

November 2024 Webinar

**FCC TASKFORCE
WEBINAR**
NOVEMBER 14, 2024
11AM-12:30PM PT

The Long and Winding Road: Implementing Family-Centered Care in Our Unit



Rafael Mendelsohn, MD (he/him)
Medical Director,
Tel Aviv Medical Center NICU

From Premie Parent to FICare Champion:
Empowering NICU Parents to Become Advocates



Fabiana Bacchini (she/her)
Executive Director,
Canadian Premature Babies Foundation
NICU Parent of Michael & Gabriel

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This Webinar is Dedicated to MICHAEL & GABRIEL BACHINNI



Michael, Born Sleeping



Gabriel, Age 12

Organizational Partners



American Academy
of Pediatrics



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Section on Neonatal Perinatal Medicine



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NPN
NICU PARENT NETWORK



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All-In Meeting

- Break down the hierarchy
- Integrate patient-families
- Prioritize funds to support patient-families
- Intentionally elevate the voices of women, diverse groups, and individuals with rare or unique experiences
- Make it relevant and personal
- Provide support to disabled individuals during in-person meetings
- Invest in building relationships
- Support and include breastfeeding mothers/parents
- Demonstrate the impact, progress, and opportunities
- Capitalize on the expertise in the room
- Remain receptive and responsive to constructive criticism



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Webinar Etiquette

Thank you for helping us make FCC Taskforce Webinars a safe & brave space for all!

By participating, you are agreeing to the following guidelines:

1. Please mute your microphone when you aren't speaking
2. Please turn off your camera if multitasking
3. All questions & comments spoken and written in the chat should be respectful, non-discriminatory, and non-judgmental

Topics discussed may illicit strong emotions and feelings. Please reach out to us if you need support.



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FCC Taskforce Core Team

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Malathi Balasundaram, MD

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Program Manager



Morgan Kowalski

Family Partner



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Jessica Fry, MD



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Lily Lou, MD, FAAP



Kerri Machut, MD



**Nicole Nyberg,
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Tim Palmer, MD



Jochen Profit, MD



Dharshi Sivakumar, MD



Vincent Smith, MD, MPH



Bob White, MD



Emily Whitesel, MD

Rest in Peace, Aida Simonian



**Aida Simonian, MSN, RNC-NIC, SCM, SRN
CEO, PAC/LAC**

Thank You Kristy & Welcome Erika!



Kristy Love
Executive Director,
National Perinatal Association



Erika Goyer
Director of Communications,
National Perinatal Association



FCC Taskforce Committee Chairs

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**Nicole Nyberg, NNP &
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*Neonatal Nurse Practitioner,
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Founder,
Empowering NICU Parents &
The Empowering NICU Parents
Podcast*



Quarterly Newsletters

Vol. 09 Pg. 1 **FCC TASKFORCE** 10/2024
NEWSLETTER

The first international, multicenter, collaborative initiative solely dedicated to quality improvement in NICU Family-Centered Care.

In This Issue

- September '24 Poll Results
- September '24 Webinar Review
- Trauma-Informed Care Corner
- NICU FCC Measures Survey
- Upcoming Office Hours
- FCC Taskforce Information

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Subscribe to our mailing list and visit our website to learn more about our advocacy efforts, read testimonials from our members, watch webinar recordings, and access free resources on all things Family-Centered Care.

Part Two:
'Aria's Journey: Connecting Through Our Shared Humanity'
 by Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW

Content Warning: The following is an artistic interpretation of what being a premature baby could be like. If you've experienced a preterm birth, please take care when reading.

