



Florida Genetics and Newborn Screening Advisory Council February 20-21, 2025

Koger Center • Alexander Building • 2020 Capital Circle SE • Tallahassee, Florida 32399

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

or

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

Thursday, February 20, 2025 1:30 p.m. – 4:00 p.m.		
<i>Approx. Times</i>	<i>Subject</i>	<i>Presenter</i>
1:30 p.m.	Welcome/Introductions ❖ Roll Call	Roberto Zori, MD Chairman
1:45 p.m.	New Conditions Ethics Discussion	Aaron Goldenberg, PhD, MA, MPH Presenter
2:15 p.m.	Krabbe Disease Overview	Joanne Kurtzberg, MD Duke University School of Medicine Presenter
2:45 p.m.	Florida NBS Krabbe Disease Review	Emily Reeves, BSN, RN, CPN Director Newborn Screening Follow-up Program
<i>Break (10 minutes)</i>		
3:10 p.m.	Krabbe Disease Screening from the Society for Inherited Metabolic Disorders (SIMD) Perspective	Susan Berry, MD Professor, Division of Pediatric Genetics & Metabolism Faculty, Department of Pediatrics President, SIMD Presenter
3:40 p.m.	Krabbe Disease Public Comment <i>(Virtual attendees must submit requests to provide comment through the GoTo chat.)</i>	Roberto Zori, MD Chairman
4:00 p.m.	Closing and Adjourn	Roberto Zori, MD Chairman



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Friday, February 21, 2025		
9:30 a.m. – 2:30 p.m.		
<i>Approx. Times</i>	<i>Subject</i>	<i>Presenter</i>
9:30 a.m.	Welcome/Introductions <ul style="list-style-type: none"> ❖ Roll Call ❖ Approval of August 2024 Minutes (handout) ❖ Housekeeping 	Roberto Zori, MD Chairman
10:00 a.m.	Council Discussion of Krabbe Disease	Roberto Zori, MD Chairman
10:15 a.m.	Newborn Screening Follow-Up Program <ul style="list-style-type: none"> ❖ Staffing Updates ❖ Newborn Screening Statistics (handout) ❖ Cystic Fibrosis Updates ❖ Critical Congenital Heart Disease Report (handout) ❖ Review of Federal Process for Adding New Conditions ❖ New Conditions 	Emily Reeves, BSN, RN, CPN Director Newborn Screening Follow-up Program
Break (10 minutes)		
11:00 a.m.	Newborn Screening Hearing Follow-Up Program <ul style="list-style-type: none"> ❖ Staffing Updates ❖ Legislative Implementation Update ❖ Grant Activity Updates ❖ Hearing Data Updates 	Kimberly Porter Early Hearing Detection and Intervention Program Coordinator Newborn Screening Hearing Program
11:30 a.m.	Marketing and Process Improvement Update <ul style="list-style-type: none"> ❖ Review of Annual Performance Statistics 	Bryan Wendel Continuous Quality Improvement Unit Supervisor Newborn Screening Follow-up Program
Noon	LUNCH (Lunch on your own, 1.5 hours)	



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1:30 p.m.	Newborn Screening Laboratory <ul style="list-style-type: none"> ❖ Testing Updates ❖ Grant Updates ❖ Quality Improvement Activities 	<p align="center">Susanne Crowe, DrPH, MHA, HCLD(ABB) Assistant Bureau Chief, Jacksonville Laboratory Director Bureau of Public Health Laboratories</p> <p align="center">Patricia A. Ryland, BS, MT, MPH Administrator, Newborn Screening Laboratory Bureau of Public Health Laboratories Jacksonville</p>
2:00 p.m.	Public Comment <i>(Virtual attendees must submit requests to provide comment through the GoTo chat.)</i>	<p align="right">Roberto Zori, MD Chairman</p>
2:15 p.m.	New Discussions	<p align="right">Roberto Zori, MD Chairman</p>
2:30 p.m.	Closing and Adjourn	<p 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.*

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