COUNCIL ON PATIENT SAFETY
IN WOMEN'S HEALTH CARE
safe health care for every woman

Wednesday, May 20, 2015

12:00 p.m. Eastern

Dial In: 888.863.0985

Conference ID: 26375175

Safety Action Series

Empowering Patients, Improving Outcomes

Speakers

Ileana Balcu
IT consultant, Dulcian, Inc.
e-Patient, Member of the Society for Participatory Medicine

Todd Heiden

Eleni Tsigas
Executive Director
Preeclampsia Foundation

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Disclosures

- Ileana Balcu has no real or perceived conflicts of interest to disclose.
- Todd Heiden has no real or perceived conflicts of interest to disclose.
- Eleni Tsigas has no real or perceived conflicts of interest to disclose.

Objectives

- Review key strategies for effective communication with patients and families
- Learn from patients and family members who have experienced a severe maternal event
- Provide tips to overcome patient education and engagement challenges
- Explore the materials available to encourage patients and families to take an active role in the delivery of care

Ileana Balcu

Story: https://obpatientinnj.wordpress.com/

Contact: yogileana@gmail.com

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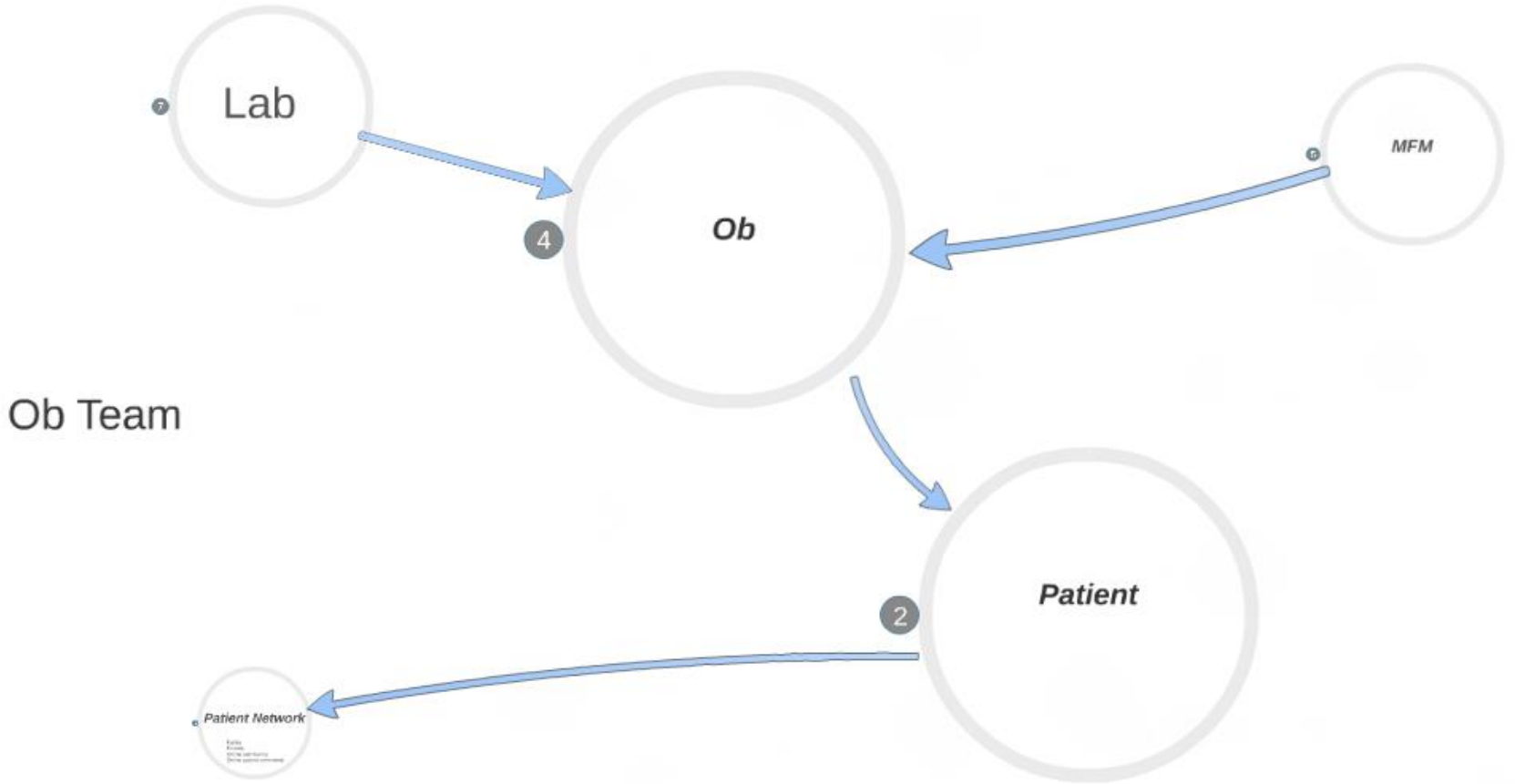
2003 - Informed Educated Compliant Patient

Management by: Ob. Patient becomes high-risk, MFM gets involved and additional tests and procedures are ordered



