



# CAP Lung Cancer Medical Writers' Circle

## Lung Cancer, again

Janet Healy

After six years working as an advocate on issues concerning lung cancer patients and their families, I changed directions and now work for an American Indian Tribe, researching and writing grants and producing a film project I'd begun long ago. My work often involves medical matters, but from a different perspective than my previous job as an advocate for lung cancer patients. However, both jobs feel more like callings, vocations, than wage labor. Both require me to explore complex issues and translate them into understandable and persuasive language. Before, I grew to know lung cancer patients personally and respectfully, learning of their struggles, and seeing their resilience against bad odds. Now, I deepen my relationships with people who strive to honor and make visible their cherished heritage in a world that often challenges or disdains their right to do so. Finding one's way, as a lung cancer patient or an American Indian, has similar pitfalls. Stigma is a common theme.

While high blood pressure, diabetes, and obesity are higher in many Indian communities than in the non-Indian population, access to adequate health care is problematic for many people in both groups. Perhaps non-Indians assume that the Indian Health Service (IHS) provides free care to all American Indians and Alaska Natives, somewhat as the Veterans Administration does for all who have been honorably discharged from the armed services. But IHS funding for most tribes is woefully inadequate, stemming from flawed allocation formulas that don't keep up with increasing tribal enrollment and a two-tiered system that includes direct care (walk-in) patients and contract health service delivery area (CHSDA) patients. CHSDA patients are those who seek medical care away from a tribal clinic or hospital, usually because they live off the reservation and are not close enough to another tribal medical facility. Or, they have a condition, such as lung cancer or serious heart disease that is not treatable at a tribal facility. If the IHS funding for CHSDA patients' medical appointments runs out mid-year, as it does for many tribes, patients cannot pay and may simply do not seek necessary care. Tribes that operate their own clinics rely on billing third-party payers to help fill the funding gap, but about one third of patients have no insurance and most tribes (the vast majority have no casinos) certainly cannot afford to provide it.

Another consequence of the fragmented IHS / Tribal clinic delivery system that mirrors the non-Indian situation is that when a patient is referred to a specialist and receives treatment for a serious condition, such as cancer, they leave their "medical home". Tracking and following up with such patients is often difficult and can strain the vital circle of care, the holistic mind/body/emotions/spirit hoop that defines so much of what tribes are and do. Bringing people back together—linking patients, their medical providers, and their families through traditional tribal practices and maybe with the use of electronic health records, is vital. With not much funding to distribute nationwide, IHS has nevertheless led in this effort, following the successful model of the Veterans Administration health system.

While gathering data recently for an electronic health records grant proposal for the tribe I work for, I looked through Washington State's most recent vital statistics report, covering 2006. I wondered how many Indians were included, what ailments they suffered, what became of them. There, in the



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mortality listings, I noticed a section on lung cancer. I knew from the annual American Cancer Society's Cancer Facts & Figures it remains the biggest cancer killer in this and every other state. But the Washington stats brought me up short. The group with the highest rate of death from lung cancer in 2006 was American Indian women and the rate at which they died closely approached that of American Indian men. Worse, there was no decrease in the rate from 1990-2006, the women's rate held steady.

I thought about how little we know about how Indian women are dealing with lung cancer and how best to reach and serve them. What happens when they get the diagnosis? Who's there? Who knows what is to be done, what might help, how to calm the terror and brace for the blame?

I thought of several breast cancer groups who sponsor initiatives and offer grants for projects with Indian women (the tribe I work for has one). Then I felt the pang of recognition, that once again, lung cancer claims so many who are lost within the healthcare maze and are often disregarded and blamed for their affliction.

So, I may become a lung cancer patient advocate again, a volunteer, but bringing more skills than before, and some new ideas grounded in connecting communities in traditional ways that can help and heal individuals. Lung cancer is not finished with us; what can I do now?

*Janet Healy is the grant writer for an Indian tribe in Washington State. Ms. Healy worked for the Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE), the first national lung cancer patient advocacy organization, from 1998 until its move to Washington, DC in 2004 and redefinition as the Lung Cancer Alliance.*