**MINUTES**

**STATE ADVISORY COUNCIL FOR EARLY IDENTIFICATION**

 **OF DEAF AND HARD OF HEARING INFANTS**

**Quarterly Council Meeting**

**Tuesday, April 27, 2018**

**LaPlace, Louisiana**

**COUNCIL MEMBERS PRESENT:** Marbely Barahona, Susannah Boudreaux, Gina Easterly, Sharon Gates, Jimmy Gore, Jay Isch, Sohit Kanotra, Melissa McConnell (by phone), Leigh Ann Norman, Thira Choojitarom

**COUNCIL MEMBERS ABSENT:** Ashley Nielsen

**GUESTS PRESENT:** Jill Guidry, Dawne McCabe, Terri Ibieta, Ashael Barahona

The meeting was called to order by Dr. Kanotra at 10:00 am. The minutes from the previous meeting were reviewed and approved as provided by motion of Dr. Kanotra and seconded by Gina Easterly with unanimous vote of attending Council members.

**Council Business:**

**Advisory Council Bylaws**.

Terri Ibieta led the discussion and review of Advisory Council Bylaws. Council members were provided a draft of the Bylaws. Corrections and modifications were discussed and noted. Council members will receive revised drafts with these in the coming weeks. Agreed upon changes will be made and revised Bylaws will be reviewed for Council approval at next Council meeting.

Discussions were also centered around the Newborn Hearing Screening Report form and brochures that are provided to families whose babies do not pass the screening at the hospital at time of discharge. Council members agree that hospitals consistently getting the right material to families is a key part of their focus at this point.

A query was made by Jay Isch as to the number of families of kids with hearing loss rejecting EHDI services when those services like Early Steps are offered. Terri clarified that no baby is identified at the hospital, only newborn hearing screenings occur there at the hospital. Identification of hearing loss occurs through outpatient audiology appointments. For newborn hearing screening, the terminology that is used is pass or further testing.

**Code of conduct / Professionalism** Dr. Kanotra discussed the need for a Code of Conduct for professionalism as to how Council members conduct themselves in Council meetings as well as outside of Council meetings. Of concern is how Council members conduct themselves in social media interactions as well. Council members should be very professional. Dr. Kanotra notes this is a very responsible Council, and that members should behave as such accordingly. Members agree that as advocates and representatives of the Council, there is a need to establish guidelines. Dr. Choo reminded Council members that all are bound by Rules of Ethics as Council members appointed by the Governor. Many of the rules are specific to receiving monetary gifts, but also that Council members may not speak out in favor or against legislation. Specifically, members may speak individually, but not mention any Council with respect to legislation. Council discussion also centered around social media; members agreed that it is unprofessional to mention the Council and speak negatively about EHDI or other related matters on social media. Members also agreed that unprofessionalism cannot be tolerated by Council members. Violations of such should be brought before the Council for action to be taken. Suggestion is also made that possibly there would be consideration by Council members for removal of that individual from the Council in extreme cases. Members also noted that it is a priority to develop a Code of Ethical Conduct that encompasses Council meetings and social media arenas continue to be developed.

**CMV**. Cytomegalovirus (CMV) is one of the leading causes of nongenetic hearing loss in children. Dr. Kanotra will forward more information on CMV to Council members. Dr. Choo provided an update on the initiative at Woman’s Hospital. Initally, Woman’s hospital was going to perform universal screening of CMV at birth, but has since switched to targeted CMV screenings through the NICU and well-baby nursery. Testing would occur in symptomatic congenital CMV. Additionally, there would be targeted testing for those not symptomatic. Several other states have done the targeted. Utah does universal CMV screening, and Texas does targeted screening. In order to qualify as congenital infection, the test must be done within two weeks of birth. Beyond that you can’t tell if it was acquired outside of the mother, from breast milk, from the environment, etc. There is difficulty with following this protocol with the capacity due to the timeliness of the testing. Cost is a factor as well, as the testing is expensive. Woman’s Hospital is trying to get the capacity to do the testing themselves instead of sending it off. In terms of therapeutics, the treatment they will use is valganciclovir for six months. Dr. Voelker is heading this initiative. She will hopefully be the new neonatologist for the council.

