



**STAR LEGACY**  
FOUNDATION

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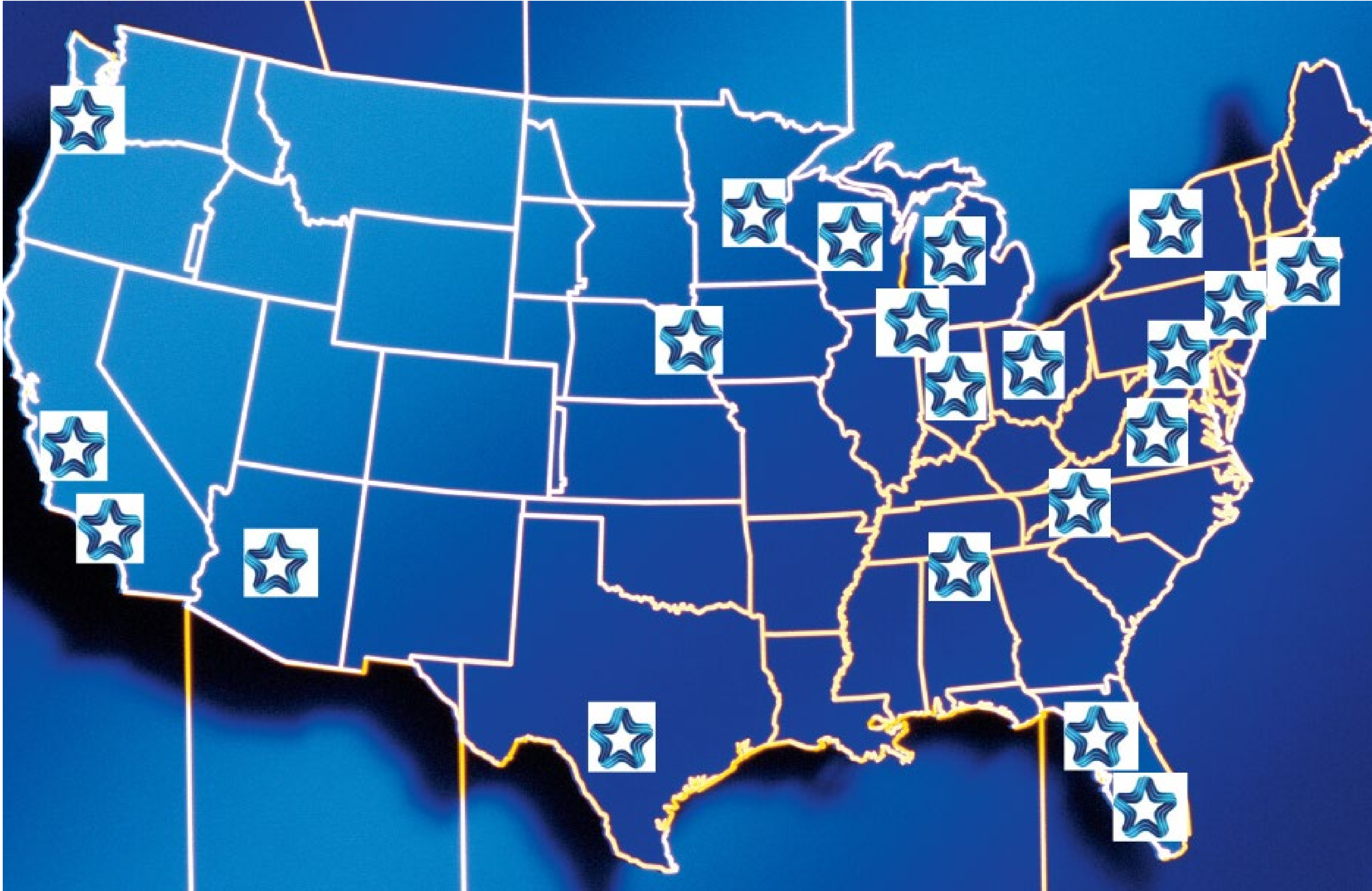
# STAR LEGACY FOUNDATION

# MISSION



*To increase awareness, support research, promote education, and encourage advocacy and family support regarding stillbirth, pregnancy loss, and neonatal death*

STAR LEGACY FOUNDATION				
RESEARCH	EDUCATION	AWARENESS	ADVOCACY	FAMILY SUPPORT





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# STAR LEGACY FOUNDATION PROGRAMS

# RESEARCH

## RESEARCH GRANTS

- \$60,000 granted in 2019

## PREGNANCY RESEARCH PROJECT

- Launched in June 2019
- 1300+ participants in first 6 months
- Includes maternal survey and review of pregnancy health records



## PREGNANCY RESEARCH PROJECT



You are invited to participate in the Pregnancy Research Project to help researchers learn more about healthy pregnancies and poor pregnancy outcomes.

