cells are a perfect match for the baby that they were collected for. There is also a 25% chance that they will be a match for a sibling. As the stem cells belong to the family, they are stored exclusively for their use.

QUESTION

06



### Why should I bank my baby's stem cells?

Saving them at birth is easy, painless and a lot less invasive than harvesting stem cells later in life.

Your chances of finding a stem cell donor match are one in 100,000 and the odds drop much further for mixed race children or ethnicities that are underrepresented on stem cell registries.

The cord blood stem cells will be a perfect match for your baby, which means there is no risk of rejection.

Stem cells collected at birth are biologically younger than stem cells collected later in life and have better regenerative potential.

QUESTION

07



### Are there instances where the stem cells collected may not be useful?

If the blood disorder is hereditary, there is a chance that the cord blood stem cells may not be used as a viable treatment as the disease could be found in the stem cells as well. In these situations, you would look to use a sibling's stem cells, should they be a tissue match.

QUESTION

08



### Are there situations where the cord blood cannot be collected, what happens then?

There can be instances in which the cord blood cannot be collected, which can occur if there are any difficulties with the labour in which your gynaecologist or midwife needs to prioritise the health and safety of mom and/or the baby over collecting stem cells. Should this happen, you will be refunded the processing and storage fees that you have paid.

#### Situations in labour and/or birth that can cause low volume or no collection:

- Placental abruption
- Placenta praevia
- Eclampsia/pre-eclampsia
- Patients request for delayed cord clamping
- Maternal or foetal distress
- Premature deliveries
- Multiple births
- Small low birth weight babies/small placenta/calcified placenta
- Thin umbilical cord that makes milking of the cord difficult
- Maternal health conditions such as hypertension, or diabetes

QUESTION

09



### **Is anyone eligible to bank with the community bank?**

There are eligibility criteria for the community bank. This is because the South African Bone Marrow Registry needs to ensure that the cord blood sample is not potentially affected by anything which may be transferred over to a recipient in need during a stem cell transplant.

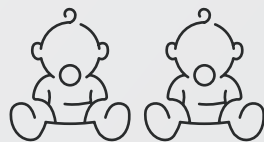
We need to look at the biological mother and fathers' and both their families, medical history to determine your risk for passing on a blood transmissible disease or an inherited blood, autoimmune, metabolic or neurological disorder to your child which may affect their cord blood.

We will screen the mother for any blood transmissible viruses she could have passed on to her child during pregnancy.



## QUESTION

# 10



### **If I am having twins/triplets do I need to store for each baby?**

We recommend that cord blood/cord tissue is banked separately for each child in the case of twins or triplets, however individual cases can be discussed with our Medical Director.

Non-identical twins and non-identical triplets are conceived from different eggs and sperm and are no more alike than siblings born at separate times. The chance of a tissue type (HLA match) between siblings is 25%. In these cases, it is advised to store for each baby as their tissue types are different. Having two units stored increases the likelihood of a useful match between family members and it is possible to combine smaller units should siblings be a match to ensure an adequate stem cell yield for transplantation if ever needed.

For identical twins or rarely identical triplets the fertilised egg divides at an early stage of development and the babies will have the same genetic information. However even in these cases, minor genetic changes may occur after conception and during foetal development. While identical twins are genetically identical, small genetic differences may exist at varying stages of development, causing a low but present risk of differences in disease profiles. For example, one twin may develop leukaemia or diabetes and the other does not.

However, if you request only one collection for cord blood and tissue for identical twins, it is possible to do so after discussing this with our Medical Director. Each case should be discussed with the Medical Director and your obstetrician and the implications of this explained to them. The obstetrician must be sure that this is a case of identical twins for this to be considered.

Either a single collection can be done from one twin with the option to use the unit for the other twin should the need arise or cord blood can be collected from each umbilical cord (in the case of a single placenta) and combined in one bag. This will lead to a situation of two genetically identical donors for a single unit and hence we recommend that in these cases the unit should be used for syngeneic transplant (i.e. a stem cell transplant only between the identical twins) and possibly not for other siblings. However, should one baby develop a genetic disorder requiring a transplant and the blood is combined, the transplant doctor may decide not to use the cord blood stem cells as they may contain the same genetic problem.

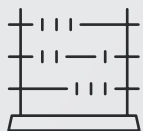
Cord tissue does not require as stringent HLA matching as cord blood so it is possible to only store one umbilical cord tissue unit for both babies.

