

**Newborn Screening Advisory Committee
Meeting Minutes
August 24, 2018
2:00 p.m.**

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

Table 1: Newborn Screening Advisory Committee member attendance at the Friday, August 24, 2018 meeting.

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

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

Table 2: Newborn Screening Advisory Committee guest attendance at the Friday, August 24, 2018 meeting.

GUEST NAME/ORG.	YES	NO	GUEST NAME/ORG.	YES	NO
Kyle Dolliver, Founder, Ryan's Challenge	x		Christine Heppe, CHAT	X	
Stephanie Simpson, Sanofi, US	x		Holli Hill, Novartis	X	
Khrystal Davis, FAST/SMA	x				

Agenda Item 1: Welcome and Introductions

Dr. Charleta Guillory, Chair of the Newborn Screening Advisory Committee, convened the meeting at 2:00 p.m. Dr. Guillory greeted everyone and requested Committee members and members of the public introduce themselves.

Agenda Item 2: Committee Business Logistics

Dr. Guillory turned the floor over to Ms. Stephanie Gutierrez, HHSC, Policy & Rules, Advisory Committee Coordination Office. Ms. Gutierrez reviewed logistics, called roll, and determined quorum.

Agenda Item 3: Review and Approve Committee Letter for Rider 37 Study

Dr. Guillory turned the floor over to Dr. Joseph Schneider, subcommittee chair of Rider 37.

Dr. Schneider briefed the full Committee regarding the business of the Rider 37 subcommittee. Dr. Schneider stated the subcommittee drafted a letter to DSHS

Commissioner Dr. Hellerstedt. Dr. Schneider reviewed the draft letter with the full committee.

Members discussed:

- Highlight in the letter that this is a cost-saving maneuver for implementing newborn testing for additional disorders based on established evidence
- Similar approaches from other states
- Reducing costs
- Billing for costs

MOTION: Ms. Gutierrez requested a motion to approve the letter with minor edits for Rider 37 Study to the lab and Dr. Hellerstedt. Dr. Schneider made a motion with Ms. Benna Timperlake seconding. A roll call vote was taken. The motion carried unanimously.

Agenda Item 4: Public Comment

Mr. Kyle Dolliver, Ryan's Challenge, inquired to the Committee why only a specific amount of rare diseases are tested rather than a greater amount.

Agenda Item 5: Adjournment

Dr. Guillory adjourned the meeting at 2:57 p.m.

Webcast: <https://texashsc.swagit.com/play/08242018-801>