



**STAR LEGACY**  
FOUNDATION

# PREGNANCY RESEARCH PROJECT

*Organizational Partnership Opportunities*

*Never doubt that a small group of thoughtful, committed citizens can change the world;  
indeed, it's the only thing that ever has.*

*~Margaret Mead*

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## Pregnancy Research Project

The Pregnancy Research Project is a collaborative source of data for researchers interested in improving pregnancy outcomes. Databases exist for many health conditions, but pregnancy does not currently have this type of information available. Studies during and immediately after pregnancy are viewed as challenging, yet many women who have had a poor pregnancy outcome want their experience to be used to prevent future tragedies.

### Why is this an important project?

In order for health professionals to identify prevention methods, interventions, or models of care, they rely on research that guides their work. Research during pregnancy has always been a challenge for ethical reasons. Researchers often report that the most time-consuming and expensive aspects of their work are enrolling individuals to participate in a study. It is not always easy to find people who meet the criteria for a specific study and are willing to contribute. Conversely, Star Legacy Foundation regularly hears from women who want their pregnancy experiences to benefit other families. It is rare that they are able to be matched with studies that are able to use their information.

This project is designed to answer many questions about pregnancy health, but also to create a central location where women can contribute their information that may be used in dozens of research studies, and where researchers can obtain data for their studies in a matter of weeks instead of years. A unique aspect is that it will combine the mother's personal observations and knowledge with the items documented in the medical record to create a more robust and holistic picture of the pregnancy.

### Goals

The overarching goal of the Pregnancy Research Project is to identify opportunities to prevent poor pregnancy outcomes and improve bereavement care when prevention isn't possible. Many research questions will be addressed through this work including, but certainly not limited to, the role of the umbilical cord, the placenta, maternal sleep position, infection, fetal movement, maternal intuition, access to care, institutional racism/stigma, trauma, and marginalization.

### How it works

Individuals who are currently at least 12 weeks pregnant, have delivered a live baby in the last 5 years, or who have ever experienced a stillbirth or neonatal death are eligible to enroll. Their participation will involve completing a survey about and allowing their medical records to be requested. The survey will focus on details about the pregnancy that are not typically documented in the medical record. The medical records requested will include prenatal office visits, laboratory and imaging, hospitalizations,



delivery, and neonatal records. Participants are not required to answer any questions and may choose if they want to participate in both aspects of the study.

Trained medical abstractors will enter the information from the medical records into a database and link their survey answers into the same database. Researchers will later be able to request de-identified data points for women who meet the criteria of an ethics-approved study.

## Eligibility

Eligible individuals will currently be at least 12 weeks pregnant, have delivered a baby in the last 5 years, or have ever had a stillbirth/neonatal death. This project is open to enrollment internationally. During the initial phases of the project, the participants must be able to complete the consent form and survey in English (online, written, or verbal) and their medical records must exist in English. Translated materials are coming soon to expand eligibility to those who prefer or require other languages.

## Enrollment

Participants will be able to enroll and complete the survey online, in-person at project events or through partnering organizations, or by requesting a phone interview.

## Data Security

All data will be housed in Redcap, a secure database housed at the University of Michigan, which has a strong record of quality and security for medical and research information. After abstraction, hard copies of records or surveys will be destroyed. Researchers requesting information must provide evidence of ethics approval and oversight and the request will be reviewed by the Medical Steering Team for the Pregnancy Research Project. Only de-identified data points will be shared. The Pregnancy Research Project Coordinator and the abstractor assigned to a participant's case will be the only individuals with access to identifiable information. Abstractors are licensed health professionals with extensive training in data abstraction, HIPAA and data security.

## Funding

Financial support for the Pregnancy Research Project is provided by the Star Legacy Foundation, a national 501(c)(3) organization based in Eden Prairie, Minnesota, and through in-kind contributions by the University of Michigan. Additional funding will be pursued through grants and donations.

Donations and sponsorships of the Pregnancy Research Project will support the costs of maintaining the database, abstracting records, enrolling new participants, printing participant recruitment materials, monitoring quality and safety, and analyzing data.



## Oversight

The Star Legacy Foundation Board of Directors will manage administrative, financial, and legal components of the project. The Medical Steering Team will serve as the Clinical Experts, manage the scientific and ethical components, review/approve requests for data, and oversee publication. Additionally, they will annually review the project and quality assurance reports and determine if any adjustments are needed.

Ethics approval and oversight is provided by the University of Michigan Institutional Review Board.

## Partnering Organizations



Star Legacy Foundation is seeking partnerships with organizations to increase the number of participants, involve a wide diversity of individuals and circumstances in the study, improve access to the data by researchers, expedite the data availability, and encourage collaboration for this and future maternal child health endeavors.

## Partners

Pregnancy Research Project Partners are asked to:

- Provide a letter of support that can be used for funding applications
- Encourage participation in the project by eligible individuals
- Offer enrollment information to eligible individuals at the organization's physical location and/or events held by the organization
- Place the Pregnancy Research Project Partner logo on organizational website
- Include details about the project on the organization's website, social media accounts, newsletters, and similar communication methods

The Pregnancy Research Project will support these partners by:

- Providing regular updates on the status of the project
- Placing the partner name on project website
- Providing enrollment materials to be given to eligible individuals
- Placement of the organization's logo of partnering organizations on the project website
- Text and logos to be used in communications about the project
- Acknowledgement in Star Legacy Foundation communication & social media channels



## Sponsoring Organizations



Organizations who wish to contribute to the financial support of the Pregnancy Research Project are welcome! All Sponsors are expected to participate at the level of a Supporter in addition to the financial contribution.

### Platinum Sponsor

\$ 50,000

Platinum Sponsors will be recognized prominently on the project website, marketing materials, and communications and are eligible for a display table at the next Stillbirth Summit. Star Legacy Foundation will issue a press release announcing the partnership. Platinum Sponsors are eligible for one researcher to obtain data for research purposes at a 100% discount and one researcher to obtain data for research purposes at a 50% discount per year of sponsorship.

### Gold Sponsor

\$ 25,000

Gold Sponsors will have their logo placed on the project website, marketing materials, and communications and are eligible for a display table at the next Stillbirth Summit. Gold Sponsors are eligible for two researchers to obtain data for research purposes at a 50% discount per year of sponsorship.

### Silver Sponsor

\$ 10,000

Silver Sponsors will have their logo placed on the project website and communications and are eligible for a display table at the Stillbirth Summit. Silver Sponsors are eligible for one researcher to obtain data for research purposes at a 50% discount per year of sponsorship.

### Bronze Sponsor

\$ 5,000

Bronze Sponsors will have their logo placed on the project website. Bronze Sponsors are eligible for one researcher to obtain data for research purposes at a 25% discount per year of sponsorship and are eligible for a display at the next Stillbirth Summit.



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## Questions

For more information, visit [www.pregnancyresearchproject.org](http://www.pregnancyresearchproject.org) or contact us at [research@starlegacyfoundation.org](mailto:research@starlegacyfoundation.org), 952-715-7731.

To register as a Pregnancy Research Project Partner and/or Sponsor, please click on the link below. You will be contacted by the Pregnancy Research Project Coordinator to be fully activated in the Pregnancy Research Project.

**[CLICK TO JOIN THE PROJECT](#)**