

## **MEMORANDUM**

To: Senator Monnes-Anderson, Chair, Senate Committee on Health Care Senator Kruse, Co-chair, Senate Committee on Health Care Members of the Senate Committee on Health Care

From: Courtni Dresser, OMA Government Relations

Date: March 2, 2015

Re: Opposition to SB 564

SB 564 removes personally identifiable information for brain and central nervous system reports made to Oregon's State Cancer Registry (OSCaR). The OMA opposes the removal of personally identifiable information as this would greatly limit the efforts of researchers to monitor and evaluate the causes of cancer as well as reduce the burden of cancer and benign brain tumors for Oregon residents.

OSCaR has been tracking the incidence of cancer since 1996 and the value of the registry depends on having accurate, individually identifiable information because the data comes from a variety of sources. Patient identifiers (such as name, address, age and sex) are used to ensure that Oregon's cancer rate is accurate; because cancer cases can be diagnosed and/or treated in more than one facility or hospital, OSCaR may receive multiple reports. Personal identifiers allow researchers to correct multiple entries and accurately track the type and incidence rate of all cancers in the state.

Under both state and federal law, personally identifiable information is protected. Both HIPAA and state law afford a high level of confidentiality to this state registry. According the OHA Public Health Division OSCaR webpage, "information collected by OSCaR is very secure from public disclosure and cannot even be subpoenaed by a court of law". Data used for research purposes outside of the registry is only given in the aggregate, which means personal identifiers have been removed. OMA is not aware of any breaches to these protections that would warrant the removal of the personally identifiable data.

The OMA urges you to oppose SB 564 in favor of continued support for the legislatively created state cancer registry program that has successfully tracked cancers in Oregon for 19 years with no data breaches. The accuracy of this information has helped researchers learn about effective treatments for cancer and maximizes future efforts to reduce and eliminate cancer for all Oregonians.