



# ASBHH

## EXCHANGE

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## Rethinking Respect for Persons Enrolled in Research

Lisa S. Parker

Contemporary bioethicists have always distinguished the different goals of clinical care and research and the distinct obligations structuring provider-patient and investigator-subject relationships. The distinctions were perhaps easier to maintain, at least at the conceptual level, when the term *therapeutic research* truly seemed an oxymoron, an illogical category mistake. Today, when it is proudly declared at research meetings that “any patient who isn’t enrolled in a research protocol for the treatment of disease X, it seems that investigators are as likely as subjects to suffer from therapeutic misconception. Those making arguments about the ethical obligations of researchers may suffer from it as well.

Arguments in favor of offering not only aggregate but individual research results to subjects of clinical research are clearly gaining traction (Partridge & Winter, 2002; Shalowitz & Miller, 2005) and are being extended to genetic research. Especially in the context of much genetic research, and indeed any research of an early exploratory nature, disclosure of individual results is ethically problematic. Troubling are the ethical appeals—consequentialist and principled—offered in support of doing so. In particular, claims that to avoid paternalism and to respect persons require offering such results suggest a reconceptualization of paternalism, of what is required to respect persons, and of the goals of research.

### Harms and benefits of offering results

It is problematic to cite participants’ positive responses to receiving aggregate treatment trial findings in support of offering individualized results (Shalowitz & Miller 2005), especially genetic research results. Also mistaken is the extrapolation of probable sequelae of receiving such

individualized results from reported psychological responses of those receiving results in clinical care or under research protocols designed to return predictive genetic test results for specific conditions (Shalowitz & Miller). In both of these contexts, individuals actively seek genetic information prior to its generation and receive pretest counseling, and the tests themselves have established clinical utility. In contrast, depending on the type of genetic research—and it is a problem to lump together such diverse designs with diverse research questions as family studies, population-based studies, and DNA mining—study results may lack clinical significance or may not even have been replicated (Clayton & Ross, 2006). Because of pleiotropy—the fact that multiple traits or conditions may be associated with a genetic mutation—research participants may not have anticipated the finding that emerges from research, supposedly ripe to be offered to them. Teasing apart different types of research and recognizing different degrees of confidence in the validity of findings, as well as variation in their utility, are critical first steps toward analyzing consequence-based arguments in favor of offering individual genetic research results (or responding to requests for the same).

It is also necessary to consider the effect on research budgets—institutional and federal—of making good on such offers and of doing so with appropriate counseling. Unless overall budgets are expanded, the costs of offering and disclosing individual research results will crowd out some expenditures on research initiatives. The prospect of returning results to individuals should also affect assessments by institutional review boards (IRBs) of the level of risk presented by genetic research protocols. Some IRBs currently assume that any genetics study poses substantial risk to

subjects until that assumption is rebutted by evidence of the investigators’ provision of adequate privacy protections, as well as assurance that no individualized results will be returned to subjects. According to traditional understandings of harm, such provisions substantially mitigate the protocol’s risk of harm and augur in favor of IRB approval. Were “failure to benefit” to become a prevalent understanding of harm, then IRBs’ assessment of probable harm-benefit ratios and of the appropriateness of various research designs would need to be revised in this and myriad other contexts. Indeed, the suggestion that researchers not strip identifiers from biological samples, because doing so may not be in the best interests of the subjects for whom “newly derived genetic information may be of great significance” (National Human Research Protections Advisory Committee, 2002, p. 22), seems to embrace such a revised understanding of harm in terms of failure to benefit.

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## Letter from the President

### The State of Our Union Is Strong

Matthew Wynia



The state of our union is strong. ASBH finished 2005 with a substantial surplus. Largely because of higher than predicted attendance and revenues from our annual meeting, we earned about \$50,000 more than we spent. From a financial standpoint, that is by far our best year since ASBH was formed by the merger of its three predecessor organizations more than 8 years ago.

If you haven't yet thanked our Program Planning Committee for a terrific meeting last year, now would be a good time to do so! Start with Felicia Cohn and Lisa Eckenwiler, conference co-chairs, but don't forget Joshua Hauser and Catherine Belling, who joined the committee last year and are serving as cochairs for our 2006 Annual Meeting in Denver (October 26–29). The theme in Denver will be "Challenging Voices," and you can expect to hear from some truly challenging speakers.

Even with 2005 being a banner year, ASBH is not entirely out of the woods. Not-for-profit organizations like ours are supposed to maintain a large financial cushion against sudden declines in revenues (like the one we saw after 9/11, when attendance at our annual meeting was lower than expected). According to accounting rules for not-for-profits, we will need another 2 years like 2005 to reach a position of really solid financial strength.

Still, having done well in 2005 allows us to build on our success. Improvements to our Web site are coming. We are incorporating more interactive features that will allow our members to provide us with immediate feedback and ideas for ASBH actions. We will have electronic registration in place for the 2007 meeting.

