Huntington's Headlines

CNI

FROM THE COLORADO NEUROLOGICAL INSTITUTE

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Genetic Discrimination

A POTENTIAL RISK TO US ALL

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The threat of genetic discrimination is troubling for most who undergo predictive genetic testing for Huntington's disease (HD), but it should be everyone's concern. While not every medical ailment has a genetic cause, many do arise in part to a predisposition that lies in the genes. The truth is that we are all at risk for genetic-based illness. Heart disease, cancer, and diabetes are among the most common causes of death for American adults, and each usually occurs as a result of genetic susceptibility. We all have at least one of these diseases in our family history, and we could all be at risk for genetic discrimination if legislation does not change.

For most people, the family medical history is currently the best tool to identify one's genetic susceptibility to disease. But this risk assessment method is much less precise than using a genetic test to determine if one has actually inherited the predisposition to the disease in question. As genetic research continues, blood tests for genetic susceptibility to common and not-so-common diseases is becoming possible. The ultimate hope is that through the identification of genetic mutations that cause risk for disease, viable treatments or cures will eventually be developed.

But even before treatments become available, information about genetic susceptibility can be important to individuals. In some cases, lifestyle modifications can reduce the risk of the particular disease. In the case of Huntington's disease, even though lifestyle modification is not known to reduce risk, and there is no prevention or cure, genetic testing can be a powerful tool. Rather than simply examining the family history and determining that someone (let's call him Tim) has a 50% risk for HD, genetic testing can determine whether he did or did not inherit the mutation. This specific genetic information allows him to plan for the future and take some control of his experience of HD while living at-risk and as the disease onsets and progresses.

Unfortunately, in today's health insurance setting, and consequently the employment setting, genetic testing for disease risk can theoretically leave Tim vulnerable to genetic discrimination. When a healthy individual like Tim has a genetic test that indicates he has inherited the mutation that will cause HD to develop in the future, an insurer could view him as a higher risk to insure. They could raise his premiums, exclude coverage for the disease he is at risk for, or drop his coverage. An employer could view him as more expensive to provide benefits for, and Tim could be less productive and require more sick time once the disease onsets. This might factor in to hiring and promotion decisions. Genetic discrimination occurs when an insurance company or employer treats Tim, who is currently healthy, differently than others without such a genetic test result.

Research has revealed that the public's fear of genetic discrimination is much greater that what actually seems to be occurring. However, when the rare case of genetic discrimination does occur, it can be financially devastating to families who are already dealing with the significant burden of illness or risk for illness in the future.

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HD AT A GLANCE

- A progressive neurodegenerative disease that causes behavioral and cognitive changes and uncontrolled movements (chorea)
- Usually onsets between ages 30-50, in the most productive time of life
- Progresses over 10-25 years, resulting in death
- Genetic testing can accurately determine if one has inherited the HD mutation
- Autosomal dominant inheritance causes 50% risk for affected individual to pass the mutation to each child
- While treatments are available to manage some symptoms, a cure is not possible, although researchers remain optimistic
- About 30,000 people in the U.S. have HD, and about 200,000 more are at risk.

WWW.THECNI.ORG

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CLINICAL TRIALS

If you are interested in participating in or would like to learn more about clinical trials for Huntington's disease, please contact Sherrie Montellano at 303-762-6674.

Huntington's Disease Society of America

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Some legal protections do exist to discourage genetic discrimination. The Health Insurance Portability and Accountability Act (HIPAA) of 1996 mandates that group health insurance companies cannot consider genetic information to be a preexisting condition. This means that people like Tim who have tested positive for the HD mutation (or any other disease mutation) but are not yet showing signs of the disease cannot have HD treatment excluded from their policy. HIPAA also mandates that Tim should be treated like everyone else in the insurance group. Tim cannot be excluded from coverage. His premium alone cannot be raised, but it can be raised for everyone in the group. Specific treatments cannot be excluded unless it is excluded for everyone in the group. Unfortunately, individual health insurance policies are not covered by HIPAA.

