



Preemie Professional

Preemie Professional

Laurel & Jerome Kapferer

Co-Founders, Team Grayson



Photo Credit: Kapferer Family

Web:

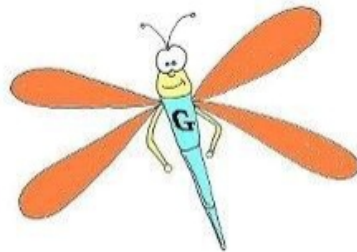
www.teamgrayson.org

Years Helping Preemies:

3 Years

Focus:

Necrotizing Enterocolitis (NEC) – raising awareness and working toward ending NEC altogether.



Professional Tip!

Always interact with compassion. Remember that every person has gone on his or her own journey.

Advocate: World Braille Day

The 4th of January 2015 is World Braille Day due to it being the birthday of Louis Braille who invented this code in 1821. In our community of preemie parents we have many families affected by blindness due to Retinopathy of Prematurity (ROP). Braille is used worldwide. To learn more about the individual behind it, go here to find out more: <http://bit.ly/BrailleDay>

To Do List



CONGRATS: [Michelle Bordelon](#) has won a copy of *little man* and [Kathy Parkes](#) won the incubator art work from EVERYtinyTHING.



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!



Picky Eaters Vs. Problem Feeders
Education Resources, Inc.
January 15-18, 2015
Johnston, Iowa
<http://bit.ly/IwadZoi>

Transport of High Risk Neonates
MCA Scientific Events
January 23-25, 2015
Genova, Italy
www.neonataltransportation2015.eu

Have an event you want to share with our community? Contact us at:
connect@preemieworld.com

*Tools and Resources
for the Preemie Community*

Preemie Resource: A Preemie's 1st Birthday Note to Mom

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 "For Mom - On Your Preemie's 1st Birthday." "That first birthday left me with such mixed emotions," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "I was

happy and sad all at the same time. So this freebie is for all of those Moms, to let them know it is perfectly normal to feel that way." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce.

Download it here: <http://bit.ly/Preemie1Bday> and **check out more here:** <http://bit.ly/PreemieFreebies>

Follow us on FB, Twitter & LinkedIn!

© 2015 PreemieWorld, LLC. All Rights Reserved.

Support:

Hailey's Hope Foundation



Named after a premie girl named Hailey, this foundation provides support across New York State.

Year Established: 2007

Outreach: State of New York

Web: www.haileyshopefoundation.org

Background: Five of the organization's Board Members had premature babies and two lost a premature baby girl.

Programs: Financial support, "Welcome Home" care packages, and "Memories of a Lifetime" care packages.

Org: Team Grayson

From their own tragedy came a special project that raises awareness about NEC and focuses squarely on ending this illness for future premies.

Website:
www.teamgrayson.org

Year Established:
2012

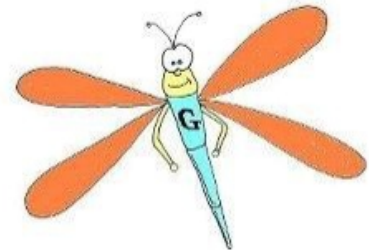
Outreach:
International

Focus:
Necrotizing Enterocolitis (NEC)

Background:
Team Grayson was created by the parents of Grayson Kapferer after he passed away from Necrotizing Enterocolitis (NEC) when he was 7 days old.

Goal:
To raise awareness about Necrotizing Enterocolitis and to end it.

"Like Them":
Make sure to "like" the organization's Facebook page to keep up on upcoming events and programs:
www.facebook.com/teamgraysonusa.



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



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

"Like" our FB page from 12/30/14 to 1/26/15 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

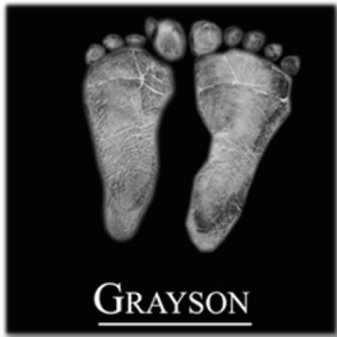


Grayson – A Documentary

The Details:

By:
Brendan Reilly

Website:
<http://bit.ly/GraysonDoc>



Grayson takes the viewer into the world of the Kapferer family and the life of their premature baby boy, Grayson, who died after birth at 34 weeks gestation and developing Necrotizing Enterocolitis (NEC).

The film is a touching tribute to not only the beloved son that died 7 days after birth but also to the incredible bond of NICU Nurse Stacy Montvilo who cared for Grayson and his parents during the NICU stay.

The film does not shy away from the raw feelings of grief and reminds us that NEC is an issue that continues to require awareness and research to end its mortality rate. Every family, every NICU professional would do well to watch this.

After the NICU: Rehospitalization Happens

Preemies are at high-risk for rehospitalization. The best defense is to be prepared ahead of time. Here is a quick list of items that will come in handy in an emergency:

- Paperwork: Copy of NICU discharge paperwork; your child's insurance card (front and back) and a *current* list of medications and dosages.
- Enough clothing and/or sleepers to last 5 days.
- If you are pumping, extra bags for milk collection and a tube of nipple cream.
- A set of casual clothes for you plus a set of travel toiletries, and a dose or two of your own medications.

Premie Professional Online

NICU Professionals Group: (www.Linkedin.com)

RESEARCH: Stanford-led study suggests changes to brain scanning guidelines for preemies – <http://ow.ly/GdIVC>

CDC ADVISORY: Infant death caused by contaminated probiotic powder – <http://ow.ly/FOW55>

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

Parent's Top Ten Tips for Making Progress in Feeding Therapy

Learning first words

Talking with a mother

Premie World (www.Twitter.com):

PREEMIE UPDATE: Premie Nova – <http://bit.ly/PremieNova>

STUDY: Former Premies More Vulnerable to Flu Complications: <http://ow.ly/GdLCE>

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

Deb Discenza of PremieWorld moderates this global network of *almost 21,000* parents from NICU to home to school. www.inspire.com/premie

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.PreemieWorld.com
www.LittleMantheMovie.com



@ PreemieWorld



- PreemieWorld
- Preemie Parent's Survival Guide to the NICU



PreemieWorld



Check out other LinkedIN groups we moderate:

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

*Tools and Resources
for the Preemie Community*



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

kangaroozak.

nurturedbydesign
It's in your hands.

www.nurturedbydesign.com



Preemie 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

Synagis Update: NPA Guidelines, Reporting RSV & Petitions

There has been a strong outpouring of frustration by both parents and professionals alike surrounding the latest Synagis guidelines put into effect by the American Academy of Pediatrics (AAP). With so much to update, we felt it important to devote this column to all things Synagis:

The National Perinatal Association (NPA) has released its updated alternative guidelines. NPA recently updated its guidelines for 2015 and they are now available here: along with other information: <http://www.nationalperinatal.org/rsv>

There is now a reporting mechanism for RSV: Until now, RSV was not reported. A new website devoted to reporting is here: <https://www.rsvhospitalization.com>

There are two petitions taking off on Change.org: Please consider signing one or both petitions:

1) <http://bit.ly/PreemiePetition> - By PreemieWorld for parents and professionals. Over 6,000 signatures already!

2) <http://bit.ly/popularRSV> - by the group POPULAR that breaks down the science of this issue.