

## **GENETICS AND NEWBORN SCREENING ADVISORY COUNCIL MEETING**

The Genetics and Newborn Screening Advisory Council (GNSAC) meeting was held Friday, February 11, 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)  
Cynthia Gauger, MD (Hematologist)  
Gary Kleiner, MD, University of Miami (UM)  
Mark Weatherly, MD, Practicing Pediatrician  
Lindsay Baker, Consumer  
Robert Karch, MD, Deputy Secretary of Children's Medical Services (CMS)  
George Fox, Consumer  
Carina Blackmore, MS Vet Med, PhD, Surgeon General Designee  
Lindsay Khan, DO (Florida Hospital Association)  
Lori Kohler, Agency for Persons with Disabilities (APD)

### **Guests:**

Alexa Bledsoe, UF  
Aliana Romero, AuD  
Amarillis Sanchez-Valle, MD, USF  
Ami Mehta  
Anna McGuinness, UF  
Chethan Rao  
Corine Orr, UM  
Corinn Rich, Perkin/Elmer (PE)  
Daphne Applebee, UF Health Jax  
Deeanna Hebrank  
Donna O'Steen, USF  
Eddy Varona  
Frances Saccoccio, MD  
Jasmine Burton-Akright, UF Health Jax  
Jeanine Onischuck  
Judith Ranells, MD, USF  
Kristin Spence  
Meagan Perry, Orchard Therapeutics (lobbyist)  
Meghan Kelley  
Melissa Racobaldo, USF  
Michelle Black, Kansas NBS  
Michelle Mills, Kansas NBS  
Milvia Tellez, UM  
Misty Browne, MD, USF Genetics  
Pamela Trapane, MD, UF Health Jax  
Paul Pitel, MD  
Riley Carroll, UF Health Jax

Shelby Jackson, UF Health Jax  
Stephanie Hacker, UM  
Tatiana Wing, USF  
Willa Thorson, MD, UM  
Yanerys Colon

**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  
Ken McCain, Tallahassee – CMS  
Lindsey Felt, Tallahassee – CMS  
Linda Ebelini, BSN, RN, Tallahassee – CMS  
Makenzie Young, RN, Tallahassee – CMS  
Chantel Alfred, RN, Tallahassee – CMS  
Sandra Crump, BSN, RN, Tallahassee – CMS  
Stephane Crumbaker, RN, Tallahassee – CMS  
Jennifer Case, Tallahassee – CMS  
Jordon Reese, RN, Tallahassee – CMS  
Kirstie Gordon, RN, Tallahassee – CMS  
Barbara Nolen, RN, Tallahassee – CMS  
Ericka Horne, MPH, CHES®, Tallahassee – CMS  
Harriet Hinson Charlton, Tallahassee – CMS  
Felicia Clowers, Tallahassee – CMS  
Jatarra Bradley, 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  
Bonnie Taffe, PhD, MPH, Bureau of Public Health Laboratories (BPHL), Jacksonville  
Patty Lewandowski, BPHL, Jacksonville  
Patti Ryland, BS MT, MPH, BPHL, Jacksonville  
Sajani Mamallapalli, BPHL, Jacksonville  
Reynaldo Abrea, BPHK, 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 inquired into the status of future meetings, virtual or in-person.
  - CMS staff will send out a survey to the council for input into future meeting platforms.

### **Approval of Minutes from Previous Meeting**

- Dr. Zori moved for the minutes to be accepted from the August 2021 meeting at 9:37 AM. The Council unanimously approved the minutes at 9:39 AM.

### **Children's Medical Services (CMS) Division Director Update**

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

- Bills impacting NBS during the 2022 legislative session:
  - HB 1073/SB 292 – Newborn Screenings
  - HB 1085/SB 1652 – Sickle Cell

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

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

- Overview of Program structure was provided.
- Review of Summer 2021 social media campaign regarding CMV prevention.
- Follow-up process overview.
  - Additional processes implemented to enhance current follow-up.
- The NBS Hearing data was reviewed with the Council.

### **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.
- Current program priorities were reviewed which include:
  - Virtual Hospital Technical Assistance
  - NewSTEPS Quality Indicator Report
  - Update the NBS Guidelines
  - Upcoming Association of Public Health Laboratories (APHL) site visit
- The NBS statistics were reviewed with the Council.
- An overview of the CCHD Reports was provided.
- COVID-19 and the impacts on the NBS Program were reviewed.

### **Newborn Screening (NBS) Marketing and Quality Improvement Update**

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

- Program overview was provided.
- Review of the NBS Awareness Campaign.
- Overview of Quality Improvement was provided.
  - Unsatisfactory rate
    - Covid impact
  - Transit rate review
- Overview of ongoing QI projects

----- Dr. Zori called for a ten-minute break at 11:22 AM-----

----- The meeting reconvened at 11:31 AM-----

### **Newborn Screening New Conditions Update**

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

- Reviewed updates to testing processes and protocols based on available data.
- Reviewed x-linked adrenoleukodystrophy (X-ALD) data/statistics.
- Review of Lysosomal Storage Disorder's (LSD) data/statistics.
- Review of Spinal Muscular Atrophy (SMA) data/statistics.
- Inclusion of Mucopolysaccharidosis Type II (MSP II) on the RUSP is being monitored.

### **Newborn Screening Laboratory Update**

Dr. Bonnie Taffe provided the Newborn Screening Laboratory update.

- Provided an overview of current laboratory Quality Improvement activities.
- Provided an overview of current grant opportunities.
- CF testing overview.

----- Dr. Zori called for a lunch break at 12:21 PM-----

----- The meeting reconvened at 12:37 PM-----

### **Newborn Screening Program Review Task Force**

Mrs. Emily Reeves provided the NBS Task Force update.

- Overview of the kick-off meeting
  - Findings review
  - Recommendations review
- Discussion of next steps.

----- George Fox and Dr. Khan motioned to move forward with all recommendations from the task force at 1:00 PM -----

### **Screening for congenital Cytomegalovirus (CMV)**

Dr. Frances Saccoccio presented on CMV.

- Provided an overview of CMV
  - Symptomatic vs asymptomatic
  - Testing methods
    - Advantages and disadvantages
  - Recommended treatment(s)

### **New Discussions**

- No new items.

### **Public Comment**

- No submitted public comments.

The meeting adjourned at 1:40 PM.