

Precious Preemie

Helping Parents Navigate The Premature Journey



EDUCATION * ADVOCACY
CARING CONNECTIONS



www.fsnhope.org



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CONGRATULATIONS!

THIS NOTEBOOK IS PRESENTED BY:
FAMILY SUPPORT NETWORK/HOPE



Dear Parent,

We hope you find this NICU Notebook helpful.

FSN/Hope provides other useful tools like this to help families meet the needs of their child with special needs. Our staff also works directly with families by providing information, training and support for families who have children of all ages and with all types of special health care needs and disabilities.

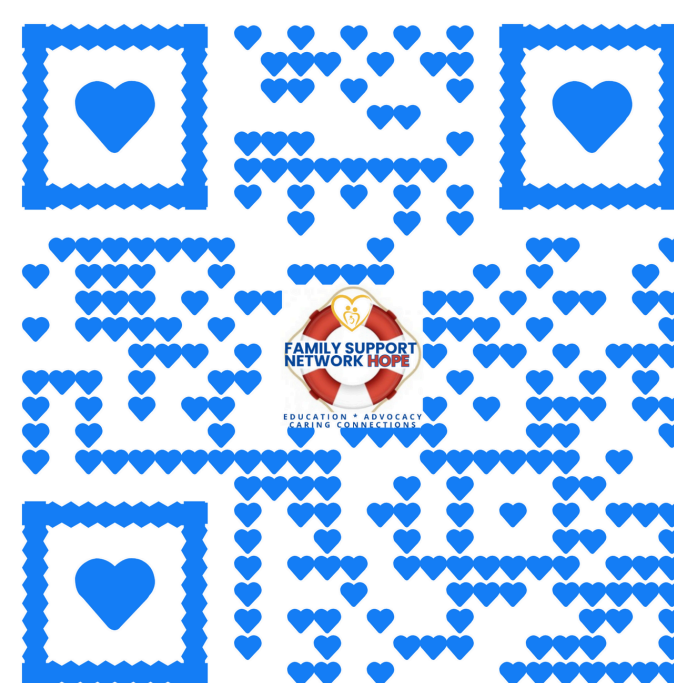
Some specific ways we can help are:

- Help find and access resources
- Provide information about disabilities and ways families can help their child learn and grow
- Help parents understand their rights
- Help parents become their child's best advocate

Please visit our website (www.fsnhope.org) or our Family Support Network/Hope Group on Facebook to find information and support or learn more about what we do.

EDUCATION * ADVOCACY
Sincerely, CARING CONNECTIONS

Vickie Dieter





You Are Not Alone



Our vision is a world where no parent goes through the experience of prematurity alone

Our mission is to inform and guide parents of premies so that they may confidently navigate the journey of prematurity



Our Premie Parent Care Package is designed for preemie parents – providing information and resources for every stage along the prematurity journey.



Our Premie Parent Mentor Program provides peer-to-peer guidance and support to preemie parents throughout the prematurity journey. Mentors are available via phone, text, email and video chat.



Our MyPremie app was created by experts and parents and is designed to inform and comfort preemie parents, help them organize and track their baby's progress, while also supporting engagement in the NICU and beyond. Our social media provides encouragement, inspiration and conversation @Grahamsfoundation



GrahamsFoundation.org



NICU NOTEBOOK



WELCOME

little one

NAME

DAY

TIME

WEIGHT



LENGTH

THE FIRST TIME WE SAW YOU.....

Lined writing area for notes.

NICU NOTEBOOK

DAILY CHECK IN

DATE _____

GESTATIONAL AGE _____

WEIGHT _____

LENGTH _____

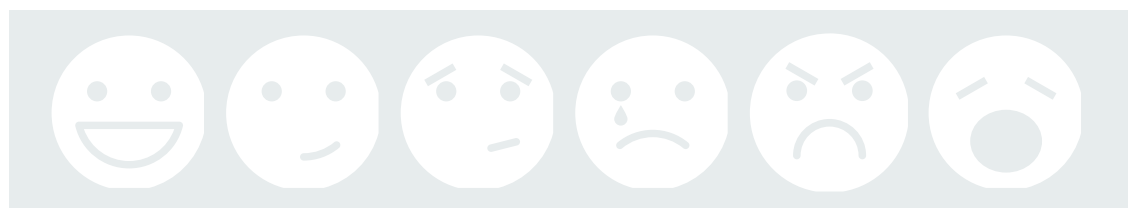
TODAY I'M GREATFUL FOR

WHAT WAS THE BEST THING ABOUT TODAY?

