

Human Radiation Experiments

ACHRE (Advisory Cmte on Human Radiation Experiments) Correspondence

Classified Research Experiments Directive

Fact Sheet, Q&A

Articles on ACHRE Report

Press - Radiation

Event Planning - ACHRE

IAWG (Interagency Working Group) - Atomic Vets

IAWG - Press

Comments on Report

Plutonium Settlements

Cheat Sheets

RECA (Radiation Exposure Compensation Act)

IAWG - Executive Summaries and Memos

Comments on Directive/Classified Research

Agendas/Briefing Papers

IAWG - Summaries of Meetings

IAWG - NBAC

Nasopharyngeal Radiation

EO on Classified Research

Clips

Gulf War Syndrome

NCI Report on Atmospheric Testing

Background - OCS (Office of Cancer Survivorship)

Speech OCS

DOD Breast Cancer Research

25th Anniversary of National Cancer Act

Cancer Event

Issue Briefings

Initiatives 8/16 - 8/30

Talking Points Spring '96

Task Force on Radiation & Human Rights



Washington, D.C. Office
National Committee for Radiation Victims
7006 Carroll Avenue
Takoma Park, MD 20912
Tel. No. (202) 775-8786
Fax. No. (301) 270-3460

March 4, 1997

Dr. John H. Gibbons
Assistant to the President for
Science & Technology
Office of Science & Technology Policy
Old Executive Office Bldg., Rm. 426
Washington, D.C. 20502

Re: Human Radiation Experiments

Dear Dr. Gibbons:

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April B-15
24-hours

**President Clinton Announces Actions
Responding to the Advisory Committee on
Human Radiation Experiments**

March 28, 1997

--DRAFT--

Background

In January, 1994 President Clinton established the Advisory Committee on Human Radiation Experiments (ACHRE) to examine reports that the government had supported unethical human radiation experiments and releases of radiation during the Cold War. He asked ACHRE to uncover the truth, recommend ways to right past wrongs, and suggest ways to make sure the government will not repeat past mistakes.

In October, 1995 ACHRE issued its report. ACHRE found that the government had conducted several thousand human radiation experiments from 1945 to 1975 and that the majority advanced biomedical research. The Committee found, however, that some were conducted unethically. For example, scientists injected plutonium into 18 patients without their knowledge, and researchers conducted experiments on indigent patients and children. ACHRE made 18 recommendations to open the public record, protect human subjects of future research, and compensate those wronged by the government's actions.

In October, 1995 the President received the Advisory Committee's report and made it clear that the report would "not be left on a shelf to gather dust" He directed his Cabinet to "use and build on these recommendations." Over the past year and a half, the Administration has acted throughout the government to implement ACHRE's recommendations to improve openness in government, strengthen ethics in human subjects research, and compensate individuals for the government's mistakes.

Today's Announcement

- **The Administration released *Building Public Trust*, outlining its comprehensive response to the President's Advisory Committee on Human Radiation Experiments (ACHRE). The report summarizes actions to address ACHRE's 18 recommendations.**
- **The Departments of Energy and Justice announced that the government has settled compensation claims with families of all of the known individuals ACHRE recommended for compensation. ACHRE recommend the government compensate the families of 18 subjects of plutonium injection experiments. The government has settled with all 16 families that came forward.**
- **President Clinton signed a memorandum to strengthen the rights and protections of people participating in secret, government-supported research. ACHRE recommended that subjects of secret experiments have special protections and information. Acting on that recommendation, the President directed agencies today to propose new rules for secret research that would require scientists to: obtain informed consent from all potential subjects of secret experiments; disclose the identity of the sponsoring agency to**

potential subjects; and tell potential subjects that an experiment is classified. The new rules would also establish a more independent review process; require the head of the agency conducting secret human research to approve the project; and require permanent records of secret experiments. The President also directed federal agencies to report annually on the number of classified human research projects and the number of subjects in each project. **A preliminary review by the Administration's human radiation Interagency Working Group indicates that the government is not supporting any classified human research at this time;** today's directive initiates a formal, routine accounting of secret human studies.

- The Administration announced proposed **amendments to the Radiation Exposure Compensation Act of 1990 to compensate hundreds of uranium miners who would not be compensated under current law.** ACHRE found that some deserving miners do not qualify for compensation under the Act. The amendments would establish fairer, science-based criteria for compensation. The Administration will also propose regulatory changes to RECA to facilitate claims processing.

