



Legislative Fiscal Bureau

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Joint Committee on Finance

Paper #436

Newborn Screening Program (Health Services -- Public Health)

[LFB 2023-25 Budget Summary: Page 271, #5]

CURRENT LAW

The DHS Division of Public Health and the UW State Laboratory of Hygiene jointly operate a program to screen newborns for congenital disorders and provide special dietary treatments, other treatments, and follow-up counseling services. A small blood sample is collected from every newborn in the state and analyzed by the State Laboratory for 48 disorders, including conditions such as cystic fibrosis and sickle cell disease. The screening also includes a hearing test and a pulse measurement to screen for critical congenital heart disease. Although rare, many of the genetic disorders detected by the screening can be life-threatening if appropriate treatments, such as special dietary supplements, are not provided shortly after birth.

The blood and heart screening, and associated treatments and services, are funded by program revenue (PR); current law requires DHS to assess a fee for each screening performed to fund the costs of analyzing the sample, providing follow-up counseling and special dietary treatment, and administering and analyzing the program. The fee is established in administrative rule at \$109 per newborn. Hospitals, or medical professionals attending a birth outside of a hospital, pay this fee by purchasing blood collection cards from the State Laboratory.

Under an agreement between the State Laboratory and DHS, the State Laboratory receives \$60.50 from the sale of each blood collection card for the costs of conducting the testing, while DHS receives the remaining \$48.50 to fund follow-up services, special dietary treatment, other treatment and counseling, and administration of the program.

The hospitals and other providers that purchase the blood collection card typically include the cost of the card, as well as costs of collecting the blood sample and any other related services they perform, in the claims they submit to the family's health plan or, if the family is uninsured, the family. However, the reimbursement the hospital or other provider receives for birth-related

services, including the cost of the card, depends on the reimbursement agreement negotiated between the provider and the health plan.

For each child whose birth costs are covered under the state's Medical Assistance (MA) program, the MA program reimburses the hospital based on the diagnoses of the patient they treat—in this case, the particular type of delivery—and the cost of the blood collection card is one factor in determining this rate. The MA program pays a reimbursement of \$115 for the screening card and handling costs when a baby is born outside a hospital (in the home or a birthing center).

The hearing screening portion of the program, also known as Wisconsin Sound Beginnings, is currently funded by federal grants. DHS currently receives \$235,000 FED per year under the Early Hearing Detection and Intervention grant program administered by the Health Resources and Services Administration (HRSA) of the federal Department of Health and Human Services (HHS), and provides additional funding for the hearing screening program from the state's allocation of the Maternal and Child Health (MCH) Block Grant, also administered by HRSA. The MCH grant supports an array of services for children and youth with special health care needs, as well as other services.

DISCUSSION POINTS

1. Assembly Bill 43 and Senate Bill 70 would provide \$3,556,300 GPR in 2023-24 and \$1,669,600 GPR in 2024-25 in a new DHS appropriation to supplement the PR funding that supports the costs of special dietary treatment, follow-up services and counseling, other treatments, and program administration. A separate provision in the bill would provide \$2,200,000 GPR annually to the State Laboratory to supplement PR funding for the costs of analyzing the blood samples; this item is described in detail Legislative Fiscal Bureau budget paper #816.

2. For at least the past six years, DHS's costs of providing dietary treatments, counseling services, and related administrative services have exceeded the Department's share of fee revenue from the blood collection cards. DHS has used a PR balance accumulated in prior years to fund the difference between annual revenues and costs. That balance has now been exhausted, and the program ended fiscal year 2021-22 with an unsupported overdraft of \$535,000. DHS estimates that the program will end 2022-23 with a negative balance of \$2,064,800. The funding increase in the bill would provide this amount in 2023-24 to address the projected shortfall. The remaining \$1,491,500 in 2023-24 and \$1,669,600 in 2024-25 would fund the Department's estimates of the ongoing difference between projected program costs and fee revenue.

3. In response to the unsupported overdraft in 2021-22 and in accordance with s. 16.513, Wis. Stats., the Department of Administration (DOA) submitted a plan to address this and other overdrafts to the Joint Committee on Finance on December 28, 2022. In its submission, DOA recommended that DHS pursue an administrative rule change to increase the blood collection card fee. This plan was approved by the Committee on January 19, 2023. However, the Administration proposed to provide GPR funding under AB 43/SB 70 as an alternative to implementing this plan, to preempt the need for a fee increase to fund the DHS portion of the newborn screening program.

4. Decreasing birth rates are reducing the amount of revenue DHS collects from the blood collection card fee. The fee was set at its current level in 2010. In that year there were 66,800 newborns born, as measured by the number of screening cards issued. In 2021-22, the most recent year of data available, there were 59,900 cards purchased, a total decline of 10.3% and an average decline of 1.0% per year. Based on an acceleration of this trend in the most recent years, DHS estimates that births will decline by approximately 3.7% per year in 2022-23, 2023-24, and 2024-25 relative to the average of the prior three years.

