

GENETICS AND NEWBORN SCREENING ADVISORY COUNCIL MEETING

The Genetics and Newborn Screening Advisory Council (GNSAC) meeting was held Friday, August 26, 2022, virtually through GoTo Meeting 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 introductions were made.

Members Present:

Roberto Zori, MD, Chair, University of Florida (UF)
Robert Fifer, PhD, Audiologist
Dorothy Shulman, MD, University of South Florida (USF)
Gary Kleiner, MD, University of Miami (UM)
Lindsay Baker, Consumer
George Fox, Consumer
Carina Blackmore, MS Vet Med, PhD, Surgeon General Designee
Lindsay Khan, DO, Florida Hospital Association
Barry Byrne, MD, Practicing Pediatrician
Jane Gibson, Ph.D., FACMG, University of Central Florida (UCF)

Guests:

Aliana Romero, AuD
Amarillis Sanchez-Valle, MD, USF
Ami Mehta
Angela Darnell
Brittany Knight
Carol Sale, MD, MPH, Miami
Corine Orr, UM
Daniel Armstrong
Deborah Barbouth, MD, Miller School of Medicine
Deeanna Hebrank
Donna O'Steen, USF
Eileen Rivera
Gerald Schiebler
Jean Polasky, All Childrens Hospital
Jeanne Brunger, PE
Judith Ranells, MD, USF
Juliette Murphy, UM Audiology
Kassi Wilson
Krista Mantay, MS, RD, LDN
Kristin Spence
Lindsey Granger
Lisa Mauck
Lizbeth Mellin
Melissa Racobaldo, USF
Melissa Reinhold, AdventHealth
Milvia Tellez, UM
Myrtha Gregoire-Bottex, MD, Miami
Natalie Shallow
Pamela Trapane, MD, UF Health Jax

Paul Pitel, MD
Shelby Jackson, UF Health Jax
Stephanie Hacker, UM
Tatiana Wing, USF
Willa Thorson, MD, UM

DOH Personnel Present:

Marcy R. Hajdukiewicz, MS, Tallahassee-CMS
Dusty Edwards, BSN, RN, Tallahassee-CMS
Kim Porter, Tallahassee-CMS
Emily Reeves, BSN, RN, CPN, Tallahassee-CMS
Bryan Wendel, Tallahassee-CMS
Kristin Barnette, RN, Tallahassee-CMS
Caitlin Roberts, Tallahassee-CMS
Amber Goodwin, Tallahassee-CMS
Kody Ledbetter, Tallahassee-CMS
Lindsey Felt, Tallahassee-CMS
Linda Ebelini, BSN, RN, Tallahassee-CMS
Mackenzie Young, RN, Tallahassee-CMS
Chantel Alfred, RN, Tallahassee-CMS
Stephanee Crumbaker, RN, Tallahassee-CMS
Jennifer Case, Tallahassee-CMS
Kirstie Gordon, RN, Tallahassee-CMS
Barbara Nolen, RN, Tallahassee-CMS
Ericka Horne, MPH, CHES®, Tallahassee-CMS
Felicia Williams, Tallahassee-CMS
Chiquita Williams, Tallahassee-CMS
Peggy Waterman, Tallahassee-CMS
Teryl Camus, Tallahassee-CMS
Miranda Nerland, Tallahassee-CMS
Natasha Rich, Tallahassee-CMS
Chiquita Williams, Tallahassee-CMS
Celica Coleman, Tallahassee-CMS
Reneeka Rogers, Tallahassee-CMS
Susanne Crowe, MHA, Bureau of Public Health Laboratories (BPHL)-Jacksonville
Patti Ryland, BS MT, MPH, BPHL-Jacksonville
Sajani Mamallapalli, BPHL-Jacksonville
Reynaldo Abrea, BPHL-Jacksonville
Elliott Bailey, BPHL-Jacksonville
Radley Remo, BPHL-Jacksonville
Najib Asgari, BPHL-Jacksonville
Reynaldo Abrea, BPHL-Jacksonville
Iruvanti Sunitha, BPHL-Jacksonville

Housekeeping Items

- Dr. Zori suggested to remove the extended break for lunch and to keep the midpoint break.
 - No objections from members; meeting agenda amended.

Approval of Minutes from Previous Meeting

- Dr. Zori moved for the minutes to be accepted from the February 2022 meeting at 9:34 AM. The Council unanimously approved the minutes at 9:35 AM.

Children's Medical Services (CMS) Division Director Update

Mrs. Marcy Hajdukiewicz provided a review of ongoing and upcoming activities within CMS.

- Dr. Karch's departure was announced to the council.
- An overview of legislative activities was provided, which included:
 - Children's Hearing Aid Program
 - Congenital Cytomegalovirus (cCMV) targeted screening development
- An overview of the development/implementation of the new Early Steps Data System was provided.

Newborn Screening (NBS) Follow-Up Program Update

Mrs. Emily Reeves provided the NBS Follow-up Program update to the Council.

- An overview of program staff was provided.
- An overview of program accomplishments was provided.
- The NBS statistics were reviewed with the Council.
- An overview of the CCHD Reports was provided.
- An overview of upcoming conditions was provided.

Newborn Hearing Screening (NBS) Follow-Up Program Update

Mrs. Kim Porter provided the NBS Hearing Screening Program update to the Council.

- An overview of legislative activities was provided
 - Upcoming implementation of cCMV
 - Development of Children's Hearing Aid Program
- An overview of current program activities was provided.
- The NBS Hearing data was reviewed with the Council.

Congenital Cytomegalovirus Presentation

Mrs. Porter and Dr. Robert Fifer provided an overview of cCMV to the Council.

- An overview of implementation activities was discussed.
- An overview of screening protocols and follow-up workflows was provided.
- An overview of upcoming staffing changes for the NBS Hearing Program was reviewed.

----- Dr. Zori called for a ten-minute break at 11:20 AM-----

----- The meeting reconvened at 11:30 AM-----

Newborn Screening (NBS) Marketing and Quality Improvement (QI) Update

Mr. Bryan Wendel provided the NBS Marketing and QI update to the Council.

- Reviewed the unsatisfactory and transit data.
- Provided a review of the 2021/2022 Fiscal year activities.
- An overview of current priorities was provided.
- Review of next steps was provided.

Newborn Screening New Conditions Update

Mrs. Kristin Barnette provided an update on new conditions that have been added to the Newborn Screening panel.

- Reviewed X-linked Adrenoleukodystrophy (X-ALD) data/statistics.
- Reviewed Lysosomal Storage Disorder's (LSD) data/statistics.
- Reviewed Spinal Muscular Atrophy (SMA) data/statistics.

Newborn Screening Laboratory Update

Ms. Susanne Crowe provided the Newborn Screening Laboratory update.

- An update on Cystic Fibrosis (CF) testing was provided.
- An update on Next Gen Sequencing was provided.
- An overview of the current electronic ordering and reporting system was provided.
- An update on Move It migration with birthing facilities was provided.
- An overview of laboratory grant activities was provided.
- An update on QI activities was provided.

Newborn Screening Program Review Task Force

Mrs. Emily Reeves provided the NBS Task Force update.

- A review of findings/recommendations from the task force was provided.
- A review of the meeting with Dr. Piero Rinaldo, held in April 2022, was provided.
- Discussion of next steps.

New Discussions

- No new items.
- Reminder that the next GNSAC meeting will be held in-person in Jacksonville.
 - All August meetings will be virtual; all February meetings will be in-person.
 - A virtual option will be available for anyone not able to attend in person.

Public Comment

- No submitted public comments.

The meeting adjourned at 12:48 PM.