

HARD CASES CLOSE TO HOME

The hypertension that doctors feared for James' mom didn't result from Potter's Syndrome; she also developed it during other pregnancies. Joseph's mom had concerns about polyhydramnios (swelling from excess amniotic fluid) but the primary concern with that (besides discomfort) is early labor or stillbirth, which again concerns the baby, not the mom. Elizabeth and Jacob's mom did not experience complications, but was told infection could follow if the baby died in the womb. All of these complications are manageable; none are life threatening or permanently damaging to the mother.

In cases such as these, some try to use the principle of double effect to justify actions that end the baby's life. But double effect can only be invoked when the primary intended effect is not morally wrong. The intended effect of "early induction" (or "termination") is to shorten the pregnancy by birthing a non-viable child. It may be a well-meaning attempt to minimize the parents' grief, but it actually does nothing to take away the pain of infant loss. Early induction does directly result in the baby dying earlier rather than later and this is the primary intended effect of the procedure, not merely an unfortunate secondary result.¹ In this case, "early induction" is not the only conceivable means of relieving grief, and is mostly ineffective. In fact, there is ample evidence that abortion often causes additional emotional complications, both from the grief of loss and from disrupted hormonal balance.² The drastic hormonal shifts have also been shown to cause dramatically increased risk for disease, notably breast cancer.³ In addition, there is evidence that

termination of pregnancy (abortion) can have a traumatic effect on those involved, including medical personnel who participate or witness the event.⁴ In any case, what if the diagnosis was wrong, which has been known to happen?

Why Couldn't We...?

It's natural for parents to ask if there is anything they can do to help their child survive as long as possible. With anencephaly and Potter's Syndrome, possibilities are extremely limited because vital organs are severely affected. Unfortunately, possibilities are further limited by the hopeless practice of early induction. Since Potter's Syndrome involves inadequate amniotic fluid, most parents ask the obvious question: "Can't we try to inject synthetic amniotic fluid into the womb as needed?" Parents are told, "No." Yet in 2013, a US Congresswoman, Jamie Herrera Beutler, and her husband wouldn't take no for an answer. They found a team of doctors willing to try the injections. Their daughter Abigail became the first known survivor of Potter's Syndrome, receiving a standing ovation on the House floor a year after her birth. Abigail's dad, Daniel, said in a *Today Show* interview, "There are no guaranteed solutions...for [Potter's Syndrome], but don't be satisfied with one opinion because there are a lot of intelligent doctors with different perspectives and experiences and opinions, so work to find one who will partner with you to find anything possible."⁵

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Citations:

1. Principle of Double Effect, download at Catholics United for the Faith: www.cuf.org/FileDownloads/doubleeffect.pdf
2. Afterabortion.org lists physiological effects of abortion.
3. The Breast Cancer Prevention Inst. (bcpinstitute.org) presents the physiological explanation and statistical correlation of abortion to breast cancer.
4. Many former abortion providers share their stories at ProLifeAction.org/providers and ATTWN.org (And Then There Were None.)
5. Steven Ertelt, "Congresswoman's Miracle Baby Still Doing Well After Doctors Said She'd Die," *LifeNews.com*, September 6, 2013.

This brochure is not intended as a resource for medical information about the conditions mentioned. Note that although Down Syndrome is included in the list (as Trisomy 21), children with Down Syndrome have a much higher chance of survival than children with the other conditions named in this brochure. The life expectancy for all of these prenatal conditions increases with advances in medical knowledge and technology.

Information for stories was collected from personal interviews and with permission from a blog about Joseph. More information from the interviews is available at ShelbyCountyRTL.org. For additional stories and resources, see PrenatalPartnersForLife.org and SufficientGraceMinistries.org.

The book, *I Will Carry You* by Angie Smith chronicles the creative ways one family found to spend time with their child in her short life. This is a helpful resource for families faced with a life-limiting prenatal diagnosis.

Benjamin Hartings, father of James Thomas, has written a book about his experience. *Return to the Altar: A Sacred Journey through Grief and Joy* is the story of a family's loss, a death of a son, and how it transformed their view of the world. What brought the family back to the Altar was not an experience that was expected, but one that was accepted as God's plan.



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"Every mom I know in anencephaly groups who has carried to term has no regrets, while there are so many who regret early induction/ termination. It is truly amazing (and not distinctly related to the parent's religion)."

