Family-Centered Care Taskforce Advocacy Work: Resolution to the **AAP Annual Leadership Conference "Parents and Family Caregivers** are Integral Members of the Patient Care Team" (Resolution #36)

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The American Academy of Pediatric Section on Neonatal-Perinatal Medicine's Family-Centered Care (FCC) Taskforce aims to encourage education, create guidelines, and facilitate unit-based interventions related to FCC in Neonatal Intensive Care Units (NICUs). A key strength of the FCC Taskforce lies in its ability to break down the silos that often hinder progress in healthcare. Through its global network of institutions, this Taskforce connects healthcare professionals, researchers, and family partners, fostering collaboration, knowledge sharing, and disseminating best practices regarding FCC. The Taskforce employs a mentored small group model and large group webinars (nine so far and many more scheduled), enabling effective communication and facilitating change across various healthcare settings. By sharing evidence-based practices and critical family perspectives during webinars and facilitating accountability through small groups, we are creating a forward movement to close this healthcare gap. For more information about the FCC Taskforce and free educational webinars, please visit our website at www.fcctaskforce.org. The FCC Taskforce's Executive Council comprises three co-chairs, a program manager, 18 family partners, 18 healthcare partners, and three committees that oversee marketing and communications, newsletters, and advocacy work.

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In March of 2023, Nicole Nyberg, MSN APRN and NICU parent, Colby Day, MD, and Kerri Machut, MD (the FCC Taskforce's Advocacy Committee chair) submitted a resolution to the AAP Leadership and Advocacy Conference titled "Parents and Family Caregivers are Integral Members of the Patient Care Team" (Resolution #36).

The resolution is as follows:

Resolution #: 2023 Annual Leadership Forum

Title: Parents and Family Caregivers are Not Visitors

Sponsored By: Section on Neonatal-Perinatal Medicine

Date: March 31, 2023

Disposition:

Whereas, consistent presence and engagement of parents and primary guardians, herein referred to as family caregivers, in neonatal and pediatric clinical settings positively impact the child's overall health and long-term outcomes.

Whereas, family caregivers who are actively involved in their child's care and shared decision-making have increased confidence, decreased stress, and improvement in the transition of clinical caretaking to the home environment.

Whereas, during the COVID-19 pandemic, children and family caregivers were unnaturally separated due to visitation restrictions since family caregivers were considered "visitors" rather than essential care team members.

RESOLVED, that the American Academy of Pediatrics (AAP) recognize family caregivers as valued contributors to their child's health, declare family caregivers as parents, not visitors, and ensure children and family caregivers are not separated in clinical settings (while following appropriate infection control guidelines).

RESOLVED, the AAP commits to this in the form of policy statements, recommended guidelines for care, and advocates for legislation for family caregiver rights in the healthcare system.

The Taskforce provided a forum to collect supportive comments. Forty parent and clinician members made statements that were shared at the AAP Leadership and Advocacy Conference. As these were so compelling, we memorialize them here:

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Supportive comments are as follows:

As the Director of a large Level 4 NICU during the pandemic, it was my responsibility to enforce the hospital's visitor restrictions. The moral distress this created for me and the NICU healthcare team was significant, and I feel [it] has been greatly under-appreciated. As a mother of a NICU graduate who had a 3-month NICU hospitaliza-

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tion, I cannot fathom undergoing that experience alone and [being cut off from my support system. Yet that is the scenario I was required to create for so many families. The emotional and psychological toll on NICU families was immense. I witnessed it daily, and the impact that it had on my own mental wellbeing was significant. I also have great concern over the long-term impact the social isolation had on parent/infant bonding. How has that impacted long-term outcomes for NICU graduates? I also wonder how much of an impact the moral distress and resulting work-related stress has played a role in the nursing turnover so many NICUs have been experiencing. My greatest hope is that we learn from this recent pandemic that NICU parents are part of the care team and should NOT be treated like visitors. With the ongoing nursing shortage, it's more important than ever that parents be fully integrated into their child's NICU care and be made to feel that they are part of the care

"We believe that nothing is more important than promoting a bond between the baby and the parent because that relationship will last a lifetime."

