FETAL DEATH EVALUATION PROTOCOL

Iowa Department of Public Health

Iowa Department of Public Health
321 E. 12th Street
Lucas State Office Building
Des Moines, Iowa
50319-0075

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Introduction

When an intrauterine fetal death occurs, a careful evaluation of the mother, stillborn infant, umbilical cord and placenta is essential to develop an understanding of the cause. An evaluation of the stillbirth occurrence will assist in the discussions with the parents, assist in the planning of any future pregnancy and perinatal care, and contribute to the understanding of the causes of fetal disease and deaths. This may help prevent future pregnancy loss and aid other families with similar conditions.

The terms stillbirth and fetal death are synonymous. For purposes of this evaluation tool, a stillbirth is defined by House File 2362 as "an unintended fetal death occurring after a gestational period of twenty completed weeks, or an unintended fetal death of a fetus with a weight of 350 or more grams." The attending physician or midwife will determine the gestational age of the fetus. Fetal deaths will have a one-minute Apgar score of zero.

In Iowa, there are approximately 200 documented fetal deaths each year. Many of these deaths are "unexplained." It is hoped that an organized, purposeful evaluation of a stillbirth will provide information helpful in the development of fetal death prevention programs.

Stillbirths are not included within the definition of a person as currently determined by Iowa Code. For this reason, stillbirths are not reportable to a medical examiner. Nevertheless, in the unusual event of a woman admitted to a hospital having delivered an infant alleged to have been stillborn, notification of a medical examiner is required if there is any reason to suspect that the infant had been born alive.

The intent of these guidelines is to provide a resource for health-care providers, families, and support systems, and to provide a consistent format for data collection for surveillance. The Iowa Department of Public Health requests that a copy of the completed Surveillance and Assessment sections be forwarded to the Center for Congenital and Inherited Disorders (address below). This information will then be forwarded to the Iowa Registry for Congenital and Inherited Disorders. The Registry will conduct an abstraction of the medical records and enter the information into the stillbirth surveillance system. This information will then be available for monitoring and analysis to determine the trends and causes of stillbirths in Iowa.

Send information to:

State Genetics Coordinator

Iowa Department of Public Health

321 E. 12th Street, 5th Floor

Des Moines, IA 50319-0075

Fax 515-725-1760

This manual is divided into six sections:

Surveillance

Maternal Family Interview

Assessment

Grief and Family Support

Follow-up

Appendices

These guidelines were developed by the Stillbirth Work Group established by the Iowa Department of Public Health, pursuant to Iowa Code, Chapter 136A, 2004 Iowa Acts, Chapter 1031 (HF 2362) from the 80th General Assembly.

Questions about these guidelines may be directed to the State Genetics Coordinator, Center for Congenital and Inherited Disorders, Iowa Department of Public Health, 1-800-383-3826.

Surveillance Fetal Death Evaluation Form

(Stamper Plate/ID label)

Hospital Name ______________________________

Individual Completing the Form ______________________________

If you would like a follow-up call re: the surveillance activities of this case, please indicate ☐ and provide contact information ______________________________

Mother's Name: ______________________________MR#: ______________

County of Residence: ______________________

Age: __________ Race: ________________ Ethnicity: ____________________

Father's Name: ______________________________ Race: ________________

Ethnicity: ____________________ County of Residence: ____________________

Date of Stillbirth Diagnosis: ____________________ EDC: __________________

Ultrasound findings at time of stillbirth diagnosis:

____

____

____

____

____

Probable factors contributing to fetal death:

____

____

OBSTETRICAL HISTORY

G ______ P ______ AB ______T ______PT ______ L ______

Prior obstetrical complications:

LMP: ______/______/______

Maternal Medical History:

Medications (Include over-the-counter medications and herbs):

Allergies: ____

Smoking: ______________________ Alcohol Use: ________________

Illicit Drug Use: ____

Maternal/Family Interview

Summary of discussion with mother and other involved family members - include baby's activity patterns (hiccups, kicks, big turns, patterns of movement etc.), when first noticed baby wasn't moving, any discomforts during day or night, and any other events deemed relevant by mother or family. Consider asking - Did you experience reduced fetal movements in the days before the stillbirth? If so how many days before? Did you experience sudden increase in fetal movements in the days before the stillbirth? If so how many days before? Did you see your care provider in the days before the stillbirth? Was this a routine visit? If it was not routine what was the reason for your visit? When do you think your baby died?:

Did the parents receive any education regarding tracking the movements of the baby, such as kick counting?

☐ Yes ☐ No

If yes, from whom? -

Which sleeping position does the mother report using the majority of the time while pregnant?

☐ Left Side

☐ Right Side ☐ Check if mother used a pillow to "prop" herself in her sleeping position

☐ Back

☐ Modified stomach

Assessment Form

ANTEPARTUM FINDINGS

Date of first prenatal visit: ______/______/______ Number of antepartum visits: ______

ABO/Rh: ______ Antibody: ______ VDRL: ______ HbsAg: _______________

Diabetes Testing: 1 hr Glucola: ___________ 3 hr GTT-FBS: ______ 1 hr: ______ 2 hr. ______3 hr. ______

Maternal Serum Screening (i.e., Integrated Screen, Expanded AFP/QUAD Screen, Triple Test, or MSAFP):

Y/N Results: ____

Amniocentesis:

Y/N Results: ____

Ultrasounds (List from most recent to initial exam):

Date: ________ Gestational Age: ____________

Findings:

____

____

Date: ________ Gestational Age: ____________

Findings:

____

____

Date: ________ Gestational Age: ____________

Findings:

____

____

Date: ________ Gestational Age: ____________

Findings:

____

____

Maternal Drug Screen:

Source: ______________________ Results: ____

Blood Pressure:

☐ Low diastolic BP consistently 60 or less

☐ Borderline Low diastolic BP consistently between 60-75

☐ Normal diastolic BP consistently between 75-90

☐ High diastolic BP consistently higher than 90

Blood Pressure range of mother prior to stillbirth: ____

HEALTH AT TIME OF DIAGNOSIS

Fever/Rash: Y/N Explain: ____

Bleeding: Y/N Pain: Y/N Explain: ____

Exposure History:

Illnesses Y/N Explain: ____

Teratogens: Y/N Explain: ____

Recent Trauma: Y/N Explain: ____

Comments:

____

____

____

____

TESTS AT DIAGNOSIS

(As ordered by attending physician)

☐ Fetal Hemoglobin in the Maternal Circulation: Kleihauer-Betke or flow cytometry: ___________________

☐ Lupus Anticoagulant: ____________________________

☐ Anticardiolipin antibodies: _________________________

☐ (If extensive placental infarction, Factor V Leiden ___________; Prothrombin gene mutation: ___________)

☐ Urine Drug Screen: ____

☐ Chromosomal analysis (amniocentesis): ____

☐ Hemoglobin A1c (HbgA1c)

☐ TSH

☐ CBC

☐ STORCH Titers: IgG and IgM for syphilis, toxoplasmosis, cytomegalovirus, herpes virus, and rubella

☐ PCR (Polymerase Chain Reaction) for STORCH

☐ Parvovirus IgG and IgM

FINDINGS AT DELIVERY

Comments:

____

____

GROSS FETAL EXAM

Fetus weight: ____________

	Normal	Abnormal (describe)		
1. General Appearance	☐	☐ trauma evidence	☐ macerated +, ++, +++	☐ edema
2. Skin	☐	☐ mec.stained ☐ jaundice	☐ bruising ☐ petechiae	
3. Head	☐	☐ hydrocephalic ☐ neural tube defect	☐ collapsed ☐ anencephalic	
4. Scalp	☐	☐ defects	☐ masses	
5. Eyes	☐	Spacing: ☐ narrow ☐ wide Slanting: ☐ up ☐ down	☐ cataracts ☐ sunken ☐ eyelids closed	☐ opaque ☐ prominent ☐ eyelids fused
6. Nose	☐	☐ flat bridge	☐ asymmetric	
7. Nostrils	☐	☐ obstructed	☐ single nostril	
8. Ears	☐	☐ abnormal position ☐ abnormal form	☐ periauricular tags/pits	
9. Mouth	☐	☐ small ☐ large	☐ cleft lip	☐ cleft palate
10. Mandible	☐	☐ micrognathia	☐ asymmetric	
11. Neck	☐	☐ short	☐ excess skin	☐ cystic mass
12. Chest	☐	☐ asymmetric ☐ small	☐ nipples wide spaced ☐ constricted	☐ sternal defects ☐ barrelled
13. Abdomen	☐	☐ flattened	☐ distended	☐ wall defect
14. Back	☐	☐ sacral dimple ☐ scoliosis	☐ neural tube defect ☐ kyphosis	
15. Arms	☐	☐ short ☐ abnormal muscle dev't	☐ long ☐ absent	☐ abnormal positioning
16. Hands	☐	☐ creases abnormal ☐ extra digits	☐ webbing fingers ☐ absent digits	☐ abnormal positioning ☐ abnormal nails
17. Legs	☐	☐ short ☐ abnormal muscle dev't	☐ long ☐ absent	☐ abnormal positioning
18. Feet	☐	☐ club foot ☐ extra toes	☐ webbing toes ☐ absent toes	☐ abnormal positioning ☐ abnormal nails
19. Genital-Rectal	Gender ☐M☐F	☐ hypospadias ☐ ambiguous	☐ undescended testes ☐ imperforate anus	

OTHER TESTS/EXAM

☐ Iowa Newborn Screen Blood Spots obtained and sent to lab.

