




The Unexpected Project
Giving a Voice to the Survivors
of Pregnancy-Related Death
and Near-Miss

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FUNDRAISER/PHILANTHROPY
ADVISOR

My Story 

I have no conflict of interest with regard to this presentation.

1985

Classic preeclampsia
with first baby.
Six weeks bedrest,
induced delivery,
"natural" birth at term.
Baby Jonathan is fine.





1986

Light-headed, spotting, confused, severe abdominal pain


Called 911
Code Blue

Emergency surgery due to ruptured ectopic pregnancy

Naturally, baby does not survive.

1990

Healthy, full-term pregnancy
Baby Sebastian is fine




1996

38-week check-up
Trace proteinuria
BP 138/78

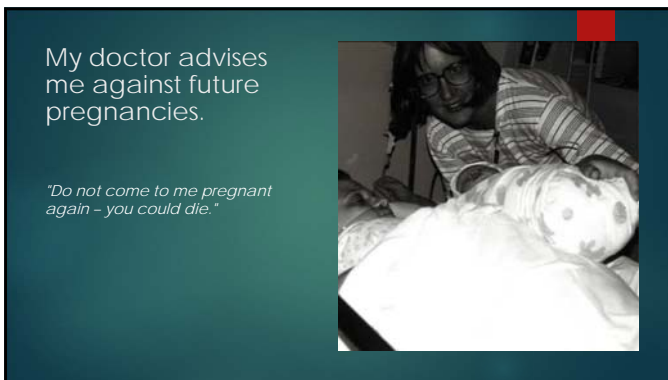
Induced, failure to progress,
C-section

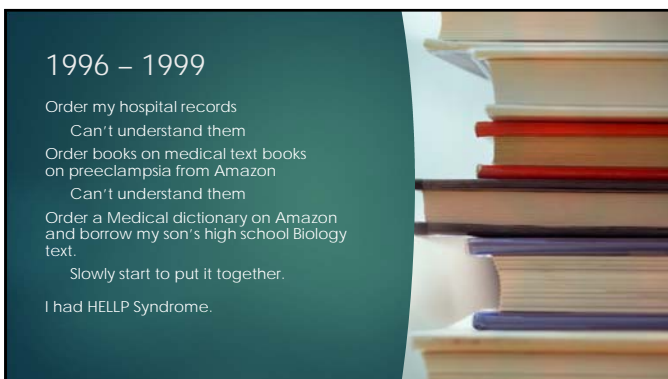
12 hours later I nearly die on the operating room table

Baby Kieran is fine









September 9, 1999



Well-managed pregnancy with Dr. Tom Easterling, MFM, at the University of Washington.

He confirms I had HELLP Syndrome in my last pregnancy but assures me I am NOT "interesting" and he will not let me die.

Planned C-section @ 36 weeks

Baby Gabriel is fine.



One week later


ELEVATED BP, TERRIBLE HEADACHE – RETURN TO THE HOSPITAL

September 16, 1999

Readmitted

- ▶ Lasix bolus
- ▶ Lasix and saline IV
- ▶ Antihypertensives
- ▶ The dreaded Mag

I am kept in intensive care overnight.




September 17, 1999

Dr. Easterling visits me in the morning and says I am "interesting" after all.

I ask him where I can send my check


He tells me there is no place and challenges me to "do something"

The Preeclampsia Foundation is born

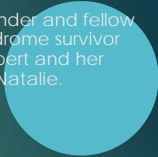


Preeclampsia
Foundation's
Beginnings





My co-founder and fellow HELLP Syndrome survivor Joan Lambert and her daughter Natalie.



PF Founders - 20th Anniversary
September 9, 2019

- Deane Easterling (Dr. Easterling's wife)
- Joan Lambert*
- Gabriel Garrett-Singh
- Anil Singh-Molares*
- Anne Garrett*
- Carrie Barrion Schmidt (first staffer)
- Dr. Tom Easterling

*Founders



1999 - Critical first decisions

- ▶ 1. It will be a US-based 501(c)(3) nonprofit
- ▶ 2. It will be research agnostic - not tied to any one university or research agenda
- ▶ 3. Firewall between the medical board and the patient support
- ▶ Dr. Easterling recruits our first Medical Board within two months.