- It is not unusual for a parent of a baby in the NICU to forget that they are, in fact, a parent, especially when their baby is on the edge of life and death. We at Graham's Foundation exist to help empower parents, so they recognize their importance while their baby is in the NICU. We believe that nothing is more important than promoting a bond between the baby and the parent because that relationship will last a lifetime.
- Parents and babies need each other!
- Every parent looks forward to the day their baby is born, and their family grows. Few of us anticipate that our babies' birth will be a medical emergency - or that we will require intensive care. But this is the reality for more than one in ten of us.
- Please appreciate that a NICU admission is an abrupt break in the birthing and bonding process.
- When this happens, families need love and support.
- If we have to be separated to provide emergency care, please reunite us as soon as possible. Help us reconnect and bond. Care for us together. And help us become the family we need to be.
- If our baby and we are experiencing the signs and symptoms associated with perinatal substance exposure, please show us extra love and care. Reject stigmatizing attitudes and language, treat us with dignity and respect, and help us by employing evidence-based care models like Eat Sleep Console. When you deliver this kind of respectful, trauma-informed care, you not only interrupt the systems

that oppress us, you help build stronger, more resilient dyads.

"We will only achieve the best outcomes for each individual infant and family by recognizing the unique and important expertise and value of the family to the care team."

- Parents, as well as extended family and community members, are critical to optimizing neurodevelopment within the NICU and for creating a supportive framework and structure that promotes long-term neurodevelopment. In addition, their presence and participation mitigate the trauma associated with a NICU admission. We will only achieve the best outcomes for each individual infant and family by recognizing the unique and important expertise and value of the family to the care team.
- I fully support that the NICU families should not have a limit on visitation rights for their child. My son spent seven months in NICU [from] March 2016 to October 2016. I spent most of my days at his bedside and gave him the care he needed. I helped clean his ostomy bag. I was able to do kangaroo care. This was all part of bonding. This was important to me and for my child's development. He was confined to tubing while in the hospital. He is now seven years old. He is still mainly fed through a g-tube and is working on his oral feeding skills with an SLP feeding specialist. There is a special bond as his mother cares for him.
- I saw information about how important the mother's role is but nothing about the father. Fathers also play an important role and feel they are often neglected and overlooked. Research shows that when fathers are involved, mothers and babies both have better outcomes. This statement needs to include the important role fathers play.
- Parenting in the NICU is the most unnatural place to be a parent. Nowhere else do parents have to ask to hold their baby and have physical barriers to comforting their child when they are in pain or scared? Nowhere else are parents as terrified and traumatized as we are in the NICU. Too often, the clinical care of the medically complex and fragile infant seems to neglect or forget that the powerful and necessary bond of the parent and infant is healing. As a mother of triplets born at 25 weeks 5 days gestation and a full-term baby, I have firsthand knowledge to truly understand and appreciate how vastly different these experiences are. With my triplets, I was separated immediately upon their delivery, did not see them for 48 hours, did not hold them for two months, and did not truly begin to bond with them for several months later. The toll on my mental health was significant as I suffered from PTSD, major depression, and generalized anxiety disorder, issues I still deal with to this day. As my surviving triplets, now 16 years old, struggle with their own mental health conditions (anorexia nervosa, depression, and

- anxiety), I can only wonder how that separation and delayed bonding may have played a role in what we are facing now. With my full-term daughter, I held her skin-to-skin immediately after birth while still in the OR. She remained on my chest for the first several months of her life unless she was being dressed, changed, or bathed. Our nurturing connection is unlike anything I had with my triplets. The healing I have experienced through her birth and development is unmistakable. I urge the AAP to consider the long-term impact those days, weeks, and months in the NICU have - not just on the baby but also on the entire family unit. YOU have the power to ensure families are kept together as early and as long as possible.
- Incredible work is being accomplished by numerous NICU Parent Leaders globally to improve the outcomes of NICU patients and their precious families. Recently, global events demonstrated how easily family caregivers were removed from the NICU in one sweep while being viewed simply as visitors of the NICU, rather than essential care providers. I support the resolution titled "Parents and Family Caregivers are Integral Members of the Patient Care Team" wholeheartedly. I also believe that not acknowledging the parents and family caregivers today has the potential for a long-lasting negative impact on the babies and their families. We must unify our voices that medicine/science/technology alone will not bring the best outcomes to the families, but properly recognizing every stakeholder and valuable role for each, which includes parents and family caregivers' role, is critically necessary today. Our parent and family colleagues are truly valuable in today's NICUs. Pandemic-led historic wrongs against parents and family caregivers must never be repeated.
- "Parents/caregivers are not visitors they are an integral part of the care team and need to be treated as such. This benefits everyone, especially the baby (ies)."
- As Parent Support Coordinator, I hear over and over again how grateful parents/family caregivers are to be able to room in with their baby (ies) due to having couplet care and private rooms and how being close to their baby benefits their coping with the stress of being in the NICU. I also hear how difficult it is when mom and baby are separated after birth when mom needs a higher level of care and how hard it is for the other parent/caregiver to go back and forth. We see the benefits of parents/caregivers being able to hold, talk to, and care for their babies. They share how relieved they are when they are able to finally all be together. Parents/caregivers are not visitors - they are an integral part of the care team and need to be treated as such. This benefits everyone, especially the baby (ies). My babies were born in the hospital I now work at, and even though the NICU was an open bay back then, we were still encouraged to participate in care, and we were told how important we were to our babies' development. We need to make sure

