



• July 2016 •

NEWSLETTER

“One person can't change the world, but it only takes one person - one tiny ripple - to BEGIN creating change.”

Keira's Thoughts:

As the President of the Preemie Parent Alliance I have the unique opportunity to get to know each of our members on a personal level. I am usually the contact who shares the many benefits of joining our network and in that initial phone call I begin to learn about their personal stories. I am privileged that they share the traumas and the triumphs that led them to working in the social sector with a focus on NICU babies and their families. Many of our members are first starting out when they join PPA. They have a vision and are chock full of ambition and determination. It is validating for me to hear that we are doing important work together and I hope it is encouraging for them to know they are not alone. We, as preemie parent leaders, are UNITED.

By far, the most enjoyable part of this job is that I get to witness the growth of each organization and each leader. The [Preemie Parent Alliance Speakers Bureau](#) recently presented a parent perspectives panel at the [AWHONN](#) Annual Convention where I shared the stage with Natalie Gordon from [NICU Helping Hands](#), Tanya Clay from [Hand to Hold](#), and Laura Martin from [Graham's Foundation](#). We closed the session to rousing applause and positive comments from the audience. But it wasn't the applause that filled my heart, it was listening to these women, these preemie moms, who carried themselves with such poise and grace. It was watching them interact as they invited the audience into their moments of vulnerability and fear. And it was remembering the first time I met each one of these ladies years ago and reflecting on their individual paths to leadership in Maternal Infant Health. Well done ladies! You made our network very proud!

CALL FOR ABSTRACTS

deadline 15.JUL.16

Due to overwhelming demand, the PPA Summit Planning Committee has extended the deadline to submit an abstract for the 2016 Premie Parent Summit. The abstract submission process will close at 11:59PM EST on Friday, July 15th, 2016.

LEARN MORE

SPEAKERS BUREAU OPENING

deadline 01.MAR.16

The PPA Speakers Bureau is an exclusive benefit of PPA membership - the only Speakers Bureau made up of premie parent leaders. PPA has been invited to speak at national provider association conferences around the country. Click below to view requirements and apply.

APPLY NOW

IN CASE YOU MISSED IT

PreemieWorld: PreemieWorld News, July 2016

The July 2016 editions of [***Preemie Family***](#) and [***Preemie Professional***](#) are now available for download. Learn More: [Here](#)

AWHONN: Call For Presenters

The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) is soliciting abstracts for oral or poster presentations at the 2017 AWHONN Annual Convention in New Orleans, June 24-28, 2017. [Full Story](#)

NEW MEMBERS

Lily's Hope Foundation

Founded in 2013, The Lily's Hope Foundation supports babies, children, and their families with unexpected and urgent needs due to premature birth. We support our NICU families by providing them with essential items since they have been unable to prepare for their child's early arrival. Our Lily's Hope Families that are in the middle of this medical crisis are referred to us by hospital case workers, hospital staff, and word of mouth. We work with each individual family to answer their specific needs by way of our Packages of Hope.

[Learn More](#)

Glo Premies

Founded in 2016, Glo Premies is a nonprofit organization that offers support and resources to parents that have premature children in the NICU. We also offer gift baskets, easy to read and understand medical terminology used while in the NICU, and Glo graduates will attend a yearly Graduate festival. We have a beauty and empowerment program where we take the mothers for a day from the NICU and give them a free beauty makeover. We also host motivational events in hopes of preventing depression and PTSD associated with having an infant in the NICU.

[Learn More](#)

2016 SUMMIT UPDATE

Advocacy Workshop

The [Alliance for Patient Access](#) (AfPA) will conduct an advocacy training workshop that will focus on how to tell your personal story to effectively develop legislative champions, testify in front of lawmakers, and influence the media. AfPA is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by

recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access.

\$100

PPA Member

Free Pre-Conference
Workshops

Pre-Conference
Networking

Free Exhibit Space

Digital Marketing
Opportunities

Register

\$250

Non-PPA Member

Pre-Conference
Workshops

Pre-Conference
Networking

Program Inclusion

Post-Conference
Networking

Register

Save on registration prices with our **Early Bird Discount!**

Join us **November 04-06, 2016** for another extraordinary gathering of like-minded parent leaders and professionals for invigorating discussion, networking opportunities, and learning workshops centered around families and their preemies. This year's summit will focus on topics surrounding **Unity, Perspective, and Leadership.**

Visit our official [PPA Summit website](#) for more details and to register!

