

The Premie Parent's SURVIVAL GUIDE to the NICU

By

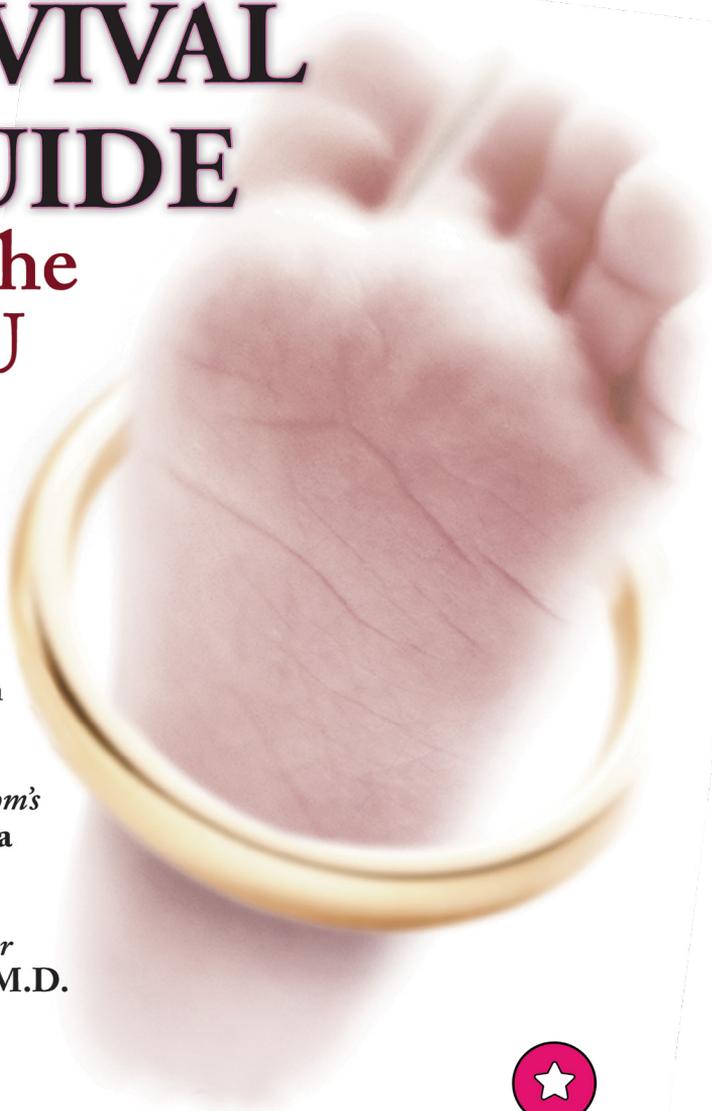
little man's
Nicole Conn

&

PremieWorld.com's
Deb Discenza

with

Medical Editor
Alan R. Spitzer, M.D.



HOW TO **second edition**
MAINTAIN YOUR SANITY
& CREATE A NEW NORMAL

THE PREEMIE PARENT'S SURVIVAL GUIDE TO THE NICU

**How to Maintain Your Sanity
& Create a New Normal**

By

Nicole Conn & Deb Discenza

**Alan R. Spitzer, M.D.
Medical Editor**



second edition



The Preemie Parent's Survival Guide to the NICU was published in 2020 by PreemieWorld, LLC
P.O. Box 10733, Burke, VA 22009
www.PremieWorld.com

Copyright © 2020 by PreemieWorld, LLC
All Rights Reserved.

No part of this book may be reproduced in any form or by any electronic or mechanical means including information storage and retrieval systems, without permission in writing from the authors. The only exception is by a reviewer, who may quote short excerpts in a review.

