



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

National Newborn Screening Stakeholder Workgroup

AGENCY: Health Resources and Services Administration (HRSA), Department of Health and Human Services.

ACTION: Notice of supplemental funding.

SUMMARY: HRSA provides funding to support a national center for newborn screening systems known as the National Center for Newborn Screening Systems Excellence (NBS Excel). In fiscal year 2026, supplemental funding is being provided to NBS Excel to establish a national newborn screening stakeholder workgroup. This workgroup will be a pathway for conditions to be considered and recommended for inclusion in the Recommended Uniform Screening Panel (RUSP) and to discuss national-level issues related to newborn screening. Membership will include representatives from a wide range of newborn screening experts and stakeholders. The award recipient will convene the workgroup and develop findings, reports, and recommendations for HRSA's review and consideration. HRSA will then make recommendations to the Secretary of Health and Human Services, who has final decision-making authority on updates to the RUSP.

FOR FURTHER INFORMATION CONTACT: Please contact the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, HRSA, at 301-443-0959 or nbsprograms@hrsa.gov.

SUPPLEMENTARY INFORMATION:

Intended Recipient(s) of the Award: Association of Public Health Laboratories

Amount of Non-competitive award: \$700,000; supplement funding for similar activities may be considered in fiscal year 2027, subject to the availability of funding for the activity and satisfactory performance of the recipient.

Project Period: July 1, 2023, to June 30, 2028

Assistance Listing Number: 93.110

Award Instrument: Supplement for Services

Authority: 42 U.S.C. § 300b-8 (Public Health Service Act §1109, as amended)

Table 1. Recipient(s) and Award Amount(s)

Grant Number	Award Recipient Name	City, State	Award Amount
U22MC24078	Association of Public Health Laboratories	Silver Spring, MD	\$700,000

Justification: Newborn screening is a successful public health program that saves lives and improves infants' health outcomes through early identification and treatment of heritable conditions. The newborn screening system relies on collaboration among families, state public health agencies, public health laboratories, and health care providers. States and territories screen over 3.6 million babies and identify approximately 12,900 infants with heritable conditions annually. Most states and territories screen for the majority of conditions on the RUSP, as recommended by the Secretary. As of May 2026, 85 percent of newborn screening programs screen for 35 out of 40 core RUSP conditions.

NBS Excel (HRSA-23-077) will establish a national newborn screening workgroup to support a new pathway for conditions to be considered for the RUSP. The RUSP is a national guideline that identifies conditions for which the Secretary recommends universal newborn screening. The RUSP contains 40 core conditions and 26 secondary conditions. Conditions listed on the RUSP are also part of the HRSA-supported preventive services guidelines for infants and children under section 2713 of the Public Health Service Act. As a result, non-grandfathered health plans are required to cover such screenings without patient cost-sharing beginning 1 year after the Secretary adopts a condition for screening. While states are not required to screen for every RUSP condition; the RUSP serves as a framework for state newborn screening programs. HRSA will focus on streamlining the review of candidate conditions to

support a more efficient, timely and evidence-based process. To inform the recommendations for potential conditions, independent evidence-based reviews will be conducted (supported by HRSA) for multiple conditions.

The recipient will also convene the national workgroup to address national newborn screening issues, including genomic sequencing, data collection, and other emerging topics. Membership will include representatives from a wide range of stakeholders, including but not limited to state newborn screening programs, family organizations, clinicians, researchers, laboratorians, and public health experts. Membership applications will be publicly announced by the recipient. The workgroup is expected to meet at least three times a year and be open to the public. Meeting information, including agendas, will be announced publicly in advance.

Under this new pathway, the award recipient will convene the workgroup and develop findings, reports, and recommendations to HRSA for review and consideration. As appropriate, HRSA may publish Federal Register notices to solicit and consider additional public input and stakeholder feedback as part of the federal review process. Following review of public comments and the award recipient's submissions, HRSA will make recommendations to the Secretary on the inclusion of conditions to the RUSP. The Secretary retains final authority over all RUSP updates.

HRSA will award \$700,000 to the recipient identified in Table I because the proposed activities directly align with the scope and objectives outlined in the Notice of Funding Opportunity for HRSA-23-077. The recipient currently serves as a national leader in newborn screening systems improvement by providing technical assistance, subject matter expertise, training, education, and quality improvement support to state newborn screening programs and stakeholders nationwide. The recipient has developed national resources and educational webinars that strengthen and support the newborn screening system. The recipient also convenes and leads expert workgroups focused on priority areas, including the use of health information technology and implementation of recently added RUSP conditions. This existing infrastructure,

technical expertise, and national reach position the recipient to effectively lead the proposed national workgroup and related activities. Providing supplemental funding is both timely and an efficient mechanism for advancing newborn screening activities at the national level.

Ann M. Sheehy,

Principal Deputy Administrator

[FR Doc. 2026-16396 Filed: 8/11/2026 8:45 am; Publication Date: 8/12/2026]