

Book Reviews

Body Bazaar: The Market for Human Tissue in the Biotechnology Age, by Lori Andrews and Dorothy Nelkin, 245 pp. \$24, ISBN: 0-609-60540-2, New York, NY, Crown, 2001.

Today, debate over harvesting and donating blood tissue seems remote when permission to harvest and donate organs is given on the back of one's driver's license. The purported need for organs has far outstripped the supply of donors. As one would expect, this disparity in supply and demand creates a black market.

Several years ago, *Scientific American* highlighted this topic by publishing a photograph of illiterate south Asians with the same visible flank incision. All had allegedly donated a kidney without knowledge of the operation.

This black market gave enterprising physician writers grist for shocking novels. Robin Cook, MD, wrote *Chromosome 6* in which human DNA is inserted into bonobo chimpanzees, producing chimeras with organs transplantable into human beings. This meddling leads to unexpected fallout in the human recipients of the organs, and creates behavioral disturbances in the primates. Tess Gerritsen, MD, wrote *Harvest*, in which the Russian Mafia purchases/kidnaps children and adolescents, types their tissues, then demands a ransom from matching recipients. The organs are harvested on a ship, then taken by helicopter to eager recipients. The corpses are fed to the sharks.

With the cloning of mammals in recent years, there was great impetus to apply this process to human beings. Many scientists and attorneys felt that this was a way to produce designer offspring with fewer surprises than in-vitro fertilization. As the problems of cloning and its adverse effects became public, there was a growing aversion to human cloning on many levels, including personal, social, moral, ethical, and scientific. As frequently occurs, determined proponents found a way around the opposition: cloning was simply repackaged as tissue-specific stem-cell research.

In an interview, internationally renowned bioethicist Lori B Andrews details a telephone conversation with a

scientist who claimed, "I have a severed head here. This man wrote in his will that he wanted his head kept and reattached to a healthy body. What are the legal rights of the severed head?" Andrews, a Chicago-Kent College of Law professor says, "I'm the cleanup person that people call after they do some new weird thing." She is also an adviser to Congress, the National Institutes of Health (NIH), and the World Health Organization (WHO). She has litigated for parents who wanted to ship a frozen embryo across the country, yet decries the practice of securing sperm from men in coma.

Andrews and coauthor Dorothy Nelkin, a law professor at New York University, detail how our human bodies, with an elemental worth of less than one dollar, have acquired currency in today's world. DNA, blood, bones, and other tissues have become the raw material for commercial products that attract millions of dollars. Our bodies have also become sources of information easily available for researchers, entrepreneurs, insurers, employers, law-enforcement authorities, and immigration officials. The authors cite evidence that this burgeoning industry threatens to wreak ethical havoc.

The human body, formerly considered private, personal, and the only thing that people could really call their own, has begun to take second place to human commerce. Medical centers have harvested rare cell types, patented them and made a fortune. Yet, none of these centers have shared the profit with the ailing donor.

The blackish market of harvesting eggs from college girls is sometimes lucrative enough to pay tuition. A colleague of mine has a daughter at USC who was offered \$5,000 for her eggs. She declined, not liking the idea of having scattered offspring, with the outside chance that a future offspring could inadvertently marry a sibling. She tells of classmates with special characteristics who were offered as much as \$25,000 for an egg harvest. Sperm is reportedly going for \$100 to \$4,000. Cell lines are now fetching up to \$3 million and genes up to \$1.5 billion.

Andrews and Nelkin cover ten major topics ranging from celebrity organs to body snatching and sequestering. Some have appeared as articles in the *New*

England Journal of Medicine. Each chapter reads like fiction, but is carefully annotated.

This book provides a scientific view of this ethical dilemma of the 21st century. As to the authors question, "Who owns your body," the answer is that in this biotechnology age, you, the patient, don't. When the courts rule against people controlling their own body, patients will protect themselves in other ways. More patients have taken the organ donor card off their driver's license. They no longer ask to go to University Medical Centers.

Andrews and Nelkin have elucidated the ethical dilemma so that the pendulum can swing again to a more appropriate position.

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When Your Doctor Is Wrong: Hepatitis B Vaccine & Autism, by Judy Converse, 294 pp., paper, \$18.69, ISBN 1-4010-2973-6, Xlibris.com, 2002.

According to Baker's Law, "The entire neurologic issue is whether the patient has a neurologic disease or not. All else is mere commentary." No neurologist, A.B. Baker declared, should ever take a psychiatric history.

One of the great neurologist's former residents, Harold Klawans, applies his mentor's advice posthumously to the case of Isaac Newton in his 1990 book *Newton's Madness: Further Tales of Clinical Neurology*. The death of Newton's mother, his religious fervor, and other psychiatric speculations were simply irrelevant. Newton himself was correct in attributing his episodic irritability, insomnia, anorexia, memory difficulties, and tremor to "sleeping too often by my fire," which was used for his chemical experiments. Newton suffered chronic mercury intoxication, recently confirmed by hair analysis.

