

2011 ANNUAL REPORT TO CONGRESS

Secretary's Advisory Committee on Heritable Disorders
in Newborns and Children

Presented by Alissa Johnson, May 6, 2011

Actions Since SACHDNC Jan. 2011 Meeting

- Reorganization of outline
- HRSA Staff, Experts, Grantees and Federal Agencies Draft Paper
- Request Comments from Committee, federal agencies and experts who contributed to report

Organization of Report

- Part 1 – SACHDNC Guidelines: The RUSP and Other Newborn Screening Guidelines, which discusses work in areas of:
 - Follow-up
 - Treatment and management,
 - Heritable disorders, newborn screening and health care reform
 - Education
 - Sickle Cell Disease Carrier Screening
 - The Retention and Use of Residual Dried Blood Specimens After Newborn Screening

Organization of Report

- Part II – Grant and Other Projects Authorized by The NBS Saves Lives Act of 2008
- Appendix
 - A – Committee Publications, which includes journal articles, reports, briefing papers and meeting summaries
 - B – Tables of Conditions Screened for in the States (NNSGRC)
 - C - List of the SACHDNC Recommendations to the HHS Secretary and Outcomes

Experts

- Alex Kemper and Nancy Green – evidence review process
- Brad Therrell – Implementation of the Recommended Uniform Screening Panel
- Carol Greene and Mike Watson – The Future of Newborn Screening
- Alan Zuckerman, Rebecca Goodwin and Sharon Terry – Health Information Exchange

Grants and Other Projects Authorized by The NBS Saves Lives Act of 2008

- Section 1109 – Improved Newborn and Child Screening for Heritable Disorders
 - Regional Genetics and Newborn Screening Collaboratives – ACMG
 - Newborn Screening Effective Follow-up Projects – HRSA
- Section 1110 – Grant Programs to Evaluate the Effectiveness of Screening Counseling, or Health Care Services
 - Newborn Screening From a Family Perspective – HRSA
 - Laboratory Quality Assurance Activity - HRSA

Grants and Other Projects Authorized by The NBS Saves Lives Act of 2008

- Section 1112 - Clearinghouse of Newborn Screening Information
 - Genetic Alliance
- Section 1113 – Laboratory Quality
 - CDC
- Section 1114 – ICC on Newborn and Child Screening
 - HRSA
- Section 1115 – CONPLAN
 - CDC

Grants and Other Projects Authorized by The NBS Saves Lives Act of 2008

- Section 1116 – Hunter Kelly Research Program
 - NIH

Committee comments

- Minor edits made with feedback generally positive
- Conclusion at end of Part 1 was moved to end of report.

Comments from Federal Agencies

- AHRQ
- CDC
- HRSA
- NIH

Comments from Federal Agencies

- Minor edits
- Addition of explanation of terms such as virtual repository and addition of text box on newborn screening
- Shortened length of future of newborn screening section, in particular HIT discussion
- Improved integration of hearing screening information into the report

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