

**DIVISION OF PUBLIC HEALTH
DPH CONTRACT 27463
AMENDMENT 4**

The Department of Health Services, on behalf of the Division of Public Health and the Milwaukee City Health Department agree to amend their original agreement for the program(s) titled Congenital Disorders (Profile 128010) as follows:

Adjustment will be made to the Community Aids Reporting System (CARS) based on the information in the table below.

Agency #	Agency Type	Profile #	Current Contract Level	Contract Change Amount	New Contract Level	Contract Period
256107	660	128010	\$0	\$142,026	\$142,026	7/1/15-6/30/16

All other terms and conditions of the original agreement remain unchanged.

GRANTEE's Authorized Representative
Name:
Title:

Date

GRANTOR's Authorized Representative
Chuck J. Warzecha
Administrator / Deputy Administrator, Division of Public Health
Department of Health Services

Date

Exhibit 1: Scope of Work

The *Wisconsin Congenital Disorder/Newborn Screening Program* will provide follow up services that include confirmatory testing, nutritional counseling and genetic counseling, care coordination and transition services for affected children and their families, as well as communication 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 non-reimbursed face to face care coordination is required to manage these cases. The purpose of this grant is to provide follow up services, salary support targeted towards enabling infrastructure, supporting non-face to face services required to maximize health outcomes while minimizing stress, ensuring return of data to the program, and enabling continuing improvement.

Congenital Disorders/Newborn Screening Program Contract Agency: Milwaukee City Health Department, \$142,026 Contract Year: 2016

Objective #1 of 5

Objective Value: \$69, 550

During the contract period, 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 City of Milwaukee Health Department, will be seen in the Children's Hospital of Wisconsin Sickle Cell Clinic by four months of age.

Deliverable Due Date: 07/31/2016

Contract Deliverable (Evidence)

A SPHERE report 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.

Data Source for Measurement

SPHERE

During State Fiscal Year 2012, 100% of infants identified with Hemoglobin SC, SS or sickle beta thalassemia received care by four months.

Context

Screening of infants at birth for sickling disorders was initiated to assure comprehensive care and penicillin initiation early in life to prevent early death due to sepsis. In 1985, it was determined that identification of sickle cell disease at birth allowed for early initiation of penicillin therapy which prevented early death from sepsis. It is also important that parents caring for a child with sickle cell disease are informed of the importance of penicillin, temperature control, and immunization. In the beginning of the newborn screening program for sickle cell disease, over 50% of the infants did not get care prior to four months. This led to early death by sepsis for some infants because the

parents were unaware of the need for care and penicillin. When infants are seen in the comprehensive clinics, counseled about penicillin and what to do in case of an elevated temperature, the chance of early death is greatly diminished. This program has been successful in assuring that 99% of the infants born in the southeast region of Wisconsin obtain care by four months.

Input Activities

Newborn screening identifies an infant born with a sickling disorder and refers the baby to the City of Milwaukee Health Department (MHD) if the infant was born in the southeast region of Wisconsin. Once a referral is received by the MHD to identify an infant with a sickling disorder: 1) the infant is entered into the SPHERE database and care is planned; 2) The physician listed on the initial report is contacted to determine if the baby is accessing care through this physician; 3) If contact has been made with this doctor, the coordinator explains the need for a whole blood sample at around one month and that a kit will come from the State Lab for specimen collection. The physician is encouraged to begin penicillin as soon as confirmation of the disease is established. The number of the sickle cell clinic is given to the doctor and an explanation of the need for comprehensive care is explained. 4) Once the disease is confirmed, the coordinator verifies that the infant has an appointment with the comprehensive clinic and is on penicillin. 5) Once the appointment is kept in the clinic, the case is referred to a Public Health Nurse from the MHD and there are visits made to assure penicillin administration and that the parents understand sickle cell disease. 6) If a physician can not be confirmed shortly after birth, a different system is needed. A home visit for specimen collection is done, the specimen is sent to the State Lab of Hygiene and a physician for the infant is established. Once the specimen confirms disease, the same process occurs to obtain care and penicillin for the infant.

Definition of Percent Accomplished

0% Accomplishment

0% 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 City of Milwaukee Health Department, will be seen in the Children's Hospital of Wisconsin Sickle Cell Clinic by four months of age.

20% Accomplishment

19% 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 City of Milwaukee Health Department, will be seen in the Children's Hospital of Wisconsin Sickle Cell Clinic by four months of age.

40% Accomplishment

38% 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 City of Milwaukee Health Department, will be seen in the Children's Hospital of Wisconsin Sickle Cell Clinic by four months of age.

60% Accomplishment

57% 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 City of Milwaukee Health Department, will be seen in the Children's Hospital of Wisconsin Sickle Cell Clinic by four months of age.

80% Accomplishment

76% 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 City of Milwaukee Health Department, will be seen in the Children's Hospital of Wisconsin Sickle Cell Clinic by four months of age.

