PROBLEM STATEMENT

In the United States, 24,000 babies are stillborn every year. Another 22,000 infants who are born alive and die shortly after birth due to the same causes. It is estimated that more than 50,000 pregnancies end in miscarriage each year. Nearly 100,000 families will experience the death of a baby during pregnancy or infancy every year in the United States alone. One in four women will experience a pregnancy loss or infant death in their lifetime. Significant racial disparities exist as rates for Black and Native American women are double the rates of other women in the United States.

The current fetal death rate in the United States (2017) is 5.9/1,000 births. It is the goal of the Star Legacy Foundation to see the fetal death rate in the United States decrease by 25% by 2025 and racial disparities to be resolved.

ASSESSMENT OF CURRENT STATUS

Strengths:

- Star Legacy has experienced tremendous growth since 2011.
- The Stillbirth Summits have been recognized by many researchers as the premier stillbirth conference
- We have a large and passionate volunteer force
- Star Legacy has constituents in all 50 states, District of Columbia, and 19 countries.
- At the end of 2020, we had 20 Chapters from coast to coast.
- Star Legacy is the largest community organization in the United States with a primary focus on stillbirth prevention
- The Pregnancy Research Project is the first database of its kind in the world and has the potential to expedite what is known about preventing poor pregnancy outcomes by 10-20 years.

Weaknesses:

- Challenges exist in establishing connections with diverse populations and under-served communities
- Fundraising has been negatively impacted by the global pandemic
- Desire better representation of US geography, cultural diversity, and needed skills on the Board of Directors

Opportunities:

- Only 21% of stillborn babies in the United States are fully evaluated.
- 11% of families were aware that babies could die during pregnancy after the first trimester
The obstetric professional organizations in several high-income countries have started to address this issue and embrace changes necessary for stillbirth prevention.

The US ranks 48th out of 49 high-income countries in Annual Rate of Reduction of stillbirth.

Healthy People 2020 posted a target for fetal death of 5.6/1000 births. Healthy People 2030 has been raised to 5.7/1000.

Majority of our funds come from Champion events and private donations compared to grants and corporate sponsorships.

Threats:

- Unborn babies do not have personhood rights. Legal and medical efforts to recognize their life value have invoked the complexities of the abortion debate in the US.
- Our society is uncomfortable with babies dying and this creates difficulties in finding individuals and organizations desiring to align themselves with our mission.
- Obstetrics carries the second-highest malpractice insurance rates in the US, indicating the significance of legal considerations of providers.
- Insurance companies do not have any financial incentives to prevent stillbirth.
- ACOG and Joint Commission have not established public efforts to prevent stillbirth or recognized this goal as a benchmark for health.
- Many organizations of various sizes exist in the United States to support bereavement efforts after pregnancy and infant loss.
- Several organizations in the United States claim to be interested in stillbirth prevention as a secondary goal, but enact policies contrary to this outcome despite raising money from stillbirth families for this purpose.
GOALS

Goal 1: Contribute to research designed to prevent stillbirth and neonatal death and improve care for families when prevention isn’t possible.

Objectives:

- Pregnancy Research Project will be a source of data for international research studies
- Provide Research Grants for studies that support the Star Legacy Foundation mission.
- Encourage and participate in international, collaborative research efforts
- Adapt and promote protocols intended to reduce the rate of stillbirth, and neonatal death

Goal 2: Educate health professionals about opportunities to prevent stillbirth, miscarriage, and neonatal death and provide optimal care for families when prevention isn’t possible.

Objectives:

- Improve health professionals’ understanding of perinatal loss prevention and bereavement topics
- Recognize excellence in prevention of miscarriage, stillbirth and neonatal death and bereavement care
- Improve access to tools and information regarding perinatal loss prevention and care

Goal 3: Empower families with information about healthy pregnancies and grief.

Objectives:

- Improve family knowledge of healthy pregnancy and bereavement topics
- Provide culturally-sensitive messages to families regarding prevention opportunities and grief

Goal 4: Raise societal awareness of poor pregnancy outcomes, opportunities for prevention, and perinatal bereavement needs.

Objectives:

- Create public awareness campaigns with statistics, prevention, and support messages
- Increase engagement of families outside the loss community
- Implement awareness programs designed to reach marginalized communities
Goal 5: Advocate for policies that encourage prevention of poor pregnancy outcomes and support bereaved families.

Objectives:
- Increase awareness of resources available to families
- Replicate initiatives that benefit families

Goal 6: Support families grieving the death of a baby through miscarriage, stillbirth, neonatal death, or other poor pregnancy outcomes.

Objectives:
- Provide support services to those affected by perinatal death
- Diversify programs to improve inclusivity of support services

Goal 7: Be the premier stillbirth organization in the United States

Objectives:
- Establish a presence throughout the United States
- Be recognized as a trustworthy and valued organization
- Secure funding needed to obtain organizational goals
- Expand and enhance committed team of staff and volunteers
- Be a leader in the maternal health and pregnancy loss communities