Health and Senior Services	HB Section(s): 10.700 and 10.710
Genetics and Newborn Services	
Program is found in the following core budget(s):	

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	DCPH Program	DCPH Programs and						
	Operations	Contracts						TOTAL
GR	187,732	942,823						1,130,555
FEDERAL	624,543	136,384						760,927
OTHER	80,170	1,574,281						1,654,451
TOTAL	892,445	2,653,488						3,545,933

# 1a. What strategic priority does this program address?

Public Health System Building; Infant and Maternal Health; Social Determinants of Health; and Whole Person Health Access.

## 1b. What does this program do?

The Genetics and Newborn Services program provides education, outreach, and interventions to improve women's prenatal, maternal, and child health; increase healthier births; promote normal growth and development outcomes; increase school readiness; and facilitate healthy outcomes throughout the lifespan. The program develops and disseminates educational materials, social media messages, and multimedia marketing campaigns to educate the public on healthy behaviors. Primary program activities and priorities are outlined below.

- Encouraging early entrance into prenatal care.
- Providing education on healthy behaviors starting at preconception, including:
  - \* the Count the Kicks program to reduce still births;
  - \* the use of folic acid to reduce birth defects;
  - \* the importance of avoiding smoking, alcohol, and other drugs during pregnancy;
  - \* breastfeeding promotion; and
  - \* helping families learn healthy parenting skills.
- Providing case management, education, and awareness for Hepatitis B (HBV) including information on disease transmission, disease process, diagnosis, and treatment, to clinical and social service providers, infected/affected individuals, and the general public to ensure infants born to HBV positive women receive timely and complete vaccination to prevent infection.
- Administering a confidential, toll-free Maternal Child Health Information and Referral Line that connects families with programs and services (TEL-LINK);
- Administering Newborn Screening Programs, which encompass the following:
  - \* newborn blood spot screening tracking and follow-up for over 70 different rare disorders to prevent death and/or disability;
  - \* early identification, diagnosis, and intervention for hearing loss to ensure communication milestones are achieved;
  - \* education, outreach, and technical assistance for families, providers, hospitals, and the general public.
- Collaborating with child abuse medical resource centers to provide training, support, and mentoring to Sexual Assault Forensic Examination-Child Abuse Resource and Education (SAFE-CARE) medical providers.
- Providing screening, diagnostic evaluations, treatment, and counseling for Missourians with genetic conditions.
- Providing metabolic formula for adults and children with metabolic conditions.

Health and Senior Services	HB Section(s): 10.700 and 10.710
Genetics and Newborn Services	• • • • • • • • • • • • • • • • • • •
Program is found in the following core budget(s):	

# 2a. Provide an activity measure(s) for the program.

Cliente Served by Newborn Health Services	FFY 2020	EEV 2021	EEV 2022	FFY 2023	FFY 2024	FFY 2025
Clients Served by Newborn Health Services		FFY 2021	FFY 2022	Proj.	Proj.	Proj.
Educational Materials Distributed	275,549	251,048	300,000	300,000	300,000	300,000
Number of TEL-LINK Referrals	3,267	2,952	3,000	3,000	3,000	3,000

Newborn Blood Spot Screening Tracking and Follow-up						
The Missouri Newborn Blood Spot Screening Program tracked, followed, and provided educational information to the parents of:	CY 2020	CY 2021	CY 2022	CY 2023 Proj.	CY 2024 Proj.	CY 2025 Proj.
Newborns referred to contracted referral centers for follow-up of abnormal newborn blood spot screening results.	567	552	600	600	600	600
Newborns diagnosed with disorders identified through newborn blood spot screening.	197	224	200	200	200	200
Newborns with hemoglobinopathy trait identified through newborn blood spot screening.	1,452	1,603	1,500	1,500	1,500	1,500
Newborns who need a repeat blood spot screening.	2,701*	3,287	3,200	3,200	3,200	3,200
Newborns who missed the blood spot screening.	429**	545**	400	400	400	400

<sup>\*</sup>The number of letters mailed to parents of newborns who were found to need a repeat newborn screen in CY 2020 decreased due to follow-up program staff reassignments.

<sup>\*\*</sup>The number of newborns in 2020 and 2021 who missed their newborn blood spot screening is likely due to parental hesitancy to seek out medical care and potential increased utilization of home birthing options during the COVID-19 pandemic.