—The mother of Baby Joseph

Best Choices for Families Dealing with Adverse Fetal Diagnosis



Discovering one's child has a serious medical condition is always devastating, whether it occurs at twenty years old or twenty weeks gestation. Among the many disorders that usually shorten a child's lifespan dramatically, causing death within the first few months of life, are various Trisomy conditions, Potter's Syndrome, and anencephaly (a neural tube disorder). Many families confronted with an adverse prenatal diagnosis have experienced a lack of resources, information, and support, and often face unwelcome pressures as well, but those who carry to term usually find peace nonetheless.

Dum Vivimus Vivamus

“Dum vivimus vivamus... While we live, let us live” is a fitting motto for families who give their babies a chance to survive, contrasting sharply with many historical and current medical practices. What follows are four stories from a limited geographical region (western Ohio) representing hundreds of regions across the country; your own communities; your own hospitals.

The life of Joseph

Diagnosed with anencephaly at 20 weeks; lived 37 weeks in the womb and 88 minutes after birth.

The ultrasound doctor who diagnosed anencephaly gave Joseph's parents one option: “we could induce early (like next week!) and then we wouldn't have

to go through the rest of the pregnancy... I thought to myself: If my firstborn, was diagnosed with a terminal illness and had only 4 months to live, would I ask the doctors to end her life right now, or would I love and cherish every moment until God called her home? Thinking of it that way, the answer was clear. It was obvious it wasn't a choice at all. I was incredibly sad and discouraged having to be in this position, but the only possible choice we could live with is to just love this baby as long as we can.” After their initial office visit, they were fortunate to experience the support of family and friends, as well as that of their trusted family physician, who “grieved with us, prayed with us.”

The life of James Thomas

Son of Ben and Lynn, diagnosed with Potter's Syndrome at 22 weeks; lived 36 weeks in the womb and 90 minutes after birth.

James' mom shared their experience, “At the initial appointment [22 week check up] when we discovered the Potter's Syndrome, the first words from the doctor's mouth were: ‘If you choose to terminate, you need to do so by the end of the week.’” James' parents were “surprised, angry and hurt by this recommendation.” So much so that, at their request, the ethics board of the hospital has changed their guidelines for doctors, instructing them to present, in a compassionate manner, a full range of options to clients. James' parents wondered, “Why was this the first option given to us?” The only risk factor for James' mom was a previous history of pregnancy hypertension unrelated to Potter's Syndrome. It was treatable and only a concern closer to term when James would be viable outside the womb.

Fortunately family and close friends were very supportive. Yet “lots of other people questioned the decision. No one could give any rationale for terminating, but the gist was ‘why would you want to continue with the pregnancy [considering it

an inconvenience] when you know he is going to die anyway?’” The response of James' parents was, “Why not? Why not give him the best chance at life that we could?”

The lives of Elizabeth and Jacob

Children of Scott and Julie, both diagnosed with Potter's Syndrome at around 20 weeks gestation, with different outcomes.

Elizabeth and Jacob's parents had a significantly different experience with their first child diagnosed with Potter's syndrome than with their second. Elizabeth and Jacob's stories are a poignant illustration of the contrast between two different decisions. With Elizabeth, their first child with Potter's, they followed advice from doctors and other counselors, undergoing “early induction” at 23 weeks. Doctors had avoided the word “termination” so they didn't realize the implications—until later—nor the deep regret that came with “early induction” of an essentially non-viable baby. Nor would they have chosen that route had they been better informed. When Jacob came along, diagnosed with the same condition, they knew they didn't have to “induce early.” This time, “we were more at peace because we had given him every chance to live.” Monitoring vital signs closely, they carried Jacob as close to term as possible, birthing him at 37 weeks after discovering he passed away in the womb. Their only living child was almost 3 as they said their goodbyes to Jacob at the birth. With both Elizabeth and Jacob, pictures from the day of birth are precious memories, even though the children had not survived. A deeper regret lingers, however, with regard to the short time leading up to Elizabeth's last day of life: “We feel like we weren't given time with Elizabeth like we were with Jacob between diagnosis and birth. With Elizabeth we had a week and a half to make a decision and prepare. That wasn't enough time and made everything harder after.” They had hoped for a live birth with both children, even if the time with

them alive would be limited. In both cases it was not as they had hoped, but with Jacob they were grateful for those extra 14 weeks they had with him alive in the womb. “Doctors are afraid of giving false hope,” they added, “but parents need hope. The hopes are not naive; they give parents the opportunity to try to do something to help their child.”

Safeguarding Women's Health and Applying Moral Principles

The short lives of the children introduced in this brochure deeply touched their families, calling them to love. All of these families experienced many blessings from choosing to carry their babies to term. They were fortunate to have access to information beyond the limited options given at the hospital, and to have ample support for their decisions from friends and family. These life-limiting prenatal conditions primarily affect the babies, not posing serious risk to the mother.

