

Illinois Department of Public Health  
Lysosomal Storage Disorders Subcommittee  
Illinois Department of Public Health  
Meeting and Conference Call Minutes: March 20, 2014

Subcommittee Members Attending:

Barbara Burton, Lurie Children's Hospital – Chair

Jennifer Burton, OSF St. Francis Peoria

Brook Croke, OSF St. Francis Peoria

Kathy Grange, St. Louis Children's Hospital (Washington University)

Amy Knight Johnson – University of Chicago

Reshma Shah – University of Illinois at Chicago

IDPH Staff:

Khaja Basheeruddin, Jean Becker, George Dizikes, Harold Duckler, Arthur Kohrman, Shannon Harrison, Claudia Nash, Rong Shao, Heather Shryock

Background

The meeting was called to order at 2:00 PM.

Dr. Kohrman, consultant to the IDPH Director, voiced concerns about sharing identifiable case data among the LSD specialist or other states to track the outcome of these cases prospectively. Dr. Kohrman suggested parent permission be obtained which the specialists can provide to parents. A separate meeting will be scheduled with internal IDPH staff to develop a consent form.

IDPH Laboratory Status Report

Lysosomal storage disorder (LSD) procedures for tandem mass spectrometers continue as expected with all instruments working properly. Perkin Elmer is preparing database changes for LSD testing. Additionally, Perkin Elmer has to roll out a database upgrade before LSD testing can begin.

The LSD pilot is now expected to begin May 19, 2014, for Northwestern Memorial Hospital, with statewide testing to begin by July 1, 2014.

Dr. Dizikes indicated they have the ability to send samples for Krabbe mutation analysis to New York and do not need a contract.

The next meeting is scheduled for April 24, 2014 at 1:00 p.m. **Please note date and time change.**  
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