

The ethics of donating breast milk

September 29 2015, by Carrie Arnold

Her milk was the only thing Jen Canvasser could give her babies.

Born at 28 weeks, three months prematurely, Zachary and Micah weighed less than two pounds and were rushed to the neonatal intensive care unit (NICU). The boys were born so early that Canvasser's milk hadn't yet come in. Canvasser may have been a first-time mother, but she knew this: her babies weren't going to receive formula. She believed that milk – specifically, her milk – would give them the best start in life.

Doctors told her to try to pump every two hours to get her milk to come in. So every other hour, around the clock, Canvasser assembled the pump in her hospital bed, attached it to her breast, and willed the milk to emerge. Nothing happened. Her long hair went unbrushed; sleep deprivation and fear lined her bright blue eyes with dark circles.

"It was really stressful," she says. "These little itty bitty guys really needed the nutrition and I was told they would be given formula if my milk did not come in."

After two days, during which the boys were given only minimal nutrients through tubes into their veins, Canvasser finally produced a few milky drops. After filling a tiny syringe, husband Noah took the elevator down to the NICU and dabbed his wife's milk on his sons' lips. Even after another day there still wasn't much milk coming, although it was enough for the tiny boys, who, like most preemies, only took a teaspoon at a time. With the children hooked up to a dizzying array of tubes and machines, their parents couldn't even hold them. Their mother's milk

was their only physical contact.

In that first, tense, terrifying week, Zachary and Micah's doctors came to Canvasser with more bad news: her milk wasn't providing enough nutrition for the twins. The doctors wanted to add a high-calorie fortifier to it to help the boys grow and develop. Canvasser agreed.

But instead of getting better, the boys began to get worse. They stopped breathing while asleep. They began to have trouble digesting.

Canvasser's worry turned to panic on the cold Friday afternoon of the second week when Micah began spitting up. Things got worse over the weekend. By Sunday morning, his belly had become swollen and he was constantly throwing up. On Sunday afternoon, Micah was rushed to the operating room to have part of his bowel removed. Just two weeks old, he had developed a life-threatening disease called necrotising enterocolitis, which had killed parts of his intestines. The infection was so severe his kidneys began to fail.

Advances in caring for premature babies and very-low-birthweight infants (defined as weighing less than 1,500 grams at birth, or 3 lb 5 oz) mean more of them survive longer. But this vulnerable group still has a high risk of necrotising enterocolitis. It affects around 1 to 3 per cent of infants in the NICU and 7 per cent of very-low-birthweight infants, and up to one-third of those infected will die. Numerous research studies have shown, however, that an all-[human-milk](#) diet for premature infants significantly reduces the risk.

With Micah seriously ill, Canvasser finally asked the doctor about the fortifier in the boys' milk.

"They called it a human milk fortifier. I assumed it was some type of benign extra vitamins or something that they were adding. I had no idea what it was," she says. "So I asked, 'What is this fortifier? Can you show

it to me?" The bottle they showed her was a brand of formula.

After searching the internet in the wee hours of the morning, Canvasser found a fortifier made from human milk and persuaded Micah's doctors to switch after two weeks on the formula, but his tiny body was already hopelessly damaged. At 11 months old, having spent 10 of those months in intensive care, Micah died from complications of necrotising enterocolitis.

Micah's brother Zachary, also given formula during his NICU stay, is now a healthy, thriving three-year-old. Still, Canvasser can't shake her fear that the formula had something to do with Micah's death, although there's no way to be sure.

Statistics suggest that Micah would have had a better chance on an all-human-milk diet rather than being fed with formula. But when a mother's own milk isn't providing enough nutrition for a vulnerable baby, the temptation is for medical staff to turn to formula rather than finding a source of human milk. Breast milk donation is on the rise, but will there ever be enough supply for all the babies who need it?

The maelstrom of hormones that help a woman give birth to her baby also tell her body to start producing milk. When the baby then sucks at her nipple, it stimulates the release of the hormone prolactin, which tells her body to produce more. Even so, it can take several days for milk to come in. For first-time mothers, those whose babies were delivered by Caesarean section, and mothers of preemies, the milk supply can take even longer to start.

