

# Care Notebook for NICU Families



This Care Notebook is provided by Family Support Network™ of Central Carolina.

1200 N Elm Street, Greensboro, NC 27401 | 336-832-6507 | fsncc.org For questions about our programs, please email support@fsncc.org.



## About FSNCC

Family Support Network of Central Carolina's (FSNCC) mission is to provide support, education, and caring connections to those who have a child with a disability, special healthcare needs, or who have experienced a NICU stay. We understand that the NICU journey can be overwhelming and challenging for families. That's why FSNCC is here to offer assistance and support.

Our experienced team provides guidance, information, and emotional support to families navigating the NICU experience and beyond. We offer resources to help parents understand medical procedures, cope with stress, and connect with other families who have been through similar journeys. We hope this Care Notebook will be a valuable tool to help you keep your child's medical information organized.

Please email us if you would like to connect with a parent mentor at support@fsncc.org or visit our website for more information about our programs. At FSNCC, you are not alone, we are here to help!

# What is a Care Notebook?

Keeping all your paperwork related to your finances and child's medical needs in one place is one of the most important things you can do. Having the right information at your fingertips saves time, helps with decision making and reduces caregiver stress.

A Care Notebook is a great record keeping tool to organize your child's health information, insurance paperwork, prepare for appointments, track changes in medicines or treatments, to file information about your child's health history, and to share with medical providers. This Care Notebook is designed to be used throughout childhood.

For easy access, keep a digital copy on hand or hard copy in a binder. The main thing is to keep your child's entire medical information in one place.

### **Getting Organized**

For printed pages, begin with a large 3-ring binder, tabs for the binder to divide the binder into sections, and a three-hole punch. The binder should be big enough and sturdy enough to hold your child's pertinent medical information for several years.

Other recordkeeping supplies you may want to consider are:

- A calendar with room for writing notes
- A spiral notebook for recording phone conversations and meetings with professionals
- A place to file papers such as a filing cabinet or file box with a lid
- Hanging file folders with plastic tabs
- · File folders and labels
- Highlighters (for drawing attention to important information)

# **Table of Contents**

Child's Information	5
Family Information	6
nsurance	7
Pharmacy	7
Appointment Log	8
Growth Tracking Form	9
Developmental Milestones	10
Scheduling Calendar	13
Emergency Health Information	14
Medications Chart	16
Medical and Specialty Providers	17
Therapists	18
Lab Work/Tests/Surgeries/Procedures	19
Respiratory/Breathing Notes	20
Hospital Visits	21
Event Tracker	22
Diet Tracking Form	23
Dental	24
Medical Billing Log	25
Equipment Providers	26
Family Support Resources	27
Home Care Providers	28
Day to Day Life of Child	29
Communication Page	30
Coping/Stress/Behaviors	31
Nutrition	32
Sleep/Rest	33
Social/Play	34
Fransitions	35
Notes	36
Resources for NICU Families	37



Name:	
Nickname:	
Birthday:	му рното
Gestational week born:	
Weight at birth: Blood type:	
Diagnosis:	
Notes	



Parent 1 Name:	
Address:	Email Address:
Phone Number:	
Parent 2 Name:	
Address:	
Legal Guardian:	
Address:	
Siblings & Other Household Members	
Name:	Birthday:
Name:	_ Birthday:
Name:	Birthday:
Name:	_ Birthday:
Name:	_ Birthday:
Name:	
Notes	



Email Address:
Group Number:
Email Address:
Group Number:
lumber:
Phone Number:
gies, etc.):

# Appointment Log

Doctor's Name	Appointment Date	Appointment Time	Questions to Ask at Appointment

# Growth Tracking

Date	Height	Weight	Head Size	B.P.	H.R.	Notes

# Developmental Milestones

Get your baby off to a good start by using this check list to keep track of their development.