Cover Photo: little man Productions
Book design by Lainie Liberti, Tuan Vu Tran, and Andrea Kuhne for jungle[8].
Production Team Manager: Bri Ziganti, Felice Media
Copy Editor: Jenny McCormick

Printed in Hong Kong
Sea-Hill Press, Inc. www.seahillpress.com
First Printing: November 2009

Printed in Canada
Premier Printing, Ltd. premierprinting.ca
Second Printing: April 2020

ISBN: 978-1-7348470-1-7

Disclaimer: This book is not a substitute for the medical care by you or your baby's doctors. It is simply a guide to help you as you navigate the NICU and it is to be used as a tool in discussions with the NICU staff as well as with your personal medical professionals.

DEDICATION

From Nicole

For Nicholas:

My little man with his gigantic spirit.

And for Gabrielle:

For being my sanity, my solace, and my rock during the crazy NICU journey.

From Deb

For Gregg & Becky:

I am so blessed to have you in my life.

For Amy R. Perlin, D.D., Senior Rabbi of Temple B'nai Shalom:

As a fellow Premie Mom you showed me the amazing power of the Mi Shebeirach (healing) prayer as we did Becky's naming ceremony in the NICU.

From Deb & Nicole

For all Premies and their Families Worldwide:

May this book give you just a little more comfort during the NICU journey.

For the Premie Professionals Worldwide:

Thank you on behalf of all Premie Parents for your amazing talents in the NICU.

THANK YOU

This book would not have been possible without an amazing team of people who helped us envision our important mission of helping preemie families thrive and as Nicole would say look “groovy” doing it.

We’d like to thank the following people for their amazing insight into the preemie parent world in the NICU:

Our Medical Editor **Alan R. Spitzer, M.D.**,

Former Senior Vice President and Director of **The Center for Research and Education at Pediatrix Medical Group**

Our Book Editor **Olivia Giovetti**

Our Book Designers from **Jungle[8]**: **Lainie Liberti**, Creative Director and Principal, **Andrea Kuhne & Tuan Vu Tran**, Designers

Our good friend **Maureen A. Doolan Boyle**, Founder & Executive Director of **Mothers of Supertwins** and Chairperson of **PreemieCare**

PERSONAL THANKS:

On a personal note we’d like to thank the following people in our lives for their love and support as this book came to be:



NICOLE:

All My Love & Gratitude To My Family:

Gabrielle – for being my bestest “Bi-Bi Bo-Bo” and forever making my heart sing

David – for your gentle nature, wicked humor and keeping me young!

Lauren – for being so smart, so very kind, and for secret candy stashes!

Alexandra – for your lyrical poetry, crazy singing, and adorable self

Daisha – for your keen wit, insight, and keeping the kids endlessly entertained!

Nicholas – for making me grateful every single day, my “little man”—my soul.

Special Thanks Always and Forever to the entire staff at **Cedars Sinai Hospital** in Los Angeles, **Good Beginnings**, **Fernanda Erlanger** and **Dorothy Williams**.

Nicholas's primary nurses—**Becky, KJ, Judy & Stephanie**.

As well as the best of home health nurses who have become our family; **Zel, “Dan-Dan,” Estee, Sonnia, Maxine & Ebony, especially “Gymbee” (Genny Verdugo) and Zel Alvarez.**



DEB:

I would like to thank both my wonderful husband, **Gregg**, and my lovely daughter, **Becky** (now 16), for their enormous support and patience as this book evolved.

I am dedicating this book in loving memory to my late parents **Garcin & Barbara Kaganowich** who inspired my love of writing and helping others.

And then there are my adopted twin brothers, **Andrew & Steven Kaganowich**, who were born prematurely and are (very appropriately) Becky's co-Godfathers and doting Uncles.

I would like to send a very special thank-you to the entire team at **Fairfax Neonatal Associates**, the team that took care of my daughter in the NICU at **Inova Fairfax Hospital for Children**. Nurse **Donna Reed**, you helped us celebrate our family for the first time in the NICU with one simple baby bath. Thank you for your amazing guidance and support then and over the years.

