

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 the Committee's website:
<https://www.hrsa.gov/advisory-committees/heritable-disorders/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 Federal Register 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