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Medical Humanities and Cultural Studies: Lessons Learned from an NEH Institute

Susan M. Squier[1,3] **and Anne Hunsaker Hawkins**[2]

In this essay, the directors of an NEH Institute on "Medicine, Literature, and Culture" consider the lessons they learned by bringing humanities scholars to a teaching hospital for a month-long institute that mingled seminar discussions, outside speakers and clinical observations. In an exchange of letters, they discuss the productive tensions inherent in approaching medicine from multiple perspectives, and they argue the case for a broader conception of medical humanities that incorporates the methodologies of cultural studies.

KEY WORDS: medicine; cultural studies; expertise; medical humanities; narrative competence; clinic; classroom; genetic engineering; compromised hearts; palliative care; cultivation.

Dear Anne:

It's a dark, rainy day in the bizarre June of 2003, and I'm at my desk, thinking back to the hot, dry days of July and August '02 when we co-directed our NEH Institute on "Medicine, Literature, and Culture." As I remember that experience, I keep thinking of the cultural studies mantra: "Teach the conflicts." The experience of teaching "Medicine, Literature, and Culture" introduced us to a whole new set of conflicts, a rich new territory to explore the tensions inherent in approaching medicine from the perspectives of medical humanities and cultural studies. No doubt each of us would provide a different narrative of that experience, given our different institutional and personal positionings. So here is a first pass at narrating mine.

For me, reading literature and cultural theory in a medical school setting clarified the different stakes behind our institutionally-embedded practices. As a feminist scholar who works in cultural and literary studies, I hope in my scholarship

[1]Brill Professor of Women's Studies and English, Penn State University.
[2]Professor of Humanities, Penn State University College of Medicine.
[3]Address correspondence to Susan M. Squier, PO Box 557, Boalsburg, PA 16827; e-mail: Sxs62@psu.edu.

and teaching to catalyze positive change in the students I teach, whom I hope to bring to a broader view of the relations between medicine and the humanities and in the larger culture, which I hope will discover the process by which medicine and humanistic realms are co-constructed and will be motivated to produce a different, and more equitable, set of relations between them. My ultimate goal is to intervene in, and change for the better, both medical practices *and* literary and cultural practices. And yet in a way, the cultural and literary changes may come first with the changes in medical practice following.

I suspect that something different is at stake in your work because of your different institutional location in a medical school. When you teach literature to medical students, your goal is presumably to induce broader, more flexible thinking in those doctors-to-be. When you do research in the field of medical humanities, your goal is to broaden the concerns of, or *humanize*, medicine. The pressures on your work, which we experienced so strongly during our packed days this summer, are not only those of the intransigent forces of illness, human embodiment and economics but also the ever-present pressure of time. Because time is at a premium in the search for treatment and cure, I imagine (but I may be wrong) that the category of "the humanities" is not questioned but rather put to use: to broaden, challenge, *reform* existing medical knowledge and medical practices.

I understand us as having different pressures or different bottom lines, then, which shaped the perspective from which we built the NEH Institute and encountered both the texts, the medical practices and the participants. Why resist the assumption that the goals of cultural studies and medical humanities are too divergent to provide a common agenda for what we came to consider "medical humanities and cultural studies"? Perhaps one way to articulate the value of juxtaposing these seemingly conflicting approaches would be to recall two moments that, for me, particularly crystallized those colliding and clashing perspectives: the visit of a performance artist whose presentation incorporated a humorous critique of the *International Classification of Diseases*, 9th Edition (ICD9-DM) and the visit of a physician whose presentation stressed the special expertise of literary scholars to educate physicians in the art of understanding patients' narratives. These two events seemed like projective tests for the different perspectives from which we were negotiating the institute and in which we hoped to foreground and confront all their productive tension. While for some of us it seemed brutal to mock the ICD9-DM, to others it seemed a salutary expression of the cultural embeddedness of supposedly "objective" diagnostic processes. The former group was appalled at the artist's humor which, they felt, was "at the expense of" those whose illnesses the ICD9-DM addressed, while the latter group applauded her ideological challenge to that supposedly objective instrument.