### AM I ELIGIBLE?

#### You are eligible to participate if:

- You are at least 18 years of age or older
- You speak English and your medical records are in English
- You have delivered a living baby within the last five (5) years
- You are currently pregnant at 12 weeks gestation or more
- You have had a poor pregnancy outcome after 12 weeks gestation at any time in the past (miscarriage, stillbirth, baby born living but did not survive the first 30 days of life, pre-term birth, etc.)

### WHAT DO I HAVE TO DO?

#### Women who participate will be asked to:

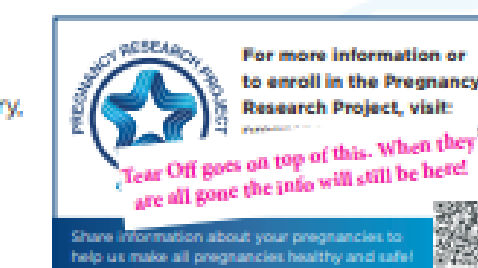
- Sign a consent form
- Allow the Project to request medical records about your pregnancy. This will include prenatal, laboratory, medical imaging, delivery, and newborn records.
- Complete a survey that will ask you questions about the pregnancy. It will focus on your experiences that are not usually recorded in medical records.

### WHAT WILL BE DONE WITH MY INFORMATION?

All data that could identify who you are will be removed. Then, medical researchers will use the information to examine trends of pregnancy outcomes in various geographic locations, pregnancy characteristics, level of care, maternal or fetal characteristics, racial or socioeconomic populations, and over time. Ultimately, we hope this project will help us learn more about what causes poor pregnancy outcomes, how to prevent them, and how to best support families.

**For more information or to enroll in the Pregnancy Research Project, visit:** [pregnancyresearchproject.org](http://pregnancyresearchproject.org)

Pregnancy Research Project  
952-715-7731, ext. 6 • [starlegacyfoundation.org](http://starlegacyfoundation.org)  
[research@starlegacyfoundation.org](mailto:research@starlegacyfoundation.org)



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



# EDUCATION



## ***HEALTHCARE PROFESSIONAL EDUCATION***

- Provide continuing education workshops for HCPs
- Accredited for physicians (ACCME), nurses (ANCC), social work (MNSW) (other disciplines available as appropriate)
- Presented 20 workshops in 2019 for over 500 health professionals





# EDUCATION

## FAMILY EDUCATION MATERIALS

- Series of family education brochures, posters, cards
- Currently offer 17 items, more in development
- Evidence-based
- Available in English and Spanish
- Free to families or health professionals

- More than 100,000 materials distributed in 2019



STICK ME ON YOUR FRIDGE, AS YOUR DAILY SAFE PREGNANCY REMINDER



October 24, 2019



READ MORE



## THE STIGMA OF STILLBIRTH

Chris Duffy visits with Danielle Pollock, a PhD candidate from the University of South Australia about the stigma of stillbirth

## PODCAST

- Stillbirth Matters
- Interviews with researchers or experts in an aspect of perinatal loss

October 2, 2019



READ MORE



## ALWAYS MY TWIN

In this episode of the Stillbirth Matters podcast, Chris Duffy visits with Valerie Samuels. In April 2002, Valerie gave birth to full term twin daughters Gina and Julia Samuels. Her daughter Gina, born with Trisomy 13 and Holoprosencephaly, lived for 9 days before she died in her mother's arms, but not in her mother's heart. [...]



# EDUCATION



## ***STILLBIRTH SUMMIT***

- 3-day medical education conference
- Bring together researchers from around the world focused on stillbirth prevention and care
- Stillbirth Summit 2019  
300 attendees  
30 states, 7 countries
- Stillbirth Summit 2021 –  
June 22-25, 2021  
San Diego, CA





# AWARENESS



## ***CHAMPION EVENTS***

- Event in a local community aiming to bring awareness, create community and raise funds for Star Legacy Foundation programs



# AWARENESS



## OCTOBER AWARENESS CAMPAIGN

Settle to **sleep** on your **side** in the **3rd trimester** to reduce stillbirth risk.

