



# premiefamily

support. educate. advocate.



## RSV, A Lifetime of Challenges

*Not just a cold . . . not just a few days . . . but a lifetime*

Respiratory Syncytial Virus (RSV) is deadly, period. It targets the most vulnerable of patients, that being the young and the old that struggle with a lowered immune system. With this in mind, **October is RSV Awareness Month.**

Even though my daughter is now 14 years old, I still dread this time of year because the families I support continue to feel kicked in the gut when it comes to the lack of protection available to their child in the NICU and at home. This illness can wreak havoc beyond requiring intensive care, beyond needing a ventilator to breathe. If the child survives and goes home, their life is dramatically different due to ongoing respiratory issues which can result in numerous hospitalizations each year. Sadly, the only drug available to pro-actively mitigate the symptoms of RSV when contracted by a premature infant is severely restricted to the very tiniest of patients. Reach out to the **National Coalition for Infant Health** and learn more: [www.infanthealth.org](http://www.infanthealth.org)

- Deb Discenza, CEO & Publisher, PremieWorld

## IN THIS ISSUE:

### ***Premie Shower***

We have the ultimate gift for a NICU specifically from PremieWorld - so get the world out to NICUs everywhere to sign up!

### ***Premie Genius: Tubesies***

We highlight the latest Premie Genius product that is making a difference with preemies everywhere.

### ***Premie Organization: World CP Day***

Preemies are at high-risk for Cerebral Palsy (CP) and there is an awareness day devoted to all CP folks.

*Look for worldwide events*

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



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

## TO DO LIST:

- Check out our latest **Premie Shower** for one NICU on Page 4. Enter your NICU today and find out last month's winner.
- Check out the latest and greatest **Freebies4You** from PremieWorld at <http://bit.ly/PremieFreebies> - feel free to share them with others.
- World CP Day (Cerebral Palsy)**  
October 6, 2017, Worldwide  
<http://worldcpday.org>
- RSV Awareness Month**  
October 1-31, 2017, United States  
<http://www.infanthealth.org>

## 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](mailto:connect@premieworld.com)!



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## YOUR PREEMIE FREEBIE: RSV & THE GAP BABY

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 an RSV Awareness video called *The Gap Baby: An RSV Story*.

This video highlights a large group of preemies that are at high-risk for RSV though the protection in place is not within their reach. This is a must-see for everyone.

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



This video highlights a serious 'gap' in care of our most vulnerable patient population, babies. This should not be about money but about decency and common sense. #RSVawareness

~ Deb Discenza, PremieWorld





# TERM: EARLY INTERVENTION

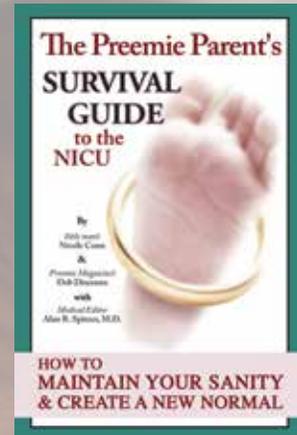
## Early Intervention:

A family-centered program, its therapists teach families how to help “exercise” their babies in order to stimulate them in terms of vision, speech, feeding, gross motor skills (walking and running), and fine motor skills (holding a crayon, self-care). While scheduling these sessions can be an overwhelming challenge, this much-needed therapy can make the difference in your baby’s quality of life. If your baby needs some help in stimulating brain development to reach those milestones, EI is a great program.

## Questions to Ask the Professional

- How is my baby doing in various skill areas for his/her gestational age vs. his/her adjusted age?
- Does my baby show any type of sensory processing issues at this time?
- What types of traditional therapy would help my child progress?
- What types of non-therapy programs (kid’s gym, swim classes) would help my child?

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



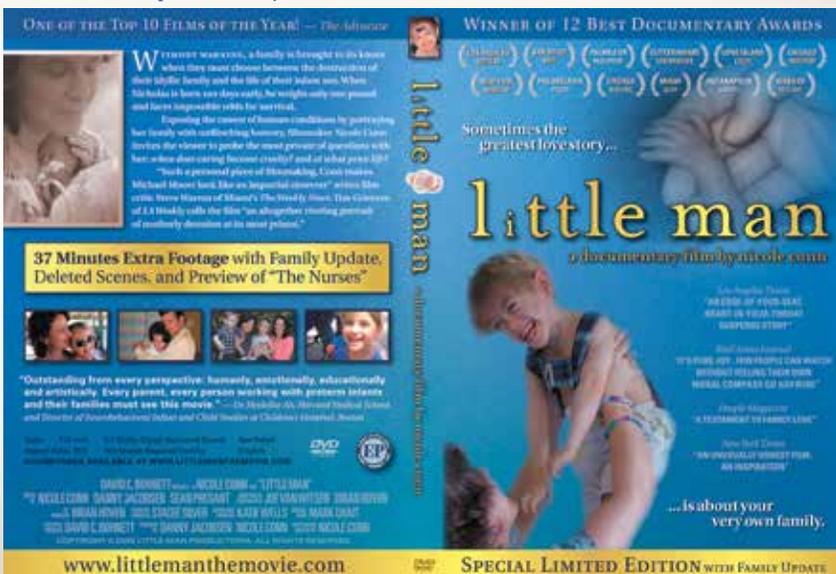
# SUPPORT: SPOONS

After her baby was born at 24 weeks gestation in 2014, **Kirsten Mitchell** encountered a difficult time following the discharge of her son from neonatal care. From that she created **Spoons** to help provide peer support in the form of emotional support and practical advice. With other parents from the unit joining her, the Spoons became a registered charity in 2016.