NAME	WHERE THEY WORKED	ON
Thomas R. Easterling, MD	University of Washington	Hemodynamics
Marshall Lindheimer, MD	University of Chicago	Nephrology
James Martin Jr., MD	University of Mississippi	HELLP Syndrome
Phyllis August, MD, MPH	Cornell University	Nephrologist
James R. Roberts, MD	Magee Women's	Endothelial Cells
John T. Repke, MD	University of Nebraska	Calcium Metabolism

- ▶ Developed logo
- ▶ Branding
- ▶ Style guide
- ▶ Mission, vision, and values
- ▶ Design the website
- ▶ Write its contents
- ▶ have it reviewed
- ▶ and reviewed
- ▶ and reviewed by our Medical Board. It passes the Medical Board review.
- ▶ Register the URL and launch : www.preeclampsia.org

1999 - 2000



Our first logo




Our site goes live July 1, 2000

One week later...

Alisa Schultz, who lost her first baby, writes us to ask us why we are not doing more.

We recruit our first volunteer. Alisa joined our Board of Directors

We also realize we have no idea what we signed up for...



2000 - 2003

- ▶ DEVELOPED IMPORTANT ALLIANCES
 - ▶ Professional organizations
 - ▶ The International Society for the Study of Hypertension in Pregnancy (ISSHP)
 - ▶ The North American Society for the Study of Hypertension in Pregnancy (NAASHP)
 - ▶ The Society of Maternal Fetal Medicine (SMFM)
 - ▶ The American College of Obstetricians & Gynecologists
 - ▶ Research Institutions
 - ▶ NIH - NHLBI, NICHD
 - ▶ WHO
 - ▶ CDC
 - ▶ Universities and colleges where members of the professional organizations work
 - ▶ Non-Governmental Organizations (NGOs)
 - ▶ March of Dimes
 - ▶ Save the Children
 - ▶ American Heart Association

2000 - 2003

- ▶ DEVELOPED MORE IMPORTANT ALLIANCES
 - ▶ Funders
 - ▶ Anil Singh-Molares and Anne Garrett continue to provide the majority of the financial support for the PF
 - ▶ The Apex Foundation grants \$25K a year for three years
 - ▶ Nancy Reiland and her husband make a major gift
 - ▶ Survivors
 - ▶ Continue to connect with survivors throughout the USA
 - ▶ Host our first Survivors Summit (Seattle, 2003)
 - ▶ Recruit our first Administrative Director - Jaime Nolan - a survivor who lost her first born - Grace
 - ▶ Volunteers
 - ▶ Angala Demooore - launched our Forums
 - ▶ Carrie Bariton Schmidt - project manager for our first NH/NICHD study

2001 - Highlights

- PF awards first two Vision Grants **March**
- Anne appointed to NHLBI Hypertension in Pregnancy Task Force. **April**
- Partner with the NICHD to do the first genetic study on preeclampsia. **June**

2002 - Highlights

- Glamour article **March**
- ISSHP Conference, Toronto **June**
- White Ribbon Alliance conference - New Delhi, India invited to apply for a grant - the Bill & Melinda Gates Foundation **December**
- Anne speaks at the press conference to announce the Smart Moms Bill, Washington, D.C. **April**
- Eleni Tsigas joins the PF. She goes on to become the Executive Director in 2007. **August**

2003 – Highlights

International Preeclampsia Summit funded by a grant from the Gates Foundation.

Launch the Patient Forums – huge success!

April

Survivor Ileana Balcu and her husband Paul Dorsey's company Dulciani donate in-kind services to develop the first patient registry

August

Issued Call to Action: The Seattle Mandate – calling for international use of MgSO4 together with the WHO and the MacArthur Foundation

July

2003

Host the first International Preeclampsia Summit

- ▶ Brought together experts in
 - ▶ Preeclampsia (Our Medical Board, other experts, the WHO)
 - ▶ Disseminating Care (Save the Children, Averting Maternal Death & Disability, etc.)
 - ▶ Patient Advocates
- ▶ Funded by our first grant from the Bill & Melinda Gates Foundation

2003

Launch the Preeclampsia Foundation online forum.

From the (mostly) women posting we recruit moderators, divide up topics, develop standards, train new moderators, and circle back for support.

