

GENETICS AND NEWBORN SCREENING ADVISORY COUNCIL MEETING MINUTES

The Genetics and Newborn Screening Advisory Council (GNSAC) meeting was held Friday, February 6, 2026, in person at the Bureau of Public Health Laboratories-Jacksonville.

Call to Order

The meeting was called to order at 9:30 a.m. EST by Dr. Roberto Zori, Council Chairperson. Roll was taken and quorum was established.

Members Present:

Roberto Zori, MD, Chair, University of Florida (UF)
Dusty Stern, BSN, RN, Delegate for the State Surgeon General
Alexis Larrea, Consumer
Barry Byrne, MD, Practicing Pediatrician
Chrishonda Jenkins, APRN, FNP-C, Agency of Persons with Disabilities
Dorothy Shulman, MD, University of South Florida (USF)
Gary Kleiner, MD, PhD, University of Miami (UM)
George Fox, Consumer
Jane Gibson, Ph.D., FACMG, University of Central Florida (UCF)
Lindsay Kahn, DO, Florida Hospital Association
Stacy Dickson, AuD, CCC-A, Audiologist
Tamara New, MD, FAAP, Pediatric Hematologist
Tenesha Avent, MPH, CCHW, March of Dimes

Guests:

Aaliya Ahmad, UF
Amarilis Sanchez-Valle, MD, USF
Amelia Donhauser, Revvity
Anna Grantham, Hunter's Hope Foundation
Anna McGuinness, UF
Cory Guilmette, Revvity
Daphne Applebee, UF-Jacksonville
David Ledbetter, PhD, FACMG
Deanna Almanza, USF
Emilia Wilburn, Orchard Therapeutics
Jeanne Brunger, Revvity
Jose Valdes
Katherine Anderson, Parent Project MD
Kansas Sampson, UF
Klaas Wierenga, MD, UF
Lauren Eckstein, MHS
Madison Lake, USF

Mariana Martinez, APRN
Megan Boothe, MD, UF
Melissa Racobaldo, USF
Nichole Daniels, Hunter's Hope Foundation
Paul Pitel, MD
Sanjiv Harpavat, MD, PhD, Texas Children's Hospital
Sharon Liebrich, FSU
Sondra Rosendahl, MN NBS Follow-up Program
Stephanie Hacker, MS, RD/N, LD/N, CSSD, UM
Willa Thorson, MD, UM

DOH Personnel Present:

Anna Simmons, MSW, Tallahassee-Children's Medical Services (CMS)
Emily Reeves, BSN, RN, CPN, Tallahassee-CMS
Amy Fritsch, RN, Tallahassee-CMS
Ashley Wiertzema, Tallahassee-CMS
Bryan Wendel, Tallahassee-CMS
Brandi McIntosh, Tallahassee-CMS
Caitlin Roberts, MS, Tallahassee-CMS
Candace Strickland, MBA, Tallahassee-CMS
Chantel Short, RN, Tallahassee-CMS
Erin Adams, Tallahassee-CMS
Jennie Carpenter, Tallahassee-CMS
Jennifer Givens, Tallahassee-CMS
Jessica Williams, RN, Tallahassee-CMS
Johnny Thompson, Tallahassee-CMS
Ken McCain, Tallahassee-CMS
Kristin Barnette, RN, Tallahassee-CMS
Miranda Nerland, Tallahassee-CMS
Natasha Rich, Tallahassee-CMS
Philicia Corbett, Tallahassee-CMS
Sandra Crump, BSN, RN, Tallahassee-CMS
Teryl Camus, AuD, Tallahassee-CMS
Tori Davis, RN, Tallahassee-CMS
Vaishnavi Gunti, Tallahassee-CMS
Susanne Crowe, DrPH, MHA, HCLD(ABB), BPHL-Jacksonville
Patti Ryland, BS MT, MPH, BPHL-Jacksonville
Elliott Bailey, BPHL-Jacksonville
Enjoli Stanley, BPHL-Jacksonville
Sajani Mamallapalli, BPHL-Jacksonville
Xihui Newman, Ph.D., HCLD (ABB), BPHL-Jacksonville
Zena Johnson, MFS, Chem MT (AAB), BPHL-Jacksonville

Housekeeping Items

- Dr. Roberto Zori announced the housekeeping items for the meeting at 9:35 a.m.
 - Criteria for submitting public comments was reviewed.
 - Purpose and goals of the meeting were reviewed.