☐ Whole Body X-Ray (limbs extended): ____

☐ Autopsy (consent obtained):

____

____

____

____

☐ Chromosomal analysis: Cell source: amniotic fluid, amnion, placenta, fetal collagen________________
DO NOT PLACE SAMPLE IN FORMALIN. PLACE IN STERILE CONTAINER

Results:

____

____

☐ Photographs: Whole Body ______________________ Face _________________________

Anomalies: ____

Gross Description of Postpartum Placenta

1. Complete	☐ yes	☐ no If incomplete, amount apparently missing ___%
2. Intact	☐ Yes	☐ No ☐Placenta accreta ☐Placenta increta ☐Placenta percreta
3. Diameter	Approximately _____cms	
4.Thickness	Approximately _____cms	
5. Shape	☐ discoid ☐ oval	☐ bilobed ☐ succenturiate lobe present ☐ other anomaly present ______________________
6. Consistency	☐ normal	☐ soft ☐firm ☐gritty
7. Hemorrhage	☐ no	☐yes ☐approximate size of hemorrhage ______cms Consistency of hemorrhage ___________________ Adherence of clot ☐yes ☐no
8. Other abnormalities	☐ Amniotic nodules ☐ Malodor	☐ Staining of amniotic surface ☐ Amniotic bands

Gross Description of Umbilical Cord

1.	Insertion	☐ Central	☐ Eccentric ☐Velamentous	☐ Marginal
2.	Length	Approximately ______cms		
3.	Diameter	Approximately ______cms		
4.	Knots	☐ No	☐ Yes Describe ____ ____	
5.	Cord around body	☐ No	☐ Nuchal x ______ ☐tight ☐loose	☐ Around torso or shoulder x _______
6.	Number of vessels	_____________	☐ Single artery	
7.	Thromboses	☐ No	☐ Yes Describe____- ____	
8.	Wharton's Jelly	☐ Present	☐ Absent	
9.	Torsion	☐ No	☐ Yes Describe ____ ____	

Return form to:

State Genetic Coordinator

Iowa Department of Public Health

321 E. 12th Street

Des Moines, IA 50319-0075

Or fax to 515-725-1760

Call 1-800-383-3826 for questions.

Grief and Family Support

See Appendix C

Notification of Death

- ☐ Family Physician
- ☐ Supervisor/Head Nurse
- ☐ Admitting/Medical Records
- ☐ Pathology
- ☐ Obstetrician/Midwife
- ☐ Family Clergy
- ☐ Pediatrician
- ☐ Social Work
- ☐ Genetic Counsellor
- ☐ Postpartum hospital unit
- ☐ Referring physician
- ☐ Hospital Chaplain

Parents offered private time with baby: ____________________________________

Photographs/Handprints/Footprints/Crib card/Name band/Lock of hair for parents/baby blankets/video (circle):

____

Family support available (chaplain, social worker, family, friends, others):

____

____

____

Father, children, grandparents, and other family offered time with baby: ______________

Grief packet provided: _______________________________

Funeral/Body disposition arrangements:

____

____

____

Referrals for grief counseling and support group information shared:

____

____

Mother offered private room off of maternity ward if desired:

____

Education for mother regarding physiologic changes postpartum (breast milk coming in, lochia, etc.):

____

Follow-up appointment with health-care provider made prior to discharge: ___________

Four week follow-up phone call information obtained/follow-up card completed: ________

Follow-Up

Follow-up phone call made four weeks postpartum:

Support system for family:
____
____
____

Parents receiving grief counseling or attending support group:
____

Follow-up appointment with health-care provider made: Yes/No

Assessment for depression or other medical issues done: Yes/No ___________________

Directions for Completing Evaluation Form

MATERNAL INVESTIGATION

1. Whenever possible, obtain an antenatal ultrasound when an intrauterine death has been confirmed prior to labor. Amniotic fluid volume, heart (full or empty), fetal position, and possible anomaly detection are all potentially diagnostic, and problems may not be evident after delivery. If amniotic fluid is abundant, genetic amniocentesis before delivery may produce better results than post-delivery samples, particularly if delivery is not imminent.

2. Review relevant maternal and family history to help identify specific risk factors:

- past obstetric history

- history of current pregnancy, specifically:

  -occurrence of flu-like illnesses

  -exposure to significant infections or chemicals during pregnancy

  -systemic disorders including diabetes, hypertension, collagen vascular diseases, seizures and severe anemia

  -maternal trauma

  -antenatal investigation including ultrasound(s), non-stress tests (NSTs), biophysical profile(s), laboratory results, amniocentesis, prenatal maternal serum screening, etc.

  -prenatal record including fetal growth, elevated blood pressure, history of bleeding etc.

  -medications used during pregnancy

  -use of tobacco/alcohol/"recreational" drugs

  -family history, particularly pregnancy losses, consanguinity, mental retardation, diabetes, congenital anomalies

3. Maternal bloodwork: refer to page 10 for recommended bloodwork

STILLBORN INFANT

Perform an initial examination of the stillborn infant, umbilical cord, and placenta. This examination should be done by someone experienced in the examination of the newborn and placenta and should be similar to and as thorough as that performed for a live-born infant.

The findings are documented in the medical chart. The purpose of this initial examination is twofold:

- It may constitute the only examination of the infant should autopsy permission not be obtainable; and
- The examination will detect growth abnormalities and fetal anomalies thus aiding in directing further investigations of the attending physician.

Obtain parental permission to take clinical photographs and x-rays. These photographs are in addition to bereavement photos. Verbal consent is sufficient but should be documented in the medical chart. The purposes of doing these are threefold:

- These may be the only x-rays and photographs obtained of the stillborn infant;
- They will supplement the initial examination already performed for consultation and future review; and
- In the case of x-rays, they may uncover anomalies not suspected on the initial examination.

Photographs and x-ray report are stored in the medical chart.

Request and obtain written consent for an autopsy. An autopsy is recommended even if the cause of death seems evident to document and confirm the antenatal or intrapartum diagnosis. The stillborn infant, placenta, and the clinical history should be sent to a pathologist familiar with the examination of placentas and stillborn infants. The stillborn infant and placenta should be sent "unfixed" (i.e. not in formalin). Clinical information should include maternal age, obstetric history, expected date of delivery, results of any antenatal investigations, labor and delivery information, and any other pertinent information. Physicians requesting an autopsy should discuss the procedure of an autopsy and the appearance of the body after an autopsy with the parents.

If consent is not given for a full autopsy, ask the parent to consider a limited autopsy, which can include any or all of the following:

- External examination by pathologist

- Internal examination limited to brain and/or spinal cord; chest organs or abdominal organs as appropriate
- Clinical photographs/x-rays
- Removal of small skin or organ samples by needle biopsy (for DNA analysis or cytogenetics studies as appropriate).

It is important to clearly indicate to the pathologist performing the autopsy any limitations in the information accompanying the infant and placenta.

