Pediatric Nutrition
CONTINUING EDUCATION FOR CLINICIANS

TRANSCRIPT

Bridging the NICU to Home: A Team-Based Approach to Infant Discharge and Follow-Up Care

Part 2: Caring for NICU Graduates in the Primary Care Setting

Editor's Note: This is a transcript of an online course released in September 2026. It has been edited for clarity.

Caring for NICU Graduates in the Primary Care Setting

Dr. Kasper: I am Dr. Jill Kasper. I'm a clinical associate professor of pediatrics at Boston University School of Medicine and I am interim division chief of primary care pediatrics at Boston Medical Center. Today, I'm going to talk with you about what happens after the NICU. What we owe these babies in the primary care office once the discharge paperwork is signed. And I'm coming at this from 2 directions. I see NICU graduates in general pediatrics and I'm also medical director of our SOFAR Clinic which stands for Supporting Our Families through Addiction and Recovery and that's our medical home for infants with prenatal opioid and polysubstance exposure. These populations overlap quite a bit and the principles I'm going to walk through apply to both.

I think it's important to highlight that the framing I want to leave you with is that discharge is a milestone, it's definitely not a finish line, and I think sometimes we tend to treat the NICU discharge summary as a closing document, but it really isn't. The infants are going home with incomplete growth, with real accrued nutritional deficits and with a developmental risk that is going to persist for years.

Activity 1 covered preparing the infant for discharge. Today, we're going to pick up on the other side of that door and talk about 3 things. We're going to talk about the unique needs of former preterm infants. We're going to talk about the evidence-based primary care involving caring for these infants, and then we're going to talk about neurodevelopmental surveillance.

This is the epidemiology and it's really the slide that changes the practice here. We're all comfortable with the idea that a 25-weeker carries developmental risk, but what this slide is showing is that the risk curve doesn't fall off at 32 weeks, but it kind of slopes. At 32 to 34 weeks, infants still have a 2.4-fold increase in risk of developmental delay. At 35 to 36 weeks, and these are the late preterm babies that we sometimes just kind of wave through in our busy clinic day, they still have a 1.4-fold increased risk of developmental delay. And I think what surprises people is that at 37 weeks there's still a 1.4-fold and even at 38 weeks, there's still a 1.3-fold elevated risk of developmental delay. 37, 38 weeks is early term, right? They're babies we call full-term in casual conversation, but they're really not developmentally equivalent to a 39- or a 40-weeker. Gestational age really belongs on your problem list; not just kind of tucked away in the birth history. Because if a 35-weeker's mom is saying that something feels off when the kid's 9 months old, I think it's a higher probability complaint than if the mom of a 40-weeker is telling you the same thing.

Next, we're going to talk a little bit about growth, because growth and neurodevelopment aren't separate. Roughly 40% of very low-birth-weight infants, so those under 1,500 g, have fallen at least 1 full standard deviation below their birth weight parameters by discharge. For infants under 1,000 g, more than half have fallen below the birth weight parameters and that's a nutritional debt that they actually leave the hospital carrying. Most are going home before 40 weeks' adjusted age, so they still need catch-up growth at exactly the moment that we're handing things over to the families and saying, okay, just go feed the baby. I think there are 3 things that are going to make this particularly challenging. One is the accrued deficits themselves, right? There's deficits in protein, energy, vitamin, minerals. Mature mother's own milk doesn't have enough protein for a catch-up growth infant. It's a wonderful milk—it's just designed for a different job. And also keep in mind that a lot of these babies have reduced muscle growth. They fatigue easily. The volume that they can take is going to be capped. Improving postdischarge growth is going to help reduce the risk of adverse cognitive and motor outcomes. When we optimize feeding, we're actually doing developmental work. I see this challenge a lot in my SOFAR clinic, so in my infants who have exposure to opioids in utero, because infants with neonatal opioid withdrawal syndrome, NOWS, have elevated caloric requirements in part because of the tremor, the hypertonia, and just their near constant motor activity, these are all raising energy expenditure. And they're often disorganized feeders on top of it. Their high caloric demand and their reduced ability to reach it is even more magnified.

What does ideal primary care for NICU graduates actually look like? The first visit should happen within days of discharge. Gone is the time where we would discharge infants from the NICU and not see them for a couple of weeks, but we need to see them within days. And really, there's 4 or so main aims of this. First, check in with the parents. How is the transition home going? You want them to tell you the honest version, not like oh everything's fine, everything's great, we're so happy he's home. You're hoping that they tell you what's hard. Does the family have help? Do they have food insecurity, transportation, financial issues? Are there caregiver mental health issues that they're struggling with? And what can we do to help decrease all these barriers and to offer supports? We need to assess ongoing medical needs. Are there labs, are there studies that we need to follow up more urgently than others? And definitely we need to review that NICU-prescribed nutrition plan. And I want to stress to get that actual plan from the NICU. If, for some reason, the NICU discharge summary says oh breast milk fortified a little bit, get on the phone, call the NICU because you want to know calories per ounce, you want to know ounces per day so that you're able to talk to the family, have the family read back that nutrition plan to you and then also you're able to adjust it if the infant isn't growing as you'd expect. And then finally, given all this, you're going to build your follow-up plan. Ensure that the infant has the specialist appointments scheduled. You want them to ideally leave your office with appointments in hand if they haven't left the NICU with the appointments in hand, sometimes they're discharged on weekends. And you also want to make sure they're connected to early intervention. We'll talk more about that later in the talk a little bit. And after that, we really should be seeing these infants on a more frequent cadence than routine babies and children. Every 2 to 4 weeks through the first year, ideally, and keep in mind that routine well-child care and the vaccinations are on a chronological age, not corrected. In our SOFAR clinic, we see these patients kind of every 2 to 4 weeks initially as well, and thinking about those visits is really doing double duty. We're checking on the kid, but we're also building that relational health component with the family so that they're really telling you when things get hard and entrusting you, as their healthcare provider.

Now we're going to talk about growth monitoring which has specific rules and I think sometimes this is where providers can vary a little bit in practice, but it's really important to keep plotting on the Fenton chart by corrected gestational age as long as you can. When the infant is at 50 weeks corrected gestational age, you can then transition to the World Health Organization growth curve, and we should be using corrected age until at least 2 years. This is a really important point because if you're plotting a former 28-weeker on chronologic age at 9 months, you're going to run the risk of creating a growth problem that doesn't exist. But mostly it's easy to get reassured in the other direction as well. I think the important point here is that growth targets really need to be individualized, with the goal being to approximately parallel the curve on the reference standard.

