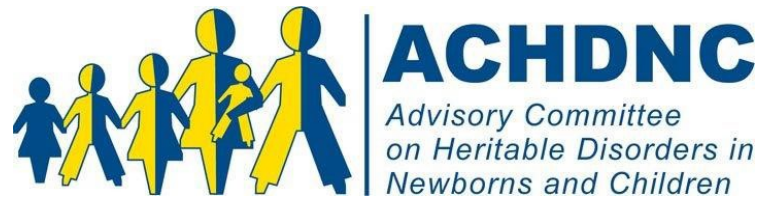


Follow Up and Treatment Workgroup

February 2023



November 2022 Meeting

Consensus on:

Request “blueprint” for follow-up and treatment as part of RUSP nominations

With the goal of using this blueprint as the basis of guidance materials for states after additional of a condition to the RUSP

February 2023 Meeting

Proposal to HRSA to:

Draft a revision to the RUSP nomination form that includes three elements of a blueprint...

February 2023 Meeting

1. Nominator's suggested short-term follow-up plan for the state NBS programs:

- What happens when a baby screens positive? (may include algorithm for different levels, etc.)
- What short-term outcomes do states need to gather to evaluate short-term (i.e. screening) outcomes?

February 2023 Meeting

2. Nominator's suggested long-term follow-up and treatment approach for providers:

- What are the relevant subgroups of screened individuals who will be identified by NBS? (suggested standardized terminology)
- How should each group be managed?
- If clinical practice guidelines are available, nominators might just need to reference these.

February 2023 Meeting

3. Nominator's suggested data collection strategy:

- Suggested data repository location/platform
- Data dictionary for variables that need to be gathered to evaluate addition of condition to RUSP (including both screening outcomes and treatment outcomes)