



premiepro  
support. educate. advocate.



## REMEMBERING PREEMIE ANGELS

recreating the PremieWorld

Many people think that once the funeral is over for a preemie, the family will find closure within time and move on. That just isn't the case. Just as any child, teen or adult is remembered and spoken about, so too the parents want to talk about their infant. The baby breathed, lived. The baby existed, even if for a very short time. They want their baby's name said aloud, to be written even weeks, months and years after the death.

With October being Infant and Pregnancy Loss Awareness Month, take a moment and reach out to an angel parent and ask how they are doing and ask them to tell you about their baby - by name. Our Premie Angel Parent survey results are here so you can learn more:

<https://preemie.us/AngelSurveyReport>

*We have a new survey this month: Prematurity Awareness - Deb #celebratepreemies*  
Prematurity Awareness: <https://preemie.us/PremieAwareness>

## IN THIS ISSUE:

*Look for worldwide events*

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

### Remembering Premie Angels

Deb Disenza talks about the importance of reaching out to Angel Parents.

### Premie Genius: Tiny: Adventures of a Micro-Premie

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

### Premie Support: The Grey Effect

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



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

## TO DO LIST:

- ✓ **PremieWorld Tags.** Tag you are it, check out page 4 for a section all about [our Instagram followers](#).
- ✓ **Freebies.** Get free downloads from PremieWorld at <http://bit.ly/PremieFreebies> Have an idea for a freebie? Contact us and let us know.
- ✓ **30th European Pediatrics Conference**  
October 7-8, 2019 | Dublin, Ireland  
<https://europe.pediatricsconferences.org/>
- ✓ **World Congress on Neonatology & Peds Medicine**  
October 21-22, 2019 | Hong Kong, China  
<https://pediatricians-medicine.conferenceseries.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](mailto:connect@premieworld.com)!

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

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

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

## PREEMIE FREEBIE: "PREEMIE ANGELS" REPORT

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 summary report of our "Premie Angels" Survey from September. You can get it by going to the link below (and watch social media for parent quotes throughout the month):**

*"Premie Angels" Survey Results:*  
<https://preemie.us/AngelSurveyReport>

“ Grief and child loss never goes away. We don't move on without our child, we move forward with them and their memory. We are who we are because we had them and they died. It changes you forever. ”

~ Sarah Glass, Mother of Premie

# SUPPORT: THE GREY EFFECT FOUNDATION



The Grey Effect Foundation was founded after the Sebastien family experienced the death of their beautiful son, Greyson from SIDS (Sudden Infant Death Syndrome).

To keep Greyson's memory alive and to help other families from enduring this unimaginable pain, the intentions of the Grey Effect Foundation is to raise SIDS awareness and to raise enough money to purchase Owlet Baby Care Monitors for new moms & dads before they leave the hospital.

The Owlet Company has agreed to match donations by giving two free monitors for every one that The Grey Effect Foundation purchases.



Year Established: 2017  
Website: [www.thegreyeffectfoundation.com](http://www.thegreyeffectfoundation.com)  
Outreach: Louisiana  
Founder: Katie Sebastien

## ORG: LEAH'S POLAR HUGS

Leah's Polar Hugs was inspired by the birth of our daughter Leah, and seeing how much difference having the right medical equipment and staff in place can make in the outcome of an HIE birth. Through our experience in the NICU and afterwards, we recognized a lack of in-the-moment information and support for what families like ours were going through. There are many programs to help premature babies in the NICU, but none for HIE babies, and we wanted to change that.

Leah's Polar Hugs is dedicated to:

- a) helping hospitals purchase the life-saving cooling equipment used to treat an HIE newborn
- b) providing care packages to families in the NICU dealing with an HIE birth.



For more information visit <https://www.leahspolarhugs.org/>

ONE OF THE TOP 10 FILMS OF THE YEAR! — *The Advocate*

WINNER OF 12 BEST DOCUMENTARY AWARDS

Without warning, a family is brought to its knees when they must choose between the destruction of their idyllic family and the life of their infant son. When Nicholas is born 100 days early, he weighs only one pound and faces impossible odds for survival.

Exposing the rawest of human conditions by portraying her family with unflinching honesty, filmmaker Nicole Conn invites the viewer to probe the most private of questions with her: *when does caring become cruelty?* and *at what price life?*

"Such a personal piece of filmmaking, Conn makes Michael Moore look like an impartial observer" writes film critic Steve Warren of Miami's *The Weekly News*. Tim Glerason of *LA Weekly* calls the film "an altogether riveting portrait of motherly devotion at its most primal."

37 Minutes Extra Footage with Family Update, Deleted Scenes, and Preview of "The Nurses"

Outstanding from every perspective: humanly, emotionally, educationally and artistically. Every parent, every person working with preterm infants and their families must see this movie. — *Dr. HeidiLise Ab, Harvard Medical School and Director of Neurobehavioral Infant and Child Studies at Children's Hospital, Boston*

Color 112 min. 5.1 Dolby Digital Surround Sound Not Rated  
Aspect Ratio 16:9 Widescreen Regional Coding English  
SOUNDTRACK AVAILABLE AT [WWW.LITTLEMANMOVIE.COM](http://WWW.LITTLEMANMOVIE.COM)

DAVID C. BOHNETT DIRECTOR OF PHOTOGRAPHY NICOLE CONN EXECUTIVE PRODUCER "LITTLE MAN"  
NICOLE CONN DANNY JACOBSEN SEAN PRESANTY PRODUCED BY JOEL VAN WITSEN BRIAN HOVEN  
EDITED BY BRIAN HOVEN EXECUTIVE PRODUCERS STRAUSZ SIEBER PRODUCED BY KATIE WELLS PRODUCED BY MARK CHATT  
DIRECTED BY DAVID C. BOHNETT PRODUCED BY DANNY JACOBSEN NICOLE CONN EXECUTIVE PRODUCED BY NICOLE CONN  
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SPECIAL LIMITED EDITION WITH FAMILY UPDATE

