

Proposed Strategies for R4 EHDI Priorities

Issue / Strategies	Include?
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"/>
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"/>

Issue / Strategies	Include?
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?	
Collect data on the diagnoses children in each state ¹	<input type="checkbox"/>
Specify	<input type="checkbox"/>
Specify	<input type="checkbox"/>

¹ Collect data on the diagnosed children in each state
 Are they referred for genetics services
 Of those that are referred and receive counseling – what is the
 breakdown of syndromic vs. non-syndromic

Outcome: formulate how to better educate families, professionals and others in early intervention about genetics and hearing loss, etc.