

Proposed Strategies for R4 EHDI Priorities

Issue / Strategies		WG Member Name	Lead
A. (Follow-up) Getting data back from Early Intervention/Part C Programs			
A1.	Develop a general brochure for Part C that discusses the importance of and need for genetic referrals for infants with diagnosed hearing loss		<input type="checkbox"/>
A2.	Develop a universal FAX back form to gather information on children with diagnosed hearing loss		<input type="checkbox"/>
B. (Referrals) Getting babies into diagnostic testing			
B1.	Regional training for audiologists regarding appropriate test protocols, including a section that directly addresses the genetic referral issues		<input type="checkbox"/>
B2.	Provide audiologists with a list of genetic contacts for each state or Region 4		<input type="checkbox"/>
B3	Develop a brief power point on genetic issues as it relates to children with diagnosed hearing loss for the EHDI programs in Region 4 to incorporate into the audiology trainings and college training programs		<input type="checkbox"/>
C. (Border Babies) Don't know about border baby births/NBS			
C1	Adopt Region 4 State to state Newborn Screening Guidelines for EHDI		<input type="checkbox"/>
C2	Continue to address the "sharing" of information between states in Region 4 (R4)		<input type="checkbox"/>
D. (Diagnosis) Following up with the PCP for older children – what is the scope of the EHDI program (after 1 Year of age)			
D1	Review spreadsheet developed by Joan		<input type="checkbox"/>
D2	Develop Region 4 guidelines for ways to obtain needed risk factor information		<input type="checkbox"/>
E. (Education) Educating practitioners about the importance of diagnostic testing			
E1	Develop Region 4 guidelines for physician follow-up of children with diagnosed hearing loss		<input type="checkbox"/>
E2	Develop a system for how this information could/should be disseminated to physicians in R4		<input type="checkbox"/>
F. (Education) Educating Practitioners about the urgency of repeat testing			
F1	Develop Region 4 Guidelines for babies who referred from UNHS for physician		<input type="checkbox"/>
F2	Develop a bullet point brochure for physicians that includes genetic referral information		<input type="checkbox"/>
F3	• Develop a system for how this information could/should be disseminated to physicians in R4		<input type="checkbox"/>
F4	• Power point (see above) could also be incorporated into any physician training		<input type="checkbox"/>
G. (Follow up) Getting PCPs to support re-screen and/or follow-up by encouraging the family			
G1	Develop Region 4 Guidelines for babies who referred from UNHS for physicians		<input type="checkbox"/>
G2	Develop a bullet point brochure for physicians that includes genetic referral information		<input type="checkbox"/>
G3	Develop a system for how this information could/should be disseminated to physicians in R		<input type="checkbox"/>
G4	Power point (see above) could also be incorporated into any physician training		<input type="checkbox"/>

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H. (Follow-up) Providing information to primary care providers at the time of identification – positive screen or reports		
H1	Develop Region 4 Guidelines for babies who referred from UNHS for physician	<input type="checkbox"/>
H2	Develop a bullet point brochure for physicians that includes genetic referral information	<input type="checkbox"/>
H3	Develop a system for how this information could/should be disseminated to physicians in R4	<input type="checkbox"/>
H4	Power point (see above) could also be incorporated into any physician training	<input type="checkbox"/>
I. (Follow-up) Providing information to family at the time of identification~ positive screen or report		
I1	Develop a general brochure for parents that discusses the importance of and need for genetic referrals for infants with diagnosed hearing loss	<input type="checkbox"/>
I2	Develop state specific brochures with genetic contact information	<input type="checkbox"/>
J. Other?		
	Specify	<input type="checkbox"/>
	Specify	<input type="checkbox"/>
	Specify	<input type="checkbox"/>