AMENDMENT TO H.R. 2507
OFFERED BY M. __________

Amend section 2 to read as follows:

SEC. 2. IMPROVED NEWBORN AND CHILD SCREENING AND FOLLOW-UP FOR HERITABLE DISORDERS.

(a) PURPOSES.—Section 1109(a) of the Public Health Service Act (42 U.S.C. 300b–8(a)) is amended—
(1) in paragraph (1), by striking “enhance, improve or” and inserting “facilitate, enhance, improve, or”;
(2) by amending paragraph (3) to read as follows:
“(3) to develop, and deliver to parents, families, and patient advocacy and support groups, educational programs that—
“(A) address newborn screening counseling, testing (including newborn screening pilot studies), follow-up, treatment, specialty services, and long-term care;
“(B) assess the target audience’s current knowledge, incorporate health communications strategies, and measure impact; and
“(C) are at appropriate literacy levels;”;

and

(3) in paragraph (4)—

(A) by striking “followup” and inserting “follow-up”; and

(B) by inserting before the semicolon at the end the following: “, including re-engaging patients who have not received recommended follow-up services and supports”.

(b) APPROVAL FACTORS.—Section 1109(c) of the Public Health Service Act (42 U.S.C. 300b–8(c)) is amended—

(1) by striking “or will use” and inserting “will use”; and

(2) by inserting “, or will use amounts received under such grant to enhance capacity and infrastructure to facilitate the adoption of,” before “the guidelines and recommendations”.

Page 2, after line 13, insert the following (and make such conforming changes as may be necessary):

(A) in paragraph (5), by inserting “and adopt process improvements” after “take appropriate steps”;

Page 2, line 17, strike “and” at the end.
Page 3, after line 9, insert the following:

(D) in paragraph (9), as redesignated—

(i) by redesignating subparagraphs (K) and (L) as subparagraphs (L) and (M), respectively; and

(ii) by inserting after subparagraph (J) the following:

“(K) the appropriate and recommended use of safe and effective genetic testing by health care professionals in newborns and children with an initial diagnosis of a disease or condition characterized by a variety of genetic causes and manifestations;”; and

Page 9, after line 20, insert the following (and make such conforming changes as may be necessary):

(8) The impact on newborn morbidity and mortality in States that adopt newborn screening tests included on the uniform panel.

(b) PUBLIC STAKEHOLDER MEETING.—In the course of completing the study described in subsection (a), NAM or such other appropriate entity shall hold not less than one public meeting to obtain stakeholder input on the topics of such study.