To: 2015 Oregon Senate Committee on Health Care
Chair Senator Laurie Monnes Anderson
Vice-Chair Senator Jeff Kruse

From: Donald F. Austin, MD, MPH

CC: Senator Tim Knopp
Senator Chip Shields
Senator Ellizabeth Steiner Hayward

Date: March 2, 2015

Re: **SB 564**

Dear Chairman Anderson, Senator Kruse, and members of the Senate Health Care Committee,

My name is Donald Austin; I am a physician, board certified in Preventive Medicine, and I'm a Professor Emeritus in the Department of Public Health and Preventive Medicine at OHSU. I am offering this testimony in opposition to SB 564

Much of my professional career has been involved in the design, operation and use of central cancer registries. I designed and implemented the statewide cancer reporting system in California; I advised on the statewide cancer registries in Kentucky and Vermont; I was the founding president of the American Association of Central Cancer Registries, which began the process of adopting standardized codes and systems for US central registries. In the second year of my tenure, that organization became the North American Association of Central Cancer Registries as we included all of the Canadian provincial central registries and included Canada in the standardization process. I worked with Sen. Bernie Sanders of VT to draft the federal legislation establishing the National Program of Cancer Registries (NPCR) and locating it at CDC, where it now funds part or all of the central registries in all the states in the US. I designed and implemented the Oregon State Cancer Registry (OSCaR) during a 4-year assignment from CDC to the Oregon Health Authority (then the Oregon Health Division). As a result of OSCaR's compliance with the standard of excellence set by CDC for accurate and timely cancer reporting, OSCaR receives over $790,000 annually to collect and report incidence data to the NPCR, not including confidential data. OSCaR is entirely funded by the federal government, except for a small amount of fees collected to provide abstracting or data analysis services to some hospitals, reporting physicians, and researchers.

Since the conclusion of my 4-year assignment at the Oregon Health Authority in 1996, I have been on the OSCaR Advisory Committee and I am generally aware of the procedures used by our state cancer registry and the rationale for those procedures, though there have been improvements and changes since then in procedures, as coding systems have changed and the registry has become more modern and efficient.

My testimony is that this bill is a poison pill for the cancer registry and the cancer control activities it supports. If this bill becomes law, our registry will cease and we will be the only state not able to protect our population from cancer problems that can be addressed on a population-wide basis. There are several points about central cancer registries, and specifically Oregon's cancer registry, that I'd like to make:

1. The data are locally useful to cancer control and research efforts in Oregon. Our registry reveals where diagnoses are made at a late stage, which population subgroups suffer disproportionately from high incidence or late diagnosis. OSCaR routinely collaborates with research that is approved by an appropriate Institutional Review Board to help patients become linked with researchers or new specialized care programs that may benefit reported patients or future cancer patients.

2. Identifying data on each patient is essential to operate the registry. Because OSCaR receives nearly 3 documents on each cancer patient, and needs to consolidate them to make sure there is no double (or triple) counting, identifying information is necessary. Without personally identifying data, accuracy is impossible. Without accurate data, federal funding and most of the cancer control uses of the data are impossible.

3. Note that even if SB 564 were enacted, cancer patients would still be contacted by hospitals with cancer registries. Every hospital in the US that has a certified training program in cancer surgery is required by the American College of Surgeons to have an operating cancer registry. Registry operations include patient follow-up to determine the long-term outcome of the treatment. This procedure is used as a method of quality of care monitoring and comparisons with other care facilities. Even if OSCaR were to cease useful operations, as would be the result of SB 564, these hospital-based registries would still continue to operate, along with periodic contact with the diagnosed patient or the doctor(s) responsible for continuing care.

4. Amendments to an existing statute should be designed to correct a problem. Here, there is no problem to correct. In the 20 years of operation of OSCaR, well over a million documents containing personally identifying data have been collected and consolidated into about 450,000 cancer cases. In that 20 years there has never been a breach of confidentiality, not one! The data in the registry have firewall protection against unwarranted intrusion, the staff have the mindset of being protectors of the data, and all identifying data sent from one location to another is encrypted. The data in the registry is far safer than it is in a hospital or doctor's office, and the encrypted transmissions between registries are far safer than your emailed financial transactions with Amazon or your bank. If this bill is to correct a problem with the registry having confidential data, I'm happy to report that the problem doesn't exist.

I ask that this destructive bill not be enacted.