

Co-Sponsored by the Association of Public Health Laboratories and  
the New York State Department of Health

## Newborn Screening for Adrenoleukodystrophy, Pompe Disease and Mucopolysaccharidosis Type I

### A Hands-On Workshop

**Date:** July 25-27, 2018

**Location:**

The NYS Department of Health  
David Axelrod Institute  
120 New Scotland Avenue  
Albany, NY 12208

### AGENDA

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#### Wednesday, July 25, 2018

<u>Time</u>	<u>Topic</u>	
11:45 am – 1:00 pm	Lunch / Registration / Pre-test	
1:00 pm – 1:30 pm	Welcome and Introductions / Ice Breaker	Dr. Michele Caggana
1:30 pm – 1:45 pm	Meet your Training Team	NYS NBS Lab and Follow-up Group
1:45 pm – 2:45 pm	Adrenoleukodystrophy – Later Onset So Why Should We Screen in the First Place?	Dr. Gerald Raymond
2:45 pm – 3:45 pm	The How and Why of Pilot Studies – MPS I, Pompe, and other LSDs	Dr. Melissa Wasserstein
3:45 pm – 4:00 pm	Break	
4:00 pm – 5:00 pm	Pompe disease – Handling Positive Screens, Infantile and Later Onset Disease	Lauren Bailey, CGC
5:00 pm	Return to Hotel	
6:00 pm	Dinner (Navona restaurant)	

**Thursday, July 26, 2018**

<u>Time</u>	<u>Topic</u>	
8:00 am – 8:30 am	Breakfast	
8:30 am – 9:15 am	Handling NBS Referrals – Interface with Follow-up	Dr. Paul Levy
9:15 am – 10:00 am	NBS Laboratory Tour	Dr. Michele Caggana
10:00 am – 10:15 am	Safety Training – Don your coats	TBD
10:15 am - 10:30 am	Break	
10:30 am -12:00 pm	Lab / Follow-up Session – Background & Methods	NYS Staff
12:00 pm – 1:00 pm	Lunch	
1:00 pm – 5:00 pm	Lab / Follow-up Session	TBD
5:00 pm	Return to Hotel Dinner on your own	

**Friday, July 27, 2018**

<u>Time</u>	<u>Topic</u>	
8:00 am – 8:30 am	Breakfast	
8:30 am – 12:00 pm	Lab / Follow-up Session	TBD
12:00 pm – 1:00 pm	Lunch	
1:00 pm – 4:00 pm	Lab / Follow-up Session	TBD
4:00 pm – 4:30 pm	Post-Test / Recap for Questions	TBD
4:30 pm	Depart for Home	

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