PREVENTION GENETICS

DISEASE PREVENTION THROUGH GENETIC TESTING

Genetic Etiquette

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Genetic Testing is expanding rapidly. Many people, however, are uncertain about how to deal with genetic information. PreventionGenetics has therefore assembled the following rules for Genetic Etiquette. These rules are only suggestions. They are not official laws or regulations.

Our suggestions apply to all types of genetic information. These include DNA sequences, chromosome analyses and results from other types of DNA testing. Typically, this information will be obtained through the patient's physician and will be included in the patient's official medical record. However, people will also sometimes obtain genetic information directly by sending samples of their DNA to testing labs.

Rule 1

Each person should keep their own genetic information private and protected. The ideal situation is for no one other than yourself and properly-credentialed health care providers to have access to this information.

A. Unless required by *law*, do NOT ever release your genetic information to employers, insurers, banks, universities, etc. Nearly all states will allow you to keep this information private. The opportunity for genetic discrimination is minimized if your genetic information is kept confidential.
B. Do NOT reveal your genetic information to biological relatives, such as siblings, children or parents. The health care providers for your relatives should have access to this information (see Point 3 below), but your relatives do not need to know it themselves. By attempting to communicate your own DNA test results, you may falsely alarm or frighten family members. It's also very easy to make mistakes when attempting to convey the genetic information itself, and especially the correct *interpretation* of this information.
C. Do NOT reveal your genetic information to friends, acquaintances, coworkers, etc. These individuals may be sympathetic and pleasant to talk with, but once you mention your DNA test results, the information will likely spread, and often inaccurately.

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Rule 2

DO reveal genetic information to qualified health care providers, such as your doctor. This is especially important if you move or otherwise change health care providers. Your physician cannot provide optimal care for you unless he/she has access to your genetic information. The health care providers are required by Federal law to keep this information confidential.

Rule 3

DO reveal your genetic information to the health care providers of your family members. Your genetic information can be of great benefit (sometimes a matter of life and death) to your biological relatives, but it is best to give the information to professionals rather than try to communicate it yourself. Often this transfer of information can be accomplished by simply signing a consent form for release of your own medical records. Alternatively, you may send this information directly to your relative's physician. In this case, you may find the following brief sample letter helpful.

Dear Dr. XXXX:

My mother/brother/granddaughter/etc. [relative's name] is in your care. [If you know your relative's birth date and/or medical record number, it should be included here.] You may find my enclosed genetic information useful in the care of [relative's name]. [It is best to send photocopies of your test results rather than trying to describe the results from memory]. Please keep this information strictly confidential, and in particular do not reveal it to [relative's name]. I am also willing to sign a release form to allow you to have direct access to my medical records.

Sincerely yours,

Your Full Name
Your Birth Date
Your Full Address
Your own Health Care Provider(s) and Medical Record Numbers (if known)

Rule 4

Genetic information of children should only be released to parents or guardians when that information is necessary to make medical decisions for the child. Although parents/guardians may have the legal right to view the full medical records of their children, in general, a child's genetic information should NOT be volunteered.

Rule 5

A young person's genetic information should be made available to them when they reach a defined age. PreventionGenetics suggests the age of majority, which is defined by the individual States and is mostly 18 or 19 years. Exceptions may be made if the young person marries or becomes pregnant at an earlier age.

Rule 6

Virtually all couples want to have healthy children. Couples planning on having children should share their genetic information *through* a genetic professional such as a genetic counselor. For the reasons described above, do NOT attempt to share the information by yourselves. Leave this task to the professionals.

The genetic professional will examine available genetic information from the couple and estimate the risks to that couple of having a child with a significant health problem or disability. Nearly everyone, regardless of their personal opinions on abortion and other reproductive issues, will benefit from such a counseling session. See the PreventionGenetics "Letter to My Children" for more information about genetic issues in reproductive planning.

Rule 7

DNA is often stored and available for testing even after a person's death. However, PreventionGenetics believes that the privacy of the deceased should be respected. Testing of a deceased person's DNA should be performed only when it can benefit a living family member. Results of such testing should be revealed only to the appropriately trained health care provider of the living family member.

Rule 8

Even quite limited genetic testing is often sufficient to reveal the nature of biological relationships. For example the parent/child relationships can easily be confirmed or contradicted. There are many thorny questions raised by the determination of biological relationships. Some of these are listed below. Societies will need to make rules and laws governing who (if anyone) should learn about these relationships.

A. Do children have the right to learn the identities of their biological parents, and if so at what age?
B. Should police and other government officials have access to parent/child information to prosecute statutory rape cases and to collect child support payments?
C. Do husbands have the right to know if children born to their wives are their own?
D. Do wives have the right to know if their husbands have fathered any children out of wedlock?

Rule 9

It is a good idea to save a full copy of your genetic information on a CD or other electronic storage media and keep it in a safe place like a safe deposit box in a bank vault.

Rule 10

If you learn about the genetic information of another person, regardless of the source, and regardless of the relationship between yourself and that person, do not EVER pass this information on to anyone else. Revealing such information can place the individual at risk of discrimination and other distress.