



A Reciprocity Obligation to Donate Cadaveric Organs: Re-Visioning Opting In

Jonathan Rackoff, JD

The supply of cadaveric organs and tissues in the United States depends on the continuing willingness of citizens to make voluntary donations. Unfortunately, our current regime for procuring donated organs is unbalanced. There is overwhelming support in the United States for organ donation (perhaps approaching 86% of the population), although only one-fifth of Americans have agreed to “give the gift of life” (Metzl, 2001). Presumably, the remainder do not intend to imply by their abstention that they would refuse to receive an organ or tissue donation. On the contrary, we can safely assume that most putative nondonors would not object to receiving a life-extending solid organ transplant, should a need arise (Eaton, 1998).

The cost in lives

Tolerance for the gap between the number of contributors and the number of eligible beneficiaries is imposing a cost in lives. Every year, consent for transplantation is obtained from fewer than half of the 15,000 people who die as viable organ donors (S. Con. Res. 63; Rother, 2000; see also Center for Organ Recovery and Education). Since 1998 more than 20,000 people have died waiting for the organ they needed. This year alone, more than 6,000 lives will be lost, and the shortfall is worsening. In the last decade, the nation’s organ transplant waiting list has increased fourfold, to more than 80,000. In 2001, for the first time, the number of cadaveric organ donors fell below the number of living donors (United Network for Organ Sharing, 2002).

Gift model versus opt-out system

The Uniform Anatomical Gift Act (UAGA) frames organ donation as gift

giving, worthy of praise and gratitude. But this attitude is counterproductive if the goal is to save lives. The gift model of organ procurement has magnificently failed to satisfy rising demand for transplants. Instead, during nearly 35 years it has advanced other values. By emphasizing voluntariness, the 1968 and 1987 UAGAs have promoted respect for individual autonomy, the dignity of the body after death, and altruism. In guarding against the development of commercial markets in organs, this moral framework of aspiration has helped to prevent commodification, exploitation, and undue inducement (Childress, 2001).

The bioethics community may have been overly kind to arguments against the selling of organs. Society may revere bodies to an unwarranted extent. But such concerns would be relevant only if a market system were to replace the gift model. That is improbable.

The question becomes whether our dual interest in autonomy and altruism justifies the organ procurement policy that exists in the United States today. Our cultural obsession with autonomy probably is responsible for our failure to adopt an opt-out scheme similar to the one that has been wildly successful for more than a decade in Belgium. Fewer than 2% of Belgians opt out of that system, and it is credited with increasing cadaveric organ donation by 55% within its first 5 years (Kennedy et al., 1998; Michelson, 1995).

At least 13 European nations and Singapore now ask their citizens explicitly to renounce organ donation or be included in the pool of potential organ donors. The results vary from country to country, and counterindications can be found. For example, Singapore initially

enjoyed a 660% increase in annual kidney procurement, but more recent data suggest that the trend has been reversed (Fitzgibbons, 1999).

The rhetorical obstacle

In the United States, opposition to an opt-out system probably has little to do with doubts about its efficacy. We face a rhetorical obstacle far more daunting. In a pure opt-out system, the organs of those who did not positively withdraw their consent during life are subject to removal after death. This “routine harvesting” is justified because, in the absence of a contrary statement, decedents are presumed to have given their consent.

The justification for presumption of consent is said to be survey data showing eager and near-universal support for organ donation. Thus, it is claimed that

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Three Cheers for Losers!

Kathryn Montgomery

It's been a long time since I've submitted a paper or a panel to the ASBH program. I've been on a panel or two, and twice I've substituted for scheduled presenters when they were overcommitted and had to withdraw. But I've ducked the whole process of generating a good idea and inviting good people to participate, then writing it all up—on time, by e-mail—and waiting to learn whether it was picked. When I'm asked (and sometimes when I'm not), I claim this reticence is because I've been around a long time and younger people ought to have the program slots. They've got the new ideas; they need to be on the program to have their institutions pay travel expenses; they have tenure reviews ahead. And besides, everyone knows what the old hands will say, even—with some of us—how we'll say it.

This feels very virtuous and, besides, I really do believe it.


But there may be another reason: Getting a presentation accepted for an ASBH program is not easy anymore. There's a big chance that a panel or a paper I submitted wouldn't be chosen. It's convenient to have a nice, generative reason for not taking that chance.

I was reminded of this when I saw the super spread of interesting presentations for the Baltimore meeting that Kristi Kirshner and Jim Nelson and their complex, even Ptolemaic program committee have chosen. Although this year members are limited to one presentation (not counting preconference workshops), there were almost as many submissions as last year. And we'll have one fewer room per session than we did in Nashville. I imagine the program committee running their hands through the submissions like misers, exulting in their great good fortune. They could hardly go wrong. Which doesn't keep the job from being thankless in many

quarters. More than twice as many people got letters of rejection as got acceptances—and many of them for wonderful papers and panels on important topics. The program co-chairs and several members of the program committee were among those who didn't make it.

