



# Helping Hands

Biannual newsletter for families affected by a NICU stay, prematurity or loss



[www.handtohold.org](http://www.handtohold.org)

Fall 2010

## MISSION

To provide comprehensive resources and support programs to parents of premies, babies born with special health care needs and those who have experienced a loss due to these or other complications.

## VISION

To enable a network of families to offer support, comfort and understanding to one another, and to provide them with knowledge, information and resources to reduce the impact of prematurity and ensure the best outcome for their children and family by:

- > Empowering parents to advocate for their children
- > Encouraging individual, couple and family counseling when needed
- > Providing resources and information for managing insurance and financial issues
- > Educating parents about the challenges their babies might face and preparing them to meet those needs
- > Sharing support and resources necessary to help all children thrive and enjoy a full and satisfying life



**HAND to HOLD**  
*Fragile Babies. Strong Support.*

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DISCLAIMER: Hand to Hold is a parent support non-profit organization and does not intend to take the place of the relationship between patient and personal physician.

## Founder's Welcome

The first time I saw my son was in a Polaroid picture, the lighting bad, and the image fuzzy—my mother had taped the photograph to the handrail of my hospital bed. Born 16 weeks preterm, weighing a pound and a half, nothing could have prepared me for such a sight. Jackson spent four long and difficult months in the Neonatal Intensive Care Unit (NICU). His first years were filled with doctors appointments, surgeries, respiratory challenges and lots of therapy. Ten years later, he is now a healthy, outgoing, smart and funny young man.

During the NICU stay and his first years at home, I was blessed by the support of our family and friends, as well as the prayers of people from across the world—many of whom I had never met. But, I truly never felt so isolated and alone. I longed for a hand to hold to provide me emotional support and reassurance, but also to guide me as I navigated our new journey. I needed the wisdom of someone who had walked in my shoes. So was born my vision for Hand to Hold.

One recent study found that as many as 76 percent of mothers who had a child in the NICU<sup>1</sup> reported signs of psychological trauma, such as depression, anxiety and/or post-traumatic stress disorder. Given these harsh statistics, help cannot come soon enough. **Hand to Hold trains and matches seasoned parents of premies (Helping Hands) with new families in need of support as well as provides support groups for those who have had a loss.** Hand to Hold has also created a website that is growing to become a clearinghouse of information and education for all issues related to prematurity, including an online resource directory of doctors, therapists, specialists and counselors. As we grow, more programs and assistance will be forthcoming.

**If you are a parent of a premie or a baby born with a special health care need, you are not alone.** Hand to Hold is here to provide the support and information you may need to navigate the journey ahead. It is my hope that Hand to Hold will be a blessing to you and to your family. Welcome to Hand to Hold.

Kelli Kelley

Source: Jotzo M, Poets CF. "Helping parents cope with the trauma of preterm birth: An evaluation of a trauma-preventive psychological intervention." *Pediatrics*. 2005; 115: 915-919.



## Help When You Need It

A non-profit organization based in Austin, Tex., *Hand to Hold* provides comprehensive resources and support programs to parents of preemies, babies born with special health care needs and those who have experienced a loss due to these or other complications. *Hand to Hold* matches parents with peers who are uniquely familiar with life in the NICU, loss and caring for their child and family under these circumstances. Many parents find that they especially need someone to talk to after they take a child home from the NICU. All support services are provided at no charge.

- > **Helping Hand (Peer-to-Peer) Match.** Call (512) 550-3181, email [support@handtohold.org](mailto:support@handtohold.org) or visit [www.handtohold.org](http://www.handtohold.org) to request a "Helping Hand" peer mentor who can provide emotional support, as much or as little as you wish. There is no time limit to request help. We are here when you need us.
- > **Bereavement Support.** Request a match with another parent who has had a similar experience and receive referral to a local counseling practice specializing in grief counseling and support groups.
- > **Quarterly Discussion Series.** Learn from an expert how to better care and advocate for your child and yourself and meet other parents, too. Watch past sessions online.
- > **Online Resource Guide.** Tap into local knowledge, recommendations and resources to help you navigate health care providers, therapies, insurance and other sources of assistance.
- > **Stay in touch.** Connect with others through upcoming gatherings and events, social media connections, news and articles on the website, and print and e-newsletters. Go online to subscribe to this newsletter and stay connected.

During the last six months since my son's birth, I have tried to be very strong and have not allowed myself to cry. My son needs so much of my time and my strength that I simply had forgotten about myself. The moment you asked me: How are you feeling? It was as if someone had squeezed my eyes! I could not stop crying! I realized that I also need help. In order to help my son, I need to accept help. Thank you for your kind words and your sincere interest in me. I felt very comfortable sharing my feelings with you. God bless you and Hand to Hold.

*{ Maribel F., parent receiving support from Hand to Hold }*

## Helping Hand Highlight { by Joan Kincaid, mom to preemie Will }

Will was born at barely 25 weeks. He was battered and bruised by the traumatic birth; he was just under 2 pounds; he was unable to breathe on his own and the doctors were not hopeful. Signing a DNR and baptizing your baby in the NICU within 24 hours of delivery is beyond horrifying. For everyone involved. But days of survival grew into weeks, and small hopeful signs joined the constant barrage of setbacks. The NICU is your only reality as you become an expert in one little baby's every physical, medical measurement of health. And you sing. Everyday. You sing to that baby.

Will is now 3 ½ years old and smart and capable and sweet and perfect. We only see the pediatrician once a year for regular "well checks." (Who knew that was a category of medical service?!) And now, with time and the wisdom that comes from this journey that includes brutal pain, grueling care-giving, love, hope, inspiration, joy and gratitude, I want to give back. It is simply the gift of listening and knowing and sharing, but only someone with this experience can give it. So I am grateful that there is Hand to Hold. Grateful, both for myself now, and also, for moms going through this right now who need someone to talk to.



Leave a comment for Joan at [www.handtohold.org](http://www.handtohold.org).



## Breathing in Well-Being and Renewal

{ by Rhonda McMahon, mom to Dylan and preemie Bryan }

Having a baby in the NICU takes so much from us physically, emotionally, mentally and spiritually. Making those daily visits to the hospital not knowing what awaits when you walk through the NICU doors each time. All while juggling work and home responsibilities, not to mention pumping milk around the clock for those moms who are able to do so. It can be an exhausting journey and one where we often feel helpless or out of control.

You might find yourself asking, “What can I do to restore my sense of well-being and keep up with all that is expected of me?” One of the best and most effective ways you can help your baby is to take care of yourself. Think about what a flight attendant instructs parents to do in the event of a midair emergency when traveling with children. “Remember to put an oxygen mask on yourself first before placing one on your child.” It’s the ultimate metaphor for all parents on the importance of practicing self-care.

And speaking of oxygen, one of the easiest forms of self-care is to notice and become more aware of your breathing. Most of us go about our day taking shallow breaths through our mouth, rarely expanding our lungs to full capacity. Those who practice yoga know the restorative qualities of breath work. One easy way is to breathe in deeply through your nose with your mouth closed filling your lungs completely while feeling your diaphragm and belly expand, hold your breath for a few seconds and then exhale through your nose. Repeat this for a few minutes several times each day and you can’t help but feel more relaxed and centered.

In the next issue I will cover the four areas of self-care—physical, emotional, spiritual and mental. Until then, be gentle with yourself, notice your breathing and find more ways to “put the oxygen mask on yourself first.” You and your baby will be glad you did.

Rhonda McMahon is the mother of two sons—Bryan, 9, who was born with Down Syndrome at 31 weeks and spent two months in the NICU. She went into preterm labor with Dylan, 6, at 28 weeks, spent four days in the hospital to stop contractions followed by two months of complete bedrest at home; and, Dylan was born full-term. Rhonda facilitates Personal Renewal Groups (PRG) for mothers of children with special needs based on Renee Trudeau’s award-winning book, *The Mother’s Guide to Self-Renewal: How to Reclaim, Rejuvenate and Re-Balance Your Life*.



### TIPS FOR SELF CARE

- > Practice taking deep belly breaths.
- > Take a walk for a physical and emotional break.
- > Focus on affirmations to calm your mind.
- > Try yoga.
- > Talk to someone, especially a peer who has had a similar experience. (Hand to Hold can help you find one!)

