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# PERINATAL HOSPICE INFORMATION ACT

Model Legislation & Policy Guide  
*For the 2014 Legislative Year*



*Changing Law to Protect Human Life, State by State*

# INTRODUCTION

Prenatal screening and diagnostic methods have improved significantly over the last few decades. As a result, increasingly more fetal anomalies are being detected at an early stage in pregnancy.<sup>1</sup> Unfortunately, when a severe congenital anomaly is diagnosed, most couples opt to terminate the pregnancy,<sup>2</sup> while approximately 20 percent decide to continue pregnancy.<sup>3</sup>

Experts explain that the options presented to parents when a lethal fetal anomaly is diagnosed generally include abortion or simply continuing the pregnancy with routine medical care.<sup>4</sup> This “bare presentation” of options can leave parents with the perceived choice of helplessly watching their baby die, which can be misunderstood as increasing the child’s suffering, or “actively doing something to end this sudden, emotionally-wrenching dilemma.”<sup>5</sup> Just as many terminally ill patients fear pain and abandonment, the families of unborn children diagnosed with fetal anomalies also fear being shunned or abandoned, which often forces such families into decisions to abort—decisions some parents have described as “almost inhuman decision[s] to take.”<sup>6</sup>

Yet studies show that aborting a child with a fetal anomaly can cause great psychological harm for some parents.<sup>7</sup> Researchers have stressed the importance of adequate psychological support and guidance from the woman’s caregiver during the decision-making process.<sup>8</sup> Clearly, parents need to know that there are more compassionate options than simply terminating a pregnancy.

Recognizing the need for more supportive care and choices for these parents, medical professionals began looking to model patient care after the 1960s hospice movement. That movement spread throughout the 1970s and 1980s and began including the treatment of

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<sup>1</sup> M.J. Korenromp et al., *Long-term psychological consequences of pregnancy termination for fetal abnormality: A cross sectional study*, *PRENATAL DIAGNOSIS* 25:253 (2005).

<sup>2</sup> *Id.*

<sup>3</sup> M. D’Almeida et al., *Perinatal Hospice: Family-Centered Care of the Fetus with a Lethal Condition*, *J. AMER. PHYSICIANS & SURGEONS* 11:52 (2006); B.C. Calhoun & N. Hoeldtke, *The Perinatal Hospice: Ploughing the Field of Natal Sorrow* (2005).

<sup>4</sup> M. D’Almeida, *supra*.

<sup>5</sup> *Id.*

<sup>6</sup> Calhoun & Hoeldtke, *supra*; Korenromp, *supra*.

<sup>7</sup> In 2004, one study revealed that maternal grieving after such abortions continued for over six months and included pathological anxiety and depression. A. Kersting et al., *Grief after termination of pregnancy due to fetal malformation*, *J. PSYCHOSOM. OBSTET. GYNAECOL.* 25:163 (2004). In 2005, a study by Korenromp et al. revealed that a substantial number of the participants (17.3 percent) showed pathological scores for posttraumatic stress. Korenromp et al., *supra*. A follow-up study in 2009 revealed that at 14 months post-abortion, 16.7 percent of women were diagnosed with a psychiatric disorder. A. Kersting et al., *Psychological impact on women after second and third trimester termination of pregnancy due to fetal anomalies versus women after preterm birth: A 14-month follow up study*, *ARCH. WOMEN’S MENTAL HEALTH* 12:193 (2009).

<sup>8</sup> Korenromp, *supra*.

terminally ill children. Dr. Jonathan Whitefield and his team further refined the hospice concept with the implementation of neonatal hospice at the Children's Hospital in Denver to support families of dying infants.<sup>9</sup> With the prevalence of prenatal diagnosis, parents need compassionate support much sooner than at birth; thus, the concept of perinatal hospice begins with the prenatal diagnosis of a lethal fetal anomaly.

Experts Dr. Byron Calhoun and Dr. Nathan Hoeldtke describe this compassionate care as encompassing three stages:<sup>10</sup>

1. Antepartum care (from diagnosis until labor and delivery)

This stage includes extensive support and birth planning. It is a multidisciplinary approach that includes loving support, freedom from the fear of abandonment, and careful counsel regarding clinical expectations. It includes the combined efforts of maternal-fetal medicine subspecialists, obstetricians, neonatologists, anesthesiologists, chaplains or pastors, social work services, and neonatal intensive care nurses. Often it includes multiple ultrasounds so that parents can experience the life of their child to the fullest before birth.