Previous and On-going Actions Described in *Building Public Trust* Include:

Actions to Improve Openness in Government.

- ACHRE transferred more than 4,000 cubic feet of documents to the National Archives. The Administration has made 300,000 fully searchable pages of documents available on the Internet, and will add an additional 200,000 pages shortly. The Departments of Energy and Defense have published document search guides.
- The President signed Executive Order 12958 directing Federal agencies to review and declassify thousands of documents, including documents on radiation experiments.
- The CIA's Inspector General reviewed and reported on the CIA's human experiments. The report is on the Internet.

Actions to Protect human subjects in the future.

- President Clinton established the National Bioethics Advisory Commission (NBAC) to examine bioethical issues, including human research issues. A subcommittee of NBAC will address certain broad questions raised by ACHRE, including how to strengthen Institutional Review Boards — the local ethics panels for Federally-sponsored research.
- In October, 1995 President Clinton directed agencies to develop plans to improve their oversight of ethics rules. The agencies have completed their review and upgraded protections, and NBAC will review agency procedures in the coming months.
- Agencies have undertaken nationwide education efforts to raise the profile of ethical considerations, and are funding research to improve our understanding of informed consent.

Actions to Right Past Wrongs.

- In October, 1995 President Clinton apologized to all subjects on behalf of the government; former Energy Secretary O'Leary made apologies in certain individual cases.
- The Administration will propose legislation to make veterans treated with nasopharyngeal radiation eligible for health care services under the Veteran's Administration's Ionizing Radiation Program.

Task Force on Radiation & Human Rights



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Task Force on Radiation & Human Rights

7006 Carroll Avenue
Takoma Park, MD 20912
(301) 270-3887
Fax: (301) 270-3460

FAX COVER SHEET

FAX NUMBER TRANSMITTED TO: (202) 456-7028

To: Ms. Diane C. Regas
Of: Domestic Policy Council

From: E. Cooper Brown

Client/Matter: Human Radiation Experiments
Date: March 7, 1997

DOCUMENTS	NUMBER OF PAGES*
Task Force Correspondence to Dr. Gibbons sans attachment	2

COMMENTS:

Original will follow by US Mail.

Dear Diane --

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* NOT COUNTING COVER SHEET. IF YOU DO NOT RECEIVE ALL PAGES, PLEASE TELEPHONE US IMMEDIATELY AT (301) 270-3887.

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Dr. Gibbons
re: Human Radiation Experiments
pg. 2

Sincerely yours,



E. Cooper Brown
Task Force Executive Committee

enclosure

cc. Ms. Diane Regas
Domestic Policy Council

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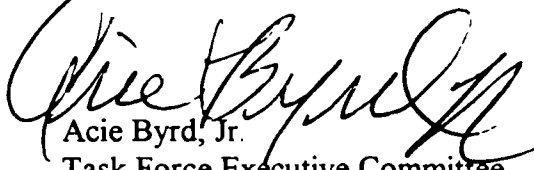
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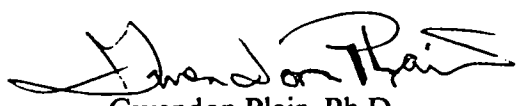
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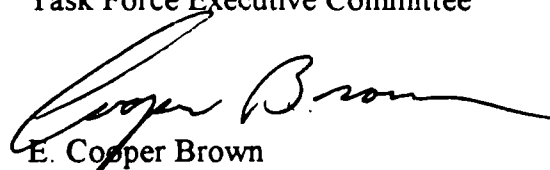
page 2

July 26, 1996

Sincerely yours,


Acie Byrd, Jr.
Task Force Executive Committee


Gwendon Plair, Ph.D.
Task Force Executive Committee


E. Cooper Brown
Task Force Executive Committee

P.S. Please note the new address for the Task Force's Washington office:

Task Force on Radiation & Human Rights
7006 Carroll Avenue, Suite 207
Takoma Park, MD 20912
Phn. No. (301) 891-3990 or 3992

cc. Senator Ted Stevens, Chairman
Senate Committee on Governmental Affairs
Senator John Glenn
Senate Committee on Governmental Affairs
Secretary Hazel O'Leary
Department of Energy
Secretary Donna Shalala
Department of Health & Human Services
Ms. Carol Rasco, Chair
Domestic Policy Council



Task Force on Radiation and Human Rights

Washington D.C. Office:
National Committee for Radiation Survivors
6935 Laurel Avenue, Takoma Park, MD 20912
Tel: (202) 775-8786 Fax: (301) 891-3992

July 26, 1996

Dr. John H. Gibbons
Assistant to the President
for Science & Technology
Office of Science & Technology Policy
Washington, DC 20502

Re: National Bioethics Advisory Commission

Dear Dr. Gibbons:

We want to thank you for providing us with the background information on the recent appointments to the National Bioethics Advisory Commission. We also thank you for having earlier provided us with information pertaining to the OTA's utilization of stakeholder advisory panels under your directorship of that office.

