

**EHDI Follow-up Workgroup Telemeeting**  
**Thursday, January 21, 1010 ~ 11 am 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> Molly Pope, IN; Kelly Daniel, KY; Joan Ehrhardt, Michelle King, MI; Yaoli Li, MN; Reena Kothari, Shelley Nottingham, Anna Starr, OH; Gary Hoffman, Ravi Shah, WI. Sally Hiner, R4.	
<b>Meeting Goals:</b> <ul style="list-style-type: none"> <li>○ <b>Workgroup will continue development of an Action Guide to increase referrals for Genetic Services</b> <ul style="list-style-type: none"> <li>▪ <b>Continue development of tools</b> <ul style="list-style-type: none"> <li>• <b>Review and finalize FAQs for physicians</b></li> <li>• <b>Review compiled action guide</b></li> <li>• <b>Identify stakeholders who should review the guide prior to release</b></li> </ul> </li> </ul> </li> </ul>	

Item	Discussion/Notes	Recommendation/Action	Follow up (who/when)
I. State Roll Call – Hoffman			
II. Updates			
A. EHDI Conference	Molly's abstract was sent to the workgroup, as requested.		
III. Developing the Action Guide – Hiner/Members			
A. FAQs for Physicians	Feedback received from 4 reviewers (one group of 3 and one individual) was compiled and sent back out to the group. Edits agreed upon were made by Hiner. Rename: Frequently Asked Questions (FAQs) about Newborn Hearing Screening, Hearing Loss and Referral to Genetics for Physicians Group suggested review by some Genetic Counselors	Finalize all edits  Send out to genetic counselors for review  Forward any additional edits/ comments	Hiner – 1/21/10  Hiner – 1/25/10  WG Members – 1/25/10
B. Compiled Action Guide	Hiner asked workgroup members to conduct a thorough critical review of content, organization and copy edit. Any thing else that should be included – opportunities, key providers, strategies, tools?	Review and comment	WG Members - 1/29

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C. Opportunities for genetic referral – EHDI is missing from this section	The group discussed. It would not be appropriate for EHDI to be included, as EHDI does not refer directly to genetic services, but do educate and provide information so that referrals happen.	N/A	N/A
D. Practice Guidelines for Physicians	<p>The group has, on and off discussed referral guidelines for physicians. One of our strategies is for physicians to develop or adapt practice guidelines that would be followed every time an infant with hearing loss is seen by the physician to ensure referral to genetic services is considered.</p> <p>Would the ACMG ACT sheets work?</p>	Joan Ehrhardt will work on this.	Ehrhardt – draft for 02/17/10 telemeeting
E. Referral Form	<p>Provider to provider “referral” to facilitate referral to genetic services is one of our strategies. We don’t have a tool for this, but have discussed having a referral form.</p> <p>All practitioners/practices seem to have their own referral form that they use when referring on or when someone is referring to them.</p>	<p>Revise this strategy to suggest including genetic referral on the practices standard referral form.</p> <p>Remove references to the tool from the action guide</p>	Hiner 01/15/10
F. What stakeholders should review the guide prior to release?	<p>Physicians</p> <p>OH volunteered to take to their advisory group (Feb5th)</p> <p>Is the information helpful? Are the tools useful? Is it user-friendly?</p>	<p>Review and comment on draft guide provided prior to this meeting</p> <p>Compile comments and include tools</p> <p>Send to WG members</p>	<p>Workgroup members 1/29/10</p> <p>Hiner 2/4/10</p>
<b>Announcements</b>			
Next Meeting	Thursday, February 17, 2010 11 1m CT / 12 pm ET	1/866/489-0573 *4545164*	