



premiepro
support. educate. advocate.

SUSAN HEPWORTH

Director, NCFIH



Credit: Jason Dixson Photography

Current Org: National Coalition for Infant Health

Website: www.infanthealth.org

Years Helping Premies:
3 years

Focus:
Advocating for premies and their families to have access to the best care possible.

Professional Tip:
Involve preemie parents - they are the most passionate advocates.

IN THIS ISSUE:

Interview with Susan Hepworth

As the Director of the National Premature Infant Health Coalition (NCFIH), she is making a huge impact for premies and their families nationwide.

Premie Genius: Tubesies

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

Premie Organization: World CP Day

Premies 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

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> and pass them onto Premie Parents in their welcome packets.
- ✓ **World Cerebral Palsy Day**
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!

@ www.facebook.com/PremieWorld

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

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

@ www.instagram.com/premieworld

YOUR PREMIE 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 premies 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



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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
Focus: Supporting families experiencing neonatal care milestones with special gifts and keepsakes
Outreach: 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>)

ORG: WORLD CEREBRAL PALSY DAY

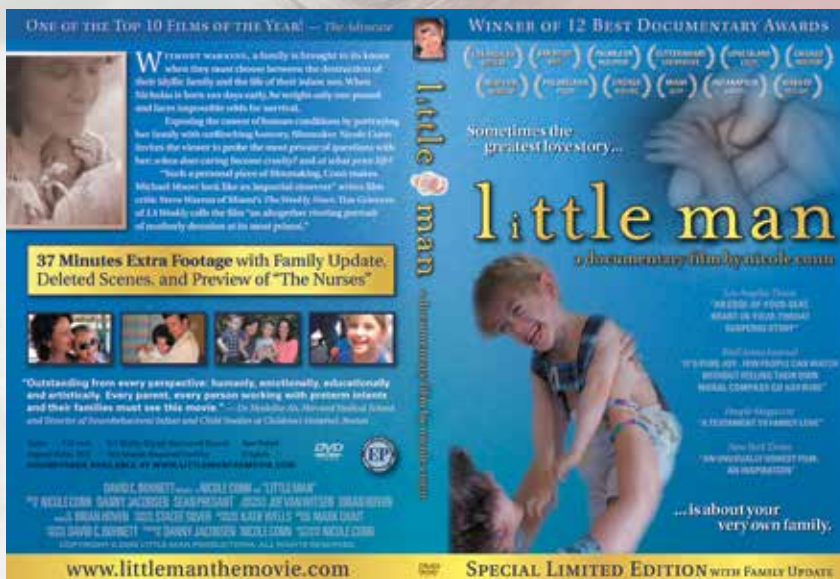
World Cerebral Palsy (CP) Day is held on **October 6** each year in more than 60 countries. It is an opportunity to celebrate the lives and achievements of children and adults with cerebral palsy, and is the focus of a global social movement to create a better world for people living with CP and their families. World CP Day was created and is auspiced by the World CP Initiative - a group of major non-profit cerebral palsy services.



Make sure to visit <https://worldcpday.org/> to add your child's story to the World CP Day Map or download the free Tools to celebrate the day. And you can find the organization's Facebook page for stories and updates at this link: <https://www.facebook.com/worldCPday>.

Year Established: 2012
Website: <https://WorldCPDay.org>
Outreach: Globally

Visit <https://worldcpday.org> for more info.



“little man” is every preemie parent’s story



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), 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

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.

Congrats to [Jacqueline Uzdriene](#), winner of September's giveaway, I was a Premie Just Like You by Ali Dunn!

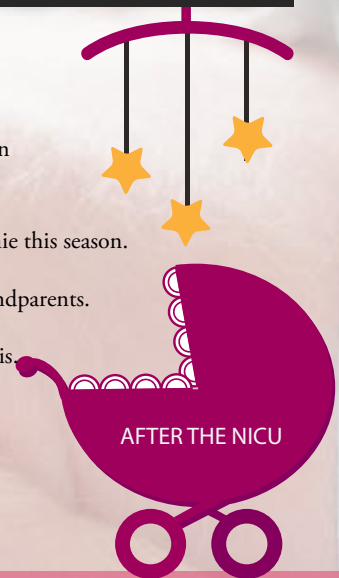


COLD, FLU & RSV SEASON

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 Instagram

<http://preemie.us/PremieInstagram>

PREEMIE SHOWER: LITTLE MAN

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, PremieWorld picks one NICU to receive donated items such as blankets, toys, and diapers 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 "Premie 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).



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



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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 **PremiePro** yet? It's free!
<http://bit.ly/preemie2>

JOIN THE CONVERSATION

“ Always remember, you know what is best for your child! ”
~ Deb Discenza, PremieWorld

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@ *Early Intervention Professionals*
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Premie Tags
Honor the Journey