

Family Centered Care (FCC) Taskforce: How to build a Family Advisory Council in your local NICU

Marybeth Fry, Jennifer Johnson, Molly Fraust-Wylie, MA

This is the second of a series of Webinars from the Family Centered Taskforce. In this first interview, Mary Coughlin, MS, NNP, RNC-E described responding to "The Biological Urgency of Families in NICU Based on our Understanding of Trauma."

MaryBeth Fry:

Good afternoon, everyone. Thank you so much for that nice introduction. Good morning also on the West Coast. So sorry for that. I'm in Ohio, so Eastern for me. I'm going to be one of our three speakers today, talking about creating and strengthening your family advisory partnership councils in the NICU. Molly and I were consulting just a little bit at the VON conference this last week. So there may be some repetition in our presentations because we're all doing similar work but at all different sites. So please take away whatever it is that's beneficial to you as you're doing this work at your own site

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So just a little bit about my site and where we're located. I am with Akron Children's Hospital, Ohio. We are a Level IV regional transport NICU. I do find that that makes us a little bit unique sometimes in the work that we do regarding patients and families because all the babies that we treat here in our unit have mamas who are at other sites at the time of their initial admissions.

We are a seventy-five-bed, single-patient room unit that is divided into two floors and three wings. In that photo, we are [on] the top two floors, seven and six, and we do have three wings on those two floors. Our patient population includes premature babies and babies requiring many of our surgical services and NAS. Another eight sites within our region are Akron Children's Hospital NICUs or SCNs, and then we also take care of babies born anywhere within the region. I share all that information demographically with you because some of our patients come from an hour to two hours away, which sometimes can create challenges for families as they come to stay with their babies here in my unit. This is a picture of

one of our single-patient rooms. I'm the NICU Family Care Coordinator here, and I have the good fortune to be able to offer support programming for families who are here with their babies.

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I did start that work as a volunteer back in 2009. My NICU experience was [in] 2004. So some of you may be thinking, Oh, wow! That's seventeen years, you're right. I have a high school senior this year. That was seventeen years ago when my actual make-you experience occurred. How do I stay relevant? Believe it or not, and I'm sure you'll hear this from others as we continue our webinar today. That experience never leaves you, but the pain and trauma of the experience here, so you can help other families as they continue the journey.

"There are those of us who work in paid roles and those of us who work in volunteer positions. I can't emphasize enough the importance of really pushing and furthering that paid position for consistency."

I did start as a volunteer and honestly didn't start until two years after I had my term baby, my son, who helped me to realize what a traumatic experience I had in the NICU. It really propelled me to want to help other families and support them, so over time, that volunteerism to become a paid parent position here in my unit as NICU Family Care Coordinator. There are those of us who work in paid roles and those of us who work in volunteer positions. I can't emphasize enough the importance of really pushing and furthering that paid position for consistency. Volunteers are phenomenal, generous folks who offer their time to make the experience better for families and who make the outcomes better for physicians and families. But it's just so important to really push for that consistency.

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tency that can come with a paid position.

At Children's, our family advisory council is set up in this structure. We do have a hospital-wide council across all departments within our Children's Hospital. Then underneath our Family Advisory Council umbrella, we have smaller FACTs. A FACT is a family action collaborative team or a unit-based council. We have PICU, NICU, and hematology FACT groups.

We are fortunate in the NICU that this has been a long-standing group formed in 2005 by a group of really motivated NICU graduate families. They worked hard as volunteers with the Peer Mentor Coordinator to establish this group, and they have kind of taken on different roles. Some of our NICU FACT volunteers serve just on that group, while others are also peer mentors. Some volunteer members have served on QI teams. We also had a hospital employee serve as the go-between for our volunteers and the clinical team. Our NICU FACT does still, at this time, report to our larger hospital-wide FAC.

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I share that timeline that really brief timeline with you because NICU FACT has had a long timeline of establishment, and along with that comes a lot of opportunities for projects and advancement. We must also talk a bit about the ebb and flow that comes with having a long-standing committee, right? At the very inception of the group, there was a great deal of motivation and excitement over supporting families, and at the time, we were a 59-bed pod-style unit. Today, we've been seven years in our current space of 75 single-patient bedrooms. So you know, those changes over time have affected our FAC population.

We had financial support from the March of Dimes at one time. We no longer have that. We now rely on donor funds and assistance from our capital budgets.

We have and do review and developed educational materials that go out to families. We do continue to try to have those celebration and support dinners. We'll talk about Covid in a little bit, because that definitely had an impact on some of the work that we've done. Being mentors, we are really fortunate enough for Children's to have an online parent mentor model. And so, if you were to go to our Admin Children's Hospital website and go under our volunteer tab, you would find a list of all our parent mentors that are available to families. We do find that it's a really nice way for families to

reach out and get the support that they need at any given time as opposed to going through a coordinator. All the parent mentor profiles are uploaded and available online. We do really encourage a lot of our FAC members to become parent mentors as well. That way, we can encourage group and individual mentorship. Face-to-face meetings, as well as phone calls and email communication. Again, Covid had a bit of an impact on that because some of our parent mentors are not vaccinated. Currently, we require all volunteers to be vaccinated if they're going to come to the hospital. That said, it's just kind of propelled us to make sure that we're using other modes of communication, such as phone calls, email, and online platforms.

