A Guide to the Archival Collection of

The Robert Cook-Deegan
Human Genome Archive

Set 1

April, 2013
Overview

The Robert Cook-Deegan Human Genome Archive is founded on the bibliography of *The Gene Wars: Science, Politics, and the Human Genome*. The archive encompasses both physical and digital materials related to The Human Genome Project (HGP) and includes correspondence, government reports, background information, and oral histories from prominent participants in the project.

Hosted by the Bioethics Research Library at Georgetown University the archive is comprised of 20.85 linear feet of materials currently and is expected to grow as new materials are processed and added to the collection. Most of the materials comprising the archive were obtained between the years 1986 and 1994. However, several of the documents are dated earlier.

Introduction

This box listing was created in order to assist the Bioethics Research Library in its digitization effort for the archive and is being shared as a resource to our patrons to assist in their use of the collection.

The archive consists of 44 separate archive boxes broken down into three separate sets. Set one is comprised of nine boxes, set two is comprised of seven boxes, and set three is comprised of 28 boxes. Each set corresponds to a distinct addition to the collection in the order in which they were given to the library. No value should be placed on the importance of any given set, or the order the boxes are in, as each was accessed, processed, and kept in the order in which they were received.

Every effort was made to maintain the integrity of the boxes in the order they were processed. Except in cases of damage and materials that were oversized that required special processing the materials have been kept in the exact order that the Bioethics Research Library received them in.

In addition, every effort was made to be faithful to the headings and labeling of the materials in the collection. If a folder, binder, or packet did not have a specific label identifying it generic labels were added to assist in processing. For example, a folder with no identifying label is identified as Folder 1 in the box listing. Any additional unlabeled folders in the same box follow a sequential pattern, i.e. Folder 2, Folder 3, etc. Each individual box holds to this pattern. This means there are multiple folders with the heading of Folder 1. Thus when citing an unlabeled item it is important to use the exact set and box number in order to locate that item. For example, Set 2, Box 6, Folder 2.
Also note that every effort was made to properly title individual items. In many cases, especially with correspondence and memos, there is not a specific title associated with that item. For clarity sakes these items are labeled as being from a specific person or department to another specific person or department. In cases where no title or author was present the first line of the document was used as a title.

Each set has a separate box listing. It is expected that researchers and scholars using the collection will need to search in each set’s listing in order to locate relevant materials. Each set is completely text searchable to aid in this process. It is highly suggested that researcher use the find feature (control + f in most applications) in order to aid in the use of the box listing. Each set’s box listing comprises dozens of pages and in the case of set three the document alone is 157 pages long.

A presence for the archive has been established on the Bioethics Research Library and can be accessed by visiting https://bioethics.georgetown.edu/library-materials/digital-collections/robert-cook-deegan-human-genome-archive/

On this page you will find links to the full version of The Gene Wars, information linking to other websites that are working on preserving the history of the Human Genome Project, and links to digital reproductions of items from the collection created by the Bioethics Research Library.

A permanent link to this series of guides will also be maintained on Digital Georgetown:

Set 1 - http://hdl.handle.net/10822/708922
Set 2 - http://hdl.handle.net/10822/708923
Set 3 - http://hdl.handle.net/10822/708925

Updated April 17, 2014 CNN
Acknowledgements

This guide would not have been possible without the significant assistance of several people.

First and foremost is Laura Ruth Barry whose able support, creativity and tireless efforts in wrangling both the physical collection and the data to create this guide cannot properly be conveyed in words.

Georgetown University students were integral in processing the materials on an item level basis. Jennifer Young, Joseph Wiedemer, Jade Walsh, Rebecca Kruser, Ta-Chueh Melody Hsu, Mary Laura Scalise, Rachel Cox, and John Sperry Nickerson. Without their assistance this project would have been stuck in neutral.

Anita Nolen, former archivist at the Bioethics Research Library, who first received and accessed the materials 20 years ago when they were first donated. She left the collection in such amazing shape that starting the process of digitizing and making the collection available to a larger audience was considerably eased. She also let a young preservationist pick her brain and play in her toy box. It was greatly appreciated.

Mark Hakkarinen who listened, advised, and help push on days when the work seemed overwhelming.

Martina Darragh, Patty Martin, and Roxie France-Nurriden, my “team” (which should really read that I am part of their team), not enough can be said for all the patience, teaching, and support you have offered me. Thank you.

Of course I’d also like to thank Dr. Robert Cook-Deegan who answered innumerable questions, made invaluable suggestions, and showed flexibility (and still does so) in how to approach the project.

Last, but not least, I would like to thank all my former and current colleagues at the Kennedy Institute of Ethics and Bioethics Research Library for creating an atmosphere where knowledge and the preservation and access to that knowledge is always strived for. I am not sure where else in the world where so many different people consistently strive to ensure that knowledge is shared freely and without concern of who benefits most from that information. It is truly inspiring.

Thank you all,

Nat Norton

4/10/2014
The Robert Cook-Deegan Human Genome
Project Archive Set 1

Box Listing
**Folder 1**

- Interview between Tom White and Paul Rainbow. January 23.

**Folder 2**

- Memo from Cook-Deegan to Elk Jordan. April 12, 1990.
  - Letter from Joseph D. McInerney to Cook-Deegan, April 6, 1990
Folder 3

Folder 4

Folder 5
- Invitation to Winding your way through DNA Symposium
- Invitation to Human Gene Mapping & Sequencing Utah Genome Technology Workshop.
Cook-Deegan Box 1/9

Not in Folder (Before Blue Folder)
- Article: Stephen Kreider Yoder. “Japanese Tap Advanced Technology to Accelerate Deciphering of DNA.

Blue Folder
- Left Sleeve: Notes from The Genome Project and the Pharmaceutical Industry.
- Right Sleeve: Notes from The Genome Project and the Pharmaceutical Industry.
Cook-Deegan Box 1/9

Not in Folder (After blue folder)

- Correspondence between Cook-Deegan to Reid Adler. Chapter drafts. September 8, 1992.
- Memo from Cook-Deegan to Mike Knapp. cDNA patenting; Watson under pressure. March 26, 1992.
  - Letter from Jose Angel Sanchez Asiain to Cook-Deegan.
- Report: Christian Burks. The Flow of Nucleotide Sequence Data into Data Banks: Role and Impact of Large-Scale Sequencing Projects.
Cook-Deegan Box 2/9

Folder 1

- Notes taken on a piece of paper.
- Memo from Lisa Raines to Cook-Deegan. IBA
  - Letter from Cook-Deegan to Bernadine Healy. (June 27, 1992). Requesting interview.
  - Letter from Cook-Deegan to Tom Harkin. Requesting interview
  - Letter from Cook-Deegan to William Natcher. Requesting interview
- Subfolder (1.2)
  - Memo from Cook-Deegan to Walter Gilbert. Gilbert chapter draft.
  - Memo from Cook-Deegan to Betty Civardi and Renato Dulbecco. (March 11, 1991). Dulbecco article.

Not in Folder


Folder 2

- Draft for Chapter 2: Mapping our genes
- Memo from Cook-Deegan to Lloyd Smith. Marvelous Machines draft.


