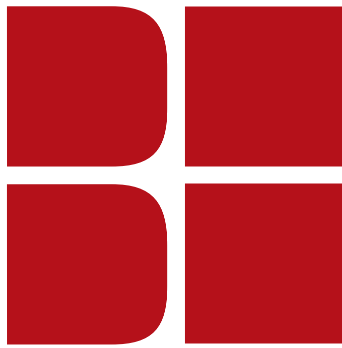

ASBH EXCHANGE

Fall 2007 • Volume 10, Number 3

Analyzing the Best Interests Standard

Loretta M. Kopelman

The best interests standard is a widely recognized guidance principle for making decisions for those lacking decision-making capacity. For example, the United Nations states "Article 3: In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities, or legislative bodies, the best interests of the child shall be a primary consideration" (United Nations Office of the High Commission for Human Rights, 1989). Many important policies also recommend using the best interests standard in making decisions on behalf of others including those of the Institute of Medicine in setting research policy for children (Institute of Medicine, 2004) and the President's Council on Bioethics in selecting care for the nonautonomous elderly (President's Council on Bioethics, 2005).

This guidance principle, however, is complex and can have different meanings when used in different contexts. It is sometimes used to express ideals or goals about what is best, such as "Every child should have a good home," and sometimes to make practical decisions, typically in less than optimal circumstances. For example, clinicians have to consider the available resources and needs of many patients in deciding the best option for a particular patient. It may be best for someone to receive a kidney for transplantation, but if others have greater need, the person may have to settle for dialysis until a kidney becomes available. When used to make practical decisions, this standard requires not what is ideal but what is reasonable given the options.

The best interests standard has both objective and subjective features (Kopelman, 1997). It has *objective* features in the sense that decision makers (typically family members) have certain duties when acting on behalf of others. They are not permitted to abuse, neglect, or endanger those for whom they make decisions. Acceptable choices are judged according to considered medical, scientific, and legal judgments, policies, and duties. Parents who believe herbal therapies are adequate to treat their child's bacterial pneumonia are endangering their child on objective grounds. The best interests standard also has *subjective* features in the sense that decision makers' values and views shape their decisions. Some families decide that comfort care is the best course for their dying relative, although others want to pursue every available path to extend life even for a short time.

When used to make practical decisions, I have argued elsewhere, the best interests standard may be analyzed into three necessary and jointly sufficient conditions (Kopelman, 2005, 2007).

First, decision makers should use the best available information to assess the incompetent or incapacitated person's immediate and long-term interests and set as their prima facie duty the option that maximizes the person's overall or long-term benefits and minimizes burdens.

This condition is relatively easy to use when informed people of good will agree about what information is salient, which values are relevant, and how to rank the potential benefits and risks (including their nature, probability, and magnitude). If a child has bacterial pneumonia, there is overwhelming agreement that he should be treated immediately. In some cases, however, it may be difficult to reach agreement about how to rank potential benefits and risks. Clinicians and families sometimes disagree about, for example, whether certain lifesaving interventions are appropriate because they place a different value on extending the life of someone who is permanently unconscious. Because of the difficulties of resolving certain disputes about how to rank potential benefits and risks, some individuals have charged that the best interests standard is vague. Yet it is no vaguer than other guidance principles once it is seen that this first condition has objective as well as subjective features and is not the whole story; two other necessary conditions exist that also offer guidance in disputed cases.

Second, decision makers should make choices for the incompetent or incapacitated person that must meet at least a minimum threshold of acceptable care; what is at least good enough is usually judged in relation to what reasonable and informed people of good will regard to be acceptable were they in the person's circumstances.

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Letter from the President

Announcing the ASBH Forum

Paul Root Wolpe

One of the advantages of being ASBH President is the ability to write a series of presidential columns and tell the membership what is on my mind. For the members, though, there is no similar forum. How can the thoughtful and creative members of ASBH debate issues of importance to the society, give quick and easy feedback to the board, and discuss current events or scholarships in bioethics and the humanities with their ASBH peers? Soon there will be a way.

I am happy to announce the establishment of the ASBH Forum. The ASBH Forum will allow members to send messages to the ASBH board and to each other, and to easily opt in or opt out of the list.

The ASBH Forum will serve both as the main conduit for ASBH business and as a lively online community of scholarly discourse. It will serve a number of important functions.

First, it will allow us to discuss issues of importance to the organization. For example, in his Winter 2006 column in *ASBH Exchange,* Matt Wynia discussed the ongoing debates about ASBH taking public positions as an organization. (To access this article, visit the *ASBH Exchange* Web site at www.asbh.org/publications/exchange.html.) The bylaws as they now exist seem ambiguous to some, which makes it difficult for the board to agree on when and how it has authority to speak for the society. But how can the membership have an ongoing, robust debate about whether ASBH should take stands and what kinds of stands it should take? Clearly, the ASBH Forum is the perfect place to debate the issue. In fact, I propose that we make the issue of taking stands the "beta test" of the ASBH Forum. After the service is up and running, let's tackle that issue as a society once and for all.

