



Florida Genetics and Newborn Screening Advisory Council
February 16, 2024
9:30 am–2:30 pm



Meeting link: <https://global.gotomeeting.com/join/989314229>

or

Meeting Conference Line #: 1-877-309-2073; Conference Room #: 989-314-229

<i>Approx. Times</i>	<i>Subject</i>	<i>Presenter</i>
9:30 am	Welcome/Introductions <ul style="list-style-type: none"> ❖ Members ❖ Approval of August 2023 Minutes (handout) ❖ Housekeeping 	Roberto Zori, MD Chairman
9:40 am	Children’s Medical Services Division Director Update	Andrea S. Gary, MS, RN Director Division of Children’s Medical Services
9:50 am	Gene Therapy for Sickle Cell Disease	Edward Dela Ziga, MD, MPH, FAAP Assistant Professor of Clinical Pediatrics Pediatric Hematology/Oncology – Blood, Marrow Transplant, & Cellular Therapy University of Miami – Miller School of Medicine/Holtz Children’s Hospital
10:20 am	Newborn Screening Hearing Follow-Up Program <ul style="list-style-type: none"> ❖ Grant Activity Updates ❖ Updated Hearing Data ❖ cCMV Implementation 	Kimberly Porter Early Hearing Detection and Intervention Program Coordinator Newborn Screening Hearing Program
Break (15 minutes)		
11:00 am	Newborn Screening Follow-Up Program <ul style="list-style-type: none"> ❖ Staffing Updates ❖ Metabolic Formula Program Update ❖ Newborn Screening Statistics (handout) ❖ Critical Congenital Heart Disease Report ❖ Upcoming Conditions Update ❖ Cystic Fibrosis Workgroup Update 	Emily Reeves, BSN, RN, CPN Program Director Newborn Screening Follow-up
11:40 am	Newborn Screening Laboratory <ul style="list-style-type: none"> ❖ Staffing Updates ❖ Grant Updates ❖ Quality Improvement Activities 	Susanne Crowe, DrPH, MHA Assistant Bureau Chief, Jacksonville Laboratory Director Bureau of Public Health Laboratories Patricia A. Ryland, BS, MT, MPH Administrator Newborn Screening Laboratory Bureau of Public Health Laboratories Jacksonville
12:10 pm	Public Comments <i>(Please submit requests to provide comments through the GoTo chat. Chair to determine length of speaking time.)</i>	Roberto Zori, MD Chairman



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12:20 pm	New Discussions	Roberto Zori, MD Chairman
12:30 pm	Closing and Adjourn ❖ Next Meeting Announcement	Roberto Zori, MD Chairman

**Times and agenda items are approximate and subject to change depending on discussion and topic coverage. Meeting may adjourn earlier or later than schedule indicates.*

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