I was asked to talk a little bit about the challenges and solutions to maintaining a FAC in the unit. Families are growing and changing and relocating over time. As I said, this group was formed back in 2005. Many of the founding members of our group are no longer involved.

Your volunteer time changes and maybe, repurposed from providing feedback to NICU to serving on PTOs at elementary school or coaching on teams as children get older, so changes in families over time can affect your membership. It's really important to have active and ongoing recruitment and really clear terms of service. It's important for families to know what they're signing up for. What is the duration of time that they're going to be serving? Is it a year or 3 years? How do those cycles work with your FACs? In terms of service, what is involved in your FAC? Are folks going to be required to come to in-person meetings? Is there going to be an online platform? Are they going to be reviewing and developing education? What are the QI needs of the team? So those things are really important to be upfront with families as they're signing up. Leadership changes can also be a big impact on FACs. Your physician and provider leaders, and your nursing leaders all impact the work of the FAC. When leadership changes occur, the FAC should remain, and parent participation should still be meaningful in projects.

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Sometimes with leadership changes, perspectives change, and it's just still really important for your FAC to continue to have meaningful and meaningful quality Improvement projects to participate in and parent support opportunities as folks are volunteering their time. It's important for them to be able to see the impact that they're making in the unit so that they have that satisfaction and they know that the time is well spent in helping families. That's really what they're there for.

Covid.

Unfortunately, the negative impact that Covid has had on everything with regard to families as partners and family-centered care is great. I think it's also been a real opportunity for us to be able to leverage online platforms to continue the work. There are some FACs who transitioned wonderfully from being in person to being online. They were able to offer support to families online, and that was really important.

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Whatever the lasting impact of Covid is on your institution, it's really important to continue to use online platforms to continue engaging families in the work. For families who may have children at home with long-term needs or families who have recently transitioned home and [are] not comfortable taking their babies out in public, this is a great opportunity to leverage online platforms. I often hear in work with families as partners. “Well, you know, we can't get families to participate in our FAC or in quality improvement. They're just not interested. I respectfully disagree. I promise there is always a family that is out there that wants to make the experience better for the next family. It's on us to make sure that we are extending the offer to engage them in that work. So I challenge all of you. Talk to your bedside staff and those frontline folks who are there day in and day out with families. They can be your point people, and they can give you a list of people to consider recruiting. Setting up tables at any of your hospital events promoting your FAC is another way to recruit members. Within your unit, promote the work of the FAC so current NICU families can see the impact of giving back to the unit. This may motivate them to seek FAC membership once they are transitioned home. Please ensure that the membership of FAC is reflective of your unit. I will be very transparent and say many units have yet to crack that nut. Many have a patient population where there are a lot of single-parent families who may not have additional support at home to take care of children or to come to meetings. It's up to us to continue to recruit families and leverage technology to gain their participation. We particularly need to be better at recruiting with a lens of equity. We need to really reach out to family members who have incredible insights in the work that we do.

Jennifer Johnson's Talk :

I just want to thank you for dedicating this talk to our NICU kids. That was really beautiful. Grace will be turning eleven this coming Monday. So any opportunity to see her voice and see her name on the screen is welcomed. So, thank you.

As Colby mentioned, I'm the Director of Family and Community Outreach, and I want to stress that there is no mention of NICU in my title. I am not NICU-specific, and quite honestly, I wondered if I was really right for this talk since my approach is very, very different. Then I kind of thought: you know what? Maybe someone will benefit from a very different approach. So bear with me. Here we go. My responsibilities in this job are really threefold, including growing an army of diverse families to give feedback and input... and of course, that's what I'll be talking about today. But I'm also out in the community representing the hospital through speaking engagements, community engagement, events, and fundraisers. And again, having been a journalist for twenty years, I still love to tell stories. I still embrace the media, and so I also work with our medical staff to help them feel comfortable working with the media and social media because, you know, we need educated voices on those platforms now more than ever. I also work with our staff to create medical education videos like the one in the lower part of your screen there on the right. This is on our NICU website about how to fortify breast milk at home, which was identified by our NICU families through discharge surveys that Dr. Jeff Meyers helped create, who, I believe, is on this call today! When we identified that families lacked confidence in this area on the surveys, we thought, well, let's do something about that. And so we created this, You know, simple video. It's about five minutes long, and families can watch it before they leave, and then they can access it on our website once they're home. So that's some of what I do. Again, some of the work that I'm talking about today is actually just a third of what I do.

“As Colby mentioned, I’m the Director of Family and Community Outreach, and I want to stress that there is no mention of NICU in my title. I am not NICU-specific, and quite honestly, I wondered if I was really right for this talk since my approach is very, very different. Then I kind of thought: you know what? Maybe someone will benefit from a very different approach.”

So about our hospital, we're a part of the University of Rochester Medical Center in Rochester, New York. Our Children's Hospital is an eight-story tower. It connects in a few places to our adult hospital. It used to be stuffed into the adult hospital, and then, seven years ago, we built this beautiful tower. As for the NICU, it is our largest unit, [with] forty-four private NICU beds in our tower, as well as twenty-four beds in the adult hospital. That's like a NICU step-down unit. Most of those are individual family rooms also. We're often at one hundred percent capacity or more, and it's the only level-one NICU in our region.

So how did you build the Family Advisory Council or Family Partnership Council Programs in your local NICU? Well, I didn't. Maybe I'm helping to rebuild them. I want to give a huge shout-out to our social work clinical manager, Carla LeVant, who, I believe,

is on this call today! She is a family-centered care pioneer and champion at our institution, especially in the NICU. In fact, what you're seeing on the left here is a poster that she presented in 2012.