"This is different than where I was before. It's still too bright and very loud. Apparently, we're in the NICU. It's a special place for people like me who need extra help after we're born. I really miss Mom. She said she will come be with me as soon as she can. Dad is around here somewhere. I heard him ask how big I was. I'm small for my age, whatever that means. I'd like to think I'm on my own growth curve! I've learned that there are a lot of people in the NICU here to help me. I'm not sure what most of them do, but they all keep talking around me. I wish there was a way to turn down the volume. This thing on my face is so tight that it hurts a little bit. Ahh, that person fixed it. Thank you, kind stranger! Now I can open my eyes a little bit. There's Dad! He looks scared. I'm okay, Dad! I'm doing my best. This being a person thing is much harder than I expected. Breathing and beating my heart at the same time is exhausting. Where's a placenta when you need one, right? He says he has to leave for them to get me settled. I don't know why he can't stay. He can help me go to sleep like he usually does. These people might know a lot about babies like me, but they're passing up a real opportunity here sending my Dad away. Ouch! Someone's pulling my arms and legs straight and I can't move them. It's for something called "lines," but it really feels unnecessary. I sure hope this is all over soon. I miss my parents. They have to miss me, too."

Join us as we continue to follow baby Aria and her family's experiences in the NICU. It is easy to get wrapped up in the tasks & technology in the NICU, and we as healthcare providers must remember to center the personhood of the infant and their family. Staying connected with our shared humanity helps us make lifesaving decisions from a place of empathy and connectedness.

If you missed Part One (Aria's birth) in Volume 8, catch up [here](#)

Vol. 09 Pg. 2 **SEPTEMBER POLL RESULTS** 10/2024

In September, we asked:
At what corrected gestational age/birth weight do neonatal therapists engage with infants in your unit?

Category	Number of Therapists
From Birth/Admission	19
32 Weeks	18
No Neonatal Therapists in NICU	7
30 Weeks	4
22 Weeks	3
23 Weeks	3
23 Weeks	2
25 Weeks	2
26 Weeks	2
29 Weeks	2
21 Weeks	1
24 Weeks	1
34 Weeks	1
>1350g	1
>1500g	1

Those who answered From Birth/Admission Regardless of CGA/Weight said:

- For parent education and procedural support
- Immediately for a second set of hands and positioning
- Immediately to participate in two-person cares!
- To engage with families in the first week of life and introduce the therapist role
- To offer nonprotective four hands care

Those who answered Dependent on Type of Therapy said:

- 28 weeks for PT/OT, 33 weeks for SLP
- 25 weeks for OT/29 weeks for SLP
- 28-29 weeks for positioning/30 weeks for positive touch
- From birth/on admission for OT/31-32 weeks for SLP
- From birth/on admission for OT/32 weeks for PT/34 weeks for SLP

Neonatal Therapy Cheat Sheet:

- OT = Occupational Therapy
- Focus: Developmental care, sensory processing
- PT = Physical Therapy
- Focus: Positioning, infant massage, motor skill development
- SLP = Speech-Language Pathology
- Focus: Feeding, communication

Resources:

- SENSE Program
- National Association of Neonatal Therapists

Thank you! Thank you to those who responded to our September Poll! To view all of the helpful answers we received, [click here](#).

OCTOBER POLL

Thank you for helping us learn more about neonatal therapists in the NICU! If you are a neonatal therapist with an active role in Family-Centered Care implementation in your NICU, please share how you were able to get involved/be included. Do you have any advice for neonatal therapists experiencing pushback around their presence in the NICU? [Click here](#) to share!

Vol. 09 Pg. 4 **TRAUMA-INFORMED CARE CORNER** 10/2024
PUTTING FAMILIES AT THE HEART OF NICU CARE
 WITH MARY COUGHLIN, MS, NNP, NCC-E

Welcome back to the Trauma-Informed Care Corner! I'm so glad you're continuing this journey with me as we explore what it truly means to support families in the NICU. As many of you know, the NICU is more than a clinical space — it's a place where families are often experiencing some of the most vulnerable moments of their lives. That's why embracing family-centered, Trauma-Informed Care is so vital. It's about recognizing that the tiniest patients and their families are on this journey together, and we as care providers, are partners in that process.