Memo from Cook-Deegan to Bruce Alberts. (March 23, 1991). New paragraph in genome book. Sub Folder (2.2)

Sub Folder (2.3)
  ○ Article: “NIH loses bid for patents on bits of human genes.”
  ○ Memo from Chris to Cook-Deegan.
  ○ Invitation from National Center for Human Genome Research. The Human Genome Lecture Series.
  ○ Memo from Cook-Deegan to Lee Hood and Mike Hunkapiller. (July 18, 1991). Section of chapter on DNA sequencing that deals with DNA sequenators.
  ○ Letter from Frederic Burke to Bernardine Healy. (February 25, 1992).
  ○ Letter from Vida Beaven to Cook-Deegan. (October 8, 1992).
Folder 3
- Email from rn@bioapps.ota.gov to Cook-Deegan. Jobs in Santa Fe.
- Memo from Cook-Deegan to Genome mavens. (February 8, 1993). Chronology of the first five years of the genome project.
- Letter from David Challoner to Cook-Deegan. (January 22, 1993).
- Letter and Replies:
  - Letter from David Challoner to Cook-Deegan. (January 26, 1993).
  - Memo from Cook-Deegan to Davis Challoner. (February 7, 1993). Windom’s letters.
- Memo from Cook-Deegan to G.L. Schiebler. Robert Windom’s letters to William Clinton and Donna Shalala.

Not In Folder
- Schedule for Legal and Ethical Issues raised by the Human Genome Project, hosted by The Health Las and Policy Institute of the University of Houston.

Blue Folder
- Memo from Seymour Perry and Susann Wilkinson to members of Planning Committee of Conference on Biotechnology for the Diagnosis of Genetic Disease. Meeting minutes and revised agenda.
- Agenda for Planning Committee for Conference on Biotechnology for the Diagnosis of Genetic Disease.

Folder 4
- Notes from Hilton Head Conference.
- Memo from Susan Wallace to Cook-Deegan. (February 14, 1991). Reimbursement from Hilton Head Conference.
- Memo from Cook-Deegan to Susan Wallace. (February 18, 1991). Receipts for Hilton Head.
Folder 1 (Docs for June Genome Meeting)

- Letters and Reply:
  - From Emauele Mannarino to Alexander M. Capron. (October 20, 1988).
- Guide: Hippocratic Oath for Scientist, Engineers, and Technologist
  - Article: “Scientist Urged to Sign Ethics Oath.”
- Letter from Technion-Israel Institute of Technology to those who the power to influence decision or the right to be consulted about them. The Mount Carmel Declaration on Technology and Moral Responsibility.
- Letters and Reply:
  - From Emauele Mannarino to Alexander M. Capron. (October 20, 1988).
- Memo from Cook-Deegan to Jim Watson, Paul Berg, Kenichi Matsubara and Andrei Mirzabekov. Attached draft statement.
- Memo from Václav Pačes to Cook-Deegan. Statement for the session to creating and sharing information in human genome.
- Letter from J.K.M. Gevers to Daniel Wikler. Provisional comments and tentative recommendation concerning issues of “Multinational corporations: insureds and employees.”
Folder 2 (Financing and Related)

- Memo from Susann Wilkinson to members of the planning committee. Finalization of agenda, funds, promotion.
- Memo from Susann Wilkinson and Seymour Perry to planning committee members
- Report: Policy issues and key questions.
- Memo from Susann Wilkinson and Seymour Perry to planning committee members. September 25, 1990. Next meeting: 10/5/90
- Letter from Susann Willkinson to Cook-Deegan.

Folder 3

- Memo from Jon Beckwith to Cook-Deegan.
- Notes: Possible topics for solicited papers and research proposals on human behavior genetics.
Cook-Deegan Box 3/9

Folder 4 (Hilton Head Meeting)
- Letter from Cook-Deegan to Susan Wallace. Summary of Meetings (DNA Sequencing Conference II & The Human Genome And the Pharmaceutical Industry).
- Memo from Cook-Deegan to J. Craig Venter, Walter Gilbert and Mark Pearson. Hilton Head summaries.
- Letter from J. Craig Venter to Cook-Deegan.
- Report: Agenda for Genome Project and Pharmaceutical industry
- Letter from Jack B. McConnell to Honorable Thad Cochran.
- Letter from Susan Wallace to Cook-Deegan.
- Report: Preliminary agenda for Genome Sequencing Conference II.
- Report: Speaker Abstract for Genome Sequencing Conference II.
- Notes on Genome Sequencing Conference II.
- Notes taken by John Mulligan on Genome Sequencing Conference II.

Folder 5
- Letter from Hessel Bouma to Cook-Deegan.
- Letter from Hessel Bouma III to Cook-Deegan.
  - Attached: Summary Reflection Statement. (June 1, 1992).
- Letter from Hessel Bouma to Cook-Deegan.
- Report (Questions): Religious/ Theological Attitudes Toward Genetic Intervention and Alteration of Life-Form.
- Letter from Elaine Lawson to Frank Seydel.
Cook-Deegan Box 3/9

- Report (Questions): Religious/ Theological Attitudes Toward Genetic Intervention and Alteration of Life-Form.
- Memo from Cook-Deegan to Frank Seydel. Names promised to send [Washington Working Group Committee members].
- Report (Questions): Religious/ Theological Attitudes Toward Genetic Intervention and Alteration of Life-Form.

Blue Folder (Biotechnology and the Diagnosis of Genetic Disease: Forum on the Technical, Regulatory and Societal Issues)

- Left Sleeve
- Right Sleeve
  - Notes from the conference
  - Notes from the conference.
Cook-Deegan Box 3/9

Not in Folder


Folder 6 (McGraw-Hill Yearbook of Science and Technology)

- Memo from Cook-Deegan to Jim Watson and Leslie Fink. Disposition of final manuscript. (August 14, 1990).
- Memo from Cook-Deegan to Elke Jordan, Leslie Fink, Eric Juengst and James Watson. (July 12, 1990).
- Memo from Leslie Fink to Cook-Deegan. Edits in manuscript.
- Memo from Cook-Deegan to Elke Jordan, Leslie Fink, Eric Juengst and James Watson. (July 12, 1990). Status of manuscript.
- Letter from Sybil P. Parker to Cook-Deegan. (August 9, 1990). Reminder of due date for submission of Human Genetics article.
Folder 7 (CIOMS mtg, Tokyo/ Inuyama July 1990).

- Program from XXIV CIOMS Round Table Conference
- Report: Preliminary List of Participants [CIOMS Conference].
- Notes from Conference
  WHO Press, 36.
- Book subscription order form: Summary Volume and Genetic Screening: From Newborn to DNA Typing.
- Report: Robertson Parkman and Donald B. Kohn. “Gene Therapy for Inborn Errors of Metabolism.”
- Notes from Conference
Cook-Deegan Box 4/9

