



# COSSA

## Washington Update

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Science Associations

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### WAXMAN EXPRESSES "OUTRAGE" OVER 'HIT LIST,' THE SCIENTIFIC COMMUNITY REACTS

On October 27, Rep. Henry Waxman (D-CA), Ranking Member of the House Committee on Government Reform, sent a letter to Secretary of Health and Human Services (HHS) Tommy Thompson expressing his "outrage" regarding the "existence of a 'hit list' identifying more than 150 scientists researching HIV/AIDS, human sexuality, and risk taking behaviors" that are supported by the National Institutes of Health (NIH).

Waxman's letter was prompted by the numerous calls he began receiving from researchers and scientists who had been notified by NIH program officers that their names were on a list of "HHS Grant Projects" that had been transmitted to the NIH from the House Energy and Commerce Committee. The Committee has congressional oversight over the agency. (See *Update*, October 20, 2003).

NIH officials began notifying researchers about the list and the congressional interest in their grants. According to the agency, it was not their intent to "threaten" the scientific community, as has been alleged, but to make researchers aware of the list and the possibility of additional scrutiny by the Congressional investigators.

There is precedent for the agency's concern. Earlier in July, Rep. Pat Toomey (R-PA) offered an amendment to the House Labor, Health and Human Services, Education Appropriations bill to rescind funding for five specific grants. The amendment was narrowly defeated by two votes. (See *Update*, July 14, 2003).

(Continued on Next Page)

### APPROPRIATIONS PROCESS MUDDLES ON

One month into Fiscal Year 2004, Congress continues to seek ways to complete the bills that will fund the government through next September. Only three of the 13 bills have been enacted and signed by the President. After a period where the proposed solution was to lump the six spending bills unenacted by the Senate into one big Omnibus Appropriations package, at the insistence of Senate Appropriations Committee Chairman Ted Stevens (R-AS) and Ranking Democrat Robert Byrd (D-WV), the Senate shifted gears and decided to take up the remaining appropriations bills one-at-a-time. Some progress has been made, but not enough to avoid another Continuing Resolution (CR) to fund the government through November 7. More CRs are expected after that date, with the specter of a full-fiscal year

(Continued on Page 3)

### *Inside UPDATE...*

- **SENATE PANEL CONSIDERS INTELLECTUAL DIVERSITY ON AMERICA'S COLLEGE CAMPUSES**
- **NIH TO TAKE INVENTORY OF ITS BASIC BEHAVIORAL AND SOCIAL SCIENCE; NIMH ESTABLISHES PANEL TO EXAMINES ITS BASIC RESEARCH**
- **CDC DIRECTOR DISCUSSES FUTURE INITIATIVES**
- **KANTER FAMILY FOUNDATION AND AHRQ HOLD 4TH ANNUAL HEALTH LEGACY PARTNERSHIP CONFERENCE**



## 'HIT LIST', (Continued from Page 1)

Waxman, who defended sexual behavior and function research at an October 2 joint hearing of the House panel and the Senate Health, Education, Labor, and Pensions Committee, observed that what was "most disturbing" about the list is that it "appears" that it "may have originated within HHS itself. . . . This 'hit list' appears to be part of a calculated effort to subvert science and scientists at NIH to a right-wing ideological agenda," noted Waxman. (See *Update*, October 6, 2003). In the letter, Waxman references the October 2 hearing and indicated that "several Republican members of Congress repeatedly asked NIH Director Elias Zerhouni about several peer-reviewed grants that they described as 'provocative.'"

The 'hit list' to which Waxman is referring is titled "HHS Grants Projects" and lists the research director, institution, project title, project duration, and funding agency. In addition, several of the entries are accompanied by notations "that apparently illustrate what those who put the list together find objectionable," Waxman noted. "More than 250 grants from more than 150 senior investigators are on the list . . . Institutions sponsoring the grants are among the most distinguished in the country," he observes.

"When the list was passed to the NIH from Republicans in the Energy and Commerce Committee several weeks ago, it was not accompanied by any official request for review," Waxman further commented. According to the Congressman, he is not aware of any plans to hold hearings or audits, and there is "nothing in writing about what the members intend to do with the list."

