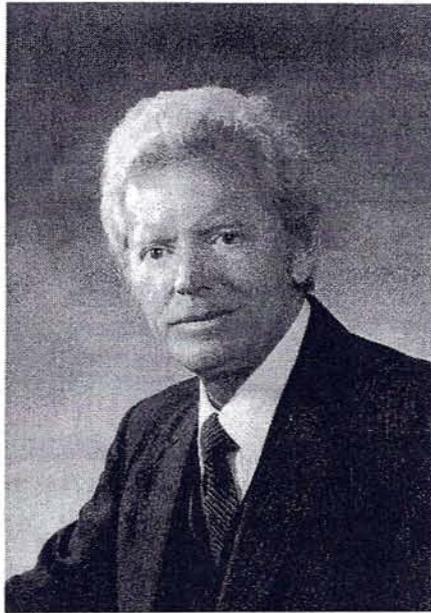


American Osler Society, Inc. John P. McGovern Award Lectureship

**Managed Fear: Contemplating Sickness  
in an Era of Bureaucracy and Chronic Disease**

Charles E. Rosenberg





John P. McGovern

## JOHN P. McGOVERN AWARD LECTURESHIP

Through the generosity of the John P. McGovern Foundation to the American Osler Society, the John P. McGovern Award Lectureship was established in 1986. The lectureship makes possible an annual presentation of a paper dedicated to the general areas of Sir William Osler's interests in the interface between the humanities and the sciences—in particular, medicine, literature, philosophy, and history. The lectureship is awarded to a leader of wide reputation who is selected by a special committee of the Society and is especially significant in that it also stands as a commemoration of Doctor McGovern's own long-standing interest in and contributions to Osleriana.

## John P. McGovern Award Lectureships

1. *Our Lords, The Sick* presented by Albert R. Jonsen, Ph.D., April 12, 1986, in San Francisco, California.
2. *To Humane Medicine: Back Door or Front Door?* presented by Edward J. Huth, M.D., April 29, 1987, in Philadelphia, Pennsylvania.
3. *Medicine and the Comic Spirit* presented by Joanne Trautmann Banks, May 3, 1988, in New Orleans, Louisiana.
4. *The 'Open Arms' Reviving: Can we Rekindle the Osler Flame?* presented by Lord Walton, April 26, 1989, in Birmingham, Alabama.
5. *Rx: Hope* presented by E. A. Vastyan, May 8, 1990 in Baltimore, Maryland.
6. *Osler's Gamble and Ours: The Meanings of Contemporary History* presented by Daniel M. Fox, April 10, 1991, in New Orleans, Louisiana.
7. *From Doctor to Nurse with Love In a Molecular Age* presented by William C. Beck, March 26, 1992, in San Diego, California.
8. *The Heroic Physician In Literature: Can The Tradition Continue?* presented by Anne Hudson Jones, May 12, 1993, in Louisville, Kentucky.
9. *'The Leaven of Science': Osler and Medical Research* presented by David Hamilton, May 10, 1994, in London, England.
10. *A Body of Knowledge: Knowledge of the Body* presented by Sherwin B. Nuland, May 10, 1995, in Pittsburgh, Pennsylvania.
11. *Other People's Bodies: Human Experimentation on the 50th Anniversary of the Nuremberg Code* presented by David J. Rothman, April 25, 1996, in San Francisco, California.
12. *The Coming of Compassion* presented by Roger J. Bulger, April 3, 1997, in Williamsburg, Virginia.
13. *Why We Go Back to Hippocrates* presented by Paul Potter, May 6, 1998, in Toronto, Ontario.

Cover — Obverse and reverse sides of John P. McGovern Award Lectureship commemorative medal which is presented to each annual lecturer.

## John P. McGovern Award Lectureships

14. *Health Care in the Next Millennium* presented by John D. Stobo, M.D., May 5, 1999, in Montreal, Canada.
15. *"Writ Large": Medical History, Medical Anthropology, and Medicine and Literature* presented by Gert H. Brieger, M.D., PH.D., May 17, 2000, in Bethesda, Maryland.
16. *Reflections on American Medical Education* presented by Kenneth M. Ludmerer, M.D., April 18, 2001 in Charleston, South Carolina.
17. *John Shaw Billings as a Historian* presented by James H. Cassedy, Ph.D., April 24, 2002 in Kansas City, Kansas.
18. *The Evolution of The Controlled Trial* presented by Sir Richard Doll, May 23, 2003 in Edinburgh, Scotland.
19. *Practising on Principles: Medical Textbooks in 19th Century Britain* presented by W.F. Bynum, MD, PhD, FRCP, April 20, 2004 in Houston, Texas.
20. *Just Call Us Children: The impact of tsunamis, AIDS and conflict on children* presented by Karen Hein, MD, April 2005 in Pasadena, California.
21. *A Leg to Stand On: Sir William Osler & Wilder Penfield's Neuroethics* presented by Joseph J. Fins M.D., F.A.C.P., May 2, 2006 in Halifax, Nova Scotia.
22. *Managed Fear: Contemplating Sickness in an Era of Bureaucracy and Chronic Disease* by Charles Rosenberg, May 5, 2008, in Boston, Massachusetts.

