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Iowa Stillbirth Surveillance Project

CDC Cooperative Agreement
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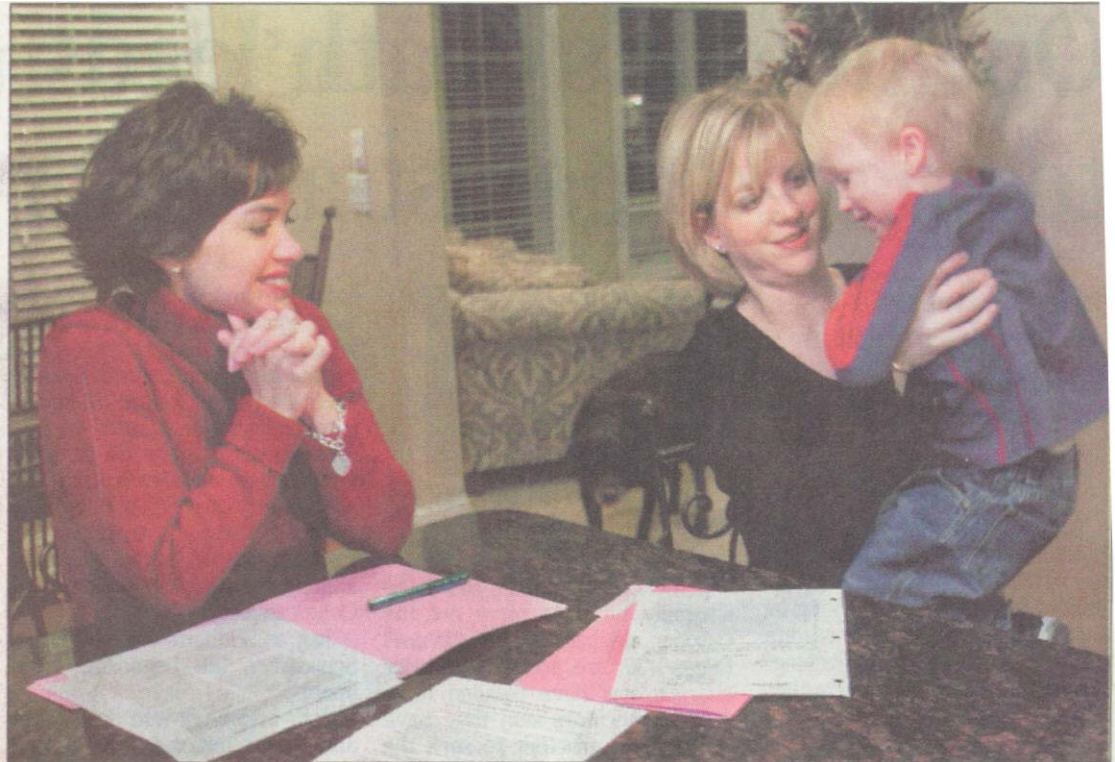
- If we could first know where we are, and whither we are tending, we could then better judge what to do, and how to do it.

Abraham Lincoln



History

- Iowa HF2362 introduced in 2005
- Established a work group to develop a stillbirth evaluation protocol
- State funds provided for start-up
- CDC received funds for pilot projects for expansion of existing birth defects registry – implemented in Iowa and five counties in metropolitan Atlanta



Strategy talks: State Rep. Janet Petersen picks up her son Charlie Pattinson, who interrupted a discussion with friend and colleague Tiffan Yamen last March when they met in Yamen's Waukee home. The two recently found success in their quest for a study of fetal deaths.

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Work Group Experts

- Perinatologists
- Neonatologists
- Pathologist
- Medical Geneticist
- OB Nurses
- Grief Counselor
- Hospital-based Risk Manager
- March of Dimes Representative
- Obstetrician (ACOG Member)
- Registry for Congenital & Inherited Disorders (epidemiologist)
- State Representative Janet Petersen
- Sonographer
- Insurance Company Representative
- General Practitioners
- Placental Pathology Expert
- CDRT Representative
- “Consumers” – families who have experienced a stillbirth
- Dr. Jason Collins
- IDPH Staff

Stillbirth Evaluation Protocol

- ❖ Designed to be useful to birthing providers
- ❖ Sections – Demographic information, History/patient interview, Pathology/post mortem, Follow up, Grief support
- ❖ Distributed to birthing hospitals and maternity care providers
- ❖ Evaluation form completed by providers, seven page checklist format
- ❖ Form submitted to IDPH

Case Finding

Sources of case identification

1. Fetal death certificates
2. Fetal death evaluation forms
3. Active surveillance
4. Statewide Perinatal Care Program stillbirth record review

Record Abstraction

1. Cases reported to the Iowa Registry for Congenital and Inherited Disorders (IRCID)
2. Field abstractors review medical records and record information in the registry
3. Information is reviewed for accuracy and quality
4. Information is available for analysis and reporting

Current status

- Over 1300 stillbirth records in the registry
- Information is being analyzed
- Determined common reporting and analysis “language”
- Reports developed
- Information available for researchers
- Reaching out to stillbirth prevention researchers in other states

Going Forward

- ◆ Information is needed from diverse communities
- ◆ The more data available, the better the analysis
- ◆ Researchers need information to inform their studies
- ◆ A national registry would provide a central source for stillbirth information, and resources for initiatives that aim to reduce the incidence of stillbirths

Stillbirth as a National Crisis

I am a firm believer in the people. If given the truth, they can be depended upon to meet any national crisis. The great point is to bring them the real facts.

Abraham Lincoln