

STILLBIRTH EQUITY RESEARCH UPDATE



TSEGASELASSIE WORKALEMAHU, PHD, MS

ASSISTANT PROFESSOR

MATERNAL-FETAL MEDICINE

OBSTETRICS & GYNECOLOGY

UNIVERSITY OF UTAH SCHOOL OF MEDICINE

Familial & Genetic Determinants of Stillbirth

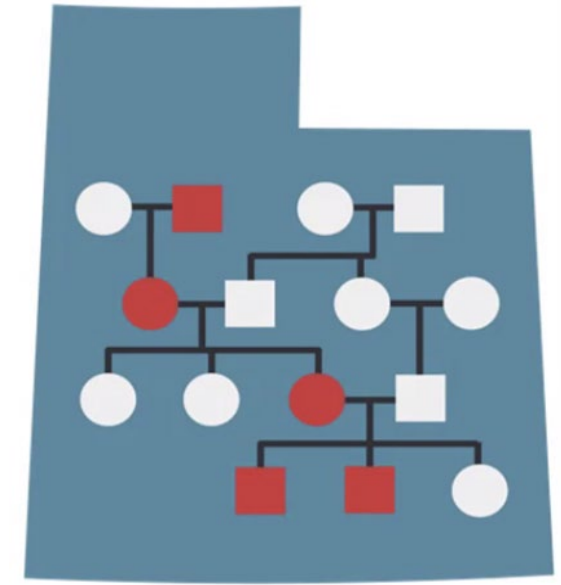


F&GDS

1978 – 2022 fetal death/birth certificates

Stillbirths

Live births



Utah Population
Database



Dr. Jessica Page



