



Preemie Professional



PREEMIE PROFESSIONAL

Traci Nagy

Founder & Executive Director, Feeding Tube Awareness Foundation



Photo: Feeding Tube Awareness Foundation

PROFESSIONAL TIP:

Having the support and experience of other parents who have been in the same position is invaluable.

Years Helping Preemies:
6

Focus:

The organization provides parents with the practical information they need to make informed decisions and navigate tube feeding their child.

Website:

www.feedingtubeawareness.org

Coming Up:

The organization has created the annual **Feeding Tube Awareness Week** which this year occurs on February 6-10, 2017. Learn more about this event at the website.

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://premie.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:** Free from PremieWorld at <http://bit.ly/PremieFreebies> and pass them onto Premie Parents in their welcome packets.
- ✓ **MARK YOUR CALENDARS:**
 - The ONE CONF: Neuro NICU Nurse Training**
February 7-9, 2017 Ontario, CA USA
<http://courses.synapsecare.com>
 - Neo Conference**
February 23-26, 2017 Orlando, FL USA
<http://www.neoconference.com>
- ✓ **CONTACT US:** Have an event to share? A pro or an organization, or product to highlight? Tell us at: connect@premieworld.com

TOOLS AND RESOURCES FOR THE PREEMIE COMMUNITY

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>

ORGANIZATION:

The Oley Foundation

In 1983, a clinician and consumer saw the need to help those living with home parenteral and/or enteral nutrition overcome challenges - such as their inability to eat, altered body image, and altered family life - and formed **The Oley Foundation**. Now, with over 17,000 members, the organization is a wealth of information and support. All programs are free of charge for consumers and caregivers.

Established: 1983

Reach: National

Website: www.oley.org



Programs:

- Bimonthly newsletter *LifelineLetter*.
- Information clearinghouse, including a toll-free number, an online education program and DVD/video library.
- Consumer networking (online chat forum plus 60+ volunteer consumers and caregivers around the world).
- Many webinars and conferences (see calendar on website).
- An equipment/supply exchange (supplies, equipment, formula donated to help those in need).

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 PROFESSIONAL ONLINE

NICU PROFESSIONALS GROUP (LINKEDIN)

A New Study Questions the Safety of this Practice

SMART: Brochure from Morgan Leary Vaughan Fund About NEC

NEC Symposium 2017 by the NEC Society - a Must-Go for All Parents & Pros

EARLY INTERVENTION PROFESSIONALS GROUP (LINKEDIN)

Here’s a Free Resource to Help Pediatric OT, PT & SLP Clinics Reach their Practice Growth Goals in 2017

A NEW App that Will Have Your Students Talking!

Empowering Carryover is One of the Cornerstones of Therapy

@PREEMIEWORLD @TWITTER.COM

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

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

BE THE SMART PRO FOR FAMILIES

Tell your families about the **Preemie Support Forum** on Inspire.com! Our own **Deb Discenza** moderates this **FREE global network of over 33,000 parents from NICU to school to adulthood**. **Visit us at <https://preemie.inspire.com>**

FIND OUT HOW TO JOIN THESE GROUPS

Refer to “Get Social with Us” on page 4 for more information. Share news and research with us at connect@preemieworld.com.

GET SOCIAL WITH US!



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- www.premieworld.com
- www.littlemanthemovie.com



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- [Premie Parent's Survival Guide to the NICU](#)



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PREMIEWORLD'S "PREMIE 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**

