2011 SENATE HUMAN SERVICES

SB 2215

2011 SENATE STANDING COMMITTEE MINUTES

Senate Human Services Committee
Red River Room, State Capitol

SB 2215
January 25, 2011
Job Number 13353

☐ Conference Committee

Committee Clerk Signature

Explanation or reason for introduction of bill/resolution:

To provide for umbilical cord blood donation information.

Minutes: Attached Testimony

Margaret Sitte, introduces SB 2215 with FN attached. She is from District 35 in Bismarck. (Attached Testimony #1).

Chairman J. Lee states that there is a FN that indicates $11,000 in expenditures, in this biennium, (2011-2013) with general funds and $3000 in the following biennium, (2013-2015).

Margaret Sitte presents testimony and refers to handouts attached to Testimony #1.

Senator Dever states it is not a mandate. He asks, "Why is it necessary, could it happen now?"

Margaret Sitte states it could happen now. She states, in fact, I have a couple of brochures. I called a local OB-GYN and asked if she had brochures, and she did, but they were not readily available. Patients aren't actively being told or subject is not being pushed. People are not being made aware of it.

Chairman Lee states she has a general policy of being opposed to "specific disease and condition" legislation, due to things becoming obsolete, over time. I see this in a different way because this is not dealing with someone who has a medical condition, that needs to be treated, but rather is a "preventative measure" in saving the stem cells for potential future use. I am feeling confident, that the physicians, who are dealing with the pregnant woman, would want to offer this opportunity to them.

Margaret Sitte states what she thinks is the most dramatic. She has a nephew with Type 1 diabetes. Some of this "umbilical cord" research is focusing on a cure for Type 1 diabetes. Another major disease, that is being treated, is cerebral palsy. We need to let people know to save this blood cord. People are not even aware that they can donate to a private "umbilical blood bank." There are so many facilities out there. I think it is a

matter of common sense, that the state would be proactive, in this regard. I feel this issue deserves widespread publicity.

Senator Mathern asks, "If someone wanted to donate today, do we have a system, operating right now, at local hospitals?

Margaret Sitte states she has talked to someone who donated and she contacted one of these national sites (public cord blood bank) and they sent out a packet of materials. It tells people in the delivery room what to do. The "umbilical cord blood" is just fine at room temperature, even for a couple of days and then they provide mailing packet and sent off. In some cases, it is frozen immediately, but other times, it is sent off. Everything is paid for by the "public blood cord bank" that is accepting the donation. They would like some lead time, to send the packet out, on behalf of that mother. I have not heard of a single objection from an OB-GYN doctor, here in Bismarck, that I talked with, from doing this. They understand how important it is.

Senator Lee states, "It also appears, if you were donating to "Family Cord", there would be some significant costs to the family but it would be a personal choice since it is an option." Do you feel, there would be a lot of people that are going to do it, if there, is that cost factor involved for them?

Margaret Sitte states that she doesn't think we would have a lot of people doing this. However, knowing how things come down in cost and knowing how fast medical technology is changing the way we live, I do see a chance, where this could be very practical. With bone marrow transplants and other stem cell transplants, you need a 6-6 markers that have to match but with "umbilical cord blood", only 4 out of the 6 markers have to match. It is far more useable by many other people. Online, it states, that there is an 86% chance, that any one of us, could find a match for those, who are White Caucasian. For those of mixed race, that drops to 40 some percent. There are certain sectors, of our society, that are not well informed about this. Then their chances, of getting transplants and help, are far less. This is aimed, at people of all races and all socio-economic strata's, of finding out about this.

Senator Lee states she certainly supports the concept. "Why wouldn't you have confidence, that the physicians would be equally excited about the options, that are available through this?" "Why would they not, as part of their general practice, be doing this, by passing a law, saying you should do this? This is a "maybe bill", not a mandate.

Margaret Sitte states she doesn't see that this has been done. In talking to the young woman I know, that are having babies, they were not even made aware of it.

Senator Berry, co-sponsor, states that he chose not to testify but rather serve as an information source to the committee in our discussions. The issue, as **Senator Sitte** mentioned, is very true. Currently, it is something that does not get discussed. Although, there is tremendous ongoing research and the enhancements that have been made, are outstanding. It has not come down to the clinical level yet. Many times, things have to work their way, from the laboratory to the research center, clinical level and then the clinician.

The reality is, it doesn't get put into place, in a busy office practice in the course of a day. Could they do it, yes? Of the 3 available sources, we have for stem cells, bone marrow, purple blood and the umbilical cord. Studies are clear, that the umbilical cord cells, are much less likely, to cause the graph vs. host, be diseased. It can be very devastating. Also, they are less likely to have the antigens on them, that a recipient may recognize as foreign and then attack and destroy them. Not only does the "host", the individual that receives the cells, not attack, the cells that they are getting. These cells do not attack the individual. It is a win- win, in that respect.
We need to raise the level of awareness. **Senator Berry** states, "It is a sound practice medically."

Senator Lee asks, "What are the physicians going to do differently because we can tell them that they can?" They already can. That is my point.

Margaret Sitte states that is why she wrote it the way she did. The state would produce and then distribute this brochure, at a cost of $14,000, in the next biennium. The awareness part of this bill is so important.

Christopher Dodd, supports bill SB 2215, representing **ND Catholic Conference**. He states that we got into this because the Church opposes "embryonic stem cell" research. The criticism stated, that the Church was opposed, to science and healthcare. We are the largest, not for profit healthcare provider in the country and that is not true. It made us aware; we need to be aware, what is happening on "alternative stem cell" research.
I think, if the state can do anything, to get the original information out, at a low cost, then I think we need to pursue it.

Bruce Levi, representing the ND Medical Association. He states he has talked to OB/GYN's, particularly Dr. Sherry Orser at MedCenter One, in Bismarck. Providing (Attached Testimony #2) from the **ACOG (American Congress of Obstetricians and Gynecologists).** In terms of encouraging physicians and to provide physicians with this information, in their own national specialty society, they are not necessarily encouraging it. ACOG does a pamphlet as well. In talking with Dr. Orser, they do not do this with every patient. AGOG does not take a position "for or against" cord blood banking. They recommend that physicians disclose, and that there is no reliable estimate, of a child's likelihood of using his/her own saved "cord blood" later. The bill has a provision, that ND law encourages, not only that you "may do this" but also "if you do this, if you are acting in good faith", that someone can't come back at you. From that perspective, it is important to point that out in SB 2215. Dr. Orser does mention that they talk about "cord blood" retrieval, if it is brought up, in the discussion.

Senator Dever states that in the 2005 session, a bill was passed, that had to do with asthma and epipens, that relieves school nurses, from the liability of dealing with this. The feeling is that, the liability issue, it is not communicated. How best can we do that?

Bruce Levi states that the general education, that goes out about what the new laws are, is the best way to educate people. We need to provide encouragement "with immunity provision" to healthcare providers.

Senator Lee states that it appears, not only to be the general public but more importantly the healthcare providers, who need to be, as well informed as possible.

Senator Berry states that the best place to bring up this subject is in the initial visit or on a questionnaire and they check it and then it is talked about.

Senator Lee asks, "We need to reach providers, how do we do this?"

Bruce Levi states that it boils down to, "what is best for the patient, what's best for patient care and what the standard of care is."

Renae Stromme, parent, states she heard about the program at a maternity store about private entities, due to money making opportunity, not necessarily public portion of it.

Opposition: None
Neutral: None

Closed Hearing on SB 2215.

2011 SENATE STANDING COMMITTEE MINUTES

Senate Human Services Committee
Red River Room, State Capitol

SB 2215
January 31, 2011
Job #13747

☐ Conference Committee

Committee Clerk Signature TA Monson

Explanation or reason for introduction of bill/resolution:

To provide for umbilical cord blood donation information.

Minutes:

Senate Human Services Committee continues discussion on SB 2215.

Senator Berry moves for a **DO PASS and rerefer to appropriations.**

Seconded by **Senator Mathern.**

Discussion ensues that it will need to go to Appropriations. The FN is for $11,000.

Senator Mathern asks, "Why would not everyone use the "public bank"?"

Senator Berry states that maybe they would use this for "family use".

Discussion ensues stating that "public bank" can be used for more than one individual. That is part of the education. We are all going to benefit from this information. It is informational purposes. There is already information but it is not getting out to the public. Why are there postage and printing costs? It could be emailed to facilities and then be printed off "in house". **Senator Mathern** states that a lot of these bills are giving further emphasis. Shouldn't all medical clinics talk to someone about mental illness, eating disorders, and cord blood? What medical provider would say, "We are not going to notify our patients of the latest thinking?" **Senator Lee** states, "none". **Senator Mathern** states that, they don't have the time or resources, to actually do it. These bills, are essentially saying to the medical providers", we want you to be doing more than you are doing". **Senator Berry** states that, in this situation, the idea of a "prenatal packet" would be a good idea. Women are highly motivated and go through all the information they are given. It would be a "good return on investment". **Senator Lee** states, more media attention needs to be paid to this. She states that SB 2215 would have a large effect on the health and well-being of citizens of ND.

Roll call vote 5-0-0. **Motion Carried.** Carrier is **Senator Berry.**

Date: 1-31-2011

Roll Call Vote # _____

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. 2215

Senate **HUMAN SERVICES** Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken: ☒ Do Pass ☐ Do Not Pass ☐ Amended ☐ Adopt Amendment

☒ Rerefer to Appropriations ☐ Reconsider

Motion Made By **Sen.** Berry Seconded By **Sen.** Mathern

Senators	Yes	No	Senators	Yes	No
Sen. Judy Lee, Chairman	✓		**Sen. Tim Mathern**	✓	
Sen. Dick Dever	✓				
Sen. Gerald Uglem, V. Chair	✓				
Sen. Spencer Berry	✓				

Total (Yes) 5 No 0

Absent 0

Floor Assignment Sen. Berry

If the vote is on an amendment, briefly indicate intent:

FISCAL NOTE

Requested by Legislative Council
01/18/2011

Bill/Resolution No.: SB 2215

1A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2009-2011 Biennium		2011-2013 Biennium		2013-2015 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures			$11,000		$3,000	
Appropriations			$11,000		$3,000	

1B. **County, city, and school district fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

2009-2011 Biennium			2011-2013 Biennium			2013-2015 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts

2A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

This bill provides for umbilical cord blood donation information. Requires the Department of Health to prepare a pamphlet that includes seven areas of information relating to umbilical cord blood donation.

