Heartland Genetics and Newborn Screening Collaborative

Advisory Board Meeting
Annual Conference—Sioux Falls, South Dakota
Wednesday, September 10, 2008—4:00- 6:30 pm
Summary

Members: Leslie Himstedt, Amy Brower, Lucy Fossen, Jamey Kendall, Jackie Whitfield, Kim Piper, Mary Riske, Sharmini Rogers, Holly Johnson, Larry Weatherford, Teresa Willige, Gina Direnzo-Coffey, Sharon Vaz,
Ex Officio: John Mulvihill and Lori Williamson
Other Attendees: Kayla Tinker, Jeanne Egger, Merlin Butler, Sookyung Shin, Tonya McCallister, Glenda Matthews, Colleen Peterson, Julie Rayburn-Miller, Kyna Byerly and Jill Shuger

Agenda Item	Discussion	Action
Introductions		

Review of Advocates' Project Review Protocol	• Discussion re: weighting advocate score in the total score. Conclusion: 30% no matter how many advocates are involved in the review process.
	
	• Changes suggested in the wording of #3,4,6
	
	    ○ Inclusion of investment from family background—change wording to make it broader
	
	    ○ Change #6 to "…proposal demonstrates likelihood of…"
	
	• Include feasibility into #3
	
	    ○ Language on publishing; feasibility of further funding, extension; national impact; feasibility and scientific merit
	
	• What about the number advocates? Is three too many? Have one as the lead or maybe up to three
	
	• Proposal should also outline how to publicize the project (manuscript, poster, media, etc…)
	
	• All proposals should have letters of support; those could come from advocates to demonstrate advocate involvement in the project
	
	• Any changes in the review protocol should be checked against the guidance for
		Lori Williamson will send out suggested changes to board for final review

Agenda Item	Discussion	Action
	consistency • Is there bias of advocates for disease in their family?	
Review of Heartland Regional Strategic Plan	• Consensus was that the core content was still good…that is, it can still serve as a timely guide; therefore, any changes to the document will be updating and reformatting • John Mulvihill suggested to update to reflect growth, expansion of mission and staffing as needed; rather than a re-write • Amy Brower suggested review work groups and the possibility of adding one related to the national focus on translational research • Merlin Butler suggested consider transition and lifestyle/life span of patients, since treated patients are living longer, adding it is a possibility not a mandate • Better to do a smaller number of projects really well versus a larger number	Board members are to review the content and submit edits to Lori by October 27th. Topic to be discussed at next meeting

Agenda Item	Discussion	Action

Evaluation Activities	• National common measures
	
	    • HRSA would like evaluation of collaborative as a whole
	
	    • Comment from the board was requested re: data collection for the national set of common measures.
	    • Lori Williamson has collected some baseline measures for D1, E2, E3 and G1
	    • Question raised about B1—is it the number of new visits? New referrals? Or just all visits? Missouri has centers report unduplicated number of services
	    • Question raised about E1—what does number of distance strategies implemented by Heartland mean? Does it mean initiated or started with input from Heartland?
	
	• Heartland evaluation plan
	
	    • Draft of the Heartland evaluation plan was presented to the board for review and comment. Roxane had to resign due to health reasons so another evaluator will be hired and the work completed.
	
	• HRSA Office of Performance Review site visit
	
	    • HRSA OPR site visit October 8-9. Board solicited for ideas of performance measures to discuss. Prioritization will take place over email.
	
	    • List of possible concepts to measure:
	
	        ▪ Consistency in NBS results reporting
	
	        ▪ Awareness of medical home
	
	        ▪ PCP education (just-in-time)
	
	        ▪ Public policy and education advances (genetics education days at capitols)
		National common measures --Lori Williamson will contact each SGC who will then collect the data for the 08 year and will announce on listserve, newsletter, and website that members need to let SGCs know of any activity. Lori will also clarify measures before contacting SGCs.
		
		Heartland Evaluation Plan—please send any comments to Lori Williamson

Agenda Item	Discussion	Action
	▪ Advocacy (involvement, growth, empowerment)	
	▪ Genetics training	
	▪ Capacity of states	
	▪ Communication	
	▪ Networking	
	▪ Shared resources and ideas	
	▪ Laboratory training opportunities	
	▪ NBS fully expanded to core panel	
	▪ Emergency preparedness	
	▪ Funding for research	
	▪ Funding for state plans	
	▪ National participation and collaboration	
	▪ Awareness of genetics in other state public health programs	

Agenda Item	Discussion	Action

Priorities for 2009-2010	Due to ever tightening budgets and many projects that we have, the Board needs to think about prioritizing the projects and activities. This is a conversation that we will continue to have over the next two months before we submit the new budget and plan for FY 09-10.
	
	• Pilot project program
	
	    • Pilot Project Program? Do we keep it? Consensus was yes, but communication from the RC needs to be better about long-term outcomes of the pilot projects and from the investigators to the RC. A web bibliography of all publications and presentations in the region. This would also be good topic for the NCC newsletter so we could learn about projects and outcomes in other regions. Information should be posted to the web and collected in the members-only area on the Heartland website. The eNewsletter would also be a good forum to communicate long-term outcomes of the pilot projects.
	
	• Sarah Lawrence program
	
	    • Sarah Lawrence Program? Do we keep it? Consensus was yes. Next application cycle will not be until 2010. Consider making partial funding an option so we can send more than one individual each year.
	
	• Growth opportunities--Heartland needs to develop a collaborative research infrastructure in order to be positioned for external funding opportunities.
	
	    • Collaborative research
	
	        • NBS Saves Lives Act
	
	    • Sharing cost information
		Sara Lawrence Program—RCC should consider partial funding so that we can send more than one person each year; seek external support; and, request trainees to do a workshop for Heartland collaborative members.
		
		Collaborative research and sharing cost information not discussed

Agenda Item	Discussion	Action
	• Other ideas???	