Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. memo	[Personally Identifiable Information] [partial] (1 page)	09/28/1995	b(6)

COLLECTION:
Clinton Presidential Records
Staff Secretary
Caplan, Phil
OA/Box Number: 11099

FOLDER TITLE:
Advisory Committee on Human Radiation Experiments-Miscellaneous [2]

2019-0803-S
rs3548

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
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P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
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C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

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95 DEC 22 P5:41

U.S. DEPARTMENT OF ENERGY
1000 INDEPENDENCE AVENUE, S.W.
ROOM 7A-075
WASHINGTON, D.C. 20585

UNCLASSIFIED FACSIMILE
OFFICE FAX: (202) 586-3552
TELEPHONE: (202) 586-9024

DATE: 12/22/95

TO: PHIL CAPLAN 456-2215

FROM: ELLY MELAMED (FOR TARA O'TOOLE & STEVE GALSON) 202 586-6857

NUMBER OF PAGES TO FOLLOW: 9

COMMENTS: Here is CHRISTMAS REPORT ON HRE
I WILL NOT BE HERE NEXT WEEK,
SO CALL LORI AZIM ON 202 586-5319
IF YOU HAVE ANY QUESTIONS. I WILL BE
BACK ON JAN. 2ND.

IF YOU EXPERIENCE PROBLEMS WITH TRANSMISSION, PLEASE CALL THE NUMBER ABOVE

On October 3, 1995, you ~~accepted~~ received the final report of the Advisory Committee on Human Radiation Experiments. At the same time, you issued Executive Order 12975 creating the National Bioethics Advisory Commission (NBAC). The Order required all Federal agencies involved in current human subject research to review this research in the light of the Advisory Committee recommendations. You asked for a status report by Christmas.

You also instructed the cabinet "to use and build on these recommendations, to devise promptly a system of relief, including compensation, that meets the standards of justice and conscience."

This report is a response to these requirements and includes the following information: first, a brief report on the review of current human subject research and associated activities that is due in its final form to NBAC in early February; second, the status of the implementation of the other recommendations of the Advisory Committee, including those relating to compensation. All agencies on the Interagency Working Group are fully committed to implementing the recommendations of this Committee and to carrying out your openness in Government initiative.

STATUS OF CURRENT HUMAN SUBJECT RESEARCH REVIEW

All Federal agencies involved in current human subject research have begun the review required by the Executive Order and will report to NBAC by early February. A number have already begun to implement changes and improvements to their programs in light of the Advisory Committee recommendations. Status information on these specific agency activities is provided as an appendix to this report.

[Phil - please insert here a paragraph of information about the status of NBAC: who has been appointed, etc.]

RESPONSE TO THE PRESIDENT ON IMPLEMENTING ADVISORY COMMITTEE RECOMMENDATIONS ON PAST HUMAN EXPERIMENTS AND OPENNESS

RECOMMENDATIONS ON PAST HUMAN EXPERIMENTS

Compensation

[Phil: J.J. Hauthier continues to press for fleshed out definitions of harm and of government involvement that will lend themselves to consistent agency action. DOE does not believe that this is achievable.]

As recommended by the Advisory Committee, in coordination with the Department of Justice, and to the extent permitted by law, subjects (or their surviving immediate family members) will be offered reasonable financial compensation for human radiation experiments in which a government agency was involved in actions falling within the Advisory Committee criteria:

1. experiments in which excessive secrecy deprived individuals of the opportunity to pursue potential grievances;

2. experiments in which there was no prospect of direct medical benefit to the subject and physical injury resulted; or

3. experiments in which interventions considered controversial at the time were presented as conventional or standard practice and physical injury resulted.

A streamlined administrative process, based on Federal Tort Claims Act procedures or other applicable law, will be used to offer compensation as part of a settlement of relevant claims. Maximum effort will be made to avoid lengthy litigation, including use of alternative dispute resolution, such as mediation or arbitration, where appropriate. The amount of compensation will be based on the extent of physical injury to the subject, the nature of the experiment, and the degree of government involvement. As needed, agencies will seek expert advice on scientific and medical issues. If compensation cannot be offered under existing law in any case under the stated criteria, the Administration will work with Congress to seek legislative relief in appropriate case.

Epidemiologic Tables Update

In response to recommendation 6, The Department of Veterans Affairs is establishing a Task Force led by the Undersecretary for Benefits to evaluate the likelihood of injury due to exposure to ionizing radiation. The Task Force will also evaluate the efficacy of the current law and regulations relating to compensation of veterans whose illnesses or deaths may be attributable to their radiation exposures while in military service. The report is expected to be completed in the late spring of 1996.

Uranium Miners

In response to recommendation 7, and as recommended by the Interagency Working Group, a committee of government scientists and attorneys with appropriate experience and expertise has been established to review the provisions in the Radiation Exposure compensation Act of 1990 (RECA) that relate to compensation for uranium miners. The committee consists of four scientists from the National Institute of Occupational Safety and Health (NIOSH) and the national Cancer Institute (NCI), and three attorneys from the Department of Justice. The committee has held a first meeting by conference call, and has scheduled a second meeting in early January . The committee anticipates submitting a final report in late April 1996.

Marshall Islanders

In response to recommendation 8, The Joint Commission for Healthcare Organizations (JCAHO) is doing an independent review of the DOE Marshall Island Medical Program which has been administered by the Brookhaven National Laboratory. JCAHO will review medical records of selected Marshallese exposed patients to determine if medical care has been provided in a manner consistent with the best medical practice at the time of care, with appropriate followup and medical treatment. The review will begin early in 1996.

RECOMMENDATIONS ON OPENNESS AND SECRECY

Members of the Interagency Working Group have initiatives underway to ensure that information retrieved for the human radiation experiments project is readily available to the public, and to respond to specific advisory committee recommendations on openness.

The Department of Energy:

- The Department has produced three publications which include background information, record series descriptions, topical essays, a list of over 400 experiments, and oral histories. Most of this information, along with over 250,000 scanned historical documents, is located on the Internet, with paper copies of all documents at the Coordination and Information Center (CIC) in Nevada.

- In response to Advisory Committee recommendations, DOE is

  - transferring over 3,000 cubic feet of records to the National Archives

  -making finding aids to records still in agency custody more readily available to the public, and has prepared records access guidance

The Department of Defense:

- The Department is preparing a guide similar to the DOE *Roadmap* that will describe DOD documents found during the human radiation records search. These documents will be available on the Internet and hard copies will be deposited at the CIC.

- DOD is expediting its response to Freedom of Information Act requests concerning human radiation experiment subjects.

The National Aeronautics and Space Administration:

- NASA is planning to maintain a permanent collection of human radiation experiment records and database at Johnson Space Center.

- The agency is also working to make radiation research documents available on the Internet. The agency is creating a NASA Radiation Review Homepage which summarizes the agency's search and findings.

The Central Intelligence Agency:

- The CIA is transferring approximately 1,000 pages of declassified documents and a CIA Inspector General report on human subject research

procedures to the National Archives. The documents will also be available on the Internet.

- The agency is reviewing for declassification a few documents relevant to the MKULTRA program that had not been previously declassified and released. An independent review of the CIA's record system has been undertaken by the National Archives and will be completed in approximately six months.

Health and Human Services and the Department of Veterans Affairs:

- These agencies are preparing documents for availability on the Internet sometime in the spring or summer of 1996. All of the paper copies have been transferred to the National Archives.

(Phil – we do not know the status of EPA activities in response to recommendation 16. We have been unable to reach the contact you provided since the agency is on furlough. Please fill in with any information you have based on your initial discussions.)

Appendix : **Agency Activities in relation to the Current Human Subject Research Review**

The Department of Energy:

- has developed a newly revised handbook on protecting human subjects which is in pre-publication review. The handbook specifically addresses issues raised by the Advisory Committee on informed consent and classified research.

- has begun a program of regular site visits, for education and review, to its facilities performing human subjects research. Each site will be visited approximately once every three years.

- has requested all DOE laboratories to provide a sample of current informed consent documents. These will be reviewed by a team charged with improving and monitoring the quality of these documents.

- has requested all laboratories to provide plans that detail local activities to improve the human subjects research review system.

- has issued a brochure to educate the DOE community on human subjects protection, updated its human subjects research database, held its annual human subjects workshop and created a World Wide Web Home Page on human subject programs.

The Department of Defense:

- has reviewed in detail the Department's existing policies and procedures for the protection of human subjects of research and has undertaken extensive revision of DOD Directive 3216,2, "Protection of Human Subjects in DOD Supported Research."

- has proposed changes to current policies that would

  -adopt investigator assurances of familiarity with the Nuremberg code, the Belmont Report, the Common Rule and related requirements;

  -incorporate research ethics into graduate medical education curricula at Military Department teaching hospitals;

-include specific language in the revised Directive that would emphasize the expedited review process for certain categories of minimal risk research that are detailed in the Common Rule (32 CFR 219);

-require education in human subjects regulations: in the executive level of training for commanders and senior civilians who may be involved in human subjects research; and for individual investigators, institutional review board members, research administrators, and support personnel;

-ensure that officers and senior NCOs in the chain of command not be present during research recruitment briefings of personnel under their command, and that and ombudsman be present at group recruitment briefings.

The National Aeronautics and Space Administration:

- has established a Bioethics Task Force composed of outside experts and headed by Dr. Baruch Brody, Director of the Center for Ethics, Baylor College of Medicine, to review all NASA human use policies and provide recommendations.

- has undertaken internal reviews at Headquarters, Johnson Space Center, and Ames Research Center to ensure that elements of the Common Rule and recommendations of the Advisory Committee on Human Radiation Experiments were incorporated into Agency and Center instructions.

- because much of its future space research will be conducted with its partners on the International Space Station, has conducted the first in a series of forums to inform NASA's international biomedical community on issues related to the ethics of human subjects research. It was agreed to establish an International Space Station Multinational Review Board to review human subject protection, safety, and ethical issues.

- has also initiated ethics forums on the Common Rule and protection of human subjects for its domestic biomedical research community.

The Central Intelligence Agency:

- has obtained the services of a prominent ethicist from the academic community to become a permanent voting member of the Agency's Human Subject Research Panel (HSRP).

- has revised agency regulations to indicate that all research carried out or sponsored by the Agency that utilizes human subjects shall be brought to the HSRP for approval. The Chairman must certify as exempt or approve a research proposal before it can proceed, and final approval rests with the Agency Director.

- has disseminated an Agency Bulletin to all employees specifying the rationale and function of the panel and necessity of referring human subject research to it for approval.

- has revised the Agency's Contracting Manual to guarantee that HSRP approval is obtained prior to approval of any contract involving human subject research.

The Department of Health and Human Services has:

- has designated the Office for Protection from Research Risks, National Institutes of Health, to coordinate the preparation of the NBAC report with information drawn from the Public Health Service agencies and other operating divisions.

- has begun activities to improve the procedures for protecting human subjects; for example, the Centers for Disease Control and Prevention are developing an on-line education system in research integrity and ethics that will be mandatory for investigators.