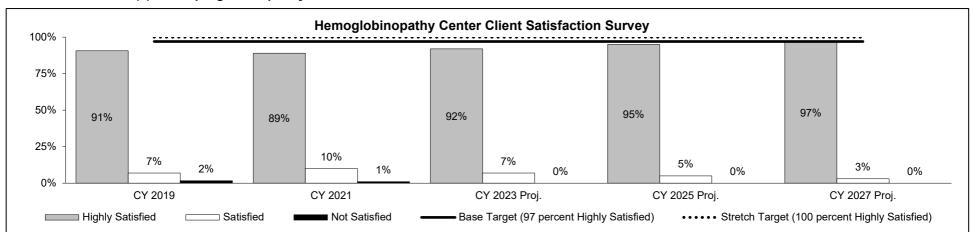
Health and Senior Services	HB Section(s): 10.700 and 10.710
Genetics and Newborn Services	·
Program is found in the following core budget(s):	

# 2a. Provide an activity measure(s) for the program (continued).

Newborn Hearing Screening Tracking and Follow-up						
The Missouri Newborn Hearing Screening Program tracked, followed, and provided educational information to the parents of:	CY 2020	CY 2021	CY 2022	CY 2023 Proj.	CY 2024 Proj.	CY 2025 Proj.
Newborns who failed to pass their initial newborn hearing screening.	2,859	2,876	2,800	2,800	2,800	2,800
Newborns who missed their hearing screening.	815*	711	700	700	700	700
Newborns who were diagnosed with permanent hearing loss and referred to early intervention via Missouri's Part C Program, First Steps.	117	104	120	120	120	120

<sup>\*</sup>The increase in newborns who missed their hearing screening in 2020 was likely due to COVID-19 policies instituted by some hospital hearing screening programs to omit the hearing screening during the height of the pandemic.

# 2b. Provide a measure(s) of the program's quality.



This survey is given to hemoglobinopathy patients to evaluate their level of satisfaction with the care they receive at the hemoglobinopathy centers. DHSS contracts with four pediatric and three adult hemoglobinopathy centers to provide newborn screening follow-up and comprehensive medical services (i.e. inpatient, outpatient, and emergency care) for individuals and families with sickle cell disease and other related disorders. The survey is conducted every two years.

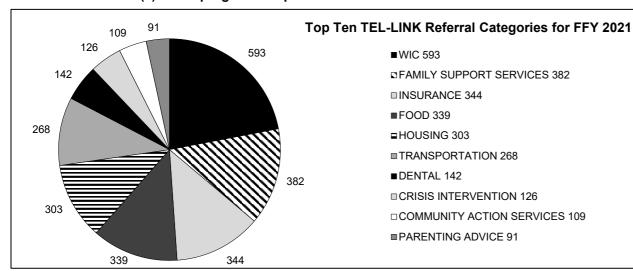
Health and Senior Services

HB Section(s): 10.700 and 10.710

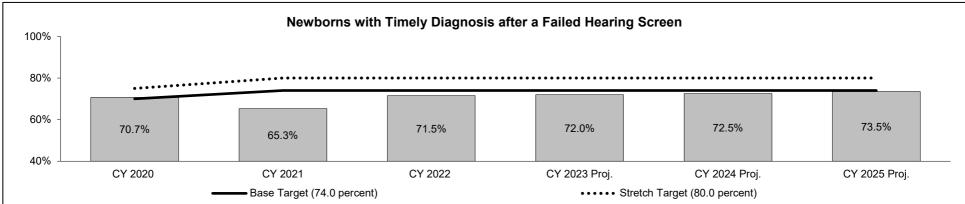
Genetics and Newborn Services

Program is found in the following core budget(s):

# 2c. Provide a measure(s) of the program's impact.



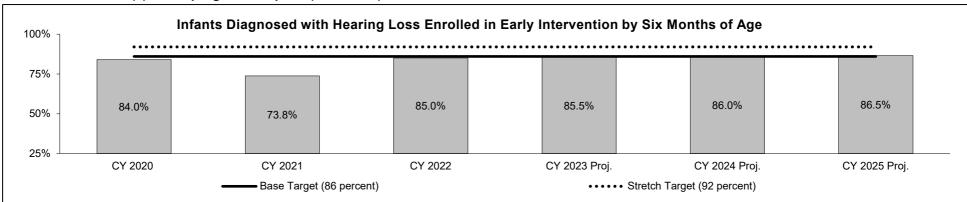
TEL-LINK is the DHSS's confidential, toll-free telephone line for maternal and child health care. The purpose of TEL-LINK is to provide information and referrals to Missouri residents concerning a wide range of health services. There are 52 different referral categories within the TEL-LINK database. The ten referral categories illustrated here represent 91 percent of the total referrals for FFY 2021. The number of referrals may fluctuate from year to year based upon available funding for advertising as well as the needs of the population.



