

GENETICS AND NEWBORN SCREENING ADVISORY COUNCIL MEETING

The Genetics and Newborn Screening Advisory Council (GNSAC) meeting was held Friday, February 16, 2024, virtually through Go To 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)
George Fox, Consumer
Carina Blackmore, MS Vet Med, PhD, Surgeon General Designee
Lindsay Khan, DO, Florida Hospital Association
Jane Gibson, Ph.D., FACMG, University of Central Florida (UCF)
Chrishonda Jenkins, MSN, RN, Agency of Persons with Disabilities
Mark Weatherly, MD, Pediatrician
Tenesha Avent, March of Dimes

Guests:

Aimee Diaz Lyon
Alexa Bledsoe, UF
Alexander Y. Kim, MD
Amy Jonasson
Anna Fowler, AuD Student, UM
Anna Grace Lewis
Anna McGuinness, UF
Biran Patel
Casey Rayfield
Cheryl Garganta, MD, UF
Daphne Applebee, UF Health Jax
Deanna Almanza, USF
Deeanna Hebrank
Deborah Barbouth, MD, UM
Donna O'Steen, USF
Eileen Rivera
Jasmine Burton-Akright, UF Health Jax
Jeanne Brunger, Revvity
Karen Beatty, Project Alive
Kassie Wilson, APRN, USF
Kim Higbee
Kris-Tina Smith, UF Health Jax
Krista Ringey (Mantay), UF
Kristin McKay
Leah Burdett
Lesley Giles
Lizbeth Mellin, UF Health Jax
Meghan Kelley

Melissa Gans, MD, UM
Melissa Racobaldo, USF
Nadia Falah, Jackson Health
Natalie Shallow
Ofelia Alvaraez, MD, UM
Omer Abdul Hamid
Pamela Trapane, MD, UF Health Jax
Paul Pitel
Rachel McCaffrey (Obi)
Riley Carroll, UF Health Jax
Sarah Goltsman, AuD Student, UM
Shelby Jackson, UF Health Jax
Terri Klein
Tyler Craddock
Vania Mishkin, UM
Willa Thorson, MD, UM
Yemila Lowry, RDN

DOH Personnel Present:

Andrea Gary, MS, RN, 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
Lindsey Felt, Tallahassee-CMS
Chantel Alfred, RN, Tallahassee-CMS
Kirstie Gordon, RN, Tallahassee-CMS
Sandra Crump, RN, Tallahassee-CMS
Gail Simpson, RN, Tallahassee-CMS
Karli Clark, RN, Tallahassee-CMS
Jessica Williams, RN, Tallahassee-CMS
Amy Fritsch, RN, Tallahassee-CMS
Tori Davis, RN, Tallahassee-CMS
Promise Santos, 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
Sharon Lundberg, Tallahassee-CMS
Eric Tano, Tallahassee-CMS
Jennifer Givens, Tallahassee-CMS
Sandy Noel, Tallahassee-CMS
Michelle Dawson, Tallahassee-CMS
Susanne Crowe, MHA, Bureau of Public Health Laboratories (BPHL)-Jacksonville
Patti Ryland, BS MT, MPH, BPHL-Jacksonville

Sajani Mamallapalli, BPHL-Jacksonville
Bijoy Anand, BPHL-Jacksonville
Elliott Bailey, BPHL-Jacksonville
Najib Asgari, BPHL-Jacksonville
Xihui Newman, BPHL-Jacksonville
Marie-Claire Rowlinson, BPHL-Jacksonville

Housekeeping Items

- Agenda format was reviewed.
- 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 2023 meeting at 9:34 AM. The Council unanimously approved the minutes at 9:35 AM.

Children's Medical Services (CMS) Division Director Update

Ms. Andrea Gary provided a review of ongoing and upcoming activities within CMS.

- An overview of legislative activities was provided.

Gene Therapy for Sickle Cell Disease

Dr. Edward Dela Ziga presented on gene therapy treatments available for sickle cell disease.

- An overview of gene therapy timeline was provided.
- An overview of approaches to gene modification was provided.
- A review of approved treatment products was provided.

Newborn Hearing Screening (NBHS) Follow-Up Program Update

Mrs. Kimberly Porter provided the NBHS Follow-Up Program update to the Council.

- An overview of legislative activities was provided.
 - Congenital Cytomegalovirus (cCMV) implementation
 - Children's Hearing Aid Program
- An overview of current program activities and accomplishments was provided.
- The NBHS data was reviewed with the Council.

----- Dr. Zori called for a fifteen-minute break at 11:16 AM-----

----- The meeting reconvened at 11:32 AM-----

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 update of the Metabolic Formula Program activities was provided.
- An overview of the NBS Annual Statistics was provided.
- An overview of the Critical Congenital Heart Disease (CCHD) Reports was provided.
- An overview of upcoming conditions was provided.
- An update from the Cystic Fibrosis Workgroup was provided.

Newborn Screening Laboratory Update

Ms. Susanne Crowe provided the Newborn Screening Laboratory update.

- An overview of current laboratory activities was provided.
- An overview of laboratory grant activities was provided.
- An update on QI activities was provided.
 - The Association of Public Health Laboratories (APHL) Informatics Messaging Services (AIMS)
- An update on future goals was provided.
- An update on laboratory regulations was provided.

Public Comments

- Ms. Kim Higbee provided a public comment regarding Pyruvate Dehydrogenase Complex Deficiency (PDCD), advocating for condition to be added to Florida's screening panel.

New Discussions

- The timeline for the addition of upcoming conditions to the NBS screening panel was discussed.
- The next GNSAC Meeting will be held Friday, August 23, 2024.
 - This meeting will be held virtually via Go To Meeting platform.
- Dr. Zori requested overview presentations related to Krabbe disease and Duchenne Muscular Dystrophy (DMD) at the next meeting.

The meeting adjourned at 12:50 PM.