



premiepro
support. educate. advocate.

PARENTS & PREEMIE NUTRITION

one issue at a time with PremieWorld

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:

Look for worldwide events

<https://premieworld.com/events/>

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.

Preemie Organization: National Child Trust

See what this U.K. organization is doing to help support families in the early years.



www.OnceUponaPreemie.com

TO DO LIST:

- ✓ **New Section.** Check out our new section, *Giving From Your Heart*, on p. 4. Have an organization event? Contact us!
- ✓ **Freebies.** Get free downloads from PremieWorld at <http://bit.ly/PremieFreebies> and pass them onto Premie Parents in their welcome packets.
- ✓ **6th Pediatric & Neonatal Int'l Conf UHS 2018** February 8-9, 2018; Dubai, United Arab Emirates <https://uhspnc.com/>
- ✓ **The 31st Annual Gravens Conference** February 28-March 3, 2018; Clearwater Beach, FL US <http://preemie.us/Gravens18>

CONNECT WITH US:

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

f @ www.facebook.com/PremieWorld

t @ [PremieWorld](https://twitter.com/PremieWorld)

in @ [PremieWorld](https://www.linkedin.com/company/premieworld)

ig @ www.instagram.com/premieworld

YOUR PREEMIE FREEBIE: PREEMIE VALENTINES

PremieWorld 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 **Premie 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://premieworld.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, PremieWorld





SUPPORT: INSPIRE PREMIE COMMUNITY

The **Inspire Premie 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 as of this newsletter going to publication.

Established: 2005
Website: <https://premie.inspire.com>
Focus: Premie Parents, Adults, Angel Families, & Premie Pregnancies
Outreach: International
Members: ~42,000



Origin

Deb began the Inspire Premie Community as an extension of *Premie Magazine*, a publication she founded in 2004. A few years later the magazine folded due to the deep recession hitting the United States at the time though she kept the free community going through Inspire.com

All Premies, All Together

“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 Premie Dads, Premie Angel parents, and families going through a Premie Pregnancy. It is a tight-knit community.”

NOTE: Inspire has many other communities for pediatrics, including NEC Society Connects at <https://necsociety.inspire>.

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

ORG: NCT

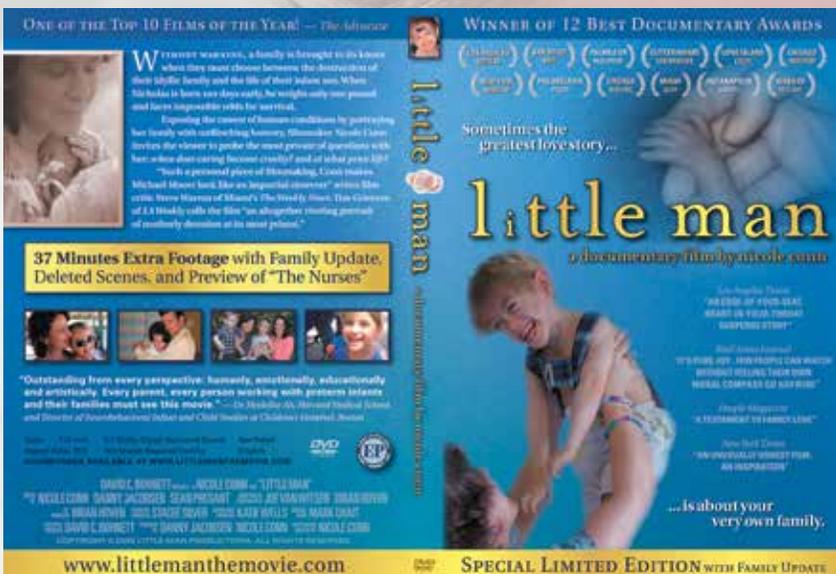
The **National Child Trust (NCT)** was founded on 4th May 1956 by **Prunella Briance** who wanted to fundamentally change how women were treated during childbirth after a ‘horribly mismanaged’ birth. Prunella put an advert in The Times newspaper calling for women to join an association based on the belief that they should be supported and empowered during pregnancy and birth.