2. Intrapartum care (during labor and delivery)

This stage includes the extensive support and labor management that is common in other deliveries.

3. Postpartum care (after delivery)

This stage is tailored to the child and family, and seeks to allow the family optimum time with their child. Parents and family members hold the baby and collect mementos such as hand and foot molds. Healthcare providers emphasize the non-anomalous features of the baby and provide comfort and palliative care as needed.

When presented with the option, more than 80 percent of parents choose perinatal hospice when it is offered in such a supportive environment.<sup>11</sup> Calhoun et al. reported that 87 percent of their

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<sup>9</sup> Calhoun & Hoeldtke, *supra*.

<sup>10</sup> *Id.*

<sup>11</sup> D'Almeida, *supra*. The type of care given from diagnosis until the child's death is discussed in detail in this study.

patients diagnosed to be carrying a child with a lethal congenital disorder choose to continue pregnancy in this environment of care.<sup>12</sup>

Unfortunately, most women and their families are not presented with the option of perinatal hospice when considering abortion of unborn children with lethal fetal anomalies. It is imperative that women considering abortion be given all information about their choices, including the choice of supportive perinatal care. To that end, it is essential for states to consider including information on perinatal hospice in their informed consent materials that must be presented to women prior to making decisions about continuing their pregnancies. To date, only three states—Arizona, Kansas, Minnesota—provide such information. In response, AUL has developed the “Perinatal Hospice Information Act,” model language that can be incorporated into states’ existing informed consent laws to address this urgent need.

For more information and drafting assistance, please contact AUL’s Legislative Coordinator at (202) 289-1478 or [Legislation@AUL.org](mailto:Legislation@AUL.org).

**DENISE M. BURKE, ESQ.**  
*Vice President of Legal Affairs*  
*Americans United for Life*

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<sup>12</sup> B.C. Calhoun et al., *Perinatal Hospice: Comprehensive Care for the Family of the Fetus with a Lethal Condition* (2005).

# PERINATAL HOSPICE INFORMATION ACT

HOUSE/SENATE BILL No. \_\_\_\_\_  
By Representatives/Senators \_\_\_\_\_

## Section 1. Title.

This Act may be known as the “Perinatal Hospice Information Act.”

## Section 2. Legislative Findings and Purposes.

- (a) The [*Legislature*] of the State of [*Insert name of State*] finds that:
- (1) As prenatal diagnosis improves, increasingly more lethal fetal anomalies are diagnosed earlier in pregnancy.
  - (2) Currently, parents are often given minimal options: terminating the pregnancy or simply waiting for their child to die. The majority of parents choose to terminate the pregnancy. Only twenty (20) percent of parents decide to continue the pregnancy.
  - (3) Studies indicate that choosing to terminate the pregnancy can pose severe long-term psychological risks for the woman, including the chance of posttraumatic stress, depression, and anxiety. On the other hand, parents who choose to continue pregnancy in the supportive, compassionate care of a perinatal hospice team report being emotionally and spiritually prepared for the death of their child.
  - (4) Studies reveal that when given the option, at least eighty (80) to eighty-seven (87) percent of parents choose to continue pregnancy in the supportive environment of perinatal hospice care.
- (b) Based on the findings in Subsection (a) of this Section, it is the purpose of this Act to:
- (1) Guarantee that women considering abortion after the diagnosis of a lethal fetal anomaly are presented with information on the option of perinatal hospice care; and
  - (2) Ensure that any abortion choice such women make has been fully informed.

### Section 3. Definitions.

For purposes of this Act only:

(a) **“Abortion”** means the act of using or prescribing any instrument, medicine, drug, or any other substance, device, or means with the intent to terminate the clinically diagnosable pregnancy of a woman with knowledge that the termination by those means will with reasonable likelihood cause the death of the unborn child. Such use, prescription, or means is not an abortion if done with the intent to:

- (1) Save the life or preserve the health of the unborn child;
- (2) Remove a dead unborn child caused by spontaneous abortion; or
- (3) Remove an ectopic pregnancy.

