

APHL Abstract (2500 characters max)

Title: Supporting Public Health Program Incorporate Newborn Screening Long- Term Follow-Up

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Topic: Short-term and long-term follow-up (engagement with specialists, methods and tools for short-term and long-term follow-up, late onset conditions, etc.)

Secondary Topic: Crosscutting- Health Outcome Evaluation

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Problem and Objective: Over 20,000 newborns are diagnosed each year with a congenital condition through the newborn screening (NBS) system. The majority of these conditions require life-long care and management, ideally with the care coordinated through a medical home, to assure the best possible outcomes for each diagnosed baby. All stakeholders in the NBS community (parents, patients, clinicians, researchers, and NBS programs) play important roles in long-term follow-up (LTFU), but there is no national system of LTFU data collection, analysis, sharing, and reporting. In addition, LTFU activities, policies, and practices vary across state NBS programs. The goal of this round table discussion is to provide state NBS programs a forum to discuss their involvement in LTFU and to create a series of definitions of LTFU for each stakeholder group. A new initiative will also be described to capitalize on clinical care efforts to deliver LTFU into a centralized resource that will improve the insight of the benefits of NBS.

Methodology: The roundtable will include three short presentations. The first two presentations will be from states with established LTFU. A third presentation will be from the American College of Medical Genetics and Genomics (ACMG) to describe the LTFU-Cares and LTFU-Checks Initiative, a LTFU model system with Spinal Muscular Atrophy (SMA) as a test case. Then the group will break into teams for further conversation on what LTFU activities are currently feasible in their state and to draft a definition of LTFU that matches current and planned efforts. Each participant will be provided with a worksheet with a working definition of LTFU for public health programs and they will identify what LTFU currently looks like in their state, discuss how their program is currently fulfilling these activities, and next steps to strengthen their program or a baseline for starting a LTFU program.

Results/Conclusion: Newborn screening is aims to assure the best possible outcomes for newborns identified with disorders that benefit from early identification and intervention. The LTFU of diagnosed newborns is an important component and this roundtable will result in a better understanding of what

LTFU means for state NBS programs, and will begin to outline recommended activities that could be included in a LTFU program.