

Newborn Screening Work Group Meeting

Wednesday, April 22, 2009

3:30-4:30 pm

Attendees: Jamey Kendall (KS), JoAnn Bolick (AR), Julie Miller (NE), Leslie Himstedt (AR), Lucy Fossen (SD), Jackie Whitfield (AR), John Adams (Ontario), Julie Raburn-Miller (MO), Linda Williams (KS), Stan Berberich (IA), Sarah Groenveld (SD), Annette Arnold (AR)

Staff: Shona Whitehead

Meeting Summary:

Agenda Item	Discussion	Action
Welcome/Attendance		
Report from Stan Berberich	<ul style="list-style-type: none"> • NBS Collection and Reporting Forms—the left column is the information on the Iowa form, and the other columns indicated the difference in each state’s form. Stan asked the group if this is an important topic to be discussed at the NBS workshop next week in Lincoln. Those on the call agreed it was important. • Emergency Preparedness National Work Group—recent meeting in Bethesda, MD. Stan reported it was a continuation of topics previously discussed, specifically back-up contingency not just for the labs, but also STFU and LTFU, including what to do about those who need access to special foods. <p>Federal level funding for the NBS Saves Lives Act was discuss.</p> <p>The CDC has also been told to create a preparedness plan, but Stan hasn’t seen the final plan. Early drafts showed the plan was more like a contingency plan rather than a true preparedness plan. However, it did show gaps in services.</p> <p>Stan shared with the National Work Group the work being done by MO and IA. He pointed out the intent was to show if a need for back-up was necessary it could be done smoothly. He also discussed that Memorandums of Understanding (MOU) could be limiting in sates even after a law is passed allowing the Depts of Health to enter MOU, because the other state has to have the same law. The only solution is EMAC, but that doesn’t allow for redundancy. Redundancy without harmonization is useless.</p> <p>John Adams asked if the National Work Group had included access to prescriptions in</p>	<p>Stan requested that in advance to the workshop, each state look at the data fields on the form and ask:</p> <ul style="list-style-type: none"> • Why is this data collected? • What is the purpose of the data? • Who uses the data? <p>States are also asked to send any educational materials (already created) that are used to explain why the data is collected to Shona at shona-whitehead@ouhsc.edu by 5:00 pm on Friday, April 24. Materials will be distributed at the NBS workshop.</p> <p>Additionally, States are asked to send any educational materials regarding access to formula in emergencies or disasters to Shona at shona-whitehead@ouhsc.edu by 5:00 pm on Friday, April 24. Materials will be distributed at the NBS workshop.</p>

Agenda Item	Discussion	Action
	<p>its preparedness in the scope of its discussions. Stan indicated that the group felt there was no clear solution at this time, but is looking at other models.</p> <p>John commented that in disasters families are likely to be scattered, but could reconnect through a specific advocacy group. Stan responded that Genetic Alliance and ACMG are looking at some type of web access to help families reconnect.</p> <p>Annette Arnold asked if most pharmacies carry the special food formulas. Jamey Kendall responded that most often it is special ordered by pharmacies and Julie Raburn-Miller also said that most small pharmacies don't have it or get it from the distributor.</p> <p>Julie Raburn-Miller said that she had distributed information to the tertiary centers in MO regarding formula. Julie Miller asked if states have this type of information materials developed and are willing to share to also send it to Shona for the NBS workshop.</p>	
NBS Workshop	<p>NBS Workshop—April 30 and May 1 in Lincoln, NE</p> <p>Requested information regarding satisfactory and unsatisfactory specimens has been received from AR, NE, MO and ND. See attached for information request.</p> <p>For NBS workshop attendees staying at the Embassy Suites, confirmation numbers were sent out this morning, April 22nd.</p> <p>The Embassy Suites offers a courtesy shuttle to/from the hotel. The phone to call the shuttle is located by baggage claim.</p>	<p>Please send --Example reports (minus identifying information) of quality assurance reports provided to specimen submitters (may include info beyond quality of specimens) and other requested information --to Shona at shona-whitehead@ouhsc.edu by 5:00 pm Friday, April 24th. Materials will be distributed at workshop.</p>
Supplemental HRSA Funding	<p>Lori will provide more information at a later date. But indicated that "it looks good, but no final word".</p>	<p>The HRCC is seeking bids from companies or individuals to conduct a multi-state data system/linkage needs assessment. For more information contact Lori at lori-williamson@ouhsc.edu.</p>
Application for LTFU project	<p>More details to follow from Lori.</p>	
Next meeting		<p>Wednesday, May 27, 2009</p>

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