

Illinois Department of Public Health  
Lysosomal Storage Disorders Subcommittee  
Illinois Department of Public Health  
Meeting and Conference Call Minutes: February 19, 2015, 2:00 p.m.

Subcommittee Members Attending:

Lurie Children's Hospital	Dr. Barbara Burton, Chair
Lutheran General	Dr. Brad Tinkle
University of Chicago	Dr. Lainie Friedman Ross
University of Illinois Chicago	Dr. Zohra Shad
	Maria Helgeson
University of Illinois Chicago at Peoria	Jennifer Burton

IDPH Staff:

Dr. Khaja Basheeruddin	Dr. Arthur Kohrman
Jean Becker	Claudia Nash
Dr. George Dizikes	Dr. Rong Shao
Shannon Harrison	Heather Shryock
Tom Johnson	

Other Participants:

Brook Croke

IDPH Report

The LSD pilot began November 3, 2014, with newborns from four hospitals being tested for five LSDs; Pompe, Gaucher, Fabry, MPS I and Niemann-Pick. Additional hospitals have been added to the pilot, and currently all specimens from 8 hospitals, including Prentice Women's Hospital, are included. To date, approximately 1,867 samples have been tested with no cases diagnosed. Six positive screens referred to specialists had parental consents to share case information.

Regarding Krabbe molecular testing, attempts to secure a contract with the New York state laboratory have failed, due to inconsistencies between IDPH and NY attorneys regarding the required contract language. A contractual arrangement is being finalized through the University of Illinois at Chicago to send samples to Mayo laboratory for this testing. Dr. Dizikes stated that Mayo will do parental testing as part of initial charge with an 11 day turnaround time, but this would not hold up reporting of the newborn test. Dr. Burton did not feel it was necessary to include parental testing especially if it increased the cost of the contract.

Dr. Kohrman reported he has briefed the new Director, Dr. Nirav Shah, on the pilot phase of lysosomal storage disorder implementation. He indicated the Director had already received a legislative request to add ALD to the newborn screening panel. Dr. Ross indicated the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (DACHDNC) were still reviewing ALD for newborn screening. The Director was aware this had not been added to the Recommended Uniform Screening Panel. Claudia will request the presentation from Alex Kemper who presented on ALD at the DACHDNC meeting in February.

Khaja indicated the testing of the new assay for MPS 2 was available and is working.

The meeting adjourned 2:33 p.m.

The next scheduled call is March 19, 2015 at 2:00 PM, but several members verbalized a conflict with the date and time of this regular monthly call. A survey will be distributed to determine a new regular time.

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**UPDATE:** With the exception of the March call, the meetings have been changed to the 4<sup>th</sup> Wednesday of the month at 4pm. Listings of those dates are below:

March 11, 4pm

April 22, 4pm

May 27, 4pm

June 24, 4pm

July 22, 4pm

August 26, 4pm

September 23, 4pm

October 28, 4pm

November 25, 4pm

December 23, 4pm

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