B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Section 2 requires the Department of Health to prepare a pamphlet that includes information regarding umbilical cord blood donation, including medical processes; medical risks to the mother and child; current and potential future medical uses, risks and benefits to the newborn child, mother and biological family; current and potential future medical uses, risks and benefits to individuals not biologically related to the newborn child or mother; costs incurred by the patient; options for ownership and future use of the donated material; and the average cost of public and private umbilical cord blood banking. Costs associated with this include professional fees (contractor), printing and postage (distribution).

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*
   A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

   B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

2011-2013
Postage: $500 - required for mailing the brochure.
Printing: $2,500 - required for printing the brochure.
Professional Fees: $8,000 - includes amount for a contractor and graphic artist (professional service agreements) to develop and design the brochure - $50/hr x 150 hours for contractor and $50/hr x 10 hours for graphic designer.

2013-15

Postage: $500 - required for mailing the brochure.
Printing: $2,500 - required for printing the brochure.

C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

Funding for this project is not included in the Department's appropriation bill (HB 1004).

Name:	Kathy J. Albin	**Agency:**	Health
Phone Number:	328.4542	**Date Prepared:**	01/22/2011

REPORT OF STANDING COMMITTEE

SB 2215: Human Services Committee (Sen. J. Lee, Chairman) recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (5 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2215 was rereferred to the **Appropriations Committee**.

2011 SENATE APPROPRIATIONS

SB 2215

2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee
Harvest Room, State Capitol

SB 2215
February 8, 2011
Job # 14188

☐ Conference Committee

Committee Clerk Signature Rose Laning

Explanation or reason for introduction of bill/resolution:

A bill to provide for umbilical cord blood donation information.

Minutes: See attached testimony - #1 – 2.

Chairman Holmberg called the committee hearing to order on SB 2215.

Becky J. Keller - Legislative Council; Sheila Peterson - OMB.

Senator Margaret Sitte, State Senator, District 35
Bill Sponsor
Testimony attached - # 1
Reading from testimony – Gave an update in the stem cell research. "Cord blood banking is a procedure in which cord blood is taken from a baby's umbilical cord shortly after delivery and preserved for possible future use in a stem cell transplant." There have been many diseases that are being treated with the stem cells from the umbilical cord blood. These stem cells are less prone to rejection than the other types of stem cells and they don't cause graft-versus-host disease. They are not rejected by the bodies.

By passing this bill, North Dakota would provide a brochure for physicians to include in the pregnancy packet each new mother receives. The cost of $11,000 is miniscule compared to the benefits of providing this crucial information.

Senator Christmann asked if anything had to be paid to the hospitals.

Senator Sitte relayed a situation where a woman found out about umbilical cord blood in a maternity store and said that her doctors never told her anything about it. Twenty states are now including this information for their young mothers.

Chairman Holmberg asked if there was a bank in MN because he has a grandson going to be born in Minneapolis this month. **Senator Sitte** told him he could pay for this insurance for his family.

Senator Warner said he was surprised you can just drop this in the mail. I would have thought that it would have had to be cryogenically frozen.

Senator Sitte said that the stem cells are fine for two days at room temperature. She also commented on a letter that was also handed out to the committee from Maria Spencer of the National Marrow Donor Program. She thinks that we need to do more because the public banks are getting overrun with donations. She wants ND to start our own umbilical cord blood bank. Someday in the future we may decide to do that in conjunction with the medical school.

Maria D. Spencer, Director, Legislative Relations, National Marrow Donor Program, Washington, DC
Written testimony in favor of SB 2215 attached - # 2.

Senator Wanzek: How long can this be banked?
Senator Sitte: Once these cells are frozen, it can be there for years. This research is 20 years old so they don't have anything long-term to tell you.

Senator Erbele: The $11,000in the appropriation, is that just a brochure that will be included in a pregnancy kit? What are we buying for $11,000? How many brochures and how long will that money last?

Senator Sitte: Some states are just referring people to the website online and this really provides all the information that we would need to provide. We debated in committee and thought people might not go online. For $11,000, it doesn't cost that much to put something in every packet. Then people could look at the information and then discuss it with their doctor.

Kim Mertz, Department of Health, Director of the Division of Family Health
Testified in favor of SB 2215. No written testimony.

She gave information on the brochure – The $11,000 is for development of the ND brochure. It takes a lot of research, money to have someone draw up the brochure, money to have it printed and money to have it mailed. If we use something that has already been developed from a national level, that will drastically reduce the cost. We could put that as a link to our website. There are national brochures that you can purchase that you can put a ND stamp on, so if we're allowed to use an already developed brochure, that would reduce the cost. However, the language in the bill currently says "a ND developed brochure."

Chairman Holmberg Part of the discussion that this committee will have when we take this bill up is that the passage of the bill is not going to generate an appropriation because we don't have the Department of Health budget. That is over in the House. The fiscal note is an $11,000 appropriation. When we get the Health Department bill, then we will have to determine whether the money is added in or just how it's funded. This tells us it will cost $11,000 and this committee can pass this bill if they choose because we won't touch the state budget on this bill. That will be handled later.

Senator Bowman: Is there any data available, as to the long term benefits for cost savings to the medical profession because if this works like it's supposed to work, in 25 years, there should be huge savings in medical costs.

Senator Sitte: On page 2 of my testimony, para 3. "Newly published data shows that the lifetime probability of needing a stem cell transplant is much higher than previous estimates

indicate. The new research says that as many as 1 in 200 people will receive a stem cell transplant during their lifetime." They don't know how far this research is going to go. It could be tremendous savings.

Senator Warner: (to dept) Some of these are going to be commercial enterprises, is there a conflict between your dept endorsing a commercial project?

Kim Mertz: When you purchase something like a national brochure, many times that brochure's name and the publishing company is on there, and then you are able to endorse that specifically for North Dakota. We would be very careful in that case saying we don't endorse any type of blood banks. There is not one in North Dakota and we don't endorse any throughout the country. If you develop something that is ND specific, again the cost is a little bit higher for that, but then that alleviates all the chances that you would have of endorsing any blood bank nationally.

Senator Warner asked if they list the blood banks and put a disclaimer at the bottom saying these are the ones that provide that service but we do not endorse any particular one of them.

Kim Mertz said that is correct. We would never endorse anything. We simply provide information. We give a live link in our brochure or things on our website so people can go and find that information on their own, but again we always say that we're not endorsing.

Senator Sitte: That is exactly what the parent's guide to Cord Blood Foundation does is that this is a foundation put together by all the public cord banks so that people can contact one location and they'll tell you which one of the blood banks in your area is looking for samples.

Senator Wanzek said it seems the need to have that information out there is probably accentuated when you consider the fact that there are so many limited opportunities to actually do this.

Senator Krebsbach asked if there is a possibility in the future that the local blood banks could be the repository for these types of donations.

Senator Sitte: This technology is far more complex than that. It's really quite expensive for us to have our own blood bank in this state. It would be ideal.

Chairman Holmberg closed the hearing on SB 2215.

Senator Warner moved Do Pass.

Senator Krebsbach seconded.

A Roll Call vote was taken. Yea: 13 Nay: 0 Absent: 0

Goes back to Human Services Committee and Senator Berry will be the carrier.

Date: 2-8-11
Roll Call Vote # 1

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. ~~2315~~

Senate Appropriations Comittee Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken: ☒ Do Pass ☐ Do Not Pass ☐ Amended ☐ Adopt Amendment
☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By Warner Seconded By Krebsbach

Senators	Yes	No	Senators	Yes	No
Chairman Holmberg	✓		Senator Warner	✓	
Senator Bowman	✓		Senator O'Connell	✓	
Senator Grindberg	✓		Senator Robinson	✓	
Senator Christmann	✓				
Senator Wardner	✓				
Senator Kilzer	✓				
Senator Fischer	✓				
Senator Krebsbach	✓				
Senator Erbele	✓				
Senator Wanzek	✓				

Total (Yes) 13 No 0

Absent 0

Floor Assignment Sen. Berry Human Services Carrie

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2215: Appropriations Committee (Sen. Holmberg, Chairman) recommends **DO PASS** (13 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2215 was placed on the Eleventh order on the calendar.

2011 HOUSE HUMAN SERVICES

SB 2215

2011 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

SB 2215
March 9, 2011
Job #15138

☐ Conference Committee

Committee Clerk Signature Vicky Crabtree

Explanation or reason for introduction of bill/resolution:

Provide for umbilical cord blood donation information.

Minutes: See attached Testimony #1

Chairman Weisz: Opened the hearing on SB 2215.

Sen. Margaret Sitte: From District 35 in Bismarck introduced the bill and testified in support of it. (See Testimony #1.)

Christopher Dobson: Executive Director of the ND Catholic Conference testified in support of the bill. The ability to use umbilical cord blood has been around for some time, but it is something that is just now known and it is a shame. Our awareness and concern about the issue really comes from our opposition of embryonic stem cell reach. As we were opposing embryonic stem cells we were aware of all of the research about so called adult stem cells; one of them which is umbilical cord blood. The Catholic health agencies have taken up the cause to spread the word about what it happening in stem cell research and particularly what can be done. So you have this (inaudible) insurance with umbilical cord blood. We strongly support this bill.

NO OPPOSITION

Chairman Weisz: Closed the hearing on SB 2215.

Chairman Weisz: Let's look at this one. It just has a fiscal note so it doesn't have to go to appropriation because it is under $50,000. This is a fiscal note not an appropriation.

Rep. Porter: I move a Do Pass on SB 2215.

Rep. Schmidt: Second.

VOTE: 12 y 0 n 1 absent – Rep. Kilichowski

Bill Carrier: Rep. Schmidt

Date: 3-9-11
Roll Call Vote # 1

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2215

House HUMAN SERVICES Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken: ☒ Do Pass ☐ Do Not Pass ☐ Amended ☐ Adopt Amendment

☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By Rep. PORTER Seconded By Rep. Schmidt

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN WEISZ	✓		REP. CONKLIN	✓	
VICE-CHAIR PIETSCH	✓		REP. HOLMAN	✓	
REP. ANDERSON	✓		REP. KILICHOWSKI	A	
REP. DAMSCHEN	✓				
REP. DEVLIN	✓				
REP. HOFSTAD	✓				
REP. LOUSER	✓				
REP. PAUR	✓				
REP. PORTER	✓				
REP. SCHMIDT	✓				

Total (Yes) 12 No 0

Absent 1

Floor Assignment Rep. Schmidt

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2215: Human Services Committee (Rep. Weisz, Chairman) recommends **DO PASS** (12 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). SB 2215 was placed on the Fourteenth order on the calendar.

2011 TESTIMONY

SB 2215

#1

Testimony on SB 2215

January 25, 2011

Madam Chairman and members of the committee,

I am Senator Margaret Sitte from District 35 in Bismarck.