Second, the ASBH Forum will provide an opportunity for you to give feedback to the board on whatever issues are of importance to you. The board is willing to listen to the ideas and concerns of the members.

Third, the innovative design of the ASBH Forum will allow the creation of subforums. Some affinity groups may want to have their own discussion groups for ease of communication among members in their interest area, and forums could be set up for particular fields of study like the history of bioethics, illness narratives, or informed consent.

The ASBH Forum will allow members to talk to one another about issues. One of the great strengths of ASBH is its diverse membership. The ASBH Forum will be a place for members to discuss literature, current events, policy, politics, clinical care, or whatever topics excite interest. I hope that such discussions will generate session proposals for the annual meeting, scholarly collaborations among members, ideas for improvement of our society, and even petitions for the board to take public positions.

The ASBH Forum will be managed by a simple, clean Web page. You will be able to sign up for the types of e-mails you want on an intuitive one-touch Web page to manage your subscription. You will be able to join the forum(s) or cancel them with a simple click of a button.

The ASBH Forum should be up and operational before this year's annual meeting. All members with e-mail addresses will be automatically enrolled in the forum, and you will receive an e-mail informing you when the service begins. Of course, you will have the opportunity to opt out of the service itself, but I hope you choose to give it a try. I have a feeling the ASBH Forum will quickly become an indispensable part of the society and a central resource for the intellectual life of scholars in bioethics and the medical humanities.

And one last thing—Please remember to recruit one new member to ASBH before the annual meeting. We are depending on you!

Paul Root Wolpe is a senior fellow of the center for bioethics and teaches in the departments of psychiatry, medical ethics, and sociology at the University of Pennsylvania, Philadelphia, PA.

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Challenges and Successes of Multidisciplinary Collaborations

Daniel Salmon

I am an epidemiologist and health services researcher who has recently had the pleasure of working with several ethicists and bioethicists on issues surrounding influenza pandemic planning. The work was funded by a state health department, and our multidisciplinary team included people with training in infectious disease epidemiology, vaccines, public health practice, philosophy, law, ethics, and bioethics. Through the project, I participated in some of the most intellectually stimulating conversations I have had professionally. Ultimately, our endeavor was highly productive as we developed several manuscripts that should be very useful for pandemic planning. I have been asked to share a bit about this experience, and what follows includes some of the challenges and opportunities inherent in this sort of multidisciplinary work.

The ultimate objective of biomedical science is to improve the health of individuals and populations. Thus, science must be translated into policy and practice. Good policy is, or at least should be, evidence based, yet many challenges arise when people are developing and implementing policy. Among these challenges are a wide array of ethical dilemmas. Often, those individuals who are only mildly aware of ethics think of the ethical implications of policy and practice in dichotomous terms—either this is or is not ethical. This simplistic thinking is typically a result of lack of understanding or expertise. Ethicists have a critical role in the translation of science into policy and practice. The complexities of this process require persons trained to understand and explain the complexities of the ethical dimensions. Ethicists have an extremely important role in health policy and practice, and we need teams of scientists, practitioners, policy makers, and ethicists who can work well together.

From the beginning of our collaborations it became clear that we were often speaking slightly different dialects of a similar language. Our use of terms was often different, and at times, this led to a bit of miscommunication. However, exploring the differences in language use ultimately led to a better understanding and appreciation for each other's disciplines. For example, a discussion of a *social environment* would conjure specific concepts in my own discipline, and in the field of bioethics this term might refer to broader considerations that include human interactions.

There were fundamental differences in the funding related to the project. Epidemiologists and ethicists have very different perspectives on the scope of funding necessary for projects. Nearly all of my funded research includes primary data collection and consequently funding "worth consideration" must be in the six- to seven-figure range. Yet the needs of our group were rather modest compared to research involving primary data collection. The comparatively small funds we required were used for a modest amount of salary support and limited travel. Although my medical college frowned at accepting such a small contract, the institutions of the ethicists were very excited to see externally funded salary support. Of course, the ethicists with whom I worked hold positions for which teaching is a large part of the job descriptions. The same would not be true for bioethicists who must fund their own salaries with extramural support. Nevertheless, in our case, these differences in the points of reference for funding scope offer opportunities for ethical work, which seems very reasonable on the biomedical financial scale.

There were also some differences in disciplines in the publication of manuscripts. Having published almost entirely in the biomedical literature, I found noticeable differences in article length, style, and authorship. I am accustomed to about 3,500 words for a manuscript and references (author, journal, date) at the end of the article without any discussion of the points. The ethics style allows far more discussion given the possibility for much longer articles and the use of footnotes, as is often the case with legal articles, and is very different from the style of biomedical literature. We needed to decide which type of journal to submit to (biomedical or ethics) and, clearly, each author's peers would understand and appreciate a publication in their field's journals more than a publication in a different field. Fortunately, our work resulted in several publications, allowing us to submit to both biomedical and ethics journals, with the primary decision based on the optimal target audience.