I want to thank my PremieWorld team for their incredible hard work on this book: **Bri Ziganti**, Designer Extraordinaire, and **Jenny McCormick**, our Amazing Assistant Editor & Social Media Mama.





FOREWORD

Many years ago, when I first decided to become a neonatologist, I had the opportunity to take my mother on a tour of the Neonatal Intensive Care Unit (NICU) at the Children’s Hospital of Philadelphia, where I was Chief Resident at the time. After wandering from bedside to bedside peering at the tiny, critically ill infants on ventilators and a variety of other amazing therapies, my mother finally stopped and said to me, “This doesn’t really exist, does it?” Since that day, I have recognized that parents of premature infants often react the exact same way when they first encounter the NICU. It is a place that never did exist for them previously, yet it becomes all too real once you find yourself captive there for however long your preemie remains a NICU patient.

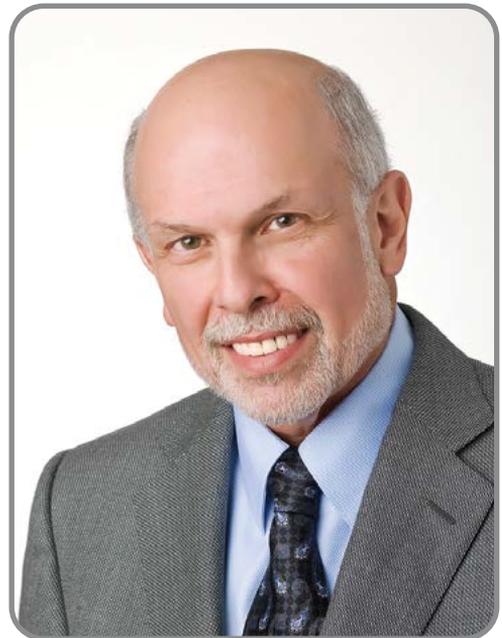
Because the NICU is an environment that relatively few individuals ever encounter in their lifetime, it can be profoundly confusing and difficult to comprehend for even the most educated of families. All the various sights and sounds, the life-saving alarms that echo constantly, the incredible pace of activity, the barrage of information, and the very difficult decisions that are showered upon parents each day can humble even the strongest of individuals. Coping with the stresses of preemie parenthood is, quite simply, an incredible challenge, one of the most difficult that the average person will ever face in his or her lifetime. As the grandfather of two premature infants myself, I can most definitely attest to the extraordinary nature of this challenge from both the viewpoint of the physician as well as from the perspective of the family.

Guiding a family through the NICU experience, therefore, has always seemed to me to be one of the most important aspects of care that a neonatologist can offer to a parent. But with many very complicated patients to care for and a limited number of hours in the day, finding sufficient time to answer each parent’s questions in detail is always problematic for the NICU physician.

Until now, few up-to-date resources have existed that the neonatologist could point to, which would allow a family to more fully understand the complex issues that constantly arise in the care of the premature infant. Fortunately, Nicole Conn and Deb Discenza, both parents of preemies themselves, have recognized this deficiency and addressed it by writing a remarkable book that, in my opinion, should be handed to every parent upon admission of their premature infant to the NICU.

Having experienced the best and the worst of the NICU themselves, they have created a manual that no mother or father of a premie should ever be without. The book that you now hold in your hands will be of enormous value to you as you personally attempt to navigate premature infant parenthood with Nicole and Deb as your guides.

Their insightful understanding and their unswerving support will be invaluable to you until your child is ready to go home and embark upon a life outside the NICU. You could not have two better guides to show you the way.