**Website:** [www.spoons.org.uk](http://www.spoons.org.uk)  
**Focus:** Supporting families experiencing neonatal care milestones with special gifts and keepsakes  
**Reach:** Regional, Greater Manchester, England, UK

- **Support:** They support all families that have experienced neonatal care, including parents who have experienced a bereavement.
- **Fundraiser Goals:** Fundraisers are used to improve services and facilities for families experiencing neonatal care.
- **Patient Experience:** Spoons aims to raise awareness of neonatal care and work closely with healthcare professionals to improve patient experiences.
- **Family Integrated Care Model:** Spoons has a special interest in the Family Integrated Care model and is working with neonatal units to include this.
- **Social Media:** In addition to the website, check out Spoons on social media at Facebook (<https://www.facebook.com/spoonscharity/>) as well as on Twitter (<https://twitter.com/SpoonsCharity>)



“little man” is every premie parent’s story



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

# PREEMIE GENIUS: TUBESIES



A preemie with a g-tube for feedings should never have to sacrifice fashion, form, or function. *Ever.* Enter **Tubesies** ([www.tubesies.com](http://www.tubesies.com)), a friend to every g-tube baby out there in the form of bodysuits that provide fun and g-tube-friendly access without issue.

Created by Cecilia Auth, RN, a peds nurse, Tubesies bodysuits will have parents and grandparents jumping for glee. On the function side, each bodysuit has a water resistant inner liner, a pocket to hold clean gauze, and provides easy access to the port. Add in designs that creatively “hide” the port door and your baby is ready to roll, crawl and more the Premie Red Carpet. And be prepared to be the talk of doctors, nurses, therapists and yes, parents everywhere.



**As a Peds RN, my passion to inspire parents with their babies in a nurturing way is my goal in creating Tubesies.™**



~ Cecilia Auth, RN & Tubesies Founder

*One lucky winner will receive TWO Tubesies bodysuits! We'll select one NEW Instagram follower prior to 10/22/17. Enter to win by following us on Instagram at [www.instagram.com/premieworld](http://www.instagram.com/premieworld).*

*Congrats to Jacqueline Uzdriene, winner of September's giveaway, I was a Premie Just Like You by Ali Dunn!*

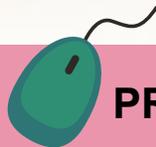


## COLD, FLU & RSV SEASON

Cold and Flu Season is on its way. Have you prepped yet? Now is the time because some of this takes planning and preparation on your part. Here's a quick checklist of items that we strongly suggest.

- ✓ **RSV.** The PremieWorld website has a number of [free PDFs](#) of information to help you plan and protect your preemie this season.
- ✓ **Flu Shot Prep Now.** Call the pediatrician or family doc to inquire about flu shot clinics for preemie, parents and grandparents.
- ✓ **Advise People Now About Protecting Your Preemie.** The sooner you email/text/call people, the better. Trust us on this.
- ✓ **Hand Sanitizer is Your Friend.** But remember that soap should be your first defense when available.

*Like our Freebies? Check out more at <https://premieworld.com> and feel free to share them with others.*



## PREEMIE FAMILY ONLINE

*Inspire Premie Community- Parents, Grandparents, Adults and High-Risk Moms to Be*

Help your families connect with almost **40,000** 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>

*PremieWorld on Twitter*

<http://bit.ly/PremieTweets>

*PremieWorld on Facebook*

<http://preemie.us/PremieFB>

*PremieWorld on LinkedIn*

<http://bit.ly/PWLinkedIN>

# PREEMIE SHOWER: LITTLE MAN PRO

PreemieWorld continues its monthly Premie Shower! Do you know a deserving NICU in need? Enter to win a Premie Shower for the NICU of your choice. Each month, PreemieWorld picks one NICU to receive donated items such as blankets, toys, and supplies to help brighten the days of preemie parents and the professionals who treat their children.

This month we are giving back to NICU professionals directly in the form of a **large venue license of our little man DVD, perfect for training the team, new recruits and more.** To enter, a professional from a NICU must sign up as a new subscriber on our Preemie Family for Pros™ list by **10/22/17.**

Enter to win at <http://bit.ly/PremieFam4Pros> Or tell us what you'd like us to include in a future shower at [#preemieshower](https://twitter.com/preemieshower)



**YAY!** We congratulate September's shower winner **Jill Evans, RN.** She will get a set of **Tubesies bodysuits** ([www.Tubesies.com](http://www.Tubesies.com)).



## FEATURED PREEMIE ANGEL:

**Sophia Ann West:**

We miss you and love you every second of our lives, baby girl.



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



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**Premie Tags**

Honor the Journey




## SNEAK PEEK

*In next month's issue.....*

### New Premie Shower

We are gearing up for a new Premie Shower for one lucky NICU. Will it be yours?

### Premie Genius

We are reviewing something real cool next edition. Don't miss it!

### And More!

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

## JOIN THE CONVERSATION

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

~ Deb Discenza, PremieWorld

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@ *Premie Parent Support Group*  
@ *Leaders*  
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