The bill before you will bring awareness to one of the most impressive medical discoveries of our time: stem cells in umbilical cord blood. Umbilical cords have traditionally been discarded as medical waste, but medical discoveries in the past two decades have been phenomenal.

The first disease treated using umbilical cord blood stem cells was in 1988. By 2000, 20 diseases were being treated. Currently more than 85 different diseases are being treated including the following: more than 26 different types of cancer, 15 different auto-immune diseases, three different neural degenerative diseases and injuries and 10 different anemias and blood conditions.

In fact, umbilical cord blood stem cell transplants are less prone to rejection than either bone marrow or peripheral blood stem cells, probably because the cells have not yet developed the features that can be recognized and attacked by the recipient's immune system. Also, because umbilical cord blood lacks well-developed immune cells, there is less chance that the transplanted cells will attack the recipient's body, a problem called graft versus host disease.

Both the versatility and availability of umbilical cord blood stem cells makes them a potent resource for transplant therapies.
Here's what Shakila Khan, M.D., wrote on the Mayo Clinic website www.mayoclinic.com. "Cord blood is a rich source of stem cells, the cells from which all other cells are created. Cord blood banking is a procedure in which cord blood is taken from a baby's umbilical cord shortly after delivery and preserved for possible future use

in a stem cell transplant. Collecting a baby's cord blood poses few, if any, risks to either mother or baby. If the cord blood isn't collected for preservation or research, it's simply discarded. Donating cord blood to a public cord blood banking facility is a tremendous opportunity to help others. Cord blood transplants from unrelated donors can be used to treat many conditions, including leukemia and various metabolic problems."

Yesterday, I received a call from a non-profit agency that promotes umbilical cord blood donations. The Parent's Guide to Cord Blood Foundation publishes the attached brochure online, so we could use their information as the basis of our state brochure. I have printed part of their website for you in a more readable font.

Family Cord is an example of a private cord blood bank and I have included some of their information as well.

I urge you to help inform the young women of our state of a powerful new medical tool, the stem cells in the umbilical cord blood.

1. Why bank cord blood?
Birth is a one-time opportunity to help society by donating your child's cord blood to a public bank. Cord blood contains stem cells that can save lives. Patients requiring a stem cell transplant will receive cells from one of three sources: bone marrow, circulating blood, or umbilical cord blood. The first two exist in all healthy adults, but cord blood can only be harvested and stored at birth. The section on cord blood transplants explains that it is easier to match transplant patients with cord blood than with the two sources of adult blood. Hence, establishing public banks of cord blood from donors with diverse tissue types can save many lives.

Birth is also a one-time opportunity to help your own family by saving your child's cord blood. Transplant patients recover better when they receive stem cells from a related donor, instead of an unrelated donor. In the future, if there are regenerative medicine advances which can repair the body with the patient's own stem cells, then children whose parents saved their cord blood will have better access to those treatments.

There is virtually no reason not to save your child's cord blood. The only cautionary remarks which can be made about cord blood banking is that the cord should not be clamped too soon after birth.

2. Why doesn't everybody bank cord blood?
Because it costs money. Whereas a bone marrow registry is based upon a computer data base of potential donors, a cord blood bank is based upon a laboratory where staff process the cord blood, freeze it in liquid nitrogen, and monitor the freezers.

Only a limited number of institutions have the funding to maintain public banks which take donations for free. This web site has a page which explains the types of cord blood banks, and another which tells you how to find a public bank in the US to accept your donation.

For most parents, cord blood donation is not an option because the number of locations served by public banks is very limited. In that case, parents have to decide if they want to and can afford to pay a private bank to process the cord blood and preserve it for the family.

Fortunately, there are financial assistance programs to help families which have a case of medical need, where a family member is at risk of needing a stem cell transplant.

3. Cord Blood Transplants (CBT)
Advantages of Cord Blood Transplants *versus*
Bone Marrow Transplants (BMT) or Peripheral Blood Stem Cells (PBSC)

- Harvesting umbilical cord blood poses no risk to mother or child, whereas a bone marrow donor must undergo a surgical procedure.
- Stored cord blood is ready for use as soon as it is needed, whereas the process of contacting and testing donors listed in a registry takes weeks to months.

- For transplants, the primary advantage of cord blood stem cells over stem cells from adults is that they cause much less graft versus host disease (GvHD). In order to safely transplant adult stem cells, the patient and donor must match over at least 10 of 12 tissue types called Human Leukocyte Antigens (HLA), or 83% HLA match. By comparison, medical outcomes are just as good with cord blood that has a 4 out of 6 or 67% HLA match. (Reference: V Rocha, et al, 2000; NEJM 342:1846)

Disadvantages of CBT *versus* BMT or PBSCT:

The main disadvantage of cord blood transplants is that they take at least a week longer to "engraft", which means repopulate the patient's blood supply so that cell counts reach minimum acceptable levels. The longer engraftment time is a risk because it leaves the patient vulnerable to a fatal infection for a longer time.

- A typical cord blood collection only contains enough stem cells to transplant a large child or small adult. This web site has a page explaining the optimum transplant dose. At one time it was believed that cell dose limitations restricted the use of cord blood transplants to children. In recent years growing numbers of adults are also receiving cord blood transplants, either by growing the cells in a lab prior to transplant, or by transplanting more than one cord blood unit at a time. More information about these trials is available on the web page about Research on Cord Blood Transplants.

The web page on Odds of Use reviews the probability that an individual in the United States will have a stem cell transplant over the course of a lifetime.

5. Your Heritage and Cord Blood

- A successful transplant requires that the patient and the donor have matching HLA types.
- HLA types are inherited, half from your mother and half from your father. The probability that two siblings will have a perfect 6/6 match desired for a bone marrow transplant is 25%, whereas the probability that they will have the 4/6 match required for a cord blood transplant is 39%.
- Given that HLA types are inherited, you certainly expect that your relatives will match you more closely than a stranger.
- In fact, HLA typing tends to run in ethnic groups, so that patients are more likely (but not guaranteed!) to find a match among donors of the same ethnic background.
- Africans have more genetic diversity than any other ethnic group. The NMDP estimates that even if the number of African-Americans in the United States who registered as adult donors were doubled or tripled, they still could not match all the African-American patients.
- Another group which is not well represented in the registry of adult donors is multi-racial Americans, most of whom are not yet adults.

Cord blood holds hope for all patients with hard-to-match HLA types, because cord blood transplants only require a 4/6 match, not a perfect match.

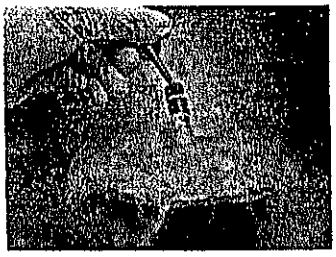
FamilyCord
a California Cryobank Company

For a personal consultation, please call:
800-490-CORD (2673)
To speak with a Cord Blood Educator

Cord Blood Stem Cells Overview

Stem cells have the power to save lives

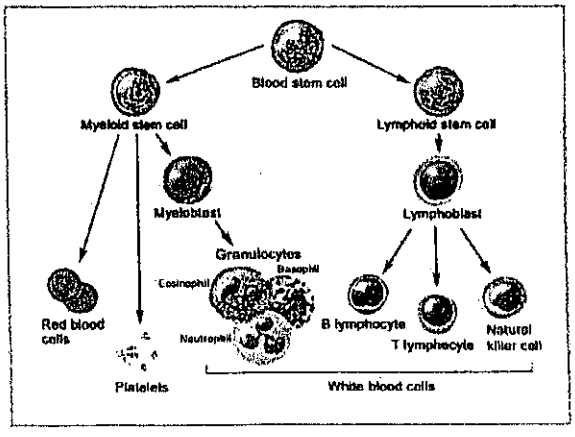
Stem cells are the "building blocks of life" that regenerate and form all other tissues, organs, and systems in the body. Ongoing stem cell research is increasing scientific understanding about how healthy cells develop and replace damaged cells.



Given that cord blood stem cells have the unique ability to develop into other cell types, these stem cells hold the potential for treating some of the most common diseases. Initially, cord blood stem cells were primarily used to treat blood cancers, but research scientists are now exploring treatments for a wide variety of diseases including cerebral palsy, diabetes, heart disease, stroke, and spinal cord injury.

Umbilical cord blood offers a perfectly natural, controversy-free method of acquiring stem cells. Until recently, the umbilical cord and its stem cells were discarded as medical waste. Today, doctors worldwide recognize that cord blood stem cells can aid in the treatment of numerous diseases by helping to generate healthy new cells and tissue.

The value and benefits of stem cells found in cord blood are clear; storing cord blood ensures that should that need ever arise, you will have a source of stem cells that is an exact genetic match to your baby, with no risk of rejection.



There is also the strong possibility that the stem cells will be a match for siblings. Clinical studies demonstrate that stem cells transplants are more successful when the stem cells come from a family member rather than from a non-related donor.

Private storing your cord blood means it will be available when you and your family need it, allowing treatment to begin almost immediately without losing valuable time searching for a matching donor.

Cord blood stem cells are not only valuable now, but they are also considered one of the most promising medical treatments of the future. Published research studies estimate 1 in 217 children will have a medical condition that may be treated with stem cells during their lifetime.

For additional information on cord blood banking, please contact a cord blood educator online or at 800-490-CORD (2673)

Step 1 of 3

Select Storage Package ***(Renewal storage packages available at the then current rate.)***

Select One	Years of Storage	Annual Storage Cost	Total Storage Cost
○	1	$125	$125
○	3	$125	$375
◉	5	$115	$575
○	10	$100	$1,000
○	20	$90	$1,800

One Time Fees	Item	Cost
◉	Enrollment Fee (Collection kit provided free upon enrollment)	$150
◉	Professional Medical Courier Fee	$150
◉	Processing Fee (Includes FDA & AABB recommended testing)	$1,550

Discounts & Promotions

Select One	Description	Discount
◉	Single Baby	$0
○	Military (ID Required)	$400
○	Student (ID Required)	$400
○	Healthcare Provider (ID Required)	$500
○	Twins (Total $1000, $500 each child)	$500
○	Triplets (Total $1800, $600 each child)	$600
○	Repeat Cord Blood Client	$600
○	Promotion Code (e.g. H0209EXE)†	N/A

† Discounts and promotions may not be combined with any other offer, they will be applied at the time of processing.

Total Fees **$2,425**

Gift Card(s)

Card number(s)

If FamilyCord cannot store the cord blood for any reason, client will only pay the $150 enrollment.