Carla and her small team – some of them are on this call, and if I'm leaving you out, forgive me. But they really moved mountains to get things going at our Children's Hospital, and by 2009 they had created a family advisory council to gain parental input on many policies and procedures. Here are some of their successes. Yes, I agree; she is amazing. Some of their successes include expanding parent visiting hours and allowing parents to stay in [the] unit during rounds and shift changes. Establishment of a parent advocate/peer support volunteer position. Yes, volunteer. We rely heavily on those at our hospital I am paid, but so many of the people that we rely on for this work are volunteers. Improvements in discharge planning and follow-up and parent participation on hospital committees for planning and quality.

“So Carla and the small team built this great foundation for this work at our Children’s hospital, even bringing in Beverly Johnson, who, we just mentioned from the Institute for Patient and Family Centered Care to really take their work to the next level, and they were off to an incredible start.”

So Carla and the small team built this great foundation for this work at our Children's hospital, even bringing in Beverly Johnson, who, we just mentioned from the Institute for Patient and Family Centered Care to really take their work to the next level, and they were off to an incredible start. The momentum for this work kind of hit a little bit of a pause, just a little bit, when our larger hospital system that we're a part of, really seeing the importance of family-centered care, wanted to take over that care and sort of bring it system-wide. Don't get me wrong: a ton of the work that Carla and her team established continues and [is] carried on like a family advisory council that continues to have representation from all across the Children's Hospital, including the NICU Advisory Council. But to be honest, in my role, I don't know as much about that. I know Dr. Meyers is on here, and I think Morgan Kowalski is here as well, and they can probably answer a lot more about the status of the NICU Advisory Council. But another thing that Carla inspired is a strong, strong core of parents who have that lived NICU experience. They remain so dedicated to our Hospital Pre-covid. They would come to the unit in person and cold call visiting with families, host family dinners once a month, and host scrapbook nights on the unit. It really is a robust effort, and my hat is off to Carla and her team. Everyone helped build this great foundation that I got to help build on top of. But that time that I mentioned when the leadership of the effort was a little bit in limbo sort of allowed some of this work to grow, organically, if you will, which is really impressive but not necessarily structured. Some pockets grew much better than others, so to try to get a snapshot of what was happening in this realm across the Children's Hospital. That

was kind of hard, and we know that tracking this work and producing data on it to measure its impact is important, you know, keeping track of the parents involved in this work. In case, for example, the Joint Commission ever comes and says, Hey, what are the qualifications of these folks? You know? That's quite important, which actually happened this week to us! And we also know that keeping track of the parents and how they're feeling about this work again and it can bring up a lot of feelings about their own time there. Keeping track of them and seeing how they're doing because we know that they're such valuable resources, and we're really trying to tap into their input now more than ever!

All that is easily said to track all of this, but not easily done, especially with limited resources. So if we can go ahead and change the slide, please.

I had actually no idea about any of this internal history that I've just shared with you. I didn't join the hospital staff until 2019, so yes, I'm experiencing a little bit of imposter syndrome right now, having just heard our last two speakers. But what I knew was after having a baby in the NICU in 2011 for seventy-two days, and bringing her home on all sorts of medical equipment, and managing her around [the] clock care at home, and then having her pass away at a year and a half was really very hard. I say that as someone who is so privileged to have, you know, a very supportive and dedicated spouse, a safe home, reliable transportation, et cetera, et cetera, and all of those supports. I say that as someone who is privileged to be able to call up the head of our hospital at the time and tell her my thoughts on what went well with our care and what didn't go well with our care, and actually to see some changes happen as a result of that conversation. And I say that as someone who is privileged to have gotten to know a lot of our hospital families and hear their ideas for change all across the hospital, and not just the NICU. And honestly, I was happy in my other job as a journalist. But I had such an urge to do something with all of this information, and I was able to brainstorm this all into a full-time job and work with the head of our hospital (A new head of our hospital came in 2018), I was able to put this job together in part because he's very encouraging family-centered care. By the fall of 2019, I was actually in place doing that job that we created, and that was actually the first time I was hearing the term “family center care.” I didn't realize that there was a term for something that I was finding was my passion.

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What were the next steps, and what were the challenges for all of this? Well, after I started in this newly dreamed up, Job Carla and I connected and tried to regain some of that momentum that she and her team had really planted the seeds for and really re-energized the effort. We identified that it'd be great to get more family advisors on the overall Family Advisory Council, you know,

and quality improvement teams, and identified it would be great to get more families on QI committees that already existed or were on a list to get started. Same for our Public Relations group, marketing group, and advancement teams, who wanted more families who'd be willing to show up and share their stories. And the same [happened] for our new bereavement coordinator, who wanted to introduce more parents to the work that she was doing. So we can go to the next slide, please.

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We named this effort to incorporate more families into our work the family connection program, and in late January of 2020, we brought a bunch of families together and told them all the ways that they could engage, and many of them signed it to engage in multiple ways. And this was really a dream come true for me to harness the power and insight of families. And then, of course, you all know what happened next. Right?

Covid was like, Yeah, not so fast, right? So many of the engagement Opportunities, of course, were put on hold. Families couldn't necessarily come in, and our staff was so busy, especially those NICU nurses, that Melanie gave a shout-out to [them] earlier.