WHAT I WANT TO REMEMBER ABOUT TODAY

THINGS I DID TODAY

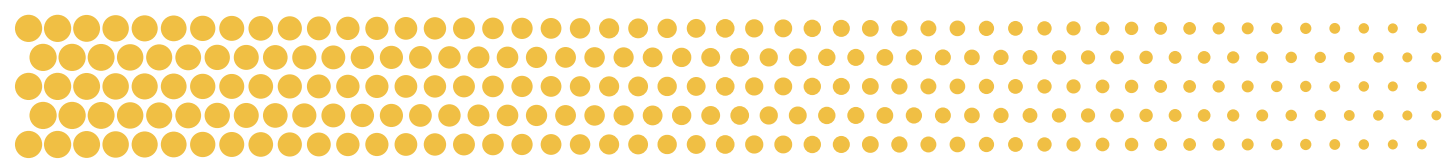
TODAY I FELT



QUESTIONS TO ASK

PEOPLE I MET TODAY

NICU NOTEBOOK



ABOUT MY CHILD

NAME: _____ DATE OF BIRTH: _____

PARENT/GUARDIAN: _____

ADDRESS: _____

PHONE NUMBERS:

HOME: _____ WORK: _____ CELL: _____

EMERGENCY CONTACT: _____

PHONE: _____ RELATIONSHIP: _____

INSURANCE INFORMATION:

INSURANCE NUMBER: _____

PRIMARY: _____ SUBSCRIBER #: _____ GROUP #: _____

PRIMARY: _____ SUBSCRIBER #: _____ GROUP #: _____

PRIMARY CARE PHYSICIAN: _____ PHONE #: _____

SPECIALTY CARE PHYSICIANS:

NAME: _____ PHONE #: _____

NAME: _____ PHONE #: _____

NAME: _____ PHONE #: _____

NAME: _____ PHONE #: _____

NAME: _____ PHONE #: _____

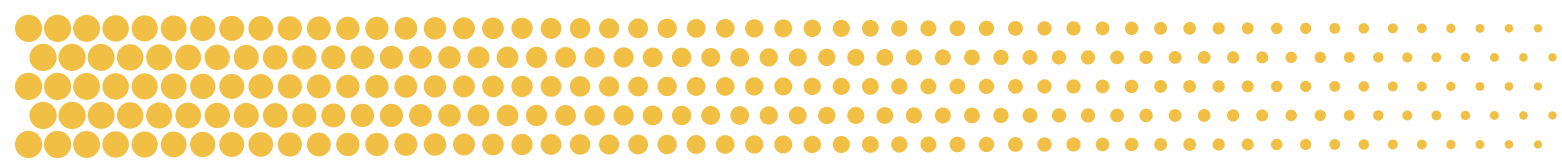
PREFERRED HOSPITAL: _____

PHONE #: _____

PHARMACY USED FOR PRESCRIPTIONS: _____

PHONE #: _____

NICU NOTEBOOK



MEDICAL HISTORY

BIRTH HISTORY:

BIRTH WEIGHT: _____ POUNDS _____ OUNCES

FULL TERM _____ PREMATURE _____ WEEKS GESTATION _____

NURSERY COURSE: _____

ALLERGIES: _____

SPECIAL DIET/NUTRITIONAL NEEDS: _____

SPECIAL EQUIPMENT/SUPPLY NEEDS:

TYPE: _____ SUPPLIER: _____

TYPE: _____ SUPPLIER: _____

TYPE: _____ SUPPLIER: _____

TYPE: _____ SUPPLIER: _____

SURGICAL HISTORY:

PROCEDURE: _____ DATE: _____

MD/FACILITY: _____

PROCEDURE: _____ DATE: _____

MD/FACILITY: _____

PROCEDURE: _____ DATE: _____

MD/FACILITY: _____

PAST MEDICAL HISTORY: _____

DEVELOPMENTAL HISTORY: _____

NICU NOTEBOOK

IMPORTANT PHONE NUMBERS

NAME: _____ TITLE: _____

PHONE: (HOME) _____ (WORK) _____ (CELL) _____

NAME: _____ TITLE: _____

PHONE: (HOME) _____ (WORK) _____ (CELL) _____

NAME: _____ TITLE: _____

PHONE: (HOME) _____ (WORK) _____ (CELL) _____

NAME: _____ TITLE: _____

PHONE: (HOME) _____ (WORK) _____ (CELL) _____

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PHONE: (HOME) _____ (WORK) _____ (CELL) _____

NAME: _____ TITLE: _____

PHONE: (HOME) _____ (WORK) _____ (CELL) _____

NAME: _____ TITLE: _____

PHONE: (HOME) _____ (WORK) _____ (CELL) _____

Oatmeal Chocolate Chip Lactation Cookies

"This recipe is great for mothers who are breastfeeding. It helps to keep your milk supply up or increase your milk supply. Use more brewers yeast and oatmeal if you are wanting to increase your milk supply. You can use more chocolate chips if you like or any kind of chips."