### 1 month:

- O Lifts head when lying on tummy
- O Stares/looks at faces
- O Responds to sounds

### 2 months:

- O Makes sounds coos and gurgles
- O Follows objects with eyes
- O Holds head up for short period of time
- O Notices his/her hands

### 3 months:

- O Recognizes faces
- O Holds head steady and upright
- O Begins to develop social smile
- O Can bear weight on legs when feet placed on firm surface

### 4 months:

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

### 5 months:

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

If your baby was born prematurely, you can learn more about adjusted age at: healthychildren. org

### 6 months:

- O Sits and stands with support
- O Rolls over in both directions
- O Turns towards sounds and voices

### 7 months:

- O Responds to others' expressions of emotion
- O Uses hands to explore, pat, touch, stroke
- O Babbles series of sounds

### 8 months:

- O Passes objects from hand to hand
- O Pulls self up to standing
- O Starts to crawl or scoot

### 9 months:

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

### 10 months:

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

### 11 months:

- O Says "Ma-Ma" and "Da-da" to appropriate parents
- O Walks holding on to furniture
- O Drinks from cup and picks up small objects

### 12 months:

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



### By the end of 18 months, most children are able to:

- O Do simple play like "talk" on a toy phone
- O Point to interesting objects pictured in books or body parts
- O Scribble with a crayon
- O Use several single words unprompted
- O Walk alone
- O Feed with a spoon

At two years of age, toddlers are increasingly more verbal, using two- to 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.

### Children's Developmental Services Agency (CDSA)

The CDSA is our area's Early Intervention office, that provides diagnostic evaluations, access to therapy services, and service coordination for children from birth to age 3. Parents, physicians, and other service providers may make referrals to the CDSA to arrange for screenings and consultations. For more information, please visit their website at www.beearly.nc.gov. or call (336) 334-5601.



N 4					10	,		
M	$\sim$	n	т	n	/Y	_	~	r

Name:	DOB:	

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday



Be sure to keep this information up to date and with all your child's caretakers and physicians.

### **Demographics**

Name:	DOB:
M O F O Age: Primary	Language:
Parent/Guardian:	Phone:
Emergency Contact:	Phone:
Preferred Hospital for Transport:	
Baseline Status	
Vital Signs HR: RR:	BP: O <sub>2</sub> Sat: %
Weight: lbs. Height:	ft./in. Best IV site:
Neuro Status/Your child's developmental I	evel:
○ Nonverbal ○ Hearing Impaired ○ \	/isually Impaired
Medical History	
Medical Conditions:	
Hospitalizations/Surgeries:	



Medications		
1	6	
2		
3		
4		
5		
Allergies/Reaction		
1.	4	
2	5	
3	6	
Special Needs/Equipm	ent	
O Feeding Pump	Oxygen	
O Suction Machine	O Apnea Monitor	
○ Wheelchair	O NG/NJ Tube	
O Gastrostomy Tube	<ul><li>Tracheostomy</li></ul>	Size/type:
O Pulse Oximeter	<ul><li>○ Ventililator</li></ul>	Type/mode:
Any Other Information fo	or Emergency Respo	onders
Primary Care Physician:		Phone:
Specialists or other services i	nvolved in your child's o	care:

Medications	ations							
harmacy:				Email:				
Address:				Allergies:				
hone:								
-ax:								
Date Started	Date Stopped	Rx	To Treat	Dose/ Route	Time Given	Prescribed By	Side Effects	



# Medical and Specialty Providers

Name:	DC	)B:	
Specialist Name:			
Clinic/Hospital:			
Address:			
City:		Zip:	
Phone:	Email:		
Specialist Name:			
Clinic/Hospital:			
Address:			
City:	State:	Zip:	
Phone:	Email:		
Dentist Name:			
Address:			
City:			
Phone:	Email:		
Public Health Nurse:			
Address:			
City:	State:	Zip:	
Phone:			
Nutritionist:			
Address:			
City:		Zip:	
Phone:	Fmail:		



