

# CHER study assesses umbilical cord blood banking by American Indian parents

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Credit: Northern Arizona University

Since the first cord blood transfusion was performed in 1988, doctors have performed more than 40,000 cord blood transplants worldwide to treat more than 80 life-threatening illnesses, including leukemia,

lymphoma, blood cancers and sickle cell disease. Despite the need, about 96 percent of cord blood is discarded from the nearly four million births in the United States each year, according to data from the [Save the Cord Foundation](#).

With less than 1 percent of the American Indian population donating [umbilical cord blood](#) to public cord blood banks, researchers at the Arizona Biomedical Research Centre (ABRC) were interested in discovering why donations were low.

"Cord blood stem cell donation is important for the treatment of several blood disorders and cancers, but many ethnic groups are underrepresented in public cord banks because they often don't have access to public cord blood banks," said Kristan Elwell, an assistant research professor at Center for Health Equity Health Research (CHER) and the Department of Health Sciences at Northern Arizona University. "Most people are more aware of the private banks, but can't afford them."

Private cord blood banking is about \$1,675 plus another \$175 a year, according to the [CBR website](#), a California cryobank company with a center in Tucson.

Elwell said the ABRC wanted to take an ethnographic approach to understanding why donations among American Indian parents were particularly low, so they contacted NAU to conduct the study, which included Elwell, Emery Eaves, an assistant research professor in Department of Anthropology and a CHER affiliate, Julie Baldwin, CHER director and Regents' Professor, Katharine Sanderson, senior program coordinator with CHER, and Robert T. Trotter II, Regents' Professor in the Department of Anthropology. Elwell and Eaves were co-principal investigators on the study.

According to the Arizona Public Cord Blood Program, umbilical cord blood remains in the blood vessels of the placenta and the umbilical cord after the baby is born and the cord has been clamped and cut. It contains blood-forming stem cells and has been proven to be a viable method for treating a variety of diseases.

Cord blood is one of the several places in the body that contain stem cells, others being the brain, heart, skin, teeth, gut, liver, skeletal muscle, testis, bone marrow and more, according to the Arizona Public Cord Blood Program.

"If we can encourage more American Indians to donate cord blood, it will provide more opportunities for patients to get stem cell transplants," Elwell said.

## **Study assesses beliefs, attitudes and cultural practices**

The primary goal of the two-year study was to better understand underlying beliefs, attitudes and cultural practices of American Indian community members that influence views and attitudes toward cord blood donation. Another goal of the study was to assess professionals, such as obstetricians, nurses and nurse-midwives, as potential sources of information for cord blood donors.

"The study was important because beliefs about cord blood donation are not well understood, and without a good understanding of what people know and think about donation, it is difficult for consenters, providers or home health workers to explain the implications of donation to American Indian parents," Eaves said. "It is important that all parents have the information they need to make an informed decision that makes sense for them and that they understand what the program is about when they're approached in the hospital."

The researchers interviewed health care providers including obstetricians, gynecologists, midwives, labor and delivery nurses, childbirth educators, cord blood program consenters, members of American Indian tribes and pre- and post-delivery mothers.

## **Study recommendations**

The researchers provided the ABRC with a list of recommendations:

- Consult with tribal leadership
- Work with hospitals that serve a large percentage of American Indian patients but do not currently have a cord blood program
- Offer training for community health representatives and other health care providers who work directly with American Indian parents
- Create health education materials that will reach a wider audience
- Recognize the role of the family
- Involve traditional practitioners in outreach activities

The researchers believe that providing educational information is crucial for parents to make an informed decision. The team also found that many interviewees who were open to cord blood donation had experience with family members or friends who influenced their beliefs. Younger people and those in urban areas were more likely to donate, according to Elwell.

"I hope that health education for pregnant women and outreach to the tribes continues so that expecting parents can make informed decisions," Elwell said.

## **Developing health education materials**

The researchers commissioned Augustine Molina, a Tucson-based American Indian artist, to create the artwork for both patient educational materials and a presentation packet for community health workers.

"Molina is incredibly talented and he knew exactly what we were looking for," Elwell said.

Project manager Sanderson hopes that American Indian parents will become more informed about the opportunity to donate cord blood and that they will have the information and time they need to make a decision that is right for them and their families.

"Understanding how American Indian belief systems intersect with the western medical perspective is very important to addressing health equity issues," Sanderson said. "It is important to explore how American Indian people know and understand [health](#) information and options that are available to them and how those understandings shape utilization. Medical information should be presented in a way that is clear and enables people to make decisions in culturally appropriate ways."

When cord blood is donated to a public center, the process is similar to blood donation—the donation is stored without connection to a donor name in a public cord blood bank and is listed on a registry to be used for a matching patient. Five hospitals in Arizona participate in public cord blood donation: St. Joseph's Hospital and Medical Center, Chandler Regional Medical Center, Maricopa Integrated Health Services, Abrazo Health Care in Phoenix and Tucson Medical Center in Tucson. There is no public cord blood bank in Arizona; all cord blood donations made in the state are sent to a cord [blood](#) bank in Aurora, Colorado, within 48 hours.

Provided by Northern Arizona University

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