

## Supplement to the brochure Life-Limiting Prenatal Diagnosis: Hard Cases Close to Home

In response to an increasing number of families feeling pressure to undergo “early induction” (or abortion) for a child with a disability, Shelby County Right to Life has authored a brochure being carried by One More Soul ([www.onemoresoul.com](http://www.onemoresoul.com)), entitled Hard Cases Close to Home (Life Limiting Prenatal Diagnosis).

The brochure explains:

“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 (e.g., Trisomy 13, 18, and 21); 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.”

Unfortunately, the pressures and misinformation many families experience today is not so different from families who had disabled children taken from them in Nazi Germany.

(This section omitted from brochure due to space limitations.)

### Some History

The Hadamar Clinic in Nazi Germany was a facility where people with incurable diseases and disabilities were “eliminated” during World War II. Initially, infants and children were prime subjects of this secretive extermination project. Early on, parents’ “consent” was allegedly needed for killing the children, but “consent” was often gained by deceiving parents that their child would receive better care at this special clinic. Causes of death were recorded deceptively, so parents were misled about how their children actually died. Eventually, disabled adults were also executed in staggering numbers. This euthanasia program, historians note, “was in itself a rehearsal for Nazi Germany’s broader genocidal policies.”<sup>1</sup> Disabled people were called “life unworthy of life,” “useless eaters,” and “the unfit.” Though we no longer use such coarse expressions, the phrase “incompatible with life”—which has now been adopted by much of the medical profession—essentially replaces those other terms. (It is more specific, however, denoting medical conditions that almost invariably result in miscarriage, stillbirth, or early infant loss.) The phrase is a misnomer because, at the time children are diagnosed with such conditions, *they are alive*. The term might just as easily be applied to anyone “judged incurably sick, by critical medical examination”<sup>2</sup> as were those killed at the Hadamar facility. The phrase “incompatible with life” raises the question: Is it a judgment on the quality of life, or merely the length? While we can’t hear from the children who have died before they could speak, it is helpful to listen to the stories of parents who have experienced early infant loss from a life-limiting condition, especially those choosing to carry to term. Unfortunately, parents today still face some of the same misinformation (and even deception) that families in Nazi Germany faced.

#### Citations:

1. “Nazi Persecution of the Disabled: Murder of the ‘unfit,’” U. S. Holocaust Memorial Museum, [www.ushmm.org](http://www.ushmm.org).
2. Robert Proctor, *Racial Hygiene: Medicine Under the Nazi’s* (Cambridge: Harvard University Press, 1990), 177.

## Dum Vivimus Vivamus

*Dum vivimus vivamus ... While we live, let us live.* It's a fitting motto for families who give their babies a chance to survive, contrasting sharply with many historical and current medical practices.

The brochure contains four stories of families who dealt with adverse fetal diagnosis. While there are stories from all around the world that could have been chosen, these are all from a limited geographical region (western Ohio) showing just how close to home these stories are. They represent thousands across the country; they happen in your community, at your hospital.

The stories of these families were gathered from personal interviews with the parents and from a parent's blog. Some additional information from the interviews—not included in the brochures—can be found here.

### FROM THE BROCHURE

#### *The life of James Thomas*

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

James' mom explained, "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. By law, doctors must inform parents that abortion is an option, but 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, but that wasn't a concern until closer to term when James would be viable anyway, and they could treat that.

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?"

### **Additional notes from the interview, not included in the brochure.**

Ben and Lynn never thought this would happen to them; they had never feared that they'd have a miscarriage or any other complications. When James was conceived they already had two girls and one boy and Lynn had never had a miscarriage. After their experience with James, Lynn said she became much more sympathetic to those who have had miscarriages. (An adverse fetal diagnosis adds a different layer of difficulty to early infant loss, but with many similarities to miscarriage.)

Potter's Syndrome is diagnosed when there is a dangerously low amount of fluid in the amniotic sac. There are various causes for the fluid being low. Of course the obvious question occurred to Ben and Lynn before James was born: they wondered if it was possible to receive saline injections as needed, in order to maintain adequate amniotic fluid levels. Although they were told that replenishing amniotic fluid was not even a remote possibility, it was only a couple of months after James was born that they heard about the first ever successful treatment given to a baby with Potter's Syndrome. (Representative

Carmen Herrera Beutler's baby, Abigail, mentioned in the brochure, was the first to receive the treatment.) At the time that the news broke, they were not emotionally ready to look into the details of that case. Of course they were glad that the Beutler's baby survived, but it was very painful for them to think that they had been denied a life saving treatment for their son—not because of any lack of technological or medical readiness—but simply because no doctor up to that point had been willing to try.

### **Hearing the Diagnosis and Preparing for Birth**

Thinking the ultrasound would be a happy event, Ben and Lynn had their other kids present for the ultrasound when they discovered the devastating diagnosis. The children will never forget the looks on their parents' faces.

Their doctor had only had one other case of Potter's and that family chose termination. Ben and Lynn, however, "never had a second thought about offering this baby as much love and as much chance at life as we could."

In previous pregnancies Lynn had hypertension so —as in the past— they planned to induce at 36-37 weeks to avoid complications related to hypertension. Because Potter's Syndrome results in fatality immediately after birth, Ben and Lynn were conscious that choosing a date for induction was choosing both a birth date and death date. Both would be experienced on whatever day they chose. It was a weighty decision. They chose June 8 (36 weeks gestation), but Lynn ended up going into labor naturally on that date.

Children with Potter's can have different levels of kidney development, but as expected based on James' tests, he had no kidneys at birth (which, according to Lynn, is 80% more common in boys.) James remained attached to the cord for the full 90 minutes that he lived after birth, and his family counted each breath. James was baptized during that time. Lynn had great peace about the whole experience and their family cherishes that time. They had invited extended family to be there so that they could all meet James in his short life. Family members headed for the hospital as soon as labor started—some travelling from 2 hours away, to love their newborn relative and grieve his untimely death.

Ben and Lynn chose to have an autopsy done and are involved in a study to help determine causes of Potter's. They will not know the details of the study for a couple of years.

Prior to the birth, they were hoping and praying for a miracle, but were very focused on funeral arrangements. James was buried in his parents' hometown, not where they were living at the time. On later reflection, they wondered if it might have been better to put off funeral arrangements and just focus on James' life, but they did what they could, in finding a balance between hope and facing reality.

During the pregnancy, they did make funeral arrangements, but they also did fun family activities with all the kids, like visiting the zoo. They were conscious that this was their family time with James. They took lots of pictures to remember that time with James. (Before the birth they didn't know whether the baby was a boy or girl, but they had chosen a name for either.) Lynn explained, "Some people can't do pictures. It's too painful for them to have any reminders in their home, but we are not those people. We chose to have a lot of pictures, including a professional photographer at the birth."

### **What the Future Holds**

The interview with Lynn was just two weeks shy of the anniversary of James' birth and death. They had certainly gone through the grieving process during that year. "We're hoping that soon we'll be able to get to the new normal; and it will be a *new* normal," Lynn added, noting the undeniable impact James' life had made on their family.

Ben and Lynn do have worries about future pregnancies, but are open to God's will in having more children. [Medical professionals generally note that after miscarriage or an early death of a baby, the mother's body does need time to heal and recover before another pregnancy.]

Ben and Lynn have been involved in support groups, which they consider to be a great help to them. They are willing to talk to others in similar situations, to try to help them cope. Most of the books they found helpful were from a mother's perspective, but Ben has published a book from his perspective, called "Return to the Altar: A Sacred Journey Through Grief and Joy." To watch a video presentation about their book or for ordering information, visit their website [Intersect-me.com](http://Intersect-me.com). The book is sold through Amazon.com.

#### FROM THE BROCHURE

##### ***The lives of Elizabeth and Jacob***

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

There were significant differences between their experiences with two different children who had similar conditions. 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." With both children, they had hoped for a live birth 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."

In their interview, Scott and Julie noted that sometimes comments, or complaints, from other people about their own children can strike a painful cord, making them long for their child who is no longer with them. They understand, however, that people don't mean any harm and can't always foresee their comments stirring painful reactions. On the other hand, they've occasionally heard comments which they feel give purpose to their pain, for example: "Hearing your story has made me appreciate my children even more."

# Hard Cases Close to Home

Best choices for families dealing  
with adverse fetal diagnosis



“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

(Pictured above is another family whose child was diagnosed with anencephaly. Photo is copyrighted, but used with permission.)

## FROM THE BROCHURE

### *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 too experienced the support of family and friends, as well as that of their trusted family physician, who “grieved with us, prayed with us.”

For more information about Joseph,  
visit his parents’ blog:

<http://beforeformedyou.blogspot.com/>

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.



### **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. 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 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.<sup>3</sup> 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.<sup>4</sup> The drastic hormonal shifts have also been shown to cause dramatically increased risk for disease, notably breast cancer.<sup>5</sup> 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.<sup>6</sup> 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."<sup>7</sup>