



**Hospital Quality Institute**  
*Leadership in quality and patient safety*



# Perinatal Mental Health Learning Community

Webinar February 18, 2021 12 – 1 p.m.

## Supporting NICU Families

Guest Speaker: Sharon Tan, Psy.D.,  
Clinical Psychologist, Miller Children's and Women's Hospital



# Housekeeping

- Everyone is automatically muted upon entry.
- Raise your hand if you'd like to be unmuted.
- Use “Chat” to interact with everyone (“all panelists and attendees.”)
- Use “Q&A” to ask questions of panelists and organizers.
- Download slides from Chat.

# Our Team



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# Program Website



Hospital Quality Institute

About HQI

Programs

The Quality Quarterly

Education

## Perinatal Mental Health Learning Community

Feb. 2020 – Dec. 2021

<https://www.hqinstitute.org/post/perinatal-mental-health-learning-community>



The Perinatal Mental Health (PMH) Learning Community provides California hospitals with education, technical assistance, and peer support to strengthen perinatal mental health. The program assists hospitals to comply with Assembly Bill 3032, the Maternal Mental Health Conditions law. The program is administered by HQI, funded by California HealthCare Foundation and delivered in collaboration with Maternal Mental Health NOW and CommonSpirit Health.

Program at a Glance

Webinars

Group Office Hours

Online Resources for Hospitals

Peer Sharing

1:1 Coaching

Participating Hospitals

Enroll

Contact

FAQs



Hospital Quality Institute

# Timeline – *Perinatal Mental Health Learning Community*



## Education and Technical Assistance (Feb '20 - Dec '21)

- Webinars (2020: Feb, Apr, Jun, Aug, Oct, Dec; 2021: Feb, Apr, Jun, Aug, Oct, Dec)
- Group Office Hours (2020: Mar, May, Jul, Sept, Nov; 2021: Jan, Mar, May, Jul, Sept, Nov)
  - 1:1 Technical Assistance (on demand)
  - In-Person Regional Events (Nov '20)

**TODAY**

## Training Tools and Resources (Apr '20 – Dec '21)

- E-learning module and quick reference guide for staff
  - E-learning module for patients
  - Brochure template

Case Studies Developed

Case Studies Available

# Schedule of Topics for 2021

Date	Topic
January 21	Perinatal Loss Office Hour
February 18	NICU and PMH Webinar
March 18	NICU and PMH Office Hour
April 15	Birth Trauma and PMH Webinar
May 20	Birth Trauma and PMH Office Hour
June 17	Substance Use Disorders Webinar
July 15	Substance Use Disorders Office Hour
August 19	Child Abuse Reporting and PMH Webinar
September 16	Child Abuse Reporting and PMH Office Hour
October 21	Breastfeeding and PMH Webinar
November 18	Breastfeeding and PMH Office Hour
December 16	Fathers and Partners and PMH Webinar

# AB-3032: Hospitals Maternal Mental Health Act

- It requires all birthing hospitals in California to provide education and information to postpartum people and their families about maternal mental health conditions, post-hospital treatment options, and community resources.
- All regular staff in labor and delivery departments (e.g. registered nurses and social workers) must receive education and information about maternal mental health disorders.
- Hospitals can offer additional services to ensure optimal care.

Law became effective on January 1, 2020.



# Focus in February and March: NICU Families

## Learning Objectives:

1. Identify two common stressors experienced by families with a child in the NICU.
2. Describe one method for assessing for emotional distress in NICU families.
3. Describe hospital best practices to support mental and physical health of NICU families.



# Guest Speaker: Sharon Tan, Psy.D.



Clinical Psychologist  
in private practice  
and at  
Miller Children's and  
Women's Hospital

A newborn baby is lying on a light-colored surface, possibly a hospital bed. The baby is wearing a white long-sleeved shirt and a blue cape with a red and yellow Superman logo. A clear nasal cannula is taped to the baby's face. The background is slightly blurred, showing medical equipment.

# Supporting NICU Families

Sharon Tan, PsyD  
[drsharontanpsyd@gmail.com](mailto:drsharontanpsyd@gmail.com)  
18 February, 2021

COURTESY EMMALEE SCHRAUBERG, SCHRAUBERG PHOTOGRAPHY

*Schrauberg*  
PHOTOGRAPHY

# Training Goals

- List 2 common stressors experienced by NICU parents
- Name 1 method of assessing emotional distress in NICU parents
- Identify 2 resources for NICU families



National Perinatal Association

## NICU AWARENESS MONTH

[nationalperinatal.org/NICU\\_Awareness](http://nationalperinatal.org/NICU_Awareness)

EACH YEAR

**HALF a MILLION  
BABIES**

are  
ADMITTED  
to the

**NEONATAL  
INTENSIVE  
CARE UNIT.**



Educate. Advocate. Integrate.