We're going to move on and talk a little bit about postdischarge formulas and nutrient enrichment. Many of these infants are not going to meet their needs on mature mother's milk or on term formula alone. It's not a failure of breastfeeding; it's the math behind it. These infants are at a high risk for growth faltering because they often have growth restriction, chronic illness, they have reflux, they have nutrient deficiencies at discharge. A lot of them have oromotor dysfunction and separately, even volume intake can be limited by developmental delay. I add prenatal substance exposure. It encaptures both oromotor discoordination and the reflux, but I think it's a really good reminder that these infants really need close monitoring after newborn discharge.

Let's talk a little bit about fortification. This field here is one of the kind of practical hearts of the talk. I'm going to orient you to it. The model here is a 3-kg infant that's taking 200 mL/kg/d. The far-right column is the target, and then your columns are going to move from left to right based on how much of the diet is the mature mom's own milk, whether it's 100%, 75%, 50%, or none. And then the formula we're talking about in this table is 22 kcal/oz, so your postdischarge preemie formula vs the regular 20 kcal/oz. If we first follow that protein row, target is 6 g. On 100% mom's milk, you're going to get 5.4 and then if you substitute 2 bottles of the postdischarge formula which is about 150 mL, you're going to get 7.2, 4 bottles 8.9 and so on. Calcium is a little bit of a starker story, as is phosphorous, and this is really important because preterm infants, as you remember, are missing that peak third trimester calcium and phosphorous transfer that's important for bone mineralization. Your calcium target is 315 mg, but exclusive breastfeeding is only going to deliver about 135. We need to think about fortifying that. And I just kind of want to point out here too that I think the 285 for calories for a preterm, 3-kg, premature infant is a little bit on the lower side, averages out to 95 kcal/kg/d and that's not accounting for catch-up growth. Might be a little bit more like 100 to 120 kcal/kg/d for most of our preterm

infants, post-discharge. Bottom line here is tailor the plan to the corrected gestational age, growth and available milk volume. Think of cost, safety, simplicity, and if a parent can't execute the plan at 3:00 AM, it's not the right plan for them.

Let's move on to how we talk with parents about asking how things are going with the feeding, right? This is a really nice structured way to assess breastfeeding and to bring it up in your conversation with families. The ABCs are attachment, breast milk production and then calories. And in the first weeks postdischarge, you're going to address them in reverse order. You're going to talk about calories first and that's kind of instinct because if your time is cut short and all things fall apart in the visit, you want to make sure how many calories this kid is getting and how much volume the mom's making. You're going to talk about how many times a day are you nursing, how do you judge if the baby's had enough, are you giving additional bottles, of what, how much, how often and then you're going to ask about production. How often are you pumping, are you pumping after you're nursing, are you making more or less than your baby needs? And the last couple of things here are, it's important to frame those as offers, not as kind of prescriptions, not, well let's cut back a little bit on your milk you're making or we need to increase your supply, but more, would you like to cut back on your supply, would you like help increasing your supply. I think the parents feel enough pressure, so we want to make sure that we're wording these things carefully in our conversations with families. And then we can move to attachment. Is the baby having trouble latching? Is the baby having problems staying latched? Have you tried a nipple shield? Do you have lactation support? Do you know who you can call if the baby won't latch?

Keep in mind about nutrition just that's in addition to the volume intake and the weight gain. Remember that an infant needs 400 units daily if they're receiving breast milk regardless of whether or not it's fortified. For infants on postdischarge formula, you're going to keep supplementing until they're taking about a liter a day. Infants are also going to need 2 mg/kg/day of iron for the first year, either until the diet is iron-fortified term formula or they're getting enough iron from complementary feeding. Keep in mind that preterm infants miss that third trimester iron accretion window so they're starting behind and then thinking about iron deficiency in infancy carrying its own neurodevelopmental cost and risk.

If we move on to bone health, human milk needs to be fortified for about 12 weeks after discharge to supply the important calcium and phosphorous needed for bone mineralization. And I think that 12 weeks is an important anchor to keep in mind when families are like, oh my gosh, how long do I have to do this for.

Then remember that a lot of these infants are going to have some feeding issues, like reflux, so think about behavioral interventions first. So, your pauses in between feeds, maximizing frequency, decreasing volume and thickening, next. Constipation usually is self-limited. Families will often kind of anchor on that though. You can use a gentle osmotic laxative if you need to. In my SOFAR patients, reflux, dysregulated feeding are super common and kind of have that same sequence of managing it. And I think it's important to remember that feeding difficulty in these infants can often be withdrawal rather than formula intolerance, rather than reflux, so making sure any withdrawal symptoms are adequately captured in ways that are necessary or helpful.

Let's talk a little bit about neurodevelopment. The 2023 AAP Clinical Report by Davis and colleagues which I think tells a pretty important take-home point here. We're looking down to the left. Gestational age. We have the gestational age band and we have comorbidities. Across the top, cerebral palsy, visual impairment, hearing impairment, intellectual disability. And the shading is risk relative to the general population. Two patterns stand out here. First, the risk rises as gestational age falls. You'd expect that, but the risk stays elevated across every band including in these weight preterm rows. And second, the comorbidities are independent risk multipliers. If an infant has HIE or PVL, grade 3 or 4 IVH, retinopathy of prematurity requiring surgery, moderate to severe BPD, NEC, they're at really high risk for neurodevelopmental issues regardless of where they're sitting on the gestational age axis. When you're looking at that discharge summary, it's important to note not just gestational age, but thinking about the other medical issues involved that are really kind of creating the infant's risk profile together. A 32-weeker with grade 3 IVH and severe BPD is going to be different and have a different risk profile than a 32-weeker with an uncomplicated course.

Why does this matter so much, right? Neuroplasticity. Early detection accelerates access to early intervention during the window when the developing brain is the most responsive, meaning it has the potential to alter the trajectory. A Cochrane meta-analysis found that early intervention programs improved cognitive outcomes in former preterm

infants at preschool age. Remember, early intervention isn't just one service. It's PT, OT, speech language pathology, nutrition and—really importantly, too—support for the caregiver and for that infant-caregiver relationship. And I think almost all infants who are discharged preterm or who are discharged having been exposed to opioids in utero should be offered an early intervention referral. If they pass their assessment with flying colors and don't seem to qualify for early intervention, great, but it's just another set of eyes on these infants in this crucial window.