Folder 1 (USSR/ US Bioethics Conference)
- Memo from Cook-Deegan to Dan Wikler, Alex Capron and Eileen Palmer. (June 6, 1991). Attached draft meeting summary.
- Report: Meeting Summary from Human Genome Research in an Interdependent World.
- Memo from Cook-Deegan to Dan Wikler and Eileen Palmer. (May 19, 1991). Attached revised statement for information flow session; other information.
- Red SubFolder 1.1 (Moscow Planning meeting 10/15-10/16/1990)
  - Letter from Kenichi Matsubara to Cook-Deegan.
  - Memo from Cook-Deegan to Dan Wikler. (October 25, 1990). Moscow follow-up.
  - Memo from Cook-Deegan to Dan Wikler and Eileen Palmer. (October 19, 1990). Invitation List.
  - Memo from Cook-Deegan to Dan Wikler and Eileen Palmer. November 6, 1990). Yesterday’s fax
  - Email from Polly Harrison to Boris Yudin.
- Email from Dan Wikler to Cook-Deegan.
- Memo from Cook-Deegan to Asao Fujiyama. (August 30, 1991). Genome centers to visit; international ethics group.
- Fax from Asao Fujiyama to Cook-Deegan.
- Fax from Cook-Deegan to Eileen Palmer and Dan Wikler. Asao Fujiyama’s comments.
- Fax from Cook-Deegan to Chris Joyce. Meeting summary draft.
- Memo from Cook-Deegan to Dan Wikler, Eileen Palmer and Alex Capron. (July 9, 1991). June meeting aftermath.
- Fax from Lev L. Kisselev to Daniel Wikler. (July 24, 1991).
• Memo from Cook-Deegan to Dan Wikler. (July 12, 1991). Wyngaarden correspondence.
• Memo from Cook-Deegan to Luca Cavalli-Sforza. (July 12, 1991). Your fax of earlier this evening.
• Letter from Dan Wikler to Cook-Deegan. (July 15, 1990).
• Letter from Maxine F. Singer to Alexander M. Capron.
• Memo from Cook-Deegan to Daniel Wikler. (July 12, 1991). Wyngaarden correspondence.
• Letter from Daniel Wikler to Cook-Deegan.
• Letter from Jonathan Glover to Cook-Deegan.
• Letter from Dan Wikler to Paul Billings. (June 13, 1991).
  ○ Letter from Paul Billings to Cook-Deegan (June 5, 1991).
• Email from Daniel Wikler to Cook-Deegan.
• Program (Draft as of April 16, 1991) for Human Genome Research in an Interdependent World.
• Email from Michael Yesley to Cook-Deegan.
• Memo from Cook-Deegan to Eileen Palmer and Daniel Wikler. (March 14, 1991). This morning’s messages.
• Fax from Chee Heng Leng to Cook-Deegan. (March 12, 1991).
• Letter from Daniel Wikler to Eris Juengst. (March 5, 1991).
• Fax from Cook-Deegan to Chee Heng Leng.
• Email from Daniel Wikler to Cook-Deegan.
• Email from Daniel Wikler to Cook-Deegan.
• Email from Diane Paul to Cook-Deegan.
• Email from Daniel Wikler to Cook-Deegan.
• Email from Daniel Wikler to Dan.
• Letter from Daniel Wikler to Eric Juengst.
• Memo from Cook-Deegan to Martinus F. Niermeijer. (December 13, 1990). Biological Warfare topic for June meeting.
• Memo from Cook-Deegan to Walter Bodmer and Nancy Wexler. (December 7, 1990). Biological Warfare topic on June conference docket.
• Letter from M.F.Niermeijer to Daniel Wikler. (December 13, 1990). Human Genome Research in an interdependent World conference
• Memo from Cook-Deegan to Daniel Wikler. (December 12, 1990). First session at June meeting.
• Letter from Daniel Wikler to Cook-Deegan. (December 11, 1990).
Memo from Cook-Deegan to Walter Bodmer and Nancy Wexler. (December 7, 1990). Biological warfare topic on June conference docket.


Agenda for Human Genome Research in an Interdependent World: Ethical, Legal and Social Issues.

Invitation Lists


Memo from Valentina Tsitovicj to Cook-Deegan. (October 5, 1990). Moscow Planning meeting.

Letter from Wataru Mori to Cook-Deegan. September 26, 1990.

Memo from Cook-Deegan to Valentina Tsitovish. (October 5, 1990). Moscow Planning meeting.

Letter from Kenichi Matsubara to Cook-Deegan. (October 1, 1990). Moscow program planning meeting.

Fax from Kenichi Matsubara to Cook-Deegan. (October 2, 1990).

Memo from Cook-Deegan to Dan Wikler. (September 27, 1990). Gros address, phone.

Memo from Cook-Deegan to Dan Wikler. (September 26, 1990). Modell data, comments.

Memo from Cook-Deegan to Eileen Palmer. (September 26, 1990). Mori.

Letter from Wataru Mari to Cook-Deegan. (September 26, 1990).

Memo from Cook-Deegan to Kenichi Matsubara. (September 26, 1990). Moscow program planning meeting October 15-17.

Memo from Cook-Deegan to Wataru Mori. (September 19, 1990). Moscow planning meeting, October 15-16 or 16-17.

Memo from Cook-Deegan to Eileen Palmer. (September 24, 1990). Mori invitation followup; speaker list.

Memo from Cook-Deegan to Ken-ichi Matsubara. (September 24, 1990). Mori invitation to international genome meeting.

Memo from Cook-Deegan to Dan Wikler and Eileen Palmer. (September 23, 1990). Moscow trip.

Faxed letter from Daniel Wikler to Cook-Deegan. (September 21, 1990).

Memo from Cook-Deegan to Dan Wikler. (September 21, 1990). Moscow planning meeting.

Report: Summary Statement, investigated by Daniel Wikler.

Memo from Cook-Deegan to Dan Wikler. (September 19, 1990). Today’s news.


Memo from Cook-Deegan to M.F. Niermeijer. (September 19, 1990). Moscow planning meeting, October 15-16 or 16-17.

Memo from Cook-Deegan to Wataru Mori. (September 19, 1990). Moscow planning meeting, October 15-16 or 16-17.

Memo from Cook-Deegan to Victor McKusick. (September 19, 1990). Moscow planning meeting, October 15-16 or 16-17.
Cook-Deegan Box 4/9

- Faxed correspondence
  - From Daniel Wikler to Cook-Deegan. (June 1, 1990).
- Faxed letter from Eileen Palmer to Cook-Deegan. (July 2, 1990).
  - Faxed letter from Dan Wikler to Victor A. McKusick. (July 2, 1990).
- Memo from Cook-Deegan to Dan Wikler. (June 28, 1990). Today’s dollop.
- Memo from Cook-Deegan to Dan Wikler. (June 27, 1990). Today’s news @ 3 p.m.
- Memo from Cook-Deegan to Dan Wikler. (June 26, 1990). Today’s four tasks.
  - Attached: letter from Sheldon Krimsky to David Wikler.
- Faxed letter from Eric Juengst to Cook-Deegan.
- Memo from Cook-Deegan to Dan Wikler. (June 6, 1990). USSR bioethics conference.
- Faxed letter from Daniel Wikler to Andrei Mirabekov. (June 18, 1990).
- Faxed letter from Daniel Wikler to Cook-Deegan. (June 18, 1990).
- Faxed letter from Daniel Wikler to Boris Yudin. (June 18, 1990).
- Memo from Cook-Deegan to Dan Wikler. (June 19, 1990).
- Faxed letter from Daniel Wikler to Cook-Deegan. (June 1, 1990).
- Memo from Cook-Deegan to Dan Wikler. (June 21, 1990). Your fax of a few years ago.
- Letter from Walter Bodmer to Daniel Wikler. (November 1, 1990).
- Email from Dan Wikler to Cook-Deegan. (February 17, 1991). Draft of schedule for the conference.
- Report: Invitation list for Conference
- Email from Cook-Deegan to Kenichi Matsubara. (February 6, 1991).
Cook-Deegan Box 4/9

- Email from Dan Wikler to Cook-Deegan. (January 28, 1991). Invitation list
- Faxed letter from Dan Wikler to Cook-Deegan. (February 3, 1991).
- Memo from Cook-Deegan to Dan Wikler and Eileen Palmer. (April 6, 1991).
  June conference news.
- Email from Dan Wikler to Cook-Deegan. (May 28, 1991). Leslie Robert will cover conference.
- Email from Dan Wikler to Cook-Deegan. (May 29, 1991). Saturday night, Wednesday evening.
- Report: Jonathan Glover. “Political uses of genetics.”

