Advisory Committee on Heritable Disorders in Newborns and Children Webinar Meeting March 22, 2019



Joseph A. Bocchini, Jr. MD Professor and Chairman Department of Pediatrics Louisiana State University Health – Shreveport

ACHDNC Business

Welcome
Roll Call
Vote – November 2018 Minutes

NEW EDUCATION AND TRAINING WORKGROUP MEMBERS

Sylvia Mann, M.S., C.G.C.

Supervisor, Genomics Section State Genetics Coordinator, Hawaii Department of Health Director, Western States Regional Genetics Network

Maa-Ohui Quarmyne, MBChB MS

Assistant Professor, Division of Pediatric Hematology/Oncology Department of Pediatrics, Emory University School of Medicine

Samantha Vergano, MD, FAAP, FACMG

Division Director, Medical Genetics and Metabolism, Children's Hospital of The King's Daughters Associate Professor of Pediatrics, Eastern Virginia Medical School

NEW FOLLOW UP AND TREATMENT WORKGROUP MEMBERS

Tracey Bishop

Chief, Newborn Screening Section Genetic Disease Screening Program California Department of Public Health

Luca Brunelli, MD, PhD

Associate Professor of Pediatrics, and Genetics, Cell Biology and Anatomy Division of Neonatology University of Nebraska Medical Center Children's Hospital & Medical Center

NEW FOLLOW UP AND TREATMENT WORKGROUP MEMBERS

J. Lawrence Merritt, II, MD

Program Director, Medical Biochemical Genetics Fellowship Associate Professor, Biochemical Genetics, Division of Genetic Medicine, Department of Pediatrics, University of Washington

Elna N. Saah, MD

Attending Physician, Pediatric Hematology Oncology Assistant Professor, Division of Pediatrics & Human Development College of Human Medicine, Michigan State University

Marci Sontag, PhD

Director, Center for Public Health Innovation, CI International NewSTEPs (Newborn Screening Technical assistance and Evaluation Program)

NEW LABORATORY STANDARDS AND PROCEDURES WORKGROUP MEMBERS

Nathalie Lepage, PhD, FCCMG, FCACB

Laboratory Head, Inherited Metabolic Diseases Newborn Screening Ontario

Miriam Schachter, PhD

Research Scientist, Newborn Screening Laboratory New Jersey Department of Health

Stan Berberich, PhD

Program Manager, Medical Screening State Hygienic Laboratory at The University of Iowa

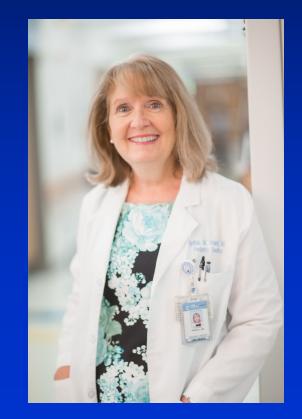
George Dizikes, PhD, HCLD/CC(ABB)

Director, Knoxville Regional Laboratory, Division of Laboratory Services

NEW ORGANIZATION REPRESENTATIVES

NEW CHAIRPERSON

CYNTHIA POWELL, MD, MS, FACMG, FAAP



FUTURE MEETINGS DATES

April 23-24, 2019 (in person and webcast)
August 1-2, 2019 (in person and webcast)
November 7-8, 2019 (in person and webcast)

Meeting dates through 2023 can be found on <u>the</u> <u>Committee's website</u>:

https://www.hrsa.gov/advisory-committees/heritabledisorders/meetings/index.html

MEETING TOPICS Friday, March 22, 2019

Updates from the Ad Hoc Workgroup on Risk Assessment and Interpretation of Newborn Screening Results

Initial presentation on the Expert Advisory Panel Meeting to Review the Committee's Nomination, Evidence Review and Decision Making Processes MEETING TOPICS Friday, March 22, 2019

Analyzing the Impact of Adding Conditions to the RUSP

Resources for facilitating Rare Disease Research and Data Collection

Advisory Committee on Heritable Disorders in Newborns and Children

Established under the Public Health Service Act, Title XI, § 1109 (42 U.S.C. 300b-10), as amended by the Newborn Screening Saves Lives Reauthorization Act of 2014 (P.L. 113-240)

All federal committees governed by the Federal Advisory Committee Act (FACA), Public Law 92-463, as amended (5 U.S.C. App. 2), and by 41 C.F.R. Parts 101-6 and 102-3

FACA sets the standards for the establishment, utilization, and management of Federal Advisory committees

Ethics and Conflicts of Interest (CIOs)

- Advisory to the Secretary of HHS
- Inquiries about the Committee
- When to recuse:
 - In all matters likely to affect the financial interests of any organization with which you serve as an officer, director, trustee, or general partner unless you are also an employee of the organization or unless you have received a waiver from HHS authorizing them to participate.

Meeting Participation

- All Committee meetings are open to the public.
- If the public wish to participate in the discussion, the procedures for doing so are published in the <u>Federal Register</u> and announced at the opening of a meeting.
- The Notice of Meeting in Federal Register indicated two options for public comment:
 - Oral Comments 2 requests received
 - Submit written statements No written statements received
 - Committee members receive copies of all written statements submitted

Any further public participation will be solely at the discretion of the Chair and DFO