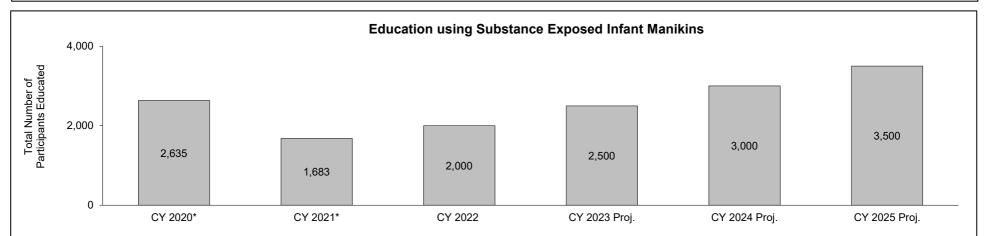
Universal newborn hearing screening, when accompanied by timely access to outpatient rescreening, audio logic diagnostic evaluation, and intervention services (e.g. training in sign language, hearing amplification services, and speech language services), can improve language, social, and emotional outcomes for children born deaf or hard of hearing and result in economic benefits to society. The purpose of Missouri's Newborn Hearing Screening Program is to screen all infants for hearing loss by one month of age, ensure those infants that fail screening are evaluated to identify hearing loss by three months of age, and ensure all infants diagnosed with permanent hearing loss are enrolled in an early intervention program by six months of age. Previous base target of 70 percent was exceeded in CY 2020, precipitating an increased base and stretch target.

Health and Senior Services	HB Section(s): 10.700 and 10.710
Genetics and Newborn Services	·
Program is found in the following core budget(s):	

# 2c. Provide a measure(s) of the program's impact. (continued)

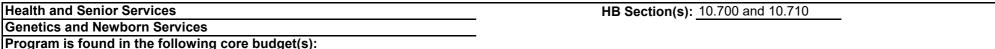


Appropriate intervention must occur within the first six months of life in order for children born with hearing loss to develop language skills' matching their typical hearing peers by five years of age. The purpose of Missouri's Newborn Hearing Screening Program is to screen all infants for hearing loss by one month of age, ensure those infants that fail screening are evaluated to identify hearing loss by three months of age, and ensure all infants diagnosed with permanent hearing loss are enrolled in an early intervention program by six months of age.

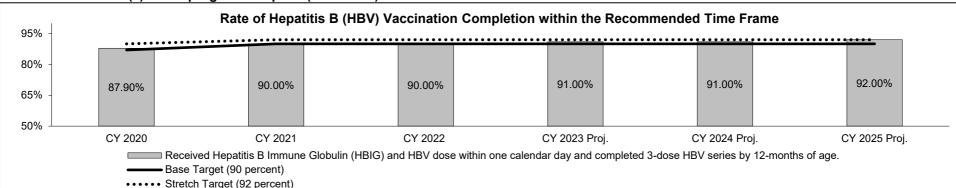


Substance exposed infant manikins are provided to 32 various sites for educational outreach. Each site receives, at no cost, infant manikins representing Caucasian and African American infants with Fetal Alcohol Syndrome, prenatal drug exposure, and healthy characteristics. Community placement sites utilize the manikins to provide education to groups such as communities, expectant parents, grandparents, treatment clinics, WIC clients, educators, students, and health care providers. Each site reports data back to DHSS for each presentation or exhibit for which the manikins are used, documenting the number of participants who received education.

\*Participant numbers have been decreasing due to COVID-19. The pandemic has affected face-to-face services for these sites, which has caused a decrease in utilization of the manikins.

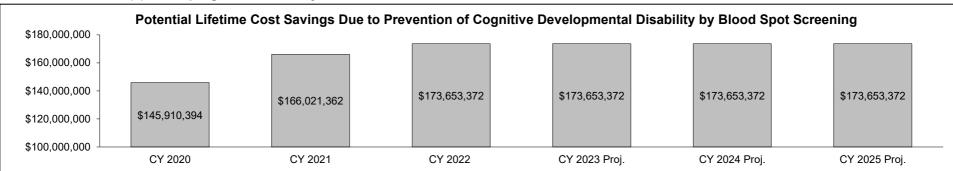


## 2c. Provide a measure(s) of the program's impact. (continued)

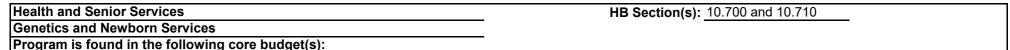


Perinatal HBV case management increases the likelihood that babies who are born to HBV positive mothers are vaccinated for HBV at birth and receive the full three month dose HBV Series by 12 months of age. Receipt of the full HBV series ensures HBV immunity among most vaccinated babies and decreases the likelihood of associated negative health outcomes including chronic HBV infection and liver disease. Approximately 120 infants are served by Missouri's perinatal HBV case management program each year.

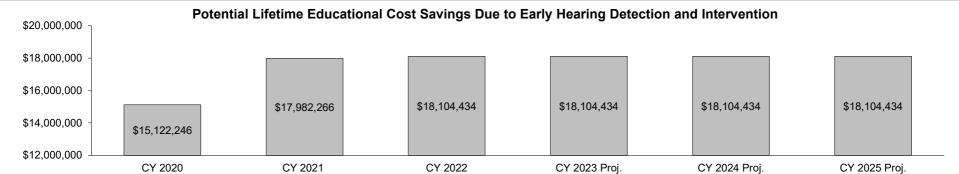
## 2d. Provide a measure(s) of the program's efficiency.



In 2003, the Centers for Disease Control and Prevention (CDC) estimated the average lifetime costs per person with cognitive developmental disability to be approximately \$1,014,000. The U.S. Bureau of Labor Statistics Consumer Price Index Inflation Calculator was used to calculate inflation over time. The number of disorders detected varies from year to year due to variables in incidence. The numbers of infants represented in this chart only includes those with disorders on the blood spot screening panel where cognitive developmental disability is a symptom and where there is evidence to show that early diagnosis and treatment prevents this specific disability. Disorders included are: biotinidase deficiency, congenital adrenal hyperplasia, congenital primary hypothyroidism, galactosemia, amino acid disorders, fatty acid disorders, and organic acid disorders. Additional cost savings are likely associated with the remaining blood spot disorders, however, there is not sufficient data to provide a dollar estimate. The program did not set targets as it is not possible to project the number of children identified with the specified conditions.

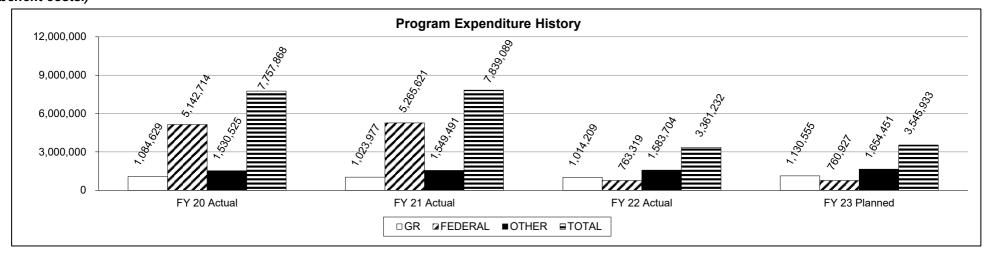


## 2d. Provide a measure(s) of the program's efficiency. (continued)



The CDC estimated the lifetime educational cost of undiagnosed or untreated hearing loss at \$115,600 per child (year 2007 value for permanent hearing loss without other disabilities). The CDC estimated cost of newborn hearing screening was \$26 in 2010. The U.S. Bureau of Labor Statistics Consumer Price Index Inflation Calculator was used to calculate inflation over time. Total savings was calculated as (number of infants diagnosed x average lifetime cost) - (cost of hearing screening x total newborns screened). The program did not set targets as it is not possible to project the number of children identified with the specified conditions.

# 3. Provide actual expenditures for the prior three fiscal years and planned expenditures for the current fiscal year. (Note: Amounts do not include fringe benefit costs.)



Health and Senior Services	HB Section(s): 10.700 and 10.710
Genetics and Newborn Services	• • • • • • • • • • • • • • • • • • •
Program is found in the following core budget(s):	

#### 4. What are the sources of the "Other " funds?

Health Initiatives Fund (0275) and Missouri Public Health Services (0298).

# 5. What is the authorization for this program, i.e., federal or state statute, etc.? (Include the federal program number, if applicable.)

Sections 191.300 - 191.380 RSMo (Adult Genetics and Metabolic Formula; Sections 191.331 - 191.332 RSMo (Newborn Blood Spot Screening)); Sections 191.925 - 191.931, RSMo (Newborn Hearing Screening); Section 191.334, RSMo (Newborn Critical Congenital Heart Disease Screening); Section 191.725, RSMo (Prenatal Substance Use Prevention Program); and the Federal Omnibus and Reconciliation Act (OBRA 89) and Maternal Child Health Information and Referral Line and Section 192.601.1, RSMo (TEL-LINK).

## 6. Are there federal matching requirements? If yes, please explain.

Yes. The Maternal and Child Health Services Title V Block Grant partially supports this program and requires a three dollar non-federal match for every four dollars of federal funds received, and requires maintenance of effort.

## 7. Is this a federally mandated program? If yes, please explain.

Yes. The Maternal Child Health Information and Referral Link (TEL-LINK) is mandated under the Federal Omnibus and Reconciliation Act (OBRA 89).