
Professional Ethics Report

Publication of the American Association for the Advancement of Science
Scientific Freedom, Responsibility & Law Program in collaboration with
Committee on Scientific Freedom & Responsibility
Professional Society Ethics Group

VOLUME XVI

NUMBER 3

Summer 2003

Good Stewards or Bad Censors?

By Michele S. Garfinkel, Ph.D.

Michele Garfinkel is a project director at the Center for the Advancement of Genomics in Rockville, MD. Her research focuses on the societal impacts resulting from the professional conduct of science. The opinions expressed here are strictly her own and do not reflect the official policies or opinion of the Center.

The study of the “social contract” with science is well-worn ground. Various commentators have described in remarkable detail the relationship between scientists, institutes of science, government, universities, industry and society as a whole.¹ The contract, which declares that society will support (both in principle, and monetarily) unfettered research and in return science will contribute to the common good, has rarely been breached: the most well-known examples tend to be the notorious, such as incidents of research misconduct. Generally, the breaches that receive the most attention are those of the scientists. Other breaches do occur, but are not generally subject to public discussion, as they fade away before real damage is done. One recent example was the bill introduced 10 July 2003 in the House by Pat Toomey (R-PA) and Chris Chocola (Toomey/Chocola amendment) to amend the fiscal year 2004 House version of the Labor, Health and Human Services, Education, and Related Agencies (L/HHS) appropriation bill. This amendment was aimed at defunding specific research projects funded through the National Institutes of Health (NIH).²

Normally, NIH funds research projects by a grant process that, first, takes into account the scientific merit of the project—asking simply, is this good science? This is done within a study section, composed of a group of scientists who review, and then priority order the grants according to their understanding of each grant’s scientific value. This list is then sent to an overarching Council, where projects can be judged for “social” merit as well as scientific merit. In practice, however, Councils take the advice of the study sections, and grants are distributed based almost solely on their scientific merit.

What happens, though, if money is granted in a way that specific actors in the governance of science (for example, legislators) find distasteful? Normally, nothing. The “social contract” dictates that scientists be trusted to self-regulate and do good work;

society will see the benefits, and everyone is happy. Occasionally, legislators will disapprove of specific research programs and attempt to strip them of their funding. But individual NIH grants are rarely defunded, again, in part because funding approval has been made by at least two levels of reviewers.

Although legislators do try to sculpt funding for the good of their constituents (both by earmarking and by deleting funding), one aspect of the Toomey/Chocola amendment was particularly noteworthy: the unusually close vote. Despite tremendous support typically for the activities of the NIH at all levels of government, this amendment was defeated by the barest of margins, 210-212.

The reaction of several scientific societies to this vote was predictable, bemoaning the insertion of raw politics into the peer review process. But it is unclear if there would have been any reaction to the amendment had not the vote on it been so close. Although many leaders of these groups expressed shock that “it came up so quickly that our leadership hadn’t even had a chance to consider it,”³ some societies at least were able to alert their members, requesting they send letters to their respective Representatives.⁴ Several of these societies anticipate the introduction of similar amendments when the Senate takes up its appropriations bills.

Although it takes only one fringe member of any legislative body to introduce such legislation, the near-even vote (which was not strictly party-line) should evoke some trepidation from those who identify themselves as part of the community interested in public perception or public understanding of science. The professional societies particularly have explicit or tacit missions to educate the public about science, which presumably includes some understanding of the modern scientific enterprise. Part of the problem is that while much effort has been put into making difficult scientific concepts digestible,⁵ the role of peer review in research funding has not been well explained.

Peer review, while straightforward in theory, is a complicated enterprise in fact, and includes many aspects beyond the review of scientific merit alone. These additional aspects usually manifest themselves outside of the study sections, occasionally at the Council meetings that occur after peer review, sometimes via priority-setting exercises. Yet it is the merit review aspects that grab the attention of scientists, and the non-merit aspects that engage politicians. The objections to the defunded grants make no mention of scientific merit. While it would no doubt be easier for scientists if politicians were swayed only by the merit of the science, these

(Congress continued on page 2)

(Congress continued from page 1)
politicians would not be doing their jobs if they unquestioningly prioritized scientific merit over societal merit.

If defunding actions by the legislature is a concern of the societies and of scientific institutions generally, then the research community needs to find ways to strengthen their arguments showing linkages between scientifically meritorious research and the public good. If such arguments cannot be made, then the directions of research may need to be rethought, both institutionally and possibly even at the principal investigator level. Practically, NIH might want to reconsider its longstanding objection to having non-scientists on peer review panels, rather than compartmentalized to its Council of Public Representatives,⁶ which has no real power to effect change. The inclusion of non-scientists on scientific review panels has been quite successful for the Army's breast cancer research program⁷, allowing a different point of view to be heard early on, rather than once funds have been committed.

