

**Newborn Screening Advisory Committee  
Meeting Minutes  
February 16, 2018  
1:00 p.m.**

**Moreton Building, Public Hearing Room M-100  
1100 W. 49<sup>th</sup> Street, Austin, TX 78756**

Table 1: Newborn Screening Advisory Committee member attendance at the Friday, February 16, 2018 meeting.

MEMBER NAME	YES	NO	MEMBER NAME	YES	NO
Nancy Beck, M.D.	X		Joseph Schneider, M.D.	X	
Alice Gong, M.D.	P		Michael Speer M.D.		X
Charleta Guillory, M.D.	X		Elizabeth "Kaili" Stehel, M.D.		X
Tiffany House, J.D.	P		Benna Timperlake, R.N.		X
Tiffany McKee-Garrett, M.D.	X		Linda Zediana, RN	P	
Scott McLean, M.D.	X				

**Yes:** Indicates attended the meeting **No:** Indicates did not attend the meeting **P:** Indicates participated by phone

Table 2: Newborn Screening Unit and other HHS staff attendance at the Friday, February 16, 2018 meeting.

HHS STAFF NAME	YES	NO	HHS STAFF NAME	YES	NO
David Martinez	X		Dr. Susan Tanksley	X	
Dr. Debra Freedenberg	X		Dr. Rachel Lee		X
Lara Anton	X		Karen Hess		X
Carolyn Pittman	X		Lynette Borgfeld	X	
Katlyn Le		X	Brendan Reilly	X	
Patricia Hunt	X		D'Andra Luna	X	
Beth Rider		X	Rhonda Stokley	X	

Table 3: Newborn Screening Advisory Committee guest attendance at the Friday, February 16, 2018 meeting.

GUEST NAME/ORG.	YES	NO	GUEST NAME/ORG.	YES	NO
Cesar Lopez, Texas Hospital Association	X		Bonnie Drumyoole, Caddo Associates	X	
Kellie Dees, Texas Pediatric Society	X		Sam Cooper III, Texas Medical Association	X	
Adam Brunsen, FAST/SMA	X		Elizabeth Moore, Cure SMA	X	
Khrystal Davis, FAST/SMA	X		Tiffany Britton, Caddo Associates	X	
Joe Scherer	X		Carrie Kroll, Texas Hospital Association	X	

### **Agenda Item 1: Welcome and Introductions**

Dr. Charleta Guillory, Neonatologist and Chair of the Newborn Screening Advisory Committee, greeted everyone and requested the members introduce themselves as well as members of the public.

### **Agenda Item 2: Committee Business Logistics**

Dr. Guillory turned the floor over to Ms. Stephanie Gutierrez, Policy & Rules Advisory Committee Coordination Office, HHSC. Ms. Gutierrez reviewed logistics, called roll, and noted quorum. Dr. Speer asked that the Minutes reflect he is at the state collaborative meeting and not able to participate in today's meeting.

### **Agenda Item 3: Review and Approval of Minutes for October 27, 2017**

Dr. Guillory announced the need to approve the October 27, 2017 minutes and turned the floor over to Ms. Gutierrez. Ms. Gutierrez requested a motion to approve the October 27, 2017 minutes. Dr. Joseph Schneider motioned with Dr. Tiffany McKee-Garrett seconding. A roll call vote was taken. The motion carried to accept the October 27, 2017 minutes as approved by unanimous vote.

### **Agenda Item 4: Newborn Screening Advisory Committee Bylaws: Review and Discussion**

Dr. Guillory informed the Committee of the System Bylaws replacing the current Bylaws. Dr. Guillory reviewed changes with the Committee and noted the Committee will not be adopting the System Bylaws during this meeting. Dr. Guillory referenced the handout, *Newborn Screening Advisory Committee Bylaws*.

The Committee had a discussion regarding the thirty-day review of the minutes before the full Committee meeting.

### **Agenda Item 5: Fee Increase Data: Follow-Up Impact to Provider Practices - Rider 37 Update**

Dr. Guillory introduced Dr. Susan Tanksley, Laboratory Operations Unit Manager and Mr. Brendan Reilly, Program Specialist Laboratory.

Mr. Reilly reviewed the handout and PowerPoint, *Impact of NBS Fee Increase as Requested by DSHS Newborn Screening Advisory Committee*.

Dr. Tanksley stated to the Committee the overall decrease in screens appeared to correlate to the decrease in births. There is no direct link with Vital Statistics so population coverage of newborn screening cannot be checked in real time. Certification and finalization of vital statistics data has approximately a two year plus lag.

It was further noted that the shift from collection by individual providers to group practices began a significant amount of time before the fee increase. The Committee discussed involving statisticians in an effort to review the data and determine whether shifts in specimen collection by individual providers to group practices demonstrated statistical significance. Dr. Tanksley informed the Committee that the Newborn Screening Program has a regular call with

stakeholders where there could be a discussion about any trends that they are seeing as well (e.g. changes in practice size). The Committee also discussed the possibility of sending the parents the lab results and the ability to obtain information directly from parents, such as change in PCP, in an effort to involve patients and parents more.