*The 23rd John P. McGovern Award Lecture*

**Managed Fear: Contemplating Sickness  
in an Era of Bureaucracy and Chronic Disease**

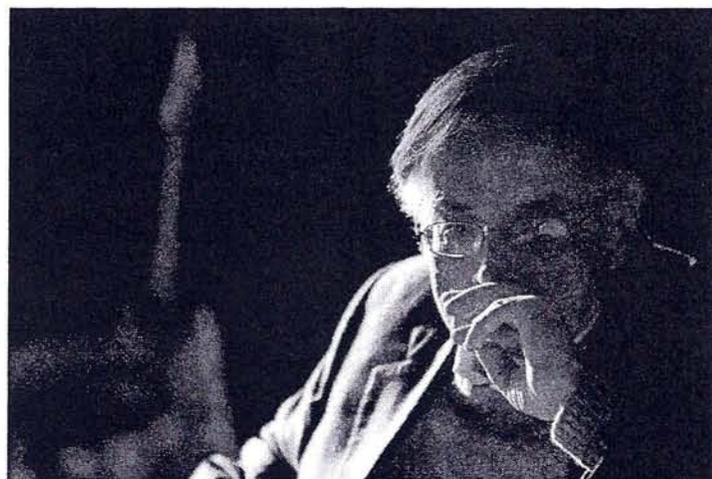
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by

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**Charles E. Rosenberg**

Delivered May 5, 2008  
at the 38th Meeting of the American Osler Society  
Boston, Massachusetts



**Charles E. Rosenberg**

Professor of the History of Science and  
Ernest E. Monrad Professor in the Social Sciences

Charles E. Rosenberg, born in 1936 in New York City, is Professor of the History of Science and Ernest E. Monrad Professor in the Social Sciences at Harvard University (as of January 1, 2001). He has written widely on the history of medicine and science and is best known for his *Cholera Years: The United States in 1832, 1849, and 1866* (Chicago, 1962, new edition, 1987); *The Trial of the Assassin Guiteau. Psychiatry and Law in the Gilded Age* (Chicago, 1968); *No Other Gods. On Science and American Social Thought* (John Hopkins, 1976, new and expanded edition, 1997); *The Care of Strangers. The Rise of America's Hospital System* (Basic Books, 1987); and *Explaining Epidemics* (Cambridge, 1992). He has also co-authored or edited another half-dozen books and is currently at work on a history of conceptions of disease during the past two centuries as well as a volume on current health policy issues in historical perspective.

Rosenberg is a recipient of the William H. Welch Medal of the American Association for the History of Medicine (AAHM) and the George Sarton Medal (for lifetime achievement) from the History of Science Society; he has served as president of the AAHM and Society for the Social History of Medicine (UK) and on the executive board of the Organization of American Historians and on the council of the History of Science Society and of the AAHM. He has been awarded fellowships by the Woodrow Wilson Foundation, the Guggenheim Foundation (twice), and the Rockefeller Foundation. He is a member (and council member) of the American Philosophical Society, Institute of Medicine, and fellow of the American Antiquarian Society and the American Academy of Arts & Sciences. His editorial responsibilities have included a term as editor of *Isis*, the History of Science Society journal, and editor of a Cambridge University Press series on the social history of medicine (including some forty titles).

At the University of Pennsylvania, where he taught from 1963-2000, Professor Rosenberg advised almost fifty doctoral students and served as chair of both the departments of History and the History & Sociology of Science. He served as acting chair of Harvard's History of Science department in 2003-2004.



*“Considering the frailty of this life, although there is nothing more certain than death, yett there is nothing more uncertain than the tyme of the coming thereof...”*

*“... A whole life is now a long and probably unwinnable struggle against the potentially incapacitating impact of fears, and against the genuine or putative dangers that make us fearful. It is best seen as a continuous search for, and perpetual testing of, stratagems and expedients allowing us to stave off, even if temporarily, the imminence of danger ... -- or better yet to shift them onto a side burner where they might, hopefully, fizzle out or stay forgotten for the duration. Our inventiveness knows no bounds...”*

This essay began inadvertently, two decades ago when I was organizing a conference on the history of disease. One of the solicited papers made a particular impression. Entitled “From Bright’s Disease to End Stage Renal Disease,” it tracked the changing nomenclature used to describe malfunctioning kidneys – from the eighteenth-century when doctors created a clinical picture contemporaries called “dropsy,” associated with fluid buildup, weakness, and ultimate death, to a late-twentieth-century dialysis era when technological change and American political circumstance created a novel bureaucratic entity called End-Stage Renal Disease (as a result of Congress’s decision in 1972 to cover the cost of dialysis for all patients with kidney failure as defined by blood chemistry criteria).<sup>3</sup> Soon after, a student of mine undertook a dissertation on diabetes as it was reconfigured in the generation after the introduction of insulin. Here too I was made to think about the ways in which technological change in diagnosis and in altered clinical practice had created a new entity – transforming diabetes in the second-quarter of the twentieth century from an acute illness with high short-term mortality to the now familiar chronic ailment marked by “complications” ranging from the ophthalmologic to the cardio-vascular.<sup>4</sup> In the years since, I have been increasingly fascinated by the late twentieth-century process through which chronic diseases have become social entities – constituted by time-specific configurations of technical capacity, bureaucratic inscription, epidemiologi-

cal findings, public policy decisions and their implementation, randomized clinical trials, pharmaceutical company strategies, media images and lay activism – as well as biological mechanisms known or unknown. Perhaps most important for my present discussion, these cumulative and interactive factors structure powerful connections between the hopes and fears of ordinary men and women and such changing disease categories. Innovations in screening and diagnosis propel many of us into a technically and bureaucratically shaped world of anxious patienthood – while promising, paradoxically, to allay our consequent fears of the immanent cancer, cardio-vascular disease, or diabetes that medicine may discern gestating silently in our bodies. We have moved from the kind of intense and visceral fear associated with acute infectious disease in earlier centuries to a species of widely-disseminated anxiety spread over time.