And then there are the nominees for ASBH office. What bravery! I know of someone who has twice accepted a nomination, lost both times, and still cheerfully comes to meetings—and in fact was on the nominating committee's list of potential candidates again this year. Did my friend accept the nomination? I hope so. But I worry about this. Losing an election, even one in which a 30% participation is regarded as a good turnout, can be really discouraging. Years ago a member who had contributed a lot all but disappeared after losing the presidency of the Society for Health and Human Values a second time. I thought a lot about that person when I was nominated 2 years ago, because it would be my second run. I had lost to Al Jonsen in a SHHV election back in the mists of time. It made me reluctant to put my name on the ballot again. Notice how quickly I name the person who won? Who remembers that I was the loser? Not even Al Jonsen, probably. So I said *yes*.

I'm convinced there's a kind of bravery, certainly a public-spiritedness, in participating in the life of an organization like ours. Those on the program, those who hold office, and those who volunteer for committees and task forces can claim those qualities. But they are equally, maybe especially, shared by those who submit proposals to the program or run for office and aren't picked but are still willing to try again the next time. Without them, where would we be?

Maybe in 2003 I'll finally put together a panel on clinical judgment and try my luck. 



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Fairness and the NIH Peer Review Process for Bioethics Research Grants

Laura A. Siminoff

Several years ago, the National Institutes of Health added three new Integrated Review Groups (IRGs). IRGs are clusters of study sections specializing in areas of the social and behavioral sciences and health services research. The three new IRGs were Social Sciences, Nursing, Epidemiology, Methods (SNEM); Biobehavioral and Behavioral Processes (BBBBP); and Risk, Prevention and Health Behavior (RPHB). Each included 4–7 study sections designed to encourage “nonbench” science applications. Within the SNEM-4 study section, a subcommittee was formed to review bioethics-related research.

How grant applications are scored

While bioethicists initially welcomed the SNEM-4 subcommittee as having expertise in bioethics, vagaries in the way its scores are calculated actually have put bioethics research proposals at a disadvantage.

A little history will explain the situation. The first score a grant application receives is a priority score—a single, global score. The best possible priority score is 100, and the worst is 500. Individual reviewers mark scores to two decimal places (e.g., 2.53). The individual scores are averaged and then multiplied by 100 to yield an overall score for the application (e.g., 253). It used to be that grants were funded based on the priority score, with the grants receiving the lowest scores having the best chance for funding.

Historically, study sections for the basic sciences have assigned scores less stringently than those for the applied sciences (e.g., epidemiology, the social sciences). Uneven scoring practices (e.g., some study sections use the entire range of scores, while others tend to cluster scores within a narrower band) meant that an application assigned to a particular study section had a built-in advantage or disadvantage. For example, 1.5 might be the best score assigned in one study section, but in another study section 1.5 might be only in the top one-third. Because of this factor, a direct comparison of the priority scores assigned to grants reviewed in different study sections consistently put research from the

applied sciences at a disadvantage in the competition for funding against grants from the basic sciences.

To compensate, it was decided that percentile rankings would be used to indicate the quality of grants *within* a particular study section. More than a decade ago, the Center for Scientific Review (CSR) began calculating percentile scores in addition to priority scores. Percentile ranking levels the playing field by scoring like grants against one another. Percentile rankings are calculated as follows: The conversion of priority scores to percentile rankings is based on scores given *by the study section that reviewed the application* from the current and past two review rounds. Thus, a grant that received a score of 156 from one study section might rank at the 5th percentile (i.e., the grant scored better than 95% of the applications reviewed by the study section), whereas the same priority score might rank in the 30th percentile in another study section. Final funding decisions are based on the percentile ranking, not the priority score.

The use of percentile rankings has created a system in which applications are judged, as much as possible, against true peer applications. It also ensures that applications from different disciplines are competitive with one another, even when scoring practices between study sections are disparate.

The system breaks down for bioethics research grants


Contrary to the guidelines outlined above, percentile rankings for grant applications reviewed in the SNEM-4 bioethics subcommittee are not compared only against other grants reviewed in that study section (as happens for almost all applications reviewed at NIH), or even all grants reviewed by SNEM IRG study sections, but against *all* applications received by CSR at NIH. CSR claims that the number of grant applications is insufficient for percentile comparison within the study section; it is not clear, however, why these grants are being compared against all grant applications.

Percentile ranking only works when grants are ranked against like grants. In

the case of bioethics, the grants are ranked against everything at NIH, including the basic sciences. The result is that bioethics grants are receiving very poor percentile scores. By contrast, grants reviewed in the other SNEM study sections are percentile-ranked only against one another. Thus, research that proposes to examine bioethical issues in medicine and health care and that is reviewed by the SNEM-4 subcommittee clearly is at a disadvantage.

When a grant application is not reviewed in comparison to its peers—as happens with bioethics grants reviewed in the SNEM-4 subcommittee—the principles and rationale of peer review are violated. Thus, while the establishment of this subcommittee should have been a positive development for our field, the aberrant way CSR calculates percentile rankings for grants reviewed by the SNEM-4 subcommittee actually discourages the development of empirical research in bioethics.