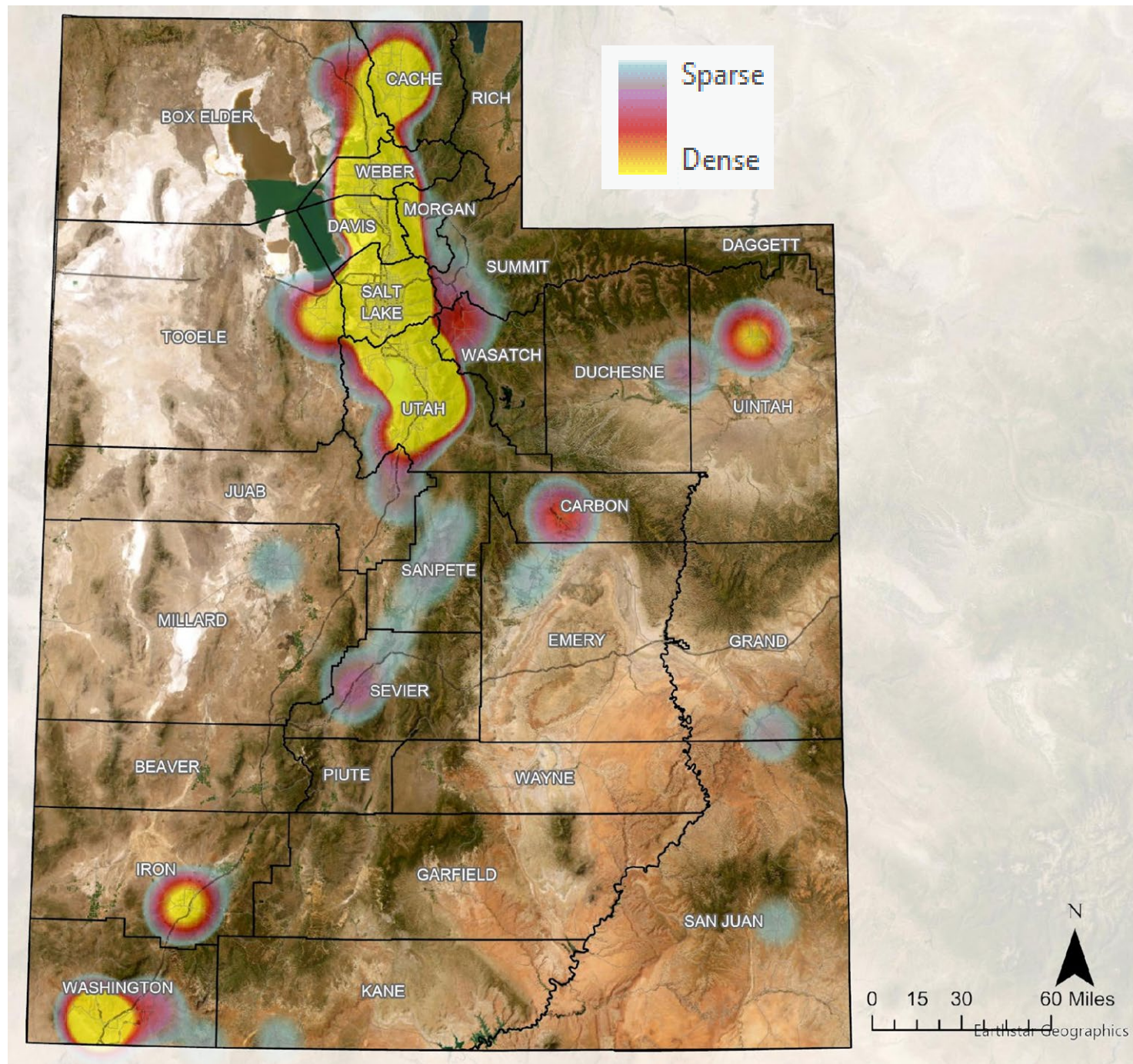
Sarah Lopez

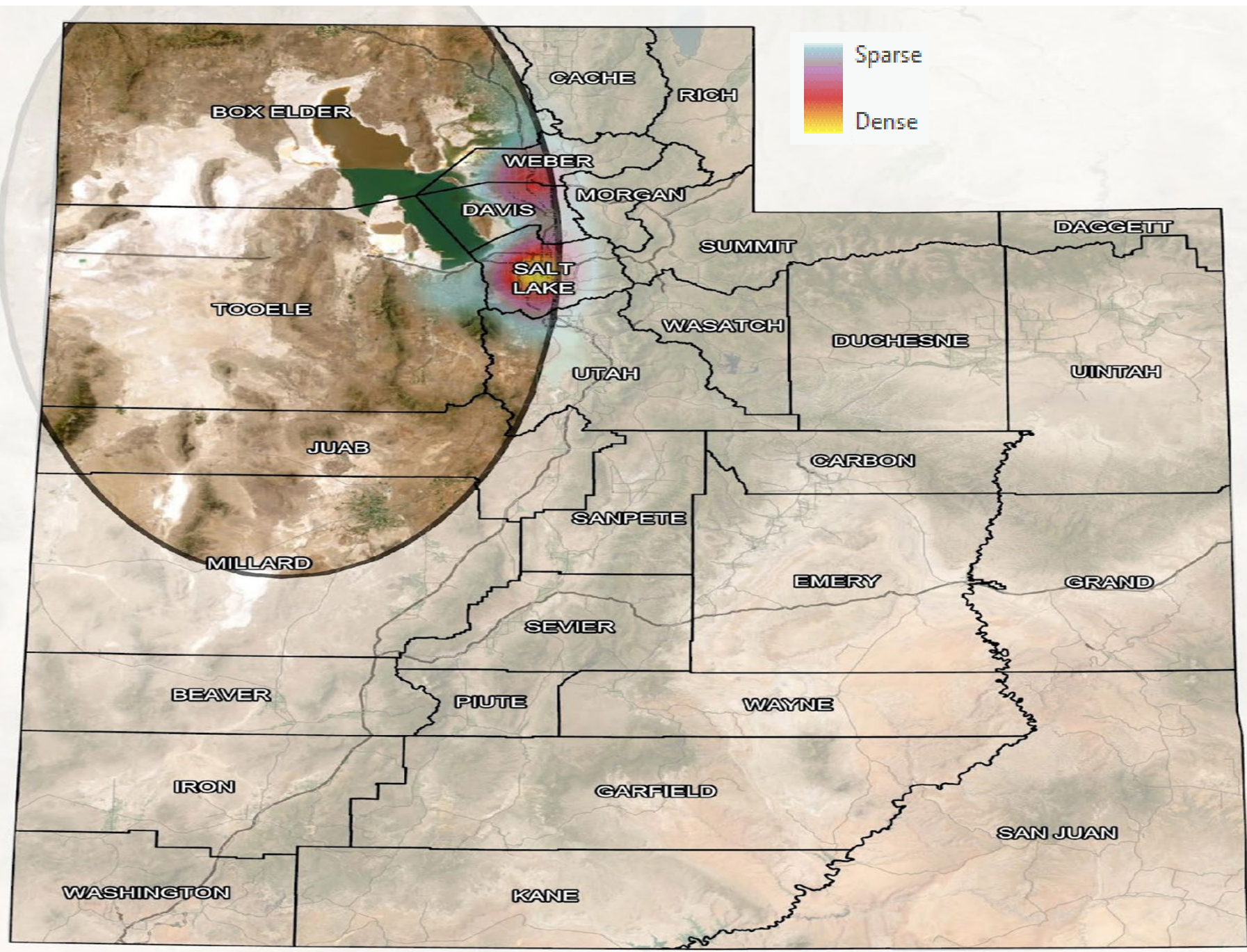


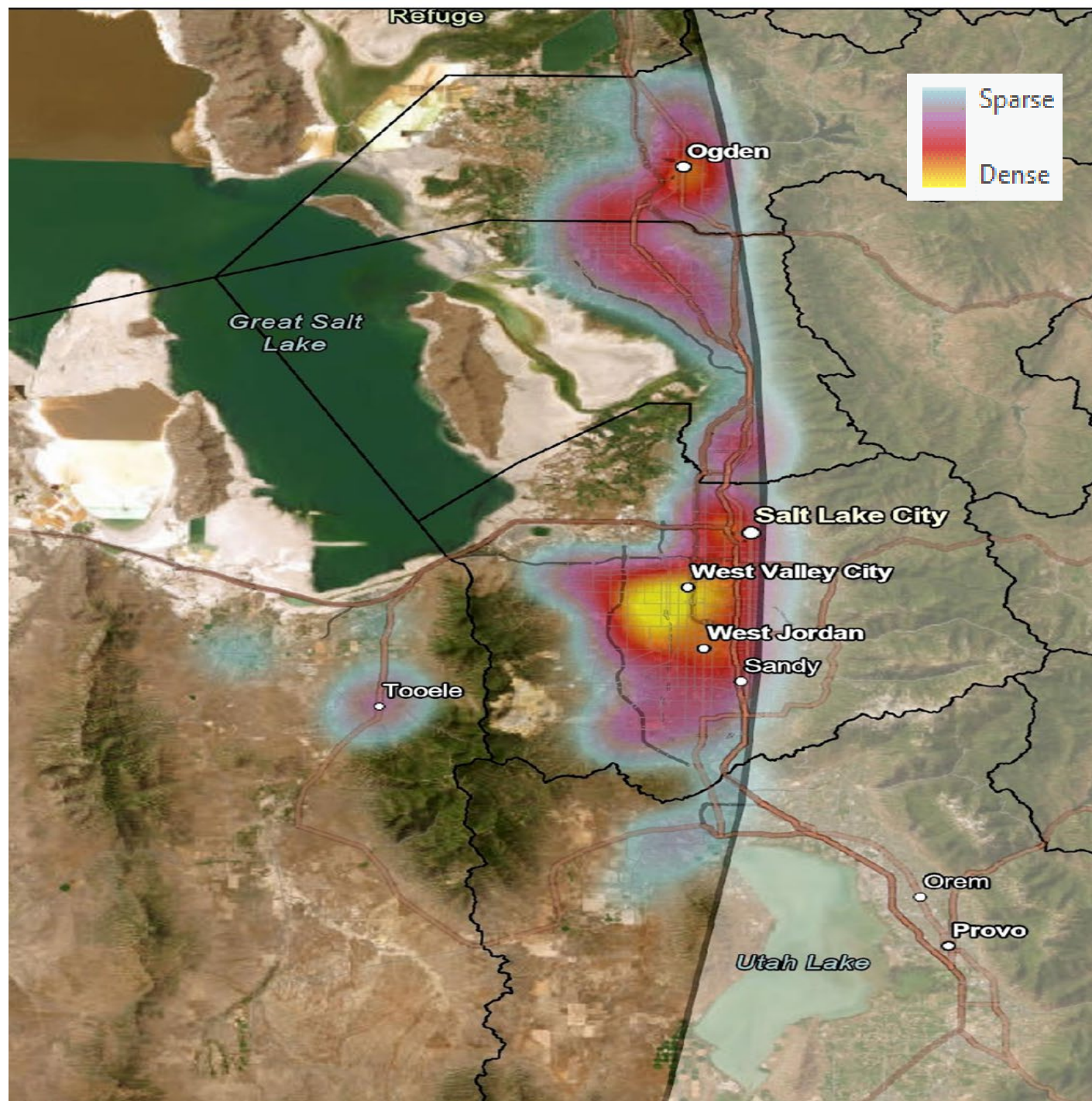
Dr. Robert Silver



Dr. Ware Branch







Rebecca Steed

Observed	Expected	RR (95% CI)	P-Value
2866	2520.6	1.20 (1.14-1.26)	1.10E-12

Data is unpublished



Dr. Paulina Devlin

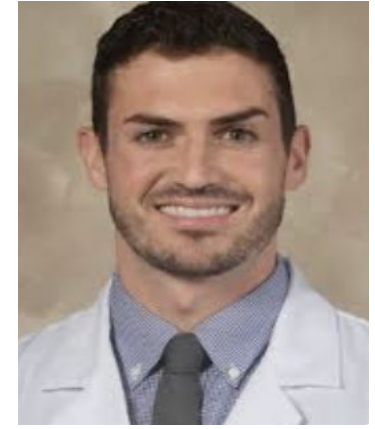
Kennedy Yara Yost



Dr. Michelle Debbink



Dr. Susannah Leisher



Dr. Kathleen Cohen

Dr. Patrick Eucalitto



Dr. Lauren
Christiansen-Lindquist



Dr. Naomi Riches

Lack of quality data on the economic burden of stillbirth

S. Veettil, W Kategeaw, A Hejazi, T Workalemahu, E Rothwell, RM Silver, N Chaiyakunapruk.

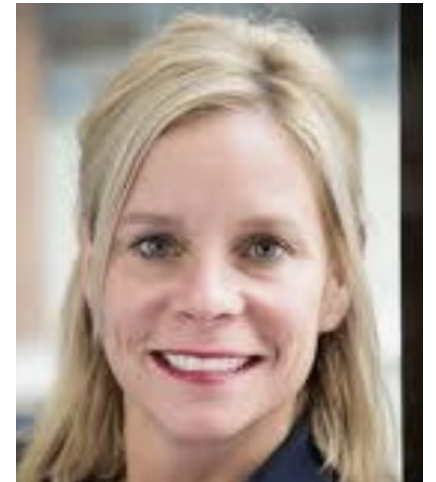
Birth Issues in Perinatal Health, 2023; PMID: 36774590