It is hard to ignore the fact that Americans like most of their peers in the developed world are part of an aging population characterized by chronic and often altered disease – like insulin-dependent diabetes, managed but not banished. When we imagine our futures we are necessarily forced to think about disease – how we will live with it and how we will play the roles dictated by its various narratives. It is hard not to contemplate future illness, especially when we are assailed on television and in newspapers and magazines with warnings about weakened bones, compromised arteries, impaired sexual function, and the ominous presence of “precancerous” lesions. We live in a world of ambient risk.

Much of this is new. Our grandparents and great-grandparents expected to die of a generalized and gradually debilitating condition they called old age – if they did not succumb before they reached such ripe years. And of course many did die before they reached middle-age, often the victims of an acute infectious disease. Today we expect to cope with and ultimately die from the effects of a specific – ordinarily chronic – disease acting its natural history out in our bodies. This way of thinking about disease as entity and nemesis has become a fundamental aspect of the way we conceptualize the world and anticipate our life chances. We have come to take such assumptions for granted.

But disease – and especially chronic disease – was something quite different in traditional medicine. Sickness was labile and individual, an aggregate of constitution, circumstance, and behavior. A cold might shift into bronchitis, bronchitis into pneumonia, or might linger in the form of “a consumption.” The body was always becoming and thus always in jeopardy – but when not undermined by constitutional predisposition ordinarily capable of overcoming a potentially mortal trajectory. Such holistic notions shifted in the nineteenth-century. Ailments were increasingly seen as ontologically distinct entities, construed as existing

in archetypal form outside their manifestations in any particular man or woman. Each of such entities exhibited a characteristic clinical course and came to be understood as the consequence of an underlying somatic mechanism (whether anatomical or physiological). When we think today about individual health and collective health policy we find it difficult to do so without the orienting help of an array of such disease entities – and for most Americans, most of the time, these are real and unambiguous.<sup>5</sup>

Elsewhere I have described the widespread acceptance of this way of conceptualizing sickness as an “invisible revolution,” one comparable to the so-called Newtonian, Darwinian, or Freudian revolutions. If measured in terms of cultural impact, the way in which ordinary men and women think about themselves and their life prospects, the disease specificity revolution was, I would contend, even more far-reaching in an everyday human sense than these more conventionally visible landmarks.<sup>6</sup> Today we see repertoires of specific diseases being used to manage deviance, rationalize and administer health policies, plan health care, sell drugs, and structure specialty relations within the medical profession.

Such pathological entities are significant not only because they are valuable heuristic concepts, guides to further research and the increased understanding of processes within the body, but because they exist in social space with an increasingly dense substance of thresholds, algorithms, screening practices, treatment protocols — not to mention reimbursement schedules, television ads, and drug company marketing strategies. Differential access to health care provides another aspect of the social flesh that helps constitute disease; race, geography, age and gender can all shape individual sickness experience. Disease categories and the rituals of objectivity that flesh them out articulate powerfully and unavoidably with the needs of a bureaucratic society to at once expedite and legitimate the countless clinical (and individual consumer) decisions that constitute our health care system.

Disease concepts are modes of communicating, linking specialists and generalists, administrators and media image-makers, policy planners and ordinary men and women. Disease categories link body, conscious self, and society. Like the Rosetta Stone, a nosology translates experience into machine readable and bureaucratically actionable form. Each diagnosis of a chronic disease or risk factor (an ambiguity to which we will return) casts an actor in a predetermined narrative. Each man and woman has then to live with – and, emotionally as well as physically, manage — that identity. In a world of ever-expanding screening and often symptomless disease, the sick role is increasingly contingent, constituted by diagnostic procedures and agreed-upon conventions negotiated and renegotiated outside the patient’s body and inaccessible to his or her feelings. One

thinks, for example, of cholesterol levels and their diagnostic, prognostic, and therapeutic significance.<sup>7</sup>

Since the beginning of the twentieth century critics have warned of the dangers implicit in reductionist ways of conceptualizing and managing sickness (treating a kidney or interrogating an electrocardiogram or x-ray image and not a person). Nevertheless, bureaucratic disease classifications have flourished in the past half-century. Although the targets of recurring academic skepticism,<sup>8</sup> sharply bounded disease entities retain their ability to manage and mobilize individual anxiety, to shape clinical encounters, and to order and rationalize administrative and therapeutic decisions. Both physicians and social critics have questioned the ontological status of particular diagnoses (think of fibromyalgia or attention deficit disorder), while an increasingly vocal minority of such commentators pose the problem in more categorical terms. They deplore the relentless proliferation of risk factors evolving into diseases and the stigmatizing character of such designations. (A recent scholar refers, for example, to "living under the prognosis" of cancer, another to "people living under the description" of mania).<sup>9</sup> But even as such relativist and humanist critiques become more ubiquitous, the disease categories they question expand in their power to designate, to define, to predict, and to direct treatment.