(b) **“Department”** means the Department of [*Insert appropriate title*] of the State of [*Insert name of State*].

(c) **“Lethal fetal anomaly”** means a fetal condition diagnosed before birth that will with reasonable certainty result in the death of the unborn child within three months after birth.

(d) **“Medical emergency”** means that condition which, on the basis of the physician's good faith clinical judgment, so complicates the medical condition of a pregnant woman as to necessitate the immediate termination of her pregnancy to avert her death or for which a delay will create serious risk of substantial and irreversible impairment of a major bodily function.

(e) **“Perinatal hospice”** means comprehensive support to the pregnant woman and her family that includes support from the time of diagnosis through the time of birth and death of the infant and through the postpartum period. Supportive care may include (but is not limited to) counseling and medical care by maternal-fetal medical specialists, obstetricians, neonatologists, anesthesia specialists, clergy, social workers, and specialty nurses focused on alleviating fear and ensuring that the woman and her family experience the life and death of their child in a comfortable and supportive environment.

(f) **“Physician”** means any person licensed to practice medicine in this State. The term includes medical doctors and doctors of osteopathy.

### Section 4. Requirements.

(a) No abortion shall be performed or induced without the voluntary and informed consent of the woman upon whom the abortion is to be performed or induced. Except in the case of a medical emergency, consent to an abortion is voluntary and informed if and only if:

- (1) In the case of a woman seeking an abortion of her unborn child diagnosed with a lethal fetal anomaly, at least twenty-four (24) hours before the abortion, the physician who is to perform the abortion or the referring physician has informed the woman, orally and in person, that perinatal hospice services are available and has offered this care as an alternative to abortion.
- (2) In the case of a woman seeking an abortion of her unborn child diagnosed with a lethal fetal anomaly, at least twenty-four (24) hours before the abortion, the woman is given a list of perinatal hospice programs available both in her state and nationally, prepared by the Department and organized geographically by location.

(b) If perinatal hospice services are declined in favor of abortion, the woman must certify in writing both her decision to forgo such services and proceed with the abortion and that she received the materials listed in Subsection (b) of this Section.

#### **Section 5. Publication of Materials.**

The Department shall cause to be published the printed materials described in Section 4 in English and Spanish [*and/or other appropriate language(s)*] within [*Insert appropriate number*] days after this Act becomes law.

#### **Section 6. Penalties.**

(a) Unprofessional Conduct. Any violation of this Act shall constitute unprofessional conduct pursuant to [*Insert appropriate statutes for 1) medical doctors and surgeons and 2) osteopathic doctors*] and shall result in permanent revocation of the violator's license to practice medicine.

(b) Trade, Occupation, or Profession. Any violation of this Act may be the basis for denying an application for, denying an application for the renewal of, or revoking any license, permit, certificate, or any other form of permission required to practice or engage in a trade, occupation, or profession.

#### **Section 7. Severability.**

Any provision of this Act held to be invalid or unenforceable by its terms, or as applied to any person or circumstance, shall be construed so as to give it the maximum effect permitted by law, unless such holding shall be one of utter invalidity or unenforceability, in which event such provision shall be deemed severable herefrom and shall not affect the remainder hereof or the application of such provision to other persons not similarly situated or to other, dissimilar circumstances.

