

## WORKGROUP REPORT

**Liaison Name:** Carol Johnson and John Thompson

**Name of Workgroup:** Short-term Follow-up Workgroup

**Meeting Date:** December 1-2, 2016

### ***Summary of Workgroup Activities:***

**Bimonthly webinars** – format is to have one state highlight their follow-up program, followed by 2-3 speakers sharing a general topic, with questions and answers at the end. We send out a survey to each of the participants asking how things went and suggestions for future topics. The workgroup reviews the feedback to improve future webinars. Here were the topics for 2016:

January – Hemoglobinopathy Follow-Up

March – Using Infographics for Data and Parent Materials

May – Follow-up for X-linked Adrenoleukodystrophy

July – Summary of Cystic Fibrosis Meeting in Denver, Colorado

September – Linkage to Care: Communication and Collaboration

November – Take Aways from the Short-Term Follow-Up Stakeholders Meeting

**Carrier Detection White Paper** – a subcommittee comprised of Erica Wright, Beth Vogel, Amy Gaviglio, Debbie Freedenberg and Lou Bartoshesky have been working on a white paper about carrier detection in newborn screening. They tried valiantly to keep a handle on scope-creep for this paper and have brought it back to focus on hemoglobin trait and CF carrier detection through routine newborn screening efforts. They have a preliminary draft of the document that needs to be finalized by the subcommittee before review of the full workgroup.

**Update of APHL’s Short-term Follow-up Position Statement** – Lou Bartoshesky took the lead in revising APHL’s Short-term Follow-up Position Statement. It has been reviewed by the full workgroup and will be pushed up through the APHL approval channels prior to releasing publically. We will be asking for a brief extension of the sunset date to allow for final approval of the updated statement.



**(First ever) Short-term Follow-up Symposium** – In October, APHL partnered with the Cystic Fibrosis Foundation to sponsor a Short-term Follow-up symposium, bringing together short-term follow-up staff from more than 40 states. This two-day meeting's theme was centered on the critical nature of communication in successful short-term follow-up efforts. Breakout session topics were false negatives, co-location of laboratory and follow-up and funding challenges. On the second day we met with cystic fibrosis clinical partners for a morning of quality improvement topics and a chance to discuss how to work more effectively and efficiently together to improve timeliness of diagnosis.

***Successes:***

- Bimonthly webinars – good attendance and positive feedback
- Short-term Follow-up Position Statement nearing completion
- Amazing success of the Short-term Follow-up Symposium with ideas for future activities and topics to address (also funded for 2018!)

***Challenges:***

- Low-hanging fruit already mostly picked – many of the high-priority remaining topics are complex and may not lend to the webinar format
- Sustainable funding is a challenge for most programs

***Salient Questions/Points/Strategic Direction Related Topics for Discussion:***

- Potential for SCID meeting, similar to CF meeting in Denver – chance to bring a clinical consultant, a NBS follow-up and a NBS lab person from each state together to talk about SCID newborn screening and work on quality improvement efforts
- Want to keep bimonthly webinar series up and running
- We want to add something impactful, but challenge is time of workgroup members – everyone is already super busy
- Trying to reach out to have participation across the board – i.e. not have the same folks/states presenting at webinars and conferences
- Sustainable funding ideas/mentoring