PLACENTA AND CORD

1. In the delivery room,
    - Obtain a sample of amnion for cytogenetics and send it to the lab
    - Obtain a 1 cm piece of placenta with sterile instruments for culture including anaerobes, GBS and Listeria. Inform the lab that Listeria is in the differential. Sensitivities are not usually required.
    - If TB is suspected, a separate piece of placenta is obtained and sent for mycobacteria
2. When consent for autopsy is obtained, the above samples of placenta are still taken. The remaining placenta including the cord and membranes should accompany the stillborn infant to pathology. Send the placenta “unfixed” (i.e. not in formalin) for examination. The “unfixed” placenta can be double-bagged in clear plastic bags.
3. If consent for autopsy is not obtained, the placenta, accompanied by clinical history, should be sent to pathology for examination by a pathologist. The placenta is sent to the laboratory, preferably “unfixed,” without formalin, to allow the pathologist the opportunity to perform ancillary studies if needed. If the preference of pathology is for a "fixed" specimen, send the placenta in a properly sealed, labeled, non-glass container and add enough formalin to equal three times the volume of the specimen. Submit the specimen in a clear plastic bag.

COUNSELING OF THE FAMILY

In addition to investigating the medical aspects of a stillbirth, it is important to consider the psychological effects on the family. The following steps are recommended.

- Grief support should be initiated as soon as the diagnosis is made.

- A packet of material should be given with immediate needs/decisions highlighted (for instance give a book or pamphlet open to the page that addresses issues the parents are facing at the time)

- All family members, especially the father and other children should be included in discussions about what is happening, common responses, suggestions for decision-making, etc.

- Encourage picture taking if the parents feel comfortable doing this. Offer a hospital camera if they don't have their own.

- An information letter for parents (sample provided in Appendix B) can be used to help obtain consent for an autopsy to be performed.

- Explain that results of all investigations may take two or three months for completion.

- All results of investigations should be forwarded to the physician who will be attending the mother following her return home after delivery. An appointment for follow-up should be made with this physician prior to discharge.

At the follow-up appointment:

-discuss and explain results of all the investigations and their significance

-discuss need for genetic counseling and/or obstetric consultation if indicated

- discuss issues they are presently dealing with

-assess if they need help understanding and working with other children

-assess if they need more resources and guidance for facing upcoming days, events, etc.

-obtain specimen for fasting blood sugar if relevant

-assess need for further grief counseling/support groups etc.

-assess for signs of depression or dysfunctional coping

-ask for feedback on how the staff handled them and their crisis – any ideas for improvement (this gives them a chance to not just receive, but share something that may be of value.)

APPENDICES

Appendix A: Placental and Umbilical Cord Exam

A pathologist with experience in the examination of placentas should always examine the placenta(s) and umbilical cord from a delivery resulting in a stillbirth or early neonatal death. However, occasionally decisions must be made before a pathological examination of the placenta and umbilical cord is complete. Therefore, it is important that the attending physician conduct a gross exam of the placenta and umbilical cord as soon postpartum as possible.

The attending clinician should also work with the pathologist to provide maternal and fetal history, and other information that may aid in the examination.

To fix or not to fix?

Place the placenta in the refrigerator as soon as possible after the gross exam. Do not let it sit on the counter. Changes go on in the placenta after it is born that could compromise the ability to identify certain pathology.

Each institution should establish its own guidelines. In the fresh state, it is easier to appreciate placental surface changes, to make membrane rolls, to palpate for solid lesions, and to perform injection studies on twin placentas. Placentas show minimal gross and microscopic changes when held at 4° C for up to seven days. Tissue sections should be placed in formalin for 24 hours prior to trimming/blocking for quality sections. The attending clinician should communicate and work with the pathologist as to whether the placenta should be placed in formalin or not.

Following are two worksheets that may be used to document the gross exam of the placenta and the umbilical cord. When noting dimensions, consider using the term "approximately," and let the pathology examination document accurate measurements.

Gross Description of Postpartum Placenta

1. Complete	☐ yes	☐ no If incomplete, amount apparently missing ___%
2. Intact	☐ Yes	☐ No ☐Placenta accreta ☐Placenta increta ☐Placenta percreta
3. Diameter	Approximately _____cms	
4.Thickness	Approximately _____cms	
5. Shape	☐ discoid ☐ oval	☐ bilobed ☐ succenturiate lobe present ☐ other anomaly present ______________________
6. Consistency	☐ normal	☐ soft ☐firm
7. Hemorrhage	☐ no	☐yes ☐approximate size of hemorrhage ______cms Consistency of hemorrhage ____________________ Adherence of clot ☐yes ☐no
8. Other abnormalities	☐ Amniotic nodules ☐ Malodor	☐ Staining of amniotic surface ☐ Amniotic bands

Gross Description of Umbilical Cord

10. Insertion	☐ Central	☐ Eccentric ☐Velamentous	☐ Marginal
11. Length	Approximately ______cms		
12. Diameter	Approximately ______cms		
13. Knots	☐ No	☐ Yes Describe ____ ____	
14. Cord around body	☐ No	☐ Nuchal x ______ ☐tight ☐loose	☐ Around torso or shoulder x _______
15. Number of vessels	_____________	☐ Single artery	
16. Thromboses	☐ No	☐ Yes Describe____- ____	
17. Wharton's Jelly	☐ Present	☐ Absent	
18. Torsion	☐ No	☐ Yes Describe ____ ____	

Send entire umbilical cord and placenta to pathology.

Fix according to pathology policy.

Appendix B: Autopsy Consent Information Form

- **What are the benefits of autopsies?**

  Benefits for families. For families, the autopsy has both tangible and psychological benefits. Uncertainty regarding the cause of an individual's death can delay payment of insurance benefits. The autopsy can also uncover genetic or environmental (for example, a bacterium or fungus) causes of disease that could affect other family members. Psychologically, the autopsy provides closure by identifying or confirming the cause of death. The autopsy can demonstrate to the family that the care provided was appropriate, thereby alleviating guilt among family members and offering reassurance regarding the quality of medical care. Lastly, the autopsy is a mechanism that enables the family to participate in medical education and research.

- Benefits for the clinician and the hospital: The procedure can confirm the accuracy of the clinical diagnoses and the appropriateness of medical care. The autopsy findings can be utilized to educate physicians, nurses, residents, and students, thereby contributing to an improved quality of care.

- Benefits to society. Many of the benefits of the autopsy are experienced by society as a whole. The autopsy aids in the evaluation of new diagnostic tests, the assessment of new therapeutic interventions (drugs, devices, surgical techniques), and the investigation of environmental and occupational diseases. Autopsy data are useful in establishing valid mortality statistics. Data derived from death certificates in the absence of autopsy data have repeatedly been shown to be notoriously inaccurate. New medical knowledge on existing diseases that is derived from autopsy-based research is important for everyone.

RESPONSIBILITY FOR AUTOPSY COSTS

- All costs of performing a medically indicated autopsy (i.e. not a Medical Examiner autopsy) are born by the submitting hospital, and may then be charged to the family. If the autopsy is requested by the Office of the State Medical Examiner, then costs are the responsibility of the Iowa Department of Public Health.

GUIDELINES FOR INFORMING AND INVOLVING FAMILIES[1]

Coronial (medical examiner cases) and non-coronial autopsies should be conducted in a manner consistent with state statute. It is important to acknowledge that in coronial autopsies the agreement of the family is not required, but wherever possible the coroner should give regard to the family's wishes.

Traditionally, professionals have sought to protect families from information that they may find distressing. However, experience has shown that timely information provided in a sensitive manner can empower families and is far less distressing than later disclosure. Bereaved families have the right to clear, factual and sensitive communication from a skilled professional. Institutions have a responsibility to ensure that in each case there is a specifically trained staff member whose role is to engage with the bereaved family and provide clear, factual information in a sensitive manner following the death of a patient. The approach to the family regarding autopsy is most appropriately made by the attending clinician treating the patient requesting an autopsy and discussing organ retention and use, and other sensitive information, should be conducted face to face. The appropriately trained person whose priority is the needs of the bereaved family should support the clinician in this role. The capabilities of such persons in providing assistance to the bereaved family should include:

- an understanding of the dynamics of the grief process
- counseling and communication skills to convey information at a pace and by using language that the family is able to understand,
- the capacity to recognize the needs of families where English is not the first language, and the potential for diminishing fluency and comprehension or reversion to the native language
- communication and advocacy skills to ensure the wishes of the family are conveyed and respected
- a good understanding of the autopsy process including the need for tissue/organ retention and options available for future use, release or disposal
- knowledge of all aspects of funeral arrangements.

Institutions involved with the bereaved family must recognize and provide for the following needs:

- a quiet, private area to undertake these discussions
- time to assimilate the impact of the death before being approached to discuss autopsy.