Rates of PMADS for NICU  
parents are 2-3 times  
higher

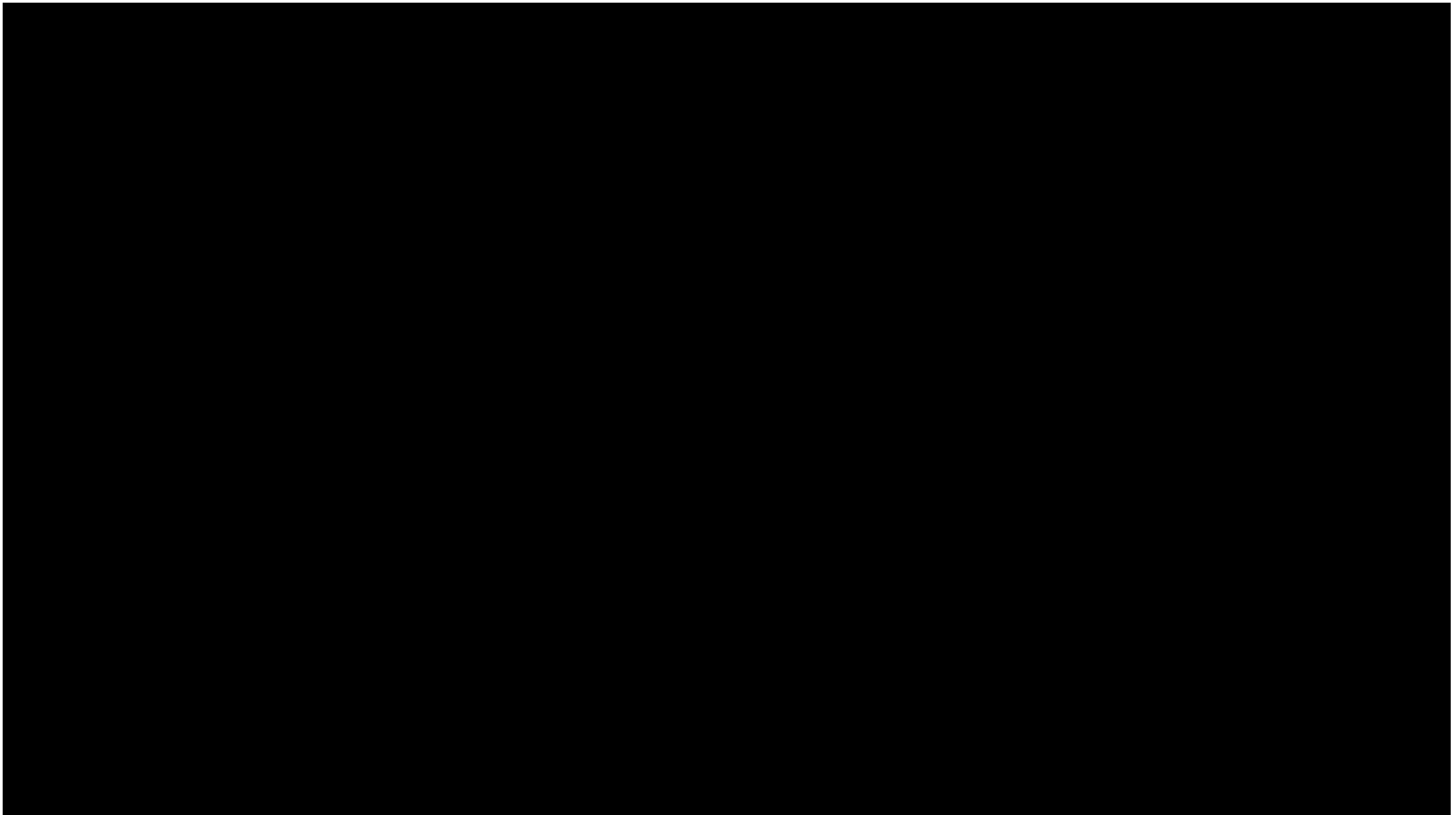


### IT'S NOT JUST PREEMIES

More than half of all babies admitted to the NICU  
are full-term infants with special medical needs.



