

Hi to all!

I took our main priorities and tried to think of some concrete ideas that we could develop as a team to incorporate the genetics component into the EHDI process. I'm sure there are many other good ideas that I didn't think about, but perhaps we can use this as a starting point to move us in the right direction. Many of the ideas are repeated through out the document as the education priorities really seemed to overlap (at least to me) so it isn't quite as overwhelming as it first appears.

Thanks,

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Ideas for Region 4 Priorities

- A. **(Follow-up) Getting data back from Early Intervention/Part C Programs**
- **Develop a general brochure for Part C that discusses the importance of and need for genetic referrals for infants with diagnosed hearing loss**
 - **Develop a universal FAX back form to gather information on children with diagnosed hearing loss**
- B. **(Referrals) Getting babies into diagnostic testing**
- **Regional training for audiologists regarding appropriate test protocols, including a section that directly addresses the genetic referral issues**
 - **Provide audiologists with a list of genetic contacts for each state or Region 4**
 - **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**
- C. **(Border Babies) Don't know about border baby births/NBS**
- **Adopt Region 4 State to state Newborn Screening Guidelines for EHDI**
 - **Continue to address the "sharing" of information between states in Region 4**
- D. **(Diagnosis) Following up with the PCP for older children – what is the scope of the EHDI program (after 1 Year of age)**
- **Review spreadsheet developed by Joan**
 - **Develop Region 4 guidelines for ways to obtain needed risk factor information**
- E. **(Education) Educating practitioners about the importance of diagnostic testing**
- **Develop Region 4 guidelines for physician follow-up of children with diagnosed hearing loss**
 - **Develop a system for how this information could/should be disseminated to physicians in Region 4**
- F. **(Education) Educating Practitioners about the urgency of repeat testing**

- Develop Region 4 Guidelines for babies who referred from UNHS for physician
 - Develop a bullet point brochure for physicians that includes genetic referral information
 - Develop a system for how this information could/should be disseminated to physicians in the Region
 - Power point (see above) could also be incorporated into any physician training
- G. (Follow up) Getting PCPs to support re-screen and/or follow-up by encouraging the family
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 - Develop a system for how this information could/should be disseminated to physicians in the Region
 - Power point (see above) could also be incorporated into any physician training
- H. (Follow-up) Providing information to primary care providers at the time of identification – positive screen or reports
- Develop Region 4 Guidelines for babies who referred from UNHS for physician
 - Develop a bullet point brochure for physicians that includes genetic referral information
 - Develop a system for how this information could/should be disseminated to physicians in the Region
 - Power point (see above) could also be incorporated into any physician training
- I. (Follow-up) Providing information to family at the time of identification~ positive screen or report
- Develop a general brochure for parents that discusses the importance of and need for genetic referrals for infants with diagnosed hearing loss
 - Develop state specific brochures with genetic contact information