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## Bobby's Dairy: Nursing a Baby with Chylothorax

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"Your baby cannot have your milk." The words shot through me like a bolt of lightning. I looked into the doctor's eyes and choked out in utter shock, "What?" He repeated softly, "The baby cannot tolerate the fat in your milk. He cannot have your milk."

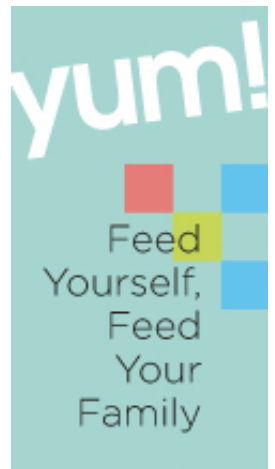
My mind went blank, and then raced with denial. As a La Leche League Leader, countless times I'd heard distraught mothers say their babies couldn't have their milk. Most of the reasons were due to misinformation and were situations where premature weaning could easily have been avoided. So the statement "Your baby cannot have your milk" was familiar to me. But somehow I knew this time it was really true.

The doctor went on to explain that my three-month-old son was experiencing a complication from his open-heart surgery to correct a congenital defect. His lymphatic system had been damaged, so his body was unable to deliver fat to his bloodstream correctly. Instead, fat was accumulating in his chest cavity. The doctor showed me a white drainage in the tubes coming from my son's chest. He said it was called "chyle" and was a form of fat.

I have nursed three children well past toddlerhood. None of them needed it as much as this one. He was septic, meaning he had a blood infection. I was sure the antibodies in my milk would pull him through. Now, a life threatening septic blood



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infection seemed insignificant in the face of not being able to nurse my baby.

Barbara Ackerman, RN, IBCLC at Yale New Haven hospital, came to support me, but she could only try to soften the blow by telling me that it was temporary, that the damage would heal, and that sometimes they can feed babies special formula mixed with a little bit of human milk.

My son, Bobby, had sustained a complication that, according to his surgeon, affects 30 percent of pediatric open-heart patients; the condition is chylothorax, from "chyle," which means emulsified fat, and "thorax," which means chest cavity.

When a healthy person eats a meal containing fat, the fat is picked up by the stomach, transported up the chest wall by the lymphatic network, and transferred via a vessel to the bloodstream. Once in the blood, the fat can be used as a nutrient to fill the body's needs. In Bobby's case, the vessel had been damaged by the surgery and now the emulsified fat was dumping out of the vessel and accumulating in the space between his lungs and his chest wall. As this space filled with fatty fluid, his lungs could not expand, resulting in respiratory distress. This made it necessary to use chest tubes to alleviate the pressure and fluid build-up. In my son's case, this resulted in two more months on a respirator.

I knew something was wrong before the doctor made his pronouncement. I had held Bobby in my arms. It was five days after the surgery. He had been off the respirator for two days and was recovering without incident, so the doctors agreed to let me begin nursing him.

Everything started to feel right again as I held him close to my body and felt his warm cheek nuzzle against my breast. As the day progressed, however, the feeling of peace I had in the morning gave way to worry, anxiety, and finally terror.

Bobby became increasingly short of breath after his 10 am nursing. By noon he had difficulty getting a deep breath and his nostrils were flaring from the effort. His chest muscles heaved, showing his ribs with each inhalation. He would wake up every 20 minutes screaming, but would refuse to be comforted at my breast. Early afternoon found him too lethargic to rouse, and struggling to breathe. By evening, he was panting at 80 to 100 breaths per minute. His only response was to sporadically open his eyes and look into mine as if to say, "I don't

know how much longer I can do this, Mom. Make it stop." My baby was suffocating.

I was actually relieved when the doctors finally decided he needed to be put back on the respirator. Heavily medicated, he once again looked peaceful while the machine did all the work of breathing. A follow-up x-ray showed the fluid build-up around his lungs, which prevented air from getting to his lungs.

The usual treatment for chylothorax is to give the patient no food by mouth (NPO) for a time, hoping that an empty stomach will allow the vessel to heal. He was given nutrients through his veins known as TPN (total parenteral nutrition). It is inferior to any oral food, but was the best they could do. Surgical repair is impossible at this time, as the vessel is the size of a strand of hair. Bobby was kept NPO for two weeks, but the drainage did not subside.

The next strategy was to feed him Portagen by mouth, a specialized formula that consists of 15 percent long chain fatty acids. I knew that human milk has 40 percent long chain fatty acids and because of that, we didn't think there was any way to use my milk. For the next two days, Bobby was given Portagen via a tube placed through his nose and into his stomach, but the drainage increased, so he was switched back to TPN.