Perhaps a more difficult challenge without an easy solution relates to the number of authors. In biomedical research, it is common to have multiple coauthors. In the fields in which my collaborators work, having five or six coauthors is highly unusual and can be perceived as diminishing the role of the first author. In our situation, we agreed from the beginning that authorship would be shared among the group. This was acceptable to the ethicists because they had already reached such a level of professional achievement that the number of authors was perhaps less important than it would be for more junior collaborators. However, the issue of authorship could pose significant hurdles for other teams, particularly teams including people with junior academic appointments.

Our multidisciplinary research team encountered some fundamental challenges, but these challenges also afforded us opportunities, and solutions were often fairly easy to find. The overall experience was outstanding from the perspective of a researcher and was seemingly a rewarding experience for the ethicists as well.

Daniel Salmon was most recently associate professor of epidemiology and health policy research at the University of Florida, Gainesville, FL. His areas of interest and expertise include infectious disease/vaccine epidemiology, health services, and policy research. He is widely considered the national expert on mandatory immunizations and the impact of nonmedical exemptions and has contributed to the development and evaluation of federal policies and programs to ensure the safety of vaccines, postlicensure.

How do you use the texts and methods of the humanities disciplines in your teaching of medical humanities, bioethics, or any other healthcare courses? We would like to share your ideas in the newsletter. Send a concrete description of a particular class or exercise that you have found effective to Catherine Belling at c-belling@northwestern.edu.

Do Not Go Gentle: Using Poetry in Teaching Bioethics

Felicia Nimue Ackerman

In the 1990s, Daniel Callahan remarked that high-tech, life-prolonging medical treatment for the dying is "universally decried these days" (Callahan, 1995, p. S34). While "universally" is an exaggeration, Callahan is correct about the general direction of the conventional wisdom. Bioethics courses should encourage students to question the conventional wisdom. I have found literary texts, including some I wrote myself, useful in alerting my students to the nuances of decision making toward the end of life.

Fiction and poetry engage readers emotionally, which helps open them up to outlooks they might otherwise reject. Students enjoy stories and are apt to retain ideas gleaned from them. Case studies of actual patients sometimes provide these benefits, but real-life cases cannot be produced at will for all bioethical twists and turns worth considering. Furthermore, real people are not always willing and able to provide the window into their inner lives that is so valuable in producing insight and empathy.

Acceptance of death is famously resisted in Dylan Thomas's magnificent "Do Not Go Gentle into That Good Night," which exhorts the elderly to "rage against the dying of the light." Thomas wrote the poem in 1951. More than half a century later, the old or terminally ill can do more than rage. They can seek the high-tech life-prolonging or experimental curative treatment that Callahan suggests is so undesirable. Here is a poem I wrote about someone who does that (Ackerman, 2006b).

This Is for My Grandmother

This is for my grandmother, Carolyn Colby.
"Terminal cancer," the doctor said. His eyes filled with tears.
"I'll get you the best hospice care in Boston." He put his arm around her.
My grandmother's eyes were cloudy but dry.
She said, "I'm 84, I've had a good life, so I don't want to die.
I want experimental treatment."
"That would ruin the time you've got left," the doctor said.
My grandmother said, "I'll risk it," and she did
And died of a stroke
On her 93rd birthday.

Hospice care has traditionally meant palliative care instead of medical treatment aimed at prolonging life. Recently, "open access" has allowed some patients to combine hospice care with high-tech, life-prolonging medical treatment, but hospice care often still promotes accepting death rather than prolonging life. This can seem paradoxical in view of hospice care's emphasis on making patients' lives comfortable, pleasant, and even meaningful. As long as a patient's life has these desirable qualities, why wouldn't the patient want to prolong it rather than accept death? Like the doctor in my poem, hospice personnel stress that many life-prolonging treatments are painful or otherwise harmful to patients' quality of life. But some treatments, such as antibiotics for pneumonia, generally are not harmful.

There are patients, like the woman in the poem, who choose to sacrifice some comfort in return for a chance at longer life. The poem challenges the clichéd thinking that follows "I've had a good life" with "I'm ready to die." Surely, it is at least as logical for "I've had a good life" to be a reason for saying "I want to prolong it." The poem's reference to "my grandmother" invites the question of whether this poem is about my actual grandmother, which often leads to speculations about whether my personal tie might have affected my view of her situation. I end such speculations by answering that Carolyn Colby is not modeled on any of my relatives or even acquaintances.

Healthy young students sometimes have trouble realizing that sick old people can still have good lives. I wrote the following poem partly in order to challenge hasty quality-of-life judgments (Ackerman, 2006a).

Henrietta Pratt, 80, Has a Surprise for You

I seldom go outside my door.
I'm 80 and can barely walk.
The girl upstairs thinks that's so sad,
She's always dropping by to talk.
Her thoughts are shining in her face:
"Poor thing, she's old and all alone
And grateful for the company
She never could get on her own."
She doesn't know that all my friends
Are with me in a better place.
There's neither old nor young nor ill
Nor healthy, here in cyberspace.

Because this poem recapitulates one of my short stories (Ackerman, 2005), I have evidence about how the two compare in generating bioethical discussion. The story has the advantage of presenting more developed characters, which promotes empathy. The poem focuses on the bioethical issue, which helps to keep discussion on track. The surprise ending of each helps fix in students' minds this way of questioning conventional wisdom.

Felicia Nimue Ackerman is professor of philosophy at Brown University. Her poems, short stories, and essays appear in various publications including English Studies Forum, Prize Stories 1990: The O. Henry Awards, *and* The Oxford Handbook of Bioethics. *She is preparing a book of her bioethics short stories and essays,* Bioethics Through Fiction, *for the Rowman & Littlefield series,* Explorations in Bioethics and the Medical Humanities.

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Drug Safety and the FDA

Law and Bioethics Affinity Group

Pharmaceutical safety, particularly safety after a drug is approved and on the market, is an area of persistent concern for patient safety. The removal of Vioxx from the U.S. market brought attention to the problem of postmarketing drug safety monitoring. Recently, the U.S. Food and Drug Administration (FDA) issued a warning about Avandia, a medication commonly used to treat hyperglycemia, and the possibility of heart attacks or other cardiac problems associated with the use of the drug (U.S. FDA, 2007). Postmarketing drug safety continues to be a problem, and the FDA is not well equipped to address it.

Under the Prescription Drug User Fee Act (PDUFA), pharmaceutical companies pay a fee for review of drugs for approval, shifting the cost of FDA review from the government to the companies seeking approval (Slater, 2005). This has resulted in decreased wait times for drugs to go to market. However, it may have also created a customer service mentality among FDA reviewers, leading to emphasis on quick approvals and limiting postmarketing surveillance (Ray & Stein, 2006). The PDUFA is up for reauthorization this year, and the Senate has already approved the reauthorization (United States Senate, 2007). Reauthorization of the existing legislation, instead of a comprehensive overhaul of the drug regulation process, undermines efforts to improve the safety of drugs on the market. Perpetuating the system where pharmaceutical companies bear the cost of the drug regulation process further undermines reform.

The problem with inadequate postmarketing surveillance is that drugs are approved after studies of safety and efficacy involving several thousand patients, at most. Adverse events that occur at a frequency of 1 in 1,000 cases or fewer won't be detected in the premarketing testing. Subtle effects may also require a large population and a long duration of monitoring to detect (Slater, 2005); however, postmarketing surveillance by the pharmaceutical companies is essentially optional. As of September 30, 2006, 71% of the postmarketing studies requested by the FDA had not been started, and only 11% were completed (McClellan, 2007). The adverse effects associated with Vioxx were identified when the company, Merck, voluntarily undertook additional studies for the purpose of expanding the FDA-approved use of the medication, not because of routine postmarketing safety surveillance (Horton, 2004). Without accountability in postmarketing surveillance, companies have little incentive to undertake the studies.

Safety surveillance is expensive, and it is difficult to do. Not all patients report all adverse events they experience. Not all doctors record all adverse events that patients report. Even fewer physicians take the time to report adverse events, which they can do online at the FDA Web site, the Center for Drug Evaluation and Research (U.S. FDA, 2007). The barriers to effective safety monitoring are not inconsequential, but they are certainly not insurmountable. There simply isn't much incentive for companies to invest in doing it.

Safety surveillance comes to public attention only if a safety problem is detected. Companies paying for most marketing studies have little to gain—safety concerns may limit marketing, cause a drug to be taken off the market, or subject the company to liability. If companies don't have to do it, they aren't likely to want to. Because there are no consequences for failing to perform postmarketing studies requested by the FDA, the risks of postmarketing surveillance certainly outweigh the benefits for the pharmaceutical companies.

With the impending reauthorization of the PDUFA, the pharmaceutical companies retain the role of consumers, and the FDA the role of service provider. Creating accountability costs money, and right now more than half of all the money needed for the FDA to function comes from the pharmaceutical companies (McClellan, 2007). It is disingenuous to expect a regulatory agency to be impartial when it is funded by the industry it seeks to regulate. The FDA exists to serve the U.S. population but currently functions to serve the pharmaceutical companies. As long as the drug companies hold the purse strings, they have disproportionate input in the process.

