APHL ASSOCIATION OF PUBLIC HEALTH LABORATORIES®

APHL Position Statement
Newborn Screening Short Term Follow-Up

A. Statement of Position
Timely, efficient and integrated short term follow-up programs are a critical and necessary component of a successful newborn screening (NBS) system.

B. Implementation

1. APHL will support information dissemination to short term follow-up personnel through bi-monthly national webinars on topics of interest such as challenges with disorder specific follow-up and home birth follow-up.
2. APHL will convene roundtables at the APHL Newborn Screening and Genetic Testing Symposium to enhance communication and collaboration among follow-up staff.
3. APHL will organize in-person meetings for short term follow-up every 18 months at the midpoint between Symposia and as funding allows.
4. APHL will coordinate site reviews, engaging experts from the newborn screening community, upon request from NBS programs. Site reviews include a thorough assessment of short term follow-up accompanied by recommendations for improvements.
5. APHL will continue to update the NewSTEPs website to ensure appropriate educational materials remain available as a resource to newborn screening programs.
6. APHL will provide a platform for data entry and analysis pertinent to short term follow- up on an ongoing basis enabling programs to make comparisons in areas such as timeliness and specimen collection errors and ultimately allowing for implementation of quality improvement measures

C. Background/Data Supporting Position
Newborn Screening (NBS) is an accepted, important and data driven public health initiative (1). Short term follow-up is an essential component of the NBS process that ensures confirmation of diagnosis or rules out conditions on the screening panel and then ensures all newborns with a confirmed diagnosis are in the care of the appropriate specialist and receiving the necessary treatment required for a better quality of life. Successful NBS requires timely collection of specimens by birthing facilities, dependable transport of specimens to the screening laboratory, prompt processing and analysis of specimens, and timely reporting of results to the follow-up team, primary care provider, subspecialty providers and families.

D. Recommendations
Short term follow-up programs should maintain and regularly review detailed written protocols that address how each aspect of short term follow-up should occur. The protocols should stress the collaboration of the screening laboratory with the follow-up team and with community resources including primary care providers, subspecialists, birthing centers, community public health programs, midwives, and families of newborns. Such protocols should include specific timelines for each component and should clarify roles and responsibilities. Written protocols should be specific enough to promote consistent follow-up, while acknowledging that the individual needs of families may differ. Timelines should reflect the relative urgency of each follow-up situation as it relates to presumptive positives (2). NBS programs should ensure their follow-up procedures are in compliance with the regulatory requirements of such institutions as CLIA and CAP. The screening laboratory and follow-up teams should pursue regular collaborative

quality assurance (QA) activities coordinated across the pre-analytical, analytical and post-analytical phases of NBS system. Similarly, subspecialty consultants and follow-up teams should regularly review the processes to assure appropriate systems for definitive diagnosis and prompt institution of necessary treatment. NBS systems should have written case definitions consistent with case definitions as defined in the NewSTEPs data repository and, when possible, should incorporate guidelines developed by the Clinical and Laboratories Standards Institute (4) and the Advisory Committee on Heritable Disorders in Newborns and Children (2). This will lead to consistent reporting of diagnosed cases by the short term follow-up coordinators.

D. References

1. Therrell BL, Panny SR, Davidson A, et al. U.S. Newborn Screening Program Guidelines. Statement of the Council of Regional Networks for Genetics Services 1992.1:135-47.

2. Recommendations from the Advisory Committee on Heritable Disorders in Newborn and Children; http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendations/timelynewbornscreeninggoalschainletter.pdf, April 2015.

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