Alan R. Spitzer, M.D.
Former Senior Vice President
and Director of The Center
for Research and Education
Pediatrix Medical Group
Photo Credit: Pediatrix Medical Group



CONTENTS

• Thank You	4
• Foreword: Alan R. Spitzer, M.D.	6
• Contents	9
I. Introduction: The Twilight Zone	10
II. How to Use This Book	22
III. The A-Z of the Neonatal Intensive Care Unit (NICU)	25
IV. The NICU: Your Baby’s Womb in a Room	93
V. Premie Parent = Advocate	110
VI. The Doctor, Nurses & You: <i>Your Role in the Bermuda Triangle</i>	119
VII. Coping with Emotions: <i>They Are All Valid</i>	134
VIII. Life Outside the NICU—Oh, Is There One? <i>What to Expect As You Live in a Vacuum</i>	143
IX. The Importance of Self-Care	158
X. Resources: Your New Best Friends	165
XI. Eek! Preparing for Discharge Day	167
XII. Premie Parent Power	185

INTRODUCTION:

THE TWILIGHT ZONE



“This isn’t medicine, it’s voodoo.”
-Resident taking care of Nicholas

Yes, you have just entered the Twilight Zone. Because being inside a Neonatal Intensive Care Unit for the first time feels like the worst kind of science fiction: isolettes that look like pods, wires everywhere, beeping machines. Nothing can prepare you for this experience.

All Nicole can really remember from the first 24 to 48 hours of her son’s life is gripping Nicholas’s isolette, his eight inch long miniature being bathed in the glow of lights, strapped up to so much machinery he looked like a mini-borg. Nicole has been told that if by some miracle, he makes it past the first 48 hours it will probably be due to the “honeymoon” period thanks to the Surfactant given for his underdeveloped lungs.

“We don’t want you to be giving any false hope.”

Trust us, all hope fades quickly enough in this mad world; a world that seems straight out of a twisted lab-gone-

bad tale. It’s a world in which the young new mom stammers in disbelief (“No really, I’m just supposed to be having a baby”), certain she is in a dream. She hasn’t even had her baby shower. She hasn’t even started the nursery. This can’t be the moment she has waited for, hungered for, planned and prayed for.

She, like you now reading, has just entered the world of the wildly unexpected. Pain and death abound here, right alongside newly minted mothers who want nothing more than to cradle their newborns to breasts. They cannot, however, because their infants scant underweight bodies are unable to hold a temperature, or their heart valves are transposed, or their intestines have grown on the outside of their bellies. Tales abound in the NICU filled with a menagerie of IUGR (intrauterine growth restriction) Premies, preeclampsia horror stories, and chromosomally-affected newborns.

At some point, the shock and agony of your delivery will subside and you and your spouse/partner will begin to calm. At some point you will slowly begin to regain your equilibrium, and you will begin to

venture out to share with other mothers, clasp hands, and shed tears.

One cannot imagine or dream up this world; a world where parents sit endlessly, bleary-eyed, and gaunt as they peer into tiny bins of plastic, their heads snapping to the blaring monitors. You feel off balance, and even though you know you have a vague recollection of high school biology, you will soon realize it's impossible to fully comprehend the effort put into keeping your child alive.

We take it for granted that our gurgling infants will breathe enough oxygen and rid themselves of too much carbon dioxide. We never consider that every system has to be calibrated: a tweak of bi-carb here, the twisting of knobs there, not only for pressure of air into the lungs, but also for the measurements of tidal volumes and lengths of inspiration. There is a menu of electrolytes constantly on the rebound from too much this and not enough that. Blood pressure cuffs the size of miniature Band-Aids. Photo light therapy for jaundice.

You will hear the term “roller-

coaster” about a hundred times a day, and possibly your tears (like ours) will come far easier than you'd like. We strongly suggest you don't hold back. Ours were a means of survival.

Your baby is born. Prematurely. What was supposed to be one of the happiest days of your life—the birth of your child—has turned into a surreal event. You've entered a world that will leave you under incredible stress and duress and, perhaps, forced to make life and death decisions.

