

Testimony
House Bill 1187
Senate Human Services Committee
Wednesday, March 1, 2017
North Dakota Department of Health

Good afternoon, Chairman Lee and members of the Senate Human Services Committee. My name is Tammie Johnson, and I am a Program Administrator for the North Dakota Department of Health (NDDoH), Division of Children's Special Health Services (CSHS). I am here today to provide information about House Bill 1187.

Optimal management of Phenylketonuria (PKU) and Maple Syrup Urine Disease (MSUD) includes a lifelong diet of medical food (formula) and low-protein modified food products. Currently, NDCC 25-17-03 requires the NDDoH to:

- Provide medical food at no cost to males under age twenty-two and females under age forty-five who are diagnosed with phenylketonuria or maple syrup urine disease, regardless of income.
- Offer for sale at cost, medical food to males age twenty-two and over and females age forty-five and over who are diagnosed with PKU or MSUD, regardless of income.
- Provide low-protein modified food products, if medically necessary as determined by a qualified health care provider, to males under age twenty-two and females under age forty-five who are receiving medical assistance and are diagnosed with PKU or MSUD.

CSHS has managed this Metabolic Food Program since 2001. The formula provided by CSHS is purchased from a small number of medical food companies. The division maintains an inventory of frequently ordered formulas, which assures timely access for individuals served through the program. To date, twenty-eight individuals have received metabolic formula and/or low-protein food products through CSHS during the 2015-2017 biennium.

The NDDoH would like to provide information regarding the following sections of HB 1187:

- Section 1, Part 4, 5 and 6 – The proposed changes would expand the program to include provision of medical food (formula) at no cost to males

with PKU or MSUD under age twenty-six, regardless of income. Low-protein modified food products would also be available for males under age twenty-six who are receiving medical assistance (Medicaid). Lastly, medical food would be offered for sale at cost, to males age twenty-six and over who are diagnosed with PKU or MSUD, regardless of income.

The fiscal note for this bill totals \$31,200, which is the estimated cost to expand the Metabolic Food Program to include five additional males between age twenty-two and twenty-six during the 2017-2019 biennium. Average formula costs for individuals served through the Metabolic Food Program during the current biennium were compiled. Costs per individual averaged \$260/month. Based on the incidence of PKU and MSUD, the department estimated there would be five additional males between ages twenty-two and twenty-six with PKU and MSUD that could potentially order formula.

Without an appropriation to cover the costs of the additional formula, CSHS would have to utilize general funds from within the division (e.g., catastrophic relief). This would impact other programming and decrease services and/or assistance needed throughout the department.

This concludes my testimony. I am happy to answer any questions you may have.