

Exhibit 1: Scope of Work

The *Wisconsin Congenital Disorder/Newborn Screening (NBS) Program* will provide follow up services that include enhancing the early hearing detection and intervention system of services and supports, short term follow up services, nutritional counseling and genetic counseling, care coordination and transition services for children who screen positive on the blood screening and their families, as well as communication and consultation on confirmatory testing with the patient's primary healthcare provider. It is expected that routine clinical care will be provided in accordance with standard clinical practice and reimbursed through routine mechanisms. However, significant care coordination including telehealth is required to manage these cases. The purpose of this contract is to provide salary support targeted towards enabling infrastructure in the form of follow up assistance, supporting services required to maximize health outcomes, ensuring return of data to the program, and enabling continuing improvement.

**Newborn Screening Program (Congenital Disorders) Contract Agency: Milwaukee Health Department (MHD), \$284,052**

**Contract Year: 2026 (July 1, 2025 – June 30, 2026)**

**Objective #1 of 4 – 60%**

**Goal: Reduce lost to follow up for infants who have barriers to screening, follow up care or services**

During the contract period, the Wisconsin State Laboratory of Hygiene (WSLH) Newborn Screening will refer infants who live in Wisconsin Southeast Region to the MHD when they need newborn blood screening specimen re-collection, or when primary care provider (PCP) information is not provided or providers are unreachable. Primary care providers may also refer babies to MHD for re-collections when families face significant barriers to returning to birth hospital for rescreen. Referrals from the WSLH or primary care providers will be triaged within four business days by the MHD. 95% of infants who are identified with a sickling disorder on newborn screening including infants with sickle cell disease, sickle beta thalassemia, or Hemoglobin SC disease, and are referred to the MHD, will be seen in the Children's Wisconsin Sickle Cell Clinic by four months of age.

MHD will coordinate, perform, and follow-up on newborn hearing screenings, including care coordination and on-site or in-home hearing screenings, for families in Southeastern WI who are at-risk for loss to follow-up. This includes following up with hospitals, midwives, birth centers, audiology clinics, and families through phone calls, emails, letters, and video meetings. MHD will conduct outreach to families or providers at least a minimum of 3 times to help ensure follow-up is completed when needed.

For hearing screening follow up, MHD will document outreach attempts in the admin case management form in WE-TRAC in a timely and accurate way. 98% of infants born in SE Wisconsin hospitals will receive their hearing screening by one month of age and 75% of infants will be identified with hearing loss by 3 months old or younger.

MHD will coordinate Critical Congenital Heart Disorders (CCHD) follow-up efforts with hospital and NICU staff, primary care providers, and midwives for infants born in Southeast WI to collect CCHD screening results and ensure the data is returned to the Screening Hearts in Newborns (SHINE) program within WE-TRAC.

Deliverable Due Date: 07/31/2026

### **Contract Deliverable (Evidence)**

A REDCap report will be provided to the Wisconsin NBS (Department of Health Services (DHS)) to document by birth date: 1) all infants with a sickling disorder who were referred to the City of Milwaukee Health Department, 2) date(s) of sickle cell clinic visits, 3) counseling and penicillin initiation, and 4) documentation of final result.

A REDCap report provided to the Wisconsin NBS Program (DHS) to document: 1) the number of infants rescreened by MHD through referrals generated by the Wisconsin Newborn Screening Program and primary care providers, and 2) the number of those infants who have an identified provider.

A WE-TRAC report will be provided to the Wisconsin NBS program (DHS) to document a minimum of five hearing screenings on infants having significant barriers to accessing care.

A WE-TRAC report will be provided to the Wisconsin NBS program (DHS) to document the collection of CCHD pulse oximetry results for 98% of babies born in Southeast WI hospitals.

Annually, a brief qualitative report will be written and provided to the Wisconsin NBS program (DHS) to share a success story from the MHD PHN's outreach to a specific family.

### **Input Activities**

#### **Blood Screening**

WSLH Newborn Screening or PCP identifies an infant who needs initial or repeat newborn blood screening and refers the baby to the MHD if the infant was born in the southeast region of Wisconsin. Once a referral is received by the MHD, the following steps will be taken:

- 1) The infant information is entered into MHD's electronic health record.
- 2) Provider and/or family are contacted to inform of need for initial/repeat screening and options for blood collection.
- 3) Outreach contact is entered into MHD electronic health record.
- 4) Screening is completed per family's preference and specimens are sent to WSLH.
- 5) Infant demographic information and screening results entered into REDCap.

If blood screening identifies hemoglobinopathy disorder, the following steps will be taken:

- 1) The PCP listed on the initial report is contacted to determine if the baby is accessing care through this physician;
- 2) When contact has been made with PCP, MHD Public Health Nurse (PHN) explains the need for a whole blood sample at around one month and that a kit will come from the

Wisconsin State Lab of Hygiene for specimen collection. *(Kits for follow-up hemoglobin testing are sent to the physician of any patient with a disease state at approximately three weeks after initial testing. Kits for follow-up testing on patients with HGB S or HGB C trait with an elevated A:S/C are mailed at approximately 3 months of age).*

3) The physician is advised to inform family of diagnosis and is encouraged to initiate penicillin therapy as soon as confirmation of the disease is established.

4) Once the disease is confirmed, the MHD PHN verifies that the infant has an appointment with the comprehensive clinic and is on penicillin.

The WSLH and PCP offices call or securely email referrals to the MHD. Based on the need of the case, care is planned by the MHD. Follow-up is sent to the WSLH by secure email or phone call. The WSLH can contact the PHN assigned to NBS when assistance is needed.

