



**Joint Advisory Committee for Newborn Bloodspot Screening  
May 8, 2019 1:30-4:00pm, Room 12  
Meeting Minutes**

<b>Members Present:</b>	Abigail D'Ambruoso, MaryAnn Gordon, Jerri Olshan, Jodi Philippon, Katherine Reilly, Holly Richards, Wendy Smith, Jeff Stone, Kassi Swallow, Melissa Whitcomb
<b>Members by Phone:</b>	Kelley Bowden, Caroline Bowman, Tom Brewster, Meghan Dumas, Dan Sobel
<b>Guests:</b>	Emily Besse (Parent), Matthew Guilbault (Novartis), Denise Osgood (Maine CDC), Katrina Patel (Biogen), Molly Perry (Parent), Jack Quinn (Sanofi)
<b>Recorder:</b>	Holly Richards

<b>Welcome and Introductions</b>	<ul style="list-style-type: none"> <li>• Holly welcomed everyone to the meeting and introductions were made.</li> <li>• MaryAnn Gordon agreed to facilitate the meeting since there are no co-chairs.</li> <li>• Holly announced both Laurie Brooks and Kelley Wheeler are no longer able to serve in their roles.</li> </ul>	
<b>Committee Business</b>	<p><b>Review the minutes</b> The 10-09-18 minutes were reviewed, and a few changes were noted needing changes:</p> <ul style="list-style-type: none"> <li>• Maryann stated there is not a chair and a co-chair but two co-chairs.</li> </ul> <p><b>Follow up tasks from last meeting</b></p> <ul style="list-style-type: none"> <li>• Holly stated she was having a hard time reaching suggested new members but announced there were three new members to JAC: Dr. Katherine Reilly (Pediatrician, Pen Bay Medical Center), Dr. Jeffrey Stone (Pediatrician, Waterville Pediatrics), and Frank Chessa (Medical Ethicist, Maine Medical Center)</li> </ul>	

	<ul style="list-style-type: none"> <li>• Holly will reach out to someone in Public Health Nursing.</li> <li>• Holly checked in with the AG's office and you will now see a public comment added for those when the public attends JAC meetings.</li> </ul> <p><b>Co-Chairs Discussion</b></p> <ul style="list-style-type: none"> <li>• Holly announced that Laurie Brooks is no longer able to serve in her co-chair capacity.</li> <li>• MaryAnn encouraged new members to consider being a co-chair and stated one needed to be a professional and one needed to be a parent. She expressed that what this entails is that ensure meeting flows with pertinent items discussed, being mindful of the clock (time keeper/facilitator) and seek feedback.</li> <li>• Jerri nominated Wendy, but she declined.</li> <li>• Holly stated people could think about it and email her with an interest.</li> <li>• Melissa stated she would be willing to serve in the parent role as co-chair and Abigail stated she would be willing to serve in the professional role as co-chair.</li> </ul>	<p>Holly will send out new member information to new members.</p>
<p><b>Updates and Highlights</b></p>	<p><b>Clinic Updates</b> Portland</p> <ul style="list-style-type: none"> <li>• Kassi stated thee was 1 baby with Tyrosinemia Type 1</li> <li>• Wendy stated there has been a flurry of MCAD and VLCAD markers.</li> <li>• Kassi stated that MaineCare is now covering food and formula for metabolic clients and its going well for those who have ordered so far. Holly stated that she tried to encourage other DME's to participate but only Herron and Smith in NH has responded and currently are the only DME vendor for MaineCare.</li> <li>• Wendy stated that the Bangor clinic is struggling staff wise.</li> </ul> <p><b>Other Members</b></p> <ul style="list-style-type: none"> <li>• No other updates</li> </ul>	
<p><b>NBS Program Updates</b></p>	<p><b>Program Updates</b> Holly shared data from the program for the period of January 1, 2019-April 30, 2019.</p> <ul style="list-style-type: none"> <li>• 2018 to date: <ul style="list-style-type: none"> <li>a. Approximate Births: 3,721</li> <li>b. Total Number of Out of Range Results: 170 <ul style="list-style-type: none"> <li>i. Metabolic: 57</li> </ul> </li> </ul> </li> </ul>	

- ii. Endocrine: 46
- iii. CF: 19
- iv. Hemoglobin: 48
- v. SCID Initial: 7
- vi. SCID: 0
- c. Identified Cases: 8
  - i. Congenital Hypothyroidism: 4
  - ii. CAH: 0
  - iii. Cystic Fibrosis: 1
  - iv. Beta Thalassemia: 1
  - v. MVAD: 1
  - vi. Tyrosinemia Type 1: 1
- d. Incidental Findings: 26
  - i. CAT B CF: 13
  - ii. Sickle Cell Traits: 13
  - iii. Other Conditions: None
- e. Unsat Specimens: 79

**Staff Updates/Introductions**

- Holly introduced Jodi Philippon who is the Newborn Screening Follow-up Nurse and began in the program in January.
- Holly reported that the Newborn Screening Coordinator's position is now vacant.
- Holly introduced Denise Osgood, Director of Division of Disease Prevention. Denise is sitting in for Maryann Harakall who was unable to join us.
- Holly announced a new Care Coordinator, Pam Martin has been hired. Pam was the medical secretary for the program for almost two years before accepting this new role.

**Program Updates**

- MaineCare's coverage for individuals prescribed specially modified low-protein foods is now final and children and adults are being covered through this process. The program is still enrolling clients over from our assistance program to MaineCare coverage.
- Dr. Pezzullo who was MaineCare's Medical Director, no longer works for the Department. The program thanks him for all his hard work working for the programs.