This is not to suggest that Congressional Members do not need to be cognizant of the realities of peer review and the real successes and power of investigator-initiated research. The introduction of the Toomey/Chocola amendment and the House discussion of it reveal unsurprising inconsistencies in the identification of "offensive" projects. For example, at first glance, the selection of

Editor: Mark S. Frankel
Deputy Editor: Kristina Schaefer
Contributing Authors: Kevin Alleman, Brent Garland, Bryn Lander, Crystal Liu

The *Professional Ethics Report* is published quarterly by the Scientific Freedom, Responsibility and Law Program in collaboration with the Committee on Scientific Freedom and Responsibility and the Professional Society Ethics Group, American Association for the Advancement of Science, 1200 New York Avenue, NW, Washington, DC 20005, (202) 326-6217; Fax (202) 289-4950; E-mail: kschaefe@aaas.org; WWW <http://www.aaas.org/spp/dspp/sfrrl/sfrrl.htm>. Back issues of *Professional Ethics Report* are now on-line at <http://www.aaas.org/spp/dspp/sfrrl/per/per.htm>

This newsletter may be reproduced without permission as long as proper acknowledgement is given. ISSN: 1045-8808

these particular grants seemed to indicate a bias against the study of human sexuality. The set of four sexuality grants deal with Asian prostitutes in San Francisco, masturbation in older men, transgendered Native Americans, and state of mind on sexual risk-taking. What is confusing is that these are by no means the only grants on sexuality in the NIH database of funded grants. A glance at the NIH's database of funded grants suggests no discernible pattern regarding the selection of the particular four grants selected for defunding over other grants studying human sexuality. For example, in fiscal year 2002 alone, 33 unique grants contain the word "sexuality." These included "Social Context and HIV Risk Among Mexican Gay Immigrants," "Female Sexual Arousal: Clitoral and Vaginal Physiology," and "Sexuality, HIV/ Drug in 3 Groups of Asian/Gay/Bi Men/ MSM [men who have sex with men]." Yet none of these was singled out for defunding. Another clue to why the vote was so close may be the many times in the transcript of the floor debate that Representatives told stories about constituents seeking help, wanting more money for NIH to "find a cure" for a terrible disease suffered by themselves or their family members.⁸ Some members of Congress (or their constituents) may believe that only "debilitating disease" is worthy of study by the NIH, and therefore object to other areas of research. Whether that is an appropriate stance towards NIH research or not, such positions need to be debated openly and honestly, recognizing that management of research at the project level will always leave out a particular group or include a particular group in a way that looks arbitrary, or does not seem to display the same possibility of return on investment. To some extent, what constitutes a "good" study will always be, to some degree, subjective, scientific merit notwithstanding.

Although we cannot (and would not want to) subject particular projects to a direct vote ("vulgar democracy"), it is certainly within the realm of legitimate governmental action, particularly as practiced by the Congressional branch of the US government, to weigh the tradeoffs between funding different kinds of programs within appropriations committees (at least one aspect of "enlightened democracy").⁹ Classes of research can certainly be

Letters to the Editor: The editors welcome comments from our readers. We reserve the right to edit and abridge letter as space permits. Please address all correspondence to the deputy editor.

excluded but these exclusions are rare (and frequently controversial, as with human embryonic research). The problem with the Toomey/Chocola amendment is in the arbitrariness of the actions of the amendment. In this case, although the identified projects are few in number, the selection criteria, or lack thereof, in identifying the research to defund are crucial. Further, the mandate of the legislative branch with regard to science is somewhat different than the executive: in the latter case, funding good science, informed by peer review, is at the forefront. Legislators, though, have a distinctly different goal: control spending in a way that reflects their constituents' needs. Most of the time, these goals interleave, resulting in good science for society. But occasionally these groups find themselves working at cross purposes; scientists, science, and society all suffer.

A growing unease in the research community is not attributable to the actions of the Congress alone: there is a sense that the Executive branch as well is moving beyond its knowledge base in its interference in things scientific. The current Bush administration's presumptive transgressions have been documented by the staff of Representative Henry Waxman (D-CA).¹⁰ These range from the "manipulating scientific advisory committees" (which is a purely political, though legal, move), to "distorting and suppressing scientific information" (including the Administration's statement that "more than 60" stem cell lines were available, when it now appears to be closer to ten¹¹), to "interfering with scientific research." As with the concerns over the Congressional amendments, the question arises as to whether such issues that might influence scientific research are primarily moral issues (Toomey's argument in his part of the amendment) or national interest issues (Chocola's argument). Certainly, any administration could argue a national interest concern in virtually all of its forays into the inner

(Congress continued on page 3)

(Congress continued from page 2)
sanctums of science and these could be legitimate areas of concern for both the legislative and executive branches. How the executive branch deals with national interest issues will become more important as the linkages between research and national security become more explicit.

