



premiepro
support. educate. advocate.



OLDER PREMIES MATTER

one issue at a time with PremieWorld

Most Premies Are Lucky Enough to Grow Up. Parents dream of this time while at bedside in the NICU, professionals ponder those outcomes. But in reality, it is not just families walking out of the NICU with their child at discharge that drops a premie off the radar. It is society as a whole. There is this myth that everything is *just fine* once the baby goes home. NICU admission is an emergency state, where the art and science of medicine can provide amazing results. The babies that live, they go home and everyone is happy, right? But these babies that grow up, what do we *really know* about their outcomes? We know very little as it turns out. Data sample sizes (i.e. number of premies enrolled in research studies) are small in numbers and even smaller once that baby goes home. Just because that baby went home does not mean everything is “just fine.” Ask any premie Mom. Ask any premie Dad. Ask the premie as a child, a teen, an adult. They defied the odds early on but they still need support.

This month PremieWorld will #celebratepreemies - the young and young at heart.

- Deb (former 36-week premie, Mom to a 30-weeker) #celebratepreemies

IN THIS ISSUE:

Look for worldwide events

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

Older Premies Matter

Deb Discenza talks about the importance of remembering that the older premies post-NICU, in school and in adulthood matter.

The Dad Pad Neonatal

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

Premie Support: Pipsqueak's

A group that is making a difference in the field of prematurity and neonatology.

PREMIE FREEBIE: WORLD PREMATURETY AWARENESS LISTING

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 listing of **World Prematurity Day Awareness Activities** worldwide.

Our annual listing continues to grow and incorporate more and more events happening worldwide.

Get this at Premie Freebies at <https://premieworld.com>

“ Each year, renew your pledge to do more to advocate for premie families working through their journey. The more we do, the more we dramatically change numerous lives and affect taxpayer costs. ”

~ Deb Discenza, PremieWorld



www.OnceUponaPremie.com

TO DO LIST:

New - PremieWorld Tags. Tag you are it, check out page 4 for a section all about **YOU**.

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

EAPS 2018

October 30 - November 3, 2018 | Paris, France
<https://eaps.kenes.com/2018#.W4mlMZNKhyq>

26th Int'l Conf on Neonatology & Perinatology

November 15-17, 2018 | Edinburgh, Scotland
<https://neonatology.insightconferences.com/>

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

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@ www.instagram.com/premieworld

SUPPORT: PIPSQUEAK'S

Founded in 2018, **Pipsqueak's** is a non-profit organization based out of Yorkshire, United Kingdom. Ian Twitchett and his wife were the proud parents of **30 week twins, Pippa and Penelope**.

Pippa and Penelope were in the NICU for a little under two months before going home. Sadly, Pippa grew very ill eight days post-discharge. She was rushed to the hospital and eventually placed into the neonatal unit on a ventilator and being treated for two viruses and which left her liver unable to cope. Weeks later, having gone through an emotional and physical roller coaster, her parents held her as she passed away in hospice care. **Pipsqueak's** is named in Pippa's memory.

The organization provides regional support to units in Yorkshire, fundraising to buy new equipment for the NICUs and providing supports for the families. The organization also has an ongoing effort to celebrate Pippa's life called #pipparocks where participants paint a rock to remember Pippa or another baby and place it in a special place. #pipparocks has taken on an international interest.

Year Established: 2018
Website: www.pipsqueakscharity.com
Outreach: Yorkshire, UK
Founders: The Twitchett Family



ORG: RYAN HOUSE

Anyone looking for a special place for a child up to the age of 18 with a life-limiting diagnosis should be aware of **Ryan House**. Launched in Arizona in 2004 by **Jonathan and Holly Cottor** in honor of their son Ryan born with Spinal Muscular Atrophy, the organization embraces families and provides them with a safe place, a safe space for palliative care and respite care that "addresses the emotional, spiritual, and social needs of the family, continuity of care from diagnosis to end-of-life, expert care provided by our prestigious care partners and highly-trained staff and a loving community that offers ongoing support and compassion. Ryan House is the only facility of its kind in the state and only one of three in the country."



With facilities set in cheerful and peaceful surroundings, families can leave behind everyday life and focus on the immediate needs of their child. It is truly a gift.