NUTRITION INFO	
Serving Size: 1 (34) g	
Servings Per Recipe: 54	
AMT. PER SERVING	% DAILY VALUE
Calories: 138.1	
Calories from Fat 47 g 34 %	
Total Fat 5.3 g	8 %
Saturated Fat 2.9 g	14 %
Cholesterol 15.9 mg	5 %
Sodium 101 mg	4 %
Total Carbohydrate 20.8 g	6 %
Dietary Fiber 1.4 g	5 %
Sugars 9.4 g	37 %
Protein 2.6 g	5 %

🕒 Ready In: 27mins

📦 Yields: 4 1/2 dozen

🥄 Ingredients: 13

👤 Serves: 54

DIRECTIONS

1. Preheat oven to 350°.
2. Mix the flaxseed meal and water and let sit for 3-5 minutes.
3. Beat butter, sugar, and brown sugar well.
4. Add eggs and mix well.
5. Add flaxseed mix and vanilla, beat well.
6. Sift together flour, brewers yeast, baking soda, and salt.
7. Add dry ingredients to butter mix.
8. Stir in oats and chips.
9. Scoop onto baking sheet.
10. Bake for 12 minutes.
11. Let set for a couple minutes then remove from tray.

INGREDIENTS

- 1 cup **butter**
- 1 cup **sugar**
- 1 cup firmly packed **brown sugar**
- 4 tablespoons **water**
- 2 tablespoons **flax seed meal**
- 2 **eggs**
- 1 teaspoon **vanilla**
- 3 cups **flour**
- 1 teaspoon **baking soda**
- 1 teaspoon **salt**
- 3 cups **oats**
- 1 cup **chocolate chips**
- 2 -4 tablespoons **brewer's yeast**

yummy





NC Infant-Toddler Program

the **earlier** you know, the **better** they'll grow

Developmental Milestones

Children grow, learn and develop at different rates. One may walk earlier than another, while another might talk first. Use this chart as one way to check whether your child is meeting developmental milestones during the first three years. Remember that every child is unique. If you have questions or concerns about how your child sees, hears, moves, communicates, learns, plays or interacts with others, talk with your primary care physician or contact your local Children's Developmental Services Agency (CDSA). Success in your child's growth and development benefits from EARLY action if you have a concern.

1 month: Lifts head when lying on tummy
Stares/looks at faces
Responds to sounds



2 months: Makes sounds - coos and gurgles
Follows objects with eyes
Holds head up for short periods of time
Notices his/her hands

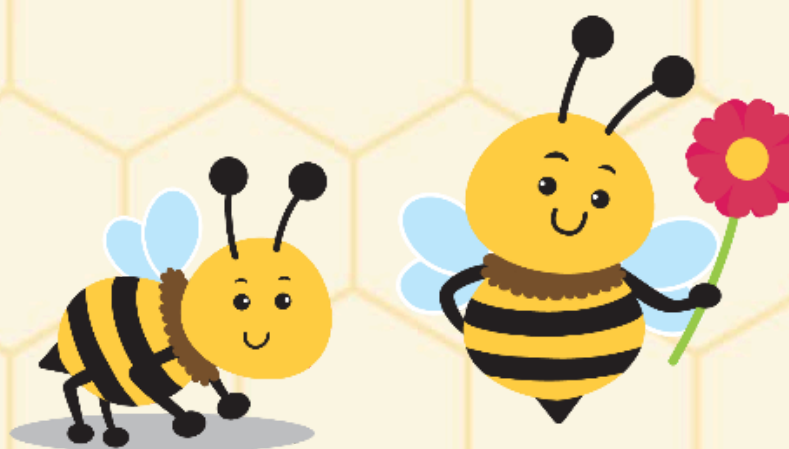
3 months: Recognizes faces
Holds head steady and upright
Begins to develop a social smile
Can bear weight on legs when feet placed on firm surface
Follows moving objects

4 months: Smiles, laughs, and coos when talked to
Rolls over from back to side or stomach
Reaches for and bats objects
Recognizes parent's voice and touch