While the list came to NIH from Congress, Waxman stresses that "it is very unlikely that such a list originated in Congress. In fact, there are strong clues that this was an inside job. Officials within HHS itself appear to have been directly involved in the creation of this list." He notes that some of the information on the list is not publicly accessible. HHS officials have denied any role in putting together the list and have stated all of the information is available through two public databases.

In an Associated Press story following the release of Waxman's letter to Thompson, the Traditional Values Coalition (TVC), a lobbying group opposed to homosexuality and abortion, in an effort to deflect attention from the Energy and Commerce Committee, claimed responsibility for generating the list. While a list is currently posted on their website, when the story broke it had not been posted. Additionally, the list on the

website is not the list sent to the NIH from the House panel.

In a subsequent October 28 letter to Thompson, Waxman informed the Secretary of TVC's claim and stated, "Notwithstanding the Coalition's statement, it remains important for HHS to clarify any role it had in the creation of this list." Waxman also noted that since sending the October 27 letter, he had learned that some "financial data about NIH grants is publicly accessible on the web site. However, the information at this location does not match what is on the list," he remarked further.

Waxman reiterated his request that the Secretary investigate "whether anyone at HHS played any role in the creation of this list." He also requested:

1. A list of dates and times of all meetings and phone calls between HHS officials and employees of the TVC, as well as a list of topics discussed and the information exchanged, since January 2001.
2. Copies of all correspondence, e-mails, faxes, computer files, and any other information exchanged between HHS officials and the TVC since January 2001.

Waxman requested a response from the Secretary by November 8th.

### The Scientific Community Reacts

Reaction to these developments from the scientific community has been quick. A number of groups have spoken out and individual researchers have defended their projects from the attacks by the TVC. COSSA Executive Director Howard Silver has noted that there are groups in this country who "want to keep their heads in the sand" when it comes to behaviors they don't like. "Given the AIDS pandemic, the significant numbers of people with STDs, and the volatile mix of drug, sex, and disease, this research is necessary," he added. "There is a vital public health interest in these studies and they deserve and merit government support," Silver concluded. This support is provided by NIH through a merit review process that has made the Institutes the premier biomedical and behavioral research agency in the world.

Norman B. Anderson, Chief Executive Officer of the American Psychological Association (APA) and the first Director of the NIH Office of Behavioral and Social Sciences Research (OBSSR), reiterated the value



of the research being conducted by the NIH, noting that examining the "behaviors of at-risk populations, such as prostitutes and drug users is crucial to public health. . . This research is absolutely necessary to fully understand how sexually-transmitted diseases, including HIV/AIDS, are spread from high-risk communities to those traditionally considered low-risk. This research is also necessary if we are to continue our national and international efforts to prevent these diseases," Anderson declared.

Other reactions included:

"The spread of HIV/AIDS, drug abuse, and other public health crises cause tremendous human suffering all over the world. If we're ever going to get a handle on these issues and help to improve human well-being, we must learn more about them through high-quality, peer-reviewed research," said Alan I. Leshner, Chief Executive Officer of the American Association for the Advancement of Science and Executive Publisher of its journal, *Science*. "The question of whether or not such behaviors are moral is irrelevant. They occur frequently and they are key factors in the spread of disease. We must have the courage, as scientists and citizens, to understand and confront them. Society deserves no less," he emphasized.

"The Association of American Medical Colleges (AAMC) is deeply concerned about news reports implying that some 200 NIH-funded research grants on controversial, but critically important public health issues, largely dealing with sexual behaviors, are being subjected to extraordinary scrutiny as a result of pressure from either members of Congress or private advocacy groups," said AAMC President Jordan J. Cohen. "While congressional oversight of the merit review process plays an essential role in ensuring appropriate accountability for the nation's investment in scientific research, the integrity of the oversight processes themselves should never be compromised by intrusion of extraneous sectarian or ideological issues."