FedEx Envelope

- Notes and Participant Index cards
- Letter from Cook-Deegan to table speakers. (February 5, 1991).
- Memo from Cook-Deegan to Dotty Smith, AAAS. (September 27, 1990).
  Abstract for Wikler Session, 19 Feb 91.
- Letter from Dan Wikler to Cook-Deegan.
- Fax from Frantisek Kalousek to Cook-Deegan. (September 12, 1990).
- Memo from Cook-Deegan to Eileen Palmer. (July 17). AAAS connection.
- Memo from Cook-Deegan to Dotty Smith, AAAS meetings office. (October 7, 1990). Final program MS, symposium on “International Aspects of Ethical and Social Issues in Human Genome Research.”
- Memo from Michelle D. Games to Program Organizers. (October 1, 1990). Edited Final program manuscripts.
- Memo from Cook-Deegan to Dan Wikler. (September 17, 1990). Session on international aspects of social and ethical issues related to genome research.
- Letter from Elizabeth Zeutschel to Daniel Wikler. (July 1990).
- Schedule for AAAS Annual Meeting.
- Preliminary program for AAAS 91 Annual Meeting.
- Fax from Vaciav Paces to Cook-Deegan. (November 19, 1990).
- Information for session presiders pamphlet.
Cook-Deegan Box 4/9

- Letter from Elisabeth Zeutschel and Rosita Johnson to Cook-Deegan. (November 1, 1990).
- Preliminary program for AAAS 91 Annual Meeting.
- Instructions and Samples for preparation of symposium manuscript. AAAS.

Folder 2 (Pink folder labeled Invitations to June meeting)
- Fax from Dan Wikler to Cook-Deegan.
  - Program for Conference.
  - Agenda for Conference.
  - Invitation list
- Fax from Cook-Deegan to Dan Wikler. Niermeijer’s comment.
  - Fax from M.F. Niermeijer to Cook-Deegan.
- Letter from Peter Herby to Cook-Deegan. (March 20, 1991).
- Email from Cook-Deegan to Dan Wikler and Eileen Palmer. (March 15, 1991).
  Last of invitation inserts.
- Memo from Cook-Deegan to Dan Wikler and Eileen Palmer. (March 13, 1991).
  Today’s messages.
- Email from Dan Wikler to Cook-Deegan. (March 11, 1991). Invites
- Email from Dan Wikler to Cook-Deegan. (February 22, 1991). Mis-addressed revised agenda; wade through the opening nonsense.
- Email from Dan Wikler to Cook-Deegan. (March 2, 1991). Here is a model invitation, with text on the subject of the talk.
- Fax from François Gros to Cook-Deegan. (February 15, 1991).
- Letter from Cook-Deegan to Federico Mayor. (February 11, 1991).
- Memo from Cook-Deegan to Daniel Wikler. (January 22, 1991). Update
- Letter from Dorothy Nelkins to Dan Wikler. (December 6, 1990).
Memo from Cook-Deegan to Dan Wikler. (December 21, 1990). Recent
development.
Letter from James D. Watson to Cook-Deegan. (December 12, 1990).
Memo from Cook-Deegan to Eileen Palmer and Dan Wikler. (December 1, 1990).
June meeting status.
Memo from Cook-Deegan to Erhard Geissler. (December 1, 1990). Washington,
Letter from Cook-Deegan to Walter F. Bodmer. (December 1, 1990).
Letter from Cook-Deegan to James D. Watson. (December 1, 1990).
Letter from Cook-Deegan to C. Thomas Caskey. (December 1, 1990).
Letter from Cook-Deegan to Phillip Reilly. (December 1, 1990).
Memo from Cook-Deegan to Dan Wikler. (December 13, 1990). Capron
discussion; Geissler accepts; Faxed Bodmer memo to Niewmeijer.
Faxed letter from Dan Wikler to Asao Fujiyama.
Letter from Alberto Piazza to Dan Wikler. (February 20, 1991).
Letter from F. Gray Handley to Cook-Mulligan.

SubFolder 3 (Blue Folder labeled ELSI working group mtg 2/6-2/7/95
Document: Senate- Mitchell Bill.
Memo from Nancy S. Wexler to Cook-Deegan. (January 3, 1995). Nominating
Committee.
Document: Draft meeting [meeting of the NIH-DOES joining working group on
ethical, legal, and social implications of Human Genome Research] agenda
Senate Committee lists.
Document: Informed consent for genetic research on stored tissue samples.
(Draft: December 13, 1994).
Memo from Anne E. Rufo to NIH-DOE ELSI Working group members and
liaisons. (January 19, 1995). Materials for the ELSI working group meeting-
February 6-7, 1995.
Document: NIH-DOE ELSI working group roster
Article: (December 13, 1994). “Mainstream Science on Intelligence.” The Wall
Street Journal.
York Times.
Article: (Nov 13, 1994). “New Laws to ban sex tests on foetuses.”
Document: Final Meeting Agenda.
Document: NIH-DOE ELSI working group roster
Report: Summary of Meeting [Eighteenth meeting of the NIH-DOE Joint
Working Group on Ethical, Legal, and Social implications of Human Genome
Research]
Document: New Statement 12-17-94 (Herrnstein’s and Murray’s The Bell Curve).
Memo from Teresa Doksum to ELSI Working Group members. (February 7,
Cook-Deegan Box 4/9

- Document: ELSI Products by Grant. (Draft: August 12, 1994).
- Report (Graphs): Number of Applications [ELSI Applications through out fiscal years 90-94).
- Document: Citations by authors.
- Memo from Teresa Doksum to ELSI working group member. (February 2, 1995). Annotated Bibliography of Behavioral Genetics.

Blue folder
- Left side
  - Letter from M.F. Niermeijer to Cook-Deegan. (May 1, 1991).
    - Article: Mark Frankel. A Draft Resolution on the Responsibilities of Scientists in the Global HGR Community.
  - Report: Declaration on the Rights of Individuals in Insurance and Employment.
  - 4 pages of notes (can’t really read handwriting).
  - Article: Cook-Deegan. Integrating Social Analysis with Science.
  - 2 pages of notes
- Right Side
  - Memo from Kathleen Stratton to Cook-Deegan.
  - Article: Cook-Deegan. Integrating Social Analysis with Science.
Folder 4 (Labeled Montreal 10/16-18/94)

- Letter from Cook-Deegan to Beth A. Fine. (November 4, 1994).
- Report: Montreal NGSC trip expenses.
- Letter from Beth A. Fine, Virginia Corson, and Audrey Heimler to Cook-Deegan. (October 24, 1994).
- Memo from Ginny Corson to Cook-Deegan. (September 21, 1994). Montreal meeting.
- Fax from Cook-Deegan to Ginny Corson. (September 12, 1994). Biographical sketch.
- Letter from Joy Kahn to Cook-Deegan. Statistics from ETHX.
- Memo from Cook-Deegan to Bea Leopold. (August 1, 1994). Abstract for October 18 talk; background readings.
- Memo from Ginny Corson to Cook-Deegan. (July 1, 1994).
Cook-Deegan Box 5/9

- Fax from Anne Rufo and Elizabeth Thomson to NIH-DOE ELSI working group members. (September 13, 1994). Draft: NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research.
- Fax from Nancy S. Wexler to Francis Collins. (September 11, 1994). ELSI Mission Statement.
- Fax from Francis S. Collins to Cook-Deegan. (August 29, 1994). Letter from Maimon M. Cohen to Francis S. Collins.
- Email from Michael Yesley to Cook-Deegan and Anne Rufo. (August 24, 1994). Genetics provisions in the House report.
- News: Database available on current research involving human subjects. (April 4, 1994).