 **STAR LEGACY FOUNDATION**  
October is Pregnancy and Infant Loss **Awareness Month**

**#NEVERBESTILL**  
Because Every Pregnancy Deserves A Happy Ending

Light a candle to honor babies amongst the stars.

Int'l Wave of Light,  
October 15th at 7pm

 **STAR LEGACY FOUNDATION**  
October is Pregnancy and Infant Loss **Awareness Month**

**#NEVERBESTILL**  
Because Every Pregnancy Deserves A Happy Ending

**Fact:** Babies **DO NOT** slow down at the end of pregnancy.

 **STAR LEGACY FOUNDATION**  
October is Pregnancy and Infant Loss **Awareness Month**

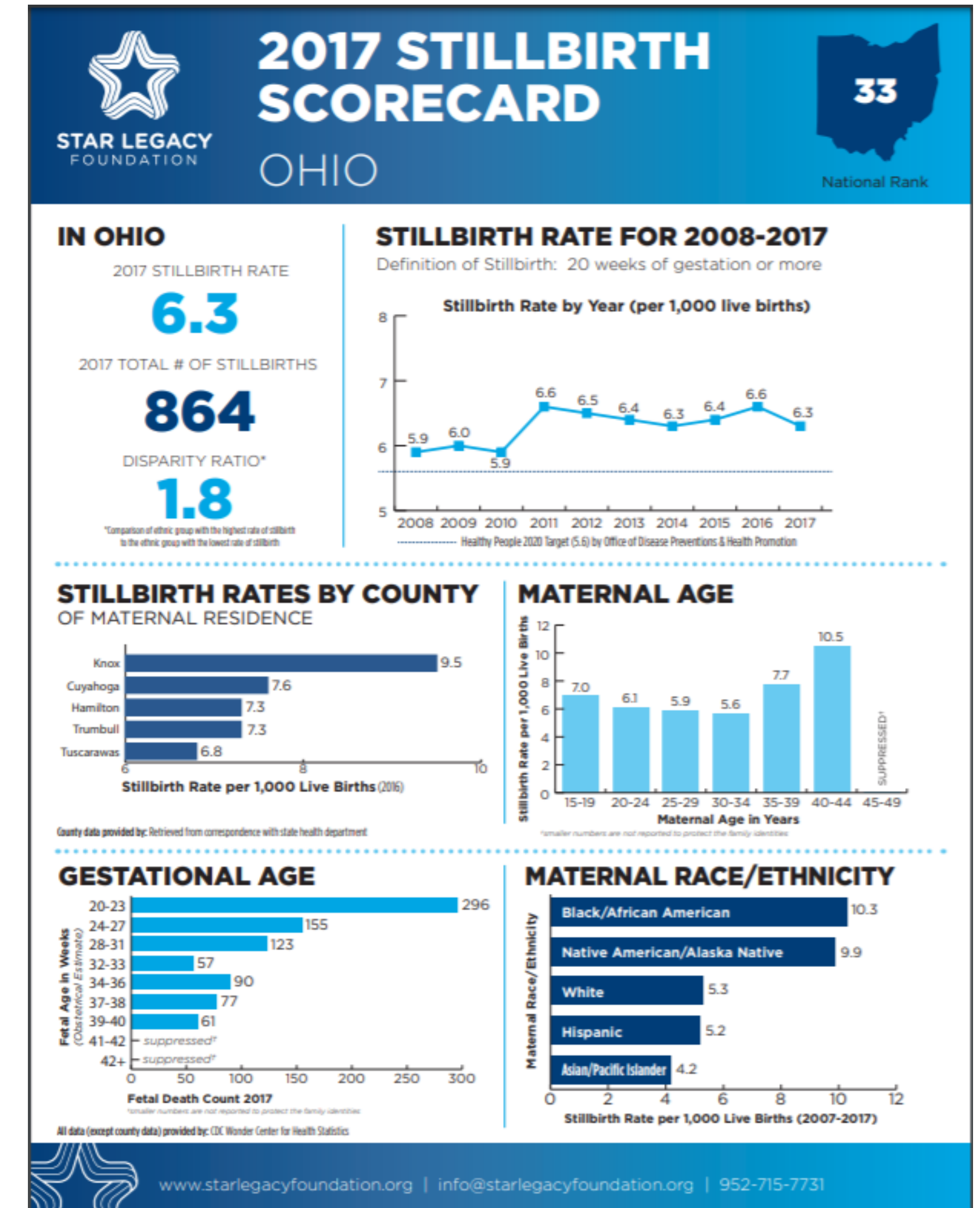
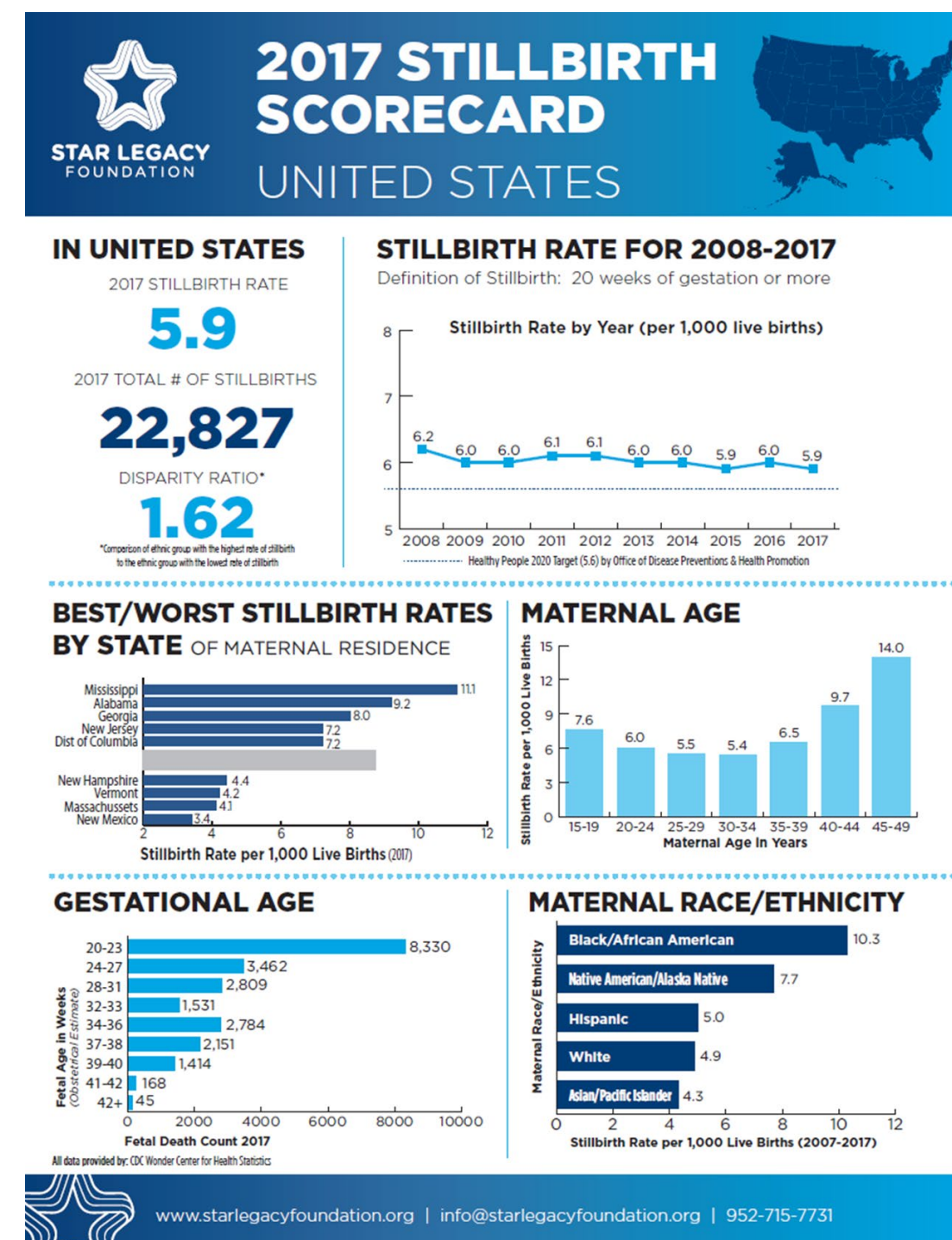
**#NEVERBESTILL**  
Because Every Pregnancy Deserves A Happy Ending



# AWARENESS

## STILLBIRTH SCORECARD

- Compilation of statistics about stillbirth in the US and in each state
- Data from CDC and state health departments