While it is acknowledged in certain situations the treating clinician may have had extensive discussions about the prognosis of the patient and the benefits of an autopsy may have already been raised with the family, in most situations it is inappropriate to raise the issue until the family has had time to take in the death of the baby.

- information about events leading to the death, treatment attempts etc. before feeling ready to discuss other issues
- support to facilitate their "goodbye" to their baby
- any special religious or cultural rituals that must be acknowledged and met where possible
- clear honest information

- Specifically, families must be clearly informed of their rights:
  - to refuse the performance of a hospital autopsy
  - in hospital autopsies, to limit the extent of the examination and retention of tissue and organs, understanding that such limitations may compromise the information obtained from the autopsy
  - in regard to disposal options for retained tissues and organs
  - to be advised about uses other than diagnosis to which retained tissues/organs can be put
- access to interpreters and appropriate health workers where necessary
- information and assistance to make funeral arrangements
- assessment and referral for ongoing counseling if required.
- provision of autopsy results in an understandable form. In some situations discussion with the pathologist may be appropriate.

[1]From the National Code of Ethical Autopsy Practice - Australian Health Ministers' Advisory Council
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Consent Procedures

Parental consent for evaluation of a stillborn baby should always be obtained even though in most states no formal consent is needed for photographs, x-rays, clinical examination or placental evaluation..
Although we recommend inclusion of all segments of the protocol for all stillbirth evaluations, some families do not wish to consent to completion of an internal postmortem examination. Internal postmortem examination has been found to be critical in a large numbers of stillbirth assessments (that is, a specific diagnosis would not have been made without its completions). Nevertheless, many diagnoses will be made through completion of all of the other segments of the protocol. All of these (i.e. clinical examination, radiographs, photographs and sampling for chromosome testing) can be completed even if an internal autopsy is not wanted by the parents. Therefore a second sample form for consent for evaluation not including internal postmortem examination is also available.

HOW IS AN AUTOPSY PERFORMED?

The extent of an autopsy can vary from a single organ, such as the heart or brain, to a very extensive examination. Examination of the chest, abdomen and brain is probably considered by most as the standard autopsy and one technique is briefly described below.

The autopsy begins with a complete external examination. The body weight and height are recorded, and identifying marks such as scars and tattoos are documented.

The internal examination begins with the creation of a Y or U-shaped incision from both shoulders joining over the sternum and continuing down to the pubic bone. The skin and underlying tissues are then separated to expose the rib cage and abdominal cavity. The front of the rib cage is removed to expose the neck and chest organs. This opening allows the trachea (windpipe), thyroid gland, parathyroid glands, esophagus, heart, thoracic aorta and lungs to be removed. Following removal of the neck and chest organs, the abdominal organs are cut (dissected) free. These include the intestines, liver, gallbladder and bile duct system, pancreas, spleen, adrenal glands, kidneys, ureters, urinary bladder, abdominal aorta, and reproductive organs.

To remove the brain, an incision is made in the back of the skull from one ear to the other. The scalp is cut and separated from the underlying skull and pulled forward. The top of the skull is removed using a vibrating saw. The entire brain is then gently lifted out of the cranial vault. The spinal cord may also be taken by removing the anterior or posterior portion of the spinal column.

In general, pieces of all of the major organs mentioned above are converted into thin sections of tissue that can be placed on slides and studied under a microscope. The organs may be returned to the body or may be retained for teaching, research, and diagnostic purposes.

Concerns over disfigurement of the remains or delays in funeral arrangements may prevent a vast majority of families from consenting to an autopsy. In reality, however, the visual examination of the body and the removal of tissues and/or organs for microscopic examination can be completed in a few hours. Furthermore, there are no visible external changes that would preclude an open-casket funeral service.

Appendix C: Grief and Family Support

When an older child dies, or an adult loved one dies, the mourning process includes relating closely to the deceased by remembering times and relationships shared. When a child dies during pregnancy or as a newborn, there has been little time to share a relationship with the child as a separate person. As a result, the family is left to mourn the loss of a part of themselves without the aid of memories and mementos.

It is recommended that the care givers talk of the tasks of grief and the feelings of grief (tasks being to share stories and memories, create and nourish any and all memories, say hello before goodbye, make the best decisions they can, keep their love alive, plan for and celebrate holidays and anniversaries including their baby whenever possible, taking care of themselves, feeling their feelings – not denying them, etc..) Feelings of grief may include shock or denial, anger, bargaining (usually with God), guilt, depression, and sadness; plus, anguish, emptiness, shame/blame, hopelessness and hopefulness, love, etc. All of these feelings may come and go in an uncontrollable manner. Not to be predicted or even understood but hopefully accepted as the process of mourning.

These emotions are real and a normal part of grieving. Grieving is a process of making meaning out of the loss of hopes, dreams and wishes that were real long before the loss of a baby. Grieving is an unpredictable process, and parents may move back and forth between these stages. Grieving is necessary to work through the pain toward healing.

While the initial response to keeping footprints, pictures, crib card, or lock of hair may be negative; these items take on special significance as proof that the child existed. It is important to encourage families to spend time saying hello, getting to know their child. This is critical before they say goodbye. They are "squeezing" a lifetime of memories and mothering/fathering in to those few hours and days. Naming the child, which can be done at any time, can help to confirm the reality. A funeral or memorial service is appropriate according to the parent's wishes. It is the one thing they can do for their child and is an important ritual for saying goodbye, also providing for memories that can help heal over time.

Mothers and fathers can be expected to mourn and to grieve in different ways. One spouse may believe their role is to protect the other and, without meaning to, shut them out of the important decisions in which they may need to have a part, such as funeral arrangements. One spouse may feel that if only he or she can contain their expression of grief, they will not burden the other. Family members may blame each other for things they should have or should not have done or said. At this point, misunderstandings abound. Communication is key for the grieving parents. Couples may need to set aside time to talk about their loss and their feelings about it. This can provide some sense of control in a situation where the feeling of having lost control can be overwhelming.

Another way for parents to have some control over the situation is to develop a birth plan. In circumstances where a stillbirth is anticipated, or where it is known that the infant will not survive beyond the initial newborn period, a birth plan can help the family make it through the pregnancy, delivery, and what follows. A birth plan can be developed from the questions asked in the Grief and Family Support Section of the manual.

What can you do to support the family?

The most important thing you can do is just be there as the family asks. They need your understanding right now. You might not know what to say or do, but don't let your discomfort keep you away from supporting the family. When in doubt, error on the side of silence. Offer eye contact or the squeeze of your hand. You don't have to have all of the answers. Provide an environment in which the family can talk about the baby who has died. Talk candidly about the baby by name – ask sensitive questions without being nosy – e.g. "Does her red hair come from your side of the family?" or "Is __________ a family name?"

Be sure to offer help with decisions; helping them to see that it might be easy to take what they think is the easier road of avoiding pain right now, but in the long run the good decisions they make now will sustain them over time. While seeing, bathing, holding, taking movies and pictures, including other children and family members in this, etc. may seem hard, it will likely be better in the long run as they have this to hold on to. One nurse described it in this way, "When a child scrapes her knee, she may say don't touch it; leave it alone; it hurts. However, if we don't clean out that wound it may get infected over time. If however, we do the hard and painful job of cleaning it, in time it will heal. Embracing the baby and doing the hard, painful work of spending time with the baby who has died or is dying, will bring comfort over time and keep one from being haunted by regrets and even more pain."

The following pages contain some dos and don'ts for friends and family supporting the grieving parents.

What to say and do to and for grieving parents:

- First, be yourself and act normal.
- You can send flowers, cards, or take food, but do not wear out your welcome.
- Do say, "I love you."
- Do say "Can I do anything for you?"
- Do say, "I am here to listen when you want to talk about <u>(baby's name)."</u>
- Do say "Can I watch the other children so you can rest?"
- Do say "Can I clean the house for you (or run errands, etc.) so you can rest?"
- The greatest gift you can give them is your love and support in anyway they need.

What not to say or do:

- Do not avoid the couple because you are uncomfortable.
- Do not try to distract the parents from grieving and cheer them up.
- Do not ask, "How are you doing?"
- Do not say -
    - Don't think about it
    - I know how you feel
    - I understand
    - You shouldn't feel bad (or sad)
    - Don't question God's will, or say it was God's will
    - It was for the best
    - You'll get over it, or you're so strong
    - You should be over it by now
    - You need to get on with your life

As a trusted friend or family member, you have the opportunity to monitor the bereaved person. This can be tricky, because you do not want to be perceived as insensitive or offering unwanted advice. Instead of telling the person what to do, try stating your own feelings or observations. For example, "I noticed you haven't been sleeping – perhaps you should talk with your doctor."