On the other hand, mothers can find themselves producing more milk than their baby needs, especially if they use an electric breast pump. This has given some the option of sharing the milk their child doesn't need.

Sharing [breast milk](#) is not new. Women have done it for millennia, letting friends' or relatives' hungry children nurse at their own breasts. Other times, women would hand-express their milk into pots or jars to give to families in need. And wet nurses, often impoverished or enslaved women, were often used to provide milk for wealthy children, even if it came at their ability to nurse their own. In the early 1900s, hospitals and charities began freezing and banking breast milk for sick babies.

North America is currently home to 19 milk banks, with nine more opening their doors soon. The Human Milk Banking Association of North America, which helps to run and accredit these banks, has gone from dispensing around 400,000 ounces of pasteurised donor human milk per year in 2000 to 3.8 million ounces in 2014. John Honaman, its Executive Director, says that the rise is due to both an increase in awareness of the health benefits of breast milk and an increase in the number of preterm infants who desperately need donated milk.

"More people understand the importance of what pasteurised donor human milk can do for a child," Honaman says. "We're a bridge from the time that a child is born to the time that their mom can breastfeed... Because at the end of the day, we all know the benefits of breastfeeding."

Breast milk can vary substantially from woman to woman. Mothers of preterm infants have milk that is higher in protein and fat. A vegan might produce breast milk with different nutritional content than a woman who eats meat. The composition of breast milk also changes as the baby gets older, becoming less nutrient-dense over time. But although [donor milk](#) isn't identical to the baby's own mother's milk, it still has many of the same benefits, passing along valuable antibodies that protect the baby from disease.

Some parents are squeamish about giving their children milk from a

stranger, but more and more neonatologists are framing it much more simply.

"We tell them that this milk is medicine," says Amy Hair, a neonatologist at Texas Children's Hospital in Houston.

The last few weeks of pregnancy are a busy time. Not only does the fetus continue to grow in size, but organ systems are rapidly maturing. Some of the last organs to finish developing are the brain, lungs, stomach and gut. Not surprisingly, this means that babies born prematurely often have difficulties with brain development, breathing and digesting food. Many preemies, especially those born before 32 weeks, have a digestive tract that is as thin and fragile as tissue paper, making them especially vulnerable to diseases like necrotising enterocolitis (NEC).

NEC was first described in 1965, but 50 years later scientists still aren't sure what causes it. Mark Underwood, a neonatologist at the University of California, Davis, and leading expert on the disease, believes it is caused by an interaction between normal gut bacteria and the preemie's still-developing immune system.

Even as a baby is being born, bacteria from the outside world begin to colonise the skin and intestines. Far from being harbingers of disease, many of these bacteria are neutral, even helpful. Breastfed babies have a more diverse range of microbes living in their guts than formula-fed babies; researchers believe this helps prevent damaging infections from taking hold. The fragility of the digestive tract in preemies means that even small numbers of dangerous bacteria can cause diseases like NEC.

But bacteria on their own aren't enough. What seems to cause most damage to the digestive tract of an infant with NEC is the baby's own immature immune system. Underwood helped to discover this interaction when investigating a strange aspect of the disease. His work

showed that the earlier a preemie is born, the older they are when they develop it. Babies born around 24 weeks are most likely to develop NEC when they are six weeks old, but babies born at 29 or 30 weeks are only two or three weeks old when their risk is highest. A quick calculation reveals a high-risk period when a preemie is around the equivalent of 30 to 32 weeks' gestation – the age of Micah Canvasser when he got sick.

Extremely premature infants – those born before 30 weeks – lack much of an immune response at all. But once a baby gets beyond 32 to 33 weeks of gestational age, the immune system has matured enough to be able to turn on a response to potential pathogens and also to turn it back down when the danger has passed. That middle period, however, is when the immune system is only partly mature. Preemies in this period, Underwood believes, lack the capacity to switch off the immune system's attack on bacteria living in the gut.