Patient safety is a top priority for all of health care. The process of creating safe systems to ensure safe practices is the proper emphasis to maximize impact. The drug regulation process is a system that clearly needs modification, and it is an easy target for safety-based reform. Providers and patients need to take authority for safety in regulating back from the pharmaceutical companies and restore it to a well-funded and well-organized federal regulatory agency. There is a natural opportunity to do this with the impending reauthorization of the PDFA; however, this opportunity may already be lost with the Senate approval accomplished and no obvious barriers to approval in the House. But the cause should not be abandoned, and patients and providers need to advocate for true accountability in safety of postmarketing medications. A system is in place to ensure safety, and it is up to those promoting quality and safety in health care to ensure that this system functions optimally.

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American Society for Bioethic

Membership

ASBH began in 1998 with 1,200 members. Membership grew during the first several years and has remained steady since. Currently, ASBH has approximately 1,500 members.

Annual Meetings

In 2006, the ASBH Annual Meeting was held October 26–29 in Denver, CO, and nearly 750 attendees gathered to discuss current issues in bioethics and medical humanities.

In 2007, the ASBH Annual Meeting will take place October 18–21 at the Renaissance Washington DC Hotel in Washington, DC.

Affinity Groups

Affinity groups convene during the annual meeting, and several have established e-mail discussion groups to promote communication throughout the year. Affinity groups and their primary contacts are listed below.

Dental Ethics, Laura Bishop
Disability and Rehabilitation Ethics, Mark Kuczewski
Environmental Bioethics, Mary T. White
History of Medical Ethics, Robert B. Baker
Hospice and Palliative Medicine, Joshua Hauser
International Network on Feminist Approaches to Bioethics (FAB), Hilde Lindemann
Jewish Bioethics, Jennifer S. Bard
Law and Bioethics, Erin Egan
Literature and Medicine, Rebecca Garden
Mental Health Ethics and Policy, Christy A. Rentmeester
Neuroethics, Judy Illes
Nursing, Vicki D. Lachman
Organizational Ethics, Charlotte McDaniel
Pediatric Ethics, D. Micah Hester
Philosophy, Toby Schonfeld
Philosophy of Medicine, Barry DeCoster
Program and Course Directors of Humanities and Bioethics in Health Profession Education, Mary T. White
Race and Culture/Ethnicity, Claretta Y. Dupree
Religion, Spirituality, and Bioethics, Stuart R. Sprague
Research, Laura A. Siminoff
Residency Interest Group, Eugene Boisaubin
Rural Bioethics, Lisa Anderson-Shaw
Student Interest, Chirag Patel and Gaia Muallem
Visual Arts and Cultural Representations, Tess Jones

2007 Committees and Task Forces

Affinity Groups, Pam Miya
ASBH Exchange, Ryan Spellecy, Editor
Awards, Matthew Wynia
Career Development Services, Gail Geller
Clinical Ethics (Greenwall Foundation Grant), Mark Aulisio and Sue Rubin, Cochairs
Core Competencies, Anita Tarzian
Educational Services, Robert Pearlman
Ethics Standards, Art Derse
Finance, Tess Jones
LCME Syllabus Exchange, Kelly Fryer-Edwards and Clarence Braddock, Cochairs
Membership and Member Services, Glenn McGee
Nominating, Alexander Kon
Program Planning, Jessica Berg and Ruth Levy Guyer, Cochairs
Public Communication and Outreach, Mark Kuczewski
Publications, Tod S. Chambers
Publishing, Steve Latham
Salary Survey, Toby Schonfeld
Tenure and Promotions Criteria, Jonathan Moreno

Financial Summary

ASBH concluded its ninth year of operations (fiscal year ending December 31, 2006) with a gain of $26,437. This net gain was due primarily to a successful annual meeting in Denver. The audited financial results are as follows:

Income Statement	**2006**	**2005**
Revenue	$452,487	$503,070
Expenses	$426,050	$449,149
Excess of revenue over expenses	$ 26,437	$ 53,921
Balance Sheet	**2006**	**2005**
Assets	$298,762	$252,226
Liabilities	$107,256	$ 74,391
Fund balance	$191,506	$177,835
Total liabilities and fund balance	$298,762	$252,226

Assets: The society's assets of $298,762 at year-end consisted primarily of cash and equivalents ($255,534), accounts receivable ($30,356), and prepaid expenses and inventory ($12,872).

Liabilities: Accounts payable ($25,790) included outstanding invoices, primarily from the 2006 annual meeting. Deferred membership dues ($81,466) represent dues received in 2006 but deferred to 2007 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: The fund balance at December 31, 2006, was $191,506, an increase of $13,671 or 8% more than the prior year's. The fund balance was equal to 44% of the 2007 total budget. The benchmark for reserves, as reported by the American Society of Association Executives for individual-member healthcare associations with budgets under $2 million, is an average of 50% of the total budget.

Get Involved!

ASBH relies on member volunteers in many ways to accomplish its mission. Serving as a volunteer on a committee, as a moderator at the annual meeting, or as a proposal reviewer for the annual meeting are great ways to increase your network of bioethics and humanities colleagues and help shape the direction of ASBH. We invite you to tell us about your areas of interest and how you would like to become more involved in ASBH by completing the volunteer form on the Members Only page of the ASBH Web site at www.asbh.org. The board of directors appoints committees in the fall. Most committees are self-directed and conduct their business through e-mails and conference calls.

2007 Lifetime Achievement Award

Renée C. Fox, PhD
Renée C. Fox is the Annenberg Professor Emerita of the Social Sciences at the University of Pennsylvania, where she is also a Senior Fellow Emerita of the Center for Bioethics. A summa cum laude graduate of Smith College, she holds a Ph.D. in Sociology from Harvard University, where she studied in the department of social relations. Her major teaching and research interests—sociology of medicine, medical research, medical education, and medical ethics—have involved her in first-hand participant observation-based studies in Continental Europe (particularly Belgium), in Central Africa (especially the Democratic Republic of the Congo), and in the People's Republic of China, as well as in the United States. Her best-known books are *Experiment Perilous: Physicians and Patients Facing the Unknown*, *In the Belgian Château: The Spirit and Culture of a European Society in an Age of Change*, *The Courage to Fail: A Social View of Organ Transplantation and Dialysis*, and *Spare Parts: Organ Replacement in American Society* (the last two of which were coauthored with medical historian Judith P.Swazey). She is a member of the American Academy of Arts and Sciences and of the Institute of Medicine. She is the recipient of nine honorary degrees. In 1995, the Belgian government named her Chevalier of the Order of Leopold II.

2007 Distinguished Service Award

Alex John London, PhD
London is associate professor of philosophy and director of the center for the advancement of applied ethics and political philosophy at Carnegie Mellon University, Pittsburgh, PA. A recipient of a New Directions Fellowship from the Andrew W. Mellon Foundation, his work focuses primarily on issues of justice, equality, and risk assessment in research ethics and on methodological issues in theoretical and applied ethics. He is coeditor of *Ethical Issues In Modern Medicine,* forthcoming in its 7th edition, and he has been a member of the ASBH since its inception. ASBH bestows the 2007 Distinguished Service Award to London for his dedicated service to ASBH through his work as the editor of *ASBH Exchange* from 2004 to 2006.

Laurie S. Zoloth, PhD
Zoloth is director of the center for bioethics, science and society and professor of medical ethics and humanities at Northwestern University Feinberg School of Medicine, Evanston, IL. She is also professor of religion and a member of the Jewish studies faculty at Northwestern University Weinberg College of Arts and Science, Evanston, IL. She directs bioethics at the Center for Genetic Medicine, the Center for Regenerative Medicine, and the Institute for Nanotechnology. Her book, *Health Care and the Ethics of Encounter,* on justice, health policy, and the ethics of community, was published in 1999. Her current research projects include work on the emerging issues in medical and research genetics, nanotechnology, neuroscience, and the ethical issues in stem cell research, and her research interest in distributive justice in health care continues. She served on ASBH's founding Board of Directors and in 2001 was elected its fourth president. Zoloth is recognized for her dedicated service to ASBH since its inception.

ASBH Lifetime Achievement Award

The award recognizes a person whose outstanding contributions and significant publications have helped shape the direction of the fields of bioethics and humanities. Recipients are as follows:

2007 Renée C. Fox, PhD

2006 Bernard Gert, PhD
Ronald E. Cranford, MD

2005 Eric Cassell, MD MACP

2004 James F. Childress, PhD
Tom L. Beauchamp, PhD
Joanne Trautmann Banks, PhD

2003 Jay Katz, PhD

2002 Ruth Macklin, PhD

2001 Daniel Callahan, PhD

2000 John C. Fletcher, PhD

1999 Albert R. Jonsen, PhD

1998 Edmund D. Pellegrino, MD

ASBH Distinguished Service Award

The award recognizes outstanding and dedicated service to the American Society for Bioethics and Humanities. Recipients are as follows:

2007 Alex John London, PhD
Laurie S. Zoloth, PhD

2006 Mark H. Waymack, PhD

2005 Chester R. Burns, MD PhD

2004 Thomas Murray, PhD

2003 Mark Kuczewski, PhD
Hilde Lindemann Nelson, PhD

2002 Betty Wolder Levin, PhD
Leslie S. Rothenberg

2001 David Barnard, PhD
Marian Gray Secundy, PhD
Tom Tomlinson, PhD

2000 Robert M. Arnold, MD
Steven H. Miles, MD
Stuart J. Youngner, MD

1999 Loretta M. Kopelman, PhD

A Bibliographic Tour

Les Rothenberg

Because of space limitations, "A Bibliographic Tour" will be a listing rather than a review but will include e-mail addresses to facilitate reprint requests. Suggestions of your own work or that of others, as well as suggestions for improving the column, are enthusiastically solicited. Please contact Les Rothenberg at Les.S.Rothenberg@kp.org. 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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Les Rothenberg is a clinical ethicist with Kaiser Permanente and professor emeritus of clinical medicine at University of California–Los Angeles.

Profile of the New ASBH President

Tod S. Chambers

Mark Kuczewski

I first met and came to know Tod Chambers at meetings of the Society for Health and Human Values in the early 1990s. Because we were both interested in the role of cases in ethical discourse, our papers were placed on the same panels on more than one occasion. At first glance, I suspected that I might not especially like this person. After all, he was always impeccably dressed in magnificent suits. I assumed he also clad himself in the academic pretensions available to a humanities scholar. However, what quickly came to color my opinion of my new friend was his demeanor and affect while we had dinner. In the customary thrown-together group of five or six peers, a place to eat was chosen, orders placed, and awkward conversation begun. After the plates were cleared, Tod sat back, relaxed his posture, and exhaled in a way that seemed to breathe out the anxieties of all of us. His way of being signaled that it was time to relax and simply be who we are. Of course, with that tone set, substantive and satisfying conversations laced with the deadpan and self-deprecating humor that is Tod's trademark ensued. It is this charm, humility, and regard for his colleagues that will make him highly successful as the new president of the American Society for Bioethics and Humanities.

Tod possesses a natural curiosity and evidences a deep appreciation and respect for the perspectives and contributions of others. As a result of this openmindedness, he has become a scholar who defies easy characterization. His doctorate is in religious studies. He studied Buddhism extensively and even lived as a Buddhist monk in Thailand. This background has led to a career-long interest in the place of culture in clinical medicine. Of course, many would mistake him for a literary critic because of his extensive exploration of the language and structure of ethics cases and bioethical analysis. This line of inquiry achieved its first expression in the publication of his renowned book, *The Fiction of Bioethics,* and will reach a milestone with the publication of his second book in this vein. Of course, he has also published on a variety of topical issues usually explored by bioethicists rather than medical humanities scholars. I suspect that Tod finds artificial the usual dichotomy posed between the Bs (bioethicists) and the Hs (humanities scholars) in ASBH. Nevertheless, although he finds disciplinary boundaries to be fluid, he evidences a sense of urgency to insure that the perspectives of a broad variety of disciplines are represented within ASBH.

Tod is one of those unusual people whose endeavors are directed more by curiosity and a sense of service than by ego. Although he has been a leader in ASBH through his work as a program cochair and a term as a director at large, he declined a previous nomination to run for president. But, as his service refined his intuitions regarding the organization's needs, he came to understand how he might be of use to this organization as it enters its adolescence. He signaled a new era in our self-understanding with the opening sentences of his candidate statement. Tod professed that while many say that ASBH is not their primary professional organization, it is his. He captured the sentiment that however we see the disciplines or professions of bioethics and medical humanities, we have reached an era in which we understand ourselves as an organic group whose dialogue is foundational to our work.

In many ways, Tod Chambers is our ideal president because we have all experienced "dinner with Tod," and we wish this experience to permeate ASBH. That is, after years of attempting to forge an identity for the organization and to determine how we fit together, we desire to relax, drop our pretensions, and enjoy a respectful and substantive conversation. Tod's example invites us to check our egos at the door and occasionally poke fun at ourselves. More important, his presidency represents a challenge to listen to each other's contributions rather than be distracted by disciplinary labels and boundaries.

Mark Kuczewski is the Fr. Michael I. English, SJ, professor of medical ethics and the director of the Neiswanger Institute for Bioethics & Health Policy

New Books, Videos, Etc.

David Orentlicher

We have four new books 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 either of 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.

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David Orentlicher is Samuel R. Rosen Professor of Law and codirector of the center for law and health at Indiana University School of Law–Indianapolis. He is on the faculties of the School of Medicine and the center for bioethics at Indiana University and serves in the Indiana House of Representatives.

In Memoriam: Joanne Trautmann Banks

We are saddened to announce the passing of 2004 Lifetime Achievement Award recipient Joanne Trautmann Banks, a pioneer of our field, on May 5 in St. Petersburg, FL. ASBH members at the Philadelphia meeting will recall her extraordinary explication of Margaret Edson's *Wit,* a play about ovarian cancer, her own disease. She was a fine scholar, a wonderful colleague, and a friend to many.

When she moved from Drexel University to the medical humanities department at Penn State University Hershey Medical Center in 1972, Joanne became the first literary scholar to hold a professorship in an American medical school. Even as she published (with Harold Nicholson) the six volumes of *The Letters of Virginia Woolf, 1975–80*—an edition which the *New York Review* in 2006 called one of the "great scholarly monuments"—she also compiled (with Carol Pollard) an annotated *Bibliography of Literature and Medicine* (1975, rev. ed. 1982) and convened the interdisciplinary meetings recorded in the pathbreaking *Healing Arts in Dialogue: Medicine and Literature* (1981).