Perhaps she is merely a few weeks early and all she requires are hot lights to help her with a mild case of jaundice and some therapy to properly breastfeed. Or, perhaps he is a one pound waifling, born in his 24th week. She's a 29-weeker with a congenital anomaly. They are 31-week triplets weighing between two and four pounds. You and they are all unprepared for these harsh lights, blaring monitors, shrill commands of doctors voices, chaos, and a sense of the ultimate betrayal.

Whether you live in the NICU for the next two days, weeks, or months and no matter what week or weight your baby carries with her, you have just had an infant in the NICU. Whatever the circumstances that surround your baby's birth, this will become a life altering moment.

You are about to go on the ride of your life. What may feel like the ultimate endurance race in one



“The NICU is by invitation only. And it's not an invitation you want.”

*-Kathleen Johnson,
Primary Nurse to Nicholas*



moment feels like a quick sprint over a cliff without a parachute in the next. To quote Bette Davis in *All About Eve*, “Fasten your seatbelts, it’s going to be a bumpy night.”

The good news is that there is a way to get through this. You probably won’t emerge entirely unscathed, but you will survive, even when you think that if you have to wait one more second to see your baby, one more week to hold your darling infant, go through one more interminable discussion with the doctors, specialists, and/or social workers, or have to fill out one more form, you are going to lose your mind. Permanently. But, along with this guide, the help of strangers who will become your family, and friends who will show their true mettle, you *will* make it through to the other side.

Sure, it seems like there is no possible way you’re going to make it. Your head has turned into mush; your brain is on disconnect. The doctors and nurses sound like the adults from *Charlie Brown*, their reports and jargon coming out like “Wa-wa-waws.” You feel wrecked from the hours leading up to your infant’s birth and unable to comprehend the work that still lies ahead.

You want your spouse or partner near you one moment, and you want to be alone the next. You miss your children at home but cannot

leave your sweet, helpless newborn alone in her isolette. You switch from being ravenously hungry to not being able to stand the sight of food. This contortion of emotions is absolutely mind-numbing. It’s also absolutely appropriate.



“Being in here and watching everything you are going through is like the distillation of pain and joy in every breath.”

-Visiting Friend

This is real—all too real. And what you need to do here and now is cope with this new reality. First of all, you will forget 98% of everything you are told, and probably 100% of what you will read (that’s why you have this guide to turn to again and again). So here’s a new rule: Ask the same question 50 different times. Ask 50 different people until you get an answer that sticks.

No one expects anything more of you. In fact the majority of nurses will tell the parent that they are going to forget almost everything they are told. No one wants you to try to be or do anything other than the parent you are right now.

So here goes. Hang tight.

ABOUT US



DEB'S TAKE:



Deb with Becky

Photo Credit: Robyn Kuniansky

My life changed irrevocably on a late summer day in September. “Gregg, I need to get to a bathroom right now.”

My husband looked at me in a puzzled fashion, wondering if I had lost my mind.

“You could have told me that ten minutes ago,” he noted hinting to the fact that we had just left a family outing an hour outside of town. But he did what all good dads-to-be do for their pregnant wives—he complied. What I did not want to tell him was that I had felt my bladder let go in the passenger side seat. Embarrassed, I

was hoping to get into the bathroom and clean up without a lot of ribbing from the other people in the car.

All alone in a Food Lion bathroom an hour away from home, I discovered that this was not at all an accident. My water had broken at 30 weeks’ gestation. I sobbed, apologized out loud to my unborn daughter and did the best I could to clean up. More fluid, more tears.

Desperate cell phone calls to a couple of people in the car did not work and went straight to voice mail. I made a plan to clean up quickly and get to the car.

On my way out of the store I stopped at the front office and clearly stated that I believed I was in preterm labor and asked where the nearest hospital was. Their jaws dropped open and they stammered out responses that they weren’t from this area, so I asked to borrow the phone and promptly called my doctor.

As I did this the nice store people ran out to the car and grabbed my husband. Both he and my brother in-law rushed in as I was leaving a message with the answering service. I was in no mood to wait around for a call back. We got in the car and Gregg drove like a maniac