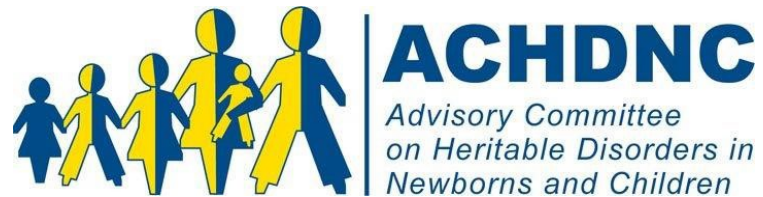


Follow Up and Treatment Workgroup

November 2022



August 2022 Meeting

- Idea 1: Recommended Uniform Follow-up Plan (RUFUP) Adjunct to RUSP laying out out universal + disease specific follow-up expectations
- Idea 2: ACHDNC officially recommends to relevant societies/colleges (e.g. AAP, AAFP, ACMG) to provide guidelines on follow-up and treatment (universal + disease specific)
- Idea 3: Request “blueprint” for follow-up and treatment as part of RUSP nominations

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

Blueprint Components (Preliminary)

- What are the relevant subgroups of screened individuals who will be identified by NBS?
 - Initially symptomatic vs. asymptomatic
 - Varying levels of relevant biomarkers
 - Different for every condition

Blueprint Components (Preliminary)

- For each subgroup:
 - Propose standardized terminology
 - Guidance on follow-up needs specific to subgroup (which professionals, which evaluations, where located, how frequent, etc.)
 - Resources that need to be in place

Blueprint Components (Preliminary)

- Blueprint would focus on follow-up needed to identify whether screened individual has the NBS primary condition
- Because this is the component of follow-up most urgent for state implementation