Folder 2

- Memo from Anne Rufo to NIH-DOE ELSI Working group members. (October 19, 1994). Follow-up materials from the ELSI working group meetings.
  - Minutes and action items from the October 3 Working group meeting
  - NCHGR Press Release on the grants awarded on genetic testing for cancer risks and the one-page abstract of each grant.
  - Book reviews from the New York Times on behavioral genetics.
  - Recent articles on the ELSI program published October 3 in The Scientist
    - Franklin Hoke. (October 3, 1994). Genome project ethics office is achieving new prominence in national policy debate. The Scientist.
  - Several articles of interest from the October 7 issue of Science Magazine.
**Cook-Deegan Box 5/9**

- Yoshi Miki, Jeff Swensen, Donna Shattuck-Eidens, P. Andrew Futreal, Keith Harshman, Sean Tavtigian, Qingyun Liu, Charles Cochran, L. Michelle Bennett, Wei Ding, Russell Bell, Judith Rosenthal, Charles Hussey, Tranh Tran, Melody McClure, Cheryl Frye, Tom Hattier, Robert Phelps, Astrid Haugen-Strano, etc. (October 7, 1994). A Strong candidate for the breast and ovarian cancer susceptibility gene BRCA 1. *Science* 266.
- P. Andrew Futreal, Qingyun Liu, Donna Sttuck-Eidens, Charles Cochran, Keith Harshman, Sean Tavtigian, L. Michelle Bennett, etc. (October 7, 1994). BRCA1 mutations in primary breast and ovarian carcinomas. *Science* 266.

- Fax from Ellen Robinson to Cook-Deegan.
  - Letter from Nancy Wexler to ELSI Working group member. (October 11, 1994).
  - Document: Mission Statement (Draft: September 27, 1994).
  - Letter from Nancy Wexler to Maimon M. Cohen.
- Letter from Nancy Wexler to Cook-Deegan. (August 12, 1994).
- Fax from Robyn Y. Nishimi to Cook-Deegan.
  - (April 27m 1994). *The Blue Sheet*.

**Folder 3**

- Article: Stealing God’s Stuff. *Christianity Today*.
- Document: Meeting [18th meeting of the NIH-DOE joint working group on ethical, legal, and social implications of human genome research] Agenda.
- Letter from Hans S. Goerl to the editors of *The Chronicles of Philanthropy*.
- Article: Barbara Reynolds. (October 21, 1994). Low-IQ hype calls for new IQ-I quit-movement. *USA TODAY*.
Cook-Deegan Box 5/9

- Letter from Jonathan Beckwith to Ann Rufo. (November 12, 1994).
  - Draft proposal for a statement to be issued by ELSI working group on Herrnstein-Murray Book.
- Article: (October 20, 1994). What if intelligence is inheritable? Nature.
- Email from Ellen Robinson to Cook-Deegan. (November 7, 1994). Mission Statement.
- Document: Mission Statement (Draft: September, 1994) and ELSI agenda.
- Fax from Anne Rufo to ELSI working group executive committee. (October 25, 1994). OTA Testimony before the Subcommittee on Energy Committee on Science, Space and Technology.
- Email from Ami Jaeger to Cook-Deegan. Genetic Privacy Act.
- Document: Meeting Agenda [18th mtg of the NIH-DOE Joint Working Group on Ethical, Legal, and Social implications of human genome research]. (Draft).
- Memo from Anne Rufo to NIH-DOE ELSI working group. (November 7, 1994). Materials for the ELSI working group meeting December 5-6, 1994).
- Letter from Ellen Wright Clayton to ELSI working group. (November 3, 1994).
- Report: (Draft: August 30, 1994).Informed consent for genetic research on stored tissue samples.
- Document: Meeting Agenda [18th mtg of the NIH-DOE Joint Working Group on Ethical, Legal, and Social implications of human genome research]. (Draft).
Cook-Deegan Box 5/9

- Email from Cook-Deegan to Ami Jaeger and Anne Rufo. (November 22, 1994). Comments on McEwen/Reilly paper.
- Memo from Cook-Deegan to Anne Rufo and Ami Jaeger. (November 28, 1994). Questions for discussion of privacy.
- Memo from Anne Rufo to NIH-DOE ELSI working group member. (November 29, 1994). Additional materials for the ELSI working group mtg December 5-6, 1994.
- Memo from Ellen Wright Clayton to ELSI Working group. (November 28, 1994). Comparison of the CDC and my drafts.
- Document: List of Participants [NIH-DOE ELSI working group mtg]
- Report: (Draft: August 30, 1994).Informed consent for genetic research on stored tissue samples.

Folder 4

- Agenda [NIH/DOE Working group on ethical, legal, and social implications of human genome research].
- Roster. [NIH/DOE Working group on ethical, legal, and social implications of human genome research].
- Participant List. [NIH/DOE Working group on ethical, legal, and social implications of human genome research].
- Request for application: studies of genetic testing and counseling for heritable breast, ovarian and colon cancer risks.
- Memo from Chief of ELSI Branch to NIH-DOE ELSI working group members. (February 18, 1994). Workshop follow-up action items.
- Agenda for The Ethical Implications of the New Genetics.
- Letter from David Rimoin to Francis Collins. (February 4, 1994).
- Letter from Robert M. Greenstein to Francis Collins.
Memo from Henry T. Lynch to Eric Jungst and Elizabeth Thomson. Statement on use of DNA testing for pre-symptomatic identification of cancer risk.


Letter from Abbey S. Meyers to Nancy Wexler. (February 14, 1994).


Guidelines: ELSI recommendations.


Letter from Alliance to Tom Harkin. (December 16, 1993).


Article: Elyse Tanouye. Gene testing for cancer to be widely available, raising thorny questions.


Document: ELSI insurance task force recommendations vs. the major health reform plans.

Folder 5
● Summary: facilitated by Barry Anderson & Gregory Fowler. (April 18. 1994). Genome pilot focus group.
● Document: National Center for Human Genome Research. Program announcement: Individuals postdoctoral and senior fellowships in genomic analysis and technology and the ethical, legal, and social implications of Human Genome Research.
Folder 1


Folder 2

- Memo from Chief of ELSI Branch to NIH-DOE working group. (April 13, 1994). Activities Update (reports and summaries from the 14 ELSI working group mtgs).
  - Tab II: Agenda Development Workshop. (February 5-6, 1990).
  - Tab VI: Summary of privacy protections for genetic information mtg (September 11-12, 1991).
  - Tab VII: Summary of February 10, 1992 mtg
  - Tab XII: summary from mtg of cystic fibrosis studies consortium and NIH/DOE joint working group on ELSI.
  - Tab XIII: December 14-15 mtg report
  - Tab XIV: February 15 mtg report
Folder 3

- Invoice for order of Genetic Discrimination and the Americans with Disabilities Act by Susan Malamate Vazakas.
- Email from Cook-Deegan to Lauren McCain. (April 28, 1994). Thought maybe you’d like to respond.
- Letter from Robert J. Pokorski to Cook-Deegan.
- Email from Robyn Nishimi to Cook-Deegan. (May 12, 1994). Failed Mail.
- Email from Eric Juengst to Cook-Deegan. (May 12, 1994). 4/20-21 ELSI working group meeting.
- Faxed memo from Tracey Wright to Cook-Deegan. (May 12, 1994). Interview questions.
- Fax from Pilar Ossorio to Cook-Deegan. (May 11, 1994). Proposal for the October mtg [Bridging the Gap].
- Itinerary for Cook-Deegan.
- Email from Francis Collins to Cook-Deegan. (May 4, 1994). Postvisit rumbles.
- Fax from Mark A. Rothstein to Francis Collins. (April 26, 1994).
- Fax from Cook-Deegan to Nancy Wexler. (March 1, 1994). ELSI and you.
- Email from Cook-Deegan to Mary-Claire King. (March 3, 1994). Slides of human rights/genetics work?
- Email from Cook-Deegan to Francis Collins and Nancy Wexler. (February 18, 1994). NCHGR ELSI policy studies.
- Email from Cook-Deegan to Francis Collins. (February 28, 1994). 2/18 message received?
- Correspondence between Lori Andrews to Cook-Deegan. (February 18, 1994). NCHGR ELSI policy studies.
- Correspondence between Francis Collins to Cook-Deegan. (March 1, 1994). ELSI and you.