Dr. Tanksley gave an update on the Rider 37 study. Dr. Tanksley referenced the PowerPoint, *Rider 37 Study Report Updates*. The Committee provided suggestions for the survey that DSHS will be sending to healthcare providers. In order to understand which types of healthcare providers are impacted, the Committee suggested DSHS gather demographic information in the survey. The survey is being distributed by list-serves and to medical associations. The Committee discussed how they can contribute to the report for Rider 37.

### **Agenda Item 6: Electronic Ordering and Reporting, Current Status and Update on Expansion Efforts**

Dr. Guillory introduced Mr. Reilly. Mr. Reilly referred to the PowerPoint and handout, *NBS Health Information Technology NBS Advisory Committee Update February 16, 2018*.

The Committee thanked Mr. Reilly for his presentation and all his hard work. The Committee stated they were not optimistic about the concept and the work.

### **Agenda Item 7: Newborn Hearing Screening in NICU**

Dr. Guillory gave a briefing regarding Newborn Hearing Screening in the NICU population. Dr. Guillory introduced Dr. Barbara Novak. Dr. Novak talked about what happens to the NICU population at the Newborn Medical Center. Dr. Novak stated screenings are done as early as possible when the patient is medically stable, this is typically decided by the physician. Screeners communicate with nurse managers daily to determine who is medically stable and available to be screened. The Committee asked Dr. Novak if there is a standard logistical method that can be used by other hospitals as well. Dr. Novak stated that it is dependent on whether the patient is on a ventilator. If the patient is on a ventilator it makes screening difficult. The Committee asked Dr. Novak if sedation is used in the hospital or outside. Dr. Novak stated that sedation is utilized for diagnostic rather than screening.

**ACTION ITEM:** Dr. Novak will provide data of how old the newborns were when they were screened.

Dr. Guillory stated this topic will remain on the agenda for next meeting and requested Dr. Novak present the data at that time.

### **Agenda Item 8: Parental Refusal Form/Process Subcommittee Reporting**

Dr. Guillory introduced Dr. Joseph Schneider. Dr. Schneider referenced the handout and PowerPoint, *Form to refuse the Newborn Screening Blood Test*. Dr. Schneider stated that the goals of the subcommittee were:

1. Improve the readability and understandability of the refusal form.
2. Set up notification so the state can ensure that 100% of babies are screened or accounted for if the screen is refused or missed.

The Committee discussed the data that was presented from the Subcommittee to the full Committee. The Subcommittee reiterated the importance of the need to account for the newborns that are not getting screened.

The full Committee offered the Subcommittee grammatical corrections to the form. The Subcommittee accepted the recommendations made by the full Committee. Dr. Scott McLean made a motion to accept the revised Parental Refusal Form to include edits made at the 02/16/2018 meeting. Dr. Nancy Louise Beck seconded the motion. A voice vote was taken. The motion carried.

The Subcommittee noted for the record the need to think about how to account for refusals and potential missed screens. The Subcommittee asked what the next steps are. Mr. David Martinez stated that a recommendation can be made to the full Committee for discussion at the next meeting.

**ACTION ITEM:** Mr. Martinez will bring ideas to the full committee regarding how to fulfill this request from the Subcommittee.

The Committee agreed to place this item on the agenda for the next full committee meeting.

### **Agenda Item 9: Critical Congenital Heart Disease- Subcommittee Reporting**

Dr. Guillory introduced Dr. Scott McLean. Dr. McLean gave the report to the full Committee regarding the work of the Subcommittee. Dr. McLean referenced handout titled, *Selected References- CCHD Newborn Screening*.

The Committee discussed the Program review the options for what is most economical and feasible. The Committee discussed developing a measure to set the foundation for further action by determining if there is a problem with screening. Dr. Guillory stated this item will be placed on the agenda for next time with a presentation on the current data. Dr. Guillory stated that the Committee will look into grant issues, improved education issues, weakness of the law, feasibility, and efficiency of feasibility.

### **Agenda Item 10: Public Comment**

Dr. Guillory turned the floor over to Ms. Gutierrez. Ms. Gutierrez read Public Announcement Logistics to the Committee. Ms. Gutierrez called Ms. Khrystal Davis and Ms. Elizabeth Moore to the podium to address the Committee.

**Public Comment:** Ms. Khrystal Davis informed the Committee of Rare Disease Day and the statistics of clinical trials. Ms. Davis stated her concern that insurance companies are not reimbursing for the kit.

**Public Comment:** Ms. Elizabeth Moore read a statement on behalf of her friend that could not be present.

Dr. Guillory stated a letter to Dr. Hellerstedt has been sent. Dr. Guillory requested an update for the cost analysis for spinal muscular atrophy at the next meeting.

**Agenda Item 11: Future Agenda Items/ Next Meeting Date/Adjournment**

Dr. Guillory noted agenda items for the next meeting:

1. Dr. Novak will present
2. Data accounting for babies not screened
3. CCHD data
4. Bylaws
5. Update on new lab system
6. How NBSAC can contribute to Rider 37
7. Cost analysis for SMA at next meeting or in the future

The next meeting date has not been established yet. Dr. Guillory adjourned the meeting at 4:49 p.m.