Although all of the players in this particular debate professed a general admiration of NIH and basic research, not all those with legislative or executive power may feel that way. Basic biomedical research, and NIH-funded research particularly, has been fairly critic-proof for the last several decades. The close vote on the Toomey/Chocola amendment may be an indicator of a growing frustration that 30 years, or 60 years, of “pure, basic, unfettered research” has really not resulted in a demonstrable payback of increased health, with a few exceptions. This vote may be a bellwether for a change in that unfettered status; scientists, professional groups, and politicians who value the basically free conduct of research science should take these recent legislative and executive actions seriously. There must be open public discussions regarding the actions of the government in changing the course of scientific research. These discussions need to happen before the fact, not after the defunding action has been taken. *Ex post facto*, they are merely handmaidens to protesting perceived censorship. Public discussion optimally can result in a sense of inclusion for all, thus minimizing the impact of “unsuccessful” research, and helping scientists, politicians and the public to clarify the proper roles for all the actors in research science, if we want the “social contract” with science to continue to accrue to the common good.

¹ For examples, see: Michael Gibbons. 1999. “Science’s New Social Contract with Society.” *Nature* 402: C81-C84; David H. Guston. 2000. Retiring the Social Contract for Science. *Issues in Science and Technology*; Summer. Available at http://www.nap.edu/issues/16.4/p_guston.htm.

² The relevant language was as follows: “Sec. X: None of the funds made available in this Act for the National Institutes of Health may be used to fund grant number R01HD043689, R03HD039206, R01DA013896, or R01MH065871.”

¹ Ted Agres. 2003. “Politicizing research or responsible oversight?” *The Scientist Daily News* 14 July;

Quotation from Howard Garrison, Public Affairs Director, Federation of American Societies for Experimental Biology. <http://www.biomedcentral.com/news/2003714/05>

⁴ American Psychological Association. 2003.

Action Alert on NIH Peer Review. <http://www.apa.org/ppo/ppan/nihpeerrevaa703.html>; American Sociological Association. 2003. *Emergency Science Policy Action Alert*. http://www.asanet.org/members/peer_review.html; The Federation of Behavioral, Psychological, and Cognitive Sciences. 2003. *Review of the NIH Peer Review Issue*. <http://www.thefederationonline.org/PeerReview.html>

⁵ Attesting to a belief by some that by making these concepts “clear enough” lay people would, as a result, be supportive of any given line of scientific inquiry.

⁶ <http://copr.nih.gov/>

⁷ Bruce Agnew. 1999. “NIH invites activists into the inner sanctum.” *Science* 283: 1999-2001. <http://www.sciencemag.org/cgi/content/full/283/5410/1999>

⁸ Transcript available at <http://www.apa.org/ppo/issues/nihtoomeydebate.html>

⁹ Philip Kitcher. 2001. *Well-Ordered Science. In Science, Truth, and Democracy*. Oxford University Press (New York), p. 117.

¹⁰ United States House of Representatives, Committee on Government Reform—Minority Staff, Special Investigations Division. 2003. *Politics and Science in the Bush Administration*. www.reform.house.gov/min

¹¹ Elias Zerhouni. 2003. Testimony. Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education, *Federal Funding for Stem Cell Research*, May 22 (108th Congress).

IN THE NEWS

The Art of Regulating ART

With the release of the cloning report¹ in July 2002, the President’s Council on Bioethics decided to conduct an inquiry into the pressing ethical issues associated with advances in biotechnologies and practices associated with assisted reproductive technologies (ART), genetics and human embryo research. To that end, the Council has been discussing a working paper, “U.S. Public Policy and the Biotechnologies That Touch the Beginnings of Human Life,”² that examines what circumambient societal goods and values are potentially influenced—for better and for worse—by the increasingly converging fields of developmental and reproductive biology, and genetic technologies.

The Council has heard from numerous scientific and policy experts and others who are vested in the governance of these technologies, whether by self-regulation or by public oversight. The most recent draft paper³ proposes “consensus recommendations” as guidelines to improve the monitoring and oversight of assisted reproductive technologies. The recommendations attempt to address concerns that the technologies and practices might be implemented in an untoward manner, such as whether preimplantation genetic diagnosis used to prevent X-linked genetic disease or intracytoplasmic sperm injection used for male factor infertility will be used for the purpose of selecting the sex of the child-to-be for reasons of family balancing. Moreover, the paper acknowledges that concerns are raised about whether these technologies will have an adverse affect on the women and children-to-be, matters for which no thorough scientific study exists.

In the United States, the multimillion-dollar infertility industry is self-regulated and is for the most part unhampered by federal regulations, unlike other areas of biomedicine such as the regulations governing the protection of human participants in clinical research. All federally funded institutions that involve human participants in research must adhere to the strict guidelines set out under the *Common Rule* (45 CFR 46). The absence of federal regulations and public funding for human embryo research, unlike research involving human participants, stems from the aftermath of the 1973 *Roe v. Wade* decision and the government’s reluctance to intrude into a politically sensitive issue that involves clashing moral views over abortion and when life begins, i.e., the moral status of the embryo. The funding policy for such research has only been recently changed by the Bush Administration’s announcement on 9 August 2001 to permit federal funds for research on pre-existing embryonic stem cell colonies, but to prohibit support for research on colonies created after the announcement.