Select Payment Option

Select One	Option	Payment Details
○	Payment in Full	• **$150** due at enrollment. • Remaining balance of **$2,275** will be charged on credit card when cord blood is received and processed. Credit card will be charged unless check has been received prior to processing.
○	12-Month Payment Plan (available for all storage)	• **$150** is due at enrollment • **$200** is due when cord blood is received and processed (Initial Payment) • Remaining balance paid monthly and includes a $5 per month administrative fee 12-Month Plan / 5 Year Package **$194.09 per month for the remaining 11 months**

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
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.

The creative efforts for this brochure were donated by Partners+simons in memory of Shai.

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.

The Parent's Guide to Cord Blood is dedicated in memory of

Shai Miranda Verter
Dec. 9, 1992 - Sept. 2, 1997

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.marrow.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.

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.

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.

www.ParentsGuideCordBlood.org

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.

#2

ACOG NEWS RELEASE

For Release: February 1, 2008
Contact: ACOG Office of Communications
(202) 484-3321
communications@acog.org

ACOG Revises Opinion on Cord Blood Banking

Washington, DC -- Physicians should give balanced information to their pregnant patients who are considering cord blood banking, presenting both the advantages and disadvantages of public vs. private cord blood banks, according to The American College of Obstetricians and Gynecologists (ACOG) in a revised Committee Opinion published today in the February issue of *Obstetrics & Gynecology*. ACOG also advises physicians who recruit patients for for-profit cord blood banking to disclose their financial interests or other potential conflicts of interest to pregnant women and their families.

Blood from a newborn's umbilical cord, once considered a waste product that was routinely discarded along with the placenta, is now considered to contain potentially life-saving stem cells. Private banks were initially developed to store cord blood stem cells from newborns, for a fee, for potential future use by the same child or a family member if he/she developed disease later in life. Today, there are public banks that store, for free, stem cells that can be used by anyone needing them similar to how public blood banks work.

"Patients need to be aware that the chances are remote that the stem cells from their baby's banked cord blood will be used to treat that same child—or another family member—in the future," said Anthony R. Gregg, MD, chair of ACOG's Committee on Genetics. ACOG's Committee Opinion is a joint document produced by the Committee on Obstetric Practice and the Committee on Genetics.

Although ACOG takes no position for or against cord blood banking, it recommends that physicians disclose that there is no reliable estimate of a child's likelihood of actually using his or her own saved cord blood later. Some experts estimate this likelihood at 1 in 2,700, while others argue the rate is even lower. Physicians should also disclose to their patients that it is unknown how long cord blood can successfully be stored.

Pregnant women should be aware that stem cells from cord blood cannot currently be used to treat inborn errors of metabolism or other genetic diseases in the same individual from which they were collected because the cord blood would have the same genetic mutation. "Cord blood collected from a newborn that later develops childhood leukemia cannot be used to treat that leukemia for much the same reason," said Dr. Gregg.

Federal legislation was passed in 2005 that provides funding for continued growth of a national cord blood registry in the US. Several states have laws requiring physicians to inform patients about cord blood banking options. Physicians should consult with their state medical association for more information about their individual state laws.

Committee Opinion #399, "Umbilical Cord Blood Banking," is published in the February 2008 issue of *Obstetrics & Gynecology*.

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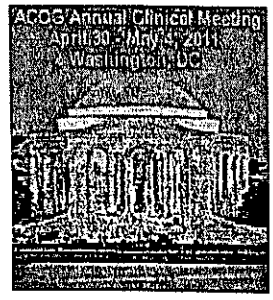

SB 2215 #2

ACOG COMMITTEE OPINION

Number 399 • February 2008 (Replaces No. 183, April 1997)

Umbilical Cord Blood Banking

Committee on Obstetric Practice

Committee on Genetics

This document reflects emerging clinical and scientific advances as of the date issued and is subject to change. The information should not be construed as dictating an exclusive course of treatment or procedure to be followed.

ABSTRACT: Two types of banks have emerged for the collection and storage of umbilical cord blood—public banks and private banks. Public banks promote allogenic (related or unrelated) donation, analogous to the current collection of whole blood units in the United States. Private banks were initially developed to store stem cells from umbilical cord blood for autologous use (taken from an individual for subsequent use by the same individual) by a child if the child develops disease later in life. If a patient requests information on umbilical cord blood banking, balanced and accurate information regarding the advantages and disadvantages of public versus private banking should be provided. The remote chance of an autologous unit of umbilical cord blood being used for a child or a family member (approximately 1 in 2,700 individuals) should be disclosed. The collection should not alter routine practice for the timing of umbilical cord clamping. Physicians or other professionals who recruit pregnant women and their families for for-profit umbilical cord blood banking should disclose any financial interests or other potential conflicts of interest.

Introduction

Once considered a waste product that was discarded with the placenta, umbilical cord blood is now known to contain potentially life-saving hematopoietic stem cells. When used in hematopoietic stem cell transplantation, umbilical cord blood offers several distinct advantages over bone marrow or peripheral stem cells. Biologically, a greater degree of human leukocyte antigen mismatch is tolerated by the recipient and the incidence of acute graft-versus-host reaction is decreased when umbilical cord blood is used (1, 2). The predominant disadvantage of umbilical cord blood use is related to the low number of stem cells acquired per unit. However, the use of combined units of umbilical cord blood allows for the expansion of umbilical cord blood volume (and increased number of stem cells) to be used for adult hematopoietic transplants. Studies are currently underway evaluating the feasibility of ex vivo expansion of the units (3, 4). Since the first successful umbilical cord blood transplant in 1988, it has been estimated that more than 7,000 transplants have been performed in children and adults for the correction of inborn errors of metabolism, hematopoietic malignancies, and genetic disorders of the blood and immune system (5).

Two types of banks have emerged for the collection and storage of umbilical cord blood—public banks and private banks. The first public bank was established at the New York Blood Center in 1991 and other public banks have since been established in various regions of the country. In 1999, the National Bone Marrow Donor Program established a network of these banks listing their units on the National Bone Marrow Donor Program Registry and established the Center for Cord Blood in 2005 (6). As part of this effort, specific subcommittees have been established to address issues related to umbilical cord blood banking, such as standards, quality improvement, donor recruitment, collection, testing, and processing methodology. In December 2005, federal legislation was enacted that provides funding for continued growth of a national umbilical cord blood registry in the United States through the C.W. Bill Young Cell Transplantation Act. Some states have passed legislation requiring physicians to inform their patients about umbilical cord blood banking options. Clinicians should consult their state medical associations for more information regarding state laws.

The American College of Obstetricians and Gynecologists
Women's Health Care Physicians

Public banks promote allogenic (related or unrelated) donation, analogous to the current collection of whole blood units in the United States. These banks typically are associated with a local network of obstetric hospitals that send their units of blood to a central processing facility. A minority of public banks will accept units from any provider through shipment by an overnight express courier (7). Units of umbilical cord blood collected for public banks must meet rigorous standards of donor screening and infectious disease testing as outlined by the U.S. Food and Drug Administration. Initial human leukocyte antigen typing of these units allows them to be entered into computerized registries so that when the need arises, a specific unit can be rapidly located for a patient.

Private banks were initially developed to store stem cells from umbilical cord blood for autologous use (taken from an individual for subsequent use by the same individual) by a child if the child develops disease later in life. There is a cost associated with the initial specimen processing and an annual storage fee for for-profit umbilical cord blood banks (8).

The utility of long-term storage of autologous umbilical cord blood has been questioned. There is no accurate estimate of an individual's likelihood of using an autologous unit of umbilical cord blood. One estimate is approximately 1 in 2,700 individuals, whereas others argue that the rate would be even lower (9). Stem cells obtained from banked umbilical cord blood cannot currently be used to treat inborn errors of metabolism or other genetic diseases in the same individual from whom they were collected because the genetic mutation would already be present in the stem cells. Autologous umbilical cord blood is not used as a source of stem cells to treat childhood leukemia because chromosomal translocations in fetal blood have been detected in some children who ultimately develop leukemia (10, 11). In addition, the use of autologous stem cells would negate the beneficial graft-versus-leukemic effect that occurs with allogenic stem cell transplants (9).

Recommendations and Conclusions

- If a patient requests information on umbilical cord banking, balanced and accurate information regarding the advantages and disadvantages of public versus private umbilical cord blood banking should be provided. The remote chance of an autologous unit being used for a child or a family member (approximately 1 in 2,700 individuals) should be disclosed.
- Discussion may include information regarding maternal infectious disease and genetic testing, the ultimate outcome of use of poor quality units of umbilical cord blood, and a disclosure that demographic data will be maintained on the patient.
- Some states have passed legislation requiring physicians to inform their patients about umbilical cord blood banking options. Clinicians should consult their state medical associations for more information regarding state laws.
- Directed donation of umbilical cord blood should be considered when there is a specific diagnosis of a disease known to be treatable by hematopoietic transplant for an immediate family member.
- Obstetric providers are not obligated to obtain consent for private umbilical cord blood banking.
- The collection should not alter routine practice for the timing of umbilical cord clamping.
- Physicians or other professionals who recruit pregnant women and their families for for-profit umbilical cord blood banking should disclose any financial interests or other potential conflicts of interest.

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Cord blood is the blood from the baby that is left in the ***umbilical cord*** and ***placenta*** after birth. It contains cells called hematopoietic (blood-forming) stem cells that can be used to treat some diseases. It is now possible to donate cord blood to a public bank or store it in a private bank for future use.

This pamphlet explains

- the difference between stem cells and other cells
- how the stem cells in cord blood can be used to treat disease
- when stem cells cannot be used to treat disease
- how cord blood is collected and stored

It is important to know all of the facts about saving cord blood for future use before making a decision.

What Are Stem Cells?

Most ***cells*** can make copies only of themselves. A skin cell can make another skin cell, for example. Stem cells are like blank slates. They can mature into different kinds of cells. The blood-forming stem cells found in cord blood make new blood cells to replace old ones in the body.

How Are Cord Blood Stem Cells Used?

Blood–forming stem cells in cord blood can be used to treat some types of illnesses, such as disorders of the blood, ***immune system***, and ***metabolism***. They also are used to offset the effects that cancer treatments have on the immune system. Other uses are being studied.

Stem cells occur in places other than cord blood. They are found in blood and ***bone marrow*** in adults and children. Using cord blood to treat disease has some benefits over using bone marrow. For example, it is harder to collect bone marrow than it is to collect cord blood. Collecting bone marrow poses some risks and can be painful for the donor.

What Are the Limits to Stem Cell Use?