We are also reaching out to those in medicine, bioethics, and the humanities who are not yet members of ASBH. Members of ethics committees, bioethics and humanities interest groups, and other relevant groups within organizations like the American Public Health Association, the American Philosophical Association, the Society for General Internal Medicine, and the Society for Literature,

Sciences, and the Arts will be hearing from ASBH. The ASBH board is developing a liaison system to ensure that these natural partner organizations know that we are interested in working with them to build onto their bioethics and humanities programming. In turn, we expect increased attendance and even better programming at our own meeting, as members of these organizations learn that the ASBH annual meeting is the one "can't-miss" meeting for anyone interested in bioethics and the medical humanities.

New task forces are developing products and services of value to ASBH members. Our Advisory Committee on Ethics Standards (ACES) Task Force is hard at work on research to inform the work of the Ethics Standards Task Force. The Ethics Standards Task Force, which comprises all the ASBH past presidents, is charged with recommending whether ASBH should have a code of ethics for our members. Another task force, headed by Steve Latham, is updating our popular handbook on how to publish in bioethics and the medical humanities (the original, available on our Web site, was created by the student interest group of the Society for Health and Human Values in 1997). A task force headed by Mark Aulisio and Sue Rubin has recently released its draft of a very useful *Learners' Guide to the Core Competencies for Health Care Ethics Consultation*.

In addition, we are continuing to build our relations with our partner journals. With eight partner journals, it is possible for an ASBH member to save more on journal subscriptions than it costs to join ASBH! You can find an alphabetical listing of our current partner journals at [www.asbh.org/partner-journals.htm](http://www.asbh.org/partner-journals.htm). Special thanks go to Tod Chambers for overseeing this very valuable program. Recently, the board decided that the task of building these relations with partner journals has become far too important to be left to a single person or even to a yearly task force. So the board is creating a new standing Committee on Publications (which Tod has agreed to chair) to ensure that relations with our partner

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## Revolutionaries in Black Robes

Kayhan Parsi

With the recent confirmations of John Roberts and Samuel Alito to the U.S. Supreme Court, a great deal of ink has been spilled (or whatever the comparable metaphor is for electronic communications) on the topic of activist judges and the role of judges in a liberal democracy. Part of my interest is academic: I teach a course on law and bioethics, and much of what my students read are judicial opinions—not laws passed by Congress or state legislatures and not administrative policies enacted by various agencies, but rather opinions written by judges who sit at either appellate or supreme courts at the state or federal level. Why should the opinions written by typically unelected jurists be the focus of our academic inquiry? And why has there been such intense interest in the role of judges over the last two decades?

We spend so much time examining judicial opinions partly because of the unique authority possessed by judges in the American legal system. As one legal scholar noted, the judge is a “culture hero. . . . Many of the great names of the common law are those of judges: Coke, Mansfield, Marshall, Story, Holmes, Brandeis, Cardozo” (Merryman, 1985). But even more important than their notoriety is the important and sometimes even revolutionary role played by judges in the United States. This view is advanced by Robert Lipkin, professor at Widener University School of Law, in his book *Constitutional Revolutions: Pragmatism and the Role of Judicial Review in American Constitutionalism*. Lipkin claims that a “constitutional revolution occurs when the Supreme Court decides an issue of constitutional law according to a principle not contained in the Constitution or in constitutional practice” (Lipkin, 2000, p. 89). Lipkin argues that cases such as *Marbury v. Madison*, *Brown v. Board of Education*, and *Griswold v. Connecticut* were examples of such revolts. Each case initiated a social revolution: *Marbury* was the first case that established judicial review, *Brown* heralded the modern civil rights movement, and *Griswold* paved the way for the personal autonomy revolution that later saw the emergence of such seminal bioethics cases as *Roe v. Wade*.

Lipkin's thesis is that “the theory of constitutional revolutions includes a dualist structure of constitutional change that gives new meaning to the idea of a ‘living’ constitution. The constitution ‘lives’ when judges transmogrify ethical and cultural factors into the formal province of constitutional law through revolutionary adjudication. Without this theory we cannot explain how American constitutional law changes” (Lipkin, 2000, p. ix). Rather than making up the law out of whole cloth, judges take their cues from the broader cultural and social changes that are already happening and then formalize them into constitutional law.

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Lipkin's thesis seems to fly in the face of what was often heard from the nominees during their Senate confirmation hearings. Roberts compared judges to umpires, whereas Alito proclaimed that a good judge has no agenda. These views suggest that judges are merely neutral technocrats who have no notions of what justice entails. Yet if we take Lipkin's thesis seriously, judges not only have some idea about what justice means substantively but also take seriously the broader cultural trends of society. Why, then, would the Warren court with 50 years of stare decisis upholding separate but equal educational policies attempt to redefine what constituted a just educational system in this country? Why would this specific court during the Eisenhower era see fit to overrule a precedent that had existed for so long? For Lipkin, these shifts on the Supreme Court are akin to Kuhnian shifts of science—judicial decision making is occasionally upended by revolutionary adjudication when our broader considered moral judgments view certain practices (such

as separate but equal education) as incompatible with our ideals of a liberal democracy.