### **National Alliance to Support Sexual Health Research and Policy**

In July, just prior to the introduction of the amendment by Rep. Toomey, several of the organizations within the behavioral and social science community, along with several women's health organizations, began discussions on forming a coalition, "The National Alliance to Support Sexual Health Research and Policy," to monitor and support issues related to sexual research and health. COSSA, along with APA, is taking the lead to bring these

communities together with other scientific, public health, and advocacy organizations to work to educate policymakers about the public health relevance of research into sexual health and behaviors and the value of utilizing this research to make sound public health policy. For more information about the Alliance contact: Angela Sharpe (COSSA) at (202) 842-3525 or Karen Studwell (APA) at (202) 336-5585.

### **APPROPRIATIONS, (Continued from Page 1)**

CR for certain bills added to the discussion. The new hoped-for adjournment date for this first session of the 108th Congress is now Thanksgiving.

Congress is about to clear for the President's signature the Supplemental Appropriations bill that will fund the rebuilding of Iraq and Afghanistan and support the American troops stationed in both nations. Although Congress rearranged some of the numbers in the President's original proposal, the Administration won the battle over whether Iraq would have to repay some of the Relief and Reconstruction Fund of \$18 billion. The Administration wanted the Fund in the form of grants, and although the Senate voted to provide part of the money as loans, the Administration got its way in the House-Senate conference.

The Interior and Related Agencies bill, including funding of \$136.1 million for the National Endowment for the Humanities, has emerged from the House-Senate conference committee. Five others are in varying stages of conference deliberations, including the Labor, Health and Human Services (HHS), Education bill. Four remain unpassed by the Senate, including: Agriculture and Rural Development; Commerce, Justice, State (CJS); and Veterans Affairs, Housing and Urban Development, Independent Agencies (VA-HUD), which includes funding for the National Science Foundation (NSF).

Some of the bills already in conference are mired in House-Senate battles over special projects and in disputes between Chairmen with different priorities. Others, including the Labor, HHS, Education bill have riders that President Bush opposes, such as a provision that would block new overtime rules promulgated by the Administration.

The Senate hopes to move the Agriculture bill the week of November 3 with VA-HUD and CJS in the wings. The House, which had passed all thirteen of the spending bills by early September, has become increasingly frustrated with its bicameral partner's

sluggishness. For those agencies without their final FY 2004 funding it is also frustrating because new solicitations seeking applications for programs like NSF's Human and Social Dynamics priority must remain on the shelf for now.

## SENATE PANEL CONSIDERS INTELLECTUAL DIVERSITY ON AMERICA'S COLLEGE CAMPUSES

On October 29, the Senate Health, Education, Labor and Pensions (HELP) Committee held a hearing entitled "Is Intellectual Diversity and Endangered Species on America's College Campuses?" Senator Judd Gregg (R-NH), the HELP Chairman, noted "I believe that, with rare exceptions, the intellectual diversity of the academy has diminished significantly over the last 30 years."

The Chairman explained that highlighting this trend has been "a proliferation of classes focused on race, class, and gender, with little intellectual substance" at the expense of broad-based overview courses. Furthermore, "Campus speech codes defining forbidden speech in overly broad terms that cannot help but have a chilling effect on open, rigorous debate are rampant on college campuses today." Gregg also mentioned "the political and ideological bias of the faculty," which is self-described as being 72 percent liberal and 15 percent conservative according to a poll conducted by the Angus-Reid firm.

Anne Neal, President of the American Council of Trustees and Alumni (ACTA), told the Committee that "our colleges and universities are increasingly bastions of political correctness, hostile to the free exchange of ideas." She asserted that threats to a robust exchange of ideas manifest themselves in the following ways:

- Disinviting of politically-incorrect speakers;
- Organizing one-sided panels, teach-ins, and conferences;
- Sanctions against speakers who fail to follow the politically-correct line;
- Instruction that is politicized;
- Virtual elimination of broad-based survey courses in favor of trendy, and often politicized courses;
- Reprisal against or intimidation of students who seek to speak their mind;

- Political discrimination in college hiring and retention; and
- Speech codes and campus newspaper theft and destruction.

Neal explained that the solution to these problems falls within the purview of college and university faculty, administrators, and boards of trustees, but that many of these officials "have clearly defaulted on their responsibility" to protect academic freedom.

