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RE: Opposition to SB 564

School of Nursing

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Dear Chair Monnes-Anders, Vice-Chair Kruse and members of the committee,

I write this letter in strong support of the Oregon State Cancer Registry as a vital tool for advancing the science of cancer care, understanding the impact of cancer on patients and their families, and identifying specific ways to support patients and family members in short and long-term ways. I am a research health psychologist and associate professor at Oregon Health & Science University. **If the proposed changes in SB 564 are allowed to move forward studies like mine will not be possible.**

My program of research focuses primarily on the mental health outcomes of illness (particularly cancer), the challenges for patients and families recognizing and managing symptoms, and the impact on marital relationships. Although I have been a collaborator on cancer studies that have recruited via the Oregon State Cancer registry, **it is my own 5-year study of lung cancer families (funded by the American Cancer Society RSGPB-07-171-01-CPPB) that I will focus this letter on.**

Lung cancer is among the leading causes of cancer deaths in the US and is a disease with a rapid progression and high symptom burden. Early detection of lung cancer is rare, with 85% of people diagnosed in advanced stages of disease; 60% of lung cancer patients die within one year of diagnosis. The rapid decline combined with the refractory response of current treatment requires patients and family members recognizing patient's symptoms in order to provide good care, adjust to the context of a life-threatening illness, and make decisions within a short window of time. For this reason, lung cancer is one of the most under-studied and under-supported cancers. We have minimal understanding of the enormous challenges these patients and families are facing and how best to support them.

My study was among the first studies to examine lung cancer families and their experiences over time. The results of this study have been published in well-respected journals related to symptom management, cancer care, and family psychology, with several more papers in progress. **I urge your opposition to SB 564 so that studies like mine can continue to make a difference in the lives of cancer patients in Oregon.** The registry, by definition, provides researchers population-based samples that are far superior to recruiting through an individual facility or provider or support group. This characteristic greatly strengthens the conclusions of the study

and the representativeness of the findings and has been considered an enormous strength of my study by funders and journal reviewers. **Additionally, the registry allows the involvement of certain participants in research, who are often overlooked, such as rural participants and those not seen in certain contexts.**

My own study was able to include patients, who lived up to 50 miles away from Portland and did not attend a Portland provider. This type of catchment would be enormously challenging and expensive without the registry. The ability to attain large enough sample sizes is also greatly enhanced by the registry. All of these factors contribute to the rigor of the research and findings so that the work can have far-reaching impact in the field of cancer science and cancer care. Finally, given the social stigma of lung cancer and the paucity of resources and support groups available to these families, this cancer context is not widely visible in the community. There are no natural places or groups to recruit from. **The Oregon Cancer Registry is imperative to the study of lung cancer and other similarly “invisible” cancers.**

I can attest that our recruitment strategy adhered to the strict guidelines of both the Oregon State Cancer Registry and the Oregon Health & Science University Institutional Review Board. Registry staff sent a letter about my study to initially eligible patients. Identifying information was only transferred to my research staff if patients returned a form to the registry stating that they would like to know more about the study and agreed to be contacted by my staff.

I was continuously impressed with how diligent and mindful and respectful registry staff was in following all guidelines and ensuring patient confidentiality. **The response to the study by patients and their family members was strongly positive, and despite receiving no tangible benefit from participating in a descriptive study, participants were eager to share their experiences in the hopes of helping others.** Anecdotally, many patients and their family members expressed their appreciation for the study and the need for much more similar work. These patients and their families wanted their voices to be heard and stayed enrolled in the study for up to 18 months or until the patient died.

I believe SB 564 will disenfranchise patients and their families who want to have their voices heard and want to participate in research, but often remain “invisible” to traditional recruitment approaches. As researchers, we will be severely hampered in our ability to advance the science of cancer care and meet the needs of a growing demographic group.

I strongly encourage your opposition to SB 564. Please feel free to contact me if you have any further questions.

Sincerely,



Karen S. Lyons, PhD, FGSA
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