A similar division occurred over the presentation of the second guest: a physician who moved from the discussion of a canonical short story to a plea for "narrative competence" in medical practice. To privilege the *expertise* of humanities

scholars in the analysis of narrative seemed to some to reinforce a hegemonic and oppressive construction of "the literary" in the service of a medicine still conceived as an apolitical and scientistic endeavor. Yet to others, the same presentation seemed a pragmatic adaptation to the discursive demands of the medical environment, a strategy well worth embracing if it produced more sensitive physicians.

These concrete examples of the day-to-day tensions within the NEH Institute seminar can be set against another kind of tension: the kind than shows up in my journal entry for July 17 as I respond to the experience of clinical shadowing:

> It feels so very delicate, trying to keep us moving forward without losing anybody, trying to keep our eyes on the main task (Whatever that is! To forge a field? To map a field? To enable different kinds of perspectives under a general rubric that people are becoming aware of????) while trying to head off the countless theory wars that threaten to break out at any time. And those theory wars can be set off by anything, including by something not at all theoretical, like the anxiety bred by identification with a sick patient, or by reading something scary in a medical article.
>
> In terms of our discussions, what was interesting today? Hmmm. I guess the resident's admission that she used cold terms when she was talking because otherwise she'd have to be crying all the time. I was actually struck with how little attention our seminar participants gave to that point. I wonder why it didn't get at least an acknowledgement. And also to the physician saying it was so hard to be a doctor, & all of us kind of laughing ("poor you!") when in fact he was just trying to say what is manifestly true: that you're juggling a lot of demanding stuff in your head at any one time, stuff that calls on a range of very different types of thinking, and to add to that the 10% of humanist or caring relatedness sometimes feels like more than can be done.

Given the tensions that the NEH Institute obviously catalyzed, as represented in this journal entry, the question remains: Why try to teach across the fields of cultural studies, literature and medicine? Why deal with both the clinic and the classroom? Why even dwell on what may seem like impossibly divergent opinions? We chose to do so and would do so again because we are convinced that each field promises to learn from, as well as to inform, the other by providing the limit case, or reality principle, for its practices. Thus, the cultural studies critique of the humanistic focus on "narrative expertise" reminds us that both what counts as narrative, and what counts as literature, are ideologically inflected terms, producing an inside and an outside with distinct implications for the distribution of power and agency. And similarly the medical humanities stress on the pragmatic, the urgent, the negotiated provides a salutary challenge to any ungrounded "theory," reminding us that no critique can be effective if it can't be *communicated* to an audience whose assumptions and mode of articulation may be very different indeed.

So, there's my first attempt at articulating both what I valued and what felt difficult about the NEH Institute in "Medicine, Literature, and Culture." When I started writing, it was rainy and cold, but now, the sun is out, and it is in the 90s. A reminder of the one constant, both in the institute experience and in life more

broadly experienced: impermanence or change. Theory needs to attend to this, much as does medical practice.

Love, Susan

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Dear Susan:

Writing this letter certainly brings me back to that incredibly intense month you and I spent at Hershey. I find myself missing the intensity and stimulation provided by the participants—their energy, their intelligence, their diversity. Institute participants reported how much they gained through their various clinical activities at the Institute—shadowing nurses and doctors, attending rounds and case conferences—but I wonder if they realize how much they gave back by bringing their unique and very different perspectives to bear on those experiences in both formal and informal discussions.

It was wonderful working with you that summer, in part because we always seemed to have very different responses to everything we read or saw: the two anecdotes you describe—the one speaker's humorous riff on the ICD9-D and the other's endorsement of narrative competence—are illustrative of the kind of differences in our own responses as well as those of the participants. I invited you to collaborate on this Institute because I knew you would bring to it an expertise in feminist and cultural studies, but I didn't realize that the interactions between us would be so intellectually exciting. I'm so glad that, in the form of this exchange of letters, we're finally having the conversation that we both wanted to have (but couldn't find time for!) during the Institute.

I was struck by the cultural studies mantra you mention at the very beginning of your letter: "Teach the conflicts." This seems to mark an important difference between the approach of cultural studies and that of the medical humanities. Those involved with humanities programs in medical schools tend to focus not on conflicts but on complementarity, reflecting the differences less in our academic backgrounds (after all, you and I are both trained as literary scholars) but more in our institutional settings. Although we both work in the Penn State system, my perspective on medicine and medical science is from within a teaching hospital, while yours is from within a university. This seems important in several ways.