Etched in my mind forever will be the day I was at my son's bedside during a routine dressing change of one of his four chest tubes. When the nurse unveiled the area, I was appalled to see that a 2 inch (5 centimeter) crater had formed around the half inch (2 centimeter) chest tube, a sure sign that the nutrients he was absorbing were not adequate. Skin health is considered one of the most accurate indicators of nutritional status. Though I knew physical touch was vital in this situation, I was discouraged from holding my child in my arms because the sutures, which held the chest tubes in place, often tore through his fragile skin as if they had been sewn into butter. The breathing tube, which barely rested against his lips and chin, had caused a large bruise underneath. I thought of my other, healthy robust breastfed babies, and here was my son, my beautiful breastfed baby boy, literally starving to death. It seemed as if his life was draining out the tubes.

The physician in charge of the pediatric intensive care unit, Dr. George Lister, was brought into the case and spoke to us about the need for Bobby's nutrition to be maximized. He explained to us that

we were in a tough situation. If Bobby continued to drain the amount of nutrients at his present rate, he would not have the nutrients he needed to heal the duct. But if the duct did not heal, he would continue to drain the needed nutrients. The doctor made nutrition an absolute priority and fortified the nutritional components in the TPN as high as safely possible. Ideally we needed a fat-free form of food for Bobby's stomach, but there was nothing available.

During that time I continued to pump and freeze my milk, praying for the day he would be able to receive it. Pump, freeze, and wait was my daily routine. After weeks of drainage and no food by mouth, Bobby's condition was deteriorating rapidly. John and I decided that if we wanted our son to come home alive, we had to take the matter into our own hands.

While the medical team was trying these interventions, my husband, John, and I had already begun tapping into our LLL network for possible solutions. We received a short article from the LLL Area Professional Liaison, Sue Iwinski, that told of a mother in 1995 who had been in a similar situation who made skimmed human milk for her baby in Alabama, USA. It listed all the names of the people who helped. Sharon Joslin, APRN, CNS, IBCLC, NNP also of Yale New Haven Hospital, attempted to contact those involved. Unfortunately, we found out all the people involved had left the University of Alabama Medical Center, but we were able to locate Connie Carlisle (who is an RN, BSN, and IBCLC), the original lactation consultant. Sharon and Connie discussed the specifics of what needed to be done, and passed the information on to my husband, John, who would actually do it.

The milk needed to be spun in a centrifuge at a specific force of gravity over a specific amount of time. The only problem was that we did not own a centrifuge, and we could not use the centrifuges at Yale New Haven Hospital. Centrifuges were normally used to spin "blood and body fluids," so whatever human milk we would spin in these would not be fit for human consumption. John would not be deterred. If necessity is the mother of invention, then desperation is the father of creativity. John spun it in our top-loading automatic washing machine.

His first attempt to centrifuge the milk was to tape full bottles along the inside of the washer drum and put it on the spin cycle. However, while the fat went

to one side of the bottle and the skimmed to the other, there was no way to drain the skim from the cream when the washer stopped. Next he tried drilling some holes in pine boards and inserting them into the washer. This positioned the tubes of milk at an angle so the components would separate—fat to one end, skimmed to the other—and could be carefully poured into separate containers when removed from the washer.

When John wasn't busy finding a way to spin the milk, he and Sharon Joslin were searching the hospital supply rooms for ideas to aspirate (pull) the fat out of the milk, while leaving the skim behind. Bonnie King, a researcher at the hospital, happened to be conducting work on the potential use of human milk cells as a means of detecting early stages of breast cancer. She had experience with the physical properties of human milk, and after much trial and error, the three comrades were able to find a device and method that would fit our needs.

I was now in charge of finding a place where the milk could be tested. The research hospital labs were not capable of analyzing milk components accurately, and Dr. Lister required proof that we had fat-free milk before he would allow its use. I called local health food stores, which finally led me to Organic Valley Farm, an organic dairy farm. They explained that they sent their milk samples to a lab in Berlin, Connecticut, USA, called Northeast Labs.

Dr. Alan Johnson, Director of Northeast Labs, explained that the test we needed was called a Babcock butterfat test. After hearing the situation, he told John to bring the samples as quickly as possible to the lab and he committed to having the results faxed to the hospital within hours of receiving the needed samples.

The skim milk idea was now going to become reality. The biggest problem was the hospital did not have an area or a centrifuge to produce skim milk. So John went to the Internet, found Labnetlink.com, purchased a lab quality centrifuge, and had it delivered to the house the next day. He set up a lab area in our computer room and ran the first batch of skim milk.

John made five samples of milk that day: whole breast milk, breast milk aspirated after it was left to stand for 48 hours and naturally separated, milk spun in the washer, and two centrifuge samples. As

promised, the results were faxed to the pediatric intensive care unit. It showed that the centrifuged milk was the best by far with .02 percent fat per 100 cc of skim milk.

We finally had "fat-free" milk. We talked with the doctors and gave our son every ounce of our healing energy during the day, and then took turns making the skim milk by night. I pumped, John spun. I spun, John delivered. Each day we brought in a fresh batch of milk.

