



• August 2016 •

NEWSLETTER

“Parents need all the help they can get. The strongest as well as the most fragile family requires a vital network of social supports.”

- Bernice Weissbourd

Exclusive PPA Opportunities!

PARENT SPEAKER WANTED!

We're thrilled to announce an exciting opportunity that has been extended to Preemie Parent Alliance members.

Dr. Mitch Goldstein has asked the PPA for a parent speaker to present at a patient safety conference in Feb 2017, to be held in Southern California.

The speaker must have personal experience where you were unable to access medication or the appropriate dose of medication for your child that then resulted in morbidity or mortality.

An example would be the inability to obtain RSV prophylaxis resulting in hospitalization and long term medical repercussions. Please note this does NOT have to be related to RSV prophylaxis, any access issue to a pediatric medication will suffice.

If you have this experience or know of a seasoned parent speaker who has please reply to keira@preemieparentalliance.org with a brief synopsis (2-3 sentences) by MONDAY, AUGUST

15th.

SEEKING VOLUNTEERS!

The PPA Standards Committee has been working with the International Neonatal Consortium to develop a protocol for approaching and educating NICU families on informed consent. We are looking for 20 PPA members (can be a director, staff, board member, volunteer, etc) to review an informed consent form and answer a short survey. Please email keira@preemieparentalliance.org BY THIS FRIDAY if you are able to participate. The only requirement is that the participant must have had a baby in the NICU. The turn around time for this request is one week.

STANDING PPA MEETING TIMES

(Individual login for meetings will be sent separately)

- **Standards Committee**
 - 4th Wednesday, every other month at 11am CST, starting September 28th
- **Member Engagement Committee**
 - 2nd Tuesday, every other month at 1pm CST, starting September 13th
- **Summit Planning Committee**
 - 3rd Friday of every month at 1pm CST, next meeting August 19th
- **PPA Member Chat**
 - 1st Thursday of every month at 12pm CST, next chat will be a webinar on Sept 1st, see registration below.



Please register for September PPA Member Chat on Sep 01, 2016 12:00 PM CDT at:

<https://attendee.gotowebinar.com/register/3689942707659894275>

Our monthly PPA members only chat will feature an online walk through of the recently updated PPA website including everything you need to know to access your PPA member account and exclusive PPA members only resources.

After registering, you will receive a confirmation email containing information about joining the webinar.

IN CASE YOU MISSED IT

AWHONN: Call For Presenters - Deadline September 10th

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](#)

2016 Premie Parent Summit

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 premies. 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!

\$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

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.

UPCOMING EVENTS



Lily's Hope Family Run, Walk or Stroll September 10, 2016

Lily's Hope Foundation 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.

[MORE INFO](#)

PPA THANKS YOU!!



Preemie Parent Alliance extends a special thank you to Jennifer Canvasser, founder of NEC Society, for representing all PPA members at the next INC Workshop in London on Sept 12-13th.



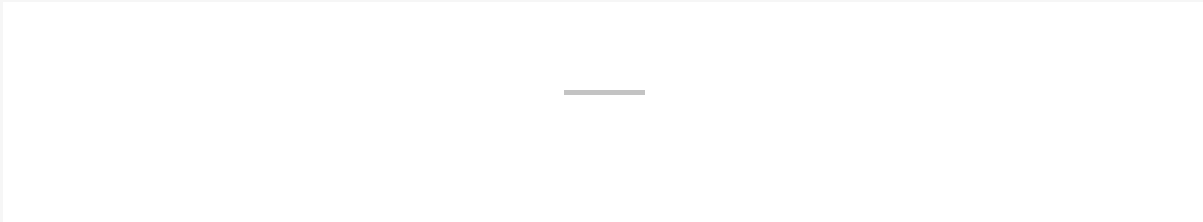
Preemie Parent Alliance also extends a heartfelt thank you to Deb Discenza, founder of PreemieWorld, for representing Preemie families during your session in Vancouver at the annual COINN mtg on August 14th.

SPEAKERS BUREAU OPENING

deadline 01.OCT.16

The PPA Speakers Bureau is an exclusive benefit of PPA membership - the only Speakers Bureau made up of preemie 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



Preemie Parent Alliance

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