



Guiding Principles on Human Genetic Technologies

These Guiding Principles are designed to serve as the governing context and standard of reference for all present and future policies, practices, laws, regulations and educational initiatives related to human genetic technology in the State of Nebraska. The Nebraska Human Genetic Technologies Commission's central purpose is to encourage uses of human genetic technologies that contribute to the improvement of the human condition while assuring the protection of fundamental human rights. In these principles the term "respect" acknowledges that compelling social interests may at times require abridgement of individual liberties regarding the use of genetic technologies in order to protect the well-being of society as a whole.

Respect for Humanity

- " The inherent dignity and intrinsic value of human beings must govern all uses of human genetic technologies.
- " Human uniqueness and diversity must be respected as a cherished part of our shared humanity.

Respect for the Individual

- " Genetic information should not be used to deny individual opportunity.
- " Confidentiality and privacy concerning genetic information should be respected.
- " Individuals should be fully informed and give their voluntary consent prior to genetic testing or genetic intervention.

Respect for the Community

- " The social values of justice, equity, beneficence, do no harm, and veracity must be respected in the development and implementation of human genetic technology.
- " No group should become the subject of unfair discriminatory policies or practices on the basis of its genetic makeup.
- " Thoughtful on-going civic discourse about the role of human genetic technologies in furthering the common purposes and goals of our shared humanity is essential.


For more information on the Nebraska Human Genetic Technologies Commission's Report visit <http://www.hhs.state.ne.us/ced/genrep.htm>

Commission Recommendations

The following are distilled from committee and full Commission research and deliberations. For further information see the Findings and Recommendations section referred to in parentheses.

The State of Nebraska should:

- *☐ require appropriate certification of all forensic DNA laboratories performing work on behalf of the State. (Criminal Justice)
- *☐ develop a mechanism for providing ongoing recommendations regarding the current and future application of genetic technologies in the criminal justice system. These recommendations should be developed with input from a diversity of viewpoints. One component should act as support for the State Patrol in operating its laboratory and implementing the DNA Detection of Violent and Sexual Offenders Act. (Criminal Justice)
- *☐ establish a pilot program in one or more communities for the purpose of discussing ethical, legal and social implications of modern genetics with the goal to prepare citizens to make informed decisions in this area. (Education)
- *☐ sponsor and support a Governor's conference designed to provide updated knowledge concerning the ethical, legal, and social implications of recent advances in human genetic technologies for those working in the media, health care, legal, and criminal justice professions. (Education)
- *☐ provide teachers in the public schools with opportunities to update their scientific knowledge about human genetic technologies. (Education)
- *☐ encourage the development or implementation of public school curricula about human genetics that includes the ethical, legal, and social implications of human genetic technology. (Education)
- *☐ encourage the post-secondary schools to develop courses in human genetics that would include not only the scientific but also the ethical, legal and social implications of human genetic technology. (Education)
- *☐ protect employees and applicants for employment by
 - " prohibiting all employers from performing genetic tests on or obtaining genetic test results from an employee or applicant without informed consent, including disclosure of the use to be made of the information and to whom it will be disclosed; (Employment)
 - " prohibiting all employers from requiring employees and applicants to undergo genetic tests or to submit previously obtained genetic test results as a condition for employment or as part of any employment practice; (Employment)



" prohibiting the release or use of genetic test results without consent of the individual, (Employment)

" permitting exceptions to the above by an employer only if the employer demonstrates a compelling need to do so on the basis of public or work place health or safety, and then only with timely disclosure to the affected individual. (Employment)

*□ charge the Nebraska Department of Insurance and health insurance organizations licensed in Nebraska to inform health insurance policyholders and the general public of the following:

" the existing state and federal protections requiring health insurers to guarantee issue coverage to groups and certain individuals and guarantee renewal of that coverage at the policyholder's discretion, (Insurance)

" the criteria for individuals to obtain health insurance through the Nebraska Comprehensive Health Insurance Pool, and (Insurance)

" the role of the Nebraska Department of Insurance to receive and act upon complaints filed with it concerning any question regarding coverage or charge of a higher premium based on a genetic test. (Insurance)

*□ require appropriate certification for all laboratories performing human genetic testing for a fee in Nebraska. (Testing and Services)

*□ require that individuals providing clinical diagnostic and genetic counseling services have appropriate state license or American Board of Medical Genetics or American Board of Genetic Counselors certification. (Testing and Services)

*□ provide support for the Nebraska Health and Human Services System to establish a state advisory committee on clinical genetic services to address questions and concerns about access, cost, and quality. (Testing and Services)

*□ support continuation and extension of Commission activities including the study of issues not covered in this report, the monitoring of new developments, and the implementation of these recommendations.

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