



# preemiefamily

## support. educate. advocate.

## PARENTS & PREEMIE NUTRITION

*one issue at a time with PreemieWorld*

**We Need YOU.** One of the first priorities for me in the new year was to address the inequality of preemie nutrition in NICUs. Too many times preemie parents are not given decision-making power of what the NICU provides their child in terms of nutrition.

**A Personal Story.** Read my story in the petition at <http://preemie.us/NECPetition>. This petition comes from personal experience of having my voice not heard. I have heard you all tell me the same. This needs to change . . . now. *All I ask is one minute to speak your mind and share it.*

**2018: Giving preemies the tools to thrive, not just survive.**

- Deb Discenza, Publisher & CEO



## IN THIS ISSUE:

### Parents & Preemie Nutrition

Join the NEC Petition that gives parents the rights to be informed and to have input on how their preemie is fed in the NICU.

### Preemie Genius: Lily's Hope

A book written by Preemie Mom Jennifer Driscoll and her Preemie daughter, Lilian Hope, to help other families in the NICU.

### Book Excerpt: Interviewing a Pediatrician

After the NICU can be just as complicated as in the NICU. Read more from this excerpt of Deb Discenza and Nicole Conn's book, *The Preemie Parent's Survival Guide to the NICU*.

## YOUR PREEMIE FREEBIE: PREEMIE VALENTINES

PreemieWorld provides a number of free handouts to be used in the NICU and beyond on the "Freebies For You" page of our website. This month's freebie is a set of Preemie Valentines.

Print them out as a gift to that special person in your life. Or consider posting this on your social media and tag that dear family member, friend or pro.

To download this freebie, visit <https://preemieworld.com>



**Valentine's Day is a great time to celebrate with preemie style! Giving a special person a valentine either in person or by social media posting is a great way to recognize their important role in your preemie's life.**

~ Deb Discenza, PreemieWorld



[www.OnceUponaPreemie.com](http://www.OnceUponaPreemie.com)

## TO DO LIST:

**New Section.** Check out our new section, *Giving From Your Heart*, on p. 4.

**Freebies.** Get free downloads from PreemieWorld at <http://bit.ly/PreemieFreebies> Have an idea for a freebie? Contact us and let us know.

### Support for Infant Loss

February 1, 2018; McLean, Virginia, USA  
<http://www.preemiestoday.com>

### Rare Disease Day

February 28, 2018; Worldwide  
<http://www.rarediseaseday.org>

## CONNECT WITH US:

Have an event you want to share with our community? Visit <https://preemieworld.com> or drop us a line at [connect@preemieworld.com](mailto:connect@preemieworld.com)!



@ [www.facebook.com/PreemieWorld](https://www.facebook.com/PreemieWorld)



@ [PreemieWorld](https://twitter.com/PreemieWorld)



@ [PreemieWorld](https://www.linkedin.com/company/preemie-world)



@ [www.instagram.com/preemieworld](https://www.instagram.com/preemieworld)

# PREEMIE TERMS IN THE NICU



## Bilirubin/Bili Lights:

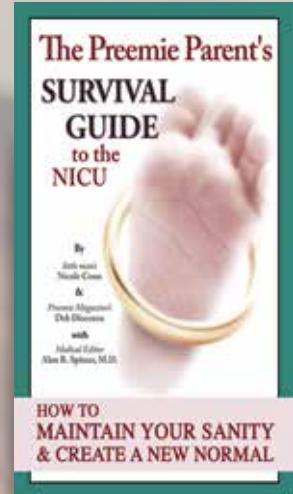
Bilirubin is the breakdown product made by the body from old red blood cells that are being removed from the circulation. Bilirubin is processed through the liver but many premature infants' livers are too underdeveloped to process the by-product known as bilirubin from the blood. This leftover bilirubin accumulates and travels throughout the body and turns the skin yellow (a condition known as jaundice). **Bili lights** are **photo-therapy** light sources which help to resolve this issue. Note the old Model-T goggles Becky wears to keep her eyes protected from the lights.

## Jaundice:

A yellow discoloring of the skin due to immature livers having too much of a substance called bilirubin in the blood. This is a common diagnosis in preemies. To combat this, your baby will undergo **photo-therapy**.

## Photo-therapy:

The "lights" under which your baby goes to relieve **jaundice**.



*This excerpt is from The Preemie Parent's Guide to Survival in the NICU, PreemieWorld's widely circulated support book, on sale at <https://premieworld.com>. Get yours today!*

# SUPPORT: INSPIRE PREEMIE COMMUNITY

The Inspire Preemie Community was started by **Deb Discenza** with under 5 members back in 2005 and has had unprecedented growth since then, closing in at almost 42,000 members worldwide as of this newsletter going to publication.