The Council’s paper is still a work in progress, with a final report expected by November. That timetable was influenced in large part by uncertainty about whether the Bush Administration would extend the

(News continued on page 4)

(News continued from page 3)

Council's charter, due to expire at the end of November. The uncertainty ended on September 17, when the President issued Executive Order 13237 extending the charter effective through 30 September 2005. *KA

¹ President's Council on Bioethics, *Human Cloning and Human Dignity: An Ethical Inquiry*, Washington, D.C., 2002; www.bioethics.gov/reports/cloningreport/fullreport.html.

² As of this writing, the staff working paper is separated into 4 sections—overview, findings, policy options, and draft recommendations—all of which can be found online at www.bioethics.gov/background/.

³ Staff Working Paper: "U.S. Public Policy and the Biotechnologies That Touch the Beginnings of Human Life: Draft Recommendations."

EPA TAKES NEW APPROACH TO ADVISORY COMMITTEE APPOINTMENTS

The Environmental Protection Agency's Science Advisory Board (SAB) recently issued a request to the public for nominations of experts for the Bioethics Advisory Committee (BAC), which will advise the EPA on "ethics issues that might arise in a number of situations involving the generation and/or use of human and animal data."¹

A second stage of public input comes in the form of inviting public comment on the short list of candidates for the BAC by posting their names and bios on the SAB website. During the comment period (21 calendar days), the public is asked to contribute to the evaluation of the nominees by providing information on the candidates.²

These two stages involving public input are all part of the formal process of panel formation adopted by the EPA's Science Advisory Board in May of 2002. This process was designed by the Policies and Procedures Subcommittee (PPS), created in response to concerns in a report issued by the General Accounting Office, *EPA's Science Advisory Board Panels: Improved Policies and Procedures Needed to Ensure Independence and Balance*.³

The PPS created a four-stage process, two of which involve public input, in an attempt to address and ameliorate two main concerns:⁴

- 1) that the members of each panel are independent and that the panels themselves are balanced⁵
- 2) that the public is properly informed about the formation of each panel

It may be a little premature to assess the effects of this process of panel formation, but on the surface it does seem to have widened the scope of public involvement. Posted on the SAB Federal Register Notices are several requests for nominations for panelists – the Council for Regulatory Environmental Modeling Guidance Advisory Panel and the Panel on Illegal Competitive Advantage Economic Benefits, to name a couple.

On the other hand, the public has no control over two other stages of the process – the formation of the short list and the final panel selection.⁶ Thus, it remains to be seen whether the opportunity to nominate candidates and provide feedback on nominees has significant impact on the overall process. *CL

¹ "SAB Federal Register Notices." EPA Science Advisory Board. Available on-line at: <http://www.epa.gov/science1/federal.htm>

² "Science Advisory Board, Request for Nominations, Bioethics Advisory Committee (BAC), an ad hoc Committee of the U.S. EPA Science Advisory Board." EPA: Federal Register. Available online at: <http://www.epa.gov/fedreg/EPA-SAB/2003/July/Day-10/sab17511.htm>

³ GAO-01-536. June 12, 2001.

⁴ EPA-SAB-EC-COM-002-003. Available online at: <http://www.epa.gov/science1/pdf/ecm02003.pdf>

⁵ As stated in EPA-SAB-EC-COM-002-003, a balanced panel is characterized by inclusion of the necessary domains of knowledge, the relevant scientific perspectives (which, among other factors, can be influenced by work history and affiliation), and the collective breadth of experience to address the charge adequately.

⁶ EPA-SAB-EC-COM-002-003. Available online at: <http://www.epa.gov/science1/pdf/ecm02003.pdf>

MEDICAL SCHOOL SURVEYS RAISE PRIVACY CONCERNS

On July 21, 2003, Public Citizen, a public interest group, issued a letter to the acting director of the Federal Office for Human Research Protections, asking for an investigation into the "unethical and possibly illegal research" conducted by

the Association of American Medical Colleges (AAMC). The research in question is the Graduation Questionnaire (GQ), given to graduating medical students by AAMC, in partnership with 126 American medical colleges. Begun in 1978, more than 15,000 students are now surveyed annually, with a response rate of 91% in 2002.

The questionnaire's stated goal is to help medical colleges improve the quality of their programs. While Public Citizen agrees that a GQ is useful, it argues that the survey should be conducted in a more ethical fashion. The very nature of the questionnaire, which includes such personal questions as student debt and views of the current health care system, causes it to transcend education evaluation into a broader research scope. Specifically, Public Citizen points to the coercive nature of the GQ (students who don't participate are often penalized); the lack of Institutional Review Board (IRB) involvement; and the use of its data in journal articles without student permission.