### **Ageless Fear**

Our ancestors thought very differently about impending illness. Perhaps most important, they faced the everyday onslaughts of acute infectious disease and occasional terrifying epidemics that threatened whole communities. The tuberculosis that wasted and killed year-round and the "fluxes" and "fits" that killed babies every summer were a kind of experiential background noise, part of any community's reckoning with the individually random yet collectively predictable incursions of sickness and death. Few families had never experienced a tense and watchful sickbed vigil in which a parent or child hovered feverishly between life and death. Every thoughtful adult was an expert in interrogating their own bodies and those of family members. Abnormal urine and feces, a coated tongue or blood-shot eyes, a loss of appetite or disordered sleep could all provide clues to health and disease; only in alarming or exceptional circumstances was diagnosis outsourced to a physician. All disease was self-reported.

The portion of infectious diseases experienced as epidemics has always had a special visibility and cultural salience. Today when we refer to an epidemic of traffic fatalities, drug use, or even obesity and type 2 diabetes, we use the term metaphorically and rhetorically to invoke a sense

of urgency and to mobilize collective social action. In the past, that collective action often centered on flight. Readers of the *Decameron* will recall its protagonists' prudent distancing of themselves from the plague; similarly, readers of Samuel Pepys' diary can imagine the fear of one Londoner who stayed in his plague-ridden city. Much later, those Philadelphians who could afford to, fled their city in 1793 when yellow fever invaded from the Caribbean; similarly well-off New Yorkers decamped from their cholera-beset community in 1832 and 1849; as late as the 1890s, India's cities emptied out as those who could fled in the face of impending bubonic plague, while San Francisco and Honolulu responded to plague threats by turning fearfully on their stigmatized Chinese communities.<sup>10</sup>

Unless one includes the early years of AIDS, we have moved past such panicked fears of contagion and acute infectious disease. Epidemics are something distant and exotic, media-articulated spectacles that bring a shiver of shallow and commodified fear – rather different from the visceral reactions that characterized epidemics in earlier eras. Few of us think that we will in fact be victims of mad cow disease, Ebola, or even Eastern Equine Encephalitis. Recent responses to severe acute respiratory syndrome and avian influenza provide examples of such social phenomena. SARS certainly did mobilize genuine fear but one distant from the lives of most Europeans and Americans (though citizens of Toronto might question this generalization).<sup>11</sup> As I write this page, Asian flu has not yet made an appearance in Europe or North America. Yet it already exists virtually in Western cultural space, in terms of planning, laboratory research, social expectations and imagery, media representations, and a specific structuring history based on the collective memory of the 1918 influenza pandemic.<sup>12</sup> Bioterrorism provides another example of our capacity to anticipate and fear epidemic disease as a kind of collective and consumable fantasy; our fears of acute infectious disease remain nevertheless shallow, spotty, and selective.<sup>13</sup> These are not the narratives most of us anticipate inhabiting.

### **A New Kind of Fear**

The burden of our health anxieties has over the course of the twentieth-century shifted to the chronic and to the individual – to the risk of cancer, diabetes, cardiovascular disease as well as behavioral ills, most conspicuously depression in its protean varieties. In recent years one might add fears of impending senile dementia (a traditional descriptive, now routinely and casually rendered as Alzheimer's disease in keeping with the stylistic dominance of disease specificity models).<sup>14</sup>

Cancer has been the most powerful case. By the late eighteenth century it was recognized as an inexorable nemesis.<sup>15</sup> Once symptomatic,

the outcome was foreordained. It constituted an entity that lay people could see as discrete – the malignant tumor alien, tragically embedded, and relentless in its uncontrolled growth. Not surprisingly, early and mid-twentieth century anti-cancer efforts turned on early detection – on educating the public to be aware of breast lumps, unnatural colored moles, or abnormal bleeding. The American Society for the Control of Cancer sought, for example, to inform both physicians and laypeople of the need to identify and to treat “precancerous conditions” in a timely manner.<sup>16</sup> In retrospect, such educational efforts probably had little effect on the ultimate fate of most cancer patients. But they do illustrate the emotional logic of focusing on activism and the fostering of a hope based on a narrative of cancer as monolithic entity spreading inevitably and unavoidably over time. Surgery seemed the only way to interrupt this ominously unfolding narrative.

Diabetes played a rather different but complementary role. Juvenile diabetes, like cancer was understood to be a process internal to the body and progressively fatal; its characteristic sweet and insect-attracting urine had indicated for centuries that some fundamental metabolic process within the body had gone awry. (By the end of the nineteenth-century — in 1889 — German experimental pathology had demonstrated a connection between the pancreas and the pathogenesis of diabetes). The introduction of insulin therapy only underlined the soundness of the view that a discrete and peculiar biochemical nemesis lay behind this rapidly fatal disease. The efficacy of insulin attested to both the specificity and stability of the mechanism underlying and in a sense constituting the illness unfolding within a patient’s body.<sup>17</sup> Magic bullets demand a target and menacing targets elicit magic bullets.