Let's talk about family engagement for a moment. When we say "engagement," it's not just about having families present — it's about inviting them into the care experience in a meaningful way. Picture this: a family not only observing their baby in the NICU but being an active part of the care team, feeling empowered, heard, and respected. When we bring families into the fold, we create a sense of belonging and trust, both crucial elements in a trauma-informed approach. After all, when families feel like they truly belong, they're better able to support their baby's healing, and they feel more equipped to handle the challenges that come their way.

But we also have to acknowledge that not every family has the same path into this experience. For some, the barriers — whether it's transportation, language, or simply navigating the overwhelming world of medical information — can make engagement feel impossible. That's where we, as compassionate caregivers, can step in with thoughtful solutions. Simple acts like offering transportation assistance or providing health information in clear, accessible language can make a world of difference. It's all about meeting families where they are and helping them feel empowered, no matter their circumstances.

This is where Trauma-Informed Care really shines. It encourages us to view every interaction through a lens of compassion and understanding. By recognizing the potential stress and trauma that families face, we can offer support that not only helps their baby but also helps them as a whole family. When we do that, we're not just providing care, we're building resilience. We're creating a space where healing happens not just in the medical sense, but in an emotional and psychological sense, too. So, as we continue to reflect on how we can best serve families in the NICU, let's keep this at the forefront: **Engagement is about partnership. It's about ensuring that every family feels welcomed, supported, and empowered to take an active role in their baby's care. Together, we can create NICU environments where families and babies thrive, both in the moment and long after they leave our care.**

Until next time, let's keep striving to put families at the heart of everything we do.
 Hugs, Mary

Scan the QR code to check out past publications!

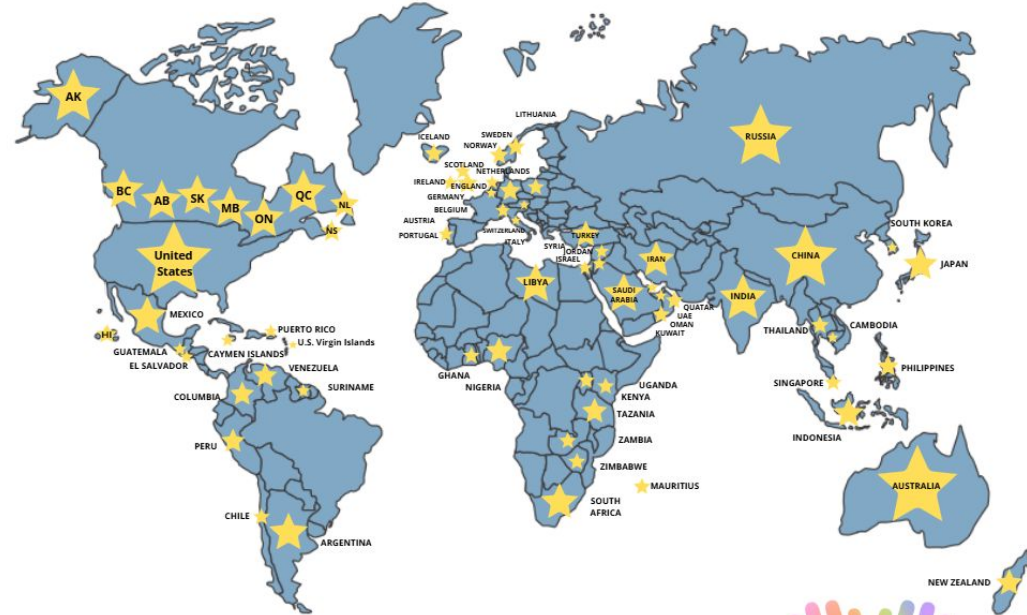


Family-Centered Care Around the Globe!

The FCC Taskforce began in February 2022 with just 50 members.