5 months: Reaches, grasps, and puts objects in mouth
Holds out arms to be held
Plays peek-a-boo
Plays with hands and feet

6 months: Sits and stands with support
Rolls over in both directions
Turns toward sounds and voices
Imitates sounds

7 months: Responds to other's expressions of emotion
Uses hands to explore, pat, touch, stroke
Babbles series of sounds



8 months: Passes objects from hand-to-hand
Pulls self up to standing
Starts to crawl or scoot

9 months: Says "Ma-ma" or "Da-da" to either parent
Exchanges expressions with you (smile)
Jabbers or combines syllables
Responds to own name

10 months: Waves bye-bye
Crawls well on hands and knees
Drinks from a cup when cup is held

11 months: Says "Ma-ma" and "Da-da" to appropriate parent
Walks holding onto furniture
Drinks from cup and picks up small objects

12 months: Makes sounds and simple gestures
Uses at least three words
Lets you know what he/she wants and doesn't want

Continued on next page





the **earlier** you know, the **better** they'll grow

Developmental Milestones

13 months: Stands well

Bends over to pick up objects and can take a few steps

14 months: Imitates others' activities

Plays with a variety of toys like blocks, cars, books, stuffed animals and dolls
Empties containers of contents

15 months: Plays with a ball

Walks well and can stoop
Listens to stories
Can point to own body parts

16 months: Turns pages of a book

Forms attachment to a stuffed toy or other object
May have temper tantrums when frustrated

17 months: Learns the correct way to use common objects

like a telephone
Likes pretend games
Likes riding toys

18 months: Can say 10-20 words

Asks for help
Uses single words to make his needs/wants known
Scribbles with a crayon
Shows affection, kisses
Follows simple directions
Can walk backwards



19 months: Uses a spoon or fork

Can run
Throws a ball underhand
Enjoys helping around the house

20 months: Can undress him/herself

Can understand as many as 200 words

21 months: Will combine words like "want bottle" and "go bye-bye"

Can walk up the stairs one step at a time
Sets simple goals like where to put toys

22 months: Kicks ball forward

Follows two-step requests like "get the doll and bring it to me"

23 months: Can identify simple pictures in a book

Refers to self by name - uses "me/mine"
Can open cabinets and boxes
Uses "hi," "bye," and "please" if reminded

24 months: Will answer simple questions like "What's this?"

Names at least six body parts
Uses two- and three-word phrases
Kicks a ball Goes up and down stairs one step at a time Takes turns in play with other children



At two years of age, toddlers are increasingly more verbal, using two- and three-word phrases and making requests like "more juice." They have a vocabulary of 50-100 words and understand 250-300 words. They can feed themselves and open cabinets and boxes. They also like to take things apart, explore their surroundings, and imitate their parents and other children. Common socio-emotional behaviors are showing affection, playing independently, and acting shy around strangers. Two-year-olds can be very determined to have things their way, thus temper tantrums can occur.

By three years of age, children may be very independent. Physically, they can walk up and down steps and put on their own shoes. With the verbal ability to say three-to-five-word sentences, they can repeat common rhymes, understand most sentences, and say their names and age. Three-year-olds can play make-believe with toys, animals, and people. They can play simple games with other children, name at least one color correctly, and ride a tricycle. Three-year-olds express a wide range of emotions.

Though exact times for reaching these milestones can vary among children, these milestones can serve as a guide as you watch your child grow and develop.



NICU NOTEBOOK



Premature Infant Bill of Rights:

I have a right to expect that my caregivers' practices reflect evidence-based best practice.

I have the right to be considered an active participant in my life capable of feeling and responding in all situations.

I will be cared for in a developmentally supportive way and a measurement tool will be used to ensure consistency of my care.

I have the right to an environment that protects my vision and hearing by maintaining sound and light levels within recommended levels.

I will drive my feeding schedule- not doctors or nurses- and a feeding readiness scale will be used to ensure that I am in control.

My family can visit me at any time.

My family can participate in all activities that involve me.

I can enjoy kangaroo care any time my family wants, emergency situations being the obvious exception.

My care will be standardized across all shifts by all clinical staff that interacts with me.

My care will be clustered so that my precious sleep cycles are minimally disturbed.

I have the right to know a pain scale will be used to minimize causing me pain.

I have the right to expect that all my caregivers will keep in mind as Horton said, "A person's a person, no matter how small."

I have the right to be discharged home as soon as medically appropriate and not be kept in the Neonatal Intensive Care Unit one day longer because it may be financially beneficial to the hospital.