- that parents/family caregivers are able to be present for their babies, even during a pandemic. It is what is best for everyone involved!
- I am the other of twin girls born at 26 weeks in the year 2000. My experience led me to be a founding board member and develop the psychosocial support programs of The Tiny Miracles Foundation in 2004. I cannot express how important and essential it was for me as a mother and my husband as a father to be in the neonatal unit, advocating for and sharing in the care of our twins in the NICU. I know for a fact that their recovery to typical children today and our emotional recovery as parents had a lot to do with our specific involvement as parents. I've been a Preemie Parent mentor and advocate in five hospitals in CT for 20 years, mentored thousands of parents through the NICU, and followed their kids' progress into adulthood. I know firsthand the difference in the outcome for the kids that didn't have their parents as involved, and also the difference in how those parents have recovered emotionally from the trauma of premature birth. It's staggering, and the studies are clear the parents are "essential "caregivers in the NICU and in all healthcare of their child. COVID restrictions created catastrophic long-term emotional trauma for parents and their children, who have suffered physically and emotionally from the restrictions. This cannot happen ever again.

"We know outcomes of neonates are largely impacted by family care - nursing, skin-to-skin, parental advocacy, etc. Further, forming attachments to their parents (which will impact them and their relationships throughout their lives) is crucial during this time."

- We know outcomes of neonates are largely impacted by family care - nursing, skin-to-skin, parental advocacy, etc. Further, forming attachments to their parents (which will impact them and their relationships throughout their lives) is crucial during this time. This is just on the neonates' end - parental trauma and mental health are an entirely different ball game! Parents and family caregivers are most definitely not visitors but part of their baby's treatment and care. They MUST be included every single step of the way.
- Parents and Caregivers are an essential part of a baby's development and growth. The separation of parents from their newborn is detrimental to the newborn. Newborns and their parents/caregivers both benefit from being together, as study after study has shown. Just a mother's scent alone has been shown to stabilize the heart rate and breathing of a distressed newborn. The separation of a mother from her baby can increase postpartum depression and add to the anxiety and stress of a NICU experience, as well as increase PTSD. Caregivers/Parents should not be separated from

their children in the hospital.

- I am in complete support of ensuring that parents are at the center of patient care when it comes to their child(ren) in the Neonatal Intensive Care Unit. As a NICU mother myself, I can not imagine being told that I was unable to be with my daughter during care, or unable to do kangaroo care to help regulate her temperature and encourage breastfeeding. It is also unfathomable to think of doing it alone without my husband by my side had one of us only been allowed in the room. These are stories that I have heard time and time again from parents who found themselves in the NICU during the COVID-19 pandemic. Birthing and non-birthing parents are essential to the wellbeing of not only their child(ren), but to their mental health as well. Parents should be at the center and involved in as much as possible while in the NICU with their child(ren).
- Considering that parents and caregivers bear the responsibility of caring for NICU babies for a much longer duration than any other hospital provider, it seems most logical that the medical team would, as a whole, work to foster and support parents and caregivers in any way possible. When hospital teams help in this way, it might make the transition to home much more seamless, as caregivers have already begun to see themselves in an essential light and might provide further encouragement and confidence for them where it once was lacking, thereby enabling them to be both more prepared and more knowledgeable caregivers.