# The NICU Journey

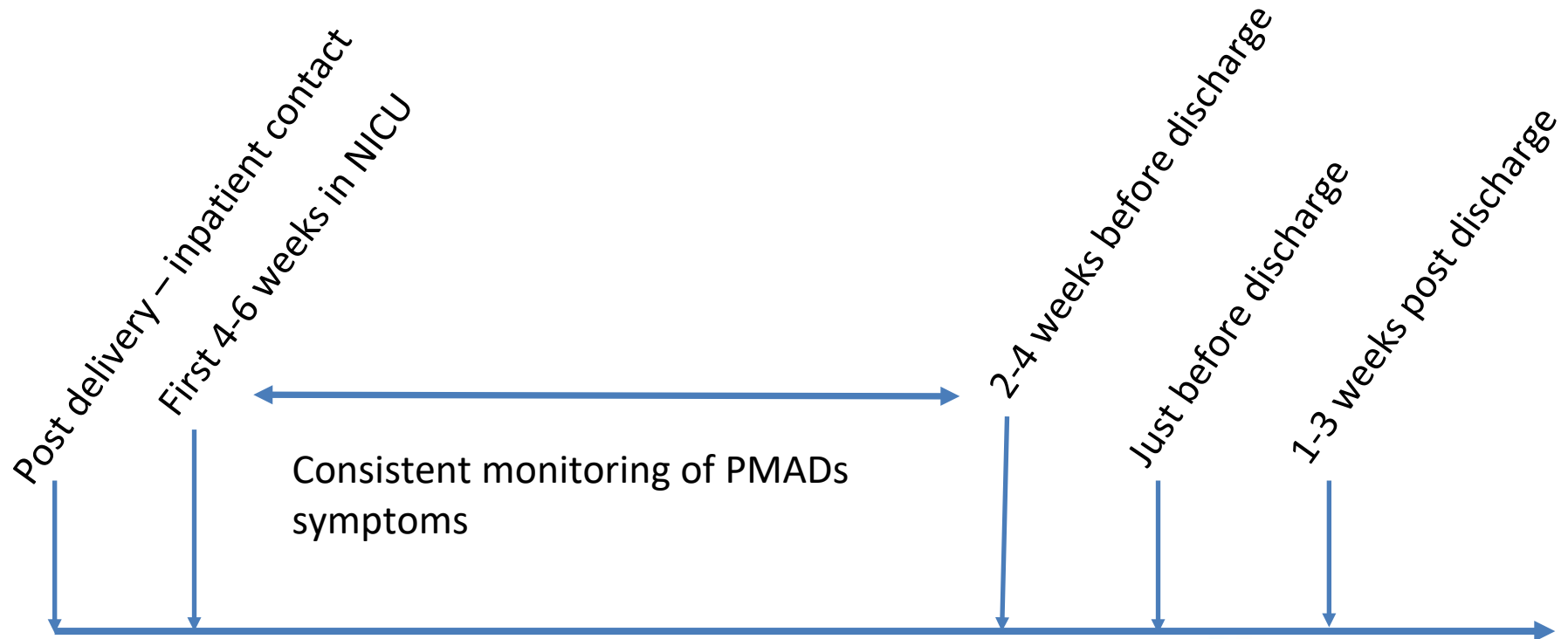


# The NICU journey

Some common reactions:

- Stressed (Traumatized?), overwhelmed
- Confusion, difficult putting thoughts together
- **Anxiety, Worry, Fear, Depression**
- Guilt & Shame
- Loneliness. **Social isolation**
- Loss of control
- Grief

# Suggested points of contact/ support





# A word on grief & loss...

- We're in Holland? I'm suppose to be in Italy!
- Grief
  - Over loss of full pregnancy
  - **Ideal child, real child, feared child**
  - Slow growth of parental identity
  - Frequent connection and disconnection (especially if bond is deepening)

# The NICU journey

- ▶ Guilt and shame
  - ▶ It was my body that did this (I'm a failure as a mom)
  - ▶ I should have not been so stressed; Why didn't I take better care of her
  - ▶ I told her "you're gonna be ok"
  - ▶ Why didn't I take this pregnancy seriously
- ▶ Loss of Control of the most basic attachment needs and urges that lead to loss of confidence as a parent/loss of parental role
  - ▶ Feeding, Diapering, Holding, Bathing
  - ▶ Eye contact, touching, kissing
  - ▶ "I didn't know I could ask to hold my baby"
  - ▶ Loss of expected birth plan

# The NICU journey

Sources of stress:

- Intrapersonal
- Interpersonal
- Extrapersonal
- Environment

Grosik et al (2013) , Williams et al (2018)

