

*Advocating for the health of your baby. If not you, then who?*

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**Marama** (miscarried), **Brennan William** (fullterm born still),  
**Bryna** (ectopic)

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[www.babylossfamilyadvisors.org](http://www.babylossfamilyadvisors.org)



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*Learning Objectives*

- List 2-3 stories of mothers who successfully or unsuccessfully used their intuition/mothers' sense when advocating for their baby.
- Speak/write 2-3 examples of what parents might say to a medical provider to show their concern for the health of their baby and to seek a care strategy that may or may not be supported by the provider
- What 2-3 options do mothers have to seek/gain care for their baby when they are turned down or not heard by their medical provider



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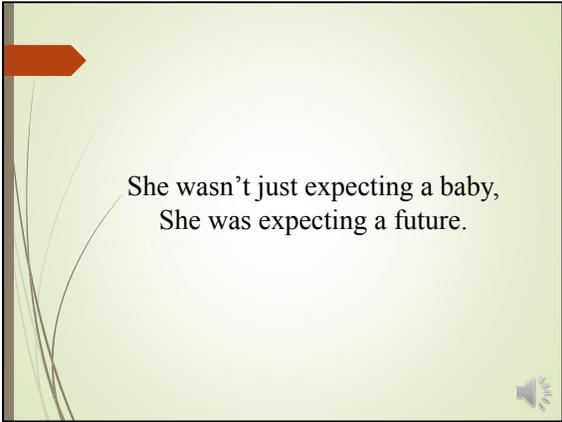
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She wasn't just expecting a baby,  
She was expecting a future.

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WE HAVE  
THE RIGHT  
TO BE  
HEARD

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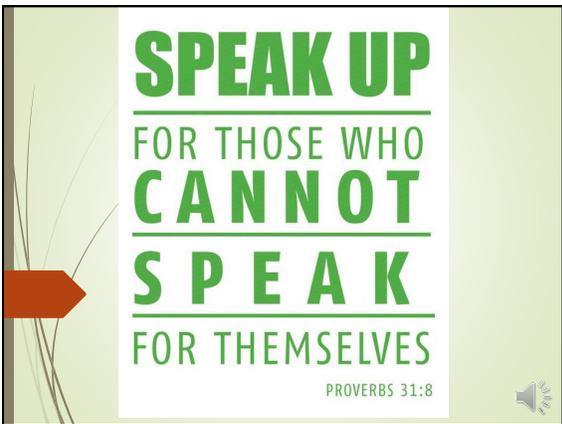
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**SPEAK UP**  
FOR THOSE WHO  
**CANNOT**  
**SPEAK**  
FOR THEMSELVES

PROVERBS 31:8

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**Who is This Session For?**

Both Parents and Professionals deserve to better understand each other's role when a fragile pregnancy or a serious problem occur. It is the parents' baby and the caregivers are invited in to give care to both mom and baby. All want the same result- a healthy mother and child.



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**Who is This Session For?**  
**PARENTS...**

Who understand that things can go wrong and want to do their best to have a healthy pregnancy and baby. And who want to learn how to be an effective advocate for mom and baby's health.

And

Those who have had a loss (baby with problems or who has died) and who seek ways to go forward in a rainbow pregnancy with more preparation, plans and strategies to do things differently.



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**Who is This Session For?**  
**MEDICAL PROVIDERS...**

Who wish to be respectful and good communicators with, and care providers to, families under stress and in crisis, including when there are health issues, an abnormal pregnancy diagnosis, a baby dies, a baby ends up in the NICU or in subsequent pregnancies after losses such as serious illness and death.



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*How to communicate assertively*

- Be the highest version of yourself when you communicate. When stressed it is easy to get angry and defensive.
- There may be times where you realize your patient/your provider may be mad or upset with you. If you worry about that, your communication and the fears will make you weak (or too bold) and ineffective.
- You can say anything when you say it with love in your heart. Say what needs to be said but don't do it from a frail, defensive ego or with harshness, but with strength and compassion



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*The Goals of this Presentation*

**Both medical professionals and parents**

- To promote clear, respectful, assertive communication
- To promote mutual respect in decision-making and best care practices
- To teach parents to self-advocate for mom and preborn/newborn baby, having an active, assertive and courageous voice
- To respect and promote mother's intuition/sense as valid and important
- To make the best decisions at the time with what is known, since no one is perfect
- To promote healthy adaptation to tragic and less than ideal/planned for outcomes during pregnancy, at birth and afterwards