# ADVOCACY



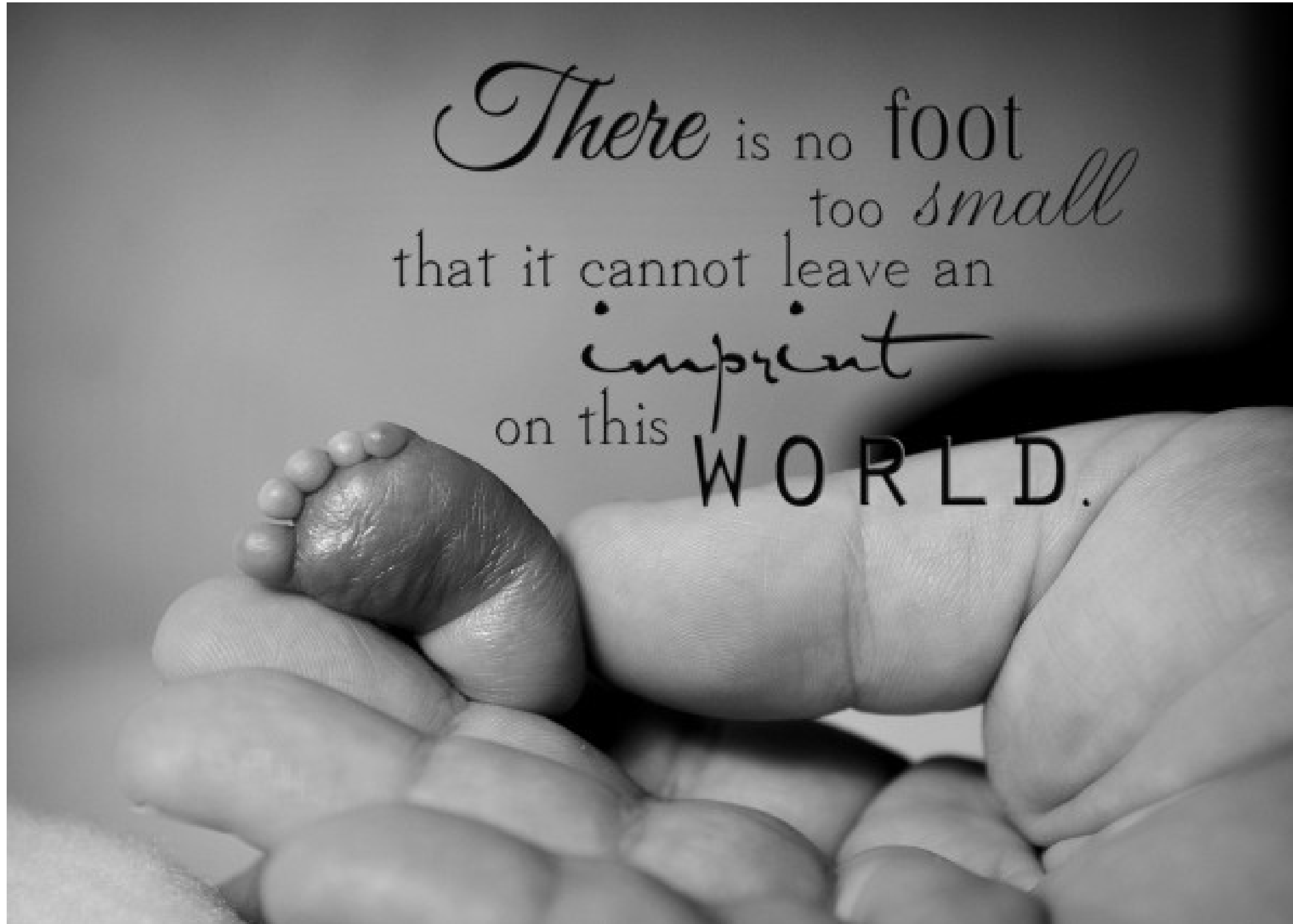
***CERTIFICATE OF BIRTH RESULTING  
IN STILLBIRTH***

***STILLBIRTH TAX CREDIT/DEDUCTION***





# FAMILY SUPPORT



## **SUPPORT LINE**

- Staffed by professionals
- Open to anyone impacted by perinatal loss

## **PEER SUPPORT**

- Connection with an individual who has had a similar experience

More than 600 families supported through the support line and peer support in 2019



# FAMILY SUPPORT




## SUPPORT GROUPS

- Live, online support groups
- Free to participate
- Facilitated by professionals
- PAL Childbirth Education