### Hearing Screening

As WE-TRAC identifies an infant in Southeast WI who needs initial or repeat newborn hearing screening, an audiologic evaluation, or a referral to early intervention, the MHD will follow up with providers and the family. Once a case is assigned in WE-TRAC, the following steps will be taken:

- 1) The MHD will follow up with the midwife, birth center, or hospital unit to determine if the data has been collected.
- 2) The MHD will follow up with the PCP to see if there has been a discussion with the family about the next step in the newborn hearing screening protocol.
- 3) The MHD will follow up with the family to see if they need resources or assistance to schedule an appointment or understand the next step.
- 4) The MHD will make sure all children with a diagnosis of a hearing difference are referred to their local Birth to 3 program for early intervention.

### CCHD Screening

As WE-TRAC identifies an infant who needs initial CCHD screening, the MHD will reach out to the midwife, birth center, hospital unit, or PCP to ensure the return of data to the SHINE program within WE-TRAC. The following steps will be taken:

- 1) The MHD will follow up with the provider or organization where the baby was born to gather a pass or fail result from pulse oximetry.
- 2) The MHD will monitor pulse ox fails or Confirmed Heart Disease cases in WE-TRAC to assure they get moved to the SHINE queue for clinical follow-up.

### **Objective #2 of 4 – 15%**

#### **Goal: Explore collaboration and care coordination opportunities for patients with sickle cell disorders.**

During the contract period, the MHD will explore working with organizations like the Wisconsin Sickle Cell Clinic or Sickle Cell Warriors to support families with infants newly diagnosed with sickle cell disease or a sickling disorder. This potential work could include meeting with families, offering home visits, providing family education, exploring youth health transition, reviewing best practices, and completing an environmental scan. The goals of this collaboration would be to assess barriers to care, learning deficits and overall family needs.

MHD will share findings to the NBS Program (DHS) at quarterly check-in meetings. The findings might incorporate recommendations for next steps for the upcoming year.

Deliverable Due Date: 07/31/2026

#### **Contract Deliverable (Evidence)**

The MHD staff will document their work completed and meet with DHS newborn screening staff on a regular basis to check in and show progress on their work.

#### **Input Activities**

The MHD will work as needed with the Wisconsin Sickle Cell Clinic to support families with babies newly diagnosed with sickle cell disease or a sickling disorder.

#### **Objective #3 of 4 – 20%**

#### **Goal: Improve provider and family knowledge of NBS through education and outreach**

MHD will attend tabling events in Southeast WI, especially those with a focus on prenatal education. These events will include networking with providers, families, home visiting teams, and the Prenatal Care Coordination program. Prenatal education aims to empower expecting parents with knowledge and skills to navigate pregnancy, labor, delivery, and the early stages of parenting. Educating parents about NBS early will allow parents to ask questions or address any hesitations they have. MHD will share the most current newborn screening publications and help providers fill out print request forms as needed to offer materials in their office.

MHD will assist with training regional screeners of last resort who receive new (or new to them) hearing screening equipment. They will provide environmental and technical troubleshooting tips and tricks. This training may occur in person or online.

Deliverable Due Date: 07/31/2026

#### **Contract Deliverable (Evidence)**

MHD PHN staff will document six or more events attended and meet with DHS newborn screening staff on a regular basis to check in and share progress, successes, and challenges about this work. These might include conferences or expos, free hearing clinic events, Plain community birth attendant meetings, Guild of Midwives meetings, public health clinics or events, etc.

MHD staff will plan, coordinate, and offer training for new users of hearing screening equipment and how to conduct a newborn hearing screening as needed, promoting the importance of EHDI and all parts of newborn screening.

#### **Input Activities**

MHD will assist with distributing the most current newborn screening publications at exhibitor halls and tabling events in the community. MHD will represent the EHDI program

and/or the NBS program at six or more conferences or community events.

A report to document the outreach education efforts accomplished by the MHD, to include 1) when and where the Newborn Screening Display unit was shown, and 2) a list of speaking engagements that included newborn screening information, which includes the number of attendees.

During the contract period, outreach education efforts will be enhanced through MHD participating in prenatal education opportunities in Southeast WI by presenting on the importance of newborn screening to families and providers.

**Objective # 4 of 4 - 5%**

**Goal: Improve professional knowledge of NBS through articles, conferences, and webinars.**

In order to stay current in the NBS world, MHD staff will attend conferences, trainings, webinars or read articles that allow for learning and growth of their profession. These could be in the fields of genetics, newborn screening, public health, improving health outcomes, or any technical trainings of their choosing.

Deliverable Due Date: 07/31/2026

**Contract Deliverable (Evidence)**

The MHD staff will document the educational opportunities (at least one conference, training, webinar or the names/links of at least three articles) and meet with DHS newborn screening staff to check in and share knowledge gained by these educational opportunities. If a meeting is not necessary, sharing information with DHS staff over email is welcomed.

**Input Activities**

MHD will review conferences held in Wisconsin or nationally. Examples include: the Early Hearing Detection and Intervention Conference, Wisconsin Speech and Hearing Association Conference, Wisconsin Public Health Association conference, Circles of Life conference, Wisconsin Genetics Exchange, etc. MHD will represent the EHDI program and/or the NBS program at one conference or community event.

A summary of the key takeaways from the conference will be shared either over email or in a meeting with DHS staff. A short document can be provided summarizing three articles related to newborn screening or public health.