Now I'm going to talk about recommendations for developmental surveillance in these age groups. And everybody is going to get developmental screening as recommended by the AAP, whether you use the PEDS or the SWYC with the M-CHAT at 18, 24 and 30 months. But these children need like an additional eye, an additional level of the developmental surveillance. Really in the 0- to 9-month age range, look for any signs of nystagmus or not visually tracking, the infant not alerting to sound, having any sorts of asymmetry or the closed fist in the past 3 months, not reaching at 4 months. And then persistent feeding and sleeping issues. For the kids who are a bit older in that 9- to 18-month range, watching their visual attention, if they're responding to name, if they're pointing for things, how they're starting to sit and cruise and crawl and walk, and really paying close attention to their social communication, to their speech and looking for the subtler findings that may not appear until the kid is closer to 5 years old. Kids who may have mild delays, mild hearing loss, clumsiness, hyperactivity, anxiety because some of these disabilities aren't going to be picked up in infancy, but can be traced back to prematurity. Really continuing to add an additional layer of developmental surveillance when you see these kids in your office for primary care. And I think it's important to highlight here also what's across the top of every column, discussing caregiver concerns and then performing targeted evaluation. Pay close attention to what the parent's worried about. It's one of the highest yield things we can do as primary care pediatricians.

Later in the series, we'll be hearing from a parent advocate, but I just wanted to share a word on talking with families. These parents have often spent weeks or months in a unit where every conversation contains a number or a risk and they often arrive in your office braced for bad news. How we deliver our messages and how we talk about the surveillance and the importance is really important because, at the end of the day, most of these kids do well and the surveillance exists precisely so we can act early if they're not doing as well as we'd like. Our tone is really important. I think, in the infant exposed patients that I care for, there's even an added layer because the families are arriving in your office expecting to be judged. But if they're not judged, they're going to keep coming back and then we can actually do the surveillance and the work that needs to be done to keep the kids on track.

Five take-home points here. Lower gestational age means higher risk, risk stays elevated even in late-preterm infants though, so don't forget that concern at 35 weeks. Communication is super important. If you don't know the nutritional history, the medical history, the discharge feeding plan, pick up the phone and talk to somebody. Growth goals should be individualized, should approximate the curve on an appropriate reference standard, the Fenton, the WHO once they're at 50 weeks, and then correcting it until age 2. Not just calorie, but also nutrient enrichment is key to catch-up growth and proteins, minerals, nutrients are important in addition to the calories. And these infants often need postdischarge preemie formula or some sort of fortification to breast milk or regular formula alone. And the right strategy is the strategy that the family can sustain. And then monitor frequently for developmental delays, and refer promptly, even at the slightest suspicion.

Case 2: A Medically Complex Infant (continued from part 1)

Dr. Smith: Let's continue our discussion again with our medically complex infant. At this point, just as kind of a brief reminder, the baby was born at 28 weeks, 850 g at birth, had multiple surgeries associated with gastroschisis, was on TPN for 6 weeks and then was sent home looking pretty stable, with instructions to follow up with her primary care provider and with various specialists. She was discharged 2 weeks prior and subsequently came in, after 2 weeks, to see her primary care pediatrician. At this point, she's corrected at 42 weeks. Her current weight is 2.9 kg and she's been gaining about 12 g per day since she left the hospital 2 weeks ago. I've already gone over the medical history, so I won't go through that again. I'll say the only medication she's taking is a multivitamin with iron and her current feeding status, she's on fortified breast milk 24 kcal/oz. Of that, she's taking about 65% orally and the remainder is going through an NG tube. The parents do report that occasionally she spits up and does seem sometimes fussy after feeds. And again, her weight gain is now only 12 g per day. There's a lot kind of challenges associated with this particular case for where we are now, because we start off at a relatively good position, which I even highlighted how

well the growth had been, and now the growth seems to be faltering. There's concerns that this infant, because they were discharged home with NG feeds and not a more stable method of feeding like a G tube, and the follow-up was pretty delayed from what Jill had already expressed being comfortable with. It's 2 weeks as opposed to 72 hours. Jill, given all of these challenges, and with the poor kind of discharge coordination, what would you want to address first when this kid arrives in primary care a whole 2 weeks later?

Dr. Kasper: I'm so anxious. I mean, I will have canceled my dinner plans already because this is going to be where my focus is. I think in my brain, my mind, I want to go right to, oh my gosh, why 2 weeks, right, and talk to the family. I need to consciously table that because I don't want to start with a difficult conversation and kind of put up a wall or a barrier for the family. And I need to plot this kid's weight, right? I need to click my little buttons in Epic to make sure that I've got the Fenton coming up and see what the kid looks like on that. I need to think about the grams per day. I need to take a really detailed feeding history here. Hopefully, the parents have a log and if they don't, I'm going to sit down, again, and ask how are you mixing, how much are you taking, not just how often but how many times a day, is the kid sleeping more overnight and so on and so forth. I need to check in with the mom, right? How are you doing? This seems like a lot—or the caregiver—I shouldn't just say mom, but any caregiver. How are you doing? This seems like a lot! Who are your supports? Who's helping you? Because I'm thinking about maternal mental health as a barrier to getting her into appointments too. And so that's kind of where my mind, where I'm trying to focus my energies first.

Dr. Smith: That makes perfect sense for ongoing kind of management. And Cuyler, I want to focus a little bit on this feeding because at time of discharge, this baby was taking about 60% and in the 2 weeks that have passed, it's only about 65%. It's barely more. What does that tell you?

Cuyler: What this tells us is that we need to take a deeper look at what is happening within the feeding routine and what's happening with the feeding pattern. I would, one, have an in-depth conversation with the family of what does oral vs gavage feedings look like, how long is it taking them to complete them, is all the nutrition staying in the infant, are we having spit-ups, are we having vomiting, are we seeing signs of gastric stress or are the parents coming to the table with stress. It's very important to pick up some of these early warning signs and the first often is a plateau or a lack of progression. It just really calls for us to look deeper.

Dr. Smith: Cuyler, if you put your OT hat on, what would make you say this baby needs a formal feeding evaluation, swallow study or, and what would you be looking for if you actually did the evaluation on the baby?

Cuyler: In order to determine if this infant needs a more in-depth look, we would first need to see an oral feeding as well as a gavage. We would need to see the big picture of what mealtime looks like. Prolonged dependence on NG feeds or nonoral feeds can kind of set the stage for an infant not being able to develop the stamina and the endurance that they need to complete a full feed by mouth if the family isn't making changes to how the tube is being utilized. And often, that's out of the skill set of a family. They need someone to help them make those decisions of how to use the tube vs how to support oral feeding, so we start transitioning our skills more predominantly to oral feeding. Based on this presentation, I would say that this infant absolutely needs to be referred to a feeding specialist. They can help determine is this plateau due to the oromotor or the oropharyngeal function, are there any aspiration or swallowing risks that may be evolving that are more common in children with BPD, or is this plateau due to the mealtime routine, due to the scheduling, how gavage feeds are being delivered, or how we haven't yet started to shift calories from gavage into oral feeding. Since there's so many pieces that really need to be picked apart, a feeding specialist would be a good addition to the team at this point.

Dr. Smith: Molly, I'd like to turn it over to you because, in the chart, it says that mom reports that there are some spit-ups and some fussiness, but from a parent perspective, you're exhausted, the baby's already been through so much and it's all just kind of stacking on top of each other in addition to all those appointments that Heidi was telling us about and all the challenges. What might a parent not be saying and may not even know it's worth saying?