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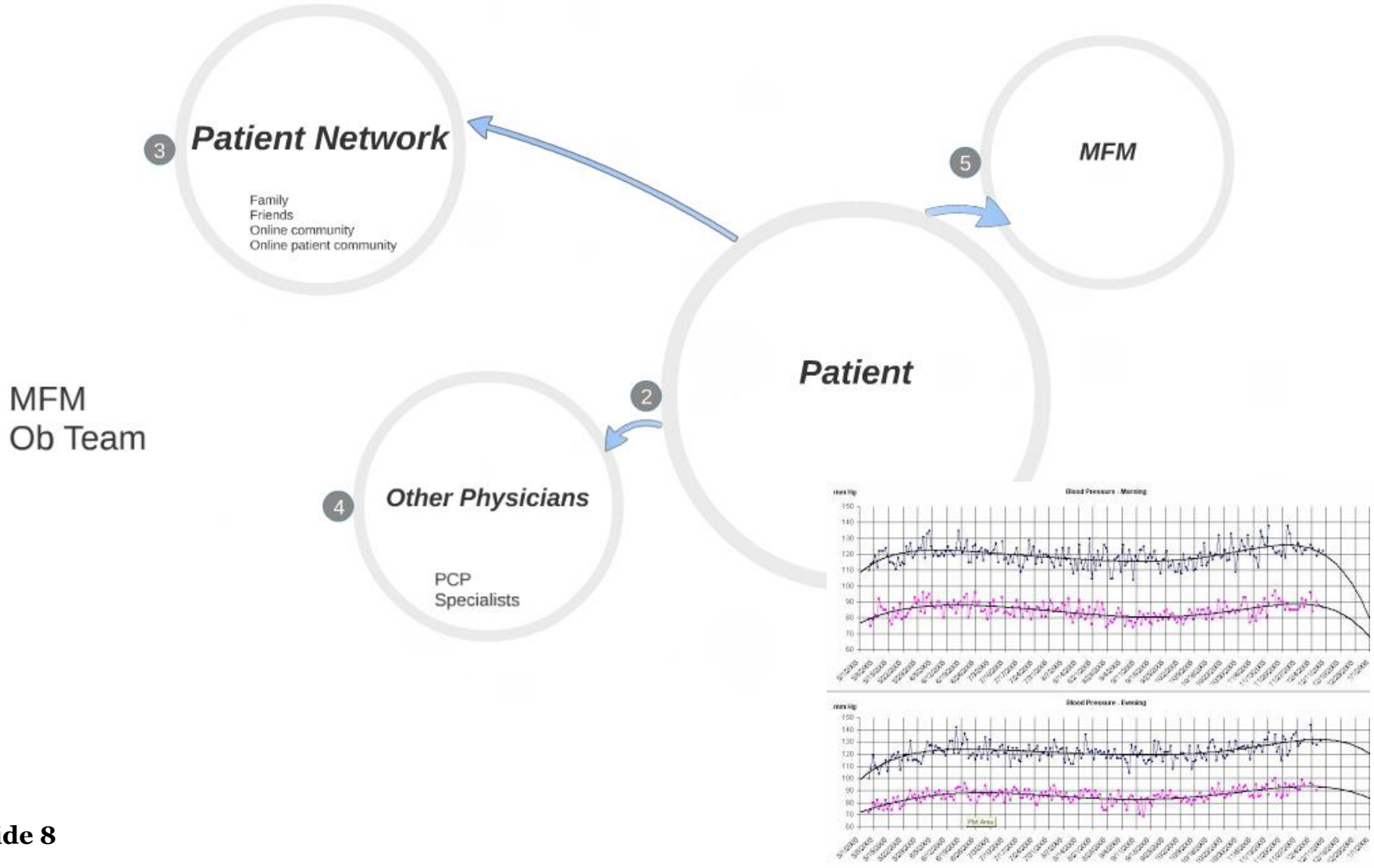
Checklist for making sure communication is straightforward:

Considerations to discuss with the patient and team	What happened in my case
Does the patient understand the problems and the risks associated with them?	I had bleeding at 11 and 13 weeks. At 11 weeks we were told this put my pregnancy at a 50% rate of success. At 12 weeks, my Ob high-fived me that making it to 12 weeks puts me at 90% success – this seems unrealistic. After that, nobody gave us any idea of where we are in terms of probability of success. When given no idea of probability one thinks that doctors just practice defensive medicine.
What kind of support does the patient have?	I had support at home, but very few friends that were pregnant and that could advise what to do. I knew nobody that had preeclampsia. I read books and the Internet and thought I knew all there is to know.
Is the MFM – Ob communication open? Does everyone have access to all the information about the patient in real time?	MFM advised Ob at 20 weeks to watch for signs and symptoms of preeclampsia. MFMs did not do patient education and had no apparent oversight over the day to day management. The MFMs advised the Ob, but the Ob missed the diagnostic.
Is the lab/testing facility sharing test or procedure results timely? Is the information included in the common knowledge about the patient?	I was sent to do a 24 h protein test, but the lab did not report the very high result until the doctor's office called them two weeks later.
Does the patient know what are the signs and symptoms we are all looking for?	I was told there was nothing I could do. I did not know to be watching for headaches, swelling, RUQ pain, discolored urine, high blood pressure, nothing. I drove for 3 hours and I slept alone in a hotel while having undiagnosed severe preeclampsia. I had an MFM U/S appointment during that time as well.
Can the patient do anything?	Patients can take their blood pressure, learn more about their condition, make realistic contingency plans. We all "pack our hospital bag" when pregnant, but it is realistic to have a few different scenarios for the woman that is watched for preeclampsia. The only plan we knew/had is call your doctor and go to ER if you feel really bad.
Can we recommend other patients that might have had a similar situation in the past to volunteer to talk to the patient to help with planning, decision support, and emotional support?	Patients know what other patients need to know. I know a lot of patients that had preeclampsia that would do anything to help other patients have an easier ride. When a patient sees you for the 6 weeks post-partum visit ask if they would be willing to share their journey with other patients that might have a similar problem. I bet you would get a high percentage of people willing to help.

