

- Jelili Ojodu: If you're speaking, you're on mute.
- Joan Scott: Can you hear me now?
- Jelili Ojodu: I can. Thank you. I just wanted to quickly mention, we are still in the process of working on our closed captioning. We had a little bit of technical difficulty with that, but please bear with us while we work through that, and as I noted earlier, we are recording this at the moment. So thank you.
- Joan Scott: Thank you, [Jelili 00:00:39]. So, I'll take another stab here. On behalf of the Maternal Child Health Bureau and HRSA, I want to thank you all for taking the time out of your schedules to attend this webinar. Given the number of registrants, the impact of COVID-19 on the newborn screening system is clearly a very important issue to many, many people.
- Joan Scott: So this webinar today is an opportunity to hear from the entire newborn screening systems, to talk about challenges, and to share potential solutions. In particular, I want to thank the staff at NewSTEPS at APHL, who in conjunction with NCHAM, the National EHDI Technical Resource Center have worked so hard to put together this webinar and the presenters who agreed to be sharing information with you today.
- Joan Scott: But last but not least, I want to thank all of you. As part of the newborn screening stakeholder community, what you do every single day is critically important. What you've been doing in the face of these unprecedented times is even more critical. So thank you. Thank you all.
- Jelili Ojodu: Thank you, Joan. So as noted, the purpose of our gathering today is to host the national listening session with a panel of newborn screening experts and thought leaders to highlight, among other things, challenges, opportunities, and solutions to our dry blood spot newborn screening, as well as hearing newborn screening. We are also going to be hearing from the family aspect and family engagement perspective during this pandemic. Next slide please. Thank you.
- Jelili Ojodu: So the agenda is as follows. Here, I mentioned that we will get a brief overview from the national newborn screening resource centers, whether it's APHL through NewSTEPS, as well as NCHAM for hearing. We will also be hearing from thought leaders in newborn screening programs for blood spot as well as hearing screening. And then from the family perspective, we will be hearing from our partners and genetic clients as well as, on the hearing side, Hands and Voices: Family, Language, and Learning. Hopefully there will be time at the end of this to be able to have some discussion and an open dialogue with all of the attendees that are on the webinar here. So next slide please. Thank you.
- Jelili Ojodu: So a brief introduction about APHL. For those who may not know, APHL is a nonprofit membership association that works to strengthen laboratory systems, serving the public health need in the United States and globally. We represent

state and local governmental health laboratories in the United States. Our members in state, local, environmental, and cultural labs across the country monitor and detect and respond to health threats. Programmatic areas related to what we do at APHL would mimic what you would see in, for example, a public health program, and it would include, among other things, preparedness and response, environmental health, health information exchanges and interoperability, diseases, whether it's HIV, H1N1, Ebola and now this pandemic. And then, of course, newborn screening and genetics. For more information about all of the activities, and most especially the efforts of our association in addressing our members' needs related to this pandemic, please check out our website, www.aphl.org. Next slide, please.

Jelili Ojodu: I'm going to be focusing, obviously as a newborn screening staff here, my part of the presentation on newborn screening. As we all know, newborn screening saves lives and is an essential public health service across the United States. It is a state-based and is a unique program that touches the lives of almost all of the babies, all of the 4 million babies that are born each year in the United States.

Jelili Ojodu: As you can imagine, there are multiple stakeholders in the newborn screening system, whether it's the families of the affected newborns, policy makers, medical specialists, corporate vendors and partners, laboratorians, and then pretty much the newborn screening workforce as a whole. It is a multifaceted system that encompasses a number of activities that include, obviously, the lab tests, follow-up, diagnosis, treatment, management, education, and policy. And then because babies are born every day in the United States, at least 10,000 babies are born every day, there is a major emphasis on the continuum of newborn screening systems on a daily basis. Next slide please.

Jelili Ojodu: So, over the last several months, we at APHL have provided a number of services and resources to the newborn screening community that has included a dedicated website for COVID-19 correlating the information and best practices in state newborn screening programs that is updated on a daily, weekly basis, providing individual focused outreach to states, utilizing our vast organizational activities, whether it's our committee, sub committees and work group expertise to be able to address individual member needs, host a number of a hot topic, pertinent webinars. It was a couple of weeks ago, I think, that we hosted a webinar on unsatisfactory specimens. And this week on Friday at 2:00 PM, I think, there is going to be a hot topic session on tele-health, and next week, Thursday at 1:00 PM Eastern, we're going to be hosting a hot topic session on biosafety. For more information on any of this, please check out our website, newsteps.org. Next slide.

Jelili Ojodu: So we've invited speakers today to be able to highlight a number of pertinent activities related to newborn screening and COVID, but also to highlight and talk about the emotional, physical, and mental well-being of the newborn screening staff and workforce, as well as the emotional, physical, and well-being of the families and all of the things that it takes to continue providing essential services

while we social distance without missing a beat to stabilize every day. Next slide.

Jelili Ojodu: Oh, in all of this, it's important to remember that as states are dealing with these new challenges that are going to be with us for a while as it relates to COVID, newborn screening systems around the country continue to add new conditions to their state panels, maintain the highest quality of newborn screening practices, continue to engage in continuous quality improvement collaborative projects, continue to adhere to a number of accreditations, whether it's CLEA or CAP, as well as other certifications, and making sure that the ultimate goal of getting a newborn with a confirmed case of a newborn screening conditions that we screen for gets into a medical home as soon as possible while addressing the shortages in newborn screening staff, the social distancing that we have to implement as part of our daily routine and making sure that we continue to save lives on a daily basis. Next slide.

Jelili Ojodu: So again, this is a high-level overview. Dr. Michele Caggana will be presenting in depth about the activities that are going on in the state of New York among other things there, but I wanted to use this opportunity to say thank you. Thank you to all of you for making sure that you continue to do what you do under these circumstances. The fact that newborn screening is an essential service is something that certainly is unprecedented at this time, and your efforts and sacrifices are helping numerous families. And certainly from the association's point of view, we are deeply grateful for all of your activities. And so next slide, please.

Jelili Ojodu: So next, I'd like to welcome and please introduce Dr. Karl White. Dr. White is the director of the National Center for Hearing Assessment and Management with the Utah State University.

Dr. Karl White: Thank you, Jelili. And I am appreciative of being invited to be a part of this webinar today. Let me get my slides showing, I hope. There we go. Compared to bloodspot screening, newborn hearing screening is a relatively young program. We've been around now for about 25 years and is often referred to as early hearing detection and intervention programs or EHDI programs. I appreciate HRSA for making the effort to bring together the people who are doing bloodspot screening and the people who are doing hearing screening. I don't think there's enough interaction between those groups, and sometimes it takes a crisis like the COVID-19 pandemic to bring us together. And so this is a great opportunity to learn more from each other about what's happening in those programs.

Dr. Karl White: Real briefly, all 50 states and territories receive funding from HRSA to operate an early hearing detection and intervention program. Those programs are focused on the goals established by the Centers for Disease Control that all babies will be screened for hearing loss before one month of age, those that do not pass will receive a diagnostic evaluation before three months of age, and

that those identified with hearing loss will be referred to and enrolled in early intervention programs before six months of age. For all of that to happen, a lot of components have to be in place, in terms of linking to the medical home, providing culturally competent support and information, linking to other public health information systems, and making sure that children receive appropriate follow-up, because there are about as many children who develop hearing loss during the first few years of life, as there are who are identified during that newborn hearing screening period.

Dr. Karl White: So we've made a lot of progress over the years, and certainly the conditions associated with COVID-19 have tested that infrastructure, and we're finding that there's some areas that we need to bolster during this pandemic, but in general, the system is performing very well. And we'll hear some more from one of our state EHDI coordinators about some of the challenges that they've been facing.

Dr. Karl White: Over the years, since the efficacy of newborn hearing screening was demonstrated in the early 1990s, it took a while for us to reach the point that we're at now, where we're screening, essentially, all babies, 97-98%, and then those babies go on to be diagnosed and referred to early intervention programs.

Dr. Karl White: It's important to remember that we serve all children who are born. So as Jelili said, 4 million babies a year, approximately, are screened. Of those, about 7,000 babies are identified each year now with permanent congenital hearing loss. As shown on this slide, those babies represent a range of types and degree of hearing loss. It's important to remember that about half of those babies will be babies with unilateral or mild hearing loss. And then there are all the babies who have more severe and profound levels of hearing loss. But all of those babies need services through the EHDI system and the PARCC system for early intervention if they're going to achieve their full potential. And so EHDI programs in each of the states are focused on making sure that all of those babies across that continuum receive services.

