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In the Telling

They waited together for hours in plastic chairs bolted to the floor.

The doctor came out. She had made it. They would need 30 minutes to settle her into a room in the PICU.

The mother left the hospital, walked the streets of the busy city until she could return and see her again. She passed many people. Most of them looked bored, tired, exhausted. One woman walked with tears and did not return her gaze.

Five months later they took their daughter home.

When the red-headed charge nurse poked her head into her room, she had a funny expression on her face, like the one our favorite nurse from upstairs had worn on our daughter's birthday, when she arranged for a little surprise party from the medical staff on the floor. Of course, our poor baby was in a sorry state from all the toxins her failing liver was unable to filter before they passed on to her brain, leaving her less an infant on the cusp of toddlerhood and more like a helpless newborn. A newborn jaundiced deep yellow, hungry, sleepy and easily frightened. A newborn who cried forlornly as they sang "Happy Birthday" to her.

And then everyone shuffled out of the room, uncomfortably aware that sometimes making the best of an awful situation turns the whole thing into something like comical tragedy, a reminder of how grotesquely abnormal life has become. I appreciated their efforts, anyway, and I still have the card with a handwritten message from our first resident.

So when this nurse popped her head into the PICU room, looking like she was about to offer gifts, and perhaps even sing a few celebratory tunes, I felt pretty sure I wasn't in any emotional state to deal with whatever she had to offer. But instead of breaking into a rousing chorus of "Tomorrow," she only said, "I'm going to transfer a call into your room, OK?"

Figuring that the lateness of the hour had required her to check with me before allowing the call through and that I must have simply misread her expression, I reached for the phone when it rang a few seconds later. It was Angel, an employee of the transplant program I had met a few times when our daughter was first placed on Chicago's waiting list for

liver. He had never called before, and I knew immediately why he was calling this time.

I hadn't misread the expression on the charge nurse's face, after all.

For the nurse, the moment was perhaps one of those that make her grueling job worthwhile. A child on her unit was being given a chance at life. She was not new at her job. She knew that some could be saved, and others could not, and that there was no cosmic arithmetic sparing some at the expense of others. There was nothing to be done but celebrate the saves and mourn the losses, and try not to tote them up against one another on a whiteboard, as if proper analysis would yield the answer to the "Why?" she saw written on most of the faces leaned over beds up and down the hall.

For me, only my head could take that global view. An overflow of sorrow many weeks ago left my heart mostly in charge of my reactions. And, thus, even this news, great, fantastic, shout-it-from-the-mountain news if ever there were something worth shouting, was suffused with the sorrow of our months of waiting. We were told the donor was a teenager and from somewhere just outside Chicago. That families' grief and our reprieve were bound together, now through the tenuous connection of a telephone line, but soon to be through the most physical connection imaginable.

Over the next hours, they prepared her body for the strenuous surgery ahead. She was cleansed, carefully and thoroughly. I had to turn her away from my breast when she snuffled in, looking for the ever-present comfort. Instead I could finally allow myself to whisper into her ear all the amazing moments of life just waiting for her on the other side of just one more difficult night.

We didn't see her surgeon before they took her, which was probably for the best. He is an amazingly skilled man with a fantastic reputation, but surely he must have noticed the disbelieving look parents give him when they shake his hand, certainly more bear-like than seems reasonable for a man who makes a living operating on the tiniest blood vessels in the tiniest of places. It's hard to imagine such a big guy safely cutting my baby's fingernails, despite what all our research told us about his success.

At the scheduled time, we signed the last of the paperwork. And, then, one last gift for us before they carried her off for the most important hours of her life since she managed to squeeze herself under my unfortunately inverted pelvic bones. They give her something, some drug, that finally freed her from



Annika

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the oppression of her sick body, and we see her smiling goofily back at us as the anesthesiologist wheels her off.

We hadn't seen that smile in ages, and it's like a promise to us that our child is still in there and all this has been worth it.



Once, when he was little, her son had been flipping through the channels when he happened upon one of those commercials with a trembly-lipped Sally Struthers explaining how little money it would take to save the life of a child in a poor village halfway across the world. He rushed upstairs to dig out the change he'd squirreled around the room he shared with his younger brother. When he explained to her that he already had one year covered, she wrapped him in her arms.

Eight years later, she held his hand and watched him breathe in and out. Watched a machine breathe in and out for him. She heard the doctors explain the situation; she heard them tell her that he was already gone; she heard them, but she didn't believe them. She just wanted this to be over. She wanted him to wake up and come home and flip through channels again instead of doing his homework. She did not even want to think about what was being asked of her. Better just to turn off the machines and let it be peaceful.

Then, in a rush of memory so forceful she almost had to let go of his hand, she saw him holding out his change to her.