# The NICU journey

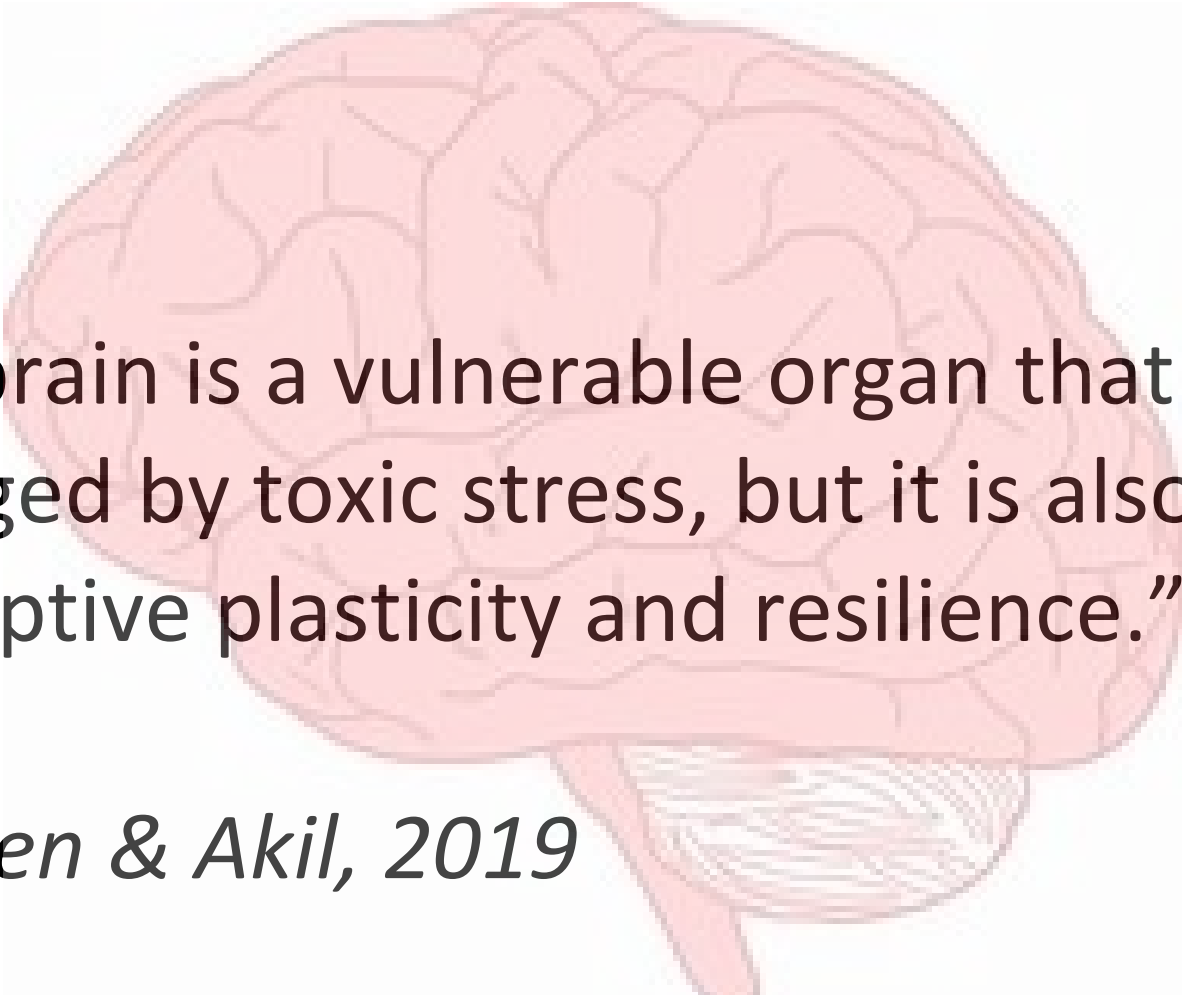
Additional stress due to COVID situation:

- Fears of baby getting ill with coronavirus (heightened anxiety over germs; preemie lungs more susceptible to sickness)
- Visitation restrictions; increased social isolation
- Have to wear a mask at all times – impact of social interactions?
- Lack of volunteer supports e.g. cuddlers
- Decreased options for soothing and connection
- Lack child care options
- Increased financial strain
- Staff burnt out

# The NICU journey

## Effects of stress:

- Physical
- Emotional/Psychological
- Cognitive
- Spiritual
- Relational



“The brain is a vulnerable organ that can be damaged by toxic stress, but it is also capable of adaptive plasticity and resilience.”

*McEwen & Akil, 2019*

Revisiting the Stress Concept: Implications for Affective Disorders (2019) McEwen, B.S. & Akil, H., The Journal of Neuroscience, 40(1): 12-21

# Risk factors for PMAD in the NICU

- Difficult or High-risk pregnancy
- Traumatic birth
- Pre-existing PMAD (prenatal fetal diagnosis, cortisol to baby)
- Can be result of drug abuse –mom self-medicating? – possible history of mental health issues
- Physical separation from infant and loss of control



# Common NICU Predictors of PMADs

- Lower birth weight
- Long length of stay predicts overall stress
  - Psychiatric history can predict length of stay
  - Substance abuse history can predict length of stay
- Gestational age (GA) predicts frequency of perceived stress– micro-preemies
- Severity of illness
- Cardiac diagnosis predicts highest level of stress
- Prolonged ventilation – can't see baby's face
- Lack of social support

# Diversity issues to consider

- Ethnicity
- Religion
- SES/Education
- Age/Gender
- Mental Health
- Underserved  
e.g. DCFS involved, substance abusing parents, immigrant families

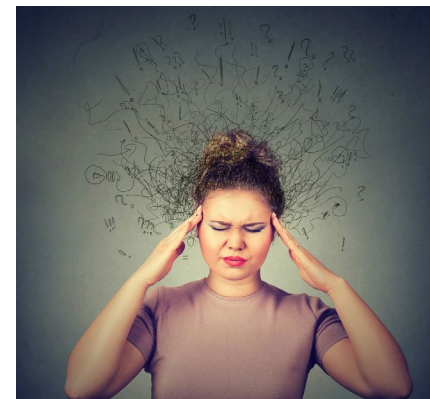
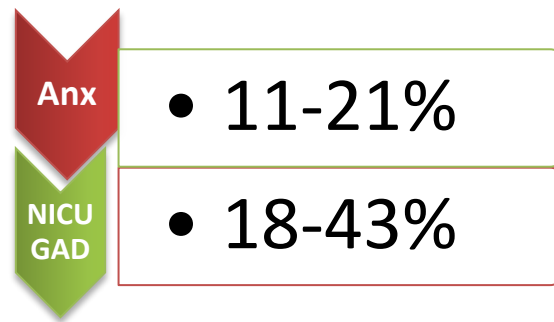
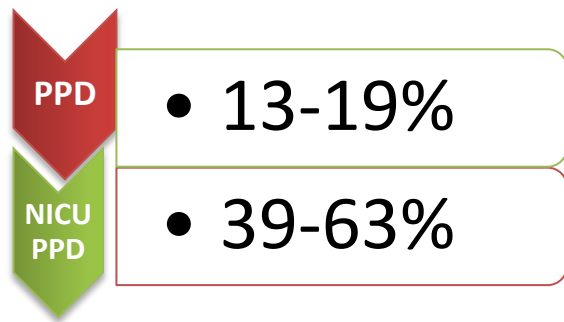
# NICU parents have higher rate of PMADs