As devastating as Covid has been, it really gave us the wake-up call and, honestly, the time to realize that we needed to build this program in a way that it could exist virtually and actually, a few other ways that have been important to me as well, and I'm going to talk more about that in just a moment. But first, I want to go over our engagement opportunities as they currently exist, and are presented to all of our families, including our NICU families, so we can go ahead and change the slide, please.

So It might be kind of hard to read on this screen, but I put together this chart, and actually, there are a few other pages to it. Not only this description of the opportunity but the paperwork that's required and the training that is required. The time commitment that's involved, and who are the contacts for a lot of this work. For example, a quality improvement family advisor. We have a CLABSI committee, NICU handoffs committee going, employee safety, and patient behavior that we have parents actively on right now, and I think they're seeing the benefits of having families involved. If we go to the next section, There are our buddy programs! We actually built this during Covid as a way for families with lived NICU experience who were at least two years out from that experience to be matched with a family that was currently in the NICU, and these connections were meant to be virtual. So we said, you know, connect by text, phone, email or a platform like zoom, kind of like whatever works for you guys. And this has been a really big lift. We have now a 19-page handbook for our Buddy Mentors to follow as they onboard. But it has really caught

on and is being replicated by our trach and ventilator program, as well as our g-tube program, with many more units interested in starting a buddy program, including our bereavement coordinator, who i'll talk about in just a moment. But our third graph there, sharing with the public, you know, whether it is again speaking at a fundraiser like a golf tournament, or a gala, or simply sharing a picture of your child who has a g-tube on our hospital's social media, as we celebrate g-tube awareness month or something like that. A lot of families are wanting to share their stories to help promote the good that happens at our hospital, so that's an opportunity for families to engage. Bereavement advisors: I mentioned the future bereavement buddy program... our advisors are doing things like reviewing and standardizing what units give to families when a child passes away in the hospital, like a memorial box, like if there's a child in the NICU versus the PICU there might be different things that families get. So they're looking at standardizing those things. We have our Family Advisory Council and Family Support there on the right that I mentioned - that strong core of making parents cold calling on the unit and host those monthly dinners and scrapbooking events before Covid. They've missed this work. They are itching to get back in our hospital physically, and I think you're just getting the green right now. We want to really expand this concept of support out of the NICU into other units. For example, in our hospital, a lot of our oncology patients have great community supports, our cardiac patients have great community support, but maybe other patients like burn patients or orthopedic patients - maybe there aren't as many community supports, so maybe we could create those supports for them through involving families.

So those are the engagement opportunities, and we're in the process right now, literally right now, of adding this chart to our website so that everyone is aware of what these opportunities are and what it takes to be involved. If we can go to the next slide, please.

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So what did Covid teach us about how we should build and run this program? I think that they should exist in these ways. Really, what's important to me is that so much of this can run virtually, and that's both internally and externally. And what I mean by that is, you know, externally, even after this pandemic is hopefully over connecting virtually instead of in person may be easier for families with medically complex kids or medically fragile kids, of course, for families who live far away and can't make that drive into the hospital for a meeting., Internally, many of us doing this work, myself included, are working from home. Space is at a real premium at our hospital. So the office that I used to have - I don't have any more at the hospital. I'm talking to you from my basement. So it's kind of hard to stay on the same page, being in a lot of different places when we really do cross-disciplinary work! And so this has been a huge challenge because we already have a

focus on meeting industry standards for the training and paperwork required of our families while at the same time making it not too much of a burden that it is a barrier for them to participate. It's figuring out how that whole system can work, and then how it can actually all work virtually -it's been a big lift, but I think one that is important to gather more voices of more families. This program, of course, needs to be HIPAA compliant as we talk about all of these, you know, paperwork papers flying back and forth. It needs to exist in an equitable fashion, and it needs to reflect and meet our values. For example, diversity, equity, and inclusion training. So a little bit more kind of about what that means. The whole process of getting family advisors into our system will soon start online. So yes, we do definitely want recommendations from staff, but we also don't want it to be a barrier. We want anyone to be able to find us and be able to say, Hey, I want to be a part of this. So this is a Redcap form that gives us their basic information, their lived experience, and how they are actually interested in engaging in our system. And this also allows us to track them in our system, and shout out to Dr. Meyers, who helped me create this a long time ago because that Redcap can be a beast!

“The Canadian Premature Baby Foundation - it has this introduction to NICU Peer support training that is online and in video form, and it is absolutely great. Again, Dr. Meyers found this as well. You can access it anytime, and it covers empathetic listening and the importance of HIPPA, which are hallmarks of our program.”

The Canadian Premature Baby Foundation - it has this introduction to NICU Peer support training that is online and in video form, and it is absolutely great. Again, Dr. Meyers found this as well. You can access it anytime, and it covers empathetic listening and the importance of HIPPA, which are hallmarks of our program. We have a HIPAA document advisors signed to go along with that as well. And what do I mean by existing in an equitable fashion? Well, not everyone you know working from home, like has access to a printer, for example. So someone sending someone an attachment to print and fill out and then send back by snail mail may exclude some people. It's also extra steps for already busy families to print it. Fill it out. Find a stamp and put it in the mailbox, right? So we're trying to create forms that can be filled out online instead. You know, for example, our public relations team. They need parents and guardians to sign this very specific HIPAA form before they do an interview with the media sharing their child's health journey, or sharing a picture on our social media pages. So we're working on making this form electronic and looking to see if Docusign might be an option that checks all the privacy boxes.