A university is made up of faculty, students and ancillary staff; a medical center also includes healthcare providers and patients. The presence of patients makes an enormous difference, especially in providing a constant reminder of actual human beings of all ages and from a variety of racial, cultural and socioeconomic backgrounds who are undergoing suffering, loss, grief, hope and fear. The result for medical humanities teaching and research seems to be an emphasis on the concrete and the particular, a concomitant disavowal of the purely abstract and theoretical,

and a wide tolerance of and demonstrated respect for persons (healthcare providers as well as patients and their families) with opinions and views radically different from one's own.

Second, you are working in the same system in which you were trained, while I am always aware of being in some sense a participant/observer in the workplace. Not only is my formal training different from that of my medical colleagues, but there are differences in our assumptions, allegiances and ways of understanding experience. In some ways, the role of a humanist in a medical school resembles that of the anthropologist doing fieldwork in a different cultural milieu—and medicine is, as we try to teach our students, in many ways a culture all its own. If I am to contribute anything, I must demonstrate respect for my clinical colleagues, their work with patients and the goals of medical education. Unlike you, I do not necessarily seek to change medical teaching and practice; rather, I see myself as working alongside my clinical colleagues to facilitate change when we agree that change is needed but—-perhaps even more importantly—to preserve the ideals of a profession jeopardized by financial constraints and in sharp conflict with marketplace values.

The ability to work alongside clinical colleagues is essential to my work at Hershey as well as my scholarship; this means not only seeking collaboration rather than provoking conflict but also paying close attention to issues of relevance, accessibility and ethical value. What we do in the medical humanities both in our publications and in the classroom must pass the "so what" test; it must in some way connect literary works and literary theory to real problems in the real world of doctors and patients. In addition, we must be careful that the language that we use in our interactions both with medical students and physicians is clear and lucid. Medical personnel have little tolerance for the obfuscating prose or jargon of the humanities, even though, ironically, the discourse of medicine is full of Latinate terms and acronyms known only to the initiate. And lastly, medical humanities work is directed towards *practical* ethical considerations. In this, medicine as well as nursing are very different from the academic professions. In most medical schools across the country, graduating students recite some version of the Hippocratic Oath. Think of how different this is from what happened when you and I graduated! The latter issue of practical ethical value undoubtedly reflects the fact that doctors, unlike academics, deal with people who are sick, often in pain and often scared, and who may be facing death or the loss of a loved one. It is true that cultural studies has created in the academy a heightened awareness of cultural problems and issues especially in regard to race, class and gender. In the academy, however, these are ideological issues, whereas doctors deal with actual people with concrete, specific and immediate needs and problems.

I agree with your surmise that in my teaching and research I seek to foster humanism in medical practice, but the humanist physician I envision is not some

kindly, empathic, twinkly-eyed stereotype from a Norman Rockwell cover for the *Saturday Evening Post*. Rather, it is someone who is aware of the values and ideals that she or he brings to medical practice and who is alert to the ways these can be shaped and even distorted by the professional and institutional matrix; who is sensitive to the wide range of economic, social, psychological and spiritual concerns of patients; and who is informed about the larger political and economic forces that can so drastically affect the practice of medicine. This is why our required course for first-year students begins with a discussion of medical culture, including its negative aspects. We want our students to be aware of how their immersion in that culture, as medical students, residents and practicing physicians, will condition their understanding of such issues.

But I'd like to return to my analogy of the medical humanist as a kind of anthropologist doing fieldwork in the culture of medicine. There seem, to me, to be two dangers signaled by this analogy. The first is that of the missionary tendency, fueled by the assumption that one brings a kind of enlightenment to those with whom one interacts. I do believe, however, that any medical humanist in a teaching hospital is safe from what one might call this "missionary positionality." Working in a teaching hospital is a humbling experience for academics in fields like literature, history and philosophy since our abstract concepts are constantly challenged by the concrete problems of diagnosing and treating individual patients. The second is that like some anthropologists, humanists can become assimilated to the culture which they observe and in which they work. When this happens, one can lose both critical distance and the impulse to question and challenge. To some extent, I suspect I have become so assimilated, and it is for this reason that the Institute was such an eye-opening experience for me. While I certainly felt "at home" in discourse with my fellow academics at the Institute, I realized the extent to which my positionality had blunted the kind of critical edge that is fostered—and rightly so—by the academy.

