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I. Reference Sources

**Dictionaries**


*2005 Update (PDF)*

This extensive PDF file consists of specialized terms used by the National Library of Medicine’s database, including MEDLINE and PUBMED. The terms listed here will also be helpful to researchers with no medical background who wish to search for bioethics literature in other databases or search engines. It is particularly useful for identifying a hierarchy of broader and narrower terms of art.

**National Reference Center for Bioethics Literature (NRCBL) Classification Scheme – Kennedy Institute of Ethics, Georgetown University [http://bioethics.georgetown.edu/databases/classscheme/index.htm](http://bioethics.georgetown.edu/databases/classscheme/index.htm)**

The classification system used by the NRCBL to identify bioethics materials in their library collection enumerates relevant terminology based on a hierarchic schema. The list may be viewed as a hierarchy of terms or as an alphabetical list. The terms in the list will be helpful when using print indexes, reviewing tables of contents, or constructing online search queries.


The dictionary includes specialized medical terms as well as related scientific terms in language accessible to the layperson.

**Encyclopedias**

**Encyclopedia of Bioethics, 3rd ed.**


Sci/Tech Lib Sci/Tech Lib-Reference Room 103 (does not circulate)

QH332 .E52 2003

The encyclopedia includes perspectives on bioethical issues from the fields of: behavioral and human sciences; medicine and biology; economics; ecology; ethics;
feminism; law; philosophy; and world religions. Each entry includes a detailed bibliography and cross-references. The source, which is addressed to a broad audience, provides a useful overview of historical and current issues in the field. Researchers should consult more current sources for the most recent developments in the field.

**Encyclopedia of Ethical, Legal, and Policy Issues in Biotechnology, 2 vols.**  
Reference TP248.16 .E539 2000

This scholarly reference work, edited by Thomas Murray (The Hastings Center) and Maxwell Mehlman (Case-Western Reserve's Law-Medicine Center), with contributions by renown scholars in many fields, addresses ethical, regulatory, and policy issues in biotechnology.

**Source Book in Bioethics: A Documentary History**  
R724 .S599 1998

The Source Book provides quick access to a collection of primary source documents (or excerpts from documents) in the areas of: research involving human subjects; death and dying; human genetics; human reproductive technology; and changes in the healthcare system. Examples include the Baby M and Karen Quinlan rulings, the Baby Doe regulations, and the Uniform Anatomical Gift Act.

**Bibliographies**

**Basic Resources in Bioethics - National Reference Center for Bioethics Literature**  
Scope Note 15  
[http://bioethics.georgetown.edu/publications/scopenotes/sn15.htm](http://bioethics.georgetown.edu/publications/scopenotes/sn15.htm)

This is a well-organized introduction to sources on a number of bioethics subtopics. The sources listed and described in the guide were selected from the collection of the National Reference Center for Bioethics Literature library, so researchers should check the SUMMIT catalog or ask a librarian to determine which sources are available locally.

**Bibliography of Bioethics**  
Detroit, Gale Research Co.  
Z6675.E8 B53  
Law Library has v.4, v. 10 -

This annual volume includes abstracts and references to popular and professional literature, legislative activity, books (and chapters in books), essays, reference resources and court decisions.
Bibliography of Ethics, Biomedicine, & Professional Responsibility
Frederick, MD : University Publications of America in Association with
the Hastings Center, c1984.
R724 .H2699 1984

The Hastings Center is an independent, nonpartisan, and nonprofit bioethics research institute
founded in 1969. The Center’s primary emphasis is on “emerging questions in health care,

HumGen: International Database on the Legal, Social and Ethical Aspects
of HUMan GENetics – University of Montreal
http://www.humgen.umontreal.ca/int/GB_q.cfm

HumGen at the University of Montreal is a searchable database of international, regional and
national reports and publications produced by bioethics-related agencies. It consists of the
following major categories: Genbiblio (all subjects); Pediagen (Pediatrics); Stemgen (Stem
Cells); Popgen (Population Genetics); and Ipgen (Intellectual Property). Under each category,
select the organizations, keywords, countries, and dates you wish to search. Where available,
links are provided to the full-text of documents.

The National Information Resource on Ethics & Human Genetics (NIREHG) -
Annotated Bibliographies; Scope Note Series
http://bioethics.georgetown.edu/publications/scopenotes/index.htm

The project, funded by the National Human Genome Research Institute and the National
Institutes of Health, offers detailed, current web guides on topics related to ethics and human
genesetics. Current topics include: eugenics; genetic testing and screening; human genome
project; genes, patents & bioethics; bioethics resources on the web. Each guide is preceded by
a table of contents; the date of publication appears at the bottom of the guide.

A very useful feature in each guide is QuickBib. This feature allows you to view the 100 most
recent bibliographic citations in the Kennedy Institute databases for quick bibliographies on
topics related to the subject of the guide. Check SUMMIT or ask a librarian to determine
which of the items are available locally.

II. Bioethics Internet Portals

The following sources provide extensive access to primary and secondary material and/or
provide numerous links to relevant sources.

Bioethics Resources on the Web - National Institutes of Health
This authoritative web resource offers annotated links on issues in bioethics education, research involving human participants and animals, medical and health care ethics, and the implications of applied genetics and biotechnology.

Materials are organized under the following categories:

- Research resources
- Federal resources
- General resources (lists of journals, web sites, news, tutorials)
- Research by topic
- Organizations of interest

You can browse the categories and topics, or search the entire site.

**Bioethics Resources on the Web - The National Information Resource on Ethics & Human Genetics (NIREHG); Scope Note 38**
http://bioethics.georgetown.edu/publications/scopenotes/sn38.htm

This is a comprehensive, annotated guide to research sources in bioethics and genetics available on the Internet. Under each broad category, researchers can locate U.S. and some international and comparative information on the following subtopics: Directories; Electronic Journals; Full-Text Documents; News/Current Awareness; and, Teaching Resources. A third general category, Evaluation and Searching Tools, provides access to general resources on conducting and analyzing research in bioethics and related fields.

This resource offers browsing functionality only; there is no search function.