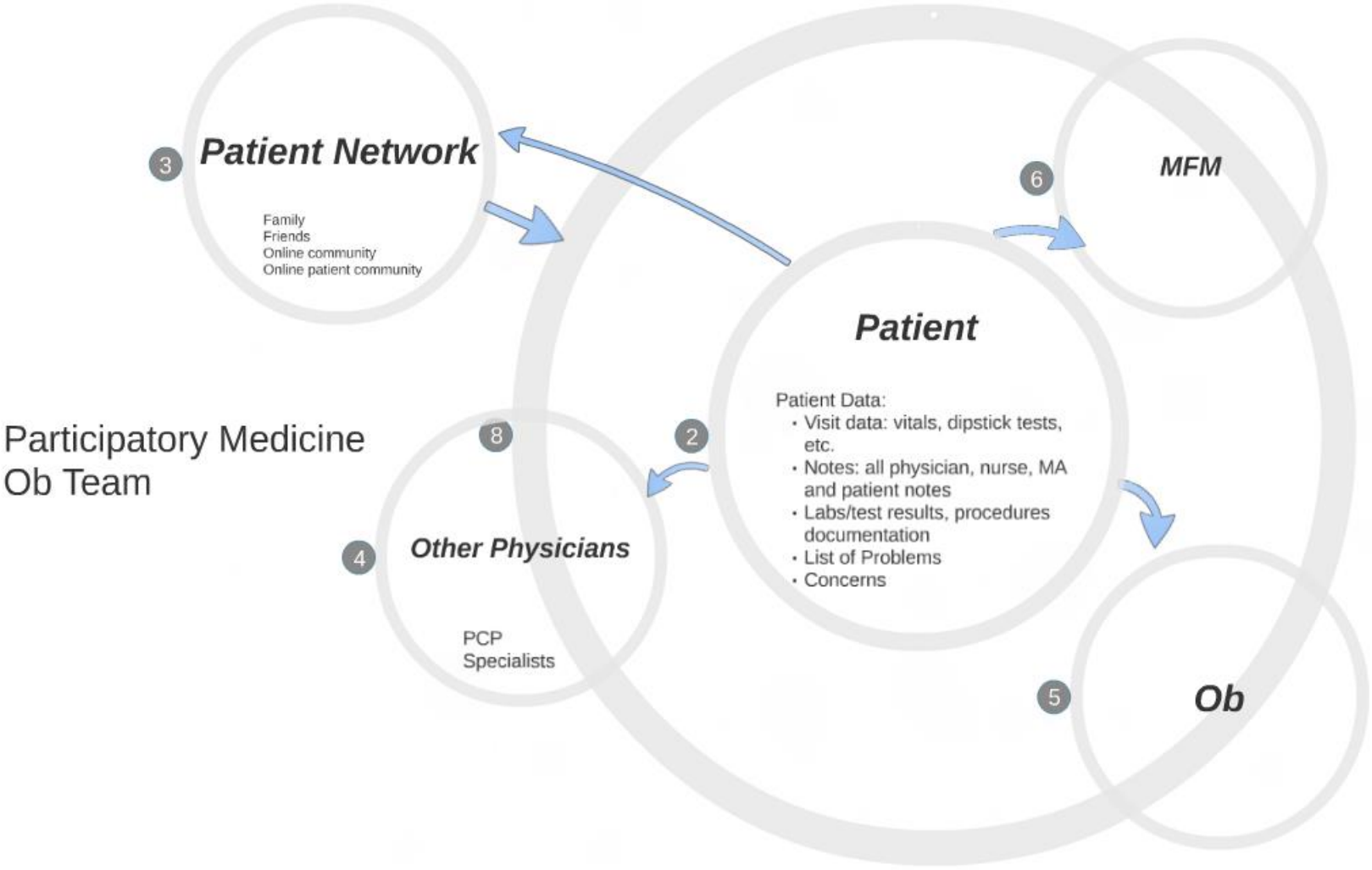
2005 High risk pregnancy (Hypertension in Pregnancy), e-Patient –Engaged, Empowered, Equipped, Enabled

Management by: MFM group – main managers, PCP – Ob Internist, Nephrologist, patient served as case manager making sure everyone has the same information



Additional Considerations

Considerations to discuss with the patient and team	What happened in my case
Is there an official case manager? Is the case manager's communication with the patient and all parties open?	The MFM group assigned a nurse as a case manager, but she did not trust my blood pressure measurements and she did not seem to hear m y worries and complaints. It is easy to dismiss pregnant women as overly hormonal. Can we learn to reassure while still listening?
Does the patient wish to include other physicians in her care?	Especially with MFM groups where care is episodic and with preeclampsia that has implications beyond pregnancy, it is reasonable to keep the PCP and other specialists informed and involved. In my experience, some MFMs were offended that I would see an internal medicine doctor or other specialists and ignored their letters and recommendations.
Does everyone in the team/group have access to all the data about the patient. Is the information easy to browse?	In the MFM group, I saw a different doctor at each visit and they seldom knew what went on. They had no records of L&D visits and tests done in the same hospital, the L&D had no access to my outpatient records. It felt like nobody owned that patient. I had to keep everyone in the loop every single time.
Do we get adequate feedback from patients to improve safety?	Always ask the patients what you can do to improve care: during pregnancy, and after pregnancy. Not the surveys that come weeks later, immediate, direct, person to person feedback: How could we have made this better for you? How can we make it better for other patients?
Does patient have the right support?	Again, making sure that the patient has the support she needs is essential. The high risk pregnancies are high anxiety events. Patients needs support from family, friends, other patients that had similar issues, a trusted PCP for continuity of care, mental health support.



