

Illinois Department of Public Health
Lysosomal Storage Disorders Subcommittee
Illinois Department of Public Health
Meeting and Conference Call Minutes: May 15, 2014

Subcommittee Members Attending:

Lurie Children's Hospital
University of Chicago

Barbara Burton, Chair
Amy Knight Johnson
Lainie Friedman Ross
Darrel Waggoner
Jennifer Burton
Brook Croke
Jen Tarpinian

University of Illinois Chicago at Peoria

IDPH Staff:

Jean Becker
Matt Charles
Maria Crain
George Dizikes
Claudia Nash
Tom Schafer

IDPH Report

Dr. Dizikes reported the mutations testing agreement for Krabbe was in progress with New York State Health Department Wadsworth Laboratory. In the interim, Mayo Laboratory will be used. At this time, two Krabbe results have been received from Wadsworth, one was normal, the other was a carrier. Additionally three other samples were sent to Mayo Clinic Lab representing two children. None of the samples showed elevated psychosine levels. (UPDATE: One child was closed as normal per diagnostic testing, and the other the specialist is waiting for enzyme and DNA testing from Mayo). All newborns with an abnormal test identified during the validation phase are being tracked by the Follow-Up Program and no other tests will be done until the pilot testing is begun at Northwestern.

The laboratory database is scheduled for an update on May 18 with implementation of pilot testing June 9 at Northwestern. (UPDATE: Due to an unexpected need for additional air conditioners necessary for the LSD equipment, room remodeling and construction have delayed the start of the pilot. Anticipated start date is June 23.)

Program provided the subcommittee with a draft parental consent for confidential information or sample sharing which would be used with LSDs to share case specific information among all the specialists. Once approved, it will be distributed to specialists so that they may discuss with families when LSD screening is statewide.

Next call is scheduled for June 26, 2014 at 2:00 pm.

Meeting adjourned 2:17 p.m.