Greg Lukianoff, Legal Director of the Foundation for Individual Rights in Education (FIRE), explained that his organization has been fighting for free speech and academic freedom on college and university campuses across the nation for four years. He noted that FIRE defines a campus speech code as "any regulation that punishes, forbids, heavily regulates, or restricts a substantial amount of expression that would be protected in the larger society."

Lukianoff stated that FIRE has compiled its research on campus speech codes on a website ([www.speechcodes.org](http://www.speechcodes.org)) that features nearly 200 public and private colleges and universities. The schools are rated on the site using a green/yellow/red light scheme for increasing levels of speech regulation. "Of 176 rated universities, only 20 have earned green lights, while 80 earned yellows. A distressing 76 – forty-three percent of the institutions rated – earned red lights," Lukianoff explained.

During a brief question and answer session, Senator Lamar Alexander (R-TN) pondered involving accrediting organizations to solve this "problem" of a lack of intellectual diversity. Neal mentioned that there's a general perception that the accrediting bodies have failed in this respect.

None of the Committee's Democrats, including Ranking Member Ted Kennedy (D-MA) attended the hearing. It wasn't immediately clear whether this was due to an intentional boycott or scheduling conflicts. Full testimony by members of the witness panel, which also included Robert David Johnson, a Professor of History at Brooklyn College and the Graduate Center of the City University of New York, and Anthony Dick, a student at the University of Virginia, can be found at <http://health.senate.gov/calendars/all.html>.

## NIH TO INVENTORY ITS BASIC BEHAVIORAL AND SOCIAL SCIENCE; NIMH TO EXAMINE ITS BASIC RESEARCH

Led by the Office of Behavioral and Social Sciences Research (OBSSR), the National Institutes of Health (NIH) is in the process of establishing an agency-wide Basic Behavioral and Social Sciences Research Working Group to the Advisory Committee to the Director (ACD). The purpose of the working group is to evaluate the NIH's basic behavioral sciences portfolio. ACD member Linda Waite, a Professor of Sociology at the University of Chicago, will chair the working group, which will consist of extramural scientists who will make recommendations to NIH Director Elias Zerhouni.

The Working Group is seen as an effort by the agency to begin to respond to the repeated urgings the National Institute of General Medical Sciences (NIGMS) has received through the years in report language accompanying the Labor, Health and Human Services (HHS), Education Appropriations bills to support basic behavioral science research.

This summer during the consideration Labor-HHS-Education bill, Senators Daniel Inouye (D-HI), Arlen Specter (R-PA), and Tom Harkin (D-IA) engaged in a colloquy, or planned discussion, on the Senate floor to highlight their frustration with "the largely unresolved" issue and the lack of action on the part of the Institute to include basic behavioral research in its portfolio. Inouye observed that that the statutory language authorizing NIGMS states that "one of the purposes of NIGMS is to conduct and support behavioral research."

Successful efforts by the Labor-HHS-Education Appropriations Subcommittee, which doubled the NIH budget over the last five years, "speaks to this Subcommittee's commitment to all types of scientific health research, including behavioral health," emphasized Subcommittee Chairman Specter. "Basic behavioral research is essential if we are to successfully address the many public health issues plaguing our nation. . . . The leading causes of death and chronic illness are related to high-risk behaviors such as: unintentional injuries and violence, tobacco use, alcohol and drug use, dietary behaviors, sexual behaviors, and inactivity.

Harkin, echoing Inouye and Specter, noted "the significance of behavioral health research has never been as important as it is now."

### NIMH

At its September 2003 meeting, the National Advisory Mental Health Council (NAMHC) created a working group to examine the role of basic behavioral, cognitive, molecular, and cellular research within the Institute. At the meeting, National Institute of Mental Health (NIMH) Director Tom Insel indicated that the Institute would review its basic science portfolio to ensure that research that has the most promise for combating public health burdens is funded. The NAMHC requested that a workgroup be organized to review the basic science portfolio to provide scientific guidance to NIMH as it sets priorities among basic research.

Acting OBSSR Director Virginia Cain will serve as a liaison between the two working groups.