Molly: I think that often parents leave the NICU with all the supports of the NICU and then they get home and it's immediately so overwhelming, especially when you have an infant with a complicated feeding plan like this baby. You're talking about someone who is a first-time parent, who doesn't necessarily have all the supports in place that they were accustomed to when they were in the NICU, you're exhausted, you're very overwhelmed, you're managing multiple medical appointments for your complicated and

complex infant. And you are trying to navigate all of these things, potentially without the resources that you might need and without having a clear sense of what needs to happen when. We also, to Jill's point, don't know what's going on with the primary caregiver's mental health and I think this is where we need to be really specific about the types of questions that we're asking the parent and also not making the parent feel like it's their fault that this happened, right? Because we know that that is so key, with the mental health piece, but also in not making things worse before they get better, because we want to make sure that both this caregiver-baby dyad stays well, and that we can help them get on a better path. But I do think like normalizing these struggles is really important because every NICU parent goes home and feels so overwhelmed by the feedings, by this sense of exhaustion that happens because a lot of us don't even have a sense of processing our NICU experience. You get home and you realize just how hard your experience is and also you're caring now for a baby.

Dr. Smith: That is a lot, and I do think it's important to not blame the family even in a situation like this where you see the kid is obviously growth faltering. I mean, Jill, from your perspective, this baby only has about 175 g of growth in 2 weeks, that's about 12 g a day, and we know in the NICU, before discharge, the baby was gaining 15 to 20 g per day on average. Is 12 g a day enough? How do you make that judgment and what do you say to the family?

Dr. Kasper: This little guy isn't even gaining great weight compared with what he was doing previously, let alone what the standards are and what the rest of the population is doing on the growth curves. I'm worried and again, I'm going to try to get a really good history, what's changed, is the baby not eating as frequently as was in the hospital? Is the baby eating something different or not as much? Thinking about volume, concentration, spacing, and then just kind of naming it that this is a medically complex kiddo. I mean, his BPD alone is increasing his energy expenditure here, so I need to see a good 20 to 30 g a day in this kid and I'm not. I'm worried, and I'm going to be kind of reading the room, gauging how I can communicate that to the mom emphatically, without overwhelming her. And that's the dance, right?

Dr. Smith: That's really important, but Jill, I'm not quite ready to move on quite yet. You're a medical home provider. This baby is really complex and, based on your assessment, is not really doing as well as desired. What is it that you feel like you're going to manage yourself and what is it you're going to refer for? And how do you make the most efficient use of the healthcare system in this particular situation?

Dr. Kasper: I love Boston Medical Center because I'm going to run down the hall and I am going to grab a gastroenterologist or one of our feeding team and tap them on the shoulder and say, help. In a private practice, you don't have that luxury. I have to decide is this urgent or is this like I can give this baby perhaps another day or two at home? I think, figuring out that basic medical school like "sick or not sick" and then figuring out how I'm going to do it. Phoning the friends, getting the specialist involved and really having the conversation about what I need to see. If I'm not admitting this baby to the hospital, which I'd probably give him another day or two at home, then what is going to be the point at which I say, "I hate to do this, but I think we need to go back into the hospital?" Having the parent hear that not as a "you need to go back to the hospital now" but hearing it as "we need to see this get better or you might need to go back to the hospital."

Dr. Smith: Cuyler, Jill is sprinting down the hallway because she is concerned about this baby and she's trying to keep from admitting this baby in the hospital and she wants to make a referral to you. What would be the most helpful way for that referral to come and what should it include?

Cuyler: I find a conversation with the pediatrician is absolutely critical and one of the most helpful aspects of handing off to a feeding therapist. If we just look at what we receive in a typical referral, it may only list the diagnosis and a few of the primary concerns, but it doesn't really give us a picture of the medical profession, home life and environment and, really importantly, what the PCP or the pediatrician is concerned about. Part of our job is to ensure that we have medical wellness and that we're considering any medical complications before we walk into a feeding assessment. So, better understanding what the pediatrician wants and needs is very helpful for making that evaluation the most informative.

Dr. Smith: Molly, I want to come back to you just from a parent perspective. We sent this family home with a complicated feeding plan, fortified feedings, on a schedule, an NG tube, keep advancing oral feeds. That's all written on a paper that Heidi wrote out beautifully for this family to take home, but what happens in real life when they get home and they're sleep-deprived and they're tired? What actually happens in that first couple of weeks?

Molly: I think that it is a big ask to have a family go home and be discharged with essentially setting up a medical home, right? And to have this complex feeding plan on paper, we know that it's what the baby needs to thrive, and in the NICU it is what we are implementing. But when you add all the other roles and responsibilities that we know that our parents have to take on, that maybe they were also juggling while they were caring for their hospitalized infant, and there's also just that need for and want for normalcy, right? It's really hard for us, as NICU parents, to manage kind of this idea that we had that we would bring our baby home and we would breast feed or we would bottle feed or we would feed our babies. And when you're feeding them 3 different ways and then you have to do it again an hour later, it's a lot. You're managing all the bottles. You're managing cleaning the bottles. You're pumping. You're fortifying. Not to mention not just the emotional cost that takes, but the actual cost that takes in terms of time and money. It's a huge commitment, and it's exhausting, and that's something that we don't really talk about in the NICU because we put it on paper and we say this is what you have to do. And it's very easy to do that in the NICU, but it's much harder to do that at home, especially when you're sleep-deprived.

Dr. Smith: Molly. Those are very valid points and, Heidi, I do want to point out that was not your discharge plan and I was not throwing you under the bus. I would never do that.

Molly: I would never do that either, Heidi. The discharge plan is so important, and Heidi wrote my son's discharge plan, by the way. But it is, when you get home and you're fortifying that milk, it's hard, it's a really hard thing to do and to keep up with and sometimes you're just too tired.

Dr. Smith: One hundred percent!. Heidi, with what Molly just said in mind, is that something that you would be worried about and would that impact how you did your discharge preparation for this family?

Heidi: If we're not, we should be. It's a big issue and I think that we need to have an honest, frank discussion with the families about what taking a baby home on NG feeding entails. They've only seen it done in the hospital. It seems pretty easy when the nurses come in and they pull up the feeding and they hook it up, but, as Molly says, when you're home, you're in the middle of the night and you've got to get these feedings going, it's a lot. I think, as I say, talking to the families. I think we need to do a better job sometimes of making sure they understand that nutrition is the basis of how these babies are going to grow, how all of these problems are going to get better over time. It's all based on nutrition. I think it's really important for the parents to understand if they're struggling at home, if they want to make a change to the feeding plan, people will listen, but you need to discuss that with your PCP before you change things. Let them know you're struggling and they will do as much as they can to help you, but you don't want to compromise your baby's nutrition because that is so important to their future well-being, to their development, to their growth and the repairing of the lungs and the abdomen and so on. I would just say to really talk to parents and make sure that they understand what this is going to be like and let them know they're going to be exhausted. It is just a fact of life, and these parents are more exhausted than most because they've got more on their plate.