Mother's name _____

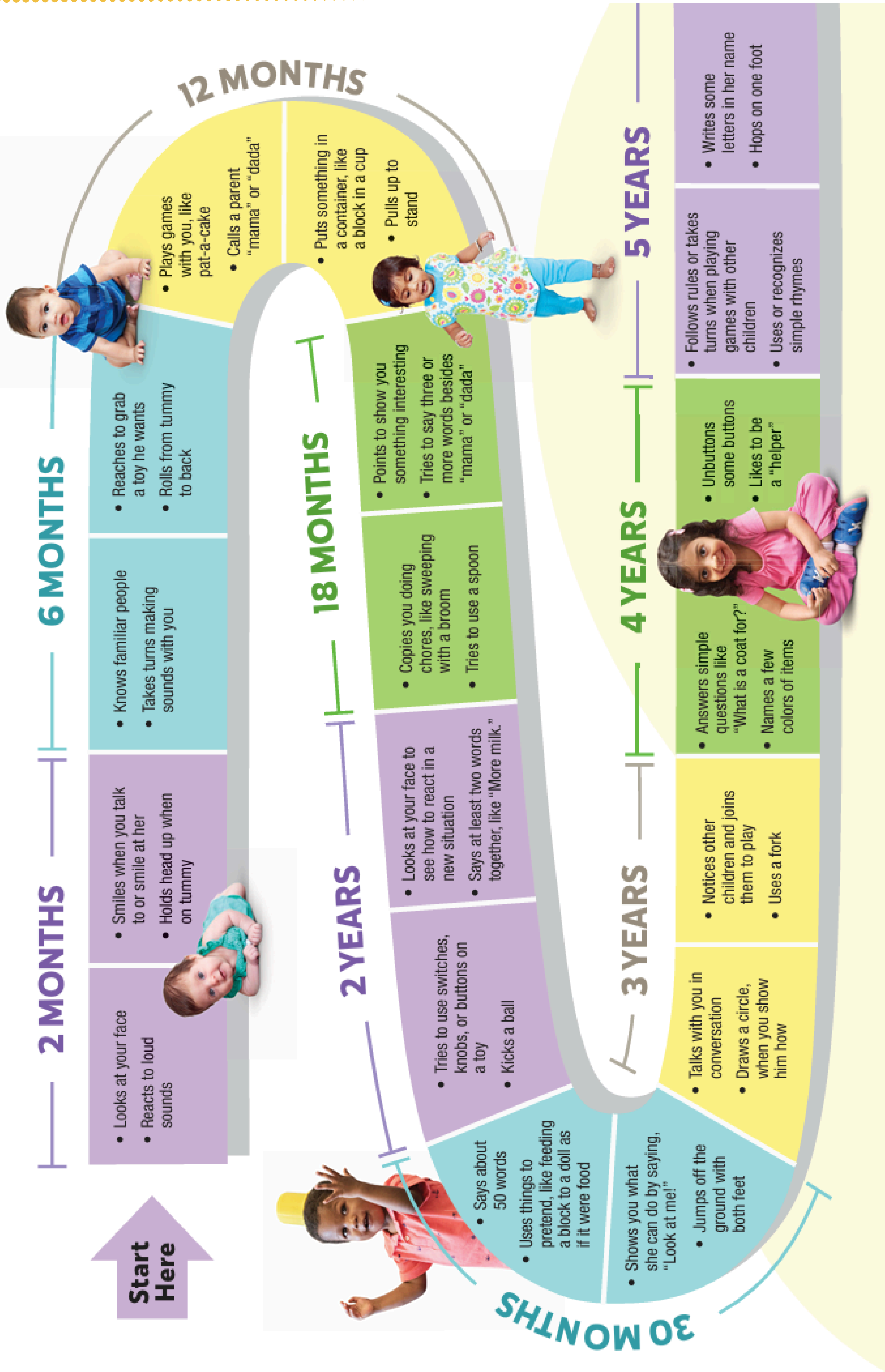
Baby's name _____

Doctor's name _____

This document can be added to your baby's chart or placed by their bed as part of their birth plan.

Your Child's Early Development is a Journey

These are just a few of many important milestones to look for. For complete checklists for your child's age visit www.cdc.gov/Milestones or download CDC's free *Milestone Tracker* app.



Milestone Moments



For more information about your child's development and what to do if you have a concern, visit:

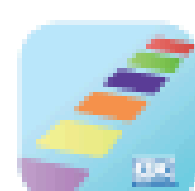
www.cdc.gov/ActEarly

OR CALL:

**1-800-CDC-INFO
(1-800-232-4636)**

to get help finding resources in your area.