As has been mentioned to members of your staff, we are interested in pursuing establishment of an NBAC radiation experiment victims/survivors' stakeholder advisory panel. We note that the NBAC charter issued July 19th appears to authorize the use of such panels. We also understand that the decision to establish such a panel for the radiation experiment victims/survivors is nevertheless within the discretion of the Advisory Commission.

We would like to pursue this matter expeditiously, and for that reason request your assistance in arranging a meeting for the Task Force Executive Committee with Dr. Harold Shapiro, at his earliest convenience.

In closing, we request copies of the *curricula vitae* for each of the recently-appointed members of the National Bioethics Advisory Commission. We also wish to express our appreciation for your willingness -- and that of your staff -- to find constructive solutions to the concerns of our membership that have been raised.

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E. Cooper Brown
Task Force Executive Committee

enclosure

cc. Ms. Diane Regas
Domestic Policy Council

NATIONAL ASSOCIATION OF RADIATION SURVIVORS

February 11, 1997

Ms. Diane Regas, Senior Policy Analyst
Domestic Policy Council
The White House
Washington, DC

Dear Ms. Regas:

I am writing you on behalf of the National Association of Radiation Survivors as we understand you are heading up the efforts to finalize the implementation plan to the findings of the President's Advisory Committee on Human Radiation Experiments (ACHRE). As a member organization of the Task Force on Radiation and Human Rights we have actively followed, and made some minor contributions to, the work of the ACHRE and participated in follow-up meetings with the Inter-agency Working Group on the implementation plan.

We and our members have been waiting for the final plan to be announced and disseminated for almost a year and a half and were recently advised that the final plan is being held up for some unknown reason at the White House level. There are citizens outside the beltway who have been awaiting the final plan and delaying their responses to the Advisory Committee's recommendations pending the release of the final implementation plan. It would be helpful to these people, who have already suffered indignities, if the final plan were released.

We are currently working to assemble the leadership of the 30+ groups belonging to the Task Force in Washington, DC within the next month or so and believe it would be a shame if the final plan has not been released by the time of our meeting. These groups have put a great deal of energy and faith in the final outcome of this tragic part of our history, and as we gather to discuss our futures, it would be helpful to know what our government plans to do.

Anything you could do to expedite the release of the final plan would be helpful and appreciated. I understand that you are busy, but would appreciate a letter, telephone, fax or e-mail reply to this letter so I can advise our groups as to an expected release date.

Sincerely,

Fred Allingham
Executive Director

cc: Task Force Members

THE WHITE HOUSE

WASHINGTON

June 20, 1996

Dr. Gwendon Plair, Governing Board
Task Force on Radiation and Human Rights
National Committee for Radiation Survivors
6935 Laurel Avenue
Takoma Park, MD 20912

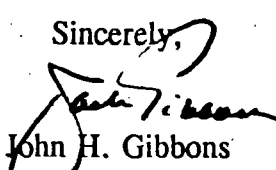
Dear Dr. Plair:

I appreciated the opportunity to meet with you on Friday to discuss issues of concern to the Task Force on Radiation and Human Rights. Thank you for your continuing interest in the Administration's work to resolve the many issues connected with the human radiation experiments of prior decades and to ensure such experiments do not take place again.

During our meeting, I mentioned that the Congressional Office of Technology Assessment (OTA), which I directed until 1992, made extensive use of advisory panels comprising stakeholders on particular issues. Although I cannot predict or determine how the National Bioethics Advisory Commission's (NBAC) efforts will develop, OTA's advisory panel process is one that NBAC could consider.

Enclosed you will find material describing the formation and operation of advisory panels that were used at the OTA. I have sent the same material to Mr. Byrd and Mr. Brown. As I mentioned, a typical advisory panel advised OTA study teams on key issues, provided a wide range of perspectives and views relevant to the study topic, and reviewed and commented on draft materials and reports. Panel input was taken very seriously by OTA project staff. In my experience, these panels greatly increased the quality and utility of our results.