Public Citizen argues that these three factors put the GQ, the AAMC, and its partner medical colleges, in violation of the Federal Policy for the Protection of Human Subjects and several international standards related to human subjects research. Public Citizen urges that IRBs be implemented on the College and AAMC level, and that for students taking the questionnaire, coercion be eliminated and information about the potential uses of the data be disclosed.

The AAMC response, published July 23, 2003, argues that Public Citizen has fundamentally misunderstood the nature and purpose of the survey, which solely evaluates education programs, not individuals, and that questionnaire answers are only released with student permission. In addition, AAMC had already initiated an in-house IRB.

For additional information see the following:

Public Citizen's Letter "Publication Letter to HHS Urging a Federal Investigation of Medical Schools Conducting Unethical Research on Their Own Students" July 21, 2003, Available online at:

(News continued on page 5)

(News continued from page 4)

<http://www.citizen.org/publications/release.cfm?ID=7268&secID=1158&catID=126>

“AAMC Responds to Public Citizen’s Complaints about Medical School Graduation Survey”. July 23, 2003. Available online at: <http://www.aamc.org/newsroom/pressrel/2003/030723.htm>

The Graduate Questionnaire homepage: <http://www.aamc.org/data/gq/start/htm>.
*BL

INTERACADEMY PANEL ISSUES STATEMENT ON HUMAN CLONING

The InterAcademy Panel on International Issues (IAP) issued a statement on September 22, 2003, calling for a worldwide ban on human reproductive cloning. The statement, endorsed by over sixty member science academies from all over the world, will be presented to delegates of the United Nations Committee on Cloning¹.

This Ad Hoc Committee was created by the United Nation’s General Assembly in 2001² for “the purpose of considering the elaboration of an international convention against the reproductive cloning of human beings.”³ Almost two years later, the committee still has not issued a convention endorsing a ban on cloning, largely in part from internal disagreements regarding whether the ban should extend to cloning for research and therapeutic purposes.

The IAP declaration endorsed a ban on reproductive cloning of humans, but excludes cloning to obtain embryonic stem cells for research and therapeutic purposes. They stated that at present, scientific knowledge and technology are not at a point where human reproductive cloning can be performed without significant threat to both the cloned human and pregnant mother. Even if these barriers were overcome, they held that strong ethical, social and economic objections would continue to argue against human reproductive cloning.

The IAP goes on to distinguish between human reproductive cloning and cloning for research and therapeutic purposes – while they both involve “generating a human blastocyst via somatic cell nuclear transfer [...] the crucial difference is that the cloned blastocyst is never implanted

into the uterus”⁴ in cloning for research and therapeutic purposes. Instead, the cloned blastocyst is used to make stem cell lines. There is a general consensus among scientists that embryonic stem cells hold tremendous potential for medical treatment. This consideration was key in why the IAP, while endorsing a ban on human reproductive cloning, did not extend it to include cloning for research and therapeutic purposes. *CL

¹ The UN Committee on Cloning is scheduled to meet at UN headquarters in New York City from 29 September to 3 October 2003.

² Resolution 56/93 of 12 December 2001

³ “Ad Hoc Committee on an International Convention against the Reproductive Cloning of Human Beings.” Available on-line at: <http://www.un.org/law/cloning/>

⁴ “Statement on Human Cloning from the InterAcademy Panel on International Issues.” Available online at: <http://www4.nationalacademies.org/news/nsf/isbn/s09222003b?OpenDocument>

OMB PROPOSES INCREASED PEER REVIEW REGULATION

A proposed Bulletin released on August 29, 2003 by the Office of Management and Budget’s (OMB) Office of Information and Regulatory Affairs (OIRA), proposes basic standardization of the peer review process for significant regulatory science documents (defined as any science that is influential and relevant to regulatory policies) across all governmental agencies. OIRA argues that peer review standardization will introduce a minimum, uniform, government standard; ensure an independent, unbiased, transparent process and make studies, and the regulations that they uphold, more credible.

According to the Bulletin, agencies will still formulate their own peer review process for most regulatory science documents. But for studies that will be widely disseminated, have an estimated policy impact of more than \$100 million a year, or that are deemed a priority by OIRA’s administrator, the agency will be required to conduct a formal, independent, external peer review based on specific guidelines outlined in the Bulletin. These include an expectation that peer reviewers are unbiased experts, independent of the agency conducting the review, who are given a sufficiently broad mandate and access to all neces-

sary information. In addition, an opportunity must be provided for public comment. Agencies must then consult with OIRA and the Office of Science and Technology Policy (OSTP) regarding the planned review process before it is adopted. For all science and technology studies that will be disseminated in the upcoming year, agencies are required to submit an annual summary and a peer review plan.