## Emotional Fallout Expected for Parents with a Baby in the NICU

OB/GYN, Author and Mom of Premie Triplets Dr. Gunter Shares Ways to Cope

{ by Kelli Kelley, mom to preemies Jackson and Lauren }

A study from the Stanford University School of Medicine showed over half the parents whose babies were in the NICU for an extended period of time either had post-traumatic stress disorder, or were at high risk for developing it.<sup>1</sup> Symptoms can include feeling detached from others and emotionally numb, angry and irritable, guilt, shame, depressed, hopeless and hyper-vigilant—feeling as if on constant “red alert.”

Many parents feel cheated out of a healthy or “normal” birth experience. Parents must relinquish the care of their newborn to medical professionals and often feel a lack of control over their baby’s medical situation and an uncertain future. Emotional, physical and psychological fallout from a NICU visit is not uncommon.<sup>2</sup>

“I could see my old life, one of constancy and control, slip away into the darkness and a new existence, more painful and uncertain, emerging,” said Dr. Jennifer Gunter, OB/GYN, mother of premie triplets and author of *The Premie Primer* when speaking about the birth of her triplets born premature.

Dr. Gunter, a Hand to Hold Board Member, shared an intimate look at her journey with prematurity at the first Hand to Hold Quarterly Discussion Series in June. (*Full video available online at [www.handtohold.org](http://www.handtohold.org)*). Dr. Gunter admits that even thirteen years in the field of medicine left her feeling unprepared for the life-altering experience of preterm birth, the loss of a baby and the care and raising of two medically-fragile boys.

“The journey of having a premature baby isn’t something you should go through alone. The emotional and physical roller coaster calls for a firm support group, such as Hand to Hold, to get you through and keep you positive,” says Gunter.

*The Premie Primer* is a must read for all parents of preemies as it offers a complete guide from preterm birth through the toddler years and beyond. Combining just the right mix of medical information, illustrations, research and statistics, as well as an intimate glance into the personal journey of Dr. Gunter and her family, it can serve to help other parents navigate the emotional, medical and financial minefield of the NICU and beyond the hospital doors.

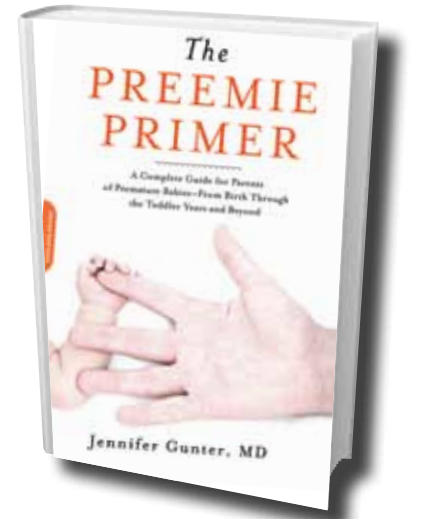
To read excerpts from *The Premie Primer* visit: [www.premieprimer.com](http://www.premieprimer.com)



Kelli Kelley is the founder and executive director of Hand to Hold. She is the mother of two preemies, Jackson and Lauren.

<sup>1</sup>Shaw RJ, Bernard RS, Deblois T, Ikuta LM, Ginzburg K, Koopman C. “The relationship between acute stress disorder and posttraumatic stress disorder in the neonatal intensive care unit.” *Psychosomatics*. 2009 Mar–Apr; 50 (2): 131–7.

<sup>2</sup>Miles MS, Carter MC, Riddle I, et al. “The pediatric intensive care unit environment as a source of stress for parents.” *American Journal of Maternal/Child Nursing*. 1989; 18:199–206.



## Seeing Another Specialist? Reduce Your Paperwork!

{ by Marty Barnes, mom to preemie Casey }

Over the years we have learned that most doctor's offices, hospitals, therapist offices and specialist care facilities ask the same questions. We have filled out countless forms while sitting in waiting rooms. Some of these forms do not even allow space for a complete answer. Many years ago we created a document that has all of our daughter Casey's pertinent information. We print it out and take it with us when we go to a new doctor, the emergency room or anywhere we expect to have more paperwork. The staff LOVES this! It is readable, organized and complete. We usually put our child's name on their form then write "See Attached" in the answer section. It has saved us so much time. Not to mention, I don't have to worry about forgetting a medication.



Visit [www.handtohold.org](http://www.handtohold.org) or [www.caseybarnes.org](http://www.caseybarnes.org) to download a template!