Dr. Nathorn Chaiyakunapruk

Warittakorn Kategeaw

Kennedy Yara Yost



Dr. Erin Rothwell

Equitable Investigation of Stillbirth

- Inclusion of dads and family members to investigate causes of stillbirth
- Addressing environmental contributors to stillbirth
- Addressing economic & psychosocial burden of stillbirth

Clinical:

Dr. Robert Silver
Dr. Jessica Page
Dr. Ware Branch
Sarah Lopez
Dr. Nathan Blue

Genetics:

Dr. Lynn Jorde
Dr. Aaron Quinlan
Dr. Deb Neklason

Epidemiology:

Dr. Michelle Debbink
Dr. Hilary Coon
Dr. Nicola Camp
UPDB team

Bioinformatics:

UCGD/UU HSC
Myke Madsen

Patient advocacy:

Dr. Susannah Leisher
Dr. Naomi Riches
Dr. Nui Chaiyakunapruk

Budget & Regulatory:

Mandy Aucutt
Elizabeth Turner
Elizabeth Woolsey
OGRN

Residents and Students:

Rebecca Steed
Dr. Paulina Devlin
Kennedy Yost

Biospecimen and data
collection:

Danae Reyes
Ashley Joseph
Rose Peckham

THANK YOU!



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American Society of Reproductive Medicine ASRM/RPLA Pilot Grant

Center for Genomic Medicine, University of Utah Pilot Grant

Families who are participating in our Familial & Genetic Determinants
of Stillbirth (F&GDS) Study



