



Preemie Family



NICU LIFE

Silvana Quinn Smith (aka Silvie)



Photo Credit: Family Photo

Introducing "Silvie" of *Silvie's Bells* (www.SilvieBells.com), the new best friend of preemie and NICU families.

Birth Weight: 8 lb. 1 oz.

Days in the NICU: 49 Days

Proudest Moment: When Silvie drank from a bottle for the first time. After being intubated for so long, her natural nursing reflex was not there and she had to be taught how to nurse.

SEE MORE:

Visit www.premieworld.com late February to read a special update.

PARENT TIP:

Trust your gut and be your baby's advocate. Always speak up and remember that you know your baby better than anyone, even if they aren't at home.

ADVOCATE: Feeding Tube Awareness Week

Many preemies have a feeding tube during the NICU stay as they work toward eating orally. And many also go home on feeding tubes. **February 6-10, 2017 is Feeding Tube Awareness Week** brought to you by the **Feeding Tube Awareness Foundation**. Learn more and get great resources and inspiration at their website: <http://www.feedingtubeawarenessweek.org>

PREEMIE FREEBIE: I Love a Tubie Badge

PremieWorld provides a number of free handouts to be used in the NICU and beyond in its "[Freebies](#)" section of the website.

This month's freebie is a "**I love a Tubie**" badge. "In honor of **Feeding Tube Awareness Week**, we should celebrate families working through what are very common feeding challenges in our community," comments **Deb Discenza**,

Founder of PremieWorld. "It is important to recognize these very special families and support them."

DOWNLOAD IT: <https://preemie.us/Tubie>

MORE FREEBIES: <https://bit.ly/PremieFreebies>

TO DO LIST:

- ✓ **CONGRATS!: Mackenzie Garrett** (Premie Shower), **Patrick Moran** (*little man DVD*) & **The Oley Foundation** (Premie Genius).
- ✓ **LIKED US YET?:** PremieWorld is doing another PremieWorld Facebook page contest. See page 2 of this newsletter for details!
- ✓ **DOWNLOAD FREE TOOLS:** From PremieWorld at <http://bit.ly/PremieFreebies> to use and pass onto other Premie Parents.
- ✓ **MARK YOUR CALENDARS:**
February 11, 2017: P4P Polar Bear Plunge <http://www.pennies4preemies.com>
February 2, 2017: Support for Infant Loss <http://www.PremiesToday.com>
- ✓ **CONTACT US:**
 - Have an event you want to share with our community?
 - Have an organization or product we should know about?
 - Know of a family or pro to highlight?
 - Email us at connect@premieworld.com

TOOLS AND RESOURCES FOR THE PREEMIE COMMUNITY

TERM:

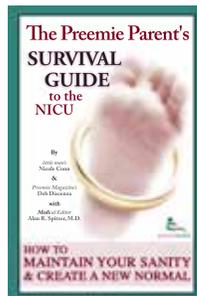
Gastrostomy Tube/Button (G-Tube)

G-Tube: Placed in the stomach when your baby cannot feed due to illness, being on the ventilator, etc. This is generally the best remedy for severe GERD or reflux. As their feedings increase, your baby will be pumped their allotment of food through a feeding bag that hangs from a medical (“tree”) stand. It is run through a pump which delivers the dose of food at the rate that your infant can digest. This often happens during your stay at the NICU and continues after bringing your baby home.

Questions to Ask the Doctor:

- Will someone train me on how to use the feeding tube?
- Can the tube come out as my baby is more active?
- Who do I contact in emergencies (when home)?

This excerpt is from
*The Premie Parent's Guide
to Survival in the NICU*
on sale at
www.premieworld.com



SUPPORT:

Silvie Bells



After her daughter **Silvie** was born with life-threatening complications and rushed to the NICU, her mother, **Jennifer Smith**, made a promise that if her daughter survived she would give back in some way. Silvie recovered and **Silvie Bells** was born.

