Did you know?
All Iowa newborns are screened for over 50 congenital or inherited conditions (unless the parent refuses). That’s over 38,000 babies a year. If you placed 38,000 bassinets end-to-end, it would form a line 22 miles long!

A focus on health equity
CCID programs provide services to all Iowans statewide. All Iowa newborns receive screening for hearing loss, the blood spot panel and critical congenital heart disease (unless the parent has refused the screening). To ensure access to genetic services, the Regional Genetics Consultation Service and the Neuromuscular Disorders programs offer outreach clinic sites across the state. The newborn screening programs specifically reach out to community-based birth providers to ensure families have access to newborn screening services.

What does the department do?
- The Early Hearing Detection and Intervention (EHDI) program ensures universal newborn hearing screening and ensures infants who do not pass their hearing birth screen are diagnosed and referred to early intervention and family support services in a timely manner.
- Iowa Newborn Screening Program (INSP) ensures mandated blood spot screening for all Iowa newborns for over 50 conditions on the Iowa newborn screening panel and provides follow-up for abnormal results through diagnosis of a condition or resolution of a normal result.
- Newborn Screening for Critical Congenital Heart Disease (CCHD) - Every newborn receives screening for CCHD by pulse oximetry prior to discharge from the birth center. Newborns that fail the screen are referred to specialists.
- Metabolic Food and Formula program - Individuals with a diagnosed inborn error of metabolism, such as PKU, that requires low-protein nutrition receive funding support to purchase medically necessary formula and foods.
- Iowa Maternal Prenatal Screening Program (IMPSP) - Pregnant women may elect to have prenatal screening for potential fetal birth defects. The IMPSP provides testing and follow-up with the woman’s provider for any abnormal results.
- Regional Genetic Consultation Service (RGCS) and Neuromuscular and Related Disorders Program (NM) provide regional clinics across Iowa for individuals with congenital and inherited disorders. Services are provided by specialists, genetic counselors, nurse practitioners and nursing staff. (cont.)
Center for Congenital and Inherited Disorders (CCID)

Iowa Department of Public Health

What does the department do? (cont.)

- **Iowa Registry for Congenital and Inherited Disorders (IRCID)** - Iowa’s active surveillance program of reportable birth defects and heritable conditions.
- **Stillbirth surveillance and prevention** - Cases of stillbirth (fetal death) as reported by birthing hospitals are reviewed by CCID staff for trends and contributing factors.

What can Iowans do to help?

- Support and promote newborn screenings by having your children screened and encouraging others to do the same. If your infant or someone you know has an infant that did not pass their screenings at birth, make sure the infant is re-screened in a timely manner and visit with your primary care provider about next steps through the point of diagnosis and referral to early intervention, family support and genetics, as needed.
- Conduct your family health history and discuss with your healthcare provider.

How do we measure our progress?

**Percentage of infants who did not pass their hearing screen at birth diagnosed with a hearing loss no later than 3 months of age**

**Percentage of newborn screening specimens that are received by SHL within 65 hours of birth**

### Resources

<table>
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<tr>
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<th>SFY 2018 Actual</th>
<th>SFY 2019 Actual</th>
<th>SFY 2020 Estimate</th>
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<td>State Funds</td>
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For more information, please visit [http://idph.iowa.gov/](http://idph.iowa.gov/) or call us at (515) 281-7689.

Dec 2019