Dr. Smith: So, something that you and Molly are really both highlighting is the importance of anticipatory guidance as part of the discharge planning process to give the family kind of a more realistic picture of what that's going to look like. Molly, I'm going to turn it back to you just for a second. This family has a laundry list of appointments. I mean, Jill is managing them, but like there's a bunch of them and a bunch of phone numbers and a bunch of people and now we're adding Cuyler in addition to this because the growth hasn't been good since they've been home. What does that feel like from a family perspective?

Molly: Jill mentioned this earlier that thankfully some physicians and care coordinators try and consolidate all of that—but the NICU is death by a thousand paper cuts because the ongoing cost, especially for a complex infant like this where you don't anticipate a NICU stay, so you're not prepared for the cost of the transportation and the parking, supplementing feeds, things like that. All of that adds up. The parking when you're going to the appointments, getting meals at the hospital, all of those costs are so expensive. And then you think about the psychological burden on NICU families, trying to be okay in some way and that doesn't even take into account the impact of potentially a traumatic birth experience, what it's like to see this family navigating the trauma of watching their infant have multiple surgeries, the anticipating of additional surgeries. All of that is really hard. You have missed work for all of these appointments and follow-up appointments that they now have to account for. They couldn't anticipate any of this. And the constant feeling that 1 wrong decision or missed appointment would have a really catastrophic outcome. A lot of self-doubt. A lot of questioning. There's always the guilt and the feeling of guilt

and shame, like did I cause the premature birth, that is a constant drumbeat in a NICU parent's life, particularly a birthing person. There's a lot of these feelings that kind of catalyze together when we're talking about the overlap in the layers when our NICU parents are juggling all of these follow-ups because it's not just this one thing. It's the layers of an onion, right? There's so many different things at play, so it's not just this appointment. It's what does the appointment mean to a family and if they miss 1 appointment, what happens next, and then how much does the appointment cost, and are they missing work? Again, it's overwhelming and there's so many different things. And this is why I think that the peer support piece of it and not feeling alone is so huge too.

Dr. Smith: That's really great. I want to think about this just a little bit more, not from the perspective of the family that's kind of worried about missing an appointment. I'm going to say like for the family that's kind of a little bit more overwhelmed and perhaps so overwhelmed that they kind of end up shutting down. And Jill, for this, I want to go to you. Hearing the things that Molly talked about, does that resonate with some of your patient experiences, and how do you keep this load from being so much that the family just gets lost to care because they're just shut down?

Dr. Kasper: I think it's important that we help prioritize for the family, and ask the hard questions. Again, like who is helping you? Say it. Like, this is a lot! How are you doing? And to really having an empathetic conversation with the parents and it's like, in pediatrics, we tell the grade school kids, ask me 3 things, right? Let me help with the moms and the dads, the caregivers, let's just focus on these 3 things for now. And I think we often create a feeding plan that we think is going to work for the family without checking in if it's something that they can actually do! Because if a feed is happening 8 to 10 times a day and then they've got to clean the NG tube pieces and things like that afterwards, these are caregivers who haven't slept 3 hours in a row in quite some time. We really have to keep their mental health in mind.

Dr. Smith: I think that's a good way to wrap up this portion of the discussion and I want to give everybody a chance to share your closing thoughts. Molly, as a parent representative, would you mind leading us off?

Molly: I would just say that going home from the NICU is the most absolutely wonderful and totally overwhelming experience. I think that to NICU parents, it means so much to have the ability to make them feel like they're able to advocate for themselves and build that trusting relationship with their pediatrician and their PCP because, to Jill's point, it's really hard to ask for help and to feel that it's okay to acknowledge, for example, that this feeding plan isn't working for us, or I am totally overwhelmed because being really vulnerable and asking for help is really hard, especially when you're talking about your infant and your own health.

Heidi: I think we've alluded to this or actually talked about it a little bit, but I think you really need to sit with the parents and help them think about what life is going to be like at home. They're taking home a preterm baby that isn't fully mature yet. Sometimes parents have this image in their head that everything's going to be great once I get home, leaving the NICU behind, and everything's going to be fine. And it takes time, and they need to understand that, and they also need to understand that parental exhaustion is real and it can be overwhelming, and when you're struggling, you just need to share it with somebody, your PCP, ideally, but your other caregivers, your support people. You've got a team there and you have to share your concerns. As Molly says, it's hard, but that's what you need to do when you're home and things are really difficult.

Dr. Smith: That trauma for families is definitely real. Cuyler, is there anything that you'd like to highlight based on the discussion so far?

Cuyler: I would just like to highlight a theme that I've been hearing throughout the discussion, which is the call for recognition of the parental role, their experiences in the NICU, traumatic experiences in the NICU, and the supports that are needed for them to continue to be their child's advocate and to serve their child. Feeding is the foundation for this child's brain growth, developmental skills, health and nutrition. And there can be quite a lot of internalization and pressure on families, particularly when feeding is not going well. If we can come together as a support team and recognize that feeding is going to look different depending on the health and the wellness of that infant, I'm hoping that families feel better about their feeding journeys.

Dr. Smith: Thank you for that. Jill, I'm going to let you close us out with your final thoughts as the PCP because after all, the buck stops with you.

Dr. Kasper: I think the discharge plan only works if we build it for the family's reality; not ours.

Case 3: Pediatric Follow-Up of "Healthy" NICU Graduate

Dr. Smith: I'm going to give us little highlights on the case. This infant was born at 32 weeks, with a birth weight of 1750 g which is between the 50th and 90th percentile. Was in the NICU for 4 weeks dealing with issues related to prematurity, feeding immaturity and mild apnea prematurity. The discharge corrected gestational age—because Jill told us that was very important—is 36 weeks. The baby is still preterm. The discharge weight is 2350 g, which is between the 10th and 50th percentile. At time of discharge, the baby was eating fortified breast milk 22 kcal via the bottle and occasionally going directly to breastfeeding. The baby was discharged on iron and vitamin D. The discharge instructions, discharge planning, were to continue the fortified breast milk feeds and the supplement, to weigh the infant twice per week and to schedule a pediatric follow-up within 1 week and then a follow-up ROP exam was already scheduled. The first pediatric visit was 1 week after discharge and, at that point, the baby was corrected at 37 weeks with a weight of 2510 g, which means the baby was gaining about 23 g per day since discharge. The feeding, breastfeeding is going well. They're doing occasional bottles and the infant occasionally tires during feeds but otherwise seems comfortable. The pediatrician has reassured the family that the infant is doing well, and no changes need to be made at that time.