Diabetes thus presented another template for a highly-visible twentieth-century disease narrative. It is a story of disease altered and managed – at persistent individual and social cost. (There are many such instances. Cystic fibrosis, for example, presents a rather different but parallel instance of individual lives extended but at the cost of an anxious, expensive, and emotionally-debilitating vigilance). An aging population presents a variety of less dramatic, but more common examples of illness altered and deferred.<sup>18</sup> After World War II, the American Diabetes Association began a campaign to urge mass screening for “hidden diabetes” – mirroring the cancer society’s campaign for breast self-examination.<sup>19</sup> Not surprisingly, this program was to reveal a dramatic increase in type 2 or non-insulin dependent diabetes. As in the case of hypertension and elevated cholesterol levels we have in this ubiquitous entity created what I have called elsewhere a proto-disease – a symptomless deviation from the statistical normal inhabiting the ambiguous and increasingly well-populated bor-

derland between risk factor and manifest illness.<sup>20</sup> Much has been written in the past decade about the proliferation of such ills, and in late years in particular pharmaceutical companies have been widely and perhaps justifiably criticized for research and marketing strategies that profit from and in their turn encourage popular acceptance of such ever-widening disease categories.

Each diagnosis of hypertension, of elevated cholesterol, of impending glaucoma, of "pre-diabetes" – all artifacts of screening and an ever-more sophisticated technology – places an individual on a kind of pathological slippery slope, protagonist in a narrative of declension. It is not surprising that men and women should want to step out of that narrative or at least alter its trajectory by making the propitiatory ritual libations or applications of Lipitor, Zocor, Xalatan or whatever drug their physician prescribes. Cancer is of course particularly feared and fearsome and screening for "pre-cancerous lesions" has also metastasized in the past half-century. Mammography, PSA tests, and colonoscopies have become routine components of medical practice in developed countries. And social critics and students of health care delivery have already begun a nuanced cost/benefit evaluation of this trend, a kind of buyer's remorse as we contemplate a downside of unnecessary surgery, and anxiety-provoking false positives in a world in which most laypeople have learned all too well the message that cancer is monolithic, progressive, deadly, and must be confronted early. "The word cancer still carries with it the specter of death and suffering," explained a psychiatric oncologist in a recent newspaper interview. "It's like a monster is coming into your house."<sup>21</sup>

The growth of genetic screening in the past generation has added a new layer of expectation, complexity, cost – and ambiguity – to this situation. We seek predictive reassurance but often create new uncertainties. In breast cancer, for example, genetic testing seems only to have raised the moral and emotional stakes. For some women found to harbor the cancer-correlated BRCA1 and BRCA2 genes, bilateral mastectomies have seemed a reassuring and anxiety reducing way of reordering risk by changing one's individual odds. As a letter writer to the *New York Times* put it: "I wanted to fight the breast cancer on my terms, proactively. ... Please recognize that action isn't a sign of panic, rather a move toward empowerment for BRCA1 carriers."<sup>22</sup> Another woman explained her decision to opt for a prophylactic mastectomy in similar terms. "Every day I am aware of my new and different body. But I will tell you this: I don't think about getting cancer anymore. Anxiety, as I keep saying, I can get anywhere. Read the papers."<sup>23</sup> Statistical risk is hard to explain and the same numbers hold different meanings for different people, but immanent nemesis is easily communicated in newspapers, magazines,

television, and on countless websites.<sup>24</sup>

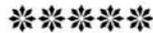
Elevated cholesterol, pre-diabetes, hypertension, BRCA mutations. These are new diseases in a sense, in their several ways as novel as insulin after diabetes, yet even more arbitrary in their definition and prognosis. But they have shown themselves to have enormous social visibility and tenacious plausibility. It is not only because they point to real risks and mobilize predictable fears – but because powerful groups have a stake in their proliferation. I refer not only to pharmaceutical companies alert to shareholder profits, but to health care administrators, public health workers, and disease advocates who have bought into the doctrine of screening, risk management, and therapeutic preemption. Physicians too have – on the whole and not without some reservations – come to accept the usefulness of this paradigm even when they deplore “diagnosis creep” and suspect the motives and tactics of the pharmaceutical industry. (And most American physicians deplore as well the shift in decision-making authority that has come with managed care and the guidelines and protocols that inhibit their therapeutic autonomy). But ordinary men and women are stakeholders too; we seek the assurance of disease prevention through early warning and subsequent altered behavior – whether taking a pill, altering our diet, or adopting an exercise regime. We are almost all of us co-conspirators in this way of conceiving disease – even if the cost often includes a persistent and characteristically modern unease. It is one of the prices we pay for the medical care we — generally — value.

### **The More things Change**

It is tempting to put this argument into a larger historical framework, to see changing disease incidence and understandings as an aspect and indicator of Western society’s larger move from a traditional face to face village world – one we have lost — to a technologically oriented, bureaucratically structured society in which we are born and die in hospitals, not our own beds, where we are treated episodically by subspecialists, and where knowledge has become intensely specialized. Just as risk and disease have been conflated, so have prevention and treatment, diagnosis and prognosis. It is easy enough that is to construe contemporary disease categories and the treatment protocols connected with them as a variety of iron cages into which we have been cast by history. And we do live in a world of technological change, corporate reach, credentialed expertise, and bureaucratic imperative; it is a reality that can hardly be disputed. But such observations merge seductively with a cultural jeremiad that flattens and homogenizes both past and present.

