

Newborn Screening Advisory Committee (NBSAC)

Agenda

April 29, 2022

12:00 p.m.

Meeting Site:

Texas Department of State Health Services (DSHS)
Robert Bernstein Building Room K-100, First Floor
1100 West 49th Street
Austin, TX 78756

This meeting will be webcast. Members of the public may attend the meeting in person at the address above or access a live stream of the meeting at <https://texashhsmeetings.org/HHSWebcast>. Select the tab for the Bernstein K-100 Room Live on the date and time for this meeting. Please e-mail Webcasting@hsc.state.tx.us if you have any problems with the webcasting function.

This meeting will also be conducted via videoconference call in accordance with the requirements of Section 551.127, Government Code. The member of the Committee presiding over the meeting will be physically present at the location specified above.

Attendees who would like to provide public comment should see the **Public Comment** section below.

1. Welcome, introductions, and logistical announcements
2. Consideration of October 8, 2021, draft meeting minutes
3. Whole genomic sequencing in newborn screening
4. Status of Memorandum of Understanding and Data Use Agreement with Medicaid and Vital Statistics
5. Screened conditions status updates
 - a. Diagnosed cases
 - b. Spinal Muscular Atrophy (SMA) screening implementation
 - c. X-linked Adrenoleukodystrophy (X-ALD) screening implementation
 - d. Electronic ordering and reporting
6. Congenital Hypothyroidism Pilot Project
7. Future condition implementation updates
8. Sickle Cell Subcommittee Reporting
9. Rare Diseases Subcommittee Reporting
10. Health Information Technology Subcommittee Reporting
11. Hearing Screening Consent Form
12. Public comment
13. Future agenda items, next meeting date, and adjournment

The committee may take action on any agenda item.

Public Comment: DSHS welcomes public comments pertaining to topics related to newborn screening. Members of the public who would like to provide public comment may choose from the following options:

1. **Oral comments provided virtually:** Members of the public must pre-register to provide oral comments virtually during the meeting by completing a Public Comment Registration form at https://texashhsmeetings.org/NBSAC_PCReg_Apr2022 no later than 5:00 p.m. Wednesday, April 27, 2022. Please mark the correct box on the Public Comment Registration form and provide your name, either the organization you are representing or that you are speaking as a private citizen, and your direct phone number. Public comment is limited to three minutes. Each speaker providing oral public comments virtually must ensure their face is visible and their voice audible to the other participants while they are speaking. Each speaker must state their name and on whose behalf they are speaking (if anyone). If you pre-register to speak and wish to provide a handout before the meeting, please submit an electronic copy in accessible PDF format that will be distributed by HHS staff to NBSAC members and State staff. Handouts are limited to two pages (paper size: 8.5" by 11", one side only). Handouts must be emailed to newbornadvisory@dshs.texas.gov immediately after pre-registering, but no later than 5:00 p.m. Wednesday, April 27, 2022, and include the name of the person who will be commenting. Do not include health or other confidential information in your comments or handouts. Staff will not read handouts aloud during the meeting, but handouts will be provided to NBSAC members and State staff.
2. **Written comments:** Members of the public may provide written public comments by completing a Public Comment Registration form at https://texashhsmeetings.org/NBSAC_PCReg_Apr2022. A member of the public who wishes to provide written public comments must email the comments to newbornadvisory@dshs.texas.gov no later than 5:00 p.m. Wednesday, April 27, 2022. Please include your name and the organization you are representing or that you are speaking as a private citizen. Written comments must be emailed to DSHS immediately after pre-registering and include the name of the person who will be commenting. Written comments are limited to two pages (paper size: 8.5" by 11", one side only). Do not include health or other confidential information in your comments. Staff will not read written comments aloud during the meeting, but comments will be provided to NBSAC members and State staff.
3. **Oral comments provided in-person at the meeting location:** Members of the public may provide oral public comment during the meeting in person at the meeting location either by pre-registering using the form above or without pre-registering by completing a form at the entrance to the meeting room. Do not include health or other confidential information in your comments.

Note: These procedures may be revised at the discretion of HHSC.

Contact: Questions regarding agenda items, content, or meeting arrangements should be directed to Aimee Millangue, Newborn Screening Unit, DSHS, newbornadvisory@dshs.texas.gov, 512-776-3386.

This meeting is open to the public. No reservations are required, and there is no cost to attend this meeting.

People with disabilities who wish to attend the meeting and require assistive technology or services should contact Aimee Millangue, at newbornadvisory@dshs.texas.gov, or 512-776-3386 at least 72 hours prior to the meeting so that appropriate arrangements can be made.