



Preemie Professional

Preemie Professional

Mandy Daly

Dip. H Diet & Nutrition, Dip. Ki Massage, Diploma in Life & Disability Underwriting,
Associate of the Chartered Institute of Insurance

Dir. of Advocacy & Policy Making, Irish Neonatal Health Alliance



Photo Credit: Ger Dunne,
Fantastic Photography

Years in Field: 7

Preemie Focus: Empowering and educating families and fostering partnerships with stakeholders in the field of neonatology.

Check Out:

Irish Neonatal Health Alliance
<http://bit.ly/IrishNeonatalAll>



Professional Tip!

Listen to, learn from, and understand the feelings and embrace the family.

Advocate: World Autism Day

Preemies are at high-risk for a variety of developmental disabilities and parents need resources to be solid advocates. With that in mind April 2, 2014 is **Autism Awareness Day**. Learn more about this special day as well as month as well as through our friends at **Autism Speaks**: <http://bit.ly/1cVoKDK>

To Do List



CONGRATS: Kellie Hunt is the winner of the *little man* DVD and Crista Hopp has won a copy of *From Hope to Joy* by Jennifer Degl.



LIKED US YET?: PreemieWorld is doing another PreemieWorld Facebook page contest. See page 2 of this newsletter for details!



Download PreemieWorld's FREE tools <http://bit.ly/PreemieFreebies> and pass them onto NICU Parents as part of your welcome packet.

MARK YOUR CALENDAR!



11th Nat'l Adv. Practice Neonatal Nurses Conference
Academy of Neonatal Nursing
April 23-26, 2014
Honolulu, Hawaii
<http://www.academyonline.org>

2014 NANT Conference
National Assoc. of Neonatal Therapists
April 24-26, 2014
New York, NY
<http://www.NANTconference.com>

Tools and Resources
for the Preemie Community

Preemie Resource: <3 Preemies

PreemieWorld provides a number of free handouts to be used in the NICU and beyond in its "Freebies For You" section of the website. **This month's freebie is a special logo, <3 Preemies.** "We want parents to celebrate their preemies," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "This logo will give them the chance to do that and to connect with

other preemie parents in a very special way. Tweet it, FB it, whatever you want. Love it and enjoy it!"

Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce.

Download it here now: <http://bit.ly/HeartPreemies>
and check out more like this here:
<http://bit.ly/PreemieFreebies>

Support:

Prematurforeningen Mirakel



Year Established: 2013

Web: www.prematurmirakel.se

Outreach: National (Sweden)

Background: Pernilla Brown had twin girls at 28 weeks and lost one, Anna-Charlotta Hellner had twin boys at 25 weeks and one has cerebral palsy and other challenges. Together they work to make a difference for all preemie families before and after the hospital stay and also families that have lost a baby.

Programs: Annual holiday gifts to mothers on bed rest as well as weekly massages and more; funerals and clothing at no charge for babies that have passed away in hospitals in Gothenburg; Skype courses.

Org: The Linden Fund

Over 10 years ago, Lauren Michie-Hunter gave birth to her son, Linden Allister Pezzullo. Linden went through two bouts of meningitis during his NICU stay among other issues. Today he is a happy, healthy little boy. Out of her son's traumatic start in life, Lauren was determined to help others through the Linden Fund.

Established:
2005

Type of Outreach:
International

Website:
www.thelindenfund.com
www.prematurity.ca

Focus:
To raise funds to purchase specialized medical equipment for the Neonatal Intensive Care Unit

such as incubators, intravenous pumps and other lifesaving apparatus. In addition the fund also supplies items of comfort and security to assist the mental, physical and emotional development both the infants and their families. This includes special developmental mobiles, breast pumps, as well as meaningful items to assist with neonatal bereavement.

Programs:

Coming up is the 7th Annual Pedal for Premies Walk/Run Bike-a-thon on 5/31/14. Learn more about this event at: www.Pedal4Premies.com



PreemieWorld: "Like" Us On Facebook & You Could Win!