Managed fear is everywhere, but it is neither unavoidable nor uniform. Sickness, pain, and disability remain ultimately individual and

idiosyncratic. We can choose, for example, to avoid the behavioral admonitions built into the guidelines of chronic disease management. Some of us employ alternative healing practices; others opt out through what is euphemistically termed non-compliance or non-adherence: we choose that is not to take our prescribed pills or have our regular blood tests, mammograms, or colonoscopies. We may eat the guilt-oozing cheeseburger or smoke the even more stigmatized cigarettes. A woman may opt for a bilateral mastectomy or simply choose to live with what is, after all, a heightened statistical risk and not a disease. There are different ways to balance nemesis and contingency; and even the same choice among available prophylactic options may reflect different emotional orientations – one man’s fatalism is another’s rational choice. Health and illness cannot be reduced to morally neutral terms; we are commended for “fighting cancer,” for mastering impulse and adhering to medical discipline. We can also blame ourselves and judge others for actions that seem in retrospect to have invited sickness; there is, for example, a comforting order in the link between cigarette smoking and lung cancer. Disease trajectories are narratives and thus stages on which we perform as individuals and moral actors.<sup>25</sup> In the West’s bureaucratic and technology-dependent environment it is ironic that in some ways pain, sickness, and incapacity remain a final and ultimately inaccessible citadel of human idiosyncrasy. We are shaped by our diagnoses, but we are not reduced to them.<sup>26</sup>



## End Notes

<sup>1</sup> From an English yeoman's will of 1649 as cited in: Margaret Spufford, *Contrasting Communities: English Villagers in the Sixteenth and Seventeenth Centuries* ([Cambridge]: Cambridge University Press, c. 1974), p. 321.

<sup>2</sup> Zygmunt Bauman, *Liquid Fear* (Cambridge; Malden, Ma.: Polity, 2006.) p. 8.

<sup>3</sup> Steven J. Peitzman, "From Bright's Disease to End-Stage Renal Disease, In: Charles E. Rosenberg and Janet Golden, eds., *Framing Disease. Studies in Cultural History* (New Brunswick, N.J.: Rutgers University Press, 1992), pp. pp. 3-19. For a more recent synthesis, see the same author's *Dropsy, Dialysis, Transplant. A Short History of Failing Kidneys* (Baltimore and London: The Johns Hopkins University Press, 2007). The edematous swelling, called "dropsy" two hundred years ago, could in fact have been caused by a number of pathological conditions other than kidney disease, most commonly circulatory ills.

<sup>4</sup> Chris Feudtner, *Bittersweet. Diabetes, Insulin, and the Transformation of Illness* (Chapel Hill and London: The University of North Carolina Press, 2003); Feudtner, "A Disease in Motion: Diabetes History and the New Paradigm of Transmuted Disease," *Perspectives in Biology & Medicine* 39(1996), 158-70; Feudtner, "Pathway to Health: Juvenile Diabetes Mellitus and the Origins of Managerial Medicine," In: Alexandra Stern and Howard Markel, eds., *The Formative Years: Childhood Health and Health Care, 1880-2000* (Ann Arbor: University of Michigan Press, 2002), pp. 208-32. I would like to thank a number of other students and post-doctoral fellows who have worked on the history of disease and from whom I have learned a great deal: Warwick Anderson on kuru and tropical medicine; Elizabeth Armstrong on fetal alcohol syndrome, Robert Aronowitz on chronic disease and breast cancer, Jeremy Greene on pharmaceuticals in managing chronic disease, Joel Howell on heart disease and clinical pathology, Susan Jones on anthrax and animal disease, Carla Keirns on asthma, Aaron Mauck on type 2 diabetes, Steven Peitzman on kidney disease, Naomi Rogers on polio, Nancy Tomes on germ theory, Sara W. Tracy on alcoholism and constitutional disease, and Keith Wailoo on anemias and genetic disease.

<sup>5</sup> Ills manifesting themselves in the form of emotions and behavior remain an area of persistent contestation. But even such controversies turn on the legitimacy of putative disease entities as mechanisms sufficient to explain/determine deviance and emotional pain. I refer, of course, to highly-visi-

ble debates over such phenomena as substance abuse, chronic fatigue, borderline personality, ADHD, and chronic fatigue.

<sup>6</sup> This passage is adapted from Charles Rosenberg, "The Tyranny of Diagnosis: Specific Entities and Individual Experience," *Milbank Q.* 80(2002), 238 and passim. For discussions of the role of classification, quantification, and bureaucratic practice in the social embodiment of disease entities, see, for example: Geoffrey C. Bowker and Susan Leigh Starr, *Sorting Things Out. Classification and its Consequences* (Cambridge and London: MIT Press, 1999); Gerard Jorland, Annick Opinel, and George Weisz, *Body Counts. Medical Quantification in Historical and Sociological Perspective* (Montreal and Kingston: McGill-Queens-Queens' University Press, 2005); Harry Marks, *The Progress of Experiment: Science and Therapeutic Reform in the United States, 1900-1990* (New York: Cambridge University Press, 1997); David Mechanic, *The Growth of Bureaucratic Medicine. An Inquiry into the Dynamics of Patient Behavior and the Organization of Medical Care* (New York: John Wiley, 1976); Stefan Timmermans and Marc Berg, *The Gold Standard. The Challenge of Evidence-Based Medicine and Standardization in Health Care* (Philadelphia: Temple University Press, c. 2003); Jeanne Daly, *Evidence-Based Medicine and the Search for a Science of Clinical Care* (Berkeley: University of California Press, 2005).

<sup>7</sup> Jeremy A. Greene, *Prescribing by Numbers. Drugs and the Definition of Disease* (Baltimore: The Johns Hopkins University Press, c. 2007), Ch. 5, "The Fall and Rise of a Risk Factor: Cholesterol and its Remedies," and Ch. 6 "Know your Number: Cholesterol and the Threshold of Pathology," pp. 151-219.