Jill, I want to turn it to you as a primary care pediatrician. We're 1 week postdischarge and, on the surface, everything actually looks pretty good. She has gained 160 grams since discharge which averages about 23 grams per day and, but what do you actually see and what are we missing in this visit?

Dr. Kasper: I'm still worried. I think I said this throughout each case, but I worry that the kid's going to struggle to catch up still. I think that 23 g a day here sounds a little bit reassuring in absolute terms, but she's 2.5 kg at 37 weeks, so she still has quite a way to go. And then, just to highlight that she was born between the 50th and 90th percentile and now she's getting discharged at a lower percentile, between the 10th and the 50th. She's crossed a full percentile band here during her NICU stay, I'm worried that we're labeling it uncomplicated. Our kind of quick glance at the chart is going to have us a little bit less concerned here. And I think it's important to note, at this first visit, that the baby's feeding changed, right? They're breastfeeding a whole lot more. They're not getting that 22 kcal and I want to know more about that. And why and what's going on, just to really unpack the factors, the things involved here.

Dr. Smith: Cuyler, I want to turn it to you just for one second because there's a note in here, in one of the visits, that says the baby occasionally tires during feeds but otherwise seems comfortable. And to Jill's point, it seems like that wasn't highlighted. Is it something that should have been and is that something that we should be thinking about a little bit more, something that we should be worried about?

Cuyler: Yes, I agree. It seems that people glossed over a red flag of feeding. Occasionally, fatiguing during feeds may not be a concern with an infant that's growing well, was full-term, doesn't have any medical complications. But in a former preterm infant, this is often an early sign of feeding inefficiency, and it does warrant a second look, particularly closer following of weight and growth. My other concern is that the infant basically shifted methods of oral feeding. The baby was primarily bottle feeding when in the NICU and now at home is primarily breastfeeding, and I would just wonder if we have a robust milk supply, if the feeding occupation at the breast is also safe, functional and efficient, and do they need to take a deeper look at what's happening at the breast to support growth and nutrition.

Dr. Smith: Heidi, I want to turn it to you. From a hospital discharge standpoint, what should have left the NICU with this family. So, the first visit wasn't like a shot in the dark?

Heidi: First of all, the parents, at least in our NICU, receive a copy of the discharge summary. I tell them this is your baby's history from the time they were born until this moment right now. In our NICU, they are asked to read the discharge summary but usually we have a NICU team member sit with them, either a doctor, a nurse or a nurse practitioner, so that we can explain things to them, answer any questions. The parents really need to understand what happens with their baby, and sometimes the moms don't remember. They had a C-section, they were medicated. Sometimes the first couple of days are really a blur. It's important for them to know what has happened with their baby and, going forward, what are the issues that are going to be followed by the PCP. Then, we talked about this, they should have a home feeding plan which details how often the baby's feeding, how much the baby had been taking in the hospital, and so they have an idea of what's happened before then and hopefully what's going to happen at home. And we do encourage the families to take that paperwork to their first PCP visit so the doctor knows what the

instructions from the NICU were and what we had expected for them to do at home, how they're going to feed the baby, how they're going to know when to increase and so on. And then, lastly, we make sure that the parents know that they shouldn't change the feeding plan until they talk to their PCP. Not that the feeding plan can't be changed; they absolutely can and they are partners. They're seeing the baby, so if they see something in the feeding plan—or what they're trying to accomplish by the feeding plan—and it's not working, that's great information, but it doesn't work if they don't convey that information. And when they're viewed as a partner in the team caring for their baby with valuable information, it goes a long way to boosting their confidence as parents and improving the relationship between the family and the PCP. They know that they can trust their PCP who's going to listen to them and say, okay, that's not working, how can we make this work better for you.

Dr. Smith: Heidi. It sounds like there could've been some tweaks to the discharge planning, discharge preparation that could've made this all have gone smoother and could've put this family in a slightly better position. Let's move forward in time and we're going to say, now it's been 3 months of chronological age, or 1 month corrected age, and the baby is back for a routine well-child visit. At this point, the weight is now 3.65 kg which is between the 10th and 50th percentile. The feeding plan is exclusive breastfeeding with sessions that last between 35 and 40 minutes and sometimes the baby falls asleep before finishing. The fortification was discontinued due to challenges with pumping and mixing and it seemed kind of unnecessary to the family. The growth seems to have plateaued in the last 10 days, but prior to that, it had otherwise been adequate. Listening to this and thinking about this, there comes a point where the care goes from the NICU team to the medical home and that's why the transition is so important, to Heidi's point, to make sure that all the information gets passed from the NICU providers to the medical home to put the medical home in the best position to be able to help and support this family during times like this. And in addition to that, talking about things like the feeding plan isn't working, we need to modify this, but let's do it in a thoughtful way. Molly, I would say, as a parent, by 3 months of age, the fortification was stopped and the reason that was put into the chart, I'll put quotes around it, it seemed unnecessary and the real story is that the pumping and the mixing were probably challenging. Can you walk us through that decision-making and what that probably was like at home?

Molly: I think probably the idea for this family is that when they thought it was unnecessary, they thought it probably did not apply because the baby was "healthy," right? They might not have had that conversation with their pediatrician about what the goal of the fortification was and also we don't know what the feeding goals for this family were. To Jill's point, we know that the feeding plan changed and they were breastfeeding more, so we don't know what this birthing parent expected or anticipated or had hoped for when they were thinking about what their feeding plan would be. Those kinds of conversations are really important to have with a family when you think about it. Again, we also know that a multi-step feeding process is exhausting and the parents are probably very sleep deprived, particularly after a NICU stay, and when we're fortifying and having this multi-step process, it's hard. It's labor intensive. We're talking about washing multiple parts, it's expensive, so those are all things to consider with a multi-step feeding plan. Those kinds of conversations really need to factor in, and I think what's important to consider is it's not 1 discussion; it's an ongoing discussion, right? Just because you're fortifying now doesn't mean you're always going to fortify. There's a conversation about maybe if a parent wants to breast feed, you can do that, you can have that breastfeeding for 1 or 2 feeds, but maybe not every feed. Think about what that looks like and have some flexibility for those open and honest conversations with a family.

Dr. Smith: Molly, I feel like you brought up a lot of really important things and, Jill, I would say you're going to be the provider who's receiving the family on the other end of it. What kind of other things are you going to be looking at to figure out what's going on at home and especially when there's been a change in the feeding plan that may or may not have been discussed with the medical home?

