Media	Xagena Medicine	
	http://www.xagena.it/news/medicinenews_net_news/5e2020a9be8dde3fd1fdd77c4d3b9762.html	
Section	Medicine News	
Date	2006	

# Why is it so hard to store your baby's 'life-saving' stem cells?

Blood cells from your baby's umbilical cord can be stored to fight deadly diseases such as leukaemia and sickle cell. So why is it so hard to find a hospital that will do it? JUDY HOBSON investigates:

Claudia Harrison is expecting her second child this week. She has multiple sclerosis, and would like the stem cells from her newborn's umbilical cord so they can be used in the for treatment against any serious illnesses.

But there is little chance of that happening on the NHS, and she had to battle to persuade the authorities to allow her to do it privately.

## Case study

• I feared taking cord blood from my son was wrong

Stem cells are the building blocks of life — they can turn into different types of tissue in the body and are used to treat conditions that would otherwise need bone marrow transplants.

Such cells taken from umbilical cord blood — in a five to ten-minute procedure immediately after the baby is born — can be used to treat diseases such as leukaemia, anaemia, sickle cell and thalassaemia. Some experts even say they could eventually be used to help Parkinson's, Alzheimer's and MS.

Last week, it was announced that the Department of Health is to invest £4.2million in a 'bank' of cord blood stem cells, providing hope for families with genetic diseases. But it has since emerged that this £4.2million is not extra money, but simply the normal funding for the scheme for the next two years. And for couples such as the Harrisons, the scheme offers little or no hope.

This is because the NHS collects cord stem cells just for families with a high risk of a genetic disorder, such as sickle cell disease — and only then if their doctor considers it appropriate.

So far, 200 at-risk families have stored blood samples on the NHS. Of these, only 13 have been used to help treat a family member.

The NHS cord blood bank also takes altruistic donations — similar to when people give blood — but this is possible only at three hospitals in the London area: Northwick Park, Barnet General and Luton & Dunstable NHS Trusts.



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	http://www.xagena.it/news/medicinenews_net_news/5e2020a9be8dde3fd1fdd77c4d3b9762.html	
Section	Medicine News	
Date	2006	

#### **Treating life-threatening diseases**

The NHS cord blood bank has around 10,000 donations — most of the cord blood from the 600,000-plus births each year is disposed of, despite the fact new research has shown its value in treating life-threatening diseases.

Professor Colin McGuckin, professor of regenerative medicine at Newcastle University, is working on using umbilical cord stem cells to repair heart tissue.

"Our research shows that cord blood has amazing capacity to develop into a wide range of human tissues, including blood, blood vessels, liver and nerves," he says.

"It could not only have a huge impact on treating human disease, but also provide human tissue for drug development and testing, removing the uncertainty of whether new medications will have side-effects."

His team is the first in the world to produce embryonic-like cells from cord blood, and is developing a range of treatments for liver complaints that could be in use in five years.

Professor McGuckin believes prospective parents should be encouraged to bank their baby's cord blood, ideally for the general good through a public bank. But there are not the facilities nationally to make this possible.

# He sees nothing wrong if parents use a private bank "as long as it is properly run and accredited".

Some experts say the likelihood of a child needing their own stem cells is one in 20,000, but a Dutch study shows that over the course of a lifetime, the chances of a person requiring a transplant from their own cells is one in 400.

As for the question of whether these cells can be stored and remain useful, a study by the Indiana University School of Medicine found cord blood stem cells could be retrieved after at least 15 years.

An estimated 11,000 parents in Britain have paid to have stem cells taken from their baby's cord blood and frozen for possible future use — the ballerina Darcey Bussell and footballer Thierry Henry reportedly among them— even though, in many cases, there is no known risk of disease to their children. Globally, the figure is around a million.

Private cord stem cell banking is not cheap. Future Health Technologies in Nottingham — the only private bank in Britain accredited by the regulatory body, the Human Tissue Authority — charges £1,250 for processing plus £300 to store cells for 20 years.



Media	Xagena Medicine	
	http://www.xagena.it/news/medicinenews_net_news/5e2020a9be8dde3fd1fdd77c4d3b9762.html	
Section	Medicine News	
Date	2006	

But even if parents can afford to bank stem cells, they can face difficulty arranging to have it done.

Claudia Harrison, 33, a former financial consultant, first heard about cord blood stem cells when doing her own research into multiple sclerosis.

She asked her MS consultant about having her baby's cells removed and stored, but was told this would be considered only if she had leukaemia. Then the head of midwifery and the clinical director at her maternity hospital, the Princess of Wales, Bridgend, told her it was not hospital policy.

Her MP Madeleine Moon raised the issue in the Commons in March, and a few weeks ago Mrs Harrison received an e-mail from the deputy head of midwifery at the Princess of Wales to say she could pay to have her own private nurse extract and collect the blood.

"There doesn't seem to have been a change in hospital policy — I think it's only because I've been noisy," says Mrs Harrison.

So, when she goes into hospital to have her baby, her husband Neil will have to contact an agency nurse to come to the delivery room to extract the cord blood immediately after the birth.

Neil will also have to arrange for a courier to collect the sample and transport it to the private bank. Mrs Harrison's case is not unusual. The Royal College of Obstetricians & Gynaecologists has recently warned of the 'considerable logistical burden' on 'already over-stretched staff ', with collection of the blood being carried out during a particularly risky time for mother and baby.

George Macridis, the managing director of Future Health Technologies, estimates that fewer than one in three hospitals are allowing new parents to bank cord blood stem cells privately.

## 'An insurance policy'

However, in the public sector, the situation is slowly improving. The NHS cord blood bank — set up in 1996 and run by the National Blood Service — is considering establishing other hospitals as collection sites.

"As these treatments increase, the NHS will become more involved and the service enabling the banking of such cells will be expanded," says Rakesh Vasishtha, the bank's communications manager.

"We want to have a broader spectrum of tissue types on our register so we can provide an equal chance of treatment to everyone who needs it."

Such aims are laudable, but critics claim this is not enough. "Storage and processing is expensive, so it is understandable the NHS's public banking service is limited," says Mr Macridis.



Media	Xagena Medicine	
	http://www.xagena.it/news/medicinenews_net_news/5e2020a9be8dde3fd1fdd77c4d3b9762.html	
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"But many US states not only inform but encourage parents to consider banking. Here, the vast majority of parents get little or no advice from healthcare professionals and have no idea how useful the blood could be."

As Claudia Harrison says: "It is an insurance policy for me and my children. Every woman should have the right to that."

