

**Evidence-Based Review for NBS:
Considering screening for additional
disorders**

ACHDGDNC

Criteria Work Group:
Additional Recommendations

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Criteria Work Group: Additional Recommendations to the *ACHDGDNC*

- Establish a core Evidence Review Group (ERG) via contract
- Considerations for the ERG:
 - ERG composition to include:
 - Core experts on genetics, on the methodology of evidence-based review, public health, consumer, pediatrics
 - *Ad hoc* members for specific expertise
 - 2 AC members (rotating) as liaison members
 - 3 immediate tasks
 - Determine definitions of those terms used in the Nomination Form
 - Delineate the processes for gathering and weighing evidence
 - Work through the 2 above while considering 2 (or 3) additional disorders for NBS

Recommendations to the *ACHDGDNC* (*continued*)

- Determine what to assess in a different context (i.e. *NOT the ERG*):
 - Cost analysis
 - Certain ELSI issues, such as defining non-medical benefits
- Relationship between the AC and the ERG:
 - Iterative and dynamic, with 2 overlapping members of the EWG to sit on the ERG.
Rotate AC membership.
 - ERG reports to a sub-group of the *ACHDGDNC*.

Next Steps for the *ACHDGDNC*

- Advise HRSA on the terms of a contract for the ERG leadership
- Solicit nominations for those 2 (or 3) disorders to be considered for evaluation of the other disorders.