Newborn Screening (NBS) Follow-Up Program Update

Mrs. Emily Reeves provided the NBS Follow-up Program update to the Council at 9:40 a.m.

Updates included:

- An overview of program staff
- An overview of NBS annual statistics
- An overview of the Critical Congenital Heart Disease (CCHD) reports
- An update on new conditions implemented
- Legislative Updates
 - Duchenne Muscular Dystrophy (DMD) added to Florida's screening panel by statute; implementation pending appropriations
 - Metachromatic Leukodystrophy (MLD) added to federal Recommended Uniform Screening Panel; state review required by December 2026
- Future Focus
 - Outreach to pediatric offices for repeat screens and timely specimen shipping.

Approval of Minutes from Previous Meetings

- Dr. Dorothy Shulman motioned for the August 2025 meeting minutes to be approved at 10:37 a.m. Dr. Jane Gibson seconded the motion, and the Council unanimously approved the minutes at 10:37 a.m.

Duchenne Muscular Dystrophy (DMD) Review

Ms. Sondra Rosendahl, Minnesota Newborn Screening Program presented to the Council at 10:40 a.m. During her presentation she:

- Shared Minnesota's experience implementing DMD screening
- Discussed creatine kinase assay, cutoffs, and follow-up protocols
- Identified challenges: High borderline rates in early newborn period and strategies to minimize false positives
- Emphasized the importance of genetic counseling and confirmatory testing

---- Dr. Zori declined to break at 11:10 a.m. to ensure time for Dr. Ledbetter to present ----

Sunshine Genetics Pilot Program Overview

Dr. David Ledbetter, Florida State University provided an overview to the Council at 11:12 a.m.

During this overview he reviewed the legislative initiative for a statewide genomic newborn sequencing pilot, including:

- Project goals:
 - Recruit 100,000 newborns for sequencing
 - Develop pediatric genetics network across Florida institutions

- Current status: Institutional Review Board approval in progress; pilot launch anticipated Spring 2026
- Gene list to align with National Institutes of Health Beacons project (746 genes)
- Discussion: Infrastructure needs, genetic counseling workforce, and ethical considerations

----- Dr. Zori called for a lunch break at noon -----

-----The meeting reconvened at 1:16 p.m. -----

Biliary Atresia Screening Review

Dr. Sanjiv Harpavat, Texas Children's Hospital provided an overview to the Council at 1:16 p.m. This included:

- A condition overview
- Current screening methodology
- Review of pilot data

Newborn Hearing Screening (NBHS) Program Update

Ms. Ashley Wiertzema provided the NBHS Program update to the Council at 1:45 p.m. This included:

- NBHS performance data
- An update of the program's grant activities
- Collaboration activities with Nemours for data analysis and quality improvement

----- Dr. Zori declined to break at 2 p.m. -----

Newborn Screening Laboratory Update

Dr. Susanne Crowe provided the Newborn Screening Laboratory update at 2:04 p.m. This included:

- Testing updates: Quality improvement projects, turnaround time improvements
- Grant activities: Informatics messaging services, NBS Center of Excellence initiatives

Public Comments

Mrs. Reeves opened the floor for public comment at 2:20 p.m.

- Anna Grantham, Hunter's Hope Foundation, supports screening for Krabbe
- Katherine Anderson provided resources for MLD
- Nichole Daniels, supports screening for MLD
- Submitted in writing, in support of screening for MLD, Olivia Faye Scott and Michelle Tamano

New Discussions

Mrs. Reeves opened the floor for new discussions at 3:02 p.m.

- Dr. Zori thanked the presenters
- Mrs. Reeves announced that the next GNSAC meeting will be held virtually and is scheduled for August 28, 2026.

----- George Fox motioned to adjourn, Dr. Tamara New seconded the motion -----

----- The meeting adjourned at 3:04 p.m. -----