Joint Advisory Committee for Newborn Bloodspot Screening
October 2, 2019 1:30-4:00pm, Room 16
Meeting Minutes

Members Present:	Frank Chessa, Mary Ellen Corrigan, Abigail D'Ambruoso, Meghan Dumas, MaryAnn Gordon, Maryann Harakall, Nola Metcalf, Jean Moreno, Jodi Philippon, Katherine Reilly, Holly Richards, Wendy Smith, Kassi Swallow, Anne Watson, Melissa Whitcomb
Members by Phone:	Caroline Bowman, Tom Brewster
Guests:	Sarah Webster-Mellon (CF Foundation)
Recorder:	Holly Richards

Welcome and Introductions	• Abby and Melissa welcomed everyone to the meeting and introductions were made. • Holly announced new seats: Colleen McCorkell (Public Health Nursing) and Jean Moreno (Birth Hospital Nurse)	
Committee Business	**Review the minutes** The 05-08-19 minutes were reviewed, and a few changes were noted needing changes. Holly will make those changes. **Follow up tasks from last meeting**	
Updates and Highlights	**Clinic Updates** Portland ○ Wendy talked about the beach day held for PKU family in the Summer in Northern Maine. ○ MaryAnn talked about PKU camp being held on September 14th. **Other Members** • No other updates	

NBS Program Updates	2019 newborn screening numbers to date (through September 30, 2019) Approximate Births: 8,601 a. Total Number of Out of Range Results: 389 i. Metabolic: 136 ii. Endocrine: 126 iii. CF: 40 iv. Hemoglobin: 135 v. SCID Initial: 22 vi. SCID: 0 b. Identified Cases: 17 i. Congenital Hypothyroidism: 4 ii. CAH: 0 iii. Cystic Fibrosis: 4 iv. Alpha Thalassemia: 1 v. PKU: 2 vi. MCAD: 2 vii. Tyrosinemia Type 1: 1 c. Incidental Findings: 26 i. CAT B CF: 30 (one was a gene mutation that was determine Cat C) ii. Sickle Cell Traits: 31 iii. Other Conditions: None d. Unsat Specimens: 171 New staff ○ Jordan Dean, Medical Secretary who started in July ○ Anne Watson, NBS Screening/MFIMR Coordinator who started 9/23 Medical Home Learning Collaborative ○ Maine was invited to participate in a 6-month long innovative Action Learning Collaborative designed for state Title V/Children and Youth with Special Health Care Needs programs. This collaborative will be focused on partnership building, social determinants of health screenings and referrals, addressing psychosocial factors, and medial home access to improve systems of services for CSHN and their families. NBS Rules ○ Holly stated the rules are still in process and are being combined to include all CSHN programs (birth defects, hearing, newborn bloodspot, CCHD, and the new law around preventative care for prophylactic ointment and vitamin K) Maine Newborn Screening Portal	

	○ A new data/surveillance system went out to bid and a new company, Nebulogic, won the bid. The contract began July 1st and October 1st the new system was launched to users. This system replaces ChildLink and is called the Maine Newborn Screening Portal.
	CMV
	○ Workgroup meeting will occur in November…focusing on educating families/providers then working on screening protocols.
	○ We have had around 5 requests for CMV testing vis the newborn bloodspot.
	Website
	• Our website has been updated but we are looking for new ways to make it even better.
	Midwife refusal
	○ Midwives started paying for the newborn screening filter papers.
	○ There have been 24 specimens submitted since January which isn't higher than normal.
	Professional Education
	○ Newborn Screening Tandem Mass Spectrometry Workshop for Follow-up Staff
	    ○ 10 states were chosen. Maine was chosen and Jodi will be attending in January.
	○ NERGG will be December 5tyh and 6th and Holly will be attending as she sits on the Board of Directors.
	New conditions
	    ○ Increase fee/notice to hospitals
	    ○ Conditions book or online resource
	    ○ The NBS program is participating in a SMA webinar series.
	    ○ We are in the process of updating all our SOPs
	Assistance Program
	    ○ CF $100,729.30 92/167 clients
	    ○ Metabolic $72,985.41 43/65 clients
	Data
	    ○ Annual Report for NBS Screening…the program would like to create one annually for our website and providers who might be interested.	

Public Comments	• Sarah from the CF Foundation introduced herself and was joining to hear more about the assistance program changes.	
JAC Membership	• Holly mentioned that we are still in need a social work seat and two more families. If anyone knows anyone who might these roles, please encourage them to join JAC.	
New Conditions discussion	• There was a discussion about the new conditions. Wendy and Megan volunteered to be a part of a sub-committee for looking at these.	Anne will set up a meeting after the holidays.

	• Holly shared the program's budget and talked about the need to increase the fee of filter papers to accommodate the new conditions.	
Other	• New England Consortium meeting is November 8th. Holly is going to work with administration to get approval for Anne to attend. • Meghan stated she could reach out to the CF foundation to see if any families were interested in joining JAC.	
Next meeting dates	**May 13, 2020, 1:30-4:00p.m. at Maine CDC, 286 Water Street, Augusta** **October 14, 2020, 1:30-4:00p.m. at Maine CDC, 286 Water Street, Augusta**	