- has ensured that the Food and Drug Administration will respond to NBAC not only as part of the Department but also in its capacity as a regulator of research done by private industry.

Other Agencies:

- The Department of Veterans Affairs has planned IRB site visits to review procedures and the Office of Research and Development is reviewing its policy manual to identify any needed revisions.

- The Department of Education anticipates reporting to NBAC on ongoing training activities, and efforts to disseminate information through guidance documents and establish networks within the Department.

- The Environmental Protection Agency is planning to issue an internal order implementing the Common Rule.

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DRAFT ADMINISTRATION RESPONSE ON

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1 - 5

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E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

28-Sep-1995 01:14pm

TO: Carolyn E. Cleveland

FROM: Mail Link Monitor
Office of Administration, IST

SUBJECT: CONFIRMATION: APPT. REQUEST FOR CAPLAN, PHILLIP

FROM: WAVES OPERATIONS CENTER - ACO: scott walters
Date: 09-28-1995
Time: 13:09:41

This message serves as confirmation of an appointment for the visitors listed below.

Appointment With:	CAPLAN, PHILLIP
Appointment Date:	9/28/95
Appointment Time:	4:00:00 PM
Appointment Room:	188
Appointment Building:	OEOB
Appointment Requested by:	CLEVELAND CAROLYN E.
Phone Number of Requestor:	61735
Comments:	

WAVES APPOINTMENT NUMBER: U15609

If you have any questions regarding this appointment, please call the WAVES Center at 456-6742 and have the appointment number listed above available to the Access Control Officer answering your call.

****
TOTAL NUMBER OF NAMES SUBMITTED FOR ENTRY : 3
TOTAL NUMBER OF NAMES OF CLEARED FOR ENTRY: 3
****

OTOOLE, TARA
PREWITT, JANA
WEISS, ELLEN

(b)(6)

PH

Advisory Committee on Human Radiation Experiments
1726 M Street, NW
Suite 600
Washington, DC 20036
phone (202) 254-9795
fax (202) 254-9827

FAX COVER SHEET

To: Phil Caplan

From: Dan Guttman

Re: White House visitor passes

Date: March 27, 1995

Total pages including cover - 1

Phil-

As discussed, it would be appreciated if White House visitor passes could be arranged for Dr. Jonathan Winn and family (total of six) for April 17th or April 18th.

Thank you very much.

Dan

Caplan

95 SEP 15 P4:21

RUTH'S MEDIA SCHEDULE

Monday 9/18

8 am Breakfast talk, NY Academy of Sciences
11:30 am New York Times editorial board (Postponed, will reschedule)

Tuesday 9/19

4 pm AAMC (via S. Galson)

Wednesday 9/20

9:30 am Earl Lane, Newsday (Waiting for new release date to decide whether to reschedule)

11 am Karen MacPherson, Albuquerque Tribune (ditto)

Noon Gary Lee/David Brown, The Washington Post (ditto)

Thursday 9/21

10 am Lee Davidson, Deseret News (ditto)

2:30 pm Washington Post editorial board (ditto)

Monday 10/2

9:00 am Newsmaker, Press Club (ditto)

Day after release

Good Morning America

Others to Reschedule

Boston Globe editorial board
USA Today, editorial board
Paul Hoversten, USA Today
Colin Macilwain, Nature
Lori Wolfgang, Science
Richard Harris, NPR
Charles Osgood, CBS Radio
Marge Kriz, National Journal
Phil Hilts, New York Times

Caplan

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Lori Wolfgang, Science
Richard Harris, NPR
Charles Osgood, CBS Radio
Marge Kriz, National Journal
Phil Hilts, New York Times

- DOE press person → meeting
- brief wires - Mon 4:00 pm for middle Oct 3 embargo (Ruth Faden)
- longer piece → DOE
  - Am Agenda
  - Eye on America
  - In-Depth
- Hazel- oped → Post - WH approval Time!
- no lovely room
- DOE - write talking pts WH approval

March 3, 1995

Mr. Steve Silverman
President's Advisory Committee on Human Radiation Experiments
1600 Pennsylvania Ave., NW
Washington, DC 20500

Dear Mr. Silverman,

It is hard for me to believe the Committee on Human Radiation Experiments is scheduled to finish its work in April of this year. Not that I do not want the committee to finish its work in a timely manner. I simply do not believe enough contact with possible victims could have been completed since this issue first became widely publicized.

Also, a representative from the human experiment community should be placed on the committee.

Sincerely,

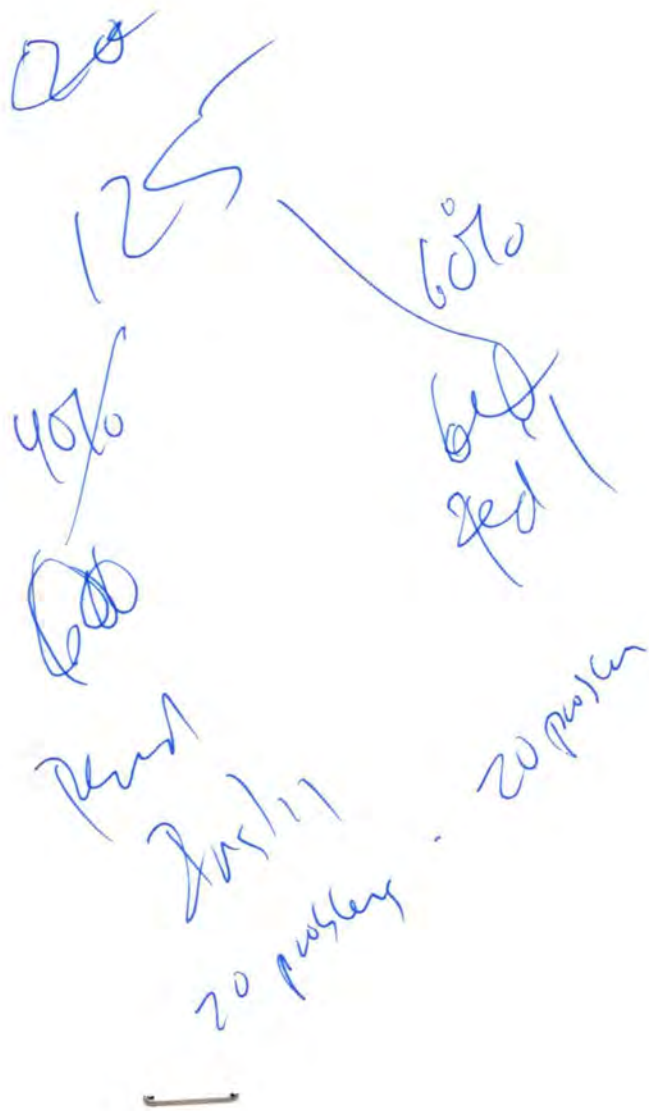
Colleen Lancaster

COLLEEN LANCASTER
801 DAVIS DR
BRENTWOOD TN 37027

NASHVILLE TN 372
PM
4 MAR
1995

ALWAYS
USE
ZIP CODE

Mr. Steve Silverman
President's Advisory Committee on Human Radiation
Experiments
1600 Pennsylvania Ave., NW
Washington, DC 20500



THE WHITE HOUSE
WASHINGTON

OFFICE OF THE STAFF SECRETARY

Fax Transmittal Sheet

TO: Kevin Thurm

Fax Number: 690-7755 **Phone Number:** 690-6133

FROM: Phil Cogen

SUBJECT:

DATE:

NUMBER OF PAGES (including cover sheet):

MESSAGE:

Let me know what you think.
Event with POTUS is on 9/22. Donna should come.

If all pages are not received, please call 202/456-2702

TRANSMIT CONFIRMATION REPORT

NO.	:	002
RECEIVER	:	96907755
TRANSMITTER	:	
DATE	:	AUG 17'95 13:14
DURATION	:	10'38
MODE	:	STD
PAGES	:	19
RESULT	:	OK

ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENT
1726 M Steet, N.W., Suite 600
Washington, D.C. 20036
(202) 254-9795 (Phone)
(202) 254-9827 (Fax)

FAX TRANSMITTAL

NUMBER OF PAGES (including cover): 2

TO: Philip Caplan

FROM: Steve Klaidman

DATE: 9/22/95

RE: Press

If there are any problems with the transmission of this fax, please call (202) 254-9795.

MESSAGE:

Phil

This was the reason for my second phone call yesterday. It was to run after the "9/22" release of the report on 9/27. When we learned of the delay it was too late to stop it. There is nothing in it that the NYT did not run two months ago.

Steve

c:\phil\Radtodo.925

Radiation - to do September 25, 1995

-Congressional briefing
    -Ruth to attend?
    -move to Thursday?
    -Tracey and DOE person to talk
    -T.J. wants to go..what do we say on compensation
-respond to Boston Globe story?
-call Markey's AA
-call Wendy Baldwin - EO must be in house by Tuesday (stronger than just education...ask IRBs to review procedures)
-talk to Kevin Thurm...sign off on EO
-memo to Leon, Erskine, Harold, Don Baer, McCurry
    -4 things President will do...press plan
-TURN INTO MEMO TO POTUS...get to him by Friday
-Talking points...due Wednesday
-Press Packet
-how to distribute report to Congress
-Compensation...can we say more than just principle
-get exact text of recommendation 2 and 3 from Committee
-begin speech draft...Shipley (see steno pad) - "doing the right thing"
-get invitees for event (name, DOB, SS#)
    -40 from Ruth
    -agency numbers:
        DOE
        HHS
        DOD
        DOJ
        VA
        NASA
        OMB
        CIA
    -Congressional
    -victims groups?
-press pool

Cab Affairs
-announce radiation event on morning of October 3
    -DOE, HHS, DoD, DoJ, CIA, NASA, OMB, VA

Other:
-call Rey Post
-determine who is attending meeting
-check with Billy...run with soccer team?

- Stewart Udall - Eva Plaza
- McCain, Hatch
- Trig Mtg

- need from Wendy Baldwin today

- memo to POTUS over weekend?
  with drafts

- Boston Globe article

~~New FP talking pts~~

~~11:00 am Sit Room Mtg.~~

- ~~Weber ASTC~~
- ~~China memo~~ — Carl

- ~~Panel — Q+A~~

- "Doing the right thing"

Peter — air time, flights
time for event

DATE:

ASSISTANT SECRETARY
OFFICE OF ENVIRONMENT, SAFETY AND HEALTH
U.S. DEPARTMENT OF ENERGY
1000 INDEPENDENCE AVENUE, S.W.
WASHINGTON, D.C. 20585

95 SEP 20 A9:28

OFFICE: (202) 586-6151 FAX: (202) 586-0956

TO: Phil Caplan

FROM: Steve Gaboon

NO. OF PAGES TO FOLLOW: 1

___For your information ___Please call upon receipt

___As requested ___For review and comment

___Original copy to follow via mail

COMMENTS/MESSAGES:

DEPARTMENT OF ENERGY
WASHINGTON, DC 20585

Assistant Secretary
Environment, Safety
and Health

Phil

How about "atonement" as a part of President's message? He could mention the holiday and tie-in. Ruth would be happy. The excluded Advisory Committee members may be cooled down.