These developmental milestones show what most children



Download CDC's free Milestone Tracker app



Milestones Matter!

Look inside for milestones to watch for in your child and tips for how you can help your child learn and grow.

Learn the Signs. Act Early.

Learn the signs of your child's development and act early if you ever have a concern.

To complete a milestone checklist, **download CDC's FREE Milestone Tracker app** or visit cdc.gov/Milestones, and talk to your child's doctor at every well-child visit about the milestones your child has reached and what to expect next.

You know your child best

If your child is not meeting milestones or you are concerned about the way your child plays, learns, speaks, acts, or moves, talk with your child's doctor, share your concerns, and ask about developmental screening. Don't wait.

If you or the doctor is still concerned

1. Ask for a referral to a specialist and,
2. Call for a free evaluation to find out if your child can get services to help:
 - **If your child is under age 3:** Call your state or territory's early intervention program. Learn more and find the phone number at cdc.gov/FindEI.
 - **If your child is age 3 or older:** Call any local public elementary school.

For more on how to help your child, visit cdc.gov/Concerned.

Don't Wait.

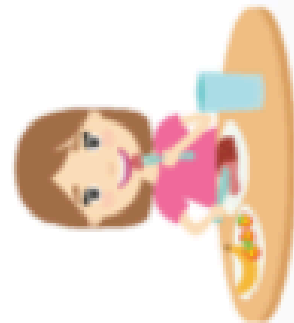
Acting early can make a real difference!

SELF-CARE At a Glance



1 Get Some Rest

Just as your baby needs sleep in order to grow and be healthy, parents need to sleep as well. Whether you are spending hours by the bedside every day, balancing the NICU while caring for older children at home or back at work full time, adequate rest is essential for both mothers and fathers.



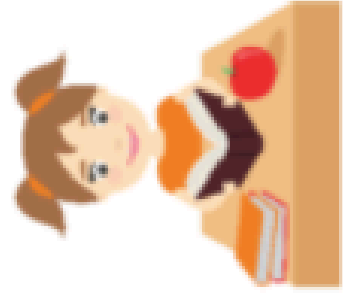
2 Fuel your Body

Many new parents in the NICU struggle to maintain their own health. Eating a healthy diet and drinking plenty of water is essential to not only your physical health but your emotional health as well. It also helps breastfeeding mothers establish their milk supply. Nutritionally deficient parents do not have the energy needed to cope with all the various challenges in the NICU so make time to practice self care when it pertains to your diet.



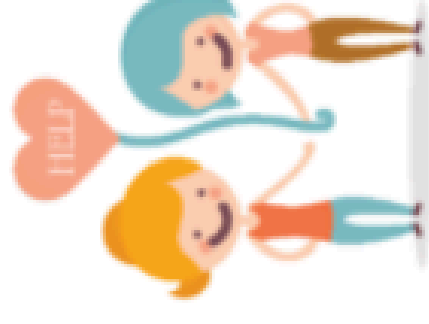
3 Move it

Being physically active boosts your spirits, releases endorphins that encourage positive moods and emotions and is a great source of stress relief during a NICU stay.



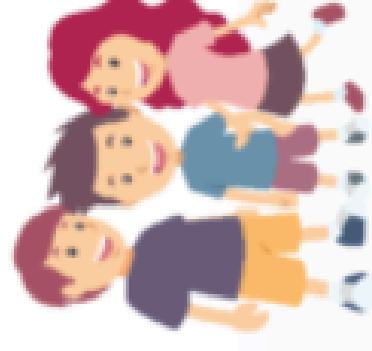
4 Be Still

Take 10 minutes a day and just breathe. Center yourself. It is important to take time for personal care. Whether it is a hot shower, new haircut, reading a book, an afternoon nap, or massage, take time to meet whatever needs are important to YOU. Stepping away from the bedside is not a luxury - it is a necessity.



5 Ask for Help

Talking about what you are feeling with a support network can sometimes be difficult, but it is vital for your emotional health and the health of your baby during this time. Asking for help is a sign of strength not weakness. Having extra hands to help with the to-do list will help you and your family focus on what is truly important right now - each other and your baby.



6 Connect with Others

Finding someone to talk to who has experienced the NICU journey will provide support, hope and inspiration when you need it most. Whether you meet families in your NICU or seek out NICU families within your community, connecting with other NICU parents is one of the most positive things you can do. NICU peer-mentoring programs can provide you with a trained graduate NICU parent who can support you during this time.