It is surprising and unfortunate that CSR is singling out a handful of applications to be scored in a way that violates the intent of the percentile-ranking mechanism. In so doing, bioethics research grants reviewed by the SNEM-4 subcommittee become the least competitive grants—less competitive than basic science applications and not even as competitive as those in the other applied sciences. This situation has had and will continue to have a chilling effect on the development of empirical research in bioethics.

Letters urging NIH to change the review process for bioethics applications in the SNEM-4 subcommittee can be sent to Dr. Robert Weller, Center for Scientific Review, Division of Clinical and Population-Based Studies, Room 3160, 6701 Rockledge Drive, Bethesda, MD 20892, Wellerr@csr.nih.gov. 

Laura A. Siminoff is professor of bioethics and oncology at Case Western Reserve University School of Medicine. She is the bioethics department's director of research and the director of the new PhD program in empirical bioethics.

Policy News from Washington

Felicia Cohn and Melissa Goldstein

Congress introduces patient safety legislation

Senators Jim Jeffords (I-VT), Bill Frist (R-TN), John Breaux (D-LA), and Judd Gregg (R-NH) introduced the Patient Safety and Quality Improvement Act (S. 2590) on June 5. The legislation, a congressional response to the 1999 Institute of Medicine report *To Err is Human*, would encourage the reporting, analysis, and prevention of medical errors by establishing legal protections for providers. The legislation establishes a framework for the voluntary reporting of medical errors to “patient safety organizations.” These organizations would have the option of voluntarily sharing their data with a national patient safety database linked to the Agency for Healthcare Research and Quality (AHRQ).

Specifically, the legislation

- recognizes AHRQ as the leader in patient safety for funding and disseminating patient safety research and establishes a Center for Quality Improvement and Patient Safety at AHRQ
- provides legal protections for information submitted voluntarily to patient safety improvement systems that are designed solely for the purposes of quality improvement and patient safety
- creates a National Patient Safety Database at CQuIPS that will consist of aggregate, deidentified patient safety information for education and dissemination
- requires AHRQ to work with experts in the field to develop a common format acceptable to healthcare providers for reporting patient safety data to the Patient Safety Database
- creates incentives for voluntary reporting systems that are nonpunitive and promote learning
- requires the Health and Human Services (HHS) Secretary to report to Congress regarding steps that should be taken to implement the adoption of safe practices.

The legislation does not affect current remedies for injured patients or limit patients’ access to their medical records.

A number of healthcare organizations

have expressed support for the legislation. Among them are the Association of American Medical Colleges, the Joint Commission for the Accreditation of Healthcare Organizations, the American College of Physicians–American Society of Internal Medicine, and the Institute for Healthcare Improvement.

Legislation to limit residents’ work hours

The federal government, through its Medicare program, spends approximately \$8 billion per year to train resident physicians in the United States. The long hours resident physicians work have raised concerns about patient care as well as the lives and health of resident physicians. Research indicates that sleep deprivation such as that experienced by residents results in cognitive impairment and that the excessive hours worked by resident physicians lead to higher rates of medical error, motor vehicle accidents, depression, and pregnancy complications. Resident physicians spend a significant amount of their time performing activities not related to the educational mission of training competent physicians. Consumer advocates, medical professional organizations, and medical educators suggest that the medical community has not adequately addressed the issue of excessive resident physician work hours.

To address these issues, U.S. Representative John Conyers Jr. (D-MI), introduced the Patient and Physician Safety and Protection Act of 2001 (H.R. 3236) on November 6, 2001. The bill was referred to the Subcommittee on Health on March 5, 2002. This legislation would establish specific limits on resident work hours, allow residents to file anonymous complaints regarding any violations, and impose financial penalties for noncompliance. Additionally, the legislation would appropriate “amounts as may be required” to help hospitals cover the costs of compliance. Specifically, the legislation would

- limit residents’ work hours to 80 hours per week
- limit the length of a single shift to 24 consecutive hours

- limit the length of emergency department shifts to 12 hours
- limit “on-call” shifts to no more than every third night
- ensure residents a minimum of 10 hours between shifts, at least 1 of every 7 days off, and one full weekend off per month
- provide for public disclosure of hospitals found in violation of work-hour limits
- instruct HHS, with help from the medical community, to develop regulations ensuring appropriate supervision of resident physicians
- provide for annual surveys of residents’ working conditions
- provide for anonymous resident complaints about work-hour violations
- provide for civil penalties for hospitals refusing to follow reasonable work-hour limits
- provide funds for additional hospital staff to relieve residents of the burden of noneducational activities.

On June 12, 2002, the Accreditation Council for Graduate Medical Education (the organization that oversees residency education) announced new limits on resident work hours, similar to those proposed in the legislation. The rules limit the resident work week to 80 hours and require 10-hour rest periods between shifts and 1 day off per week. In addition, the rules restrict “moonlighting” (patient care activities outside of the educational program) and require closer faculty supervision.