5. Table 1 shows the number of newborns born, total fee revenue, and DHS's portion of the fee revenue in 2010-11 and the most recent three fiscal years (2019-20 through 2021-22), and estimates of the number of newborns and revenue in 2022-23, 2023-24, and 2024-25, based on the current \$109 total fee and \$48.50 portion allocated to DHS.

TABLE 1
Screening Card Revenue under Current Fee Structure

	<u>Number of Newborns</u>	<u>Total Fee Revenue</u>	<u>DHS Portion of Revenue</u>
2010-11	66,800	\$7,280,000	\$3,372,800
2019-20	60,600	6,601,600	2,937,400
2020-21	57,700	6,286,500	2,797,200
2021-22	59,900	6,532,000	2,906,500
2022-23	55,500	6,048,200	2,691,200
2023-24	53,500	5,831,600	2,594,800
2024-25	51,500	5,615,000	2,498,400

6. In addition to declining revenue, program costs have increased over this period and are likely to continue to grow. Expenditures for the DHS treatments, services, and administrative costs were \$2,861,500 in 2010-11, and had increased to \$3,598,500 in 2021-22, a total increase of 25.8% and average increase of 2.1% per year. DHS projects expenditures of \$4,006,200 in 2022-23 and cost growth of 2% per year in subsequent years.

7. Special dietary treatment accounts for most of DHS's current costs. DHS contracts with several hospital systems and the State Laboratory to provide special dietary treatment products prescribed by a doctor, such as infant formula, for people who test positive for cystic fibrosis or a metabolic disorder and reside in Wisconsin. These contracts also include nutrition and genetic counseling and referrals to appropriate follow up care. In 2021-22, these contracts totaled \$2,170,900 for dietary treatment and \$948,200 for related ongoing clinical care.

8. DHS also contracts with the Medical College of Wisconsin and Children's Hospital of Wisconsin to support their programs providing treatment for sickle cell trait and disease and other hemoglobinopathies. These contracts totaled \$368,200 in 2021-22. DHS treatment and services expenditures also include the critical congenital heart disease screening program administered by the

UW School of Medicine and Public Health, which received \$92,800 in 2021-22. In addition to these treatment and services contracts, DHS expended \$258,500 for administration of the program, including data management and outreach. DHS primarily contracts with the State Laboratory to perform these administrative functions.

9. The State Laboratory reports that approximately 125 to 140 babies born in Wisconsin each year are found to have one of the 48 disorders detected by the blood screening. In 2021, an additional 94 newborns had hearing loss detected by the hearing screening program, and the heart screening identified 111 cases of critical congenital heart disease.

10. The DHS program provides ongoing special dietary treatment for people with one of the congenital metabolic disorders included in the screening or cystic fibrosis, and supports ongoing treatment for people with one of the included congenital hemoglobinopathies, such as sickle cell disease. In some cases, these treatment programs serve adults as well as children. Table 2 summarizes the number of patients served by the congenital disorder treatment programs in 2021, the most recent year available.

TABLE 2

2021 Congenital Disorder Treatment Programs Caseload

<u>Congenital Disorder Type</u>	<u>Children</u>	<u>Adults</u>	<u>Total</u>
Metabolic	357	242	599
Cystic Fibrosis	345	117	462
Hemoglobinopathies	<u>268</u>	<u>9</u>	<u>277</u>
Total	970	368	1,338

11. DHS estimates that, in 2022-23, its PR-funded program costs will total \$4,006,200, consisting of \$2,170,900 for special dietary products (for patients with metabolic disorders and cystic fibrosis), \$1,409,200 for ongoing clinical care for all types of congenital disorders, and \$426,200 for program administration, including outreach to hospitals and other partner organizations and data management and analysis. DHS estimates that total program costs will increase by 2% per year to \$4,086,300 in 2023-24 and \$4,168,100 in 2024-25.

12. Under the DHS estimates, expenditures in 2024-25 will exceed revenues by \$1,669,600. Correcting this structural deficit by increasing fee revenue would require a \$33 increase in the amount DHS receives from each card. Such an increase would be in addition to any change made to provide increased revenue to the State Laboratory. Because the number of screenings is expected to continue declining while treatment costs continue to increase, regular fee increases would be necessary beyond this biennium. For example, meeting the forecasted structural deficit of \$1,937,000 in 2026-27 would require \$40 per card above the current fee level. These forecasted expenditure levels are within the current appropriation limits of the PR appropriations that fund the program (\$5,966,600 total), so it is not necessary to increase the base PR appropriations for the program.

13. Newborn screening programs and the services provided vary from state to state, including in the number and type of disorders they can identify. The structure and funding of most states' programs are broadly similar to Wisconsin's, however, including the reliance on fee revenue collected for each test performed. For comparison, Michigan's fee per newborn is currently \$144.50 and Iowa's is \$122, and in both states the fee revenue supports similar testing, coordination, and referral services.