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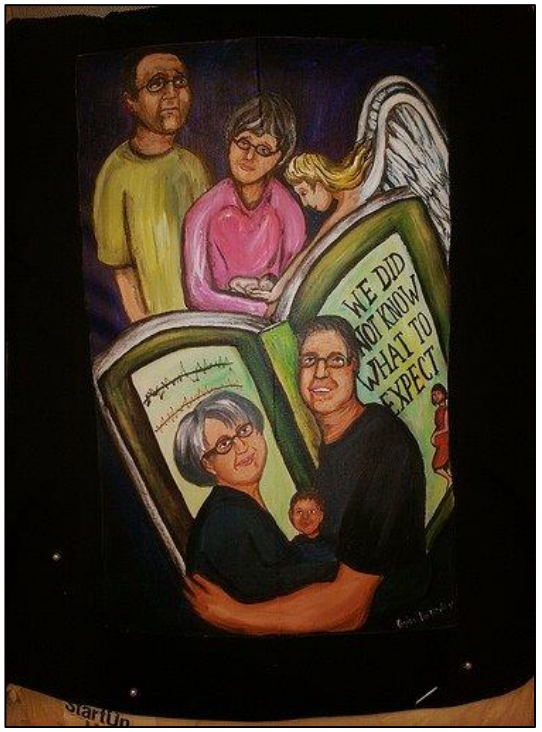
Suggestions for Next Steps

1. Learn about participatory medicine and e-patients
   - Website http://participatorymedicine.org/provider
   - Short Book Let Patients Help! - E-Patient Dave,
   - Whitepaper E-Patients Whitepaper or a shorter version compiled by E-Patient Dave
2. Advocate for better access and usability of electronic medical records for all care members and patients. Share the OpenNotes study of the Robert Wood Johnson Foundation where patients given access to their physician's notes were more involved in their own care.
3. Consider using the Patient Toolkit from the Society to Improve Diagnosis in Medicine to help patients keep track of their signs and symptoms between visits
4. Create Patient Advisory Boards/Councils
5. Investigate Social Media options to connect to patients (mostly listen) – http://www.preeclampsia.org/
6. Contact patient groups - online and offline – http://www.preeclampsia.org/
7. Build a list of patients wanting to support other patients
8. Survey patients on what could be to improve safety and care



Artist: Regina Holliday
#thewalkinggallery
http://reginaholliday.blogspot.com

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Todd Heiden

"…the cure for preeclampsia is delivery."

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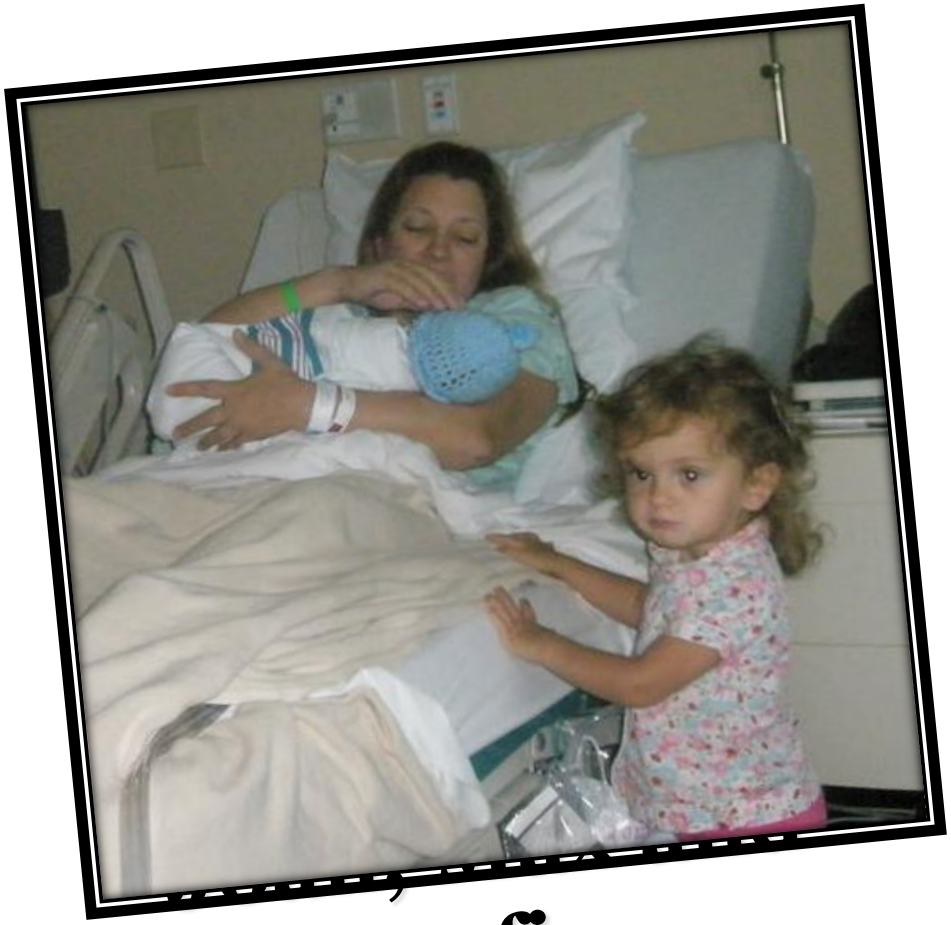

Sofie

Joan and Max

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Joan Donnelly

May 24, 1967 – August 6, 2010

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Adding the Patient to the Care Team: A Little Education Goes a Long Way