<sup>8</sup> Perhaps most conspicuously in the ongoing by now clichéd controversy surrounding the American Psychiatric Association's *Diagnostic and Statistical Manual*. See, for example, Ronald Bayer, *Homosexuality and American Psychiatry. The Politics of Diagnosis* (Princeton: Princeton University Press, 1987, orig pub. 1981); Gerald N. Grob, "Origins of DSM-1: A Study in Appearance and Reality," *Am. J. Psychiatry* 148(1991), 421-31; Allan V. Horwitz, *Creating Mental Illness* (Chicago and London: University of Chicago Press, University of Chicago Press, c. 2002); Stuart A. Kirk and Herby Kutchins, *The Selling of DSM. The Rhetoric of Science in Psychiatry* (New York: A. De Gruyter, 1992); Kutchins and Kirk, *Making us Crazy: DSM, the Psychiatric Bible and the Creation of Mental Disorders* (New York: Free Press, 1997). Questioning of the epistemological legitimacy of disease categories is at least as old as the anti-psychiatry movement – that is the late 1950s and 60s. See, for example, Erving Goffman's characteristically

epigrammatic reference to the "crime [that] must be uncovered that fits the punishment." *Asylums. Essays on the Social Situation of Mental Patients and Other Inmates* (New York and London: Doubleday Anchor Books, 1961), p. 384, and similarly, pp. 84-5. There is an instructive parallel with contemporary pharmaceutical company strategies that link drugs with usage-legitimizing if sometimes ontologically problematic disease entities.

<sup>9</sup> Sarah Lochlann Jain, "Living in Prognosis: Toward an Elegaic Politics," *Representations* 98(2007), 77-92; Emily Martin, *Bipolar Expeditions. Mania and Depression in American Culture* (Princeton and Oxford: Princeton University Press, 2007). For more general discussions of risk and modernity, see, for example: Ulrich Beck, *Risk Society: Towards a New Modernity* (London: Sage, 1992); Mary Douglas, *Risk and Blame: Essays in Cultural Theory* (London: Routledge, 1992); Deborah Lupton, ed., *Risk and Sociocultural Theory: New Directions and Perspectives* ([Cambridge]: Cambridge University Press, c. 1999); Alan Peterson and Deborah Lupton, *The New Public Health: Health and Self in the Age of Risk* (St. Leonards, Australia: Allen & Unwin, 1996).

<sup>10</sup> Charles E. Rosenberg, *Cholera Years. The United States in 1832, 1849, and 1866* (Chicago: University of Chicago Press, 1987); J.H. Powell, *Bring Out Your Dead. The Great Plague of Yellow Fever in Philadelphia* (Philadelphia: University of Pennsylvania Press, 1949); J. Worth Estes and Billy G. Smith, eds., *A Melancholy Scene of Devastation. The Public Response to the 1793 Philadelphia Yellow Fever Epidemic* ([Canton, Ma.]: Science History Publications, 1997); James C. Mohr, *Plague and Fire. Battling Black Death and the 1900 Burning of Honolulu's Chinatown* ([Oxford and New York]: Oxford University Press, 2005); Susan Craddock, *City of Plagues. Disease, Poverty, and Deviance in San Francisco* (Minneapolis: University of Minnesota Press, c. 2000); Nayan Shah, *Contagious Divides. Epidemics and Race in San Francisco's Chinatown* (Berkeley, Los Angeles, and London: University of California Press, c. 2001); David Arnold, *Colonizing the Body. State Medicine and Epidemic Disease in Nineteenth-Century India* (Berkeley and Los Angeles: University of California Press, 1993).

<sup>11</sup> Arthur Kleinman and James L. Watson, eds. *SARS in China: Prelude to Pandemic?* (Stanford: Stanford University Press, 2006). For an illuminating study of the post-HIV mini-genre of "outbreak narratives," see Priscilla Wald, *Contagious. Cultures, Carriers, and the Outbreak Narrative* (Durham and London: Duke University Press, 2008).

<sup>12</sup> This point is adapted from Charles E. Rosenberg, "Siting Epidemic

Disease: 3 Centuries of American History," *J. Infectious Disease*, 197 [Suppl. 1, 2008]: S4-S6.

<sup>13</sup> The fear of terrorist-disseminated anthrax spores has, for example, already faded into the short-term historical past, as much an event in the world of media as in security policy. At the same time we tolerate the socially invisible background noise of endemic hospital infection and our annual toll of influenza deaths – not to mention automobile accidents. Lyme disease was and, to an extent, remains an anomaly – an infectious disease whose major and more alarming if controversial symptoms are chronic and not life-threatening. Yet it too has faded in the past decade from the foreground of cultural visibility.

<sup>14</sup> Jesse F. Ballenger, *Self, Senility, and Alzheimer's Disease in Modern America. A History* (Baltimore: The Johns Hopkins University Press, c. 2006); Lawrence Cohen, *No Aging in India. Alzheimer's, the Bad Family, and Other Modern Things* (Berkeley, Los Angeles, and London: University of California Press, c. 1998); Peter J. Whitehouse, Konrad Maurer, and Jesse F. Ballenger, eds., *Concepts of Alzheimer Disease. Biological, Clinical, and Cultural Perspectives* (Baltimore and London: The Johns Hopkins University Press, c. 2000).