Stem cells are not a "miracle cure." Only a few diseases can be treated with stem cells. There also are other limitations:

- If a baby is born with a genetic disease, the stem cells from the cord blood cannot be used for treatment because they will have the same ***genes*** that cause the disorder.
- A child's stem cells cannot be used to treat that child's leukemia, a cancer of the blood. However, stem cells from a healthy child can be used like any other donated organ to

treat another child's leukemia. Careful matching of the recipient and donor are done to make sure that the stem cells will work. urn. If symptoms recur after the treatment is finished, see your doctor. A different treatment may be needed.

How Is Cord Blood Stored?

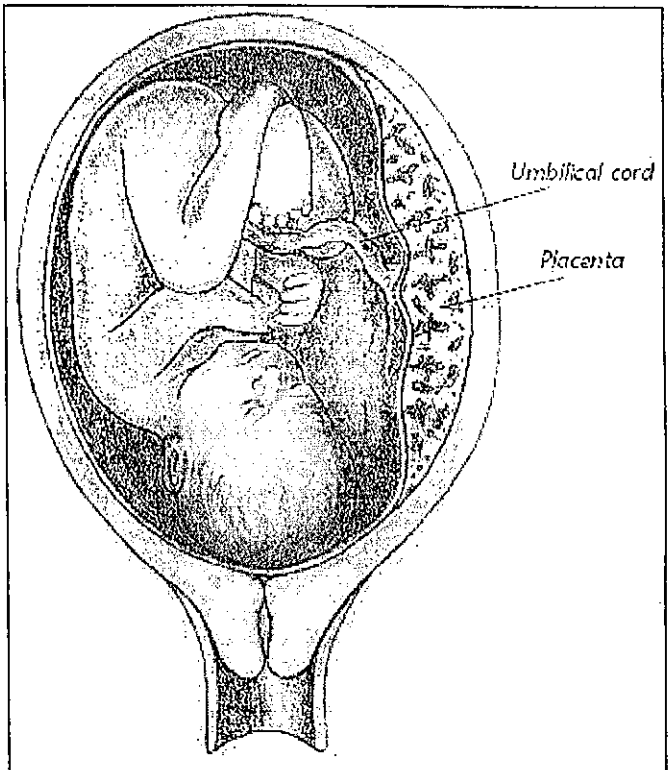
Cord blood is kept in one of two types of banks: public or private. They differ in important ways that may affect your choice.

Public Cord Blood Banks

Public cord blood banks operate like blood banks. Cord blood is collected for later use by anyone who needs it. The stem cells in the donated cord blood can be used by any person who "matches." The cord blood is tracked in a database so that a unit can be found quickly when needed.

Public banks do not charge to collect cord blood. The National Marrow Donor Program (http://www.marrow.org/) is a network that has a list of public banks. Public banks are not available in all areas.

Donors to public banks must be screened before birth. Screening entails a detailed medical history of the mother and father and their families. The goal is to learn of any blood or immune system disorders or other problems. Donors also are asked about their lifestyles. Many people will not meet these screening standards.



Blood in the baby's umbilical cord and placenta contains stem cells that can be used to treat some diseases. After the baby is born, some of this blood can be saved in a private or public bank for future use.

Some of the following factors rule out donating to public banks:

- Travel to certain countries
- Exposure to some vaccines
- Use of illegal drugs
- High-risk sexual behavior
- History of cancer on either side of the family
- Mother or father being adopted

Before the mother gives birth or right after, more screening is done. The mother's blood is checked for certain diseases. This is the same kind of screening that is done when you donate blood to a blood bank.

Private Cord Blood Banks

Private banks store cord blood for "directed donation." The blood is held for use in treating your baby or relatives.

Private banks most often charge a yearly fee for storage. There also will be a fee for collecting the cord blood. Some doctors may have a financial or other conflict of interest in a private bank. Your doctor should tell you about any conflicts.

How Is Cord Blood Collected?

Cord blood is collected by your health care pro-vider or the staff at the hospital where you give birth. Not all hospitals offer this service. Some charge a separate fee that may or may not be covered by insurance. Certain steps must be done in advance:

- The bank must be notified far in advance (usually 6 weeks or more) of the due date.
- A family medical history must be provided.
- A consent form must be signed before labor begins.
- Collection materials must be obtained.

If you choose a private bank, you will sign a contract and pay a fee before the baby is born. The process used to collect cord blood is simple and painless. After the baby is born, the umbilical cord is clamped. Blood is drawn from the cord with a needle that has a bag attached. After the bag is sealed, the placenta is delivered. The process takes about 10 minutes.

Sometimes, not enough cord blood can be collected. This problem can occur if the baby is premature or if there is more than one baby and they share a placenta. It also can occur for no reason. If an emergency occurs during delivery, it may not be possible to collect cord blood.

Problems with the mother may not allow any cord blood to be collected. These problems make it more likely for cord blood to carry an infection:

- Herpes or genital warts
- Infection of the placenta or amniotic fluid

Making A Decision

The decision about whether to store cord blood needs to be made several weeks before delivery. Whether to donate cord blood is up to you. You have three choices:

1. Donate the cord blood to a public bank to possibly help others.
2. Store the cord blood in a private bank in case your child or a relative has a disease that can be treated with stem cells.
3. Do not donate cord blood.

There are some points to think about when making your choice:

- Many diseases cannot be treated with a person's own stem cells.
- The chance that cord blood stem cells will be needed to treat your child or a relative is very low—about 1 in 2,700. However, research is being done into new uses for stem cells. Research also may uncover new ways of treating disease that do not involve stem cells.

- Currently, it is not known how long cord blood can successfully be stored.

If you decide to store cord blood, you will need to choose a cord blood bank. Listed are some questions to ask yourself when deciding on a bank:

- What will happen to the cord blood if a private bank goes out of business?
- Can you afford the collection fee and yearly storage fee for a private bank?
- What are your options if results of the screening tests show you cannot donate to a public bank?

Finally...

The stem cells in cord blood can be used to treat some diseases, but their uses are limited. Cord blood banking makes it possible to store these cells in case they are needed in the future. You should know all of the facts about cord blood banking before making a decision. Your health care provider can help you decide whether cord blood banking is a good option for you and your baby.

Glossary

Cells: The smallest units of a structure in the body; the building blocks for all parts of the body.

Bone Marrow: The spongy tissue in bone cavities that produces new blood cells.

Genes: DNA "blueprints" that code for specific traits, such as hair and eye color.

Immune System: The body's natural defense system against foreign substances and invading organisms, such as bacteria that cause disease.

Metabolism: The physical and chemical processes in the body that maintain life.

Placenta: Tissue that provides nourishment to and takes waste away from the fetus.

Umbilical Cord: A cordlike structure containing blood vessels that connects the fetus to the placenta.

ISSN 1074-8601

Testimony on SB 2215

Senate Appropriations

9:15 a.m. February 8, 2011

Mr. Chairman and members of the committee,

I am Senator Margaret Sitte from District 35 in Bismarck. The bill before you will bring awareness to one of the most impressive medical discoveries of our time: stem cells in umbilical cord blood. Umbilical cords have traditionally been discarded as medical waste, but medical discoveries in the past two decades have been amazing.

The first time umbilical cord blood stem cells were used to treat disease was in 1988. By 2000, 20 diseases were being treated. Currently, more than 85 diseases are being treated including more than 26 types of cancer, 15 auto-immune diseases, three neural degenerative diseases and injuries, 10 anemias and blood conditions, leukemia, Type I diabetes and cerebral palsy.

Umbilical cord blood stem cell transplants are less prone to rejection than either bone marrow or peripheral blood stem cells, probably because the cells have not yet developed the features that can be recognized and attacked by the recipient's immune system.

Also, because umbilical cord blood lacks well-developed immune cells, there is less chance that the transplanted cells will attack the recipient's body, a problem called graft-versus-host disease.

These readily available cells are a potent resource for transplant therapies. Shakila Khan, M.D., wrote on the Mayo Clinic website, "Cord blood is a rich source of stem cells, the cells from which all other cells are created. Cord blood banking is a procedure in which cord blood is taken from a baby's umbilical cord shortly after delivery and preserved for possible future use in a stem cell transplant. Collecting a baby's cord blood poses few, if any, risks to either mother or baby. If the cord blood isn't collected for preservation or research, it's simply discarded. Donating cord blood to a public cord blood banking facility is a tremendous opportunity to help others. "

Attachment 1 is a page from the United States Department of Health and Human Services web page where the department discusses cord blood and advises pregnant women to discuss all options that may be available to them with their healthcare providers.

There are currently 18 public banks in the country. A non-profit agency that promotes umbilical cord blood donations, The Parent's Guide to Cord Blood Foundation, publishes the attached brochure online (Attachment 2), so North Dakota could use this information as the basis of our state brochure. I have printed part of their website for you in a more readable font. (Attachment 3)

Here is part of a letter I received from the Foundation: "Newly published data shows that the lifetime probability of needing a stem cell transplant is much higher than previous estimates indicate. The new research says that as many as 1 in 200 people will receive a stem cell transplant during their lifetime, based on current therapeutic use."

I spoke to a young mother who recently donated her baby's umbilical cord blood. She said the process was simple. She contacted a public cord bank, and they sent her a kit, which she took with her to the hospital. The hospital staff spent just a few minutes processing the sample according to instructions, and they put it in the postage-paid carton, and mailed it.

Family Cord is an example of a private cord blood bank. (Attachment 4) We buy car insurance, home insurance, and life insurance. Some people call this $2500 investment the new form of "treatment" insurance because these stem cells will most likely be a match for all sorts of treatments for family members.

By passing this bill, North Dakota would provide a brochure for physicians to include in the pregnancy packet each new mother receives. The cost of $11,000 is miniscule compared to the benefits of providing this crucial information. North Dakota would inform young women of the value of their infant's cord blood before it is discarded and lost forever. I urge you to help inform the young women of our state of a powerful new medical tool, the stem cells in the umbilical cord blood.

Enacted umbilical cord blood education legislation as of 1/12/11

Arizona HB 2286

Texas HB 709

Illinois HB 642

New York S1265-A

California SB 1555 (pages 2, 5-7)

Michigan HB 6293

Georgia SB 148

New Jersey A312

Arkansas HB2416

Massachusetts SB2039

Pennsylvania HB874

Washington State HB 243

Oklahoma HB 3060

Louisiana HB861

Rhode Island SB2160A

North Carolina HB1331

Connecticut HB6678

Virginia HB85

Tennessee HB3202

Ohio HB102

Missouri has just introduced SB17

Florida recently introduced a similar bill

Health Resources and Services Administration, U.S. Department of Health and Human Services

Bone Marrow and Cord Blood Donation and Transplantation

Access to information provided through the C.W. Bill Young Cell Transplantation Program

Options for Umbilical Cord Blood Banking and Donation

Blood from the umbilical cord and placenta is unique because it contains a relatively large number of blood-forming cells. These cells may be potentially life-saving for someone who has a disease such as leukemia or lymphoma or certain inherited metabolic or immune system disorders. A cord blood transplant, like a bone marrow transplant (also called a BMT), replaces a patient's diseased cells with healthy cells.