With regard to autism, Baker's Law is apparently forgotten, as Mrs. Converse testifies in her book, originally titled "Saving Ben." Her child's extreme sensitivity, sleep disturbances, vomiting, bowel symptoms, and incoordination were

at first called “normal,” and her concerns ascribed to the anxieties of a new mother. Later the no-longer-deniable symptoms were blamed on the parents. His mother's observation that worsening followed vaccinations was dismissed, and on one occasion she was actually threatened with a report to Child Protective Services if she delayed a scheduled shot.

Were Ben's terrible afflictions the result of the hepatitis b vaccine that he received immediately after birth, without her knowledge, much less her consent? Mrs. Converse eventually came to that conclusion. Her predictions were borne out in Ben's response to the equivalent of challenge testing insisted upon by his pediatricians.

The book is really intended for parents of autistic children, who will find practical ideas on diet and therapeutic exercises. What helped Ben may help others.

Doctors can learn a lot from it too. It is a scathing indictment of the medical profession for clinical ineptitude and callousness bordering on brutality in relating to parents of a seriously ill child. It raises penetrating questions on the vaccine approval process, and the uninformed nonconsent for their use.

One could wish for better editing, references rather than a simple bibliographic listing, and an index. But while Mrs. Converse is not an exemplary scientific writer, she is an heroic mother and a better physician than many with the degree of M.D., employing techniques of careful observation and experimentation, while putting the patient first whatever the cost.

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The Burzynski Breakthrough, Rev. Ed., by Thomas D. Elias. 338 pp, \$27.95, ISBN 0-938530-66-6. Nevada City, CA 95959, 2001, Lexikos.

Subtitled “The Most Promising Cancer Treatment...and the Government's Attempt to Squelch It” (40% New Content with Clinical Trial Statistics), this book is intended for cancer victims rather than medical scientists or practitioners.

The book is well-edited and beautifully written in a tone that is unrelentingly even-tempered despite revelations of the most unimaginable behavior by the US Food & Drug Administration (FDA) and the National Cancer Institute (NCI).

To scientists, its most serious flaw is the lack of specific literature citations for facts; but this is partially compensated by the

inclusion of a list of the clinical trial results for more than 400 patients treated with the antineoplastons discovered and developed by Stanislaw R. Burzynski, MD, PhD, in his clinic in Houston, TX. More than half the patients benefited from this treatment, which is not startling in itself, until the reader comprehends that nearly all the patients had been considered terminal by mainstream oncologists, and had been harmed by conventional treatments.

Antineoplastons are simple peptides normally found in the human body that signal cells when to quit dividing and when to undergo apoptosis. In people with cancer they are not present in a high enough concentration. Elias described how Dr. Burzynski identified and synthesized a number of them, and manufactured the best ones as supplements, rather than drugs, since they are identical with the naturally occurring ones.

Antineoplastons are usually administered by catheter into a major blood vessel in the chest, but this has to be done as part of a clinical trial in Burzynski's clinic in Houston, and the most effective antineoplastons are not allowed in interstate commerce. However, an orphan drug called Buterate, made by the Ucylyd Pharma Co. of New Jersey, was approved by the FDA in the 1990s for an unrelated disease, thus providing a capsule form to be taken by mouth. Burzynski recognized that Buterate was metabolized to certain antineoplastons, and that it could be prescribed for lawful “off-label” use to treat cancer, and this has been done since 2000 for patients located anywhere; however, this is not as effective as the best of the antineoplastons are when they are administered intravenously.

The structure of the book is idiosyncratic, but effective, with 13 individual case studies interspersed within each chapter, with both the history of antineoplastons and the biography of Burzynski as a series of flashbacks. The case studies are used to provide background on the utter inadequacy and toxicity of conventional cancer treatment. Selection bias may have been inevitable, based on expected reader interest, but the case studies did include a number of patients who died.

Elias actually wrote the case studies with great compassion, and used them to show the contrast between the effects and side-effects of conventional and antineoplaston treatments. All of the mainstream physicians involved in the cases were contacted for confirmation of what their patients said; very few would respond to Elias in any manner, in contrast to Burzynski, who spent days with him. Nevertheless, Elias's lack of general overview and the absence of a comparison

of all-cause death rates between conventional and antineoplaston treatments is bothersome.

Elias began the biographical part with a description of Burzynski's criminal trial in Houston in January, 1997, on 75 charges of contempt of court, interstate commerce in drugs not approved by the FDA, and insurance fraud. This resulted in a hung jury (6-6). A second trial resulted in complete acquittal after just 3 hours of jury deliberation. Patients campaigned in every possible manner for their hero, and not even a single relative of deceased patients gave a negative word of testimony about Dr. Burzynski. Elias details the persecution of Burzynski by the FDA and the Texas Health Department, spanning about 17 years, which was unparalleled in its persistence and ferocity, and corroborated by at least four other authors.¹⁴

After describing the court trials, Elias presents Burzynski's entire career in long flashbacks, including his education, his escape from Communist Poland's Army to the USA, his association with Baylor College of Medicine in Houston, his decision after non-renewal of an NCI Grant at Baylor to set up his own clinic in Houston, and his lawful treatment of the first patients in 1977, and subsequent developments.