Dr. Kasper: I think Molly raised so many good points that I just want to echo. I don't know that anybody's had a conversation with the mom up to this point. Like, do you really want to breast feed and what were you expecting, having this baby, and how does that look differently now? What is her capacity? Again, who is helping her? And then I think doing formal screening. This is where it's critical to do formal screening at every visit for postpartum depression, postpartum anxiety and such things. I think the AAP recommends up to 6 months to be screening. In our practice we do it up to a year and I think it's critical because these issues might not arise until later. Parents might not feel comfortable talking about it until later. We need to name that and then I think one of the challenges with identifying parental mental health issues is the well now

what? I am not an adult therapist. Thankfully we have robust integrated behavioral health supports and I am able to page somebody who can come in and check in with the family, check in with the caregivers. What does this look like? What kind of supports do you need? Can we connect you to your own therapist? That's kind of where I'm at.

Dr. Smith: I'm going to pivot from you for one second, but I'm coming right back, so hold tight! I want to just ask Cuyler, there's a line in the chart that says the baby's now exclusively breastfeeding but it's running 35 to 40 minutes and sometimes she's falling asleep before she finishes. As a feeding specialist, what are you hearing when you hear that?

Cuyler: Yes, in this case, now we're getting into prolonged feeds, 35 to 40 minutes is starting to extend. It sounds like the baby is compensating for not having as efficient feeds and so is spending more time at the breast. But, by spending more time at the breast, is then also getting fatigued is what I hear. I would want to know more about mom's milk supply. I would want to know, for instance, how has she maintained her supply, is she continuing to pump, what's her milk availability and what can we do from the feeder side or from the mother's side to help promote efficiency at the breast? And if supports that promote efficiency aren't well-received by the infant or aren't improving in intake, then we probably need to start talking about how can we provide additional calories safely to this baby.

Dr. Smith: That makes sense. Thank you for that, Cuyler. Jill, I want to come back to you. The postpartum mental health for both parents is actually really important. Another piece I want to come back to is the chart mentioned that the growth seems to have plateaued in the last 10 days, but otherwise appears adequate. You were already concerned about the growth when the baby was gaining 23 g per day. Now that it's plateaued, what are you thinking? How are you feeling?

Dr. Kasper: I'm concerned by what otherwise appears adequate because I think that can lead providers and families to just be kind of falsely reassured. And I think that that also can mean that someone just looked at the number and didn't really look at what the trajectory has been over time. A 10-day plateau at 1 month isn't really normal and we should be getting 25 to 30 g of weight gain a day and this kid needs more, rather than less, to catch up. And I think we know what happened here, right? The kid's intake is a different concentration. It's a different calorie per ounce. But we need to really come up with a plan and I think pediatricians should be empowered to be able to understand what it takes to tweak a feeding plan while we're waiting for the supports to come in. Hey, I see it's important that you breast feed. Maybe what we can do is try adding and think about other options. Can we do some feeds with a 24-kcal formula and what does that look like? It's a lot of math, a lot of math.

Dr. Smith: Speaking of math, we're going to move us forward in time just a little bit. At this next visit, we're 4 months of chronological age, which is 2 months corrected age. In the schedule, the visit is scheduled to discuss some fussiness and some increased spit-ups which seems to have happened in between visits. The weight now is 4.3 kg which is between the 3rd and the 10th percentile. If you reflect back on our growth curve, we're slowly trending downward. The caregivers report frequent spit-ups after feeding and some arching during feeding and stooling only once every 3-5 days. The infant is diagnosed with gastroesophageal reflux disease, GERD, and the caregivers feel reassured. Cuyler, I want to turn it to you. Now that you're seeing this family for fussiness and frequent spit-ups after feeding, arching during feeding, stooling once every 3-5 days and since this is labeled as GERD, the family's reassured. If you were in the room, would you feel like you've gotten the whole story or that GERD explains everything that you're seeing?

Cuyler: If I were part of the treatment team and in the room hearing this case presentation, I would say GERD isn't the entire story. This infant is now a candidate for a comprehensive feeding and developmental evaluation which does have multiple parts to really get a big picture of the mealtime occupation and where changes would be impactful. I would feel that this baby would benefit from a skilled breast as well as a bottle assessment. A breast assessment would include test weights and often we need multiple in order to know what this looks like over time. I would want mom to pump after a feed and see if the baby was actually completing a full feed or what are mom's reserves. And then I would also want to take a look at what's going on motorically and developmentally. This baby would probably benefit from a general movements assessment, maybe the test of infant motor performance. There's a wide variety of motor assessments or developmental assessments that can give you a bit more information on why the baby is presenting the way they are with bottle and breast. And then, of course, I would say the largest influential factor is really looking at caregiver involvement at mealtimes and where they feel the baby is

and what they feel is going well and where are the points of stress, because it's the caregiver aspect, the feeding, that really opens the door for intervention. I would want to know from the caregiver perspective where we need to make some initial changes.

Dr. Smith: Jill, I'm going to come back to you on this. This is the third visit in a row where the family has gotten reassured. What is it about a healthy preterm infant framing that makes a clinician think it's benign?

Dr. Kasper: I think we focus on the healthy and we don't focus on the preterm. If this were a healthy term infant who was doing some of these things, who was sitting, gaining great weight, was arching a little, maybe a little fussy, I'd be like, ah, it's probably some colic, some normal baby spit-up. I see this all the time. No, babies don't poop every day and kind of reassure it, and I think we're forgetting that the kid is a preterm baby. I think how we label it is important and how we're framing it.

Dr. Smith: Molly, I see you shaking your head. Three visits, 3 times they were told it's fine and even when they came in for this last time, they came in because there was something they were worried about. From a parent's perspective, what does this repeated reassurance, when you're worried about something, what does that mean? What does that feel?

Molly: Premature babies have premature parents, right? And they were doing an incredible job advocating for their baby and they were given a false reassurance which just causes doubts. They're going to be so much less likely to bring those issues to their pediatrician in the future and they're going to doubt their gut instincts and their gut instincts were probably right because no one knows their baby better than them. That's also, if something is going to happen, going to create a feeling of mistrust in that relationship between the caregivers and the provider which is really, really dangerous. From a parent perspective, it's I think a real concern that their voice isn't being heard, which is going to cause them to doubt themselves.

Dr. Smith: Alright, I'm going to move us forward yet again in time. Now the baby is 6 months chronologic age, which is 4 months corrected age. It's a routine well-child visit. The weight now is 5.15 kg which is approximately the 5th percentile. The feeding, the baby continues to spit up frequently. Complementary feeding has not been introduced, and the parents believe that breastfeeding is adequate because the infant seems satiated after feeding. The growth is now crossing percentiles downward and is at the 5th percentile for the corrected age. Development-wise, the baby has limited control when prone and the parents report that the baby dislikes tummy time and shows minimal pushing up on the forearms. Jill, as a pediatrician, you're concerned about the poor weight gain, the possible feeding insufficiency and that it's contributing to potential motor delay. What do you think happened? What happens during this visit and what do you think should've happened a couple of visits ago?

