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TO:
The Honorable Laurie Monnes Anderson, Chair
The Honorable Jeff Kruse, Vice Chair
Senate Committee on Health Care

FROM:
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Center for Prevention and Health Promotion
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SUBJECT: Senate Bill 564, State Cancer Registry

Chair Monnes Anderson and members of the committee, I am Karen Girard, the Health Promotion and Chronic Disease Prevention Section Manager for the Oregon Health Authority.

I am here today to present information related to SB 564, which would eliminate reporting of personally identifiable information to the Oregon cancer reporting system established under ORS 432.510.

Cancer is the leading cause of death in Oregon; the more we understand about cancer and how to treat it, the better able we are to improve patient outcomes. The Oregon State Cancer Registry is the most complete and meaningful data source available to monitor cancer incidence, treatment and mortality. The integrity of the registry hinges on protecting personal information. The registry adheres to security and confidentiality practices for data collection, storage and reporting as required by federal and state law. This confidentiality practice is integral to maintaining quality standards for the statewide registry.

The registry’s mission is to provide accurate data on cancer in Oregon for cancer control activities, public health policy-making and epidemiological research.

Having a statewide registry is the best way to learn more about cancer and its progression, to be able to determine possible environmental or occupational causes of cancer, and to evaluate cancer within a state, community or population.

Data from the registry also confirm the effectiveness of screening tests used to identify cancers early and whether prevention efforts are working. For example, data show that high rates of breast cancer screening is finding 4 of 5 cancers at early stages; late stage colorectal cancers are dropping as screening rates increase; and that lung cancer rates are dropping due to tobacco prevention efforts.

The registry was established by the 1995 Oregon Legislature, which made cancer a mandatory reportable disease for purposes of conducting statewide cancer surveillance. Each year the registry receives more than 60,000 cancer reports that, when consolidated, result in 24,000 individual cancer records. Cancer data are reported from multiple providers for each individual case record. Reporting entities include healthcare providers, hospitals, treatment facilities, and pathology labs. The registry consolidates these reports into one comprehensive case record including all diagnostic and treatment data.

SB 564 directly affects the ability of the registry to maintain a statewide cancer data system. The registry has continuously met national standards for quality cancer data since 1996. As a state cancer registry created under a mandatory cancer reporting system, the registry is uniquely positioned to collect, monitor and analyze cancer data from diagnosis through end of life for all reportable cancers.

Eliminating the requirement to report personally identifiable information to the registry would result in:

- A failure to comply with national standards established by the Centers for Disease Control and Prevention’s National Program of Cancer Registries and would likely result in a loss of this federal funding from the Centers for Disease Control and Prevention, which is the only source of funding for Oregon’s registry.

- A diminished ability to perform state cancer registry functions, as defined under ORS 432.510, including targeting populations in need of cancer screening, supporting hospital registries in monitoring outcomes of cancer treatment, and evaluating policies addressing cancer prevention, screening, treatment and survivorship.

Cancer accounts for more than 20 deaths in Oregon each day. Oregon’s gold standard registry relies on rigorous compliance with all confidentiality practices; because without personally identifiable cancer information, the integrity of the registry data would be compromised. Data from the registry are used to monitor cancer incidence, treatment, and mortality to achieve better health, better care and lower costs, resulting in increased cancer survivorship and improved quality of life for all Oregonians.

Thank you for the opportunity to testify today. I am available to answer questions about the operations of the Oregon State Cancer Registry.