Over the last three years, our membership has increased to:

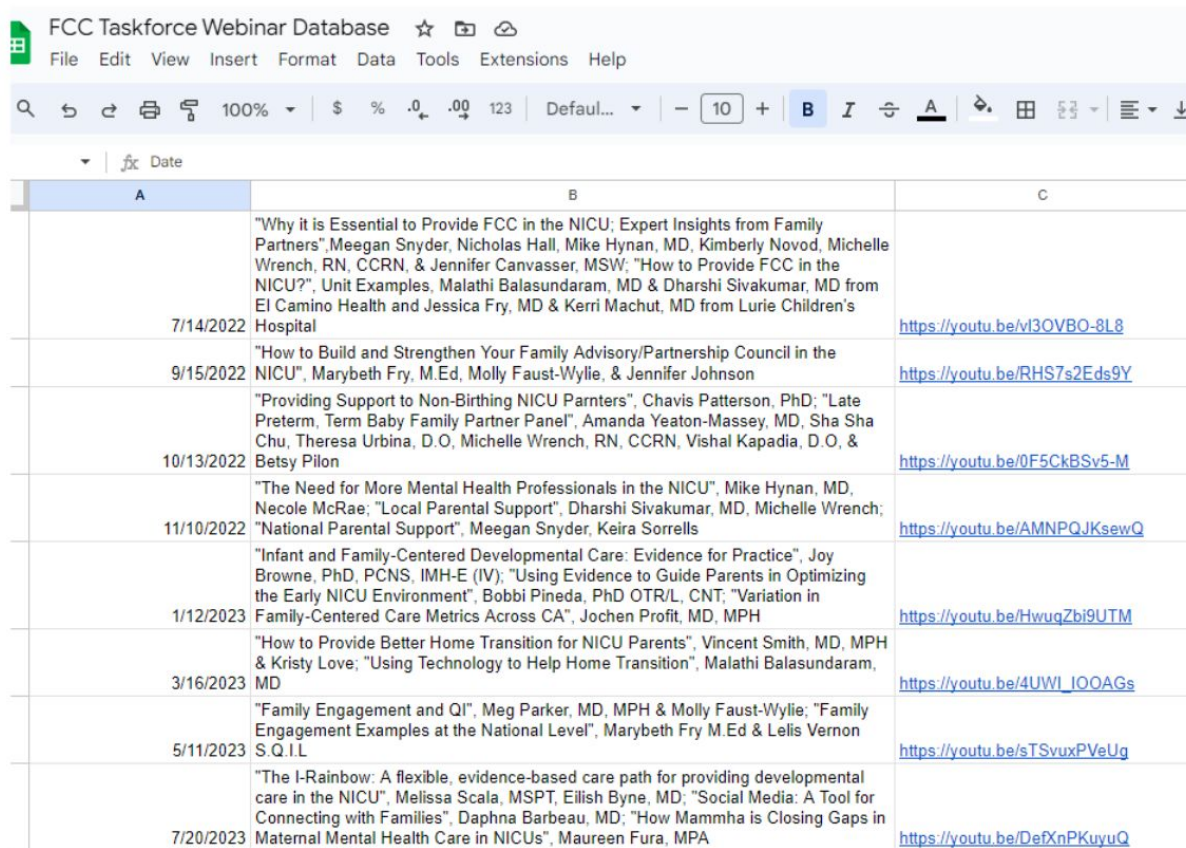
- more than **1,700** members
- **48/50** U.S. States & Puerto Rico
- **8/10** Canadian Provinces
- **58** Countries!!!



