



Dear Chairwoman Senator Monnes Anderson and members of the Senate Health Care Committee,

My name is Jennifer Knapp, I am director of Adrenal Insufficiency United and am here representing our members with ALD.

I'm also the OREGON Volunteer State Ambassador for the National Organization for Rare Disorders and in that role am speaking for all Oregonians affected by rare disease.

I am testifying in support of SB 808

When my daughter was born in 1995, her life threatening genetic condition was not on the newborn screening panel. It was the experience of our pediatrician that saved her life. Soon after her birth our pediatrician suspected by daughter's condition due to the two other babies that he had treated with the condition. My now 21 year old daughter is still living with that life threatening condition, but only because we knew to seek treatment. Had our pediatrician not been practicing long enough to see other babies with my daughter's condition she could have died within the first few weeks of her life.

Not all infants with debilitating and life threatening conditions are so lucky. And while my daughter's condition was rare, it's not as rare as some of the others on the Recommended Uniform Screening Panel or (RUSP). This makes it even more unlikely that those conditions will noticed in time to prevent disability or death.

Through a very thorough review and scientific process the US Department of Health and periodically adds conditions to the RUSP. It takes years to add a condition to the RUSP and babies suffer preventable disabilities and death while waiting.

However even after a condition is added babies still suffer because it's up to the States to take the action necessary to save lives by testing babies. Every year that Oregon waits to start testing for a condition that has been added to the RUSP means more harm comes to our tiniest citizens and more of them loose their lives.

CA passed this legislation last year without a single no vote in just 7 months and the similar legislation in Florida has passed out of both the House & Senate Health committees unanimously.

It's time for Oregon to step up to help it's most vulnerable by passing SB 808.

Thank you