Dr. Karl White: Another important demographic is to remember that about 90% of babies who are born with congenital hearing loss are born to two hearing parents, and based on data collected by a number of groups over the years, we know that most of those parents are very surprised to have a child with congenital hearing loss and aren't sure what to do. And so that's where the family support aspect of this, that is being led nationally by the people at Hands and Voices, becomes such an important part of this system.

Dr. Karl White: So our National Technical Resource Center provide services to all of those state-based programs. We provide training and technical assistance. We don't have any authority over those programs. Those are all state-based programs, but we do provide resources to them to assist in developing programs and maintaining programs that are effective in all of these different areas. So I'm looking forward to hearing more about the specifics of what's happening on the ground, and we'll turn the time back to Jelili.

- Jelili Ojodu: Thank you, Karl. Next up it is my pleasure to introduce Dr. Michelle Caggana. Dr. Caggana received her doctorate degree from the Harvard School of Public Health and completed her doctoral work in clinical medical genetics at Mount Sinai School of Medicine. She is board certified in clinical molecular genetics by the American Board of Medical Genetics. And a fellow of the American College of Medical Genetics and Genomics. Dr. Caggana has been employed with the Wadsworth Center since 1996, where she's the Deputy Director of the Division of Genetics, Chief of the Laboratory of Human Genetics, and the director of the newborn screening program. She is involved in many newborn screening efforts and works with the Centers for Disease Control and Prevention and the Association of Public Health Laboratories. She is the chair of the APHL Newborn Screening Committee and a member of the National Advisory Child Health and Human Development Council. Dr. Caggana?
- Dr. Michele Caggana: Thanks Jelili, and thanks to APHL for organizing this webinar and also for inviting me to talk about the New York experience, and also a shout out to our New York newborn screening staff for powering through the last 10 weeks. Next slide, please.
- Dr. Michele Caggana: So in general, we always think of spring as a time for rebirth, and in upstate New York, everyone was looking forward to the closing of winter and the blooming of flowers in the springtime. So we're always focused on newborn screening and new births in our state and all newborn screening programs across the country. However, we became much more focused on other things quickly. So we had some focus and some discussions from our providers, especially down state, regarding early discharges, whether our specialists would be available for newborn screening referrals. We were hearing about parental hesitancy in coming back to either hospital or their providers to get repeat specimens collected.
- Dr. Michele Caggana: Also some providers were closing their office hours and going totally into telehealth and only seeing emergencies or very limited patients. We had to ensure that we maintained our central operations, and we've heard that from Jelili's intro, that that was one thing we definitely had to be cognizant of. And then there were also concerns about staff and familial well-being because, as everyone knows, people with children, their daycares closed, schools closed and there was a lot going on in people's lives in general at that point. Next slide.
- Dr. Michele Caggana: So we decided that we really needed to start thinking outside the box, and we had thought about a lot of efficiencies in the pipeline that we were thinking about doing. And a lot of those things became accelerated because we basically went into emergency preparedness mode. And so we had to engage staff from all different perspectives in order to get their input. And so we thought about our data entry staff, our lab sections, what we're required to do by clinical lab law, the well-being of our staff, and follow-up as well. And so we really went from zero to 60 and spent a lot of time, particularly mid to late March, trying to

streamline our operations and make sure that we still could remain fully functional.

Dr. Michele Caggana: And so we, next slide, decided to take a systems based approach, and we wanted to review each section of our laboratory. And so I'm going to go through each of these areas and talk about some of the external changes and challenges that occurred, how we changed our accessioning, data entry, follow-up, laboratory, and then some other areas, particularly around IT and staff. Next slide, please.

Dr. Michele Caggana: So first were external challenges, and this is what really alerted us because we obviously, a lot of changes were happening down in New York City. And so we'd gotten some calls from some of our hospitals downstate that were telling us that their parents were refusing to come back to the hospital for repeats. And along with that, a lot of hospitals downstate were also closing their outpatient clinics and not allowing people to come, and families weren't allowed to come back on the floors. And so we had to think about how we could deal with getting repeat specimens in borderlines, and I'll cover that a little bit in a minute.

Dr. Michele Caggana: We also got a call, and this luckily was a limited thing, that some of our couriers were either not allowed to go to nursery floors, and we had some drivers who actually refused to go to the hospital or go into the lab or the nursery. And so UPS worked with us to change our pickup locations so that we could make sure that newborn screening specimens weren't left somewhere in the hospital because a driver missed the pickup or didn't know where they needed to go. So that work was done to make sure that that was all managed.

Dr. Michele Caggana: We also got a call right around the same time that the neonatologists were being told that they were going to have to discharge babies at 12 to 24 hours, which meant that specimens were going to be collected earlier than normal, within that 12 to 24 hour range. And our reference ranges and our lab testing is all set up, and our computer system is all set up, based on managing specimens collected after 24 hours. We always have the possibility of having a day-of-birth specimen, but we prefer the babies to be at least 24 hours of age when collected so that we didn't have to follow a lot of parents around to try and get repeat samples.

Dr. Michele Caggana: We asked the hospitals at that point, if anyone was going to go that route, that they would please send home a form with mom, an educational brochure, make sure that they had the For Your Baby's Health brochure, and then also to educate the parents why it was important to get that newborn screen collected after the baby was older.

Dr. Michele Caggana: We'd also heard at the end of March that some of our specialty care center staff and directors were being redeployed to other parts of the hospitals downstate, especially to ICUs and emergency departments, and then a lot of them were going have to go the telemedicine route. And so they were calling to tell us that

they might not be able to accept referrals immediately and how were we going to manage that.

Dr. Michele Caggana: And then the newborn coordinators were also very busy and were not able to necessarily process the routine paperwork that we send. And also we typically would call the hospitals to make sure that they knew every piece specimen needed to be collected if a baby had a borderline result.

Dr. Michele Caggana: I saw that was going on in the hospitals across the state. We had several different changes to who was to report to work. And so they're listed here, I won't go through them all, but needless to say, we went from one day having only 50% nonessential staff plus all essential staff reporting, to within a couple of weeks, basically the full New York pause, and all the businesses were closed. And we were told that we needed to limit the number of staff that could be present. Next slide.

Dr. Michele Caggana: So in the accessioning section, we came up with a protocol to handle forms from babies of COVID positive moms. We let the hospital's newborn coordinators know that they should just label them separately, and we changed the way we handled them so that our data entry staff did not handle forms that were collected from the COVID positive moms. We sent out a frequently asked question, kind of an FAQ, to our entire health commerce system, that included all of our providers and anyone who accessed results from our health commerce system at the New York State Department of Health. We told them that the health care providers, IE the general practitioners out in the field, the pediatricians, we gave them resources for education. We also gave them information on how to get collection forms that they needed and to be prepared that they might be asked to collect repeat specimens.

Dr. Michele Caggana: We have an online video, so the link was also sent with them. And again, we told the hospital staff to send moms home with forms if the babies were discharged early. We also initiated Saturday testing, and there were multiple reasons for this. One was we wanted to potentially increase the time to find babies within the acceptable release of time, critical results, thinking that we might have a harder time finding families out there and getting families to get in to be seen once they were referred.

Dr. Michele Caggana: And we also, in New York state, our Wadsworth Center biology lab developed a zero prevalence antibody test to pick up antibodies for COVID-19 in dried blood spots, and our forms were a nice source for collection of dried blood spots from finger pricks. And so there was a big initiative in New York to do the public, zero prevalence, healthcare workers and other different types of essential workers. And so we were used to managing high volumes. We were used to punching specimens. And so we helped with accessioning serology, and our staff really, really spent a lot of time in the mornings helping out with that. And so we ended up managing and helping them get specimens ready to test from the public. Next.

Dr. Michele Caggana: As far as data entry, one of the things that we did right around the middle of March was to move staff to a different building and decrease the density of people, and that also freed up space for some of the virology and zero prevalence testing to be set up on our floor. We had been already scanning our demographic forms, the collection forms, into a file, and we went totally remote with that, so that someone could sit remotely at their home and be able to call up a pack of demographic forms and actually be able to enter our data, enter information remotely. First, we had to flip through individual forms, and now we have them such that an entire pack comes up and somebody can just sit home and do that, and so some of our data entry staff and helpers are doing that from home. We also set up an electronic tracking sheets-

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Dr. Michele Caggana: We also set up an electronic tracking sheet so that when people were working off site the others would know which pack of specimens people were entering, and so that kept the order. And then we could track where we were in data entry. And we had set up our administrative staff and grant staff, as possible, to work remotely. And again, that was to reduce density of laboratory staff, because obviously a lot of staff have to be present.

