March 16, 2023

Minnesota House Judiciary Finance and Civil Law

RE: HF1329

Dear Chair Becker-Finn and Committee Members:

Thank you for the opportunity to submit this letter in support of House File 1329. This legislation allows Minnesota to share its cancer data with other state cancer registries and with the Surveillance, Epidemiology, and End Results (SEER) Program registries of the National Cancer Institute (NCI) and with the National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC).

First established in 1935, state cancer registries provide crucial information on reported cancer cases. To build on the work of several individual registries, in 1973, NCI, through its SEER program, established the first national cancer registry. Nearly twenty years later, in 1992, Congress established NPCR which allowed the CDC to provide funds to states and territories to improve existing registries and to create registries in states and territories without one. Today, 46 states, the District of Columbia, and three territories, plus several localities, have a cancer registry to which physicians must report cases. Cancer registries can then provide high quality data to inform policy at the local, state, and national levels; registry data map out the fight against cancer for the public, policy makers, and researchers.

Registries collect information such as patient demographics, primary tumor site, stage at diagnosis, initial treatment, and outcomes. This data allows researchers to estimate the number of people diagnosed each year with specific cancers. In 2023, 34,380 Minnesotans are expected to be diagnosed with cancer and 10,280 are expected to die of the disease. According to our state's registry, the Minnesota Cancer Reporting System (MCRS), we know that **cancer is the leading cause of death in Minnesota**. We know further that tobacco is the leading single cause of cancer in Minnesota; it is responsible for 30% of cancer deaths. Data from the MCRS on causes allows public health officials to identify priorities around prevention and to develop appropriate prevention strategies.

Registry data can also show when people in certain parts of the state (e.g., rural areas or specific counties) are diagnosed with a specific type of cancer more often or when their cancer is diagnosed at a later stage when treatment is more difficult. That information can then be used to increase appropriate prevention, screening, and education strategies in those areas. All in all, MCRS ensures that Minnesota patients, providers, and researchers have vital resources in the fight against cancer.

Yet coordinating with other states and sharing de-identified information on cancer cases in our state can help Minnesotans even more without jeopardizing patients' privacy. Both the information and registries are governed by strong security and existing privacy laws. **Minnesota's participation in the registries would have no impact on the strong patient informed consent requirements already in state law. Patients would not be affected and would remain at the center of decisions around their care and other aspects of privacy.** Nearly every other state already coordinates with other state and federal cancer registries. Such coordination provides several benefits to patients, providers and researchers. Coordination amongst registries also ensures better data for researchers across the country, including in Minnesota, to help advance cancer research and care more quickly and effectively. For example, the Centers for Disease Control and Prevention (CDC) compiles data from the cancer registries and issues a number of reports such as "Geographic Variation in Pediatric Cancer Incidence—United States, 2003–2014" published in a 2018 Morbidity and Mortality Weekly Report (MMWR). This report gave state-level estimates on nationwide pediatric cancer incidence, not just differences by U.S. census regions of Northeast, Midwest, South, and West. CDC findings on high rates of pediatric cancer incidence can help to advance health care providers' awareness of pediatric cancer, enhance treatment capacity and survivorship care where needed, and foster cancer surveillance.

HF1329 ensures that Minnesotans may benefit fully from coordination with cancer registries. We strongly encourage legislators to support this proposal and appreciate your consideration.

Sincerely,

American Cancer Society Cancer Action Network Cancer Health Equity Network Children's Minnesota CentraCare The Leukemia and Lymphoma Society Masonic Cancer Center, University of Minnesota Mayo Clinic Minnesota Cancer Alliance Sanford Health