

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

The Genetics and Newborn Screening Advisory Council (GNSAC) meeting was held Friday, February 3, 2023, in-person at the Bureau of Public Health Laboratories-Jacksonville.

### **Call to Order:**

The meeting was called to order at 9:38 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, PhD, University of Miami (UM)  
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)  
Mark Weatherly, MD, Practicing Pediatrician  
Cynthia Gauger, MD, Hematologist  
Tenisha Avent, March of Dimes  
Chrishonda Jenkins, Delegate, Agency of Persons with Disabilities

### **Guests:**

Aaliya Ahmad  
Alexa Bledsoe, UF  
Amarillis Sanchez-Valle, MD, USF  
Ami Mehta  
Amy Johnson  
Andrea Gary  
Anna McGuinness, UF  
Cheryl Garganta, MD, UF  
Corine Orr, UM  
Daphne Applebee, UF Health Jax  
Deanna Almanza  
Deeanna Hebrank  
Donna O'Steen, USF  
Eileen Rivera  
Jasmine Burton-Akright, UF Health Jax  
Jeanne Brunger, PE  
Joseph Muenzer, MD, PhD, UNC  
Judith Ranells, MD, USF  
Juliette Murphy, UM Audiology  
Kansas Sampson  
Kassi Wilson, ARNP, USF  
Kristin Spence, MHSc, RD, LD/N, USF  
Lizbeth Mellin  
Madison Lake  
Matthew Ellinwood, CSO, National MPS Society  
Megan Boothe

Melissa Racobaldo, USF  
Milvia Tellez, UM  
Natalie Shallow  
Pamela Trapane, MD, UF Health Jax  
Peri Cavusgil, UF  
Terri Klein, CEO, National MPS Society  
Tucker Sanford  
Willa Thorson, MD, UM

**DOH Personnel Present:**

Marcy R. Hajdukiewicz, MS, Tallahassee-CMS  
Dusty Stern, 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  
Kari Hope, Tallahassee-CMS  
Ken McCain, Tallahassee-CMS  
Gerry Hicks, Tallahassee-CMS  
Lindsey Felt, Tallahassee-CMS  
Chantel Alfred, RN, Tallahassee-CMS  
Stephanee Crumbaker, RN, Tallahassee-CMS  
Jennifer Case, Tallahassee-CMS  
Kirstie Gordon, RN, Tallahassee-CMS  
Sandra Crump, RN, Tallahassee-CMS  
Jessica Williams, RN, Tallahassee-CMS  
Barbara Nolen, RN, Tallahassee-CMS  
Tori Davis, RN, Tallahassee-CMS  
Philicia Corbett, Tallahassee-CMS  
Felicia Williams, Tallahassee-CMS  
Chiquita Williams, Tallahassee-CMS  
Peggy Waterman, Tallahassee-CMS  
Teryl Camus, AuD, Tallahassee-CMS  
Miranda Nerland, Tallahassee-CMS  
Natasha Rich, Tallahassee-CMS  
Dajana Ujka, Tallahassee-CMS  
Jennifer Givens, Tallahassee-CMS  
Susanne Crowe, MHA, Bureau of Public Health Laboratories (BPHL)-Jacksonville  
Patti Ryland, BS MT, MPH, BPHL-Jacksonville  
Jennifer Martin, BPHL-Jacksonville  
Sajani Mamallapalli, BPHL-Jacksonville  
Bijoy Anand, BPHL-Jacksonville  
Radley Remo, BPHL-Jacksonville  
Najib Asgari, BPHL-Jacksonville  
Reynaldo Abrea, BPHL-Jacksonville  
Iruvanti Sunitha, BPHL-Jacksonville  
Shelly Dawson, BPHL-Jacksonville  
Stephanie Taylor, BPHL-Jacksonville  
Mary Jean Datin, BPHL-Jacksonville  
Virginia Simmons, BPHL-Jacksonville

### **Housekeeping Items**

- New council members to be introduced.
- Criteria for submitting public comments was reviewed.

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

- Dr. Zori moved for the minutes to be accepted from the August 2022 meeting at 9:47 AM. The Council unanimously approved the minutes at 9:48 AM.

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

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

- An overview of legislative activities was provided, which include:
  - Genetic counselors bill
  - Medicaid coverage bill
  - Universal CMV screening bill
  - Health authority bill
- An overview of the Division related activities 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 NewSteps Report was reviewed with the Council.
- An overview of the NBS Annual Statistics was provided.
- An overview of the CCHD Reports was provided.
- An overview of upcoming conditions was provided.

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

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

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

----- Dr. Zori called for a ten-minute break at 11:30 AM-----

----- The meeting reconvened at 11:41 AM-----

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

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

- An overview of the unit was provided.
- An overview of the 2021/2022 Fiscal year activities was provided.
- An overview of current priorities was provided.

## **Newborn Screening Laboratory Update**

Ms. Susanne Crowe provided the Newborn Screening Laboratory update.

- An overview of the Laboratory COOP Plan was provided.
  - 2022 Hurricane response was reviewed.
- An overview of current laboratory activities was provided.
- An overview of laboratory grant activities was provided.
- An update on QI activities was provided.
- An update on future goals was provided.

----- Dr. Zori called for a ten-minute lunch break at 12:15 PM-----

----- The meeting reconvened at 12:25 PM-----

## **New Conditions: Mucopolysaccharidosis Type II (MPS II)**

Dr. Joseph Muenzer presented on MPS II.

- An overview of MPS II was provided.
- A review of current treatment options was provided.
- A review of newborn screening for MPS II was provided.
- A review of recommendations for MPS II newborn screening was provided.

## **Public Comments**

- Dr. Sanchez-Valle from USF provided a comment related to MPS II screening.
- Mr. Ellinwood, from the National MPS Society, commented in support of adding MPS II to Florida's screening panel.

## **Mucopolysaccharidosis Type II Consideration**

- Consideration for adding MPS II to the NBS screening panel was conducted by the Council.
- Dr. Kahn made a motion to add MPS II to the NBS screening panel at 1:14 PM.
  - The motion was seconded by Dr. Byrne.

----- The Council voted to add MPS II to the NBS screening panel at 1:16 PM-----

## **New Discussions**

- The upcoming timeline for the addition of MPS II to the NBS screening panel was discussed.
  - Florida statutes outlines, the NBS Program must implement screening within 18 months, August 2024.
- The next GNSAC Meeting will be held Friday, August 18, 2023.
  - The Council has elected to keep the upcoming meeting virtual.

The meeting adjourned at 1:36 PM.