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Database of Webinar Recordings & Topics



A	B	C
7/14/2022	"Why it is Essential to Provide FCC in the NICU; Expert Insights from Family Partners", Meegan Snyder, Nicholas Hall, Mike Hynan, MD, Kimberly Novod, Michelle Wrench, RN, CCRN, & Jennifer Canvasser, MSW; "How to Provide FCC in the NICU?", Unit Examples, Malathi Balasundaram, MD & Dharshi Sivakumar, MD from El Camino Health and Jessica Fry, MD & Kerri Machut, MD from Lurie Children's Hospital	https://youtu.be/vI3OVBO-8L8
9/15/2022	"How to Build and Strengthen Your Family Advisory/Partnership Council in the NICU", Marybeth Fry, M.Ed, Molly Faust-Wylie, & Jennifer Johnson	https://youtu.be/RHS7s2Eds9Y
10/13/2022	"Providing Support to Non-Birthing NICU Parnters", Chavis Patterson, PhD; "Late Preterm, Term Baby Family Partner Panel", Amanda Yeaton-Massey, MD, Sha Sha Chu, Theresa Urbina, D.O, Michelle Wrench, RN, CCRN, Vishal Kapadia, D.O, & Betsy Pilon	https://youtu.be/0F5CkBSv5-M
11/10/2022	"The Need for More Mental Health Professionals in the NICU", Mike Hynan, MD, Necole McRae; "Local Parental Support", Dharshi Sivakumar, MD, Michelle Wrench; "National Parental Support", Meegan Snyder, Keira Sorrells	https://youtu.be/AMNPQJKsewQ
1/12/2023	"Infant and Family-Centered Developmental Care: Evidence for Practice", Joy Browne, PhD, PCNS, IMH-E (IV); "Using Evidence to Guide Parents in Optimizing the Early NICU Environment", Bobbi Pineda, PhD OTR/L, CNT; "Variation in Family-Centered Care Metrics Across CA", Jochen Proff, MD, MPH	https://youtu.be/HwuqZbi9UTM
3/16/2023	"How to Provide Better Home Transition for NICU Parents", Vincent Smith, MD, MPH & Kristy Love; "Using Technology to Help Home Transition", Malathi Balasundaram, MD	https://youtu.be/4UWI_JOAGs
5/11/2023	"Family Engagement and QI", Meg Parker, MD, MPH & Molly Faust-Wylie; "Family Engagement Examples at the National Level", Marybeth Fry M.Ed & Lelis Vernon S.Q.I.L	https://youtu.be/sTSvuxPVeUg
7/20/2023	"The I-Rainbow: A flexible, evidence-based care path for providing developmental care in the NICU", Melissa Scala, MSPT, Eilish Byne, MD; "Social Media: A Tool for Connecting with Families", Daphna Barbeau, MD; "How Mamma is Closing Gaps in Maternal Mental Health Care in NICUs", Maureen Fura, MPA	https://youtu.be/DefXnPKuyUQ



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October Poll

If you are a neonatal therapist with an active role in Family-Centered Care implementation in your NICU, **please share how you were able to get involved/be included.**

Do you have any advice for neonatal therapists
experiencing pushback around their presence in the NICU?



**All poll responses
can be found here!**



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Upcoming Office Hours Sessions

Thursday, November 21st

Tuesday, December 17th



250+ Members are registered for monthly office hours sessions! Attendance is typically 40-80 healthcare professionals and Family Partners

Topics Discussed:

- Discharge readiness/transitions home
- Implementation of a Small Baby Program
- Trauma Informed Care
- Communication; information-sharing as pillars of NICU care
- Care conferences & including families in rounds
- Communication with families around FCC & Kangaroo Care
- Obtaining leadership buy-in and recruiting diverse Family Partners
- Generating a NICU support service



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2024 FCC NICU Measures REDCap Survey & Benchmarking

- Collaborated with Family Partners to **create NICU FCC Measures in seven categories**
- Created **comprehensive REDCap survey** to be completed by clinicians and their teams
- **NICU FCC Measures Survey**
 1. NICU Framework/Infrastructure (9)
 2. Family Support (19)
 3. Family Integration into Care (16)
 4. Family Integration into QI & Processes (1)
 5. NICU Environment (7)
 6. Staff Education (2)
 7. Balancing Measures (4)

Why should your unit participate?

