77th OREGON LEGISLATIVE ASSEMBLY – 2013 Regular Session **MEASURE: SB 284 A**
STAFF MEASURE SUMMARY **CARRIER: Rep. Weidner**
House Committee on Health Care

REVENUE: No revenue impact
FISCAL: Minimal fiscal impact, no statement issued

Action:		Do Pass
Vote:		9 - 0 - 0
	Yeas:	Clem, Conger, Harker, Kennemer, Keny-Guyer, Lively, Thompson, Weidner, Greenlick
	Nays:	0
	Exc.:	0
Prepared By:		Tyler Larson, Administrator
Meeting Dates:		4/22

WHAT THE MEASURE DOES: Directs Oregon Health Authority adopt rules to conduct two-year study relating to infants with lysosomal storage disorders (LSDs). Sunsets March 2, 2015. Declares emergency, effective on passage.

ISSUES DISCUSSED:
- Impact of Krabbe disease
- Personal story of children with Krabbe disease
- Importance of early detection in treating lysosomal storage disorders (LSDs)
- Current treatment of LSDs
- Costs of caring for children with LSDs
- Administrative process for adding diseases to newborn screening
- Current technological limits on LSD screening and ongoing efforts to find effective testing methods

EFFECT OF COMMITTEE AMENDMENT: No amendment.

BACKGROUND: Lysosomal storage disorders (LSDs) are inherited disorders caused by a deficiency of specific enzymes that are normally required for the breakdown of certain complex carbohydrates known as glycosaminoglycans (GAGs). If a specific lysosomal enzyme is not present in sufficient quantities, the normal breakdown of GAGs is incomplete or blocked. The cell is then unable to excrete the carbohydrate residues and they accumulate in the lysosomes of the cell. This accumulation disrupts the cell's normal functioning and gives rise to the clinical manifestations of LSDs. LSDs are a group of at least 50 diseases, caused by a genetic deficiency, which causes the accumulation of substances in lysosomes with the cells.

Currently, all newborns in Oregon are screened for 39 diseases at birth through newborn screening. LSD screening is not included. These diseases are not otherwise clinically recognizable at birth, and if untreated can cause irreversible damage both physically and mentally to children. For these diseases, early detection is essential to avoid damaging outcomes.

Senate Bill 284-A directs the Oregon Health Authority (OHA) to conduct a study relating to infants with lysosomal storage disorder and assess the feasibility of requiring newborn screening. OHA is directed to report to the Legislative Assembly on or before March 1, 2015.