**Bioethics Web:**
Intute: Health and Life Sciences
http://bioethicsweb.ac.uk/browse/mesh/C0017398L0017398.html

Bioethics Web is a British gateway to authoritative English language Internet sources relating to biomedical ethics, including ethical, social, legal and public policy issues that have arisen in as a result of advances in medicine and biology as well as issues relating to biomedical research. The site is searchable by keyword, with advanced search techniques for limiting search results by resource type (e.g., case studies, papers, statistics).

**Ethics Update - Applied Ethics**
http://ethics.sandiego.edu/

Founded by Lawrence Hilman at the University of San Diego, “Ethics Update – Applied Ethics”, offers a variety of research information and links on topics in applied ethics, including (but not limited to) bioethics and reproductive technologies. Content is more diverse than other portals and includes conference presentations and papers, lectures, case studies and links to a wide-range of related material.
Hastings Center
http://www.thehastingscenter.org/

“The Hastings Center is an independent, nonpartisan, and nonprofit bioethics research institute founded in 1969 to explore fundamental and emerging questions in health care, biotechnology, and the environment. The Center's ... range from genetic paternity testing to newborn screening to palliative care. The work is carried out by interdisciplinary teams that convene at the Center's home... to frame and examine issues that inform professional practice, public conversation, and social policy.”

The web site describes the center’s research initiatives and provides access to its reports and other publications as well as links to related resources.

Nuffield Council on Bioethics
http://www.nuffieldbioethics.org/go/Default.html

“The Nuffield Council on Bioethics examines ethical issues raised by new developments in biology and medicine. Established by the Nuffield Foundation in 1991, the Council is an independent body, funded jointly by the Foundation, the Medical Research Council and the Wellcome Trust. The Council has achieved an international reputation for addressing public concerns, and providing independent advice to assist policy makers and stimulate debate in bioethics.”

The Council’s working groups investigate a wide-range of specific topics within the area of bioethics. Topics include:

- Critical care decisions in fetal and neonatal medicine: ethical issues
- Public health: ethical issues
- The forensic use of bioinformation: ethical issues
- The ethics of research involving animals
- The ethics of research related to healthcare in developing countries
- Pharmacogenetics: ethical issues
- Genetics and human behaviour: the ethical context
- The ethics of patenting DNA
- Genetically modified crops
- Stem cell therapy: ethical issues
- Mental disorders and genetics: the ethical context
- Animal-to-human transplants: the ethics of xenotransplantation
- Human tissue: ethical and legal issues
- Genetic screening: ethical issues

Each issue has its own web page, which includes: reports, recommendations, and discussion papers; latest news; external consultation papers (input from experts, organizations and others); minutes of meetings; press releases; and, a list resources.
University of Pittsburgh Bioethics & Law Links
http://www.pitt.edu/~bioethic/links.htm

This site provides extensive links to sources at the University of Pittsburgh as well as links to other bioethics and health law research sites in the U.S. and abroad.

III. Databases

Which databases should you use? For a useful comparison of bioethics databases, see, “Bioethics Databases – Comparison” (Georgetown University Law Center, E.B. Williams and John Wolff Law Libraries)
http://www.ll.georgetown.edu/guides/bioethics_chart_Feb_16.pdf

National Reference Center for Bioethics Literature
(NRCBL Databases & National Library of Medicine Databases)
http://bioethics.georgetown.edu/databases/index.htm

The NRCBL has prepared this access portal for their ethics databases and the databases of the National Library of Medicine.

The NRCBL databases, searchable by basic search, advanced search, and Boolean search are:

**ETHX on the Web:** Journal articles, book chapters, bills, laws, court decisions, reports, books, audiovisuals, and news articles relating to bioethics and professional ethics

**GenETHX:** Books, journal articles, book chapters, bills, laws, court decisions, reports, news articles and audiovisuals relating to ethics and public policy issues in genetics

The National Library of Medicine public databases are:

**PubMed:** Journal articles, court decisions, bills, laws, and news articles (limit to the bioethics subset) dating from the 1950s. PubMed is broader in scope than MEDLINE, described below. It covers a broader range of topics, includes some current material not yet indexed in MEDLINE, and encompasses some older material not covered in MEDLINE. However, the PubMed search functionality is not as flexible as the search features offered by the S.U. Library version of MEDLINE.

Please note: this database is also available through the Syracuse University Library system (see, http://library.syr.edu/cgi-bin/Xdatabases.cgi?title=Databases+by+Title%3A+P&sort_a=Name&Name=%5Ep).

The PubMed database provides citations and abstracts only. Ask a librarian for assistance with locating the full-text of the materials cited here.
**NLM Catalog:** The online catalog of the National Library of Medicine (NLM) collections. Very similar to our SUMMIT catalog, you can search for material the NLM collections by author, title, subject, MeSH terms (see Changing Vocabularies, above, for these terms), etc.

This database provides citations only. Ask a librarian for assistance with locating the full-text of the materials cited here.

**MEDLINE**
[Syracuse University Library Licensed Resource]
http://library.syr.edu/cgi-bin/Xdatabases.cgi?title=Databases+by+Title%3A+M&sort_a=Name&Name=%5Em.

MEDLINE, also from the National Library of Medicine, is one of the source journal indexes for PubMed. The S.U. Library’s MEDLINE database employs a different search engine than PubMed, so it worthwhile searching both indexes. Unlike PubMed, you can search for material on MEDLINE using the MeSH terms (see Changing Vocabularies, above, for these terms). Citations and abstracts (and a few full-text articles) from scholarly journals dating from the 1950’s are provided. Ask a librarian for assistance with locating the full-text of the materials cited here.

**National Technical Information Service (NTIS) Database**
[Syracuse University Library Licensed Resource]
http://library.syr.edu/cgi-bin/Xdatabases.cgi?title=Database+Search+Results&sort_a=Name&search=NTIS

The NTIS database indexes unclassified reports from selected U.S. and international government agencies and educational institutions (including the National Bioethics Advisory Commission, President’s Council on Bioethics, the Congressional Research Service, and academic journals covering bioethics).

The database includes over 2 million citations. Ask a librarian for assistance with locating the full-text of materials cited here.