Dr. Michele Caggana: Next. As far as follow-up was concerned, we also moved those individuals to another building for the same reason, to free up space for other testing and to spread out the number of people. And most of the follow-up staff began working remotely at the end of March. We did have a couple of hiccups along the way, and we had staff come back for a day or two until we worked it all out, but since then it's been going quite well. And all but one of our follow up staff are now working remotely, and then the supervisors come in a couple of days a week.

Dr. Michele Caggana: Beth Vogel spent a lot of time with Mark Morrissey and others in the lab looking at data to update the language of reports. And so instead of just asking for a borderline repeat collection we actually now have a risk based notation on the reports that go out when we need a repeat specimen. So instead of saying that a repeat is absolutely required, we now say for some conditions a repeat should be collected when practical, and we give, actually, a risk assessment with that. So to say, as far as phenylketonurias and the number of babies who have PKU with this type of result is one in six risk.

Dr. Michele Caggana: And so that tells the provider that they really need to work to get that baby in, and then other conditions that aren't as time critical, they can do it a little bit later. We also updated language for the babies who we suspect are on TPN based on the profile. And again, that was sort of a risk assessment. And then we also decided to refer all of our suboptimal babies rather than use an emergency level, which is what we had done previously. And as Jelili alluded to, there's a lot of discussion about whether or not someone tests unsatisfactory specimens, we call them suboptimal. And now we do refer those kids based on the level, and

then we ask for a repeat when practical. We also sent emails out to all of our specialty care center directors, alerted them to the different changes that were going on, and requested that they update their contact information.

Dr. Michele Caggana: And the same day we had a call with our CF docs, we had a check-in, and we went over the release of the CF Foundation guidelines about how to manage babies. And they're almost all working remotely and doing telemedicine. And so sweat tests are on hold, but they are treating infants with urgency based on their clinical opinion and the results from newborn screenings. Sarah Bradley produced educational disorder packets to be sent out to the primary care providers in the event that that was the only place the baby showed up and that they never made it to a specialty care center, so all of those went out and were available and go out with the referrals. And because the zero prevalence specimens, in the beginning, were taken on our card, when people got their little form to take home it had the newborn screening number and our website. And so our follow-up staff had to field a lot of zero prevalence calls from the community of people who were looking for their results. So that was from the antibody screening. Okay, next slide.

Dr. Michele Caggana: And then the laboratory piece, we implemented a lot of changes as well. Like I mentioned, we began Saturday testing which meant we opened the mail, we punched our specimens, and we ran all the lab sections. That allowed people to then, Beth would scan the forms, and then we could all begin remote data entry to get the demographics entered into the system. The least difference storage data analysis was analyzed from Fridays, and then we also would report out results on the Saturday. And it just sort of sped up and evened out our workflow. And that also was coupled with the fact that we might be, at any point, accessioning many of the COVID zero prevalence specimens. As it stands now, we're sort of monitoring the need for Saturday testing, and that was effective the weekend of May 16th.

Dr. Michele Caggana: One thing that was a huge lift for us was setting up remote connection to our instruments and data analysis. And so we were able to have staff at home on a laptop and remote in and actually analyze data and cue the retests and merge the data, and also operate the instruments remotely. And that was done over about a two week period and tested out in all the lab sections with the idea that if we only had one person available to actually put the specimens on the instrument, could we manage getting the results still out the door if people were working from home? We had some staff who preferred to work at night and handled some of the retests for mass specs, which meant that the referrals were ready first thing in the morning the following morning, and so that has worked out quite well. And we also separate some of the work areas to control density, and we implemented some cross-training of staff to make sure we had coverage in the event someone got sick and many of us would be out of the laboratory.

Dr. Michele Caggana: And so we also took on some folks from the environmental lab who had experience in mass spec, and they've been cross-trained in the mass spec lab, and they actually help us with some of our daily functions as well. The other thing that we wanted to make sure, based on all of the other viral testing and antibody testing going on out there, was that we would have reagents for our testing. So all of our operations specialists contacted the various vendors that we deal with to make sure we had sufficient supply of reagents and plastics that we use quite a lot of in our laboratory. And so that worked out okay as well. Next slide.

Dr. Michele Caggana: So basically we tried to manage our workload and the need to continue operations. As I mentioned before, our newborn screening staff also helped actually accessioning the PCR tests on virology test, and that was done, is it still done, after workday is complete here in newborn screening, and also on the weekends. We helped out with accessioning and punching over 15,000 serology samples, and that was done over a period of just a couple of weeks. We wanted to get all of this serology testing prepared so that they could go ahead and prepare their assays before our newborn screening mail came in, so staff came in between 5:30 and 6:00 AM to manage all of that. And I think on our largest day we were over 3,700 specimens that we accessioned in about two and a half hours, so it was a pretty big lift for us. Our IT, Chris Joan Scottson is off site, and all the changes to mailers and algorithms was done remotely and rapidly, and that has worked out quite well.

Dr. Michele Caggana: All of our essential staff still report to the lab. We get temp checks on arrival. We wear masks. We went from being asked to making it mandatory on April 6th, and that continues today. And we obviously canceled any meetings and use WebEx even for general lab meetings and whatnot, so it's been kind of interesting. So I just want to wrap up with some data slides. We were concerned about the early collection. So this is a plot that's been done and updated every week by Denise Kay in our group.

Dr. Michele Caggana: We wanted to look at all the specimens that were collected less than 24 hours and to see, do we see a change in early collections? Maybe a little bump up, but not anything that stands out. And then also when you look at the 12 to 24 hour, it's a little bit noisy and you do see a bit of an uptick back in the March, April timeframe of some specimens collected. But again, the N is pretty small on any given day. And so a change will fluctuate quite a bit. So we didn't see any real change overall in collections, maybe a little bit on the earlier collections. But I have some data sites to show you that more in a histogram. So on the next slide.

Dr. Michele Caggana: If you look at the age at initial specimen collection, this is a data across the entire graph for almost 301,000 specimens, and then parsed out by the hours of collection. And if you look, generally you don't see a big decrease or a big change in the total number of initial specimens collected. As you can see, it's variable across the year. This, again, is plotted from mid-January of 2019 to present, but you do see a little bit of a rise in the 24 to 26 hour collection. And

on the next slide, if you look at their proportion. A specimen, you can really appreciate that the 24 to 26 hour collection and the 27 to 29 hours of age of collection, those have increased and have sort of stabilized. So we do see a higher frequency of babies being discharged probably right at 24 to 25 hours. And when we're opening mail and we're looking at the specimens, we definitely have observed that as well, so anecdotally as well. Next slide.

Dr. Michele Caggana: And the other thing we were worried about was about the repeat collections. And so, overall, if you look at the proportion of repeats here, and also if you look at the VPs just in general, we don't really see any real pattern emerging, and we haven't really noticed that the number of repeats has dropped. And so whether they're going to their pediatricians or they're going now maybe back to the hospital, we're able to get the repeat specimens in. And so, as I said, this is a little bit difficult to look at because it's a relatively short timeframe, but we're going to continue to monitor this. And I think that's my final slide. Sarah Bradley's husband, Shane, is an artist and he drew us this nice newborn screening superhero. And this whole process has really helped pull our team together, and I think we've settled into a new normal now. So hopefully we will hold, and at some point we'll all be together again. I'm looking forward to that. So thank you.

Dr. Michele Caggana: (silence).

Jelili Ojodu: Thank you, Dr. Caggana. Next we have Marcia Fort that will be presenting on the challenges of newborn hearing screening during COVID-19. Dr. White, do you want to introduce Marcia?

Dr. Karl White: Yes. Thank you. I was on mute. Marcia is one of our longest serving EHDI coordinators in North Carolina. She's also in the fairly unusual position that she is responsible for providing supervision to not only the newborn hearing screening program, but also to the Bloodspot Program and the Congenital Critical Heart Disease Program. She's currently serving as one of the co-presidents of the professional organization that all the EHDI coordinators belong to, it's called the DSHPSHWA, the Directors of Speech and Hearing Programs and State Health and Welfare Agencies. So it's a mouthful, but Marcia's done a lot of great work over the past years, and we're looking forward to hearing from her. Marcia, remember to take yourself off mute.

Jelili Ojodu: And also if I should add here, for all of the speakers, if you don't mind turning on your video. We still continue to have technical difficulties related to closed captioning, and so enabling your video will certainly be very helpful at this time. Thank you.