"The physical bond between parent and infant is biological. It is also paramount for their physical and mental health and can have long-term negative consequences when denied."

- We were well informed of our children's progress and felt at ease when we were educated on their conditions. This is never easy for families, but there was a lot of emotional support and resources made available to us to help get us through the challenges. The teams that cared for our children were amazing and sensitive to our needs.
- The physical bond between parent and infant is biological. It is also paramount for their physical and mental health and can have long-term negative consequences when denied. As a NICU parent, I understand firsthand the anguish of this physical separation and the long-

term impact on my mental health and that of my son.

- In the NICU setting, the infant-parent bond becomes even more important because of the proven medical benefits to the medically fragile infant and the improved mental health outcomes for parents. As the Founder of Hand to Hold, a national nonprofit that provides direct mental health support services to more than 40,000 NICU and bereaved parents each year, I can confirm the significant impact the restrictive visitation policies enacted in response to COVID-19 unmistakably had on the mental health of NICU parents across the country.
- I urge the AAP to acknowledge, affirm, and protect parents' rights to be with their children to not only serve as their advocate but to provide the loving, healing power of their presence. It is imperative that parents not be seen as visitors but as essential care team members because they are!

"Babies respond to their parents' touch and voice, and the parents learn to care for their medically fragile child by being involved in the baby's care during the NICU stay. Breastmilk is lifesaving for NICU babies, but breastmilk supply is often low in breastfeeding parents whose baby is premature ... there is far more benefit than risk in allowing them both to be present as often as possible while their baby is admitted to the ICU."

The involvement of parents/guardians of a NICU baby makes a huge difference in the baby's health and life. Kangaroo care, or "skin-to-skin," from both parents/guardians helps with bonding, temperature regulation, and improvement in attention, response, reflexes, and other markers for the baby. Babies respond to their parents' touch and voice, and the parents learn to care for their medically fragile child by being involved in the baby's care during the NICU stay. Breastmilk is lifesaving for NICU babies, but breastmilk supply is often low in breastfeeding parents whose baby is premature or NICU-bound. A parent who is able to pump breastmilk in the NICU near their baby or while touching their baby is able to produce more milk. So long as both parents/guardians are in excellent health, there is far more benefit than risk in allowing them both to be present as often as possible

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while their baby is admitted to the ICU.

Parents and family caregivers are essential to their infants' health and development in the NICU. Positive and repetitive bonding experiences and care interactions support infant neurodevelopment, attachment, and parental competence and confidence. Parents and family caregivers are an integral part of the healthcare team. Ensuring 24/7 access, inclusion in medical rounds on their infant, and supportive integration into bedside care (diapering, skin-to-skin holding, feeding, human touch, graded sensory input, reading, non-pharmacological pain strategies, etc.) are examples of the many ways parents and family caregivers can bond, learn early parenting skills, advocate, and come to know their infants' unique cues. This critical period of survival and development demands a full spectrum of support for optimal experiences and outcomes. Parents and family caregivers play an elemental role in providing the highest level of care and fundamentally humane care.

"I had seen a parent's love and healing touch help their baby survive and thrive when medical care was at its maximum, and there was nothing else to offer."

- Parents are also patient. When children cannot speak for themselves, parents should be allowed and encouraged to be at their bedside as much as possible so that they can be a large part of the caregiving team. Parents will be the long-term caregivers after discharge and should be present as much as possible to learn and bond. There should never be a time when a parent is considered a visitor. They are not visiting their child. They are parenting their child and should have full access at all times unless surgery is required. Parents are the patients.
- Parents are not considered visitors in our NICU and shouldn't be considered as such in any NICU or SCN. They are an integral part of the baby's care team. I had seen a parent's love and healing touch help their baby survive and thrive when medical care was at its maximum, and there was nothing else to offer. They provide insight and perspective about their baby that no one else can, and they understand the interpersonal dynamics of the family that the baby will go home to. This is a no-brainer. Parents are NOT visitors. They are the whole world to the baby.
- As both a NICU Mom and a NICU Parent Advocate employed by a hospital, I could not agree more that parents are not and are never visitors. The love and experience parents and family caregivers bring [in] is unique and an essential part of the growth and development of the baby and critical to the growth and development of the family, as well. We know that the integration of a baby's family into all aspects of their care improves outcomes, shortens stays, and helps build connections at a time