Folder 4

- Email from Lori Andrews to Michale Yeasley. IOM committee recommendations about privacy.
- Letter from Mark A. Rothstein to Eric Juengst. (March 24, 1994).
- Memo from Executive committee to ELSI working group. Summary of executive committee conference calls.
- Survey of members of genetic support groups. GU Child Development Center and The Alliance of Genetic Support Groups.
Folder 5

- Correspondence between Cook-Deegan to Francis Collins. (April 14, 1994).
- BCD/Sykes aftermath.
- Email from Cook-Deegan to Francis Collins. (April 13, 1994). Revised response strategy.
- Email from Cook-Deegan to Francis Collins. (April 9, 1994). More on Kathy Sykes.
- Email from Cook-Deegan to Lori Andrews. (April 6, 1994). Congrats.
- Email from Cook-Deegan to Eric Juengst. (April 4, 1994). Extended ELSI staff meeting. April 20.
- Email from Cook-Deegan to Eric Juengst. (April 4, 1994). ELSI intramural program.
- Correspondence between Francis Collins to Cook-Deegan. (April 1, 1994). Jobstuff
- Email from Cook-Deegan to Francis Collins. (April 1, 1994). Next steps.
- Email from Francis Collins to Cook-Deegan. (March 31, 1994). Job Particulars.
- Correspondence between Cook-Deegan to Eric Juengst. (March 30, 1994). ELSI intramural program.
- Email from Cook-Deegan to Francis Collins. (March 29, 1994). Job particulars.
- Email from Cook-Deegan to Francis Collins. (March 22, 1994). Michael Yesley. Tomorrow night’s mtg still on?
- Email from Cook-Deegan to Francis Collins. (March 3, 1994). Wed @ 4:30 fine

National Center for Human Genome Research Folder

- Task Force on Genetic Testing: Background and Purpose. (May 19, 1994 draft).
- Mission Statement (Sept. 27, 1994).
- Memo from Nancy Wexler to Cook-Deegan. (sept. 30, 1994). Dinner on Sunday, oct 2.
- Meeting agenda. 17th mtg of the NIH-DOE joint working group on ELSI.
- Summary of remarks: discussion on the ELSI working group mission statement national advisory council for human genome research. (sept. 22, 1994).
- Roster: NIH-DOE joint working group on ELSI of human genome research.
Memo from ELSI branch chief to NIH-DOE working group members. (July 6, 1993).
- Concept paper for ELSI’s initiative on the implications of non-medical genetic information. D. Nelkin.

Email from Lori Andrews to Jean McEwen and Philip Reilly. (July 18, 1994).
- Report: Jean McEwen and Philip Reilly. Regulating DNA banks and DNA databases: Recommendations for a model code of conduct.
- Registration form and tentative agenda for Informed Consent for Genetic Studies on Stored Tissue Samples.
- Informed consent for genetic studies on stored tissue samples. (June 28, 1994).

Memo from Kay Johnson to Genetics and Health Care Reform Group. Next Steps.
- HCR target list.
- Senate Labor and Human Resources Committee, Amendments to Health Security Act.
- The White House Health Care Delivery Room. (July 20, 1994).
- Report: March of Dimes FY 95 Federal Funding Priorities.

ELSI portfolio review and database mockups. (June 29, 1994).
- The NIH policy promise: Can ELSI deliver?
- Memo from Cook-Deegan to Francis Collins. (April 23, 1994). Proposed next steps to establish NIH-ELSI intramural program.
- Memo from Cook-Deegan to Francis Collins. (April 25, 1994). Details about establishing an NIH intramural ELSI program.

Conference Description (July 1994 draft #6).
- Conference Proposal (draft # 5 June 16, 1994).
- Potential participants for the Oct meeting.
- Conference proposal (draft #3 May 31, 1994).

Draft comment on H.R. 4077.
- Philip Reilly’s recommendations regarding privacy policies.
- Draft set of guidelines on research use of stored human tissue.
- Language on Kennedy health reform bill.
- Outline for and an example of the “portfolio review”
- DEO Staff proposal for the Oct ELSI mtg.
- Leslie Robert’s report on our health reform workshop.
- Pilar Ossorio’s report on ELSI’s genetic privacy workshop.
- Status report on University of Maryland conference planning.
Folder 8 (ELSI mtg 12/93 and follow-up on mission)

- NIH-DOE ELSI working group December 14-15 meeting report. (draft Jan 21, 1994).

National Center for Human Genome Research (Left Sleeve)

- Participants of NIH-DEO joint working group on ELSI. (December 14-15, 1993).
- Memo from ELSI branch chief to NIH-DOE ELSI working group. (December 10, 1993). Another view of the ELSI program.
- Memo from Genetics services research coordinator to interested individuals in attending NIH/DOE joing working group on ELSI. (December 1, 1993). Upcoming meeting December 14-15, 1993.
- Memo from ELSI branch chief to participants. (December 1, 1993). Meeting plans.

National Center for Human Genome Research (Left Sleeve)


- Article: (Nov. 6, 1993). Genetic testing: Committee raise the right questions. The Dallas Morning News.
- Article: Research and policy agenda for the future.
National Center for Human Genome Research Folder (left sleeve)

- ELSI: First five year goals of completion plan (and second five year goals initiation plan. (Draft April 18, 1993).
- Report: Task force on genetic information and insurance delivers reports to ELSI working group. (May 10, 1993).
- Fax from Eric Juengst to Cook-Deegan. (May 6, 1993). Finalized agenda and corrected page to substitute in the insurance task force report.
- Memo from ELSI branch acting chief to ELSI working group members. (May 4, 1993). Candidates for ELSI working group.

National Center for Human Genome Research Folder (right sleeve)

- NIH/DOE working group on ELSI of human genome research. May 10-11 meeting agenda
- NIH/DOE working group on ELSI of human genome research roster
- Memo from ELSI branch acting chief to NIH/DOE working group members. (May 3, 1993). May 10-11 meeting.
- Email from Michael Yesley to Eric Juengst.
- Report: NIH/DOE working group on ELSI of human genome research. (pre-publication copy may 10, 1993). Genetic information and health insurance.
Folder 2 (ELSI mtg 1/93 through 5/93)

- Letter from Sue Levi-Pearl to Abbey Meyers. (May 19, 1993).
- Memo from ELSI Program analyst to all interested parties. (Jan 28, 1993). February meeting.
- Roster of Insurance task force members.
- Roster of participants
  - Books and articles supported by the NIH/DOE working group on ELSI of human genome research
  - NIH/DOE working group on ELSI of human genome research roster
  - NIH/DOE working group on ELSI Strategic planning workshop Jan 28-29, 1992.
  - Memo from Eric Juengst to ELSI strategic planning workshop participants. (Jan. 25, 1993). Mailing confirmation and additional information item.
  - NIH/DOE working group on ELSI of human genome research Strategic planning workshop agenda.
  - Memo from ELSI branch acting chief to NIH/DOE working group on ELSI of human genome research. (January 19, 1993). January 28-29 meeting.
  - NIH/DOE working group on ELSI of human genome research roster
  - Memo from ELSI program analyst to ELSI working group. (Jan 19, 1993). January 28-29, 1993 meeting.
  - Memo from ELSI branch acting chief to January 28-29 ELSI planning workshop participants. (Jan. 19). New Horizons for the ELSI programs.
Folder 3 (pedigree research OPRR/NCHGR conference, NIH 5-6 Oct 1992).

