



**Florida Genetics and Newborn Screening Advisory Council**  
**August 23, 2024**  
**9:30 am–3:15 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	<b>Welcome/Introductions</b> <ul style="list-style-type: none"> <li>❖ Members Attendance</li> <li>❖ Approval of February 2024 Minutes (handout)</li> <li>❖ Housekeeping</li> </ul>	Roberto Zori, MD Chairman
9:45 am	<b>GNSAC By-Laws</b>	Roberto Zori, MD Chairman
10:00 am	<b>Krabbe Disease Presentation</b>	Barry J. Byrne, MD, PhD Member
10:30 am	<b>Krabbe Public Comments</b> <i>(Please submit requests to provide comments through the GoTo chat. Chair to determine length of speaking time.)</i>	Roberto Zori, MD Chairman
<b>Break (10 minutes)</b>		
11:00 am	<b>Duchenne Muscular Dystrophy (DMD) Presentation</b>	Barry J. Byrne, MD, PhD Member
11:30 am	<b>DMD Public Comments</b> <i>(Please submit requests to provide comments through the GoTo chat. Chair to determine length of speaking time.)</i>	Roberto Zori, MD Chairman
12:00 pm	<b>LUNCH (Lunch on your own, 30 minutes)</b>	
12:30 pm	<b>Newborn Screening Follow-Up Program</b> <ul style="list-style-type: none"> <li>❖ Staffing Updates</li> <li>❖ Newborn Screening Educational Opportunities</li> <li>❖ NBS Co-Propel Grant</li> <li>❖ Newborn Screening Statistics (handout)</li> <li>❖ Critical Congenital Heart Disease Report</li> <li>❖ New Conditions</li> </ul>	Emily Reeves, BSN, RN, CPN Director Newborn Screening Follow-up Program



# Florida Genetics and Newborn Screening Advisory Council

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1:00 pm	<b>Newborn Screening Hearing Follow-Up Program</b> <ul style="list-style-type: none"> <li>❖ Staffing Updates</li> <li>❖ Legislative Implementation Update</li> <li>❖ Grant Activity Updates</li> <li>❖ Hearing Data Updates</li> </ul>	<p style="text-align: right;">Kimberly Porter Early Hearing Detection and Intervention Program Coordinator Newborn Screening Hearing Program</p>
1:30 pm	<b>Marketing and Process Improvement Update</b> <ul style="list-style-type: none"> <li>❖ Website and Outreach Activities</li> <li>❖ Quality Improvement Activities</li> <li>❖ Marketing Focus Groups</li> <li>❖ NBS Unit Review</li> </ul>	<p style="text-align: right;">Bryan Wendel Continuous Quality Improvement Unit Supervisor Newborn Screening Follow-up Program</p>
<i>Break (10 minutes)</i>		
2:10 pm	<b>Newborn Screening Laboratory</b> <ul style="list-style-type: none"> <li>❖ Testing Updates</li> <li>❖ Grant Updates</li> <li>❖ Quality Improvement Activities</li> </ul>	<p style="text-align: right;">Susanne Crowe, DrPH, MHA, HCLD(ABB) Assistant Bureau Chief, Jacksonville Laboratory Director Bureau of Public Health Laboratories</p> <p style="text-align: right;">Patricia A. Ryland, BS, MT, MPH Administrator, Newborn Screening Laboratory Bureau of Public Health Laboratories Jacksonville</p>
2:40 pm	<b>Public Comments</b> <i>(Please submit requests to provide comments through the GoTo chat. Chair to determine length of speaking time.)</i>	<p style="text-align: right;">Roberto Zori, MD Chairman</p>
2:55 pm	<b>New Discussions</b>	<p style="text-align: right;">Roberto Zori, MD Chairman</p>
3:10 pm	<b>Closing and Adjourn</b> <ul style="list-style-type: none"> <li>❖ Next Meeting Announcement</li> </ul>	<p style="text-align: right;">Roberto Zori, MD Chairman</p>

*\*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.*

**\*\*Disclaimer**

*All council meetings are audio recorded and a matter of public record. By participating in open council meetings, individuals consent to the use and disclosure of the information shared at the meeting (including any personal/sensitive information), for the purposes of council carrying out its functions.*