Steven

THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release **June 7, 1995**

Statement by the President

Having met this morning with Chair Barbara Jordan, I want to congratulate the Commission on Immigration Reform for its recommendation on legal immigration. Consistent with my own views, the Commission's recommendations are pro-family, pro-work, pro-naturalization. As with the Commission's first report on illegal immigration, which we are now aggressively implementing, the Commission has again laid out a road map for the Congress to consider. It appears to reflect a balanced immigration policy that makes the most of our diversity while protecting the American workforce so that we can better compete in the emerging global economy. The Administration looks forward to working with Congress on this issue.

-30-30-30-

Advisory Committee on Human Radiation Experiments

1726 M Street, NW, Suite 600
Washington, DC 20036
202/254-9795
Fax: 202/254-9827

FAX TRANSMISSION COVER SHEET

Date: May 8, 1995

To: Philip Caplan

Fax: 456-6704

Re: Request for Charter Extension

Sender: Ruth Faden

YOU SHOULD RECEIVE 4 PAGE(S), INCLUDING THIS COVER SHEET. IF YOU DO NOT RECEIVE ALL THE PAGES, PLEASE CALL 202/254-9795.

ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS
1726 M STREET, N.W., SUITE 600
WASHINGTON, D.C. 20036

MEMORANDUM

TO: **Members of the Human Radiation Interagency Working Group**

Secretary Hazel O'Leary, Department of Energy
Secretary William Perry, Department of Defense
Secretary Donna Shalala, Department of Health and Human Services
Secretary Jesse Brown, Department of Veterans Affairs
Acting Director William Studeman, Central Intelligence Agency
Administrator Daniel Goldin , National Aeronautics and Space Administration
Attorney General Janet Reno, Department of Justice
Director Alice Rivlin, Office of Management and Budget

FROM: **Ruth R. Faden, Chair**
Advisory Committee on Human Radiation Experiments

DATE: **May 8, 1995**

RE: **Request for Charter Extension**

This letter is to outline the intentions of the Advisory Committee on Human Radiation Experiments for completion of its mandate and issuance of its final report. In our Interim Report of October 21, 1994, we indicated several additional months might be necessary to answer as fully as possible the questions posed to the Committee. Although we are rapidly moving toward a successful completion, and experiencing no difficulties as a Committee, it is now clear that this is the case. Specifically, we respectfully request that our Charter be extended to September 15, with our final report to be issued no later than this date.

Please note that after May 31 we expect to be operating with a significantly reduced staff and will be issuing no further new requests for documents except under extraordinary circumstances. Nevertheless, we feel that we will be able to responsibly fill our charge. Specifically, we expect to have identified the relevant ethical and scientific standards for evaluating human radiation experiments and to address the question of notification of former subjects for health protection purposes. We also are homing in on judgments about the extent of

harm to the public's health attributable to human radiation experiments. What has become clear is that while the number of experiments in which subjects may have realized physical harm may be limited to a small proportion of experiments performed, the increasingly compelling issue is not harm to physical health but a very real and serious harm to the public's trust of government. This is compounded by a failure to accurately communicate the risks of participation to potential subjects.

The additional time sought should guarantee that we have a level of confidence about our conclusions on these matters that the American people no doubt expect, and certainly deserve. We believe that a September release date will ensure a product that preserves the integrity of the Committee and its process and delivers to the Interagency Working Group solid answers to the questions it has posed.

I know I speak for my colleagues in expressing my appreciation for the Interagency Working Group's continued support of the Committee's work. I would be happy to discuss these or any other issues with you at your convenience.

cc: Tara O'Toole, Department of Energy
Ellyn Weiss, Department of Energy
Gordon Soper, Department of Defense
Wendy Baldwin, Department of Health and Human Services
Harry Holloway, National Aeronautics & Space Administration
Nancy Tackett, Department of Veterans Affairs
Brian Latell, Central Intelligence Agency
Patrick Glynn, Department of Justice
T. J. Glauthier, Office of Management and Budget
Philip Caplan, White House
Members of the Advisory Committee on Human Radiation Experiments

THE WHITE HOUSE

WASHINGTON

May 9, 1995

MEMORANDUM FOR TARA O'TOOLE
LISA SCHIAVO

FROM: PHIL CAPLAN

SUBJECT: Extension of Human Radiation Charter

Attached is an edited version of the letter responding to Ruth's memorandum of May 8 (these are Steve Neuwirth's edits).

Yesterday's conference call served as the Interagency Working Group's approval of the extension of the Advisory Committee's charter; the letter can now be sent. Steve will then take care of the proper paperwork extending the charter.

Please call if you have any questions.

Thanks.

DRAFT

Dr. Ruth R. Faden, Chair
Advisory Committee on Human Radiation Experiments
1726 M Street, NW #600
Washington, DC 20036

Dear Dr. Faden:

The Human Radiation Interagency Working Group is in receipt of your request that the charter of the Advisory Committee on Human Radiation Experiments be extended to September 15, 1995, with the final report issued no later than that date. Your letter stated that the additional time sought is necessary to ensure a product that preserves the integrity of the Committee and its process, and that provides answers to questions posed by the Interagency Working Group.

The final report submission date was April 21, 1995, and the charter is now due to expire on May 21, 1995. ~~Executive Order 12891 (January 15, 1994), which established the Advisory Committee and the Human Radiation Interagency Working Group, also provides that functions of the President under the Federal Advisory Committee Act, shall be performed by the Interagency Working Group. Furthermore, the~~ the Advisory Committee's Charter authorizes the Interagency Working Group to extend the time period for submission of the final report. In order to ensure a thorough report that covers all the necessary material, the Interagency

↑ as paragraph 5 ↑

DRAFT

Group grants your request to extend ~~the charter's termination date~~ until September 15, 1995 ~~,~~ the date by which the Advisory Committee shall submit its final report.

~~Extension of the report submission date will necessitate a minor technical amendment of the Charter, specifying the termination date of September 15, 1995, and that the report is due no later than that date. The President will be amending the Accordingly, attached are the amendments, which will be filed with the General Services Administration and the Library of Congress.~~ Pursuant to paragraph 6 of the Charter, the President shall be ~~amending~~ extending the Charter's expiration date until ~~30 days after~~ ~~September 15, 1995~~ October 1, 1995.

Sincerely,

Secretary O'Leary

on behalf of the Human Radiation Interagency Working Group

Attachment

~~cc: James Dean, General Services Administration~~

~~September~~ October 1, ~~1995~~.

30 days after submission of the final report.

DRAFT

AMENDMENTS TO CHARTER FOR ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS

1. Replace section 5. entitled "To Whom the Advisory Committee Reports" with the following:

> The Advisory Committee shall report to the Interagency Working Group. The Advisory Committee shall submit its final report to the Interagency Working Group no later than September 15, 1995, unless such period is extended by the Interagency Working Group.

2. Replace section 6. entitled "Duration and Termination Date" with the following:

> The Advisory Committee and the charter will terminate on September 15, 1995.

3. Add signature and date blocks for the Department of Energy Advisory Committee Management Officer.

OFFICE OF THE GENERAL COUNSEL

U.S. DEPARTMENT OF ENERGY

WASHINGTON, D.C.

FAX #:
COML:

Date: 5/3/95

TO: Phil Caplan
W.H. Counsel

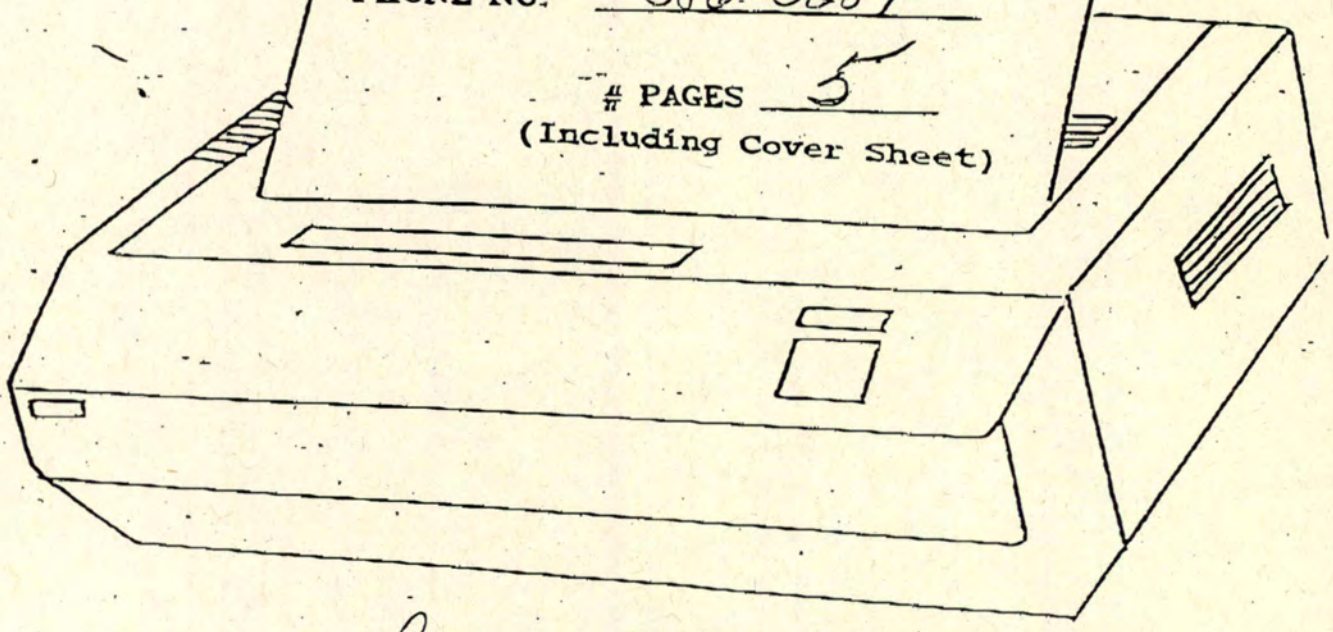
FAX NO: 456-6704

VERIFY NO. _____

FROM: Lisa Schiavo

PHONE NO. 586-5289

PAGES 5
(Including Cover Sheet)



REMARKS: Draft Letter to Ruth Faden

Department of Energy
Washington, DC 20585

May 3, 1995

By telecopier (202) 456-6704

Phil Caplan
Office of Cabinet Affairs
The White House
Washington, D.C. 20500

Dear Phil:

Attached for your review is a draft letter from the Human Radiation Interagency Working Group to Dr. Ruth R. Faden granting the request of the Advisory Committee on Human Radiation Experiments to extend its charter to September 15, 1995. The current charter expires on May 21, 1995.

The draft letter reflects our belief that the Interagency Working Group may extend the Committee's charter. As we have discussed, however, we will need to decide who will sign on behalf of the Interagency Working Group. Please contact me if I can be of further assistance on this matter.