Forum	Topic	Start Date	Participants
1	1. Preeclampsia: What is it? How do I know if I have it? How do I prevent it?	4/1/03	100
2	2. Preeclampsia: How do I know if I have it? How do I prevent it?	4/1/03	100
3	3. Preeclampsia: How do I know if I have it? How do I prevent it?	4/1/03	100
4	4. Preeclampsia: How do I know if I have it? How do I prevent it?	4/1/03	100
5	5. Preeclampsia: How do I know if I have it? How do I prevent it?	4/1/03	100
6	6. Preeclampsia: How do I know if I have it? How do I prevent it?	4/1/03	100
7	7. Preeclampsia: How do I know if I have it? How do I prevent it?	4/1/03	100
8	8. Preeclampsia: How do I know if I have it? How do I prevent it?	4/1/03	100
9	9. Preeclampsia: How do I know if I have it? How do I prevent it?	4/1/03	100
10	10. Preeclampsia: How do I know if I have it? How do I prevent it?	4/1/03	100

Forum		Topics	Posts	Last Post	Moderator(s)
- Announcements					
What's new	We have added a new forum facility to our website to allow our community to discuss important issues, concerns, and to share information.	20	20	04/04/2003 05:37:29 by: announcements	announcements
- Preeclampsia foundation					
Ask the Experienced	This section is for discussions with other women who have probably been through the same signs/symptoms that you may be experiencing. Please note, if you require a response from a medical representative of the Foundation, please refer to the Ask The Experts section.	67	393	04/07/2003 19:55:54 by: announcements	announcements announcements
Ask the Experts	Do you have a question that you would like a medical representative to answer? Post and read previous questions and answers here! Please note, if asking a question in this section, to ensure that a response is given via a medical expert, we lock your question to the general public, allowing viewing only.	57	101	04/04/2003 18:27:44 by: AnneB_Belmont	announcements Esst_Gil_Lafl
Charity events & donations	This forum is to announce charity events and donation information.	3	10	08/28/2003 09:22:24 by: announcements	announcements
Dads	Are you worried about your partner's pregnancy? Has your partner already had preeclampsia? Do you have advice for other dads who could be going through similar experiences as yours? Post here.	0	0	03/26/2003 00:39:15 by: announcements	announcements
First-time Moms	Are you pregnant with your first child? Are you up to speed with the symptoms of preeclampsia? Post your thoughts here!	1	8	03/04/2003 12:15:32 by: KissMeBeezus	announcements
Person More Involved		3	10	02/11/2003 15:06:50	announcements

A glimpse of the Forums - 2003

2003

- ▶ Speak at the U.S. Senate conference to announce the SMART Moms Act.
- ▶ Convince the March of Dimes to work with us.
- ▶ Issue a Call to Action with the WHO at Bellagio.
- ▶ And my mother dies of breast cancer.



2004

- ▶ March 2, 2004
 - ▶ Jaime and Joe Nolan lose their baby - Grace Ann
- ▶ Shortly after that - Jaime signs on to be a volunteer and becomes one of the most important volunteers the Preeclampsia Foundation ever has.

2005 - Highlights

<p>Shelly Warner Bridgewater, Iowa schoolteacher, dies. Her baby survives</p> <p>January</p>	<p>1st Fundraising walk - Promise Walk. 18 locations nationally.</p> <p>May</p>	<p>NICHHD Study Complete</p> <p>December</p>
<p>1st Fundraising Gala Saving Grace - a Night of Hope</p> <p>October</p>	<p>2nd Survivors gathering - Wheeling, W. Virginia</p> <p>August</p>	


2005

- ▶ Shelly Warner Bridgewater dies January 9, 2005
- ▶ Shelly is from Iowa
- ▶ She was a teacher
- ▶ Her family operates a heritage farm in Walcott

Shelly's death made everything very real for me...

- ▶ My family is 5th generation Iowa farmers
- ▶ I was a teacher when I nearly died
- ▶ Neither of us were "supposed" to die





My
epiphany

The Myths

- ▶ Women don't die in childbirth in the USA ❌
- ▶ Preeclampsia only happens in the first ❌ pregnancy
- ▶ Only "old, fat, sick, poor, (insert any negative stereotype)" women get sick during pregnancy ❌
- ▶ Once you have the baby – you are fine – the preeclampsia goes away. ❌
- ▶ Racism does not contribute to maternal death. ❌



2010 Amnesty International Sounds the Alarm

March 12, 2010, Amnesty International issued a report entitled *Deadly Delivery: The Maternal Health Care Crisis in the USA*, documenting that despite the USA spending more on health care than any other country, it ranked 41st (at the time of publication) in terms of maternal death.

Half of these deaths are preventable, and the report clearly demonstrated many barriers women face in accessing high quality maternal care.



2011
Co-founded the Unexpected Project

2012
Anne Garrett Addison and Jennifer Binkley Carney establish a small production company for the purposes of filming a documentary - UNEXPECTED.