Elias has, among other writers¹⁴ made a persuasive case that antineoplastons are both safe and effective. He did this without a single accusation of conspiracy, a single supposed motive, or a single ad hominem attack.

Elias could have made a stronger case by trying to estimate the increase in lifespan among the small number of cancer patients who took antineoplastons before conventional treatments. If Elias's conclusions are correct, we may begin to think about the number of person-years of life lost to medical intransigence. If a mere two years of life could be gained on average by using antineoplastons first in the 1 million new annual cancer patients (in the USA alone) before subjecting them to the rigors of conventional treatments, 2 million patient-years of life could have been gained annually; over the last 20 years, this could have been 40 million patient years, all at a cost of five to ten percent of conventional treatments.

Elias should have written that oncologists generally do not recognize that the common failure in reports of clinical trials on chemotherapy and high-dose radiation to distinguish between lowered cancer death rates (RR) and unchanged all-cause death rates, even in oncology texts,⁵ has led to misinterpretation of the results of screening and treatments and, consequently, resources are wasted on treatments

that do not extend life or its quality.^{6,8} Elias also failed to emphasize Burzynski's stellar publication record.⁹

Despite the caveats, this book is highly recommended.

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Dependent on D.C.: The Rise of Federal Control over the Lives of Ordinary Americans, by Charlotte A. Twight, 422 p., index, \$26.95, ISBN 0-312-29415-8, New York, NY, Palgrave, 2002.

How did it happen that Americans “traded individual liberty piecemeal for dependence on government, without revolution, without reflection, often without systematic understanding”? How could a nation rooted in liberty accept the unchecked, pervasive federal intrusions into our lives?

Dr. Twight invokes no conspiracy theories. The problem is much more

difficult than simply thwarting the monolithic agenda of an elite group. The book describes actions taken by various individuals and groups pursuing their own separate agendas, trying to get their way through strategies that simply *work* in politics.

Dr. Twight's key insight is the importance of manipulating political transaction costs: the cost of perceiving and acting upon our assessment of the net costs of a particular government action. Government grows by progressively raising the cost of resistance.

There is the naturally high transaction cost of organizing large groups whose members have small individual stakes in a policy outcome. In addition, there are “contrived” transaction costs, such as those created by deliberately concentrating benefits and diffusing costs. Covert manipulations make it possible for government officials to sustain outcomes that contravene the popular will without the overt use of force. It is a crucial technique for creating that “servitude of the regular, quiet, and gentle kind” described by Tocqueville.

The foundations of the welfare state—Social Security and income tax withholding—are explained in depth. Harsh reality has been disguised by such methods as splitting the payroll tax. A pretense of compassion veils the true motive, best expressed by Bismarck in 1881: “Whoever has a pension for his old age is far more content and far easier to handle than one who has no such prospect.” Dr. Twight tells it like it is in her subtitles, such as “Wealth Destruction through Social Security: Forced Nonsaving.”

Contrary to the common perception, there was no public outcry for compulsory old-age insurance in the wake of the Depression. Roosevelt, in fact, urged the deferral of a widely supported bill for needs-based assistance in order to preserve it as a lever for the later enactment of universal insurance.

Getting Americans to relinquish the cherished right to shape the education of their children—essential for achieving consolidation of federal power—is another example of transaction-cost manipulation. Incrementalism is an important feature of the strategy. The appalling results have led to pressure for even more federal intervention. Yet, Dr. Twight points out that in 1812, 40 years before the first compulsory school laws, fewer than 4 in 1,000 Americans lacked the ability to read and do numbers well. In 2000, 37 percent of children couldn't read. The method was, again, imported from Prussia:

Froebel's “kindergarten” with its early removal of the child's parents

and culture from the scene, and its replacement of serious learning with songs, games, pictures and organized group activities was remarkably effective in delivering compliant material to the State.

Of greatest interest to AAPS members is the chapter on “Health Care Controls: Exploiting Human Vulnerability.” There is an excellent summary of the political machinations that culminated in the enactment of Medicare and of its predictable, not necessarily unintended consequences.

The erosion of privacy is of special concern to Dr. Twight. She refers to government-compelled information collection as “dependency's forgotten vector,” quoting a 1971 admonition by H.B. Acton:

When a large part of the information about economic statistics or administrative arrangements is collected and issued by government, investigators and critics are forced to approach the very officials they may criticize for the information that might give substance to their criticism.

The end result of dependence on government is evisceration of the rule of law. Physicians are not the only citizens affected by the rampant federal criminalization of all manner of ordinary private acts not generally regarded as criminal. However, too many AAPS members have first-hand experience of being charged with “money laundering,” aptly defined as the single, basic prohibited act of “doing something and not telling the government about it.”

Dr. Twight's lively and lucid style, her trenchant legal analysis and careful annotation, and her sense of history make this work a book for reading cover to cover as well as for keeping on the reference shelf.

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