Sincerely,

Lisa C. Schiavo

Attachment

cc: Tara J. O'Toole
Stephen Neuwirth
(by fax 456-1647)

DRAFT

Dr. Ruth R. Faden, Chair
Advisory Committee on Human Radiation Experiments
1726 M Street, NW #600
Washington, DC 20036

Dear Dr. Faden:

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DRAFT

Group grants your request to extend the charter's termination date until September 15, 1995.

Extension of the report submission date will necessitate a minor technical amendment of the charter, specifying the termination date of September 15, 1995, and that the report is due no later than that date. Accordingly, attached are the amendments, which will be filed with the General Services Administration and the Library of Congress.

Sincerely,

_____

on behalf of the Human Radiation
Interagency Working Group

Attachment

cc: James Dean, General Services Administration

DRAFT

AMENDMENTS TO CHARTER FOR ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS

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2. Replace section 6. entitled "Duration and Termination Date" with the following:

> The Advisory Committee and the charter will terminate on September 15, 1995.

3. Add signature and date blocks for the Department of Energy Advisory Committee Management Officer.

Ph21

fax # 6-2215

THE WHITE HOUSE

WASHINGTON 95 JUL 19 P6:27

July 19, 1995

MEMORANDUM FOR:

FIRST LADY'S STAFF (MELANNE VERVEER)
TODD STERN (PHIL CAPLAN)
ABNER MIKVA (JAMES COSTELLO)
KITTY HIGGINS
PAT GRIFFIN
CAROL RASCO
DOUG SOSNIK
ALEXIS HERMAN (DANA WYCKOFF)
JODIE TORKELSON
BILLY WEBSTER - FYI
ANTHONY LAKE

FROM: Lana Dickey/Maureen Hudson
for JIM DORSKIND

SUBJECT: (Draft Proclamation)
National Korean War Veterans
Armistice Day

Attached for your review is the above-mentioned proclamation designating July 27, 1995 as "National Korean War Veterans Armistice Day."

It was drafted and edited/revised by the Presidential Letters and Messages Office.

IMMEDIATE ATTENTION REQUIRED. Written or oral response required by no later than Noon, Friday, July 21, 1995. IF WE HAVE NOT HEARD FROM YOU BY 12:00 P.M., WE WILL ASSUME THAT THE DRAFT IS ACCEPTABLE TO YOU.

For questions, discussion, or routine clearance, contact Lana Dickey, extension 67487, or Maureen Hudson, extension 65902, via phone or interoffice mail, in room 91. Thank you.

cc: Tim Saunders

NATIONAL KOREAN WAR VETERANS ARMISTICE DAY, 1995

- - - - - - -

BY THE PRESIDENT OF THE UNITED STATES OF AMERICA

A PROCLAMATION

On July 27, 1953, the guns finally fell silent over the Korean peninsula. Three years of fierce struggle, costing over 600,000 deaths among U.S. and allied combatants and more than a million casualties, ended with a negotiated cease-fire at Panmunjom. At that moment, weary from two wars and shouldering the burden of maintaining an unrelenting vigilance against the hostility of the communist world, America could not see clearly what the Korean War had achieved.

Time and history have cleared our vision. More than 4 decades later, we look back in awe at what our valiant Armed Forces and their allies accomplished in Korea. They helped the Republic of South Korea to grow, survive, and prosper as an independent and democratic nation and a strong friend of the United States. At a defining moment in the early years of the United Nations, they rallied to the UN's call to defend freedom and human dignity in the Korean peninsula, demonstrating to the world's totalitarian regimes that men and women of goodwill were ready to pay with their lives so that others might enjoy the blessings of liberty. With their quiet courage and stern resolve, American troops sowed the seeds for the triumph of democracy that is sweeping across the globe today.

Now, at long last, we have a fitting memorial to honor the achievements and the sacrifice of our Korean War veterans. From across this country and around the world, these veterans will gather in our nation's capital to dedicate the Korean War Veterans Memorial, the enduring testament to their valor and generosity of spirit. America honors their service; we remember their sacrifice; and we are forever in their debt.

NOW, THEREFORE, I, WILLIAM J. CLINTON, President of the United States of America, by virtue of the authority vested in me by the Constitution and laws of the United States, do hereby proclaim July 27, 1995, as "National Korean War Veterans Armistice Day." I call upon all Americans to observe this day with appropriate programs, ceremonies, and activities in honor of our Nation's Korean War veterans.

IN WITNESS WHEREOF, I have hereunto set my hand this day of , in the year of our Lord nineteen hundred and ninety-five, and of the Independence of the United States of America the two hundred and twentieth.

NATIONAL COMMITTEE FOR RADIATION VICTIMS
6935 Laurel Avenue, Suite 207
Takoma Park, MD 20912

95 OCT 12 P6:28

X-RAYED BY USSS-NEOB

X-RAYED BY USSS-NEOB

President William Clinton
White House
Washington, DC

Attn: Phil Kaplan
Office of Staff Secretary

A CITIZEN'S GUIDE TO THE NATION'S ARCHIVES

WHERE THE RECORDS ARE AND HOW TO FIND THEM

SOME INITIAL QUESTIONS AND ANSWERS

How can I find out if I or my relative was in a radiation experiment?

This was one of the most commonly asked questions from the hundreds of individuals who contacted the Committee. There is no simple answer. Medical records are the place to start. They should provide information on what condition you or your relative was treated for, what treatment was actually given, and who administered this treatment. See part III.A for further details.

How can I obtain medical records? What should I do with them once I have them?

You have a legal right to your own medical records and, with the proper authorization, to a relative's medical records. By contacting the facility where the treatment occurred, you should be able to request and obtain the records. The next step is to have a qualified medical professional review the records to ascertain whether the treatment administered was acceptable for the patient's condition. See part III.B for further details.

What ACHRE materials are available to the public? Where are they stored and who can look at them?

All documents obtained by and produced by the Advisory Committee are public information, available to anyone. A large portion of Committee materials is available through the Internet. Hard copies of all materials will be stored at the National Archives and Records Administration in Washington, D.C. See part IV.A for further details.

Whom should an individual call to request an investigation into his or her particular case?

This was another very common question. No office currently exists that is specifically chartered to investigate individual cases with respect to human radiation experiments. That is one reason for this guide: to provide individual citizens with enough guidance to begin their own investigations. See part II for details.

Where should an individual researcher turn to learn more about radiation experiments with government involvement?

Researchers can use a number of resources, including the ACHRE collection. If more information is desired, the federal agencies have reported to the Advisory Committee that the public may contact their designated offices. See part II for details.

Whom should the public work through after the Advisory Committee is disbanded?

No extant government body is chartered to provide such guidance. It is the purpose of this appendix to provide individuals with enough direction to begin their own investigations.

CONTENTS

> . . . I have been to Oak Ridge, Tennessee, and Washington, D.C. I have seen a lot of documents. I have learned some of the codes, so please don't try to shaft me. I know a lot. The records are not here in Cincinnati, all of them on my grandmother. And I have been trying to find them. And I just would like to know where the rest of them are. So please, will you help me find them?
>
> --Citizen at the ACHRE public forum in Cincinnati
> 21 October 1994

As the Advisory Committee traveled across the country taking public testimony, it heard citizens describe many of the same experiences over and over. One common thread that struck a particularly responsive chord with the Committee was the sheer frustration felt by many, even experienced researchers, who had tried to find their own records or to find out the details of government programs. The difficulty we have all faced in doing this research yields an important lesson: The government must be honest about the nature and purposes of the studies it sponsors and conducts; in sponsoring human experimentation, it has an even higher obligation to keep a fair record and provide those involved with meaningful access. The Advisory Committee has done what it can to open the door to our nation's archives. We all must see that it remains open.

This appendix is intended to help. For those who want to know whether a relative was involved in an experiment, and for historians, journalists, and others with a more general interest in human radiation experiments (HREs) and the general topic of government-sponsored research, the following pages discuss what to ask for, whom to write to, and where to go.

The Advisory Committee's records are one important place to turn (see part IV). It should be understood, though, that the Advisory Committee did not find everything there is to find about human radiation experiments, nor could we review what we did find in the detail we would have preferred. Moreover, neither the Advisory Committee nor the agencies, generally speaking, sought the medical records of individuals. But there is much information that we did recover, and the efforts of the Advisory Committee and the agencies have increased the likelihood that citizens will be able to find the personal documents they need.

This *Guide* has four parts: part I is an introduction to finding and using federal records; part II covers agency facilities and services, including what information is available at which agencies, and where to go and how to get it; part III focuses on finding medical records. And part IV is an introduction to the records collected and created by the Advisory Committee.

PART I: FINDING FEDERAL RECORDS

Finding the most general information about the activities of the federal government can be as easy as picking up the telephone or looking in a reference book, but those approaches do not provide the detail necessary to understanding how a program operates or why it does what it does. Finding information like this requires research, and research in government documents may require time and effort. The government's records are stored in a sprawling, decentralized, and sometimes haphazard system, and particular records are often hard to locate. It may be difficult simply to determine whether the records still exist. Federal records laws and rules provide for the periodic review and destruction of certain categories of records. However, the Committee found that the documents that recorded the destructions of other documents were themselves often later destroyed. Thus, it is often difficult to know for certain whether particular documents have been destroyed or are simply hard to locate.

This part of the *Citizen's Guide* provides information that will allow the researcher to focus more quickly on where the desired information may be or, that being determined, how to go about retrieving it.

Types and Sources of Federal Information

Although there are many ways to categorize the types of information citizens seek, the one that will have the most profound effect on what to look for and where to look for it is whether the citizen is interested in *records of individual experience* or in *program records*. Records of individual experience are those that document the history of a particular person--medical records, personnel records, tax returns, memberships, and so forth--and are usually kept for the private use of that person and the institution whose relationship they record. Such records will only rarely include information about a program in which the individual participates. For example, an individual's medical records will not likely contain information on the government program that funded the medical research or the ethical guidelines applicable to the use of human subjects in the program.

Program records, on the other hand, document the purposes, organization, staffing, and funding of an activity--minutes, proceedings, memorandums, proposals, contracts, and so forth--and are likely to be available to the public in some form. Such records will only rarely contain information about individuals. For example, agency records on a biomedical research program will not contain the names of the patients involved in it or their medical histories.

As is obvious from these descriptions, records of individual experiences and program records hold very different types of information.[1] The significance for the researcher is that the two types of records are kept in different places, and his or her approach to finding the information must reflect this fact. For example, if information about the physical condition and treatment of an individual is what is wanted--that is, medical facts--a search for medical records is likely to be more useful than a search for records of experiments. Medical information about the condition and treatment of experimental subjects is generally contained in medical records and not in the scientific records of experiments.[2] On the other hand, information about a study in which citizens participated

is unlikely to be found in their medical records, but in the investigator's records and those of his institution and the study's sponsors.

Further information on finding program records, which are generally publicly available in large repositories, may be found in the remainder of part I and in parts II and IV. Those sections also provide information on government-held records of personal experience. For information on finding medical records, see part III.

