



**Joint Advisory Committee for Newborn Bloodspot Screening
October 14, 2020 1:30-4:00
Virtual Meeting Minutes**

Members Present:	Kelley Bowden, Thomas Brewster, Barbara Chilmonczyk, Abigail D’Ambruoso, Mary Ann Gordon, Maryann Harakall, Deidre Hogan, Alex Marcotte, Colleen McCorkell, Nola Metcalfe, Jean Moreno, Jodi Philippon, Katherine Reilly, Holly Richards, Wendy Smith, Daniel Sobel, Kassie Swallow, Anne Watson, Melissa Whitcomb.
Members by Phone:	Meghan Dumas
Guests:	
Recorder:	Amy Fair

Welcome and Introductions	-New member Dee-Dee Hogan, a social worker with the Maine Children’s Cancer Center, working specifically supporting families with sickle cell. -Announcement that meeting was being recorded.	Abigail D’Ambruoso
Committee Business	-Correction for May 2020 meeting minutes: On the last page “Abby has emailed Erin Weiss” corrected to “Abby has emailed Dee-Dee Hogan who works with Erin Weiss. -Discussion and clarification of procedures governing the presence of the general public at virtual committee meetings – the meetings will be announced on the website with instructions for anyone interested to contact the ME NBS Coordinator. May 2020 meeting minutes were accepted with correction.	Abigail D’Ambruoso Daniel Sobel Amy Fair Holly Richards
Updates and Highlights	<u>Clinics</u> -The MMC metabolic program shifted to a significant amount of remote care due to COVID-19, but continued to see patients in person as needed. Several patients had just started therapies that required observation periods. The program successfully combined	Wendy Smith Dee-Dee Hogan Daniel Sobel Abby D’Ambruoso

in person and telehealth care for three new babies with PKU. Remote telehealth care worked out very well for many families as they did not need to travel long distances to the clinic. They are slowly ramping up to see more people in person. The Bangor Metabolic Clinic has been entirely virtually since March for a variety of different reasons, mainly because it hasn't been approved for Dr. Smith to travel there yet by MaineHealth.

-Medical staff at the Sickle Cell clinic not present at the meeting, but update from the clinic social worker was provided. The clinic has grown quite a bit over the past few years with the refugees and asylum seekers coming to the Portland area -from a population of 13 patients about 4 years ago, to almost 40 now. It is an ever-growing population and the staff are strategizing about how to meet all of the needs of these new patients. The main therapy for their patients is Hydroxyurea, and they are keeping up to date with colleagues in New England on other options. No Maine patients have been sent to transplant as the risk is so high, and there are some other drugs in the works that are in Phase 1 trials.

-No one from the CF clinics on the meeting.

NBS Program (see attached slides)

-UMMS Lab Screening Center – Updated ME NBS Policies and Procedures

-Discussion about process for rulemaking and the new conditions. Holly Richards will obtain more information, but it will involve a public hearing after the rules are reviewed. The new conditions may not be on the screening until the summer of 2021. The CDC/MCH monies for the new conditions has already been allotted and the cost of the filter papers will go from \$110 to \$220, the first increase since 2008.

-Grand Rounds at MMC planning for presentation on SMA therapies. The only Maine family that has obtained any of the new therapies had it done under a clinical trial (MRNA not gene therapy).

-Maine infant with SCID did not get transplanted after transfer to Boston – infant doing well and may have some sort of unknown variation that does not need transplant.

Website

-NBS staff would like to update the website. All Maine DHHS/CDC websites are in the process of major upgrading. They requested input from committee members. and it was suggested that linking to other websites with information (like APHL or Babies First Test) would be optimal.

Preventative Care for Infants

Anne Watson
Holly Richards
Melissa Whitcomb
Maryann Harakall
Kelley Bowden
Barbara Chilmonczyk
Nola Metcalf
Thomas Brewster
Jodi Philippon

	<p>Vitamin K and Erythromycin information was sent to JAC, along with the agenda, for informational purposes only. The NBS program is overseeing the program, including creating the rack cards and tracking refusals</p> <p><u>QI Reports to Hospitals (see slides attached)</u> -The Maine NBS program used to be able to send out reports to hospitals individually and have their performance on the QI measures compared to the group average. However, with the new tracking system that we are using for both hearing and bloodspot for Maine we have not been able to keep generating them. We are able to track missing or incorrect demographic data and fix.</p> <p><u>Confirmed Cases (see slides attached)</u></p> <p><u>2019 NBS Infographic (see slides attached)</u></p> <p><u>COVID 19</u> -The program may have to restart some of the continuity of operations procedures that were put into place last spring if things get worse this fall.</p>	
Public Comments	No members of the public in attendance.	
JAC Membership	<p>(see slide attached)</p> <ul style="list-style-type: none"> -New members representing social work -Need to bring on 2 more family members -Frank Chessa, Mary Ann Gordon, and Anne Watson will continue to work on filling the 2 family member spots. Both of our current parents have children with PKU. Attempts will be made to recruit a CF parent and an Endocrine parent. -Anne Watson noted that it is important to have representation from each specialty provider clinic at each meeting, and she will work with the clinics to ensure attendance, along with adding “Clinic Updates” as an official agenda item. 	<p>Anne Watson Mary Ann Gordon Abigail D’Ambruoso Meghan Dumas</p>
Other	-Discussion about Confidentiality Agreements: Forms sent out to committee members as Anne Watson had noted that they had been used before. Some committee members had concerns about signing; other members had concerns about having the public or reps from laboratory organizations or industry in attendance and whether they would understand HIPPA compliance. Anne Watson and Holly Richards will consult with the Attorney General’s office about this. When others are present and there is a need for	<p>Anne Watson Abby D’Ambruoso Holly Richards Melissa Whitcomb Kelley Bowden Wendy Smith Mary Ann Gordon</p>

	<p>confidentiality, we may be able to go into executive session and not need the confidentiality statements for members.</p> <p>-Additional discussion occurred about committee member efforts to get the new condition rulemaking completed sooner. The rules are being held up due to legal proceedings involving the governor over COVID issues. Committee members are welcome to try to push this along more quickly, but the NBS staff are not going to provide guidance as far as what should or should not be done. If members do take action, they were asked to cc the NBS staff on any contacts made. As decided earlier, Holly Richards will work to obtain as much information as possible about the process and timeline. Non-CDC committee members then discussed how they might pursue action (e.g., Dr. Smith talking to Dr. Mary Ottolini at Barbara Bush Children's).</p>	<p>Daniel Sobel Barbara Chilmeczyk Maryann Harakall Thomas Brewster</p>
<p>Next meeting dates</p>	<p>May 12, 2021 1:30-4:00 October 13, 2021 1:30-4:00</p>	