Joanne was a mainstay of *Literature and Medicine,* the Johns Hopkins University Press journal she helped found in 1982. She edited some of its liveliest issues: "The Use and Abuse of Literary Concepts in Medicine" (1986), the "Tenth Anniversary Retrospective" (1991), "The Art of the Case History" (with Anne Hunsaker Hawkins, 1992), and "Moving Pictures" (1998). She remained an associate editor until her death.

Twenty-five years ago, in the lead article of *Literature and Medicine*'s first issue, Joanne wrote, "Let us investigate in the pages of this journal all those concepts that literature has to offer medicine and vice versa. Keeping humbly to what our talents and trainings allow us to see, let us nonetheless refuse to accept so thorough a fragmentation that we endanger the mental and physical health of our community."

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Laurence McCullough, PhD, Baylor College of Medicine*

Alicia Ouellette, JD, Albany Law School

Robert Orr, MD, Fletcher Allen Medical Center & University of Vermont

Bonnie Steinbock, PhD, the University at Albany/SUNY

Martin Strosberg, MA, MPH, PhD, Union Graduate College

Robert Veatch, PhD, Kennedy Institute of Ethics, Georgetown University*

* *Indicates visiting lecturer on-site Health and Human Values Proseminar*

Analyzing the Best Interests Standard *continued from page 1*

This condition acknowledges that decision makers sometimes can and should make different choices in deciding what is best for people lacking decision-making capacity, but it requires them to select options meeting at least a minimum threshold of acceptable care. Both families favoring comfort care and families favoring highly experimental care for their dying relatives may make acceptable choices. From a legal perspective, family members are permitted to decide what is best for relatives unless they neglect, abuse, or endanger them. Because guardians have the right to decide what is best for their family members and how to balance their interests unless they endanger their wards, it is a mistake to judge that the best interests standard is excessively focused on the needs and interests of the person for whom decisions are being made. It may be best for one child to have the best music education in the country, but parents have no duty to move their family across the country to provide this benefit for one child at the expense of the interests of all others in the family. This standard would be incoherent and self-defeating if it required "the best" for everyone because not everyone can have the ideal treatment, the best surgeon, or the best lawyer if these resources are scarce. It is a mistake to view the best interests standard as so excessively individualistic that all interests other than those of the person for whom one decides must be set aside.

The best interests standard is an umbrella principle because it can be used differently in different situations. For example, what parents happen to think is best may be acceptable from a legal perspective because a child is not endangered within their care, yet the decision may be far from what is optimal. A decision that is "good enough" from a legal perspective, then, may be far from ideal. The best interests standard should not be regarded as the "good enough" standard because choices should be better than merely acceptable. For example, this guidance principle directs doctors who have duties to provide the best available option for their patients, not merely what is barely good enough.

Third, decision makers should make choices on behalf of people unable to make decisions for themselves that are compatible with moral and legal duties.

The meaning of the best interests standard should be understood in relation to the contexts where it is used, and these contexts include established rights for and duties to people who lack decision-making capacity. For example, in medicine the standard is linked to duties relating to good patient care, and in law it is tied to policies about making appropriate custody decisions or judgments about when children are abused or neglected. Establishing policies about how to treat others helps ground the best interests standard and answer the charge that the standard is vague or means whatever anyone thinks it means. It is a complex guidance principle that was introduced to undercut policies that guardians could make decisions for their wards as they did for themselves. If a father wishes to treat his bacterial pneumonia with herbal tea, he is at liberty to do so, but he has no right to make this decision for his child.

This new analysis of the best interests standard can provide caregivers considerable guidance in resolving problems about how one ought to act on behalf of people lacking decision-making capacity. It instructs caregivers to rank potential benefits and hazards in making decisions for others (the first condition). Although this ranking may reflect decision makers' subjective preferences, it also needs to be objectively justified as an acceptable ranking of potential benefits and risks. The decision must also meet considered thresholds of acceptable care (the second necessary condition) and established duties to and rights of the incapacitated people (the third necessary condition).

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ASBH-Endorsed Meetings

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2007 ASBH Annual Meeting October 18–21

You'll find fresh ideas at the 2007 ASBH Annual Meeting as we examine current issues in bioethics and the humanities. Special guests include Harriet Washington, Raphael Campo, and Nancy Scheper-Hughes, all of whom will provide insights into how to better connect and collaborate and work toward justice.

- *American Janus: Some Historical Notes on U.S. Medicine, Race, and Ethics.* Visiting scholar Harriet Washington will discuss the history and ethics of medical research carried out in the United States with African Americans on Thursday.
- *The Poetry of Healing: A Doctor's Education in Identity, Desire, and Empathy.* Poet and physician Rafael Campo will discuss and read from his work on Friday.
- *A World Cut in Two: Global Justice and the Traffic of Human Organs.* Professor of medical anthropology Nancy Scheper-Hughes will discuss the ethics, economics, and consequences of the global trafficking in human organs on Saturday.

Save the Dates

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