

# Family Advisory Council News



*The purpose of this newsletter is to provide information to families and visitors about our NICU at Alta Bates Summit Medical Center. We hope you will find it helpful during your stay here.*

## The Three of Us By: Janine Kovac

When the midwife said, "Oh, wait. There are two heartbeats, not one," I thought, who plays a joke like that on a pregnant woman?

But my husband understood right away. He bounced on the balls of his feet. He swung his arms.

"Just two, right?" he joked. "We don't want to be on a reality show or anything!"

"We don't do multiples here at the clinic. But I can give you the referral for a great obstetrician who does." The midwife handed my husband a business card.

Multiple. Multiple? Multiple *babies*? Oh no oh no oh no. You have the wrong mom. At forty years old, I didn't expect to be pregnant again in the first place, let alone with twins. My husband and I were fine with our toddler daughter, just the three of us and I was OK with the idea of adding a fourth to the family. But *twins*? I couldn't be the mother of three kids under three years old. For one thing, I couldn't fit that many car seats in my car. Two tears rolled down my cheek. Not tears of joy, but tears of arithmetic. Twins equaled twice as many diapers and twice as many college funds plus sixteen times the work, half as much sleep and no more paychecks ever. I couldn't do it.

But then it turned out that my twins were mono-chorionic/mono-amniotic. In other words, they shared a placenta and an amniotic sac, while 99.9% of twins had their own. One placenta and one amniotic sac meant there was nothing to separate their umbilical cords. What was supposed to be a lifeline of blood and oxygen for one twin was also a cord that could strangle his brother. If one twin died in utero, there was no way to save the surviving twin. If we lost one, we'd lose both. Mono-chorionic/mono-amniotic twins had only a fifty percent chance of survival without complications. If they did survive, they'd be delivered via mandatory C-section at 32 weeks' gestation and likely spend a month or more in the NICU.

"There's a lot we can do with three-pound babies," the fetal/maternal specialist told my husband and me.

Another specialist warned, "You have to be prepared at every ultrasound to have a dead baby."

"Some couples in your situation choose to terminate," said a third.

Suddenly I wanted twins very bad. I wanted twins who sucked on each other's thumbs in utero and had special psychic twin powers. I wanted mirror images, twins who would take tests for each other and play tricks on their teachers. Most of all, I wanted fat, healthy bundles who weighed more than three pounds.

In the end, I got much of what I'd imagined: twins who, six years later, still sleep in identical positions. Who buy each other the same LEGO set for Christmas and have to play at least three rounds of Rock-Paper-Scissors because they always tie the first two games. Brothers who have been pretending to be the other twin since before they could speak. Things are pretty rockin'.

But I don't know if I would have told that to my forty-year-old self who was busy crying over twin math. And I don't think I would have told that to the mother I was a few months later, crying over her one-and-a-half pound babies in their NICU isolettes, the one who would visit the NICU twice a day for three months. The mother who, after the twins left the NICU, would then take them to weekly appointments with early intervention specialists. Knowing that things would eventually get better is not what I wanted to hear when my babies were in the NICU. I didn't want to pin my hopes on the future; I wanted to be happy with *now*, even though our "now" did not look pretty.



## Events

### June 23<sup>rd</sup> 6:30-7:30 pm “Me & My Family”

An opportunity to meet with Kelly Ransom, psychologist and Alesia Eutsler Infant Developmental Specialist to discuss strategies that support the development of socio-emotional skills and relationships.  
Herrick Campus, Rm 2190, 2001 Dwight Way, Berkeley.

### June 16<sup>th</sup> 6-7:00 pm Father's Day Celebration

NICU Family Room  
Hosted by Family Advisory Council members Marianna & Ali .  
Food will be served.

## Ongoing Events:

### Parent Share:

Thursdays 2- 3 pm in the NICU Family Room hosted by Family Advisory Council member Kelly Ransom, PhD.

### Antepartum Support Group:

Thursdays 1-2 pm in antepartum, hosted by Kelly Ransom PhD.

### NICU graduate Infant Massage classes:

Wednesdays 1:30-3:30 pm in the Family Resource Center. Sign up at the front desk in the NICU.

### Developmental Play Groups:

Thursdays 2:30-4 pm at the Herrick Campus, Room 2190—2001 Dwight Way, Berkeley (June 2,9 & 16). Sign up at the front desk in the NICU.

## Check Us Out:

[NICU Family Advisory Council \(FAC\)](#)

[Alta Bates' Newborn Intensive Care Unit \(NICU\)](#)

## Disclaimer:

This newsletter is for informational purposes only. Please check with our physicians about your specific health questions and/or concerns

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So I might tell my just-pregnant self that one day soon, when she's twenty-three weeks pregnant, she'll be sitting on the couch, too exhausted to do anything else, with her hands on her belly. One belly lump will dash and dart around as if he is running laps. The other lump will move around, too, but he is more of a swimmer than a kicker. She'll stay like that for twenty or thirty minutes. In a rare moment of clarity, she won't dwell on the doctors' grim predictions and of course, she's totally oblivious to the fact that she'll go into labor two weeks from now. She'll just sit there enjoying the moment for what it is—time spent with her babies.

This is the moment I will remember when one of the twins has a collapsed lung. I'll remember it when the doctors explain the surgical procedure the twins will undergo to fix their heart murmurs and again when I'm sitting in the emergency room 18 months later because one of the boys has 105 fever.

I will return to that moment on the couch, just the three of us, because that afternoon was proof that I could sit and enjoy life for what it was, proof that I didn't need the promise of a happy ending in order to be happy.

Janine Kovac is a contributor to the anthology *Multiples Illuminated* available for pre-order [here](#).

## Traveling With Your Baby

Taking a trip with your baby may feel exciting and overwhelming all at once! But with a little planning, you can enjoy your trip and make special memories for your family. How can you get ready for your trip?

Plan ahead and follow these tips to stay safe when traveling with your baby:

1. Call your baby's health care provider before your trip to make sure your baby's healthy for travel.
2. Find out if your health insurance covers medical care for your baby when you're out of town. Health insurance helps you pay for medical care. Most insurance plans cover emergency medical care no matter where you are. But you need to know what your plan means by "emergency" to know exactly what it pays for.
3. Think about buying travel insurance. This is insurance you buy in addition to your regular health insurance. It covers your baby for medical care during a trip. Visit [USA.gov](#) to learn more about travel insurance.
4. Learn about medical care that's available where you're headed. Your baby's provider may recommend a provider in the place you're visiting, or you can find a pediatrician through the American Academy of Pediatrics. This helps if your baby gets sick when you're away from home. If you're traveling outside of the United States, find a provider through the International Association for Medical Assistance to Travelers website.
5. Visit the Centers for Disease Control and Prevention (CDC) for information about vaccinations, safety tips and other information that can help keep your baby healthy during travel. What should you pack for baby? Pack a large diaper bag for your baby and keep it with you at all times. This way, everything you need is always handy. Babies usually adjust to changes in their eating and sleep schedules without much trouble. But if you're switching time zones, it may take a little longer for your baby to adjust. Bringing a few things from home helps your baby get used to travel and new places. Pack these items in your baby's bag:
  - Baby food, bottles and formula. Bring extra food or formula in case of travel delays.
  - Changing pad, diapers and diaper ointment. Throwaway changing pads can make changing your baby's diaper easier.
  - Extra baby clothes, pacifier, and wipes
  - Rattle, book or favorite toy

For additional tips on traveling with your baby, including travel by air, car, and ship, click [here](#).



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## Eight Invaluable Pieces of Advice from NICU Nurses

By: Catherine Pearson (Reprinted with permission from the [Huffington Post](#) )

Ask any parent who's had a preemie in the neonatal intensive care about their experience, and they'll no doubt say something along the lines of "... but the nurses ... they were *incredible*." Because NICU nurses are, indeed, incredible. They dedicate their lives to supporting the most medically fragile babies while simultaneously guiding their parents through a life experience that is unimaginably intense. And they do it every single day.



Along the way, neonatal nurses develop considerable wisdom — both in the manner of practical tips that can help parents navigate the strange, suspended world that is the NICU, as well as broad, big-picture type stuff about parenting and the healing power of love.

Here, in the words of four NICU nurses, are things all parents of preterm babies should know:

### **No questions are off-limits.**

No parent ever expects to have their baby end up in the NICU and once they're there, there is so much new and complex information to process. So remember: "There are never any silly questions," said Megan Presutti, a NICU nurse with Rush University Medical Center in Chicago. "The more you can understand what's happening, the more it will help lessen your fears." Since parents are likely stressed and extremely tired, she urges them to keep a notebook or iPad on hand to jot down questions that come up between rounds.

Melissa Dunleavy, clinical practice leader in the intensive care nursery at the Hospital of the University of Pennsylvania, believes that parents should really think of nurses as their go-to resource when it comes to getting questions answered — and they should never hold back. "If a physician says something and they don't know what that meant, we can talk about it with them," Dunleavy said. "If they're not getting the answers they need, there's always someone they can ask."

