

MINUTES
STATE ADVISORY COUNCIL FOR EARLY IDENTIFICATION OF HEARING IMPAIRED
INFANTS

Quarterly Council Meeting
Thursday, January 21, 2016
411 South Prieur Steet,
Classroom 405
New Orleans, Louisiana 70802

COUNCIL MEMBERS PRESENT: Thiravat Choojitarom, Naomi DeDual, Gina Easterly, Linda Frantz, Juan Gershanik, Jill Guidry, Penny Hakim, Nancy Hicks, Anita Jeyakumar (by phone), Patti Moss, Staci Sullivan, and Alla Tarasyuk

GUESTS PRESENT: Terri Mohren, Jeanette Webb, Melinda Peat, Susannah Boudreaux, Tri Tran, Wendy Jumonville

The meeting was called to order by Dr. Choojitarom at 10:00 am. The minutes from the October 15, 2015 meeting were adjusted and approved with a unanimous vote of attending Council members. Council member attendees and guests introduced themselves.

Council Discussion of Old Business

PPEP Follow-up: Susan Boudreaux discussed there are currently 4 statewide staff persons and 210 families currently being served. You can see from the flyer pictures from many of the events hosted by PPEP over the last quarter. I was able to speak at the invitation of Wendy Jumonville to a group of senior audiology students, presented a webinar for FHF of Jefferson and presented at December RICC meeting in December in Monroe, as well as attended the Hearing for Life event in New Orleans at Ochsners. We also did two "how we hear" events. When we have children who might be the only child in their area with hearing aids, we go into their classroom and present to their peers and answer questions about the device, and we do in a celebratory way. We've even prepared a book and put it in the library about the things we talked about and did so that they can go back and read about it. We've continued to host about 4-5 activities per month throughout the state. We've had more families attend. We've also hosted more lunch n learns where we have the three cochlear implant companies come out and speak to the families with hands on activities. One of the representatives has even made home visits. We've also been accompanying families to audiological visits. Even the most educated parents have difficulty processing the information given at audiology visits. Many parents have expressed their appreciation for PPEP staff attending with them. Also our team has had an increase for advocacy for IEPs and IFSPs with some of

our Hands & Voices members. Often times if the parent doesn't have the strength and training to stay there and push, sometimes those things don't happen. We're really excited for the ASTra advocacy training so that parents can attend. We're also utilizing social media through Facebook to share information.

Dr. Gershanik suggested that information could be shared through Youtube videos and that their possibly be outreach to Spanish speaking families as well. Susannah expressed appreciation to Hands & Voices and Marbely Barahona for bridging that gap and helping to reach those families.

Nancy Hicks that Department of Education funds Families Helping Families across the state and they go to IEP meetings all the time and perhaps could be linked with them.

Dr. Jeyakumar shared that their program has concerns about the cochlear implant companies having access to families directly. They feel there is value in having an audiologist share information since they don't have a bias with a particular company so it is a more unbiased view that they get than what they get from the company which is very very biased. It's just something that they've noticed a pattern changes with their families. I would urge you to use caution as many of these companies can be quite pushy. Ms. Boudreaux shared that the reason they had invited them was to try to provide access to their families and invite all three so that they do not appear biased. Dr. Jeyakumar suggested caution.

Upcoming events sponsored by EHDI:

ASTra training is scheduled for next week in Baton Rouge. Currently we have 85 registered to attend. We are giving stipends to parents to attend. Each family only receives one stipend, and we have 39 stipends. So we have more than 39 families attending. We currently have parents, grandparents, speech therapists, teachers. We are very excited about this opportunity. On Monday, it is open to anyone registered. It is free. We have national speakers from Hands & Voices presenting on evaluations, regulations, rights and laws and IEPs specific to deaf and hard of children. Our last conference we had someone come from Families Helping Families come do IEPs and it was a general presentation for anyone with an IEP. This time it is specific to child with hearing loss. On Tuesday, we have a smaller group, we will have twelve people trained to be ASTra advocates, certified advocates and families will be able to request assistance specifically for deaf and hard of hearing kids for any issues or concerns, helping them prepare ahead of time to go to an IEP meeting prepared. Dr. Jeyakumar shared that she thinks this is a great program.

Then, our next big event is in New Orleans. The day the flyer went out we had 20 people register. Making an Impact: From Identification to Early Intervention. Initially we were calling it our early intervention conference, yet realized we wanted to involve everyone. We wanted to include audiologists, and may of the people who have

registered are audiologists. We also want families to be there. We want those providing early intervention services. It will be on Monday, February 22. On February 23-24, we will have all the teachers from PPEP, Bright School. The training on Tuesday and Wednesday will be very specific to those providing services to deaf and hard of hearing children – Birth through age 5. Certainly appropriate for those providing services to school age children, ie speech language pathologists, audiologists and early steps as well.

Hands & Voices. Shared information about annual fundraiser at RocknBowl. Opportunities for support through raffle tickets for Parade of Prizes and Sponsorship. this is an awesome event to see that many children all in one place, doing great and having a great time. Alla Tarasyuk asked about interpreters, and there will be interpreters available. Shared information about sponsorship opportunities for RocknBowl. The Council members individually donated for a group sponsorship at Gold level.