**IV. Major Print Resources**

**Loose-leafs**

**Bioethics Reporter (1983-1985)**
University Publications of America
QH332 .B36

This is a comprehensive collection of resource materials that address the medical, legal, philosophical, religious, economic and social aspects of bioethics. The
Reporter changed title and continued as BioLaw (see below), which consists of current loose-leaf volumes that are updated bi-monthly.

Continues as:

**BioLaw (1986)**
Edited by James F. Childress and Ruth D. Gaare
Frederick, MD : University Publications of America, c1986-
KF3821.A6 B56 (2 volumes)

See also, *BNA Topical Services*, below.

**How to Find Texts and Treatises**

To find available treatises on issues in bioethics, search the SUMMIT online catalog using terms from the *MesH Vocabulary*, terms from the *NRCBL Classification Scheme*, Library of Congress Subject Headings, or keywords of your choosing.

**Library of Congress Subject Headings**
Washington : Library of Congress, 1975-
Reference Z695 .L695

V. **Journals**

See also, *Databases*, for databases that contain references to journal literature as well as other relevant materials.

**Journal Databases and Indexes**

**Bioethics Journals - Bioethics Resources on the Web**

The NIH has compiled an annotated list of online bioethics journals and newsletters. Some content may be restricted to subscribers only. For licensed journals, check the SUMMIT online catalog to determine if the Law Library or Syracuse University Library has a subscription that provides full-text.

To determine holdings in the Barclay Law Library & SU/ESF Libraries,
1) Access SUMMIT from the Law Library home page
2) Select “Journal Title” search
3) Search under exact journal title (omit initial article)

**Annual Reviews [Syracuse University Library Licensed Resource]**
Annual Reviews indexes literature from academic annual reviews in the biomedical sciences, physical sciences and social sciences from 1996 to the present. Most articles are in full-text.

**Bibliography of Bioethics**
Detroit, Gale Research Co., Z6675.E8 B53
Law Library has 1975-

This annual volume includes abstracts and references to popular and professional journal literature.

**Biomedical Ethics Reviews**
Law Library has 1983-

This is an annual series on contemporary issues in biomedicine, ethics, and society.

**Academic OneFile [Syracuse University Library Licensed Resource]**

http://library.syr.edu/cgi-bin/Xdatabases.cgi?title=Database+Search+Results&sort_a=Name&search=expanded+academic

“Academic OneFile is the premier source for peer-reviewed, full-text articles from the world's leading journals and reference sources. With extensive coverage of the physical sciences, technology, medicine, social sciences, the arts, theology, literature and other subjects, Academic OneFile is both authoritative and comprehensive…Updated daily.”

**JSTOR [Syracuse University Library Licensed Resource]**

http://library.syr.edu/cgi-bin/Xdatabases.cgi?title=Databases+by+Title:+J&sort_a=Name&Name=^j.

JSTOR offers a full text archive of scholarly publications in mathematics, science, and the social sciences. Click on the ‘proceed with printing’ link to see full-text in PDF.

**ProQuest Research Library [Syracuse University Library Licensed Resource]**

http://library.syr.edu/cgi-bin/Xdatabases.cgi?title=Databases+by+Title:+P&sort_a=Name&Name=^p.
ProQuest provides access to thousands of current periodicals and newspapers, many updated daily and containing full-text articles from 1986. Search multiple databases by topic or customize your list of multiple databases from a list.

Science Direct [Syracuse University Library Licensed Resource]
http://library.syr.edu/cgi-bin/Xdatabases.cgi?title=Databases+by+Title:+S&sort_a=Name&Name=^s.

Science Direct is a major electronic collection of peer-reviewed, full text journals in the areas of science, technology and medicine.

**Selection of Journals By Title**

**American Journal of Bioethics**
Hein Online, v. 1 (2001)-
Paper, v. 2 (2002)-
To access, search SUMMIT-Journal Title under “American Journal of Bioethics”

**American Journal of Law & Medicine**
Hein Online, v.1 (1975/76) –
Paper, v. 1 (1975-76)-
Westlaw, Database Identifier: AMJLM, begins 12/2000; full coverage begins with 1993 (vol. 19, no. 3)
Lexis, from 1981 through current

**Bioethics (Online) [Syracuse University Library Licensed Resource]**
Electronic holdings begin with v.11 (1997)
To access, search SUMMIT – Journal Title under “Bioethics”

**Biomedical Ethics Reviews**
R724.B4
Paper, 1983-

**Cambridge Quarterly of Healthcare Ethics (Online) [Syracuse University Library Licensed Resource]**
Electronic holdings begin with v.7 (1998)
To access, search SUMMIT – Journal Title under “Cambridge Quarterly of Healthcare Ethics”

**Ethics and Medicine (Online) [Syracuse University Library Licensed Resource]**
Available from 2001
To access, search SUMMIT – Journal Title under “Ethics and Medicine”
see also:
Westlaw, Database Identifier: ETHMED, coverage begins 06/2001

**Hastings Center Report**
R724 .H27
Paper, v. 17 (1987)-

[Syracuse University Library Licensed Resource]
Electronic holdings begin with v.1 (1971)
To access, search SUMMIT – Journal Title under “Hastings Center Report”

**HEC Forum (Online) [Syracuse University Library Licensed Resource]**
Electronic holdings begin with v.9 (1997)
To access, search SUMMIT – Journal Title under “HEC Forum”

**Health Care Analysis (Online) [Syracuse University Library Licensed Resource]**
Electronic holdings begin with v.7 (1999)
To access, search SUMMIT – Journal Title under “Health Care Analysis”

**Issues in Law & Medicine**
Hein Online, v. 1 (1985-86) –
Paper, v. 1 (1985-86)-
Westlaw, Database Identifier: ISSULM, selected coverage begins with 1985 (vol. 1)
Lexis, from Winter 1996

**Journal of Clinical Ethics**
Paper, v. 5 (1994)-

**The Journal of Contemporary Health Law and Policy**
Hein Online, v. 1 (1985)-
Paper, v. 1 (1985)-
Westlaw, Database Identifier: JCHLP, selected coverage begins with 1985 (vol. 1); full coverage begins with 1993 (vol. 10)

**Journal of Health and Biomedical Law**
Westlaw, Database Identifier: JHTHBL, selected coverage begins with 2004 (vol. 1)
Lexis, begins Volume 1, 2004

**Journal of Health Politics, Policy and Law**
Hein Online, v. 25 (2000)-
Paper, v. 1 (1976-77)-
Westlaw, Database Identifier: JHPPL, selected coverage begins with 1990 (vol. 15);
The Journal of Law, Medicine & Ethics
Paper, v. 21 (1993)-
Westlaw, Database Identifier: JLMEDETH, coverage begins with 1998 (vol. 26)
Lexis, begins with volume 26, 1998

Journal of Medical Ethics
Westlaw, Database Identifier: JMEDETHICS, coverage begins 03/1990; abstracts begin 2/2004 to present.

