

House _____ Amendment NO. _____

Offered By _____

1 AMEND Senate Bill No. 194, Page 1, Section A, Line 2, by inserting after said section and line the
2 following:

3
4 "191.332. 1. By January 1, 2002, the department of health and senior services shall, subject
5 to appropriations, expand the newborn screening requirements in section 191.331 to include
6 potentially treatable or manageable disorders, which may include but are not limited to cystic
7 fibrosis, galactosemia, biotinidase deficiency, congenital adrenal hyperplasia, maple syrup urine
8 disease (MSUD) and other amino acid disorders, glucose-6-phosphate dehydrogenase deficiency (G-
9 6-PD), MCAD and other fatty acid oxidation disorders, methylmalonic acidemia, propionic
10 acidemia, isovaleric acidemia and glutaric acidemia Type I.

11 2. By January 1, 2017, the department of health and senior services shall, subject to
12 appropriations, expand the newborn screening requirements in section 191.331 to include severe
13 combined immunodeficiency (SCID), also known as bubble boy disease. The department may
14 increase the fee authorized under subsection 6 of section 191.331 to cover any additional costs of
15 the expanded newborn screening requirements under this subsection.

16 3. By January 1, 2019, the department of health and senior services shall, subject to
17 appropriations, expand the newborn screening requirements in section 191.331 to include spinal
18 muscular atrophy (SMA) and Hunter syndrome (MPS II). The department may increase the fee
19 authorized under subsection 6 of section 191.331 to cover any additional costs of the expanded
20 newborn screening requirements under this subsection. To help fund initial costs incurred by the
21 state, the department shall apply for available newborn screening grant funding specific to screening
22 for spinal muscular atrophy and Hunter syndrome. The department shall have discretion in
23 accepting the terms of such grants.

24 4. The department of health and senior services may promulgate rules to implement the
25 provisions of this section. No rule or portion of a rule promulgated pursuant to the authority of this
26 section shall become effective unless it has been promulgated pursuant to chapter 536."; and

27
28 Further amend said bill by amending the title, enacting clause, and intersectional references
29 accordingly.

Action Taken _____ Date _____