IOM releases second report on the uninsured

The Committee on the Consequences of Uninsurance of the Institute of Medicine (IOM) has issued the second of six reports reviewing the problems of uninsurance in the United States.

The first report, *Coverage Matters: Insurance and Health Care*, addresses the extent to which Americans are without coverage; identifies social, economic, and policy factors contributing to that situation; and describes the likelihood that members of certain population groups are without insurance. It provides an

overview of health insurance in the United States and examines barriers to health insurance coverage. The report debunks a number of popular misconceptions about health insurance coverage, identifies factors related to the loss of coverage, explains why so many people lack health insurance, describes the individuals and groups most affected, and provides data about the size and nature of the problem. It also establishes a conceptual framework for subsequent reports.

The second report, *Care Without Coverage: Too Little, Too Late*, examines the relationship between insurance status and the health of American adults. The committee examined the consequences of being uninsured in people suffering from cancer, diabetes, HIV infection and AIDS, heart and kidney disease, mental illness, traumatic injuries, and heart attacks among the approximately 30 million working-age Americans without health insurance. The over-65 population covered by Medicare and the almost 10 million uninsured children were excluded. The committee found that (a) the health of uninsured adults is worse than it would be if they were insured, (b) providing health insurance to uninsured adults would improve their health and life expectancy, and (c) increasing the numbers of insured adults probably would reduce health disparities among racial and ethnic groups by increasing access to care for those who are disadvantaged and in poor health.

The next three reports will address health and economic consequences of uninsurance for families, communities, and the nation. The final report will consider model strategies for addressing those consequences and identify policy criteria for assessing the features of alternative reform strategies. These reports are expected before the end of 2004. The text of the first two reports is available at www.nap.edu.

GAO releases study of financial conflicts of interest in research

The U.S. General Accounting Office (GAO) released the results of a study into how universities address financial conflicts of interest in biomedical research. The study, requested by Sen. Bill Frist (R-TN), found that current institutional systems for collecting and reviewing financial disclosure information vary widely, address different aspects of research and research relationships, and are not well integrated with human-subjects protections. In addition, confusion

exists about current reporting requirements (i.e., what conflicts must be reported and when reports must be made). GAO recommended that federal officials improve oversight and regulations governing financial conflicts of interest and that they help institutions identify and manage these conflicts. The five universities studied in the GAO investigation were the University of California, Los Angeles; University of North Carolina, Chapel Hill; University of Washington, Seattle; Washington University, St. Louis; and Yale University. The report, *HHS Direction Needed to Address Financial Conflicts of Interest*, is available online at www.gao.gov.

Further changes to HIPAA privacy regulations

HHS Secretary Tommy G. Thompson in March proposed changes to the health privacy regulations adopted in December 2000 after extended government and public review by the Clinton administration, submitted to further public comment by the early Bush administration, and finally put into effect in April 2001. Thompson stated that the current changes are aimed at ensuring strong privacy protections while correcting what the Bush administration views as unintended consequences threatening patients' access to quality health care. HHS will consider public comments on the proposed changes before issuing a final rule. The proposal would make the following revisions, among others:

- **Strengthen notice provisions and remove prior-consent requirements.** The administration fears that the privacy rule's general requirement that patients give consent on privacy practices before receiving treatment is creating serious unintended consequences that interfere with patients' access to health care. To fix these problems, the proposal would remove the consent requirement for treatment, payment, and healthcare operations that could interfere with efficient delivery of health care, while strengthening requirements for providers to notify patients about their privacy rights and practices. Patients would be asked to acknowledge the privacy notice, but doctors and other providers could treat them if they did not.
- **Maintain the "minimum necessary" rule, while allowing treatment-related conversations.** The Bush administration is concerned that,

because the privacy rule covers oral communications and limits the use of personal health information to the "minimum necessary," routine conversations between doctors and patients, nurses, and others involved in a patient's care could violate the rule. HHS's proposed changes stipulate that, as long as a covered entity meets the "minimum necessary" standards and takes reasonable safeguards to protect personal health information, incidental disclosures (e.g., another patient's hearing a snippet of conversation) would not be subject to penalties. Disclosures classified as "improper" would still violate the rule.

- **Ensure appropriate access by parents to their child's records.** The administration believes the current rule may unintentionally limit parents' access to their child's medical records. The proposal clarifies that state law governs disclosures to parents, but in cases in which state law is silent or unclear the revisions would permit a healthcare provider to use discretion to provide or deny a parent access to such records.
- **Prohibit use of records for marketing, while allowing appropriate communications.** In response to consumer groups' concerns that the marketing provisions were ineffective to protect patient privacy, the proposal would explicitly require pharmacies, health plans, and other covered entities to obtain an individual's specific authorization before sending any marketing materials.

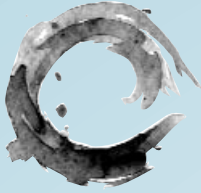
NIH posts Human Embryonic Stem Cell Registry

On August 9, 2001, President Bush announced his decision to allow federal funds to be used for research on existing human embryonic stem cell lines as long as, *before* the date of his announcement, (a) the derivation process (which commences with the removal of the inner cell mass from the blastocyst) had been initiated; and (b) the embryo from which the stem cell line was derived no longer had the possibility of development as a human being.