## CDC DIRECTOR DISCUSSES FUTURE INITIATIVES

"We Need Your Input" was the central theme of the Centers for Disease Control and Prevention's (CDC) Washington Office Future Initiative-Stakeholder meeting held on October 28. The meeting's objective was to provide an overview of the Future Initiatives of CDC and to create an opportunity for participants to share ideas about CDC's strategic direction. Donald Shriber, Director of CDC's Washington Office, convened the session by informing attendees about how excited he was to see groups collectively working to improve the CDC and expressed a great deal of gratitude to the long standing partners of CDC as well as welcoming new ones.

### Setting the Directions for CDC's Future

Julie Gerberding, CDC Director, gave insight as to where her agency is right now and then preceded to discuss future directions. According to Gerberding, "the CDC's mission is to promote health and quality of life by preventing and controlling disease, injury, and disability." Emphasizing "we live in a small world that is connected," Gerberding explained that the CDC needs to be a public health agency that is adaptable and resilient when new infectious diseases, such as SARS, emerge and become problematic for not only our nation, but also pose a threat to the world's public health. With the CDC taking a holistic approach to community health, Gerberding added that the core mission of the agency is the dissemination of



scientific-based research through a strategic information process.

Through collaborations and partnerships with other Federal agencies, such as the National Institutes of Health, the Centers for Medicare & Medicaid Services, and the Health Resources and Services Administration, CDC hopes to leverage the knowledge between the agencies and develop a “seamless pipeline of research.” Gerberding noted that CDC’s future initiatives will address issues dealing with emerging public health threats, globalization, an aging society and workforce, rising health care costs, public health infrastructure, changing demographics, and information technology.

### **Challenges for the CDC**

“The critical challenges for CDC include building a 21st century public health system, preparing for health threats here and abroad, transforming knowledge into impact, and reducing racial and ethnic health disparities,” she stated. The CDC hopes to combat these challenges by focusing on customers and partners, public health research, global health, and examining Health Systems, a scheme that includes schools or agencies that have a direct impact on children’s health. Although the CDC is viewed as a credible, trustworthy, and mission-driven agency, Gerberding clarified that the CDC’s mission to improve health is “not an event that will take place every ten years, but is an ongoing process.” After examining feedback from partners and customers of the CDC, Gerberding concluded that there is room for improvement of the agency’s internal processes and welcomed any innovative ideas that the CDC could implement into its future goals because “after all we are all in this fight together to build a better public health infrastructure.”

### **Building Partnerships with Local and State Agencies**

After Gerberding’s remarks, Leah Devlin, State Health Director for North Carolina’s Department of Health and Human Services, explored the idea of the CDC forming partnerships with community-based profit and non-profit organizations. Devlin praised the CDC for being the backbone of America’s public health, but urged the agency to forge partnerships with state and local governments to advance the health of the nation. With all levels of government taking an active role in improving public health, Devlin believes that the partnerships with the CDC will generate coalition building. “The CDC should create inroads into the community and work with state and local agencies that focus on determinants of health,” she asserted.

Nevertheless, the CDC must maintain scientific integrity when engaging in new areas of research, Devlin added.

The meeting concluded with an open forum, moderated by Ed Thompson, Deputy Director of the CDC, for partners of the CDC to offer insight on the agency’s strengths and weaknesses, possible threats to the CDC mission, new opportunities for the CDC, and major public health issues facing the nation that the agency could influence. For more information on the CDC’s Future Initiatives, please visit [www.cdc.gov/futures](http://www.cdc.gov/futures).

## **KANTER FAMILY FOUNDATION AND AHRQ HOLD 4TH ANNUAL HEALTH LEGACY PARTNERSHIP CONFERENCE**

On October 22, the Joseph H. Kanter Family Foundation and the Agency for Healthcare Research and Quality (AHRQ) held its 4th Annual Health Legacy Partnership conference entitled “Power to Patients: Moving to Consumer Controlled Health Care Decisions.” Founded in 1964 by Joseph H. Kanter, the Foundation’s mission is to improve the quality of health care by supplying patients and doctors with actual data about which treatments work best for the diseases and conditions they confront. “I believe that every citizen of this great Republic has the inalienable right to know what medicine knows or doesn’t know about their diseases and to have access to detailed data on what works in treating it,” Kanter explained. In 1988, the Kanter Foundation, in a public-private partnership with AHRQ, began to develop a national database of medical treatment information. The Foundation contends the database will serve as an essential component of America’s public health infrastructure because it will give patients and doctors statistically reliable information to consider as they weight options for treating diagnosed illness.