The umbilical cord is routinely discarded after the baby is born — unless the parents choose otherwise. Today, expectant parents may choose to have the blood remaining in the umbilical cord and placenta collected and:

- **Donated to a public cord blood bank.** Cord blood donated to a public cord blood bank is available to patients who need a transplant. The donation process is free to the parents donating the umbilical cord blood. Today, however, only certain hospitals are able to collect umbilical cord blood for storage in public cord blood banks. Learn about Donating Umbilical Cord Blood.
- **Stored in a family (private) cord blood bank.** Cord blood stored in a family cord blood bank is saved for that family. Family cord blood banks are available throughout the country for anyone who chooses to pay for the collection and storage of the umbilical cord blood. If you are considering family banking, contact a family cord blood bank as soon as possible.
- **Saved for a sibling who has a medical need**. When a biological sibling has a disease that may be treated with a bone marrow or cord blood transplant, parents can choose to save their baby's cord blood for directed donation. Collecting and storing cord blood for directed donation is offered at little or no cost. To learn more, contact a public or family cord blood bank, or the Related Donor Cord Blood Program.
- **Used for research studies** by a laboratory or technology company. These studies help improve the transplant process for future patients or may lead to new therapies using cord blood. (This cord blood is not stored for transplant.) The collection process for research is free. Talk with your doctor to determine if this option is available to you.

If you are an expectant parent, talk with your health care provider about the options that may be available to you. By making an informed decision, you can take steps to have the umbilical cord blood collected and possibly give someone another chance at life.

Last Updated: December 1, 2010

Attachment 2 p1

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
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.

The creative efforts for this brochure were donated by Partners+simons in memory of Shai.

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 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 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.

p2

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.marrow.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.

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.

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.

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.

1. Why bank cord blood?
Birth is a one-time opportunity to help society by donating your child's cord blood to a public bank. Cord blood contains stem cells that can save lives. Patients requiring a stem cell transplant will receive cells from one of three sources: bone marrow, circulating blood, or umbilical cord blood. The first two exist in all healthy adults, but cord blood can only be harvested and stored at birth. The section on cord blood transplants explains that it is easier to match transplant patients with cord blood than with the two sources of adult blood. Hence, establishing public banks of cord blood from donors with diverse tissue types can save many lives.

Birth is also a one-time opportunity to help your own family by saving your child's cord blood. Transplant patients recover better when they receive stem cells from a related donor, instead of an unrelated donor. In the future, if there are regenerative medicine advances which can repair the body with the patient's own stem cells, then children whose parents saved their cord blood will have better access to those treatments.

There is virtually no reason not to save your child's cord blood. The only cautionary remarks which can be made about cord blood banking is that the cord should not be clamped too soon after birth.

2. Why doesn't everybody bank cord blood?
Because it costs money. Whereas a bone marrow registry is based upon a computer data base of potential donors, a cord blood bank is based upon a laboratory where staff process the cord blood, freeze it in liquid nitrogen, and monitor the freezers.

Only a limited number of institutions have the funding to maintain public banks which take donations for free. This web site has a page which explains the types of cord blood banks, and another which tells you how to find a public bank in the US to accept your donation.

For most parents, cord blood donation is not an option because the number of locations served by public banks is very limited. In that case, parents have to decide if they want to and can afford to pay a private bank to process the cord blood and preserve it for the family.

Fortunately, there are financial assistance programs to help families which have a case of medical need, where a family member is at risk of needing a stem cell transplant.

3. Cord Blood Transplants (CBT)
Advantages of Cord Blood Transplants *versus*
Bone Marrow Transplants (BMT) or Peripheral Blood Stem Cells (PBSC)

- Harvesting umbilical cord blood poses no risk to mother or child, whereas a bone marrow donor must undergo a surgical procedure.
- Stored cord blood is ready for use as soon as it is needed, whereas the process of contacting and testing donors listed in a registry takes weeks to months.

- For transplants, the primary advantage of cord blood stem cells over stem cells from adults is that they cause much less graft versus host disease (GvHD). In order to safely transplant adult stem cells, the patient and donor must match over at least 10 of 12 tissue types called Human Leukocyte Antigens (HLA), or 83% HLA match. By comparison, medical outcomes are just as good with cord blood that has a 4 out of 6 or 67% HLA match. (Reference: V Rocha, et al, 2000; NEJM 342:1846)

Disadvantages of CBT *versus* BMT or PBSCT:

The main disadvantage of cord blood transplants is that they take at least a week longer to "engraft", which means repopulate the patient's blood supply so that cell counts reach minimum acceptable levels. The longer engraftment time is a risk because it leaves the patient vulnerable to a fatal infection for a longer time.

- A typical cord blood collection only contains enough stem cells to transplant a large child or small adult. This web site has a page explaining the optimum transplant dose. At one time it was believed that cell dose limitations restricted the use of cord blood transplants to children. In recent years growing numbers of adults are also receiving cord blood transplants, either by growing the cells in a lab prior to transplant, or by transplanting more than one cord blood unit at a time. More information about these trials is available on the web page about Research on Cord Blood Transplants.

The web page on Odds of Use reviews the probability that an individual in the United States will have a stem cell transplant over the course of a lifetime.

5. Your Heritage and Cord Blood

- A successful transplant requires that the patient and the donor have matching HLA types.
- HLA types are inherited, half from your mother and half from your father. The probability that two siblings will have a perfect 6/6 match desired for a bone marrow transplant is 25%, whereas the probability that they will have the 4/6 match required for a cord blood transplant is 39%.
- Given that HLA types are inherited, you certainly expect that your relatives will match you more closely than a stranger.
- In fact, HLA typing tends to run in ethnic groups, so that patients are more likely (but not guaranteed!) to find a match among donors of the same ethnic background.
- Africans have more genetic diversity than any other ethnic group. The NMDP estimates that even if the number of African-Americans in the United States who registered as adult donors were doubled or tripled, they still could not match all the African-American patients.
- Another group which is not well represented in the registry of adult donors is multi-racial Americans, most of whom are not yet adults.

Cord blood holds hope for all patients with hard-to-match HLA types, because cord blood transplants only require a 4/6 match, not a perfect match.

Attachment 4

p 1

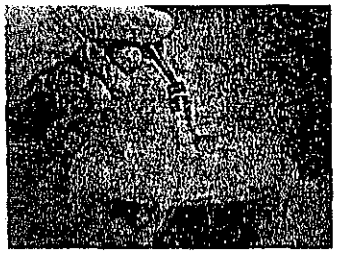
FamilyCord
a California Cryobank Company

For a personal consultation, please call:
800-490-CORD (2673)
To speak with a Cord Blood Educator

Cord Blood Stem Cells Overview

Stem cells have the power to save lives

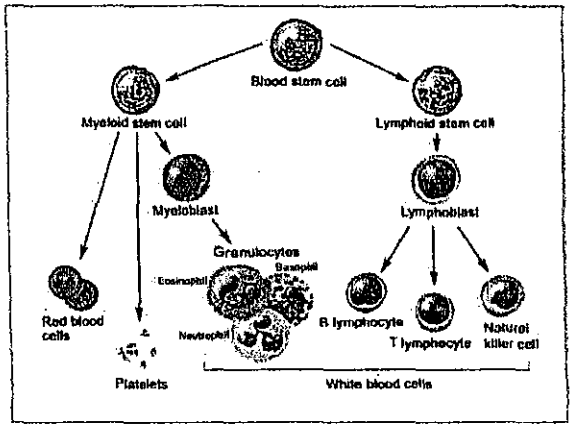
Stem cells are the "building blocks of life" that regenerate and form all other tissues, organs, and systems in the body. Ongoing stem cell research is increasing scientific understanding about how healthy cells develop and replace damaged cells.



Given that cord blood stem cells have the unique ability to develop into other cell types, these stem cells hold the potential for treating some of the most common diseases. Initially, cord blood stem cells were primarily used to treat blood cancers, but research scientists are now exploring treatments for a wide variety of diseases including cerebral palsy, diabetes, heart disease, stroke, and spinal cord injury.

Umbilical cord blood offers a perfectly natural, controversy-free method of acquiring stem cells. Until recently, the umbilical cord and its stem cells were discarded as medical waste. Today, doctors worldwide recognize that cord blood stem cells can aid in the treatment of numerous diseases by helping to generate healthy new cells and tissue.

The value and benefits of stem cells found in cord blood are clear; storing cord blood ensures that should that need ever arise, you will have a source of stem cells that is an exact genetic match to your baby, with no risk of rejection.



There is also the strong possibility that the stem cells will be a match for siblings. Clinical studies demonstrate that stem cells transplants are more successful when the stem cells come from a family member rather than from a non-related donor.

Private storing your cord blood means it will be available when you and your family need it, allowing treatment to begin almost immediately without losing valuable time searching for a matching donor.

Cord blood stem cells are not only valuable now, but they are also considered one of the most promising medical treatments of the future. Published research studies estimate 1 in 217 children will have a medical condition that may be treated with stem cells during their lifetime.

For additional information on cord blood banking, please contact a cord blood educator online or at 800-490-CORD (2673)

Step 1 of 3

Select Storage Package ***(Renewal storage packages available at the then current rate.)***

Select One	Years of Storage	Annual Storage Cost	Total Storage Cost
○	1	$125	$125
○	3	$125	$375
◉	5	$115	$575
○	10	$100	$1,000
○	20	$90	$1,800

One Time Fees	Item	Cost
◉	Enrollment Fee (Collection kit provided free upon enrollment)	$150
◉	Professional Medical Courier Fee	$150
◉	Processing Fee (Includes FDA & AABB recommended testing)	$1,550

Discounts & Promotions

Select One	Description	Discount
◉	Single Baby	$0
○	Military (ID Required)	$400
○	Student (ID Required)	$400
○	Healthcare Provider (ID Required)	$500
○	Twins (Total $1000, $500 each child)	$500
○	Triplets (Total $1800, $600 each child)	$600
○	Repeat Cord Blood Client	$600
○	Promotion Code (e.g. [illegible])†	N/A

† Discounts and promotions may not be combined with any other offer, they will be applied at the time of processing.

Total Fees **$2,425**

Gift Card(s)

Card number(s)

If FamilyCord cannot store the cord blood for any reason, client will only pay the $150 enrollment.