How about diversity, equity, and inclusion training? Many workplaces, mine included, required DEI training for employees, and we think it's important to bring this to our family advisors in a form that is tailored to them. A lot of us have to sit down and do those

hours-long trainings where volunteers don't have time for hours-long stuff. So we created our own by working with our office of equity and inclusion, as well as a grateful mom who is also a DEI consultant, and our hope is that this one-hour virtual, authentic advocacy and unconscious bias training are helpful, as our advisors support a family that may be very different from them, or they may be advocating for the diverse and beautiful families of our hospital through a place on a committee, for example. I'll be honest. Not everyone embraced this unconscious bias training at first, but I'm happy to report that our first training session over the summer was a real success, and we actually have our second session happening next week.

Finally, setting up a system to track all of these trainings and all of this paperwork -- and honestly, right now, I kind of feel more like a virtual structural architect than someone who is actually connecting with humans on a day-to-day basis. So I'm excited to finally get all of this done and transition to, you know, connecting with other parents and seeing how we can support parents. So if we could go to the next slide, please.

Did you have financial support? And how are you planning to sustain this? Well, I'm calling for backup. Carla is my partner in crime on a lot of this, and we rely heavily on a former NICU Mom as a volunteer to help with the day-to-day logistics and keeping track of all that paperwork I talked about. I have asked for a Family Connection Program Coordinator to be funded through our hospital's budget, which my boss, who is the head of the hospital, supports, but we're currently in a hiring freeze. So that's not an option right now. Another approach, our NICU, which has a lot of representatives on this call, is really looking to kick our family-centered care into high gear, so we've asked a NICU-focused donor to fund a position that would head up the NICU-focused components of the Family Connection Program that I've talked about, and many other NICU focused projects. We're hoping we'll hear back on that very soon. As far as logistical support, we connected with an office that tracks our on-site volunteers like our in-person volunteers. Even though most of our Family Connection Program advisors are engaging virtually, that office still has the capacity to track people. So we were able to rope them in to get some help with some of this paperwork.

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How do you get buy-in from staff and physicians to engage in family-centered care?... that's a good question. We have some

staff that are all about family involvement, like Dr. Day, for example. Dr. Meyers and Dr. Day - thank you for the invite to talk today. But we do have other staff that I worry about when it comes to engage with families. As mentioned, quality improvement can mean looking at where your strengths aren't, which isn't necessarily easy to hear. So human nature may mean that we become defensive. I worry about that when it comes to staff and parent adviser interactions because it takes a lot for a parent or guardian who maybe has been hurt by the system or doesn't trust the health care system to choose to engage back into the system. We really need those voices now more than ever. So, we need to make sure that everyone's on the same page about the importance of this family-centered care and family-centered care for all types of families. We're also working on having Bev Johnson come back to do a grand round and talk about why is it important to have diverse voices? Why do we need to hear this feedback? And where does our hospital stand in regard to this work? And hopefully, by then, in November, it'll be our chance to highlight this Family Connection Program, which will hopefully be all online by then so that everyone knows it as the one place to go for families to start their engagement journey in our hospital.

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And finally, on my last slide, like Molly, I just want to highlight the kids in our hospital and say thank you because, yes, like you, this slide brings me joy.

Molly's Talk:

I always like to center my talk around my son Max. Max is why I am here. ! This is my son Max. This is the very first time I met him. He was born at thirty-two weeks after I was on bed rest for six weeks. ... I always like to use this photo because I don't remember this moment. I don't remember this photo being taken at all, but a very amazing nurse told my husband to take this picture, and on my son's first birthday, my husband gave it to me, and I just love it. . Look at my smile. I finally got to touch him. I didn't get to hold him for quite some time. This photo means the world to me, so I always like to share it, and here are some pictures of us during our NICU stay, Max doing skin-to-skin with my husband and, of course, making our way out of the NICU in front of the exit doors.

Max is now nine and a half. He's in fourth grade. He's healthy. He's doing beautifully. He's the big brother to a younger brother, Renzo, but our NICU experience changed our lives. Now I work with families like ours to try and make the experience a little gentler.

I want to center this talk around our NICU family advisory and how we approach family engagement with our philosophy of care. So in my unit, several years ago, right before the pandemic, we came up with a philosophy of care, and I actually learned about philosophies of care through similar networks like this one. Ours was co-created by NICU families for NICU families, and the goal is to just really show our parents our commitment to them being a part of the care team.

“Our philosophy of care reads: Welcome to the Klarman Family NICU. Your family is part of the care team. Here, we value families and all the love and knowledge they bring and support the uniqueness of all families and cultures.”

Our philosophy of care reads: Welcome to the Klarman Family NICU. Your family is part of the care team. Here, we value families and all the love and knowledge they bring and support the uniqueness of all families and cultures. The BI (Beth Israel Deaconess Medical Center) is a sixty-three-bed level three NICU in Boston. We are not a surgical unit. Our rooms are semi-private. We have a main unit, and then we have a step-down special care unit as well, and we are part of a network hospital system, and we are the main level three unit. We get outborn and retro transfers to about seven different area hospitals.

Our NICU family Advisory committee has about twenty-five members, and they inform all aspects of what we call our NICU Cares program. So I'm going to talk a bit about our NICU Cares program today and the work that I do with the support of the NICU Family Advisory Committee and talk a little bit more about sort of how those roles intersect.

