

GENETICS AND NEWBORN SCREENING ADVISORY COUNCIL MEETING

The Genetics and Newborn Screening Advisory Council (GNSAC) meeting was held Friday, August 28, 2020, 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 Bryne, MD, Practicing Pediatrician
Brian Kirk, March of Dimes
Heather Smith, Consumer
Lindsey Khan, DO, Neonatologist, Florida Hospital Association
Robert Karch, MD, Deputy Secretary of Children's Medical Services
Mark Weatherly, MD, Practicing Pediatrician
George Fox, Consumer

Guests:

Alan Smith, WellCare
Alexa Bledsoe, UF
Amarillis Sanchez-Valle, MD, USF
Anatalia Labilloy, UF
Anna McGuinness
Amy VanMeter, UF
Ann Lucas
Brittani Lewis, WellCare
Brooks Landry, eviCore
Cheryl Garganta, MD, UF
Christopher Chapman, eviCore
Corine Orr, UM
Craig Hightower, eviCore
Cynthia Henderson, Lobbyist
Denise Needham
Donald Fillipp, WellCare
Donna O'Steen, USF
Duenna Dorsett, WellCare
Elizabeth Vengoechea, Sanofi
Heather Stalker, UF
Jeanne Brunger, PerkinElmer, Inc.
Jacquelyn Smith
Jesse Bottcher, Agency for Health Care Administration (AHCA)
Kristin Spence, USF
Larry Vroegindewey, PerkinElmer, Inc.
Lon Castle, eviCore
Lori Kohler, Agency for Persons with Disabilities (APD)

Mike Murphy, WellCare
Milvia Tellez
Misty Browne
Natalie Shallow, UF
Pamela Trapane, UF
Sarah Nimrichter, UF
Stephanie Hacker, UM
Tanya Hillary, WellCare
Wendy Pitts, WellCare
William Hinsdale, WellCare
Willa Thorson, MD, UM

DOH Personnel Present:

Marcy R. Hajdukiewicz, MS, Tallahassee – CMS
Dusty Edwards, BSN, RN, Tallahassee – CMS
Jessica Meyer, MSW, Tallahassee – CMS
Emily Reeves, BSN, RN, Tallahassee – CMS
Bryan Wendel, Tallahassee – CMS
Caitlin Roberts, Tallahassee – CMS
Teryl Camus, Tallahassee – CMS
Chrishonda Jenkins, Tallahassee – CMS
Lindsey Felt, Tallahassee - CMS
Kristin Barnette, RN, Tallahassee – CMS
Linda Deterding, BSN, RN, Tallahassee - CMS
Paula McKnight, Tallahassee – CMS
Kirstie Gordon, RN, Tallahassee – CMS
Allison Westphal, RN, Tallahassee – CMS
Jennifer Case, Tallahassee – CMS
Ken McCain, Tallahassee – CMS
Jordon Waldron, RN, Tallahassee – CMS
Barbara Nolen, RN, Tallahassee – CMS
Andrea Gary, Tallahassee – Office of CMS Plan
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
Najib Asgari, BPHL, Jacksonville
Bijoy Anand, BPHL, Jacksonville
Jennifer Martin, BPHL, Tallahassee
Christina Parmer, BPHL, Tallahassee
Stacy Shiver, BPHL, Tallahassee

Children’s Medical Services (CMS) Division Director Update

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

Newborn Hearing Screening (NBS) Follow-Up Program Update

Mrs. Jessica Meyer provided the NBS Hearing Screening Program update to the Council.

- Hearing staff continues to train and enroll audiologists in the new electronic reporting system that was initially rolled out in 2019.
 - a. New enhancements to the system are currently in production.
- 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

Ms. Dusty Edwards 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.
- NBS Awareness Campaign overview.
- The newly updated NBS website, which went live in June 2020, was reviewed in order to demonstrate new features for both parents and medical professionals.
- An overview of the current Advisory Council Task Forces was provided.
 - Formulary Review Task Force
 - Critical Congenital Heart Disease Task Force
- COVID-19 and the impacts on the NBS Program were reviewed.
 - Increase in teleworking, telehealth, and virtual meetings.

----- Dr. Pitel called for a ten-minute break at 11:20am.-----

----- The meeting reconvened at 11:30am.-----

Newborn Screening New Conditions Update

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

- X-ALD went live in May 2018, reviewed new testing and referral processes.
- Pompe and Mucopolysaccharidosis Type I (MPS I) went live February 3, 2020.
- SMA went live April 27, 2020.

Newborn Screening Laboratory Update

Dr. Bonnie Taffe provided the Newborn Screening Laboratory update.

- An overview of the SMA laboratory process.
- Provided an overview of current lab Quality Improvement activities.

Approval of Minutes from Previous Meeting

- Dr. Pitel moved for the minutes to be accepted from the February meeting at 12:00 pm. The Council unanimously approved the minutes at 12:01pm.

CMS/WellCare Presentation

- A review of the transition to WellCare was provided.
 - The new CMS Plan model was reviewed.

- Quality Improvement measures were reviewed.
- Key features of the new WellCare model plan was discussed.
 - Expanded benefits; in lieu of services; special programs.
 - Regional Care Coordination.
- Provider Services and Engagement were reviewed.
 - Due to Covid-19, focus has shifted to virtual appointments and telehealth.

New Discussions

- Creation of a new task force focusing on standards for genetic centers and how to better provide services to areas identified as needing improvement
 - Dr. Zori put forth a motion to create the new task force.
 - Dr. Shulman seconded the motion.
- Pompe long-term follow-up.
 - The NBS Program will begin reviewing data points and timeframes related to long-term follow-up.
- Dr. Pitel will be retiring after the next meeting in February 2021, therefore two positions on the council will need to be filled.
 - A new chairperson will need to be selected at the next meeting.

Public Comment

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

- No public comments submitted.

The meeting adjourned at 1:05 pm.