# **BEST PRACTICES:** Umbilical Cord Blood and Tissue Preservation: Tips for Patient Counseling

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#### **INTRODUCTION**

Talking with expectant parents about umbilical cord blood and cord tissue banking is an important component of

pregnancy, and education should be introduced during a patient's routine obstetric visits. Providing families with information regarding the current and potential future applications of newborn stem cells and the options of public donation and family banking early in pregnancy will help families make an informed decision about newborn stem cell preservation. There is only one window of opportunity—at the time of birth—to collect cord blood and cord tissue, and education must be provided and decisions made well in advance. This article reviews some key points of education to help clinicians effectively discuss these issues with expectant parents.



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#### **BACKGROUND**

Once considered medical waste, umbilical cord blood is now understood to be an important source of multipotent hematopoietic stem cells. Since the late 1980s, 35,000 hematopoietic stem cell transplants (HSCTs) using stem cells derived from cord blood from public banks and privately stored units have been performed worldwide.1 Cord blood stem cells may be used in the treatment of more than 80 diseases and disorders as part of a HSCT.2 Although blood and immune producing hematopoietic stem cells can be obtained from multiple adult tissues such as bone marrow and peripheral blood, cells derived from cord blood offer several advantages. First, cord blood is quickly and easily collected at birth, and the collection is non-invasive and poses no risk to mother or infant. Because newborn stem cells are collected at the time of birth and then preserved, they have limited exposure to viral contamination, environmental stressors, and aging that may impact the cells. Another important distinction is that newborn stem cells exhibit reduced alloreactivity and require less stringent human lymphocyte antigen (HLA) matching in traditional transplant applications than adult stem cells derived from other sources such as bone marrow. This advantage extends to the fact that newborn stem cells obtained from cord blood are also associated with a lower risk of graft-versus-host disease than cells from other sources. 1,3

Newborn stem cells found in cord blood and cord tissue are actively being researched within the field of regenerative medicine. In fact, cord blood is currently the subject of clinical trials in which it is being evaluated as a potential treatment for children with autism, cerebral palsy, and congenital heart disease.4 In addition, preclinical research studying mesenchymal stem cells has demonstrated in the laboratory their ability to modify the immune system and inflammatory responses, making these cells excellent candidates for potential therapeutic applications in treating autoimmune disorders and ischemic injury.5 Cord tissue\* is a rich source of mesenchymal stem cells and while there are currently no established treatments, it is being actively evaluated in over 30 clinical trials, most taking place outside of the United States.4

#### **TALKING TO PATIENTS**

Umbilical cord blood and cord tissue collection and preservation options should be discussed with every expectant parent early in pregnancy, and ideally as early as the 2nd trimester. Parents are often excited and overwhelmed at this time, so it is important to complement any discussion with written information that can be reviewed at home, and again during follow-up visits.

Preserving newborn stem cells today may give families opportunities to access stem cell treatments in the future. It is important to take a proactive patient counseling approach

to actively educate all expecting families. Families with a history of malignant and nonmalignant hematologic disorders that are treatable with a stem cell transplant may be

> candidates for extra education on the therapeutic potential of stem cells, as these are the families who may have the greatest future need for HSCT. Likewise, additional education may be appropriate for families from racial or ethnic minority groups, as suitably matched donors may be scarce.3

Providing patients with this information during the very early stages of pregnancy gives them an opportunity to consider whether they wish to collect and bank newborn stem cells privately or donate their newborn stem cells to a public bank, and enables them to make a choice prior to delivery, including pre-term delivery. There is only one window of opportunity to collect cord blood and/or tissue and broaching the

topic early is the best way to prevent last-minute stress for the family and health care providers.

#### **Scientific Education for Parents**

The education provided should address the science behind current newborn stem cell applications, and future potential. When discussing current cord blood clinical applications, it is important to address differences between autologous and allogenic stem cell transplantation, and in what type of conditions each type of transplantation is most applicable. With respect to allogenic transplant medicine it is important to review HLA matching, and the differences between related versus unrelated stem cell donors. Consider including the discussion point that close family members are the most likely to be a well-matched donor. In addition, clinicians should outline emerging research evaluating newborn stem cells such as clinical trials evaluating cord blood in autism and hearing loss, and the potential for mesenchymal stem cells in regenerative medicine.

#### **Family and Public Banking Options**

To provide patients with a full set of options, it is likewise important to discuss the differences among discarding newborn stem cells, donating stem cells to a public bank, and storing stem cells in a family bank.

Families who wish to have their newborn's stem cells available for potential future use by first and/or second degree family members should consider preserving this resource with a family bank. It is important for parents to research the various family banks and select a company with which they are comfortable. Advise parents to assess a company's reputation, experience, years of operation, and financial stability, as well as the company's role and investment in newborn stem cell research, and availability of additional resources, e.g., genetic counselors available to provide education about newborn stem cells. Patients should also research if a company has programs to make family banking affordable for all families.

In addition to storing privately, parents have the option to donate cord blood to a public bank. By donating the cord blood, the stored cells would be saved specifically for an unrelated patient in need of a stem cell transplant. However, parents must be clear that this is truly a donation and they do not retain access to the cord blood should their family need it in the future. It is important to note that most units donated to public banks, up to 75% based on some estimates, fail to meet sample requirements and may be discarded.<sup>2</sup> Parents interested in public donation should inquire about their potential as donors to a public bank before the 32<sup>nd</sup> week of pregnancy. Unfortunately, not all delivering hospitals have the option of public donation and parents should visit www.bethematch.org to determine if donation is an option for them.

#### **Cost to Family**

Since family banks preserve the newborn stem cells exclusively for family use, there are fees attached to this option. Currently, the one-time shipping and processing fee is approximately \$1500, plus an annual storage fee of \$150.2 It should be noted some family banks may offer payment plans to fit every family budget.

#### **The Collection Process**

The collection process should be described, making sure parents understand that the collection of cord blood and/or tissue is performed after the umbilical cord is cut, so there is no risk to mother or infant. Parents should also be made aware that cord blood collection can be performed even in the setting of delayed umbilical cord clamping (DCC), however this may result in a smaller collection volume. The potential benefits of DCC versus collection volume should be discussed, along with the potential future of cell expansion technology. Cord blood and/or cord tissue may still be collected if DCC is practiced and it is recommended that the collection start as soon as the cord is clamped and cut.

#### CONCLUSIONS

With the progress of stem cell science and recent momentum in research, newborn stem cell preservation has become an important decision for expectant parents. Providing families with complete and balanced information about the science, therapeutic potential, and banking options early in pregnancy is the essential first step in helping parents make decisions.

In addition to understanding the science and options available, parents must understand that there is only one window of opportunity to collect umbilical cord blood and tissue, and this decision needs to be made before delivery.

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#### **DISCLAIMER:**

\*Cord tissue use is still in early research stages, and there is no guarantee that treatments using cord tissue will be available in the future. Should such use become available, cord tissue will require additional processing prior to use. CBR is currently evaluating the potential to isolate and prepare multiple cell types from cryopreserved cord tissue for potential future use.

Cbr, Cord Blood Registry's activities for New York State residents are limited to collection of umbilical cord tissue and long-term storage of umbilical cord-derived stem cells. Cbr, Cord Blood Registry's possession of a New York State license for such collection and long-term storage does not indicate approval or endorsement of possible future uses or future suitability of these cells.

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