2013 – Crowdsourcing Campaign

Raised \$10,675 through Indiegogo to fund our documentary

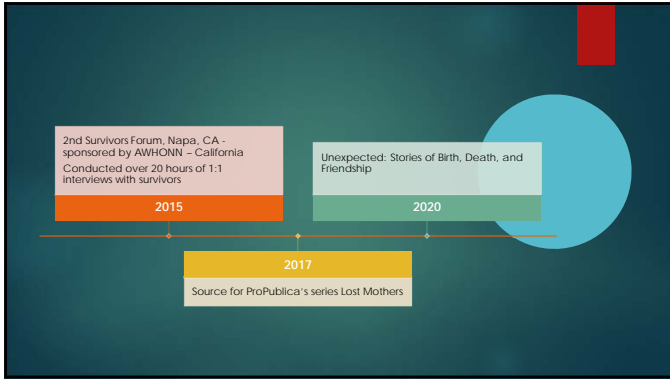
Unexpected

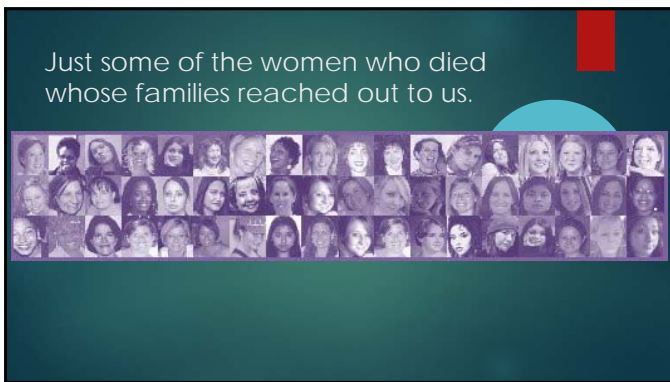
With that we were able to:

- ▶ Incorporate Unexpected Productions
- ▶ Purchased equipment (camera, microphone, laptop, software)
- ▶ Travelled to Chicago and Iowa
- ▶ Launched our Facebook pages "Save a Mother's Life" and "Unexpected Project"
- ▶ Save a Mother's Life – Mother's Day Campaign with Lucina Maternity

2014

- ▶ Travel and filming in Minnesota and California
- ▶ Huffington Post blog
- ▶ Filmed CA Democratic delegate Karleen Basch as she advocated for mandated reporting of maternal death, Sacramento, CA.
- ▶ 1st Survivors Forum, San Jose, CA – sponsored by Lucina Maternity and the Sobrato Family Foundation.
- ▶ Supported near-miss survivor and family in crisis










Jennifer
Young
Tait



Joan
Donnelly



Nicole
Nyboer



VIP BOOTH


RUBY

Kristie Rubino

SO


IEF

A dark teal slide with a red square in the top right corner and a light blue circle. The left side features a photo of Kristie Rubino in roller derby gear, including a helmet with 'RUBY' on it, a red tank top, and black arm guards. The background of the photo includes a sign for 'VIP BOOTH' and a banner with 'SO' and 'IEF'.



June Higson

A dark teal slide with a red square in the top right corner and a light blue circle. The left side features a photo of June Higson, a young girl in a yellow shirt, holding a framed portrait of a woman. There is some small, illegible text in the top left corner of the photo.



Karen Sclafani

A dark teal slide with a red square in the top right corner and a light blue circle. The left side features a black and white photo of Karen Sclafani wearing a hat and a dog, possibly a husky, in a snowy or mountainous setting.



Caroline
Still Wiren



Tatia
Oden
French

And sometimes,
life gets in the
way

- ▶ Two divorces
- ▶ The premature death of my mother at 69
- ▶ I was diagnosed with chronic pulmonary sarcoidosis
- ▶ One son was diagnosed with schizoaffective disorder, but...

My four sons are amazing, healthy, and well. We are blessed.



Now what?

- ▶ We continue to support a community of over 1K survivors through our Facebook page
- ▶ Funds permitting, we hope to take the book on a national "Couch-to-Couch" tour to meet our friends and fellow survivors and hear their stories
- ▶ We are throwing our weight behind the important work of other organizations that have sprung up and legislation to change the course of care, particularly for women of color.

What has changed?

- ▶ Most of the myths that impacted my pregnancies have been debunked
 - ▶ It only happens in first pregnancies
 - ▶ You cannot get again
 - ▶ Delivery is the cure
 - ▶ Only fat/old/drug addicts/poor women get it
 - ▶ Only seizures can kill you
 - ▶ Women don't die in childbirth in the US
 - ▶ It is rare

Maternal death in the USA is now considered a real and important issue.

Unexpected:
Stories of Birth, Death & Friendship

available October 2020

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