"Embracing Hope"
~ Ellen Pavlakos

PREECLAMPSIA foundation®

Eleni Zuras Tsigas

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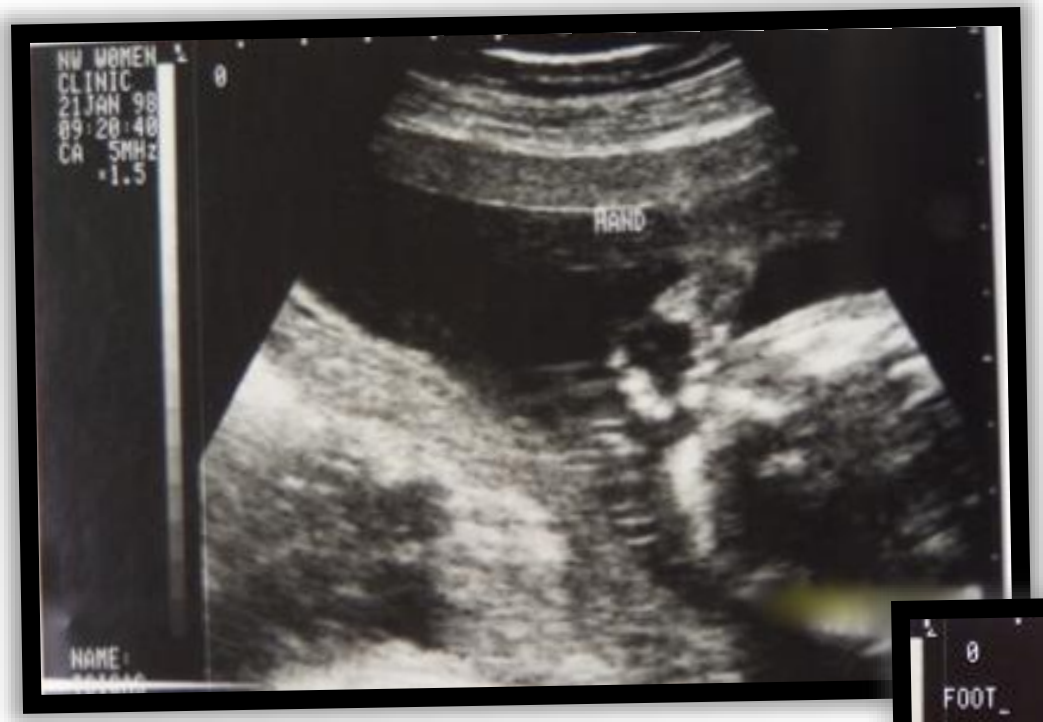
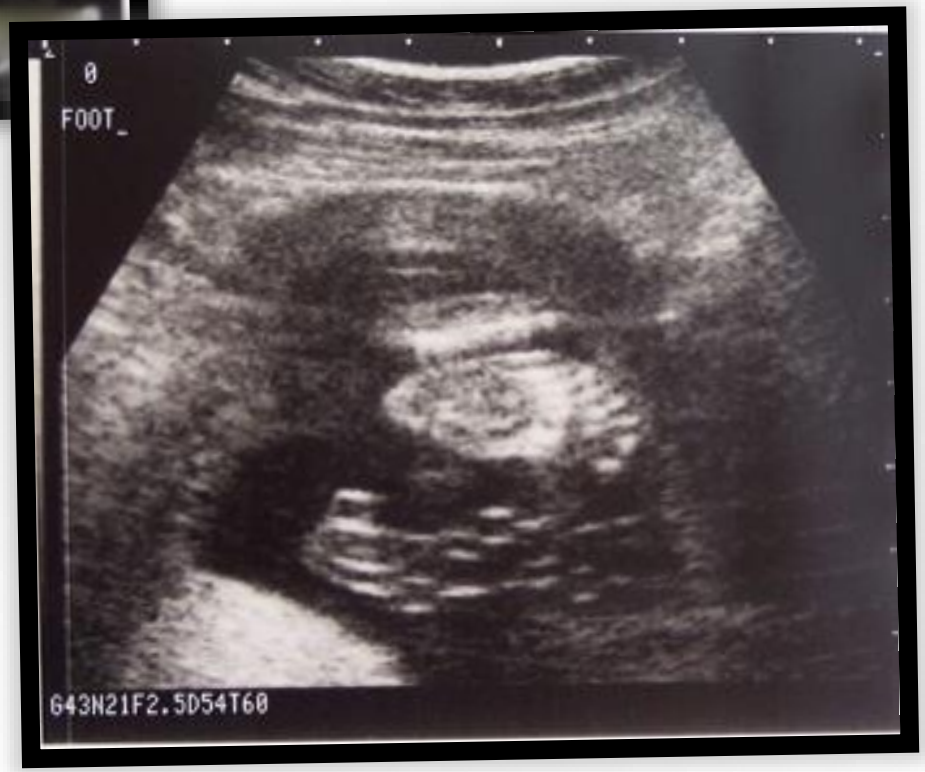