Lipkin's ideas of revolutionary courts and cases may suggest that we are somehow predestined to a more progressive ideal of a liberal democracy, but this is not so. More reactionary judges could appropriate the prevailing cultural zeitgeist and determine that a liberal democracy should not allow certain forms of political expression. Thus Lipkin argues that “the existence of revolutionary adjudication in the wrong hands can be a disaster, and neither law nor legal theory can tell us when revolutionary decisions are wrong. Only political and moral argument can do that, and in a pluralist society it can do so only contestably. Although no guarantees are possible, revolutionary decisions in the right hands can be a vital part of a progressive, deliberative democracy. It is the people's responsibility to make sure that the right judges are selected” (Lipkin, 2001, n.p.).

Although some commentators have recently argued that the Senate confirmation hearings of Supreme Court nominees are mostly a sham and have very little substance, they nonetheless serve an important function—helping better educate the American public concerning who will sit on the U.S. Supreme Court and have the opportunity to occasionally wield this revolutionary authority. 

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"Literature and Medicine" is devoted to the literature and history of bioethics and medical humanities. Poetry, short stories, and short descriptions of important episodes are welcome. Please send submissions to Catherine Belling at [cbelling@notes.cc.sunysb.edu](mailto:cbelling@notes.cc.sunysb.edu).

This is the first in a series of columns focusing on literary and humanities publications produced in medical schools.

## The Healing Muse

*Deirdre Neilen*

*In memoriam: B. A. St. Andrews, poet, scholar, and trusted colleague, died from a brain tumor October 21, 2003. Her loss to us, both personally and professionally, is immeasurable and endless.*

The journal *The Healing Muse* was founded by Bonnie St. Andrews in 2001. She described her own work as a poet and literature professor in this way: "Entering a medical university, I was transported to a world of open-heart surgeries, DNRs, neonatal ICUs, and MRIs. I had found my strange way home to a place I'd never been before, leaving the illuminating questions of the liberal arts and entering the dubious certainties of medical science. Far from being separate, art and science are Siamese twins joined at the heart. They are two hands clapping."

Bonnie started the journal to provide opportunities for medical students, patients, caregivers, physicians, and nurses to bear witness to all aspects of modern medicine. Telling stories is one way we organize and shape our own experiences. Bonnie knew that when we fall ill, we take the often-chaotic materials of a new diagnosis and seek to create from them a self and life that we can still claim and recognize as our own. She saw that medical practitioners have a similar need to create clarity and engage in empathic dialogue with those who are suffering. Writing provides one way for physicians and other healthcare professionals to grieve the bad news they must deliver and to accompany their patients through the fear and sadness that follow.

Bonnie's poetry was enriched by her interactions with her medical and nursing colleagues; her poems about what she saw with them in operating rooms and clinics appeared regularly in *Journal of the American Medical Association*. In a landscape of suffering, her poetry created oases of hope and goodness. This part of her vision is what *The Healing Muse* continues to explore and encourage. Within its pages, the reader will find how writing transforms both practitioner and patient from merely exhausted warrior and frightening disease back into two people who have a shared story to tell; in the telling comes our comfort, perhaps even our triumph.

"Your Breast a Unicorn" is Bonnie's eloquent reminder of the people behind the statistics on breast cancer mortality.

### **Your Breast a Unicorn**

*Bonnie St. Andrews*

- I. Uncut and unsewn my breasts nuzzle yellow silk secure as two fauns nestled in Debussy's dream, sun-dappled and safe, finding solace singly and together. My heart beats staccato under slumbering glands of these breasts and I think about the milk of human kindness and my friend who, unaware, suckled an abomination which curled inside her

softness and betrayed her. Like Cleopatra's asp awakening on compassion's mound, on passion's curve, at consolation's center one aberrant cell metastasized, stirring from slumber to pierce with death that tender sweetness it had dreamt upon.

- II. She hates that phrase "lost a breast" with its insinuation of carelessness. "It's not as if the three of us went off to market," she says, "my left breast, my right breast and I and one zipped off to ice cream while the other darted to bottled dressings and me just meandering beside vegetables stacked and clotted like a painter's palette with apricot, celeriac, eggplant, muscadine. It's not as if I realized suddenly one of my breasts had gone missing and charged the courtesy counter breathless on the PA system announcing: I'm waiting on aisle nine for my right breast, my recalcitrant child who has spent her full, fragile, throbbing life with me so please return please and help me push the cart piled high with treats for her: my other darling, my rose-tipped girl, my comfort."
- III. Breasts make money, cut or uncut. We speak of capital "B" breasts as if they were priceless organisms to be mined or culled or caught in the teeth and so they are. The Breast is a bronze pendant, a cocoa fruit lopped from its emerald vine. Breast is an apricot moon pinned to the vineyard of night, a pool mirroring the love-sustaining needs of women and men, women and women, mothers and sucklings. Breast, tumescent and detumescent as any male part, is mystical and defiled, swollen and confined, life-giving and powerful as Africa's Nile. The Breast reigns: Queen of Solace, Empress of Amazons, Priestess of Pleasure. We all worship the Breast, ripening or withered: first pillow, first nation, first food.
- IV. Your breast is gone, medically incinerated before we could place it among stars. Lost as the unicorn, that ancient sigil of innocence, your legendary breast is extinct and wandering in fields of praise. Like the Unicorn's, let your struggles be woven into tapestries and hung in halls of queens and heroes. Let your face be fashioned of herbs and flowers; let your courage be emblazoned in golden thread so light-yielding, so steadfast that fragile sister ships may, by your radiance, glide unperturbed past shoals and reefs of fear and anguish which lay siege on every heart. By your burning may ships heavy laden, carved with busts of mermaids and deities who tame wild seas, deliver safely their cargo of women brave and beautiful as you.

