

Newborn Screening Work Group Meeting

Wednesday, January 27, 2010
3:30- 4:30 pm—Conference Call

Summary

Members: Jackie Whitfield (AR), Leslie Himstedt (AR), Kim Turner (IA), Colleen Peterson (KS), Julie Raburn-Miller (MO) Patrick Hopkins (MO), Karen Eveans (NE), Sarah Groeneveld (SD), JoAnn Bolick (AR), Jamey Kendall (KS), Casey Mullins (OK), John Adams (ON); Marcia Valbracht (IA)

Staff: John Mulvihill and Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
NBS Summit Update	Not discussed: Amy Brower unavailable Presentations and session recordings available online: http://www.geneticalliance.org/nbs.summit.agenda	
Data Linkage State Assessment: Update	Not discussed: Amy Brower unavailable	
IBEM-IS Meeting in Chicago: Update	Not discussed: Dawn Peck unavailable	
NBS Spring Workshop	Agreed dates for the workshop in Kansas City are April 8-9, 2010. Heartland will reimburse up to 3 people per state to attend (2 lab and 1 LTFU), plus the state genetics coordinator. Possible agenda items include: <ul style="list-style-type: none"> • Disaster preparedness • Blood spot repository • Review of blood spot card harmonization Addition of SCID to recommended panel; and other conditions suggested by states <ul style="list-style-type: none"> ○ “Steps to implement SCID” and budgetary costs ○ How to panel additions change current practices in the lab and clinic ○ SCID assay in premie babies—now what? Who do you refer them to for treatment if not available in your state • Guest speaker suggestions: Gary Hoffman, Mary Baker or Rebecca Buckley 	Please send agenda ideas or suggestions for meeting locations in Kansas City to Shona Whitehead at shona-whitehead@ouhsc.edu .

Agenda Item	Discussion	Action
Priorities for Next Project Year (FY 10-11)	<ul style="list-style-type: none"> • Next step in back-up drills—splitting the specimens between states • Expanding the NBS Program Exchange to include the labs (for example; if OK is to add biotinidase, other labs may be able to learn from their implementation plan) 	Please send project ideas for FY 10-11 to Shona Whitehead at shona-whitehead@ouhsc.edu .
Other business	John Adams suggested looking at the Jeffery Modell Foundation website for a resources list of clinical services for SCID and other Primary Immunodeficiencies. http://www.info4pi.org/	
Next meeting		February 24, 2010--3:30 pm