IMPROVING EQUITY WITH THE USE OF A STILLBIRTH EVALUATION DECISION AID



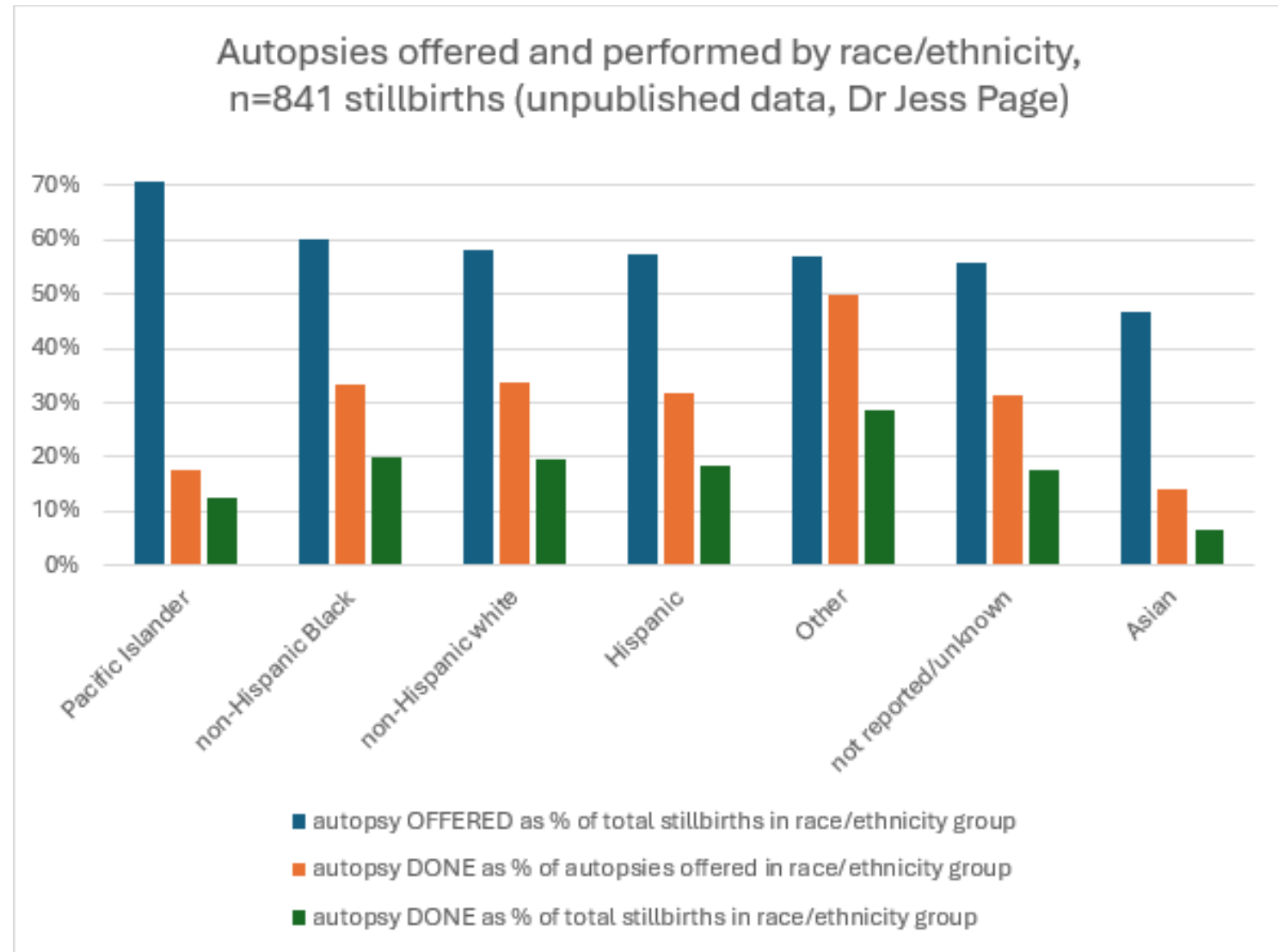
Naomi O. Riches PhD, MSPH

Research Assistant Professor
University of Utah School of Medicine,
Dept. ObGyn



STILLBIRTH

BRIEF BACKGROUND



1. Westby, C.L., Erlandsen, A.R., Nilsen, S.A. *et al.* Depression, anxiety, PTSD, and OCD after stillbirth: a systematic review. *BMC Pregnancy Childbirth* **21**, 782 (2021). <https://doi.org/10.1186/s12884-021-04254-x>
2. Nappi L, Trezza F, Bufo P, Riezzo I, Turillazzi E, Borghi C, *et al.* Classification of stillbirths is an ongoing dilemma. *J Perinat Med* 2016;44(7):837–43.
3. Nes, e N, Bülbül Y. Diagnostic value of perinatal autopsies: analysis of 486 cases. *J Perinat Med* 2018;46(2):175–81. [
4. Jaiman S. Performing a perinatal autopsy. *J Fetal Med* 2015;2(3):101–11. [
5. Auger N, Bilodeau-Bertrand M, Poissant J, Shah PS. Decreasing use of autopsy for stillbirths and infant deaths: missed opportunity. *J Perinatol* 2018;38(10):1414–9.
6. Oliver EA, Finneran MM, Rood KM, Ma'ayeh M, Berghella V, Silver RM. Fetal autopsy rates in the United States: analysis of national vital statistics. *Obstet Gynecol* 2022;140(5):869–73.

DECISION-MAKING

Making a decision when distressed:

1. ↑ Stress = ↓ Rational decision-making^{1,2} & ↓ Memory use²
 - a) Interferes with cost-benefit assessment²
 - b) Immediate gain over better options²
2. Impacted by an individual's background: emotional processes, interpretation of the situation, personality traits, and cultural background²

1. Marques da Rocha MC, Malloy-Diniz LF, Romano-Silva MA, Joaquim RM, Serpa ALO, Paim Diaz A, de Paula JJ, Costa DS, da Silva AG, Pinto ALCB, de Miranda DM. Decision-making styles during stressful scenarios: The role of anxiety in COVID-19 pandemic. *Front Psychiatry*. 2023 Apr 5;14:1105662. doi: 10.3389/fpsy.2023.1105662. PMID: 37091714; PMCID: PMC10115220.
2. Sarmiento LF, Lopes da Cunha P, Tabares S, Tafet G, Gouveia A Jr. Decision-making under stress: A psychological and neurobiological integrative model. *Brain Behav Immun Health*. 2024 Apr 16;38:100766. doi: 10.1016/j.bbih.2024.100766. PMID: 38694793; PMCID: PMC11061251.