Never feel guilty for taking care of yourself. You must take care of yourself first in order to take care of your baby.



PREEMIE POWER





[Building Confidence and Parenting Skills When Your Child is in the NICU-](#)
a GREAT overview and list of resources and for parents who are navigating a NICU stay
<https://nursinglicensemap.com/blog/parents-of-baby-in-nicu/>



CaringBridge

In the midst of a stressful NICU stay, CaringBridge can help in so many ways. Send updates and photos to your family, friends, and colleagues all at once (meaning fewer phone calls & e-mails to return); connect with other parents experiencing a similar situation; and receive messages of hope and support. A CaringBridge site is absolutely free and easy to create.

<https://www.caringbridge.org/>



Day 2 Day Parenting

Offers parents & caregivers the tools, resources, & advice to have a happy, calm, & successful home. Whether you're a first-time parent, the parent of a child with special needs, a parent looking for milestone-specific advice or someone in between, we're here to support you so that you can help your child thrive. All of the content on our website is developed & written by our team of early childhood professionals: Physical Therapists, Occupational Therapists, Speech-Language Pathologists, Developmentalists, & Dietitians.

<https://teis-ei.com/>



Feeding Tube Information

It can feel overwhelming to learn your child needs a feeding tube. We have gathered all of the information and resources you need the most, right from the very beginning.

https://oley.org/page/TF_Troubleshooting



Graham's Foundation

Provides free care packages for families facing a long NICU stay. You can request to have a package delivered right to the hospital.

<https://www.grahamsfoundation.org/>



GI Kids

For help and hope as you navigate parenting a child with a digestive disorder.

<https://gikids.org/>



Hand to Hold

Offers a variety of incredible resources to NICU families, including peer to peer support, an online community, hospital resources, a blog, and podcasts.

<https://handtohold.org/>



March of Dimes

We lead the fight for the health of all moms and babies. We believe that every baby deserves the best possible start. Unfortunately, not all babies get one. We are changing that.

<https://www.marchofdimes.org/>



NC Infant Toddler Program

The mission of the NC Infant-Toddler Program is to provide supports and services to families and children to help them be successful in their homes and communities, by using every-day learning opportunities. We will respect the diversity of families and use evidence-based practices to guide our work.

<https://www.ncdhhs.gov/itp-beearly>



Peek a Boo

To empower parents with information that will not only help them understand their preemies but also help them to learn what they can do so their baby will thrive beyond the NICU days. We take the focus off of some of the more medical aspects & put the focus back on the baby & the parent's relationship with their baby. Helping parents be parents and giving them an opportunity to celebrate their baby while understanding their needs as they grow and develop in the NICU.

<https://www.peakabooicu.com/>



Skin-to-Skin Care

Watch and learn about the importance of skin-to-skin time with your little one, especially while they navigate a NICU stay.

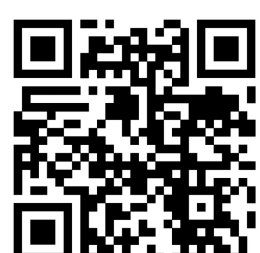
https://www.youtube.com/watch?v=_MateX87u9k



Tummy Time

Helps your baby develop the neck, back, and shoulder muscles needed to meet infant developmental milestones. It may also help prevent early motor delays and conditions such as flat head syndrome and twisted neck (positional torticollis). The American Academy of Pediatrics recommends placing babies on their backs to sleep and on their tummies to play.

<https://www.tummytimemethod.com/>



Zero to Three

Our mission is to ensure that all babies and toddlers have a strong start in life. They envision a society that has the knowledge and will to support all infants and toddlers in reaching their full potential.

<https://www.zerotothree.org/>



Bee Mighty

Provides support and resources to families before, during and after their NICU journey in the greater Charlotte, NC area

<https://www.beemighty.org/>



Postpartum Support International

Offers various free support groups including a NICU Support Group. Led by trained PSI facilitators, our online NICU group is intended for parents of babies who are currently or formerly in the NICU.

<https://postpartum.net/get-help/psi-online-support-meetings/#toggle-id-7>



Sahara's Project

Provides financial support for therapies

<https://www.ncdhhs.gov/itp-beearly>



Kids with PossAbilities

Funding therapy, assistive technology and educational scholarships for children.

<https://kidswithpossabilities.org/>



Madelyn's Fund

Our mission is to support infant and pediatric patients in the NICU and their families, as well as those who experience the trauma of infant loss..

<https://madelynsfund.org/>



United Healthcare Children's Grant

Our mission is to help fill the gap between what medical services/items a child needs and what their commercial health benefit plan will pay for. UHCCF grants provide financial help/assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan.

