Illinois Department of Public Health
LSD Ad Hoc Subcommittee Meeting Summary Notes
March 19, 2009 Conference Call: 2:00 pm-2:45 pm

Participants:
Dr. Barbara Burton-Subcommittee Chair-Children's Memorial Hospital
Dr. Joel Charrow-Children's Memorial Hospital
Dr. Lainie Friedman Ross-University of Chicago
Dr. Darrel Waggoner-University of Chicago
Dr. George Hoganson-University of Illinois at Chicago
Dr. Kathy Grange-Washington University-St. Louis Children's Hospital
Tess Rhodes- Division of Specialized Care for Children
Dr. David Jinks-IDPH Newborn Screening Laboratory
Mike Petros-IDPH Newborn Screening Laboratory
Claudia Nash-IDPH Newborn Screening Program
Barb DeLuka-IDPH Newborn Screening Program
Kate Seymore-IDPH Newborn Screening Program

Dr. Burton asked for an update from IDPH on plans for LSD testing. Claudia Nash indicated the proposed Administrative Rules have been returned to IDPH from the Governor's Office and are now ready for submission to the Joint Committee on Administrative Rules (JCAR). The proposed Rules indicate a pilot testing period for all babies born at Northwestern (Prentice) and University of Chicago which will take place from November 1, 2010 through May 31, 2011; then full scale statewide testing will begin. She also reported that the current balance in the Metabolic Screening fund is low, and that $500,000 was removed from the fund this fiscal year in a fund sweep, which could impact the ability to procure equipment for LSD testing.

Dr. Jinks indicated that IDPH did submit a grant application to CDC, in conjunction with Dr. David Millington at Duke and Advanced Liquid Logics, for development of a microfluidics system for LSD screening which is less costly/labor intensive than MS/MS. Grant notification should occur by September. If the grant is not obtained, Dr. Jinks felt that IDPH would find other sources of funding for the pilot testing. The IDPH lab would need to contract with an outside lab for the molecular testing initially, but ultimately would set this up in house.

Dr. Burton briefly indicated that she felt this Subcommittee should develop recommended protocols for screen positive babies to assure consistency in evaluating these infants and to gather data in a consistent manner, and that IL will be a model for other states.

Dr. Ross asked about the degree of follow up that would be required of families, and it was discussed that it is important to build measures into the protocols to assure that parents feelings/wishes are considered. Dr. Burton asked Dr. Ross to provide guidance regarding this matter.

There was a discussion about whether one or more labs would provide the follow up confirmatory testing; whether IDPH or the geneticist would submit the sample, and how this would be billed and if DSCC would cover these costs.

Dr. Burton asked if Subcommittee members would be willing to do a literature search and develop draft protocols for review by the Subcommittee at a face to face meeting in September.

Members agreed to address disorders as follows:

Krabbe-Dr. Waggoner
Pompe-Dr. Grange
Niemann-Pick-Dr. Hoganson
Gaucher-Dr. Charrow
Fabry-Dr. Burton

Claudia Nash will contact Subcommittee members to set up a meeting date for September to review the protocols drafted for each disorder.

Note: the proposed Administrative Rules indicate that designated specialists should have 'certification by the American Board of Medical Genetics in Clinical Biochemical Genetics or certification by the American Board of Medical Genetics in Clinical Genetics, with at least one year experience post-training in the diagnosis and treatment of LSDs. Medical specialists should have the capacity to provide enzyme replacement infusion therapies and to provide a multidisciplinary approach to care, including the availability of pediatric specialists in neurology, cardiology and pulmonology. In addition to the above requirements, for Krabbe disease, medical specialists should be affiliated with a facility that has experience in performing stem cell transplantation.'