Human milk helps support the immature immune system, according to Hair and Underwood. Besides water, fat and lactose, the three largest components of breast milk, it contains many things that help fight disease, such as antibodies. It also contains human milk oligosaccharides, which can't be digested by the baby but are the preferred food for many healthy bacteria living in the gut. If there are large numbers of healthy bacteria in the gut, that doesn't leave room for disease-causing ones. Another component of breast milk is lactoferrin, which tightly binds iron, making it unavailable to dangerous bacteria that need it in order to survive. In short, breast milk creates an optimal gut environment, especially in premature infants.

Still, Underwood points out, breast milk isn't perfect for preemies.

"Preemies are unfortunately limited in the volume they can take, and the amount of nutrients in human milk really didn't evolve for preemies. And so we know pretty clearly, [small premature] babies who get

unfortified human milk, their rate of growth is going to be poorer than if they get fortified milk, and that has an impact on their brain development as well," he says.

Trials in the 1980s and 1990s that first compared breast milk to formula found that preemies grew better on formula because it had more calories per ounce than breast milk. More recently, NICUs have begun to fortify human milk to ensure that these babies have the nutrients they need to grow and develop as well as all the benefits of breast milk.

"If you don't focus on nutrition and give them the appropriate amounts of protein, they rapidly lose protein... The way you add the human milk fortifier, you can actually give high protein," says Hair. "We know mother's milk has antibodies, immune factors; while donor milk is pasteurised and has a little less of those components, it still has quite a bit of those immune factors."

Angel works on the fourth floor of an ageing brick high-rise, at the end of a dim, narrow hallway. The windows of her office look out onto a leafy courtyard where physicians and support staff bustle in white jackets and scrubs. The noise from Angel working nearly drowns out all sounds of conversation in the room. Angel is a squat silver chest about waist-high. She is the \$100,000 milk pasteuriser imported from England to Norfolk, Virginia. At North America's newest milk bank at the Children's Hospital for the King's Daughters, Angel sterilises around 2,000 ounces of milk every week, Monday through Friday.

The manager of the hospital's Mother's Milk Bank, Ashlynn Baker, gave Angel her nickname because she kills deadly microbes that can sometimes be found in donor milk, playing a key role in the process that takes milk from donating mothers and gets it to babies in hospital. Donors can bring their milk in person or freeze it and have it shipped overnight in a cooler at no cost.

"We have a lot of [military] moms come in wearing combat boots and fatigues, and they're getting a lot of support and they're pumping a lot at work and they're bringing us a lot of milk," says Baker. "But we get donors from up and down the east coast. It really blows my mind."

To balance the milk's nutritional content and maximise the antibodies that the fragile babies receive, Baker pools the milk of five mothers before heating it to 62.5°C in Angel. The milk is then frozen and can be safely stored for up to a year in two- or four-ounce bottles. A single ounce of milk can provide up to four feedings for a baby in the NICU.

The idea for this milk bank was planted in 2012. A statement from the American Academy for Pediatrics said: "all preterm infants should receive human milk. Mother's own milk, fresh or frozen, should be the primary diet, and it should be fortified appropriately for the infant born weighing less than 1.5 kg. If mother's own milk is unavailable despite significant lactation support, pasteurized donor milk should be used."

Not long after reading this statement, Baker held a baby who had been born at 27 weeks as he died in her arms from a disease that human milk might have helped to prevent. She herself was 27 weeks pregnant at the time. "I knew it was time to advocate," she says.

Baker and the NICU began working with the nearest milk bank – in Raleigh, North Carolina, a three-hour drive to the south-west. Not long after, the hospital's board of directors asked her to give a presentation on the new protocol and several days later said they would put up the \$500,000 to build a milk bank. In just 15 months, Baker had it up and running.

Local mother Stephanie Leverett has been their largest donor, providing 10,882 ounces of milk that her daughter Kennedy didn't need. "A quarter of an ounce is one treatment, so that's almost 50,000 treatments,"

she says. "It's pretty emotional to think about it."