*Deirdre Neilen is associate professor of bioethics and humanities at the Center for Bioethics and Humanities, State University of New York Upstate Medical University, Syracuse. She is the editor of The Healing Muse ([www.thehealingmuse.org](http://www.thehealingmuse.org)).*

# Medical Futility and Professional Integrity, Religious Tolerance, and Social Justice

Sarah E. Shannon

Nurses cite unrealistic expectations as the most common barrier to their communication with families of patients who are seriously ill and possibly dying in the intensive care setting (Shannon, Engelberg, Treece, & Curtis, 2004). Healthcare professionals claim that these families want too much at the end of life or expect miracles that cannot be delivered. The shift in the past 50 years from physician paternalism to patient autonomy appeared to tie the hands of healthcare professionals in these situations, forcing them to provide therapies that seemed at best ineffective and at worst abusive. Healthcare professionals responded that this dilemma threatened their professional integrity; that to provide such therapy was an affront to their training and professional values.

Medical futility has been invoked as a defense against this imbalance, allowing healthcare professionals, specifically physicians, to refuse to provide therapies they believe to be ineffective or of little to no benefit. However, an objective definition of *medical futility* has remained elusive, with providers often equating continued existence that is dependent on critical care with futility (Nelson, 2003). Meanwhile, isolated cases of medical futility began making their way to court over the past decades; physicians, healthcare institutions, and others challenged the rights of patients and their surrogates to demand therapies for Helga Wanglie, Baby K, Ryan Nguyen, Sonya Causey, and Barbara Howe. To avoid such litigation, several states enacted legislation dictating a procedure for negotiating claims of medical futility and providing physicians, nurses, and others with protection from liability when treatment is withheld or withdrawn on the basis of futility. The Texas Advance Directives Act of 1999 is the most defined of these laws (Fine & Mayo, 2003).

If requests for aggressive end-of-life treatment were randomly distributed, preferences for medically futile treatment among Americans would be idiosyncratic, and laws such as Texas's allowing healthcare professionals to trump patients' and families' views might be

justified on the basis of the principle of nonmaleficence, or rationing based on distributive justice. But preferences for "excessive care" are not randomly distributed. Research has consistently shown that they are associated with several characteristics, most notably racial or ethnic background and religiosity.

African Americans consistently report stronger preferences for aggressive care at the end of life than do white Americans (Kwak & Haley, 2005). Some authors have suggested that this is attributable to the distrust that many African Americans have for the healthcare system. Reasons for this distrust abound, including poorer access to medical care, poorer outcomes from medical care, and poorer experiences with medical care (Institute of Medicine, 2002). Another

### Does it matter that identifiable groups are disproportionately affected by claims of medical futility?

reason may be that not all Americans share a common definition of "the good death." Many white Americans hope for a death that is free of pain, with family near, and with little technology (tubes). Yet for African Americans, a good death may be the good fight, a death where everything was done to prevent it. In 2003 at the ASBH annual meeting in Montreal, colleagues reported on the initial 23 cases considered by one group of institutions as medically futile under the new Texas Advance Directives Act (Cagriotta, Smith, Flamm, & Gremillion, 2003). Demographic data revealed that 14 of these cases, 61%, were African American patients and families—far more than could be accounted for by the percent of African Americans in the general population or in the patient population. Is this because treatment for African Americans was more likely to be judged as futile, as Curtis and colleagues found in research on physicians' judgments of the futility of cardiopulmonary resuscitation (Curtis, Park, Krone, &

Pearlman, 1995)? Or was this because African Americans were more likely to prefer aggressive care at the end of life, more aggressive than healthcare providers thought was appropriate?

Religiosity is the degree to which people report that religion plays an important role in their lives. America is increasingly religious and increasingly conservative in these religious beliefs (Land, 2004). Evangelical Protestants account for 30% of all Americans and represent the fastest-growing faith group in the United States. Teno and colleagues (1994) examined the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) study data to provide an estimate of the effects of a policy that would limit life-sustaining treatments in situations of futility, defined as the patient's having less than or equal to a 1% chance of surviving for 2 months. Of 4,301 patients, 115, or 2.7%, had a prognosis of surviving for 2 months or less. All but one died within 6 months, and the majority died within 5 days of prognosis. These authors estimated that if life-sustaining treatments had been withheld or withdrawn for these patients, approximately \$1.2 million in hospital charges would have been saved. But the majority of these savings would have come from 12 patients, all of whom were more likely to have religious convictions not to have life support withdrawn.