The following warning signs need to be taken seriously:

Extremely poor personal hygiene

Drastic weight gain or loss

Alcohol or drug abuse

Pain or constriction in the chest

Disturbed sleep patterns

No interest in previously enjoyable activities

Persistent suicidal thoughts

Encourage or seek professional help for the person if they demonstrate any of these warning signs. Especially pay attention to the person who seems to be stuck, needs plenty of advice, wants to ward off problems and seems to need more help then they are getting (this is prevention and a good idea); as well as if they have any of the more serious issues that go on and on.

Sensitivity to cultural beliefs is of utmost importance during the event of a stillbirth.

The following tables provide information regarding immigrant groups and cultural beliefs and practices.

From: The American Public Health Association. The Maternal and Child Health Community Leadership Institute. Understanding the Health Culture of Recent Immigrants to the United States: a Cross-Cultural Maternal Health Information Catalog. http://www.apha.org/ppp/red/summary.htm . Accessed July, 2005.

Examples of Cultural Beliefs Held by Certain Immigrant Groups

Immigrant Group	**Timing**	**Cultural Belief/Practice**
Latin American; Asian; African	General	Health care decision-making centers on the family as a whole. Often individual needs are secondary to family needs. Family is strong support system. Patient autonomy and patient confidentiality are often culturally irrelevant.
Latin American; Asian; some African	Prenatal	Food cravings of a pregnant woman should be satisfied because they are thought to be the cravings of the baby. If cravings are left unsatisfied, the baby might take on certain unpleasant personality and/or physical traits, perhaps characteristic of the food (Burk, Wieser, and Keegan, 1995; Geissler, et al, 1999; Taylor, Ko, & Pan, 1999).
Latin American; Asian; African	Prenatal; Postpartum	"Hot-cold" theory of illness. Pregnancy, for most cultures, is considered a "hot" condition (exception: Chinese believe it is a "cold" condition [Taylor, Ko, & Pan, 1999]). To maintain health and balance, pregnant woman is restricted to "cold" foods (Chinese, "hot" foods). After childbirth, heat is believed to be lost, so "hot" foods are encouraged to help the new mother recuperate. Categorization of "hot" and "cold" for illnesses, medications, and foods does not necessarily relate to the literal meaning of hot and cold. These classifications are instead defined by culture, tradition, and personal experiences over time.
Latin American	Prenatal	Women avoid cutting their hair while pregnant. It is believed that cutting the hair will result in cutting the vision of the baby (Taylor, Ko, & Pan, 1999).
Asian	Postpartum	Mother and newborn should not have visitors who are in mourning, are widows, or have deceased children. Belief is that a visit by such persons will bring bad luck (Assanand, Dias, Richardson, & Waxler-Morrison, 1990).
African	Prenatal	Geophagia, or the ingestion of soil, chalk, or clay, is not uncommon during pregnancy. Not only is it considered appetizing and the craving of the developing baby, but soil is a symbol of female fertility (Geissler, et al, 1999; Jacobson-Whidding & van Beek, 1990).

Examples of Epidemiological Data Affecting the Health of Childbearing Women

Immigrant Group	**Epidemiology/ Health Indicator/ Maternal Health Risk**
Latin American	Foreign-born are more likely than US-born Hispanics to die of pregnancy-related causes (*Hopkins, et al, 1999*).
Guatemalan	Syphilis prevalence = 298/100,000 population (*CRLP, 1997*) (U.S. population = 3.2/100,000 population, 1996-1997) (*CDC, undated*) Gonorrhea prevalence = 1670/100,000 population (*CRLP, 1997*) (U.S. population = 123/100,000 population, 1996-1997) (*CDC, undated*)
Asian	75% of the world's chronically infected with Hepatitis B are in Asia (*Hann, 1994; Takada, Ford, & Lloyd, 1998*). Largest new sexually transmitted infections (STIs) worldwide in 1995 occurred in South and Southeast Asia (45.6%) (*Gerbase, Rowley, & Mertens, 1998*).
Indian (Asian)	Lifetime risk of maternal death = 1 in 37 women, where 1/3000 is considered a low risk of dying of pregnancy and childbirth and 1/100 is considered a high risk (*WHO/WB, 1997*).
African	Of all women of reproductive age, the World Health Organization estimates that 3-5 million are HIV-positive, with about 80% of them living in Sub-Saharan Africa (*Chin, Remenyi, Morrison, Bulatao, 1992; Koblinsky, 1995*).
Somali	MMR = 1600 (per 100,000 live births) (1990) (*UNICEF, 2000*).

Examples of Proposed Links between Epidemiological Data and Cultural Beliefs/Practices; and Associated Health Risks to Pregnant Women and Infants

Immigrant Group	**LATIN AMERICAN**
Cultural Belief/ Practices	Often feel no need for pap smears and gynecological exams, especially when already married and having children (*Chiang, 2000; Gutierrez-Ramirez, Burciaga Valdez, & Carter-Pokras, 1994; Harlan, Bernstein, Kessler, 1991*). Belief is that when they are already having children, they are no longer at risk.
Epidemiology/ Health Indicator	Cervical cancer rates are higher in Latinos than whites. For instance, incidence is 2-3 times higher in Mexican and Puerto Rican women than in whites (*En Accion, 1993; Suarez & Ramirez, 1999*). The rates are also higher for immigrant women than for US-born Latino women (*Gutierrez-Ramirez, Burciaga Valdez, & Carter-Pokras, 1994*).
Health Risks to the Mother	Cervical cancer; incompetent uterus; hysterectomy; infertility; mortality.
Health Risks to the Infant	Possibly human papillomavirus (HPV) in throat (*if exposed during vaginal delivery and if HPV is present*).

Immigrant Group	**GUATEMALAN**
Cultural Belief/ Practices	In 1995, only 26% of all women of reproductive age in Guatemala used modern methods of contraception, with only 2.2% using condoms (*PAHO, 1998*). Attitudes of male partners toward contraceptives often "nonsupportive, resistive, or controlling," further hindering women's family planning practices (*Callister &Vega, 1998*).
Epidemiology/ Health Indicator	Rate for gonorrhea in Guatemala is 1670/ 100,000 population (*CRLP, 1997*), versus a rate of 123/ 100,000 population for the U.S. as a whole, 1996-1997 (*CDC, undated*).
Health Risks to the Mother	Chronic pelvic inflammatory disease (PID); endometriosis; infertility.
Health Risks to the Infant	Ophthalmia neonatorium (*if exposed during vaginal delivery*); low birthweight.

Immigrant Group	**ASIAN**
Cultural Belief/ Practices	De-worming pills and other biomedical/Western medications may not be taken properly because of the belief that these create too much "heat" and may cause a miscarriage (*DeSantis, 1998; Dinh, Ganesan, Waxler-Morrison, 1990; Nichter & Nichter, 1996; O'Connor, 1998*).
Epidemiology/ Health Indicator	Helminthic diseases, including tapeworm, roundworm, and hookworm infections, are endemic in Asia and other parts of the world (*Georgiev, 1999; Nishimura & Hung, 1997*).
Health Risks to the Mother	Anemia; diarrhea; altered appetite/ anorexia; malabsorption of necessary nutrients for pregnancy and general health.
Health Risks to the Infant	Possible developmental problems due to nutritional deficiencies; repercussions of maternal anemia in severe cases, such as low birth weight, premature birth, poor fetal growth, asphyxia, and stillbirth.

Immigrant Group	**INDIAN (ASIAN)**
Cultural Belief/ Practices	Iron-rich foods during pregnancy are often avoided because they are thought to be "hot" and may therefore cause miscarriage, as it contradicts the prescribed food for pregnant women as associated with the "hot-cold" theory of illness (*DeSantis, 1998; Kendall, 1987; Landerman, 1987; Nichter & Nichter, 1996*).
Epidemiology/ Health Indicator	Iron-deficiency anemia (IDA) occurs in about 50% of all women in India and in >70% of pregnant women in India (*ISTI, 1996*).
Health Risks to the Mother	Lowered resistance to infection; other maternal morbidities associated with concurrent obstetric complications, including hemorrhage and shock; maternal mortality.
Health Risks to the Infant	Low birthweight; premature birth; poor fetal growth; asphyxia; stillbirth.

Immigrant Group	**AFRICAN**
Cultural Belief/ Practices	Belief that condoms can get lodged in the abdominal cavity and result in obstruction, infection, or cancer (*DeSantis, 1998; Helman, 1994*).
Epidemiology/ Health Indicator	Of all HIV/AIDS infected people worldwide, 63% live in Sub-Saharan Africa (*NomadNet, 2000*). About 90% of all HIV cases in Sub-Saharan Africa are transmitted through heterosexual contact (*NomadNet, 2000; World Bank Group, undated*). About 3-5 million women of reproductive age worldwide are HIV-positive, with about 80% of them living in Sub-Saharan Africa (*Chin, Remenyi, Morrison, Bulatao, 1992; Koblinsky, 1995*).
Health Risks to the Mother	HIV/AIDS; immunosuppression and increased susceptibility to other illnesses; mortality.
Health Risks to the Infant	Congenital HIV/AIDS; increased susceptibility to other illnesses; mortality.
Immigrant Group	**SOMALI**
Cultural Belief/ Practices	Belief that without infibulation, a woman's health and fertility weakens, among other reasons for FC/FGM (*Ntiri, 1993*). Some believe in reducing prenatal food intake to limit the baby size and ensure an easier birth (*Calder, Brown, & Rae, 1993*).
Epidemiology/ Health Indicator	Female circumcision/female genital mutilation (FC/FGM) is performed on over 98% of the female population, with infibulation as the most common type (*Arbesman, Kahler, & Buck, 1993; Dirie & Lindmark, 1991; El Dareer, 1983*).
Health Risks to the Mother	Tetanus; chronic pelvic infection; urinary tract infection; infertility; incontinence; difficulty urinating. During birth: severe perineal lacerations, obstructed labor, and uterine rupture.
Health Risks to the Infant	Severe asphyxia; brain damage; developmental problems; stillbirth; mortality.

Example Lessons for Health Care Professionals from Knowledge of Cultural Beliefs or Immigrant Experiences

Culture or Immigrant Experience	**American Health Care Professional**
Sexual abuse is prevalent among some Southeast Asian and African refugees. This makes pelvic	Not all immigrants have the same immigration history or the same reasons for migrating to the

exams traumatic and difficult, and may lead to low rates of regular pap smears and gynecological exams.	U.S., and patients usually do not openly discuss their refugee experiences. Therefore, the health-care provider should go beyond race/ethnicity and recognize the possibility that their patient might have undergone traumatic experiences as refugees.
Religious beliefs and/or sexual taboos in some cultures can result in a lack of basic knowledge of reproductive anatomy.	Health-care providers should not assume that all women, even well educated immigrant women, have a basic knowledge of reproductive health and anatomy.
"Hot-cold" theory of illness is prevalent across many cultures throughout the world.	According to this theory, women may follow specific diets for certain health conditions, including pregnancy. Knowing this theory, the health-care provider can anticipate possible deviations from prescribed diets and treatments. The health-care provider can then ascertain the specific dietary beliefs and practices observed by a given patient.
For many cultures, there is strong extended family support and interdependency among members of a family. Usually during health care decisions and other major decisions, the issue is discussed as a family and the decision defers to the needs of the family over those of the individual.	It is important for health-care providers to respect the essential role that family members play in a patient's care. Western concepts of patient autonomy and patient confidentiality are often culturally irrelevant to many immigrants. Inviting and addressing the opinions and concerns of family members can be quite helpful.
Many Asian cultures believe it to be important to be stoic, believing that suffering is a part of life (*Uba, 1992*). Moreover, there is a great deal of reverence toward physicians. Thus, many Asian immigrants often remain quiet, respectfully answering the health-care provider's questions and accepting advice without asking questions (*Assanand, Dias, Richardson, & Waxler-Morrison, 1990; Takada, Ford, & Lloyd, 1998*). In fact, asking questions may be considered a sign of disrespect, which is why Asians may refrain from doing so (*Miller, 1995; Takada, Ford, & Lloyd, 1998*).	Even if patients seem to agree with what was discussed during an appointment, they may not follow the health-care provider's recommendations if they lacked confidence and trust in the provider (*Assanand, Dias, Richardson, & Waxler-Morrison, 1990*). In fact, they may not complain or ask questions, but they also may not return for their next visit (*Mattson, 1995*). This can cause problems when managing pregnancy-related illnesses and complications. Some Asians and individuals from other cultures as well, believe that unless they are given some tangible form of medication, they do not feel that the health-care provider has really done anything. Subsequently, they may lose confidence in the provider's knowledge and abilities. Missing future follow-up appointments can also result from having the patient wait too long for her appointment, or from asking her to return a number of times for follow-up (*Mattson, 1995*).

Appendix D: Iowa Code and Administrative Rules

Iowa Code

Chapter 136A, 2004 Iowa Acts, Chapter 1031 (HF 2362)

HOUSE FILE

BY COMMITTEE ON HUMAN RESOURCES

(SUCCESSOR TO HF 2074)

A BILL FOR

An Act relating to the duties of the birth defects institute by providing for a work group to study stillbirths and renaming the institute.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

Section 1. LEGISLATIVE INTENT AND PURPOSE == STILLBIRTHS PROTOCOL WORK GROUP.

1. It is the intent of the general assembly that the department of public health study and develop prevention strategies to reduce stillbirths and other congenital or inherited disorders which cause the death and disability of newborns in this state. It is the purpose of this Act to enable the department to carry out the intent of the general assembly through a stillbirths protocol work group and the redesign of the birth defects institute.

2. The Iowa department of public health shall establish a work group to develop protocol and implementation guidelines for the evaluation of causes and prevention of stillbirths including environmental and maternal factors. The director of public health shall select the members of the work group, which may include representatives from the child death review team, the health care industry, the health insurance industry, and parents or other interested parties as deemed appropriate by the director. The director shall submit a report from the work group to the general assembly on or before July 15, 2005.

Sec. 2. NEW SECTION. 136E.1 PURPOSE.

To reduce and avoid adverse health conditions of inhabitants of the state, the Iowa department of public health shall initiate, conduct, and supervise screening and health care programs in order to detect and predict congenital or inherited disorders. The department shall assist in the translation and integration of genetic and genomic advances into public health services to improve health outcomes throughout the life span of the inhabitants of the state.

Sec. 3. NEW SECTION. 136E.2 DEFINITIONS.

As used in this chapter, unless the context otherwise requires:

1. "Attending health care provider" means a licensed physician, nurse practitioner, certified nurse midwife, or

physician assistant.

2. "Congenital disorder" means an abnormality existing prior to or at birth, including a stillbirth, that adversely affects the health and development of a fetus, newborn, child, or adult, including a structural malformation or a genetic, chromosomal, inherited, or biochemical disorder.

3. "Department" means the Iowa department of public health.

4. "Disorder" means a congenital or inherited disorder.

5. "Genetics" means the study of inheritance and how genes contribute to health conditions and the potential for disease.

6. "Genomics" mean the functions and interactions of all human genes and their variation within human populations, including their interaction with environmental factors, and their contribution to health.

7. "Inherited disorder" means a condition caused by an abnormal change in a gene or genes passed from a parent or parents to their child. Onset of the disorder may be prior to or at birth, during childhood, or in adulthood.

8. "Stillbirth" means an unintended fetal death occurring after a gestation period of twenty completed weeks, or an unintended fetal death of a fetus with a weight of three hundred fifty or more grams.

Sec. 4. NEW SECTION. 136E.3 ESTABLISHMENT OF CENTER FOR

CONGENITAL AND INHERITED DISORDERS == DUTIES.

A center for congenital and inherited disorders is established within the department. The center shall do all of the following:

1. Initiate, conduct, and supervise statewide screening programs for congenital and inherited disorders amenable to population screening.

2. Initiate, conduct, and supervise statewide health care programs to aid in the early detection, treatment, prevention, education, and provision of supportive care related to congenital and inherited disorders.

3. Develop specifications for and designate a central laboratory in which tests conducted pursuant to the screening programs provided for in subsection 1 will be performed.

4. Gather, evaluate, and maintain information related to causes, severity, prevention, and methods of treatment for congenital and inherited disorders in conjunction with a central registry, screening programs, genetic health care programs, and ongoing scientific investigations and surveys.