DECISION-MAKING

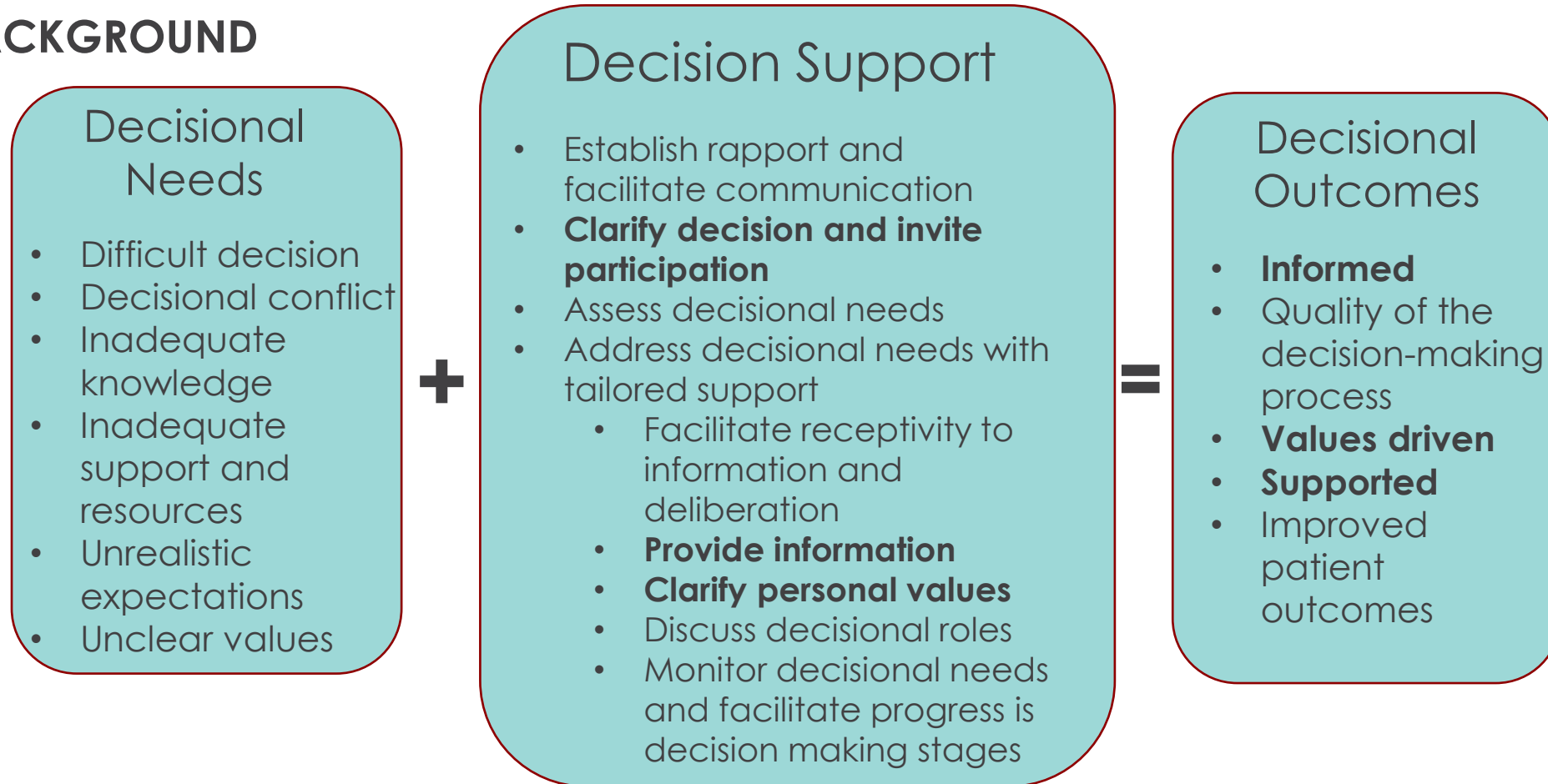
Making a decision with low health literacy:

1. ↓ Health Literacy impacts participation in decision-making & health outcomes¹
 - a) ↓ patient involvement in the decision
 - b) Difficulty understanding the information
 - c) Lack of self-efficacy

1. Seo J, Goodman MS, Politi M, Blanchard M, Kaphingst KA. Effect of Health Literacy on Decision-Making Preferences among Medically Underserved Patients. *Medical Decision Making*. 2016;36(4):550-556. doi:[10.1177/0272989X16632197](https://doi.org/10.1177/0272989X16632197)

WHAT ARE DECISION SUPPORT TOOLS

BRIEF BACKGROUND



ODSF Theoretical Framework adapted from Stacey et al (2020)¹

1. Ottawa Decision Support Framework (ODSF). Stacey, Legare, Boland, et al (2020). <https://decisionaid.ohri.ca/models.html>. Accessed Sept. 27, 2024

STILLBIRTH

STUDY AIM

The aim of this study was to create a patient-informed decision support tool for stillbirth evaluations.

METHODS

METHODS

INTERVIEWS WITH PARENTS¹



Participants.

- Patients who received care for a stillbirth at the University of Utah in the previous 5 years.
- ≥18 years old
- Understand and speak English



Recruitment.

- Email invitations sent to patients
- Patients were called to determine interest and scheduled.
- Patients could opt in or out via email or phone at any time.



Data collection.

- A semi-structured interview guide used to interview patients
- Audio recorded
- Transcribed



Narrative analysis.

- Transcripts were analyzed by qualitative content analysis.
- Similarly themed data coded.
- Two coders

1. Riches NO, Workalemahu T, Johnson EP, Silver RM, Lopez S, Page J, Sartori B, Rothwell E. Creating a postmortem examination decision aid: Suggestions from bereaved parents of a stillborn. Patient Educ Couns. 2023 Jul;112:107746. doi: 10.1016/j.pec.2023.107746. Epub 2023 Apr 11. PMID: 37060683; PMCID: PMC10184762.