**Section 8. Right of Intervention.**

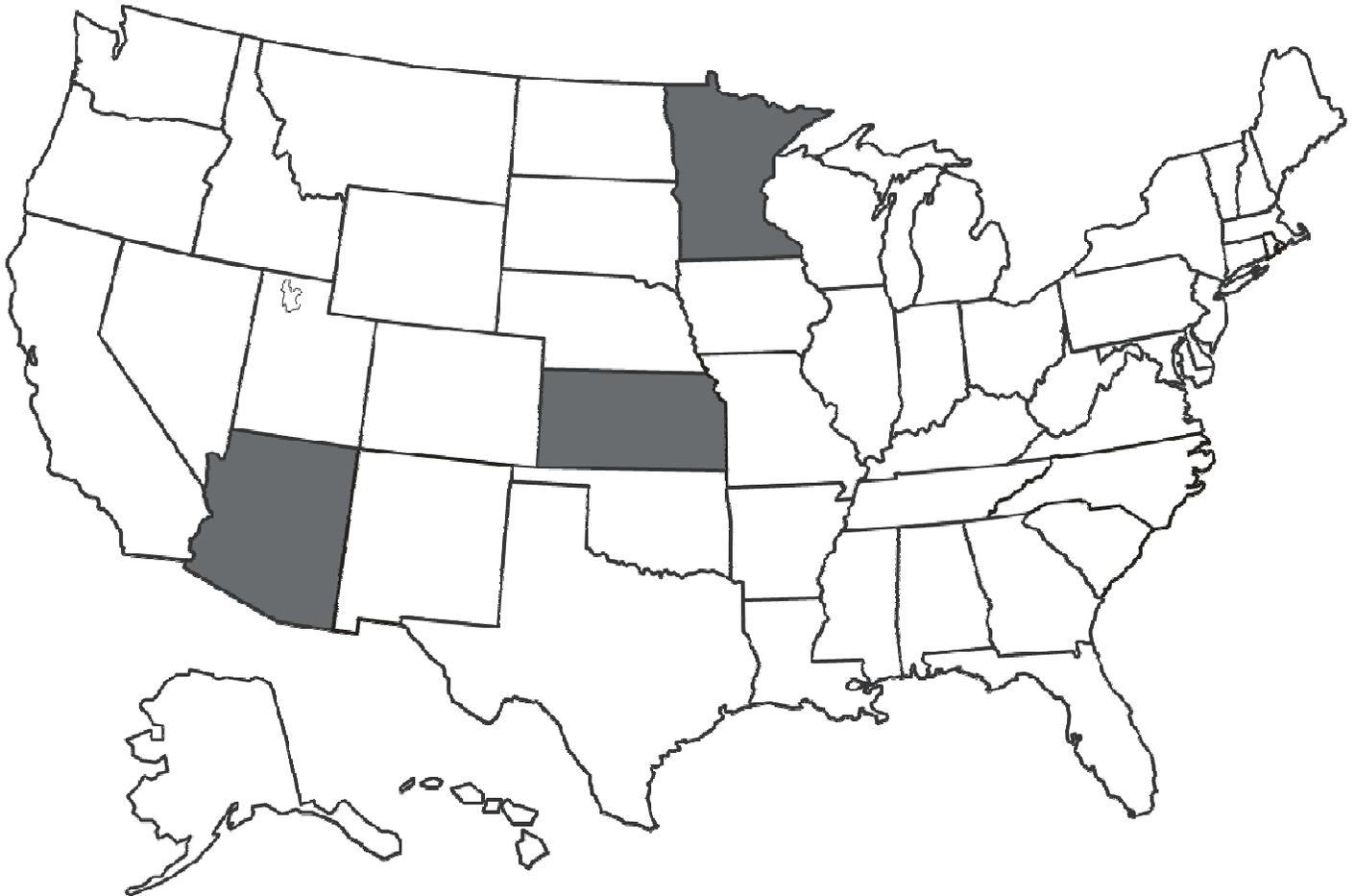
The [*Legislature*], by joint resolution, may appoint one or more of its members who sponsored or co-sponsored this Act, as a matter of right and in his or her official capacity, to intervene to defend this law in any case in which its constitutionality is challenged or questioned.

**Section 9. Effective Date.**

This Act takes effect on [*Insert date*].

# STATE OF THE STATES: WHERE ARE WE NOW? PERINATAL HOSPICE

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Three states require the provision of information about perinatal hospice in the context of informed consent before abortion: AZ, KS, and MN.

More information regarding informed consent for abortion can be found in AUL's annual publication *Defending Life*.

*Defending Life 2013, Deconstructing Roe: Abortion's Negative Impact on Women* is available online at [www.AUL.org](http://www.AUL.org) and for purchase at Amazon.com.

For further information regarding this or other AUL policy guides, please contact:

AMERICANS UNITED FOR LIFE  
655 15th Street NW, Suite 410  
Washington DC 20005  
202.289.1478 | Fax 202.289.1473 | [Legislation@AUL.org](mailto:Legislation@AUL.org)

[www.AUL.org](http://www.AUL.org)

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