National Newborn Screening Meeting on New Disorders [Pompe, MPS I, X-ALD]

June 20-21, 2018

Washington Marriott at Metro Center

Washington, DC
DRAFT
About NewSTEPs:
NewSTEPs (Newborn Screening Technical assistance and Evaluation Program) is a program of the Association of Public Health Laboratories in collaboration with the Colorado School of Public Health. It is a national newborn screening program designed to provide data, technical assistance, and training to newborn screening programs across the country and to assist states with quality improvement initiatives. NewSTEPs is a comprehensive resource center for state newborn screening programs and stakeholders.

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Pompe was added to the Recommended Uniform Screening Panel (RUSP) in March 2015, and X-Linked Adrenoleukodystrophy (X-ALD) and Mucopolysaccharidosis I (MPS I) were added in February 2016. State newborn screening programs pursuing universal implementation of these three new disorders encounter laboratory, staffing, clinical follow-up, personnel, equipment, education and legislative challenges.

The purpose of this meeting is to convene newborn screening personnel (both APHL awardees and non-awardees) who support the implementation of new disorders added to the RUSP, as well as pertinent partners and stakeholders who have experience with implementing new disorders.

1. Discuss current status of as well as future for MPS I, x-ALD and Pompe newborn screening in the United States.
2. Discuss decision points, barriers, unintended consequences to address in preparing for and implementing population screening for new disorders.
3. Identification and sharing of tools/resources used by newborn screening programs to prepare for and conduct screening for new disorders.

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DAY 1

8:00 – 8:30 am
Arrival/Continental Breakfast

8:30 – 9:00 am
Welcome

9:00 – 9:30 am
Lessons Learned: New Disorders Project Meeting

9:30 – 10:30 am
Building a Cost Analysis
  • Scott Grosse (Centers for Disease Control and Prevention)
  • State Representative (TBD)

10:00 – 10:45 am
Budget Tools: Nisha Quasba and Jelili Ojodu

10:45 – 11:00 am
Break

11:00 – 11:10 am
Surveillance Case Definitions around Pompe: Careema Yusuf and Marci Sontag

11:10 – 11:40 am
Long Term Follow-Up Clinical Guidelines for Pompe: TBD

11:40 am – 12:00 pm
Q & A

12:00 – 1:00 pm
Lunch (provided)

1:00 – 1:10 pm
Surveillance Case Definitions around MPS I: Careema Yusuf and Marci Sontag

1:10 – 1:55 pm
Long Term Follow-Up Clinical Guidelines for MPS I: TBD

1:55 – 2:40 pm
Group Discussion and Breakout Sessions

2:40 – 2:55 pm
Break

2:55 – 3:05 pm
Surveillance Case Definitions around X-ALD: Careema Yusuf and Marci Sontag

3:05 – 3:50 pm
Long Term Follow-Up Clinical Guidelines for X-ALD: TBD

3:50 – 4:30 pm
Facilitated Group Discussion

4:30 – 5:00 pm
Wrap Up and Adjourn
DRAFT AGENDA

DAY 2

7:30 – 8:00 am
Arrival/Continental Breakfast

8:00 – 8:15 am
Overview of Day 1: Sikha Singh and Kshea Hale

8:15 – 9:00 am
Educating Newborn Screening Staff: Mei Baker

9:00 – 9:15 am
Group Discussion/Q&A

9:15 – 9:45 am
Educating Clinicians, Genetic Counselors, & Providers: Amy Gaviglio

9:45 – 10:15 am
Baby’s First Test and Family Education: Amelia Mulford and Kimberly Piper

10:15 – 10:30 am
Break

10:30 – 11:30 am
Educating Providers: Clinician and Families Panel

11:30 am – 12:00 pm
Q & A

12:00 – 1:00 pm
Working Lunch (Q & A)

1:00 – 1:30 pm
Next Steps/Wrap Up

1:30 pm
Adjourn