### **The field is changing fast — and that's a good thing.**

Things in neonatology are constantly evolving, which is why babies who'd have faced terrible odds in the past are now able to survive, and even thrive. But it also means that things change constantly in terms of best practices, technology and research, explained Meg Fulmer, a nurse in the intensive care nursery at the Hospital of the University of Pennsylvania — and that may make things feel especially overwhelming to parents. "Neonatology is a fairly new practice. It's not like cardiology, which has been around forever and ever," Fulmer said. Again, parents should *absolutely* feel empowered to ask questions and explore the scientific literature, she said, but they should also be prepared for the fact that things change quickly. "[Parents should] feel encouraged by the progress researchers and doctors and nurses are making to come up with new technologies," Fulmer said.

### **Your baby needs to feel your touch...**

All four of the nurses interviewed for this story made a point to emphasize [just how important touch can be](#). But while parents may ache to hold their small, fragile babies close, they may also feel nervous — especially early on. "Parents are often so scared to hold the baby in the beginning, because they think, 'What if the breathing tube comes out?'" Dunleavy said. But it's nurses' job to take care of managing and monitoring all the equipment, so you don't have to think about it. Instead, focus on the truly awesome power of skin-to-skin. "When parents hold their babies, you often see their vital signs all become more normalized; their heart rate goes down in a good way," Dunleavy said. "You can see that the baby calms down and for parents, that really is the best part of their day."

### **...but you *must* give yourself breaks.**

While it might feel impossible to leave your baby for even a minute, let alone for a few hours or overnight, it is *essential* that you give yourself a break. "We see it so many times — parents come in and they don't want to leave the bedside. I can't even imagine what that feels like," said Fulmer. "But if [caregivers] don't take care of themselves, they're not going to be focused completely. They're not going to be as strong as they could be." Your baby may be in the NICU for months, and the first couple of weeks are often the most difficult weeks of any parent's life, she said. It's so important to find some way to take care of yourself.

### **Go ahead and celebrate good days.**

"Everyone always talks about [the NICU] being an emotional rollercoaster, and it is," said Presutti. "It's very important for parents to celebrate and savor small milestones." Did your baby gain an ounce or two? Move up to a bigger bottle? Whatever step it is, and however small it may seem, embrace it. It's a big deal. Each of the nurses emphasized that a stay in the NICU has a lot of highs and lows — a string of good days, followed by a really hard one — so "savor every one of those positive moments," Presutti said. They'll help buoy you in more difficult moments.



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That also means [remembering to take photos](#), said Christie Lawrence, a NICU nurse with Rush University Medical Center in Chicago — which can be difficult when you're in such a strange environment, and likely as stressed and tired as you've ever been before. "Sometimes when parents are uncertain about the prognosis, they're a little more nervous or guarded, but regardless of the outcome, those are memories you'll want to have," she said.

### **Try not to compare.**

As difficult as it may be, try and ignore what's happening around you. "Sometimes parents compare their baby to the baby across from them," said Dunleavy. "But each baby has their own story and their own course and you can't compare one patient to the next." Just because a baby who was born around the same time as yours gets discharged, or you watch a family celebrating some milestone your baby hasn't reached, does *not* mean anything is wrong with your own child or that she is somehow falling behind. Remember, your baby's healthcare providers' only goal is to make sure your baby is safe and able to thrive, Dunleavy said. It may take a while, and that's OK.

### **You did nothing wrong.**

Parents with children in the NICU are often filled with guilt and regret, wondering what, if anything, they did to end up in their present situation. But Dunleavy said that in most cases, the causes of preterm birth are complex and totally out of moms' control. "We always stress that there is nothing you did wrong," she said. "Our primary goal — together — is to get the baby safe and take care of the baby *now*." There might be a time when you want to explore what may have contributed to your baby's early arrival, but it's not about assigning blame. So keep your mantra simple, and as the days pass, repeat it as often as you need: *I did nothing wrong*.

### **You know your baby best of all.**

There are so many people helping your baby in the NICU — rotating teams of physicians and nurses, not to mention a lot of machines. But that doesn't change the fact that you, as the baby's parent, are the most important person to him, and you already know him better than anyone else. "Recognize how essential you are," Lawrence said. She shared her experience with one mother who mentioned her baby hadn't been moving as much as usual that day. The baby's care team investigated and found out that she was, in fact, developing a serious infection. In that case, it was the mother who picked up on her baby's subtle clues and saved her life.

So make no mistake, you are the number-one expert on your baby, and your baby depends on you.

"Babies do respond to their parents," added Fulmer. "I believe in my heart of hearts that they can feel the power of their parents' love."