Colorado's state law offers protection against genetic discrimination in individual and group health insurance, just not self-funded plans which are not governed by ERISA. The Colorado law also covers group disability insurance and longterm care insurance. Most other states have laws addressing genetic discrimination, but they offer varying degrees of protection. If you are looking to relocate after genetic testing, you should know about the state law that would apply to you. This information can be found at www.genome.gov.

Protection from genetic discrimination in the workplace has not been well addressed yet. Federal employees are protected against genetic discrimination, due to President Clinton's Executive Order in 2000, but non-federal employees, have no protection.

The Genetic Information Nondiscrimination Act (GINA) is currently under consideration in the Senate and the House of Representatives. It aims to offer more comprehensive protection against genetic discrimination in insurance and employment. If you have not done so already, please consider contacting your representative and Senators to discuss why GINA is important to you. More information about GINA is available at www.geneticfairness.org.

At CNI, patients come to the HD Predictive Genetic Testing Program to learn whether they inherited the mutation that causes HD. Most of them are very concerned about the risk for genetic discrimination. When Tim came, we discussed several points with him. First, to protect his health insurability, he should try to maintain group health insurance. If his insurance coverage must end, he should investigate how a COBRA policy can protect his insurability while he or his spouse acquires another job with group health insurance benefits. Second, Tim should consider whether adding other types of insurance to his coverage is possible and necessary in his situation. Longterm disability insurance can offer additional income for Tim and his family after he can no longer work due to the progression of HD. Longterm care insurance can offer Tim more choices for care once living at home is no longer ideal. Life insurance can offer money to pay for debt that Tim's family will be responsible for after his death and for funeral expenses. Some life insurance policies allow the policy owner to draw money prior to death. While it is not always financially feasible to obtain all of these coverages, obtaining them prior to genetic testing will allow Tim to move forward with testing without as much worry about genetic discrimination.

Whether or not to proceed with predictive genetic testing is a very personal decision. Many variables impact a person's choice. The risk for genetic discrimination should not be a barrier for people who feel they will benefit from testing. Some protection from genetic discrimination does exist through state and federal legislation, but more needs to be done.

THE VALUE OF SUPPORT GROUPS

Jan Jerome LCSW, HDSA Center of Excellence at Colorado Neurological Institute Clinic Social Worker

I have had the privilege of facilitating support groups for our HD patients and families for the past 2 years. We recommend support groups to our patients and family members for several reasons. A support group offers a confidential, non-judgmental space for sharing and meeting other people who truly understand what you are going through. The group also provides education, resources and the opportunity to meet professionals who can direct and assist you with referrals to the appropriate individual or organization for help. Each group opens with check-in time for introductions, announcements and sharing resources. In Denver, we are fortunate to have 6 professional facilitators and we are able to do small break out groups each month for persons according to how they are affected by HD. These groups include presymptomatic persons (diagnosed gene positive with HD but not symptomatic), family members/significant others, caregivers, at-risk for HD-not tested, persons who are symptomatic with HD, children and teen groups. We also provide educational groups periodically and invite speakers to present on a variety of topics of interest to our groups. The groups also include time for networking and socializing with one another. Each support group in Colorado is facilitated by a professional counselor or social worker.

We have received so much positive feedback from group members as to how they have been helped by the support groups. Many tell me they would never miss a group and experience a strong sense of community and a feeling of not being alone with the experience of HD in their lives.

We currently have 5 active support groups in Colorado, see below for times and locations.

North Metro Group
Second Tuesday of each month, 6:30-8pm
Capabilities Store, 6805 W. 88th Ave., Westminster

Southern Colorado Group
Second Wednesday of each month, 7-8:30pm
Health South Hospital, 325 Parkside Dr., Colorado Springs

Northern Colorado Group
Third Thursday of each month, 6:30-8pm
Pathways to Hope and Healing, 305 Carpenter Rd., Fort Collins

Denver Metro Group and Youth Group
Fourth Wednesday of each month, 7-9pm
Johnson Adult Day Center, 3444 S. Emerson St., Englewood

Western Slope Group
Last Tuesday of each month, 6:30-8pm
First United Methodist Church, 522 White Ave., Grand Junction

Please contact Jan Jerome for more information at 720-974-4092.