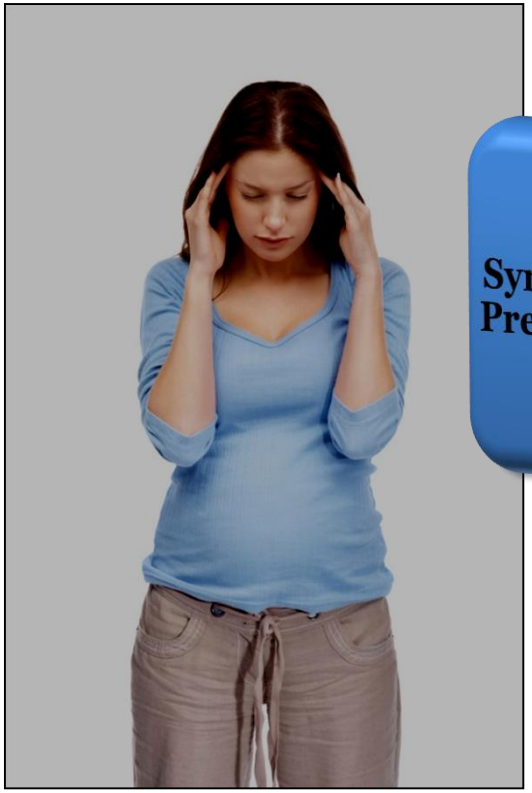


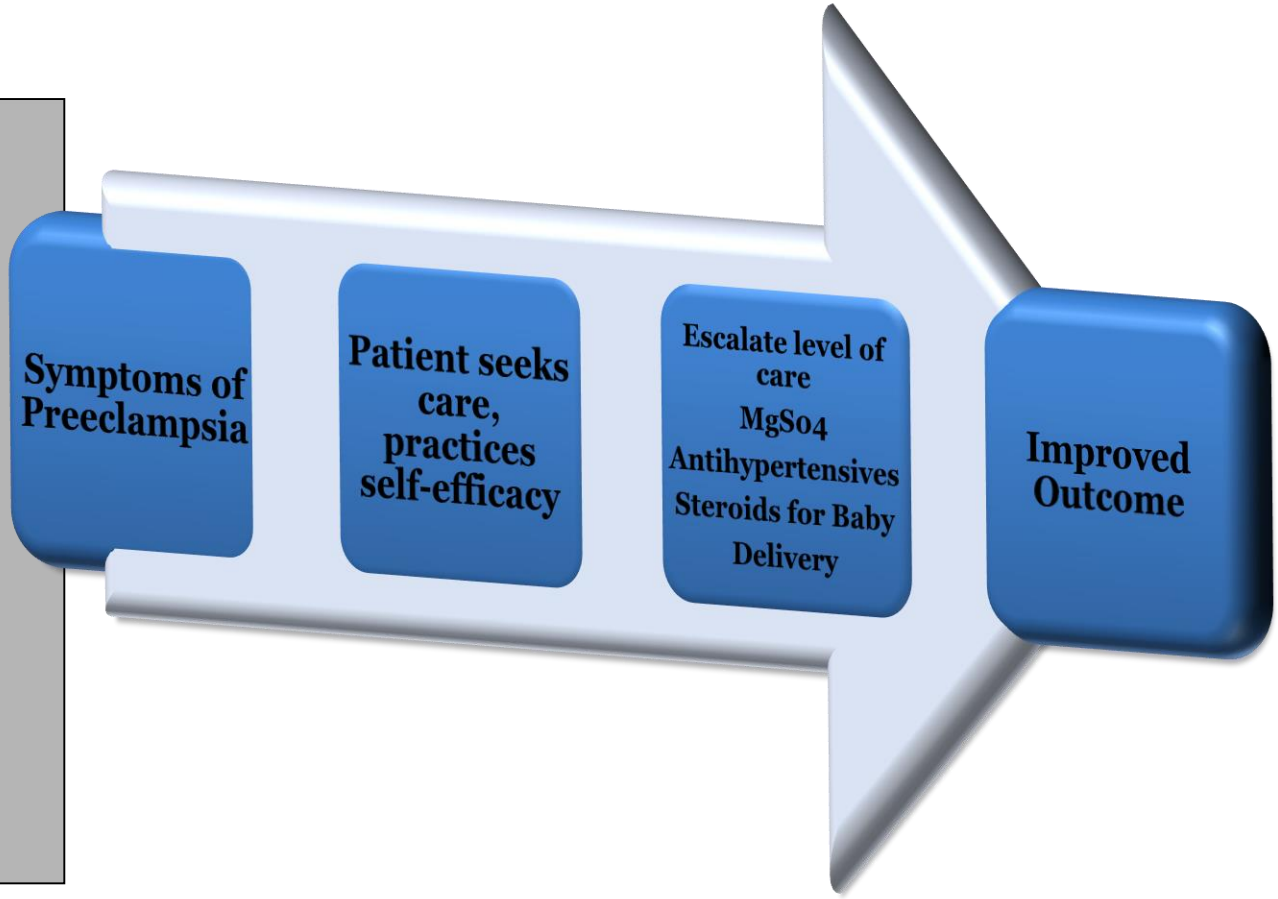
The thrill of the first look.

The horror of goodbye.

March 3, 1998 – 3 weeks earlier

Maternal Recognition Improves Outcomes





"The best way to diagnose preeclampsia is to listen to your patients."

~ Dr. Baha Sibai

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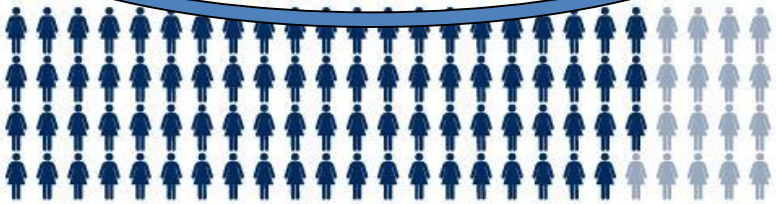
Preeclampsia Awareness

2014 Survey Results Show:

PREECLAMPSIA foundation

High overall awareness of preeclampsia among expectant and new mothers*

83% had heard of preeclampsia



Yet despite high overall awareness, there is less knowledge of the symptoms

More than half
of respondents did not associate many known symptoms with preeclampsia

Most are also aware that this serious condition related to high blood pressure requires immediate medical evaluation

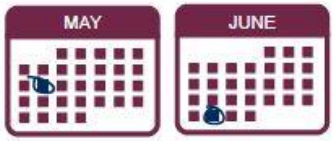
99% knew
preeclampsia is serious, even life-threatening, for mother and baby

88% knew
high blood pressure is a sign of preeclampsia

96% would call
their doctor or midwife if they experienced symptoms

Other important aspects of preeclampsia are also less known

44% didn't know
that preeclampsia can occur up to six weeks after delivery



46% didn't know
that women with preeclampsia are at greater risk for future health problems

*Survey conducted among visitors to the BabyCenter website from January 17 to January 20, 2014. Total of 1,591 respondents completed the survey; qualified respondents defined as female U.S. residents, 18 years or older, who are pregnant or have at least one child three years of age or younger.