Please note that collections for any multiple pregnancy has a higher risk of a lower volume with lower cell counts. This is because multiple pregnancies can often be premature, with smaller babies with lower birth weights and smaller placentas. In the case of emergencies where the mother's health or that of the babies is of utmost importance, the doctor may decide to abandon the cord blood collection procedure and safely deliver the babies.



QUESTION

11



### What are the odds of using cord blood stem cells?

Ideally, your child or their sibling's stem cells will never be needed and should be regarded as an extra form of medical insurance.

Studies in the United States of America have been done to calculate a lifetime probability (age 0 – 70) that a person will undergo a stem cell transplant:

- One in 435 people may receive their own stem cells
- One in 400 people will receive someone else's cells
- The total combined number of stem cell transplants is one in 217 people.

As more clinical uses become evident, these statistics are likely to increase the likelihood of use particularly for more commonly occurring medical illnesses.

QUESTION

12



### What happens if I have paid in full and the cord blood is unable to be sorted?

Next Biosciences will always refund the portion of the fee relating to the service that wasn't utilised. Additionally, Next Biosciences takes on the risk of processing, so if for whatever reason there are not enough stem cells for storage and you don't store, then you will receive a refund for the banking and storage fees.





#### QUESTION

# 13



### **Can one family donate their stored cord blood stem cells to family and friends?**

Cord blood stored with the private bank belongs to that family – the parents are the guardians of the cord blood until the child is 18 years old. They are entitled to store the cord blood for however long they like, and they are entitled to donate it to whoever they like. If it is found that a friend's child needs a stem cell transplant and that their child's stem cells are a match, they are allowed to donate the stored stem cells if they wish. They are not allowed to receive remuneration for the donation. South Africa has laws prohibiting the sales of organs, blood etc.

Before releasing stem cells, Netcells will insist on documentation from the transplanting doctor. If this is found to be legitimate and the stem cells are going to a registered doctor/hospital/institution, we will not have a problem releasing them to the transplanting clinic.

#### QUESTION

# 14



### **What is the procedure if the cells are needed?**

The cord blood stem cells are ready for use. The administering doctor will contact us, provide the relevant documentation and we will co-ordinate the transport of the cells to them.

Cord tissue stem cells will need to be cultured to whatever use they are needed for e.g. bone regeneration or skin regeneration etc. Those protocols are still in development and another laboratory who specialise in this may need to be used. However, that is all to be assessed in the future.

QUESTION

15



### What are the retrieval costs for cord blood and cord tissue?

With regards to cord blood, there are no retrieval costs. The stem cells are ready to be used.

With regards to cord tissue, the cells need to be extracted from the tissue and cultured. The cells may then need to be manipulated further depending on the treatment required. There will be a charge for this process, but it is unknown as treatments have not been developed yet.

Finding a match through the bone marrow registry is approximately R250,000.

The cost of buying the stem cells from overseas is anywhere between R300,000 and R1 million.

QUESTION

16



### Has Netcells released any stored units for treatment?

Netcells has released three stem cells units.

We released our first cord blood unit in March 2015 to treat an eight-month-old baby boy at Duke University in the United States of America.

We released our second cord blood unit in June 2016 to treat a three-year-old boy with cerebral palsy at Duke University.

We have had a few siblings who required stem cell transplants but these were unfortunately not a match. Our sister company Smart Cells in the United Kingdom has already released 21 cord blood units for the treatment for cerebral palsy, thalassaemia, leukaemia, brain injury, severe combined immunodeficiency disorder, sickle cell anaemia and encephalitis.

QUESTION

# 17



## How many stem cells are needed for a transplantation?

This depends on the number of stem cells stored in each individual unit and the size of the person who requires the transplant. The optimal dose is 10 – 20 million nucleated (CD45) cells per kilogram of body weight. The cell counts are different for every collection and depend on the volume of blood collected as well as other factors in pregnancy. Your baby's cell counts will be reported to you on your storage certificate.

The average number of stem cells collected from an average volume of 100 ml can usually treat up to a 50 kg person, but this varies. Some of the units contain large numbers of cells which would be enough to treat adults with a single unit and others are much smaller and are suitable for smaller children. In larger adults, often two matched units can be combined (either from a sibling or an unrelated donor).

Companies are developing techniques to expand (grow more) stem cells in a laboratory environment, and we hope this will become a reality soon.

It must be noted that lower stem cell counts are currently being used in clinical trials for cerebral palsy and brain injury, as these recipients are often small, low birth weight babies and children.





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