Visit PreemieWorld's FB page at:
<http://bit.ly/FBPreemie>

**"Like" our FB page
from 4/1/14 to 4/24/14
and you could win a copy of the
award-winning *little man* DVD
from PreemieWorld!**

<http://bit.ly/FBPreemie>

Parents & Professionals:
Subscribe to our FREE newsletters
today @ www.PremieWorld.com

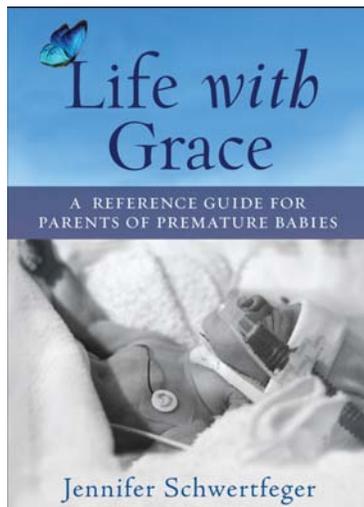


BOOK: Life with Grace

The Details:

By:
Jennifer Schwertfeger

Website:
<http://lifewithgracebook.com>



The Genius:

With great honesty, author Jennifer Schwertfeger takes us through her 24-weeker Grace's miraculous 9-month NICU journey from troublesome pregnancy to birth to NICU to home and into the school years. This book is helpful to parents of premies at any stage in the journey as the author provides meaningful tips and definitions throughout. It is also a fabulous book for professionals to gain perspective on the preemie parent experience when working with a child with complex medical needs and a long-term NICU/PICU stay.

COOL: 2 people could win a copy of this book! For your chance to win sign up for Premie Family (<http://bit.ly/preemie1>) or Premie Professional at <http://bit.ly/preemie2> from 4/1/14 - 4/24/14.

After the NICU: Resources for Trach Babies

Having a preemie is isolating post-NICU, but it can be even moreso with a baby on medical equipment. Below are resources for families with a baby on a tracheostomy at home:

- *Life with Grace* by Jennifer Schwertfeger
<http://lifewithgracebook.com>
- Moms of Trach Babies
(<http://bit.ly/TrachBabies>)
- Aaron's Tracheostomy Page
(www.tracheostomy.com)
- Global Tracheostomy Collaborative
(www.globaltrach.org)
- Tracheostomies: The Complete Guide (<http://bit.ly/trachguide>)

Premie Professional Online

NICU Professionals Group: (www.LinkedIN.com)

"Neonatal Organ Donation"

"PREEMIE UPDATE for MARCH: Sofia -
<http://bit.ly/PremieSofia>"

Early Intervention Professionals Group: (www.LinkedIN.com)

"Help Out Our EI Folks in New York"

"What Do Avocados Have to Do with Toddlers?"

"COOL : Music & Premies this Month in
Premie Professional -
<http://bit.ly/PremiePro24>"

Premie World (www.Twitter.com):

"What Do You Think of This Study/ Article? Should a Child's Gestation Be Put on their Record? -
<http://ow.ly/uz7ql>"

BE THE COOL PRO: Tell Your Families about the "Premie Network" on Inspire.com:

Deb Discenza of PremieWorld moderates this global network of *over 18,000 parents* from NICU to home to school. www.inspire.com/preemie

Check out these groups and more by referring to the "Get 'Social' With Us" on page 4 for more information. Have news or research to share with us? connect@preemieworld.com

Get "Social" With Us!



www.PremieWorld.com
www.LittleMantheMovie.com



@PremieWorld



- PremieWorld
- Premie Parent's Survival Guide to the NICU



PremieWorld



Check out other LinkedIN groups we moderate:

- NICU Professionals
- Early Intervention Professionals
- Premie Parent Support Group Leaders
- Premie Parents
- Little Man the Movie

*Tools and Resources
for the Premie Community*



Prolonged, effective, safe, and hands-free Kangaroo Care sessions. Guaranteed.

 kangaroozak.

 nurturedbydesign
It's in your hands!

www.nurturedbydesign.com



Premie Rattles

Developed by a Physical Therapist

www.magicalinnovations.com

(407) 230-4491



NICU *Hope* Beads



COMMEMORATE & SHARE

Your NICU journey through jewelry...



facebook.com/NICUHopeBeads | 979.635.0825

Interested in advertising? Contact us at connect@preemieworld.com

Tips: Top 3 Tips for Preparing & Going Home On a Trach

Jennifer Schwertfeger, *author of the new book, Life with Grace* (www.lifewithgracebook.com), has some tips for parents considering a tracheostomy:

1. Hindsight is 20/20. Although we agonized over the decision of getting our daughter the trach, we could see it was the best decision the moment she came back from surgery. She was smiling, and breathing more comfortably. After seeing how happy Grace was, it was obvious that we had made a great decision.

2. Ask tons of questions at the hospital. Work with your social worker, ENT specialists, take a

CPR class, ask if they have a trach doll for practice. After your child goes through the trach surgery, make sure you stay overnight taking care of your child alone . . . with nurses there nearby to guide you. You will want to feel comfortable enough on your own, *before* going home.

3. Preparation is Key at Home. Have your home inspected before bringing your child home and a back-up plan for all emergencies in the home. And make sure you have a great connection with a home equipment company/supplier for all of your child's medical needs.