RESULTS

Table 1. Demographics		
Variables		Mean (S.D.)
Age of parent at stillbirth		31.1 (6.3)
Time since stillbirth (years)		3.9 (1.4)
Gestational age of stillborn (weeks)		26.2 (7.2)
Number of pregnancies, including losses		4.4 (2.7)
	Number	Percent of total
Religion		
Agnostic	1	5%
Atheist	1	5%
Catholic	1	5%
The Church of Jesus Christ of Latter-Day Saints	8	42%
No Spiritual preference	3	16%
Missing/prefer not to answer	5	26%
Race/Ethnicity		
Hispanic/Latino	1	5%
White or Caucasian	16	84%
Native Hawaiian and Other Pacific Islander	1	5%
Missing/prefer not to answer	1	5%
Marital status		
Married	14	74%
Single/Divorced	4	21%
Missing/prefer not to answer	1	5%
Parent's education		
GED	1	5%
Some college	3	16%
Bachelor's degree	5	26%
Master's degree	2	11%
Doctorate	2	11%
Missing/prefer not to answer	6	32%
Household income*		
< US\$24,999	2	11%
US\$25,000 – US\$50,000	0	0%
US\$50,001 – US\$75,000	0	0%
US\$75,001 – US\$100,000	3	16%
> US\$100,001	6	32%
Missing/prefer not to answer	8	42%

Table 2. Evaluation of stillbirth decision

Variables	N
One or more evaluation of stillbirth	13
Perinatal autopsy	11
Placental histology	3
Genetic testing	7
None	4
Not offered	2

Riches NO, Workalemahu T, Johnson EP, Silver RM, Lopez S, Page J, Sartori B, Rothwell E. Creating a postmortem examination decision aid: Suggestions from bereaved parents of a stillborn. Patient Educ Couns. 2023 Jul;112:107746. doi: 10.1016/j.pec.2023.107746. Epub 2023 Apr 11. PMID: 37060683; PMCID: PMC10184762.

BARRIERS AND FACILITATORS

STILLBIRTH EVALUATION DECISION-MAKING

Barriers:

- Wanting to protect their baby from harm
- Wanting to spend time with their baby
- Cost
- They believed they already knew the cause of death

Facilitators:

- Having a strong belief in science
- Wanting information to inform future pregnancies
- Altruism
- Simply wanting to know why
- Treating the baby with respect

