

Analogical Trends in US Umbilical Cord Blood Legislation

Karama C. Neal
Emory University

“Sickle cell is now a part of my past. One year after my transplant, I was pronounced cured. Stem cells saved my life. Thank you.”

- *Keone Penn, 2003, the first person cured of sickle cell anemia by umbilical cord blood donation from an unrelated donor, in a US Senate hearing.*

Since the first successful human cord blood transplant in 1988 (Gluckman *et al.* 1989), advances in cord blood collection and storage, and in medical technology have resulted in the expanded use of hematopoietic stem cells from umbilical cord and placental blood for treatment and research. In response, since 2001, 19 US states and the national government have enacted or are considering legislation that promotes the use of cord blood in various ways. Here, this legislation will be discussed in the context of the analogies proposed and reviewed by Hofmann and his colleagues (2006).

Types of legislation

The existing and pending US cord blood laws work in at least four ways (see Table below; also see Cord Blood Registry [CBR] 2006). Thirteen states currently have or are considering laws that would require hospitals, physicians or others to distribute information on cord blood donation, some of which would directly promote donation. Illinois law, for example, requires that hospitals notify pregnant patients of their cord blood donation options (CBR 2006). Nine states and the federal government have or

are considering laws that establish or support existing public cord blood biobanks. New Jersey will provide funding to help two non-profit blood banks create cord blood storage facilities (CBR 2006). Louisiana’s legislature is considering a bill that would create an incentive for families that choose to donate cord blood, and three states have laws that create advisory boards charged with the development and/or administration of cord blood donation programs (CBR 2006). Oklahoma’s Danielle Martinez Act of 2005 created an “Advisory Council on Cord Blood Donations,” leaving the policy details of the cord donation program to that Council. Note that many state cord blood laws, like the one in Florida, specify multiple modes of action.

Table: US Cord blood legislation by type and analogy.

Types of legislation	Analogies	Jurisdictions (CBR, 2006)
Information dissemination and donation promotion	Organ donation, gift	Arizona, California*, Florida, Georgia, Illinois, Maryland, Massachusetts, New Jersey, New Mexico, New York*, South Dakota, Virginia, Wisconsin
Public biobank establishment or support	Natural resources, waste	Arkansas*, Connecticut*, Florida, Massachusetts, Missouri, New Jersey, New York*, Texas, United States**, Virginia
Incentives for donation	Charitable contribution	Louisiana*
Advisory board creation	Natural resources, stewardship	Georgia, Missouri, Oklahoma

* Indicates pending legislation.

** Source: Stem Cell Therapeutic and Research Act of 2005

There are several sources of US cord blood legislation. For example, several state legislative bodies passed laws promoting cord blood donation and use (e.g., Wisconsin), while another, South Dakota, passed a resolution with similar goals (CBR 2006). In some states, cord blood policy is determined by an executive order of the governor (e.g., Georgia; CBR 2006).

Applicable analogies

The analogies discussed by Hofmann, Solbakk and Holm (2006) can be used to describe US cord blood legislation and identify trends in their use (see Table).

Analogies that make use of the concept of generosity dominate. The organ donation analogy is suggested by many of these laws. However, the blood donation model seems less appropriate, because, unlike renewable, circulating blood, a specific cord blood type can only be donated once. The gift analogy also is frequently used, particularly in legislation that is designed to promote cord blood donation from the public. It is important to note that the 'gift' is of some, perhaps high value. This is suggested in the summary of the US Stem Cell Therapeutic and Research Act of 2005:

Cord blood stem cells are already treating patients, and this legislation will provide new opportunities for patients to access cures. It is critical that this resource be made widely available because of the rapidly growing number of devastating diseases which *could be addressed* through cord blood stem cell research and treatments. (Emphasis added).

Even if a "growing number of devastating diseases" cannot be treated using cord blood stem cells, a growing number of *people* certainly can be.

The proposed Louisiana law is unique in that it would provide a tax credit for families that choose to donate cord blood (CBR 2006). This may be most like a charitable contribution. The donor gives to promote the common good, and while she

may benefit directly or indirectly from that contribution in the long term, she receives an immediate benefit in the form of a tax write-off.

The legislation that focuses on public treatment and research biobanks is best described by analogies that view cord blood as a resource that can either be discarded (waste) or used (natural resource). The South Dakota (2005) resolution states, in part “Whereas, umbilical cord blood may be donated to a publicly accessible certified umbilical cord blood bank rather than be *thrown away as medical waste*“ (emphasis mine). States that have created advisory boards may also see cord blood as a valuable resource, specifically one whose ethical and responsible use requires appropriate oversight. This understanding evokes the stewardship analogy.

Implications

It is important to ask if these laws will actually promote cord blood donation, research and therapeutic use. However, given that the laws are relatively recent, it may still be too early to determine their effectiveness. Most states have not yet passed cord blood legislation, and of those that have, some have not provided money to support this work. For example, Texas’ 2001 legislation establishing a public umbilical cord blood bank is “dependent on available funds” (CBR 2006). Although a resolution, like the one passed in South Dakota to “encourag[e] citizen awareness of umbilical cord blood donation” (South Dakota House 2005), may increase public appreciation of the benefits of cord blood biobanking, it is unlikely to have a wide-ranging impact unless followed by other legislative actions and associated with funding. Still, publicity about such legislation, regardless of associated funding, may increase public interest in cord blood donation. Motivated individuals may then decide to take advantage of existing methods

for cord blood donation, collection, storage, research and therapeutic use (e.g., National Marrow Donor Program 2006).

Unlike embryonic stem cells, the hematopoietic stem cells derived from cord blood donation are generally not controversial. If politicians misunderstand or misrepresent the differences in stem cell biology or in potential usefulness of these types of stem cells (NIH 2006b), promotion of research using cord blood may be used as a politically expedient way of publicly supporting stem cell research without supporting *embryonic* stem cell research. The summary of the US Stem Cell Therapeutic and Research Act of 2005 reads,

[I]n addition, published studies have shown that cord blood stem cells have the capacity to change into other cell types, which give them the potential to treat many fatal, terminal and debilitating conditions, including spinal cord injury, Parkinson's, diabetes and heart disease.

The conditions listed are often associated with expectations from and goals of *embryonic* stem cell research (NIH 2006a; 2006b).

Finally, given that analogies of generosity predominate in existing US cord blood legislation, legislators that are considering introducing bills in support of cord blood donation and use may want to focus on the analogies of generosity, even if their legislation includes creation of public biobanks or advisory boards. These are, admittedly, “value-laden” analogies (Hofmann, Solbakk and Holm 2006). But, at least for now, the use of analogies of generosity seems to resonate with the American public and their lawmakers. Consequently, they may be useful in developing and passing cord blood legislation and providing funding to support it.

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