100% Accomplishment

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 City of Milwaukee Health Department, will be seen in the Children's Hospital of Wisconsin Sickle Cell Clinic by four months of age.

Objective #2 of 5

Objective Value: \$42,800

Throughout the contract period, 95% of referrals from the Wisconsin Newborn Screening Program will be triaged within two business days by the City of Milwaukee Health Department.

Deliverable Due Date: 07/31/2016

Contract Deliverable (Evidence)

A SPHERE report to document the number of infants referred to the City of Milwaukee Health Department (MHD) from the Wisconsin Newborn Screening Program, and the number of those infants who were triaged within two business days by MHD.

Data Source for Measurement

SPHERE

During State Fiscal Year 2006, there were 66 infants referred from the State Lab of Hygiene, and all were triaged within 2 days.

Context

It is important to maintain systems for early screening and rescreening to prevent complications of the disorders screened for through the Newborn Screening Program. Early detection is key and it may require more intervention and follow-up than is available through the Newborn Screening Lab in Madison. The City of Milwaukee Health Department provides home visits; which has been the key in rescreening infants, establishing a final result, and obtaining care.

Input Activities

The State Lab of Hygiene or the Department of Health and Family Services calls, faxes or mails referrals to the City of Milwaukee Health Department (MHD). Based on the need of the case, care is planned by the MHD. Follow-up is sent to the Newborn Screening (NBS) Lab by fax or phone call. The NBS Lab can contact the coordinator, Public Health Nurse assigned to NBS or the clinical assistant when assistance is needed.

Definition of Percent Accomplished

0% Accomplishment

0% of referrals from the Wisconsin Newborn Screening Program will be triaged within two business days by the City of Milwaukee Health Department.

20% Accomplishment

19% of referrals from the Wisconsin Newborn Screening Program will be triaged within two business days by the City of Milwaukee Health Department.

40% Accomplishment

38% of referrals from the Wisconsin Newborn Screening Program will be triaged within two business days by the City of Milwaukee Health Department.

60% Accomplishment

57% of referrals from the Wisconsin Newborn Screening Program will be triaged within two business days by the City of Milwaukee Health Department.

80% Accomplishment

76% Of referrals from the Wisconsin Newborn Screening Program will be triaged within two business days by the City of Milwaukee Health Department

100% Accomplishment

95% of referrals from the Wisconsin Newborn Screening Program will be triaged within two business days by the City of Milwaukee Health Department.

Objective #3 of 5

Objective Value: \$8,894.91

During the contract period, 90% of infants rescreened by the City of Milwaukee Health Department through referrals generated by the Wisconsin Newborn Screening Program will have an identified provider.

Deliverable Due Date: 07/31/2016

Contract Deliverable (Evidence)

A SPHERE report to document: 1) the number of infants rescreened by the City of Milwaukee Health Department through referrals generated by the Wisconsin Newborn Screening Program, and 2) the number of those infants who have an identified provider.

Data Source for Measurement

SPHERE

Baseline for Measurement

During State Fiscal Year 2006, 100% of infants screened by the City of Milwaukee Health Department who were referred by the State Lab of Hygiene for rescreening had an identified provider.

Context

Primary care for infants is an important part of medical care. Often children do not receive ongoing care from one physician, but receive sporadic care through emergency departments. When a child receives ongoing care from an established provider, immunizations are kept up-to-date, growth and development is established and ongoing

screening is possible. Often times, parents are unaware of the availability of a provider with their insurance, and when assisted, can begin to use a provider.

Input Activities

1) An infant is referred to the City of Milwaukee Health Department for rescreening. 2) A home visit is made to obtain a specimen. 3) A provider is determined for the infant. If the parent does not have an established provider for the infant, insurance is determined and appropriate referrals are made. Information on the provider is then indicated in the SPHERE database.

Definition of Percent Accomplished

0% Accomplishment

0% of infants screened by the City of Milwaukee Health Department through referrals generated by the Wisconsin Newborn Screening Program will have an identified provider.

20% Accomplishment

8% of infants screened by the City of Milwaukee Health Department through referrals generated by the Wisconsin Newborn Screening Program will have an identified provider.

40% Accomplishment

36% of infants screened by the City of Milwaukee Health Department through referrals generated by the Wisconsin Newborn Screening Program will have an identified provider.

60% Accomplishment

54% of infants screened by the City of Milwaukee Health Department through referrals generated by the Wisconsin Newborn Screening Program will have an identified provider.

80% Accomplishment

72% of infants screened by the City of Milwaukee Health Department through referrals generated by the Wisconsin Newborn Screening Program will have an identified provider.

100% Accomplishment

90% of infants screened by the City of Milwaukee Health Department through referrals generated by the Wisconsin Newborn Screening Program will have an identified provider.