Becoming a donor was relatively easy. The Human Milk Banking Association of North America (HMBANA) requires that all donors fill out a lifestyle questionnaire that asks questions like what medications and supplements a mother takes and whether she smokes. Blood tests check for communicable diseases that can be passed through breast milk, such as HIV and hepatitis B. Lastly, Leverett had to get letters from Kennedy's doctor and her own saying that she and her baby were healthy. Then she was free to start making donations to help sustain fragile babies until their own mothers can begin providing breast milk.

Hair, the neonatologist in charge of nutrition at the Texas Children's Hospital NICU, found that when her hospital shifted to all-human-milk diets, infants were able to move off feeding tubes more quickly and go home sooner. Premies who exclusively received breast milk, whether from their own mother or from a milk bank, were also less likely to die from a number of causes.

But what she found most promising was a dramatic fall in cases of NEC. At her NICU, rates of NEC in very-low-birthweight babies plunged from 10 per cent (the US nationwide average) to just 2 per cent.

"There have been studies that show babies grow a certain way while they're still in the womb... The challenge has been how can we mimic that and try to do the best job we can to give the nutrition as if the baby were still in utero," Hair says.

"These babies don't receive formula, they don't receive cow protein, and they have amazing outcomes. They're healthier. They have less infection. They grow better."

It all seems very simple. Some babies need breast milk that their mother

can't produce; other mothers are producing more than their babies need; human milk banks take the excess and give it to those in need. But as more parents and hospitals seek to use pasteurised donated milk, HMBANA banks have begun experiencing shortages. For-profit milk banking companies have sprung up, and milk can be bought and sold online, with fewer or no checks on quality or contamination. It's becoming a lot more complicated than simply sharing.

In 2015, Sarah Keim, an epidemiologist at Ohio State University, published an analysis of 102 samples of breast milk she'd purchased online. Eleven had significant amounts of cow's milk. "That is a concern," she says. "We were surprised to find the extent of that problem." Once money becomes involved, she adds, it becomes more likely that people will adulterate breast milk to make a quick buck.

But more than that, does paying for donated milk change the nature of the relationship between the women involved?

In 2011, Afrykayn Moon, then 32 years old, was nearly arrested for breastfeeding on a city bus in Detroit, Michigan. What angered her the most wasn't the bus driver calling the police but rather the response she got from other mothers: "I was getting emails from people telling me how horrible a mother I am for wanting to breastfeed and doing it in public," she says. "I had a lot of people who were actually surprised that a black woman was breastfeeding, period. They didn't know we still do that."

It is true that fewer black mothers in the US breastfeed than white and Hispanic mothers – 59 per cent of black mothers versus 75 per cent of whites and 80 per cent of Hispanics. In Detroit, only 40 per cent of mothers ever even plan to breastfeed their children. Determined to change this, Moon founded Breastfeeding Mothers Unite to educate black women in Detroit about the health benefits of breastfeeding in the

hopes that more of them would do so.

Then she learned about a new initiative by a company called Medolac.

In late 2014, the Oregon-based company had partnered with the Clinton Global Initiative to reach out specifically to low-income Detroit mothers and pay them a dollar an ounce for their breast milk. While these payments were to compensate donating mothers for their time and effort, the idea behind this particular scheme seemed to be that if cash-strapped women could make money from their milk, then more of them might breastfeed their children, if only to keep producing milk.

Moon immediately cried foul. The idea that the ability to earn money from breast milk would encourage low-income mothers to breastfeed their children was "absurd" to her.

"If I'm breastfeeding but my electric bill needs to be paid or my rent needs to be paid, or my water bill needs to be paid, and I know I can sell my milk to this company and then I can get my bills paid, well guess what I'm going to do," she says. "I'm going sell my milk to keep my bills up, and not a drop of that milk is going to go to my child."

With Detroit's low rate of breastfeeding and one of the country's highest rates of infant mortality (15 of every 1,000 children in Detroit die before their first birthday), Moon says that the city needs every last drop of breast milk. The Medolac move also brought back a sinister association to Moon. Enslaved black women were often used as wet nurses for white children, leaving them unable to provide milk for their own children.

"This is the face of slavery coming back," she says.