Sincerely,


John H. Gibbons
Assistant to the President
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Science and Technology

Attachment:

"The Structure and Function of OTA Advisory Panels,"
Gellband/Windle (1985)

THE WHITE HOUSE

WASHINGTON

June 20, 1996

Mr. Acie L. Byrd, Jr., Governing Board
Task Force on Radiation and Human Rights
National Committee for Radiation Survivors
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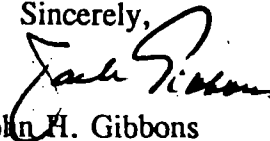
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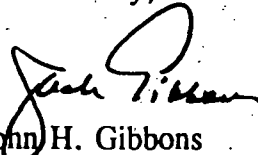
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THE STRUCTURE AND FUNCTION OF OTA ADVISORY PANELS

Sources: Hellen Gelband, Health Program, OTA, undated; revised for use by Health and Life Science Division, 1/1/92; revised by Phyllis Windle, May 1985.

An advisory panel of 15-25 experts and stakeholders is appointed by OTA's Director for each major OTA assessment. Individuals from outside the Federal Government, including scientists, engineers, affected and interested parties from labor, industry, the academic community, public interest groups, state and local governments, and the citizenry at large are invited to serve on these panels, selected according to the specifics of each assessment. The aim is to represent the major known viewpoints, perspectives of the involved sectors of the national community, and the areas of expertise for each subject. Panel participation is essential to producing fair, evenhanded, complete, accurate and authoritative reports.

Generally, two to four advisory panel meetings per project are held over an average study span of eighteen months to two years. Meetings are held at OTA in Washington, usually lasting one to two days. During this time, the panel may meet in plenary session or break into smaller working groups for specific tasks. In addition, staff may telephone advisory panel members during the course of the assessment for information, discussion of issues, or referrals to others for information. In general, the panel process is marked by flexibility, with possible variations in timing and number of meetings, possible addition of special members for particular aspects of a study, and the interspersing of workshops and other advisory mechanisms as needed. Some panel members are very active participants, supplying additional material and initiating conversations with staff, but such involvement is not required.

The advisory panel comes together early in the process to help define the scope and content of the study and to provide OTA staff with information and sources of information for carrying out the study. Controversies, areas of uncertainty, and inadequacies in the information base, as well as areas of agreement emerge from early advisory panel discussions. In the course of most assessments, OTA contracts with experts for background papers and analyses to support staff research. Ideas for the areas of contract research and suggestions of individuals and institutions with expertise in those areas often come from advisory panel members.

The meeting(s) during the middle portion of the assessment allow review of early staff work (and contract reports not reviewed by mail), and in depth discussion of particular problem areas. The last meeting usually concentrates on review of a draft final report that has been written by OTA staff. The advisory panel critique may precede or be concurrent with a wide outside review by experts and interested parties within and outside the Federal Government. Also, careful review for consistency with OTA standards, objectivity and lack of bias is carried out internally within OTA up to and including the Director.

Advisory panel meetings are mostly chaired by a panel member, not by OTA staff. On occasion, the chair has been a facilitator rather than an expert panelist. Panel members do not write any parts of the report, and the panel is not asked to come to consensus, vote on issues or on any part or the whole of the report. Nor does the panel take any responsibility for the report; this remains entirely with OTA. This means that there are no "minority reports" or sections or opinions, but an OTA report should capture areas of controversy and disagreement. Thus OTA staff will ordinarily seek to include the full diversity of relevant and important opinions and viewpoints. In these areas OTA will not necessarily embrace one side or the other unless new analyses shift the weight of evidence.

TASK FORCE ON RADIATION & HUMAN RIGHTS***FAX TRANSMISSION***

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To: Diane Regas**Date:** December 13, 1996**Fax #:** 202-456-7028**Pages:** 4, including this cover sheet.**From:** E. Cooper Brown**Subject:** DOE / Secretary**COMMENTS:**

Dear Diane --

Would you please see that the enclosed is forwarded to Carol, plus anyone else you deem appropriate.

Thank you.