Informational queries by council members: It is estimated that up to 20% of late onset hearing loss is due to CMV. Other issues caused by congenital CMV are brain issues, respiratory, hematologic issues and even death. Others are non-symptomatic and since there is not universal screening, it is not known if CMV without symptoms causes issues later on. Is there a cure? No there is no cure, but there are two treatments – ganciclovir which is an IV medicine that you take for six weeks, and then there is an oral form, valganciclovir which you take for six months. There are still only studies that indicate effective, yet this is not well enough studied yet. There is a multi-state study called the Chimes study that is looking at those things. There is a national CMV conference in Vermont in September. The Council’s CMV subcommittee goals could be awareness and education to pediatricians and working towards getting CMV testing in our state.

**EHDI Facebook page**. Since people are on Facebook a considerable amount of time, it could prove to be a great avenue to provide information. Questions at this point are: is it feasible, who would manage, how as a council would contributions be made. Terri agrees that from a program perspective, it would be beneficial. As far as management, it would need a dedicated person responsible to do that (possibly two to three hours a week). Updates on that page would go directly to persons who ‘like’ the page, thus getting more info out there to consumers in the community. Gina Easterly mentions that there may be some restrictions since EHDI is part of Office of Public Health, Bureau of Family Health, and suggests discussing with the Communication Innovation and Action team to see what can be done. Terri will check into that.

**Brochure Committee**. Council members reviewed the Newborn Hearing Screening Report form (the pink form). Every hospital in Louisiana provides a copy of this form to parents with their newborn hearing screening results. Also, from this form, results are entered into LEERS and transmitted to EHDI nightly. Council members discussed reviewing and updating the back of the form with better language, absent connotations that might be associated with using terminology (risk should be changed to succeptible to be compliant with Act 417). Babies who leave the hospital needing further resting as outpatient, will receive additional information about the outpatient testing that is needed. Suggestion was made by LeighAnn Norman that possibly the last page could be changed in that if you check something on the first page, that it lines up with wording different on the last page (the parent copy) that would be easier for families to understand. Marbely Barahona provided input on keeping this language simple, family friendly, and to the point on what needs to be done. Terri also mentioned that the JCIH will be soon setting forth new recommendations, so all could be changed at the same time.

**LEAD-K legislation**. Language Equity and Acquisition for Deaf Kids (LEAD-K) will provide a mechanism to collect data on Deaf children’s language development. There will be 23 members on the Task Force to investigate mechanisms for assessing language in deaf kids. Often children with hearing loss are well below their hearing peers in language development. Dr. Choo asked Jay Isch to bring a copy of the new updated legislation to next Council meeting.

**Deaf Mentor Program**. There is currently no Deaf mentor program in Louisiana. Jay Isch shared that sharing information with families about all options would inform parents more fully. Marbely Barahona mentions that as a parent she would love to have Deaf role models for her son and other children in Louisiana. She also mentioned a concern that mentors would be unbiased. It is important that mentors remain mindful, not to tell parents or their children that the choices they make for their children are wrong. As parents of children with hearing loss, there is a process which parents go through when they learn their child is deaf. Some parents grieve, some go more slowly through the process than others. Marbely shared that when parents learn that their child has a hearing loss, parents may feel sad. It is not because there is something wrong with deafness or hearing loss, but parents are not expecting it. Marbely likens it to when parents learn their child has autism or has downs syndrome; they are not expecting it. They learn to embrace and love that. Having someone come to us and teach us what is Deaf, that is good and can be wonderful. Terri said that she will invite Ariel Bumbala to share information at the next Council meeting about the Deaf mentoring program in Louisiana.

**Hands & Voices update**. Jill Guidry shared Louisiana Hands & Voices annual report and information about the Lafayette Roller Derby team. Hands & Voices was chosen to receive donations as the feature nonprofit for their first bout. Also, we’re providing for interpreters for every Roller Derby bout this year in Lafayette, thanks to a generous donation earmarked for that. Summer activities are planned in various regions throughout the state this summer.

**Update on Council vacancies**. Currently vacancies exist for pediatrician and most recently for speech language pathologist due to Amy D’Alfonso moving out of state. Dr. Voelker, neonatologist, is in the process of recommendation and appointment to the Council.

**Next Advisory Council Meeting:**

The next Advisory Council meeting will convene on Friday, August 3, 2018 in Baton Rouge.

**Adjournment:**

A motion to adjourn the meeting was made by Dr. Choojitarom and seconded by Gina Easterly. By unanimous vote the meeting was adjourned.