5. Perform surveillance and monitoring of congenital and inherited disorders to determine the occurrence and trends of the disorders, to conduct thorough and complete epidemiological surveys, to assist in the planning for and provision of services to children with congenital and

inherited disorders and their families, and to identify environmental and genetic risk factors for congenital and inherited disorders.

6. Provide information related to severity, causes, prevention, and methods of treatment for congenital and inherited disorders to the public, medical and scientific communities, and health science disciplines.

7. Implement public education programs, continuing education programs for health practitioners, and education programs for trainees of the health science disciplines related to genetics, congenital disorders, and inheritable disorders.

8. Participate in policy development to assure the appropriate use and confidentiality of genetic information and technologies to improve health and prevent disease.

9. Collaborate with state and local health agencies and other public and private organizations to provide education, intervention, and treatment for congenital and inherited disorders and to integrate genetics and genomics advances into public health activities and policies.

Sec. 5. NEW SECTION. 136E.4 GENETIC HEALTH SERVICES.

The center may initiate, conduct, and supervise genetic health services for the inhabitants of the state, including the provision of regional genetic consultation clinics, comprehensive neuromuscular health care outreach clinics, and other outreach services and clinics as established by rule.

Sec. 6. NEW SECTION. 136E.5 NEWBORN METABOLIC SCREENING.

1. All newborns born in this state shall be screened for congenital and inherited disorders in accordance with rules adopted by the department.

2. An attending health care provider shall ensure that every newborn under the provider's care is screened for congenital and inherited disorders in accordance with rules adopted by the department.

3. This section does not apply if the parent objects to the screening. If a parent objects to the screening of a newborn, the attending health care provider shall document the refusal in the newborn's medical record and shall obtain a written refusal from the parent and report the refusal to the department as provided by rule of the department.

Sec. 7. NEW SECTION. 136E.6 CENTRAL REGISTRY.

The center for congenital and inherited disorders shall maintain a central registry, or shall establish an agreement with a designated contractor to maintain a central registry, to compile, evaluate, retain, and disseminate information on the occurrence, prevalence, causes, treatment, and prevention of congenital disorders. Congenital disorders shall be considered reportable conditions in accordance with rules adopted by the department and shall be abstracted and maintained by the registry.

Sec. 8. NEW SECTION. 136E.7 CONFIDENTIALITY.

The center for congenital and inherited disorders and the department shall maintain the confidentiality of any identifying information collected, used, or maintained pursuant to this chapter in accordance with section 22.7, subsection 2.

Sec. 9. NEW SECTION. 136E.8 RULES.

The center for congenital and inherited disorders, with assistance provided by the Iowa department of public health, shall adopt rules pursuant to chapter 17A to administer this chapter.

Sec. 10. NEW SECTION. 136E.9 COOPERATION OF OTHER AGENCIES.

All state, district, county, and city health or welfare agencies shall cooperate and participate in the administration of this chapter.

Sec. 11. Chapter 136A, Code 2003, is repealed.

Sec. 12. CODE EDITOR DIRECTIVE.

1. The Code editor may transfer chapter 136E to chapter 136A.

2. The Code editor is directed to strike the words "birth defects institute" and insert the words "center for congenital

and inherited disorders" where the words appear in section 144.13A.

3. The Code editor shall correct any references to the center for congenital and inherited disorders as the successor to the birth defects institute, including grammatical constructions, anywhere else in the Code, in any bills awaiting codification, and in any bills enacted by the Eightieth General Assembly, 2004 Regular Session.

EXPLANATION

This bill relates to the duties of the birth defects institute established in Code chapter 136A by providing for a work group to study stillbirths and by renaming the institute.

A work group is required to be created by the Iowa department of public health to develop protocol and implementation guidelines for the evaluation of causes and prevention of stillbirths. Members of the work group will be selected by the director of public health who must report the results of the work group to the general assembly by July 15, 2005.

The bill renames the birth defects institute the center for congenital and inherited disorders. The bill expands the institute's scope of study beyond birth defects to include the study of the causes and prevention of all congenital and inherited disorders, including stillbirths. The center will continue the duties of the institute to maintain a central registry, conduct screening programs, provide statewide health care programs, and provide information to and educate the public and medical and scientific communities. The center may provide genetic health services through clinics or outreach services. The bill permits parents the option to refuse screening for their child.

The bill provides for confidentiality of identifiable information collected, used, or maintained by the center or department and provides the center authority to adopt rules.

The Code editor is directed to make all necessary changes to existing provisions of the Code and prospective enactments by the general assembly to codify the new Code chapter.

Iowa Code:

144.29 Fetal deaths.

A fetal death certificate for each fetal death which occurs in this state after a gestation period of twenty completed weeks or greater, or for a fetus with a weight of three-hundred- fifty grams or more shall be filed as directed by the state registrar within three days after delivery and prior to final disposition of the fetus. The certificate shall be registered if it has been completed and filed in accordance with this chapter.

The county in which a dead fetus is found is the county of death. The certificate shall be filed within three days after the fetus is found. If a fetal death occurs in a moving conveyance, the county in which the fetus is first removed from the conveyance is the county of death.

[C24, 27, 31, 35, 39, § 2405; C46, 50, 54, 58, 62, 66, §144.20; C71, 73, 75, 77, 79, 81, §144.29]

88 Acts, ch 1158, §41; 97 Acts, ch 159, §17

144.30 Funeral director's duty - fetal death certificate.

The funeral director who first assumes custody of a fetus shall file the fetal death certificate. In the absence of such a person, the physician or other person in attendance at or after the delivery shall file the certificate of fetal death. The person filing the certificate shall obtain the personal data from the next of kin or the best qualified person or source available and shall obtain the medical certification of cause of death from the person responsible for completing the certification. When a person other than a funeral director assumes custody of a fetus, the person shall be responsible for carrying out the provisions of this section.

[C71, 73, 75, 77, 79, 81, §144.30]

97 Acts, ch 159, §18

144.31 Medical certification - fetal death.

The medical certification shall be completed within twenty-four hours after delivery by the physician in attendance at or after delivery except when inquiry is required by the county medical examiner.

When a fetal death occurs without medical attendance upon the mother at or after delivery or when inquiry is required by the county medical examiner, the medical examiner shall investigate the cause of fetal death and shall complete the medical certification within twenty-four hours after taking charge of the case. The person completing the medical certification of cause of fetal death shall attest to its accuracy either by signature or as authorized by rule.

[C24, 27, 31, 35, 39, § 2322, 2323, 2405; C46, 50, 54, 58, 62, 66, §141.6, 141.7, 144.20; C71, 73, 75, 77, 79, 81, §144.31]

97 Acts, ch 159, §19

144.56 Autopsy.

An autopsy or post-mortem examination may be performed upon the body of a deceased person by a physician whenever the written consent to the examination or autopsy has been obtained by any of the following persons, in order of priority stated when persons in prior classes are not available at the time of death, and in the absence of actual notice of contrary indications by the decedent or actual notice of opposition by a member of the same or prior class:

1. The spouse.

2. An adult son or daughter.

3. Either parent.

4. An adult brother or sister.

5. A guardian of the person of the decedent at the time of the decedent's death.

6. Any other person authorized or under obligation to dispose of the body.

This section does not apply to any death investigated under the authority of sections 331.802 to 331.804 .

[C75, 77, 79, 81, S81, §144.56; 81 Acts, ch 117, §1207]

Iowa Administrative Code

IAC 2/10/99 Public Health[641] Ch 101, p.1

CHAPTER 101

DEATH CERTIFICATION, AUTOPSY AND DISINTERMENT

[Prior to 7/29/87, Health Department[470] Ch 101]

641—101.1(144) Report of autopsy findings.

101.1(1) In cases where an autopsy is to be performed, it shall not be necessary to defer the entry of the cause of death pending a full report of microscopic and toxicological studies.

101.1(2) In any case where the gross findings of an autopsy are inadequate to determine the cause of death, the physician or medical examiner shall enter the cause as "pending" on the certificate and sign the certification. Immediately after the medical data necessary for determining the cause of death have been made known, the physician or medical examiner shall forward the cause of death to the registrar on a supplemental form provided by the state registrar and signed by the physician or medical examiner.

101.1(3) In any case where the autopsy findings significantly change the medical diagnosis of cause of death, a supplemental report of the cause of death shall be made by the physician or medical examiner to the registrar as soon as the findings are available. Such report shall be made a part of the original certificate.