Critics of the Bulletin worry that it will increase the time needed to adopt regulations, and that more studies will be discounted, leading to less regulation. They argue that this will enable the private industry to lobby more effectively to have negative studies discounted. In addition, they see the centralization of the current peer review system as taking power from agencies and giving it to White House Offices, with the potential for increased political manipulation, misuse, and mismanagement of the peer review system to advance political agendas.

OMB is calling for public comment on the proposed Bulletin. The deadline for comments is December 15, 2003.

For additional information see the following:
Mckinnon, John D “Regulations Face Stiffer Review in Win for Bush Business Allies” *Wall Street Journal*, Aug. 29, 2003

“Office of Management and Budget: Proposed Bulletin on Peer Review and Information Quality,” *Federal Register*, Vol.68, No. 178, pp.54023-54029

“OMB Bulletin on Peer Review: Making Science Vulnerable to Political Manipulation,” OMB Watch, Aug. 29, 2003 <http://www.ombwatch.org/article/articleprint/1771-1/18/>

“OMB Proposes Draft Peer Review Standards for Regulatory Science,” Office of Management and Budget, Aug 29, 2003, <http://www.whitehouse.gov/omb/pubpress/2003-34.pdf>

Vedantam, Shankar, “Bush would add Review Layer for Rules: Industry Cheers Science Peer-Appraisal Plan; Critics say it will Discourage Regulation,” *The Washington Post*, August 30, 2003, p. A10.
*BL

(News continued on page 6)

(News continued from page 5)

POLITICS AND SCIENCE IN THE BUSH ADMINISTRATION

A report from the Minority staff of the House Committee on Government Reform – *Politics and Science in the Bush Administration* – identifies over twenty issues that, according to the report, have been affected by the Bush Administration’s politicization of science. These include such issues as global warming, abstinence-only education, and environmental health. The report charges the Bush Administration with manipulating scientific advisory committees, distorting and suppressing scientific information, and interfering with scientific research.

More specifically, the staff report charges that the Bush Administration has been manipulating scientific advisory committees by appointing unqualified persons with industry ties and/or ideological agendas, stacking advisory committees, and opposing qualified experts. For example, in 2002, the Department of Health and Human Services proceeded to replace 15 of the 18 members of the National Center for Environmental Health’s Advisory Committee. Several of the new members appointed have close ties to industries that have opposed regulation in public health and environment.

One might claim that a newly elected President, chosen in part because of his policy objectives, should be expected to make appointments to reflect those objectives. However, according to the staff report, the Bush Administration goes “far beyond the typical shifts in policy that occur with a change in the political party occupying in the White House.”¹

In regards to breast cancer, the Bush Administration is charged with distorting information to “misleadingly portray abortion as a risk factor in breast cancer.”² Prior to the summer of 2002, the National Cancer Institute (NCI) held the position that most current studies had generally concluded that there was no association between breast cancer and spontaneous or induced abortions.³ However, in the fall of 2002, the Bush administration altered the NCI website to state:

Some studies have reported statistically significant evidence of an increased risk of breast cancer in women who have had abortions, while others have merely suggested an increased risk. Other studies have found no increase in risk among women who had an interrupted pregnancy.⁴

But contrary to this charge made by the staff report, some have argued that it was not President Bush, but NCI’s website in the summer of 2002 that distorted information. The Coalition on Abortion/Breast Cancer believes that there is overwhelming evidence supporting a positive relationship between the two, and hence applauded the removal of what they called an “inaccurate web page.”⁵

In the midst of all this controversy, one tenet holds true – that potential abuses of science that are not consistent with providing objective and reliable technical information to our policy makers must be guarded against – and this holds true regardless of whether or not one agrees with the accusations brought forth by the staff report. *CL

¹ Politics and Science in the Bush Administration. Available online at: http://www.house.gov/reform/min/politicsandscience/pdfs/pdf_politics_and_science_rep.pdf

² *Ibid*

³ National Cancer Institute, *Abortion and Breast Cancer* (Mar. 6, 2002). Available online at: http://www.house.gov/reform/min/pdfs/pdf_inves/pdf_admin_hhs_info_abc_fact_sheet_orig.pdf

⁴ National Cancer Institute, *Early Reproductive Events and Breast Cancer* (Nov. 25, 2002). Available on-line at: http://www.house.gov/reform/min/pdfs/pdf_inves/pdf_admin_hhs_info_abc_fact_sheet_revis.pdf

⁵ “National Cancer Institute Pulls Inaccurate Web Page Repudiating Abortion-Breast Cancer Link.” Coalition on Abortion/Breast Cancer, Press Release, July 2, 2002. Available on-line at: <http://www.abortionbreastcancer.com/070202.htm>

IN THE SOCIETIES

AAAS HELPS BRING “GALILEO” TO THE STAGE

AAAS and the Studio Theatre in Washington, DC, are joining forces to promote the premier showing in the United States of *The Life of Galileo*, a Bertolt Brecht play adapted by playwright Sir David Hare. In addition to organizing two matinee performances for Washington, DC high school students, AAAS is sponsoring a special matinee for local scientists and their families. This special performance takes place on Sunday, December 7, at 2:30pm, followed by a reception with the actors. To learn more, visit <http://www.aaas.org/spp/galileoplay>.