A humanities program may properly be expected to critique the institution and the culture in which it operates as we do in our courses at Hershey, and, indeed, our Dean has referred to the Humanities Department as "the conscience of the institution." But no dean is going to fund a comprehensive assault on institutional practices or a drastic revision of the whole professional system. That must come from outside the institution. It is here that the very detachment of the university, its freedom from constraint and compromise, is its special advantage. The work of unfiltered critical analysis, the exploration of broad professional reform and socioeconomic change, is what the academy is both free and superbly equipped to do. In this respect, cultural studies can make a unique contribution. For example, you in the university and I in the medical school would probably both agree that the system of healthcare provision in this country is unfair and out of control with more and more people falling into the category of the uninsured or the underinsured. In our humanities courses, we can and do work to make our

students aware of such problems, but that does little to change or solve them. Your vantage point gives you a much broader perspective on health care in general, producing a broader, more comprehensive articulation of important issues and problems.

Paradoxically, though the goals of the medical humanities may be more modest than those of cultural studies, one could argue that our impact may be greater through our ability to effect small changes in the practice of individual caregivers and in the policies of particular medical institutions. But our attempt to encourage habits of critical engagement within medicine is necessarily limited by time available to us in the crowded schedule of medical training. We need cultural studies programs in colleges and universities to alert premed students to the issues surrounding medical culture and to foster among the general student population a deeper awareness of these issues in the society at large.

To conclude, while we've both been focusing on differences between cultural studies and the medical humanities, I think that there are some important similarities between the two approaches and among the scholars who represent them. Both of us seek to understand medical culture and, in various ways, to affect its behaviors and practices. But despite the energy scholars both in cultural studies and the medical humanities direct to analyzing the culture of medicine and critiquing its theory and practice, inevitably, we are conditioned by the larger society in which we live and work—and die. This generalization, I think, becomes obvious in issues and practices surrounding dying and death in the U.S., where physicians, patients, and family members—in short, all of us—seem unable to prevent needless intervention, pointless expense and practices that are not only irrational but ultimately inhumane.

Your very eloquent concluding remarks about the way that scholars in cultural studies and the medical humanities can learn from each other's approaches remind me of a passage from Donna Haraway's *Situated Knowledges*, which we discussed at length in the Institute's Haraway reading group: "I think my problem, and 'our' problem, is how to have *simultaneously* an account of radical historical contingency for all knowledge claims and knowing subjects, a critical practice for recognizing our own 'semiotic technologies' for making meanings, *and* a no-nonsense commitment to faithful accounts of a 'real' world, one that can be partially shared and that is friendly to earth-wide projects of finite freedom, adequate material abundance, modest meaning in suffering, and limited happiness."[4] It seems to me that Haraway's "I" and "our" could apply to you and me since each of us recognizes the importance of what the other can bring to an understanding of medicine and medical culture. I think, too, that the most important word in

[4]Donna Haraway, *Simians, Cyborgs, and Women: The Reinvention of Nature* (London and New York: Routledge, 1991) 187.

this quotation is "simultaneously." In providing our colleagues who attended the Institute with academic lectures and scholarly readings as well as a wide variety of clinical experiences, we gave them a chance to experience the possibility, as well as the challenge, of the simultaneity that Haraway celebrates.

Love, Anne

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Dear Anne:

We began this exchange of letters in a rainy June, and now I'm writing the concluding letter on a beautiful snowy December day, having just finished my grading for a hectic semester. Your letter arrived in November, while I was in the midst of team-teaching a combined graduate-undergraduate seminar in Feminist Science Studies. It felt frustrating, to say the least, to have to shelve the many thoughts your letter prompted in order to keep my focus on teaching that very challenging class. What possible link could there be between those intense days of our NEH Institute held in a medical school and teaching hospital and my current role as a professor of Women's Studies and English teaching undergraduate and graduate students in disciplines ranging from English, philosophy and history to psychology, chemistry and rural sociology? Yet now, as I look back at the semester's end, I realize that many of the issues you raise in your letter were actually before our class every day. Perhaps, one example will make that clear.