In addition, the President established the following criteria:

- The stem cells must have been derived from an embryo that was created for reproductive purposes.
- The embryo must no longer be needed for these purposes.

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American Society for 2001-2002

Task Forces, Surveys, and Debates

ASBH's year was marked by the completion of a significant number of unique projects that were coordinated and managed by a variety of task forces developed under the direction of the ASBH Board of Directors.

Positions Debate

The debate on whether ASBH should take or endorse positions will conclude in September 2002, as the question will be put to the members in the form of proposed bylaws revisions. This debate has been a focus for the board since the 2000 Annual Meeting in Salt Lake City. The board of directors, working with a task force of past, present, and future ASBH presidents, has narrowed the options to two, which will be explained in documents and a ballot included with the 2002 election materials.

Status of the Field

The Status of the Field Committee, chaired by Les Rothenberg and staffed by Mark Aulisio, issued its report, *North American Graduate Bioethics and Medical Humanities Training Program Survey*. The report was developed from a survey of bioethics and medical humanities programs at medical schools, graduate schools, and other institutions designed to find out, among other things, where bioethicists and medical humanists are being trained; whether they have educational stipends and, if so, in what amounts; and where and in what capacity they find employment after receiving their degrees, finishing their fellowships, or completing comparable activities. The full report is available on the ASBH Web site, www.asbh.org/taskforce. The project was generously supported by a grant from the Greenwall Foundation.

Member Survey

Preliminary results of the survey of members on a variety of issues were reported at the 2001 annual meeting by Betty Wolder Levin, chair of the Member Survey Task Force.

Ethics in Public Health

The first topic for the Ethics in Public Health Task Force, chaired by Steven Miles, was healthcare reform and universal access. The task force has produced an extensive report that was widely circulated for comment and input and now is available on the ASBH Web site, www.asbh.org/taskforce.

Biotech/Pharmacology and Bioethics Consultancy

In partnership with the American Society for Law, Medicine, and Ethics, supported by a grant from the Greenwall Foundation, and chaired by Baruch Brody, this task force explored the role of consultants in bioethics for biotechnology and pharmaceutical companies. The complete report was published in the May-June 2002 issue of the *Hastings Center Report*.

Disability Issues

Chaired by Adrienne Asch, the task force developed recommendations that will be published on the ASBH Web site

(www.asbh.org). The report addresses two topics: removing barriers to the full participation of interested persons with disabilities in ASBH activities; and ensuring that more discussion of disability, from differing perspectives, finds its way into ASBH meetings and into the education of people in bioethics, medical humanities, and the health professions.

Membership

The ASBH "Member-Get-a-Member" campaign that began in 2001 has generated 65 new members. They were referred by 54 current ASBH members who received recognition in the form of coffee mugs, T-shirts, and hats.

Annual Meetings

The 2001 ASBH Annual Meeting followed the tragic events of September 11, 2001, by just 6 weeks. Nearly 600 attended the meeting. A special presentation, "Ethics and Humanities After 9-11-01: A Town Hall Meeting," was added.

The 2002 ASBH Annual Meeting will be held October 24-27 at the Wyndham Baltimore Inner Harbor in Baltimore.

Affinity Groups

The affinity groups have grown remarkably during the past several years, to become one of the most active areas of ASBH. Current affinity groups and their primary contacts are listed below.

All affinity groups are offered time and space to meet during the annual meeting, and several have established an e-mail discussion group to foster communication throughout the year.

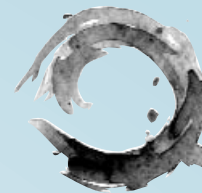
Affinity Group

Dental Ethics
Disability and Rehabilitation Ethics
Environmental Bioethics
History of Medical Ethics
Hospice and Palliative Medicine
International Network on Feminist Approaches to Bioethics (FAB)
Jewish Bioethics
Law and Bioethics
Literature and Medicine
Nursing
Organization Ethics
Osteopathic Medicine
Philosophy
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Bioethics and Humanities Annual Report



Committees

ASBH committees elected or appointed during 2001 and 2002 are as follows:

Committee	2001 Chair	2002 Chair
Affinity Groups	Pam Miya	Pam Miya
<i>ASBH Exchange</i>	Hilde Nelson (Editor)	Hilde Nelson (Editor)
Awards	Thomas Murray	Laurie Zoloth
Finance	Courtney Campbell	Jaqueline J. Glover
History	Chester Burns	Chester Burns
Nominations	David Doukas	Larry Churchill
Program	Tod Chambers, Suzanne Holland, John Lantos	Kristi Kirchner, James Lindeman Nelson
Web Site	Tom Tomlinson	Mark Kuczewski

Awards

ASBH Lifetime Achievement Award: The ASBH Lifetime Achievement Award recognizes a person whose outstanding contributions and significant publications have helped shape the direction of the fields of bioethics and humanities. The award recipient makes a major presentation at the ASBH Annual Meeting. Recipients are as follows:

2002	Ruth Macklin
2001	Daniel Callahan
2000	John Fletcher
1999	Albert R. Jonsen
1998	Edmund Pellegrino

ASBH Distinguished Service Award: The ASBH Distinguished Service Award recognizes outstanding and dedicated service to the American Society for Bioethics and Humanities. Recipients are as follows:

2002	Betty Wolder Levin, Les Rothenberg
2001	David Barnard, Marion Secundy, Tom Tomlinson
2000	Robert Arnold, Steven Miles, Stuart Youngner
1999	Loretta Kopelman

Financial Summary

ASBH concluded its fourth year of operations (fiscal year ending December 31, 2001) with a loss in net operating revenue. The audited financial results are as follows:

Income Statement	2001	2000
Revenue	\$340,104	\$310,902
Expenses	<u>\$375,539</u>	<u>\$337,505</u>
Excess of revenue over expenses	(\$35,435)	(\$26,603)

Balance Sheet	2001	2000
Assets	\$191,779	\$197,955
Liabilities		
Accounts payable	\$28,726	\$13,762
Deferred membership dues	\$65,577	\$36,741
Deferred revenue (grant)	<u>\$8,334</u>	<u>\$22,875</u>
Total liabilities	\$102,637	\$73,378
Fund balance	<u>\$89,142</u>	<u>\$124,577</u>
Total liabilities and fund balance	\$191,779	\$197,955

Assets: The society's assets of \$191,779 at year end consisted primarily of cash and equivalents (\$164,650), accounts receivable (\$13,491), and prepaid expenses (\$11,320).

Liabilities: Accounts payable (\$28,726) included outstanding invoices, primarily from the 2001 annual meeting. Deferred membership dues (\$65,577) represent dues received in 2001 but deferred to 2002 to reflect the 12-month anniversary system (in which membership runs for 1 year from the date joined rather than for a calendar year).

Fund balance and reserves: Cash reserves at year end included the fund balance of \$89,142 plus the deferred membership dues of \$65,577 for a total of \$154,719. This sum is equivalent to 43% of the 2002 operating expenses budget of \$355,716. ASBH's financial position, reflected in total cash reserves, is slightly below the standard benchmark, which is an average of 50% for individual-member healthcare associations with budgets under \$2 million, as reported by the American Society of Association Executives.

A Tour of Dissertations

Jonathon Erlen and Kelly Fryer-Edwards

"A Tour of Dissertations" provides a partial listing of the dissertations published each year addressing bioethics and medical humanities issues. Space limitations prevent us from listing all of the work completed in a given quarter, but we will try to select dissertations that appeal to the diverse interests of ASBH membership. A more complete listing of bioethics and medical humanities dissertations, sorted by topic, can be found on the University of Pittsburgh Health Sciences Library System Web site, www.hsls.pitt.edu/guides/histmed/dissertations.

- Brinkmann, Elisabeth.** (2001). *Embracing the deficient body: Alternative responses to infertility*. Boston College. [Theology; Medicine and Surgery]
- Conneen, Sheila Lenora.** (2001). *Talking with the dying: An ethnographic study of an educational intervention regarding narrative competency and communication between physicians and dying patients*. University of New Mexico. [Education, Sociology of; Medicine and Surgery; Speech Communication]
- Cook, Ann Freeman.** (2001). *A rural perspective on modern bioethics*. University of Montana. [Philosophy; Health Care Management]

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- Kurtz, Kathleen Susan.** (2001). *Medical ethics decision-making in three hospitals: A look at dilemmas, decision-makers, and the practice of clinical ethics*. Syracuse University. [Sociology; Health Care Management]
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- women who have been circumcised*. Massachusetts School of Professional Psychology. [Psychology, Clinical and Social; Medicine; Nursing; Women's Studies; Speech Communication]
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- White, Sanford Dale.** (2001). *A microethnography of secondary traumatic stress in hospice culture*. Florida State University. [Social Work; Mental Health; Anthropology, Cultural]

Jonathon Erlen was responsible for the initial culling of material from the printed version of Dissertation Abstracts. He is curator, History of Medicine, Health Sciences Library System; assistant professor, Graduate School of Public Health; and affiliated faculty in the Center for Bioethics and Health Law, all at the University of Pittsburgh. Kelly Fryer-Edwards is assistant professor, Department of Medical History and Ethics, University of Washington School of Medicine in Seattle.

New Books, Videos, Etc.

David Orentlicher

We have three new books and one new videotape to announce. We look forward in future issues to highlighting your books, videos, and other publications (other than articles, which are the subject of "A Bibliographic Tour"). Please let us know about them when they become available to the public.

To notify us of the publication of either your own work or that of someone else, contact David Orentlicher at dorentli@iupui.edu or Indiana University School of Law-Indianapolis, 530 W. New York Street, Indianapolis, IN 46202-3225.

- Cameron, Miriam E.** (2001). *Karma and happiness: A Tibetan odyssey in ethics, spirituality, and healing*. Minneapolis: Fairview Press (www.fairviewpress.org/ViewBook.asp?BookID=150).