### STAR LEGACY FOUNDATION

### SUPPORT GROUP SESSIONS

All support groups are held on a HIPAA compliant video-conferencing line and are facilitated by a trained professional

<b>BEREAVED PARENTS GROUP</b> 1st & 3rd Mon of the Month  Eastern: 7:15pm Central: 6:15pm Mountain: 5:15pm Pacific: 4:15pm	<b>PREGNANCY AFTER LOSS GROUP</b> Weekly on Mon  Eastern: 8:30pm Central: 7:30pm Mountain: 6:30pm Pacific: 5:30pm	<b>DAD'S GRIEF DISCUSSION GROUP</b> 2nd Mon of the Month  Eastern: 7:15pm Central: 6:15pm Mountain: 5:15pm Pacific: 4:15pm	<b>GRANDPARENTS GROUP</b> 1st Wed of the Month  Eastern: 8:15pm Central: 7:15pm Mountain: 6:15pm Pacific: 5:15pm
<b>PARENTING AFTER LOSS GROUP</b> 1st Wed of the Month (2 times in one day)  Eastern: 1pm & 9:30pm Central: 12pm & 8:30pm Mountain: 11am & 7:30pm Pacific: 10am & 6:30pm	<b>PARENTING AFTER LOSS GROUP</b> 3rd Wed of the Month (2 times in one day)  Eastern: 1pm & 9:30pm Central: 12pm & 8:30pm Mountain: 11am & 7:30pm Pacific: 10am & 6:30pm	<b>COPING WITH INFANT DEATH</b> 2nd Wed of the Month  Eastern: 7pm Central: 6pm Mountain: 5pm Pacific: 4pm	 <b>STAR LEGACY FOUNDATION</b>

Visit <https://starlegacyfoundation.org/support-groups/> for more info or to register

# FAMILY SUPPORT

## ***FAMILY SUPPORT ITEMS***





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# WORKING WITH BEREAVED FAMILIES



# GRIEF EXPERIENCE

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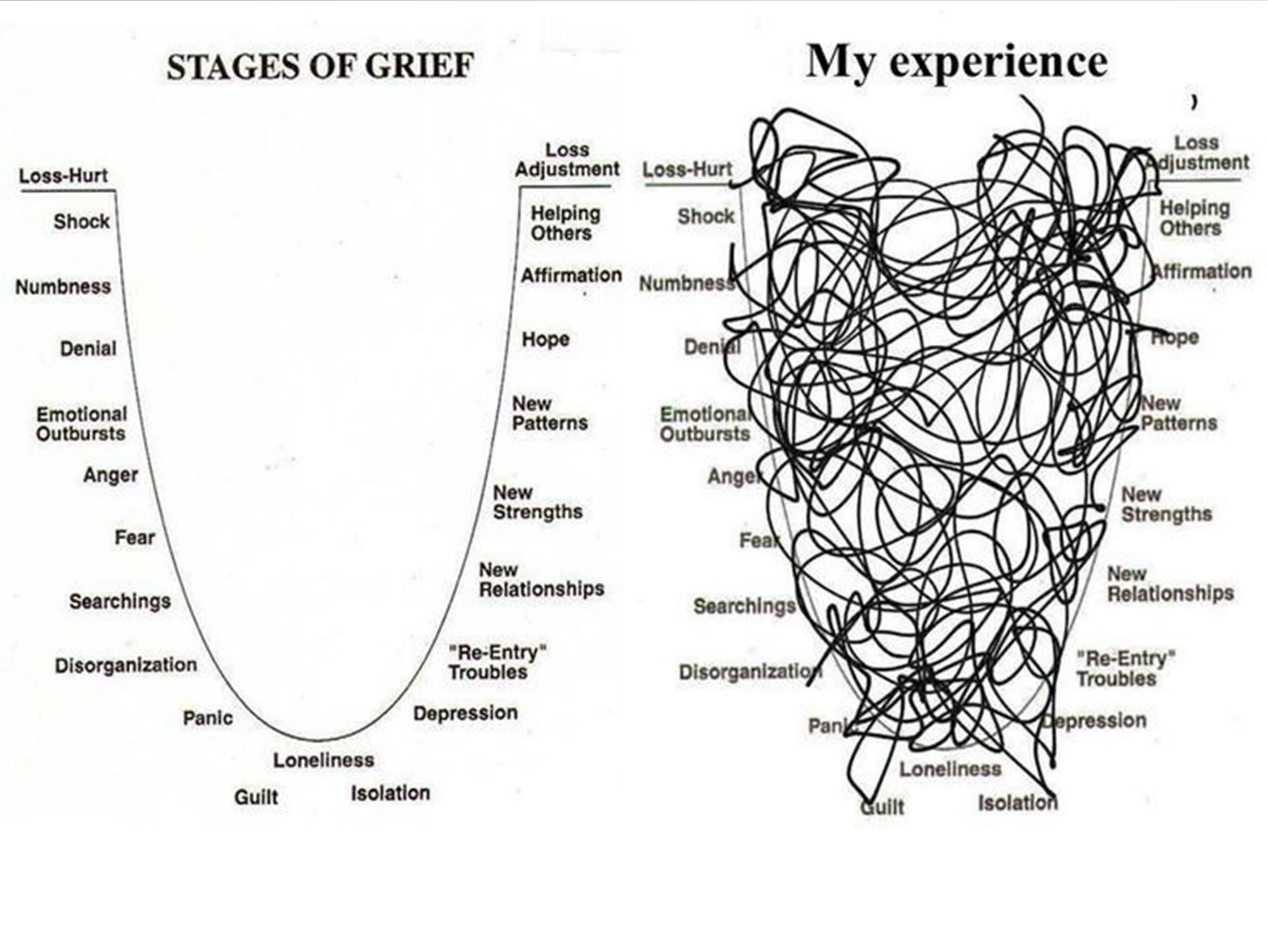
Affected by:

- \* age
- \* gender
- \* culture
- \* family structure and dynamics
- \* previous experience with death
- \* socioeconomic status/resources
- \* support system
- \* mental/physical health issues
- \* stress/trauma





# GRIEF EXPERIENCE





# EMOTIONAL SYMPTOMS OF GRIEF

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- \* Shock
- \* Guilt
- \* Anger
- \* Loneliness
- \* Sadness
- \* Failure
- \* Fear
- \* Issues with spirituality
- \* Vulnerability
- \* Hopelessness





# PHYSICAL SYMPTOMS OF GRIEF

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- \* Headache
- \* Nausea/vomiting
- \* SOB/heavy pain in chest
- \* Physical illness
- \* Increased/decreased sleep
- \* Increased/decreased activity
- \* Promiscuity/loss of libido
- \* Hallucinations/dreams
- \* Decreased concentration
- \* Irritability



# SEQUELAE OF PERINATAL LOSS

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- \* loss of friends
- \* depression
- \* anxiety
- \* PTSD
- \* marriage/relationship issues
- \* re-evaluation of spirituality
- \* decreased productivity
- \* need to create a new “normal”
- \* grief can be a life-long experience





# EXTENDED FAMILY

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## Fathers/partners

- \* often forgotten mourners
- \* guilt, fear, jealousy, helplessness
- \* active grievers
- \* societal pressure to be strong
- \* support the mother