<https://www.uhccf.org/apply-for-a-grant/>



Novant Health Developmental and Behavioral Pediatrician

Offers medical evaluations for NICU graduates with developmental delays.

<https://www.novanthealth.org/locations/clinics/developmental-behavioral-pediatrics-eastover>



ECAC

A private non-profit parent organization committed to improving the lives and education of ALL children through a special emphasis on children with disabilities and special healthcare needs. ECAC affirms the right of all individuals, from all backgrounds and cultures, with or without disabilities, to an appropriate education and other needed services. ECAC seeks to make that right a reality by providing information, education, outreach, and support to and for families with children across the state of North Carolina.

<https://www.ecac-parentcenter.org/>



InReach

Provides a wide variety of supports and services across the lifespan for individuals with intellectual/development disabilities and their families. Services take place in a wide variety of settings based on the needs of the individual, the funding requirements and in some instances, availability of housing. Focus on each individual's unique needs and deliver the highest quality services possible by ensuring that each individual receives the right supports, at the right time and frequency by a caring qualified staff member in the most independent setting appropriate. Using the Person-Centered Plan or Individual Support Plan as the map, we provide choice and ensure a good fit between the individual's personal preferences and support needs and the staff providing supports.

<https://www.inreachnc.org/>



First in Families

A First In Families local chapter can support any family in which one family member has a developmental disability or delay, or is at risk of the same, or has a traumatic brain injury. Families or the individual must live in a county served by the Chapter and they must meet financial eligibility requirements. The residence must be a home, not a licensed facility.

<https://fifnc.org/index.html>



Easter Seals UCP

Easter Seals UCP is a leading provider of disability related-services in the communities in which we serve. Our purpose is to provide meaningful and exceptional services so that children and adults living with disabilities and mental health challenges can live, learn, work and play in their communities.

<https://eastersealsport.com/>



IDEA

S. Department of Education's Individuals with Disabilities Education Act (IDEA) website, which brings together IDEA information and resources from the Department and our grantees. Whether you are a student, parent, educator, service provider, or grantee, you are here because you care about children with disabilities and their families and want to find information and explore resources on infants, toddlers, children, and youth with disabilities.

<https://sites.ed.gov/idea/>



MyPremie App by Graham's Foundation

MyPremie is a complete toolkit for the unique practical and emotional needs of families of premature babies, available in English and Spanish. Includes a pocket guide to issues of prematurity; suggest questions for providers; a baby book diary; trackers; to-do lists; and ways to share information with family and friends.

<https://apps.apple.com/us/app/mypreemie-app/id931150109>

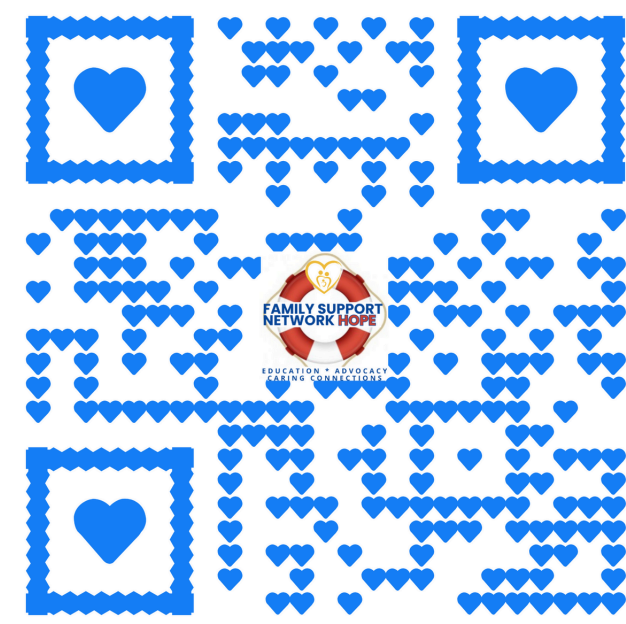


Dear NICU Mama

Dear NICU mama is a nonprofit and global community that provides immediate peer support to NICU mothers and their families through diverse programs and services. Such services include a private support group with over 6000 members worldwide, dedicated to provide encouragement and peer-to-peer support.

<https://www.dearnicumama.com>

www.fsnhope.org



WE HOPE YOU FIND THIS
NOTEBOOK USEFUL. YOU CAN
FIND REFILLABLE/PRINTABLE
PAGES ON OUR WEBSITE.



A person's
a person
no matter how small
- Dr. Seuss