

**EHDI Follow-up Workgroup Telemeeting**  
**Thursday, July 30, 2009 ~ 11am CT/ 12 pm ET**  
**1 866/ 489-0573; \*4545164\***

<b>Lead:</b> Gary Hoffman	<b>Facilitator:</b> Sally J. Hiner, Region 4 Genetics Collaborative Senior Project Coordinator
<b>Participating:</b> Gail Tanner, IL; Molly Pope, IN; Joan Ehrhardt, Michelle Garcia, MI; Yaoli Li, MN; Gary Hoffman, Ravi Shah, WI; Sally Hiner, Region 4.	
<b>Meeting Goals</b>	
<ul style="list-style-type: none"> <li>• Workgroup will           <ul style="list-style-type: none"> <li>○ continue development of an Action Guide to increase referrals for Genetic Services</li> <li>○ Identify next steps</li> </ul> </li> </ul>	

Item	Discussion/ Notes	Recommendation/ Action	Follow up (who/ when)
I. State Roll Call – Hoffman			
II. Meeting			
A. Materials Overview (Hiner)	H.O.#1 Meeting Guide H.O.#2 Action Guide Intro H.O.#3 Recommended Referral Guidelines H.O.#4 Encounters/ Opportunities H.O.#5 Provider Strategies H.O.#6 Tools	H.O.#5 has #6 in the header. This will be fixed and re-posted.	Hiner 07.31.09
B. Agenda Additions – (Hoffman/ Group)	None		
III. Developing the Action Plan – Hiner/ Members			
A. Activities Update	Since we last met, Sally went through all workgroup outputs to-date and began to organize them into the tool kit/ action guide.		

Item	Discussion/ Notes	Recommendation/ Action	Follow up (who/ when)
B. Action Guide Intro (H.O.#2)	Sally asked the group to respond to whether or not this guide is targeted to increasing referrals for children with confirmed hearing loss only or also for children at-risk of hearing loss. This information was inconsistent across the various group outputs. What makes sense within the EHDI system?	Children who have risk factors for hearing loss also may benefit from a genetic referral. This is particularly true if there is a family history of hearing loss. However, these children are not followed up in EHDI systems at this time. Our action guide should focus on children with confirmed hearing loss.	
		<ul style="list-style-type: none"> <li>A statement in the introduction to suggest children with certain risk factors for hearing loss also may benefit from genetic services will be included. Guide will focus on children with confirmed hearing loss.</li> </ul>	Joan Ehrhardt 08.06.09
		<ul style="list-style-type: none"> <li>Workgroup review and comment on revised into</li> </ul>	Sally disseminate 08.07.09 Group review and comment 08.15.09
C. Referral Guidelines (H.O. #3)	The group briefly reviewed the most current draft of the referral guidelines. What to expect/ happens at a genetic referral was removed from the referral guidelines – this is beyond the scope of what this group can influence and is more appropriate as a tool to communicate to families and providers what happens at a genetic referral	Change Commission to Committee, Add see Tools section for state resources	Sally 07.31.09
		Send out for review and comment	Sally 08.07.09
		Review and comment	08.15.09
D. Encounters/ Opportunities (H.O. #4)	The group briefly reviewed this document - No suggestions received	Send out for review and comment	Sally 08.07.09
		Review and comment	08.15.09
E. Provider Opportunities (H.O.#5)	Provider opportunities were reviewed. Sally did not identify any activities for	Draft EHDI actions	Molly 08.07.09

Item	Discussion/ Notes	Recommendation/ Action	Follow up (who/ when)
	EHDI in any of our outputs. Otolologists and ENT are the same.	Combine ENT and otologists	Sally 07.3109
<p>F. Tools/ Resources</p> <p>a. Does the State To State Protocol go in the Guide?</p>	<p>This is a list of the strategies the workgroup has identified over time to increase referrals for genetic services.</p> <p>Sally noted that she did not include the state-to-state protocols in the guide. Group consensus – they are not appropriate for the guide as they focus on communication between EHDI programs on all kids having UNHS</p>	<p>Identify resources to adapt. The group split up the tools and will forward identified resources for adapting. Some suggested tools still will need volunteers to identify existing sources/ resources for. –</p> <p>MedPage Today and Hands and Voices may provide us with additional ideas/ resources</p> <p>Michelle suggested some workgroup members may find it useful to put inquiries out through the CDC listserv.</p>	<p>Members report to Sally by 08.15</p> <p>FAQs- Yaoli          Family Brochures – Michelle          Physician Training – Molly          PCP Follow-up Guidelines – Ravi          Part C materials - Joan</p>
IV. Next Steps			
A. Immediate	Next steps are noted in the follow up column	All workgroup members will be asked to respond to materials disseminated for today's meeting.	07.3109
B. Long Term	Region 4 Staff have been brainstorming how to get workgroup products out to appropriate audiences. A project to support presentation of our guide at appropriate conference and meeting venues will be recommended to the Advisory Group for consideration to be supported with carryforward funding. Also, workgroup members should be thinking about ways we can work with providers to implement some of the actions. We could then do a follow-up evaluation to see if there has been a subsequent increase in referrals.		

Item	Discussion/ Notes	Recommendation/ Action	Follow up (who/ when)
Announcements			
Next Meeting	Thursday, August 20, 2009 11 m CT / 12 pm ET		

Notes by Hiner