



Parent's Guide to Cord Blood Banking

The blood in a baby's umbilical cord has the power to save lives. By choosing to bank this cord blood, parents could help their child, a family member or even a stranger. Many states in the US have passed laws requiring expectant parents to receive information about cord blood banking. This brochure is intended to address the educational requirements of these laws and to answer many questions that parents-to-be may have. Please ask your health care provider about your options for banking your child's cord blood.

Mission Statement

The primary mission of the Parent's Guide to Cord Blood is to educate parents with accurate and current information about cord blood medical research and cord blood storage options. The second mission of the Parent's Guide to Cord Blood is to conduct and publish statistical analyses on medical research or policy developments which could expand the likelihood of cord blood usage.

Q&A Important information about cord blood banking

What is "cord blood"?

The term "cord blood" is used for blood that is drawn from the umbilical cord and the placenta after a baby is born. Up until recently this afterbirth was discarded as medical waste. Cord blood contains stem cells which may be frozen for later use in medical therapies, such as stem cell transplantation or regenerative medicine.

What are cord blood stem cells?

The umbilical cord and placenta are rich sources of stem cells. These are different from both the embryonic stem cells in a fertilized egg or any stem cells obtained from a child or adult person. The stem cells in cord blood can grow into blood and immune system cells, as well as other types of cells.

How is cord blood collected and banked?

Cord blood collection does not cause harm or pain to either the mother or the baby. Blood is drawn from the umbilical cord after the baby is delivered and the cord is clamped and cut. The stem cells in cord blood remain viable for a couple of days at room temperature, providing sufficient time for the blood to be shipped to a laboratory in another city or state. At the laboratory the cells are processed and cryogenically frozen. Once frozen, stem cells remain viable for decades.

How are cord blood stem cells used today?

Today a growing percentage of stem cell transplant patients are receiving cord blood to cure over 70 diseases. Seventy percent of patients who need a transplant of blood-forming stem cells do not have a matching donor in their own family, and their physician must search public registries of donors. The National Marrow Donor Program (www.marlow.org) is dedicated to matching US patients with donors of either bone marrow or cord blood from anywhere in the world. There is a shortage of bone marrow

donors who match minority patients. Cord blood donations are very helpful to patients of minority or mixed heritage, because cord blood cells do not have to be matched as closely to the patient as cells from an adult bone marrow donor.

How may cord blood stem cells be used in the future?

Medical research is developing new therapies where stem cells help the body to repair itself, called regenerative medicine. So far, these therapies require the patient's own stem cells, not those from a donor. Children who have their own cord blood in storage may have more medical options later in life. Currently clinical trials for Cerebral Palsy and Type 1 Diabetes are being conducted using a child's own cord blood.

Suppose someone in my family has a disease which can be treated with cord blood?

If there is a chance that your baby's cord blood might be needed to treat a family member, then you may be eligible to receive free cord blood storage in a bank which offers a related donor program. Check our website for lists of these charitable programs. In order to qualify you will need to have the patient's doctor fill out an application.

What choices do I have for the storage of my child's cord blood?

You always have the choice to do nothing and let the cord blood be discarded after birth. The choice to save the blood for the family is usually open to any family that can afford the cost. The choice to donate to a public bank is only available to mothers who meet the eligibility criteria. Whatever choices you have and whatever decision you make, remember there is no single correct answer for all families. Only you know which choice feels right for you and your family.

Can my child use his/her own cord blood?

Most of the diseases for which children receive stem cell transplants, including most cancers and all genetic diseases, require that the cells come from another person, not the patient. Transplants among adults are split pretty evenly between transplants with the patient's own cells and transplants from a matching donor. At present, the odds that a person will have any type of transplant of blood-forming stem cells before age 20 are about 1 in 1700, whereas by age 70 the odds are 1 in 200. In the future, if cord blood is routinely used for regenerative medicine, then the odds of personal use could increase greatly.

What types of banks store cord blood?

There are two types of cord blood banks:

1. Public banks
2. Family banks

Public banks store donated cord blood for potential use by transplant patients. The blood is listed in a registry by its tissue type, and the donor remains anonymous. Over half the donations received by public banks are too small to qualify for long-term storage and are used for research or discarded. If you give your child's cord blood to a public bank, your donation may save a life, but you have no guarantee that you can retrieve the blood for use by your family later. Family banks store cord blood with a link to the identity of the donor, so that the family may retrieve it later if it is needed. The parents have custody of the cord blood until the child is an adult. The cord blood might someday be needed by the donor baby, or it could be used by a relative who is a close enough match to receive a transplant from the donor (typically a sibling).

What are the costs of banking cord blood?

Public banks do not charge parents for donating cord blood. Some public banks receive support from government grants, and they charge on average \$28,000 when a cord blood collection is released for a transplant. The costs of the transplant are charged to the patient's health insurance. Family banks charge parents between \$1000 and \$2000 to process and store cord blood privately. There is also an annual storage fee of about \$125.

Who is eligible to donate cord blood to a public bank?

In order to donate to a public cord blood bank, the mother must

1. Contact a public bank which either accepts donations at the hospital where she will deliver or accepts mail-in donations (see the list on our website),
2. Register before the third trimester of pregnancy, and
3. Pass a health history screening.

Note: Premature cord clamping is required.

Who is eligible to preserve cord blood in a family bank?

Except in cases of rare medical complications, most mothers are eligible for family (also known as private) cord blood banking. No matter where you live or where you will deliver the baby, you can obtain a collection kit to take with you to the hospital which includes instructions on how to ship the blood to the lab. If you do wish to bank privately, be sure to discuss your decision with your delivery team and check if there are any special requirements at the hospital where you plan to deliver.

What is the Parent's Guide to Cord Blood Foundation?

We are the only organization in the United States which maintains databases of both public and family (also known as private) cord blood banks. Since 1998, our website has provided parents with accurate medical information about cord blood banking options. Our founder, Frances Verter, PhD, is both a mother who lost a child to cancer, plus a scientist who studies and publishes on the topic of cord blood stem cell preservation. The information in this pamphlet was reviewed by the Scientific and Medical Advisory Panel of the Parent's Guide to Cord Blood Foundation. Our panel includes prominent doctors and scientists, as well as nurses and educators who work closely with expectant parents. The Foundation is a 501(c)(3) non-profit charity and your donations to our education mission are tax deductible.

Where can I find more information?

ParentsGuideCordBlood.org

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In memory of Shai.