LTF/LTD Follow up Report: Jeanette Webb, followup coordinator reports: For the first time in two years our loss to followup rate is drastically going down. When last reported the data that has been registered with the CDC we were at nearly 32% overall LTF. Then in 2014, which has yet to be submitted to CDC it is down to 28% overall LTF. Overall LTF for 2013, which is our only legal data with quarters 1-3 and the overall is 26.9%, still too early for quarter 4. This handout shows the areas we are addressing: physicians, audiologists, hospitals and the families. What has impacted is the overall is our new LaEHDI Information System. More people are using it, reporting more timely, parents (who are employed), and our team. We are sending our information starting at three weeks of age and doing it consistently. Their response rate is much better. We are now sending out pending appointment fax when sending to primary provider to ask the physicians to remind and stress the importance of followup. We haven't compared to those who have appointments that have already passed. Our overall goal, Tri did this – is to improve by five percent each year to reach the goal they want us to reach. We are certain that next funding go around, funding will be tied to using quality improvement and having improved over three years. Grants are becoming competitive. That's a 15% increase from 2013 births to three quarters of 2015 – that's 5% over our yearly goal. It should be even lower by next council meeting. We feel LA EHDI system has been the catalyst for this change.

Melinda asked Jeanette to share comparison from national to state. Jeanette reports that 2013 was around 33-34% national average. Overall lost to followup has two components, they've been reported as lost to followup or their failed at the hospital and we have no documentation. What we've done is started sending out letters at six weeks of age. In years past, we were waiting til six months. Parents report they didn't know that they needed followup. It all goes back to the hospital and what they're letting the families know. Tri has some marvelous ideas through data matches.

Council Discussion of New Business

Audiologic Challenges: I wanted to share information about concerns that we have about some trends we've noticed with pediatric audiologists and wanted to report to you what we're doing. We receive this information from a variety of circumstances. One example is an audiologist who was sending a report to us. Basically some of the things we are seeing is incomplete testing, hearing loss not being identified and reported, particularly ABR testing, misdiagnosis of auditory neuropathy. One of the things we've started is Hot Topics. It's something like a newsletter, but not as detailed. It goes to the audiologists via email using an email called mailchimp. One of the topics this year was to remind audiologists what a complete ABR should look like. Here are the elements that should be in a complete ABR, and I'll post the standards from the American Academy of Audiology guidelines. That is just one of the ways we're addressing it. We're still not sure 100% that the people that need the Hot Topics are reading the Hot Topics. Another way is by letter to the audiologist, and Melinda has helped us with this. We are working on another to a second audiologist that will probably go out this month. These are very specific to the problems and concerns we are seeing. Secondly there were some hospitals that were having problems with the program supervisor in followup, so Jeanette and I are going to be work on a letter and possibly have Dr. Choo and the advisory council because that audiologist is not following through with that program supervision, so that's an idea there. Just wanted to let you know we're trying to address the issues. With the EHDI computer system we are able to see more things. We're really trying to push the upcoming conference to the audiologist because that is one way – we need to get some education out there. We talked with the Aud. Program here in New Orleans and talked about targeting those in programs there. On the way here I talked with the LaTech group, another Aud. program in Louisiana and partnering with them. I shared some concerns about what audiologists are not learning or not following through with when they get out in the real world.

EHDI Meeting: The EHDI meeting will be in San Diego, CA. Jeanette, Wendy, Terri, Melinda, and a parent will be going. There will be two poster sessions by two of Tri Tran's students there at the EHDI Conference.

Presentation/Webinar: Dr. Choojitrom shared about the presentation which he and Ian presented at the last EHDI meeting and the subsequent webinar to be presented February 18. The presentation speaks about a lot of the things we talked about with LTF, LTD, audiologic training, and repeat testing. Further, info on what CDC looks at, what we look at and how we look at the data in a novel way and see if it helps in addressing LTF and LTD. A new slide was added to talk about and show the overview process and demographic factors that affect all of this, but that medical factors may have more influence around newborn screening because of low birth weight, etc. We usually tend to work farther on the other side, program and process factors, reporting, method of testing and getting reports to the EHDI program. These are the three factors that we

are looking at to the audiologic testing. Age a newborn screening, age at followup and the total number of followups. Looking at the data really sheds light on audiologic information and testing and diagnosis. Wendy suggested that when ready to share this information publicly, it really goes back to the audiologists and educating them highlighting the information about more than one screening and the length of time between screening and diagnosis. Those two pieces of information are very important and perhaps we could share that in our email blasts, another education piece.

Next Advisory Council Meeting:

The next Advisory Council meeting will convene Thursday, April 21, 2016 from 10:00 with location to be announced in the Baton Rouge area.

Adjournment:

A motion to adjourn the meeting was made by Dr. Gershanik and seconded by Dr. Choojitarom. By unanimous vote the meeting was adjourned at 12:00 pm

Committee Meetings:

Committees met briefly.