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*The Goals of this Presentation*

- To promote clear, respectful communication which includes listening to each other, rephrasing, reviewing and refocusing
- To promote mutual respect – with realizations that:
  - The parents should be able to be in control about what happens to, and decisions about, 'mom/baby' within the law and their rights
  - The medical professionals may/will have strong options, expertise, and feelings about how they are being addressed and their knowledge/experiential base



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### *Important to Remember*

Parents are in shock and may have serious worries/fears – it might be hard for them to be calm and act respectfully despite their normal nature to do so. And some have high drama/emotions in their personalities and experience; this may not be the time to expect them to change.

- Providers are often impacted by the potential of complications and loss of the baby (or mother). This can color their behaviors and ability to remain calm keeping their emotions in check. They may also not respond well to anger, blaming, raised voices, etc from parents and families, despite their best intentions.

Can we seek to *give each other grace* as we honor each other's humanness and attempts to do our best, despite the stress that comes with unexpected outcomes?

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### *Love Stories*

Parents whose concerns were disregarded resulting in the death of their baby

Kristina  
Emilie 12 #, stillborn at 41.5 weeks  
Yadira  
[www.gbs-intl.org/Santiago-nicholas](http://www.gbs-intl.org/Santiago-nicholas)  
Amy  
[gbs-intl.org/elijah](http://gbs-intl.org/elijah)

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Kristina R.  
Emilie

Stillborn baby - 12 # baby, gestational diabetes missed, extreme swelling, excessive weight gain, fever, begged for induction, kept calling, made to go 41.5+ weeks before allowing baby to be born-Emilie had died by then.

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### *Kristina's Advice*

I would tell other mothers to go to L & D and have them check you.

If I had done that when I didn't feel good, things might have been different. The difference from what I've learned is that L & D must check you out. They will look at the baby, check the heart rate, etc. **Now the difficult part is that the doctors tell you to call and talk with someone. I followed that advice and it failed me.** If I had instead just gone to L & D and told them I wasn't feeling good or that I had a fever, they would have checked me over, realized my baby was HUGE and gotten her out asap. But I called and they said to stay home.

**Mothers must remember that they know themselves more than the doctors do.** If you don't feel good or something doesn't seem right, then go. **DO NOT CALL**, just go. Trust yourself, mothers are usually right.



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**SANTIAGO NICHOLAS**  
— USA

**June 26, 2018- July 2, 2018**

**Early-onset**

**Mother's GBS Status:**

Tested Negative

**Gestational Age:** 38 weeks,  
4 days

**Age harmed:** 1 day old  
Membrane sweep 38 weeks,  
1 hour old problems began,  
mother could tell, worried, kept  
telling staff something was  
seriously wrong. Staff did not  
see problems or act on them for  
many hours.

Baby did not get antibiotics  
early, died after 11 days. **GBS**  
sepsis and meningitis.



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**ELIJAH** — USA      **Prenatal-onset**

**Died in utero June 21, 2016 and was delivered June 22, 2016**

**Mother's GBS Status:** Positive in urine culture

**Gestational Age:** 22 weeks

**Age Harmed:** 22 weeks in utero

In painful labor at 14 weeks, wanted a specialist, shut down by  
doc, told by nurse premature labor doesn't start till 3<sup>rd</sup> tri, wanted  
GBS treatment, not given, placenta was severely infected



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*Love Stories*

A Parent who changed the outcome  
Shannon

A Provider who changed the outcome  
Dr. K. G.

Mom in ER  
Almost a tragedy




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Savannah

Irelynn




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*Shannon's Advice*

Find a doctor you trust who will listen to you and who respects you. If you have any problems or concerns request your doctor to examine you, not just any doctor. They know you and (hopefully) trust you.

- Always, always, always trust your gut. You can be wrong 10 times, but what about that 1 time you were right?
- Find someone who will listen to you. If not your doctor or hospital, go to another hospital. Fight to get that baby here safely. You will never regret it, but if you don't have a happy ending, you will regret it the rest of your life.
- Pay close attention to your baby's patterns. If there is a change - increase or decrease - it could be the only warning you ever get that something could be wrong. Don't call your nurse or OB - just show up!
- Surround yourself with a trusted team of advocates. It might be your doctor, another Mom, a doula or midwife, or a good friend. If a crisis ever happens, you will need their support.




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Savannah

Irelynn

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