- Left sleeve
  - Agenda for Human Subjects in Genetic Research involving families: points to consider
  - Report: Nancy E. Kass. Participation in pedigree studies and the risk of impeded access to health insurance.
  - Memo from ELSI program analyst to Genetic family studies workshop participants. (Sept. 25, 1992). Background information paper.

- Right Sleeve
  - Participant Roster: human subjects in genetic research involving families: points to consider.

Folder 4 (ELSI mtg 9/93)

- Memo from ELSI branch acting chief to ELSI working group members. (Sept. 7, 1993). Revised agenda for Friday.
- NIH/DOE working group on ELSI of human genome research planning summary
- Meeting agenda for 3rd mtg of the cystic fibrosis studies consortium and joint meeting with NIH-DOE ELSI working group meeting
- Roster: policy consultant for 3rd mtg of the cystic fibrosis studies consortium meeting with the joint NIH-DOE ELSI working group meeting
- Reference list
- Principal investigators for cystic fibrosis studies consortium
- Roster for NIH-DOE joint ELSI working group
- List of organizations sending representatives to meeting of CFSC and NIH-DOE joint ELSI working group
- Memo from genetics service research coordinator and ELSI branch acting chief to members of the NIH-DOE joint ELSI working group. (Aug. 3, 1993). Background materials for the upcoming meeting of the NIH CFSC and the ELSI working group.
- Memo from ELSI branch acting chief to NIH-DOE ELSI working group members. (July 12, 1993). September meeting and attached materials.
- Memo from Genetics services research to participants on upcoming meeting of CFSC and ELSI. (Sept 1, 1993). Final mailing for Sept. 8-10, 1993 meeting.

- Attendees List (10th Judicial conference)
- 3 Programs for 10th circuit judicial conference.
Folder 6 (ELSI working grp 5/92-9/92)

- NIH and DOE programs on ELSI workshop folder
  - Working group roster
  - Staff roster
  - Roster of participants
  - Pacific Center for Health Policy and Ethics and UniHealth America Foundation of UniHealth. Invitation to Charting the Genome: Implications of genetic technology for healthcare practitioners in the 1990’s.

- Binder clip 1
  - Letter from Daniel Drell and Eric Juengst to ELSI working group. (Nov. 20, 1992).
  - Draft letter to grantee workshop participants from Eric Juengst. NIH-DOE grantee workshop roster of participants.
  - Draft new member solicitation letter from Eric Juengst.
  - Agenda for Human subjects in genetic research involving families: points to consider.
  - Participant roster for Human subjects in genetic research involving families: points to consider.
  - Names and addresses of the members of working group for ELSI for the human genome analysis programme.


- Revised Agenda for ELSI of Human Genome Research.

- Memo from ELSI branch acting chief to NIH/DOE Grantees. September 14-16 Grantee Workshop Background Materials II.


- Binder Clip 2
  - Memo from ELSI branch acting chief to ELSI working group members. (July 24, 1992). September meeting.
Cook-Deegan Box 7/9

- Memo from NCHGR acting director to NCHGR staff. (June 19, 1992). Establishment of the ELSI branch within the NCHGR
- Dept of Health and Human Service. Statement of organizations, functions and delegations of Authority.
- 2 pages of notes.
- Report: NIH. Report on Social, Legal, and Ethical Issues in biomedical and behavioral research.
- Memo from ELSI director to ELSI working group members. (April 9, 1992).
  - Preliminary agenda for meeting
  - Memo from ELSI program director to ELSI working group members. (April 15, 1992).
  - HR 685.
- Memo from ELSI program analyst to all interested parties. (May 14, 1992). ELSI insurance task force meeting NIH cystic fibrosis consortium meeting. Agenda and tentative agenda.
- Memo from ELSI program director to ELSI working group. (April 3, 1992). ELSI update.
- Memo from ELSI program director to ELSI working group members. (April 15, 1992).
Folder 1 (AAAS genetic testing mtg Los Alamos 6/92).

- Tourette Syndrome Envelope
  - Letter from Sue Levi-Pearl to Cook-Deegan. (June 23, 1992).

- Letter from Gilbert S. Omenn to Alta Charo. (June 30, 1992).

- Letter from Michael S. Yesley to Cook-Deegan. (June 22, 1992).


- Agenda for AAAS/ABA Conference on Frontier Issues in Ethics, Law, and Genetic Testing.

- Preliminary agenda for AAAS/ABA Conference on Frontier Issues in Ethics, Law, and Genetic Testing.

- Invitations sent 4/7/92 for AAAS/ABA Conference on Frontier Issues in Ethics, Law, and Genetic Testing.

- List of participants as of 4/7/92 for AAAS/ABA Conference on Frontier Issues in Ethics, Law, and Genetic Testing.


Folder 2 (ELSI mtg, 2/92)
- Agenda for 2nd workshop on pre-symptomatic testing for germ line p53 mutations in cancer families.
- Memo from ELSI program analyst to all interested parties. (March 11, 1992). Insurance task force meeting.
- Mtg of the NIH-DOE working group folder
  - Agenda (Draft) for conference on legal and ethical aspects of large pedigree research.
Cook-Deegan Box 8/9

- Memo from ELSI Director to ELSI working group members. (Dec. 11, 1991). Next meeting postponed.
- Memo from Michael Yesley to Eric Juengst. Genetic Privacy collaboration.
- Agenda for NIH-DOE ELSI working group meeting Feb. 10, 1992.
- Agenda for NIH-DOE ELSI working group meeting Feb. 10, 1992.
- Possible ELSI working group schedule for remainder of phase I.
- ELSI’s genome. (diagram)
- Possible ELSI working group schedule for remainder of phase I.
- Agenda for NIH-DOE ELSI working group meeting Feb. 10, 1992.
- Proposed topics for “core concepts” papers.
- Attendance list for conference on the Ethical and Legal Implications of large pedigree research. (as of Feb. 3, 1992).
- Article: DOE Competition for awards on ethical, legal, and social issues studies concerning the human genome program.
- Memo from ELSI director to NIH-DOE ELSI working group. (Jan. 29, 1992). February 10 meeting.
Cook-Deegan Box 8/9

- Memo from ELSI director to ELSI working group members and guest. (Feb. 4, 1992). February 10 workshop materials.
- Memo from ELSI program analyst to ELSI working group meeting attendees. (Feb. 4, 1991). Logistics for Feb 10 meeting.
- Agenda for reproductive genetic testing: Impact on women.
- Report: NIH. Summary from the planning meeting of the cystic fibrosis studies consortium.

Unfiled
- Memo from Al Teich [and] Mark Frankel to advisory committee members. (Sept. 17, 1991). Results of September 7 advisory committee meeting.
Folder 3

- Memo from Al Teich [and] Mark Frankel to conference on ethical and legal aspects of large pedigree genetic research participants. (Feb. 28, 1992). Conference Arrangements.
- Memo from Cook-Deegan to Al Teich, Mark Frankel, Deborah Runkel, [and] Elizabeth Broughman. (March 9, 1992). Questions for this weekend’s discussion.

