OREGON HEALTH & SCIENCE UNIVERSITY

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Kerri Winters-Stone, Ph.D.
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February 28, 2015

To: Senate Committee on Health Care
From: Kerri Winters-Stone, PhD, Oregon Health and Science University

Re: Written testimony in opposition to SB 564

Dear Chair Monnes-Anderson, Vice-Chair Kruse, and members of the Committee,

My name is Kerri Winters-Stone and I am a Research Professor in the OHSU School of Nursing and Co-Program leader of the OHSU Knight Cancer Institute Cancer Prevention and Control program. Over the past 12 years, my research program has focused on understanding the persistent health effects of cancer treatment and the development of specific rehabilitation programs that can improve the length and quality of life for cancer survivors. The number of cancer survivors in the U.S. is expected to double by 2050 and our healthcare system is unprepared to address their long-term health concerns unless we better understand their needs and implement evidence-based programs to optimize their health and wellbeing.

I am writing to encourage your opposition to SB 564. The research that I do, both observational studies to understand the impact of cancer treatment on health and quality of life and clinical trials to test the efficacy of rehabilitation strategies to improve and lengthen survival, depends upon my ability to recruit people with a history of cancer to participate in studies. Rather than restrict our study samples to cancer patients at OHSU, we draw participants from a community-based sample, by collaborating with the Oregon state cancer registry. This approach is important for three primary reasons:

1) It enables us to offer as many cancer survivors as possible in Oregon the opportunity to participate in research that is meaningful to them. While we cannot ensure that a participant will benefit directly from participating in research, we know from participants in our rehabilitation trials that many report a significant benefit from being in a study. Similarly, most participants are grateful for the opportunity to contribute to scientific knowledge that may benefit other cancer survivors, including those yet to be diagnosed.

2) We are able to include a sample that is as representative of the Oregon population as possible. This is particularly important for ensuring samples have adequate representation of racial/ethnic, gender, age, geographic and socioeconomic diversity with in the state; allowing them to be translated back to all Oregonians.

3) We must be able to draw from a large enough pool of people to ensure that we have the right number of participants to produce robust findings. There is no comparable approach available to myself nor any other investigator to recruit large number of cancer survivors, which is particularly critical for studies that include outcomes such as disease incidence, falls, and survival.

To date we have collaborated with the state cancer registry to recruit participants into eight studies funded by the NIH, American Cancer Society, Livestrong Foundation and Susan G. Komen for the Cure Foundation. We have had over 700 cancer survivors participate, with anywhere from 70%-90% of these recruited in collaboration with the registry. We have had representation across race/ethnic groups, socioeconomic status, age (35-92 years of age) and geographic residence with participants willing to drive to Portland from as far as Medford, OR for

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observational studies and from Welches, OR to participate in an exercise trial. Without the registry we would not be able to achieve these numbers nor this diversity and persons living outside of Portland would be unlikely to be informed about our studies.

In order for the registry to identify potential participants that meet study eligibility criteria and to inform potential participants about a study opportunity, identifiable information must be included in the registry. Our collaboration with the registry for notification of study opportunities was developed many years ago and with the utmost concern and attention to processes that would protect patient confidentiality. There has never been a breech of confidentiality using this approach.

In summary, I hope you will find the above information as valuable testimony for the importance that the state cancer registry plays in scientific research aimed to improve public health, particularly for Oregonians who have battled cancer. **Without identifiable information we could not conduct research that we expect can positively influence cancer care for Oregonians and reduce cancer burden in our state.** Without this access, the vast majority of cancer survivors who are looking for ways to help themselves and others would remain uninformed about opportunities to do so. The careful procedures that the state registry uses to maintain and protect patient confidentiality are robust and ensure that the patient’s interest is always the primary goal. On behalf of myself and fellow investigators and many, many of the cancer survivors who participated in our research, we ask that you oppose this bill so that the registry can continue to serve Oregonians with cancer in meaningful and impactful ways.

Sincerely,

Kerri Winters Stone

Kerri Winters-Stone, PhD, FACSM
Research Professor
Oregon Health and Science University