- Acute Stress Disorder
- PMAD – Postpartum depression; anxiety
- PTSD

“Don’t worry, your baby will only here for a few days/your baby will be well taken care of”

**It’s the parents’ subjective perception not the objective nature of the event that leads to an emotional experience and mental state of being.**

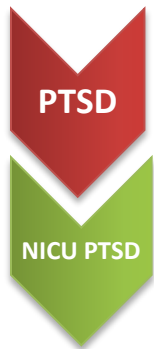
# NICU Parents & Postpartum Depression & Anxiety



- Disruptions in sleep and appetite
- Feels in a fog – disoriented, confused
- Emotionally detached, flat affect
- Feeling overwhelmed
- Extreme anxiety (excessive worry about medical care, bedside care)
- Fear for life of the baby
- Guilt & Shame
- I don't feel like a mother
- Struggles with pumping



# NICU Parents & Postpartum Post Traumatic Stress Disorder



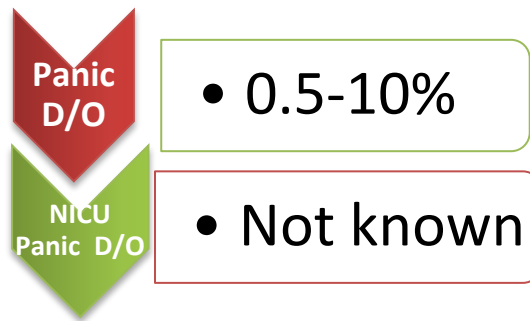
- 3% (mom)

- 15%(mom), 8%(dad)

- Reliving of traumatic birth event e.g. flashbacks, nightmares, images
- Avoid seeing their infant in extreme pain/distress
- Sense of doom e.g. isolette as a reminder of near death
- Hyper vigilance/watchfulness; more controlling behavior
- Increased arousal e.g. averse to alarms in the NICU
- Reminders from past NICU experiences e.g. previous infant losses

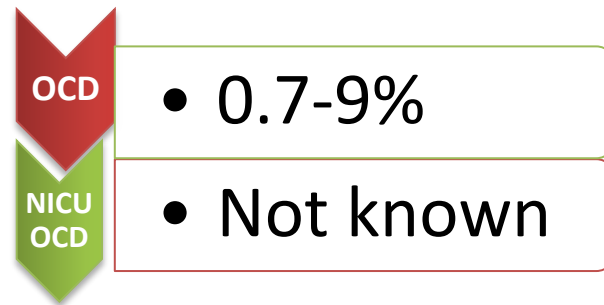


# NICU Parents & Postpartum Panic Disorder



- shortness of breath or a sensation that you are choking or unable to breathe
- intense fear of death (for you or your baby)
- chest pain
- dizziness
- racing heart

# NICU Parents & Postpartum Obsessive Compulsive Disorder



- Intrusive/repetitive thoughts/images (e.g. infant suffocating, cleaning the isolette)
- Can present as thoughts of harming child
- Accompanied by anxiety-reducing behaviors e.g. avoid holding the infant, need someone by bedside with mom
- Very upsetting to mother; she recognizes these thoughts as “foreign”



# NICU Parents & Postpartum Psychosis

- Prevalence not known

**A true emergency: protocol necessary**

# Assessment

- EPDS
- PHQ-9
- GAD
- Perinatal PTSD Questionnaire (PPQ-2)
- Impact of Event Scale –Revised (IES-R)

# NICU Protective Factors

- Prior knowledge of likely admission – provide NICU tour, introduce support staff available
- **Communication with NICU staff**
  - Family meeting with neonatologist and social worker, nurses
- Encourage touch
  - Baby massage
  - **Kangaroo care [skin to skin holding]**
- Breastfeeding
- Redefine “good enough mother”
- **Social support**
  - Peer supports in unit
  - Good family cohesion + coping skills = Resilience

“Am I a good parent?”  
“Is my baby ok?”

