

## GENETICS AND NEWBORN SCREENING ADVISORY COUNCIL MEETING

The Genetics and Newborn Screening Advisory Council (GNSAC) meeting was held Friday, August 29, 2025, virtually through GoToMeeting Platform.

### **Call to Order:**

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

### **Members Present:**

Roberto Zori, MD, Chair, University of Florida (UF)  
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

### **Guests:**

Aaliya Ahmad, UF  
Aleskia Fernandez, AdventHealth  
Alexa Bledsoe, UF  
Amarilis Sanchez-Valle, MD, USF  
Amy Jonasson, UF  
Anna Grace DePaolo, MHD Firm  
Anna McGuinness, UF  
Christina Samper, AdventHealth  
Deanna Almanza, USF  
Jeanne Brunger, Revvity  
Jennifer Stallworth, Sanofi  
Leslie Dughi, Metz Husband & Daughton, PA  
Megan Boothe, UF  
Meghan Kelley, USF  
Melissa Racobaldo, USF  
Michelle Beekman, AdventHealth  
Natalie Shallow, UF Health Jax  
Rachel Burnside, UF  
Sarybeth Tirado Cordova, UM  
Shelby Jackson, UF Health Jax  
Stephanie Hacker, MS, RD/N, LD/N, CSSD, UM  
Vania Mishkin, UM  
Willa Thorson, MD, UM  
Yemila Lowry, UF

**DOH Personnel Present:**

Andrea Gary, MS, RN, Tallahassee-Children’s Medical Services (CMS)  
Dusty Stern, BSN, RN, Tallahassee-CMS  
Emily Reeves, BSN, RN, CPN, Tallahassee-CMS  
Kim Porter, Tallahassee-CMS  
Amy Fritsch, RN, Tallahassee-CMS  
Ashley Wiertzema, Tallahassee-CMS  
Bryan Wendel, Tallahassee-CMS  
Caitlin Roberts, MS, Tallahassee-CMS  
Celica Coleman, Tallahassee-CMS  
Chantel Short, RN, Tallahassee-CMS  
Erin Adams, Tallahassee-CMS  
Jennifer Givens, Tallahassee-CMS  
Jessica Williams, RN, Tallahassee-CMS  
Kari Hope, Tallahassee-CMS  
Ken McCain, Tallahassee-CMS  
Kirstie Gordon, RN, Tallahassee-CMS  
Kristin Barnette, RN, Tallahassee-CMS  
Linda Ebelini, BSN, RN, Tallahassee-CMS  
Margaret Waterman, MA, Tallahassee-CMS  
Natasha Rich, Tallahassee-CMS  
Sandra Crump, BSN, RN, Tallahassee-CMS  
Shareese Hardy, MSN, RN, Tallahassee-CMS  
Tori Davis, RN, Tallahassee-CMS  
Marie-Claire Rowlinson, PhD, D(ABMM), Bureau of Public Health Laboratories (BPHL)-  
Jacksonville  
Susanne Crowe, DrPH, MHA, HCLD(ABB), BPHL-Jacksonville  
Patti Ryland, BS MT, MPH, BPHL-Jacksonville  
Elliott Bailey, BPHL-Jacksonville  
Sajani Mamallapalli, BPHL-Jacksonville  
Xihui Newman, Ph.D., HCLD (ABB), BPHL-Jacksonville

**Housekeeping Items**

- Dr. Roberto Zori announced the housekeeping items for the meeting at 9:31 AM.
  - Criteria for submitting public comments was reviewed.
  - Purpose and goals of the GNSAC meeting were reviewed.

**Approval of Minutes from Previous Meetings**

- Dr. Dorothy Shulman motioned for the February 2025 meeting minutes to be approved at 9:34 AM. Dr. Jane Gibson seconded the motion, and the Council unanimously approved the minutes at 9:35 AM.
- Dr. Dorothy Shulman motioned for the June 2025 meeting minutes to be approved at 9:35 AM. Dr. Jane Gibson seconded the motion, and the Council unanimously approved the minutes at 9:36 AM

**Newborn Screening (NBS) Follow-Up Program Update**

Mrs. Emily Reeves provided the NBS Follow-up Program update to the Council at 9:36 AM. This included:

- An overview of program staff
- An overview of the NBS annual statistics
- An overview of the Critical Congenital Heart Disease (CCHD) reports
- An overview of newly added conditions to the Florida NBS panel
- An overview of upcoming conditions:
  - Duchenne Muscular Dystrophy (DMD) and Metachromatic Leukodystrophy (MLD)
- An overview of the 2025 National Academies of Sciences, Engineering, and Medicine (NASEM) report

**Newborn Hearing Screening (NBHS) Follow-Up Program Update**

Mrs. Kimberly Porter provided the NBHS Follow-Up Program update to the Council at 10:42 AM. This included:

- An overview of program staff
- An update of the program’s grant activities
- NBHS performance data

----- Dr. Zori called for a ten-minute break at 11:30 AM-----

----- The meeting reconvened at 11:40 PM-----

**Newborn Screening Laboratory Update**

Ms. Susanne Crowe provided the Newborn Screening Laboratory update at 11:40 AM. This included:

- An overview of Guanidinoacetate Methyltransferase deficiency implementation testing
- An overview of the current ordering and reporting system, including electronic ordering and reporting
- An overview of the Association of Public Health Laboratories Informatics Messaging Services project
- An overview of ongoing quality assurance projects
  - Laboratory turnaround time
  - Unsatisfactory specimens
  - Confirmed cases versus reported cases
    - Severe Combined Immunodeficiency
  - False positives
    - Collaborative Laboratory Integrated Results
    - Updates to Cystic Fibrosis reporting
  - Document control system
- An overview of the NBS Center of Excellence Grant
- A review of laboratory regulations

----- Dr. Zori called for a ten-minute break at 12:00 Noon-----

----- The meeting reconvened at 12:30 PM-----

### **Duchenne's Muscular Dystrophy (DMD) Update**

Mrs. Emily Reeves provided an update on DMD at 12:30 PM. This included:

- A review of legislation to add DMD to Florida's screening panel, HB1089
- An update on Florida's implementation of DMD
- A review of Ohio's DMD screening and follow-up process

### **Public Comments**

Dr. Zori opened the floor for public comment at 12:54 PM.

- No comments from the public.

### **New Discussions**

Mrs. Reeves opened the floor for new discussions at 12:54 PM.

- Dr. Zori thanked the presenters.
- Mrs. Reeves announced that the next GNSAC meeting will be held in-person on Friday, February 6th, 2026.

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

----- The meeting adjourned at 12:57 PM-----