Malignant: Cancer Politics and Policy

HON 494/HSD 598
Tuesdays, 3:00-5:45pm
Sage Hall 141

Dr. Robert Cook-Deegan
Office: Interdisciplinary B, Rm B360C
(enter through B366, then turn left)
Office hours: Wed 1:30-2:30
E-mail: bob.cd@duke.edu

Dr. Jenny Dyck Brian
Office: Sage Hall 150
Office hours: Tu 11-12, Wed 1:30-3:30
E-mail: jenny.brian@asu.edu

Synopsis
We will examine cancer as a social, political, cultural, economic, literary, and historical construct. In other words, we will try to understand how the cluster of diseases we call cancer do what they do, from the molecular level through the individual to the social and political levels. This discussion-intensive course will center on how people react to cancer, why cancer research has long been a policy priority, and the role of science and policy in understanding and ameliorating its ravages. We will ask and answer questions such as: Why is cancer so feared? What is the role of cancer research? How are new medical technologies developed? What are the processes of commodification and exploitation in cancer treatments? What are the images and concepts that frame how we think about cancer? How do illnesses become “illnesses” and how do those illnesses become industries? Why is cancer treatment so expensive? Does it need to be? Together we will seek to better appreciate the complex ecosystem of cancer research and cancer care. Creatures in that ecosystem include individual patients and health professionals, abiding in a forest of nonprofit
organizations, research institutions, government agencies, and companies. We will look for answers and insight from science and technology studies, history, economics, sociology, and bioethics, as well as fiction, movies and personal narratives.

This is a mixed course for graduate and professional students (candidates for degrees in law, medicine, business, public policy, global health, sciences, social sciences, or humanities) and advanced honors undergraduates. It revolves around course readings and films that are discussed in class. At first, the structure will be set by the syllabus, but as the course progresses, students will take more responsibility for identifying topics, analyzing readings, and guiding discussion.

Assessment:

The elements of the course are the readings and other materials, the weekly blogs, course discussion, and the group project (this year, a proposed exhibit), and a take-home final. The grade weighting is:

- Blogs: 20%
- Discussion and class participation: 25%
- Short paper: 10%
- Final project: 25%
- Take-home final: 20%

Readings

Readings, viewings and other homework are not separately graded, but they are essential to all the other elements in this course.

Blogs

Weekly blogs have several purposes. First, they hold everyone accountable for the reading. Second, they greatly enrich the discussion. Classroom discussions are the beating heart of this course. Your blogs raise points warranting class discussion that each of you have picked up. Third, blogs encourage us to approach course material multiple times. By blogging in advance, you think about the material before class, and then come back to it again for discussion—and then come back yet again in the take-home final at the end of the semester.

The blogs will be due each week on Sunday at midnight (unless we indicate otherwise for that week). Pose a question based on the following week’s readings and other materials, either at the beginning or end of your blog. The blogs are mainly a way to share what you have noticed, and to use that initial perception to guide discussion later in the week. That is, the blogs are written in advance of the discussions and after doing the readings. They should be short (a paragraph or two). Raise questions you want to see discussed, or make observations, or ask others what they thought of this person or that point or some feature that caught your attention.

Discussion and class participation

This class demands respectful engagement with one another and with the texts. We recognize that it seems odd to demand participation, and yet, this seminar class will not function without your engagement. We want to hear what you think of the texts and the ideas. Some of them are very challenging; our class is a place for you to take (intellectual) risks, to ask questions, to share insights and respond to one another seriously and generously.

A note on readings: This class only meets once a week; plan expect to spend at least 6

hours outside of class reading, rereading, annotating, and preparing for each class meeting. It is impossible to play catch up in this class, so plan ahead and finish the readings before you come to class.

**Short paper**

About halfway through the semester, you will write a short four to five-page paper on one of the following themes:

- Pediatric leukemia and other childhood cancers went from uniformly fatal to often curable over several decades. Why *didn’t* this happen with breast, colon, prostate, lung or other “adult” cancers? Will it now that we’re dissecting the genomic profiles and underlying biology of cancers?
- Cancer enjoys a privileged position in health policy and science policy. It has long commanded more money for research, more public attention than other disorders, and a disproportionate share of health care expenditures. Should it? Why or why not? Or
- Develop a 4-5 page treatment of what will become your final project, including at least part of the literature review.

This paper will be due November 7 at 5 p.m. Deposit your digital paper in the assignment section of the Blackboard site.

**Final project**

The final project can be a paper, video, website, artwork, podcast, etc, on a topic of your choosing. The topic will be due Sept 22, the outline due Oct 9. You may work individually or in groups. More information is forthcoming.

**Final exam**

This is truly a final *examination*. It is not a regurgitation of what you know, but instead a close inspection and recapitulation of the themes that have come up during the course. That is, it will center not on parroting back the facts we covered in the course, but rather on exploring the issues. The format will be two or three clusters of questions. You will address one question from each cluster. You will write **no more than three hours** total. You are free to talk to one another about the course themes and your thoughts, but the final examination is to be your own thoughts in your own words.

