By Sue Steen, A member of the Stillbirth Advocacy Working Group.

When I first came to Uganda 15 years ago, I was touring Mulago Hospital, the major hospital in Uganda. It is now called Kawempe and they deliver up to 100 babies a day, yes, a day! I asked the midwife how they handled the babies who died. She took me behind a counter in the Surgical area and showed me a cardboard box filled with stillborn babies. I was stunned and saddened. Each of those precious babies deserved better.

As the years went by, I learned that stillborn babies were not shown to mothers, but whisked away by family members, put in a sealed cardboard box and taken back to the village to be buried. During a recent visit to Uganda, we heard heart-wrenching stories. One mother shared her deep resentment towards her husband and mother-in-law because they had done this very thing. We heard tales from psychologists who described women grappling with intense grief, trying to make sense of where their baby had gone. We heard stories of women returning to their villages after their baby died, and rather than finding support were faced with stigma and a community who believed that they were cursed.

Over these years, I along with my colleague Lynn, created <u>Birth with Dignity</u>, not only to care for bereaved families, but also to work towards decreasing maternal and neonatal mortality. Birth with Dignity is a program that trains and educates Ugandan midwives and physicians to give high-risk care to women in childbirth and also introduces the concept of perinatal bereavement care. Thousands of health care providers have received this training over the past 7 years and 5 healthcare facilities have adopted our program.

The 250 midwives, from many districts around Uganda, who attended our conferences in January 2025 received the concept of compassionate bereavement care with enthusiasm. Many said that they did not know about this care and how important it was for the family. One midwife approached us after the conference and promised that she would begin to provide bereavement care. Another midwife mentioned that the challenge of having one midwife on duty at night was great, but that she would try hard to support the bereaved family.

At two of the hospitals where there are Birth with Dignity (BWD) programs, Mbale Regional Referral Hospital and Lira Regional Referral Hospital, we heard very different stories. One of the families pictured below had come to the hospital with a live baby ready for delivery. Somewhere along the way, the baby died before birth. The family was devastated and angry. They refused the baby after delivery and said it was not theirs. However, after one of our midwife leaders, Judith, counseled them, they began to accept the situation. They held their beautiful baby, took pictures, and named her.

Our BWD teams shared how the families are now open to wrapping and holding the stillborn baby. They told stories of how families received their counseling and began to support the mother. And they told us that now families carry their wrapped babies back to the village in their arms, not in a box.

Our goal is that every Ugandan healthcare provider will be competent in providing high-risk care to mothers as well as competent in providing perinatal bereavement care. Our hope is that every family that experiences a stillbirth would be offered this care and supported in their grief.

Both of the families pictured have given us permission to share their stories and pictures in hopes of offering bereavement care to all Ugandan families. This is our goal!



Photo by Sue Steen



Sue Steen RN MS, Birth with Dignity.

Sue works as a Perinatal Nurse Navigator at Maple Grove Hospital, with families who have suffered the early or late loss of a baby. She is also an adjunct nursing professor at Bethel University. She is currently serving on the board with the International Stillbirth Alliance. Sue, along with her colleague, Lynn, founded Birth with Dignity, whose mission is to save Ugandan mothers and babies in childbirth and care for those whose babies die.