



Preemie Family

Preemie Life

Grayson Edward Kapferer



Photo Credit: Kapferer Family

Gest. Age:
34 weeks

Weight:
2 lbs. 14 oz.

Time In NICU:
7 days

Proudest Moment (NICU):
When Grayson let his personality shine with everyone. He had more personality and spunk in his tiny little body than most people I know show in their lifetime

Coming Soon: Check www.PreemieWorld.com to read Grayson's full journey.

Parent Tip:

Both parents should take the time to Kangaroo with their child. It's healing for parents and babies.

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>

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!

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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> to use and to pass onto others.



MARK YOUR CALENDAR!

Monthly Preemie Playgroup
Preemies Today
January 8, 2015 11 a.m.- Noon
Wings to Fly Therapy Center
www.PreemiesToday.com

Have an event you want to share with our community?

Contact us at:
connect@preemieworld.com

*Tools and Resources
for the Preemie Community*

Term: Necrotizing Enterocolitis (NEC)

Necrotizing Enterocolitis

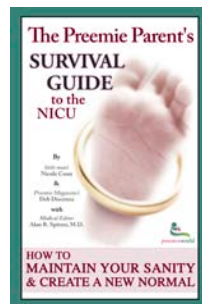
(NEC): A disease that primarily infects the immature bowel of the premature infant. Intestines are perhaps the weakest in the body's systems and are easily infected by infection and blood flow changes. NEC is a toxic inflammation in the intestine that literally kills the intestine.

Your baby's medical team knows that it is so very important to watch for this and catch it immediately since it can spread so quickly and cause significant and quite serious damage.



Often, NEC is caught by the signs of sepsis in the blood stream.

The least invasive measure of treatment is to have your infant be treated with a series of antibiotics while remaining off foods and being fed through a central line or Broviac. In the worst-case scenario your baby will be subjected to surgery where the sick part of the intestine is removed.



This excerpt is from
**The Premie Parent's
Guide to Survival in the
NICU on sale at**
www.PremieWorld.com
****We do bulk orders for
hospitals****
connect@preemieworld.com

Support:

Hailey's Hope Foundation



HAILEY'S HOPE
FOUNDATION
SUPPORTING FAMILIES IN THE NICU

Named after a preemie 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.

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



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

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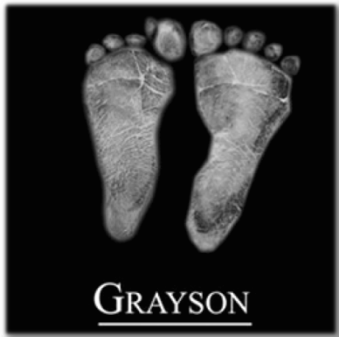
Grayson – A Documentary

After the NICU: Rehospitalization Happens

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.

Preemies are at high-risk for re-hospitalization. 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.

Preemie Support Online

On the Preemie Support Forum on INSPIRE:

Connect with *almost 21,000 other parents of preemies online* at www.Inspire.com/preemie for the *Preemie Support forum*. It is the largest and most active forum online, *moderated by PreemieWorld's own Deb Discenza*.

Cough after Cold – *In the NICU/PICU*

New Grandparent to a Preemie – *Intro Your Very Important Preemie (VIP)*

Preemie with Possible CVI – *at Home (Years 1-5)*

Bottle Feeding 24 Weeker– *Preemies with Feeding Issues*

Severe Grade IVH – *in Open Discussion*

On PreemieWorld's Twitter Page:

PREEMIE UPDATE: Preemie Nova – <http://bit.ly/PreemieNova>

On PreemieWorld's Facebook Page:

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

On PreemieWorld's LinkedIN Group:

LOVE: Meet 51 Babies Who Were Born Too Soon – and See How Far They've Come – <http://ow.ly/GdHA0>

PETITION UPDATE: First Preemie Death Due to RSV – <http://ow.ly/GfzTL>

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

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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/PremiePetition> - By PremieWorld 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.

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