



The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Department of Public Health
250 Washington Street, Boston, MA 02108-4619

CHARLES D. BAKER
Governor

KARYN E. POLITO
Lieutenant Governor

MARYLOU SUDDERS
Secretary

MONICA BHAREL, MD, MPH
Commissioner

**Massachusetts Department of Public Health (DPH)
Universal Newborn Hearing Screening Program
Advisory Committee Meeting, 250 Washington Street, Boston, MA
Public Health Council Room, 2nd floor
Meeting Date: Monday, January 22, 2018**

Quorum was reached for this meeting – 1/22/18

Appointed members present: Kathy Manfield, Jennifer Fleming, Marly Kenna, Darla Gundler, Michelle Eisan-Smith, Christine Majeskey, Sarah Stone, Peg Toro, Jennifer Bentley and Jane Stewart

Appointed members not present: Aimee Knorr

UNHS Staff in attendance: Martha Morris

Others in attendance: Julia Dunning, Gloria Pearsen, Cheryl Glovsky, Regan Andrade, Laura Pomponi, Todd Higgins, Aimee Stevens, Joan Rafferty, Elaine Gabovitch, Jayme Rivas Robertson, Melissa Dowler, Kristen Hartman Joshi, Lauren McGrath, and Suzanne Gottlieb

Materials distributed:

1. Agenda
2. Draft minutes from May 15, 2017 meeting
3. MCDHH Nomination Forms for individuals to be recognized at the Deaf and Hard of Hearing Constituents Day at the State House
4. Starting Points for EI Service Coordinators, Deaf and Hard of Hearing
5. Call for Proposals, Clarke Mainstream Conference
6. Article from JEHD "Are Audiologists Directly Referring Children Who are Deaf or Hard of Hearing to Early Intervention?"
7. Article from JEDHI "Parental Satisfaction and Objective Test Measurement Associated with Post-Partum versus Nursery Newborn Hearing Screening"

Welcome and Introductions: Kathy Manfield, Chair, welcomed the group and introductions were made. It was announced that this would be Darla Gundler and Peg Toro's last Advisory

Committee meeting. Darla is leaving DPH and Peg is retiring. A certificate of appreciation was given and remarks were made.

The meeting notes from May 15, 2017 were provided and a motion was made by Jennifer Fleming to accept them. Darla Gundler seconded. The committee voted and it was unanimous.

Sarah Stone, Director of the Universal Newborn Hearing Screening Program, provided updates. Jennifer Fleming has been hired as the Special Projects Coordinator for UNHS. Sarah is also now officially the Director of the program. UNHSP applied for, and received, a CDC cooperative agreement. Stakeholder meetings have continued to be held outside of the annual EHDI meeting. Events for families were held at the Worcester Bravehearts, cooking event, Wiggle Kids (SE part of state), Sunnyside (W.Mass). Upcoming events include LEGOLAND over February vacation and Jam Time in March. The Parent Forum is scheduled for April 7th at the Conference Center at Waltham Woods. The EHDI meeting will be in Denver this year March 19-20. UNHS is sponsoring 5 parents to attend.

Martha Savaria Morris, Ph.D., epidemiologist for UNHS, presented “Finalized Massachusetts Universal Newborn Hearing Screening Program 2015 Data”. Martha began her presentation by reminding the audience that a goal of EHDI is to enroll babies who are deaf and hard of hearing into early intervention by 6 months of age. 99.5% of babies born in MA receive a hearing screen. 1.8% of those babies referred (1,254 babies) and 182 were identified as deaf or hard of hearing. Only 376 babies born in Commonwealth do not have a documented hearing screen. Almost half of those babies were home births and a third were transfers. The lost to follow up rate for diagnostics was 4.6%. Nationally it is around 30%. An additional 39 babies that passed the hearing screen, but have a risk indicator were also identified with hearing loss. Of the 182 babies identified with hearing loss, almost 85% were enrolled in EI. However, only 71% were enrolled by 6 months of age. 8.2% of babies identified with hearing loss were lost to follow up for early intervention. The UNHS program is continuing to work on improving the timeliness of enrollment into early intervention.

Marly Kenna and Julia Dunning presented “The Power of an Usher Syndrome Community”. The mission of the Usher Syndrome Coalition is to raise awareness and accelerate research for Usher syndrome, the most common genetic cause of combined deafness and blindness and to provide information and support to individuals and families affected by Usher syndrome. The goal is to identify and support every person in the world with Usher syndrome. The Usher Syndrome Coalition exclusively focuses on Usher syndrome worldwide. Usher syndrome was described and how it affects hearing, vision and balance. Marly reviewed the clinical types of Usher syndrome and the frequency. She described the diagnostic process for Usher syndrome and showed examples of what the vision for a person with Usher Syndrome might look like. Marly described the negative messaging that many parents receive and the impact that it has on them. She described the benefits of early diagnosis. The Usher Syndrome Coalition is looking to connect people with Usher syndrome with researchers as well as with other families. They hold annual conferences, have a comprehensive website, host a video podcast series and a blog. They also hold an international symposium every 4 years. The next one is in July in Mainz, Germany. Julia Dunning then shared her family’s experience with newborn hearing screening and then the diagnosis of Usher syndrome for her daughter. Her daughter is in college and doing

well. She discussed the power of community and connecting families. The website link was shared www.usher-syndrome.org

Jennifer Fleming made a motion to adjourn. Michelle Eisan-Smith seconded, and the committee voted unanimously to adjourn.