For more information visit www.RyanHouse.org

Year Established: 2004
Website: www.ryanhouse.org
Location: Phoenix, Arizona, United States
Outreach: National

"little man" is every preemie parent's story



www.littlemanthemovie.com

BOOK: THE DAD PAD NEONATAL

Dad Pad Neonatal developed by **Professor Minesh Khashu** and **Inventor Julian Bose** have created the ultimate book for families with a baby in the United Kingdom's National Health Service (NHS). With a strong look and feel that is focused on fathers, it mimics an iPad but in book form.

With solid pages that are easy to clean off and be written upon, the Dad Pad Neonatal is full of great information that will guide a father through those tough days, hours, and minutes in the Neonatal Unit (NNU) right up until discharge day. The overviews go into great detail about the equipment, the team members and then bonding with baby, helping the baby developmentally as well as taking care of oneself and one's partner. A very impressive item useful for anyone in the NNU, but especially fathers.

“ One of your first questions, on hearing that your baby has been admitted to the Neonatal Unit, is likely to be “What does that mean?”

~ The Dad Pad Neonatal



One winner will receive a FREE copy of this book.

We'll select one NEW Instagram follower prior to 11/22/18. Enter to win by following us on Instagram at www.instagram.com/PreemieWorld

Congrats to [Emma's Footprints](#) the winner of October's giveaway, a copy of [Amie Land's Our Only Time](#) (<https://www.amielandsauthor.com/>)

QUESTIONS ON PREEMIE OUTCOMES

This is the reality of prematurity. A lot of the focus of research is on the NICU time period in treatments and the effectiveness of those treatments. The outcomes studies for after the NICU on through adulthood lessen considerably when it comes to sample sizes. Questions parents and preemies themselves should be asking as life moves forward:

- What outcomes data currently exists regarding a preemie at this current age?
- Is there anything I should be on the watch for at this time and going forward?
- Do you have written into my record to keep an eye on these potential concerns?
- If you are not the right professional to handle these follow-ups, who is the right professional to seek out for further follow-ups?



PREEMIE FAMILY ONLINE

Inspire Preemie Community:

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

Help your families connect almost 46,000 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 Instagram

<http://preemie.us/PreemieInstagram>

PW TAGS: PREEMIE DIESEL

Our latest preemie highlight: Dashing #dcsuperhero, Diesel Cruze (@russthe dad husband):

Loving Diesel Cruze (aka DC) so much can't wait to get him home at some point he's such a fighter nearly completely tube free and only 31 days old and thinks he wasn't a 29weeker but full-term

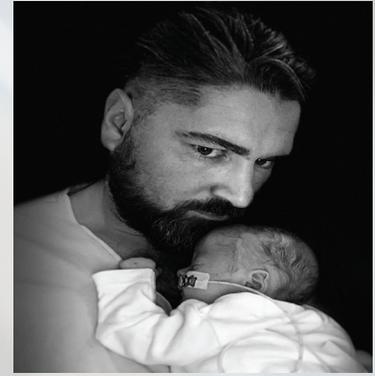
#family #premiestrong #nicu #nicubaby #nicudad #nicufamily #fightingspirit #beastmode #dcsuperhero #daddysontime #daddysonggoals #insta #instagood #instagram #picoftheday #babypictures

We Could Highlight Your Preemie in Our Newsletters & Online!

Deadline: Like, tag & include @PremieWorld in your update post by the 15th of the month.

Who: Premies in the NICU, Preemie Angels, Post-NICU, Children, Teens, Adults.

Networks: Twitter (@PremieWorld), Facebook (PremieWorld, The Preemie Parent's Survival Guide to the NICU, NICU Nurses' Day, Preemie Study), Instagram (@PremieWorld).



FEATURED PREEMIE PRAYER:

Leah-Lee:

I pray for Leah-Lee to have a healthy life and that every negative thing said over her life to be broken in Jesus name . Amen.

- Anonymous



We welcome your submissions for this section of Preemie Pride, Preemie Angel, and Preemie Prayer at PremieWorld.com

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SNEAK PEEK

In next month's issue....

New Section: Preemie World Tags

Tag us and we're it! But it is really all about you, Social Media Follower! We share the love right back to you.

Preemie Genius

We are reviewing a new item of interest to parents of premies and pros. 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, PremieWorld

f @PremieWorld
@Premie Parent's Survival Guide to the NICU

🐦 @PremieWorld

in @PremieWorld
@NICU Professionals
@Early Intervention Professionals
@Premie Support Group Leaders
@Premie Parents

📷 @PremieWorld

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

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