

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

The Genetics and Newborn Screening Advisory Council (GNSAC) meeting was held Friday, February 26, 2021, virtually through Go To Meeting platform.

### **Call to Order:**

The meeting was called to order at 9:30 am, EST, by Paul Pitel, MD, Council Chairperson. Roll was taken and introductions were made.

### **Members Present:**

Paul Pitel, MD, Chair, Hematologist  
Robert Fifer, PhD, Audiologist  
Dorothy Shulman, MD, University of South Florida (USF)  
Roberto Zori, MD, University of Florida (UF)  
Gary Kleiner, MD, University of Miami (UM)  
Barry Byrne, MD, Practicing Pediatrician  
Brian Kirk, March of Dimes  
Heather Smith, Consumer  
Robert Karch, MD, Deputy Secretary of Children's Medical Services  
George Fox, Consumer  
Carina Blackmore, MS Vet Med, PhD, Surgeon General Designee  
Jane Gibson, Ph.D., FACMG, University of Central Florida (UCF)

### **Guests:**

Alexa Bledsoe, UF  
Aliana Romero, AuD  
Amarillis Sanchez-Valle, MD, USF  
Anna McGuinness, UF  
Cedric Pritchett, MD, Nemours  
Cheryl Garganta, MD, UF  
Donna O'Steen, USF  
Elizabeth Stoltz  
Gerold Schiebler, MD  
Jeanne Brunger, PerkinElmer, Inc.  
Judith Ranells, MD, USF  
Krista Mantay, UF  
Kristin Spence  
Laurel Jeter  
Majed Dasouki, MD, AdventHealth  
Marisa Fassnacht  
Mark Hudak, MD  
Sabah Bissainthe, Agency for Persons with Disabilities (APD)  
Sarah Bernacki  
Sarah Nimrichter, UF  
Stephanie Hacker, UM  
Wes Walker, MD, AdventHealth  
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  
Caitlin Roberts, Tallahassee – CMS  
Teryl Camus, Tallahassee – CMS  
Peggy Waterman, Tallahassee – CMS  
Lindsey Felt, Tallahassee – CMS  
Ashley Bailey, Tallahassee - CMS  
Kristin Barnette, RN, Tallahassee – CMS  
Ericka Horne, Tallahassee - CMS  
Linda Deterding, BSN, RN, Tallahassee - CMS  
Jessica Meyer, MSW, Tallahassee – CMS  
Kirstie Gordon, RN, Tallahassee – CMS  
Sandra Crump, BSN, RN, Tallahassee – CMS  
Jennifer Case, Tallahassee – CMS  
Ken McCain, Tallahassee – CMS  
Jordon Reese, RN, Tallahassee – CMS  
Barbara Nolen, RN, Tallahassee – CMS  
Amie Bounds, Tallahassee – CMS  
Lisa Gidula, 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  
Elliott Bailey, BPHL, Jacksonville  
Ming Chang, BPHL, Jacksonville  
Najib Asgari, BPHL, Jacksonville  
Bijoy Anand, BPHL, Jacksonville  
Jennifer Martin, BPHL, Tallahassee  
Christina Parmer, BPHL, Tallahassee  
Stacy Shiver, BPHL, Tallahassee

**Housekeeping Items**

- Dr. Paul Pitel has retired and is stepping down as chairperson.
- At 9:45 AM, Dr. Pitel nominated Dr. Roberto Zori as the new chairperson. Dr. Robert Fifer seconded the motion. The Council approved the nomination of Dr. Zori as the chairperson for the Genetics and Newborn Screening Advisory Council (GNSAC).
- Heather Smith, Consumer, has decided to step down from the Council.
- Dr. Jane Gibson was introduced as the newest member of GNSAC, representing the University of Central Florida.

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

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

- Staffing update:
  - Marcy Hajdukiewicz has been appointed to CMS Division Director.
  - Dusty Edwards has been named Bureau Chief of Newborn Screening/Early Steps Programs.
  - Emily Reeves has been named Program Director for the Newborn Screening Follow-up Program.
  - Kristin Barnette was promoted as the Newborn Screening Nursing Supervisor.
  - Jessica Meyer has been named the Part C Coordinator within the Early Steps Program.
  - Kim Porter was named EHDI Coordinator for the Newborn Hearing Screening Program.

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

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

- Hearing staff continues to train and enroll audiologists in the electronic reporting system.
  - Enhancements to the system are currently in development.
- Collaboration with the School for Deaf and Blind and the EHDI Program has led to an increase in families across the state receiving service and support.
- 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
- The NBS statistics were reviewed with the Council, including statewide Unsatisfactory data.
- An overview of outreach activities was provided.
- An overview of the Funding Allocation Project was provided.
  - Began January 2021
- An overview of the NBS Saves Lives Reauthorization Act was provided.
  - Legislation submitted on January 25, 2021.
- COVID-19 and the impacts on the NBS Program were reviewed.

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

- Dr. Pitel moved for the minutes to be accepted from the August 2020 meeting at 11:04 AM. The Council unanimously approved the minutes at 11:05 AM.

----- Dr. Pitel called for a ten-minute break at 11:05 AM.-----

----- The meeting reconvened at 11:15 AM.-----

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

Mrs. Emily Reeves 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-ALD data/statistics.
- Review of Pompe and Mucopolysaccharidosis Type I (MPS I) data/statistics.
- Review of SMA data/statistics.

### **Newborn Screening Laboratory Update**

Dr. Bonnie Taffe provided the Newborn Screening Laboratory update.

- An overview of the SMA/SCID laboratory process.
- Provided an overview of current lab Quality Improvement activities.
- Provided an overview on the Tennessee Continuity of Operations (COOP) response.

### **Task Force Reviews**

- CCHD
  - Dr. Hudak, chair.
  - Five meetings held between July 2020 and January 2021.
  - An overview of findings was provided.
  - An overview of recommendations was provided.
- Formulary Review
  - Stephanie Hacker, chair.
  - Seven meetings held between July 2020 and February 2021.
  - An overview of findings was provided.
  - An overview of recommendations was provided.

### **New Discussions**

- Dr. Pitel honored for his years of service to the council.
- Dr. Pitel provided a presentation on the history of Genetics and Newborn Screening.

### **Public Comment**

Dr. Pitel called for public comment at 1:00 PM.

- Lisa Gidula, CMS Plan, gave an update following the August 2021 GNSAC Meeting.

The meeting adjourned at 1:14 PM.