The Genetics and Newborn Screening Advisory Council (GNSAC) Task Force meeting was held by telephone conference call on Thursday, June 28, 2018.

Call to Order and Roll Call
Welcome/Introductions

The meeting was called to order at 1:08 pm EST by the chair, Dr. Paul Pitel. Those who identified themselves on the conference call are captured below.

GNSAC Task Force Members Present

Paul Pitel, MD, Chair, Hematologist
Barry Byrne, MD, Practicing Pediatrician, Cardiologist
George Fox, Parent Consumer
R. Rodney Howell, MD, Clinical Biochemical Genetics-Medical Genetics
Emily Reeves, BSN, RN, Newborn Screening Nurse Consultant
Patricia Ryland, Administrator, Newborn Screening Laboratory, attended on behalf of Bonita G. Taffe, Ph.D, MPH, Director of Chemistry & Newborn Screening

Department of Health Personnel Present

Cassandra G. Pasley, BSN, JD, Director, Division of Children’s Medical Services
Dusty Edwards, BSN, RN, Director of Newborn Screening Follow-up Program
Ivy Shivers, Government Operations Consultant III
Marcy Hajdukiewicz, Bureau Chief, Early Steps and Newborn Screening
Rachel Eastman, Contract Manager, Newborn Screening

REVIEW OF MINUTES

May 22, 2018 Genetics and Newborn Screening Advisory Council Task Force Meeting Minutes

Dr. Pitel called for concerns about the minutes. Ms. Reeves asked for the end time to be corrected. Dr. Howell moved to approve the minutes. Dr. Pitel seconded the motion. The motion passed unanimously.

DISCUSSION

Data from states that screen for Pompe and Mucopolysaccharidosis Type I (MPS I)

Ms. Edwards provided a briefing on the charts provided by Ms. Reeves as well as the data sheets on Pompe and MPS I.

Discussion continued.

• Task Force will review documents and return any suggestions.
• Mr. Fox would like to see the total number screened added to the chart.
• Dr. Howell would like to see additional information related to 2\textsuperscript{nd} Tier testing and pseudo deficiencies.
• Review of the required infrastructure for the laboratory to use CLIR on a daily basis.
• Benefits of identifying IOPD and LOPD.

NEXT STEPS

• Ms. Edwards to send out Word documents with deadline for edits.
• Ms. Ryland to obtain additional information regarding CLIR and what would be required.

UPCOMING MEETINGS

• Ms. Shivers to send out a doodle poll for the next proposed meeting.

The meeting adjourned at 2:26 pm.