Select Payment Option

Select One	Option	Payment Details
○	Payment in Full	• **$150** due at enrollment. • Remaining balance of **$2,275** will be charged on credit card when cord blood is received and processed. Credit card will be charged unless check has been received prior to processing.
		• **$150** is due at enrollment • **$200** is due when cord blood is received and processed (Initial Payment) • Remaining balance paid monthly and includes a $5 per month administrative fee
○	12-Month Payment Plan (available for all storage)	12-Month Plan / 5 Year Package **$194.09 per month for the remaining 11 months**

NATIONAL MARROW DONOR PROGRAM®

Entrusted to operate the C.W. Bill Young Cell Transplantation Program,
including Be The Match Registry®

The Honorable Margaret Sitte
North Dakota State Senate
808 Avenue C West
Bismarck, ND 58501-2400

The Honorable Lois Delmore
North Dakota House of Representatives
808 Avenue C West
Bismarck, ND 58501-2400

February 2, 2011

Re: Educating expectant mothers about umbilical cord blood banking (SB 2215)

Dear Senator Sitte:

On behalf of the National Marrow Donor Program (NMDP), I am contacting you today regarding your legislation, SB 2215, which would require health care professionals to and the state Department of Health (via a pamphlet) to educate expectant mothers about umbilical cord blood donations.

The National Marrow Donor Program is a leader in the field of unrelated marrow and umbilical cord blood transplantation, dedicated to creating an opportunity for all patients to receive the transplant therapy they need, when they need it. Since 1987, the National Marrow Donor Program has facilitated more than 40,000 transplants.

Your proposed bill would require health care professionals to educate expectant mothers about their umbilical cord blood banking options. We applaud your efforts to raise that awareness. However, we are concerned that as drafted, this legislation creates a demand among North Dakota mothers to publically donate their cord blood that can not be met by current resources. Presently, there are no hospitals in your state where mothers can donate their baby's cord blood unit; therefore, most North Dakota mothers who would receive this information would not be able to donate their baby's cord blood unit publically, and instead would either have to bank privately at a fee, or not donate at all.

Many states are currently passing legislation that mandates public awareness campaigns and/or development of educational materials for expectant mothers/parents about cord blood banking. While these laws result in providing valuable information to the public, many sates do not also provide the means for expectant mothers to donate cord blood. As a result, these educational efforts can create a demand that cannot be met in most local areas. Additional financial resources are needed to increase opportunities for donation, collection and storage of cord blood units. States can help expand the inventory through building

partnerships with existing public cord blood banks and local hospitals in their communities and by appropriating additional resources for the collection and storage of donated cord blood units. A comprehensive cord blood banking program within a state should include funding for education, collection, and storage of donated cord blood units. Although we applaud state education campaign efforts, these laws do little to expand cord blood collection.

Again, the National Marrow Donor Program applauds your efforts to educate expectant mothers about the merits of donating their baby's umbilical cord blood; however, we hope you will consider our recommendations to help increase public donations in your state. The NMDP is here to assist you as you pursue these efforts. We would welcome the opportunity to speak with you directly about this legislation, and look forward to working with you to increase the number of cord blood units available on the national registry. If you have any additional questions or comments please don't hesitate to contact me directly. I can be reached at 202.626.8668 or via email at mspencer@nmdp.org.

Sincerely,

Maria Spencer

Maria D. Spencer, Director
Legislative Relations

#1

Testimony on SB 2215
House Human Services
Wednesday, March 9, 2011, 9:45 a.m., Fort Union Room

Mr. Chairman and members of the committee,

I am Senator Margaret Sitte from District 35 in Bismarck. The bill before you will bring awareness to one of the most impressive medical discoveries of our time: stem cells in umbilical cord blood. Umbilical cords have traditionally been discarded as medical waste, but medical discoveries in the past two decades have brought amazing results.

The first disease treated using umbilical cord blood stem cells was in 1988. By 2000, treatments had been discovered for 20 diseases. Currently, more than 85 different diseases are being treated, including 26 types of cancer, 15 auto-immune diseases, three neural degenerative diseases and injuries, 10 anemias and blood conditions, Type I diabetes and cerebral palsy.

Both the versatility and availability of umbilical cord blood stem cells make them a potent resource for transplant therapies. Transplants using umbilical cord blood stem cells are less prone to rejection than either bone marrow or peripheral blood stem cells, probably because the cells have not yet developed the features that can be recognized and attacked by the recipient's immune system. Also, because umbilical cord blood lacks well-developed immune cells, there is less chance that the transplanted cells will attack the recipient's body, a problem called graft versus host disease.

Here's what Shakila Khan, M.D., wrote on the Mayo Clinic website: "Cord blood is a rich source of stem cells, the cells from which all other cells are created. Cord blood banking is a procedure in which cord blood is taken from a baby's umbilical cord shortly after delivery and preserved for possible future use in a stem cell transplant. Collecting a baby's cord blood poses few, if any, risks to either mother or baby. If the cord blood isn't collected for preservation or research, it's simply discarded. Donating cord blood to a public cord blood banking facility is a tremendous opportunity to help others. "

This bill is simple. It asks the Department of Health to provide a brochure for physicians to include in the pregnancy packet they give to each new mother. The bill does not promote public or private cord banking but simply provides expectant parents

with comprehensive and up-to-date information on their options. The cost of $11,000 is miniscule compared to the benefits of providing this crucial information. Young women will learn the value of their infant's cord blood before it is discarded and lost forever.

Attachment 1 is a page from the United States Department of Health and Human Services webpage in which the department discusses cord blood and advises pregnant women to discuss all options that may be available to them with their health care providers.

There are currently 18 public banks in the country. A non-profit agency that promotes umbilical cord blood donation, the Parent's guide to Cord Blood Foundation, publishes the attached brochure online (Attachment 2), so North Dakota could use this information as the basis of our state brochure. I have printed part of their website for you in a more readable font. (Attachment 3)

According the foundation, "Newly published data shows that the lifetime probability of needing a stem cell transplant is much higher than previous estimates indicate. The new research says that as many as 1 in 200 people will receive a stem cell transplant during their lifetime, based on current therapeutic use."

I spoke to a young mother who recently donated her baby's umbilical cord blood. She said the process was simple. She contacted a public cord bank, and they sent her a kit, which she took with her to the hospital. The hospital staff spent just a few minutes processing the sample according to instructions, and they put it in the postage-paid carton and mailed it.

Family Cord is an example of a private cord blood bank and I have included some of their information as well (Attachment 4). Just yesterday, a news report from Spain reported that a four-year-old girl in Spain was cured of brain cancer using her own umbilical cord stem cells (Attachment 5).

We buy car insurance, home insurance, and life insurance. Some people call this $2500 investment the new form of "treatment" insurance because these stem cells will most likely be a match for all sorts of treatments for family members. I urge you to help inform the young women of our state of a powerful new medical tool: the stem cells in umbilical cord blood.

Enacted umbilical cord blood education legislation as of 1/12/11

Arizona HB 2286

Texas HB 709

Illinois HB 642

New York S1265-A

California SB 1555 (pages 2, 5-7)

Michigan HB 6293

Georgia SB 148

New Jersey A312

Arkansas HB2416

Massachusetts SB2039

Pennsylvania HB874

Washington State HB 243

Oklahoma HB 3060

Louisiana HB861

Rhode Island SB2160A

North Carolina HB1331

Connecticut HB6678

Virginia HB85

Tennessee HB3202

Ohio HB102

Missouri has just introduced SB17

Florida recently introduced a similar bill

Attachment 1

Health Resources and Services Administration, U.S. Department of Health and Human Services

Bone Marrow and Cord Blood Donation and Transplantation

Access to information provided through the C.W. Bill Young Cell Transplantation Program

Options for Umbilical Cord Blood Banking and Donation

Blood from the umbilical cord and placenta is unique because it contains a relatively large number of blood-forming cells. These cells may be potentially life-saving for someone who has a disease such as leukemia or lymphoma or certain inherited metabolic or immune system disorders. A cord blood transplant, like a bone marrow transplant (also called a BMT), replaces a patient's diseased cells with healthy cells.

The umbilical cord is routinely discarded after the baby is born — unless the parents choose otherwise. Today, expectant parents may choose to have the blood remaining in the umbilical cord and placenta collected and:

- **Donated to a public cord blood bank.** Cord blood donated to a public cord blood bank is available to patients who need a transplant. The donation process is free to the parents donating the umbilical cord blood. Today, however, only certain hospitals are able to collect umbilical cord blood for storage in public cord blood banks. Learn about Donating Umbilical Cord Blood.
- **Stored in a family (private) cord blood bank.** Cord blood stored in a family cord blood bank is saved for that family. Family cord blood banks are available throughout the country for anyone who chooses to pay for the collection and storage of the umbilical cord blood. If you are considering family banking, contact a family cord blood bank as soon as possible.
- **Saved for a sibling who has a medical need**. When a biological sibling has a disease that may be treated with a bone marrow or cord blood transplant, parents can choose to save their baby's cord blood for directed donation. Collecting and storing cord blood for directed donation is offered at little or no cost. To learn more, contact a public or family cord blood bank, or the Related Donor Cord Blood Program.
- **Used for research studies** by a laboratory or technology company. These studies help improve the transplant process for future patients or may lead to new therapies using cord blood. (This cord blood is not stored for transplant.) The collection process for research is free. Talk with your doctor to determine if this option is available to you.

If you are an expectant parent, talk with your health care provider about the options that may be available to you. By making an informed decision, you can take steps to have the umbilical cord blood collected and possibly give someone another chance at life.

Last Updated: December 1, 2010

Attachment 2 p1

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
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.

The creative efforts for this brochure were donated by Partners+simons in memory of Shai.

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 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 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.

p2

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.marrow.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.

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.

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.

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.

www.ParentsGuideCordBlood.org

1. Why bank cord blood?
Birth is a one-time opportunity to help society by donating your child's cord blood to a public bank. Cord blood contains stem cells that can save lives. Patients requiring a stem cell transplant will receive cells from one of three sources: bone marrow, circulating blood, or umbilical cord blood. The first two exist in all healthy adults, but cord blood can only be harvested and stored at birth. The section on cord blood transplants explains that it is easier to match transplant patients with cord blood than with the two sources of adult blood. Hence, establishing public banks of cord blood from donors with diverse tissue types can save many lives.

Birth is also a one-time opportunity to help your own family by saving your child's cord blood. Transplant patients recover better when they receive stem cells from a related donor, instead of an unrelated donor. In the future, if there are regenerative medicine advances which can repair the body with the patient's own stem cells, then children whose parents saved their cord blood will have better access to those treatments.