She squeezed his hand when she said, "Yes. OK." Of course, he didn't squeeze back. But there was something in her chest, some sort of pressure, pleasant like the heavy feeling of a child's sleeping head nestled between your breasts. And then it was gone.

Posted by thewaitandwonder on 08/01/2006. Thewaitandwonder.com is a blog on ClubMom written by Moreena, mom to 5-year-old Annika, who is currently waiting for her third liver transplant, and 2-year-old Frankie.

Moreena has never met the donor family that gave her child life, but she thinks of them often, in awe of their strength and compassion. In this blog entry she has imagined the donor mom's thoughts.

PARTNERS IN LIFE LAW ENFORCEMENT PROGRAM

In October 2005 the Partners in Life law enforcement program was launched in Oregon by the Oregon State Police in cooperation with the Lions Eye Bank of Oregon and Community Tissue Services of Portland. In the first five months of the program there were eight donors, resulting in 11 cornea transplants and over 150 tissue transplants.

The program, which began in the state of Washington in 2003, was created in order to offer donation to those families whose loved ones died outside of the hospital setting. Under current federal guidelines families are given the option of donation only when a loved one dies in a hospital. With less than one third of all deaths in Oregon each year taking place in a hospital and with over 1.4 million Oregonians having a "D" code on their drivers license, a system of notification was lacking until now.

With the passage of House Bill 3197, ordered by the House May 2, 2005, and including House amendments dated May 2, 2005, the Lions Eye Bank of Oregon and Community Tissue Services of Portland have begun working with local law enforcement agencies to implement the changes throughout the state of Oregon. In June we began our first test phase, which consisted of the Washington and Multnomah County sheriffs' offices. Each county opted for a different policy to determine which would be the most successful. In the first two months of the test, we had five donors, resulting in 10 cornea transplants and over 100 tissue grafts for transplant.

The process is simple, but the impact is great. With one phone call to the donor referral line, Oregon's law enforcement personnel are providing families an opportunity to turn some of our community's most heart-wrenching tragedies into improved quality of life, or even life itself, for others.

In early November we will begin rolling out the program to all law enforcement agencies throughout the rest of the state. Because of the increased number of referrals, the Lions Eye Bank of Oregon and Community Tissue Services of Portland are busy implementing changes to accommodate the ongoing in-house and remote needs. Given the early success of the program, we are excited about the possibilities for the future and look forward to keeping you up to date on this program's progress.

TISSUE GRAFT RECIPIENT AMAZED AND THANKFUL FOR HER RECOVERY

As an intensive care unit nurse in Portland, Ore., Cynthia Peachey's work day is very active. She helps take care of patients who've had kidney and pancreas transplants and is very familiar with organ donation because of her job – through both direct care and through her role as a member of the hospital's transplant committee. But it wasn't until she injured her knee in a kick-boxing class that she learned about tissue donation and about how the use of donation tissue enhances, and sometimes saves, lives.

When Cynthia met with her surgeon to discuss her torn interior cruciate ligament, he explained to her his desire to use a 14-year-old's Achilles tendon to repair her injured knee. He indicated her recovery would be much quicker and better with the donated tissue. Amazed that this was possible, Cynthia readily agreed to the proposed surgery and was thankful for the donated graft.

Always an active person, Cynthia remains involved in hiking, biking and swimming. And she is still amazed at the benefits of tissue donation. "Prior to my surgery," Cynthia says, "my awareness of transplantation was limited to major organs. But after my surgery, I realized there is so much more which can be donated to help so many people – so many people can be helped a lot."



Cynthia Peachey, tissue graft recipient

OREGON DONOR PROGRAM NEWS

Save the date – Thurs., Nov. 2! Oregon Donor Program's signature fundraising event, the Lifesaver Breakfast, is scheduled for 7:30 a.m. at the Governor Hotel in Portland. Joining emcee Craig Walker, former K103 radio personality and a liver recipient, will be Olympic snowboarder and liver recipient Chris Klug as featured speaker. Proceeds from the event will help launch the *DonateLifeOregon* registry in 2007. Contact ryand@ohsu.edu or 503.494.7888 for more information about the Lifesaver Breakfast.

Oregon Donor Program is participating in the Donor Designation Collaborative (DDC), the exciting national effort to increase the number of Actionable Donor Designations in the U.S. from the current estimate of 60 million to over 100 million by April 2008. This will mean that 100 million Americans will have done what they need to do in their state to ensure that their donor designation is recognized and honored.

Currently in Oregon, the most important step is to tell your family of your wishes to be a donor. The *DonateLifeOregon* electronic registry to be launched in 2007 will obtain and store affirmative wishes of Oregonians to become organ and tissue donors, legally protect a person's decision to be a donor, provide the donation agencies with a formalized consent process, and serve as a central location for donation information. Idaho and Washington already have registries in place: visit www.livinglegacyregistry.org.



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