641—101.2(144) Attending physician not available. An associate physician, who relieves the attending physician while on vacation or otherwise unavailable, may certify to the cause of death in any case where the associate physician has access to the medical history of the case, provided that the associate physician views the deceased at or after death occurs and the death is from natural causes. In all other cases in which a physician is unavailable, the medical examiner shall prepare the medical certification of cause of death.

641—101.3(144) Hospital or institution may assist in preparation of certificate. When death occurs in a hospital or other institution and the death is not under the jurisdiction of the medical examiner, the person in charge of such institution or the designated representative where the cause of death is known may aid in the preparation of the death certificate as follows:

Place the full name of the deceased, date and place of death on the death certificate blank and obtain from the attending physician the medical certification of cause of death and the signature of the attending physician;

Present the partially completed death certificate (identified by the name) and the completed medical certification to the funeral director or person who acted as such.

641—101.4(135) Removal of dead body or fetus.

101.4(1) Before assuming custody of a dead human body or fetus, any person shall:

a. Contact the attending physician and receive assurance that death is from natural causes and that the physician will assume responsibility for certifying to the cause of death or fetal death; or

b. If the case comes within the jurisdiction of the medical examiner, contact the medical examiner and receive authorization to remove the dead human body or fetus.

101.4(2) If a person other than a funeral director, medical examiner, or emergency medical service assumes custody of a dead human body or fetus, the person shall secure a burial-transit permit.

641—101.5(144) Burial-transit permit.

101.5(1) The burial-transit permit shall be issued upon a form prescribed by the state registrar and shall state:

a. The name, date of death, cause of death and other necessary details required by the state registrar;

b. That a satisfactory certificate of death has been filed;

c. That permission is granted to inter, remove or otherwise dispose of the body; and

d. The name and location of the cemetery or crematory where final disposition of the body is to be made.

The burial-transit permit shall be issued by the county medical examiner, a funeral director, or the county registrar of the county where the certificate of death or fetal death was filed.

101.5(2) The burial-transit permit shall be delivered to the person in charge of the place of final disposition.

101.5(3) The person in charge of every place of final disposition shall see that all of the requirements of this chapter relative to burial-transit permits have been complied with before disposition.

Such person shall retain the burial-transit permit for a period of one year from the date of final disposition.

101.5(4) A burial-transit permit shall not be issued prior to the filing of a certificate of death or fetal death in the county where the death occurred.

101.5(5) A burial-transit permit shall not be issued to a person other than a licensed funeral director if the death or fetal death is of a suspected or known communicable disease as defined by 641— paragraph 1.2(1) *"a."*

101.5(6) In all cases where a fetus has reached a gestation period of 20 completed weeks or more, or with a weight of 350 grams or more, a burial-transit permit must be obtained for the disposition of the fetus.

641—101.6(135) Transportation and disposition of dead body or fetus.

101.6(1) A dead human body or fetus shall be transported only after enclosure in a container for transfer that will control odor and prevent the leakage of body fluids, unless the body or fetus has been embalmed, or is being transported by a licensed funeral director, emergency medical service, or medical examiner. In addition, the transport of a dead human body or fetus shall be in a manner that, applying contemporary community standards with respect to what is suitable, is respectful of the dead, the feelings of relatives, and the sensibilities of the community.

101.6(2) When a dead human body or fetus is transported from the state, the burial-transit permit shall accompany the body or fetus. When a dead human body or fetus is brought into the state, a burial transit permit under the law of the state in which the death occurred shall accompany the body or fetus.

101.6(3) If the final disposition of a dead human body or fetus is cremation at a licensed cremation establishment, scattering of cremated remains shall be subject to the local ordinances of the political subdivision, and any and all regulations of the cemetery, if applicable, in which the scattering site is located. However, such local ordinances and cemetery regulations shall not allow scattering of cremated remains upon state property or upon private property without the property owner's consent. In the absence of an applicable local ordinance or cemetery regulation, scattering of cremated remains shall not be allowed upon any public property or upon private property without the property owner's consent. Cremation shall be considered final disposition by the department and no further burial transit permits shall be required.

101.6(4) If the final disposition of a dead human body or fetus is burial, interment or entombment, local ordinances of the political subdivision in which the final disposition site is located and any and all regulations of the cemetery, if applicable, shall apply. In the absence of an applicable local ordinance, the depth of the grave at its shallowest point shall be at least three feet from the top of the burial container.

These rules are intended to implement Iowa Code sections 135.11(9), 144.3 and 144.32.

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Appendix E: Resources

For referrals for family support:

1. The Compassionate Friends, Inc. (Grief support after the death of a child)
   P. O. Box 3696 Oak Brook, IL 60522-3696
   Toll-free: 877-969-0010 PH: 630-990-0010 FAX: 630-990-0246

2. WiSSP Lending Library (resources available for a one month loan covering information, comfort and advice in the months and years following miscarriage, stillbirth, and death of a child) WiSSP Lending Library c/o Peggy Modaff, MS. Waisman Center, Room 343, 1500 Highland Avenue, Madison, WI 53705-2280

3. Postpartum Support International (issues concerning postpartum mood changes or depression) Co-Coordinator: Dona Wessels --- Contact: 1201 North 4th Street, Manchester, IA, 52057 USA. Telephone: 563 927-2336. Email: ezpar3@iowatelecom.net Co-Coordinator: Sarah Fowler --- Contact: 6918 East Park Road NE, Cedar Rapids, IA, 52402 USA. Telephone: 319 294-1356 Email: obrnnoc@aol.com (please note PSI or PPD in the subject line of your email to Sarah, so she will know that your email is not spam).

Books on Perinatal Bereavement:

1. BEREZIN, Nancy -- *After a loss in pregnancy; help for families affected by a miscarriage, a stillbirth or the loss of a newborn.* Simon and Schuster, 1982, 174p. Based on many interviews with mothers, this book also includes medical information and statistics on the causes of perinatal death.

2. DAVIDSON, Glen W. -- *Understanding the death of the wished for child.* OGR Service Corp., 1979, 31p. About mothers who lose a child at birth.

3. DEFRAIN, John -- *Stillborn, the invisible death.* D.C. Heath and Company, 1986, 247p. For parents coping with this heartbreak

4. ERLING, Susan and Jake -- *Our baby died. Why?* The Pregnancy and Infant Loss Center, 1986, 36p. Thoughts and feelings of a bereaved brother about his stillborn brother and a subsequent baby.

5. FRIEDMANN, Rochelle and GRADSTEIN, Ronnie -- *Surviving pregnancy loss.* Little Brown, 1982, 244p. About miscarriage, stillbirth and ectopic pregnancy. Deals with the emotional impact and offers practical suggestions

6. SCHWIEBERT, Pat -- *When hello means goodbye. Perinatal loss, 1985, 48p. For those whose child dies before, at, or shortly after birth.*

7. ILSE, SHEROKEE *Empty Arms: A Guide to Help Parents and Loved Ones Cope with Miscarriage, Stillbirth and Neonatal Death*. Sherokee Ilse, P.O. Box 165, Long Lake, MN 55356

Books on Placental Examination:

1. BAERGEN RN. *Manual of Benirschke and Kaufmann's Pathology of the Human Placenta.* Springer; 1st ed. March 25, 2005.

2. BENIRSCHKE K, KAUFMANN P. *Pathology of the human placenta.* 4th ed. New York: Springer-Verlag, 2000.

3. LEWIS SH (EDITOR), PERRIN EVDK (EDITOR). *Pathology of the Placenta.* Churchill Livingstone; 2nd ed. January 15, 1999.

4. YETTER JF 3RD *Examination of the placenta.* Am Fam Physician. 1998 Mar 1;57(5):1045-54. Available at: http://www.aafp.org/afp/980301ap/yetter.html

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2. The National Code of Ethical Autopsy Practice - Australian Health Ministers' Advisory Council 14

3. Iowa Code, Chapter 136A, 2004 Iowa Acts, Chapter 1031 (HF 2362) from the 80th General Assembly.

4. Schuler-Maloney D, Lee S, Bosenberg M. The Placenta: To Know Me is to Love Me. A reference guide for gross placental examination. DSM PathWorks, Inc. P.O. Box33, Saint Mary's, Iowa 50241.

5. Collins JH, Collins CL, and Collins CC. "Silent Risk: issues about the human umbilical cord." The Pregnancy Institute, New Orleans, LA Text available on the Web at http://www.preginst.com/.

6. The Wisconsin Stillbirth Service Program (WiSSP). www.wisc.edu/wissp

7. The American College of Obstetricians and Gynecologists