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CONNECTICUT'S UMBILICAL CORD BLOOD LAW

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You asked if Connecticut has any laws regarding umbilical cord blood donation, transportation, and storage.

SUMMARY

During the past few years, Connecticut has enacted legislation to help increase awareness among expectant parents and their health care providers of their options for donating or storing newborn's umbilical cord blood. While the umbilical cord is usually discarded after birth as medical waste, cord blood is now known to contain stem cells that may be used to treat blood cancers and inherited immunodeficiencies and blood diseases.

A 2009 law requires health care providers who provide pregnancy-related care for women during their third trimester to provide women with information about umbilical cord blood and cord blood banks.

In addition, the law required the Department of Public Health (DPH), by October 1, 2007, to request information from umbilical cord blood banks on their interest in partnering with the state to create a public collection program. Based on DPH's findings, the General Assembly enacted legislation in 2011 creating a Connecticut Umbilical Cord Blood Collection Board to establish such a program.

By law, the program must facilitate and promote collecting cord blood units from genetically diverse donors for public use (e.g., medical research, state and national cord blood registries, and transplant centers). The board must, based on available funding, contract with experts to designate at least two collection centers in the state.

The law allows the board to raise funds and accept public or private grants. It created an Umbilical Cord Blood Collection account in the state's General Fund to deposit program funds.

The board must report quarterly to the governor and the Appropriations and Public Health Committees on the program's status. It must also provide these legislative committees copies of any board audits conducted by an independent auditing firm.

Although the law required the board to implement the program by July 1, 2012, it has not yet done so. According to the board's chair, Dr. Edward Snyder, the board has received no state funding to plan and implement the program. Dr. Snyder indicated that the board recently received \$13,000 in donations which will be used for this purpose.

CONNECTICUT UMBILICAL CORD BLOOD COLLECTION PROGRAM

Information Request

The law required DPH, by October 1, 2007, to request information from umbilical cord blood banks on establishing a public collection program in the state to collect, transport, process, and store cord blood units from Connecticut residents for therapeutic and research purposes. The DPH commissioner submitted his findings and recommendations to the governor and Public Health Committee in January 2008 ([CGS § 19a-32m](#)).

Among other things, the report found that there was interest in both the private and public sector blood banking communities in partnering with Connecticut to establish a public bank (a copy of the report is available at:

http://search.ct.gov/search?q=umbilical+cord&site=dph_collection&client=dph&output=xml_no_dtd&proxystylesheet=dph.

Umbilical Cord Blood Collection Board

Legislation in 2011 ([PA 11-60](#)) created an eight-member Connecticut Umbilical Cord Blood Collection Board to establish a state umbilical cord blood collection program. The board can raise funds, apply for and

accept public or private grant money, and hire staff. The board consists of the DPH commissioner or her designee and seven members appointed by the governor and legislative leaders as shown in Table 1.

Table 1: Connecticut Umbilical Cord Blood Collection Board Membership

Appointing Authority	Qualifications
Governor	Medical director or chief scientist with knowledge of umbilical cord blood banking and affiliated with an entity recognized by DPH
House speaker	Licensed physician experienced in transplanting units of umbilical cord blood or other stem cells
Senate president pro tempore	Licensed physician with expertise in and currently practicing in obstetrics at a birthing hospital that participates in umbilical cord blood collection and who is affiliated with a private university hospital
House majority leader	Licensed physician with expertise in and currently practicing in obstetrics at a birthing hospital that participates in umbilical cord blood collection and is affiliated with a public university hospital
House minority leader	Licensed physician with expertise in and currently practicing in obstetrics at a birthing hospital that participates in umbilical cord blood collection
Senate majority leader	Member of a nonprofit umbilical cord blood foundation with knowledge of umbilical cord blood banking issues
Senate minority leader	Expert in regulatory practices of the federal Food and Drug Administration (FDA) and the federal Health Resources and Services Administration

The law required appointing authorities to make their initial appointments by October 1, 2011. The governor appointed the first board chairperson from among its members. The chairperson had to hold the first meeting by November 1, 2011 and quarterly meetings thereafter (according to Dr. Snyder, the board has not met quarterly because of the lack of program funds). The law also specifies appointment terms, conditions for transacting business, and conflict of interest parameters ([CGS § 19a-32q](#)).

Program Purposes

The law required the board to establish, by July 1, 2012, the umbilical cord blood collection program and administer it (the program has not yet been implemented). The program must facilitate and promote the collection of umbilical cord blood units from genetically diverse donors for public use. The law defines “public use” as:

1. use of umbilical cord blood units by state, national, and international cord blood registries and transplant centers to increase the likelihood of providing suitably matched donor umbilical cord blood units to patients in need of such units or research participants in need of a transplant;

2. biological research and new clinical use of stem cells derived from umbilical cord blood and tissue; and
3. medical research that uses umbilical cord blood units that could not otherwise be used for transplants or other clinical use ([CGS § 19a-32r](#)).

The board must, based on available funding, contract with experts in collecting and transporting umbilical cord blood units to establish or designate at least two collection centers in the state (sites have not yet been designated). These centers must be at a birthing hospital with (1) at least 3,750 births per year and (2) a disproportionate share of births involving minority women. To the extent practicable, the board must encourage the collection of units of umbilical cord blood at other non-fixed state locations.

The board must solicit contracts through a competitive process and provide that:

1. the state retains an interest in any umbilical cord blood collected in the state commensurate with its investment in the program;
2. income the board receives as a result of the contract is used to ensure that the umbilical cord blood collection program is self-sustaining by July 1, 2020; and
3. umbilical cord blood units deemed unsuitable for transplantation are returned to the state for use in biological or medical research

Any entity the board contracts with must:

1. comply with federal FDA requirements for manufacturing clinical-grade cord blood stem cell units for clinical purposes;
2. report quarterly to the board on the (a) total number of umbilical cord blood units collected, (b) number of collected units suitable for transplant, (c) number suitable for research only, and (d) clinical outcomes of any transplanted units; and
3. comply with state and federal law on protecting medical information and personally identifiable information contained in, or obtained through, the umbilical cord blood collection inventory ([CGS § 19a-32r](#)).

Umbilical Cord Blood Collection Account

The law established an Umbilical Cord Blood Collection account as a separate, nonlapsing General Fund account. The account can hold any funds required or allowed by law to be deposited in it and any public or private grants or contributions. The board can spend account funds needed to administer the program ([CGS § 19a-32t](#)).

Audits and Reports

The law requires board members to provide the Public Health and Appropriations committees with a copy of any board audit conducted by an independent auditing firm within seven days after the board receives the audit.

The board must also report quarterly to the governor and Public Health and Appropriations committees on the status and effectiveness of the program (CGS §§ [19a-32u](#) & [19a-32v](#)).

UMBILICAL CORD BLOOD EDUCATION AND OUTREACH

By law, physicians and other health care providers who provide pregnancy-related care for women during their third trimester must provide women with timely, relevant, and appropriate information about umbilical cord blood and cord blood banks. The information must be sufficient to allow women to make informed choices about banking or donating their child's cord blood.

In addition, the Connecticut Umbilical Cord Blood Collection Board must, within available appropriations, engage in public education and marketing activities to promote and raise awareness among physicians and pregnant women of the umbilical cord blood collection program ([CGS § 19a-32n](#)).

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