AAAS LAUNCHES NEW PROJECT IN SCIENTIFIC FREEDOM AND NATIONAL SECURITY

Since 9/11, finding the right balance between national security and maintaining the openness needed for the advancement of science has become more challenging than ever. A new project launched by the American Association for the Advancement of Science (AAAS) intends to address this concern by analyzing the changing relationship between science and national security in five main areas: visa policies and practices, select agent rules, federal grants and contracts, scientific publication policies, and “sensitive but unclassified” information. Through a series of data gathering techniques, AAAS will collect information from scientists and engineers whose professional work has been affected by post 9/11 policies, compiling the results into a database for documentation and analysis. In you have been affected by post 9/11 policies or know of a colleague who has, please visit the project’s website at <http://www.aaas.org/spp/post911>. *BL

SOCIETY FOR RESEARCH ADMINISTRATORS ESTABLISHES SPECIAL INTEREST GROUP

The Society for Research Administrators (SRA) is establishing a Responsible Conduct of Research Special Interest Group. The RCRSIG will have its inaugural meeting at the Annual SRA meeting in Pittsburgh on Sunday, October 19, 2003. For more information, contact Ed Gabriele at efgabriele@earthlink.net.

RESOURCES

GROW OLD ALONG WITH ME?

A REVIEW OF *MERCHANTS OF IMMORTALITY: CHASING THE DREAM OF HUMAN LIFE* EXTENSION BY STEPHEN S. HALL

By Brent Garland

When Robert Browning wrote

“Grow old along with me!
The best is yet to be,
The last of life, for which the first was made.”¹

he pretty much precluded himself from a job at Geron, Osiris Therapeutics, or any of the host of other companies chronicled in Stephen Hall’s account of modern day life-extension research. The book focuses on those scientists and companies that are seeking to understand the mechanisms of aging and, in many cases, retard or reverse such effects, and it is a fascinating read.

Hall’s book is for the general reader, and contains no technical scientific content. Yet, the book is still likely to be of great interest to scientists, as it does an excellent job of reporting on the cultural, political and social forces that influence not only how research is done, but whether it is done at all. Along the way, Hall gives serviceable accounts of the scientific concepts involved, and includes a veritable Who’s Who of scientists and entrepreneurs in the field, including Leonard Hayflick, Elizabeth Blackburn, Roger Pedersen, Cynthia Kenyon, John Gearhart, Irving Weissman, Ali Hemmati Brivanlou, Thomas Okarma, and the seemingly omnipresent Michael West.

The book begins with the discovery of the Hayflick limit in cell biology, leads into the quest for telomerase, and hurdles through the present day biotech frenzy surrounding stem cells, therapeutic cloning, and regenerative therapies. The common link between many of the tales in *Merchants of Immortality* is the involvement of Michael West, the controversial and entrepreneurial scientist who has funded a substantial amount of research personally, through a company he founded, Geron², and through the company he currently heads, Advanced Cell Technology. Hall spends a substantial amount of the book examining the

role West has played in both advancing the science and engendering controversy about it as well.

Hall does not focus on the scientific players alone. Also captured in *Merchants* are the tensions that arise among various groups: academia and industry; scientists and politicians; and anti-abortion activists and research advocates, among others. Hall identifies many key players in the national ethical dialogues surrounding stem cell use, human cloning, and the fundamental issue of whether seeking to extend the human life span is an ethically acceptable goal for science, and recounts their various roles in the still unfolding debates.

Overall, Hall has produced a provocative book that will serve as an excellent primer for those who want to acquaint themselves with the current scientific questions and societal controversies surrounding human life-extension. For those unfamiliar with the policy aspects of science, the sections of the book dealing with President Bush’s stem cell policy and the Congressional hearings on cloning will offer an arrow glimpse into the policy arena. For people interested in the ethical issues raised by life-extension research, *Merchants of Immortality* provides a rich background of context in which to examine the issues involved, as well as for considering how those questions are addressed and discussed at a national level.

Hall, Stephen S. *Merchants of Immortality: Chasing the Dream of Human Life Extension*. Houghton Mifflin, 2003. \$25.00

¹ From Browning’s “Rabbi Ben Ezra.”

² Dr. West is no longer affiliated with Geron. His departure from Geron and his joining of Advanced Cell Technology is covered in the book.

