



# Advisory Committee on Heritable Disorders in Newborns and Children

## 2011 Report for Congress

---

**Alaina M. Harris, M.S.W., M.P.H.**

Health Resources and Services  
Administration



# Legislative Requirement

---

- Section 1111 of the NBSSLA reauthorized and expanded the activities of the Advisory Committee on Heritable Disorders in Newborns and Children
  - a) Establishment
  - b) Duties
  - c) Membership
  - d) Decision on Recommendations
  - e) Annual Report
  - f) Continuation of Operation of Committee
  - g) Authorization of Appropriations

# Legislative Requirement

---

ANNUAL REPORT—Not later than 3 years after the date of enactment of the Newborn Screening Saves Lives Act of 2008, and each fiscal year thereafter, the Advisory Committee shall—

- publish a report on peer-reviewed newborn screening guidelines, including follow-up and treatment, in the United States;
- submit such report to the appropriate committees of Congress, the Secretary, the Interagency Coordinating Committee established under Section 1114, and the State departments of health; and
- disseminate such report on as wide a basis as practicable, including through posting on the internet clearinghouse established under section 1112.



# Legislative Intent

---

- Report is to be published by April 28, 2011
- Intention was for the Advisory Committee to report on what it has done since reauthorization and it's plans for the future.



## Topic for discussion today:

---

- What does the Advisory Committee want for the content of the yearly report to Congress and the public on newborn screening guidelines, including follow-up and treatment, in the United States?



# Potential items for the report

---

1. Revise the evidence workgroup reports
2. Provide updates from the subcommittees
3. Include information on the heritable conditions that States require and offer in their NBS programs
4. The incidence and prevalence of conditions on the recommended screening panel
5. If available, information on the health status of individuals with these conditions