Dr. Marcia Fort: Hi, thank you for the introduction, Karl, and thank you to HRSA and APHL for putting on this webinar. It's a great opportunity for us to think collaboratively about the challenges that are facing the entire newborn screening system of care as we live in this new COVID-19 world we find ourselves in. It's really

exciting to explore this together and find common challenges and opportunities as we move forward, considering both laboratory screening and point of care screening, as well as the challenges of follow-up related to both. Different states, and even sometimes different parts of the same state, are dealing with different sets of challenges, and we have, through a lot of conversation, been able to identify some common themes in the challenges that newborn hearing screening programs are facing. And so I'm going to try to summarize some of those for us today. Next slide, please.

Dr. Marcia Fort: To start with, early hearing detection and intervention, as Karl so eloquently explained earlier, does extend through not just the newborn screening but all the way through the diagnosis of hearing loss and into intervention services for children who are identified as deaf or hard of hearing. So we have a short timeframe that we try to work in, but it also is pretty critical to lifelong learning for these children. So one of the first challenges that we encompass are encountered in the screening process with staffing. That became critical pretty early in the process. Who would be determined to be essential staff? Newborn hearing screening is completed in hospitals by variety of different staff including nurses, CNAs, respiratory therapists in some States, and sometimes volunteers.

Dr. Marcia Fort: So who among those groups were going to be deemed essential staff, and not only deemed essential staff, but essential staff who would remain available to do newborn hearing screening. I know in Vermont, respiratory therapists were, in the pre-COVID days, the staff that typically completed their newborn hearing screenings, and in the era of COVID they were no longer available. So that created a need to identify additional staff people and also get them trained and ready to go with the screening.

Dr. Marcia Fort: So we also had questions very quickly about what was essential screening. And in North Carolina, and I know several other states, there were health advisories sent out from the Departments of Health stating that newborn screening, including all of the screening components, metabolic screening, laboratory screening, and hearing screening, and CCHD screening all were considered essential and should continue on for inpatient admissions as usual. That brought us to vendors. Some newborn hearing screening is contracted from hospitals to outside vendors. Were those vendors going to be allowed into the hospital to complete the screening or not? Did the vendor company request to not screen? We had a variety of questions that came up along those lines. And very quickly, once it was determined that newborn hearing screening was in fact part of newborn screening and should be considered essential service, those vendors were allowed to keep screening in most hospitals.

Dr. Marcia Fort: So we may have had a temporary stoppage of screening but it did not typically last very long before we were able to get those vendors back in the building. The other staffing challenge regarding screening is changes, anecdotally at least, in home birth rates or midwife assisted births. And in some states there were very well coordinated newborn hearing screening efforts with midwives in the

state, and in other locations that was not as well coordinated or there was not readily available hearing screening equipment available for those midwives. So that has caused us to have to evaluate not only equipment, but staffing and making sure people who are doing the hearing screenings on those populations have been trained to accurately screen. I'll move on to the length of hospital stay. Those typically reduced down to under 24 hours, as was mentioned previously, which resulted in some infants being missed or not screened at all, and others refusing or declining screening because the families wanted to not stay in the hospital any longer.

Dr. Marcia Fort: It also affected the screening quality for hearing screening, meaning that, typically we want to screen as close to the discharge of the baby as possible, and if the screening is completed too quickly refer or fail rates tend to increase necessitating extra follow-up. Also many hospitals have a protocol where they would complete the newborn hearing screening inpatient, and if the baby did not pass they would repeat that screening before the baby was discharged from the facility. But with the shorter hospital stay that repeat screening was not able to occur as frequently, which then had the effect of increasing the fail or refer rate. And though those increases in rates, haven't been high percentage increases in larger population areas, even a 1% change in a refer rate can result in a need for much greater follow-up.

Dr. Marcia Fort: We also have CMV screening, congenital megalovirus screening. At least 18 States, and there are more I think but 18 that I knew, have either statewide mandates or some hospitals within their state that do implement targeted CMV screening, meaning that CMV screening is completed on babies who don't pass their hearing screening. The typical protocol for that used to wait to do the CMV screening until after the outpatient rescreening occurred, so the targeted CMV screening would be completed on an infant who did not pass their inpatient newborn hearing screening and then also did not pass their outpatient rescreen. Due to COVID, some states did try to modify their procedures to ask for the CMV screening to be done on all babies who did not that initial inpatient screening. That became difficult to accomplish due to the shorter hospital stay stays, and also availability of staffing to complete an additional screening. So we do anticipate that there will be a change in the timeliness of CMV screening following failed hearing screening as we move forward. Next slide please.

Dr. Marcia Fort: So then we move into follow up, which again, as I mentioned earlier, includes not just a repeat screening but also the diagnostic audiology evaluation, amplification fitting if that's appropriate for children, assistive devices, and connection to early intervention services. So we were initially concerned that there might be a reluctance of families to attend those follow-up visits in light of COVID, so one of the first things that we did was revise our communication that we sent to parents regarding how important it was to have the follow-up screening, including messaging about, it was important that if you could not complete the screening as originally scheduled that it was important not to

decline or neglect the screening but to continue going, even if it was later than you had anticipated.

Dr. Marcia Fort: So we had some concern here in North Carolina and other states as well about in-home screening. So the Division of Public Health here in North Carolina has staff that are a screener of last resort, but we provide in-home hearing screening for home births or families who have other challenges getting to outpatient locations for that screening. Several challenges came with that. Would families want somebody coming in their house? We had stay at home orders that we had to deal with. We had need for PPE, and change of protocols, and stricter infection control that has to be implemented for those in-home screenings. Travel has been another concern for outpatient follow-up, and not just travel from families but also, in some cases... Well, travel for families primarily. Alaska is a unique situation in that they frequently have to fly families to locations for follow-up testing and screening, and some of the regional air companies actually closed, and may have closed permanently.

Dr. Marcia Fort: So they're facing some really uphill challenges with getting children back for follow-up in that location. In other places it's questions around, will Medicaid reimburse for travel or pay for travel? Can travel services be reimbursed for families to get to the outpatient procedure? Hospitals stopped some outpatient procedures, but not all hospitals. So we were dealing with some inconsistency even within a state about which hospitals might be open or closed, and which hospitals were completing inpatient but would not allow outpatient rescreenings to occur. That leads us to another challenge about infants being too old to return to the hospital for a rescreen once they do reopen and allow those procedures to continue.

Dr. Marcia Fort: We've also seen some increase in the rate of outpatient rescreenings not being completed or not being completed in a timely manner. We do think this will be a temporary change and that that will resolve when things get opened back up. For diagnostic audiology evaluation, and amplification and assistive devices, I can address those together. Again, facility closures for outpatient procedures, limited availability of staff. Either they are working fewer hours or the facility is only open limited hours or limited days of the week. Many of our audiologists who were previously located inside hospitals have had to look at relocating to a location outside of the hospital where COVID patients are being treated so that they can have a COVID-free environment for diagnostic and amplification services. And then we've had the challenge of, how do you prioritize patients? Looking at, we had some children who kind of got caught. They had appointments for their follow-up scheduled and then we had states stay at home orders. And so those appointments have to be rescheduled.

Dr. Marcia Fort: At the same time, we are still having babies born and having to schedule those follow-up visits as they happen. So how do we prioritize those patients? Some audiology facilities have come up with curbside service, both for hearing screening and for amplification hearing aid services and ear mold services,

where families can drive up. The audiologist may come out to the car, complete the hearing screening with the baby and the family in the car, and then go in and prepare for another patient. Or they may be able to drop off their hearing aid and pick it up at a later time if hearing aids or amplification devices need service. The other challenge that we face is, if an infant needs a diagnostic audiology evaluation, and they have now become too old for natural sleep during the test, these infants do need to be sleeping while we do the diagnostic.

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Dr. Marcia Fort: Since do need to be sleeping while we do the diagnostic auditory brainstem response evaluation. If there's a need for sedation that opened up a whole nut... a whole other group of challenges in that respiratory therapist and anesthesiologist may have been redirected and needed for COVID-related activities and not these activities or the outpatient surgeries or elective, more elective, type procedures may have been canceled altogether.

Dr. Marcia Fort: For intervention services. Challenges that we've seen are related to federal guidelines and being able to make adaptations to those guidelines, to allow for a shift to telehealth. And we've also had provider closures for speech language pathologists and other related services that might be provided by typical parts C programs.

Dr. Marcia Fort: And then we have tele-health and tele=audiology there've been many questions about tele-audiology and this COVID environment. However, tele-audiology for diagnosis and screening still requires that there will be a person in the room with the family at a remote location, as well as the audiologist in their office. So that doesn't really solve the issues and concerns around COVID.

Dr. Marcia Fort: And then there's also reimbursement around that. And I will try to wrap up really quickly. In some locations, we've had concerns about the families being afraid to come back for follow up. And in other places that doesn't seem to be a concern. I have a feeling that our family engagement presenters may address that a little bit, so I won't say any more about that/

Dr. Marcia Fort: Addressing the backlog, we do realize that we do have a backlog of patients who are going to need follow up. We're trying to work with our audiologist on situations to prioritize those, looking at perhaps scheduling children who fail their hearing screening in both ears for an appointment slot that will be longer and allow for diagnostic testing. And those who refer in one ear, maybe having a shorter, typical rescreen visit.

Dr. Marcia Fort: And I can't finish without saying as previous speakers have, that it is an important challenge to focus on self-care and supporting our workforce. Our EDDIE community really does have a long history of being very supportive of each other. And it has become even more important during this time where we're isolated and dealing with changes that are coming in a rapid-fire way. So I

encourage all of you to reach out and support each other, not just as professionals, but as fellow human beings, it really does make a difference. Thank you so much.

Jelili Ojodu: Thank you very much. Next up, we have Annie Evans from the Genetic Alliance. Annie is a program development specialist with genetic clients. He is passionate about helping families find a good quality health care that transcends cultural and language barriers. I'm going to leave out the rest of the introduction, Annie, at this point, and let you focus on your presentation, being that we're a little bit behind schedule. And if you can put on your camera, that would be nice.

Annie Evans: Thanks Jelili. My camera's actually on, are you all able to see me?

Jelili Ojodu: I can see you loud and clear. Thank you.

Annie Evans: Okay. Well, thank you for the introduction and thank you for the opportunity to present today. So as Jelili mentioned, I am Annie Evans from Baby's First Test, a program of Expecting Health. And I will focus my presentation today on sharing family perspectives on the way COVID-19 has created new challenges and exasperated old barriers in the newborn screening system.

Annie Evans: And we'll take a particular focus on communications for new and expecting parents. But before I get started, I want to address this little photo that we have on the side here. I think in public health, sometimes it's really easy to see things as systems that really need to be fixed, but it's really key to remember for all of us, that there are tangible impacts for families on an individual level.

Annie Evans: So I wanted to share this photo of my friend's sister, who had a baby just a few days ago, very exciting, but also very scary for her and her family. They were definitely very intimidated by the situation that was happening in their city. And it was a scary process for them. They had a lot of questions, but luckily things went smoothly and they were able to welcome a healthy baby to their family. So, just some context there.

Annie Evans: I'm also going to add some additional context here right now, because even though newborn screening doesn't exist in a vacuum ever, it's especially important for us right now during COVID-19 to continually ask the question, what are families experiencing around pregnancy right now?

Annie Evans: So we're seeing people have a lot of concerns about being alone in the delivery room. A lot of families are concerned that partners won't be able to join them while they're giving birth. And that's obviously a very scary process. We're also seeing parents be very concerned about the long-term impact of COVID-19 on their child's healthcare. We all know how important a healthy start is to life, so parents just want to make sure that they are still giving their child the best chance at a healthy start that they can, even right now.

Annie Evans: COVID-19 is also exacerbating concerns for communities of color, but particularly, the black community, because they were already facing a maternal health crisis before COVID-19, and things have just been even worse and even scarier now. Fear and panic is also very present for pregnant essential workers because there is a higher risk of exposure for them, but they do need to work to maintain their income and insurance to pay for their delivery. Essential workers are also more likely to be people of color and women, as we found over the last few weeks. So that's just an opportunity for health disparities to be expanded even more.

Annie Evans: We're finding that families really don't have all the information they need to check themselves and their babies. They're concerned about being separated from their babies at birth, or being forced to switch to a new birth plan very late in their pregnancy. And that's really scary as a birth plan is something that people spend months working on, so last minute changes can be really intimidating for a lot of families. So we'll transition now to a discussion of home birth, which I think has been a big topic on a lot of our minds over the last couple months. At Baby's First Tests, we had been seeing a lot of questions about home births on our forums, but also on the parenting site that we keep an eye on. And I'm sorry there. And we definitely heard from midwives that they are really being inundated with questions at this time.

Annie Evans: I think I recently read a report where one midwife stated that she had had the same number of inquiries about home birth that she usually receives in a month in a single day. So that's obviously a big influx and we need to keep tracking those questions and keeping an eye on that data to understand how this is really impacting not only midwives and doulas for what they need to provide, but also for families in terms of how they need to prepare.

Annie Evans: I think we've seen an increased interest in home births at this time, but not really an increased rate of home births itself. So because parents aren't really going from that point in asking about home births to making the switch to switching their birth plan to a home birth. I think that's because, again, like a lot of parents are, we're not as interested in changing things up last minute, but for those that were only part way through their pregnancy when the pandemic struck, they may be more interested in switching to a home birth plan as we continue to move forward in time.

Annie Evans: So again, we really need to be tracking those questions that families are asking and passing that information onto midwives and doulas. So I think this just really means that we as a newborn screening community needs to be proactive about what information we're providing to families and professionals on that.

Annie Evans: So now we'll just talk a few, a little bit about some questions that we're seeing on newborn screening specifically. And I will note before I get too much into this, that a lot of these questions are coming from the Baby's First Test, Ask An Expert module, which is a question module on Baby's First Test that allows any

visitor to our site to ask an anonymous question that will come to one of our program staff, and we will either answer it ourselves or tap an additional expert to help us respond to their question.

Annie Evans: So a few of the ones that we've seen are, are hospitals considering newborn screening non-essential? How are providers dealing with this strain of a pandemic and what are hospitals and healthcare facilities doing to ensure their staff are safe and functioning well during this time? Do hospitals have dedicated staff who will continue to conduct all three components of newborn screening? As healthcare offices close or reduce staff, are there clear instructions for how to maintain newborn screening follow-up processes? Will my baby be exposed to COVID-19 while at the hospital for testing? What plans do we have in place for babies who are not screened and for those who need additional testing?

Annie Evans: So let's break down some of the themes here. What we're seeing is that hospitals each have different policies. So there's additional variation than the typical state-to-state variation that we usually see in newborn screening. We're also seeing that there's a lot of concern for support to the healthcare workforce, as they do have an increased risk of exposure to COVID-19.

Annie Evans: We're also seeing some complications with staffing as hospitals and offices shift their staff to varying priorities. Some processes are unclear to that new staff and they don't necessarily have the right points of contact to find more information or get some training that might be really helpful for them. We've had several questions through Ask an Expert on that, particularly, which I do think indicates an increased need for staff education. There still may be a lot of disruptions in service, particularly again, if we see a rise in home births in the coming months, so we need to plan for that and plan to communicate it. So again, let's stress being proactive and not reactive.

Annie Evans: So each of these questions need to be addressed in communications that we're sending out now, as well as in long-term communications plans, as we continue to prepare for the long-term impacts of COVID-19.

Annie Evans: So I want to touch briefly on point of care testing, but I'll allow and [inaudible 01:07:20] and Hands and Voices to answer questions more specifically on that. But I just want to make sure that we included it in this discussion as well.

Annie Evans: Some hospitals are seeing new staff performing these tests, as I mentioned. So that's kind of a shift in how people communicate or perform processes on point of care testing specifically. Additionally, we're seeing a lot of specialist offices closed, so families are really having to wait to receive treatment and that can be a very scary process. I think this is particularly the case for pediatric cardiologists. So that's just some point that we need to give families additional education and instruction on what steps they need to take while they have to wait.

Annie Evans: So I think a lot of these questions indicate some systemic concerns right now. As I mentioned, a new staff are collecting blood splats. So there needs to be additional training and access to education for those new staff, as well as training on communication specifically so they can make sure that they're clearly communicating to families what next steps they may have to take. We're seeing families being discharged early. So the screen is happening a little bit earlier as I think one of our earlier presenters indicated. So do those families have clear instructions on what that earlier screen means and how they need to follow up on it?

Annie Evans: We're also seeing some treatments delayed, not only because offices are closed, but also because there are some disruptions in the drug supply. So families are very concerned about this. It's obviously very scary to have to wait to get treatment for your child. So again, we need to be clear about what are the next steps that they need to take and what can they do while they're forced to wait?

Annie Evans: And I think we're seeing the same disruptions in clinical trials and pilot studies.

Annie Evans: So now I'd like to highlight some ways that the rare disease community has stepped up for support to families. Genetic Alliances Disease Info Search and Luna have partnered to collect data through the fight to end COVID platform on Peer, which is a data repository. So this is one way that we're collecting COVID-19 data. The Mighty is collecting COVID-19 health stories. Here, SMA is providing a bunch of direct support to SMA families, one being \$50 gift cards to anyone who has somebody with SMA in their household, as well as a COVID-19 support package, which includes a lot of essential items, but particularly hand wipes and tissues and other items that I think all of us are having trouble accessing right now, but are particularly important to SMA patients. NORD has moved their living bear form to a virtual platform. So families are really still able to have an outlet to connect with the rare disease community. Every Life Foundation has created a COVID-19 policy center to lay out some action points for advocacy for rare disease needs during COVID.

Annie Evans: So there's really a lot going on here, but we need to make sure that we're including disease advocacy groups in discussions on long-term solutions to COVID-19 issues and make sure that we're not only partnering to reduce duplication in our efforts, but also to make sure that we're getting the right information into the hands of families that need it.

Annie Evans: So now I'd like to highlight a few particular points of how we can effectively communicate during a crisis. So again, this is really just going to make sure that we get the right information to families and staff that need this.

Annie Evans: So it's really important for us to return to risk communications principles during this time. So some of these principles I've laid out on the slide here, I'll just go through them. First and foremost, it's really important to be empathetic and reaffirming, but not to use platitudes. It's also important to have consistent

communication messages and confirm what you do know, although it is okay to say if you don't have all the answers. Definitely mentioning that you may not know an answer to a question is better than talking around it during a crisis. Also, it's always important to share trusted resources.

Annie Evans: So now I'd like to share a couple of key messages for newborn screening, particularly. And these are messages that we think it's really important to communicate out to make families feel comfortable and prepared to handle the situation. As well as we've seen some success with the messages that I've mentioned here.

Annie Evans: So the first is that newborn screening is an essential public health service that families can still access today. The second is that healthcare facilities and teams are taking precautions to keep families safe and healthy. So these are really important points to stress. And if you have any interest in getting some support or customizing your graphics materials, maybe a risk communication strategy, please reach out to expecting help. We're here to help you as a resource for those points at this time. I'll just make a note of an additional resource here as well.

Annie Evans: As many of you may know, Expecting Health recently launched Navigate Newborn Screening, which is a free online educational module for families that they can access from the safety of their own homes. So it's really important for them to ,again, feel like they can take actionable steps to prepare themselves for birth and afterwards in COVID-19. So this is a great resource that families can take to do something active at home. Additionally, we will be launching a newborn screening and COVID-19 module for families soon. We anticipate that will be available in early June.

Annie Evans: So just two other expecting help resources that you can use to provide information to families. The first is that we have some information for pregnant and new parents on the Expecting Health website. We also recently launched a newborn screening and COVID-19 page on Baby's First Test. So please do feel free to reach out to me if you'd like the direct links to either of those, but feel free to visit our websites and locate them.

Annie Evans: Before I log off, I just want to give a brief thanks to the rest of the Expecting Health team, the Natasha Bonhomme, Jamie Loey, who provided me some support on this presentation, as well as several of our advisors who helped us by providing a little bit of fact checking and keeping us informed of feedback from their community. So thanks to Amy Gaviglio, Vicki Hunting and Alison Ward, who I think are all on this call right now, as well as Elisa Wear, Mary Jo Palladino, and Ashley Crowley. And finally, just please feel free to get in touch with me if you have any additional questions, or if you're interested in getting some support on some of the items that I mentioned. You can also follow along with Expecting Health as we launch additional resources for families through our

social media, as well as our newsletters. So please feel free to check out our website,

Jelili Ojodu: Thank you Annie. And Karl, can you introduce the next speaker, please?

Dr. Karl White: I'd be happy to.

Jelili Ojodu: Thank you.

Dr. Karl White: Our next speaker is Janet DesGeorges, who is the executive director of Hands and Voices, which is a national organization of parents who provide support to early hearing detection and intervention programs. Janet is also the principal investigator for the FL3 center, which is the Family Leadership in Learning. And I always miss that Janet. Language and learning. So thank you. So we look forward to hearing from Janet, she's got some great insights and Janet will probably run over a few minutes, but you should give your whole presentation. So go ahead.

Janet DesGeorges: This is Janet. Thank you very much for this introduction. You can go to the next slide. Thanks to all of you who are listening today. In fact, you are the most important people in this panel in thinking about what we're talking about, the information we're delivering, how you can utilize it where you're at in the work that you do.

Janet DesGeorges: I decided today to start with one of the most famous opening lines of a book, and I'm going to close with one of the most famous lines in the close of a book. If you know the Tale of Two Cities, it was the best of times, it was the worst of times. You should Google this and read the whole first paragraph. In fact, there's one place in there talks about the despair of winter and the light of spring.

Janet DesGeorges: COVID-19 has affected all of us and so, as we're emerging through both the crisis and the recovery period, every single thing in our society has been impacted. Today, I'm going to talk a little bit about family engagement during COVID-19 and hearing screening, and particularly focus on the screening part. You can go to the next slide.

Janet DesGeorges: Having said that, I think it's always important, no matter what piece of the system that you are part of, whether you're a clinician in a hospital, whether you're an audiologist or a family member, or a family leader, it serves us well, and I think it's particularly in times of crisis to always stay focused on what the outcomes are. I liked Jelili's opening statements about hearing our newborn screening, the lives of babies. I think for newborn hearing screening, our hope and work and effort is that all children will be able to achieve their full potential.

Janet DesGeorges: And you can go to the next slide. Let's just pause for a second and actually talk about what family engagement is. We use that term often, and for today's

purposes, I wanted to just parse it out a little bit. What is family engagement? HRSA defines it as patients' families, their representatives and health professionals working in active partnership at various levels across the healthcare system to improve health and healthcare. Why is this important? If you've never heard of co-production theory, I encourage you to look up... There's one resource here, I'm looking it up. I remember when I first read about this, it really resonated for me. I didn't do a lot of introduction about myself in the beginning of this presentation. I am a mom. I am a parent of a daughter whose deaf, hard of hearing. So we've lived through the systems of care.

Janet DesGeorges: And co-production theory comes from the evidence-based perspective that good outcomes are more likely if the patient, the family, consumer or youth, communicates effectively, develops a shared understanding of the problem, and generates a mutually acceptable evaluation and management plan. And then when we talk about family engagement, where does that happen? Obviously for our own children, a lot of times we think about family engagement in terms of that direct recipient of the services that you're giving. And for sure, that's true. This is a model from Hands and Voices. We also understand and know that parent to parent support is one of the mechanisms in which to ensure the integrity that parents are involved and directing the care for their own children. And then overall, as parents move through those other layers, and in addition to parent participation through advocacy in the system, I've always said, it doesn't matter how well a system is built, if it doesn't work for families, it's not a good system.

Janet DesGeorges: I'd like to challenge you right now in thinking about this current COVID-19 crisis, as you are confronted with wave after wave of things that are out of your control in terms of the systems that you've set up. Have you actually gone to wherever you can and whoever you can to actually ask families, how could we solve some of these problems from your point of view, as the parents, both going through the system, and parent advocates who have already been through the system? You can go to the next slide.

Janet DesGeorges: I wanted to just pick a few items from newborn hearing screening that I think have both been impacted by COVID-19 from the parent perspective, and also in our world at Hands and Voices, we have 44 chapters throughout the US and Canada. Our Family Leadership and Language and Learning Center, the FL3, is serving all 59 States and territories and ensuring the integrity of family engagement and training parent leaders to be effective advocates in the EDDIE system.

Janet DesGeorges: As Karl mentioned earlier on, screening is really just one part of the system. We talk all of the time in hearing screening around one, three, six. Screening by one month of age, identification by three months, entrance into early intervention by six months of age. If you think even in the best of times, the chart that Karl shared in terms of the percentage of babies that are being screened are, is very high, almost 98% of the population. A lot of times we think, wow, we've got that

covered. I think COVID-19 has impacted the flow of that. But even that was one of the first things I think to be moving along that in general, babies are being screened.

Janet DesGeorges: I think one of the reasons is that families are a captured population during that point in the EDDIE system. They're in, for the most part, in hospitals where the system can create a mechanism to ensure the integrity of that babies are screened. But think about it. The other parts of the system move from the control of the system to the family. Because the minute the family walks out the hospital door, whether they come back for follow-up and re-screening, retesting, and diagnostic, and whether they go into early intervention is really, at that point, in the control of the family. So what we want to think about is what are the influential factors in getting families through that system of care? What are the things that we say and provide and give to families at the point of screening? I'm going to share an example of a COVID response from one of our family-based organizations.

Janet DesGeorges: So we want to think about how can we influence a family at the point of screening particularly with the pause and delay and parts of the system right now of families not being able to come back. Thinking about how families... Going on to the next part of the slide and in hearing screening, having a little bit of a different focus and thought around newborn hearing screening not only is one part of the 136. The reality is, for families who have a child whose deaf or hard of hearing the medical part of this experiences is for sure one part of it, but there's a holistic nature to the journey of deafness. And so I'm thinking about how we can increase understanding for families. And I'll go into that in my next slide. I'm trying to hurry through, cause I know we want to do questions and answers.

Janet DesGeorges: So I'm going to just go ahead and come to this next slide. I want you to think about family engagement. We were built for this. Our systems of care are flexible. I want to share one of the things that a family-based organization did in context to knowing that families were still being screened, but some of the other parts of the system were being dropped, like coming back for re-screening or moving on to audiologists. By dropped, I mean that sometimes those facilities were closed. The families thought about some of the information they were delivering to typically to families in the past. You wouldn't give all families all the information right at the screening. Good information is delivered at points of care when families need it. But in this particular instance, because they knew that families were having a hard time getting back to some of the other areas, they made a decision to give more information to families, right at that point. And so they moved up some of the delivery of information that they felt needed to be.

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Janet DesGeorges: Well, the delivery of information that they felt needed to be able to influence the importance of screening and, and the follow-up pieces at the hospital. I thought that was a really innovative way to think about this. I'm thinking about family engagement is the world I live in. In some ways we've been responding like everyone else trying to come up with good solutions to some of the areas. But in some ways we feel we are both are enduring and feel we are started saying that we're kind of built for this as family to family supporters and our networks. We know how to be able to get into contact with families in a lot of ways, we often don't have some of the bureaucratic barriers in terms of being able to get directly to families. During this time, we've been able to support hundreds and hundreds of thousands of families at the local level of our family based organizations and for us at hands and voices and being in direct communication with our family leaders.

Janet DesGeorges: I would say we're both zoomed in and zoomed out. I think everybody here talks about that zoomed in, I mean, emotionally, we're able to have the pulse on families in terms of where their emotions are at, in context to what's going on and zoomed out, which is, I think we have to watch how we're supporting families that everything going virtual, families are reporting over and over again, a bit of fatigue and the ability to be zeroed in on some of the supports that are being provided virtually. I think we need to think about other innovative ways of being able to reach families. We are trying to hold a healthy tension of two things in our hands as parent support providers for families who have kids who are deaf or hard of hearing. And that is both that this is a marathon and a sprint.

Janet DesGeorges: By sprint, I mean, we have set in motion in our system. We know that the earlier the better the early kids are identified, the better they do in their language development. The better though potential. However, we also don't want to make families feel that if they miss one of those markers during that time that their child doesn't have the ability to reach their potential. I love what one mom said to another, which was, this is a season, not your entire journey We'll get through this. We want to make sure that families understand that as soon as possible to follow those markers. But on the other hand, raising a child who's deaf or hard of hearing is along marathon and just giving a lot of encouragement through our networks that your child is going to be okay. We are also supporting our workforce as family leaders to make sure that the end of this, that we have a strong standing core of family leaders who are engaged in the system.

Janet DesGeorges: You can go to the next slide. Here's the end of the story. I am going to tell one quick story though, and the next slide, but this one, we all know this one Scarlet says after all tomorrow's another day, I want to encourage all of you. You can go to the next slide, hang in there, do what you can. We will get through this. We always want to start in with Joyce. I'm just going to tell a 32nd story of my own family. I've been telling lately when my middle hearing daughter was pregnant, getting ready to give birth we were talking about the birth experience. I made a joke. We were all standing in the kitchen. My deaf daughter was with us and I

made a joke. Well, if I miss the birth, whatever, just to make sure I don't miss the newborn hearing screening, our whole family ended up going down the hallway for the newborn hearing screening.

Janet DesGeorges: But as we were talking about it, my hearing daughter, who's sitting there pregnant nine months, looked over at my deaf daughter and she said, wouldn't it be great if I had a baby that was deaf. For me, that epitomizes the journey of raising a child who is deaf or hard of hearing the potentiality of our children is they're the systems were built to ensure the integrity of that and even though we're in a hard situation, I just want to thank all of you for the work you're doing and we will get through this. Thank you

Jelili Ojodu: Splendid. Thank you, Janet. Thank you for all the speakers. We really do appreciate your time and input this afternoon during this listening session. I know we're a little bit over time, but being that this is being recorded and I would love to be able to accommodate at least the next 10 minutes of at least the speakers time to be able to respond to the questions that we received in the chat box. If that's okay, I think we should just still binge right away. The first question is directed to Dr. Caggana, do you consider SCID severe combined immune deficiency as a time critical or time sensitive, especially on holidays.

Dr. Michele Caggana: For the purpose of what I described here today, we use the advisory committee's recommendations on what was time critical. We got those results out on the weekends. We did do SCID and on the occasion that the people who are responsible for that kind of volunteered to come in on those Saturdays.

Jelili Ojodu: Splendid. Thanks. The next question is for both of Dr. Caggana as well as Marcia. They attest to the incredible job that you're doing in New York. Dr. Caggana, can you talk a little bit about how relevant your previous continuity of operation plan was given this on unprecedented pandemic? How might you change the plan in the future? And the same goes for Marcia in reference to a hearing screening as well. So Michele.

Dr. Michele Caggana: Actually, kind of made me smile because I don't think we could have ever planned for something like this. We had in the last, I guess probably six months prior had kind of revisited our scoop plan and submitted that to the center. There had been some talk with APHL at the newborn screening committee meeting about States working to formalize their plans, but we sort of had planned for the inability to test, not the staff issue of spreading out. I guess the short answer is it didn't help us a whole lot, but it certainly gave us something to plan for in the future to consider this type of event when you know, happening again.

Marcia Fort: This is Marcia answering the same question. I would agree that our previous continuous of operation planning was definitely more laboratory specific as far as what would happen with laboratory testing and was not as comprehensive as far as congenital heart screening, CCHD screening and hearing screening. So we

have some work to do to improve that planning. I agree with the statement. None of us could have planned, we could have anticipated something like this. So I think it has opened our eyes to some planning opportunities that we need to take advantage of.

Jelili Ojodu: Thank you, Marcia. I'm going to point the next two questions to my co-moderator Dr. White. Karl.

Dr. Karl White: I'm not sure which question do you want me to ask? I'm sorry.

Jelili Ojodu: No problem. There was a question about who would be doing the home hearing screen? I guess that's the question.

Dr. Karl White: Yeah, so I can respond to that. And so can Marcia. In most States, home-based births are being screened by midwives. There are a few States who contact those families and have them come into a center to be screened. But most of it is moving towards the midwives and those who are attending the home births and then a number of States that actually purchased equipment and made it available to the midwives to do. Marcia, do you have anything else to add there?

Marcia Fort: The only thing that I would add is here in North Carolina, I have a regional consultants that are hired through our division of public health and our staff can go in and provide those home screenings. And on occasion, I believe there are some States that also have potentially used some home visitors to complete those screenings as well.

Dr. Karl White: So about 2% of births and the U.S. Are born at home as you probably all know, but that means it's a very significant part of the population. About 80,000 births a year, which would be similar to the number of births in a state like Colorado or Virginia. It's a lot of babies that we need to be taking care of.

Jelili Ojodu: Thank you. I'm going to keep the next couple of questions on the hearing side as well. So how are the experts planning to move to JCIH 2019 modification of one, two, three, to one, three, six.

Dr. Karl White: So let me start with that. JCI H is the joint committee on infant hearing that makes recommendations of how EDDIE program should be organized. And then their last statement, which was published just a couple of months ago at the end of 2019, they said that for those programs that are having success and have achieved the goals of screening by one month of age diagnosis, before three months of age and referral to intervention before six months of age, they should consider whether they can reduce that even further to screening before one month of age diagnosis, before two months of age and referral to early intervention, before three months of age, now, they didn't recommend that everybody was ready to move to that goal. But the essence of their recommendation was that we have a lot of information and research literature

showing that earlier is better and that every day matters. If we can reduce even further from the one, three, six goals, that is good, and we see a number of programs moving in and in that direction now, but the official goal from CDC is still one, three, six. It's important to note that that goal is before those markers and not by those markers. So certainly accomplishing diagnosis by six weeks of age would be even better than eight weeks of age. So we should do it as early as we can.

Jelili Ojodu: Thank you, Karl. Anything else Marcia?

Marcia Fort: No, I think Karl summarized that perfectly.

Jelili Ojodu: Excellent. Then I'm just going to go back to a question that was asked before the call today. What are the protocols for the OAENABR screening?

Dr. Karl White: That's a more complicated question than I think we have time to get into now. However, if you go to our website and go to the state EDDIE programs page, there is a table there that shows the protocols that have been developed by all those States that have shared them with us. That goes into a great amount of detail about protocols for OAE screening and automated ABR screening. There are strong feelings among some people about which technique is most appropriate. I think that the fact that about half the country is using OAE screening and half the country's using AVR screening. Those are general numbers, but that demonstrates that they both work very well. In some ways it's like discussing whether PCs or Macintosh computers are best. They each have their proponents, but they each work very well.

Jelili Ojodu: Okay. Thank you. This question is for Dr. Caggana, Michele, and I did know this. Maybe you can confirm, I think many of the New York hospitals shifted to 24 to 48 hours for discharge of vaginal deliveries in order to get newborn screening elements needed to be done in 24 hours of age in this day and age of COVID, our site is obtaining newborn screening blood spot at 24 hours. Do you have any information about that Michele?

Dr. Karl White: You may be on mute, Michele, you are on there.

Dr. Michele Caggana: Thank you. I started talking. We had heard that hospitals were going to do early discharge and that some hospitals were actually testing all newborns for COVID, particularly if the mother was positive. And so that kind of makes sense and what we've seen, and we've also seen some of our nurseries shut down some of their testing and then move bursts actually to other hospitals. So we've kind of been monitoring that, but this is the first time I heard that this is kind of the rationale for why that was happening. And so, thanks for that.

Jelili Ojodu: No problem.

Dr. Michele Caggana: Jelili, I see a message in the chat box from a person asking me to mention briefly the newborn hearing screening training curriculum that is available on our site. It is a set of modules that many States are using to help people do newborn hearing screening and a standard way it's available at no cost. You can download it and watch it. Many hospitals require their screeners now to go through that on an annual basis, just to stay up to date with the rationale and the basic protocols of newborn hearing screen.

Jelili Ojodu: Great. I think that the rest of the questions here involving hearing screening in the Q&A box. You want to take those as well Karl?

Dr. Karl White: I'm not seeing them if you can repeat the question.

Jelili Ojodu: I can sure. How our hearing screening programs handling the inpatient newborn hearing screen of babies that are positive for COVID and are babies in the room with a mom positive with COVID?

Dr. Karl White: Marcia. Do you want to respond to that? You're closer to that than I am probably.

Marcia Fort: Sure. I think we've not had a large number of those cases. Information is the that I have heard so far is that the screening has been postponed for 10 to 14 days on most of those babies.

Jelili Ojodu: Thank you. Going back to Dr. Caganna here due to COVID in some hospitals across the nation, careers are no longer allowed to enter facilities to pick up newborn screening specimens. Are there alternative solutions to this problem other than purchasing a lockbox?

Dr. Michele Caggana: In cases where we've heard that we've worked with our courier to get a box set up somewhere else in the hospital, whether it's even at the entrance or the lobby so that they can collect the specimens. We've kind of done that in one office as we've heard, that was a problem and I haven't heard too much about missed pickups since we've made those changes in the places that were impacted.

Jelili Ojodu: Thank you. I'm back to Marcia. Marcia mentioned that there are some, we are some reimbursement issues related to Tele-audiology, any further info that can be provided on this? And it was specific from a contact at M chip.

Dr. Karl White: Marcia here, let me say one thing. Well, while you think about it, but if you go to, this is Karl. If you go to our website, infanthearing.org under the resources section, there is a whole section on Tele-audiology and Tele-intervention. And a part of that section relates to the reimbursement issues of both reimbursement and licensing across state lines have been two of the biggest challenges with implementing more widespread Tele-intervention and Tele-audiology. The techniques and the technical aspects of doing it are well-established now they

continue to improve, but that it's not the biggest barrier to more widespread implementation of these programs. The biggest barriers are probably related to the reimbursement issues on the licensing issues. Anything else to add Marcia?

Marcia Fort: I think you summarized that pretty well. The audiologists are frequently not listed as providers that are allowed to bill for tele-medicine in many States. So that would be my only other comment.

Sikha Singh: Jelili, you're on mute.

Jelili Ojodu: Thank you for that, Sikha. I didn't know that. So let's take two more questions here. There was, even though we didn't focus on critical congenital heart disease, there is a question about what are States doing to assist midwives and out-of-hospital birthing practitioners with accessing or getting their own pulse oximetry instrument is no longer an option due to COVID? I don't know if anyone here wants to take a swipe at that question, but I know that this is something that we certainly will plan to pay more attention to and moving forward.

Dr. Karl White: Just as a naive person, Jelili. So maybe I'm way off base here, but I'm surprised that you can't sanitize the pulse oximetry equipment from baby to baby, and maybe that's not the kind of sharing the question was referring to sharing between facilities. But the other thing is that the pulse oximetry equipment is moderately inexpensive. So that wouldn't seem like it would be a big roadblock, at least in my opinion.

Jelili Ojodu: Yeah. And I think this is newborn screening and COVID then CCHD is something that at least as an association is through new steps is something that we probably will have a hot topic session around to be able to focus a little bit more on in the near future. I'm going to just read it the last question here. I know that there are other questions that are being asked. We'll try our best to be able to answer those and for everyone else, let me see here. This is a question that I think is directed to either Annie or Janet. We know it's a challenge to get parents to complete the second hearing or actually Marcia. We know it's a challenge to get parents to complete a second hearing screen or move to diagnostic and States are now reopened. What creative approaches are we taking to get parents to be more comfortable to move towards identification of a second potential short shutdown to prevent any longer delay in identification?

Janet DesGeorges: This is Janet I'll start. I think that if you look at the statistics in general for one, three, six, it's been an area our system has been addressing for a long time in terms of ensuring that families can get back. While COVID-19 has created other barriers that are separate from how we've tried to influence parents in the past, those products are still really useful at hand and voices on the front of our website, we have a link to call loss and found that shares the importance on why families should be following up. We have to address safety issues. A lot of families, as we know, are concerned about their safety of their babies are themselves going into medical facilities. And I think there's a lot of good

resources and supports that talk about that. I think we also have to focus on ensuring families do understand the importance of follow-up screening and also when, families are trying to do that and can't get into it.

Janet DesGeorges: Let's also remember the basics in terms of what we tell families in the beginning anyway, with their infants bonding eye gaze, holding your baby clothes for some families, being able to use sign language with their kids, if they don't have access to technology. I didn't mean to say that even when kids do have access to technology, many families already are utilizing the communication and option choices in deafness. And so I think we need to be flexible in making sure that families still get all the information about the different ways that they can communicate with their baby, whether it's through visual means visual sign language systems, the techniques that families would be using any way with very young infants and on learning and spoken language. There's a lot of really good resources across those modalities around how to communicate effectively with an infant that I think we should also be focusing on for families.

Annie Evans: Hi, this is Annie. I will also hop in on that. So thanks for the opportunity to answer this question. I would second what Janet was saying in that education and communications that are really essential part of addressing parent concerns. So really coming back to providing them with all of the information, they need to make an informed decision on whether or not to follow up on a screen is a really important part of that. I think right now we have obviously unique challenges in terms of how to design those communications. But once parents understand the importance of it, there'll be able to make that informed choice. Please feel free if anyone has any additional questions. I popped my email address on the answer to that question. So please feel free to follow up with me specifically on how we can approach that as well.

Jelili Ojodu: All right, well, thank you everyone. Thank you to our speakers for your time this afternoon. Thank you to the participants for hanging in with us through some of the technical difficulties earlier, as noted my apologies in reference to the captioning. It just didn't work out at the very last minute there, but as noted, we will, we have recorded this and we are planning to have it transcribed and available on our website as soon as possible on behalf of APHL new steps and INCHAM our funders at HRSA and the many, many, many folks that work around the newborn screening system. We sincerely appreciate everything that you do in this time of COVID and certainly plan to continue to keep the dialogue going. Karl, any final thoughts from you?

Dr. Karl White: Thank you for including us. This has been a great session and we've had a lot of people and I want to reemphasize what you're saying. We really appreciate our federal partners for encouraging us to go in this direction.

Jelili Ojodu: Thank you all. Happy Thursday. Take care. Goodbye.

Dr. Karl White: Bye. Bye.

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