Aids for Focusing Research

Because the federal government is vast, it is vitally important to identify as quickly as possible the government components whose records may contain the needed information; as will be discussed in the section below on the National Archives, that understanding is also important to using the records once they are found. Unfortunately, one of the things that the Advisory Committee learned in our research is that many government agencies do not have complete information on all the programs they sponsored through the years or on the records that were created or preserved or where they are located. And, furthermore, there is no central, comprehensive source of information for the history of the federal government: Even the collections of the National Archives do not reflect the full and complete history of the government and its programs. In some cases extensive research was required to discover or to understand the histories of certain parts of the agencies in order to identify the organizational components whose work was potentially relevant to the Advisory Committee's research. Only then could the search for records begin.

Fortunately, however, much unearthing of the histories of government organizations and locating of pertinent records has been done by agency personnel and Advisory Committee staff. The fruits of these efforts are available in three resources that may assist the citizen researcher in finding agency information. First, the relevant organizational components; the location, classification, and review of their records; and what records were never located are all described in great detail on an agency-by-agency basis in the supplemental volume, *Sources and Documentation*. This volume serves as an excellent guide for those doing their own research.[3] The second is the ACHRE collection itself; as explained in more detail in part IV below, most records in the ACHRE collection can be traced to the agency collection and repository from which they came. The third is the February 1995 Department of Energy publication, *Human Radiation Experiments: The Department of Energy Roadmap to the Story and the Records* and its July 1995 supplements (see part II, below).[4] This work describes in considerable detail many relevant DOE record collections that are located at various repositories in the Washington, D.C., area and the national laboratories around the nation (see part II, below, for further information about the laboratories). We note that, in addition to resources created during the life of the Committee, agencies may have created other guides to agency history and records collections. See, for example, "A Guide To Resources on the History of the Food and Drug Administration," Food and Drug Administration, History Office.

Where Federal Records Are

Unless they have been lost or destroyed, almost all federal records[5] created since the founding of the Republic are in agency files, stored at a federal records center, or preserved in the National Archives.[6] Generally, agencies are required to transfer to the National Archives records that are of sufficient historical or other value to warrant preservation. Documents are transferred when they are thirty years old or, regardless of age, when the originating agency no longer needs them for its regular business and will be satisfied accessing them through the National Archives.

In actual practice, few, if any, agencies have fully complied with these requirements. Most records are still under the control of the agencies that created them, though some are stored with the National Archives and Records Administration (NARA). Even for quite old records, therefore, the citizen will often find it necessary to look beyond the National Archives into the federal record centers and the agencies. The use of these three repositories is described below; further information on the agencies is contained in part II.

National Archives

Collections

NARA does not refile the records it receives according to some grand theoretical scheme but, rather, preserves them in as close to their original order as is practical, arranging them according to *provenance*.[7] This means that the structure and organization of records in the National Archives reflects the structure and organization of the office that created them, using the same divisions and titles that were used by the office originally. For this reason, all records of an individual agency--or in the cases of very large agencies such as the military services, the records of various commands, headquarters, and other major organizational units--are placed by the National Archives in a separate *record group* with a distinctive title and number. The approximately 475 record groups at the National Archives vary in size from less than 100 cubic feet to tens of thousands of feet. Record groups are divided into subdivisions called *entries* that often hold the records of a single division, department, bureau, or office. The access tool generally used to find basic information in a record group (e.g., brief descriptions of individual entries) is the *finding aid* created by the National Archives. Not all record groups have finding aids, however, and some older ones have not been kept up to date. The archivists who work with the record groups are often an invaluable source of information as well.

Services

The National Archives is the one repository holding agency records specifically charged with accommodating the public. In addition to a staff of professional archivists, the Archives provide large research rooms, copiers, and complete access to unclassified and declassified collections.

The National Archives has two major public facilities in the Washington area: the

National Archives, Pennsylvania Avenue between 7th and 8th Streets, N.W., Washington, D.C., and the National Archives at College Park ("Archives II"), 8601 Adelphi Road, College Park, Maryland 20740-6001. (Telephone 202-501-5400 to request reference help, or write Reference Services Branch, National Archives and Records Administration, Washington, D.C. 20408.) Research hours at both the downtown Washington and College Park facilities are 8:45 a.m. to 9:00 p.m., Tuesday, Thursday, and Friday; 8:45 a.m. to 5:00 p.m., Monday and Wednesday; and 8:45 a.m. to 4:45 p.m. on Saturday, except federal holidays.

Records that are generated by regional offices are maintained in regional archives:

Anchorage, Alaska: 654 W. 3rd Avenue, 99501; 907-271-2441
Chicago, Illinois: 7358 S. Pulaski Road, 60629; 312-581-7816
Denver, Colorado: Building 48, Denver Federal Center, 80225; 303-236-0817
East Point, Georgia: 1557 St. Joseph Avenue, 30344; 404-763-7477
Fort Worth, Texas: 501 W. Felix Street, 76115; 817-334-5525
Kansas City, Missouri: 2312 E. Bannister Road, 64131; 816-926-6272
Laguna Niguel, California: 24000 Avila Road, 92677; 714-643-4241
New York, New York: 201 Varick Street, 10014; 212-337-1300
Philadelphia, Pennsylvania: 9th and Market Streets, 19107; 215-597-3000
San Bruno, California: 1000 Commodore Drive, 94066; 415-876-9018
Seattle, Washington: 6125 Sand Point Way N.E., 98115; 206-526-6507
Waltham, Massachusetts: 380 Trapelo Road, 02154; 617-647-8100

For Freedom of Information Act (FOIA) and Privacy Act requests, speak with the archivists who work with the record group concerned, or write: Office of the National Archives, National Archives and Records Administration, Washington, D.C. 20408; telephone 202-501-5300. For further information see the section on Rights and Restrictions on Access to Information, below.

Federal Records Centers

When an agency determines that it no longer needs to house a group of records it can transfer them to a federal records center in its geographical area. Federal records centers have been established solely to assist the agencies in the storage and processing of their records. There is no requirement that any agency transfer its records to a records center. Although the records centers are managed by NARA, the agencies retain legal custody and control of the records.

Collections

Records held in federal records centers are also organized into record groups (using the same titles and numbers as at the National Archives), but are not further broken down into entries. Instead, a record group at a records center consists simply of a series of *accessions*, the shipments of records added to it. Record groups may contain from a few

to thousands of accessions, and an individual accession may hold one to many hundreds of boxes of records. Unfortunately, there are no archivists or finding aids at federal records centers to assist the public. The only means of determining what is in a record group is by examining the *Standard Form 135 (SF-135)* prepared by the agency for each individual shipment. These forms contain a great deal of information, including the accession number, name and address of the office shipping the records, point of contact, security classification of the records, quantity of records in cubic feet, and a description of the records that often includes a folder listing.[8] The examination of SF-135s can be a very tedious process, for they may total many thousands of pages.

Services

The public does not have free access to records at a federal records center, not even to completely unclassified or declassified accessions. Permission first must be obtained from the agency that owns the records, and this can be a time-consuming process. Personnel at the federal records centers will provide information on who should be contacted at an agency about obtaining such permission.

The one federal records center in the Washington, D.C., area is the Washington National Records Center, 4205 Suitland Road, Suitland, Maryland 20409; telephone 301-763-7000. The hours are 8:00 a.m. to 4:30 p.m., Monday through Friday except federal holidays. There are thirteen regional federal records centers, which hold records generated by federal offices in that particular geographical region of the nation. Many, but not all, are located in the same place as the regional National Archives:

Bayonne, New Jersey: Building 22, Military Ocean Terminal, 07002; 201-823-7161
Chicago, Illinois: 7358 S. Pulaski Road, 60629; 312-352-0164
Dayton, Ohio: 3150 Springboro Road, 45439; 513-225-2878
Denver, Colorado: Building 48, Denver Federal Center, 80225; 303-236-0804
East Point, Georgia: 1557 St. Joseph Avenue, 30344; 404-763-7476
Fort Worth, Texas: Building 1, Fort Worth Federal Center, 76115; 817-334-5515
Kansas City, Missouri: 2312 E. Bannister Road, 64131; 816-926-7271
Laguna Niguel, California: 24000 Avila Road, 92677; 714-643-4420
Philadelphia, Pennsylvania: 5000 Wissahickon Avenue, 19144; 215-951-5588
San Bruno, California: 1000 Commodore Drive, 94600; 415-876-9015
Seattle, Washington: 6125 Sand Point Way N.E., 98115; 206-526-6501
St. Louis, Missouri: National Personnel Records Center, 9700 Page Boulevard, 63132; 314-263-7201
Waltham, Massachusetts: 380 Trapelo Road, 02154; 617-647-8745

FOIA requests for records in the custody of the federal records centers must be submitted to the federal agency that transferred the records to the federal records center. Records center personnel will provide addresses and contacts. For further information, see the section "Access to Information: Rights and Restrictions," below.

Records Still Held by Agencies

Several agencies retain great volumes of records that have never been sent to the National Archives or a federal records center. Such records may be stored at any number of places, including internal record storage facilities and history offices. With a few exceptions, these collections are generally less well organized and described than those at the National Archives or federal records centers. Furthermore, most agencies have only a limited ability to accommodate researchers. The names, addresses, and telephone numbers of the locations where the agencies store records are available in part II, below.

Access to Information: Rights and Restrictions

This section addresses some government policies that control access to information--on privacy, freedom of information, and national security classification--and some of a citizen's rights to information and how to exercise them.

Privacy and Freedom of Information

The Privacy Act and the Freedom of Information Act (FOIA)[9] are the most critical components of the legal framework that supports public access to federal records. The Privacy Act defines certain types of information as privileged to the individual, and during his or her lifetime it prevents their public dissemination or their use for purposes other than those originally authorizing their collection. This means, for example, that one agency may not share personal information about citizens with another government agency, and it means that one person may not have access to such information about any other person without authorization. This protection of privacy extends to records in the National Archives as well. The Freedom of Information Act guarantees, with some categories of exceptions, that all records created by the executive branch of the federal government are available to citizens. Among those exemptions are a privacy clause that broadens the scope of the Privacy Act by extending protection to personnel and medical files by category rather than limiting protection to the lifetime of individuals, and a national defense and foreign policy clause that precludes one from obtaining certain classified information under FOIA.

The next two sections discuss the effect of these laws on obtaining information based on the names of individuals, and the procedures and requirements for making Freedom of Information Act Requests.

Name Searches

Access by citizens to federal records that are retrievable by the names of individuals or other personal information are controlled by the Privacy Act and by the privacy clause of the Freedom of Information Act. The Privacy Act restricts access to information contained in what are called *Privacy Act systems of records*, records arranged by the names of individuals or other personal information. In general, during an individual's lifetime, records retrieved by the use of personal information are available only to that person or with his or her authority,[10] although redacted copies of such documents--that is,

copies from which private information has been removed--may be available if the records are retrievable in some other way.[11] If, therefore, a citizen is interested in obtaining records that concern him or her or, with the appropriate authority, those that concern a close relative, there should be no legal restrictions on access; to the extent, however, that a citizen wishes more information about other individuals who are mentioned in those records, there may be considerable difficulty. In such cases one would probably have greater success identifying the program in which he or she participated, determining where the records of that program are housed, and extracting information from those records.

