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Expectations

the newsletter of the Preeclampsia Foundation

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JULY 2011

PROMISE WALK UPDATE

Tour the "Field of Cradles" at the Boston Walk

The grassy field of empty cradles is a poignant reminder to all that pass by of the devastating impact of preeclampsia.

This is the scene that walkers at the first Boston Promise Walk for Preeclampsia will experience on July 24, 2011 at Castle Island Park. The exhibit is the vision of writer, exhibit organizer and walk coordinator **Susannah Pabot**.

With this traveling public exhibit, Susannah hopes to increase awareness of preeclampsia and its symptoms and raise money to support the Preeclampsia Foundation's programs. Each empty cradle holds a handcrafted blanket and poem written in memory to a child who lost his or her life, while gentle lullabies play in the background.

Read More About the Boston Promise Walk

Upcoming Activities

DONA Conference
07/21-24/2011
Boston, MA Promise Walk
07/24/2011
Birth (AABC) Conference
09/1-3/2011
Lamaze Int'l Conference
09/15-18/2011
EuroISSHP Conference
10/5-7/2011
Saving Grace NYC
11/12/2011

RESEARCH ROUNDUP

Evaluating the L-Argenine study: Could this help your future pregnancies?

A new study came out this month evaluating supplementation of l-arginine as a means of reducing preeclampsia risk. There was a lot of media coverage - you probably had friends and relatives sending you articles like this - and there's been some discussion of it on the Preeclampsia Foundation Community Forum as well.

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Why did researchers think this might work? Well, partly for the same reason that smoking reduces the risk of preeclampsia. Smoking activates a chemical pathway which uses l-arginine to build a protein called "nitric oxide synthase" (NOS). NOS is a vasodilator - it expands blood vessels - which could help to lower maternal blood pressure and might increase blood flow to the placenta, reducing production of the chemicals that the placenta produces when it runs short of oxygen.

So what did the data suggest? And is there cause for hope?

FEATURED STORY

Meet Kristen Simmons: Twice A Survivor

Like many of those involved with the Preeclampsia Foundation, Kristen Simmons has a unique story of survival, but Simmons' case included a very unusual complication. In July 2009, Simmons developed severe preeclampsia and HELLP syndrome shortly before the birth of her daughter Sydney. Sydney was born not breathing, but was successfully resuscitated, while her mother bleed internally, going into multi-organ failure. Simmons ended up needing a liver transplant only days after giving birth and was transferred from her home state of New York to a high risk facility in Pittsburgh, where she was placed in a medically-induced coma for weeks.

"Life had changed so drastically it was very hard for me to accept what had happened," Simmons said. "For a long time I couldn't even hold Sydney because of the pain from the transplant. I became very depressed and cried nonstop."

To complicate her health even more, less than a year after the trauma of Sydney's birth, Simmons was diagnosed with Stage IV Post Transplant Lymphoproliferative Disease (PTLD) cancer, a very rare cancer that usually occurs in pediatric transplant patients because of their underdeveloped immune system.

Read More of Kristen Simmon's Survival Story...

HEARD ON THE HILL

Does a Diagnostic or Screening Test Matter? FDA Wants to Know What Patients Think

Whether a pregnant woman would opt to take a screening test that could determine her risk of having preeclampsia and whether she would change her health care practices or care provider if she received a diagnosis or a clear determination of

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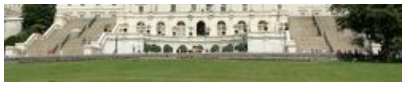

risk for preeclampsia from such a test are two big questions facing the research and development community.

The Preeclampsia Foundation is developing a survey of its members to understand the level of interest in diagnostic or screening testing. No such tests for preeclampsia and its related conditions are currently available, and the Foundation believes the U.S. Food and Drug Administration (FDA) should be more open to biomarker tests and encourage their safe production. In conversations with bio-pharmaceutical companies around the globe, there is a sense within these companies that the FDA has had a dampening effect on the development and eventual approval of these tests.

Read More about the meeting with FDA

FUNDRAISING AND AWARENESS

8 Steps to Turn Summertime Fun into Big Impact

Whether it's a backyard barbeque in Dad's honor, hot dogs in the park or a play date at the swings, summer is the time to turn off the television and enjoy the easy spirit of extended daylight. It's also when we reconnect with our neighbors and friends... but it can also be a great fundraising and awareness opportunity!

Not only is it fun, but neighborhood yard sales and block party picnics are great chances for people to learn about preeclampsia and contribute to the work of the Foundation. Here's how to enjoy the sun and organize a local neighborhood block party:

1. Invite each family to provide a side dish. Ask the manager of your local grocery store, hotdog stand or ice cream shop to donate food, water, or a sheet cake. With enough notice, most will be happy to get behind a community charity event.
2. Line up activities like Frisbee, water balloon toss, face painting, basketball, family sack races, or inflatable bounce rental.
3. Host in several adjoining back yards or at your community clubhouse.
4. Spread the word with fliers, email, social media, and most importantly, in-person invites. We can help you announce your event on our website calendar and regional forum.
5. Organize a 50/50 ticket raffle where half of the money raised from ticket sales is donated to the cause and the other half is given to winner.
6. Get gift certificates to local businesses (floral shops, restaurants) donated as prizes. Note: When planning raffles, always be sure to check with your state laws, since some states have very specific rules about money raffles and some may require a permit.
7. Approach local businesses to sponsor your event. Giving a donation in exchange for them having a table to promote their products or

services (with a portion of that day's sales going to the cause) could be a win/win.

8. Be aware of liability issues. Work with your municipality to make sure you have the right coverage for your event. Note: We can provide you with charity information that may be needed when applying for permits, but this would not be a PF sponsored event, therefore coverage is the responsibility of the volunteer coordinator.

And don't forget to contact Dawn Detweiler who can help you with your neighborhood fundraiser to support preeclampsia research and education!

VOLUNTEER OF THE MONTH PROFILE

Tiffany Trevers, San Jose Walk Coordinator

What volunteer position(s) have you held?

I organized the first Promise Walk for Preeclampsia in the Northern California region that was held in May 2011 in San Jose. Over 250 people attended and because of everyone's efforts, we raised over $31,000 for the Preeclampsia Foundation! Though it was a ton of work, it was an incredibly gratifying and educational experience.

Why do you volunteer for the Preeclampsia Foundation?

The Preeclampsia Foundation was such a supportive environment for me after my experience in 2005 and again as I went through a high risk pregnancy in 2010. I got so much from the Foundation and from the many wonderful volunteers that I felt it only right to try and give back something. Many of us preeclampsia survivors want to put our experiences behind us and forget this painful chapter in our lives. And yet I remember meeting a father earlier this year as we planned our local Promise Walk whose wife died from preeclampsia roughly the same time I had it, leaving behind a baby she never knew. We survivors can move on and continue with our lives, but that mother and thousands like her worldwide, cannot. We survivors must fight for a cure on behalf of these women and babies taken from us too soon who cannot fight.

Read More About Tiffany's Amazing Volunteer Efforts

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