

Wolbert, Werner. Is there a duty to create saviour siblings? *Human Reproduction and Genetic Ethics: An International Journal* 2008; 14(1): 22-28. 12 refs. 11 fn. NRCBL: 15.2; 4.4; 1.1; 8.3.2; 14.4; 19.5. SC: an.

Keywords: *human dignity; *moral obligations; *moral policy; *parents; *preimplantation diagnosis; *reproduction; *siblings; *tissue donors; autonomy; beneficence; children; embryos; ethical analysis; genetic counseling; in vitro fertilization; killing; moral status; organ donors

Zeiler, Kristin. Complexities in reproductive choice: medical professionals' attitudes to and experiences of preimplantation genetic diagnosis. *Human Fertility* 2007 September; 10(3): 165-174. 25 refs. 6 fn. NRCBL: 15.2; 14.4. SC: em.

Keywords: *attitude of health personnel; *preimplantation diagnosis; autonomy; clinical genetics; coercion; conscience; decision making; directive counseling; embryo transfer; genetic counseling; genetic disorders; informed consent; international aspects; interviews; obstetrics and gynecology; patients; physicians; prenatal diagnosis; psychology; qualitative research; regulation; risks and benefits; selective abortion; Keyword Identifiers: Great Britain; Italy; Sweden

Zeiler, Kristin. Gynaecologists and geneticists as storytellers: disease, choice and normality as the fabric of narratives on preimplantation genetic diagnosis. In: Lauritzen, Sonja Olin; Hydén, Lars-Christopher, eds. *Medical Technologies and the Life World: the Social Construction of Normality*. London; New York: Routledge, 2007: 69-92. 49 refs. 24 fn. NRCBL: 15.2; 14.4. SC: em.

Keywords: *attitude of health personnel; *preimplantation diagnosis; autonomy; choice behavior; disabled persons; genetic counseling; genetic disorders; genetic screening; international aspects; interviews; metaphor; morality; normality; obstetrics and gynecology; physicians; prenatal diagnosis; reproductive technologies; uncertainty

Zlotogora, Joël; Haklai, Ziona; Leventhal, Alex. Utilization of prenatal diagnosis and termination of pregnancies for the prevention of Down syndrome in Israel. *IMAJ: Israel Medical Association Journal* 2007 August; 9(8): 600-602. 9 refs. NRCBL: 15.2; 12.5.1. SC: em.

Keywords: *Down syndrome; *prenatal diagnosis; *selective abortion; age factors; Arabs; choice behavior; ethnic groups; Islamic ethics; Jewish ethics; Jews; pregnant women; religion; statistics; Proposed Keywords: retrospective studies; Keyword Identifiers: *Israel; Orthodox Judaism

GENETIC DATABASES AND BIOBANKS

Andorno, Roberto. Population genetic databases: a new challenge to human rights. In: Lenk, Christian; Hoppe, Nils; Andorno, Roberto, eds. *Ethics and Law of Intellectual Property: Current Problems in Politics, Science and Technology*. Aldershot, Hampshire, England; Burlington, VT: Ashgate, 2007: 27-45. 65 fn. NRCBL: 15.11; 15.1; 1.3.12; 8.4; 18.3; 21.1. SC: rv.

Keywords: *confidentiality; *genetic databases; *genetic privacy; *genetic research; *informed consent; *population genetics; *research subjects; access to information; benefit sharing; biological specimen banks; disclosure; genetic re-

sources; human rights; international aspects; legal aspects; medical records; property rights; research findings; research subjects; right not to know; Proposed Keywords: Estonia; Estonian Genome Project; Germany; Iceland; Icelandic Health Sector Database

Archibald, Tom; Lemmens, Trudo. Data collection from legally incompetent subjects: a paradigm legal and ethical challenge for population databanks. *Health Law Journal* 2008; Special Edition: Visions: 145-192. 94 fn. NRCBL: 15.1; 1.3.12; 18.3; 18.5.6; 8.4; 15.11; 18.5.7. SC: le. Conference: Visions: National Health Law Conference; Banff, Alberta; 2007 November 8-10; Health Law Institute.

Keywords: *age factors; *competence; *decision making; *genetic databases; *genetic epidemiology; *genetic research; *informed consent; *legal aspects; *research subjects; *third party consent; *time factors; access to information; adults; advance directives; aged; autonomy; confidentiality; consent forms; dementia; ethical review; guidelines; human experimentation; privacy; population genetics; Proposed Keywords: *aging; *cohort studies; Keyword Identifiers: *Canada; Canadian Lifelong Health Initiative; Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans

Artizzu, Federica. The informed consent aftermath of the genetic revolution. An Italian example of implementation. *Medicine, Health Care and Philosophy* 2008 June; 11(2): 181-190. 36 refs. 3fn. NRCBL: 15.1; 1.3.12; 18.3; 15.11. SC: an.

Keywords: *biological specimen banks; *genetic databases; *genetic research; *informed consent; autonomy; community consent; data collection; duty to recontact; exceptionalism; genetic information; genetic privacy; industry; population genetics; research subject; risks and benefits; Keyword Identifiers: *Italy; *SharDNA Project

Abstract: A great part of human genetics research is carried out collecting data and building large databases of biological samples that are in a non-anonymous format. These constitute a valuable resource for future research. The construction of such databases and tissue banks facilitates important scientific progress. However, biobanks have been recognized as ethically problematic because they contain thousands of data that could expose individuals and populations to discrimination, stigmatization and psychological stress if misused. Informed consent is regarded as a cornerstone in the protection of personal autonomy in research involving human subjects. Yet in recent years this fundamental concept has been overwhelmed by the genomic revolution. From a general overview of international literature, it seems evident that informed consent issues have come into sharp focus, in particular in relation to the twin issues of time extension (blanket versus specific/repeated consent) and personal extension (group consent). After an introduction on obtaining informed consent in the context of genetic research, this paper addresses the apparent lack of a single, universal model of obtaining informed consent among populations involved in genetic research and it argues for the need to develop an ethical framework tailored to the specific features of each project. In order to support this theory of contextualizing, the case of a private biotechnology company, SharDNA is presented. The present paper explores the management of its biobank, developed from a genetic research project carried out on isolated populations living on the Italian island of Sardinia. In particular, the paper highlights how the company is tackling the problem of informed consent and other ethical requirements for genetic research, such as the respect of individual privacy,