There is virtually no reason not to save your child's cord blood. The only cautionary remarks which can be made about cord blood banking is that the cord should not be clamped too soon after birth.

2. Why doesn't everybody bank cord blood?
Because it costs money. Whereas a bone marrow registry is based upon a computer data base of potential donors, a cord blood bank is based upon a laboratory where staff process the cord blood, freeze it in liquid nitrogen, and monitor the freezers.

Only a limited number of institutions have the funding to maintain public banks which take donations for free. This web site has a page which explains the types of cord blood banks, and another which tells you how to find a public bank in the US to accept your donation.

For most parents, cord blood donation is not an option because the number of locations served by public banks is very limited. In that case, parents have to decide if they want to and can afford to pay a private bank to process the cord blood and preserve it for the family.

Fortunately, there are financial assistance programs to help families which have a case of medical need, where a family member is at risk of needing a stem cell transplant.

3. Cord Blood Transplants (CBT)
Advantages of Cord Blood Transplants *versus*
Bone Marrow Transplants (BMT) or Peripheral Blood Stem Cells (PBSC)

- Harvesting umbilical cord blood poses no risk to mother or child, whereas a bone marrow donor must undergo a surgical procedure.
- Stored cord blood is ready for use as soon as it is needed, whereas the process of contacting and testing donors listed in a registry takes weeks to months.

- For transplants, the primary advantage of cord blood stem cells over stem cells from adults is that they cause much less graft versus host disease (GvHD). In order to safely transplant adult stem cells, the patient and donor must match over at least 10 of 12 tissue types called Human Leukocyte Antigens (HLA), or 83% HLA match. By comparison, medical outcomes are just as good with cord blood that has a 4 out of 6 or 67% HLA match. (Reference: V Rocha, et al, 2000; NEJM 342:1846)

Disadvantages of CBT *versus* BMT or PBSCT:
The main disadvantage of cord blood transplants is that they take at least a week longer to "engraft", which means repopulate the patient's blood supply so that cell counts reach minimum acceptable levels. The longer engraftment time is a risk because it leaves the patient vulnerable to a fatal infection for a longer time.

- A typical cord blood collection only contains enough stem cells to transplant a large child or small adult. This web site has a page explaining the optimum transplant dose. At one time it was believed that cell dose limitations restricted the use of cord blood transplants to children. In recent years growing numbers of adults are also receiving cord blood transplants, either by growing the cells in a lab prior to transplant, or by transplanting more than one cord blood unit at a time. More information about these trials is available on the web page about Research on Cord Blood Transplants.

The web page on Odds of Use reviews the probability that an individual in the United States will have a stem cell transplant over the course of a lifetime.

5. Your Heritage and Cord Blood

- A successful transplant requires that the patient and the donor have matching HLA types.
- HLA types are inherited, half from your mother and half from your father. The probability that two siblings will have a perfect 6/6 match desired for a bone marrow transplant is 25%, whereas the probability that they will have the 4/6 match required for a cord blood transplant is 39%.
- Given that HLA types are inherited, you certainly expect that your relatives will match you more closely than a stranger.
- In fact, HLA typing tends to run in ethnic groups, so that patients are more likely (but not guaranteed!) to find a match among donors of the same ethnic background.
- Africans have more genetic diversity than any other ethnic group. The NMDP estimates that even if the number of African-Americans in the United States who registered as adult donors were doubled or tripled, they still could not match all the African-American patients.
- Another group which is not well represented in the registry of adult donors is multi-racial Americans, most of whom are not yet adults.

Cord blood holds hope for all patients with hard-to-match HLA types, because cord blood transplants only require a 4/6 match, not a perfect match.

Attachment 4

p 1

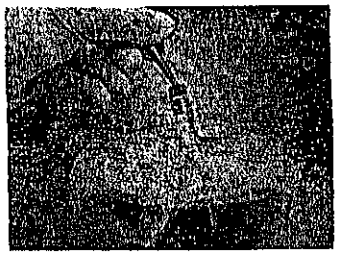
FamilyCord
a California Cryobank Company

For a personal consultation, please call:
800-490-CORD (2673)
To speak with a Cord Blood Educator

Cord Blood Stem Cells Overview

Stem cells have the power to save lives

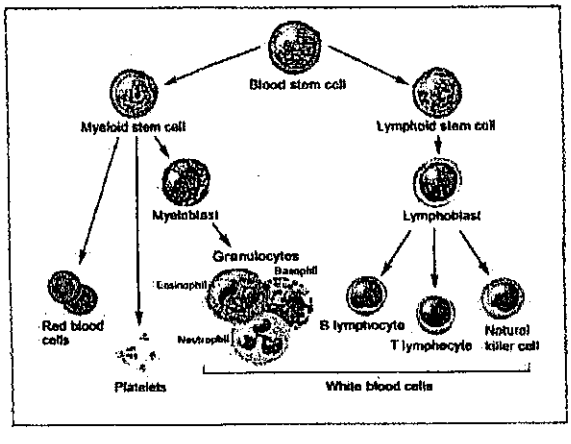
Stem cells are the "building blocks of life" that regenerate and form all other tissues, organs, and systems in the body. Ongoing stem cell research is increasing scientific understanding about how healthy cells develop and replace damaged cells.



Given that cord blood stem cells have the unique ability to develop into other cell types, these stem cells hold the potential for treating some of the most common diseases. Initially, cord blood stem cells were primarily used to treat blood cancers, but research scientists are now exploring treatments for a wide variety of diseases including cerebral palsy, diabetes, heart disease, stroke, and spinal cord injury.

Umbilical cord blood offers a perfectly natural, controversy-free method of acquiring stem cells. Until recently, the umbilical cord and its stem cells were discarded as medical waste. Today, doctors worldwide recognize that cord blood stem cells can aid in the treatment of numerous diseases by helping to generate healthy new cells and tissue.

The value and benefits of stem cells found in cord blood are clear; storing cord blood ensures that should that need ever arise, you will have a source of stem cells that is an exact genetic match to your baby, with no risk of rejection.



There is also the strong possibility that the stem cells will be a match for siblings. Clinical studies demonstrate that stem cells transplants are more successful when the stem cells come from a family member rather than from a non-related donor.

Private storing your cord blood means it will be available when you and your family need it, allowing treatment to begin almost immediately without losing valuable time searching for a matching donor.

Cord blood stem cells are not only valuable now, but they are also considered one of the most promising medical treatments of the future. Published research studies estimate 1 in 217 children will have a medical condition that may be treated with stem cells during their lifetime.

For additional information on cord blood banking, please contact a cord blood educator online or at 800-490-CORD (2673)

Step 1 of 3

Select Storage Package ***(Renewal storage packages available at the then current rate.)***

Select One	Years of Storage	Annual Storage Cost	Total Storage Cost
○	1	$125	$125
○	3	$125	$375
◉	5	$115	$575
○	10	$100	$1,000
○	20	$90	$1,800

One Time Fees	Item	Cost
◉	Enrollment Fee (Collection kit provided free upon enrollment)	$150
◉	Professional Medical Courier Fee	$150
◉	Processing Fee (Includes FDA & AABB recommended testing)	$1,550

Discounts & Promotions

Select One	Description	Discount
◉	Single Baby	$0
○	Military (ID Required)	$400
○	Student (ID Required)	$400
○	Healthcare Provider (ID Required)	$500
○	Twins (Total $1000, $500 each child)	$500
○	Triplets (Total $1800, $600 each child)	$600
○	Repeat Cord Blood Client	$600
○	Promotion Code (e.g. R0209EXE)†	N/A

† Discounts and promotions may not be combined with any other offer, they will be applied at the time of processing.

Total Fees **$2,425**

Gift Card(s)

Card number(s)	

If FamilyCord cannot store the cord blood for any reason, client will only pay the $150 enrollment.

Select Payment Option

Select One	Option	Payment Details
○	Payment in Full	• **$150** due at enrollment. • Remaining balance of **$2,275** will be charged on credit card when cord blood is received and processed. Credit card will be charged unless check has been received prior to processing.
○	12-Month Payment Plan (available for all storage)	• **$150** is due at enrollment • **$200** is due when cord blood is received and processed (Initial Payment) • Remaining balance paid monthly and includes a $5 per month administrative fee 12-Month Plan / 5 Year Package **$194.09 per month for the remaining 11 months**

Attachment 5

Cord blood stem cells used to cure girl of brain cancer in Spain

Seville, Spain, Mar 8, 2011 / 02:04 pm (CNA/Europa Press).- A four-year-old girl has become the first patient in Spain to recover from brain cancer after being treated with stem cells from her own umbilical cord blood.

The announcement of the girl's recovery came March 7 from the company Crio-Cord, a stem cell bank in Spain.

Alba was born healthy in 2007, but at age two she was diagnosed with a rare form of brain cancer. Her treatment consisted of extracting the majority of the tumor from her brain. She was then given chemotherapy to reduce and eventually eliminate the remainder of the tumor.

Alba's blood system was destroyed during the final round of chemo, thus requiring a transplant of cord blood stem cells.

The procedure was carried out in 2009 by Dr. Luis Madero of the Department of Oncology and Hematology at the Nino Jesus Hospital in Madrid.

Today, four year-old Alba is a healthy girl.

Periodic Reviews

Sixty days after the transplant, Alba was given new stem cells taken from her peripheral blood in order to accelerate the production of platelets. Fourteen months after the transplant, her blood system was completely restored, and she has since enjoyed a normal life.

Dr. Madero called her case unique in Spain. "The use of stem cells to regenerate the blood system is an extended treatment for this form of cancer," he said. What makes her case unique, he added, "is that for the first time in our country, the stem cells came from a patient's own umbilical cord, preserved from birth."

"In recent years, transplants of cord blood stem cells have become increasingly common. In the case of siblings, these stem cells are the best therapeutic option that exists," he said.

"Our best investment"

Alba's father, Santiago, who is a computer engineer, and her mother, Teresa, a literature professor, agreed that keeping the blood from Alba's umbilical cord was the "best investment" they ever made.

Santiago said he had previously seen a report "on the treatment for Parkinson's using stem cells ... and was sympathetic to the idea of using stem cells to treat degenerative diseases."

"Keeping the umbilical cord is a wager for the future, a life insurance policy that you don't know if you will need but that could save a life," Teresa added.

The head of Crio-Cord, Guillermo Munoz, also said he was pleased at the results of the therapy. He noted that the organization was "proud to have participated in Alba's healing process."

Cases like these confirm "that umbilical cord blood is an excellent source of stem cells. Being the youngest cells of their kind in the human body, they have great potential to cure," Munoz explained.