Journal of Medical Humanities (Online) [Syracuse University Library Licensed Resource]
Electronic holdings begin with v.18 (1997)

Also available in print:

The Journal of Medicine and Philosophy
Sci/Tech Library R723 .J66
Paper, v.1 (1976)-

Kennedy Institute of Ethics Journal (Online) [Syracuse University Library Licensed Resource]
Electronic holdings begin with v.6 (1996)
To access, search SUMMIT – Journal Title under “Kennedy Institute of Ethics Journal”

Also available in print:

Medical Law Review Online [Syracuse University Library Licensed Resource]
Oxford, UK : Oxford University Press
Electronic holdings begin v.6 (1998)
To access, search SUMMIT – Journal Title under “Medical Law Review”

Also available on Lexis, from 1998 through current

Michigan State University Journal of Medicine & Law
Hein Online, v. 1 (1997)- [listed under Journal of Medicine & Law]
Westlaw, Database Identifier: MSUJMEDL, full coverage begins with 2004 (vol. 8)
Social Science & Medicine (Online) [Syracuse University Library Licensed Resource]
Electronic holdings begin with v.40 (1995)
To access, search SUMMIT – Journal Title under “Social Science & Medicine”

Also available in print:

Yale Journal of Health Policy, Law and Ethics
Hein Online, v. 1 (2001)-
Paper, v. 1 (2001)-
Westlaw, Database Identifier: YJHPLETH, begins Spring 2001
Lexis, begins Spring 2001

Finding Additional Journals

Access to Print & Electronic Journals through SUMMIT
http://summit.syr.edu/cgi-bin/Pwebrecon.cgi?DB=local&PAGE=First

You can search for print and electronic journals by keyword or journal title through our online public catalog, SUMMIT. The catalog integrates the holdings of all SU Libraries plus Moon Library at ESF. For electronic journals, a link to the journal will appear in the item record. To access electronic journals remotely from SUMMIT, you must be connected to the proxy server. Access varies. Please ask a librarian for information about access to a particular journal.

SU Library’s E-Journal Locator
http://libsfx.syr.edu:9003/syracuse/azlist/default

If you know the name of the journal you are seeking, you can use the E-Journal Locator to determine if the SU Library has a subscription to that journal.

Social Science and Health/Medical Journals on Westlaw & Lexis

In addition to traditional law reviews and legal journals, Westlaw and Lexis both offer journal literature in the areas of social sciences and/or health and medicine.

Westlaw

Health Law Library

American Health Lawyers Association (AHLA) Seminar Papers
Database Identifier: AHLA-PAPERS

Health Policy Tracking Service (HPTS)
Consists of *Snapshots* (concise pictures of current health care legislation) and *Issue Briefs* (expert analysis and guidance on hot topics in health care). To view, go to the Westlaw Directory, and, in the search box, enter HPTS.

For **Social Sciences Databases**, go to the Directory and follow these breadcrumb trails:

- All Databases > Directories and Reference Materials > Social Sciences & Humanities > Social & Behavioral Sciences
- All Databases > Directories and Reference Materials > Social Sciences & Humanities > Society, Religion & Other Social Concerns

**Lexis:**

For **Health & Medical Databases**, click on the “Sources” tab and follow this breadcrumb trail:

- Sources > News & Business > Science & Technology > Medical & Healthcare

### VI. Current Awareness Sources

**BNA Topical Services [Newsletters on Bioethics-Related Topics]**

The Bureau of National Affairs (BNA) has created a number of newsletter style services on health related topics. These frequently updated resources (print and online) provide access to current news and articles on developments in law and policy. Online products may browsed or searched.

Note: The BNA services listed below are licensed resources of the H. Douglas Barclay Law Library. Access restrictions apply.

**BNA Medical Research Law & Policy Report (Online)**


The BNA Medical Research Law & Policy Report offers bi-weekly coverage of topics such as: bioterrorism; cloning; data safety monitoring; genetic research; human subject protections; informed consent; institutional review board activities; intellectual property rights; patients' rights; privacy and security; scientific misconduct; and, stem cell research.

The BNA Health Care Policy Report offers weekly coverage on issues in health care policy. Among the major topics are medical error and organ transplants.

BNA Health Care Daily offers daily coverage of health care policy and law, including focused coverage of Medicare, Medicaid, and managed care. Begins 10/1/1996.

The BNA Health Law Reporter offers weekly coverage on a broad range of topics in health law and policy.

“This broad-based notification service connects the dots among the many disciplines that make up the burgeoning life sciences industry, with biweekly updates on current regulatory, legislative, and legal issues.”

BioEdge is a good source for U.S., international and foreign news in the area of bioethics law and policy. The site is operated by Australasian Bioethics Information, an independent information clearinghouse.
Bioethics.net  
http://www.bioethics.net  

Bioethics.net produced by the publishers of the *American Journal of Bioethics*. International in scope, the web site is a goldmine of news from authoritative news sources and updates on current global activities in all area of bioethics.


**CDC: Genomics in the News**  

The CDC site offers current news as well as summaries (through PubMed) of recent scientific literature.

**HealthBlawg: Medical Ethics**  

Written by a health law attorney, this blawg discusses developing law in medical ethics and other health topics.

**MSNBC Breaking Bioethics**  

MSNBC has devoted a web page to developments in bioethics. The site’s author, Arthur Caplan, is Director of the Center for Bioethics at the University of Pennsylvania.

