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Editors  
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To the Editors,

The Alliance of Genetic Support Groups wholeheartedly endorses the principles enunciated by Dr. Heyman in his article "A Balance Between Healing and Harm." As a national voice for individuals and families affected by genetic conditions, the Alliance of Genetic Support Groups has long campaigned in support of privacy and confidentiality protections, written informed consent procedures, anonymity of test results and medical records and improved access to quality health care services.

Most of us -- patients and professionals -- grew up counting on a relationship of trust and confidence with our family physicians. As new and exciting technical discoveries appear, it's important not to lose sight of two critical medical rights: maintaining a trusting relationship with our doctor and securing the privacy of our personal medical records.

With the advance of managed health care delivery systems and new genetic technological discoveries come serious concerns about genetic privacy and potential unauthorized access to personal medical information. Increasingly the health care provider, case manager and insurance company operate within one decision-making and communication loop, sharing medical records in macro computer information systems. While genetic and biotechnological discoveries will open the doors to medical advances, full access will depend on the availability of quality service within a confidential doctor/patient relationship protected by federal and state statutes. Without TRUST, without FULL disclosure, without a FULL medical history, without appropriate and necessary tests, without preventative procedures, and without ASSURANCE of continued insurance coverage, we and our families will not see the medical cures and treatments envisioned by new genetic technologies.

Dr. Heyman's remarks are an especially timely and critical reminder to the Genetic Testing Task Force, meeting next week to finalize guidelines for quality, effective, and ethical genetic testing procedures. People with genetic disorders are eager participants in medical research programs and are motivated to take advantage of new medical advances, like genetic testing. However, for scientists, doctors and patients to be of meaningful help to one another, patients must have the assurance that their medical records will not fall into the wrong hands or be used to deprive them of insurance coverage, medical treatment or employment.

As we approach the 21st century -- the century of the genetic revolution -- the challenge for Congress is to devise legislation protecting the genetic and medical privacy of the citizen while giving research and medical professions the incentive to innovate, implement and to cure.

Thank you to the Post and to Dr. Heyman for your articulate presentation of these difficult issues.

*Joan K Burns*

Joan K. Burns  
President

Sincerely,

*Mary E. Davidson*

Mary E. Davidson  
Executive Director