Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Hemoglobinopathy Subcommittee Meeting
Tuesday, November 17, 2020
2:00-3:00 pm
Zoom: https://dhswi.zoom.us/j/95407001320?pwd=YVVEdVM1MDNmai90RjAzYndYTjI5Zz09
Or Call: +1 646 558 8656 or +1 301 715 8592
Meeting ID: 954 0700 1320 Passcode: 018362

Minutes

Meeting Invitees:

X	Dr. Mei Baker	X	Dr. Patrice Held		Dr. Jennifer Orozco
X	Dr. Jon Brandt	X	Tami Horzewski	X	Dr. Paul Scott
X	Dr. Carol Diamond	X	Dr. Michelle Manalang	X	LuAnn Weik
Meeting Guests:					
X	Dr. Ashima Singh				

Agenda:

Tuesday, November 17, 2020 2:00–3:00 PM				
Time:	**Topic:**	**Lead:**	**Follow-up Items:**	**Notes:**
2:00-2:05	Welcome and Review of Minutes	Dr. Scott		Motion to approve October 31, 2019 minutes: 1st motion: Dr. Carol Diamond 2nd motion: Dr. Mei Baker Motion approved.
2:05 – 2:10	Newborn Screening Program: Department of Health Services Updates	Tami Horzewski		Tami Horzewski shared the following DHS updates: • Spinal Muscular Atrophy was added by permanent rule in January 2020. • Pompe Disease was approved by the Secretary of DHS for addition to the Newborn Screening (NBS) panel of conditions. Pompe is

				currently going through the rule writing process. • Krabbe Disease recently went through the nomination process and the recommendation was to table a decision pending more information. The Secretary's Advisory Committee on Newborn Screening is finalizing their report for the Secretary of DHS. • The newborn screening program is working with our dietitians and clinics/centers to determine how to best implement the Medicaid policy for coverage of oral nutrition, which took effect on April 1, 2020. The Secretary's office directed the program to work on implementation of this policy for coverage of special dietary treatment within the newborn screening program. Policy implementation is also important to address given the direction to begin the blood card fee increase process. The fee increase is

				processed through administrative rule-making and will take up to 18-24 months. The NBS Program is in the very early stages of the rule-writing process for a blood collection card fee increase.
2:10 – 2:20	2019 Screening Summary	Dr. Baker		Mei summarized the 2019 screening positive cases. The incidence of SS and SC cases was similar to the ones in the previous years. There were three beta thalassemia major cases, which are more than we had in previous years, and likely resulted from the increased immigrants from South Asian countries.
2:20 – 2:40	CDC Grant to Combine Programmatic Data	Dr. Ashima Singh		Dr. Singh shared the following project summary below. The hope is to get all data together in a standardized manner to understand the natural history of SC Disease. There were questions about the need for IRB (the project is currently under IRB review, though there is question as to whether the project is considered "research"), would UW be able to share their data, and what steps are needed for DHS approval. A Data Use Agreement would be needed with DHS. Tami to provide contact information for Kelsey Stevenson, NBS Data

				Integration Specialist to follow up with Dr. Singh. The project data would be provided to the CDC. PROJECT ABSTRACT SUMMARY Sickle cell disease (SCD) is a rare genetic condition that affects approximately 100,000 individuals in the United States of America. The Newborn Screening Program exists in every state of the country to help identify babies born with SCD. However, there is no national surveillance system for SCD. This results in a lack of knowledge about the epidemiology and natural history of the disease. In addition to Newborn Screening data, there are various other existing data sources including Vital Records, State Medicaid data and electronic health records (EHR) data that can help identify individuals with SCD. These data collectively are a rich source to inform healthcare practices and health outcomes of those with SCD, however they are currently not linked. In this project we propose to establish a sickle cell data collection program, leveraging and

				linking the various data sources for the state of Wisconsin. Specifically, we will develop a Wisconsin SCD (WI-SCD) Registry, with individual level data linked from the State's Newborn Screening Laboratory, Vital Records, Medicaid, and EHR. The program will result in standardized data collection methods for all individuals with SCD in Wisconsin, which will be disseminated regularly in an aggregate manner. The proposed program will establish data collaborations from partners across the state of Wisconsin and engagement with stakeholders including researchers, clinicians, policy makers and individuals with SCD, to inform policies and improve health outcomes for individuals with SCD in Wisconsin. This will result in a comprehensive understanding of the epidemiology, clinical practices, laboratory result profiles and health outcomes for the SCD population in Wisconsin. Our proposed application has the unique strength of being able to link EHR data and data from state partners for the majority of

				individuals living with SCD in Wisconsin. The principal investigator (Singh) has extensive experience analyzing big data including EHR and Medicaid data for the SCD population, making her well-qualified to lead the proposed project. The co-Investigator (Panepinto) is a pediatric hematologist and a well-established researcher with multiple years of experience in health services research and SCD. All program personnel have worked together on numerous federally funded projects and have a track record of working efficiently as a team. The program team's distinct experience, along with engagement with SCD stakeholders, will ensure the success of the proposed WI-SCD Registry.
2:40 – 2:50 2:50 – 3:00	Update Guidelines for PCP's Who Refer Babies for Bart HGB on Newborn Screen Update NBS Hemoglobinopathy Brochures/Educational Materials as Needed	Dr. Scott All		There was a review of language in the Bart letter. Dr. Scott will be revising the letter with the suggested language and Tami will send out for subcommittee members to give their final input. Tami will also send out the list of hematology specialists for updates to be made to contact information as well as send

				out the current hemoglobinopathy-related brochures and educational materials for review to determine if any updates/edits are needed.
	Announcements			Dr. Diamond announced that Dr. Anne Marsh will be taking over administration of the Sickle Cell Program at UW and will be joining the hemoglobinopathy subcommittee.
3:00	Plan Next Meeting/Agenda Items			Tami will ask Dr. Scott for potential meeting dates for next fall 2021 and send out a doodle poll to the subcommittee.

“Parking Lot” Items: