

Amy Gaviglio: All right. Hi everyone. Welcome and happy American Heart Month. I'm Amy Gaviglio co-chair of APHL's Critical Congenital Heart Disease Data Response Team, and want to start out by thanking all of you for joining us today for the third webinar, in our joint APHL and National Birth Defects Prevention Network Webinar Series that has been focused on newborn screening and surveillance of critical congenital heart diseases. Next slide, please.

So before we get to today's program, we wanted to provide a quick recap of the first two webinars in this series, and I'll also put a link to both of these in the chat box shortly. So, our first webinar really focused on current implementation status and in thinking through some of the future considerations around newborn screening for CCHD as I provided an overview of newborn screening and its implementation, as well as, I've mentioned those future needs.

The second in the webinar series, pivoted a bit to look at clinical aspects and implications of newborn screening, so this provided a review of the various ways that CCHDs can be detected, as well as considerations around public health definitions of CCHD. And then again, looked into the future in terms of ways to improve CCHD detection. And next slide, which brings us to today's webinar and the objectives for today. We have really a jam packed schedule full of a lot of information. So we'll start by describing some of the federally-funded surveillance activities for both congenital heart defects, as well as the subset of CCHDs. We hope that by the end, you can understand the various state program practices for the surveillance and follow-up of CCHDs. And then we'll end with the discussion on the neurodevelopmental and care coordination needs of individuals identified with CCHD. Next slide.

Thank you. So with that introduction, I am more than pleased to introduce my co-chair extraordinaire of the Data Response Team, Lisa Hom. And I'll let Lisa take it from here for some housekeeping and further introductions.

Lisa Hom: Thanks so much, Amy, welcome to everyone. So many people helped put this together, and we're really excited to be presenting the third part to our three-part webinar.

To get us started. We have the great privilege of Jill Glidewell. She will be providing an introduction for our webinar. Jill is a health scientist at the CDC's National Center on Birth Defects and Developmental Disabilities. She's led the CDC's multi-site CHD surveillance projects since 2012. She started at the CDC in 2010 as an Epidemic Intelligence Officer. Prior to joining the CDC, Jill worked as a nurse consultant for the Georgia Department of Health Newborn Screening Program, and also as the inpatient NICU nurse. And so welcome, Jill.

Jill will be my co-moderator, and she'll also be introducing to you the speakers as they present for this webinar. So, Jill, I think, were you going to introduce the speakers right before they presented? Okay.

Jill Glidewell: Yeah, we'll do a short bio before everyone's presentation.

Lisa Hom: Fantastic. Thanks so much. So this is just a short foreshadowing of who will be speaking on this webinar.

Jill Glidewell: All right. Thank you, Lisa. And I think, as we go through the presentations, we will proceed to each presentation and speaker and hold questions until the end given our packed agenda. If you do think of a question along the way, please do put that in the chat box and we'll try to respond to those questions throughout the webinar. And again, I'm Jill Glidewell. I am a health scientist at CDC's National Center on Birth Defects and Developmental Disabilities. And I'll spend the next few minutes giving a brief overview of our CHD surveillance activities. Next slide.

This graphic celebrates CDC's and its partners' work on congenital heart defects since the Congenital Heart Futures Act was passed. Where I will not be discussing each of these milestones today, I will be highlighting a few of our key CHD surveillance activities. Next slide.

I'd like to call out these two time points. In 2010, the Congenital Heart Futures Act was passed. It was the first legislation of its kind authorizing funding for and directing CDC to enhance and expand surveillance of individuals with CHD.

And in 2018, the Congenital Heart Future Reauthorization Act was passed allowing for continuation of funding and authorization of CDC's CHD surveillance activities. Next slide.

Something that CDC, as well as many of your state programs focus on with surveillance is the emphasis on population-based findings. Meaning we've worked toward describing the health of all individuals living with CHD, not only those receiving specialized care or care at congenital cardiac clinics, since those may represent a small percentage of all people living with CHD. Next slide.

Since 2012, we've funded sites to conduct population-based surveillance by linking birth defects surveillance, electronic healthcare and claims data. We've increased the number of CHD surveillance sites since our pilot project in 2012 to five sites in 2015, and are currently able to support seven sites for our project - Congenital Heart Defect Surveillance Across Time and Regions or CHD Star. And these seven sites are Arizona, Georgia, Iowa, New York, North Carolina, South Carolina, and Utah.

We've used the surveillance data to examine health outcomes in healthcare utilization among children, adolescents, and adults with CHD. For example, we've shown that children and teens with CHD are more likely to have problems with breathing, mental health issues and other heart problems. And also that pregnant women with CHD may experience pregnancy-related health complications. In South Carolina, in one of our CHD Star funded sites, is

presenting later in this webinar and we'll provide a few specifics of their state's project. Next slide.

As many of you know, the birth prevalence of CHD, including CCHD is about 10 in a thousand. When we use Canadian estimates of people living with CHD and apply that to the US population, we estimate that about eight per thousand individuals have CHD. Further, based on our healthcare surveillance data from 5 of the funded sites across the US, which were shown on the previous slide, about two and a thousand individuals had a CHD documented at a healthcare encounter over a three-year period, indicating that many people with CHD may not be receiving healthcare for their heart defect or are lost to cardiac care. Next slide.

This is why in collaboration with March of Dimes, we initiated CH Strong - the congenital heart survey to recognize outcomes, needs and well-being with the objective to identify people with heart defects, from birth defect surveillance programs in Atlanta, Arkansas, and Arizona who survive into adulthood and survey them on healthcare use and barriers to care, health concerns, and outcomes, social and educational outcomes, reproductive health, and quality of life. Next slide.

Using CH Strong data, we recently reported that adults living with heart defects were more likely than the general population to report additional cardiovascular issues such as stroke and heart failure. We also found that young adults with heart defects were eight times more likely to have a disability than young adults without heart defects. And in the interest of time, I will drop these article citations in the chat box if you're interested in learning more. And all of our CH Strong findings can be found on the CHStrong.org website. Next slide.

I'll now briefly transition to our CCHD specific activities. Next slide.

CDC tracks and evaluates CCHD screening policies. A CDC analysis showed that state mandates for CCHD screening might decrease early infant death by 33%. So we know that the uptake of CCHD screening is very important. And as of 2018, all states in DC had implemented policies to screen for CCHHD however, as also emphasized in the first webinar of this series, not all states systematically collect and analyze data on timing and method of CCHD detection, which could help identify program improvement opportunities and monitor the impact of early identification of CCHD. Next slide.

Therefore, we funded a new project this year as a component of CDC's population-based surveillance of birth defects program to collect data from eight states on timing and method of CCHD detection. The goal of the project is to understand the timing and method of CCHD detection, any disparities in timing of detection and whether the timing of detection is associated with newborn healthcare utilization.

The eight funded sites will conduct surveillance on CCHD cases, ascertain when and how the CCHD was discovered and collect data on CCHD screening results and timing of confirmatory echocardiogram. And three of the eight funded the sites are presenting today and will give some specifics on their state work during the next section of the webinar. Next slide.

Before I turn it over to the next speaker, I'd like to make you all aware of an upcoming funding opportunity. Our center is planning a new surveillance project with the anticipated funding in August of 2022, to identify a population-based sample of children and adolescents with CHD identified through US state birth defect surveillance systems and collect information via a parent or caregiver survey regarding the child's cardiac and other healthcare utilization, barriers to care, quality of life and other outcomes.

And this funding opportunity has been forecasted on grants.gov with the publication of the full notice of funding opportunity being anticipated within the next month. And I'll also drop the link to the forecasted summary in the chat box shortly.

And with that, I would like to turn it over to one of my colleagues, Erin Stallings. Erin received her Masters of Public Health with a concentration in epidemiology from Emory University's Raleigh School of Public Health. She currently works as an epidemiologist and data analyst within the Metropolitan Atlanta Congenital Defects Program at the National Center on Birth Defects and Developmental Disabilities. She'll spend the next few minutes giving a brief overview of some newly-published research. Erin?

Erin Stallings:

Thank you, Jill.

As Jill said, I'm Erin Stallings, an Associate Service Fellow in the National Center on Birth Defects and Developmental Disabilities. I'm going to give a brief overview of our recent analysis, looking at CCHDs in selected co-occurring congenital anomalies. Next slide.

For this analysis, we sent emails to all US state and territorial-based birth defects, surveillance programs, requesting mind-level data on CCHD cases delivered during the years 2014 to 2018. We asked for data on maternal race and ethnicity, maternal age, infant sex, pregnancy outcome, gestational age at delivery and infant birth weight. We also requested any additional diagnosis codes in the cardiovascular and chromosomal birth defect ranges using the code ranges shown on the slide. For our denominator, we requested aggregated data on total live births for each area, including maternal race, ethnicity, maternal age, and infant sex. Next slide.

For this analysis, we sought data on infants and fetuses with the following 12 CCHD diagnoses: Coarctation of the aorta, Common truncus, Dextro-transposition of the great arteries, Double outlet right ventricle, Ebstein

anomaly, Hypoplastic left heart syndrome, Interrupted aortic arch, Pulmonary valve atresia, Single ventricle, Tetralogy of Fallot, Total anomalous pulmonary venous connection and TriCuspid valve atresia. The diagnosis codes we used in our analysis are detailed in our paper in the January issue of Birth Defects Research and follow the NBDPN guidelines for these conditions. Next slide.

19 state and territorial-based birth defects surveillance programs submitted data for the CCHD spotlight paper. Surveillance programs were designated as using either active or passive case-finding based on how they routinely receive of data on their cases. Cases were excluded from our data set if they were less than 20 weeks gestation, if gestational age was missing, cases were excluded based on having a birth weight less than 350 grams. Cases were also excluded if both gestational age and birth weight were missing. When examining co-occurrence, data were limited to active case finding programs that could ascertain at least live birth and fetal death cases. Next slide.

This slide shows estimated prevalence and 95% confidence intervals for the 12 CCHDs we included in our analysis. Data for this analysis were limited to programs with active case finding who could ascertain at least five births and fetal deaths. Prevalence ranges from 5.4 per 10,000 live births for coarctation of aorta, 0.6 per 10,000 live births for common truncus. Our estimates are in line with previous national estimates using a similar profile of surveillance programs, including Mai et al's 2019 National Estimates paper in the 2012 NBDPN Data brief on CCHDs. By contrast, the range of variability in our prevalence estimates is much smaller than previously measured in the 2012 Data Brief, which may be an indication that case ascertain for CCHDs has improved in recent years. This could be a result of increased screening at birth. Next slide.

Our findings help confirm an association between CCHDs in advanced maternal age. The strongest associations were seen with Double outlet right ventricle, Ebstein anomaly, and Tetralogy of Fallot. Our analysis also showed a high prevalence of CCHDs among infants and fetuses, born to American Indian and Alaska native mothers.

One of the strengths of our analysis was the inclusion of racial-ethnic groups beyond White, Black, and Hispanic, as many analyses are forced to drop these smaller groups due to sample size. Previous reports by Aggarwal and Canfield also showed elevated prevalence in this group for a more limited set of individual CHDs and CCHDs, which suggests that this association may warrant for their study.

Our analysis also showed that 15% of CCHDs co-occurred with a chromosomal defect. Chromosomal defects co-occurred most frequently with interrupted aortic arch, common truncus and Tetralogy of Fallot, while the most common co-occurring chromosomal conditions among any of the 12 selected CCHDs were deletion 22q11.2 and trisomy 21. Next slide.

I would like to thank my co-authors on this manuscript. All contributing state and territorial birth defects surveillance programs and the NBDPN data committee for their input and work on this analysis. Thank you.

Jill Glidewell:

Thanks Erin.

Next up on our agenda, we're going to have three states describe their state-specific practices for surveillance and follow-up of CCHD and we'll start with South Carolina.

Vinita Leedom is the first speaker for South Carolina. Vinita manages the South Carolina Birth Defects Program at the South Carolina Department of Health and Environmental Control. Vinita went to LSU for a dual BA in International Studies in French, Tulane School of Public Health for her master's degree and is working on her doctoral dissertation at the University of South Carolina in the area of Birth Defects in Healthcare Utilization.

Vinita is also the mother of a seven year-old, a toddler, and is expecting her third child in May and Vinita, I will turn it over to you. And again, for those of you that joined a few moments late, we're going to hold all questions till the end of all the presentations, but feel free to drop a question in the chat box and Vinita, take it away.

Vinita Leedom:

Hi, I'm Vinita. Thank you for having us. So my colleague Minna Miller and I are today going to talk to you about what we're doing here in South Carolina in regard to CCHD detection surveillance. Next slide, please.

So just a quick refresher, in case anybody on the phone doesn't know. So there's different kinds of surveillance, whether there are data reports accepted from administrative data or case confirmation of that administrative data. There's also active surveillance, which is what we do here. And several other states, too. We look at medical records to confirm the presence of a birth defect, that it actually occurred, because as we know, administrative data can be flawed. Next slide please.

And then just also in case you're not familiar with the NBDPN, they set the guidelines for birth defect surveillance, and that is what we follow in South Carolina. Next slide, please.

In South Carolina, we're very fortunate to have a really robust law that allows us to monitor all birth defects, make referrals of families impacted by birth defects and all healthcare providers; and this is just a snapshot. All healthcare providers, payers, facilities, genetic centers are required to report birth defects to us, and the entirety of the medical record. Next slide, please.

So our nurses receive a monthly discharge report from all the hospitals and all the healthcare providers from whom we request reports. And then they go into

the medical records and verify the presence of a birth defect. Some of our case inclusion criteria are children under age two, problem pregnancies at every single still birth. And now because of the CHD Star Grant, we look at every CHD for any age, and then our data are automatically linked to vital records databases. When we enter a case for live births and demographic information from the birth certificate is auto-populated in. We are now working on getting access to vital records, but we're working on getting the data populated as well. Next slide, please.

So just a quick, again, overview of our data. This is our cases from 2008 to 2020. We actually go back a couple further years, but almost half of our cases were congenital heart defects. And if we were looking at, we don't look at ASDs in isolation, but if we were looking at those, this number of CHDs would be even higher. So of the 16,000 plus birthday defects we've identified, almost half of them were CHDs and nearly 2000 were CCHDs.

And then as you might be familiar, not all, some children have more than one birth defect. So while we had 1,600 confirmed cases in 2020, we had 982 children who might have had more than one birth defect. Next slide, please.

And then again, just a quick visual of the spread of our cases. So CHD is being the highest, next slide, please.

So, tying it together, let me just tell you before moving on about how we work together with pulse oximetry data, we do have a law here called the Emerson Rose Act that was started by the Emerson Rose Foundation, a really lovely family here who unfortunately lost their baby to hypoplastic left heart. And in 2013, worked very hard to institute an act that basically mandated pulse oximetry screening here. And so while facilities are required to perform pulse oximetry, they don't actually have to report any results. So they're sort of tasked with keeping the log of their passes and fails of babies that had pulse oximetry done. Data isn't linked on a programmatic level between newborn screening, blood spots screening, and birth defects, because there's not data to be linked. So while birth defects look at every baby that had a birth defect, including CCHDs, we currently don't, on and a regular basis, have access to the pulse oximetry data from newborn screening. So next slide, please.

So what we did, as a result of the CHD Star Grant from the National Center for Birth Defects and Developmental Disabilities that Jill discussed earlier, we first, we expanded our case ascertainment to include surgical databases. So for example, STS, we're working with PC four data. We are pretty confident that we're getting all of our CCHDs that are South Carolina residents here. Now that we have that, we're tying it together with the pulse oximetry data, we're doing a retrospective review of all cases of CCHD that were identified in 2014 to present and through 2026, at least.

The law was enacted in 2013 and it required the facilities to report. So our first full year of data was 2014, but it required facilities to actually conduct pulse oximetry screening, so some of the questions we're trying to answer are was a pulse oximetry done? Was an echo performed? What were the results and how can we describe the failed and successfully detected cases, including the timing and the outcomes. And again, just mentioning, this was due to the NCBDD grants for CHD Star and as well as the advancing population-based surveillance. Next slide, please.

Just a quick review of our referrals. We refer everybody with a neurology defect, every family, to Greenwood Genetic Center, but then we also refer every single child that we see, including with CHCs, to early intervention, so that's about 3,500 children since 2018. And that's when we started doing that. What's interesting to me is here in South Carolina, CHDs are not automatic qualifiers for early intervention services, but as we get reports back from early intervention about who's becoming eligible for the first time, we're finding it's the kids with the CHDs that we're referring. So while they might have had advanced surgeries, they might not even have a major CCHD, definitely the ones with CCHDs, those are the kids that are getting screened because of the referral from birth defects. And they're finding they do have developmental delays. And I believe that's in my slides. The next slide...

PART 1 OF 4 ENDS [00:24:04]

Vinita Leedom: ... Development delays. I believe that's the end my slides. The next slide, please. And then, I'll turn it over to Minna Miller, my colleague here at DHEC.

Jill Glidewell: Just a short while for Minna. Thanks for joining us, Minna. Minna Miller is a registered nurse abstractor for the South Carolina Department of Health and Environmental Control. She's been there for a year and a half, coming to public health with nearly 20 years of clinical nursing experience. Minna.

Minna Miller: Thank you, and thank you [Vineeta]. Good afternoon, everyone. My name is Minna Miller and, as she just said, I'm the lead abstractor for this DCEH project here in South Carolina. Today, I will be discussing our data quality for this project. Next slide please.

As a surveillance program, we collect data and use that data to prevent adverse health conditions. Specifically for CCHD, we are collecting time and method of detection, and this data will be used to show the true impact of the CCHD screening. Next slide please. There are many variables that we are abstracting from the medical records. These that I have listed are examples of the variables related to just the pulse ox set. These highlighted in yellow are what I found to be most difficult to find. Extremity used to measure oxygen saturation, oxygen saturation of the right hand and foot, age at pulse ox, screening in hours, location or a pulse ox screening performed at or around time of delivery.

Next slide. Here in South Carolina, we have identified 816 CCHD cases dating from 2014 to 2020. Most of these cases are found at the bigger hospital systems like MUSC and Prisma. If a CCHD has been identified after delivery at a rural or smaller hospital, they will usually end up at MUSC or Prisma. These two hospital systems use EPIC and Cerner, and these are two of the easier charting systems to navigate. One of the drawbacks of finding information on older cases is that sometimes the older information does not transfer over during a system change, especially the prenatal information.

Next slide. Strength [inaudible] project, as a birth defects program, we have already abstracted many of these CCHD cases over the years. Also, it is easy to find certain variables such as the mom and infant delivery information, CCHD diagnosis and other birth defects and CCHD pass or fail. Also, vital records will be providing us with the mom's demographic information, number of prenatal visits, entry into prenatal care and exact time of birth. We will also be asking for death certificate information.

Next slide. More strengths for us. We already have remote access to all the birthing hospitals in South Carolina. We already have a data system in place that we use for our birth defects program and, finally, we have two clinical abstractors working on this data with a third to be hired very soon.

Next slide. Along with our strengths, we also have our challenges. Some of these obstacles include when and where CCHD screening is done, maternal education, number of prenatal visits and just prenatal care in general. These have been difficult to find at times. Sometimes records are scanned into EPIC or Cerner. However, at times, these records are not easy to read if they're scanned in improperly. Even though we will be getting the number of prenatal visits from the birth certificate or vital records, this number is not always reliable, but it is a start. Sometimes it may say five visits, but the mom actually had 17 visits.

A few more challenges we have seen involve when the infant was discharged from the NICU, prenatal echo information, especially for those older cases where charting systems are different and, lastly, ICD cause of death code and cause of death verbatim. That concludes our overview of data quality here in South Carolina. If you have any questions or comments, feel free to ask us later, or you can always email us at this address here. Thank you for your time today.

Jill Glidewell:

Great. Thank you, Vineeta and Minna. Now, we'll turn it over to Dianna Contreras from Arizona. Dianna is the manager of the Arizona Birth Defects Monitoring Program within the Arizona Department of Health Services. She has experience in public, private and community health settings. Her current role includes activities in birth defect surveillance, referral to services, birth defects prevention efforts within internal and external partners. She's actively serving as the Co-chair of the Programs and Professional Development Committee of the National Birth Defects Prevention Network. Dianna.

Dianna Contrera...: Thank you so much, Jill. As Jill mentioned, I'm the manager of the Birth Defects Program in Arizona. Next slide. A really brief overview just to give you a little glimpse of what we do compared to South Carolina. In Arizona, birth defects surveillance is mandated by legislation. We are grant and state funded. We have a variety of partners at all different levels. We currently monitor about 40 categories of birth defects, which result in about 180 diagnoses, including all CCHDs and most CHDs.

Next slide. In Arizona, surveillance is active. Case finding through our hospital discharge data and vital records, and a few other sources, results in a little over 2000 potential cases each year. We review each of those medical charts for confirmation and any cases confirmed, we go into more detailed abstraction and entry into our Birth Defects Registry. As a population based program, there is specific criteria for inclusion to be a reportable defect, although we do catch all confirmed birth defects in our database, regardless of if they're officially reportable or not.

Next slide. The background of CCHD screening in our state is a little bit different than South Carolina as well. CCHD, as a point of care test, was added to our newborn screening panel in Arizona in 2015. We recognize that most states were already screening so we didn't want to mandate that portion. However, different than South Carolina, we do mandate reporting. Screening itself is not mandated, but most facilities do it. But if a facility screens or if a screen is done, that result has to be reported to newborn screening. Only pass/fail or not screened is officially reported on the Newborn Screening Bloodspot Card. And then, if a fail is reported, it's mandated that a failed form be followed within 30 days. With all of these pieces in place, it took a little while to get all of the forms completed and delivered to facilities. True reporting began more in 2016.

Next slide. I get asked this question a lot about why we only require the pass/fail portion. I do want to say our rule writing and rule making process was a great opportunity for different programs to come together. It involved newborn screening, our birth defects program, and several levels of leadership. We debated the value and the importance of specific numbers versus just the pass/fail. We argued that we needed those values. The counterpoint was that it was well within the scope and jurisdiction of birth defects to request or review or follow up on any of these potential infants. The short answer is that we lost, but we were granted the piece where that failed form is mandated within 30 days so we were able to get a little bit more data, little bit more information without having to specifically review or request every chart.

Next slide. The importance of this form is that, again, with just pass/fail or not screened mandated or required initially, we really need to be able to understand our data better. The forum is meant to help us verify and validate the values that it is, in fact, a true fail to ensure that proper follow is done for the newborn. We assume that it is because of the severity and the potential diagnoses, but that's not always the case. To help us facilitate referral to

services, if we get early identification of these children, then we could process those a little bit faster and get them support services. And then, of course, as a quality assurance piece for birth defects case finding. If these are true fails, we expect to find them later on. This form is critical in our process.

This is just a little glance of the screening card, and this is part of why we weren't able to ask for more. There's a lot of information on our newborn screening card. The bottom left of that card is the pulse ox portion and below that image of the card is what it looks like. It's pass and we ask for which attempt they passed on, the not screened and we ask for the reason and then, of course, the fail. Next slide.

And then, the follow up to that is this Pulse Oximetry Failed Form. We ask for a lot more demographic information so we'd be able to find the baby if necessary, pulse oximetry results, detailed hand/foot percentages, and all of the attempts, and then what happened to the baby? Were they referred out? Were they diagnosed? Did they have surgery or an echo? Was there a co-occurring disorder? Really, all the information that would help us better serve the infant and also be able to follow up both for services and as far as data. Next slide.

A couple of years after screening and reporting started, we were invited to share our data at Newborn Screening Advisory Council. They had a lot of questions. This was still a fairly new program and a fairly new process, and they wanted to know how it was going. We went to pull our data and we found issues. We found inconsistencies. It was the first time we really thoroughly looked at what was going on. And so, that led to taking on a continuous quality improvement project. The basic problem statement is on the slide. We had a lack of accurate and current data, and that caused an inability to be able to evaluate the process to the program, the screening. We had mandated this, and we couldn't provide our stakeholders proper answers to questions that they were asking. Next slide.

This was the data that prompted our first kind of whoa, what's going on? The blue line were the reported fails of the screening it in our Neometrics, our newborn screening database. The solid red line were the fax forms that we received. The dotted line were the fax forms that we received that actually had a fail. A lot of inconsistencies. Clearly, even though we had mandated reporting, reporting was not working the way we had envisioned. Next slide.

When I say we turned this into a formal CQI project, we went through every piece, every process. This was our formal process map, including all of the players, all of the steps, what was happening, where and why. We really dove into our data and all of our processes. Next slide.

The initial internal and external issues we identified, really quickly early on, were, first, that the algorithm wasn't necessarily being properly interpreted. The newborn screening card was not being filled out correctly or accurately at times.

There was a complete lack of awareness of the CCHD form within facilities. Even facilities that were aware of it, they didn't necessarily have it listed in their policies and procedures. When people went to review their processes, it wasn't always included. The Neometrics, newborn screening database, contained a number of inconsistencies. And then, the process of receiving those failed forms at the lab, and then next step to birth defects, it was a little bit broken. Next slide.

We dove deeper into a lot of these issues, starting with the state lab. We glanced at a handful of newborn screening cards and found that some of the fails were not reported in the database or some of the fails in the database were not documented as that on the card. We actually reviewed all fails for 2017 and 2018, and we compared the card to what was in the database and then we, ultimately, looked at the medical charts as well. We found a lot of inconsistencies between the card and the database, whether it be typos or misunderstanding, misinformation. We corrected all of those, of course, and then we also implemented a quality assurance report process where every month newborns screening reviews 20 random cases within Neometrics, compares it to the card to make sure that we're accurately reporting those. Even after training and some process improvement, the first year that we did this process, we still found 2% needing edits. It's definitely a valuable process alone, and that continued. Next slide.

At the facility level, we knew we were having issues with, again, the policy, the implementation, the process of filling out the card. We started with a survey of our partners, birthing hospitals and nurse managers, and we used those responses to kind of develop education and outreach. Next slide.

Just to glance at what we asked and what we received. If they had a policy and procedure related to CCHD screening, and if part of that included a quality control process, most fortunately did have something in writing that they followed. Some didn't answer and some didn't know or said no. Next slide.

The big question was if they even knew about that CCHD failed form. A lot of them did. A lot of them didn't. Even if they did, again, that wasn't necessarily part of their policies, procedures. We took all of this information and we created an outline for training and outreach. Next slide.

We started with the hospitals that had the highest number of CCHD fails, the hospitals that were the least compliant with reporting, and the hospitals with the largest number of births, and then we reached out from there. We went start to finish with this process. We looked at the newborn screening process, the actual screening technique that was being used, how to fill out the form, reviewed that failed form and talked about it in depth with them, trained them on how to fill it out. Really tried to emphasize the importance of that. It's not just about data. It's really about getting those babies into care and services a

little bit more quickly, and connect them to resources. That helped the nurses certainly understand the value of it instead of just thinking it was data for us.

We actually did a data review though. Oh, sorry. We did a data review with them. We showed them how many babies at their facility had birth defects, specifically heart defects. We looked at their newborn screening data and we did customized score cards for each of them. It really helped for them to own what they were doing when we presented personalized information. And then, we talked about training new employees or offered assistance in policy updates. We really went every branch that we could and we included both birth defect staff and newborn screening staff for these training and outreach and meeting with hospitals. Next slide.

The short version is, after these intervention, it greatly improved. It's not perfect, but clearly our lines are a little bit closer together. If you look at that 2019 quarter one where we had zero failed reports and 2020 quarter one, it definitely improved. The number of appropriately reported fax forms compared to fails had definitely come together a little bit more. You see the dates that we did this. We stopped in March of 2020. Clearly everything got stopped because of COVID, but even the improvements that we found in that process were valuable and we do hope to resume that. Next slide.

The basic processes that we included and we've continued, the feedback from the facilities did prompt some revisions of that failed form and the processes for submission. We started sending reminder letters to our facilities if they had fails that had not been followed up by that form. We offered quarterly score cards with data for the facilities, again, helping them see their own data rather than statewide data. We offered annual training for facilities. We implemented monthly metrics and processes, including that randomized QA report for newborn screening. We also started validating all of our failed screening. Every fail that comes across, we enter their information into a database, it automatically calculates the values and confirms that it was a fail. On those spreadsheets, we also look at the outcomes. What potentially caused that fail? What's going on at the hospital level? What's going on with the process, and really trying to look further into those outcomes of the children that are failing in the screening? We've taken it from this quality project to really trying to evaluate the value of the screening, which was what we started with initially. Next slide.

The project takeaways were really that we had improved data and reporting for CCHD screening. It definitely fostered a better relationship between newborn screening, birth defects and the facilities and created a better joint effort. It wasn't just us or newborn screening with the facilities. It was all of us as one team. It was the potential to continue with annual training, service outreach for facilities, really trying to offer them assistance and technical support rather than just mandating data. The bottom line that even though the timing was awful with COVID starting and we were only able to implement a few of these

processes, in just the project period, the appropriate reporting of those failed forms compared to fails went from 13% to 20%. We do consider that a win. Next slide.

Broader than the project, we also had some program takeaways. Issues remain even with mandatory reporting. South Carolina mentioned that they don't get that glimpse that we get. Even with the mandated reporting, we still see issues. The process provides an opportunity for QA at all levels, both screening, reporting, newborn screening data, and birth effects data, which is huge for all of our programs. We definitely needed the reminder that even with reporting and different programs involved, we all need to take accountability for that.

We assumed that follow up was the responsibility of the facility because of the potential seriousness of the diagnosis and outcomes for a failed screen but we found that that wasn't always the case. We had a few poor outcomes because follow up wasn't done. And so, we have a bigger conversation now at the table and that's positive because at least we're talking about it. With a few extra eyes in the process, we can certainly hope to improve outcomes even further. Early intervention and referrals are not always possible because of the errors of reporting, because we don't always think it's as seamless as we had hoped. That's certainly a conversation that we continue to have. We are working on that and we hope to expand it, but we do recognize that, programmatically, we have some things to work on. Next slide.

Basically, our future plans and goals are to do all of those things, really streamline that referral process and the early intervention, because we know it's so important. We know that these babies have different outcomes and poor outcomes as far as developmental and behavioral issues and we want to improve those outcomes. We do plan to continue to evaluate our data, of course. Our initial CQI project has now led us to having about three different spreadsheets of data and all of this information. We really hope to be able to report soon on false positives and false negatives to really better evaluate the screening in general. That is all I have. Thank you so much.

Jill Glidewell:

Thanks so much, Dianna. Next, we'll move to Minnesota. Heather Pint will be the speaker for Minnesota, and she received her Bachelor of Science in Nursing from the University of Minnesota. She has nursing experience in obstetrics, home care and public health, both at the county and state level. She's worked at the Minnesota Department of Health for 12 years, six of those years at the Vaccines for children Program and the other six with the Children and Youth with Special Healthcare Needs Section. Heather, I will turn it over to you.

Heather Pint:

Hello, good afternoon. My name is Heather Pint and I do long term follow up for CCHDs in Minnesota. First, I'll start with just a high overview of how we collect our CCHD screening results, but I'll focus the majority of my presentation on my role and our partnership between the newborn screening program and birth defects and how we connect kids to services in Minnesota. Next slide, please.

This is a high level summary of our Minnesota legislation and all babies are required to be screened unless they get an echo. The other good thing about our legislation is that we were able to determine the mechanism of reporting for those results. And so, we decided to collect the screening results using an electronic screening collection method, and we called this software MNScreen, and so that's made things a lot easier for us. Next slide, please.

I'm not going to go into too much detail on this today because my presentation is mostly about services, but our CCHD screening results are collected directly from the screening device. This goes directly into MNScreen and this collects both the CCHD screening results and the hearing screening results together. Next slide.

You can, next. You can do the next too. There we go. This is an example of the data that we get. Oh, go back one. This is an example of the data that we get for the CCHD screen, and we're able to tell the age at screening, how many...

PART 2 OF 4 ENDS [00:48:04]

Heather Pint:

Screen. And we're able to tell the age at screening, how many screens are done, the oxygen saturation on the hand and the foot and our system also gives the screener the suggested answer of pass rescreen or fail, and we're using this data for our component C part reporting for the CCHD grant that South Carolina talked about in their presentation.

Next slide.

So although our programs work very closely together, the Newborn Screening Long-term Follow-up and the Birth Defects Programs are located in a completely different division than the Public Health Lab, where the Short-term Follow-up is done. Both Newborn and Child Follow and Birth Defects are located in the Child and Family Health Division, and at a more granular level, we are located in the Children and Youth of Special Health Needs Section. My position is a shared position between Newborn and Child Follow-up and Birth Defects and focuses on the development of the Long-term Follow Program for CCHD. I also review and confirm the coding for the 12 CCHD Newborn Screening Target Conditions that Birth Defects collects.

Next slide.

And even though the Newborn Screening Short-term Follow-up is not co-located with us, we still work very closely together. This slide gives an example of the collaboration that goes on for CCHD case finding between the programs. If a baby failed the CCHD screening, the Birth Defect Program is able to look for the echoes as a possible Birth Defects Case, and if it turns out to be a case, they're able to collect the information for their surveillance data. If it's not a case, the Birth Defects Program is still notified of the normal echo or that Birth Defects

was not able to find an echo so then they're able to do their quality assurance part and contact the hospital for education purposes. I also do the reviews for the 12 CCHD Newborn Screening Targets so I'm able to put information into MNscreen on a rolling basis for the Newborn Screening System on those cases. At the end of each year, the programs do a case match to confirm all cases of CCHD that each program is aware of for both surveillance and data of quality public health activities.

Next slide.

I wanted to take a little time to talk about some of the pros and cons that we have observed with our Newborn Screening and Birth Defect partnership. The first being our Birth Defects Program has very skilled coders and they're able to easily look at the echoes for the failed screens using remote access to the EHRs to determine if it is a case or not. This makes less burden for the hospitals and also faster case identification and confirmation for both programs. This process also connects families to resources sooner, which I will talk about a little more in the next slides. Some of the cons would be this is a change from the normal workflow of how cases would come into the Birth Defects Program, but the ABS directors don't miss a beat and this has not really been a problem. There can be delays if there is trouble with remote access, but this has been very minor for us. And the last issue is the lack of interoperability between the two systems as each system has its own data collection software that do not currently speak to each other, and this causes for a lot of hand entry for me between the two programs, but we are looking at some solutions for that in the future.

Next slide.

Next I'll talk about our partnership with Local Public Health.

Next slide.

So our partnership with Local Public Health began back in 2005 with an informal partnership with Birth Defects, and this includes the CCHD's. EHDI began a more formal partnership in 2009 with a contract and formal processes. In 2011 Both Birth Defects and EHDI had partnerships, but they were collecting different information. In 2017 they streamlined the process and began collecting the same information with the standardized family assessment. With our new five year grant that just started in 2022 we added the blood spot conditions. So now all of our Newborn Screening Conditions and Birth Defect Conditions are getting a referral to Local Public Health.

Next slide.

So for our CCHD families we are sending a letter and a resource brochure to all of families that are identified with a CCHD through either failed screening or the Birth Defects Registry. The flyer contains resources that were identified as

needed in a parent survey with a special focus on parents-to-parent support and financial resources. This for was developed by a mother of a child with a CCHD as a special project while she was one of our student interns. Families also receive a referral to their Local Public Health agency.

Next slide.

I talked about our partnership with Local Public Health a little earlier, and through that partnership, we have a contract with our Local Community Health Bards to contact families and do a family needs assessment. We have implemented a standard tool that they are using for documentation of the family needs and interventions that they provide. There are five different focus areas, income, growth and development, care taking and parenting, healthcare supervision and communication with community resources. The assessment is used to identify needs, connect the family with resources and gather relevant public health follow-up information. This assessment is conducted within about three months of Local Public Health receiving the referral. They are mostly done before one year of age, but this can vary a little bit depending on the program.

We will also pay them for a second assessment if they feel like the family needs some additional follow up in the next month or so after the first assessment. This is an example of the early intervention status of children with the CCHD that we have reached for first assessment. So for 2018, there were 146 total CCHD reimbursable cases sent to Local Public Health and 82 assessments that were completed. So of the 82 assessments 43% of those children were enrolled in early intervention at that time. Keep in mind that these are only the families that Local Public Health was able to reach and do an assessment on. So this isn't all of the kids that are in early intervention that have, have a CCHD, but it gives us a picture of the families we're able to reach and the interventions that Local Public Health is providing.

Next slide.

I know this one is hard to see, but this is a poster looking at the growth and development and care and parenting interventions that we presented it at the last EPHL conference. I wanted to show these examples so you can get an idea of some of the public health information that we are collecting from the assessments, as well as getting families connected to important local resources that they may need. That local connection is so important and those Local Public Health nurses know all the resources and in their communities the best.

Next slide.

Our Birth Defects Program also has a Grief and Loss Support Grant. Since 2020 our Birth Defects Program has partnered with our Infant Mortality Program to provide bereavement support to all Minnesota families after the death of a baby during pregnancy or infancy.

Next slide.

MDH sends weekly fetal death reports and infant death certificate information to the grantee. Each family receives a sympathy card and a resource guide. A follow-up phone consultation is also made by a case manager with follow-up through the first 12 months. The case manager does an assessment, and is able to make referrals and provide access to resources.

Next slid.

This slide shows some of the different resources that Star Legacy is able to offer to the families, support groups, funeral/memorial assistance, and mental health professionals are important resources that they're able to offer. In the first nine months of 2021 the grantee received information for 441 stillbirths and infant deaths. 99 of these deaths were to a child with a birth defect, and this includes the CCHD's, all families received a sympathy card and resource guide. The grantees reached out to 90% of families within three weeks of the death report by the case manager. So 80 of those families received that call also within three weeks of that death report. So a great resource for families as well.

Next slide.

And this is my contact information. If you have any additional questions, I'm happy to connect or share anything that we're doing.

Jill Glidewell:

Thank you so much, Heather. Our last speaker today will be Dr. Brad Marino to describe neurodevelopmental and care coordination needs for individuals with CHD. Dr. Marino is the chair of the department of Pediatric Cardiology at Cleveland Clinic Children's and the Executive Co-director of the Pediatric and Adult Congenital Heart Center at Cleveland Clinic. He's an internationally recognized Pediatric Cardiovascular Outcomes Researcher with interest in focusing on the impact of surgical and intensive care unit factors on morbidity and mortality. He's also pursuing novel investigations of the impact of neurodevelopmental health on cardiovascular health in the young. Dr. Marino was also so the inaugural co-chair of the Cardiac Neurodevelopmental Outcomes Collaborative, Dr. Marino.

Bradley S. Mari...:

Thanks Jill I really appreciate you and the organizers having me here today, and I'm excited to chat with you about neurodevelopmental care coordination needs of children with CHD.

For my disclosures I am the Creator of the Pediatric Cardiac Quality of Life Inventory, I do have National leadership roles with the Cardiac Developmental Collaborative, Congenital Heart Public Health Consortium, and the AHA.

This is slide from Cleveland Clinic relative to our STS Congenital Heart Surgery Operative Mortality results. You can see on the right side, higher volume centers

and left side, lower volume centers, and you can see that overall across the country for the 120 Pediatric and Adult General Cardiac Surgical Programs. Overall now is about 3.2%. And at the best programs is less than 1%. So extensively. If you have congenital heart surgery in the United States today, it is expected you will survive. Excellent.

There are important morbidities after repair versus palliation, then there are Neurodevelopmental, Neurocognitive, Psychosocial and Psychiatric, Late Surgery or catheter based re-interventions, incidence of of arrhythmias, chronic heart failure, transplantation, pulmonary hypertension in some patients, Endocarditis in some patients and other important end organ dysfunction, including chronic renal insufficiency, as well as liver insufficiency and coagulopathy leading to thromboembolic complications.

Today, I'm going to talk to you specifically about Neurodevelopmental/Neurocognitive and Psychosocial and Psychiatric issues in this population.

We just click through these as we go- there we go, thank you. So ultimately when we think about a child with congenital heart disease, after conception, during the in utero development, there's obviously the genetic predisposition that leads to congenital heart disease, and then based on altered cerebral blood flow and oxygen delivery and Environmental Exposures, including Placental Impact, there's delayed brain maturation with white matter injury at birth. Then we have surgery and then through a host of events we have acquired white matter injury with abnormal microstructure and decreased connectivity. The several factors that impacts how much acquired white matter injury there will be including hypoxemia, additional surgeries, developmental interventions that may help, you know the white matter injury, drug exposures, specifically narcotics and benzodiazepines then obviously protective type may be home environment, socioeconomic status.

One more click. There you go.

There are susceptibility genes that obviously interact with the environment that may result in more delayed brain maturation, white matter injury, as well as the acquired white matter and abnormal microstructure decreasing activity. All of this leads to neurodevelopmental disabilities.

Next slide.

So what is neurodevelopmental phenotype CHD survivors? Well, first we see mild cognitive impairment with normal to slightly lower IQ and Academic Achievement and master language. We see impaired pragmatic language skills, decreased visual construction, perception, poor executive functioning, inattention and increased impulsivity, higher risk of attention deficit hyperactivity disorder, and then diminished fine and gross motor.

These individual deficits or delays may be mild, but often occur across multiple domains. This high prevalence-low severity picture does not meet the classic criteria of a learning disability. Many of these children have difficulties in school who may not qualify for special services.

There's also a psychosocial pain attack that we see in these survivors with impaired social interaction deficit and social cognition, impaired core communication skills, including a higher incidence of autism spectrum disorders, increased insulin, psychiatric disorders, specifically anxiety and depression as well as issues of behavioral, emotional functioning, in addition to anxiety, depression, post-traumatic stress.

Next one.

We know from my colleague Kathleen Mussatto who published a paper in 2014 that the developmental delay that we notice in our infants changes over time.

Next please.

And that the quote from that "Exposure to risk and prevalence of delay change over time, therefore, repeat evaluations of warrant."

Next slide.

So how should we maximize long term outcomes of children with CHD? Well, from my perspective, both as a clinician and as a scientist, we really have the patient reported outcome measures, including Health-related Quality of Life. And I would argue that Health-related Quality of Life is a new Vital Sign. We know the pediatric population of patients with cardiac disease based on disease complexity. They have various medical surgical cancer based therapies. Only as I showed you know, less than 3% now in the country, mostly, those patients will die and 97% will survive the better percent of 98, 99%, that results in morbidity, including their developmental, psychosocial, physical morbidity, all of which impact, quality of life.

Next slide.

How is the quality of life defined? It's defined as physical health and physical functioning, psychological functioning, social functioning, and describes the child's ability to function in situational context and derive personal satisfaction from doing so. You notice that the brain impacts all three of those domains, social functioning, psychological functioning, as well as physical functioning.

Next slide.

I created the Pediatric Cardiac Quality of Life Inventory. It's been validated, it was in 2010.

Next slide.

I apologize for the spacing here. It didn't look like that on my computer. So from the Pediatric Cardiac Quality of Life Inventory Research Consortium, which has 19 centers in the US and the UK. Of more than 3000 patients and their parents we know that quality of life in CHD survivors is lower than heart healthy children. The quality of life and CHD survivors worsened with increasing disease complexity, increasing medical materialization is associated with low quality life CHD survivors. Most importantly, with any specific cardiac subgroup, like for example, the five, 10 group or children with biventricular cyanotic patients out of surgery or a child with mild congenital heart disease like ASD or mild PS. There is wide variation called life school within these specific subgroups.

Next slide please.

So, and obviously in a 12 minute talk, I can't show you all the data, but basically our, our quality of life scientific predictor analysis have shown that there are multiple issues that create this variation to quality of life score, and that if you really do want to nurture neurodevelopment and psychosocial resilience to improve quality of life, we need to set up surveillance programs and evaluate from management programs that provide neurobehavioral and psychotherapy in the child and adolescent with CHD to minimize the impact of social cognition issues, psychiatric issues, specific anxiety, depression, autism spectrum, and affective disorder, and ADHD. We have psychosocial support to have the child improve the self-perception. We have therapy in the patient, the parent to prevent and treat PTSD prior to invasive procedures in the ICU, and during follow-up and prevent and treat anxiety and depression. These programs also need to reduce parental stress while raising a child with chronic disease.

So how should we follow these patients evaluate and manage them over time? This is an AHA AEP statement that came out in 2012, which was the first of its kind laying out the landscape and the specific requirements to evaluate and management of children with CHD relative to the neurodevelopment psychosocial deficits.

Next slide.

In these guidelines we talk about diagnosing developmental disability and developmental delay through Surveillance, Screening, Evaluation, and Management. We want to put interventions in place to prevent or treat the ND Psychosocial phenotype noted in the pediatric cardiac population to maximize long term outcome.

Just click through the bullets please.

In order to maximize health-related quality of life, maximize educational attainment, to reduce the incidence of anxiety, depression, and stress in family

members and family dysfunction to maximize the adult transition ACHD for outcome.

Here's the algorithm you'll notice at the top, it is a 2006 AAP algorithm of developmental assessments specifically for children, but then you'll notice where it says three B. If a child is considered high risk pediatric general heart disease, they immediately move into the ND high risk population, which can gray on the bottom. And they are referred directly for both a medical and developmental evaluation.

Next slide.

So whose high risk? Neonates, infants requiring open heart surgery, children with other cyanotic heart lesions not requiring open heart surgery, neonatal or infant period, specifically those with eponyms anomalies to try and [inaudible] treated, for example. Terms of any combination CHD and other co-morbidities we'll talk about one second, then other conditions, determinate discretion of medical providers.

Next Slide.

So if a child is CHD and has any of the following co-morbidities they are considered high risk. Prematurity, developmental delay recognized in infancy, suspected genetic abnormality and/or syndrome, history of mechanical support, heart transplantation, CPR at any point, prolonged hospitalization defined as greater than two weeks, perioperative seizures related to CHD surgery, and then significant abnormalities under neuroimaging and/or microcephaly.

Next Slide.

The neurodevelopment recommendations for patient stratified and high risk include referral to formal development of medical evaluation. So errors you do not screen, you literally just refer them as the high risk immediately for developmental evaluation. Referral to early interventions are as or early childhood special ed services, prior to confirmation developmental diagnosis, these children are very high risk for developmental delay, and they should have early intervention services in place during infancy. There should be periodic re-evaluations for developmental disabilities in developmental delays at 12 to 24 months, three to five years, 11 to 12 years. The 12 to 24 months to make sure these influence get plugged into early intervention so that they're seen by a cardiac developmental program with developmental pediatrician. Three to five so they can have a preschool assessment prior to starting kindergarten and 11 to 12 years of age before when they're middle school before one high school and obviously referral of young adults for higher education educational count.

Next slide.

So another way to monitor these patients is through CNOC. So CNOC is a Cardiac Neurodevelopmental Outcome Collaborative, as Jill told you earlier, it's the first co-chair for CNOC. The team started meeting in 2013 it became a 501c3 in 2015.

Next slide.

CNOC is a multi-centered multi-national multi-disciplinary group with healthcare professionals committed to working together and partnering with families to optimize their neurodevelopmental outcomes for individuals with pediatric, and congenital heart diseases, through clinical, quality, research initiatives, intending to maximize quality of life across the life span. CNOC has a data coordinating center, it has a data analytics core, it has a registry, it's currently involved in three countries, 46 participate institutions, and 1000 members. Remember I said, there were 120 pediatric cardiac surgical programs in the country, more than one third of them now belong to CNOC.

Next slide.

So CNOC has put out specific recommendations for evaluations in the birth through five group, as well as in the school age group as well. This is additive to the AHA guidelines. And if you look at the AHA guide of 2012, and these two page came out in the last 18 months, you'll have all the extant literature on how to evaluate and manage patients during childhood.

Next slide.

So when we think about how we should care for children with heart disease and their families long term-

And quickly click again, click one more time. There you go.

So the primary cardiologist will take of physical morbidity. They're really not trained to nor do they really have any interest in dealing with neurodevelopmental morbidity or psychosocial morbidity. The first cardiac development form was created in 2007 by Cathy Mussatto in a children's house of Wisconsin with her colleague Cheryl Brosig. I created the third one in the country in 2011 at Cincinnati children's and it was the first one at that time that some kids, not just birth through age three, but through young adults with college age years, since that time, more than 50 of them have opened across the country over the last decade, which is a dramatic, dramatic change in our field.

These [inaudible] homes addressed could have been.

PART 3 OF 4 ENDS [01:12:04]

Bradley S. Mari...: ... Change in our field, these cardiac ND program address a critical gaps in how we care for these children with heart disease and their families. Next slide. This is an example of my program when I was at Lurie Children's, now obviously Cleveland Clinic, and we're about to open our program here. These programs are often generally the high risk cardiac patients in my program in Chicago with NICU and cardiac patients. It's a combined program. There was regular developmental evaluation's infancy through adolescence. Psychology and neuropsychology evaluation management, PT, OT, speech therapy, access to dieticians, social workers, nursing, and APNs. And care from developmental pediatricians and special educators. Next slide. So the care model within in the medical home for all these programs is basically at this cardiac developmental program team interacts with the pediatric cardiologist or ACHD provider, as well as the generalist, the general pediatrician, family practitioner, internist. They don't take the care over, a medical care of the patient over, but they do become the focus for the neurodevelopmental psychosocial assessment. Next Slide.

So there are multiple different models that you can use to follow these patients. When I was in Cincinnati Children's and I asked my NICU colleagues there, could we work together to build a cardiac butler program? They said, absolutely not. And they want ever siloed approach. So we built separate high risk NICU and cardiac populations involves in two separate clinics with no interaction. You could also have a separate NICU and cardiac population set of clinics, but the non MD core staff works in both for efficiency standpoint. You could do it in Chicago, which is having a single developmental support follow for a high risk NICU cardiac population, which is highly efficient financially, highly effective because a lot of white men incur that the high risk NICU babies is similar to the high risk cardiac patient, or you can do what we're building right now in Cleveland Clinic, which is a singular developmental follow up medical home for high risk children that includes many populations.

Go to next slide. So right now Cleveland Clinic, we're basically having multiple populations follow up with quickly, a core team of developmental pediatrics, neuropsychology, psychology, psychiatry, advanced practice nursing, habilitated services, speech, PT, OT, audiology, nutrition, and social work. Click please. Who will have specialty physicians and here are some examples here, cardiology, critical care, neonatology, neurology, pulmonology, surgery parachute in on particular days in the clinic to work with this core team to take care of these specific populations. While I've shown here, neurology, neurosurgery follow up cardiac ND developmental follow up, neonatal follow up. These are just some examples of a much broader population patients that you could see with frequent obviously additional consults, including adolescent care, palliative care, genetics and obviously education from the school education. Next slide.

So the CNP team that I have created at several institutions now includes what we call Developmental Intensivists, who are basically NICU, PICU, cardio ICU doctors that have specific interest in these populations. As well as developmental pediatrician, PT, OT, and educators. That core team with social

work has been a very successful core team for me. Both at Cincinnati Children's and that when I was at Rye were building that in the clinic, but you have to have access to, a neuropsychologist for testing in two thirds of the patients, a psychologist for a lot of the issues with the patient and the family geneticist, neurologist, dietician, speech and speech language pathologist, but the educators particularly important. Next slide.

We know that patients with CHD survivors will, one third and one half of them, will have special ed programming. We know one in six are placed in substantially separate classrooms. We know one out of five were repeated grade, at least once. And one out of four receive occupational therapy, physical therapy, speech therapy, and psychotherapy. Next slide. As a result, the educator becomes very important. So we have always had an educator in our clinic, the talk scan before they come in there, the child of a 5 0 4, an IEP, if so, what send it to us and can review it. Then the patient comes into the clinic, then meet with the educator quickly. And then that same educator works with this family outside the clinic, in the community schools. You can have the greatest assessment and have a 12 page document that you send to the pediatrician.

It's like no one to advocate for that family. With the community schools, it's as if the tree fall in the far and there's no one there. Next slide. So you have to have what I call the tip of the spirit, have someone who can take these important evaluations and bring them to the schools with the families for free. As we know, sometimes getting this kind of educational support in the schools can be hundreds of dollars from educational lawyer or an educational advocate. 50 percent of the patients who have heart care in this country, Medicaid and they cannot absolutely not pay for that. So I think it's incumbent upon all of us to provide that support to the patients available. Next slide.

Getting patients into these clinics, their developmental clinics is not easy and it takes a lot of communicating with both the general cardiologists and patients and families. When I was a fellow in the 1990s, I used to walk in a room and say to families, take great care of your baby when you do surgery and they're going to be just fine. Well guess what? That's a big lie. Half of them, aren't just fine and we have to provide those great supports. And then there's obviously the grand re-education. Most cardiologists think, oh they're not hypertensive. They've got great a reduction they're on the diuretics, etc. They're fine. And they don't even delve into any of the nerve develop psychosocial issues that these patient family face and that grand re-education is ongoing. And I think we've made a huge headway in the last 10 years with pediatric cardiologist and pediatricians about this, but it's an ongoing process. Next slide.

So when you think about care for patients with the general heart disease, you have to think in terms of cardiovascular care and neurodevelopmental and psychosocial support across the life span. Click here. So it starts in the fetal care center, talking to families ahead of time about what the neurodevelopmental may or may not be in educating the family. You have to have the best

preoperative experience relative to CICU to minimize and mitigate brain injury. You have to have a great developmental support program, that's going to see that patient follow them into young adulthood and then have appropriate cardiovascular bridge programs to transition patients into the adult care. So the best programs provide comprehensive cardiovascular care and comprehensive neurodevelopmental and psychosocial follow. Next slide.

So the last piece of this is having appropriate transition. And transition not something that just miraculously happens. It has to be organized, has to be created, has to be built into the DNA of a cardiac program to make sure that the patients getting what they need as they move to the adult hospital and the adult program. It's a paper from Craig Sable, a close colleague of mine, circulation 2011, identifying the best practices in managing transition in pediatric to adult congenital care. Next slide. If you haven't seen a [gottransition.org](http://gottransition.org), it's an amazing website that lays out all the details of how transition should occur. Next slide.

And the AP as well has published important papers on transition and show exactly what should be done when it should be done to make sure that we do this appropriately. Next slide. I think the key things are that, first of all, you have to have a, again, sorry about the typo. This is not how it appeared on my computer. You want to have transition policy, you want to have transition tracking and monitoring. You have to talk about transition readiness between 16 and 21. We do transition planning between age 16 and 21. You have to transfer care between age 21 and 26 and then complete transition.

Hopefully by age 26 with a follow up with at least three to six months after transferring to make sure the transfer is complete. Next slide. Just want to thank you for your time today. In summary CHD is the most common birth defect, survival after neonatal heart surgery is expected neurobehavioral dysfunction in CHD surgical survivors results from white matter injuries. To maximize long-term health related quality of life, you want to adhere to the AHA/AAP and CNOC evaluation and management guidelines. When a monitor and intervene on development through cardiac neurodevelopmental programs, you want appropriately transition teens with CHC to ACHD medical care and most importantly mental health support programs. Thank you much for your time. I really appreciate you having me here today.

Jill Glidewell:

Thank you so much, Brad. I think now we have about eight minutes for some questions. We've had some pop into the chat box. If anyone would like to take themselves off of mute and ask a question, you are welcome to do so now. We'll quickly read through some of the questions. I think one of the most recent ones and Brad, I believe this is directed towards the information you shared. Can the links to the articles mentioned in the presentation be shared. This information could potentially help with some of the NICU pushback our state is get getting on performing screenings in their eligible patient population. There needs to be ascertain as to whether or not a CHD is present. When we're talking about

infants with prolonged links of length of stay in the hospital. So the quick answer is this presentation is recorded and will be posted to the APHL website. And Lisa, I think Amy's already left us. I'm not certain if the actual slide set itself will be available so that someone could slowly go through the citations or how most efficient we could handle that.

Bradley S. Mari...: Yeah, the three links are pretty easy and I'll make sure Joe gets those. The first one, just put Marino Circulation 2012 and the AHA/AAP guideline will pop up and then cardiology young published those two management guidelines from snot about two years ago. And we'll make sure you get the links.

Jill Glidewell: Excellent. Thank you. Let's see. And Lisa hop in, if you've seen any other questions pop in the chat box, some folks, some questions for Venita, and we could certainly recap those. If you weren't able to read those really characterizing the 816 cases. Some questions about if an infant is prenatally diagnosed, are they screen through pulse imagery screening, which is state and program specific, but Vanita or anyone else Diana, if you'd like to jump in here.

Vinita Leedom: Yeah, to her question to Erinith question, we do look at prenatally diagnosis information and Nina feel free to add, but you know, we, even though it's a requirement, the hospitals don't have to report results. And part of it is probably because they know they will skip to an echo for really critically ill children. So that's right, what was said was correct.

Dianna: And same in Arizona, a baby prenatally diagnosed or if the NICU doesn't have to be screened. We do ask for that reason, if they mark that box of not screened on the card so that we can confirm kind of what's going on and get better data, but as same as other states, some are some aren't, it's not a clean answer or a clean process

Heather: For Minnesota, there is an option. They can do a physician override within the system and indicate that the baby was prenatally diagnosed.

Lisa Hom: Sure and I think, we like the data to be cleaner. I know, sometimes I think it's really fantastic. I think Vanita mentioned that in South Carolina, they're linking to the STS continental heart database. And sometimes we've found at our center that sometimes the prenatal data is in there. And sometimes it's not, I don't think it was one of the mandatory fields. So I think that even when you get data there with things like prenatal diagnosis, there's still some opportunities for improvement. And there are several national quality improvement metrics that are looking at how to not only get better data, but how to move that, move that bar and have more infants prenatally diagnosed and intervened upon even sooner. I saw a little bit of back and forth in the chat box too, about who's being screened, whether those prenatally infants need to be screened and whether NICU infants need to be screened. And I think there's a lot of variation, certainly there's the science and the intention that when CCHD screening became

recommended, it was really meant and geared toward identifying infants that were asymptomatic in the well baby nursery.

However, some states do require that all infants, regardless of any physician override, exemptions or ICU stay, things like that. Sometimes there's just a blanket statement. And the state law saying that all infants need to be screened regardless of whether they were prenatally diagnosed or required in ICU stay.

So I don't know if there were other questions. People can feel free to either raise your hand or unmute yourself. But Dr. Marino, I had a question for you. While we're seeing if any other questions come in and I loved your presentation. Thank you so much for being on this webinar. I know you talk a lot about making sure the referrals are being made and getting children evaluated, in terms of the newborn screening and birth defects community, do you see any kind of systems level needs for either for data or things that could be done better? Things that look at in terms of improving the system and really helping these infants really get the neurodevelopmental assessments and interventions that they need throughout their life, not just in the newborn period?

Bradley S. Mari...

Yeah. Lisa, first of all, thank you and that's a great question. I'm going to give you a little bit of a convoluted answer, but there are already a couple things happening right now, which are impacting the community significantly to make sure these kids are getting evaluated. The first one is you US news. So I happened to sit on the working group have for the last six years, and once Sina became large enough, it became an actual item on US news, which then drove cardiac programs to create more cardiac developmental programs, because you want to get the points. The second thing is that with the HOAS follow up, one of the questions that was added in US news was, do you developmentally assess them at 12 to 24 months? And what percent do you do? And you get points in that as well. So just putting those two things in US news, dramatically up regulated, most cardiatic cardiac programs to put these programs in place to actually get these patients seen.

Now I will tell you that the vast majority of children that are high risk with cardiac disease in this country are not seen for evaluation. Despite all the work we've done in the last 10 years, the majority don't see it, get seen. And I'll give you an example of what I experienced in Chicago. So if you look at Medicaid financing in most states in the country, they do not pay for neuropsychological testing. They do not pay for developmental support testing. So when I went to Lurie and I looked the CO in the eye and I said, I'm not going to build the cardiac for white wealthy kids in the suburbs and ignore all of the patients in Chicago that are underrepresented minorities that are on Medicaid. And most of these programs lose money in the short term, but in terms of the ability to brand them and bring in more patients that make a ton of money to the hospitals, it's a positive net benefit financially.

But when we opened our program and we started seeing what percent of the patients actually got referred in, it was only 10% of the eligible patients in Chicago for coming to our clinic. The only way we got around that was basically again, through philanthropy and through the hospital, helping to pay for the providers was in epic, having the nurses at every one of our outpatient clinics that saw cardiac patients answer those three basic questions. Did you have infant heart surgery on bypass? Did you chronic sinus infant? Do you have CDC one of those comorbidities. In doing so with a quality improvement product went from 10% capture to 85% capture in six months. So using the EMR to allow nurses on the frontline in these outpatient biology clinics to find these patients and then get them referred into the central hubs, the vital program has been very helpful.

Now that's not the holy grail. What I've told you right now is workarounds and political pressure on people that hold the finances. Working through UUs for example, what's really going to change this is CMS. It is a national shame. It's literally shameful that CMS is not said that every patient who's a NICU grad or cardiac grad or some other high risk newborn that we can define, doesn't get appropriate developmental assessment. And CMS has chosen not to do that because it's expensive, even though it's absolutely needed. So if we really want to change the platform nationally, for all of our patients, CMS insurers half the children in this country. Just by having CMS, make the mistakes, pay for these required assessment services that would dramatically change the plan period. Most of the primary insurer will pay some of the neurodevelopmental assessment costs that are involved in these cardiac and follow programs. But they line item lots of things out and instead of paying \$3,000, they paid \$1,500.

So I know for example, when I came to Cleveland Clinic, I had to raise at least a million dollars for the first five years that our program is open. To pay for the deficit in neuropsychology dollars that come in terms of revenue and for the educators to make these programs go. So I apologize for the convoluted answer, but those are some of the ways in which we have gotten these services to patients. And I think the way we have to really help 50% of the kids in this country through CMS.

Lisa Hom:

So thanks for that. Thanks for that very broad answer. And I think it really captures a lot of what we see at the local level in terms of reimbursement. I was really surprised to hear from one of our states that it wasn't an automatic acceptance to have a diagnosis of CHG, but that most kids were eligible. I'm really sorry. We are actually are right at the end of the webinar. We are at a time and I just wanted to say, thank you. This has been an amazing experience to be a part of. Certainly we covered a lot of ground in our three series webinar, but we really just want this to be the starting point. I know a lot of the states today reported on how to improve data, the work that they've done to improve integration and communication between stakeholders and really get us better data and be able to use the data, not only to analyze it, to create better systems

for the patients, for the infants born with CCHD, but also to help try to improve outcomes.

So thank you very much to everyone. And we wanted to especially put our contact information because we really want this just to be the beginning of the conversation in terms of being able to provide you for some of the national work that's going on. So please feel free to email us if you have ideas about future webinars or potentially in-person meetings or collaborations that you would like to see being made between newborn screening, clinical providers and hospitals, as well as of course the national birth effects prevention network. So thank you, Russell, Dianna, Amy, Jill, Lexi, and everyone that made this webinar series possible. I'm sure I missed the one, but thank you everyone.

Dianna: Thank you.

Jill Glidewell: Thanks everyone.

PART 4 OF 4 ENDS [01:33:19]