<sup>15</sup> Of course, many if not most of those conditions recognized as cancer today would have remained obscure to physicians and laypeople in this period. Skin and breast cancers could, on the other hand, hardly be ignored. Breast cancer presented a particularly unavoidable instance; for therapeutic responses see: Julia L. Epstein, "Writing the Unspeakable: Fanny Burney's Mastectomy and the Fictive Body," *Representations* 16(1986), 131-66; Robert A. Aronowitz, *Unnatural History. Breast Cancer and American Society* ([Cambridge and New York]: Cambridge University Press, c. 2007), pp. 21-84. Leland J. Rather, *The Genesis of Cancer: A Study in the History of Ideas* (Baltimore: The Johns Hopkins University Press, 1978) remains a valuable short introduction to theories of cancer pathology.

<sup>16</sup> The ASCC warned physicians that "the 'wait see fools' paradise is not restricted to the lay mind" From an undated and unpaginated (New York, circa 1925) circular on *The Prevention and Cure of Cancer. The Responsibility of Physicians in the Campaign Against Cancer*. "Cancer of the skin, breast, and uterus; and to a certain extent, of the more inaccessible organs and structures, have a pretty well defined precancerous period before malignancy." This was the time to intervene. Robert A. Aronowitz, "Do Not Delay: Breast Cancer and Time, 1900-1970," *Milbank Q.* 79(2001):

355-86; Kirsten E. Gardner, *Early Detection: Women, Cancer, and Awareness Campaigns in the Twentieth-Century United States* (Chapel Hill: University of North Carolina Press, 2006).

<sup>17</sup> The seeming efficacy of liver extracts in pernicious anemia or lithium in bipolar disease seemed in a parallel way to demonstrate the way in which specific biochemical abnormalities could constitute and thus legitimate disease. This style of ontologically legitimating disease by citing a – presumed – specific drug efficacy has become commonplace, and has often helped pharmaceutical companies in their advertising campaigns. In recent months, for example, Pfizer has pursued this strategy in marketing of “Lyrica” for the treatment of fibromyalgia – the drug’s putative clinical efficacy legitimating the controversial ailment’s existence.

<sup>18</sup> A didactically circumstantial instance is provided by Kayla Rachlin Small, “Modern Love. The Steep Price of our Forbidden Kiss,” *New York Times*, March 16, 2008. (Peculiarly, or perhaps revealingly, this essay appeared in the Sunday Styles section. For background, see Keith Wailoo and Stephen Pemberton, *The Troubled Dream of Genetic Medicine: Ethnicity and Innovation in Tay-Sachs, Cystic Fibrosis, and Sickle Cell Disease* (Baltimore and London: The Johns Hopkins University Press, 2006); M. Susan Lindee, *Moments of Truth in Genetic Medicine* (Baltimore and London: The Johns Hopkins University Press, 2005).

<sup>19</sup> Aaron P. Mauck, “The American Diabetes Association and the Promotion of Type 2 Diabetes Awareness, 1945-1960,” Paper presented at the Annual Meeting of the American Association for the History of Medicine, April 12, 2008.

<sup>20</sup> Rosenberg, “Disease in History: Frames and Framers,” *Milbank Q.*, 67, suppl. 1, 1989), 1-15.

<sup>21</sup> Dr. Donna Greenberg of the Massachusetts General Hospital, cited in Stephen Smith, “Fear Itself. When Patients are diagnosed with cancer – or even if they’re just being tested – they’re often engulfed by anxiety. ...,” *Boston Globe*, C1, March 10, 2008.

<sup>22</sup> Susan K. Cashen, to the Editors, September 23, 2007.

<sup>23</sup> Liz Emmert, Kempton, Pa., to the Editor, Letters on “Genetic Knowledge and Breast Cancer,” *New York Times*, September 23, 2007.

<sup>24</sup> For an introduction to the complex story of breast cancer, its changing diagnosis and treatment, see Aronowitz, *Unnatural History*; Patricia Jasen, "Breast Cancer and the Language of Risk, 1750-1950," *Social History of Medicine* 15 (2002), 17-43; Barron H. Lerner, *The Breast Cancer Wars. Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America* ([New York]: Oxford University Press, 2001); Lerner, "Great Expectations: Historical Perspectives on Genetic Breast Cancer Testing," *Am. J. Public Health* 89 (1999): 938-44; James T. Patterson, *The Dread Disease. Cancer and Modern American Culture* (Cambridge and London: Harvard University Press, 1987); David Cantor, ed. "Special Issue. Cancer in the Twentieth Century," *Bull. Hist. Med.* 81 (Spring, 2007): 1-334.

<sup>25</sup> Disease incidence also creates an opportunity to judge society generally – and to see differential morbidity and mortality as symptomatic of a society in need of therapeutic intervention. Discussions of asthma and the obesity/type 2 diabetes complex are highly visible examples of such analysis. So too are those contemporary discussions of cancer incidence that focus on environmental causes. Gregg Mitman, *Breathing Space. How Allergies Shape Our Lives and Landscapes* (New Haven and London: Yale University Press, 2007); Carla Keirns, "Short of Breath: A Social and Intellectual History of Asthma in the United States" (PhD Diss., University of Pennsylvania, 2004); Robert N. Proctor, *Cancer Wars. How Politics Shapes What We Know and Don't Know about Cancer* ([New York: Basic Books], c. 1995).

<sup>26</sup> This point-of-view is developed more fully in Charles E. Rosenberg, "What is Disease? In Memory of Owsei Temkin," *Bull. Hist. Med.* 77 (2003), 491-505.