Year Established: 1956
Website: <https://nct.org.uk/>
Outreach: National (United Kingdom)

Visit <https://nct.org.uk/> for more info

NCT is the UK’s largest charity for parents. Each year it supports millions of parents through their First 1,000 Days, offering evidence-based information and trusted practical and emotional support through its website, helpline, a nationwide network of over 300 local branches, antenatal and postnatal classes, breastfeeding counselling and peer support schemes.



“little man” is every preemie parent’s story



www.littlemanthemovie.com

BOOK: LILY'S HOPE



Children's books in the premie community are rare and special. The latest book, *Lily's Hope: A Premie's Journey of Hope*, by Jennifer M. Driscoll and her premie 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.

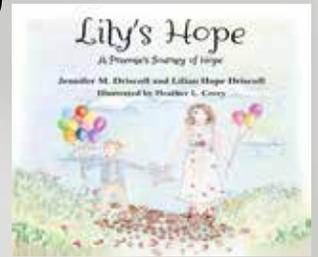
With child-friendly illustrations this book provides families in the NICU with a wonderful story to read daily in the NICU and also later on at home. It will not only help their child in terms of hearing a parent's (or grandparent's!) voice but also in terms of relaxing and sleeping.

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

“ 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/premieworld.

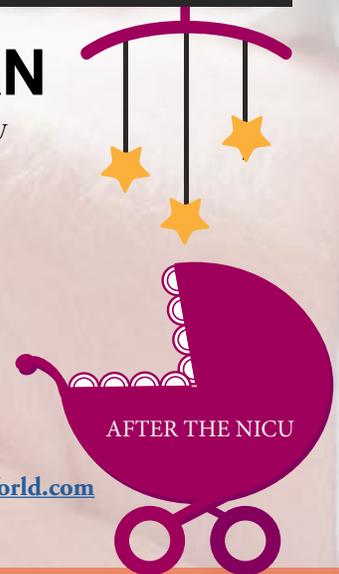


Congrats to [Zeppelin Eli](https://LullaDoll.com), the winner of January's giveaway, a Lulla Doll by Roro (<https://LullaDoll.com>)

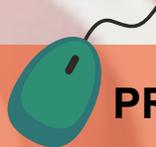
INTERVIEWING A PEDIATRICIAN

The following are some sample questions to ask a prospective pediatrician as listed in *The Premie Parent's Survival Guide to the NICU* by Deb Disenza 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 premies upon discharge? Is it the same as non-premies?



*Find these questions and more in *The Premie Parent's Survival Guide to the NICU*, available at www.PremieWorld.com*



PREMIE FAMILY ONLINE

Inspire Premie Community:

*Parents, Grandparents, Adults
& High-Risk Pregnancies*

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

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

<http://premie.inspire.com>

PremieWorld on Twitter

<http://bit.ly/PremieTweets>

PremieWorld on Facebook

<http://premie.us/PremieFB>

PremieWorld on Instagram

<http://premie.us/PremieInstagram>



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) 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*

Does your organization have a special event focused on helping preemies? Contact Us: connect@premieworld.com

Give From Your Heart



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



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



www.nurturedbydesign.com

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 item for the preemie community. 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 that parents knew their child first and they know their child best!
~ Deb Discenza, PreemieWorld ”



[@PreemieWorld](https://www.facebook.com/PreemieWorld)
[@Preemie Parent's Survival Guide to the NICU](https://www.facebook.com/PreemieParentSurvivalGuide)



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



[@PreemieWorld](https://www.linkedin.com/company/PreemieWorld)
[@NICU Professionals](https://www.linkedin.com/company/NICUProfessionals)
[@Early Intervention Professionals](https://www.linkedin.com/company/EarlyInterventionProfessionals)
[@Preemie Support Group Leaders](https://www.linkedin.com/company/PreemieSupportGroupLeaders)
[@Preemie Parents](https://www.linkedin.com/company/PreemieParents)



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

NICU Hope Beads

COMMEMORATE & SHARE

Your NICU journey through jewelry...

facebook.com/NICUHopeBeads | 979.635.0825

Preemie Tags

Honor the Journey

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