PLANNING YOUR TRIP

Special guest room rates for ALL attendees.

Visit our [Travel Information](#) page for maps, conference info, and booking information!

UPCOMING EVENTS



NIU Helping Hands

July 15, 2016

For the month of July, NICU Helping Hands will be celebrating NICU siblings. On the morning of July 15th, NICU Helping Hands will host our Sibling Superhero party, inviting all past and previous NICU families who have more than one child at home.

Snacks will be provided as our superheroes show their super powers while tackling our obstacle course, participating in arts & crafts, and much much more.

[MORE INFO](#)



Little Giraffe Foundation

July 17, 2016

**CHICAGO ROCK 'N' ROLL
HALF MARATHON**

Support preemies and neonatal research by running in the Rock 'n' Roll Chicago Half Marathon presented by Humana! For the third year, The Little Giraffe Foundation is an official charity partner for the Rock 'n' Roll Chicago Half Marathon.

Register with us today and your spot in the half marathon is guaranteed at a discounted rate!

Not a runner? **Support our team** by donating to one of our participants!

[MORE INFO](#)



Join us for a wonderful day of golf as we raise funds to fight for premature babies.

Graham's Foundation

July 18, 2016

Join Graham's Foundation for a wonderful day of golf as they raise funds for premature infants.

Golfing for Graham's Foundation is just one of several signature events that Graham's Foundation has created to increase awareness of the severe emotional, physical, and financial toll premature birth takes on moms and dads.

[MORE INFO](#)



Fragile Beginnings

July 28, 2016

The JF&CS [Center for Early Relationship Support®](#) and the [Massachusetts March of Dimes](#) are offering parents whose babies or young children spent time in the NICU an opportunity to share their experiences, listen to each other, and join in community. Parents will have the chance to hear each other's voices about expectations, loss, surprises, and challenges of the journey of parenting a child born prematurely or under special circumstances. This parent-centered group will be led by a clinician from the JF&CS [Oliver, Ian, and Serenity Wolk Fragile Beginnings](#) program.

MORE INFO



Lily's Hope Foundation

September 10, 2016

Lily's Hope Family Run, Walk or Stroll

Lily's Hope is thrilled to announce that registration is now up and available for the Lily's Loop 5K Run, Walk & Stroll!! Please join Lily's Hope for a fun Saturday morning on September 10th at Valley Preferred Cycling Center in Breinigsville, PA.

Breakfast and Snacks will be provided for all participants. Special thanks to our presenting sponsors, Walgreens and PDC Machines!!

We are looking forward to an amazing event!

MORE INFO



International Neonatal Consortium

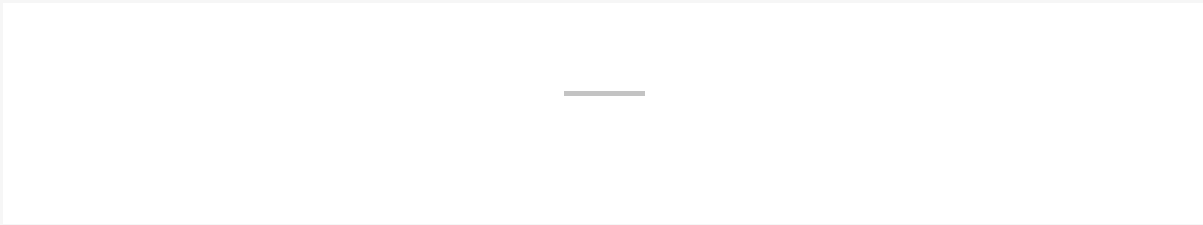
Sept 13-16, 2016

Applying Regulatory Science to Neonates: Second Annual Scientific Workshop at European Medicines Agency (EMA)

Focused on applying regulatory science to neonates, INC members will explore approaches that family and neonatal nursing organizations can take to embrace a research culture.

Workshop participants will also provide an update on INC's progress in the first year and identify additional initiatives to accelerate the development of safe and effective therapies for neonates.

MORE INFO



Preemie Parent Alliance

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