**Schedule of Readings**

25 Aug    Introduction to the course — Expectations, goals


**Cancer: Politics of Research and Philanthropy**

**Metaphors and Imagery of Cancer**

**Assignment**: Find an image you think represents cancer. Bring a copy to present to the class.

**Deadline**: Topic of final project due in class. Describe in 200 words what topic or idea you’d like to explore in your final project.

**Cancer Narratives**
29 Sept  Choose your own adventure (in cancer memoirs):
Read one of: *Death Be Not Proud* (John Gunther), *A Whole New Life* (Reynolds Price), *Eating Pomegrantes* (Sarah Gabriel) or another of your choice (check with one of us in advance).

**Palliative Care**

**Deadline**: Outline of final project due in class. Sketch out your plan for your final project in a two-page draft. Include 4-5 key citations.

13 Oct  **Fall Break — No class**

**Pediatric cancer history, policy, and narrative**
22 Oct  Screening of the film “I Want So Much to Live” (Genentech).
*Cottonwood 103, 7-9 p.m.* Catered by Curry Corner (we hope; if not, still food).
Feel free to invite friends.

**Behind the Scenes in Cancer Care and Research**

27 Oct  *Part I:* HeLa Cells and Their Legacy

*Part II:*
Discussion of the film “I Want So Much to Live”

**Numbers and the Work They Do**

[http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html](http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html)


**The Business of Cancer**

10 Nov  *Part I: Case Study: Myriad Genetics*
Material selected from the September 15 investor call for Myriad Genetics. Will be posted when it is available.

*Part II: Regulatory and Business Aspects*

**Drug Pricing**


Memorial Sloan-Kettering Cancer Center website on cancer drug pricing: http://www.mskcc.org/research/health-policy-outcomes/cost-drugs


**Tobacco Politics**


1 Dec  Last day of class

**Policies**

Attendance: Daily attendance is required. Each student is allowed one absence, with no explanation necessary. Additional absences will negatively affect your final grade (e.g., taking you from a B to a B-). The instructor reserves the right to fail those who miss twenty percent of the class meetings or more for any reason.

Penalty for late assignments: *Late assignments are not accepted.*

Regrading policy: If you think the grade we gave you on an assignment is wrong, you may submit it to be regraded. It must be resubmitted within one week, with a paragraph explanation as to why you think our assessment was incorrect and why the paper or project deserves a different grade. Please refer to our grading rubric when making your case and remember that grades are earned, not given.

Electronic devices: You are welcome to use a laptop or tablet in class if you are referencing relevant readings. Do not use the laptop or tablet to check e-mail or Facebook or shop for shoes because that will significantly affect your overall participation grade. (It will affect your grade for the worse, just to be clear). **Our preference is no use of phones or laptops except one designated online**
A note on content: We will be exploring sensitive subjects in this class, concerning death and illness, health and well-being, art and nudity, and the nature of charity. If you are uncomfortable with any of the topics, please schedule an appointment to speak with one of us, and we will discuss possible accommodations.

Unless you are otherwise instructed, all assignments are to be submitted to Blackboard via dropbox, which simplifies time-stamping and ensures fairness, and hard copies directly to the Instructors.

Reading assignments are to be completed in advance. You must come to class prepared and ready to participate in discussion. Please bear in mind that theoretical literature often must be read two or three times to achieve comprehension.

At ASU, we work very hard to promote a campus environment that is safe and conducive to learning and university-related business. Interfering with the peaceful conduct of university-related business or activities or remaining on campus grounds after a request to leave may be considered a crime. If someone is being disruptive, we reserve the right to ask them to stop, and if that does not resolve the problem, to eject that person from class.

Students with permanent or temporary disabilities who would like to discuss course requirements and accommodations are asked to see the instructors within the first week of class. Any athletes or others with school-related special scheduling needs should feel free to approach us.

The syllabus is a contract between the student and the teachers. If you come back for the second class, you agree to abide by the terms we have laid out in the syllabus. While we reserve the right to make small changes to the reading schedule, policies or due dates, we agree to not make any significant changes to the syllabus without consulting the class.

**Academic Integrity**

If you submit work that is not your own, you will be fully disciplined in accordance with university policies. Cheating, plagiarism, or other forms of academic dishonesty are strictly forbidden and will result in a failing grade for the assignment, the class, and disciplinary action with the Dean. It is your responsibility to be aware of, understand, and adhere to the rules and regulations of Barrett, The Honors College and Arizona State University. If you have questions about this, raise them with one of us. The art of scholarship is weaving together ideas from others in useful and distinctive ways.

The general rules are these: do not claim someone else’s work as your own. If you are using someone else’s concepts, cite them. If you cite a fact, then trace it to its primary source and cite that (not the New York Times reporter who was also just using it or the review article that cited it). If you are using that person’s reporting on it or the review article that cited it, make that distinction and tell us where to find the quote (including page number).