"little man" is every preemie parent's story



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

# TINY: ADVENTURES OF A MICRO-PREEMIE

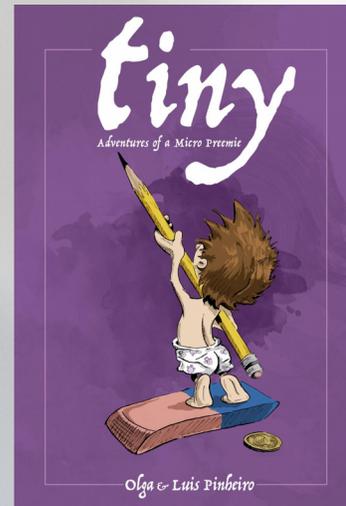


Luis & Olga Pinheiro share their tender story of Nilah, their sweet preemie daughter, born 3 1/2 months early and “smaller than a can of soda.”

Their book, “Tiny: Adventures of a Micro-Preemie” is an easy to read poem filled with boundless love and hope amidst the fear and chaos of the NICU journey. This book is uniquely told through the eyes of micro-preemie, Nilah and will tug on your heart-strings. The colorful, narrative illustrations add life and tenderness to the story. This is a delightful read for parents who have experienced the preemie journey.

A portion of the proceeds from the sale of this book are donated to Children’s Hospitals and NICU’s around the world.

**ONE LUCKY Instagram winner that TAGS @PremieWorld in a post on Instagram will get a copy of this book. Ends 10/15/19.**



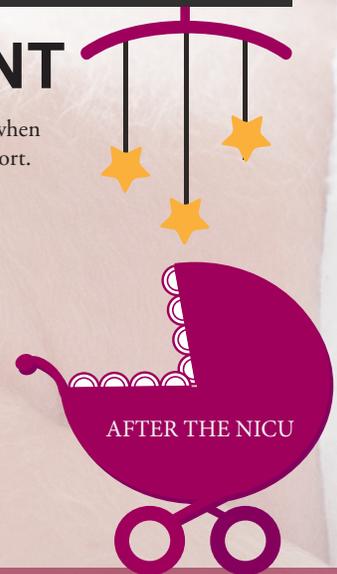
**For more information visit:** <https://www.amazon.com/Tiny-Adventures-Preemie-Olga-Pinheiro/dp/1511993286>

## SUPPORTING A GRIEVING PARENT

The death and loss of a child is frequently referred to as the ultimate tragedy. Nothing can be more devastating and unnatural when the death of a child of whom parents have put hopes and dreams into watching them grow and mature, is cut tragically too short. How can we help our loved ones as they grieve this unimaginable loss?

- ✓ **Forget preconceived notions about how long grief should last.** The time scale for grief is different for everyone. Grief is a life-long process that changes and evolves but never truly goes away. Never put a time limit on someone’s grief.
- ✓ **Talk about their baby. SAY THEIR NAME.** The greatest way to acknowledge life lost it to say their name. He or she was a real human being. Talk about milestones and find ways to celebrate baby’s life with parents.
- ✓ **Understand that there is no “Perfect” thing to say.** Words cannot diminish pain. It’s not about having the right words, but rather a listening ear. Listen and validate their feelings.
- ✓ **Don’t always ask how you can help.** Many grieving parents don’t always know what they need help with. Try dropping off a meal, sending supportive text messages, handwritten cards and sometimes the greatest help is just being accepting, patient and non-judgemental.

- Jenny McCormick, PremieWorld



## PREEMIE FAMILY ONLINE

### ***Inspire Premie Community:***

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

**Help your families connect with over 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.

<https://premie.inspire.com>

*PremieWorld on Twitter*

<http://bit.ly/PremieTweets>

*PremieWorld on Facebook*

<http://premie.us/PremieFB>

*PremieWorld on Instagram*

<http://premie.us/PremieInstagram>

# HIGHLIGHTING @HAPPILYEVERBELLS

Our latest preemie highlight: [@happilyeverbells](#)

Meet adorable Za'vae, born at 34 weeks, weighing 4 lbs, 11 oz and is now almost 7 months old.  
"Za'vae was in the hospital for feeding issues, but now that's all she wants to do!" - Dariyan

## We Could Highlight YOUR PREEMIE

Deadline: Like, tag and include [@PremieWorld](#) in your Instagram update post by the 15th of the month.



## FEATURED PREEMIE ANGEL:

Waylon James:

*We love you and miss you every day. We will tell your twin brother of your strength and spunk! I wish you could have lived this life on Earth with us, but we can't wait to be reunited!*

- Ashley Aseneth Garcia



We welcome your submissions for this section of Preemie Pride, Preemie Angel, and Preemie Prayer at [PremieWorld.com](#)



**Something SPECIAL is coming soon.....**

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

"The story of our brand is the story of our family. We invite you to be part of it" -Yamile C. Jackson, PhD, PE, PMP




A brand by Nurtured by Design

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



*Premie Tags*  
*Honor the Journey*




## SNEAK PEEK

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

### Premie 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.

### Premie Genius

We are reviewing a new item of interest to parents of preemies and pros. Don't miss it!

### And More!

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

## JOIN THE CONVERSATION

“When you help a family bond in the NICU, it lasts a lifetime.”  
~ Deb Discenza, PremieWorld

**f** [@PremieWorld](#)  
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**t** [@PremieWorld](#)

**in** [@PremieWorld](#)  
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