

# Gabriel's Courage

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## 1 Background

In-utero hospice or palliative care for the imperiled newborn is a relatively new concept in perinatal bereavement. Parental values are honored and ethical guidelines are considered. The gift of time is bequeathed. Choosing to continue a pregnancy with a life-limiting fetal diagnosis is a heart-wrenching decision and a choice that is important to support unconditionally for healing to begin.

*Together we embrace this significant life one moment at a time with hope and faith.*

*Together with God's grace, we walk the road to bittersweet where hello is also goodbye.*

## 2 Our Mission And Vision

This program is a liaison between hospice/bereavement services/ home care providers; chaplains/genetic counselors/child-life specialists; labor & delivery/NICU nursing staff; obstetricians, perinatologists & neonatologists. The goal is to help families prepare for the birth and death of their baby with emphasis on their preferences, wants, needs and desires.

*Whether their wished for child lives in his/her mother's womb, for minutes, hours, days, weeks, months or years, they start their journey as parents and end their journey as parents.*



*"What we have once enjoyed we can never lose...all that we love deeply becomes a part of us." (Helen Keller)*

## 3 The Beginning

All involved team members participate in Resolve Through Sharing® training which is a two-day facilitator workshop with additional precursor online modules that focuses on relationship-based & family-centered care. (Gundersen Health System; La Crosse, Wisconsin)

A referral process was developed in order to identify families in need and ensure a consistent, interdisciplinary, holistic approach and a standardized, collaborative plan of care.

## 5 The Culmination

**Case Presentation:** D.P. is a 44 year old G3 P2002 who was referred to us through her obstetrician and perinatologist at 29 weeks gestational age. Her fetus had a confirmed diagnosed chromosomal abnormality of trisomy 13. Patient and family were aware of the prognosis, the high risk of fetal death in utero and likely neonatal death shortly after birth. She desired to continue the pregnancy. Visits to MFM revealed Intermittent AEDV (absent end-diastolic flow). Patient desired a live born and the chance to hold and baptize the baby. Risk/benefits/alternatives were discussed in regard to mode of delivery. Patient was visited in her home several times and a team meeting was held at the hospital. She agreed to a trial of labor, but it was not tolerated well and she ultimately had a cesarean birth. He was born at 32.3 weeks gestational age on January 27th 2014 at 1850...he was baptized and died at 2045...in his mother's arms, surrounded by family, friends, nurses, doctors, clergy and his social worker with a lullaby whispered in his heart.

*His name was Pablo.*



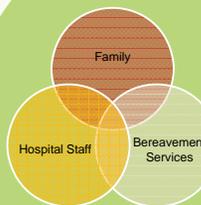
## 4 The Continuance

An individualized BirthPlan is crafted so each moment can be cherished and each touch dearly treasured.

*Wishes for*

- ...labor and Delivery
- ...comfort care at time of birth
- ...feeding/breast milk donation
- ...sibling education
- ...spiritual rituals
- ...memory-creation
- ...desired keepsakes
- ...end-of-life care

*are shared.*



*Clear communication is an essential component.*

## 6 Authors:

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*We are ever grateful to each of these miraculous children who have their own story to tell.*