What are we to make of these data, and more important, does it matter that identifiable groups are disproportionately affected by claims of medical futility? The answer is yes. In the 1960s and 1970s when cases of Jehovah Witnesses' refusals of blood transfusions were heard in the courts, healthcare professionals claimed that their professional integrity would be threatened if they were not allowed to provide all the means at their disposal to save lives. The courts disagreed, demanding that healthcare professionals honor the sense of spiritual harm associated with blood transfusions for some. Later, as other

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### Respect for persons

Of particular concern, however, are the nonconsequentialist justifications mustered for offering to disclose individualized research results. Respect for persons, not treating subjects as means to an end, and avoiding paternalism have each been proffered as such a justification. The offer of individual results is sometimes considered a matter of reciprocity or as thanks for study participation, a reward for altruism. It is said that subjects are entitled to the information that they “voluntarily helped generate” (Shalowitz & Miller, 2006, p. 37). Given pleiotropy, it is not clear that subjects voluntarily or knowingly help generate all genetic information that may, for example, be derived from their contribution of biological material and health information. What they do voluntarily and knowingly help to generate are data needed to address the study’s research question, the aggregate research results. Informing them of such aggregate results, unless they prefer not to receive them, certainly expresses respect for them as persons and acknowledges their contribution to the study.

In contrast, I believe, respect for persons (as well as concern for their welfare) requires resisting the trend toward disclosure of individualized research results. Of course, if an individual study finding met Tarasoff-informed criteria of a duty to warn or disclose, then arguably concern to protect the subject’s welfare would warrant the offer (perhaps even the imposition) of such highly valuable (read: reliable life-saving or severe-morbidity-preventing) information. Such cases are likely to remain rare; however, the possibility of such a disclosure should be included as part of the informed consent protocol (ICP) and study designs. This is the sort of exceptional circumstance, contemplated by the National Bioethics Advisory Commission (n.d.), in which an investigator, like the psychiatrist who could have warned Tatiana Tarasoff not to open her door to her armed assailant, is in a unique position to help protect someone from what is deemed, by strong social consensus, to be an imminent serious harm. Paternalistic concern for the subject’s welfare would justify disclosure.

But what of individual data generated in research that fail to meet these

stringent criteria? Whether respect for persons requires (or even permits) affirmative response to requests for such data (perhaps in contravention of terms of the ICP) or design of future studies to include routine offer of individualized results does not depend solely or primarily on the information’s value. It also depends on a substantive understanding of the principle of respect for persons in general and in the research context, as well as the terms of the ICP and the reasonable expectations created in the subject. Yet those who resist the trend toward offering individual results are sometimes characterized as occupying a bizarre normative position. It is suggested that they are relying solely

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**Respect for persons (as well as concern for their welfare) requires resisting the trend toward disclosure of individualized research results.**

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on the terms and fact of informed consent to render a research study ethical, while failing to respect subjects’ autonomy and personhood by both exploiting them for scientific ends and being inappropriately paternalistic (Shalowitz & Miller, 2006). In fact, one can recognize that more than informed consent is required for a research project to be ethical and for researchers to discharge their obligations to subjects—and one can believe that justice and avoidance of exploitation are as important in research as respect for autonomy and welfare protection—without embracing the trend toward disclosure of individualized research results.

### Respecting respect for persons

If a study is truly exploitive, then it ought not to be done. Offering subjects an individual benefit will rarely turn an exploitive study into a fair one. Moreover, failing to afford someone a benefit to which he would not otherwise be entitled is not exploitation. Compensation for study participation should be given, if it is given at all, to all subjects. The possibility of being compensated should not depend on one’s particular genome (giving rise to an incidental


finding) or the success of the study in answering the research question and one’s relation to that finding (e.g., possession of a mutation or not). If offering a benefit is necessary to compensate or to avoid exploiting subjects, then the benefit should not be of dubious scientific or personal value; out of fairness, the benefit should be of established and relatively uniform value to all subjects—for example, money in exchange for inconvenience. Worries about payment creating inappropriate incentives to participate are well known, but the offer of learning genetic information may similarly prompt people to enroll in studies they otherwise would rather not. (Think of enrolling in a study seeking a genetic association with sexual identity in hope of learning clinically relevant information about cancer risk for which one cannot afford clinical genetic testing.) Failing to offer individualized results does not treat subjects solely as a means to the scientific end of generalizable data. Setting out terms of participation and respecting individuals’ choice to participate or not respects subjects as self-determining persons.