**APHL Database MOU update**

- All data is updated through 2017 in this data repository. Holly reiterated for new member that repository is a centralized secure database that is designed for state newborn screening programs to explore data to meet local program needs (Quality Indicators). The collection of data at the national level allows for quality improvements in the newborn screening.

**NBS Rules update**

- Holly will begin working on updating the rules add the four conditions approved as well as increasing the fees for the filter paper.

**Upcoming Conferences**

- June 3-6, 2019 Association of Public Health Laboratories (APHL) annual meeting in St. Louis, Missouri.
- November 8, 2019 New England Consortium Annual Meeting in Boston Massachusetts.
- December 5-6, 2019 New England Regional Genetics Group (NERGG) will hold their annual meeting in Portsmouth, New Hampshire.
- May 12-13, 2020 NewSTEPS National New Disorders Meeting

**Assistance Program**

- Denise began the conversation by stating the program and CDC leadership have been meeting with the Commissioner's office and AG's office to look at statutory language, rules, budget etc.... for having an assistance program. Denise talked about how all the issues raised from this group have been brought forward to DHHS Leadership. She stated the bigger picture is what should our role be long term for Children with Special health Needs?
- Wendy talked about the stop/gap issues for families with high deductibles. She feels the easiest way to remedy the issue to use assistance program and MaineCare
- Tom stated that many states use Medicaid for Assistance/Care Coordination.
- MaryAnn talked about how self-insured companies often refuse to cover food and formula.
- Holly mentioned the other avenues that the program investigated: WIC and Office of Family Independence (TANF) for coverages but not an end all for folks.

	<ul style="list-style-type: none"> <li>Holly stated changes would be occurring to the assistance program, but it was not ending completely. She said for now, we aren't having clients re-enroll, they will remain on the program until changes occur. True care coordination will now be occurring now that Pam is hired.</li> </ul> <p><b>Clinic Visits</b></p> <ul style="list-style-type: none"> <li>Holly announced that she has set up site visits with the MMC clinic for her staff and herself. Some staff have attended, and it was enriching to see how the clinics are run and some are scheduled to attend within the next month.</li> </ul> <p><b>Midwives</b></p> <ul style="list-style-type: none"> <li>Holly announced that the program would begin charging midwives for filter papers such as the hospitals get charged. This change is likely to occur in July.</li> <li>Midwives are supposed to be licensed by January 2020 but there are no updates on what the status of that is.</li> </ul>	
<b>Public Comments</b>	<p>There were five guests present all interested in SMA being added to Maine's newborn screening panel.</p> <ul style="list-style-type: none"> <li>Emily Bessey from Hallowell is a parent who shared her story of a child who passed away from SMA.</li> <li>Molly Perry from Harpswell is a parent who shared her story of her child who has SMA and how she was diagnosed. She talked about the Spinraza drug from Biogen which is \$2 million dollars for treatment and the first drug approved to treat children and adults with SMA.</li> </ul>	
<b>New Conditions</b>	<ul style="list-style-type: none"> <li>Jerri stated that the JAC approved adding MPS-1, Pompei, and X-ALD and suggested the committee vote to approve SMA. The committee unanimously voted to add SMA.</li> <li>Holly talked about from the program side that adding the four new conditions was going to cost over \$400,000 in just laboratory costs. The remedy will be to increase the filter paper costs. No cost increases have occurred since 2008.</li> <li>Jerri talked about system inadequacies for treatment.</li> <li>Wendy talk about the process for adding the new conditions on the RUSP (Recommended Universal Screening Panel).</li> <li>Holly stated once a newborn screening coordinator was hired, they would be taking the lead on getting these four new conditions added; including education process for new conditions (AAP, Birth Hospitals, Midwives, PCPs).</li> </ul>	<p>Holly will begin the process for increasing fees.</p> <p>Jodi will work on program SOPs this summer.</p>

	<ul style="list-style-type: none"> <li>• Holly will start the rule making process to increase the fees to accommodate the new conditions.</li> <li>• Jodi will begin to work on a draft this summer of SOPs for the program for these new conditions.</li> </ul>	
<b>Other</b>	<ul style="list-style-type: none"> <li>• Kelley encouraged people to look at Baby's First Steps website (app for desktop and smartphone.</li> <li>• Wendy stated that our information on Genes.RS is wrong. It had a former Newborn Screening Coordinator listed. Holly stated she has tried to reach out to Genes.RS six times to get the information corrected and has had no luck reaching anyone.</li> <li>• Jerri mentioned that Jeanne Parker, RN in Endo is interested in participating in JAC.</li> <li>• MaryAnn asked to have minutes/agendas put on the program's website for JAC meeting.</li> <li>• Meghan stated she could reach out to the CF foundation to see if any families were interested in joining JAC.</li> <li>• Wendy stated we need other parents from CAH,</li> <li>• The committee wants to change the next meeting from October 9<sup>th</sup> to October 2<sup>nd</sup>.</li> </ul>	<p>Holly will continue to follow up with Genes.RS to get contact information changed.</p> <p>Holly will reserve a room for October 2<sup>nd</sup> and will send a meeting invite out the group so its on members calendars who use outlook.</p> <p>Holly will follow up with Jeanne to see of her interest.</p> <p>Holly will get minutes/agendas up on the website.</p> <p>Meghan to reach out to CF Foundation.</p>
<b>Next meeting dates</b>	<p><b>October 2, 2019, 1:30-4:00 p.m. at Maine CDC, 286 Water Street, Augusta</b></p> <p><b>May 13, 2020, 1:30-4:00p.m. at Maine CDC, 286 Water Street, Augusta</b></p>	

