Iowa Registry for Congenital and Inherited Disorders

Iowa Department of Public Health

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FREQUENTLY ASKED QUESTIONS

What is the Iowa Registry for Congenital and Inherited Disorders?
In 1983, a law was passed in Iowa that required birth anomalies to be reported. The law also required the Iowa Department of Public Health to establish a Registry to collect and maintain this information. Parental permission is not required for information on congenital and inherited disorders to be collected. This information is important because it is used to:

- Explore changes in the occurrence of these disorders around the state.
- Conduct research to determine possible causes.
- Promote educational activities for the prevention of birth anomalies.

How does my family benefit from the Iowa Registry for Congenital and Inherited Disorders and its activities?

- The Registry provides valuable information to the Iowa Department of Public Health about the health status of children in Iowa in order to plan future services for those with special health or education needs.
- The information provided by the Registry has the potential to help identify contributing factors of birth anomalies and allow for prevention education.
- The Registry may connect families to local resources, which in turn may benefit your family by connecting you with other families that have similar circumstances or other resources in your community.

Do all states have similar Registries?
At this time, 44 out of the 50 states along with the District of Columbia, Puerto Rico, and the U.S. Department of Defense have similar registries. Some registries collect information for many types of conditions, while some collect information for just a few. Some registries conduct research in their state, while others do not.

Is the information contained in the Iowa Registry for Congenital and Inherited Disorders confidential?

- Information collected by the Registry is kept confidential using computer security measures, and locked files and offices.
- The only people that have access to your child's information are Registry staff.
- Your child's identity is secret. We will never use your child's name or your family's name in any report or publication.

What is a birth anomaly?
A birth anomaly is defined as a structural, genetic or chromosomal abnormality that can affect the child's health and development. A birth anomaly may affect how the body looks, works, or both. Conditions range from mild to severe and some may put a child at risk for a developmental delay.

What are some examples of birth anomalies?
Examples are congenital heart defects, spina bifida, cleft lip/cleft palate, phenylketonuria (PKU), club foot, urinary tract conditions, and Down syndrome.

What may cause birth anomalies?
For many conditions, the cause cannot be determined. Some factors that may contribute to birth anomalies include:

- Use of drugs or medications
- Smoking or drinking alcohol during pregnancy
- Genetic factors
- Diets lacking in folic acid

Who is included in the Registry?

- Infants who have a reportable diagnosis within the first year of life born on or after January 1, 1983, whose mother was an Iowa resident.
- Iowa mothers with affected pregnancies.

How does the Registry gather information about birth defects?
Trained personnel review medical records in all hospitals in Iowa and in neighboring states that serve Iowa residents. They also consult with local doctors.

Why are parents being notified now?
For children born on or after January 1, 2003, the Registry is required to inform the parent or legal guardian when their child has been identified. The Registry is also responsible for sharing information with the family about resources that they may be eligible for.

How can collecting birth defect information be helpful in preventing birth defects?
The review of medical information can provide important clues as to the potential causes or contributing factors of birth defects. Research can lead to prevention strategies, as well as to intervention strategies for babies that have birth defects. For example, research on folic acid led to a prevention strategy for a birth defect. Scientists showed that by taking folic acid prior to and in the early weeks of pregnancy, the risk of having a baby with a birth defect of the brain or spine is significantly reduced.

Is research currently being done to determine the causes or contributing factors of birth defects?
The Iowa Birth Defects Registry is performing several research studies. For more information about the current research projects, please visit the Registry's web site at http://www.public-health.uiowa.edu/ircid . Family participation in research is essential to determine potential causes of birth defects. If research opportunities are available and your child is eligible because of his/her diagnosis or condition, you may be contacted in the future. Participation in this research is always voluntary.

If my family was contacted to participate in research, what are the "typical" expectations?

- Participating families usually provide information via mailed or telephone surveys.
- Some research projects ask for you to provide a blood sample or a swab of cheek cells from the child and his or her family members.

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