FOIA Requests

In general, the Freedom of Information Act requires that the individual[12] make inquiry in writing[13] directly to the appropriate agency, in conformity with the established procedures of the agency, and that agreement on the payment or inapplicability of fees is reached between the requester and the agency. The first requirement usually is understood to include identification of the records in which the information is to be found. Agencies are not required to do research for the citizen but only to conduct "reasonable searches" of their records in an attempt to meet the request.[14] The second requirement recognizes that different agencies may have different procedures for handling public inquiry.[15] The third requirement permits the agency to determine before accepting the request that the requestor will pay all the applicable fees or, in the alternative, that there are valid grounds for waiving the fees.[16]

Once an agency has accepted a FOIA request, the law establishes very short periods of time for the agency to respond. If the request is accepted, the agency is obligated to decide within ten working days of acceptance whether or not it will provide the information within a reasonable length of time,[17] and if the request is denied and an appeal is made, it must provide a response within twenty working days. In actual practice, however, agencies rarely meet these time limits. Depending on the backlog of requests, the number of other agencies that must be contacted, and other factors, a FOIA can take one to five years to process.

Agencies are most likely to reproduce and mail copies of records to requesters, but they are not required to do so and are permitted to provide access to the records at a central location (see also the information on the FOIA reading rooms and offices at the agencies in Part II).

If an agency denies a request in whole or in part, the requester then has the right to make one administrative appeal. If after these the requester is still not satisfied, the only recourse is federal court.

Classified Records

There is a vast number of records at the National Archives, in the federal records centers, and at the agencies that are still classified and therefore unavailable to the public. The government is obliged by executive order to review its records periodically for declassification, but citizens may request a review on their own initiative. Submitting a request, of course, does not guarantee that the records will be declassified either in whole

or in part. The government authorities conducting the review may conclude that the documents should remain classified.

There are three methods under which the public can request that documents at the National Archives be reviewed for declassification. The first is under FOIA, and the second is under the Mandatory Declassification Review (MDR) provisions of Executive Order 12958 of April 17, 1995.[18] Under both methods, a request is submitted to the National Archives (rather than to the agency that generated the records), whose archivists will provide information on how the request should be handled further. The third method for requesting declassification is under the Special Declassification Review procedure. This informal procedure, which is only applicable to records at the National Archives, is much quicker than either FOIA or MDR, but there are some records--intelligence records, for example--that cannot be reviewed in this way. The archivists working with the records should be consulted to determine whether a Special Declassification Review may be used.

To access classified collections at federal records centers or agencies, either a FOIA or an MDR request must be submitted to the agency. Classified records that turn up in the course of a document search are sent through declassification review. There is no Special Declassification Review procedure at federal records centers or agencies.

PART II: AGENCY INFORMATION AND SERVICES

As part of the Advisory Committee's effort to improve citizen access to information, we asked the agencies providing information to the Committee--chiefly the members of the Interagency Working Group and the Nuclear Regulatory Commission--to respond to a series of questions concerning the handling of private information requests. We asked how citizens should make requests, what services the agencies would provide, what information resources were available, and how agencies would handle requests for information held by agency contractors and grantees. Each agency's response is summarized in its section, below. Those sections also include general information obtained from the *U.S. Government Manual*,[19] including the location of FOIA reading rooms and offices.[20]

Department of Energy

General

DOE maintains a Freedom of Information Act Reading Room at its headquarters in Washington. The address is FOIA Reading Room, Forrestal Building, Room 1E-190, Department of Energy, 1000 Independence Avenue, S.W., Washington, D.C. 20585; telephone 202-586-6020. The reading room is open 9:00 a.m. to 4:00 p.m., Monday through Friday, except federal holidays. General information on filing FOIA requests may be obtained from the FOIA office, 202-586-5955.

As described both in *Sources and Documentation* and in *Human Radiation Experiments: The Department of Energy Roadmap to the Story and the Records*, the History Division at DOE headquarters has custody of many collections of records. The relatively few unclassified and declassified collections that the division maintains can be

examined at its office in DOE's Germantown facility: U.S. Department of Energy, History Division, HR-76, Room F031, 19901 Germantown Road, Germantown, Maryland 20874-1290; telephone 301-903-5431. The hours are from 8:00 a.m. to 4:00 p.m., Monday through Friday, except federal holidays. An appointment must be made, as there is limited space to accommodate the public.

In addition, the national laboratories around the nation hold a huge volume of records. Information at those locations is available as follows:

Argonne National Laboratory: There is no reading room at Argonne, but citizens may write: Argonne National Laboratory, Office of Public Affairs, 9700 South Cass Avenue, Argonne, Illinois 60439; 708-252-5575.

Brookhaven National Laboratory: There is no reading room at Brookhaven, but citizens may write: Brookhaven National Laboratory, Office of Public Affairs, Building 134, P.O. Box 5000, Upton, New York 22973; 516-282-2345.

Hanford: DOE Public Reading Room, P. O. Box 999 - Mail Stop H2-53, Richland, Washington 99352; 509-376-8583. This facility is in the library at Washington State University - Tri-Cities Campus, 100 Sprout Road, Richland, Washington. The hours are 8:00 a.m.-noon and 1:00-4:30 p.m., Monday through Friday.

Los Alamos National Laboratory: Public Reading Room, 1350 Central Avenue - Suite 101, Los Alamos, New Mexico 87544; 505-665-2127 or 800-343-2342. The reading room is open 9:00 a.m. - 5:00 p.m., Monday through Friday, except federal holidays.

Idaho National Engineering Laboratory: DOE Idaho Operations Public Reading Room, 1776 Science Center Drive, Idaho Falls, Idaho 83415-2300; 208-526-9162. The hours are 8:00 a.m. - 5:00 p.m., Monday through Friday, except federal holidays.

Lawrence Livermore National Laboratory: There is no reading room at Lawrence Livermore, but citizens may write: Area Relations - Mail Stop L404, Lawrence Livermore National Laboratory, P.O. Box 808, Livermore, California 94550.

Oak Ridge National Laboratory: Oak Ridge Operations (ORO) Public Reading Room, 55 Jefferson Circle, Oak Ridge, Tennessee 37831; 615-241-4780. The hours are 8:00 - 11:30 a.m. and 12:30 - 5:00 p.m., Monday through Friday, except federal holidays. In addition to the laboratory itself (ORNL), the Oak Ridge complex also encompasses the regional DOE office (ORO) and an independent research institute (ORISE) operated by a consortium of universities. The regional office may be contacted by writing: Oak Ridge Operations Office (ORO), P.O. Box 2001, Oak Ridge, Tennessee 37831. The research institute may be contacted by writing: Oak Ridge Institute for Science and Education (ORISE), P.O. Box 117, Oak Ridge, Tennessee 37831-0117.

Information on Human Radiation Experiments

In response to the Advisory Committee's request, the Department of Energy has provided the following information about its resources and services for citizens inquiring about human radiation experiments.

General Department of Energy information about human radiation experiments sponsored by DOE and its predecessors, and referrals, may be requested through the Radiation Research Helpline (1-800-493-2998) or by writing to the Department of Energy, Office of Human Radiation Experiments (OHRE), EH-8, 1000 Independence Avenue, S.W., Washington, D.C. 20585.

The largest body of pertinent records is maintained by the Coordination and Information Center (CIC).[21] All CIC material is declassified, screened, and redacted for public dissemination. The CIC may be contacted by writing to the Coordination and Information Center, 3084 South Highland Street, Las Vegas, Nevada 89109, or by calling 702-295-0731. Although generally equivalent for DOE-related human radiation experiment records, the ACHRE and CIC collections are not identical: The ACHRE collection contains most but not all of CIC's Human Radiation Experiments records series and has some DOE records not represented in CIC collections. For further information on CIC documentation, see "How to Go From the ACHRE Collection to Agency Records" in part IV, below.

Medical records should be requested from the facility where the medical services were performed. Current or former DOE employees may obtain their medical records from the site where they worked or from the National Personnel Record Center in St. Louis, Missouri, which may be contacted directly (314-538-3882).[22] Dosimetry records documenting occupational radiation exposures are maintained for both government and contractor personnel; they should be requested from the DOE manager at the site where exposure may have occurred. DOE also maintains a consolidated collection of dosimetry records related to weapons testing, including both civilian and military information. Information may be requested by writing to the Dosimetry Research Program (DRP), P.O. Box 98521, Las Vegas, Nevada 89193-8521, or by calling 702-295-0731. DOE will also help to identify and locate records that are not in the custody of the department, although citizens must contact those institutions or individuals themselves.

Several DOE departments have created finding aids that may be useful in finding HRE records: (1) As mentioned above, the report *Human Radiation Experiments: The Department of Energy Roadmap to the Story and the Records*, prepared by the Office on Human Radiation Experiments, provides summaries of that office's findings and descriptions of some relevant record collections. (2) An electronic index to pertinent CIC holdings is available at the CIC and OHRE offices and at DOE's reading rooms. Citizens may request searches or do their own at those locations. (3) For those with Internet access, recently declassified documents are available from DOE's Office of Scientific and Technical Information through its World Wide Web[23] presence, Opennet (http://www.doe.gov/html/osti/opennet/opennet1.html). And another group of databases on the Internet, created by OHRE, provide full access to the documents in the CIC collection. (Further information about OHRE and this complex of databases [called HREX] may be obtained from its World Wide Web site, http://www.ohre.doe.gov.) Finally, OHRE issued a supplement to its February 1995 report in July 1995 entitled

Human Radiation Experiments Associated with the U.S. Department of Energy and Its Predecessors.[24] This volume adds to the information reported in the February 1995 volume, and also includes summaries of the nearly 150 HREs reported by DOE.

Department of Defense

General

The Department of Defense's Freedom of Information Act offices may be contacted as follows: DOD, 703-697-1180; Army, 703-607-3452; Navy, 703-697-1459; Air Force, 703-697-3467.

Information on Human Radiation Experiments

In response to the Advisory Committee's request, the Department of Defense has provided the following information about its resources and services for citizens inquiring about human radiation experiments.

Information concerning human radiation experiments sponsored or conducted by the Department of Defense is available chiefly through the Radiation Experiments Command Center (RECC), the DOD equivalent of DOE's Office of Human Radiation Experiments. RECC is operated under contract by Science Applications International Corporation (SAIC). The primary method of contacting RECC is by referral from the DOE Radiation Research Helpline (1-800-493-2998)--RECC does not provide direct telephone assistance. Citizens may also write directly to RECC: Radiation Experiments Command Center, 6801 Telegraph Road, Alexandria, Virginia 22310-3398. Individuals contacting RECC will be requested to fill out a survey form to facilitate the search for records responsive to their requests. The RECC collection and the ACHRE collection of DOD materials are generally equivalent. For further information on RECC documentation, see "How to Go From the ACHRE Collection to Agency Records" in part IV, below.