- Immediate unit performance score upon survey completion
- Benchmark unit performance with participating NICUs (all identifying data kept anonymous) at end of study
- Collaborate with participating NICUs on topic-specific QI work

Please reach out to receive our survey!



Received Independent Educational Grant from Chiesi USA

A special thank you to Lelis Bauza Vernon, Joy Browne, Bob Cicco, Jessica Fry, Marybeth Fry, Mitch Goldstein, Annie Janvier, Morgan Kowalski, Henry Lee, Kerri Machut, Mia Malcolm, Vincent Smith, Keira Sorrells, and Bob White for providing invaluable feedback on survey structure and questions. Thank you to Lelis Bauza Vernon, Yamile Jackson, Kelli Kelley, Mia Malcolm, Kimberly Novod, Beth Simonton for their help in creating a video to help us spread the world about this project!

Changing Neonatal Care in Tel Aviv

SMALL GROUP 5

Robert White, MD

Beacon Children's Hospital

Malathi Balasundaram, MD

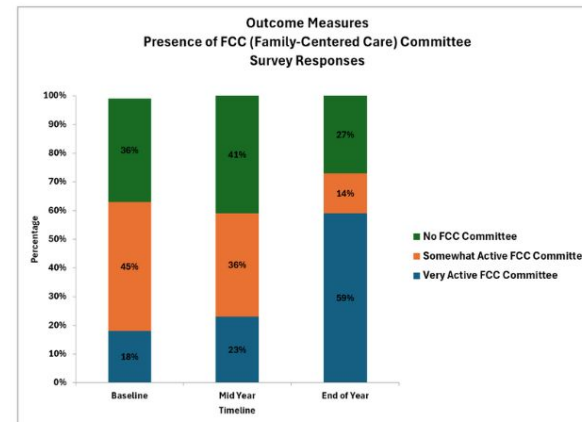
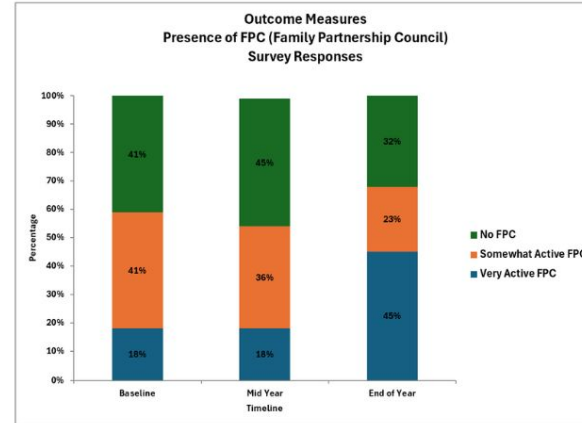
Stanford/El Camino Health NICU

Keira Sorrells, Family Partner

Founder & Executive Director,
NICU Parent Network

Michelle Wrench, Family Partner

Chair, Family Advisory Committee CPQCC



FCC TASKFORCE WEBINAR

NOVEMBER 14, 2024

11AM-12:30PM PT

The Long and Winding Road: Implementing
Family-Centered Care in Our Unit



Rafael Mendelsohn, MD (he/him)

Medical Director,
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From Premie Parent to FICare Champion:
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Fabiana Bacchini (she/her)

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2025 Webinars

January 9th:

Elizabeth Rogers, MD

Terri L. Major-Kincade, MD, MPH, FAAP

March 13th:

Erick Rideout, MD

Ellery Spencer, BSN, RN & Molly Fraust-Wylie

May 8th:

Kari McCallie, MD & Ashley Omwando, MBA

Lelis Bauza Vernon, S.Q.I.L. & Sue Bowles, DNP, APRN

July 10th:

Mary Coughlin, MS, NNP, NCC-E

Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW

September 11th:

FCC Taskforce Phase 4 Work

Lauren Ingledow

November 13th:

Deborah Buehler, PhD

Sue Ludwig & Christy Gliniak, PhD, OTR/L, CNT,
CPXP, NTMTC



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