



February 27, 2015

Senator Laurie Monnes Anderson, Chair, Senate Committee on Health Care
And members, Senate Committee on Health Care

Re: Legacy Health Opposes SB 564

The National Cancer Act of 1971 was enacted on December 23, 1971. The bill strengthened the National Cancer Institute (NCI) in carrying out the national effort against cancer by creating the National Cancer Program. The National Cancer Act budgeted monies to the National Cancer Institute for research, detection and treatment of cancer, and in 1973, the Surveillance, Epidemiology and End Results (SEER) Program of NCI established the first national cancer registry.

In October 1992, Congress established the National Program of Cancer Registries (Public Law 102-515, The Cancer Registries Amendment Act). The legislation authorized the Centers for Disease Control and Prevention (CDC) to provide funds to states and territories to enhance existing cancer registries and to plan and implement registries where they do not exist. As a result, **cancer is the ONLY reportable chronic disease allowing CDC to disseminate accurate national incidence data. By understanding the burden of cancer, public health organizations, including the CDC, can create programs and interventions for prevention and early detection.**

In 1995, 42 states and the District of Columbia received CDC support for cancer registries. Today, the CDC funds 45 states, the District of Columbia, and two US territories.

Today cancer registries collect, analyze, and report cancer data on all patients diagnosed with cancer. Details on diagnosis, treatment, cancer recurrence, and survivorship are collected for every cancer patient. Data is reported, by law, to the state and federal government, including the Centers for Disease Control and Prevention (CDC) and the NCI.

The long term patient follow up performed by registries is at the core of the national fight against cancer. Annual follow up data allow for the comparison of outcomes with regional, state, or national statistics- which leads to research studies, changes in practice, changes in treatment, improved patient care, and improved survival. **Without patient identifying information, valuable patient follow up cannot be performed by hospital- based or the state cancer registries.** This enormous responsibility could potentially fall to physician offices to report yearly patient follow up.

Patient identifying information is required in order to achieve and maintain cancer program accreditation with the American College of Surgeons Commission on Cancer-

- Standard 5.3: Follow-Up of All Patients- requires at least 80% follow-up rate of all cancer patients since cancer program reference date



- and Standard 5.4: Follow-Up of Recent Patients- requires at least 90% follow-up rate of all cancer patients within the last five years

In the rare occasion that a patient asks to be removed from Legacy's yearly follow up activities, the patient's electronic file is immediately flagged as "DO NOT CONTACT" with no questions asked. Once this flag is put in place, the patient will not be included in any yearly follow up.

During the continuum of care a patient may be seen by several different providers within different health systems. Without patient identifying information there would be no way for the state to reconcile the data. It would be a mistake to decrease or eliminate the collection of patient identifying information for the state registry.

Legacy Health urges you to oppose SB 564. Patient identifying information is required for yearly patient follow up and ultimately saves lives.

Sincerely,

A handwritten signature in black ink, appearing to read "Tony Melaragno", with a long horizontal line extending to the right.

Tony Melaragno, MD

Vice President, Behavioral Health and Oncology Services