Why should the terms of participation be set by investigators and given in take-it-or-leave-it style to prospective subjects? For the same reason that the study design and terms of the ICP should be designed to answer the study question while minimizing risks to subjects. That is, because doing so pursues the goal of research tempered by the fundamental requirement of protections for human subjects, protections that are fundamentally and appropriately paternalistic in two senses. First, those evaluating research protocols are charged with substituting their judgment of the balance of harms and benefits for those of prospective subjects and necessarily use social consensus-based conceptions of what is harmful or beneficial. Second, in exercising their judgment, they are to privilege protecting welfare over promoting exercise of autonomy. Finally, by its nature, research is standardized, “protocolized,” as are subject protections. Even if an individual subject might not be harmed, or might even be benefited, by departing from protections designed to minimize “potential harm associated with

decision-making around incomplete, unreliable or uncertain information” (National Bioethics Advisory Commission, n.d.), considerations of fairness and respect for persons do not warrant engaging in a utilitarian calculation in the research context. Research is distinguished from individualized clinical care in this regard.

The idea that, to avoid inappropriate paternalism, investigators should offer and then provide individual data along with an indication of their degree of validity (Shalowitz & Miller, 2006)—i.e., supply data and let recipients sort them out—reflects adherence to a caricature of respecting autonomous choice, not respect for persons. In clinical end-of-life decision making, anguished decision making and the quagmire of arguments about futility resulted from merely providing a list of all possible interventions, tagged with their likelihood of efficacy, and leaving it to patients or surrogates to sort out whether to continue or forgo life-sustaining treatment. In such cases, most patients welcome their physician’s recommendation informed by her expertise, experience, and understanding of her patient’s goals and values. A substantial minority of patients do not even want to exercise decisional authority (Schneider, 1998). In clinical contexts, the degree of clinical validity and utility of information is established. To suggest that in research contexts substantial uncertainty about the accuracy and meaningfulness of findings actually militates in favor of disclosing it and leaving it to individuals to evaluate is to treat data like a hot potato that once obtained should be passed along. The motive for treating information like a hot potato is perhaps to avoid being (inappropriately) blamed for withholding something that only in retrospect can be reasonably deemed valuable, to avoid being sued, or to avoid the discomfort of possessing information about someone that the person himself doesn’t know. Sometimes respecting persons may require not acknowledging all that one knows about another in order to allow that other to pursue life plans unencumbered by such information or by the need to decide whether to acquire it (Nagel, 1998).

Advocacy of offering to disclose individual data generated in research either treats such data like a hot potato that

investigators should cool by tossing responsibility for it to subjects or conceptualizes and socially constructs the data as putatively valuable, as something subjects could generally and reasonably want, a suitable thank-you gift for participation. Both views misrepresent the goals of research and the obligations of researchers, and treating such data as valuable participates in and perpetuates therapeutic misconception. Research is a context where respect for the personhood of each subject requires adherence to standardized welfare protections that admittedly may not afford the maximal possible benefit to each participant. Affording such individual benefit and recognizing its subjective nature is appropriate to clinical care, but not to research, where the goal is the social benefit of generalizable knowledge. 

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# Learning to Avoid Research Misconduct—in Any Language

*Martin Strosberg, Glenn McGee, Robert Baker, Eugenijus Gefenas*

Advances in stem cell research involving somatic cell nuclear transfer reported by Hwang et al. (2004, 2005) in South Korea were at least in large part fabricated, produced not only by individual scientists but in concert by what investigators in that nation describe as the conspiracy of coauthors from several institutions, including agencies of that government. Seldom if ever has scientific misconduct involved such intricacy of wrongdoing, tit-for-tat accusations, conflicts of interest, and even across-the-border payoffs to scientists' families.

And never has bioethics been “used” more effectively: Hwang gave a US\$250,000 grant to one influential South Korean official to conduct a “study” of bioethics, surrounded himself with American ethicists, and, most notably, supported the development of (and purported to have executed a protocol for) the ethical procurement of eggs, which involved so much continuing involvement by ethicists that Hwang was able to honestly claim that his effort was devoted to bioethics.

It turns out, though, that the purposes bioethics served, in reporting on the implementation of an ethical practice, were not those the bioethicists intended. And even had the results of Hwang's 2004 and 2005 publications on somatic cell nuclear transfer proved to be true, the violations of research ethics in his lab and more broadly in that effort are an indicator, if there ever was one, of the need for training research ethics for frontier science. Cho, McGee, and Magnus (2006) note, for example, that “it was reported that 85% of over 900 biotechnology researchers surveyed in South Korea did not know what the Declaration of Helsinki was, and that 42% did not know about Institutional Review Boards.”

Although Hwang was financially well supported by the South Korean government, that nation's total expenditure on scientific research is comparatively small. Hwang himself accounted for his success in at least one prominent forum by invoking the “chopstick

theory of scientific supremacy,” by which he meant that his highly devoted and mostly junior staff labored intensely, forgoing even the most meager release time from their duties (Plotz, 2005).