**Women’s Bioethics Project**  
[http://womensbioethics.blogspot.com/](http://womensbioethics.blogspot.com/)  

Scholars and public policy analysts from around the world provide daily news and commentary on the implications of bioethical issues for women.

**VII. Federal & State Law**

**Legislation - Federal**

**NHGRI Policy and Legislation Database - National Human Genome Research Institute:**  
[http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm](http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm)  

The NHGRI database contains federal and state laws/statutes; federal legislative materials; and federal administrative and executive materials, including regulations,
institutional policies, and executive orders. The database currently focuses on the following subject areas: privacy of genetic information and confidentiality; informed consent; insurance and employment discrimination; genetic testing and counseling; and commercialization and patenting.

You can search the site using the easy-to-use ‘search boxes’ which allow you to select relevant search criteria such as content type, topic, source and keyword.

**Biotechnology and Genetics Law (MegaLaw.com)**

http://www.megalaw.com/top/biotech.php

MegaLaw is an Internet directory of online content organized by subject. Included here are links to:

- Federal statutes
- EPA regulations
- USDA regulations
- USFDA regulations

**Statutes Affecting Bioethics. University of Minnesota Center for Bioethics [PDF]**

http://www.ahc.umn.edu/img/assets/23396/bioethicslaw.pdf

A short list of relevant federal statutes and regulations.

**Legislation - State**

**Genetics Laws and Legislative Activity - National Council of State Legislatures**

http://www.ncsl.org/programs/health/genetics/charts.htm

There are two components to the web site. The **State Genetics Laws** section summarizes in tabular form (with links to full text, where available) relevant state statutes and cases on ten topics, including:

- Embryonic and Fetal Research
- Employment
- Frozen Embryos
- Genetic Counselor Licensing
- Genetic Privacy
- Health Insurance
- Health Insurance Enforcement
- Human Cloning
- Life, Disability and Long-Term Care Insurance
- Newborn Screening
The Genetics Legislation Database is a searchable database that contains information on current bills considered in state legislatures. “Topics covered in the database include newborn screening, stem cell research, privacy, discrimination, and other issues. NCSL updates the database at least once a month.”

Bioethics Law in New York State - University of Buffalo Center for Clinical Ethics and Humanities in Health Care
http://wings.buffalo.edu/faculty/research/bioethics/legal.html

Although brief and somewhat out of date (last updated 5/12/2005), this is a useful snapshot, with links, to relevant New York law and government entities.

Case Law

In addition to case law identified through the BNA topical services and through traditional online and print case finding methods, see:

Case Law Influencing Bioethics - University of Minnesota Center for Bioethics [PDF]
http://www.ahc.umn.edu/img/assets/23396/bioethicslaw.pdf

This site provides summaries of selected, leading cases on the following issues:

- Autonomy/Self Determination
- Medically Futile Treatment
- Morals Legislation
- Parental Rights/Surrogacy
- Patent Law
- Physician Assisted Suicide
- Property Rights Concerning One's Own Body
- Reproductive Rights/Abortion
- Right to Die

Please note that the list may not include the most recent decisions, and cases cited here should be Shepardized (or KeyCited) to determine current status.

VIII. Government Departments and Agencies

President's Council on Bioethics
http://www.bioethics.gov/

The Council’s reports and meeting transcripts are available here, as are selected background materials consisting of scholarly articles and book excerpts.
Genome.gov: Policy & Ethics - National Human Genome Research Institute, National Institutes of Health
http://www.genome.gov/

The National Human Genome Research Institute (NHGRI), previously known as the National Center for Human Genome Research, conducts research on the application of genome technologies in the study of disease. The “Policy & Ethics” page explores the critical issues and legislation surrounding genetic research.

This is an excellent source for identifying current government initiatives, pending legislation, and administrative guidance material on specific issues in genetics and bioethics. The site can be browsed by topic or searched.

US Department of Energy Biological and Environmental Research Program
http://www.science.doe.gov/feature/BER.htm

The DOE’s Biological and Environmental Research (BER) program conducts “competitive and peer-reviewed research at national laboratories, universities, and private institutions.” The web site offers the texts of occasional papers and program reports, and describes current program activity.

US Department of Health and Human Services, Office for Human Research Protections
http://www.hhs.gov/ohrp/about/

In addition to a description of the office’s activities, researchers can access relevant regulations, policy and guidance materials, compliance oversight procedures and determination letters, and reports of the Secretary’s Advisory Committee on Human Research Protections (SACHRP).

US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation; Privacy Committee – Health
http://aspe.hhs.gov/datacncl/privacy/#health

The DHH Privacy Committee issues reports on privacy of genetic information and related topics. The site offers access to these documents and provides information on the current status of research projects in the area of privacy of genetic information.

XIV. Starting Points for International Bioethics Law & Policy Research

Bioethics Portals (International and Foreign)

DRZE (German Reference Centre for Ethics in Life Sciences)
http://www.drze.de/?la=en
This expansive resource provides access to information about: international and foreign bioethics and medical ethics journals; relevant law and statements of organizations; and, bioethics and medical ethics institutions and commissions (international, regional and national).

The site also provides access to a number of databases, including:

**BELIT**: BELIT “provides access to about 320,000 records from the integrated German, American and French databases. It is an extensive bibliographic directory of literature in the area of bioethics unique worldwide, containing references to monographs, grey literature, legal documents, journal articles, newspaper articles and book contributions.”

**BEKIS**: BEKIS lists national and international academic institutions, projects, working groups, individual researchers, and funding bodies working in the field of ethics in the life sciences.

**International Bioethics Links: New Zealand Bioethics Council (Toi Te Taiao)**

Although not as comprehensive as the DRZE site, above, this list of links to international, regional and national bioethics organizations and initiatives includes materials such as bioethics blogs and relevant news sites not found in the DRZE listings.