- Koch, Tom.** (2001). *Scarce goods: Justice, fairness, and organ transplantation*. Westport, CT, and London: Praeger Publishers (www.greenwood.com/books/BookDetail.asp?dept_id=1&sku=C7432).
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- Strauss, Kenneth.** (2002). *La tendresse*. Forfar, Scotland: Black Ace Books (www.blackacebooks.com).

David Orentlicher is Samuel R. Rosen Professor of Law, codirector of the Center for Law and Health, Indiana University School of Law-Indianapolis, and a member of the core faculty of the Indiana University Center for Bioethics.

ASBH Job Listing Service

The e-mailed ASBH job listing service is a membership benefit available to all ASBH members who have e-mail addresses on file. If you haven't yet received the bimonthly list, contact Terrie McKissack (tmckissack@amctec.com, 847/375-4784) to add your current e-mail address to the ASBH Database.

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A Bibliographic Tour

Les Rothenberg

Because of space limitations, the format is a listing rather than a review but includes mail or e-mail addresses to facilitate reprint requests. Suggestions of your own work or that of others, as well as any suggestions for improving the column, are enthusiastically solicited. Please contact Les Rothenberg by e-mail (lrothenberg@mednet.ucla.edu) or snail mail (UCLA Department of Medicine, Box 951736, Los Angeles, CA 90095-1736). An alphabetized list of all references in this and past columns can be found on the ASBH Web site at www.ASBH.org/exchange/biblio.htm.

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L.S. Rothenberg is in the division of medical genetics, UCLA Department of Medicine, Los Angeles, CA.

A Reciprocity Obligation to Donate Cadaveric Organs

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an absence of expressed dissent is a statistically valid proxy for agreement. But this argument is vulnerable, and not simply because the data are shaky. Where rigorous standards are not met and proxy validity cannot be maintained, the implication is that opting out is unjustified in principle.

To proceed with organ donation without direct or statistical evidence of the donor's consent would violate the autonomy principle—and, in this society, that settles the matter. It probably is a mistake to grant this trump to autonomy. Autonomy is only one value among many to be respected, although the presumed-consent rhetoric has long obscured this pluralism. Instead, the relevant test should be whether the state and public interest in healing the gravely ill outweighs whatever disutility is imposed by compelling organ donation from the bodies of people whose dissent was of insufficient magnitude or salience to motivate them to express it. Obstacles to communicating one's preferences should be acknowledged (e.g., the aversion of Old Order Amish to signing forms). Such complications notwithstanding, maximizing the social welfare function probably will require a price in autonomy.

Such a balancing of values already is embodied in the coroner-release provisions of the 1968 and 1987 UAGAs (Liddy, 2001). It also is broader U.S. public health policy to weigh autonomy against competing major interests. For example, mandatory vaccine policies are on the books in 42 states; a child commonly is required to undergo 22 injections before entering first grade (Association of American Physicians and Surgeons, 2002). Therefore it is anomalous to insist on the right to absolute control over bodily integrity in organ donation.

An alternative tack

In the United States, a viable opt-out regime probably is a political non-starter. The evocative power of autonomy is too great a barrier. Yet in a healthcare system facing ever-rising pressures to ration care, a model of organ transplantation that deems all citizens to be eligible recipients but only the few volunteers to be eligible donors looks increasingly anachronistic. I propose an alternative tack: The opt-in system should be revised to

incorporate a reciprocity obligation to donate cadaveric organs.

When people get sick, they confidently expect society to use all technology and expend every resource, bar none, to make them well. Included, of course, is full access to transplantable organs—or at least a fair opportunity to receive the needed organ. The institution of medicine shapes the contours of people's lives, enabling them to pursue the goods and values of their own choosing. All citizens are beneficiaries of this infrastructure and ought to consider themselves duty bound to share the costs of maintaining it. As Callahan (1987) observes, people “owe to those coming after [them] at least what [they] were given by those who came before...the possibility of life and survival.” Ensuring the availability of effective transplantation services in the United States requires mutualism. To deny the reciprocal obligation to donate is to miss that, like it or not, we all live embedded in the larger community. It also represents a free-rider problem abhorrent to ordinary notions of fair play.

**The gift model
of organ procurement has
magnificently failed to satisfy
the rising demand for
transplants.**

Finding balance

Every ethical obligation need not be legally enforced, but in organ transplantation the rare symmetry of contribution and benefit should be leveraged. The UAGA has codified and institutionalized a model of cadaveric organ donation as supererogatory. Correcting this error means coming to understand that opting *in* is giving consent for both a benefit and a burden—for transplant eligibility bundled with organ-donor status. It scarcely impinges on autonomy to refuse to grant an entitlement if a closely related social obligation is not met. Health care routinely is denied for less sensible reasons, such as the ability to pay.

