WHEREAS, recent developments in the area of information technology have stimulated public concern over confidentiality of patient-identifiable medical information: and

WHEREAS, the federal Health Insurance Portability and Accountability act (HIPAA) requires the development of detailed federal standards with respect to the privacy of individuality identifiable health information; and

WHEREAS, confidentiality requirements should be comprehensive in assuring patients that information identifying them and their medical condition or predisposition to any specific condition is confidential information; and

WHEREAS, state and federal policies must accomplish twin objectives of protecting the privacy of individual patients, while also protecting the continued viability of research and the coordination of health care research to promote improved quality of health care for all patients; and

WHEREAS, patients benefit from improved health care interventions, including early detection and timely preventive services, as well as the many new medicines which have been brought to the market this past year: new weapons against HIV/AIDS, several new anti-cancer drugs, a new anti-depressant and a new anti-psychotic drug, new treatments for chronic diseases such as diabetes and asthma, and for many other deadly and debilitating diseases: and

WHEREAS, innovations in medical science, in combination with developments in genomic technologies are revolutionizing medical research and the future of health care as they begin to reveal the molecular basis of human illnesses; and

NOW THEREFORE BE IT RESOLVED that any state or federal legislation to protect the confidentiality of individually identifiable medical information should ensure that vital medical research is encouraged and facilitated, should protect the current practice of storing tissue samples and medical information which is critical to medical research and the legal operation of health care.
institutions and the delivery of quality health care, and should not require the
destructions of medical information and samples; and

FURTHER, BE IT RESOLVED that establishing ownership of medical
information and samples is not an appropriate mechanism for protecting
privacy.

Adopted by the HHS Task Force and approved by the ALEC Board of Directors in
1997.