In other nations, clinical activity in stem cell research has proceeded much further. This is nowhere as noticeable as in Russia. Clinical “treatments” involving stem cells have proceeded at breakneck pace in that nation, where by any measure the very poor and even the tiny middle class receive terrible health care, but the wealthy and powerful—and even some who are poor and desperate—avail themselves of boutique clinical services consisting

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**How does one create a generation of researchers and research ethicists in a country that has been isolated from the international community for a half-century or more, that missed the bioethics revolution and the development of modern research ethics, and that has no formal tradition of research ethics?**

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of injections of both adult and embryonic stem cells. These so-called therapies are purveyed as internationally as possible because researchers and clinicians in Russia are not constrained by the politics of the stem cell debate or any resulting regulation. The result is extraordinary, if one believes the leaders of clinics where such therapy is available. Dr. Alexander Teplishin, head of one clinic, told the British Broadcasting Company that “when you inject stem cells [into] someone it's like putting good petrol in your car . . . the person blossoms. . . . Stem cells help fix any organs that have problems” (Grammaticas, 2006).

Facilities like that run by Teplishin are framed as beauty clinics, but their

leaders describe themselves as scientists whose work will lead to Russia's having the status of a pioneer in stem cell research. The head of Russia's public health agency has expressed grave concern about the clinics and the unethical research offered in them. Clinics claiming to be able to make the paralyzed walk—now—are among those with which she deals, and indeed Russia has closed down many such clinics. But it has also licensed at least two. Research ethics is not just a matter for discussion in Russian universities and ethics committees; it is a pressing matter for yet another nation engaged in frontier research with only limited resources for building policies based on ethical principles or for teaching and policing research ethics. And this is true also for much of Central and Eastern Europe.

Those whose countries fell under the sway of communism were isolated from the international community by bureaucracies and borders, and, most notoriously, by walls like the one that divided Berlin. Like most other countries, the countries that once lay behind the Iron Curtain now adhere to the voluminous body of laws and regulations promulgated by the European Union and the Council of Europe to protect human subjects and promote scientific integrity. They also subscribe to various national and international ethical codes, guidelines, and declarations. Laws, regulations, and codes are one thing; implementing them is another. Implementation requires social and intellectual infrastructure, political support and authority, resources, and management expertise.

But how does one create a generation of researchers and research ethicists in a country that has been isolated from the international community for a half-century or more, that missed the bioethics revolution and the development of modern research ethics, and that has no formal tradition of research ethics? The answer begins with education. Central and Eastern European research ethics is a central focus for

the Alden March Bioethics Institute (AMBI), in Albany, NY. Funded by the U.S. National Institutes of Health Fogarty Institute, the Advanced Certificate Program is offered in partnership with the medical faculty of the University of Vilnius in Lithuania to teach research ethics in Central and Eastern Europe (see [www.bioethics.net/europe/index.php?id=index](http://www.bioethics.net/europe/index.php?id=index)).

Currently the program has 15 students (including physicians, scientists, and lawyers) from 11 countries in Central and Eastern Europe and the former Soviet Union. The students chosen to participate have shown promise in their positions in academic departments, national ethics committees, and bioethics commissions. The 18-month Advanced Certificate Program is designed not only to educate them about research ethics but also to make a difference in their career trajectory. Most of the courses are taught online, supplemented by a few short intensive seminars or practica taught in Eastern or Central Europe. The online courses are taught by teams of American faculty (from AMBI) and European faculty (from Estonia, Germany, Lithuania, Poland, Russia, and the United Kingdom) who tailor discussion of international bioethics and research ethics—including research integrity—to the Eastern and Central European context. The practica are designed to teach and assess skills in reading research protocols and mediating disputes. Students also carry out projects in their home institutions: developing and teaching short courses on research ethics, conducting empirical studies of research ethics practices, writing and implementing policies and standard operating procedures for research ethics committees, improving the management of research ethics committees, and influencing the public policy agenda of governmental bodies and nongovernmental organizations.

The collaboration has proved extraordinarily productive for both faculty members and students. Curriculum brings into focus areas of overlapping consensus but also subjects where interpretations of concepts, precepts, and principles differ subtly or even dramatically.

Similarly, as the American AMBI faculty members work with their European colleagues to design and deliver distance-learning courses, areas of

profound differences in beliefs about what constitutes effective pedagogy come to the surface. Yet goodwill and an underlying belief in the value of the enterprise have prevailed. Three of the seven courses in the program have been launched. Ideally, the program aims to do more than train a few dozen research ethicists, furnish them with certificates, and burnish their careers. The aim is to produce a critical mass of research ethicists, supported by an ongoing online community, who will provide the kernel of an intellectual and social infrastructure for a robust research ethics community in Central and Eastern Europe.

Perhaps nothing could have prevented a sole researcher from engineering great fraud in South Korea. But the collusion of so many—involving pressures on junior researchers, participation by unwitting political officials, international partnerships based on insufficient information, and perhaps most important, the successful exploitation of bioethics, ostensibly to prevent the discovery of misdeeds by those who invited us in—would have been much less likely had a well-developed program in research ethics been in place. Bioethicists cannot stop misdeeds, and indeed we ourselves are not perfect. But our experiment in the teaching of research ethics in Central and Eastern Europe is predicated on the view that well-intentioned partnerships to develop capacity in research ethics are the first step toward preventing research misconduct generally—and in particular to prevent the export of the South Korean catastrophe. 