Survey by BabyCenter®

Design by rEVO Biologics Inc.

Key Strategies for Effective Patient Communication

- In both oral and written communication, use plain, non-medical language
- Organization information into a few components ("chunk & check")
- Use "teach back" to confirm understanding with open-ended Q's
- Do not assume your patient's literacy level or understanding by appearance
- Use proven tools that support consistent message

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Other patient education materials include:

- Brochures
- Magnets
- Videos

Clinicians can order at:
preeclampsia.org/store

You, Whitney B. et al. (2012) Improving patient understanding of preeclampsia: a randomized controlled trial. *Am J Obstet Gynecol, 206, 5,* 431.e1 - 431.e5.

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IUGR baby

Buying time…

Now, a doctor-in-training!

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J Womens Health (Larchmt). 2011 Oct;20(10):1535-42. doi: 10.1089/jwh.2010.2584. Epub 2011 Aug 4.

Postpartum depression after mild and severe preeclampsia.

J Psychosom Obstet Gynaecol. 2011 Sep;32(3):126-34. doi: 10.3109/0167482X.2011.599460.

Symptoms of post-traumatic stress after preeclampsia.

J Psychosom Obstet Gynaecol. 2004 Sep-Dec;25(3-4):183-7.

Posttraumatic stress disorder following preeclampsia and HELLP syndrome.

Gen Hosp Psychiatry. 2002 Jul-Aug;24(4):260-4.

Posttraumatic stress disorder after pre-eclampsia: an exploratory study.

BMC Pregnancy Childbirth. 2012 Nov 10;12:125. doi: 10.1186/1471-2393-12-125.

A systematic review of the relationship between severe maternal morbidity and post-traumatic stress disorder.

Psychosomatics. 2009 Mar-Apr;50(2):131-7.

The relationship between acute stress disorder and posttraumatic stress disorder in the neonatal intensive care unit.

Birth. 2011 Sep;38(3):246-55. doi: 10.1111/j.1523-536X.2011.00477.x. Epub 2011 May 20.

Poor health-related quality of life after severe preeclampsia.

J Turk Ger Gynecol Assoc. 2013 Mar 1;14(1):11-4. doi: 10.5152/jtgga.2013.03. eCollection 2013.

Increased psychological trauma and decreased desire to have children after a complicated pregnancy.

Reprod Sci. 2011 Jul;18(7):645-53. Epub 2011 Mar 18.

Posttraumatic stress disorder following preeclampsia and PPROM: a prospective study with 15 months follow-up.

Arch Gynecol Obstet. 2013 Apr;287(4):653-61. doi: 10.1007/s00404-012-2611-0. Epub 2012 Nov 23.

Fathers with PTSD and depression in pregnancies complicated by preterm preeclampsia or PPROM.

J Dev Behav Pediatr. 2009 Feb;30(1):50-6.

Acute posttraumatic stress symptoms among urban mothers with newborns in the neonatal intensive care unit: a preliminary study.

Acta Obstet Gynecol Scand. 2013 Jul;92(7):746-61. doi: 10.1111/aogs.12175.

Anxiety and depression following preeclampsia or hemolysis, elevated liver enzymes, and low platelets syndrome. A systematic review.

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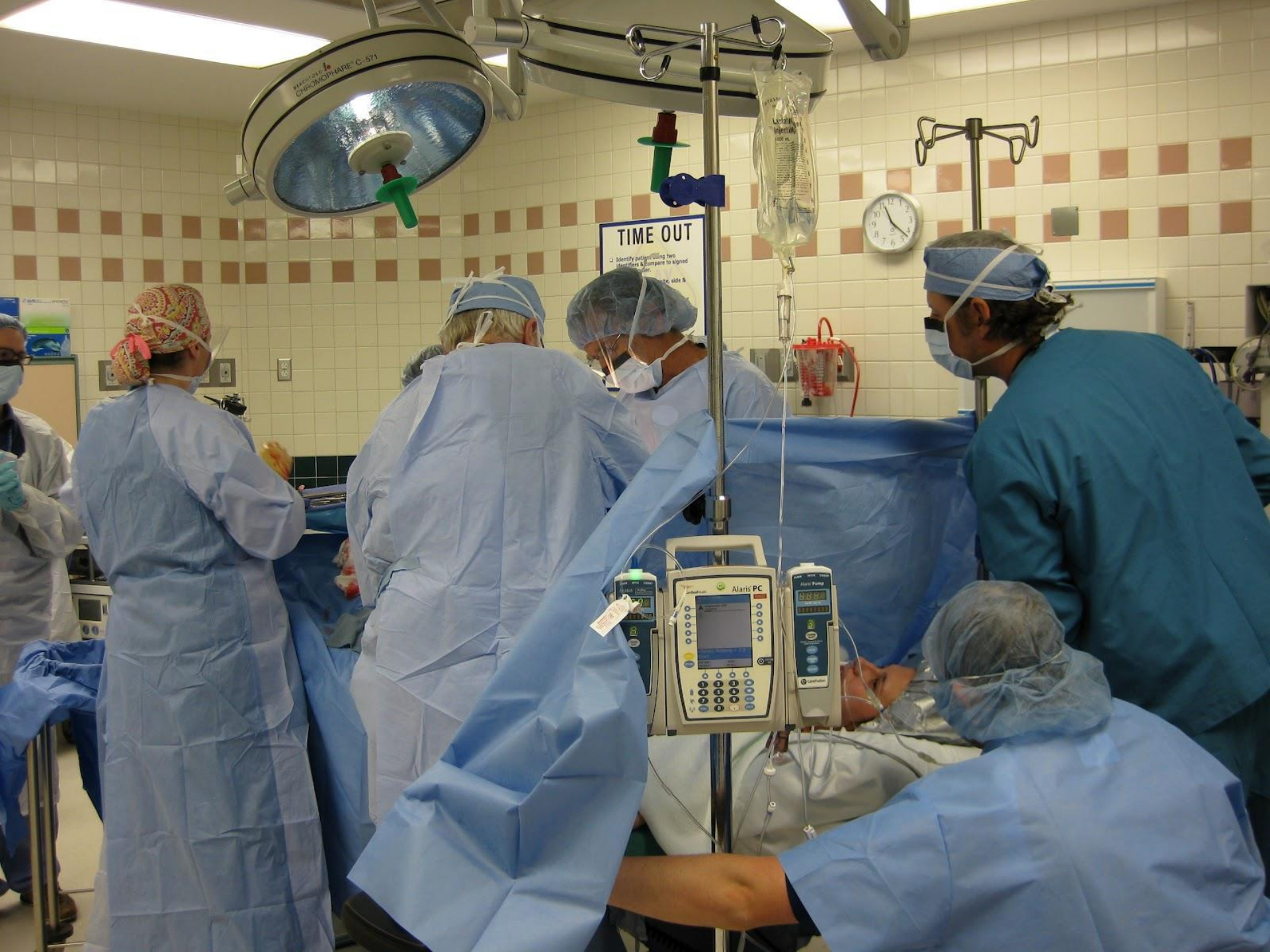
TIME OUT
Alaris PC