About this same time, the medical team was doing research of their own, and found there had been success in treating chylothorax conditions with a drug called Octreotide, which slows the absorption of food from the stomach. The drug is a synthetic form of a hormone in our blood called somatistatin. The drug was originally intended for use in people with persistent diarrhea from chemotherapy, but it had only been used once before in treating a baby after open-heart surgery. It was worth a try. Months later, we discovered that human milk contains a high level of somatistatin—four times more than human blood.

My skim milk was started, slowly at first. We all held our breath as we watched the chest tubes, hour after hour, for a change in the drainage. To our relief, it did not turn a whitish color, nor did the drainage begin to increase. In fact, it started to subside. We slowly increased the amount of milk Bobby was receiving, and by the end of the week, Bobby was receiving full feeds of one ounce (30 cc) per hour. When he could tolerate it, the skim milk was then fortified with protein and carbohydrate supplements. MCT (medium-chain-triglyceride) oil was added to increase the caloric content of the skim milk, and the essential fatty acids were supplemented by adding a small amount of Evening Primrose oil.

Bobby began to thrive. The infections subsided, his skin began to heal, the bruise from the breathing tube faded away, and his vital signs improved. Two months after his surgery, Bobby finally came off the respirator. All the doctors at the hospital eventually realized that my milk saved Bobby's life. Bobby became quite popular, as he was "shown off" to visiting doctors, specialists, and other lactation consultants. One of the nurses jokingly said one day, "You know, I've given all kinds of medications in all kinds of doses, and it doesn't disturb me at all. But when I pick up this milk, knowing all that went into making it, I shake and just pray I won't drop the

bottle.”

After three months in intensive care, Bobby finally came home. Initially he continued on the skim milk, but after about a month, he had trouble gaining weight. We decided it was time to try full fat human milk again, which we introduced very slowly. At first, to every 100cc skim milk, we would add 10cc whole milk. Three days later we increased it to a ratio of 80cc to 20cc, all the while staying keenly alert to his effort in breathing.

A month later, Bobby was receiving full fat human milk. I remember thinking how satisfying it was to see his feeding tube an opaque white color instead of the transparent, watery hue it showed with the skim milk. We then did the whole process backwards, and fed the cream to Bobby at night to boost his caloric content. He was able to gain weight beautifully and increased his strength.

Unfortunately, though he could now receive whole milk into his stomach and would have been able to nurse once again, he would no longer suck. Bobby had experienced so many invasive procedures in his mouth, his body moved the gag reflex from the normal position on the back of his tongue to the front of his mouth. He developed an oral aversion because his mouth did not feel safe. Even light touch on his cheeks would result in him screaming, turning blue, and throwing up. Not exactly the warm fuzzies I was used to with laughing eyes and contented gurgles from a satiated breastfed baby.

The first breakthrough to the oral aversion was being able to put my finger or nipple in his mouth, just past his lips. He would lick the dripping milk from my breast, and it left us both feeling hopeful as we joyfully anticipated the day he would latch on and suck the food he was meant to have, the way he was meant to have it. I will never again take for granted nursing a child. I now have seen the true benefits of a human baby receiving human milk, and I know that Bobby has served as an instrument for the medical community to witness that as well. We now hope that when other mothers hear the words, “Your baby cannot have your milk,” they will be receiving care from a knowledgeable health care provider who also says, “But there may be another way.”

***Editor's note:*** Trish has continued to pump. Bobby still receives her milk by cup or occasionally by bottle. Trish has been told by his doctors that human milk is the reason Bobby has been able to

*avoid being readmitted to the hospital.*

#### Making Human Skim Milk

1. The whole human milk is placed into tubes that have outlets at the base.
2. The tubes are placed in the centrifuge.
3. The milk is centrifuged for six minutes at 1.03Gs to obtain the required force to separate the milk parts. (The centrifuge used determines the RPMs per the manufacturer's recommendations.)
4. When the centrifuge opens, the tubes of separated milk are gently taken from the centrifuge.
5. The "skim" milk can be removed from the tube. The end cap at the base of the tube is removed allowing for the "skim" milk to flow out. As the "fat" layer gets near the tube exit port the flow is stopped. The remaining "fat" layer from the tube is put into another container for use later.

For more information on making human skim milk, you can contact John Zabarsky at 203-262-1154 or by writing to Chester2001 at earthlink.net (email).

*Trish Whitehouse is the mother of four children: Hannah, 12; Nathan, 9; Carrie, 6; and Bobby, 3. She lives in Southbury, Connecticut, USA, with her children and husband, John. She is a registered nurse who, when working outside the home, was a cardiac rehabilitation nurse. She has been a La Leche League Leader for the past 10 years. Trish's hobbies include writing, swimming, and obedience training her Golden Retriever dog, Canyon. Patty Spanjer is the Contributing Editor for feature articles in Leaven.*

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