of crisis. Parents are actively involved in their baby's care in the NICU. They may participate in activities such as skinto-skin contact (kangaroo care), feeding, and even assisting with medical procedures under the guidance of healthcare professionals. By being present, parents learn how to care for their baby's unique needs and are better prepared for their transition home. Parents are advocates for their babies in the NICU. They have the right to be involved in discussions about treatment plans, interventions, and decisions affecting their child's care. By being present and engaged, parents can actively participate in these discussions and contribute their insights and preferences. To use the language visitor with respect to NICU parents/caregivers is to frame families as outsiders, which denies the importance of the parent-child relationship at its most vulnerable and delicate stage. And we know just how vulnerable NICU parents are, how traumatic the separation of parent and child is, how much more at risk they are for things like PTSD and other perinatal mood disorders - coupled with the anxiety of the unknown outcomes for their fragile baby, and the guilt, trauma, and emotions they may be feeling about their pregnancy or delivery only add to the heightened state of distress NICU family caregivers find themselves in. NICU parents have no choice but to leave our hearts in the hospital every day - to trust these excellent providers with our babies. The trust has to work both ways- where families are seen as valued and necessary as the clinical providers.

"By being present, parents learn how to care for their baby's unique needs and are better prepared for their transition home."

If parents can be seen and FEEL that they are valued as caregivers in the hospital, and staff recognize and treat them as such, I can't see how it would do anything other than empower parents to be the best caregivers they can be for their child both in the hospital and after discharge home-which is what everyone wants in the long term. It feels like a win/win for all involved. And perhaps most importantly, for some parents, the time in the NICU with their child may be the only time they will ever have with their child, and that is certainly not visiting. Language matters, particularly during a time of crisis, and we have an opportunity to make a simple change that will validate NICU parents, make them feel more included, and demonstrate the critical role they play in their infants' lives, starting at the bedside in the NICU and hopefully beyond the doors of the unit with time. I cannot see any downside to empowering parents and welcoming them as an integral part of the care team. "One doesn't have to operate with great malice to do great harm. The absence of empathy and understanding are sufficient." - Charles Blow (and quoted frequently at the Graven's Conference mid-pandemic while talking about the impact of COVID restrictions on NICU Parents) I know that no NICU provider would ever intend to cause harm to a

parent/family and here we have the chance to make a change that would impact the next generation of NICU parents and show they are truly vital, involved, necessary collaborators.

- NICU patients are not individual patients. Rather, they come with parents and family members who are critical components of their care and wellbeing. Parents learn to support and tend to their baby's medical needs as important members of the care team, and they provide an emotional connection for the baby. It is important to remember that no parent is a "visitor" when their child is in the hospital; they are thrust into a world of caregiving that many are not prepared for. My son was a 23-weeker, and my husband and I became experts on mundane things like temperature-taking and weighing, but also in complex medical conditions such as ostomies, stomas, and g-tubes. Supporting families and reminding them of the important role they play as part of their baby's care team sets up families for success.
- The Tiny Miracles Foundation was established to provide the emotional, practical, and financial needs of the families of premature babies. The Tiny Miracles Foundation strongly believes that parents and family caregivers need access to every moment in the NICU and strongly supports the proposed resolution as we know the critical role that parents and family caregivers play in patient care in the NICU.
- Parents and family members are not visitors in the NICU - they are a fundamental part of the NICU ecosystem. Parents need to be an integral extension in the health care decision-making and hands-on involvement in the care of NICU babies.

"We support resolution #36, "Parents and Family Caregivers are Integral Members of the Patient Care Team." As a national nonprofit working with a serious highrisk pregnancy complication, the leading identifiable cause of preterm birth, The PPROM Foundation acknowledges the critical importance of family caregivers in the perinatal and neonatal space."