Georgetown University philosopher and bioethicist Rebecca Kukla says that, while some tactics used by companies might be perceived as

exploitative, there's nothing inherently unethical about a woman selling her breast milk. "There's a difference between what someone does out of economic necessity and what they do as a private choice to make their life work," she says.

It's the choice 33-year-old Detroit area mother Andrea Short made. She breastfed her first child, Jaden, with no difficulties, but when her daughter Johanna was born, she wouldn't latch on. So Short began to pump in order to feed Johanna breast milk with a bottle. Soon, however, Short had pumped way more than Johanna would ever need and was running out of freezer space to store the milk. That's when she found out that Medolac was willing to buy.

Over several months, Short sold more than 5,000 ounces of milk that Johanna wasn't using, providing her young family with needed income. Although both Short and her husband, Jonathan, work full-time (she in a hospital and he as a firefighter), the family relies on benefits from the Women, Infants and Children programme to make ends meet. With part of the money from Medolac, Short bought a swing for their large front porch that gives her children a safe place to play.

"I was grateful for the money and the opportunity I had," she says.

Short, who is biracial, says that she represents Medolac's target audience and resents the implications that mothers who sell their breast milk would do so at the expense of their children. "I will always put my children first," she says. "Always."

As soon as Moon heard about Medolac's plan, however, she teamed up with other local non-profits, including the Black Mothers' Breastfeeding Association, and began sharing as much information as she could online. Women from around the country wrote and signed an open letter to Medolac, asking them how paying mothers for breast milk would ensure

that more local children were breastfed.

Medolac, which defines itself as a "public benefit corporation", was taken aback by the furore. Doug Hawkins, its Senior Vice-President for Corporate Affairs, says that in all his years of working in the for- and non-profit sectors, he had never seen anything like it. "We partnered with local organisations," he explains. "Those that weren't in the circle got their knickers in a twist, so to speak. They completely poisoned the environment," he adds, calling the response "completely irrational".

Nine days after the open letter was published, Medolac abruptly cancelled its plans.

State Representative Erika Geiss has since drafted a bill for the Michigan legislature that sets up guidelines for companies that want to purchase breast milk. Her bill requires that all collected milk is pasteurised and tested, that the milk goes to the infants most in need first, and that participating women get support and education about breastfeeding. If they have a nursing baby, the infant must get as much of their mother's own milk as required before any excess milk gets sold.

"I would never want to see a system set up where someone could 'farm' a mother out to provide milk," says Geiss.

Blood and tissue donation work entirely on altruism; many people think breast milk should be no different. John Honaman says the Human Milk Banking Association of North America sees no place for profiting from breast milk, and thinks the system is at its best when mothers who have received donated milk decide to then donate in turn.

"If we were faithful to the needs of a community, we would always want to be in a position whereby the need is associated with the supply because you have a perfect circle," he says. "Moms need to give, kids

need to receive."

Morgan Bryan is a schoolteacher in Houston. She saw the benefits of an all-human-milk diet for her twin boys, Austin and Jonah, who were born at 24 weeks. Her milk hadn't come in, and with the agonising stress of watching her tiny, vulnerable infants barely cling to life, she had trouble producing any milk at all. So when Austin and Jonah's doctor asked the Bryans if they would be okay with their children receiving donor human milk, they didn't hesitate.

"I didn't ever think twice. They had multiple blood transfusions and it's the same thing. And if that is what they needed, that is what we're going to give them," says Bryan. "I was so excited that Jonah could take milk, I was in immediately."

Several days later, Bryan was producing enough milk that she was able to feed her sons with her own. The twins also received a fortifier made from donor human milk. As a result, Austin and Jonah sailed through the high-risk period for NEC.

At eight weeks, Austin died of an unrelated infection, but Bryan was so grateful for the donor milk her sons received that she donated her own excess [milk](#) to the Texas Children's Mothers' Milk Bank.

"There's just a nice feeling," she says, "because I know that my kid needed it at one point and I know that when you're sitting in the NICU and you can see all the other babies, you know that those babies are getting it as well."

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