

# NEONATOLOGY TODAY

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# Family-Centered Care Taskforce April 2024 Update and Poll Results

Morgan Kowalski

The Family-Centered Care Taskforce stands as a pioneering force, being the FIRST international, multicenter, collaborative initiative solely dedicated to quality improvement in family-centered care. The Taskforce has over **900 members** and employs a small group model with free monthly Office Hours for those looking to overcome barriers to implementing FCC and a large group model with bi-monthly webinars, enabling effective communication and facilitating change across various healthcare settings. By sharing evidence-based practices and critical family perspectives during webinars and promoting accountability through Office Hours, we are creating a forward movement to close the healthcare gap. Click [here](#) to sign up for office hours at no cost, and visit our website, [www.fcctaskforce.org](http://www.fcctaskforce.org), to subscribe and receive invitations to our free, educational webinars! **Our next webinar takes place May 9th at 11 am PT.**

*“By sharing evidence-based practices and critical family perspectives during webinars and promoting accountability through Office Hours, we are creating a forward movement to close the healthcare gap. Click here to sign up for office hours at no cost, and visit our website, [www.fcctaskforce.org](http://www.fcctaskforce.org), to subscribe and receive invitations to our free, educational webinars!”*

In addition to providing small and large group learning opportunities, we've created a monthly poll to address specific questions from our members. Take a look at our February Poll and results below. To access previous polls and poll results, click [here](#).

## February Poll Results:

You asked, “Typically, centers ask NICU parents to wait 1-1.5 years after discharge to join a Family Advisory Council. Considering this, **how long should a family who had a neonatal loss journey wait when they are eager to join?**”

We received many thoughtful answers, some from bereaved NICU parents themselves. Thank you to those brave individuals

for providing insight on this sensitive topic.

*“You asked, ‘Typically, centers ask NICU parents to wait 1-1.5 years after discharge to join a Family Advisory Council. Considering this, how long should a family who had a neonatal loss journey wait when they are eager to join?’”*

## Responses:

“Depends on the family, but our rule of thumb is 12 months”

“Whenever they feel ready”

“For as long as THEY are not ready to resume exposure to a clinical environment”

“1 year”

“1.5 years:

“2 years”

“Minimum 2 years”

“2-4 years”

“I think this is such a case-by-case basis. Bereaved parents may want to start working on meaning-making soon after their child dies. I think it would be important to have a meeting with them and discuss the impact of being back in the hospital and what to do if they have an emotional reaction. I could see asking them to wait at least a few months - [giving them] a chance to experience grief reactions [that may] become more intense and frequent (which can happen months after). Maybe take a break from [in-person] meetings, move to provide feedback online, etc., and maybe have a check-in with the chair of the FAC regularly. The goal would be to ensure they are protected from retraumatization and know what to do if they find themselves impacted or triggered during or after meetings.”

“Speaking as a bereaved parent and knowing that each parent’s grief journey looks different, this is a tricky question. At Hand to



Hold, we typically encourage peer mentors and Family Support Specialists to wait up to two years before applying. This allows them to surpass the one-year and two-year milestones that are often the most difficult. If they are at risk of prolonged or complicated grief, this also allows more time to identify and address these risk factors. While I have come across parents who donate items to the NICU early on in memory of their child and who are eager to give back in other ways, it can sometimes catch them off guard when they are back in the hospital, and they realize they are not quite ready to go back into that environment, and that they may need a little more time to heal. It can be incredibly healing to start paying it forward immediately, and some parents demonstrate more resilience than others.”

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**“I could see asking them to wait at least a few months - [giving them] a chance to experience grief reactions [that may] become more intense and frequent (which can happen months after). Maybe take a break from [in-person] meetings, move to provide feedback online, etc., and maybe have a check-in with the chair of the FAC regularly.”**

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“It’s different for each family. Some families can join one year after their loss.”

“They should be allowed to join whenever they’re ready - no gate-keeping!”

“As soon as they feel ready, and feel like it will help them in their healing.”

“I had a NICU loss, and I just can’t imagine a family being ‘eager to join’ an FAC. There is a lot of processing and healing that needs to take place after a NICU journey, especially when there is a loss. Having said that, sometimes processing and healing takes place by sharing that story and serving other NICU families, which causes me to ask: Why do we wait a year? Perhaps it would be better to consider the individual and their reasons for joining the FAC. It could be a very healing experience for them.”

“I myself am a NICU parent who had twins that were born at 34 weeks. I was very unprepared after a life-threatening C-Section and my twins going to the NICU. They did very well in the NICU, despite a COVID setback, and went home stable and healthy a few weeks later. I personally do not have the same journey experience as someone who has gone through losing their child and cannot attest to how I might feel afterward in regards to wanting to be a part of a Family Advisory Council. However, knowing the circumstances are different for parents who have had a neonatal loss journey, I can only give my best assumption as to why they may be eager to do so and how long to wait to allow them to. There is a possibility part of their healing process is to join the Family Advisory Council and help advocate for others who may go through a neonatal loss journey. I also understand that it can cause a lot of negative emotions and triggering memories to be a part of something related to their loss too soon. The time recommended of 1-1.5 years could be a good recommendation for parents wanting to join the council and return to support when they have had a successful discharge and time to recover and bond

with their baby/babies. Considering these are two very different NICU experiences, my opinion would be that very different neonatal journeys (comparing neonatal loss with successful discharge) would probably need different recommended wait periods to join the Family Advisory Council. For some it may help them heal; for others, it may be may take longer than the 1-1.5 years.”

“I had a 24-weeker who survived, but I have had multiple pregnancy losses and work for a local nonprofit called [HAND: Helping After Neonatal Death](#). Our bereaved families can volunteer at any time, but they can only volunteer for parent-facing roles starting one year after their loss. It is very triggering to volunteer in the area in which your trauma is based, so we encourage eager volunteers to check in with seasoned volunteers regularly to see if they’re getting burned out. If they are, then we scale back their workload or have them wait a bit longer before they volunteer again.”

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**“ ‘Considering these are two very different NICU experiences, my opinion would be that very different neonatal journeys (comparing neonatal loss with successful discharge) would probably need different recommended wait periods to join the Family Advisory Council. For some it may help them heal; for others, it may be may take longer than the 1-1.5 years.’ ”**

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“We have found it varies from one family to another. Generally, groups wait one year, but then again, this may not be enough for some, and some are ready quicker. Then, it depends on the “task” parents want to do. Many do not want to come back to the hospital, but can help in several ways. Others teach palliative care courses with us, while others come to the unit. We have documented this in an article [here](#).”

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**NT**

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