### **Being a Patient**

Kanter, Chairman of the Health Legacy Partnership, explained his own experiences in the public health system, noting that it “changed my whole outlook on the health care system when I became a patient.” Kanter believes setting a uniform standard for the electronic exchange of clinical health information will serve as a major milestone in public health and can only be accomplished through a bi-partisan effort. The use of information technology (IT), in concurrence with a bi-partisan effort, he stated, will be the link in lowering medical costs and improving patient safety, which will

save lives. Emphasizing Power to Patients (PTP) in his closing remarks, Kanter proclaimed that people want enhanced health information that can be used to make better medical decisions and stressed that “although we are all different people from different parts of the country, we share one common thread; we are all patients.”

### **AHRQ Supports Information Technology to Improve Patient Safety**

Carolyn Clancy, Director of AHRQ, praised the Kanter Foundation for its passion and commitment to improving patient safety through consumer knowledge. Picking up on Kanter’s theme, Clancy explained that the key players in the disbursement of clinical information are clinical decision makers, leaders of large health care systems that purchase health care on behalf of large groups of people, and public policy makers. Clancy also outlined how pivotal research is in AHRQ’s mission and discussed the importance of IT in health care as society moves into the 21st century. “The three overarching themes of the research and work we support include: research that improves health outcomes, and by health outcomes I mean end results that people experience and care about; research that improves quality of care; and research that promotes access to effective services.”

With AHRQ’s funded research being “patient centered, not disease specific,” Clancy reiterated how vital IT is and how useful it will be in improving the quality of health for the nation. Information technology, Clancy stated, “can enhance the precision and decrease the cost of measurements; provide a very important platform for translating strategies to improve quality of care through decision support; greatly enhance the timing associated with collection; enhance communication between patients and their clinicians; provide better clinical knowledge; provide online support; and lead to decreased hospitalization and shorter lengths of stays.” Despite the astounding rewards of IT, the fact remains that this type of technology does pose challenges to AHRQ. Some of the critical challenges that face AHRQ are common data elements, definitions and standards for IT, and how to make improvements. Nevertheless, AHRQ hopes to issue a blueprint to implement IT in America’s health care system in the near future.

### **HHS Responds to Public Health**

Enlightening the conference attendees about how the Department of Health and Human Services (HHS) plans to improve the health care system, Claude Allen, Deputy Secretary of HHS, discussed how the Administration plans to convey to physicians that the quality of care should be the focus of health, not the quantity of patients. Moreover, “we want to deliver choices, additional benefits, and modern medicine in a modern way combining the very best practices of government programs with those of a competitive free market system that benefits America so well,” he explained. With the help of modern medicine and information technology, Allen believes that closing the gaps that exist between communities of color and the majority white community will become a reality. Reducing health disparities will come as a result of educating communities of color about the essential components of health, he explained, and once those communities implement lifestyle and behavioral change, only then will the gaps no longer exist.

According to Allen, one of the biggest challenges that faces America’s public health paradigm is the psychological challenge. “Giving beneficiaries more choices means giving them more control. It’s easy to support on the merits but it is hard for politicians and for bureaucrats to give up that power even for a good cause. But we can and we will get through these growing pains,” he asserted. With the infiltration of information technology into America’s public health system, the idea of beneficiaries possessing more power tends to alarm policymakers. Conversely, politicians should consider if they would rather relinquish some choices to beneficiaries or have policies that inhibit people from making wise decisions based on clinical information obtained from a national database that will serve as a knowledge tool that patients and their doctors can utilize to make better treatment decisions.

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The Consortium of Social Science Associations (COSSA), an advocacy organization for federal support for the social and behavioral sciences, was founded in 1981 and stands alone in Washington in representing the full range of social and behavioral sciences.

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