Towards the end of November, our seminar brought to campus novelist Ruth Ozeki, author of *All Over Creation* (2003).[5] This book was included among the year's "Fifty Most Notable Books" by the *New York Times Book Review*, whose columnist described it as a "sophisticated novel in which dread and hope co-exist and the end of nature is envisioned through the impact of genetically modified crops on a potato-growing family and the representatives of pro- and antimodification factions who descend on their Idaho potato farm."[6] We invited Ozeki because her novels address issues of importance to feminist science studies; we chose to conclude our seminar with *All Over Creation* because of its exploration of a range of technoscientific issues central to modern agricultural practices especially genetic engineering and the uses of GMO crops. As I think back on Ozeki's visit, I realize that although we chose to assign *All Over Creation* because of its engagement with technoscientific practices, we *taught* it in ways that put in high relief many of the central, productive tensions that characterize this hybrid entity we are calling "medical humanities and cultural studies."

To begin with, I realize now that despite its categorization by the *Times Book Review* as a novel about the debate over biotechnology in agriculture, Ozeki's

[5]Ruth Ozeki, *All Over Creation*. (New York: Viking, 2003).
[6]"Notable Books," *New York Times Book Review*, December 7, 2003.

novel richly incorporates medical themes. Cass, a central character, has had several miscarriages of indeterminate cause; after a diagnosis of breast cancer, she has also had a (partially-prophylactic) double mastectomy. Her husband Will, a Vietnam veteran, has suffered exposure to Agent Orange. Yumi Fuller, the main character, had an illegal abortion at age fourteen. In response to the shock of finding out about his daughter's abortion, Lloyd Fuller has a heart attack. When the novel opens, Lloyd has been hospitalized with a repeat coronary while his wife, Momoko, is in the early stages of Alzheimer's disease. As Cass and Yumi negotiate a response to Lloyd's illness and death and Momoko's increasing dementia, the novel explores the physical and emotional impact of those illnesses on the patients and their relatives as well as addresses classic topics for medical humanities courses: hospital versus home care for dying patients; advance directives; nursing techniques. Yet when the novel is read with a focus on the tension between bioengineering and social responsibility, these medical issues seem at best subsidiary themes explored in subplots.

To say that *All Over Creation explores* medical *themes* isn't sufficient, however. Not if we put this novel to what you (wonderfully) call the "so what" test: the requirement that one's teaching "must in some way connect literary works and literary theory to real problems in the real world." You add "of doctors and patients," and yet the students in our class are preparing for a "real world" out there beyond the clinic and the hospital in which everyone must live. If we apply the "so what" test in the university setting, we will teach works like *All Over Creation* in terms of how they illuminate that broader world as well. Indeed, approached in light of this wider perspective, the medical themes and the biotechnological issues in the novel are intimately related, for Ozeki does more than *represent* themes of medical diagnosis, treatment and care, she also *resituates* every one of those medical issues in a socio-cultural and technoscientific context, and in so doing intervenes in our understanding of, and approach to, contemporary U.S. medical practice.

Let me be specific. As readers, we are moved to consider what relationship exists between Cass's miscarriages and breast cancer and the toxic chemicals to which both she and her husband have been exposed: Will during his tour of duty in Vietnam and both of them as potato farmers who use "conventional practices" that include "inputs," chemical pesticides. If we move further still from an explicitly medical context, we can explore the tensions between the different versions of "respect for life" that the novel dramatizes. So we can note that as co-proprietor of Fullers' Seeds, which sells only open-pollinated seeds and argues in its newsletter against the "novel life forms" created by genetic engineering, farmer Will Fuller demonstrates a nurturance and respect for life that seems starkly at odds with his indifferent abandonment of his "bad seed" daughter, Yumi, when she is sexually abused and impregnated at fourteen by her high school history teacher. We can explore how a deeply caring and talented psychiatric nurse and hospice worker might find common cause with a group of anti-biotechnology activists who call

themselves the "Seeds of Resistance." Finally, we can question what "seed saving" might mean in the broadest context: is it the careful perpetuation of heirloom crop varieties, as Lloyd and Momoko do through Fullers' Seeds, or is it the more basic struggle to save any natural, uncommodified, un-engineered life form? Lloyd Fuller articulates this broader mission when he makes a speech to farmers and seed savers protesting:

> a new agricultural biotechnology that quite literally takes the breath of life right out of a seed. This patent permits its owners to create a sterile seed by cleverly programming a plant's DNA to kill its own embryos. This technology, nicknamed the Terminator, can be applied to plants and seeds of all species, including food crops, thereby, and in one ungodly stroke, breaking the sacred cycle of life itself.[7]