## Siblings

- \* developmental age
- \* interaction with the baby





# EXTENDED FAMILY

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Grandparents

- \* two losses
- \* unresolved grief from own losses

Aunts/Uncles/Friends

- \* at similar life stage

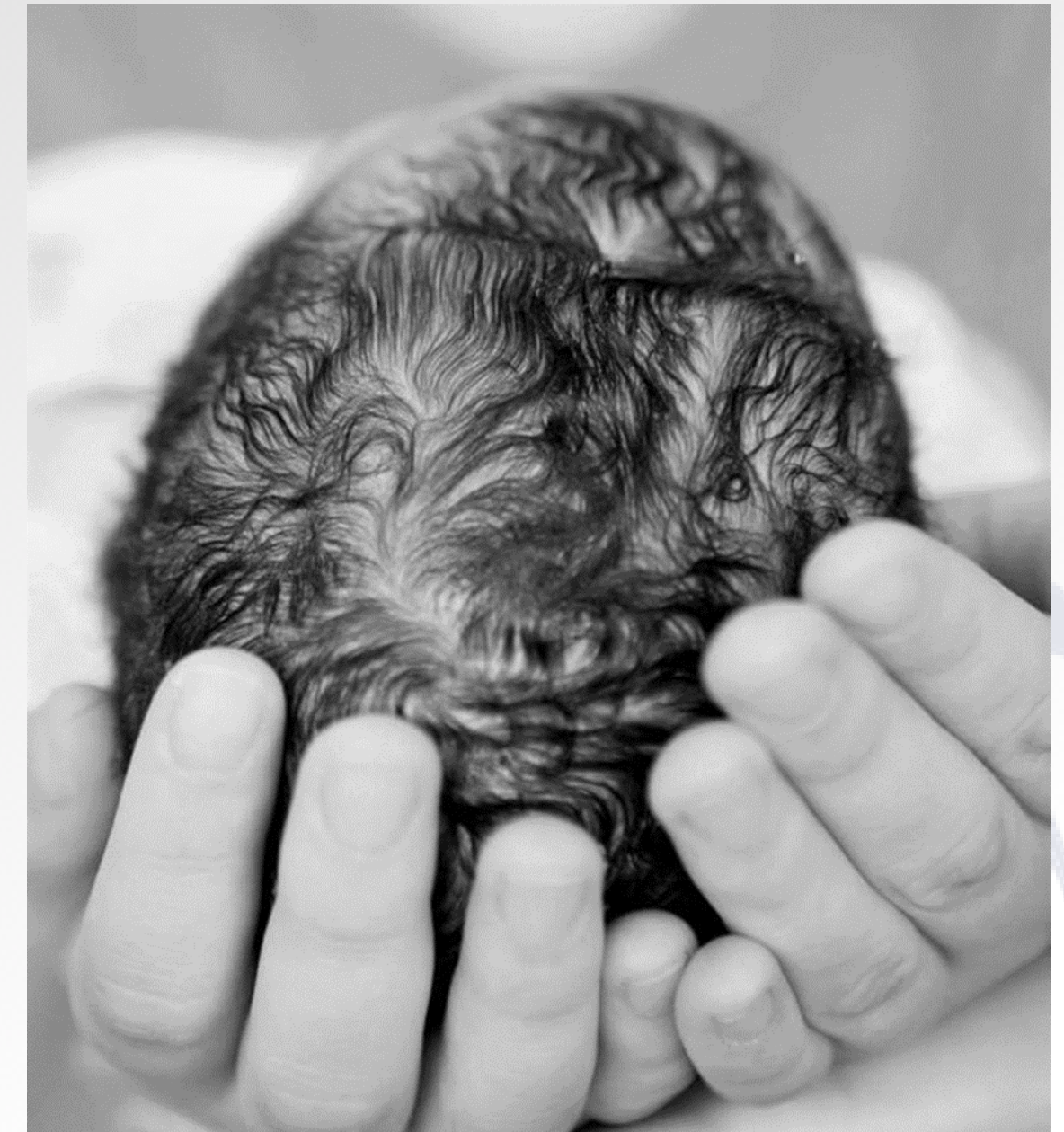




# COMMUNICATION

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- \* Communication is impacted by stress
- \* Use caution with too many words
- \* May need to repeat yourself several times
- \* Tone or phrasing can be more important than the words
- \* Medical terminology can be problematic
- \* Tools for language barriers
- \* Non-verbal communication most important
  - \* active listening
  - \* un-hurried demeanor





# PHRASES TO AVOID

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- \* “It was for the best”
- \* “This is how God fixes His mistakes”
- \* “At least she didn’t suffer”
- \* “It would have been worse if ....”
- \* “I know how you feel.”
- \* “You have an angel now.”
- \* “You can have more children.”
- \* “It will be good for you to ...”





# HELPFUL PHRASES

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- \* “I’m sorry.”
- \* “Tell me about your pregnancy or baby.”
- \* “We are here to support you.”
- \* “This isn’t your fault. You didn’t do anything wrong.”
- \* “It’s an honor to meet her.”
- \* “I wish we had more answers.”
- \* “What is important to you at this moment?”
- \* “Some parents find it helpful to ...”
  
- \* Nothing (silence, but not avoidance)
- \* Show emotion





# CULTURAL CARE

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- \* Ask how you can help or support their traditions
- \* Involve members of the community
- \* Be flexible
- \* Avoid assumptions
- \* Involve hospital chaplain
- \* Repeat questions, and ask when mother is alone
- \* Practice may be affected by generation, mixed marriage, previous experience with loss





# FOLLOW UP

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- \* Physical care
- \* Postpartum visits
  - going to office can be challenging
  - assess entire family
  - may need more than one visit
- \* Milestones
  - memorial services
  - photography/mementos ready
  - holidays and anniversaries
- \* Resources
  - peer support
  - financial support
  - emotional support
  - social support







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