**United Nations Bioethics Activities**

**U.N. Inter-Agency Committee on Bioethics**
http://www.who.int/ethics/about/unintercomm/en/index.html

In March 2003, representatives of a number of United Nations organizations and specialized agencies established the U.N. Inter-Agency Committee on Bioethics to “promote coordination and cooperation among themselves and other regional and international inter-governmental groups that deal with the field of bioethics, including its human rights aspects and other related issues.” The U.N. agency members of this committee are the Food and Agriculture Organization (FAO), the International Labor Organization (ILO), the Office of the U.N. High Commissioner on Human Rights (UNHCHR), the U.N. Educational, Scientific, and Cultural Organization (UNESCO), the World Intellectual Property Organization (WIPO), and the World Health Organization (WHO). Other international organizations participate as Associate Members.
Below are details about the major U.N. entities engaged in bioethics initiatives:

**World Health Organisation (WHO)**
http://www.who.int

In addition to the “Ethics and Health” web site, below, there are a number of WHO sites that provide information about bioethics related WHO initiatives and activities.

To identify sites by topic, see the alphabetical listing of “WHO Sites” by topic at http://www.who.int/entity/en/. Possible topics include (but are not limited to): Biologicals, Genomic Resource Centre, Health and Human Rights, Reproductive Health and Research (RHR), and Ethics, Trade, Human Rights and Health Law (ETH).

**WHO: Ethics and Health Unit**
http://www.who.int/ethics/en/

The Ethics and Health unit collaborates on research projects with the Joint Center for Bioethics, University of Toronto (PAHO/WHO Collaborating Center) and the Center for Law and the Public's Health at Georgetown University,

The web page provides access to information about ethics-related activities and events, publications (some available in full-text), a list of WHO National Bioethics Committees, and a very useful list of links to international and regional organizations engaged in bioethics related activities and initiatives.

Of particular note is the section on “Ethical standards and procedures for research with human beings,” (at http://www.who.int/ethics/research/en/) which provides access to the texts of selected research ethics guidance materials developed by WHO and cooperatively with other groups.

**WHO: Strategic Initiative for Developing Capacity in Ethical Review (SIDCER)**
http://www.who.int/sidcer/en/

SIDCER is a network of regional forums for ethical review committees, health researchers and selected “partner” organizations. Publications on the site include *Operational Guidelines for Ethics Committees That Review Biomedical Research (PDF)* and *Surveying and Reviewing Ethical Review Practices.*

**UNESCO International Bioethics Committee (IBC)**
http://www.unesco.org/ibc/
The Bioethics Programme is part of UNESCO’s Division of the Ethics of Science and Technology in the Social and Human Sciences Sector. The web site provides access to committee documents and links to relevant international law instruments.

**Universal Declaration on Bioethics and Human Rights**

The Universal Declaration was adopted by the General Conference of UNESCO in October 2005. This document demonstrates the first commitment by Member States to apply fundamental principles of bioethics as set forth within a single text.

In addition to the text, the web site offers commentary about the history and development of the declaration, with links to related articles.

**Preliminary Draft Declaration on Universal Norms on Bioethics**

The draft was finalized by the International Bioethics Committee (IBC) at its Extraordinary Session on 28 January 2005. The draft resulted from numerous consultations at international, regional and national levels (including within the framework of the UN Interagency Committee on Bioethics), a session of the Intergovernmental Bioethics Committee (IGBC) and a joint session of IBC and IGBC (January 2005).


**Council for International Organizations of Medical Sciences (CIOMS)**
http://www.cioms.ch/

The Swiss based CIOMS is an international, non-governmental, non-profit organization established jointly by WHO and UNESCO in 1949. The main objectives of CIOMS are: “to facilitate and promote international activities in the field of biomedical sciences; to maintain collaborative relations with the United Nations and its specialized agencies, in particular with WHO and UNESCO; and, to serve the scientific interests of the international biomedical community in general. In addition to a description of the organization’s programs and initiatives, the web site lists CIOMS publications (ask a librarian for assistance in locating the full-texts) and provides texts of CIOMS bioethics guidelines and other normative documents (see below).
Texts of Guidelines and Other Normative Documents of the Council for International Organizations of Medical Sciences (CIOMS):

The web page provides links to guidelines, principles and declarations on bioethics issued by the CIOMS.

Food and Agriculture Organization (FAO): Biotechnology in Food And Agriculture

In a March 2000 statement on Biotechnology in Food and Agriculture (available at, http://www.fao.org/biotech/stat.asp), the FAO expressed concerns about the implications of genetic engineering, specifically, “the effects on human and animal health and the environmental consequences.” The web site provides access to recent policy documents on biotechnology, including policy documents of FAO member countries and regions (arranged alphabetically by country or region; documents in reverse chronological order).

World Intellectual Property Organization (WIPO): Traditional Knowledge, Genetic Resources and Traditional Cultural Expressions/Folklore
http://www.wipo.int/tk/en/

WIPO “provides a forum for international policy debate and development of legal mechanisms and practical tools concerning the protection of traditional knowledge (TK) and traditional cultural expressions (folklore) against misappropriation and misuse, and the intellectual property (IP) aspects of access to and benefit-sharing in genetic resources.”

Related WIPO web sites include:

WIPO: Genetic Resources

The WIPO Intergovernmental Committee (IGC) addresses the interplay between intellectual property and genetic resources. The focus of the committee’s work has been on;

- “Defensive protection of genetic resources through measures which prevent the grant of patents over genetic resources that do not fulfill the requirements of novelty and non-obviousness.”

- “IP aspects of access to genetic resources and equitable benefit-sharing arrangements that govern use of genetic resources.”
“Disclosure requirements in patent applications that relate to genetic resources and associated traditional knowledge used in a claimed invention.”

WIPO: Intellectual Property and Life Sciences
http://www.wipo.int/tk/en/lifesciences/

A Working Group of experts in the field of biotechnology was organized by WIPO “for the purposes of identifying issues related to biotechnology and IP, which might be included in future WIPO work programs.” Among the issues addressed are “legal standards related to the scope and character of patent protection for inventions in the field of biotechnology.”

Other International Organizations with Significant Bioethics Activity

World Medical Organization (WMA)
http://www.wma.net/e/

The WMA is an international organization representing physicians. The WMA “provides a forum for its member associations to communicate freely, to co-operate actively, to achieve consensus on high standards of medical ethics and professional competence, and to promote the professional freedom of physicians worldwide.”