Operationalizing this reciprocal-duties version of opting in could require that,

upon reaching legal age, a person would have to elect to accept or decline transplant services (e.g., by checking a box when initially signing up for health insurance). Consent to donation would be embedded. Educational steps would be essential during the transition, and minors would have to be excepted. By expecting full participation from those who wish to be eligible for benefits, a new opt-in scheme could increase the supply of transplantable organs while reminding people of the scope of their ethical obligations.

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Professional Opportunity

Distance-Learning Master's in Bioethics Program

At the request of health professionals in upstate New York, Albany Medical College and Union College have formed a consortium with other Northeast institutions to offer an online Master's Degree Program in Bioethics. The curriculum is modeled on the American Society for Bioethics and Humanities' *Core Competencies for Health Care Ethics Consultation* and is designed for working healthcare administrators, lawyers, nurses, pharmacists, physicians, research scientists, and other professionals

seeking further education and professional involvement in bioethics. The 3-year degree involves 12 courses: three are 2-week intensive summer courses and practica, and nine are taught by distance learning.

After a successful local offering in 2001–2002, the program is now inviting applications without geographical restriction. Each year's program commences with a 2-week intensive August proseminar at Albany Medical College taught by Robert Baker (Union), Jane Greenlaw (University of Rochester), Susan Lederer (Yale), Laurence

McCullough (Baylor), Wayne Shelton (Albany Medical College), and Robert Veatch (Kennedy Institute of Ethics, Georgetown). Enrollment is limited, and applications are reviewed in the order received.

Student loans and occasional research support are available, as is a fellowship for students with a degree in pharmacy. For applications and further information see www.bioethics.union.edu or contact Ann Nolte, Administrator, Center for Bioethics, Union College, Schenectady, NY 12308, 518/388-8045, bioethics@union.edu.

Policy News from Washington

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- Informed consent must have been obtained for the donation of the embryo.
- No financial inducements can have been provided for donation of the embryo.

The National Institutes of Health (NIH) has created the Human Embryonic Stem Cell Registry, which lists the human embryonic stem cell lines, at varying stages of development, that meet the eligibility criteria. The list is posted at <http://escr.nih.gov>. Seventy-two lines are listed, some of them subclones of previously announced lines; this number may change depending on new applications. In light of the President's criteria, NIH has withdrawn several of its guidelines for the use of human embryonic stem cells, deeming them no longer necessary.

Investigators or institutions who have additional human embryonic stem cell lines that they believe are eligible for listing on the registry can contact NIH at dder@nih.gov. Instructions for preparing requests for funding of research using human embryonic stem cells can be found at <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-02-006.html>. Investigators are requested to use the NIH codes in their grant applications to identify the cell lines to be used.

Felicia Cohn is director of medical ethics education at the University of California, Irvine College of Medicine. Melissa Goldstein is an attorney with Skadden, Arps, Slate, Meagher & Flom in Washington, DC, and an instructor at George Washington University.

Calendar of Events

December 9–12, 2002

Ethics in Research: An Intensive Training Course Focusing on Behavioral Health Sciences

Sponsor: University of South Florida, National Institutes of Health

Location: St. Petersburg, FL

Contact: www.fmhi.usf.edu/mhlp/ethics/ethics.html

March 31–April 2, 2003

Death Without Suffering: Ethical Issues of Palliative Care

Sponsor: University of Nijmegen

Location: Nijmegen, The Netherlands

Contact: Norbert Steinkamp, n.steinkamp@efg.kun.nl

April 4–6, 2003

Clinical Ethics Consultation: First International Assessment Conference

Sponsor: Department of Bioethics, Cleveland Clinic Foundation

Location: Cleveland Renaissance Hotel, Cleveland, OH

Contact: www.clevelandclinic.org/bioethics

October 23–26, 2003

ASBH 6th Annual Meeting

Sponsors: ASBH, Canadian Bioethics Society

Location: Wyndham Hotel, Montreal, QC, Canada

Contact: ASBH, 847/375-4745, info@asbh.org, www.asbh.org

Bioethics in the First Person

ASBH Spring Meeting in Chicago

Cosponsored by Northwestern University

Friday, April 11–Sunday, April 13, 2003

Plenary speakers: Paul Lauritzen, Sue Rubin, Hilde Lindemann Nelson, Jane Greenlaw, and Timothy Quill

Deadline for submission of abstracts (250 words): January 10, 2003

Possible topics: The moral authority of personal narrative, voice in ethics cases, patients' documentary videos, feminist epistemology, who may tell patients' narratives?, ethnography of ethics consultation, particularity in moral reasoning, self-reflexive bioethics

For more information: Kathryn Montgomery, kmontgomery@nwu.edu



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- The Theory and Practice of Clinical Ethics: Charting the Course for Effective Ethics Consultation
- Codes of Ethics: Understanding the History and Writing of Codes of Ethics

Plenary Sessions

- The Impacts of Racism on Health
Camara Phyllis Jones
- Protection or Disrespect: Courts and the Conscious Incompetent Patient
Rebecca Dresser
Michael Bérubé
Lawrence Nelson

Lifetime Achievement Award Presentation

Ruth Macklin

Arts Events

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- Photography Exhibit and Lecture: 'Vignettes from Life and Death'

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