RECC does not keep medical records but will assist those who request them by contacting the appropriate facility and referring the individual there. Active duty military personnel will find their complete medical records at their current duty stations; upon retirement or discharge, their files are transferred to the National Personnel Records Center in St. Louis. Former military personnel may contact the center directly (314-538-3882).[25]

RECC maintains a database of information on human radiation experiment documents identified during DOD's search and a database of secondary information concerning the history and policy behind the activities. Case files on individuals exposed to radiation are being created and categorized by exposure. RECC will also help citizens contact private institutions involved in DOD-sponsored programs, within the limits of the Privacy Act.

Another DOD resource is the Nuclear Test Personnel Review Program (NTPRP) operated by the Defense Nuclear Agency (DNA), which has obtained a considerable volume of records and information related to military and civilian participants in atmospheric nuclear tests between 1945 and 1962. Unclassified and declassified records that do not contain privacy information can be reviewed by the public at a special library at DNA headquarters. The program also provides certain informational and referral

services to participants. The address is Defense Nuclear Agency, Nuclear Test Personnel Review Program, 6801 Telegraph Road, Alexandria, Virginia 22310; telephone 1-800-462-3683. Additional services may be available through the VA's Ionizing Radiation Registry Examination Program (see VA section, below).

Department of Health and Human Services

General

There is no general reading room for the Department of Health and Human Services, nor for its research divisions, the Public Health Service and the National Institutes of Health.[26] Each institute of NIH[27] maintains its own information facilities, including its own office of public affairs. For help in identifying the sort of information needed and how to obtain it, a good place to start is the National Library of Medicine, 8600 Rockville Pike, Bethesda, Maryland. The general information line for NIH is 301-496-4000.

Information on Human Radiation Experiments

In response to the Advisory Committee's request, the Department of Health and Human Services has provided the following information about its resources and services for citizens inquiring about human radiation experiments.

DHHS sponsors two types of research--intramural ("within the walls"), research conducted by DHHS staff members, and extramural ("outside the walls"), research conducted outside DHHS by contractors or grantees. DHHS keeps medical records only for individuals who participated in intramural research. Inquiries concerning such records should be directed in writing to the Deputy Assistant Secretary for Health/Communications, Department of Health and Human Services, Hubert Humphrey Building - Room 701H, 200 Independence Avenue, S.W., Washington, D.C. 20201.

There are four DHHS databases that may help identify potential human radiation experiments. The first is the Clinical Center intramural protocol database (also called the Protocols by Institute database), which was created at the Advisory Committee's request to index information about NIH intramural research. This database was completed in February 1995 and contains more than 5,000 entries for the period 1953 through November 1994. More recent information on extramural research is included in the CRISP (Computer Retrieval of Information on Scientific Projects) database, which contains records for all PHS extramural projects and for NIH and Food and Drug Administration (FDA) intramural projects. The most comprehensive database is called IMPAC and includes information on awards as far back as 1944, although not all programs are included for their entire tenure and the information on early awards is limited. Finally, the National Library of Medicine (NLM) is creating a database with entries for all articles written by investigators whose human radiation experiments were supported by NIH. (Thus the database will contain citations for both radiation and nonradiation research.) NLM expects the database will eventually contain approximately 100,000 entries.

DHHS has a contractual relationship with its contractors and grantees that limits its access to the records they create to those occasions required by agency functions.

Consequently, although DHHS will help citizens identify the independent researchers and institutions that hold their medical records, it asks that the initial contact be made by the citizen. If that approach is unsuccessful, DHHS will attempt to obtain the records. Citizens are encouraged to contact DHHS to make a precise determination of whom to contact and what information to include in their inquiries.

Department of Veterans Affairs

General

The VA maintains a reading room at its central office in Washington, D.C., where citizens may inspect or copy VA records available to the public. The address is Room 170, 810 Vermont Avenue, N.W., Washington, D.C. 20420; telephone 202-233-2356. For further information, contact the Office of Public Affairs, Department of Veterans Affairs, 810 Vermont Avenue, N.W., Washington, D.C. 20420; telephone 202-273-5700.

Information on Human Radiation Experiments

In response to the Advisory Committee's request, the Department of Veterans Affairs has provided the following information about its resources and services for citizens inquiring about human radiation experiments.

The VA is continuing to look for information on human radiation experiments in its own records and will assist citizens in identifying nongovernment records related to their case histories. It has also published a fact sheet, "Information for Veterans Exposed to Radiation" (November 1994). Requests for information about participation in experiments may be made directly to the director of the appropriate VA medical center or to the director of the regional VA office (toll-free 1-800-827-1000). The VA maintains an Ionizing Radiation Registry Examination Program for veterans who may have been exposed to the ionizing radiation while on active duty in the period 1945-1962. Information about the program may be requested in writing from: Director, Environmental Epidemiology Service (103E), Department of Veterans Affairs, 1120 20th Street, Suite 950, Washington, D.C. 20036-3406, telephone 202-606-5420. Additional information may be requested from DOD's Nuclear Test Personnel Review Program (see DOD section, above).

National Aeronautics and Space Administration

General

The NASA Headquarters Information Center is in Room 1H23, 300 E Street, S.W., Washington, D.C. 20546, and is open 8:00 a.m. to 4:30 p.m., Monday through Friday, except federal holidays. For information about holdings, telephone 202-358-1000.

Information on Human Radiation Experiments

In response to the Advisory Committee's request, the National Aeronautics and Space

Administration has provided the following information about its resources and services for citizens inquiring about human radiation experiments.

NASA's records concerning human radiation experiments are generally limited to summary reports from principal investigators and do not contain medical information on individuals, apart from the records of astronauts. Information about individual participation may be requested in writing under the Privacy Act using FOIA procedures and NASA's standard Human Radiation Exposure Log form. Inquiries should be directed to: NASA Johnson Space Center, Freedom of Information Coordinator, Public Affairs Office, Mail Code AP2, Houston, Texas 77058, Attn.: Director, Space and Life Sciences Directorate. NASA's information retrieval systems in this area are limited, and success will largely depend on the quality and detail of the information provided to NASA. NASA will refer requests for information requiring access to non-NASA records to the appropriate individual or institution.

Central Intelligence Agency

General

The CIA does not maintain a public reading room but does issue several publications that may be of interest. For information, write: Central Intelligence Agency, Public Affairs Office, Washington, D.C. 20505, or telephone 703-351-2053.

Information on Human Radiation Experiments

In response to the Advisory Committee's request, the Central Intelligence Agency has provided the following information about its resources and services for citizens inquiring about human radiation experiments.

The CIA has no special facilities for handling requests concerning human radiation experiments nor any information resources specifically concerned with them. Privacy Act and Freedom of Information Act requests should be filed in the usual ways. The CIA is not prepared to facilitate the identification or the retrieval of nongovernment records that may be associated with government activities. Requests should be addressed in writing to: Information and Privacy Coordinator, CIA, Washington, D.C. 20505.

Nuclear Regulatory Commission

General

The Nuclear Regulatory Commission (NRC) Headquarters Public Document Room maintains an extensive collection of documents related to NRC licensing proceedings and other significant decisions and actions, and documents from the regulatory activities of the former Atomic Energy Commission. The reading room is located at 2120 L Street, N.W., Washington, D.C.; telephone 202-634-3273, toll-free 800-397-4209 or fax 202-634-3343. The Public Document Room is open Monday through Friday from 7:45 a.m. to 4:15 p.m., except on federal holidays. Reference librarians are available to assist users with information requests. A bibliographic database is available for on-line

searching twenty-four hours a day. For additional information call the above telephone number or write: Nuclear Regulatory Commission, Public Document Room, Washington, D.C. 20555.

The commission also maintains eighty-eight local public document rooms in libraries in cities and towns near commercially operated nuclear power reactors and certain nonpower reactor facilities. A list of local public document rooms is available from the Director, Division of Freedom of Information and Publications Services, Nuclear Regulatory Commission, Washington, D.C. 20555-0001. To obtain specific information about the availability of documents at the local public document rooms, NRC's Local Public Document Room Program staff may be contacted directly by calling, toll-free, 800-638-8081. Citizens may also request the publication *Users' Guide for the NRC Public Document Room* (NUREG/BR-0004, Rev. 2).

Freedom of Information Act inquiries should be directed in writing to the Director, Division of Freedom of Information and Publications Services, Nuclear Regulatory Commission, Washington, D.C. 20555-0001. For further information, call 301-415-7175.

For general information, contact the Office of Public Affairs, Nuclear Regulatory Commission, Washington, D.C. 20555-0001; telephone 301-415-8200. Citizens may request the publication *Citizen's Guide to U.S. Nuclear Regulatory Commission Information* (NUREG/BR-0100, Rev. 2).

Information on Human Radiation Experiments

In response to the Advisory Committee's request, the Nuclear Regulatory Commission has provided the following information about its resources and services for citizens inquiring about human radiation experiments.

Although the NRC and its predecessor, the regulatory division of the Atomic Energy Commission (AEC), have not conducted or sponsored human radiation experiments, their license files do contain some relevant information about the radioactive materials that were distributed and the purposes to which they were put, human radiation experiments among them. AEC and NRC records do not contain names or other identifying information about the subjects of such experiments and only rarely contain detailed information about the experiments themselves. The NRC also collects information about occupational exposures, medical misadministrations, and other cases of overexposure. This information is available to the public, subject to the restrictions of the Privacy Act and FOIA. Citizens may request agency documents under the Freedom of Information Act and/or the Privacy Act by writing to: Director, Division of Freedom of Information and Publication Services, Office of Administration, Nuclear Regulatory Commission, Washington, D.C. 20555-0001.

The agency will search all agency records, if requested to do so, and can search license files by institution.

PART III: PERSONAL MEDICAL RECORDS

Citizens who participated in experiments have medical records of the same type as those created by their personal physicians, whether the experiments were conducted in

doctors' offices, research laboratories, or medical facilities such as hospitals and sanatoria. As discussed in part I, these records are distinct from the scientific records of the experiments and must be sought in different places. Medical records, unlike scientific records, will contain most of the information necessary to finding out what medical actions were taken and why specific procedures were followed.

Citizens share ownership of their medical records with their physicians and the medical facilities where they were treated and have the right to copies of these records. The records should be available to the individual or an authorized relative for the asking (though there may be a copying charge). In this part, we discuss how to find personal medical records and where those records may be located.

A Basic Distinction

Many individuals who contacted the Advisory Committee were understandably confused by the difference between the broad array of medical interventions involving radiation and the "human radiation experiments" that the Committee was chartered to review. The difference is this: While medical interventions are not expressly intended to accomplish anything more than therapy, "experiments" are designed to yield generalizable scientific knowledge. This is not to imply that experiments offer no therapeutic benefit (many do), only that they are organized in a different way, taking place in a controlled setting and potentially involving thousands of subjects.

It is not always easy for a patient to tell from circumstances whether he or she is involved in a larger study. One reason for the difficulty is semantic. Some ad hoc medical interventions are loosely called "experimental," meaning that they have not been proven effective or generally accepted as safe by the medical community. Experiments, meanwhile, are commonly known by another name: "human subject research."[28] Matters are complicated by the dual role many doctors play, rapidly switching hats between physician and investigator. Given all this potential for misunderstanding, those who conduct human research are under an acute ethical responsibility to clearly explain the purposes of a procedure in obtaining the subject's consent.