Marty Barnes is the mother to Casey who was born just a few days before 37 weeks and was diagnosed with HIE (Hypoxic Ischemic Encephalopathy). Follow her remarkable journey at [www.caseybarnes.org](http://www.caseybarnes.org).



## Navigating Claims, Explanation of Benefits and Insurance Companies

{ by Kathryn Whitaker, mom to Will, John Paul, Anna-Laura, Clare and preemie Luke }

- 1 **Create a notebook.** A big one! Some suggested dividers include: Bills - Paid, Bills - Unpaid, Insurance Information (EOBs), Medical Information (discharge summaries, doctor instructions) and Government / ECI. The visual learner in me used that system to keep the mountain of paperwork straight. Having that data at your fingertips makes conversations with medical providers and others go much more efficiently.
- 2 **Keep a log.** Every time you talk to a doctor's office, government office or insurance company, write it down. Jot down the name of the person you spoke to, the date and time and the outcome or requested action. This comes in incredibly handy the *next* time you call and they have difficulty remembering or pulling up the topic you discussed. They need to know you are keeping them accountable and it helps *you* keep things straight!
- 3 **Ask for a supervisor or manager.** If you have a complex problem, never talk to the first person that answers the phone. Instead, ask for a supervisor right off the bat. This will save you hours sitting on hold.
- 4 **Request an e-statement.** Ask for an e-statement (every insurance company has a related version), which outlines every claim, what was paid, what amount was applied to your deductible and to your in-network out-of-pocket expenses for every provider. It's best to ask for this information after the new year for the previous calendar year, but you might also consider asking for a report in July for the previous six months, as a double check.
- 5 **Negotiate.** Providers are notorious for saying things like, "We only have a three-, six- or nine-month payment plan" and then making you choose. Here's the deal. You don't have to pay on their schedule, you pay on yours. Don't let them convince you there's a service charge associated with paying on your schedule either. After you set the payment plan, you can always call back a few days later and see what discounts are offered if you settle the bill in full, sometimes up to 40 percent!



Read more tips at [www.handtohold.org](http://www.handtohold.org)

Kathryn Whitaker is the mother of five, ages 9 to 1. Her youngest, Luke, born at 3lbs. 9oz., developed a severe surgical case of necrotizing enterocolitis and has various medical needs as a direct, and indirect, result.



## Human Milk Saves Babies, Reduces Complications

{ by Neven Simpson, staff writer }

Studies show that the health benefits of human breast milk have the potential to save the lives of babies born preterm. Human milk provides optimal nutrition, boosts immunity and reduces the incidence of medical complications so newborns can come home from the hospital more quickly. Unfortunately, many mothers of preterm babies are unable to produce milk. To meet this growing need, the Mothers' Milk Bank of Austin, which opened in 1999, has increased access to breast milk for preterm and sick babies.



"Research... provides strong evidence that **human milk feeding decreases the incidence and/or severity of a wide range of infectious diseases**— including bacterial meningitis, bacteremia, diarrhea, respiratory tract infection, necrotizing enterocolitis, otitis media, urinary tract infection, and late-onset sepsis..."

Source: Gartner, L.M., et al. "Breastfeeding and the use of human milk." *Pediatrics*. 2005 February, 115(2):496–506.

"When a mother's own milk is not available, pasteurized donor human milk is a life saving therapy for premature infants in our neonatal intensive care unit," says Sonny Rivera, Jr., MD, Neonatologist with Pediatrix Medical Group/St. David's Medical Center and co-founder of the Mothers' Milk Bank of Austin.

The Mothers' Milk Bank of Austin is one of only twelve milk banks in the U.S. and serves 44 NICU's in six states. They also dispense milk to outpatients with a physician's prescription. Their mission is to accept, pasteurize and dispense donor human milk by physician prescription to premature and ill infants. They have set up a safe distribution system that ensures that these babies get the nutrients they need during the first few crucial weeks of life in order to help prevent future medical complications.



For more information on the Mothers' Milk Bank of Austin, visit their website: [www.milkbank.org](http://www.milkbank.org).

