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## BUDGET UNIT BRIEF – FY 2024

Fiscal Services Division

July 1, 2023



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Ground Floor, State Capitol Building

Des Moines, Iowa 50319

515.281.3566

# Congenital and Inherited Disorders Registry

## History and Purpose

The Iowa Department of Health and Human Services (HHS) is required to develop and administer the State's policy with respect to the conduct of scientific investigations and research concerning the causes, prevention, treatment, and cure of birth defects. The [Center for Congenital and Inherited Disorders](#) was established in 1976 to initiate, conduct, and supervise genetic investigations and research to provide for the protection and promotion of the health of Iowans. Since its creation, the Center for Congenital and Inherited Disorders, in partnership with the University of Iowa (UI) and health care providers throughout the State, has developed programs that have provided Iowa with state-of-the-art genetics health care. The programs of the Center for Congenital and Inherited Disorders address all steps of the life cycle: prenatal, neonatal, pediatric, and adult.

The Registry for Congenital and Inherited Disorders is the reporting system to identify and monitor birth defects and stillbirths in the State of Iowa. Birth defects and stillbirths are reportable conditions in Iowa, and the records of these birth defects and stillbirths are abstracted and maintained. The Registry was established in 1983 through the joint efforts of the UI the Iowa Department of Public Health, and the Iowa Department of Human Services. The Program is located within the College of Public Health at the UI. The mission of the Iowa Registry for Congenital and Inherited Disorders is as follows:

- Maintain statewide surveillance for collecting information on birth defects and stillbirth occurrence.
- Monitor annual trends in birth defects and stillbirth occurrence and mortality.
- Conduct research to identify genetic and environmental risk factors for birth defects and stillbirths.
- Promote educational activities related to the prevention of birth defects and stillbirths.

There are seven programs within the Center for Congenital and Inherited Disorders, which include: the [Regional Genetic Consultation Service](#) (RGCS), the [Iowa Newborn Screening Program](#) (INSP), the [Iowa Maternal and Prenatal Screening Program](#) (IMPSP), the [Iowa Registry for Congenital and Inherited Disorders](#) (IRCID), the [Iowa Neuromuscular and Related Genetic Disorders Program](#) (INMP), the [Iowa Early Hearing Detection and Intervention Program](#) (EHDI), and the [Stillbirth Surveillance and Prevention Program](#).

Established within the Center for Congenital and Inherited Disorders is the [Congenital and Inherited Disorders Advisory Committee](#) (CIDAC). This Committee acts in an advisory capacity to the programs of the Center. The Committee is composed of representatives from each of the Center programs, various professional health care groups, and the HHS; consumers; and two legislators.

## Funding — State General Fund

There is a standing unlimited appropriation from the General Fund in Iowa Code section [144.13A\(5\)\(a\)](#) that permits the HHS to retain \$10 of the \$20 Birth Certificate Registration Fee for the Registry. The other \$10 of the fee is appropriated for the Child Abuse Prevention Program Administration.

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## More Information

Center for Congenital and Inherited Disorders: [hhs.iowa.gov/genetics](https://hhs.iowa.gov/genetics)  
LSA Staff Contact: Chris Ubben (515.725.0134) [chris.ubben@legis.iowa.gov](mailto:chris.ubben@legis.iowa.gov)

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There are allocations from the General Fund Chronic Conditions and Healthy Children and Families appropriations to the HHS for programs in the Center for Congenital and Inherited Disorders. Additionally, there is an annual General Fund appropriation to the UI for the Iowa Birth Defects Registry in the Education Appropriations Act.

**Related Statutes and Administrative Rules**

Iowa Code chapter [136A](#)

Iowa Code section [144.13A](#)

Iowa Administrative Code [641—4](#)

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