

**CAB Conference Call  
October 24, 2019  
12:00 EST  
Meeting Minutes**

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**Participants:**

<b>Andrea</b>	Jacobi Medical Center
<b>Anisa</b>	Harvard University
<b>Antionette</b>	University of Miami
<b>Carrie</b>	University of Colorado, Denver
<b>Claire</b>	Harvard University
<b>Delia</b>	University of Miami
<b>Emily</b>	FSTRF
<b>Exzavia</b>	Children's Diagnostic and Treatment Center
<b>Jarmel</b>	University of Illinois, Chicago
<b>Jennifer</b>	University of Colorado, Denver
<b>Julie</b>	Westat
<b>Kimbrae</b>	Texas Children's Hospital
<b>Kylie</b>	Texas Children's Hospital
<b>Latanya</b>	Tulane University
<b>Latonia</b>	University of Illinois, Chicago
<b>Lesley</b>	Texas Children's Hospital
<b>Liz</b>	Harvard University
<b>Megan</b>	Westat
<b>Peter</b>	San Diego State University
<b>Stephanie M.</b>	University of California, San Diego
<b>Stephanie S.</b>	University of Miami
<b>Veronica</b>	University of California, San Diego

• **APPROVAL OF MINUTES**

The minutes from the September 26, 2019 call were approved with no changes.

• **FEEDBACK ABOUT PHACS HEARING TESTS FOR THE HEARING AND LANGUAGE WORKING GROUP (WG)**

**Peter Torre** talked about the Hearing and Language WG. At the 2019 Fall Network Meeting, the Study Coordinators talked about difficulties scheduling hearing testing. **Megan** and **Stephanie M.** joined the Hearing and Language WG call earlier this month to talk about barriers to scheduling PHACS hearing testing appointments. **Stephanie** previously talked about how hearing testing can be hard to schedule. At some sites, hearing testing is done at a different clinic than the regular clinic. **Peter** asked the CAB about barriers to hearing testing.

**Kim** talked about hearing. Many CAB members at Texas Children's Hospital expressed concern about ringing in the ears. They also expressed concern about partial deafness. CAB members wondered whether HIV or long-term use of HIV medications may cause hearing issues. **Peter** talked about tinnitus (ringing in the ears). Researchers have not yet found out an exact cause for tinnitus. There are some known underlying causes of tinnitus. These include change in diet, caffeine use, and sodium intake. Medication changes and underlying causes can potentially cause tinnitus. There is also central tinnitus, which occurs in the brain. That is one of the reasons researchers have a hard time pinpointing the location and cause of tinnitus. There are also outside factors that can cause tinnitus. This includes listening to loud music. PHACS researchers get data on tinnitus through surveys. In the future, PHACS hopes to collect more data on tinnitus.

**Veronica** talked about hearing testing at the SMARTT 5-year-old study visit. This visit is very long. Typically, families have to complete the visit over a few days. This is because they need to do the regular assessment, ND testing, and hearing testing. **Veronica** recommended that the hearing testing be done at a different study visit since the 5-year-old study visit is so long.

**Carrie** talked about barriers to hearing testing. At the University of Colorado, Denver participants have to schedule hearing testing far in the future (as much as six months). This means families may have a hard time picking a date. If the visit is then missed, rescheduling may take many more months.

**Lesley** asked about which study visits have hearing testing. **Peter** explained that hearing testing was previously done in AMP. In SMARTT, hearing is tested at birth and at five years of age. Hearing testing in AMP Up is done using the Words-In-Noise test at Entry, Year 3, and Year 6. An assessment of hearing problems is only done via surveys in AMP Up Lite. The Hearing and Language WG is interested in doing more hearing testing in AMP Up. **Lesley** asked whether hearing testing done as part of routine clinical care can be used for PHACS. This would help families so that participants do not have to be re-tested. **Peter** explained that because hearing testing in PHACS is standardized for research purposes, it is unlikely that PHACS researchers can use data from outside hearing tests.

**Kim** talked about hearing loss related to listening to loud music and loud sounds. **Peter** explained that he studies hearing loss at San Diego State University. PHACS collects data on loud noise exposure through surveys in AMP Up.

**Kim** talked about family history and hearing problems. **Peter** explained that family history can be a risk factor. Genetic factors may be responsible for early onset hearing loss.

**Veronica** talked about hearing testing in PHACS. Some families may say that they have no concerns about their child's hearing. They may also say that their child was tested at school and their hearing is fine. **Veronica** wondered how to encourage these families to do hearing testing in PHACS. **Peter** talked about these barriers to hearing testing. Hearing tests done in schools are typically only screenings. The PHACS testing is more thorough. Site staff are encouraged to remind families that the PHACS hearing tests are more comprehensive. Additionally, the HECC and Hearing and Language WG put together an infographic about hearing findings in PHACS. Site staff may consider showing the infographics to families to show the importance of hearing testing.

**Veronica** talked about inadvertent disclosure. It might be helpful to remind audiologists that families might not have disclosed to their children. Sites could consider sending a letter to audiologists to remind them.

- **CAB WISH LIST FOR PHACS IV**

**Megan** talked about PHACS IV (the next round of funding for PHACS). Megan encouraged CAB members to send her their wish list for PHACS IV (what do you want PHACS to research with the next round of funding?). **Kim** recommended that PHACS study dyslexia and other learning disorders.

- **PHACS CAB NEWSLETTER, JANUARY 2020**

**Megan** talked about the PHACS CAB Newsletter, January 2020 Edition. The newsletter will follow a theme of "U=U, adherence, and relationships." Newsletter submissions are due by Friday, January 10<sup>th</sup>. Megan will send out newsletter reminders in November.

- **RESCHEDULING NOVEMBER AND DECEMBER CAB CALLS**

**Megan** talked about rescheduling the November and December CAB calls due to the fall/winter holidays. The CAB agreed to reschedule the November CAB call to Thursday, December 5, 2019 and the December CAB call to Thursday, December 19, 2019.

**NOTE: The next CAB call will be on Thursday, December 5, 2019 at 12:00 pm EST.**