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Task Force on Radiation and Human Rights

Washington D.C. Office:
National Committee for Radiation Survivors
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Tel: (202) 775-8786 Fax: (301) 891-3992

December 12, 1996

President William J. Clinton
The White House
1600 Pennsylvania Avenue
Washington, DC 20500

Re: Nomination for Secretary of Energy

Dear President Clinton:

Recently the Task Force on Radiation and Human Rights has shared with the White House our concerns about two individuals who had been mentioned by the media as being under consideration for Secretary of Energy - former Senator J. Bennett Johnson and CIA Director John Deutsch. Having heard from us as to those our members organizations would oppose, we thought it appropriate that we also indicate to you those we feel our member organizations would support.

Of the names that have most often been mentioned for Secretary of Energy, the Task Force would certainly support former Senator **Tim Wirth**. (We would also support EPA Director Carol Browner, but understand she is no longer interested in the position, preferring to stay at EPA.) In addition to those presently under consideration for Secretary of Energy, the Task Force urges that serious consideration also be given both to former Congresswoman **Claudine Schneider** and former T.V.A. Chairman **David Freeman**. The Task Force is of the firm conviction that both not only have the necessary qualifications for Secretary of Energy, they both - because of their proven outstanding leadership in the area of energy policy and development - would restore a much-needed sense of mission to a beleaguered agency.

Claudine Schneider, during her years in the House of Representatives, was a leading advocate on the Energy & Commerce Committee for sound energy policies, environmental protection, and ecologically sustainable development. An excellent example of her commitment to these issues was the leadership she demonstrated in introducing the Global Warming Preservation Act of 1989. Ms. Schneider was also a strong advocate for radiation victims rights, playing an instrumental role in Congressional efforts on behalf of Atomic Veterans.

• Alliance of Atomic Veterans • American Environmental Health Studies Project • Atomic Reclamation & Conversion Project • Center for Atomic Radiation Studies • Cincinnati Families of Radiation Victims Organization • Citizens Call • Citizen Soldier • Colorado Atomic Agent Orange Veterans Coalition • Committee of Atomic Bomb Survivors in the USA • Concerned Relatives of Cancer Study Patients • Fernald School "Science Club" • Hanford Downwinder Health Concerns • Hiroshima/Nagasaki Peace Committee • Indigent Transients & Survivors of Oak Ridge • Laguna-Acoma Coalition for a Safe Environment • National Association of Atomic Veterans • National Association of Radiation Survivors • National Committee for Radiation Victims • Native Alaskans of Point Hope • Navajo Uranium Radiation Victims Committee • Oak Ridge Health Liaison • Oregon State Prison Experiment Victims • Portsmouth-Piketon Residents for Environmental Safety & Security • Rochester Radiation Victims/Survivors Association • Survivors of Medical Radiation Experiments • Trinity Post 7-45 • Vanderbilt Irradiated Victims Organization •

David Freeman served during the Carter Administration as an official within the Department of Energy. He was subsequently appointed by President Carter to serve as Chairman of the Tennessee Valley Authority. Both before entering, and since leaving government service, Mr. Freeman has been at the forefront of energy policy development. He offers over 18 years of experience as the CEO of four major electrical utilities, including the New York Power Authority, the Sacramento Municipal Utility District, the Lower Colorado River Authority, as well as the TVA. He has also served as Chairman of the Solar Electric Light Fund, playing a leading role in a global effort to provide power to rural people in developing countries. He is currently working as an energy consultant with the State of California.

On October 3rd of last year, at the time of your receipt of the final report of the Advisory Committee on Human Radiation Experiments, you correctly noted that cynicism about government often has its roots in historical circumstances. You stressed that if ever we are to restore the peoples' faith in their government, it is essential that the government be held accountable for its sins of the past. As you know, holding the government accountable for its sponsorship of the Cold War human radiation experiments is a task not as yet completed. The appointment of either Mr. Freeman, Ms. Schneider, or Mr. Wirth would, in our estimation, send a clear and unmistakable message to the American People that we are truly moving as a nation into a new era, one in which everyone will be able to trust their government because their government will, at every step, hold itself accountable - particularly to those it has abused.

Sincerely yours,



E. Cooper Brown

Task Force Executive Committee

enclosure: "About the Task Force"

cc. Vice President Albert Gore, Jr.
Mr. Erskine Bowles, White House Chief of Staff
Ms. Carol Rasco, Domestic Policy Advisory
Senator Frank Murkowski
Senator Dale Bumpers
Senator John Glenn
Senator John Chafee
Senator Barbara Boxer