

## Assembly Concurrent Resolution No. 74

### RESOLUTION CHAPTER 116

Assembly Concurrent Resolution No. 74—Relative to umbilical cord blood banking.

[Filed with Secretary of State September 7, 2010.]

#### LEGISLATIVE COUNSEL'S DIGEST

ACR 74, Portantino. Umbilical cord blood banking.

This measure would state that the Legislature desires to find ways to help California gain a viable public umbilical cord blood banking system to ensure that all races and ethnicities have an equal probability of finding a match when medically necessary. This measure would also specify that the Legislature supports related research being done with collected units that are not suitable for transplantation.

WHEREAS, Since the first umbilical cord blood transplant in 1988, the industry of collecting umbilical cord blood for public or private use has grown rapidly, both as a treatment for over 70 medical conditions and as an industry of biological insurance; and

WHEREAS, Even with the industry's rapid growth and umbilical cord blood's current use to treat blood cancers, such as leukemia, myeloma, and lymphoma, and more than 70 inherited immunodeficiencies and other genetic and acquired blood diseases, including sickle cell anemia, thalassemias, hemoglobinopathies, aplastic anemias, and marrow failure disorders, and inherited disorders or errors of metabolism, the public is largely unaware of the critical differences between public umbilical cord blood banking and private umbilical cord blood banking systems; and

#### Private Umbilical Cord Blood Banking

WHEREAS, Umbilical cord blood can be collected privately for any consumer who wishes to pay for both collection and storage. The private umbilical cord blood banking industry is entirely supported by consumers who pay about \$2,000 to collect, and \$125 annually to store, their families' umbilical cord blood. Private banks do not charge consumers for release of their umbilical cord blood and any decision regarding the use of the unit is up to the donor or the donor's family; and

WHEREAS, Consumers are informed that banking their families' umbilical cord blood may be clinically useful for their future medical needs, but should be aware that to date, most transplants have been provided by public banks because a patient's malignant or genetic disease was most

effectively treated by stem cells from another individual, although stem cells from a matched sibling have been especially suitable; and

WHEREAS, The exploration of umbilical cord blood's capacity to cure is in its early stages, but since there is a strong likelihood that the use of one's own stem cells, specifically in regenerative medicine, will increase, the future of this incredible potential supports private umbilical cord blood banking as a prudent choice for those who can afford it; and

WHEREAS, Over the last 20 years, transplant physicians chose family banks to transplant perfectly matched siblings. Recently, neurological disorders, such as cerebral palsy and other injuries to the brain, are being treated with the donor's own stem cells, and there are clinical trials approved by the United States Food and Drug Administration (FDA) to evaluate the use of a child's own umbilical cord blood in regenerative therapies for diseases and conditions that could not previously be treated, such as juvenile diabetes. These indicate many future cures may come from autologous cells using the patient's own immune system; and

WHEREAS, The private banking industry has been largely responsible for the public's current knowledge of umbilical cord blood banking and has been a consistent advocate of disseminating information about umbilical cord blood banking to pregnant women and their families; and

WHEREAS, The trend of disseminating information about umbilical cord blood banking culminated in California with the enactment of Senate Bill 1555 (Chapter 484 of the Statutes of 2006) that authorizes distribution of information to families about umbilical cord blood banking; and

WHEREAS, Several other states passed similar laws around the same time as the enactment of Senate Bill 1555; and

#### Public Umbilical Cord Blood Banking

WHEREAS, In 2007, the California Legislature shifted its focus from disseminating information about umbilical cord blood banking to taking measures to ensure all races and ethnicities of all incomes have an equal probability of finding a suitable match on public umbilical cord blood registries; and

WHEREAS, Umbilical cord blood collected for public use is in high demand; and

WHEREAS, The collection and storage of umbilical cord blood for public use is free of charge to the donor and listed on public registries for access by health providers for transplantation; and

WHEREAS, Public umbilical cord blood banks have been chosen by transplanting physicians to provide stem cell units for approximately 95 percent of the 20,000 transplants performed to date; and

WHEREAS, Since the probability of finding a tissue match is greatest among persons of similar genetic backgrounds and the current inventory is deficient of genetically diverse umbilical cord blood, especially from specific ethnic, racial, and multiracial individuals, collection efforts are aimed directly at underrepresented groups; and

WHEREAS, Since only about one-third of collected umbilical cord blood is usable for transplantation, the remaining units should be provided to research institutions exploring the potential of umbilical cord blood stem cells to treat many debilitating and lethal medical conditions; and

WHEREAS, The public umbilical cord blood banking system needs financial support to ensure inventories can provide all ethnic and racial groups with an equal probability of a match. Since public umbilical cord blood systems do not charge donors, funds do not flow until units are released to transplanting health providers, at a cost of about \$20,000 to \$25,000 per unit. However, the current low inventory means the number of matches are limited, and this system under which payment is made after a match is found makes it difficult for public banks to generate enough capital to fund significant increases in the inventory without outside support; and

WHEREAS, The federal government enacted the Stem Cell Therapeutic and Research Act of 2005 to collect and maintain umbilical cord blood for public use in transplantation and research. To help in this effort, Assembly Bill 34 (Chapter 516 of the Statutes of 2007) was enacted to create a public banking infrastructure in California that adds genetically diverse umbilical cord blood units to the national public inventory to ensure Californians, who are ethnically and genetically diverse, have their ethnic and genetic diversity reflected in the inventory. The more the inventory mirrors the genetic makeup of our state's population, the greater the chance our constituents will find a match when they are in need; and

WHEREAS, These actions changed California's focus from being about disseminating information about umbilical cord blood banking to funding efforts that would collect and store umbilical cord blood for public use; and

WHEREAS, Since almost half the births in California are to mothers enrolled in state-funded programs who cannot afford to bank privately, their only option is public banking; and

WHEREAS, The National Marrow Donor Program, in a recent plea to states to help increase the national umbilical cord blood public inventory, stated the following:

(1) States can help expand the number of publicly available umbilical cord blood units by appropriating additional resources for the collection and storage of units.

(2) Many states are currently passing legislation that mandates public awareness campaigns or development of educational materials, or both. These efforts can create a demand that cannot be met in many areas and they do little to expand the national public umbilical cord blood inventory; and

WHEREAS, The future of medicine that relies on umbilical cord blood stem cells will likely require both public and private family umbilical cord blood banking systems and collaborations between the two systems. However, without building a viable public banking system, these joint ventures will not be realized and many Californians will be unable to access the benefits of current and future health remedies umbilical cord blood does and will provide; now, therefore, be it

*Resolved by the Assembly of the State of California, the Senate thereof concurring,* That the Legislature desires to find ways to help California gain a viable public umbilical cord blood banking system to ensure all races and ethnicities have an equal probability of finding a match when medically necessary; and be it further

*Resolved,* That the Legislature supports related research being done with collected units that are not suitable for transplantation; and be it further

*Resolved,* That the Chief Clerk of the Assembly transmit copies of this resolution to the State Department of Public Health and the California Institute for Regenerative Medicine.