WISCONSIN DEPARTMENT of HEALTH SERVICES

Division of Public Health

Newborn Screening Program Overview

Newborn screening (NBS) is a vital public health program implemented 60 years ago that identifies infants with conditions impacting long-term development, health, or survival. Every year, approximately 60,000 babies in Wisconsin are screened for congenital disorders. Most disorders detected by NBS program are life-threatening or have permanent detrimental effects on health if appropriate treatments are not provided shortly after birth.

By Wisconsin state statute (Wis. Stat. ch. 253), the newborn screening program:

- Screens newborns for congenital disorders (blood).
- Provides special dietary and other treatment to individuals with congenital disorders identified by NBS.
- Provides follow-up diagnostic and counseling services.
- Administers the newborn hearing and heart screening programs.

Details

NBS is a three-part system. Blood screening run by Wisconsin Department of Health Services (DHS) and contracted agencies including the Wisconsin State Lab of Hygiene (WSLH). WSLH carries out laboratory testing for nearly 50 conditions.

NBS was initially developed to screen for Phenylketonuria (PKU) but currently screens for that condition plus many others including Cystic Fibrosis and Sickle Cell Disease. The conditions chosen to be screened are informed by the Recommended Uniform Screening Panel (RUSP) at the federal level and guided by the DHS Secretary's Advisory Committee on Newborn Screening (SACNBS) at the state level. Heart and hearing screenings are run by DHS staff and contracted agencies to detect serious heart conditions and hearing impairment.

Costs

The newborn screening program's costs are funded primarily through a fee paid by hospitals and birthing centers.

- The fee was increased to $195 per card through the biennial budget process in 2023.
- The fee had been $109 per card since 2010 with no increase in 13 years.
- Hospitals bill the fee to the family's health insurance where possible.
- The Medicaid program reflects the blood card fee cost in its reimbursement rate for births for families enrolled in Medicaid.
- Revenue that supports the program is split between WSLH 53.7% (~$105 per card) and DHS 46.3% (~$90 per card).

The proposed increased fee to $223 per card would:

- Support WSLH to carry out blood screening (~$125 per card).
- Allow DHS to administer the program (~$98 per card), avoiding deficit spending.

Overall, NBS program costs increase when new conditions are added to the screening panel. This happens through a formal nomination and review process administered by DHS. Also, ongoing Special Dietary Treatment (SDT) costs are subject to rise, as the treatment is provided for life, affected by inflation, and involves critical functions such as rapid courier transport of blood cards to the lab.

Screenings

By statute, Wisconsin is required to screen every infant born in a hospital prior to discharge, and every infant born outside of a hospital within one week of birth. DHS is required to provide or ensure provision of diagnostic and testing services and follow up services for all three screenings.

Blood screening

Blood screening services are primarily comprised of Special Dietary Treatment (SDT) and Ongoing Clinical Care (OCC) through contracts with 10 agencies, including specialty clinics and health departments across the state. Patients with a confirmed diagnosis receive ongoing clinical care (clinical care, SDT, genetic counseling, and care coordination). They are also assessed for nonmedical needs and receive services to promote transition to adult health care. DHS is responsible for coordinating Ongoing Clinical Care (OCC), the SDT program, data and system analysis, and Out of Hospital Screening (OOH) and follow up care. DHS coordinates the NBS Committees, conducts budget monitoring, and program evaluation. Currently, more than 1,500 individuals with disorders identified by blood screening alone are being served by the program's ongoing clinical care and special dietary treatment.

Hearing screening

Hearing screening services consist of data tracking and monitoring, loss-to-follow-up prevention, and referral and provision of early intervention and family support. DHS staff spend significant effort coordinating outreach activities and contacting hard-to-reach populations to make sure that each infant born in Wisconsin has access to hearing screening. For Plain Community populations (Amish, Mennonite, and Hutterite), this is particularly important due to the high rates of deafness and other screened conditions.

Heart screening

Heart screening follow up includes data tracking and monitoring, loss-to-follow-up prevention, referral, and the provision of early intervention and family support.

Summary

Blood screening includes approximately 50 disorders and is carried out using blood collected on filter paper from the baby's heel. Both hearing and heart screening are carried out by instruments at the baby's bedside.

Each year in Wisconsin:

- Approximately 130 babies will have a disorder detected by the blood screen.
- Approximately 100 babies will have hearing loss detected.
- Approximately 100 babies will have identified critical congenital heart disease.

References

- Wis. Stat. ch. 253
- Wis. Admin. Code § DHS 115
- Visit us online to learn more.