BLOODLINES, PBS DOCUMENTARY ON GENETIC AND REPRODUCTIVE TECHNOLOGIES, NOW AVAILABLE

The *Bloodlines: Technology Hits Home* project is a coordinated PBS documentary, web site and (free) discussion guide now available to educators and professionals. Produced by award-winning Backbone Media, *Bloodlines* uses actual legal cases to explore how genetic and reproductive technologies challenge many of our fundamental beliefs about

what it means to be human, to be a parent, to inhabit our bodies, and to have rights.

We seldom have the opportunity—or the tools—to explore systematically the relationship between our gut-level feelings and our fundamental beliefs. The intersection of biotechnology and the law, however, creates a unique and compelling chance to do just that. Through actual cases, *Bloodlines* helps articulate the direct relationship between what we feel, the fundamental, ethical and philosophical principles embedded in those feelings, and the legal institutions and social relations we have built to honor them.

In *Bloodlines*, broader social and ethical dramas emerge from very closely observed local one: a technology patent case raises the very basic question of what constitutes a human being; a conflict involving reproductive technology highlights the fundamental problem of who is a parent; an employment discrimination suit challenges our ideas about who has a right to our bodies and the meaning of “normal.”

Bloodlines will be the focus of a special symposium at the AAAS 2004 Annual Meeting (Seattle, February 15). *Bloodlines* is on the web at <http://www.pbs.org/bloodlines>, and copies of the film and the free discussion guide are available by emailing education@backbonemedia.org.

JOINT EFFORT RELEASES MODEL CURRICULUM IN ETHICS AND PUBLIC HEALTH

A collaborative effort among the Association of Schools of Public Health (ASPH), the Health Resource Services Administration (HRSA) and The Hastings Center, with additional support from the Robert Wood Johnson Foundation, has resulted in a model curriculum for teachers of ethics in schools of public health and professional public health settings. The curriculum is designed to enhance and encourage thoughtful, well-informed and critical discourse of the ethical issues inherent in the public health field. The curriculum consists of self-contained modules, each written by a leading expert in the area. The curriculum, in its entirety or module-by-module, can be downloaded free of charge at <http://www.asph.org/document.cfm?page=723>. For a hardcopy, or more information, contact Monica Stadler at mstadler@asph.org.

Professional Ethics Report

Scientific Freedom, Responsibility and Law Program
American Association for the Advancement of Science
1200 New York Avenue, NW, Washington, DC 20005

ANNOUNCEMENTS

Conference — The **Center for Academic Integrity's** International Annual Conference will be held October 17-19, 2003 at the University of San Diego. The theme is "Integrity in our Institutions: Leadership, Courage, and Commitment." For more information call 919-660-3045, or visit <http://www.academicintegrity.org>.

Call for Papers and Meeting — A special session for the presentation of undergraduate papers will be held at the **Annual Meeting of the Association for Practical and Professional Ethics**, February 26-28, 2004. The deadline for submission of papers is October 30, 2003. The meeting registration fee will be waived for those students whose papers are accepted. More information is available at <http://www.indiana.edu/~appe>.

Fellowships — Applications for the 2004-05 Faculty Fellowships in Ethics at the **Harvard University Center for Ethics and The Professions** are now being accepted. Applicants with a professional degree in law, medicine, business or government, or a doctoral degree in philosophy or related discipline are encouraged to apply. The application deadline is December 4, 2003. For more information, visit <http://www.ethics.harvard.edu>.

Fellowships — The **University Center for Human Values at Princeton University** is currently accepting applications for the 2004-05 Laurence S. Rockefeller Visiting Fellowships. Those awarded the fellowship will devote a year in residence at Princeton, writing on ethics and human values. Applications are due December 5, 2003, and recipients will be announced on March 15, 2004. For more information, visit <http://www.princeton.edu/values>.

Conference — **PRIM&R's** 2003 Annual IRB Conference will be held from December 6-7, 2003 at the Marriott Wardman Hotel in Washington, DC. This focus of this year's conference is "Reclaiming the Belmont Principles for Human Research Protections: Looking Back to Move Forward." Just prior to the conference, on December 4, PRIM&R will offer eight educational programs for beginners or those in need of a "refresher" in research regulations and ethics. The Applied Research Ethics National Association (ARENA) will hold its 18th Annual Meeting on December 5. For more information, visit www.primr.org.

Fellowships — The **Institute for Advanced Studies on Science, Technology, and Society (IAS-STS)** is offering 5 grants for fellowships at the IAS-STS in Graz, Austria from October 1, 2004-June 30, 2005. The grants are dedicated to the following subject areas: Gender, Technology and Environment; Ethical, Legal and Social Aspects of Genome Research and Biotechnology; and Technology Studies and Sustainability. The deadline for applications is January 15, 2004. Forms and information are available at <http://www.sts.tu-graz.ac.at>.

Support From the Following Societies and Organizations is Gratefully Acknowledged:

American Anthropological Association
American Association of University Professors
American Political Science Association
American Psychological Association
American Psychological Society
American Society for Engineering Education
American Sociological Association
Botanical Society of America