Established: 2016

Outreach: Ft. Lauderdale, FL with national plans

Web: www.SilvieBells.com

Programs: Silvie stayed in the NICU for two months, throughout the holiday season. Silvie Bells is dedicated to giving families the items and the support that helped their own family through the holiday season.

Video: <http://premie.us/SilvieBells>

PREMIEWORLD: “LIKE US” ON FACEBOOK & YOU COULD WIN!

LIKE US HERE:



<http://bit.ly/FBPreemie>

“Like” our FB page from **1/31/17 to 2/22/17** and you could win a copy of the award-winning *little man* DVD documentary from PremieWorld!



READ AND SUBSCRIBE:

Premie parents and professionals are invited to subscribe to our **FREE** newsletters today @ www.PremieWorld.com

PREEMIE GENIUS:

Book: *On Coming Alive - A Journal Through Grief*



by Lexi Behrndt

www.OnComingAlive.com

For many preemie parents, a baby dying in utero, in the NICU and even post-NICU is a horrible reality. Life and parents change forever, marked by this incredible tragedy that does not “get better with time” as so many well-meaning family and friends think or expect. So in navigating life after a baby dies, how can you express yourself and be gentle with yourself?

This is where grieving mother Lexi Behrndt has created a poignant journal encourages parents to express their grief and explore it too. With “100 prompts to guide you from darkness to light” the journal is a beacon of hope for families worldwide. Make sure to check out the On Coming Alive website at www.OnComingAlive.com too.



WIN THIS ITEM!

Follow us on Twitter by 2/22/17 to enter: <http://bit.ly/PreemieTweets>



AFTER THE NICU:

Feeding Tubes & the Public

So like many preemie parents that bring a baby home on a feeding tube or end up on a feeding tube during the home years, you have likely endured stares and inappropriate comments. Some well-versed retorts:

- In response to general stares, “Oh, *I know*, isn’t he/she *adorable*????!! I get compliments like that *all* of the time! Thank you!”
- In response to people staring during feeding time at restaurants, “Wow, look at you (child’s name), you have a fan club!”
- In response to asking what is wrong with your child: “What’s wrong with your question?”

SHARE YOUR TIPS:

Have you had some tough moments in public? Tell us about it using the hash tag [#preemieworld](https://twitter.com/preemieworld)

PREEMIE FAMILY ONLINE

PREEMIE SUPPORT FORUM ON INSPIRE.COM

Connect with over 33,000 parents of preemies for FREE at <http://preemie.inspire.com> for the **Preemie Support Forum**. It is the largest and most active parent forum online, **moderated by our own Deb Discenza**.

In the NICU/PICU: Rollercoasters are Really Not My Kind of Thing

Preemies w/Feeding Issues: Swallowing, Eating & Hearing Problem

Preemie Hope: Hope for Those Who Need It

Open Discussion: The Guilt of A Preemie Mom

@PREEMIEWORLD @TWITTER.COM

Conference: For Parents & Pros - National Perinatal Association, March 9-11, 2017

PREEMIEWORLD AT FACEBOOK.COM

AMAZING: A California Non-Profit Helping Low Income NICU Families with Grants

PREEMIEWORLD’S GROUP ON LINKEDIN

CALLING ALL PREEMIE PARENTS: NEC Registry Started by the Morgan Leary Vaughan Fund & NORD

Conference: For Parents & Pros - National Perinatal Association, March 9-11, 2017

GET SOCIAL WITH US!



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PREMIEWORLD'S "PREEMIE SHOWER"

PremieWorld continues its monthly **Premie Shower!** Each month we will be picking *one* NICU to receive donated items.

Our friends at Kozie Clothes will be providing ONE NICU with: a dozen of their stylish and fun g-tube covers

We will select one NICU from our "Premie Family for Professionals" list **by 2/22/17** at www.bit.ly/PremieFam4Pros



NICUs: What do YOU want for a Premie Shower?
Tell us using the hash tag **#premieshower**