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Birth Trauma? Get Help!

Failure **Guilt** **Anxiety**

Anger **Depression**

- Breslau Short Screening Scale (7 Qs) for PTSD
- Psychological assessment & treatment
- Chaplain or spiritual leader
- Local or online support groups (the more topic-specific, the better)
- Grief counselor

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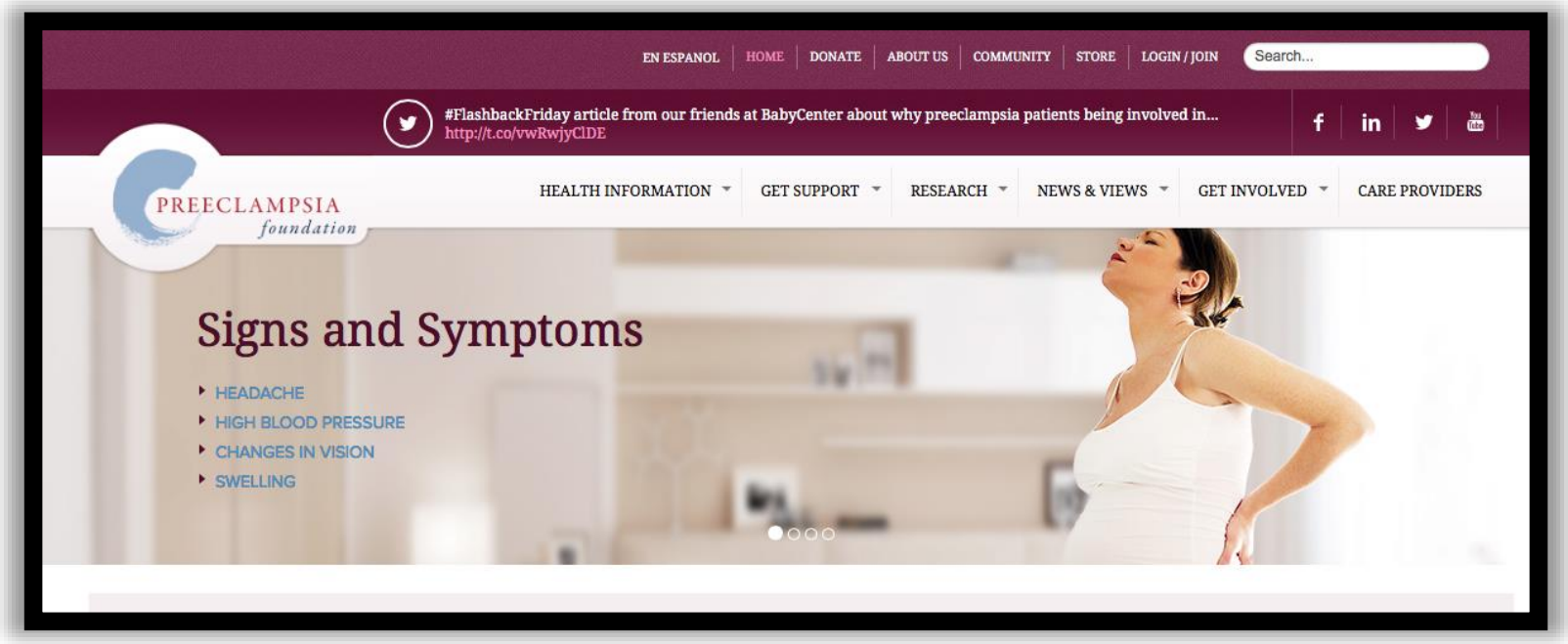

www.preeclampsia.org

A trusted resource for your patients

The PREECLAMPSIA Registry™

www.preeclampsiaregistry.org

A trusted resource for researchers

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Q&A Session

Press *1 to ask a question



You will enter the question queue
Your line will be unmuted by the operator for your turn

A recording of this presentation will be made available on our website:
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Next Safety Action Series

Presentation of the Hypertension Patient Safety Bundle

Friday, June 26, 2015 | 1:00 p.m. ET

Peter Bernstein, MD, MPH, FACOG
Director, Maternal-Fetal Medicine
Professor of Clinical Obstetrics & Gynecology and Women's Health
Montefiore Medical Center/Albert Einstein College of Medicine

Jennifer Frost, MD, FAAFP
Medical Director, Health of the Public and Science
American Academy of Family Physicians

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