In *All Over Creation*, Ozeki suggests that the inability to connect the medical and the biotechnological, the responsibility to nurture our children and to nurture our earth, is a sickness as profound as the one facing Lloyd in his final hospitalization. Let's return to the "so what" test that medical humanities must pass in a clinical setting, connecting literary works to real problems in the real world of doctors and patients. Once again, Ozeki's novel moves that "so what" question beyond the clinic into the larger "real" world, making it the responsibility not just of doctors or patients but of everyone in Yumi's description of Lloyd's medical condition:

> He's stable now, but his heart was fibrillating again last night. He's delusional . . . He keeps moaning on about seeds, how he's got to save them. . . . The doctor says his heart has been severely compromised," she said. "It makes it sound like it's someone's fault, doesn't it? Maybe mine . . .
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> "No," said Cass. "It's not your fault."
>
> "A compromised heart," she said. "Kind of poetic, isn't it?"[8]

Poetic, yes, and also deeply relevant to medical humanities and cultural studies. Ozeki's novel explores the compromised hearts that keep us from connecting our medical practices with our cultural practices. I mean that latter term to include its old connotative connection to both meanings of the word *cultivation*: farming the land and educating the mind and heart.

This has been a long detour through my semester's teaching to return to the subject of last summer: what medical humanities and cultural studies have to say to each other. Whether we are working in the university or in the hospital, we are working to *cultivate* our minds and hearts. I began with the cultural studies mantra, "Teach the conflicts," but I want to end with another cultural studies-based insight that our NEH institute put into practice in the seminar room and the clinic: that *all* forms of cultural activity are illuminating from the canonical to the everyday. It is only what we might call, with Ozeki, our *compromised hearts* that have kept us from seeing the connection between them.

[7]Ozeki, 301.
[8]*Ibid*., 316.

We can see that kind of cultivation exemplified once again if we turn from Ruth Ozeki's novel to her Web Log, a newer, distinctly non-canonical genre.[9] The first narrative, her blog entry for November 10, 2003, describes "The Meatrix," a witty animated "agitprop" parody of *The Matrix* which challenges the social, medical and ethical costs of factory farming. Ozeki observes how "The Meatrix" demonstrates that Resistance, as a narrative concept, is indeed still romantic, and Resistance as a social practice is alive, funny and thriving on all fronts. The second narrative, her blog entry for Friday November 7, 2003, provides a detailed account of her mother's series of ten radiation treatments for a squamous cell carcinoma of the jaw: "The radiation treatment was palliative and never meant to cure the cancer, but rather just to control its metastasis, and it has succeeded in doing this." Ozeki's blog demonstrates this struggle to see the connection between the medical and the social, the personal and the political, moving from an articulation of resistance to biotechnology when its unlimited use becomes socially, environmentally and ethically damaging to an embrace of appropriate, and limited, biomedical technology.

In your letter, you acknowledge that "despite the energy scholars both in cultural studies and the medical humanities direct to analyzing the culture of medicine and critiquing its theory and practice, we still find ourselves conditioned by the larger society in which we live and work—-and die . . . [so that] physicians, patients, and family members all seem equally unable to prevent needless intervention, pointless expense, and practices that are not only irrational but ultimately inhumane." Perhaps, in order to change the culture of medicine, we need to see its relation to the broader culture where we are also trying to limit interventions that are needless, pointless, irrational and ultimately inhumane. I would argue that this is another important contribution that we can make in medical humanities and cultural studies. Understood in that broader light, our shared goal is, as Haraway puts it just after that wonderful passage you cited earlier, to forge "an earth-wide network of connections, including the ability to translate knowledges among very different—and power-differentiated-communities. We need the power of modern critical theories of how meanings and bodies get made, not in order to deny meaning and bodies, but in order to live in meanings and bodies that have a chance for a future."[10] Whether we teach in a university or a medical school, whether we write for humanities scholars or physicians, the medical humanities and cultural studies can enable us to make those connections: to see how bodies get made (and remade) in the hospital, the farm, the school and the home, and how in each site we have the choice to cultivate better, less compromised, lives.

Merry Christmas! Love, Susan

[9]Ruth Ozeki, "The Meatrix," 2003, http://www.ruthozeki.com/weblog/ [accessed on 18 December 2003].
[10]Haraway, 187.