
BUDGET UNIT BRIEF – FY 2026

Fiscal Services Division

July 1, 2025



Ground Floor, State Capitol Building

Des Moines, Iowa 50319

515.281.3566

Congenital and Inherited Disorders Registry — Standing

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 Registry 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.

The programs within the Center for Congenital and Inherited Disorders include the Regional Genetic Consultation Service, the Iowa Newborn Screening Program, the Iowa Maternal and Prenatal Screening Program, the Iowa Registry for Congenital and Inherited Disorders, the Iowa Neuromuscular and Related Genetic Disorders Program, the Iowa Early Hearing Detection and Intervention Program, the Stillbirth Surveillance and Prevention Program, and the Family Health History Initiative.

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 average amount generated is approximately \$200,000 annually. The other \$10 of the fee is appropriated for the Child Abuse Prevention Program administration.

The HHS also uses funding from the appropriation 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.

More Information

Congenital and Inherited Disorders:

hhs.iowa.gov/programs/programs-and-services/family-health/congenital-inherited-disorders

LSA Staff Contact: Louie Hoehle (515.281.6561) louie.hoehle@legis.iowa.gov

Related Statutes and Administrative Rules

Iowa Code chapter [136A](#)

Iowa Code section [144.13A](#)

Iowa Administrative Code [641—4](#)

Budget Unit Number

40008440001

Doc ID 1520234