The WMA Ethics Unit (http://www.wma.net/e/ethicsunit/index.htm) “establishes and promotes the highest possible standards of ethical behaviour and care by physicians. In pursuit of this goal it has adopted policy statements on a large number of ethical issues related to medical professionalism, patient care, research on human subjects and public policies.”

[WMA] Declaration of Helsinki (and Related Documents)
http://www.wma.net/e/policy/b3.htm

WMA International Code of Ethics
http://www.wma.net/e/policy/c8.htm

WMA Declarations
http://www.wma.net/e/ethicsunit/policies.htm

Recent WMA Statements, Resolutions, and Policies
http://www.wma.net/e/index.htm

WMA Council Resolutions
http://www.wma.net/e/policy/councilresolutions.htm
The OECD is a “forum where the governments of 30 market democracies work together to address the economic, social and governance challenges of globalisation as well as to exploit its opportunities.” Their work in the area of biotechnology includes scientific, industrial, health and agricultural applications. Among their major efforts is harmonisation of regulatory oversight in biotechnology “while avoiding non-tariff trade barriers to products of the technology.”

The web site offers OECD guidance and consensus documents, statistics, publications and reports, and developments of individual countries.

**Human Genome Organization (HUGO): Ethics Committee**
[http://www.hugo-international.org/committee_ethics.htm](http://www.hugo-international.org/committee_ethics.htm)

The Human Genome Organisation (HUGO) is an international organization of scientists involved in human genetics. The primary mission of the Human Genome Organisation is “to promote and sustain international collaboration in the field of human genetics.”

The organization has posted a number of members’ PowerPoint presentations on the web site.

**Regional and National Bioethics Organizations and Information**

**Australasia**

**Asia/Asian Bioethics Association (ABA) [no web site currently available]**

“The objective of this Association is to promote scientific research in bioethics in Asia through open and international exchanges of ideas among those working in bioethics in various fields of study and different regions of the world.”

**2007 Conference Web Site:**
**March 19-23, 2007, Century Park Hotel, Bangkok, Thailand**

Provides information about the conference agenda and insight into the association’s activities.
**Eubios Ethics Institute**

[http://www.eubios.info/](http://www.eubios.info/)

The Eubios Ethics Institute is “a nonprofit group that aims to stimulate the international discussion of ethical issues, and how we may use technology in ways consistent with "good life" (eu-bios). It aims at an integrated and cross-cultural approach to bioethics, and at building up an international network.”

The web site offers free access to the organization’s journal, Eubios Journal of Asian and International Bioethics (EJAIB), 1995-, as well as a selection of scholarly papers, reports, teaching materials, and links to related sources.

**Government of Australia: Biotechnology Australia – Bioethics Portal**


This portal links all the key bioethics websites and issues in Australia. In addition to descriptions of various federal and territory bioethics initiatives in Australia, the site links to databases, publications, papers, reports, fact sheets and related resources.


**Africa**

**[WHO] Pan-African Bioethics Initiative**


PABIN is “committed to developing ethics in the context of African culture and practices.” PABIN provides a forum for education, meetings, and discussion on bioethics in Africa among researchers, ethicists and healthcare providers.


**European Union**

**European Union: EU Policy on Biotechnology, 2006 (PDF)**


The report provides a comprehensive overview of EU policy on biotechnology, with references to specific European Union directives and regulations that address all aspects of biotechnology in the region.
European Group on Ethics in Science and New Technologies
http://ec.europa.eu/european_group_ethics/index_en.htm

The group is a “neutral, independent, pluralist and multidisciplinary body, composed of fifteen experts appointed by the Commission for their expertise and personal qualities…The task of the Group is to examine ethical questions arising from science and new technologies and on this basis to issue Opinions to the European Commission in connection with the preparation and implementation of Community legislation or policies.”

The web site provides access to the group’s current (2005-2009) mandates, opinions and activities. In addition, the site links to the full-text of important papers, studies and reports on various aspects of bioethics regulation and policy in Europe and beyond.

European Commission Forum of National Ethics Councils (NEC Forum)

The Forum of National Ethics Councils (NEC Forum) consists of the chairpersons and the secretaries of the National Ethics Councils. It is an “independent informal platform for exchange of information, experience and best practices on issues of common interest in the field of ethics and science.”

The web site describes the activities of the forum, provides access to the forum meeting minutes held in member states, and provides links to individual countries’ national ethics committees (http://ec.europa.eu/research/biosociety/bioethics/bioethics_ethics_en.htm).

Privacy in Research Ethics and Law (PRIVIREAL)
http://www.privireal.org/

This project examined the implementation of the Data Protection Directive (95/46/EC) in relation to medical research and the role of ethics committees. The recommendations of the study are available on the web site.

European Union: Community Research & Development Information Service (CORDIS)

CORDIS facilitates and coordinates European research and development in science and technology, including projects relating to bioethics and biotechnology. The European Union’s Framework Programs (the current program is the 7th) fund research projects. Information about the Framework Programs and research conducted under their auspices are available on the website.

An overview of Bioethics in the European Community’s Seventh Framework Program for RTD (2007–2013) may be found at:
http://www.ostina.org/content/view/1702/646/
CORDIS Life Sciences, Genomics & Biotechnology for Health
http://cordis.europa.eu/lifescihealth/home.html

Life sciences, genomics and biotechnology constitute one of seven major thematic priorities of the European Union’s Sixth FrameWork Programme (FP6). The objective “is to help Europe exploit, in this post-genomic era, the unprecedented opportunities for generating new knowledge and translating it into applications that enhance human health. Research areas include fundamental genomics, applied genomics and biotechnology, and Genomic approaches to health and disease. Research reports, updates and links to related documents may be found here.

Council of Europe

Convention on Human Rights and Biomedicine Convention on Human Rights and Biomedicine (Oviedo Convention) and Additional Protocols
http://www.coe.int/t/e/legal_affairs/legal_co-operation/bioethics/Texts_and_documents/ITreaties_COE.asp

see also:

Council of Europe Steering Committee on Bioethics. Draft Explanatory Report on the Additional Protocol [PDF]
http://www.coe.int/t/e/legal_affairs/legal_co-operation/bioethics/News/INF%20_2007_%205%20e.pdf

Council of Europe Steering Committee on Bioethics
http://www.coe.int/T/E/Legal_affairs/Legal_co-operation/Bioethics/

The Council of Europe’s aim “to protect the individual’s dignity and fundamental rights with regard to the application of ordinary medicine and new medical techniques (genetics, medically assisted procreation, etc.). It wants to strike a balance between freedom of research and protection of persons, while fostering reflection and public discussion, ensuring respect for fundamental values, and arbitrating between different viewpoints and interests by drawing up principles and legal standards which reflect these values.”