## Origin

Visit <https://preemie.inspire.com> to join for FREE



**Established:** 2005

**Website:** <https://preemie.inspire.com>

**Focus:** Preemie Parents, Adults, Angel Families, & Preemie Pregnancies

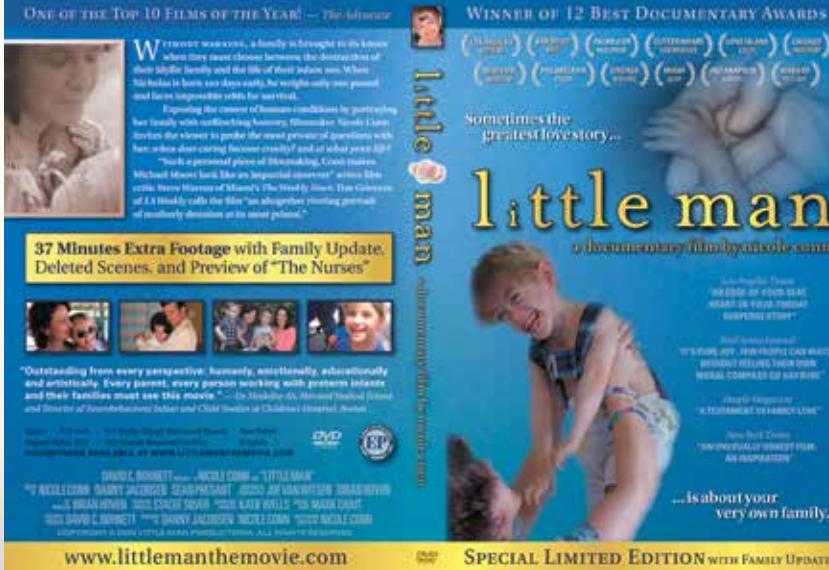
**Outreach:** International

**Members:** ~42,000

## All Preemies, All Together

*Inspire has other communities for pediatrics, like NEC Society Connects at <https://necsociety.inspire.com>*

"As the community grew," Discenza notes, "I felt the need to expand the general audience to one with specialty "rooms" for our very diverse population. In addition to having discussion sections or rooms devoted to parents with babies in the NICU or PICU, we also focused on after the NICU in a variety of age groups even up to adulthood. And we included sections for Preemie Dads, Preemie Angel parents, and families going through a Preemie Pregnancy. It is a tight-knit community."



*"little man" is every preemie parent's story*



[www.littlemanthemovie.com](http://www.littlemanthemovie.com)

# BOOK: LILY'S HOPE

Children's books in the preemie community are rare and special. The latest book, *Lily's Hope: A Preemie's Journey of Hope*, by Jennifer M. Driscoll and her preemie daughter, Lillian Hope Driscoll takes the reader on a journey through Lily's own story of her birth and stay in the NICU and then later on as her brother is born early as well.

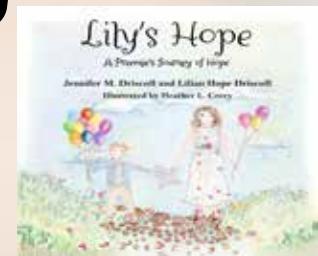
With child-friendly illustrations this book provides families in the NICU with a wonderful story to read daily in the NICU and also later on at home. It will not only help their child in terms of hearing a parent's (or grandparent's!) voice but also in terms of relaxing and sleeping.

**Cool Facts:** All proceeds from Lily's Hope will be donated to Lily's Hope Foundation, a 501(c)(3) non-profit organization. You can order this book on Amazon or through the organization's website (the latter will get you a copy autographed by Lily herself) at [www.LillysHopeFoundation.org](http://www.LillysHopeFoundation.org)

**“ I surprised my parents and was born two months early. Because I was born prematurely, I was sick and spent a long time in the hospital. My parents' hope gave me strength to get well. ”**

~ Lillian Hope Driscoll in *Lily's Hope*

*One lucky winner will receive a copy of this book! We'll select one NEW Instagram follower prior to 2/22/18. Enter to win by following us on Instagram at [www.instagram.com/preemieworld](http://www.instagram.com/preemieworld).*

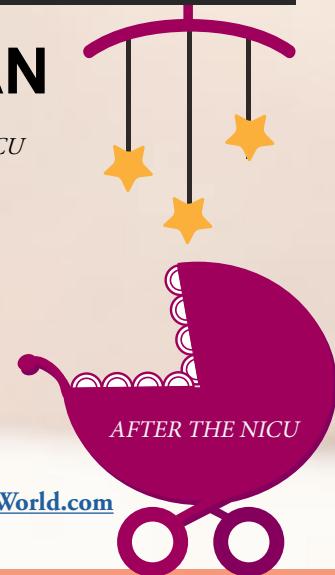
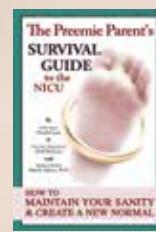


Congrats to Zeppelin Eli, the winner of January's giveaway, a Lulla Doll by Roro (<https://LullaDoll.com>)

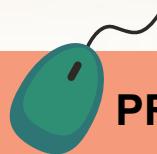
## INTERVIEWING A PEDIATRICIAN

The following are some sample questions to ask a prospective pediatrician as listed in *The Preemie Parent's Survival Guide to the NICU* by Deb Discenza and Nicole Conn.