Folder 4 (AAAS Sci/ Law Genetic testing project)

- Memo from Albert Teich [and] Mark Frankel to AAAS/ABA conference on Frontier issues in Ethics, law and genetic testing. (June 10, 1993). Review of Conference Publication; Timely Response Requested.
- Memo from Cook-Deegan to Mark Frankel, Al Teich [and] Alta Charo. (March 8, 1993). Draft commentary on Shinn and Charo articles.
- Letter from Kate H. Murashige to Cook-Deegan. (March 17, 1993).
- Notes
- Memo from Cook-Deegan to Al Teich, Mark Frankel, and other AAAD Staff. (Oct. 7, 1991). Addendum to memo of last week.
- Agenda for AAAS Conference
- Letter from John A. Robertson to Mark Frankel. Outline for the paper on legal issues in genetic testing.
- Memo from Deborah Runkle to Genetic testing project advisory committee. (Feb. 20, 1991). Review of Murray’s Draft Outline.
Memo from Albert Teich [and] Mark Frankel to Genetic testing project advisory committee. (April 22, 1991).

Roster for AAAS conference

Agenda for conference on Ethical and Legal Implications of Genetic Testing

Memo from Deborah Runkle to Genetic testing project advisory committee. (April 8, 1991). Review of Billing’s Draft Outline.


Memo from Cook-Deegan to Elizabeth Broughman. (June 17, 1991). Expenses for Coolfront meeting.

Memo from Cook-Deegan to Audrey Chapman. (June 17, 1991). Much traveled memo to AIUSA board.

Memo from Al Teich and Mark Frankel to Genetic testing project advisory committee. (July 17, 1991). Project Update and Advisory committee meeting.


American Association for the Advancement of Science Conference (June 14-16 1991)

List of observers

Speaker biography (Michael Wright)

Speaker biography (LeRoy Walters)

Speaker biographies ( Margaret Anderson, Bob Bier, Audrey Chapman, Deborah Chollet, Robert Cook-Deegan, Lorraine Flaherty, Ellen Flannery, Mark Frankel, Jane Fullarton, Ruth Greenstein, Mark Hall, John Hicks, Neil Holtzman, Arthur Horwich, Eric Juengst, Phyllis L. Kahn, Lee Loevinger, Mary Mahowald, Richard Meserve, Thomas Murray, James Nash, Gilbert Omenn, Kimberly Quaid, Deborah Runkle, Paul Silverman, Irene Stith-Coleman, Laurence Tancredi, Albert Teich, Martha Volner, Victor Weedn, Bruce Wilder, Steven Zimmerman)

Memo from Cook-Deegan to Al Teich [and] Mark Frankel. (August 1, 1991). Legal and ethical implications of genetic testing (marked copy of Tammy’s draft meeting report)

Agenda for the conference

List of participants
American Association for the Advancement of Science Conference (March 13-15, 1992)

- Left Sleeve
  - Description of Depressive and Maniac-Depressive Disorders. National Depressive and Maniac-Depressive Association.
  - Guide: Conference on Ethical and Legal Aspects of Large Pedigree Genetic Research: Discussion Group Questions.
  - Attendance List
  - Agenda
  - Discussion Groups.
  - Letter from Dorene Markel to Cook-Deegan. (February 17, 1992).

- Right Sleeve
  - Notes from the meeting
  - Consent forms
  - Guide: Johns Hopkins Genetic Linkage Study of Bipolar I Affective Disorder
  - Biographies
Folder 7

- NIH-DOE ELSI working group folder
  - Left Sleeve
    - Memo from Eric Juengst to ELSI working group members. (Aug 28, 1991). Long Range Scheduling for the ELSI working group
    - Memo from ELSI program analyst to ELSI working group members. (Sept. 5, 1991). Reading material for upcoming workshop.
    - Memo from ELSI program director to ELSI working group member. (Aug. 29, 1991). Sept. 11-12 meeting and workshop
    - Notes
    - Agenda
    - Letter from Michael Yesley to Cook-Deegan.
  - Right Sleeve
    - Participant list
    - Agenda
- Letter from Nancy Wexler to ELSI working group members.
  - Draft program
Cook-Deegan Box 8/9

- Minutes of Planning meeting for Sept. 11-12 workshop.
- Memo from Eric Juengst to ELSI working group members. (October 10, 1991).
- Roster [committee on predicting future disease: issues in the development, application and use of tests for genetic disorders].
Folder 1 (NCURA 11/8/94 Hyatt Conf Hotel)
- Memo from Perrie Adams to Cook-Deegan. (Nov. 3, 1994). MCURA meeting
- Letter from Perrie Adams to Cook-Deegan. (Sept. 30, 1994).
- Letter from Perrie Adams to Cook-Deegan. (June 28, 1994).

Folder 2 (ELSI relevant materials Feb-April, 1990)
- Minutes of the NIH-DOE working group on ELSI [2nd mtg, Williamsburg, VA Feb. 6, 1990].
- Summary (draft) of first workshop of the joint working group on ELSI [Williamsburg, VA, Feb. 5-6, 1990].
- Statement from the NIH workshop on population screening for the cystic fibrosis gene. (March 6, 1990).
- Proposal for the Beckman Center Program. (Draft)
- Memo from Kathi E. Hanna to Cook-Deegan. (Feb 27).
  - For Action New Project
- Article: Mark A. Rothstein. Legal and ethical issues in the laboratory assessment of genetic susceptibility to cancer.
- Letter from J. Robert Nelson to Nancy Wexler. (April 4, 1990),
Cook-Deegan Box 9/9

- Report: Benjamin S Wilfond & Norman Fost. The cystic fibrosis gene: Medical and social implications for heterozygote detection
- Memo from Cook-Deegan to self. (April 13, 1990). Things we need to do for the ethical, social, and legal issues working group.

Folder 3 (ELSI WG mtg, Los Alamos 29-30 April (ADA rec to EEOC)).

- Fax from Eric Juengst to Cook-Deegan.
- Agenda for NIH-DOE ELSI working group meeting V.

Folder 4 (CF testing)

- Meeting Summary [workshop on clinical studies of cystic fibrosis carrier testing on Jan. 31, 1991]
- Meeting summary [workshop on the introduction of new genetic tests on Sept. 10, 1990]
- Guidelines: Request for applicants: Studies of testing and counseling for cystic fibrosis mutations
- Memo from Eric Juengst to participants along the way to the NIH of CF testing studies initiative. (Oct. 9, 1991).
- Statement from the NIH workshop on population screening for the cystic fibrosis gene. (March 6, 1990).
Cook-Deegan Box 9/9


Folder 5 (ADA-ELSI)
- Memo from Francis Collins to members of the NIH-DOE ELSI working group. (Jan. 14, 1993). NIH-DOE ELSI working group statement on employment discrimination—ACTION

White Binder (Interdisciplinary Colloquy on Genetic Predisposition)
- Interdisciplinary colloquy participants
- NIH-DOE joint ELSI working group participants
- Conference description
- Statements
- Report: Susan Mahler. Genetic predisposition and the Courts: Legal fact or science fiction?
Folder 6 (ELSI 4/29-30/91 mtg, Los Alamos

- Memo from Lori Andrews to ELSI working group members. (April 26, 1991). Questions to aid in developing genetic confidentiality policies.
- Memo from Cook-Deegan to Nancy Wexler. (June 24, 1991).
- Roster for ELSI working group
- List of participants
- Memo from Michael Yesley to NIH-DOE ELSI working group members. (April 125, 1991). Additional reading materials for April meeting of the ELSI working group.
- Tourette Syndrome Association brochures
  ○ Program on the ELSI of Human Genome Research: A guide for Applicants