“These are some examples of the day-to-day work and really what we care about. So some of our alumni events, some of our support documents. The bereavement work and memorial service work, which is such an important piece of our NICU sibling work, on the bottom, you'll see all sorts of roadblocks, and this is sort of a painful reminder.”

It's incredible how much the NICU world loves acronyms. That's something that I've learned in my almost eight years in this field... you guys really love acronyms! So, of course, NICU Cares is an acronym. These are some examples of the day-to-day work and really what we care about. So some of our alumni events, some of our support documents. The bereavement work and memorial

service work, which is such an important piece of our NICU sibling work, on the bottom, you'll see all sorts of roadblocks, and this is sort of a painful reminder. During the pandemic, when our resources were very limited, we were not able to have our families in some of our shared family spaces. My co-worker and I met very regularly to pack brown snap bags for our families, so they had a little nutrition and a little bit of, you know, just a little bit of sugar, a little bit of salt so that they could, you know, have help for that long day, and then some of the fun events. We do like photography.

Our acronym stands for compassion, advocacy, respect, empathy, and support.

But what does that really look like? It looks like remembering to celebrate all the little things that happen in the NICU. All these beautiful, incredible milestones for these families that we get to be a part of. We have front-row seats to the best and the worst days of some of these families' lives, and it's really important to honor that.

“So our NICUCares program was developed to coordinate social and informational programs, and it’s meant to help families during their baby’s hospitalization. But additionally, NICU Cares program helps families connect with other parents during and after their hospital day and to stay in touch with us at the hospital.”

So our NICUCares program was developed to coordinate social and informational programs, and it's meant to help families during their baby's hospitalization. But additionally, NICU Cares program helps families connect with other parents during and after their hospital day and to stay in touch with us at the hospital.

We involve our parents during and after their NICU stay in a lot of different ways. This is just kind of wanted, you know, one slide that shows all the different ways, but things from parents at grounds for an if you family advisory committee Uh, with your parents on our subcommittees graph. We have an online support community for our needs to graduate families. We have different documents to help them be more involved in the day-to-day care of their infants, you know, not. Everybody is ready to be hands-on [with] it, so it gives them some very focused things that they can do every day to help care for their infants. ! We have a family integrated, terrified here uh curriculum and program on our special care and unit that we're about to roll out to our main unit. ! A lot of us just came back from VON. We have ongoing and active bond collaborations, and we typically have anywhere between twelve and fifteen parent advisors. This year, I was the only parent who came, and in past years we brought some of our families with us to bond. We do one-to-one virtual.

We have a NICU app that is beautiful. We have a music therapy program that I'm very hopeful will restart soon. During the pan-

dem, Of course, we had to get really creative and flexible about how we engaged our families. Through a donor program, we were able to secure some iPads and kindles. We have a reading and literacy program. We have support documents and alumni events. A beautiful meditation and relaxation program for our families through our pastoral care services. . And we have a bi-annual Memorial Service.

“Our NICU family Advisory committee is the oldest patient and family advisory committee in our hospital, and it was created to increase programs for NICU Families and create more opportunities to support NICU Caregivers.”

Our NICU family Advisory committee is the oldest patient and family advisory committee in our hospital, and it was created to increase programs for NICU Families and create more opportunities to support NICU Caregivers. It was also created based on our family satisfaction surveys. I'm sure all of you are collecting data and doing longitudinal studies at discharge about your patient and family satisfaction. And So this was in direct response to some of the feedback from families. We saw there was a growing demand for parent involvement. Parents really wanted to give back.

Thanks to our amazing NICU Leadership team, There was a really high value placed on that unique parent perspective and also a need for funding. The inception of our family advisory committee was about finding opportunities for grateful families to be philanthropic and give back. Our family advisory committee has grown substantially since two thousand five. We now have anywhere between twenty and twenty-five members who attend our meetings, and I want to highlight that one of the most significant things about our family advisory is we have seven different bereaved families who also participate. I think it really speaks to the level of care that we're providing even in the most difficult of circumstances that our families want to stay involved and stay connected and improve the hospital experience for families that come after them.

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So the mission of our NICU Family Advisory Council is to touch the lives of each NICU family in a positive and lasting way. Our goal is to complement a NICU's outstanding clinical care and embrace the hospital's commitment to family-centered care with programs and initiatives that acknowledge and support the family and the time of crisis and extend the relationship between the family

and the hospital well beyond making your discharge.

So the NICU, in fact, supports this mission through representative feedback on existing and future programming, facility and policy enhancements, redesign and renovation, staff and family relations, development/ fundraising, and other issues related to the needs of NICU families.

We also have eighteen different subcommittees from our NICU leadership team. So we have three to four parents on most of our subcommittees. So this is another way for our families to be involved. They're not able to join our advisory committee. We often find opportunities for them to join these sorts of subcommittees, which are more of a working group, roll up your sleeves type of opportunity. They meet monthly. But we only ask our parents to join about two to three meetings.

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They're now virtual, for the most part, though they were in person before the pandemic, in person. Generally, we start talking to parents about their involvement a year post-discharge, and we talk to all the staff who have worked for the family or who have been exposed to the family to see if they might be a great fit. We connect with anyone from their bedside team to their neonatologist, respiratory therapist, as well as their social workers to see

If they think a family or individual would be a good fit. We do this thoughtfully and carefully because we are certainly surfacing some complicated issues in some of these subcommittees and in some of our meetings. It's delicate, and we want to make sure that we're not traumatizing our families but also that they're ready to share their experience. And if they're able to take that expertise and that experience, and to build better programming and to improve care for other NICU Families.