Name:	DOB:
Therapist:	
Start Date:	
Contact Person:	
Address:	
Phone: Fax:	Email:
Important Information:	
Therapist:	
Start Date:	
Contact Person:	
Address:	
Phone: Fax:	Email:
Important Information:	
Therapist:	
Start Date:	
Contact Person:	
Address:	
Phone: Fax:	Email:
Important Information:	
Therapist:	
Start Date:	
Contact Person:	
Address:	
	Email:
Important Information:	

# Lab Work/Tests/Surgeries/Procedures

Date	Test	Result	Comments



Use this page to write about your child's respiratory care needs. Describe the care or treatments your child needs and any special techniques or precautions you use when giving care. Include any special routines your child has for respiratory care.

Date	Event	Notes

# Hospital Visits



Use this page to track any events related to your child's health (seizures, behaviors, injuries, etc.).

Name: _		DOB:		
Date	Activity/Information			
Date	Activity/mormation			

# Diet Tracking Form

Sat.						
Fri.						
Thurs.						
Wed.						
Tues.						
Mon.						
Sun.						
	Tube Feeding	Breakfast	Lunch	Dinner	Snacks	Notes



Child's Name:	
Dentist's Name:	
Address:	
Phone:	
O Dentist has been informed of child's medical condition and medical	
specialists' recommendations.	

All children should have routine dental care. Such care may be even more important when your child has a special health care need. He or she may need to be followed by a dentist with special skills. Consult with your family dentist or your child's medical specialist to determine if he or she requires specialized dental services.

Before your child is examined, the dentist should have information regarding your child's medical condition and current care. Any precautions recommended by your child's medical specialist should be discussed with the dentist. It is also essential that you provide the dentist with a list of current medications received by your child.

You can use the space below to keep track of your child's dental appointments.

Date	Time	Activity/Information

# Medical Billing Log

What bill Date of Contact Time is for



Medical Equipment Supplier (DM			
Contact Person:			
Phone: Fax:			
Notes (delivery schedule, order sc			
	· · · · · · · · · · · · · · · · · · ·		
Name of Equipment:			
Description (brand name, size, etc	:.):		
Contact Person:		Phone:	
Date Obtained:	Service Schedule:		
Name of Equipment:			
Description (brand name, size, etc	:.):		
Contact Person:		Phone:	
Date Obtained:	Service Schedule:		
Name of Equipment:			
Description (brand name, size, etc	:.):		
Contact Person:		Phone:	
Date Obtained:	Service Schedule:		
Name of Equipment:			
Description (brand name, size, etc	:.):		
Contact Person:		Phone:	
Date Obtained:	Service Schedule:		



Support Group/Orga	nization:	
Phone:	Fax:	Email:
Group Focus:		
Religious Organization	on:	
Dhana		Fracil
		Email:
Notes :		
Counseling Service:		
Phone:	Fax:	Email:
Group Focus:		
Dept. of Human Serv	rices::	
Phone:		Email:
Notes:		
Other:		
Phone:	Fax:	Email:
Notes:		

Home Care Age	ncy:		
Case Manager:			
		ng, etc.):	
Primary Care Nu	ırse:		
Phone:	Fax:	Email:	
Home Care Ager	ncy:		
Address/Directio	ns:		_
Phone:	Fax:	Email:	
Notes:			
Home Care Agend	cy:		
Contact Person: _			
Phone:	Fax:	Email:	
Notes:		_	
Home Care Agend	:y:		
Contact Person: _			
Address/Direction	ns:		
	Fax:	Email:	
Notes:			
71 11 <b>44</b> 4.			



Use this page for your child's words and thoughts about his or her life now as well as later.

Date:	



Use this page to write about your child's ability to communicate and to understand others. Describe how your child communicates. Include sign language words, gestures, or any equipment or help your child uses to communicate or understand others. Include any special words your family and child use to describe things.

Date:	



## Coping/Stress/Behaviors

Use this page to write about how your child copes with stress. Stressful events might include new people or situations, a hospital stay, or procedures such as having blood drawn. Describe what things upset your child and what your child does when upset or when he or she has "had enough." Describe your child's way of asking for help and things to do or say to comfort your child.

