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**Joint Advisory Committee Maine Newborn Bloodspot Program
Meeting Minutes
Wednesday, May 12, 2021 1:30-4:00 p.m. ZOOM**

Welcome and Introductions	Individual introductions	Abigail D’Ambruoso
Committee Business	<p>Review and acceptance of minutes from 10-14-20 meeting,</p> <ul style="list-style-type: none"> • Repeat specimens, 12.7% this was through January 1st-September 30th. • 99.97% of Maine births in 2019 babies received a newborn bloodspot screen. (This percent corrected after the meeting – percent is 99.7) • Are these picked up on antenatal screening before they are picked up on bloodspot screening? No, not usually. The two cystic fibrosis screenings, for one family both parents were known carriers so this was suspected. The second was an unknown and there was no carrier testing during pregnancy. • Move to approve minutes Daniel Sobel, second MaryAnn Gordon. All in favor, no opposed. <p>Membership</p> <ul style="list-style-type: none"> • Tori Masters, mother is a child with CF joining the meeting today. <p>Refusals</p> <ul style="list-style-type: none"> • Legislation requires that any birth attendant explain the NBS program, the conditions included in the screening, and what can be missed that is treatable if the screening is not done. If a parent decides to refuse, the birth attendant must fill out the NBS refusal form within 5-7 days and have the parent sign and send to the office. • MCH tracks missing NBS refusal forms - letters are sent to the parents of babies with no NBS result or NBS refusal form. 	<p>Anne Watson Holly Richards Daniel Sobel MaryAnn Gordon Maryann Harakall Tori Masters</p>

- Plan to create a new post birth NBS refusal form to mail to parents that does not require the birth attendant's signature.
- Changes to be made to the NBS refusal form: 1) opening sentence to change "intellectual and developmental disabilities" to "serious illnesses which if identified early can be correctable"; 2) add that the baby could look and act fine at birth because many of these illnesses do not show clinical symptoms until later; 3) add a parent testimonial (probably of an infant with congenital hypothyroidism); 4) move "was I informed" to the beginning of letter; and 5) add option that these can also be submitted by email.
- Discussion about grant money to offset the costs of NBS. Cost is often a reason that parents refuse bloodspot screen when paying out of pocket, even though the only exception is supposed to be for religious beliefs and objections. Should JAC consider revising this part of the statute?
- Communications to look at this document to rework it to the appropriate reading level.
- Send comments for edits on NBS refusal form to Anne W.
- Tori Masters is willing to provide testimony for NBS.
- Holly will check to see if there are any funds to do some promotional material for NBS.

Confidentiality Agreements

- Worked with the Attorney General's office, these are not required. This is a public forum; we can go into a private session if we need to discuss something confidential.

Website

- Meeting was posted on the website.

COVID –

- CDC CSHN Staff were redeployed to do COVID-related work. As of now, all NBS staff are back and not reassigned. Our care coordinator is still averaging 18-20 hours a week on COVID-related business. Staff still working remotely, tentative early July return to office although specifics have not yet been decided.

	<ul style="list-style-type: none"> No specimen collection changes for NBS filter papers for COVID positive patients. 	
New Conditions	<ul style="list-style-type: none"> No changes to the current specimen collection practices when added the new conditions. We have worked with the lab and providers as the conditions have been added. SMA – normal results will be reported sooner than abnormal. All abnormal results will be called out to genetics/metabolic and PCP with request for RFP. Started testing for new conditions as of April 1, 2021. Public comment has come and gone and there were no issues raised. Filter paper cost has doubled to cover the cost of these conditions and to cover the shortfall of the program. We had our first call out, actively dealing with a case who has the IDUA enzyme (related to Pompe and MPS-1) level below 15%. 	Holly Richards Anne Watson Jodi Philippon
Updates and Highlights	<p>Portland Metabolic Clinic</p> <ul style="list-style-type: none"> 4 new diagnosed babies in the clinic. Because some babies were born during the pandemic, they still brought them into the clinic for in person visits and have also had telehealth follow up with families. Haven't been able to do camp due to the pandemic. Wendy Smith has been doing telehealth in the Bangor clinic throughout the pandemic. <p>NBS Program</p> <ul style="list-style-type: none"> We have been able to streamline processes with respect to electronically faxing vs mailing NBS hospital reports. SOP's have been updated and doing QI projects. <p>APHL Data for 2020 (preliminary)</p> <ul style="list-style-type: none"> 11341 babies screened, 550 babies with OOR results 99% collected within the correct timeframe Days lapsed between sample collection and date received <ul style="list-style-type: none"> <2 days: 52.7% 2 days: 25.5% 3 days: 15.3% 4 days: 4.5% 5 days: 1.2% 	Wendy Smith Meghan Dumas Holly Richards Anne Watson

	<p>>6 days: 0.3%</p> <ul style="list-style-type: none"> • UNSATs (e.g., poor soak, clotted, contaminated) 24/26 Maine Birth Hospitals <=3% • 72.1% of mothers plan to breastfeed only • Maine Newborn Bloodspot identified confirmed cases • Conditions N <table> <tr> <td>Congenital Adrenal Hyperplasia</td> <td>1</td> </tr> <tr> <td>Congenital Hypothyroidism</td> <td>23</td> </tr> <tr> <td>Cystic Fibrosis</td> <td>4</td> </tr> <tr> <td>PKU</td> <td>3</td> </tr> <tr> <td>Hb-SS</td> <td>4</td> </tr> <tr> <td>Classic Galactosemia</td> <td>1</td> </tr> <tr> <td>Total</td> <td>36</td> </tr> </table>	Congenital Adrenal Hyperplasia	1	Congenital Hypothyroidism	23	Cystic Fibrosis	4	PKU	3	Hb-SS	4	Classic Galactosemia	1	Total	36	
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Public Comments	<ul style="list-style-type: none"> • Tori is interested in becoming a member of JAC 	Tori Masters														
Wrap-Up	<p>Dates for upcoming meetings (Meetings are the 2nd Wednesday from 1:30-4 in May & October)</p> <ul style="list-style-type: none"> • October 13, 2021, 1:30-4:00 pm • May 11, 2022, 1:30-4:00 pm 	Abigail D'Ambruoso														