14. In light of the public health benefits of the program, and to reduce the need to increase the blood collection card fee, the Committee could determine that GPR is an appropriate fund source to support congenital disorder treatments and services. As proposed in AB 43/SB 70, the Committee could create a new GPR appropriation for this purpose, provide \$1,491,500 GPR in 2023-24 and \$1,669,600 GPR in 2024-25 to address the structural deficit arising from the declining revenues and increasing program costs, and provide an additional \$2,064,800 GPR in 2023-24 to eliminate the projected PR deficit at the close of 2022-23. [Alternative 1]

15. Alternatively, the Committee could decide that the congenital disorders program should continue to be supported by revenue from the blood collection card fee, paid by hospitals and other providers and typically reimbursed, as part of birthing services, by health plans. The Committee could, as part of the budget bill, modify the administrative rule to increase the screening card fee by any amount or establish a minimum fee in statute and grant rule-making authority to implement this change. An increase of \$33, effective for screening cards purchased on or after July 1, 2023, would meet the anticipated costs in the 2023-25 biennium. [Alternative 3]

16. In conjunction with a fee increase (Alternative 3), or independent of any other action (Alternative 5), the Committee could provide a one-time revenue transfer from the General Fund in 2023-24 to address the estimated negative balance of \$2,064,800 at the close of 2022-23.

17. To address the estimated negative balance at the close of 2022-23 as well as meet the anticipated costs in the 2023-25 biennium without transferring or appropriating any money from the general fund, the Committee could provide a larger fee increase. An increase of \$50, effective for screening cards purchased on or after July 1, 2023, would eliminate the negative balance by the close of 2024-25, and generate revenue sufficient to meet estimated expenditures for several subsequent years. [Alternative 4]

18. The Committee could provide any combination of a fee increase and GPR funding to support the program. For example, the Committee could increase the blood collection card fee by \$16, effective immediately, to fund approximately half of the estimated structural deficit in 2024-25 (increasing PR revenues to DHS by approximately \$856,000 in 2023-24 and \$824,200 in 2024-25) and provide \$2,700,300 GPR in 2023-24 and \$845,400 GPR in 2024-25 to address the projected 2022-23 shortfall and the remaining share of ongoing costs. [Alternative 2]

19. In recognition of DHS's current authority to adjust the screening card fee in rule as necessary, and the unsupported overdraft plan recommending doing so, the Committee could take no action. This would be consistent with what the Administration sought and the Committee approved in addressing the unsupported overdraft request in January, 2023. [Alternative 6]

ALTERNATIVES

1. Provide \$3,556,300 GPR in 2023-24 and \$1,669,600 GPR in 2024-25 to increase funding for treatment, follow-up services, and administration of the DHS congenital disorder program. Create an annual GPR appropriation for this purpose.

ALT 1	Change to Base
GPR	\$5,225,900

2. Provide \$2,700,300 GPR in 2023-24 and \$845,400 GPR in 2024-25 to increase funding for treatment, follow-up services, and administration of the DHS congenital disorder program. Create an annual GPR appropriation for this purpose. Modify the administrative rule to increase the screening card fee by \$16. Increase estimates of program revenue DHS would collect to administer the program by \$856,000 in 2023-24 and \$824,200 in 2024-25. This increase would be intended to provide additional revenue only to the DHS program, and would be cumulative with any separate increase made to the fee to provide additional revenue to the State Laboratory.

ALT 2	Change to Base
GPR	\$3,545,700
PR-REV	\$1,680,200

3. Provide a one-time transfer in 2023-24 of \$2,064,800 from the General Fund to the PR appropriation that funds the DHS congenital disorder treatment program to address the projected appropriation deficit at the close of 2022-23. Modify the administrative rule to increase the screening card fee by \$33 effective for screening cards purchased on or after July 1, 2023. Increase estimates of program revenue DHS would collect to administer the program by \$1,765,500 in 2023-24 and by \$1,700,000 in 2024-25. This increase would be intended to provide additional revenue only to the DHS program, and would be cumulative with any separate increase made to the fee to provide additional revenue to the State Laboratory.

ALT 3	Change to Base
GPR-Transfer	\$2,064,800
PR-REV	\$3,465,500

4. Modify the administrative rule to increase the screening card fee by \$50 effective for screening cards purchased on or after July 1, 2023. Increase estimates of program revenue DHS would collect to administer the program by \$2,675,000 in 2023-24 and by \$2,575,700 in 2024-25. This increase would be intended to provide additional revenue only to the DHS program, and would be

cumulative with any separate increase made to the fee to provide additional revenue to the State Laboratory.

ALT 4	Change to Base
PR-REV	\$5,250,700

5. Provide a one-time transfer in 2023-24 of \$2,064,800 from the General Fund to the PR appropriation that funds the DHS congenital disorder treatment program to address the projected appropriation deficit at the close of 2022-23. Make no change to ongoing funding.

ALT 5	Change to Base
GPR-Transfer	\$2,064,800

6. Take no action.

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