Date:	



Use this page to write about your child's nutritional needs. Describe foods and any nutritional formulas your child takes, any food allergies or restrictions, and any special feeding techniques, precautions, or equipment used for feedings. Describe any special mealtime routines your family and child have.

Date:	



Use this page to write about your child's ability to get to sleep and to sleep through the night. Describe your child's bedtime routine and any security or comfort objects your child uses.

Date:			



Use this page to write about your child's ability to get along with others. Describe how your child shows affection, shares feelings, or plays with other children. Describe what works best to help your child get along or cooperate with others. Describe your child's favorite things to do. Include any special family activities or customs that are important.

Date:	



### **A** Transitions

Your child and family will experience many transitions, small and large, over time. Three predictable transitions occur for most children: reaching school age, approaching adolescence, and moving from adolescence into adulthood. Other transitions may involve moving into new programs, working with new agencies and care providers, or making new friends. Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go.

Looking at transitions may be hard, depending on your circumstances. You may have limited time just to do what needs to get done today. You may find it helpful, though, to jot down a few ideas about your child's and family's future. You might start by thinking about your child's and family's strengths. How can these strengths help you plan for "what's next" and for reaching long-term goals? What are your dreams and your fears about your child's and family's future?

Date:			



Date:	
	_
	_
	_



## Resources for NICU Families



### Family Support Network of Central Carolina:

Provides support for families with infants in the NICU and children with special healthcare needs or disabilities. fsncc.org/our-nicu-services



Healthy Start: Healthy Start is a home-based support program that works with pregnant women and new parents with stress factors that make parenting an even tougher job. Healthy Start Home Visitors help parents to nurture their children's development and create a positive living environment for their families.

fspcares.org



March of Dimes: March of Dimes leads 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.

marchofdimes.org/nicu-family-support



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.

beearly.nc.gov



Hand to Hold: 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. handtohold.org



Parents as Teachers: Parents as Teachers promotes early development for children through supporting parents and caregivers. Parents as Teachers partners with families to increase children's readiness for school. parentsasteachers.org



Ready for School Ready for Life: Ready for school Ready for Life is committed to building a connected system of care for Guilford County's youngest children and their families. This system is for ensuring that every child enters kindergarten on track and ready for success in school and in life. getreadyguilford.org



**Smart Start**: Smart Start is dedicated to promoting high quality early child care and family support programs that promote parent involvement develop early literacy skills for children. smartstart.org



BackPack Beginnings: BackPack Beginnings mission is to serve Guilford families and deliver child-centric services to feed, clothe, and comfort children in need. Distributions include food, fresh produce, formula, baby food, comfort items, books, baby accessories and baby equipment. backpackbeginnings.org



**Every Baby Guilford**: Every Baby Guilford is determined to work with communities to build collaborative solutions that disrupts the longstanding health outcomes and racial disparities within Guilford County.

guilfordcountync.gov/our-county/human-services/health-department/every-baby-guilford



Child Care Resource & Referral: CCR&R assists families with finding child care and services and offers parenting workshops, hotlines, and newsletters. CCR&R also provides information on where to receive help to pay for child care. childcareservices.org/programs/ccrr/



Children's Developmental Services Agency IT program: The CDSA supports families with children from birth age to age three who have developmental delays or are at the risk for problems with their development. Case management and therapy services are also provided in the local communities they serve.

ncdhhs.go/itp-beearly



Care Management for At-Risk Children: The Medicaid Program offers a set of care management services for at-risk children from ages zero -five. This program coordinates services between health care providers, community programs, and support programs.

medicaid.ncdhhs.gov/care-management



Dolly Parton's Imagination Library: Dolly Parton's Imagination Library gifts free books to children from birth age to five. Upon registration, each month a specially selected and age appropriate book will be mailed to your home at no cost. imaginationlibrary.com