When babies are born with a concern: prematurity, illness, disorder...the thought that “my baby is vulnerable/fragile” impact the dyadic relationship for a very long time

# Six Parent Needs

- Accurate info: Inclusion in care and decision-making: words matter
- Vigilance: Watch over and protect
- **Contact with infant: Be near if not able to touch**
- **To be positively perceived by NICU staff**
- Individualized care: E.g., needs of dads, IVF situations, working parents, DCFS parents, breastfeeding needs
- Therapeutic, supportive relationship with nursing

## Fathers in the NICU

- second citizens: I'm an accessory
- fear of hurting baby
- fear of triggering mom's emotions: "I don't want her to be sad"





# A word about siblings...

- Where's the baby?
- What happened to the baby?
- When can the baby come home?
- Do you still love me? You love the baby more...



<https://adventuresinchildlife.com/2018/03/05/nicu-siblings/>  
<https://handtohold.org/nicu-family-support/sibling-support/>  
(See book list on this site)



# GOAL: BONDING

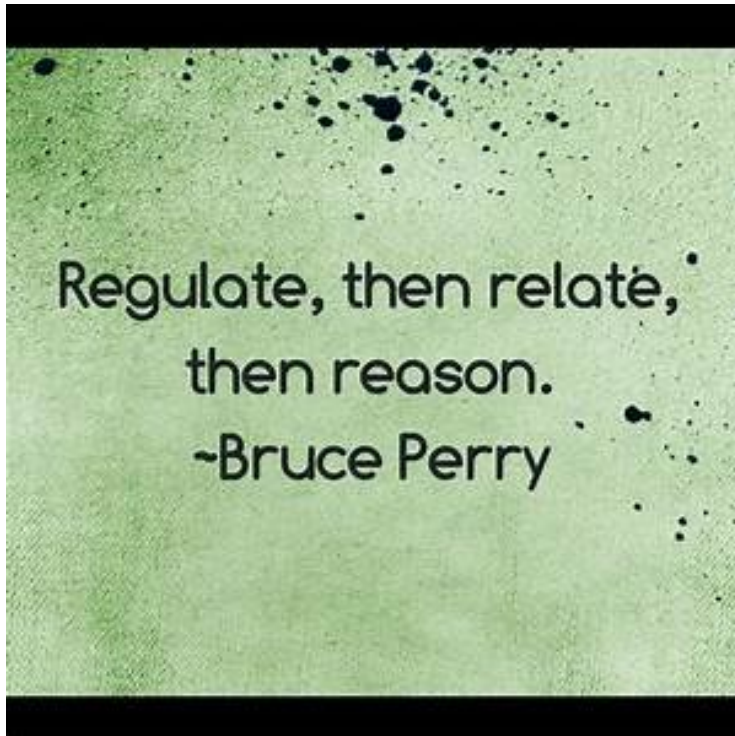


# Bonding in the NICU

- I felt like I wasn't really sure this was my baby
- I looked for signs of problems more than looking at him, I suppose
- Does he know I'm his mommy?
- I didn't let myself feel like a mom until I didn't have to worry so much about losing her
- It was weeks before I felt like she was mine...my feelings of failure over her birth were multiplied by my guilt over not feeling loving toward her.

*Davis & Stein(2004)Parenting your Premature Baby & Child: The Emotional Journey*

# How to support the parent-infant bond?



## BREATHE!

- Parents' own stress/emotional regulation
- Recognize and deal with grief/trauma
- Importance of bedside presence and touch e.g. Contained hold, kangaroo care, infant massage
- Learning to recognize signs of infant stress and be empowered to comfort/soothe physically
- Encourage breastfeeding (even if nonnutritive)
- Increase awareness of the relational process of daily caregiving e.g. feeding, bathing, changing diapers

# Finally taking baby home...

- Ideal baby vs Real baby vs Feared baby
- What happens when my life ahead is with the “feared” baby?
- Who helps me to recognize this is a kind of grieving and who helps me grieve and accept?
- Even when my baby comes home healthy without oxygen, without a feeding tube, etc...
  - My baby still seems so vulnerable – because my first experience bonding with him/her was when he was so vulnerable.



## Special Health Needs

Babies who have had a NICU stay are more likely to need specialized care after they go home. **Timely follow-up care is important.**

NICU babies have a higher risk for re-hospitalization. So every medical appointment is important. Especially during cold and flu season when these babies are especially vulnerable to respiratory infections.

### Who Can Help

- pediatricians
- neonatal therapists
- pulmonologists
- neurologists
- gastroenterologists
- cardiologists
- nutritionists
- CSHCN - Programs for Children with Special Health Care Needs

## Special Developmental Needs

**Any NICU stay can interrupt a baby's growth and development.**

Needing specialized medical care often means that they are separated from their parents and from normal nurturing.

While most NICU graduates will meet all their milestones in the expected developmental progression, It is typical for them to be delayed. This is especially true for preterm infants who are still "catching up" and should be understood to be developing at their "adjusted age."

### Who Can Help

- IBCLCs and lactation consultants
- Early Childhood Interventionists
- developmental pediatricians
- occupational therapists (OTs)
- physical therapists (PTs)
- speech therapists (SLPs)
- WIC - Special Supplemental Nutrition Program for Women, Infants, and Children
- social workers and case managers

## Special Educational Needs

Every child has their own unique developmental needs and **every student has their own unique and special educational needs.**

Take advantage of the services and support that can meet your child where that are and help them reach their future educational goals.