Dr. Kasper: We should've listened to the parents, right? If a parent's concerned, we, as providers, should be concerned and we missed this. We should've acted a long time, like a couple of visits back, if not like even earlier, I think. Because now I'm like, okay, this kid is going to have to get admitted. How am I going to do that? Who do I need to get involved? How am I going to get the family on board? They came into my office today. They weren't expecting to end up in the hospital. But this kid needs a full feeding evaluation, probably is going to even need admission for a longer stay at a rehab hospital to get some targeted intensive feeding therapy. I'm not going to get the parent's trust back after this, but I need to get this kid into the care that the kid needs and figure out how to get them admitted.

Dr. Smith: So that's where, Molly, I feel I'm obliged to come to you now. I feel, in this particular situation, maybe trust has been lost a little bit because parents had things that they were worried about, but they were repeatedly told she's fine, and now Dr. Kasper is saying baby may need to get admitted to the hospital. What's this like as a parent?

Molly: I think a parent's worst nightmare is readmission because there's so much trauma and many of us have PTSD from our NICU stays, and we really want to avoid a readmission. And in this particular case, the family came to their trusted provider with concerns and were told that they didn't need to worry or that it wasn't a real concern. And so now they had that self-doubt. They trusted their instincts and were told not to listen to them. So they have this broken trust with their provider and now their baby is losing significantly and is at a very low weight and has to have pretty dramatic interventions in order to become well again. There's a huge amount of frustration at play which isn't particularly helpful in this moment because now they have to focus on their child's well-being. They have to put all of that on pause while they focus on their child's well-being which they've already had to do once during that initial NICU admission. There's a ton of guilt. There's frustration. It's a really difficult feeling to navigate this once again and,

on top of this, you're probably talking about having to look for a new pediatrician and reestablish all of that once again, once they get through this huge hurdle. And all of this was preventable if the parents' voice had been heard that first time. And if that awareness had occurred, because, particularly when it comes to feeding plans and growth, we know this isn't sickness, this isn't a viral illness, or something like that. This is something—monitoring a growth curve—that should have been more quickly attended to.

Dr. Smith: That's powerful. Cuyler, I want to bring this all together. I want to say, medically, what is happening here. Can you bring this together for us? It's a feeding history, a motor delay. Is it 2 different things or are they part of something kind of bigger or collective?

Cuyler: We know that feeding and development are intrinsically linked. If an infant is having a feeding difficulty and they're undernourished or malnourished, we are going to see impact on development. This is where we're seeing poor development of head control, avoidance of tummy time, starting to be expressed in motor delays. And then unfortunately, that compounds because if we have motor delay, it's also more difficult for that infant to then move to the next developmental stage of feeding which is oromotor skills that make it possible to enjoy and safely consume and swallow purees or more textured foods. One really feeds the other. This is why either you need a feeding specialist that's an occupational therapist and also trained in motor or, if you're working with a speech language pathologist, then we need to add in that developmental assessment from your OT and PT partners because one doesn't exist without the other.

Dr. Smith: Heidi, I want to give the last word from the NICU side to you on this particular aspect. Knowing how things kind of started when they were in the NICU at time of discharge and how they turned out in the end, is there something that could've happened at the time of NICU discharge planning and preparation that could've changed the whole trajectory of this outcome in your opinion?

Heidi: I'm going to go back to the fact that we need to talk to families about what's going to happen after discharge. When they're going to go to the pediatrician, what's going to happen with the pediatrician, and I think it's really important to talk about their goals. Is their goal to exclusively breast feed? I think a guidance as far as the fact this is a preterm infant is that you may not be able to achieve that goal right away. It may take time and they have to be aware that they know their baby better than anyone and they need to communicate with their PCP. But sometimes, it's not a good fit, and I tell parents that. You need to feel comfortable talking to your pediatrician. If you don't feel comfortable, if you don't think they're listening to you, before you get 6 months into this, you might want to look at switching your pediatrician. There may be somebody else in the practice. But it's really important to feel you can talk to your pediatrician and that they're listening to you. there's a lot of anticipatory guidance about what's going to happen, what can you expect, and that the baby is not going to be your full-term, totally breastfeeding baby. It may take many months, and they need to be prepared for that, but that eventually, given the support, and given their growth and development, they can get there.

Dr. Smith: I'm going to close off our case discussion for today and say this is a case of a great pretender. This baby started out well, and was doing well, and the family was doing well, until they weren't. And now, this isn't a baby that was lost to follow up. The baby was very much getting care throughout the whole time. Still, things didn't work out. There's obviously some room for improvement and room for growth. With that in mind, I'm going to ask each of us to give our 1 last little spiel and Cuyler, I'm going to turn to you first.

Cuyler: For me, this is a case that calls for early identification and really highlights the power of early identification and early intervention on a child's developmental trajectory. If we can identify feeding difficulties early or pediatric feeding disorder early and screen early, then we have the opportunity to intervene and set that family hopefully on a better path. My closing statement would be screen early, screen often, so we can identify feeding challenges.

Dr. Smith: Alright, thank you for that. Jill, as a medical home provider, I'm going to come to you next.

Dr. Kasper: I think we have to watch the line, not the dots. Every visit, here, somebody looked at the weight and was reassured, but nobody looked at this kid's growth trajectory.

Dr. Smith: Thanks. Heidi, discharge planner, I'm going to give you the next word.

Heidi: I guess I would just repeat what we said before. Giving the parents a realistic expectation of what's going to happen and talk to people. Trust yourself. We trust you. You know your baby. Tell them what's happening and if you

don't think that there's appropriate things taking place, then continue to advocate, continue to say I'm worried about this.

Dr. Smith: Thank you. Molly, the parent's voice is such an incredibly important voice. I'm going to give you the last word to close us out.

Molly: I think that this is an example where you really have to listen to families and know that no one knows a baby better than the caregivers and the parents and we have to listen and trust their instincts. Parents are their baby's first advocates and if we're really going to care for these babies, we have to partner with their parents and providers who partner with parents make excellent providers. And if providers aren't doing that, then, to Heidi's point, then they need to continue to advocate and if that's not happening, then it might not be the right provider. Again, just keep advocating for your baby, keep listening and trusting your instincts because this is the most important thing about being a parent because it doesn't end after you get discharged. It doesn't end when you walk out of the pediatrician's office. Your job, as a parent, on an ongoing basis, is to advocate for your child. It's something that we will always need to do as NICU parents and as parents in general.

⊙ *To complete this course and claim credit, click here.*

This activity is supported by an educational grant from **Mead Johnson Nutrition**.