Council of Europe – Bioethics – Texts and Documents
http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/Texts_and_documents/

Includes: current treaties; a compendium of texts of the Council of Europe on bioethical matters (PDF); recommendations by the Committee of Ministers Concerning Bioethics; recommendations, opinions and
resolutions of the Parliamentary Assembly of the Council of Europe Concerning Bioethics; publications; and, reports.

**European Conference of National Ethics Committees (COMETH)**
http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/COMETH/

The Conference, composed of representatives of national ethics committees (or equivalent bodies) in Member States of the Council of Europe, meet to “promote co-operation between national ethics committees, help countries wishing to set up a national ethics committee and to promote public debate on ethical issues raised by progress in the fields of biology, medicine and public health.”

**South America**

**South America – Bioethics Links**

**German Reference Center for Ethics in the Life Sciences**
http://www.drze.de/links/Einrichtungen/SuedamerikaEinricht?la=en

A list of links, by country, to bioethics organizations and associations in South America.

**Pan American Health Organization [PAHO]- Bioethics and Health**
http://www.paho.org/Project.asp?SEL=TP&LNG=ENG&ID=95

PAHO is the regional WHO Office. Some English language resources, including reports, journal articles technical documents, are available on this site.

**Directories of Other Associations and Organizations Relating to Bioethics**

**BEKIS: the Bioethics Communication and Information System**
**DRZE (German Reference Centre for Ethics in Life Sciences)**
http://www.drze.de/links?la=en

**Directory of National, Regional and International [Medical Ethics] Associations & Organizations; Baylor College of Medicine: Center for Medical Ethics & Health Policy**
http://www.bcm.edu/ethics/Links.htm

**NRCBL Searchable Directory of Bioethics Organizations by Country**
http://bioethics.georgetown.edu/databases/Organizations/index.htm

**European Commission Forum of National Ethics Councils (NEC Forum)**
http://ec.europa.eu/research/biosociety/bioethics/bioethics_ethics_en.htm
Bioethics Related Laws, Documents, Guidelines and Policies – Collections

Bioethics and Human Rights Links - University of Minnesota Human Rights Links
http://www1.umn.edu/humanrts/links/bioethics.html

The University of Minnesota Law Library has prepared this extensive list of international and regional treaties, declarations, guidelines, codes and other documents relating to bioethics.

UNESCO Publications and Documents on Bioethics: Selected Bibliography
http://www.unesco.org/shs/shsdc/bioethics/bioethics/bib.htm

This source is especially useful for identifying bioethics related documents of international organizations adopted since 1975.

Biotechnology Policy Documents of FAO Members
http://www.fao.org/biotech/country.asp

Country and regional policy documents are arranged alphabetically by country or region, then listed in reverse chronological order. Note: These policy documents are not limited to biotechnology in food and agriculture.

XV. Academic Sites & Research Centers-Directories

Bioethics: Academic Centers & Programs-
Bioethics Resources on the Web, National Institutes of Health
http://bioethics.od.nih.gov/academic.html

The site lists and describes bioethics academic centers and research sites.

Bioethics Links
University of Pittsburgh Center for Bioethics & Health Law
http://www.pitt.edu/~bioethic/links.htm

This is another excellent list, with descriptions, of bioethics academic programs and research sites.

DRZE (German Reference Centre for Ethics in Life Sciences) – Bioethics Links - Institutions
http://www.drze.de/?la=en

The DRZE lists research and documentation centers for ethics in the life sciences worldwide. Links are in a geographical order and subdivided into Science & Information, Public Institutions, Bodies & Ministries, Associations, Economic Associations
and Church Institutions. Academic centers are generally listed under Science & Information.

XVI. Other Libraries and Interlibrary Loan

SUNY Upstate Medical University: Health Sciences Library
http://www.upstate.edu/library/

Law students and others have access to the library’s facilities and print collections. Databases are available to the public in the library (no remote access). Currently, law students do not have borrowing privileges at SUNY Health Sciences Library. However, students may complete an Interlibrary Loan request for items by completing the appropriate ILL form on the Law Library’s web site.

Please note: During times of heavy use, priority will be given to Upstate/VA students and staff. Non-Upstate or recreational users may be asked to move to the Visitor computers. Printing of full text resources is limited to 20 pages. When retrieving large files, users are encouraged to email or download.

See the SUNY Health Sciences Library’s web site (http://www.upstate.edu/library/) for detailed information and to link to the library’s online catalog.

Access to Other Libraries’ Catalogs

You can expand your research by searching other libraries’ catalogs and requesting materials through Interlibrary Loan Service (see below). Cornell’s libraries, for example, have a wealth of valuable information, all within a short drive.

Law Library Catalogs List from Washlaw (University of Washington)
http://www.washlaw.edu/lawcat/

LIBWEB: Libraries on the Web (Directory of USA Academic Libraries)
http://sunsite.berkeley.edu/Libweb/Academic_main.html

This directory links to library home pages; catalogs are usually accessible from the home page.

Medical Research Libraries (National Institutes of Health)

The NIH directory provides information and links to federal, national, state, consumer health and Washington, D.C. medical and health libraries.
College of Law Interlibrary Loan Services

There is a universe of information available to you beyond the College of Law, Westlaw & Lexis. If you locate citations to books, media or articles that are not available at the law school or SU Library, you can request the item by Interlibrary Loan.

Read about our ILL Service
http://www.law.syr.edu/lawlibrary/student/circ.asp

ILL Book Request Form
http://www.law.syr.edu/lawlibrary/libraryservices/formbooks.asp

ILL Article Request Form
http://www.law.syr.edu/lawlibrary/libraryservices/formperiod.asp

Please note: Depending on available sources, ILL may require several weeks to arrive. Please plan ahead!