- What kind of experience do you have with babies graduating from the NICU?
- Does your practice feature separate sick and well visit waiting rooms?
- Can fragile infants be shown directly into an exam room upon arrival and wait there?
- What well-check schedule does your practice follow for preemies upon discharge? Is it the same as non-preemies?



Find these questions and more in *The Preemie Parent's Survival Guide to the NICU*, available at [www.PreemieWorld.com](http://www.PreemieWorld.com)



## PREEMIE FAMILY ONLINE

### Inspire Preemie Community:

Parents, Grandparents, Adults  
& High-Risk Pregnancies

Help your families connect with almost 42,000 parents of preemies worldwide! This close-knit forum is moderated by our own Deb Discenza.

The community connects families in the NICU, at home, into the school years, adult preemies and women with high-risk pregnancies.

<http://preemie.inspire.com>

PreemieWorld on Twitter

<http://bit.ly/PreemieTweets>

PreemieWorld on Facebook

<http://preemie.us/PreemieFB>

PreemieWorld on LinkedIn

<http://bit.ly/PWLlinkedIN>



# swaddle4swaddle

PreemieWorld is honored to bring you programs or special events that will serve to help others in the form of education, in terms of help where needed and more. Help spread the word using this hashtag: #givefromyourheart

Our friends at **swaddle4swaddle** ([www.swaddle4swaddle.org](http://www.swaddle4swaddle.org)) have a mission to help families in the NICU and pediatric cancer centers across the United States. swaddle4swaddle started as a simple swaddle blanket donation program with the intent to bring smiles and comfort to NICU babies and their families. The founder of swaddle4swaddle, **Rachel Quarnberg**, has a nephew who was born with several complications and spent many months in a NICU. She started swaddle4swaddle as a way to give back, at least in a small way, by helping families in similar situations celebrate the miracle of their child's life. *To date the organization has donated over 8,000 swaddles. Are you a non-profit that would like to help distribute the swaddles? swaddle4swaddle would love to partner with you. Contact them at [partners@swaddle4swaddle.org](mailto:partners@swaddle4swaddle.org)*

Does your organization have a special event focused on helping preemies? Tell us about it at [connect@preemieworld.com](mailto:connect@preemieworld.com)

## FEATURED PREEMIE PRIDE:

*My son Timothy (TJ) was born at 33 weeks 6 days and spent a month in the NICU. He is 9 months (7 months adjusted) and just graduated from physical therapy (he was in for hip dysplasia). He is meeting many of his milestones on time. Our son is a fighter.* - Anonymous

We welcome your submissions for this section of Preemie Pride, Preemie Angel, and Preemie Prayer at [PreemieWorld.com](http://PreemieWorld.com)



Prolonged, effective,  
safe, and hands-free  
Kangaroo Care  
sessions.  
Guaranteed.



[www.nurturedbydesign.com](http://www.nurturedbydesign.com)

NICU *Hope* Beads

facebook.com/NICUHopeBeads | 979.635.0825

COMMEMORATE & SHARE  
Your NICU  
journey through  
jewelry...

Preemie Tags  
Honor the Journey

NAME: BABY DOE  
DOB: 01/01/2006  
WT: 500 GRAMS  
GEST. WEEK: 25.5



Give From Your Heart



## SNEAK PEEK

In next month's issue....

### New Item: Giving From the Heart

There is another special program where you can make a difference in the preemie community.

### Preemie Genius

We are reviewing a new book focused on a very special preemie. Don't miss it!

### And More!

Have you subscribed to Preemie Family yet? It's free!  
<http://bit.ly/preemie1>

## JOIN THE CONVERSATION

Always remember, you know what is best for your child!

~ Deb Discenza, PreemieWorld

,



@ [PreemieWorld](#)  
@ [Preemie Parent's Survival Guide to the NICU](#)



@ [PreemieWorld](#)



@ [PreemieWorld](#)  
@ [NICU Professionals](#)  
@ [Early Intervention Professionals](#)  
@ [Preemie Support Group Leaders](#)  
@ [Preemie Parents](#)



@ [PreemieWorld](#)