In what service industry does the person paying for the service get treated like a visitor or a non-human? None. So parents and caregivers are essential members of the NICU team, and without them, facilities do not get access to the best medicine possible in the form of a Mother's breastmilk. To date, it truly is the best medicine for the baby. No other treatment can do what it does. Add to this, the baby knows the parents first and foremost unless there is a situation surrounding adoption. And because of this, the parents know that the baby [comes] first and can provide comfort to the

- infant. That affects the infant's ability to function, fight infection, and so much more. As someone who advocates on behalf of Adult Preemies, I can tell you the ramifications of separating families from the baby for whatever time has a truly brutal outcome for that infant and that family.
- We support resolution #36, "Parents and Family Caregivers are Integral Members of the Patient Care Team." As a national nonprofit working with a serious high-risk pregnancy complication, the leading identifiable cause of preterm birth, The PPROM Foundation acknowledges the critical importance of family caregivers in the perinatal and neonatal space. In addition, this inclusion and involvement should continue postdischarge. Ensuring that parents and families are active participants in the interdisciplinary care team results in better outcomes for all involved.

"Shared decision-making is critical in the NICU, where parents and providers must work together to optimize decisions that can have lifelong health implications for the infant."

- My daughter was born three months premature in 2019. We spent 112 days in the NICU. Having your baby in the NICU is traumatic...walking into the NICU for the first time to see your baby is intimidating. I learned very quickly that I was my daughter's voice. I have about ten years in the medical field, so I was not shy [about] voicing what she needed... didn't need...who[m] I felt comfortable caring for her and certain staff that I did not want to care for her. I feel like the majority of families that are in the NICU are too intimidated and/or scared to speak for their babies. These families should be welcomed with open arms and encouraged to advocate for their babies. Communication between families and staff must be constant and consistent.
- Shared decision-making is critical in the NICU, where parents and providers must work together to optimize decisions that can have lifelong health implications for the infant. Because things can change so rapidly in a sick newborn, parents need to be at their child's bedside so they can be informed and participate in these vital health decisions.
- I fully support this resolution. Caregivers need education and support while in the NICU. This will improve health outcomes and integrate caregivers into the care team instead of labeling them as visitors.
- As a former NICU mom, I can attest to the integral role that parents and caregivers play in their children's health care team. At the beginning of a NICU stay, medical professionals are often the first to interact with our children; however, as we (parents) spend more time with our children in the hospital, we begin to pick up their tics and tendencies. We learn their mannerisms, and their cries are recognizable to us. As we connect with our children, we begin to establish a

connection, a bond. You know the saying, a mother's love knows no bounds, and it's true. We are their greatest advocate. Their fiercest protector. It may take some time to get to that point in the NICU, but being there day in and day out only helps us gain confidence, self-efficacy, and strength to support our children outside of the NICU.

- Parents spend countless hours in the NICU at their baby's bedside and are essential members of their baby's care team. They know their babies better than anyone else and are often the first to recognize when something is wrong.
- Bonding during this developmentally fragile newborn period is crucial. Extensive research has shown that for vulnerable newborns, particularly premature and sick newborns, their mother's milk is a lifesaving intervention. Skinto-skin time promotes infant growth and healthy developmental milestones. Limiting parents' access disrupts the nurturing interactions that are necessary for an infant's cognitive development and that are also essential to parents' mental health.
- We need to ensure that all NICU families receive highquality care by giving parents access to their medically fragile infants. Parents' basic rights to see and care for their own child are infringed upon when they are inaccurately categorized as visitors. Healthcare providers and parents should work together at local and state levels to ensure safe practices that honor the unique situation and needs of sick newborns. The way families experience care in the NICU remains with them for their lifetimes.
- As a physical therapist who has provided direct bedside care in the NICU for over 20 years, I cannot emphasize enough the importance of including the parents/caregivers in the NICU as true team members. Parents often feel intimidated in the NICU. They sometimes feel "in the way." But in truth, they are the most important people in the NICU. We must change our culture around this and make parents feel that they are needed and wanted in the NICU. Thank you.

Outcome:

Unfortunately, the resolution was not adopted due to the lack of a specific venue and to broaden the scope to include adolescents seeking care without parents for certain conditions. The Taskforce initially focused on NICU patients but expanded to include all pediatric patients to receive more support, which ultimately worked against their goal. The FCC Taskforce plans to refocus this resolution on NICU patients next year. Nicole Nyberg presented oral testimony at the Leadership Conference. Additionally, we want to thank Munish Gupta, MD, Mitchell Goldstein, MD, and Lily Lou, MD, for their review, sponsorship, and support and for presenting this at the Leadership Conference.

Disclosure: The authors have no disclosures.

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