But how are we getting these folks involved? So that's sort of the meat of this, right? So we use a lot of different channels to connect with our families. . . everything from emails and phone calls. We have an alumni group online and on Facebook. ! We have a discharge nurse who calls families and specifically says, Hey, do you want to stay in touch. And then we're given those emails, and we're able to communicate with our families and figure out what level of involvement they'd like.

I'm in a paid family position. I know I've seen some questions in the chat about that, and I'd be happy to talk about that a bit more. But I'm paid part-time. The hospital employed a program manager within my hospital. So that's another way that I engage because I'm able to be present at the bedside and build relationships with these families. So we cast a really wide net because we know a lot of families will express interest, right? But you know, things like a pandemic happen. . . And also we know,

as NICU providers, that sometimes a NICU Baby is not the most critical thing happening in a family's life. There are so many different things that happen to our families at any given time. So we really want to figure out ways that we can engage our families but not add to their stress.

“One of the things that I think is most effective. Some of you may have heard me say this earlier this year when I gave a similar talk at the Gravens Conference earlier this year if you don't have a stay-in-touch document or someone reaching out to your graduate families to check in and to see if they want to stay in touch, start there.”

One of the things that I think is most effective. Some of you may have heard me say this earlier this year when I gave a similar talk at the Gravens Conference earlier this year if you don't have a stay-in-touch document or someone reaching out to your graduate families to check in and to see if they want to stay in touch, start there. That's a really low-lift thing that you can do to help you understand what their interests are, and also to what degree they want to be involved. If you're keeping something like that active and updated, and if you can find a way to just get in touch with your families and ask what they want to stay in touch with you. That's a good starting point. We know that our families want to be really a part of things. They want to be involved in our Qi work coming off of the heels of a bond. It's amazing to see what families can add to our quality, improvement, and to our advising. So you're giving them a really great way to help future families and give back after their experience.

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But it's all about relationships, right? Because if we're inviting families to come back and share in a vulnerable way. We really need to build trust and establish connections and relationships. So this starts at the bedside during their NICU day, and it lasts for many, many years, or in some cases, a lifetime. They've been sitting on our advisory committee since its inception more than twenty years ago. You know they Really,

This is such a critical part of their lives, and it was such a touch-

stone for them that they want to be involved. The NICU has changed wildly. I know, even for myself. My NICU stay was almost ten years ago, and the way that we provide care has dramatically changed. So it's really beautiful to see those changes over time and to see how things are moving forward and how your feedback is being used.

“But in order to get that feedback right. It’s really important to have trust. Families need to feel safe in sharing the good and the bad about their NICU experiences. It’s not easy to tell the people who have taken care of your infant that while everything was beautiful, there were some things that could have been better.”

But in order to get that feedback right. It's really important to have trust. Families need to feel safe in sharing the good and the bad about their NICU experiences. It's not easy to tell the people who have taken care of your infant that while everything was beautiful, there were some things that could have been better. So when we're talking about,

Sometimes it's really hard to hear about your child as a data point, right? Or when we talk about some of the more difficult topics, we need to make sure we're always using content warnings when they're appropriate. We always need to make sure that we're giving families a heads-up. We're going to talk about something that may bring up some feelings and emotions for them. So we need to really think about the clinical language that we're using in our NICU settings when we're bringing parents into this type of work., it's really important to talk to NICU Staff, and the nurses, especially about what projects you've got going on, so they can see if they can think of any families that might be a good fit, and a lot of our families are still in touch with their day to day nurses. Right? They are updating them, and you know how to their homes. So that's great, that's a great starting point, and then we also need to be really flexible. ! A lot of our working families may not be able to be regular at all soon. Zoom has been an incredible option for engaging families, getting them involved in the day today, and sort of making sure that they're once a month, and then is it too much? ! something that we're trying to do in our hospital that we haven't had much success with, but I know that it works at other units is some night meetings. Not everybody is able to meet and burn during the day. But could you do, you know, even if it's one or two night meetings a year or a night zoom meeting. Is that something that can happen? ! Also? Are there opportunities for you to involve families over email? , we're gonna work online. So just be flexible and be upfront about the task. So what is the time commitment looks like? What staff are going to be involved in? Do you want to be forthcoming about that? And also, will they have a chance to connect with other nations' families, and do they want to do that?

Compensate if you can? I know this is, you know this is hard, right. Not a lot of our units even have a paid parent advisor role. But,

you know, we need to be paying people for the time that they're giving us, and if you're writing a budget for a grant, or you're putting a proposal together, add some time for parent participation, for their time and for their expertise. We're not currently compensating our NICUfamily advisory committee, but we do offer them free parking and meals when they call in person for things and for NICU projects like ours. You know our co-creation of our family integrated care program. We had two co-eds who were to keep graduate families, and we offered them a stipend, even if it's just some hospitals. Why [do] you just really want to show your appreciation for the expertise and for the time commitment because a lot of these things can be very time-intensive.