Call your local school district to request a free educational evaluation. Learn about all the available programs and support.

### Who Can Help

- Preschool Program for Children with Disabilities (PPCD)
- Special Education programs under the Individuals with Disabilities Education Act (IDEA)
- educational psychologists
- speech therapists (SLPs)
- occupational therapists (OTs)
- reading specialists





# Psychosocial program standards for NICU parents

## The Recommendations cover six domains:

- Involving the family in developmental care of the NICU baby
- Peer-to-peer support for NICU parents
- Mental health professionals in the NICU
- Palliative and bereavement Care
- NICU discharge planning and beyond
- Staff education and support

<https://www.nature.com/collections/vrqhjdywxv>

# Levels of Care

**Clinical Care**

Targeted Care

**Universal Care**

Kazak, A.E. (2006)



# Recommendations

- A. Health care providers should provide parents **information about premature infant characteristics** and how **to become involved early in their infant's care**.
- B. Parenting interventions should begin early to help parents **establish a pattern of positive parent-infant interaction**
- C. Symptoms of **parental anxiety and depression should be assessed** and targeted before they impact the parent-infant relationship
- D. **Parental beliefs** should be assessed to identify parents who are likely to benefit most from behavioral/informational programs
- E. **Interventions should be feasible, timely, and cost-effective** if they are to be implemented as part of routine clinical care.

Melnyk et al (2002)

# What kinds of Interventions work in the NICU?

- **Journaling** (Carley A., 2012) Expressive Writing Intervention (Horsch et al, 2016)
- **Parent Support** e.g. Psychiatric treatment, emotional support, buddy system/peer support, CBT, IPT
- **Parent Education** e.g. Daily care of infant, infant massage, infant cues, preemie development
- **Support Parent-infant interactions**, improve attachment (Browne & Talmi, 2017 – IFMH; Brisch et al, 2003; Welch & Myers, 2016)
- **Family based interventions** (Browne & Talmi, 2005)
- **Therapeutic child development support** e.g. Family centered developmental care, Kangaroo care, NIDCAP (Feldman et al, 2002; Als et al, 2003)

# NIDCAP

Heidi Als, PhD

## Newborn Individualized Developmental Care and Assessment Program

- Developed by Heidi Als, PhD and her colleagues at Boston Children's Hospital and Harvard Medical School
- Seeks to provide a comprehensive approach that is supportive and individualized the each infant's goals
- Seeks to emotionally support professionals and families of infants in the NICU to prevent accumulation of stress
  - Professionals are required to receive on-going reflective supervision
  - Extensive training on baby's nonverbal cues for discomfort, pain, how they prefer to calm and connect with caregivers, etc.



# Interventions After Discharge Home



# Interventions After Discharge Home

- Some interventions **begin prior to discharge**
- **Home visitation** i.e. Educational, socio-emotional support
- **Mother-infant group**

# A case example....

## At Delivery....

- 22 year old African American mother
- has a history of trauma, and anxiety symptoms exacerbated by traumatic birth history – “I felt like I was going to die”
- Baby born at 24 weeks, brought to the NICU
- Limited social supports
- Mother often appearing to have flat affect
- Had a stillborn(26 week) a year ago
- EPDS score of 10
- Mother has 3 year old at home

## Interventions

- Patient identified through OB round as needing follow up for PTSD
- SW, Chaplain and Psychologist coordinate care for community resources for PMADs and post hospitalization follow up by Psychologist
- Risks and concerns for family support conveyed to NICU support team
- Provided some anticipatory guidance regarding being a NICU parent
- Visits to NICU encouraged and facilitated by care team to initiate physical contact with baby before discharge

# A case example....

## In the NICU....

- Now 26 weeker(born at 24 weeks), male, African American infant
- Intubated, on iNO, IVH (grade 2 & 4)
- First baby in the NICU
- Mom calls 2-3 times during the week
- Struggling with child care for 3 year old (possible diagnosis of autism pending)
- EPDS score of 8
- Expresses fear of losing baby like before
- Fearful to touch baby on visits; tends to have flat affect

### Interventions

- NICU SW providing support for child care and supports for a child with special needs
- Continued screening for PMADS, especially anxiety disorders
- Psychoeducation on PMADS and resources for support
- Attempt to secure bond with infant through IFMH support; bedside support by Psychologist to increase awareness of impact of mental health and trauma on Interaction with baby
- Primary nurses sought for family

## After Discharge....

- Baby discharged home at 46 weeks with gtube and oxygen
- Baby failed to connect to Regional center for Services
- Mother able to bring baby to some follow up appointments: GI, Pulmonary. Missed appts with HRIF, OT,PT
- Mother not sleeping well as she is hyperalert about baby's breathing and constantly checks to make sure he is breathing
- Tearfully expresses financial stress and struggle to meet needs of 3 year old

### Interventions

- Discharge RN called a week after discharge to assess for added needs
- Referral for MMH trained therapist and for continued IFMH services (home based?)
- Assist with linkage to Regional Center
- Expand social support system
- Infant massage?
- Parent-infant groups?