Read more of this article at [www.handtohold.org](http://www.handtohold.org)

## Breastmilk Storage Guidelines

	EXPRESSED BREAST MILK	THAWED BREAST MILK
ROOM TEMPERATURE	4-6 hours at 66-78° F	do not store
COOLER WITH 3 ICE PACKS	24 hours at 59° F	do not store
REFRIGERATOR	3-8 days at 32-39° F	use within 24 hours
FREEZER	6-12 months at 0-4° F	Never refreeze thawed milk

Source: [www.breastmilkguidelines.com](http://www.breastmilkguidelines.com)

Note: Always consult with your health care provider before following guidelines.

I've never felt so hopeful and lost at the same time. To know that she is being taken care of, but not be able to see her all the time. To want to breast feed her, but know she isn't coordinated or strong enough. The regular ways a mother cares for a baby and the ways the baby feels her love weren't possible. But, there was one thing I could do. I could provide breast milk for my baby. This would make her stronger and healthier and I could show my love by feeding her, even if there was a pump, a refrigerator, nurses and a feeding tube in-between us.

{ Carol R., mother of two preemies }

## Your Experience is Valuable! Become a Helping Hand


If you are a parent of a preemie or experienced a loss and you feel ready to give back, we encourage you to become a *Helping Hand*. You may support another parent by email, phone, text or in person and the time commitment is left to your discretion. If you're interested in learning more, contact us to sign up for a one-time training session. Trainings are held monthly on a Saturday. Visit [www.handtohold.org](http://www.handtohold.org) or call us to sign up.

## Spread Hope! Expand Our Reach With Your Support

As a nonprofit organization, Hand to Hold plans to use all Founder's Circle gifts to pay for family support and resources to parents who have had a child in the NICU or who have experienced loss. Gifts can be made in memory of a baby who has passed away, in celebration of a child who is thriving or in honor of a special medical professional who worked tirelessly to care for your precious baby.

Hand to Hold invites families to consider joining *The Founder's Circle* with a gift of \$1,000 or more. Best of all, you can raise the money from friends and family who would like to contribute in your family's honor. The visionaries belonging to this elite group will receive special benefits including lifetime acknowledgement of their founding gift.

As a nonprofit organization, Hand to Hold plans to use any funding received to pay for family support navigators who manage the Helping Hand peer match program, growing the resource database, creation of more support groups and the expansion of assistance available. All services are provided at no charge.

 To make a donation or find out about the many ways to contribute, visit [www.handtohold.org/get-involved/donate](http://www.handtohold.org/get-involved/donate) or contact Director of Resource Development, Babs Haller, at [babs@handtohold.org](mailto:babs@handtohold.org).



When my son, Parker, was born at 26 weeks of gestation, there was a lot to deal with very quickly. He was in very critical condition and I was having to juggle my health, work and insurance. Most of my friends and relatives were sympathetic, but so freaked out by the situation that they weren't much help. The NICU nurses were my lifeline at first, but they were obviously focused on the medical issues and were no longer there when my son was discharged. You need someone to talk to that gets it, and is not so busy having her own emotional reaction to your child's early birth that she is unable to support you. I am proud to be a Helping Hand to another mom.

*{ Parker's Mom, Helping Hand peer mentor through Hand to Hold }*



## Hand to Hold

c/o Austin Community Foundation  
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**HAND to HOLD**  
*Fragile Babies. Strong Support.*



Austin  
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*Hand to Hold is a fund of the  
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[www.handtohold.org](http://www.handtohold.org)



# Learn More About Hand to Hold!



Watch and share the Hand to Hold video:  
[www.tinyurl.com/h2hvideo](http://www.tinyurl.com/h2hvideo)

### Hand to Hold Quarterly Discussion Series:

Learn how to better advocate and care for your child and meet other families at this informal evening gathering featuring experts on a variety of topics of interest to parents like you. Visit [www.handtohold.org](http://www.handtohold.org) to see previous speakers and to learn of the next date.

### Read online and connect with other parents who have had similar experiences to yours

Visit Hand to Hold online at [www.handtohold.org](http://www.handtohold.org) to learn about:

- > What parents are saying
- > Family blogs
- > Family stories (consider contributing your own story!)



*Anywhere you see this icon throughout the newsletter,  
we invite you to log onto the Internet and learn more!*

## upcoming Calendar

November

Prematurity Awareness Month

November 1

Premie Power Photo & Essay Contest

November 14

Hand to Hold "Premie Power"  
Family Celebration

November 16

Prematurity Awareness Day

November 20

Helping Hand Volunteer Training

January 8

Helping Hand Volunteer Training