We know that it's really important to bring in all aspects of NICU families. So if you have families who are limited in efficiency, or who do not speak English or are limited, using interpreters, having staff involved who speak those languages is really important to engage those families. And then transportation. I'm not. You know some of you may have closer units, but we're a main level, and some of our families live hours away. Different states. So providing transportation, parking, and child care, if possible, is really helpful,

and we know, as Mary vested, and I want to echo the importance like we need to be recruiting in ways that represent and reflect our patient population. So we need to be prioritizing welcoming people from all different backgrounds, so races, and ethnicity. But not only that, sexual orientation, family structures, gender financial situations, and physical and mental abilities, Right? The experience of disabled parents is very different in the making. So are we. Are we doing what we can to listen to their experience, and also education, level, diversity, and family structures. So are you engaging LGTQI, headed families? Are you teaching single parents and then culture and adversity. So again, families who are not speaking the dominant language in your unit reach out to them and find ways to connect with them. We have some incredible family advisors in our bond who work and speak different languages. So it's always great to sort of tap an expert and see and see how they can help you engage.

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So, of course, one of the things we were asked to talk about was the impact of our family advisory and Covid and parent participation. And you know something that has sat with me the uh at the Gravens Conference earlier in March. Someone, I believe, from

the IPCC in the Institute for patients, and I'm getting all my acronyms to use. Anyways, there is a really powerful quote that said something along the lines of the pandemic detainee parents.

“What the pandemic did to make your parents want the asteroid to design a source. I think a lot of families are really feeling like we have a lot to come back from, and that, I think, resonated with a lot of us, like your families and people in roles like mine. You know everything moved virtual, so you know, on the fortunate side, at least for our family advisory committee.”

What the pandemic did to make your parents want the asteroid to design a source. I think a lot of families are really feeling like we have a lot to come back from, and that, I think, resonated with a lot of us, like your families and people in roles like mine. You know everything moved virtual, so you know, on the fortunate side, at least for our family advisory committee. We moved to virtual quarterly zoom calls, and surprisingly we found there was increased participation. Our family provides feedback and hears updates about Indicators and Covid in an increased way. But our subcommittee sort of our working groups that were regularly. We saw that participation sort of dropped off, so less parents are available to join the monthly calls. We saw a lot of zoom fatigue. I'm: Sure, we're all experiencing the same. And we, you know, we really had to do things like, get really creative emailing for feedback, for documents and engaging them in different ways. And we're still working our way out of that, you know, transparent. I think you know what that was saying. Sort of similar. It's. This is hard work, and it's not easy, and when it works for a little while, something may happen, and you'll have to kind of start over again at the ground. But, I'm able to have a community of family advisors who are more like one to pick their brains. So know that if you don't have questions and they're building a family advisory, you don't have to do it alone. There's ten of us who are doing it, too, who, you know. We may not have all the answers, but we can hopefully find you a way to work together to build this. So that's what I've got for today. I just wanted to say, Thank you again. Here's my contact information. And here are some pictures that bring me some joy. It's not easy. , but I think it's so important, and you know I think our families appreciate this work. So much so. Thank you for your time.

Disclosures: No conflicts have been identified. .

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Marybeth Fry is the NICU Family Care Coordinator at Akron Children's Hospital in Akron, Ohio. In her role, she mentors and coordinates programming to support current NICU families. Additionally, she serves on a number of unit and hospital based committees as the parent voice in quality improvement projects. Ms. Fry is Vermont Oxford Network faculty as the lead Family Partner of their NICQ and iNICQ collaboratives, and Experience Based Co-Design program.

Jennifer Jones is Director of Family and Community Outreach at UR Medicine Golisano Children's Hospital. Her child Grace was in the NICU. When you report the news for 17 years in one city the name "TV news lady" is hard to shake but it's one Jennifer Johnson embraces after a career as a television news anchor. Journalism is what brought Jennifer to Rochester, New York but three years ago she started a new career inspired by her late daughter Grace. Grace was born very sick in 2011 and was not expected to survive but because of the exceptional care she received Grace lived almost 17 months. You learn a lot being the parent of a medically-fragile child. Jennifer began advocating on behalf of patients and families and soon realized there was so much work to be done in this area that it could be a full-time job. Now, as the Director of Family and Community Outreach at the children's hospital that cared for Grace (UR Medicine Golisano Children's Hospital), Jennifer is working to bring the voices of families with diverse backgrounds, diagnoses, outcomes and experiences into the decision-making process at the hospital. She is often out in the community speaking about the hospital and also works with medical teams in Rochester and across the county to help them feel more comfortable with the media and social media.

Molly Fraust-Wylie is a NICU Parent and a NICU Family Program Manager at Beth Israel Deaconess Medical Center in Boston. As a direct result of her experience both on bed rest for 6 weeks with her son, to being in the NICU with her premature infant, Molly believes in the importance of community support and shared experience for NICU families. Molly provides the unique parent voice on multidisciplinary teams with the aim of improving the overall experience for families with infants in the hospital. From developing materials and running educational programming on the unit, to leading quality improvement efforts and collaborating on family engagement, to bedside support and advocacy both locally and nationally, her focus is empowering NICU Families and integrating NICU parents into all aspects of decision making and caretaking. Molly is the Chair of the Family Advisory Leadership Committee for the Neonatal Quality Improvement Collaborative of Massachusetts Family Engagement Collaborative and serves as a Board Advisor to Project Sweet Peas, a national nonprofit that supports families of hospitalized infants and those who have been affected by pregnancy and infant loss. Molly holds an MA from Emerson College in Integrated Marketing Communication and is a graduate of Dickinson College.