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## Nursing Matters

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cases of refusal of life-sustaining therapies came before the courts, healthcare professionals again claimed (among other arguments) that their professional integrity was threatened when they were asked to withdraw Karen Ann Quinlan's ventilator or Paul Brophy's feeding tube. Again the courts disagreed, affirming that death with dignity was a benefit that some might value over prolonged life. Today healthcare professionals are again challenged by different definitions of harm and benefit. How are we to reconcile ourselves with the fact that for some groups in America, continued life, even a life in the intensive care setting, has value? Or that doing everything, rather than representing torture, can be a "good" to be promised and defended by a loving family? America was arguably founded on religious tolerance. How do we recognize and honor religious values that differ from those held by most healthcare professionals?

American healthcare professionals practice in the most unjust healthcare system in the world because as the richest nation in the world, which spends the greatest percent of gross domestic product on health care, we tolerate the fact that 15 out of every 100 Americans lack health insurance. How do we keep from having end-of-life care become just another arena for inequity? Claiming that medical futility is primarily a challenge to professional integrity is wrong-headed. Instead, the issue of differing preferences for aggressive care at the end of life is an issue of social justice and religious tolerance. How we resolve these issues is as much a political question as it is a medical one. As this debate ensues in the courts and legislatures, the challenge for professionals is to learn to provide *life with dignity* just as we struggled to learn to provide death with dignity a few short decades ago. 

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## Letter from the President

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journals continue to benefit both our members and the journals.

ASBH will continue to grow and to reflect your needs and values. We will grow because we are an interdisciplinary home for scholars of bioethics and the medical humanities. And we will reflect your values because the accomplishments I've just listed could never have occurred without the dedication of hundreds of ASBH member volunteers. These members make our organization what we want it to be. 

# 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 by e-mail at Les.S.Rothenberg@kp.org. An alphabetical list of all references in this and past columns can be found on the ASBH Web site at [www.asbh.org/exchange/biblio.htm](http://www.asbh.org/exchange/biblio.htm).

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# Challenging Voices

## ASBH 8th Annual Meeting

### October 26–29, 2006

**Denver Marriott City Center, Denver, CO**

The ASBH 2006 Program Planning Committee has been working since last fall to put together an inclusive, innovative, and interactive program for the 8th Annual Meeting. The conference will feature an array of preconference workshops, interdisciplinary panels, workshops, and paper and poster presentations.

This year's meeting will be organized around the theme "Challenging Voices," and sessions will address such questions as these: Is bioethics being subverted by corporate or other agendas? Can the medical humanities reframe the key medical issues of the day? Is advocacy for policy change a professional obligation for bioethics and medical humanities practitioners? Who is challenging us, and

why? And how should we be challenging each other? Whose voices do we listen to?

Plenary sessions will address the theme from different perspectives:

- Sally Satel, MD, author of *PC, MD: How Political Correctness Is Corrupting Medicine* and scholar at the American Enterprise Institute, will present "Who Needs Medical Ethics?"
- Richard Lamm, JD, former governor of Colorado and current codirector of the Institute for Public Policy Studies at the University of Denver, will present "A New Moral Vision for Health Care."

Richard Krugman, MD, pediatrician and dean of the University of Colorado

School of Medicine, will be featured in the session "Is a Health-Based Child Protection System Feasible?"

As in past years, the committee has reserved time for exploration of late-breaking issues in bioethics.

Additional events include an art exhibit at the conference, an evening outing to the Denver Art Museum and the new wing by architect Daniel Liebeskind, and a daylong public service activity in Denver.

The committee is excited about our 8th Annual Meeting, and we are grateful for the participation of all ASBH members. We look forward to seeing you this October in Denver. (Please go to [www.asbh.org](http://www.asbh.org) for more information.)

## ASBH Meet-the-Professor Program

The ASBH Meet-the-Professor Program gives students and early-career scholars an opportunity to meet with distinguished faculty in bioethics and the medical humanities at the annual meeting. This year's mentoring breakfast will be held 7:30–8:45 am, Friday, October 27, 2006, in Denver.

Students will be assigned to mentors according to the area of interest selected on the registration form: arts, literature and cultural studies, clinical ethics, education, empirical research, history, law, philosophy, policy and public health, religious

studies, research ethics, or social science. Students are responsible for sending biographical information or a curriculum vitae to the mentor before the meeting so that time spent on introductions during the session can be minimized.

There is no additional fee for the mentoring session, but advance registration is required. Additional information and a registration form will be included in the ASBH annual meeting registration confirmation letter.

## Early-Career Scholars: Support for Travel to the 2006 ASBH Annual Meeting

The ASBH Early-Career Scholars Program offers support to early-career scholars and students for travel to the 2006 ASBH Annual Meeting. For information and an application form, visit the ASBH Web site at [www.asbh.org](http://www.asbh.org), or contact Amy Claver at [aclaver@connect2amc.com](mailto:aclaver@connect2amc.com). The deadline for receipt of requests is **August 25, 2006**.



# ASBH

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Bioethics and Humanities

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