# Final Thoughts...

- Frequent screening for Depression **AND** anxiety; adequate resources to refer
- Clinicians better trained to support families with medically fragile babies; someone who can help navigate the systems
- Create a system of care from delivery to post-discharge
- More post discharge, home visitation support needed
- how to build resilience? Build on existing strengths
- How to help parents..
  - Set a new normal at home (instead of taking hospital experience home with them)
  - Help them continue to fall in love with their baby
  - Cope with guilt
  - Create new set of meanings with baby



# Resources

- [www.maternalmentalhealthnow.org](http://www.maternalmentalhealthnow.org)
  - Online provider directory
  - Trainings
- [www.postpartum.net](http://www.postpartum.net)
  - Local resources
  - Online support groups

# Resources

## Staff Training/Support

- [http://www.nationalperinatal.org/NICU\\_Staff\\_Education](http://www.nationalperinatal.org/NICU_Staff_Education)
- <http://www.nationalperinatal.org/psychosocial>
- <https://handtohold.org/medical-professionals/>  
(podcast for professionals)

## NICU parent support

- <http://support4nicuparents.org/where-to-find-peer-to-peer-support/>  
(March of Dimes, Hand to hold, NICU Helping Hands on the list can match a peer NICU parent mentor to a parent in the NICU)
- <https://www.marchofdimes.org/complications/the-nicu.aspx>

# Resources

## My NICU Baby® App

You don't have to go it alone if you have a baby who is admitted to the newborn intensive care unit (NICU), a nursery in a hospital that provides around-the-clock specialized care to newborns. We've created the March of Dimes My NICU Baby® App

to provide answers, tools and support, so you can focus on your baby during what is often a difficult time. Learn about NICU staff, policies, equipment and terminology on your own schedule. The app has been developed and designed by experts to help you advocate for the best care for your baby.

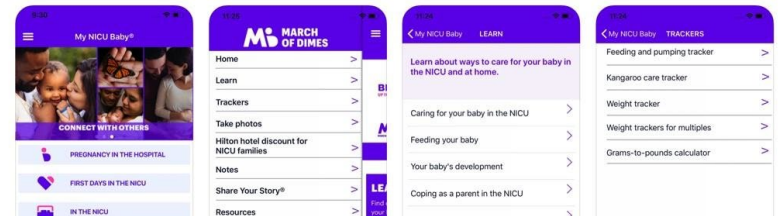
## Answers at your fingertips

Use My NICU Baby to do things like:

- Get tips and helpful videos to care for your baby in the NICU and at home
- Track breastfeeding sessions and baby's weight
- Track breast pumping and kangaroo care
- Take photos and add filters
- Connect with other families with similar experiences
- Create a customizable checklist to prepare to take your baby home



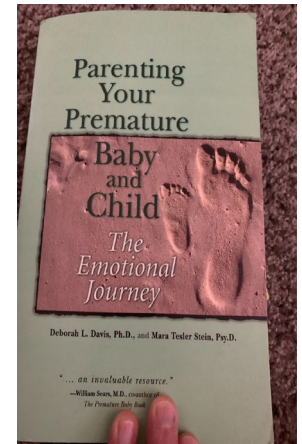
iPhone Screenshots



# Resources

## Books/Articles

- D.L. Davis & M.T. Stein(2004) Parenting your premature baby & child: The Emotional Journey
- Hynan & Hall(2015) Psychosocial program standards for NICU parents,  
*Journal of Perinatology*, 35, S1-S4
- Hall et al(2015) Recommendations for enhancing psychosocial support of NICU parents through staff education and support, *Journal of Perinatology*, 35, 529-536
- Purdy, Craig, Zeanah(2015) NICU discharge planning & beyond: recommendations for parent psychosocial support, *Journal of Perinatology*, 35, 524-528



<https://www.nature.com/collections/vrqhjdywxv>

# Questions



# Coming Up

## Mar 18: Group Office Hours (Noon – 1 pm)

Register on HQI website (<https://www.hqinstitute.org/pmh-learning-community>)

Program at a Glance	Webinars	Group Office Hours	Online Resources for Hospitals	Peer Sharing
1:1 Coaching	Participating Hospitals	Enroll	Contact	FAQs

### Group Office Hours

Virtual opportunity for hospital participants to receive practical implementation advice from program faculty and experienced peers. Office hours are held in the alternate months between webinars.

#### ▼ Upcoming Group Office Hours

- March 18, 2021
  - Noon – 1 pm, PST
  - [Click here to register](#)

*March 18 Group Office Hours will feature a discussion on the topic of Supporting NICU Families, which was started at the February 18 webinar. We will discuss sources and common effects of stress on NICU families, as well as ways hospitals can help support their mental and physical health.*

## Apr 15: Webinar (Noon – 1 pm): Birth Trauma & PMH

# Webinar Evaluation

## Polling questions:

- 1) Today's webinar was a good use of my time  
(agree-disagree-unsure)
- 2) Today's webinar increased my confidence in my ability  
to provide support to families in the NICU  
(agree-disagree-unsure)

## Open Text feedback – type into “Chat”:

What could have been done better or differently?