

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

We are the only organization in the United States that 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 storage.

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 nonprofit charity and your donations to our education mission are tax deductible.

Where can I find more information?

ParentsGuideCordBlood.org

23110 Georgia Ave.

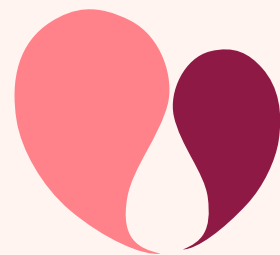
Brookeville, MD 20833

info@parentsguidecordblood.org

This space to be used for a sticker giving the name and address of your medical practice, state's department of health, or other organization.

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**Parent's Guide
to Cord Blood**
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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 U.S. have passed laws requiring expectant parents to receive information about cord blood banking. This brochure is intended to address the educational requirements of those 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 Parent's Guide to Cord Blood is dedicated in memory of

Shai Miranda Verter

Dec. 9, 1992 - Sept. 2, 1997

The primary mission of the Parent's Guide to Cord Blood is to educate parents with accurate and balanced 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 that could expand the likelihood of cord blood usage.



Important information about cord blood banking.

What is cord blood?

The term "cord blood" is used to describe the blood that remains in the umbilical cord and the placenta after the birth of a baby. Up until recently this blood was discarded as medical waste. Cord blood contains stem cells that may be cryopreserved for later use in medical therapies, such as stem cell transplantation or new emerging therapies.

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 the stem cells obtained from a child or an adult. 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. The cord blood is drawn after the baby has been delivered and the cord is clamped and cut. The 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 where the stem cells in the blood are processed and cryogenically frozen. Once properly frozen, stem cells remain viable for decades.

How are cord blood stem cells used today?

Today cord blood is often used as a substitute for bone marrow in stem cell transplants. More than 80 diseases are treated this way, including cancers, blood disorders, genetic and metabolic diseases. Seventy percent of patients who need a stem cell transplant do not have a matching donor in their own family, and their physician must search public registries of donors. The National Marrow Donor Program (BeTheMatch.org) is dedicated to matching patients with donors worldwide. There is a shortage of bone marrow donors who match minority patients. Cord blood donations are particularly helpful to patients of minority or mixed heritage because cord blood does not have to be matched as closely to the patient as stem cells from a 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 recover from various injuries and repair itself. Children who have their own cord blood in storage may have more medical options later in life. Therapy with cord blood has been proven effective in the treatment of cerebral palsy. Ongoing clinical trials are using cord blood to treat cerebral palsy and similar disorders, brain and spine injuries, autism, acquired hearing loss, and type 1 diabetes.

Can my child use his or her own cord blood?

Most of the diseases for which children receive stem cell transplants require that the cells come from another donor, not the patient. If a child has cancer or a genetic disease, they cannot be treated with their own cord blood. The odds that a child will have a transplant by age 20 are 1 in 2,500 for transplants from donors and 1 in 5,000 for transplants with their own cells. However, if cord blood is routinely adopted for the treatment of cerebral palsy or other emerging therapies, then the odds of using one's own cord blood would increase greatly.

What types of banks store cord blood?

There are two types of cord blood banks:

1. Public Banks

Public banks store donated cord blood for potential use by transplant patients. The blood is listed on a registry by its tissue type, and the donor remains anonymous. Most of 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 later for use by your family.

2. Family Banks

Family banks (also known as private) store cord blood exclusively for use by the baby's family. 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 (typically a sibling).

What are the costs of banking cord blood?

Public banks do not charge parents for donating cord blood. It costs about \$30,000 to obtain a cord blood collection from a public bank, and that cost is charged to the patient's health insurance. Family banks currently charge the family between \$1300 and \$2200 to process and store cord blood privately. Family banks also charge a \$125 annual storage fee.

Who is eligible to bank cord blood?

In order to donate cord blood, the mother must

1. Contact a public bank that either collects donations at the hospital where she will deliver or accepts donations using a mail-in kit (see the list on our website),
2. Register by the 34th week of pregnancy, and
3. Pass a health history screening.

Except in cases of rare medical complications, most mothers are eligible for family banking. For all forms of cord blood banking, be sure to discuss your decision with your healthcare provider, who may be required to take collection procedure training. If the parents have been given a collection kit, they must remember to bring it to the hospital.

Suppose someone in my family has a disease that 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 that 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 storing 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.



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