RECOMMENDATIONS

STILLBIRTH EVALUATION DECISION AID

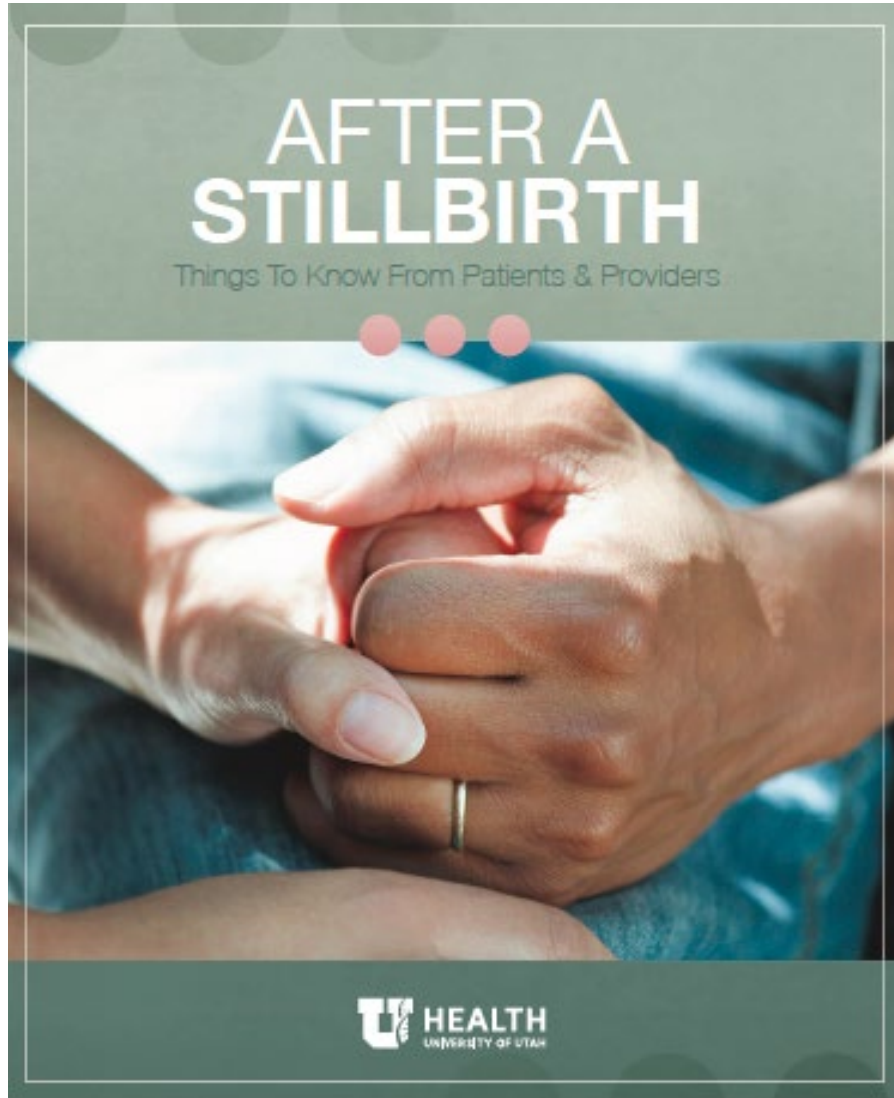
Desired information

1. Provide a description of evaluation options
2. Provide a timeline
3. Provide cost information

Timing & Format

1. Slowly & in-person
2. With time to process
3. Pamphlet, video, or website

STILLBIRTH EVALUATION DECISION AID



Losing a Baby is Hard



YOU ARE STILL
A PARENT

Stillbirth can happen to any family, even if the pregnancy was uncomplicated.

There is no right way to feel after something like this happens.

*But even though your baby has passed away,
you are still a mother. You are still a parent.*

1

2

It's Your Choice.



On the next few pages, you'll learn more about available tests which may help explain why this happened.

All of these tests are optional.

9

“

I can look back on it and say, 'You know what? At least we tried,' or at least if there was something super obvious as to what happened, we would have found out.

”

10

Fetal Autopsy



YOUR BABY IS TREATED
WITH DIGNITY AND
RESPECT
DURING AUTOPSY.

An autopsy or post-mortem exam is one of the best ways to understand why your baby died.

During this exam, babies are treated with dignity and respect.

- All incisions are easily hidden with regular cloths.
- You can still have an open casket burial if desired.
- Face and hands are not part of the exam.

You can choose to do an autopsy anytime during your hospital stay, or before the baby is cremated or discharged to a funeral home.

NEXT STEPS

WHAT IS THE IMPACT OF THE STILLBIRTH EVALUATION DECISION AID IN THE CLINIC



Stillbirth evaluation rates

Does the DA increase uptake of one or more of the stillbirth evaluations?



Shared decision-making

Does the decision aid increase shared decision-making?



Decisional regret

Does the decision aid improve satisfaction with their choice?



Provider satisfaction

Do providers' interactions improve with use of a decision aid?



Deliberation

Does the decision aid increase deliberation?



Translation to other languages

Does the decision aid translate to other languages & cultures?

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Team



Erin Rothwell , PhD



Robert Silver, MD



Erin Johnson, PhD



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Jessica M Page, MD



Sarah Lopez, MPH, MHA

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THANK YOU

naomi.riches@hsc.utah.edu

Equity & Research

Sarah Lopez
Senior Stillbirth Clinical Research Coordinator
MHA/MPH

Challenges with Research

- **Consents and study materials need to be translated**
 - Many times this is only done in English, especially if the hospital doesn't have any translation services to utilize
 - Must be done by a certified interpreter, added cost to study, longer time to get IRB approved
- **Interpreters**
 - Added time and cost to incorporate interpreters for studies
 - Can disrupt clinical flow or can be difficult to get an interpreter since they're also used for clinical support and that must take priority
 - Virtual interpreters can be helpful, but can also have barriers
 - Ensuring participant has access to technology needed
 - Poor connection can disrupt the overall process and understanding of the study
- **Culture Sensitivity and context needs to be added to each study**
 - Finding the appropriate people to help us incorporate this into our studies
 - Ensuring you're incorporating all the possible groups you need represented in your research study



Researchers



- **Parent Voices in design & implementation of research is vital!**
 - Researchers should do everything they can to include parents in this process & discussion as early as possible
 - You'll have stronger recruitment, a better design, and you will ensure your materials are sensitive and comprehensive!
 - Be as inclusive as possible!
- **Parents want more research & to get involved in the process!**
 - Many parents are more than willing to participate in research! They want to see more of it and better understand what is and is not happening in this field!
 - It can be healing to contribute to the literature that may help prevent stillbirths down the road, or improve care overall!

Finding Research & Resources for Parents

Australia Stillbirth of Research Excellence has an amazing PDF you can download for free! →



- Many academic centers conduct research, you can google your local hospital or research center to find enrolling studies.



← Current U of U Pregnancy Loss & Stillbirth Studies:

Join the Stillbirth Advocacy Working Group (SAWG) - USA

- We share frequent opportunities to this entire group
- Email swag-usa@hsc.utah.edu to join!



Thank you to all the amazing **parents**
that have supported research!

Thank you to our wonderful **research team**:

- Ashley Joseph, Sr. CRC
- Danae Reyes, Stillbirth Study Coordinator
- Rose Peckham, Study Coordinator
- Isaac Shelton, Study Coordinator
- Inez Scott, Research Assistant
- Everyone in OGRN
- Everyone in the Department of OB/GYN who make our research possible!