Objective # 4 of 5

Objective Value: \$8,895.98

During the contract period, outreach education efforts will be enhanced through presentations by the City of Milwaukee Health Department of the Newborn Screening Display Unit at two conferences or health events, and integration of newborn screening information into six speaking engagements.

Deliverable Due Date: 07/31/2016

Contract Deliverable (Evidence)

A SPHERE report to document the outreach education efforts accomplished by the City of Milwaukee Health Department, 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.

Data Source for Measurement

SPHERE

Baseline for Measurement

During the State Fiscal Year 2006, the Newborn Screening Display Unit was shown at 4 conferences or events and newborn screening information was presented at 10 speaking engagements.

Context

Outreach education efforts have been a goal of the Wisconsin Newborn Screening Program. The display is important to increase the awareness by professionals of the Program.

Input Activities

The Newborn Screening Display unit will be shown at two conferences or events. Newborn screening information will be presented in at least six speaking engagements.

Definition of Percent Accomplished

0% Accomplishment

0% of outreach education efforts were enhanced through presentations by the City of Milwaukee Health Department of the Newborn Screening Display Unit at two conferences or health events, and integration of newborn screening information into six speaking engagements.

50% Accomplishment

50% of the outreach education efforts were conducted through presentations by the City of Milwaukee Health Department of the Newborn Screening Display Unit at two conferences or health events, and integration of newborn screening information into six speaking engagements.

100% Accomplishment

100% of the outreach education efforts were conducted through presentations by the City of Milwaukee Health Department of the Newborn Screening Display Unit at two conferences or health events, and integration of newborn screening information into six speaking engagements.

Objective # 5 of 5

Objective Value: \$11,885.56

90% of infants who are identified with a sickling disorder by newborn screening and are screened by the City of Milwaukee Health Department will receive at least one follow-up phone call and one follow-up visit from Department staff. All other babies who are identified with sickling disorders by Newborn Screening will receive at least one contact by either phone or home visit.

Deliverable Due Date: 07/31/2016

Contract Deliverable (Evidence)

A SPHERE report to document: 1) the number of infants diagnosed with a sickling disorder by newborn screening and referred to the City of Milwaukee Health Department, 2) the number of infants who receive a follow-up phone call from Department staff, and 3) the number of infants who receive a follow-up visit from Department staff.

Data Source for Measurement

SPHERE

Baseline for Measurement

During state fiscal year 2011 90% of infants who were identified with a sickling disorder by newborn screening and were screened by the City of Milwaukee Health Department received at least one follow-up phone call and one follow-up visit from Department staff. All other babies identified with sickling disorders by Newborn Screening received at least one contact by either phone or home visit.

Context

Infants identified with a sickling disorder receive proper medical care and treatment, but may still require assistance in identifying resources and obtaining non-medical care. The City of Milwaukee Health Department will follow-up with these infants and their families in order to ensure all necessary services are being received in the context of a medical home.

Input Activities

City of Milwaukee Health Department staff will track infants identified with a sickling disorder by newborn screening and referred to the Department. Department staff members will call families of each infant at least once to determine appropriate treatment and disease management is being obtained. Staff will also visit families of each infant at least once to determine same.

Definition of Percent Accomplished

0% Accomplishment

0% of infants who are identified with a sickling disorder by newborn screening and are screened by the City of Milwaukee Health Department will receive at least one follow-up phone call and one follow-up visit from Department staff. All other babies who are identified with sickling disorders by Newborn Screening will receive at least one contact by either phone or home visit.

20% Accomplishment

8% of infants who are identified with a sickling disorder by newborn screening and are screened by the City of Milwaukee Health Department will receive at least one follow-up phone call and one follow-up visit from Department staff. All other babies who are identified with sickling disorders by Newborn Screening will receive at least one contact by either phone or home visit.

40% Accomplishment

36% of infants who are identified with a sickling disorder by newborn screening and are screened by the City of Milwaukee Health Department will receive at least one follow-up phone call and one follow-up visit from Department staff. All other babies who are identified with sickling disorders by Newborn Screening will receive at least one contact by either phone or home visit.

60% Accomplishment

54% of infants who are identified with a sickling disorder by newborn screening and are screened by the City of Milwaukee Health Department will receive at least one follow-up phone call and one follow-up visit from Department staff. All other babies who are identified with sickling disorders by Newborn Screening will receive at least one contact by either phone or home visit.

80% Accomplishment

72% of infants who are identified with a sickling disorder by newborn screening and are screened by the City of Milwaukee Health Department will receive at least one follow-up phone call and one follow-up visit from Department staff. All other babies who are identified with sickling disorders by Newborn Screening will receive at least one contact by either phone or home visit.

100% Accomplishment

90% of infants who are identified with a sickling disorder by newborn screening and are screened by the City of Milwaukee Health Department will receive at least one follow-up phone call and one follow-up visit from Department staff. All other babies who are identified with sickling disorders by Newborn Screening will receive at least one contact by either phone or home visit.