A citizen who believes that he or she or a relative may have been a subject in government-sponsored human research should begin the search for facts in the medical records, which provide the details of the patient's condition and the treatment administered for it. A medical professional should be asked to review these records and check for signs of a research purpose. In many cases, having the records reviewed by a professional will answer most questions and concerns. The next two sections give advice on finding one's records.

Personal Medical Records Created by Physicians and Hospitals

Physicians and medical facilities should be approached directly by the individual or by an authorized relative. As with any request for private information, a request for medical records should be formal, direct, and clear, and it should include significant personal details to assure the identity of the correspondent and, thus, the legitimacy of the request. These details are similar to those needed to request a birth certificate--date and place of birth, parent's names, and so forth. The letter should also include as many details as

possible about the circumstances of interest, such as the dates of treatment, the names of the physicians, and any other information that will help locate the records. Institutions may have standard forms that need to be used; if the request occurs at some distance in time or geography, the identity of the correspondent may have to be certified in some way. These are common procedures, designed to protect an individual's privacy by preventing the unauthorized release of information.

If the name of the physician or medical facility that conducted the procedure in question is known but the address is unknown, one of the indexes of physicians and facilities available at a public library should be useful.[29] If the names are unknown, one place to start is with the individual's current physician and local hospital. They may have copies of older medical records because they were authorized to obtain medical histories. They are also likely to have (or to be able to get) information about how to contact physicians or medical facilities in other locations.

If the names of the physician and facility are not readily found, more extensive research in family papers and a broader correspondence with individuals who may have information will be necessary. Former friends, neighbors and co-workers, extended family members, clergy, and any other associates are all potential sources of information, as is the patient's health insurance company. Without the names of the medical personnel and facilities involved it will be very difficult to find records at nongovernmental facilities. If the treatment received occurred in a government facility, see part II of this appendix, which describes how to find those records. Outside the military services and large government research and social benefit programs, however, there are no large lists of individual citizens matched to their medical experiences that would provide the needed information.

Where Else Could the Information Be?

In general, unless there are regulations or legal obligations that require other arrangements, records stay where they are created. For example, if a patient was treated at Hospital X, Hospital X is likely to be where those records are kept. It is possible that Hospital X destroys all records that are, say, thirty years old; it is also possible that Hospital X stores those records with a firm that specializes in document storage. In either case, the disposition and location of the records will be known to Hospital X and possibly to no one else.

Physicians and institutions, however, create records other than patient medical records that may also contain important medical information. When asked for medical records, Hospital X may not think of all the records that an individual might find valuable in reconstructing his or her medical history, other records that reflect activities under its sponsorship.

These records may not be coordinated or housed with any of the others. Departmental records at a hospital may be retired with those of the hospital generally or they may not. Departmental records at a university are typically retired to the university archives, usually housed in the university library; a hospital department's records at a university with a medical school may be retired to the medical school library. The academic records of faculty members are treated similarly. Records of private research and personal papers, however, are often given to the faculty member's alma mater rather than to the

university where the research was done, so that both locations need to be searched. If the faculty member was a physician, it is also possible that such records were given to the institution where he or she attended medical school rather than to an undergraduate school (and then to the medical school, rather than to the university itself). In either case, it is unlikely that actual patient records would be included in an institution's archives. Many retiring physicians offer former patients (or their successor physicians) their files or may destroy these records if the patients cannot be reached.

As reported to the Advisory Committee, in some cases (see part II of this appendix) federal agencies will help citizens locate or retrieve records that were created or are held by nongovernment organizations or individuals.

PART IV: USING THE ACHRE COLLECTION AS A PLACE TO START

What Is in the Collection and What Is Not

The ACHRE research collection, which will be deposited in its entirety at the National Archives as part of Record Group 220, Presidential Committees, Commissions, and Boards,[30] is composed primarily of documents identified through agency search processes or selected by the Advisory Committee through requests or site visits to forty-five nonfederal as well as federal institutions. These efforts have not exhausted all research possibilities, but the volume of materials now identified and available to the public is very large. The Advisory Committee has not attempted to collect everything that might be pertinent, but has emphasized primary materials of wide importance. The resulting collection is rich in its breadth and variety, but frequently limited in the depth to which individual events or people are documented. Most records in the collection do not contain information about the individual subjects of human radiation experiments.

ACHRE records can make two significant contributions to the efforts of the individual researcher. First, there is no other collection in which pertinent materials from so many different sources are available in a scholarly arrangement with a substantial finding aid. Second, the collection deposited with the National Archives also includes the Advisory Committee's own research documents, including substantial unpublished notes, histories, analyses, and findings. The comprehensiveness of the collection and the added value of the Advisory Committee's scholarship make the ACHRE records a good starting point for citizens researching the public and private histories of human radiation experiments.

Experiments

The Advisory Committee's general charge was to provide advice on the character of historical and present-day policies and practices in human radiation research. The scope of such activities and the difficulty in identifying and retrieving relevant records were initially underestimated, but agency and Advisory Committee staff sought out and documented as many experiments as resources permitted. Two points should be emphasized here. First, the agencies and the Advisory Committee collected and recorded information about every experiment that could be documented. The inclusion of an

experiment should not be taken as an indication that the experiment was ethically improper or likely to have caused harm to those involved.

Second, there was never an expectation that this effort would succeed in assembling a complete list of experiments or that full documentation for any large proportion of those identified could be discovered and retrieved within the time permitted. The Advisory Committee's research interest was focused on understanding the scope of activity (for example, the number and types of subjects typical for experiments of a certain character) and the policy context (for example, institutional procedures for the review of informed consent practices), than on accumulating the details of particular cases. As a result, although the Advisory Committee's log of such experiments is the most comprehensive and detailed assembled to date, the records of particular experiments are incomplete. Many experiments are documented entirely through a publication of results and many others are documented by references to even briefer descriptions of experiments in records reviewed by the Interagency Working Group or ACHRE.

The chief value of the Advisory Committee's experiment record series is in providing identifying information such as location, dates, and researchers' names--a good place to start. The experiment records are indexed by location, financial sponsorship, principal investigator (and his or her home institution), and other key pieces of information that could support extended research. Such information may be used to find additional information either in the ACHRE collection or elsewhere.

Finding Aids

There are two sets of finding aids for the Advisory Committee's records. The first is entitled *Sources and Documentation*, a supplement to this final report. The two-volume supplement features accounts of the agency and ACHRE research processes, descriptions of the record collections assembled by the Advisory Committee and of individual documents identified as significant, a complete bibliography of the published sources used in the Advisory Committee's research, brief descriptions of individual experiments, lists of testifiers and interviewees, indexes, collections of documents, and other research aids.

The second aid is the electronic record upon which much of the supplemental volume is based. Unfortunately, the National Archives is unable to make this information available in its original format, although it will be available there in simplified electronic formats with explanatory documentation. Copies of the original databases, documentation, and operating instructions will be available at the National Security Archive, an independent research institute whose offices are in the Gelman Library at George Washington University.[31] In addition to these facilities, both the National Archives and the National Security Archive provide access to the electronic records contained in the Advisory Committee's original gopher.[32] The gopher materials include electronic copies of the Advisory Committee meeting documents (briefing books, minutes, and transcripts), condensed descriptions of record collections and experiments, and other information.

How to Go From the ACHRE Collection to Agency Records

There are two sources of information that connect records contained in the ACHRE collection with those of the agencies and the National Archives. The first are document identifiers provided by the agencies; the second are transmittal records that identify the origins of the records.

Agency Document Identifiers

Most Department of Energy and a large proportion of Department of Defense documents are marked with unique identifiers that will allow location of those documents in DOE and DOD retrieval systems. Those retrieval systems include provenance information,[33] that is, information that identifies the record's office of origin and other information about its creation and current location.

DOE documents are stamped with a CIC number,[34] a six-digit accession number that uniquely identifies a document or document set (that is, documents described as a group rather than individually) that can be used to retrieve CIC records with their attendant provenance and other information management information. DOE's Internet facility can be used to identify these documents. Information is also available directly from the CIC, which also provides its index on CD-ROM using Folio Views text retrieval software.

Beginning in the fall of 1994, DOD documents supplied to the Advisory Committee were assigned accession numbers by the Radiation Experiments Command Center (RECC). These numbers denote a document's origin and the date it was sent to ACHRE. For example, records bearing numbers beginning "ARM" originated with the U.S. Army. Later in 1994 the RECC began to assign accession numbers retroactively to documents transmitted earlier. These accession numbers are available in the RECC library catalog, which was converted by ACHRE staff and is available among the Advisory Committee's records in both hard copy and electronic formats.[35]

Records of Agency Transmittal

Most records accessioned into the ACHRE collection were transmitted or deposited with documents indicating their origins. For example, materials obtained from the National Archives usually have notations indicating record group, series, and box numbers; agency records have accompanying documents indicating where materials were obtained; and donations from individuals include such information as the address of the donor. This information is collected in a ACHRE Records Management Series, Records Accession and Disposition File. Summaries of this information are included in the electronic records kept in the Document Collection database. Additional information concerning specially requested information is contained in the Agency Data Requests records file, which includes the Agency Data Requests Tracking database.

THE WHITE HOUSE

WASHINGTON

June 28, 1995

MEMORANDUM FOR RECORDS MANAGEMENT

FROM: PHIL CAPLAN

The attached four boxes contain the following:

Box 1: National Service binders and briefing books from the Advisory Committee on Human Radiation Experiments

Box 2: Briefing books from the Advisory Committee on Human Radiation Experiments

Box 3: Briefing books from the Advisory Committee on Human Radiation Experiments

Box 4: Briefing books from the Advisory Committee on Human Radiation Experiments

THE WHITE HOUSE

WASHINGTON

May 26, 1995

Mr. Jim Dean
Director, Committee Management Secretariat
General Services Administration
1730 K Street, N.W., Suite 816
Washington, D.C. 20006

Dear Mr. Dean:

On January 25, 1994, this office delivered to you, for filing with the General Services Administration, a Charter for the Advisory Committee on Human Radiation Experiments, established pursuant to Executive Order 12891 (January 15, 1994).

This is to advise you that, pursuant to paragraph 6 of the Charter and the authority vested in the President by the Constitution and the laws of the United States, the President has extended the Charter's expiration date until October 15, 1995.

Sincerely,

Abner J. Mikva
Counsel to the President

City of Warren Law Department

Atty. Gregory V. Hicks, Law Director

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FAX: (216) 841-2676

April 12, 1995

Phillip Caplan
OEOB Room 160
The White House
Washington, DC 20500

Dear Phil:

It was a pleasure meeting you last Monday. Thank you for taking the time out of your busy day to discuss the possibility of having the Secretary of Labor attend the United Auto Worker's anniversary celebration on August 6, 1995.

I have talked to the Union and they are generating formal invitations. I will send you copies as soon as I have them.

I look forward to talking to you again soon.

Very truly yours,

GREGORY V. HICKS
Law Director

GVH:dpp

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